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The Three Steps Needed to End the COVID-19 Pandemic: Bold Public Health Leadership, Rapid Innovations, and Courageous Political Will

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Abstract

The world is experiencing the expansive spread of severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2) in a global pandemic that is placing strain on health care, economic, and social systems. Commitment to implementing proven public health strategies will require bold public health leadership and courageous acts by politicians. Developing new innovative communication, mitigation, and health care approaches, particularly in the era of social media, is also clearly warranted. We believe that the best public health evidence must inform activities in three priority areas to stop this pandemic: (1) coordinated and consistent stay-at-home orders across multiple jurisdictions, including potential nationwide mandates; (2) rapid scale-up of SARS-CoV-2 testing; and (3) improved health care capacity to respond. This editorial outlines those areas, the rationale behind them, and the call for innovation and engagement of bold public health leadership to empower courageous political action to reduce the number of deaths during this pandemic.

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KEYWORDS

COVID-19; coronavirus; SARS-CoV-2

Introduction

The world is experiencing the expansive spread of severe acute respiratory syndrome-coronavirus 2 (SARS-CoV-2) in a global pandemic that was first reported on December 31, 2019, in Wuhan, China. What began as cases of pneumonia with unknown etiology was identified as a novel coronavirus on January 7, 2020. Coronavirus disease 2019 (COVID-19), the illness that comes from SARS-CoV-2, was named a pandemic by the World Health Organization (WHO) on March 11, 2020 [1]. By that time, it had ravaged much of China. The epidemic is accelerating; the time from the first reported case to the first 100,000 cases was 67 days. It took 11 days for the next 100,000 cases, 4 days for the following 100,000 cases, and 3 days for the subsequent 100,000 cases. As of March 31, 2020, there are 858,669 cases and 42,151 deaths in the world attributed directly to COVID-19 (188,530 cases and 3,889 deaths in the United States, a 50.3% and 68.5% increase, respectively, in 2 days). We should remember that 1 month ago, on March 1, there were only 30 cases in the United States [2]. Every region of the globe is currently impacted by COVID-19 [3].

The enormous strain this pandemic is placing on health care systems across the world is palpable, from testing capacity to supply chains for personal protective equipment (PPE); specimen collection swabs; and supplies and equipment, including ventilators, for those requiring hospital care. New approaches are needed to scale up testing for COVID-19, to reduce the needs for PPE and specimen collection swabs and to allow testing for SARS-CoV2 outside of health care facilities.

New cases of COVID-19 infection and casualties continue to multiply and mixed messages abound. As the public health world has urgently recommended COVID-19 prevention

measures, they are being questioned as being too vast, hard to follow, invasive to our lifestyle, and damaging to the economy. Public health experts have either been sidelined in the COVID-19 response decisions or have found themselves at odds with much of the information being presented by political leadership. In the United States, the country currently with the largest number of COVID-19 cases, President Trump extended the initial 15-day national slow down and called for social distancing until April 30, 2020, in an attempt to reduce the spread of the virus [4,5]. States like California, Illinois, and New York have implemented state-wide "stay-at-home" ordinances, while other states have implemented less restrictive measures or no statewide measures at all [6-8]. Determining the proper scale and timing of these measures is critical to controlling the spread of COVID-19 and the numbers of lives lost. We believe that the best public health evidence must inform activities in three priority areas to stop this pandemic: (1) coordinated and consistent stay-at-home orders across multiple jurisdictions, including potential nationwide mandates; (2) rapid scale-up of SARS-CoV-2 testing; and (3) improved health care capacity to respond.

Coordinated Stay-at-Home Orders

There is public health consensus that limiting the number of contacts between persons can slow COVID-19 transmission in a community and give time for health care systems to respond. The most substantial of these approaches is a government order to stay at home except for food and medical needs. Although there are now multiple theoretical and practical models about how stay-at-home orders and travel restrictions could slow COVID-19 transmission, it is clear from all of them that consistency in implementation and communication is key. These policies will only be effective if they are implemented in a coordinated manner across large geographic regions where people commonly move, but there remain multiple examples of these public health interventions not being uniformly implemented. For instance, our city (Atlanta, Georgia) quickly implemented several local variations of stay-at-home recommendations from multiple city and county levels that comprise our metropolitan area, yet the state-wide recommendation was only implemented several weeks later. This meant that people who are told not to come to work in one Atlanta county had no such order where they lived and continued to congregate in public places. This patchwork response is not unique to the United States and illustrates an underlying lack of understanding about how to use these public health measures to slow the transmission of infectious diseases.

This inconsistency in implementing public health measures has also created substantial amounts of public confusion and fodder for social media conspiracy theories, hyperpartisanship, and distrust of experts. COVID-19 is the first true global pandemic of the social media era, offering new opportunities for rapid distribution of accurate public health information to millions of people. Unfortunately, these critical public health communications about actions to take to protect oneself from COVID-19 are not easy to differentiate from inaccurate or even dangerously wrong information. Having correct information that is well reasoned and delivered through consistent messaging are all pillars of behavior change, including changing people's transmission-related behaviors in response to COVID-19 [9]. Social media is now one of the most predominant ways that people get information, and public health must find better ways to communicate about mitigation plans through these forums.

Rapid Scale-Up of Testing

Decisions about COVID-19 mitigation policies must be informed by the best epidemiologic information, which requires rapid scale-up of COVID-19 testing. This will require rapid development of new diagnostic tests, laboratory capacity, testing supply chains, and health care personnel to collect the specimens. Novel testing strategies under development, including the use of rapid diagnostic tests, serological tests, and self-collected specimens, will improve our ability to screen a large number of people quickly and give us a new understanding of the extent of exposure, disease, and recovery. This information will be vital to epidemiologic modeling to support information-driven decision making on the appropriate timing and scope of the response. There are also a rapidly growing number of examples of innovative approaches to implementing COVID-19 testing, including some examples of successful large-scale screening programs like drive-up testing in South Korea where thousands of tests were delivered each day [10].

Changing the course of COVID-19 disease in heavily impacted countries such as the United States, will require a massive scale-up of testing compared to what has been conducted to date. For instance, in the United States, the rate of total COVID-19 testing up to this point is just under 3000 tests per 1 million people, or 964,865 overall since January 10, 2020 [11]. That has been an admittedly dismal response to testing, with a focus mainly on those who are most severely ill. This rate of testing does not meet the needs of the health care sector response, much less the needs to better understand COVID-19 epidemiology in a way that will make control measures most effective. We should be testing at least *1 million US residents every week* (0.3% of the population) during this phase of the pandemic. Additionally, there is a need for shorter time from test to results, to better guide care and isolation decisions, and we must find new ways of reaching more people with testing without overburdening our already taxed health care systems.

Improve the Capacity of Health Care

The control of movement and scale-up of COVID-19 testing will only be successful in truncating the COVID-19 pandemic and reducing lives lost if there is an immediate commitment of resources to improve the capacity of the health care sector to respond. Reports from multiple countries already impacted by COVID-19 predict that health care capacity will be rapidly exceeded as transmission grows under the current predictions of COVID-19 transmission. The ability of the health care sector to respond will certainly require coordination of efforts to increase the capacity of hospital beds, ventilators, protective equipment, and the clinicians who use them.

Protecting the health and safety of health care workers is vital to the health of each of us and to the workings of our health

care system. There needs to be a high level of commitment to the safety of health care professionals by providing them with the tools to prevent nosocomial COVID-19 infections. Although this implicitly means making sure all health care workers have appropriate PPEs, this can also come in the form of telemedicine and other virtual care trends such has chatbots that capitalize on advances in technology to provide care for patients outside of a hospital setting until the time hospitalization is needed. This form of care protects our health care workforce and maximizes the scope of care that can be provided with less impact on the hospital setting.

Conclusion

Our global public health response to COVID-19 will only be successful if we rapidly generate the best data to inform decisions from our political leaders regarding resources and policies to slow transmission and improve our response. This is an unprecedented global public health crisis that will require not only strong political commitment and courage, but also innovation on a capacity and timing scale that was inconceivable 3 months ago. What we do right now and how quickly we do it will directly change how long COVID-19 is with us and how many people will die. It is critical that science-based information guide our public health strategies and that leaders listen to our best information.

Much of public health is about making changes to improve human life but without much announcement. It is impossible to determine the number of lives saved due to epidemiologic research, yet it is unquestionable that our discipline has saved millions of lives, through the implementation of interventions and preventative programs. Our training to understand and use data to protect our communities has not been needed more. It is also our responsibility to use our skills wisely and in a steadfast way that does not bend to the whim of politics, but instead, affirms what we know, loudly, if needed, and highlights what we still need to determine as quickly and accurately as possible to protect our world.

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Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease 2019

PPE: personal protective equipment
SARS-CoV-2: severe acute respiratory syndrome-coronavirus 2
WHO: World Health Organization

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Editorial

Iraq Mass Gathering Preparedness and Public Health Recommendations

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mass gathering; Iraq

Iraq is the host to the largest Eastern Mediterranean Region's religious mass gathering. In the last decade, the number of people visiting Karbala on the anniversary of Imam Husseyn's death has increased considerably from year to year. According to 2014 estimates, Karbala City has a local population of approximately 1.1 million individuals in an area of approximately 43.7 km^2 [1]. Millions of people gather at the "Arbaeenia" gathering in Karbala to mark this important event. The approximate number of visitors has increased from 3 million individuals in 2003 to 25 million in 2016, with about 20% coming from countries external to Iraq [2].

As of the 2014 anniversary, preventive measures such as the request for visit permit and proof of vaccination upon entry to Iraq were not in place. However, many sectors are involved in the gathering's proceedings once the city starts welcoming its visitors. The Operations Department at the Iraq Ministry of Health (MOH) and the Health Directorates in Karbala, Najaf, Babel, Aldwanya, Thi Qar, Wassit, and Baghdad (ie, Karkh and Rusafah) contribute to the local planning before the event. Medical services are provided by primary health care centers from the MOH and governmental and nongovernmental health clinics. The local municipalities provide water and hygiene services, and the Sacred Al Abbas Mosque and the Sacred Al Husayn Mosque nongovernmental authorities provide accommodations, covers, food, and medical services.

In the face of the high volume of population movement, the changing date of the anniversary, and short latency, public health authorities need to have preparedness plans and resources to effectively manage the additional pressure on the country's system. Although the Iraq Ministry of Health has been passing the test of safely caring for the large number of visitors every year, it is presented with challenges of providing quality health services and mitigating the increasing risks.

In reviewing the literature of Iraqi mass gatherings, it becomes apparent that the scale of the health strain is not quantified, and the gaps are not identified. In view of the challenges presented by this mass gathering, whether they are related to quantity or quality of services provided to attendees, public authorities and supporting organizations should be ready to accommodate masses throughout the event including pre-event preparation and postevent activities.

Keeping abreast of the economic and political situation in Iraq, the Eastern Mediterranean Public Health Network (EMPHNET) with Iraq Ministry of Health and support from the US Department of State's Biosecurity Engagement Program and Centers for Disease Control and Prevention launched a mass gathering project for the Field Epidemiology Training Program and public health professionals working at the Iraq Ministry of Health from different public health departments. The major aim of this mass gathering project was to strengthen the public health system efforts in accommodating masses and reducing morbidity and mortality during the anniversary of Imam Husseyn's death. The project encompassed three phases and resulted in eight manuscripts. The first phase was conducting an introductory workshop to public health in mass gatherings for field epidemiologists and other health professionals. The second phase focused on the implementation of operational research and holding a policy brief meeting on the findings of the research. The third phase entailed conducting a scientific writing workshop in preparation for manuscripts on the research carried out around the 2014 anniversary of Imam Husseyn's death.

This e-collection [3-10] of the EMPHNET Iraq Mass Gathering Project (2014-2015) was published to promote better readiness and identify any health risk management gaps. Additionally, these publications will help proliferate the much-needed research and literature on public health issues related to mass gathering

in the Middle East. The publications included were peer reviewed by Baghdad University, EMPHNET, and other external technical experts. The articles presented in this supplement will hopefully provide data to initiate better preparedness and planning for future mass gatherings in Iraq.

Conflicts of Interest

None declared.

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Abbreviations

EMPHNET: Eastern Mediterranean Public Health Network
MOH: Ministry of Health

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Original Paper

Antimicrobial Resistance of Neisseria Gonorrhoeae in a Newly Implemented Surveillance Program in Uganda: Surveillance Report

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Abstract

Background: Neisseria gonorrhoeae (commonly known as gonorrhea) has developed resistance to all first-line therapy in Southeast Asia. East Africa has historically had absent or rudimentary gonorrhea surveillance programs and, while the existence of antimicrobial-resistant gonorrhea is recognized, the extent of its resistance is largely unknown. In 2016, the World Health Organization's Enhanced Gonococcal Antimicrobial Surveillance Program (EGASP) was initiated in Uganda to monitor resistance trends.

Objective: This study characterizes gonorrhea and antibiotic resistance in a large surveillance program of men with urethral discharge syndrome from Kampala, Uganda.

Methods: Men attending sentinel clinics with urethritis provided demographic information, behavior data, and a urethral swab in line with the World Health Organization's EGASP protocols for culture, identification, and antibiotic-sensitivity testing using 2 methods—disk diffusion (Kirby-Bauer test) and Etest (BioMérieux Inc). A subset of samples underwent detailed antimicrobial resistance testing.

Results: Of 639 samples collected from September 2016 to February 2018, 400 (62.6%) were culture-positive though 414 (64.8%) had microscopic evidence of gonorrhea. The mean age of the men from whom the samples were collected was 26.9 (SD 9.6) years and 7.2% (46/639) reported having HIV. There was high-level resistance to ciprofloxacin, tetracycline, and penicillin (greater than 90%) by Kirby-Bauer disk diffusion and 2.1% (4/188) had reduced azithromycin sensitivity by Etest. Of the early isolates that underwent detailed characterization, 60.3% (70/116) were culture-positive, 94% (66/69) isolates were either ciprofloxacin-resistant or ciprofloxacin-intermediate by Etest, 96% (65/68) were azithromycin-sensitive, and 96% (66/69) were gentamicin-sensitive. Resistance profiles were comparable between methods except for ceftriaxone (disk diffusion: 68/69, 99%; Etest: 67/69, 97%) and for gentamicin (disk diffusion: 2/8, 25%; Etest: 66/69, 96%) sensitivity.

Conclusions: This is the first report from a systematic gonorrhea surveillance program in Uganda. Findings demonstrated resistance or increased minimum inhibitory concentration to all key antigonococcal antibiotics. There was evidence of poor antibiotic stewardship, near-universal resistance to several antibiotics, and emerging resistance to others. Individuals in the population sampled were at exceptionally high risk of STI and HIV infection requiring intervention. Ongoing surveillance efforts to develop interventions to curtail antimicrobial-resistant gonorrhea are needed.

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KEYWORDS

gonorrhea; antimicrobial resistance; surveillance; Uganda; STD; STI; sexually transmitted; Neisseria Gonorrhoeae; antibiotic resistance, EGASP

Introduction

Neisseria gonorrhoeae (also known as gonorrhea) is a common sexually transmitted infection (STI) and a major cause of morbidity. Gonorrhea has developed antimicrobial resistance to all classes of antibiotics used in its treatment. Gonorrhea can cause sequelae such as pelvic inflammatory disease with resultant ectopic pregnancy [1] and increases HIV transmission [2]. In 2016, 86.9 million of an estimated 376.4 million new, curable STIs in adults aged 15 to 49 years were attributed to gonorrhea [3]. In 2016, the global annual incidence rate of gonorrhea was estimated at 2.6% among men and 2.0% among women. In Africa, the incidence rates were 1.6% and 1.9% among men and women, respectively [3], which was an increase from 2012 [4]. In the 1970s, gonococcal plasmid- and chromosomally mediated resistance to penicillin and tetracycline emerged in Asia, and within a decade, had spread globally [5]. High-level fluoroquinolone resistance evolved in the early to mid 2000s [6]. Third-generation extended-spectrum cephalosporins are the mainstay of gonorrhea therapy in many regions; however, their minimum inhibitory concentration has been increasing since their widespread introduction as a treatment for gonorrhea. More recently, clinical gonorrhea isolates with high azithromycin minimum inhibitory concentration have been recognized and increasingly reported [5,7].

Cases of highly resistant gonorrhea have been reported in several regions [8-10] and likely represent international clonal expansion [11,12]. Sub-Saharan African gonorrhea data are minimal [13-17]; gonorrhea resistance has been documented in Uganda [18,19], but its prevalence is unknown. In 2016, the WHO initiated its Enhanced Gonococcal Antimicrobial Surveillance Program (EGASP) in Uganda to monitor patterns of resistance. The Gonococcal Antimicrobial Surveillance Program (GASP) had been in place since 1992 to monitor antimicrobial resistance worldwide with the aim of informing treatment guidelines [20]. The WHO released the Baseline Report on Sexually Transmitted Infection Surveillance [21] in 2012, at which time there were no GASP regional focal points in Africa; in contrast, in all other WHO regions, there was at least one. In addition, only 5 countries in Africa were participating in GASP at that point in time which was an inadequate response given the burden of gonococcal disease in the region [4]. WHO GASP data from 2009 to 2014 [22] which were reported from 3 sites in Africa (South Africa, Kenya, and Côte d'Ivoire) showed persistent and widespread resistance to penicillin, tetracycline, and ciprofloxacin; increasing resistance to azithromycin (greater than 5%); and emerging resistance and decreased susceptibility to extended-spectrum cephalosporins (although only 15% of countries in Africa reported extended-spectrum cephalosporin data). Data collected from 2015 to 2016 in Zimbabwe described 9.5%-30.8% ciprofloxacin resistance and 100% sensitivity to extended-spectrum cephalosporins [23]. With EGASP, the WHO aimed to address the limitations that were identified in implementing GASP [20]. EGASP protocols standardize sampling strategies, laboratory methods, demographic information, and quality assurance procedures for use in sentinel surveillance sites in selected countries. Focusing EGASP on resource-limited settings allows more detailed scrutiny of the global burden of antimicrobial resistance in areas where prevalence is high. EGASP strengthens and streamlines reporting mechanisms for specified alert values for antimicrobial resistance, thus facilitating timely responses. In Uganda, EGASP represents a collaboration between the National STI Control Program at the Ugandan Ministry of Health, the Infectious Disease Institute in Kampala, and is carried out in partnership with the Centers for Disease Control and Prevention to implement a gonorrhea surveillance program. Herein, we report initial antimicrobial resistance and epidemiological results of the gonorrhea surveillance program in Kampala, Uganda.

Methods

Clinical Setting

Between September 2016 and February 2018, urethral samples were collected from men at nine sentinel clinics in and around Kampala, Uganda. Clinics were selected after reviewing health management information system records at the Ministry of Health and were based upon their ability to meet several criteria. Clinics were required to have high patient volumes in order to collect a sufficient number of samples regularly, an ability to collect data in accordance with Uganda's national STI guidelines which involved recording a patient's full medical history and performing a clinical examination (see Multimedia Appendix 1), and the capacity to collect and maintain sample viability until transportation to the reference laboratory. In order for samples to be properly collected, trained clinical staff were required, and to ensure safe handling of samples, a system for storage until samples were collected and transported (which occurred daily) was required.

Sample Collection and Testing

Urethral Amies swabs without charcoal (Deltalab SL) were used to consecutively collect specimens from men who presented with urethral discharge syndrome. Samples were stored at ambient temperature and atmosphere and were transported within 12 hours to the designated reference laboratory site in Kampala (Infectious Disease Institute Translational Laboratory). Samples were inoculated on modified Thayer-Martin and chocolate agar and incubated between 35°C and 36.5°C in 5% carbon dioxide. Isolation and confirmation of *N gonorrhoeae* was performed with technical assistance from the Department of Microbiology, Makerere University. Presumptive identification of *N gonorrhoeae* was based upon (1) growth of typical colonies on modified Thayer-Martin agar between 35°C

and 36.5°C in 5% carbon dioxide, (2) a positive oxidase test, and (3) observation of Gram-negative, oxidase-positive diplococci in stained smears. Antimicrobial susceptibility tests using Kirby-Bauer disk diffusion were performed for the following antibiotics: penicillin, tetracycline, ciprofloxacin, cefoxitin, gentamicin, spectinomycin, ceftriaxone, and cefixime. Additional antimicrobial susceptibility tests were performed using Etest strips (BioMérieux Inc) to determine minimum inhibitory concentration for a subset of isolates for the following priority antibiotics: cefixime, ceftriaxone, cefuroxime, ciprofloxacin, azithromycin, and gentamicin on gonococcal medium base inoculated with 10^4 colony forming units. Etest strips are expensive and difficult to source in Uganda, and therefore, were used routinely early in the program, after which disk diffusion was used routinely to determine antimicrobial susceptibility. Presumptive *N gonorrhoeae* isolates with minimum inhibitory concentrations that exceeded criteria specified by EGASP protocols (antibiotic alert value criteria: ceftriaxone, ≥0.125 µg/mL; cefixime, ≥0.25 µg/mL; azithromycin, ≥2 µg/mL; gentamicin ≥16 µg/mL) underwent additional Etest analysis according to Biochemical Test Clinical and Laboratory Standards Institute Guidelines within five working days.

Quality Assurance and Quality Control

Due to constraints on resources, the EGASP-recommended WHO *N gonorrhoeae* K and L control strains were not used. Alternative quality measures that could be locally implemented were used. The Becton-Dickinson control strain (American Type Culture Collection; ATCC 49226) was used in the place of WHO *N gonorrhoeae* K and L strains. Control tests were carried out monthly or upon receipt of a new batch of antimicrobial susceptibility disks, Etest strips, or the introduction of a new batch of media. Isolate identification was performed to ensure consistency in methods and the zones of clearance for the control strain were compared to the reference standards for each drug.

Data Management and Analysis

Demographic and behavior data were collected using the combined WHO–Ministry of Health Uganda data collection form, albeit the same-sex sexual activity question was removed to reduce the risk of harm to respondents [24]. Data were manually entered into Access database software (Microsoft Inc) prior to data analysis. Minor amendments were made to the questionnaire partway through the time period under review to be more realistic in expectations of the individual's ability to recollect events and to reduce the chance of recall bias—the period for number of gonorrhea episodes and number of sex partners was reduced from 12 to 6 months. Similarly, the period for recent, previsit antibiotic use was reduced from 60 to 14 days. These differences were reflected in the different timeframes used for reporting. Antimicrobial susceptibility data were exported to WHONet, a WHO information system for managing, analyzing, and reporting antimicrobial resistance data. If confirmed, minimum inhibitory concentrations that exceeded alert criteria were promptly reported to the Ministry of Health and to sentinel clinics.

Disk diffusion for isolates for all antibiotics, with the exception of cefoxitin, were reported. Etests were used for an initial subset of 116 isolates as well as for some later specimens (if Etest strips were available) or when isolates met minimum inhibitory concentration alert value criteria. Data on cefoxitin were included in the comprehensive analysis of 116 samples using Etest. P values ≤.05 were deemed statistically significant. Data were compared using two-tailed independent t tests with unequal variance for continuous variables and using the chi-square test for categorical variables. Odds ratios (OR) and their associated confidence intervals were calculated using logistic regression. All analyses were performed using SAS statistical software (version 9.4; SAS Institute Inc).

Ethical Approval

The gonococcal surveillance program was performed as part of public health surveillance activities under the purview of the Ugandan Ministry of Health and approved by the Director General. As the activity was permitted by the Ministry of Health in the interest of public health practice for disease surveillance in Uganda, it did not fall within the realm of research. The gonococcal surveillance program legitimately involved individuals who were not explicitly asked to provide informed consent and did not require further institutional review board approval.

Results

Overall Sample Characteristics

Results are presented for the overall sample characteristics and are further analyzed by gonorrhea culture–status.

Urethral samples (N=639) were collected from men whose mean age was 26.9 (SD 9.6) years, and of whom, 7.2% (46/639) self-reported HIV-positive (Table 1). Microscopic diagnosis of presumptive gonorrhea was positively made from evidence of Gram-negative intracellular diplococci from urethral material in 414/639 (64.8%) samples; evidence of Gram-negative intracellular diplococci was not present in 225/639 (35.2%) of samples. Only 400 (400/414, 96.6%; 400/639, 62.6%) Gram-negative intracellular diplococci–positive samples on Gram staining were culture-positive, based on the growth of typical small translucent colonies on modified Thayer-Martin medium, and of these 399 (399/414, 96.4%; 399/639, 62.4%) were oxidase- and superoxidase-positive consistent with gonorrhea. Overall, 36% of samples (230/639) were culture-negative. Of the culture-positive samples, 60.8% (243/400) were from individuals self-reported without HIV, 7.5% (30/400) were from individuals self-reported HIV-positive, and 31.8% (127/400) were from individuals whose HIV-status was unknown.

Reported condom-use was low; 2.7% (18/639) reported always using a condom and 69.3% (443/639) reported one or more sexual partners within the past 6-12 months (mean 1.4; SD 1.49; range 0-20). Full demographic, behavior, and health-related characteristics are presented in Table 1.

Table 1. Demographic, health-related, and behavior factors.

Variable	Samples (N=639), n (%)
HIV-status	
Positive	46 (7.2)
Negative	393 (61.5)
Unknown	200 (31.3)
Condom use[a]	
Always	18 (2.8)
Sometimes	403 (63.1)
Never	176 (27.5)
Number of sex partners[b,c]	
0	189 (29.1)
1	196 (31.0)
2	146 (23.1)
3	61 (9.7)
4	12 (1.9)
5	14 (2.2)
6	7 (1.1)
7	1 (0.2)
8	1 (0.2)
10	4 (0.6)
20	1 (0.2)
Symptoms	
Discharge	590 (88.2)
Dysuria	553 (86.5)
Other	36 (5.6)
Previous history of gonorrhea	
Yes	286 (44.8)
No	353 (55.2)
Sex for money[b]	
Yes	98 (15.3)
No	541 (84.7)
Recent antibiotic use[d]	
Yes	209 (32.7)
No	430 (67.3)

[a]n=42 responses were missing.

[b]in the past 6 or 12 months.

[c]n=7 responses were missing.

[d]in the past 14 or 60 days.

Resistance Profiles

Table 2 and Table 3 show the resistance characteristics found by disk diffusion and by Etest, respectively. Fewer Etests were performed because of difficulty in obtaining test kits. Disk diffusion showed greater than 91% (364/399) resistance to penicillin and greater than 99% (397/399; 399/399) resistance to both tetracycline and ciprofloxacin. A resistance of 1.06% (2/188) to ceftriaxone and resistance or intermediate resistance of 2.1% (4/188) to azithromycin were found using Etest. Early samples (n=116) collected from September 2016 to March 2017 underwent comprehensive microbiological analysis and 59.5%

of these (69/116) underwent complete Etest resistance profiles. Of these, 96% (66/69) were ciprofloxacin-resistant or ciprofloxacin-intermediate, no resistance (0/69) to cefixime was demonstrated, and 96% (66/69) of isolates were azithromycin- and gentamicin-sensitive (Table 4).

The minimum inhibitory concentrations needed for inhibiting 50% of microbial growth for ceftriaxone, cefixime, gentamicin, ciprofloxacin, and azithromycin were 0.003 µg/mL, 0.0016 µg/mL, 3 µg/mL, 2 µg/mL, and 0.19 µg/mL, respectively. Additionally, 2 isolates demonstrated high-level resistance to azithromycin by Etest (minimum inhibitory concentrations=12 µg/mL and 16 µg/mL) and 1 isolate demonstrated intermediate resistance to azithromycin (minimum inhibitory concentration=3 µg/mL); 3 isolates were gentamicin-intermediate (all 3 with minimum inhibitory concentration=6 µg/mL) and were sensitive to azithromycin.

Table 2. Disk diffusion resistance characteristics.

Antibiotics	Breakpoint in mm	ZOI[a] range in mm	Resistant, n (%)	Intermediate, n (%)	Sensitive, n (%)
Cefixime (n=395)	S[b]≥31	28-60	0 (0)	1[c] (0.25)	394 (99.7)
Ceftriaxone (n=397)	S≥35	28-62	2[d] (0.5)	2[d] (0.5)	393 (99.0)
Ciprofloxacin (n=399)	≥41	0-27	399 (100)	0 (0)	0 (0)
Penicillin G (n=399)	≥47	10-52	364 (91.2)	34 (8.5)	1 (0.25)
Spectinomycin (n=34)	≥18	18-34	0 (0)	1 (2.9)	33 (97.1)
Tetracycline (n=399)	≥38	6-40	397 (99.5)	1 (0.25)	1(0.25)

[a]ZOI: zone of inhibition.

[b]S: sensitive.

[c]ZOI of 28 mm.

[d]2 had ZOI of 28 mm, 1 had ZOI of 32 mm, and 1 had ZOI of 34 mm.

Table 3. Etest resistance characteristics.

Antibiotics		Resistant		Intermediate		Sensitive	
	Range (µg/mL)	n (%)	Breakpoint (µg/mL)	n (%)	Breakpoint (µg/mL)	n (%)	Breakpoint (µg/mL)
Azithromycin (n=188)	<0.016-16	2 (1.1)[a]	≥8	2 (1.1)[b]	—	184 (97.9)	≤2
Cefixime (n=185)	<0.016-0.16	0 (0)	—	—	—	185 (100)	≤0.25[c]
Ceftriaxone (n=188)	0.002-1.5	2 (1.1)[d]	—	—	—	186 (98.9)	≤0.25[c]
Ciprofloxacin (n=192)	0.002-32	188 (97.9)	≥1	—	—	4 (2.1)[e]	≤0.061
Gentamicin (n=189)	0.38-48	1 (0.5)[f]	≥32	3 (1.6)[g]	8-16	185 (97.9)	≤4

[a]Minimum inhibition concentrations (MIC) are noted here;1 sample had MIC=12 µg/mL; 1 sample had MIC=16 µg/mL.

[b]2 samples had MIC=3 µg/mL.

[c]2 samples had MIC=0.125 µg/mL.

[d]1 sample had MIC=1.5 µg/mL; 1 sample had MIC=0.5 µg/mL.

[e]2 samples had MIC=0.02 µg/mL; 1 sample had MIC=0.016 µg/mL; 1 sample had MIC=0.008 µg/mL.

[f]1 sample had MIC=48 µg/mL.

[g]3 samples had MIC=6 µg/mL.

Table 4. Percentage of isolates susceptible to the antibiotic tested.

Antibiotic	Disk diffusion	Etest (%)
Azithromycin	NT[a]	95.6
Cefixime	100	100
Ciprofloxacin	4.3	0.0
Ceftriaxone	99.0	97.0
Cefuroxime	100	90.0
Cefoxitin	84.0	NT
Gentamicin	25.0	95.7
Penicillin	0.0	NT
Spectinomycin	97.0	NT
Tetracycline	0.0	NT

[a]NT: not tested.

The gonorrhea samples (4/400, 1% of culture-positive) that demonstrated decreased susceptibility to ceftriaxone by disk diffusion were different by Etest where resistance was set at ≥0.25 µg/mL. In the 5 isolates with results by both methods, 2 were intermediate, 1 was resistant, and 2 were sensitive by disk diffusion, compared with 2 resistant and 3 sensitive by Etest; full details are in Multimedia Appendix 2. The 2 (0.5%) gonorrhea isolates demonstrating intermediate or decreased minimum inhibitory concentration to cefixime by disk diffusion were found to be sensitive by Etest, when that test was performed, where resistance was set at ≥0.25 µg/mL (Multimedia Appendix 2). There were 4/188 (2.1%) gonorrhea isolates that demonstrated intermediate or decreased minimum inhibitory concentration to azithromycin by Etest where sensitivity was set at ≤2.0 µg/mL (Multimedia Appendix 2).

Table 5 categorizes the data by gonorrhea culture–status. Men with HIV were significantly older (P<.001). Self-reported HIV positivity of 7.2% was higher than the national 5.3% (range 5.0%-5.7%) in men aged 15 to 49 years and substantially higher than the 1.9% reported in those aged 15 to 24 years reported by Joint United Nations Program on HIV/AIDS [25]. Rates of condom use were significantly different with men with HIV more likely to report always using a condom (P<.001); these men were more likely to have accessed antibiotics prior to their clinic visit for urethritis (P=.006; data not shown). Men whose samples were gonorrhea culture–positive were younger (P=.01) and less likely to always use condoms (P=.003). Men who reported sometimes using condoms were more likely to be found *N gonorrhoeae* culture–positive compared to those who never used condoms (Odds ratio [OR] 1.77, 95% CI 1.23, 2.55). Men whose samples were *N gonorrhoeae* culture–positive had fewer numbers of previous *N gonorrhoeae* episodes than those whose samples were culture-negative (P<.001); for every previous episode they had a 0.68 odds of being *N gonorrhoeae* culture–positive. Only 43.3% (173/400) of men whose samples were culture-positive had been prescribed the recommended treatment of an extended-spectrum cephalosporin and doxycycline as syndromic management of urethral discharge syndrome [26].

Table 5. Variables by gonorrhea culture–status.

Variable	All[a], N=639	Negative, n=230	Positive, n=400	Odds Ratio (95% CI)	*P* value
Age, mean (SD)	26.9 (9.6)	28.3 (10.2)	26.3 (9.0)	0.98 (0.96, 0.99)	.01
HIV-status, n (%)					.67
Positive	46 (7.2)	16 (7.4)	30 (7.8)	1.13 (0.60, 2.15)	
Negative	393 (61.5)	147 (68.1)	243 (64.5)	REF	
Unknown	200 (31.3)	67 (29.1)	127 (31.8)	1.147 (0.80, 1.64)	
Engage in commercial sex, n (%)					.13
Yes	98 (15.3)	42 (18.3)	55 (13.8)	0.71 (0.46, 1.11)	
No	541 (84.7)	188 (81.7)	345 (86.3)	REF	
Condom use[b], n (%)					.003
Always	18 (3.0)	8 (3.8)	7 (1.9)	0.71 (0.25, 2.05)	
Sometimes	403 (67.5)	126 (59.4)	274 (72.7)	1.77 (1.23, 2.55)	
Never	176 (29.5)	78 (36.8)	96 (25.5)	REF	
Previous episodes of gonorrhea[c], n				0.68 (0.56, 0.83)	<.001
mean (SD)	0.43 (0.87)	0.62 (1.13)	0.32 (0.66)	N/A	
range	0-8	0-8	0-3	N/A	
Number of sex partners[d], mean (SD)	1.4 (1.7)	1.4 (2.0)	1.4 (1.5)	0.99 (0.91, 1.10)	.98
Recent antibiotic use, n (%)				0.73 (0.52, 1.02)	.07
Yes	209 (32.7)	86 (37.4)	121 (30.3)	N/A	
No	430 (67.3)	144 (62.6)	279 (69.8)	N/A	
Antibiotic therapy[e], n (%)					.17
Correct combination	254 (42.3)	85 (39.7)	173 (43.3)	REF	
Correct combination plus metronidazole or tinidazole	199 (33.2)	65 (30.4)	132 (35.0)	0.94 (0.64, 1.40)	
Overtreatment	42 (7.0)	19 (8.9)	23 (6.1)	1.58 (0.82, 3.07)	
Incorrect antibiotic combination	106 (17.5)	45 (21.0)	59 (15.7)	1.46 (0.92, 2.34)	

[a]n=9 missing culture-status.

[b]n=42 responses were missing.

[c]n=21 responses were missing.

[d]n=7 responses were missing.

[e]n=38 responses were missing.

Discussion

Principal Findings

The WHO STI guidelines currently recommend that reliable and recent local resistance data should guide the choice of either single or dual therapy for genital and anorectal gonococcal infection [27]. While agar dilution is considered the gold standard for determining antimicrobial susceptibility of *N gonorrhoeae* [28], it is labor-intensive and requires technical expertise that is often not available in resource-limited settings. Disk diffusion is widely used in microbiology laboratories for antibiotic-sensitivity testing, but reproducibility is a significant issue. While Etests are more reliable, simpler, and faster to perform, and its results have demonstrated acceptable agreement with those from agar dilution [29,30], the cost of Etests may be an issue in resource-limited settings. Our data demonstrate good concordance between resistance measured by disk diffusion and that measured by Etest for most antibiotics that were tested (with the exception of gentamicin). For other antibiotics, where comparison between methods was possible, discordance ranged from 0% to 10%. The reason for the 71% difference between the two different sensitivity-testing methods for gentamicin is not known and requires further investigation. Gentamicin's Etest results are most likely to be correct; similar, though less pronounced differences by assay type have been reported [31].

In Uganda, between 1993 and 2010, ciprofloxacin was the recommended first-line antibiotic for presumptive gonorrhea. Since 2012, Ugandan Clinical Guidelines recommend a single dose of cefixime with doxycycline taken over 7 days for syndromic management of urethral discharge syndrome [26].

The antimicrobial resistance profiles reported here have profound public health implications; they support arguments for expanded surveillance programs and investment in first-line antibiotic supplies which could improve population health and slow the spread of antimicrobial-resistant gonorrhea in Uganda. In 2018, the annual cost of EGASP in Kampala was approximately 247,000,000 UGX (US $64,996; an exchange of 1 UGX=US $0.0026 was applied). Of the total, 23% of costs were for antimicrobial testing, 4% for clinic staff, and 17% for the sites.

Recently, ceftriaxone-resistant gonorrhea strains have been found in Asia, Europe, and North America [8,11,32]. High-level azithromycin resistance has also been reported [7,10]. This marks a low point in the battle against antimicrobial-resistant gonorrhea since both ceftriaxone and azithromycin are recommended by the Centers for Disease Control and Prevention and other agencies as first-line therapies [27,33]. As a result, the Centers for Disease Control and Prevention and WHO have called for the strengthening of global surveillance [20]; in Africa, surveillance has been inadequate or virtually absent [34]. The emergence of gonorrhea with decreased sensitivity to current first-line antibiotics raises the specter of untreatable multidrug resistance. *N gonorrhoeae* has evolved to outpace every new class of antibiotic that has been routinely used in its treatment. The pipeline for new antigonococcal therapies is narrow with no readily available, affordable, and orally administered drugs close to being accessible for routine clinical use [5]. New drugs such as the novel oral fluoroketolide or solithromycin show potential but are not FDA-approved, and the recycling of older drugs, such as gentamicin, is limited by potential toxicity and less-than-ideal effectiveness (<92% microbiological cure). Even carbapenems are not guaranteed to have enduring efficacy since extended-spectrum cephalosporin resistance determinants (for example, mosaic *penA* alleles, *mtrR*, and *penB*) also increase the ertapenem minimum inhibitory concentration [12].

Antimicrobial resistance can readily develop in sub-Saharan Africa because of limited surveillance and poor antimicrobial stewardship. The feasibility of undertaking gonorrhea surveillance in a resource-limited setting on a relatively large scale has been established [35]. It is likely that urethral discharge syndrome represents a small portion of actual antibiotic resistance since cervical, rectal, and pharyngeal infections are often asymptomatic [36,37].

These data reveal a population with higher than national average HIV prevalence (7.2% versus 5.3%), substantial rates of transactional sex (15.3%), a high number of partners, and very low consistent condom-use (less than 3.0%). Those who reported sometimes using condoms in comparison to those who reported never using condoms were found to be *N gonorrhoeae* culture–positive more often. This counterintuitive finding may reflect that men who engaged in lower-risk sexual encounters with regular partners were less likely to use condoms but requires further exploration. Men with previous episodes of gonorrhea were found to be less likely to have a positive *N gonorrhoeae* culture. The explanation for this is not clear but may reflect differences in antibiotic use prior to attending clinic, or raises the possibility of unexplained, modest, inducible immune responses to repeated *N gonorrhoeae* infection [38]. Less than 50% received recommended first-line antibiotic treatment. Even in high-resource countries such as the United States, in 2016, approximately 20% of individuals received nonrecommended regimens for gonorrhea [39]. Ciprofloxacin use was common despite its almost universal resistance; indeed, ciprofloxacin antimicrobial resistance appears to have increased dramatically in the past decade from 83.1% in 2008 and 2009 [18] to 97.9% in this analysis (measured by Etest). Azithromycin resistance has increased from 2.7% in 2008 and 2009 [18] to 4% in this analysis. In 2008 and 2009, there was no documented cefixime resistance which should offer some reassurance, since cefixime is a WHO and Ugandan recommended first-line treatment; however, anecdotal evidence suggests that cefixime is generally unavailable in STI clinics, and that patients are unable to afford the drug. Cefixime's continued potency may be the result of its own scarcity. Data on same-sex sexual activity were not collected, since disclosure could be potentially dangerous [24]. The Joint United Nations Program on HIV/AIDS reported a much higher rate of HIV in Ugandan men who have sex with men (13.2%) than that in men who have sex with women (5.3%) [25], so it is likely that *N gonorrhoeae* prevalence is also higher, particularly at extragenital sites. There were low rates of antimicrobial resistance to both gentamicin and extended-spectrum cephalosporins, but they were measurable so, nevertheless, require monitoring. In contrast, there was no recorded gentamicin resistance in Malawi in 2007 [31]. The finding of isolates (4/188, 2.1%) with increased minimum inhibitory concentration to azithromycin was concerning since, in many regions, azithromycin is a common component of dual *N gonorrhoeae* therapy [33], and Uganda may be compelled to follow suit given the extremely high rates of doxycycline resistance.

There was overtreatment in up to 11.6% of men which included oral cefixime and parenteral ceftriaxone in the same individual. Only 414/639 (64.8%) of men presenting with discharge had Gram-negative intracellular diplococci on Gram stain or a positive gonorrhea culture, compared with 73.5% in an earlier Zimbabwean study [40] that used multiplex polymerase chain reaction which is more sensitive than culture. The remaining 35.2% had, by definition, nongonococcal urethritis and were likely to have other unrecognized STIs.

Limitations

The study was limited by several factors including the lack of biochemical or molecular testing to confirm nutrient requirements and that typical morphologies and oxidase reactions represented *N gonorrhoeae* rather than related *Neisseria* species. In addition, the data on previous gonorrhea- and HIV-status were collected by self-report and 31.3% of the men were not aware of, or did not report, their HIV-status. There was no clinical outcome data, and the nature of antibiotic treatment taken prior to clinic attendance was unknown. Of the 414 samples with Gram-negative intracellular diplococci on microscopy, 400 (96.6%) were *N gonorrhoeae* culture–positive while the remainder resulted in nonsignificant growth which could represent culture failure or the presence of other morphologically similar species. Firm conclusions about concordance between antibiotic sensitivity methods in the

samples that demonstrated intermediate or decreased minimum inhibitory concentration to azithromycin is difficult because of incomplete testing by both methods.

We had no data on same-sex activity or extragenital exposures nor did we have data on the prevalence of other STIs. Finally, different data collection or case report forms were used; therefore, some of the data points were collected across different periods (over 6 months versus 12 months) which may have influenced recall bias.

Conclusion

Data on *N gonorrhoeae* resistance in sub-Saharan Africa have been lacking to date, with the exception of sporadic studies and reports [21,22,41], and more recently, increasing systematic efforts [35]. This study has clearly demonstrated resistance to and increased minimum inhibitory concentration for vital antigonococcal antibiotics. It supports the hypothesis that several antibiotics are obsolete for use in the treatment of gonorrhea in Uganda. Ciprofloxacin resistance is much higher in Uganda than described elsewhere despite its removal from treatment guidelines more than 5 years ago—resistance to it has persisted and ciprofloxacin cannot be recycled. Measurable azithromycin and gentamicin resistance and decreased sensitivity as well as increasing minimum inhibitory concentration for ceftriaxone are worrisome. With selection pressure being exerted by the frequent use of extended-spectrum cephalosporins for numerous febrile illnesses in Africa, it may not be long before these strains are endemic in Uganda. There were very high rates of sexual risk in this population and there is a need for prevention interventions such as HIV pre-exposure prophylaxis. Antimicrobial stewardship programs in conjunction with continued surveillance will be critical in preventing the expansion of antimicrobial-resistant gonorrhea and will be important for filling gaps in knowledge, identifying emerging trends, and creating data-driven action plans.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Ugandan National treatment guidelines.
[DOCX File , 63 KB - publichealth_v6i2e17009_app1.docx]

Multimedia Appendix 2
Additional results.
[DOCX File , 19 KB - publichealth_v6i2e17009_app2.docx]

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Abbreviations

EGASP: Enhanced Gonococcal Antimicrobial Surveillance Program
FDA: Food and Drug Administration
GASP: Gonococcal Antimicrobial Surveillance Program
GNID: gram-negative intracellular diplococci
HIV: Human Immunodeficiency Virus
MIC: minimum inhibitory concentration
OR: odds ratio
STI: sexually transmitted infection
UGX: Ugandan shilling
WHO: World Health Organization
ZOI: zone of inhibition

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Original Paper

The Surveillance Outbreak Response Management and Analysis System (SORMAS): Digital Health Global Goods Maturity Assessment

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Abstract

Background: Digital health is a dynamic field that has been generating a large number of tools; many of these tools do not have the level of maturity required to function in a sustainable model. It is in this context that the concept of global goods maturity is gaining importance. Digital Square developed a global good maturity model (GGMM) for digital health tools, which engages the digital health community to identify areas of investment for global goods. The Surveillance Outbreak Response Management and Analysis System (SORMAS) is an open-source mobile and web application software that we developed to enable health workers to notify health departments about new cases of epidemic-prone diseases, detect outbreaks, and simultaneously manage outbreak response.

Objective: The objective of this study was to evaluate the maturity of SORMAS using Digital Square's GGMM and to describe the applicability of the GGMM on the use case of SORMAS and identify opportunities for system improvements.

Methods: We evaluated SORMAS using the GGMM version 1.0 indicators to measure its development. SORMAS was scored based on all the GGMM indicator scores. We described how we used the GGMM to guide the development of SORMAS during the study period. GGMM contains 15 subindicators grouped into the following core indicators: (1) global utility, (2) community support, and (3) software maturity.

Results: The assessment of SORMAS through the GGMM from November 2017 to October 2019 resulted in full completion of all subscores (10/30, (33%) in 2017; 21/30, (70%) in 2018; and 30/30, (100%) in 2019). SORMAS reached the full score of the GGMM for digital health software tools by accomplishing all 10 points for each of the 3 indicators on global utility, community support, and software maturity.

Conclusions: To our knowledge, SORMAS is the first electronic health tool for disease surveillance, and also the first outbreak response management tool, that has achieved a 100% score. Although some conceptual changes would allow for further improvements to the system, the GGMM already has a robust supportive effect on developing software toward global goods maturity.

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KEYWORDS

mHealth; eHealth; contact tracing; case management; epidemiology; Ebola Virus Disease; West Africa; infectious diseases

Introduction

Overview

Digital health is a dynamic field with a rapidly growing number of initiatives and tools, many of which operate in certain geographic areas and for a limited period [1]. This lack of sustainability may be due to a variety of reasons, including the lack of integration in standard frameworks, lack of diverse and continuous donor support, lack of serving the objectives, and limited generalizability of its application among others [2-4]. In the field of public health, funding for such initiatives relies mostly on scarce public resources. Many such parallel initiatives do not seem to be mature enough to survive their pilot phase, which makes it particularly unfortunate. It is in this context that the concept of global goods maturity is gaining importance [5,6].

Global Goods

The concept of global goods stems from guidelines influencing health policies to support technologies that are meant to assist government agencies and policy makers in launching, scaling, and sustaining digital health innovations [7]. Different ministries of health convened advisory committees, including members of the digital health ecosystem and new multifaceted enterprises such as the Digital Impact Alliance and Digital Square [7]. These included global agencies, governments, philanthropies, funders, and academics to improve health data through shared investments in global goods and to fast-track the development and scale-up of successful digital health solutions to campaign for improvements in the facilitating environment for digital health [6,8]. To address the current lack of donor coordination, the committees created a framework to allow shared investments in specific countries and global goods. Health strengthening through enhancing country information systems would contribute to better decision making and, ultimately, better health [6]. The digital investment principles state that the funding donors within countries who are looking to prioritize their needs to improve the health of populations should align their resources around scalable, sustainable, accessible, interoperable, and evidence-based digital health global goods [6].

Surveillance Outbreak Response Management and Analysis System

The Surveillance Outbreak Response Management and Analysis System (SORMAS) is an open-source mobile and web application software that we developed to enable health workers to notify health departments about new cases of epidemic-prone diseases, detect outbreaks, and manage outbreak response at the same time. SORMAS is a management process system that supports supervisors to validate cases and control the spread of disease. As a multifunctional software, it can be used for case surveillance, laboratory data management, contact tracing, and disease detection to prevent and manage outbreaks that may occur. SORMAS also uses a bidirectional information exchange synchronizing user requests as well as sending feedback to the different users within the existing surveillance system [9-11].

Digital Square Global Goods Maturity Model

Digital Square, which is an initiative aimed at coordinating international efforts to develop and broadly share useful, free, and open-source digital tools, included 18 mobile health (mHealth) tools into the database of digital health software referred to as “global goods software” [12,13]. Digital Square developed a global good maturity model (GGMM) for digital health tools, which engages the digital health community to identify areas of investments for global goods [12,13]. We identified the GGMM to be a suitable concept in assessing the maturity of SORMAS for the following reasons: (1) GGMM has a particular focus on health software and on that being used in low-resource settings [12,13], (2) the objectives of GGMM matches well with the mission of SORMAS [12,13], and (3) the scope of most of the tools included in the GGMM guidebook fits that of SORMAS [12,13].

The following key concepts are prevalent throughout the study in determining the maturity of SORMAS according to the GGMM: global utility, community support, and software maturity. The objective of this study was to assess the level of global goods maturity that SORMAS has attained using the GGMM version 1.0.

Methods

We applied the GGMM version 1.0 on SORMAS from November 2017 until October 2019 to assess the level of global goods maturity that it has attained [13]. The GGMM contains 15 subindicators grouped into the following 3 core indicators: (1) global utility, (2) community support, and (3) software maturity. Each subindicator is divided into 3 possible values from −1 for “low,” 0 for “medium,” to 1 for “high.” Each value contains a definition that is listed in Table 1. Given that the GGMM scoring values range from negative to positive values, we applied the following transformation to allow percentage values for summary scores, as shown in equation (1), where, MS=maturity score for each core indicator, Si=vector containing scores of the subindicators, and i= *1*,..., *5*:

$$MS=5 * [MEAN (S_i)] + 5 \quad (1)$$

Table 1. Global good maturity model 1.0 guideline of digital intervention tools containing 15 subindicators from global utility, community support, and software maturity global indicators.

Indicator	Low	Medium	High
Global utility			
Country utilization	Less than two countries or states actively use the tool for use as part of their health information system	At least four countries or states actively use the tool for use as part of their health information system, with at least 20% of total nation-wide or state-wide target users routinely using product or service as intended	At least ten countries or states actively use the tool for use as part of their health information system, with at least 30% of total nation-wide or state-wide target users routinely using product/service as intended
Country strategy	Less than two countries or states have included the tool as part of their electronic health (eHealth) strategy or framework	At least four countries or states have included the tool as part of their eHealth strategy or framework	At least ten countries or states have included the tool as part of their eHealth strategy or framework
Digital health interventions	The tool does not meet digital functional requirements (as defined by World Health Organization's [WHO's] Classification of Digital Health Interventions) without significant customization or configuration	The tool does partially meet digital functional requirements (as defined by WHO's Classification of Digital Health Interventions) without significant customization or configuration	The tool does fully meet digital functional requirements (as defined by WHO's Classification of Digital Health Interventions) without significant customization or configuration
Source code accessibility	Source code not publicly available or not released under an open-source license	Source code exists on a publicly accessible repository and licensed under an open-source initiative approved license	Source code exists on a publicly accessible repository and licensed under an open-source initiative approved license. The software is structured to allow local customizations and new modules and functionality without requiring forking of main code
Funding and revenue	At most, two revenue streams exist. Revenue streams are largely dependent on time-bound project implementations	Multiple revenue streams/funders exist across project implementations	Multiple revenue streams and funding mechanisms exist, including at least one that provides for multi-year support of core software development, documentation, and other key artifacts
Community support			
Developer, contributor, and implementer community engagement	Less than 10% of the estimated total of developers, contributors and implementers are on a communication platform	Up to 20% of the estimated total of developers, contributors, or implementers, including some country representation, are engaged on a communication platform	At least 30% of estimated total developers, contributors, and implementers are engaged on a communication platform. Community leadership includes representation from countries where the tool is deployed
Community governance	There is no community governance structure in place to direct continued development of the digital health tool	Some informal processes for community management exist to direct continued development of the digital health tool	Formal community structures (eg, leadership, technical advisory group, and community representatives) exist and are practiced with documented roles and responsibilities in a transparent fashion and are used to direct continued development of the digital health tool
Software roadmap	No software roadmap exists, or there is no publicly accessible and routinely maintained platform for new feature requests	There is a publicly accessible and routinely maintained platform for new feature requests. A software roadmap exists describing currently planned and resourced development activities	New features and functionality are documented as part of a software roadmap as part of a release cycle. There are forums for community members to discuss new feature requests. A clear prioritization process exists and is utilized for the development of new features and functionality as part of a product backlog

Indicator	Low	Medium	High
User documentation	No user documentation exists	Some user documentation exists (training manual, demo videos) but only addresses a limited subset of common functionality	A full suite of user documentation exists, including training manuals, web-based courses, tutorials, and implementation guides addressing most of the common functionality. Documentation has been released under a Creative Commons license
Multilingual support	Limited or no support in the software for multiple languages. Multilingual documentation/user resources are practically nonexistent	Software has been internationalized to support multiple languages (though may not have been translated) for primary portions of the user interface. Some user documentation exists in more than one language	Software has been translated into multiple languages and fully supports internationalization requirements. There is an easy tool for new translations to be added. Significant parts of user and implementer documentation has been translated into at least one other language
Software maturity			
Technical documentation	No substantial documentation of the software exists	Some technical documentation exists of the source code, use cases, and functional requirements	Source code is documented to the point that new adopters can customize and add new functionality with relying on significant help from one of the core developers. Online courses or tutorials are available to address common development and deployment tasks. Core business workflows and functional requirements are fully documented using use cases, user stories, or other equivalent methodology
Software productization	No documentation available for deployment and configuration	Full documentation available for deployment and configuration. A new implementation does not require the involvement of the core development team	Software has been packaged for one or more common operating systems or platforms. Software upgrades can largely be achieved without manual intervention. Unit or integration testing is part of the release process
Interoperability and data accessibility	Extract or import data into the system usually requires looking at source code and/or directly accessing database	Some application programming interfaces (APIs) are available for accessing and managing data. There are user-facing interfaces to export core data and metadata in the system (eg, in CSV format) for further analysis and data transfer purposes	A robust API is available for key data and metadata exchange needs for the primary business domain with functional requirements for the API having been developed in conjunction with appropriate country, regional, and global stakeholders. API endpoints exist for core data and metadata elements that adhere to standards developed by an appropriate Standards Development Organization relevant to the tools business domain. Standards-based API endpoints are used in at least four jurisdictions (eg, countries or states)
Security	No security controls or implementation guidance is in place	Role-based authorization exists, if appropriate. Guidance on encrypting all remote access (web interface and APIs) is available to implementers	Role-based authorization exists, if appropriate. All remote access (web interface and APIs) are encrypted by default using current best practices. An independent security audit of the software has taken place within the last 12 months

Indicator	Low	Medium	High
Scalability	There are no jurisdictions (eg, country and state) that manage 10% of their "entities" within the tool, and no performance and load statistics exist	There is at least one jurisdiction (eg, country and state) deployment for which 20% of all "entities" are managed within the software. There has been at least one evaluation of software performance/load testing	There is at least one jurisdictions (eg, country, state) deployment for which 30% of all "entities" are managed within the software. Performance and load testing is a part of routine releases, and results are publicly available

We put together a GGMM assessment group consisting of a public health expert from the Nigerian Centre for Disease Control, a medical epidemiologist, an international health expert, an information technology specialist and a statistician from the Helmholtz Centre for Infections Research, and 2 software engineers from Symeda, a company for developing health software. This group periodically assessed the completion of SORMAS in the 15 subindicators. Subsequently, the software roadmap and the work plan of SORMAS was reprioritized to dedicate resources to and obtain progress in those subindicators that did not reach a full score. To reduce selection bias, as members of the assessment group were part of the development and deployment of SORMAS, and to reduce the potential partiality resulting from it, we also asked 2 external experts to review the findings made by the assessment group. These external experts had contributed to the development of the GGMM and were not involved in the development of SORMAS.

Results

In November 2017, SORMAS had migrated from a tabletop pilot version to a real-life deployed open-source software and was deployed in 8 federal states and 33 local government areas (LGAs) during the monkeypox outbreak. From September 2016 until November 2017, SORMAS was piloted in 1 state in 2 LGAs and 85 health facilities [14,15]. By February 2018, SORMAS was deployed in 3 additional federal states (71 LGAs) for meningitis outbreak. In March and April 2018, SORMAS was further deployed in 3 additional states (49 LGAs; 5 health facilities) for the Lassa fever outbreak. As of October 2019, SORMAS has been fully established for all epidemic-prone diseases in 15 federal states (including the federal capital), 287 LGAs, 37 health facilities, and approximately 700 users covering a population of 75 million. SORMAS managed multiple outbreaks simultaneously across the country. The assessment of SORMAS applying the GGMM showed that SORMAS had a 10-point score each in global utility, community support, and software maturity (see Table 2).

Table 2. The distribution of subindicator mean scores among the 3 core indicators (global utility, community support, and software maturity) for Surveillance Outbreak Response Management and Analysis System development from November 2017 to October 2019.

Core indicator[a]	Score			Status of SORMAS[b]
	2017	2018	2019	
Global utility	6	9	10	N/A[c]
Country utilization	1	1	1	SORMAS has been fully established for all epidemic-prone diseases in 15 federal states (including the federal capital), 287 local government areas, 37 health facilities, and approximately 700 users covering 75 million population (November 2017)
Country strategy	0	1	1	SORMAS has now been fully integrated into the revised technical guidelines of the *Integrated Disease Surveillance and Response* strategy and eHealth framework (September 2019)
Digital health interventions	−1	1	1	SORMAS can be configured and deployed without significant customizations or configuration (July 2019)
Source code accessibility	0	0	1	SORMAS has an open-source initiative approved license (GNU General Public License, Version 3, June 29, 2007) and is structured to allow local customizations and SORMAS is web-based and provides a relatively clear application programming interface (API) and database model. So, it is easy to build new modules and functionalities and host it on the same server (August 2019)
Funding and revenue	1	1	1	SORMAS is has been funded by the following donors and partners since its inception; Federal Ministry of Economic Cooperation and Development and the European Union via Deutsche Gesellschaft für Internationale Zusammenarbeit, BMBF[d], Bill and Melinda Gates Foundation, Nigerian Basic Health Care Provision Fund, US Centers for Disease Control and Prevention, Deutschen Zentrum für Infektionsforschung (DZIF). Funding sources for SORMAS increased from 1 in 2017, 3 in 2018, to 7 in 2019 (October 2019)
Community	3	7	10	N/A
Developer, contributor, and implementer community engagement	−1	1	1	SORMAS currently has at least 30% of estimated total developers from Nigeria, Tanzania, Ghana, and Germany (May 2018)
Community governance	1	1	1	In Nigeria, the steering board consists of representatives of Helmholtz Centre for Infection Research (HZI), Nigeria Centre for Disease Control, and in Ghana, the steering board includes Ghana Health Service, Ghana Community Network (GCNET), and HZI. The steering board is furthermore supported by an international external advisory board and an open-source clearance board (January 2018)
Software roadmap	−1	0	1	New features and functionalities are documented as part of the SORMAS road map and are also part of a biweekly release cycle (May 2019)
User documentation	0	0	1	SORMAS currently has user guides and technical documentation in which the source codes, use cases, and functional requirement exists, including training videos that are available to address everyday deployment tasks (August 2018) [16]
Multilingual support	−1	0	1	SORMAS has a multilingual support mechanism for English and French on its platform. The language translation component in SORMAS is easy to configure by a non-information technology (IT) person and can be adapted into any language required (February 2019)
Software	1	5	10	N/A
Technical documentation	0	0	1	SORMAS has full documentation for deployment and configuration, which does not require the involvement of the core development team. The SORMAS mobile app has only been packaged for the Android version operation system and not yet packaged for the iPhone operating system. The SORMAS web app has been packaged for Windows, Apple, and Linux operating systems (August 2018)

Core indicator[a]	Score			Status of SORMAS[b]
	2017	2018	2019	
Software productization	−1	0	1	SORMAS has automatic software upgrades without the manual intervention of the developers and also has integrated unit testing as part of the release process (August 2019)
Interoperability and data accessibility	−1	0	1	API end points exist within SORMAS for accessing and managing data, and SORMAS has user interfaces to export core data and metadata in the system (CSV format) for further analysis and data transfer purposes (August 2017)
Security	−1	0	1	Role-based authorization exists within SORMAS and all remote access via the web interface and APIs are encrypted by default. SORMAS has undergone an independent security audit of the software, which has taken place within the past 12 months (May 2019)
Scalability	−1	0	1	We have deployed SORMAS in at least 30% of all entities, which are managed within the software. There has been a surge in the number of users and deployments across the country in the last year (Indicator 2, subindicators J criteria). For every SORMAS release, we evaluate the software performance and perform load testing and IT integrated testing (October 2019)
Total score, n (%)	10 (33)	21 (70)	30 (100)	N/A

[a]The global good maturity model assigned scores for each subindicator as −1 for "low," 0 for "medium," and 1 for "high," and computed average values for the 5 subindicators of each core indicator using the formula in equation (1) MS=5 *[MEAN (Si)] + 5, where, MS=Maturity score for each core indicator S, i=subindicator, i=1,...,5 (vector containing score of the subindicators).

[b]SORMAS: Surveillance Outbreak Response Management and Analysis System.

[c]N/A: not applicable.

[d]BMBF: German Federal Ministry of Education and Research

Discussion

Principal Findings

SORMAS has reached the full score of the GGMM. The process from the decision to migrate a prototype based on a Systems, Applications, and Products proprietary technology stack to open-source software in 2016 until the accomplishment of the full score lasted 3 years [10]. There is no registry or publicly available documentation of tools that have applied the GGMM assessment except the District Health Information System 2 [17]. Of all the mHealth tools selected as global goods software listed in the GGMM guidebook, none have accomplished over 90% of the full score nor are we aware of any other tool that has obtained it [13]. Thus, it appears very likely that SORMAS may be the first and, so far, only digital tool that has reached the full score of the GGMM. SORMAS has multiple revenue streams and funding mechanisms that have been enabling progress in its development since 2016. SORMAS requires funding for software adaptations to country-specific requests, personnel for training, and supervision and maintenance of the tool.

The outline and the scoring principle of the GGMM version 1.0 was easy to apply. However, there were some limitations concerning the clarity of the definition of each of the 3 possible criteria of the subindicators. Many of those definitions contained a combination of several contextually independent items, for which the wording did not clearly distinguish between "AND" or "OR" combinations. Some definitions left room for interpretation, which may be necessary for some but also be too ambiguous in other situations. The 30 subindicators grouped into 3 core indicators all have equal weights keeping the model and its handling simple.

On the other hand, it may also not represent the difference in importance that different indicators may have. For example, it may be considered essential for global goods maturity to have repetitive external security tests implemented than multilinguarity. Once the full score has been accomplished, these differences are no longer relevant. However, as long as the total score is only partially completed, the quantitative value may be very misleading in the attempt to compare tools. A way to improve this dilemma would be to add weights to each indicator. A more natural way would be to discourage the computation of proportional completion and to categorically apply a dichotomous all-or-nothing principle, by which all requirements have been either fully fulfilled or not fulfilled [18]. Some indicators address items that may develop into two directions. For example, the number of countries using the tool may not always diminish but also increase, or an external penetration test may not be repeated as required. It may increase scaling if those subindicators that do require a regular renewal or update be explicitly highlighted to facilitate monitoring of the status. Another difficulty appeared with the subindicator for global utility, "Source Code Accessibility," as it was not entirely clear what "new modules" and "functionality" meant in the context of this model: In contrast to modular systems, some mHealth apps are built specifically to deliver a ready-to-go solution for a specific task, and they are defined by external standards that govern how the internal processes of the end users work. In such a situation, the requirement for facilitating options

for developing new modules and functionalities without prematurely forking the code may not be applicable.

For the time being, the GGMM serves as a self-assessment system. In that, the authors can confirm that in the case of SORMAS, it has dramatically guided the prioritization and acceleration of its development. It appears to be the main objective of the model. On the other hand, self-assessment also allows for a certain degree of subjectivity or bias [19]. To reduce this risk, we contacted 2 external experts who were not involved in the development and deployment of SORMAS but were instead instrumental in the development of the GGMM. Through this we aimed to reduce conflicts of interest and maximize the expertise on SORMAS as well as on the interpretation of the GGMM. We believe that inviting independent external experts in reviewing this assessment may be a model for other projects and tools to apply the GGMM assessment. We do not entirely recommend an external assessment, as practiced in many accreditation procedures, because it carries the risk of creating a business that will only but draw resources needed for the actual development of the tools.

Conclusions

To our knowledge, SORMAS is the first electronic health tool for disease surveillance, and also the first outbreak response management tool, that has reached the full score (100%) of the GGMM. The GGMM is clear in most of its definitions and is easy to apply for self-assessment, although some indicators require more resources for completion than others. Some conceptual modifications would allow for further improvements to the system. Nevertheless, it already has a supportive effect on developing software toward global goods maturity.

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Authors' Contributions

DT, BS, and GK searched, selected, and extracted data based on the criteria. DT conceptualized the first draft and GK analyzed and interpreted the results of the data. DT, GK, BS, CA, and JD reviewed the GGMM criteria for SORMAS development. MW and MS contributed to the development of SORMAS software. CL and CF represented Digital Square and the initiative that convened the initial creation of the GGMM version 1.0 and assisted in the SORMAS GGMM assessment. GK initiated the study approach and supervised all steps of the study. All authors revised and contributed to the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

GGMM: global good maturity model
LGA: local government area
mHealth: mobile health
SORMAS: Surveillance and Outbreak Response Management and Analysis System

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Review

Cluster Detection Mechanisms for Syndromic Surveillance Systems: Systematic Review and Framework Development

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Abstract

Background: The time lag in detecting disease outbreaks remains a threat to global health security. The advancement of technology has made health-related data and other indicator activities easily accessible for syndromic surveillance of various datasets. At the heart of disease surveillance lies the clustering algorithm, which groups data with similar characteristics (spatial, temporal, or both) to uncover significant disease outbreak. Despite these developments, there is a lack of updated reviews of trends and modelling options in cluster detection algorithms.

Objective: Our purpose was to systematically review practically implemented disease surveillance clustering algorithms relating to temporal, spatial, and spatiotemporal clustering mechanisms for their usage and performance efficacies, and to develop an efficient cluster detection mechanism framework.

Methods: We conducted a systematic review exploring Google Scholar, ScienceDirect, PubMed, IEEE Xplore, ACM Digital Library, and Scopus. Between January and March 2018, we conducted the literature search for articles published to date in English in peer-reviewed journals. The main eligibility criteria were studies that (1) examined a practically implemented syndromic surveillance system with cluster detection mechanisms, including over-the-counter medication, school and work absenteeism, and disease surveillance relating to the presymptomatic stage; and (2) focused on surveillance of infectious diseases. We identified relevant articles using the title, keywords, and abstracts as a preliminary filter with the inclusion criteria, and then conducted a full-text review of the relevant articles. We then developed a framework for cluster detection mechanisms for various syndromic surveillance systems based on the review.

Results: The search identified a total of 5936 articles. Removal of duplicates resulted in 5839 articles. After an initial review of the titles, we excluded 4165 articles, with 1674 remaining. Reading of abstracts and keywords eliminated 1549 further records. An in-depth assessment of the remaining 125 articles resulted in a total of 27 articles for inclusion in the review. The result indicated that various clustering and aberration detection algorithms have been empirically implemented or assessed with real data and tested. Based on the findings of the review, we subsequently developed a framework to include data processing, clustering and aberration detection, visualization, and alerts and alarms.

Conclusions: The review identified various algorithms that have been practically implemented and tested. These results might foster the development of effective and efficient cluster detection mechanisms in empirical syndromic surveillance systems relating to a broad spectrum of space, time, or space-time.

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KEYWORDS

sentinel surveillance; space-time clustering; aberration detection

Introduction

Background

Late detection of disease outbreaks has long been a threat to global health security, costing the world many lives, resources, fear, and panic. Case-fatality rates of pandemic diseases are still rising, the most recent being Ebola virus disease in Liberia, West Africa, the Democratic Republic of the Congo, and Uganda [1]. Apart from global fear and panic, Ebola virus disease caused over 11,000 deaths, with national case-fatality rates of about 70% and local economic losses of US $3 to 4 billion [2,3].

Traditional surveillance systems are mostly passive and rely on laboratory confirmations to detect disease outbreaks. These have been enhanced by syndromic surveillance systems [4], which largely depend on visible signs and symptoms and data sources including emergency department records [5], school absenteeism, work absenteeism, disease reporting systems, and over-the-counter medication sales [6,7]. Nevertheless, the existing syndromic surveillance systems cannot detect the disease outbreak early enough, and their data sources and processes exclude the incubation phase of the infection [7]. Disease outbreaks are mostly detected after the infected person is ill or after the terminal stage, thereby increasing the disease burden.

Clustering Approach and Outbreak Detection

Generally, outbreaks of infectious or communicable diseases are more likely to present in cluster form either in space, time, or both [8,9]. Clustering methods to detect disease outbreaks help identify environmental factors and spreading patterns linked to certain diseases [10]. This was realized many years ago by John Snow, who observed a correlation between cholera disease and a public water source [11]. Barker et al reviewed the dispersal, persistence, and control of some common viruses in the domestic home and in community facilities and concluded that “there is growing evidence that person-to-person transmission via the hands and contaminated fomites plays a key role in the spread of viral infections” [12].

Clustering approaches can be roughly categorized as temporal, spatial, and spatiotemporal. Spatial clustering uses multidimensional vectors with longitudinal and latitudinal coordinates. There are variety of related algorithms, such as density-based spatial clustering of applications with noise (DBSCAN) [8,9,13]. Temporal clustering deals with data points associated with time [14,15]. It includes various algorithms such as cumulative summation (CUSUM) and considers what is strange about a recent event [16-18]. Spatiotemporal clustering involves a time dimension (temporal information) and space dimension (spatial information) [8,9,13]. There are a variety of strategies, including different distance functions [19,20], importing time to the spatial data, transforming spatiotemporal data to the new objects, progressive clustering, and spatiotemporal pattern discovery [8,13]. Aberration detection is mainly performed through thresholding mechanisms, including various forms such as the number of standard deviations from the mean (*z* score), generalized likelihood ratio, recurrence interval, and confidence intervals [21,22].

Objectives

There have been notable efforts to bridge the gap between a disease outbreak and its late detection. Research in syndromic surveillance is aimed at detecting disease outbreaks at the presymptomatic stage [7]. One of the main concerns is the choice of reliable algorithms that can be used for empirical implementations. Therefore, our general objective was to systematically review reports of practically implemented disease surveillance algorithms for their usage and performance efficacies, and to develop an efficient cluster detection mechanism framework. The results are targeted at people who need to implement efficient syndromic surveillance systems for applications such as over-the-counter medication, school and work absenteeism, and disease surveillance relating to presymptomatic stages, among others. The scope was to review practically implemented state-of-the-art algorithms relating to temporal, spatial, and spatiotemporal clustering mechanisms. We considered various challenges such as user mobility, privacy and confidentiality, and geographical location estimation.

Methods

Inclusion and Exclusion Criteria

We developed the inclusion and exclusion criteria based on the objective of the study and through rigorous discussions among the authors. For an article to be included in the review, the study required the following criteria: (1) a study of a practically implemented syndromic surveillance system with cluster detection mechanisms or that was thoroughly assessed with real data (such studies also contributed to the understanding of how privacy and security-preserving methods could be adopted in related studies), (2) a focus on surveillance of infectious diseases such as influenza, cholera, severe acute respiratory syndrome, and Ebola virus disease, (3) a focus on humans, (4) reported in English, (5) journal articles, conference papers, or presentations.

All searches were done without restriction on time boundaries. We excluded any article outside the above-stated scope.

Literature Search

We conducted a literature search between January and March 2018 in Google Scholar, ScienceDirect, PubMed, IEEE Xplore, ACM Digital Library, and Scopus. We used keywords such as “spatiotemporal clustering,” “syndromic surveillance,” “real time,” “cell phone,” “mobile phone,” “smart phone,” “trajectory,” “aberration detection,” and “clustering.” To improve the search strategy, we combined keywords using the Boolean operators AND, OR, and NOT. We considered peer-reviewed journals and articles.

Guided by the inclusion and exclusion criteria, we conducted a basic filtering by skimming the titles, abstracts, and keywords to retrieve records that seemed relevant. We removed duplicates and fully read and judged articles that seemed relevant based on the inclusion and exclusion criteria. We retrieved other relevant articles from the reference lists of the accepted articles. We recorded the article selection and screening in a Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram [23].

Data Collection and Categorization

We developed our data collection and categorization methods based on the objective and through literature reviews and discussions among the authors. We defined the categories exclusively to assess, analyzed, and evaluate study (Table 1) [21,24,25].

Table 1. Data categories and their definitions.

Category	Definition
Clustering and aberration detection algorithm	The kind of clustering and aberration detection algorithm used and implemented in the study.
Type of clustering algorithm	The type of algorithm used (spatial, temporal, or spatiotemporal algorithm).
Threshold	The type of threshold used to generate alarms and alerts in the study.
Design method	The design method used in implementing the system, such as prototype, participatory or joint application development, or agile or waterfall model.
Evaluation criteria	The criteria used to evaluate the algorithms.
Performance metrics	The performance metrics used to evaluate the algorithms, such as sensitivity, specificity, and positive predictive value.
Type of location	Locations used in clustering, including geolocation, postal codes, and counties; specifies the exact type of location used in the system.
Source of location	Where the type of location information was obtained.
Nature of location	State of the location as static or dynamic.
Visualization tool	The type of tool used to implement the visualization aspect of the system.
Display report	The type of visual displays (eg, graphs, maps, time series) implemented by the various systems in the study.
Design layout	The stages and processes used in the architectural design of the syndromic surveillance system (eg, a layout may consist of data acquisition, clustering and aberration detection, and visualization [21], or may include privacy-preserving mechanisms, machine learning techniques in processing the data, and other layers [24,25]).

Literature Evaluation and Analysis

We assessed, analyzed, and evaluated eligible articles based on the above-defined categories. We analyzed each of the categories listed in Table 1 to evaluate the state-of-the-art approaches. We calculated percentages of the attributes of the categories based on the total count of each attribute. Note that some studies used multiple categories; therefore, the counts of these categories could exceed the total number of articles reporting on these systems.

Framework Development

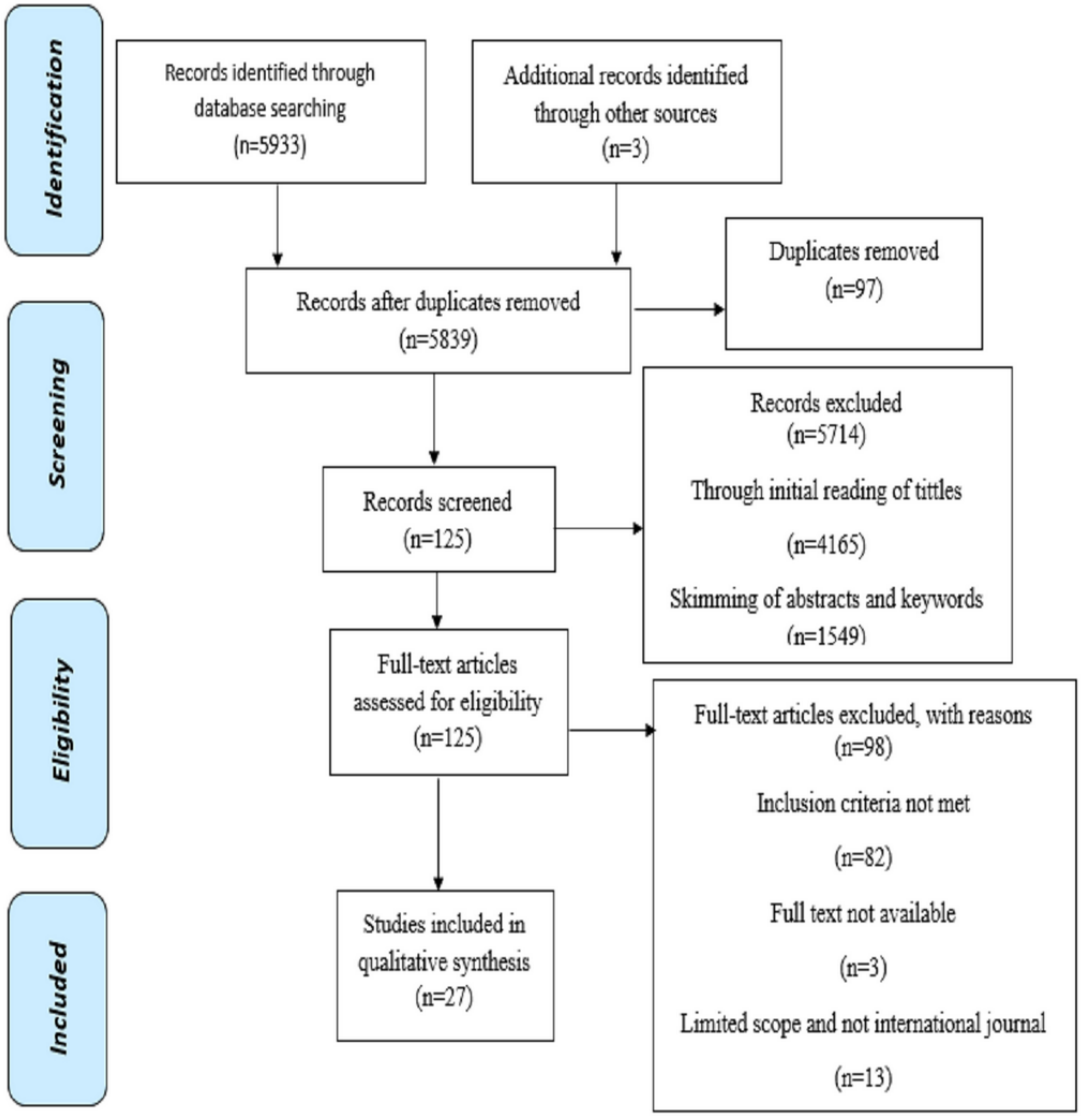
We used state-of-the-art methods from the review as input to develop a cluster detection mechanism framework for disease surveillance systems, including those relating to emergency department records, school and work absenteeism, over-the-counter drugs, and medication sales.

Results

Relevant Articles

Our search of the various online databases found a total of 5936 records. Removal of 97 duplicates resulted in 5839 records. An initial reading of titles excluded 4165 articles. We excluded a total of 1549 through skimming of abstracts and keywords. An in-depth full-text analysis of the resulting 125 articles, guided by the inclusion and exclusion criteria, excluded 98 articles. Thus, we included a total of 27 articles in the qualitative synthesis (Figure 1).

Figure 1. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram of the literature review process.



Literature Evaluation and Analysis

We assessed, analyzed, and evaluated the 27 articles based on the above-defined categories. The following sections describe the findings.

Articles Reviewed

Table 2 [16,21,22,24-47] lists the articles reviewed with their respective targeted diseases, input source, and where and when they were used. Most of the input sources were chief complaints and symptoms reported at the emergency department.

Types of Clustering Algorithms

Among the 3 types, namely spatial, temporal, and spatiotemporal, of clustering algorithms, the spatiotemporal algorithm (19/50, 38%) was the most preferred approach, followed by spatial (16/50, 32%) and temporal algorithms (15/50, 30%).

Clustering and Aberration Detection Algorithms

A variety of clustering and aberration detection algorithms were implemented in the reviewed articles. Space-time permutation scan statistic (STPSS) and CUSUM algorithms were most widely used, followed by space-time scan statistic and space scan statistic (Table 3).

Table 2. Summary of articles reviewed.

Reference (first author, year)	Target disease	Place	Period	Input source
Gesteland, 2003 [26]	Bioterrorism	2002, Olympics	2002	Chief complaints from emergency departments
Yan, 2013 [27]	Infectious diseases	Rural China	2012	Symptoms of patients from health facilities, medication sales from pharmacies, and primary school absenteeism
Maciejewski, 2009 [28]	Detection of public health emergencies	Indiana State Department of Health	2009-2010	Symptoms in emergency departments
Thapen, 2016 [29]	Generalized disease nowcasting	United Kingdom	2014	Twitter and *GP In Hours* weekly bulletin
Thapen, 2016 [30]	Infectious diseases, eg, hay fever and flu	England and Wales	2014	Twitter
Gomide, 2011 [31]	Dengue	Observatório da Dengue website (www.observatorio.inweb.org.br/dengue/)	N/A[a]	Twitter
Qi, 2013 [32]	Influenza infection	University campus	Spring 2011	Movement trajectory
Mathes, 2017 [33]	Infectious diseases	New York City	Since 2001	Emergency department visits with infectious diseases such as cough, sore throat, and fever for influenzalike illness
Yih, 2010 [34]	Acute illness for bioterrorism event	Greater Boston area, Greater Twin Cities area, Austin and Travis County, San Mateo County	2007-2008	Ambulatory care encounters
Kleinman, 2005 [16]	Lower respiratory tract infection	Boston area	N/A	Ambulatory care encounters
Dafni, 2004 [35]	Emergency department data	Athens, 2004 Olympic Games	2002-2003	Symptoms in emergency department
Wagner, 2004 [36]	Infectious disease	Utah, Atlantic City	1999	Chief-complaint data
Weng, 2015 [37]	Enterovirus and influenza	Taipei	2010/2011	School-based syndromes
Maciejewski, 2010 [38]	Respiratory illness	State of Indiana	2007	Infectious disease
Higgs, 2007 [39]	Comprehensive tuberculosis data	San Francisco homeless	1991-2002	Tuberculosis
Ali, 2016 [24]	Infectious disease	Pakistan	2011-2015	Chief complaints from emergency departments
Groeneveld, 2017 [25]	Infectious disease	Netherlands	2014/2015	Respiratory tract infection, hepatitis, and encephalitis/meningitis
Kajita, 2017 [22]	Emergency department data	Los Angeles County Department of Public Health, 2015 Special Olympic Games	2015	Monitor health impact
Choi, 2010 [40]	Infectious disease	Hong Kong	2005	Febrile patients
Heffernan, 2004 [41]	Emergency department chief complaint	New York City Department of Health and Mental Hygiene	2001-2002	Infectious disease, eg, respiratory, fever, diarrhea, and vomiting
Takahashi, 2008 [42]	Infectious disease	Massachusetts	2005	Daily syndromic surveillance data
Besculides, 2005 [43]	Infectious disease	New York City	2001-2002	School absenteeism data
Blake, 2016 [44]	Poliomyelitis outbreaks	N/A	2003-2012	Reporting of acute flaccid paralysis cases and laboratory confirmation
Greene, 2012 [45]	Gastrointestinal disease outbreak detection	Kaiser Permanente Northern California	2009	Data streams from electronic medical records

Reference (first author, year)	Target disease	Place	Period	Input source
Vilain, 2016 [46]	Infectious disease	French Institute for Public Health Surveillance, Reunion Island	2013-2014	Emergency department visits
Sharip, 2006 [21]	Infectious disease	Los Angeles County	2003-2004	Emergency department syndromic data
Duangchaemkarn, 2017 [47]	Infectious disease	N/A	2016-2017	Chief complaint symptoms

[a]N/A: not available.

Table 3. Frequency of clustering and aberration detection algorithms (n=66).

Algorithm	Usage, n (%)
Cumulative summation	10 (15)
Space-time permutation scan statistic	10 (15)
Space-time scan statistic	5 (8)
Space scan statistic	4 (6)
Kernel density	3 (5)
Moving average	3 (5)
Log-linear regression	2 (3)
Density-based spatial clustering of applications with noise	2 (3)
Recursive least square	2 (3)
Statistical process control	2 (3)
Autoregressive integrated moving average	2 (3)
Risk-adjusted support vector clustering	1 (2)
Bayesian spatial scan statistic	1 (2)
Exponentially weighted moving average	1 (2)
Flexible space-time scan statistic	1 (2)
k-means clustering	1 (2)
K-nearest neighbor with Haversine distance	1 (2)
Shewhart chart	1 (2)
Pulsar method	1 (2)
Risk-adjusted nearest neighbor hierarchical clustering	1 (2)
Small area regression and testing	1 (2)
Spatiotemporal density-based spatial clustering of applications with noise	1 (2)
What is strange about recent event	1 (2)
Bayesian space-time regression	1 (2)
Generalized linear mixed model	1 (2)
Generalized linear model	1 (2)
Holt-Winters exponential smoother	1 (2)
Temporal scan statistic	1 (2)
Modified Early Aberration Reporting System C2	1 (2)
Temporal aberration detection	1 (2)

Threshold Detection Mechanisms

An aberration is detected mainly using thresholding mechanisms and, in this regard, various types of approaches were implemented in the reviewed articles. Recurrence interval (10/17, 37%) and *z* score (10/17, 37%) were the most widely used, followed by generalized likelihood ratio (5/17, 18%), confidence interval (1/17, 4%), and incidence ratio (1/17, 4%).

Design, Evaluation Methods, and Performance Metrics

The most widely used performance metrics were sensitivity (11/25, 44%) and specificity (9/25, 36%), followed by timeliness (2/25, 8%), and consistency, correlation, and positive predictive value (each 1/25, 4%). The reviewed studies used various evaluation strategies, among which simulation with historical data (12/15, 80%) was the most widely used approach, followed by comparison with known outbreak (2/15, 13%) and power of cluster detection test (1/15, 7%).

At specificities and sensitivities ranging from 82% to 99.5%, spatial and spatiotemporal algorithms detected on average more cases (Figure 2, Table 4). Prototype and participatory design were used in the studies. Of 5 systems that disclosed their design methods, 4 used a participatory approach.

Figure 2. Sensitivity and specificity of the evaluated algorithms.

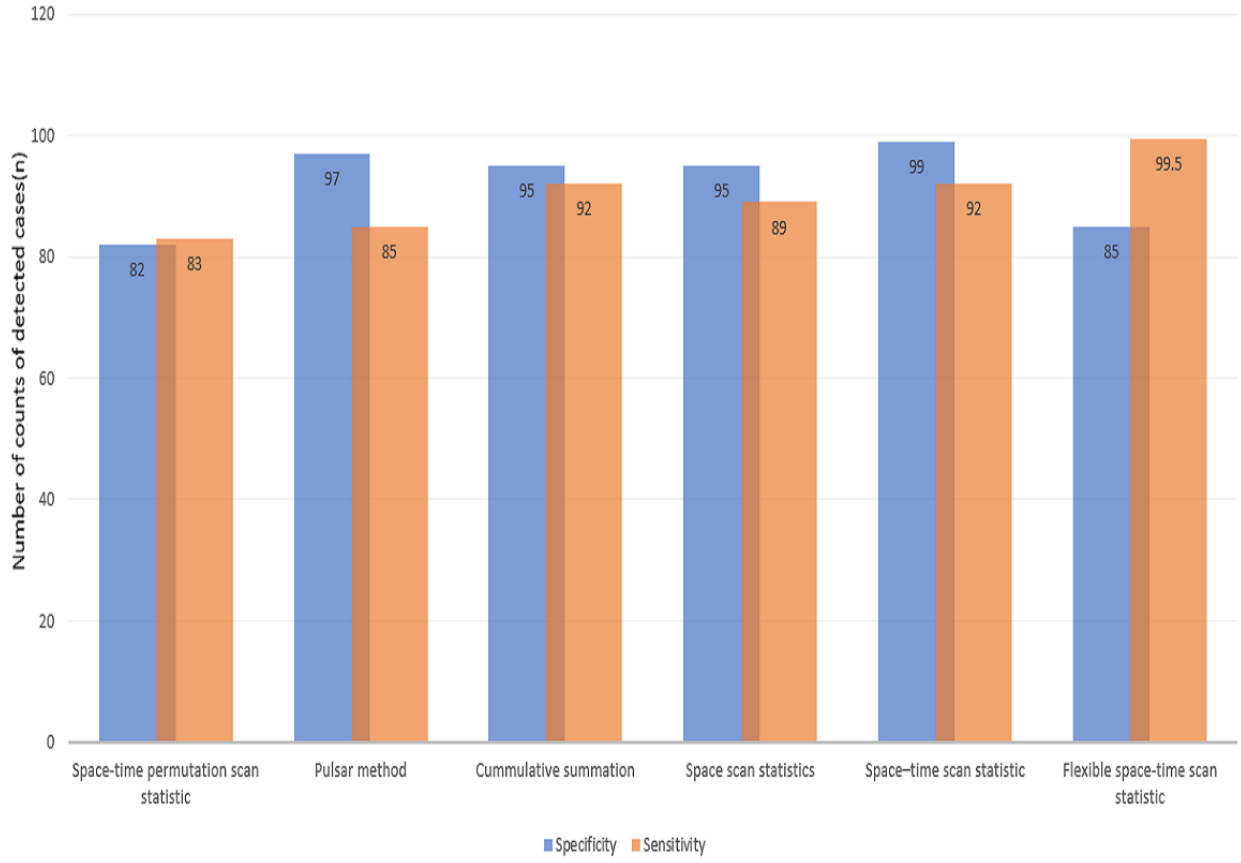


Table 4. Evaluation metrics of some algorithms.

Algorithms	Specificity (%)	Sensitivity (%)	Detected cases (n)
Space-time permutation scan statistic	82	83	26
Pulsar method	97	85	223
Cumulative summation	95	92	212
Space scan statistic	95	89	790
Space-time scan statistic	99	92	3
Flexible space-time scan statistic	82	99.5	4

Location Type and Nature, and Source of Location

The studies used a variety of location type, nature, and source. The majority of studies used static location (22/26, 79%) and the rest used a dynamic location (6/26, 21%). The studies used various address: geocode (14/37, 50%), zip code (13/37, 46%), and county (1/37, 4%). Various sources of locations were used: patient health record (18/27, 64%), mobile device (4/27, 14%), Transport Control Protocol/Internet Protocol (3/27, 11%), county (1/27, 4%), and school address (1/27, 4%).

Visualization Tools and Visual Displays

Clustering and aberration detection mechanisms in disease outbreaks need to be supported by excellent visualization tools and display to facilitate a quick response from the concerned bodies on the exact timing and place. In this regard, the reviewed articles used various kinds of tools: ArcGIS (3/9, 24%), Google Maps (2/9, 22%), Twilio (2/9, 22%), OpenStreetMap (1/9, 11%), and JFreeChart (1/9, 11%) were the most widely used. For displaying mechanisms, a map (14/30, 47%) was the most

widely used, followed by time series (7/30, 27%), graphs (8/30, 23%), and color indicators (1/30, 3%).

Design Layout

Table 5 lists the design layouts identified in the studies and their frequencies of use. Space scan statistic, which is a spatial algorithm, was also able to detect an average of 790 cases.

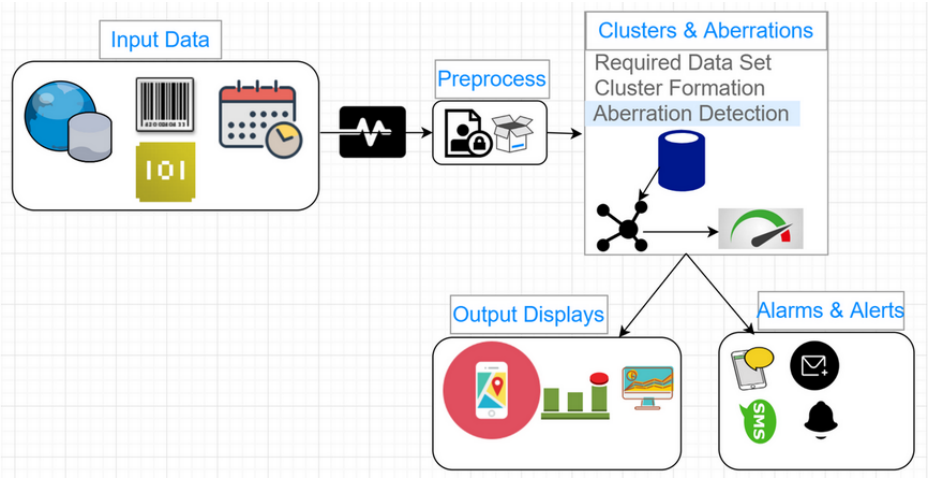
Table 5. Design layouts and their frequencies (n=22).

Design layout	Description	Usage, n (%)
Data clustering and aberration detection, alarms and alerts (DCADAA)	This layout consists of obtaining data first. Then clustering and aberration detection are done, followed by generating alarms to create alerts of aberrations [16].	12 (55)
Data clustering and aberration detection, visualization, alarms and alerts (DCAVAA)	A visualizing module is built in addition to processes defined in DCADAA [24].	1 (5)
Data cleaning and transformation, clustering and aberration detection visualization, alarms and alerts	In addition to the DCAVAA layer, this layer has data cleaning and transformation features.	3 (14)
Data clustering, filtering or categorizing, aberration detection, alarms and alerts	In addition to DCADAA, this layout filters data or categorizes the data into some defined groups, either manually or by employing machine learning techniques.	2 (9)
Data clustering and aberration detection, privacy-preserving mechanism (DPVCAAA)	In addition to DCAVAA, this layout has privacy-preserving mechanisms, such as anonymization and pseudonymization [27,48].	2 (9)
Real time, privacy-preserving mechanism, data clustering and aberration detection, alerts and alarms	On top of the DPVCAAA layout, there is an additional module for real-time data processing [24,48].	1 (5)
User tracking, data clustering, aberration detection, visualization, alarms and alerts	In addition to DCAVAA, this layout tracks the user's movement to obtain data. This is followed by validating the data before clustering and aberration detection [24,25].	1 (5)

Framework on Cluster Detection Mechanism

We developed a conceptualized framework on cluster detection mechanisms (Figure 3) with input from the principal findings of the systematic review on cluster detection methods. We discuss the various components of the framework below.

Figure 3. Cluster detection mechanism framework.



Input Data

Generally, syndromic surveillance systems require input data varying from structured to semistructured data such as comma-separated values, xml, or JavaScript Object Notation (JSON) formats (Figure 3). Ultimately, some key data input elements are highly required for these algorithms. These data elements include the data points with their associated geolocations, date, and time of occurrences [47]. The data points would also have unique nonpersonal identifications and would be associated with their corresponding date, time, and geolocation of occurrences. The data could be in a certain format such as xml, which can be accessed online.

Preprocessing Phase

The preprocessing phase is to ensure that the input data is in the right format for the cluster and aberration detection phase to use. Therefore, the framework provides for data conversion. For instance, online data in xml format can be converted to JSON format. Missing data would also be handled in various ways. In most instances, missing data were excluded from the analysis [29]. This and other methods would be used.

Another provision is to ensure that privacy-preserving mechanisms are in place. This framework has a provision in the data preprocessing section to ensure that the input data are devoid of personal data. This would be done by following layout

standards and regulations such as the General Data Protection Regulation established by the European Union [48,49]. According to Data are considered nonpersonal if pseudonymization and anonymization methods of privacy-preserving mechanisms are used [50]. Such techniques mitigate risk and assist the data processors in meeting their data compliance requirement. Pseudonymization replaces the most identifying fields within a data record with artificial identifiers or pseudonyms, but it does not replace all personal identifiable information from the data. It basically reduces the linkage of a dataset with the original identity of an individual. Pseudonymization methods use techniques including encryption schemes. With anonymization, a variety of methods are available, and the choice will depend on the degree of risk and the intended use of the data. Some of the methods are direct replacement, scramble, masking, and blurring.

Cluster and Aberration Detection Phase

The heart and brain of this framework is the cluster and aberration detection phase. In this layout, clusters and aberrations would be detected by considering the clustering and aberration detection algorithms found in the review. STPSS is very outstanding, since it does not require population-at-risk data to draw the expected baseline value. Rather, it uses the detected cases to determine the expected count [51]. This approach provides significant trend-of-baseline data while avoiding inclusion of historical data that is irrelevant to the current period.

Visualization, Alert, and Alarms

The main output of the framework is timely alerts through alarms and visualizations of detected aberrations. In the studies, various visualization tools and output displays were used. Guided by the results and discussion sections of this review, ArcGIS or Google Maps can be used to implement the visualization module. This visual display would mainly be a map with other displays such as a time series and graph. The maps would indicate where and when clustering and aberrations occur. Also, alerts would be triggered through alarms and messaging.

Discussion

Overview

The general objective of this study was to systematically review practically implemented disease surveillance algorithms for their usage and performance efficacies and to develop an efficient cluster detection mechanism framework. The results were targeted at individuals and organizations who want to implement efficient syndromic surveillance systems for applications such as over-the-counter medication, school and work absenteeism, and disease surveillance relating to presymptomatic stages, among others. The scope was to review the practically implemented state-of-the-art algorithms relating to temporal, spatial, and spatiotemporal clustering mechanisms. We proposed a framework based on the results of the review and considered various challenges, such as user mobility, privacy and confidentiality, and geographical location estimation. In exploring suitable algorithms, we included in the review studies that assessed syndromic surveillance systems with real data. In addition to thoroughly assessing these algorithms, such studies also contributed to the understanding of how privacy- and security-preserving methods could be adopted in related studies. This is also very important in this field, since personal data need to be handled properly in related studies to preserve security and privacy. For instance, in a related study [16], a privacy agreement with the health plan that provided the data required the researchers to use the exact locations only to get the grouped data.

Principal Findings

Table 6 summarizes the principal findings of the review. Below, we discuss the algorithms and other dimensions of the findings.

Table 6. Summary of the most used categories.

Category	Most used
Clustering algorithm	Space-time permutation scan statistic
Type of clustering	Spatiotemporal type
Threshold	Recurrence interval
Design method	Participatory design
Evaluation method	Simulation with historical data
Performance metric	Sensitivity
Type of location	Geocode
Source of location	Patient health record
Nature of location source	Static
Visualization tool used	ArcGIS
Displayed output	Maps
Layout	Data clustering and aberration detection, alarms and alerts

Spatiotemporal Methods

The review identified various spatiotemporal algorithms used for disease surveillance systems, including STPSS, space-time scan statistic, generalized linear mixed model, Bayesian space-time regression, and flexible space-time scan statistic. Spatiotemporal methods generally aimed at detecting disease outbreaks in both spatial and temporal patterns.

STPSS, which was used in many of the studies, was developed to detect hot spots of space-time interaction within space and time pattern occurrences of diseases [52]. Space and time of potential disease outbreak detection is a very efficient method, since health management services can plan for potential outbreaks, knowing where and when to allocate resources to potential outbreak areas. Another reason for its high usage count could be that the algorithm does not require data on the population at risk to draw the expected baseline value, but rather dwells on the detected cases to determine the expected count [51]. This approach provides a significant trend-of-baseline data while avoiding inclusion of historical data that is irrelevant to the current period. STPSS, unlike most of the algorithms, does not draw its baseline data (expected cases) from inaccurate population-at-risk, a control group, or other data that provide information about the geographical and temporal distribution of the underlying population at risk. Such baseline data are inaccurate because there is significant geographical variation in health care utilization data due to differences in disease prevalence, health care access, and consumer behavior [51]. Because of its popularity, Malizia evaluated STPSS for its efficiency and deemed it to be accurate [52].

On the other hand, STPSS is more accurate when used for outbreaks that start locally [51]. Chen et al, who studied spatial and temporal aberration detection methods for disease outbreaks in syndromic surveillance systems, observed that spatial scan methods only detect clusters in basic regular shapes such as cylindrical, circular, or spherical [18]. The spatial scan algorithm does not also consider prior knowledge such as the impact of the infection rate, or size or shape of the outbreak, and it is computationally expensive, as local cluster search requires searching over a large geographical region. These suggest that STPSS is not suitable for detecting disease outbreaks that occur simultaneously in the entire surveillance area. For instance, disease outbreaks that occur through exposure to an infectious agent implies that infected people might be living in different neighborhood. Thus, STPSS will not detect disease outbreaks with very few cases, such as 1 case of smallpox or 3 cases of anthrax in the anthrax bioterrorism that occurred in 2001 [51]. STPSS is only efficient on disease outbreaks with a higher rate of early symptoms [51]. An evaluation using syndromic surveillance data spiked with simulated injections revealed low detection in the spatial and spaciotemporal algorithms [33]. For instance, in an evaluation exercise, at a specificity of 95%, the STPSS detected none [33]. This was due to the geographically disaggregated data, which resulted in a loss of power of detection by the STPSS algorithm [33]. Syndromic surveillance systems are optimally effective when both spatial and temporal cluster detection methods work in unison to track emerging infectious diseases at an early stage over the surveillance area [18,53].

Spatial Methods

The spatial methods we identified in this review were space scan statistic, kernel density, Bayesian spatial scan statistic, k-means clustering, DBSCAN, and K-nearest neighbor (K-NN). Unlike spatiotemporal algorithms, spatial algorithms basically concentrate on where aberrations would occur. This makes planning difficult for health management, since it is difficult to know when to implement health interventions, if potential outbreak areas are known. Thus, spatial algorithms are suggested to be implemented together with temporal algorithms [47] to give the surveillance system spatiotemporal properties. According to Duangchaemkarn et al, who evaluated symptom-based data preprocessing for the detection of disease outbreaks with time series and the K-NN algorithm [47], K-NN algorithms potentially are an efficient method for syndromic surveillance; they suggested that the algorithm be further assessed with temporal methods. K-NN and CUSUM were also statistically assessed to be feasible for analyzing nearest neighbor statistics [54]. In such a combined approach of spatial and temporal methods, K-NN would provide clustering patterns of disease occurrences and CUSUM would provide the temporal aspect. CUSUM can spot an aberration in the surveillance area with the mean distances of emerging diseases of various points in the surveillance area [53,54]. Kulldorff et al also supported this opinion by emphasizing that “efficient disease surveillance will need the parallel use of different methods, each with their own strengths and weaknesses” [51]. A syndromic surveillance system is optimally effective when both spatial and temporal cluster detection methods work in unison to track emerging infectious diseases at an early stage over the surveillance area [18,53].

Temporal Methods

As Table 3 shows, temporal methods found in the study were CUSUM, moving average, recursive least square, autoregressive integrated moving average, pulsar method, temporal scan statistic, temporal aberration detection, and small area regression and testing. Among these methods, CUSUM was the most commonly used temporal algorithm in our review.

CUSUM is a statistical control method that has traditionally been used for industrial process control. It has been predominantly used in tracking changes in average production process levels since the 1950s [55,56]. The main role of CUSUM in production control is to generate an alert if products from a production process do not conform to defined limits [57]. CUSUM has also been found to be very useful in electronic disease surveillance. The CUSUM algorithm accumulates the variances between detected or observed cases and baseline values over a given time [53,55]. If the CUSUM value is greater than the baseline by a specified threshold, a likelihood aberration is detected [55]. In disease surveillance, CUSUM has been demonstrated to be a very sensitive, fast-reactive method of detecting disease outbreaks and to generate fewer false-positive alarms than more conventional methods [44,55,58]. CUSUM is also among the most commonly used temporal algorithms due to its powerful and straightforward design and implementation [59]. An evaluation study comparing the autoregressive integrated moving average, temporal aberration

detection, CUSUM, and Pulsar methods showed temporal aberration detection to be more timely in some syndromes, further empirical assessments in varying datasets are required to conclude which are the best methods [35].

Thresholding

The most used threshold for aberration detection in spatiotemporal algorithms was the recurrence interval, possibly as a result of the combination of recurrence interval and Monte Carlo replication, which helps to easily determine and set the specificity of the system [42]. The Monte Carlo simulation is a probability module that is often used with the recurrence interval in clusters to draw a threshold and to determine the likelihood occurrence of a cluster by chance within a specified period for which the analysis is repeated in a regular basis. For instance, in a daily analysis, if the Monte Carlo replication is set to 999 with a statistical significance of $P<.001$, the recurrence interval would be 1000 days, since in disease surveillance the recurrence interval is the inverse of the P value [42]. This implies that, for each 1000 days, the expectation of false alarms would be an average of 1 false signal per 1000 days, or 2.7 years, and the recurrence interval would be set to the number of days of the baseline data [34]. The significance level of $P<.001$ is the probability of accepting the occurrence of a cluster by chance within a specified period.

In the reviewed studies, CUSUM is a temporal algorithm that was mostly used together with special algorithms to form spatiotemporal algorithms [60]. Its ease of use and efficiency might have accounted for the high usage [60]. About 60% of the algorithms were classified in the threshold-based category [8]. This corresponded to relatively high usage of spatiotemporal algorithms. Most of these algorithms employed cylindrical risk regions to detect clusters. The radius formed the area of the map, while the height represented the time. The radius and time were varied to some upper bound thresholds.

Design and Evaluation

Participatory design was mostly used at the design stage, while simulation with historical data was mostly used to evaluate the clusters in most of the algorithms. Historical data were mostly used perhaps because those records were known to have aberrations, making it possible and easy to determine the performance of the system. Sensitivity and specificity were the most used performance metrics in the evaluation. This could be because users wanted a system with reduced false-alarm rates.

Some of the algorithms were compared based on their performance metrics of sensitivity, specificity, timeliness, and positive predictive value (Figure 2, Table 4) [33,61]. Considering Table 4 and Figure 2, at an average sensitivity and specificity of 82%, STPSS detected more cases (n=26). At a very high sensitivity and specificity up to 99.5%, the special and spatiotemporal algorithms continued to detect high numbers of cases. At a slightly lower sensitivity and specificity ranging from 82% to 92%, the temporal algorithms also detected some cases. In using spatiotemporal clustering algorithms in syndromic surveillance, various methods such as temporal methods and near neighbors should be considered. These measures may augment for the sparseness of data, which could result in a loss of power to detect areas with local excess aberrations in spatial and spatiotemporal methods [44,58].

An evaluation that was performed through injection of spikes of a known outbreak revealed low detection in the space and spaciotemporal algorithms [33,44,58,61]. Space scan statistic detected 3% of all injections, but STPSS detected none at a specificity of 95% [33]. However, the temporal algorithms detected higher percentages ranging from about 2% to 19% of the injections under the same level of sensitivity [33,58,61]. The low detection rates of the spatial and spatiotemporal algorithms could have been because the algorithms were not adjusted to increase their power of detection when applied to disaggregated data [33,44,58,61]. Also, the performance of the algorithms could be enhanced with a higher number of input cases and better coverage in spatial and spatiotemporal algorithms [34].

In terms of location, geocodes of census tracking or hospitals and zip codes were mostly used as location points for the clustering algorithms. These data were mostly retrieved from patient health records. The dynamic nature of the sources of location caused a low count, which could have been because they have not been comparatively assessed and due to difficulties associated with acquiring and processing the dynamic nature of location source data for syndromic surveillance. Privacy-preserving polices and a high computational time requirement prohibited the use of exact location of persons for syndromic surveillance. Exact locations such as house numbers and tracking of individuals were mostly used for group data at the zip code or county level. Information on the exact place of infection is also vital for early prevention and control of morbidity and mortality. But these limitations often hamper the accuracy of information on place of infection, since the information collected often relates to the place of notification, which is usually far from the place of infection [32,48,62]. Also, systems that provided text space for users to indicate their location had some limitations. Users did not indicate proper locations or addresses, so their locations could not be geocoded. This resulted in limited sample sizes [27,29].

Visualization and Alerting

ArcGIS was mostly used to display graphs in the studies in this review. It is possible that maps were the most common display type because they can be used to represent both spatial and spatiotemporal data. This could have accounted for their high usage of 34% and 47% in their respective categories. In the system design layout category, most of the systems obtained data from various sources first. Clustering and aberration detection were done, followed by generating alarms to create alerts of aberrations. Tracking for data, acquiring data in real time, privacy-preserving mechanisms, filtering, and data cleaning were some of the layout processes employed in a few of the systems studied. The low rate of tracking persons for data sources could be due to legal, privacy, and ethical reasons [48]. The low count of filtering and data cleaning could be due to implementation challenges, as machine learning algorithms and natural language processing tools are used for effectiveness [32,48,62].

Conclusion

Despite the numerous availabilities of disease surveillance algorithms, their lack of efficacy in detecting disease outbreaks remains a threat to global health security. To overcome this problem, the main objective of this study was to systematically review practically implemented disease surveillance algorithms for their usage and performance efficacies, and to develop an efficient framework. The results were targeted at individuals and organizations who wish to implement efficient syndromic surveillance systems in applications such as over-the-counter medication, school and work absenteeism, and disease surveillance relating to presymptomatic stage, among others. The scope was to review the practically implemented state-of-the-art algorithms relating to temporal, spatial, and spatiotemporal clustering mechanisms. We considered various challenges such as user mobility, privacy and confidentiality, and geographical location estimation.

The study revealed that STPSS and CUSUM were the most frequently implemented algorithms. These algorithms can be used in syndromic surveillance systems that are aimed at implementing state-of-the-art cluster detection mechanisms, although STPSS was shown to be efficient only in a surveillance system with a high rate of infections. Temporal and spatial algorithms such as CUSUM and K-NN can also be combined in an empirical study to achieve efficient results. This study provided wide data categorization, ranging from design of the system to the display of reports which we used in the development of the framework. These results might foster the development of effective and efficient cluster detection mechanisms in empirical syndromic surveillance systems relating to a broad spectrum of space, time, or space-time.

Conflicts of Interest

None declared.

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Abbreviations

CUSUM: cumulative summation
DBSCAN: density-based spatial clustering of applications with noise
JSON: JavaScript Object Notation
K-NN: K-nearest neighbor
STPSS: space-time permutation scan statistic

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Original Paper

An Internet-Based, Peer-Delivered Messaging Intervention for HIV Testing and Condom Use Among Men Who Have Sex With Men in India (CHALO!): Pilot Randomized Comparative Trial

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Abstract

Background: Leveraging internet-based communication tools (eg, messaging apps, SMS text messaging, and email) may be an effective avenue for delivery of HIV prevention messages to men who have sex with men (MSM) in India, but there are limited models for such internet-based interventions.

Objective: The CHALO! pilot was an online educational and behavioral intervention aimed to determine the feasibility, acceptability, and preliminary impact of a peer-delivered, internet-based messaging intervention for HIV testing and consistent condom use for MSM in India. The messages addressed barriers to HIV testing and condom use and were theoretically based on the information-motivation-behavioral skills model.

Methods: Between February and March 2015, we recruited, enrolled, and randomized 244 participants via online advertisements on mobile dating apps and Facebook. Eligible men (18 years or older, sexually active with other men, and self-reported HIV-negative or unknown status) were randomized to receive educational and motivational messages framed as either approach (ie, a desirable outcome to be achieved) or avoidance (an undesirable outcome to be avoided) over 12 weeks via internet-based messaging platforms. Participants completed online surveys at baseline and immediately postintervention.

Results: Participants were similar across arms with respect to sociodemographic and behavioral characteristics. Over 82.0% (200/244) of participants were retained (ie, viewed final messages), and 52.3% (130/244) of them completed the follow-up survey. Of those completing the follow-up survey, 82.3% (107/130) liked or strongly liked participating in CHALO!. The results showed a significant increase in self-reported HIV testing in the past 6 months from baseline to follow-up (41/130, 31.5% to 57/130, 43.8%; P=.04). When including those who reported intentions to test, this percentage increased from 44.6% (58/130) at baseline to 65.4% (85/130) at follow-up (P<.01). When examining intentions to test among those without prior HIV testing, intentions increased from 32% (16/50) of the sample at baseline to 56% (28/50) of the sample at follow-up (P=.02). Condom use during anal sex did not significantly change from baseline to follow-up. HIV testing and condom use did not significantly differ between approach and avoidance conditions at follow-up.

Conclusions: As one of the first studies of an online HIV prevention intervention for Indian MSM, CHALO! was feasible to implement by a community-based organization, was acceptable to participants, and demonstrated potential to improve HIV testing rates.

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KEYWORDS

HIV; internet; mHealth; eHealth; men who have sex with men; sexual minority; LGBT; India; intervention; prevention; mobile phone

Introduction

Background

India has the third largest population of people living with HIV globally, with an estimated 2.1 million infected persons, and more than 80,000 new infections occurring annually [1]. Globally and in India, HIV disproportionately affects men who have sex with men (MSM), who are designated a key priority population by the Indian health ministry for targeted HIV prevention interventions [2]. HIV prevalence among MSM in India is 10 to 15 times higher than in the general population (4.3% vs 0.3%, respectively) [1], and although MSM are conservatively estimated to make up less than 2% of the population, they comprise over 20% of HIV-infected individuals [1,2]. Thus, current interventions for Indian MSM have been limited in their reach and impact [3], partly because of the social stigma associated with same sex behaviors and marginalization [4,5]. The cultural emphasis on heterosexual marriage and traditional family structure, coupled with the constant fear of one's sexuality being *outed* [6-9], drive many MSM *underground* and out of the purview of various HIV interventions currently being implemented. To reduce the burden of HIV among Indian MSM, rapid development and wide-scale dissemination of interventions promoting effective prevention strategies are urgently needed.

Currently, over 430 million individuals in India access the internet, with 95% using mobile devices. Although access is currently greater among individuals younger than 35 years and those with higher incomes [10], these gaps are quickly closing, given the rapid decline in the cost of smartphones and data plans and the increasing availability of free Wi-Fi spots. Globally and in India, MSM are increasingly using internet-based communication technologies (ICTs; eg, Facebook, geolocation-based mobile dating apps, and email)—to socialize, seek sexual and romantic partners, and find a sense of community [11-14]. Conducting traditional face-to-face HIV prevention outreach for MSM can be challenging within stigmatized settings, but given the increasing use of technology by MSM to find partners and supportive social networks, ICTs now allow for an unprecedented opportunity to engage Indian MSM into HIV prevention, linkage to care, and other support services. Data indicate that the populations that can be reached online are in dire need of increased access to prevention services. Recent studies of MSM reached online in India have found that, among sexually active MSM, over 50% had never had an HIV test, a quarter had not been tested in more than 12 months, and between 40% and 80% were not out to others about their sexuality [15,16]. Thus, ICT-based interventions for MSM could dramatically improve the health of MSM in India and globally by helping support behavior change for HIV prevention (eg, HIV testing and condom use) [13].

International organizations, including India's National AIDS Control Organization, recognize the public health potential of ICTs and have called for the development and implementation of ICT-based HIV prevention strategies [2]. Besides evidence of their being acceptable to MSM, ICTs also offer considerable scalability and efficiency of wide reach with high impact potential, even with relatively low-intensity interventions [17,18]. Technology-based, peer-led approaches could be used to enhance efforts by community-based and other organizations for dissemination of health messages and service availability [19]. Thus, rather than an alternative medium for implementation of existing interventions designed for face-to-face contact, social media may be a *game changer* to engage MSM in India [20]. A meta-analysis found that social media interventions were effective in increasing HIV testing; however, none of the studies were conducted in a low-income country [21]. Two recent systematic reviews describing internet-based interventions for HIV care continuum found diverse models targeting HIV testing and prevention; however, most (over 85%) were in well-resource settings [22,23]. Few effective, scalable, and low-cost ICT-based interventions targeting HIV testing and prevention exist for low-income countries [24-27], and no published data are available on the effectiveness of ICT-based approaches in India or other South Asian countries.

In addition to the paucity of data about internet-based interventions in low-income settings for any population, there is little empirical data to guide health communication, that is, messaging, for online dissemination to increase HIV testing and condom use. Two messaging approaches, often called *frames* are widely used in health communication: the first, called *approach* or *gain framed*, highlights the benefits of engaging in a specific health behavior and the second, called *avoidance* or *loss framed*, focuses on negative consequences. Metanalytic reviews have indicated that gain-framed messaging is more effective in promoting prevention behavior, but loss-framed messaging may be more effective in promoting screening or illness detection behavior [28-30]. However, it is unclear which framing strategy is most effective when promoting a comprehensive approach to HIV prevention that includes promoting both HIV testing and condom use. Prior research from a high-income country (United States) has found mixed results with regard to condom use intentions [31,32] and HIV testing behaviors [33]. However, to our knowledge, no published data exist with regard to the framing effects of health messages for HIV testing and condom use for MSM or for any other populations in India or other low-income countries.

Objectives

To help close the gap in the use of ICT for public health purposes in India and address the high HIV prevention needs of Indian MSM, the CHALO! (*Let's Go!*) pilot study developed and tested the feasibility, acceptability, and preliminary impact of an ICT-based HIV prevention intervention to increase HIV

testing and consistent condom use among MSM reached on internet-based social and dating platforms in Mumbai, India. CHALO! also tested whether prevention messages using an approach frame (ie, messages highlighting a desirable outcome to be achieved or benefits of engaging in testing and condom use) were more effective in increasing HIV testing and consistent condom use behaviors compared with messages using an avoidance frame (ie, HIV infection as an outcome to be avoided or consequences of not engaging in a behavior). Our central hypothesis was that a peer-delivered, ICT-based behavioral intervention can efficiently identify and reach sexually active Indian MSM, enroll them into an exclusively online study, motivate them to seek in-person health services (ie, HIV testing), and modify health promotion behaviors (increase consistent condom use). This study was a peer-delivered intervention that recruited participants online and then disseminated HIV prevention messages via internet-based messaging platforms.

Methods

Study Design and Overview

The study was conducted in partnership with the Humsafar Trust (HST), one of India's largest community-based organizations based in Mumbai, providing culturally sensitive clinical and social services to sexual and gender minority populations. CHALO! was a two-arm, parallel, randomized (1:1 randomization) comparative effectiveness trial comparing two message-framing strategies (avoidance- and approach-framed messages) to promote HIV testing and consistent condom use. Messages were delivered by four peer-outreach staff (two per arm) via email, a private Facebook group, or WhatsApp (as chosen by the participant). Participants received the intervention messages twice a week for 12 weeks. In addition to the messaging, other intervention components were (1) the ability to communicate with the peer outreach staff via their chosen messaging modality and (2) a mobile-friendly Web page containing information on accessing MSM-sensitive, free HIV testing in Mumbai; free condoms and instructions on use; and a listing of available services for MSM at HST (eg, counseling, sexually transmitted infection [STI] treatment, and support groups). We used self-administered online surveys at baseline and 12-week postintervention for study assessments. The study was approved by the Humsafar Trust's and Albert Einstein College of Medicine's institutional review board.

Setting

The study took place online, between February and June 2015, targeting MSM living in Mumbai—India's largest city with a population of over 18 million, and a city with one of the highest HIV burdens in India. Mumbai accounted for over 19,000 new HIV diagnoses in 2016-2017 [1,2], with the prevalence of HIV among MSM estimated to be 7%. At the time of the study, Mumbai had high internet connectivity, with an abundance of free or low-cost Wi-Fi spots, low-cost internet cafes, and mobile service providers offering internet and data plans for mobile phones at a relatively low cost. For this pilot, we recruited participants from two of India's most used MSM-specific dating sites (which have now become the most commonly used avenues for MSM meets in urban India [34,35]) and from HST-operated Facebook pages. HST has three drop-in centers and a central office in the three major subdivisions of Mumbai, where HIV and STI testing, sexual health and psychosocial counseling, and linkage-to-care services are available. At the time of the study, HST was the only established community organization providing such services to MSM.

Participants

Eligible individuals were aged at least 18 years, identified as male, reported anal sex with another male partner in the past 2 years, lived in Mumbai, were fluent in either English or Hindi, self-reported being HIV negative or unaware of their status (ie, never tested or never received results), and provided a valid contact (email, mobile phone number, or Facebook ID—validated by a response to a confirmation message). Individuals were excluded if they reported being a staff member or any type of outreach worker for HST. Participants were screened into the study using an online screening survey.

Theoretical Basis

The CHALO! pilot drew on theories from health psychology (information-motivational-behavioral [IMB] skills theory [36,37]) and health communication (Prospect Theory) [38]. The IMB model posits that fostering information acquisition, increasing motivation, and enhancing behavioral skills are needed to change behaviors (eg, HIV testing and condom use). We used the IMB model to inform the specific message contents used in the intervention. We next used the Prospect Theory to frame the messages for each arm. Framing effects are a central tenet of the Prospect Theory [39], which posits that decision making is affected by the manner in which choices are presented; for example, behavioral science has demonstrated differences in health screening behaviors and other health-related decisions, when options for engaging in a health-related activity are framed in terms of potential benefits (*gain* frame) compared with potential harm (*loss* frame [39-41]). As past research suggests a significant impact of messaging framing on HIV testing behaviors [33], we incorporated tenets of this theory to help ensure that CHALO! messages were framed in a manner that would promote optimal decision making and behavior change with regard to HIV testing and consistent condom use. Messages in CHALO! were framed to either an *approach* frame (ie, highlighting a desirable outcome to be achieved or benefits of engaging in HIV testing or consistent condom use) or to an *avoidance* frame (ie, focusing attention on a negative outcome to be avoided or consequences of not engaging in HIV testing or not using condoms) [29,33].

Intervention Development

We used a participatory process with an interdisciplinary team at HST to develop all components of the intervention in an iterative process over a 3-month period. The core team members at HST consisted of 8 individuals: 2 community-based researchers, 2 HIV testing and counseling staff members, an HIV-positive peer patient navigator, and 3 peer outreach workers experienced in using MSM dating websites and apps for outreach to MSM in Mumbai. This intervention development team informed all aspects of the study including study design,

participant eligibility, recruitment and retention, study measures, intervention implementation, and evaluation.

Target Selection and Message Development

The intervention target selection (ie, which barriers to address) and message development and refinement process was a community-led multiphase and iterative process occurring over a 2-day workshop with an interdisciplinary team: 3 facilitators (HST research staff members experienced in conducting HIV-related trainings) and 10 participants (HST's community advisory board members and peer outreach workers experienced in outreach and care linkage for >5 years and with online MSM dating apps), and HIV counseling and testing staff. The members had diverse sexual identities common in India (gay, bisexual, *kothi*, and *panthi)* [42,43], genders (male, female, and *hijra or transgender individuals)*, and demographic characteristics (with regard to education, age, and primary language used (English or Hindi). Three members of the group were people living with HIV.

We used *open space technology* to facilitate communication and participation by all workshop members [44]. Open space technique is a process that has been used across disciplines to help ensure inclusion of diverse attitudes and experiences and has been used to facilitate identification of challenges or barriers to a task or behavior (eg, HIV testing) and identification of potential solutions to overcome them. For this study, workshop members first identified challenges to HIV testing and consistent condom use, and then mapped these to the IMB domains (ie, the targets). The following targets were identified within the IMB model:

- *Information*: information about HIV transmission and prevention with condoms and logistical information (eg, testing locations and hours)
- *Motivation*: risk perception and stigma
- *Behavioral skills*: how to access or make an appointment for free testing

Next, after receiving a brief orientation to *approach* and *avoidance* messaging frames, participants in small groups developed short social marketing messages that could be disseminated online addressing the above-identified targets or provided solutions for overcoming the barrier (eg, a webpage vetted to be MSM friendly listing free HIV testing centers, which addressed lack of knowledge about safe HIV testing venues). Workshop participants developed between three and five messages for every identified target for both approach and avoidance frames. Thus, we developed approximately 25 to 30 messages for each message frame (approach and avoidance). All messages were transcreated into English or Hindi based on the original language (eg, messages initially developed in Hindi were then transcreated into English, and conversely, from English into Hindi). We used transcreation (as opposed to translation) to retain the essence of the original message [45], while the text was then refined using a consensus approach to further ensure comprehension and equivalency in meaning, sentiment, and framing. Next, 30 peer staff and MSM community members at the HST drop-in center (not involved in the workshop) voted for their favorite top 3 messages for each factor in each of the approach and avoidance frames. Finally, we selected the top 1 or 2 messages receiving the most votes for each target within each frame for use in the intervention, resulting in 15 messages for each arm: 8 messages focused on HIV testing and 7 messages focused on condom use. Here are two examples of messages used (avoidance and approach):

> *It doesn't matter if you sleep with only 4 or 5. It only takes one. Not using condoms puts you at risk for HIV. Avoid HIV by using condoms!*
>
> *Whether you ride from the front seat or back seat, you both need a helmet. Use a condom either way. Keep yourself and your partner healthy!*

Peer Recruitment and Training

HST research staff selected 4 MSM peer outreach workers for the intervention who were fluent in Hindi and English and reported comfort and experience with using online dating apps, Facebook, and email and not involved with development of the messages. Chosen peers had previously received training in HIV-related communication and community engagement and were experienced in HIV-related outreach in Mumbai. For this pilot, the peer outreach worker received additional specific training on online research ethics, maintaining confidentiality and privacy, and communicating via online tools. Two peer outreach workers were randomly assigned to each arm. Peers were then randomly assigned to serve as the online peer outreach worker for half the participants within their assigned arm. Each peer was responsible for sending intervention messages to their assigned participants and to communicate with participants if and when a participant chose to initiate any communication. There was no cross-arm communication from the peer outreach workers to participants in the arm to which they were not assigned.

Intervention Procedures

First, from February to March 2015, recruitment advertisements were disseminated on a popular MSM-specific dating website, a geosocial networking mobile app, and on HST-operated Facebook pages. Potential participants clicked through the ads to complete an online consent and eligibility screener; if eligible, they automatically continued to the baseline survey. After confirming the contact information provided, participants were randomized 1:1 to either the approach- or avoidance-framed conditions.

Next, from March to June, 2015, the 4 peer outreach workers (two per arm) sent a standardized introductory message via the participant's chosen communication modality (ie, email, WhatsApp, or private Facebook group), followed by intervention messages 2 or 3 times per week for 12 weeks. Each set of 15 messages was sent out twice over the 12 weeks to help ensure that participants viewed them and reinforce the information contained within the messages. Thus, after the first set of 15 messages were sent out, another round of the same 15 messages was sent again. Messages for all participants were sent by the peer outreach worker on the same days and times each week. Participants were also able to communicate with their assigned peer outreach worker for any reason via multiple modalities (text message, email, Facebook Messenger, or phone call), but

only if the participant initiated the contact. This was to avoid being overly intrusive and prevent potential intervention fatigue based on input from the peer staff. Participants then received a final intervention message and a personal link to the follow-up survey. All messages were sent with arm-specific links to the study webpage, with additional information about HIV testing, condom use, and HST services. We compensated participants with Amazon India vouchers worth INR 300 (approximately US $4.75) on successful completion of baseline survey and INR 400 (approximately US $6.30) on successful completion of the final follow-up assessment.

Measures

Sociodemographic Characteristics

At baseline, we collected information on age, monthly income, preferred language (indicated by language of survey taken—English or Hindi), and an account of household members.

Sexual Identity and Behaviors

We assessed sexual identity with mutually exclusive categories often used in India (*panthi*, *kothi*, double decker, gay or homosexual, bisexual, and straight or heterosexual [9-11]), but because very few respondents selected *panthi*, *kothi*, or double decker, we collapsed these categories into gay or homosexual. We asked about participants' level of outness, whether they had sex with or were attracted to men (none, some, or most), if they had a primary male sexual partner (Yes or No), and the number of male sexual partners in the past year.

HIV Testing

To assess the HIV testing outcomes, we asked at baseline and follow-up, "When was your last HIV test?" with response categories of *less than 1 month ago*, *2 to 6 months ago*, *7 to 12 months ago*, *more than 12 months ago*, and *never*. We then dichotomized the responses for analysis to 6 months vs all others based on the recommended testing guidelines for MSM [46]. To ascertain testing intentions during and immediately after the intervention ended, we asked, "Do you intend to test in the next 3 months?" (at baseline) and "Do you intend to test in the next month?" (at follow-up) with the answer options of yes or no.

Consistent Condom Use

Condom use outcomes was assessed at both baseline and follow-up using the question "In the last three months, how often have you used condoms during anal sex?", with the response options of *always*, *Most of the time*, *sometimes*, *rarely*, and *Never* for analyses, we dichotomized responses as always vs inconsistent (including all the other response options).

Qualitative Feedback

To evaluate acceptability, identify implementation challenges, and elicit suggestions to refine CHALO!, we collected field notes from (1) our weekly project meetings with the research team, (2) peer outreach staff during and at the end of study, and (3) two focus groups of CHALO! participants (n=6-8 per group) after intervention completion. Peer intervention staff also elicited feedback via email, WhatsApp, or Facebook Messenger from those not completing the follow-up assessment to evaluate reasons for survey noncompletion.

Analyses

To determine feasibility, we assessed three process measures: (1) enrollment data (number of individuals completing the screening survey, the proportion eligible, and the proportion enrolling into the study); (2) retention (measured by a composite indicator consisting of WhatsApp and Facebook message viewed indicators, participant responses to reminder emails about completing the follow-up assessment, or completion of the follow-up assessment), and (3) completion rate (proportion of participants completing the follow-up assessment). We also assessed the relationship between completion of the follow-up assessment and baseline participant characteristics using the chi-square, Fisher exact, or *t* tests as appropriate.

To determine acceptability, we tabulated the Likert scale responses to questions about how much the group liked participating in CHALO! and used the chi-square test to examine differences between conditions. We thematically analyzed and coded the field notes and the brief open-ended responses on the follow-up survey based on three general categories: what was most liked, what was most disliked, and suggestions for improving the intervention. Two team members independently coded the responses, and discrepancies were resolved through discussion.

To determine early efficacy, we undertook several steps. We first described the sample using frequencies and means and examined potential differences in baseline characteristics and behaviors using the chi-square and *t* tests, as appropriate. To assess the intervention's early impact, we examined potential changes in four outcomes: (1) composite of HIV testing plus intention to test, (2) HIV testing alone, (3) intention to test for HIV, and (4) consistent condom use. We first compared the two arms among those completing the postintervention assessment using chi-square tests. Next, we conducted a pooled pre-post analysis (ie, within-subjects and across time) for HIV testing, intention to test for HIV, and consistent condom use using the McNemar test.

Results

Participant Characteristics

From February 2015 to March 2015, 982 individuals clicked through the advertised links, 357 (36.4%) individuals completed the online screening survey, of whom 244 (68.3%) were eligible; all eligible individuals enrolled (244/244, 100.0%) and were randomly assigned 1:1 to either the avoidance- or approach-framed conditions (122 in each arm; Figure 1).

Baseline participant characteristics by group assignment appear in Table 1. Overall, majority of participants were aged between 18 and 29 years (156/244, 63.9%), had monthly incomes of over INR 18,001 (155/244, 63.5%), and lived with other family members (151/244, 61.9%). Most individuals identified as gay or homosexual (175/244, 71.7%) or bisexual (63/244, 25.8%), nearly a quarter (56/244, 23.0%) were not out to anyone, and almost half (128/244, 52.5%) had never visited HST for any reason. Half of the participants (122/244, 50.0%) had a main

male partner, and the overall sample reported a mean of 3.7 (SD 5) male sexual partners in the past 12 months. Half of all participants (128/244, 52.5%) chose to receive intervention messages via email, 35.7% (87/244) via WhatsApp, and 11.5% (28/244) through a private Facebook group. There were no significant differences at baseline between conditions with regard to any of the demographic characteristics, chosen mode for message delivery, or preferred language (Table 1).

Figure 1. Consolidated Standards of Reporting Trials (CONSORT) flow diagram of CHALO! participants.

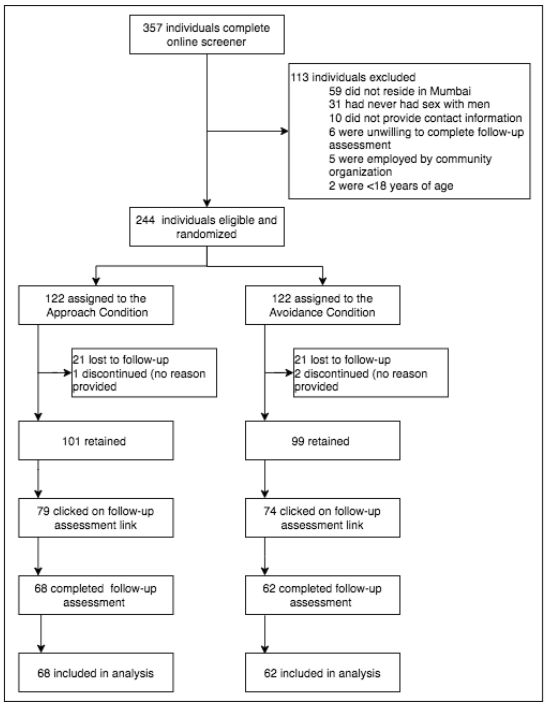

Table 1. Baseline characteristics of participants in the CHALO! pilot.

Characteristics	Total (N=244)	Approach condition (n=122)	Avoidance condition (n=122)
Age (years), n (%)[a]			
18-29	156 (63.9)	77 (63.1)	79 (64.8)
30-41	64 (26.2)	33 (27)	31 (25.4)
42 and above	24 (9.8)	11 (9)	12 (9.8)
Monthly income (Indian Rupees), n (%)[a]			
Rs 3000-9000 (approximately US $50-150)	55 (22.5)	28 (23)	27 (22.1)
Rs 9001-18,000 (approximately US $150-300)	33 (13.5)	15 (12.3)	18 (14.8)
> Rs 18,001 (> approximately US $300)	155 (63.5)	79 (64.8)	77 (63.1)
Household members, n (%)[a]			
Alone	33 (13.5)	20 (16.4)	13 (10.6)
Friends or nonrelative roommate	31 (12.7)	15 (12.3)	16 (13.1)
Boyfriend, husband, male partner	9 (2.3)	2 (1.6)	7 (5.7)
Joint family (eg, parents, siblings, relatives)	151 (61.9)	77 (63.1)	74 (60.7)
Wife (female) or own children	14 (5.7)	7 (5.7)	7 (5.7)
Preferred language, n (%)[a]			
English	225 (92.2)	113 (92.6)	112 (91.8)
Hindi	19 (7.8)	9 (7.4)	10 (8.2)
Sexual orientation, n (%)[a]			
Gay, homosexual, or queer	175 (71.7)	88 (72.1)	87 (71.3)
Bisexual	63 (25.8)	31 (25.4)	32 (26.2)
Straight or heterosexual	8 (3.3)	4 (3.3)	4 (3.3)
Level of outness, n (%)[a]			
No one	56 (23.0)	27 (22.1)	29 (23.7)
Some people	144 (59.0)	73 (59.8)	71 (58.2)
Most people	44 (18.0)	22 (18)	22 (18)
Aware of Humsafar Trust (lesbian, gay, bisexual, transgender, and queer + community based organization), n (%)[a]	222 (91.0)	109 (89.3)	113 (92.6)
Have never visited Humsafar Trust, n (%)[a]	128 (52.5)	67 (54.9)	61 (50)
Has a main male partner, n (%)[a]	122 (50.0)	62 (50.8)	60 (49.2)
Number of male sexual partners in past year, mean (SD)	3.7 (5)	3.1 (3.2)	4.5 (6.4)
Access to intervention contents, n (%)[a]			
Personal smartphone	136 (55.7)	66 (54.1)	70 (57.4)
Home computer	73 (29.9)	39 (32)	34 (27.9)
Work computer	20 (8.2)	9 (7.3)	11 (9)
Friend’s computer	7 (2.9)	6 (4.9)	1 (0.8)
Internet cafe	3 (1.2)	1 (0.8)	2 (1.6)
Mode of message delivery, n (%)[a]			
Email	128 (52.5)	60 (49.1)	68 (55.7)
Private Facebook group	28 (11.5)	15 (12.3)	13 (10.7)

Characteristics	Total (N=244)	Approach condition (n=122)	Avoidance condition (n=122)
WhatsApp	87 (35.7)	46 (37.7)	41 (33.6)

[a]Percentages do not add up to 100% for all variables because of rounding.

Feasibility and Retention

Overall, 82.0% (200/244) of the enrolled participants were retained through the end of the intervention (Figure 1). The postintervention assessment link was clicked on by 62.7% (153/244) participants and was completed by 53.3% (130/244) participants. There were no significant differences between conditions in the proportion of participants retained, accessing the follow-up assessment, and completing the follow-up assessment. There were also no significant differences in baseline demographic and behavioral characteristics among those retained or completing the follow-up assessment, except with regard to sexual orientation (Multimedia Appendix 1). Participants identifying as gay were more likely than those identifying as bisexual or straight to complete the follow-up assessment: 59.2% (103/174) for gay, 41% (26/63) for bisexual, and 13% (1/8) for straight; $P<.01$.

Intervention Acceptability and Suggestions for Improvement

Of the 130 participants completing the postintervention assessment, 106 (81.5%) liked or strongly liked their experience in CHALO!, 17.9% (19/106) neither liked nor disliked their experience, and only 4.7% (5/106) disliked or strongly disliked their experience in CHALO! Content analysis of free-text responses about what participants liked most about CHALO! revealed the following themes: the intervention was useful and provided supportive information; messages were engaging or motivating; created a sense of community and acceptance; and made them feel good about helping their community by participating in the study. With regard to what participants least liked about CHALO!, individuals reported the survey was too long or redundant, reported feeling that messages were not frequent enough, or had comments pertaining to the graphical appearance of the messages. Suggestions for improvement included having a larger social media presence, continuing the messaging for a longer duration, expanding topics, and using audiovisual or interactive graphics (eg, video clips). Field notes and feedback from the peer outreach staff indicated that the most common reason for not completing the follow-up assessment was not finding the online Amazon India incentives useful.

Potential Contamination

Of the participants completing the postintervention assessment (n=130), similar proportions of participants overall and in both conditions reported sharing the received digital messages with their friends (24% in both groups). In addition, 24% of individuals reported knowing someone else participating in CHALO! Only 6.1% (8/130) reported both knowing someone else in CHALO! and sharing the digital messages in general (which may or may not have been with the other CHALO participants).

Preliminary Efficacy

HIV Testing

Table 2 shows the results of HIV testing outcomes for those who completed the follow-up survey (N=130). At baseline, 31.5% (41/130) of participants reported HIV testing in the past 6 months; at follow-up, 43.8% (57/130) of them reported having been tested ($P=.04$). When including those who reported intentions to test, this percentage increased from 44.6% (58/130) at baseline to 65.4% (85/130) at follow-up ($P<.01$). Finally, when examining intentions to test in the next month, among those without prior HIV testing, intentions increased from 32% (16/50) of the sample at baseline to 56% (28/50) of the sample at follow-up ($P=.02$).

At follow-up, fewer participants in approach vs avoidance reported being HIV tested in the past 6 months (26/68, 38% vs 31/68, 50%; $P=.18$) or intended to get an HIV test among those not tested in the past 6 months (47% vs 58%; $P=.21$), but these differences were not statistically significant (Table 2).

Table 2. HIV testing and condom use at baseline and follow-up.

Outcomes	Pre-post analysis				Approach			Avoidance			*P* value[a]
	N	Baseline, n (%)	Follow-up, n (%)	*P* value[b]	N	Baseline, n (%)	Follow-up, n (%)	N	Baseline, n (%)	Follow-up, n (%)	
HIV testing											
HIV tested in the past 6 months (self-reported)	130	41 (31.5)	57 (43.8)	.04	68	22 (32)	26 (38)	62	19 (31)	31 (50)	.18
HIV tested in the past 6 months (self-reported) or intent to test	130	58 (44.6)	85 (65.4)	<.01	68	32 (47)	41 (60)	62	26 (42)	44 (71)	.20
Intent to HIV test among those not tested in the past 6 months	50	16 (32)	28 (56)	.02	28	10 (36)	15 (54)	22	6 (27)	13 (59)	.21
Condom use[c]											
Always used condoms	76	47 (62)	46 (61)	.71	36	24 (64)	24 (64)	40	23 (58)	22 (55)	.41
Condom use at the last anal sex encounter in the past 3 months	76	58 (76)	53 (70)	.29	36	28 (78)	29 (81)	40	27 (67)	23 (58)	.18

[a]Comparison between approach vs avoidance at follow-up.

[b]Comparison between baseline and follow-up.

[c]Condom use is among those reporting anal sex in past 3 months.

Condom Use

Among those having had anal sex in the past 3 months (n=76), the percentage of participants reporting always using a condom did not change overall (47/76, 62% at baseline vs 46/76, 61% at follow-up; *P*=.45), and there were no differences by arm (Table 2). There were also no significant differences in condom use at the last anal sex encounter between baseline and follow-up or between arms at follow-up (Table 2).

Discussion

Principal Findings

Using a community-based participatory research process, we developed and implemented an internet-based HIV prevention intervention for MSM in India. The findings from this pilot study showed that the CHALO! intervention delivery model was feasible to implement by a community-based organization and acceptable to participants, particularly those identifying as gay or homosexual. The intervention also demonstrated preliminary evidence for improving HIV testing and intention to test for HIV across both trial arms by self-report, with a greater increase in the avoidance-framed arm. However, the intervention had no impact on condom use.

To our knowledge, this is the first HIV-related intervention for MSM in India conducted exclusively online, using internet-based platforms to recruit, enroll, deliver a behavioral intervention, and follow-up participants longitudinally. We were able to reach and retain diverse MSM participants with respect to their sociodemographic characteristics, sexual identity, and level of outness. To our knowledge, almost all previous HIV-related intervention studies and service delivery programs in India have primarily relied on in-person approaches to initial outreach, and there exists only one published study that used mobile phones, but integrated the mobile device with in-person approaches for reaching individuals and delivering interventions [47]. A few other studies using diverse ICT-based platforms and intervention procedures have evaluated whether internet-based platforms can increase HIV testing among MSM in other low- and middle-income countries and, in general, have found overall positive effects, although none of them have been conducted in India or other South Asian countries and few are readily scalable with limited resources [27,48-52].

Our pilot study extends the literature by demonstrating the potential utility of a peer-delivered messaging intervention in a low-income country setting. Our findings also support the feasibility of implementing online interventions for MSM in India, with other recent data showing the ability to rapidly engage diverse Indian MSM online, including in rural areas [16]. Fully powered internet-based intervention studies are warranted to examine the impact of these online models with more objective measures of HIV testing and assessment of downstream outcomes of linkage to care (for both treatment and prevention). In addition, HIV prevention studies of longer duration of fully online interventions in India and other low-income settings are needed to understand long-term retention and program effectiveness. Unlike online interventions that rely on specific software platforms or require high technical expertise and resources, the CHALO! intervention

model—including the rigorous community-based development process for message creation—may also serve as a model for future ICT-based interventions that are able to accommodate the constantly shifting sociotechnical landscape [53].

The use of message framing to inform online HIV-related messages has not previously been investigated anywhere; this study suggests that online educational and outreach interventions may need to consider the manner in which information is presented, depending on the health behavior being targeted. We found differences by study arm in the reports of HIV testing and intention to test, suggesting an influence of the message frame. Although both groups had significant increases in HIV testing outcomes from baseline to follow-up, we observed a greater increase among participants randomized to the avoidance-framed arm. This finding is consistent with the Prospect Theory [38], which posits that decision making is affected by framing effects. This study provides further support that framing effects may be dependent on whether the behavior is diagnostic (eg, HIV testing) or preventive (eg, condom use), which is consistent with previous studies [30,31,33,41]. In addition, framing effects on HIV testing behaviors may also be moderated by prior testing experiences; for example, avoidance- or negative-framed messages may work better for those who have never been tested for HIV but approach or positive-framed messages may work better for individuals previously tested for HIV [41,54], although we are unaware of any studies examining this issue. Although we were precluded from examining these types of potential effects stratified by prior testing history because of the small sample size, future studies could further examine these interactions to inform more tailored messaging interventions.

The CHALO! pilot did not have an impact on reported condom use behaviors. Increasing and sustaining condom use over time have been challenging across different contexts globally and interventions have had mixed findings [52,55,56]. This may be because of condom use being a complex behavior and one that requires the cooperation of the individual and their partner(s). Condom use is influenced by a variety of complex factors, including skills to use a condom, risk perception, influence of substances, community norms, desire for intimacy, stigma, and situational factors [57-61]. Thus, messaging alone is insufficient to address all these barriers. We hypothesize that CHALO! increased reported HIV testing behaviors but not condom use because obtaining an HIV test, in general, is an infrequent event compared with having sex. In addition, getting an HIV test may be more within the control of an individual's decision making, whereas for using condoms they have to also rely on the preferences and decisions of the partner(s) [60,61]. Given the continued challenges in promoting and sustaining consistent condom use over time, other prevention modalities such as HIV pre-exposure prophylaxis (PrEP) and further development of online educational, outreach, and behavioral interventions are warranted. Although no single prevention modality will work for all, PrEP provides another highly effective option that is user centered. Notwithstanding other barriers to PrEP implementation, including awareness, access, cost, and provider-related obstacles, future research should examine the use of online interventions to promote PrEP adoption to MSM and other key populations in low- and middle-income countries.

Limitations

This study should be interpreted in light of its limitations. First, our measures were self-reported, which may have introduced social desirability bias. However, given that we only observed changes in HIV testing and not for condom use, as well as the relatively anonymous nature of participant enrollment, social desirability may have played a limited role. Future studies with more objective measures are nevertheless needed. Second, this study recruited MSM online who reported living in Mumbai and thus may not be generalizable to online MSM elsewhere in India, particularly in settings that may not have MSM-sensitive physical services or a wide range of HIV testing sites available. Third, men who identified as bisexual and straight had low retention, indicating this pilot intervention likely had minimal impact on these groups who may be at higher risk for HIV [62,63]. Future internet-based interventions for HIV prevention may benefit from taking into account sexual identity and tailoring contents specific to bisexual- and straight-identifying MSM. Finally, there could have been potential contamination between the study arms, given that a quarter of participants reported sharing the digital messages and a quarter knew of others participating in the study. Given the nature of online interventions with commonly used platforms, some degree of contamination is inevitable, and further research is needed to understand how best to measure and minimize contamination in online studies. Studies with larger samples are also needed to examine the impact of contamination on outcomes. However, a strength of social media and online interventions is their ability to rapidly diffuse information, and thus research is needed to understand how interventions could leverage the possibility of contamination as a strength rather than a limitation.

Conclusions

As one of the first studies of an online HIV intervention in India, this pilot study demonstrated preliminary efficacy for increasing self-reported HIV testing in an urban sample of MSM reached online, with the potential for wide national reach and high feasibility and acceptability. Given the continued structural challenges in engaging MSM in public health efforts (eg, stigma at various levels and lack of MSM-affirmative health care), changes in how MSM socialize and find partners and the suboptimal HIV testing rates—particularly in stigmatized settings—ICT-based intervention delivery models present new opportunities to engage MSM with or at high risk of HIV into care and prevention. Our findings signal the need for efficacy testing of this type of scalable intervention in a fully powered trial with objective measures of actual HIV testing and assessing its impact on downstream outcomes of linkage to care and prevention services.

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Conflicts of Interest

None declared.

Editorial note: This pilot randomized study was not prospectively registered. The editor granted an exception to ICMJE rules for prospective registration of randomized trials because the risk of bias appears low and the study was considered formative. However, readers are advised to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

Multimedia Appendix 1
Baseline demographic characteristics of intervention participants completing and not completing the postassessment survey (N=244).
[DOCX File , 14 KB - publichealth_v6i2e16494_app1.docx]

Multimedia Appendix 2
CONSORT-EHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 434 KB - publichealth_v6i2e16494_app2.pdf]

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Abbreviations

HST: Humsafar Trust
ICT: internet-based communication technology
IMB: information-motivational-behavioral
MSM: men who have sex with men
NIH: National Institutes of Health
PrEP: pre-exposure prophylaxis
STI: sexually transmitted infection

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Original Paper

Classification of Health-Related Social Media Posts: Evaluation of Post Content–Classifier Models and Analysis of User Demographics

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Abstract

Background: The increasing volume of health-related social media activity, where users connect, collaborate, and engage, has increased the significance of analyzing how people use health-related social media.

Objective: The aim of this study was to classify the content (eg, posts that share experiences and seek support) of users who write health-related social media posts and study the effect of user demographics on post content.

Methods: We analyzed two different types of health-related social media: (1) health-related online forums—WebMD and DailyStrength—and (2) general online social networks—Twitter and Google+. We identified several categories of post content and built classifiers to automatically detect these categories. These classifiers were used to study the distribution of categories for various demographic groups.

Results: We achieved an accuracy of at least 84% and a balanced accuracy of at least 0.81 for half of the post content categories in our experiments. In addition, 70.04% (4741/6769) of posts by male WebMD users asked for advice, and male users' WebMD posts were more likely to ask for medical advice than female users' posts. The majority of posts on DailyStrength shared experiences, regardless of the gender, age group, or location of their authors. Furthermore, health-related posts on Twitter and Google+ were used to share experiences less frequently than posts on WebMD and DailyStrength.

Conclusions: We studied and analyzed the content of health-related social media posts. Our results can guide health advocates and researchers to better target patient populations based on the application type. Given a research question or an outreach goal, our results can be used to choose the best online forums to answer the question or disseminate a message.

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KEYWORDS

social media; demographics; classification

Introduction

Background

There is a huge amount of knowledge waiting to be extracted in health-related online social networks and forums, which we collectively refer to as social media. Health-related social media store the interactions of users who are interested in health-related topics [1]. These users share their experiences, share information of friends and family, or seek help for a wide range of health issues [1]. In the United States, more than 60 million Americans have read or collaborated in *health 2.0* resources [2]. In addition, 40% of Americans have doubted a professional opinion when it conflicted with the opinions expressed in health-related social media [2]. Health-related social media widen access to health information for the public, regardless of individuals' race, age, locality, or education [1].

In this study, we evaluated the content of posts in various health-related social media. We analyzed two types of health-related social media: (1) health-related online forums: WebMD and DailyStrength and (2) general social networks: Google+ and Twitter. This was a 4-step process comprising data collection, identifying post content categories, performing classification experiments, and performing a demographics analysis. We first collected large datasets of posts from each source and identified several categories. Afterward, we identified meaningful categories from randomly selected posts from each source. In our classification experiments, we labeled data from each source and trained classifiers to identify post content categories. Finally, we used classifiers trained on our labeled data to identify categories in the remaining data and analyzed how often posts in these categories are made by various demographic groups.

The goal of this study was to provide researchers with information and tools to support further research. For example, researchers looking for clinical trial participants can use DailyStrength, where users often share experiences about a particular condition, and health advocates seeking to spread awareness about a condition that affects men can use WebMD, where men often ask for advice. To this end, we also made comparisons between platforms to suggest where such a researcher might begin looking. The classifier models built in this study can assist with this task as well as other analyses involving health-related online postings.

Related Work

Analysis of Health-Related Social Media

Many studies have been performed to characterize health-related social media communities. Hackworth and Kunz [3] reported that 80% of Americans have searched the internet for health-related information, more than 60 million Americans are consumers of social networks in the Web 2.0 environment (health 2.0), and consumers, especially those with chronic conditions, are leading the health 2.0 movement by seeking clinical knowledge and emotional support. Wiley et al [4] studied the impact of different characteristics of various social media forums on drug-related content and demonstrated that the characteristics of a social media platform affect several aspects of discussion. Eichstaedt et al [5] predicted the county-level heart disease mortality by capturing the psychological characteristics of local communities through expressed text in Twitter. However, these studies do not describe or compare specific demographics in terms of their post content.

Further work has focused on categorizing health-related posts based on their content. Yu et al [6] performed a preliminary content analysis of D/deaf and hard of hearing discussion forum, AllDeaf, to observe different types of social support behaviors and identify social support features for a future text classification task. Reavley and Pilkington [7] analyzed the content of tweets related to depression and schizophrenia, finding that tweets about depression mostly discussed consumer resources and advertisements, whereas tweets about schizophrenia mostly raised awareness and reported research findings. Lee et al [8] analyzed the content of tweets from health-related Twitter users, finding that they tweet about testable claims and personal experiences. Lopes and Da Silva [9] collected posts from a health-related online forum, MedHelp, and used them to propose and refine a scheme for manually classifying health-related forum posts into 4 categories and a total of 23 subcategories. Our work was built upon these studies by defining our own categories of post content, some of which have analogues in these studies.

Health-Related Demographic Analysis

Other work has compared health issues between demographics or examined the demographics within a population participating in health-related research. Krueger et al [10] studied the mortality attributable to a low education level in the United States across several demographics, where they found people with an education level below a high school degree to have a higher mortality rate. Anderson-Bill et al [11] examined the demographics and behavioral and psychosocial characteristics of *Web-health users* (adults who use the Web to find information on health behavior and behavior change) recruited for a Web-based nutrition, physical activity, and weight gain prevention intervention. Their results suggest that users participating in online health interventions are likely "middle-aged, well-educated, upper middle-class women whose detrimental health behaviors put them at risk of obesity, heart disease, some cancers, and diabetes" [11]. These studies describe the demographics of the populations in their studies but do not describe the demographics of health-related social media users.

Previous work has focused on characterizing demographics on health-related social media. Sadah et al [12] analyzed the demographics of health-related social media and found that users of drug review websites and health-related online forums are predominantly women, health-related social media users are generally older than general social media users, black users are underrepresented in health-related social media, users in areas with better access to health care participate more in health-related social media, and the writing level of health-related social media users is lower than the reading level of the general population. Sadah et al [13] also performed a demographic-based content analysis of health-related social media posts to extract top distinctive terms, top drugs and disorders, sentiment, and emotion, finding that the most popular topic varied by demographic, for example, pregnancy was popular with female users, whereas cardiac problems, HIV, and back pain were the most discussed topics by male users. They also found that users with a higher writing level were less likely to express anger in their posts. We expanded upon this work by characterizing and comparing the demographics of health-related social media websites in terms of the frequency of post content categories.

Text Classification in Social Media

Text classification is frequently employed by researchers to gain insights into social media users and trends, both in and out of health-related settings. Sadilek et al [14] studied the spread of infectious diseases by analyzing Twitter data using a support vector machine (SVM) model. Huh et al [15] developed a naïve Bayes model to help WebMD moderators find posts they would likely respond to. Nikfarjam et al [16] proposed a machine learning–based tagger to extract adverse drug reactions from

health-related social media. Mislove et al [17] estimated the gender and ethnicity of Twitter users using the reported first name and last name. Sadah et al [12] expanded upon the work of Mislove et al [17] by considering screen names in estimating gender. In this study, we used text classification techniques to identify categories of post content in health-related social media and used the techniques proposed in the studies by Sadah et al [12] and Mislove et al [17] to study the frequency of these categories within several demographics.

Methods

Datasets

For health-related online forums, we selected 2 different websites, WebMD and DailyStrength. The reason for selecting 2 health-related online forums is to cover the different types of health-related online forums that they each represent. Although WebMD consists of multiple health communities where people ask questions and get responses from the community members [18], DailyStrength enables patients to exchange experiences and treatments, discuss daily struggles and successes, and receive emotional support [19]. For each post collected from these websites, we extracted the URL, title, author's username, post time, the body of the post, and the name of the message board. For each user of a collected post, we also collected the author's age, friends, gender, and location, where applicable. As crawling of these sites has been performed at different times, some of the data we have collected do not reflect the current availability of certain attributes because of website format changes, for example, age and gender are currently available from WebMD user profiles but were not available before. In this study, the selection of demographic attributes we used for a source is based on the availability reflected by the majority of posts collected from that source, for example, most of the WebMD posts in our data were collected before age and gender were available, thus we did not use these attributes for an analysis of WebMD user demographics. We restricted the posts used from these sources to the first post in each thread. In our analysis, we used the post body, post title, message board name, and username from WebMD and the post body, post title, message board name, and user's gender, age, and location from DailyStrength.

For general social networks, we chose Twitter and Google+ as they offer interfaces to easily collect their data (in contrast to Facebook). For each Twitter post, we collected the post content, post time, location, and the author's username and location. For each Google+ post we collected the title, post time, update time, the post content, the location, and the author's username, first and last names, age, gender, and location. As Twitter and Google+ are general social networks, we used 274 representative health-related keywords to filter them as follows: (1) Drugs: from the most prescriptions dispensed from RxList [20], we selected the 200 most popular drugs. By removing the variants of the same drug (eg, different milligram dosages), the final list of drugs contained 124 unique drug names. (2) Hashtags: 11 popular health-related Twitter hashtags, such as #BCSM (Breast Cancer and Social Media). (3) Disorders: 81 frequently discussed disorders, such as AIDS and asthma. (4) Pharmaceuticals: the names of the 12 largest pharmaceutical companies, such as Novartis. (5) Insurance: the names of the 44 biggest insurance companies, such as Aetna and Shield. (6) General health-related keywords "healthcare" and "health insurance." To reach the final keyword counts for hashtags, disorders, pharmaceuticals, and insurance, we sampled each keyword from a larger list for each of these categories and kept keywords with a high ratio of health-related posts. In our analysis, we used the tweet body, user's first and last name, and user's location from Twitter and post body, post title, and user's gender, age, first and last name, and location from Google+.

To filter Twitter with the health-related keyword list to retrieve relevant tweets for TwitterHealth, we used the Twitter streaming application programming interface (API) [21]. Similarly, we used Google+ API [22] to extract the relevant posts for Google+Health. For health-related online forums WebMD and DailyStrength, we built a crawler for each website in Java using jsoup [23], a library to extract and parse HTML content. Table 1 lists for each source the number of posts collected, the date ranges of collected posts, and whether the demographic attributes used in this study are present, and Table 2 lists the distribution of demographics for each source across each demographic attribute. For all 4 of these sources, we did not specifically focus our search on English-language posts aside from using English drug names; however, the majority of posts collected from these sources were in the English language.

Table 1. List of all sources used with their number of posts, date range of posts, and the available demographic attributes.

Source	Number of posts	Date range	Gender	Age	Ethnicity	Location
TwitterHealth [24]	11,637,888	May 2, 2013 to November 11, 2013	Gender classifier [17]	No[a]	Ethnicity classifier [17]	Yes[b]
Google+Health [25]	186,666	August 24, 2009 to January 5, 2014	Yes	Yes	Ethnicity classifier [17]	Yes
DailyStrength [26]	1,319,622	June 21, 2006 to December 3, 2017	Yes	Yes	No	Yes
WebMD [27]	318,297	December 24, 2006 to May 11, 2019	Gender classifier [12]	No	No	No

[a]The demographic attribute is not provided by the source and no classifier is used because of low accuracy.

[b]The demographic attribute is provided by the source.

Table 2. Demographics of users from each source.

Attribute and demographic	TwitterHealth, %	Google+Health, %	DailyStrength, n (%)	WebMD, n (%)
Gender				
Male	48.19[a]	64.64[a]	95,269 (17.26)[b]	6769 (32.41)[b]
Female	51.81[a]	35.36[a]	456,600 (82.74)[b]	14,117 (67.59)[b]
Age (years)				
0-17	N/A[c]	3.42[a]	6656 (1.33)[b]	N/A
18-34	N/A	53.21[a]	187,966 (37.55)[b]	N/A
35-44	N/A	21.89[a]	126,646 (25.30)[b]	N/A
45-64	N/A	19.02[a]	149,487 (29.86)[b]	N/A
≥65	N/A	2.46[a]	29,847 (5.96)[b]	N/A
Ethnicity				
Asian	3.24[a]	5.60[a]	N/A	N/A
Black	0.30[a]	0.30[a]	N/A	N/A
Hispanic	23.50[a]	17.40[a]	N/A	N/A
White	73.00[a]	76.60[a]	N/A	N/A
Region				
Northeast	165,531 (19.83)[d]	2598 (17.86)[d]	73,221 (19.58)[b]	N/A
Midwest	174,620 (20.92)[d]	2393 (16.45)[d]	84,302 (22.55)[b]	N/A
South	313,350 (37.53)[d]	4863 (33.44)[d]	123,556 (33.05)[b]	N/A
West	181,400 (21.73)[d]	4690 (32.25)[d]	92,809 (24.82)[b]	N/A

[a]Based on Sadah et al [12].

[b]Calculated with user data collected or estimated from this study.

[c]N/A: not applicable.

[d]Calculated from user counts reported in the study by Sadah et al [13].

Identifying Post Contents

From each source, we randomly selected 500 posts. We then manually identified the different categories of shared content for each type of health-related social media. As shown in Table 3, we identified 9 different categories. The first 4 categories were identified for both types of health-related social media (hence, all 4 sources). Of these first 4 categories, 3 were also identified by Lopes and Da Silva [9], for example, *share experiences*, which we defined as posts in which a user shared a personal experience related to a health-related topic. This is similar to their *sharing personal experiences* category, except that we did not restrict our definition to experiences shared in response to another post. *About family* has no equivalent in their scheme, but it can be covered by other categories that they have defined, for example, by asking a specific question about or expressing sadness over a family member's illness. Our share experiences category was also similar to categories in other work, for example, the *personal experience of mental illness* category in the study by Reavley and Pilkington [7], the *personal* category from Lee et al [8], the *personal event* category from Robillard et al [28], and the *first-hand experience* category from Alvaro et al [29]. As Twitter and Google+ are more news-based social media, we identified 5 additional categories from these sources. *Educational material* can be considered equivalent to the *teaching* category defined by Lopes and Da Silva [9]. Despite the differences between the categories we defined and those proposed by Lopes and Da Silva [9], we believed that our categories are sufficient for a *proof of concept* for automatic post content category classification in the two types of health-related social media that we investigated. It should be noted that the identification of specific experiences is outside the scope of this study; the *share experiences* category is a catch-all for any experiences shared in a health-related post from any source.

We asked 3 graduate students to label the selected data from WebMD, Twitter, and Google+; we used a majority vote as the final result for each of these sources. Table 4 lists the intercoder agreement as given by a Krippendorff alpha for our labeled datasets from WebMD, Twitter, and Google+. The selected DailyStrength data were labeled by the labeler with the highest agreement with the majority averaged over each category from the other 3 sources (average alpha=.680). As shown in Table 5, the distribution of categories in each source is different, for

example, the share experiences category is more common in health-related online forums (WebMD and DailyStrength).

Table 3. List of all identified categories for health-related online forums and general social networks.

Category	Health-related online forums	General social networks	Example
Share experiences	Yes	Yes	• "I could not work after Tylenol." • "I have taken Lipitor every day."
Ask for specific medical advice or information	Yes	Yes	• "Is honey allowed for diabetics?"
Request or give psychological support	Yes	Yes	• "I hope your diabetes is under control." • "We're thinking of you."
About family (not about self)	Yes	Yes	• "My son is now nine months old and teething like crazy."
Share news	No	Yes	• "Kaiser Permanente Invites Software Developers To Build Apps—Forbes. http://feedly.com/k/Zojwq"
Jokes	No	Yes	• "Got any jokes about Sodium Hypobromite? NaBro."
Advertisements	No	Yes	• "Check out these two vitamins for one recipe! http://bit.ly/1471dbn"
Personal opinion	No	Yes	• "Main frustration of lupus is losing the ability to do things that used to be normal"
Educational material	No	Yes	• "Side Effects of Alzheimer's and Dementia Drugs http://bit.ly/cK7L1f"

Table 4. Intercoder agreement for our labeled datasets (Krippendorff alpha).

Category	WebMD	TwitterHealth	Google+Health
Share experiences	0.349	0.446	0.109
Ask for specific medical advice or information	0.768	0.225	0.108
Request or give psychological support	0.219	0.090	−0.007
About family (not about self)	0.736	0.322	−0.010
Share news	N/A[a]	0.083	0.083
Jokes	N/A	0.177	0.029
Advertisement	N/A	0.220	0.107
Personal opinion	N/A	0.103	0.038
Educational material	N/A	0.164	0.091

[a]N/A: not applicable.

Table 5. Percentages of categories in each source from the labeled data (N=500).

Category	WebMD, n (%)	DailyStrength, n (%)	TwitterHealth, n (%)	Google+Health, n (%)
Share experiences	236 (47.2)	400 (80.0)	74 (14.8)	65 (13.0)
Ask for specific medical advice or information	270 (54.0)	173 (34.6)	3 (0.6)	10 (2.0)
Request or give psychological support	126 (25.2)	247 (49.4)	9 (1.8)	7 (1.4)
About family (not about self)	68 (13.6)	37 (7.4)	5 (1.0)	34 (6.8)
Share news	N/A[a]	N/A	56 (11.2)	145 (28.9)
Jokes	N/A	N/A	38 (7.6)	33 (6.6)
Advertisement	N/A	N/A	26 (5.2)	70 (14.0)
Personal opinion	N/A	N/A	35 (7.0)	84 (16.8)
Educational material	N/A	N/A	36 (7.2)	137 (25.7)

[a]N/A: not applicable.

Bot Filtering

We examined the impact of automated accounts (ie, *bots*) on our study using OSoMe's Botometer (formerly BotOrNot, Indiana University) [30], a tool that estimates how likely a Twitter account is to be a bot. We used the Botometer API to score each account that has a tweet in our initial sample of 500. The API assigned each of the 345 accounts that were still active a score in the range 0 to 1, with higher scores corresponding to a higher likelihood of an automated account. We manually evaluated each account with a score above 0.5. With this threshold, which was chosen because it is a natural choice that avoids possible bias from a more arbitrary choice of threshold value, we found a total of 33 likely bot accounts. We found that tweets from these accounts make up a substantial portion of the categories share news (11 tweets), advertisement (12 tweets), and educational material (10 tweets). As Botometer's API rate limit makes removing all bot tweets from our Twitter corpus of over 11 million tweets unfeasible, we instead randomly selected 1000 posts from each day in the date range of our Twitter data. For each author of these selected posts, we again used Botometer to evaluate the likelihood of an automated account, removing tweets from accounts with a score above 0.5 for a total of 142,411 tweets used in our analysis.

We also manually examined 100 posts each from WebMD and DailyStrength to determine the prevalence of bots on these websites, which consisted of one of the authors reading each of these posts and determining whether or not it appeared to be posted by a spambot. In the context of online forums, a spambot is an automated agent that posts promotional content [31]. By this criterion, none of the posts examined appeared to have been posted by a bot. Although this does not guarantee that there are no posts from bots in the data from these websites used in our study, it does suggest that posts from bots may be much less prevalent in these sources, likely because of the smaller volume of posts and more active moderation compared with Twitter and Google+.

Building Post Content Classifiers

For each category, we performed binary classification experiments with three classifier algorithms: random forest [32], linear SVM [33], and convolutional neural network (CNN) [34].

We first extracted and concatenated the features shown in Table 6. These features include the title of a post, the main text of a post (body), and the name of the message board that contains the post (board name). For the random forest and SVM classifiers, we converted the features to a term frequency-inverse document frequency vector with stop words removed and the remaining words lemmatized. For the CNN classifier, we converted the features to sets of fastText [35] vectors pretrained on Wikipedia. For all classifiers, we applied class weights to the training data such that the weight of the positive class (the post is in the category) is balanced with the weight of the negative class (the post is not in the category). These weights are used with random forest and SVM according to their implementations by Pedregosa et al [36], whereas CNN uses oversampling of the least frequent class as recommended by Buda et al [37].

To build the classifiers, we excluded the categories where the percentage is less than 10.0% (50/500), and for the rest, we first split the labeled data to two datasets as follows: (1) a training dataset (450 posts) and (2) a test dataset (50 posts), held out for a final test after training is complete. Afterward, for each classifier algorithm, we trained each classifier by varying the hyperparameters shown in Table 7, considering each combination of hyperparameter values. For all combinations, we performed a 5-fold cross-validation on the training dataset to select the combination of hyperparameter values with the highest balanced accuracy [38]. Finally, we used these hyperparameter values to create a model trained on the full training dataset and tested this model on the test dataset that was held out before the cross-validation experiments. Note that we did not use a nested cross-validation, as our goal in these experiments was to find a single combination of hyperparameter values that we could use to apply a sufficiently accurate classifier model to the rest of our data.

Table 8 shows the classifiers' accuracy for WebMD, DailyStrength, Twitter, and Google+. We have shown only the classifiers for categories that have more than 10% of labeled data.

For the remainder of our analysis, we only considered source-category combinations with a classifier that achieved a balanced accuracy higher than 0.75.

For the source-category combinations that did not have a classifier that achieved a balanced accuracy of at least 0.75, we performed another round of experiments in which we attempted to classify posts using the best-performing classifier trained on a corresponding category from another source, for example, random forest for share experiences from WebMD. In these experiments, we used 500 posts from one source for training and 500 posts from another source for testing and again finding the best combination of hyperparameters via a 5-fold cross-validation of the training data. Table 9 shows the results of these experiments. Classifiers trained on the DailyStrength and Twitter data achieved a balanced accuracy of over 0.75 on the share experiences category from Google+, so we added this category to the set of categories considered for further analysis. For each category in this set, we used the model with the highest balanced accuracy for that category to label the rest of the data. We reported our findings on the frequency of these categories by several demographics according to their respective classifiers in the Results section.

Table 6. All classifiers' training features.

Source	Extracted features
WebMD	Title, body, and board name
DailyStrength	Title, body, and board name
Google+	Title and body
Twitter	Body

Table 7. Classifier hyperparameter values evaluated in our experiments.

Classifier and hyperparameter	Values
Random forest	
Maximum tree depth	2, 4, 8, 16, 32, 64
Number of trees, n	10, 100, 1000
Support vector machine	
C	0.001, 0.01, 0.1, 1, 10
Loss function	Hinge, squared hinge
Convolutional neural network	
Filter window sizes	(2, 3, 4), (3, 4, 5), (4, 5, 6)
Feature maps per filter window size, n	100, 200, 300, 400, 500, 600

Table 8. Classifier results for each category (N=50).

Source and category	Random forest		Support vector machine		Convolutional neural network	
	Accuracy, n (%)	Balanced accuracy	Accuracy, n (%)	Balanced accuracy	Accuracy, n (%)	Balanced accuracy
WebMD						
Share experiences[a]	41 (82)	0.83[b]	41 (82)	0.81	41 (82)	0.82
Ask for specific medical advice or information[a]	40 (80)	0.82	41 (82)	0.83[b]	37 (74)	0.76
Request or give psychological support[a]	39 (78)	0.71	43 (86)	0.8 [b]	38 (76)	0.68
About Family (Not about self)[a]	38 (76)	0.56	40 (80)	0.89[b]	47 (94)	0.81
DailyStrength						
Share experiences[a]	41 (82)	0.80	40 (80)	0.70	41 (82)	0.82[b]
Ask for specific medical advice or information[a]	39 (78)	0.71	38 (76)	0.70	37 (74)	0.7 [b]
Request or give psychological support	34 (68)	0.68	33 (66)	0.65	38 (76)	0.68[b]
TwitterHealth						
Share experiences[a]	39 (78)	0.77	41 (82)	0.82[b]	43 (86)	0.74
Share news[a]	41 (82)	0.64	40 (80)	0.73	47 (94)	0.81
Google+Health						
Share experiences	44 (88)	0.48	35 (70)	0.72[b]	45 (90)	0.60
Share news	26 (52)	0.48	28 (56)	0.52	33 (66)	0.59[b]
Advertisement	38 (76)	0.59	24 (48)	0.53	42 (84)	0.6 [b]
Personal opinion	39 (78)	0.48	37 (74)	0.71[b]	42 (84)	0.60
Educational material[a]	40 (80)	0.66	34 (68)	0.76	41 (82)	0.79[b]

[a]The category of each source-category combination with at least one classifier that achieved a balanced accuracy of at least 0.75.

[b]The highest balanced accuracy for each source-category combination.

Table 9. Results of classifiers trained on a corresponding category from another source (N=500).

Training source	Test source	Category	Classifier	Accuracy, n (%)	Balanced accuracy
WebMD	DailyStrength	Psychological support	SVM[a]	328 (65.6)	0.656
WebMD	Google+Health	Share experiences	Random forest	428 (85.6)	0.584
DailyStrength	*Google+Health* [b]	*Share experiences*	CNN[c]	383 (76.6)	*0.800*
Twitter	*Google+Health*	*Share experiences*	SVM	408 (81.6)	*0.770*
Twitter	Google+Health	Share news	CNN	360 (72.0)	0.562

[a]SVM: support vector machine.

[b]The test source, category, and balanced accuracy of each classifier that achieved a balanced accuracy of at least 0.75 are italicized for emphasis.

[c]CNN: convolutional neural network.

Demographic Analysis

We chose four demographic attributes as shown in Table 1: gender, age, ethnicity, and location. Where possible, we extracted these attributes from user profiles. These attributes are not available for every source, so we used existing classifier models where available to estimate their values. Specifically, we used the classifiers from Mislove et al [17] to estimate gender for Twitter users and ethnicity for both Twitter and Google+

users. To estimate gender for WebMD users, we used the classifier from Sadah et al [12], an extension of the classifier by Mislove et al that considers a user's screen name when the user's first name is not present. These classifiers use the 1000 most popular male and female birth names reported by the US Social Security Administration for each year from 1935 to 1995 as ground truth for gender and the distribution of ethnicities for each last name as reported by the 2000 US Census as ground truth for ethnicity. For each of these attributes, we used the data labeled by our post content category classifiers to determine how frequently users of each demographic write a post with one of these categories, for example, the percentage of posts made by male users in which a user shared his experiences. When comparing these percentages, we calculated statistical significance via a Pearson chi-square test. Note that a post can be in more than one category, for example, a post can both share experiences and ask for medical advice.

Top Distinctive Message Boards

For each combination of demographic and category (eg, male and share experiences) analyzed in WebMD and DailyStrength, we found the most distinctive message boards for that combination. For WebMD, we considered only boards that have at least 0.01% of posts for a given combination, or 30 if 0.01% is less than 30. Owing to the large number of message boards on DailyStrength (1608 analyzed in this study), we reduced this restriction to only consider boards with at least 30 posts for a given combination. We then determined distinctiveness by calculating the relative difference of each board. On the basis of the calculation for top distinctive terms by Sadah et al [13], we calculated the relative difference of board *b* within the combination of category *c* and demographic *b* of demographic attribute *a* as shown in equation (1):

$$RelDifcd(b)=[Freqcd(b)-AvgFreqca(b)]/AvgFreqca(b) \quad (1),$$

where $Freq_{cd}(b)$ is the normalized frequency of posts on board *b* in category *c* by a user in demographic *d*, for example, the number of posts on the WebMD Breast Cancer message board that share experiences and were written by a female user divided by the number of posts on WebMD that share experiences and were written by a female user. $AvgFreq_{ca}(b)$ is the average $Freq_{cd}(b)$ across all demographics *d* within the demographic attribute *a*, for example, male and female for the demographic attribute, gender.

Results

Demographics

In this section, we presented the categories' results by each demographic where possible. For age demographics, we organized users into five groups: 0 to 17 years, 18 to 34 years, 35 to 44 years, 46 to 64 years, and older than 65 years. For ethnicity, we considered four possibilities: Asian, black, Hispanic, and white. For location, we considered the four regions designated by the US Census Bureau: Midwest, Northeast, South, and West. As explained in the Methods section, we considered the following categories for each source: (1) WebMD: share experiences, ask for advice, psychological support, and about family; (2) DailyStrength: share experiences and ask for advice; (3) TwitterHealth: share experiences and share news; and (4) Google+Health: share experiences and educational material.

WebMD

As shown in Table 1, our WebMD dataset includes gender predicted by the gender classifier from Sadah et al [12]. Therefore, we have reported the distribution of gender among its categories. Table 10 shows the frequency of posts made by male and female users for each category. We found that 70.04% (4741/6769) of posts written by male WebMD users asked for advice, compared with 45.14% (6372/14,117) of posts by female users (P<.001). Table 11 shows the top 10 most distinctive WebMD message boards by the number of posts for each combination of gender and category. Unsurprisingly, these results show that female users were more likely to post on boards about pregnancy and parenting than males in all categories, whereas male users were more likely to discuss men's health issues. Men also gave psychological support and discussed family members on the message board for the infertility drug, Clomid, more frequently than women.

Table 10. WebMD category frequency by gender.

Category	Gender, n (%)	
	Male (n=6769)	Female (n=14,117)
Share experiences	3290 (48.60)	4835 (34.25)
Ask for advice	4741 (70.04)	6372 (45.14)
Psychological support	1914 (28.28)	5515 (39.07)
About family	1986 (29.34)	3623 (25.66)

Table 11. Top 10 most distinctive WebMD message boards for male and female users in each category.

Gender	Share experiences	Ask for advice	Psychological support	About family
Male	• Men's Health • Erectile Dysfunction • Relationships and Coping • Cholesterol Management • Epilepsy • Depression • Allergies • Oral Health • Knee & Hip Replacement • Ear, Nose & Throat	• Erectile Dysfunction • Cholesterol Management • Men's Health • HIV/AIDS • Depression • Epilepsy • Prostate Cancer • Sports Medicine • Pain Management • Ear, Nose & Throat	• Relationships and Coping • Epilepsy • Depression • Back Pain • Heart Disease • Pain Management • Anxiety & Panic • Clomid • Diabetes • Parenting: 4 & 5-Year-Olds	• Relationships and Coping • Depression • Erectile Dysfunction • Back Pain • Clomid • Epilepsy • Anxiety & Panic • Pain Management • Sleep Disorders • Digestive Disorders
Female	• Sexual Abuse Survivors Support • Trying to Conceive: 12 Months, Still Trying • Endometriosis • Breast Cancer • Infertility Treatment • Pregnancy: After Infertility • Pregnancy: After 35 • Parenting: Elementary Ages • Self-Harm • Menopause	• Trying to Conceive: 12 Months, Still Trying • Infertility Treatment • Dieting Club: 25-50 Lbs • Parenting: Preteens & Teenagers • Skin & Beauty • Breast Cancer • Food & Cooking • Lupus • Parenting: 3-Year-Olds • Parenting: 9-12 Months	• Chronic Fatigue Syndrome • Lupus • Sexual Abuse Survivors Support • Breast Cancer • Endometriosis • Dieting Club: 10-25 Lbs • Trying to Conceive: 12 Months, Still Trying • Pregnancy: After 35 • Dieting Club: 100+ Lbs • Pregnancy: After Infertility	• Sexual Abuse Survivors Support • Pregnancy: After 35 • Trying to Conceive: 12 Months, Still Trying • Trying to Conceive: After Loss • Breast Cancer • Self-Harm • Parenting: Preteens & Teenagers • Parenting: 9-12 Months • Dieting Club: 50-100 Lbs • Parenting: 6-9 Months

DailyStrength

For our DailyStrength demographic attributes, gender, age, and location, we reported the results for the categories share experiences and ask for advice. Table 12 shows the category frequencies for each demographic. The majority of posts (over 80%) from every demographic share experiences; but among the different age demographics, we saw a clear decline in frequency as age increases, from 92.77% (6175/6656) for users aged younger than 18 years to 81.82% (24,420/29,847) for users 65 years and older (P<.001). The frequency of posts that ask for advice is similar for almost every demographic (30%-40%), with the exception of posts from users younger than 18 years 25.45% (1694/6656). P<.001 for all comparisons between users younger than 18 years and other age groups.

Tables 13-15 show the top 10 most distinctive DailyStrength message boards by the number of posts for each combination of gender and category, age group and category, and location and category, respectively. From these lists, we saw a wider variety of topics compared with WebMD, likely because of the large number of message boards on DailyStrength. However, we still saw some trends when considering broader topics. Male users tend to share experiences on message boards related to personal and social issues. Both male and female users asked for advice most frequently on boards related to physical conditions.

We also observed a general tendency for younger users (aged younger than 45 years) to share experiences on message boards about personal and social issues, whereas older users favored message boards for general support and discussion. Users in all age groups frequently asked for advice about physical conditions. We found no clear trend in sharing experiences when evaluating census regions, but we saw that users from the Northeast region share experiences about physical and psychological conditions, whereas users from the West region often shared experiences on message boards for general support and discussion. Users from all regions frequently asked for advice about physical conditions except the West, whose users tended to ask for advice on message boards for general support and discussion. Note that there are fewer than 10 message boards listed for users of age 0 to 17 years who asked for advice in Table 14 because of the lack of message boards that also met our restriction of having at least 30 of these posts.

Table 12. DailyStrength category frequency by gender, age, and location.

Attribute and demographic	Total number of participants	Share experiences, n (%)	Ask for advice, n (%)
Gender			
Male	95,269	78,760 (82.67)	31,706 (33.28)
Female	456,600	409,640 (89.72)	167,867 (36.76)
Age group (years)			
0-17	6656	6175 (92.77)	1694 (25.45)
18-34	187,966	173,226 (92.16)	65,191 (34.68)
35-44	126,646	113,796 (89.85)	48,335 (38.17)
45-64	149,487	127,089 (85.02)	54,008 (36.13)
≥65	29,847	24,420 (81.82)	10,581 (35.45)
Region			
Northeast	73,221	65,761 (89.81)	28,196 (38.51)
Midwest	123,556	76,630 (90.90)	31,600 (37.48)
South	123,556	110,597 (89.51)	46,933 (37.99)
West	92,809	76,797 (82.75)	31,481 (33.92)

Table 13. Top 10 most distinctive DailyStrength message boards for male and female users in each category.

Gender	Share experiences	Ask for advice
Male	• Vow To Live LGBT Against Suicide • Christian Church 24.7 Ministry • Gay Men's Challenges • Single Dads • GOYA • Dealing with Diabetes2 and remembering Goldi • A Child Abuse Survivors Group • CALM and EASY GAMES • Financial Challenges • Liars Anonymous	• A Laughter Club • Dealing with Diabetes2 and remembering Goldi • Impotence & Erectile Dysfunction • Sex/Pornography Addiction • High Cholesterol • Tinnitus, Deafness and Ear Problems • Urinary Incontinence • Atrial Fibrillation (AFib) • MRSA • LDN .. Low Dose Naltrexone
Female	• helping with the housework • Lesbian Relationship Challenges • prompts • AlAnon One Day At A Time • Daughters of Abusive Mothers • Breastfeeding • Parenting Toddlers (1-3) • Post-Partum Depression • Infertility • Vulvar Cancer	• Pregnancy • Menopause • Trying To Conceive • Miscarriage • Polycystic Ovarian Syndrome (PCOS) • Family & Friends of Bipolar • WHY WEIGHT? LET'S LOSE WEIGHT AND FEEL GREAT! • Infertility • Vulvar Cancer • Breastfeeding

Table 14. Top 10 most distinctive DailyStrength message boards for each age group in each category.

Age group (years)	Share experiences	Ask for advice
0-17	• Weight Loss For Teens • Gay & Lesbian Teens • Depression–Teen • Bipolar Disorder–Teen • Self-Injury • Transgender • Depression • Coming Out • Bisexuality • Eating Disorders	• Weight Loss For Teens • Depression–Teen • Self-Injury • Eating Disorders • Anxiety
18-34	• Sunny and Peaceful Skies • Parenting Toddlers (1-3) • Daily Positive Thoughts • Trying To Conceive • Parenting Newborns & Infants (0-1) • College Stress • Arnold-Chiari Malformation • ALL MOODY BLUES • Career Changes • Cerebral Palsy	• Trying To Conceive • Neuropathy • Pregnancy • Miscarriage • Polycystic Ovarian Syndrome (PCOS) • Cerebral Palsy • Endometriosis • Pseudotumor Cerebri • Sexually Transmitted Diseases–Female • Schizophrenia
35-44	• Vow To Live LGBT Against Suicide • Parenting 'Tweens (9-12) • Twins, Triplets & More • Self-Hate Syndrome • Parents Whose children have been sexually abused • HOPEFUL HEARTS...LIVING AGAIN AFTER THE LOSS • Neurofibromatosis • Breastfeeding • Hyperparathyroidism • Stillbirth	• kindredspirits • Hyperparathyroidism • Multiple Sclerosis (MS) • Pseudotumor Cerebri • Allergies • Hemochromatosis • Hypothyroidism • Addison’s Disease • MCTD • Graves’ Disease
45-64	• acoa sanctuary • prompts • Christians with MS • InHisCare Bible Study • The Serenity Room • Ticked off about Lyme • Biblical Studies and Archaeology • Alanon support group • Just support • WHY WEIGHT? LET’S LOSE WEIGHT AND FEEL GREAT!	• WHY WEIGHT? LETS LOSE WEIGHT AND FEEL GREAT! • MS People Dealing with MS Pain • Dealing with Diabetes2 and remembering Goldi • Multiple Myeloma • Menopause • High Cholesterol • LDN .. Low Dose Naltrexone • Myofascial Pain Syndrome • Neurocardiogenic Syncope • Amputees
≥65	• Banana • A Little Bit Of Kindness Goes A long Way! • AlAnon One Day At A Time • VOICES OF RECOVERY • The Walking Group • The Front Porch • Over The Fence • Muscular Dystrophies • CALM and EASY GAMES • movie lovers	• AlAnon One Day At A Time • VOICES OF RECOVERY • I can’t HEAR you! • COPD & Emphysema • Meniere’s Disease • Parkinson’s Disease • Sleep Apnea • Interstitial Cystitis (IC) • Atrial Fibrillation (AFib) • Acromegaly

Table 15. Top 10 most distinctive DailyStrength message boards for each region in each category.

Region	Share experiences	Ask for advice
Northeast	• WHY WEIGHT? LET'S LOSE WEIGHT AND FEEL GREAT! • Self-Hate Syndrome • Smoking Addiction & Recovery • Urinary Incontinence • Families of Prisoners • Agoraphobia & Social Anxiety • Cocaine Addiction & Recovery • Obesity • CHRISTIAN PARENTS of ESTRANGED ADULT CHILDREN • Brain Injury	• WHY WEIGHT? LET'S LOSE WEIGHT AND FEEL GREAT! • Obesity • Hidradenitis Suppurativa • Endometriosis • Deep Vein Thrombosis (DVT) • Atrial Fibrillation (AFib) • Diets & Weight Maintenance • Gastritis • Polycystic Kidney Disease (PKD) • Hypothyroidism
Midwest	• Just support • acoa sanctuary • helping with the housework • kindredspirits • The Coffee Shop • aa Spoken Here • Highly Sensitive People HSP • Financial Challenges • I can't HEAR you! • Pseudotumor Cerebri	• kindredspirits • Neurocardiogenic Syncope • Pseudotumor Cerebri • Gastritis • Irritable Bowel Syndrome (IBS) • COPD & Emphysema • Parkinson's Disease • Polycystic Kidney Disease (PKD) • Pancreatitis • Graves' Disease
South	• prompts • Beyond Medication • InHisCare Bible Study • Ticked off about Lyme • Muscular Dystrophies • aa friends • Anxiety and POSITIVE CHOICES • Games for Fun and Relaxation • MS People Dealing with MS Pain • Parents Whose children have been sexually abused	• MS People Dealing with MS Pain • High Cholesterol • Cirrhosis • Polymyositis & Dermatomyositis • Addison's Disease • Meniere's Disease • MCTD • Trying To Conceive • Endometriosis • Polycystic Ovarian Syndrome (PCOS)
West	• A Little Bit Of Kindness Goes A long Way! • The Walking Group • Alanon support group • VOICES OF RECOVERY • AlAnon One Day At A Time • BIBLICAL STUDIES • The Sunflower group • My Favorite Things. • FrIeNdShIpRoOm • three prayerpraise	• AlAnon One Day At A Time • Banana • The Sunflower group • WINGS • VOICES OF RECOVERY • A Laughter Club • FrIeNdShIpRoOm • Myofascial Pain Syndrome • Hemochromatosis • Colon Cancer

Twitter

For our Twitter demographic attributes, gender, ethnicity, and location, with gender and ethnicity predicted by the classifier from Mislove et al [17], we reported the results for categories share experiences and share news using our sample of 142,411 tweets in Table 16. As described in the Methods section, this dataset was created from our full corpus by first sampling 1000 posts for each day represented in the dataset and then pruning tweets from likely bot accounts. All demographics analyzed shared experiences more often than they shared news. Hispanic users had the largest difference, with 29.16% (826/2833) of them shared experiences versus 5.47% (155/2833) of them shared news (P<.001). Users from the Northeast census region had the smallest difference, with 20.38% (1093/5362) of them shared experiences versus 10.16% (545/5362) of them shared news; P<.001. Where comparison is possible between these demographics and their counterparts in WebMD and DailyStrength, we saw that Twitter users shared experiences less frequently (P<.001 for all such comparisons).

Table 16. Twitter category frequency by gender, ethnicity, and location.

Attribute and demographic	Total number of participants	Share experiences, n (%)	Share news, n (%)
Gender			
Male	16,092	3188 (19.81)	1277 (7.94)
Female	17,850	4835 (27.09)	1091 (6.11)
Ethnicity			
Asian	626	166 (26.52)	34 (5.43)
Black	56	12 (21)	3 (5)
Hispanic	2833	826 (29.16)	155 (5.47)
White	9992	2259 (22.61)	728 (7.29)
Region			
Northeast	5362	1093 (20.38)	545 (10.16)
Midwest	4686	1084 (23.13)	380 (8.11)
South	9855	2162 (21.94)	850 (8.63)
West	5448	1164 (21.37)	515 (9.45)

We also performed this analysis on our full Twitter dataset of 11,637,888 tweets. We compared these results with the results shown in Table 16 and found that the differences were generally not statistically significant (with statistical significance defined as $P<.05$) for the share experiences category but were significant for all but one demographic in the share news category. These findings agree with our evaluation of bot likelihood using our initial sample of 500 tweets, where we found that the share news category had a substantial number of tweets from likely bot accounts, but the share experiences category did not. The *P* values of these comparisons are shown in Table 17.

Table 17. *P* values of comparisons between Twitter results using pruned data and results using all data.

Category	Male	Female	Asian	Black	Hispanic	White	Northeast	Midwest	South	West
Share Experiences	<.001	.47	.24	.80	.68	.15	.13	.048	.002	<.001
Share News	<.001	<.001	<.001	.23	<.001	<.001	<.001	<.001	<.001	<.001

Google+

Our Google+ demographic attributes include gender, age, ethnicity, and location, with ethnicity predicted by the classifier from Mislove et al [17], and for these attributes we reported the results from the share experiences and educational material categories in Table 18. As classifiers trained on our labeled Google+ dataset did not achieve a sufficiently high balanced accuracy for the share experiences category, we considered classifiers trained on the labeled DailyStrength and Twitter data as described in the Methods section. The full set of Google+ posts were classified as 34.13% (63,709/186,666) share experiences by the DailyStrength-trained classifier and 18.83% (35,149/186,666) share experiences by the Twitter-trained classifier. As the latter distribution of the share experiences category is closer to the distribution reported in Table 5, 13.0% (65/500), we used the Twitter-trained classifier for the remainder of our analysis in the share experiences category.

From these results, we saw that most demographics appeared to share experiences more frequently than the set of all Google+ users. This is likely the effect of a bias toward users who chose to report these attributes (or a real name, in the case of ethnicity). When comparing how often a demographic shares experiences with how often posts from users with no data on that demographic's corresponding attribute share experiences (eg, posts from men vs posts from users who did not report gender), we found that $P<.001$ for all such comparisons except for users aged ≥65 years ($P=.83$). Where comparison is possible between these demographics and their counterparts in WebMD and DailyStrength, we saw that Google+ users shared experiences less frequently ($P<.001$ for all such comparisons).

Educational material was shared less frequently by users aged between 35 and 44 years, 14.9% (46/308) than by users of any other age group. In particular, they shared educational material much less frequently than both the previous age group, 18 to 34 years, 25.5% (141/552), $P<.001$; and the following age group, 45 to 64 years, 34.3% (171/499), $P<.001$. Asian Google+ users, 35.75% (1010/2825), substantially shared more educational material than users of any other ethnicity ($P=.002$ vs black users, $P<.001$ vs Hispanic users, and $P<.001$ vs white users).

Table 18. Google+ category frequency by gender, age, ethnicity, and location.

Attribute and demographic	Total number of participants	Share experiences, n (%)	Educational material, n (%)
Gender			
Male	61,479	15,234 (24.78)	16,200 (26.35)
Female	32,082	9803 (30.56)	8029 (25.03)
Age group (years)			
0-17	42	19 (45.24)	8 (19.05)
18-34	552	189 (34.24)	141 (25.54)
35-44	308	101 (32.79)	46 (14.94)
45-64	499	62 (12.42)	171 (34.27)
≥65	45	9 (20.00)	13 (28.89)
Ethnicity			
Asian	2825	730 (25.84)	1010 (35.75)
Black	72	28 (38.89)	13 (18.06)
Hispanic	3389	1137 (33.55)	707 (20.86)
White	17,230	5076 (29.46)	3340 (19.38)
Region			
Northeast	4510	1097 (24.32)	957 (21.22)
Midwest	4210	1310 (31.12)	716 (17.01)
South	9532	2636 (27.65)	1913 (20.07)
West	7959	2279 (28.63)	1708 (21.46)

Discussion

Principal Findings

Our analysis shows several interesting results. From our initial samples, we found that health-related posts from general social networks often shared news and educational material, and posts on health-related online forums frequently shared experiences, asked for medical advice, and requested or gave psychological support (Table 5). Our evaluation of three classification algorithms on the post content categories described by our study showed that, in terms of balanced accuracy, SVM tended to perform well on WebMD, whereas CNN performed better on DailyStrength data. Of the 2 Twitter categories used in our experiments, share experiences and share news, SVM performed the best in share experiences and CNN was the best in share news. None of the classifiers we evaluated performed particularly well when trained with the Google+ data; only the CNN classifier was able to meet our performance threshold in the Google+ educational material category. However, in the share experiences category, classifiers trained on the DailyStrength and Twitter data were able to meet our performance threshold in the Google+ share experiences category, suggesting that at least some transferability is possible with classifiers trained on other datasets.

A further analysis of our health-related online forum data showed distinct differences between users of WebMD and DailyStrength. On WebMD, we found that the majority of posts made by male users and almost half of all posts made by female users asked for advice. This would seem to contradict an earlier study that found that women were the predominant users of the internet for health advice [39], but when considering the overall number of posts from male and female WebMD users included in our study (41,422 posts by men vs 93,293 by women), we saw that posts asking for advice were still more likely to be written by a woman than a man. DailyStrength users shared experiences frequently in all demographics analyzed in our study, even more so than WebMD users; however, asking for advice was less common than on WebMD. These differences may be explained by the differences in the 2 health-related online forums; although DailyStrength offers support groups for a variety of topics, WebMD communities are often frequented by experts who can provide advice to users.

An analysis of health-related posts on general social networks, Twitter and Google+, suggested differences that they have from health-related online forums. Compared with WebMD and DailyStrength, sharing experiences, which identifies posts in which a user shared a personal experience related to a health-related topic, is far less frequent in posts from Twitter and Google+ that contain one or more of the health-related keywords used in this study. The relatively low frequency of sharing experiences in our sample of several health-related topics on general social networks compared with the frequency of sharing experiences on health-related online forums may be due to a variety of factors, such as Twitter's lack of health-related communities because of its structure as well as WebMD's and DailyStrength's focus on answering medical questions and providing support, respectively. Some subsets of health-related tweets studied in other work have low proportions

of sharing experiences similar to our observations, such as tweets about depression [7], schizophrenia [7], and dementia [28], as well as tweets from health-related Twitter users [8]. However, other work has shown that the proportion can be much higher, such as in tweets about dental pain [40] and prescription drug use [29]. Many health-related topics had high proportions of posts that shared experiences in our Google+ data, for example, *headache*, 93.22% (6572/7050); *migraine*, 78.77% (2029/2576); *insomnia*, 71.41% (2430/3403); *cold sore*, 58.0% (370/638); and *diazepam*, 51.1% (95/186). This suggests that the proportion of sharing experiences in health-related posts may be highly dependent on the topic or topics studied; thus, our findings on the share experiences category may not generalize to other studies on health-related social media posts.

Our comparison of results between our stratified sample of Twitter data with tweets from suspected bots removed and our full Twitter dataset showed that automated accounts had a significant impact on the share news category. Other work has also shown that bots can have an effect on health-related Twitter conversations, particularly on the subject of vaccination. Bots post both pro- and antivaccine tweets [41] and retweet vaccine-related tweets at higher frequencies than human users [42]. The use of bots in this manner amplifies the debate and further polarizes the communities involved. It is clear that bot activity must be considered when analyzing health-related conversations on Twitter.

The differences in how often educational material is shared on Google+ between the demographics we studied highlight potential targets for informational health care campaigns. A health care campaign is a health care–related broad nationally or subnationally driven, led, or coordinated activity [43]. Users in the age demographic of 35 to 44 years, who share educational material less often than other age groups, may benefit from being provided with medical information that they are not aware of. Demographics that share educational material more frequently than others, such as Asian Google+ users, may also be of interest to medical experts. If a further analysis of the educational material shared by these groups shows that the information is inaccurate or misleading, providing correct information may benefit them.

Our results provide useful information that can help health care providers to reach the right demographic group. For example, researchers looking for clinical trial participants can use health-related online forums, where many posts are about sharing experiences. Moreover, demographic-specific results can help guide the targeted educational campaigns. As an example, male WebMD users ask specific medical advice questions more often than females, so male WebMD users may be more receptive to a campaign offering advice from medical experts.

The classifier models used in this study can also be useful for researchers who want to study posts that contain the categories we studied. For example, a researcher who wants to study experiences about a particular drug can use these classifiers to find posts that share experiences from a larger dataset of posts that mention that drug. As another example, a researcher who wants to find out which disorders are frequently mentioned among users who share news can use a classifier to gather a dataset of news-sharing posts. In general, we provided researchers with tools that enable them to answer hypotheses and do research on the subject of health-related social media posts. These tools are provided by the description of our methodology, which describes how one might build these classifier models, and by trained classifier models that are available on request. Similar tools may also be applicable to the categories in the scheme proposed by Lopes and Da Silva [9]. We leave this as future work.

Limitations

As users of health-related social media use an informal writing style, our selected 274 words to filter Twitter and Google+ as described in the Methods section may not cover all health-related posts or their variability in topics. For example, the abbreviation *IUI* (intrauterine insemination) is widely used in health-related posts but not included in the health-related keyword list. Another limitation is the different uses of terms used to filter Twitter and Google+. For example, the word “cancer” yields many tweets that talk about zodiac signs.

We found that some Twitter categories have a high proportion of tweets from automated accounts. Although we have attempted to filter out tweets from such accounts, some such tweets may still exist in the data used in our analysis, and tweets from legitimate accounts may have been filtered out. Our initial evaluation of bot prevalence also found that the educational material category had a high proportion of tweets from bots. This may be also true of that category in the Google+ data, which was not filtered for bots; thus, those results may not accurately represent the demographics studied.

Our demographic populations may not be fully representative of all users from the sources in our study. As shown in Table 1, some of our demographics were estimated using classifiers, and these estimates are not always correct. Other demographics in our study are optionally reported by users. This introduces a bias toward users who choose to report their age, gender, and/or location, as noted in our results from Google+. We also assumed these reported demographics are correct for each such user.

Conclusions

In this study, we analyzed the content shared in two different types of health-related social media: health-related online forums and general social networks. For the two types of health-related social media, we manually identified 4 post categories: share experiences, ask for specific medical advice, request or give psychological support, and about family; and we additionally identified 5 categories for general social networks: share news, jokes, advertisements, personal opinion, and educational material. After labeling randomly selected data for each source, we built classifiers for each category. Finally, we made demographic-based content analyses where possible.

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Authors' Contributions

RR conducted the experiments and analysis and wrote the manuscript. SS conducted earlier versions of the experiments and analysis and assisted in the writing of the manuscript. YG coordinated the labeling of the training datasets and conducted preliminary research. VH conceived the study and provided coordination and guidance in the experiments and writing of the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
CNN: convolutional neural network
SVM: support vector machine

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Original Paper

Google Searches and Suicide Rates in Spain, 2004-2013: Correlation Study

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Abstract

Background: Different studies have suggested that web search data are useful in forecasting several phenomena from the field of economics to epidemiology or health issues.

Objective: This study aimed to (1) evaluate the correlation between suicide rates released by the Spanish National Statistics Institute (INE) and internet search trends in Spain reported by Google Trends (GT) for 57 suicide-related terms representing major known risks of suicide and an analysis of these results using a linear regression model and (2) study the differential association between male and female suicide rates published by the INE and internet searches of these 57 terms.

Methods: The study period was from 2004 to 2013. In this study, suicide data were collected from (1) Spain's INE and (2) local internet search data from GT, both from January 2004 to December 2013. We investigated and validated 57 suicide-related terms already tested in scientific studies before 2015 that would be the best predictors of new suicide cases. We then evaluated the *nowcasting* effects of a GT search through a cross-correlation analysis and by linear regression of the suicide incidence data with the GT data.

Results: Suicide rates in Spain in the study period were positively associated (r<-0.2) for the general population with the search volume for 7 terms and negatively for 1 from the 57 terms used in previous studies. Suicide rates for men were found to be significantly different than those of women. The search term, "allergy," demonstrated a lead effect for new suicide cases (r=0.513; P=.001). The next significant correlating terms for those 57 studied were "antidepressant," "alcohol abstinence," "relationship breakup" (r=0.295, P=.001; r=0.295, P=.001; and r=0.268, P=.002, respectively). Significantly different results were obtained for men and women. Search terms that correlate with suicide rates of women are consistent with previous studies, showing that the incidence of depression is higher in women than in men, and showing different gender searching patterns.

Conclusions: A better understanding of internet search behavior of both men and women in relation to suicide and related topics may help design effective suicide prevention programs based on information provided by search robots and other big data sources.

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KEYWORDS

suicide; big data; infodemiology; infoveillance; incidence; help-seeking behaviors; searching behavior; early diagnosis

Introduction

Background

According to the World Health Organization (WHO) projections, by 2030, there will be 1,007,000 deaths by suicide, making suicide the 15th leading cause of death globally and accounting for 1.4% of all deaths [1]. Despite the common idea that suicide is more prevalent in high-income countries, about 75% of suicides worldwide occur in low- and middle-income

countries. In general, suicide rates are lower among people aged <15 years and >70 years [2].

With a rate of 10 cases every day, suicide is the leading cause of unnatural death in Spain, producing more than twice as many deaths than traffic accidents, 7 times more deaths than workplace accidents, and 70 times more deaths than domestic violence. It is also the leading cause of death among men aged 20 to 24 years [3].

The incidence of suicide in a society depends on a range of factors, of which clinical depression is a particularly common cause [4]. Substance abuse, severe physical disease, and disability are also recognized causes of suicide. Countries in Eastern Europe and East Asia have the highest suicide rate in the world. The region with the lowest suicide rate is Latin America. Gender differences also play a significant role: Among all age groups in most parts of the world, females tend to show higher rates of reported nonfatal suicidal behavior and males have a much higher rate of completed suicides.

Availability of Google and the Internet

As Howe [5] reports, the internet was the result of some visionary thinking by people in the early 1960s who saw great potential in allowing computers to share information on research and development in scientific and military fields. There is the common idea that widespread media coverage of specific methods of suicide may induce copycat deaths and initiate changes in the popularity of certain methods since at-risk individuals may use the internet to research particular methods of suicide that can be more lethal than the commonly used methods [6]. It is unclear whether the information obtained on the internet is reducing the risk of suicide or contributing to suicide promotion; there is evidence to suggest that the internet may facilitate suicide in various ways [7], but the influence of the internet on the incidence of suicide is not well known. On the contrary, efforts to carry out epidemiological monitoring of suicide are hampered by gaps in data availability. At present, the lag time for reporting data is 3 years for the Centers of Disease Control and Prevention (CDC) in the United States, ≥5 years for the WHO [8], and about 3 years for the Instituto Nacional de Estadística (INE, National Statistics Institute) in Spain.

Using Google Search Totals to Predict Social Trends

Increasingly, the volume of internet searches is being used as a social indicator (eg, in the field of epidemiology), and recently, this method has been applied to studies on suicide. We can establish a chronology of studies that began to use internet search volumes following the study of Choi and Varian [9], who reviewed the pioneering studies that suggested that web search data are useful for forecasting in various fields. In economics, the first such study was performed by Ettredge et al [10], who examined the association between search volumes and unemployment rates in the United States. In the same year, Cooper et al [11] described the use of internet search volumes for cancer-related topics. Since then, there have been several papers that have examined web search data in numerous fields.

In the field of epidemiology, Eysenbach [12]—as the initiator—and Ginsberg et al [13] showed that search data could help predict the prevalence of influenza-like diseases by finding a positive relationship between the number of influenza-related search queries and pneumonia and influenza mortality. These papers were widely publicized and stimulated several further findings in epidemiology, including those by Brownstein et al [14], Hulth et al [15], Pelat et al [16], and Valdivia and Monge-Corella [17].

In the field of economics, Choi and Varian [9] showed how Google Search Insights data could be used to predict some economic metrics including initial claims for unemployment, vacation destinations, and automobile demand. Askitas and Zimmermann [18] and Suhoy [19] inspected unemployment data in the United States, Germany, and Israel. Guzman [20] examined Google data as a forecaster of inflation, pointing out that the Google Inflation Search Index (GISI) indicator is a good way of measuring inflation. Baker and Fradkin [21] have used Google search data to examine how job search activity was influenced by policies on unemployment payment extensions. Radinsky et al [22] and Preis et al [23] examined the use of search data for measuring consumer confidence, and Vosen and Schmidt [24] studied consumption and retail sales metrics.

Shimshoni et al [25] verified the predictability of Google Trends data, showing that substantial quantities of search terms are greatly predictable using simple seasonal statistical methods. Goel et al [26] offered a useful survey of work in this area, revealing some of the limitations of web search data. As they pointed out, obtaining search data is easy and often helpful in making predictions but it may not provide significant increases in predictability.

Recent studies have shown the usefulness of new methodologies known as *Infoveillance*, *Infodemiology*, or *Digital Disease Surveillance*. For example, Adler et al [27], through projections of known correlations, identified various states in India with poor surveillance of the incidence of suicide or states with limited or no access to the internet.

Forecasting Suicide

Work on suicide has predominantly focused on traditional forms of media, particularly surrounding the issue of suicide contagion.

Daine et al [28] conducted a systematic review investigating the influence of the internet on self-harm and suicide in young people. They provided evidence of both positive influences, such as web-based media being used as a form of support, and negative influences, such as internet addiction, cyberbullying, and the internet being a source of information on suicide and self-harm. Mok et al [7] expanded on previous work by focusing explicitly on suicide-related internet use. They define suicide-related internet use as the "use of the Internet for reasons relating to an individual's own feelings of suicide" [7]. This paper summarized and assessed the existing work on not only the influence of suicide-related internet use but also its nature by presenting the main findings and discussing the types of studies that have been conducted, their strengths and limitations, and recommendations for future research. These findings are reported in Textbox 1.

In this study, we have focused on the topic, "Suicide-related internet search trends can provide an indicator of suicide risk

in a population" in Textbox 1. According to Mok et al [7], most of the 9 articles give credence to a link between suicide-related search activity and suicide rates.

Some papers studied the correlation between search terms such as "suicide" and "depression" [8] in searches and news reports [29], or between searches and unemployment rates [30]; therefore, we have excluded this kind of semantic or mass media correlation, focusing only on the correlation between search terms and actual death rates reported by official institutions (ie, the INE for the 2004-2013 period). We did not find Chen's 2013 paper reported by Mok et al [7] and Gunn and Lester [31]; as such, we interpreted this as a citation error in the Mok et al [7] paper. Therefore, we finally used 6 articles (Table 1) that studied a total of 57 terms, of which 14 do not return results in Spanish in Google Trends for the period studied in Spain (Table 2).

Textbox 1. Main findings of the literature on suicide-related internet use [7].

- Use of the internet to search for suicide-related content:
  - Suicide-related internet search trends can provide an indicator of suicide risk in a population (number of articles, n=9).
  - Users conducting suicide-related searches typically access scientific information and community resource websites (n=1).
- Use of the internet to express suicide-related feelings (n=7)
- Suicide-related internet use and suicidal behavior:
  - The internet may facilitate suicide in various ways (n=17).
  - Internet-related suicides are rare when compared with overall suicides (n=1).
  - There is no evidence of increased suicidal behavior in response to a suicide on a web-based forum (n=1).
- Suicide-related internet use and suicidal ideation:
  - Individuals who engage in suicide-related internet use report higher levels of suicidal ideation (n=4).
  - There are mixed findings regarding the influence of suicide-related internet use on suicidal ideation over time (n=6).
  - Informal web-based suicide communities can maintain suicidal feelings (n=1).
- Role of the internet in suicide prevention:
  - Informal web-based suicide communities can function as support groups (n=1).
  - Web-based suicide forums staffed by trained volunteers can have positive effects (n=3).
  - Professional web-based interventions can reduce suicidal ideation (n=2).

Table 1. Previous studies on the topic, "Suicide-related internet search trends can provide an indicator of suicide risk in a population," according to Mok et al [7]; the terms from this topic were tested in Spanish.

Year	Authors	Title	Region of study	Period	Language	Data	Studio unit	Statistical method
2010	McCarthy [8]	Internet monitoring of suicide risk in the population	United States	2004-2007	English	Centers for Disease Control and Prevention (CDC), United States	Year	One-way analysis of variance with Tukey-Kramer post-hoc analysis
2011	Sueki [32]	Does the volume of Internet searches using suicide-related search terms influence the suicide death rate: Data from 2004 to 2009 in Japan	Japan	2004-2009	Japanese	Demographic statistics released by the Ministry of Health, Labour, and Welfare	Month	Cross-correlation
2011	Yang et al [33]	Association of internet search trends with suicide death in Taipei City, Taiwan, 2004–2009	Taipei City, Taiwan	2004-2009	Chinese (traditional)	Department of Health, Taiwan	Month	Cross-correlation, multiple linear regression with a stepwise method
2012	Hagihara et al [34]	Internet suicide searches and the incidence of suicide in young people in Japan	Japan	2004-2010	Japanese	Statistics and Information Department of the Japanese Ministry of Health, Labour and Welfare	Month	Cross-correlation
2013	Gunn and Lester [31]	Using google searches on the internet to monitor suicidal behavior	United States	2009	English	McIntosh and Drapeau [35]	Month	Pearson correlations
2014	Bruckner et al [36]	A time-series analysis of google searches for suicide and the risk of completed suicide in England and Wales, 2004–2010	England and Wales	2004-2010	English	Publicly available database	Month	Time-series routines

Table 2. Terms used in previous studies with their Spanish translation.

Paper (English) search term	Spanish translation
Bruckner et al [36]	
Depression and help[a]	depresión y ayuda
Suicide and depression	suicidio -gran + depresion -gran
Suicide and help[a]	suicidio y ayuda
Suicide and methods	suicidio metodos
Gunn and Lester [31]	
Commit suicide	suicidarse
How to suicide[a]	cómo suicidarse
Suicide prevention[a]	prevención del suicidio
Evans [37]	
A suicide	suicida -ataque -escuadron -fuga -comico -reportero -tango -letra -extremoduro
Bulletin board system on suicide[a]	BBS[b] sobre el suicidio
Depression suicide[a]	depresión suicida
Hydrogen sulfide	sulfuro de hidrógeno + sulfuro de hidrogeno
Hydrogen sulfide suicide[a]	sulfuro de hidrógeno suicidio
Sites on suicide[a]	sitios sobre suicidio
Suicide by jumping[a]	suicidio saltando
Suicide hydrogen sulfide[a]	suicidio por sulfuro de hidrógeno + suicidio por sulfuro de hidrogeno
Suicide methods	maneras de suicidarse
Suicide rates[a]	tasas de suicidio
McCarthy [8]	
Teen suicide	suicidio adolescente
Hagihara et al [34]	
Abuse	abuso
Alcohol	alcoholismo
Alcohol abstinence	dejar alcohol
Allergy	alergia
Antidepressant	antidepresivo
Anxiety disorder	trastorno de ansiedad
Asthma	asma
Bipolar disorder	bipolar -pol -letra -chiguire -cancion
Cáncer	cancer -horoscopo
Charcoal burning	carbón vegetal + carbon vegetal
Chronic illness	enfermedad cronica
Complete guide of suicide[a]	guía completa de suicidio
Divorce	divorcio
Domestic violence	violencia domestica + violencia doméstica
Drunkenness	emborracharse
Hanging	colgarse
Headache	dolor de cabeza

Paper (English) search term	Spanish translation
Hypnotics	somniferos
Illicit drugs	drogas
Insomnia	insomnio -filmaffinity -la -pelicula -wow -dun
Job	trabajo
Jumping from a height[a]	saltar desde altura
Lawsuit	demanda judicial
Major depression	depresión mayor + depresion mayor
Marriage	matrimonio
Pain	dolor
Psychiatric service[a]	servicio psiquiátrico
Relationship breakup	ruptura amorosa
Religious belief	creencias religiosas
Schizophrenia	esquizofrenia
Social benefits	ayuda social
Social welfare	bienestar social
Stock market	bolsa de valores
Stress	estres -bancos + estrés -bancos
Taiwan economy	economia + economía
Unemployed + lost job	paro; desempleo
Bruckner et al, Evans, Hagihara et al [34,36,37][c]	
Suicide methods	maneras de suicidarse
Bruckner et al, Yang et al [33,36][c]	
Depression	depresion -meseta -gran + depresión -meseta -gran
McCarthy, Bruckner et al, Hagihara et al, Yang et al [8,33,36][c]	
Suicide	suicidio

[a]Terms for which Google Trends returned the result, "your search does not return enough data to show results."

[b]BBS: bulletin board system.

[c]Several studies evaluating the same term.

Objectives

The study has two objectives: (1) It evaluates the correlation between suicidal rates released by the INE and internet search trends in Spain reported by Google Trends for 57 suicide-related terms representing major known risks of suicide; these terms have already been tested in previous scientific studies systematized by Mok et al [7] (topic "Suicide-related internet search trends can provide an indicator of suicide risk in a population"). (2) It examines the differential association between male and female suicide rates published by the INE and internet searches related to the aforementioned 57 terms. The study included data from 2004 to 2013, as this was the maximum period for which relevant data were available from the INE and Google Trends.

Methods

In this section, we have addressed two issues: (1) how Google presents the results of search volume and how those results are normalized over time and in different geographical areas and (2) presentation of the variables we worked with—the expressions or terms used whose search volumes are reported by Google Trends and suicide rates (globally and segregated by gender) provided by the INE.

Google Trends

Google Trends provides a time-series index of the volume of queries users entered into Google in a given geographic area. Wikipedia explains it as follows [38]:

> *Google Trends is a public web facility of Google Inc., based on Google Search, that shows how often a particular search-term is entered relative to the total*

search-volume across various regions of the world, and in various languages.

Although Google Trends does not show the absolute number of searches, it calculates a query share for a search term. This means that Google calculates the number of searches for a given term as a proportion of the total number of searches in each location at a given time. These calculations are then normalized to a Google Trends *Relative Search Volume* (RSV) index between 0 and 100, where an RSV index of 100 designates the date when there was the highest amount of search activity for that given term. Thus, a search index of 40 equates to 40% of the most intense search activity in the selected country at a given period.

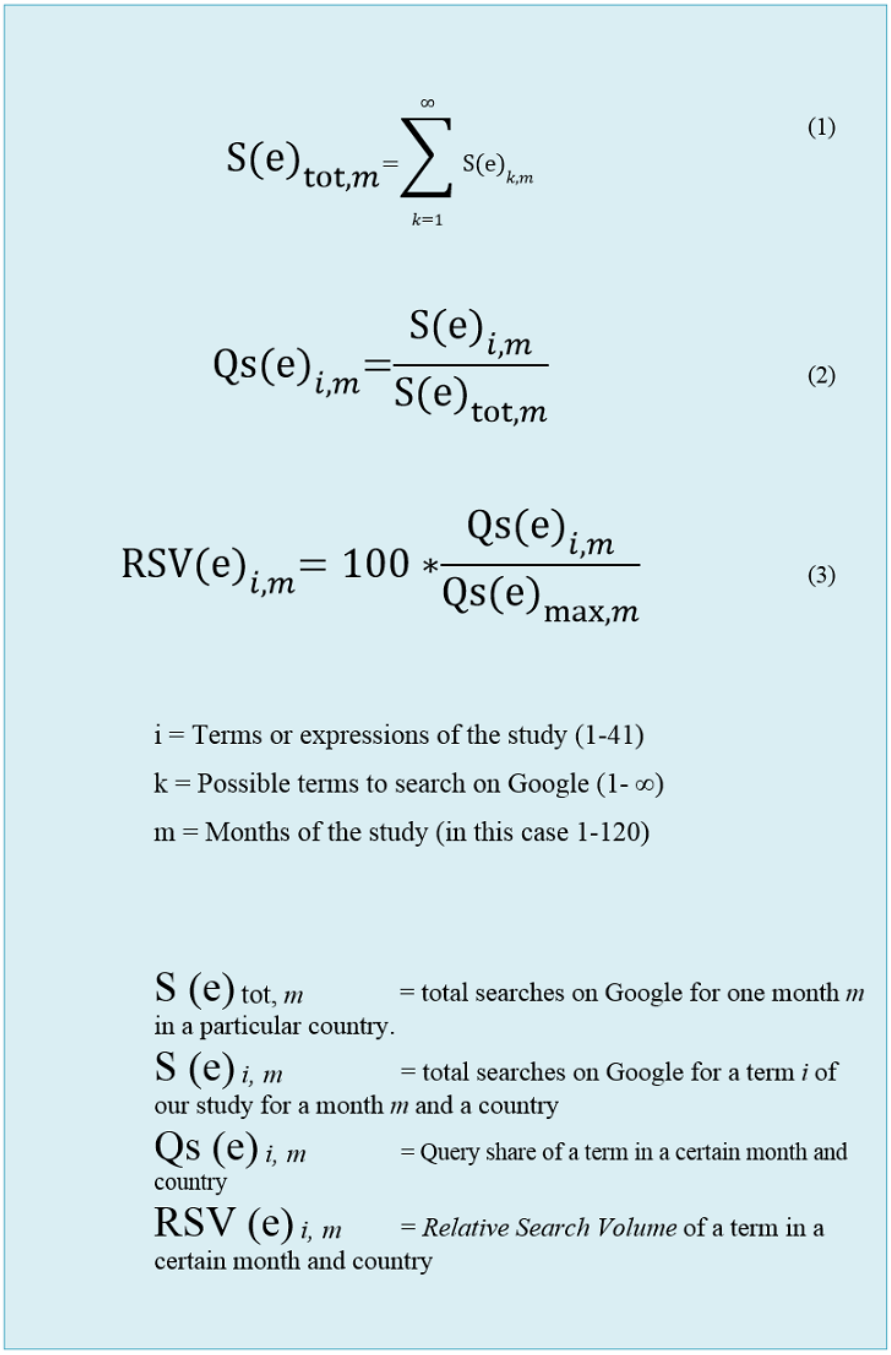
Thus, the RSV index is a way to normalize (from 0 to 100) the query share that is the total volume of queries of the search term in question within a particular geographic region divided by the total number of searches in that region for the period under review. The maximum percentage of consultation in the specified time period is normalized to 100, and the other measures for that period of time are calculated relative to this value.

Google Trends also allows for the comparison of the relative volumes of blocks of searches for up to 5 terms or phrases. In this case, the RSV of other terms that did not reach the peak of 100 is normalized to the 100 value of the term with the highest search volume of the 5 terms of phrases in the block. However, in our work, terms were consulted one by one.

It is interesting to point out that although, according to Google Scholar, more than 10,000 scientific papers used or mentioned Google Trends service, we did not find any mathematical formulation of how the RSV value was calculated or operationalized by Google Trends. Therefore, we proposed a tentative mathematical formulation of how this value is calculated (Figure 1).

In short, Google Trends calculates the number of searches as percentages (formula 2 of Figure 1) based on the total searches in a month (formula 1 of Figure 1), normalizes the series allocated to the highest value (ie, the value of 100), and scales all other values accordingly (formula 3 of Figure 1).

Figure 1. Mathematical formulation of how Google Trends operationalizes its monthly relative search volume for a particular term. RSV: relative search volume.



Variables

Search Term Variables Group

As variables, 57 query terms (Table 2) have been used that relate to suicidal ideation studied in the 6 articles mentioned in Table 1. These terms were translated into Spanish with the help of the website WordReference [39]; note that for cases in which the original language is different from the language of the articles (ie, English), this meant a third translation, as some of the papers were in Japanese and traditional Mandarin Chinese, which can be a significant semantic shift.

Queries to Google Trends are not case sensitive but are diacritical mark sensitive, so Google Trends has different results (eg, for "enfermedad cronica" (chronic illness) than for "enfermedad cronica + enfermedad crónica" [written with Spanish accent]).

Google queries are "broad matched" in the sense that queries such as "great depression" are counted in the calculation of the query index for "depression," which is why we mentioned above that when searching for a term, we should look up what related queries pop out to exclude unwanted terms by placing a dash before them, as required by the Google Trends interrogation syntax. In addition, we have performed a back translation procedure to confirm the accuracy of the translation.

In the related searches, we found terms that did not include the one we were searching for; this is because Google showed other

terms that were searched for in the same searching session as the one we were interested in, so we included that term preceded by a hyphen after ours to exclude this spurious concept out of our dataset. In this regard, we devised a set of terms (Table 2) to search in Google Trends; 14 returned no results for their Spanish translation (marked with "no" in the results column in Table 2), and the term "suicide methods" occurred 3 times in previous studies, so duplicates were removed. Therefore, in our final analysis, only 41 terms were included.

We performed an individual search for each of these terms in Spanish, and Google Trends returned 120 values, one for each month of the study period. In each series, there was one term with a value of 100 and the remaining were presented as percentages in reference to this.

Our search was limited to Spain for the period from January 1, 2004, to December 31, 2013, and the final configuration of the search for each term was as follows:

https://www.google.es/trends/explore?date=2004-01-01%202013-12-31&geo=ES&q="term".

It is worth mentioning that Google Trends data were computed using a sampling method, and therefore, the results vary within minutes.

Group Suicide Rate Variables Collected by the Spanish National Statistics Institute

The variables that we used for correlations are the absolute actual suicide rates of Spain (around 4000 deaths per year) reported by the INE, the official organization in Spain that collects statistics on demography, economy, and Spanish society. We have obtained this information through the National Epidemiology Center, which is part of the Instituto de Salud Carlos III, a public research center of the Government of Spain. This information was segregated into totaled data for men and women; Google Trends data were not segregated in this manner.

The period that collected data for was from January 2004 to December 2013, which is, as mentioned earlier, the maximum period covered by both data sources, Google Trends and the INE, at the time of study.

Statistical Analysis

Data were analyzed using the statistical package IBM SPSS Statistics, version 22 (IBM Corporation). The Pearson correlation coefficient was used to assess a possible monthly correlation between suicidal rates and Google Trends RSV data for the search terms that we defined. Next, we performed a multiple linear regression analysis to propose an explanatory-predictive model of the variance of the suicide rates variable.

Results

Results of Objective 1: Correlation Between Suicidal Rates and Internet Searches

With regard to the first objective of our study, the values for correlation between suicide-related terms and suicide rates for Spain from Google Trends data are shown in Table 3 after calculating the Pearson correlation coefficient. We centered moderate or superior results of correlation values according to Evans' study [37], as detailed in Table 4, with a significance value $P<.05$ (in italics). Since the study terms are Spanish translations of ones already studied in English, Japanese, and Mandarin in the mentioned studies, we devised a *Reference* column indicating the previous study and a *Correlation* column to indicate the presence of a correlation according to the original study, with values *yes*, *insufficient*, or *no*.

A linear regression analysis (steps forward) was performed; predictors included all variables (search terms) that demonstrated a significant correlation with previous suicide rates collected by the INE and had an $r>0.2$. These are the terms in Table 3 that have at least one *P* value with a significant correlation in the men, women, or total columns. Table 4 presents the explanatory-predictive model.

Overall, the model predicts a significant percentage of variance (adjusted $r^2=0.387$) of the suicide variable. The term "unemployment" translated as "paro" in Spanish has a high beta value and a positive sign, whereas the term "unemployment" translated as "desempleo" has a lower and negative value. This may seem contradictory because both terms are, a priori, synonyms. However, searches of the term "desempleo" could be carried out, in greater proportion, by people seeking information related to the official term "unemployment benefits and aid" offered by the Spanish Government, while the term "paro," which is used more colloquially, may be associated with searches carried out by people who are suffering due to "unemployment." This may explain why searches for that term are positively associated with the incidence of suicide committed in Spain between 2004 and 2013.

Regarding the beta value for "headache," which has a high and negative correlation with the variable "incidence of suicide," it could be argued that people who search for headache (a condition that can be associated with a wide variety of medical conditions) do so with an intent of self-care, which is contrary to the intention of committing suicide.

Table 3. Correlation coefficient obtained for each Spanish term related to suicide, and suicide rates for men and women in Spain in the 2004-2013 period. Significant values (ie, $P<.05$) are italicized.

Translated search term (original in Spanish)	Monthly correlation: GT[a] RSV[b]/INE[c] suicide rates (2004-2013)						Previous studies	
	Total		Men		Women		Reference	Correlation
	r [d]	*P* value	*r*	*P* value	*r*	*P* value		
Allergy	0.513	*<.001*	0.491	*<.001*	0.374	*<.001*	Yang et al [33]	Yes
Antidepressant	0.295	*.001*	0.291	*.001*	0.194	*.02*	Yang et al [33]	Insufficient
Alcohol abstinence	0.295	*.001*	0.251	*.003*	0.296	*.001*	Yang et al [33]	Yes
Relationship breakup	0.268	*.002*	0.191	*.02*	0.365	*<.001*	Yang et al [33]	No
Unemployed + lost job	0.253	*.003*	0.234	*.005*	0.206	*.012*	Yang et al [33]	No
Pain	0.239	*.004*	0.208	*.011*	0.230	*.006*	Yang et al [33]	No
Drunkenness	0.211	*.01*	0.142	.06	0.310	*<.001*	Yang et al [33]	No
Suicide	0.199	.02	0.133	.07	0.296	*.001*	McCarthy [8]; Yang et al [33]; Bruckner et al [36]; Sueki [32]	Yes; Yes; No; No
Insomnia	0.193	*.02*	0.160	*.04*	0.204	*.013*	Yang et al [33]	Yes
Suicide and depression	0.186	*.02*	0.116	.104	0.298	*<.001*	Bruckner et al [36]	Yes
Major depression	0.184	*.02*	0.118	.099	0.285	*.001*	Yang et al [33]	Yes
Headache	0.183	*.02*	0.163	*.04*	0.165	*.04*	Yang et al [33]	No
A suicide	0.174	*.03*	0.145	*.06*	0.183	.02	Evans [37]	Yes
A suicide	0.171	*.03*	0.181	*.02*	0.079	.19	Yang et al [33]	No
Marriage	0.130	.08	0.083	.18	0.201	*.014*	Yang et al [33]	Yes
Anxiety disorder	0.126	.09	0.084	.18	0.185	*.02*	Yang et al [33]	Yes
Charcoal burning	0.120	.097	0.044	.32	0.271	*.001*	Yang et al [33]	Insufficient
Chronic illness	0.115	.11	0.097	.15	0.119	.098	Yang et al [33]	No
Lawsuit	0.115	.11	0.094	.15	0.124	.09	Yang et al [33]	Yes
Cancer	0.113	.11	0.093	.16	0.122	.09	Yang et al [33]	No
Hanging	0.110	.12	0.077	.20	0.154	*.046*	Yang et al [33]	Insufficient
Divorce	0.064	.24	0.028	.38	0.133	.07	Yang et al [33]	Yes
Suicide methods	0.042	.32	–0.005	.48	0.149	.053	Yang et al [36]; Evans [37]; Sueki [32]	No; No; No
Hypnotics	0.042	.33	0.015	.44	0.096	.15	Yang et al [33]	Insufficient
Depression	0.038	.34	0.001	.497	0.120	.096	Bruckner et al [36]; Sueki [32]	Yes; Yes
Commit suicide	0.032	.37	–0.015	.44	0.141	.06	Gunn and Lester [31]	Yes
Stress	0.010	.46	–0.043	.32	0.144	.06	Yang et al [33]	Yes
Hydrogen sulfide	0.009	.46	–0.022	.41	0.087	.17	Evans [37]	Yes
Teen suicide	–0.018	.42	–0.023	.40	0.002	.49	McCarthy [8]	Yes
Bipolar disorder	–0.029	.38	–0.051	.29	0.041	.33	Yang et al [33]	Yes
Schizophrenia	–0.042	.33	–0.098	.14	0.121	.09	Yang et al [33]	No
Social benefits	–0.043	.32	–0.001	.495	–0.135	.07	Yang et al [33]	No
Domestic violence	–0.048	.30	–0.093	.16	0.089	.17	Yang et al [33]	Yes
Job	–0.048	.30	–0.068	.23	0.024	.40	Yang et al [33]	No

Translated search term (original in Spanish)	Monthly correlation: GT[a] RSV[b]/INE[c] suicide rates (2004-2013)						Previous studies	
	Total		Men		Women		Reference	Correlation
	r [d]	*P* value	*r*	*P* value	*r*	*P* value		
Asthma	–0.092	.16	–0.098	.14	–0.040	.33	Yang et al [33]	Yes
Abuse	–0.103	.13	–0.071	.22	–0.147	.06	Yang et al [33]	No
Taiwan economy	–0.105	.13	–0.114	.11	–0.043	.32	Yang et al [33]	Yes
Religious belief	–0.109	.12	–0.132	.08	–0.006	.47	Yang et al [33]	Yes
Alcohol	–0.113	.11	–0.132	.08	–0.019	.42	Yang et al [33]	No
Illicit drugs	–0.127	.08	–0.158	*.04*	0.003	.49	Yang et al [33]	No
Social welfare	–0.146	.06	–0.116	.10	–0.167	*.03*	Yang et al [33]	Yes
Stock market	–0.231	*.006*	–0.222	*.007*	–0.166	*.04*	Yang et al [33]	No

[a]GT: Google Trends.

[b]RSV: Relative Search Volume.

[c]INE: Spanish National Statistics Institute.

[d]Column from which the table is sorted.

Table 4. Predictive-explanatory model obtained by linear regression using as predictors search terms with a significance *P*<.05 and the variable suicide rates in Spain collected by the Spanish National Statistics Institute in the 2004-2013 period.

Predictors: search terms	*r*	r^2	r^2 adjusted	Standard error of estimation	Beta (standard)	*t* test	*P* value
a: Allergy	0.513	0.264	0.257	28.2157	0.441	5.845	<.001
b: a + Relationship Breakup	0.552	0.304	0.292	27.5421	0.205	2.823	.006
c: b + Unemployment (paro)	0.583	0.340	0.322	26.9515	1.134	3.710	<.001
d: c + Headache	0.607	0.369	0.347	26.4618	–0.721	–3.279	.001
e: d + Unemployment (desempleo)	0.631	0.398	0.371	25.9586	–0.366	–2.294	.02
f: e + Antidepressant	0.647	0.418	0.387	25.6255	0.152	1.996	.048

Results of Objective 2: Differences Between Men and Women

With regard to the second objective of our work, we found correlations between the terms of study and suicide rates between women and men (Table 5). To describe the strength of the correlation between our variables, we have used the interpretation by Evans [37]; as it can be seen in absolute terms, there is an important difference between the correlation of men and women.

The significant difference between male and female correlations can be explained by women's use the internet for searching for health and lifestyle information. In contrast, men tend to focus on information about investment, purchase, and personal interests [40]. Moreover, this would be consistent with the idea that women have higher emotional intelligence and more communication skills than men [41].

Table 5. Number of positive (+) or negative (–) correlations found among the 41 Google search terms or phrases and suicide rates according to sex as reported by Spanish National Statistics Institute for the 2004-2013 period.

Correlation strength by gender	Evans' scale	Total	Men	Women
Very weak or none	0.00-0.19	34	36	30
Weak	0.20-0.39	6+, 1–	4+, 1–	12+
Moderate	0.40-0.59	1	1	0
Strong	0.60-0.79	0	0	0
Very strong	0.80-1.0	0	0	0

Discussion

Correlation Between Suicidal Rates and Internet Searches

It is not clear whether the information found on the internet contributes to the promotion of suicide and inspires suicidal thoughts or reduces the risk of suicidal behavior. The causal relationship between suicide and the use of the internet to search for topics related to self-harm or suicide is difficult to prove; however, the results of our study suggest a significant correlation for a number of the search terms that we have studied. This is consistent with previous studies that have been outlined throughout this paper that mostly state that there is indeed some association between certain searches and social phenomena in the economics, health, and other sectors.

Suicide rates in Spain for the 2004-2013 period were examined for their association with search volume on Google for 41 suicide-related searches already tested in scientific studies in other countries and languages. For the general population, suicide rates in Spain were positively associated with the search volume (r>0.2) for 7 terms and negatively associated with the search volume for 1 of the 41 terms. Our interpretation of the results is that they corroborate the hypothesis that certain searches on Google may serve as an indicator of a country's suicide rate, perhaps even of its social well-being.

The negative correlations that we would call "protective" (for searches aimed at finding a solution to the problem) are interesting; the 41 searches in the original studies were supposed to be "risk related" in relation to suicide incidence, but one of them, *Stock Market* (r=–0.231; P=.006), correlated negatively along with some others that may have a "protective" significance (Social welfare, Religious belief, etc). As a preliminary explanation, we believe that this is due to the social and cultural translocation of the search terms, eg, in Spain unlike Taiwan—where the previous study for the search *Stock Market* was performed—only wealthy people are concerned about the topic.

In the case of *Drunkenness* (r=0.211; P=.01) versus the negative correlation for *Alcohol* (r=–0.113; P=.11), the latter could be interpreted as a protective search to find a solution to the problem, while the former may be used in a leisurely way (ie, without a problematic consciousness). This led us to an important point: Google Trends includes data from subjects with suicidal behavior searching in Google in addition to searches by other people concerned about the issue. We called these two perspectives as "first person" and "third person." We then realized that Google Trends data includes "first person" searches from subjects with suicidal ideation and "third person" searches from their relatives, social surroundings, and institutions; therefore, it is crucial to try to segregate one from the other for future studies. Perhaps, this can be done with the help of linguistics differentiating the denotative aspects of words from their connotative aspects.

Comparison With Prior Work

The term that correlates more strongly with the overall rate of suicide is *Allergy* (r>0.5 and P<.001), which is consistent with other studies linking depression and allergy [42,43].

However, the overlap between the terms that correlate in our study and those that correlate in other studies is only about half. This could be due to cultural differences between the regions of the study subjects. It could also be due to semantic changes lost (or gained) in translation: Although the studies that we used to build our research were written in English, the original language of the study was Japanese or Mandarin Chinese in several cases, which resulted in two nested translations in this study.

Comparing our results for Spain with some of the results from a study by Yang et al [33] for Taiwan, there are differences that we can charge to cultural or sociological variances between the subjects of each study. Although in the Taiwanese study, the term *Divorce* correlates with suicide rates, in our study, it does not correlate with suicide rates. *Unemployed* does not correlate with suicide rates, according to Yang et al [33], but it does so in Spain, where unemployment is approximately 4 times higher than it is in Taiwan. We interpret these as indicators of issues that have a different significance and social context in these two regions. It should be noticed that while the search term *Divorce* (r=0.064; P=.24) does not correlate with suicide rates in Spain, *Relationship Breakup* (r=0.268; P=.002) does and this is the second strongest correlation among women. Further consideration on gender differences are made in the following section.

Another reason for these disparities might be deficiencies in the study methodology since using Google Trends as a diagnostic indicator of a society's well-being is still fairly new.

Other interesting evidence our study demonstrates is that well-known risk factors (eg, depression) and explicit searches (eg, suicide) are not correlated with suicide rates; this could be interpreted as follows: the better the knowledge of the risk situation, the less likely it is that this risk of suicide will materialize.

Differences Between Men and Women

Although there is no gender segregation in Google Trends RSV data, as Spanish suicide rates from the INE are segregated by gender, we were able to find differing gender-based correlations: We have found 5 terms that correlate for suicide rates among men and 12 terms in the case of women. Search terms that correlate with suicide rates of women are consistent with previous studies, showing that the incidence of depression is higher in women than in men [44].

In short, we have obtained more than twice the correlations between suicide rates for women compared with those obtained for men. We understand that this is due to the fact that patterns of internet usage among women are more oriented toward searches on health or lifestyle [40], which is also very much in line with the idea that women have more emotional intelligence than men [41]. This would explain why their suicide rate is much lower than that of men in Spain.

Limitations

Owing to the limitations of evidence, we cannot actually predict increases of suicidal mortality using web search data. Rather, we undertook a preliminary investigation using the entire available dataset to establish a statistical association between search term usage and actual suicides in Spain. Further studies should compute time-lagged correlations between Google searches and suicides to help prevent suicide-related deaths.

Social Applications

The practical implication of our results are as follows: It is desirable that competent authorities establish agreements with Google to facilitate suicide prevention by monitoring searches in Google for any of the terms that have been shown to correlate with suicide statistics and other terms that are proven to be significant in future studies.

We also hope that our research will help design and maintain websites that provide better education for suicide prevention, focusing on the treatment of depression and management of labor or emotional problems, as these fields show greater explanatory-predictive value in the incidence of suicide according to our regression model.

Future Developments

An interesting avenue for future research on suicide-related searches is obtaining data from large social networks such as Facebook or Twitter, rather than just metasearch engines like Google.

In addition, the results of this study suggest the feasibility of using the Google search volume to predict other social risk behaviors such as traffic accidents, domestic violence, and bullying, and for the epidemiological monitoring of the evolution of emotional disorders in society. In general, we believe that tracking the search volumes of certain terms (eg, ones related to suicide) represents satisfaction in and well-being of a society. Hence, there may even be an application to the field of politics.

Other Considerations

We want to point out some interesting facts that we have come across in our research and that we consider to be significant in correctly interpreting the world of big data and metasearch engines.

First, as mentioned earlier, it is interesting to note that despite the fact that more than 10,000 scientific papers used or mentioned the Google Trends service, according to Google Scholar, we did not find any mathematical formulation of how Google Trends operationalizes the values that it returns, which is the reason why we have developed it ourselves (Figure 1).

Another fact that seems significant is the case of GISI [20] or the Google Price Index (GPI), which are Google initiatives from 2010, that disappeared despite evidence of good results for forecasting phenomena. According to comments on web-based forums, Google chief economist, Dr Hal Varian, said that GPI was never intended be a project or public source of data; it was simply an internal Google project made visible by the press [45].

In any case, the opportunities and risks of using information from internet metasearches are yet to be determined; with this work, we hope to have contributed some clarity to this field of study.

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Conflicts of Interest

None declared.

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Abbreviations

GISI: Google Inflation Search Index
GPI: Google Price Index
INE: Spanish National Statistics Institute
RSV: Relative Search Volume
WHO: World Health Organization

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Original Paper

Comparison of Social Media, Syndromic Surveillance, and Microbiologic Acute Respiratory Infection Data: Observational Study

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Abstract

Background: Internet data can be used to improve infectious disease models. However, the representativeness and individual-level validity of internet-derived measures are largely unexplored as this requires ground truth data for study.

Objective: This study sought to identify relationships between Web-based behaviors and/or conversation topics and health status using a ground truth, survey-based dataset.

Methods: This study leveraged a unique dataset of self-reported surveys, microbiological laboratory tests, and social media data from the same individuals toward understanding the validity of individual-level constructs pertaining to influenza-like illness in social media data. Logistic regression models were used to identify illness in Twitter posts using user posting behaviors and topic model features extracted from users' tweets.

Results: Of 396 original study participants, only 81 met the inclusion criteria for this study. Of these participants' tweets, we identified only two instances that were related to health and occurred within 2 weeks (before or after) of a survey indicating symptoms. It was not possible to predict when participants reported symptoms using features derived from topic models (area under the curve [AUC]=0.51; P=.38), though it was possible using behavior features, albeit with a very small effect size (AUC=0.53; P≤.001). Individual symptoms were also generally not predictable either. The study sample and a random sample from Twitter are predictably different on held-out data (AUC=0.67; P≤.001), meaning that the content posted by people who participated in this study was predictably different from that posted by random Twitter users. Individuals in the random sample and the GoViral sample used Twitter with similar frequencies (similar @ mentions, number of tweets, and number of retweets; AUC=0.50; P=.19).

Conclusions: To our knowledge, this is the first instance of an attempt to use a ground truth dataset to validate infectious disease observations in social media data. The lack of signal, the lack of predictability among behaviors or topics, and the demonstrated volunteer bias in the study population are important findings for the large and growing body of disease surveillance using internet-sourced data.

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KEYWORDS

social media; infodemiology; influenza, human; selection bias; bias; logistic models

Introduction

Background

Internet data have been used in several contexts to improve infectious disease surveillance and prediction for many diseases, including influenza [1], cholera [2], dengue [3], and malaria [4]. They have been shown, in some instances, to be predictive of the incidence of infectious diseases (eg, seasonal influenza [1,5-8]), but there are also cases where the data hold little predictive value [8,9]. In general, disease prediction based on internet-sourced data utilize explicit mentions of symptoms or references to illness. Some have identified symptom reports from social media data using machine learning classifiers [7,10]. Others use search queries related to a disease of interest [1,11,12]. These counts are then used to infer population-level statistics such as from the US Centers for Disease Control and Prevention. A major advantage is that internet data can be obtained in real time, whereas traditional public health data can take weeks or even months to compile [13]. Research has also found that the combination of internet data with traditional sources can improve forecasts [6,14].

Only recently has data representativeness been explored. Some works have explored the degree to which social media users are representative of the broader population [15,16] or methods to account for biases [17]. However, little is known about the validity of health information such users share on the internet and conversely how information is shared when users are actually sick. In other words, although social media disease detection systems have been validated against official reports at the population level [10,18], the relationship between population-level models and individual-level information is not well understood—for example, how often do social media users post that they are sick, and in what ways?

Answering these questions requires data about individuals. Although infectious disease research with internet data has largely not had access to ground truth datasets, there is substantial prior work in related domains. Researchers have used crowdsourcing methods to create ground truth datasets of individuals with clinical depression [19], compared electronic medical records with topics of Facebook posts [20], and used self-disclosures of attention deficit hyperactivity disorder on the internet as ground truth datasets [21].

This study sought to advance our understanding of the relationship between people's actual health statuses and their social media activity. We used influenza-like illness and similar syndromes, such as the common cold, as a case study. We leveraged individual-level health data, including weekly symptom self-reports and viral diagnostic data collected through the GoViral platform, an internet-based influenza-like illness surveillance system, in which participants returned a weekly symptom survey when sick. Data from these reports were used alongside Twitter messages posted by the individuals (each individual considered here also shared their public Twitter profile information). Our experiments examined how often and in what ways individuals tweeted about their health in relation to the health status described by their survey responses. We measured whether survey-derived health statuses can be predicted with social media–derived variables about individuals and if the study participants differed predictably from Twitter users.

Objectives

Specifically, we answered three research questions (RQs).

- RQ1: How often and in what ways do people share their illnesses on Twitter when they are ill?
- RQ2: How predictable is someone's illness status from their tweets?
- RQ3: How are results from individuals in the GoViral study potentially representative (or not representative) of Twitter users more generally?

RQ1 and RQ2 sought to improve our understanding of the relationship between an individual's health status and social media activity, whereas RQ3 seeks to understand how representative were the data we used.

Methods

Data Collection

The GoViral platform was developed to generate self-reported symptoms and biospecimens from a cohort of lay volunteers. Although the GoViral platform had been in operation since November 2013, the operationalizing of Twitter handle collection commenced in August 2016. This study includes data from participants recruited between August 2016 and November 29, 2017.

Recruitment, eligibility, and enrollment procedures remained consistent with the existing platform. Enrollment was driven largely by recruitment in person at relevant community outposts and events. Paid online advertisements and social media were also used as a means of recruiting volunteers to the study. The study size was limited by the ability to recruit and engage participants. To register, volunteers signed an electronic consent form and reported their email address, name, mailing address, gender, and age. Volunteers were sent a kit that included collection materials and customized instructions to keep at home. Users were instructed to perform a specimen collection (nasal swab) if they became sick with symptoms of a cold or the flu. Participants also reported symptoms through weekly surveys. Symptoms included those common to acute respiratory infections and seasonal cold and flu-like illnesses (fever, cough, sore throat, shortness of breath, chills, fatigue, body aches, headache, nausea, and diarrhea). If a participant reported any symptoms on their weekly survey, they were immediately sent an email reminder to submit specimens. Specimens were tested for the presence of a panel of acute respiratory infections. Demographic information (age, gender, ethnicity, and location) and Twitter handle (optional) were also collected from each participant. Additional details of the protocol can be found in studies by Goff et al and Ray and Chunara [22,23].

We used the Tweepy application program interface (API) [24] to collect available tweets from participants, limited by the Twitter API, which only allows 3200 most recent tweets per user. The Twitter API only allows for collection of profiles that are shared publicly. These timelines were collected in March

2018. In addition, we collected data from a random set of Twitter users for comparison. These timelines were obtained in October 2018. We identified all users in a 2-week, 1% random Twitter stream and randomly selected users from this sample. Users were kept in the final random dataset if we were able to obtain tweets back to the start of the GoViral study (n=118). This was done to allow for matching between study participants and the random sample. However, this decision does bias the dataset away from very prolific users.

Keyword Analysis and Topic Modeling

To answer RQ1, we identified tweets that explicitly referenced the individual's current health status, focusing on colds or flu-like illness. As the number of individual tweets precluded manual coding, we used a keyword filtering approach. This is a common approach to increase the fraction of relevant instances [25-28]. We queried all timelines for tweets that included the following keywords:

- General words: flu, sick, throat, hurt, sinus, influenza, stomach, tummy, respiratory, nose, feeling, cold, feel, h1n1, h3n2, h5n1, flua, flub, infection, ill
- Symptoms: fever, cough, congested, stuffy, headache, ache, sore, head, phlegm, sneeze, asthma, pneumonia
- Medications: medicine, dayquil, nyquil, tamiflu, mucinex, theraflu, tylenol, motrin, aleve, naproxen, ibproufen, acetaminophen, advil, virus, oseltamivir, peramivir, infection, zanamivir, antiviral, guaifenesin, robitussin, phenylephrine, decongestant, pseudoephedrine, antihistamines

For use in the analyses described in the following section, we extracted topics from all tweets using latent Dirichlet allocation (LDA) [29] and a Gibbs sampling implementation with automatic hyperparameter optimization described in the study by Paul and Dredze [30]. Before feature extraction, all tweets were preprocessed in the same manner: usernames and URLs were replaced with generic tokens and emojis, nonalphanumeric characters, and extra letters were removed (eg, *greaaaat* is truncated to *great*). The Gibbs sampler was run for an initial 1000 iterations, and 100 samples were collected at the end and averaged to estimate the model parameters. The number of topics was set to 100. Each of the 100 topics has a distribution over words, characterizing the content of the topic, and each tweet has a distribution over the 100 topics. The topic probabilities in each tweet are used in the predictive models to describe tweet content.

Predictive Modeling

To answer RQ2, we created several training and testing datasets (n=100) because the overall GoViral dataset was small. For each, 90% (73/81) of the eligible GoViral participants were randomly selected to be in the training set. The remaining 10% (8/81)were reserved for the test set. Using this method instead of creating one training/testing dataset allowed us to measure the robustness of the models on a number of datasets and generate summary statistics (area under the curve [AUC] and *P* values reported below). We then constructed 3 datasets.

The first dataset was used to discern if we could identify when participants were sick. For each participant, we randomly sampled one survey to include in the dataset. If that survey had no symptoms, we then randomly sampled another survey from the selected participant that had at least one symptom. Conversely, if the survey did report a symptom(s), we randomly sampled a survey with no symptoms. In this fashion, we balanced the number of asymptomatic and symptomatic data points and balanced the number of surveys per participant (to avoid bias from individuals who were particularly prolific survey respondents).

The second and third datasets were used to measure differences between the GoViral dataset and the Twitter random sample (RQ3). Here, each survey selected initially was matched with two additional data points. For each survey, we selected a random date during which the user tweeted but did not return a survey within a week on either side. We also selected a random date from the Twitter users collected at random. These datasets allowed us to measure if a GoViral user would return a survey in a particular week and if an individual was in the GoViral dataset. The purpose of this dataset was to measure if there was evidence of external factors that impacted study participants; for example, it could be that individuals were more likely to return surveys with symptoms because they stayed home when ill and had more time to fill out the survey.

For all predictive models, two types of features were used: topic features and behavior features. To construct topic features, we obtained all tweets for 1 week before the date of interest (eg, the date a survey was returned). We then obtained the topic distribution for those tweets and used the average of the topic distributions as a 100-dimensional feature vector. We selected a week (as opposed to other time frames) because the incubation of common flu and cold illnesses is approximately 1 to 4 days [31]. As such, 1 week is an appropriate buffer around the date of interest. We used the average topic distribution instead of individual tweet distributions because this allowed us to have the same dimensional feature vector for each user.

Behavior features included the (1) number of @ mentions, (2) number of retweets, and (3) daily tweet frequency. All features were averaged over the previous week. These metrics have been used in prior research to describe information dispersal [32], information communication between friends [33], and user behaviors such as response rate for question-answering behaviors on social media [34]. When using features to distinguish between the GoViral sample and the random Twitter sample, we used the raw values. When using the features to identify user differences within the GoViral sample, values were Z-score normalized by the user ($\mu=0$, $\rho=1$).

We built regression models to predict the symptoms of an individual using the topic and behavior features derived from Twitter. We used a binary logistic regression classifier built in Python 3.6.3 (Python Software Foundation) to predict whether or not a report contains at least one symptom using the implementation from Scikit-learn (version 0.19.1) [35]. Tenfold cross-validation on the training data was used to select the regularization parameter (using a grid search of values between 0.000001 and 100,000 in orders of magnitude). We also built individual classifiers for each symptom reported. Here, we

included a survey in the positive class if it included the symptom of interest, regardless of if it also included other symptoms.

In addition to binary prediction, we used linear regression to predict the number of symptoms reported (a proxy for the severity of illness). Ridge regression using the Scikit-learn implementation [35] was used to force coefficients to be small while keeping all features. The regularization parameter for ridge regression was selected using 10-fold cross-validation on the training data. This study was approved by the University of Colorado Boulder institutional review board (protocol number 17-0470).

Results

Cohort Description

Overall, 396 individuals participated in the GoViral project and shared their Twitter handles, of which 186 returned at least one survey. Study participants returned 6.4 surveys on average, resulting in a total of 1283 surveys. Of these 1283 surveys, 417 included a report of at least one symptom. Participants were geographically widespread, representing 43 different states in the United States. Most participants were from New York, California, Texas, Washington, Massachusetts, Florida, New Jersey, and Virginia.

Of the original sample of 396 individuals, Twitter data were unavailable for 84 because they had private accounts (n=25), had never tweeted (n=4), or because the Twitter handle provided did not exist on Twitter at the time we collected data (n=55). Moreover, of the remaining sample, only 81 could be included in the final dataset as we required that any included individual returned both a survey with no symptoms and a survey with at least one symptom.

Demographic information (gender and ethnicity frequencies and mean age) for the overall GoViral dataset (*original data*) and the final set of individuals included in this study (*study cohort*) are shown in Table 1. Two individuals in the study cohort did not respond to demographic questions. Individuals in the original study were allowed to select multiple ethnicities; therefore, total across all ethnicity categories is greater than the number of individuals. Demographic distributions between the original data and study cohort are similar, with notable differences. The study cohort had more women compared with the full GoViral sample; it had a higher proportion of individuals who identified as white and had a smaller proportion of individuals identifying as black. Among the study cohort, individuals tweeted an average of 613 times during the study for a total of 51,141 tweets. These individuals also returned a total of 343 surveys (4.2 surveys per person on average).

Table 1. Study demographics.

Variable	Study cohort (n=81)	Original data (N=396)
Gender, n (%)		
Male	54 (30)	235 (38)
Female	24 (67)	149 (59)
Other	1 (1)	6 (2)
Ethnicity, n (%)		
Black	1 (1)	18 (5)
White	69 (85)	311 (79)
Native	2 (3)	9 (2)
Latino	2 (3)	32 (8)
Islander	11 (14)	58 (15)
Age (years), mean (SD)	40.91 (14.01)	37.47 (14.24)

Health Disclosure in Tweets

To answer RQ1, we examined the 436 tweets that included health-related keywords and were tweeted during the GoViral study period. Each tweet was hand-coded as relevant or not relevant; relevant means that the tweet appeared to be an authentic description of the individual feeling poorly, with no other explanation. Mentions of events outside of infectious disease that could account for feeling ill were excluded (eg, recent surgery, consumption of alcohol, and the temperature was cold). Each tweet was annotated by two of the authors, and disagreements were resolved by the remaining author. Cohen kappa values were 0.66, 0.60, and 1.0 between the three pairs of annotators.

This process resulted in only 26 health-related tweets that could potentially be attributed to seasonal cold or flu viruses. Of these, only 2 were tweeted within 2 weeks (1 week before or 1 week after) of a positive symptom survey.

Overall, we found that health tweets were a small percentage of the tweets written near a positive symptom survey (only 2 tweets, 0.0039% of all tweets in the dataset). In the overall dataset, users tweeted 35 times a week on average (95% CI 34.6-35.3). We found that even among people who were active on Twitter and reported feeling sick, it was rare for them to actually tweet about sickness.

Symptom Prediction

Results of the binary models are presented in Table 2.

Table 2. Logistic regression model results.

Outcome of interest and feature set	Area under the curve	*P* value
Was an individual ill?		
Any symptom		
Topic model	0.51	.38
Behavior features	0.30	<.001
Body aches		
Topic model	0.57	<.001
Behavior features	0.50	__[a]
Runny nose		
Topic model	0.47	.02
Behavior features	0.50	—
Leg pain		
Topic model	0.47	<.001
Behavior features	0.50	—
Nausea		
Topic model	0.52	.11
Behavior features	0.50	—
Vomiting		
Topic model	0.50	—
Behavior features	0.50	—
Sore throat		
Topic model	0.46	<.001
Behavior features	0.50	—
Shortness of breath		
Topic model	0.50	—
Behavior features	0.50	—
Fever		
Topic model	0.51	.28
Behavior features	0.50	—
Fatigue		
Topic model	0.50	—
Behavior features	0.50	—
Diarrhea		
Topic model	0.48	.27
Behavior features	0.50	—
Cough		
Topic model	0.47	<.001
Behavior features	0.50	—
Chills		
Topic model	0.48	.002
Behavior features	0.50	—
Was an individual a GoViral participant?		
GoViral participant		

Outcome of interest and feature set	Area under the curve	*P* value
Topic model	0.67	<.001
Behavior features	0.50	—
Did the participant return a survey in the week of interest?		
Returned a survey		
Topic model	0.50	—
Behavior features	0.50	—

[a]Instances where *P* value cannot be calculated.

Table 2 shows the average AUC for all 100 models built, along with the *P* value for each (calculated using a *t* test, with a null hypothesis of H_0=0.5). The AUC is a measurement of how well the model is able to correctly classify the outcome. An AUC of 1 would be a perfect classifier, whereas an AUC of 0.5 is a classifier operating at chance. An AUC less than 0.5 is a classifier operating worse than chance. It was not possible to predict if a user would return a survey with at least one symptom with logistic regression using the topic features (AUC=0.51; *P*=.38); however, it was significantly predictable using user behavior features, with a small effect size (AUC=0.53; *P*≤.001). There were only a few instances where individual symptoms were predictable using our models, and none when using the behavior features. When using topic modeling features, body aches were significant (AUC=0.57; *P*≤.001), and nausea and fever were nonsignificant but had AUC values over 0.5 (AUC=0.52; *P*=.11 and AUC=0.51; *P*=.28, respectively).

No relationship existed between either feature set and the number of symptoms using a ridge regression analysis (tweet topics: *r*=−9.03; Twitter behaviors: *r*=−0.05). Typically, negative *r* values indicate the model was overfit. However, in this instance, the models always selected the most aggressive regularization parameter, meaning all coefficients were extremely close to 0. Thus, we interpreted this finding to show that the number of symptoms reported (a proxy for illness severity) was not predictable using either feature set.

Cohort Bias

To answer RQ3, we considered how this study cohort might differ from a sample selected at random from Twitter (see Table 2). When using topic model features, the random sample and the GoViral sample were predictably different on held-out data (AUC=0.67; *P*≤.001). Table 3 shows the most common topics associated with those in the GoViral sample compared with the random Twitter sample. Topics appear in the table if they were associated with at least one-third of the models built. The last column denotes which cohort the topic was associated with. In terms of themes, all the topics associated with science, research, or health were associated with the GoViral sample.

Importantly, the two samples were indistinguishable using behavior features (AUC=0.50; *P*=.19). In addition, it was not possible to predict if a GoViral participant returned a survey in a given week (AUC=0.5 with both feature sets). Thus, we found that there were no observable differences in tweet content or Twitter use patterns in weeks that participants returned a survey compared with the weeks they did not.

Table 3. Most important topics for the in-sample classifier and direction of association.

Topic	Top words	Associated with
13	science new human scientists data microbiome learning research study using great lab dna brain gt machine biology paper talk work wcsj2017 project interesting cool ai deep citizen check bacteria	In sample
24	cancer study disease research new risk brain join heart treat-ment scientific patients contributed health pain blood hu-manitar-ian drug help gut therapy depression diseases flu high dr women years vaccine	In sample
36	spread help share awareness terrible disease time cpu wcg earned points donating results days word donated past wcgrid week month years day hours son old semicolon badge 3026 1650935 raise	In sample
97	5points genes gene human dna cancer notes new data cells genome tumor cell variants genomes vs bog15 genetic rare finds expression nygc rna non agbt15 gt pg14 protein paper	In sample
16	gold olympics usa olympic ich medal die org und silver team der ist rio2016 old medals contact es ein hockey won win das teamusa women nicht wins war einen	Random sample
29	que la el en se es lo por los mi para una te del las ya si como pero todo ser yo su tu da eu os est qu hoy	Random sample
38	hai a1 ho ke india ki modi a3 ka a2 se hi a5 nahi kya ko bhi toh a4 na timepass aur ab main contest mein tu ye kar	Random sample
52	new photo facebook posted martin instagram king photos luther video page yorker album pic shoot jeff caption cover credit selfie beijing york shkreli beatbaker burger ad repost fb likes selfies	Random sample
53	follow retweet gain trapadrive followers fast let thanks appreci-ate gainwithxtiandela retweets 1ddrive likes tweet active time rts naijafollowtrain follows 500 bam gainwithpyewaw ifb gaining turn 100 quick mzanzifollotrain gainwithtrevor	Random sample
69	launch shared rocket sd first spacex holbrook falcon test elon musk space satellite ship says fund 10 percent barrier mission join landing location second stage project life new cruise	Random sample

Discussion

Principal Findings

This study found that there were instances of self-disclosure of flu-like symptoms on social media that correspond to disclosed survey symptoms, but they were exceedingly rare. Although it has always been obvious that only a fraction of people disclosed their health status on the internet, that fraction has not previously been quantified for flu-like illness. Out of 426 self-reports of illness, only 2 coincided with a user tweeting about their own poor health.

The fact that self-disclosure of flu-like illness on Twitter happens so rarely, even among active Twitter users, opens the possibility that there is a selection bias in terms of who chooses to disclose this information on the internet when they are feeling ill. Whether such a bias exists, as well as its characteristics, has not been measured to date. Unfortunately, this study was not able to provide more insight into this potential effect because of the very small number of disclosures in our dataset. Importantly, prior work has not observed this bias, and future work attempting to better characterize this will need to recruit a large number of participants to effectively measure it.

In addition to identifying disease mentions, we attempted to predict disease state from users' tweet content (using topic models) and social media behaviors. Our models were not able to predict if an individual would return a symptomatic survey from their tweet content alone. Our study found that behavior features (the frequency of tweets, retweets, and @ mentions) were significantly but only slightly predictive of illness, and this effect was only present with classification, not regression.

This is in contrast to work that found that social media post content might be related to illness status. Smith et al recruited participants from an emergency department and correlated health conditions with posting frequency on Facebook [20]. Topics on Facebook, ascertained through LDA were also examined in relation to posting frequency. Although the actual correlation coefficients were small, they found that individuals who posted more often tended to have more complaints such as *headache* and *sick* in comparison with the infrequent posters who used words such as *birthday* and *enjoy* [20].

Finally, efforts to individually validate infectious disease mentions on the internet are further complicated by multiple additional sources of bias. The 81 individuals included in this study were biased from the original GoViral dataset (Table 1). In addition, although the GoViral cohort certainly included active Twitter users (tweeting an average of 35 times per week), the respondents were not representative of all Twitter users, in particular with respect to their tweets' topics. We found that the study participants discuss topics about science and health more frequently, whereas more diverse topics (eg, those about sports and social media) were more predictive of the random sample. This could indicate that those in the GoViral population were more interested in public health problems than the average Twitter user. However, we found the 2 populations to be indistinguishable based on their Twitter use behaviors. Those in the random sample and the GoViral samples used Twitter with similar overall frequencies and with similar hashtag and @ mention frequencies.

It is well known that internet data are demographically biased [36-38], for example, social media platforms are typically biased toward young adults compared with the elderly [37]. Prior work has also demonstrated that subsets of Twitter data are also biased; for example, Sloan et al showed that geotagged tweets are not representative of the Twitter base [38]. Taken together, this illustrates the numerous levels of bias that those who work with social media data face.

Recruitment bias is known to happen in most cohort-based studies and has been shown in a variety of contexts, including twin studies [39], physical activity studies [40], and paid vs unpaid studies [41]. More recent research has shown that studies recruiting using online data also experience this bias [42,43]. However, this is the first study, to our knowledge, to explore recruitment bias on a social media platform for infectious disease research.

Limitations of the Study

As noted above, the sample size of this study is a substantial limitation. We found only 2 instances of tweeting about illness while sick from a collection of 396 participants who shared their Twitter handles. However, it should be noted that it would be labor- and cost-intensive to amass ground truth data at a much larger level, and it may be especially difficult to collect enough data in this domain. To obtain a sizeable number of instances where users tweet about illness they are sick, one may have to scale up recruitment efforts [22] or define more specific inclusion criteria. In addition, we noted that we observed some trends in social media behavior and disease severity that would be worth testing in a larger sample with greater statistical power. We discuss the trends we observed in exploratory analyses in Multimedia Appendices 1 and 2.

As it was not required that individuals return a survey each week of the study, it is impossible to ascertain if there are response biases associated with survey response. We attempted to measure this by building the classifier to predict if a user responded in a given week. This outcome was completely unpredictable by our feature sets, but it is still possible that there were unmeasured differences.

We also noted the substantial number of individuals in the original GoViral dataset who could not be included because we were unable to obtain their Twitter data. It is possible that individuals with private accounts disclose illness at different rates than those with public accounts, and it is impossible to measure that with this dataset.

Finally, we acknowledge the possibility that our keyword-based procedure for identifying health-related tweets may have missed relevant tweets, which thus would have been excluded from our analysis. We attempted to reduce this risk by using a large set of terms, including very general words such as *feel* and *feeling.*

Conclusions

Overall, we did not find strong evidence that health status with respect to cold and flu-like illness can be predicted from tweet content or behavior. A larger and more representative study

would help verify this on a broader scale. However, in general, we posit that verifiable traces of illness on the internet might be rarer than initially believed by the social media monitoring community. It is possible that there may be an informative signal from social media platform behaviors (eg, tweet frequency) for individual health status that would be interesting to study in a larger dataset. Finally, we demonstrate a clear recruitment bias that should be considered when building large ground truth datasets for the infectious disease domain.

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Authors' Contributions

RC led the GoViral project and collected and provided data. ARD, RC, and MJP designed the studies. MJP performed topic modeling. ARD wrote the code to conduct the studies and wrote the initial paper. RC and MJP provided critical revisions to the paper.

Conflicts of Interest

MP holds equity in Sickweather, a company that uses social media to forecast illness.

Multimedia Appendix 1

Normalized tweet frequency near a survey. Normalized tweet frequencies (y-axis) are shown with respect to the number of days before or after a survey (x-axis), where day 0 is the day a survey is returned on. Data are stratified by the number of symptoms. Lines show the average value and shaded regions represent the 95% confidence interval. This figure was generated by comparing the normalized tweet frequency of users in the week prior to and the week after a survey response. We stratify by the number of symptoms reported by a user in order to observe the effect of illness severity on tweet frequency. In some cases (e.g., Figure S1 at ≥ 5 symptoms), the differences are nearly statistically significant, though they are never actually significant on the day of a returned survey.

[PNG File , 429 KB - publichealth_v6i2e14986_app1.png]

Multimedia Appendix 2

Normalized tweet frequency near a survey. Normalize tweet frequencies (y-axis) are shown with respect to the number of days before or after a survey (x-axis), where day 0 is the day a survey is returned on. Data are stratified by the symptoms reported. Lines show the average value and shaded regions represent the 95% confidence interval. This figure was generated by comparing the normalized tweet frequency of users in the week prior to and the week after a survey response. Data are stratified by the symptom reported by a user (where the survey is included if the symptom of interest is reported, regardless of if there are additional symptoms reported). There are some symptoms that show significant patterns, in particular leg pain, nausea, shortness of breath and chills or night sweats have sections that are statistically significantly different from users with no symptoms reported.

[PNG File , 364 KB - publichealth_v6i2e14986_app2.png]

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Abbreviations

API: application program interface
AUC: area under the curve
LDA: latent Dirichlet allocation
RQ: research question

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Original Paper

Comparison of Clinical Outcomes of Persons Living With HIV by Enrollment Status in Washington, DC: Evaluation of a Large Longitudinal HIV Cohort Study

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Abstract

Background: HIV cohort studies have been used to assess health outcomes and inform the care and treatment of people living with HIV disease. However, there may be similarities and differences between cohort participants and the general population from which they are drawn.

Objective: The objective of this analysis was to compare people living with HIV who have and have not been enrolled in the DC Cohort study and assess whether participants are a representative citywide sample of people living with HIV in the District of Columbia (DC).

Methods: Data from the DC Health (DCDOH) HIV surveillance system and the DC Cohort study were matched to identify people living with HIV who were DC residents and had consented for the study by the end of 2016. Analysis was performed to identify differences between DC Cohort and noncohort participants by demographics and comorbid conditions. HIV disease stage, receipt of care, and viral suppression were evaluated. Adjusted logistic regression assessed correlates of health outcomes between the two groups.

Results: There were 12,964 known people living with HIV in DC at the end of 2016, of which 40.1% were DC Cohort participants. Compared with nonparticipants, participants were less likely to be male (68.0% vs 74.9%, *P*<.001) but more likely to be black (82.3% vs 69.5%, *P*<.001) and have a heterosexual contact HIV transmission risk (30.3% vs 25.9%, *P*<.001). DC Cohort participants were also more likely to have ever been diagnosed with stage 3 HIV disease (59.6% vs 47.0%, *P*<.001), have a CD4 <200 cells/μL in 2017 (6.2% vs 4.6%, *P*<.001), be retained in any HIV care in 2017 (72.9% vs 59.4%, *P*<.001), and be virally suppressed in 2017. After adjusting for demographics, DC Cohort participants were significantly more likely to have received care in 2017 (adjusted odds ratio 1.8, 95% CI 1.70-2.00) and to have ever been virally suppressed (adjusted odds ratio 1.3, 95% CI 1.20-1.40).

Conclusions: These data have important implications when assessing the representativeness of patients enrolled in clinic-based cohorts compared with the DC-area general HIV population. As participants continue to enroll in the DC Cohort study, ongoing assessment of representativeness will be required.

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KEYWORDS

HIV; DC Cohort; cohort studies; HIV clinical outcomes

Introduction

Cohort studies have commonly been used to examine the progression of a disease or an intervention and have also been shown to be an important tool in assessing health outcomes and effective treatments among study populations [1]. However, people who are approached and agree to participate in research studies may not completely represent the general population, and study results cannot necessarily be generalized [1-3]. Care providers may be biased as to which patients they approach to be in research studies, which may then lead to insufficient or unrepresentative recruitment [4-7]. Further, subjects may self-select for inclusion into the study based on perceived benefits of participation or incentives provided or may decline participation because of perceived obstacles to participation [7]. Perceived obstacles, including HIV stigma, access to care, economic challenges, and wariness to partake in research may hinder potential participants from engaging in research studies. These differences in perception may correlate with underlying demographics and outcomes, which result in selection bias in the data [7]. This self-selection, better known as participation bias, is a common occurrence in research studies and impacts the reliability of results [3,7].

It is, however, possible to evaluate differences and similarities between a cohort and the source population in a few different ways [8-15]. For instance, a study comparing data from the Ontario HIV Treatment Network with hospital records was able to classify individuals who participated in the study, those who declined to participate in the study, and those who were not approached at all [13]. Study participants tended to be older, white, men who have sex with men (MSM), and on antiretroviral therapy (ART) and have a longer duration of HIV infection [13]. Furthermore, while individuals who declined to participate had similar rates of viral suppression, individuals who were not approached tended to have higher rates of not being virally suppressed [13]. In another cohort study comprising MSM (HIV infected or not), it was found that compared with participants and those who later dropped out of the study, nonparticipants tended to have lower incomes and education levels and were less likely to identify as gay or bisexual and more likely to be nonwhite and married [8]. Interestingly, those who were lost to follow-up were most likely to be HIV positive [8].

The power and usefulness of findings from cohort studies rely upon the assumption that research participants represent the population from which they were drawn and, therefore, these findings can be generalized toward the total population. Biases stemming from differential patterns of enrollment may lead to overestimates or underestimates of the effectiveness of an intervention or outcome measure, particularly among nonparticipants [3,4]. Similarly, studies that provide prevalence estimates of specific risk factors or health-related outcomes can be affected by these biases, leading to over or underestimation of important population parameters [4].

Since 2011, the DC Cohort study has enrolled people living with HIV who receive care at one or more of 15 medical care sites in Washington, DC [16]. One objective of the study is to enroll a representative sample of people living with HIV disease in DC. The purpose of this analysis was to compare DC Cohort study participants to the general population of people living with HIV in DC who were not enrolled in the study and assess whether cohort participants are representative of people living with HIV in DC. This analysis sought to assist in determining whether demographic and clinical outcomes among cohort participants can be generalized to those diagnosed with HIV and living in DC.

Methods

Surveillance Data

HIV surveillance data from DC Health (DCDOH) enhanced HIV/AIDS Reporting System, the hepatitis surveillance registry, and the DC Public Health Information System were extracted. People living with HIV who were in DC at the end of 2016 were included in this analysis. People living with HIV in DC at the end of 2016 were defined as people (1) diagnosed with HIV; (2) whose last reported HIV lab result (eg, CD4 or HIV RNA) included a DC address and was reported between January 1, 2011, and December 31, 2016, to the DCDOH HIV/AIDS, Hepatitis, STD and TB Administration (HAHSTA); and (3) who were alive at the end of 2017. All lab-confirmed gonorrhea; chlamydia; primary, secondary, and early latent syphilis; and chronic hepatitis B virus (HBV) and hepatitis C virus (HCV) diagnoses were included. This work has been approved by both the DC Health and George Washington University School of Public Health institutional review boards.

DC Cohort Study

The DC Cohort study is a prospective, longitudinal, observational cohort study whose primary goal is to contribute to improving the quality of care and treatment of HIV-infected patients in DC. Details of the design of the study have been previously described [17,18]. Briefly, children, adolescents, and adults diagnosed with HIV disease who receive medical care from at least one of 15 HIV care sites provide informed consent to participate in the study and have their data from electronic medical records (EMRs) extracted on a monthly basis. Sites for the DC Cohort study were methodically selected to include a variety of sites with respect to size, patient population served (by risk, race/ethnicity, age), and services provided [17]. The facilities included in the DC Cohort study represent the major HIV care sites in DC, including hospitals and hospital-based and community-based HIV clinics, with the exception of private providers and one DC-based hospital [17,19]. These HIV care sites are located in the 6 wards in DC where HIV prevalence is highest (out of 8 total wards). Of the 15 sites currently participating in the DC Cohort study, only 14 sites contributed to this analysis as one HIV care site began enrollment after 2016. All participants who consented to participate between January 1, 2011, and December 31, 2016, were included in this analysis [16]. Participants who lived outside of DC were excluded from this analysis as their data would not be routinely captured in the DCDOH HIV surveillance database.

Data Match

DC Cohort study and DCDOH HAHSTA surveillance data are matched every 6 months as part of the study protocol. DC Cohort study data were matched based on an 11-key algorithm linking first name, last name, date of birth, and social security number [18-21]. Linkage keys range from including social security number or full first name, last name, and date birth to only including the first 3 letters of the first name, last name, and the date of birth year. Matches made through keys 7-11, which all consist of only partial first and last names and dates of birth, were manually reviewed and checked for accuracy (Table 1) [21]. Of the initial 275 patients who matched through keys 7-11, after deduplication nearly 30% (79/275) were not true matches and were eliminated from the dataset. Total matches were then validated using LinkPlus, a record linkage application. All linkages with a score of at least 80 were included in the final dataset. Data were then stratified by demographics, including current gender identity, race/ethnicity, median age, mode of HIV transmission, ever diagnosed with a sexually transmitted infection (STI), and ever diagnosed with confirmed chronic HBV or HCV. While surveillance data collects longitudinal data on STIs, HBV, and HCV, we limited diagnoses to those reported between 2011 and 2016 to mirror the enrollment period of the DC Cohort study patients. Although the DC Cohort study collects data from EMRs, for the purposes of this analysis DC Cohort study identification (ID) numbers were used to identify cohort participants, and only data from the DCDOH surveillance databases, and not the EMRs, were used to compare the two groups.

Table 1. Surveillance data matching algorithm.

Match level	Match criteria
Match 1	If social security number
Match 2	Else if, first name (first 6 letters), last name, date of birth
Match 3	Else if, last name (first letter), last name (letters 3 through 8), first name (letters 2 through 8), date of birth
Match 4	Else if, last name (first letter), last name (letters 3 through 8), first name (letters 2 through 8), birth month, birth year
Match 5	Else if, last name (first letter), last name (letters 3 through 8), first name (letters 2 through 8), birth day, birth year
Match 6	Else if, last name, first name (letters 1 through 2), date of birth
Match 7	Else if, last name (letters 1 through 3), first name (letters 1 through 3), date of birth
Match 8	Else if, last name (letters 1 through 4), first name (letters 1 through 4), birth year
Match 9	Else if, first name (letters 1 through 3), last name (letters 1 through 3), birth month, birth year
Match 10	Else if, first name (letters 1 through 3), last name (letters 1 through 3), birth day, birth year
Match 11	First name (letters 1 through 3), last name (letters 1 through 3), birth month, birth year

HIV Disease Stage in 2017

Current US Centers for Disease Control and Prevention guidelines provide a classification system for assessing the severity of HIV disease based on CD4 cell counts and the presence of specific HIV-related conditions [22,23]. Stage 1 HIV disease is defined by having a CD4 count of more than 500 cells/μL or a CD4 percentage of more than 29%. Stage 2 is defined by having a CD4 count between 200 and 500 cells/μL or a CD4 percentage between 14% and 28%. Stage 3 (AIDS) infection is defined as having a CD4 count of less than 200 cells/μL, a CD4 percentage of less than 14%, or a diagnosed AIDS-related condition (ie, an HIV-related opportunistic infection). These stages of HIV disease were categorized using laboratory values from the last lab result reported on or before December 31, 2017.

Receipt of HIV Medical Care

To measure receipt of HIV care, lab results reported to the DCDOH were further evaluated. Cases were considered to have received care if they had at least one lab result (CD4 or viral load [VL]) between January 1, 2017, and December 31, 2017 [22,23]. People living with HIV that did not show any evidence of having a lab result reported in 2017 were categorized as not engaged in care in 2017.

Viral Suppression

"Ever virally suppressed" was defined as having at least one VL test result less than or equal to 200 copies/mL between 2011 and 2017. Viral suppression in 2017 was described as having a VL test result less than or equal to 200 copies/mL between January 1, 2017, and December 31, 2017 [22,23]. Time to viral suppression was defined as the length of time from first reported detectable VL to first reported VL lab result of less than or equal to 200 copies/mL among those who have ever been virally suppressed.

Confirmed Chronic Hepatitis B Virus and Hepatitis C Virus Diagnoses

All positive hepatitis antibody tests are reported to DCDOH by all commercial laboratories conducting this testing in DC. All HBV and HCV labs reported to DCDOH and identified as chronic or probable were assessed. Chronic HBV and HCV lab results with a positive RNA test result were considered confirmed and included in this analysis.

Statistical Analysis

Statistical analyses were performed using SAS version 9.4 (SAS Institute Inc). Univariate analysis using Pearson chi-square tests and *P* values for categorical data and analysis of variance for continuous data was performed to identify differences in cohort

and noncohort participants with respect to demographics, comorbid conditions (ie, STIs, hepatitis), clinical and virologic outcomes (ie, CD4, VL, viral suppression), and receipt of HIV care. Multivariate log binomial regression was used to assess differences in clinical outcomes between DC Cohort and noncohort participants adjusting for demographics, time since HIV diagnosis, and mode of transmission.

Results

At the end of 2016, there were 12,964 people living with HIV in DC, of which 5193 (40.1%) were DC Cohort study participants. Compared with nonparticipants, analysis showed that cohort participants were less likely to be male but more likely to be non-Hispanic black and have heterosexual contact as their HIV transmission risk (Table 2). Cohort participants had been living longer with HIV (12.6 years vs 10.7 years, *P*=.048) and were more likely to have a chronic HCV diagnosis but less likely to have been diagnosed with an STI between 2011 and 2016. There were no differences in median age at the end of 2017 or in chronic HBV diagnoses between the two groups.

Table 2. Demographic characteristics of DC Cohort and non-DC cohort participants living in DC as of December 2017 (n=12,964).

Characteristic	DC[a] cohort n=5193 n (%)	non-DC cohort[b] n=7771 n (%)	*P* value
Gender identity			**<.001**
Male	3533 (68.0)	5818 (74.9)	
Female	1580 (30.4)	1816 (23.4)	
Transgender	80 (1.5)	137 (1.5)	
Race/ethnicity			**<.001**
White	515 (9.2)	1561 (20.1)	
Black	4271 (82.3)	5399 (69.5)	
Hispanic	302 (5.8)	582 (7.5)	
Other[c]	105 (2.0)	229 (3.0)	
Transmission risk			**<.001**
MSM[d]	1977 (38.1)	3764 (48.5)	
IDU[e]	768 (14.8)	604 (7.8)	
MSM/IDU	198 (3.8)	219 (2.8)	
Heterosexual contact	1571 (30.3)	2014 (25.9)	
Perinatal	94 (1.8)	43 (0.6)	
Other[f]	3 (0.1)	7 (0.1)	
Not identified	582 (11.2)	1121 (14.4)	
Age in years[g], median (IQR[h])	50 (18)	48 (20)	.65
Time since HIV diagnosis in years, mean (SD)	12.6 (6.9)	10.7 (7.4)	.048
STI[i] diagnosis between 2011-2016	906 (17.4)	1471(18.9)	.03
Hepatitis B coinfection between 2011-2016	87 (1.7)	100 (1.3)	.07
Hepatitis C coinfection between 2011-2016	282 (5.4)	345 (4.4)	.009

[a]District of Columbia.

[b]Non-DC cohort participants include persons who have consented and subsequently withdrawn from the study and persons diagnosed with HIV and reported to the DC Health who were alive as of the end of December 2017.

[c]Other race includes mixed race individuals, Asians, Alaska Natives, American Indians, Native Hawaiian, Pacific Islanders, and unknown race.

[d]MSM: men who have sex with men.

[e]IDU: injection drug user.

[f]Other mode of transmission includes perinatal transmission, hemophilia, blood transfusion, and occupational exposure (health care workers).

[g]Age as of December 31, 2017.

[h]IQR: interquartile range.

[i]STI: sexually transmitted infection.

In evaluating clinical outcomes, DC Cohort study participants were more likely to have been diagnosed with stage 3 HIV disease, have a CD4 count of <200 cells/μL in 2017, and have received any HIV care in 2017 (Table 3). DC Cohort study participants were also more likely to have ever been virally suppressed and more likely to be virally suppressed in 2017 but were less likely to be suppressed within 2 years of HIV diagnosis. There was no difference in median CD4 count at the end of 2017 between the two groups.

After adjusting for gender identity, current age, race/ethnicity, time since HIV diagnosis, and mode of HIV transmission, DC Cohort study participants were 24% more likely to have received any care in 2017 (adjusted odds ratio 1.24, 95% CI 1.21-1.28), and over 10% more likely to ever have been virally suppressed (adjusted odds ratio 1.11, 95% CI 1.07-1.15; Table 4).

Table 3. Clinical characteristics of DC Cohort and non-DC cohort participants living in DC as of December 2017 (n=12,964).

Characteristic	DC[a] cohort	Non-DC cohort[b]	*P* value
Ever stage 3 diagnosis (eg, AIDS, CD4 <200 cells/μL, or OI[c]), n (%)	3093 (59.6)	3652 (47.0)	<.001
Engaged in HIV care in 2017, n (%)	4336 (83.5)	5572 (71.7)	<.001
CD4 count (cells/μL) in 2017, median (IQR[d])	618 (440)	610 (431)	.83
CD4 count (cells/μL), most recent			**.19**
<200, n (%)	365 (8.5)	455 (8.4)	—
200-500, n (%)	1159 (27.0)	1495 (27.6)	—
>500, n (%)	2764 (64.5)	3473 (64.0)	—
Virally suppressed[e] between 2011-2017, n (%)	4348 (83.7)	6070 (78.1)	<.001
Virally suppressed[e] at last lab in 2017, n (%)	3189 (61.4)	3921 (50.5)	<.001
Time to first known viral suppression[e], n (%)			**<.001**
0-24 months	1472 (33.4)	2382 (39.2)	—
>24 months	2876 (65.6)	3688 (60.7)	—

[a]DC: District of Columbia.

[b]Non-DC Cohort participants include persons who have consented and subsequently withdrawn from the study, as well as persons diagnosed with HIV and reported to the DC Health who were alive as of the end of December 2017.

[c]OI: opportunistic infection.

[d]IQR: interquartile range.

[e]Viral suppression defined as HIV RNA <200 copies/mL.

Table 4. Adjusted prevalence ratios for clinical characteristics of DC Cohort and non-DC cohort participants living in DC as of December 2017.

Factor[a]	APR[b] (95% CI)
Model 1: retained in any care	1.24 (1.21-1.28)
Model 2: ever virally suppressed	1.11 (1.07-1.15)
Model 3: virally suppressed at last lab result in 2017	1.03 (0.97-1.02)
Model 4 (among those ever virally suppressed): suppressed ≥24 months versus 0-12 months	1.02 (1.08-1.14)

[a]Adjusting for gender identity; age on December 31, 2017; race/ethnicity; time since HIV diagnosis; and mode of HIV transmission.

[b]APR: adjusted prevalence ratio.

Discussion

Principal Findings

We sought to determine if the characteristics of a study cohort of consenting people living with HIV receiving care in DC were representative of the population of people living with HIV in a large urban city. When comparing DC Cohort study enrollees to that of the overall population of people living with HIV in DC, we identified notable demographic, disease transmission, and clinical differences. The greatest absolute differences with respect to demographics and disease transmission were observed in the proportion of those who identified as black, identified as female, or had a mode of HIV transmission of MSM, IDU, or heterosexual contact. While differences in race/ethnicity and gender identity were not expected, cohort data on people who refuse to participate in the DC Cohort study have identified differences in consenting with respect to sex at birth and race (data unpublished). Additionally, given the large sample size in our analysis, we may have been able to detect statistically smaller differences between the two groups [24-26]. Third, differences in race/ethnicity and mode of HIV transmission

between DC Cohort and noncohort participants may be related to the clinics and care facilities to which cohort patients are enrolled.

Differential representation in the DC Cohort study may be explained in part by the characteristics of the participating clinic sites and demographics of the patients to whom they provide care. For example, although the largest HIV care providers and those that care for particular subpopulations are currently participating in the DC Cohort study, smaller and private health care facilities that may provide HIV care services to specific HIV-positive subpopulations such as those that have more non-Hispanic white or predominantly MSM populations are not currently included as recruitment sites. In the HIV Prevention Trials Network (HPTN) 065 study, also known as the Test, Link-to-Care Plus Treat (TLC-Plus) study, research was conducted in 6 major US cities using health centers, major hospitals, community-based organizations, and private medical facilities to enroll patients to assess the feasibility of expanding HIV testing across medical settings and providing incentives for improved health outcomes [27]. Of the care sites participating in HPTN 065, private medical practices accounted for 26.3% of all HIV care sites that participated in the DC arm of the study [27] and 40.1% of all non-Hispanic white MSM participants in the study (data unpublished), demonstrating that private medical practices provide HIV care to a substantial number of distinct populations, including white MSM. Laboratory and case report data reported to DCDOH have also shown that among newly diagnosed persons in 2017, private medical practices accounted for 32.6% of non-Hispanic white diagnoses and 46.4% of diagnoses among white MSM (data unpublished). As the DC Cohort study expands and continues to enroll clinical sites contributing data collection, these disparities may be reduced. Despite the differences demographically, length of time since HIV diagnosis and diagnoses of STIs, HBV, and HCV were similar across the two groups suggesting that analysis of these outcomes in the DC Cohort study population are likely to be fairly generalizable to people living with HIV in DC.

The evaluation of clinical outcomes revealed expected differences between DC Cohort and noncohort participants. Ever having stage 3 HIV disease (AIDS) was higher among DC Cohort participants. The DC Cohort appears to be consenting individuals who were diagnosed at a more advanced stage of HIV disease; individuals with declining health outcomes may be more likely to seek treatment and therefore have more opportunities to be approached for study enrollment. Having a history of AIDS may predispose an individual to opportunistic infections and non-AIDS conditions that are affected by prolonged viremia and immune activation such as cardiovascular events and certain cancers. Thus, studies in the DC Cohort that measure outcomes that are affected by ever having AIDS should be cautious about extrapolation of findings.

Receipt of any care in 2017 was 12% higher and viral suppression in 2017 was 11% higher among DC Cohort participants versus noncohort people living with HIV. These two key indicators of engagement in HIV care suggest a few possibilities: (1) since the DC Cohort study enrolls people at their site of care, it is likely that DC Cohort participants are more likely to be engaged in HIV care, (2) DC Cohort participants are more engaged in HIV care or the clinic is more active in engaging their patients in care, and/or (3) the proportion of noncohort people living with HIV who are no longer living in DC outweighs that of the cohort people living with HIV and the denominator used for this group in this analysis may be too large. Any of these explanations is possible. In an analysis evaluating a local HIV lab data exchange, DC residents diagnosed with HIV and with a current address found nearly 2000 people living with HIV residents were no longer living in DC between 2012 and 2016, with over 80% relocating to surrounding areas [21]. Further, this analysis found differences in relocation by race/ethnicity, gender identity, and mode of transmission, and those who moved out of DC were more likely to be male, black, between the ages of 30 and 39 years, and have a mode of HIV transmission of MSM [21].

Univariate analysis revealed differences in HIV-related health outcomes but after adjusting for demographics, time since HIV diagnosis, and mode of HIV transmission, DC Cohort participants continued to be significantly more engaged in HIV care and have better clinical outcomes compared with noncohort participants. Age at the end of 2017 and mean time since HIV diagnosis most impacted this result, indicating that older age and longer duration of HIV diagnosis were associated with having more recent viral suppression among people living with HIV in DC, which is similar to findings in past research [28-31].

Limitations

Although this analysis provides insight into whether DC Cohort study participants represent the general HIV population in DC, it was subject to several limitations. First, it was limited to only those who were living in DC at the end of 2016, excluding patients who live outside of the jurisdiction but receive care in DC. In the DC Cohort, approximately 25% of participants are non-DC residents at the time of enrollment and thus were excluded from this analysis. Although these patients were excluded, including them would not have changed the demographic differences between cohort and noncohort participants, as a sensitivity analysis showed that there were still variations by race/ethnicity, gender identity and mode of HIV transmission (Multimedia Appendix 1). Furthermore, lab results from those who live outside of DC are not routinely reported to DCDOH. Second, surveillance-based lab data were used to quantify HIV clinical outcomes, including median CD4 count, HIV stage, receipt of care, and viral suppression. Analyses of these variables were based on lab data reported to DCDOH surveillance databases. If residents were diagnosed in DC but later moved out of the city, lab information may no longer be reported to the local health department, resulting in an underreporting of clinical outcomes. Third, neither ART use nor treatment adherence were measured in this analysis. Although this information would better characterize differences between DC Cohort and noncohort patients, these data are not routinely submitted to DCDOH for all people living with HIV. Further, this analysis does not categorize noncohort participants who were approached and declined to participate or those who have not yet been approached. Although these data would give insight into any self-selection bias that may have occurred among patients, this information is not reported to the health

department and therefore not included in this analysis. Moreover, the DC Cohort data provides information that is not routinely disclosed to DCDOH, including information on antiretroviral use, employment, housing status, insurance type, and other non–HIV-related laboratory tests, diagnoses, and treatments. Finally, linkage results have shown that the DC Cohort study provides additional VL lab results to DCDOH that may not have been previously reported [20]. These data were not used as part of this analysis as we relied solely on surveillance data to make the comparisons.

Conclusion

Although participants from the DC Cohort study may not represent the broader citywide population of people living with HIV, they do provide an important snapshot of HIV care and related clinical outcomes that can assist with understanding the quality of HIV care delivery in a highly impacted urban area. In conducting this analysis, we identified variances between the two groups and intend to use these findings from a practical level to increase the number of patients who are approached at current participating sites to improve the study's representativeness; at a statistical level, we could consider developing weights to apply to DC Cohort data to increase its generalizability. Despite its limited representativeness in some respects, the DC Cohort study still enhances our ability to describe, monitor, and improve outcomes among large numbers of people living with HIV receiving care in DC. The DC Cohort study provides information on insurance status, clinic visits, ART prescribing, behaviors such as smoking and alcohol use, screening for certain conditions, and other comorbidities (eg, cardiovascular, metabolic) that are not routinely captured in surveillance data yet are useful in contextualizing clinical outcomes among people living with HIV. In addition, the ability to link data between DCDOH and the DC Cohort study is of added value to both researchers and DOH as we aim to address the epidemic. As participants and health care facilities continue to enroll in the DC Cohort study, ongoing assessment of representativeness will be required.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Demographic characteristics of DC Cohort and non-DC cohort participants as of June 2017, including non-DC residents (n=15,273).
[DOCX File , 15 KB - publichealth_v6i2e16061_app1.docx]

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Abbreviations

ART: antiretroviral therapy
DC: District of Columbia
DCDOH: DC Health
EMR: electronic medical record
HAHSTA: HIV/AIDS, Hepatitis, STD, and TB Administration
HBV: hepatitis B virus
HCV: hepatitis C virus
HPTN: HIV Prevention Trials Network
ID: identification
MSM: men who have sex with men
NIAID: National Institute of Allergy and Infectious Diseases
NIH: National Institutes of Health
STI: sexually transmitted infection
TLC-Plus: the Test, Link-to-Care Plus Treat
VL: viral load

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Original Paper

Effectiveness of a Web-Based Intervention to Support Medication Adherence Among People Living With HIV: Web-Based Randomized Controlled Trial

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Abstract

Background: Taking antiretroviral therapy (ART) is part of the daily life of people living with HIV. Different electronic health (eHealth) initiatives adjunctive to usual care have been proposed to support optimal medication adherence. A web-based intervention called HIV Treatment, Virtual Nursing Assistance, and Education or VIH-TAVIE (from its French version Virus de l'immunodéficience humaine-Traitement assistance virtuelle infirmière et enseignement) was developed to empower people living with HIV to manage their ART and symptoms optimally.

Objective: We aimed to evaluate the effectiveness of VIH-TAVIE in a web-based randomized controlled trial (RCT).

Methods: This RCT was entirely web-based, including recruitment, consent granting, questionnaire completion, and intervention exposure (consultation with VIH-TAVIE [experimental group] or websites [control group]). To be eligible for the study, people living with HIV had to be 18 years or older, be on ART for at least 6 months, have internet access, and have internet literacy. Participants were randomly assigned to either the experimental group (n=45) or control group (n=43). The primary outcome was ART adherence. The secondary outcomes included self-efficacy regarding medication intake, symptom-related discomfort, skills and strategies, and social support. All outcomes were measured with a self-administered web-based questionnaire at the following three time points: baseline and 3 and 6 months later. A generalized linear mixed model was built to assess the evolution of ART adherence over time in both groups.

Results: The sample included 88 participants, and of these, 73 (83%) were men. The median age of the participants was 42 years. Participants had been diagnosed with HIV a median of 7 years earlier (IQR 3-17) and had been on ART for a median of 5 years (IQR 2-12). The proportion of treatment-adherent participants at baseline was high in both groups (34/41, 83% in the experimental group and 30/39, 77% in the control group). Participants also reported high treatment adherence, high self-efficacy, and high skills; perceived good social support; and experienced low discomfort from symptoms. Analyses revealed no intergroup difference regarding ART adherence (OR 1.9, 95% CI 0.6-6.4).

Conclusions: This study highlights the challenges and lessons learned from conducting an entirely web-based RCT among people living with HIV. The challenges were related to the engagement of people living with HIV on the following three levels: starting the web-based study (recruitment), completing the web-based intervention (engagement), and continuing the study (retention). The results contribute to the existing body of knowledge regarding how to conduct web-based evaluation studies of eHealth interventions aimed at developing and strengthening personal skills and abilities.

Trial Registration: ClinicalTrials.gov NCT01510340; https://clinicaltrials.gov/ct2/show/NCT01510340

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KEYWORDS

medication adherence; people living with HIV; antiretroviral therapy; self-management; nursing; web-based intervention; web-based randomized controlled trial

Introduction

Background

Living with HIV means living with a chronic disease that requires taking antiretroviral therapy (ART) for life. It is important to properly coach people living with HIV on this matter in order to encourage them to engage in this health behavior at an optimal level. Various electronic health (eHealth) initiatives adjunctive to the face-to-face services provided by health care teams have been implemented to support people living with HIV in this regard. Daher et al classified eHealth innovations into the following three categories: mobile health-based innovations (essentially SMS text messaging), internet-based mobile innovations (eHealth), and combined innovations (including both SMS text messaging and internet-based eHealth innovations) [1]. Until recently, HIV interventions had been delivered predominantly through SMS text messaging. Systematic reviews and meta-analyses have proved the efficacy of SMS text messaging to enhance treatment adherence [1-4]. Thus, since 2016, the World Health Organization has recommended in its therapy guidelines the inclusion of treatment adherence interventions involving SMS text messaging [5].

In their systematic review covering the period from 1996 to 2017, Daher et al underscored the existence of other less prominent types of internet-based eHealth innovations [1]. These included a two-session computer-delivered motivational intervention to facilitate adherence to newly prescribed ART among youth with HIV [6]; a web-based symptom self-management system for people living with HIV [7]; and a computerized counseling intervention for individuals with adherence problems [8]. At present, research supports the feasibility [7] and efficacy of certain internet-based eHealth innovations to optimize antiretroviral intake [8-10].

Within this context of innovation, we developed a web-based intervention called HIV Treatment, Virtual Nursing Assistance, and Education or VIH-TAVIE (from its French version *Virus de l'immunodéficience humaine-Traitement assistance virtuelle infirmière et enseignement*) to empower people living with HIV to manage their ART and symptoms optimally. VIH-TAVIE consists of four interactive computer sessions (each 20-30 min long) hosted by a virtual nurse who leads the user through a learning process geared to acquiring the requisite skills for treatment adherence. The sessions target self-assessment, motivation, problem solving, emotion regulation, and social skills. These enable people living with HIV to integrate the therapeutic regimen in their everyday routine, manage side effects, and handle problem situations that might interfere with drug intake; interact with health professionals; and mobilize their social network. The development of VIH-TAVIE has been described elsewhere [11]. This web-based nursing intervention is grounded in a disciplinary perspective (the McGill nursing model [12]) and, by extension, in the strength-based approach [13]. Under this model, people and their families are perceived as active participants in health care and learn new ways to cope with the challenges related to the chronic illness. The self-efficacy theory of Bandura was also used [14], particularly to develop skills and strategies to self-manage treatment and symptoms and reinforce one's self-confidence to take ART.

This web-based tailored nursing intervention demands a certain degree of active engagement on the part of the user in order to develop and strengthen the self-regulatory skills required to deal with difficult situations as they arise. Initially, VIH-TAVIE was evaluated in a hospital setting as an adjunct to conventional care. Participants completed the intervention sessions onsite in a clinical setting. The results of this quasi-experimental study comparing the efficacy of two types of follow-up (conventional vs conventional plus adjunctive web-based sessions [VIH-TAVIE]) in promoting ART adherence among people living with HIV revealed that both groups showed adherence improvement over time but did not differ in this regard [15]. The absence of randomization and a deep selection bias led to the formation of highly heterogeneous groups that limited the scope of the results. Considering the key advantage that web-based tailored interventions afford, namely 24/7 access, we were interested in testing the use of VIH-TAVIE over the internet outside an institutional care setting with a view to reach a broader client group.

Against this background, we conducted a randomized controlled trial (RCT) solely over the internet to test the effectiveness of this web-based intervention for improving and optimizing treatment adherence.

Study Aim and Hypothesis

The aim of the study was to evaluate the effectiveness of a web-based intervention for optimizing ART adherence among people living with HIV.

Our primary hypothesis was that a higher proportion of participants in the experimental group would show treatment adherence at 6 months (T6) as compared with the control group. Our explanatory hypothesis was that the following variables measured at three time points (baseline [T0], 3 months [T3], and 6 months [T6]) would prove to be mediators capable of explaining the intervention's effect on treatment adherence: sense of self-efficacy, degree of symptom-related discomfort, skills and strategies used, and perceived social support. These variables are the targets of our intervention [11].

Methods

Study Design

A prospective RCT was conducted from February 2012 to September 2017. The study was entirely web-based, including recruitment, consent granting, questionnaire completion, and

intervention exposure (consultation with VIH-TAVIE [experimental group] or ART-related websites [control group]).

This RCT is reported according to the CONSORT eHealth Statement [16]. We provide only a brief overview of the study methods, as it has been published elsewhere [17]. The trial has been registered at ClinicalTrials.gov (CE 11.184 / NCT01510340).

Participants

To be eligible for the study, people living with HIV had to be 18 years or older, be on ART for at least 6 months, have internet access, and be internet literate to be able to complete all web-based procedures by themselves. Participants were recruited via the internet but could have been advised of the study by their health care team and handed a pamphlet with a link to the study's website. The study was advertised on social networks (Facebook) and on the websites of resources available to people living with HIV, where a hyperlink redirected individuals interested in participating in the web-based research to the study's website. Recruitment was conducted mainly in the Province of Quebec (Canada). To ensure participants were authentic, we set up validation measures (CAPTCHA authentication and cross validation of sociodemographic variables in the questionnaire).

Interventions

Participants in the experimental group were invited to consult with VIH-TAVIE that offers four sessions. A 1-week interval was imposed between sessions to ensure the progressive acquisition and consolidation of skills. To encourage participants to complete the next session of the intervention, one email reminder was sent out automatically. Access was thus controlled and predetermined initially. After this period, access to the intervention was unlimited in terms of intensity, frequency, and time of use for the duration of the study. There was no human involvement over the course of the intervention.

Participants in the control group were invited to consult (at their convenience and from the location of their choice) a list of websites offering information on antiretrovirals, their side effects, and their interactions.

Outcome Measures

The primary outcome was the proportion of ART-adherent participants at T6. Adherence was evaluated by means of a self-administered questionnaire. At the time when the study was planned, there was no clear minimum cutoff point defining what constituted sufficient ART adherence to achieve optimal treatment effectiveness. The cutoff was generally set at greater than 90% or greater than 95% [18]. For this study, optimal adherence was defined as intake of at least 95% of the prescribed tablets in the past 7 consecutive days at T6. The questionnaire was developed and validated among HIV patients [19]. The questionnaire comprised seven items to measure how often a person forgot to take their medication. It was designed to place the respondent in a context where events and situations could lead to lapses.

The secondary outcomes evaluated at T6 are presented below.

Sense of self-efficacy regarding medication intake was measured using 14 items rated on a five-point Likert scale. Two items were added to the original 12-item version used in a previous study [15]. A Cronbach alpha of .92 was obtained for this assessment.

Symptom-related discomfort was measured with an adapted version of the 20-item Self-Completed HIV Symptom Index [20]. Five other items regarding state of health were added to the original 20 items. The 25 items served to determine the presence of symptoms (scale of 0-4, with 0 indicating absent) and degree of discomfort experienced (scale of 1-4). A Cronbach alpha of .89 was obtained for this assessment.

Skills and strategies were measured with a 25-item instrument developed by the research team according to many sub-behaviors required to manage daily antiretroviral treatment over the long term [11]. On a scale of 1 to 5 (1 indicating never and 5 indicating all the time), participants had to gauge how much they used the given skills and strategies. A Cronbach alpha of .92 was obtained for this assessment.

Social support was evaluated using the Medical Outcome Survey [21] and its French version [22]. One dimension of social support was measured with the emotional/informational support subscale, which comprised eight items rated on a five-point Likert scale. The instrument has shown good content validity and appreciable internal consistency [22]. A Cronbach alpha of .96 was obtained for this assessment.

Participants completed a sociodemographic questionnaire covering various characteristics, including gender, age, family situation, education level, annual income, and employment situation, and questions regarding self-perceived state of health, HIV (diagnosis and therapeutic regimen), and immunologic and viral indicators (CD4 cell count and viral load).

All outcomes were measured with a self-administered web-based questionnaire at the following three time points: T0, T3, and T6. Email reminders (maximum of three) were automatically sent out at 7-day intervals prior to measurement.

Sample Size

The sample size was estimated according to studies by Tuldrà et al [23] and Pradier et al [24] involving people living with HIV and a systematic review by Haynes et al [25] involving adherence-related interventions intended for various groups. To detect a difference of 20 percentage points at 80% power and a chi-square test two-tailed α value of .05, with the benchmark proportion of ART-adherent participants set at 50% and an attrition rate of 20%, the required sample size was 232 participants.

Randomization and Allocation Concealment

Centralized block balanced randomization in a 1:1 ratio was computer generated. The allocation process was entirely computerized. The participants were informed automatically by email of their group assignment. Only after completion of the baseline questionnaire, participants were randomly assigned to the experimental group (web-based intervention) or control group (general information websites).

Blinding

Participants were not totally blinded to group assignment. They were aware of randomization to consult a detailed list of websites or complete a web-based nursing intervention. However, the experimental and control groups were not necessarily evident to the participants. During data analysis, the research team was blinded to participant group assignment.

Statistical Methods

Statistical analyses were based on a per-protocol population and on an intention-to-treat (ITT) population for sensitivity analyses, as recommended in the CONSORT eHealth guidelines [16]. Baseline participant characteristics were reported using frequencies and percentages for categorical variables and medians and IQRs for continuous variables.

The primary outcome was analyzed using the Pearson chi-square test. The Student *t* test (continuous variables) and Pearson chi-square test or Fisher exact test (categorical variables) were used to test for differences in secondary outcomes between the two groups at T6.

In the ITT analysis, participants with missing data at T6 were considered nonadherent.

For exploratory purposes, a generalized linear mixed model (GLMM) with a binomial distribution [26] was built to assess the evolution of the primary outcome over time in both groups in the per-protocol population at T0 (n=80), taking into account hierarchical data and using SAS PROC GLIMMIX (SAS Institute Inc, Cary, North Carolina, USA) [27]. Explanatory variables included strategies used, measurement time points (T0, T3, and T6), and interaction between strategies and time points.

All tests were two-sided, and statistical significance was set at $P<.05$. Analyses were performed using SAS software, version 9.4 (SAS Institute Inc).

Ethics and Informed Consent

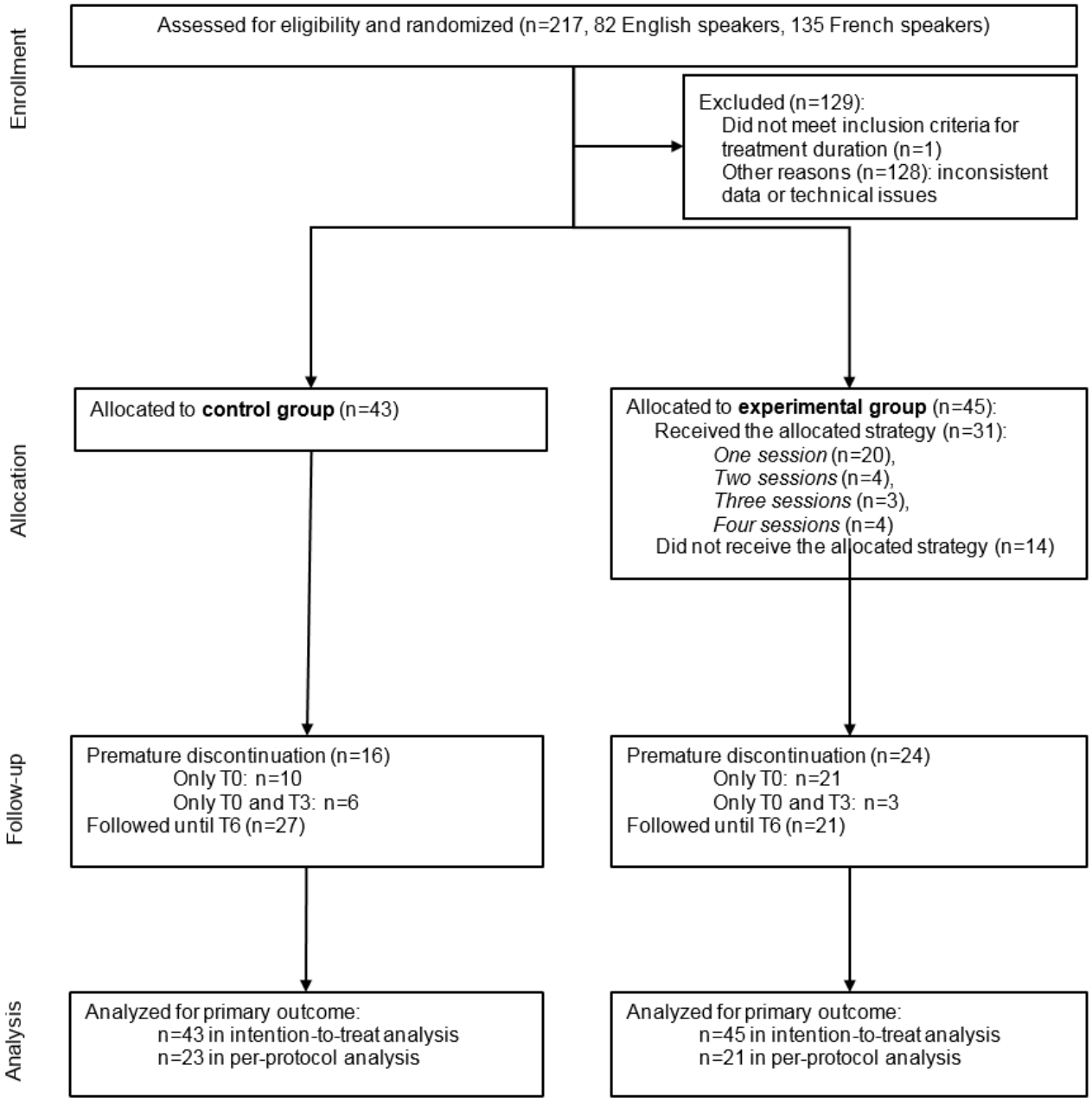
This study was approved by the Research Ethics Board of the Université de Montréal (881) and the Research Centre of the Centre Hospitalier de l'Université de Montréal (11.184). The particularities of the web-based consent procedure have been discussed in detail in the protocol article [17]. Participants were compensated for their participation in the study with a gift certificate of Can $20 after T3 and T6.

Results

Participant Characteristics

Overall, 217 participants were enrolled (Figure 1). Regarding recruitment, the participants were informed about the study primarily by leaflets (32/82, 39%), health care providers (18/82, 22%), and websites (13/82, 15%). One participant was excluded for not meeting the inclusion criteria and 128 were excluded for having inconsistent data. A total of 88 participants were assigned to the experimental group (n=45) or control group (n=43).

Figure 1. Flow diagram. The measurement time points are baseline (T0) and 3 months (T3) and 6 months later (T6).



Baseline Sociodemographic and Clinical Data

Baseline sociodemographic and clinical characteristics are described in Table 1. The sample included 13 women and 73 men (two participants with missing data), and the median age of the participants was 42 years (IQR 33-52). In both groups, participants had been diagnosed with HIV a median of 7 years earlier (IQR 3-17) and had been on ART for a median of 5 years (IQR 2-12), with 94% (75/80) declaring an undetectable viral load. Overall, 77% (63/82) of the participants declared homosexual orientation. Further, 56% (44/78) were employed and 72% (57/79) had an annual income greater than Can $15,000. They lived mainly in urban areas. Finally, 94% (82/87) of the participants considered the internet easy or very easy to use and 89% (77/87) used it every day (data not shown).

Table 1. Baseline sociodemographic and clinical characteristics of the participants.

Characteristic	Experimental group (N=45), n (%) or median (IQR)	Control group (N=43), n (%) or median (IQR)
Age, years	43 (33-53)	40 (32-50)
Male gender[a]	41 (91)	32 (78)
Canadian born[b]	38 (86)	32 (84)
Yes	38 (86)	32 (84)
No	6 (14)	6 (16)
Marital status[c]		
Single	28 (65)	26 (68)
In a relationship	15 (35)	12 (32)
Sexual orientation[b]		
Heterosexual	8 (18)	9 (24)
Homosexual	35 (80)	28 (74)
Bisexual	1 (2)	1 (3)
With children[b]	6 (14)	5 (13)
HIV-infected children	0 (0)	0 (0)
Education level[b]		
Primary	0 (0)	0 (0)
Secondary	9 (21)	13 (34)
College	11 (25)	14 (37)
University	24 (55)	11 (29)
Annual income (in Can $)[d]		
<14,999	11 (26)	11 (30)
15,000-34,999	10 (24)	12 (33)
35,000-54,999	11 (26)	8 (22)
>55,000	10 (24)	6 (16)
Employment status[e]		
Employed	27 (64)	17 (47)
Student	1 (2)	4 (11)
On welfare	8 (19)	5 (14)
Others	6 (14)	10 (28)
Housing/accommodation[c]		
Living alone	22 (51)	21 (55)
Living with spouse	12 (28)	9 (24)
Living with family or friend	3 (7)	4 (11)
Others	6 (14)	4 (11)
Self-perceived health (0-10)[e]	8 (7-8)	8 (7-9)
Years of HIV infection[f]	7 (3-18)	8 (3-16)
Years of antiretroviral therapy[f]	5 (1-16)	6 (2-10)
Undetectable viral load[g]	41 (95)	34 (92)
CD4 cell count[e]		

Characteristic	Experimental group (N=45), n (%) or median (IQR)	Control group (N=43), n (%) or median (IQR)
Did not know	8 (21)	7 (18)
Knew	30 (79)	33 (83)
Value of CD4 cell count (cells/µl)[h]	555 (410-690)	650 (480-800)
CD4 trend[g]		
Increasing	8 (19)	11 (30)
Decreasing	7 (16)	3 (8)
Stable	16 (37)	18 (49)
Did not know	12 (28)	5 (14)
Months since last blood control[i]	1 (1-3)	2 (0-3)
Treatment change in the past 3 months[c]	2 (5)	4 (11)
Reasons for change[j]		
To switch to more effective drugs	1 (50)	3 (75)
To reduce adverse events	2 (100)	2 (50)
To simplify treatment	0 (0)	3 (75)
Others	1 (50)	0 (0)

[a]Total 86 participants (two missing).
[b]Total 82 participants (six missing).
[c]Total 81 participants (seven missing).
[d]Total 79 participants (nine missing).
[e]Total 78 participants (10 missing).
[f]Total 87 participants (one missing).
[g]Total 80 participants (eight missing).
[h]Total 61 participants (two missing).
[i]Total 85 participants (three missing).
[j]More than one reason possible.

Attrition and Engagement in the Study Process and Intervention

Of the 88 participants, 48 (55%) completed the questionnaire at T6, with a median of 7 months (IQR 6-8) after baseline, and the attrition rate was 45% (40/88). In terms of engagement in the intervention, in the experimental group, 69% (31/45) of the participants accessed the intervention (Figure 1). Of these participants, 65% (20/31) completed only session one and 36% (11/31) completed more than one session. Among those who complete more than one session, 13% (4/31) completed sessions one and two, 10% (3/31) reached session three, and 13% (4/31) reached session four.

Primary Outcome

The proportion of treatment-adherent participants (defined as intake of at least 95% of the prescribed tablets in the past 7 consecutive days) at baseline was high, reaching a mean of 80% in both groups (34/41, 83% in the experimental group and 30/39, 77% in the control group). The proportion of treatment-adherent participants at T6 did not differ between the experimental and control groups in the per-protocol analysis (19/21, 91% vs 19/23, 83%; *P*=.67). Results were similar in the ITT analysis (Table 2).

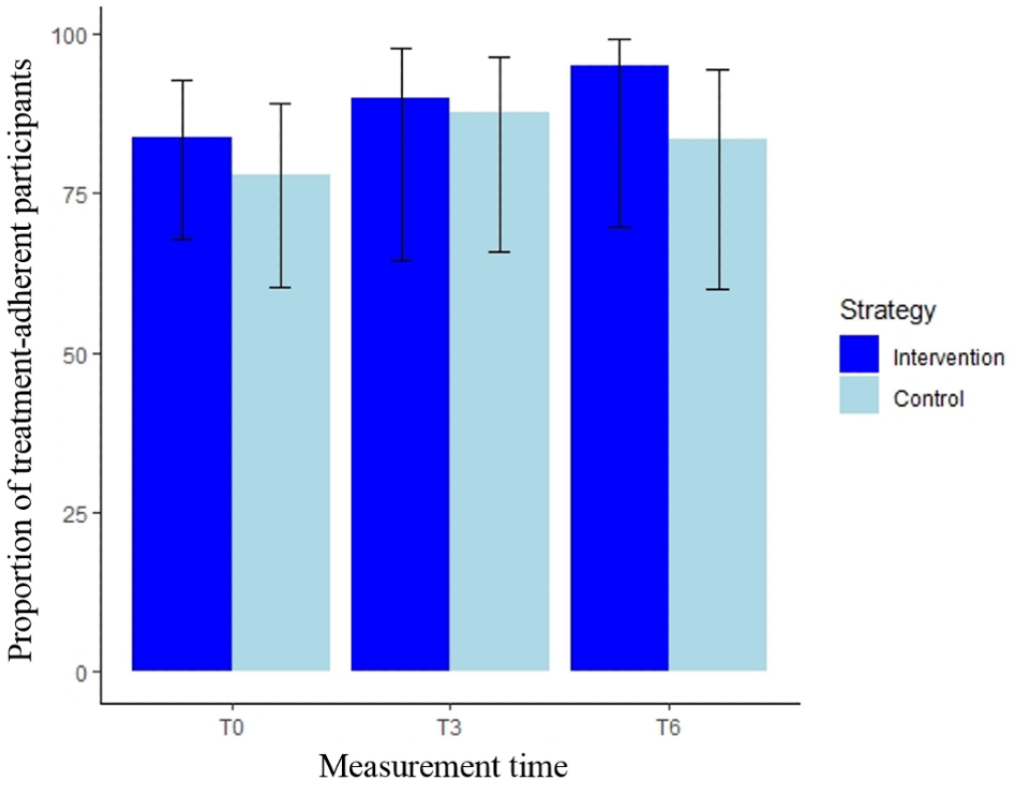
Similar results were confirmed in the exploratory analysis using a GLMM. No intergroup difference was observed (OR 1.9, 95% CI 0.6-6.4). No significant time effect (OR 0.4, 95% CI 0.1-1.6 for the proportion of treatment-adherent participants at T0 vs T6; OR 0.8, 95% CI 0.2-3.8 for the proportion at T3 vs T6) and no strategy-by-time interaction effect on treatment adherence were found (Figure 2).

Table 2. Proportion of antiretroviral-adherent participants.

Time point	Experimental group		Control group		*P* value
	Total, n	Value, n (%)	Total, n	Value, n (%)	
Baseline (T0)					
Per-protocol analysis	41	34 (83)	39	30 (77)	
Intention-to-treat analysis	45	34 (76)	43	30 (70)	
3 months (T3)					
Per-protocol analysis	19	17 (90)	25	22 (88)	
Intention-to-treat analysis	45	17 (38)	43	22 (51)	
6 months (T6)					
Per-protocol analysis[a]	21	19 (91)	23	19 (83)	.67
Intention-to-treat analysis[a]	45	19 (42)	43	19 (44)	.85

[a]For the primary outcome, groups were compared using the Pearson chi-square test.

Figure 2. Adherence over time. The solid bars represent the estimated proportion of treatment-adherent participants, and the error bars (lines) indicate the corresponding 95% CIs from the generalized linear mixed model. The measurement time points are baseline (T0) and 3 months (T3) and 6 months later (T6).



Secondary Outcomes

Table 3 presents a description of the secondary outcomes. At T6, participants reported low discomfort in terms of symptom count or bother, and there was no intergroup difference in this regard. Participants also expressed a high sense of self-efficacy and an elevated level of social support, both of which tended to improve over time. There was again no intergroup difference in this regard. Reported skills and strategies were high at baseline and T6.

Table 3. Secondary outcomes at 6 months (T6).

Variable	Experimental group (N=45), median (IQR) score	Control group (N=43), median (IQR) score	*P* value[a]
Symptom count[b]	9.0 (6.0-14.0)	7.5 (5.0-17.5)	.68
Symptom bother[c]	17.0 (11.0-29.0)	18.5 (8.5-47.0)	.70
Self-efficacy[d]	67.5 (60.5-70.0)	66.0 (62.0-69.0)	.81
Social support[e]	32.0 (28.0-39.0)	32.0 (27.0-38.0)	.83
Skills and strategies[f]	97.0 (82.0-118.0)	98.0 (90.0-111.0)	.90

[a]Groups were compared using the Student *t* test or Fisher exact test.

[b]Total 45 participants (three missing). Possible score range 0-25.

[c]Total 45 participants (three missing). Possible score range 1-100.

[d]Total 39 participants (nine missing). Possible score range 14-90.

[e]Total 47 participants (one missing). Possible score range 8-40.

[f]Total 46 participants (two missing). Possible score range 25-125.

Discussion

The objective of this study was to evaluate the effectiveness of a web-based intervention for optimizing adherence to antiretroviral intake in people living with HIV. The results showed no intergroup difference for treatment adherence. Participants in both the experimental and control groups had been living with HIV for 7 years and had been on ART for 5 years. They self-reported high treatment adherence, high self-efficacy, and high skills; perceived good social support; and experienced low discomfort from symptoms.

These results are comparable to those obtained in our previous study involving people living with HIV frequenting a clinic [15]. However, the participants in this study and our previous study differ in terms of sociodemographic characteristics. The participants in this study were younger (this study vs previous study: 41 years vs 48 years), had been living with HIV for a shorter period of time (7 years vs 11 years), had a higher education level (college or university diploma: 60/82, 73% vs 86/179, 48%), and had a higher income (>Cad $15,000: 57/79, 72% vs 70/179, 39%). Regarding internet literacy, the majority went online every day and considered web navigation easy.

Contrary to our results, Kurth et al found an improvement in self-reported treatment adherence (on a 30-day visual analog scale) among people living with HIV (n=240) exposed to a computerized counseling tool [8]. More specifically, among participants with a nonsuppressed viral load at baseline, adherence increased by about 10% in the experimental group (76% at baseline to 85% 9 months later), whereas in the control group, the rate started at 74% and showed no improvement over time. In other words, the adherence effect was more pronounced among people living with HIV having a detectable viral load. A suppressed viral load was noted in 66% of participants in their sample as compared with more than 90% of participants in our sample (self-reported viral load). We believe that the high rate of adherence and suppressed viral load among participants in our study might have left little room for improvement, unlike that in the study by Kurth et al [8]. Their intervention, which shares similar components with our intervention, is based on Bandura theory and consists of four sessions that include audio-narrated assessment, tailored feedback, skill-building videos, a health plan, and printouts. This intervention, much like VIH-TAVIE, is geared for skill building and patient empowerment. According to a systematic review by Zhang et al, the use of information and communication technology in HIV self-management interventions is an emerging field [28]. They identified the following three major functionalities of such interventions: deliver information modules, support self-monitoring medical adherence, and provide access to HIV self-management information.

To determine treatment adherence, we set the cutoff point at 95%, which was commonly used at the time we planned and conducted our study. However, according to a recent meta-analysis by Bezabhe et al, adherence levels as low as 80% to 90% are good enough to achieve viral suppression [29]. As stated by these researchers, the clinical importance of this finding lies in the fact that the “level of adherence behavior capable of sustaining viral suppression is broader than previously thought.” Considering this, in our sample, it is possible and even plausible that all of the recruited people living with HIV were treatment adherent before being exposed to the intervention. Indeed, they might already have been nearly fully engaged in the adherence behavior and strongly mobilized regarding ART intake, as evidenced by their self-reported high levels of self-efficacy and skills.

Compared with our previous study conducted in a clinical setting with nurses present onsite to facilitate the overall flow of research and the consultation with VIH-TAVIE [15], the present study was entirely web-based, including participant recruitment, consent granting, data collection, and participant follow-up across 6 months. Various challenges emerged relative to this approach of conducting a study that aimed to not only evaluate a web-based intervention but also conduct the evaluation entirely over the internet. According to a literature review by Pham et al, the vast majority of mHealth clinical trials conducted in the past favored onsite study implementation (69/71, 97%). In fact, they found only two web-based trials that recruited and collected data via the internet (2/71, 3%) [30]. Recently, a systematic review (n=41) by Price et al on the quality of web-based self-management trials underscored the challenges related to

this type of study and concluded that web-based trials were still an emergent field [31].

In our study, challenges were related to engagement on the following three levels: starting the web-based study, completing the web-based intervention, and continuing the study.

Participant recruitment and engagement to start the study are key stages in the research process. Different modalities must be implemented to reach the target client group and to ensure their participation. In our study, we employed a multimodal strategy of offline and web-based recruitment that involved a mix of traditional and innovative channels, including newspapers, magazines, hospitals, health care providers, free internet methods, and Facebook. However, the majority of participants reported being reached by more traditional methods (61% by leaflets and health care providers). As many authors have pointed out in the past, the importance of cultivating close ties with health care settings is all the more obvious when seeking to reach a client group with a health problem [32]. A strong alliance with the care setting is imperative to ensure the credibility of the proposed approach and intervention, which should be in line with the care delivered in the clinical setting. Indeed, participant engagement in a web-based RCT requires a great deal of motivation that goes beyond an initial interest or curiosity. Millard et al performed a study of the efficacy of a web-based self-management program in improving health outcomes for people living with HIV and revealed that only 58% (132/227) of the participants recruited for the study completed the web-based registration form and baseline questionnaires [33].

Engagement in the intervention is another challenge. Among 69% (31/45) of participants who accessed the intervention, the majority completed only the first session (20/31, 65%). Yet, in our previous study conducted in a clinical care setting, engagement seemed optimal, although participants had to travel to the site. In that case, 74% (73/99) of the participants completed all four VIH-TAVIE sessions and only four participants completed none of the sessions (4/99, 4%) [15]. However, a review by Price et al on the quality of web-based self-management trials evidenced that engagement in interventions over time was not optimal [31]. According to Sieverink et al [34], participants did not use technologies in the desired way most of the time. These researchers raised the following question: Do all users need to experience all of the elements of a technology to obtain effects? In the opinion of Sieverink et al [34], depending on the user's goals and the desired outcomes, technology could be employed in many different ways in terms of features used, frequency of use, time of use, and place of use. Moreover, individuals might also stop using technology once they reach their personal goals. This sort of dropout was not necessarily a consequence of losing interest. Another important aspect is whether engagement should be measured according to the number of logins, number of sessions completed, or number of pages viewed. According to Sieverink et al [34], the unspoken rule is "the more, the better." They concluded that adherence to eHealth technology was an underdeveloped and often improperly used concept in the existing body of literature. In the case of our study, given that participants manifested high levels of sense of self-efficacy, skills, and treatment adherence at baseline, it is not unreasonable to think that after the first session, skills were already consolidated and participants had no reason to continue with the intervention.

Participant engagement to see the study through (ie, retention over 6 months) was low (48/88, 55%), indicating that attrition was high at 45% (40/88). In the studies reviewed by Price et al, 73% (30/41) of the web-based trials reported high attrition rates with incomplete or unreported data [31]. To ensure a high rate of retention, Watson et al used intensive follow-up modalities in their web-based RCT in the general population [35]. These modalities were deployed sequentially over time until the survey was completed (web, telephone, mailed survey, and a postcard with selected outcomes). According to these authors, offering bonus incentives and diverse follow-up modalities were key factors contributing to a high rate of data retention. In our study, incentives and email reminders were used to engage and follow the participants. However, intensive follow-up modalities (telephone and mail survey) might be difficult to implement and inappropriate or irrelevant for people living with HIV, given the persistent stigmatization of the illness. Despite their success, Watson et al [35] recognized that obtaining an adequate sample size, keeping participants engaged in the study, and achieving adequate rates of outcome data retention were extremely challenging tasks.

Presently, there are no best-practice standards for recruiting or retaining participants in web-based trials. However, the lack of face-to-face interaction is a major issue in terms of how interventions are delivered [28] and how studies are conducted [31]. Regarding engagement and recruitment relative to digital health interventions, a more hybrid approach (face-to-face and web-based components) appears to be a serious option to consider [32,36]. Still, notwithstanding all these difficulties and challenges, there are advantages to conducting a web-based RCT. It may allow reaching and including people with limited mobility, people in nonurban areas (where the study is not available), and people with stigmatizing conditions (offers greater sense of confidentiality and anonymity). According to Watson et al, this type of study affords a multitude of advantages, including automated data collection and high control over intervention content and format [35]. The use of a comparative intervention constitutes a further strong point of our parallel RCT design. Regarding the study's limitations, those related to engagement in the intervention and attrition have been discussed in detail above. Despite using a conservative approach to eliminate false participants and ensure data quality, our study may have suffered from selection bias (participants willing to respond over the internet) and reliance on self-reported outcomes. On account of these limitations, Price et al [31] believed that this type of web-based trial is more pragmatic than explanatory trials.

Al-Durra et al revealed that 27% of the results from digital health registered clinical trials had never been published [37]. This is lower than the nonpublication rate in other fields (impact and risk of publication bias in the field of digital health trials) and is attributed to challenges specific to digital heath randomized clinical trials (high attrition rate and usability issues). Despite these limitations, the findings of our study add

to the existing body of knowledge regarding how to conduct web-based studies that evaluate eHealth interventions aimed at developing and strengthening personal skills and abilities.

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Conflicts of Interest

JC and MPRG declare granting of licensing options for marketing VIH-TAVIE. The remaining authors declare no conflict of interest.

Multimedia Appendix 1
CONSORT-eHEALTH checklist (V 1.6.1).
[PDF File (Adobe PDF File), 1630 KB - publichealth_v6i2e17733_app1.pdf]

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Abbreviations

ART: antiretroviral therapy
eHealth: electronic health
GLMM: generalized linear mixed model
ITT: intention-to-treat
RCT: randomized controlled trial
VIH-TAVIE: Virus de l'immunodéficience humaine-Traitement assistance virtuelle infirmière et enseignement (HIV Treatment, Virtual Nursing Assistance, and Education)

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Original Paper

Recommendations From a Descriptive Evaluation to Improve Screening Procedures for Web-Based Studies With Couples: Cross-Sectional Study

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Abstract

Background: Although there are a number of advantages to using the internet to recruit and enroll participants into Web-based research studies, these advantages hinge on data validity. In response to this concern, researchers have provided recommendations for how best to screen for fraudulent survey entries and to handle potentially invalid responses. Yet, the majority of this previous work focuses on screening (ie, verification that individual met the inclusion criteria) and validating data from 1 individual, and not from 2 people who are in a dyadic relationship with one another (eg, same-sex male couple; mother and daughter). Although many of the same data validation and screening recommendations for Web-based studies with individual participants can be used with dyads, there are differences and challenges that need to be considered.

Objective: This paper aimed to describe the methods used to verify and validate couples' relationships and data from a Web-based research study, as well as the associated lessons learned for application toward future Web-based studies involving the screening and enrollment of couples with dyadic data collection.

Methods: We conducted a descriptive evaluation of the procedures and associated benchmarks (ie, decision rules) used to verify couples' relationships and validate whether data uniquely came from each partner of the couple. Data came from a large convenience sample of same-sex male couples in the United States, who were recruited through social media venues for a Web-based, mixed methods HIV prevention research study.

Results: Among the 3815 individuals who initiated eligibility screening, 1536 paired individuals (ie, data from both partners of a dyad) were assessed for relationship verification; all passed this benchmark. For data validation, 450 paired individuals (225 dyads) were identified as fraudulent and failed this benchmark, resulting in a total sample size of 1086 paired participants representing 543 same-sex male couples who were enrolled. The lessons learned from the procedures used to screen couples for this Web-based research study have led us to identify and describe four areas that warrant careful attention: (1) creation of new and replacement of certain relationship verification items, (2) identification of resources needed relative to using a manual or electronic approach for screening, (3) examination of approaches to link and identify both partners of the couple, and (4) handling of *bots*.

Conclusions: The screening items and associated rules used to verify and validate couples' relationships and data worked yet required extensive resources to implement. New or updating some items to verify a couple's relationship may be beneficial for future studies. The procedures used to link and identify whether both partners were coupled also worked, yet they call into question whether new approaches are possible to help increase linkage, suggesting the need for further inquiry.

(JMIR Public Health Surveill 2020;6(2):e15079) doi:10.2196/15079

KEYWORDS

couples; methods; internet

Introduction

Background

In the United States, 90% of adults use the internet for social connections and information searching [1], suggesting internet usage has become increasingly a normative behavior. More adults own a smartphone than not (83% in urban and suburban, 71% in rural areas), with a similar representation of having broadband internet at home [2]. Further, 70% of adults have and use at least one social media account, and usage—across multiple accounts—continues to increase with respect to a person's age, race, gender, income, education, and community (ie, urban, suburban, rural) [3]. These trends equate to more and more research studies being conducted on the Web.

There are a number of advantages to conducting research studies on the Web. Compared with in-person methods, the internet enables researchers with more efficient modes (eg, targeted social media advertisements) to access small and/or hard-to-reach populations, including sexual and gender minority groups [4]. With respect to time, Web-based recruitment efforts can reach larger samples of potential research participants in shorter periods of time compared with more traditional in-person outreach methods. Use of Web-based methods to enroll and collect data from participants may also benefit researchers by shortening the amount of time needed to prepare data for use in analytic software programs.

There are, however, methodological challenges associated with conducting studies on the Web with respect to data validity [5-10], as anonymity and lack of in-person contact prohibits researchers from knowing who or what are providing data. Data validity may be a particular concern when incentives or compensation are offered. For instance, a participant may enter false information about themselves for purposes of earning the incentive (ie, misrepresentation for eligibility) [5,11-16], or enter the study multiple times to earn multiple incentives or increase the chances of earning an incentive, by either pretending to be different participants or the same individual (ie, deduplication or multiple data entry) [8,10,12,13,17]. Web-based research that lacks mechanisms to detect such instances of invalid data entries will negatively impact the study's findings and associated recommendations.

In response to this concern, researchers have provided recommendations related to screening for fraudulent survey entries and regarding how best to handle potentially invalid responses when they do occur. One recommendation is to *use* all data by categorizing survey entries into groups—valid, suspicious, and invalid—along with accompanying pre and post hoc decisions for how best to handle the data [6]. This approach allows researchers to keep all data for analysis, assess differences between the categories of survey entries, detect whether any data entries were incorrectly categorized, and to fine-tune the pre and post doc decisions to categorize or label data entries in future studies. This process uses a less conservative approach by examining all data entries and requires more time to execute, although it may help expedite the screening process (ie, detecting invalid data) in future Web-based projects. Another recommendation is to assess survey responses for patterns, such as whether the same response was repeatedly used to answer questions (eg, always the second response option), if a consistent pattern was used to respond to questions throughout the survey (eg, acbd, acbd), and whether a participant provided the same response to the same question asked at different points in the same survey (ie, internal consistency) [4,16,18]. Another recommendation includes reviewing the internet protocol (IP) address in conjunction with other data collected from the participants, such as their state of current residence or zip code to examine whether this information concurs with one another (ie, IP address matches state) [7,13,16,19].

The majority of this previous work focuses on screening (ie, verification that individual met inclusion criteria) and validating data from one individual, and not from two people who are in a dyadic relationship with one another (eg, same-sex male couple, mother, and daughter). Although many of the same data validation and screening recommendations for Web-based studies with individual participants can be used for those with dyads, there are differences and challenges that need to be considered. In particular, verification must be expanded beyond the individual-level, such that eligibility screener data must be collected from both participants of the dyad to compare and assess whether the two individuals represent a dyad (or not). As noted in a previous study, it is recommended for researchers to use predetermined decision rules regarding what response ranges will be acceptable per dyad when comparing one member's answer with the other member's answer [7]. Similar recommendations for validity data checking, as described above, can be applied to Web-based studies with dyads, yet other considerations must be made with respect to back-to-back data entries and multiple entries originating from the same IP address. For instance, some dyads may have both members using the same IP address and/or have one member refer the other to participate, resulting in back-to-back data entries for the dyad. As such, Web-based research studies with dyads may require different parameters or decision rules for validating dyadic data.

Goal of the Study

With the overarching goal of improving Web-based verification and validation of couples' relationships and associated data, we conducted a descriptive evaluation of the procedures used in a Web-based study with same-sex male couples. Specifically, this paper will describe the methods we used to verify and validate couples' relationships and data (ie, whether two partners were in a relationship together as a couple, detection of fraudulent cases). The lessons we learned from this project can then be applied to future Web-based studies that involve

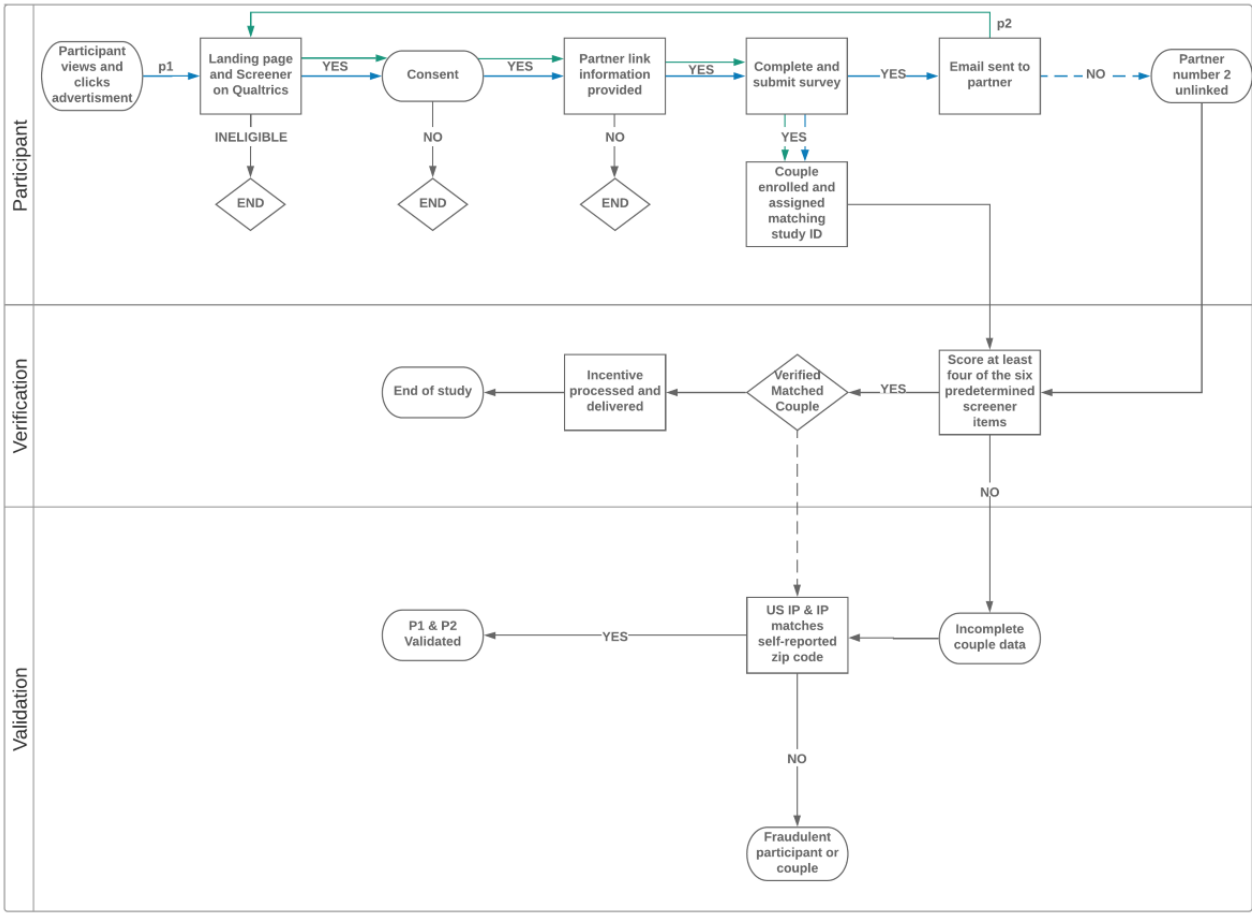
screening and enrollment of couples with the collection of dyadic data.

Methods

Procedure Overview

The University of Michigan Institutional Review Board (Protocol number HUM00125711) approved all study procedures. To accomplish the overarching goal of this study, we used data from a mixed methods study conducted about how factors shape partnered men's support and willingness to use pre-exposure prophylaxis among concordant HIV-negative and HIV-discordant same-sex male couples in the United States. A variety of social media platforms (eg, Facebook, Instagram, Scruff) were used to target and recruit the convenience study sample. Figure 1 illustrates the enrollment procedures used for this study. Specifically, interested men who clicked on a social media advertisement were taken to the study landing webpage that briefly described the study and linked them to the eligibility screener before proceeding to the consent webpage. After providing consent, potential participants were then asked to provide their own and their partners' contact information before accessing the online, cross-sectional study survey; we refer to this participant as the index partner of the couple. At this point in time, the partner of the index partner (ie, partner number 2) would then receive an email invitation containing a weblink with an embedded linkage code to the study landing webpage that would allow the individual to follow the same procedures for eligibility, consent, and accessing the survey as the index partner (green line in Figure 1). The linkage code and screener items were used to help match and then verify whether the two partners were a couple. To enroll into the study as participants, both partners of each couple had to meet all the eligibility criteria, consent, complete the study survey, and pass the verification and validation benchmarks. Each individual who completed the study survey was provided with an incentive (US $50 Amazon gift card), irrespective of his partner's participation.

Figure 1. Overview of screening and enrollment procedures used. IP: internet protocol; p1: partner 1 ; p2: partner 2.



Eligibility Criteria

Through self-reports, both partners of the couple had to meet the following study eligibility criteria: (1) self-identify as a cisgender male, (2) be 18 years of age or older, (3) live in the United States, (4) be in a sexual and romantic relationship with each other for 3 or more months, (5) engage in condomless anal sex at least once with their partner in the 3 months before assessment, and (6) both be HIV negative or be HIV sero-discordant.

Procedures Used to Verify Couples' Relationship and Validate Their Data

On the basis of our previous experiences of conducting Web-based studies with same-sex male couples [7], we developed and employed a process to help verify whether both partners were a true couple, as well as whether valid data were collected from each respective partner of the couple (Figure 1). The aim was to prevent individuals registering twice as a fake couple, or two people who were not in a relationship registering as a couple. For example, a feature we used in the eligibility screener on Qualtrics (SAP) was the *prevent ballot box stuffing*, which helps prevent someone from taking the same survey multiple times by attaching a cookie to their web browser to produce a message stating they had already taken the survey if they tried to take it again. *Verification of a couple's relationship* was based on participants' responses to six screener items with predetermined decision rules and the degree to which the couple had both partners concur on these items or reported responses within an acceptable range. As shown in Table 1, some items used to verify a couple's relationship required that both partners of the couple report the same response, whereas other items allowed a reasonable margin of error (eg, within 1 year of age) to account for the potential of normalcy of human error as well as real life occurrences between the times of when each partner completes the screener (eg, possibility of a birthday happening). Six screener items with corresponding decision rules (ie, benchmarks) were used to verify the couple's relationship.

Verification of each couple's relationship was conducted manually by downloading data from Qualtrics, comparing both partner's responses with these six items, and assigning the couple a score (range 0-6) based on the number of items passed following the predetermined decision rules (eg, 5 out of 6). Two team members compared the dyadic data and initially assigned the couples a verification score. A third team member then cross-checked the work conducted by the two team members. Data verification took 10 to 15 minutes per couple. Couples with a score of 4 or higher were considered as being in a relationship, whereas those who received a score of 3 or lower did not pass this benchmark and were marked as unverified. The use of a conservative score of 4 as the minimum to verify a couple's relationship was based on balancing between the possibility for recall bias and human error, in recognizing that some partners may have multiple email addresses, not accurately recall when they last had condomless anal sex, or may have different initials from the name(s) one prefers or is often called (eg, John Paul Maxlin, goes by JP yet has first and last name initials of JM).

Once a couple passed the relationship verification benchmark, the *validity of their data* was assessed to determine that responses came from two unique individuals in a relationship and not from one person pretending to be two people (ie, fraudulent). Our validity test consisted of an evaluation of four criteria: US-based IP address (yes or no), IP address matched self-report of zip code (yes or no), number of data entries from the same IP address (3 or less), and start and stop times of each partner's survey response. In addition to requiring the first two items passing the criteria (ie, both yes), no more than three entries were permitted to occur from the same IP address to allow for the possibility of fluxes in internet connectivity and both partners using the same internet connection. Back-to-back survey entries (ie, one survey completed, then second survey started shortly after) were permitted as long as the other three validation criteria passed. Overall, each couple had to pass the first two validation criteria and have no more than three screener entries between the two partners. Couples which passed the relationship verification test but failed the validation were deemed as fraudulent.

Table 1. Screener items with accompanying decision rules used for couple verification test.

Item	Relationship verification rules for responses	
	Partner 1 (index)	Partner 2
1. Partner 1 age	N/A[a]	± 1 year
1. Partner 2 age	± 1 year	N/A
2. Partner 1 birthday month	N/A	Exact
2. Partner 2 birthday month	Exact	N/A
3. Relationship length	Same response	Same response
4. Recently had condomless anal sex with partner	Same response	Same response
5. Partner 1 initials of first and last name	N/A	Exact
5. Partner 2 initials of first and last name	Exact	N/A
6. Partner 1 email/cell number	N/A	Must match one
6. Partner 2 email/cell number	Must match one	N/A

[a]N/A: not applicable.

Analyses

Descriptive statistics (counts, proportions) were calculated to describe the sample relative to the verification and validation procedures. Comparative analyses via chi-square tests were used to assess whether any significantly meaningful demographic differences existed by couples' verification score

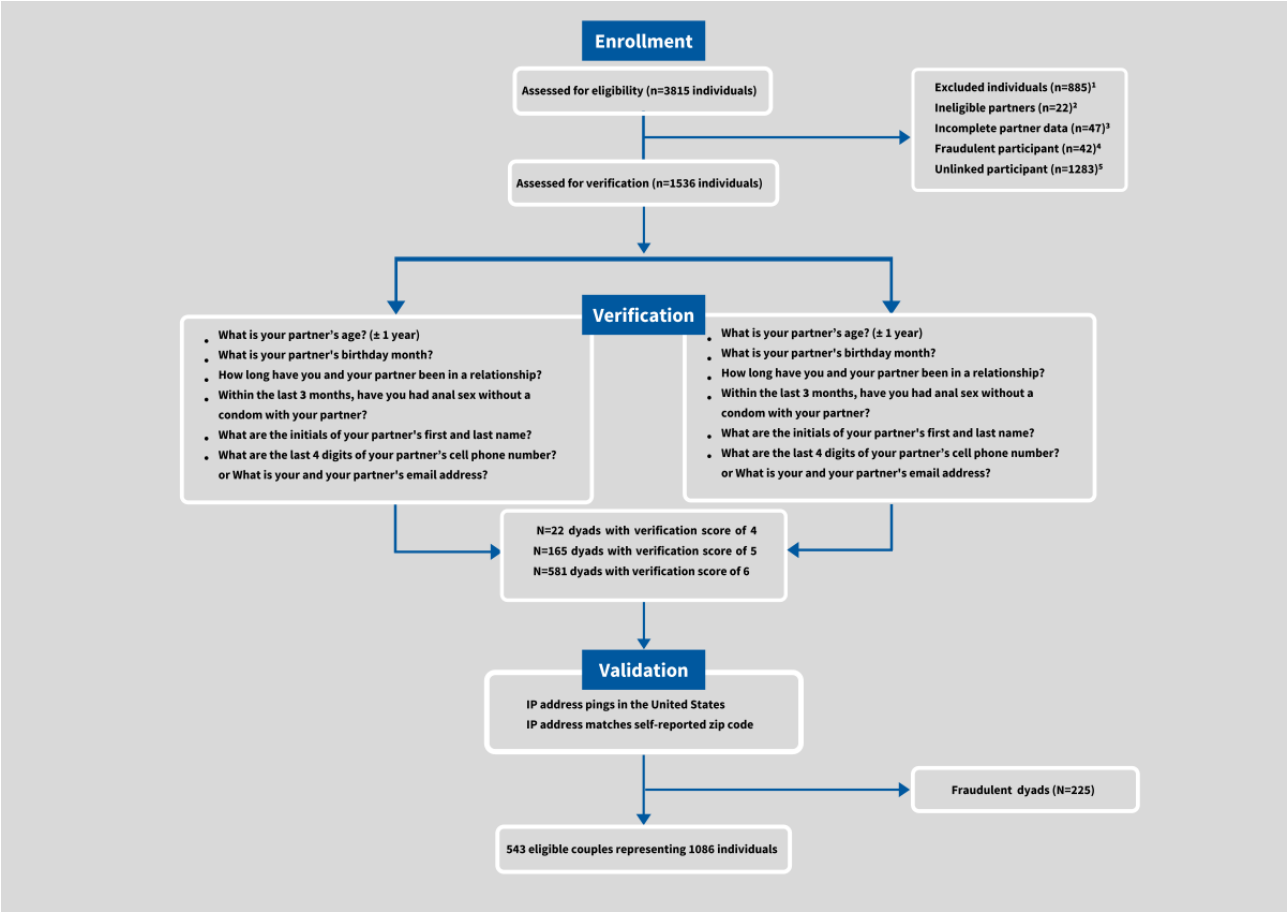
among those who had a benchmark of 4 and higher (ie, 4 vs 5 vs 6). Analyses were conducted using STATA version 15.

Results

Eligibility

As shown in Figure 2, 3815 individuals were assessed for eligibility. Of these 3815 individuals, 2279 were excluded and the remaining 1536 individuals were matched with a corresponding partner (768 dyads) and evaluated for the relationship verification test. Of the 2279 who were excluded, the primary reasons were having an unlinked partner (n=1283; only partner A provided contact information) and partner A not completing all the questions on the screener (n=885). Others were excluded for having ineligible partners (n=22), incomplete partner data (n=47), and being detected as a fraudulent participant (n=42). The primary reasons detected for fraud were not living in the United States and/or having a fictitious identity. All 768 dyads passed the verification test by receiving at least a minimum score of 4 out of 6 screening rule items.

Figure 2. Consolidated Standards of Reporting Trials diagram of couple verification and validation procedures for enrollment. IP: internet protocol.



Relationship Verification and Data Validation

Our descriptive analysis of the verification rules revealed approximately 2.9% (22/768) of dyads received a score of 4, 21.5% (165/768) of dyads received a score of 5, and 75.7% (581/768) of dyads received a score of 6. Some items used for the verification screening were missed more than others (Table 2) and tended to vary by couples' verification score. A higher proportion of dyads with a score of 4 failed to pass the verification test for any given item, except their email addresses. Some dyads with a verification score of 4 or 5 had responses that did not match for their partner's first and last name initials, relationship length, or both of these criteria. Interestingly, a similar proportion of dyads with a verification score of 4 or 5 had partners whose responses about their recent engagement in condomless anal sex in the relationship did not match.

Table 2. Proportion and identification of eligibility screening items that did not pass the verification test, by couples' passing verification score.

Item	Couple verification score		
	4 (n=22), n (%)	5 (n=165), n (%)	6 (n=581), n (%)
Partner's initials	19 (86.4)	86 (52.1)	0 (0.0)
Partner's age	1 (9.0)	3 (1.8)	0 (0.0)
Partner's birthday month	3 (13.6)	10 (6.0)	0 (0.0)
Relationship length	17 (77.3)	93 (56.4)	0 (0.0)
Recent condomless anal sex with partner	3 (13.6)	18 (10.9)	0 (0.0)
Partner's cell numbers	4 (19.2)	13 (7.9)	17 (2.9)
Partner's email addresses	0 (0.0)	32 (19.4)	24 (4.1)

For validation, 225 of the 768 dyads (29.3%) did not pass our test and were considered fraudulent. The 225 dyads did not pass the data validity test because one or both 'partners' used an IP address located outside of the United States and/or the IP address did not match the zip code self-reported in the survey. Overall, a total of 543 couples (consisting of 1086 partnered men) passed our verification and validation procedures and were enrolled into the study as participants.

To help improve screening procedures for verification of a couple's relationship, we also explored whether demographic differences comparatively differed by a couple's passing verification score (Table 3). Relationship length significantly differed between the three groups of couples according to their passing verification scores (4 vs 5 vs 6; $P<.001$. No other demographic characteristic significantly differed when comparing couples by their passing verification score.

Table 3. Descriptive statistics for participant demographics, by couples' verification score (CVS).

Demographic	Total (n=1086), n (%)	CVS=4 (n=44), n (%)	CVS=5 (n=324), n (%)	CVS=6 (n=718), n (%)	*P* value
Race/ethnicity					.13
Non-Hispanic white	811 (74.68)	28 (63.64)	242 (74.69)	541 (75.35)	
White/Hispanic	76 (7.00)	4 (9.09)	23 (7.10)	49 (6.82)	
Black/Latino	57 (5.25)	7 (15.91)	12 (3.70)	38 (5.29)	
Hispanic/Latino	47 (4.33)	2 (4.55)	18 (5.56)	27 (3.76)	
Asian	34 (3.13)	2 (4.55)	11 (3.40)	21 (2.92)	
Other[a]	61 (5.62)	1 (2.27)	18 (5.56)	42 (5.85)	
Age (years)					.58
18-24	160 (14.73)	3 (6.82)	46 (14.20)	111 (15.46)	
25-34	637 (58.66)	28 (63.64)	191 (58.95)	418 (58.22)	
35-44	217 (19.98)	9 (20.45)	61 (18.83)	147 (20.47)	
45+	72 (6.63)	4 (9.09)	26 (8.02)	42 (5.95)	
Region					.50
Northeast	186 (17.22)	10 (22.73)	51 (15.74)	125 (17.56)	
South	333 (30.83)	14 (31.82)	102 (31.48)	217 (30.48)	
West	223 (20.65)	12 (27.27)	63 (19.44)	148 (20.79)	
Midwest	338 (31.30)	8 (18.18)	108 (33.33)	222 (31.18)	
Education[b]					.08
Up to high school graduate or equivalent	77 (7.12)	3 (6.81)	27 (7.39)	47 (7.05)	
Some college education or technical school graduate	245 (22.65)	18 (40.91)	63 (26.52)	164 (21.91)	
College graduate	378 (34.94)	12 (27.27)	115 (31.30)	251 (35.64)	
Some graduate school or degree	382 (35.31)	11 (20.45)	118 (34.78)	253 (62.13)	
Employment					.78
Work full-time (30+ hours)	863 (79.76)	35 (79.55)	251 (77.71)	577 (80.70)	
Work part-time (1–29 hours)	122 (11.28)	4 (0.09)	40 (12.38)	78 (10.91)	
Unemployed/retired	97 (8.97)	5 (11.36)	32 (9.91)	60 (8.39)	
Housing status					.72
My own house or apartment	882 (81.52)	37 (84.09)	270 (83.59)	575 (80.42)	
In my significant other's house or apartment	106 (9.80)	2 (4.55)	30 (9.29)	74 (10.35)	
At my parent's house or apartment	44 (4.07)	2 (4.55)	10 (3.10)	32 (4.48)	
Other[c]	50 (4.61)	3 (6.82)	14 (4.03)	34 (4.76)	
Relationship type					.08
Boyfriend/lover	416 (38.45)	13 (29.55)	122 (37.77)	281 (39.30)	
Partner	232 (21.44)	7 (15.91)	64 (19.81)	161 (22.52)	
Husband/spouse	404 (37.34)	24 (54.55)	131 (40.56)	249 (34.83)	
Other[d]	30 (2.77)	—	6 (1.86)	24 (3.36)	
Relationship length					<.001
More than 3 months but less than 1 year	132 (12.15)	4 (9.09)	46 (14.20)	82 (11.42)	
1 year but less than 3 years	348 (32.04)	12 (27.27)	85 (26.23)	251 (34.96)	
3 years but less than 5 years	231 (21.27)	17 (38.64)	63 (19.44)	151 (21.03)	

Demographic	Total (n=1086), n (%)	CVS=4 (n=44), n (%)	CVS=5 (n=324), n (%)	CVS=6 (n=718), n (%)	*P* value
More than 5 years	375 (34.53)	11 (25.00)	130 (40.12)	234 (32.59)	

[a]Includes 5 Native American/Alaskan Native, 5 Native Hawaiian/Other Pacific Islander, 1 Indian, 1 Middle Eastern, 1 Caribbean, and 48 mixed.

[b]For Education, Employment, Housing status, Relationship type, and Relationship length, the sample size is 1082 for total, 44 for CVS=4, 323 for CVS=5, and 715 for CVS=6.

[c]Includes college dorm, employee housing, sharing with significant other.

[d]Includes fiancé, mates, interchanging use of partner, boyfriend, or husband.

Discussion

Principal Findings

Several lessons were learned from the descriptive evaluation we conducted on the verification and validation procedures used to screen and enroll same-sex male couples in this Web-based study. First, some of the screening items used in the verification test were missed more than others, suggesting the need to consider either amending these items or to use entirely different items to verify a couple's relationship. The measure used for relationship length contained overlapping categorical response options (eg, 3-6 months, 6-12 months) that may help explain why some partners of couples had reported different responses. It is also possible that partner's definition of *when* their relationship began may have differed from one another. To help prevent the potential for measurement and interpretation error, we recommend improving the response options for this item by: 1) eliminating any overlap of time between each potential response and 2) using a suggested *event* as a potential start date of the couple's relationship (eg, first date, decided to be in a relationship with one another). However, this item alone will not account for the possibility for recall bias or that some couples may have broken up for a short period of time and had gotten back together, suggesting the potential for partners to still report different timeframe responses for their relationship length, depending on when they consider the start or restart of their relationship. Thus, we recommend adding an additional screening item to the verification procedure to assess whether the couple had previously broken up or taken a break in their relationship (yes or no), in addition to asking about their relationship length. In sum, these suggestions may help with future assessment of a couple's relationship length and the degree to which partners concur about their relationship length as an item to include in a verification test.

The other verification item missed by a substantial proportion of couples was partner's initials for their first and last name. In our analysis of the data, we noticed two trends that may help explain why some couples did not pass this item. Some participants may have mistyped and entered the incorrect letter either for their own or partners' initials. Other participants reported more than two initials for their own and/or partners' name, whereas their partner reported exactly two initials. It is possible that a participant's name may have more than two initials, such as having a middle name or two first names (eg, John Paul), as well as preferring to be called and known by their middle name instead of their first name given at birth (eg, Xavier Michael, goes by Michael). Given the variability between actual, known, and preferred name, we recommend replacing this verification item and using a simpler one (eg, cohabitation, presence of tattoos) with a categorical response (eg, yes or no) for future Web-based studies with couples. Thus, verification items which contain responses with concrete interpretation may help reduce the chances for human error although they also increase ease of interpretation for the participant. Future research that uses qualitative methods to explore couples' thoughts and suggestions for what questions researchers could use to verify their relationship in Web-based studies is needed. For instance, couples could assist with identifying new topics (eg, pet ownership), as well as with the creation of new screening items with accompanying decision rules, thereby updating and potentially improving the verification process with their input.

Next, a large amount of resources (eg, personnel, time) were needed to apply the verification and validation tests. Both tests were manually checked for a total of three times, with each check being done by a different, independent member of the research team. Discrepancies were resolved through discussion, referring back to the predetermined decision rules (eg, exact response required) and reaching a consensus. No human errors were found for the validation tests, but several errors were found for the verification tests. Although human error will always remain a possibility when cross-referencing and comparing data responses, we recommend that future work consider for this possibility by allocating appropriate time and personnel. As noted by a previous Web-based study with couples [7], another option for researchers to consider is the creation and use of an electronic algorithm that automatically compares partners' responses with the eligibility screener for the relationship verification test. At present, it is unclear whether the manual check or electronic algorithm option would be more cost and time effective to conduct to verify whether both partners of the couple or dyad are in a relationship with one another (ie, verification test). Future research is needed in this area to assess and compare which approach (ie, manual vs electronic algorithm) would be more time and/or cost efficient, while accounting for variability in a study's sample size (eg, 50 couples vs 500 couples).

Third, the email invitation containing the weblink with an embedded linkage code was not 100% reliable to exclusively link both partners together as a couple. To recap, the email with the embedded code was sent to partner 2 once index partner provided consent and entered partner 2's contact information. Some partners (ie, partner 2's) independently completed the screener not using the email invitation containing the embedded linkage code. As we required contact information from each participant for both partners of the couple, we were still able to link partners together as a couple by cross-referencing to see

whether their emails and/or mobile phone numbers matched. Although we still recommend using an email invitation delivery system with an embedded linkage code for the index partner to refer their partner to participate, we also highly recommend for researchers to require each partner to input his own and his partner's contact information as an additional safeguard. This two-pronged mechanism will help researchers identify any potential mismatched partners of couples when implementing the verification and validation procedures. In other words, the phone numbers and email addresses can be used to cross-reference to help find pairs of partners as potential couples.

Finally, the order in which we applied the verification and validation tests (ie, procedures) for this study did not account for the possibility of when fraudulent cases could flood the eligibility screener (eg, *bots*) database system, and how best to handle when these instances occur. For this study, we applied the verification test before the validation test for each couple. Toward the end of recruitment, we received over 400 entries in the study eligibility screener in a relatively short period of time; all of these data entries passed the verification test perfectly (6/6) yet failed the validation test and were labeled as fraudulent data. Evaluating these fictitious data entries was time consuming and yet, had we not implemented this step, approximately 30% of fraudulent couples would have been included in the study and would have impacted the overall findings. For future Web-based studies that seek to enroll data from both partners of a couple, we recommend for researchers to monitor data entries for the eligibility screener on a daily basis (if possible) to note if and when any patterns emerge during recruitment. In our case, we noted that hundreds of odd email address handles (eg, jlqdpz7dm2@live.com) and/or highly similar phone numbers (eg, 888-123-3435, 888-123-3434) were imputed for each given dyad, along with back-to-back screener entries (ie, consecutive start and stop times). Further, these fraudulent data entries occurred in a relatively small period of time (eg, 24 hours), adding to the suspicion that the data were invalid. Inserting captchas—a mechanism that requires an individual to recognize and identify a certain object within a larger image—at the beginning of a survey could provide researchers with a good option to help deter bot survey responses. In addition, if an electronic algorithm method is used, then safeguards could be implemented to help block and prevent instances of when large volumes of *bots* and other forms of fictitious data flood an eligibility screener database. Specifically, an electronic algorithm method could enable researchers to set parameters about the number of eligibility screener entries to permit per IP address, requiring the IP address to be US-based, and whether a minimum amount of time is needed between the stop time of one partner's data entry relative to the start time of the second partner's data entry (ie, back-to-back). These suggestions may help block *bots* and other forms of fictitious data from flooding an eligibility screener database, which may be more likely to happen when a Web-based research study offers a participant an incentive. Other studies have reported such instances relative to fraudulent data entries [5,11-17], though none were with couples and dyadic data. As such, the use of an automated, electronic algorithm may serve as an additional advantage to help deter the receipt of large volumes of fraudulent and fictitious data entries during the enrollment process for Web-based research studies.

Limitations

This study is not without limitations. First and foremost, all data come from a Web-based, convenience sample of same-sex male couples who may not be representative of other same-sex male couples in the United States (and elsewhere). Further, individuals who decided to complete the eligibility screener may be different from others, given the topic of the research study was about HIV prevention as opposed to another health topic, such as stress. The efficacy of the items used to verify couples' relationships has also not been done and warrants future investigation with this population and other groups of couples. Nonetheless, the recommendations we provide based on the experiences of using the present verification and validation enrollment procedures are applicable to other Web-based studies which seek to enroll and collect dyadic data from couples.

Conclusions

Findings from this descriptive evaluation draw from our experience of recruiting and enrolling a large sample of same-sex male couples into a Web-based HIV prevention study. The procedures we used to verify and validate that both the partners were in a relationship together and had independently provided data illuminated potential areas for improvement. We offer examples and considerations relative to improving screening items for the verification process, and a call for further research to compare the advantages and disadvantages of implementing such procedures manually versus electronically. Collectively, additional methodological research that aims to streamline the process of enrolling verifiable couples and collecting valid dyadic data is needed, as more and more research studies are conducted over the Web.

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Conflicts of Interest

None declared.

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Abbreviations

IP: internet protocol

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Original Paper

Time From HIV Diagnosis to Viral Suppression: Survival Analysis of Statewide Surveillance Data in Alabama, 2012 to 2014

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Abstract

Background: Evaluation of the time from HIV diagnosis to viral suppression (VS) captures the collective effectiveness of HIV prevention and treatment activities in a given locale and provides a more global estimate of how effectively the larger HIV care system is working in a given geographic area or jurisdiction.

Objective: This study aimed to evaluate temporal and geographic variability in VS among persons with newly diagnosed HIV infection in Alabama between 2012 and 2014.

Methods: With data from the National HIV Surveillance System, we evaluated median time from HIV diagnosis to VS (<200 c/mL) overall and stratified by Alabama public health area (PHA) among persons with HIV diagnosed during 2012 to 2014 using the Kaplan-Meier approach.

Results: Among 1979 newly diagnosed persons, 1181 (59.67%) achieved VS within 12 months of diagnosis; 52.6% (353/671) in 2012, 59.5% (377/634) in 2013, and 66.9% (451/674) in 2014. Median time from HIV diagnosis to VS was 8 months: 10 months in 2012, 8 months in 2013, and 6 months in 2014. Across 11 PHAs in Alabama, 12-month VS ranged from 45.8% (130/284) to 84% (26/31), and median time from diagnosis to VS ranged from 5 to 13 months.

Conclusions: Temporal improvement in persons achieving VS following HIV diagnosis statewide in Alabama is encouraging. However, considerable geographic variability warrants further evaluation to inform public health action. Time from HIV diagnosis to VS represents a meaningful indicator that can be incorporated into public health surveillance and programming.

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KEYWORDS

HIV; public health surveillance; sustained viral suppression

Introduction

The HIV care continuum (“treatment cascade”) is a unifying framework delineating the successive steps following acquisition of HIV infection needed to achieve optimal individual and population health outcomes [1]. The continuum, beginning with serostatus awareness via HIV testing and culminating in plasma HIV viral suppression (VS, <200 c/mL), has been widely adopted for clinical, public health, advocacy, and policy purposes. Indeed, six of the 10 targeted outcomes in the updated National HIV Prevention Indicators for the United States [2] represent discrete steps along the continuum. Individual-level

goals focus on attaining higher levels of VS (80% among persons with diagnosed HIV) through increased diagnosis, linkage, and retention in HIV care. A population health-level goal is to reduce new HIV diagnoses by 25%. Similarly, the Joint United Nations Programme on HIV/AIDS has put forth global "90-90-90" targets for three distinct steps on the HIV care continuum: 90% serostatus awareness, 90% antiretroviral therapy (ART) receipt among those with diagnosed HIV, and 90% VS among those receiving ART [3].

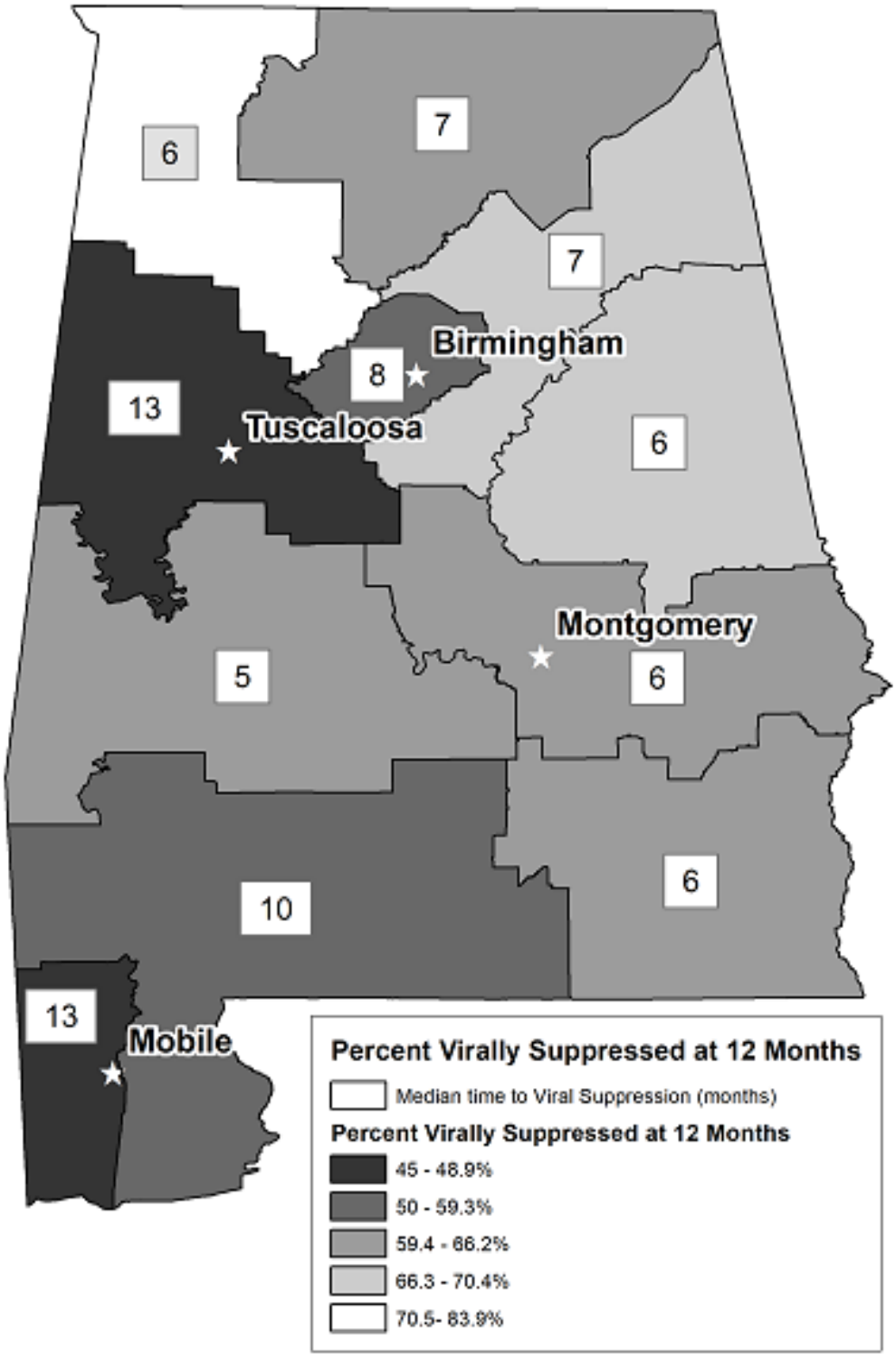
Although the value of delineating performance at the successive steps on the continuum is clear, there is an opportunity to take a broader view evaluating success traversing the anchoring steps on the continuum, HIV diagnosis, and VS. Indeed, as HIV surveillance data reported to public health departments and the US Centers for Disease Control and Prevention (CDC) now include reporting of individual-level plasma HIV viral load (VL) values in most jurisdictions in addition to reporting of diagnoses, there is an opportunity to use surveillance data to evaluate VS among persons with newly diagnosed HIV. To this end, we published on a novel HIV surveillance indicator, time from HIV diagnosis to the initial report of VS (<200 c/mL) using publicly reported HIV surveillance data from 19 jurisdictions with comprehensive plasma VL reporting in 2009 [4]. In this study, we observed a median time of 19 months from HIV diagnosis to VS among 17,028 diagnosed persons across jurisdictions. Notably, linkage to care within 3 months of diagnosis (hazard ratio, HR 4.84, 95% CI 4.27-5.48) and better retention in care, as indicated by a higher number of time-updated care visits (HR 1.51 per additional visit, 95% CI 1.48-1.52), were associated with more expeditious VS. From a clinical and public health perspective, a shorter time from HIV diagnosis to VS translates to a reduction in morbidity and mortality and to a reduction in time during which an individual is viremic and likely to transmit HIV [5,6]. People living with HIV who take HIV medicine as prescribed and get and keep an undetectable VL have effectively no risk of transmitting HIV to their HIV-negative sexual partners [7,8]. Similarly, decreasing time between HIV diagnosis and VS and support for the maintenance of VS corresponds to a decrease of circulating virus in the population that can ultimately reduce HIV incidence [9].

Supportive services (eg, case management and transportation assistance), such as those provided through the Ryan White HIV/AIDS Program, are vital for helping shepherd people living with HIV (PLWH) through the HIV care continuum and attaining VS [10]. Similarly, enhanced personal contacts (eg, personalized reminder calls for upcoming appointments and check-ins after missed appointments) increases retention in care [11]. However, evaluation of the time from diagnosis to VS captures the collective effectiveness of HIV prevention and treatment activities in a given locale, including testing, clinical, ART, and supportive services provided by public health, community-based organizations (CBOs), and clinical entities to move persons across the steps of the HIV care continuum [10]. As such, it provides a more global estimate of how effectively the larger HIV care system is working in a given geographic area or jurisdiction and serves a complimentary role to evaluating individual steps on the continuum. In particular, evaluation of temporal and geographic variability in median time from diagnosis to VS may serve as a powerful public health indicator to measure changes over time in response to HIV treatment and prevention initiatives and, more so, identify areas in need of process improvements and/or additional resources. Here, we use data from National HIV Surveillance System (NHSS) to evaluate temporal and geographic variability between 2012 and 2014 across the 11 public health areas (PHAs) in Alabama as a case study of the utility of this novel HIV surveillance indicator to inform public health practice and policy.

Methods

Historically, Alabama is divided into 11 PHAs (Figure 1), with statewide coordinated HIV prevention and treatment activities led by the Alabama Department of Public Health (ADPH) in conjunction with local health departments, CBOs, and clinical agencies, with HIV care largely supported by the Health Resources and Services Administration via Ryan White funding [12]. Our primary objective was to evaluate temporal and geographic variability in median time from HIV diagnosis to VS by PHA to inform public health action. The ADPH reports cases of HIV, including demographic, clinical, and risk characteristics, to CDC's NHSS. Reporting was expanded by law in 2011 to include HIV VL test results. All labs in Alabama are required by state law to report diagnostic tests confirming HIV diagnoses and all VL results, including undetectable VLs, to the ADPH. In addition, community and clinical agencies providing HIV testing services are required to submit case report forms, including sociodemographic data, to the ADPH for persons with newly diagnosed HIV to allow for monitoring of epidemiological trends over time. Trained ADPH staff are responsible for follow-up with community and clinical agencies when there is incomplete data reporting on new HIV cases, in many instances extracting the requisite data from agency medical records to ensure complete data capture. The ADPH transmits statewide HIV surveillance data to the CDC without personal identifiers.

Figure 1. Viral suppression (<200 c/mL) within 12 months of HIV diagnosis and median time to suppression among 1,979 persons with newly diagnosed HIV in Alabama, by Alabama Public Health Area (PHA), 2012-2014.



For these analyses, we used Alabama statewide HIV surveillance data for calendar years 2012 to 2014 reported to CDC through June 2017 on persons with newly diagnosed HIV aged 13 years or older at diagnosis and residing in Alabama. Vital status of patients and VL test results received from diagnosis till December 2015 were used in the analysis. Analyses are presented by age, sex at birth, race/ethnicity, HIV transmission category (male-to-male sexual contact [men who have sex with men, MSM], injection drug use [IDU], both MSM and IDU, heterosexual contact, or other transmission category), HIV stage at diagnosis (stage 3 [AIDS] or not stage 3) [13], year of diagnosis, PHA of diagnosis as determined by resident county at time of diagnosis, and facility where diagnosis occurred. Descriptive statistics were used to describe the study population as well as the number and proportion of persons achieving VS (<200 c/mL) within 12 months of diagnosis according to

sociodemographic, temporal (median times to VS), and geographic variables. Kaplan-Meier approach was used to evaluate proportion without VS and time from HIV diagnosis to VS, defined as the first date with a VL value <200 c/mL. All analyses were conducted using SAS software, version 9.3 (SAS Institute) [14].

As the data for this study was void of personal identifiers and analysis conducted by members of the study team at the CDC in a way that participants cannot be identified, review by an institutional review board was not required.

Results

Among 1979 persons with HIV infection newly diagnosed in Alabama during 2012 to 2014, most were male (1573/1979, 79.48%), black/African American (1382/1979, 69.83%), aged 20 to 29 (840/1979, 42.45%) or 30 to 39 years (20.87%, 413/1979), MSM (1077/1979, 54.42%), and were not in stage 3 (1537/1979, 77.68%), indicative of less-advanced infection [15] (Table 1). Three PHAs collectively accounted for almost 60% of the new HIV cases—PHA04 (511/1979, 25.82%), PHA08 (369/1979, 18.65%), and PHA11 (284/1979, 14.35%)—which include the urban centers of Birmingham, Montgomery, and Mobile, respectively.

Overall, 1181 persons (1181/1979, 59.68%) achieved VS (<200 c/mL) within 12 months of HIV diagnosis. A higher percentage of women (253/406, 62.3%), whites (311/472, 65.9%), or PLWH of other race/ethnicity (not black, white, or Hispanic/Latino) (50/70, 71%), persons aged 30 to 39 (261/413, 63.2%) or 50 to 59 years (124/195, 63.6%), and those with stage 3 disease (311/442, 70.4%) achieved VS within 12 months of HIV diagnosis (Table 1). Notably, 52.6% (353/671) of persons with HIV diagnosed in 2012 achieved VS within 12 months, whereas 59.5% (377/634) of those with HIV diagnosed in 2013 and 66.9% (451/674) of those with HIV diagnosed in 2014 achieved this biomarker of HIV treatment success. Considerable geographic variability was observed; cross-sectional 12-month VS had a range of 45.8% (130/284) to 84% (26/31) across PHAs in the state (Figure 1).

Among persons with HIV infection diagnosed in Alabama between 2012 and 2014, the median time to achieve VS (<200 c/mL) was eight months. Shorter median time to VS was seen in women, whites, and those identified as other race/ethnicity (not black, white, or Hispanic/Latino), persons over the age of 30 years, those with HIV attributed to IDU or heterosexual contact, and persons with stage 3 disease (all groups ≤7 months; Table 1). Compared with persons with HIV diagnosed in 2012 who achieved VS in a median of 10 months, those with HIV diagnosed in 2013 required a median of eight months, and those diagnosed in 2014 required a median of six months to achieve this HIV biomarker (Figure 2). Considerable heterogeneity was observed in the median time from HIV diagnosis to VS across Alabama's PHAs, with the exception of PHA03 and PHA11 (Table 1 and Figure 3). The median time of 13 months in these 2 PHAs is considerably higher than 5 to 8 months in the other nine PHAs. PHA03 (including the Tuscaloosa metropolitan statistical area, MSA) and PHA11 (including the Mobile MSA) include more populous regions of the state. In contrast, PHA07, which includes a mostly rural, less-resourced area within Alabama's Black Belt, had the shortest median time from HIV diagnosis to VS, that is, five months.

Table 1. Viral suppression among 1979 persons with newly diagnosed HIV aged 13 years and older in Alabama, 2012 to 2014.

Characteristic	Total, n (%)	VS[a] within 12 months, n (%)	Median time to VS (95% CI), months[b]
Overall	1979 (100)	1181 (59.7)	8 (7-8)
Sex			
Male	1573 (79.5)	928 (59.0)	8 (8-9)
Female	406 (20.5)	253 (62.3)	7 (6-8)
Race			
Hispanic/Latino	55 (2.8)	31 (56.4)	11 (5-14)
Black	1382 (69.8)	789 (57.1)	9 (8-10)
White	472 (23.9)	311 (65.9)	7 (6-7)
Other	70 (3.5)	50 (71.4)	6 (5-8)
Age at diagnosis (years)			
13-19	120 (6.1)	69 (57.5)	9 (7-13)
20-29	840 (42.4)	486 (57.9)	9 (8-10)
30-39	413 (20.9)	261 (63.2)	7 (6-8)
40-49	318 (16.1)	195 (61.3)	7 (6-9)
50-59	195 (9.9)	124 (63.6)	7 (6-8)
60+	93 (4.7)	46 (49.5)	7 (5-13)
Transmission category			
Male-to-male sexual contact	1077 (54.4)	671 (62.3)	8 (7-9)
Injection drug use (IDU)	38 (1.9)	25 (65.8)	7 (5-16)
Male-to-male sexual contact and IDU	24 (1.2)	10 (41.7)	16.5 (7[c])
Heterosexual contact	232 (11.7)	145 (62.5)	7 (6-9)
Other	608 (30.7)	330 (54.3)	8 (7-10)
HIV stage at diagnosis			
Not stage 3	1537 (77.7)	870 (56.6)	9 (8-10)
Stage 3	442 (22.3)	311 (70.4)	6 (5-6)
Year of diagnosis			
2012	671 (33.9)	353 (52.6)	10 (9-13)
2013	634 (32.0)	377 (59.5)	8 (8-10)
2014	674 (34.1)	451 (66.9)	6 (5-7)
Public Health Area (PHA)			
PHA01	31 (1.6)	26 (83.9)	6 (4-8)
PHA02	177 (8.9)	116 (65.5)	7 (6-9)
PHA03	139 (7.0)	68 (48.9)	13 (9-21)
PHA04	511 (25.8)	303 (59.3)	8 (7-10)
PHA05	98 (5.0)	69 (70.4)	7 (5-9)
PHA06	104 (5.3)	73 (70.2)	6 (4-6)
PHA07	68 (3.4)	45 (66.2)	5 (5-7)
PHA08	369 (18.6)	233 (63.1)	6 (6-7)
PHA09	89 (4.5)	49 (55.1)	10 (7-14)
PHA10	109 (5.5)	69 (63.3)	6 (5-9)
PHA11	284 (14.4)	130 (45.8)	13 (10-19)

[a]VS: viral suppression.

[b]Median time and 95% CI from diagnosis to the first time of viral suppression during 2012 to 2015.

[c]The upper boundary of the 95% CI for MSM and IDU was missing because its value was beyond the 48 months of the study period from 2012 to 2015.

Figure 2. Kaplan-Meier plots of time from HIV diagnosis date to reported first viral suppression (VS, <200 c/mL) among 1979 persons with newly diagnosed HIV ≥13-years-old in Alabama, 2012-2014, stratified by year of diagnosis.

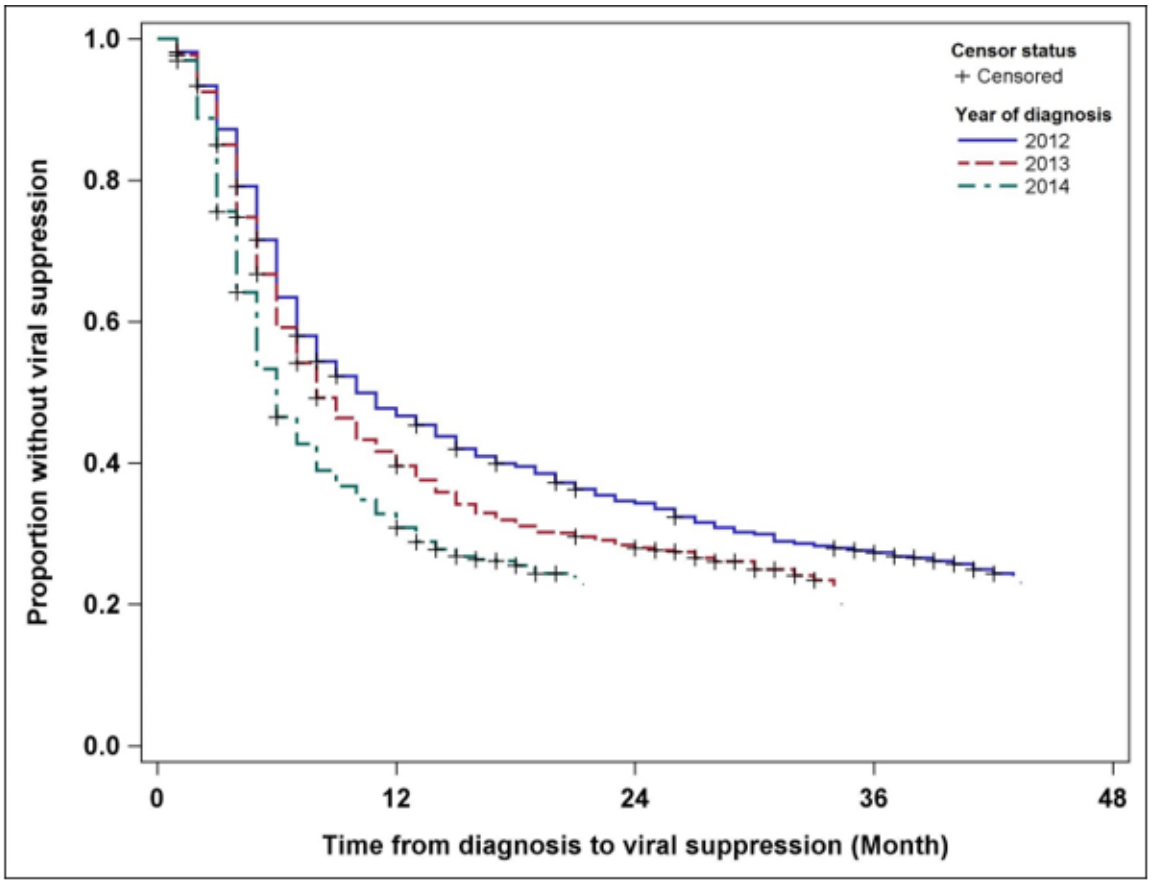
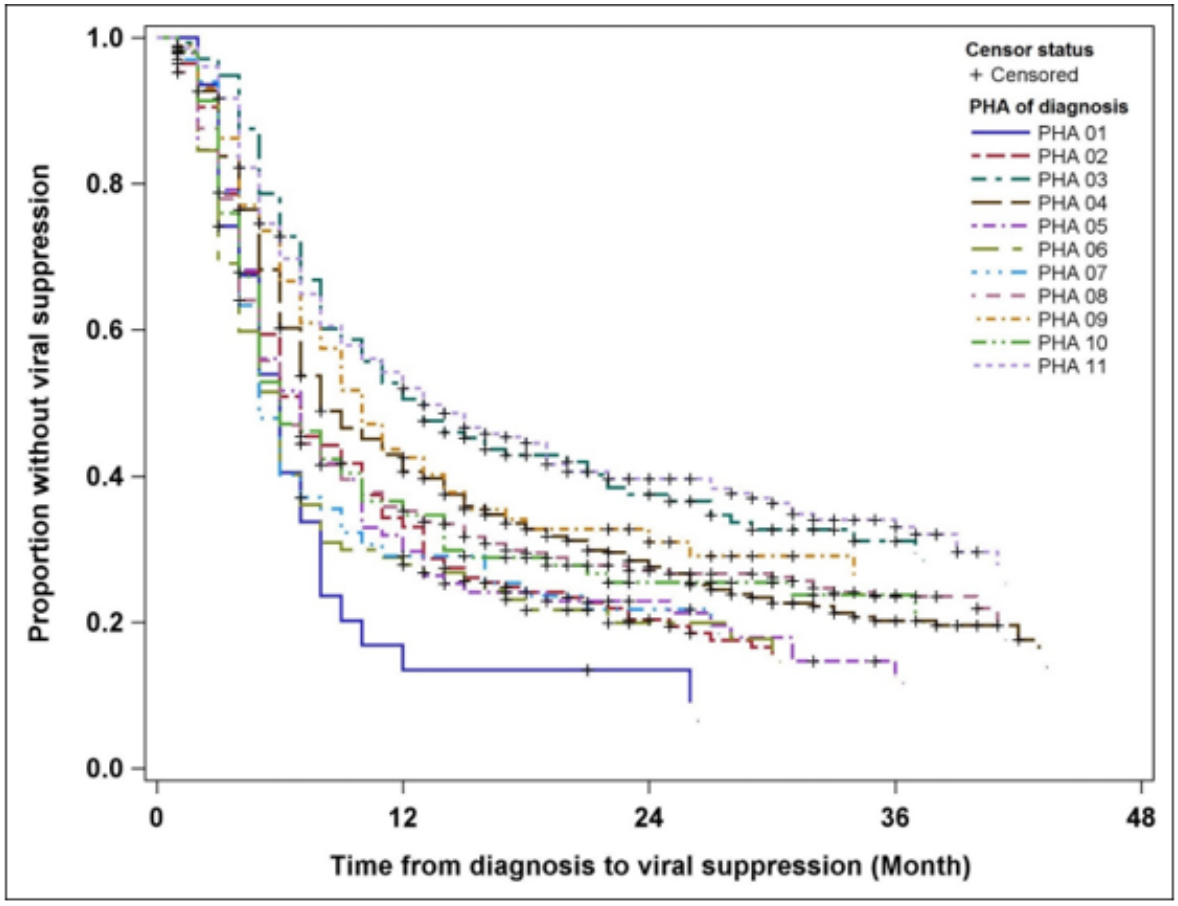


Figure 3. Kaplan-Meier plots of time from HIV diagnosis date to reported first viral suppression (VS, <200 c/mL) among 1979 persons with newly diagnosed HIV ≥13-years-old in Alabama, 2012-2014, stratified by Public Health Area (PHA) of diagnosis.



Discussion

We observed substantial temporal and geographic variability in VS among persons with HIV infection diagnosed in Alabama between 2012 and 2014. Among 1979 persons, 1181 (1181/1979, 59.67%) achieved VS within 12 months of diagnosis; 52.6% (353/671) in 2012, 59.5% (377/634) in 2013, and 66.9% (451/674) in 2014, with a large decrease in the median time from diagnosis to VS from 10 months to six months, from 2012 to 2014. Considerable geographic variability in 12-month VS and median time to VL suppression was seen across Alabama's 11 PHAs. Taken together, these observations highlight the considerable heterogeneity and variability in short-term VS, over time and across geographic spaces that include public health areas and geographic regions, among persons with HIV infection diagnosed in Alabama between 2012 and 2014. In the era of rapid ART start programs, time to VS has become a critical indicator of programmatic success. However, it is well noted that sustained VS is essential to maximize individual health outcomes and the population health benefits of U=U (Undetectable=Untransmittable) [16]. As such, cross-sectional 12-month VS gives some indication of sustained VS beyond the initial time to VS metric. However, other methods of measuring sustained VS clearly have value and are needed to best measure longitudinal VL trajectories and maintenance of VS beyond initial success. We suggest that readily available HIV surveillance data, including the novel time from diagnosis to VS indicator, can be used to inform public health action. This can extend to aid in the evaluation of new and ongoing HIV prevention and treatment initiatives in a community, as well as targeted allocation of limited resources to maximize HIV outcomes.

Temporal trends in Alabama from 2012 to 2014 are encouraging, with a four-month decrease (from 10 months to six months) in the median time to achieve VS. Notably, adoption of changes in HIV treatment guidelines recommending universal ART treatment for all persons living with HIV, as well as the increased uptake of integrase strand inhibitors during the observation period, which have more rapid decline in plasma viremia relative to other antiretrovirals, may contribute to the observed large improvement over a relatively short period of time. Our findings provide proof of concept that there is value in monitoring this surveillance indicator to evaluate temporal variability at a population level, as well as to provide a critical variable for modeling exercises evaluating how variability over time (eg, shorter median time to VS following HIV diagnosis) has population-level impact on new HIV infections. Simulation modeling exercises (eg, Markov modeling and agent-based simulations), as espoused by Skarbinski and colleagues [17], could evaluate the impact of varying median times from diagnosis to VS over time and across geographic areas, accounting for disease prevalence, to estimate how shortening the interval to VS would translate to anticipated new HIV cases. As time elapses and more data are available, time from diagnosis

to VS could be used in population modeling approaches to evaluate the impact of this interval on observed new HIV cases longitudinally and across geographic areas.

Interestingly, we observed that larger municipalities with likely more resources for HIV prevention, treatment, and supportive services did not necessarily have shorter median times from diagnosis to VS. The broad range of five to 13 months to achieve VS among 1979 persons with diagnosed HIV across Alabama's 11 PHAs is a call to action. To understand this variability, further research is needed within each PHA into the services offered and lived experiences of PLWH, traversing the care continuum from initial diagnosis to VS. We posit that a range of factors at various levels grounded in a socioecological framework, from the individual, interpersonal, community, and health care system, will impact individuals' trajectories across the continuum, as measured by time from diagnosis to VS [18]. Potentially salient multilevel factors accounting for the variation found among Alabama PHAs may include those associated with suboptimal adherence to ART, such as poverty [19,20] and neighborhood disorder in the community (eg, crime and drug use) [21]. As adherence is an important step in the HIV care continuum and is necessary for achieving VS [22], it is likely that factors which affect adherence also influence time to VS.

Although not the focus of this study, it is also important to consider some of the racial, structural, and geographic factors in Alabama that affect HIV incidence in the state, as these help to contextualize our findings. Black/African Americans are disproportionately affected by HIV in Alabama: although our study found that 69.8% (1382/1979) of new HIV diagnoses in Alabama between 2012 and 2014 were among black/African American people, just over one-quarter (26.8%) of persons living in Alabama identify as black or African American, according to 2018 estimates [23]. Alabama is also one of 14 states to date that has not expanded Medicaid following implementation of the Affordable Care Act [24], thereby creating a coverage gap whereby people with the lowest incomes, below 138% of the Federal Poverty Level, are ineligible for subsidized health insurance through the Marketplace [25]. Lack of Medicaid expansion has negative implications for HIV health, as being uninsured (and without any other health care assistance, as in from the Ryan White HIV/AIDS Program) is associated with increased odds of viral nonsuppression [26]. In addition, as one of the seven states highlighted in the national "Ending the HIV Epidemic" initiative as having a disproportionate incidence of HIV in rural areas [27], Alabama experiences a high HIV burden in rural regions of the state. Although these contextual factors are important for assessing differences in VS across states, they may also help to illuminate some of the intrastate variation in VS found in our study. For example, a possible reason why the mostly black/African American, rural PHAs in Alabama performed better than some of the other, more metropolitan areas of the state may be because of racial segregation, which is common in most Alabama cities. As racial discrimination has been linked to suboptimal ART adherence [28], racial segregation and resultant racial discrimination may help to explain this finding.

As this study exemplifies, it is imperative to gain a better understanding of shared and unique factors across geography to identify the most salient barriers and facilitators, as well as best practices, to emulate toward efforts of expediting the time to VS following HIV diagnosis for all persons, regardless of geography. This oversight would also be applicable and beneficial in other states to inform the generalizability of our findings. Such analyses could provide additional insights on shared and discrepant performance of this HIV surveillance indicator, according to a range of factors grounded in a socioecological framework, which could further inform public health action and resource allocation.

In recent years, increased attention has focused on reducing the time from initial HIV diagnosis to linkage to medical care and ART initiation to achieve better early engagement in HIV medical care and more expeditious VS [29]. Notably, there are often numerous agencies that interact with an individual across the HIV prevention and treatment continua. CBOs and public health departments tend to offer extensive HIV testing as well as other prevention and supportive services. High-impact prevention activities, as defined by the CDC as evidence-based, have expanded in many instances to include linkage to care and ART adherence programs, affecting subsequent steps on the care continuum. Evidence informed activities, such as the Data to Care initiative to use surveillance data to identify out-of-care PLWH and link them to care, are also important for helping PLWH move through steps of the HIV care continuum [30]. On-going attendance and retention in medical care is also needed to optimize sustained ART receipt to achieve VS. Rather than evaluating individual steps along the HIV care continuum, time from diagnosis to VS is a surveillance indicator that captures the successful, expeditious traverse through the care continuum as a result of the collective efforts between numerous agencies. As such, the performance of this indicator may represent the effectiveness of the response and delivery of services within a community or geographic area. However, we suggest these data can provide an objective measure that can be tracked over time to assess, in part, the effectiveness of linkage to care and treatment services affecting the disease locally. The results of several recent trials in urban domestic and international settings have indicated that rapid ART initiation, including starting ART on the same day as HIV diagnosis, shows promise in improving patient and programmatic outcomes, including improved linkage to care, early retention in care, and, indeed, shorter time to VS [29,31,32]. As suggested earlier, a more detailed understanding of an individual's experience traversing the care continuum within a geographic area, such as within each PHA in Alabama, is essential to inform our interpretation of the widespread variability in VS by place and to guide a more efficient and effective statewide coordinated HIV plan.

Limitations of our study include the potential for underreporting of VL values that could impact the time from HIV diagnosis to VS. However, we note that widespread efforts from the ADPH to monitor laboratory reporting and provide feedback as well as technical assistance would negate impact on study findings. Furthermore, we were only able to observe persons with HIV diagnosed over a three-year period from 2012 to 2014 because of the relatively new implementation of HIV biomarker reporting in our state and the required lags for data reporting. However, temporal improvement was still observed and lends

to this surveillance indicator being a useful tool to monitor efficacy of community-level programs. In addition, its application in other states and jurisdictions will allow for more mature and robust reporting through the National HIV Surveillance System. It was beyond the scope of this study to further explore other factors that may have been associated with the geographic heterogeneity seen, including locally coordinated high-impact prevention efforts, barriers to and facilitators of primary medical care access, and the lived experiences of individuals with diagnosed HIV, especially as these are affected by HIV-related stigma. These will be critical areas for future research. As the focus of our study was on temporal and geographic variability, we did not control for sociodemographic differences in assessing VS within 12 months and median time to VS. Future research should account for individual-level variation. In addition, future research should assess whether these differences in VS across Alabama PHAs represent durable patterns or vary over time.

Public Health Implications

We describe the application of a novel HIV surveillance indicator, time from HIV diagnosis to VS, which is readily captured from data that are reported to state health departments and the CDC. The temporal and geographic variability in this HIV surveillance indicator among persons with HIV diagnosed in Alabama between 2012 and 2014 provides proof of concept of how incorporation of this metric could inform public health practice within jurisdictions, states, and geographic regions in the United States. This novel surveillance indicator, spanning the steps of the HIV care continuum from testing to VS, represents a composite measure of the effectiveness of HIV prevention, treatment, and supportive service provision within a locale and can be used to measure trends over time and across geographic territory. Further research, grounded in a socioecological framework, exploring individual and contextual factors that may contribute to heterogeneity seen in this study, is essential to inform and to guide a tailored public health plan to maximize population health impact.

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Conflicts of Interest

None declared.

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Abbreviations

ADPH: Alabama Department of Public Health
ART: antiretroviral therapy

CBOs: community-based organizations
CDC: Centers for Disease Control and Prevention
IDU: injection drug use
MSM: men who have sex with men
NHSS: National HIV Surveillance System
PHA: public health area
PLWH: people living with HIV
VL: viral load
VS: viral suppression

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Original Paper

Rates and Correlates of HIV Incidence in Namibia's Zambezi Region From 2014 to 2016: Sentinel, Community-Based Cohort Study

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Abstract

Background: Direct measures of HIV incidence are needed to assess the population-level impact of prevention programs but are scarcely available in the subnational epidemic hotspots of sub-Saharan Africa. We created a sentinel HIV incidence cohort within a community-based program that provided home-based HIV testing to all residents of Namibia's Zambezi region, where approximately 24% of the adult population was estimated to be living with HIV.

Objective: The aim of this study was to estimate HIV incidence, detect correlates of HIV acquisition, and assess the feasibility of the sentinel, community-based approach to HIV incidence surveillance in a subnational epidemic hotspot.

Methods: Following the program's initial home-based testing (December 2014-July 2015), we purposefully selected 10 clusters of 60 to 70 households each and invited residents who were HIV negative and aged ≥15 years to participate in the cohort. Consenting participants completed behavioral interviews and a second HIV test approximately 1 year later (March-September 2016). We used Poisson models to calculate HIV incidence rates between baseline and follow-up and multivariable Cox proportional hazard models to assess the correlates of seroconversion.

Results: Among 1742 HIV-negative participants, 1624 (93.23%) completed follow-up. We observed 26 seroconversions in 1954 person-years (PY) of follow-up, equating to an overall incidence rate of 1.33 per 100 PY (95% CI 0.91-1.95). Among women, the incidence was 1.55 per 100 PY (95% CI 1.12-2.17) and significantly higher among those aged 15 to 24 years and residing in rural areas (adjusted hazard ratio [aHR] 4.26, 95% CI 1.39-13.13; *P*=.01), residing in the Ngweze suburb of Katima Mulilo city (aHR 2.34, 95% CI 1.25-4.40; *P*=.01), who had no prior HIV testing in the year before cohort enrollment (aHR 3.38, 95% CI 1.04-10.95; *P*=.05), and who had engaged in transactional sex (aHR 17.64, 95% CI 2.88-108.14; *P*=.02). Among men, HIV incidence was 1.05 per 100 PY (95% CI 0.54-2.31) and significantly higher among those aged 40 to 44 years (aHR 13.04, 95% CI 5.98-28.41; *P*<.001) and had sought HIV testing outside the study between baseline and follow-up (aHR 8.28, 95% CI 1.39-49.38; *P*=.02). No seroconversions occurred among persons with HIV-positive partners on antiretroviral treatment.

Conclusions: Nearly three decades into Namibia's generalized HIV epidemic, these are the first estimates of HIV incidence for its highest prevalence region. By creating a sentinel incidence cohort from the infrastructure of an existing community-based testing program, we were able to characterize current transmission patterns, corroborate known risk factors for HIV acquisition, and provide insight into the efficacy of prevention interventions in a subnational epidemic hotspot. This study demonstrates an efficient and scalable framework for longitudinal HIV incidence surveillance that can be implemented in diverse sentinel sites and populations.

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KEYWORDS

HIV; incidence; risk factors; sentinel surveillance; longitudinal studies; cohort studies

Introduction

Background

Namibia has a generalized epidemic with 237,000 adults (13.3%) living with HIV [1]. The prevalence varies by geography, ranging from 7.3% in the Omaheke region to 23.7% in the Zambezi region [2]. Namibia's epidemic response is robust. The number of people living with HIV (PLHIV) on antiretroviral treatment (ART) increased from 10,200 in 2004 [3] to 166,000 in 2016 [4]. By 2022, Namibia seeks to reduce new HIV infections by 75% through scaling-up evidence-based interventions such as medical male circumcision, viral suppression through ART for all PLHIV, and pre-exposure prophylaxis (PrEP) in high-burden regions [5].

Namibia, like most countries with generalized epidemics, has limited ability to assess the impact of prevention interventions and monitor HIV incidence over time. The gold standard for measuring HIV incidence is a longitudinal cohort study, which entails enrolling persons uninfected at baseline and following them over time with repeated testing to detect acquisition of infection. Owing to the perceived high cost and logistical complexity, few surveillance cohort studies have been conducted around the world in recent years [6-10]. Alternative approaches to estimate incidence, including mathematical models [11-13] and assays for recent infection [14], are available. However, models depend on assumptions that are difficult to prove, do not establish causality, and are imprecise at subnational levels. Assays for recent infections have multiple sources of variability, which necessitate large sample sizes and correction factors [14].

A pragmatic method for tracking HIV incidence may be found in the sentinel approach to surveillance [15,16], which involves using data from selected clinics, facilities, or programs. The program's clientele, while not necessarily representative of everyone at risk, is held to reflect changes in the epidemic in the surrounding population. Community-based HIV testing programs, now common in many regions of sub-Saharan Africa, may provide a platform for sentinel incidence surveillance [17,18]. Home, mobile, workplace, and school-based programs can increase testing in populations, including repeat testing, by removing social and logistical barriers associated with testing at facilities [19-21]. Therefore, the basic infrastructure for longitudinal sentinel incidence surveillance may already be present in certain high-prevalence areas.

Objectives

We conducted a sentinel HIV incidence cohort study by adding behavioral measurements and repeated testing to an existing community-based program offering home testing in Namibia's Zambezi region. Our objectives were to estimate HIV incidence, detect new or confirm known risk and preventive factors for HIV acquisition, and assess the feasibility of the sentinel approach to HIV incidence surveillance in a subnational epidemic hotspot.

Methods

Study Setting and Design

The study was a prospective cohort implemented in households in Namibia's Zambezi region, situated in the northeast bordering Angola, Botswana, Zambia, and Zimbabwe. Zambezi was chosen because it has the highest prevalence of HIV in the country (23.7%) [2]. Additionally, a community-based program, Total Control of the Epidemic (TCE), initiated HIV testing and case management for residents of all households in the Zambezi region (20,603 people, 2011 Census) in 2014. TCE's home-based program entailed HIV testing and prevention plans focusing on abstinence, being faithful to 1 partner, condom use, medical male circumcision, repeated testing every 6 to 12 months, and referrals to ART with case management for HIV-positive clients.

TCE mapped all households in the Zambezi region and divided them into 60 programmatic *fields*, each composed of 6 to 7 geographically contiguous clusters of 60 to 70 households. We selected 1 cluster from each of the 10 fields to include in the sentinel incidence cohort. Clusters were purposively selected to include urban or rural areas of varying distance from the regional capital (Katima Mulilo). Adjacent clusters were paired to form 5 study *sites*. All households in the sites were eligible for the study. Cohort activities were integrated into the routine activities of TCE's program as they worked on these sites. The cohort aimed to enroll and complete a 1-year follow-up of 1500 persons to obtain reasonably precise HIV incidence estimates and sufficient power to identify strong correlates of seroconversion.

Recruitment and Procedures

TCE staff approached all households in the sites to offer home-based HIV testing to all residents from December 2015 to July 2016. Residents were identified by the head of the household and assigned unique testing codes. GPS coordinates

were recorded at each household to facilitate household identification. Residents aged ≥15 years who received the TCE program were invited to complete a baseline interview. Clients who tested negative for HIV were invited to participate in the cohort.

Data on exposure to prevention interventions (eg, HIV testing outside the study, ART use in serodiscordant partnerships, and medical male circumcision), HIV-related risk and preventive behaviors (eg, multiple partners and transactional sex), and demographic characteristics (eg, sex, age, and marital status) were obtained in face-to-face interviews.

Rapid HIV testing was done in the participant's household by TCE staff following the national parallel algorithm, including Alere Determine HIV-1/2 (Abbott Diagnostic Division) and Uni-Gold Recombigen HIV-1/2 (Trinity Biotech) with Clearview Complete HIV-1/2 (Inverness Medical) to resolve discrepant results. Results from the rapid testing algorithm were immediately returned to participants with posttest counseling.

TCE staff collected dried blood spot (DBS) specimens from participants by finger prick on Whatman 903 filter paper. DBS were dried and packaged according to the manufacturer's instructions and shipped weekly to the National Institute of Pathology reference laboratory in Windhoek and stored at −70°C to −80°C. A fourth-generation enzyme-linked immunosorbent assay (Vironostika Uniform II bioMérieux-Diagnostics) was used on DBS for quality assurance to confirm every 10th HIV-negative and all HIV-positive rapid test results at baseline and follow-up. Quality assurance results were not returned to the participants. Additional quality assurance was performed according to national standards, including proficiency panels for counselors throughout the study.

Cohort participants were recontacted approximately 12 months after enrollment to complete a follow-up interview and HIV test using the same procedures.

Statistical Analysis

Proportions and 95% CIs were calculated to describe the characteristics of the cohort. We used baseline interview data for demographic characteristics, prior testing history, partner's HIV status, and male circumcision. We used follow-up interview data for variables that may have changed from baseline to follow-up, including seeking testing for HIV outside of the study, transactional sex, sex with partners residing outside of the study sites, condom use, and multiple sex partners. We used generalized linear models to assess baseline correlates of cohort participation and completion of follow-up.

Rates of HIV incidence were calculated as the number of seroconversions per 100 person-years (PY) of follow-up. PY was calculated as the number of days between baseline and follow-up/365 for participants who did not seroconvert and one-half the number of days between baseline and follow-up/365 for participants who seroconverted, which is a commonly used technique when the exact date of seroconversion is unknown [7,22,23]. To account for possible dependence among participants in the selected field sites, we used the *field* variable to calculate cluster-robust 95% CI for incidence rates [24], except when a variable's strata contained 1 or no seroconversions. For these cases, the exact 1- or 2-sided Poisson CI was calculated. We used Cox models to assess potential correlates of HIV seroconversion. Since patterns of intergenerational heterosexual transmission resulting in a higher HIV incidence among young women and older men have been observed elsewhere in sub-Saharan Africa, along with different risk factors for HIV infection prevailing for men and women [1,8,9,25], we modeled data among men and women separately. Variables that had zero seroconversions or failed to meet the proportional hazard assumption were excluded. Variables that produced *P* values <.10 in the bivariate models were included in the initial multivariable models. We used the variance inflation factor with Stata's *vif* command to assess the potential for multicollinearity of variables [26]. Any variable with a variance inflation factor greater than 10 was excluded from the multivariable model. Variables with $P<.05$ in the final models were considered significant. The risk of seroconversion was expressed as adjusted hazard ratios (aHR). The analysis was performed using Stata version 12.1 (StataCorp).

Ethical Information

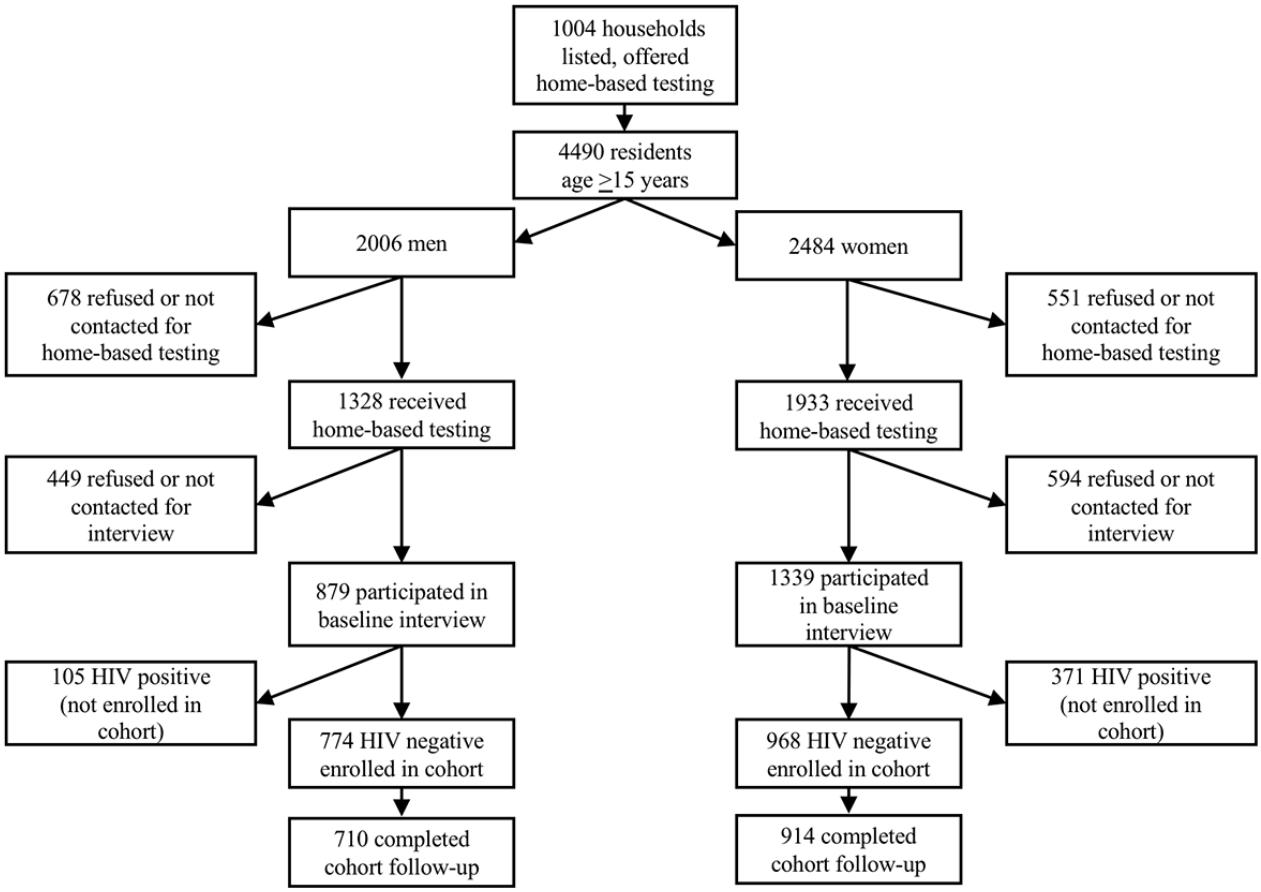
Participants gave verbal informed consent at baseline and again at follow-up. Participants aged 15 to 17 years gave their assent and were required to have consent from a parent or guardian. No monetary or material incentives were provided. The study was approved by the Institutional Review Boards of the Ministry of Health and Social Services in Namibia and the University of California, San Francisco. The study was reviewed in accordance with the Centers for Disease Control and Prevention (CDC) human research protection procedures and determined to be research, although CDC investigators did not interact with human subjects or have access to identifiable data or specimens for research purposes. All procedures were implemented in accordance with the ethical standards of the abovementioned ethics committees and the Helsinki Declaration of 1975, as revised in 2000.

Results

Participation and Retention

The TCE program offered home-based testing to 1004 households across the 5 sites (Figure 1). Among persons aged ≥15 years residing in these households, 72.63% (3261/4490) received home-based testing, of whom 68.02% (2218/3261) completed the baseline interview. Among HIV-negative persons who participated in the baseline interview, 93.2% (1624/1742) completed the follow-up HIV test and interview. The median follow-up time was 433 days (IQR 397-478), which was notably higher than the intended follow-up time of 365 days. There were no significant differences in follow-up time by age, sex, or urban vs rural sites. Women were more likely than men to receive home-based testing, agree to the baseline interview, and be retained for follow-up.

Figure 1. Flow diagram of household listing, receipt of home-based HIV testing, participation in the cohort study and follow-up measurements among adults age ≥ 15 years in five community-based sites of the Zambezi region of Namibia, 2014-2016.



Description of Cohort Participants

Demographic characteristics and HIV-related risk behaviors of the cohort participants who completed the follow-up are shown in Table 1. Young women aged 15 to 24 years comprised 43.6% (398/914) of female participants, 25.2% (230/914) lived in the urban Ngweze site, 65.5% (599/914) had not tested for HIV in the 12 months before baseline, and 0.9% (8/914) had engaged in transactional sex in the 12 months before baseline. Key characteristics among men were 5.9% (42/710) being aged 40 to 44 years, 11.1% (79/710) seeking HIV testing outside the study in the year before follow-up (ie, in addition to the testing provided by the study), and 4.6% (32/710) self-reporting circumcision before baseline. Among HIV-negative participants who tested with their partner, 8.6% (40/463) had an HIV-positive partner, of whom 28% (11/40) were on ART. Quality assurance through retesting DBS from baseline and follow-up participants detected no misclassification of serostatus. All counselors scored 100% on the rapid testing proficiency panels during the study.

Table 1. Demographic and behavioral characteristics of HIV-negative participants who completed baseline and follow-up measurements—household cohort study of adults aged ≥15 years in the Zambezi region of Namibia, 2014 to 2016 (N=1624).

Variable	Total, n (%)	Women (n=914), n (%)	Men (n=710), n (%)
Age (years)[a]			
15-19	301 (18.53)	176 (19.3)	125 (17.6)
20-24	379 (23.34)	222 (24.3)	157 (22.1)
25-29	253 (15.58)	134 (14.7)	119 (16.8)
30-34	195 (12.01)	107 (11.7)	88 (12.4)
35-39	152 (9.36)	69 (7.5)	83 (11.7)
40-44	92 (5.67)	50 (5.5)	42 (5.9)
45-49	63 (3.88)	30 (3.3)	33 (4.6)
50-64	189 (11.64)	126 (13.8)	63 (8.9)
Site[a]			
Ngweze urban	384 (23.65)	230 (25.2)	154 (21.7)
Mavuluma urban	356 (21.92)	217 (23.7)	139 (19.6)
Bukalo rural	368 (22.66)	175 (19.1)	193 (27.2)
Ngoma rural	201 (12.38)	101 (11.1)	100 (14.1)
Sibbinda rural	315 (19.40)	191 (20.9)	124 (17.5)
Residence[a]			
Rural	887 (54.62)	468 (51.2)	419 (59.0)
Urban	737 (45.38)	446 (48.8)	291 (41.0)
Age (years) and residence[a]			
15-24, rural	328 (20.20)	169 (18.5)	159 (22.4)
15-24, urban	354 (21.80)	229 (25.1)	125 (17.6)
≥25, rural	559 (34.42)	299 (32.7)	260 (36.6)
≥25, urban	383 (23.58)	217 (23.7)	166 (23.4)
Currently married[a]	644 (39.66)	381 (41.7)	263 (37.0)
Tested for HIV in the 12 months before enrollment[a]	485 (29.86)	315 (34.5)	170 (23.9)
Tested with a partner at enrollment[a]	463 (28.51)	264 (28.9)	199 (28.0)
Had a serodiscordant positive partner (among those tested with a partner at enrollment)[a]	40 (8.6)	13 (4.9)	27 (13.6)
Partner on antiretroviral treatment (among those with serodiscordant positive testing partner)[a,b]	11 (27.5)	4 (30.8)	7 (25.9)
Circumcised (among men only)[a]	N/A[c]	N/A	32 (4.6)
Sought HIV testing outside the study in past 12 months[d]	212 (13.05)	133 (14.6)	79 (11.1)
Had sex partner residing outside study area in the past 12 months[b,d]	144 (11.70)	84 (12.4)	60 (10.8)
Engaged in transactional sex in the past 12 months[d]	44 (2.71)	8 (0.9)	36 (5.1)
Used a condom at the last sexual encounter[b,d]	677 (54.82)	381 (56.0)	296 (53.3)
Used condoms consistently with all sex partners in past the 12 months[b,d]	119 (9.64)	58 (8.5)	61 (11.0)
Had multiple sex partners in the past 12 months[d]	38 (2.34)	12 (1.3)	26 (3.7)

[a]Data collected at baseline.

[b]Among participants who reported having any sex partners between baseline and follow-up (n=1235, including 680 women and 555 men).

[c]N/A: not applicable.

[d]Data collected at follow-up.

Rates of HIV Incidence

There were 26 seroconversions in 1954 PY among the 1624 baseline HIV-negative participants who completed the follow-up (Table 2), equating to an overall incidence rate of 1.33 per 100 PY (95% CI 0.91-1.95). When pooled across age groups, the overall incidence was not significantly higher for women (1.55 per 100 PY, 95% CI 1.12-2.17; *P*=.26) relative to men (1.05 per 100 PY, 95% CI 0.54-2.31). Among women, most seroconversions occurred in the younger age groups, with 10 out of 17 among women aged 15 to 24 years and 5 among those aged 15 to 19 years (2.42 per 100 PY, 95% CI 0.97-7.34). Among men, the incidence was highest among those aged 40 to 44 years (8.21 per 100 PY, 95% CI 3.76-21.14). When participants were grouped into 8 demographic categories by sex, age (15-24 vs 25 and above), and residence (urban vs rural; Table 2 and Figure 2), the highest incidence was among rural adolescent girls and young women (AGYW) aged 15 to 24 years (3.59 per 100 PY, 95% CI 1.60-8.69). Rural, older men (>25 years) had the second highest incidence (1.93 per 100 PY, 95% CI 0.94-5.01). No seroconversions occurred among men who self-reported being circumcised at baseline (0 per 100 PY, 97.5% CI 0-9.78). No seroconversions occurred among women (0 per 100 PY, 97.5% CI 0-80.02) or men (0 per 100 PY, 97.5% CI 0-45.26) who had an HIV-positive partner on ART.

Table 2. HIV incidence per 100 person-years by sex and demographic and behavioral characteristics—household cohort study of adults aged ≥15 years in the Zambezi region of Namibia, 2014 to 2016 (N=1624).

Variable	Women			Men		
	Incident infections	Rate per 100 person, years (CI)[a]	*P* value	Incident infections	Rate per 100 person, years (CI)	*P* value
Overall	17	1.55 (1.12-2.17)	.29	9	1.05 (0.54-2.31)	Ref[b]
Age (years)[c]						
15-19	5	2.42 (0.97-7.34)	.42	0	0.00 (0.00-2.44)	—[d]
20-24	5	1.88 (1.05-3.57)	.68	1	0.53 (0.01-2.93)	Ref
25-29	2	1.23 (0.31-8.52)	Ref	1	0.69 (0.02-3.87)	.80
30-34	4	3.09 (1.68-6.61)	.40	2	1.86 (0.50-12.51)	.25
35-39	0	0.00 (0.00-4.53)	—	1	1.00 (0.03-5.57)	.60
40-44	0	0.00 (0.00-6.25)	—	4	8.21 (3.76-21.14)	<.001
45-49	1	2.89 (0.07-16.10)	.61	0	0.00 (0.00-9.23)	—
50-64	0	0.00 (0.00-2.34)	—	0	0.00 (0.00-4.95)	—
Currently married[c]						
No	14	2.20 (1.38-3.49)	.03	6	1.12 (0.49-2.87)	.79
Yes	3	0.65 (0.25-2.21)	Ref	3	0.94 (0.38-3.08)	Ref
Site[c]						
Ngweze urban	5	1.88 (1.23-3.02)	<.001	1	0.58 (0.01-3.21)	Ref
Mavuluma urban	3	1.17 (0.41-3.86)	Ref	2	1.29 (0.16-4.64)	.75
Bukalo rural	3	1.47 (0.41-5.40)	.36	3	1.31 (0.27-3.84)	.58
Ngoma rural	2	1.59 (1.46-1.76)	.005	2	1.61 (1.34-1.96)	.34
Sibbinda rural	4	1.81 (0.75-5.83)	.11	1	0.70 (0.02-3.89)	.94
Residence[c]						
Rural	9	1.62 (0.99-2.76)	.53	6	1.20 (0.51-3.60)	.54
Urban	8	1.47 (0.91-2.48)	Ref	3	0.85 (0.23-5.36)	Ref
Age (years) and residence[c]						
15-24 and rural	7	3.59 (1.60-8.69)	.04	0	0.00 (0.00-1.94)	—
15-24 and urban	3	1.08 (0.66-1.93)	.58	1	0.65 (0.02-3.64)	Ref
≥25 and rural	2	0.56 (0.14-3.59)	Ref	6	1.93 (0.94-5.01)	.08
≥25 and urban	5	1.88 (0.83-4.92)	.18	2	0.99 (0.31-4.48)	.36
Tested for HIV in the 12 months before enrollment[c]						
No	14	1.97 (1.32-2.95)	.05	5	0.77 (0.32-2.31)	.11
Yes	3	0.78 (0.33-2.41)	Ref	4	1.95 (1.03-4.24)	Ref
Tested with a partner at enrollment[c]						
No	16	2.05 (1.41-2.98)	.05	7	1.15 (0.54-2.75)	.57
Yes	1	0.30 (0.01-1.69)	Ref	2	0.82 (0.22-5.47)	Ref
Had a serodiscordant positive partner (among those tested with a partner)[c]						
No	0	0.00 (0.00-1.18)	—	1	0.47 (0.01-2.63)	Ref
Yes	1	6.82 (0.17-38.01)	Ref	1	3.06 (0.08-17.03)	.23
Partner on antiretroviral therapy (among those with serodiscordant positive partner)[c]						

Variable	Women			Men		
	Incident infections	Rate per 100 person, years (CI)[a]	*P* value	Incident infections	Rate per 100 person, years (CI)	*P* value
No	1	9.94 (0.25-55.38)	Ref	1	4.07 (0.10-22.68)	Ref
Yes	0	0.00 (0.00-80.02)	—	0	0.00 (0.00-45.26)	—
Circumcised (among men only)[c]						
No	N/A[e]	N/A	—	9	1.13 (0.58-2.49)	Ref
Yes	N/A	N/A	—	0	0.00 (0.00-9.78)	—
Sought testing for HIV outside the study in past 12 months[f]						
No	11	1.17 (0.68-2.12)	.14	4	0.53 (0.17-2.42)	.03
Yes	6	3.72 (1.64-9.27)	Ref	5	5.23 (1.99-16.65)	Ref
Had a sex partner residing outside of study area in past 12 months[f]						
No	13	1.82 (1.31-2.57)	.13	4	0.67 (0.30-1.73)	.05
Yes	3	2.98 (1.62-6.71)	Ref	2	2.79 (0.34-10.07)	Ref
Engaged in transactional sex in the past 12 months[f]						
No	15	1.38 (0.88-2.24)	.01	9	1.11 (0.55-2.51)	Ref
Yes	2	22.75 (3.79-100)	Ref	0	0.00 (0.00-8.52)	—
Used a condom at the last sexual encounter[c]						
No	9	2.52 (1.15-5.08)	.37	1	0.32 (0.08-1.76)	.23
Yes	7	1.53 (0.84-3.03)	Ref	5	1.41 (0.45-7.42)	Ref
Used condoms consistently with all sex partners in the past 12 months[f]						
No	14	1.88 (1.45-2.48)	.98	7	1.21 (0.62-2.72)	.64
Yes	2	2.82 (0.67-20.52)	Ref	1	0.87 (0.02-4.60)	Ref
Had multiple sex partners in the past 12 months[f]						
No	15	1.38 (0.89-2.25)	.02	9	1.09 (0.56-2.41)	Ref
Yes	2	14.78 (3.81-94.41)	Ref	0	0.00 (0.00-12.07)	—

[a]CIs are cluster-robust unless there are 1 or 0 seroconversions, in which case the CI is Poisson exact. CI is 2-sided 95% except when there are 0 seroconversions, in which cases CI is 1-sided 97.5%.

[b]*Ref* is the reference group for Cox models.

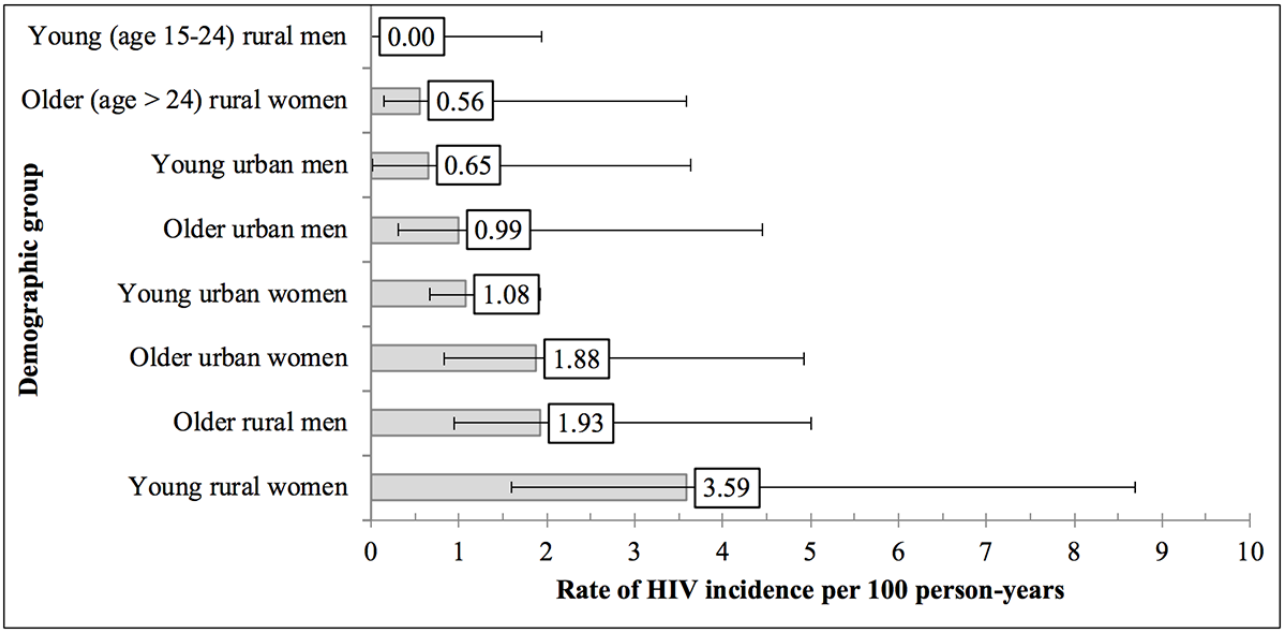
[c]Data collected at baseline.

[d]*P* values were not calculated when there were 0 seroconversions.

[e]N/A: not applicable.

[f]Data collected at follow-up.

Figure 2. HIV incidence per 100 person-years by age, residence, and sex; household cohort of adults age ≥ 15 years in the Zambezi region of Namibia, 2014-2016 (N=1624). Error bars in the figure represent two-sided 95% CI, except when there were 0 seroconversions, in which case CI are one-sided and 97.5%.



Correlates of HIV Incidence

In the multivariable model for women (Table 3), factors associated with increased risk for seroconversion were AGYW residing in rural sites vs other women (aHR 4.26, 95% CI 1.39-13.13; *P*=.01), residing in the Ngweze urban site vs other sites (aHR 2.34, 95% CI 1.25-4.40; *P*=.01), not testing for HIV in the 12 months preceding baseline vs testing (aHR 3.38, 95% CI 1.04-10.95, *P*=.05), and engaging in transactional sex vs no transactional sex (aHR 17.64, 95% CI 2.88-108.14; *P*=.02). In the multivariable model for men, the risk of seroconversion was higher among those aged 40 to 44 years relative to other age groups (aHR 13.04, 95% CI 5.98-28.41; *P*<.001). Men who sought HIV testing between baseline and follow-up outside of the study also had a higher risk for seroconversion than men who had not sought testing between baseline and follow-up (aHR 8.28, 95% CI 1.39-49.38; *P*=.02). No multicollinearity among the variables in the models was observed.

Table 3. Correlates of HIV seroconversion among women and men, multivariable Cox proportional hazards models, and household cohort study of adults aged ≥15 years in the Zambezi region of Namibia, 2014 to 2016 (N=1624).

Variable	Full model, adjusted hazards ratio (95% CI)[a]	*P* value	Final model, adjusted hazards ratio (95% CI)[a]	*P* value
Women				
15-24 years old and resident of rural site (vs other age and residential groups)[b]	4.17 (1.37-12.65)	.01	4.26 (1.39- 13.13)	.01
Resident of Ngoma rural (vs residents of other sites)[b]	0.55 (0.05-5.70)	.62	__[c]	—
Resident of Ngweze urban (vs residents of other sites)[b]	2.13 (1.08-4.18)	.03	2.34 (1.25- 4.40)	.01
Not currently married (vs married)[b]	1.34 (0.58-3.07)	.49	—	—
Not tested with partner at enrollment (vs tested with partner)[b]	5.95 (0.65-54.3)	.13	—	—
Not tested for HIV in the 12 months before enrollment (vs tested)[b]	3.12 (0.91-10.68)	.07	3.38 (1.04-10.95)	.05
Engaged in transactional sex (vs did not engage in transactional sex)[d]	10.33 (2.48- 42.95)	.001	17.64 (2.88-108.14)	.02
Had multiple sex partners in the past 12 months (vs did not have multiple partners)[d]	3.17 (0.58-17.48)	.19	—	—
Men				
Age 40-44 years (vs other age groups)[b]	6.90 (2.75-17.34)	<.001	13.04 (5.98-28.41)	<.001
Older and residing in a rural site (vs other age and residential groups)[b]	7.90 (0.65-96.49)	.11	—	—
Sought testing for HIV outside the study in the past 12 months (vs did not seek testing)[d]	35.23 (12.40-100.06)	<.001	8.28 (1.39-49.38)	.02
Had a sex partner residing outside the study area (vs did not have partner outside study area)[d]	2.31 (0.68-7.88)	.18	—	—

[a]All CIs are 2-sided 95% and cluster robust.

[b] Data collected at baseline.

[c]Variables at $P \leq .10$ in the bivariate models (Table 2) were included in the multivariable Cox models. Variables at $P > .10$ in the full model were removed for the final model. Variables at $P < .05$ in the final multivariable models were considered statistically significant.

[d]Data collected at follow-up.

Discussion

Principal Findings

Our longitudinal, sentinel cohort study reports the first directly observed measure of HIV incidence in the adult population of Zambezi, Namibia. Nearly three decades into Namibia's epidemic, this is the first estimate of incidence for its most severely affected region. Our measure of 1.33 per 100 PY, compared with modeled HIV incidence for all Namibia during this period (0.78 per annum) [1], corroborates that Zambezi is a region where higher levels of HIV transmission persist. Our method, which uses an existing community-based testing program, is a replicable framework for sentinel HIV incidence surveillance that can be used in the absence of or supplemental to data obtained from other methods.

We were able to detect significant correlates of HIV seroconversion that can be used to understand the extent to which existing HIV prevention interventions are working and where additional interventions should be delivered. These include where to prioritize the deployment and scale-up of effective biomedical interventions such as enhanced test and treatment strategies and PrEP. AGYW living in rural areas had more than four times the likelihood of acquiring HIV infection compared with other women. HIV incidence among men was highest in the 40- to 44-year-old group and among older men in rural areas. These findings are consistent with a pattern of intergenerational, heterosexual transmission observed across sub-Saharan Africa [1,8,9,25], which may be explained by the early sexual debut in AGYW, harmful gender norms, transactional sex, and income disparities in sexual relationships [25,27]. The latter two hypotheses are supported by our study's observation that transactional sex was a significant predictor of seroconversion, and by the extremely high prevalence observed among female sex workers in a separate cross-sectional study in the Zambezi region [28]. We also observed that men who sought HIV testing outside of the study between baseline and follow-up were more likely to seroconvert, suggesting men who seek frequent testing may be correctly perceiving themselves to be at elevated risk. The finding stood in contrast to women; those who did not have a history of a test before baseline were more likely to seroconvert. Women may be less likely to perceive their risk of infection (eg, their risk is from their husbands' or regular partners' behaviors), highlighting the need for home-based, provider-initiated, or other forms of testing to reach women who do not seek testing on their own. High HIV

incidence was also observed in the Ngweze urban site. Multiple cases within this small neighborhood may suggest that we found a hotspot of transmission, highlighting the potential yield of index client partner tracing for case detection. Alternatively, the high incidence in this neighborhood may be correlated with another factor, in which case area mobile testing may diagnose additional cases. Although we observed no seroconversions among circumcised men and persons whose partners were on ART, the sample sizes were small, and we were unable to test for significance in our models. Future applications of this surveillance method would need to enroll a larger sample to assess whether the population-level prevention effects of these biomedical interventions are consistent with those observed in randomized controlled trials [6,7,29]. In summary, our results point to specific sexual risk and health-seeking behaviors that can be prioritized for enhanced behavioral and biomedical prevention interventions, particularly focusing on the populations and areas in the Zambezi region identified as having a higher incidence.

Comparison With Prior Work

Few recent direct measures of HIV incidence are available from longitudinal studies elsewhere in sub-Saharan Africa. HIV incidence was 2.4 per 100 PY (95% CI 2.00-2.54) in a national population-based cohort in Eswatini from 2010 to 2011 [8], 0.27 per 100 PY (95% CI 0.18-0.35) in a national population-based cohort in Rwanda from 2013 to 2014 [9], 1.11 per 100 PY (95% CI 0.91-1.31) in a regional population-based cohort in Gem, western Kenya from 2006 to 2016 [10], and 0.55 per 100 PY (95% CI 0.45-0.66) in a study in rural Uganda that measured HIV incidence through home-based testing campaigns across two rounds in 2006 and 2008 [22]. The only other longitudinal measure of HIV incidence from Namibia was 2.4 per 100 PY (95% CI 1.9-2.9) in a household-based study in Windhoek from 2007 to 2009 [23], a time when few PLHIV were on ART [1,3]. In an era of working to achieve HIV epidemic control worldwide, more incidence estimates from cohorts such as these are needed to assess prevention efforts and target hotspots of continuing transmission. A longitudinal sentinel incidence surveillance approach similar to ours can strike a balance of efficiency and rigor by leveraging existing HIV testing programs in high-risk areas and populations below the national level.

Strengths and Limitations

Our longitudinal sentinel incidence surveillance study points to moderately high internal validity (eg, the robustness of correlates of HIV acquisition within the sentinel population). Nearly three-fourths (3261/4490, 72.63%) of residents accepted home-based testing by TCE, of whom 68.02% (2218/3261) participated in our cohort. Participation was lower than that observed in the Eswatini (73.8%) [8], western Kenya (82.6%) [10], Rwanda (98.4%) [9], and Windhoek cohorts (88%) [23]. Nonetheless, our retention rate of 93.23% (1624/1742) was comparable with or higher than 41.3% in western Kenya [10], 58.0% in Windhoek [23], 64.4% in rural Uganda [22], 91.7% in Rwanda [9], and 94.4% in Eswatini [8]. Moderate levels of participation and high levels of retention in our cohort led to an overall incidence estimate that was reasonably precise (95% CI 0.91-1.95). However, greater precision and power to detect differences in incidence between subgroups may have been possible if more residents had participated in our cohort.

Although our results are encouraging that sentinel surveillance integrated within existing testing programs can track HIV incidence and demonstrate prevention impact, we recognize limitations. First, the sample size and few incident infections resulted in low precision for HIV incidence in subgroups, low statistical power to detect smaller effects for HIV acquisition, and an increased chance that some correlates may be because of chance. As the incidence is declining in the current era, larger sample sizes are needed to measure the impact of prevention programs. Nonetheless, the sentinel incidence surveillance approach has two advantages for increasing statistical power: purposely choosing populations with high HIV incidence and leveraging programs already testing large numbers of persons at risk. If community-based testing programs are already in place, the sentinel approach can be scaled up to include more sites with minimal additional resources, forming an integrated national system similar to antenatal clinic sentinel surveillance for HIV prevalence [30]. A second limitation is representativeness, affected by the choice of sites and by lower participation for some groups, including men, who are consistently less likely to be tested for HIV than women in settings across Africa [31]. Our incidence estimates and factor analyses among men may be biased if those who participated had different risk profiles than those who did not. Furthermore, men in our study were not asked if they had sex with other men. As such, we were not able to assess behavior among men who have sex with men (MSM) as a potential correlation of seroconversion. Other studies have shown a high prevalence among MSM in Windhoek, but the prevalence is approximately equal among MSM and the general population in less densely populated areas outside the capital [32]. Given that our study setting more closely resembles those less densely populated areas, we believe the potential biases of noninclusion or nonself-identification of MSM in our cohort to be likely low.

By design, we deliberately chose the sentinel population within the most severely affected region of Namibia and purposively selected a limited number of clusters for the sake of efficiency. Unlike the studies in Eswatini [8] and Rwanda [9], our estimates do not extrapolate to the national level. Unfortunately, data on the characteristics of clients reached by the TCE program in nonsampled areas of Zambezi were not available for analysis. Although we assume that the demographic and risk profiles of residents in sampled and nonsampled urban and rural areas across the region are comparable, we were not able to confirm this assumption and its effect on the generalizability of our results. Nonetheless, our sentinel approach produced a precise estimate for a high-priority subnational area. Moreover, the design and intention of the sentinel surveillance approach are to select sites that can provide early signals of changes in the epidemic over person, place, and time. A third limitation is that we depended upon having a large-scale, pre-existing community-based HIV testing program. The TCE program was funded to test the entire Zambezi population using a door-to-door home-based approach, presenting an opportunity to coordinate longitudinal sentinel incidence surveillance across

a defined geographic area with minimal additional resources. The sentinel incidence surveillance approach may require the identification of other programs that conduct repeat HIV testing in defined populations or within consistent catchment areas. Fourth, participation rates in the TCE program and cohort leave room for potential bias with reduced external validity. Finally, the act of counseling and testing for HIV at baseline and the anticipation of follow-up testing may reduce risk behavior and therefore underestimate HIV incidence relative to the surrounding population.

Conclusions

We tested an efficient method to obtain a directly observed, longitudinal measure of HIV incidence in a high-prevalence region of Namibia. Nearly three decades into Namibia's epidemic, this is the first estimate of the incidence for this region. With the achievement of its target sample, high retention, and ability to detect correlates of seroconversion, our approach appears to be a viable community-based surveillance method that could be replicated in other settings serviced by similar testing programs. We believe this approach can strike a reasonable balance between the additional resources required and the ability to generate direct measures of prevention impact. As HIV testing becomes increasingly accessible and frequent, more opportunities to measure incidence through active and passive repeat testing will arise. Longitudinal sentinel incidence surveillance can be integrated into other community-based programs or facilities conducting high numbers of repeat HIV tests, such as antenatal and sexually transmitted infection clinics [16,33,34], and those servicing key populations at high risk for HIV. The hard-won tools to treat and prevent HIV have placed epidemic control and elimination within reach. We need to take every opportunity to demonstrate and ensure that they are working.

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Conflicts of Interest

None declared.

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Abbreviations

AGYW: adolescent girls and young women
aHR: adjusted hazard ratio
ART: antiretroviral treatment
CDC: Centers for Disease Control and Prevention
DBS: dried blood spot
MSM: men who have sex with men
PLHIV: people living with HIV
PrEP: pre-exposure prophylaxis
PY: person-years
TCE: Total Control of the Epidemic

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Original Paper

Participatory Surveillance Based on Crowdsourcing During the Rio 2016 Olympic Games Using the Guardians of Health Platform: Descriptive Study

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Abstract

Background: With the evolution of digital media, areas such as public health are adding new platforms to complement traditional systems of epidemiological surveillance. Participatory surveillance and digital epidemiology have become innovative tools for the construction of epidemiological landscapes with citizens' participation, improving traditional sources of information. Strategies such as these promote the timely detection of warning signs for outbreaks and epidemics in the region.

Objective: This study aims to describe the participatory surveillance platform Guardians of Health, which was used in a project conducted during the 2016 Olympic and Paralympic Games in Rio de Janeiro, Brazil, and officially used by the Brazilian Ministry of Health for the monitoring of outbreaks and epidemics.

Methods: This is a descriptive study carried out using secondary data from Guardians of Health available in a public digital repository. Based on syndromic signals, the information subsidy for decision making by policy makers and health managers becomes more dynamic and assertive. This type of information source can be used as an early route to understand the epidemiological scenario.

Results: The main result of this research was demonstrating the use of the participatory surveillance platform as an additional source of information for the epidemiological surveillance performed in Brazil during a mass gathering. The platform Guardians of Health had 7848 users who generated 12,746 reports about their health status. Among these reports, the following were identified: 161 users with diarrheal syndrome, 68 users with respiratory syndrome, and 145 users with rash syndrome.

Conclusions: It is hoped that epidemiological surveillance professionals, researchers, managers, and workers become aware of, and allow themselves to use, new tools that improve information management for decision making and knowledge production. This way, we may follow the path for a more intelligent, efficient, and pragmatic disease control system.

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KEYWORDS

participatory surveillance; epidemiology; infectious diseases; pandemics; health innovation; digital disease detection; disease surveillance; mobile phone

Introduction

Participatory surveillance has been a reality in many parts of the world, improving traditional health surveillance systems and engaging the population to build epidemiological scenarios [1-8]. The use of mobile devices to improve the data collection, processing, and analysis processes for epidemiology and surveillance has contributed to great advances in public health in the aspects of innovation and digital transformation in this area [9-15]. With the evolution and ubiquity of mobile devices and their operating systems, in addition to increasing digital inclusion and internet connectivity, research and collaborative strategies have been adopted to improve the quality of information generated in health, especially in the understanding of epidemiological patterns [16-18]. Strategies for monitoring respiratory, diarrheal, and rash syndromes due to arboviruses are examples of how to drive digital disease detection platforms to address the production of strategic information for health surveillance based on crowdsourcing in the American, European, African, and Asian continents; some platforms include Flu Near You, Influenza.Net, AfyaData, Vigilant-e, Saúde na Copa, and Guardians of Health [4,19-29]. The use of crowdsource-based platforms has also been observed in foodborne disease surveillance, which has enabled the anticipation of disease outbreak detection and evaluation of policies for food safety, as is the case for the website iwaspoisoned.com [30].

Participatory surveillance systems usually work in similar ways, where the user is able to make a self-report of symptoms periodically. The periodicity varies from daily to weekly frequency. The collected data—symptoms and geolocation—are sent to cloud-computing servers, where data points are processed and analyzed. From the extracted data, epidemiologists, researchers, data scientists, and government agents analyze the information identifying the distribution of people with symptoms during a certain time frame [3]. Usually the approach adopted is syndromic (ie, the data collection is specific for symptoms that make up groups of diseases), thus calibrating the sensitivity and specificity of the systems. Some platforms, such as Saúde na Copa [22], Flu Near You [16], or FluTracking [31], use engagement strategies to ensure the user's adherence for regular participation within the system. In the first example, gamification was used; during the 2014 World Cup, users could play a soccer-themed game, where evolution within the game was conditional on users' health reports. In the second example, nudges, such as referring a friend, showing the number of active users by region, awarding heavy users with badges, push notifications, and email reminders, were used to encourage participation.

Parallel to the advances of participatory surveillance, some health outcomes still need more intelligent and agile monitoring, such as the case of mass gatherings. Mass gatherings are situations involving large numbers of people participating in a specific cause, planned or not, related to leisure, religion, politics, sports, and other reasons [32].

Leal Neto et al [22] pointed out the use of participatory surveillance in mass gatherings for the first time during the 2014 FIFA World Cup, where a mobile app based on crowdsourcing was developed to identify health threats and was officially used by the Brazilian Ministry of Health. With this experience, and with the aim of improvement, a new platform for participatory surveillance in mass gatherings was developed and adopted, this time focusing on the 2016 Olympic Games [8]. Initiatives conducted by other countries during the 2016 Olympic Games were carried out, demonstrating the understanding of the importance of new participatory surveillance approaches using mobile devices to serve as an additional support for traditional health systems [33]. In addition, this work pointed out the relevance of this approach in finding outbreaks in a faster way [34].

This work aims to describe the participatory surveillance platform Guardians of Health, a project conducted during the 2016 Olympic and Paralympic Games in Rio de Janeiro, which is officially used by the Brazilian Ministry of Health for the monitoring of outbreaks and epidemics.

Methods

Overview

Skoll Global Threats Fund and Epitrack, with the support of the Brazilian Ministry of Health and the Pernambuco Research Support Foundation, developed a mobile app, a web app, and a dashboard platform to implement participatory surveillance in Brazil during the 2016 Olympic Games. The Rio de Janeiro-based project also included five other Brazilian cities that hosted events and games related to the 2016 Olympic Games: Manaus, Salvador, São Paulo, Brasilia, and Belo Horizonte. The platform was called Guardiões da Saúde (Guardians of Health in Portuguese). The study period was divided into a pre-event period (March 28-August 4, 2016) and an event and postevent period (August 5-October 26, 2016). The first period aligned with the time when the platform Guardians of Health was officially launched by the Brazilian Ministry of Health. The second period aligned with the occurrence of the 2016 Olympic and Paralympic Games and the 45 days following the Games.

The management structure of the platform worked across multiple centers: a base at the General Coordination of Surveillance and Response to Events of Public Health, Secretariat of Health Surveillance in the Ministry of Health in Brasilia; a base in Washington, DC, USA; and a base for development and support in Recife, Brazil.

When people downloaded the app, they were only considered as users if they agreed with the terms of use and privacy policy, checking a box before they started. The participants gave informed consent when they registered in the app. All participants were volunteers and the study caused no harm to any of them. The whole app was translated into seven languages: English, Spanish, Portuguese, French, Arabic, Chinese, and Russian. For the purpose of this work, we accessed the open data available at the platform's project page on GitHub via Epitrack [35]. This project followed the Brazilian regulation regarding information access and handling, according to the Access to Information law (Law No. 12.527/2011). Since this project was performed by the Brazilian Ministry of Health in a

nonacademic way, submission for ethical clearance was not required. The authors were involved in the system development and deployment, marketing campaigns, and user acquisition; however, the authors did not have access to participant identification or anything that could identify individual users.

System Development

The Guardians of Health platform was composed of three segments: (1) iOS and Android apps, (2) a web app, and (3) a dashboard. The mobile app was developed using the native technology of the respective operating systems: for Android, Java was used; for iOS, Objective-C and Swift were adopted. Users who registered with information about sex, age, and city were motivated daily—by push notification, gamification, and marketing—to report their health condition. Within the options of the report, the user was able to state whether he or she was well (ie, without symptoms) or ill, where the following list of symptoms was shown, asking the user to pick one or more: body pain, headache, joint pain, cough, sore throat, fever, shortness of breath, nausea and/or vomiting, diarrhea, itching, rash, red eyes, and bleeding. The symptoms were strategically defined from a syndromic approach with the purpose of the identification of diarrheal, respiratory, and rash syndromes (see Table 1). For this project, rash syndrome was defined as symptoms related to arboviruses—dengue, Zika, and chikungunya—and the rash (ie, exanthema) symptom was necessary. For diarrheal syndrome, the diarrhea symptom was mandatory. For respiratory syndrome, cough and fever were mandatory symptoms.

Registrations and self-reports were completed and sent to the database. Their geographic coordinates—latitude and longitude per Universal Transverse Mercator—were then collected, favoring the geolocation of the records within the app. For devices that did not allow location tracking, we used the proxy location of the users' Internet Protocols (IPs). The list of symptoms was accompanied by three more questions: (1) Did the user have contact with anyone with these symptoms? This served to establish possible links for eventual chain of transmission, (2) Did the user seek a health service to understand the severity of reported symptoms? and (3) Did the user travel abroad? This served to determine the possible introduction of acquired disease outside Brazil.

The choices of symptoms and syndrome definitions were based on guidelines from the Brazilian Ministry of Health, with aspects of the Information System of Notifiable Diseases' daily routine and other prerogatives (ie, guidelines) defined by the competent technical areas of the institution. The same methods of collecting daily reports could also be done via our web app, which was developed in AngularJS, a JavaScript framework; the app could be accessed through its website [36], which is hosted on DreamHost servers. The back-end server was developed in NodeJS and the web server used Nginx; both ran on a Linux Ubuntu server. As a third-party application programming interface (API), we used Google Maps and Git as versioning systems.

In addition to the mobile and web apps for collecting data via crowdsourcing, Guardians of Health also had a data visualization dashboard that provided monitoring of metrics and results acquired by the apps. The dashboard was developed in AngularJS; the JavaScript D3 library was used for the construction of the graphics. In this segment of the platform, the k-means algorithm was used to identify the syndromic clusters, considering the distribution of the points in the territory and a predefined radius.

The purpose of the dashboard was to serve as an early-warning alert system for possible syndromic clusters; epidemiological surveillance technicians used the dashboard to monitor epidemiological patterns and possible disease outbreaks. To this end, component scripts and algorithms were developed in R, version 3.2.4 (The R Foundation), which worked on the cloud using cronjobs—a time-based job scheduler—and triggered changes in epidemiological patterns with color codes and alert signals.

From data reported by users, a time series was created by counting the number of events per day in each location for each of the signs and/or symptoms. One of the main challenges was to choose a technique that fit *count data*, possibly inflated by zeros, that presented small mean events per day with great variability, as observed in Saúde na Copa [22], which served as a test set for the methodologies to be applied. Given the characteristics of the data described above—count data inflated by zeros with overdispersion (ie, variance greater than the mean)—traditional methods were not applied. For instance, the *autoregressive integrated moving average* model requires data with normal average distribution; it does not reach convergence when dealing with quantities with high exponential coefficients, with many zeros, or with very small quantities, in addition to a larger set of observations. Model-based methods also exhibit the same nonconvergence constraints, even if using negative Poisson or binomial regression. Some methods, such as *cumulative sum* and *exponentially weighted moving average*, are more complex and the detection techniques for average changes can be challenging for the type of system to be implemented.

For these reasons, we chose an ad hoc approach by constructing a strategy to monitor signals from the Guardians of Health using the *locally estimated scatterplot smoothing* (loess) function in R. This technique uses a semiparametric local regression method, which has a smoothing parameter that defines how the function will be adjusted to the observed data. In addition to the smoothing parameter, we can also manipulate the confidence interval of the smoothed function; both parameters are easy to understand and, together with a simple rule, we have created the algorithm described below. From the series of signals, a *loess* is defined at the points passed and an associated confidence interval is established. Thus, the data arriving at the processing server can be checked against the series, and when a value passes the upper interval as defined by the parameters, a *yellow* alert is triggered. If the next point continues to exceed the upper limit, an *orange* alert is triggered. If the limit is exceeded three or more times, a *red* alert is triggered. Figure 1 shows the prototype output and simulation from the algorithm that we used.

It is important to note that because loess is a local regression method, a slow increase in cases also leads to an increase, albeit with a delay, in the upper range. This allows a very gradual

increase in reported cases to be viewed as an *average process increase*, such as more people entering the system, so we have an increase in reported cases. Another important point is that as we adjust the parameters, possibly having different values for each signal or for each syndrome, we can calibrate the alert. If it is very sensitive we can reduce the number of alerts, and if the trend is rising slowly we can choose to have an alarm with a shorter latent memory.

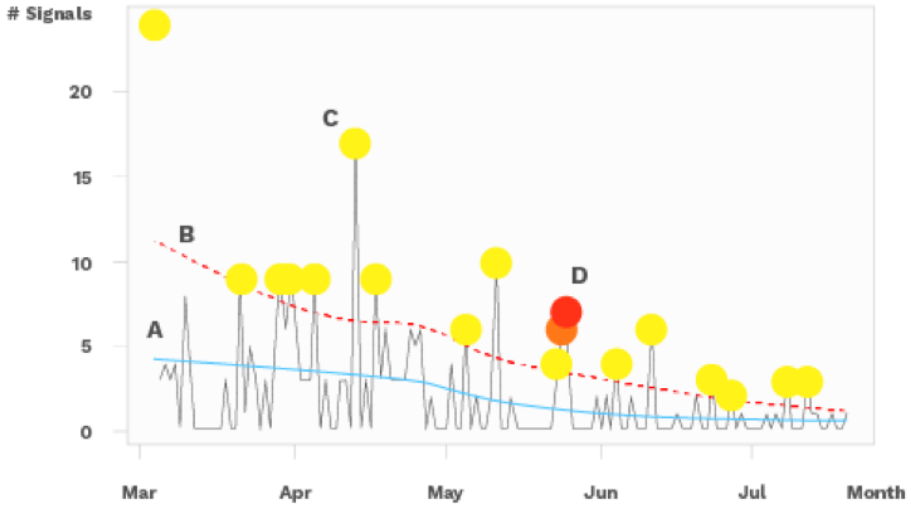
The whole system used an API developed using the Sails framework that communicates with representational state transfer technology API (REST API). The database model used was MongoDB and the system was hosted by Amazon Web Services.

Table 1. Relationship between symptoms and syndromes.

Symptom	Diarrheal syndrome	Respiratory syndrome	Arbovirus (ie, rash) syndrome
Body pain	__[a]	—	Optional
Headache	—	—	Optional
Joint pain	—	—	Optional
Cough	—	Mandatory	—
Sore throat	—	Optional	—
Fever	Optional	Mandatory	Optional
Shortness of breath	—	Optional	—
Nausea and/or vomiting	Optional	—	—
Diarrhea	Mandatory	—	—
Itching	—	—	Optional
Rash	—	—	Mandatory
Red eyes	—	—	Optional
Bleeding	—	—	Optional

[a]Not applicable.

Figure 1. Prototype output implementation of the warning system used in the dashboard of the Guardians of Health platform. The line in blue (A) represents the locally estimated scatterplot smoothing (loess) function with a certain window; this value is known as "span" and controls the smoothness. If it is 1, the line will almost equal the mean value of the series; if it is close to zero, each point will be interpolated by the function. Thus, the function is adjusted by varying this parameter between 0 and 1. The dotted line in red (B) represents the upper range of the loess function; this amplitude was obtained by multiplying the SD by a sigma. Thus, the variability of the series decreases, which makes the interval closer to the loess function.In the event of the graduation of alerts, C indicates one of the points where the value was exceeded, but only at a moment in time which causes that point to generate a "yellow" signal. At D, the observed values exceeded the upper limit three times, the first time generating a "yellow" alert, the second time an "orange" alert, and finally a "red" alert. Then the number of cases fell below the limit and no more alarms were triggered. If this high value persisted, the alarm would have remained "red." A span of 0.75 and a sigma of 1 were used.



Engagement: Acquisition, Adherence, and Permanence of Users in the Platform

One of the biggest challenges for digital platforms that require users to participate via crowdsourcing in information building is recruiting and engaging them to use the apps. There are a few examples of this recruitment and engagement, such as the Waze traffic app that has 65 million active users in more than 185 countries [37]. In the case of health, numerous strategies described by Smolinski at al [8] describe how participatory surveillance platforms seek to motivate and connect more and more with users. In the case of Guardians of Health, some strategies were developed to achieve good levels of acquisition, adherence, and engagement among users.

The distribution of the app was carried out by the Apple App Store and the Android Google Play Store. Within app store profiles, criteria that favored *app search optimization* were met, including using keywords and strategic terms that would improve the positioning of apps when users were looking for health-related terms. As users could also register on the web, elements of *search engine optimization* were implemented, with the aim of improving Google's search positioning with terms related to the health scenario. In-store ratings and comments were also monitored, where a team was responsible for responding to questions, comments, and criticisms in a timely manner, thereby by improving customer relationship management.

From the perspective of marketing as a way of acquiring users, vertical tactics of launch and media buzz were developed to target the knowledge and dissemination of the app to the regions that were associated with the 2016 Olympic Games. Press conferences, for spontaneous media generation, were given and app information was placed in Brazil's main offline and online media channels, press releases, and press kits, among others. Inbound and outbound marketing approaches were developed to target the most reach, impressions, and conversions of leads as well as users. For a marketing outbound approach, Facebook Ads, Google AdWords, YouTube ads, mobile ad networks, Google paid search, and Twitter campaigns were circulated, focusing mainly on the region of Rio de Janeiro where users were impacted by the media. For inbound marketing, blog posts were used for health issues with a high number of visits, directing readers to the distribution channels of the apps.

A gamification piece within the mobile app and the web app was developed, reinforcing the goal of user engagement in a systematic and recurring way. A game was developed into the app that consisted of a quiz with more than 300 questions about health promotion issues, disease prevention, and vector-borne diseases; this brought a health education component to the active users. The questions in the quiz were prepared by the Brazilian Ministry of Health. When answering the questions, the users were presented with information and curiosities about Olympic sports and led users through an Olympic journey, bringing the theme to the digital environment and building an imaginary mindset of the Olympic Games.

The apps also featured a health guide with information on arboviruses, travelers' health, location of emergency room units, vaccines, useful telephone numbers, drugstore locations, basic health care recommendations, and prevention of sexually transmitted infections.

One of the limitations of crowdsourcing is the reliability of information coming from users. The validation of a possible health threat, such as the beginning of an outbreak or epidemic, is made based on groups of people reporting similar symptoms in near time and space. In the analyses performed, a *spam* classification was created, which included records with eight or more symptoms reported. It was agreed that reports with these characteristics would be removed from the analyses, as they were characterized as *spam* or *noise* within the registration database.

Another element that was considered in constructing the platform was the possibility of including secondary users nested within a primary user in Guardians of Health. In this way, a family could have one primary user and other family members added as secondary users to the account.

Data from the results of downloads, registrations, and user reports within the Guardians of Health platform were analyzed using RStudio and the Exploratory.io framework. Guardians of Health is an open source and open data project available at the platform's project page on GitHub via Epitrack [35].

Results

During the study period (see Figure 2), the app was downloaded 59,312 times: 95.47% (56,628/59,312) on Android devices and 4.53% (2684/59,312) on iOS devices. These downloads generated 7848 users (13.23%), where 5987 users (10.09%) sent at least one report about their health status. Of this total, 76.37% (4572/5987) were users with Android devices and 19.21% (1150/5987) were users with iOS devices. Only 265 users of the platform out of 5987 (4.43%) came via the web app. At the end of the 2016 Olympic Games period, we saw that Android device users' churn (ie, loss of users) was 68.66% (38,878/56,628) and iOS device users' churn was 60.39% (1621/2684).

This universe of users generated a total of 12,743 reports; after the classification and filtering of spam, this resulted in 71.79% (9148/12,743) of valid reports. A total of 80.92% (7403/9148) of reports had no symptom status and 19.08% (1745/9148) of reports presented at least one symptom in the period studied.

Regarding the users' demographic profiles, 60.13% (5501/9148) were male and 39.89% (3649/9148) were female. The users' ages ranged from 8 to 97 years, with a median of 39 years and a mean of 40.39 years (SD 14.06). Based on gender and ethnic policies of the Brazilian Ministry of Health, the app included a question about the race or color of the user: 30.31% (2773/9148) declared themselves as *white*, 28.54% (2611/9148) selected *black*, 21.28% (1947/9148) selected *yellow*, 18.10% (1656/9148) selected *brown*, and 1.78% (163/9148) declared themselves as *Indigenous*. Most of the reports (4601/9148, 50.30%) came from the city of Rio de Janeiro. The city of São Paulo had the second-highest number of reports (937/9148, 10.24%). Less than 5% of the reports came from other cities that had Olympic Games events, for all cities combined. Even with the platform's promotion focused on Rio de Janeiro and other host cities,

18.89% (1728/9148) of the reports came from other cities in Brazil and, in some cases, from other countries. The average number of reports per user was 1.54 (SD 3.18, IQR 0.0) and 97.72% (8939/9148) of reports were made by the main user of the account. The average number of reports per day was 45.06 (SD 54.52).

Regarding the Guardians of Health syndromic profile, 1.76% (161/9148) of the reports were classified as diarrheal syndrome, 1.59% (145/9148) were classified as rash syndrome by arboviruses, and 0.74% (68/9148) were classified as respiratory syndrome. The frequencies of the most-reported symptoms are reported in Table 2 and the syndrome distribution is demonstrated in Figure 3.

Regarding the auxiliary questions, 1.96% (179/9148) of the reports were from users who had contact with someone with any of the symptoms described in the list. Regarding those who reported having sought health services, 2.87% (263/9148) were observed by a heath care professional. In addition, 3.05% (279/9148) of the reports were made by users who had been out of the country during the previous 2 weeks at the time of the competition. Figure 4 shows the spatial distribution of users who were feeling ill, with some symptoms. Figures 5-7 show the spatial distribution of reports that were compatible with diarrheal, respiratory, and rash syndromes, respectively.

Throughout the study period, whether during the pre-event period or during the 2016 Olympic Games, despite the evidence of reports compatible with the syndromes described above, there was no concentration of these reports in the same space and time; this excluded the possibility of the beginning of outbreaks, according to the information collected by the Guardians of Health. We have tested this using k-means and the Hartigan-Wong algorithm.

Regarding the results obtained via the engagement strategies, marketing campaigns were made through the study's YouTube channel to deliver video campaigns about the app, which were viewed 253,061 times. Regarding Facebook, content-placement strategies on the study's own fan page were adopted, leveraging 439 followers. However, Facebook also posted on partner pages, such *Razões para Acreditar*, which has 692,297 followers, with Guardians of Health content being disseminated through these vehicles. Regarding scores on app stores, the Guardians of Health app averaged 4.1 out of 5.0 in the Google Play Store and 3.0 out of 5.0 in the Apple App Store.

Figure 2. Distribution of downloads, registered users, and active users by operating system and app during the study period.

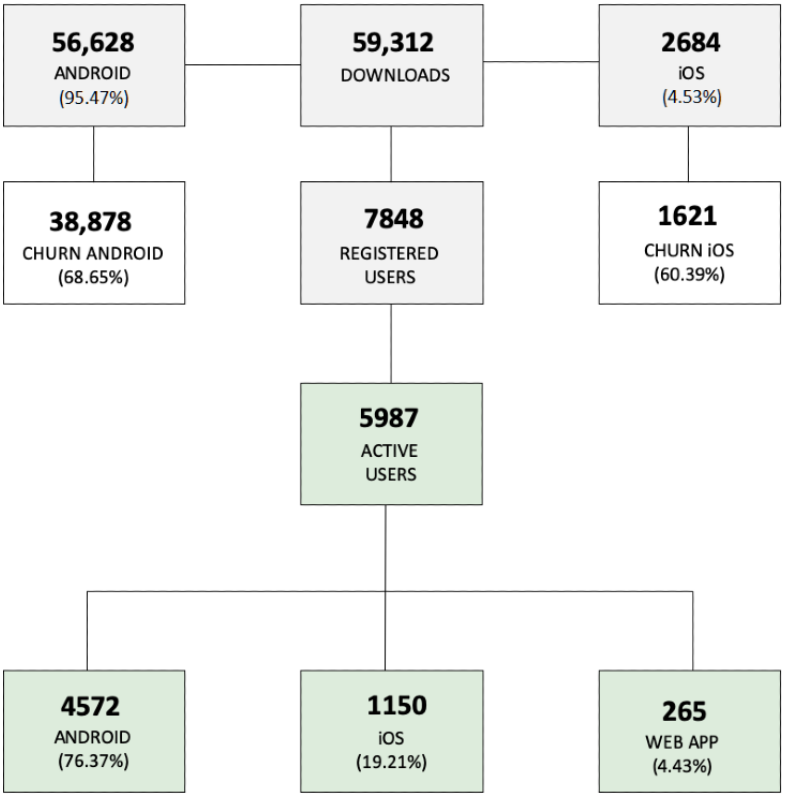


Table 2. List of symptoms reported via Guardians of Health during the Rio 2016 Olympic Games period.

Symptom	Number of reports (N=1746 users with at least one symptom), n (%)
Body pain	607 (34.77)
Headache	593 (33.96)
Joint pain	487 (27.89)
Cough	419 (24.00)
Sore throat	277 (15.86)
Fever	269 (15.41)
Shortness of breath	218 (12.76)
Nausea	204 (11.68)
Diarrhea	161 (9.22)
Itching	145 (8.30)
Rash	145 (8.30)
Red eyes	132 (7.56)
Bleeding	57 (3.26)

Figure 3. Temporal distribution for syndrome cases during the period of study.

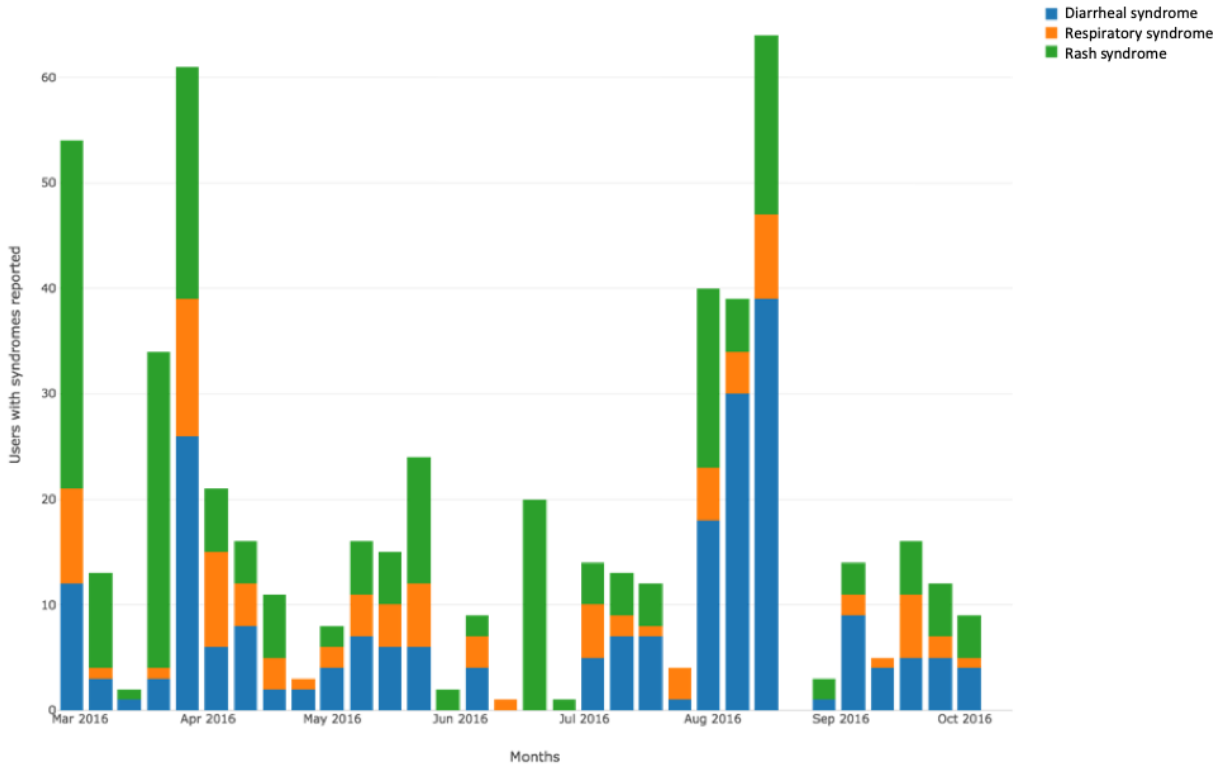


Figure 4. Spatial distribution of reports from Guardians of Health users with symptoms.

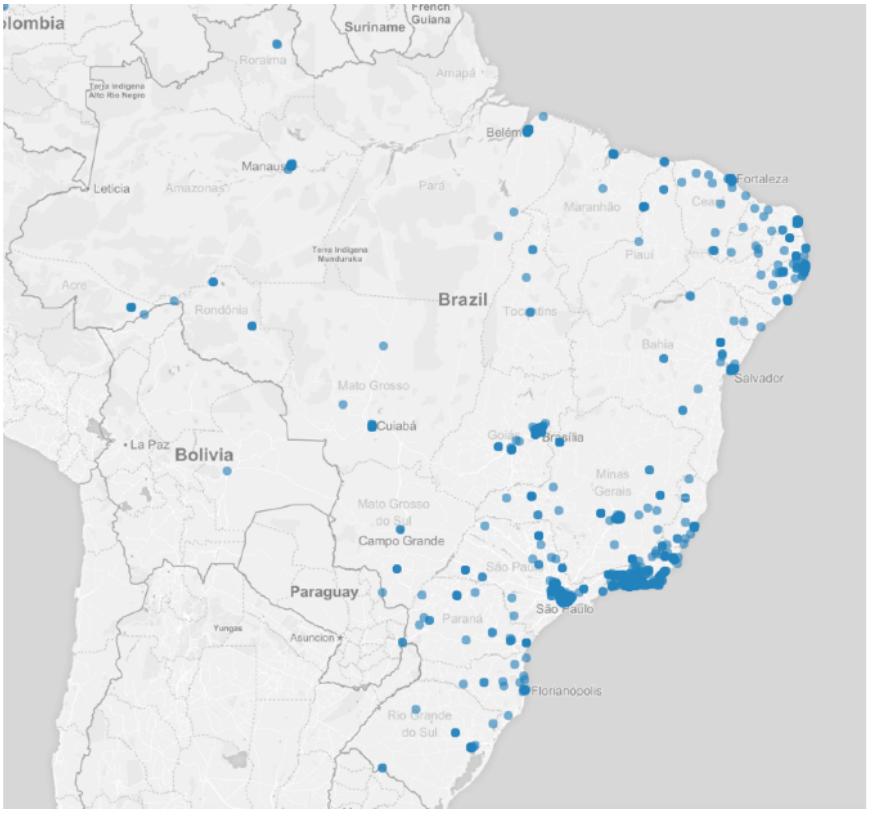


Figure 5. Spatial distribution of reports from users with diarrheal syndrome during the 2016 Olympic Games.

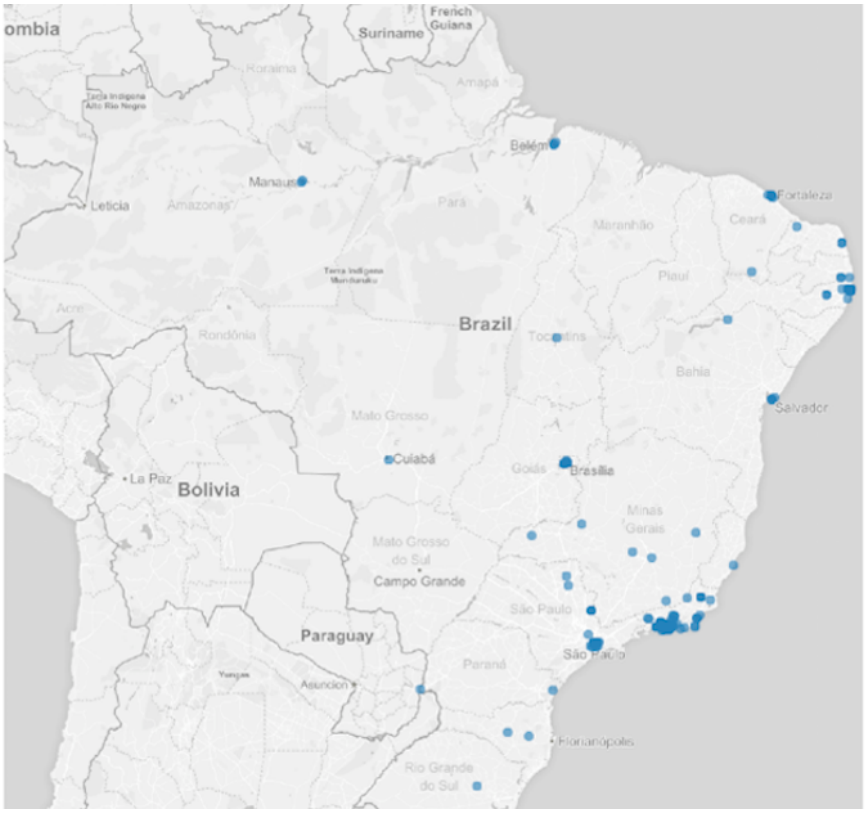


Figure 6. Spatial distribution of reports from users with respiratory syndrome during the 2016 Olympic Games.

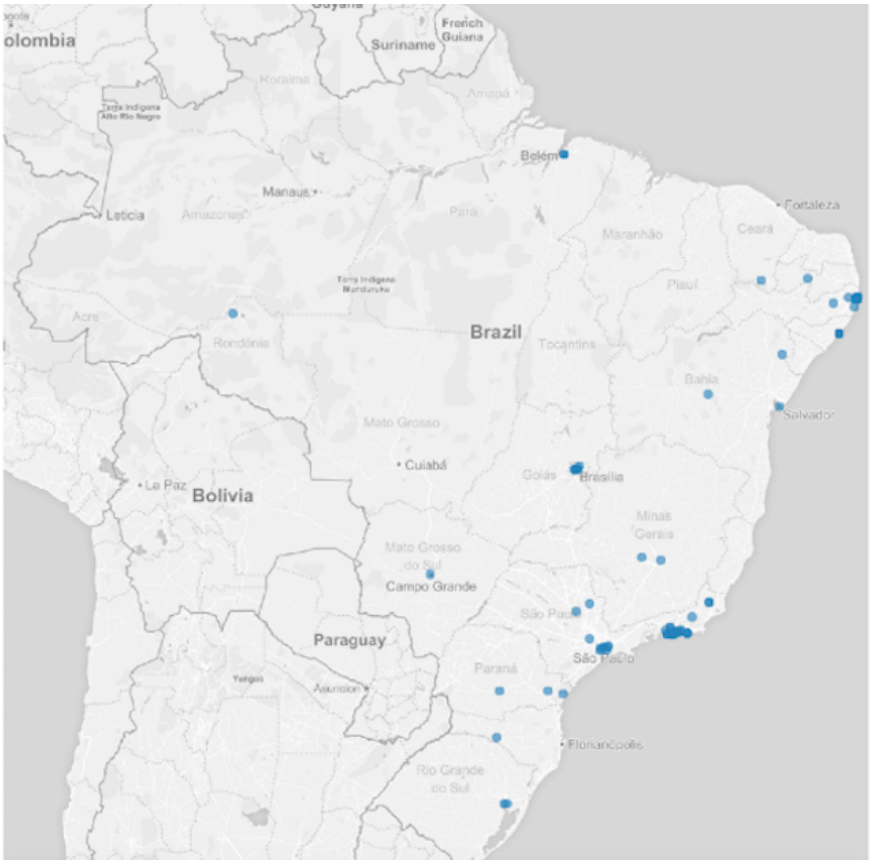
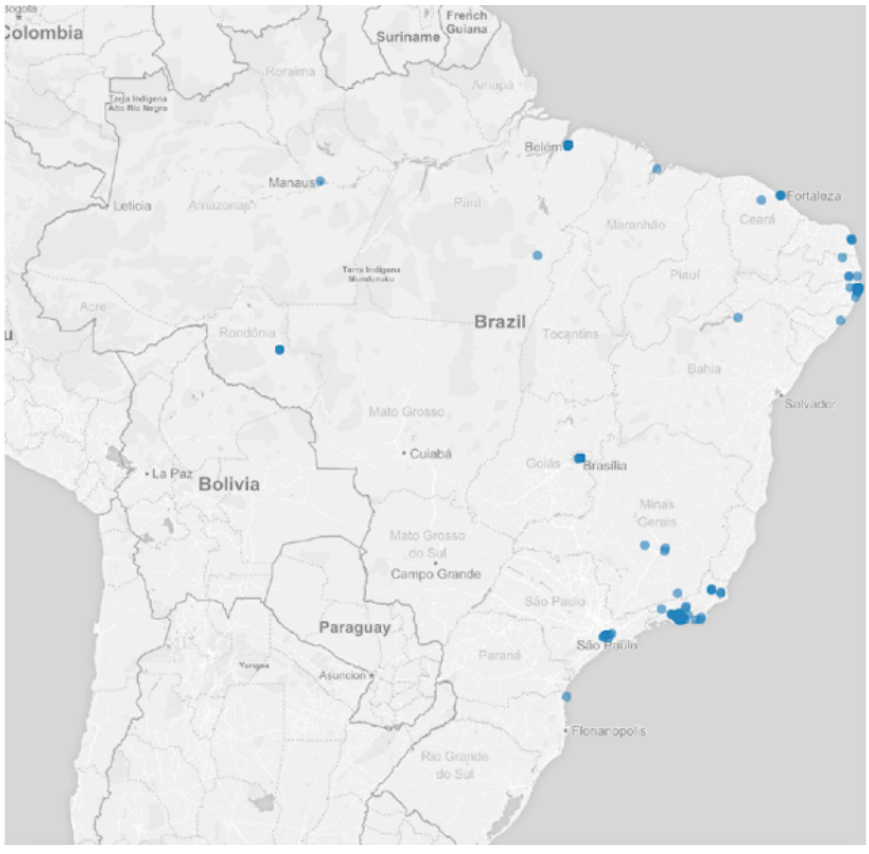


Figure 7. Spatial distribution of reports from users with rash syndrome during the 2016 Olympic Games.



Discussion

Participatory surveillance continues to be an alternative for health services innovation in the digital age, spreading to various parts of the world and increasingly gaining strength as an additional platform to traditional epidemiological surveillance systems [3,8,22]. The use of this platform on a national scale in Brazil during the 2014 FIFA World Cup and the 2016 Olympic Games shows that the government is willing to take a new position regarding disease surveillance; combining tools can bring modernization and substantial improvements to the sensitivity and specificity of the production and consumer structures of strategic information in health surveillance.

Experiences using mobile devices take advantage of the population's access to smartphones; this facilitates the spreading of projects that are based on real-time data collection with remote transmission of information and dashboards to support decision making [10,38-41]. In the case of Guardians of Health, for the period of operation, the high number of downloads was not effectively converted into the creation of users, where 13.23% of all who downloaded the app became registered users. This behavior can be explained with some hypotheses, such as the innovative potential of the tool, invoking the criterion of *deceptive* growth [11], that is, the incredulity of the population in something more modern than the traditional systems. The tone and sentiment observed in the comments at the virtual stores and on Facebook point to another hypothesis linked to political instability at that time in Brazil.

There was a majority of users who used the Android operating system compared to the iOS operating system. The direct explanation is the lower cost of smartphones with the Android operating system in Brazil, in keeping with the financial reality of the population. Gotz et al [39] questioned whether there was a difference in personality between the users of both systems, but no relevant results were found to support this. Therefore, it can be suggested that the economic factor involved in the acquisition cost of these devices is what generated the greater preference for Android, at least in Brazil. Data show that Brazil currently has 77.35 million smartphone users, where 92.6% are Android users [42]. The low number of registrations and use via the web app implies that internet apps are more restricted to mobile devices, as compared to desktops or access by browsers. The churn achieved by the apps was within an expected value for apps in the health field, which is 75% [43].

Using a rule to identify spam posts [22], 28.21% of reports that were not true or had a high chance of being fallacious were eliminated. Even with this withdrawal, obtaining 9148 reports generated a reasonable amount of data for analysis. There were differences between the demographic profiles identified in the Guardians of Health platform and the Saúde na Copa app, which is a participatory surveillance app used in Brazil during the 2014 World Cup. Guardians of Health showed an overlap of approximately 20 percentage points in relation to male users. There was a difference in the age of users as well, where Saúde na Copa had a smaller age range (12-77 years) than did Guardians of Health (8-97 years). One of the elements that can explain this difference is that Guardians of Health had the functionality of adding secondary users to a primary account. That is, an adult at the median age observed (39 years) could have children or the elderly as secondary users within their account. This may also explain the difference in means achieved between the World Cup experience and the Olympic Games [22].

The population profile according to race or color was a variable used for the first time in any participatory surveillance platforms, worldwide; this prevented a comparison of this profile with other regions, even aiming to raise discussions about access to technology according to race or color. However, due to the fact that Brazil has a well-known population with a majority of Europeans and Africans, while preserving Indigenous characteristics in several regions of the country, the figures presented reflect a reality of race diversity at the national level, even those who declare themselves to have represented only 1.79% of the reports.

Most of the Olympic and Paralympic competitions were held in Rio de Janeiro, explaining that most of the reports came from this locality. One situation that has been repeated in relation to the Saúde na Copa app [22] is the demonstration of the potential for scale and dissemination of a participatory surveillance platform for mobile devices. In the Guardians of Health platform, 30.83% of the reports came from Brazilian cities or from foreign territories—the minority—that were not the headquarters of any Olympic event.

The results on the captured syndromic profiles (ie, reports that were compatible with the rules of a priori defined syndromes) were below those observed in previous experiences during mass events using participatory surveillance. However, they still show great potential for use because of their sensitivity in locally identifying concentrations of reports with similar characteristics of symptoms. Fortunately, there were no outbreaks detected by the app and this was corroborated with official information from the Brazilian Ministry of Health, assuming validation of the tool's potential in the timely detection of health threats.

Unlike the Saúde na Copa app, which had peaks of participation during matches of the Brazilian soccer team, the Olympics had a diversity of sports activities; it was possible that the peaks in the number of participating users and completion of reports were related to the days when the marketing campaigns for acquisition and adherence of users took place.

Mass gatherings continue to be sensitive situations in health management, due to the pressure caused within local systems; a sudden increase in demand of resources with a structure unable to keep up with the scale of supply; as well as the epidemiological risks of introducing eradicated, new, or nonendemic diseases as well as controlled diseases into the national context. Initiatives like Guardians of Health help to track risk factors for epidemics and diseases outbreaks. Even when these risks occur during mass gatherings, such platforms are able to minimize these health threats.

Engaging users on platforms such as this remains one of the puzzling and challenging issues in terms of participatory surveillance. Building on the importance of understanding health information around them has been a quest for various groups

working with participatory surveillance around the world; despite experiences with interesting success (ie, FluTracking [31]), a replicable path has not been found, making this a negative aspect in applying a participatory approach [44-46].

Another sensitive point that comes up on the list of challenges is the role of government and its agents as users and system managers. The importance of a prospective mindset is vital to foster abundant, innovation-oriented thinking, in order to improve and sustain these initiatives. It would be ideal for each experience, whether during the World Cup or the Olympic Games, to have, at minimum, a permanent structure of management, development, support, and dissemination that would favor growth more and more. However, these skewed interests and lack of agile capacity, which are needed to structure the sectors that managed to maintain projects like this, are also characterized as enigmatic challenges; a solution needs to be found to articulate and implement these experiences as a permanent part of innovative health policy.

In this scenario of the information capture flow for epidemiological surveillance, sick individuals are only counted by the health system upon entry to the system, which is then notified when necessary. However, the time between illness and demand for health care, assuming the health facility would report all relevant cases, demonstrates the fragility of traditional systems regarding the timely identification of diseases that can impact public health in the form of outbreaks and epidemics. One way to fill this gap between illness from a disease with outbreak potential and the record of it is the use of technologies and strategies, such as participatory surveillance; these empower citizens by making them an active part of joint information building, which contributes to the epidemiological setting of their community or region and rescues the precepts of social control widely debated in the Sistema Único de Saúde, the Brazilian National Health System.

Reaffirming the debate [12,13], the explicit evidence that disruptive innovations in public health are far more present in our national context than we imagine, because of their potential exponential growth, urges research and services to consider this new movement in their collective health practices. In this way, Sistema Único de Saúde can not only follow but can become an effective actor in this rapid transformation in the use of information to improve the quality of life for all citizens.

Many other participatory surveillance strategies keep appearing across the globe, using the same mindset where people are the primary data source, contributing to build epidemiological settings with crowdsourcing [47-51]. On the other hand, nontraditional approaches for health communication should be considered to work alongside traditional methods in order to increase the range of digital health, for instance, the use of YouTube to spread health education content [52,53].

Digital transformation is a fact; it is no longer a futuristic element, but has become today's reality. The world is changing fast and recognizing this transformation is essential to face today’s challenges. The struggle against those who continue to ignore this change encumbers the process of transformation, holding all those working in the context of public health hostage to obsolescence. It is hoped that professionals, new and old, as well as researchers, managers, and workers involved in epidemiological surveillance become aware and allow themselves to implement new tools that improve information management for decision making and knowledge production.

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Authors' Contributions

OLN, JA, and MNS were responsible for study conceptualization, data analysis, and writing of the paper. ML and MS participated in the study when it was rolled out during the Olympic Games.

Conflicts of Interest

In order to make clear the commercial affiliations of some of the authors, we would like to declare that OLN, JA, and MNS worked on the project as key professionals in the development and implementation of the Guardians of Health platform.

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Abbreviations

API: application programming interface
loess: locally estimated scatterplot smoothing
REST API: representational state transfer technology application programming interface

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Original Paper

Ambiguity in Communicating Intensity of Physical Activity: Survey Study

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Abstract

Background: Communicating physical activity information with sufficient details, such as activity type, frequency, duration, and intensity, is vital to accurately delineate the attributes of physical activity that bring positive health impact. Unlike frequency and duration, intensity is a subjective concept that can be interpreted differently by people depending on demographics, health status, physical fitness, and exercise habits. However, activity intensity is often communicated using general degree modifiers, degree of physical exertion, and physical activity examples, which are the expressions that people may interpret differently. Lack of clarity in communicating the intensity level of physical activity is a potential barrier to an accurate assessment of exercise effect and effective imparting of exercise recommendations.

Objective: This study aimed to assess the variations in people's perceptions and interpretations of commonly used intensity descriptions of physical activities and to identify factors that may contribute to these variations.

Methods: A Web-based survey with a 25-item questionnaire was conducted using Amazon Mechanical Turk, targeting adults residing in the United States. The questionnaire included questions on participants' demographics, exercise habits, overall perceived health status, and perceived intensity of 10 physical activity examples. The survey responses were analyzed using the R statistical package.

Results: The analyses included 498 responses. The majority of respondents were females (276/498, 55.4%) and whites (399/498, 79.9%). Numeric ratings of physical exertion after exercise were relatively well associated with the 3 general degree descriptors of exercise intensity: light, moderate, and vigorous. However, there was no clear association between the intensity expressed with those degree descriptors and the degree of physical exertion the participants reported to have experienced after exercise. Intensity ratings of various examples of physical activity differed significantly according to respondents' characteristics. Regression analyses showed that those who reported good health or considered regular exercise was important for their health tended to rate the intensity levels of the activity examples significantly higher than their counterparts. The respondents' age and race (white vs nonwhite) were not significant predictors of the intensity rating.

Conclusions: This survey showed significant variations in how people perceive and interpret the intensity levels of physical activities described with general severity modifiers, degrees of physical exertion, and physical activity examples. Considering that these are among the most widely used methods of communicating physical activity intensity in current practice, a possible miscommunication in assessing and promoting physical activity seems to be a real concern. We need to adopt a method that represents activity intensity in a quantifiable manner to avoid unintended miscommunication.

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KEYWORDS

exercise; health communication; exercise intensity

Introduction

Importance of Capturing Information on Physical Activity Intensity

Being physically active is essential for maintaining good health [1]. Assessment, intervention, and outcome evaluation related to one's health status now require incorporating a patient's lifestyle information [2-5]. To facilitate the use of lifestyle information in patient care, the Office of National Coordinator for Health Information Technology (ONC) and the National Academy of Medicine (NAM; formerly known as the Institute of Medicine) recognized the 9 social and behavioral health domains, including physical activity, that need to be incorporated into electronic health records (EHRs) in a structured format [6,7].

Undoubtedly, regular and sufficient physical activity is among the most essential lifestyle approaches for staying healthy. Health care professionals often prescribe physical activity as part of a treatment regimen for a patient to facilitate recovery from a disease or to prevent further aggravation of the disease. Ascertaining whether a person is getting a sufficient level of physical activity requires examining 4 attributes characterizing physical activity, including frequency, intensity, time (ie, duration), and type (FITT) of the activity [8]. Specifying activity FITT is also essential when recommending physical activity to a patient, as it helps patients understand what constitutes an adequate level of physical activity that can have a positive impact on their health.

It is relatively straightforward to describe the frequency, time, and types of physical activity, as there are agreed-upon methods of objectively representing these data types. However, communicating the notion of intensity can be challenging because of its subjective nature and dependence on individual biases and internal calibrations.

Quantifying Physical Activity Intensity

There are several methods for quantifying the intensity level of a physical activity. The metabolic equivalent of task (MET) value is a measure of energy expenditure required to perform a task relative to the energy expenditure of an average person seated at rest. Thus, if an activity has an MET value of 2, this translates to an activity intensity that requires twice the energy of the resting reference event [9,10]. The MET value thus provides a relatively standardized means of describing the intensity level of a particular physical activity for healthy adults [11]. In general, we classify activities with a MET value less than 3 as light-intensity activities, those between 3 and 6 as moderate-intensity activities, and those greater than 6 as vigorous-intensity activities. Individuals may require a different amount of energy to complete the same task depending on the person's age, BMI, and overall physical fitness. The corrected MET value is a weighted MET value calculated incorporating such dependencies [12].

The maximum oxygen uptake rate (%VO_2 max) refers to the relative amount of oxygen a person uses during physical activity. Slightly different range values may apply for the intensity categories for %VO_2max depending on gender and age. For example, the classification of *vigorous* for an adult female aged between 18 and 40 years has a %VO_2 max range of 64% to 91% [13]. In other words, if a young adult female is consuming 64% to 91% of her %VO_2 to perform an activity, she is involved in an activity with vigorous intensity.

Finally, maximum heart rate (%HR max) is another widely used method for quantifying activity intensity [14]. In general, when using this metric, an activity is vigorous if it causes the heart rate (HR) of the person performing the activity to increase to 76% to 96% of his or her %HR max.

Although these metrics allow one to quantify the intensity level of a physical activity event, they are often not practical to obtain because they require specialized instruments and calculations. Therefore, they are not widely used to describe activity intensity in normal communications with patients. In addition, these measures are not free from limitations, and numerous studies suggested revisiting the reliability and validity of these measures [14-16].

Various qualitative characterizations have also been defined to assess a patient's activity intensity. The Rating of Perceived Exertion (RPE) scale represents a person's self-reported exertion level after a particular activity. The Borg scale, the most widely used RPE, rates a perceived exertion level from a value of 6, which indicates no exertion at all, to a value of 20, which indicates maximum exertion [8,17]. The Borg scale is easy to implement and is considered sufficiently accurate for many purposes [18]. However, studies also reported limitations of this scale, for example, underestimating activity intensity compared with what is reflected in exercise HRs [19,20].

The talk test is another simple method of describing the intensity level of physical activity that a person perceives. The talk test is based on the extent to which a person can verbally respond in a conversation during the exerted activity [21]. For example, if a person is unable to converse during physical activity, he or she is considered engaged in a vigorous-intensity activity. However, similar to the other intensity assessment methods described earlier, studies have reported mixed findings on the validity of the talk test as a clinical tool for assessing activity intensity [8,22,23].

Limitations in the Daily Communication of Physical Activity Intensity

As described earlier, a number of efforts have been put forward to devise means for characterizing physical activity intensity, although none are free from the aforementioned limitations. The granularity and levels of agreement among these measures can be quite variable. In addition, the real-world constraints associated with the application of these measures in the clinical setting are important to consider. In most everyday communication with patients, inquiry of activity intensity is presented to the patient using everyday natural language expressions. Compared with calibrated measures, the response from these types of inquiries can have widely varied interpretations.

As shown in Table 1, general degree descriptors, such as light, moderate, and vigorous, are among the most frequently used

methods for describing activity intensity. Many questionnaires and scales that assess people's physical activity level also add additional descriptors to express activity intensity. Many of them include the exertion levels expressed with a degree of increment in sweating, HR, and breathing after exercise to denote activity intensity. In addition, specific activity types are often accompanied by appropriate performance descriptors (eg, fast and for pleasure) to provide additional specificity.

Table 1. Activity intensity descriptions used in various physical activity questionnaires.

Questionnaire	Intensity description examples
California Health Interview Survey 2009 Adult Questionnaire	Think about *vigorous activities* you did in your free time that *take hard physical effort*, such as *aerobics, running, soccer, fast bicycling, or fast swimming*. Again, do not include walking. During the last 7 days, did you do any *vigorous physical activities* in your free time?
Neighborhood Physical Activity Questionnaire	In a usual week, how many times do you do *moderate-intensity* leisure-time physical activities that *do not make you breathe harder or puff and pant*?
National Health and Nutrition Examination Survey Physical Activity and Physical Fitness Physical Activity Questionnaire (version 1998)	Moderate activity: Over the past 30 days, did you do *moderate activities* for at least 10 min that *caused light sweating*? (*brisk walking or bicycling for pleasure*)
Health-enhancing physical activity and Office in Motion Questionnaire	Think about *moderate physical activities* that *make you breathe somewhat harder* and may include *continuous walking, hiking, dancing, gardening, or sport activities*. Currently, do you do any physical activities that *make you breathe somewhat harder*?

In 2014, the ONC and the NAM [6,7] proposed recommendations to document a patient's physical activity information in the EHR using the following 2 questions from *Exercise Vital Signs* [24]: (1) *On average, how many days per week do you engage in moderate to strenuous exercise (such as walking fast, running, jogging, dancing, swimming, biking, or other activities that cause a light or heavy sweat)?* and (2) *On average, how many minutes do you engage in exercise at this level?*

These 2 questions are assumed to capture the minimum necessary information related to a patient's overall exercise habits, including frequency, intensity, and duration. However, the intensity information related to the first question might not adequately reflect individual patients' exercise level and potentially hamper a clinician's effort to make an accurate assessment and/or provide an effective recommendation for physical activity as part of a treatment regimen.

In summary, the intensity characterization of physical activity is an essential component when assessing and recommending a physical activity. There exists a risk of missing vital details when the intensity of physical activity is expressed using general descriptors that do not incorporate individual differences in intensity experience and/or perception. As a first step to identify potential gaps in communicating activity intensity, we investigated how people perceive or interpret the intensity levels when described with general degree modifiers, physical exertion descriptions, and activity scenarios.

Study Aims

We conducted a survey to assess how people perceive the intensity levels of physical activity expressed by methods commonly used to inquire exercise intensity in daily communication. In particular, we aimed to answer the following research questions: (1) How different or similar are people's perception of physical activity intensity with respect to the use of general degree modifiers, degree of physical exertion, and activity examples? and (2) Are there any patterns or associations between people's characteristics and perception of the presented intensity descriptions?

Methods

Survey Questionnaire

We designed a questionnaire survey to collect 3 types of information: (1) survey participants' demographics, which included age, gender, race, and ethnicity; (2) participants' exercise habits, including frequency, duration, and intensity (this information category also included each respondent's overall health status and attitude toward regular exercise); and (3) the perceived intensity levels of different physical activity examples. Survey participants were asked to rate the intensity levels of 10 everyday physical activities using numeric scores ranging from 0 to 10, where 0 indicates activity causes no exertion and 10 indicates activity causes extreme exertion. We selected the 10 activity examples used in the 2011 Physical Activity Compendium [9]. Survey participants had the option to mark "don't know" if they were unfamiliar with the presented activity. The survey questionnaire is included as a supplemental file (Multimedia Appendix 1).

Recruitment

We recruited survey participants using the Web-based framework provided by Amazon Mechanical Turk (MTurk). MTurk is a crowdsourcing marketplace where various tasks are outsourced to a distributed workforce who can perform these tasks virtually [25,26]. Tasks completed using MTurk vary from conducting simple data validation to more subjective tasks such as survey participation. This study was exempted by the institutional review board. We limited participation to adults residing in the United States.

Statistical Analysis

We descriptively analyzed the participants' demographics, exercise habits, and perceived intensity of different activity types. We also examined whether there were any significant associations between participants' characteristics and their

intensity perception. This survey asked people's subjective perception and experience of the intensity of physical activity, where no gold standard answer exists. Therefore, the analysis focused on examining how similar or dissimilar people's perceptions of physical activity intensity were. All data analyses were performed using the R statistical package, version 3.5.1 [27].

Power

To be able to generalize the survey results to the general adult population living in the United States with a 95% CI and a 5% margin of error, we estimated a sample size of at least 385 responses. We received a total of 522 responses.

Data Exclusion

After removing 24 unreliable responses (eg, too many unanswered questions or implausible answers), there remained 498 responses for analyses.

Results

Survey Participants' Characteristics

The participants' age, race, and sex statistics are summarized in Table 2. The majority of the survey participants were white (399/498, 79.9%), and there were more females (276/498, 55.4%) than males. The mean age of the respondents was 40.59 (SD 12.56) years. The majority of the participants reported that they were in good (290/498, 58.23%) or excellent (43/498, 8.63%) health and considered regular exercise as being very (184/498, 36.95%) or extremely important (108/498, 21.69%) for their health.

Approximately 72.6% (362/498) of the respondents answered that they exercised regularly. The frequency, duration, and intensity level reported by the majority of these 362 regular exercisers were 3 to 4 days a week (n=162), for 30 to 60 min (n=228), at a moderate intensity level (n=227). Among the 136 people who responded that they did not exercise regularly, 93 answered exercising occasionally. The majority of these 93 sporadic exercisers indicated that they exercised, on average, about 1 or 2 days per week (n=85), for less than 30 min (n=63), at a mild intensity level (n=69). The remaining 43 people responded that they were not exercising at all.

The proportions of regular exercisers differed according to the respondent's characteristics, as shown in Table 3. The significance of the differences was tested using the two-sample proportion test and the chi-square test. Men, people without a known medical condition that limits their physical activity, those using an activity tracker, those considering themselves to be in good health, and those thinking that regular exercise is important for their health were more likely to exercise regularly. There was no significant difference in the age distributions between regular exercisers and nonregular exercisers (P=.82) when tested with Student t test.

Table 2. Age, sex, and race distributions of the survey participants.

Race	Age (years), mean (SD)	Number of respondents by sex and race, n (%)		
		Female (n=276)	Male (n=221)	Other (n=1)
American Indian or Alaska Native	40 (5.66)	1 (0.36)	1 (0.45)	0 (0)
Asian	34 (8.92)	12 (4.3)	13 (5.8)	0 (0)
Black or African American	37 (12.38)	23 (8.3)	15 (6.7)	0 (0)
Hispanic or Latino	32 (10.67)	9 (3.2)	16 (7.2)	0 (0)
Native Hawaiian or Other Pacific Islander	52 (NA)	0 (0.0)	1 (0.45)	0 (0)
Other	41 (12.68)	6 (2.1)	2 (0.90)	0 (0)
White	39 (8.23)	225 (81.5)	173 (78.2)	1 (100)
Total	40.59 (12.56)	276 (100)	221 (100)	1 (100)

Table 3. Regular exercise ratios by participants' characteristics.

Participants' characteristics	Regular exerciser, n (%)	*P* value
Sex		**.002**
Female	185 (67.0)	
Male	177 (80.1)	
Using activity tracker		**<.001**
Yes	134 (86.5)	
No	228 (66.5)	
Race		**.49**
American Indian or Alaska Native	1 (50)	
Asian	18 (72)	
Black or African American	31 (82)	
Hispanic or Latino	17 (68)	
Native Hawaiian or Other Pacific Islander	1 (100)	
Other	4 (50)	
White	290 (72.7)	
Perceived health status		**<.001**
Excellent	41 (95)	
Good	229 (78.9)	
Fair	75 (54)	
Poor	17 (68)	
Age (years)		**.82**
≥65	14 (78)	
<65	348 (72.5)	
Importance of regular exercise		**<.00**
Extremely important	103 (95.4)	
Very important	160 (86.9)	
Moderately important	89 (65)	
Somewhat important	9 (16)	
Not at all	1 (8)	
Having a medical condition limiting physical activity		**<.001**
Yes	63 (64)	
No	293 (75.7)	

Perceived Exercise Intensity

We asked 455 participants who exercised regularly (n=362) or sporadically (n=93) to describe the intensity of the exercise they usually performed in 2 ways: (1) using general degree modifiers and (2) based on the physical exertion they experienced after the exercise. As a means of describing the level of exertion, we presented 3 types of physiologic responses: an increment in HR, breathing rate, and sweating. Note that these physiologic responses are also commonly used to describe intensity levels in various validated physical activity questionnaires. Figure 1 shows that the exertion levels reported by the participants after exercise were not always linearly related to the exercise intensity they described using general degree modifiers. For example, a few respondents reported only a minor increase in breathing, sweating, and HR after vigorous exercise. Similarly, some people reported experiencing a significant increase in these physiologic parameters after mild-intensity exercise.

The participants who exercised regularly or sporadically (n=455) were also asked to rate the perceived intensity level of the exercise they usually performed using 3 general intensity levels and a 20-point scale, where 0 indicates no exertion at all and 20 indicates extreme exertion. Figure 2 shows how the numeric ratings of perceived exertion are distributed in the 3 intensity levels. Although there were small overlaps, the distributions of the ratings were well differentiated among the 3 intensity levels. The average numeric intensity ratings were significantly

different among the 3 intensity levels when tested with the Kruskal-Wallis test ($P<.001$).

Figure 1. Level of physical exertion reported for the different intensities of exercise.

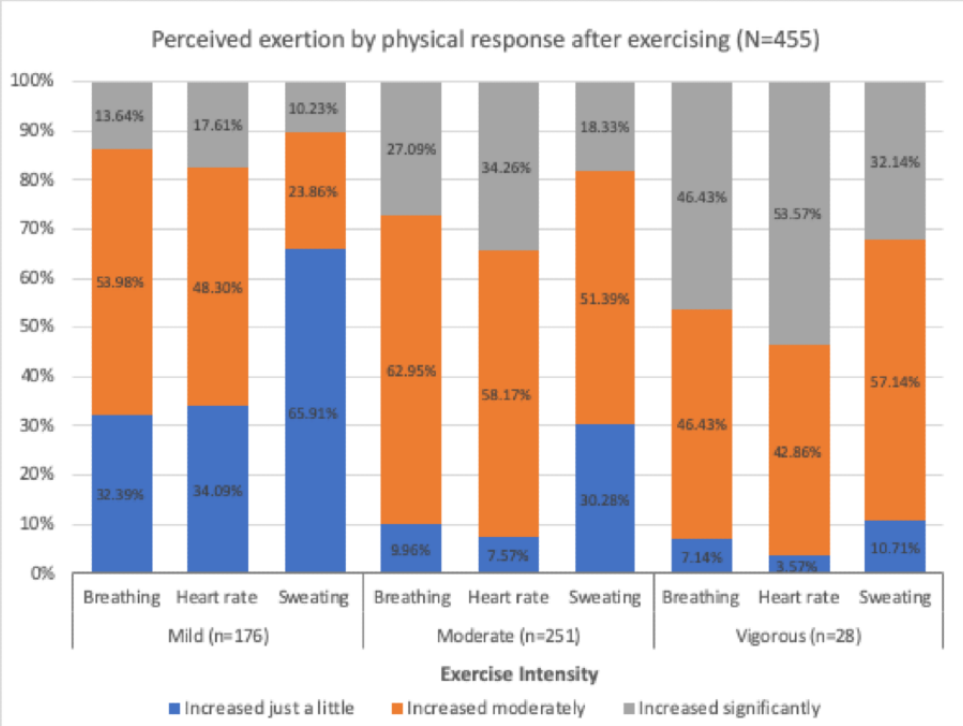
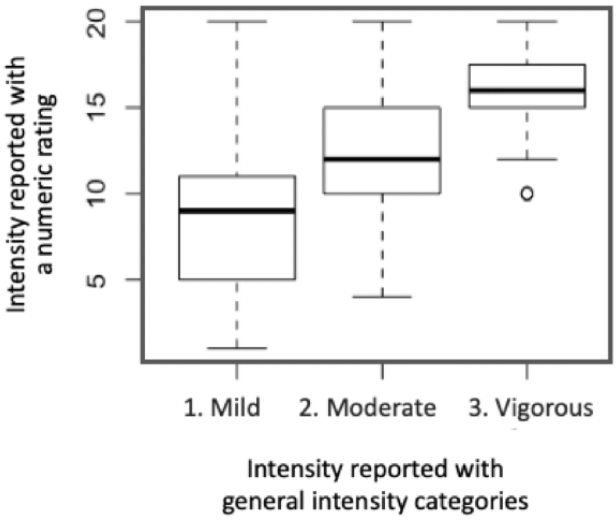


Figure 2. The distribution of numeric intensity rating reported for the general intensity categories.

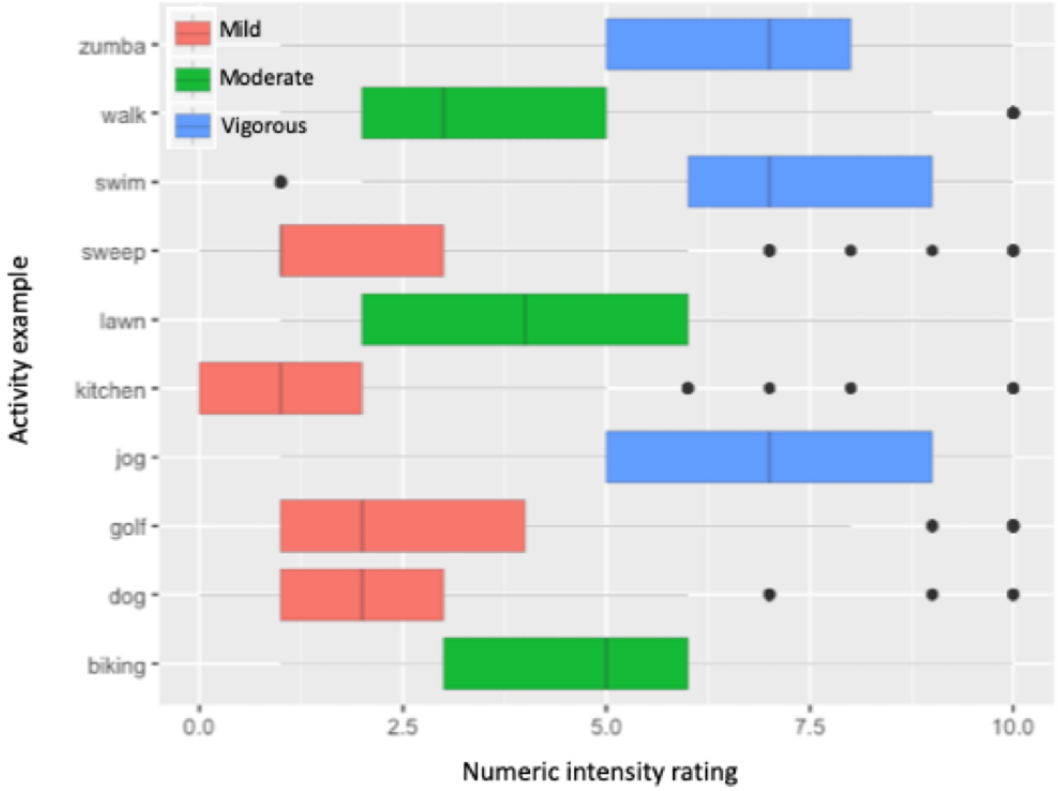


Perceived Intensity Levels of 10 Physical Activity Examples

Figure 3 shows the overall distribution of the intensity ratings that the participants assigned to the 10 activity examples. Although there exist substantial variations in the ratings of all 10 activities, the participants tended to perceive aerobic dancing, fast lap swimming, and jogging as more intense, whereas they considered kitchen works, walking the dog, and sweeping a driveway as less intense.

The 10 activity examples formed approximately 3 intensity groups as color coded in Figure 3. As a reference to standardized intensity information, we included in parentheses below the corresponding MET values proposed in the study by Ainsworth et al [9] for each activity. The activities that received relatively high-intensity ratings included *jogging at a pace of 5 to 7 miles per hour* (MET 8.3-11), *fast lap swimming–freestyle* (MET 9.8), and *aerobic dancing such as Zumba* (MET >5.0). The activities with middle range intensity ratings are *biking at a park* (MET 4.0), *lawn mowing with a hand mower* (MET 6.0), and *walking at a pace of 3.5 miles per hour* (MET 4.3). *Walking a dog* (MET 3.0); *golf—walking and carrying clubs* (MET 4.3); *kitchen activities such as cooking, washing dishes*, and *cleaning up* (MET 3.3); and *sweeping garage, sidewalk, or outside of the house* (MET 4.0) received relatively low-intensity ratings from the participants.

Figure 3. Numeric intensity ratings assigned to 10 activity examples (zumba: aerobic dancing such as Zumba; walk: walking at a pace of 3.5 miles per hour; swim: fast lap swimming–freestyle; sweep: sweeping garage, sidewalk, or outside of the house; lawn: lawn mowing with a hand mower; kitchen: kitchen activities such as cooking, washing dishes, and cleaning up; jog: jogging at a pace of 5 to 7 miles per hour; golf: golf—walking and carrying clubs; dog: walking a dog; and biking: biking at a park).

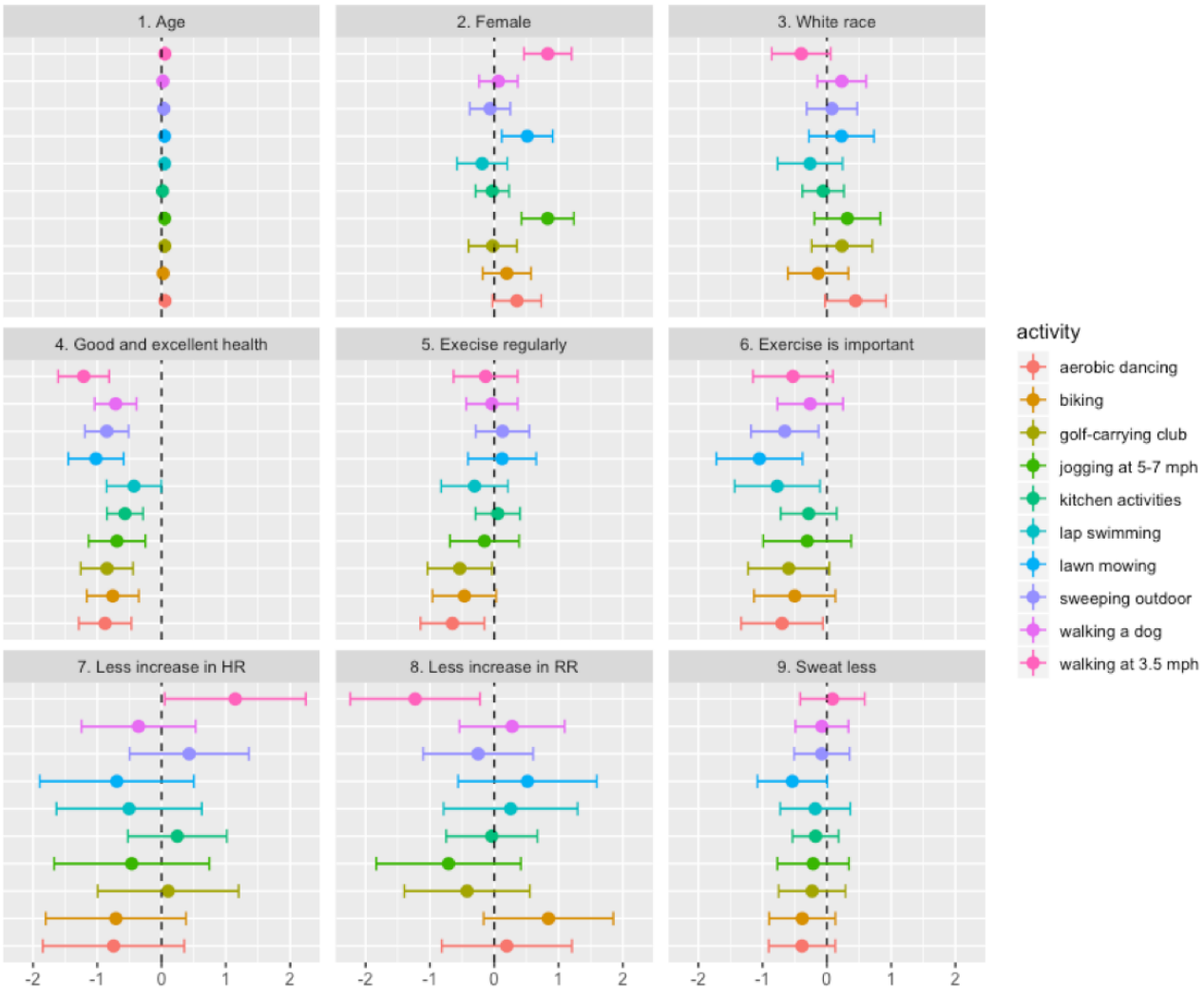


Factors Associated With the Differences in Perceived Intensity Ratings

We conducted regression analyses to examine how the participants' characteristics affect the perceived intensity ratings of the 10 activity examples. We dichotomized race (white vs nonwhite), perceived health status (good/excellent vs fair/poor), and importance of exercise (moderately/very/extremely vs slightly/not at all). We also created 3 additional characteristics that reflect the relative exertion level experienced by the participants by comparing the participants' self-reported physical exertion level with the self-reported exercise intensity. The respondents were classified as *less increase in HR or respiratory rate* or *sweat less* if they reported a lesser level of exertion than the level of the exercise intensity they performed. For example, we classified a respondent to a *lesser increase in HR* group when she reported experiencing a small increase in HR after performing a moderate- or vigorous-intensity exercise.

Figure 4 presents the coefficients of the 9 explanatory variables and their 95% CIs in predicting the numeric intensity ratings of the 10 activity examples. The regression analysis showed that age did not affect the intensity ratings at all. In addition, race, regular exercise, and physical exertion levels the respondents usually experienced after exercise were not strong predictors of the intensity ratings, except for a few activity types. For example, regular exercisers tended to rate lower the intensity of walking, golfing, and aerobic dancing than their counterparts. Overall, those who reported being in good health and considered regular exercise was important for their health tended to rate lower the intensity of the example activities. Female participants tended to rate higher the intensity of walking, walking a dog, lap swimming, and jogging than male participants.

Figure 4. Regression coefficients and 95% CIs of the participants' characteristics in predicting the intensity ratings of the 10 activity examples. HR: heart rate; RR: respiratory rate.



Discussion

Principal Findings

The survey results showed that significant variations exist in how people perceive and express the intensity level of physical activity. Numeric rating of intensity with the perceived exertion level seemed to differentiate the 3 general intensity levels of mild, moderate, and vigorous relatively well. However, significant inconsistencies were observed in how the survey participants associated the descriptors commonly used in communicating exercise intensity with the intensity levels they perceived for various types of physical activity.

Physical exertion expressed with an increase in HR, breathing rate, and sweating did not always have a positive linear relation with exercise intensity. For example, some respondents indicated only a mild increase in these parameters after a moderate- or vigorous-intensity exercise, whereas others indicated a significant increase following a mild- or moderate-intensity exercise. This result underscores the importance of considering individual fitness levels and prior exercise habits when expressing activity intensity with these simplified degrees of physical exertion.

Providing specific activity examples is another popular method of describing activity intensity, as shown in many physical activity questionnaires. For example, jogging and aerobic exercise are often used as examples of moderate or vigorous activities, whereas walking is presented as an example of light- or moderate-intensity exercise. Although the intensity of certain activities was consistently rated higher than others in this survey, we also observed a wide variation in individual ratings given by the participants.

All the 10 activity examples have standardized MET values greater than 3, which indicates at least a moderate level of intensity. The participants gave different intensity ratings to the activities that shared the same standardized MET value. This finding confirms that standardized MET values are not a robust method for communicating activity intensities. Corrected MET values that incorporate one's gender, age, and BMI can be an alternative that better quantifies the activity intensity at an individual level [12,28]. However, its usefulness as a means of representing and communicating personalized activity intensity should be further investigated.

Various characteristics of the respondents affected the intensity ratings of the 10 activity examples to varying degrees. The regression analysis showed that perceived health status and

attitude toward regular exercise were stronger predictors of the intensity ratings of the example activities. Those who were in good health perceived presented activities less physically demanding, thus tended to rate lower than their counterparts. Similarly, those who responded that regular exercise is important for their health tended to rate the intensity of the presented activities significantly lower than their counterparts. The respondents' demographics were not strong predictors of the numeric intensity rating, although the female respondents tended to rate jogging, swimming, and walking activities higher than the male respondents. In this survey, the race effect on the intensity rating was not apparent, except that the respondents with white race tended to rate walking higher than the respondents with other races.

According to the survey results, the majority of the participants who considered themselves in good health responded that they exercised regularly and that regular exercise was important to their health. One possible explanation for the significantly lower intensity ratings among the participants with good health is that, overall, they were in better physical fitness and thus usually experienced relatively less exertion from various physical activities. This finding suggests that physical fitness and exercise habit directly affect one's intensity perception. Therefore, we may need to pay more attention to an individual person's fitness and exercise habits when selecting physical activity examples to communicate activity intensity.

The survey results did not show any noticeable associations between the intensity level of exercise that the participants usually performed and the physical exertion they experienced after exercise measured with the simplified degrees of increase in HR, breathing rate, and sweating. Similarly, the relative exertion levels experienced after exercise were not among the participants' characteristics most significantly associated with the different intensity ratings of the 10 activity examples. Those who reported experiencing relatively lower exertion after exercise tended to give lower intensity ratings than their counterparts for some activities, but this trend did not stand out compared with other participants' characteristics. This finding suggests that describing activity intensity solely with the simplified degrees of exertion presented with the level of increase in HR, breathing rate, and sweating can be vulnerable to misinterpretation.

Limitations

As per any study that involves survey data, this study is not free from data quality issues. As an attempt to include valid responses only, we removed the cases with a large percentage of missing or implausible answers (eg, giving an intensity rating of 10 to all 10 activity examples). However, there is no guarantee that the anonymized responses collected for this study are the truthful reflection of participants' characteristics and their perceptions of physical activities.

Using the MTurk, we obtained study participants who were restricted to being enrolled in a crowdsourcing venue as a worker. The participants of such surveys may not represent the health status and behaviors of the general US population [26,29]. The sampled participants also comprised the majority (399/498, 79.9%) of white individuals. These 2 sample characteristics could limit the generalizability of the findings of this study.

Practical Implications

Despite the limitations noted earlier, this study provides useful insights into communicating physical activity with patients. This study confirmed that wide variations exist in how people perceive and interpret the activity intensity expressed by general degree modifiers, physical exertion levels, and activity examples, which are the commonly used methods of describing physical activity intensity in everyday communication. The main lessons learned from this study are highlighted next.

First, this study showed the importance of considering individual differences in exercise habits and physical fitness when discussing physical activity with patients or assessing participants' physical activity level in health behavioral studies. Second, the findings of this study indicate the need to adopt activity intensity descriptors that are easily implementable and sensitive to individual variations in intensity perception. For example, numeric intensity ratings seemed to provide a relatively reliable quantification of activity intensity that individual people experience. The talk test is another simple method for assessing and describing an individualized activity intensity level. Studies have reported mixed findings of their validity as a means of assessing physical exertion after exercising at a precise level [8,22,23]. However, they offer a quick and intuitive method for expressing a personalized intensity level of physical activity and thus can be considered as an alternative approach to describe activity intensity when communicating healthy lifestyle recommendations with patients. Mobile sensor devices may also provide a workable solution to this problem, given that the physical activity types, physical exertion level, and amount are accurately captured. Health behavioral studies that quantify participants' physical activity may need to extend the use of mobile sensor devices to measure activity intensity.

Conclusions

A survey of 498 adult volunteers showed that there exist statistically significant variations in how they perceived and interpreted the intensity of physical activity described using methods widely used in physical activity assessment and documentation. General degree modifiers, activity examples, and the simplified degree of physical exertion do not always convey accurate intensity information because of an individual's internal calibration of the concept of activity intensity. The connection between quantitative standardized metrics and self-reported responses to clinically routine inquiry methods shows wide variations because of individual differences in one's perception and interpretation of those intensity descriptions. If the purpose of assessing and documenting a patient's physical activity level is simply to inquire whether a patient is physically active or not, scrutinizing the precise semantics of intensity concepts might not practically be a critical task. However, to provide clinically meaningful information, revisiting how we describe the intensity attribute of a patient's physical activity seems necessary. We believe there is a need to consider an alternative approach that allows a more accurate and reliable characterization of the intensity level that an individual patient experiences with various physical activities.

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Authors' Contributions

HK designed the study, conducted the literature review and synthesis, conducted the survey, analyzed the data, and wrote the manuscript. JK conducted the literature review and synthesis, designed the survey, interpreted the data analysis results, and wrote the manuscript. RT interpreted the data analysis results and edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The survey questionnaire implemented for this study.
[PDF File (Adobe PDF File), 63 KB - publichealth_v6i2e16303_app1.pdf]

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Abbreviations

%HR max: maximum heart rate
%VO2 max: maximum oxygen uptake rate
EHR: electronic health record
FITT: frequency, intensity, time, and type
HR: heart rate
MET: metabolic equivalent of the task
MTurk: Amazon Mechanical Turk
ONC: Office of National Coordinator for Health Information Technology
RPE: Rating of Perceived Exertion

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Rapid Surveillance Report

The Annual American Men's Internet Survey of Behaviors of Men Who Have Sex With Men in the United States: 2017 Key Indicators Report

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Abstract

The American Men's Internet Survey (AMIS) is an annual Web-based behavioral survey of men who have sex with men (MSM) who live in the United States. This Rapid Surveillance Report describes the fifth cycle of data collection (July 2017 to November 2017: AMIS 2017). The key indicators are the same as those previously reported for past AMIS cycles (December 2013 to May 2014: AMIS 2013; November 2014 to April 2015: AMIS 2014; September 2015 to April 2016: AMIS 2015; and September 2016 to February 2017: AMIS 2016). The AMIS methodology has not substantively changed since AMIS 2016. The MSM were recruited from a variety of websites using banner advertisements and email blasts. Additionally, participants from AMIS 2016 who agreed to be recontacted for future research were emailed a link to AMIS 2017. Men were eligible to participate if they were aged ≥15 years, resided in the United States, provided a valid US zone improvement plan code, and reported ever having sex with a man or identified as gay or bisexual. The analysis was limited to those who reported having oral or anal sex with a male partner in the past 12 months. We examined demographic and recruitment characteristics using multivariable regression modeling (P<.05) stratified by the participants' self-reported HIV status. The AMIS 2017 round of data collection resulted in 10,049 completed surveys from MSM representing every US state, Puerto Rico, and Guam. Participants were mainly non-Hispanic white, over the age of 40 years, living in the Southern United States and urban areas, and recruited from geospatial social networking websites. The plurality (4485/10,049, 44.6%) of participants was in the 40 years and older age group, followed by the youngest age group, 15 to 24 years (2726/10,049, 27.1%). Self-reported HIV prevalence was 9.6% (964/10,049). Compared with HIV-negative or unknown-status participants, HIV-positive participants were more likely to have had anal sex without a condom with a male partner in the past 12 months (adjusted odds ratio [aOR] 2.21, 95% CI 1.86-2.63) and more likely to have had anal sex without a condom with a serodiscordant or an unknown-status partner (aOR 3.13, 95% CI 2.71-3.62). The reported use of marijuana in the past 12 months was higher among HIV-positive participants than HIV-negative or unknown status participants (aOR 1.29, 95% CI 1.09-1.51). The reported use of methamphetamines and other illicit substances in the past 12 months was higher among HIV-positive participants than HIV-negative or unknown status participants (aOR 5.57, 95% CI 4.38-7.09 and aOR 1.93, 95% CI 1.65-2.27, respectively). Most HIV-negative or unknown status participants (7330/9085, 80.7%) reported ever taking an HIV test previously, and 60.6% (5504/9085) reported undergoing HIV testing in the past 12 months. HIV-positive participants were more likely to report testing and diagnosis of sexually transmitted infections than HIV-negative or unknown status participants (aOR 2.85, 95% CI 2.46-3.31 and aOR 2.73, 95% CI 2.29-3.26, respectively).

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KEYWORDS

HIV; internet; men who have sex with men; sexually transmitted infections: surveillance; survey

Introduction

The American Men's Internet Survey (AMIS) is an annual Web-based behavioral survey of men who have sex with men (MSM) who live in the United States. AMIS was developed to produce timely data from large-scale monitoring of behavior trends among MSM recruited on the Web. It was designed to complement the Centers for Disease Control and Prevention's National HIV Behavioral Surveillance (NHBS) system, which collects data on MSM in major US cities every 3 years through venue-based recruitment [1]. An increasing number of MSM are meeting sexual partners through the internet and may have different patterns of sexual risk and HIV testing behaviors compared with MSM recruited through physical venues. AMIS is able to generate annual snapshots of behaviors in a large sample of internet-using MSM with broad geographic diversity as a supplement to venue-based studies, such as the NHBS system. We were also able to collect, update, and share state-level data with public health authorities to inform issues of local relevance by using AMIS.

The methods and past AMIS cycle data (AMIS 2013, AMIS 2014, AMIS 2015, and AMIS 2016) have been previously published [2-5].

This supplemental report has updated the existing information with data collected in AMIS 2017. The methods in AMIS 2017 have not changed from the previously published methods, unless otherwise noted. An in-depth analysis and discussion of multiyear trends for indicators reported herein has been published and includes data for the first 4 cycles of AMIS (AMIS 2013 to AMIS 2016) [6].

Methods

Recruitment and Enrollment

Similar to the previous year's recruitment process, AMIS participants were recruited through convenience sampling from a variety of websites using banner advertisements or email blasts to members of the website (hereafter referred to generically as *ads*). For AMIS 2017, data were collected from July 2017 to November 2017. The survey was not incentivized. Data on the number of clicks on all banner ads were obtained directly from the websites. Men who clicked on the ads were taken directly to the survey website hosted on a secure server administered by SurveyGizmo (Boulder, Colorado). Recruitment was also done by emailing participants from the previous cycle of AMIS (AMIS 2016) who consented to be recontacted for future studies. To be eligible for the survey, participants had to be aged ≥15 years, be a cisgender male, reside in the United States, and report that they either had oral or anal sex with a male partner at least once in the past or identify as gay or bisexual (hereafter referred to as MSM). Persons who were aged <15 years or refused to provide their age were not asked any other screening questions. MSM who met the eligibility criteria and consented to participate in the study started the Web-based survey immediately. The full questionnaire for AMIS 2017 is presented in Multimedia Appendix 1.

Several data cleaning steps were performed on the raw dataset of eligible responses to obtain the final analysis dataset, in the same manner as in previous AMIS cycles [2-6]. Briefly, these steps were as follows: deduplication; limiting to surveys deemed successful, ie, observations with no missing values for the first question of at least two consecutive sections; limiting to participants who reported having oral or anal sex with a male partner in the past 12 months; and zone improvement plan (ZIP) code validation. These steps are further described in detail.

First, to deduplicate survey responses, demographic data for near-complete (>70%) survey responses with nonunique internet protocol addresses were compared, and responses that showed a 100% match for all characteristics were considered to be duplicate responses. Only the observation with highest survey completion was retained. The dataset was, then, limited to those surveys that were deemed successful. Finally, the dataset was restricted to include participants who reported having oral or anal sex in the past 12 months and who provided a valid US ZIP code. ZIP codes were validated in the same manner as done in AMIS 2016 [5]. Valid US ZIP codes were those that could be matched to the ZIP code of county crosswalk files created by the US Department of Housing and Urban Development [7]. Any ZIP codes that could not be matched to this list were, then, hand-validated by checking against the ZIP code locator tool in the US Postal Service website [8]. ZIP codes that could not be found were classified as invalid.

Measures and Analyses

For the AMIS 2017 analyses, participants were categorized as either AMIS 2016 participants who took the survey again or new participants from the website/app based on the target audience and purpose: gay social networking (n=2), gay general interest (n=1), general social networking (n=4), and geospatial social networking (n=2). Recruitment outcomes and demographic characteristics for the AMIS 2017 participants are presented in Tables 1 and 2, and thereafter, they are recategorized according to their original source of recruitment. We did not provide the names of the websites/apps to preserve operator and client privacy, particularly when a category has only 1 operator. Participants whose data were eligible, unduplicated, and successful and who provided consent, reported having male-male sex in the past 12 months, and provided a valid US ZIP code were included in analyses of participant characteristics and behavior.

To facilitate comparisons, the key indicators and analytic approach used in AMIS were designed to mirror those used by the NHBS system [9]. Population density was defined in the same manner as defined in AMIS 2016 and was based on the National Center for Health Statistics Rural-Urban classification scheme for counties [10]. The self-reported HIV status was categorized as HIV-positive, and HIV-negative or unknown status, consistent with surveillance reports produced by the NHBS system [9]. In total, 3 substance use behaviors in the past 12 months were assessed: use of nonprescribed marijuana, use of methamphetamines, and use of any illicit drug other than marijuana or methamphetamines. All other indicators assessed remained unchanged from AMIS 2016 [5].

The analysis methods for AMIS 2017 did not substantively differ from those previously published but are repeated in this report for clarity. Overall, chi-square tests were used to identify whether participant characteristics differed significantly among recruitment sources. Multivariable logistic regression modeling was used to determine significant differences in behaviors based on the self-reported HIV status while controlling for race/ethnicity, age group, NHBS city residency, and type of recruitment website. The metropolitan statistical areas included in the NHBS system in 2017 were as follows: Atlanta, Georgia; Boston, Massachusetts; Chicago, Illinois; Dallas, Texas; Denver, Colorado; Detroit, Michigan; Houston, Texax; Los Angeles, California; Memphis, Tennessee; Miami, Florida; Nassau-Suffolk, New York; New Orleans, Louisiana, New York City, New York; Newark, New Jersey; Philadelphia, Philadelphia; Portland, Oregon; San Diego, California; San Francisco, California; San Juan, Puerto Rico; Seattle, Washington; Virginia Beach-Norfolk, Virginia; and Washington, District of Columbia. HIV testing behaviors were only examined among those who did not report that they were HIV positive, and these data were presented in participant characteristics. The multivariable logistic regression results were presented as Wald chi-square *P* values to denote an independently significant difference in the behavior for each subgroup compared with a reference group. Statistical significance was set at $P<.05$.

Table 1. Recruitment outcomes for the American Men's Internet Survey, United States, 2017.

Recruitment outcomes	Total	Gay social networking (n=2)[a]	General gay interest (n=1)[a]	General social networking (n=4)[a]	Geospatial social networking (n=2)[a]	AMIS[b] 2016 participants
Clicked ad, N	210,505	4700	421	191,958	13,426	N/A[c]
Screened[d], n (%)	69,002 (32.78)	3136 (66.72)	394 (93.59)	51,472 (26.81)	12,306 (91.66)	1694
Ineligible[e], n (%)	40,299 (58.40)	461 (14.70)	247 (62.69)	36,970 (71.83)	2507 (20.37)	114 (6.73)
Not >15 years of age[f]	5297 (13.14)	34 (7.38)	2 (0.81)	5025 (13.59)	230 (9.17)	6 (5.26)
Not male[f]	21,409 (53.13)	345 (74.84)	59 (23.89)	19,084 (51.62)	1832 (73.08)	89 (78.07)
Not MSM[g] ever or not identifying as gay/bisexual[f]	39,528 (98.09)	414 (89.80)	68 (27.53)	36,746 (99.39)	2191 (87.40)	109 (95.61)
Nonresident[f]	19,997 (49.62)	280 (60.74)	236 (95.55)	17,619 (47.66)	1800 (71.80)	62 (54.39)
Eligible[e], n (%)	28,703 (41.60)	2675 (85.30)	147 (37.31)	14,502 (28.17)	9799 (79.63)	1580 (93.27)
Consented[h], n (%)	21,731 (75.71)	2065 (77.20)	129 (87.76)	10,483 (72.29)	7578 (77.33)	1476 (93.42)
Unduplicated[i], n (%)	18,346 (84.42)	1874 (90.75)	120 (93.02)	8328 (79.44)	6682 (88.18)	1342 (90.92)
Success[j], n (%)	11,159 (60.83)	1398 (74.60)	95 (79.17)	4298 (51.61)	4170 (62.41)	1198 (89.27)
MSM in the past 12 months[k], n (%)	10,113 (90.63)	1305 (93.35)	86 (90.53)	3675 (85.50)	3953 (94.80)	1094 (91.32)
Valid ZIP[l] code[m], n (%)	10,049 (99.37)	1293 (99.08)	85 (98.84)	3648 (99.27)	3931 (99.44)	1092 (99.82)

[a]Refers to the number of websites or apps in this category.

[b]AMIS: American Men's Internet Survey.

[c]N/A: not applicable.

[d]Proportion of total participants who clicked the ad, including those who started the screening questionnaire.

[e]Proportion of total participants screened. Participants who did not complete the screening questionnaire were considered ineligible.

[f]Proportion of total ineligible participants, including those who did not respond to the question.

[g]MSM: men who have sex with men.

[h]Proportion of eligible participants.

[i]Proportion of participants who consented. Deduplication removes participants who were marked as duplicates using the internet protocol address and demographic data matching.

[j]Proportion of unduplicated participants. Success removes participants who did not pass the test for survey completeness.

[k]Proportion of successes.

[l]ZIP: zone improvement plan.

[m]Proportion of men who had sex with men in the past 12 months. Valid US ZIP codes were those that could be matched to the ZIP code for county crosswalk files created by the US Department of Housing and Urban Development. Any ZIP codes that could not be matched to this list were then hand-validated by checking against the ZIP code locator tool in the US Postal Service website. ZIP codes that could not be found were classified as invalid.

Table 2. Characteristics of men who have sex with men in the American Men's Internet Survey by recruitment type, United States, 2017.

Participant characteristics	Total	Gay social networking (n=2)[a]	General gay interest (n=1)[a]	General social networking (n=3)[a]	Geospatial social networking (n=2)[a]	AMIS[b] 2016 participants	*P* value[c]
Race/ethnicity, n (%)							**<.001**
Black, non-Hispanic	654 (6.51)	93 (7.19)	1 (1.18)	255 (6.99)	230 (5.85)	75 (6.87)	
Hispanic	1538 (15.31)	69 (5.34)	9 (10.59)	719 (19.71)	614 (15.62)	127 (11.63)	
White, non-Hispanic	6955 (69.21)	1056 (81.67)	70 (82.35)	2371 (64.99)	2662 (67.72)	796 (72.89)	
Other or multiple races	687 (6.84)	51 (3.94)	4 (4.71)	234 (6.41)	315 (8.01)	83 (7.60)	
Age (years), n (%)							**<.001**
15-24	2726 (27.13)	28 (2.17)	6 (7.06)	1736 (47.59)	779 (19.82)	177 (16.21)	
25-29	1246 (12.40)	43 (3.33)	11 (12.94)	288 (7.89)	696 (17.71)	208 (19.05)	
30-39	1592 (15.84)	113 (8.74)	18 (21.18)	358 (9.81)	887 (22.56)	216 (19.78)	
40 or older	4485 (44.63)	1109 (85.77)	50 (58.82)	1266 (34.70)	1569 (39.91)	491 (44.96)	
Region, n (%)							**<.001**
Northeast	1875 (18.66)	266 (20.57)	19 (22.35)	636 (17.43)	763 (19.41)	191 (17.49)	
Midwest	1917 (19.08)	274 (21.19)	11 (12.94)	671 (18.39)	750 (19.08)	211 (19.32)	
South	3849 (38.30)	448 (34.65)	31 (36.47)	1504 (41.23)	1436 (36.53)	430 (39.38)	
West	2398 (23.86)	305 (23.59)	24 (28.24)	837 (22.94)	972 (24.73)	260 (23.81)	
US dependent areas	10 (0.10)	0 (0)	0 (0)	0 (0)	10 (0.25)	0 (0)	
NHBS[d] city resident, n (%)							**.004**
Yes	4127 (41.07)	533 (41.22)	38 (44.71)	1393 (38.19)	1655 (42.10)	508 (46.52)	
No	5922 (58.93)	760 (58.78)	47 (55.29)	2255 (61.81)	2276 (57.90)	584 (53.48)	
Population density[e], n (%)							**<.001**
Urban	4230 (42.09)	481 (37.20)	45 (52.94)	1449 (39.72)	1708 (43.45)	547 (50.09)	
Suburban	2181 (21.70)	351 (27.15)	13 (15.29)	811 (22.23)	793 (20.17)	213 (19.51)	
Small/medium metropolitan	2821 (28.07)	323 (24.98)	23 (27.06)	1104 (30.26)	1101 (28.01)	270 (24.73)	
Rural	806 (8.02)	138 (10.67)	4 (4.71)	284 (7.79)	318 (8.09)	62 (5.68)	
Self-reported HIV status, n (%)							**<.001**
Positive	964 (9.59)	145 (11.21)	12 (14.12)	268 (7.35)	433 (11.02)	106 (9.71)	
Negative	7180 (71.45)	964 (74.56)	64 (75.29)	2268 (62.17)	2954 (75.15)	930 (85.16)	
Unknown	1905 (18.96)	184 (14.23	9 (10.59)	1112 (30.48)	544 (13.84)	56 (5.13)	
Total, n (%)	10,049 (100)	1293 (12.33)	85 (0.85)	3648 (36.30)	3931 (39.12)	1092 (10.87)	N/A[f]

[a]Refers to the number of websites or apps in this category

[b]AMIS: American Men's Internet Survey.

[c]A chi-square test for the difference in characteristics between recruitment types.

[d]NHBS: National HIV Behavioral Surveillance.

[e]The National Center for Health Statistics urban/rural category could not be assigned for 10 participants living in US territories.

[f]Not applicable.

Results

Recruitment Outcomes

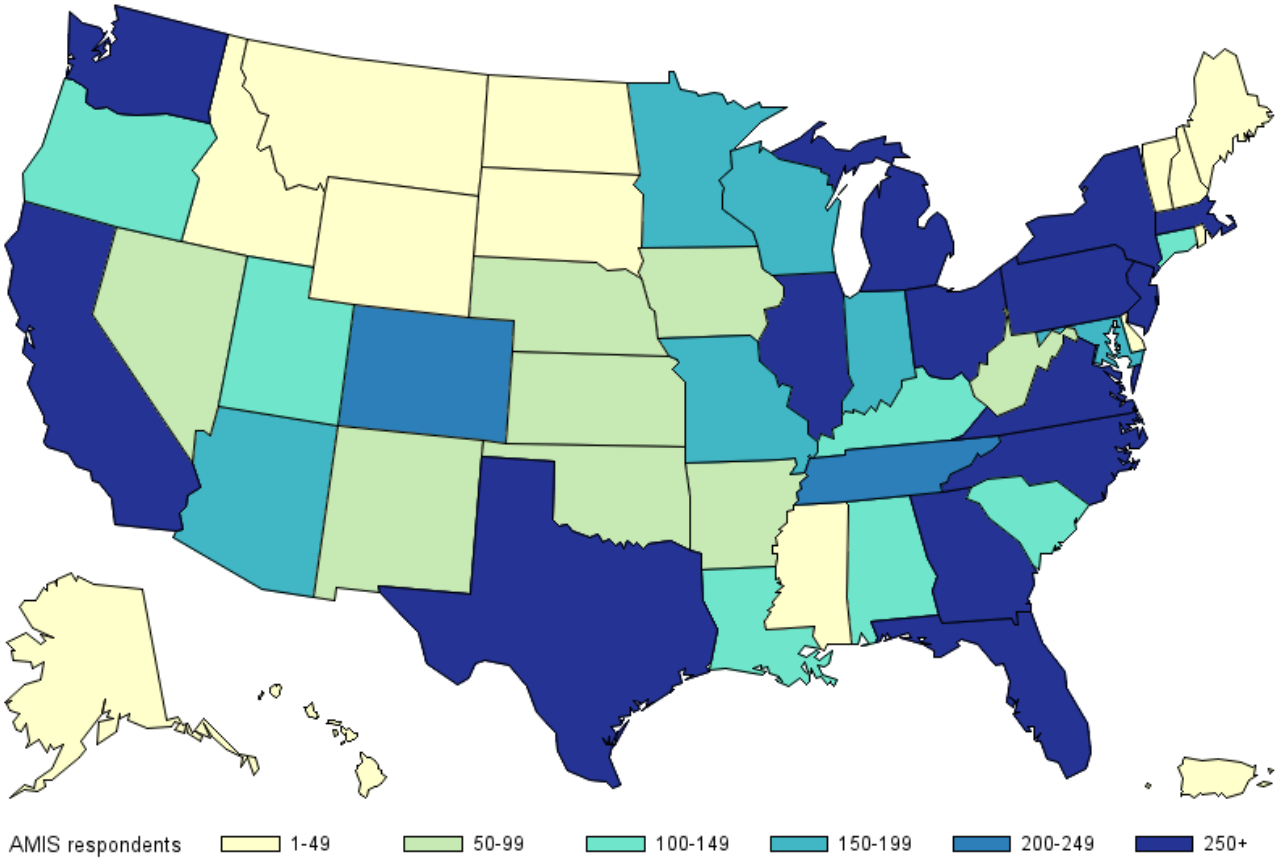
AMIS 2017 was conducted from July 2017 to November 2017 and resulted in 210,505 persons clicking on the ads and landing on the study's recruitment page (Table 1). Most persons who clicked on the ads were from general networking websites (191,958/210,505, 91.1%). Of the 3713 participants who completed the AMIS 2016 survey and were emailed links to the AMIS 2017 survey, 45.6% (1694/3713) clicked on the link. About one-third (32.8%) of all participants who landed on the study page started the screening process and 41.6% of them

were eligible. The most common reason for ineligibility was not ever having male-male sex or not identifying as gay or bisexual. Three-quarter (75.7%) of participants who were eligible consented to participate in the survey. A total of 3385 (15.6%) surveys were likely from duplicate participants. Among unduplicated surveys, 60.8% were considered successful. Most successful surveys were from men who reported having sex with another male in the past 12 months (90.6%). Almost all of these surveys (10,049/10,113, 99.4%) provided a valid US ZIP code. Overall, the completion rate was 4.8%, with an analytical sample consisting of 10,049 surveys from 210,505 clicks.

Participant Characteristics

In total, 69.2% (6955/10,049) of the participants included in this report were non-Hispanic white and 44.6% were ≥40 years of age (4485/10,049); the most common region of residence was the South followed by the West (Table 2). Participants were recruited from all US states, and there were at least 100 participants each from 29 states and the District of Columbia (Figure 1). About 4 in 10 (4127/10,049, 41.1%) participants resided in an NHBS city and about the same proportion (4230/10,049, 42.1%) lived in an urban county. Overall, 9.6% (964/10,049) of participants were HIV positive, 71.5% (7180/10,049) were HIV negative, and 19.0% (1905/10,049) had an unknown HIV status. All participant characteristics differed significantly based on the recruitment source (Table 2).

Figure 1. The number of men who have sex with men who participated in the American Men's Internet Survey (AMIS) by state, 2017.



Sexual Behaviors

Around two-third (6761/10,049, 67.3%) of participants reported having anal sex without a condom with another male in the past 12 months and about one-fifth (2135/10,049, 21.3%) reported doing so with a partner of a discordant or an unknown HIV status (Table 3). Compared with HIV-negative or unknown status participants, those who were HIV positive were significantly more likely to report anal intercourse without a condom (adjusted odds ratio [aOR] 2.21, 95% CI 1.86-2.63), including with male partners who were of a discordant or an unknown status (aOR 3.13, 95% CI 2.71-3.62). Stratified by the serostatus group, anal intercourse without a condom differed significantly by race/ethnicity (HIV-negative or unknown status participants only), age group (HIV-negative or unknown status participants), and recruitment website (HIV-negative or unknown status participants only). Anal intercourse without a condom with partners of a discordant or an unknown HIV status differed significantly by age and residence in an NHBS city for HIV-negative or unknown status participants only and race/ethnicity for both HIV-negative or unknown status participants and HIV-positive status participants.

Table 3. Sexual behaviors with male partners of men who have sex with men in the American Men's Internet Survey, United States, 2017.

Participant characteristics	Participants (N)	Sexual behaviors with male partners in the past 12 months			
		Anal intercourse without a condom		Anal intercourse without a condom with a partner of a discordant or an unknown HIV status	
		n (%)	*P* value[a]	n (%)	*P* value[a]
HIV positive	964	781 (81.01)	<.001[b]	408 (42.32)	<.001[b]
Race/ethnicity					
Black, non-Hispanic	138	102 (73.91)	.07	39 (28.26)	.01
Hispanic	139	115 (82.73)	.54	56 (40.29)	.66
White, non-Hispanic	617	511 (82.82)	Ref[a]	292 (47.33)	Ref[a]
Other or multiple races	53	42 (79.25)	.70	18 (33.96)	.47
Age (years)					
15-24	39	29 (74.36)	.09	22 (56.41)	.16
25-29	78	70 (89.74)	.05	38 (48.72)	.55
30-39	172	151 (87.79)	.28	86 (50.00)	.75
40 or older	675	531 (78.67)	Ref[a]	262 (38.81)	Ref[a]
NHBS[c] city resident					
Yes	454	377 (83.04)	.11	187 (41.19)	.95
No	510	404 (79.22)	Ref[a]	221 (43.33)	Ref[a]
Recruitment type					
Gay social networking	157	119 (75.80)	.16	80 (50.96)	.12
General gay interest	12	11 (91.67)	.40	6 (50.00)	.80
General social networking	332	261 (78.61)	Ref[a]	126 (37.95)	Ref[a]
Geospatial social networking	462	389 (84.20)	.98	195 (42.21)	.34
HIV negative or unknown status	9085	5980 (65.82)	Ref[b]	1727 (19.01)	Ref[b]
Race/ethnicity					
Black, non-Hispanic	516	332 (64.34)	.34	129 (25.00)	.007
Hispanic	1399	953 (68.12)	.008	288 (20.59)	.85
White, non-Hispanic	6338	4186 (66.05)	Ref[a]	1161 (18.32)	Ref[a]
Other or multiple races	634	398 (62.78)	.04	121 (19.10)	.23
Age (years)					
15-24	2687	1665 (61.97)	<.001	476 (17.72)	.02
25-29	1168	849 (72.69)	<.001	235 (20.12)	.45
30-39	1420	1042 (73.38)	<.001	311 (21.90)	.02
40 or older	3810	2424 (63.62)	Ref[a]	705 (18.50)	Ref[a]
NHBS[c] city resident					
Yes	3673	2464 (67.08)	.10	746 (20.31)	.047
No	5412	3516 (64.97)	Ref[a]	981 (18.13)	Ref[a]
Recruitment type					
Gay social networking	1268	723 (57.02)	<.001	247 (19.48)	.42
General gay interest	102	68 (66.67)	.98	18 (17.65)	.57

Participant characteristics	Participants (N)	Sexual behaviors with male partners in the past 12 months			
		Anal intercourse without a condom		Anal intercourse without a condom with a partner of a discordant or an unknown HIV status	
		n (%)	*P* value[a]	n (%)	*P* value[a]
General social networking	4022	2588 (64.35)	Ref[a]	748 (18.60)	Ref[a]
Geospatial social networking	3688	2597 (70.42)	<.001	713 (19.33)	.74

[a]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) between groups with specific characteristics and a reference group (Ref).

[b]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) among HIV-positive participants and HIV-negative or unknown-serostatus participants. Model controlled for race/ethnicity, age, NHBS system city residency, and recruitment type.

[c]NHBS: National HIV Behavioral Surveillance.

Substance Use Behaviors

In total, 27.6% (2775/10,049) of participants reported using marijuana, 5.9% (363/10,049) reported using methamphetamines, and 20.8% (2086/10,049) reported using other illicit substances in the past 12 months (Table 4). Compared with HIV-negative or unknown status participants, HIV-positive participants were significantly more likely to report the use of marijuana (aOR 1.29, 95% CI 1.09-1.51), methamphetamines (aOR 5.57, 95% CI 4.38-7.09), and other illicit substances (aOR 1.93, 95% CI 1.65-2.27) in the past 12 months. Among HIV-positive participants, the use of marijuana varied significantly by NHBS city residency, and the use of methamphetamines varied significantly by the recruitment website. In this group, the use of other illicit substances varied significantly by race/ethnicity and residence in an NHBS city. Additionally, the use of marijuana, methamphetamines, and other illicit substances differed significantly by age among HIV-negative or unknown status participants. In this group, the use of marijuana and other illicit substances differed significantly by race/ethnicity and residence in an NHBS city, and the use of other illicit substances differed significantly by the recruitment website.

Table 4. Substance use behaviors of men who have sex with men in the American Men's Internet Survey, United States, 2017.

Participant characteristics	Participants (N)	Used marijuana		Used methamphetamines		Used other substance(s)	
		n (%)	*P* value[a]	n (%)	*P* value[a]	n (%)	*P* value[a]
HIV positive	964	255 (26.45)	.002[b]	136 (14.11)	<.001[b]	274 (28.42)	<.001[b]
Race/ethnicity							
Black, non-Hispanic	138	28 (20.29)	.16	10 (7.25)	.09	23 (16.67)	.003
Hispanic	139	41 (29.50)	.24	17 (12.23)	.77	40 (28.78)	.74
White, non-Hispanic	617	172 (27.88)	Ref[a]	100 (16.21)	Ref[a]	192 (31.12)	Ref[a]
Other or multiple races	53	10 (18.87)	.35	5 (9.43)	.74	15 (28.30)	.58
Age (years)							
15-24	39	12 (30.77)	.76	5 (12.82)	.89	9 (23.08)	.41
25-29	78	22 (28.21)	.95	8 (10.26)	.33	26 (33.33)	.36
30-39	172	62 (36.05)	.20	35 (20.35)	.10	68 (39.53)	.07
40 or older	675	159 (23.56)	Ref[a]	88 (13.04)	Ref[a]	171 (25.33)	Ref[a]
NHBS[c] city resident							
Yes	454	135 (29.74)	.02	67 (14.76)	.27	146 (32.16)	.006
No	510	120 (23.53)	Ref[a]	69 (13.53)	Ref[a]	128 (25.10)	Ref[a]
Recruitment type							
Gay social networking	157	31 (19.75)	.76	11 (7.01)	.02	33 (21.02)	.09
General gay interest	12	2 (16.67)	.41	0 (0.00)	N/A[d]	5 (41.67)	.37
General social networking	332	92 (27.71)	Ref[a]	40 (12.05)	Ref[a]	86 (25.90)	Ref[a]
Geospatial social networking	462	129 (27.92)	.26	84 (18.18)	<.001	149 (32.25)	.66
HIV negative or unknown status	9085	2520 (27.74)	Ref[b]	227 (2.50)	Ref[b]	1812 (19.94)	Ref[b]
Race/ethnicity							
Black, non-Hispanic	516	132 (25.58)	.40	11 (2.13)	.27	73 (14.15)	.001
Hispanic	1399	456 (32.59)	.33	34 (2.43)	.51	322 (23.02)	.002
White, non-Hispanic	6338	1703 (26.87)	Ref[a]	152 (2.40)	Ref[a]	1259 (19.86)	Ref[a]
Other or multiple races	634	166 (26.18)	.046	22 (3.47)	.08	113 (17.82)	.22
Age (years)							
15-24	2687	1016 (37.81)	<.001	35 (1.30)	.002	597 (22.22)	.09
25-29	1168	394 (33.73)	<.001	25 (2.14)	.51	297 (25.43)	<.001
30-39	1420	444 (31.27)	.048	55 (3.87)	.001	377 (26.55)	<.001
40 or older	3810	666 (17.48)	Ref[a]	112 (2.94)	Ref[a]	541 (14.20)	Ref[a]
NHBS[c]city resident							
Yes	3673	1097 (29.87)	<.001	103 (2.80)	.56	823 (22.41)	<.001
No	5412	1423 (26.29)	Ref[a]	124 (2.29)	Ref[a]	989 (18.27)	Ref[a]
Recruitment type							
Gay social networking	1268	240 (18.93)	.66	48 (3.79)	.10	190 (14.98)	.90
General gay interest	102	25 (24.51)	.97	4 (3.92)	.88	19 (18.63)	.68
General social networking	4022	1243 (30.91)	Ref[a]	57 (42)	Ref[a]	767 (19.07)	Ref[a]

Participant characteristics	Participants (N)	Used marijuana		Used methamphetamines		Used other substance(s)	
		n (%)	*P* value[a]	n (%)	*P* value[a]	n (%)	*P* value[a]
Geospatial social networking	3688	1012 (27.44)	.80	118 (3.20)	.46	835 (22.64)	.046

[a]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) between groups with specific characteristics and a reference group (Ref).

[b]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) among HIV-positive participants and HIV-negative or unknown-serostatus participants. Model controlled for race/ethnicity, age, National HIV Behavioral Surveillance system city residency, and recruitment type.

[c]NHBS: National HIV Behavioral Surveillance.

[d]N/A: not applicable.

HIV Testing Behaviors

HIV testing behaviors were examined among participants who were not HIV positive (Table 5). Most participants (7330/9085, 80.7%) were previously tested for HIV infection, and 60.6% (5504/9085) were tested in the past 12 months. HIV testing behavior, both ever tested and tested in the past 12 months, differed significantly by race/ethnicity, age, residence in an NHBS city, and type of recruitment website.

Table 5. HIV testing behaviors of HIV-negative or unknown-status men who have sex with men in the American Men's Internet Survey, United States, 2017.

Participant characteristics	Participants (N)	HIV testing behaviors			
		HIV tested, ever		HIV tested, past 12 months	
		n (%)	*P* value[a]	n (%)	*P* value[a]
Race/ethnicity					
Black, non-Hispanic	516	445 (86.24)	.005	353 (68.41)	.01
Hispanic	1399	991 (70.84)	.09	814 (58.18)	.51
White, non-Hispanic	6338	5244 (82.74)	Ref[a]	3814 (60.18)	Ref
Other or multiple races	634	489 (77.13)	.23	398 (62.78)	.95
Age (years)					
15-24	2687	1478 (55.01)	<.001	1210 (45.03)	<.001
25-29	1168	1034 (88.53)	.05	846 (72.43)	<.001
30-39	1420	1310 (92.25)	<.001	1032 (72.68)	<.001
40 or older	3810	3508 (92.07)	Ref	2416 (63.41)	Ref
NHBS[b] city resident					
Yes	3673	3081 (83.88)	<.001	2417 (65.80)	<.001
No	5412	4249 (78.51)	Ref	3087 (57.04)	Ref
Recruitment type					
Gay social networking	1268	1094 (86.28)	<.001	741 (58.44)	.03
General gay interest	102	94 (92.16)	.17	60 (58.82)	.24
General social networking	4022	2916 (72.50)	Ref	2076 (51.62)	Ref
Geospatial social networking	3688	3222 (87.36)	<.001	2623 (71.12)	<.001
Total	9085	7330 (80.68)	N/A[c]	5504 (60.58)	N/A

[a]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) between groups with specific characteristics and a reference (Ref) group.

[b]NHBS: National HIV Behavioral Surveillance.

[c]N/A: not applicable.

Sexually Transmitted Infection Testing and Diagnosis

In total, 42.2% (4243/10,049) of participants reported sexually transmitted infection (STI) testing in the past 12 months and just 11.5% (1153/10,049) reported a diagnosis of STI in the past 12 months. Compared with HIV-negative or unknown status participants, HIV-positive participants were significantly more likely to report STI testing (aOR 2.85, 95% CI 2.46-3.31) and STI diagnosis (aOR 2.73, 95% CI 2.29-3.26) in the past 12 months (Table 6). The most common STI diagnosis among HIV-positive participants was syphilis (137/964, 14.2%), followed by gonorrhea (116/964, 12.0%), and chlamydia (112/964, 11.6%). Chlamydia was the most common STI diagnosis among HIV-negative or unknown status participants (501/9085, 5.5%), followed by gonorrhea (481/9085, 5.3%) and syphilis (267/9085, 2.9%). STI testing significantly differed by age, residence in an NHBS city, and recruitment website among both HIV-positive status participants and HIV-negative or unknown status participants. STI testing also significantly differed by race/ethnicity for HIV-negative or unknown status participants. STI diagnosis significantly differed by race/ethnicity (HIV-negative or unknown status participants only), age (HIV-negative or unknown status participants only), residency in an NHBS city (both HIV-positive status participants and HIV-negative or unknown status participants), and recruitment website (HIV-negative or unknown status participants only).

Table 6. Sexually transmitted infection testing and diagnosis of men who have sex with men in the American Men's Internet Survey, United States, 2017.

Participant characteristics	Participants (N)	STI[a] history in the past 12 months			
		Tested for any STI		Diagnosed with any STI	
		n (%)	*P* value[b]	n (%)	*P* value[b]
HIV positive	964	641 (66.49)	<.001[c]	236 (24.48)	<.001[c]
Race/ethnicity					
Black, non-Hispanic	138	94 (68.12)	.82	43 (31.16)	.08
Hispanic	139	97 (69.78)	.75	42 (30.22)	.68
White, non-Hispanic	617	401 (64.99)	Ref[b]	133 (21.56)	Ref[b]
Other or multiple races	53	39 (73.58)	.57	12 (22.64)	.31
Age (years)					
15-24	39	25 (64.10)	.31	13 (33.33)	.52
25-29	78	64 (82.05)	.03	28 (35.90)	.40
30-39	172	131 (76.16)	.44	60 (34.88)	.48
40 or older	675	421 (62.37)	Ref[b]	135 (20.00)	Ref[b]
NHBS[d] city resident					
Yes	454	324 (71.37)	.005	128 (28.19)	.04
No	510	317 (62.16)	Ref[b]	108 (21.18)	Ref[b]
Recruitment type					
Gay social networking	157	96 (61.15	>.99	27 (17.20)	.29
General gay interest	12	7 (58.33	.53	3 (25.00)	.79
General social networking	332	193 (58.13	Ref[b]	61 (18.37)	Ref[b]
Geospatial social networking	462	344 (74.46	.01	145 (31.39)	.07
HIV negative or unknown status	9085	3602 (39.65)	Ref[c]	917 (10.09)	Ref[c]
Race/ethnicity					
Black, non-Hispanic	516	248 (48.06)	.009	84 (16.28)	<.001
Hispanic	1399	609 (43.53)	.26	177 (12.65)	.56
White, non-Hispanic	6338	2409 (38.01)	Ref[b]	568 (8.96)	Ref[b]
Other or multiple races	634	262 (41.32)	.11	68 (10.73)	.07
Age (years)					
15-24	2687	875 (32.56)	<.001	227 (8.45)	.004
25-29	1168	606 (51.88)	<.001	172 (14.73)	<.001
30-39	1420	714 (50.28)	<.001	217 (15.28)	.003
40 or older	3810	1407 (36.93)	Ref[b]	301 (7.90)	Ref[b]
NHBS[d] city resident					
Yes	3673	1740 (47.37)	<.001	482 (13.12)	<.001
No	5412	1862 (34.41)	Ref[b]	435 (8.04)	Ref[b]
Recruitment type					
Gay social networking	1268	416 (32.81)	.005	74 (5.84)	.009
General gay interest	102	42 (41.18)	.92	9 (8.82)	.92

Participant characteristics	Participants (N)	STI[a] history in the past 12 months			
		Tested for any STI		Diagnosed with any STI	
		n (%)	*P* value[b]	n (%)	*P* value[b]
General social networking	4022	134 (33.37)	Ref[b]	297 (7.38)	Ref[b]
Geospatial social networking	3688	1799 (48.78)	<.001	537 (14.56)	<.001

[a]STI: sexually transmitted infection (includes chlamydia, gonorrhea, and syphilis).

[b]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) between groups with specific characteristics and a reference (Ref) group.

[c]Wald chi-square *P* values from the multivariate logistic regression model comparing behavior (yes vs no) among HIV-positive participants and HIV-negative or unknown-serostatus participants. Model controlled for race/ethnicity, age, NHBS system city residency, and recruitment type.

[d]NHBS: National HIV Behavioral Surveillance.

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Conflicts of Interest

TS and PS are members of the Editorial Board of JMIR Public Health and Surveillance. However, they had no involvement in the editorial decision for this manuscript. It was reviewed and handled by an independent editor.

Multimedia Appendix 1
American Men's Internet Survey 2017 questionnaire.
[DOCX File , 357 KB - publichealth_v6i2e16847_app1.docx]

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Abbreviations

AMIS: American Men's Internet Survey
MSM: men who have sex with men
NHBS: National HIV Behavioral Surveillance System
STI: sexually transmitted infection
ZIP: zone improvement plan

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Original Paper

Collateral Crises of Gun Preparation and the COVID-19 Pandemic: Infodemiology Study

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Abstract

Background: In the past, national emergencies in the United States have resulted in increased gun preparation (ie, purchasing new guns or removing guns from storage); in turn, these gun actions have effected increases in firearm injuries and deaths.

Objective: The aim of this paper was to assess the extent to which interest in gun preparation has increased amid the coronavirus disease (COVID-19) pandemic using data from Google searches related to purchasing and cleaning guns.

Methods: We fit an Autoregressive Integrated Moving Average (ARIMA) model over Google search data from January 2004 up to the week that US President Donald Trump declared COVID-19 a national emergency. We used this model to forecast Google search volumes, creating a counterfactual of the number of gun preparation searches we would expect if the COVID-19 pandemic had not occurred, and reported observed deviations from this counterfactual.

Results: Google searches related to preparing guns have surged to unprecedented levels, approximately 40% higher than previously reported spikes following the Sandy Hook, CT and Parkland, FL shootings and 158% (95% CI 73-270) greater than would be expected if the COVID-19 pandemic had not occurred. In absolute terms, approximately 2.1 million searches related to gun preparation were performed over just 34 days. States severely affected by COVID-19 appear to have some of the greatest increases in the number of searches.

Conclusions: Our results corroborate media reports that gun purchases are increasing amid the COVID-19 pandemic and provide more precise geographic and temporal trends. Policy makers should invest in disseminating evidence-based educational tools about gun risks and safety procedures to avert a collateral public health crisis.

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KEYWORDS

COVID-19; gun; firearm; surveillance; injury

Introduction

Collateral threats to population health from the coronavirus disease (COVID-19) pandemic should not be ignored. COVID-19 has effected political and economic uncertainty worldwide, and the World Health Organization has called for public health practitioners to monitor health hazards that may emerge from individuals' attempts to cope with these exceptional circumstances [1].

Firearm injuries may be one such hazard. Citing examples of past emergencies [2], it has been suggested that individuals will respond to the uncertainty of the COVID-19 pandemic by

preparing guns, including buying new guns or removing guns from lockers or other storage units. The link between gun access and unintentional firearm injury/death is well established in the literature. For example, Bangalore and Messerli [3] used survey and administrative data from 27 developed countries and found a significant correlation between the number of guns per capita in a country and the rate of firearm-related deaths (P<.001). Within the United States, Miller et al [4] found a strong and robust correlation between gun availability and unintentional firearm deaths at the state level. For example, they estimated that the risk of unintentional firearm death in US states with the highest level of gun availability was approximately nine times that in states with the lowest level of gun availability.

Unfortunately, traditional surveillance of gun preparation is limited [5]. Since 1996, the US Congress has dramatically restricted the ability of the National Institutes of Health and the Centers for Disease Control and Prevention to conduct gun violence research. This constraint was recently eased; however, funding for this research still only totals $25 million [6]. The main source of public data related to legal gun sales is monthly reports from the Federal Bureau of Investigation (FBI) National Instant Criminal Background Check System (NICS); however, these reports only represent background checks, not sales, and they are only available on a monthly basis at nationally aggregated and state levels. Many of these background checks are conducted for purposes other than new gun sales (ie, permit renewals). Further, these data may be unhelpful to local stakeholders who are hoping to respond to weekly or even daily changes in the sentiment surrounding guns. Finally, this system only accounts for people buying guns from sellers who require a background check; it does not include online firearms sales from private sellers, sales at gun shows, or illegal purchases. The uncertainty and rapidly changing circumstances of a pandemic such as COVID-19 only amplify the limitations of traditional data, as policy makers and other stakeholders have limited time to design and implement interventions before permanent damage to population health is incurred.

Consequently, we turn to infodemiology [7-9], a field defined as “the science of distribution and determinants of information in an electronic medium, specifically the Internet, or in a population, with the ultimate aim to inform public health and public policy” [10]. Infodemiology is particularly useful in situations where relevant traditional data is not readily available, such as when researchers wish to provide a timely response to an epidemic [11-13] or to predict emerging population health concerns [14].

One prominent infodemiology tool that has been used frequently in public health as well as in other gun control research is Google Trends [15], a web application and application programming interface (API) that allows users to provide a set of keywords and a timeframe of interest and retrieve the proportion of all Google searches containing those keywords over that timeframe. Google Trends has become an important data source for studies in public health surveillance generally [16] and for gun violence research in particular. For example, in past studies, Google Trends was used to assess the effect of mass shooting incidents on public interest in gun control [17], to approximate gun ownership [18], and to predict gun purchases [19] and firearm injuries [20]. In this study, we used Google Trends to assess gun preparation amid the COVID-19 pandemic.

Methods

Data

We extracted weekly data on all US Google searches (including state-level data) related to gun preparation, that is, searches that contain the terms “buy gun(s)” or “clean gun(s)” (eg, “how to clean gun” or “where to buy guns”), executed between January 4, 2004 and April 11, 2020 from the Google Trends for Health API. That is, we programmatically queried the Google Trends for Health API for the United States and for each individual US state for weekly data regarding searches matching any combination of those two lists between January 1, 2004 and April 12, 2020. The code used to pull this data from the Google Trends for Health API is available from the authors upon request. The API reports these data as “query fractions,” or the fraction of all Google searches that include the focal terms, thereby accounting for differences in overall Google usage over time and across locations.

Statistical Analysis

We first described trends in US gun preparation searches. We extrapolated query fractions to raw count estimates using publicly available data from Comscore [21]. Specifically, we assumed that the number of searches remained at the level of the most recently available data (February 2020), that searches were conducted uniformly throughout the month, and that desktop searches represented 35% of all searches. Using these assumptions, we calculated estimates for the number of Google searches per day, which allowed us to extrapolate the number of searches related to gun preparation from the Google Trends query fraction. Although this method only provides a rough estimate, it is a common approach in the Google Trends health literature [22].

Next, we fit an Autoregressive Integrated Moving Average (ARIMA) model using the Hyndman-Khandakar algorithm [23] over all US query fraction values up to March 7, 2020. We chose this cutoff because US President Donald Trump declared COVID-19 a national emergency on March 13, 2020, which is included in the data for the following week. We forecasted query fraction values for the United States from March 8, 2020 to April 11, 2020 and reported the difference between the actual and forecasted values. Finally, we calculated the percentage change ((after – before)/before × 100%) in the mean query fractions before and after the onset of the pandemic (using January 1, 2020 to March 7, 2020 as the preperiod) for each state with bootstrapped confidence intervals. We used a univariate linear regression and data from USAFacts.org [24] to calculate the correlation between this percentage change and the number of COVID-19 deaths per capita in the postperiod by state.

Analyses were conducted using R version 3.6.3 (R Foundation) with α=.05.

Results

By March 21, 2020, approximately 1000 of every 10 million Google searches were related to gun preparation. For reference, this query fraction is 35% and 48% greater than the spikes occurring after the mass shootings in Sandy Hook, Connecticut in 2012 and in Parkland, Florida in 2018, respectively (Figure 1A). The fraction of Google searches related to gun preparation significantly (P<.05) exceeded the ARIMA-forecasted values for each week since President Trump declared a national emergency. Approximately 2.1 million gun preparation searches were executed between March 8 and April 11, 2020, which is 158% greater (95% CI 73-270) than would be expected if the COVID-19 pandemic had not occurred.

Figure 1A shows the fraction of Google search queries that relate to gun preparation between January 1, 2004, the first date for which data is available, and April 11, 2020. The blue line is the actual fraction of Google searches. The dotted vertical line is placed at March 7, 2020, denoting the breakpoint between the preperiod and the postperiod, which was chosen based on the week in which President Trump declared COVID-19 a national emergency. Figure 1B shows the fraction of Google search queries that relate to gun preparation between January 1, 2020 and April 11, 2020. The dark blue line is the actual fraction of Google searches. The light blue line represents the expected fraction of Google searches based upon the ARIMA model fitted over data from January 1, 2004 to March 7, 2020. The dotted vertical line is placed at March 7, 2020. The shaded area represents excess searches (ie, searches in excess of the number forecasted by the ARIMA model). Figure 1C shows the percentage change in the query fractions for the preperiod between January 1, 2020 and March 7, 2020 and the postperiod between March 8, 2020 and April 11, 2020.

Forty-nine states (all but Alaska) and the District of Columbia experienced increases in gun preparation searches. The states most affected by the pandemic in the early period examined in this study appear to have particularly high percentage changes in searches, including California (269%, 95% CI 120-477), New York (210%, 95% CI 81-380), Connecticut (201%, 95% CI 90-356), and Washington (167%, 95% CI 85-262). In an ecological, state-level univariate regression, we found that a 1 percent increase in the COVID-19 death rate (ie, COVID-19 deaths per 100,000) was correlated at the state level with an approximately 0.31 higher percent change (95% CI 0.10-0.51) in gun preparation searches. Figure 2 shows the correlation between the natural logarithm of the number of COVID-19 deaths per 100,000 people occurring during the postperiod (plus 1 to correct for infinite values) and the percentage change in gun preparation searches between the preperiod and the postperiod. The preperiod is defined as the dates between January 1, 2020 and March 7, 2020 and the postperiod is defined as dates between March 8, 2020 and April 11, 2020. The labels represent individual states, the red line represents a univariate linear regression model, the gray area represents the confidence interval for that univariate regression model, and the parameter estimates in the bottom right corner refer to the results of that model.

Figure 1. Google searches for gun preparation before and during the COVID-19 pandemic. A) The fraction of Google search queries that relate to gun preparation between January 1, 2004 and April 11, 2020. B) The fraction of Google search queries that relate to gun preparation between January 1, 2020 and April 11, 2020. C) The percentage change in the query fractions for a preperiod between January 1, 2020 and March 7, 2020 and a postperiod between March 8, 2020 and April 11, 2020.

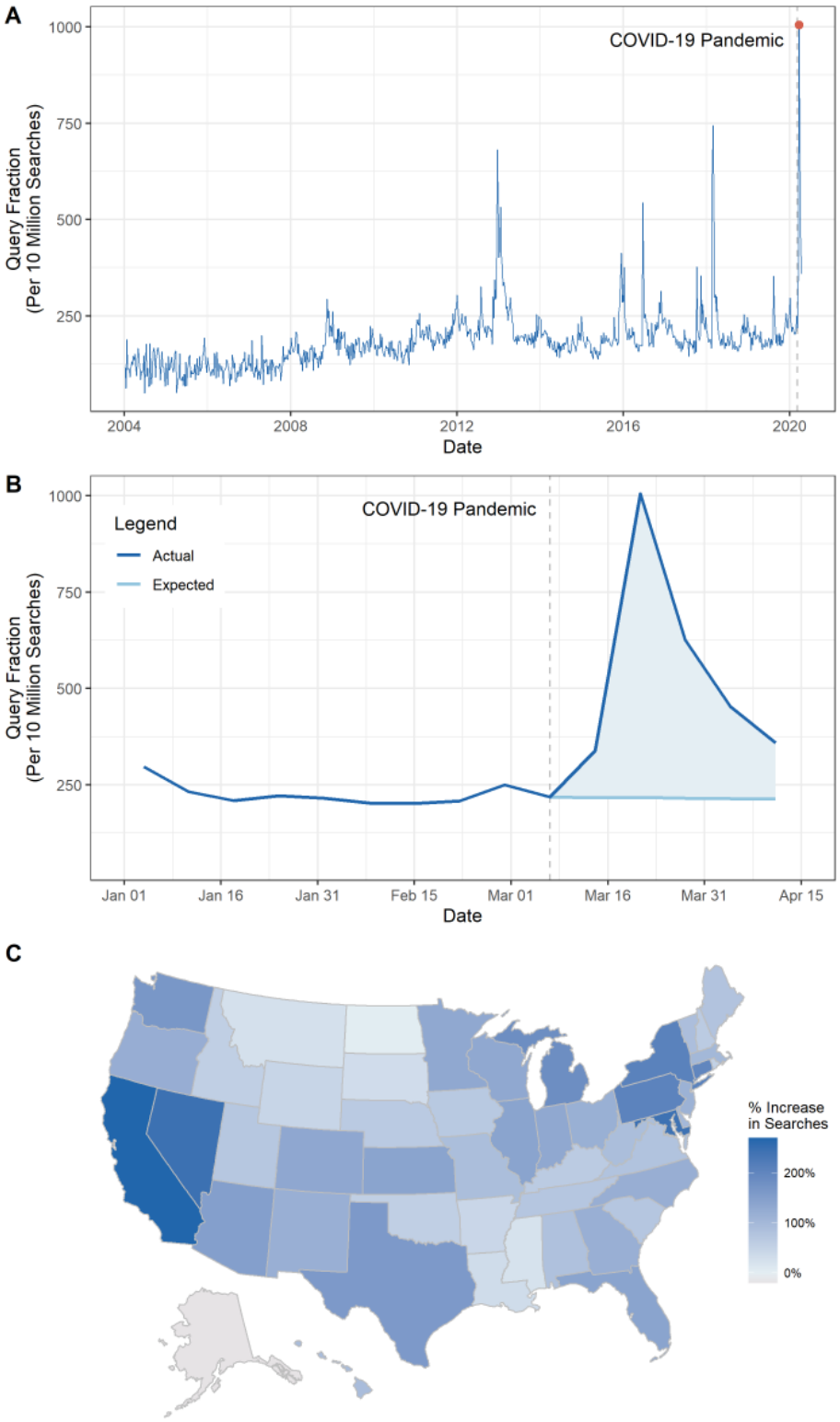
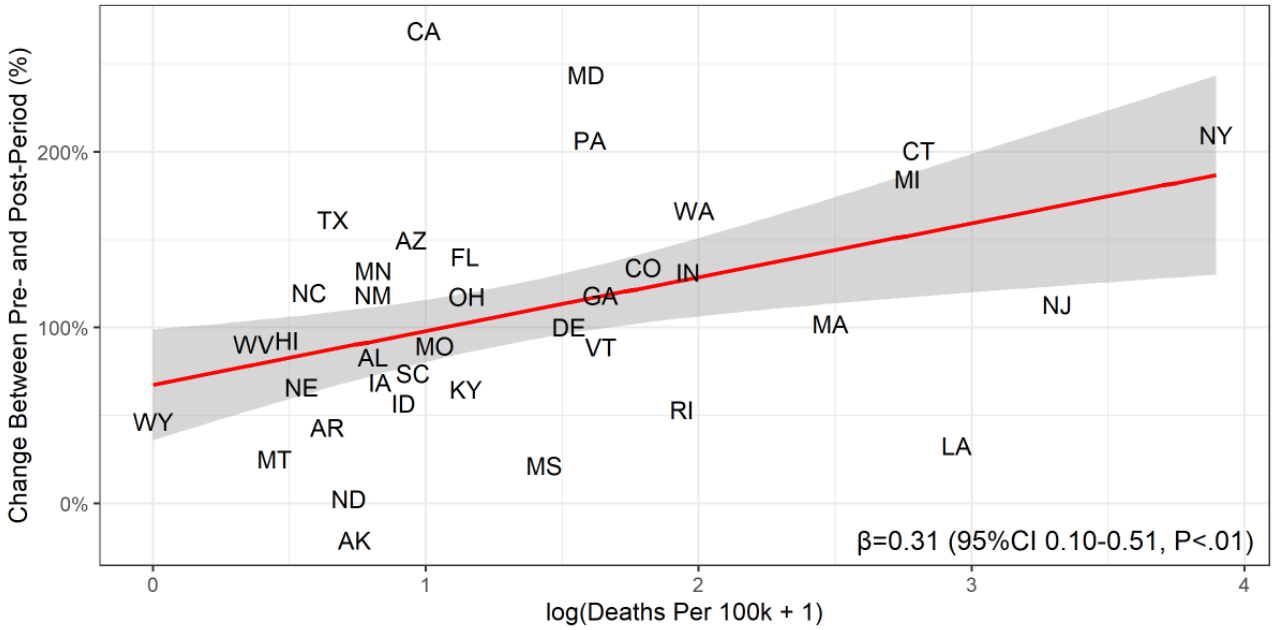


Figure 2. State-level correlation between the COVID-19 death rate and the percentage increase in gun preparation searches.



Discussion

Principal Findings

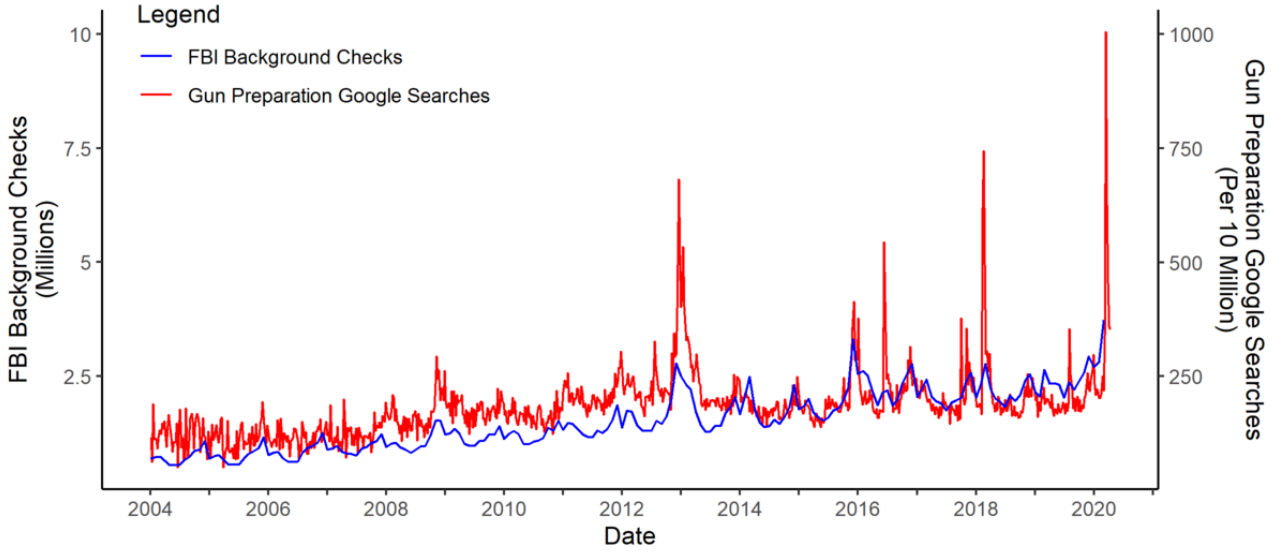
Public interest in gun preparation has reached unprecedented levels amid the COVID-19 pandemic, approximately 40% greater than the spikes occurring after the Sandy Hook and Parkland, Florida shootings. Increases in interest appear to be concentrated in the areas most affected by COVID-19.

This study demonstrates the value that Google search data presents to policy makers, regulators, advocates, and other stakeholders for surveillance of gun preparation. Public health professionals must be able to nimbly respond to the changing and frequently diverse health needs of the public. Google search data is timelier and has better temporal and geographic precision than the administrative data available for gun violence in the United States, and public health professionals should leverage these advantages so they can respond to the public at the exact times and in the exact states that are necessary. For example, our study shows that Google searches related to preparing guns are still elevated relative to expectations.

Limitations

This study has limitations. We only observed the volume of Google searches related to gun preparation, not the motivation for each search. All studies using aggregate Google searches are limited in that it is impossible to observe the etiology of a search. However, a previous study found that search volumes using these exact search terms significantly predicted both gun purchases and firearm injuries/deaths [20], and we observed similar trends between these searches and FBI NICS estimates in past periods (Figure 3); this increases our confidence that these searches will predict similar outcomes. Additionally, studies across several public health domains have demonstrated that Google searches can predict traditional surveillance metrics [25-27]. Analytically, our state-level correlation is an ecological analysis and does not imply an individual-level correlation between COVID-19 deaths and gun preparation [28].

Figure 3. Correlation between gun preparation Google searches and FBI background checks. The weekly gun preparation Google searches (red line) are overlaid with the monthly numbers of background checks provided by the FBI National Instant Criminal Background Check System. FBI: Federal Bureau of Investigation.



Conclusions

Given the well-established association between access to guns and firearm injuries, this surge in interest may compound the health risks of the COVID-19 pandemic.

Gun safety organizations, such as Everytown for Gun Safety, have created evidence-based materials and programs to educate the public on the risks of owning a firearm and the necessary safety precautions responsible gun owners should take to reduce the risk to themselves and their families [29]. Our results represent a call to action for policy makers, advocates, and public health officials to invest in educating the public and broadly disseminating these materials.

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Conflicts of Interest

MD receives consulting fees from Bloomberg LP and Good Analytics.

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Abbreviations

API: application programming interface
ARIMA: Autoregressive Integrated Moving Average
COVID-19: coronavirus disease
FBI: Federal Bureau of Investigation
NICS: National Instant Criminal Background Check System

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Original Paper

Assessing Bias in Population Size Estimates Among Hidden Populations When Using the Service Multiplier Method Combined With Respondent-Driven Sampling Surveys: Survey Study

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Abstract

Background: Population size estimates (PSEs) for hidden populations at increased risk of HIV, including female sex workers (FSWs), are important to inform public health policy and resource allocation. The service multiplier method (SMM) is commonly used to estimate the sizes of hidden populations. We used this method to obtain PSEs for FSWs at 9 sites in Zimbabwe and explored methods for assessing potential biases that could arise in using this approach.

Objective: This study aimed to guide the assessment of biases that arise when estimating the population sizes of hidden populations using the SMM combined with respondent-driven sampling (RDS) surveys.

Methods: We conducted RDS surveys at 9 sites in late 2013, where the Sisters with a Voice program (the program), which collects program visit data of FSWs, was also present. Using the SMM, we obtained PSEs for FSWs at each site by dividing the number of FSWs who attended the program, based on program records, by the RDS-II weighted proportion of FSWs who reported attending this program in the previous 6 months in the RDS surveys. Both the RDS weighting and SMM make a number of assumptions, potentially leading to biases if the assumptions are not met. To test these assumptions, we used convergence and bottleneck plots to assess seed dependence of RDS-II proportion estimates, chi-square tests to assess if there was an association between the characteristics of FSWs and their knowledge of program existence, and logistic regression to compare the characteristics of FSWs attending the program with those recruited to RDS surveys.

Results: The PSEs ranged from 194 (95% CI 62-325) to 805 (95% CI 456-1142) across 9 sites from May to November 2013. The 95% CIs for the majority of sites were wide. In some sites, the RDS-II proportion of women who reported program use in the RDS surveys may have been influenced by the characteristics of selected seeds, and we also observed bottlenecks in some sites. There was no evidence of association between characteristics of FSWs and knowledge of program existence, and in the majority of sites, there was no evidence that the characteristics of the populations differed between RDS and program data.

Conclusions: We used a series of rigorous methods to explore potential biases in our PSEs. We were able to identify the biases and their potential direction, but we could not determine the ultimate direction of these biases in our PSEs. We have evidence that the PSEs in most sites may be biased and a suggestion that the bias is toward underestimation, and this should be considered if the PSEs are to be used. These tests for bias should be included when undertaking population size estimation using the SMM combined with RDS surveys.

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KEYWORDS

service multiplier method; respondent-driven sampling; population size estimation; female sex workers; key populations; HIV; Zimbabwe

Introduction

Background

In sub-Saharan Africa, female sex workers (FSWs) are at increased risk of HIV acquisition compared with the general population [1,2]. The Joint United Nations Programme on HIV/AIDS recommends targeted HIV surveillance among FSWs and other highly at-risk yet socially marginalized populations [3]. Population size estimates (PSEs) of these key populations are important for the design and evaluation of public health policy and serve as the basis for allocation of resources for treatment and prevention programs as well as informing modeled estimates of the epidemic [4]. However, there is no *gold standard* population size estimation method; estimates are subject to a range of different biases, and studies employing multiple approaches can show a wide variance in the estimates from each method [5-7]. Methods and standards for investigating and reporting assumptions and likely biases would improve the ability of policymakers to interpret and utilize PSEs appropriately.

The service multiplier method (SMM) is a commonly used method to estimate the size of key populations. The method uses 2 data sources [5-12], one of which is a count or listing of clients who are accessing a service, for example, the number of FSWs who attended a certain program or who were arrested by the police over a given period. The second data source is a probability-based sample of the population [3,11,13] in which participants are asked about their attendance at that program or arrest over the same period. The service usage count is divided by the proportion of participants in the survey who report using the service within the given time frame to yield a PSE.

In recent applications, respondent-driven sampling (RDS) surveys have been used to obtain a probability-based estimate of the proportion of the target population who are service users [5,7,11]. RDS exploits the social network structure of hard-to-reach populations for recruitment. If a given set of assumptions holds, weighted data from RDS can be interpreted as providing a representative sample of the network of the population sampled [14,15]. Although RDS has become an increasingly popular means of surveying key populations, the extent to which RDS estimates can be taken as representative has been questioned [16-18]. Investigating the sampling process over the network against assumptions can help us understand potential biases. There are now guidelines for conducting relevant diagnostics [19] and reporting them [20], but there is a need to illustrate the use of this guidance for use in obtaining PSEs with the SMM.

In addition to the SMM, various approaches for population size estimation have been used, including the enumeration method [3,12], the census method [3], the capture recapture method [3,12,21,22], and the unique object multiplier method [3,23]. As recommended, triangulating data from multiple methods have also been used to estimate the size of hard-to-reach populations [5,7,10]. In some settings, a high degree of agreement between methods has been found [12], whereas in other settings, there was evidence of bias between methods that could go in either direction [24,25].

Objectives

In this paper, we build on existing guidance for implementing the SMM with RDS data [11] to critically appraise the assumptions and likely biases arising from using the SMM and RDS surveys to estimate the population sizes of FSWs at 9 sites in Zimbabwe, providing an illustrative example for assessing bias in future applications of the method.

Methods

We first describe the data sources used, our application of the SMM, and then our approach to investigating the degree to which our study met the methodological assumptions and the potential resulting biases.

Data Sources

Service data come from the *Sisters with a Voice* program (hereafter, *the program*) run on behalf of Zimbabwe's National AIDS Council and Ministry of Health and Child Care. The program provides reproductive and sexual health services to women, identifying themselves as sex workers [26]. During their first visit to the program, FSWs are given a unique program identifier so that their visits to the program can be linked over geography and time [26]. For each individual who attends a program site, her unique identifier, date of visit, demographic information, HIV testing history, and the main reason for the visit are recorded. The program identifier is a combination of the first 2 letters of the name of the site where they first accessed program services and some numbers. The identifier should not be missing because it is a requirement for a woman to access services and in the event that they have forgotten their identifier, demographics are used to retrieve their history as well their identifier.

The probability-based sample comes from a baseline RDS survey of the Sisters Antiretroviral therapy Program for Prevention of HIV—an Integrated Response (SAPPH-IRe) trial, a cluster randomized controlled trial that was conducted among FSWs at 14 different sites across Zimbabwe in November and December 2013 (PACTR201312000722390) [27,28]. RDS recruitment took a maximum of 35 days across the 14 sites. In this PSE study, we included 9 sites that had had the program operational for at least six months before the baseline survey. These were all small towns and truck stops, not big cities. The estimated population size of all adult females aged 15 to 49 years during the 2012 census at these 9 sites was 33,302 at site 1, 8399 at site 2, 8694 at site 3, 15,407 at site 4, 10,329 at site

5, 7484 at site 6, 26,745 at site 7, 9085 at site 8, and 30,633 at site 9 [29]. Women were eligible to participate in the SAPPH-IRe baseline trial survey if they were aged ≥18 years on the survey date; had exchanged vaginal or anal sex for money, goods, or gifts at one of the study sites in the past month; and presented a valid recruitment coupon as explained below [30]. We asked survey participants for information on sociodemographics, sexual behavior, and HIV testing practices.

To initiate RDS recruitment, we purposively sampled 6 to 8 participants (*seeds*) from subgroups of the target population at each site, through the mapping of sex work in each community by geography, age, and sex work typology [31,32]. Seeds were not identified through program attendance to avoid bias. After participation in the survey, participants who were seeds were each provided with 2 uniquely coded coupons to recruit their peers [15,30,33]. Recruited peers then undertook study procedures and were further provided with 2 coupons that they used to recruit more members of the target population [14,15,19]. The process proceeded until the desired sample size (determined according to the trial's primary outcome [31]) was attained, with 5 waves of recruitment following seeds, to approximately 200 FSWs at each site.

Determining Unique Visits to the Program

To determine *M*, the number of visits to the program of unique women within the reference period, FSWs were counted only once using their identifier [11]. We excluded women aged <18 years to match the eligibility criteria for RDS participation, which was ≥18 years. We did not make any other restrictions as the RDS was attempting to sample from the same group of women accessing the program. Visits to the program by unique FSWs at each site were assumed to have happened at a constant rate, therefore following a Poisson distribution with the mean number of counts being the number of FSWs who were counted to have attended the program in the specified 6 months [11]. We used the normal approximation to Poisson distribution with the mean and variance equal to the number of FSWs who attended the program to determine the variability in the number of FSWs who attended the program at each site in the specified 6 months [11].

Population Size Estimation

We applied the formula for the SMM,  where *N* is the estimated population size of FSWs at each site, *P* is the RDS-adjusted population proportion of FSWs who reported program attendance 6 months before the RDS survey, and *M* is the total number of FSWs who attended the program within a period of 6 months before the RDS survey [5,7,11]. The proportion of women who reported attending the program in the previous 6 months was determined by first asking if the participant had heard of the program and then asking if they had attended in this time. To solicit for the last 6-month recall period for program attendance, the question in the RDS questionnaire relating to this was, "In the past 6 months, i.e. since dd/mm/yyyy, have you attended the *Sisters with a Voice* clinic."

The RDS-II estimator was used to estimate P [34], and the network size used for weighting was the number of FSWs a participant would consider recruiting to the study among the total number of FSWs they knew would meet the eligibility criteria, and whom they had met in the last month. The network size question was asked after 2 follow-up questions and in the following order: How many sex workers do you know personally who live in your area, who are over 18, where you know their name and they know yours?; How many of those sex workers who you know personally have you seen in the last month?; and How many of those sex workers who you know personally would you consider recruiting to the study?

As recommended, we used the delta method to estimate the variance of *N* by combining the variances of *P* and *M* using the following formula:  where μ_m is the mean of *M* and μ_p is the mean of P [11,35].

Checking the Validity of Population Size Estimates

The SMM makes at least four assumptions, including (1) all members of the population being counted should have a chance of being included in both sources [3,11], (2) data sources should have the same and clear time references, age ranges, geographic areas, and individuals should not be counted more than once in each data source [3,7,11], (3) the 2 data sources should be independent of each other, that is, the inclusion of individuals in one source should not be related to the inclusion of individuals in the other source [3,11], and (4) the representative data source should be a random sample of the target population [7,11]. In our case, this latter assumption relates to the extent to which the (weighted) RDS survey sample can be treated as a representative sample, that is, met the assumptions of the RDS estimation.

For RDS-II estimates to be considered unbiased, assumptions including reciprocity, sampling with replacement, a completely connected networked population at each site, accurate report of personal network size, final sample independent of the original seeds, and random recruitment have to be satisfied [14,19,33,34,36-40]. We used existing guidance relating to RDS-II diagnostics [19] and interpreted them for their effect on the PSEs.

Reciprocity is an assumption of the Markov process, which states that if individual A recruited individual B, then in principle, B could have recruited A [36]. Given the dual system of incentives, this assumption is most likely to hold because participants would prefer to pass coupons to their friends and acquaintances rather than strangers [38]. The assumption is violated if respondents recruit strangers [36]. Sampling with replacement is also a Markov assumption that states that the respondent could be contacted again to participate in a study more than once [14,33,36]. Sampling with replacement assumption is violated when using RDS-I or RDS-II estimators, because in real-life RDS studies, sampling is without replacement, that is, the same individual cannot participate more than once in the survey. One could choose to use the RDS successive sampling estimator, which does not rely on the sampling with replacement assumption [41], but this estimator requires a PSE to already be available. A completely networked population requires that individuals from the target population should know each other and should communicate [36]. If

individuals do not know each other, then it is not possible to come up with a representative sample of the sampled population because some individuals will not be accessible through the network and hence have zero probability of inclusion. Accurate report of personal network size by each RDS survey participant is important because network size is used in the computation of weights [34]. The final sample that is independent of the original seeds is the RDS-II estimator assumption that the sampling waves are sufficiently large such that the final estimates are independent of the bias that can be induced by the purposively selected seeds [14,19]. Another assumption of the RDS-II estimator is random recruitment, which states that respondents recruit randomly from their personal network [33,36]. This assumption is violated if recruiters preferentially recruit recruitees with particular characteristics from among their personal networks [36].

Other potential biases in *P* include recall bias where women may misremember dates and/or may not have recognized a service they visited as the program service and mobility (including mobility in and out of sex work) as a sampling bias where women who access the program may not be sampled at the time of the survey, and those who are sampled may not have potentially used these services over the past 6 months. A bias in the estimation of *M* could arise if the program failed to perfectly identify unique women visiting in the reference period.

We, therefore, investigated some of the RDS and SMM assumptions listed in Table 1 that were possible to investigate using available data and considered the resulting potential for biases in the PSEs.

Table 1. Respondent-driven sampling and service multiplier method assumptions.

Assumption	Criteria	Expected outcome
Representative data source should be a random sample of the target population		
Check all RDS-II[a] assumptions		
Reciprocity (N/A[b])	Ask participants' relationship to the person who gave them a study coupon and if they say *stranger* then reciprocity will not be fulfilled.	Participants more likely to be recruited by friends and acquaintances.
Sampling with replacement (N/A)	Always violated in real-life RDS[c] studies, when the RDS successive sampling estimator is not used.	—[d]
Accurate report of personal network size (N/A)	Sensitivity analysis of different network size questions.	RDS estimates should agree with each other regardless of different network size questions used.
Final sample independent of the original seeds	Assess whether seed dependence was removed using convergence plots.	Overall estimate of *P* converges to the final estimate of *P* and remains stable as additional participants are recruited.
Completely connected networked population at each site	Assess whether the FSW[e] population is networked using bottleneck plots.	Estimate of *P* from individual seeds converge to a shared estimate.
Random recruitment	Assess whether there is an indication of nonrandom recruitment by measuring recruitment homophily.	Recruitment homophily should be approximately 1.
Two data sources combined are drawn from the same population, with the RDS data being representative of the target population	Compare sociodemographic and other characteristics of RDS surveys participants reporting program attendance with records of program attenders for the same time reference using logistic regression.	No evidence of difference in characteristics of RDS surveys participants who report program attendance within the reference period and the characteristics of program attenders in the program dataset during the reference period.
All members of the population being counted should have a chance of being included in both sources	Assess if all RDS surveys participants are familiar with the existence of the program by using chi-square tests to compare characteristics of individuals who had ever heard of the program with those who had not across sites.	No evidence of difference between individuals who had ever heard of the program with those who had not.
Data sources should have the same and clear time references, age ranges, geographic areas and individuals should not be counted more than once in each data source.	Assess if time references, age ranges and geographic areas of RDS and program data are similar or not; deduplicate program data if participants visited the program several times during the reference period.	Report if time references, age ranges and geographic areas are similar or not. Deduplicated program data.
The 2 data sources should be independent of each other, that is inclusion of individuals in 1 source should not be related to the inclusion of individuals in the other source.	Do not identify seeds and participants in general through the program; given that seed participants might also be more likely to be program attenders, even if they are not selected on this basis, assess convergence of *P* over time for evidence of seed dependence using convergence plots.	Report how RDS participants were identified and recruited; overall estimate of *P* converges to the final estimate of *P* and remains stable as additional participants are recruited.

[a]RDS-II: RDS Volz-Heckathorn estimator.

[b]N/A: denotes the assumptions that could not be investigated with the data available in this study.

[c]RDS: respondent-driven sampling.

[d]Assumption always violated when other RDS estimators (not the RDS successive sampling estimator) are used.

[e]FSWs: female sex workers.

Assessing Whether Seed Dependence Was Removed

In the RDS framework, seeds are selected purposively with the assumption that if recruitment is done with a sufficiently large number of waves, then the final sample would be independent of the seed characteristics [14]. We used convergence plots to examine whether the cumulative estimate of *P* stabilizes as the sample size increases [19]. A convergence plot shows the estimate of the RDS proportion on the vertical axis and the cumulative RDS sample size on the horizontal axis and is used to show how the overall RDS estimate changes as the sample size increases from wave 0 [19]. If the cumulative estimate appears to be continuing to rise or fall at close of the study, this could imply that the estimate was still dependent on the initial seed characteristics and could overestimate or underestimate the PSE.

Assessing Whether the Female Sex Worker Population Is Networked

We assessed whether the RDS-II weighted cumulative estimates of *P* varied by seed using bottleneck plots. The vertical axis of the bottleneck plot shows the estimate of the RDS proportion and the horizontal axis shows the cumulative RDS sample size, and these are shown separately for each seed (rather than altogether as in a convergence plot). If the individual seed estimates are not all converging toward a shared estimate, it might imply that the population is not really well networked, there is strong segregation into subgroups or that recruitment has got stuck in one branch of the network (a *bottleneck*).

Assessing Whether There Is an Indication of Nonrandom Recruitment

The indication of nonrandom recruitment was investigated by measuring recruitment homophily on *P*. Recruitment homophily is the tendency for women to recruit others like themselves with respect to reporting program attendance. In this case, it is the ratio of the number of recruits that have the same program attendance status as their recruiter to the number, we would expect by chance. If recruitment homophily on *P* is approximately 1, then there is little evidence of recruitment homophily, whereas values larger than 1 indicate more homophily.

Assessing Whether All Members of the Population Have a Chance of Being Included in the Program Data

The SMM requires that all members of the target population have a nonzero probability of being included in both the RDS survey and the program data [3,9], indicating that the target population should be familiar with the existence of the program. If members of the population with certain characteristics seem not to know about the existence of the program, then in theory they might have zero probability of being included in the program data, which violates the stated assumption of the SMM. We used the chi-square test of the RDS-II weighted proportions to compare the characteristics of individuals who had ever heard of the program with those who had not across sites. We used logistic regression models (interaction test of characteristics of individuals and site) to assess whether the association between characteristics and program knowledge differed among sites. The logistic regression model we used for each particular sociodemographic characteristic was $\log(Y_i) = \beta_0 + \beta_1 X$*Site where Y is knowledge of the existence of a program and X represents each individual characteristic.

Assessing Whether the Two Data Sources Combined Are Drawn from the Same Population, With the Respondent-Driven Sampling Data Being Representative of the Target Population

We also assessed the SMM assumption that the 2 data sources to be combined should be drawn from the same population, with the RDS data being representative of this population [3]. Under this assumption, those sampled by RDS who reported attending the program 6 months before the RDS survey was conducted should be representative of those who actually attended the program in the same period of time, that is, they should be similar with respect to sociodemographic and other characteristics. If the characteristics are different, it might suggest that the women included in the RDS survey are not a representative sample of the population, or that there is bias in reporting program attendance among those in the RDS survey. We pooled both data sources and used logistic regression with data source as the outcome to compare the characteristics of FSWs who reported program use in the RDS survey with the characteristics of those in the program data to determine if this was likely the same population. RDS data were RDS-II weighted and program data were not weighted. Again, the interaction test of characteristics of individuals and site was used to assess whether the comparison between RDS data and program data differed among sites.

Statistical Analysis

Unweighted descriptive analyses of program data and RDS-II weighted descriptive analyses of RDS data as well as comparison of the 2 data sources were performed using Stata version 14.2 (StataCorp LLC), and all the other RDS diagnostics were performed using RDS Analyst version 0.5.1, which is based on the RDS package for R [42]. PSE calculations were undertaken for each site separately, as were assessments of convergence, bottlenecks, and homophily. When investigating the association between characteristics of those who had and had not heard about the program, and between characteristics of those who visited the program and those recruited to RDS surveys, we pooled the data across sites. We investigated whether the associations in questions differed by site using an interaction test, and present regression analyses adjusting for a fixed term for site. In pooled site analyses, we used a normalized weighting variable. Pooling of RDS data overcame potential problems with small sample sizes but was a violation of the RDS assumption of 1 complete network component [43].

Results

We recruited a total of 1739 FSWs from 8 seeds at site 1 and 6 seeds from each of the other 8 sites. Of these seeds at each site, only 1 seed had attended the program at site 1, 3 at sites 7 and 9, 5 at sites 2, 3, 5, 6, and 8, and all 6 at site 4.

Population Size Estimates

The PSEs and 95% CIs calculated using the SMM are shown in Table 2.

Table 2. Population size estimates of female sex workers and 95% CI.

Site	RDS[a] sample size	Number of FSWs[b] who attended the program within the last 6 months (M)	SE for M[c]	Percent[d] reporting visit (*P*; 95% CI)	SE for P	Population size estimate	SE for the population size estimate[e]	95% CI	Percent of FSWs among all women aged 15 to 49 years
1	220	57	7.4	20.3 (11.6-29.1)	4.5	281	70.1	133-407	0.8
2	196	100	10.0	25.0 (15.3-34.7)	4.9	400	87.2	225-566	4.8
3	153	111	10.5	46.1 (35.1-57.1)	5.7	241	37.2	166-311	2.8
4	202	372	19.2	68.7 (60.8-76.5)	4	541	42.0	455-619	3.5
5	197	84	9.2	20.6 (5.4-35.8)	7.8	408	160.4	93-722	3.9
6	200	28	5.3	14.3 (5.6-22.4)	4.2	194	67.0	62-325	2.6
7	165	34	5.8	11.0 (7.2-14.8)	1.9	310	75.4	162-458	1.2
8	198	46	6.8	16.7 (7.4-26.1)	4.8	275	88.7	101-449	3.0
9	208	165	12.8	20.5 (12.4-28.7)	4.2	805	175.1	456-1142	2.6

[a]RDS: respondent-driven sampling.

[b]FSWs: female sex workers.

[c]Calculated using the normal approximation to Poisson distribution.

[d]RDS-II adjusted percentages.

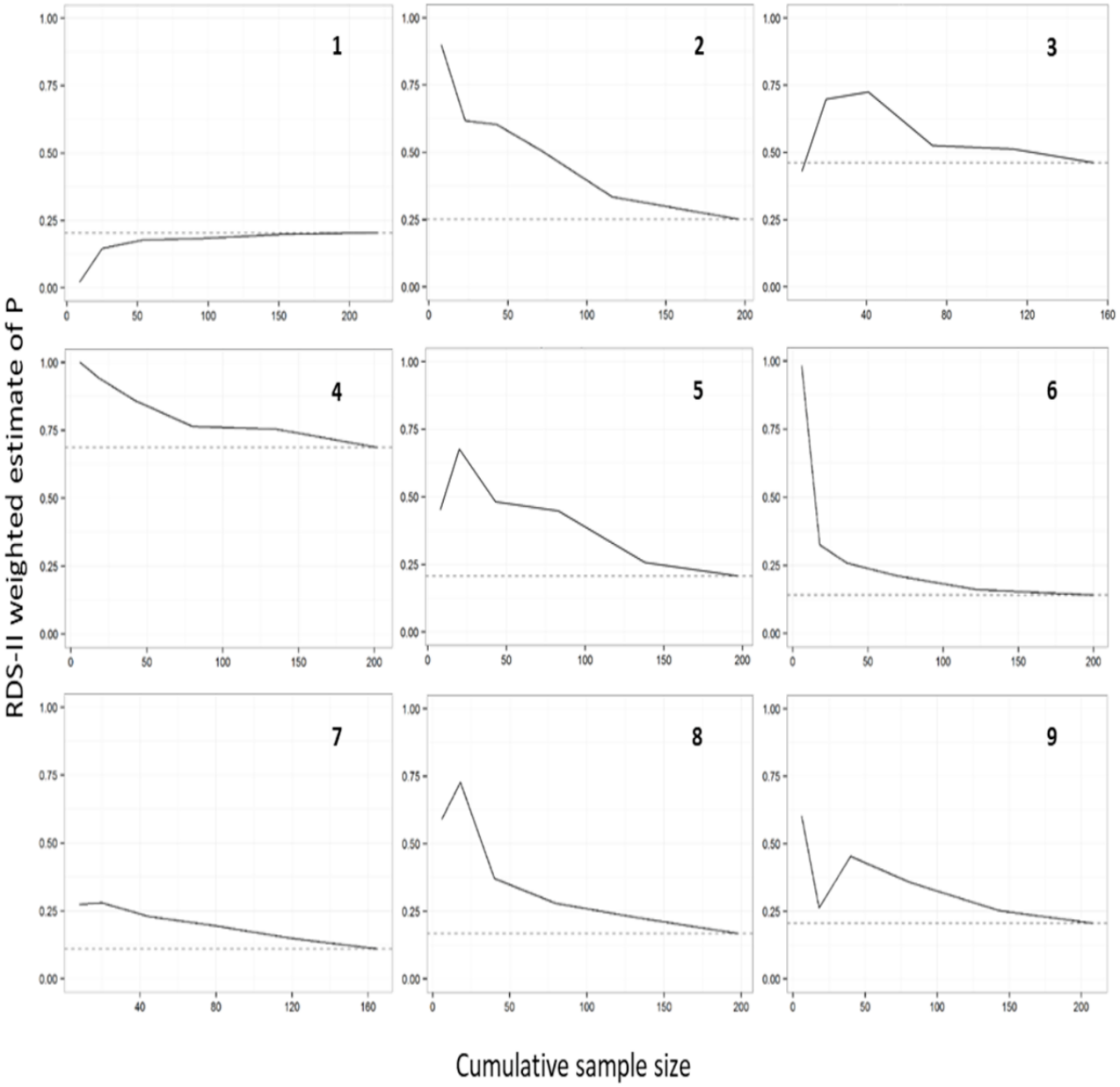
[e]Calculated using the delta method.

The number of women who attended program sites in the previous 6 months before the survey ranged from 28 at a site where the program was relatively new to 372 at a site where the clinic had been established for 2 years. The proportion of FSWs reporting program attendance varied from 11% to 69%. The highest PSE was 805 FSWs (95% CI 456-1142) and the lowest was 194 FSWs (95% CI 62-325). The 95% CIs for the majority of sites were wide (Table 2).

Convergence Plots of P

At sites 1 and 6, the estimate of *P* converged as the sample sizes increased, indicating that the final estimate of *P* might be independent of the seeds (Figure 1). However, at the other 7 sites, the estimate of *P* did not converge and continued to decline as recruitment continued, indicating that the final estimate was still influenced by the characteristics of the seeds and was likely an overestimate of *P*.

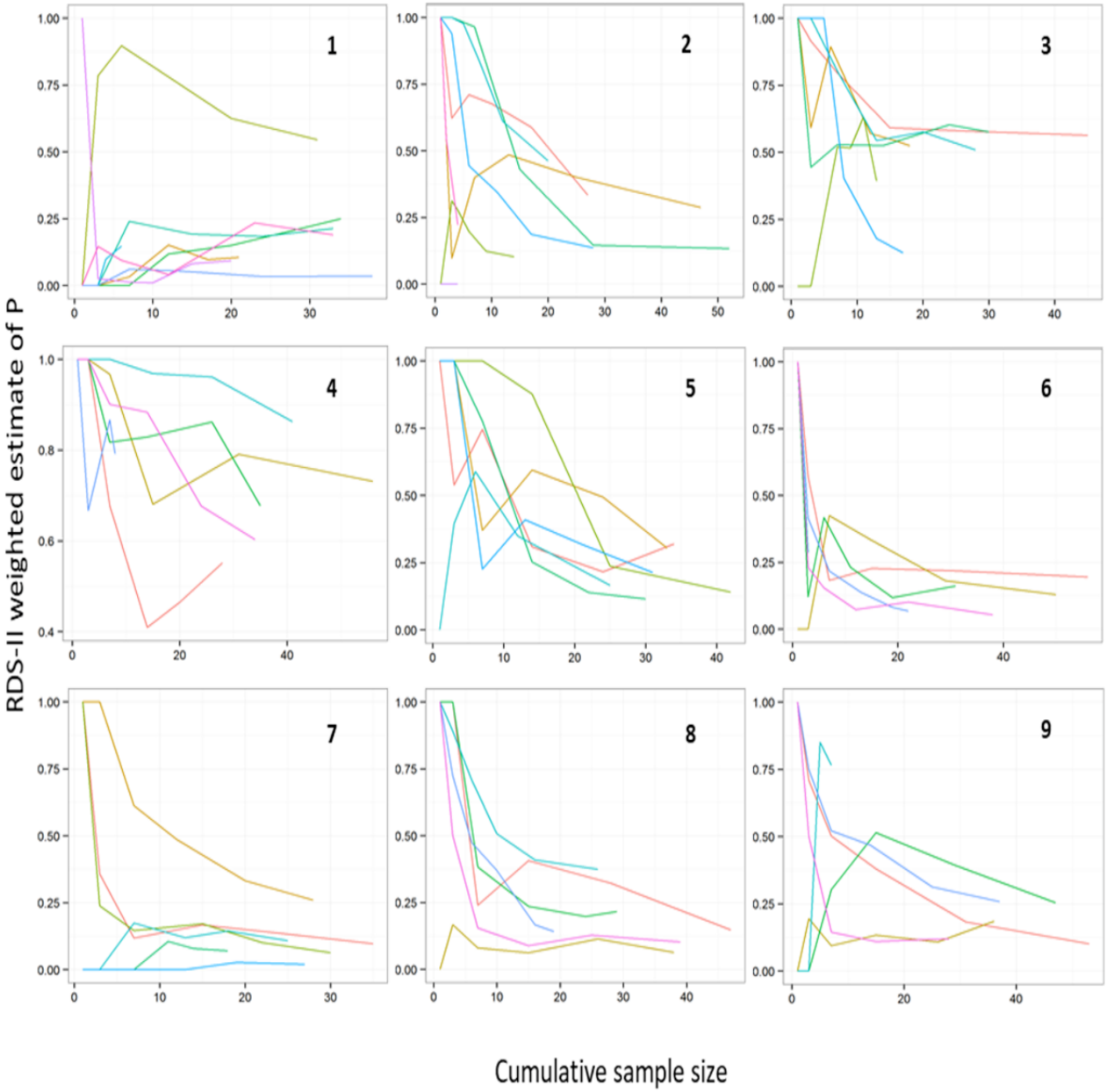
Figure 1. Site convergence plots. RDS-II: respondent-driven sampling Volz-Heckathorn estimator.



Bottleneck Plots

The bottleneck plots (Figure 2) at sites 5, 6, 7, and 8 show the individual tracks converging to a shared estimate, potentially indicating a lack of subgroups in the target population at these sites. The final estimates were 0.21 at site 5, 0.14 at site 6, 0.11 at site 7, and 0.17 at site 8. However, at sites 1, 2, 3, 4, and 9, where the final estimates were 0.20, 0.25, 0.46, 0.69, and 0.21, respectively, individual tracks did not converge, suggesting distinct subgroups.

Figure 2. Site bottleneck plots. RDS-II: respondent-driven sampling Volz-Heckathorn estimator.



Recruitment Homophily

There was little evidence of recruitment homophily, ranging from 0.9 to 1.1 at sites 2 to 9, suggesting a weak tendency for women to recruit others like themselves with respect to reporting program attendance in the past 6 months. However, at site 1, recruitment homophily was moderate (1.4; Table 3).

Table 3. Recruitment homophily in P.

Site	Recruitment homophily in *P*
1	1.39
2	1.14
3	1.04
4	0.96
5	1.05
6	0.97
7	1.00
8	0.92
9	1.21

Distribution of Respondent-Driven Sampling Survey Participants According to Their Knowledge of the Existence of a Program

There was little evidence of an association between the majority of sociodemographic characteristics and knowledge of program existence. Evidence of association was seen for education, where a higher proportion of women who reported secondary school or higher had heard about the program compared with those who reported primary school or none (44% vs 36%; *P*=.02), and for HIV testing, where relatively more women who had ever been tested for HIV had knowledge of program existence compared with those who had not tested (42% vs 27%; *P*=.01; Table 4). There was also little evidence that these relationships were different among sites for the majority of sociodemographic characteristics, except for the number of close friends (*P*=.02) and number of children aged under 18 years (*P*=.01).

Table 4. Association between sociodemographic characteristics and knowledge of program existence among respondent-driven sampling survey participants by site.

Characteristics	Total individuals (N=1739), n	Individuals who have ever heard about the program (N=803), n (%)	Comparison *P* value[a]	Interaction *P* value[b]
Age (years)			.40	.40
18-24	418	174 (36.8)		
25-29	424	202 (40.1)		
30-39	597	284 (43.1)		
40+	299	143 (44.6)		
Marital status			.06	.10
Never married	356	170 (42.1)		
Married or widowed	335	139 (33.3)		
Divorced or separated	1047	494 (43.31)		
Education			.02	.47
Primary or none	531	209 (35.7)		
Secondary or higher	1192	590 (44.13)		
Age when started sex work (years)			.87	.23
<18	343	157 (41.5)		
18-24	630	284 (39.3)		
25-29	398	195 (42.9)		
>30	367	167 (41.2)		
Duration at the site (years)			.32	.52
0-1	186	86 (36.8)		
2-5	587	245 (39.3)		
>5	956	468 (43.7)		
Number of FSWs[c] who are close friends			.13	.02
0	79	43 (49)		
1	372	179 (40.6)		
2-4	1031	457 (38.83)		
>5	256	124 (50.4)		
Number of commercial partners in last week			.24	.32
0	132	59 (36.6)		
1-4	705	312 (38.2)		
5-9	415	205 (45.2)		
>10	486	227 (44.7)		
Number of children < 18 years			.24	.01
0	360	167 (37.5)		
1-2	912	425 (43.8)		
>3	466	211 (38.7)		
Ever been tested for HIV				
No	110	36 (27.0)		
Yes	1628	767 (42.02)		
How many times been tested for HIV[d]			.50	.89
1	292	124 (38.3)		

Characteristics	Total individuals (N=1739), n	Individuals who have ever heard about the program (N=803), n (%)	Comparison *P* value[a]	Interaction *P* value[b]
2-4	910	431 (42.2)		
>5	417	209 (44.9)		
Most recent HIV test result[d]			.36	.93
Negative	898	413 (40.7)		
Positive	720	349 (44.0)		
Condom use			.91	.32
Consistent	1180	540 (40.79)		
Nonconsistent	369	171 (40.3)		

[a]Chi-square *P* value for the association of each characteristic with knowledge of program existence.

[b]*P* value assessing the interaction between sociodemographic characteristics and site.

[c]FSWs: female sex workers.

[d]Among those ever tested for HIV.

Comparison of Program Data With Respondent-Driven Sampling Data

There was little evidence of differences in the distribution of most sociodemographic characteristics between women who attended the program and those who reported program use in RDS data (Table 5). Evidence of a difference was only seen for duration at the site, where a higher proportion (84%) of women who reported program use in the RDS survey reported that they had lived at their respective sites for 2 or more years compared with 75% of those who actually attended the program. There was also no evidence that the distribution of these characteristics was different between sites.

Table 5. Comparison of sociodemographic characteristics of individuals who attended the program and individuals who reported program use in respondent-despondent sampling surveys.

Characteristic	Individuals who reported program use in RDS[a] data (N=535), n (%[a])	Individuals who actually attended the program (N=997), n (%)	Comparison *P* value[b]	Interaction *P* value[c]
Age (years)			.88	.67
18-24	108 (22.4)	187 (19.2)		
25-29	137 (22.7)	246 (25.2)		
30-39	192 (35.1)	370 (38.0)		
>40	98 (19.8)	171 (17.6)		
Marital status			.61	.52
Never married	110 (19.4)	194 (19.8)		
Married or widowed	93 (15.3)	192 (19.6)		
Divorced or separated	332 (65.3)	594 (60.6)		
Education			.47	.16
Primary or none	146 (31.7)	243 (28.0)		
Secondary or higher	386 (68.3)	625 (72.0)		
Duration at the site (years)			.01	.22
0-1	64 (16.1)	225 (25.3)		
>2	467 (83.9)	666 (74.7)		
Number of children under 18 years			.42	.17
0	108 (23.0)	238 (24.0)		
1-2	288 (56.6)	593 (59.8)		
>3	139 (20.4)	161 (16.2)		
Ever been tested for HIV			.18	.75
No	26 (4.9)	64 (6.6)		
Yes	509 (95.1)	911 (93.4)		
Most recent HIV test result			.42	.48
Negative	262 (53.4)	442 (49.7)		
Positive	242 (46.6)	447 (50.3)		

[a]RDS-II (respondent-driven sampling) weighted percentages.

[b]Wald *P* value comparing program data with RDS data.

[c]*P* value assessing the interaction between sociodemographic characteristics and the site.

Discussion

Principal Findings

We combined data on the proportion of FSWs recruited to RDS surveys in 9 Zimbabwean sites and who reported attending the program (*P*), with data relating to the program encounters at these same sites over the same recall period (M). Using these data, we estimated the size of the FSW population at each site using the SMM. Estimated population sizes ranged from 194 (95% CI 62-325) to 805 (95% CI 456-1142) across the sites for the period from June to December 2013, reflecting between 1% and 5% of the total female population aged 15 to 49 years in these sites.

We employed existing RDS diagnostics [19] alongside some additional analyses to explore potential biases affecting the PSEs. We found that FSWs who had accessed the program were more likely to be recruited earlier on in the RDS surveys. In the majority of sites, the estimate of program attendance, *P*, might have been overestimated, which would result in an underestimated PSE. The sources combined were likely not to be independent because some of our seed participants in the RDS surveys were program users who were more likely to recruit program users as evidenced by convergence and bottleneck plots. Having longer recruitment chains could have reduced our likelihood of getting stuck in a subgroup and allowed us to reach parts of the network not previously sampled. A positive correlation resulted in *P* being inflated, ultimately resulting in the underestimation of PSEs. This was also reported by Johnston et al [11] in their size estimation study. In the majority of sites, there was little evidence for high levels of recruitment homophily by program attendance (*P*), with the exception of 1 site. At this same site (site 1), although

convergence had been achieved, the bottleneck plot appeared to show that program attendance might have differed substantially by the subnetwork of FSWs.

We found little evidence that women with particular characteristics were likely excluded from the program, suggesting that the SMM assumption that all members of the target population should have a nonzero probability of being included in both the RDS survey and the program was met. Characteristics of program attendees were similar to RDS participants, suggesting that the data sources were likely from the same population with the RDS surveys representative of the population, therefore partly satisfying the requirements of the SMM.

Strengths and Limitations

The major strength of the SMM is that it can be implemented using data collected for other purposes [21,23,44], unlike other methods such as the enumeration method and the census method [3]. However, this can also be viewed as a weakness: if the existing data are poorly documented or are duplicated, the PSEs will be biased [11,13]. In most cases, sample size calculations for RDS surveys may not have been based on the need to estimate the population size with a reasonable level of precision [45], and the program might be poor in reaching a certain subset of the population of interest such that the subset will not be counted. Additionally, SMM is based on numerous assumptions, and the degree to which they are met is often not reported. The SMM can be expensive if RDS surveys are specifically conducted for population size estimation. On the other hand, this allows the collection of other data with the possibility of estimating population sizes using more than one method, for example, the RDS successive sampling size estimator [46] and a unique object multiplier [3].

This study has several strengths. Our simple and straightforward diagnostics were able to identify potential biases and suggest the potential direction of bias in the PSEs. The RDS survey data were carefully collected with an in-house coupon manager software to track coupons, verify them, and check that they were redeemed only once [32]. The definition of the population of interest was consistent across the program and RDS survey data [11]. Our program records allowed us to compare their characteristics with those recruited to RDS surveys. We clearly and consistently defined time references in both data sources, and this was a strength over other size estimation studies where inconsistent time references were reported [8,9]. Geographic areas in both data sources were clearly defined, and these were discrete urban or peri-urban settings such that anyone from around those specific areas could come to the program or participate in the RDS survey. Our size estimates for each site are plausible given other literature of the estimated proportion of adult women engaged in sex work in a setting similar to ours [47].

Study limitations include the inability to investigate all assumptions made by RDS and SMM. The SAPPH-IRe trial baseline was not set up to be used to estimate PSEs, and as such could not investigate all assumptions made by RDS and SMM. We were not able to assess the RDS assumption of accurate reporting of personal network size by participants. We also could not assess the SMM assumption that the 2 data sources should be independent of each other. We do not have data about every sex worker that a woman knows and all of their characteristics to assess whether the ones she recruits for the survey are a random sample or not (though this would be challenging to collect in practice). The assessment of convergence and bottleneck plots is rather qualitative and relies upon visually assessing graphics, which might result in making subjective conclusions.

Although we checked the design effect for the primary outcome of the trial for which these data were collected, which confirmed that the target sample sizes of 200 were adequate, we did not check the design effect for *P*, and we are not sure about the implications of this. To get an indication of whether the population of FSWs recruited to RDS surveys and those recruited to the program differed, and to assess whether women who had heard of the program differed to those who had not, we combined the RDS samples. This overcame the difficulty of making these assessments with small sample sizes, but it violates the RDS assumption of a completely networked population to do this [43].

Recommendations

Although there is guidance on RDS sample size calculations [45,48] and guidance about assessing the assumptions made for RDS surveys [19], our findings indicate the importance of using RDS diagnostics to assess the estimate of *P* obtained for use in the multiplier method PSEs, and in assessing further multiplier method assumptions where data sources allow. We recommend that they are included when undertaking population size estimation using SMM combined with RDS surveys. PSEs are increasingly being taken up in policy making and by funders to set program targets, even at subnational levels. If the PSEs are assumed to be unbiased, programs may either be expected to reach people who do not exist or be inadequately funded to meet the needs of key populations who are undercounted.

We used a single multiplier for illustrative purposes, but in line with other groups, we recommend the use of more than one as multipliers are prone to unmeasurable bias [49]. PSEs may be considered unbiased when convergence has been reached, no bottlenecks, low homophily, program data are deduplicated, and the 2 study populations have similar characteristics among other criteria.

When incorporating the SMM in RDS surveys for population size estimation, it is important to understand the context in each site, which can be achieved through detailed mapping [5]. Key dynamics include seasonal migration patterns of the population of interest [50] to avoid overestimation in areas where they are immigrating and underestimation in areas where they are emigrating. The way that women meeting study criteria as a *sex worker* actually self-identify and are identified by their peers [51], as well as transition into and out of sex work, are important factors to consider. High-quality survey data are critical. It is recommended to include a large number of waves in RDS studies, although in some of our sites the overall population size was likely relatively small, practically limiting the number of waves that could be implemented. This might have been overcome by having fewer seeds, provided the full diversity of

the FSW population could still be reached. There is a need to keep track of estimates based on program use by using convergence and bottleneck plots such that the sample size could possibly be increased if the estimates do not stabilize [19]. Some further areas of interest include data on reciprocity and questions to assess the random recruitment of the composition of personal networks (though this can be difficult to do in practice) to the RDS questionnaire to enable the further investigation of RDS assumptions [19].

Double counting of participants in program data needs to be minimized, as this could potentially result in overestimation of the PSEs. The program to be used in population size estimation should be accessible to all members of the target population, and members need to be given unique identifiers coupled with collection of additional information such that if they forget their program unique identifiers, they can easily be reminded. This will reduce the problem of duplication in the counting of individuals who attend the program on several occasions and partly contribute to the accurate calculation of PSEs. When estimating key population sizes, the SMM will ideally be triangulated with other population size estimation methods (capture-recapture, census, network scale-up, and SS-PSE). The size estimates obtained from each of these methods can be quite variable [5,7] such that results can be compared and more robust estimates such as the median of all the estimates can be used, with the lowest and highest estimates among the methods treated as the lower and upper confidence bounds, respectively [7].

Conclusions

The SMM can be used to incorporate RDS proportion estimates [11]. Without a *gold standard* method for estimating the population sizes of hard-to-reach populations, the SMM is a recommended method to use [3,7]. We implemented a range of established and bespoke diagnostics in our application and suggest that it is important for researchers to use and publish similar diagnostics when using the SMM combined with RDS surveys.

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Conflicts of Interest

None declared.

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Abbreviations

FSW: female sex worker
PSE: population size estimate
RDS: respondent-driven sampling
SAPPH-IRe: Sisters Antiretroviral therapy Program for Prevention of HIV—an Integrated Response
SMM: service multiplier method

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Corrigenda and Addenda

Correction: Preventive Behaviors Conveyed on YouTube to Mitigate Transmission of COVID-19: Cross-Sectional Study

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Related Article:

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The authors of “Preventive Behaviors Conveyed on YouTube to Mitigate Transmission of COVID-19: Cross-Sectional Study” (JMIR Public Health Surveill 2020;6(2):e18807), noticed the following errors in their published article.

In Table 1, in the row “Stay home when ill”, under the column “News (n=85), n (%)”, the values have been revised from “12 (14)” to “22 (26)”. In the same row, the value under the column “*P* value” has been revised from “.03” to “.28”.

This error did not have any substantive effects on the results or conclusions of the study.

Additionally, the URL in Reference 9 was inadvertently listed as a proxy. Reference 9 has been revised from:

> *Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19): prevention & treatment 2020 URL: https://www-cdc-gov.ezproxy.cul.columbia.edu/coronavirus/2019-ncov/about/prevention-treatment.html [accessed 2020-03-08]*

to:

> *Centers for Disease Control and Prevention. Coronavirus disease 2019 (COVID-19): prevention & treatment 2020 URL: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/prevention.html [accessed 2020-03-08]*

These corrections will appear in the online version of the paper on the JMIR website on May 6, 2020, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Corrigenda and Addenda

Correction: Estimating the Size of Key Populations in Kampala, Uganda: 3-Source Capture-Recapture Study

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Related Article:

Correction of: https://publichealth.jmir.org/2019/3/e12118/

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The article entitled “Estimating the Size of Key Populations in Kampala, Uganda: 3-Source Capture-Recapture Study” (JMIR Public Health Surveill 2019;5(3):e12118) published with a technical error that was introduced after proofreading.

The inline figure was incorrectly inserted as Figure 4. Figure 4 has now been removed from the manuscript.

The correction will appear in the online version of the paper on the JMIR website on May 12, together with the publication of this correction notice. Because this was made after submission to PubMed, PubMed Central, and other full-text repositories, the corrected article has also been resubmitted to those repositories.

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Original Paper

Comparing Methods for Record Linkage for Public Health Action: Matching Algorithm Validation Study

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Abstract

Background: Many public health departments use record linkage between surveillance data and external data sources to inform public health interventions. However, little guidance is available to inform these activities, and many health departments rely on deterministic algorithms that may miss many true matches. In the context of public health action, these missed matches lead to missed opportunities to deliver interventions and may exacerbate existing health inequities.

Objective: This study aimed to compare the performance of record linkage algorithms commonly used in public health practice.

Methods: We compared five deterministic (exact, Stenger, Ocampo 1, Ocampo 2, and Bosh) and two probabilistic record linkage algorithms (fastLink and beta record linkage [BRL]) using simulations and a real-world scenario. We simulated pairs of datasets with varying numbers of errors per record and the number of matching records between the two datasets (ie, overlap). We matched the datasets using each algorithm and calculated their recall (ie, sensitivity, the proportion of true matches identified by the algorithm) and precision (ie, positive predictive value, the proportion of matches identified by the algorithm that were true matches). We estimated the average computation time by performing a match with each algorithm 20 times while varying the size of the datasets being matched. In a real-world scenario, HIV and sexually transmitted disease surveillance data from King County, Washington, were matched to identify people living with HIV who had a syphilis diagnosis in 2017. We calculated the recall and precision of each algorithm compared with a composite standard based on the agreement in matching decisions across all the algorithms and manual review.

Results: In simulations, BRL and fastLink maintained a high recall at nearly all data quality levels, while being comparable with deterministic algorithms in terms of precision. Deterministic algorithms typically failed to identify matches in scenarios with low data quality. All the deterministic algorithms had a shorter average computation time than the probabilistic algorithms. BRL had the slowest overall computation time (14 min when both datasets contained 2000 records). In the real-world scenario, BRL had the lowest trade-off between recall (309/309, 100.0%) and precision (309/312, 99.0%).

Conclusions: Probabilistic record linkage algorithms maximize the number of true matches identified, reducing gaps in the coverage of interventions and maximizing the reach of public health action.

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KEYWORDS

medical record linkage; public health surveillance; public health practice; data management

Introduction

Background

A central goal of public health surveillance is to provide continuous and systematically collected health-related data to inform public health practice and guide interventions to improve individual and population health [1]. For example, health departments in the United States use HIV surveillance data [2-5] to identify people living with HIV (PLWH) who are not engaged in HIV care to provide assistance and services to facilitate care engagement—a strategy known as Data to Care [6-12]. In this way, surveillance data are used to improve both HIV care and prevention as well as to reduce inequities in access and utilization of HIV care resources to improve the well-being of vulnerable populations with HIV.

When used in isolation from other sources of information, public health surveillance can be inefficient and ineffective. In the case of Data to Care, many PLWH who appear to be out of care in HIV surveillance data because they have not had a recent HIV viral load or CD4 test have actually moved out of the jurisdiction and engaged in HIV care elsewhere [4,13,14]. Thus, Data to Care strategies that rely entirely on HIV surveillance data involve time-consuming individual case investigations to determine whether persons are truly out of care, although that information is often readily available in other data sources, such as Ryan White–funded care programs, sexually transmitted disease (STD) surveillance, electronic health records, or HIV surveillance systems in other jurisdictions. The Centers for Disease Control and Prevention (CDC) is supporting efforts to match surveillance data between jurisdictions through programs such as the *black box* system, in which HIV surveillance data from multiple jurisdictions are matched to identify PLWH who have moved from one jurisdiction to another [15,16]. In addition, several health departments are seeking to improve real-time record linkage between HIV and STD surveillance to provide HIV care relinkage services as part of STD partner services [12,17].

Despite the widespread use of record linkage techniques throughout public health, little information is available to guide this process from the perspective of algorithm accuracy and the implications of missing true matches and identifying false matches. There are two primary approaches to record linkage: deterministic algorithms and probabilistic algorithms [18-20]. Deterministic algorithms use exact matching on specific variables or a set of matching rules to identify matched record pairs [18]. In contrast, probabilistic algorithms use statistical methods to identify the optimal set of matches, which often involves estimating and thresholding the probability that two records are a match [18,21,22]. Probabilistic algorithms typically have higher recall than deterministic algorithms, especially when linking databases that have high rates of data quality errors [23,24]. However, probabilistic algorithms also tend to be more computationally complex than deterministic algorithms and may require more computing resources to implement in practice [18,20].

Recent studies of record linkage involving health department HIV/STD surveillance data have presented deterministic algorithms to link HIV surveillance data with other data sources, improve the quality of HIV surveillance data, and facilitate Data to Care investigations [16,25]. These algorithms are enticing because they are not computationally complex and can be executed quickly [18-20]. As they are rule based, deterministic algorithms are intuitive to understand, easy to implement, and easy to modify. In addition (and perhaps more importantly), deterministic algorithms typically have low rates of false-positive matches. As a major concern of working with HIV data is inadvertent disclosure of HIV status, minimizing false matches is crucial to preserving individual privacy. However, although deterministic algorithms may be highly specific, they may be overly conservative in identifying matches, leading to large numbers of missed matches. Missed matches represent missed opportunities to deliver public health interventions to individuals who need them, and depending on their population distribution, missed matches could magnify health inequities. Probabilistic algorithms could potentially offer increased sensitivity compared with deterministic algorithms, while still identifying a small number of false matches.

Objectives

The performance of deterministic algorithms compared with probabilistic algorithms in the context of public health record linkage is unknown. The goal of this study was to compare the recall, precision, and computation time of record linkage algorithms often used in HIV/STD programs to better define the trade-offs between these algorithms in a variety of record linkage scenarios.

Methods

Study Design

We compared deterministic and probabilistic record linkage algorithms using two approaches. First, we compared the recall, precision, and computation time of different algorithms using paired simulated datasets, varying the quality of the data and overlap between datasets (ie, the proportion of true matches in each pair of datasets). Second, we conducted a *real-world* matching scenario involving public health surveillance data from Public Health—Seattle & King County (PHSKC) to assess whether our simulation findings were generalizable to record linkage involving real datasets, where the exact error rate and overlap are difficult to assess.

This study received a human subjects research exemption from the University of Washington Institutional Review Board because it involves the use of simulated data and public health surveillance data used to inform and improve existing operational public health department activities.

Matching Algorithms

We compared seven algorithms used to conduct record linkage involving public health surveillance data: exact matching, four deterministic, and two probabilistic algorithms (Table 1). The exact matching algorithm identifies the matched pairs of records between two datasets using an exact match on first name, last name, and year of birth. This was chosen as a *base case* algorithm because it uses the simplest rule set to match two datasets. The four deterministic algorithms (*Stenger*, *Ocampo*

1, *Ocampo 2*, and *Bosh*) define rule sets for identifying a match using patient-identifying information, such as first name, last name, date of birth, gender, and race (Table 1) [16,25]. The Ocampo and Bosh algorithms also include matching criteria that require social security numbers (SSNs), which were omitted from our study because we did not have SSNs in the datasets used. In addition, the original Ocampo and Bosh algorithms used sex at birth, whereas we have used current gender. These modifications to these algorithms are noted in Table 1. These algorithms were chosen because they have been recently cited as matching algorithms used to conduct record linkage involving HIV surveillance data. Notably, the Ocampo algorithms have been used by the CDC to match interstate HIV surveillance data [15]. The Stenger algorithm was obtained directly from the PHSKC HIV/STD program, where it has been implemented for several record linkage projects involving HIV surveillance data. This algorithm was also recently used by the Mississippi State Department of Health to link their HIV and STD surveillance databases to integrate HIV care relinkage services into STD partner services [17].

The two probabilistic algorithms are *fastLink* and *beta record linkage* (BRL). fastLink is an implementation of the traditional Fellegi-Sunter approach to record linkage [21,26]. This approach uses comparisons of the shared fields between two datasets (ie, first name, last name, year of birth, month of birth, day of birth, gender, and race) to compute the conditional probability that each record pair is a match. Record pairs are classified as *matches* or *nonmatches* based on thresholding these conditional probabilities. BRL is similar to the Fellegi-Sunter approach but uses a Bayesian implementation to explore the space of plausible matching configurations between the datafiles [22]. By using a Bayesian approach, BRL allows for quantifying uncertainty on the matching decisions and finds the optimal set of matches by minimizing the expected misclassification errors based on a loss function.

Table 1. Record linkage algorithms.

Algorithm	Match criteria	Source
Exact match	Exact match on first name, last name, AND year of birth	Not applicable
Stenger	Best record pairs with a score of 50+ based on the following criteria: • +20 points: first 3 letters of the last name and 2 letters of the first name • +15 points: exact match on the full name • +15 points: match on birth year (±2 years) • +5 points: exact match on the year of birth • +10 points: exact match on the month of birth • +5 points: exact match on the day of birth	Public Health Seattle King County and Avoundjian et al [17]
Ocampo 1	Record pairs that met the following criteria: • Exact[a]: last name, first name, date of birth, race, gender[b], AND SSN[c] OR • Very high[a]: (last name, first name, date of birth, AND gender[b]) OR SSN OR • High: last name, first name, date of birth, AND (gender[b] OR race)	Ocampo et al [16]
Ocampo 2	Record pairs that matched in Ocampo 1 OR met the following criteria: • Medium high: last name, first name (Soundex), date of birth, or gender[b]	Ocampo et al [16]
Bosh	Records that met any of the following matching keys: • Full last name+first 6 letters of first name+full date of birth • First letter of the last name+letters 3 to 10 of the last name+letters 2 to 9 of the first name+full date of birth • Letters 2 to 7 of the last name+first 6 letters of the last name+full date of birth • First 2 letters of the last name+first 3 letters of the first name+full SSN+full date of birth[d] • Full last name+first 3 letters of the first name+full date of birth • Letters 3 to 5 of the last name+first 3 letters of the first name+full date of birth • First 4 letters of the last name+first 4 letters of the first name+full date of birth • First letter of the last name+letters 3 to 10 of the last name+letters 2 to 9 of the first name+month and year of birth[e] • First letter of the last name+letters 3 to 10 of the last name+letters 2 to 9 of the first name+day and year of birth[e] • Full SSN[d,e] • First 5 letters of the last name+first 4 letters of the first name+month and year of birth[e] • First letter of the last name+letters 3 to 10 of the last name+letters 2 to 9 of the first name+(day OR month of birth)+year of birth, switching the first and last names in 1 dataset[e] • First 5 letters of the last name+first 4 letters of the first name+month and year of birth, switching the first and last names in 1 dataset[e]	Bosh et al [25]
fastLink (Fellegi-Sunter)	Calculates match/nonmatch weights using an expectation maximization algorithm and computes a match probability for each record pair. Pairs are classified as a match if their match probability is above 0.85. The following fields are used to estimate the match probability: • First name and last name: partial match using Jaro Winkler string distance, with 3 agreement levels[f] • Year of birth, month of birth, day of birth, gender and race: exact match	Enamorado et al [26]
Beta Record Linkage	Uses a Gibbs sampler to sample plausible matching configurations and uses a loss function to identify the optimal set of matching pairs. The following fields are used by the algorithm: • First name and last name: partial match using Levenshtein string distance, with 4 agreement levels[g] • Year of birth, month of birth, day of birth, gender, and race: exact match	Sadinle [22]

[a]We omitted social security number from the exact and very high match tiers because of lack of social security number data.

[b]Original algorithm used birth sex instead of gender.

[c]SSN: social security number.

[d]Key was not implemented because of lack of social security number data.

[e]These keys require the following additional criteria to be met to be considered a match: exact match on gender OR full date of birth AND first name in the HIV dataset not among the 20 most common names in the HIV dataset AND last name in the HIV dataset not among the 20 most common names in the HIV dataset. Note: the original algorithm used birth sex instead of gender in these criteria. In addition, the original criteria also required a match on digits 1 to 4 and 6 to 9 of social security number, which was not implemented because of lack of social security number data.

[f]FastLink's default agreement levels for partially matched fields: 0 to 0.87: not a match, 0.88 to 0.91: partial match, and 0.92+: exact match.

[g]Beta record linkage's default agreement levels for partially matched fields: 0 to 0.49: not a match, 0.5 to 0.74: probable nonmatch, 0.76 to 0.998: probable match, and 0.99+: exact match.

Hypothetical Matching Scenario

To compare record linkage algorithm performance in the context of public health action, we considered the scenario of linking records between HIV and STD surveillance data to identify syphilis cases reported in the past year among PLWH. Such record linkage is conducted by many health departments in the United States as a way to integrate HIV care engagement activities into syphilis partner services. We assumed that both HIV and STD surveillance data contain the following shared fields that can be used for record linkage: first name, last name, date of birth (year, month, and day), gender, and race.

Simulation Study

Simulations were used to compare the accuracy of the selected record linkage algorithms in scenarios with varying dataset size, overlap, and measurement error. GeCo (Australia National University, Canberra, Australia), a Python-based program that creates realistic datasets of personal information, was used to generate pairs of datasets based on STD surveillance data from PHSKC's partner services data system, known as Public Health Information Management System (PHIMS) [27]. In each simulation, we generated two datasets containing records of 2000 individuals each. A number of individuals were included in both datasets, which we refer to as the *overlap* between the datasets. We considered scenarios where 5%, 10%, 25%, and 50% of individuals overlapped. To generate each pair of datasets, we used the distribution of values for each field from PHIMS. Using PHIMS, we created frequency tables for first and last names, year of birth, gender (male, female, transgender male, and transgender female), and race/ethnicity (Asian, black, Hispanic/Latinx, Native American/Alaska Native, Native Hawaiian/other Pacific Islander, white, other, and multiple race). We created a joint frequency table for month and day of birth, giving an equal sampling weight for each day of the year. For each individual, a value was sampled from each frequency table to generate a number of clean records, which were then *corrupted* to create the datasets. For each pair of datasets, the first dataset consisted of *clean* records, and the second dataset consisted of *corrupted* records. Each corrupted record has a fixed number of erroneous fields that are selected at random. For each dataset size and overlap scenario, we generated datasets containing 1, 2, 3, 4, and 5 erroneous fields per record. The types of errors introduced into each field were selected at random from a set of possibilities that vary from field to field (Multimedia Appendix 1). The types of errors are edits (insertions, deletions, substitutions, and transpositions of characters in a string), keyboard (typing errors based on a QWERTY keyboard layout), phonetic (using a list of predefined phonetic rules), value swap (an entire value is swapped with another value selected from a predefined list of possible values), and missing values. The probability of missing values was determined by the frequency of missing values for each field in PHSKC's STD surveillance data. The probabilities of the remaining error types were defined based on the default probabilities provided by GeCo.

We matched each pair of datasets using each record linkage algorithm. After simulated data were created, we did not further modify the data (eg, modifying date values with missing date parts) before inputting them into any of the algorithms. We measured each algorithm's *recall* (ie, sensitivity, the proportion of true matches identified by the algorithm) and *precision* (ie, positive predictive value, the proportion of algorithm matches that were true matches). Each matching scenario was simulated 100 times, and we calculated the mean and standard deviation of recall and precision for each algorithm across these replicates. In addition, we measured the computational performance of each algorithm in terms of their average runtime. We ran each matching algorithm 20 times while fixing the overlap between the two datasets (50% of the individuals in the second dataset overlap with those in the first dataset) and the number of erroneous fields (one erroneous field per record) and varying the size of the second dataset (10%, 25%, 50%, and 100% of the first dataset). We then calculated the mean and standard deviation of computation time for each algorithm.

Real-World Matching Scenario

In our *real-world* matching scenario, we linked PHSKC HIV (Electronic HIV/AIDS Reporting System [eHARS]) and STD (PHIMS) surveillance data to identify PLWH who had a syphilis diagnosis in 2017. In 2017, there were 885 case-patients with a syphilis infection reported in King County. There were 17,415 PLWH in eHARS, which includes all persons living with diagnosed HIV in Washington state. As there is no shared unique identifier between PHIMS and eHARS, we did not have a gold standard against which we could compare each matching algorithm's performance. Thus, we defined true matches and true nonmatches using a composite of the matching decisions made by each of the algorithms (*composite standard*). If all the algorithms identified a pair of records as a match, we considered it a true match. If none of the algorithms identified a pair of records as a match, it was considered a true nonmatch. When there was a lack of consensus between the record pairs, we manually reviewed the records to determine whether they were a true match or nonmatch. As in the simulations described above, we made no modifications to any date values with missing date parts before inputting them into the algorithms (<0.1% of records had missing date parts). We calculated the precision and recall of each algorithm. In addition, we measured the *value and error added* by each algorithm beyond exact matching, which we considered as the baseline algorithm. We measured *value added* as the number of additional true matches and *error added* as the additional false matches identified by each algorithm over and beyond exact matching.

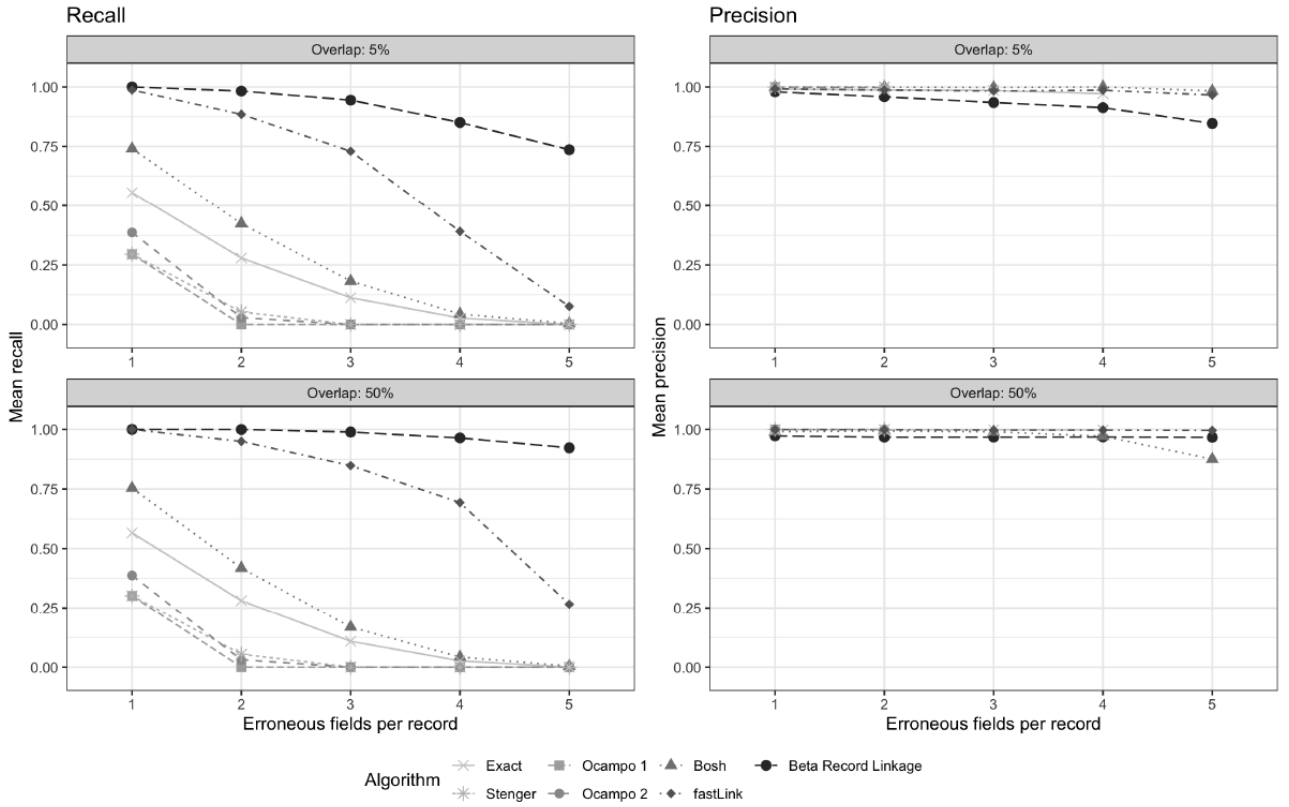
Dataset generation and corruption were done using GeCo and Python 2.7. All other analyses were done using R version 3.5.2. Python and R programs used to perform simulations, perform the real-world match, and measure computational performance are provided as supplemental material (Multimedia Appendix 2).

Results

Simulations

The selected deterministic algorithms had a lower recall than the selected probabilistic algorithms, regardless of the overlap or the number of erroneous fields per record (Figure 1 and Multimedia Appendix 1). The exact algorithm had a recall of between 56% (5% overlap) and 57% (50% overlap) when there was one erroneous field per record, and its recall decreased as the number of erroneous fields per record increased. The exact matching algorithm's precision was between 99% and 100% when there were three or fewer erroneous fields per record (Multimedia Appendix 1). The Stenger, Ocampo 1, and Ocampo 2 algorithms had similar recall and precision but had lower recall than the exact match. When there was only one erroneous field, both the Stenger and Ocampo 1 algorithms had a recall of 30%, whereas the Ocampo 2 algorithm had a recall of 39%, regardless of the dataset size and overlap. The precision for all three algorithms was 100% when there was only one erroneous field per record. All three algorithms failed to identify any matches when there were at least three erroneous fields. The Bosh algorithm had the highest recall of the five deterministic algorithms. When there was one erroneous field per record, the Bosh algorithm's recall ranged between 74% (5% overlap) and 75% (50% overlap). However, its recall decreased to less than 20% in scenarios with at least three erroneous fields per record. The precision for the Bosh algorithm was high across all scenarios (between 88% and 100%).

Figure 1. Simulations: record linkage algorithm recall/precision.

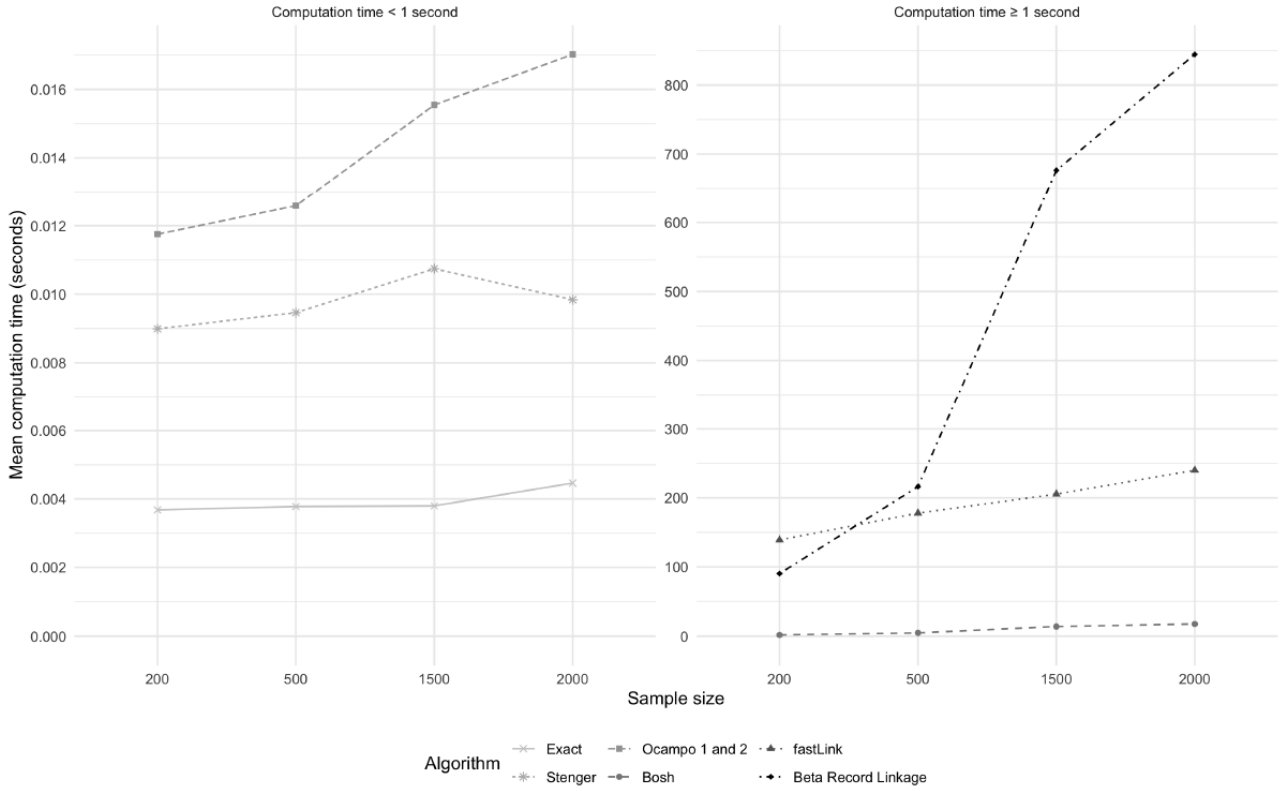


fastLink and BRL had better recall than the deterministic algorithms. In the one erroneous field per record scenario, both fastLink and BRL had about 100% recall, regardless of the dataset overlap. In the three erroneous field scenario, fastLink's recall ranged between 73% (5% overlap) and 85% (50% overlap), whereas BRL's recall ranged between 94% and 99%. In the five erroneous field scenario, fastLink's recall was between 8% and 27%, whereas BRL's recall was between 74% and 92%. The precision of both algorithms was high across all scenarios (fastLink: 97%-100% and BRL: 85%-100%).

Computational Performance

The exact, Ocampo, and Stenger algorithms took an average of about 0.01 seconds to compute, even when the datasets being compared contained 2000 records (Figure 2). The Bosh algorithm took between 2 seconds and 18 seconds to compute, depending on the dataset size. The two probabilistic algorithms took a longer time to compute than all the deterministic algorithms. fastLink took an average of between 2.3 min and 4 min to compute. On average, BRL performed faster than fastLink when the second dataset contained 200 records (1.5 min vs 2.3 min) but was the slowest algorithm in every other scenario. BRL, on average, took between 3.6 min (second dataset N=500) and 14.1 min (second dataset N=2000) in the remaining scenarios.

Figure 2. Record linkage algorithm matching computational performance. Average computational time after 20 replications in scenario where overlap (50%) and number of erroneous fields per record (1) were fixed and size of second dataset was varied (10%, 25%, 50%, and 75% of first dataset [N=2000]).



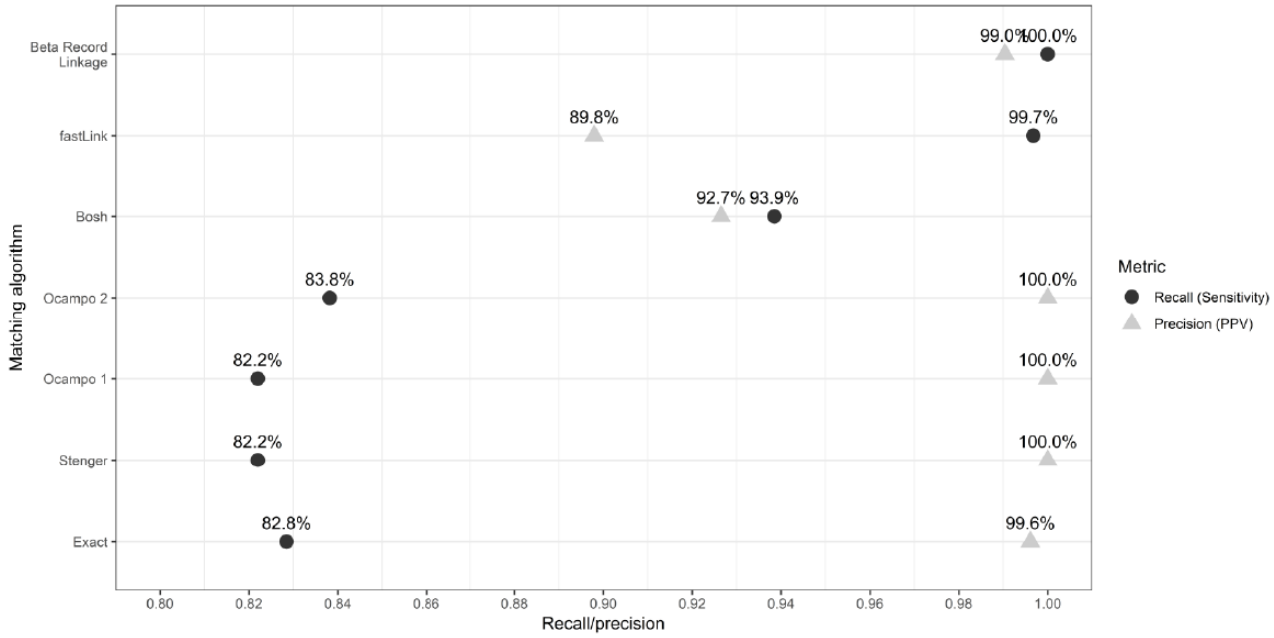
Real-World Matching Scenario

Among the 885 case-patients with any syphilis infection in King County in 2017, a majority (760/885, 85.8%) were men who have sex with men (MSM). Nearly half of the patients were white (436/885, 49.3%), 12.8% (113/885) were black, and 20.5% (182/885) were Hispanic/Latinx. Among the 17,415 PLWH in PHSKC's eHARS database, 14,887 (85.48%) were male (12,640/17,415, 72.58% MSM), 10,293 (59.10%) were white, 2965 (17.10%) were black, and 2376 (13.67%) were Hispanic/Latinx.

There were 367 record pairs classified as a match by any of the algorithms. Of these, the algorithms disagreed on 113 record pairs, which were manually reviewed to determine their true match status. According to our composite standard, there were 309 true matches, representing 35% of all case-patients with a syphilis infection in 2017 and 1.8% of all PLWH in eHARS. The exact matching algorithm identified 256 true matches and one mismatch (Multimedia Appendix 3). Compared with this algorithm, the Stenger and Ocampo 1 algorithms identified two fewer true matches and did not have any mismatches. The Ocampo 2 algorithm identified three more matches than the exact matching algorithm and also had no mismatches. The Bosh algorithm identified 36 additional true matches but also identified 20 additional false matches. Both fastLink and BRL identified 53 additional true matches. However, fastLink had 33 additional false matches, whereas BRL only had two additional false matches.

Compared with our composite standard, all the deterministic algorithms had lower recall than the probabilistic algorithms (Figure 3). The recall of the exact, Stenger, Ocampo 1, and Ocampo 2 algorithms ranged between 82% and 84%. The recall of the Bosh algorithm was about 94%, and the recall of fastLink and BRL was 100%. The precision of the deterministic algorithms (except for Bosh) was overall higher than the precision of the probabilistic algorithms. The Stenger, Ocampo 1, and Ocampo 2 algorithms had 100% precision, whereas the exact algorithm had 99.6% precision. The precision of the Bosh algorithm was about 93%, and the precision of fastLink was about 90%. BRL had a precision of 99%, which was the lowest trade-off between recall and precision.

Figure 3. Real-world matching scenario: record linkage algorithm recall and precision. PPV: positive predictive value.



Discussion

Principal Findings

Using simulations, we found that the probabilistic algorithms we evaluated had substantially better recall than the selected deterministic algorithms, while the deterministic algorithms had higher precision. However, in scenarios with three or more erroneous fields per record, nearly all the deterministic algorithms (except the Bosh algorithm) failed to identify any matches, which diminishes their utility in record linkage scenarios where data quality is poor. In contrast, both BRL and fastLink offered high recall without sacrificing much in terms of precision. In addition, in a *real-world* comparison, BRL had the highest recall with only a minimal sacrifice in precision and was the best performing algorithm overall.

Our findings suggest that although deterministic algorithms offer a high degree of precision, they are highly sensitive to data quality issues and may miss a substantial number of matches even in situations where there is only one erroneous field per record. The recall of deterministic algorithms can be improved by implementing more matching rules (as in the case of the Bosh algorithm [25]), but this also results in lower precision. Furthermore, even with additional match keys, deterministic algorithms still do not reach the level of recall offered by probabilistic algorithms.

Surprisingly, the Bosh and fastLink algorithms had low precision in our real-world match, despite having very high precision in simulations. For fastLink, this may be a limitation of the algorithm, which tends to lose precision in situations where the overlap between datasets is small or there is a large difference in the size of the datasets being linked [26]. The lack of SSN may have led to the Bosh algorithm's lower precision in the real-world match. The false matches identified by the Bosh algorithm were identified because they met matching keys 8 to 14, which require additional criteria to be considered a match (Table 1). As noted in the original Bosh article, these additional criteria were added to reduce possible false matches. Although we implemented most of the additional criteria, they include a partial match on SSN (ie, match on digits 1-4 and 6-9 of SSN), which was omitted from this study. If SSN was included, we may have eliminated the false matches identified by the less strict matching keys, resulting in a higher observed precision for this algorithm.

Public Health Implications

In the context of public health action, choosing a record linkage algorithm that prioritizes the identification of true matches is critical to preventing gaps in the provision of public health interventions to those who are most in need of assistance. Choosing overly conservative record linkage algorithms that prioritize precision over recall could increase gaps among these groups in public health prevention delivery and may amplify disparities among marginalized populations. Previous studies have demonstrated that imperfect record linkage algorithms may disproportionately miss women, older individuals, and persons of minoritized races/ethnicities and lower socioeconomic status [28-31]. The use of probabilistic record linkage methods (such as BRL and fastLink) or more complex deterministic algorithms (such as the Bosh algorithm) would result in a large increase in the reach of public health interventions relying on the linkage of data systems, which offsets small decreases in match precision.

A disadvantage of probabilistic algorithms is their computational complexity. While the computational time of the deterministic algorithms is generally under 1 second, both probabilistic methods took minutes to compute. For applications that require near-instant record linkage of large databases, probabilistic algorithms may not be practical because of their slow computation time; however, such applications may be relatively uncommon in practice. When record linkage is done on a daily or less frequent basis, the increased computation time of fastLink and BRL is less problematic. Importantly, fastLink was designed to outperform other approaches to probabilistic record linkage

algorithms when datasets are very large [26]. In these situations, fastLink may have even greater gains compared with slower methods such as BRL, although it may still be slower than deterministic algorithms. In addition, because of their increased computational complexity, BRL and fastLink require more memory and processing power than the deterministic algorithms. Both BRL and fastLink required over 4 GB of RAM and a 64-bit version of R, which may be a limitation of using these algorithms in resource-limited settings. However, 64-bit computing and 4 or more GB of RAM are becoming increasingly common, suggesting that these barriers would be less problematic in the future. As of May 2019, the estimated minimum cost of a new business desktop with these specifications is about US $400.

Another advantage of deterministic algorithms is that these are easier to implement in different programming languages. Matching rules used by the deterministic algorithms we evaluated are relatively intuitive and translatable to multiple programming languages. Although fastLink has thorough documentation and support, modifications to the algorithm require an understanding of the Fellegi-Sunter record linkage methodology and the R programming language [26]. Modifications to BRL are particularly challenging, as there is currently limited documentation on the method [22]. In addition, much of the BRL algorithm is implemented in the C programming language, an additional prerequisite to making modifications to the algorithm. To address these barriers, we have provided R programs for each algorithm in a *Load, Clean, Func, Do* framework, a portable and flexible organizational structure for developing R projects, to implement them in practice (Multimedia Appendix 2) [32].

Limitations

Our study has several limitations. First, in our simulations, we assumed a uniform error rate across all records in each matching scenario. As our probabilistic algorithms use information from all records, this may have misrepresented how well they perform when linking datasets that contain a wide range of erroneous fields per record, including records that have 0 erroneous fields. Indeed, in our real-world match scenario, in which record quality was more variable, BRL had much higher precision than in our simulations, suggesting that it is able to leverage information from record pairs that have high data quality to make decisions about record pairs that have poor data quality.

Second, both the Bosh and Ocampo algorithms include matching keys that involve SSN, which is not available in PHSKC's STD surveillance database. This may have resulted in an underestimation of the performance of these algorithms. In the Bosh algorithm, SSN is used as additional criteria to reduce mismatches for matching keys that are very broad, and its inclusion may have resulted in improved precision. In the original Bosh study, 1.7% of true matches were identified using SSN alone, suggesting that if SSN was available, we would have observed a very slightly improved recall of the Bosh algorithm, although it probably would not have reached the levels of recall observed with the probabilistic algorithms [25]. In addition, if SSN had been available, it could have also been included in both probabilistic algorithms, which could have possibly improved their recall and precision as well.

Third, we have only considered deterministic and probabilistic algorithms that can be implemented in R and have excluded algorithms that require third-party software (eg, the Link King and CDC's Link Plus) and novel record linkage methodologies (eg, active, supervised, and unsupervised learning algorithms). Third-party software for record linkage offers a point-and-click interface for implementing probabilistic (and deterministic) record linkage methodologies. Both the Link King and Link Plus, two popular applications for conducting record linkage involving public health surveillance databases, use the Fellegi-Sunter methodology for conducting probabilistic record linkage, which is the same methodology used by fastLink. Supervised learning–based and active learning–based algorithms may yield greater match quality than probabilistic or deterministic algorithms in cases where databases are to be linked prospectively or when training data are available (in the case of supervised learning) [19]. These algorithms use data on record pairs that are known to be matches or nonmatches to develop a predictive model that is used to classify record pairs in the databases that are being linked as matches or nonmatches. As these algorithms require a training dataset of known matches and nonmatches (something neither the probabilistic nor the deterministic algorithms we evaluated required), we chose to exclude them from our analysis. Further research is needed to assess the performance and utility of these techniques in conducting record linkage for public health action as well as the feasibility of implementing them in practice.

Finally, for the probabilistic matching algorithms we evaluated, we only considered their default parameterizations. We chose to evaluate these algorithms using their default (or *out-of-the-box*) implementations, as this would represent a baseline level of their performance. Modifying the parameters for fastLink and BRL, such as the string distance measure used to match string variables or the number of partial agreement levels, could improve their performance. Importantly, fastLink and BRL use different default methods to match string variables (eg, first name and last name). This may partially explain why BRL had better recall than fastLink in our simulations and a lower trade-off between recall and precision in our real-world match. In addition, the use of a blocking scheme, such as grouping record pairs on the first two letters of the first name before they are compared by the algorithm, may have improved both the precision and computational performance of these algorithms. Future studies should consider evaluating the use of blocking on algorithm performance in the public health practice setting.

Conclusions

In conclusion, public health interventions that involve record linkage of multiple data systems should carefully consider their choice of record linkage algorithm. This choice should be based not only on reducing false matches but also on maximizing intervention coverage. Record linkage methodologies that do not seek to maximize true matches, especially in the context of imperfect data quality, limit the reach of public health interventions and could exacerbate existing health disparities.

Probabilistic algorithms, such as BRL, can maximize the number of true matches identified without sacrificing precision and should be considered as the first choice when using record linkage for public health action.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional details about data generation and tables describing simulation results.
[DOCX File , 24 KB - publichealth_v6i2e15917_app1.docx]

Multimedia Appendix 2
Python and R programs used to conduct simulations and real-world match.
[DOCX File , 14 KB - publichealth_v6i2e15917_app2.docx]

Multimedia Appendix 3
Real-world matching scenario: value and error added over exact matching algorithm.
[DOCX File , 63 KB - publichealth_v6i2e15917_app3.docx]

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Abbreviations

BRL: beta record linkage
CDC: Centers for Disease Control and Prevention
eHARS: Electronic HIV/AIDS Reporting System
MSM: men who have sex with men
PHIMS: Public Health Information Management System

PHSKC: Public Health—Seattle & King County
PLWH: people living with HIV
SSN: social security number
STD: sexually transmitted disease

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Original Paper

Prediction of the COVID-19 Pandemic for the Top 15 Affected Countries: Advanced Autoregressive Integrated Moving Average (ARIMA) Model

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Abstract

Background: The coronavirus disease (COVID-19) pandemic has affected more than 200 countries and has infected more than 2,800,000 people as of April 24, 2020. It was first identified in Wuhan City in China in December 2019.

Objective: The aim of this study is to identify the top 15 countries with spatial mapping of the confirmed cases. A comparison was done between the identified top 15 countries for confirmed cases, deaths, and recoveries, and an advanced autoregressive integrated moving average (ARIMA) model was used for predicting the COVID-19 disease spread trajectories for the next 2 months.

Methods: The comparison of recent cumulative and predicted cases was done for the top 15 countries with confirmed cases, deaths, and recoveries from COVID-19. The spatial map is useful to identify the intensity of COVID-19 infections in the top 15 countries and the continents. The recent reported data for confirmed cases, deaths, and recoveries for the last 3 months was represented and compared between the top 15 infected countries. The advanced ARIMA model was used for predicting future data based on time series data. The ARIMA model provides a weight to past values and error values to correct the model prediction, so it is better than other basic regression and exponential methods. The comparison of recent cumulative and predicted cases was done for the top 15 countries with confirmed cases, deaths, and recoveries from COVID-19.

Results: The top 15 countries with a high number of confirmed cases were stratified to include the data in a mathematical model. The identified top 15 countries with cumulative cases, deaths, and recoveries from COVID-19 were compared. The United States, the United Kingdom, Turkey, China, and Russia saw a relatively fast spread of the disease. There was a fast recovery ratio in

China, Switzerland, Germany, Iran, and Brazil, and a slow recovery ratio in the United States, the United Kingdom, the Netherlands, Russia, and Italy. There was a high death rate ratio in Italy and the United Kingdom and a lower death rate ratio in Russia, Turkey, China, and the United States. The ARIMA model was used to predict estimated confirmed cases, deaths, and recoveries for the top 15 countries from April 24 to July 7, 2020. Its value is represented with 95%, 80%, and 70% confidence interval values. The validation of the ARIMA model was done using the Akaike information criterion value; its values were about 20, 14, and 16 for cumulative confirmed cases, deaths, and recoveries of COVID-19, respectively, which represents acceptable results.

Conclusions: The observed predicted values showed that the confirmed cases, deaths, and recoveries will double in all the observed countries except China, Switzerland, and Germany. It was also observed that the death and recovery rates were rose faster when compared to confirmed cases over the next 2 months. The associated mortality rate will be much higher in the United States, Spain, and Italy followed by France, Germany, and the United Kingdom. The forecast analysis of the COVID-19 dynamics showed a different angle for the whole world, and it looks scarier than imagined, but recovery numbers start looking promising by July 7, 2020.

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KEYWORDS

SARS-COV2; COVID-19; coronavirus; forecast; prediction; ARIMA models

Introduction

Background

At the World Health International Conference in Geneva in January 2020, the World Health Organization (WHO) announced an outbreak of the new coronavirus. The novel coronavirus (severe acute respiratory syndrome [SARS] coronavirus 2) from Wuhan, China has continued to spread around the world since January 2020 and has turned into a pandemic of the coronavirus disease (COVID-19) [1,2]. Due to the rapid spreading potential and the absence of vaccines and drugs, the contagious COVID-19 devastated normal life around the world. Currently, COVID-19 has infected more than half a million of the population, has killed more than 25,000 people, and has forced more than 3 billion to stay in their homes [3]. Many people started getting pneumonia without any reason, and most of the cases were linked to Wuhan Seafood Market, where they sell fish and trade live animals. The new coronaviruses lurking around the world are threatening our rule, and the prevalence of fear and panic is increasing. This has also affected the cryptocurrency market [4,5]. The country in which the coronavirus has caused the most devastation after China is Italy. In Italy, hundreds of people are dying every day due to this deadly virus. The corona virus is 900 times smaller than a human hair. Despite its size, this small virus has scared the whole world. In December 2019, the first case of COVID-19 came from Wuhan City in China [6-8].

During the Chinese New Year migration, the virus spread to other Chinese provinces in early and mid-January 2020. The WHO [3] revealed that cases began to be detected in other countries by international travelers. Due to a lack of knowledge about this virus, the COVID-19 pandemic placed tremendous strain on everyone around the world. To prevent further transmission, strong preventive measures have intensified week-to-week; however, the numbers of infected cases are consistently increasing around the world, even after undergoing lockdown. Mathematical approaches have been widely used to infer critical epidemiological transitions and parameters of COVID-19. Epidemic curve fitting, surveillance data during the early transmission, and other epidemic models have been frequently applied to generate forecasts of the COVID-19 pandemic across the world [9-11]. This study aims to identify the top 15 countries with the most confirmed cases with spatial mapping. A comparison was done between the identified top 15 countries for confirmed cases, deaths, and recoveries, and an advanced autoregressive integrated moving average (ARIMA) model was used for predicting the spread of COVID-19 trajectories for the next 2 months (until July 7, 2020).

Study Area

Various studies have been presented for forecasting many epidemic diseases. This research study analyzes dynamic models to generate 20-day forecasts of cumulative confirmed deaths and recoveries from COVID-19 cases by country, territory, or conveyance generated on April 24, 2020. The United States, Spain, Italy, France, Germany, the United Kingdom, Turkey, Iran, China, Russia, Brazil, Canada, Belgium, the Netherlands, and Switzerland were taken from the top 20 countries based on cumulative effect data. The ARIMA model assigns a weight to the considered past values and an error value to correct the modelling; other basic regression and exponential models use all past values to predict future values, so the ARIMA model is preferred. This study analyzed and extracted worldwide data based upon a time series data-based advanced prediction ARIMA model approach for the top 15 COVID-19-infected countries.

Methods

Data

We used data from Worldometer, which reports the approximate data of cumulative cases for more than 170 countries worldwide including state- or province-level cases for some countries [12]. We have collected the case data for each day at given stipulated times, from January 21, 2020, to April 24, 2020. Furthermore, we preprocessed the top 15 countries' data with their spatial locations to collect and create some spatial attributes for the overall available data sets to forecast the trajectory of COVID-19 cases. In addition, as whole worldwide data is not available for stipulated times, we did not create any worldwide pandemic

forecasting. Some dates with cases of confirmed COVID-19 along with total cumulative results of recovered cases and death cases were analyzed using statistical analysis along with spatial extinct. We used the ARIMA model with R (R Foundation for Statistical Computing) and validated it using Akaike information criterion (AIC). The new projected data was used up to July 2, 2020, for the creation of a trajectory projected score for each category: case confirmed, recovered, and death.

Recent reported cumulative data of confirmed cases, deaths, and recoveries of COVID-19 from January 21 to April 26, 2020, were obtained from Worldometer. The reported data were used to predict more than 60 days and to understand the positive effects in the near future as well as the projected trends over trajectories. The different statistical phenomenological models in the R-language platform were used to analyze the disease-based trajectories model for prediction purposes. The four models were used to analyze the aggregate data set for time series analysis. This includes the ARIMA model, which is a mass model of two different models, including the autoregression (AR) model and the moving average (MA) model [13]. This model also used AIC statistics and coverage of regression analysis.

Another type of COVID-19, like SARS disease, was analyzed without breaking the current situation or predicting the future perspective [14]. The vector auto-average model was used to predict the spatial extinct while using remote sensing data for the purpose of the creation of a worldwide geographic information system (GIS) map for three different variables [15]. These three variables in the GIS environment created a map of cumulative confirmed cases by country as well as recovered and death maps [16]. The use of another statistical analysis was a generalized logistic growth model, which generally is depicted as a scaling parameter for integrating an additional result-oriented value put method [17]. Some epidemic models used in disease epidemic conditions measure oscillates, which are multiple peak parameters inferred in subepidemic and pandemic conditions to determine the projected outcomes [18].

After standardizing all the models, the data of the top 20 countries were included to analyze the forecasting models of differential spatial adjacent and projected trajectories, which were analyzed up to July 2, 2020. We used the GIS and remote sensing to determine the pandemic mapping and analyze the upcoming effects of COVID-19.

ARIMA

MA is the present value of a series, which is defined as a linear combination of past errors. Assuming the errors to be independently distributed with the normal distribution [13,19], order q is defined as:

$$y_t = c + \varepsilon_t + \theta_1 y_{t-1} + \theta_2 y_{t-2} + \ldots\ldots\ldots\ldots\ldots + \theta_q y_{t-q} \textbf{(1)}$$

Where:

- ε_t=white noise
- y_{t-1} and y_{t-2}=lags

Order q of the MA process is obtained from the autocorrelation function (ACF) plot; this is the lag after which ACF crosses the upper confidence interval for the first time. We combined differencing with MA and AR models, and the combined model can be expressed as:

$$y'_t = c + \varphi_1 y'_{t-1} + \varphi_2 y'_{t-2} + \ldots + \varphi_p y'_{t-p} + \theta_1 y_{t-1} + \theta_2 y_{t-2} + \ldots\ldots + \theta_q y_{t-q} + \varepsilon_t \textbf{(2)}$$

Here, y'_t is the differenced series. The "predictors" on the right-hand side include both lagged values of y_t and lagged errors. We call this an ARIMA (p, d, q) model, where:

- q=order of the MA part
- d=degree of first differencing involved
- p=order of the AR part

Results

The top 15 countries were identified using mapping of cumulative confirmed COVID-19 cases from January to April 24, 2020, for 200 nations as presented in Figure 1. The top 15 countries with a high number of confirmed cases were stratified to include the data in a mathematical model. The top 15 countries' (the United States, Spain, Italy, France, Germany, the United Kingdom, Turkey, Iran, China, Russia, Brazil, Canada, Belgium, the Netherlands, and Switzerland) cumulative cases, deaths, and recoveries from COVID-19 were compared in Figure 2. The United States, The United Kingdom, Turkey, China, and Russia saw a relatively fast spread of the disease. There was a fast recovery ratio in China, Switzerland, Germany, Iran, and Brazil, but a slow recovery ratio in the United States, the United Kingdom, the Netherlands, Russia, and Italy as shown in Figure 2. In addition, there were higher death rate ratios in Italy and the United Kingdom, and lower death rate ratios in Russia, Turkey, China, and the United States (Figure 2).

Figure 1. COVID-19 pandemic spatial pattern of total confirmed cases (top), deaths (middle), and recoveries (bottom) from January 19 to April 24, 2020, in countries and territories. COVID-19: coronavirus disease; JHUCSSE: Johns Hopkins University Center for Systems Science and Engineering; WHO: World Health Organization.

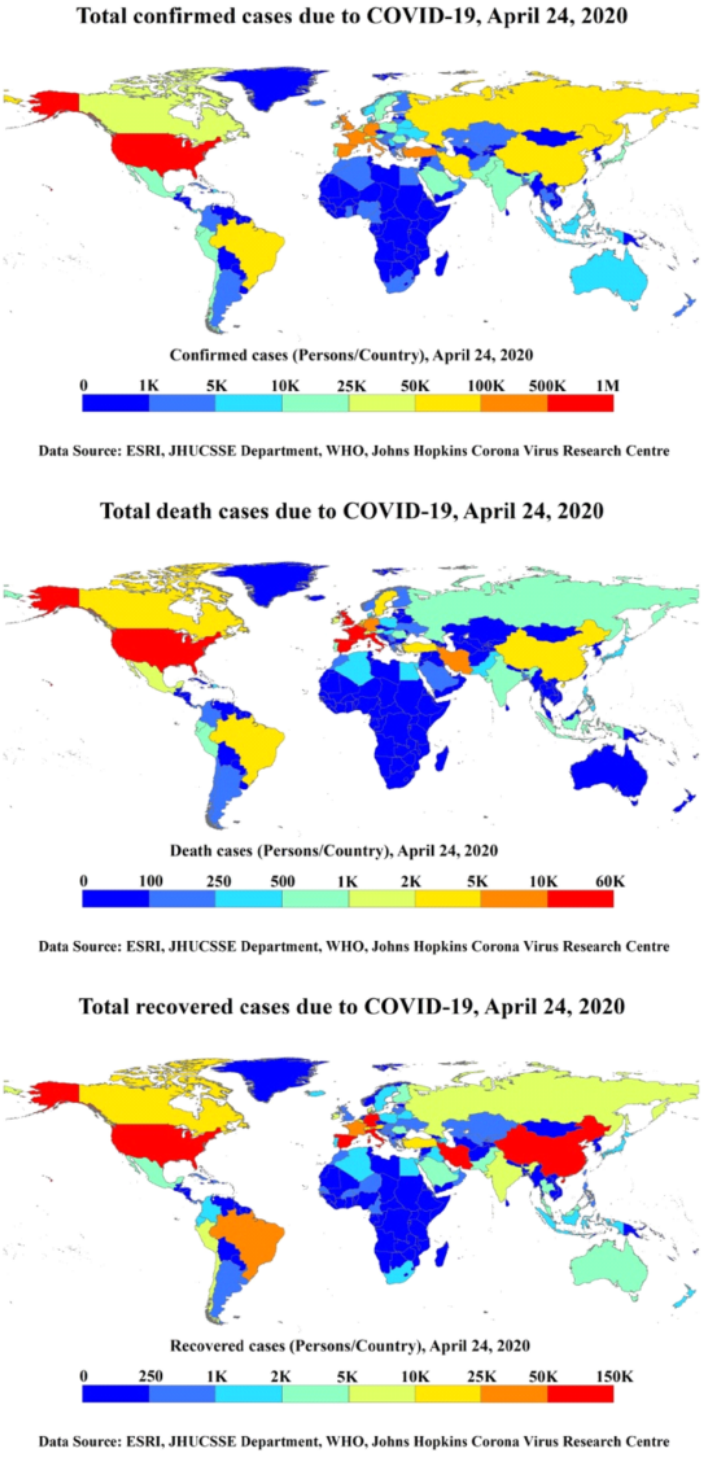
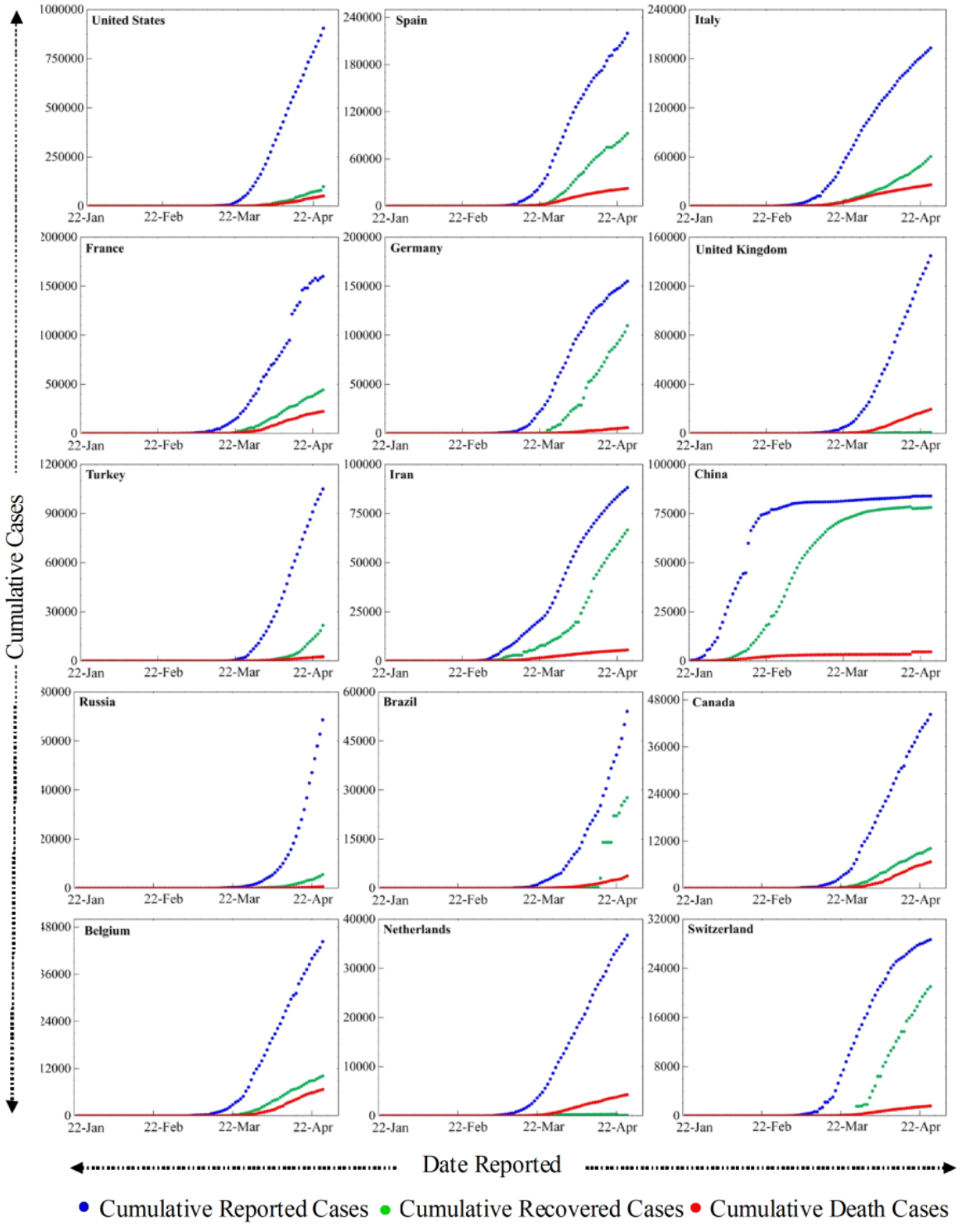


Figure 2. Comparisons between cumulative confirmed cases, recoveries, and deaths of coronavirus disease in the top 15 affected countries.



Furthermore, data smoothening was applied to stabilize the data by removing changes in the level of a time series and, therefore, eliminating (or reducing) the trend and seasonality. After this, the forecast prediction model was applied by using AR and MA models to generate plots of the different trends in upcoming days. The ARIMA model was validated for the available current data using the AIC value; it estimates that the out-of-sample prediction error and lowest value are preferable. Its value were around 20, 14, and 16 for cumulative confirmed cases, deaths, and recoveries from COVID-19, respectively, which represents less error. The outcome of these predictions is presented in Figure 3. Our findings revealed linearity in the confirmed cumulative cases and showed a rapid exponential growth phase in the world, which might occur roughly from April 8 to April 24, 2020, when the number of COVID-19 cases may rise steeply to nearly 1 million in the United States, 220,000 in Spain, 200,000 in Italy, 180,000 in France, and 190,000 in Germany. Other countries that have a smaller number of cases but show

a declining upward trend include Switzerland, Germany, and Italy (Figure 2). However, the cases of COVID-19 in China remain stable (Figure 2). The ARIMA model predicted confirmed cases, deaths, and recoveries for the next month from April 24 to July 7, 2020, using the past 3 months of data in Figure 3 (cyan color), Figure 4 (brown color), and Figure 5 (green color) with 95% confidence intervals. Along with the 95% confidence predicted line after April 24, the 80% and 70% confidence wide values are shown in light grey and light-yellow colors, respectively. The wide confidence intervals help to manage any sudden changes in the prediction of dynamic COVID-19 cases.

During the next 2 months between April 24 and July 7, 2020, the model predicted that the confirmed cases, deaths, and recoveries would be doubled in all countries except China, Switzerland, and Germany (Figures 3-5). It was also observed that the death and recovery rates will be faster when compared to confirmed cases during the next 2 months. The associated mortality rate will be much higher in the United States, Spain, and Italy followed by France, Germany, and the United Kingdom. The recovery rates will stay slow at first but then rapidly increase in the United States, Italy, Germany, and France by the end of June 2020 (Figure 5).

Figure 3. The autoregressive integrated moving average model prediction for more than 2 months of cumulative confirmed coronavirus disease cases in the top 15 affected countries shown in a cyan color (95% confidence).

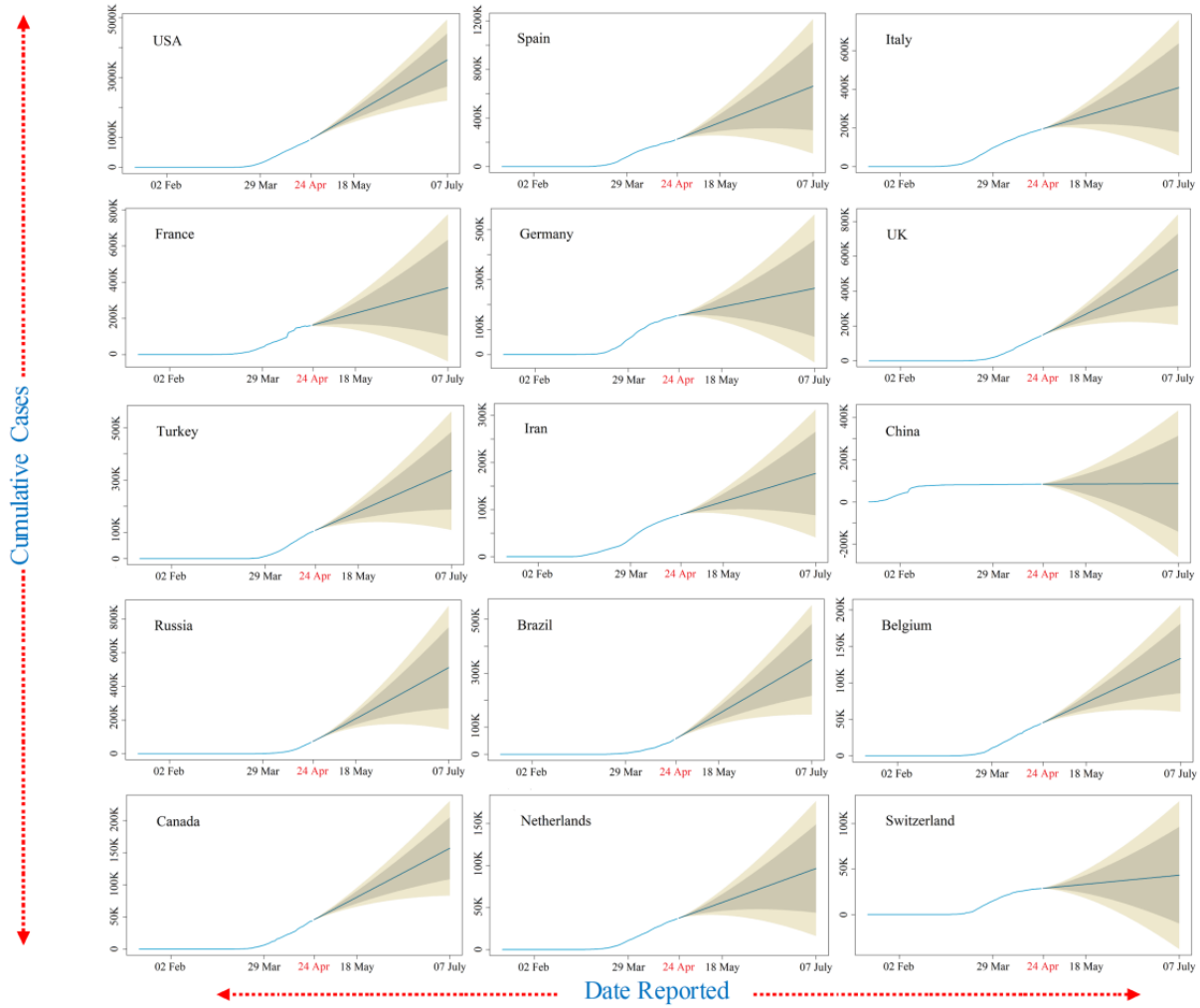


Figure 4. The autoregressive integrated moving average model prediction for more than 2 months of cumulative confirmed coronavirus disease cases in the top 15 affected countries shown in a brown color (95% confidence).

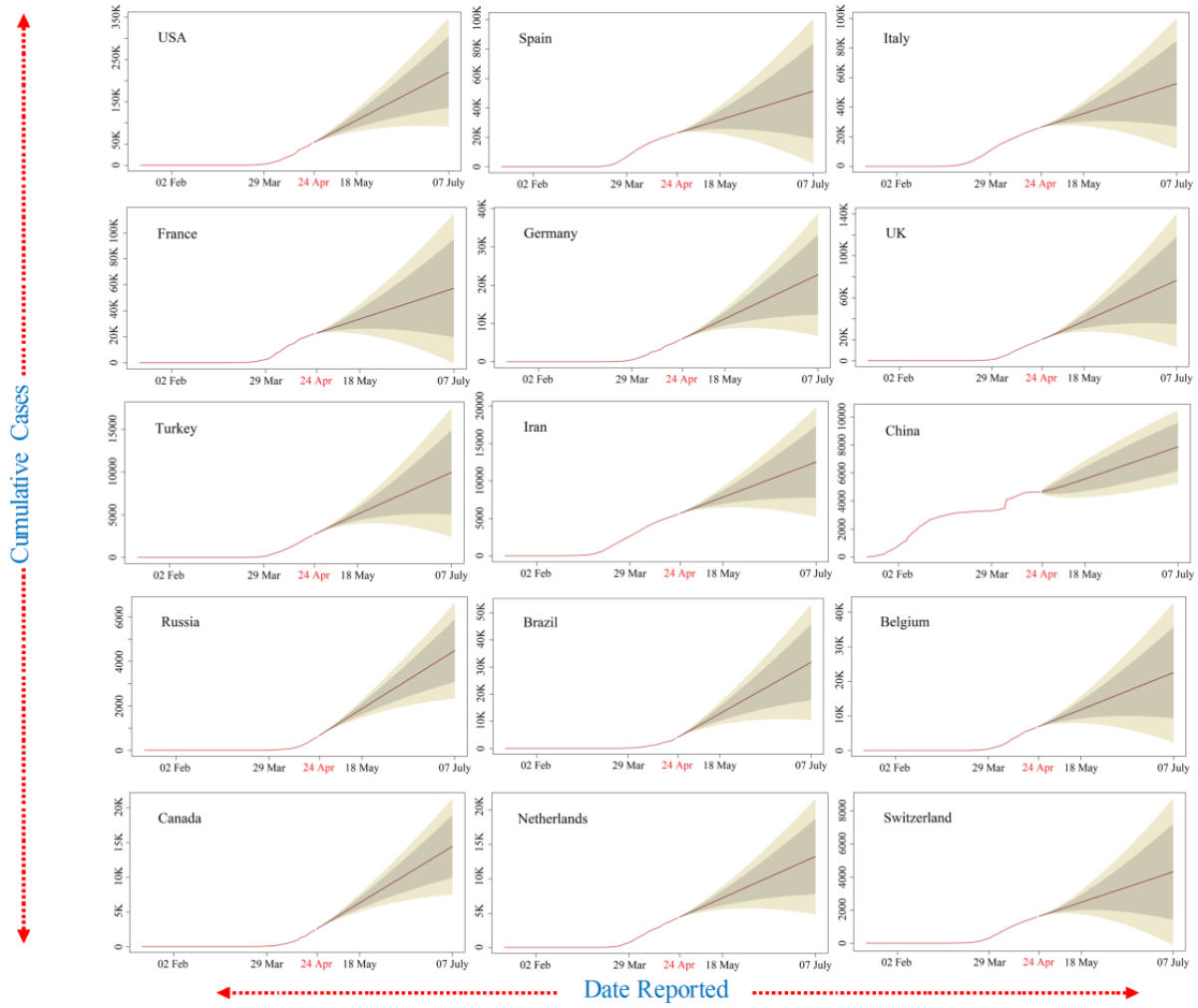
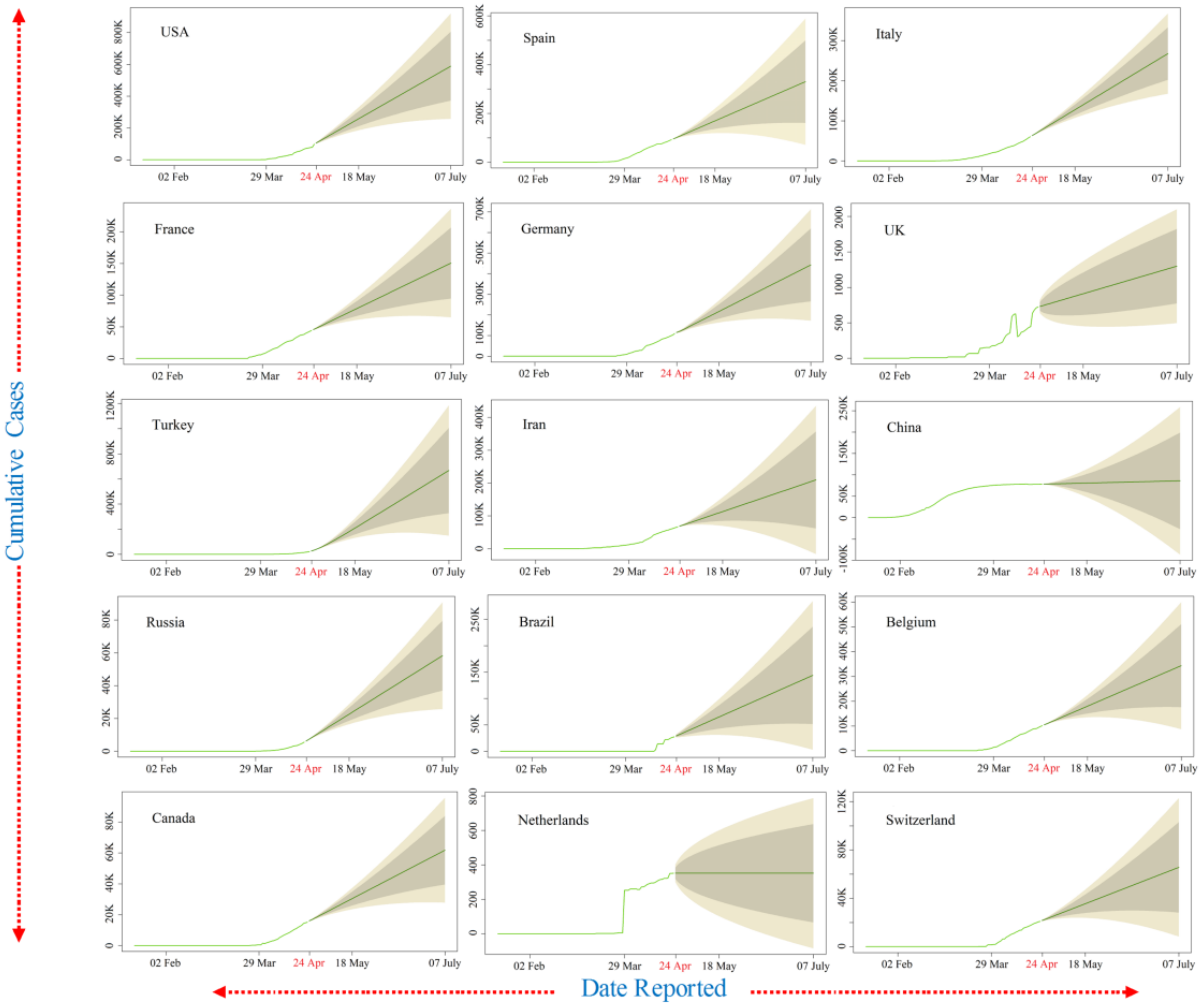


Figure 5. The autoregressive integrated moving average model prediction for more than 2 months of cumulative confirmed coronavirus disease cases in the top 15 affected countries shown in a green color (95% confidence).



Discussion

Principal Findings

The COVID-19 daily data was collected and cumulatively represented as a spatial map for more than 170 countries and territories. The spatial map is useful to identify the intensity of COVID-19 infections in the top 15 countries and the continents. The recent reported data for confirmed cases, deaths, and recoveries for the last 3 months from January to April 2020 was represented and compared between the top 15 infected countries. The ARIMA model was used to predict estimated confirmed cases, deaths, and recoveries for the top 15 countries from April 24 to July 7, 2020. Its value was represented with 95%, 80%, and 70% confidence intervals, and the 95% confidence intervals were shown as the median interval between the 80% and 70% wide values. The validation of the ARIMA model was carried out using the AIC for the available recent data; its values were about 20, 14, and 16 for cumulative confirmed cases, deaths, and recoveries from COVID-19, respectively, which represents acceptable results. The observed predicted values showed that the confirmed cases, deaths, and recoveries will double in all countries except China, Switzerland, and Germany. It was also observed that the death and recovery rates were faster when compared to confirmed cases during the next 2 months. The associated mortality rate will be much higher in the United States, Spain, and Italy followed by France, Germany, and the United Kingdom. The limitation of the ARIMA model is that it does not support any volatility or in-between changes in the prediction periods. The accuracy of the countries' data accumulated from Worldometer was a matter of trust for the representation of the whole study.

The forecast analysis of COVID-19 dynamics showed a different angle for the whole world, and it looks scarier than imagined. Interestingly, the recovery numbers also look promising, with resistance starting by July 2020. Thus, a slowdown in the surge of the COVID-19 pandemic during the proceeding months depends upon various administrative interventions and public awareness about the spread of the COVID-19 pandemic.

Authors' Contributions

RS, AAR, ARM, and ASB designed and proposed the research. PK, ASB, HK, CN, SP, and YDS processed the data, implemented the techniques, analyzed the results, and drafted and edited the article. KD, MR, JR, and RKS joined the discussions and provided constructive suggestions on writing the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

ACF: autocorrelation function
AIC: Akaike information criterion

AR: autoregression
ARIMA: autoregressive integrated moving average
COVID-19: coronavirus disease
GIS: geographic information system
MA: moving average
SARS: severe acute respiratory syndrome
WHO: World Health Organization

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Original Paper

Injuries Reported by Selected Health Facilities During the Arbaeenia Mass Gathering at Babel Governorate, Iraq, 2014: Retrospective Records Analysis

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Abstract

Background: Arbaeenia is the largest religious mass gathering in Iraq. The conditions associated with mass gatherings result in high rates of injury. There have been no prior studies on injuries during the Arbaeenia mass gathering.

Objective: This study describes the injuries observed during the Arbaeenia mass gathering in Babel Governorate in Iraq between November 24 and December 14, 2014.

Methods: The study was conducted in Babel Governorate at the emergency departments of six public hospitals and two major temporary medical units that were located along the three roads connecting the Middle and Southern Iraqi governorates. We used the Iraq Injury Surveillance System modified form to collect information on injured patients treated in the selected facilities. Data on fatal injuries was obtained from the coroner's office. The following data were collected from the patients: demographics, outcome of injury, place and time of occurrence, mode of evacuation and medical care before arriving at the hospital, duration of travel from place of occurrence to hospital, disposition of non-fatal injury, cause and mode of injury, and whether the injury occurred in connection with the Arbaeenia mass gathering.

Results: Information was collected on 1564 injury cases, of which 73 were fatal. About half of the reported nonfatal injuries, 687/1404 (48.9%), and a quarter of fatalities, 18/73 (25%) were related to the Arbaeenia mass gathering (P<.001). Most of the reported injuries were unintentional, 1341/1404 (95.51%), occurred on the street, 864/1323 (65.6%), occurred during the daytime 1103/1174 (93.95 %). Most of those injured were evacuated by means other than ambulance 1107/1206 (91.79%) and did not receive pre-hospital medical care 788/1163 (67.7%). Minor injuries 400/1546 (25.9%) and traffic accidents 394/1546 (25.5%) were the most common types of injuries, followed by falls 270/1546 (17.5%). Among fatal injuries, traffic accidents 38/73 (52%) and violence 18/73 (25%) were the leading causes of death. Mass gathering injuries were more likely to occur among individuals aged 21-40 years (odds ratio [OR] 3.5; 95% CI 2.7-4.5) and >41 years (OR 7.6; 95% CI 5.4-10.6) versus those <21 years; more likely to be unintentional than assault (OR 5.3; 95% CI 1.8-15.5); more likely to happen on the street versus at home (OR 37.7; 95% CI 22.4-63.6); less likely to happen at night than during the day (OR 0.2; 95% CI 0.1-0.4); and less likely to result in hospital admission (OR 0.5; 95% CI 0.3-0.7).

Conclusions: The study shows that most injuries were minor, unintentional, and nonfatal, and most people with injuries had limited access to ambulance transportation and did not require hospitalization.

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KEYWORDS

mass gathering; Injury; Karbala, Iraq

Introduction

Mass gatherings are defined as events with an attendance of more than 1000 persons or as events attended by more than 25,000 people [1]. Injuries that occur during mass gatherings are often due to overcrowding, stampedes, terrorism, and spiritual acts [2,3]. Injuries and noncommunicable diseases are responsible for more deaths and morbidity during mass gatherings than communicable diseases [4].

During the annual Hajj, trauma is a major cause of injury and death. Pilgrims walk long distances through or near dense traffic and motor vehicle accidents are inevitable; however, the most feared trauma hazard is a stampede [5]. In Iraq, injuries are the second leading cause of death and violence, while road traffic, fire, and drowning are among the main causes of injury-related deaths [6,7]. In 2010, the Iraq Injury Surveillance System (IISS) was established in major hospitals and coroners' offices to enable timely electronic reporting of injuries. Al-Hilla hospital, a major referral hospital in Babel Governorate, and the Babel Coroner's Office were added to the roll of IISS reporting facilities in 2013 [8].

The ability of the Iraq health system to respond to injuries is challenged during mass gatherings, during which the risk of injury increases. The Arbaeenia mass gathering is the largest gathering of Shia Muslims worldwide and occurs annually in Karbala, Iraq. During this mass gathering, approximately 20 million pilgrims from nearly 40 countries attend the ceremony [9,10]. Many of the pilgrims travelling to Karbala walk a distance of up to 600 kilometers through several Iraqi governorates, and millions of Arbaeenia attendees pass through Babel Governorate along the three roads connecting Middle and Southern Iraqi governorates to Babel.

There are few studies on the public health problems associated with mass gatherings [11]. During a mass gathering, road traffic injuries and terrorism are major risks to the health of pilgrims and the local community [12]. Because of cultural or religious beliefs, some attendees practice self-harm such as laceration of their scalp using sharp knives and other risky practices [11]. There is particularly limited information available on injury surveillance systems at mass gatherings [13]. The importance of developing public health surveillance system in mass gatherings has been emphasized in recommendations from previously published reports [12,14]. Public health for mass gatherings health is an evolving niche of prehospital care rooted in emergency medicine, emergency management, public health, and disaster medicine [15].

This study describes the mass gathering injuries reported at selected health facilities in Babel Governorate in Iraq during the Arbaeenia mass gathering in 2014.

Methods

We conducted this study in Babel Governorate between November 24, 2014 and December 14, 2014. The emergency departments (ED) of six public hospitals in six districts and two major temporary medical units were selected for convenient data collection. The selected facilities were located along the three roads connecting the Middle and Southern Iraqi governorates to Babel Governorate.

We used an IISS modified form to collect information on injury cases treated in the selected facilities. Data on fatal injuries were obtained from the coroner's Office in IISS sentinel sites in the selected areas. The following data were collected: patient demographics, injury outcome, place and time of occurrence, mode of evacuation and medical care before arriving the hospital, duration of travel from place of occurrence to hospital, disposition of nonfatal injury, cause and mode of injury, and association with the Arbaeenia mass gathering.

Data entry was performed using Epi Info and SPSS Statistics was used for data analysis. We estimated the injury frequencies and percentages by demographics and odds ratios of the factors associated with injuries at the mass gathering. Chi-square statistics were used to test significance at $P<.05$. We estimated the 3-period moving average for the daily trend of fatal and nonfatal injuries to remove trend fluctuations.

Results

There were 1564 injuries treated in the health facilities selected for this study. Of these, 687/1404 (48.9%) were injuries related to the Arbaeenia mass gathering; of the 73 (5%) fatal injuries, 18/73 (25%) were related to the mass gathering. The majority of the injuries, 1096/1564 (70.1%), were collected from the ED of six public hospitals, 395/1564 (25.2%) were from the two temporary health facilities, and 73/1564 (5%) were from the coroners' offices. A major proportion of victims were aged less than 21 years old (44.8%, 685/1564), 72.6% (1136/1564) were males, and 63.4% (955/1564) were residents of Babel Governorate (Table 1).

Table 1. Demographics of patients with sustained injuries during the Arbaeenia mass gathering in Babel Governorate, Iraq, 2014 (N=1564)[a].

Characteristics	n (%)
Reporting sites	
Hospitals (emergency departments)	1096 (70.1)
Temporary health care facilities	395 (25.3)
Coroner's office	73 (4.7)
Total	1564
Injury related to mass gathering	
Yes	687 (48.9)
No	717 (51.1)
Total	1404
Age groups (years)	
<21	685 (43.8)
21-40	571 (36.5)
≥41	279 (17.9)
Total	1535
Sex	
Male	1136 (72.6)
Female	428 (27.4)
Total	1564
Place of residence	
Babel Governorate	955 (63.4)
Other Iraqi Governorates	534 (35.4)
Other countries (Iran, Saudi Arabia, Turkey, Afghanistan)	17 (1.2)
Total	1506

[a] Totals may be <1564 due to missing data.

Table 2 shows the location and time of injuries, factors related to medical services, and relationship to the mass gathering. Most injuries (864/1564, 55.2%) occurred on the street and 580/680 (67.2%) of these were mass gathering-related. Approximately 93.9% (1103/1174) of injuries occurred during the day, and 605/619 (54.9%) of these associated with the mass gathering. The injuries were predominantly unintentional 1341/1404 (95.5%). Only 17/1404 (1%) of injuries were intentional (self-inflicted) and 16/687 (94%) of these were related to the mass gathering. Ambulance services were used for only 99/1206 (8%) of injuries, whereas 661/1206 (54.8%) and 446/1206 (36.9%) were transported in other vehicles or carried directly by people to the hospital. The majority 749/1186 (63.2%) of the injured people reached the hospital within an hour of injury, 258/1186 (21.7%) reached between 2 hours and 24 hours, and 179/1186 (15.1%) reached after >24 hours. Of the injuries that reached the hospital after more than an hour, 208/623 (80.6%) – 168/623 (93.9%) were injuries related to the mass gathering. Only 375/1163 (32.3%) of injuries were medically treated before reaching the hospital, 333/603 (88.8%) of these associated with the mass gathering; and 148/1133 (11%) of injuries were admitted to the hospital, 55/667 (38%) of these were related to the mass gathering.

The moving average daily trend for nonfatal injuries showed a gradual increase from the start of the study on November 24 and peaked on December 8, then declined prior to the day of the Arbaeenia celebration (December 13, 2014). The daily trend for fatal injuries was constant throughout the period, using the moving average (Figure 1).

Figure 2 shows the distribution of injury causes. Of the fatal injuries, 52% were due to traffic accidents and 25% were due to gun violence. Of the nonfatal accidents, the leading causes were injuries related to walking (27%), traffic accidents (24%), and falls (18%).

Table 3 shows the factors associated with injuries incurred during the Arbaeenia mass gathering injuries. Fatal injuries were less likely to be associated with the mass gathering (OR 0.3; 95% CI 0.2-0.4) compared to nonfatal injuries. Compared to the people in the <21 years age group, those 21-40 years of age (OR 3.5; 95% CI 2.7-4.8) and >40 years of age (OR 7.6; 95% CI 5.4-10.6) were more likely to be injured in the mass gathering. Injuries among women were more likely to be associated with the mass gathering (OR 1.4; 95% CI 1.1-1.8). Compared to injuries from assault, self-inflicted and unintentional injuries were more likely to be associated with

the mass gathering (self-inflicted: OR 88, 95% CI 9-863; unintentional: OR 5.3, 95% CI 1.8-15.5). Compared to injuries that occurred at home, injuries that occurred in the street, at work, and elsewhere were more likely to be associated with the mass gathering (OR 37.7, 95% CI 22.4-63.6; OR 25.7, 95% CI 14.1-47.3; and OR 9.2, 95% CI 2.5-33.8, respectively). Injuries that occurred at night were less likely to be mass gathering-related than those that occurred during the day (OR 0.2; 95% CI 0.1-0.4). MG injuries were more likely to be evacuated by other means (e.g., carried by humans; OR 19.8, 95% CI 11-35.8) than by ambulance. People with injuries who took 2-24 hours and >24 hours to reach a hospital were more likely to have mass-gathering-related injuries (OR 8.5; 95% CI 6-11.9 versus OR 31; 95% CI 16.6-58.2), compared to those with injuries who reached a facility in <2 hours. Injuries that received medical care before reaching the hospital were more likely to be mass gathering-related than those that did not receive medical care (OR 15.2, 95% CI 11.1-20). Injuries admitted to the hospital were less likely to be mass gathering-related than those not admitted (OR 0.5, 95% CI 0.3-0.7).

Table 2. Injury characteristics and relationship to the Arbaeenia mass gathering in Babel Governorate, Iraq, 2014 (N=1564).

Variables	Relationship to the mass gathering		
	Yes (%)	No (%)	Total[a] n (%)
Place of occurrence			
Home	16 (5.2)	294 (94.8)	310 (23.4)
Street	580 (67.2)	864 (32.8)	864 (55.2)
Workplace	80 (58.4)	57 (41.6)	137 (10.3)
Others	4 (33.3)	8 (66.7)	12 (1.1)
Total	680 (51.4)	643 (48.6)	1323 (100)
Time of occurrence			
Day time (6 am to 5 pm)	605 (54.9)	498 (45.1)	1103 (93.9)
Nighttime (6 pm to 5 am)	14 (19.7)	57 (80.3)	71 (6.1)
Total	619 (52.8)	555 (47.2)	1174 (100)
Cause of injury			
Assault	4 (15.4)	22 (84.6)	26 (1.8)
Intentional	16 (94.1)	1 (5.9)	17 (1.2)
Unintentional	658 (49.1)	683 (50.9)	1341 (95.5)
Unknown	9 (45.0)	11 (55.0)	20 (1.5)
Total	687 (48.9)	717 (51.1)	1404 (100)
Mode of evacuation			
Ambulance	50 (50.5)	49 (49.5)	99 (8.3)
Other vehicles	171 (25.9)	484 (74.1)	661 (54.8)
Other means (carried by people)	425 (95.3)	21 (4.7)	446 (36.9)
Total	646 (53.6)	560 (46.4)	1206 (100)
Prehospital time interval (hours)			
1	247 (33.0)	502 (67.0)	749 (63.2)
2-24	208 (80.6)	50 (19.4)	258 (21.7)
>24	168 (93.9)	11 (6.1)	179 (15.1)
Total	623 (52.5)	563 (47.5)	1186 (100)
Prehospital medical care			
Not received	270 (34.3)	518 (65.7)	788 (67.7)
Received	333 (88.8)	42 (11.2)	375 (32.3)
Total	603 (51.8)	560 (48.2)	1163 (100)
Disposition of nonfatal injuries			
Not admitted (treated and discharged)	585 (55.7)	468 (44.3)	1053 (79)
Admitted [b]	55 (37.8)	93 (62.2)	148 (11)
Unknown	27 (20.8)	103 (79.2)	130 (10)
Total	667 (50.2)	664 (49.8)	1331

[a]Totals differ due to missing data or lack of response.

[b]Including self-discharged and referred.

Figure 1. Trend of reported injuries during Arbaeenia mass gathering in Babel Governorate, Iraq, 2014 (N=1561).

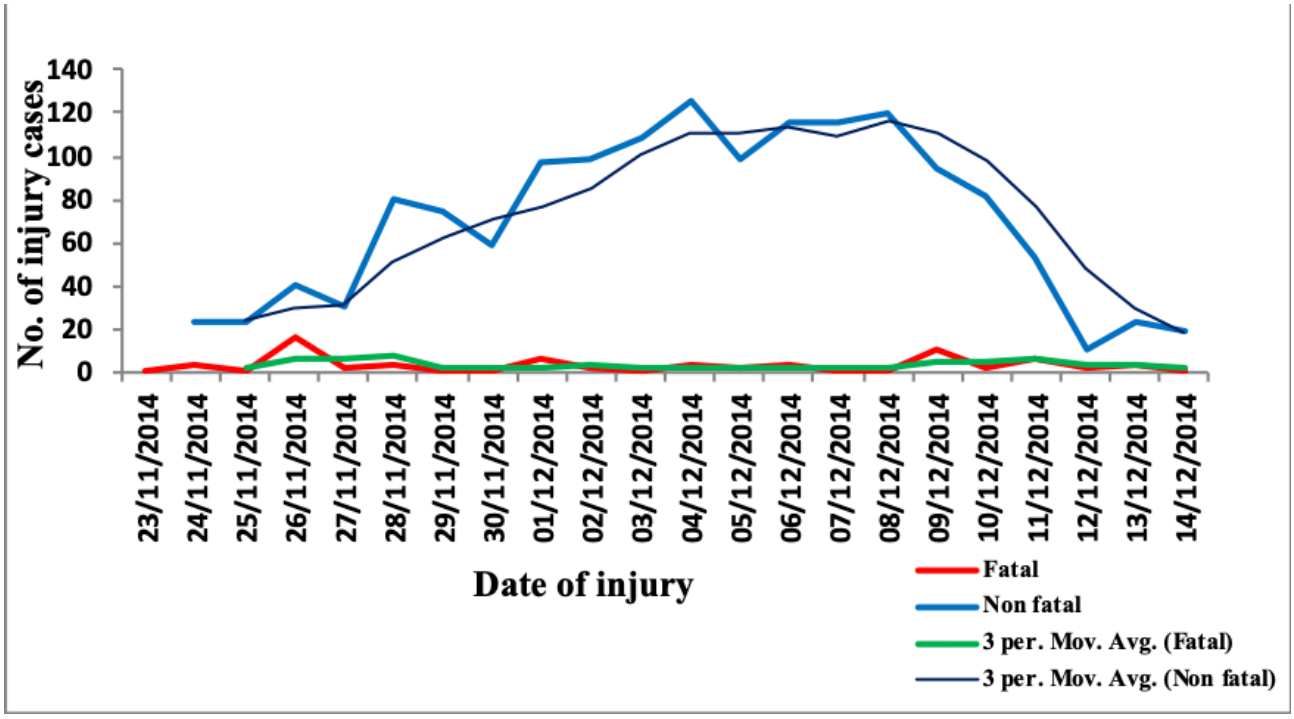

Figure 2. Distribution of causes of injuries by outcome during the Arbaeenia mass gathering in Babel Governorate, Iraq, 2014 (N=1564).

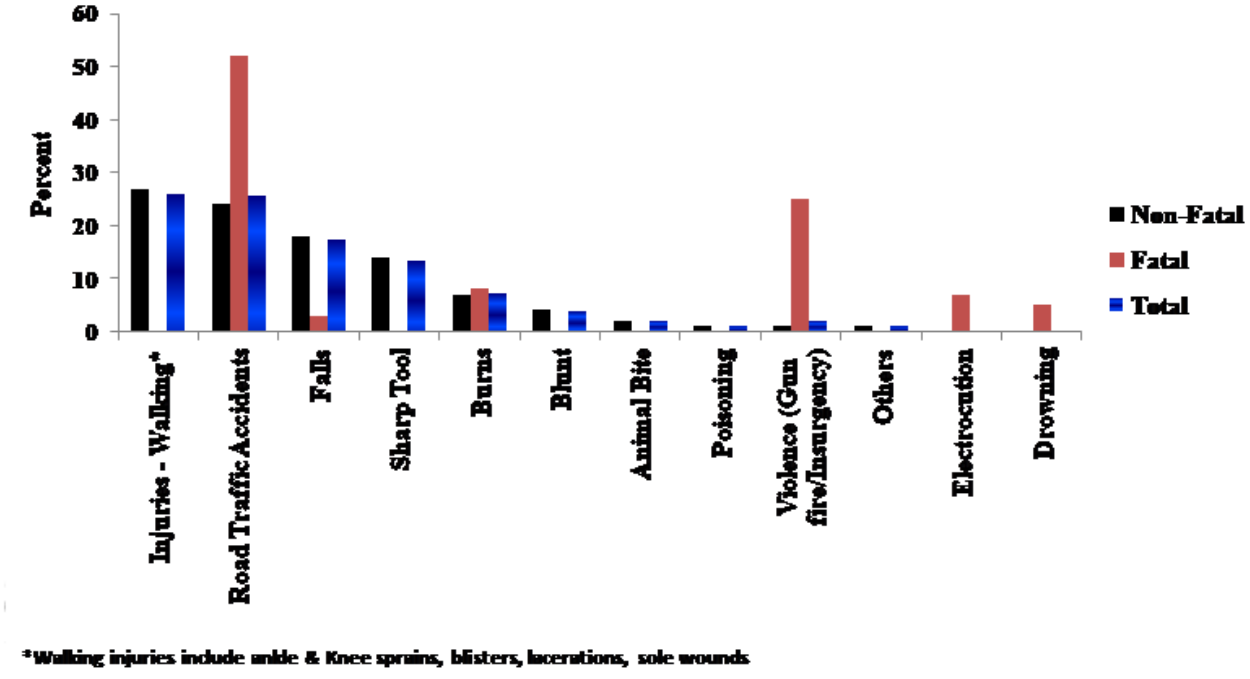

Table 3. Factors associated with injuries occurring during the Arbaeenia mass gathering in Babel Governorate, Iraq, 2014 (N=1564)

Variables	Mass gathering-related		Total, n (%) [a]	Odds ratio (95% CI)	*P* value
	Yes (%)	No (%)			
Outcome					
Nonfatal	670 (50.3)	661 (49.7)	1331 (94.8)	1	
Fatal	18 (25)	55 (75)	73 (5.2)	0.3 (0.2-0.6)	<.001
Total	688 (49)	716 (51)	1404 (100)		
Age (years)					
<21	174 (29.3)	429 (70.7)	594 (43.1)	1	
21-40	306 (59.1)	212 (40.9)	518 (37.6)	3.5 (2.7-4.5)	<.001
≥41	201 (75.8)	64 (24.2)	265 (19.3)	7.6 (5.4-10.6)	<.001
Total	681 (49.5)	696 (50.5)	1377 (100)		
Sex					
Males	474 (46.6)	544 (53.4)	1018 (72.5)	1	
Females	213 (55.2)	173 (44.8)	386 (27.5)	1.4 (1.1-1.8)	.004
Total	687 (48.9)	717 (51.1)	1404 (100)		
Intent of injury					
Assault	4 (15.4)	22 (84.6)	26 (1.8)	1	
Self-harm	16 (94.1)	1 (5.9)	17 (1.1)	88 (9-863	<.001
Unintentional	659 (49.1)	682 (50.9)	1341 (95.6)	5.3 (1.8-15.5)	.02
Unknown	9 (45.0)	11 (55.0)	20 (1.5)	4.5 (1.1-17.9)	.033
Total	688 (49.0)	716 (51.0)	1404 (100)		
Place of occurrence					
Home	16 (5.2)	294 (94.8)	310 (23.4)	1	
Street	581 (67.2)	283 (32.8)	864 (65.3)	37.7 (22.4-63.6)	<.001
Workplace	80 (58.4)	57 (41.6)	137 (10.3)	25.7 (14.1-47.3)	<.001
Others	4 (33.3)	16 (66.7)	12 (1.0)	9.2 (2.5-33.8)	.001
Total	681 (51.5)	642 (48.5)	1323 (100)		
Time of occurrence					
Daytime (6 am to 5 pm)	605 (54.9)	498 (45.1)	1103 (93.9)	1	
Nighttime (6 pm to 5 am)	14 (19.7)	57 (80.3)	71 (6.1)	0.2 (0.1-0.4)	<.001
Total	619 (52.8)	555 (47.2)	1174 (100)		
Mode of evacuation					
Ambulance	50 (50.5)	49 (49.5)	99 (8.2)	1	
Other vehicles	171 (25.9)	490 (74.1)	661 (54.8)	0.34 (0.2-0.5)	<.001
Other means (carried by other people)	425 (95.3)	21 (4.7)	446 (37.0)	19.8 (11-35.8)	<.001
Total	646 (53.6)	560 (46.4)	1206 (100)		
Prehospital time interval (hours)					
1	247 (32.9)	502 (67.1)	749 (63.1)	1	
2-24	208 (80.6)	50 (19.4)	258 (21.8)	8.5 (6-11.9)	<.001
> 24	168 (93.9)	11 (6.1)	179 (15.1)	31 (16.6-58.2)	<.001
Total	623 (52.5)	563 (47.5)	1186 (100)		
Prehospital medical care					
Not received	270 (34.3)	518 (65.7)	788 (67.7)	1	

Variables	Mass gathering-related		Total, n (%) [a]	Odds ratio (95% CI)	*P* value
	Yes (%)	No (%)			
Received	333 (88.8)	42 (11.2)	375 (32.3)	15.2 (11.1-20)	
Total	603 (51.8)	583 (48.2)	1163 (100)		<.001
Disposition of nonfatal injuries					
Not admitted (treated and discharged)	586 (55.7)	467 (44.3)	1053 (79.1)	1	
Admitted	56 (37.8)	92 (62.2)	148 (11.1)	0.5 (0.3-0.7)	<.001
Unknown	27 (20.8)	103 (79.2)	130 (9.8)	0.2 (0.2-0.3)	<.001
Total	669 (48.9)	464 (51.1)	1331 (100)		

[a]Totals are different due to missing data or lack of response.

Discussion

The study describes injuries reported at several health facilities during the Arbaeenia mass gathering in Babel Governorate, Iraq. Most of the injuries were minor (walking-related), unintentional, or nonfatal with limited or no access to ambulance transportation and the affected people did not require hospitalization. The injured individuals often reached a hospital within an hour of injury. People with injuries who took more than 1 hour to reach a hospital but received medical care prior to arrival were more common among people with injuries associated with the mass gathering than those that were not.

During mass gatherings, trauma is one of the most common medical problems [16]. The health consequences of mass gatherings include injuries resulting from crowd density and inadequate infrastructure, exposure to extreme weather events, and escalation of violence as a result of crowd behavior [17]. The injured patients during the Arbaeenia mass gathering were mostly young, consistent with the global figures on injuries [18]. Youth are more likely to take risks than older individuals, increasing their risk of injury [19]. Unintentional injuries accounted for the vast majority of cases reported, which was consistent with the findings of global and national injury surveillance reports [8].

In contrast to reports from IISS data and other sources, this study found that nearly two-thirds of the injuries occurred in the street, as opposed to in the home [8,20,21]. The high occurrence of injuries in the street is a result of the nature of the mass gathering, during which pilgrims travel long distances on foot to attend the event in Karbala.

Few of the injuries were transported to the hospital by ambulance, which could explain the lack of prehospital medical care for the majority of injuries. Despite the lack of ambulance services to evacuate the injuries, the majority of patients reached a health care facility within an hour of injury, which trauma experts consider the critical timeframe for lifesaving efforts. In general, few injury victims receive prehospital medical care and ambulance transportation [22,23]. This study showed that people with injuries related to the mass gathering were less likely to reach the hospital within the critical 1-hour timeframe. Road congestion during the mass gathering may have delayed patients in reaching the hospitals. The majority of injured patients did not require hospitalization, consistent with other religious mass gatherings and injury surveillance reports [8,11,23,24].

The ratio of injury deaths to hospital admissions and ED attendants in this study was 1:2.7:15.7, whereas the IISS report cited a ratio 1:1.5 6 [8]. Our study included minor injuries, which comprised the majority of mass gathering-related injuries, possibly increasing the observed ER burden. Traffic accidents, which accounted for half of injury deaths and a quarter of nonfatal injuries, may also have contributed to the high admission ratio. Hospital admission rates depend on the severity of injury, access to hospital services, and health system structure [25].

The majority of injuries occurred during the daytime, which is consistent with information observed in the IISS report and other studies [8,19,26]. The high occurrence of injuries during the daytime may be explained by the high traffic volume during the day. The pilgrims walk during the day and often rest in the evening, which reduces their risk of traffic accidents during the night.

Injuries among women were more likely to be mass gathering-related than those among men. Burns are common among females in Iraq and worldwide, as women have higher exposure to heat or hot surfaces during cooking, and probably this is the case in mass gathering. In contrast, men are mostly the victims of the traffic accident injuries [8,24,27].

Traffic accidents are the leading cause of fatal injuries in Iraq and globally [6]. Traffic accidents accounted for more than half of the fatal injuries in this study, which is higher than the global figures on fatal injuries (24%) [28]. This may be due to the large number of pilgrims traveling on foot and the high traffic volume on the roadways. A review of studies in low-to-middle-income countries revealed that traffic accidents accounted for one-third to four-fifths of traumatic injury admissions, one-tenth to one-third of all injuries treated in hospitals, and almost half of all bed occupancies in surgical wards [26]. This study showed similar findings on injuries treated in hospitals.

Most of the injuries reported were minor (75%), which is consistent with prior reports on injuries related to other mass gatherings and may explain why the majority of the injury cases were not admitted to the hospitals [29]. This information is consistent with a study among Iranian pilgrims during the Hajj mass gathering [30-32].

This study had several limitations. Some potential subjects may have been missed during data collection. In addition, data for some items, particularly the disposition variable, were missing. Injury data were not collected from all health facilities, which limits generalizability. Injury data collected from health facilities may have underestimated the total injuries that occurred because individuals with minor injuries may not seek medical care from the health facilities [33]. Injury rates could not be calculated, because the population at risk is unknown and could not be determined.

Conflicts of Interest

None declared.

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Abbreviations

LMIC: low and middle-income countries

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Review

Assessing the Emergent Public Health Concern of All-Terrain Vehicle Injuries in Rural and Agricultural Environments: Initial Review of Available National Datasets in the United States

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Abstract

Background: Injuries related to the operation of off-road vehicles (ORVs), including all-terrain vehicles (ATVs), continue to be a significant public health concern, especially in rural and agricultural environments. In the United States alone, ATVs have played a role in thousands of fatalities and millions of injuries in the recent decades. However, no known centralized federal surveillance system consistently captures these data. Traditional injury data sources include surveys, police reports, trauma registries, emergency department data, newspaper and online media reports, and state and federal agency databases.

Objective: The objectives of this study paper were to (1) identify published articles on ORV-related injuries and deaths that used large databases and determine the types of datasets that were used, (2) examine and describe several national US-based surveillance systems that capture ORV-related injuries and fatalities, and (3) promote and provide support for the establishment of a federally-funded agricultural injury surveillance system.

Methods: In this study, we examined several national United States–based injury datasets, including the web-based AgInjuryNews, the Fatality Analysis Reporting System, databases compiled by the US Consumer Product Safety Commission, and the National Fatality Review Case Reporting System.

Results: Our review found that these data sources cannot provide a complete picture of the incidents or the circumstantial details needed to effectively inform ORV injury prevention efforts. This is particularly true with regard to ORV-related injuries in agricultural production.

Conclusions: We encourage the establishment of a federally funded national agricultural injury surveillance system. However, in lieu of this, use of multiple data sources will be necessary to provide a more complete picture of ORV- and other agriculture-related injuries and fatalities.

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KEYWORDS

agriculture; all-terrain vehicle; fatality; injury; off-road vehicle; rural

Introduction

Background

The group of vehicles generically referred to as off-road vehicles (ORVs) are gasoline- or diesel-powered motor vehicles designed to be used on a wide variety of off-road surfaces, including packed or loose dirt, rocks, sand dunes, snow, and marshlands. They typically have large low-pressure tires with knobby treads to grab off-road terrains. Vehicles equipped for use on sand dunes often have tires with paddle-like treads.

A popular ORV, which has been available since the 1970s, is the all-terrain vehicle (ATV; Figure 1). On ATVs, the rider straddles a motorcycle-like seat and uses handlebars to steer, brake, or accelerate. In many other countries, these vehicles are referred to as quads or quad bikes. ATVs have a narrow track width (distance between the middle of the right and left tires), a short wheelbase (distance between the axle or center point of the front and rear wheels), and a high center of gravity. Together, these result in low stability. Given their design, an ATV operator is required to use *active riding*, which involves the operator moving their pelvis and torso laterally and/or longitudinally on the seat, or vertically off the seat, while keeping both hands on the handlebars and both feet on the footrests throughout a maneuver, thus increasing the stability of the ATV and reducing the chance of a rollover [1].

Figure 1. All-terrain vehicle.

A second type of ORV that has gained increasing popularity over the past few decades is generically called a side-by-side (S×S). This includes recreational off-highway vehicles (ROVs; Figure 2) and utility task/terrain vehicles (UTVs). ROVs and UTVs have automobile-like bench or bucket seats, a steering wheel, and foot pedals to activate the brake and accelerator. Some people refer to all S×Ss as UTVs, but, technically, light utility vehicles have maximum speeds of 25 mph, whereas all ROVs are capable of traveling greater than 30 mph [2]. Owing to this, ROVs are required in the United States to have rollover protective structures (ROPS) and restraint devices such as seat belts or a harness system [3]. Although some UTVs have ROPS, many do not.

Figure 2. Recreational off-highway vehicle.

Off-Road Vehicle Related Exposure and Injury

Both ATVs and S×Ss are used for a wide range of recreational activities, such as trail and dune riding, hunting, and fishing, and occupational activities, such as forestry, farming, and ranching. In the spring of 2017, an estimated 10.5 million households owned an ATV (with many households owning more than one vehicle), and an additional 2.4 million reported that they intended to purchase an ATV within the next year [4]. This compares with an estimated 5.6 million ATVs in use in 2001 [5]. There is no similar publicly available data on the total number of S×Ss in the United States. However, in its annual report filed with the US Securities and Exchange Commission, Polaris Industries estimated that during 2016, the worldwide sales of ATVs were approximately 400,000 vehicles and of ROVs were about 480,000 [6]. These data also show that the ORV market has been shifting from ATVs to ROVs in recent years.

Loss of control is a common risk resulting in traumatic injuries among ATV operators and passengers. Factors that increase the risk include younger age, being a male driver, inexperience, riding the wrong size ATV, carrying passengers, riding on the road, lack of helmets, and alcohol use [7]. ATVs have been implicated in 15,250 deaths between 1982 and 2017 in the United States [8]. During that period, 22% of the deaths were of children aged under 16 years, with 44% of those younger than 12 years [8]. Most of the deaths and injuries to youth (95%) occur in adult-size vehicles, which they are neither supposed to operate nor ride as passengers [5,9-11]. In fact, more children aged under 16 years in the United States die from ATVs than from bicycle crashes [12], and they have 12 times higher risk of injury than older adults [13]. Furthermore, the economic costs of morbidity and mortality from ATV crashes are high [12].

Public Roadways

Despite ORVs being designed for off-road use only and manufacturers warning that the vehicles should not be used on public roads, most ATV fatalities occur on roadways [7,14,15]. Between 2004 and 2013, the National Highway Traffic Safety Administration (NHTSA) reported that ATV-related fatalities in their Fatality Analysis Reporting System (FARS) ranged from a low of 307 in 2012 to a high of 381 in 2008. Data from 2017 showed that 87% of ATV-related roadway deaths were of drivers [16]. Helmet use was low, with only 9% wearing helmets. Most of the deaths occurred in single-vehicle crashes (71%) and in rural areas (79%). In addition, 40% of fatally injured ATV operators had a blood alcohol level (BAC) of 0.08 or higher, compared with 28% of motorcycle operators [16].

Surprisingly, despite the trends of injury and death associated with ORVs on public roadways, many municipalities and counties have already enacted or are considering ordinances that would allow open access to ORVs on their roads [17]. Elected officials and law enforcement personnel are often contacted by concerned citizens, health care providers, and injury prevention experts who oppose such legislation. However, more often than not, evidence-based arguments, peer-reviewed literature, testimonials, and media reports have had little to no effect. According to the Consumer Federation of America (CFA), a nonprofit research and education organization, there is a national trend that is gaining greater traction to enact local and state laws to allow ORVs on public roads, with no decline in the foreseeable future [17]. From April 2014 to September 2018, the CFA sent more than 180 letters opposing the use of ORVs on public roads to state and local officials in 27 states, with 40 in the state of Wisconsin alone [18].

Off-Road Vehicles in Agriculture

Farmers and ranchers were early purchasers and have described ATVs as filling a valuable niche between a truck and a tractor [19]. These versatile machines are leveraged for a variety of agricultural work–related tasks [20]. These include inspecting crops and livestock, tilling, herding animals, spraying pesticides and herbicides, plowing or blowing snow, towing or hauling farm supplies and products, and other general transportation and labor tasks. It is expected that the prevalence of ORV use in farming and ranching, both occupational and recreational, will continue to increase [21].

The incidence of fatal and nonfatal injuries in the Agriculture, Forestry and Fishing industrial sector has become difficult to quantify, particularly after the National Institute for Occupational Safety and Health (NIOSH) discontinued national surveys of nonfatal injuries to self-employed farmers, ranchers, and children on farms. However, the Occupational Safety and Health Administration (OSHA) reported that from 2003 to 2013, there were 2090 injuries and 321 deaths because of occupational use of ATVs, with 60% of ATV-related fatalities occurring in agriculture [22]. The use of ATV-mounted weed sprayer tanks is especially problematic as mounting the tank on the vehicle both raises and shifts the center of gravity, making an already unstable vehicle even more likely to overturn [23].

Objective

The objectives of this study were to (1) identify published articles on ORV-related injuries and deaths that used large databases and determine the types of datasets that were used, (2) examine and describe several national United States–based surveillance systems that capture ORV-related injuries and fatalities, and (3) promote and provide support for the establishment of a federally funded agricultural injury surveillance system.

Methods

Review of Injury Data Sources

An electronic literature search of all articles published between 2014 and 2018 was conducted using PubMed to identify ORV-related articles. The terms used in various combinations in Medical Subject Headings and keyword searches included “off-road vehicles,” “fatalities,” “accidents,” “wounds,” “injuries,” “ATV,” “UTV,” and “mortality.” Our search yielded 70 results, and the abstracts of these articles were reviewed. Published reports were included in this study if they had used a large database of stored information from which they identified ORV-related crashes, injuries, or deaths. A total of 17 articles met the inclusion criteria.

National Datasets

In this report, 4 national United States–based datasets that include ORV-related crashes and injuries were selected for review: AgInjuryNews, Consumer Product Safety Commission (CPSC), FARS, and the National Fatality Review Case Reporting System (CRS). Although this paper focuses on 4 US databases, there are several other national datasets that include ORV-related injuries and/or deaths. For example, the Bureau of Labor Statistics (BLS) collects the US occupational injury and fatality data. Under the auspices of the BLS, the Census of Fatal Occupational Injuries captures occupational fatalities, including those of volunteers and undocumented workers [24], and the Survey of Occupational Injury and Illnesses database collects nonfatal occupational injuries, including those solicited from agricultural employers having more than 10 employees [24]. The OSHA also investigates work-related fatalities, but excludes self-employed individuals, members of the immediate family of farm employers, and employees of state and local governments. In addition, the OSHA investigation's inclusion/exclusion and general oversight criteria vary from state to state [25]. Neither BLS nor OSHA captured bystander or passenger injuries, unless the bystander or passenger was also working at the time of the incident. In summary, BLS and OSHA data provide a very limited view of agricultural injuries, and for these reasons, they were not included or further explained in this review.

Ethics Approval and Informed Consent

No human subjects were involved in this project.

Results

Systematic Review

Table 1 summarizes the 17 ORV-related articles published between 2014 and 2018 that used large datasets. Most researchers have used trauma center and/or emergency department (ED) data as well as data from the FARS; the CPSC, including their National Electronic Injury Surveillance System (NEISS); and state departments of transportation (DOTs). These studies primarily focused on demographics, severity of injury, body part injured, and risk factors. However, sources that included a variety of vehicle- and crash-related variables rarely indicated whether the vehicle was used for recreational or occupational purposes [26].

Table 1. Summary of off-road vehicle–related studies (2014-2018) and the data sources used.

Reference (year)	Data source	Study period	Study populations
Richardson et al (2018) [27]	FARS[a], CPSC[b], and vehicle sales database	2000-2015	All age groups
Nabaweesi et al (2018) [28]	National Emergency Department Sample	2006-2011	Pediatric (0-17 years)
Karkenny et al (2018) [29]	NEISS[c]	1991-2014	2-18 years
Testerman et al (2018) [30]	Level I trauma center	2005-2015	All age groups
Nolan et al (2018) [31]	Level I trauma center	1999-2005	All age groups
Flaherty et al (2017) [32]	Massachusetts emergency departments	2002-2013	Pediatric (0-17 years)
Benham et al (2017) [33]	Level I trauma center	2008-2012	Adult and pediatric
Lombardo et al (2017) [34]	NEISS	2007-2012	Pediatric (0-17 years)
Garay et al (2017) [35]	Pennsylvania State Trauma Database	2004-2014	Pediatric (0-17 years)
Qin et al (2017) [36]	Iowa Department of Transportation, Department of Natural Resources, and State Trauma Registry	2002-2013	All age groups
Gorucu et al (2017) [37]	Pennsylvania Department of Transportation roadway crash data	2010-2013	All age groups
Linnaus et al (2016) [38]	Level 1 pediatric trauma center	2007-2015	Pediatric (0-17 years)
Bethea et al (2016) [39]	Level 1 trauma center	2005-2013	All age groups
Lagerstorm et al (2016) [40]	CPSC	2011-2013	All age groups
Sciarretta et al (2016) [41]	Level II trauma center	Not available	Pediatric (0-17 years)
Williams et al (2014) [42]	FARS	2007-2011	All age groups
Denning et al (2014) [9]	CPSC	1985-2009	Pediatric (0-17 years)

[a]FARS: Fatality Analysis Reporting System.

[b]CPSC: Consumer Product Safety Commission.

[c]NEISS: National Electronic Injury Surveillance System.

National Datasets for Off-Road Vehicle–Related Injuries and Deaths

Similar to many other subsectors of injury prevention and injury epidemiology, there is a lack of a comprehensive national injury surveillance system for ORV-related injuries, including those from agricultural use of the vehicle. In the following sections, descriptions of the 4 selected national datasets are provided. Table 2 summarizes the characteristics of these national data sources for ORV-related injuries and deaths.

Table 2. Characteristics of national data sources for all-terrain vehicle–related injuries.

Properties	AgInjuryNews	CPSC[a]	Fatality Analysis Reporting System	The National Fatality Review CRS[b]
Responsible organization	National Farm Medicine Center and Marshfield Clinic Research Institute	Independent agency of US government	National Highway Traffic Safety Administration	National Center for Fatality Review and Prevention
Purpose	To provide an interactive display of publicly available injury reports data involving AgFF[c]-related injuries and fatalities	To protect the public against unreasonable risks of injury or death from consumer products through education, safety standards activities, regulation, and enforcement	To provide an overall measure of highway safety, to help suggest solutions, and to help provide an objective basis to evaluate the effectiveness of motor vehicle safety standards and highway safety programs	To promote, support, and enhance fatality review methodology and activities for fetal and infant mortality review and CDR[d]
Inclusion and exclusion criteria	Included: injuries and fatalities related to AgFF; excluded: recreational and non-AgFF cases	Included: consumer product–related injuries evaluated at NEISS[e] emergency departments and consumer product–related fatalities; excluded: CPSC notes that some states may not report all all-terrain vehicle deaths within their state	Included: fatal traffic crashes involving a motor vehicle on public roadways; excluded: motor vehicle deaths occurring >30 days after the incident	Included: all child deaths reviewed by local review teams in states that utilize the CDR CRS
Data collection period	2015 to present	1982 to present	1975 to present	2005 to present
Primary data sources	News media, social media, obituaries, police reports, and Fatality Assessment and Control Evaluation reports	NEISS, death certificates, in-depth CPSC investigations, news media, and coroner/medical examiner reports	Police crash reports, death certificates, state vehicle registration files, coroner/medical examiner reports, state driver licensing files, hospital medical reports, state highway department data, emergency medical service reports, vital statistics, and other state records	Agencies represented on CDR teams share case-specific information at multidisciplinary meetings. Represented agencies include, but are not limited to, medical examiner or coroner, law enforcement, child protective services, medical providers, and school districts
Data collection methods	News media monitoring service, Google Alerts, and submissions from colleagues and users	Death certificates, news media monitoring, and CPSC crash investigations	State submission of police crash reports and other data	Cases are identified through medical examiners, coroners, and vital records
Crash location–related variables	Location and type of road	Location and type of road	Location, type of road, crash characteristics, environmental conditions, and first harmful event	Location and driving conditions
Vehicle-related variables	Vehicle type	Engine size; vehicle type, make, and model; and the presence of passengers	Vehicle type, make, and model; most harmful event; extent of damage; and vehicle- and driver-level related factors	Child's vehicle, other primary vehicle, and number of occupants
Victim-related variables	Demographics, operator/passenger, injury severity (fatal/nonfatal), agricultural work relatedness, safety equipment (eg, helmet, seatbelt, and gear), injury event, and injury sources	Demographics, vehicle safety training, operators' height/weight, and alcohol/drug usage	Demographics, seating position, alcohol/drug usage and test results, fatal injury at work, and safety equipment (eg, helmet, seatbelt, and gear)	Demographics, seating position, causes of incident (eg, speeding and distraction), vehicle safety training, safety equipment (eg, helmet, seatbelt, and gear), and alcohol/drug usage

[a]CPSC: Consumer Product Safety Commission.

[b]CRS: Case Reporting System.

[c]AgFF: agriculture, fishing, and forestry.

[d]CDR: child death review.

[e]NEISS: National Electronic Injury Surveillance System.

AgInjuryNews

AgInjuryNews was developed by the National Farm Medicine Center and launched in 2015 [24]. The team responsible for this endeavor compiles AgFF-related injuries and fatalities from publicly available sources such as news media outlets, obituaries, social media, and police reports [24]. This is accomplished through several search platforms, including a media monitoring service, Google Alerts, social media (eg, sheriff departments' Facebook pages and GoFundMe), and submissions from colleagues [24]. Data are collected, coded, uploaded to the center's interactive searchable website, and made available for public use. The goal of this repository is to provide a comprehensive list of all deaths and injuries occurring on farms and ranches, including cases involving children as bystanders and/or farm visitors [20]. Data collection methods of the AgInjuryNews initiative are further described in a different paper [43]. Data for this study were available to the authors of this paper through prearranged administrative privileges.

ORV-related injuries occurring on a farm or ranch are included in the AgInjuryNews database. To distinguish occupational ORV-related fatalities, AgInjuryNews researchers use farm and agricultural injury classification (FAIC) codes. FAIC codes provide a systematic scheme for separating farm/agricultural production work cases [44]. It is often difficult to differentiate between occupational and nonoccupational ORV-related cases as there might not be enough detailed information from news reports to use the FAIC. AgInjuryNews researchers often follow-up and try to gather more information to distinguish occupational from nonoccupational cases.

With regard to ORV-related cases, AgInjuryNews uses the Occupational Injury and Illness Classification System (OIICS) for coding the vehicle involved in the injury. There is a specific OIICS code for ATVs (code: 8611), but not for other types of ORVs. AgInjuryNews coders use the OIICS code 8619 (off-road passenger vehicles—powered, not elsewhere classified) for ORVs other than ATVs [45]. Other variables available in the database include demographics of injured victims, crash location (eg, roadway, farm, field, or orchard), whether the incident was work-related or recreational, injury source (eg, vehicle type), event/activity at the time of the incident (transportation, fall, or contact), and others. Detailed information on the available variables can be found in AgInjuryNews [46].

In the past, a collection of news reports could successfully capture nearly all fatal incidents and identify agricultural injury and fatality cases at the local, regional, and national levels [47,48]. The AgInjuryNews initiative has become a systematic, up-to-date, web-based collection of agriculture-related injuries and fatalities that fill a surveillance gap and provide national-level data to guide research, injury prevention efforts, and organizational policy for agribusiness [24]. Media reports collected by AgInjuryNews over time have shown how the ATV-related injury category has quickly risen to the top as a source of injury among youth in agriculture, with ATVs being the second leading cause of nonfatal injuries and the leading cause of fatal injuries among those younger than 18 years [24].

The AgInjuryNews dataset, established in 2015, is limited by the information available in the original sources, which are primarily web-based news media reports [43]. These types of reports likely capture more serious traumatic injuries and fatalities. However, media reports are inherently inconsistent in the type of information they provide. For example, not every journalist asks the same questions, or they may simply redistribute statements from the responding sheriff's department or fire chief. When the injury is nonfatal, data variables such as age and gender are not always reported. Moreover, journalists often mislabel the various types of ORVs involved, for example, calling an S×S an ATV. Sometimes this error can be identified by other information included in the article, such as the rider not using their seat belt (only available on S×Ss), but not always. To further complicate things, DOT data also vary across states, based on how ATVs and S×Ss are coded. In addition, this dataset may inadvertently include cases that are not agricultural because of the difficulty in identifying vehicle use at the time of the crash.

Consumer Product Safety Commission

As ORVs are designed for off-road use only, manufacturers are not regulated by the Federal Motor Vehicle Safety Standards issued by NHTSA for roadway vehicles. Instead, they are regulated by the CPSC, an independent 5-member commission. The CPSC releases an annual report on the deaths and injuries related to ATV use in the United States. There are no comparable annual reports on the deaths and injuries related to S×Ss. On the basis of the cases collected by the CPSC, estimated deaths from the use of ATVs peaked at 923 in 2005 and declined to 651 in 2013. However, the number of fatalities appears to be increasing again, as there were an estimated 708 deaths in 2015 [8].

Data collected by the CPSC on ATV-related fatalities are available to researchers upon request for secondary analyses. This is accomplished by completing and submitting a Freedom of Information Act request form through the CPSC website [49]. The CPSC also prepares estimates of hospital ED-treated injuries related to consumer products through its NEISS, which is a probability sample of EDs in the United States. There were an estimated 93,800 ATV-related injuries treated in EDs in 2017. Of those injuries, the CPSC estimates that 24,800 (26%) were to children under 16 years [8].

Public access to the NEISS is available through the CPSC website, and individuals may view and download the national injury estimates for a multitude of consumer products, including ATVs [50]. NEISS uses 4 different codes for ATVs based on the number of wheels (3, 4, more than 4, and unspecified number of wheels). Through the NEISS Query Builder, customized searches may be performed, and deidentified case data may be downloaded for further analysis. Variables available include demographics (age, sex, and race), product involved, date of injury, general location where the injury occurred, body part injured, diagnosis, and patient disposition. There is also a brief narrative that provides a description of the incident.

The CPSC fatality data are limited with regard to information about crash events and driver actions [42]. Some variables such as information on the make and model of the ATV involved in

the crash are restricted and not made available to the public [47]. A major limitation of the CPSC data is that there is a substantial time lag in reporting data on ATV fatalities. For example, the most recent annual report was released in February 2019, but the last year for which ATV fatality data in this report were considered complete was 2014. Data collection was still ongoing at the time of this study for 2015 to 2017 [8].

Although the CPSC began its collection of ATV fatality data in 1982, the agency switched from using death certificate mortality codes under the ninth revision of the International Classification of Diseases to the tenth revision in 1999. The CPSC says that comparisons of pre-1999 data with the later data "should be undertaken with caution" [51]. In addition, CPSC death counts by state reflect the state in which the death occurred rather than the state in which the crash occurred. Using emergency medical services' air and ground transportation for the most critically injured ATV riders to level 1 trauma centers in other states may inflate the number of deaths reported for a state in which the rider was finally treated. Unfortunately, the CPSC does not actively collect data related to S×Ss and does not include them in their annual ATV death and injury reports.

The NEISS is an easily accessible database that provides probability sampling of national ED data, but it is fairly limited in the information it collects. The mechanism of the crash and injury is not coded, and information regarding key risk factors for ATV crashes and injuries such as helmet use, presence of passengers, vehicle engine size, alcohol and other drug use, and vehicle speed are also not specifically recorded. The short narrative often provides some of this information, but it is not reliably documented. Although the NEISS does have a code for *utility vehicle*, there are no further categorizations in the system for this type of vehicle, and vehicles other than UTVs and ROVs may be coded under this designation.

Fatality Analysis Reporting System

NHTSA maintains the FARS, which is a census of and the sole source of all police-reported motor vehicle–related fatalities on public roads in the United States [52]. This data collection system, which was established in 1975, includes both motorists and nonmotorists who die within 30 days of being involved in a motor vehicle traffic crash [53]. Through a cooperative agreement with agencies in each state, NHTSA collects fatality crash data that are converted to the SAS data format. The sources of the FARS data include, among other things, police crash reports, death certificates, and coroner/medical examiner reports [53]. FARS cases are only considered to be work-related if the *injury at work* response item on the death certificate is checked [54].

The FARS query system allows public access to the database. Data may be processed utilizing the site's interactive user interface, and customized searches may be performed. A create-a-map feature allows individuals to build county-by-county and state-by-state maps displaying personally selected results from the FARS data. Published files may also be downloaded from the FARS website (ftp://ftp.nhtsa.dot.gov/FARS) as compressed delimited text files or SAS data files. Requests for specific data may be made to the NHTSA National Center for Statistics and Analysis at no charge, and it usually takes about 2 weeks depending on the complexity of the data requested.

The FARS data contain more than 100 separately coded elements [53]. In addition to demographic information, the dataset includes a number of variables noted to be risk factors for ATV crash and injury, including helmet use, seating position, presence of passengers, speed, and BAC. The roadway type and type of surface, specific location of the crash on the road, and rural/urban location data are also available. FARS provides a number of variables that distinguish what happened in the crash, including the number and type of vehicles involved; the first harmful event that occurred; the crash configuration and maneuvering of each vehicle involved; and driver-related contributing factors for every vehicle, based on police judgment.

In 2013, the Insurance Institute for Highway Safety, a nonprofit research and communications organization funded by motor vehicle insurers, released the first study to use FARS data to identify the characteristics of on-road fatal ATV crashes [42]. A primary reason for conducting the study was that CPSC data showed that most ATV deaths occurred on public roadways rather than off road [14,15].

The FARS dataset is limited to police-reported fatalities on public roadways and does not include those occurring off road. Moreover, FARS uses body type code 90 for ATVs with 3 or 4 wheels, but S×Ss, including ROVs and UTVs, have also been coded under this body type as well as in the *other vehicle* category. Although one could try to use vehicle identification numbers (VINs) to delineate these ORV types, only about one-half of VINs could be decoded in an ATV study utilizing FARS data [42]. Beginning with its report on 2017 fatalities, NHTSA added a new category, *recreational off-highway vehicles*, to cover ROVs [55,56]. Therefore, this database may be more useful to conduct studies related to ROVs on public roadways in the future. In addition, FARS inclusion requires the person's death to be within 30 days of the crash, and fatalities occurring beyond this period would be missed.

The National Fatality Review Case Reporting System

The National Center for Fatality Review and Prevention (NCFRP) is funded by the Maternal and Child Health Bureau under the Health Resources and Services Administration and is the national resource and data center for fetal and infant mortality review and child death review (CDR) [57]. The NCFRP manages and promotes the use of the National Fatality Review CRS, which is a standardized case report tool made available to all states. Currently, 43 states utilize CRS with over 2100 data users [57].

The National Fatality Review CRS contains more than 2600 variables that describe in detail the risk factors and circumstances surrounding a child's death. Although each state varies in its data collection process, information for the case report is generally gathered through multidisciplinary team meetings. The case report is deidentified at the national level. Many states will disseminate their CDR findings into reports to educate policy makers and the general public about the key risk factors and opportunities for injury prevention. Researchers may apply to utilize the national dataset for injury prevention

studies [58]. NCFRP's policies and guidelines should be followed by researchers to apply and use their data.

The dataset only includes deaths reviewed by CDR teams, not all child deaths; therefore, it cannot be used to calculate incidence. In addition, case reports are completed by numerous data users, which can lead to variability in data completeness.

Discussion

Principal Findings

A plethora of published research shows that ATV-related deaths and injuries are a significant and ongoing public health concern, including in rural areas and among youth. Although few studies of S×S-related crashes are available, data suggest that injuries and deaths associated with them are an emerging public health issue. Ongoing research is critically needed, including research on agricultural ORV injury prevention.

One of the greatest challenges to ORV-related research is the lack of a single comprehensive data source for fatalities and injuries. This review of some national databases providing information on ORV-related deaths and injuries demonstrates that each database has significant limitations, especially regarding the ability to distinguish recreational from occupational crashes.

Although AgInjuryNews provides agricultural work–related information, it is unable to provide a comprehensive picture of all ORV-related crashes on farms and ranches, as not all rural injuries will be covered by media. Despite this, state and regional efforts to collect media related to agricultural injuries and deaths have grown in number. There are no federally supported comprehensive national databases on agricultural work–related deaths and injuries; such efforts provide some insight into work-related injuries and emerging issues to those involved in agricultural injury prevention. As AgInjuryNews collects data nationally and makes it available to the public, it may supersede more localized efforts and become increasingly more important as a supplemental surveillance system to study agricultural work–related injuries and deaths, including those because of ORVs.

The CPSC ATV fatality database provides information on most, but not all, ATV-related fatalities in the nation. Although it codes whether the activity at the time of the crash was work-related, there is little additional information, and it is not possible to determine if it occurred while agricultural work was being performed.

The NEISS database, also maintained by the CPSC, does not specify whether the injury was work-related, limiting its utility for the study of agricultural work–related ATV injuries. As a part of its proposed rulemaking in 2009, designed to create an improved safety standard for ROVs, CPSC released studies on S×S-related fatalities and injuries [3]. However, CPSC has not updated that information to cover more recent years, and the CPSC does not publish an annual report on ROV-related deaths and injuries, similar to what they do for ATVs.

The FARS database provides a great deal of information regarding ORV-related roadway fatalities; however, ORVs are designed to be used off road, and there are a substantial number of fatalities that are not included. In addition, FARS identifies work-related fatalities using only the *injury at work* item on the death certificate, and it does not indicate what type of work activities were being performed at the time of the incident. Thus, identifying agricultural work–related fatalities is not possible using FARS data. As noted previously, with the new code of ROV added in 2017, FARS data could be used to study ROV roadway crashes in the future.

National Fatality Review CRS data comprise many details regarding the mechanisms and activities that were being performed at the time of the fatal crash. This includes the vehicles involved in the incident, including ORVs, and information regarding whether work was being performed. Unfortunately, not all child deaths fall under the auspices of a state or county CDR team. Thus, the CRS data may be rich in detail but may not provide accurate total counts of ORV-related deaths. Moreover, not all states participate in the system. These identified gaps not only hinder the lines of inquiry but also highlight important future work for the discipline.

Although there are challenges in law enforcement, the passage of laws (such as those requiring helmet use while riding ORVs and seat belt use while riding in ROVs) is another important method to reduce the frequency and severity of injuries when ORVs crash [59-64]. Moreover, crash and injury prevention measures found to be effective should be replicated across the country. Given the prevalence of ORV-related injuries and deaths, solutions beyond traditional approaches to improve the health and safety of rural ORV operators need to be found and disseminated.

There is also an upward trend of municipalities permitting the use of ORVs on paved and unpaved public roads to appease constituents, power sport dealerships, and ORV clubs. Active efforts by individuals and community groups are greatly needed to affect decision making and ordinances at the local level [65]. Safety and health professionals and associated organizations should advocate for policy change at the state and national levels, and policy makers need to be made more aware of the issue, encouraged to pass evidence-based safety laws, and discouraged from passing laws that decrease safety, such as opening public roadways to recreational use of ORVs [14,15,42]. Such efforts need to be considered a priority by injury prevention stakeholders, including legislators, to address this growing public health concern.

Conclusions

Deficiencies in national agricultural injury surveillance efforts continue to plague subsectors of injury prevention research and practice, including efforts to reduce ORV-related injuries. Our review provides illustrations of how the currently available datasets used to perform agricultural ORV-related injury surveillance, and in fact, all agricultural injury surveillance, are inadequate. Significant limitations exist for both individual data sources and even, where possible, merged data from multiple sources. These limitations provide a strong rationale for a robust national surveillance system for agricultural deaths and injuries, which could facilitate the development and evaluation of injury prevention approaches, including evidence-based safety

engineering and legislation. A discussion of what such a surveillance system should look like and how it should operate is highly complex and, thus, beyond the scope of this review. However, robust injury surveillance is an essential element in successful efforts to save lives, protect health, and reduce the high costs of preventable injuries.

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Authors' Contributions

All authors participated in the conception or design of the work; the acquisition, analysis, or interpretation of data for the work; drafting the work and revising it critically for important intellectual content; and final approval of the version to be submitted/published; and all authors agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Conflicts of Interest

None declared.

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Abbreviations

AgFF: agriculture, fishing, and forestry
ATV: all-terrain vehicle
BAC: blood alcohol level
BLS: Bureau of Labor Statistics
CDR: child death review
CFA: Consumer Federation of America
CPSC: Consumer Product Safety Commission
CRS: Case Reporting System
DOT: department of transportation
ED: emergency department
FAIC: farm and agricultural injury classification
FARS: Fatality Analysis Reporting System
NCFRP: National Center for Fatality Review and Prevention
NEISS: National Electronic Injury Surveillance System
NHTSA: National Highway Traffic Safety Administration
NIOSH: National Institute for Occupational Safety and Health
OIICS: Occupational Injury and Illness Classification System
ORV: off-road vehicle
OSHA: Occupational Safety and Health Administration
ROPS: rollover protective structures
ROV: recreational off-highway vehicle
S×S: side-by-side
UTV: utility task/terrain vehicle
VIN: vehicle identification number

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Original Paper

Survival Rate of Gastric Cancer Patients in Jordan: Secondary Data Analysis

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Abstract

Background: Gastric cancer accounts for 2.7% of all newly diagnosed cancer cases in Jordan.

Objective: The aim of this study was to calculate the survival rate and its determinants among Jordanian patients who were diagnosed with gastric cancer between 2010 and 2014.

Methods: A descriptive study was conducted based on secondary analysis of data from the Jordan Cancer Registry during the period of 2010-2014. Only cancer-related deaths were recorded as “death” in the survival analysis.

Results: A total of 1388 new cases of gastric cancer were recorded between 2010 and 2014. Of these, 872 (62.8%) were Jordanians and 60.5% were males. The mean age at diagnosis was 58.9 years and the median follow-up time was 1.6 years. The 5-year survival rate decreased significantly from 89% in patients with well-differentiated cancer to 32% in patients with poorly differentiated cancer (*P*=.005). The overall 5-year survival rate was 37.7% and the median survival was 1.48 years (95% CI 1.179-1.783). The 5-year survival rate decreased significantly with increasing age and with advanced stage of the disease: the 5-year survival rate was 75% for localized-stage, 48% for regional-stage, and 22.7% for distant-metastasis disease (*P*=.005).

Conclusions: This study showed that the overall 5-year survival rate among patients with gastric cancer in Jordan between 2010 and 2014 was 37.7%, which is higher than the reported rates from different countries in the Eastern Mediterranean region such as Egypt.

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KEYWORDS

gastric cancer; survival rate; Jordanian cancer cases

Introduction

Gastric cancer, also known as stomach cancer, develops from the lining layers of the gastrointestinal tract. The cancer may spread from the gastric region to other parts of the body, particularly the liver, lungs, bones, lining of the abdomen, and lymph nodes. The cancer survival rate measures the proportion of people with cancer who will be alive at a certain time after diagnosis, given that they did not die from a cause other than their cancer. Survival rates are important for prognosis, social planning, new intervention evaluation, and future expectation.

Gastric cancer currently ranks fourth in cancer incidence worldwide and is the most common type of cancer among Japanese men [1]. More than 70% of cases occur in developing countries [1]. The gastric cancer incidence rate differs among regions in the Middle East, from very high in Iran (26.1/100,000) to low in Lebanon (6/100,000) and very low in Egypt (3.4/100,000), although all countries are classified as developed

at an intermediate socioeconomical level [2-4]. Epidemiological studies show that the prevalence of *Helicobacter pylori* infection is similar in these countries, with a particularly high level of infection in childhood. People who are infected with *H. pylori* are also up to 8 times more likely to develop a certain kind of stomach cancer; however, this bacterium is only one of the possible causes of stomach cancer. Smoking, a diet low in fruit and vegetables, and a history of stomach surgeries can also raise the risk. Nevertheless, *H. pylori* infection prevalence, distribution pattern of virulence factors, diet, and smoking could not adequately explain the observed differences in cancer rates. This reflects the multifactorial etiology of gastric cancer, and suggests that *H. pylori* infection does not always directly correlate with the risk of gastrointestinal diseases such as gastric cancer.

In Jordan, gastric cancer accounts for 2.7% of all newly diagnosed cancer cases, and affects men more frequently than women with a ratio of 1.7:1. Gastric cancer contributes to 4.6% of all deaths due to all types of cancer, ranking sixth among the top 10 cancer-related mortality causes in Jordan [4]. The number of cases of gastric cancer increased in 2010-2014, reaching the ninth position of the top 10 causes of cancer for men in Jordan and the sixth cause of cancer-related deaths. However, very few studies have investigated the survival of gastric cancer and its determinants [5]. Therefore, the aim of this study was to calculate the survival rate and evaluate its determinants among Jordanian patients who were diagnosed with gastric cancer between 2010 and 2014.

Methods

This study was based on data from the Jordan Cancer Registry, which accounts for more than 95% of all cancer cases in Jordan. The Jordan Cancer Registry uses forms for data collection on sociodemographic characteristics, including national identification number, name, age, marital status, and address, and information related to cancer, including histopathology, morphology, stage of cancer, location of tumor, date of diagnosis, date of last visit, and outcome. All gastric cancer cases among Jordanians who were registered in the Jordan Cancer Registry during the period of 2010-2014, with or without a histopathology report, were included in the study and the data were analyzed using survival analysis. Patients with multiple cancers were not included in this study.

The demographic and clinical characteristics of each registered patient were obtained from the Jordan Cancer Registry files and hospital medical records through the standard data request form. Data on the type and stage of cancer were obtained from histopathology reports from governmental and private laboratories in addition to the medical records of hospitals. The histopathology type was categorized according to the cancer site. The cancer stage was classified into localized, regional, distant metastasis, and unknown stage.

To identify the vital status of these patients, the date of the last visit was obtained from the medical records. In addition, the vital status was ascertained from the Civil Registration Department using a unique national identification number. Only cancer-related deaths were recorded as “death” in the survival analysis. The few noncancer-related deaths, as ascertained from the Civil Registration Department, were considered as censored cases. The period of observation was set for the included patients from the date of diagnosis to the last date of observation if the patient was alive (December 31, 2016) and to the date of death if the patient died during the observation period. The follow-up end point was death from cancer. Ethical approval was obtained from the Institutional Review Board at the Ministry of Health.

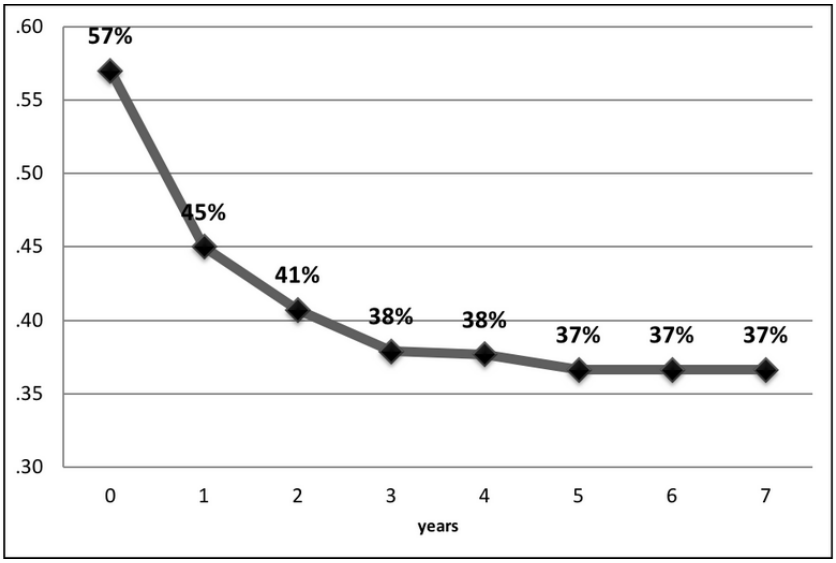
Data were analyzed using Statistical Package for Social Sciences Software (SPSS) version 23 (IBM, New York, NY, USA). Data are described using means and percentages. The overall survival was estimated using the Kaplan-Meier product limit technique. The log-rank test was used to compare survival rates between groups. Cox regression analysis was used to determine factors associated with the time to death. $P<.05$ was considered statistically significant.

Results

A total of 1388 new cases of gastric cancer were recorded during the period of 2010-2014. Of these, 872/1388 (62.8%) were Jordanians, and 60.5% were males and 39.5% were females. The mean age at diagnosis was 58.9 years (59.7 years for males and 57.8 years for females). Almost half of the patients (48.4%) were above 60 years of age. The most commonly affected age group was 60-69 years. The majority of patients were married. Approximately 20.4% were current or past smokers. The grade of the tumor was poorly differentiated in 39.6% of the cases, and 37.9% of cases had an unknown stage. Approximately 40.3% of all cases underwent surgical interventions and 31% had received chemotherapy. The follow-up ranged from 0 to 7.1 years with a mean of 1.5 years. The median follow-up time was 1.6 years.

The proportion of patients surviving at each time interval and the cumulative survival are shown in Figure 1.

Figure 1. The proportions of Jordanian patients surviving gastric cancer by year.



The overall 5-year survival rate was 37.7%, and the median survival was 1.48 years (95% CI 1.179-1.783). The 5-year survival rate was 93.5% among non-Jordanian patients and 37.7% among Jordanian patients (*P*=.005). The 5-year survival rate was 89% in patients with well-differentiated cancer and 32% in patients with poorly differentiated cancer (*P*=.005). The 5-year survival rate decreased significantly according to age group, from 43% for patients <40 years old to 29.8% for patients ≥70 years old (*P*=.005). The survival rate also decreased significantly with advanced stage of the disease: the 5-year survival rate was 75% for localized stage, 48% for regional stage, and 22.7% for distant metastasis (*P*=.005). The median survival for patients with gastric cancer according to demographic and clinical characteristics is summarized in Table 1. The 5-year survival rate of patients receiving surgical procedures with neither chemical nor radiological therapy was 43.3%. Patients who were treated with chemotherapy only had a 5-year survival rate of 27.8%, and patients who received radiotherapy only had a 5-year survival rate of 15.7%. The 5-year survival rate was 43.1% for patients who did not undergo any therapy.

Table 2 shows the results of the multivariate analysis of factors associated with the hazard of death from Cox regression analysis. The only factors that were significantly associated with death were age, nationality, and grade and stage of cancer. The hazard ratio (HR) of death increased significantly with increased age, and was the highest for the group aged ≥70 years (HR=1.68). The hazard of death increased significantly among Jordanian patients compared to non-Jordanian patients (HR=5.27). The hazard of death was significantly higher for those with poorly differentiated cancer compared to those with well-differentiated cancer (HR=5.93). The hazard was also much higher for patients whose cancer stage was regional (HR=2.35) and in those with distant metastasis (HR=5.65) compared to those with localized cancer.

Table 1. Median survival time for patients with gastric cancer according to demographic and clinical characteristics.

Patient characteristics	Median survival time			*P* value
	Estimate	SE	95% CI	
Gender				.75
Male	2.12	0.29	1.54-2.70	
Female	2.17	0.90	0.40-3.94	
Age (years)				<.001
<40	2.11	0.80	0.52-3.70	
40-49	—	—	—	
50-59	3.42	N/A[a]	N/A	
60-69	2.47	0.78	0.94-4.00	
≥70	1.06	0.20	0.67-1.46	
Marital status				.69
Single	2.28	1.62	0.00-5.47	
Married	2.12	0.27	1.59-2.65	
Smoking status				<.001
Never smoked	1.80	0.28	1.26-2.35	
Current smoker	1.47	0.26	0.96-1.97	
Past smoker	1.11	0.62	0.00-2.32	
Site				.20
Cardia, NOS[b]	1.84	0.33	1.20-2.49	
Fundus of stomach	5.64	2.58	0.58-10.70	
Body of stomach	2.46	0.48	1.51-3.41	
Lesser curvature of stomach	2.01	1.17	0.00-4.30	
Overl. lesion of stomach	0.95	0.40	0.17-1.74	
Stomach, NOS	2.03	0.38	1.27-2.78	
Grade				<.001
Well-differentiated	—	—	—	
Moderately differentiated	1.98	0.35	1.30-2.66	
Poorly differentiated	1.26	0.13	1.00-1.52	
Undifferentiated/Anaplastic	1.87	0.93	0.03-3.71	
Unspecified	2.47	0.98	0.55-4.39	
Stage				<.001
Localized	—	—	—	
Regional direct extend	2.96	2.15	0.00-7.18	
Regional direct extend and lymph node stage 2	1.88	0.35	1.18-2.58	
Distant stage 3 and 4	0.89	0.09	0.70-1.07	

[a]N/A: not applicable.

[b]NOS: not otherwise specified.

Table 2. Multivariate analysis of factors associated with the hazard of death in Cox regression analysis.

Category	Hazard ratio	95% CI	*P* value
Age (years)			
≤40	1.00	—	—
40-49	0.88	0.64-1.21	.44
50-59	0.80	0.59-1.10	.18
60-69	0.96	0.71-1.29	.78
≥70	1.68	1.26-2.24	<.001
Nationality			
Non-Jordanian	1.00	—	—
Jordanian	5.26	3.58-7.73	<.001
Grade			
Well-differentiated	1.00	—	—
Moderately differentiated	4.74	1.74-12.95	.002
Poorly differentiated	5.93	2.20-16.00	<.001
Undifferentiated/Anaplastic	5.93	1.58-22.31	.008
B cell	2.08	0.74-5.82	.16
Unspecified	4.91	1.81-13.31	.002
Summary stage			
Localized	1.00	—	—
Regional direct extend	2.35	1.34-4.12	.003
Regional lymph node	1.50	0.79-2.86	.21
Regional direct extend and lymph node	3.07	1.83-5.14	<.001
Regional NOS[a] Stage 2	4.08	2.06-8.09	<.001
Distant Stage 3&4	5.65	3.52-9.08	<.001
Unknown	2.90	1.80-4.65	<.001

[a]NOS: not otherwise specified.

Discussion

Data on the survival analysis of gastric cancer in Eastern Mediterranean countries are scarce, including Jordan. Previous studies in other countries have reported variable gastric cancer survival rates. Approximately 71% of gastric cancer cases occur in less developed countries, with the highest incidence reported in Asia, Latin America, and the Caribbean, and the lowest incidence in Africa and North America [6]. The Republic of Korea was reported to have the highest rate of gastric cancer, followed by Mongolia and Japan [6]. A case-control study indicated that several food items and cooking methods were associated with an increased or decreased risk of stomach cancer among Koreans [2]. Specifically, an increased risk of stomach cancer was noted among people who frequently consumed broiled meats and fishes, salted side dishes (salted/fermented fish products), and salty stewed foods such as soybean paste thick stew. Frequent consumption of mango bean pancake, tofu, cabbage, spinach, and sesame oil decreased the risk. Analysis by cooking method showed that the risk of stomach cancer from the same foods varied according to the preparation method. For meat and fish, pan frying was associated with a decreased risk, whereas stewing or broiling was associated with an increased risk. This study showed that the overall 5-year survival rate was 37.7% for all patients in Jordan, with an estimated median of 1.481 years (95% CI 1.179-1.783). This rate is higher than those reported from different countries in the Eastern Mediterranean region, including Egypt with a median overall survival rate of 6 months (95% CI 3.3-8.9) [7].

Various studies from Iran have reported a 5-year survival rate of gastric cancer of 12.8% [5]. The disparities in gastric cancer survival among Eastern Mediterranean countries may be attributed to several factors, including differences in socioeconomic status, stage at diagnosis, treatment, physician characteristics, and hospital factors. The better survival in Jordan compared with other countries in the region might be explained by the fact that cancer care in Jordan is more advanced in comparison to that of most neighboring countries, and the country hosts many local and Western-trained physicians who can deliver various cancer treatment modalities [8]. Currently, the King Hussein Cancer Foundation and Center (KHCC) treats around 60% of all cancer cases in Jordan. The KHCC is a specialized tertiary-care hospital that provides all treatment

modalities and services to Jordanian patients as well as other patients from neighboring countries. However, further studies are needed to examine the differences in gastric cancer survival between these countries. There was no significant difference in the survival rate between men and women in the univariate analysis and multivariate analysis. This lack of gender difference in survival rate was also reported in some of the previous studies mentioned above.

This study showed that the hazard of death increased significantly with increased age, and the highest hazard was found in the age group ≥70 years. This result was similar to previous studies [5,7] showing that older patients had a poorer survival rate compared to younger patients. The contradictory results of previous studies on age may be due to inclusion of patients from single referral centers and poor adjustment for the effect of possible confounders.

Different clinical and pathological prognostic factors have been proposed for gastric cancer in the literature to date, including location of the tumor, tumor stage, differentiation of the tumor, and surgical and distant metastasis. The present multivariate analysis using Cox regression showed that age, nationality, grade, and stage were significant predictors of survival. The hazard of death was significantly higher for patients aged >70 years compared to those in other age categories due to the increased probability of death with increasing age. The higher hazard of death for Jordanian patients compared to non-Jordanian patients may be explained by the shorter period of follow-up for non-Jordanian patients because they departed after they received medical treatment and therefore could not be followed up. The hazard of death was also significantly higher for those with poorly differentiated cancer compared to those with well-differentiated cancer. Moreover, it was much higher for patients whose cancer stage was regional and those with distant metastasis compared to those with localized cancer. Therefore, the earlier the stage at diagnosis, the higher the chance of survival. The differences in survival according to stage are explained by the differences in the extent to which the cancer has spread and how many lymph nodes have been affected.

Data from the Jordan Cancer Registry should be interpreted with caution. Similar to many registries in the region, the Jordan Cancer Registry does not collect information on other possible predictors of mortality such as occupation, level of education, economic status, and comorbidity. Therefore, our HR estimates might be biased owing to the lack of adjustment for the effect of unmeasured variables.

In conclusion, this study showed that the overall 5-year survival rate among patients with gastric cancer in Jordan was 37.7%, which is higher than the reported rates from different countries in the Eastern Mediterranean region, including Egypt. Increased age, poor differentiation, and advanced cancer stage were associated with lower survival rates. The survival rate of patients who underwent surgical interventions alone was 43.3%, whereas that among patients who received chemotherapy or radiotherapy alone was 27.8% and 15.7%, respectively, which differs from the results of other regional studies. This finding may be explained by the fact that patients underwent surgical interventions at an early stage of cancer, whereas chemotherapy and radiotherapy are given to patients with much worse cases. It is well established that gastric cancer progression can be largely prevented by early detection and removal of the adenomatous tissues, and survival is therefore significantly better when gastric cancer is diagnosed while still localized. Therefore, improved screening strategies are needed for the early detection of gastric cancer.

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Conflicts of Interest

None declared.

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Abbreviations

HR: hazard ratio
KHCC: King Hussein Cancer Foundation and Center
NOS: not otherwise specified

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Original Paper

Using Twitter to Surveil the Opioid Epidemic in North Carolina: An Exploratory Study

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Abstract

Background: Over the last two decades, deaths associated with opioids have escalated in number and geographic spread, impacting more and more individuals, families, and communities. Reflecting on the shifting nature of the opioid overdose crisis, Dasgupta, Beletsky, and Ciccarone offer a triphasic framework to explain that opioid overdose deaths (OODs) shifted from prescription opioids for pain (beginning in 2000), to heroin (2010 to 2015), and then to synthetic opioids (beginning in 2013). Given the rapidly shifting nature of OODs, timelier surveillance data are critical to inform strategies that combat the opioid crisis. Using easily accessible and near real-time social media data to improve public health surveillance efforts related to the opioid crisis is a promising area of research.

Objective: This study explored the potential of using Twitter data to monitor the opioid epidemic. Specifically, this study investigated the extent to which the content of opioid-related tweets corresponds with the triphasic nature of the opioid crisis and correlates with OODs in North Carolina between 2009 and 2017.

Methods: Opioid-related Twitter posts were obtained using Crimson Hexagon, and were classified as relating to prescription opioids, heroin, and synthetic opioids using natural language processing. This process resulted in a corpus of 100,777 posts consisting of tweets, retweets, mentions, and replies. Using a random sample of 10,000 posts from the corpus, we identified opioid-related terms by analyzing word frequency for each year. OODs were obtained from the Multiple Cause of Death database from the Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research (CDC WONDER). Least squares regression and Granger tests compared patterns of opioid-related posts with OODs.

Results: The pattern of tweets related to prescription opioids, heroin, and synthetic opioids resembled the triphasic nature of OODs. For prescription opioids, tweet counts and OODs were statistically unrelated. Tweets mentioning heroin and synthetic opioids were significantly associated with heroin OODs and synthetic OODs in the same year (P=.01 and P<.001, respectively), as well as in the following year (P=.03 and P=.01, respectively). Moreover, heroin tweets in a given year predicted heroin deaths better than lagged heroin OODs alone (P=.03).

Conclusions: Findings support using Twitter data as a timely indicator of opioid overdose mortality, especially for heroin.

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KEYWORDS

opioids; surveillance; social media

Introduction

Opioid overdose deaths (OODs) constitute a significant public health burden for the United States. In 2018, of the 67,367 drug overdose–related deaths, 70% (46,802) were attributed to opioids, with increases across demographic and geographic subgroups. Additionally, OODs involving synthetic opioids (eg, fentanyl) increased 10% from 2017 to 2018 and accounted for two-thirds of opioid-related deaths [1]. By contrast, rates of

OODs involving heroin and prescription opioids decreased between 2017 and 2018 (by 4.1% and 13.5%, respectively).

Reflecting on the evolving nature of the opioid crisis, Dasgupta, Beletsky, and Ciccarone [2] present an explanatory triphasic framework. The first phase, beginning in 2000, was based on prescription opioids for pain. The second involved a sharp increase in heroin overdose deaths between 2010 and 2015. The third phase saw a rapid increase in overdose deaths attributable to synthetic opioids, beginning in 2013.

Currently, the monitoring of OODs relies primarily on mortality data that lag between 12 to 18 months behind real time. Given the rapidly shifting nature of OODs, timelier surveillance data are critical to inform strategies that combat the opioid crisis. Over the last several years, there have been over 1000 health-related publications using Twitter to inform health research. This body of science spans a number of disparate areas, including tracking the spread of influenza [3,4], oral health problems [5], sleep issues [6], obesity [7], cardiovascular disease [8], diabetes [9], mental health [10], and health care enrollment [11]. In addition, there is burgeoning interest in the use of innovative and nontraditional methods (such as mining and analyzing social media data) as a means to better surveil the opioid epidemic, with Twitter becoming a complementary data source for pharmacovigilance [12,13].

Regarding opioids specifically, researchers have analyzed Twitter messages and other social media posts from forums such as Reddit to understand their role in recovery from opioid use disorder [14], and access to and diversion of prescription drugs [15-18] and illicit opioids [19]. Twitter data have also been mined to study perceptions and attitudes toward opioids [20-22], including those held by specific groups such as youth [23]. Researchers have used other data streams, including Google Trends to forecast premature death from alcohol, drugs, and suicides [24]; a cryptomarket forum on the Dark Web to assess the emergence of new psychoactive substances [25]; and WebMD to explore motivations to use buprenorphine [26,27]. Recently, Graves et al [28] reported that thematic patterns of opioid-related tweets correlated with opioid overdose rates at the state and county levels. Sarker et al [29] reported that opioid-related tweets in Pennsylvania correlated with county-level OODs over 3 years. However, no study investigated whether opioid-related tweets in a given year can predict subsequent OODs.

This study explored Twitter data to monitor the opioid epidemic. Specifically, this study investigated the extent to which the content of opioid-related tweets corresponds with the triphasic nature of the opioid crisis and correlates with OODs in North Carolina between 2009 and 2017. North Carolina was selected because of its high rates of OODs, which increased notably during the study period.

Methods

Data collection from Twitter involved retrospectively monitoring the platform using Crimson Hexagon to access all English opioid-related posts from January 1, 2009, through December 31, 2018, in North Carolina. We created queries (opinion monitors) with a set of parameters (search terms) in Crimson Hexagon including commercial (eg, oxycodone, codeine, and morphine) and “street” names (eg, white, syrup, and tar) of drugs. We cast a broad net to capture terms referencing both trade and generic names. In order to identify such terms, we searched for common slang words referring to opioids using the Drug Enforcement Administration’s (DEA) Intelligence Report titled “Slang Terms and Code Words: A Reference for Law Enforcement Personnel” [30]. We subsequently eliminated posts in which the slang term (eg, “China”) appeared without any mention of the identified search term parameters elsewhere in that post. We excluded posts that contained hyperlinks as well as those containing solicitation-related words such as “buy” and “sell” as these were likely to be related to illegal online drug promotion or spamming techniques encouraging users to link to other sites.

Post location was determined through cross-verification of the geotag, profile information, time zones, content, and image data. This process resulted in a corpus of 100,777 posts consisting of tweets, retweets, mentions, and replies. We made the decision not to exclude retweets with the understanding that retweets signify a unique form of communication through an implied endorsement or agreement with the initial post [31].

Using a random sample of 10,000 posts from the corpus, we identified opioid-related terms by analyzing word frequency for each year. Next, we coded these terms into three tweet categories: prescription opioids (eg, codeine, morphine, pain, hydrocodone, pills, syrup, oxycodone, oxycontin, Percocet, and Vicodin), heroin (eg, heroin, tar, and white), and synthetic opioids (eg, fentanyl, synthetic, and laced).

We obtained annual mortality data from 2009 to 2018 from the Multiple Cause of Death database from the Centers for Disease Control and Prevention Wide-ranging Online Data for Epidemiologic Research (CDC WONDER) [32]. Drug overdose deaths were classified using the 10th revision of International Classification of Diseases (ICD-10), based on the ICD-10 underlying cause-of-death codes X40-X44 (unintentional), X60-X64 (suicide), X85 (homicide), or Y10-Y14 (undetermined intent). Drug overdoses with the following codes were considered OODs: opium (T40.0), heroin (T40.1), natural and semisynthetic opioids (T40.2), methadone (T40.3), synthetic opioids other than methadone (T40.4), and other unspecified narcotics (T40.6).

We estimated the association between the opioid-related tweet categories and OODs using ordinary least squares regression with either the current tweet count or a 1-year lag of tweet count as the independent variable. We also fit a vector autoregression and used Granger tests [33] to determine whether lagged tweet counts predict OODs better than lagged OODs alone. Stationarity for each of the six series was tested using an augmented Dickey-Fuller [34] unit root test with up to two lags and a linear trend. Analyses used Stata/MP (Version 15.1; StataCorp LLC).

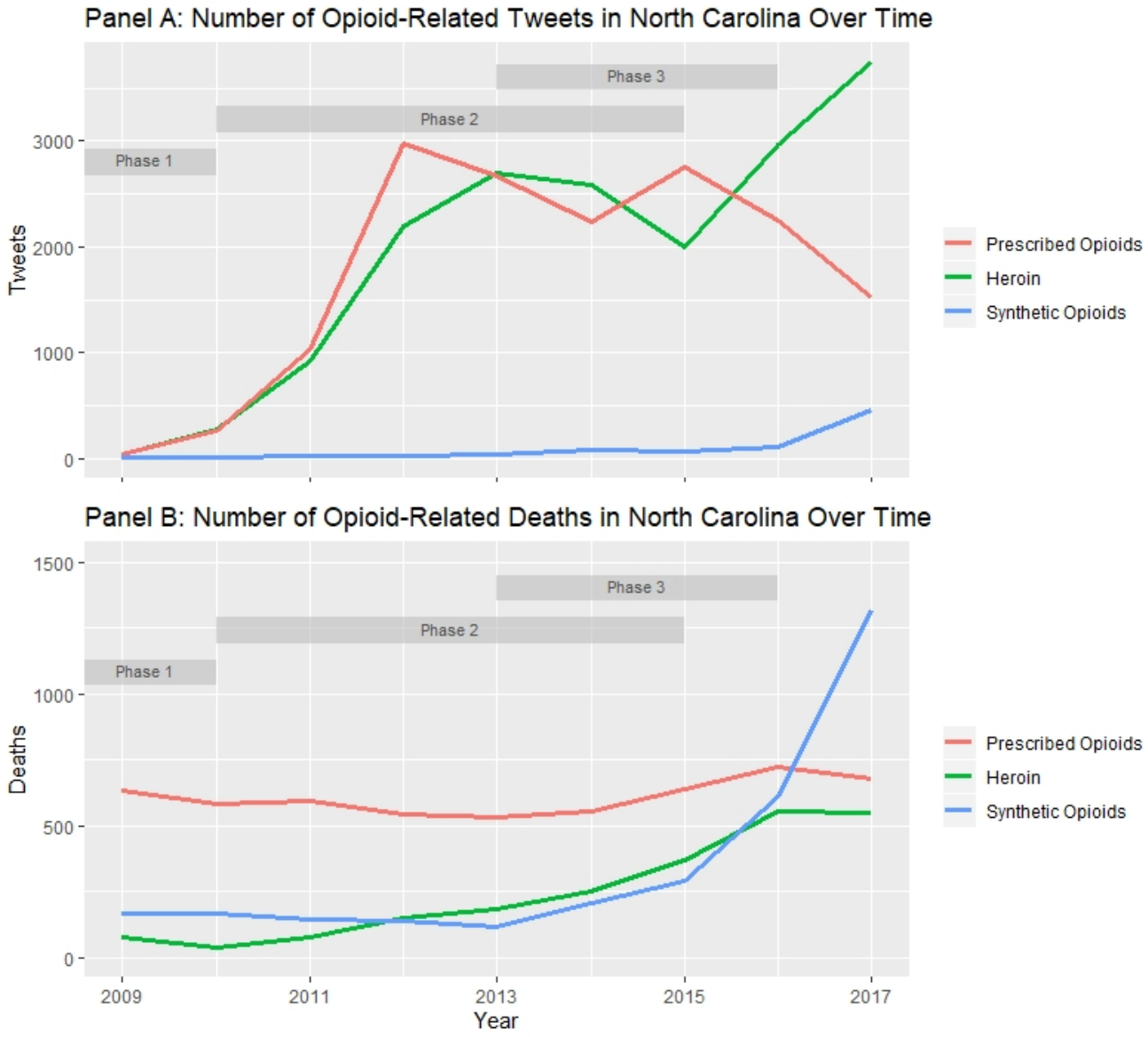
This study consisted of secondary analyses; no individuals were involved. As data do not include any personally identifiable information, Institutional Review Board approval was not required.

Results

The pattern of opioid-related Twitter posts in North Carolina appears in Figure 1A. Tweets about prescription opioids and heroin progressed in a similar, nonlinear pattern until they diverged in 2015, when heroin tweets increased and tweets for prescription opioids decreased. Tweets about synthetic opioids were virtually nonexistent until 2016, when they increased.

The progression of OODs in North Carolina appears in Figure 1B. Prescription opioids were the leading cause of OODs from 2009 to 2016. Heroin was the third leading cause of OODs until 2012, the second leading cause until 2016, and the third leading cause in 2017. Fentanyl became the leading cause of OODs in 2017.

Figure 1. Pattern of opioid-related deaths and tweets in North Carolina over time.



Using the augmented Dickey-Fuller tests, we failed to reject stationarity up to two lags for all variables except for prescription OODs. The association between tweet count and OODs was not significant for prescription opioids in either the one-year lag model (coefficient=0.01; *P*=.58) or the no-lag model (coefficient=0.01; *P*=.64). In contrast, tweet counts for both heroin and synthetic opioids were significantly associated with OODs. On average, each additional heroin tweet in a given year corresponded to 0.13 additional heroin overdose deaths that same year (*P*=.01) and 0.13 additional deaths the following year (*P*=.03). Each additional tweet mentioning synthetic opioids in a given year corresponded to 2.68 additional synthetic opioid overdose deaths that year (*P*<.001) and 9.24 additional deaths the next year (*P*=.01).

Granger tests following vector autoregression estimation with one and two lags (only one lag was estimated for prescription OODs) were consistent with the regression results but significant only for heroin tweets; tweets mentioning heroin in a given year significantly predicted subsequent heroin OODs (*P*=.03) over and above lagged heroin OODs.

Discussion

The pattern of opioid-related Twitter posts in North Carolina resembled the triphasic nature of the opioid crisis as described by Dasgupta et al [2]. Tweets about prescription opioids and heroin were intertwined through the end of Phase 2, when tweets about prescription opioids declined and tweets about heroin surged. During Phase 3, tweets about synthetic opioids emerged around 2016.

Results from the regression models and Granger tests indicated that the association with OODs differed by the type of opioid. For prescription opioids, tweet count and OODs were unrelated. The lack of association observed between prescription opioid tweets and overdose deaths may underestimate the true association therein, particularly because some patients who are treated with prescription opioids are chronic pain patients or older individuals [35], who may be less likely to have an active presence on Twitter. Indeed, almost half of Twitter users are aged 18 to 24 years (44%), followed by those aged 25 to 29 years (31%), 30 to 49 years (26%), 50 to 64 years (17%), and ≥65 years (7%) [36]. Although our sample may underestimate the association among individuals aged 50 years and older, this bias seems likely to be minimal because the majority of opioid overdose–related deaths in 2018 occurred among individuals aged 25 to 44 years [1].

Tweets mentioning heroin and synthetic opioids were significantly associated with heroin OODs and synthetic OODs, respectively. Moreover, results from the Granger tests showed that heroin tweets in a given year predicted subsequent heroin deaths better than lagged heroin OODs alone. These predictive results extend recent reports of correlations between opioid-related tweets and opioid overdose rates at the state and county levels [28,29].

There are a number of limitations to be considered. First, the scope of the terms used in our search parameters was somewhat subjective, in that there are hundreds of terms representing opioids [30], and we selected the most frequently used terms. This may have underestimated the breadth of opioid-related tweets in our sample. Second, we were limited in our ability to validate whether a tweet was indeed about opioids, as it was not possible to identify and query the tweet author about his or her intention. However, research on social media discussions related to cardiovascular mortality [37] and depression [38,39] indicate that these discussions reflect behavioral intentions. Third, filtering out solicitation-related terms and posts with hyperlinks was predicated on the assumption that these tweets reflect illicit opioid sales, which may constitute a unique phenomenon. Indeed, Katsuki et al [15] found that 75.2% of tweets containing URLs linked to an illicit online pharmacy, and Mackey et al [16] found that 90% of online marketing tweets included hyperlinks. Our decision certainly reduced the number of posts in our sample and may have resulted in misclassification. However, given that the overwhelming majority of individuals who misuse opioids report obtaining opioids from friends and family [40], it is likely that this decision had only a small impact on our results. Future research should examine whether tweets that include drug solicitation terms correlate with overdose rates in ways that differ from posts that exclude such terms. Finally, we were limited to correlational analyses without statistical controls, due to insufficient time points needed to run more sophisticated analyses. Our results should be considered preliminary; more research is needed with additional time points and data before making definitive statements.

Limitations notwithstanding, to our knowledge, this study is the first to report that the pattern of opioid-related Twitter posts in North Carolina not only resembles the triphasic nature of the opioid crisis [2], but that tweets mentioning heroin and synthetic opioids also correlate with and predict OODs. Findings suggest that Twitter data should be further evaluated as a novel and timely indicator of opioid overdose mortality, especially for heroin. Twitter use is widespread; of the 68 million Twitter users in the United States, 87% keep their feed public, nearly half of whom report daily usage [41]. Thus, tweets have the potential to serve as a readily available, unique, and real-time data source for surveilling the opioid crisis.

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Authors' Contributions

MA, DK, and KPC contributed to the study concept and design. All authors contributed to the acquisition, analysis, or interpretation of data. APA did the statistical analysis. DK, KPC, MA, and APA drafted the manuscript. All authors critically revised the manuscript for important intellectual content. DK and SJP provided administrative, technical, or material support. KPC obtained funding and provided supervision.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
DEA: Drug Enforcement Administration
ICD-10: International Classification of Diseases, 10th revision
OOD: opioid overdose death
WONDER: Wide-ranging Online Data for Epidemiologic Research

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Original Paper

Online Conversation Monitoring to Understand the Opioid Epidemic: Epidemiological Surveillance Study

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Abstract

Background: Between 2016 and 2017, the national mortality rate involving opioids continued its escalation; opioid deaths rose from 42,249 to 47,600, bringing the public health crisis to a new height. Considering that 69% of adults in the United States use online social media sites, a resource that builds a more complete understanding of prescription drug misuse and abuse could supplement traditional surveillance instruments. The Food and Drug Administration has identified 5 key risks and consequences of opioid drugs—misuse, abuse, addiction, overdose, and death. Identifying posts that discuss these key risks could lead to novel information that is not typically captured by traditional surveillance systems.

Objective: The goal of this study was to describe the trends of online posts (frequency over time) involving abuse, misuse, addiction, overdose, and death in the United States and to describe the types of websites that host these discussions. Internet posts that mentioned fentanyl, hydrocodone, oxycodone, or oxymorphone were examined.

Methods: Posts that did not refer to personal experiences were removed, after which 3.1 million posts remained. A stratified sample of 61,000 was selected. Unstructured data were classified into 5 key risks by manually coding for key outcomes of misuse, abuse, addiction, overdose, and death. Sampling probabilities of the coded posts were used to estimate the total post volume for each key risk.

Results: Addiction and misuse were the two most commonly discussed key risks for hydrocodone, oxycodone, and oxymorphone. For fentanyl, overdose and death were the most discussed key risks. Fentanyl had the highest estimated number of misuse-, overdose-, and death-related mentions (41,808, 42,659, and 94,169, respectively). Oxycodone had the highest estimated number of abuse- and addiction-related mentions (3548 and 12,679, respectively). The estimated volume of online posts for fentanyl increased by more than 10-fold in late 2017 and 2018. The odds of discussing fentanyl overdose (odds ratios [OR] 4.32, 95% CI 2.43-7.66) and death (OR 5.05, 95% CI 3.10-8.21) were higher for social media, while the odds of discussing fentanyl abuse (OR 0.10, 95% CI 0.04-0.22) and addiction (OR 0.24, 95% CI 0.15-0.38) were higher for blogs and forums.

Conclusions: Of the 5 FDA-defined key risks, fentanyl overdose and death has dominated discussion in recent years, while discussion of oxycodone, hydrocodone, and oxymorphone has decreased. As drug-related deaths continue to increase, an understanding of the motivations, circumstances, and consequences of drug abuse would assist in developing policy responses. Furthermore, content was notably different based on media origin, and studies that exclusively use either social media sites (such as Twitter) or blogs and forums could miss important content. This study sets out sustainable, ongoing methodology for surveilling internet postings regarding these drugs.

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KEYWORDS

epidemiological surveillance; infoveillance; infodemiology; opioids; social media; misuse; abuse; addiction; overdose; death

Introduction

Curbing the opioid misuse and abuse epidemic has proven to be a challenging public health problem [1-4]. Although opioids are effective for the management of pain related to acute injury or cancer [5], they have a high potential for causing dependence; opioids are more likely to be abused or misused than other pain management treatments, which has resulted in an alarming increase in the number of overdose deaths compared to the number of other nonprescription opioid-related deaths [5]. The mortality data indicate a continued rise—the national mortality rate involving opioids rose 12.0% from 2016 to 2017 [6]. Oxycodone and hydrocodone are among the most highly dispensed prescription opioids and are also among the most common prescription opioids involved in overdose [7].

The United States Food and Drug Administration (FDA) has responded by identifying 5 key risks and consequences that are part of boxed warnings for opioids: misuse, abuse, addiction, overdose, and death [8]. Understanding the qualitative nature of these risks and consequences (herein termed *key risks*) has also been highlighted as important supportive information to establish context for societal, behavioral, and clinical aspects of risk; this qualitative information could be used to support submissions for abuse-deterrent labeling of opioid products [9]. Reviewing internet postings provides an opportunity to delve into the societal and behavioral causes of the 5 key risks.

One of the more recent additions to public health surveillance of opioids is the monitoring of internet discussions on public blogs, forums, and social media [10]. In contrast to surveys, interviews, or other traditional public health data collection methods, the use of social media, blogs, and forums as a tool for data collection allows for the observation of real-time, unsolicited opinions, feelings, or thoughts [11]. It is possible that online users feel more comfortable sharing covert behaviors in this setting which allows for more truthful perspectives to be shared. Given the danger surrounding some drugs, these unsolicited expressions could shed light in areas that traditional survey instruments cannot. Examples of recent uses of social media data in research include discovering adverse drug events [12], studying addiction [13], tracking the popularity of marijuana concentrates [14], quantifying drug abuse [15], and characterizing discussion surrounding the introduction of an abuse-deterrent product [16].

The Researched Abuse, Diversion and Addiction-Related Surveillance (RADARS) System is a compilation of individual data collection programs that collect product-specific and geography-specific data to form a mosaic understanding of the abuse, misuse, and diversion of prescription drugs [1]. The Web Monitoring Program, established in 2014, focuses on the collection and organization of real-time web content about prescription drugs from over 150 million sites on the internet, including social media, blogs, and forums. The RADARS System Web Monitoring Program combines qualitative and quantitative data collection methods; a team of trained researchers collect daily opioid-related posts and manually code them for variables of interest [16].

The purpose of this study was to characterize the trends of abuse, misuse, addiction, overdose, and death in the United States using internet posts that mention fentanyl, hydrocodone, oxycodone, or oxymorphone and to establish a sustainable ongoing methodology for surveilling internet postings regarding these drugs.

Methods

Data Collection

Data were collected by scraping internet posts that mentioned 1 of 4 drugs of interest: fentanyl, hydrocodone, oxycodone, or oxymorphone. These drugs were selected because they have been involved in a variety of behaviors, have been subject to differential regulation, or were frequently prescribed in the United States. Branded oxymorphone and oxycodone products have undergone increasingly restrictive regulation due to findings related to their abuse (such as Opana ER [17] and OxyContin [18]), the potency of fentanyl likely makes it a desirable substance for diversion [19], and hydrocodone is often prescribed within the United States [20]. Posts underwent an algorithmic screening process where posts without substantive content were removed. The remaining posts were sampled and the contents of these posts were reviewed manually and categorized as misuse, abuse, addiction, overdose, or death. Posts that indicate discussion of counterfeit formulations (such as heroin mixed with homemade fentanyl) were excluded prior to analysis.

Data for this project were collected as part of RADARS System ongoing surveillance of the abuse, misuse, and diversion of prescription opioids. All data were collected using a web-crawling platform (Salesforce.com Inc) that scrapes data from public websites that permit content viewing by a third party. Examples of sites that permit this type of crawling include Twitter, Reddit, public blogs and forums, and comment sections on many news sites, while private sites such as personal Facebook pages, Bluelight, and other password-protected sites do not permit this type of crawling. Posts mentioning fentanyl, hydrocodone, oxycodone, or oxymorphone were identified based on specified search-string criteria (such as opioid name, associated misspellings, product names, and unique slang terms) for the 4 opioids (Multimedia Appendix 1). The keywords for each drug substance and product were generated using a phonetic algorithm and then validated using number of hits when entered into a common search engine. Other keywords were identified during the manual coding process.

The study protocol was reviewed and approved by the Colorado Multiple Institutional Review Board prior to the initiation of the RADARS System Web Monitoring Program. Since the publicly available posts were obtained through the Web Monitoring Program and are reported in an aggregated, anonymous manner, it was determined that it was not necessary to consider the Web Monitoring Program as research involving human subjects.

Data Cleaning

As part of routine web monitoring, posts were screened for predetermined exclusion criteria using a 2-step process. The

scraped posts were programmatically screened for predetermined keywords; phrases associated with uninformative posts were excluded. Programmatic exclusions did not remove all uninformative posts; therefore, manual screening for exclusion was also used. The exclusion criteria (for both steps) were defined as posts occurring outside of the surveillance period; in a language other than English; originating outside of the United States; from originating sources other than social media, blogs, or forums; containing the name of a drug of interest that was used in a context unrelated to that drug; that were considered spam (unsolicited online messages); that referenced online pharmacies, news, or pop-culture with no further commentary concerning the drug of interest; or for which the coder was unable to determine a theme. For posts that met one or more exclusion criteria, only the originating posts were removed. If related posts contained informative content (such as a comment mentioning overdose appearing below a news article), then they were not excluded.

Each post was classified by origin as either *social media* or *blogs and forums* based on the originating website. Social media posts originated from sites with a focus on social networking; users on these sites are typically not anonymous, discussions are unguided in nature (ie, not limited to predetermined topics), and commentary is often brief by design (character limits). Examples of social media sites include Twitter, Facebook business pages (which have different privacy rules than those of personal Facebook pages), and Myspace. Blog or forum posts originated from sites that, often, are created to facilitate conversation among users with similar interests; users are often anonymous or not connected to a real-world identity, discussions are topic-specific, and commentary is not limited and can be extensive in nature. Examples of blogs and forums include Reddit, Blogger, and specialized medical forums.

Sample Design

Due to the very large volume of posts collected, sampling was necessary to identify a subset of posts for manual coding. Posts were required to have occurred between January 1, 2015 and December 31, 2018. A total of 5,048,517 posts were collected for sampling. A stratified random sample without replacement and with proportional allocation was taken from the population of identified posts. Strata included both time (by week) and origin (social media or blogs and forums) of the online posts. If there were less than 2 posts that fell into a given week, that week was folded into a biweekly stratum and weights were adjusted accordingly [21]. The sample size for each opioid was determined based on an expected proportion of 0.05 with a measured precision of 0.015. Sample sizes were selected such that 95% of all confidence intervals of the proportion (calculated from the hypergeometric distribution) obtained the desired precision [22].

Definitions

A team of 3 trained coders manually reviewed the sample of posts in order to identify reasons for opioid-use outcomes (abuse and misuse), and key medical outcome measures (addiction, overdose, and death). Table 1 contains definitions of the terms as they were used in this study. Extensive training was conducted to ensure that consistent coding was achieved across the team of three coders. A codebook with outlined definitions, examples, and scenarios specific to these data was utilized in the training of each of the 3 coders. Training was complete when the trainee was able to meet the predefined criteria for interrater reliability. These definitions are specific to the RADARS System Web Monitoring Program and may differ from those of other surveillance programs. Each post may contain one or more key risks; are defined as the discussion of any instance of actual misuse, abuse, addiction, overdose, or death involving a drug or drug class of interest; and may include multiple mentions of the opioid or opioids of interest in a single post. Because misuse and abuse were defined similarly, they were coded into a single variable. In any cases of disagreement in coding, the case data were reconciled by an additional coder, and, when necessary, a senior researcher verified the coding.

Table 1. Definitions of terms used in the RADARS System Web Monitoring Program.

Term	Definition
Abuse	"A mention that indicates the use of a drug to gain a high, euphoric effect or some other psychotropic effect."
Addiction	"A mention that indicates one or more of the following: 1) psychological or physical dependence on a drug; 2) tolerance to the psychotropic effects of a drug; 3) withdrawal effects when discontinuing use of a drug."
Death	"A mention that indicates a death has occurred due to a drug of interest."
Mention	"Any occasion of a reference to a drug or drug class that appears in a post. One post may contain multiple mentions."
Misuse	"A mention that indicates the improper or incorrect use of a drug for reason other than the pursuit of a psychotropic effect."
Overdose	"A mention that indicates the accidental or intentional overdose of a drug, using a dangerous amount of a drug (i.e. a quantity greater than recommended or generally prescribed), or use which may result in a medical intervention."
Post	"A single point of communication entered by one individual at one specific time point."

Statistical Analysis

After manual coding, sampling weights were applied to calculate the estimated number and percentage of posts for each substance in the original population. Odds ratios (OR) and corresponding 95% confidence intervals were calculated from weighted logistic regression for the origin of the posts (social media versus blogs and forums) using all posts in the study period; odds ratios greater than 1.0 indicated higher odds that the post originated from social media. Interrater reliability was calculated between the 3 coders. Predefined acceptability criteria were set, and results were deemed acceptable if 3-way agreement was greater than 90% and if the average coefficient (Gwet AC1) was greater

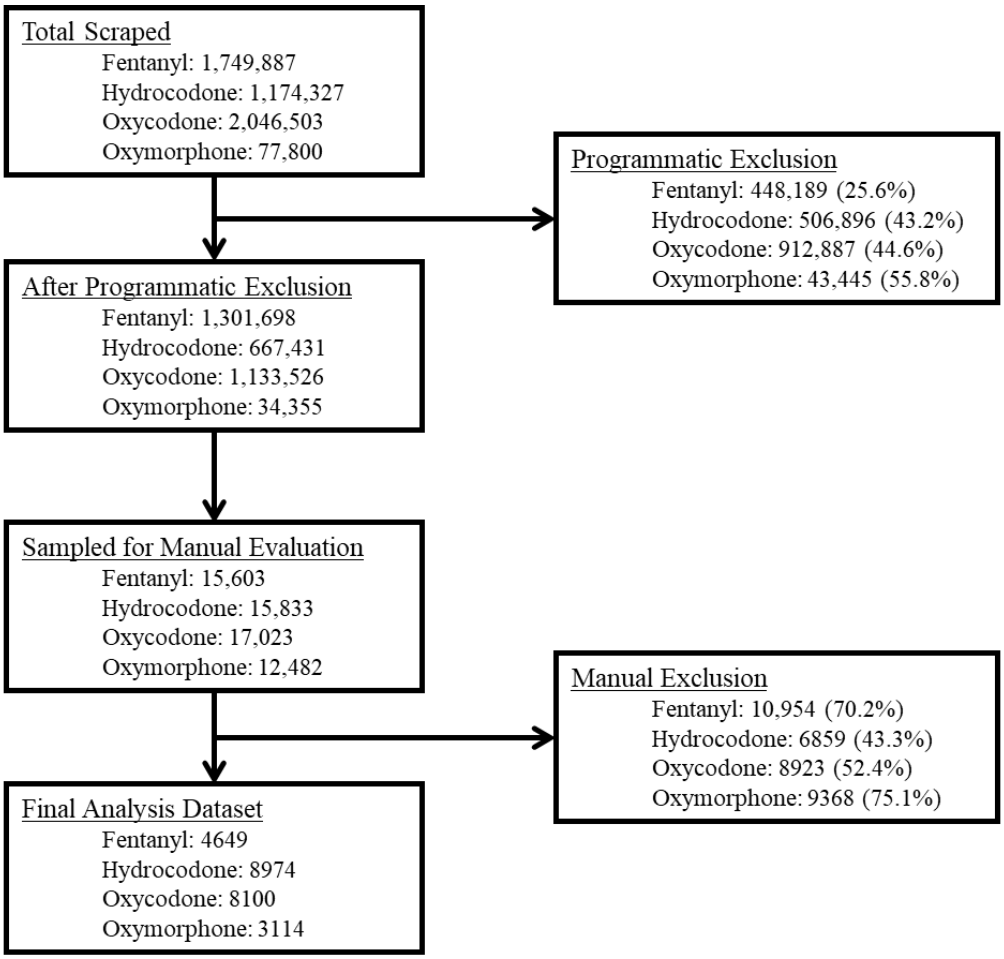
than 0.60 [23]. Statistical analyses were performed in R (3.4.2) and in SAS (version 9.4; SAS Institute Inc).

Results

Frequency of Posts Discussing Key Risks

Figure 1 depicts the data cleaning process and provides the number of opioid-specific mentions that were sampled and the number of mentions that were analyzed after exclusion criteria were applied. In the final sample (n=24,837), the outcomes were infrequently observed. Out of all posts for all drugs, 1.95% (485/24,837) mentioned misuse, 0.67% (166/24,837) mentioned abuse, 2.35% (584/24,837) mentioned addiction, 1.53% (379/24,837) mentioned overdose, and 2.15% (534/24,837) mentioned death.

Figure 1. Flowchart of data cleaning process for data collected from the 1st quarter of 2015 through to the 4th quarter of 2018 where percentages represent the proportion of exclusions at each step.



Interrater reliability was acceptable according to both criteria for all the coding variables. Three-way percent agreement was high for misuse and abuse (97.8%), addiction (99.4%), overdose (99.9%), and death (99.6%). Gwet AC1 coefficient was also high for misuse and abuse (0.98), addiction (0.99), overdose (1.0), and death (1.0)

Table 2 describes the estimated number of mentions by drug on the public internet that discuss the 5 key risks. The top 3 highest estimated frequencies involved fentanyl (death, overdose, and misuse). Misuse had the highest estimated frequency for hydrocodone. Addiction had the highest estimated frequency for oxycodone. All key risks involving oxymorphone were infrequently discussed, with fewer than 600 posts discussing each of the 5 key risks. Fentanyl-related death had the highest estimated frequency of any key risk–drug combinations which was from 10- to 100-fold higher than the frequency of death mentions for other drugs. Figure 2, Figure 3, Figure 4, and Figure 5 describe the estimated number of posts (per 10,000 posts) for fentanyl, hydrocodone, oxycodone, and oxymorphone, respectively, throughout the surveillance period. The estimated number of posts discussing misuse, abuse, and addiction generally decreased across the study period for hydrocodone, oxycodone, and oxymorphone. Discussions of fentanyl misuse, overdose, and death surged at the end of 2017 and continued to surge through 2018.

Table 2. Number of posts analyzed in samples and corresponding population estimates.

Key risks	Drug Mentions							
	Fentanyl		Hydrocodone		Oxycodone		Oxymorphone	
	Sample analyzed[a] (n=4649), n	Population estimate[b], n (95% CI)	Sample analyzed, n (n=8974)	Population estimate, n (95% CI)	Sample analyzed, n (n=8100)	Population estimate, (95% CI)	Sample analyzed, n (n=3114)	Population estimate, n (95% CI)
Abuse	24	627 (351-902)	42	2181 (1503-2858)	43	3548 (2424-4672)	57	189 (140-239)
Misuse	130	41808 (34,058-49,559)	199	10379 (8857-11,900)	107	7997 (6393-9601)	49	165 (118-211)
Addiction	73	4435 (3209-5662)	183	8766 (7419-10,113)	176	12679 (10,721-14,637)	152	526 (442-610)
Overdose	271	42659 (34,750-50,568)	36	1911 (1257-2564)	48	3633 (2583-4682)	24	84 (50-119)
Death	427	94169 (83,575-104,763)	23	913 (514-1312)	47	3291 (2326-4256)	37	125 (84-166)

[a]Sample analyzed refers to the number of posts manually reviewed by the team of coders.

[b]Population estimate refers to the extrapolated number of posts.

Figure 2. Estimated number of quarterly fentanyl posts.

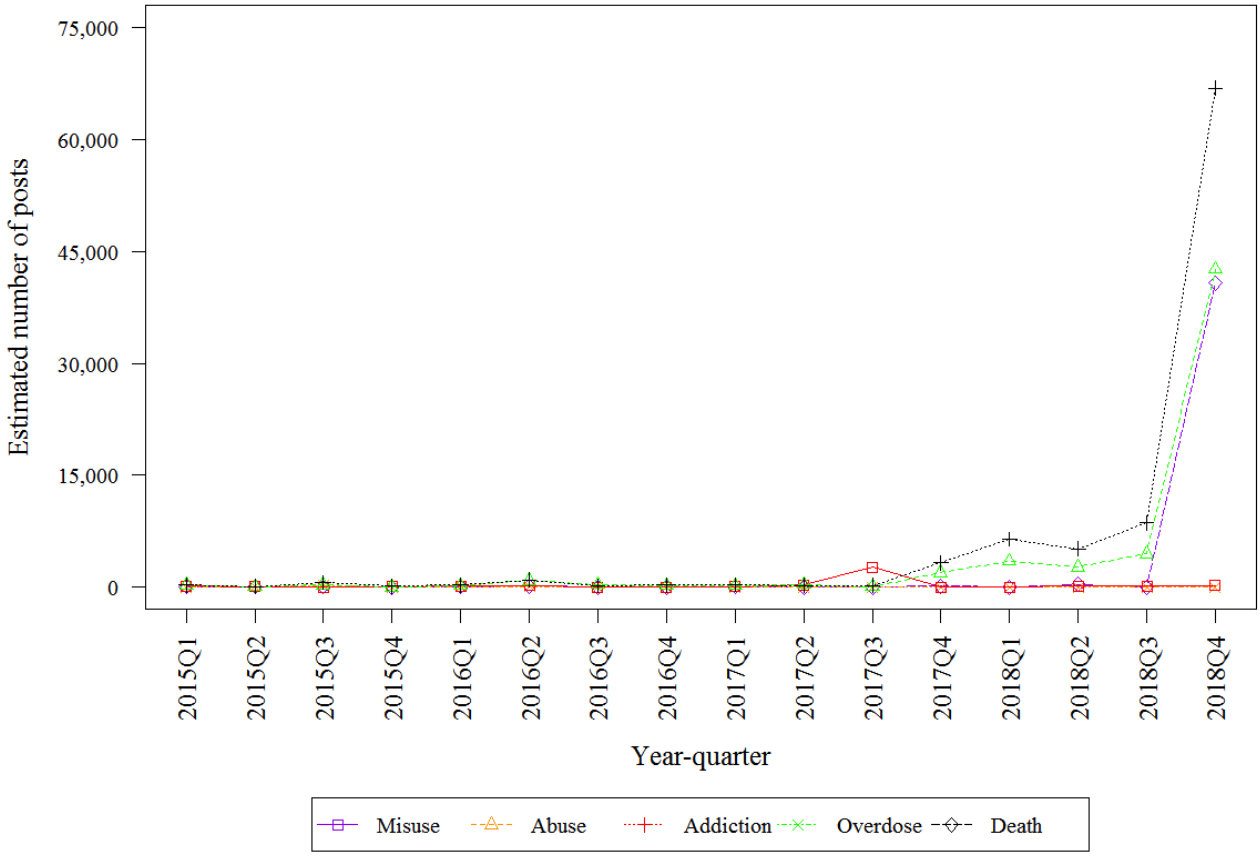


Figure 3. Estimated number of quarterly hydrocodone posts.

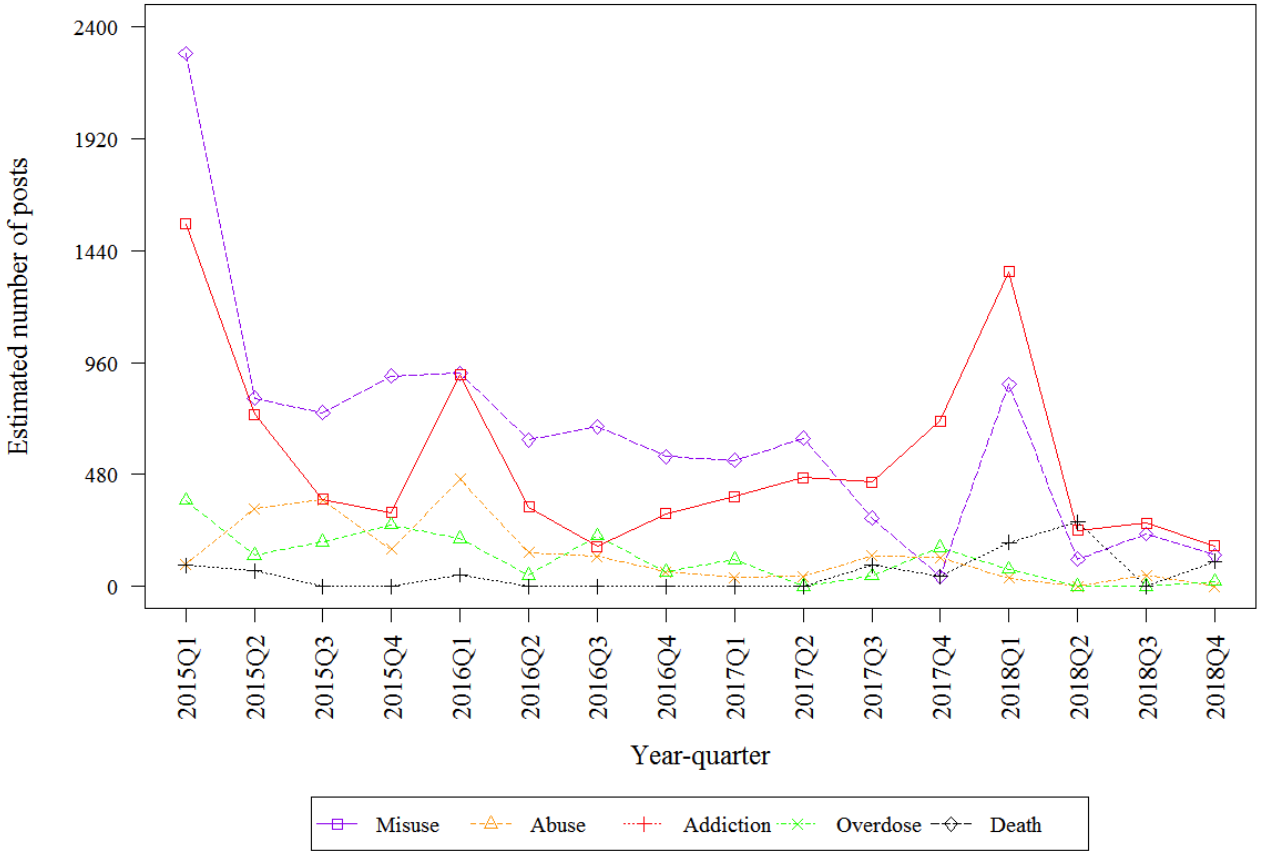


Figure 4. Estimated number of quarterly oxycodone posts.

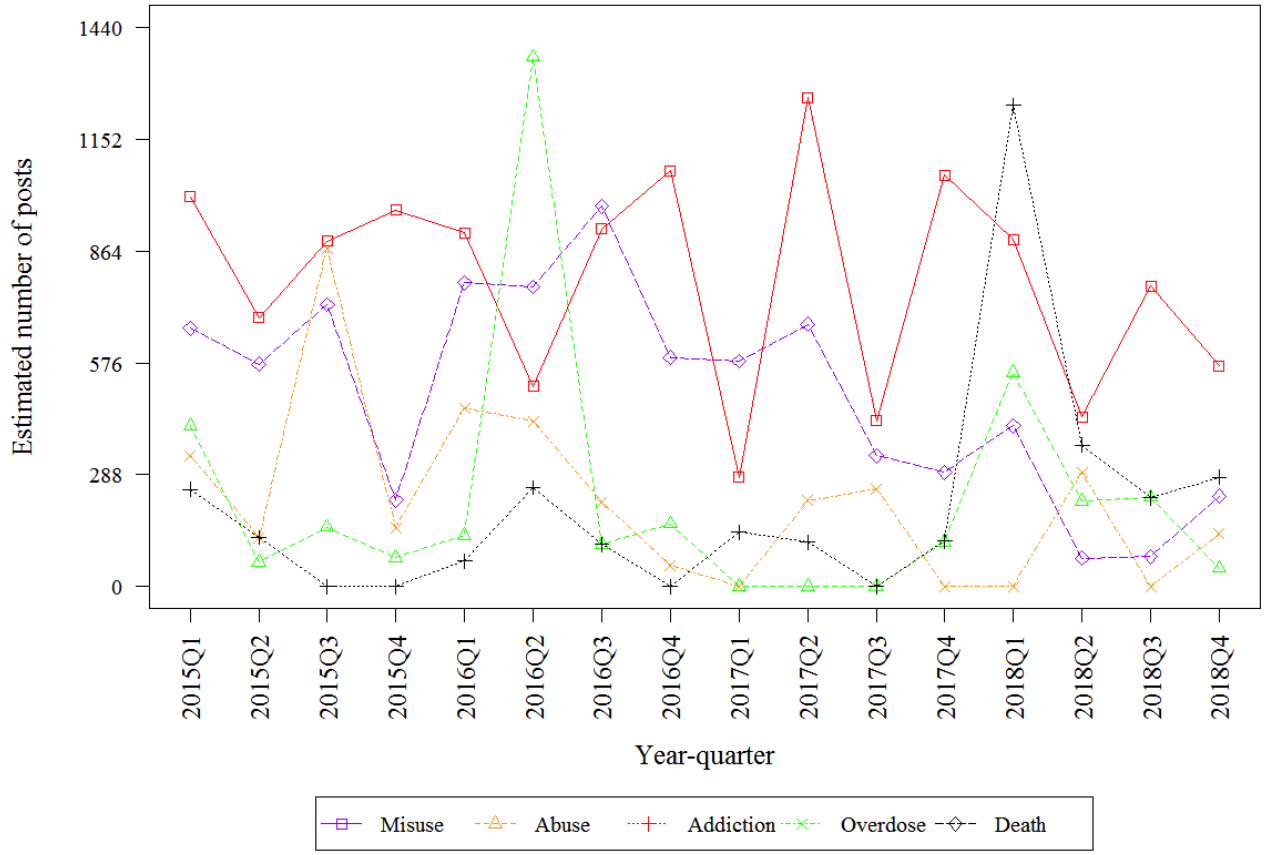
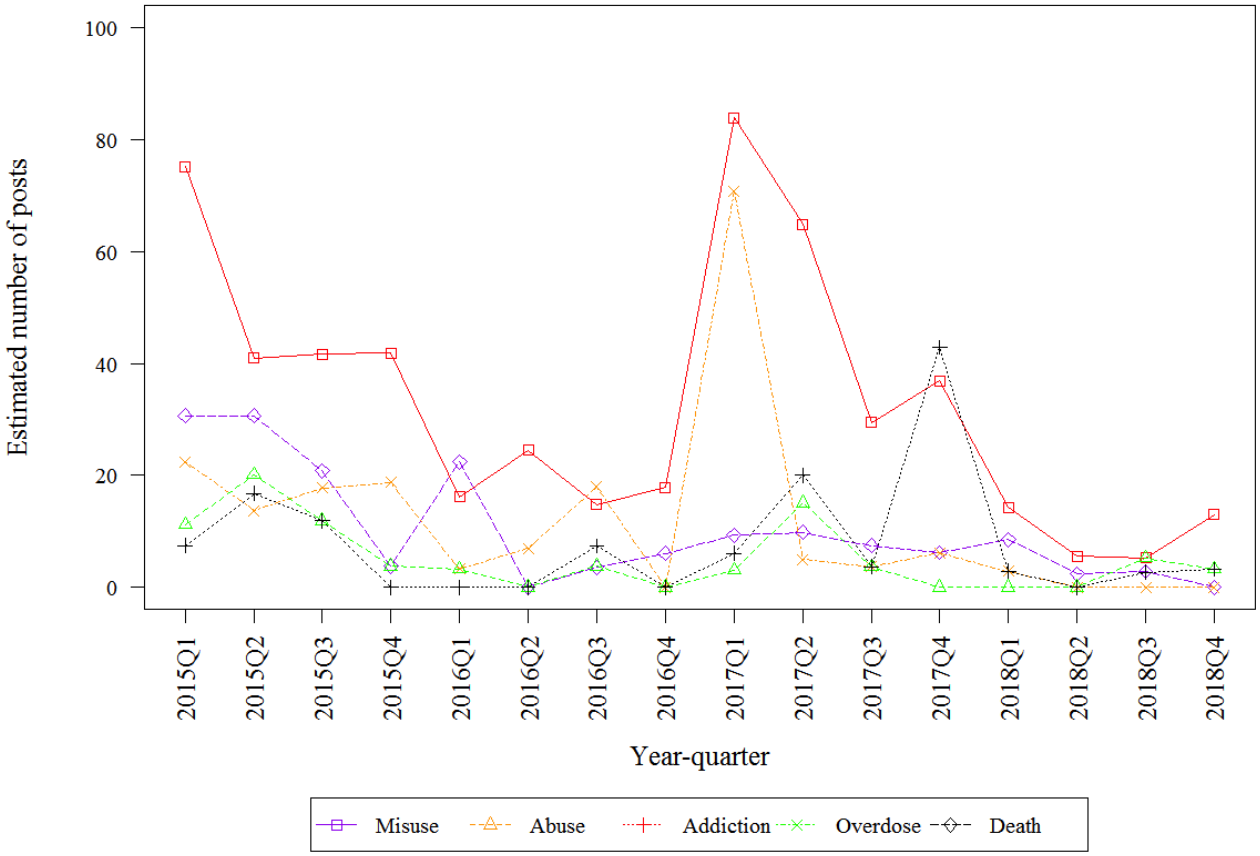


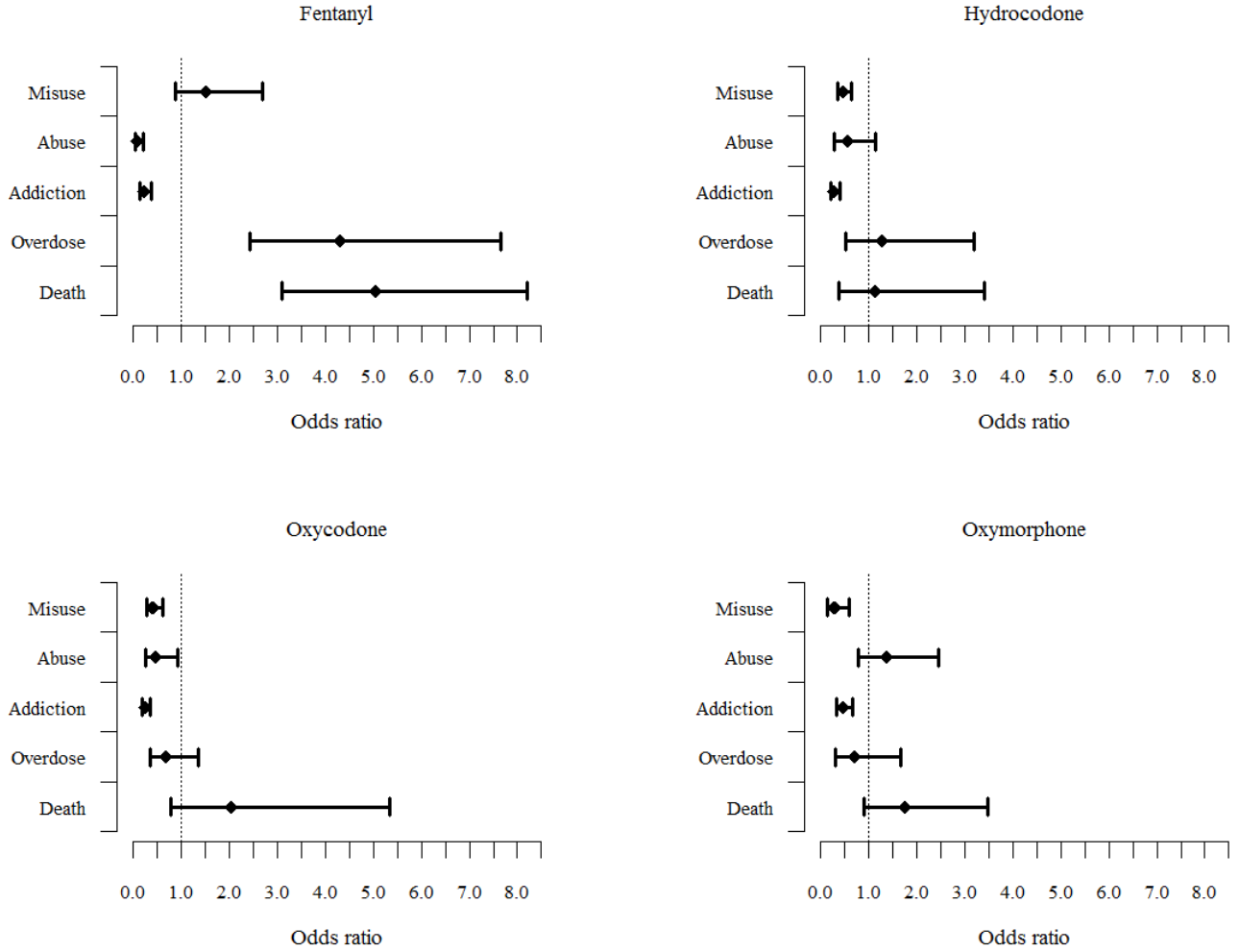
Figure 5. Estimated number of quarterly oxymorphone posts.



Origin of Posts Discussing Key Risks

Substantial proportions of posts discussing key risks originated outside of social media. An estimated 48.0% (95% CI 46.2%-49.8%) of oxymorphone posts, 16.8% (95% CI 15.9%-17.6%) of oxycodone posts, 18.3% (95% CI 17.5%-19.1%) of hydrocodone posts, and 14.6% (95% CI 13.6%-15.6%) of fentanyl posts originated from blogs and forums. Out of all social media posts discussing key risks, Twitter was a substantial origin. An estimated 19.9% (95% CI 18.9%-20.8%) of oxymorphone social media posts, 49.8% (95% CI 48.9%-50.7%) of oxycodone social media posts, 62.8% (95% CI 61.9%-63.7%) of hydrocodone social media posts, and 30.6% (95% CI 29.8%-31.4%) of fentanyl social media posts originated from Twitter. Odds ratios for the origin of discussion of key risks are shown in Figure 6. For ease of presentation, all odds ratios refer to social media as the reference. For all drugs, the estimated odds of discussing addiction were higher in blogs and forums than in social media. Odds of posting about addiction on social media were smaller than on blogs and forums; odds ratios ranged from (fentanyl) 0.24 (95% CI 0.15-0.38) to (oxymorphone) 0.46 (95% CI 0.32-0.67). Conversely, the estimated odds of discussing death were higher in social media than in blogs and forums for all drugs. The odds ratios for discussions of misuse, abuse, and overdose also differed by drug. Notably there was a distinct separation of fentanyl abuse and addiction discussions from fentanyl overdose and death discussions. Odds of discussing fentanyl overdose and death were higher for social media (overdose: OR 4.32, 95% CI 2.43-7.66; death OR 5.05, 95% CI 3.10-8.21), while odds of discussing fentanyl abuse and addiction were higher for blogs and forums (abuse: OR 0.10, 95% CI 0.04-0.22; addiction: OR 0.24, 95% CI 0.15-0.38). For other drugs, odds of discussing misuse were higher in blogs and forums.

Figure 6. Post origin by key risk across drugs. Odds ratios greater than 1.0 indicate higher likelihood of discussion on social media.



Discussion

Principal Findings

The purpose of this study was to demonstrate a sustainable, ongoing methodology of evaluating internet posts that mention drugs by presenting the trends of online discussion regarding abuse, misuse, addiction, overdose, and death and documenting the post origin of these key risks. The estimated numbers of posts that discussed misuse, abuse, and addiction decreased for hydrocodone, oxycodone, and oxymorphone over the surveillance period, which is not surprising since prescription guidelines have tightened the availability of these drugs [24]. Discussion of fentanyl rose sharply in 2017 and 2018, coincident with increased fentanyl mortality, increased illicit fentanyl production, and public awareness campaigns about the dangers of fentanyl. Further content evaluation of fentanyl posts could elucidate specific societal events that caused the sudden increase. Three strengths of the study results presented herein that distinguished this surveillance system from other opioid abuse internet surveillance programs [10] were that content coverage included originating sources beyond social media; the focus was on the FDA key risks—misuse, abuse, addiction, overdose, and death; and the originating sources of these key risk discussions were identified. It was noted that discussions of several key risks were more likely to be found on blogs and forums than on social media. This could result in selection bias in studies that focus only on social media. For example, if a study on substance-use behavior involving these four opioids used only social media, the post content would select against discussions of addiction and addiction-related behaviors.

Anonymity has a profound influence on the likelihood of revealing sensitive behaviors [25]. Traditional public health surveillance programs typically rely on confidentiality, and use of anonymous posts and social media may allow for reporting of behaviors or opinions not normally captured by traditional systems. Moreover, the diversity of online data sources used in this study allowed more comprehensive assessment of online discussion content than that which would have been allowed with an approach that targeted a single social media site (such as Twitter) or forum (such as drugs-forum). One review of studies that collected data on illicit drug use from a variety of platforms [10] found 14 studies that met inclusion criteria. Using our definition of media originating source, only 2 of those studies collected data from blogs and forums. Our results show that the discussions on social media often involve different information or outcomes compared to those on blogs and forums. There could be several reasons for this; social media posts were more likely to discuss overdose and death, outcomes that could elicit strong emotion and vocal responses. Blogs and forums were more related to misuse, abuse, and addiction, outcomes that could generate less strong response. We speculate the blogs and forums tend to have larger character limits, and

could be better suited for complex topics, such as addiction. As social media are commonly associated with an actual identity of the user, it is frequently less anonymous and can easily be searched by employers, family, and friends; this might drive discussion of stigmatizing behaviors, such as misuse, abuse, and addition, to blogs and forums where individuals can use pseudonyms. Research focused on overdose and death outcomes will likely find more valuable data on social media, while research around misuse, abuse, and addiction should look toward blogs and forums; however, a mosaic approach should ideally include both originating sources. Our results indicated that content originated from different sectors of the internet for addiction and death discussions, and qualitative analyses that focus only on subregions of the internet could miss important information on these key risks.

Due to the unsolicited nature of internet postings, qualitative analysis of web content can be used to identify unknown knowledge gaps in substance-abuse research. For future research efforts using the method reported here, data can be examined for polysubstance use, methods of tampering with abuse-deterrent formulations, or low-frequency side effects. Furthermore, negative outcomes are not the only topic to study. Events can stimulate online discussion that supports the proper therapeutic use of a drug or discussions can compare the efficacy of similar drug products.

Limitations

One limitation of this study is that only publicly available websites were studied. Unique information likely exists on websites with policies that prevent public scraping (such as most of Facebook or Bluelight). The second limitation was the unstructured nature of the raw data and the potential ambiguity associated with manually coding these key risks, which was addressed by team meetings to ascertain group consensus. Furthermore, interrater reliability was assessed and found to be satisfactory. Finally, separating illicit from licit fentanyl was challenging, and likely much of the discussion referred to illicit instead of licit fentanyl.

Conclusions

Use of internet posts reveals a unique perspective to the opioid epidemic that is not found using traditional surveillance systems and can be a gateway to understanding qualitative aspects of drug use. Anonymity and the unsolicited nature of these data offer advantages to understanding emerging trends. Surveillance of diverse content providers should be used to understand how policy or other interventions are received by the broader community.

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Authors' Contributions

All authors contributed equally to the work.

Conflicts of Interest

Authors were employed by Denver Health and Hospital Authority during this work.

Multimedia Appendix 1
Search keyword examples.
[DOCX File , 14 KB - publichealth_v6i2e17073_app1.docx]

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Abbreviations

FDA: Food and Drug Administration
RADARS: Researched Abuse, Diversion and Addiction - Related Surveillance

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Original Paper

Knowledge and Perceptions of COVID-19 Among Health Care Workers: Cross-Sectional Study

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Abstract

Background: During the first week of March, the coronavirus disease 2019 (COVID-19) outbreak reached more than 100 countries with over 100,000 cases. Health care authorities have already initiated awareness and preparedness activities worldwide. A poor understanding of the disease among health care workers (HCWs) may result in delayed treatment and result in the rapid spread of the infection.

Objective: This study aimed to investigate the knowledge and perceptions of HCWs about COVID-19.

Methods: A cross-sectional, web-based study was conducted among HCWs about COVID-19 during the first week of March 2020. A 23-item survey instrument was developed and distributed randomly to HCWs using social media; it required 5 minutes to complete. A chi-square test was used to investigate the level of association among variables, with significance set to $P<.05$.

Results: Of 529 participants, a total of 453 HCWs completed the survey (response rate: 85.6%); 51.6% (n=234) were male, 32.1% (n=147) were aged 25-34 years, and most were doctors (n=137, 30.2%) and medical students (n=134, 29.6%). Most participants (n=276, 61.0%) used social media to obtain information on COVID-19. A significant proportion of HCWs had poor knowledge of its transmission (n=276, 61.0%) and symptom onset (n=288, 63.6%) and showed positive perceptions of COVID-19. Factors such as age and profession were associated with inadequate knowledge and a poor perception of COVID-19.

Conclusions: As the global threat of COVID-19 continues to emerge, it is critical to improve the knowledge and perceptions of HCWs. Educational interventions are urgently needed to reach HCWs worldwide, and further studies are warranted.

(JMIR Public Health Surveill 2020;6(2):e19160) doi:10.2196/19160

KEYWORDS

coronavirus; outbreak; COVID-19; knowledge; perception; health care; questionnaire; health care worker

Introduction

Coronavirus (CoV) infections are emerging respiratory viruses that are known to cause illness ranging from the common cold to severe acute respiratory syndrome (SARS) [1]. CoV is a zoonotic pathogen that can be transmitted via animal-to-human and human-to-human interactions [2]. Multiple epidemic outbreaks occurred in 2002 (SARS), with approximately 800

deaths, and in 2012 (Middle East respiratory syndrome coronavirus, MERS-CoV), with 860 deaths [2,3]. About 8 years after the MERS-CoV epidemic, the current outbreak of coronavirus disease 2019 (COVID-19) in Wuhan City, Hubei Province, China, has emerged as a global outbreak and significant public health issue [4]. On January 30, 2020, the World Health Organization (WHO) declared COVID-19 a public health emergency of international concern [5]. Astonishingly, during the first week of March, a devastating number of new cases were reported globally, and COVID-19 emerged as a pandemic. As of March 12, 2020, more than 125,000 confirmed cases across 118 countries and over 4600 deaths had been reported [6].

COVID-19 is spread by human-to-human transmission through droplet, feco-oral, and direct contact and has an incubation period of 2-14 days [7]. To date, no antiviral treatment or vaccine has been explicitly recommended for COVID-19. Therefore, applying preventive measures to control COVID-19 infection is the most critical intervention. Health care workers (HCWs) are the primary sector in contact with patients and are an important source of exposure to infected cases in health care settings; thus, HCWs are expected to be at high risk of infection. By the end of January, the WHO and Centers for Disease Control and Prevention (CDC) had published recommendations for the prevention and control of COVID-19 for HCWs [8,9]. The WHO also initiated several online training sessions and materials on COVID-19 in various languages to strengthen preventive strategies, including raising awareness and training HCWs in preparedness activities [10]. In several instances, misunderstandings among HCWs have delayed controlling efforts to provide necessary treatment [11], led to the rapid spread of infection in hospitals [12,13], and put patients' lives at risk.

Knowledge can influence the perceptions of HCWs due to their past experiences and beliefs [14-16]. Indeed, it can delay recognition and handling of potential COVID-19 patients during the pandemic period. However, the level of knowledge and perceptions of HCWs toward COVID-19 remain unclear. In this regard, the COVID-19 pandemic offers a unique opportunity to investigate the level of knowledge and perceptions of HCWs during this global health crisis. In addition, we aim to explore HCWs' source of information of COVID-19 during this peak period.

Methods

Survey Instrument and Dissemination

A web-based, cross-sectional study was conducted using a survey instrument to obtain responses from HCWs globally during the first week of March 2020.

A 23-item survey instrument was developed using WHO course materials on emerging respiratory viruses, including COVID-19 [17]. The survey covered HCWs' characteristics, awareness, information sources, and knowledge and perceptions related to COVID-19. The developed draft survey instrument was made accessible through a link and was distributed to 10 experts from different geographic regions to comprehensively assess the content domains of the questionnaire (using a scale of 1-5 points and encouraged open commentaries). In addition, the materials used for developing the survey questionnaire were also provided for any further clarifications. Moreover, to assess readability, 10 randomly selected faculty members read the questionnaire for 15 minutes and rated the ease of readability of the questionnaire ranging from 0 to 100 (0-30: confusing; 31-50: difficult; 51-70: standard; 70-90: easy; and 90-100 very easy). The pilot web survey was then conducted among 10 randomly selected HCWs to assess clarity, relevance, and acceptability. Feasibility and time required to answer the survey were evaluated on another 5 participants. These participants were not included in the research.

Refinements were made as required to facilitate better comprehension and to organize the questions before the final survey was distributed to the study population through a URL link. Briefly, we used Telegram, a cloud-based instant messaging app, used by more than 200 million people every month. The "Clinical Updates" group was established on December 28, 2017 to provide the latest medical research updates. The group includes more than 2500 active members of HCWs all over the world. In the group, the survey link was advertised to the target population and was opened in March 2020 for 10 days.

Content of the Survey Instrument and Scoring System

The survey instrument comprised 23 closed-ended questions and took approximately 5 minutes to complete. The 23-item questionnaire was divided into three parts: participant characteristics (3 items), awareness of COVID-19 (2 items), source of information (4 statements/4-point Likert scale: 1 [least used] to 4 [most used]), knowledge about symptoms of COVID-19-affected patients (2 items), different modes of transmission (2 items), precautions and risk prevention (3 items) and perceptions of COVID-19 (7 items/true or false questions) (Multimedia Appendix 1). We used Qualitrics [18], an online survey tool to distribute the survey, and participants were given 30 mins to read, comprehend, and answer all the questions.

Knowledge was assessed by questions focusing on COVID-19 etiology, signs and symptoms, transmission, and risk prevention. Each response was scored as "1" (correct) and "0" (wrong), with scores ranging from 1 to 7. A cutoff level of ≤4 was considered to indicate poor knowledge about COVID-19 whereas >4 was considered adequate knowledge about COVID-19.

Perceptions toward COVID-19 were assessed using 7 items, and each question was labeled as good (scored as "1") or poor perception (scored as "0"). Scores ranged from 0 to 7. The participants' perceptions are classified as good (score >5) or poor (score ≤5).

Data Analysis

The obtained data were coded, validated, and analyzed using SPSS version 24 (IBM). Descriptive analysis was applied to calculate frequencies and proportions. The chi-square test was used to investigate the level of association among variables. A *P* value of less than .05 was considered statistically significant.

Ethical Considerations

Confidentiality of personal information was maintained throughout the study by making participants' information anonymous and asking participants to provide honest answers. Eligible HCWs' participation in this survey was voluntary and was not compensated. Electronic informed consent was shown on the initial page of the survey. The study was performed following the Declaration of Helsinki as revised in 2013. The study was conducted following the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [19] (Multimedia Appendix 2).

Results

Overview

A total of 529 HCWs participated, 453 of whom completed the study questionnaire (85.6% response rate), including 234 (51.6%) men and 219 (48.3%) women. Most participants were below 44 years of age (n=378, 82.4%). The majority of participants were doctors (n=137, 30.2%) or medical students (n=134, 29.6%) and were from Asia (n=308, 68%). Table 1 shows the sociodemographic characteristics of the participants. Almost all participants agreed that they had heard about COVID-19 (n=443, 97.8%), but only 44.1% (n=200) of them had the opportunity to attend lectures or discussions related to COVID-19.

Source of Information

When we asked about participants' source for reliable information about COVID-19, the primary sources mentioned were official government websites and social media (Table 2). Approximately 30% (n=134) of the participants reported that they used news media (TV/video, magazines, newspapers, and radio) and social media (Facebook, Twitter, WhatsApp, YouTube, Instagram, Snapchat) to obtain information about COVID-19. Moreover, nearly 40% (n=179) of the participants sometimes discussed COVID-19-related topics with family and friends.

Knowledge About COVID-19

Table 3 shows the level of knowledge about COVID-19 among HCWs. We identified significant knowledge gaps between doctors and other HCWs. For instance, 90 doctors (65.7%) and 176 allied health workers (55.7%) thought that COVID-19 originated from bats. The majority of the HCWs (n=338, 85.6%) agreed that maintaining hand hygiene, covering the nose and mouth while coughing, and avoiding sick patients could help to prevent COVID-19 transmission. Most doctors agreed that COVID-19 could lead to pneumonia, respiratory failure, and death (n=115, 84%; P=.04) and that supportive care is the only treatment option that is currently available (n=114, 83.2%; P<.001). However, participants' knowledge of questions related to the mode of transmission and the incubation period of COVID-19 was poor.

Table 1. Sociodemographic characteristics of health care workers (N=453).

Characteristic	Participants, n (%)
Sex	
Male	234 (51.6)
Female	219 (48.3)
Age range (years)	
<25	145 (31.6)
25-34	147 (32.1)
35-44	86 (18.7)
45-54	47 (10.2)
55-64	28 (6.1)
Occupation	
Doctor	137 (30.2)
Medical student	134 (29.6)
Pharmacist	61 (13.5)
Academic doctor	61 (13.5)
Nurse	24 (5.3)
Lab technician	22 (4.9)
Dentist	14 (3.1)
Location	
Asia	308 (68)
Africa	72 (15.9)
Europe	40 (8.8)
North America	11 (2.4)
South America	7 (1.5)
Unspecified	13 (2.9)
Heard about COVID-19[a]	
Yes	443 (97.8)
No	10 (2.2)
Attended lectures or discussions about COVID-19	
Yes	200 (44.1)
No	253 (55.8)

[a]COVID-19: coronavirus disease 2019.

Table 2. Participants' sources for reliable information about coronavirus disease 2019 (COVID-19) (N=453).

Response	Source of COVID-19 information			
	News media, n (%)	Social media, n (%)	Government websites, n (%)	Family and friends, n (%)
Least used	134 (29.56)	139 (30.62)	151 (33.41)	53 (11.73)
Sometimes	139 (30.72)	139 (30.62)	101 (22.51)	91 (20.00)
More often	115 (25.40)	104 (22.97)	121 (26.71)	179 (39.51)
Most used	65 (14.34)	72 (15.9)	78 (17.21)	129 (28.47)

Table 3. Knowledge about coronavirus disease 2019 (COVID-19) among health care workers (N=453).

Question	Doctors (n=137), n (%)	Allied health workers (n=316), n (%)	Total correct responses, n (%)	*P* value[a]
COVID-19 is thought to originate from bats	90 (65.7)	176 (55.7)	266 (58.7)	.046
COVID-19 is transmitted through air, contact, fecal-oral routes	50 (36.5)	127 (40.2)	177 (39)	.46
Headache, fever, cough, sore throat, and flu are symptoms of COVID-19	109 (79.6)	223 (70.6)	332 (73.2)	.046
The incubation period of COVID-19 (2-14 days)	62 (45.3)	103 (32.6)	165 (36.4)	.01
COVID-19 leads to pneumonia, respiratory failure, and death	115 (84)	238 (75.3)	353 (77.9)	.04
Supportive care is the current treatment for COVID-19	114 (83.2)	193 (61)	307 (67.7)	.001
Hand hygiene, covering nose and mouth while coughing, and avoiding sick contacts can help in the prevention of COVID-19 transmission	117 (85.4)	271 (85.6)	388 (85.6)	.96

[a]*P*<.05 considered statistically significant between the groups.

Perceptions About COVID-19

Over 78% (n=353) of the HCWs exhibited a positive perception of COVID-19. The majority of HCWs knew that sick patients should share their recent travel history (n=420, 92.7%), that flu vaccination is not sufficient to prevent COVID-19 (n=411, 90.7%), and that COVID-19 is not fatal (n=401, 88.5%). In addition, 87% (n=394) felt that washing hands with soap and water could help to prevent COVID-19 transmission; 84.3% (n=394) knew that symptoms appear in 2-14 days; and 85.6% (n=388) agreed that all equipment used in wet markets should be cleaned every day. However, 20.9% (n=95) of HCWs answered “no” when asked about eating well-cooked meat during the outbreak (Table 4).

Items related to perceptions of COVID-19 among HCWs were analyzed separately using a chi-square test to examine their association with age and sex and across different professions (Table 5).

Table 4. Health care workers’ perceptions toward coronavirus disease 2019 (COVID-19) (N=453).

Statement	Yes, n (%)	No, n (%)
COVID-19 symptoms appear in 2-14 days	394 (84.3)[a]	71 (15.6)
COVID-19 is fatal	52 (11.4)	401 (88.5)[a]
Flu vaccination is sufficient for preventing COVID-19	42 (9.2)	411 (90.7)[a]
During the outbreak, eating well-cooked and safely handled meat is safe	358 (78.1)[a]	95 (20.9)
Sick patients should share their recent travel history with health care providers	420 (92.7)[a]	33 (7.3)
Disinfect equipment and working area in wet markets at least once a day	388 (85.6)[a]	65 (14.3)
Washing hands with soap and water can help in the prevention of COVID-19 transmission	394 (87)[a]	59 (13)

[a]Indicates the correct answer.

Table 5. Association between respondent characteristics and perceptions of coronavirus disease 2019 (COVID-19).

Question and response	Sex			Age				Profession			
	Male (n=234), n (%)	Female (n=219), n (%)	*P* value[a]	<25 years (n=145), n (%)	25-44 years (n=233), n (%)	45-65 years (n=75), n (%)	*P* value[a]	Doctors (n=137), n (%)	Medical students (n=134), n (%)	Others (n=182), n (%)	*P* value[a]
COVID-19 symptoms appear in 2-14 days			.75				*.001*				*.011*
Yes[b]	198 (84.6)	183 (83.5)		130 (89.6)	207 (88.8)	39 (52)		126 (92)	116 (86.5)	146 (80.2)	
No	36 (15.3)	36 (16.4)		15 (10.4)	26 (11.1)	36 (48)		11 (8)	18 (13.5)	36 (19.8)	
COVID-19 is fatal			.19				.78				.31
Yes	22 (9.4)	29 (13.2)		127 (87.5)	207 (88.8)	68 (90.6)		116 (84.6)	112 (83.5)	143 (78.5)	
No[b]	212 (90.6)	190 (86.7)		18 (12.5)	26 (11.1)	7 (9.4)		21 (15.4)	22 (16.5)	39 (21.5)	
Flu vaccinated is sufficient for preventing COVID-19			.94				.07				.11
Yes	24 (10.2)	22 (10.1)		21 (14.5)	19 (8.1)	5 (6.6)		18 (13.1)	16 (12)	36 (19.8)	
No[b]	210 (89.7)	197 (89.9)		124 (85.5)	214 (91.9)	70 (93.4)		119 (86.9)	118 (88)	146 (80.2)	
During the outbreak, eating well-cooked and safely handled meat is safe			.67				.13				*.099*
Yes[b]	192 (82)	183 (83.5)		113 (77.9)	200 (85.8)	63 (84)		114 (83.2)	98 (73.1)	136 (74.7)	
No	42 (18)	36 (16.4)		32 (22)	33 (14.2)	12 (16)		23 (16.8)	36 (26.9)	46 (25.3)	
Sick patients should share their recent travel history with health care providers			.84				.51				*.02*
Yes[b]	228 (97.4)	214 (97.7)		141 (97.2)	229 (98.2)	72 (96)		131 (95.6)	124 (92.5)	158 (86.8)	
No	6 (2.6)	5 (2.3)		4 (2.8)	4 (1.8)	3 (4)		6 (4.4)	10 (7.5)	24 (13.2)	
Disinfect equipment's and working area in wet markets at least once a day			.26				.54				.41
Yes[b]	205 (87.6)	199 (90.8)		131 (90.3)	206 (88.4)	64 (85.3)		116 (84.6)	117 (87.3)	149 (81.8)	
No	29 (12.4)	20 (9.2)		14 (9.7)	27 (11.6)	11 (14.7)		21 (15.4)	17 (12.7)	33 (18.2)	
Washing hands with soap and water can help in prevention of COVID-19 transmission			.58				.24				.88
Yes[b]	204 (87.2)	187 (85.3)		120 (82.7)	207 (88.8)	65 (86.6)		118 (86.1)	116 (86.5)	160 (87.9)	
No	30 (12.8)	32 (13.6%)		25 (17.3)	26 (11.1)	10 (13.4)		19 (13.9)	18 (13.5)	22 (12.1)	

[a]Significant at *P*<.05 (italicized) between the groups.

[b]Indicates the correct answer.

Nearly 90% (n=130) of the youngest participants (<25 years) and 92% (n=126) of the doctors believed that the symptoms of COVID-19 appeared as early as 2-14 days; the differences among the respondent groups were statistically significant (*P*<.001). Moreover, a significant proportion of doctors perceived eating well-cooked/handled meat to be safe (n=114, 83.2%). Medical students were found to have the perception that flu vaccination is not sufficient to prevent COVID-19

transmission (n=118, 88%). A large number of allied health workers incorrectly believed that it is not safe to eat well-processed meat during the COVID-19 outbreak (n=46, 25.3%), that COVID-19 is fatal (n=143, 78.5%), that there is a delay in symptoms (n=36, 19.8%), and that flu vaccination is sufficient (n=36, 19.8%) compared with other participants in the respective groups.

Discussion

Principal Findings

At present, COVID-19 is a global topic of discussion in the media and among the public, especially among HCWs and patients. With the currently mounting COVID-19 transmission raising tensions for everyone, including for health officials and health systems, an important question arises regarding how we manage information to help frontline HCWs in times of public health crisis. For this reason, we investigated HCWs' knowledge and perceptions of the prevention and control of COVID-19 at the pandemic level.

Knowledge and perceptions of COVID-19 varied across different categories of HCWs. Our study revealed that HCWs have insufficient knowledge about COVID-19 but showed positive perceptions of COVID-19 transmission prevention. We also found that more than 33% (n=151) of HCWs used official government websites as a primary source of information about COVID-19. This indicates that the COVID-19-related updates posted online by official government health authorities had positive implications for improving HCWs' knowledge levels. Obtaining information from authentic sources is pivotal for disseminating unbiased and reliable data about the emerging COVID-19 infection and is essential for HCWs' preparedness and response. However, a finding of considerable concern is that more than 61% (n=278) of HCWs used social media as a source of information. Currently, there is a vast diversity of information available through the internet, including unverified malicious information, that can spread quickly and misguide HCWs. In particular, health authorities and scientists have warned that widespread misinformation about COVID-19 is a serious concern causing xenophobia worldwide [4,20-22]. In this regard, HCWs should carefully evaluate COVID-19-related information and should use scientific and authentic content as information sources.

The findings of this study suggest a significant gap between the amount of information available on COVID-19 and the depth of knowledge among HCWs, particularly about the mode of transmission and the incubation period of COVID-19. Additionally, many allied health workers had inaccurate knowledge of COVID-19 (eg, can be treated with antivirals and that there is a vaccine available). This is unfortunate because the surge of COVID-19 is globally devastating, and a large number of resources are provided by health care authorities to educate HCWs and improve their knowledge of COVID-19. One possible explanation for these differences in knowledge is that doctors are more educated in infectious diseases and pharmacotherapy because of their continuous professional development. Therefore, our findings suggest that greater encouragement from health authorities is needed to distribute COVID-19-related knowledge to all categories of HCWs.

Generally, most participants had a positive perception of the prevention and control of COVID-19. However, discrepancies were identified in the perceptions of different categories of HCWs. For instance, only half (n=32, 52%) of the HCWs aged 45-65 years believed that the symptoms of COVID-19 appeared as early as 2 or as late as 14 days (P<.001). If these responses are truly representative of HCWs, this could have adverse consequences on patient care and also on the dynamics of potential COVID-19 outbreaks. This apparent lack of knowledge could result in delays in the implementation of necessary confinement measures and personal protective equipment, which may increase the burden of COVID-19. In our study, more than a quarter of the medical students thought that eating meat during the outbreak was unsafe. This may be due to the fact that COVID-19 was closely linked to a wet market in China and other viral diseases such as SARS, MERS, and Ebola emerged from zoonotic origins [23-25]. Thus, people often believe that the consumption of undercooked meat may enhance viral transmission. However, further investigation is still required. Approximately 20% (n=36) of allied health workers believed that the flu vaccine is sufficient for COVID-19 prevention. Finally, a vast majority of HCWs strongly agreed that maintaining hygiene activities, reporting recent travel history when individuals are sick, and cleaning the equipment used in wet markets are strongly recommended.

Limitations

We used WHO training material for the detection, prevention, response, and control of COVID-19 to develop a validated questionnaire. The developed questionnaire was pilot tested, and open-ended questions were limited to reduce information bias.

However, this study has some limitations that should be considered. This is a cross-sectional study conducted online among HCWs during a time (ie, first week of March 2020) when an alarming number of cases were being reported globally; this might limit generalizations. In addition, the data presented in this study are self-reported and partly dependent on the participants' honesty and recall ability; thus, they may be subject to recall bias. Lastly, due to the 4-week closure of higher educational institutions in the United Arab Emirates during the COVID-19 outbreak [26], the institutional review board was not approached. Despite these limitations, our findings provide valuable information about the knowledge and perceptions of HCWs during a peak period of the pandemic.

Conclusion

We identified a significant gap in information source, poor knowledge levels, and discrepancies in perceptions of COVID-19 among our study participants. As the global threat of COVID-19 continues to emerge, greater efforts through educational campaigns that target HCWs and the wider population beyond borders are urgently needed.

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Authors' Contributions

ASB designed the study, developed the questionnaire, collected the data, analyzed the data, and prepared the manuscript. WAA designed the questionnaire and conducted the pilot test and the literature review. MAM and JR distributed the questionnaire and filtered and analyzed the data. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questionnaire.
[DOCX File , 29 KB - publichealth_v6i2e19160_app1.docx]

Multimedia Appendix 2
Checklist for Reporting Results of Internet E-Surveys (CHERRIES).
[PDF File (Adobe PDF File), 176 KB - publichealth_v6i2e19160_app2.pdf]

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Abbreviations

CDC: Centers for Disease Control and Prevention
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
CoV: coronavirus
COVID-19: coronavirus disease 2019
HCW: health care worker
MERS-CoV: Middle East respiratory syndrome coronavirus
SARS: severe acute respiratory syndrome
WHO: World Health Organization

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Original Paper

Assessment of Health Information About COVID-19 Prevention on the Internet: Infodemiological Study

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Abstract

Background: The internet is a large source of health information and has the capacity to influence its users. However, the information found on the internet often lacks scientific rigor, as anyone may upload content. This factor is a cause of great concern to scientific societies, governments, and users.

Objective: The objective of our study was to investigate the information about the prevention of coronavirus disease 2019 (COVID-19) on the internet.

Methods: On February 29, 2020, we performed a Google search with the terms “Prevention coronavirus,” “Prevention COVID-19,” “Prevención coronavirus,” and “Prevención COVID-19”. A univariate analysis was performed to study the association between the type of authorship, country of publication, and recommendations to avoid COVID-19 according to the World Health Organization (WHO).

Results: In total, 80 weblinks were reviewed. Most of them were produced in the United States and Spain (n=58, 73%) by digital media sources and official public health organizations (n=60, 75%). The most mentioned WHO preventive measure was “wash your hands frequently” (n=65, 81%). A less frequent recommendation was to “stay home if you feel unwell” (n=26, 33%). The analysis by type of author (official public health organizations versus digital media) revealed significant differences regarding the recommendation to wear a mask when you are healthy only if caring for a person with suspected COVID-19 (odds ratio [OR] 4.39). According to the country of publication (Spain versus the United States), significant differences were detected regarding some recommendations such as “wash your hands frequently” (OR 9.82), “cover your mouth and nose with your bent elbow or tissue when you cough or sneeze” (OR 4.59), or “stay home if you feel unwell” (OR 0.31).

Conclusions: It is necessary to urge and promote the use of the websites of official public health organizations when seeking information on COVID-19 preventive measures on the internet. In this way, users will be able to obtain high-quality information more frequently, and such websites may improve their accessibility and positioning, given that search engines justify the positioning of links obtained in a search based on the frequency of access to them.

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KEYWORDS

COVID-19; coronavirus; prevention; internet; information; evaluation; authorship; World Health Organization; official public health organizations; digital media; infodemic; infodemiology

Introduction

Internet access has increased worldwide during the past decade, reaching 79.6% of the European population and 48% of the world population in 2017 [1]. In the United States, 90% of adults access the internet [2] and 53.1% look for health information online [3].

As with previous epidemics such as Ebola or Zika infections, the internet has become a favored mechanism for the spread of misinformation [4,5]. This has implications for public health behavior and health-related decision making [6].

At present, an outbreak of coronavirus disease 2019 (COVID-19) has occurred and has spread throughout China and to dozens of countries [7]. As in other epidemics, people want to know what can be done to prevent and treat the disease [6]. Since there is currently no vaccine or specific antiviral treatment, the application of preventive measures is essential.

In this context, we aimed to conduct an infodemiological study [8,9] to investigate the information about the prevention of COVID-19 available on the internet.

Methods

On February 29, 2020, we performed a Google search and selected the first 20 links [5] of the Google search results, excluding advertisements. The search terms used were "Prevention coronavirus," "Prevention COVID-19," "Prevención coronavirus," and "Prevención COVID-19". Two reviewers (HG-I and GJ-T) viewed the links independently, and the following information was extracted from each link: type of authorship (official public health organizations, scientific societies, digital media, libraries, private health care system, articles from biomedical journals, or other), language, country of publication, and recommendations to avoid COVID-19. The information was obtained by making up to four clicks on the different sublinks of each link, as has been done in other studies [10,11]. Subsequently, the degree of adherence to the following World Health Organization (WHO) basic protective measures against the new coronavirus in force on February 29, 2020, was checked: wash your hands frequently; maintain at least 1 meter (3 feet) distance between yourself and anyone who is coughing or sneezing; avoid touching eyes, nose, and mouth; cover your mouth and nose with your bent elbow or tissue when you cough or sneeze (then dispose of the used tissue immediately); stay home if you feel unwell; if you develop fever, cough, and difficulty breathing, seek medical advice promptly (call in advance and tell your provider of any recent travel); if you are healthy, you only need to wear a mask if you are taking care of a person with suspected COVID-19; and wear a mask if you are coughing or sneezing [12].

We performed a descriptive analysis of all the variables and evaluated the association of the independent variables (type of authorship and country of publication) with the degree of adherence to the WHO basic protective measures by means of a chi-square test or Fisher exact test. When a significant association was found ($P<.05$), this was quantified with the odds ratio (OR) and its 95% CI obtained from univariate logistic regression analysis. The agreement between the two reviewers regarding the adherence to the WHO basic protective measures was analyzed using the Kappa index. All analyses were performed using SPSS v20.0 (IBM Corp) and EpiInfo (Centers for Disease Control and Prevention).

Results

In total, 80 weblinks were reviewed (Textbox 1). Most of them were produced in the United States and Spain (n=58, 73%) by digital media and official public health organizations (n=60, 75%; Table 1). There were no discrepancies between the authors regarding the degree of adherence to the WHO basic protective measures (Kappa=1).

In addition, information that was ambiguous or did not adhere to the WHO recommendations was found in 8 weblinks (5 from Spain and 3 from the United States; 6 of the 8 were from digital media). In particular, 3 Spanish links indicated "maintain a distance of approximately one meter between people." One Spanish link mentioned that "for people without respiratory symptoms a surgical mask is not required, although masks can be worn in some countries according to local cultural customs." One link in Spain and another in the United States specified that "someone should only wear a mask if a healthcare professional recommends it." One link in the United States mentioned, "If you're going to around a lot of sick people, like if you're visiting a friend in the hospital, a mask might be a good idea," and one link in the United States recommended, "Stay three feet away from people when you talk to them."

Textbox 1. Electronic addresses of the 80 weblinks by search term.

Search term: Prevention coronavirus

- https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment-sp.html
- https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment.html
- https://www.ecdc.europa.eu/en/current-risk-assessment-novel-coronavirus-situation
- https://www.who.int/emergencies/diseases/novel-coronavirus-2019/advice-for-public
- https://www.who.int/emergencies/diseases/novel-coronavirus-2019/technical-guidance/infection-prevention-and-control
- https://choice.npr.org/index.html?origin=https://www.npr.org/2020/02/27/810016611/coronavirus-101-what-you-need-to-know-to-prepare-and-prevent
- https://www.nytimes.com/2020/02/26/health/coronavirus-cdc-usa.html
- https://cuidateplus.marca.com/enfermedades/infecciosas/Coronavirus.html
- https://www.osha.gov/SLTC/covid-19/
- https://www.conehealth.com/services/primary-care/coronavirus-get-the-facts-on-symptoms-and-prevention-with-cynthi/
- https://edition.cnn.com/2020/02/28/health/how-to-wash-hands-coronavirus-trnd/index.html
- https://www.nbcnews.com/health/health-news/main-focus-preventing-coronavirus-spread-should-be-hand-hygiene-not-n1144346
- https://www.businessinsider.com/wuhan-coronavirus-face-masks-not-entirely-effective-2020-1?IR=T
- https://abc7news.com/5971803/
- https://www.mobihealthnews.com/news/coronavirus-prevention-may-be-your-pocket
- https://www.washingtonpost.com/gdpr-consent/?next_url=https%3a%2f%2fwww.washingtonpost.com%2fhealth%2f2020%2f02%2f26%2fhow-to-prepare-for-coronavirus%2f
- https://www.cnbc.com/2020/02/26/cdc-confirms-first-possible-community-spread-coronavirus-case-in-us.html
- https://foreignpolicy.com/2020/02/28/taiwan-who-coronavirus-china-international-organizations/
- https://parade.com/987803/lisamulcahy/coronavirus/
- https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/prevention-risks.html

Search term: Prevention COVID-19

- http://www.euro.who.int/en/health-topics/health-emergencies/coronavirus-covid-19/news/news/2020/2/joint-who-and-ecdc-mission-in-italy-to-support-covid-19-control-and-prevention-efforts
- https://openwho.org/courses/COVID-19-IPC-EN
- https://www.ecdc.europa.eu/en/novel-coronavirus-china
- https://www.ecdc.europa.eu/en/publications-data/infographic-covid-19
- http://bvsalud.isciii.es/covid-19/
- https://abc7news.com/5971803/
- https://www.japantimes.co.jp/opinion/2020/02/27/editorials/covid-19-preventing-medical-system-breakdown/#.XlrmyahKg2w
- https://jamanetwork.com/journals/jama/fullarticle/2762130
- https://www.iata.org/contentassets/7e8b4f8a2ff24bd5a6edcf380c641201/airport-preventing-spread-of-coronavirus-disease-2019.pdf
- https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment-sp.html
- https://www.cdc.gov/coronavirus/2019-ncov/index-sp.html
- https://www.osha.gov/SLTC/covid-19/controlprevention.html
- https://www.cnbc.com/2020/02/27/coronavirus-latest-updates-outbreak.html
- https://www.mica.edu/campus-operating-status-updates/coronavirus/best-practices-and-preventive-measures/
- https://www.kuow.org/stories/new-coronavirus-cases-found-in-king-and-snohomish-counties
- https://www.euronews.com/2020/02/26/coronavirus-prevention-how-effective-are-masks-closed-borders-screenings-and-quarantines
- https://www.health.govt.nz/our-work/diseases-and-conditions/covid-19-novel-coronavirus/covid-19-novel-coronavirus-health-advice-general-public
- https://www.canada.ca/en/public-health/services/diseases/2019-novel-coronavirus-infection/prevention-risks.html
- https://www.bmj.com/content/368/bmj.m810

- https://vietnamnews.vn/society/652839/pm-pushes-for-covid-19-preventive-measures.html

Search term: Prevención COVID-19

- https://www.cdc.gov/coronavirus/2019-ncov/index-sp.html
- https://www.saludcastillayleon.es/profesionales/es/enfermedades-infecciosas/nuevo-coronavirus-covid-19/plan-especifico-prevencion-riesgos-laborales-nuevo-coronavi
- https://www.alimente.elconfidencial.com/bienestar/2020-02-29/coronavirus-covid19-que-es-sintomas-contagio_2431343/
- https://www.saludcastillayleon.es/profesionales/es/enfermedades-infecciosas/nuevo-coronavirus-covid-19
- https://www.who.int/es/emergencies/diseases/novel-coronavirus-2019/advice-for-public/q-a-coronaviruses
- https://www.ibsalut.es/es/info-ciudadania/cuidar-la-salud/3710-preguntas-y-respuestas-sobre-el-nuevo-coronavirus-2019-n-cov
- https://www.campusvirtualsp.org/es/curso/virus-respiratorios-emergentes-incluido-el-2019-ncov-metodos-de-deteccion-prevencion-respuesta
- https://www.alimente.elconfidencial.com/bienestar/2020-02-29/coronavirus-covid19-que-es-sintomas-contagio_2431343/
- https://www.semfyc.es/como-prevenir-infecciones-por-virus-respiratorios-como-el-coronavirus-que-causa-la-enfermedad-covid-19/
- http://bvsalud.isciii.es/covid-19/
- https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov-China/documentos/20200224.Preguntas_respuestas_COVID-19.pdf
- https://www.mscbs.gob.es/profesionales/saludPublica/ccayes/alertasActual/nCov-China/documentos/Documento_Control_Infeccion.pdf
- https://www.lasexta.com/noticias/internacional/coronavirus-covid19-que-puedes-hacer-protegerte-como-actuar_202002245e53fcca0cf2547d2a31e546.html
- https://www.unicef.org/es/historias/coronavirus-lo-que-los-padres-deben-saber
- https://www.lavanguardia.com/vida/20200229/473828128008/coronavirus-espana-madrid-barcelona-wuhan-china-italia-covid-19-contagios-sintomas-fallecidos-ultima-hora-hoy-en-directo.html
- https://www.univision.com/local/philadelphia-wuvp/prevencion-del-coronavirus-que-funciona-para-evitar-la-propagacion-de-covid-19
- http://bvsalud.isciii.es/covid-19/
- https://medlineplus.gov/spanish/ency/article/007768.htm
- https://sano-y-salvo.blogspot.com/2020/02/infografias-para-prevenir-la-infeccion.html
- https://www.bbc.com/mundo/noticias-51683330

Search term: Prevención coronavirus

- https://cuidateplus.marca.com/enfermedades/infecciosas/Coronavirus.html
- https://www.quironprevencion.com/es/campanas-prevencion-riesgos-laborales/coronavirus-covid-2019
- https://medlineplus.gov/spanish/coronavirusinfections.html
- https://www.cdc.gov/coronavirus/2019-ncov/about/prevention-treatment-sp.html
- https://www.saludcastillayleon.es/profesionales/es/enfermedades-infecciosas/nuevo-coronavirus-covid-19/plan-especifico-prevencion-riesgos-laborales-nuevo-coronavi
- https://elpais.com/elpais/2020/02/25/ciencia/1582645440_172885.html
- https://www.elperiodico.com/es/sanidad/20200225/coronavirus-que-es-sintomas-contagio-prevencion-7814261
- https://vacunasaep.org/profesionales/noticias/coronavirus-desarrollo-de-vacunas
- https://www.hola.com/estar-bien/20200123158838/coronavirus-sintomas-prevenir-contagio/
- https://www.alimente.elconfidencial.com/bienestar/2020-02-29/coronavirus-covid19-que-es-sintomas-contagio_2431343/
- https://www.diariocordoba.com/noticias/sociedad/que-es-coronavirus-sintomas-contagio-prevencion-virus_1351515.html
- https://www.who.int/csr/disease/coronavirus_infections/ipc-mers-cov/es/
- https://www.intramed.net/contenidover.asp?contenidoid=95410
- https://www.bbc.com/mundo/noticias-51683330
- https://www.semes.org/semes-divulgacion/medidas-de-prevencion-ante-la-neumonia-por-coronavirus/
- https://www.lavanguardia.com/seguros/empresa/20200217/473630100957/mwc-alerta-sanitaria-contagio-corona-virus-riesgos-laborales-seguros.html
- https://chile.gob.cl/chile/medidas-de-prevencion-ante-el-nuevo-coronavirus
- https://www2.cruzroja.es/-/como-puedes-reducir-el-riesgo-de-infeccion-del-coronavirus-

- https://temas.sld.cu/coronavirus/coronavirus/medidas-preventivas/
- https://www.lavanguardia.com/ciencia/20200225/473756254816/coronavirus-covid-19-mascarilla-prevencion.html

Table 1. Characteristics of the 80 weblinks.

Characteristics	Frequency, n (%)
Country of publication	
United States	30 (38)
Spain	28 (35)
Switzerland	6 (8)
United Kingdom	3 (4)
Sweden	3 (4)
Canada	2 (3)
Others	8 (10)
Type of authorship	
Digital media	33 (41)
Official public health organizations	27 (34)
Libraries	6 (8)
Scientific societies	3 (4)
Articles from biomedical journals	2 (3)
Private health care system	2 (3)
Others	7 (9)
Language	
Spanish	45 (56)
English	35 (44)
Available recommendation according to the World Health Organization	
Wash your hands frequently	65 (81)
Maintain at least 1 meter distance	56 (70)
Cover your mouth and nose when you cough or sneeze	54 (68)
Avoid touching eyes, nose, and mouth	44 (55)
Wear a mask if you are coughing or sneezing	39 (49)
If you develop fever, cough, and difficulty breathing, seek medical advice	37 (46)
If you are healthy, wear a mask if you are taking care of a person with suspected COVID-19[a]	37 (46)
Stay home if you feel unwell	26 (33)

[a]COVID-19: coronavirus disease 2019.

Univariate analysis by type of author (official public health organizations versus digital media) revealed statistically significant differences regarding the recommendation to wear a mask if you are healthy only if caring for a person with suspected COVID-19 (OR 4.39; Table 2). The analysis according to country of publication (Spain versus the United States) detected statistically significant differences regarding some recommendations such as “wash your hands frequently” (OR 9.82), “cover your mouth and nose with your bent elbow or tissue when you cough or sneeze” (OR 4.59), or “stay home if you feel unwell” (OR=0.31; Table 3).

Table 2. Recommendations to avoid COVID-19 according to the World Health Organization and information about them available on the internet according to their authorship.

Recommendation, type of authorship	Available, n (%)	Unavailable, n (%)	Odds ratio (95% CI)	*P* value
Wash your hands frequently (available n=65, unavailable n=15)				
Official public health organizations	23 (35)	4 (27)	2.16 (0.58-7.99)	.35
Libraries	6 (9)	0 (0)	__[a]	.31
Others	12 (19)	2 (13)	2.25 (0.42-12.09)	.46
Digital media	24 (37)	9 (60)	1	—
Cover your mouth and nose when you cough or sneeze (available n=54, unavailable n=26)				
Official public health organizations	19 (35)	8 (31)	1.98 (0.68-5.79)	.21
Libraries	6 (11)	0 (0)	—	.07
Others	11 (20)	3 (12)	3.06 (0.72-13.01)	.19
Digital media	18 (33)	15 (58)	1	—
Maintain at least 1 meter distance between yourself and anyone who is coughing or sneezing (available n=56, unavailable n=24)				
Official public health organizations	21 (38)	6 (25)	2.00 (0.63-6.33)	.24
Libraries	6 (11)	0 (0)	—	.15
Others	8 (14)	6 (25)	0.76 (0.21-2.72)	.68
Digital media	21 (38)	12 (50)	1	—
Avoid touching eyes, nose, and mouth (available n=44, unavailable n=36)				
Official public health organizations	16 (36)	11 (31)	2.24 (0.79-6.32)	.13
Libraries	6 (14)	0 (0)	—	.008
Others	9 (21)	5 (14)	2.77 (0.76-10.13)	.12
Digital media	13 (30)	20 (56)	1	—
If you develop fever, cough, and difficulty breathing, seek medical advice (call and tell your provider of any recent travel; available n=37, unavailable n=43)				
Official public health organizations	11 (30)	16 (37)	1.06 (0.38-2.99)	.92
Libraries	5 (14)	1 (2)	7.69 (0.81-73.55)	.08
Others	8 (22)	6 (14)	2.05 (0.58-7.29)	.27
Digital media	13 (35)	20 (47)	1	—
Stay home if you feel unwell (available n=26, unavailable n=54)				
Official public health organizations	12 (46)	15 (28)	2.13 (0.73-6.27)	.17
Libraries	1 (4)	5 (9)	0.53 (0.06-5.21)	>.99
Others	4 (15)	10 (19)	1.07 (0.72-4.28)	>.99
Digital media	9 (35)	24 (44)	1	—
Wear a mask if you are coughing or sneezing (available n=39, unavailable n=41)				
Official public health organizations	17 (44)	10 (24)	1.81 (0.64-5.09)	.27
Libraries	1 (3)	5 (12)	0.21 (0.02-2.02)	.21
Others	5 (13)	9 (22)	0.59 (0.16-2.14)	.43
Digital media	16 (41)	17 (42)	1	—
If you are healthy, wear a mask if you are taking care of a person with suspected COVID-19[b] (available n=37, unavailable n=43)				
Official public health organizations	20 (54)	7 (16)	4.39 (1.45-13.32)	.008
Libraries	1 (3)	5 (12)	0.31 (0.03-2.94)	.39
Others	3 (8)	11 (26)	0.42 (0.09-1.79)	.32
Digital media	13 (35)	20 (47)	1	—

[a]Not available.

[b]COVID-19: coronavirus disease 2019.

Table 3. Recommendations to avoid COVID-19 according to the World Health Organization and information about them available on the internet according to their country of publication.

Recommendation, type of authorship	Available, n (%)	Unavailable, n (%)	Odds ratio (95% CI)	*P* value
Wash your hands frequently (available n=65, unavailable n=15)				
Spain	27 (42)	1 (7)	9.82 (1.14-84.61)	.03
Switzerland	4 (6)	2 (13)	0.73 (0.11-4.77)	>.99
Others	12 (19)	4 (27)	1.09 (0.27-4.39)	>.99
United States	22 (34)	8 (53)	1	—[a]
Cover your mouth and nose with your bent elbow or tissue when you cough or sneeze (available n=54, unavailable n=26)				
Spain	24 (44)	4 (15)	4.59 (1.27-16.53)	.02
Switzerland	4 (7)	2 (8)	1.53 (0.24-9.68)	>.99
Others	9 (17)	7 (27)	0.98 (0.29-3.34)	.98
United States	17 (32)	13 (50)	1	—
Maintain at least 1 meter distance between yourself and anyone who is coughing or sneezing (available n=56, unavailable n=24)				
Spain	22 (39)	6 (25)	1.57 (0.48-5.18)	.46
Switzerland	4 (7)	2 (8)	0.86 (0.13-5.55)	>.99
Others	9 (16)	7 (29)	0.55 (0.16-1.94)	.36
United States	21 (38)	9 (38)	1	—
Avoid touching eyes, nose, and mouth (available n=44, unavailable n=36)				
Spain	13 (30)	15 (42)	0.43 (0.15-1.25)	.12
Switzerland	3 (7)	3 (8)	0.50 (0.09-2.94)	.65
Others	8 (18)	8 (22)	0.50 (0.15-1.73)	.28
United States	20 (46)	10 (28)	1	—
If you develop fever, cough, and difficulty breathing, seek medical advice (call and tell your provider of any recent travel; available n=37, unavailable n=43)				
Spain	19 (51)	9 (21)	3.17 (1.08-9.31)	.04
Switzerland	4 (11)	2 (5)	3.00 (0.47-19.04)	.37
Others	2 (5)	14 (33)	0.21 (0.04-1.12)	.09
United States	12 (32)	18 (42)	1	—
Stay home if you feel unwell (available n=26, unavailable n=54)				
Spain	6 (23)	22 (41)	0.31 (0.09-0.99)	.045
Switzerland	2 (8)	4 (7)	0.57 (0.09-3.61)	.67
Others	4 (15)	12 (22)	0.38 (0.09-1.46)	.21
United States	14 (54)	16 (30)	1	—
Wear a mask if you are coughing or sneezing (available n=39, unavailable n=41)				
Spain	13 (33)	15 (37)	0.66 (0.24-1.87)	.44
Switzerland	3 (8)	3 (7)	0.77 (0.13-4.43)	>.99
Others	6 (15)	10 (24)	0.46 (0.13-1.59)	.22
United States	17 (44)	13 (32)	1	—
If you are healthy, wear a mask if you are taking care of a person with suspected COVID-19[b] (available n=37, unavailable n=43)				
Spain	11 (30)	17 (40)	0.57 (0.19-1.61)	.29
Switzerland	3 (8)	3 (7)	0.88 (0.15-5.05)	>.99
Others	7 (19)	9 (21)	0.68 (0.20-2.31)	.54
United States	16 (43)	14 (33)	1	—

[a]Not available.

[b]COVID-19: coronavirus disease 2019.

Discussion

This study is the first to evaluate the adherence of the information available on the internet to the WHO basic protective measures against COVID-19. It shows a level of adherence that can be improved and a difficulty in obtaining such information, since it was only available in 32.5%-81.3% of the links.

The difficulty of finding WHO-promoted measures to prevent other infectious diseases on the internet has also been described previously by other authors, such as Covolo et al [13]. The authors, when studying the information on the internet about the pandemic flu vaccine, showed that only 80.3% (61/76) and 53.9% (41/76) of the websites they evaluated contained information on the indications and contraindications, respectively, of the vaccine that correctly adhered to the WHO guidelines [13].

Less than half of the weblinks provided information on the correct use of masks and, together with the fact that some of the links provided information that was ambiguous or did not adhere to the WHO guidance, may have contributed to the misuse of masks by the population and with the subsequent shortage of these devices that is occurring worldwide [14,15].

As with other studies that evaluated information on the internet on preventive measures for other infections [11], our work shows that, in general, official public health organizations provide more correct information on measures to avoid COVID-19, which confirms what other authors have said about the reliability of the information provided by such institutions [10,13]. However, the fact that only 34% (n=27/80) of the links referred to such organizations is an aspect that could be improved and shows the need to implement some interventions to increase the number of links of this type and their visibility on the internet. In addition, digital media must take responsibility for providing correct information and creating comprehension among citizens [16].

According to the analysis by country, the Spanish links provided more information on measures to prevent COVID-19 that adhered to the WHO than did the links produced in the United States. The measures to prevent COVID-19 by the Centers for Disease Control and Prevention [17] are the same as those of the WHO, and the proportion of links with information that was ambiguous or did not adhere to these guidelines is similar in terms of originating in the United States (n=3/30) and Spain (n=5/28). Therefore, an explanation for these differences could be that at the time of data collection, COVID-19 was considered to pose a moderate risk to public health in Spain (with 50 cases among 46 million people [18]), while in the United States, the problem was still far away (with 66 cases among 327 million people [18]). For this reason, the links from the United States did not provide as much information as the Spanish links on how to prevent COVID-19.

One of the limitations of our study is intrinsic to the nature of internet, namely that information changes continuously; like others [5,10,11,13,19], this paper analyzed the information available at a particular time. On the other hand, as in previous studies on other infectious diseases [5], only the first 20 links obtained were evaluated, because it has been observed that internet users only use the first two pages of results [20]. Likewise, the search was carried out only with the Google search engine because it is the most popular search engine, covering nearly 90% of the total online searches [21]. Finally, like other studies [11,13], the search terms were chosen by the authors assuming that an internet user would probably use one of them to perform simple searches on the web with respect to preventative measures for COVID-19.

In conclusion, it is necessary to urge and promote the use of the websites of official public health organizations (and specifically those originating from Spain for Spanish-speaking users) when seeking information on COVID-19 preventive measures on the internet. In this way, they will be able to obtain high-quality information more frequently, and such websites' accessibility and positioning may improve, given that search engines justify the positioning of links obtained in a search based on the frequency of access to them.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease 2019
OR: odds ratio
WHO: World Health Organization

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Viewpoint

Global Telemedicine Implementation and Integration Within Health Systems to Fight the COVID-19 Pandemic: A Call to Action

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Abstract

On March 11, 2020, the World Health Organization declared the coronavirus disease 2019 (COVID-19) outbreak as a pandemic, with over 720,000 cases reported in more than 203 countries as of 31 March. The response strategy included early diagnosis, patient isolation, symptomatic monitoring of contacts as well as suspected and confirmed cases, and public health quarantine. In this context, telemedicine, particularly video consultations, has been promoted and scaled up to reduce the risk of transmission, especially in the United Kingdom and the United States of America. Based on a literature review, the first conceptual framework for telemedicine implementation during outbreaks was published in 2015. An updated framework for telemedicine in the COVID-19 pandemic has been defined. This framework could be applied at a large scale to improve the national public health response. Most countries, however, lack a regulatory framework to authorize, integrate, and reimburse telemedicine services, including in emergency and outbreak situations. In this context, Italy does not include telemedicine in the essential levels of care granted to all citizens within the National Health Service, while France authorized, reimbursed, and actively promoted the use of telemedicine. Several challenges remain for the global use and integration of telemedicine into the public health response to COVID-19 and future outbreaks. All stakeholders are encouraged to address the challenges and collaborate to promote the safe and evidence-based use of telemedicine during the current pandemic and future outbreaks. For countries without integrated telemedicine in their national health care system, the COVID-19 pandemic is a call to adopt the necessary regulatory frameworks for supporting wide adoption of telemedicine.

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KEYWORDS

telemedicine; telehealth; digital health; digital medicine; COVID-19; coronavirus; SARS-CoV-2; public health; surveillance; outbreak; pandemic

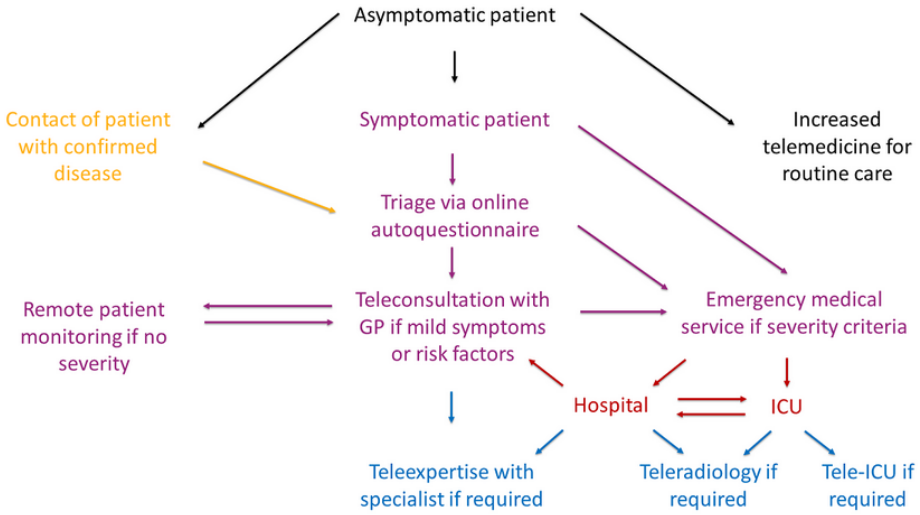
On March 11, 2020, the World Health Organization declared the coronavirus disease 2019 (COVID-19) outbreak as a pandemic, with over 720,000 cases reported in more than 203 countries as of 31 March. This announcement followed the declaration of a Public Health Emergency of International Concern (PHEIC) on January 30. The response strategy included early diagnosis, patient isolation, symptomatic monitoring of contacts, as well as suspected and confirmed cases, and a public health quarantine. The confinement of population and the outbreak impact on health care systems is disrupting routine care for non COVID-19 patients. In this context, telemedicine, particularly video consultations, has been promoted and scaled up to reduce the risk of transmission, especially in the United Kingdom [1] and the United States of America [2,3]. Telemental

health services have been reported in China [4] and Australia as well [5].

Telemedicine was shown to be helpful in previous outbreaks, including former coronavirus outbreaks such as SARS-CoV (severe acute respiratory syndrome–associated coronavirus) and MERS-CoV (Middle East respiratory syndrome coronavirus), or PHEICs related to Ebola and Zika viruses [6,7]. Based on a literature review, the first conceptual framework for telemedicine implementation during outbreaks was published in 2015 [7]. The framework included tele-expertise, remote patient monitoring of contact cases, and teleconsultation for triage and isolated cases.

An updated framework for telemedicine during the COVID-19 pandemic has been defined in Figure 1. This framework could be applied at a large scale to improve national public health response, and should be shaped on the basis of scientific evidence arising from implemented telemedicine activities.

Figure 1. Conceptual framework of telemedicine for the coronavirus disease 2019 (COVID-19) pandemic. GP: general practitioner; ICU: intensive care unit.



Technological improvements and cost reduction of telemedicine solutions combined with both the high-speed internet and mass spread of smartphones makes it possible to apply this framework and quickly deploy video teleconsultations from a patient's home.

Most countries, however, lack a regulatory framework to authorize, integrate, and reimburse telemedicine in their care delivery for all patients, particularly in emergency and outbreak situations [8]. Two possibilities are currently available for patients: (1) direct-to-consumer telemedicine with private providers mostly relying on out-of-pocket or private insurance payment and (2) free solutions, mainly from US-based companies (for example, WhatsApp, Skype, or Facetime), that may not respect national health data privacy and security requirements. Although these solutions may be useful to support and alleviate the pressure on health care systems during the outbreak, to date, they are mostly unintegrated within national health care systems and not sharing data with public health authorities for epidemiological surveillance.

With the second largest burden of COVID-19 in the world, Italy does not include telemedicine in the essential levels of care granted to all citizens within the National Health Service. No formal input was given on telemedicine by health authorities, despite high pressure on health services during the first phase of the epidemic [9,10]; not until an open call for telemedicine and monitoring system technologies proposals on March 24th was jointly issued by the Ministry for Technological Innovation and Digitalization, the Ministry of Health, the National Institute of Health and the WHO [11].

In France, the Ministry of Health signed a decree on March 9, 2020, allowing the reimbursement of video teleconsultations and tele-expertise by the National Health Insurance (NHI), for patients with COVID-19 symptoms and those confirmed with COVID-19 throughout the country, without the need to know the patient beforehand [12]. The decree was aimed to decrease unnecessary travel for medical consultations, limit the number of individuals grouping in waiting rooms, screen and detect suspected patients, and allow follow-up of mild confirmed cases from home. As the outbreak worsened, temporary funding for follow-up by nurses via video or phone as well as video teleconsultations by midwives (March 19, 2020) and speech therapists (March 25, 2020) was legally allowed.

The pre-existing telemedicine regulations also enabled primary care and hospital doctors to switch scheduled face-to-face consultations with known patients to reimbursed teleconsultations, when suitable. This model was activated in the largest national public academic hospital (AP-HP) in Paris, to encourage mass use of outpatient teleconsultations to reduce patient visits to the hospital (March 13, 2020). This has been reinforced by the High Council of Public Health, which recommended prioritization of teleconsultations for people with risk factors for severe disease in primary care (March 14, 2020) [13], followed by clinical and practical guidelines for patient examination by video consultation published by the Ministry of Health (March 16, 2020) [14]. Between 23 and 29 March, on the second week of national confinement, 486,369 teleconsultations were invoiced to the NHI, representing around 11% of all consults of the week [15]. Among general practitioners, 44% conducted at least one teleconsultation. Until

early March, less than 10,000 teleconsultations a week were invoiced to the NHI.

In this context, several challenges remain for telemedicine to be globally used and integrated into the public health response to COVID-19 and future outbreaks:

1. The integration of telemedicine into international and national guidelines for public health preparedness (in keeping with International Health Regulations, 2005) and response [16]
2. The definition of national regulations and funding frameworks for telemedicine in the context of public health emergencies
3. A strategy to quickly define telemedicine frameworks; use case scenarios; develop clinical guidelines; and standardize triage auto questionnaire and remote patient-monitoring algorithms for any outbreaks at local, national, or global scales
4. A strategy and operational plan guiding health care providers to switch to outpatient teleconsultations and increase tele-expertise and remote patient monitoring
5. A communication toolkit to inform and educate the population on the recommended use of telemedicine
6. A data-sharing mechanism to integrate telemedicine providers' data with epidemiological surveillance
7. A scientific evaluation framework and dedicated research funds to describe and assess the impact of telemedicine during outbreaks

All stakeholders are encouraged to address the challenges and collaborate to promote the safe and evidence-based use of telemedicine during the current pandemic and future outbreaks. For countries without integrated telemedicine within their national health care system, the COVID-19 pandemic is a call to adopt the necessary regulatory changes supporting wide adoption of telemedicine.

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Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease 2019
MERS-CoV: Middle East respiratory syndrome coronavirus
PHEIC: Public Health Emergency of International Concern
SARS-CoV: severe acute respiratory syndrome–associated coronavirus

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Protocol

Emergence of a Novel Coronavirus (COVID-19): Protocol for Extending Surveillance Used by the Royal College of General Practitioners Research and Surveillance Centre and Public Health England

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Abstract

Background: The Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) and Public Health England (PHE) have successfully worked together on the surveillance of influenza and other infectious diseases for over 50 years, including three previous pandemics. With the emergence of the international outbreak of the coronavirus infection (COVID-19), a UK national approach to containment has been established to test people suspected of exposure to COVID-19. At the same time and separately, the RCGP RSC's surveillance has been extended to monitor the temporal and geographical distribution of COVID-19 infection in the community as well as assess the effectiveness of the containment strategy.

Objectives: The aims of this study are to surveil COVID-19 in both asymptomatic populations and ambulatory cases with respiratory infections, ascertain both the rate and pattern of COVID-19 spread, and assess the effectiveness of the containment policy.

Methods: The RCGP RSC, a network of over 500 general practices in England, extract pseudonymized data weekly. This extended surveillance comprises of five components: (1) Recording in medical records of anyone suspected to have or who has been exposed to COVID-19. Computerized medical records suppliers have within a week of request created new codes to support this. (2) Extension of current virological surveillance and testing people with influenza-like illness or lower respiratory tract infections (LRTI)—with the caveat that people suspected to have or who have been exposed to COVID-19 should be referred to the national containment pathway and not seen in primary care. (3) Serology sample collection across all age groups. This will be an extra blood sample taken from people who are attending their general practice for a scheduled blood test. The 100 general practices currently undertaking annual influenza virology surveillance will be involved in the extended virological and serological

surveillance. (4) Collecting convalescent serum samples. (5) Data curation. We have the opportunity to escalate the data extraction to twice weekly if needed. Swabs and sera will be analyzed in PHE reference laboratories.

Results: General practice clinical system providers have introduced an emergency new set of clinical codes to support COVID-19 surveillance. Additionally, practices participating in current virology surveillance are now taking samples for COVID-19 surveillance from low-risk patients presenting with LRTIs. Within the first 2 weeks of setup of this surveillance, we have identified 3 cases: 1 through the new coding system, the other 2 through the extended virology sampling.

Conclusions: We have rapidly converted the established national RCGP RSC influenza surveillance system into one that can test the effectiveness of the COVID-19 containment policy. The extended surveillance has already seen the use of new codes with 3 cases reported. Rapid sharing of this protocol should enable scientific critique and shared learning.

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KEYWORDS

general practice; medical record systems; computerized; sentinel surveillance; coronavirus; COVID-19; SARS-CoV-2; surveillance; infections; pandemic; records as topic; serology

Introduction

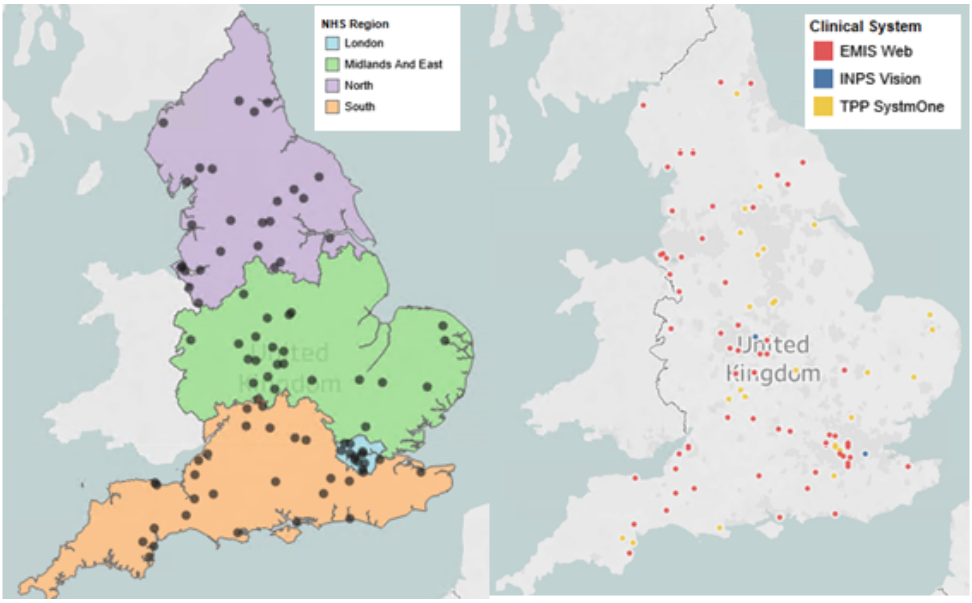
Background

The Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) is a network of general practices (GPs) with a nationally representative population [1] that provides pseudonymized data for weekly surveillance of infectious diseases. The disease surveillance program is commissioned by Public Health England (PHE) and covers 37 infectious diseases, including influenza. The RCGP RSC and PHE have an established collaboration of over 50 years in influenza and respiratory disease surveillance [2] and are now in their 53rd season of surveillance and analysis.

The RCGP RSC extracts pseudonymized data from a nationally representative sample of over 500 urban and nonurban GPs each week covering a population of over 4 million. Data from these practices are reported online in a weekly return [3], which includes monitoring weekly rates of influenza-like illness (ILI) and other communicable and respiratory diseases in England. We also produce an annual report [4]. The RCGP RSC data set includes all coded data and all prescribed items including vaccine exposure [1].

The RCGP RSC conducts virology surveillance each influenza season, with 100 GPs participating in the 2019-2020 season (Figure 1). These virology sampling practices are also recruited to be nationally representative (Figure 1). GPs take nasopharyngeal swabs from persons showing acute respiratory illness within 7 days of the onset of symptoms. Nasopharyngeal swabs are taken from children younger than 5 years showing symptoms of acute bronchitis or bronchiolitis. Additionally, nasopharyngeal samples are taken from anyone 5 years and older showing acute onset of ILI and respiratory synctial virus [5]. Swabs are tested at the PHE Respiratory Virus Unit for influenza to monitor positivity rates and circulating strains, as well as for measuring vaccine effectiveness.

Figure 1. RCGP RSC virology sampling sites. Distribution by National Health Service region and by brand of computerized clinical systems supplier. RCGP RSC has 100 virology sampling sites, there are >500 practices in total signed up to RCGP RSC across England. NHS: National Health Service. RCGP: Royal College of General Practitioners; RSC: Research and Surveillance Centre.



The RCGP RSC successfully conducted a pilot collecting serological samples from adults and linking them to a patient's medical records during the 2018-2019 influenza season [6]. This pilot was in collaboration with the PHE Seroepidemiology Unit and added to the residual blood samples submitted to PHE by National Health Service (NHS) laboratories [6,7]. Serology can provide important information about background population immunity [6], and sentinel networks can provide a mechanism for systematic data collection and linkage to medical records and health outcomes [8]. The serology pilot has demonstrated the ability of the network to collect serology samples in adults [9].

With the COVID-19 outbreak, PHE and RCGP RSC have adapted existing influenza surveillance to monitor the spread of COVID-19 in the community, and this protocol sets out the basis for that collaboration. The primary national strategy for COVID-19 infection is containment, with patients who are at high risk managed via the telephone help system NHS111 and the PHE health protection teams, but the RCGP RSC surveillance is entirely separate. The RCGP RSC, by extending its established work, will provide virological and serological surveillance to monitor the temporal and geographical distribution of COVID-19 infection in the community, and assess the effectiveness of the containment strategy.

We would not be working in isolation on this research. We will share the protocol with UK colleagues and the I-MOVE consortium who have recently obtained EU Horizon 2020 funding from the stream "Advancing knowledge for the clinical and public health response to the novel coronavirus epidemic" [10]. It is anticipated that great efficiencies in project management will result through this collaboration than that obtained from countries acting alone.

Aim

The aim of this study is to identify whether there is undetected community transmission of COVID-19, estimate population susceptibility, and monitor the temporal and geographical distribution of COVID-19 infection in the community.

Objectives

The objectives of this study are as follows:

1. To monitor the burden of suspected COVID-19 activity in the community through primary care surveillance and clinical coding of possible COVID-19 cases referred into the containment pathway
2. To provide virological evidence on the presence and extent of undetected community transmission of COVID-19 and monitor positivity rates among individuals presenting ILI or acute respiratory tract infections to primary care
3. To estimate baseline susceptibility to COVID-19 in the community and estimate both symptomatic and asymptomatic exposure rates in the population through seroprevalence monitoring
4. To pilot implementation of a scheme for collection of convalescent sera with antibody profiles among recovered cases of COVID-19 discharged to the community

We intend to capture the following.

- Clinical workload related to reports of COVID-19 using the codes created to flag cases, those being assessed and where the infection is located are excluded (Figures 2-4)
- Foreign countries visited in the last 28 days
- Existing codes that may have utility (Tables 1-3). Many GPs and primary care teams may not realize that important relevant data can be coded. There is also the potential during any pandemic to monitor the effectiveness of any transmission control measures.
- Reliable coding of letters and test results that will show an infection has become either confirmed or excluded

Figure 2. Screenshot of the COVID-19 codes activated in EMIS web. "COVID-19" search terms finds the codes. Ada Ant is NOT a real patient.

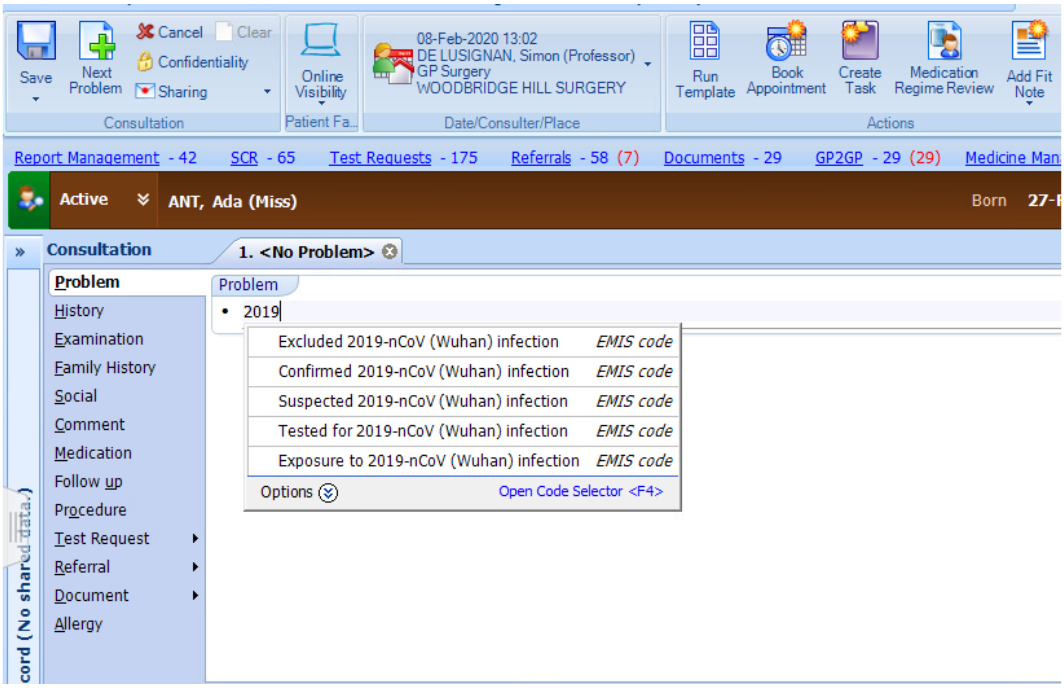


Figure 3. Screenshot showing coding of public health measures in EMIS web.

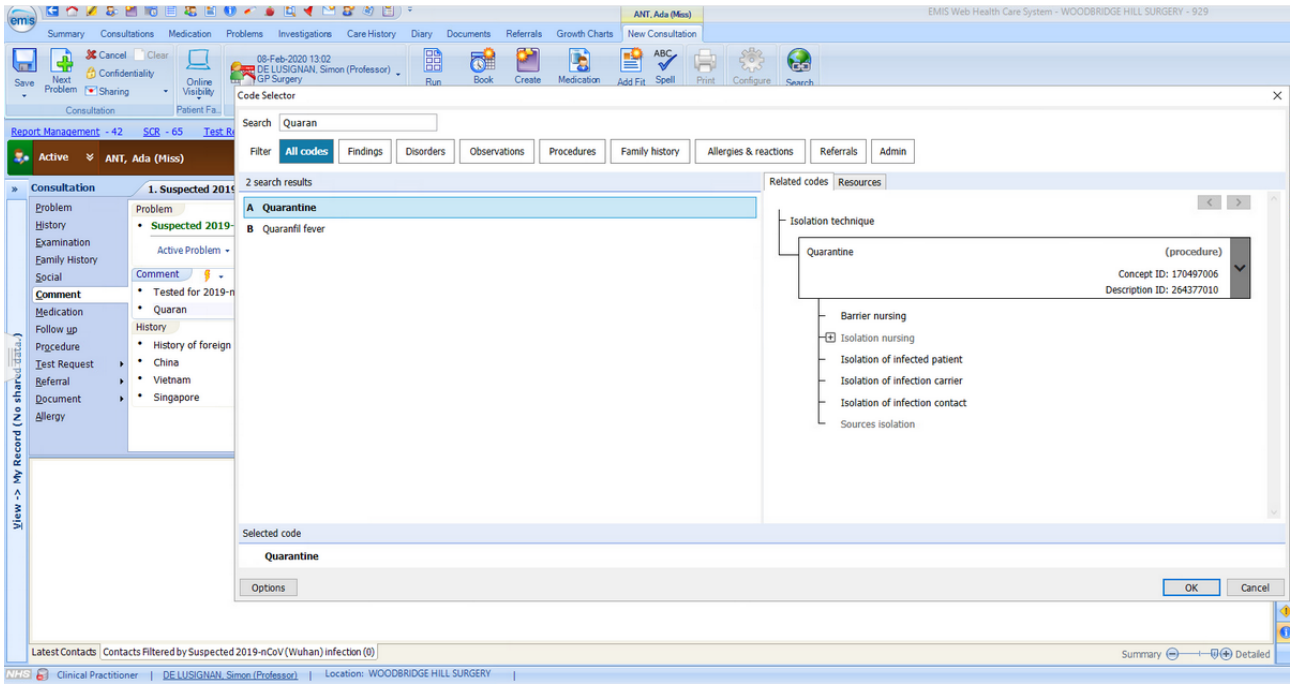


Figure 4. Screenshot of codes available in TPP SystemOne. SNOMED: Systematized Nomenclature of Human Medicine; 2019-nCoV: novel coronavirus.

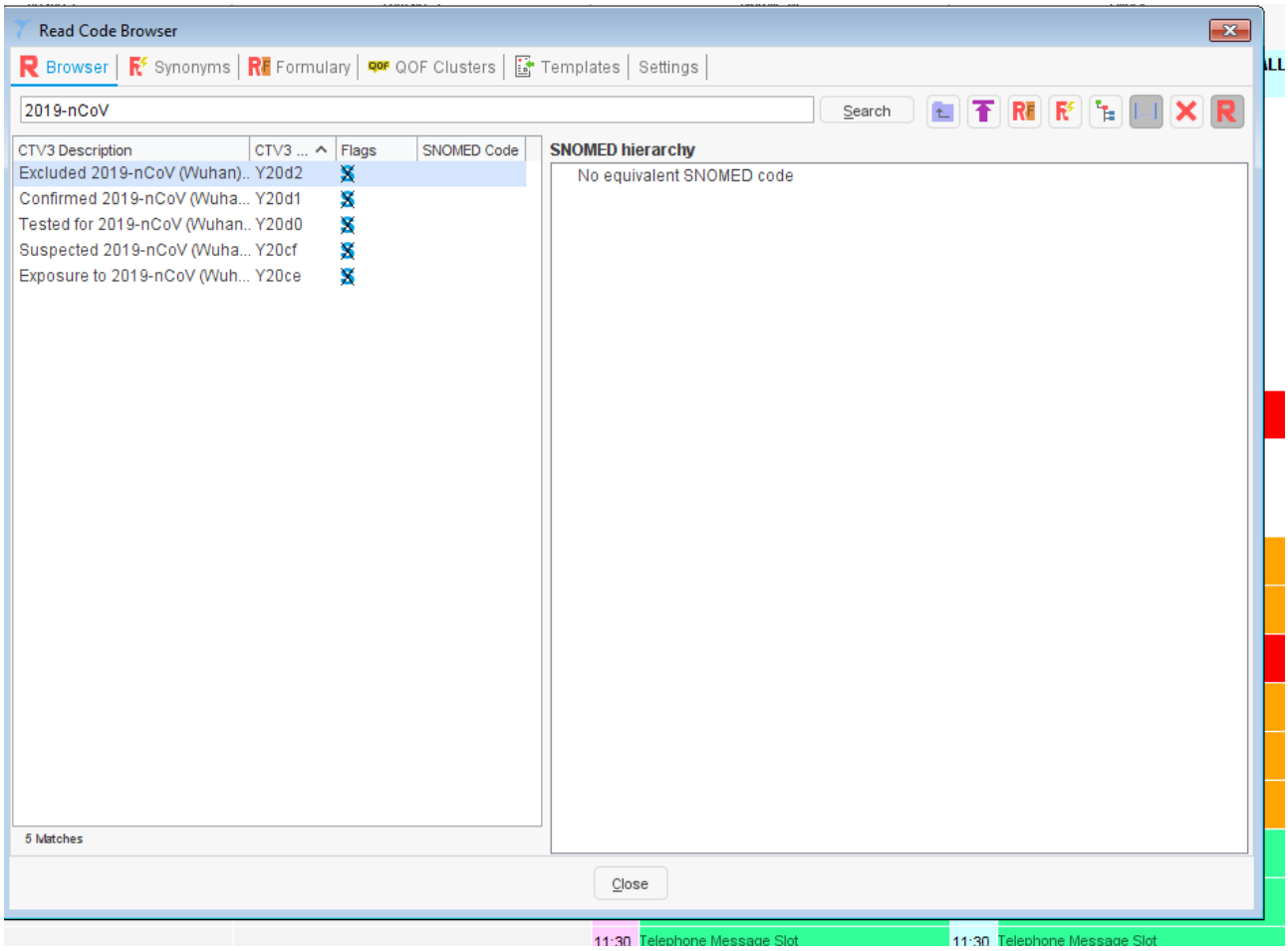


Table 1. Codes in the Systematized Nomenclature of Human Medicine to flag control measures and audit their effectiveness.

SNOMED[a] concept ID	Description ID	Preferred term
170497006	264377010	Quarantine
170499009	264381010	Isolation of infection contact
170500000	264384019	Isolation of infection carrier
170503003	264387014	Surveillance of contact
225368008	338663017	Contact tracing
305559001	448017014	Under care of contact tracing nurse
305736005	448259018	Seen by contact tracing nurse
306030003	448793018	Referral by contact tracing nurse
306323004	449303018	Referral to contact tracing nurse
306497009	449538017	Discharge by contact tracing nurse
361235007	477879011	Isolation of infected patient
370835007	1209564019	Monitoring for signs and symptoms of infection
444908001	2871575019	Isolation nursing in negative pressure isolation environment
506931000000109	1126681000000110	Recent travel to disease affected area
710874007	3046686011	Education about cross infection prevention
737612005	3528595017	Education about isolation for infection control
742879000	3550369015	Management of isolation for infection control
9478004	16593015	Prospective focused infection control surveillance

[a]SNOMED: Systematized Nomenclature of Human Medicine.

Table 2. Read 2 codes to flag control measures and audit their effectiveness.

Read 2 code	Term
ZV07.00	[V] Need for isolation and other prophylactic measures
65R2.00	Isolation of infection contact
65R3.00	Isolation of infection carrier
65S1.00	Surveillance of contact
65X..00	Contact tracing
8HlA.00	Referral to contact tracing nurse
65R1.00	Isolation of infected patient
13XG.00	Recent travel to disease affected area

Table 3. Clinical Terms Version 3 codes to flag control measures and audit their effectiveness.

Clinical Terms Version 3 codes	Preferred terms
ZV07.	[V] Need for isolation and other prophylactic measures
65R2.	Isolation of infection contact
65R3.	Isolation of infection carrier
65S1.	Surveillance of contact
Ua1RW	Contact tracing
XaAQX	Under care of contact tracing nurse
XaATu	Seen by contact tracing nurse
XaAb1	Referral by contact tracing nurse
XaAgt	Referral to contact tracing nurse
XaAk2	Discharge by contact tracing nurse
65R1.	Isolation of infected patient
XaQVi	Recent travel to disease affected area

Methods

Overview

The methods will follow the approach used in the current influenza surveillance system [5] and recent serology study [6], and includes five components: (1) primary care clinical surveillance; (2) virological surveillance; (3) population serological surveillance; (4) convalescent sera in cases; and (5) data curation.

Primary Care Clinical Surveillance

Clinical Coding

The NHS uses the Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) system of coding, which is normally only updated twice annually. There was added complexity as some computerized medical record (CMR) suppliers use the Read coding systems (Read clinical terms version 3 – CTv3), which is no longer updated. Additionally, there were no clinical codes to record COVID-19 in early February 2020. Therefore, the two main GP system suppliers added the five terms shown in Table 4 as system-wide local codes. A UK emergency release of SNOMED CT concepts for COVID-19 was also subsequently made available across all CMR systems (Table 4). The intention is that these will eventually be mapped to the new SNOMED CT concepts as they become available, allowing recording of relevant data (Multimedia Appendix 1).

The key requirements for this release were the ability to code (Table 4) a case of COVID-19, exposure to risk of infection (travel to an area where there may be a higher risk), contact with anyone infected with COVID-19, a report that a person had been tested for COVID-19, and that the disease had been excluded (likely a negative test).

In addition, practices are now able to code any foreign travel undertaken, including the ability to record visits to multiple countries (implemented February 8, 2020). Figures 2-4 show the EMIS web implementation.

Currently, virology samples for influenza surveillance are accompanied by a standard request form.

For COVID-19, we will create a new request form that will record:

- Date of onset of symptoms
- Diagnosis of any of the following:
  - Acute bronchitis/bronchiolitis in those younger than five years
  - ILI
  - Lower respiratory tract infection (LRTI)
- Cough (Y/N)
- History of fever (Y/N); measured (Y/N); if yes, level
- Shortness of breath (Y/N), if measured: oxygen saturation and respiratory rate
- Recent travel (Y/N); if yes, countries visited in last 14 days
- Contact with a named person with confirmed COVID-19 (Y/N) with a free text comment about the level of certainty

These codes will be grouped ontologically into “definite”, “probable”, “possible”, and “not a case” using our standard approach [11] to grouping codes (Table 5), which has been used previously across disease areas [12-14]. The RCGP RSC definition for ILI is shown in Multimedia Appendix 2.

Table 4. Local EMIS Health namespace descriptions and TPP system-wide codes for COVID-19.

EMIS Health code description	TPP system-wide code
Excluded 2019-nCoV[a] (Wuhan) infection	Y20d2
Confirmed 2019-nCoV (Wuhan) infection	Y20d1
Tested for 2019-nCoV (Wuhan) infection	Y20d0
Suspected 2019-nCoV (Wuhan) infection	Y20cf
Exposure to 2019-nCoV (Wuhan) infection	Y20ce

[a]2019-nCov: novel coronavirus.

Table 5. Ontological approach to mapping COVID-19 codes.

Category	Code (and its certainty of mapping)	Notes
Confirmed case	• Confirmed 2019-nCoV[a] (Wuhan) infection • (Direct mapping codes)	Careful training will be required to ensure validity and reliability. TBC[b] whether we will require reference lab report
Probable case	N/A[c]	It is possible we will use this category if we do not see data quality problems with definite cases. The WHO[d] definition is a positive pan-coronavirus assay but without sequencing and absence of other respiratory infections.
Possible case	• Exposure to 2019-nCoV (Wuhan) infection • Suspected 2019-nCoV (Wuhan) infection • Tested for 2019-nCoV (Wuhan) infection • (Partially mapping codes)	While awaiting confirmation, we will need to set a time limit (proposed 6 weeks), after which possible cases are reclassified to not a case
Not a case	• Excluded 2019-nCoV (Wuhan) infection • (Relevant codes with no clear mapping to 2019-nCoV)	As tested patients have negative cases and contacts do not develop symptoms. they will be placed in this category.

[a]2019-nCoV: novel coronavirus.

[b]TBC: to be confirmed.

[c]Not applicable.

[d]WHO: World Health Organization..

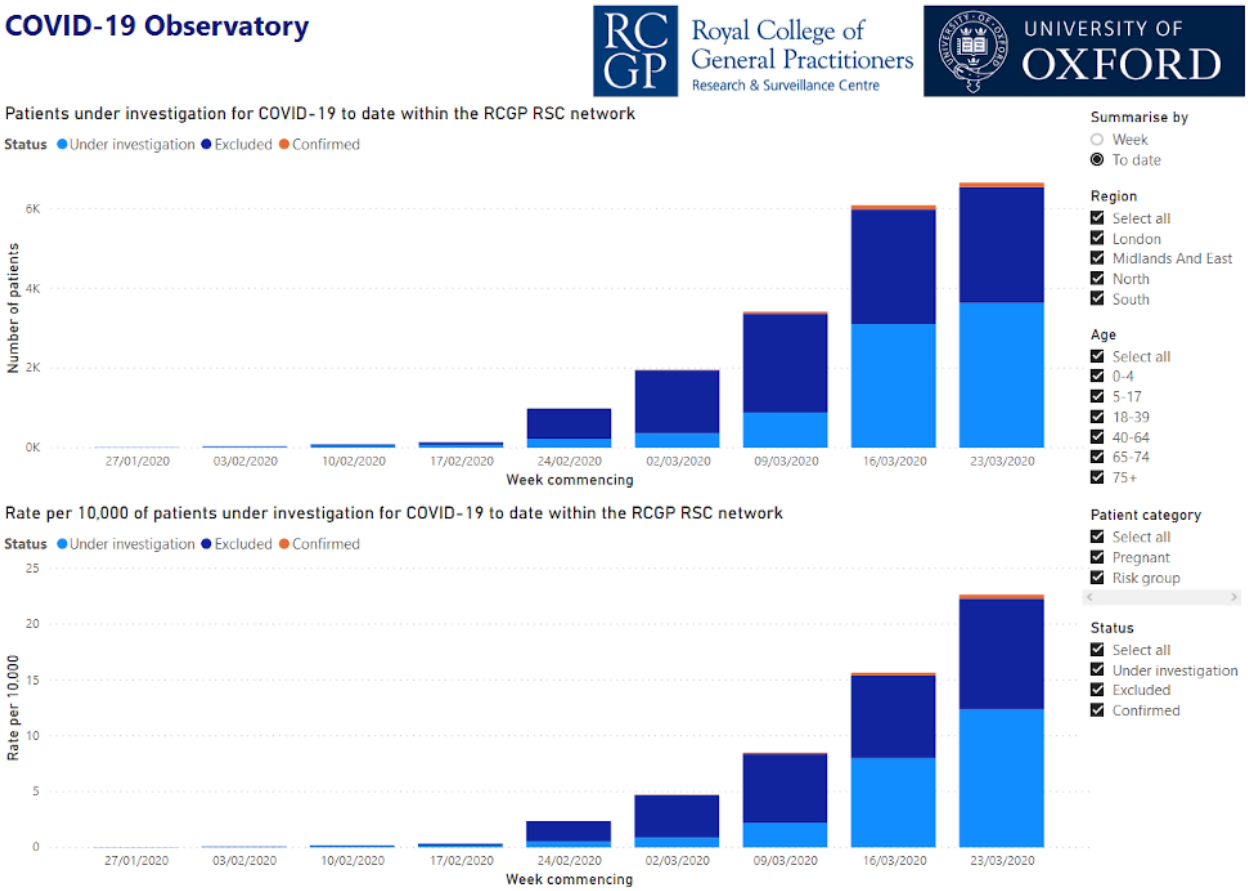
Public Presentation of Data Using an Observatory and Dashboards

We will develop an observatory to present data nationally and a dashboard for feedback to practices about their data quality and collection of virology and serology samples. This is based on coding described in Table 4.

- Definite case will be presented on our dashboard as “cases” of COVID-19.
- Possible cases will be presented as “Under investigation” (investigating).
- “Not a case” will be presented as “Excluded”.

Online data has been established within the initial few weeks in the COVID-19 Observatory (Figure 5), indicating the overall number of patients and rate per 10,000 patients of cases confirmed or under investigation, as well as where the virus is excluded [15].

Figure 5. Screenshot of COVID-19 Observatory showing number and rate per 10,000 patients investigated for COVID-19 to date within the RCGP RSC network.



Increasing Report Frequency

We have the option to move to twice weekly surveillance reports with a scope to change this to daily reporting.

Virological Surveillance

We will continue virology sampling from our sentinel practices, rather than discontinuing as seasonal influenza declines. Additionally, we will recruit more surveillance practices.

The RCGP RSC virology practices will aim to undertake 200-300 nasopharyngeal swabs per week across the RCGP RSC sentinel network, collecting specimens across all age bands. In addition to the inclusion criteria for influenza virology surveillance (ILI, acute bronchitis/bronchiolitis), participating practices will take nasopharyngeal swab samples from any people showing acute symptoms of LRTI if the onset of symptoms is within 7 days.

Sampling will include:

- Taking 4-10 samples per week per practice. RCGP RSC research officers and practice liaison staff will manage practices to achieve a total national sample of 200-300 swabs per week. This could be increased if PHE modelers require more samples.
- Samples from each practice would be spread across the following age groups: <5 years, 5-17 years, 18-64 years, and 65 years and older

Samples (swabs or serum) collected will be sent via prepaid envelopes addressed to the appropriate PHE laboratory for analysis. All samples collected will be tested for the presence of influenza and COVID-19. Additionally, PHE will retrospectively test any influenza virology samples collected between early and mid-February 2020 for COVID-19.

Practices will still follow the PHE protocol [16] for COVID-19 with respect to people at risk of infection who should be signposted down the containment pathway, rather than physically attend their practice. Direct testing of those who attend surgery remains permitted, but we have also rolled out self-swabbing at home [17]. Summary of processes are detailed in Multimedia Appendix 3.

Everyone with an ILI or a respiratory illness who contacts a GP (eg, phones for an appointment) should be asked specifically about recent travel to China and other countries flagged in current PHE advice, or if they have had contact with other people with COVID-19. If these screening enquiries are positive, the patient would be advised to not come to the practice but instead to follow the PHE flow sheet [16]. This can be by a reception or clinician staff, depending on individual practice protocol. These calls should be coded into the GP CMR system and can be reported as part of the RCGP RSC weekly return. We have developed training material to support this coding (Multimedia Appendix 4). These include prompt cards for:

- Practice reception or triage staff: for coding of any patients calling the practice with symptoms of acute respiratory

infection with a history of travel to important areas based on PHE advice
- Administrative staff or clinicians who code: to encourage consistent coding of results for any suspected cases, including coding of negative results for exclusion

Population Serological Surveillance

Practices participating in virology surveillance will opportunistically collect blood samples from patients coming into the practice for a routine blood test. Patients who attend their practice for a routine blood test will be asked to provide an additional sample for serology.

We have conducted initial searches within the RCGP RSC database to look at the number of full blood count (FBC) results and overall rates in adults and children (Figures 6-9). An FBC is one of the most common tests performed, and we hope this will give an approximate indication of overall numbers of blood tests performed. The sampling rate, per 100,000 patients was highest for children 15-17 years of age and 60 year or older in adults, with the lowest rates in children 0-4 years of age and 18-29 years of age in adults (Figures 6-9).

We will provide 1000 serology baseline samples across all ages that reflect the varying rates of attendance by age. Additionally, we will test if we can obtain these all from virology practices to enhance the yield. A good geographical spread is important, so PHE can advise on areas where serology will most usefully be collected.

This will be followed by 800 samples monthly.

- The sample will be stratified with 200 specimens for prepandemic survey (100 for monthly) in the following age groups: <5 years, 5-17 years, 18-64 years, and 65 years or older.
- The younger patients, in many practices younger than 14 years, and in nearly all for children younger than 8 years will require pediatric serology surveillance.

We will develop a new request form for practices to capture recent travel and exposure to COVID-19.

Figure 6. Number of full blood count results in RCGP RSC 2019-2020 virology practices for different child and young adult age groups. Practice unique identifiers have been removed. FBC: full blood count.

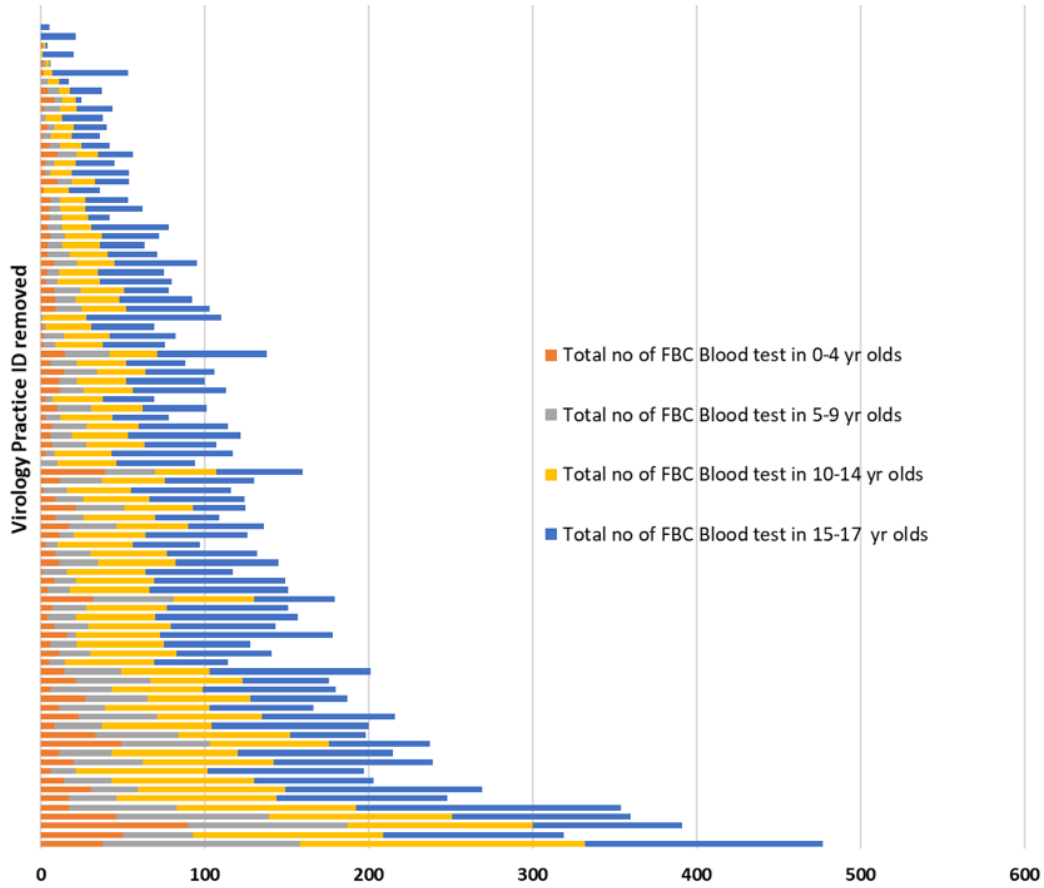


Figure 7. Number of blood tests in Adults.

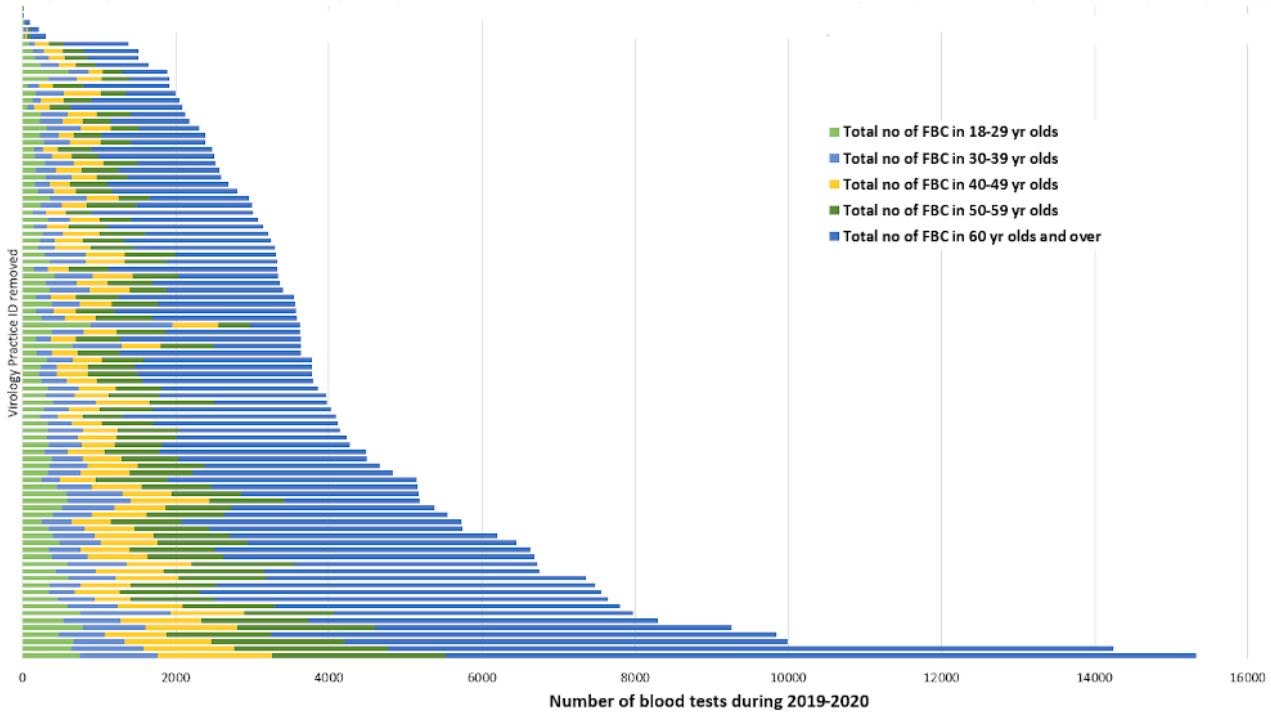


Figure 8. Variation of blood sampling in children and young adults according to age. Data on rate of full blood count sampling per 100,000 registered patients for each children and young adult age groups, per year, by individual virology practice. Practice unique identifiers have been removed.

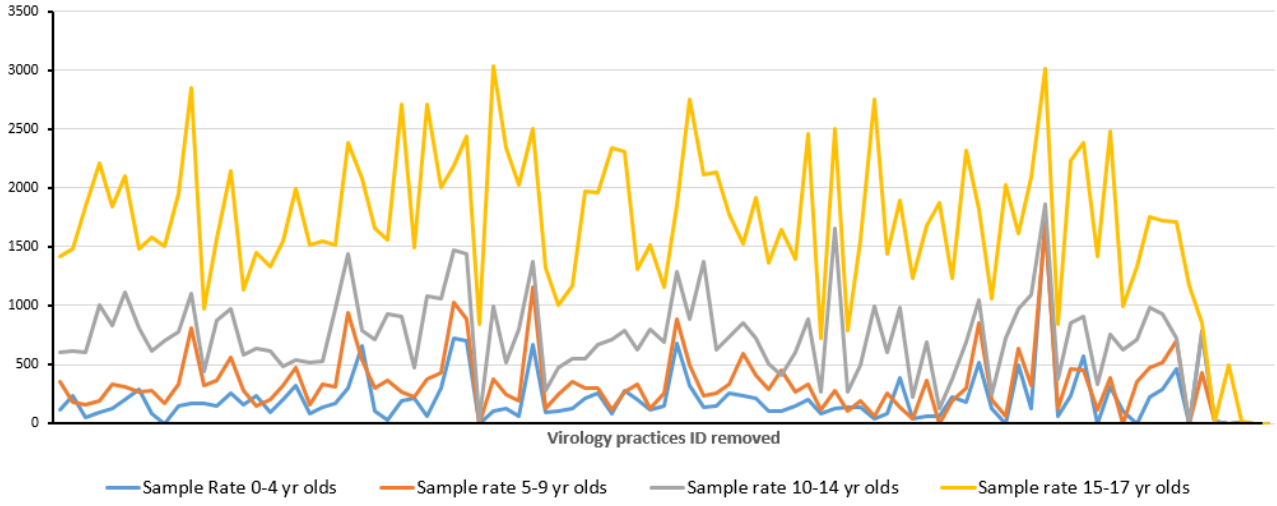
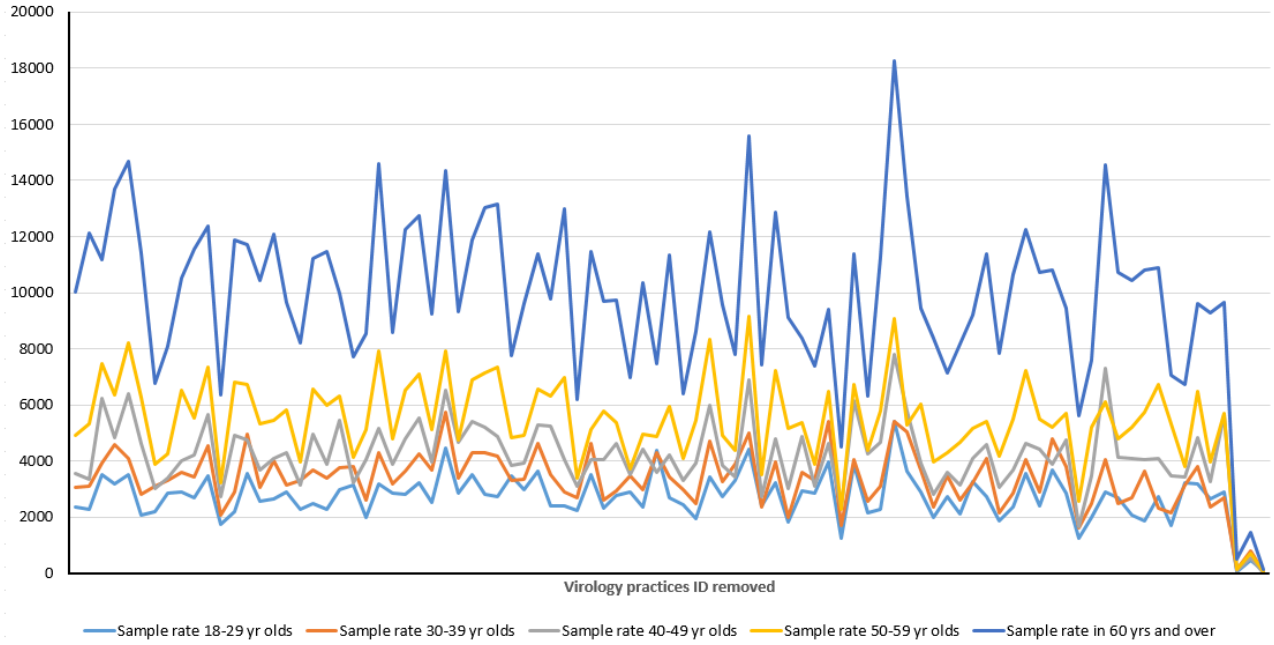


Figure 9. Variation of blood sampling in adults according to age. Rate of full blood count sampling per 100,000 registered patients for each adult age group, per year, by individual virology practice. Practice unique identifiers have been removed.



Convalescent Sera in Cases

We will pilot a scheme for collecting convalescent serology from people with confirmed cases and who have had an acute virology sample at the time of their infection. This is to identify a carrier state in patients who have recovered from the virus but may continue shedding the virus.

If there are a small number of cases, this may assist in developing a test kit for patients to take to their own GP and explore its acceptability to patients.

If there are a large number of COVID-19 cases nationally, convalescent samples could be collected from RCGP RSC practices where there are confirmed cases, with the ability to link to the full medical record. This process may include checking pseudonymized NHS numbers for positive individuals at RCGP RSC practices, checking current PHE guidance regarding considerations of infectiousness for confirmed cases, and offering the patient an appointment following the previously mentioned process.

This needs to be carefully coordinated nationally across the network and may require PHE to ensure individuals are not contacted by multiple agencies. RCGP RSC could provide a useful structure to channel the initial contact once PHE has made a request. The RCGP RSC practices participating in the annual influenza virology surveillance have started sampling from patients showing symptoms of a LRTI. All samples received are being tested for influenza and COVID-19.

The RCGP RSC will explore ways to collect convalescent samples from any patients tested positive for COVID-19 through the extension of the virological surveillance.

Data Curation

From the start, we will be carefully curating data to ensure that it can be used for future studies. Our clinical data will be linked to virology. We will curate our data using the Findable, Accessible, Interoperable, Reusable principles. To facilitate this our data set is listed with Health Data Research UK [18] and the European Health Data Evidence Network [19].

Statistical Methodology

The statistical methodology is in support of a policy approach to widespread disease outbreak, where so-called nonpharmaceutical interventions (NPIs) are used to respond to an emerging pandemic to produce disease suppression. This policy aims to reduce contact rates in the population and thereby reduce transmission of the virus. To implement this the UK government has recently articulated the desire to implement population self-isolation measures. By targeting the reproduction number (R) (the average number of secondary cases each case generates) and aiming to reduce the R to below 1, the policy seeks to reduce case numbers to low levels or (as seen in previous outbreaks with severe acute respiratory syndrome and Ebola) to eliminate human-to-human transmission.

As the experience from the 2009 H1N1 pandemic has shown, NPIs can be a crucial component of pandemic mitigation [20]. Key to the focus of our study will be the estimation of peak cases in the population and continual monitoring by data collection and modelling the potential growth and emergence of subsequent peaks in new cases as social distancing measures are relaxed.

There has already been publication of important disease epidemiological measures concerning the outbreak of COVID-19 in mainland China [21]. A further fundamental measure in pandemic dynamics is the length of time from infection to when a person is infectious to others and the mean duration of infectiousness. These factors, if estimated accurately, will give good predictions for the likely length of the pandemic, the final number of infected cases.

We intend to apply approximate Bayesian inference (ABC) to (possibly spatially heterogeneous) Susceptible-Exposed-

Infectious-Removed (SEIR) stochastic epidemic models [22]. Such techniques are highly parallelizable and have been successfully applied to many fields including disease transmission modelling. They are particularly suited to situations where likelihood functions are absent and where more traditional approaches such as Markov chain Monte Carlo are impractical. Such an approach has been demonstrated to work effectively on the ASPREN surveillance data, a network of sentinel GPs and nurse practitioners who report deidentified information on ILIs and other conditions [23], where issues such as missing data and the need to model the observation process itself has been successfully addressed [24]. Furthermore, peaks in new cases have been estimated by distributional methods.

Estimates of the parameters of the SEIR model are tractable on large data sets because of parallelizability, and these methods have been implemented in several R libraries; we intend to use the libraries ABSEIR (deposited on GitHub: https://tinyurl.com/vqu35cj) and abctools (https://tinyurl.com/tfjavz4) to estimate epidemic measures on a weekly basis.

Since we are fitting an SIR-epidemic model in the ABC routine, we anticipate that our results will be robust against weekly case data containing relatively small counts. For example, see [25] for the ABC methodology applied to the Tristan da Cunha common cold data from 1967, where counts of *I* (number of infectious cases) and *R* (number of recovered cases) are in the tens at most.

Finally, in addition to the above methodology we will employ the Kaplan-Meier method with two outcomes (death and recovery) to estimate the case fatality ratio [26]. This approach is independent of the ABC methodology [27] and will allow comparisons between estimates from the two modelling approaches to judge robustness of results.

Ethical Considerations

RCGP RSC's surveillance with PHE is defined as *Health Protection* under Regulation 3 of The Health Service (Control of Patient Information) Regulations 2002. This has been confirmed by PHE's Caldicott Guardian's Office.

We do not see any increased risk to practices or practitioners taking part in this surveillance. Infection prevention and control advice will follow extant national guidance. Any cases identified will be managed according to the PHE/NHS guidance in force at the time, including advice for identified contacts.

However, our training will include reminders about safe handling of specimens and revision of infection control measures anticipated to be high in our practices. It is a key part of Regulation 12 about safe care and treatment, periodically inspected by the Care Quality Commission [28].

Results

Travel History and Clinical Descriptors of the COVID-19 Infections

The RCGP RSC practices have been advised on the clinical coding that has been made available for COVID-19 across all CMR systems. This includes information on coding of clinical descriptors (Table 4) and any recent travel history.

Establishment of Extended Virology Sampling

The RCGP RSC practices participating in the annual influenza virology surveillance have started sampling from patients showing symptoms of LRTI. All samples received are being tested for influenza and COVID-19. This has led to initial early identification of background spread in low-risk patients.

As of March 7, 2020, the surveillance system has detected 2 cases of COVID-19 in low-risk patients with no history of travel through extended virological sampling.

Discussion

Overview

This protocol describes how we have adapted a national influenza surveillance system to monitor community spread of an unexpected infection of COVID-19. We have rapidly created and incorporated new codes to allow data recording, and are collecting data to monitor the effectiveness of containment strategies.

Through this surveillance, we intend to find out more about the epidemiology of COVID-19 in ambulatory care. In particular, its rate of spread, both temporal and geographical. Our testing of low-risk patients will also inform whether the containment strategy that is based on virology testing of high-risk patients and their contacts plus self-isolation is effective. Containment should slow the spread, and there may be benefits in the management of spread from intense surveillance [28]. However, there may come a point at which the virus spreads more widely into the population, as has happened in Italy [29]. Surveillance of low-risk patients should inform when we reach this tipping point and when infection rates start to remit.

The epidemiology of COVID-19 remains emergent [30]. The registration-based nature of UK primary care means that we will be able to create a complete picture of the cumulative incidence and duration.

The surveillance system should be able to identify areas where COVID-19 spread is taking place that might be suitable for trials of antiviral therapy. We could also follow up on the effectiveness or any adverse reactions to these medicines or vaccinations.

Finally, early detection of a confirmed COVID-19 case has exemplified the rapid implementation of this enhanced surveillance in the national network.

Comparison with Prior Work

Safety of practices is our primary concern. The RCGP RSC has operated for over 50 years and has been involved in collecting samples to monitor disease and vaccine effectiveness through the Hong Kong flu pandemic of 1968/69, the Russian flu of 1977/78, and the 2009 Swine flu pandemic [31,32]. We are not aware of any increased risk to practice staff or other patients from involvement in surveillance. Pandemic preparedness is part of the role of the RCGP RSC.

It is plausible that enhanced coding of information from contacts with the practices in RCGP RSC will reduce the likelihood of people who may be suspected COVID-19 cases being brought to the surgery inadvertently. Where cases are detected unexpectedly, it is probably helpful for that patient, their contacts, and the practice to know. The impact on practices has been to close for a day, if a case is found, for deep cleaning and then reopen.

Limitations

The principal limitations of our system are the number of data points. We are collecting serology and virology data from 100 sites, which covers a small group of the population. This has been satisfactory for monitoring influenza, but we are not certain if this is a sufficiently large sample for the COVID-19 outbreak. Our sites (surveillance practices) are currently fixed, and it could be helpful to be able to rapidly onboard practices in regions where there are more cases. Currently, we will be reporting weekly. Our existing system can be enhanced to twice weekly, but maybe daily or hourly data should be our current approach.

Opportunistic sampling for serology in children younger than 10 years might be limited due to the overall reduced rate of blood tests in children.

Conclusions

The extended surveillance using the RCGP RSC-PHE network for the emergent COVID-19 outbreak has been established rapidly. The model of getting the appropriate informatics to enable capture of the required data has already been a success, with data recording starting the week the codes were created. In addition, modifying the existing surveillance system to collect population data in a parallel way has also been effective. However, we are at present unsure as to whether the scale of this surveillance provides sufficient data to drive local containment strategies or if reporting infrequently meets the need of our information age.

Acknowledgments

We would like to thank the patients and practices who are members of the RCGP RSC network and colleagues at the PHE laboratories and the University of Oxford. We would also like to give special thanks to Praveen Sebastian Pillai and his team at the PHE Colindale for all their support.

Conflicts of Interest

SdL has had unrelated projects in influenza and gastroenteritis funded by GSK, Takeda, and Seqirus, and has been a member of Global Advisory Boards for Seqirus and Sanofi.
The RCGP RSC surveillance work is funded by PHE.

Multimedia Appendix 1
New relevant SNOMED CT codes.
[DOCX File , 14 KB - publichealth_v6i2e18606_app1.docx]

Multimedia Appendix 2
The RCGP RSC definition of influenza-like illness.
[DOCX File , 14 KB - publichealth_v6i2e18606_app2.docx]

Multimedia Appendix 3
Main programme.
[DOCX File , 15 KB - publichealth_v6i2e18606_app3.docx]

Multimedia Appendix 4
Training materials for practices.
[DOCX File , 633 KB - publichealth_v6i2e18606_app4.docx]

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Abbreviations

CMR: computerized medical record
FBC: full blood count
GP: general practice
ILI: influenza-like illness
LRTI: lower respiratory tract infection
NHS: National Health Service
NPI: nonpharmaceutical intervention
PHE: Public Health England
R: reproduction number
RCGP: Royal College of General Practitioners
RSC: Research and Surveillance Centre
SEIR: Susceptible-Exposed-Infectious-Removed
SNOMED CT: Systematized Nomenclature of Medicine Clinical Terms

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Original Paper

Preventive Behaviors Conveyed on YouTube to Mitigate Transmission of COVID-19: Cross-Sectional Study

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Abstract

Background: Accurate information and guidance about personal behaviors that can reduce exposure to severe acute respiratory syndrome coronavirus 2 are among the most important elements in mitigating the spread of coronavirus disease 2019 (COVID-19). With over 2 billion users, YouTube is a media channel that millions turn to when seeking information.

Objective: At the time of this study, there were no published studies investigating the content of YouTube videos related to COVID-19. This study aims to address this gap in the current knowledge.

Methods: The 100 most widely viewed YouTube videos uploaded throughout the month of January 2020 were reviewed and the content covered was described. Collectively, these videos were viewed over 125 million times.

Results: Fewer than one-third of the videos covered any of the seven key prevention behaviors listed on the US Centers for Disease Control and Prevention website.

Conclusions: These results represent an important missed opportunity for disease prevention.

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KEYWORDS

YouTube; COVID-19; social media; pandemic; outbreak; infectious disease; public health; prevention

Introduction

In December 2019, several cases of pneumonia of an unknown etiology were reported in Wuhan, China [1]. On January 20, 2020, the Centers for Disease Control and Prevention (CDC) as well as state and local health departments began monitoring the burgeoning situation [2]. By the end of January, the World Health Organization (WHO) had declared the outbreak to be of serious concern [3]. The disease, now known as coronavirus disease 2019 (COVID-19) and caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was officially named by WHO on February 11, 2020 [4]. By March 7, 2020, the global number of reported cases had surpassed 100,000 [5].

As a novel global health threat, the scientific community has only begun to investigate the distinguishing features of COVID-19. Epidemiological and biomedical research thus far suggests the following. The incubation period ranges from 1-14 days [6]. COVID-19 is largely spread by contact with respiratory droplets from an infected individual. Symptoms most commonly include fever, fatigue, and a dry cough [6]. The Chinese Center

for Disease Control and Prevention reports from mid-February indicated a case fatality rate of 2.3% and that 81% of cases were mild in nature [7]. It is understood that the case fatality rate will shift as more cases are identified. However, it also became clear that COVID-19 is substantially deadlier than seasonal influenza [8]. The risk of severe illness and death appears to be concentrated among older populations and those with underlying medical conditions [9].

It is unclear how long SARS-CoV-2 survives on surfaces, but estimates suggest anywhere from a few hours to several days [10]. Community spread has been reported worldwide [3], and on March 11, 2020, the WHO declared COVID-19 a pandemic [11]. Testing in the United States was delayed in late February and March, hampering case identification efforts [12]. Testing may have been hindered initially by not only a lack of tests but also out-of-pocket costs for those uninsured or underinsured [13]; on March 5, 2020, America's Health Plans indicated they would waive copays for COVID-19 testing. Containment is complicated by the fact that substantial numbers of Americans lack paid sick leave [14], and, as of March 13, 2020, public schools in densely populated urban areas such as New York continued to remain open. Projections of widespread transmission indicate that health care systems may rapidly become overwhelmed [3]. There are no specific treatments for the virus at present [9]. Concerns over COVID-19 have had a swift impact on global financial markets with potential long-term repercussions on a number of sectors [15]. As with SARS-CoV, a number of news outlets have reported a swift uptick in anti-Asian racism [16-18]. In some areas, public fears about COVID-19 have led to panic buying of supplies including personal protective equipment, reducing the availability of necessary supplies for health care workers [10].

One of the most important aspects of an effective campaign to minimize COVID-19 transmission is accurate information that is conveyed in a way that is understood by the public. Google Trends demonstrates a substantial spike in interest in COVID-19 since early February 2020 [19], and the WHO has characterized the exponential increase in information (and misinformation) about COVID-19 as an "infodemic" [20]. The CDC and WHO have steadily been posting content discoverable on the internet. Moreover, the WHO has been working with social media outlets to ensure users searching for information on COVID-19 are guided to reliable sources [21]. Despite these efforts, in novel and rapidly evolving situations, there is a high potential for misinformation and disinformation to spread through online sources [22,23]. As the second most popular social media platform after Google [24] and with over 2 billion users [25], YouTube is a media channel that millions turn to when seeking information on COVID-19. Even videos that cover COVID-19 in a particular national context likely have a global reach. Although previous investigations have examined the content of YouTube videos on infectious diseases such as Ebola [26,27], H1N1 influenza [28,29], West Nile virus [30], and Zika virus [31], we did not identify any published studies that have investigated the content of YouTube videos related to COVID-19. This study, therefore, aimed to address this gap in current knowledge.

Methods

The sample of videos was delimited to the 100 most widely viewed YouTube videos uploaded throughout the month of January 2020. The keyword "Coronavirus" was used as the search term, which was the most widely used terminology to describe COVID-19 at that time. The videos were sorted by view count to identify the 100 most widely viewed videos (in both English, including subtitles, and Spanish). There were 7 videos excluded and replaced: 5 for irrelevance (not about the virus) and 2 because they were in a language other than English or Spanish.

Coding categories (Table 1) were created using a CDC fact sheet on COVID-19 [3,9] and prior YouTube studies on Ebola and Zika [26,31]. Content was classified into 5 categories: prevention behaviors, mortality and fear, symptoms, transmission and natural history, or other precautions. The characteristics of videos that were coded included number of views, length in minutes, language, presentation style, and source and date of upload. Three sources of upload comprised mutually exclusive and exhaustive categories: consumer, professional (MD or RN), and television- or internet-based news. Author CJ coded content across all videos, and a second author (CHB) coded a randomly selected subset of 10 videos to ascertain inter-rater reliability, which was assessed using Cohen kappa and found to be excellent (k=0.971).

Descriptive statistics were calculated, including frequencies and percentages and, where appropriate, means and standard deviations. Differences between content covered in videos uploaded from different sources was assessed by chi-square tests using a two-sided P value <.05. All analyses were performed using SPSS version 26 (IBM Corp).

Table 1. Description of content covered in 100 widely viewed YouTube videos about coronavirus disease 2019, January 2020.

Categories	Total (N=100), n (%)	Number of views (n=125,286,561), n (%)	Consumer (n=11), n (%)	Professional (n=4), n (%)	News (n=85), n (%)	*P* value
Prevention behaviors						
Hand hygiene	26 (26)	33,268,243 (26.55)	4 (36)	2 (50)	20 (24)	.39
Avoid close contact with those who are sick	31 (31)	41,269,546 (32.94)	5 (45)	3 (75)	23 (27)	.09
Stay home when ill	29 (29)	42,647,990 (34.04)	5 (45)	2 (50)	22 (26)	.28
Cover cough/sneeze with tissue; throw tissue away	14 (14)	19,625,830 (15.66)	3 (27)	1 (25)	10 (12)	.36
Use facemask for protection if you are caring for the ill	0 (0)	0 (0.00)	0 (0)	0 (0)	0 (0)	N/A[a]
Use facemask for protecting others if you are ill	2 (2)	1,152,765 (0.92)	1 (9)	0 (0)	1 (1)	.36
Clean and disinfect highly touched objects and surfaces	16 (16)	17,545,061 (14.00)	4 (36)	2 (50)	10 (12)	.04
Mortality or fear						
Mentions death	84 (84)	101,216,230 (80.79)	9 (82)	4 (100)	71 (84)	.49
Suggests anxiety or fear	79 (79)	101,017,274 (80.63)	10 (91)	3 (75)	66 (78)	.53
Symptoms						
Coughing	37 (37)	48,785,552 (38.94)	5 (45)	1 (25)	31 (36)	.74
Shortness of breath	26 (26)	36,446,095 (29.09)	4 (36)	1 (25)	21 (25)	.72
Fever	43 (43)	59,530,161 (47.52)	7 (64)	3 (75)	33 (39)	.12
Transmission and natural history						
Modes of transmission	42 (42)	63,474,010 (50.66)	5 (45)	4 (100)	33 (39)	.025
Incubation period	47 (47)	55,706,189 (44.46)	7 (64)	3 (75)	37 (44)	.23
Treatment	21 (21)	33,676,717 (26.88)	2 (18)	1 (25)	18 (21)	.96
Other precautions						
Quarantine	89 (89)	109,741,111 (87.59)	11 (100)	4 (100)	74 (87)	.15
Remain indoors	39 (39)	59,527,347 (47.51)	6 (55)	2 (50)	31 (36)	.47
Restrict travel	84 (84)	96,914,919 (77.35)	10 (91)	3 (75)	71 (84)	.71

[a]Not applicable.

Results

At the time of data collection (January 31, 2020), the videos in the sample were viewed more than 125 million times (by March 5, 2020, these videos garnered an additional 41 million views). The mean number of views per video was 1,252,865.6 (SD 954,752.0), and the mean length was 6.4 minutes (SD 6.4 minutes; range 15 seconds to 45 minutes). Of the 100 videos, the majority (n=85, 85.0%) were uploaded by news agencies (aired on television or the internet). Most were created in English (n=72, 72.0%) or with English subtitles (n=14, 14.0%), but 14.0% (n=14) were in Spanish. The large majority (n=87, 87.0%) featured a live presenter and 13.0% (n=13) featured animation.

Fewer than one-third of the videos covered any of the seven key prevention behaviors listed on the CDC website (Table 1). Just over a quarter of the videos covered hand hygiene and less than one-fifth mentioned covering a cough or sneeze with a tissue and then discarded. Although 45.0% (n=45) mentioned using a face mask, none recommended using a face mask when caring for someone who is sick, and only 2 mentioned using a face mask if you are sick to protect others. Cleaning and disinfecting frequently touched surfaces was mentioned in less than one-fifth of the videos.

The majority of videos mentioned death, or suggested anxiety or fear. Symptoms, transmission, and natural history were covered in fewer than half of the videos. Quarantine and travel restrictions were mentioned in the majority of videos. The content covered generally did not vary by source of upload.

Discussion

The videos in the study sample were viewed over 125 million times as of January 31, 2020 (and increased by over 30% to over 165 million views by March 5, 2020), indicating the considerable reach of YouTube as a way to communicate with

the public. Knowledge about the biology, pathophysiology, and epidemiology of COVID-19 is evolving rapidly. What we do know at this time is that personal behaviors are the best way to prevent disease transmission and COVID-19.

Accurate information and guidance about personal behavior is, therefore, one of the most important elements in mitigating the spread of COVID-19. Primary prevention of any disease relies on two components: reducing exposure and reducing susceptibility. Given that no vaccine is currently available to reduce susceptibility, the most effective way to prevent disease transmission and prevent illness is by preventing exposure. COVID-19 is a propagated epidemic (spreads from person-to-person) and is thought to be transmitted through both direct and indirect contact [32]. The CDC recommends behaviors to protect individuals by reducing exposure: proper hand hygiene (including avoiding touching one's nose, mouth, and eyes with unwashed hands) and avoiding close contact, not only with people who are sick, but also through social distancing (especially for those at higher risk, namely, older adults and those with chronic illnesses). The CDC further recommends behaviors to protect others: staying home when sick (except to receive medical care); covering one's sneeze or cough with a tissue (or inside of elbow), then discarding the tissue in trash, immediately followed by proper hand hygiene; wearing a mask if ill when around others or caring for someone who is sick; and cleaning and disenfecting frequently touched surfaces [33]. These recommendations may be difficult to understand, especially for the considerable proportion of the public with low levels of reading literacy. Video presentation is a potentially useful alternative for communicating key information to the public. We found that fewer than one-third of the most widely viewed YouTube videos covered any of these behavioral recommendations, which we believe represents an important missed opportunity for disease prevention.

In contrast, the majority of the 100 videos mentioned number of deaths or estimated mortality rates, or suggested fear and anxiety, and these videos were collectively viewed over 100 million times. Communications that increase fear and anxiety may prompt preventive actions, but may also lead to maladaptive, socially irresponsible behaviors such as hoarding medical supplies, hygienic supplies, and food items and making unnecessary visits to physicians and emergency rooms [34]. Accurate information must be conveyed by designated spokespersons who can promote primary and secondary prevention behaviors, model rational thinking, and allay unrealistic or excessive fears about the future [35]. The most widely viewed YouTube videos on COVID-19 do not achieve these aims. Thus, we conclude that in addition to reducing risk of exposure through recommended behaviors, it is clear that consumers must also become critical evaluators of disseminated information about COVID-19 found on YouTube.

This study extends awareness about the content of widely viewed videos on YouTube during the early days of the COVID-19 outbreak, but there are limitations that must be mentioned. Recommendations are being updated frequently and more recent YouTube videos may cover preventive behaviors to a greater extent. Nevertheless, the number of views garnered by videos in our sample continued to grow. As with all cross-sectional studies, the use of one data collection point is limiting. As the state of YouTube is in a state of fluctuation, thus, the videos with the most views may change over time. It is also possible that, as more information is learned about the disease, common search terms and content will evolve, despite older videos remaining online.

It is often not possible to determine the geographic location of YouTube posters. With over 2 billion users worldwide, many users likely watch videos regardless of the national origin of posters. Given this, we cannot make claims about the regionality or lack thereof of YouTube videos on COVID-19. Nevertheless, it is fair to assert that the Spanish and English language videos on COVID-19 in this sample could be reaching viewers around the world. Additionally, the prevention behaviors noted in this study could be applicable worldwide. In addition, our sample of videos was small, and 100 was an arbitrary cut point for inclusion. Further, there are issues with the impermanence of video content in that highly viewed videos may contain outdated information regardless of the accuracy of the information when the videos were produced. In addition to efforts to promote authoritative information, YouTube could benefit from clearly demarcating the most current, valid information. This would be especially useful in instances such as the COVID-19 pandemic, where information is changing rapidly. Although this study represents this sample of videos at a point in time, it offers insight about the nature of content that is and is not covered, and suggests opportunities to convey information to mitigate the spread of COVID-19 and help people make informed decisions about caring for and protecting themselves and their families.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease 2019
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Viewpoint

Conducting Clinical Research During the COVID-19 Pandemic: Investigator and Participant Perspectives

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Abstract

As the medical landscape changes daily with the coronavirus disease (COVID-19) pandemic, clinical researchers are caught off-guard and are forced to make decisions on research visits in their ongoing clinical trials. Although there is some guidance from local and national organizations, the principal investigator (PI) is ultimately responsible for determining the risk-benefit ratio of conducting, rescheduling, or cancelling each research visit. The PI should take into consideration the ethical principles of research, local/national guidance, the community risk of the pandemic in their locale, staffing strain, and the risk involved to each participant, to ultimately decide on the course of action. While balancing the rights and protection of the human subject, we seldom examine patients' views and opinions about their scheduled research visit(s). This article discusses the ethical principles of beneficence and autonomy in helping the decision-making process. We discuss ways to weigh-in local and national guidance, staffing strain, and institutional support into the decision-making process and outline potential changes needed for regulatory bodies depending on the decision. Further, we discuss the need to weigh-in the individual risk-benefit ratio for each participant and present a decision tree to navigate this complex process. Finally, we examine participant and caregiver perspectives on their fears, sense of preparedness, and factors that they consider before deciding whether to keep or postpone the research appointments. This entry also provides PIs ways to support their research participants in both scenarios, including provision of psychological support.

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KEYWORDS

clinical research; COVID-19; pandemic; outbreak; infectious disease; public health; ethics

Introduction

As the medical landscape changes daily with the coronavirus disease (COVID-19) pandemic, clinical researchers are caught off-guard and must make tough decisions about research visits in ongoing clinical trials. Although there is some guidance from local and national organizations, the principal investigator (PI) is ultimately responsible for determining the risk-benefit ratio of conducting, rescheduling, or cancelling each visit. The PI should take into consideration the ethical principles, local/national guidance, the community risk of the pandemic in their locale, staffing strain, and the risk involved to each participant, to ultimately decide the course of action. While balancing the rights and protection of the human subjects, we seldom examine patients' views and opinions. Here, we present patient perspectives from active research participants (N=51) along with other important considerations to inform the decision-making processes.

Visit-Related Factors

The fundamental question is whether the research visit changes the risk-benefit ratio discussed in the consent. The ethical principles of beneficence and autonomy should help the PI do what is best for the participants while discussing with each participant about the risk of exposure and the best available knowledge, in order to facilitate their self-determination. At minimum, each participant should be made aware that COVID-19 is now being transmitted from human to human, with a transmissibility rate of 4 [1]. It is particularly infectious due to asymptomatic transmission and symptoms akin to influenza. Ideally, a phone call should be conducted to update the research participant on the current information, screen them for COVID-19, and reassess the risk benefit.

The risk of contagion may vary based on the setting of the research facility. A tertiary care research facility wherein patients with COVID-19 are actively being quarantined or treated, may be at a higher risk than a standalone private research facility. Research participants are at increased risk for COVID-19 infection if they have any comorbidities. Immunocompromised people, pregnant women, and older adults with multiple comorbidities may be particularly vulnerable to serious sequelae [1]. If the risk of contagion or sequela is high, all measures need to be taken to protect the participant. Discussion should also include the risks associated with delay or discontinuation of the study interventions including monitoring, investigational product, and psychological support (if applicable).

Policy-Related Factors

Local guidance is usually informed by national guidance from the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and the Office of Research and Development (ORD). The NIH is aware of the potential disruptions to research and has several directives to guide PIs while placing highest priority on ensuring safety of all participants and allowing for delays in reaching milestones [2]. CDC guidance will help determine the screening process for participants that choose to keep their appointments [3]. The research institution might implement added screening based on the risk of contagion. Such additional screening will need to be conveyed to the participant ahead of time in order to make the best-informed decision about the appointment. If the research institution deems that all research visits need to be halted, such information will need to be communicated to the participant as soon as possible, and alternate arrangements to deliver the intervention/investigational product need to be made.

Workforce-Related Issues

PIs will need to monitor the staffing of their facility due to sickness or assignment to COVID-19–related tasks. Many institutions are mandating daily screening of their staff with the COVID-19 travel screen. This may add responsibilities to the research staff, necessitating streamlining of the research appointments. Research staff may be concerned about the added risk of infection during in-person visits. Making appropriate information and counseling available could help allay some of these worries. It may be best to prioritize the outcome measures to be collected at each visit, paying particular attention to visits/measures that can be collected over the phone, telehealth, or video chats.

Investigator Perspective

PIs are best qualified to determine whether their studies can be safely continued, continued with modifications, or temporarily halted. PIs should anticipate disruptions to the study and inform the sponsors and regulatory bodies promptly. When appropriate, they should consider revising their protocol to allow data collection and interaction without in-person contact using phone or videoconference apps such as Skype. Some protocols may already have flexibility regarding visits; otherwise, modification to the protocol may be needed. Informing the institutional review board that the modifications are being made to adapt to COVID-19 may help expedite the review process.

Research Participant Perspective

Caregiver and participant perspectives are often missed when conducting clinical research during pandemics. Gobat et al [4] reported that 82% of the participants (N=6804) believed it was important to conduct medical research during epidemics. The authors concluded that greater knowledge about pandemics, trust in a health professional, and trust in the government predicted increase in willingness to participate in research. In our convenient sample of 51 informants scheduled for ongoing clinical research studies over a period of 2 weeks on increased surveillance for COVID-19, most felt safe attending the scheduled research appointment (40 reported feeling safe and provided a rating of ≥4 on a Likert scale of 1-5). They also felt that the medical center was well prepared and expressed that the additional screening put them at ease.

Trust in the health care system and the fact that the visit was not in a group format were some of the positive factors reported by the patients in their decision to come for their scheduled appointment. News channels and close family members and friends were the resources that participants most commonly reached out to for decision making. One informant reported to have signed up for the CDC newsletter, while another completely relied on Rush Limbaugh radio coverage. Several participants expressed concern that social media may be contributing to the spread of unauthenticated information and that the public should turn to experts. Informants reported that the general public was in panic about COVID-19 (rating of 4.47 on a Likert scale from 1-5), while some felt that the concern was excessive:

> *I don't think it is as serious as people are making it to be.*

Preparation for Distant Visits

If participants or their study partners are not able to come into your site for scheduled visits or a determination has been made for offline visit, have assessments that can be collected by phone or online. Out-of-window visits because of COVID-19 or safety

precautions may lead to minor protocol deviations but may not lead to required discontinuations from the study. Institutional and sponsor policies will need to be followed regarding protocol deviation reporting. One positive outcome of the COVID-19 pandemic has been the shift in attitude of the regulatory bodies toward the use of telehealth. Clinical researchers can play a significant role in helping institutional review boards with approval of the use of mobile apps, Skype, Facetime, and other remote platforms to conduct research visits.

Preparation for In-Person Visits

If the participant or their caregiver decides to come in, make sure that your team is well prepared to handle the visit; for example, avoid any group interactions, provide private rooms for interviews, sanitize the high-traffic and high-touch areas well, minimize contact with the participant, sanitize reusable medical devices per standard operating procedures, and do not share pens for signing forms. Have protective gear such as masks and hand sanitizers ready for both the participants and staff members.

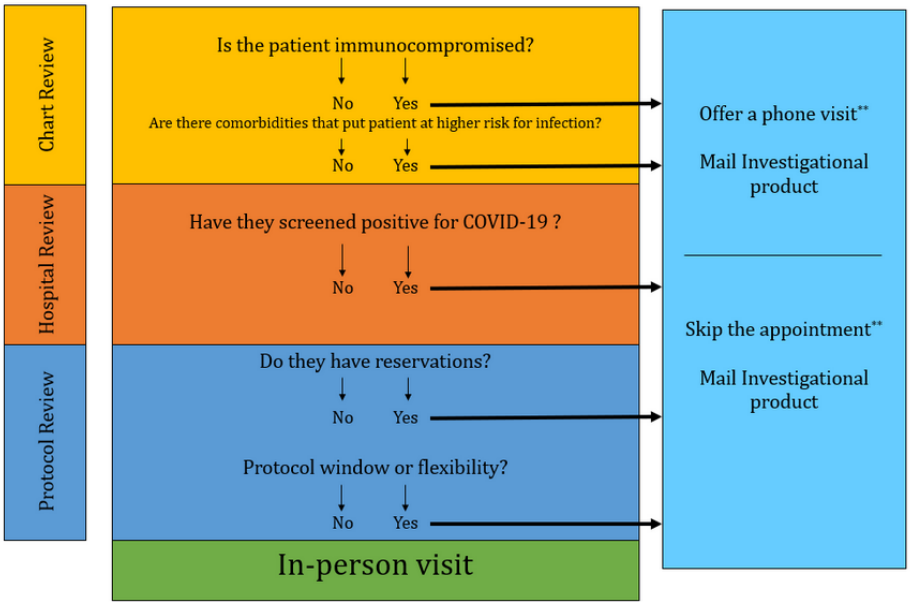
Addressing Psychological Needs During the Pandemic

Research staff and clinicians have a unique opportunity to address psychological stress due to their ongoing relationship with the participants. A variety of negative psychological effects including posttraumatic stress symptoms, confusion, and anger have been reported as consequences of quarantine [5]. Worry about their family members contracting COVID-19 is a huge concern [1]. Take extra time to address any questions that the participant or their caregiver might have. Assess for any undue mental stress that they might be undergoing and make sure that you have resources or referral services available. Encourage them to be informed about COVID-19 while monitoring that they are not overly exposed. It may be best to limit the checking in to once or twice a day, just enough to take action. Give them practical tips on handling the disruption in their work life by planned breaks during the day, if they are working from home, and leave them with hope that normal processes will resume once the pandemic subsides. Older adults should be screened for loneliness and isolation, an important contributor to all-cause mortality in this age group [6]. Researchers could help older adult participants with tips on ways to stay connected with family and support groups remotely.

Conclusions

There is no question that clinical researchers are having to make tough decisions about ongoing clinical trials due to the widespread COVID-19 pandemic. Although some guidance has been offered from local and national organizations, it is still ultimately the responsibility of the PI to evaluate the risk-benefit ratio of ongoing research. When making research decisions, PIs should consider all factors that affect the risk-benefit ratio of continuing research during this time. Balancing visit- and policy-related factors as well as the possible lack of a workforce with the perspectives of the research participants can help PIs identify various courses of actions for continued research. Figure 1 presents a decision tree to assist PIs in this decision-making process based off of national recommendations. If PIs chose to and are able to continue clinical research, preparation should be considered in various degrees. PIs' ability to provide participants with the latest information about COVID-19, provision of a safe environment, and preparedness to address psychological needs will help reassure participants that you have made the most informed decision to continue research.

Figure 1. Decision tree for research visits*. COVID-19: coronavirus disease. *Check the local and national guidelines periodically, as the information is changing rapidly. **May need institutional review board approval unless such contingency was built into the protocol. Protocol deviation could be used to take care of the subject, and a modification may need to be applied if you anticipate this to be a recurring issue.



Conflicts of Interest

None declared.

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Abbreviations

CDC: Center for Disease Control and Prevention
COVID-19: coronavirus disease
NIH: National Institutes of Health
ORD: Office of Research and Development
PI: Principal Investigator

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Original Paper

Novel Coronavirus in Cape Town Informal Settlements: Feasibility of Using Informal Dwelling Outlines to Identify High Risk Areas for COVID-19 Transmission From A Social Distancing Perspective

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Abstract

Background: The challenges faced by the Global South during the coronavirus disease (COVID-19) pandemic are compounded by the presence of informal settlements, which are typically densely populated and lacking in formalized sanitation infrastructure. Social distancing measures in informal settlements may be difficult to implement due to the density and layout of settlements. This study measures the distance between dwellings in informal settlements in Cape Town to identify the risk of COVID-19 transmission.

Objective: The aim of this paper is to determine if social distancing measures are achievable in informal settlements in Cape Town, using two settlements as an example. We will first examine the distance between dwellings and their first, second, and third nearest neighbors and then identify clusters of dwellings in which residents would be unable to effectively practice social isolation due to the close proximity of their homes.

Methods: Dwellings in the settlements of Masiphumelele and Klipfontein Glebe were extracted from a geographic information system data set of outlines of all informal dwellings in Cape Town. The distance to each dwelling's first, second, and third nearest neighbors was calculated for each settlement. A social distance measure of 2 m was used (buffer of 1 m, as dwellings less than 2 m apart are joined) to identify clusters of dwellings that are unable to effectively practice social distancing in each settlement.

Results: The distance to each dwelling's first 3 nearest neighbors illustrates that the settlement of Masiphumelele is constructed in a denser fashion as compared to the Klipfontein Glebe settlement. This implies that implementing social distancing will likely be more challenging in Masiphumelele than in Klipfontein Glebe. However, using a 2-m social distancing measure, it was demonstrated that large portions of Klipfontein Glebe would also be unable to effectively implement social distancing.

Conclusions: Effectively implementing social distancing may be a challenge in informal settlements due to their density. This paper uses dwelling outlines for informal settlements in the city of Cape Town to demonstrate that with a 2 m measure, effective social distancing will be challenging.

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KEYWORDS

COVID-19; Cape Town; informal settlements; social distancing; GIS; pandemic; outbreak; infectious disease; public health; geographic data; risk

Introduction

The World Health Organization (WHO) declared the outbreak of the novel coronavirus disease (COVID-19) to be a pandemic on March 11, 2020, with the WHO director-general stating, "This is not just a public health crisis, this is a crisis that will touch every sector. So every sector and every individual must be involved in the fights," [1]. In the absence of a vaccine, tools

such as isolation and quarantine, social distancing, and community containment become vital in preventing the person-to-person spread of disease by separating people to interrupt transmission [2]. COVID-19 statistics for South Africa show that, as of March 30, 2020, there were 1326 cases in South Africa with 324 reported cases in the Western Cape Province with a total of 3 deaths in the country [3]. In response to the COVID-19 pandemic, President Cyril Ramaphosa announced a nationwide lockdown for 21 days effective at midnight on March 26, 2020 [4]. This paper was first published online prior to this announcement; however, the method and results can be interpreted in light of the lockdown decision and can be used to guide any easing of restrictions going forward.

The challenges faced by the developing world during the pandemic are compounded by the presence of informal settlements, which are typified by being densely populated and lacking formalized sanitation infrastructure [5]. Cape Town, the capital city of the Western Cape Province with an estimated population of 4 million, is South Africa's second most populous city after Johannesburg and Africa's 10th most populous city [6]. Cape Town has not been immune to the rise of urbanization, and migration to the city has led to the establishment of many informal settlements. Housing in informal settlements is unregulated by the state, planned by local communities, and typically constructed in a haphazard fashion using cheap and recycled building materials. Due to competition for space, homes can be built close together with only narrow access paths. Some settlements are less densely constructed, but these tend to be the newer settlements located further away from the city in locations where there is little economic opportunity. There are an estimated 146,000 households living in informal settlements in Cape Town, many of which are not recognized as permanent, with the residents lacking occupation rights and security of tenure [7]. It is further estimated that only one-third of the toilets in Cape Town's informal settlements are permanent infrastructure with the rest being temporary toilets that are provided and cleaned by private companies [7]. Other challenges include the particularly high HIV burden borne by residents of informal settlements in comparison to other settlement types [8]. Although there is no evidence that the risk of infection or complications of COVID-19 are different amongst people living with HIV when compared with the general population, people living with advanced HIV disease and who are not taking antiretroviral treatment are at an increased risk of infections, in general [9].

Social distancing aims to reduce the interactions between people in a broader community and is useful for communities where individuals may be infectious but have not yet been identified and are thus not isolated [2]. Furthermore, it has been proposed that social distancing be implemented in a rationally layered manner to protect individuals with a higher risk of mortality [10]. Should social distancing measures not be effective, the next stage, known as community containment, may need to be implemented. This involves reduction of personal interaction at the community level, which is ethically more challenging, and its implementation requires close partnership and cooperation with law enforcement [2].

Given the nature of informal settlements, if social distancing is implemented by the state, it should be established whether an individual urban settlement is able to achieve this based on the layout of the particular settlement. Due to the density of dwellings in informal settlements, effectively implementing social distancing may be a challenge. The objective of this paper is to determine if social distancing measures are achievable in informal settlements in Cape Town using two settlements as an example. First, we examined the distance between dwellings and their first, second, and third nearest neighbors. Second, we identified clusters of dwellings in which residents would be unable to effectively practice social isolation due to the close proximity of their homes. It should be noted that this study is based solely on one data set (the outline of informal dwellings), and it is envisaged that public health scientists could incorporate this data set as one of many parameters in specific risk modelling, should it prove useful. Vulnerability mapping of COVID-19 in the South African context, which considers factors other than distances between dwellings, has been written for the Gauteng Province [11] and could similarly be applied elsewhere in South Africa.

Methods

This paper looks at the feasibility of social distancing in two informal settlements in Cape Town as an effective measure to prevent transmission of COVID-19 in these urban environments. In particular, it looks at the layout of the settlements with respect to the distance between dwellings and their nearest neighbors to determine if a social distancing approach is feasible in these environments. The assumption was made that all outer boundaries of a dwelling are a potential zone of transmission. It is likely that the risk of transmission will be higher at openings such as doors and windows; however, in the absence of these data, all boundaries of a dwelling were treated equally.

Two informal settlements in Cape Town have been selected to demonstrate the application. The location of these two settlements and zoomed in aerial photography of typical areas within the settlements are shown in Figure 1. It has been widely reported that settlements are typically overpopulated with a high dwelling density, but quantitative data on this has been lacking until now. Roof outlines of all informal dwellings in informal settlements in the city of Cape Town have been mapped from aerial photography captured in February 2018 [12] and can be used to obtain data on the distance between a dwelling and the nearest neighbors.

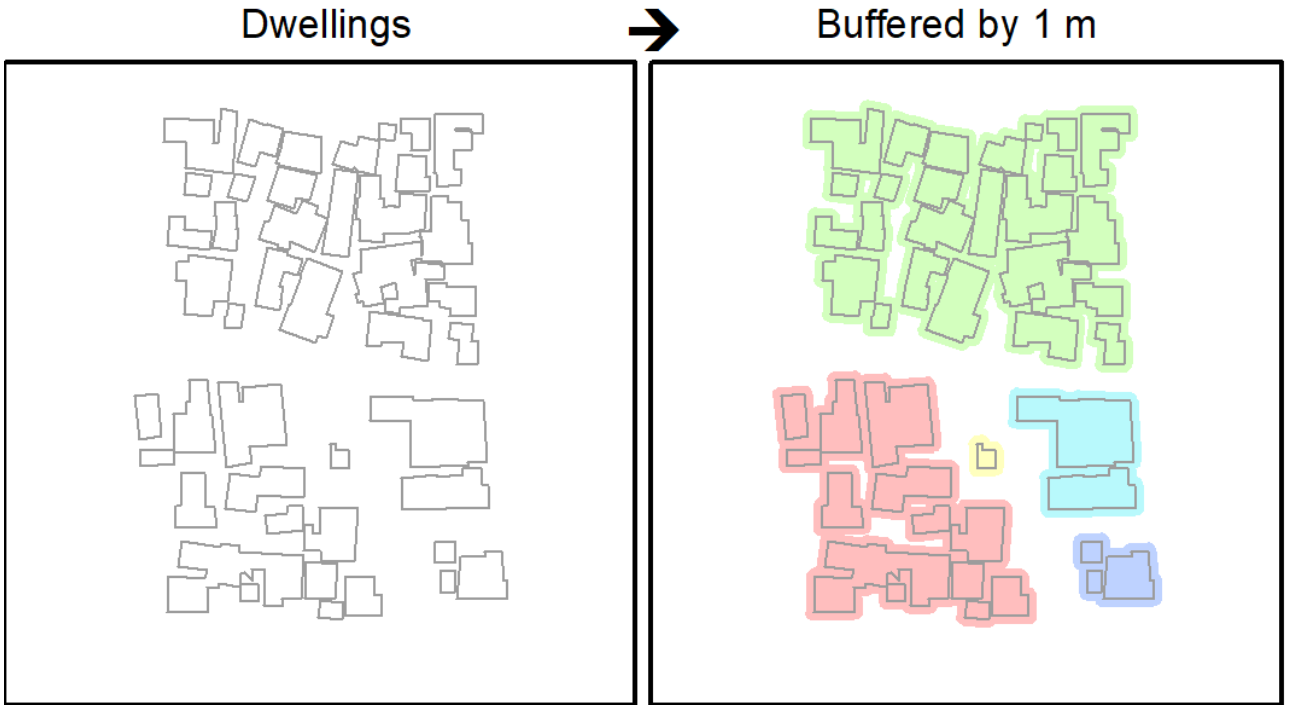
The dwelling outlines are in the form of a geographic information system (GIS) vector data set (shapefile), with individual polygons representing either individual dwellings or, in cases where dwellings are built so close to each other that they cannot be visually separated, clusters of connected dwellings. Working within the GIS software ArcGIS 10.5.1 (Esri), dwellings corresponding to each settlement were selected and saved into separate shapefiles. The proximity tool "Generate Near Table" was then used to calculate the distance to each dwelling's first, second, and third nearest neighbors. Subsequently, in Microsoft Excel, the normalized distribution of these distances was calculated for the first, second, and third

nearest neighbor in each settlement to provide an overview of the density of each settlement in relation to social distance measures.

The UK guidelines on social distancing state that if a person meets another while outdoors, they should ensure a 2-m distance between them [13]. If such a measure was to be implemented in Cape Town, using the dwelling data set, it is possible to identify clusters of homes that are unable to effectively self-isolate due to their proximity to neighbors (ie, a person who leaves their home will immediately be within 2 m of another home and may either spread or become infected by the virus). This would be exacerbated if more than one person in a cluster was outside their home at the same time. Taking the dwellings' outline data set in ArcGIS 10.5.1, the proximity tool "Buffer" was used to expand the outline of individual dwellings by 1 m. Thus, if two dwellings are within 2 m of each other, their buffers intersect and a single polygon grouping of these dwellings is drawn. This is illustrated in Figure 2 where each color represents the groupings of dwellings that would have to self-isolate together, as individual self-isolation would likely be ineffective.

Figure 1. City of Cape Town and the location of Masiphumelele and Klipfontein Glebe.

Figure 2. Illustration of how self-isolating clusters of dwellings are identified.



Results

Calculating the distance between each dwelling and its first, second, and third nearest neighbors allows for a better understanding of density and separation distances within individual settlements. Examining the normalized distribution (Figures 3 and 4) can give an indication of the likelihood of a value on the x-axis occurring. The results show that the settlement of Masiphumelele has lower separation distances (small distance to first nearest neighbor) and is more dense (smaller distance to second and third nearest neighbors) with a high probability density (y-axis) of the distances (x-axis) being small. On the other hand, Klipfontein Glebe has larger distances to the first 3 nearest neighbors with a smaller probability indicating a more dispersed settlement. It should, however, be noted that where two or more dwellings' roofs touched, the cluster of dwelling was digitized as a single dwelling; in reality, the graphs would be slightly skewed to the left (enhanced positive skew).

In Figure 3 it can be seen that Masiphumelele is a denser settlement than Klipfontein Glebe (Figure 4) with homes being built close together. The distance to the first nearest neighbor in Masiphumelele peaks at <0.5 m, the second nearest neighbor peaks at just less than 1 m, and the third nearest neighbor peaks at around 1.5 m. On the other hand, Klipfontein Glebe is a more dispersed settlement ,with the first nearest neighbor peaking at around 0.7 m, the second nearest neighbor peaking around 1.4 m, and the third nearest neighbor peaking just over 2 m. This analysis can be carried out for all informal settlements in Cape Town individually.

Figure 3. Normalized distribution of the distance between dwellings and their first, second, and third nearest neighbors in Masiphumelele.

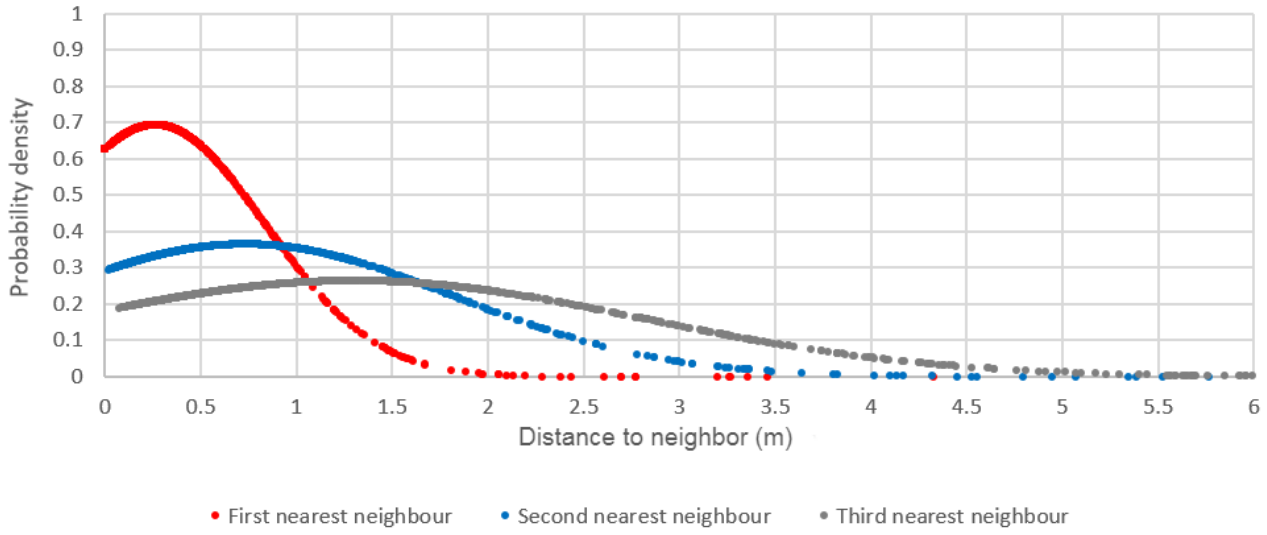
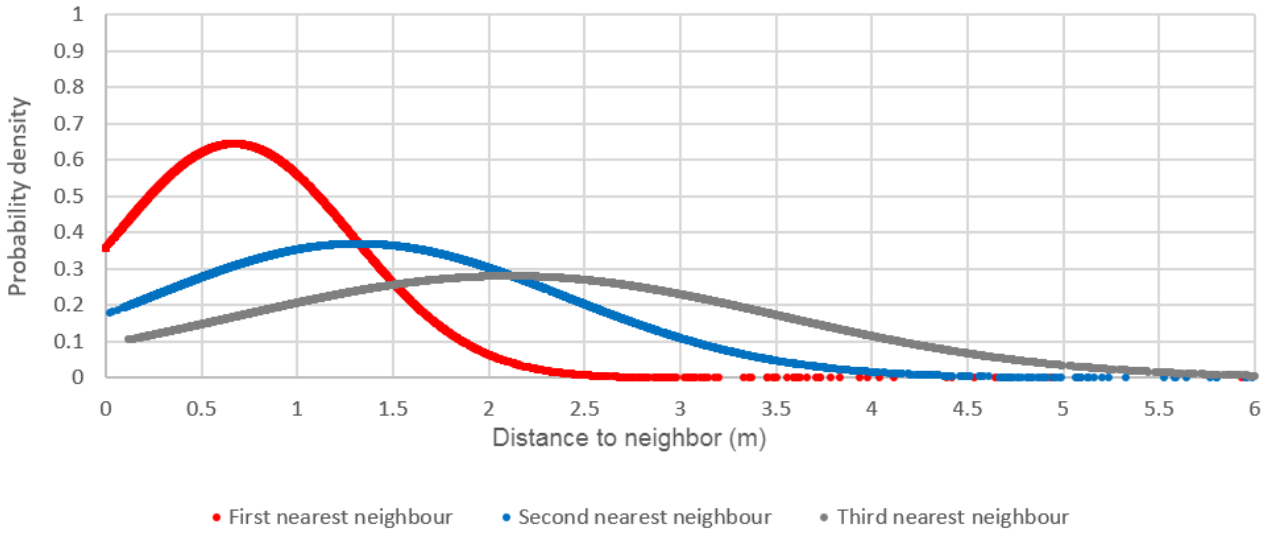


Figure 4. Normalized distribution of the distance between dwellings and their first, second, and third nearest neighbors in Klipfontein Glebe.



The results of buffering the dwelling outlines by 1 m are shown for Masiphumelele (Figure 5) and Klipfontein Glebe (Figure 6). It can clearly be seen that Masiphumelele poses a high risk for COVID-19 spread, as the groups of dwellings that would have to self-isolate together are typically large. The canals in Masiphumelele are effectively acting as breaks between dwellings, preventing even larger clusters.

For Klipfontein Glebe (Figure 6), the picture is more varied. There are some large clusters (for example, the bottom center olive green cluster) that represent a high transmission risk, but there are also smaller clusters throughout the settlement where the residents of these homes would be able to self-isolate with a smaller neighborhood.

Figure 5. Clusters of dwellings in Masiphumelele that would need to self-isolate together. Different colors indicate group of dwellings that will be unable to practice social distancing from neighbors within the same color cluster.

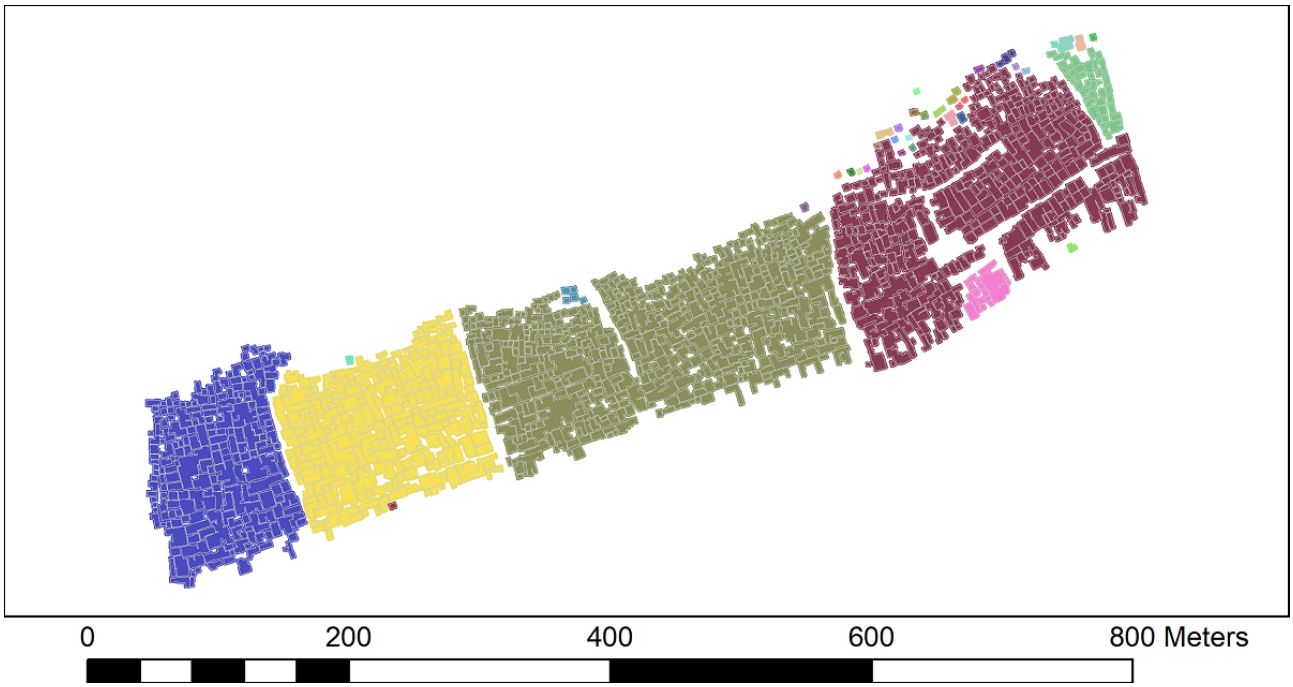
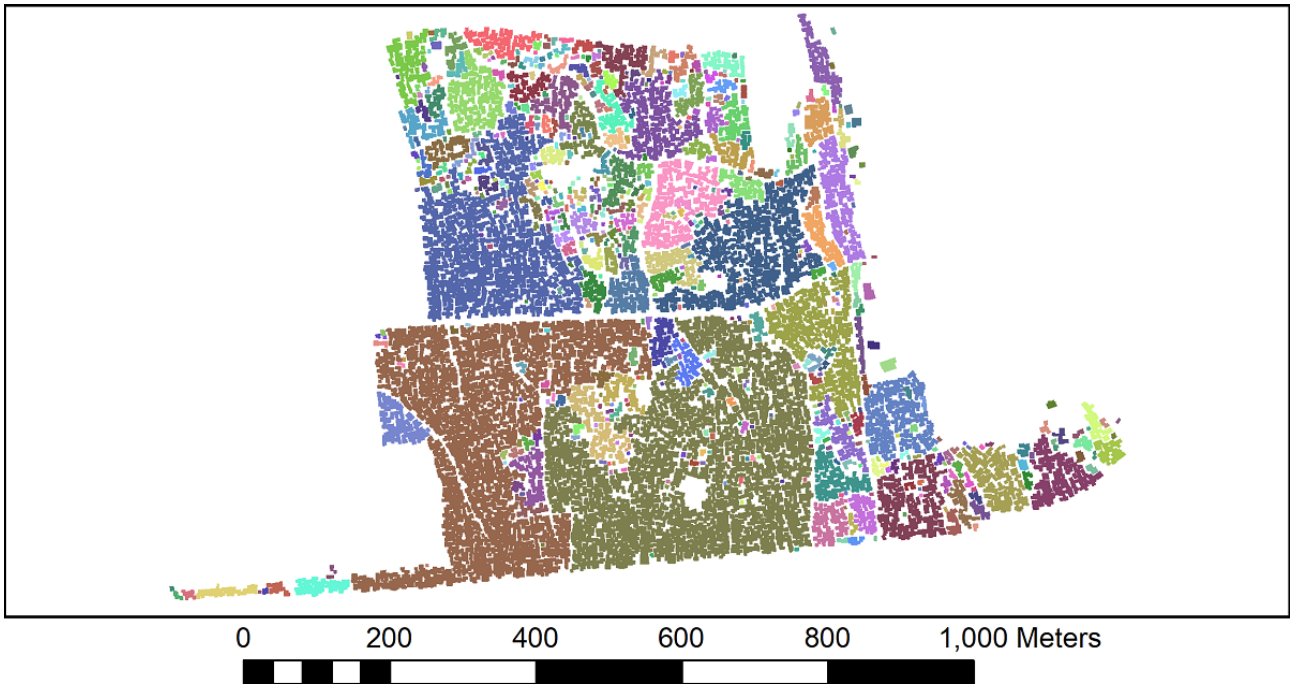


Figure 6. The clusters of dwellings in Klipfontein Glebe that would need to self-isolate together. Different colors indicate group of dwellings that will be unable to practice social distancing from neighbors within the same color cluster.

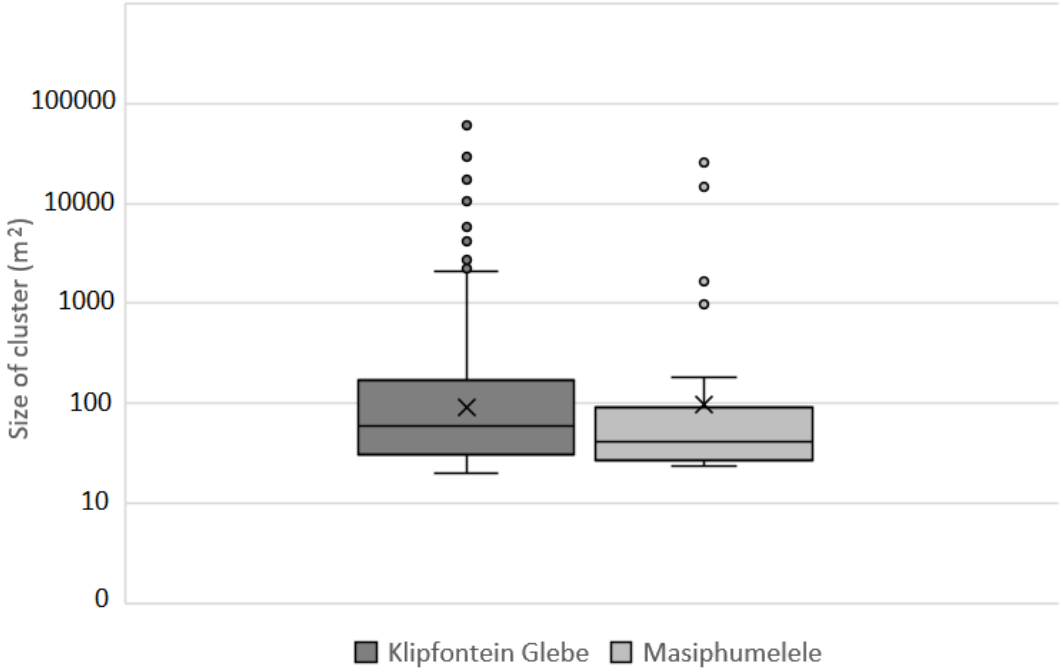


Descriptive statistics of the size of the clusters for Masiphumelele and Klipfontein Glebe (Table 1) show that the largest cluster occurred in Klipfontein Glebe; however, the mean value for Masiphumelele exceeded that of Klipfontein Glebe. The number of people living in these clusters is unknown, and it is unlikely that data at this level exists; however, a count of the dwellings is possible, and extrapolations about the estimated number of people per household can be made. The normalized distribution graphs (Figures 3 and 4) seem to show that Masiphumelele posed a higher risk with respect to the nearest neighbors than Klipfontein Glebe; however, the box and whisker chart in Figure 7 together with the descriptive statistics (Table 1) appear to paint a somewhat different picture. Klipfontein Glebe has the larger maximum cluster size and the larger median with a smaller standard deviation. However, the presence of some large clusters within the Masiphumelele data set, together with the lower count, result in a higher mean in Masiphumelele.

Table 1. Descriptive statistics of the size (m2) of clusters in Klipfontein Glebe and Masiphumelele.

Statistics	Klipfontein Glebe clusters	Masiphumelele clusters
Mean, m^2	581	2432
Standard error, m^2	164	1156
Median, m^2	60	42
Standard deviation, m^2	3999	7124
Minimum, m^2	20	24
Maximum, m^2	67312	30350
Number of clusters, n	593	38

Figure 7. Box and whisker chart of size of clusters in Klipfontein Glebe and Masiphumelele. Note the log scale on the y-axis.



Discussion

Principal Results

The results imply that social distancing (short of a lockdown) would be difficult to achieve in the two selected settlements. To effectively maintain social distancing, residents would, in effect, be unable to leave their homes. This is impractical, given that many homes are not serviced and lack toilets and running water. Even in the case of a complete lockdown (as is currently underway), residents would be asked to do the impossible, as they would be unable to leave their homes to access toilets and water while maintaining a safe 2-m separation distance. In addition, the living conditions inside homes are generally cramped and overcrowded with inadequate insulation, making staying indoors unbearably uncomfortable, particularly on hot days. Given the results of this paper, when implementing lockdowns, the authorities may need to take a more nuanced approach and consider implementing shut down at the community level, rather than at the household level.

The principal finding of this research is that, in the selected settlements, distance to each dwelling's first 3 nearest neighbors illustrated that the settlement of Masiphumelele is constructed in a denser fashion when compared with the Klipfontein Glebe settlement, which, although some portions of the settlement are dense, is generally more dispersed. The first, second, and third nearest neighbors peak at approximately 0.5 m, 1.0 m, and 1.5 m, respectively, for Masiphumelele, and approximately 0.7 m, 1.4 m, and 2 m, respectively, for Klipfontein Glebe. This implies that implementing social distancing will likely be more challenging in Masiphumelele than in Klipfontein Glebe. However, using a 2-m social distancing measure, it was demonstrated that large portions of Klipfontein Glebe would also be unable to effectively implement social distancing.

Limitations

A known limitation to this method is that many residents have to walk to a water stand and toilet, as many of the informal settlements are not serviced at the dwelling level. This creates unavoidable movement of people, and the pathways taken from dwellings to these communal points will be frequently used. Furthermore, these communal points will themselves be locations for potential disease spread, and, much like John Snow's original research on epidemiology in 1854 [14], actions to prevent disease spread at these locations should be taken (although different from those implemented by Snow). Analysis of these data, if they indeed exist, should occur in parallel and in combination with the work presented here. Furthermore, it is reiterated that this method alone does not represent the entire picture of vulnerability to COVID-19 transmission in Cape Town informal settlements.

Comparison to Prior Work

Similar work has not been found in the literature. Where vulnerability to COVID-19 or other disease has been mapped, it tends to consider data such as census data to identify density of populations, poverty indicators, and proportion of the population that fall in the vulnerable category [11]. Other uses of GIS in the COVID-19 pandemic has been widespread, mostly showing the location and magnitude of caseload or fatalities (a list is available on the website of the Center for Infectious Disease Research and Policy [15]).

Conclusions

If the assumption presented earlier in the paper holds true, then effectively implementing social distancing in informal settlements in Cape Town will present a challenge. However, community containment poses its own challenges. Thus, containment of the spread of COVID-19 in Cape Town to prevent it reaching the informal settlements is likely to be a key consideration for authorities and decision makers. This will

hold true for many other cities within Africa and the developing world, in general. However, data on informal settlements at the level that has been presented here is lacking in most, if not all, cities. Should the method presented here be deemed useful to decision makers, a mobilization of volunteer GISs as well as a machine learning approach would be proposed to produce the data required in the shortest a time period possible.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
GIS: geographic information system
WHO: World Health Organization

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Original Paper

Population-Level Interest and Telehealth Capacity of US Hospitals in Response to COVID-19: Cross-Sectional Analysis of Google Search and National Hospital Survey Data

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Abstract

Background: As the novel coronavirus disease (COVID-19) is widely spreading across the United States, there is a concern about the overloading of the nation's health care capacity. The expansion of telehealth services is expected to deliver timely care for the initial screening of symptomatic patients while minimizing exposure in health care facilities, to protect health care providers and other patients. However, it is currently unknown whether US hospitals have the telehealth capacity to meet the increasing demand and needs of patients during this pandemic.

Objective: We investigated the population-level internet search volume for telehealth (as a proxy of population interest and demand) with the number of new COVID-19 cases and the proportion of hospitals that adopted a telehealth system in all US states.

Methods: We used internet search volume data from Google Trends to measure population-level interest in telehealth and telemedicine between January 21, 2020 (when the first COVID-19 case was reported), and March 18, 2020. Data on COVID-19 cases in the United States were obtained from the Johns Hopkins Coronavirus Resources Center. We also used data from the 2018 American Hospital Association Annual Survey to estimate the proportion of hospitals that adopted telehealth (including telemedicine and electronic visits) and those with the capability of telemedicine intensive care unit (tele-ICU). Pearson correlation was used to examine the relations of population search volume for telehealth and telemedicine (composite score) with the cumulative numbers of COVID-19 cases in the United States during the study period and the proportion of hospitals with telehealth and tele-ICU capabilities.

Results: We found that US population–level interest in telehealth increased as the number of COVID-19 cases increased, with a strong correlation (r=0.948, P<.001). We observed a higher population-level interest in telehealth in the Northeast and West census region, whereas the proportion of hospitals that adopted telehealth was higher in the Midwest region. There was no significant association between population interest and the proportion of hospitals that adopted telehealth (r=0.055, P=.70) nor hospitals having tele-ICU capability (r=–0.073, P=.61).

Conclusions: As the number of COVID-19 cases increases, so does the US population's interest in telehealth. However, the level of population interest did not correlate with the proportion of hospitals providing telehealth services in the United States,

suggesting that increased population demand may not be met with the current telehealth capacity. Telecommunication infrastructures in US hospitals may lack the capability to address the ongoing health care needs of patients with other health conditions. More practical investment is needed to deploy the telehealth system rapidly against the impending patient surge.

(JMIR Public Health Surveill 2020;6(2):e18961) doi:10.2196/18961

KEYWORDS

COVID-19; telehealth; telemedicine; screening; pandemic; outbreak; infectious disease; public health

Introduction

As the novel coronavirus diseases (COVID-19) spreads widely across the United States, telehealth capabilities have never been more important [1]. To boost telehealth use in response to COVID-19, the Centers for Medicare and Medicaid Services (CMS) has now expanded telehealth services for all Medicare beneficiaries [2], and national health agencies have urged health care providers to implement telehealth systems [3]. Virtually all electronic communications between patients and providers, including asynchronous modalities (eg, virtual check-ups or electronic visits [e-visits]) and real-time communication (eg, videoconferencing) can now be paid at the same rate as in-person visits [2].

This expansion of telehealth services is expected to alleviate the overload of the nation's health care capacity by delivering timely care for initial screening of symptomatic patients (eg, forward triage) and potentially keep them away from hospitals to protect clinicians and other patients [2-5]. Although a massive surge of patients with COVID-19 or other pre-existing conditions is projected [6], it is currently unknown whether US hospitals have the telehealth capacity to meet the increasing demand and needs of patients. To address this gap and provide a snapshot of telehealth capacity in the United States, we investigated the relationship of population-level internet search volume for telehealth (as a proxy of population interest and demand) with the number of new COVID-19 cases and the proportion of hospitals that adopted the telehealth system (eg, telehealth capacity) in US states. Because a large concern with COVID-19 cases is the potential need for ICU beds and ventilators, we also identified the telemedicine intensive care unit (tele-ICU) capacity of US hospitals. Tele-ICU is "technology-enabled care delivered from off-site locations that was developed to address the increasing complexity of patients and insufficient supply of intensivists" [7]. As COVID-19 cases in the United States increase exponentially, tele-ICU may be able to provide an additional layer of care remotely, potentially easing some of the expected forthcoming capacity constraints.

Methods

We used internet search volume data from Google Trends [8]. Given that Google Search is the most widely used search engine, we assumed users' search volume would represent a national interest in telehealth [9]. We used two search terms—"telehealth" and "telemedicine"—since they are frequently used interchangeably. To compare the population interest with the trends in COVID-19, we obtained search data from January 21, 2020 (when the first COVID-19 case reported), and March 18, 2020 (most current data available). Search data are presented using a relative search volume (RSV) index ranging from 0 to 100, where 100 indicates the peak of search volume. For example, if the RSV is 70, 70% of the highest search volume is recorded, given the search period, geographic area, and population size [7]. Data on COVID-19 cases in the United States were obtained from the Johns Hopkins Coronavirus Resources Center [10]. To determine whether a hospital provides telehealth services (including telemedicine, e-visit, remote monitoring), we obtained data from the 2018 American Hospital Association Annual Survey (AHAAS) and the AHAAS Information Technology (IT) Supplement [11]. We estimated the proportion of hospitals that adopted the telehealth system and tele-ICU capacity by combining positive responses to the AHAAS survey and the IT supplement questions. We used Pearson correlation to examine the association of the population search volume for telehealth and telemedicine (composite RSV score) with the cumulative numbers of COVID-19 cases in the United States during the study period and the proportion of hospital-level telehealth and tele-ICU capabilities. The level of search volume and telehealth capability by quintiles were also mapped using state-level Federal Information Processing Standards codes. All analysis was conducted using SPSS version 26 (IBM Corporation) and SAS version 9.4 (SAS Institute Inc).

Results

The US population's interest in telehealth increased as the number of COVID-19 cases increased (Figure 1). There was a strong correlation between population interest and COVID-19 cases reported (r=0.948, P<.001). Figure 2 presents the state-level population interest in telehealth (5 quintiles). Figures 3 and 4 show the proportion of hospitals with telehealth and tele-ICU capabilities. Of the 6146 US hospitals included, 3727 (60.8%) adopted telehealth and 788 (13.4%) had tele-ICU capability. We observed a higher population interest in telehealth in the Northeast and West census region (Figure 3), whereas the proportion of hospitals that adopted telehealth was higher in Midwest region (Figure 4). There was no significant association between population interest and proportion of hospitals that adopted telehealth (r=0.055, P=.70) nor hospitals having tele-ICU capability (r=–0.073, P=.61). The proportion of hospitals with telehealth and tele-ICU capabilities in the 50 states are listed in Table 1.

Figure 1. Trends in search volume for telehealth and the number of COVID-19 cases in the United States.

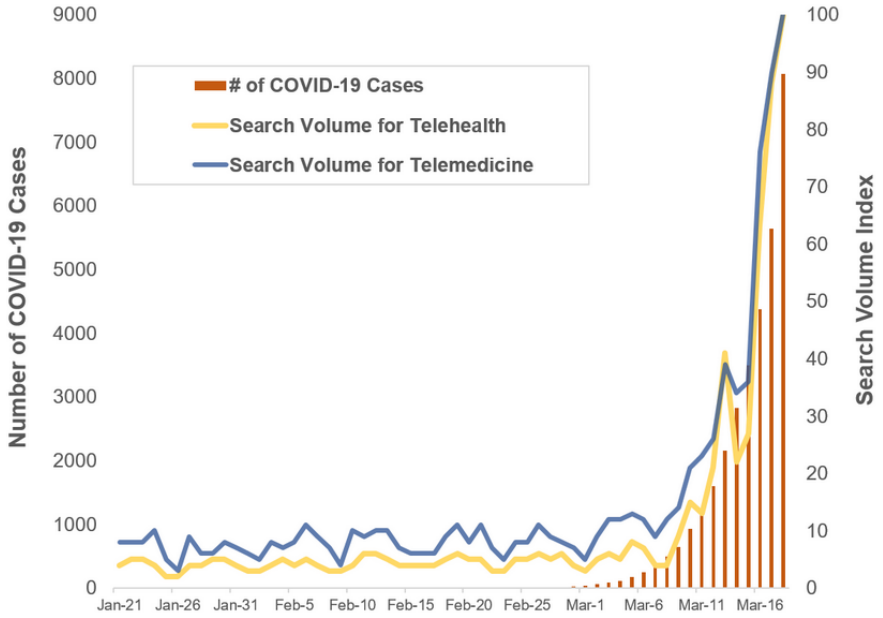

Figure 2. Population interest in telehealth by US state. RSV: relative search volume.

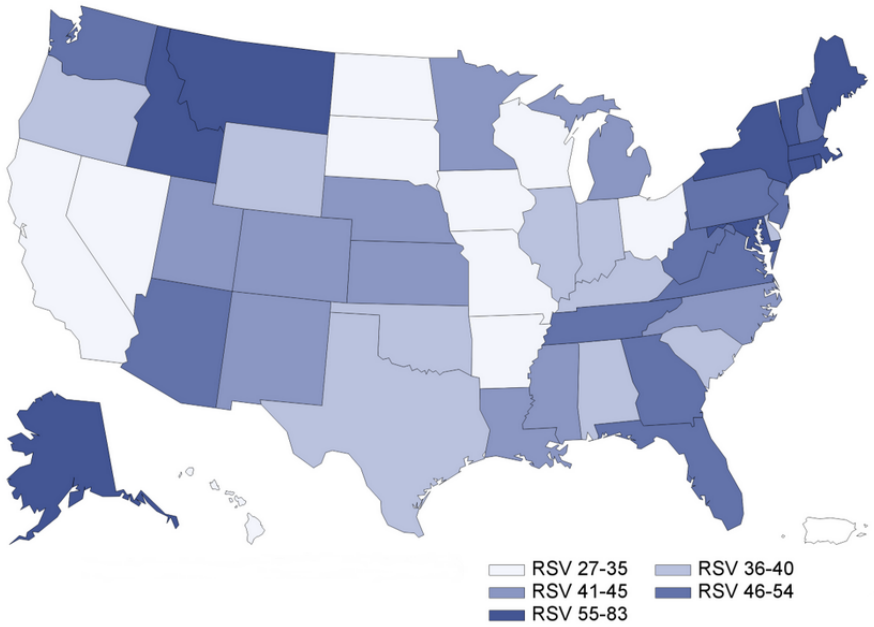

Figure 3. Proportion of hospitals that adopted the telehealth system by US state. RSV: relative search volume.

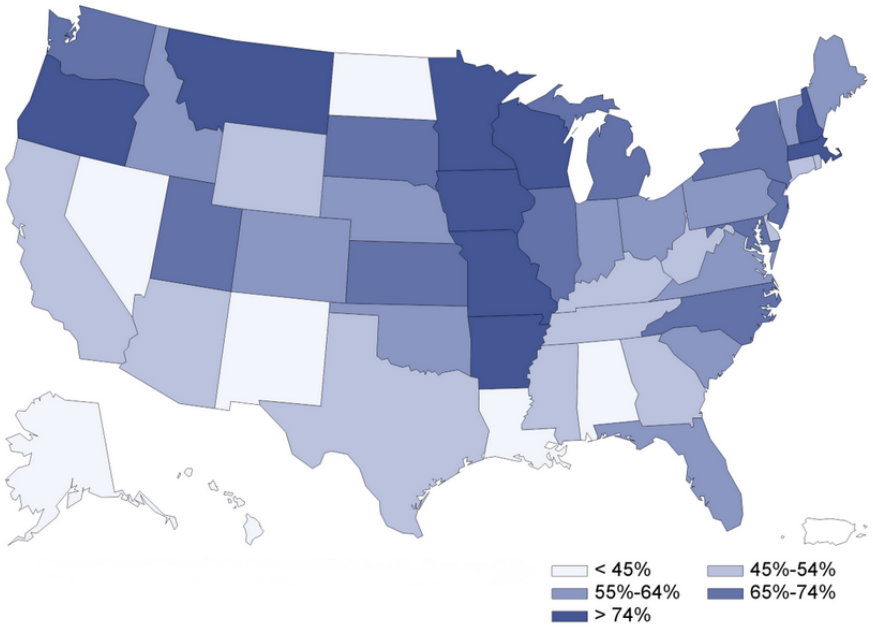

Figure 4. Proportion of hospitals having telemedicine intensive care unit capability by US state. RSV: relative search volume; ICU: intensive care unit.

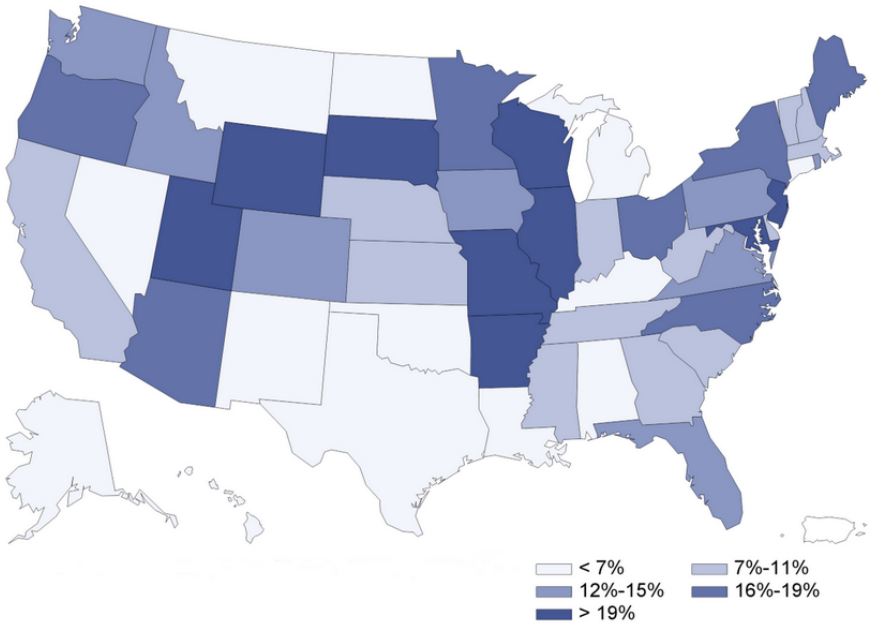

Table 1. Proportion of hospitals having telehealth and telemedicine intensive care unit capabilities in the 50 US states[a].

States	Telehealth system (%)	Tele-ICU[b] (%)
Alabama	39.7	0.9
Alaska	40.7	7.4
Arizona	50.9	17.9
Arkansas	79.4	22.5
California	51.3	7.8
Colorado	62.5	13.5
Connecticut	53.5	2.3
Delaware	46.2	7.7
Florida	59.1	12.8
Georgia	54.3	7.5
Hawaii	39.3	7.1
Idaho	55.8	15.4
Illinois	71.6	25.6
Indiana	62.2	8.5
Iowa	79.8	12.1
Kansas	66.4	8.6
Kentucky	47.1	7.4
Louisiana	36.9	7.4
Maine	57.8	17.9
Maryland	70.3	21.9
Massachusetts	87.2	11.8
Michigan	72.6	1.2
Minnesota	89.5	18.2
Mississippi	47.7	8.1
Missouri	76.4	21.5
Montana	77.3	4.5
Nebraska	55.6	11.1
Nevada	37.9	1.7
New Hampshire	80.6	9.7
New Jersey	65.0	36.0
New Mexico	40.7	5.6
New York	67.6	19.7
North Carolina	72.4	16.4
North Dakota	40.0	6.0
Ohio	63.7	17.9
Oklahoma	57.1	4.1
Oregon	76.9	16.9
Pennsylvania	61.5	13.1
Rhode Island	46.7	13.3
South Carolina	55.8	9.3
South Dakota	65.6	26.6

States	Telehealth system (%)	Tele-ICU[b] (%)
Tennessee	53.7	8.8
Texas	54.1	6.0
Utah	70.5	41.0
Vermont	62.6	11.8
Virginia	58.8	15.4
Washington	66.4	15.9
West Virginia	49.2	7.7
Wisconsin	82.0	32.0
Wyoming	51.5	24.2

[a]Hospitals reporting the provision of virtual visits in the American Hospital Association Annual Survey (AHAAS) or functioning tele-capacity in the AHAAS Information Technology Supplement were identified as providing some form of telehealth and therefore tele-capacity. All other hospitals were recorded as not providing telehealth.

[b]ICU: intensive care unit.

Discussion

As the number of COVID-19 cases increases, the US population's interest in telehealth also increases. However, the level of population interest did not correlate with the proportion of hospitals providing telehealth services in the United States. These observations may raise a question of whether hospitals and health care systems have the capacity to meet the increasing health care demand in their service area. Although telehealth can help to improve the triage and coordination of care for patients with COVID-19 [3-5], telecommunication infrastructures in US hospitals may lack the capability to address the ongoing health care needs of patients with other health conditions. There is still ongoing debate regarding the quality of care delivered using telehealth. Future studies should explore how the expansion of telehealth services influences the providers' scope of practice (eg, chronic condition management and surveillance, other preventive care services) and patient outcomes (eg, quality of care, patient experience, and unintended outcomes).

This study is limited by the use of internet search data to assess population interest, which may not reflect genuine population interest. However, the utility of Google Trends and its representativeness of US population has been demonstrated [9,12]. Our study is also limited by our measures of telecapacity, which were limited in at least 2 ways: (1) We were limited to hospitals that responded to the AHAAS. Although a majority of hospitals responded and the AHAAS is commonly used for research purposes in the literature, the missing responses limit the generalizability of our findings to only hospitals responding to the AHAAS. (2) Our definitions of telecapacity were limited to hospitals, and the provision of nonhospital teleservices were not identified. Although there are nonhospital providers of telemedicine services, the need for tele-ICU services is expected to be more relevant in the hospital setting. Thus, our inclusion of the tele-ICU measure demonstrates, to some degree, the provision of teleservices geographically, which are relevant to current and forthcoming patient needs related to COVID-19.

Our findings have important implications for the nation's current effort to address COVID-19. The CMS' rapid response under the Coronavirus Aid, Relief, and Economic Security (CARES) Act is expected to help hospitals and other health care facilities manage their capacity and workflow [2,13]. Subsequently, increased use of telehealth services may help flatten the transmission curve overall [3,4]. However, hospitals in some regions may not have the capacity to handle the surge in telehealth and remote critical patient care. Moreover, there is uncertainty about whether hospitals can actively expand their telehealth platforms or implement a new system if they have not adopted them previously because the CMS' waiver only extends until the end of the COVID-19 emergency. Additional investment is needed, at least in regions with low telehealth adoption, to increase capacity for population demand and empower hospitals with the flexibility to plan patient care transition against the impending patient surge [3,14]. For those who were not using telehealth to optimum capacity, structured guidelines may be needed to stimulate the effective implementation of telehealth services [15,16]. Health care decision makers may also need to appreciate the potential role of tele-ICU that enables remote ICU care by connecting intensivists or critical care teams to hospitals with limited capacity [7]. Expanding tele-ICU capability could be a promising strategy throughout this pandemic, given the shortfalls of ICU beds in rural hospitals and the growing number of patients in need of intensive care [3,17].

Conflicts of Interest

None declared.

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Abbreviations

AHAAS: American Hospital Association Annual Survey
CARES: Coronavirus Aid, Relief, and Economic Security Act
CMS: Centers for Medicare and Medicaid Services
COVID-19: coronavirus disease
IT: information technology
RSV: relative search volume
Tele-ICU: telemedicine intensive care unit

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Original Paper

Misinformation of COVID-19 on the Internet: Infodemiology Study

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Abstract

Background: The internet has become an important source of health information for users worldwide. The novel coronavirus caused a pandemic search for information with broad dissemination of false or misleading health information.

Objective: The aim of this study was to evaluate the quality and readability of online information about the coronavirus disease (COVID-19), which was a trending topic on the internet, using validated instruments and relating the quality of information to its readability.

Methods: The search was based on the term "Wuhan Coronavirus" on the Google website (February 6, 2020). At the search time, the terms "COVID-19" or "SARS-CoV-2" (severe acute respiratory syndrome coronavirus 2) did not exist. Critical analysis was performed on the first 110 hits using the Health on the Net Foundation Code of Conduct (HONcode), the Journal of the American Medical Association (JAMA) benchmark, the DISCERN instrument, and Google ranking.

Results: The first 110 websites were critically analyzed, and only 1.8% (n=2) of the websites had the HONcode seal. The JAMA benchmark showed that 39.1% (n=43) of the websites did not have any of the categories required by this tool, and only 10.0% (11/110) of the websites had the four quality criteria required by JAMA. The DISCERN score showed that 70.0% (n=77) of the websites were evaluated as having a low score and none were rated as having a high score.

Conclusions: Nonhealth personnel and the scientific community need to be aware about the quality of the information they read and produce, respectively. The Wuhan coronavirus health crisis misinformation was produced by the media, and the misinformation was obtained by users from the internet. The use of the internet has a risk to public health, and, in cases like this, the governments should be developing strategies to regulate health information on the internet without censuring the population. By February 6, 2020, no quality information was available on the internet about COVID-19.

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KEYWORDS

HONcode; JAMA benchmarks; DISCERN instrument; Wuhan coronavirus; COVID-19; nCoV; epidemiology; health information seeking; information quality; misinformation; public health

Introduction

The coronavirus disease (COVID-19) is spreading globally from its epicenter in Hubei, China. The incidence and mortality rate have been difficult to calculate because milder cases are not being diagnosed; despite this, the World Health Organization (WHO) on March 5, 2020, declared that the latest global death rate for the disease was 3.4%, and about 80% of COVID-19 cases are mild. The cases are changing daily and can be tracked worldwide in almost real time by different websites like the one supported by Johns Hopkins University [1].

This new disease is caused by a virus from the Coronaviridae family, identified in people exposed to seafood and wild animals in a local market. Researchers in the university in Guangzhou, China, have suggested that pangolins, a mammal used in

traditional Chinese medicine, could be the intermediate vector between bats and humans, because the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) genome sequence is 99% similar to the bat coronavirus according to Zhang et al [2].

In the Munich security conference that occurred on February 15, 2020, the general director of WHO commented, "We´re not just fighting and epidemic; we're fighting an infodemic." It is clear that there is no way to prevent the spread of COVID-19, but it is important to verify the information on the internet to prevent the panic and misinformation associated with the disease. The fake news spreads faster than the virus. The internet is the main information source worldwide; currently 2 billion people have access to it. Online health information has grown since the 1990s, becoming popular among nonhealth personnel users; nevertheless, most of the information on the internet is unregulated, and its quality remains questionable. For users with nonmedical education, it is difficult to judge the reliability of health information on the internet. Therefore, the need for critical evaluation has taken a new dimension, and indicators of importance and quality of the content have been developed.

The likelihood that a person will view a particular website is influenced by its order of appearance on major search engines, and, in some cases, this can also be influenced if they are paid sites. It has been shown by many authors that most of the users do not go beyond the first 2 pages of citations (20-40 links) that they find [3]. The most popular search engine worldwide is Google, and it ranks its search results based on link popularity, which means that for any website, the number of hyperlinks pointing to it from other web pages will improve its rank in Google search [4].

Due to the importance of internet health searches nowadays for health personnel and nonhealth personnel, scoring systems or quality evaluation tools have been developed as a set of indicators applied to a website to provide a quality score. The most used scoring systems nowadays are the Health on the Net Foundation Code of Conduct (HONcode), the Journal of the American Medical Association (JAMA) benchmarks, and the DISCERN instrument [5-7]. Eysenbach et al [8], reported that 70% of websites presenting care information had significant quality issues. The greatest problem of the internet health information is finding valid and reliable information [8].

The HONcode is a nonprofit and nongovernmental organization that promotes transparent and reliable health information online. It is a certification of the websites based on an "ethical standard aimed at offering quality health information". The HONcode was founded under the auspices of the Geneva Department of Employment, Social Affairs and Health in 1995. It is a code used and approved by the Economic and Social Council and the WHO. It is also one of the first URLs used as a guide to reliable sources of health care information on the internet. The HONcode consists of a minimum mechanism to provide quality, objective, and transparent medical information to the internet users. The website may display the HONcode seal if they agree to comply with the standards listed, and they are subjected to random audits for compliance [9].

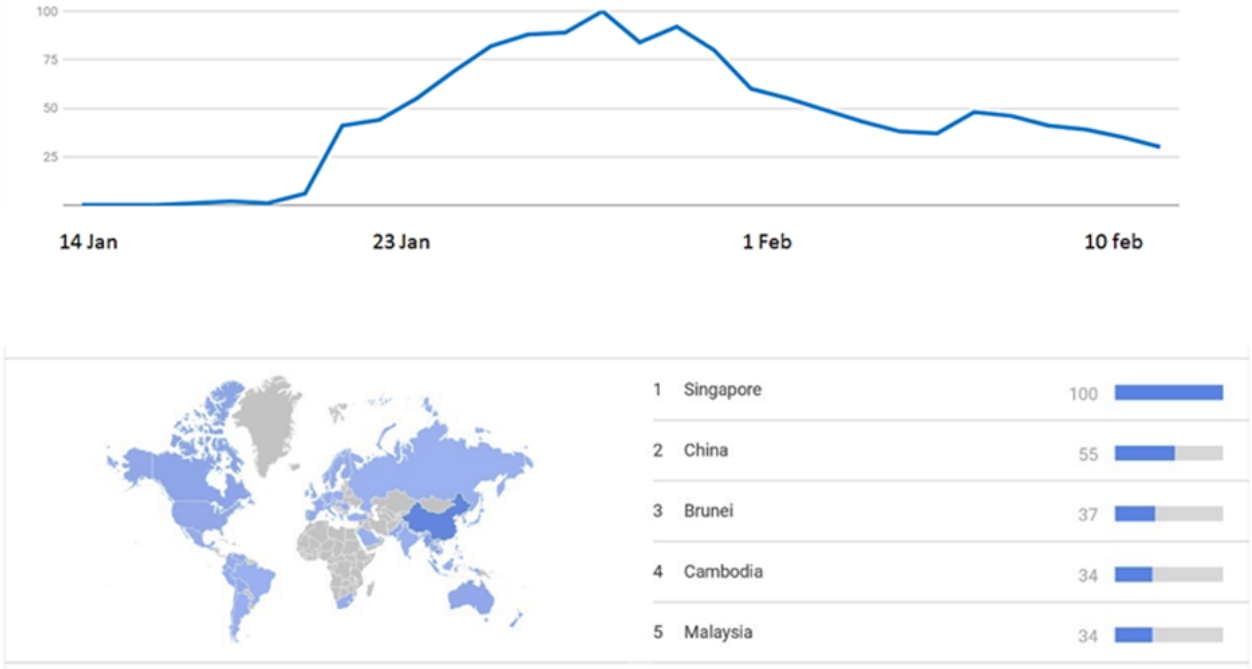
The JAMA benchmarks were published in 1997. According to Silberg et al [10], it is a set of four criteria designed to assess and evaluate the quality of health information on the internet. These benchmarks are authorship, attribution, disclosure, and currency. This tool lets the reader easily decide if the site has the basic components like transparency and reliability [11].

The DISCERN instrument is a valid and reliable tool to evaluate health information. It is the first standardized quality index and was created by the Division of Public Health and Primary Health Care at Oxford University, London. It is a valid and reliable 16-point questionnaire to aid health consumers and information providers in evaluating the quality of health information on any website [12].

The Google rank, or page rank, is an algorithm developed in 2002 used by Google to give a numeric value to websites depending on the number of times that other websites are directed to a particular site, and this determines a webpage's importance. This was one of the first tools used by Google to define the importance of websites, and currently, the algorithms are public [11].

Currently, COVID-19 has been a trending topic worldwide. Around January 10, 2020, most of the news around the world talked about a new coronavirus strain that started in China and was spreading fast. This created an avalanche of search for information on the internet called an "infodemic." In a few days, the network was filled with information, sometimes with accurate content and sometimes with fake content that pointed toward the possibility of becoming infected even after receiving regular mail from China [13]. By the end of January 2020 (20 days later), this infodemic increased, as the new disease had become a trending topic with the maximum search for a term reported by Google according to Google Trends, especially after the WHO declared COVID-19 as a global health emergency on January 31, 2020 (Figure 1) [14].

Figure 1. Data obtained through the Google Trends tool with the search term "Wuhan Coronavirus" between January 14 and February 14. The map shows the world trend of the searched terms on the same dates by country. Figures were obtained from Google Trends.



In this work, we evaluate the quality of online health information that internet users found about COVID-19 at the beginning of the epidemic from January until February 6. The search was performed using "Wuhan" and "Coronavirus" as keywords because, at that moment, these were the most popular keywords, and the objective was to evaluate what nonhealth personnel users found on the network. By February 6, 2020, the terms COVID-19 or SARS-CoV-2 were still not established.

Methods

Search Strategy

The search terms "Coronavirus" and "Wuhan" were used (February 6, 2020) on the Google search engine (google.com). The search was done using an updated browser of Google Chrome version 79.0.3945.130. We accessed Google from the University Anáhuac Puebla at Tlaxcalancingo, Puebla, México

Before the search, all existing cookies were deleted from the browser, and the Google settings were used to establish the English language as a condition.

We performed one search and the first 110 websites obtained were shared with the observers, who worked with each website. Websites that were not in the English or Spanish language were excluded. All the instruments were assessed by four independent observers for each website, and any disagreements were resolved by consensus prior to the final analysis.

The Google search engine itself was evaluated as part of the critical assessment and not just the landing page of the Google search results. Therefore, if further information was obtained elsewhere on the website via subheadings, links, or leading pages, this information was obtained as a result of being directed to it, either directly or indirectly, via the *original* Google search.

Quality Assessment Instruments

Quality evaluation tools have been developed to assess health information using various criteria. Amongst the tools available, we selected three different validated evaluation tools, the HONcode, the JAMA benchmarks, and the DISCERN tool.

HONcode

The HONcode is based on an 8-point code of conduct comprising of authority, complementarily, confidentiality, attribution, justifiability, transparency of authorship, financial disclosure, and advertising policy. Any website that complies with this code is granted permission to display the HON award-like badge on its website. The certificate is valid only for 1 year. The HONcode is the oldest quality evaluation tool being used to date [9]. To evaluate the HONcode, we downloaded its software, and, for each link, we searched for the seal.

JAMA Benchmarks

The JAMA benchmarks evaluate the following points: authorship (authors and contributors, their affiliations, and relevant credentials should be displayed), the attribution (clear references and sources for all content should be provided), the disclosure (ownership of the website, the sponsorship, the advertising, the underwriting, the commercial funding or support sources, and any potential conflicts of interest), and currency (dates of initial posting and updating of the content should be noted) [10]. For each criteria (authorship, attribution, currency, and disclosure) the website received 1 point; the range was from 0 to 4 points.

DISCERN Instrument

The DISCERN instrument comprised 3 sections, the first 2 assesses the reliability and the quality of the written information. The third section rates the publication as a whole. Each question

is scored on a range from 1 (definite no) to 5 (definite yes). A score of 2 and 4 is a range given for cases in which the criterion is partially met to some extent. The maximum total score is 80, and the quality of each website is classified as high (≥65 points), moderate (33-64 points), or low (16-32 points) [12]. To evaluate the DISCERN score, we designed a Microsoft Excel page where a row was assigned to each question of the instrument. Each website was evaluated, and the value of each question was introduced manually into the corresponding cell; the score for each question was from 1 to 5. For the 16th question, the function of mode was used with rows 1-15. The 17th row was the addition of rows 1-16, and that was the DISCERN value of the website.

Google Rank

Google Rank, or page rank, uses the URL of the site and the keyword used. The algorithm then determines the position number of the website. In this study, two free use rank sites were used [15,16]. They were used by entering the URL of each of the 110 sites and the same keywords that were used in the search: “coronavirus” and “Wuhan.”

Categorization

The websites reviewed were categorized based on affiliation (commercial, news, university or medical center, a nonprofit organization, or government), content type (medical facts, clinical trials, human interest stories, and questions and answers), and specialization of topic and content (website exclusively related to coronavirus or only part of the website).

Contrast to Medical Bibliography

From the results, the main ideas of the first 50 websites were compared to the medical literature available on PubMed, considering main ideas as all the facts mentioned on a website (eg, days between contagion and the onset of symptoms, genomic characteristics of the virus, recommendations to prevent contagion among others). The information was classified as true (if everything on the website was found in any published paper found in PubMed), partially true (if most of the information on the site was found in one or more papers published and found in PubMed, but there is still missing information), or false (if everything on the site was not found in any published article in PubMed). We avoided information on the number of cases and territorial virus expansion because this information could quickly change. The websites in which there was no health information to discuss, non-free-access websites, and websites considered medical literature were excluded.

Statistics

Quantitative analysis of the database was done. Besides comparisons of the values obtained in JAMA and DISCERN scores between the first 50 websites, the rest of the comparisons were determined using an unpaired *t* test. The statistical analysis was performed using the GraphPad Prism software.

Results

Google Trends

As previously mentioned, according to Google Trends, the search for coronavirus in the last 30 days was observed as is shown in Figure 1. It reached its maximum value on January 30; during this period of 30 days, the search was also a trending topic. The Google Trends also showed the behavior on a map, where countries with the highest levels of the search were highlighted. The more searched keywords according to Google Trends were “Coronavirus,” “outbreak epidemic,” “gross death rate,” “Coronavirus symptoms,” and “Coronavirus and China.”

The Google search for COVID-19 retrieved 309,000,000 results, and the first 110 websites were critically analyzed (Multimedia Appendix 1).

HONcode

The analysis of the HONcode showed that from the survey of 110 websites, only 1.8% (2 websites) had the HONcode seal (Table 1).

Table 1. Results of the analysis of the 110 websites consulted.

Variables	Websites, n
HONcode[a]	
Certified	2
Not certified	108
JAMA[b]	
0	43
1	26
2	19
3	11
4	11
DISCERN score	
High (≥65)	0
Moderate (33-64)	33
Low (16-32)	77
Categorization or affiliation	
News	61
Commercial	21
Nonprofit organization	5
Government	9
University	0
Medical center	1
Nonprofit organization or government	3
University or medical center	8
News or commercial	1
University or medical center and nonprofit organization	1
Exclusivity	
Partly exclusive	61
Exclusive	49
Subtype or content	
Medical facts	11
Question and answer	10
Human interest stories	43
Clinical trials	0
Medical facts and question and answers	5
Medical facts, human-interest stories, and question and answer	5
Medical facts and human-interest stories	27
Medical facts and clinical trial	3
Human-interest stories and question and answer	6
Language	
English	103
Spanish	7

[a]HONcode: Health on the Net Foundation Code of Conduct.

[b]JAMA: Journal of the American Medical Association.

JAMA Benchmarks

The JAMA benchmark analysis showed that, of the 110 websites, 39.1% (43 websites) did not fit any of the JAMA benchmark criteria, 23.6% (26 websites) achieved only 1 criterion, 17.3% (19 websites) achieved 2 criteria, 10.0% (11 websites) achieved 3 criteria, and 10.0% (11 websites) achieved all 4 criteria (Table 1).

On average, all the websites achieved a mean of 1.28 (SD 1.34) criteria; the first half of websites achieved a mean of 1.95 (SD 1.35) and the second half achieved a mean of 0.68 (SD 0.95) criteria. There was a significant difference between the first half and the second half (P<.001).

Of the 43 websites that did not achieve any of the JAMA benchmark criteria, 9 appeared in the first 50 websites. In addition, from the 11 websites that achieved four criteria, 10 were found on the first 50 websites, suggesting that the quality of the information may reduce after the first 55 websites.

DISCERN Score

The DISCERN score for the analyzed websites' results are as follows. Of the 110 websites, a high score (65 or more points) was not achieved by any of the websites, a moderate score (33-64) was achieved by 30.0% (n=33) of the websites, and a low score (16-32 points) was achieved by 70.0% (n=77) of the websites (Table 1).

On average, all websites achieved a mean score of 28.91 (SD 10.34). The first half of the websites achieved a mean score of 24.36 (SD 8.36), and the second half achieved a mean score of 33.43 (SD 10.21). There was a significant difference between the first half and the second half (P<.001).

Google Rank

The Google ranking yielded 7 websites with a ranking position for "Coronavirus" and 5 websites with a ranking position for "Wuhan"; only 2 websites had rankings for both keywords (website 1 and 28 in Multimedia Appendix 1). The best ranked website for the word "Wuhan" was the first website (Multimedia Appendix 1), and for the keyword "Coronavirus" it was the second website, which was also ranked in the top 10 websites of the Google ranking. Only 9.1% (n=10) of the 110 visited websites had a position in the Google ranking for one or both keywords in the top 100 positions.

Website Categorization

The analysis on the website categorization or affiliation showed that, of the 110 websites visited, 56.4% (n=62) were on general news pages, 19.1% (n=21) were on commercial pages, 8.2% (n=9) were on pages associated with a government, 7.3% (n=8) were on pages considered nonprofit organizations, and only 0.9% (n=1) were on the pages associated with universities or medical websites.

Of the 110 websites reviewed, 44.5% (n=49) of them presented exclusive information about the coronavirus, while 55.5% (n=61) presented it as part of the notes on the website.

Despite the fact that most of the sites were not specialized in medicine, 39.1% (n=43) of the information presented was considered health information; the rest of the websites presented epidemiological data, stories about the patients, or how people were living through the epidemic.

Language analysis showed that 92.7% (n=102) of the pages had English as their main language (Table 1).

Comparison to Medical Bibliography

The main ideas found in the text of the first 50 websites were analyzed to compare with the information from the medical bibliography. Website numbers 3, 10, 13, 22, 32, 33, 34, 39, 42, 43, 46, and 48 in Multimedia Appendix 1 were excluded, as there were no main ideas to compare with the medical bibliography. Website number 18 was excluded since it was not free access. Website 26 was excluded because it was considered medical literature.

From the remaining 36 websites, 15 had main ideas considered "True," 16 had main ideas considered "Partially true," and 5 had main ideas considered "False" compared to the medical literature present in PubMed at that specific time [17-24] (Multimedia Appendix 2).

Discussion

Due to the novelty of the disease, it was a trending topic by February 6, 2020. Google Trends reported it with a 100 factor before the Coronavirus had its final name, COVID-19 or SARS-CoV-2. It was not until Tuesday, February 20, that the WHO agency announced the official name as COVID-19. This name was chosen to avoid indicating a geographical location, animal species, or human ethnic group [25].

Most of the information that the internet users got came from news sources, representing 56.4% (62/110) of the websites returned by Google. At best, this news presented a summary interpretation of the statements from the health personnel involved in the treatment of the patients or information provided from health organizations like WHO. The infodemic at this time was that there was no information with clear scientific basis.

The evaluation of the quality of health information presented by the first 110 websites retrieved by the Google search engine showed that only 2 websites have the HONcode, 11 websites achieved the four JAMA benchmark criteria, and none of the websites were evaluated as excellent with the DISCERN instrument.

According to the Google ranking, the most influential websites were in English and appeared in the first 3 links displayed; although there was no direct relation between the position in the Google ranking and the site content's quality. The Google ranking might be influenced by the country where the search was performed (Mexico); COVID-19 was not present and people with no medical training were looking at news sites. From the website analysis of the health information quality at the time of the search, it became clear that the information provided by the Google search engine did not have the quality standards

required for health information, and it was not entirely reliable. The excess of poor-quality information without scientific support from the news and social media increased the interest in the information search, putting the world on alert for a possible pandemic that would cause many deaths, alerting users about an unknown virus, and presenting cataclysmic images.

It is important to emphasize that the internet users are responsible for the quality of information they obtain from websites. Nowadays, misinformation is an important problem; people do not tend to critically assess the information they read and often when making important decisions regarding their lives and health. The misinformation is associated with panic shopping, buying medical supplies or drugs, and, even worst, taking drugs without a medical prescription. The misinformation impact can be devastating, social media providers are trying to filter the fake news, but this has not stopped the conspiracy theorists, swindlers, and liars on the internet. The financial markets and governments are looking to avoid panic. The scientific information about COVID-19 flows freely in the networks like never before, but it must be accompanied with a proper interpretation by the media and internet users. In countries where drugs are sold without a prescription, people read clinical trials on social media and go to the pharmacy to buy all the drugs in stock as if it were toilet paper.

The internet is the most powerful force disrupting the news; the internet shifts the power from governments to society, and it is society who is pressuring the governments to make decisions, sometimes based on fake news. During the COVID-19 pandemic, it has been difficult for governments and search engines to control the quality and flow of information concerning the experiences of this pandemic. It is clear that governments as well as institutions like WHO must work together to create guidelines and control mechanisms over the information flow on the internet and establish global ethical codes under which health information can be published, as it also affects the politics and economies of the countries. It is also important to consider that some part of the population may prefer to receive information by other methods than the internet, such as radio, television, or newspapers. In 2019, It was estimated that only 53.9% of the world population has internet access, leaving the rest, mainly in the third world, without the tool of information searching [3].

To prevent inadequate responses and fears from the population, it is important that governments develop a strategy to teach their residents how to verify the quality of what they read, especially in the case of health information. Every day, the number of users looking for their diagnosis and treatment on the internet increases, making the internet a two-edged tool for the health sector. Government agencies should consider the use of a regulatory mechanism to control false or misleading health information. False health information can cause significant social harm by feeding false concepts of disease. In addition, health personnel must assume a role in society with these 5 recommended actions: (1) don’t share information if its veracity has not been proven; (2) participate on mass media programs to share legitimate information; (3) promote hygiene actions and vaccination; (4) educate patients to identify alarm symptoms and instruct them on what to do if these symptoms appear; (5) produce media content and promote websites of academic institutions.

The governments and health organizations like the WHO should take an active role of information on cases like the COVID-19 pandemic. Some of the actions that should be considered to spread correct and reliable information on the internet amongst their populations are to share reliable information or suggest some sources of reliable information on the government’s websites, subsidize more visibility of reliable information on massive search engines, subsidize scientific institutes or organizations to share reliable information, develop a tool where health personnel may assess the quality of information on websites, and use these assessments to find reliable information.

Authors' Contributions

ES-V contributed the idea and conception of the study, the work design, the analysis and interpretation, and gave the final approval. ES-V is the guarantor of the article. YC-B contributed to data acquisition and team organization. MM-P contributed to Google rank acquisition and evaluation. YC-B and MM-P contributed to data interpretation and writing. CR-V and MP-Z contributed to the literature search and information acquisition.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary file 1.
[DOCX File , 43 KB - publichealth_v6i2e18444_app1.docx]

Multimedia Appendix 2
Supplementary file 2.
[DOCX File , 31 KB - publichealth_v6i2e18444_app2.docx]

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Abbreviations

COVID-19: coronavirus disease
HONcode: Health on the Net Foundation Code of Conduct
JAMA: Journal of the American Medical Association
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Dentists' Awareness, Perception, and Attitude Regarding COVID-19 and Infection Control: Cross-Sectional Study Among Jordanian Dentists

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Abstract

Background: Despite the availability of prevention guidelines and recommendations on infection control, many dental practices lack the minimum requirements for infection control.

Objective: This study aimed to assess the level of awareness, perception, and attitude regarding the coronavirus disease (COVID-19) and infection control among Jordanian dentists.

Methods: The study population consisted of dentists who worked in private clinics, hospitals, and health centers in Jordan. An online questionnaire was sent to a sample of Jordanian dentists in March 2020. The questionnaire was comprised of a series of questions about dentists' demographic characteristics; their awareness of the incubation period, the symptoms of the disease, mode of transmission of COVID-19 and infection control measures for preventing COVID-19; and their attitude toward treating patients with COVID-19.

Results: This study included a total of 368 dentists aged 22-73 years (mean 32.9 years, SD 10.6 years). A total of 112 (30.4%) dentists had completed a master or residency program in dentistry, 195 (53.0%) had received training in infection control in dentistry, and 28 (7.6%) had attended training or lectures regarding COVID-19. A total of 133 (36.1%) dentists reported that the incubation period is 1-14 days. The majority of dentists were aware of COVID-19 symptoms and ways of identifying patients at risk of having COVID-19, were able to correctly report known modes of transmission, and were aware of measures for preventing COVID-19 transmission in dental clinics. A total of 275 (74.7%) believed that it was necessary to ask patients to sit far from each other, wear masks while in the waiting room, and wash hands before getting in the dental chair to decrease disease transmission.

Conclusions: Jordanian dentists were aware of COVID-19 symptoms, mode of transmission, and infection controls and measures in dental clinics. However, dentists had limited comprehension of the extra precautionary measures that protect the dental staff and other patients from COVID-19. National and international guidelines should be sent by the regional and national dental associations to all registered dentists during a crisis, including the COVID-19 pandemic, to make sure that dentists are well informed and aware of best practices and recommended disease management approaches.

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KEYWORDS

COVID-19; infection; dentist; infection control

Introduction

Background

The coronavirus disease (COVID-19) is a newly discovered viral infection that started in Wuhan, China and caused the outbreak of pneumonia in the rest of the world. It seems that the rapidly spreading virus is more contagious than severe acute respiratory syndrome coronavirus and Middle East respiratory syndrome coronavirus [1]. A suggested route of human-to-human transmission is through airborne droplets, touching or coming into contact with an infected person or a contaminated surface. Moreover, other routes such as blood or saliva have not been explored but are possible because of the documented transmission of blood-borne infectious diseases such as HIV/AIDS, hepatitis C virus, and hepatitis B virus through blood or saliva. These routes of transmission increase the concern about a similar route of transmission for COVID-19 in the dental setting [2].

COVID-19 and Dental Treatment

A large number of medical staff were reported to have acquired the disease while working with infected individuals [3]. The dental clinic is not an exception for a similar possibility of transmitting and acquiring the infection between staff or individuals; moreover, the dental clinic could be a riskier environment for spreading the virus because of the close contact with patients and the nature of the dental treatment [4]. Although patients diagnosed with COVID-19 are not supposed to receive dental treatments, dental emergencies can occur, and close contact would be unavoidable. Furthermore, both the relatively prolonged incubation period of the disease (the median incubation period was estimated to be 5.1 days, 95% CI 4.5-5.8 [5] or up to 14 days for some cases [6,7] before any symptoms could even be detected) and the postinfection period make it challenging for medical staff to recognize the existence of COVID-19 infections, which could increase the transmission of the disease during these lay periods. Therefore, patients infected with COVID-19, without showing symptoms, are of a great threat to dentists and other members of the dental team. Dentists, thereby, should entertain a high level of awareness and integrity to deal with the disease and be able to control and manage its spread.

There are practical guidelines recommended for dentists and dental staff by the Centers for Disease Control and Prevention (CDC), the American Dental Association (ADA), and the World Health Organization to control the spread of COVID-19 [8-10]. Like with other contagious infections, these recommendations include personal protective equipment, hand washing, detailed patient evaluation, rubber dam isolation, antiretraction handpiece, mouth rinsing before dental procedures, and disinfection of the clinic. In addition, some guidelines and reports have provided useful information about the signs and symptoms of the disease, ways of transmission, and referral mechanisms to increase dentists' knowledge and prevention practices, so they could contribute, at a population level, in disease control and prevention [1,8].

Objectives

Despite the availability of prevention guidelines and recommendations on disease control, many dental practices lack the minimum requirements of infection control, which resulted from the low interest in taking the mandatory precautions. This lack of interest in making an extra, but essential, effort could be attributed to the high volume of patients treated in clinics that charge low or reduced dental fees [11,12]. This situation is true for many settings, including some dental clinics in Jordan, which, like many other countries, has a wide range of dental facilities from clinics that properly apply infection control measures to clinics that poorly apply prevention measures. It is important to implement sound prevention measures in dental clinics and to increase the level of awareness among dentists to improve their prevention. Hence, this study aimed to assess the level of awareness, perception, and attitude regarding COVID-19 and infection control among Jordanian dentists.

Methods

Study Population

Our study population consisted of dentists who work in Jordan, regardless of their place of work, in either private clinics, hospitals, or health centers. This survey was conducted in March 2020. An online questionnaire using Google Forms was used to collect the data. The sample of dentists was selected through Facebook groups for dentists. These groups were created by members of the Jordan Dental Association, and only dentists who work in Jordan can be involved in these groups by confirming their registration with the Jordanian dental association and their places of work. Although there were numerous groups, only five groups were randomly chosen: Jordanian dentists, dentists without borders, Jordanian dental club, Jordanian society of pediatric dentistry, and Jordanian dentists' forum. Within the five selected groups, 700 dentists were randomly selected to participate in the study by their Facebook profiles. However, each participant who was randomly selected was contacted individually to make sure that they were a dentist and worked in Jordan. The questionnaires were anonymous to maintain the privacy and confidentiality of all information collected in the study. Ethical approval was obtained from the Institutional Review Board at Jordan University of Science and Technology.

Study Instrument

The questions on the survey were developed after reviewing pertinent literature and the international guidelines [1,8-10]. The questionnaire was designed in English and comprised of a series of questions pertaining to sociodemographic characteristics, the knowledge of dentists, and their attitudes and perceptions toward COVID-19 and infection control in dental clinics. The survey was a structured multiple-choice questionnaire divided into sections: dentists' demographic and profession-related characteristics; dentists' awareness of incubation period, the symptoms of the disease, the mode of transmission of COVID-19, and infection control measures for preventing COVID-19; and dentists' attitude toward treating patients with COVID-19.

Data Analysis

Data were analyzed using SPSS (IBM Corp). Descriptive statistical analysis was used to describe items included in the survey. Means and standard deviations were used to describe the continuous variables, and percentages were used to describe the categorical data.

Results

Participants' Characteristics

This study included a total of 368 (245 females and 123 males) dentists, forming a response rate of about 52.6% (386 participated out of 700 invited dentists). Their age ranged from 22-73 years with a mean of 32.9 (SD 10.6) years. Years of dental practice ranged from 1-30 years with a mean of 9.4 (SD 8.9) years. The participants' characteristics are shown in Table 1. A total of 112 (30.4%) had completed a master or residency program in dentistry, 195 (53.0%) had received training in infection control in dentistry, and 28 (7.6%) had attended training or received lectures regarding COVID-19.

Table 1. The characteristics of the 368 dentists enrolled in the study.

Variable	Dentists, n (%)
Gender	
Female	245 (66.6)
Male	123 (33.4)
Age (years)	
<30	199 (54.1)
≥30	169 (45.9)
Years of practice	
<5	185 (50.3)
5-10	59 (16.0)
>10	124 (33.7)
Region	
Middle	190 (51.6)
North	148 (40.2)
South	30 (8.2)
Health sector	
University clinics	112 (30.4)
Military sector	28 (7.6)
Private sector	144 (39.1)
Public sector	84 (22.8)

Awareness About the Incubation Period, Symptoms, and Mode of Transmission of the COVID-19 Infection

When asked about the incubation period, over one-third of dentists correctly reported 1-14 days. The percentage of dentists who reported the different symptoms of the COVID-19 infection are shown in Table 2. The majority reported fever and cough as symptoms. Diarrhea, vomiting, and runny nose were reported by almost one-third of dentists. Joint and muscle pain was reported by only a few dentists. Over one-third of the dentists reported that patients with COVID-19 infection may present with no symptoms. When they were asked about aspects that should be considered to identify patients at risk of having COVID-19, 316 (85.9%) mentioned the presence of symptoms of a respiratory infection, 347 (94.3%) mentioned history of travel to areas experiencing transmission of COVID-19, and 345 (93.8%) mentioned history of contact with possible infected patients. In addition, most dentists correctly reported known modes of transmission (Table 2).

Table 2. Dentists' awareness about incubation period, symptoms, and mode of transmission of the coronavirus disease infection (N=368).

Variable	Dentists, n (%)
Incubation period (days)	
1-14	133 (36.1)
2-7	12 (3.3)
7-14	162 (44.0)
7-21 days	61 (16.6)
Symptoms of the COVID-19[a] infection	
Fever	363 (98.6)
Cough	335 (91.0)
Shortness of breath	316 (85.9)
Diarrhea	147 (39.9)
Vomiting	119 (32.3)
Runny nose	133 (36.1)
Sore throat	105 (28.5)
Red eyes	28 (7.6)
Skin rash	21 (5.7)
Joint or muscle pain	7 (1.9)
May present with no symptoms	127 (34.5)
Mode of transmission	
Coughing and sneezing	333 (90.5)
Hand shaking	315 (85.6)
Touching surfaces such as doorknobs and tables	343 (93.2)

[a]COVID-19: coronavirus disease.

Awareness of Measures for Preventing COVID-19 Transmission in Dental Clinics

The majority of the 368 dentists reported that cleaning hands frequently by using alcohol-based hand rub or soap and water, routinely cleaning and disinfecting surfaces in contact with known or suspected patients, and wearing personal protective equipment can help prevent transmission from patients with known or suspected COVID-19. The percentages of dentists who reported other specific measures are shown in Table 3. Almost all dentists (n=359, 97.6%) reported that it is important to change both masks and gloves regularly to decrease the possibility of transmitting infections to patients and to themselves.

Table 3. Dentists' awareness of measures for the prevention of coronavirus disease transmission in dental clinics (N=368).

Measures for prevention	Dentists, n (%)
Frequently clean hands by using alcohol-based hand rub or soap and water	354 (96.2)
Routinely clean and disinfect surfaces in contact with known or suspected patients	347 (94.3)
Personal protective equipment such as dental goggles, masks, and gloves	342 (92.9)
Put facemask on known or suspected patients	325 (88.3)
Avoid moving and transporting patients out of their area unless necessary	310 (84.2)
All health staff members wear protective clothing	304 (82.6)
Place known or suspected patients in adequately ventilated single rooms	284 (77.2)

Perception of COVID-19

A total of 65 (17.7%) of the 368 dentists perceived COVID-19 as very dangerous, 264 (71.7%) perceived it as moderately dangerous, and 35 (9.5%) perceived it as not dangerous. Almost one-third (n=135, 36.7%) of dentists believed that COVID-19 is not a serious public health issue. The majority (n=360, 97.8%) reported that it is important to educate people about COVID-19 to prevent the spread of the disease.

Attitude Toward Treatment of Patients With COVID-19

More than half (n=203, 55.2%) of the 368 dentists reported that COVID-19 symptoms often resolve with time and do not require any special treatment. Regarding dentists' precautionary actions in the dental clinic, a total of 275 (74.7%) believed that it was necessary to ask patients to sit far from each other, wear masks while in the waiting room, and wash hands before getting in the dental chair to decrease disease transmission, while 80 (21.7%) believed that this was not necessary and could cause panic. However, a total of 304 (82.6%) dentists reported that they prefer to avoid working with a patient with a suspected case of COVID-19.

Dentists reported different attitudes toward a patient sneezing or coughing in their clinics: 161 (43.8%) mentioned that they would refer the patient to the hospital without treating them, 17 (4.6%) mentioned that they would refuse treating the patient and ask them to leave the clinic, 182 (49.5%) mentioned that they would treat the patient and ask them to go to the hospital.

Moreover, a total of 119 (32.3%) dentists reported that they would allow any of their dental staff to work with patients if they had flu-like symptoms. Only 214 (58.2%) reported that they know whom to contact in a situation where there has been an unprotected exposure to a patient with known or suspected COVID-19, and 279 (75.8%) reported that they know what to do if they have signs or symptoms suspected of COVID-19 infection.

For the dentists' role in spreading information and increasing awareness, a total of 249 (67.7%) dentists reported that the dentist role in teaching others about COVID-19 is very significant, and 94 (25.5%) reported that it is moderately significant.

Discussion

This survey provides an insight on the level of awareness, perception, and attitude of Jordanian dentists on infection control with a special emphasis on COVID-19 at the time of the outbreak in 2020. This study included a sample of Jordanian dentists. Females were predominant in this sample, which might be explained because the number of female dentists in Jordan is higher than the number of male dentists based on the latest Jordan Dental Association statistics [13].

The estimated incubation period of COVID-19 is up to 14 days [6,7]. Dentists in this study varied in their knowledge about the incubation period of the disease, but it is essential to know the right incubation period because of its role in determining the safe period to treat suspected patients [14]. However, it's imperative for dentists to carry on with preventive measures for all their patients, all the time. Knowledge about respiratory disease contagion was noticed in other studies to be lower among dentists [15] than among other health care providers [16], despite the proximity of patient to provider present in dental care [4]. Nonetheless, Jordanian dentists in this sample could identify the main symptoms of COVID-19, which helps dentists to recognize the threat and take the necessary actions and is considered essential in the management [14] and control of the spread of the disease [1]. Dentists response to prevention measures were better for personal protective equipment and disinfection and sanitation procedures than for measures applied to dental staff or patients, such as special clothing or ventilation. The latest precautionary actions could possibly be viewed by dentists as extra protective measures that are not necessary when combined with their understanding that infections occur mainly through direct contact between mucous membranes and contaminated hands [9].

There has been no evidence-based specific treatment for COVID-19, and management of COVID-19 has been largely supportive [8]. The current approach to COVID-19 is to control the source of infection; use infection prevention and control measures to lower the risk of transmission; and provide early diagnosis, isolation, and supportive care for affected patients [17]. This fact was reflected by the response of participants to treatment; almost half of dentists thought that the disease self-resolves over time with no need for special treatment. This perception about the disease self-resolution resulted in most participants perceiving COVID-19 as moderately dangerous (n=264/368, 71.7%), and almost one-third believed that COVID-19 was not a serious public health issue. Although their perception about the disease self-resolution could have been explained by their perception about its threat; there were no "local" cases in Jordan at the time of data collection. In addition, dentists' perception about the seriousness of the disease could be because some (n=80, 21.7%) did not see a need to ask patients to sit far from each other, wear masks while in the waiting room, or wash hands before getting in the dental chair to decrease disease transmission. However, the vast majority (n=304, 82.6%) would prefer to avoid working with a patient with suspected COVID-19 because of the possibility of disease transmission during incubation periods, during which no symptoms may appear [1].

The attitude of dentists regarding what to do in case a patient was sneezing or coughing in their clinics varied; 43.8% (n=161) would refer the patient to the hospital without treating them, 4.6% (n=17) would refuse treatment, and 49.5% (n=182) would treat the patient and then refer them to the hospital. Some dentists (n=119, 32.3%) would allow their dental staff to work with patients if they had flu-like symptoms. During the outbreak of COVID-19, dentists should evaluate risk of transmission through measurements of the temperature of every staff and patient as a routine procedure. Patients should be asked about their health status and any history of recent contact or travel [8]; patients and their accompanying persons should be provided with medical masks upon entry to the clinic. Patients with a fever should be registered and referred to designated hospitals. If a patient has been to any epidemic regions within the past 14 days, quarantining for at least 14 days is recommended. In areas where COVID-19 spreads, nonurgent dental treatment should be postponed [18]. It is still not known when treatments can be done.

Over half of the dentists (n=214, 58.2%) knew whom to contact in a situation of an unprotected exposure to a known or suspected COVID-19 patient, and 75.8% (n=279) reported that they knew what to do if they had signs or symptoms of a suspected COVID-19 infection. By now, there has been no

consensus on provision of dental treatment during the COVID-19 epidemic. Based on relevant guidelines and research, dentists should take strict personal protection measures and avoid or minimize operations that may produce droplets or aerosols [18]. A 4-handed technique is useful for infection control, and use of saliva ejectors with low or high volume reduces droplet and aerosol production [1,9]. The consensus of the vast majority (n=360, 97.8%) of dentists about the importance of educating others about COVID-19 to prevent the spread of the disease was high, but they should follow the guidelines from the CDC and ADA and recommendations for infection prevention and control based on the local epidemic situation.

Despite the findings introduced here, it is important to stress that this survey had limitations, including the relatively low response rate, which resulted in a smaller than expected sample size. This could have been caused by the short period of data collection. However, this is considered a moderate sample size. Moreover, this pandemic has caused many to be busy with watching the news and taking care of personal affairs. This means that those who were active on social media during the short period of data collection were the only ones that had the chance to participate in the study. This could result in selection bias and sampling error, which prevents the ability to generalize our results.

In conclusion, Jordanian dentists were aware of COVID-19 symptoms, mode of transmission, infection control, and measures in dental clinics. However, dentists had limited comprehension of the extra precautionary measures that protect the dental staff and other patients from COVID-19. Guidelines released by reputable institutions should be sent by the regional and national dental associations to all registered dentists during a crisis, including this COVID -19 pandemic, to make sure that dentists are well informed and aware of the best practices and recommended disease management approaches.

Conflicts of Interest

None declared.

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Abbreviations

ADA: American Dental Association
CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease

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Original Paper

Predicting COVID-19 Incidence Through Analysis of Google Trends Data in Iran: Data Mining and Deep Learning Pilot Study

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Abstract

Background: The recent global outbreak of coronavirus disease (COVID-19) is affecting many countries worldwide. Iran is one of the top 10 most affected countries. Search engines provide useful data from populations, and these data might be useful to analyze epidemics. Utilizing data mining methods on electronic resources' data might provide a better insight into the COVID-19 outbreak to manage the health crisis in each country and worldwide.

Objective: This study aimed to predict the incidence of COVID-19 in Iran.

Methods: Data were obtained from the Google Trends website. Linear regression and long short-term memory (LSTM) models were used to estimate the number of positive COVID-19 cases. All models were evaluated using 10-fold cross-validation, and root mean square error (RMSE) was used as the performance metric.

Results: The linear regression model predicted the incidence with an RMSE of 7.562 (SD 6.492). The most effective factors besides previous day incidence included the search frequency of handwashing, hand sanitizer, and antiseptic topics. The RMSE of the LSTM model was 27.187 (SD 20.705).

Conclusions: Data mining algorithms can be employed to predict trends of outbreaks. This prediction might support policymakers and health care managers to plan and allocate health care resources accordingly.

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KEYWORDS

coronavirus; COVID-19; prediction; incidence; Google Trends; linear regression; LSTM; pandemic; outbreak; public health

Introduction

Recently, a respiratory disease originating from coronavirus occurred in Wuhan City of China. Since the first positive case of this virus was in 2019, this coronavirus was named coronavirus disease (COVID-19) by the World Health Organization (WHO) [1]. Some hypotheses attribute the origin of this virus to seafood and bats [2].

COVID-19 has spread globally and has affected most countries; it was defined as a pandemic by the WHO in March 2020 [3]. As of March 21, 2020, COVID-19 has affected 186 countries and territories around the world, with more than 280,000 confirmed cases and 11,842 deaths [4]. Iran is one of the top 10 countries affected by this virus [4].

As COVID-19 is spreading rapidly worldwide, prediction models can help in health resource management and planning for prevention purposes. Google search data is one information resource that contains useful information to predict and estimate epidemics [5]. Data mining algorithms and techniques are well-known tools for predictive model development and data analysis. They can implicitly extract useful information from raw data [6-8]. The extracted knowledge can be used in different areas such as the health care industry. Recently, a large amount of data was generated in health care, including those on patients, diseases, and diagnoses.

The tasks in data mining fall into two categories: (1) descriptive tasks that deal with the general properties of the data and (2) predictive tasks, wherein the goal is to build models that can estimate the mapping from inputs to outputs by using a sample of data called training data. The trained models can be deployed to make predictions of the outputs for unseen inputs. These techniques are more flexible and efficient for exploratory analysis than the traditional statistical analysis [9].

In this study, data mining models were used to build predictive models from Google search data to predict the incidence of COVID-19 in Iran.

Methods

Dataset

The daily new cases of coronavirus (daily incidence) from February 15, 2020, to March 18, 2020, in Iran were obtained from the Worldometer website [10].

Google Trends [11] was searched for concepts related to COVID-19, from February 10, 2020, to March 18, 2020. The related concepts were suggested by one of the authors. A dataset consisting of 10 input features including the previous day's search trends, cases of the previous day, and a target value (new cases of that day) was created. The total number of entries was calculated for the 37 days. The list of features is shown in Table 1. The terms in square brackets were searched in the corresponding Persian language words. The "pd" postfix in the features' name indicates that the features are related to the previous day.

Google Trends does not provide absolute search numbers but instead, provides a measure entitled interest over time, which is described as "A value of 100 is the peak popularity for the term. A value of 50 means that the term is half as popular. A score of 0 means there was not enough data for this term" [11]; for consistency, the values of the daily new cases were transformed to the range between 0 to 100.

Table 1. Features used for predicting new COVID-19 cases.

Feature name	Description
[Corona]_pd	The interest of "Corona" search term in Persian for the previous day in Iran
COVID-19_pd[a]	The interest of "COVID-19" search term for the previous day in Iran
Coronavirus_pd	The interest of "Coronavirus" topic for the previous day in Iran
[Antiseptic selling]_pd	The interest of "Antiseptic selling" search term in Persian for the previous day in Iran
[Antiseptic buying]_pd	The interest of "Antiseptic buying" search term in Persian for the previous day in Iran
[Hand washing]_pd	The interest of "Handwashing" search term in Persian for the previous day in Iran
Hand sanitizer_pd	The interest of "Hand sanitizer" topic for the previous day in Iran
Ethanol_pd	The interest of "Ethanol" topic for the previous day in Iran
Antiseptic_pd	The interest of "Antiseptic" topic for the previous day in Iran
Cases_pd	COVID-19 Incidence of the previous day in Iran
New cases	COVID-19 Incidence of prediction day in Iran (Label)

[a]COVID-19: coronavirus disease

Modeling and Evaluation

Linear Regression

One of the data mining techniques used for prediction tasks is linear regression. In a problem with one predictor, this technique tries to find the best line to fit. That line could relate the predictor and prediction values. The extended version of this one-predictor regression is called multiple linear regression and is used for multiple-predictor problems [12]. We used this type of linear regression in this study.

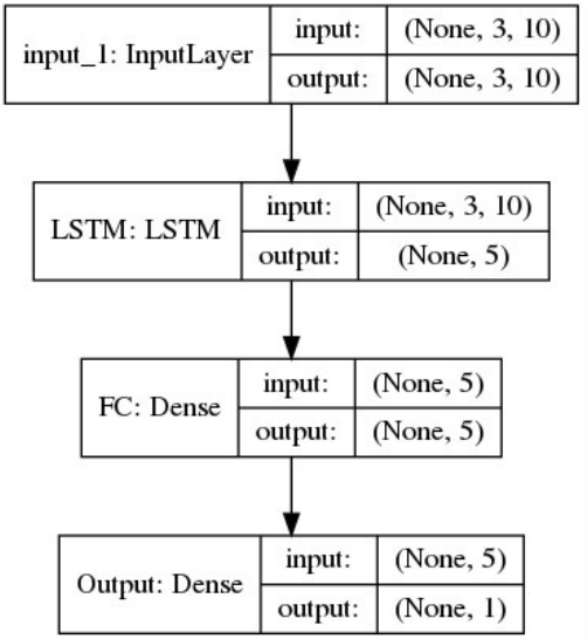
Long Short-Term Memory

Long short-term memory (LSTM) is an artificial recurrent neural network that is an effective model for the prediction of time series where data are sequential [9]. By storing the past in hidden states, they can predict the outputs more accurately. In this study, the aim was to estimate the number of positive COVID-19 cases through time; as this is a well-suited task for the LSTM model, we used this model in our study.

The linear regression model and a 3-layer LSTM model (Figure 1) are employed to predict the daily new cases. RapidMiner Studio 9.3.001 (RapidMiner GmbH) and Python 3.7.3 (Python Software Foundation) were used for modeling and evaluation.

Tensorflow (Google Brain Team) and Keras (François Cholle) were used as frameworks for training LSTM models. In addition, 10-fold cross-validation was used to evaluate the performance of the models, and the root mean square error (RMSE) metric was chosen for performance evaluation:

Figure 1. Proposed LSTM network architecture. LSTM: long short-term memory.



Results

The features' effect in the linear regression model is shown in Table 2. The RMSE for the linear regression model was 7.562 (SD 6.492). The LSTM RMSE was 27.187 (SD 20.705). The training and validation loss of the LSTM model is shown in Figure 2. The predictions made by these models are shown in Figure 3.

Table 2. Features' effect on new daily cases in the linear regression model.

Feature	Coefficient (SE)	*t* value	*P* value
[Corona]_pd	–1.58 (0.77)	–2.05	.05
COVID-19_pd[a]	0.27 (0.12)	2.28	.03
Coronavirus_pd	1.55 (0.69)	2.26	.03
[Antiseptic selling] _pd	–0.09 (0.11)	–0.78	.44
[Antiseptic buying] _pd	0.32 (0.14)	2.33	.03
[Hand washing] _pd	0.44 (0.15)	3.01	.006
Hand sanitizer_pd	–2.01 (0.50)	–4.00	<.001
Antiseptic	1.52 (0.54)	2.80	.009
New cases_pd	1.03 (0.17)	6.05	<.001

[a]COVID-19: coronavirus disease

Figure 2. Training and validation loss of the long short-term memory model. MSE: mean squared error.

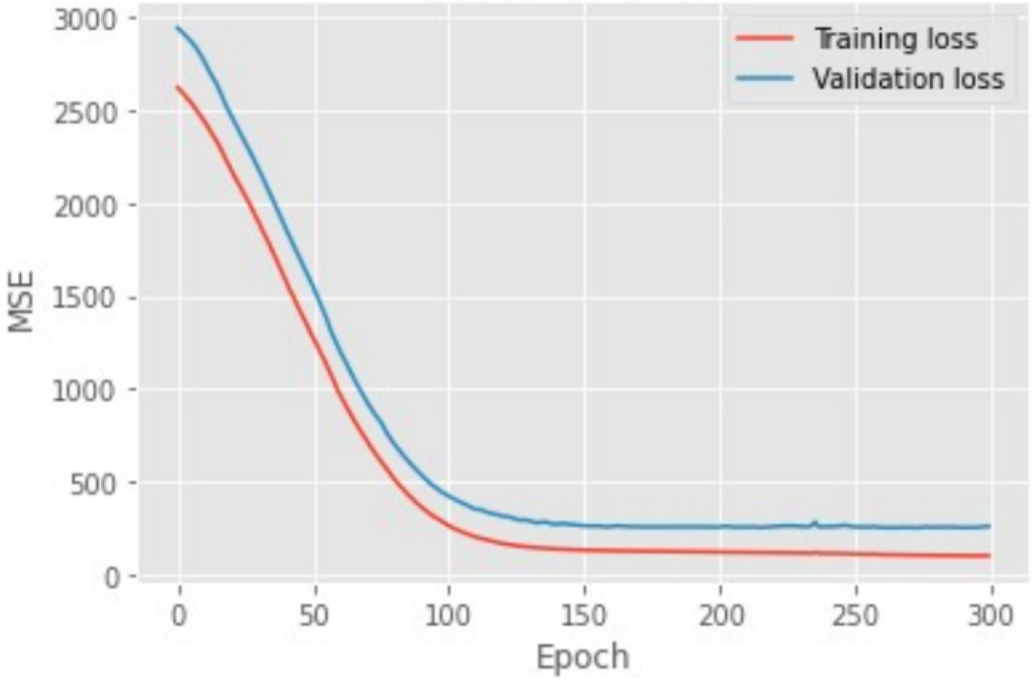
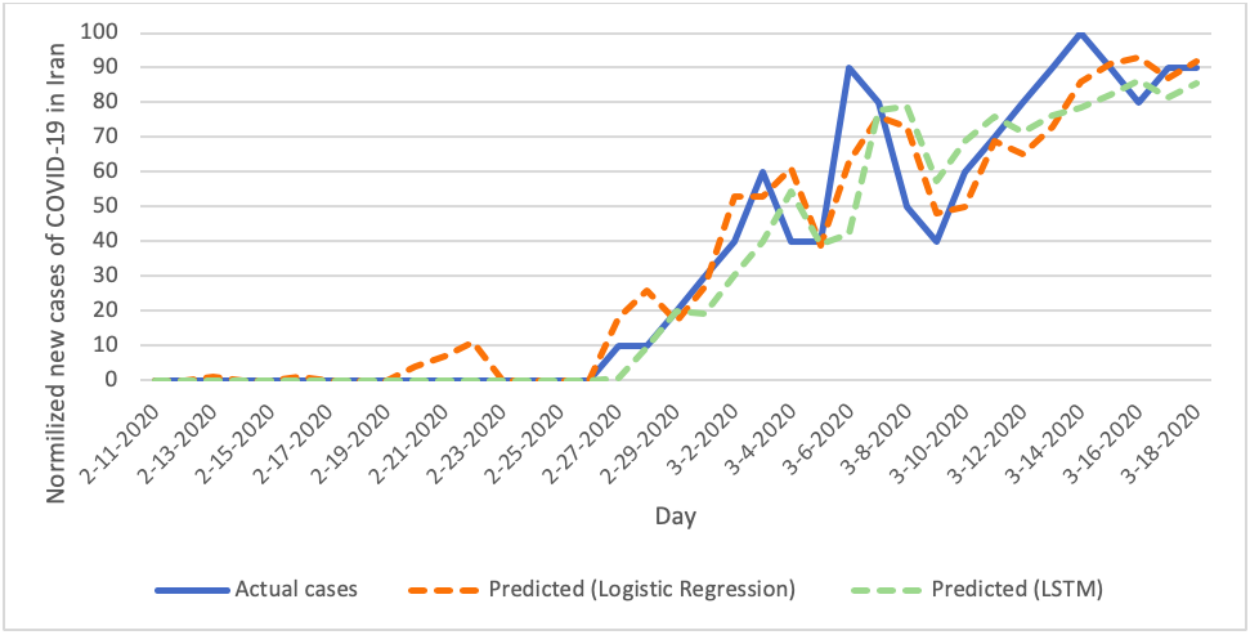


Figure 3. Actual and predicted new cases of COVID-19. LSTM: long short-term memory; COVID-19: coronavirus disease.



Discussion

In this study, we proposed the use of prediction models for COVID-19 incidence in Iran using Google Trends data. Although the predictions are not very precise, they can be helpful for a base idea to build accurate models from more aggregation of data.

The features' effect of the linear regression model shows that besides new cases in the previous day, hand sanitizer, handwashing, and antiseptic topics were the focus of the population. It could be inferred that people's worries were increasing, and they were seeking prevention solutions. The lags in the prediction might have originated from other countries' incidence. In other words, the population could be more sensitive and engaged in their health care after hearing news about the epidemic in other countries. This model could be used for other types of interventions such as assessing individuals' awareness and engagement. Health authorities might use these data for measuring the information's broadcast effect on the population and obtaining feedback from the search statistics.

The LSTM model showed a fluctuated performance in the folds while training loss was low. This indicates overfitting in the LSTM model because of the limited amount of training data. However, a low training error shows that the LSTM model can extract the pattern in the data. Therefore, we believe that by

increasing the amount of training data, the LSTM model can outperform other models for this task. In addition, owing to the presence of just a few samples in each test fold (4 instances) and the subsequent high variation in RMSE, evaluation of the LSTM model was repeated with 3-fold cross-validation and the obtained RMSE was 13.45 (SD 7.90).

Past work on influenza and Zika virus predictions, for example, in the study by Santillana et al [13] in 2015, proposed a machine learning method for predicting influenza in the United States. In their study, the authors used data from Google searches along with Twitter data, hospital visit records, and a surveillance system. They provided multiple estimates to have an unbiased and more accurate prediction. They also showed that social media contains important information for effectively predicting disease incidence.

In 2017, McGough et al [14] also proposed a Zika virus prediction system by using Zika-related Google searches, Twitter microblogs, and a digital surveillance system. They also showed that the internet-based sources were useful to predict weekly Zika cases. In another related study in 2016, Majumder et al [15] used HealthMap surveillance data and Google Trends to predict cases of Zika virus in Colombia [15] and showed that digital surveillance data could be useful for the prediction of Zika cases. Further, in 2017, Teng et al [16] proposed a prediction model for Zika virus using search data from Google Trends and built the model using an autoregressive integrated moving average. They found a strong correlation between Zika-related searches and Zika cases. For the incidence prediction of influenza, socioenvironmental factors were considered when developing an epidemiological model named Susceptible Exposed to Infectious Recovered (SEIR) [17]. The model supports decision makers to factor the mass media and climate factors into the classical epidemic models. Another study emphasized the importance of environmental factors for the development of an influenza prediction model [18]. The findings of these studies along with our study show that internet resources could be helpful in pandemic forecasting.

The easy-to-obtain Google search data is a more dynamic and available source in comparison with traditional data sources. It could be a representation of the population's thoughts, concerns, conditions, and needs in multiple periods. The major strength of this study is use of these data to predict the epidemiology of COVID-19 for the first time in the country.

In contrast, one major limitation of this study is the limited access to the Google Search data. Since Google Trends just provides data based on "interest" measure, more accurate and informative models could be built if the absolute search frequency is available for the researchers. It is worth mentioning that we used some of the keywords related to COVID-19 for extracting Google search frequencies; the selected keywords may have been incomplete and further research could aim to identify the most relevant set of keywords. In addition, future research should combine other data sources such as social media information, people's contacts with the special call center for COVID-19, mass media, environmental and climate factors, and screening registries. Furthermore, in the broader context, such predictions could be made for other countries and even globally.

In conclusion, the data mining models could help policymakers and health managers to plan health care resources and control the prevention of an epidemic outbreak. The availability of high-quality and timely data in the early stages of the outbreak collaboration of the researchers to analyze the data could have positive effects on health care resource planning.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
LSTM: long short-term memory
RMSE: root mean square error
SEIR: Susceptible Exposed to Infectious Recovered
WHO: World Health Organization

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Viewpoint

Urban Intelligence for Pandemic Response: Viewpoint

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Abstract

Previous epidemic management research proves the importance of city-level information, but also highlights limited expertise in urban data applications during a pandemic outbreak. In this paper, we provide an overview of city-level information, in combination with analytical and operational capacity, that define urban intelligence for supporting response to disease outbreaks. We present five components (movement, facilities, people, information, and engagement) that have been previously investigated but remain siloed to successfully orchestrate an integrated pandemic response. Reflecting on the coronavirus disease (COVID-19) outbreak that was first identified in Wuhan, China, we discuss the opportunities, technical challenges, and foreseeable controversies for deploying urban intelligence during a pandemic. Finally, we emphasize the urgency of building urban intelligence through cross-disciplinary research and collaborative practice on a global scale.

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KEYWORDS

urban informatics; urban science; data science; health emergency; medical informatics; COVID-19; pandemic; outbreak; public health; infectious disease

Introduction

Cities have become the "locus of risks" due to increasing natural disasters, health pandemics, political protests, and organized crime [1]. Megacities, which the United Nations defines as more than 10 million citizens, face increasing risks in environmental and population health, despite their economic prosperity and status as hubs for cultural exchange and technological innovation. The United Nations predicts that there will be 43 megacities by 2030, with the majority of them in developing countries. By 2050, the world population will be nearly 10 billion, with an estimated 68% living in urban areas [2]. Due to their population density and connectivity, megacities are particularly vulnerable to infectious diseases as seen in the dengue, Zika, and severe acute respiratory syndrome epidemics. Meanwhile, the rapid development of information and communications technology (ICT), Internet of Things, cloud computing, and smartphone apps has enabled near real time information sharing. The large volume, velocity, and variety of urban data enable a deeper and holistic understanding of urban conditions and real time situations.

The unfolding of the current coronavirus disease (COVID-19) pandemic has drawn significant global attention. The outbreak was first identified in Wuhan, a megacity with more than 11 million people in China [3]. The soaring number of confirmed cases and deaths immediately drew serious attention from the medical community to address the pandemic by employing different approaches. Although there is extensive scientific literature on the environmental, social, economic, and health aspects of urban epidemics, most studies focus on long-term planning and public policy research. Studies have revealed that the city-level endogenous differences, including geography, population characteristics, spatial structure, regional connectivity, and microclimate, are associated with variations in epidemic dynamics (eg, transmission potential and infection patterns) across cities [4]. However, few studies have addressed

how urban data and data science methodologies can be applied for pandemic response. As an interdisciplinary field, data science provides tools for better and timely information management and data use. In this article, we highlight the urgency to develop city data expertise and data science practice to better design information collection and integrate predictive analytics to implement real time responses in cities. Reflecting on the ongoing novel coronavirus pandemic, we explore two critical questions: What are currently available data in cities? What are the possible uses of urban data for the epidemic response?

First, we define urban intelligence as a capacity that analyzes city-level information using data science methods and explore its role in a pandemic response. In this context, we present five well-investigated urban research areas that are crucial components of urban intelligence in a disease outbreak. Second, reflecting on the current novel coronavirus outbreak, we summarize the opportunities and challenges in the preparation, containment, and recovery from a pandemic. Third, we discuss arguments and debates around uncertainty, privacy, information security, as well as the trade-off between timeliness and accuracy of data exchange during an outbreak.

Methods, Search Strategy, and Selection Criteria

Data for this viewpoint were identified by searches of PubMed, Social Sciences Citation Index, Science Citation Index, Scopus, and references from relevant articles using the search terms “urban intelligence,” “urban health,” and “pandemic response”. Reports, news articles, or websites were included only when they related directly to previously published work, or they were the only currently available information source at the moment of manuscript preparation. Only articles in English between 1965 and 2020 were included. One Chinese website was cited since it was the only available and most widely adopted media platform during the COVID-19 outbreak in Wuhan in February 2020.

Defining Urban Intelligence

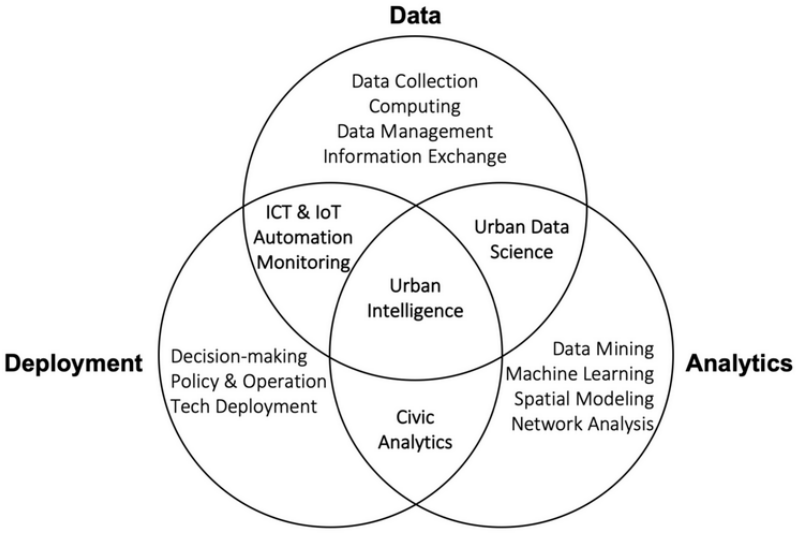
Urban Intelligence Capacity

The concept of a “smart city” is arguably new, but there was considerable research done in urban intelligence during the aftermath of World War II. In 1965, Webber [5] proposed “intelligence centers that bring scientific morality into urban affairs” to address an increasing complexity of cities with interactional consequences among transportation, communication, organization, and social behavior. Sternberg describes intelligence as “complex analytics, modeling, optimization, and visualization in the operational business processes to make better operational decisions” [6]. For cities in particular, Kitchin [7] describes urban intelligence as a capacity “to monitor, manage and regulate city flows and processes, often in real-time, and mobile computing, ..., and uses rich seams of data that can used to better depict model and predict urban processes and simulate the likely outcomes of future urban development”. Day and Schuler [8] provide an extended sociotechnical view on civic intelligence with inclusiveness and engagement as “the capacity that organizations and society use to *make sense* of information and events and craft responses to environmental and other challenges collectively”. In summary, intelligence is a capability to collect urban contextual and situational data as digital representations of the reality (input); perceive information from various sources of data (processing); generate knowledge (output); and direct responses, behaviors, or decisions within a specific environment (action).

Figure 1 shows the core components of urban intelligence. We identified three fundamental capacities enabling urban intelligence: city information resources, data science skills, and executive power to operate. Urban intelligence derives from information that requires in-depth knowledge of different sources and types of data in cities, as well as processes for their collection, management, and exchange. The transdisciplinary field is referred to as urban informatics, which encompasses the generation and application of data and related information technology in the context of cities, and lies at the intersection of people, places, and technology [9]. A more specific definition describes it as a study of urban phenomena to address domain-specific urban challenges such as a pandemic response through a data science framework and computational techniques including sensing, data mining, information integration, modeling, analysis, and visualization [10]. Experts in this field collect and analyze data by using a wide range of scientific, engineering, and computational methods, such as sensing (in situ, remote, or mobile sensing), imagery processing, natural language processing, statistical modeling, graph-based network analysis, machine learning, and geographical information system.

The second component of urban intelligence is the analytical capacity using data science. A definition of data science describes it as a discipline of knowledge extraction from data using computer science, statistics, and domain expertise [11]. The distinction of data science from conventional statistics is its capacity for handling a much larger volume of heterogeneous and unstructured data [12]. Most experts in big data computing, machine learning, and artificial intelligence are proficient in computer science and statistics, but there are few who also have domain knowledge. Domain expertise is essential for identifying actionable insights (feasibility for deployment and measurable improvement of actual operation), validating meaningful predictions (including its accuracy, sensitivity, and relevance to decision making), and evaluating potential impact (eg, expected and unexpected social, economic, and political consequences). The last, arguably the most crucial component for urban intelligence in the context of a pandemic, is the emergency operational and executive power for critical event preparedness and response.

Figure 1. A graphic illustration of urban intelligence core components. ICT: information and communications technology; IoT: Internet of Things.



Urban Intelligence During a Pandemic

We present five components of urban intelligence (movement, facilities, people, information, engagement) that are well-researched but remain too siloed to successfully orchestrate an integrated pandemic response. Table 1 summarizes specific data sources, analytical tasks, and actions to take during a pandemic.

Table 1. A summary of five critical urban intelligence components for a pandemic response.

Components	Data sources	Analytical tasks	Actions and operations
Movement	Air flights, ground transportation, GPS tracing, cellphone pings	Identify mobility hot spots and develop network algorithms to analyze spatial patterns and flows	Transportation control, checkpoints, identify quarantine zones, contact tracing
Facilities	Facility catalog, resource inventory, infrastructure performance	Model capacity and optimize medical staffing and resource triaging	Logistical distribution and human resources, capital planning
People	Population census, community survey	Quantify local population characteristics and neighborhood health baseline measures	Provide additional services to vulnerable population groups and communities
Information	User agreement and protocols for data exchange	Develop an information exchange and coordination pipeline during a pandemic	Integrate and manage data across various resources and agencies
Engagement	Digital platforms, news and social media, open data portal	Identify high influencers on social media and less active sectors or regions that require proactive outreach	Broadcast news and crowdsource local information

Movement

Quantification of spatial connectivity and mapping real time human mobility at the intraurban scale provide actionable insights for a pandemic response. The impact of geography on epidemic dynamics and pandemic transmission hubs at the regional scale have been reported [4,13], but there are limited investigations in inter- or intraurban connectivity and human mobility. The human movement between cities needs better data sources and quantification methods. Conventional data such as population census or community survey reveal regional connectivity and spatial structure of the human movement. Real time or near real time human mobility data during a pandemic is valuable since regional population movement may unmask abnormal behavior during a critical event. In a study on the COVID-19 outbreak in Wuhan, the research team measured intercity connectivity by using three data sources, including global flight bookings from the Official Aviation Guide, the prefecture-level daily passenger volume (by transportation modes) based on location-based services provided by Tencent (one of the largest information technology companies and the operator of WeChat), and the historical estimation of Spring Festival travelers reported by the municipal transportation department [14]. Such information may guide national pandemic forecasting and regional interventions (eg, reschedule the flights and high-speed railway operations); however, it does not provide intracity human mobility for modeling complex spatial-temporal patterns. Relevant data includes human mobility trajectory mapping based on cell phone pings [15], real time local population estimation using public Wi-Fi probe [16], intracity mobility pattern detection using GPS loggers or General Transit Feed Specification data provided by buses, taxis, and bike-share operators [17,18], and spatial analysis of human-scale economic and social activities using geotagged social media feeds (eg, Twitter, Instagram, Foursquare, Yelp) [19-21]. During a pandemic, all these data provide more spatially specific indications for containment strategy and inform contact tracing.

Facilities

City agencies collect and manage information on large data inventory of critical facilities and resources. A study from Johns Hopkins University evaluated hospital surge capacity for maintaining basic operation (eg, sanitation, food, communication, security) and standards of care during four catastrophic scenarios (pandemic influenza, radiation, explosive, and nerve gas attack). In a pandemic influenza scenario particularly, the top five critical facilities and resources are: isolation room or cohorting, respiratory therapist, face masks, antiviral agents for influenza, and dialysis [22]. Besides public health systems, other facilities owned and operated by cities play supportive roles during a pandemic. The New York City Department of City Planning manages the City Planning Facilities Database with more than 35,000 city, state, or federal-owned facilities and program sites, including public schools, daycare service providers, public libraries, parks, sports stadiums, and recreational centers [23]. The initial purpose of this data inventory is for public budget allocation, neighborhood funding evaluation, and capital planning, but data reporting the location and capacity of facilities provide valuable information for disaster planning and response. Private mapping or navigation application program interfaces, including Google Maps, TomTom, and Foursquare, provide near real time information on geolocation and operations (business hours and peak hours). Studies on sensor data applications and computing in the urban environment have identified points of interest (POI) as one of the critical measures for estimating local human activity and related exposure risk for disaster management [24,25]. Besides public-owned facilities, POI in cities, such as local clinics, drug stores, convenience stores, and grocery shops, become critical nodes and suppliers to ensure uninfected people's well-being during the outbreak.

People

Neighborhood demographics including socioeconomic profiles provide essential baseline measures for identifying underlying infection risks based on population characteristics. One example is the New York City Community Health Profiles, a census on 59 community districts of population health, reporting more than 50 metrics on neighborhood environmental and population health along with social and behavioral indicators (eg, education, income, smoking, alcohol consumption) [26]. The initial purpose of the data collection is to quantify neighborhood health and quality-of-life metrics, but population data by specific age groups (eg, infants, children, or older adults), health condition, and socioeconomic status identify vulnerable communities. Recent research and practice have proven that urban data sources with high spatial resolution can support better operations that target specific population groups such as children, older adults, and the homeless population [27]. Beyond estimating the vulnerable population at risk for infections, ICT can provide educational and other care services for older adults or "left-behind" children at the community scale [28-30]. Under a data governance that protects information security and respects personal privacy, these additional data can inform city agencies, social institutions, and community-based organizations to provide local and targeted services during a pandemic.

Information

During the Obama administration, the Open Government Partnership focused on the role of integrated data and urged city agencies to generate cross-cutting initiatives and data exchange protocols [31]. As a result, interorganizational institutions for better information integration, such as the New York City Center for Innovation through Data Intelligence, were created [32]. A citywide interagencies data exchange protocol is crucial to inform public and private sectors on who collects what data and for what purposes. Better data exchange will reduce response time and information discrepancy to mobilize resources and coordinate multiagency operations (eg, an outbreak in a public school may require both the health and education departments). Data exchange protocol also optimizes delegation of duties at different levels of urgency during a pandemic. During the 2009 H1N1 pandemic, NYC 311, a citywide agency managing nonemergency service requests, received and triaged approximately 54,000 phone calls regarding possible influenza [33]. In a pandemic situation, interagency coordination does not only improve information exchange but also appropriately triages health care service response for a more efficient operation.

Engagement

Active and productive engagement between city agencies and the general public plays a vital role during a pandemic outbreak. Government-citizen communication and social media analytics can raise people's awareness, monitor public sentiment, and identify false alarms or fake news. During the 2009 H1N1 pandemic in Mexico City, Telmex, a major telecommunication operator in Mexico, managed more than 5 million phone calls, 140 million text messages, and 18 million email messages containing official communications from the Ministry of Health [33]. Besides the traditional telecommunication services, social media platforms play a critical role in broadcasting news and promoting preventive actions to the general public. Crowdsourcing data collection provides a unique value for infectious disease surveillance [34]. Crowdsourcing provides alternative information when no other data are available, improves the spatial-temporal resolution of disease analysis with geotagged high-frequency data, and increases public health awareness through the participatory process. During the COVID-19 outbreak, Ding Xiang Yuan (DXY), a leading digital health platform in China, provided a stage for broadcasting real time information and public engagement [35]. The platform had three components: real time mapping of confirmed cases and deaths, dispelling rumors and fake news, and public education on prevention. By combining crowd-sourced data on the DXY platform with data from news sources and national health agency websites, researchers were able to gather information that would be otherwise difficult to obtain from aggregate data released by health authorities, such as the delay between symptom onset and detection by the health care system, reporting delays, and travel histories [36]. Engagement also mitigates the massive societal disruption during the outbreak. Multiple service companies have emerged that offer platforms to support virtual offices and online education. Such platform-based services are critical for reducing unnecessary travel demands and physiological stress during the quarantine.

Challenges

Information transparency remains a major issue, but there is a parallel issue of the disconnect between information and data. In recent years, Chinese public information platforms and mobile phone apps have generated massive amounts of data. During the COVID-19 outbreak, the majority of information was released in the format of news, texts, infographics, tables, or map images for public disclosure purposes only, leading to limited data for computation. Chinese public officials regularly shared information of high-speed rail departures and aircraft flights with suspected cases, but as infographics through social media (WeChat or Weibo). Even when information was released, no publicly available data was provided due to a lack of data standards or guidelines. Although crowdsourcing has become an accepted approach for collecting data on a large scale, the quality and consistency of data collection remain a challenge due to its participatory nature. Social media provides near real time information on newly confirmed cases, but it is necessary to consider the trade-offs between timeliness and accuracy. Machine learning and deep learning that train on retrospective data are promising for artificial intelligence-assisted diagnoses and other population health tasks, but they currently have limited real time practical value. As of early February 2020, almost 2 months since the COVID-19 outbreak, the most comprehensive research resource only had 1334 patient-level records [37].

Even for data-savvy cities such as New York City or Singapore, heterogeneous data sources produce messy and typically biased data from a lack of representativeness. These limitations create so-called “signal problems” that skew the understanding of reality [38]. As the former Director of Analytics of New York City described, a fire hose of information is of no use unless it points to a fire [39]. During a pandemic, information initiatives require tremendous cross-disciplinary knowledge, resources, network, and a political willingness to connect and link data with the right people with domain expertise for the right problems.

Insights do not guarantee actions. Data scientists are prone to be “paralyzed by analysis,” while ground operations in a real world urban environment must be responsive, proactive, and agile to act with incomplete data and missing information. Moral dilemmas around optimization criteria, the liability associated with uncertainties, and concerns around unexpected public reactions, engender social, technical, and political challenges for transforming insights into actions. Privacy threats, cybersecurity vulnerability, ethical controversies, and unanticipated societal impact further create risks for scaling urban intelligence.

Conclusion

The impact of a pandemic is far beyond public health and medical care. It brings large scale economic risks and social instability, especially for densely populated megacities. Expertise in the generation, collection, analytics, and application of urban data can bring tremendous value to support better response and prevention during a pandemic. Even when a situation gets effectively controlled, urban intelligence can provide continuous risk assessment and support economic recovery. As we continue to face an unprecedented pandemic, we need to identify and implement best practices in urban intelligence to define the critical role of cities in the global public health crisis.

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Authors' Contributions

YL led the drafting of the report. LC coordinated contributions and redrafting. All authors provided content and comments that informed the drafting process.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
DXY: Ding Xiang Yuan
ICT: information and communications technology
POI: point of interest

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Short Paper

A Mobile Health Platform to Disseminate Validated Institutional Measurements During the COVID-19 Outbreak: Utilization-Focused Evaluation Study

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Abstract

Background: As part of the response plans for the current outbreak of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), authorities are drafting and implementing containment measures across jurisdictions worldwide in the effort to slow down transmission and reduce the infection rate. A solid communication strategy is needed to increase the reach of valid information to health professionals, reduce misinformation, and efficiently implement recommended measures.

Objective: The aim of this paper is to describe the utilization of a dedicated mobile health (mHealth) platform to disseminate up-to-date and validated information about SARS-CoV-2 to all medical staff of the Children's Hospital at the University Hospitals of Geneva.

Methods: Three documents containing institutional information concerning screening, local containment procedures, and frequently asked questions and answers for parents were made available to the staff through a mobile app developed in the University of Geneva, Switzerland. Using a third-party statistics tool, we anonymously monitored user activity as well as content utilization patterns since the diagnosis of the first case of SARS-CoV-2 in Switzerland on February 25, 2020.

Results: From February 25, 2020, to March 13, 2020 (18 days), information documents on SARS-CoV-2 were viewed 859 times, which accounted for 35.6% of the total content views (total views=332). User activity increased significantly with 50.8 (SD 14.4) users per day in this period as compared to the previous weeks (mean 26.4, SD 9.8; $P<.001$). In addition, session numbers per day more than doubled during the aforementioned period ($P<.001$). In a survey, medical staff found the information easy to find within the app. On a 10-point Likert scale, the ability of the app to reassure staff in clinical practice was rated as 7.6 (SD 2.1), time-saving ability was rated as 8.5 (SD 2.1), and the need to look for information from other sources was rated as 5.9 (SD 3.3).

Conclusions: The use of an mHealth solution to disseminate novel coronavirus–related information seemed to be an effective and time-saving communication channel within our institution during the SARS-CoV-2 outbreak. Medical staff felt reassured and informed in daily practice. More research should be done on the clinical impact and outcomes of the integration of mHealth solutions as a communication channel of validated information within health institutions.

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KEYWORDS

covid-19; novel coronavirus; smartphone; SARS-COV-2; mHealth; knowledge; information; dissemination; health policy; infectious disease; outbreak; public health; preparation

Introduction

The global outbreak of the novel coronavirus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) responsible for coronavirus disease (COVID-19) infection and its implications are still unfolding. With more than 800,000 confirmed cases worldwide [1], governments and local authorities are working on different response plans that are adapted to local epidemiology and resources in order to reduce the risk of community spread and slow down disease transmission [2].

Local and global response plans include classic outbreak measures such as travel restrictions to and from high-risk areas, social distancing, community containment, quarantine for confirmed or suspected cases, and cancellation of large-scale public events and gatherings [3-5]. On the personal level, the World Health Organization (WHO) is recommending hygiene measures such as avoiding contact with confirmed cases and hand washing, in an effort to reduce viral transmission rate [2].

In parallel, local hospitals and health authorities worldwide are bracing themselves for the possibility of a large influx of suspected and confirmed cases and aiming to prevent nosocomial transmission to patients' families and health workers [2,3]. For example, in the Children's Hospital at the University hospitals of Geneva, Switzerland, several local procedures were drafted to streamline patients sent for testing or medical care, diagnostic criteria were adopted and updated daily as per international consensus, and a contained screening facility was set up to separate possibly infected children from the rest of the hospital. In addition, a hotline was established and was rapidly overwhelmed.

In order to be efficient, disease containment measures require a solid communication strategy to avoid misinformation not only to the general public but also between global and local health authorities as well as within health institutions, so that validated guidance can properly reach local medical staff [6].

In fact, as seen in recent outbreaks of measles, Zika virus, and Ebola, the public is exposed to a large amount of information from both official channels such as the WHO and local authorities as well as from unofficial channels such as newspapers and social media [7-9], with obvious risk from the latter to provide confusion and misinformation [8]. Health professionals, who might have a more critical insight for these channels, would still find themselves exposed to a large amount of information for which validation could be lacking.

As mobile health (mHealth) solutions are becoming more relevant in health professions [10], the use of mobile devices via dedicated platforms as a means of communication may increase the reach of validated information to clinicians.

In this short paper, we describe our efforts to disseminate locally validated and up-to-date guidance about COVID-19 to the medical staff in the Children's Hospital in the University Hospitals of Geneva through a mobile platform developed in the University of Geneva, Switzerland. Our hypothesis was that providing guidance through the mobile app would be perceived as time effective by medical staff and would provide reassurance in clinical practice, as validated information is readily available and updated regularly.

Methods

Owing to our medical students' and residents' need to easily access locally endorsed and validated medical knowledge, we have developed a mobile platform called "HeadToToe" [11,12]. The platform provides an institutional knowledge dissemination solution and consists of iOS and Android mobile apps where medical students and health professionals can access medical content organized by medical specialties, such as local and international guidance, clinical skills videos, and administrative material. The platform provides daily practice and an administration interface accessed by delegated senior staff from each of the hospital's departments, who select and validate content they deem important for continuous medical education. Content managers define revision dates and expiration dates for each item. Obsolete items are deleted automatically by the system. Automatic and anonymous statistics collection using Yahoo Flurry [13] provide data on user activity and content views patterns.

During the COVID-19 pandemic, the platform was used as a communication channel in the Children's Hospital to disseminate local procedures, treatment plans, and general information about the novel coronavirus to health care workers, particularly physicians.

To assess the impact of such an mHealth information channel on clinical practice and provide feedback to medical leadership of its usefulness, we used a utilization-focused evaluation method [14]. We analyzed user activity and content use patterns collected by the platform since the introduction of outbreak measures in our institution. Data were collected on the average and total number of users and sessions per day, average usage time per user per day, and the total and specific number of content views per day.

In addition, we conducted an online survey among medical staff who used the platform during the same period. Survey questions focused on the impact of mHealth solutions on daily practice, specifically on time effectiveness and reassurance ability concerning a specific clinical challenge (care of patients with COVID-19).

P values were calculated using SAS JMP (SAS Institute Inc) with a *t* test for means. Values of $P<.05$ were considered significant.

Results

Three novel coronavirus–related documents (Figure 1) were made available to the medical staff of the Children's Hospital through the mobile platform: (1) institutional screening and containment procedures, (2) frequently asked questions and answers for parents, and (3) a standardized consultation sheet. The medical staff's demographics are summarized in Table 1.

Since the first case of SARS-CoV-2 in Switzerland was announced on February 25, 2020, until March 13, 2020 (18 days), the mentioned documents were viewed 859 times. This amounted to 35.6% of total documents views from a total of 332 documents.

Concerning user activity (Table 2), we observed a significant increase (92%, $P<.001$) in the number of users per day (mean 50.8, SD 14.4) from January 1, 2020, to February 24, 2020, as compared to the previous weeks (mean 26.4, SD 9.8; Figure 2A). The number of sessions per day increased significantly ($P<.001$) and more than doubled in the aforementioned period with a mean of 182.9 (SD 60.0) sessions per day compared with 84.2 (SD 33.6) sessions per day in the previous weeks. (Figure 2B).

Figure 1. Mobile app user interface displaying the documents section with COVID-19 content.

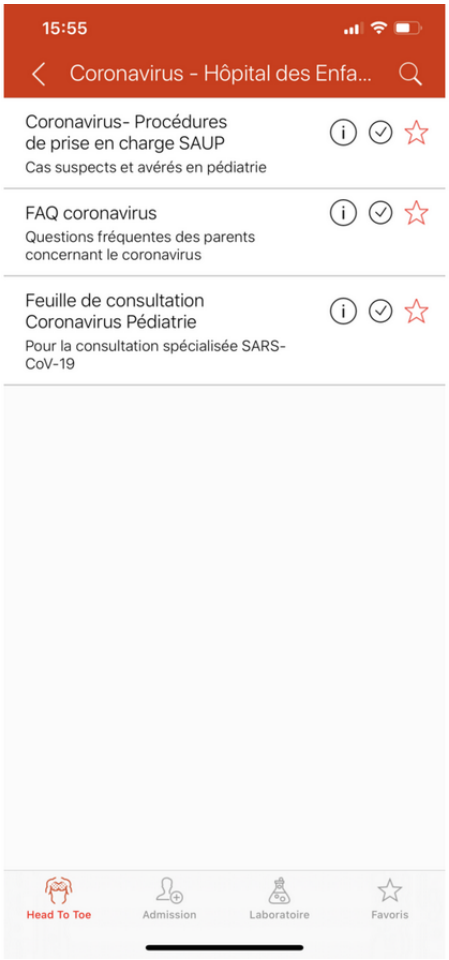


Table 1. Demographic characteristics of hospital staff (N=125).

Characteristic	Staff members, n (%)[a]
Sex	
Male	34 (27.2)
Female	87 (69.9)
Age (years)	
25-30	28 (22.4)
31-35	24 (19.2)
36-40	18 (14.4)
41-50	29 (23.2)
51-60	24 (19.2)
>60	2 (1.6)
Profession	
Medical doctor	94 (75.2)
Nurse	25 (20.0)
Other[b]	6 (4.8)
Medical unit affiliation	
Pediatric emergency room	41 (33.1)
Intensive care and neonatology	14 (11.3)
Ward	25 (20.2)
Outpatient unit	30 (24.2)
Other	14 (11.3)

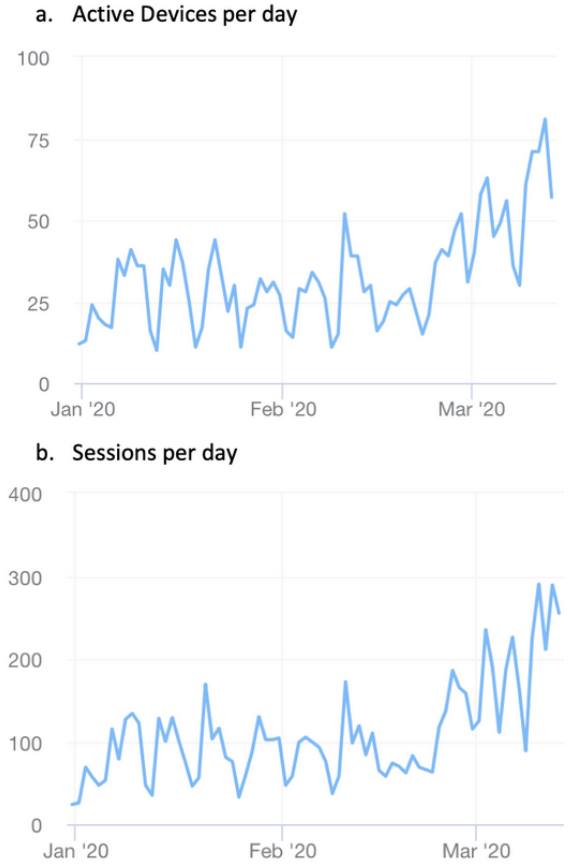
[a]Total number may sometimes not add up to a 100%, as staff members were allowed to skip questions.

[b]Psychologists, caregivers, and administrators.

Table 2. User activity on the mobile platform during the SARS-CoV-2 outbreak.

Parameter	Value, mean (SD)	*P* value
Active users per day		<.001
Jan 1, 2020 to Feb 24, 2020	26.4 (9.8)	
Feb 25, 2020 to Mar 13, 2020	50.8 (14.4)	
Sessions per day		<.001
Jan 1, 2020 to Feb 24, 2020	84.2 (33.6)	
Feb 25, 2020 to Mar 13, 2020	182.9 (60)	

Figure 2. Mobile platform user activity between January 01, 2020, and March 13, 2020.



In a survey answered by 125 health professionals of the Children's Hospital, 93 staff members (75.0%) said that they are directly concerned with care of patients with SARS-CoV-2, and 84 (67.2%) said they downloaded the mobile app. Among staff who downloaded the platform, 70 (83.3%) said that information concerning SARS-CoV-2 was easy to find because of the app. On a 10-point Likert scale, the mHealth solution was rated 8.5 (SD 2.1) for being time saving and 7.6 (SD 2.1) for reassurance concerning care of patients with SARS-CoV-2 in daily practice. Finally, when asked for the need to seek other sources of information other than the mobile platform, medical staff rated the solution a score of 5.9 (SD 3.3; Table 3).

Table 3. Medical staff's utilization of a dedicated mHealth solution for SARS-CoV-2 information seeking.

Question	Value, mean (SD)	Yes, n (%)	No, n (%)	Neutral , n (%)	Total, n
Do your clinical activity directly concern children with suspected or confirmed SARS-CoV-2 infection?	N/A[a]	93 (75.0)	31 (25.0)	1	124
Did you download the app "HeadToToe"?	N/A	84 (67.2)	41 (32.8)	-	125
Is information concerning SARS-CoV-2 easy to find thanks to "HeadToToe" app?[b]	N/A	70 (83.3)	-	14 (16.6)	84
Do you consider the utilization of this dedicated mHealth solution as timesaving for finding information concerning SARS-CoV-2?[b,c]	8.5 (2.1)	N/A	N/A	N/A	N/A
Did you feel the need to use other sources in order to find information concerning SARS-CoV-2?[b,c,d]	5.9 (3.3)	N/A	N/A	N/A	N/A
Did the use of dedicated mHealth solution for accessing information concerning SARS-CoV-2 reassured you in your clinical practice?[b,c]	7.6 (2.1)	N/A	N/A	N/A	N/A

[a]N/A: not applicable.

[b]Information presented for this question concern medical staff who downloaded the app.

[c]These questions are scored on a Likert scale from 0 to 10; 0 indicates the lowest score, 5 indicates a neutral score, and 10 indicates the highest score.

[d]0 - No need for other information sources, 10 - Important need for other information sources.

Among staff who felt the need to search for more information, 48 (42.5%) answered they used national government websites, 31 (27.4%) used dedicated websites of health institution (WHO, Centers for Disease Control and Prevention), 9 (8%) used nondedicated professional websites, and 19 (16.5%) used nonofficial sources such as newspapers and television; none declared using social media.

Discussion

Communication strategies for sound clinical guidance are important for clinicians to choose evidence-based treatment plans, even more so in the times of infectious disease outbreaks, where misinformation can play a key role in failure of containment methods [6,8].

These strategies usually involve both information sources dedicated for the general public and sources targeted for health institutions and professionals, such as dedicated websites, scientific papers, and governmental procedures. Within an institution, local leadership often uses tools such as emails, posters, and conferences to reach and inform their staff [6]. These methods, however, have obvious flaws, especially in situations like the current one, of a newly discovered virus (SARS-CoV-2), where solid scientific evidence is still lacking and new, and sometimes contradictory, information is being published on a daily basis.

Moreover, in these situations, health professionals may have to deal with not only a growing amount of workload and patient consultations, but also the difficulty of critically appraising the vast amount of published information on the subject in order to make evidence-based decisions.

Therefore, it is crucial, in our opinion, that health institutions are able to not only communicate with local, national, and international authorities in order to create response plans and protocols during outbreaks, but also communicate these protocols to their medical staff in order to inform, reassure, and help them with clinical decision making. It is crucial as well that this information reaches as many clinicians as possible, with the possibility to keep them updated as new information unfolds.

Medical leadership's dissemination of COVID-19 information through the mobile platform in our institution was answered with a significant increase in app usage and relevant content use. Medical staff found the information easy to find and the mHealth solution time saving with regard to COVID-19 information seeking. These results might provide more evidence for the time-saving benefits of mHealth solutions in daily practice.

Mobile information dissemination platforms, as used in our institution, may present an interesting communication method, especially in the era where smartphones are ubiquitous among clinicians [10]. User activity and content monitoring in real time may provide institutional leadership with valuable information regarding staff's information needs as well as information dissemination efficiency. In our institution, increased user activity and content views in the Children's hospital motivated medical leadership to produce and disseminate more COVID-19–related material through the mobile platform. In addition, due to abovementioned results, institutional leadership decided to deploy the mobile platform within all medical departments in order to disseminate institutional COVID-19 content to all of the hospital's medical staff.

mHealth solutions such as the one presented here may help in solving some of the presented challenges by increasing the reach of information for health professionals and thus decreasing misinformation and confusion, as key information is centralized in one platform and validated, up-to-date information is easy to find. Moreover, due to the administration interface, leadership was easily able to update information, and users have access only to the latest version of relevant content. These milestones would be harder to achieve with classic methods as emails, which may be hard to sort and find, or with printed material, especially when frequent content updating is necessary.

Our study's main limitation is our inability, at this stage, to provide evidence of the impact of this mHealth intervention on the quality and outcomes of patient care.

In conclusion, while more data are needed to study the short- and long-term clinical impact and outcomes of this type of mHealth intervention, the use of a mobile platform designed to disseminate information during the SARS-CoV-2 outbreak seems to be an effective and time-saving method for communicating local guidance within our institution. Medical staff felt reassured and informed about procedures for care of patients with SARS-CoV-2 and seemed to have less need to seek other sources of information.

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IZ was the main investigator and wrote the manuscript, cofounded the project, programmed the code of the platform, and took part in the analyses of results and literature review. SM critically revised the manuscript and was responsible for data collection from pediatrics emergency division staff. KB-P critically revised the manuscript and was responsible for data collection from staff from the general pediatrics wards and specialties. OW was the cofounder of the project and critically revised the manuscript and took part in the analyses of results. ES was the team leader and cofounder of the project and idea and helped in writing the first draft, critically revised the manuscript, and supervised the project. TA critically revised the manuscript and took part in the literature review.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
mHealth: mobile health
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Interpreting COVID-19 and Virtual Care Trends: Cohort Study

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Abstract

Background: The coronavirus disease (COVID-19) pandemic is rapidly spreading across the world. As of March 26, 2020, there are more than 500,000 cases and more than 25,000 deaths related to COVID-19, and the numbers are increasing by the hour.

Objective: The aim of this study was to explore the trends in confirmed COVID-19 cases in North Carolina, and to understand patterns in virtual visits related to symptoms of COVID-19.

Methods: We conducted a cohort study of confirmed COVID-19 cases and patients using an on-demand, statewide virtual urgent care center. We collected data from February 1, 2020, to March 15, 2020. Institutional Review Board exemption was obtained prior to the study.

Results: As of March, 18 2020, there were 92 confirmed COVID-19 cases and 733 total virtual visits. Of the total visits, 257 (35.1%) were related to COVID-19-like symptoms. Of the COVID-19-like visits, the number of females was 178 (69.2%). People in the age groups of 30-39 years (n=67, 26.1%) and 40-49 years (n=64, 24.9%) were half of the total patients. Additionally, approximately 96.9% (n=249) of the COVID-like encounters came from within the state of North Carolina. Our study shows that virtual care can provide efficient triaging in the counties with the highest number of COVID-19 cases. We also confirmed that the largest spread of the disease occurs in areas with a high population density as well as in areas with major airports.

Conclusions: The use of virtual care presents promising potential in the fight against COVID-19. Virtual care is capable of reducing emergency room visits, conserving health care resources, and avoiding the spread of COVID-19 by treating patients remotely. We call for further adoption of virtual care by health systems across the United States and the world during the COVID-19 pandemic.

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KEYWORDS

virtual care; COVID-19; trends; patterns; pandemic; outbreak; infectious disease; public health

Introduction

The coronavirus disease (COVID-19) pandemic is rapidly spreading across the world. As of March 26, 2020, there were more than 500,000 cases and more than 25,000 deaths related to COVID-19, and the numbers continue to increase [1,2]. The swift transmission of COVID-19 is a threat to the world. It hinders our ability to contain the spread or the damage [3]. Many countries restricted air travel in and out of the country in an attempt to stop, or at least slow down, the transmission of the disease. However, the numbers of infected people are in an exponential and rapid growth [4].

Calls were made to promote and use virtual care (VC) such as remote medical consultations as an effort toward enforcing social distancing, using resources efficiently, and improving health care access [5]. The US government and private payers

such as insurance companies have been working closely to remove any restrictions on the use of VC, also known as telehealth [6]. Now people can use consumer applications such as FaceTime, Google Hangout, and other video chat platforms to interact with a medical provider remotely [7]. Additionally, insurance coverage now covers VC between a provider and patient who have not met in person. All these attempts were necessary to avoid the gathering of large numbers of people in the same space, except for medical reasons [8]. In this study, we explored possible trends in confirmed COVID-19 cases along with COVID-19-like virtual visits. We hypothesized that there was a pattern between the location and duration of the confirmed COVID-19 cases and COVID-19-like virtual calls prior to the occurrence of confirmed cases.

The aim of this study was to explore the trends in confirmed COVID-19 cases in North Carolina, and to understand patterns in virtual visits related to symptoms of COVID-19.

Methods

Virtual Urgent Care

We conducted a cohort study of confirmed COVID-19 cases and patients using an on-demand, statewide virtual urgent care (VUC) center. The center was launched by a major health care system in the Southeast region of the United States. We collected data from February 1, 2020, to March 15, 2020. Institutional Review Board exemption was obtained prior to the study.

Our choice of study start date being February 1, 2020 stems from the first COVID-19 case in the United States, which occurred in Washington state on January 21, 2020. The first case in North Carolina was March 3, 2020 related to a person traveling from Washington state. This indicates that during the month of February there was active transmission of COVID-19 across the United States that we did not know about due to a lack of screening and testing.

Data Sources

We collected data during the selected dates using the numbers of confirmed COVID-19 cases reported by the North Carolina Department of Health and Human Services (NCDHHS). Additionally, we analyzed COVID-19-like virtual visits from February 1 to 28, 2020, prior to the first confirmed COVID-19 case (March 3, 2020).

Analysis for Virtual Visits With COVID-19-Like Symptoms

The VC data included patient demographics and chief complaints. We stratified the virtual visits into two groups: COVID-19-like visit and all other visits. We categorized a virtual visit as a COVID-19-like visit if the chief complaint mentioned by the patient overlapped with COVID-19 symptoms reported by the Centers for Disease Control and Prevention and the World Health Organization (WHO), such as “cough,” “fever,” “respiratory infection,” or “fatigue” [9,10]. Throughout the paper, we will use the term “COVID-19 like” to refer to virtual visits where patients reported chief complaints that were similar to COVID-19. At the time of the study, there were no virtual COVID-19 tests to screen if these virtual visits had patients who were indeed COVID-19 carriers.

Analysis for COVID-19 Confirmed Cases

Based on information we retrieved from the NCDHHS, we mapped the number of confirmed cases on a North Carolina map. Then, we identified the major areas of attraction within the counties with the highest concentrations of confirmed COVID-19 cases to rationalize the reasons for the high concentration of cases. Additionally, we ran a time-motion analysis on the confirmed cases over time to understand the duration and the extent of disease spread across the state counties. To demonstrate the time-motion of the disease, we used a color palette such that each color represents confirmed COVID-19 cases on a given date between March 3-18, 2020.

To plot the confirmed COVID-19 cases in North Carolina geographically, we created a map showing the number of cases for each county and assigned the color shades according to the number of cases, the deeper the color, the more cases. Furthermore, to explore the relationships between VUC COVID-19-like encounters and confirmed COVID-19 cases, we labeled the encounters as “two weeks before the outbreak” (encounters in February 2020) and “after the outbreak” (encounters from March 1 to March 15, 2020). Then, the number of encounters of each county were displayed geographically on a map based on the same rule as the map of COVID-19 cases for a straightforward concept and comparison. To delve into the trend of how local COVID-19 cases increase temporally and spatially, we divided the COVID-19 cases using 2 time ranges: a 7-day time range and a day-by-day time range. A bar chart and a pie chart on the map were created based on the broken-down data.

Data Analysis

We analyzed patient demographics of the COVID-19-related virtual visits. We conducted exploratory analysis based on their gender, age group, and state of residence. Since all visits happened through phone calls or video calls, it was important to use patients’ state of residence to analyze their characteristics. Certain tools such as Microsoft Excel were used throughout this process and to display the results. All the data processing work was conducted in Python (Python Software Foundation) using NumPy and Pandas library and the visualizations were created using Tableau Software. This was beneficial to detect any trend or patterns of patients’ behaviors.

Results

Analysis of Confirmed Cases

As of March, 18 2020, there were 92 confirmed COVID-19 cases and 733 total virtual visits. Of the total visits, 257 (35.1%) were related to COVID-19-like symptoms. Of the COVID-19-like visits, nearly three-fourths were female. People in the age groups 30-39 years and 40-49 years were half of the total patients. Additionally, almost all COVID-like encounters came from within the state of North Carolina (Table 1).

Table 1. Summary of Characteristics of Virtual Care Patients with COVID-19 Symptoms (N=257).

Virtual care demographics	Encounters, n (%)
Gender	
Female	178 (69.3)
Male	75 (29.2)
Nonbinary	4 (1.6)
Age group (years)	
<10	28 (10.9)
10-20	23 (8.9)
20-30	40 (15.6)
30-40	67 (26.1)
40-50	61 (23.7)
50-60	31 (12.1)
60-70	7 (2.7)
State of residence	
Florida	1 (0.4)
Georgia	1 (0.4)
North Carolina	249 (96.9)
New Jersey	1 (0.4)
South Carolina	2 (0.8)
Virginia	2 (0.8)
Wisconsin	1 (0.4)

North Carolina, like other US states, observed an increase in COVID-19 confirmed cases in a short time period [11]. The first case was recorded on March 3, 2020; in 10 days, the number of cases escaladed to 24 cases, and then, in only 3 days, there was a steep increase to 64 cases to reach a total of 92 confirmed COVID-19 cases by March 18, 2020.

The North Carolina map shown in Figure 1 shows that 62 (67%) of the 92 COVID-19 confirmed cases occurred within two counties with the highest density in the state and house two major international airports in North Carolina, namely Raleigh-Durham International Airport (RDU) and Charlotte Douglas International Airport (CLT). Figure 1 also shows that there are scattered individual cases of COVID-19 in the eastern and southwestern parts of the state, which are typically less dense regions.

Figure 2 shows the spread of confirmed COVID-19 cases by the day from March 3 to 18, 2020. The first confirmed case occurred on March 3, 2020, in Wake County, and the person had been travelling to Washington state and was exposed to a long-term facility where there was a COVID-19 outbreak [12]. The second case occurred on March 6, 2020 in Chatham County to a person who had returned from Italy where there had been a severe COVID-19 outbreak [13]. Chatham county is a neighboring county to Wake county where the RDU resides. The time-motion analysis shows that the first COVID-19 cases occurred in Wake county, while the highest prevalence of COVID-19 cases were in Wake county and Mecklenburg County. These two counties have two characteristics in common: they are the most populous and the only counties with an operating international airport. The color palettes in Figure 2 show that the disease systematically and quickly spread to the immediate neighboring counties in a matter of 3-5 days, and then systematically reached more distant counties in a relatively longer time span of 12-14 days.

Figure 1. Mapping of North Carolina confirmed coronavirus disease cases with airport locations.

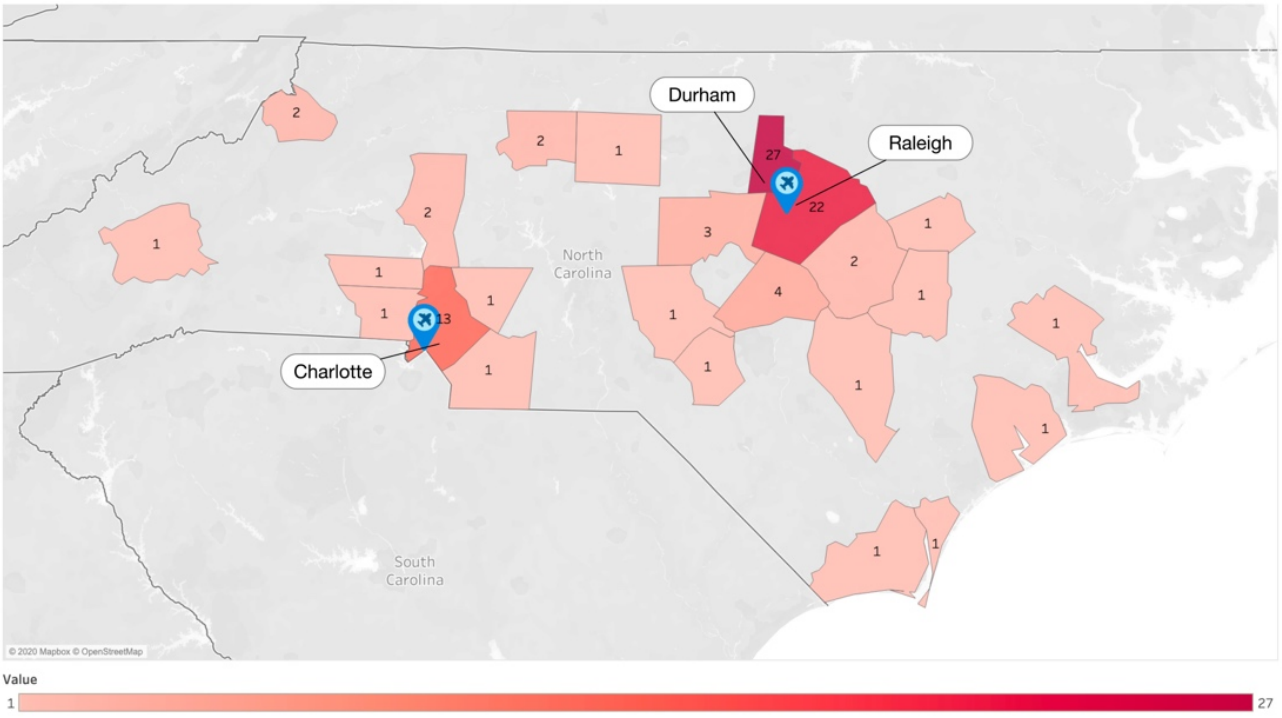
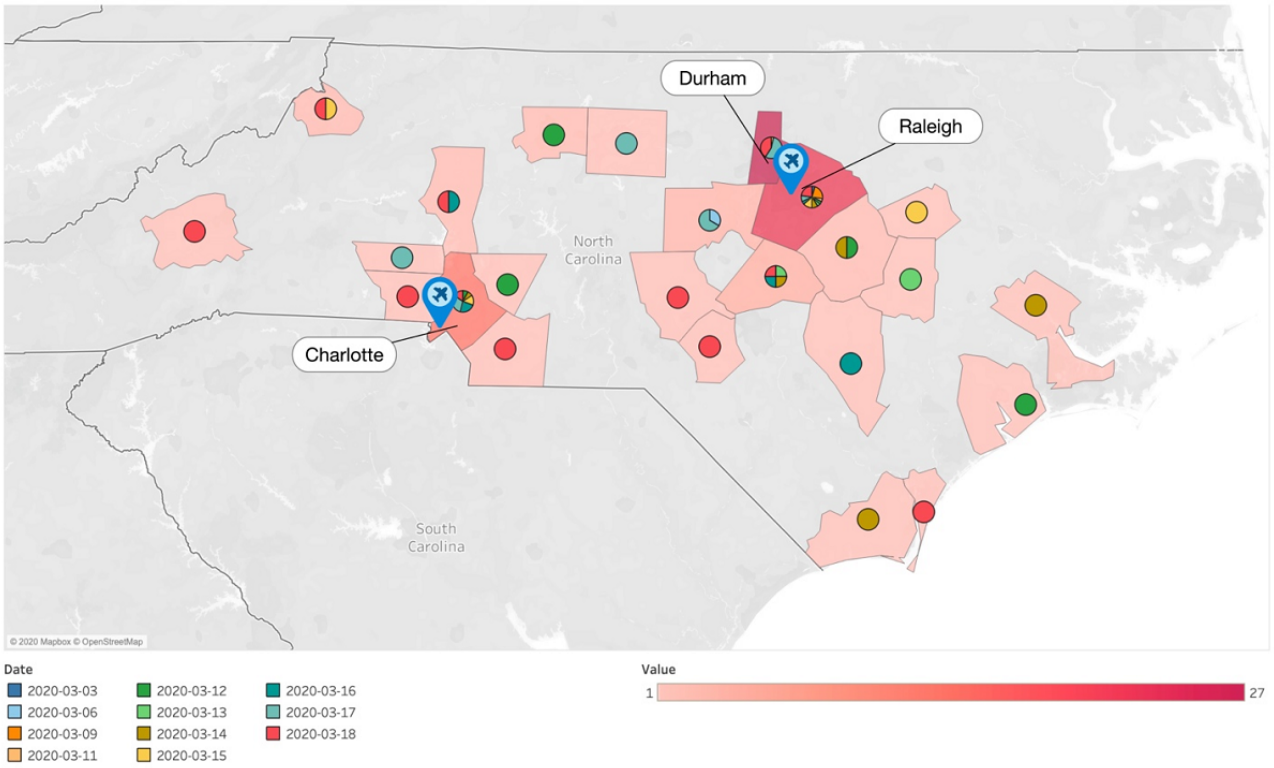


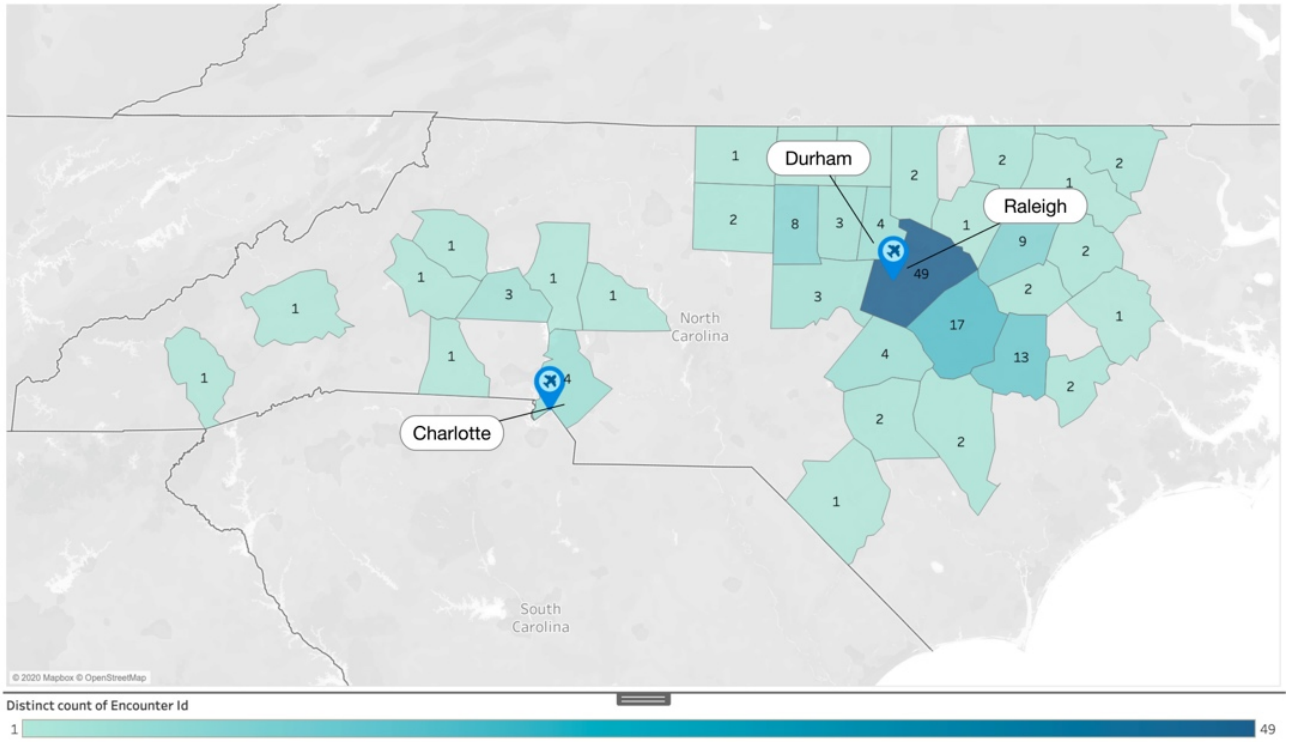
Figure 2. Time-motion analysis of confirmed coronavirus disease cases from March 3 to March 18, 2020.



Analysis of Virtual Care Visits

We reported that 57.3% of COVID-19-like visits in February, prior to any confirmed cases, were initiated by individuals residing in the same high-density counties that later had confirmed cases. Of the 92 confirmed COVID-19 cases, Wake County, where RDU resides, had 49 (53%) visits, while Mecklenburg County, home of CLT, had 4 (4.3%) COVID-19-like visits (Figure 3). Additionally, during the first 12 days after the first confirmed COVID-19 case on March 3, the number of virtual visits related to COVID-19 in Wake and Mecklenburg county was 23 (24%) and 5 (5%), respectively.

Figure 3. Quantification of virtual care visits from February 1 to 28, 2020.



Discussion

Principal Findings

We aimed to understand the trends in confirmed COVID-19 transmission and the use of VC to triage COVID-19-like symptoms. We found that a relationship exists between the geographic location of the initial confirmed COVID-19 cases with the population density and the presence of a functioning international airport. The first two cases in North Carolina came from individuals who were travelling back from areas with a COVID-19 outbreak. The spread of cases quickly transitioned into the immediate neighboring counties and then, further into more distant counties.

When looking at the number of VC COVID-19-like visits in the weeks prior to confirmed cases, we report that most of the COVID-19-like visits came from the same counties that later had confirmed cases. This has two interpretations. First, VC can help reduce the number of emergency department (ED) visits by providing remote medical consultation to patients residing in counties with increasing numbers of confirmed COVID-19 cases, which will reduce medical facilities overcrowding and thereby, control the spread of the disease. Second, it is possible that we can forecast the spread of the disease by monitoring the volume and location of confirmed COVID-19 cases, and the volume and location of visits in the VC realm, as shown in the time-motion study. Alternatively, the possibility of higher numbers of confirmed cases may lead to a higher number of virtual visits as individuals self-quarantine or exercise physical distancing.

This study provides several recommendations. First, limiting the movement of people through education and awareness of the importance of physical distancing and minimizing domestic and international travel, unless for emergencies, will help flatten the COVID-19 curve. Most of the new cases originated from people traveling to areas with active COVID-19 cases or in areas with high-population density where the probability of disease transmission is high.

Second, wider adoption and promotion of VC will reduce the number of unnecessary ED and urgent care visits, which is important during this time to avoid exhausting our health system and overcrowding, which increases the risk for transmission of the disease.

Third, we need to use artificial intelligence and geospatial analytics to monitor and predict COVID-19 spread to better understand the trends in transmission, predict possible infected areas and the rate of transmission, and manage our workforce expectations [14-16]. This aligns with other calls for more research investigating the transmission of the virus and identifying vulnerable populations and regions [14].

The Centers for Medicare and Medicaid and insurance companies have waived telehealth restrictions in fear of exhausting our health care system capacity and resources, which should drive the push for more virtual-based case interventions. Although major health care systems are launching VC clinics, there seems to be a need for more promotion, especially among vulnerable and older populations who may not have the technological means to access such a service. We suggest continued efforts to deploy and promote the importance of VC as an important medium, as we fight for our existence.

Study Limitations and Future Directions

This study presents data from a single health care system in one US state. The definition of COVID-19-like virtual visits was if the COVID-19 symptoms defined by WHO matched the chief

complaints of the patient. Due to the lack of virtual COVID-19 screening and the rapid turn of events, we could not ensure that all these visits were actual COVID-19 cases.

Our future work will include an analysis of VC accessibility pre- and post-COVID-19 with regard to specific geographic locations. We are also interested in assessing the patient experience using VC during the COVID-19 period. Finally, we aim to evaluate the effectiveness of the telehealth expansion on in-person and virtual clinics.

Conclusions

The use of VC presents promising potential in the fight against COVID-19. VC can reduce emergency room visits, conserving health care resources, and avoid the spread of COVID-19 by treating patients remotely. We confirm that the largest spread of COVID-19 cases occurs in areas with a high population density as well as in areas with operating international airports. Our study also demonstrates that virtual care can provide efficient triaging in the counties with the highest number of COVID-19 cases. We call for speedier adoption of virtual care by health systems across US and the world during the COVID-19 pandemic.

Conflicts of Interest

None declared.

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Abbreviations

CLT: Charlotte Douglas International Airport
COVID-19: coronavirus disease

ED: emergency department
NCDHHS: North Carolina Department of Health and Human Services
RDU: Raleigh-Durham International Airport
VC: virtual care
VUC: virtual urgent care
WHO: World Health Organization

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Viewpoint

A Case for Participatory Disease Surveillance of the COVID-19 Pandemic in India

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Abstract

The coronavirus disease pandemic requires the deployment of novel surveillance strategies to curtail further spread of the disease in the community. Participatory disease surveillance mechanisms have already been adopted in countries for the current pandemic. India, with scarce resources, good telecom support, and a not-so-robust heath care system, makes a strong case for introducing participatory disease surveillance for the prevention and control of the pandemic. India has just launched Aarogya Setu, which is a first-of-its-kind participatory disease surveillance initiative in India. This will supplement the existing Integrated Disease Surveillance Programme in India by finding missing cases and having faster aggregation, analysis of data, and prompt response measures. This newly created platform empowers communities with the right information and guidance, enabling protection from infection and reducing unnecessary contact with the overburdened health care system. However, caution needs to be exercised to address participation from digitally isolated populations, ensure the reliability of data, and consider ethical concerns such as maintaining individual privacy.

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KEYWORDS

participatory; surveillance; COVID-19; pandemic; outbreak; public health; infectious disease; India

Emerging diseases challenge public health and should be detected early with immediate response taken to control the spread. Disease surveillance forms an essential mechanism for understanding disease epidemiology and provides a sound basis to initiate control measures. Surveillance is the continuous, systematic collection, collation, analysis, and interpretation of health-related data needed for the planning, implementation, and evaluation of public health practices [1]. Most conventional surveillance systems are not designed to meet challenges posed by pandemics like the coronavirus disease (COVID-19). Fortunately, in the age of technology, mobile phone networks are serving as a major backbone across sectors like finance and banking, transportation, trade, commerce, education, social welfare, public administration, and entertainment. It is time we update our surveillance tool to control the current pandemic and prevent any such occurrences in the future.

Participatory disease surveillance (PDS) is an innovative tool for surveillance of communicable diseases in which citizens are engaged actively for the self-reporting of symptoms or events to help public health experts aggregate and analyze data for appropriate public health intervention [2,3]. These systems are Web 2.0, emphasizing user-generated content, ease of use, participatory culture, and interoperability for end users. They can be supplemented with software like geographical information systems, disease modeling systems, and other analytical software for better analysis of collected data [4]. Digital data through PDS can be used for studying infectious disease dynamics such as early detection of disease outbreaks by continuously monitoring disease trends. Internet-based data from social media can provide researchers with an additional method for examining the period before an outbreak and assess disease-relevant and health-related behaviors [5]

Smart phones have been deployed extensively as disease surveillance tools in public health programs. The Global Observatory of eHealth has defined mobile health (mHealth) as medical or public health practice supported by mobile devices such as mobile phones, patient monitoring devices, PDAs, and other wireless devices [6]. These have been established as effective, affordable, adaptive, and cost-effective tools aiding real time data capture. With the growing telecom sector, which is the second largest in the world, mHealth offers a promising solution for many challenges in the health sector. The Telecom Regulatory Authority of India reports 1183.41 million wireless subscribers with the internet subscriber base being 493.73 million in 2019 [7].

The above statistics make a strong case for the introduction of PDS in situations where our routine surveillance capacities are overwhelmed. Expansion of surveillance capacity is required for COVID-19, as it needs to focus on asymptomatic individuals for the quick detection of symptoms, individuals in quarantine, suspected and symptomatic individuals in isolation, and workers involved in health care delivery at all levels.

A model of PDS has already been established in various countries. Influenzanet was established, covering ten European countries, to monitor influenza-like illness (ILI) and foodborne illness. Similar surveillance systems were used effectively in Australia (Flutracker) and the United States (Flu Near You) to capture data on a weekly basis to determine the trend of ILI. Thailand launched a mobile app DoctorMe in 2014 to track ILI and has 15,000-50,000 registered users reporting symptoms on a daily basis. Mo-Buzz was launched recently in Sri Lanka in 2016 to identify dengue mosquito breeding sites and environmental pollution. It was used to track vector-borne diseases and implement preventive strategies with the help of digital connectivity. The use of such tools helped model and forecast health threats with built-in software and analytics [5,8,9]. These novel technologies and health surveillance data together estimate the range and magnitude of health problems in a community to rapidly detect and respond to outbreaks [10]. The COVID-19 pandemic has burdened health care systems worldwide and emphasized community involvement in monitoring, preventing, and controlling the disease.

Countries have introduced mobile-based apps and digital platforms to aid surveillance activities for COVID-19 control [11-14] (Table 1). In some countries, the participation is voluntary and in others it is the basis for permitting movement in society. Apps for COVID-19 surveillance are made to perform two complementary functions: syndromic surveillance and contact tracing. They have been integrated with sectors beyond health such as law enforcement.

The COVID-19 pandemic in India, with a reproduction number >1 (2-3.5), is still in the second stage of the pandemic, which is feared to progress to the third stage with established community transmission and potential for the disease to spread rapidly in the thickly populated cities and towns of India [15,16]. Currently as of April 7, 2020, there are 4306 active cases and 114 deaths with all states reporting cases. The hot spots are mostly located in densely populated cities and state capitals [17]. The pandemic has been responded to aggressively in India by initiating strong measures of lockdown well in advance. However, disease surveillance needs to strengthen for effective prevention and control of the pandemic in India. The Integrated Disease Surveillance Programme (IDSP) in India is a decentralized surveillance mechanism that uses indicator and event-based surveillance to detect outbreaks early [18]. With the disruption of routine health care services, there is less passive reporting of cases. Active surveillance is being done only for those with travel history and in the form of contact tracing confirmed COVID-19 cases. PDS at the IDSP district hub can support the existing system in locating missed cases.

India has built a coronavirus tracker based on mobile location with the name Aarogya Setu (Figure 1), which translates from Sanskrit to “A bridge of health”. For the first time, the country has introduced a PDS model for any disease. Participation in this platform is voluntary. The core function of the app is risk assessment with the option of reporting oneself to the government. It uses the phone’s location data and Bluetooth to assess the proximity from a person infected with COVID-19 by looking through databases created by the government of lab-confirmed COVID-19 cases. Questions on gender, age, symptom details, comorbidities, travel, and contact history are inquired. The app then scores the risk status of the individual as low, moderate, or high. Individuals are informed on the measures to be taken based on the risk assessment (eg, isolation, log temperature every 2 hours) and given advice for testing with details of control rooms and testing centers available in the individual’s area. It also has a chatbot feature, rolling updates from the health ministry, and helpline numbers for each state in India [19]. In the time of this pandemic, when states have implemented complete lock down, this app is an important mode of communication to address COVID-19-related queries and anxieties. Community awareness on this issue will ensure engagement in the platform; however, the information to download the app and use it must be reinforced by government and health care workers. Major drawbacks at this stage are the optional reporting to the government and an unclear process for contact tracing if a suspected case becomes confirmed. Voluntary participation in the app prevents using it for movement permits and as a basis for taking more strict actions.

Table 1. Apps available for coronavirus disease surveillance.

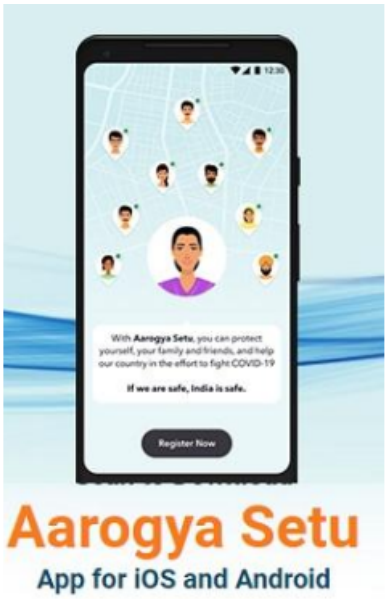
Country	Name of app	Contact tracing	Syndromic reporting	Consent	Geolocation or personal data collected	Comments
China	Alipay Health Code	Yes	Yes	No	Yes	Checklist would issue QR[a] code with one of three colors denoting quarantine status. The code is checked at various points of movement. Information is shared with the police for appropriate action, if required.
Russia	Social Monitoring	Yes	Yes	No	Yes	Government-issued QR code that needs to be presented to police, if required. It also ensures adequate check on people in quarantine and assesses their compliance with instructions.
South Korea	Corona 100m	Yes	Yes	No	Yes	Demographic data and location history is noted in the app at the time of COVID-19[b] diagnosis. It also alerts users if they come within 100 m (328 ft) of a location visited by confirmed case.
Singapore	Trace Together	Yes	Yes	No	No	Using Bluetooth, Trace Together identifies other nearby phones with the app during the period of infectiousness for SARS-CoV-2[c] (14 days). Data is stored in phone for 21 days and accessed only when the person is identified as being in close contact with a confirmed case of COVID-19 or has been diagnosed with COVID-19.
India	Aarogya Setu	No	Yes	Yes	No	Translated in 11 languages for use across all states of India. No mandatory government reporting and functions primarily as an app for self-assessment of COVID-19 risk and information if deemed necessary by an individual.

[a]QR: Quick Response.

[b]COVID-19: coronavirus disease.

[c]SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.

Figure 1. The Aarogya Setu app.



This surveillance system can potentially be used for the prevention and control of the COVID-19 pandemic. It can ensure that information about confirmed and suspected cases in the community is available for the community and government. Geotagging of cases will help in initiating control measures on field situations by the authorities and will inform the community of additional precautions needed. A restrictive testing strategy makes it imperative that data of syndromic reporting is available for the identification and containment of clusters. It will also ensure quality surveillance in areas with overburdened health care systems and resource constraints. It will reflect the trend of ILI and subsequently the disease in the community. The time lag in communication of test results by health authorities can be reduced. The entire process will bring community empowerment with no direct physical contact, adhering to the social distancing regulations currently applicable to the COVID-19 outbreak. These apps or digital platforms can be potentially used in the future to help trained volunteers deliver doorstep diagnostic curative services and implement preventive strategies appropriately. This will prevent patients coming to health care facilities and infecting other people in the process.

The tool of PDS has certain limitations. First, it works on the assumption that volunteers contributing data will be large and representative of the population. Efforts to ensure installation of the Aarogya Setu app must be made actively by the authorities in urban areas for effective surveillance. Initial focus should be given to areas identified as hot spots for transmission, which, until now in India, are mostly in urban areas. Omission of some age groups like older adults and children who use less internet can be overcome by reporting from other household members. However, it should be kept in mind that there will be concerns about populations in rural and remote areas, internet connectivity, availability of smart phones, and digital illiteracy. Second, the main ethical dilemma in cases of PDS is how to ensure adequate protection of participants' data and ensure proper ethics while obtaining the full benefits of public health surveillance involving digital representative communities of citizens [20]. Third, we also must ensure the ethical use of collected data. Digital surveillance of COVID-19 involves access to personal data and may interfere with individual privacy. It is therefore essential to ensure that the data collected is only used for the purpose of prevention and control of the pandemic, and measures are taken to ensure data security [21].

Thus, the authors strongly promote the use of PDS to support the existing IDSP in India. The tool should be used holistically to assess the behavior of communities toward the pandemic, spread awareness messages, do risk profiling and contact tracing, understand the trend of the disease, and have community-based interventions. One single platform for the state or country will ensure uniformity and participation. Adequate integration with the concerned ministries and organizations involved in the pandemic response should be ensured. The lessons learnt during the PDS of COVID-19 will be useful in future pandemics and will further aid the establishment of routine ILI surveillance in the country.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
IDSP: Integrated Disease Surveillance Programme
ILI: influenza-like illness
mHealth: mobile health
PDS: participatory disease surveillance

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Viewpoint

Global Preparedness Against COVID-19: We Must Leverage the Power of Digital Health

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Abstract

The coronavirus disease (COVID-19) pandemic has revealed many areas of public health preparedness that are lacking, especially in lower- and middle-income countries. Digital interventions provide many opportunities for strengthening health systems and could be vital resources in the current public health emergency. We provide several use cases for infection control, home-based diagnosis and screening, empowerment through information, public health surveillance and epidemiology, and leveraging crowd-sourced data. A thoughtful, concerted effort—leveraging existing experience and robust enterprise-grade technologies—can have a substantive impact on the immediate and distal consequences of COVID-19.

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informatics; global health; developing countries; internet; infection; control; COVID-19; pandemic

Introduction

As of April 8, 2020, the total number of confirmed coronavirus disease (COVID-19) cases rose to 1,279,722 with 72,614 deaths [1]. The outbreak that started at Wuhan city in China has now spread worldwide, and on March 11, 2020, the World Health Organization (WHO) declared COVID-19 a pandemic [2]. It threatens human lives and has disrupted global trade, travel, and employment, which risks triggering a global economic recession. China, India, and other countries have taken necessary strict measures to control the spread of the virus, which, although effective, can also lead to anxiety and the potential loss of livelihoods [3]. The situation escalated so dramatically that the Italian government was forced to change its lockdown of only the northern region to encompass the entire country [4]. For now, the main objectives of mitigation remain focused on reducing the velocity of the epidemic and minimizing the daily burden of morbidity and mortality, thus, reducing the risk of exhausting health care systems. This, in turn, helps to protect local and regional economies, keeping the epidemic and its impact manageable until a suitable antiviral drug is identified or a vaccine can be developed [5].

We have seen many guidelines for health care workers (HCWs) around preparedness for COVID-19 that focus on safety and minimizing the spread of infection. Most countries have yet to release a formal guideline or recommendation (either from the government or health agencies), which emphasizes the powerful role telemedicine and other digital health tools can play to contain and manage this new pandemic. Small but significant measures have made a difference, such as the US Office of Civil Rights and Department of Health and Human Services decision to suspend certain electronic communications privacy

regulations to allow providers to support patients via commercial telehealth platforms, irrespective of those platforms compliance with health information security laws [6]. The applications of digital technology for the treatment, diagnosis, support of self-management, and surveillance during public health emergencies are well known. Many countries have existing systems in place to address a variety of health care functions without face-to-face contact [7]; the importance of taking advantage of these cannot be understated. We call for governments, health agencies, and health care providers to immediately and coherently leverage the power of digital health tools to strengthen their health care system capacity to respond to the COVID-19 pandemic. This paper presents several use cases to illustrate possible applications but is not an exhaustive or prioritized list. The use, feasibility, and importance of these applications and others will vary by country needs, existing infrastructure, and other factors.

Stronger Infection Control Through Remote Monitoring and Training

Contagious diseases like COVID-19 pose a serious threat to HCWs and all levels of support staff who come into contact with patients. The Ebola outbreak of 2014-2016 resulted in a humanitarian crisis with more than 28,600 cases and 11,325 deaths [8]. During the height of the outbreak in August 2014, WHO reported that 240 health workers had become infected in West Africa; half of those workers lost their lives to Ebola [9]. The loss of HCWs exacerbates the situation and puts immense pressure on already fragile health systems of lower- and middle-income countries (LMIC) often struggling with limited clinical human resources to begin with.

Teleconsultations With Early Stage or Mild COVID-19

As there are currently no curative treatments (antiviral drugs) or preventive interventions (vaccines), the recommended treatment of uncomplicated COVID-19 cases is mostly supportive with strict infection prevention and control (IPC) measures [10]. WHO has recommended that suspected COVID-19 cases with mild symptoms and no underlying problems can usually be treated at home with careful clinical monitoring [11]. However, trying to take appropriate home-based measures without clear supervision and guidance may create stress and even panic among symptomatic people who may wonder when they are “truly sick” and need to seek professional care. The use of teleconsultations is being widely recommended in most high-income contexts to protect health facilities from being overwhelmed by cases with mild to moderate illness that can be managed at home, as well as they might be in a health care facility environment. In the United States and Europe, most large health care systems have ramped up the use of existing teleconsultation offerings to their members, and a number of private sector companies offer single-use telemedicine services to uninsured or out-of-group clients.

In other contexts, creative use of commercial video conferencing platforms usually reserved for social interactions are being repurposed for clinician-patient interactions. To prevent the spread of COVID-19 to high-risk patients with other comorbidities requiring clinical follow-up, routine health care interactions are being shifted to teleconsultations in many countries around the world. In India, high-throughput tertiary referral centers such as the All India Institute of Medical Sciences are launching telemedicine services to replace in-person check-ins during the pandemic [12], and the national government has released on March 26 a set of National Telemedicine Practice Guidelines [13]. Current levels of mobile phone penetration and the level of internet connectivity allow for telemedicine solutions to be launched in most urban areas of the world. The operational cost of running a telemedicine center can be low compared to running primary care facilities of specialized hospitals with similar catchment areas, reducing the economic burden on strained health care facilities and systems [14].

Remote Monitoring of Infection Prevention and Control

Keeping up with rapidly changing recommendations for IPC during a pandemic is challenging. As the levels of presymptomatic transmission of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) becomes clear, we see how medical staff may be vulnerable to infection or even be at an increased risk for spreading infection in the community [15]. Doctors or other HCWs may inadvertently keep attending patients even after developing symptoms, leading to possible iatrogenic infection and quarantine for many [16]. Digital tools can play a crucial role in IPC by facilitating the monitoring and quality control of IPC practices. So far during the current outbreak, the Chinese government has reported 1716 cases among health workers and 6 deaths [17]. The number of deaths may seem low, but some studies suggest that infected HCWs may have a more severe illness [18]. To reduce the risk of hospital-based transmission, Guangdong Second Provincial General Hospital in the Guangdong province of China has implemented a proactive infection control tool that resembles a security monitoring station. At this station, highly trained infection control observers monitor IPC procedures, ensure adequate IPC supplies, and provide real time aid by radio when needed. Future plans for the system include the addition of artificial intelligence algorithms to speed the ability to identify high-risk situations and mitigate them even more quickly [19].

Centralized Training and Capacity Building, Delivered Digitally

Preparedness activities to date have focused on training and capacity building of the health care staff on infection control, isolating infected people, and tracing contacts of suspected cases. All these tasks can be remotely managed from an appropriately staffed national-level call center. Centralizing training through the internet or mobile phones will make it easier to train staff in rural and remote areas where provider and training capacity is often variable. In this scenario, online courses such as those provided by WHO and other public domain courses for HCWs on COVID-19 can meet crucial training needs [20].

Some barriers must be overcome to ensure the benefits of digital health for remote monitoring, treatment, and training are

available worldwide. In the most remote areas of the world, internet connectivity is limited and not affordable for many. Online formats are also not able to address the differences in learning style or ability that might result in deviation from standard care. In some cases, voice calling may be the most appropriate way to provide telemedicine services, such as places where internet penetration is low or with subpopulations like older adults who may not be as familiar with advanced technologies yet or are at greatest risk for critical illness. Even so, leveraging digital health for remote observation and care, where possible, may reduce costs and decrease the chances of infection spreading from patients to HCWs and back to other patients. It could also greatly help to relieve the emotional turmoil and stress of a person with a suspected case and their family members. The standard clinical recommendation in most health crises to "seek medical attention" should be, in this pandemic, "stay home if you are sick and call the coronavirus hotline to find out what to do next". In fact, the US Centers for Disease Control and Prevention (CDC) website makes it clear that, during this pandemic, both patients with suspected COVID-19 and those with routine illnesses should first "call before you get medical care," to prevent unnecessary exposures to others, especially care providers [21].

Home-Based Diagnosis and Screening

Over the weekend of March 14-15, travelers returning to their home countries packed into tight queues at airports for coronavirus screening for hours. The reality of any crowded area such as testing centers is now the same; any infectious patient can transmit SARS-CoV-2 to those nearby. If a person was not infected before they went for testing, they may become infected simply by seeking testing. Testing for SARS-CoV-2 requires a minimum biosafety level (BSL)-2 to BSL-3 certified laboratory to handle infectious samples according to the newly published interim laboratory biosafety guideline from WHO [22]. Many LMIC lack these kinds of facilities. In countries where they do exist, they are usually located in major cities, which suggests that most people who may be infected cannot be tested or must travel far from home, possibly spreading infection on the way.

Home-based diagnostics can alleviate the need for suspected COVID-19 cases to travel, allowing people to continue the recommended self-quarantine. Individuals or HCWs can request a central emergency operations center hotline to deploy highly trained personnel to collect required samples or assess and transport patients to the hospital if necessary. Such an approach has been used in Milan where a specialized COVID Response Team worked with Emergency Medical Services to dispatch ambulances or test and monitor patients at home based on a procedural algorithm [23]. This centralized deployment makes sense from a resource-sparing perspective; it is obviously much easier to train a handful of sample collection personnel on infection control than trying to manage hundreds or thousands of noninfected and infected people interacting on their way to hospitals or diagnostic centers. Centralized triaging and deployment of personnel and equipment has been implemented in several countries, it is less common in the LMIC where it would preserve vital resources and act as an important form of risk mitigation.

Empowering Through Information

Critical health advice to populations at risk changes rapidly during public health emergencies. Some actions are relatively simple, such as the WHO recommendation that all persons returning from COVID-19-affected countries stay home and self-isolate for 14 days [24]. However, despite clear guidance, ensuring that the message reaches not only public health personnel but also community leaders and members is a substantial challenge.

Centralized Helplines for COVID-19 Information

Formal media channels such as TV, newspapers, or international and national website-based guidance provide a "firehose" of information. Helpful and reliable information may be difficult to pick out from the high-velocity stream, and people can often become confused with misinformation picked up from hyper-sensationalized fringe news outlets and myths floating around social media. Suspected cases and their caregivers may be frustrated by apparently contradicting messages or when encountering situations that are not clearly addressed by the information they have access to. Being able to communicate with a doctor or health professional trained in COVID-19 care can be reassuring and maximize the likelihood of appropriate and timely care. With a simple call to a helpline, both patients and their caregivers can be empowered with knowledge of how to minimize risk of spread, basic home care, and when to notify the health authority if the condition of a patient with COVID-19 deteriorates. It is likely more efficient to train call center–based doctors on management of suspected cases than to conduct mass communication campaigns necessary to ensure the general population has sufficient knowledge to protect themselves and their communities. Mass communication campaigns may also be ineffective in countries with low literacy rates. Another advantage of centralizing information provision is quality control; a digital knowledge base can be easily managed and updated on a regular basis as the outbreak evolves and new information and guidance emerges. With COVID-19, initial messaging around the disease's mild manifestation in those younger than 65 years may have contributed to the widespread misinterpretation that younger subgroups of populations are immune from potentially dangerous complications; when in reality, they are only at a lower risk than older adults.

Psychological Intervention for the Quarantined

To contain the outbreak and limit its impact, WHO and CDC experts recommend or even enforce the quarantine of infected people (ie, those who have laboratory confirmation regarding the presence of SARS-CoV-2) while suspected cases are asked to self-isolate. Today, several cities around the world are locked down, their residents prohibited from venturing outside except to visit the doctor or get food. Many governments have recommended or required suspension of mass gatherings including offices, factories, museums, schools, universities, and libraries [25]. Some cities enforce barriers to entry—no one is allowed to get into those cities unless absolutely necessary. This level of containment on a global scale is unprecedented.

These necessary but extreme measures are stressful for most and, for some, lead to panic and a loss of equanimity. News reports and social media show empty shelves in supermarkets where people depleted basic supplies like toilet paper, paper towels, cleaners, and nonperishables. These stark photos show the tenuous emotional state of those who are being asked to adopt a set of behaviors never before seen in this generation. Not surprisingly, a recently published review on the psychological impact of quarantine revealed that people in quarantine show anger, confusion, frustration, fear, and symptoms resembling post-traumatic stress disorder [26].

Asking citizens to make such sacrifices without appropriate support is unsupportable in a civilized world. We can use digital communication to deliver mental health support, provide counseling, and link individuals through online social networks. This also protects counselors and psychologists who will be able to provide support without exposing themselves to the pathogen. Digital platforms for telepsychiatry and online support are not unusual nowadays in some areas of the world, but much more could be done to leverage their unique ability to meet these needs. Many countries face severe challenges to addressing the needs for psychological support during times of crisis [27]. The addition of telemedicine means that the counsellor need not be in the same area or even in the same country. These efforts can be managed regionally or even with the minimum requirement that both the counsellor and counselee speak the same language. Some nonprofit organizations already provide peer mental health crisis support through digital platforms [28]; these models could be built on to address the needs of various populations worldwide.

Another crucial area that could be addressed through digital means is risk communication around public health measures. WHO guidelines for risk communication in public health emergencies point to the importance of unified messaging that is adaptable to local contexts [29]. People need an understandable rationale, especially in situations where longer quarantine is necessary. Various approaches can provide information and collect community feedback quite easily through digital methods without risking any healthy lives. However, one important caveat holds true for all risk communication during emergencies, as well as for any intervention in general: the acceptance and effectiveness of such measures must be rigorously evaluated, monitored, and updated as needed.

Public Health Surveillance and Epidemiology

Digital tools can be invaluable to reduce exposure risk for public health personnel. Using a variety of remote methods, critical tasks can be performed from safe environments while gathering and analyzing the high-quality data necessary to mitigate the effects of the pandemic.

Contact Tracing

Contact tracing is a standard procedure implemented during an outbreak to determine the extent of the outbreak by identifying and maintaining contact with persons who were exposed to a confirmed case (and thus have high probability of becoming cases themselves) [30]. Traditionally, outbreak investigators would go door-to-door to unearth detailed information of the contacts, which requires enormous amounts of time and human resources. If the disease is contagious enough, the speed of contact tracing can be outpaced by the number of cases and disease spread. Hellewell and colleagues [31] argued that the probability of controlling an outbreak through isolation of cases and contacts drops if initial numbers of cases are high, if there is higher transmission during incubation period, and if the transmissibility basic reproduction number stands between 2.5-3.5. Digital technology may solve that problem by providing a more agile and less resource-consuming approach. After confirming a case, their contacts can be traced over the phone while recording information into an electronic medical record (EMR) or contact management database. All contacts can then be followed up over time through the telephone without requiring face-to-face contact and further infection risk. Automated text message or interactive voice response systems can maintain continued contact over the relevant risk period of 7-14 days to detect early symptoms and refer sick persons to information about self-care or care-seeking, as appropriate.

In most parts of the world the health care system is pluralistic (made up of public, private, and nongovernment organization providers), and resource constraints make it difficult to regulate care. In these settings, services are often offered under the radar, and patients are free to choose and change hospitals at will, resulting in almost no ability to track who is going where. Even in the absence of an interoperable digital health information system that could facilitate disease surveillance, a centralized EMR system, accessible through a web interface or smartphone app, can facilitate the tracking of COVID-19 cases during this public health emergency.

Leveraging Crowd-Sourced Data

So many factors can interfere with the careful public health reporting needed in epidemics: hospital channels may require excessive paperwork or administrative procedures, training may be lacking, or resources for reporting just do not exist. Right now, we need innovative solutions to ensure health care facilities can stay prepared. In a recently published article toward early analysis of the COVID-19 outbreak, Sun et al [32] showed how a health care–oriented social network can be a source of data collection and information sharing. In such scenarios, health care–oriented social network sites can provide real time data and serve as an early alarm to an imminent outbreak, which can be contained with minimal resources if timely responses can be ensured. In this recent outbreak, Chinese doctors who sounded the alarm in early January 2020 about an unusual pneumonia were later silenced with the accusation of spreading misinformation [33]. Had that alarm been taken seriously, it may have been possible to avert to some extent a global pandemic and its potential long-term health, social, and economic consequences.

Another promising project focuses on crowd sourcing artificial intelligence tasks for a database of COVID-19 research outputs [34]. The COVID-19 Open Research Dataset, a joint project of government, academic, and private institutions, compiles

thousands of research articles on SARS-CoV-2 and related coronaviruses. Machine learning researchers are asked to complete and submit tasks that analyze data from the database, with research questions such as "What is known about transmission, incubation, and environmental stability?" Such challenges build on the success of previous efforts that showed that incorporation of corrected Google Flu Trends while forecasting influenza-like illness improves accuracy when compared to reporting done only through formal reporting channels [35]. As the WHO Scientific and Technical Advisory Group for Infectious Hazards has recommended to monitor public health strategies with intensified active surveillance, innovative data sources and crowdsourced tasks could add significant value [36].

However, the challenge remains to ensure the reliability and validity of data sourced through social media. Social media posts are voluntary submissions on the part of individuals and groups, and lack any sort of gatekeeping. Although it is reassuring to see that several major platforms recently decided to commit to working together to stop the spread of coronavirus misinformation, the global reach of these platforms means that this will be a difficult task [37]. Keeping this in mind, it is high time that relevant stakeholders and regulatory bodies determine how to tackle this problem in the era of the fake news and misinformation epidemic (infodemic) [37].

Conclusion

In the midst of such a global crisis all possible opportunities need to be adequately explored and leveraged. Some countries have started taking several initiatives but often in a siloed manner. In Bangladesh, both the government and a few private organizations have started rolling out toll-free (or with minimal charge) hotline numbers for providing people with authenticated information and guidance on what to do if someone suspects they are infected by SARS-CoV-2 or actually shows symptoms of COVID-19. We also have seen the viral spread of videos with animated viruses or catchy dance steps promoting hand washing, aimed at a tech-savvy generation of connected millennials. Such measures are sporadic with likely minimal impact on the pace and consequences of this pandemic.

A thoughtful, concerted effort leveraging existing experience and robust enterprise-grade technologies can have a substantive impact on the immediate and distal consequences of COVID-19 as well as other future health care needs. Many countries have systems in place that could be leveraged in the current emergency. Building on existing infrastructure and systems will help speed digital interventions into practice and reduce costs. As we are seeing therapeutics and vaccines against this novel coronavirus being fast-tracked, so too must we identify and accelerate the use and adoption of digital strategies such as those described in this paper. Normative agencies like WHO can help rapidly convene the expertise needed to develop the content (eg, decision logic and workflows) and data models (eg, recommended variable types and names) that would help developers expedite locally appropriate solutions that are built on validated content but also interoperable—allowing deidentified data to be rapidly pooled as part of global efforts to understand emergent pandemic threats. Unlike the 1918 influenza pandemic, which claimed an estimated 50 million lives, we are confronting COVID-19 within the context of a digital, connected planet. Digital health solutions have been reviewed and vetted by global health agencies like WHO [7] and are available to be deployed in short order through public-private partnerships. This is only possible if we move quickly, like we have for other conventional mitigation strategies, to approve their use to prepare, detect, contain, and better understand this daunting pathogen.

Conflicts of Interest

SM and KH are with Digital Healthcare Solutions, a health care technology company. MCC and AL declare no financial conflicts. Work on this paper was not funded.

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Abbreviations

BSL: biosafety level
CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
EMR: electronic medical record
HCW: health care worker
IPC: infection prevention and control
LMIC: lower- and middle-income countries
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Tracking COVID-19 in Europe: Infodemiology Approach

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Abstract

Background: Infodemiology (ie, information epidemiology) uses web-based data to inform public health and policy. Infodemiology metrics have been widely and successfully used to assess and forecast epidemics and outbreaks.

Objective: In light of the recent coronavirus disease (COVID-19) pandemic that started in Wuhan, China in 2019, online search traffic data from Google are used to track the spread of the new coronavirus disease in Europe.

Methods: Time series from Google Trends from January to March 2020 on the Topic (Virus) of "Coronavirus" were retrieved and correlated with official data on COVID-19 cases and deaths worldwide and in the European countries that have been affected the most: Italy (at national and regional level), Spain, France, Germany, and the United Kingdom.

Results: Statistically significant correlations are observed between online interest and COVID-19 cases and deaths. Furthermore, a critical point, after which the Pearson correlation coefficient starts declining (even if it is still statistically significant) was identified, indicating that this method is most efficient in regions or countries that have not yet peaked in COVID-19 cases.

Conclusions: In the past, infodemiology metrics in general and data from Google Trends in particular have been shown to be useful in tracking and forecasting outbreaks, epidemics, and pandemics as, for example, in the cases of the Middle East respiratory syndrome, Ebola, measles, and Zika. With the COVID-19 pandemic still in the beginning stages, it is essential to explore and combine new methods of disease surveillance to assist with the preparedness of health care systems at the regional level.

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KEYWORDS

big data; coronavirus; COVID-19; infodemiology; infoveillance; Google Trends

Introduction

In December 2019, Chinese researchers identified a novel coronavirus in humans that caused acute respiratory syndrome—officially called coronavirus disease (COVID-19) as of February 11, 2020 [1]. China reported its first death on January 11, 2020, and Wuhan in the Hubei province, which was identified as the epicenter of the epidemic, was cut off by Chinese authorities on January 23, 2020 [2].

COVID-19 quickly surpassed the death toll of the severe acute respiratory syndrome (SARS) pandemic on February 9, 2020 [2]. The virus had already spread to several other Chinese regions, quickly affecting many neighboring countries as well, like the Philippines and South Korea [2]. Several cases of COVID-19 were reported throughout Europe over the next days without causing any regional epidemic at the time; although this did not last long, with Italy having its first death on February 21, 2020 [3], which in a short time spread to all European countries, resulting in the World Health Organization declaring it a pandemic on March 11, 2020 [4].

As of March 25, 2020, COVID-19 cases have surpassed 471,000 worldwide, with more than 335,000 still active, and with more than 21,000 deaths. The country with the most confirmed COVID-19 cases is the United States with 81,864, almost half of which are in the state of New York. Italy is the most affected country in number of deaths as of March 25, with 74,386 cases and 7503 deaths. Lombardy, the origin of the Italy epidemic, is the most affected region, followed by Emilia-Romagna,

Veneto, Piedmont, Marche, Tuscany, and Liguria. In Europe, Spain is unfortunately following Italy's curve, with 49,515 cases and 3647 deaths. Both countries have surpassed China's 3287 reported COVID-19 death toll. France and Germany are also facing a difficult situation, with more than 29,155 and 43,646 confirmed cases, respectively. All European countries have COVID-19 cases, and most countries have at least one death. However, there is a clear geographical distribution of COVID-19 cases in Europe, with central and southwest Europe being the most affected. Figure 1 depicts the current situation in COVID-19 cases worldwide up to March 25, 2020, while Figure 2 shows the COVID-19 (total cumulative, not per capita) deaths by country up to March 25, 2020. All data on COVID-19 cases and deaths were retrieved from Worldometer [5].

Figure 1. Worldwide heat map for total COVID-19 cases by country (as of March 25, 2020).

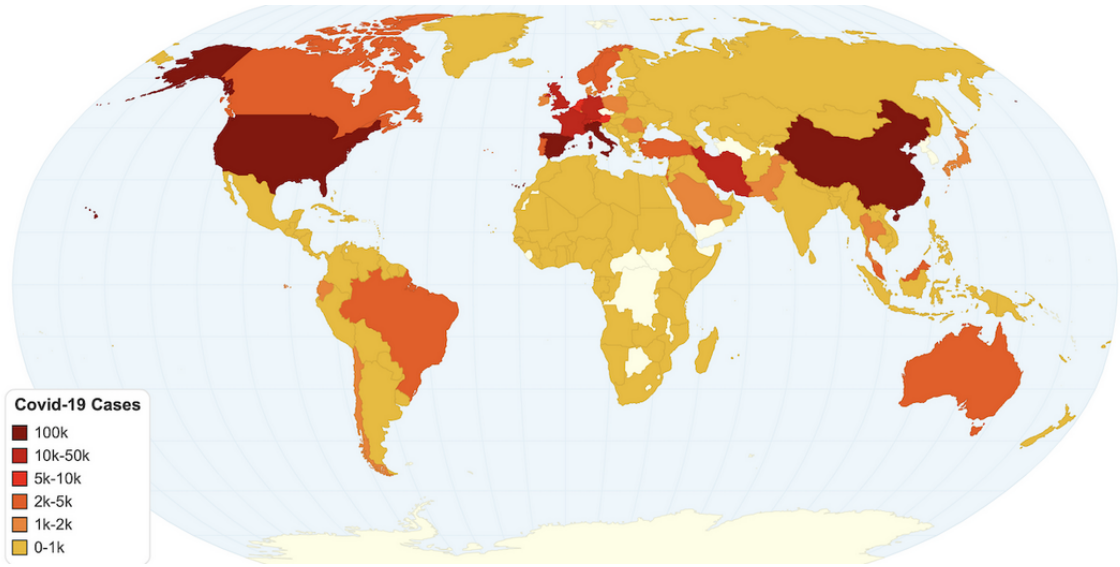
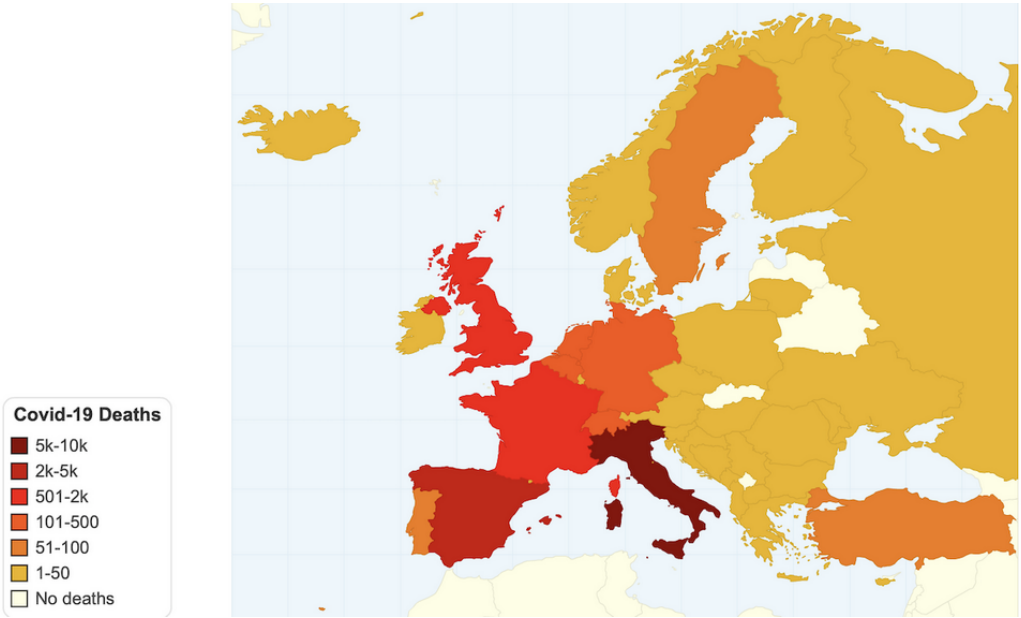


Figure 2. European heat map for total COVID-19 deaths by country (as of March 25th, 2020).



Italy is the first country facing serious issues and a large number of deaths due to COVID-19 in Europe, followed by Spain, France, Germany, and the United Kingdom [5]. The main issue in all affected countries is that of the health systems' capabilities and performance. Toward this direction and based on early Italian data about the spread of the disease, all European countries have taken measures aiming at "flattening the curve" [6], meaning to spread the cases—and, consequently, the patients that need to be admitted to the intensive care unit—over a longer period of time.

Said measures mainly consist of flight restrictions, borders closing, shutting down cafes and restaurants, closing of schools, and self-isolation at first and restriction of movement afterwards, with a total lockdown being the last resort, which has unfortunately been taken in several cases, like that of Lombardy and Spain. The United Kingdom and the Netherlands followed a different approach at first, despite the Imperial College's Response Team's reports led by Prof Ferguson [7-9], with many claiming that they were aiming at herd immunity, which also posed several ethical concerns. Even these two countries,

however, resorted to some measures and restrictions at the end [10,11].

As Gunther Eysenbach, who first proposed the concept of infodemiology (ie, information epidemiology [12-14]), suggested during the SARS pandemic, the use of population health technologies such as the internet can assist with the detection of diseases during an early stage [15]. Given the serious impact of the novel coronavirus and toward the direction of using new methods and approaches for the nowcasting and forecasting of this pandemic, in this paper, Google Trends data are used to explore the relationship between online interest in COVID-19 and cases and deaths in severely affected European countries (ie, Italy, Spain, France, Germany, and the United Kingdom). During these times, infodemiology metrics, especially if combined with traditional data, can be an integral part of the surveillance of the virus at the regional level.

Methods

Data from Google Trends [16] are normalized and retrieved online in .csv format. Note that data may slightly vary based on the time of retrieval. Time series from Google Trends for various time intervals from January to March 2020 on the Topic (Virus) of "Coronavirus" are used, combined with official data on COVID-19 cases and deaths retrieved from Worldometer [5]. The aim is to track the spread of the disease in the European countries that have been affected the most (ie, Italy, Spain, France, Germany, and the United Kingdom). Regional analysis is performed in Italy (data from the Ministry of Health [17]), and the Pearson correlation coefficients between COVID-19 cases and deaths and Google Trends time series are calculated. The Topic of "Coronavirus" was selected instead of the "COVID-19" search term, as the latter was not widely used up to the point of the analysis.

For the general worldwide interest and correlation analysis, the period was set from January 22 to March 17, 2020, while for the rest of the European countries it was set from February 15 to March 17. For the detailed European countries' correlation analysis, case and death data from March 2 to 17 were used. A new data set was retrieved for each time frame, which matched the official COVID-19 case data. The default "All categories" and "Web search" were selected. Note that each country, region, and county were examined individually, and no comparisons between countries in COVID-19 data or Google data were made. The heat maps are based on absolute numbers for COVID-19 cases and deaths, and not according to the respective population. The methodology was designed based on the Google Trends methodology framework in infodemiology and infoveillance [18].

Results

Table 1 consists of the Pearson correlation coefficients (*r*) between Google Trends data and the respective categories of total (cumulative) and daily cases and deaths (where applicable), worldwide (January 22 to March 17) and in the five most affected European countries (February 15 to March 17) (ie, Italy, Spain, France, Germany, and the United Kingdom). Note that for the total worldwide cases excluding China, the Pearson correlation coefficient (*r*) is .9430, with *P*<.001.

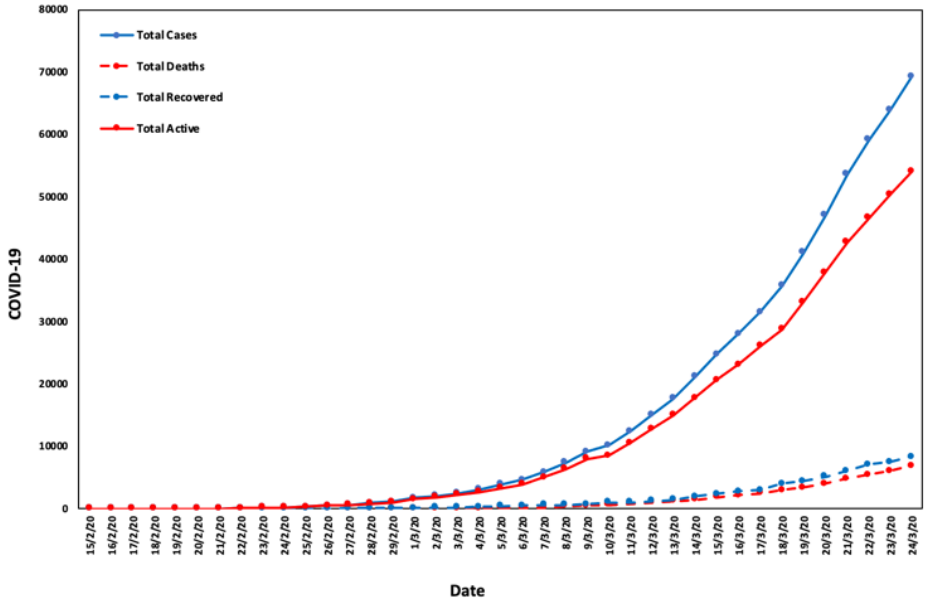
Table 1. Pearson correlation coefficients (*r*) between Google Trends and COVID-19 data.

Variables	Worldwide		Italy		Spain		France		Germany		United Kingdom	
	r	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value
Total cases	0.8293	<.001	0.3301	.07	0.7363	<.001	0.8709	<.001	0.674	<.001	0.8956	<.001
Total deaths	0.8917	<.001	0.2837	.12	N/A[a]	N/A	0.8542	<.001	N/A	N/A	N/A	N/A
Daily new cases	0.7575	<.001	0.3931	.03	0.8342	<.001	N/A	N/A	N/A	N/A	0.8479	<.001
Daily new deaths	0.8536	<.001	0.3474	.05	N/A	N/A	0.8554	<.001	N/A	N/A	N/A	N/A

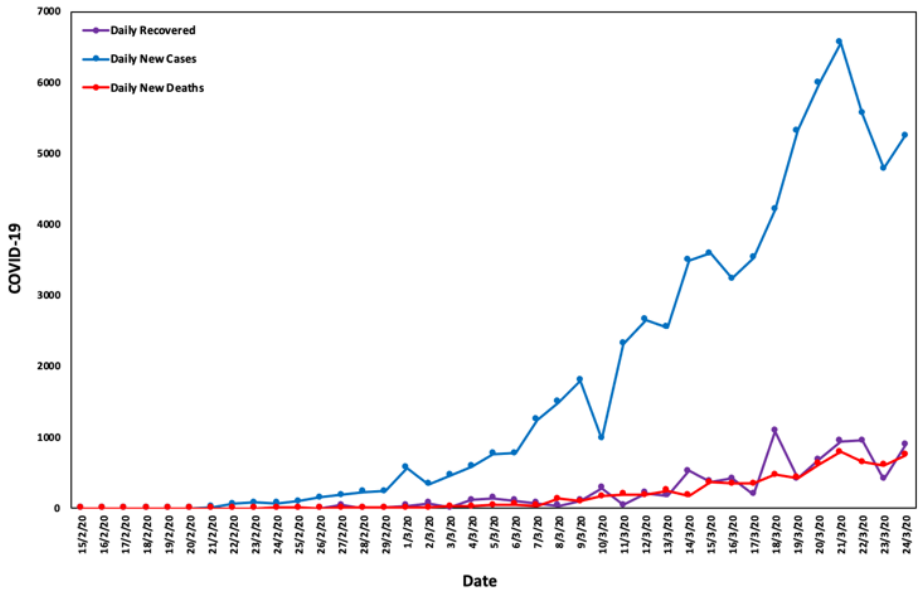
[a]N/A: not applicable.

Based on the results, high statistical significance was observed for the correlations between Google and COVID-19 data for all countries and all applicable categories, apart from Italy, where Google data and COVID-19 total deaths were not correlated. In Italy, total cases and daily deaths were statistically significant but with lower significance, which is not in line with the results for the rest of the countries. The latter could be due to Italy's current special circumstances; it is the first European country to experience such severe consequences from COVID-19 and is further along the line compared with the rest of the countries. Figure 3 depicts the cumulative and daily cases, recoveries, and deaths from February 15 to March 24 in Italy.

Figure 3. (a) Cumulative and (b) daily cases, recoveries, and deaths (Italy; February 15-March 24).



(a)



(b)

Thus, what is essential at this point is to examine if there had been periods for which COVID-19 cases and deaths in Italy correlated with Google query data. The following time frames were selected: March 2-9, March 2-10, March 2-11, March 2-12, March 2-13, March 2-13, March 2-14, March 2-15, March 2-16, and March 2-17.

Table 2 consists of the correlations between Google Trends data and cases, deaths, daily new cases, and daily new deaths in Italy for the aforementioned time frames. Tables 3-4 consist of the individual regions' correlations between COVID-19 cases and Google data.

Table 2. Pearson correlation coefficients (*r*) between COVID-19 cases and deaths and Google Trends data in Italy.

Time frames	Cases		Deaths		Daily Cases[a]		Daily Deaths[a]	
	r	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value
March 2-9	0.9484	<.001	0.9336	<.001	0.9574	<.001	0.8097	.02
March 2-10	0.9157	<.001	0.8593	.003	0.8796	.002	0.7901	.01
March 2-11	0.8951	<.001	0.8261	.003	0.8473	.002	0.7979	.006
March 2-12	0.7942	.004	0.7279	.01	0.7644	.006	0.7792	.005
March 2-13	0.6357	.03	0.5605	.06	0.6768	.02	0.6401	.03
March 2-14	0.5067	.08	0.4537	.12	0.5394	.06	0.6223	.02
March 2-15	0.4417	.11	0.3949	.16	0.4828	.08	0.5071	.06
March 2-16	0.2944	.29	0.2410	.39	0.4065	.13	0.3678	.18
March 2-17	0.1588	.56	0.1036	.70	0.0388	.89	0.2624	.33

[a]Refers to daily new cases and deaths.

Table 3. Pearson correlation coefficients (*r*) between COVID-19 cases and Google Trends data in the 20 Italian regions for March 2-9; March 2-10; March 2-11; March 2-12.

Region	March 2-9		March 2-10		March 2-11		March 2-12	
	r	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value
Lombardia	0.8987	.002	0.8876	.001	0.8625	.001	0.7502	.008
Emilia-Romagna	0.9017	.002	0.8839	.002	0.8798	<.001	0.8292	.002
Veneto	0.9117	.002	0.9230	<.001	0.9139	<.001	0.7960	.003
Piedmont	0.9494	<.001	0.8690	.002	0.8545	.002	0.7537	.007
Marche	0.8770	.005	0.8301	.006	0.8384	.002	0.7551	.007
Liguria	0.8739	.002	0.8451	.004	0.8042	.005	0.6810	.02
Campania	0.9506	<.001	0.9289	<.001	0.9175	<.001	0.8616	<.001
Toscana	0.9073	.002	0.8279	.006	0.8274	.003	0.7529	.007
Lazio	0.9458	<.001	0.9243	<.001	0.8883	<.001	0.7712	.005
Friuli	0.9310	<.001	0.9407	<.001	0.9284	<.001	0.8493	<.001
Trento	0.8722	.005	0.7934	.01	0.7364	.02	0.6978	.02
Apulia	0.9092	.002	0.9005	<.001	0.8573	.002	0.7894	.004
Sicily	0.9725	<.001	0.9691	<.001	0.9510	<.001	0.8604	<.001
Abruzzo	0.8720	.005	0.8523	.004	0.8685	.001	0.6261	.04
Umbria	0.8775	.004	0.8636	.003	0.8158	.004	0.7104	.01
Aosta	0.8704	.005	0.8179	.007	0.7870	.007	0.5679	.07
Sardinia	0.9170	.001	0.9047	<.001	0.7676	.009	0.7268	.01
Calabria	0.9054	.002	0.9004	<.001	0.8413	.002	0.7197	.01
Molise	0.7101	.048	0.7382	.02	0.7160	.02	0.6764	.02
Basilicata	0.8881	.003	0.7884	.01	0.8306	.003	0.8278	.002

Table 4. Pearson correlation coefficients (*r*) between COVID-19 cases and Google Trends data in the 20 Italian regions for March 2-13; March 2-14; March 2-15; March 2-16; March 2-17.

Region	March 2-13		March 2-14		March 2-15		March 2-16		March 2-17	
	r	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value	*r*	*P* value
Lombardia	0.5864	.045	0.4216	.15	0.348	.22	0.1676	.55	0.0693	.80
Emilia-Romagna	0.6471	.02	0.5013	.08	0.442	.11	0.2773	.32	0.1406	.60
Veneto	0.6557	.02	0.4931	.09	0.4900	.08	0.3542	.20	0.2286	.39
Piedmont	0.5599	.06	0.3969	.18	0.3181	.27	0.1341	.63	0.0329	.90
Marche	0.4817	.11	0.2615	.39	0.1687	.56	–0.0869	.76	–0.1932	.47
Liguria	0.5682	.05	0.4111	.16	0.3145	.27	0.2237	.42	0.1166	.67
Campania	0.7073	.01	0.5285	.06	0.4668	.09	0.2611	.35	0.0789	.77
Toscana	0.5822	.047	0.4447	.13	0.396	.16	0.2228	.43	0.115	.67
Lazio	0.4665	.13	0.3157	.29	0.27	.35	0.0683	.81	–0.0746	.78
Friuli	0.6211	.03	0.4791	.097	0.4274	.13	0.2872	.30	0.1774	.51
Trento	0.4813	.11	0.3592	.23	0.2652	.36	0.0553	.85	–0.0388	.89
Apulia	0.6426	.02	0.4421	.13	0.3555	.21	0.2495	.37	0.0419	.88
Sicily	0.7720	.003	0.7055	.007	0.6291	.02	0.5398	.04	0.4332	.09
Abruzzo	0.5535	.06	0.4495	.12	0.4362	.12	0.2808	.31	0.1717	.53
Umbria	0.6088	.04	0.4299	.14	0.3501	.21	0.2063	.46	0.0649	.81
Aosta	0.5123	.09	0.3779	.20	0.2761	.34	0.1942	.49	0.114	.67
Sardinia	0.6188	.03	0.5551	.049	0.5808	.03	0.4049	.13	0.3125	.24
Calabria	0.6272	.03	0.5594	.047	0.5310	.05	0.4234	.12	0.2467	.36
Molise	0.7222	.008	0.4785	.098	0.4498	.12	0.3883	.15	0.232	.39
Basilicata	0.7522	.005	0.7239	.005	0.6253	.02	0.5945	.02	0.4291	.097

As is evident, the strength of the correlation decreases as the time frame includes days when the disease was already widespread, both for cumulative and daily cases and deaths. This is due to the critical point during the spreading of the disease, after which the online interest in the virus starts declining. This is apparent especially for the cumulative cases and deaths, where one function is monotonous (increasing), while the other starts exhibiting a decrease after reaching a peak. Thus, said critical point should be identified in countries and regions with fewer cases to examine the possibility of using Google Trends data to nowcast the spread of COVID-19.

Figures 4 and 5 depict the changes in the Pearson correlation coefficients (*r*) between Google Trends data and COVID-19 cases and deaths for the aforementioned time periods in Italy and Lombardy, respectively. Graphs for the respective changes in the Pearson correlation coefficients for the 20 Italian regions can be found in Multimedia Appendix 1.

Based on these results, it is suggested that regional nowcasting of COVID-19 is possible by simply monitoring Google Trends data until that critical point. This is of high significance if it is applied locally, as it could indicate the regions that will exhibit an increase in COVID-19 cases, thus increasing the preparedness of the health care systems, while, most importantly, taking the needed measures to minimize disease spreading.

In Europe, the countries experiencing the highest case and death counts (after Italy) are Spain, France, Germany, and the United Kingdom, with Spain being in an extremely difficult position with plane traffic being restricted and the army regulating local and regional movement. Thus, for the same time frames as for the Italian regions, the correlations between COVID-19 cases and deaths (where applicable) and the online interest in COVID-19 were calculated. Figures 6-8 depict the changes in the Pearson correlation coefficients for the selected time frames for Spain, Germany, and France.

Figure 4. Changes in the Pearson correlation coefficients (*r*) for Italy.

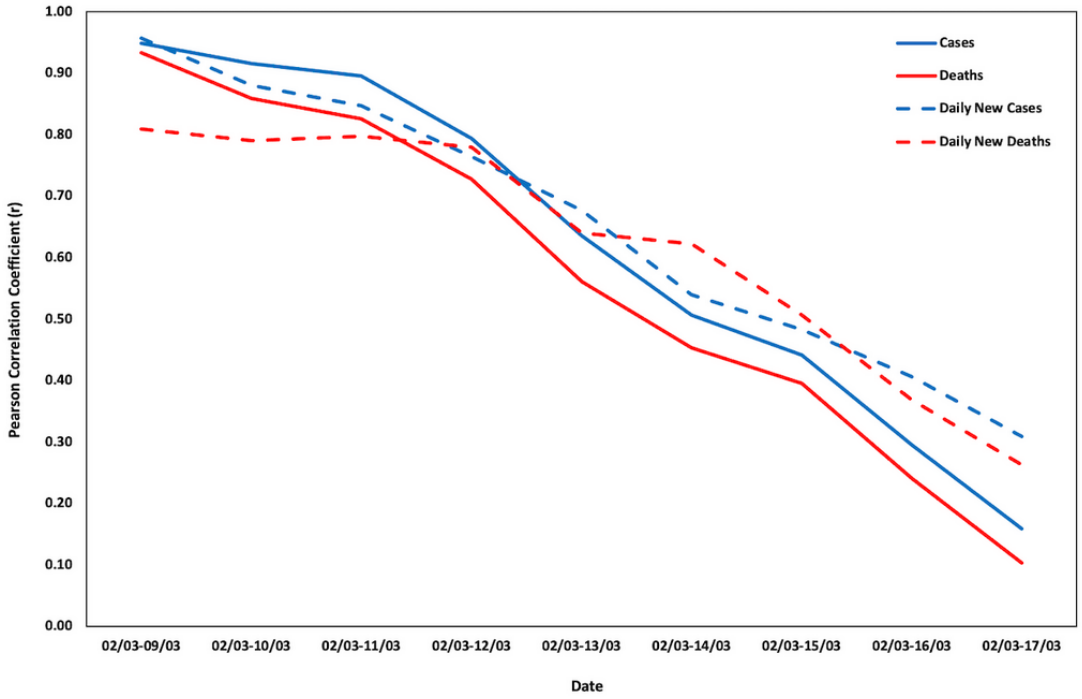


Figure 5. Changes in the Pearson correlation coefficients (*r*) for Lombardy.

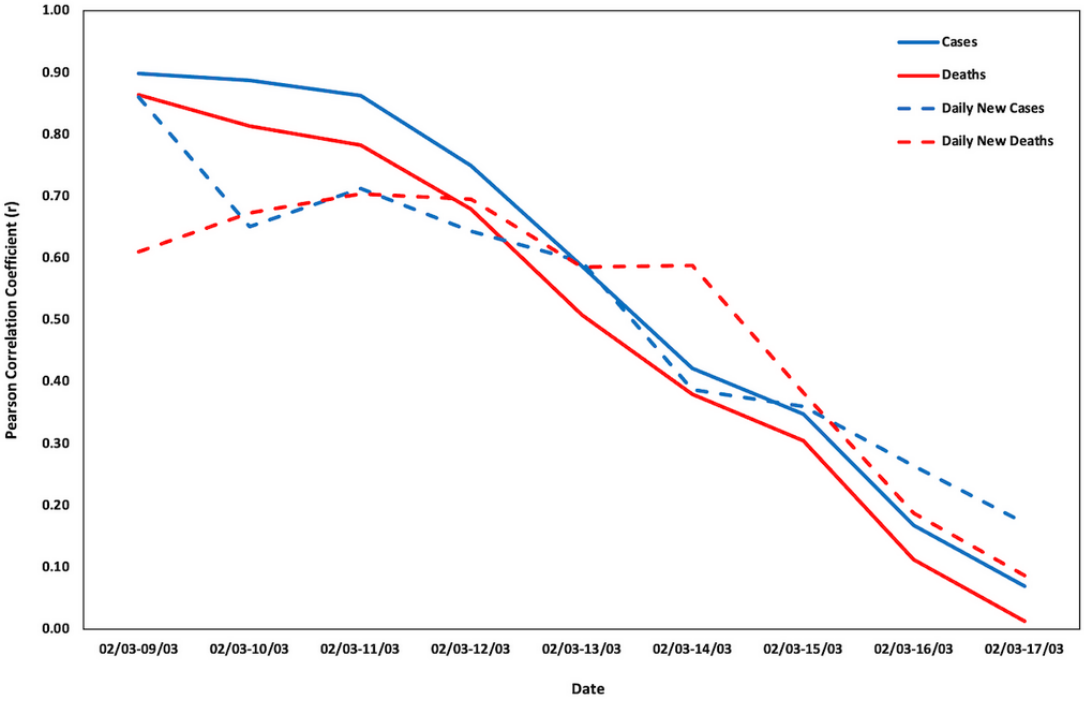


Figure 6. Changes in the Pearson correlation coefficients (*r*) for Spain.

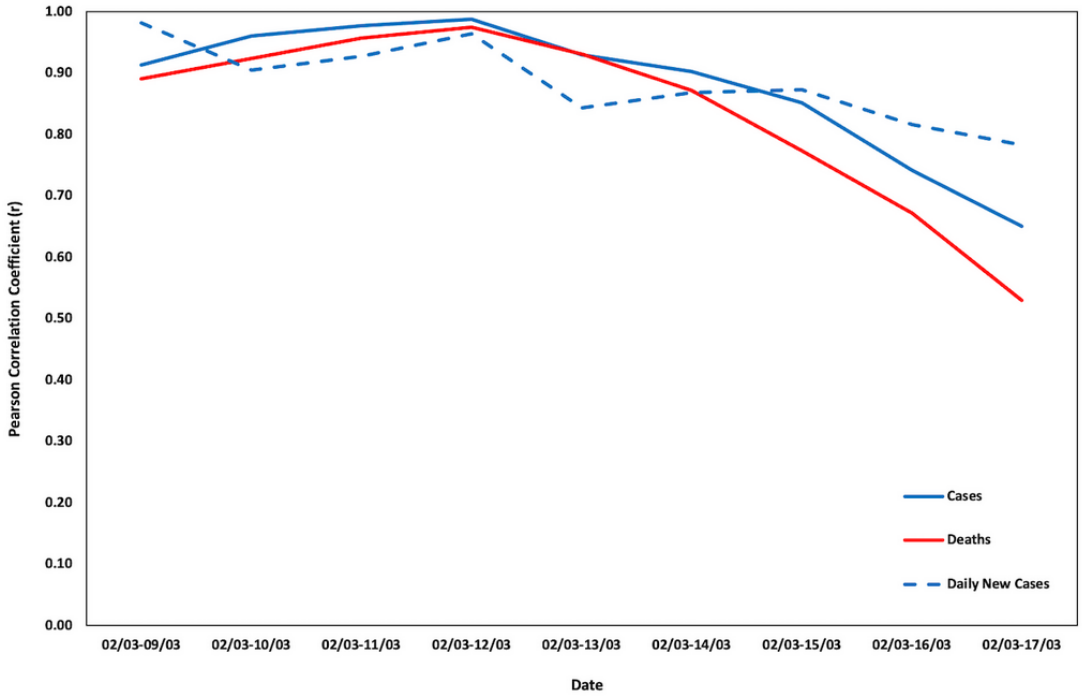


Figure 7. Changes in the Pearson correlation coefficients (*r*) for Germany.

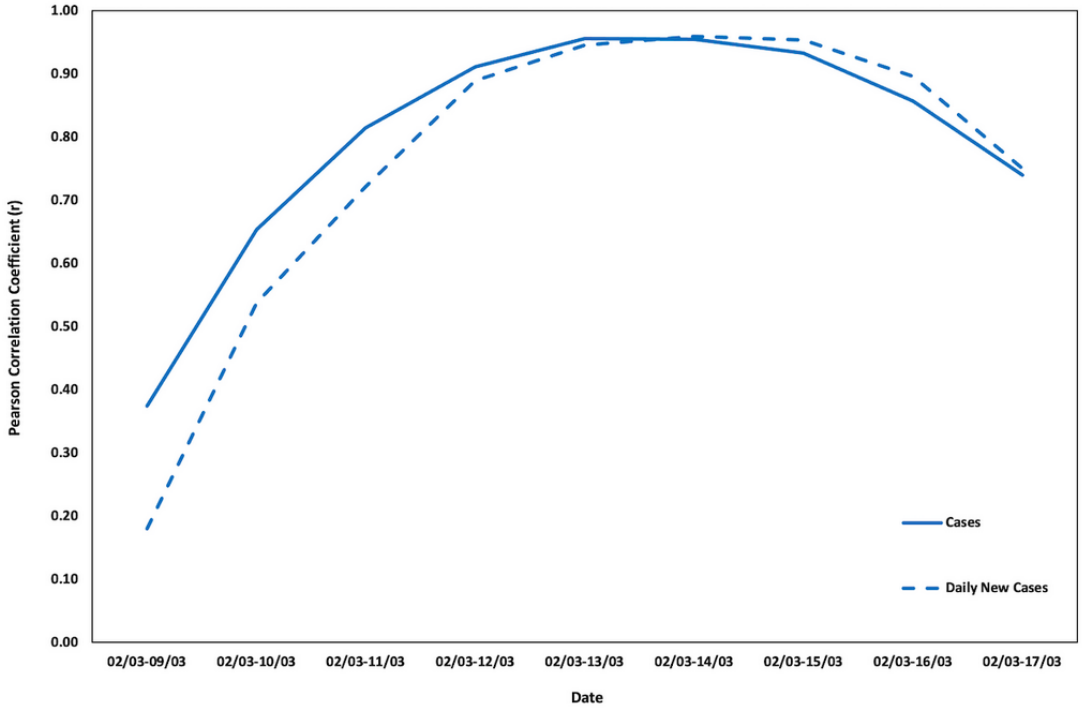
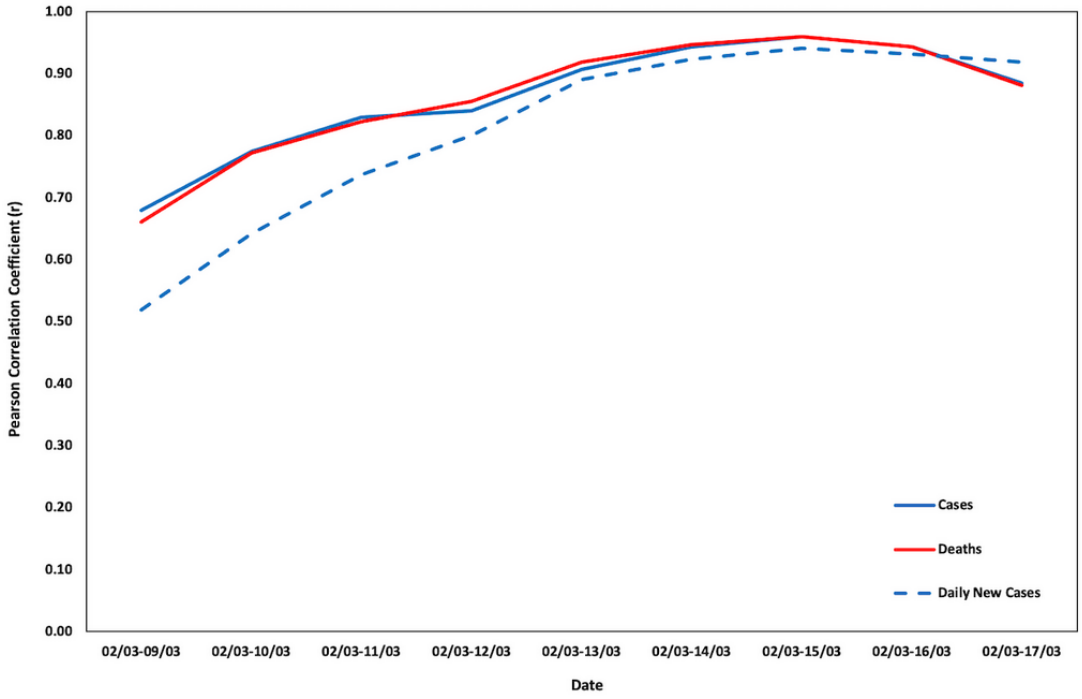


Figure 8. Changes in the Pearson correlation coefficients (*r*) for France.



For Spain, which is closely following Italy in COVID-19 cases and deaths, the Pearson correlation coefficient starts declining after March 13, 2020, which is when Spain's death toll reached 100. In France, the curve still has an increasing trend (150 total deaths as of March 16, 2020), while Germany's curve has started declining since March 15, which is when the country's casualties from COVID-19 passed 10.

Next, the most affected European country (ie, the United Kingdom with more than 10,000 cases) was selected to elaborate on the relationship between COVID-19 cases and deaths and the online interest in the topic. The United Kingdom followed a different approach than most European countries, by not taking preventive measures at an early stage. Figure 9 depicts the changes in the Pearson correlation coefficients for the same time frames selected previously. As is evident, the United Kingdom is still exhibiting high and statistically significant correlations (Table 5).

Figure 9. Changes in the Pearson correlation coefficients (*r*) for the United Kingdom.

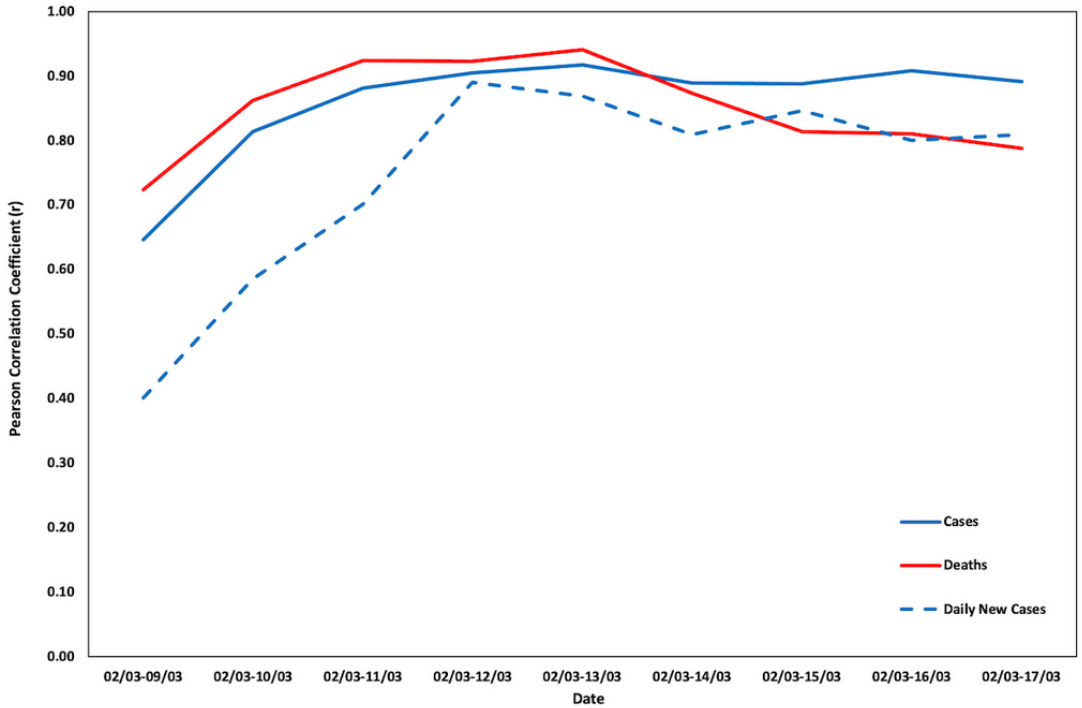


Table 5. Pearson correlation coefficients (*r*) between COVID-19 cases and deaths and Google Trends data for the United Kingdom.

Time Frames	Cases		Deaths		Daily Cases	
	r	*P* value	*r*	*P* value	*r*	*P* value
March 2-9	0.6470	.08	0.7241	.04	0.4008	.33
March 2-10	0.8144	.008	0.8629	.003	0.5863	.097
March 2-11	0.8811	<.001	0.9244	<.001	0.7021	.02
March 2-12	0.9053	<.001	0.9229	<.001	0.8907	<.001
March 2-13	0.9177	<.001	0.9408	<.001	0.8689	<.001
March 2-14	0.8896	<.001	0.8742	<.001	0.8091	<.001
March 2-15	0.8878	<.001	0.8145	<.001	0.8470	<.001
March 2-16	0.9083	<.001	0.8110	<.001	0.8010	<.001
March 2-17	0.8920	<.001	0.7878	<.001	0.8100	<.001

The relationship between COVID-19 cases and deaths shows an increasing trend over the examined period and stays high afterwards. Note that the United Kingdom had zero deaths March 2-4, 2020. The decrease is also evident in Table 5, which consists of the Pearson correlation coefficients and their significance, the latter also exhibiting increased rates as time moves forward, contrary to Italy, Spain, and all Italian regions.

Therefore, it is evident that a correlation between COVID-19 and Google Trends data exists, but the critical point, after which the online interest starts declining, should be identified in each individual case to proceed with regional nowcasting. Toward this direction, the data period should be shortened and applied to regions that have not yet been as severely affected. Google Trends provides a detailed regional break down for most countries, as well as real time and 1-hour interval data over the past week; this gives the opportunity of nowcasting users' search patterns and online behavior toward the disease.

Discussion

Principal Findings

Infodemiology metrics and approaches are an integral part of health informatics, with the most popular sources being Twitter and Google [19,20], which have been successfully employed in the past to track and forecast outbreaks and epidemics (eg, Middle East respiratory syndrome [21], measles [22,23], Ebola [24,25], the swine flu [26], and the Zika epidemic [27,28]).

However, the case of the new coronavirus is somewhat different both in terms of the qualitative and quantitative approach than the previously examined epidemics. COVID-19 has been the subject of several controversial discussions. Since China's first death report on January 11, 2020 [2], there have been several controversies regarding how China has handled the epidemic. There are ongoing debates as to whether there had been an attempt to hide the beginning of the outbreak, which became public by whistleblower Dr Li Wenliang who was reported dead as of February 7 due to COVID-19 complications [29]. There has been information about reporters being expelled from China as brought forward by New York Times reporter Amy Qin [30]. Most importantly though, there have been doubts about the accuracy of the data and results that the Chinese authorities and scientists have provided, with a much discussed incident being the announcement that "*Preliminary investigations conducted by the Chinese authorities have found no clear evidence of human-to-human transmission of the novel #coronavirus (2019-nCoV) identified in #Wuhan, #China*" [31].

However, the case of Italy, which is the country with the highest death toll and should perhaps be treated as the first case of what to expect from the virus spread, shows that the epidemic is far more serious than what the officials originally suggested, with a record daily death toll of 919 reported on March 27 [32] and total deaths slightly less than 10,000. Based on Italy's data, many European countries acted fast in imposing measures for slowing down the spread of the disease, and the next 2-3 weeks could exhibit nonexponential curves in terms of daily casualties.

Toward the direction of finding new methods for nowcasting COVID-19 to increase the preparedness of health care systems, this study suggests that Google Trends data strongly correlates with COVID-19 cases and deaths worldwide and in the examined countries. Most importantly though, there is a critical point, after which the relationship's strength (in almost all cases) monotonously decreases, even if the correlation remains statistically significant, with Italy having the sharpest downward curve.

Limitations

This study has limitations. First, since the pandemic not only is ongoing but has not reached its peak yet, the data are limited; thus, the correlations are based on fewer observations, and the results are only preliminary and subject to change as we move forward. Second, only a few countries provided, at the time of writing, sufficient data for analysis or a regional break down of the cases and deaths. Third, only the interest in the "Coronavirus (Virus)" Topic was explored, but future reports should also elaborate on more complicated search patterns, especially using the official name of the disease (ie, COVID-19) once it is used by a significant part of the population. Fourth, there are significant changes in cases, deaths, and rates even between 2 consecutive days in many regions and countries; even at the time of writing, the data can significantly vary from those at the time of retrieval.

Conclusions

In line with previous studies that have indicated that Google Trends data can assist with the tracking and nowcasting of epidemics and outbreaks, the results of this paper show that online search traffic data are highly correlated with COVID-19 cases and deaths in the examined countries and regions. Furthermore, a critical point, up to which regions not severely affected exhibit the strongest relationship between Google and COVID-19 data, was identified. This suggests that focus should shift towards these regions to make full use of what real time data assessment can offer. The latter is essential for increasing the preparedness and responsiveness of local health institutions, which is the most important aspect in handling the current pandemic.

As of March 27, the center of the COVID-19 pandemic is the United States, with New York being the most affected, and it is imperative to perform similar analyses regionally, at state, metro, and city levels. Data from the disease spread and casualties in Europe will provide a better picture as to the characteristics of the virus as well as detailed data—both traditional and infodemiological—to estimate nowcasting models.

Despite the limited data availability at this stage of the pandemic, it is essential that all results are shared and rapid publications on the topic of infodemiology are accessible. Infodemiology results from various sources such as Google, Twitter, Facebook, or other social media are valuable variables in epidemiology. It is crucial to use such preliminary findings to build novel approaches that make use of real time data for the tracking and nowcasting of COVID-19.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Changes in the Pearson correlation coefficients (r) for the 20 Italian regions.
[PDF File (Adobe PDF File), 1310 KB - publichealth_v6i2e18941_app1.pdf]

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Abbreviations

COVID-19: coronavirus disease
SARS: severe acute respiratory syndrome

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Original Paper

The Role of YouTube and the Entertainment Industry in Saving Lives by Educating and Mobilizing the Public to Adopt Behaviors for Community Mitigation of COVID-19: Successive Sampling Design Study

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Abstract

Background: Effective community mitigation through voluntary behavior change is currently the best way to reduce mortality caused by coronavirus disease (COVID-19). This study builds on our prior study based on the scientific premise that YouTube is one of the most effective ways to communicate and mobilize the public in community mitigation to reduce exposure to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

Objective: Because of the rapidly changing nature of YouTube in the context of the COVID-19 pandemic, we conducted a follow-up study to document how coverage of preventive behaviors for effective community mitigation has changed.

Methods: A successive sampling design was used to compare coverage of behaviors to mitigate community transmission of COVID-19 in the 100 most widely viewed YouTube videos in January 2020 and March 2020.

Results: Videos in the January and March samples were viewed >125 million times and >355 million times, respectively. Fewer than half of the videos in either sample covered any of the prevention behaviors recommended by the US Centers for Disease Control and Prevention, but many covered key prevention behaviors and were very widely viewed. There were no videos uploaded by entertainment television in the January sample, but this source comprised the majority of videos and garnered the majority of cumulative views in the March sample.

Conclusions: This study demonstrates the incredible reach of YouTube and the potential value of partnership with the entertainment industry for communicating and mobilizing the public about community mitigation to reduce mortality from the COVID-19 viral pandemic.

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KEYWORDS

YouTube; COVID-19; social media; pandemic; outbreak; infectious disease; public health; prevention

Introduction

When discussing the goals of community mitigation during a White House press briefing on March 31, 2020, Dr Deborah Birx, the US coronavirus response coordinator, stated that mitigation begins and ends with community [1]. She presented modeling estimates showing that without mitigation, between 1.5 and 2.2 million people in the United States would die from coronavirus disease (COVID-19); however, with effective community mitigation, mortality could be reduced to between 100,000 to 200,000 deaths. These community mitigation efforts

recommended by the US Centers for Disease Control and Prevention (CDC) and described in our prior study rely exclusively on voluntary personal behaviors such as staying home, social distancing, and hand hygiene [2]. The scientific premise for that study was that, because of its widespread reach to the American (and global) population, YouTube is one of the most effective ways to communicate with the public and mobilize them to become engaged in effective community mitigation to reduce exposure to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2).

Our prior study was the first published study on the extent to which widely viewed YouTube videos address voluntary behaviors for effective community mitigation [2]. These videos, which were uploaded during January 2020, showed that fewer than one-third of the videos addressed any of the behaviors recommended by the US CDC to protect oneself and others by reducing exposure to SARS-CoV-2—the essence of effective community mitigation [3]. Because of the rapidly changing nature of YouTube in the context of the COVID-19 pandemic, we conducted a follow-up study to identify the most widely viewed YouTube videos as of March 20, 2020 to determine how coverage of preventive behaviors for effective community mitigation has changed.

Methods

A successive sampling design was used to select the 100 most widely viewed YouTube videos on COVID-19 as of January 31, 2020, and March 20, 2020. In both cases, the methods described in our prior study [2] were followed. In the second sampling period, half of the videos were coded by author CHB and the other half were coded by author CJ. Interrater reliability was previously demonstrated and found to be excellent (Cohen kappa=0.97). The prior study focused on preventive behaviors, mortality and fear, symptoms, transmission and natural history, and other precautions, while this study focuses exclusively on prevention behaviors to mitigate community transmission. Data analysis involved descriptive statistics, and all analyses were conducted using SPSS, version 26 (IBM Corp).

Results

At the time of data collection (March 20, 2020), the videos in the sample were viewed more than 355 million times (by the afternoon of April 5, 2020, these videos garnered almost 59 million additional views; total=413,975,717 views). The mean number of views per video was 3,552,125 (SD 2,817,911), and the mean length was 12.3 minutes (SD 11.3 minutes; range 34 seconds to 89 minutes). Most were created in English (n=79, 79.0%) or with English subtitles (n=1, 1.0%), and 20.0% were in Spanish. The large majority (n=95, 95.0%) featured a live presenter, while 5.0% (n=5) featured animation.

Although all the videos in the prior study were uploaded by three sources—consumers (11%), healthcare professionals (4%), and news (85%)—by March 20, 2020, the majority (57%) of the most widely viewed videos in this study were uploaded by entertainment television, garnering almost 55% (n=193,639,691) of the total cumulative views (Tables 1 and 2). There was a large decline in the number of videos uploaded by news sources (from 85 to 19) and a commensurate decline in the proportion of cumulative views amassed from this source (from 82% to 22.5%). In contrast, there was an increase in the number of videos uploaded by consumers from 11 to 19, with the proportion of cumulative views changing from 13.8% to 18.7%. The number of videos and the proportion of cumulative views garnered by videos uploaded by professionals remained essentially unchanged (4 versus 5 and 4.2% versus 4.3%, respectively). In the short time between our first and second successive samples (48 days), there was a dramatic increase in cumulative views garnered by the 100 most widely YouTube videos (from 125,286,561 to 355,212,487). It is noteworthy that only 5 of the videos from the first sample were retained in the second sample.

Fewer than half of the videos covered any of the 8 prevention behaviors recommended by the US CDC as of March 2020. In January, 39 videos garnering almost 60 million views covered the topic of staying indoors, while in March, this recommendation was covered in 42 videos garnering over 160 million views. There was a large increase in the number and proportion of cumulative views garnered by videos regarding hand hygiene, from 33,268,243 (26.6%) to 182,331,135 (51.3%). There were also increases in the number of videos and the proportion of cumulative views garnered regarding staying home when ill and covering cough/sneeze with tissue and discarding it in the trash. In contrast, there was a decline in number of videos addressing avoiding close contact with people who are ill (from 31 to 18), even though the number of views garnered by these videos increased (from 41,269,546 to 97,013,939). In the first sample, use of a facemask for protection if you are caring for someone who is ill was not mentioned and facemask use for protecting others if you are ill was only mentioned in 2 videos; in the second sample, the first topic was covered in 8 videos that were viewed over 26 million times and the second topic was covered in 4 videos viewed over 13 million times. Cleaning and disinfecting highly touched objects and surfaces was addressed in 16 videos in the first sample (with 17,545,061 views) and 15 videos in the second sample (with 70,365,530 views).

Table 1. Behaviors to mitigate transmission of COVID-19 covered in widely viewed YouTube videos by source in January 2020.

Prevention behaviors	Total		Consumer		Professional		News	
	Total number of views (%)[a]	Total number of videos	Number of views (%)[b]	Number of videos (%)[b]	Number of views (%)[b]	Number of videos (%)[b]	Number of views (%)[b]	Number of videos (%)[b]
Overall	125,286,561 (100)	100	17,288,306 (13.8)	11 (11.0)	5,299,489 (4.2)	4 (4.0)	102,698,766 (82)	85 (85.0)
Stay indoors[c]	59,527,347 (47.5)	39	7,333,961 (12.3)	6 (15.4)	3,800,508 (6.4)	2 (5.1)	48,392,878 (81.3)	31 (79.5)
Hand hygiene	33,268,243 (26.6)	26	4,869,024 (14.6)	4 (15.4)	3,910,326 (11.8)	2 (7.7)	24,488,893 (73.6)	20 (76.9)
Avoid close contact with those who are sick	41,269,546 (32.9)	31	7,409,099 (18.0)	5 (16.1)	4,734,854 (11.5)	3 (9.7)	29,125,593 (70.6)	23 (74.2)
Stay home when ill	42,647,990 (34.0)	29	7,409,099 (17.4)	5 (17.2)	4,060,401 (9.5)	2 (6.9)	31,178,490 (73.1)	22 (75.9)
Cover cough/sneeze with tissue; throw tissue away	19,625,830 (15.7)	14	4,150,801 (21.1)	3 (21.4)	3,235,873 (16.5)	1 (7.1)	12,239,156 (62.4)	10 (71.4)
Use facemask for protection if you are caring for the ill	0 (0)	0	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Use facemask for protecting others if you are ill	1,152,765 (0.9)	2	627,664 (54.4)	1 (50.0)	0 (0.0)	0 (0.0)	525,101 (45.6)	1 (50.0)
Clean and disinfect highly touched objects and surfaces	17,545,061 (14.0)	16	4,869,024 (27.8)	4 (25.0)	3,910,326 (22.2)	2 (12.5)	8,765,711 (50.0)	10 (62.5)

[a]Column percentage.

[b]Row percentage.

[c]Universal recommendation to stay indoors did not exist in January but was coded under Other Precautions.

Table 2. Behaviors to mitigate transmission of COVID-19 covered in widely viewed YouTube videos by source in March 2020.

Prevention behaviors	Total		Consumer		Professional		News		Entertainment	
	Total number of views (%)[a]	Total number of videos	Number of views (%)[b]	Number of videos (%)[b]	Number of views (%)[b]	Number of videos (%)[b]	Number of views (%)[b]	Number of videos (%)[b]	Number of views (%)[b]	Number of videos (%)[b]
Overall	355,212,487 (100)	100	66,303,762 (18.7)	19 (19.0)	15,213,523 (4.3)	5 (5.0)	80,055,511 (22.5)	19 (19.0)	193,639,691 (54.5)	57 (57.0)
Stay indoors[c]	160,105,457 (45.1)	42	25,633,078 (16.0)	6 (14.3)	2,147,978 (1.3)	1 (2.4)	33,653,431 (21.0)	7 (16.7)	98,670,970 (61.6)	28 (66.7)
Hand hygiene	182,331,135 (51.3)	44	50,255,990 (27.6)	11 (25.0)	2,147,978 (1.2)	1 (2.3)	56,645,499 (31.1)	12 (27.3)	73,281,668 (40.2)	20 (45.5)
Avoid close contact with those who are sick	97,013,939 (27.3)	18	31,374,132 (32.3)	4 (22.2)	2,147,978 (2.2)	1 (5.6)	16,835,274 (17.4)	3 (16.7)	46,656,555 (48.1)	10 (55.6)
Stay home when ill	163,220,603 (46.0)	44	47,505,715 (29.1)	10 (22.7)	2,147,978 (1.3)	1 (2.3)	35,502,777 (21.8)	7 (15.9)	78,064,133 (47.8)	26 (59.1)
Cover cough/sneeze with tissue; throw tissue away	98,060,105 (27.6)	24	31,620,076 (32.2)	8 (33.3)	2,147,978 (2.2)	1 (4.2)	31,260,481 (31.9)	6 (25.0)	33,031,570 (33.7)	9 (37.5)
Use facemask for protection if you are caring for the ill	26,881,257 (7.6)	8	2,205,478 (8.2)	1 (12.5)	0 (0)	0 (0)	9,151,436 (34.0)	1 (12.5)	15,524,343 (57.8)	6 (75.0)
Use facemask for protecting others if you are ill	13,491,951 (3.8)	4	0 (0)	0 (0)	0 (0)	0 (0)	9,151,436 (67.8)	1 (25.0)	4,340,515 (32.2)	3 (75.0)
Clean and disinfect highly touched objects and surfaces	70,365,530 (19.8)	15	34,705,722 (49.3)	6 (40.0)	2147978 (3.1)	1 (6.7)	15,191,934 (21.6)	4 (26.7)	18,319,896 (26.0)	4 (26.7)

[a]Column percentage.

[b]Row percentage.

[c]Universal recommendation to stay indoors did not exist in January but was coded under Other Precautions.

Discussion

Over 125 million views in our first sample and the dramatic increase to over 355 million views in our second sample demonstrates the incredible reach of YouTube for communicating and mobilizing the public about community mitigation as a means to reduce mortality from the COVID-19 viral pandemic. YouTube is one of the most effective means for increasing awareness and interest in community mitigation of COVID-19 not only because of its widespread reach but also because many vulnerable people within the population may have low levels of literacy, which makes reading and deciphering behavioral recommendations described on websites difficult or impossible. Our prior studies on emerging infectious diseases such as Zika [4], Ebola [5], and other public health problems affecting population health [6-8] further demonstrate the reach of YouTube as a way to help educate people and help them make informed decisions. However, there has never been a more urgent need for such education to mobilize and engage people in communities throughout the United States and globally to understand and practice behaviors to mitigate community transmission as with the COVID-19 viral pandemic.

A highlight of the findings is the dramatic change that occurred from the first to the second sample, not only in the number of cumulative views, but also in the sources of videos that were most likely to have a widespread reach. Although there were no videos uploaded by entertainment television in our first sample, within 7 weeks, this source comprised the majority of videos (57%) and garnered the majority of cumulative views (>193 million). At this critical time, as all sectors of the American public work together toward the goal of community mitigation, we believe our findings indicate the potential role of entertainment television in saving lives. The implication is that in addition to holding regular press briefings covered by national news, public health officials may be able to achieve our collective goal of community mitigation by appearing on entertainment television and communicating clearly about the specific behaviors that people must practice to protect themselves, their families, and their communities, especially the many health care professionals and essential workers placing themselves at risk to care for others.

The behaviors we studied were identified from the US CDC website [3], but we collapsed behaviors into categories that could have been delineated in greater detail. For example, the recommendation regarding “Clean your hands often,” which we entitled hand hygiene, includes very specific advice: “Wash

your hands often with soap and water for at least 20 seconds especially after you have been in a public place, or after blowing your nose, coughing, or sneezing" [3]. This single recommendation can be disaggregated into 9 specific behaviors: Wash your hands (1) often (2) with soap (3) and water (4) for at least 20 seconds (5) especially after you have been in a public place (6), or after blowing your nose (7), coughing (8), or sneezing (9). In this same category of hand hygiene, additional recommendations pertain to the use of hand sanitizer containing at least 60% alcohol and covering all surfaces of hands and rubbing them together until they feel dry and to "avoid touching your eyes, nose, and mouth with unwashed hands" [3]. These recommendations too comprise many behaviors, which we did not specifically delineate in our coding protocol. We believe that the complexity of these behavioral recommendations highlights the value of video presentation in communicating about and demonstrating desired behaviors.

It should be noted that new knowledge, including recommended behaviors to mitigate community spread of COVID-19, are emerging rapidly and it is important to track the extent to which widely viewed videos cover up-to-date accurate information. Despite its great potential for disease prevention, it is important to identify and dispel inaccurate information that may be conveyed on YouTube, which we have documented in our previous studies on other topics [6,7]. Almost all published studies on YouTube and public health are cross-sectional, but we believe ongoing tracking of content contained in YouTube videos is necessary to improve understanding about the kinds of information people need to make informed decisions, which is especially urgent in the current virus pandemic.

Given that there is currently no vaccine to reduce personal susceptibility and no proven treatment therapies, educating and mobilizing people to practice the behaviors that we know will reduce exposure to SARS-CoV-2 is the best and only hope for dramatically reducing the number of lives that will be lost. We believe YouTube can play an important role in achieving that goal. Such communication should be a key element of a comprehensive national (and global) strategy for educating, mobilizing, and engaging the public to adopt and practice behaviors for community mitigation.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Data Mining and Content Analysis of the Chinese Social Media Platform Weibo During the Early COVID-19 Outbreak: Retrospective Observational Infoveillance Study

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Abstract

Background: The coronavirus disease (COVID-19) pandemic, which began in Wuhan, China in December 2019, is rapidly spreading worldwide with over 1.9 million cases as of mid-April 2020. Infoveillance approaches using social media can help characterize disease distribution and public knowledge, attitudes, and behaviors critical to the early stages of an outbreak.

Objective: The aim of this study is to conduct a quantitative and qualitative assessment of Chinese social media posts originating in Wuhan City on the Chinese microblogging platform Weibo during the early stages of the COVID-19 outbreak.

Methods: Chinese-language messages from Wuhan were collected for 39 days between December 23, 2019, and January 30, 2020, on Weibo. For quantitative analysis, the total daily cases of COVID-19 in Wuhan were obtained from the Chinese National Health Commission, and a linear regression model was used to determine if Weibo COVID-19 posts were predictive of the number of cases reported. Qualitative content analysis and an inductive manual coding approach were used to identify parent classifications of news and user-generated COVID-19 topics.

Results: A total of 115,299 Weibo posts were collected during the study time frame consisting of an average of 2956 posts per day (minimum 0, maximum 13,587). Quantitative analysis found a positive correlation between the number of Weibo posts and the number of reported cases from Wuhan, with approximately 10 more COVID-19 cases per 40 social media posts (P<.001). This effect size was also larger than what was observed for the rest of China excluding Hubei Province (where Wuhan is the capital city) and held when comparing the number of Weibo posts to the incidence proportion of cases in Hubei Province. Qualitative analysis of 11,893 posts during the first 21 days of the study period with COVID-19-related posts uncovered four parent classifications including Weibo discussions about the causative agent of the disease, changing epidemiological characteristics of the outbreak, public reaction to outbreak control and response measures, and other topics. Generally, these themes also exhibited public uncertainty and changing knowledge and attitudes about COVID-19, including posts exhibiting both protective and higher-risk behaviors.

Conclusions: The results of this study provide initial insight into the origins of the COVID-19 outbreak based on quantitative and qualitative analysis of Chinese social media data at the initial epicenter in Wuhan City. Future studies should continue to explore the utility of social media data to predict COVID-19 disease severity, measure public reaction and behavior, and evaluate effectiveness of outbreak communication.

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KEYWORDS

COVID-19; coronavirus; infectious disease; social media, surveillance; infoveillance; infodemiology

Introduction

The coronavirus disease (COVID-19) is a rapidly emerging infectious disease caused by a novel coronavirus named severe acute respiratory syndrome (SARS) coronavirus 2 [1]. The COVID-19 outbreak began in late December 2019 in Wuhan, Hubei Province, China, with a cluster of patients presenting with pneumonia of unknown origin and reported exposure to a seafood and live animal market in the same city [2]. The World Health Organization (WHO) confirmed 41 cases and 1 death due to the novel coronavirus by January 12, 2020 [3]. Since this initial reporting, COVID-19 has rapidly spread within China and internationally, with the WHO declaring a Public Health Emergency of International Concern (PHEIC) under the revised International Health Regulations on January 30, 2020 [4].

Since the PHEIC declaration, COVID-19 has spread to every continent except Antarctica, becoming a highly infectious global pandemic with sustained community transmission [5]. The severity of the COVID-19 outbreak, with approximately 1.8 million cases worldwide as of mid-April 2020 [6], has far surpassed past coronavirus events such as the Middle East respiratory syndrome (MERS)–related coronavirus, which had 2494 cases as of November 2019, and the 2003 SARS coronavirus, which had more than 8000 cases and affected 26 countries. It is unknown whether viral mutations will result in patterns of annual re-emergence as seen with influenza strains.

Attempts to predict epidemiological features (eg, prevalence, attack rate, replication or reproduction rate, morbidity, and mortality) of an outbreak to inform infection control and public health countermeasures are critical. This can be challenging during the earlier stages of an outbreak when there is a lack of sufficient information regarding the etiology of the disease, inadequate diagnostic and testing capabilities, and incomplete epidemiological data regarding confirmed cases [7]. In the absence of such data, the use of information in an electronic medium such as social media conversations can enable syndromic surveillance approaches to characterize disease distribution and provide accurate case counts more rapidly [8].

These “infoveillance” approaches have been used to characterize a host of public health issues including topics related to mental health, substance abuse behavior, the spread of foodborne illness, and the monitoring of infectious disease outbreaks (eg pertussis, influenza, HIV/AIDS, dengue, West Nile virus, Zika virus, H1N1, and Ebola) [8-12]. Specifically, the now ubiquitous nature of social media means it represents an important, “nontraditional” source for disease surveillance. Specifically, user-generated social media data can be mined to assess the public’s knowledge, attitudes, and behaviors toward the disease, and can be particularly informative when cross-validated with traditional disease surveillance data [13-17]. Others have also used global social media platforms such as Twitter to examine the 2009 H1N1 pandemic, conduct content analysis, and identify key trends that may also correlate with outbreak incidence data [18].

Leveraging infoveillance approaches, we conducted a retrospective observational study for COVID-19 on one of the largest Chinese social media platforms, Sina Weibo [新浪微博]. Sina Weibo is a microblogging website (also known as the Chinese equivalent to Twitter) and one of the most influential social media platforms in China. According to its own press release in August 2020, it had over 486 million active users [19]. Users can publish content such as messages in microblogs and share text, pictures, videos, and music. Compared with WeChat, another popular social media platform in China, Weibo posts are generally more publicly visible; with WeChat, posts are generally more private and only visible to certain people selected by users. Due to the public nature of the platform, we attempted to assess whether Weibo posts about COVID-19 were predictive of the number of reported cases during the outbreak’s early stages and conducted a qualitative analysis of COVID-19–related themes detected and discussed by users located in Wuhan.

Methods

Study Design

This observational infoveillance study was conducted in two phases: data collection using an automated Python (Python Software Foundation) programming script to collect COVID-19-related posts on Weibo, and quantitative and qualitative analysis to identify trends and characterize key themes discussed by Chinese users.

Data Collection

Programming scripts were written in the Python programming language to extract posts on Weibo in the Chinese language (traditional and simplified Chinese) from users self-reporting their location in Wuhan. Weibo users can post messages limited to 2000 characters with or without images, videos, and other multimedia, and can repost messages equivalent to the retweet function on Twitter. Python scripts were set to continuously collect data filtered for COVID-19–related keywords from December 23, 2019, to January 30, 2020. Keywords included the Chinese-language terms: [冠状病毒] (coronavirus), [新型肺炎] (novel pneumonia), [武汉肺炎] (Wuhan pneumonia), [疫情] (epidemic situation), [非典] (severe acute respiratory syndrome), [华南海鲜市场] (Wuhan Seafood Wholesale Market). These keywords were chosen on the basis of manual searches via the platform’s public search function to detect a baseline of user conversations related to the outbreak for our systematic data collection processes. The variation in selected keywords was also necessary, as the official name of the disease was not announced until February 11, 2020 [20]. These data collection methods are consistent with other analyses of health-related posts (including flu-related topics) on the Weibo platform not related to COVID-19 [21].

Posts were filtered for geographic location, thereby identifying users specifically within the city of Wuhan, China. Posts with geographic locations outside of Wuhan City were not included in this study, as the aim was to focus on the early origins of the outbreak in this region. Posts were collected from all account types including personal accounts, media accounts, and government accounts. Technical limitations of the Weibo platform and Python script used to collect data limited our data collection to a maximum of 2000 posts per hour. However, during the 936 hours of data collection, we did not reach this limit for any hour of collection.

The number of COVID-19 cases in all of mainland China and Hubei Province were collected for each calendar day between December 23, 2019, and January 30, 2020, inclusively. Case counts were made publicly available on the internet by the Chinese National Health Commission, a cabinet-level executive department of the Chinese central government, headquartered in Beijing [20].

Quantitative Analysis

Weibo posts with COVID-19-related keywords were binned into each calendar day to calculate posts per day. Longitudinal trends were then visually conveyed using line graphs. Regression analysis was conducted to understand the predictive value of social media posts on the number of confirmed cases reported by the Chinese government. Simple linear regression was performed between social media posts per day and the number of cases reported within mainland China, excluding Hubei Province, and the cases in Hubei Province alone. Also, a simple linear regression model was computed wherein the number of posts per day was used to predict percent daily change in cases from Hubei, and a separate model was computed to predict percent daily change in cases from mainland China (excluding Hubei). Modeling of daily changes was conducted using the final 20 days of data, as prior days did not exhibit daily changes in posts, cases from Hubei, or cases from the remainder of China. A P value <.05 was considered statistically significant for all analyses. Statistical analyses were performed using RStudio, version 3.6.1 (RStudio, Inc).

Qualitative Analysis

Qualitative content analysis was conducted on the posts collected from December 31, 2019, to January 20, 2020, for key COVID-19-related themes self-reported by Chinese users and for information posted by the media and government sources.

Content analysis focused on detection of themes associated with knowledge, beliefs, and health behaviors specifically related to COVID-19 topics. Reviewers examined a random selection of Weibo posts with stratification of time periods so as to be representative of the entire period encompassed by the 39-day data collection.

First, coders independently used a binary coding approach (ie, relevant vs nonrelevant) to filter posts related to COVID-19 conversations and news, and exclude other “noise” not related to COVID-19. Second, we used thematic content analysis coding methods by first examining the meaning of words and their sentence structure in the text of Chinese-language Weibo posts. Third, we identified parent classifications to select prevalent topics and then tagged and grouped these classifications with supporting qualitative data (eg, Weibo posts). We primarily relied on inductive coding approaches starting with Weibo COVID-19 posts identified but also informed this inductive coding based on themes detected in existing literature from prior disease outbreaks [18,21]. Coders individually selected parent topic classifications to represent different thematic areas and collapsed infrequent categories into parent classifications. We then combined the related topics, removed duplicate topics, and evaluated thematic concurrence by independently coding the entire sample of posts collected from the early period of the outbreak with detected COVID-19-related posts (December 31, 2019, until January 20, 2020.)

Results

Data Availability and Ethics Approval

Data collected on social media platforms is available on request from authors subject to appropriate deidentification. Ethics approval was not required for this study. All information collected from this study was from the public domain, and the study did not involve any interaction with users. Indefinable user information was removed from the study results.

Data Collection

There were 115,299 posts collected during the study time frame, with an average of 2956 Weibo posts per day. There was a high degree of variation in the number of posts depending on the date of collection, with 0 posts collected on one day (December 26, 2019) and the highest number of posts (13,740) collected on January 27, 2020. During this same time period, China reported 36,456 confirmed cases of COVID-19. COVID-19 cases were reported starting on January 16, 2020, when 45 cases were reported. The number of cases then increased rapidly, reaching 9692 cases on January 30, 2020, the final day of data collection for this study. For every 1 hour of data collection the average yielded posts were 128, this was much higher after official case estimates began to be reported by the Chinese government (an average of 314 posts per hour) than before reporting began (an average of 11 posts per hour). Hourly postings exhibited diurnal fluctuations, which corresponded to customary waking hours.

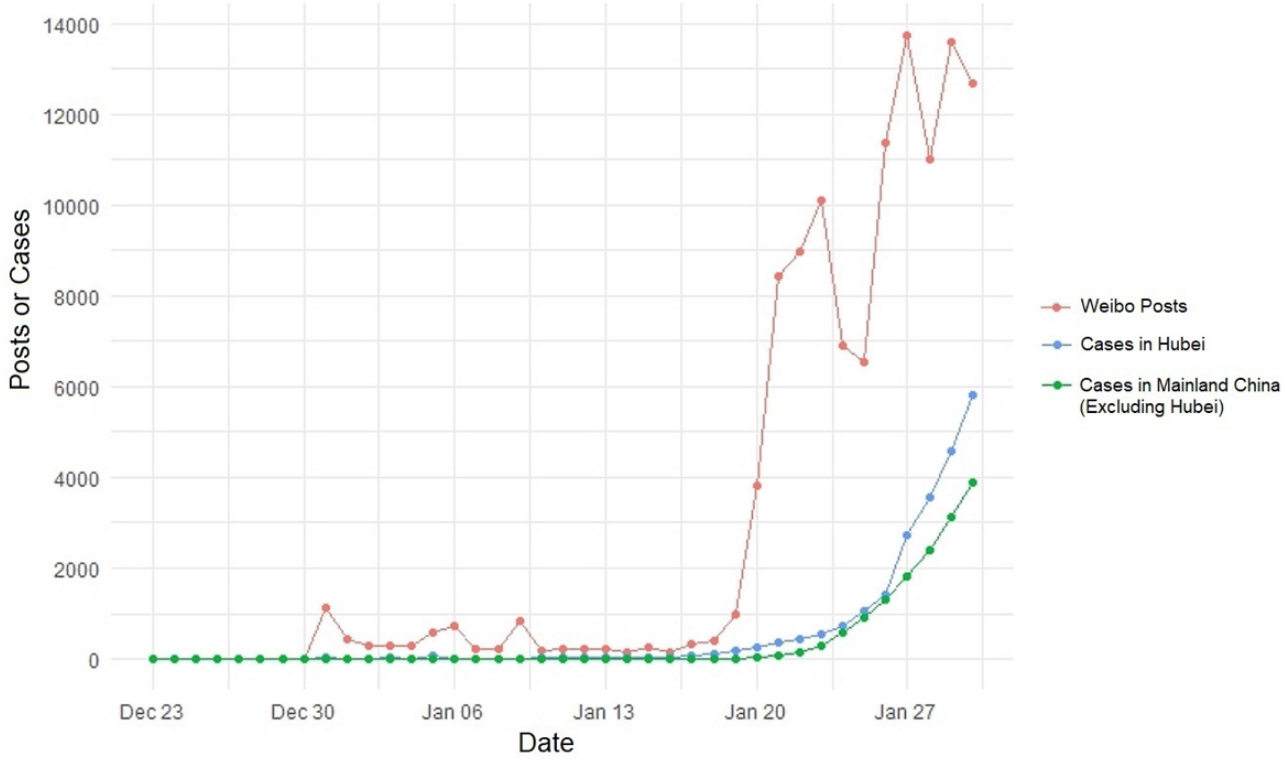
Quantitative Analysis

The linear regression showed a positive relationship between Weibo posts and the number of cases officially reported in Hubei Province, with approximately 10 more COVID-19 cases per 40 social media posts (cases=0.242*posts–201.48; P<.001; R^2=0.621). For the official number of cases within mainland China excluding Hubei Province, we found approximately 10 more COVID-19 cases per 60 social media posts (cases=0.164*posts–143.21; P<.001; R^2=0.652). These results indicate that there was a statistically significant positive relationship with Weibo posts and official case counts from within Hubei, and that the effect size was larger than what was observed in the rest of mainland China excluding Hubei. The linear regression also showed a significant inverse relationship between Weibo posts and the incidence proportion of cases

reported in Hubei among all incident cases in mainland China (Wuhan cases proportion=–0.003*posts+100.2; P<.001; R^2=0.836). Social media posts were also predictive of the percentage increase in COVID-19 cases in mainland China excluding Hubei (percent daily case increase=0.00013*posts+0.02; P<.001; R^2=0.827), but not Hubei alone (percent daily case increase=0.000016*posts+1.22; P=.23; R^2=0.091). These results may imply that 1000 additional posts from Wuhan predicted a 13% day-to-day increase in the number of cases for the rest of China but did not predict a local increase in cases. Therefore, it is possible that the numbers of outbreak-related Weibo posts are reactive to local disease conditions while being predictive of disease conditions for the broader region.

Visualization of longitudinal trends found that this association was generally uninterrupted, except for dramatically fewer posts on January 25 and January 28. The decreases for January 25 coincided with Chinese New Year celebrations, but this may not explain the decreases observed on January 28 (see Figure 1). Further observations in our qualitative analysis identified specific events and news during the study period that may have also influenced the number of user posts on certain observed dates and are further described in later sections.

Figure 1. Longitudinal trends of Weibo coronavirus disease posts and coronavirus disease official case counts.



Qualitative Analysis

A total of 11,893 posts from the first 21 days of our study (December 31, 2019, to January 20, 2020) that detected COVID-19 posts were manually coded. Qualitative analysis revealed that certain common terms or language within the corpus of collected Weibo posts were reflective of the parent classification of early COVID-19 themes including “pneumonia of unknown cause” [不明原因肺炎], “Wuhan pneumonia” [武汉肺炎], “unknown virus pneumonia” [不明病毒肺炎], and “novel coronavirus” [新型冠状病毒]. The distribution of these terms varied during the study period, with “unknown virus pneumonia” returning the largest proportion of Weibo posts during the early outbreak period until January 9, 2020, after which the term “Wuhan coronavirus” began to generate more Weibo post mentions. This is likely due to the lack of a defined name for the disease early in the outbreak, which also led to confusion about whether a novel outbreak was occurring or if it was a re-emergence of SARS.

Several important themes were identified in our inductive content analysis of Weibo posts, including four parent classifications with discussions about the causative agent of the disease, the changing epidemiological characteristics of the outbreak, and the public reaction to outbreak control and response measures (see Table 1). Authors JL and QX manually annotated posts for the previously mentioned parent classification themes detected. For inconsistent results, authors met and reviewed the posts together and conferred on the correct classification. After manually annotating the early outbreak period data (December 31, 2019, to January 20, 2020), intercoder kappa agreement scores for each theme were as follows: the causative agent of the disease was 99.04%, the changing epidemiological characteristics of the outbreak was 98.26%, and the public reaction to the outbreak control and response measures was 97.27%.

A prevailing theme throughout the outbreak period that changed based on the availability of new information was that the causative agent of the outbreak was unknown, leading to uncertainty among Chinese users regarding the risks associated

with the outbreak. This period of initial uncertainty was followed by the information disclosure about the causative agent by the Chinese National Health Commission and other official government and academic sources. As the outbreak progressed, a higher volume of more precise terms including "novel coronavirus" or "COVID-19" were detected, with a decline and shift from posts mentioning colloquial terms such as "unknown reason pneumonia" and "Wuhan pneumonia," similar to terminology adoption during the H1N1 pandemic [18].

The presence of parent classifications also changed over the time period. For example, at the onset of the outbreak, many users discussed what the causative agent of the outbreak might be, including how seasonal influenza, avian influenza, MERS, and SARS were ruled out. From January 16-20, posts about the causative agent also increased with most conversations discussing a novel coronavirus strain. There were also early conversations about the South China Seafood Market and wildlife trafficking, reflecting uncertainty regarding the zoonotic origins and possible transmission vectors of the disease. The proportion of posts with reference to the South China Seafood Market were much higher prior to January 6.

The detection of posts related to the epidemiological characteristics of the outbreak were relatively consistent throughout the entire 21-day period assessed. However, following confirmation of the outbreak as a novel coronavirus, there was a spike of discussions about whether COVID-19 was transmittable human-to-human. Relatedly, at the beginning of the outbreak, there were some posts where users expressed their own personal reaction and concerns about a potential outbreak. From January 14, after 3 cases were confirmed outside of China, there was a notable increase in the number of posts related to the public's reaction to the outbreak and its associated risks and control and response measures.

More specific subthemes regarding users' knowledge, attitudes, and responses to COVID-19 changed as more information about the underlining epidemiology became available. Specifically, the terms "confirmed case," "suspected case," "death case," "human-to-human transmission," "monitored," "public health supervision," and "quarantine" became more frequent as the outbreak progressed. Accompanying this shift in terminology, we also observed wide variation in user reactions as information from government sources was disseminated and the outbreak worsened. This included posts conveying protective behaviors (eg, cleaning hands, staying away from crowds, wearing medical masks in public areas), while others conveyed attitudes and behaviors that could potentially increase the risk of transmission (eg, going to New Year celebration events and self-evacuation from Wuhan). New user-response topics began to emerge toward the end of the early outbreak period, including criticism of the Wuhan Red Cross response and user uncertainty related to news about quarantines, travel restrictions, and new hospital construction projects.

Another subtheme detected in user responses was the discussion about COVID-19-related symptoms that appeared in both news and individual posts. At the beginning of the outbreak period, most symptom-related posts were posted by official accounts or consisted of news posts that were reposted and shared by the public that included describing symptoms of fever and shortness of breath (January 1) and coughing and weakness or fatigue (January 10). Separate from these news-related posts, some individual accounts also self-reported other symptoms including headache, diarrhea, sore throat, and perspiration during sleep. After January 20, 2020, human-to-human transmission was confirmed, and we detected an increase in posts related to user self-reported symptoms along with posts that provided second-hand reporting of symptoms from other people during our coding of the random stratified sample of the entire 39-day data study period. Though not fully coded for this study, our random selection detected a few users who reported other disputed symptoms, including a loss of taste and lack of appetite, in the last 10 days of our overall data collection (January 21-30).

Importantly, both the nature of the content and the volume of posts were likely driven by a combination of release of government information and news events. For example, December 31, 2019 had the second highest volume of posts related to the COVID-19 term "pneumonia of unknown cause," which corresponded to the confirmation from an official source (the Wuhan Health Commission) of cases of pneumonia of unknown etiology detected in Wuhan city. There was also an increase in COVID-19 Weibo posts on January 6, 2020, likely driven by news on January 5 that laboratory test results had ruled out other pathogens (eg, influenza, avian influenza, adenovirus, MERS, and SARS) as the cause of the outbreak. Additionally, on January 15, the WHO announced that the possibility of limited human-to-human transmission could not be excluded. This drove a second increase in the overall number of posts on January 16. Finally, on January 20, human-to-human transmission was confirmed, generating a large number of conversations from both media accounts and private Weibo users, resulting in the largest increase of posts observed during this time period.

Table 1. Posts on the Weibo social media platform organized according to themes detected in qualitative analysis.

Theme, Description of topic (English)	Example topics (Chinese with English translation)
Causative agent	
Concerns about potential SARS[a] re-emergence	[希望不是非典，大家安心过年] "I wish this is not SARS, hope everyone can have a peaceful New Year Eve"
Wuhan Seafood Wholesale Market considered the source of causative agent	[华南海鲜市场可能是病毒来源] "Wuhan Seafood Wholesale Market might be the source of the causative agent"
Pneumonia caused by unknown reason	[武汉出现不明原因肺炎] "cases of pneumonia of unknown etiology detected in Wuhan City"
Novel coronavirus has been confirmed as causative agent	[初步认定为新型冠状病毒] "Causative agent preliminary identification of a novel coronavirus"
Epidemiological characteristics of the outbreak	
No evidence of human-to-human transmission	[目前没有证据证明人传人] "There is no evidence of human-to-human transmission"
New confirmed cases and statistics on mortality	[截至昨日病例已增至44例，其中11例重症，均接受隔离治疗] "Until yesterday, there were 44 confirm cases, 11 severe cases, all have been isolated and treated"
Public Health supervision for people who had close contact with patients with confirmed cases	[与病患接触者进行医学观察] "People who have close connection with confirmed cases are under medical supervision"
Public reaction to outbreak control and response	
Wear masks, keep away from crowds	[虽然不知道是不是人传人，还是戴上口罩，远离人群] "Not sure if it is human to human transmissible, but wear masks and keep away from crowds would help. Just in case."
Self-evacuating Wuhan	[太可怕了，快点离开这儿吧] "It's scary, let's leave here (Wuhan)"
Will still attend New Year celebration event	[不明原因肺炎丝毫不影响大家戴口罩出来跨年] "The pneumonia of unknown cause seems not to impact people's New Year Eve celebration event"
Other topics	
Wuhan Red Cross under scrutiny	[红十字会遭到社会指责] "The Red Cross was accused by society"
Travel restrictions	[从1月23日10时起，武汉市和周边的鄂州市、仙桃市、潜江市、黄冈市、荆门市等相续宣布暂停运营城市公交、地铁、轮渡、长途客运，暂时关闭机场、火车站、高速公路等离开通道，严防武汉新型冠状病毒疫情扩散。] "From 10:00 on January 23, Wuhan and surrounding Ezhou, Xiantao, Qianjiang, Huanggang, Jingmen, etc. have successively announced the suspension of operation of city buses, subways, ferries, long-distance passenger transport, and temporarily closed airports and trains. Stations, highways, etc. leave the passage to strictly prevent the spread of new coronavirus epidemics in Wuhan."
New hospital construction projects	[新建武汉"小汤山] "Will build new hospitals in Wuhan (Lei Shen Shan & Huo Shen Shan), also called Wuhan Xiao Tang Shan"

[a]SARS: severe acute respiratory syndrome.

Discussion

Principal Findings

The vast majority of infoveillance studies have analyzed data from English-language social media platforms such as the microblogging site Twitter or Google trends data, yet only a few have examined foreign-language platforms. Due to the COVID-19 outbreak originating in Wuhan, China, this study sought to identify, characterize, and assess the potential relationship between Chinese social media conversations taking

place in Wuhan and the number of COVID-19 confirmed cases at the early stages of the outbreak, which has now transitioned into a worldwide pandemic. It also sought to understand how user perception changed as additional information became available from government and media sources as the outbreak progressed while also attempting to identify parent classifications of predominant user-generated themes that emerged as the outbreak accelerated. These study objectives and some of its general findings are consistent with prior studies, including a 2010 infoveillance study by Chew and Eysenbach [18] assessing the 2009 H1N1 outbreak. In that study, posts from Twitter were collected, thematically assessed, and found to be significantly correlated with weekly H1N1 incidence during the outbreak, with the absolute increase in H1N1-related tweet volume coinciding with major news events.

Based on our analysis, there appears to be a positive correlation between the number of COVID-19-related Weibo posts from Wuhan and the number of cases officially reported in Wuhan during the early stages of this outbreak. This effect size was larger than what was observed for the rest of China excluding Hubei Province (where Wuhan is the capital city) and held when comparing the number of Weibo posts to the incidence proportion of cases in Hubei. However, any potential predictive value of using social media data as a proxy for real world public health surveillance statistics needs more rigor and added data layers to confirm possible associations, particularly in the context of user reactions to news events as discussed in this and other studies. Despite these limitations, qualitative analysis characterized the early stages of the outbreak as having different degrees of the Chinese public's uncertainty regarding the risks posed by COVID-19. As information emerged about the disease, users expressed new concerns, which also led to changing knowledge, attitudes, and behaviors among Chinese social media users, some protective and some that may have introduced increased risks of disease spread.

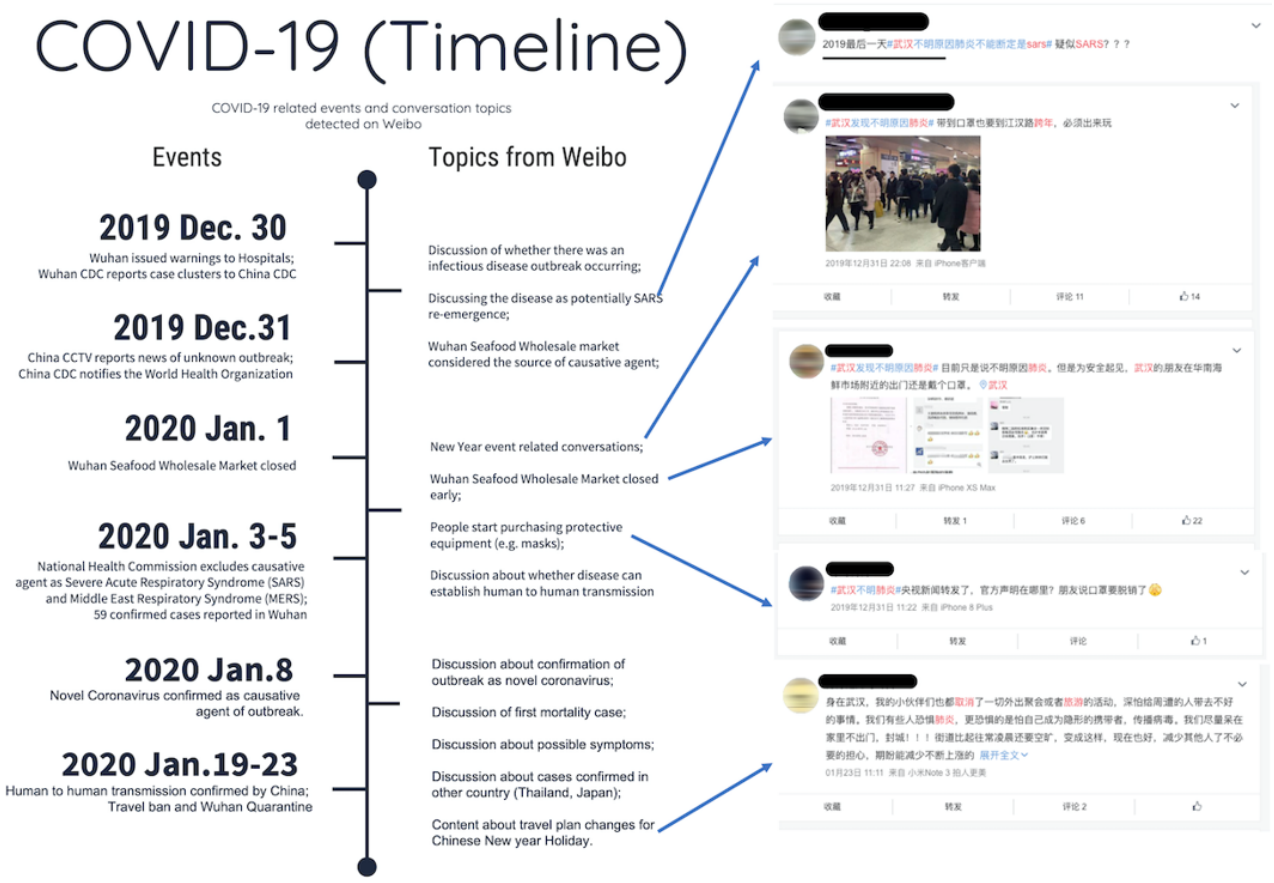
In response to public uncertainty, the Chinese government issued a series of announcements on the Weibo "official" accounts in an attempt to clarify the characteristics of the disease as they became known, including an official warning to hospitals on December 30, 2019, about how to report potential cases and a subsequent announcement on January 8, 2020, confirming a novel coronavirus as the causative disease agent (Figure 2). These events evidence that social media was used as an outbreak communication tool by the government, media, and users (who reposted content) and led to the dissemination of and user reaction to information on an outbreak whose trajectory would take it global.

Public perception about the origins and transmission patterns of COVID-19 changed over the study period, with initial conversations focusing on a possible link with the seafood market in Wuhan, later changing to discussions about the increased number of cases reporting no exposure to the seafood market, and then leading to discussions of possible human-to-human transmission, which was later confirmed by the Chinese government. Overall, we observed a wide variation in user reactions to information, with some users expressing a willingness to undertake protective behavior and other users downplaying the risks and engaging in behaviors that could have exacerbated disease spread (eg, leaving Wuhan, attending New Year events). Importantly, these observed attitudes and behaviors happened prior to the Chinese government announcing a lockdown of Wuhan and other cities in Hubei on January 23, 2020. After the announcement of these quarantine measures, there was a sizable increase in the volume of Wuhan Weibo posts we collected.

Though the mixed quantitative and qualitative results of this study are primarily exploratory, they provide important insight on the changing knowledge, attitudes, and behaviors of Chinese social media users who were at the epicenter of what is now a rapidly expanding pandemic that has impacted all facets of global society. More research is needed to better understand the effectiveness of health communication strategies during evolving outbreaks such as COVID-19, particularly in the context of how information is understood, shared, and acted upon by users in the face of uncertainty and changing information. Specifically, we need to better understand how social media platforms can influence the public's risk perception, their trust and credibility of different information sources, and, ultimately, how it changes real-world behavior that can have an impact on control measures enacted to mitigate an outbreak.

Early reports indicated that major social media platforms are struggling with the volume of COVID-19 information and user-generated content flooding their platforms, some of which is helpful and accurate and some of which are rumors and misinformation [22]. In fact, popular social media platforms TikTok, Facebook, and Twitter have all announced measures to better ensure access to credible and accurate information about COVID-19, though whether these platforms are up to this task remains an open question [22].Evaluating whether social media can act as a positive tool to promote global health objectives, particularly in the context of health emergencies, will be tested by COVID-19, along with its utility as a modern approach to public health surveillance.

Figure 2. Timeline of COVID-19 events, themes detected in Weibo posts, and examples of posts. CCTV: China Central Television; CDC: Centers for Disease Control and Prevention; COVID-19: coronavirus disease.



Limitations

This study has certain limitations. First, our data collection was limited to one Chinese social media platform over a prescribed period of time. Hence, it is not generalizable to all COVID-19 social media conversations occurring among Chinese users. We did not examine Chinese private communication apps (eg QQ, WeChat) due to the difficulty of collecting data on these platforms. Future studies should assess a broader scope of conversational data from multiple platforms and use natural language processing and machine learning approaches to help classify larger volumes of conversations. Second, our data collection started from the reported early stages of the COVID-19 outbreak. During parts of this time period, the causative agent had not been confirmed and there was no official name for the disease. Due to early inconsistency in terminology, Weibo users may have used other keywords to describe COVID-19 that were not collected in this study. Third, the simple linear regression showed a positive correlation between COVID-19 Weibo posts and the number of Wuhan cases in the study time frame, but we did not control for other potential confounders. Further, it is unclear whether our observed predictive trend line would continue or if the trend line is generalizable to other instances of COVID-19 outbreaks in other countries or communities. It is more likely that only under specific disease transmission circumstances would this correlation occur, namely a lack of knowledge and reporting of an outbreak in its early stages, a novel virus with high transmission and sustained community spread, and high social media engagement involving outbreak conversations. Further, as previously stated, it is highly likely that the volume of posts are associated with user reactions to news events and government announcements. Finally, due to censorship in China, posts may have been deleted before data collection. In fact, a few messages detected included associated comments that had been deleted and were not retrievable.

Authors' Contributions

JL collected the data; all authors designed the study, conducted the data analyses, wrote the manuscript, and approved the final version of the manuscript.

Conflicts of Interest

JL, QX, and TKM are employees of the startup company S-3 Research LLC. S-3 Research is a startup funded and currently supported by the National Institutes of Health – National Institute on Drug Abuse through a Small Business Innovation and

Research contract for opioid-related social media research and technology commercialization. Authors report no other conflicts of interest associated with this manuscript.

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Abbreviations

COVID-19: coronavirus disease
MERS: Middle East respiratory syndrome
PHEIC: Public Health Emergency of International Concern
SARS: severe acute respiratory syndrome
WHO: World Health Organization

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Original Paper

Regulation and Trust: 3-Month Follow-up Study on COVID-19 Mortality in 25 European Countries

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Abstract

Background: The outbreak of the coronavirus disease (COVID-19) has dramatically changed societies in 2020. Since the end of February, Europe has been hit particularly hard by COVID-19, but there are major country differences in both the spread of the virus and measures taken to stop the virus. Social psychological factors such as institutional trust could be important in understanding the development of the epidemic.

Objective: The aim of this study was to examine country variations of COVID-19 mortality in Europe by analyzing social risk factors explaining the spread of the disease, restrictions and control measures, and institutional trust.

Methods: The present study was based on a background analysis of European Social Survey data on 25 European countries (N=47,802). Multilevel mixed effects linear regression models focused on 84 days of the COVID-19 epidemic (January 22 to April 14, 2020) and modelled the daily COVID-19 mortality. Analysis focused on the impact of social relations, restrictions, and institutional trust within each country.

Results: The spread of the COVID-19 epidemic has been fast everywhere, but the findings revealed significant differences between countries in COVID-19 mortality. Perceived sociability predicted higher COVID-19 mortality. Major differences between the 25 countries were found in reaction times to the crisis. Late reaction to the crisis predicted later mortality figures. Institutional trust was associated with lower COVID-19 mortality.

Conclusions: The analyses demonstrated the importance of societal and social psychological factors in the spread of the COVID-19 epidemic. By considering multiple perspectives, this study showed that country differences in Europe are major, and this will have an impact on how countries will cope with the ongoing crisis in the following months. The results indicated the importance of timely restrictions and cooperation with people.

(JMIR Public Health Surveill 2020;6(2):e19218) doi:10.2196/19218

KEYWORDS

mortality; infectious diseases; sociability; trust; prevention; Europe

Introduction

The worldwide outbreak of a new type of coronavirus (severe acute respiratory syndrome [SARS] coronavirus 2) causing coronavirus disease (COVID-19) has rapidly changed societies in the first 3 months of 2020. COVID-19 was first reported in December 2019 in Wuhan, the capital of Hubei Province, China [1]. As a response to a broader disease threat, China placed restrictions on travel in and out of Wuhan on January 23, 2020, but the virus was detected in Europe already in January in countries such as France (January 24, 2020) and Finland (January 26, 2020) [2]. Currently, it is not known how long there were active COVID-19 cases circling in Europe before different countries started to react to the epidemic. The first

death caused by COVID-19 outside Asia occurred in France on February 15, 2020. In Italy, the number of infections started to rise rapidly in the last week of February [3]. During March 2020, almost all European countries placed at least some restrictions in an effort to prevent a further uncontrolled spread of the virus.

Much of the focus of COVID-19 discussion and research has centralized on epidemiological factors. The reproductive number (R_0) of COVID-19 has been considered higher than that of SARS. In a recent review study, the average R_0 of COVID-19 was found to be 3.28 with a median of 2.79 [4]. Viral shedding of the novel coronavirus is also long (median 20 days in survivors), and nonsurvivors have died, on average, after 18-19 days of illness onset [5,6]. Case fatality and infection fatality ratios have been recently reported for China, being 3.67% and 0.66%, respectively [6]. In Europe, similar estimations have not been made yet, but COVID-19 mortality has been particularly high in some regions such as Lombardy, Italy. Data shows major country variations in the spread and mortality rates of COVID-19 within Europe, but reasons behind the spread of the disease and subsequent mortality remain partly unexplained. Different countries have also responded to the epidemic at different rates, which gives a starting point for our investigations on societal and psychological factors related to the spread of COVID-19. A social scientific perspective could help us understand COVID-19 mortality.

Social factors are important in epidemics, which should always be understood in their ecological context [7]. This means, for example, that social activity has an impact on the spread of viruses. European countries vary greatly in terms of population density, and there are also differences in the number of social contacts people have and interact with on a daily basis. In addition, there are major cultural differences in the physical distance people keep when interacting with their close friends and other people [8]. For instance, Southern European countries have been traditionally considered as contact cultures in comparison to noncontact cultures, such as North Europe and Asia [8-10]. During an epidemic, both the physical and social closeness of people are factors that explain the spread of the disease.

Another important social factor explaining the spread of viruses is trust. Trust in institutions and other people is considered an important factor in the well-being and overall functioning of societies [11,12]. Institutional trust can be a crucial part of epidemic management and prevention because trust in public systems and authorities such as health care systems influences how people use services and follow instructions [13]. Trust in institutions becomes important after disruptive events such as terrorist attacks, natural disasters, or epidemics [14,15]. Research evidence from previous epidemics showed that those who had lower trust in the government were less likely to take precautions against the Ebola virus disease in Liberia and Congo during the 2014-2016 outbreak [16,17]. Similar findings were also noted during the 2002-2004 SARS outbreak in Hong Kong [18]. Great trust in authorities has also been associated with carrying out avoidant behaviors during the swine flu epidemic in the United Kingdom [19].

Dozens of studies have previously demonstrated significant country differences in institutional trust, making it an essential societal element to consider [20,21]. Trust in state institutions is typically highest in Nordic countries (Finland, Denmark, Iceland, Norway, Sweden), which also rank high in different welfare statistics worldwide [22]. Elsewhere in Europe, institutional trust is found to be low, particularly in Eastern European countries but also in Southern European countries such as Italy [23,24]. Determinants of institutional trust vary across different sides of Europe, but the perceived lack of responsiveness of political and governmental entities often results in low received trust from the public. In East Central Europe, older individuals and women have been found to show more trust toward institutions, while trust in political institutions is lower among more educated people [25]. In Southern European countries such as Italy and Spain, socialization experiences are largely associated with low institutional trust, and attitudes toward political institutions are deeply rooted in cultural legacy [26]. In other words, institutional trust is lowest in those countries characterized as contact cultures. The combination of social closeness and lack of trust in authorities might turn out to be lethal within Europe, at least for older adults.

The aim of our study was to examine country variations of COVID-19 mortality in Europe by analyzing social risk factors that may explain the spread of the disease, restrictions and control measures, and institutional trust. We expected to find societal differences especially in the capability of coping with this crisis situation.

Methods

Data Sources

This study was based on an analysis of European Social Survey (ESS) data on 25 European countries (N=47,802). Data were from 2016 (ESS8) except for Bulgaria, Cyprus, and Slovakia, whose data were from 2012 (ESS6), and Denmark with data from 2014 (ESS4). ESS data sets are openly available for research purposes at the ESS web site [27]. Additional country information was received from Eurostat and the World Bank. COVID-19 mortality and incidence figures were drawn from the database built by the Coronavirus Resource Centre at Johns Hopkins University [28]. The data were updated April 15, 2020, for this article. Country restrictions were drawn from the official websites of states and ministries, and other related webpages created for the purpose of providing COVID-19 updates.

Ethics and Open Data

ESS data are publicly available and downloadable at the ESS website. The collection of their self-reported data is based on informed consent and subscribes to the Declaration of Professional Ethics of the International Statistical Institute. All ESS surveys have gone through ethical review by the ESS European Research Infrastructure Consortium Research Ethics Board [29]. Our analyses focused on creating country-level information, and no observations at the individual level were used. Other used data were also publicly available. All data and code are available via Open Science Framework [30].

Measures

COVID-19 mortality and incidence time series data were collected for 25 European countries and covered 84 days of the COVID-19 epidemic (January 22 to April 14, 2020). Incidence rates were also collected, but they are treated only as controls, because countries differ a lot in their testing rates. Hence, mortality figures provide more accurate information on the spread of the epidemic from February to April 2020.

Information on country restrictions included national bans or restrictions. These included bans on public events, curfews, country border closures, restrictions on restaurant operations, and elementary school contact teaching. Public events, curfews, or unauthorized outings were reviewed and applied from the date when the first nationwide restriction became effective. Country border closures were determined starting from the date when all the borders of the country were closed. Restrictions on restaurant operations and elementary school contact teaching were calculated from the date when at least some national restrictions became effective. Restrictions varied in exact content and accuracy across countries.

General country information includes the size of the population, population density (persons per square kilometer), old-age dependency ratio (ie, ratio of people aged 65 years or older), gender ratio, life expectancy at birth, health care expenditure (euros per inhabitant), and number of tourist arrivals per year. Self-reported country information included perceived sociability, household size, the proportion of older people living with children, and perceived institutional trust.

The *perceived sociability* was measured with a question: "How often do you take part in social activities compared to others of same age." The given responses were 1, "Much less than most," 2 "Less than most," 3 "About the same," 4 "More than most," and 5 "Much more than most." *Household size* was based on respondents' information on how many people live regularly in their household. *The proportion of older adults living with children* was calculated by grouping respondents aged 65 years or older according to whether they currently live in the same household with children. *Institutional trust* was measured by respondents' trust in five institutions, namely, parliament, politicians, political parties, the police, and the legal system. Respondents were asked how much they personally trust these institutions on a scale from 0 to 10, in which 0 meant no trust at all, and 10 meant complete trust. Reliability of the measure was good with Cronbach alpha ranging from 0.82 to 0.92. In the analyses, institutional trust was categorized as very low (19 or less), low (20-22), high (23-29), and very high (30 or more) for an illustrative map, and as low (less than 23) and high (23 or more) based on the median for a random effects regression model.

Statistical Techniques

All statistical analyses were conducted with Stata 16 software (StataCorp). Daily COVID-19 mortality during the COVID-19 epidemic in Europe was analyzed with multilevel mixed effects linear regression models. In the multilevel models, the dependent variable was the square root transformed daily mortality count. The count was based on daily follow-ups on COVID-19 mortality cases for each country, starting from the first confirmed infection and ending April 14, 2020. This resulted in follow-up periods that varied between countries (from 82 days in France to 37 days in Cyprus).

To assess the relationship between the daily mortality count and our main theoretical variables, we conducted three separate models: model 1 included perceived sociability, model 2 included timing of national restrictions, and model 3 included institutional trust as an independent variable. All models controlled for the following between-country factors: average household size, population, population density, old-age dependency ratio, life expectancy at birth, health care expenditure per inhabitant, high tourist arrival (dummy variable based on median), and the length of the follow-up period for each country. In addition, our models included time as a within-country predictor of mortality. The end point of our follow-up period (April 14, 2020) was coded as the zero point for our time variable. Preceding days had negative values in descending order until the first day of the country's follow-up period. Thus, time was used to estimate the within-country change in mortality during the epidemic, and the between-country variables estimated the country differences in mortality. Except time and high tourist-arrival dummy variables, all independent variables were mean centered before adding them into the regression models.

All models were conducted with maximum likelihood estimation. We estimated Huber-White standard errors that were robust to within-country clustering and modelled our residuals to account for the autocorrelated error structure of our longitudinal data. The models included random intercept and random slope for time with unstructured covariances. We reported regression coefficients and corresponding 95% confidence intervals and *P* values for the fixed part of our models, and standard deviation with 95% confidence interval for the random effects.

The progression of COVID-19 mortality before and after the first COVID-19 death were analyzed with random effects models to account for clustering at the country level. We modelled the amount of daily deaths in low and high institutional trust (cutoff point median value 23) after the first COVID-19 death (time=0), which was used as a reference category. We then analyzed countries reacting late (restrictions placed after the first COVID-19 death) and early (restrictions placed before the first COVID-19 death). In both analyses each time point (day) was allowed to have a separate coefficient for the COVID-19 mortality value (presented as deaths/million persons). Models are presented as figures, and they are adjusted for population density, gender, old-age ratio, the proportion of those 65 years or older living with children, life expectancy, and tourist arrivals. Models included country restrictions as daily varying dummies (0=no control, 1=control).

Results

Descriptive statistics on the 25 European countries are shown in Table 1. The spread of the COVID-19 epidemic has been fast everywhere, but our findings reveal significant differences between countries. The most impacted countries in Europe by

April 14 are Italy, Spain, and France (see Table 2). All of these countries were also significantly late to implement national restrictions. For example, Italy placed national restrictions almost 2 weeks after the first COVID-19 incident (see Figure 1). France already had 1 death case in February and was the slowest to react nationwide. It is highly likely that during these days the virus was able to spread fast in the population, which explains the later mortality figures.

Table 1. Descriptive statistics on 25 European countries selected for the analysis.

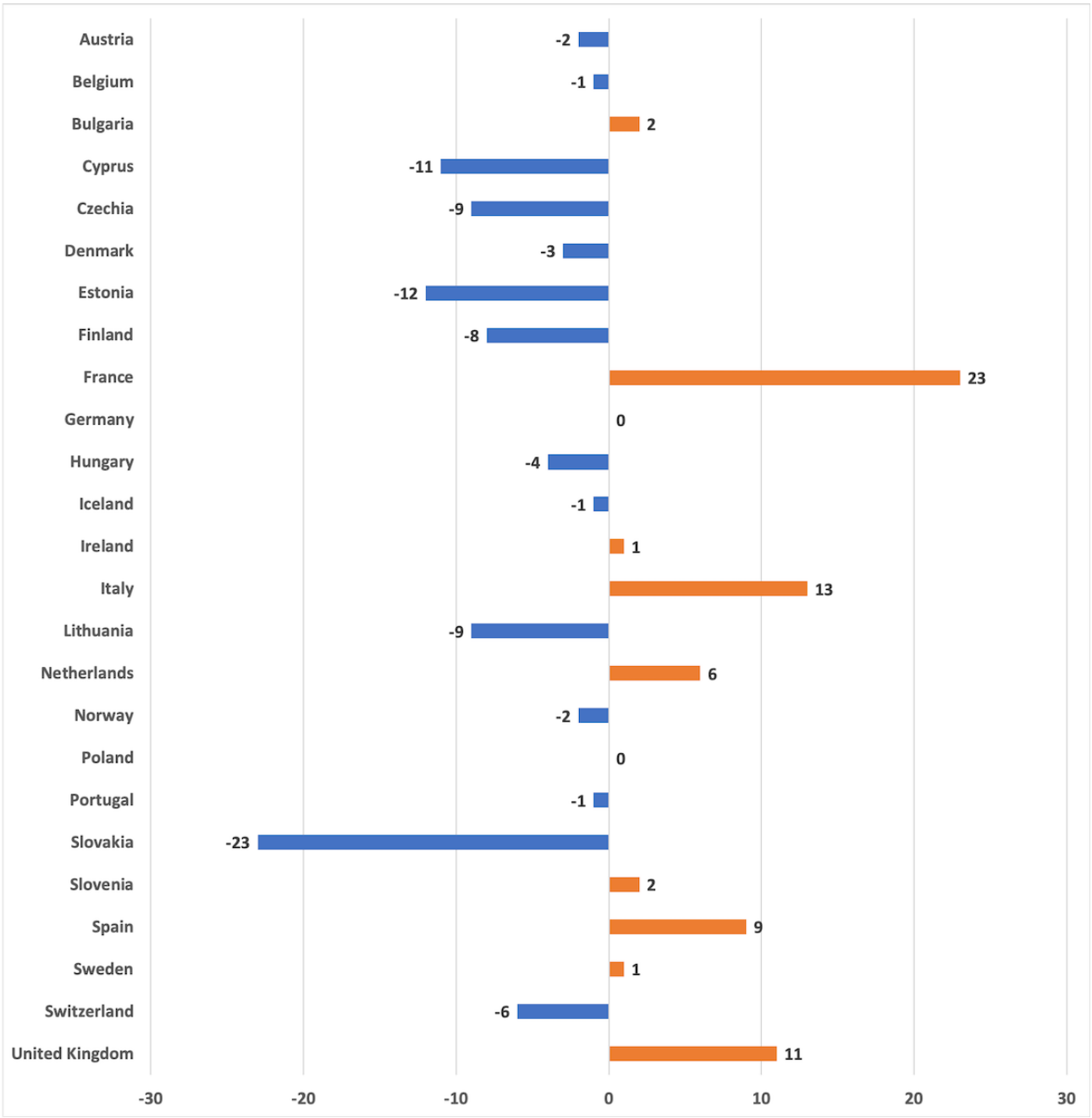
Country	Population density (persons per square km)	Old-age dependency ratio, %	Male, %	Household size average, n	Older adults (≥65 years) living with children, %	Life expectancy at birth (years)	Health care expenditure/inhabitant (euros)	Tourist arrivals (millions), n	Perceived sociability	Institutional trust
Austria	107	28.2	49.2	2.2	6.7	81.8	4248.0	30.8	2.9	25.8
Belgium	375	29.5	49.3	2.9	9.6	81.7	3744.0	9.1	2.7	24.6
Bulgaria	64	33.2	48.5	2.6	16.1	75.0	556.0	9.3	2.8	10.8
Cyprus	94	23.8	48.8	2.8	14.1	82.9	1474.0	3.9	2.4	17.9
Czechia	138	30.4	49.2	2.3	4.6	79.1	1193.0	10.6	2.6	22.2
Denmark	138	30.6	49.8	2.6	2.6	81.0	5014.0	12.7	2.9	30.7
Estonia	30	31.0	47.2	2.5	14.3	78.5	1072.0	3.2	2.5	24.0
Finland	18	35.1	49.4	2.4	6.1	81.8	3727.0	3.2	2.7	30.6
France	106	32.5	48.3	2.2	4.2	82.9	3847.0	89.3	2.9	21.0
Germany	235	33.2	49.3	2.6	6.3	81.0	4271.0	38.9	2.7	26.2
Hungary	107	29.3	47.8	2.4	11.9	76.2	853.0	17.6	2.5	23.1
Iceland	4	21.3	51.2	3.0	12.1	82.9	4539.0	2.3	2.9	27.3
Ireland	71	21.6	49.5	2.6	12.3	82.3	4242.0	10.9	2.7	23.1
Italy	203	35.7	48.7	2.7	14.5	83.4	2475.0	61.6	2.9	18.1
Lithuania	45	30.4	46.4	2.4	10.5	76.0	899.0	2.8	2.6	21.1
Netherlands	504	29.5	49.7	2.4	2.3	81.9	4274.0	18.8	2.8	28.2
Norway	17	26.4	50.4	2.6	4.0	82.8	6730.0	5.7	2.9	32.3
Poland	124	26.4	48.4	3.1	27.9	77.7	731.0	19.6	2.6	17.6
Portugal	113	33.9	47.2	2.6	15.8	81.5	1632.0	16.2	2.6	18.8
Slovakia	112	23.5	48.8	2.8	20.3	77.4	1061.0	2.3	2.4	15.8
Slovenia	103	30.5	49.9	3.2	31.1	81.5	1657.0	4.4	2.7	17.6
Spain	93	29.5	48.6	3.0	28.3	83.5	2159.0	82.8	2.7	18.8
Sweden	25	31.9	50.3	2.5	2.8	75.9	5123.0	7.4	2.9	28.0
Switzerland	214	27.8	49.6	2.8	5.7	83.8	8841.0	10.4	2.8	30.0
United Kingdom	274	28.9	49.4	2.3	5.6	81.3	3566.0	36.3	2.7	24.4

Table 2. Descriptive statistics on coronavirus disease mortality and start of national restrictions in 25 European countries.

Country	Deaths, n	Deaths/1 million inhabitants, n	National restrictions				
			Public events	Curfew	Land borders	Restaurants	Schools
Austria	384	43	March 10	March 16	March 14	March 16	March 16
Belgium	4157	361	March 10	March 17	March 20	March 14	March 16
Bulgaria	35	5	March 13	March 21	March 20	March 13	March 3
Cyprus	12	14	March 3	March 24	March 15	March 16	March 11
Czechia	161	15	March 13	March 16	March 16	March 14	March 13
Denmark	299	51	March 11	N/A[a]	March 14	March 18	March 16
Estonia	31	23	March 3	N/A	March 17	N/A	March 13
Finland	64	12	March 13	N/A	March 19	March 30	March 18
France	15,729	235	March 9	March 23	March 17	March 15	March 16
Germany	3294	40	March 9	N/A	March 16	March 20	March 13
Hungary	122	12	March 11	March 28	March 17	March 17	March 16
Iceland	8	22	March 16	N/A	N/A	N/A	March 16
Ireland	406	83	March 12	N/A	N/A	March 22	March 13
Italy	21,067	349	March 9	March 9	March 9	March 21	March 5
Lithuania	29	10	March 13	N/A	March 16	March 16	March 12
Netherlands	2945	170	March 12	N/A	March 17	March 15	March 16
Norway	139	26	March 12	N/A	March 16	March 12	March 12
Poland	263	7	March 14	N/A	March 15	March 14	March 12
Portugal	567	55	March 20	N/A	N/A	March 22	March 16
Slovakia	2	0	March 10	N/A	N/A	N/A	March 9
Slovenia	56	27	March 16	N/A	N/A	March 16	March 16
Spain	18,056	385	N/A	N/A	N/A	March 15	March 12
Sweden	1033	101	N/A	N/A	N/A	N/A	March 17
Switzerland	1174	137	February 28	N/A	March 17	March 16	March 13
United Kingdom	12,107	182	March 16	March 23	N/A	March 20	March 20

[a]N/A: not applicable.

Figure 1. First national restrictions placed before (-) or after (+) the first COVID-19 death (days).



Our multilevel linear regression models analyzed the daily mortality in 25 countries (Tables 3 and 4). The fixed effect of time was a significant predictor of mortality in all of the models, indicating the increasing trend in deaths during the crisis period. According to the random part of our models, however, there was a between-country variation in this trend. In addition to a within-country change, we found that between-country factors significantly predicted mortality. Model 1 shows that the perceived sociability predicted higher daily mortality. Model 2 shows that late restrictions were associated with higher numbers of COVID-19 deaths. Model 3 shows that institutional trust was negatively associated with daily COVID-19 mortality figures. Of our control variables, population density, life expectancy at birth, health care expenditure per inhabitant, high tourist arrival, and the length of the follow-up period were positively associated with daily mortality, yet the significance of these associations varied between models.

Table 3. Multilevel mixed effects linear regression models predicting daily COVID-19 mortality in 25 European countries (fixed part).

Variables	Model 1			Model 2			Model 3		
	b	95% CI	*P* value	b	95% CI	*P* value	b	95% CI	*P* value
Constant	6.81	4.05-9.56	<.001	5.75	3.15-8.34	<.001	5.29	2.67-7.90	<.001
Within-country effects									
Time	0.16	0.11-0.22	<.001	0.16	0.10-0.22	<.001	0.16	0.10-0.22	<.001
Between-country effects									
Perceived sociability	7.04	0.25-13.83	.04	N/A[a]	N/A	N/A	N/A	N/A	N/A
National restrictions after first death	N/A	N/A	N/A	2.55	1.08-4.02	.001	N/A	N/A	N/A
Institutional trust	N/A	N/A	N/A	N/A	N/A	N/A	–0.42	–0.65 to –0.19	<.001
Population	0.02	–0.03 to 0.08	.42	0.02	–0.03 to 0.07	.39	–0.02	–0.08 to 0.05	.60
Population density	0.00	0.00-0.01	.04	0.00	0.00-0.01	.20	0.00	0.00-0.01	.048
Old-age dependency ratio	–0.04	–0.29 to 0.20	.73	0.03	–0.20 to 0.26	.80	–0.04	–0.26 to 0.18	.73
Country household size average	0.96	–1.00 to 2.92	.34	0.98	–0.94 to 2.91	.32	–0.55	–2.45 to 1.35	.57
Life expectancy at birth	0.27	–0.01 to 0.54	.06	0.37	0.14-0.59	.002	0.29	0.05-0.52	.02
Health care expenditure per inhabitant	–0.60	–1.28 to 0.07	.08	–0.25	–0.59 to 0.08	.14	0.46	0.03-0.88	.03
High tourist arrival	0.65	–0.62 to 1.93	.32	1.11	–0.10 to 2.33	.07	2.12	0.40-3.83	.02
The length of follow-up period	0.13	0.06-0.20	.001	0.12	0.05-0.19	.001	0.19	0.12-0.26	<.001

[a]N/A: not applicable.

Table 4. Multilevel mixed effects linear regression models predicting daily COVID-19 mortality in 25 European countries (random part).

Variables	Model 1		Model 2		Model 3	
	SD	95% CI	SD	95% CI	SD	95% CI
Time	0.10	0.07-0.15	0.10	0.07-0.15	0.11	0.07-0.15
Constant	3.58	2.55-5.00	3.60	2.61-4.97	3.59	2.59-4.97

The final part of the analysis focused on the role of institutional trust and reaction time. Figure 2 shows the map of Europe and the average number of deaths per million inhabitants in the analyzed 25 countries categorized in four country groups based on their level of institutional trust. The map demonstrates that those countries with low institutional trust have more deaths per million inhabitants on average compared to countries with high trust. We analyzed the difference between countries with low vs high perceived institutional trust using a random effects regression model. Figure 3 shows development after the first COVID-19 death case in low- and high-trust countries. There are no statistically significant differences between the curves. Both curves indicate increases in mortality 2 weeks after the first COVID-19 death case, and there were no statistically significant differences between them. Figure 4 shows deaths per million inhabitants for countries reacting late and early. We can see how the number of deaths per day varied in the 24 days following the first national restrictions, and there is a statistically significant difference between the curves. Increases in mortality were more rapid in those countries reacting late than those reacting early. For example, 23 days after the first COVID-19 death there were 2.5 times more deaths in late-reacting countries (4.56 deaths/million, 95% CI 3.34-5.78) than in early reacting countries (1.83 deaths/million, 95% CI 1.02-2.65).

Figure 2. Mean deaths per million inhabitants by countries' level of institutional trust.

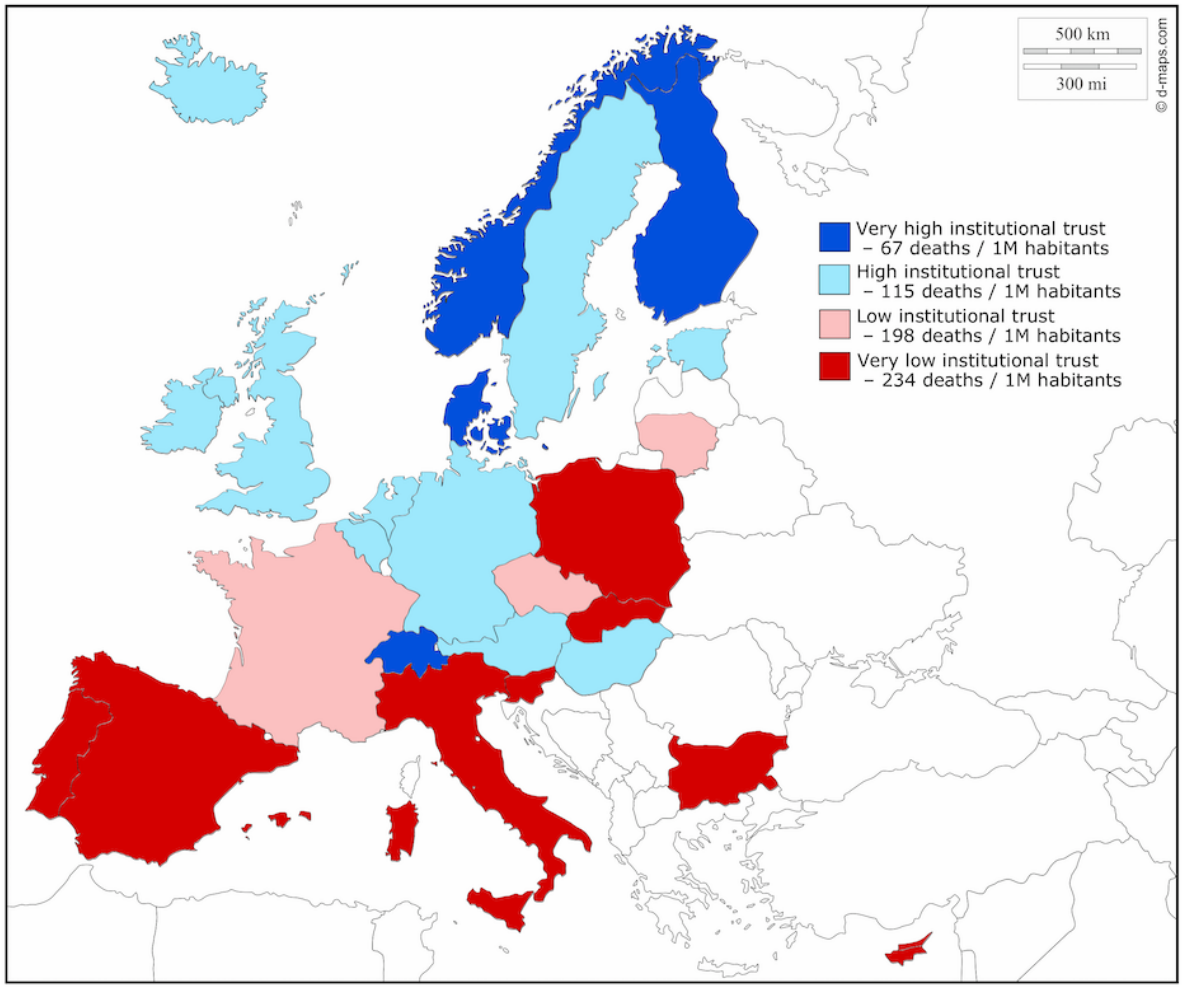


Figure 3. Deaths per day after first COVID-19 death in low- and high-trust countries. COVID-19: coronavirus disease.

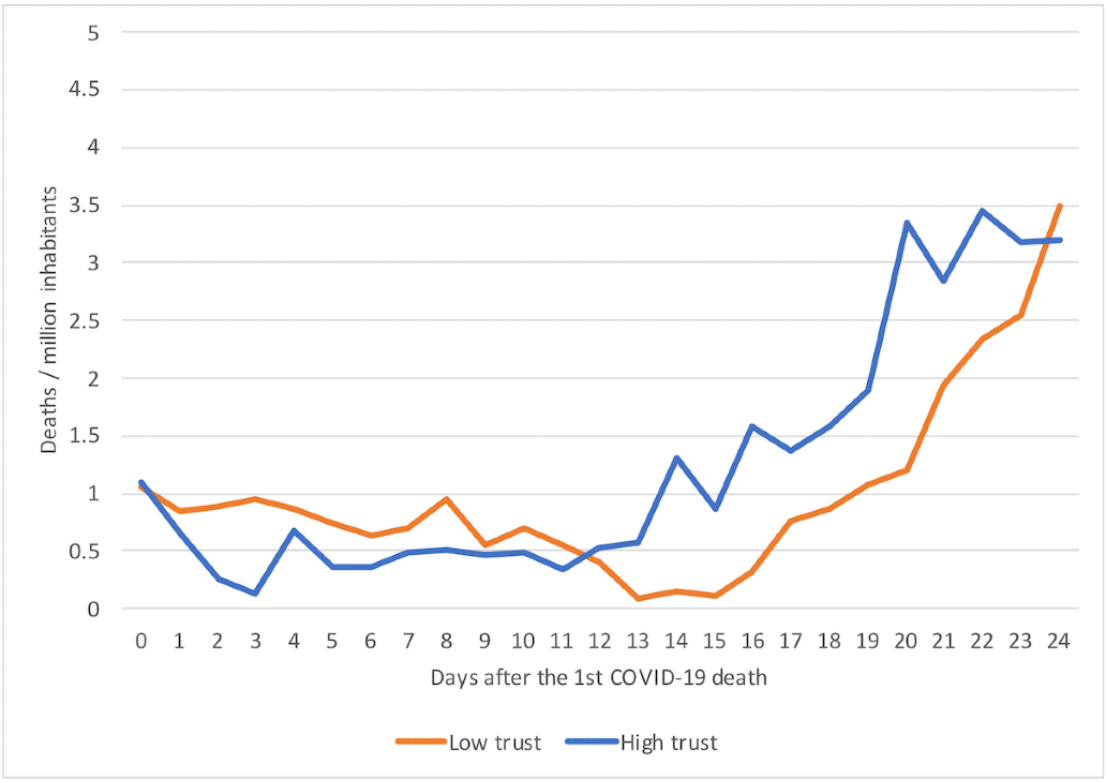
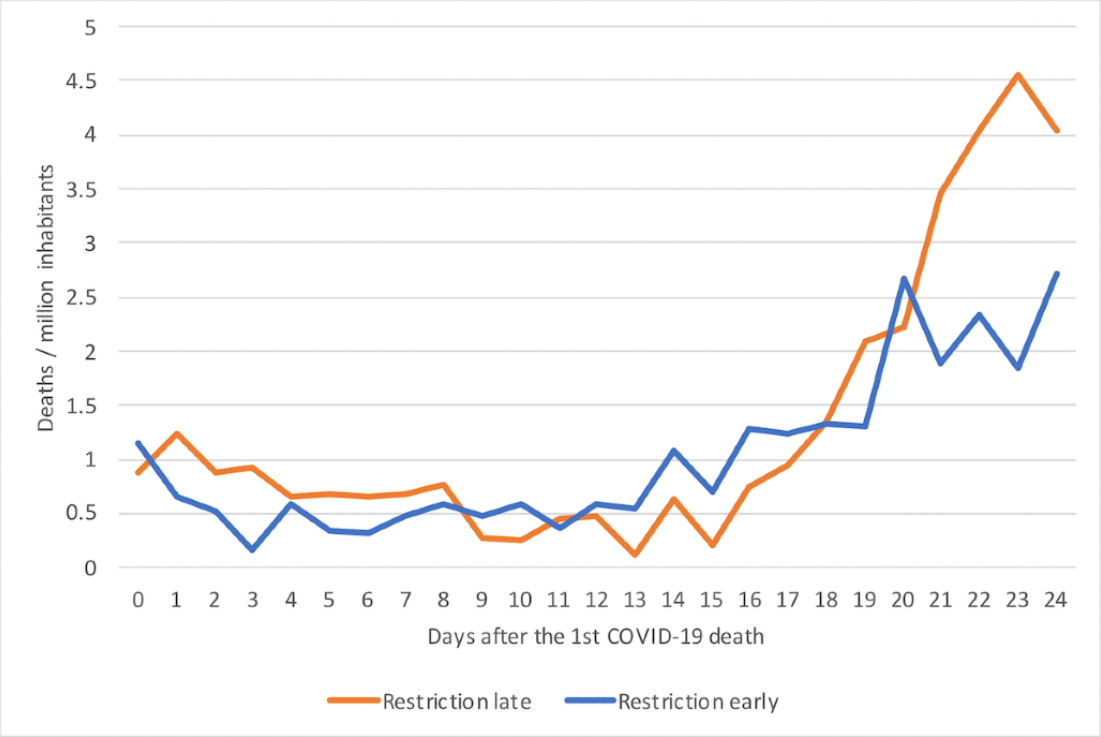


Figure 4. Deaths per day after first COVID-19 death in countries reacting late and early. COVID-19: coronavirus disease.



Discussion

The starting points for this study were the major country differences observed in COVID-19 mortality and the related societal and cultural differences, as well as how people act in different societies during the current crisis situation. We analyzed social risk factors that may explain the spread of the COVID-19, restrictions and control measures, and institutional trust in an attempt to understand the prevailing country differences.

Our analysis showed that there were major variations in reactions to the worldwide epidemic. We were able to show that mortality was significantly associated with the studied social factors. Perceived sociability was associated with higher COVID-19 mortality even after adjusting for a number of control factors. This might be important in understanding why the virus has been able to spread so fast in some countries such as Italy, which also has a dense population. The results also reflect previous cross-cultural findings showing that Italians and Spanish people have smaller social, personal, and intimate distances compared to many other European nations [8]. These countries also have strong intergenerational ties, which may explain why so many older adults got sick [31].

One of the key points of our analysis is, however, that the COVID-19 mortality is tied to societal processes. We found major differences in how fast countries were reacting to the COVID-19 outbreak. Compared to China, European countries had time to react, yet national restrictions were placed late. Those countries that are now being hit the hardest by the disease were also the ones that were slowest to react nationwide, most notably Italy, Spain, and France. Our models showed that late national restrictions predicted a higher number of deaths. Despite the unity provided by the European Union, European countries were not working together against the emerging disease threat, and the regulations progressed slowly, taking one step at a time. There were also delays in putting the restrictions into action. Some countries have also taken different strategies to the COVID-19 epidemic. In Scandinavia, for example, Sweden has adopted less restrictions than Denmark, Finland, and Norway. Sweden also had a higher number of deaths per inhabitants at the time of this writing. This example shows that even within similar neighboring countries national precautions to COVID-19 have been different.

We were able to demonstrate in our analysis that institutional trust was a protective factor. This is in line with previous studies indicating that people with higher institutional trust are more likely to follow the advice and guidelines given by the health authorities [16,17]. In our analysis, COVID-19 mortality figures have progressed differently in low-trust countries and high-trust countries. Remarkably, some low-trust countries such as Italy, Spain, and France were not only late in placing restrictions but had to place harder measures later, such as curfews, because people were simply not following the recommendations not to socialize with each other. Despite hard measures, these countries have also had to sanction disobedient citizens. For example, the Ministry of Interior in Italy reported intensive controls, and over 100,000 people were caught by the police for breaking the curfew [32].

Epidemiologists have not necessarily given enough attention to the societal and social psychological factors explaining epidemics. Although there have been virus epidemics before, the crisis caused by COVID-19 has created a unique global situation, demonstrating how poorly the previous epidemics (eg, SARS and Middle East respiratory syndrome) have prepared countries to deal with this disease [33]. What has made the COVID-19 situation unique when compared to other epidemics,

has been the rapid spread of the virus and the unusually hard restrictions placed to prevent physical contact and closeness between people. As European countries in general rely on individual freedom and democracy, it is difficult to close and shutdown societies completely. It becomes crucial to understand how different societies are capable of handling the crisis situation. This is typically reflected in the literature as societal resilience, and institutional trust is an important part of it [14]. As the crisis is not over, later developments will reveal what kind of role institutional trust eventually had on the wider picture, which also involves factors related to social contacts between people and timely restrictions placed within societies. Our analysis was limited to a relatively short follow-up period and the inability to control for all possible factors involved. We also wish to note that variations across countries exist. This involves, for example, the fact that high-trust countries have adopted different societal strategies to tackle the COVID-19 crisis. Future studies should continue using social scientific evidence in the investigations of worldwide epidemics.

Authors' Contributions

AO contributed to the conceptualization (lead), data curation (supporting), formal analysis (equal), investigation (lead), methodology (equal), project administration (lead), supervision (lead), visualization (lead), and writing of the original draft (lead). MK contributed to the conceptualization (equal), data curation (equal), formal analysis (equal), investigation (equal), methodology (equal), writing of the original draft (supporting), and reviewing and editing of the draft (equal). RL contributed to the conceptualization (supporting), data curation (equal), investigation (equal), writing of the original draft (supporting), and reviewing and editing of the draft (equal). IS contributed to the conceptualization (supporting), data curation (equal), investigation (equal), writing of the original draft (supporting), and reviewing and editing of the draft (equal). NS contributed to the conceptualization (supporting), formal analysis (supporting), investigation (supporting), visualization (equal), writing of the original draft (supporting), and reviewing and editing of the draft (equal). AK contributed to the conceptualization (equal), data curation (equal), formal analysis (equal), investigation (equal), methodology (equal), writing of the original draft (supporting), and reviewing and editing of the draft (equal).

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
ESS: European Social Survey
R_0: reproductive number
SARS: severe acute respiratory syndrome

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Protocol

Detection of SARS-CoV-2 RNA and Antibodies in Diverse Samples: Protocol to Validate the Sufficiency of Provider-Observed, Home-Collected Blood, Saliva, and Oropharyngeal Samples

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Abstract

Background: The response in the United States to the coronavirus disease (COVID-19) pandemic has been hampered by a lack of aggressive testing for the infection. Testing for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is the cornerstone of an effective public health response. However, efforts to test have been hampered by limited reagents, limitations in the availability of swabs used for the collection of nasopharyngeal swab (NPS) specimens, limitations in personal protective equipment (PPE) for health care providers collecting the NPS specimens, and limitations in viral transport media for transporting the specimens. Therefore, more flexible options for screening for SARS-CoV-2 RNA and serologic responses are critical to inform clinical and public health responses.

Objective: We aim to document the ability of patients to self-collect sufficient specimens for SARS-CoV-2 viral detection and serology.

Methods: Patient self-collection of samples will be done with observation by a health care provider during a telemedicine session. Participants will be mailed a specimen collection kit, engage in a telehealth session with a provider through a HIPPA (Health Insurance Portability and Accountability Act of 1996)-compliant video meeting, and collect specimens while being observed by the provider. Providers will record whether they are confident in the suitability of the specimen for laboratory testing that would inform clinical decision making. We will objectively assess the sufficiency of biological material in the mailed-in specimens.

Results: The protocol was approved by the Emory University Institutional Review Board (IRB) on March 30, 2020 (Protocol number 371). To date, we have enrolled 159 participants.

Conclusions: Defining a conceptual framework for assessing the sufficiency of patient-collected samples for the detection of SARS-CoV-2 RNA and serologic responses to infection is critical for facilitating public health responses and providing PPE-sparing options to increase testing. Validation of alternative methods of specimen collection should include objective measures of the sufficiency of specimens for testing. A strong evidence base for diversifying testing modalities will improve tools to guide public health responses to the COVID-19 pandemic.

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KEYWORDS

SARS-CoV-2; RNA-PCR; serology; COVID-19; PCR; public health; outbreak; infectious disease; diagnostic; telemedicine; testing

Introduction

Background

The global pandemic of SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) infection and associated illness (coronavirus disease or COVID-19) have emerged very quickly, challenging traditional systems of clinical and public health response [1,2]. There is broad consensus that adequate testing for SARS-CoV-2 is imperative as a cornerstone of public health efforts to control the spread of the virus [3-5]. The response in the United States to the SARS-CoV-2 pandemic has been hampered by a slow implementation of screening programs and by a variety of factors that have limited the extent of SARS-CoV-2 testing. Following initial problems with quality control of reagents [6], the US government allowed more liberal policies for the development of laboratory developed tests (LDTs) [7], which allowed for a massive expansion of capacity in terms of availability of equipment and staff capacity at commercial laboratories.

However, other factors now limit the reach and volume of testing for SARS-CoV-2 infection. Currently, the gold standard specimen for testing for SARS-CoV-2 RNA is a provider-administered nasopharyngeal swab (NPS) [8]; there are currently supply chain challenges, including shortages of rigid swabs for NPS collection, personal protective equipment (PPE) required for health care workers to collect NPS specimens, and viral transport media required for transporting specimens [9-12]. There are also important questions about testing sites for SARS-CoV-2 infection—should people with mild symptoms who may or may not have COVID-19 come into clinics for testing if they do not require immediate clinical care? How can people who have been quarantined receive testing to document viral shedding to guide the time of release from quarantine, without coming into places where patients are congregating? Finally, we have essentially no epidemiologic data about asymptomatic infection, which could be answered with serology data. Decisions about when to end "stay at home" curfews should likely be based, in part, on the prevalence of antibodies (and, perhaps, immunity) among populations. All these applications will require mechanisms to collect specimens that minimize the need for PPE and allow flexibility of where specimens are collected. Patient-collected samples have appeal in terms of minimizing PPE requirements and enabling the possibility of epidemiologic studies to characterize the infection and immune status of populations.

The regulatory environment governing both the development of LDTs and specifically the testing of patient-collected samples, either in the office of the health care provider or at home, is complicated [13,14]. In response to the urgency of COVID-19 in the United States, the Food and Drug Administration (FDA) has relaxed the regulatory pathways for the development of LDTs to increase the national laboratory capacity [15]. With respect to specimen types, the FDA has developed two pathways for approval for SARS-CoV-2 infection testing: (1) develop laboratory data documenting validation or performance to submit to the FDA for review as an Emergency Use Authorization (EUA); or (2) use state regulatory mechanisms when the test is developed under the jurisdiction of the state in which the lab resides. In the latter case, the state regulators take responsibility for COVID-19 testing by laboratories in their state.

Patient-collected samples have slightly different requirements. The FDA has issued clarifications that the ability of states to oversee the validation of LDTs with patient-collected samples is not covered by the general policy for the development of LDTs, and that assays with patient-collected samples will be required to submit data for review through the FDA for an EUA application [15]. The FDA recently updated guidance to allow collection of patient-collected mid-nasal turbinate samples collected in the provider office, but specifically noted that this approval did not extend to patient-collected samples collected at home [16]. Guidelines for the validation of patient-collected serology specimens do not appear to be explicitly addressed under current FDA guidance, which has focused on the collection of samples for viral detection.

Outside of the realm of SARS-CoV-2 diagnosis, the FDA has reviewed and approved patient-collected samples for a wide variety of laboratory assays, including HIV serology through dried blood spot (DBS) specimens [17]. In other fields, there is a long history of using patient-collected samples under research protocols to develop data on acceptability and to provide clinical services (eg, STI [sexually transmitted infection] testing) as part of research studies [18,19].

We anticipate that there will be biological, immunologic, and temporal aspects that will be important to consider in the design of validation studies for alternative specimen types and results interpretation. When directly comparing provider-collected and patient-collected samples of the same type (eg, provider-collected versus patient-collected oropharyngeal swab [OPS]), it is appropriate to compare the cycle threshold (C_t) for the paired samples to assess comparability. However, RNA concentrations may differ between different specimen types because of differences in RNA shedding at the two sites, such that a direct comparison of C_t results between nasopharyngeal and oropharyngeal swabs might not be an appropriate comparison. Similarly, the timing of onset and waning of IgM (immunoglobulin M) titers in patients and detection of IgA (immunoglobulin A) in saliva or serum following infection with SARS-CoV-2 are not well understood. Finally, it is unclear whether RNA might persist for variable lengths of time after infection in different specimen types. For example, To et al [20] document the presence of RNA in saliva for nearly 2 weeks post hospitalization. Ultimately, all of these questions need to be explored to make the most evidence-based recommendations

for specimen screening types and collection methods in specific time phases of the infection cycle.

Objective

In this paper, we lay out a protocol for describing the sufficiency of patient-collected samples for SARS-CoV-2 infection testing in OPS and saliva, and for immune response to SARS-CoV-2 in DBS and saliva. We consider two aspects of assessment:

1. Do providers who observe patient-collected samples consider them to be comparable to provider-collected specimens in terms of *specimen suitability* for testing for SARS-CoV-2 RNA and antibodies?
2. Do assessments of specimen quality (eg, human nucleic acid for OPS and saliva, specimen saturation and DBS size for DBS cards) document that patient-collected samples contain *sufficient biological material* for accurate testing?

Methods

We propose methods to validate multiple sample types for RNA-PCR (polymerase chain reaction) and for serology tests. Proposed specimen types and assays are depicted in Table 1.

Table 1. Specimen types and assays to be performed in an evaluation of diverse samples for SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) RNA and antibody testing.

Specimen	Oropharyngeal swab	Saliva	Dried blood spot
SARS-CoV-2 RNA	✔	✔	
IgG[a]		✔	✔
IgM[b]		✔	✔
IgA[c]		✔	✔

[a]IgG: immunoglobulin G.

[b]IgM: immunoglobulin M.

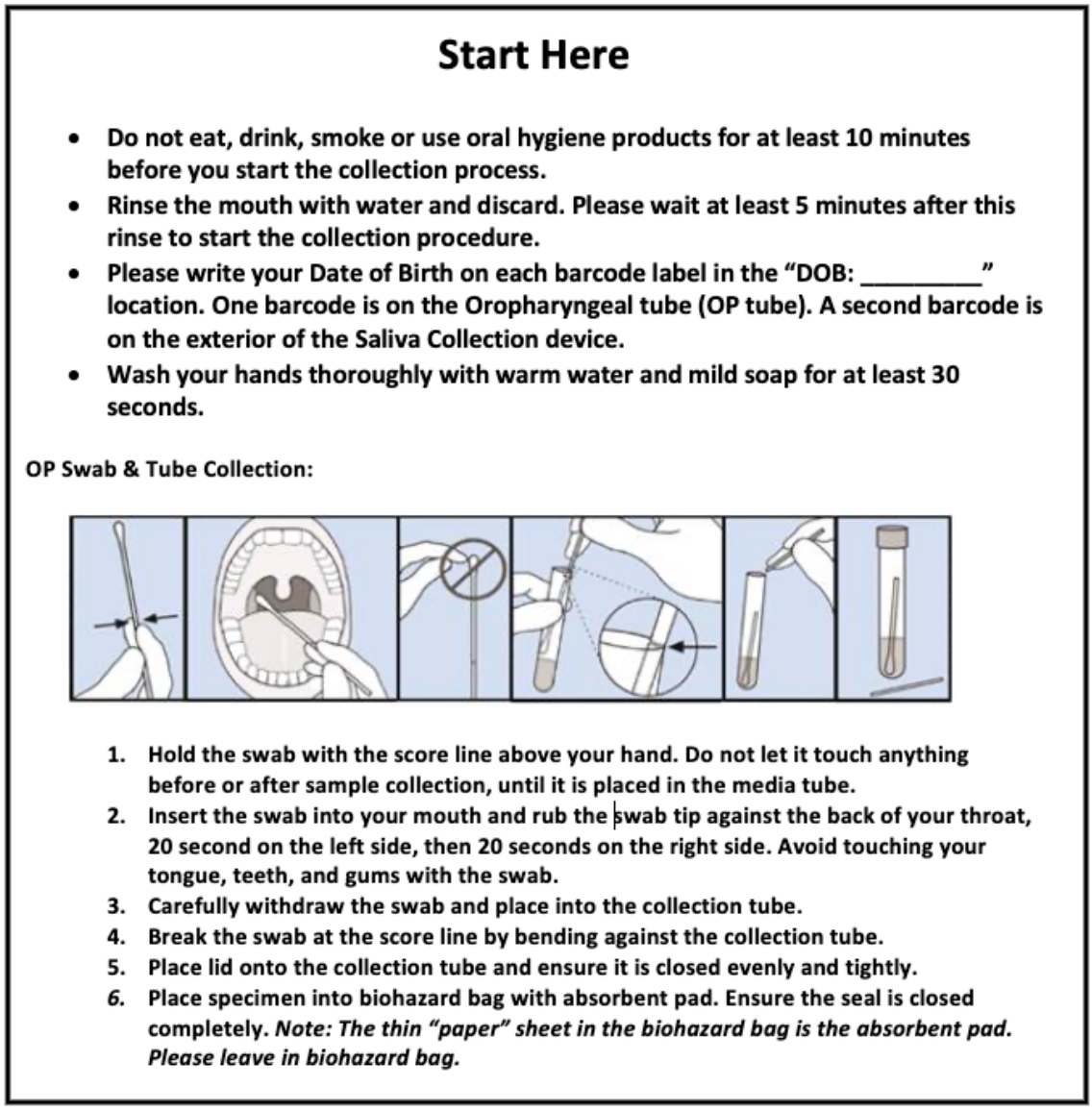
[c]IgA: immunoglobulin A.

Specimen Collection

Oropharyngeal Swab Self-Collection

Patients will be provided with printed instructions for collection (Figure 1). They will be instructed to insert the swab into their mouth and rub the swab tip against the back of their throat for 20 seconds on the left side, then 20 seconds on the right side. They are advised to avoid touching their tongue, teeth, and gums with the swab. They are instructed to insert the swab in the tube of viral transport media, break the swab at the score, and cap the tube.

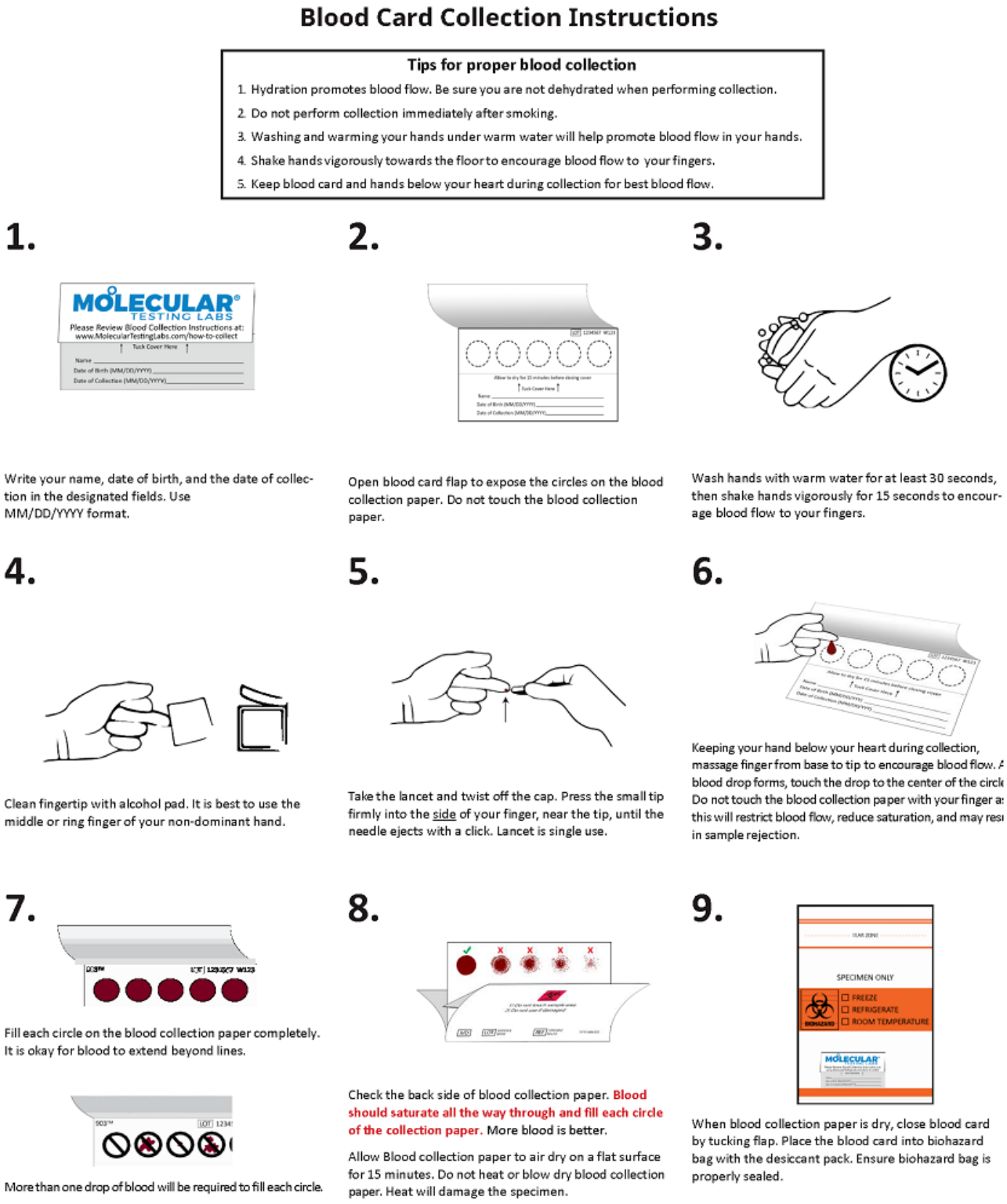
Figure 1. Participant instructions for self-collection via oropharyngeal swab.



Self-Collection of Dried Blood Spots

Patients will be provided with printed instructions for DBS collection (Figure 2). They will be instructed to wash their hands thoroughly, use an alcohol swab to clean the tip of the middle or ring finger of their nondominant hand, release the blade of the provided lancet by pressing into the side of the finger near the tip of the finger, and fill each of the 5 circles on a Whatman standard dried blood spot collection card. Participants are instructed to allow the blood card to dry for at least 15 minutes before packaging for return shipment.

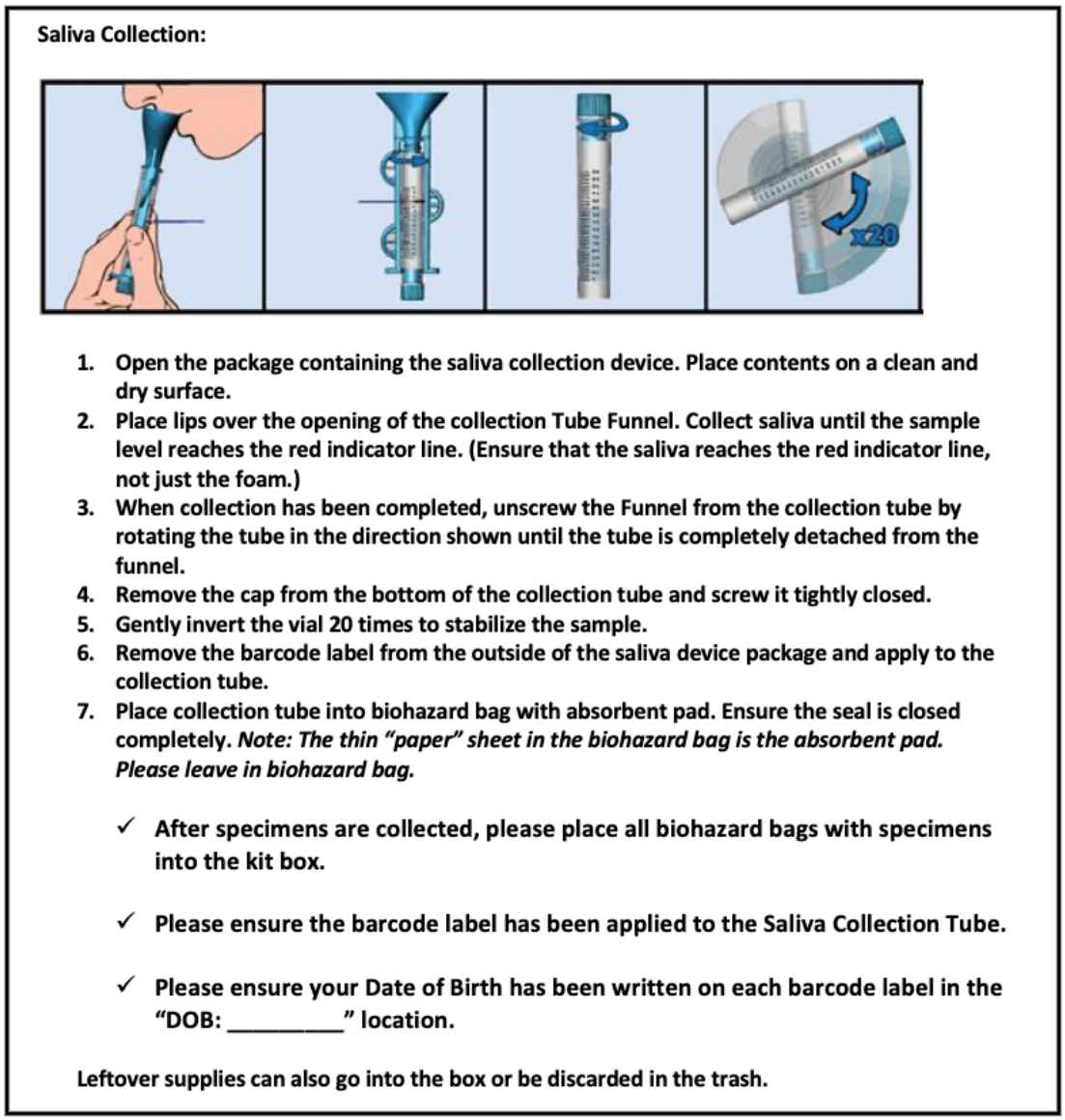
Figure 2. Participant instructions for self-collection of dried blood spots.



Saliva Self-Collection

Participants are asked not to eat, drink, smoke or use oral hygiene products for at least 10 minutes before the collection process (Figure 3). Participants will be instructed to rinse their mouth with water and discard, and then wait 5 minutes after the rinse before collecting the specimen. Participants will be instructed to place their lips over the collection tube funnel and collect saliva until the saliva reaches the red indicator line. They will then be instructed to screw the cap on the tube tightly and invert it 20 times to stabilize the sample. The participant will be instructed to write their date of birth on the tube before preparing for shipping.

Figure 3. Participant instructions for self-collection of saliva.



Provider Observations

Providers will observe participants as they collect specimens through a telehealth video session on a HIPPA (Health Insurance Portability and Accountability Act of 1996)-compliant video conference service. After establishing a secure connection and confirming the identity of participants using a study identifier, the provider will direct the participant to use the provided instructions to collect the specimen; the provider will identify their role as that of an observer. The provider will document on case report forms (CRFs) that they observed the participant collecting the specimens (see Multimedia Appendix 1 for CRFs). The provider will also record their assessment of whether the specimen collected is suitable for laboratory testing, and, as secondary assessments, complete checklists of steps in the correct collection of the specimen (eg, did not smoke or drink while collecting saliva specimen, inverted closed saliva tube 20 times as directed, dropped blood on the DBS card rather than touching the card).

Testing

RNA-PCR

Specimens will first be checked for quality. The samples will then undergo total nucleic acid extraction using the Thermo Kingfisher platform (Fisher Scientific). Isolated RNA will be reverse transcribed to DNA using a one-step, one-tube system via reagents from Thermo (Fisher Scientific). The second half of the one-tube system will involve qPCR (quantitative polymerase chain reaction). The reverse-transcribed DNA will undergo qPCR with primers and probes targeting 3 gene regions of the SARS-CoV-2 genome (N, S, ORF1), using reagents from Thermo. The results will be analyzed, and an interpretation will be made based on C_t values and positive identification of the nucleic acid.

Specimen Sufficiency for RNA-PCR

We will test OPS and saliva specimens for RNase P (ribonuclease P) as an endogenous internal amplification control and to quantify the nucleic acid content of the specimen [21]. We will consider OPS and saliva specimens with C_t values of

<30 to indicate sufficient collection of biological material in the saliva sample and the swab.

Serology Tests

Specimens will first be checked for quality. For blood, a 6 mm punch will be obtained from the DBS, and the material will undergo standard antibody extraction using Tris buffer. For saliva, the sample will be aliquoted and used directly in the serology assay. Once the material is added to the reaction tube, the enzyme immunoassay primary and secondary antibodies (SARS-CoV-2 assay, IgG and IgM, Epitope Diagnostics; IgA, EuroIMMUN) will be added using an automated liquid handler instrument (DSX; Dynex Technologies). The protocol will follow the manufacturer's guidelines for reaction conditions, data interpretation, and ensuring that internal controls pass.

Specimen Sufficiency for Serology

For DBSs, we will conduct a three-point quality check, documenting the visual appearance of the blood spot, whether it is soaked through the paper, and whether the circles are filled, as we have previously reported [22].

Analysis

We will tabulate the provider impressions of specimen suitability (primary outcome); exploratory analyses for provider observation will include enumeration of how common certain errors in self-collection were. For assessment of the sufficiency of RNA-PCR specimens, we will tabulate the proportion of OPS and saliva samples that had C_t values for RNAse P<30. As a secondary analysis, we will examine whether the RNAse P C_t values for the patient-collected OPS were different from the C_t values from a historical set of provider-collected OPS tested with the same reagents and laboratory equipment in the study laboratory. These analyses will involve comparing the means of the two groups using a *t* test.

Results

The protocol was approved by the Emory University Institutional Review Board (IRB) on March 30, 2020 (Protocol number 371). To date, we have enrolled 159 participants.

Discussion

There is an urgent need to develop and validate new methods to monitor SARS-CoV-2 infection status and immune experience [4]. Currently, provider and supply chain shortages threaten our national capacity to diagnose people who need care and monitor the growing COVID-19 pandemic. Patient-collected samples, if they are validated and approved through regulatory channels for clinical purposes, offer several advantages from clinical and public health perspectives. From a clinical perspective, patient-collected specimen options will decrease provider burden, allow for follow-up monitoring for viral shedding without the need for return office visits, and reduce risks for provider exposure during specimen collection. From a supply chain perspective, depending on the specimen that is used, self-collection can reduce the need for PPE for providers who would otherwise collect the sample, will reduce the need for rigid NPSs, and could reduce the need for viral transport media (eg, saliva samples). From a public health perspective, having options for patient-collected samples will allow for population-based studies to measure the population prevalence of current and past infection with SARS-CoV-2. Such studies are critical to understand the natural history of infection, to develop an understanding of what proportion of the population have asymptomatic infections, to monitor population immunity, and to reach patients who live in remote areas with testing.

We developed this protocol for validation, recognizing the extreme urgency of developing new testing options and appreciating the regulatory structures that ensure that clinical testing in the United States meets high standards and produces actionable results. We believe that having providers observe patients collecting specimens is an important steppingstone on the path between relying wholly on provider-collected samples (and the required PPE and clinical visits) and the use of patient-collected samples collected outside of the supervision of providers. We note that the FDA has approved SARS-CoV-2 testing on patient-collected mid-nasal turbinate swabs, but only if the patient-collected swabs are collected in the provider's office [16]. The kappa values of the mid-nasal turbinate study have not been reported, but the sensitivity of the patient-collected swabs to detect SARS-CoV-2 RNA among those known to be infected was 90% [16]. This approval is a rational decision, because modeling data suggest that testing at this stage of the epidemic is still valuable in blunting it, even if it is imperfect [3]. Recent data suggest that staff-collected and patient-collected mid-nasal turbinate swabs have high correlation for the detection of influenza viruses [23].

The COVID-19 pandemic has been remarkable for its rapid onset and spread into new populations. The public health and clinical medicine systems in the United States have not had time to respond in conventional ways to this pandemic. There is a need to be innovative in developing and deploying new strategies to meet the clinical needs of patients who are infected with SARS-CoV-2 and simultaneously to gather data to understand the broad picture of the epidemic and to monitor infections and immunity at the population level. Given the catastrophic demands on our hospitals and medical offices, we must develop ways to move testing for screening purposes and epidemiologic monitoring out of the health care system [24]. Patient-collected specimens are widely used for monitoring of other infectious diseases and health conditions, and it is imperative to validate and deploy self-collection tools to understand and respond to this pandemic. We propose a structured and objective process by which patient-collected samples can be evaluated by providers during sample collection for their suitability and by laboratorians for their biological sufficiency. As we learn more about the capacity of patients to correctly collect specimens and illustrate the use of internal controls to document the biological sufficiency of specimens, there will be opportunities to use SARS-CoV-2 testing in innovative ways to address the COVID-19 pandemic.

Conflicts of Interest

TS is editor-in-chief of *JMIR Public Health and Surveillance*. Because of this, he was not involved in the editorial handling or peer-review of this paper.

Multimedia Appendix 1
Case report forms for self-collection evaluation.
[PDF File (Adobe PDF File), 193 KB - publichealth_v6i2e19054_app1.pdf]

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Abbreviations

COVID-19: coronavirus disease
CRF: case report form
C_t: cycle threshold
DBS: dried blood spot
EUA: Emergency Use Authorization
FDA: Food and Drug Administration
HIPPA: Health Insurance Portability and Accountability Act of 1996
IgA: immunoglobulin A
IgG: immunoglobulin G
IgM: immunoglobulin M
LDT: laboratory developed test
NPS: nasopharyngeal swab
OPS: oropharyngeal swab
PCR: polymerase chain reaction
PPE: personal protective equipment
qPCR: quantitative polymerase chain reaction
RNase P: ribonuclease P
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
STI: sexually transmitted infection

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Original Paper

Surveillance of COVID-19 in the General Population Using an Online Questionnaire: Report From 18,161 Respondents in China

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Abstract

Background: The recent outbreak of the coronavirus disease (COVID-19) has become an international pandemic. So far, little is known about the role of an internet approach in COVID-19 participatory surveillance.

Objective: The aim of this study is to investigate whether an online survey can provide population-level information for observing prevalence trends during the early phase of an outbreak and identifying potential risk factors of COVID-19 infection.

Methods: A 10-item online questionnaire was developed according to medical guidelines and relevant publications. It was distributed between January 24 and February 17, 2020. The characteristics of respondents and temporal changes of various questionnaire-derived indicators were analyzed.

Results: A total of 18,161 questionnaires were returned, including 6.45% (n=1171) from Wuhan City. Geographical distributions of the respondents were consistent with the population per province (R^2=0.61, P<.001). History of contact significantly decreased with time, both outside Wuhan City (R^2=0.35, P=.002) and outside Hubei Province (R^2=0.42, P<.001). The percentage of respondents reporting a fever peaked around February 8 (R^2=0.57, P<.001) and increased with a history of contact in the areas outside Wuhan City (risk ratio 1.31, 95% CI 1.13-1.52, P<.001). Male sex, advanced age, and lung diseases were associated with a higher risk of fever in the general population with a history of contact.

Conclusions: This study shows the usefulness of an online questionnaire for the surveillance of outbreaks like COVID-19 by providing information about trends of the disease and aiding the identification of potential risk factors.

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KEYWORDS

coronavirus; surveillance; syndromic surveillance; participatory surveillance; online questionnaire; Wuhan; COVID-19

Introduction

The recent outbreak of the coronavirus disease (COVID-19) has caused over 752,000 confirmed cases and 36,000 deaths as of March 30, 2020 [1-4]. Despite a proactive policy of identifying and treating patients with infected symptoms, it remains resource intensive to screen the general population that is at risk for infection [5,6]. Moreover, inequality of health care systems among different areas brings challenges to cover remote areas, which are also at risk of the COVID-19 infection. Therefore, a new way of surveilling the general population could contribute to our understanding of COVID-19 [7]. The wide use of the internet throughout China, and in the rest of the world, may be sufficient to provide such information. Participatory disease surveillance has been increasingly investigated in recent years as a promising tool to complement traditional facility-based surveillance platforms [8]. It has the advantage of providing quick coverage of a large population during a disease outbreak. Therefore, an online survey may be valuable in monitoring disease trends in communities and providing information for making policies.

In this paper, we report the results of the first online questionnaire about COVID-19, released on January 24 and with data collected up to February 17, 2020. Our study aims to investigate how a history of contact and fever (both defined according to relevant medical guidelines) have evolved during the early phase of government lockdown policies and whether an online questionnaire can be used to identify certain risk factors related to fever among those reporting history of contact.

Methods

Questionnaire Development and Distribution

The first version of the questionnaire was developed on January 24, 2020. By that time, little evidence was known about COVID-19. Our anonymous questionnaire was primarily developed from the following 3 sources: (1) the Diagnosis and Treatments of COVID-19 (Third Version) guideline; (2) clinical courses of the first 17 death cases, both of which were released by the National Health Commission of China; and (3) the article that first analyzed the clinical features of 41 cases of COVID-19 [9-11]. The guideline requires a suspected case to satisfy the following criteria: any history of contact including living in Wuhan or having travelled to Wuhan within 2 weeks of disease onset, being in contact with any person with a fever and respiratory symptoms from Wuhan within 2 weeks of disease onset, or belonging to a cluster of infected cases; and clinical manifestations including a fever (defined as a body temperature ≥37.3 °C [99.1 °F]), imaging evidence of COVID-19, normal white blood cell count, or leukopenia or lymphopenia. A confirmed case is further established by positive findings of real time polymerase chain reaction or viral gene sequencing. The descriptions of the guideline are in good consistency with the clinical features of the first 17 death cases and later 41 infected cases reported on January 24, 2020 [9,10]. Therefore, our questionnaire evaluated the risk of COVID-19 in the general population from the following aspects:

1. History of contact: living in Wuhan, having travelled to Wuhan in the past 2 weeks, having any close contact (lived, studied, or worked together, or had any other close contact) in the past 2 weeks with a person with a fever and cough who came from Wuhan, or being in a workplace, school, or family that has at least 2 confirmed cases. Other history of contact with wildlife animals within 2 weeks of disease onset was also considered.
2. Body temperature: having a fever with a body temperature higher than 37.3 °C (99.1 °F)
3. Symptoms: we classified symptoms by their relative importance into the following 3 groups: (1) chief symptoms related to pulmonary infection (ie, cough without sputum or with little sputum) and shortness of breath; (2) secondary symptoms related to systemic changes probably caused by viral infection (ie, fatigue, headache, and myalgia); and (3) probably unrelated symptoms (ie, nasal obstruction, rhinorrhea, sneezing, sore throat, and diarrhea).
4. Comorbidities: Lung diseases, cardiovascular diseases, hypertension, diabetes, stroke, and chronic kidney dysfunction
5. Basic information: age and gender

We did not include laboratory examinations (eg, real time polymerase chain reaction, lymphopenia, white blood cell count) or thoracic imaging results (eg, multiple patchy consolidation and interstitial changes) in our questionnaire because, in general, these would unlikely be obtained by the general population.

By February 17, 2020, we had developed and released three versions of the Chinese questionnaires to the public. They were essentially similar, with the following three major revisions:

1. We divided the age group of ≤40 years used in the first version into age groups of ≤30 years and 31-40 years in the following two versions for better risk stratification.
2. History of contact with wildlife animals was removed from the third version, as we considered it to have a low value for diagnosis in the general population.
3. The question initially included for evaluating shortness of breath, “I feel extremely short of breath when climbing upstairs or walking at a fast speed” (modified from the Medical Research Council Breathlessness scale), was removed from the third version and added as an item named “shortness of breath” to the question about symptoms of COVID-19. This was done because we found an exceptionally high percentage of respondents reporting shortness of breath in the first 2 versions of the questionnaires (26.5% and 32.9%, respectively).

After completing the questionnaire, the respondents would be classified into one of the following 4 risk groups and given different suggestions:

1. High-risk group having history of contact and fever: it was suggested that they measure their body temperature after 30 minutes and immediately visit the hospital to screen for a potential COVID-19 infection.
2. Moderate-risk group having history of contact but without fever: it was suggested that they monitor their body temperature daily and get screened for a potential COVID-19 infection if fever or respiratory symptoms occurred.
3. Low-risk group without history of contact but with fever: this group probably had a common cold, and it was suggested that they make an appointment with a general practitioner for help, if necessary.
4. Very low-risk group without history of contact or fever: they were unlikely to have COVID-19 at the time they completed the questionnaire, and it was suggested that they take necessary measures such as putting on a facemask to prevent the infection.

The questionnaire was developed using a professional online questionnaire website Wenjuanxing (Questionnaire Star) [12]. It is the most popular website for online surveys in China with over 4.2 billion questionnaires recycled and over 59 million users as of February 21, 2020. Questionnaires were distributed online by WeChat (the most popular instant messaging app in China) and sharing the link of the questionnaire. Since our aim was to have an overview of situations in China during the COVID-19 outbreak, we did not target any specific groups of respondents. Distribution and filling out the questionnaires were voluntary, making our study a convenience sampling study.

According to the World Health Organization Guidelines on Ethical Issues in Public Health Surveillance, a surveillance study in emergency outbreak situations is exempted from ethical review and oversight [13]. Indeed, our online questionnaire was designed on January 23, 2020, when the lockdown of Wuhan City was officially announced and released on January 24, so it could not await the formal approval of an ethical review committee. All users were informed at the beginning of the questionnaire that their questionnaire data would be used only for medical education and research purposes. If the informed consent was rejected by the users, they could still continue the questionnaire and obtain their results.

Data Collection

The questionnaire was released on January 24, 2020, and recycled on February 17. All questionnaire results were downloaded from the website for our analysis. In addition to the items of the questionnaire, the downloaded data also included the date of submission for all respondents as well as the respondents' location at the city level.

We also collected population data of each province from China Statistical Abstract 2019 published by the National Bureau of Statistics of China [14]. The number of confirmed cases was followed up with on a daily basis since the release of the questionnaire using the NetEase News website, the largest Chinese hub for real time collection of data and news related to COVID-19 [15]. The statistics of confirmed cases per province used in this study were collected until midnight of February 11; at that time, clinically diagnosed cases without positive real time polymerase chain reaction results were also included in the official confirmed number of cases.

Statistical Analysis

Count data were expressed as number (percentage). Skewed continuous data (time to complete questionnaire) were expressed as median (IQR). Geographical distributions were drawn using Microsoft Excel Visual Basic. A Pearson correlation analysis was used to analyze the relationship between two variables of interest (mainly between date and percentage of respondents of interest per day). Comparison of respondents' basic characteristics between the inside and outside of Wuhan was performed using a chi-square test or a Fisher exact test if the sample size was <40. Risk of fever in respondents with history of contact was evaluated using a risk ratio (RR) and 95% CI. All statistical analyses were performed using Stata 14.0 (StataCorp) and MATLAB R2018b (MathWorks). Statistical significance was defined as a two-tailed *P* value <.05.

Results

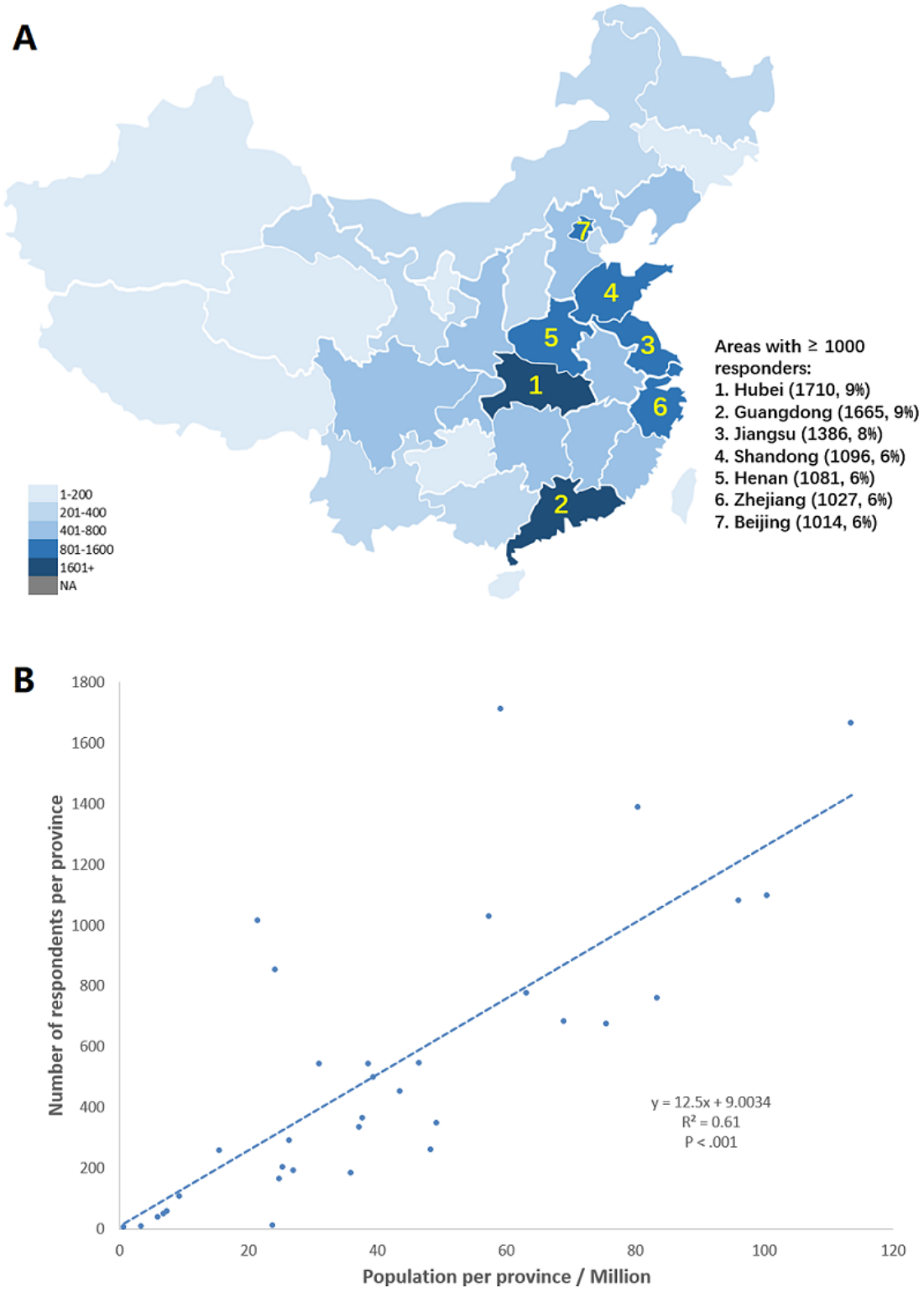
Questionnaire Respondents

By February 17, 2020 at 2:33 AM, a total of 19,449 individuals completed the questionnaires, 98.02% (n=19,064) from China. After removing 385 questionnaires from overseas countries, 575 lacking informed consent, 55 missing age, 31 missing temperature, 38 missing comorbidities, and 4 missing symptoms information, 18,161 anonymous questionnaires were analyzed. Overall, it took median 52 (IQR 41-67) seconds to complete the questionnaire. Most questionnaires were accessed by clicking on the link of the questionnaire (n=11,337, 62.42%) and by visiting the WeChat mini-app (n=6800, 37.44%).

Geographical Distributions

Figure 1A shows the geographical distributions of the questionnaire respondents in China. The questionnaire covered all 34 province-level administrative regions. For Hubei Province, 68.48% (n=1171/1710) of the respondents came from Wuhan City, which was most affected by COVID-19. A positive relation was found between the number of respondents and the population size per province (Figure 1B), demonstrating good coverage of the questionnaire across China.

Figure 1. A) Geographical distributions of questionnaire respondents in China. B) A positive correlation between the number of respondents and the size of the population of each province.



Basic Characteristics

Table 1 summarizes the demographics and basic characteristics of respondents. The population in Wuhan had similar ages and comorbidities compared with those outside of Wuhan. Age was negatively correlated with the number of respondents (R^2=0.95, P<.001). As expected, history of contact was more frequent among the respondents living in Wuhan. The percentage of fever was significantly lower among respondents inside versus outside Wuhan. Symptoms were reported in a rather high percentage of respondents. When restricting the symptoms to at least one main symptom and one secondary symptom, the number of respondents with symptoms dropped to 12.62% (n=2292/18,161).

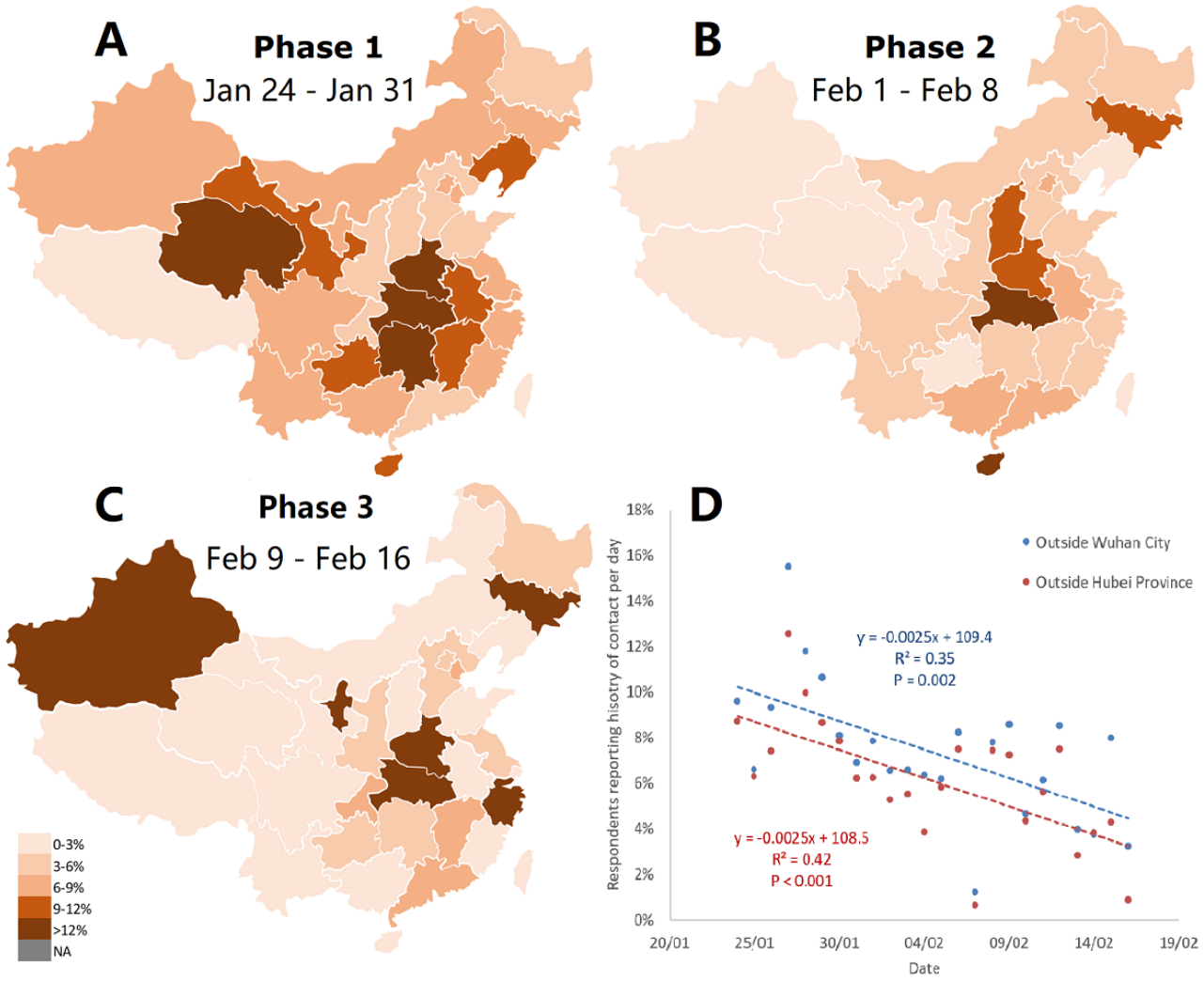
Table 1. Demographics and basic characteristics of respondents.

Characteristics	All respondents (N=18,161), n (%)	Wuhan (n=1171), n (%)	Outside Wuhan (n=16,990), n (%)	*P* value
Women	10,801 (59.47)	762 (65.07)	10,039 (59.09)	<.001
Age (years)				
≤30	12,504 (68.85)	782 (66.78)	11722 (68.99)	.11
31-40	3757 (20.69)	282 (24.08)	3475 (20.45)	.003
41-50	1154 (6.35)	70 (5.98)	1084 (6.38)	.59
51-60	532 (2.93)	28 (2.39)	504 (2.97)	.26
61-70	147 (0.81)	6 (0.51)	141 (0.83)	.24
≥71	67 (0.37)	3 (0.26)	64 (0.38)	.51
Comorbidity	1593 (8.77)	95 (8.11)	1498 (8.82)	.41
Hypertension	655 (3.61)	38 (3.25)	617 (3.63)	.49
Lung diseases	468 (2.58)	24 (2.05)	444 (2.61)	.24
Cardiovascular diseases	375 (2.06)	21 (1.79)	354 (2.08)	.50
Diabetes	223 (1.23)	16 (1.37)	207 (1.22)	.66
Chronic kidney disease	135 (0.74)	5 (0.43)	130 (0.77)	.19
Stroke	34 (0.19)	4 (0.34)	30 (0.18)	.21
History of contact	2631 (14.49)	1171 (100.00)	1460 (8.59)	<.001
Living in Wuhan now or having gone to Wuhan in the past 2 weeks	1950 (10.74)	1171 (100.00)	779 (4.59)	<.001
Contact with a person with fever and cough from Wuhan in the past 2 weeks	938 (5.16)	298 (25.45)	640 (3.77)	<.001
At least 2 confirmed cases in workplace, school, or family	532 (2.93)	122 (10.42)	410 (2.41)	<.001
Symptoms	11,796 (64.95)	699 (59.69)	11,097 (65.31)	<.001
Fever	1653 (9.10)	56 (4.78)	1597 (9.40)	<.001
Cough	5242 (28.86)	314 (26.81)	4928 (29.00)	.11
Shortness of breath	4393 (24.19)	263 (22.46)	4130 (24.31)	.15
Nasal obstruction, rhinorrhea, or sneezing	4376 (24.10)	237 (20.24)	4139 (24.36)	.001
Sore throat	3397 (18.70)	201 (17.16)	3196 (18.81)	.16
Fatigue	3245 (17.87)	148 (12.64)	3097 (18.23)	<.001
Headache or myalgia	2072 (11.41)	87 (7.43)	1985 (11.68)	<.001
Diarrhea	1360 (7.49)	70 (5.98)	1290 (7.59)	.04

History of Contact

A history of contact was reported by more than one-eighth of respondents. However, the high percentage might have been confounded considering that all respondents living in Wuhan City had a history of contact according to the definition of the official guideline, so we excluded these respondents from our analysis and divided the remaining respondents by every 8 days into 3 phases: phase 1 was from January 24 to 31, phase 2 was from February 1 to 8, and phase 3 was from February 9 to 16. Despite heterogeneous responses of different provinces, the proportion of respondents reporting a history of contact had markedly decreased over these 3 phases in most provinces (Figure 2A, B, and C). This observation was further confirmed by correlation analysis between the proportion of respondents reporting a history of contact and date in areas outside of Wuhan City and Hubei Province (Figure 2D). These findings indicate the efficacy of current policies adopted to reduce the history of contact among the general population since the lockdown in Wuhan and other areas on January 23, 2020.

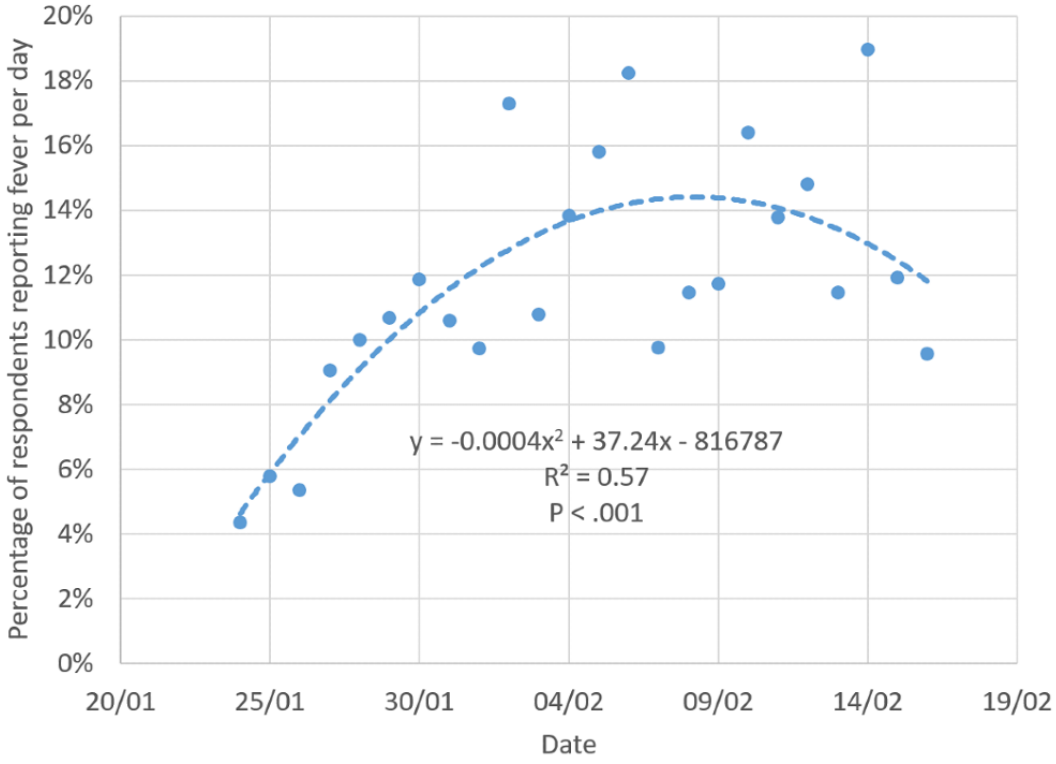
Figure 2. The geographic spread of the proportion of respondents reporting a history of contact in three phases of the COVID-19 outbreak (A, B, and C), and its time course in all regions outside Wuhan City and Hubei Province (D).



Body Temperature

Body temperature was measured in 77.49% (n=14,073/18,161) of respondents, with a higher percentage in Wuhan City (n=990/1171, 84.54%) and Hubei Province (n=1431/1710, 83.68%). Overall, fever was reported in less than one-tenth of the respondents. Unexpectedly, a lower percentage was found for Wuhan City and Hubei Province. This might be due to COVID-19 developing to a further stage in Wuhan, and fever cases were identified early and sent to hospitals without access to the internet. We further analyzed how the percentage of respondents with fever evolved with time. The trend seemed to peak on around February 8, 2020 (Figure 3).

Figure 3. Proportion of respondents reporting a fever over time.

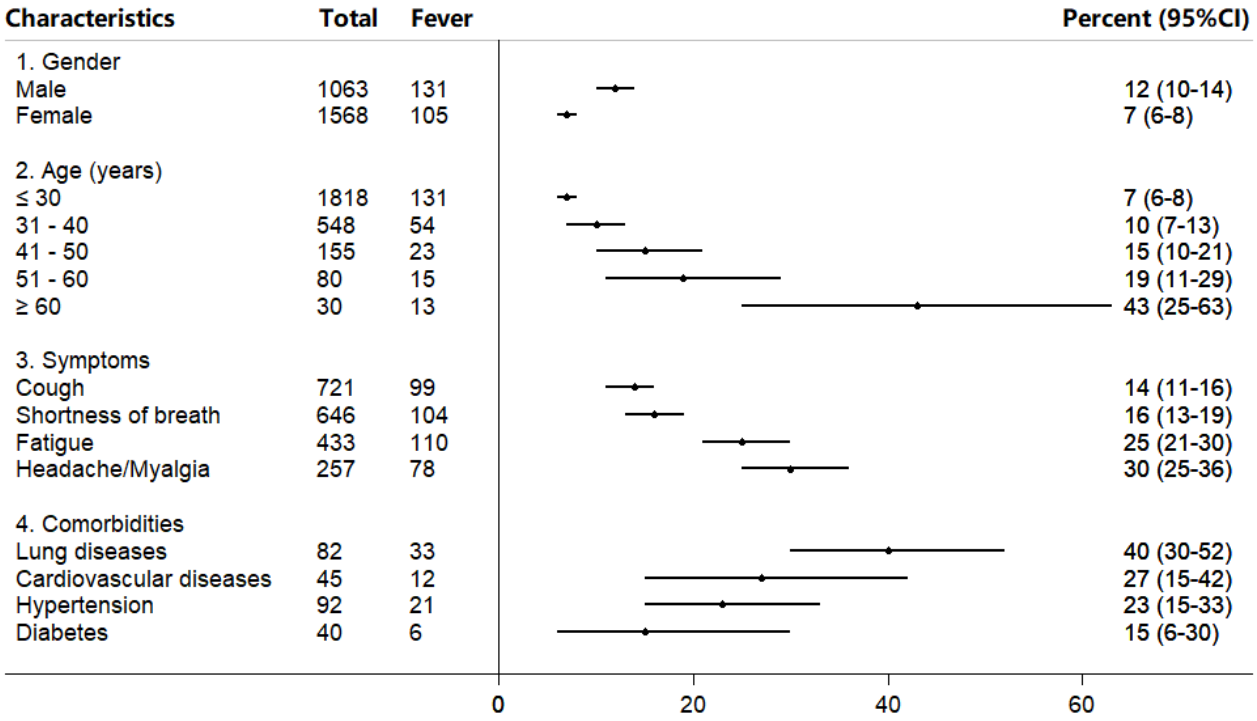


Fever in Respondents With a History of Contact

Analyzing the relationship between fever and history of contact may help develop population-based strategies for prevention purposes. For the respondents living outside Wuhan, we found a significant relation between any history of contact and fever (RR 1.31, 95% CI 1.13-1.52, *P*<.001). Travelling to Wuhan, having any close contact with a confirmed case, and having at least 2 confirmed cases at the workplace in the past 2 weeks conferred a significantly higher risk of fever (RR 1.47, 95% CI 1.23-1.77, *P*<.001; RR 1.98, 95% CI 1.67-2.24, *P*<.001; and RR 2.12, 95% CI 1.74–2.58, *P*<.001, respectively). Moreover, there was a significant positive relation between the number of officially confirmed cases and the number of respondents reporting a fever (R^2=0.41, *P*<.001) or the number of respondents reporting a fever and a history of contact (R^2=0.35, *P*<.001) on a province basis. Regarding risk stratification based on history of contact and fever, most respondents (n=14,264/18,161, 78.54%) were classified in the very low-risk group, followed by the moderate-risk group (n=1883, 10.37%) and the low-risk group (n=1428, 7.86%), whereas only 1.24% (n=225) were classified to the high-risk group.

Furthermore, comparison of fever rates among groups of various characteristics was likely to help identify risk factors (Figure 4). Males were at a higher risk of fever than females (*P*<.001). There was a positive trend between age and fever (*P*<.001). Respondents reporting fatigue and headache or myalgia were more likely to report fever (*P*<.001). Comorbidities showed various associations with fever, among which history of lung diseases seemed to confer a higher risk of fever than the others. However, the relationship needs to be further validated by studies with larger samples because of a relatively small number of respondents in each group.

Figure 4. Fever in various subgroups of respondents with history of contact.



Discussion

Principal Findings

To the best of our knowledge, this is the first large-sample online surveillance of the COVID-19 outbreak in the general population. Our major findings include: the questionnaire had a good coverage of all provinces of China in a relatively short period of time (about 3 weeks); the history of contact among the population outside of Wuhan and Hubei Province significantly decreased during the early phase of the government lockdown policy; fever reported by respondents significantly increased in the short-term of the disease outbreak and levelled off in 2-3 weeks; and, among those with history of contact, some factors (male, advanced age, and history of lung diseases) seemed to be associated with a higher risk of fever.

Values of Online Questionnaire

An online questionnaire is likely to serve as a complementary way of disease surveillance in the general population, especially during the emergent outbreak of an infectious disease [5]. It takes the advantage of low costs and efficient delivery to all areas, even the most remote areas where internet access is better than health care resources [16,17]. Our questionnaire was completed by 385 Chinese respondents from 38 overseas countries, including developed (the United States, Japan, Canada, and the United Kingdom), developing (Brazil, Russia, India, and South Africa), and underdeveloped countries (Laos, Uganda, and Cambodia). Translation of the questionnaire to other languages may further increase the coverage across the world and improve surveillance of the COVID-19 outbreak and comparable epidemics.

Compared with the conventional way of disease surveillance, the online questionnaire covers the population with generally less severe conditions but, nevertheless, is at risk of infection [7,18], taking into account that this population helps to establish the full spectrum of COVID-19 epidemiology. It may also facilitate the early triage and diagnosis of high-risk groups when combined with other digital health measures such as online physician consultation, which has been widely adopted since the COVID-19 outbreak in China. For the low-risk population, the questionnaire can also be adapted to reduce unnecessary anxiety and hospital visits, and thus, greatly relieve the workloads of health care facilities, especially when an emergent public health event occurs [19].

The questionnaire approach is advantageous compared with other approaches of online disease surveillance using data from Google Trends, Twitter, or Facebook [20-22]. It provides richer information of the respondents, as most items can be designed according to medical guidelines and characteristics of target populations. Therefore, it is a more active approach than other infosurveillance methods using social media. The information such as symptoms, history of contact, and comorbidities provided by an online questionnaire can be further combined with vital data such as body temperature, heart rate, respiratory rate, oxygenation level, and activity level obtained from wearable devices to have a more comprehensive and reliable estimation of respondent's risk of disease [23]. For the high-risk group identified using an online questionnaire, a case can be further confirmed by sending a home-testing kit and instructing the respondents to perform a rapid diagnostic test, as shown in the GoViral study [24]. Additionally, self-reported data from an online questionnaire can be linked with electronic medical records to build a long-term monitoring system [8].

Use of Questionnaire to Observe Trends

An online survey is likely to be used to observe the trends of disease prevalence in communities and, thus, support

government policy evaluation. In our study, the date February 8, 2020, when the percentage of fever respondents peaked, was 16 days following the lockdown of Wuhan City, which was close to the 14 days of the maximum incubation period of the coronavirus [25]. The delay of the fever peak might be associated with delayed quarantine policies in other cities in China. Overall, our data supported the efficacy of current policies (quarantine, social distancing, and isolation of infected populations) for containing the spread of COVID-19 from Wuhan City to the other areas of China [6,26,27]. However, the period and efficacy of quarantine may differ by country [28]. It depends on not only government policies but also local culture and more importantly active support from the general population. For other countries, which may not have quarantine policies as strict as China, the time to fever peak is probably longer among the general population. Moreover, integration of the survey data into a model for real time and long-term forecasting of disease trends is likely to provide richer information for making policies [29]. Of note, our questionnaire is more applicable to those living in China than abroad. The definition of history of contact has mostly relied on contact with a confirmed case from Wuhan. However, this can be further modified according to the earliest and generally most severely affected area of a country of interest, such as Lombardy in Italy.

Use of Questionnaire to Identify Risk Factors

Our survey also indicates that some factors such as male, an advanced age, and a history of lung disease are likely to relate to a higher risk of infection, and thus, these groups should be under close observation. Indeed, these risk factors identified from our study are consistent with the clinical features of infected cases in previous publications [9,30-33]. By quickly disseminating an online questionnaire during the early phase of a disease outbreak, risk factors can be identified at a much earlier phase rather than when enough severe cases have been collected and analyzed using a conventional surveillance method. This further allows for earlier protection of vulnerable groups from potential infection and, thus, reduces the number of cases. Internet-based surveillance approaches based on Twitter have been demonstrated to detect Ebola, avian influenza, and thunderstorm asthma at an early stage, even before the first official report [20-22].

Limitations of the Approach

The approach undoubtedly has the bias of sampling primarily internet users and their relatives. As a consequence, the population included in our study is relatively young. A previous study demonstrated that both too young (age 0-10 years) and too old (age older than 81 years) populations are underrepresented in an internet-based monitoring survey [34]. A better coverage of the general population with high representativeness generally requires a more complicated study design together with robust supports from an official institution [8]. The questionnaire can also be distributed through other web platforms such as Sina Weibo (the most popular microblogging website in China) and news media (NetEase and Xinhua), which have a wider reach of respondents in China. Furthermore, this study does not include a follow-up for individual patients. This choice was made to respect the respondents' privacy. However, in future studies it may be acceptable to allot an individual code to each individual, thereby allowing follow-ups; although, systematic follow-ups will remain a problem with internet questionnaires. Follow-ups may be further compromised by the lack of internet access when the individual is hospitalized.

Unlike hospitals, which diagnose COVID-19 using a comprehensive set of laboratory and imaging examinations, we did not include diagnostic tests such as real time polymerase chain reaction or lung computed tomography results in our questionnaire. Therefore, evaluating the respondents' risk of viral infection from the history of contact, body temperature, symptoms, and comorbidities may have the risk of underestimating some patients who are asymptomatic or presymptomatic, which are not uncommon [35,36].

Based on this study, we have updated our fourth version of the Chinese questionnaire [37] and released the English questionnaire [38] (also see Multimedia Appendices 1 and 2 for Word format files). Both questionnaires follow the Attribution 4.0 International license, meaning that they are free to be shared and adapted under the condition that this work has been properly cited. Considering privacy purposes, the survey data of this study can be obtained from the corresponding author at request.

Conclusions

This study shows that an online questionnaire may help monitor current prevalence, evaluate government policy, and identify high-risk populations during the COVID-19 outbreak. The online questionnaire approach can also be adapted to monitor other types of infectious diseases depending on areas of interest.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Coronavirus Infection Risk Self-Assessment Questionnaire (CIRSAQ 4.0).
[DOCX File , 13 KB - publichealth_v6i2e18576_app1.docx]

Multimedia Appendix 2
Coronavirus Infection Risk Self-Assessment Questionnaire (CIRSAQ 4.0) - Chinese Simplified.
[DOCX File , 14 KB - publichealth_v6i2e18576_app2.docx]

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Abbreviations

COVID-19: coronavirus disease
RR: risk ratio

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Tutorial

A Guide to Chatbots for COVID-19 Screening at Pediatric Health Care Facilities

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Abstract

The coronavirus disease 2019 (COVID-19) outbreak has required institutions to rapidly adapt to changing public health circumstances. The Centers for Disease Control and Prevention has encouraged health care facilities to explore novel health care delivery modes. However, many institutions may not be prepared to begin offering digital health and telehealth services. Chatbots are one digital health tool that can help evolve triage and screening processes in a scalable manner. Here, we present a decision-making and implementation framework for deploying COVID-19 screening chatbots at pediatric health care facilities.

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KEYWORDS

chatbots; COVID-19: pediatrics; digital health; screening

Introduction

The International Health Regulations Emergency Committee of the World Health Organization (WHO) declared that the outbreak of novel coronavirus SARS - CoV-2 (coronavirus disease 2019 or COVID-19) was a "public health emergency of international concern," on January 30, 2020 [1]. Within 6 weeks, on March 11th, the WHO declared COVID-19 a global pandemic, defined as the worldwide spread of a new disease to which most people are susceptible [2,3]. In the United States, the number of cases has rapidly grown; there are more cases here than in any other country in the world [4,5].

The Centers for Disease Control and Prevention (CDC) has created interim guidance for health care facilities to address community transmission of COVID-19 [6]. The role of this guidance is to "reduce morbidity and mortality, minimize disease transmission, protect healthcare personnel, and preserve healthcare system functioning" [6]. These include recommendations around patient screening, working closely with public health agencies, creating contingency plans, monitoring health care workers, and managing ill patients at home when possible. Of note, the CDC recommends shifting health care delivery to remote options, such as phone management and telehealth. Given that approximately 80% of affected patients have mild symptoms, remote management can provide adequate care, though careful triage and frequent monitoring will be necessary [7]. Adoption of telehealth and digital health strategies has steadily progressed over the past 10 years, but is still not widespread, primarily due to provider/payer issues rather than technical ones [8,9]. Adopting the CDC recommendations may be difficult for institutions that do not have the innovation or information technology (IT) infrastructure necessary to either ramp up or deploy new services like telehealth. As such, it is important to triage patients appropriately so as not to overload newer programs.

One useful tool for patient triage are chatbots. Chatbots are applications that provide information or services through conversation-like interactions with users [10]. The underlying infrastructure can range from true artificial intelligence with natural language processing to simple conditional logic schemes with predetermined answers, similar to an online survey or quiz. Chatbots have become ubiquitous in retail and customer service

but have only recently started expanding into health care [11]. Despite being relatively new, chatbots have already been adapted for a broad range of purposes in health care, including patient triage, clinical decision support for provider, directing patients and staff to appropriate resources, and even mental health applications, such as cognitive behavioral therapy and suicide interventions [12,13]. At least one review of the literature found that there is evidence that chatbots are both clinically effective and cost-effective [14].

Because chatbots can be deployed across email, web, social media, and text, they are an ideal tool to reach a large number of people in a short period of time. For COVID-19 and other infectious disease outbreaks, chatbots can screen patients, provide education, and triage patients to the right health care option (in-person appointment, telephone triage, telehealth appointment). One example of this is Providence Health, which deployed a COVID-19 chatbot built on a Microsoft platform to help triage patients to their telehealth services [15]. Here, we present a practical framework to help pediatric institutions think through the decision to leverage chatbot screening tools during the COVID-19 outbreak.

Pediatric-Specific Considerations

Pediatric institutions face unique challenges during this pandemic. While children seem to be less likely to be infected and have milder symptoms, they are in most circumstances living with adults who may have very different exposures and medical risk factors than the child in question [7,16,17]. Moreover, when pediatric patients seek medical care, they are typically accompanied by an adult. As such, screening for signs, risk factors, and symptoms needs to address both the child and adults with whom the child is in close contact. It should be noted that the decreased severity of COVID-19 in pediatric patients is not uniform; very young infants and children with medical complexity are at increased risk, and as these groups are more likely to seek out care at pediatric institutions, appropriate precautions should still be taken [18,19].

Reducing crowd density and social distancing can be difficult at pediatric institutions. Children can be anywhere along the neurodevelopmental spectrum, age appropriate or delayed, and may struggle with key concepts like social distancing. Children are almost always accompanied by at least one adult, and it is not uncommon for one patient to be accompanied by two parents and siblings, and even grandparents. Chatbots can help address this by directing patients to the appropriate care modality early on and providing families with information relevant to their in-person appointments, such as visitor restrictions.

Finally, there is the issue of consent and access to medical care for children under the age of 18 years. In the United States, access to and consent for care without a parent or guardian varies from state to state. If the chatbot is widely accessible, institutions should develop protocols in collaboration with their legal and compliance teams to respond to chatbot users under the age of 18 years who either reach out for care or who screen as being high-risk.

A Decision-Making Framework

Though it may seem daunting at first, deploying a health care screening chatbot can be a relatively fast process if key decisions can be clearly articulated along the way:

- Define the goal of your chatbot
- Identify the tools available for your chatbot to achieve its goal
- Choose a screening approach
- Access and distribution
- Buy versus build

Define the Goal of Your Chatbot

For rapid deployment, such as during the current pandemic, chatbots work best when they have a simple and singular goal targeted for a specific user. This should be defined in one sentence (eg, “provide screening and education to the general public,” “educate and guide campus visitors on our current visitor restrictions,” or “triage existing patients to the right resources.”). All other decisions around technical infrastructure, workflows, and language choice will be guided from the driving purpose of the chatbot and the intended user.

Identify the Tools Available for Your Chatbot to Achieve Its Goal

After screening, the chatbot will offer the user something based on their screening results (ie, information, a phone number to call, a call back, etc). These are the tools the chatbot uses to achieve its goal. Institutions should clearly define what the chatbot can and cannot offer. The possible options can be thought of in three categories:

1. The chatbot can provide information that the user can act on, either in the chat window or by directing the user to other resources (user-initiated). If the goal is to provide general information, the educational materials should be sourced from reputable sources like the CDC and other public health agencies. If the goal of the chatbot is to connect patients to specific resources, this can be done by providing the user a phone number, email, web address, etc, to reach out to request that service.
2. The chatbot can hand the user off to a human agent who can take a specific action (provider-initiated). This can be done in real time, by transitioning the conversation to a staff member, or by collecting contact information from the user, and then having staff members call the user back at a later time.
3. The chatbot can trigger an action in another software or system, such as appointment scheduling or medication refills (system-initiated). This can be the most technically challenging option and is likely not well suited for rapid deployment in a crisis situation.

User-initiated solutions are easier and faster to implement, can usually be incorporated into existing workflows, and have fewer data governance, legal, and compliance issues since there is no need to exchange Protected Health Information (PHI)/Personally Identifiable Information (PII). However, this type of solution may lead to situations in which a high-risk person still walks

into a health care facility because they did not or could not follow through with the recommendations. Provider-initiated solutions allow providers to "close the loop" and can feel more personal. They ensure that facilities can be more proactive in properly addressing high-risk patients, but they require new workflows (and therefore additional staff, or additional work for existing staff), are typically more costly, and carry additional legal and compliance considerations. Finally, this decision can help inform whether you should deploy your chatbot inside or outside your institution's secure IT infrastructure.

Choose a Screening Approach

The majority of chatbot interactions are a series of question-response dyads, with the user either free typing a response or choosing one from preselected options. Your chatbot should include a standard legal disclaimer and eligibility verification ("Are you a patient of…" or "What state/county/city do you live in?"), if relevant to the goal of the chatbot. In terms of screening for COVID-19, it is critical that institutions use the most up-to-date recommendations from trusted public agencies like the CDC. COVID-19 screening can be broken down into exposure risks, symptoms, comorbidities, and other risk factors (Table 1). Additional questions may be appropriate for your particular situation and what the follow-up to the chatbot interactions is meant to be. Institutions should be prepared to update all questions frequently as the situation develops and new criteria become relevant.

Table 1. Chatbot question structure.

Category	Sample question(s)	Notes
Disclaimer	• "If you are experiencing an emergency…" • Terms of use • Privacy policy	• Consult with your legal and compliance team on exact language/wording
Eligibility	• Are you a patient of ____? • Do you live in (city/county/state)? • Do you have an upcoming appointment?	• Eligibility criteria depend on institutional policy and preference
Exposures	• Have you recently travelled to (list of countries)? • Have you been in contact with someone who has travelled to these countries and is now sick? • Have you been in contact with someone known to have coronavirus (COVID-19)? • Have you been told by a public health official that you may have been exposed to coronavirus (COVID-19)?	• Follow recommendations of the CDC[a] and public health agencies, and update frequently • Include language to address children and their adult close contacts
Symptoms	• Are you experiencing any of the following symptoms?	• Follow recommendations of the CDC and public health agencies, and update frequently
Risk factors	• Do you have any of the following health conditions?	• Follow recommendations of the CDC and public health agencies, and update frequently
Follow-up	• Do you have access to…? • Are you interested in having a telehealth visit? • Please provide a call back number/email.	• These questions are dependent on your institution's follow-up plan for chatbot interactions

[a]CDC: Centers for Disease Control and Prevention.

Access and Distribution

Chatbots are capable of interacting with users in a variety of ways. They can be deployed natively in social media platforms, via text messages, email, and embedded in a web page. Native deployment creates a smoother user experience but requires more work and can be more costly. Deploying the chatbot on the web and redirecting users via links distributed through multiple channels (social media, email, text messages) can be more cost-effective and simpler to manage. You should make this decision based on how you will reach as many of your intended users as possible. You can consider the current utilization rates of various communication services you already offer patients and families to help make this decision. For example, if you have very few patients enrolled in your portal, then that is unlikely to be a good deployment strategy. However, if you use text reminders for appointments and families frequently reply back to confirm, then text message may be a better choice.

Buy Versus Build

For institutions with the right technical expertise, there are several frameworks that can be used to build your own chatbot, at little or no cost. For others, several companies provide low-cost chatbot services that include design, implementation, maintenance, and data reporting. Very importantly, note that if your chatbot collects PHI/PII or is integrated into a hospital information system, it will typically require legal and compliance review, along with information security assessment and (likely) a business associate's agreement (BAA). A BAA is a contract between a covered entity (a health care provider) and a third party that accesses PHI in order to perform a service for the covered entity and is required to be in compliance with the Health Insurance Portability and Accountability Act

(HIPAA) [20]. If your institution has an existing BAA with an information services company like Microsoft, Amazon, or Google, then leveraging their chatbot services may be the most expedient way to deploy a solution.

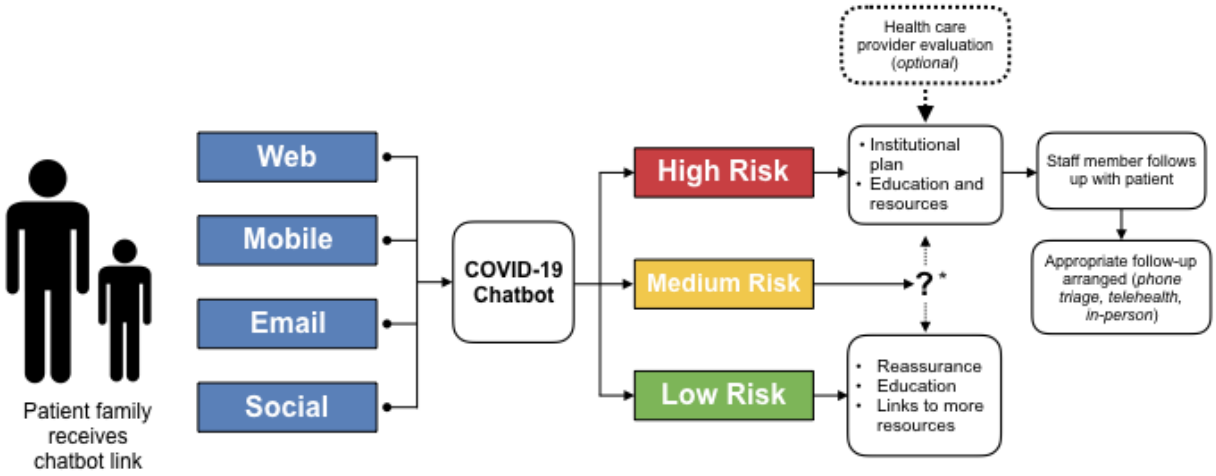
Implementation

After completing the decision-making exercise described in the previous section, the next phase of chatbot deployment is implementation. We recommended using a human-centered design approach and starting with your user experience and journey [21,22]. Technology experiences designed with the user in mind are more likely to be engaging and effective.

Map the User Experience and Workflows

Implementation is the make-or-break of any digital health project, and chatbots are no different. A valuable exercise is to make process maps and storyboard the experience for both the users and the providers that will interact with the chatbot. This is equally effective in low fidelity (eg, post-it notes, whiteboards) and high fidelity (eg, slide decks, animations) formats. A sample process map can be seen in Figure 1. In this example, the family might receive a link to the chatbot through the web, text, email, or social media, and then engage with the chatbot. The chatbot would administer the screening questions and then triage the patient into a risk category, each with a specific set of actions.

Figure 1. Sample chatbot process map. *: Institutional discretion, follow public health agency guidelines.



Chatbot Architecture

Once you have defined your ideal user experience, you can begin to explore how that chatbot integrates into your IT ecosystem. The exact specifications will be highly dependent on the decisions you made regarding goals, users, actions, and workflows. For example, a chatbot that provides users with informational resources based on their risk stratification, but does not collect any PHI/PII, may not require any data storage or tracking and could be run completely from a cloud-based web service. On the other hand, if you will be collecting PHI/PII, or connecting users to other secure hospital information systems like a patient portal, you will require a secure, HIPAA-compliant environment. Figures 2 and 3 provide two network diagram examples of how this might be set up in your local environment. In Figure 2, we see a straightforward, patient-initiated approach, where the patient interacts with a web-hosted bot that provides the patient with information that they can act on, such as calling a hotline for an appointment or logging into a telehealth portal. By contrast, the chatbot in Figure 3 is located in a secure environment (in this case, behind an institutional firewall), enabling it to collect PHI/PII and integrate into other institutional applications. Staff members can act on the collected data, while the patient is provided with appropriate education and resources.

Figure 2. A chatbot network diagram: patient-initiated approach. This diagram illustrates a generic architecture and workflow for a simple chatbot that is hosted outside the institution's secure computing environment. 1) Patient uses a personal device to access the institution's website from a link they receive in a text, email, or secure message. 2) The chatbot interacts with the patient and stratifies them according to the screening algorithm. 3) The chatbot provides the patient with education, resources, tips, and specific instructions on next steps. 4) The patient reaches out to the hospital via phone or telehealth as instructed by the chatbot. Integration with hospital systems is possible for data collection and workflow management, but not required.

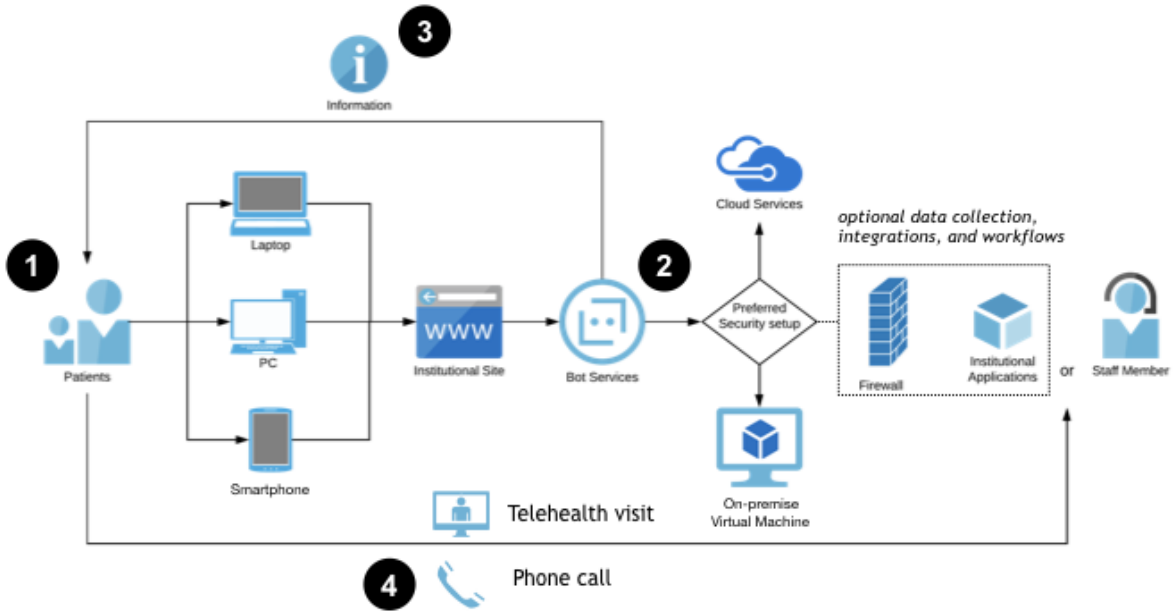
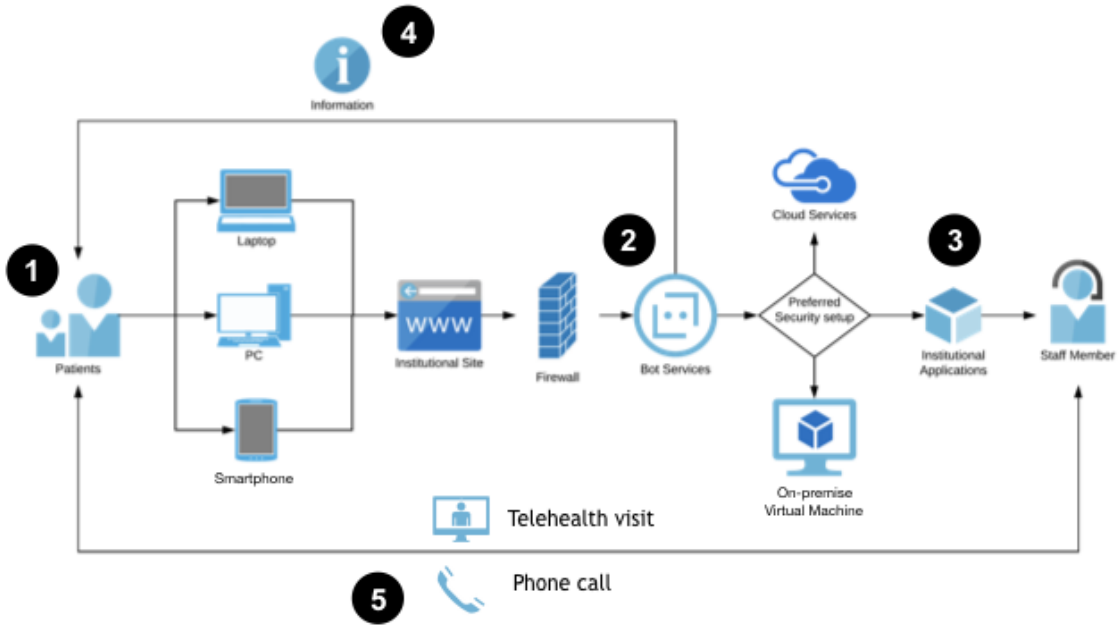


Figure 3. A chatbot network diagram: provider-initiated approach. This diagram illustrates a generic architecture and workflow for a chatbot that is hosted within the institution's secure computing environment. 1) The patient uses a personal device to access the institution's website from a link they receive in a text, email, or secure message. 2) The chatbot interacts with the patient and stratifies them according to the screening algorithm. 3) The chatbot collects data and integrates with institutional workflows, including additional clinical screening and scheduling. 4) The chatbot provides the patient with education, resources, tips, and specific instructions on next steps. 5) Staff members reach out to patients to schedule appropriate follow-up; patients are also able to reach out with further questions or requests.



Chatbot Data

Chatbots generate a significant amount of data and metadata, including user volumes, timestamps, length of conversations, user responses, and link tracking. Your institution will need to decide which data, if any, you are interested in tracking and analyzing. It may be worthwhile to collect chatbot data even if no PII/PHI is being tracked; modern informatics techniques have been used to track the spread of infectious diseases by analyzing social media posts as well as search engine queries; chatbot interactions might also be a useful source of public health data [23,24].

Testing Your Chatbot

User testing is critical prior to launch. Identify a small group of individuals who will spend time trying to "break" the tool. The goal of user testing is to discover everything that is wrong with the product you built. Your users should be looking for problems in the text, nonsequiturs in the workflow, broken links, bad phone numbers, typos, etc. This is also an opportunity to verify that your database is collecting information in the way it was designed. Once you have completed several iterative rounds of testing, you are ready for deployment to patients.

Conclusions

Chatbots are a low-cost tool that can be deployed rapidly to screen large numbers of patients before they go to a health care facility. However, there are several variables that require careful consideration. With the right design, they can provide users with appropriate education and information, and triage patients to alternative health care delivery models like telephone triage and telehealth appointments. As institutions become more familiar with these tools, they can be repurposed in the future for other public health emergencies, as well as for more standard care uses. We hope that this framework for decision making and implementation is helpful to others; our Innovation Studio team is available to support any institution considering deploying similar tools.

Conflicts of Interest

None declared.

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Abbreviations

BAA: business associate's agreement
CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease 2019
HIPAA: Health Insurance Portability and Accountability Act
IT: information technology
PHI: Protected Health Information
PII: Personally Identifiable Information
WHO: World Health Organization

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Viewpoint

Turning the Crisis Into an Opportunity: Digital Health Strategies Deployed During the COVID-19 Outbreak

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Abstract

Digital health technologies offer significant opportunities to reshape current health care systems. From the adoption of electronic medical records to mobile health apps and other disruptive technologies, digital health solutions have promised a better quality of care at a more sustainable cost. However, the widescale adoption of these solutions is lagging behind. The most adverse scenarios often provide an opportunity to develop and test the capacity of digital health technologies to increase the efficiency of health care systems. Catalonia (Northeast Spain) is one of the most advanced regions in terms of digital health adoption across Europe. The region has a long tradition of health information exchange in the public health care sector and is currently implementing an ambitious digital health strategy. In this viewpoint, we discuss the crucial role digital health solutions play during the coronavirus disease (COVID-19) pandemic to support public health policies. We also report on the strategies currently deployed at scale during the outbreak in Catalonia.

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KEYWORDS

digital health; eHealth; telemedicine; COVID-19; coronavirus; SARS-CoV-2; public health; policymaking

Introduction

Policymakers increasingly explore, accept, and apply information and communication technology (ICT) as part of health care systems. This shapes the way citizens and patients access and interact with the systems. The pathway to digital health (electronic health or eHealth) is a cultural transformation of the traditional construct of health care that encompasses multiple features, including widespread access to electronic health records, remote monitoring solutions, patient portals, wearable technologies, mobile health apps, data analytics, as well as other disruptive technologies [1].

For years, eHealth solutions have raised expectations on the cost savings associated with a reduction in travel to health care facilities and prevention of unplanned admissions due to regular check-ups [2]. In the last decade, the health care ecosystem has remarkably progressed in this direction; however, the multilevel complexity of eHealth implementation [3] is holding back the widespread use of ICT in routine practice [4].

With roughly 7.5 million inhabitants, Catalonia (Northeast Spain) has been considered a forerunner of eHealth adoption in Europe. Since 2009, a robust information exchange deployment has allowed health care providers within the public health system to share clinical information [5-7]. Currently, the region is implementing a comprehensive digital strategy—it is just one of the few ambitious initiatives that is transforming health information systems in Europe [7,8].

Worldwide, Spain is one of the most affected countries by the coronavirus disease (COVID-19) outbreak [9]. As of April 30, 2020, confirmed cases and deaths in Catalonia amounted to 54,324 and 5897, respectively. However, mathematical models predict a worsening of this scenario in the forthcoming days, which may lead to the saturation of the health care system due to the lack of intensive care specialists and complete occupation of intensive care unit (ICU) beds [10].

While clinical staff remains at the frontline to protect citizens from the pandemic, nonclinical actors like engineers, bioengineers, data scientists, and other ICT-related professionals are now taking the lead in fighting intensively to slow down the infection rate by deploying digital health solutions. In this context, the deployment of eHealth plays a major role in supporting public health policy [11,12].

The objective of this viewpoint is to present the eHealth strategies adopted by the Catalonian Department of Health and the Catalan Health Service. These strategies aimed to avoid nonessential patient contact with the health care system and to improve control and diagnosis of COVID-19 (see Figure 1 for a detailed timeline). We report on the different strategies, the main objectives they are targeting, and the impact on stakeholders (Table 1).

Figure 1. Timeline of the digital health strategies deployed in Catalonia since the onset of the coronavirus disease (COVID-19) outbreak. eHealth: electronic health; GP: general practitioner.

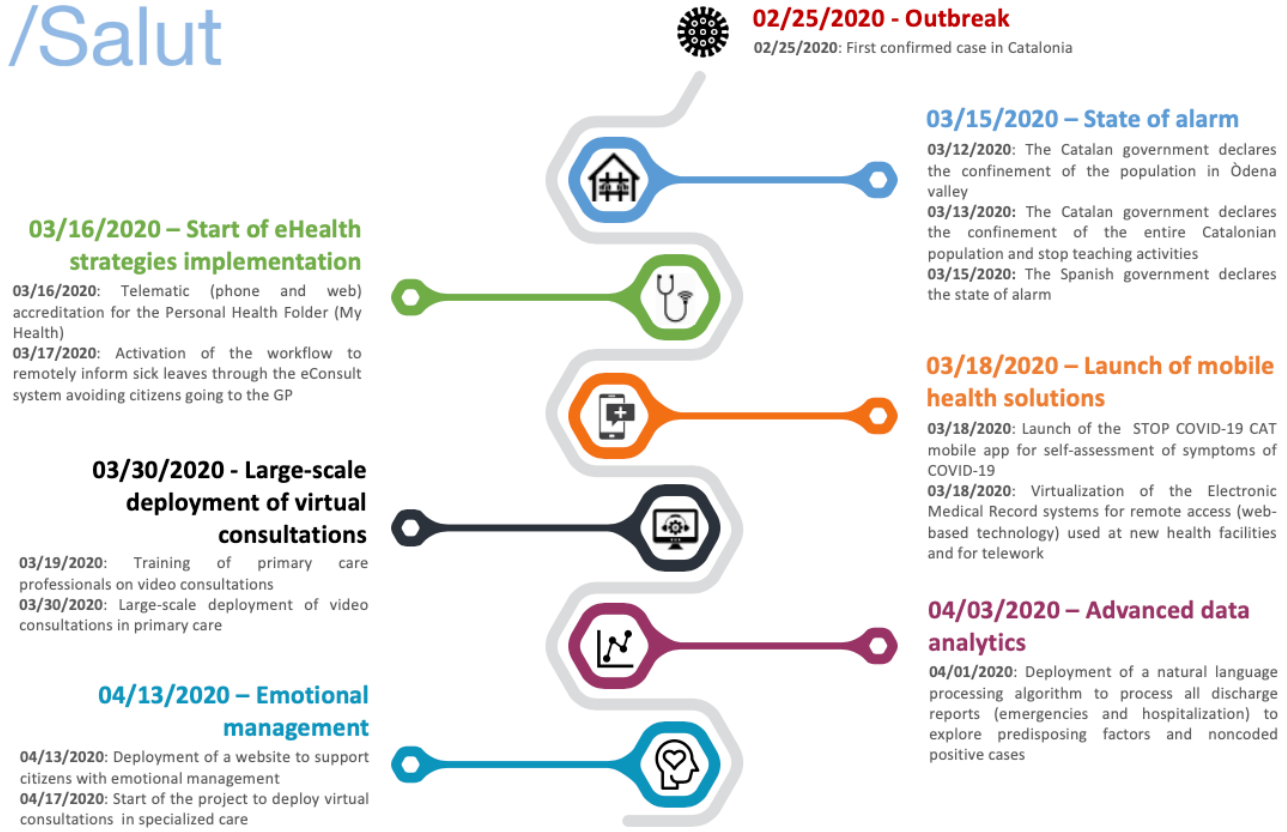

Table 1. List of digital health strategies implemented during the coronavirus disease (COVID-19) outbreak in Catalonia.

Strategy	Aims and expected benefits	Impact on stakeholders
1. Facilitation of citizens' registration on the Catalan Personal Health Folder ("My Health") [13] by creating a specific call center and enabling a webform for self-registration	• Establish a formal and secure communication channel between the citizen and the health care professional • Decrease nonessential visits to health centers by citizens • Reduce infection risk for both citizens and health care professionals	• Citizens: burden of getting used to a new communication channel; reduction in face-to-face visits • Health care providers: change of care delivery model (ie, organizational and technical workflows); training of clinical staff; change management (ie, attitudes of reluctant professionals) • Policymakers: new appointment management system; cybersecurity management; guaranteeing equity on access
2. Expansion of the virtual visits system ("eConsult") [14] by allowing the physician to appoint a videoconferencing session with the patient directly from the patient's EMR[a] in both primary and specialized care	• Establish a synchronous and asynchronous communication channel between the citizen and the health care professional • Decrease nonessential visits to health centers by citizens • Reduce the infection risk for both citizens and health care professionals • Avoid increases in waiting lists • Ensure care continuity • Avoid increase in stress in health care professionals due to not being able to attend to their patients	• Citizens: burden of getting used to a new communication channel; reduction in face-to-face visits • Health care providers: change of care delivery model (including organizational and change management); training of clinical staff; adaptation to new technologies (ie, integration with new platforms and acquisition of new hardware such as webcams and headphones) • Policymakers: development of new technologies and design of new financing models (ie, recognition of virtual visits as a billable service)
3. Development of a mobile health app for self-assessment of the disease (STOP COVID19 CAT) [15], which includes geolocation of patients	• Create a heat map of the most affected areas • Stratify patients and proactively contact high-risk individuals (Emergency Services of Catalonia) • Substitute for the lack of COVID-19 tests	• Citizens: burden of getting used to a new technological channel • Policymakers: development of new technologies; definition of new service models; facilitate the acceptance and motivation of citizens for using the mobile health app
4. Enabling of web access to EMRs throughout virtualization technologies	• Ensure that health care professionals who are working in external consultations can continue their work from home (telework) during the lockdown period • Ensure a smooth deployment of EMRs in emergency facilities (eg, hotels and pavilions) • Avoid increases in waiting lists • Ensure care continuity	• Health care providers: change of care delivery model (including organizational and change management); training of clinical staff; adaptation to new technologies • Policymakers: development of new technologies; deployment at scale throughout the region (including multiple organizations such as hotels and City Councils)
5. Reduction of bureaucratic barriers in health care processes by (a) allowing patients to access their sick leave forms in their personal health folder ("My Health"); (b) allowing pharmacies to access medication plans through the electronic prescription system of Catalonia in order to reduce the burden of citizens and primary care centers; (c) automatically extending chronic medication plans (eg, oral anticoagulant therapy)	• Decrease nonessential visits to health centers by citizens • Reduce the infection risk for both citizens and health care professionals	• Citizens: burden of getting used to a new communication channel; reduction in face-to-face visits • Policymakers: development of new technologies and organizational workflows within the health care ecosystem (ie, pharmacies)
6. Reporting of the day-to-day status of patients in nursing homes (private and public) through web service technology	• Ensure the availability of near real-time data to make informed decisions • Identify nursing homes with a high concentration of COVID-19 diagnosed patients • Ensure accurate planning of actions and allocation of resources (ie, new ICU[b] beds and isolation facilities)	• Health care providers: development of new technologies (ie, integration with the National Health Service system) • Policymakers: development of new technologies and organizational workflows within the health care ecosystem (ie, nursing homes)

Strategy	Aims and expected benefits	Impact on stakeholders
7. Use of data analysis techniques to: (a) predict the necessary number of ICU beds to prevent overburdening the health care system (using predictive modeling techniques); (b) automatically analyze emergency and hospitalization reports to explore predisposing factors and noncoded positive cases (using natural language processing techniques)	• Avoid the collapse of the health system due to a lack of hospitalization and ICU beds • Ensure accurate planning of actions and allocation of resources • Enable research to advance the knowledge of the disease	• Policymakers: development of new technologies; incorporation of new professional roles (ie, data scientists)
8. Management of the emotional status of citizens by deploying a web portal ("Emotional Management") [16]	• Ensure a stable emotional status of the population • Provide a tool for self-evaluation in order to identify risk cases and proactively contact the at-risk individuals • Provide a trusted source of information resources • Provide the contact information of professional (emergency) services lines	• Policymakers: development of new technologies and organizational workflows within the health care ecosystem (ie, professional psychology services)

[a]EMR: electronic medical record.

[b]ICU: intensive care unit.

Preliminary results related to the implementation of the abovementioned strategies show a strong paradigm shift from face-to-face visits to virtual consultations in primary care. Figure 2 shows how face-to-face visits have reduced drastically since the start of the Catalonian lockdown on March 16, 2020. Face-to-face visits have been systematically replaced by both tele-consultations and eConsultations (electronic consultations), which present a sustained growth over the observed period.

Adoption of digital health technologies can also be observed in the increased number of visits to and new registrations on the Catalan Personal Health Folder. Table 2 shows the development of metrics between April 2019 and April 2020 (up to April 20, 2020). In March and April 2020, the records clearly exceed the annual average.

Even though Spain and Catalonia have now passed the peak of the COVID-19 outbreak at the time of writing [17], we continue to observe an increase in the adoption of the digital health solutions deployed by the Catalonian health care system. The present context indicates a continuation of the implementation processes. In fact, the current situation is unprecedented; many adoption barriers have disappeared while at the same time health care providers and professionals are demanding more and more technologies.

The COVID-19 pandemic has prompted a sudden turning point in the adoption of eHealth strategies in Catalonia. We expect that the changes we achieved over the last few weeks will be sustained even after the pandemic is over.

Figure 2. Primary care visits compared to other care delivery methods in Catalonia for the period March 01, 2020, and April 19, 2020.

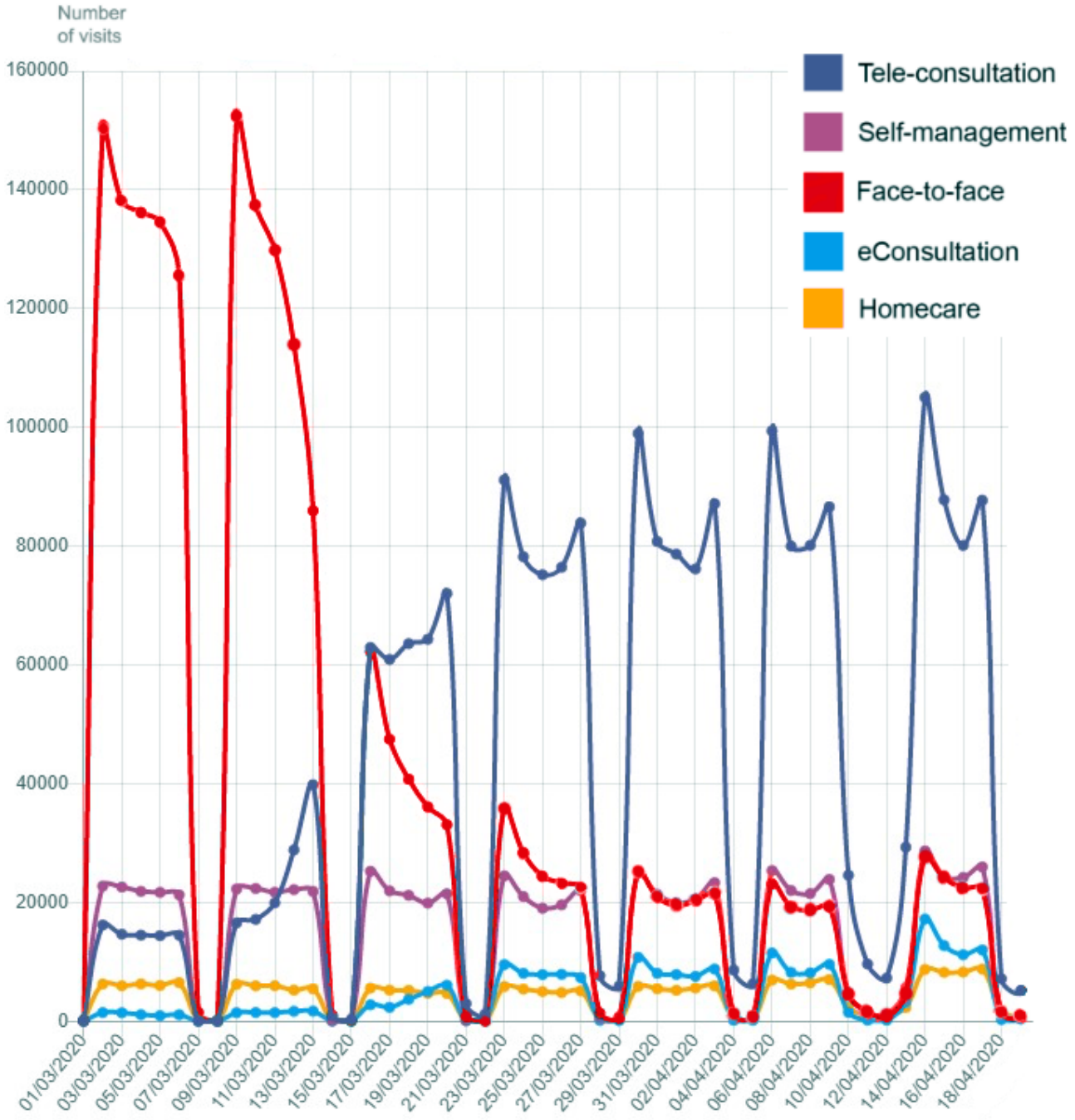

Table 2. Number of users who accessed the Catalan Personal Health Folder and new registrations for the period April 2019 to April 2020 (up to April 20, 2020).

Date	Users who accessed the Catalan Personal Health Folder, n	New users, n
April 2019	280,001	17,026
May 2019	323,035	20,400
June 2019	293,691	15,798
July 2019	319,622	18,002
August 2019	292,248	12,475
September 2019	303,754	16,547
October 2019	376,081	21,699
November 2019	353,523	20,220
December 2019	319,021	16,022
January 2020	384,290	19,434
February 2020	390,836	21,397
March 2020	649,992	52,698
April 2020	488,207	48,862

Lessons Learned and Next Steps

Below, we provide a list of lessons learned in the context of COVID-19 and future steps that should be taken:

1. The high pressure on the health care system in a situation of extreme crisis has been an outstanding driver of change. We analyzed the scenario to facilitate the adoption of eHealth technologies within our health system.
2. A long-term digital health strategy has proven to be the foundation for the accelerated change process. A good example of this is the unique EMR system we use in our primary health care system, which fostered the rollout of innovations faster than within a fragmented EMR ecosystem.
3. Having a very strong community and primary health care system has allowed us to implement different ICT strategies quickly by taking advantage of close interactions with the population.
4. ICT tools have been shown to be the main driver for decreasing health-related bureaucratic processes. This has allowed us to save professional staff time while avoiding nonessential visits by citizens to health centers and decreasing infection risks for both citizens and health care professionals.
5. No complaints against this comprehensive ICT deployment strategy have been received or noticed from health providers or citizens.
6. The deployment of ICT-enabled solutions should be accompanied by financial incentives for health providers in order to remove the financial barriers of adoption. Payment systems should adapt to facilitate easier ICT adoption.
7. Closer collaboration between health and social care services will be required in the future. The pandemic outbreak has shown us that coordination between both areas (ie, nursing homes and residential care) could be greatly improved by a stronger deployment of ICT (ie, access to primary care EMRs and/or deployment of telemonitoring solutions for residents).
8. We foresee many opportunities to further develop the virtual care model with more complex use case scenarios (ie, complex chronic needs). Current acceptance and need of ICT-enabled solutions has opened a window to further deploy the model in a system that has traditionally preferred face-to-face contact.
9. The ICT implementation may have avoided overcrowded health centers and, in consequence, lower infection and death rates. We need to further explore the impact of these deployments.
10. It is of outmost importance to assess how sustainable the adoption of the implemented digital health solutions on a long-term basis will be. We will continue monitoring the different implementation processes in order to assess use over time.

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Authors' Contributions

JP-J wrote the first draft of the paper. JP-J, PPS, AC, CVM, JSR, RRM, OS, PR, JCF, JG, MMP, and LGE revised the subsequent drafts critically for important intellectual content. All coauthors approved the final version of the manuscript. All authors agree to be accountable for all aspects of the work and for ensuring integrity and accuracy.

Conflicts of Interest

All authors are public servants involved in the deployment of the digital health strategies mentioned in this paper.

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Abbreviations

COVID-19: coronavirus disease
eConsultation: electronic consultation
eHealth: electronic health
EMR: electronic medical record
ICT: information and communication technology
ICU: intensive care unit

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Original Paper

COVID-19-Related Web Search Behaviors and Infodemic Attitudes in Italy: Infodemiological Study

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Abstract

Background: Since the beginning of the novel coronavirus disease (COVID-19) outbreak, fake news and misleading information have circulated worldwide, which can profoundly affect public health communication.

Objective: We investigated online search behavior related to the COVID-19 outbreak and the attitudes of "infodemic monikers" (ie, erroneous information that gives rise to interpretative mistakes, fake news, episodes of racism, etc) circulating in Italy.

Methods: By using Google Trends to explore the internet search activity related to COVID-19 from January to March 2020, article titles from the most read newspapers and government websites were mined to investigate the attitudes of infodemic monikers circulating across various regions and cities in Italy. Search volume values and average peak comparison (APC) values were used to analyze the results.

Results: Keywords such as "novel coronavirus," "China coronavirus," "COVID-19," "2019-nCOV," and "SARS-COV-2" were the top infodemic and scientific COVID-19 terms trending in Italy. The top five searches related to health were "face masks," "amuchina" (disinfectant), "symptoms of the novel coronavirus," "health bulletin," and "vaccines for coronavirus." The regions of Umbria and Basilicata recorded a high number of infodemic monikers (APC weighted total >140). Misinformation was widely circulated in the Campania region, and racism-related information was widespread in Umbria and Basilicata. These monikers were frequently searched (APC weighted total >100) in more than 10 major cities in Italy, including Rome.

Conclusions: We identified a growing regional and population-level interest in COVID-19 in Italy. The majority of searches were related to amuchina, face masks, health bulletins, and COVID-19 symptoms. Since a large number of infodemic monikers were observed across Italy, we recommend that health agencies use Google Trends to predict human behavior as well as to manage misinformation circulation in Italy.

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KEYWORDS

novel coronavirus, COVID-19, Google search; Google Trends; infodemiology, infodemic monikers, Italy; behavior; public health; communication; digital health; online search

Introduction

The internet is the largest and fastest source to obtain health information, and millions of people seek health information online every day [1]. In the context of the novel coronavirus disease (COVID-19) pandemic, people around the world are forced to stay at home and turn to the internet for work and to stay connected with others. As the COVID-19 outbreak continues, the need to obtain information about the disease, its prevention, and risk communication has become greater for people.

"Infodemiological" methods, such as an online search of traffic on Google, are widely used to understand the searching behaviors of the public during an epidemic, as well as for public health surveillance purposes [2-7]. Several online sources, such as Facebook, Twitter, and electronic health records, have wide application in infodemiological studies [8-10]. Indeed, the Google Trends tool provides both real-time and achieved information on trends (eg, variations in online interest in selected keywords and topics over time) [11-13]. In particular, Google Trends enables the analysis and forecasting of sensitive health topics such as AIDS, illegal drug use, and metal health [13]. Therefore, trend data generated by Google search volume can offer valuable insights into population behavior and health-related phenomena, particularly during infectious disease outbreaks [7,14-17]. Since the beginning of the COVID-19 outbreak, fake news and misleading information have circulated all over the world, which profoundly affect public health communication and diminish preventive measures [18-21]. In this context, we investigated online search query behavior related to this pandemic and the extent of infodemic monikers circulating in Italy.

Methods

Search Methodology

We used Google Trends to explore internet search activity related to COVID-19 from January 21, 2020, to March 24, 2020. Article titles from the most read national newspapers and government websites were mined to investigate the extent and attitudes of various infodemic monikers related to COVID-19 that were circulating in Italy during the study period. We defined "infodemic monikers" as information that was substantially erroneous, which gave rise to interpretative mistakes, fake news, episodes of racism, or any other form of misleading information circulating on the internet.

Google Trends is an online tool that tracks keyword search queries users input in the Google search engine and determines their popularity and volume. It provides information on the search query according to a specific time period and location. The search volume results are scaled on a range of 0 (very low) to 100 (very high). Google Trends allows for the retrieval of queries for any keyword entered; up to five groups of terms can be compared at one time to explore the online interest in each term. By using this technique, we retrieved data from Google Trends using the keywords "Coronavirus" and "Coronavirus+" in the English and Italian languages. Each query with these keywords were also researched as the "search term" and "search topic." The "search term" provides the results for all keywords that fall within the category and the "search topic" provides the results of a group of terms that share the same concept in any language.

We used a previously described framework by Mavragani et al [22] for the region selection and time period selection to retrieve query data from Google Trends. First, we searched for the keyword COVID-19 and related terms at the country level to understand overall interest. Second, using this information, we retrieved interest by city and regions across Italy. Each keyword was searched independently between January 21, 2020, and March 24, 2020. The data showing high values were further investigated manually to identify any event linked to the top searches. These queries were also cross-checked with news bulletins. By doing so, we identified the various infodemic monikers circulating across the country.

We reviewed the headlines of newspaper articles and government reports to identify their contribution in spreading infodemic monikers to the public. In order to obtain the search information from these media outlets, we used specific keywords frequently used in news and government report titles to quantify the average information values (AVs) of terms. The AVs were calculated as the number of monikers used in the headlines per 5 days. In order to characterize the obtained infodemic monikers, we categorized infodemic attitudes into 4 groups:

1. Superficial attitude:
   the user adopts words that can generate confusion since they do not uniquely identify the topic (eg, coronavirus).
2. Misinformative attitude:
   the user adopts words that can lead to the spread of fake news (eg, 5G coronavirus).
3. Racist attitude:
   the user adopts words that, voluntarily or not, generate or accentuate episodes of racism (eg, Chinese coronavirus).
4. Definitive attitude:
   the user adopts the most appropriate terms for the correct identification of the query (eg, COVID-19).

Available Data and Materials, Ethical Approval, and Funding

All materials were obtained from anonymous open-source data. Thus, ethical approval was not required. No external funding was provided for this study.

Results

Overview

The top five infodemic and scientific COVID-19 terms trending in Italy, according to inputs in Google search, were "novel coronavirus," "China coronavirus," "COVID-19," "2019-nCOV," and "SARS-COV-2" (Figure 1). From February 20 to March 24, 2020, the keyword that yielded the greatest search value was "coronavirus"; it had a search volume of 59 (SD 9). The other keywords' average peak comparison (APC) values were neglected compared to the latter (Multimedia Appendix 1). The keywords that showed APC<1 are omitted for further investigation. On March 22, 2020, excluding the term "coronavirus" from the cluster, the query related to "novel coronavirus" had the highest value (ie, 100). On the previous day, Italy recorded the highest number of new cases (n=6577), and the government enforced lockdown measures. In contrast, "China coronavirus" was the most commonly used query since the beginning of the COVID-19 outbreak in January 2020. Furthermore, the terms "China coronavirus" (value 38, SD 4), "novel coronavirus" (value 21, SD 6), and "COVID-19" (value 17, SD 3) were the most frequently used queries since February 20, 2020, when Italy become an epicenter of the COVID-19 outbreak.

With respect to public restlessness in Italy, "face masks," "amuchina" (disinfectant) (value 23, SD 6), "symptoms of the novel coronavirus," "health bulletin," and "vaccine for coronavirus" were the top five searches related to health. During the early period of the COVID-19 outbreak, there was a spike in queries regarding symptoms, followed by face masks and disinfectants (Figure 2). In particular, on February 22, 2020, disinfectant-related searches in Italy reached the breakout stage, with a search value of 100. Later, public restlessness appeared to drive an immense increase in queries related to the symptoms of COVID-19. Moreover, on March 11, 2020, there was a tremendous increase in the top five searches related to COVID-19.

We also referred to two widely read Italian newspapers—*Il Sole 24 Ore* and *La Repubblica*—that have been publishing a large number of articles related to COVID-19, as well as government websites, to investigate AVs. We found that most of the Italian public used the keyword "coronavirus" to obtain information in *La Repubblica (*AV 127, SD 50) and *Il Sole 24 Ore* (AV 113, SD 46), while government bulletins were not routinely used (AV 22, SD 9). Detailed information on the keywords used to identify information related to COVID-19 during the pandemic period is shown in Figure 3 and Multimedia Appendix 2.

Our findings indicate that the regions with the most amount of COVID-19 cases were not always the first to circulate key infodemic monikers. For instance, regions such as Umbria and Basilicata had the highest number of infodemic monikers (APC weighted total >140), while the number of cases reported in these regions was limited from January to March 2020 (Figure 4). Furthermore, the presence of these monikers was particularly pronounced (APC weighted total >100) across several cities in Italy, in particular, Pescara and Bologna (Figure 5).

Figure 1. The top infodemic and scientific terms relating to coronavirus disease (COVID-19) trending in Italy.

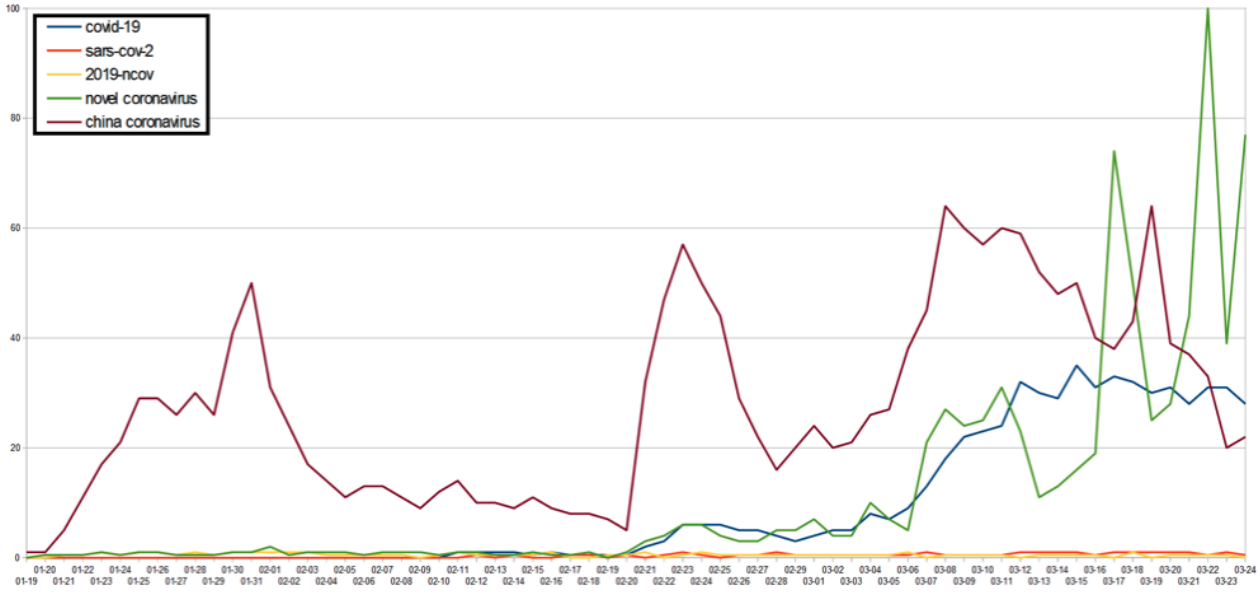


Figure 2. The top five searches related to health.

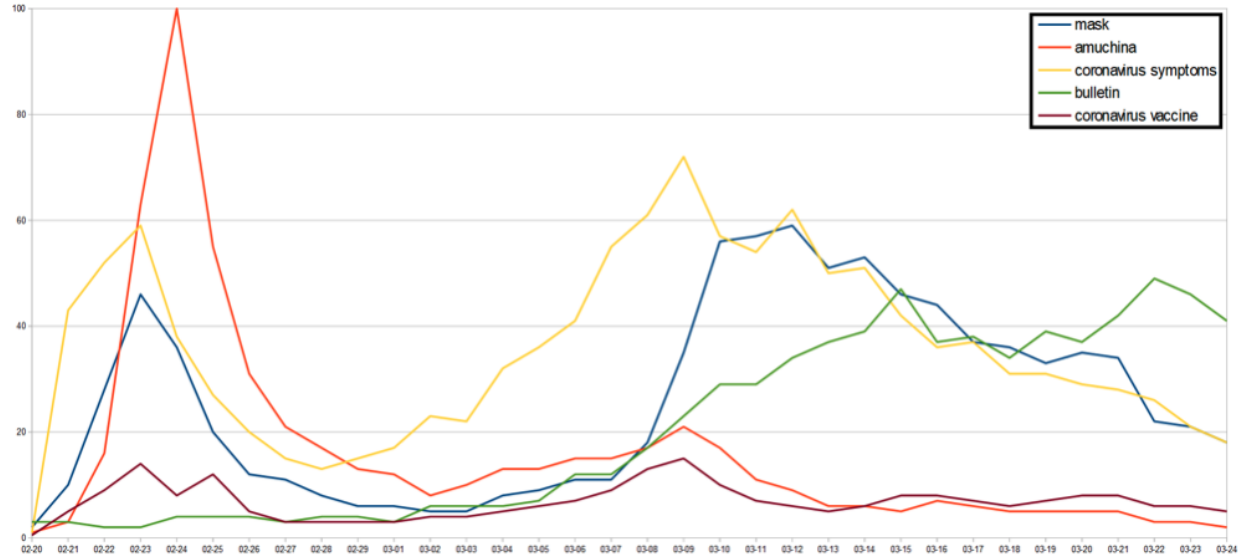


Figure 3. Keywords used to identify information related to coronavirus disease (COVID-19): *Il Sole 24 Ore* (I) and *La Repubblica* (II) newspapers, and government bulletins (III).

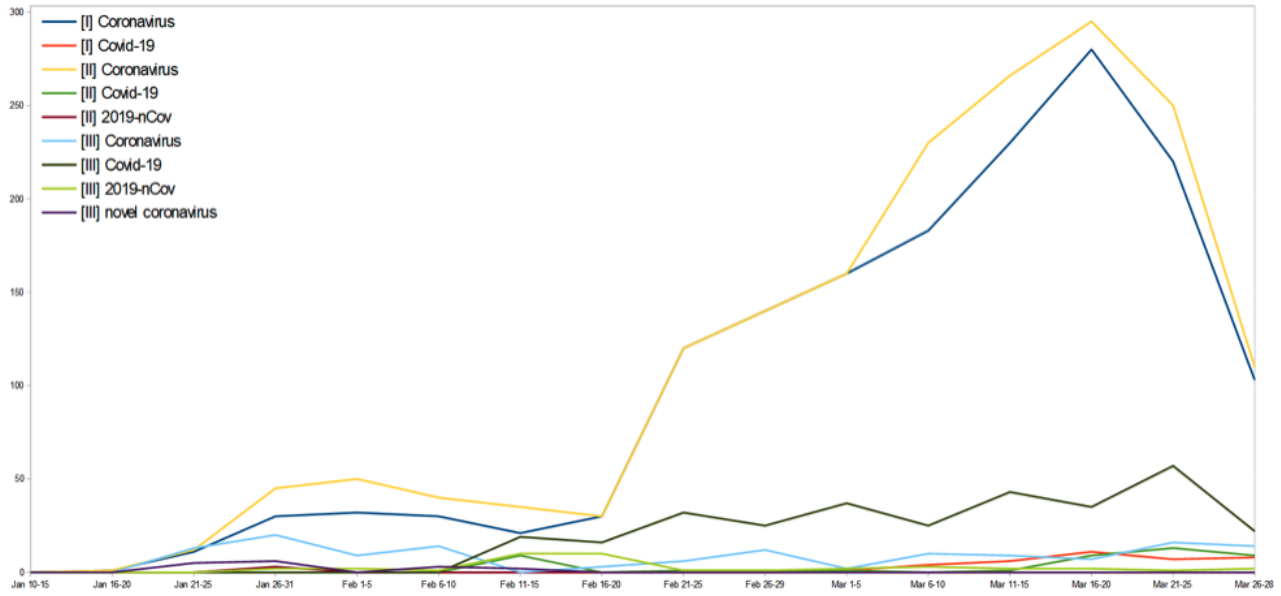


Figure 4. Regional dispersion of infodemic monikers about coronavirus disease (COVID-19) in Italy. APC: average peak comparison.

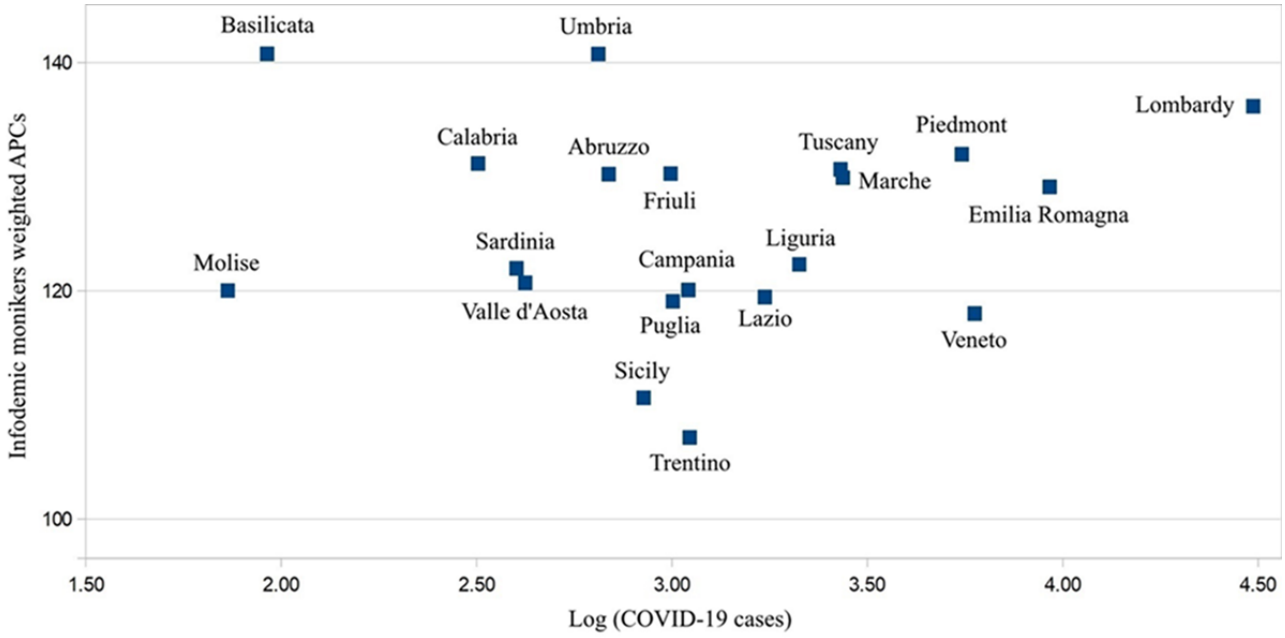
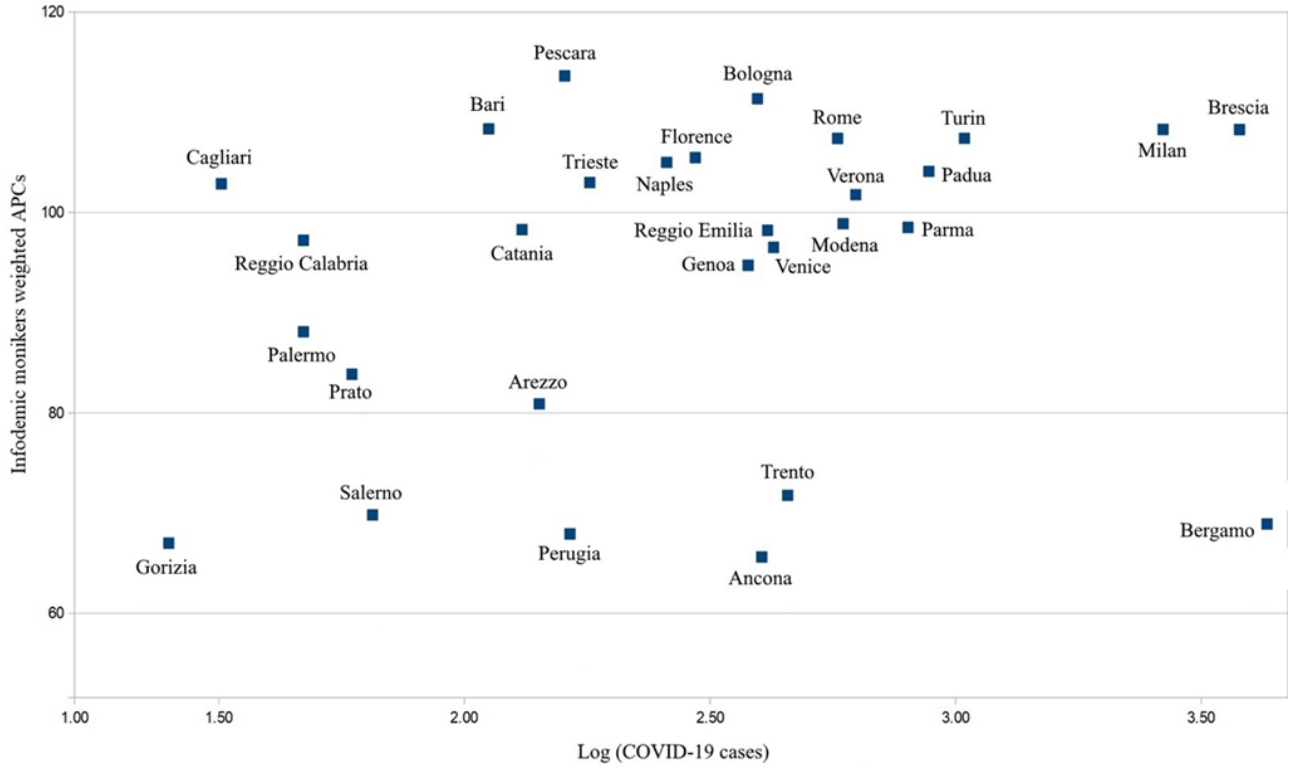


Figure 5. Dispersion of infodemic monikers about coronavirus disease (COVID-19) circulating across various cities in Italy. APC: average peak comparison.



Infodemic Attitudes

The infodemic attitudes of various types of information that circulated across Italy during the study period are presented in Table 1. Most COVID-19-related information that circulated in the regions of Basilicata, Umbria, and Emilia Romagna were found to be superficial and did not provide clearer information on COVID-19. Misinformation was widespread in Umbria and Basilicata. As COVID-19 spread across the world from China, most information related to racism, such as “China coronavirus,” “Chinese virus,” “Chinese coronavirus,” and “Wuhan virus,” were more frequently searched in the Campania and Friuli Venezia Giulia regions.

Table 1. Attitudes of infodemic monikers on coronavirus disease (COVID-19) in circulation across Italy between January 21, 2020, and March 24, 2020.

Region	COVID-19 cases[a], n	Total APC[b] value	APC values of infodemic attitudes (1-100)			
			Superficial	Misinformation	Racial	Definitive
Lombardia	30,703	275	95	68	83	71
Emilia Romagna	9254	296	97	79	89	69
Veneto	5948	256	84	61	82	71
Piemonte	5515	286	96	76	89	75
Marche	2736	279	93	78	88	80
Toscana	2699	293	94	88	89	78
Liguria	2116	270	88	74	90	82
Lazio	1728	269	89	76	79	75
Campania	1101	281	88	75	100	82
Trentino-Alto Adige	1110	228	80	63	57	72
Puglia	1005	268	87	78	87	84
Friuli Venezia Giulia	992	267	94	75	98	100
Sicilia	846	268	81	68	84	65
Abruzzo	689	292	92	84	97	81
Umbria	648	312	97	100	92	77
Valle d'Aosta	400	239	89	70	36	56
Sardegna	421	255	89	64	95	93
Calabria	319	281	91	86	87	83
Basilicata	92	306	100	92	96	82
Molise	73	237	87	84	66	92

[a]Assessed between January 21, 2020, and March 24, 2020.

[b]APC: average peak comparison.

Discussion

Principal Findings

This is the first study to investigate the online search behaviors of the public in the context of the COVID-19 pandemic. We aimed to uncover the extent and the attitudes of infodemic monikers that circulated in Italy during the study period. Previously published studies have investigated Google Trends and Twitter activities related to COVID-19 but were conducted in China [23,24], Taiwan [25], the United States [26], and Spain [27]. In summary, we identified “novel coronavirus,” “China coronavirus,” “COVID-19,” “2019-nCOV,” and “SARS-COV-2” as the top infodemic and scientific COVID-19 terms trending in Italy. “Face masks,” “amuchina,” “symptoms of the novel coronavirus,” “health bulletins,” and “vaccines for coronavirus” were the top five searches related to health. Several infodemic monikers have widespread circulation in major Italian cities. In particularly, misinformation was widely circulated in the Campania region and racism-related information in Umbria and Basilicata.

The current COVID-19 pandemic has threatened global public health and has generated millions of internet searches worldwide. In Italy, ”China coronavirus“ was the most frequently searched term on Google, coinciding with the first incidence of COVID-19 in 2 Chinese tourists, as announced by the Italian Prime Minister Giuseppe Conte at the end of January 2020 [28]. However, the increasing number of cases did not generate a significant number of web searches until the World Health Organization (WHO) declared the COVID-19 outbreak as a pandemic [29], and the Italian government imposed draconian rules to stop the spread in early March 2020 [30]. Notably, queries related to COVID-19 symptoms, disinfectants, masks, and vaccines were relatively high in the fourth week of February 2020, stabilized in 20 values during early March, and quickly increased as the number of cases increased in Italy. This is indicative of peoples’ restlessness with regard to gathering information about necessary personal protection and hygiene practices as COVID-19 cases rose in Italy. Of note, around 40,000 people were charged for violating the lockdown, and the often-mentioned reasons to go out were ”amuchina,“ ”face masks,“ and other casual reasons [31]. These reasons are also reflected in our research and, thus, diminish countermeasures for the outbreak in Italy. To curtail this, the government has initiated a “self-certification” form to declare a valid reason such as work, health reasons, or buying food that necessitates leaving the house.

The findings of our study suggest that web search interest in COVID-19, both at the regional level and in cities in Italy, were influenced by tradition, electronic newspapers, and print media coverage. For instance, people preferred to use the term ”Coronavirus“ more frequently to obtain information in newspapers instead of “COVID-19,” “2019-nCOV,” and “novel coronavirus.” Data from previous research suggest delivering information through Twitter and electronic news outlets frequently focus more on spreading news disproportionately than awareness and educational campaigns [32-34]. These observations have important implications in generating COVID-19-related restlessness in the general public in Italy. Further research is warranted.

Through our investigation, we identified several infodemic monikers of COVID-19 that impinged public communication across various cities in Italy. Misinformation during an outbreak can profoundly affect public health communication and create xenophobia between nations [35-39]. Disseminating fake news and racism across social media has become a widespread practice, and the COVID-19 outbreak is no exception [39,40]. Misinformation and anti-Asian sentiments have increased around the world [39,41,42]. In Italy, several incidences of discrimination and anti-Chinese sentiments were reported [43-45]; however, we believe that the rate of information related to racism that circulated across the country could be the true confounding factor contributing to xenophobia.

The failures of Chinese authorities to handle the virus at an early stage has resulted in the spread of COVID-19 across the world, with new cases arising from ongoing human-to-human transmission as well as from asymptomatic individuals [46]. Additionally, preliminary investigations by the WHO denied the possibility of human-to-human transmission of COVID-19 [47]. We assume that this type of misleading information may have resulted in the instigation of angry online conversations among netizens in Italy. Although we did not delve deeper into the type of potential misinformation that spread across Italy, we believe that dispersing misinformation can create agitation, cause fear, and ultimately diminish preventive measures for the outbreak. Journalists and mass media regulators have an important role in delivering comprehensive information to citizens, as well as taking serious actions on those spreading misinformation.

Limitations

Our study had some limitations to consider. Google Trends captures the search behavior of people who use the Google search engine. Consequently, people using other search engines were not investigated. Also, we relied on the accuracy of data provided by Google Trends and do not have any information about the methods used by Google to generate search data and algorithms.

Conclusion

Using Google Trends, the present study identified that Google search query data reflect a growing regional and population-level interest in COVID-19. Searches related to disinfectants, face masks, health bulletins, and vaccines and symptoms related to COVID-19 were top search keywords. However, a large number (APC weighted total >140) of infodemic monikers have been circulating in Italy. Therefore, health agencies can use Google Trends to predict human behavior as well as tackle the misinformation that is currently circulating in Italy.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The most searched infodemic words for group type.
[DOCX File , 260 KB - publichealth_v6i2e19374_app1.docx]

Multimedia Appendix 2
Keywords used to search the infodemic monikers.
[DOCX File , 13 KB - publichealth_v6i2e19374_app2.docx]

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Abbreviations

APC: average peak comparison
AV: average information value
COVID-19: coronavirus disease
WHO: World Health Organization

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Original Paper

Agile Requirements Engineering and Software Planning for a Digital Health Platform to Engage the Effects of Isolation Caused by Social Distancing: Case Study

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Abstract

Background: Social distancing and shielding measures have been put in place to reduce social interaction and slow the transmission of the coronavirus disease (COVID-19). For older people, self-isolation presents particular challenges for mental health and social relationships. As time progresses, continued social distancing could have a compounding impact on these concerns.

Objective: This project aims to provide a tool for older people and their families and peers to improve their well-being and health during and after regulated social distancing. First, we will evaluate the tool's feasibility, acceptability, and usability to encourage positive nutrition, enhance physical activity, and enable virtual interaction while social distancing. Second, we will be implementing the app to provide an online community to assist families and peer groups in maintaining contact with older people using goal setting. Anonymized data from the app will be aggregated with other real-world data sources to develop a machine learning algorithm to improve the identification of patients with COVID-19 and track for real time use by health systems.

Methods: Development of this project is occurring at the time of publication, and therefore, a case study design was selected to provide a systematic means of capturing software engineering in progress. The app development framework for software design was based on agile methods. The evaluation of the app's feasibility, acceptability and usability shall be conducted using Public Health England's guidance on evaluating digital health products, Bandura's model of health promotion, the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) framework and the Nonadoption, Abandonment and Challenges to the Scale-up, Spread and Suitability (NASSS) framework.

Results: Making use of a pre-existing software framework for health behavior change, a proof of concept was developed, and a multistage app development and deployment for the solution was created. Grant submissions to fund the project and study execution have been sought at the time of publication, and prediscovery iteration of the solution has begun. Ethical approval for a feasibility study design is being sought.

Conclusions: This case study lays the foundations for future app development to combat mental and societal issues arising from social distancing measures. The app will be tested and evaluated in future studies to allow continuous improvement of the app. This novel contribution will provide an evidence-based exemplar for future app development in the space of social isolation and loneliness.

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KEYWORDS

telemedicine; information science; data science; COVID-19; coronavirus; public reporting of healthcare data; health care quality, access and evaluation; aged; mental health; exercise; cellphone; artificial intelligence; agile; requirements engineering; social distancing; digital health; app

Introduction

Background

Social distancing measures have been put in place to reduce social interaction and slow transmission of a recently discovered novel coronavirus disease (COVID-19) [1]. For older people (defined as adults 65 years or older), self-isolation presents particular challenges for physical activity, mental health, and social relationships [2]; continued regulated social distancing could have a compounding impact on these concerns. In this population, physical activity is associated with a greater than 22% reduction in mortality [3]. The implications of social distancing could have unintended adverse mental and physical health outcomes by advancing social isolation, loneliness, and sedentary lifestyles [4].

Preliminary research suggests that the implementation of "lockdown" measures significantly reduces the doubling rate of COVID-19 [5]. As such, governments throughout Europe have implemented various degrees of containment measures to enact social distancing and limit exposure of populations to casual contact to slow the spread of the disease [6]. In Western democracies such as the United Kingdom, governments are finding it challenging to ensure people stay at home during the lockdown and do not exploit the daily exercise and essential shopping rules, especially as the weather starts to improve [6]. Such violations reduce the effectiveness of lockdown measures. There is no practical way of monitoring the status of people with minor symptoms, especially those who are unable to get tested. These patients are not considered in the national statistics and cause the overall patient numbers to be underestimated, making evidence-based policy making unreliable. These circumstances prevent health systems from having accurate information on inbound case numbers, which makes managing case volume challenging and often results in resource overloads.

Preliminary data suggests that the rate of patients requiring hospitalization due to COVID-19 increases dramatically with age. Based on data from COVID-19 cases in China, approximately 16% of people aged 60 years or older who become infected are expected to need hospital care [7]. Case fatality rates for people 60 years or older are estimated (from international cases) to be 4.5%, compared to 1.4% for those younger than 60 years [8]. In 2015, 32.1% of the European population was aged 65 and older [9]. Although public health strategies to slow the spread of the disease may prove useful, they also introduce a burden of social isolation at home and in the hospital. Even before COVID-19, older people—particularly those who spend the majority of their time alone—were at a higher risk of social isolation [10,11]. Social isolation—having few social interactions—has been linked to an increased risk for a range of physical and mental health problems, including cardiovascular disease, stroke, dementia, and depression [11]. Loneliness, the subjective perception of inadequate social connection, has also been independently associated with depressive symptoms [2,10,12]. The current limitations on social contact exacerbate the vulnerability of older people to social isolation, loneliness, and the associated mental and physical effects on well-being.

Current solutions include schemes to have volunteers call and talk with older people or use established social media platforms as mechanisms to promote social interaction [13]. The challenge with each of these approaches is, although they may be useful in establishing baseline contact, they are generic approaches that are not customized to the nature of the current problem. Additionally, systems often have a limited theoretical basis in evidence-based health behavior change frameworks. Many families are attempting to use social media platforms (eg, Skype, Facebook Messenger, or Zoom) to connect with older members of their families [14]. However, these platforms were not designed to address the needs of older users in both application and user experience, and have limited functions. Prevention of social isolation can be achieved through one-on-one communication, group interactions, and structural interventions; although the sustainability of intervention is a crucial factor in long-term effectiveness [11].

This pandemic creates an overwhelming demand on hospitals that is challenging to coordinate proactively [15]. Managing the inbound flow of care delivery resources is difficult because health systems (primary, secondary, and tertiary care) are not linked in a capacity to draw on data sources that could indicate trends on potential new cases [16]. Design standards that would promote interoperability necessary to integrate patient-facing and hospital-wise care systems are still emerging [17]. However, the need for such integration is more urgent than ever because the ability to plan for care based on health system capacity is especially vital during this time.

Aim and Objectives

The purpose of this paper is to provide details to the user needs and subsequent system design for the Activating Digital to Support Social Distancing COVID-19 Aware Family Engagement (ADAPT-CAFÉ) solution. As this is an in-progress initiative, it is hoped that peer review and dissemination of the project design and associated implementation details will generate further discussion and reflection on digital health solutions being used as tools for engagement during and after the pandemic.

Project ADAPT-CAFÉ

This project team will design, develop, and deploy a digital health mobile app to provide a means of assisting families and peer groups in maintaining contact with older people. The app will use goal setting and online communities to encourage positive nutrition, physical activity, and virtual interaction during social distancing. Although there is mixed evidence on the effectiveness of electronic interventions for loneliness in older

people [18], through an examination of strengths and weaknesses of previous studies, we hypothesize that it is possible to build a successful intervention with a user-centered and behavioral change theory-based design. Anonymized data from the app will be aggregated with other real-world data sources to develop a machine learning algorithm, with the objective of improving identification of patients with COVID-19 and tracking the real time use by health systems.

We aim for the immediate impact to be 27,450 users (approximately .01% of the older population in the United Kingdom, France, and Sweden) within the United Kingdom and the European Union. The target impact will be achieved over a series of months following the app's release, implemented via targeted paid advertising (eg, search engines, social media, news, television, and radio) and placement on app stores to promote uptake. The project impact will be quantitatively measured by registration and app use data. The solution platform could also be exploited worldwide if the initial implementation achieves its objectives.

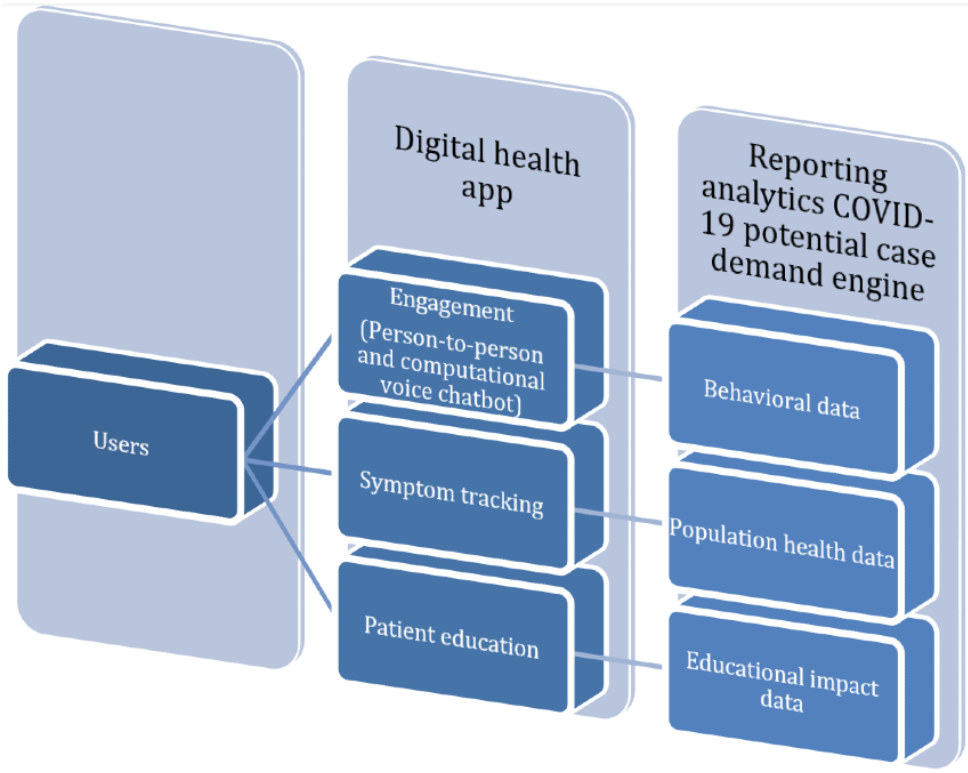
Solution Overview

The solution is a combination of:

- A mobile digital health app that provides older people, their families, and peers with a structured medium for social interaction.
- An analytics reporting engine that provides anonymized data from the app on potential cases, which can be used to anticipate hospital demand.

Both technologies are based on pre-existing software frameworks that will be modified for this use case, allowing for rapid app development and deployment for immediate impact. Figure 1 shows the ADAPT CAFÉ high-level implementation features.

Figure 1. ADAPT-CAFÉ high-level implementation features. ADAPT-CAFÉ: Activating Digital to Support Social Distancing COVID-19 Aware Family Engagement; COVID-19: coronavirus disease.



Design Extensibility

A vital aspect of this system is to provide the capability of enabling user engagement across multiple priorities. Although the proposed use case is focused on older users, hospitalized patients of all ages are increasingly socially isolated [19]. It is also a significant public health concern that many patients with cardiac conditions (particularly those with heart attacks) are presenting too late or not at all during the pandemic as a result of shielding. The solution is designed to be extensible to these and other implementation scenarios to encourage engagement and promote positive behaviors during social isolation and health system interaction.

Solution Overview: Mobile Digital Health App

The digital health app targets older users and their family members. Previous research suggests that there is mixed evidence that information communication technology interventions can be useful in reducing social isolation in older people [10]. The critical challenge in these technologies is mitigating issues centered on app usability and accessibility. This project will implement a simple-to-use interface with built-in accessibility functions such as font size adjustment, a chatbot (text and voice), a voice control assistant, and voice messaging with family members.

The app will allow family members to remotely access the interface of the older user's app so that family members can

teach the user how to use it without face-to-face contact. Suggested daily checkup messages can be sent from family members and friends in-app or via text messaging depending on the older users' preferences. Social interaction suggestions for virtual family gatherings, physical activity, and healthy nutrition will be provided with cues in-app to encourage consistency and sustainable uptake. Gamification, achievement, and in-app rewards will also be incorporated to incentivize users to schedule and plan for activities with family members.

Daily automated voice messages to collect well-being data from users will also be used to actively track real world data, including activities, location, and symptom data, in the user population. Natural language recognition will be used to analyze responses from users to collect relevant epidemiological and geographical data and allow earlier identification and treatment of infected older people. This will prevent symptoms from worsening and thus reduce death rates. The data generated by the app, including voice and text interactions, geographical location, and other activity patterns, will be anonymized, securely stored, and analyzed for insights to be extended as a signal used by health systems as predictors of potential new patients with COVID-19.

There are over 238 million older citizens throughout Europe [9]. Although the initial implementation will be provided in English, French, and Spanish, this app has the potential to be extended to older populations around the world.

The app will be developed using the behavior change wheel (BCW) framework [20]. This theory was designed to guide the development of behavior change interventions by outlining three behavioral components—capability, opportunity, and motivation—that interact to affect behavior. Effective interventions can be developed by evaluating which of these components need to be changed and how to achieve a target behavior [20]. The BCW framework also links these behavioral components with various intervention strategies (eg, persuasion, education) so that intervention types can be chosen concerning the behavioral components to be changed [20]. This framework will be used as a basis for evaluating what is preventing individuals from engaging in digital social interactions, physical activity, and symptom reporting so that the interventions incorporated in the mobile app will target those aspects specifically. The behavior change techniques (BCT) taxonomy will also be used to provide a clear description of the specific techniques being used in the app [21]. The clarity that this taxonomy provides will enable easy and rapid evaluation and adaptation of the BCTs used in the app in response to interim data so that the app will use the most effective BCTs in this context.

Solution Overview: Reporting Analytics COVID-19 Potential Case Demand Engine

Anonymized data from the ADAPT CAFÉ app will be a source of real-world evidence for understanding people's movement within lockdown regions as well as the occurrence of symptoms within the user group. This data can be aggregated with other data sources to provide a complete picture of the geographical region and insights into both the social and physical needs of users under lockdown. This data will be used as a source of information to create dynamic stratified patient demand forecasts with both machine learning transferred parameters and an agent-based simulation of patient demographics. This data will develop a geographical model superimposed on a health system's capacity to serve care, which will be analyzed against current and future availability of care delivery resources. These features will enable the capability to quickly see critical paths and provide the health system with the ability to plan and allocate providers and assets. This will enable the ability to simulate "what-if" scenarios and enable operational decision support for logistical placement, resource assignment, and management.

GE Healthcare's Command Center (GE Healthcare) provides a "wall of analytics" that draws on data from multiple systems within a clinical care setting; this data is displayed across a hospital and is accessible via tablets and mobile devices [22]. Advanced algorithms are used to help staff predict and resolve bottlenecks in care delivery before they occur, recommending actions to enable faster, more responsive patient care and better allocation of resources [22]. GE is using a significance and inferiority ranking approach [23] to develop an agent-based simulation to stratify people and networks of interactions. This insight could enable the transfer of learnings from one region to another to tailor demand capacity testing. This aim would be to identify trends by gaining an understanding of behaviors that are leading to infections and associated precursors. This will enable hospital information flow to be bidirectional: the creation of a propensity for future demand by demographic and an increase to the effectiveness of the digital health ADAPT-CAFÉ app at delaying or preventing infections that health systems do not have the capacity to serve due to overwhelming demand.

Anonymized real world evidence gathered through ADAPT-CAFÉ will be used by GE's Command Centre technology or as a stand-alone dashboard and data source for integration with other clinical care data systems to improve the general model predictive power and optimize clinical resources for the treatment of patients with COVID-19.

Methods

Case Study Design

In-depth data on the effectiveness and acceptability of the proposed app will be collected using a case study method [24]. Focused qualitative and quantitative research on the user's experience of this app will allow further development to target-specific issues identified. The case study development will follow seven stages, outlined in Table 1.

Table 1. Case study framework (based on [24,25]).

Number	Stage	Corresponding agile stage	Outcomes
1	Plan	Discovery phase	• Description of problem, user journeys, and data aggregation approach
2	Design	Alpha phase	• Construction of research design and linkage of research questions, data, and criteria for evaluation and synthesis • Development and design of app prototype based on the behavior change wheel theoretical framework [20], which will be iteratively updated based on new incoming evidence from steps 4 and 5
3	Prepare	Alpha phase	• Drafting, approval, and execution of study ethics followed by the performance of user recruitment protocols • Design of short-term and long-term app evaluation protocols
4	Collect	Beta phase	• Deployment of a beta version of the app and conduction of qualitative semistructured interviews and in-app surveys, and collection of app use data.
5	Analyze	Beta phase	• Iterative user data analysis for continuous app improvement
6	Create	Live phase	• Finalize app for publishing on Google and Apple app stores
7	Share	Live phase	• Ongoing paid advertising to promote uptake of the app • Creation of interim and long-term reports based on iteratively collected data and a final report of the impact of the app on reducing social isolation, improving well-being, and providing useful tracking data • Publishing of the reports in a peer-reviewed journal.

Nonadoption, Abandonment, Scale-Up, Spread, and Sustainability Framework

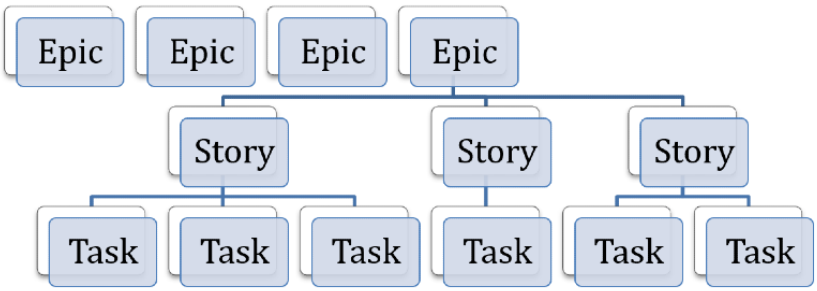
Comprehensive planning for the potential sustained impact and long-term use of this platform will be done using the nonadoption, abandonment, scale-up, spread, and sustainability (NASSS) framework [26]. Adaptation of the solution use case will commence with consideration of the issues concerning social isolation and older users, with user-centered design and patient and public engagement in solution design to ensure the appropriateness of the solution design. Considerations of the broader health system, organizational, value proposition, and longer-term adaptation over time shall be planned and iterated throughout the app life cycle using the 7 stages for the framework and recorded in subsequently published reports on the implementation of the system.

Agile Software Development Process

The software product development is following the agile framework defined by the UK Government Service Manual [27], as well as lean methodology [28] and iterative design and development sprints. The approach relies on reuse and iterative improvements of the code and user experience elements, in particular via deploying open-source tools and codebase, conducting fast validation with real users, and maintaining consistent performance measurements against predefined key performance indicators, including adoption and retention metrics. Figure 2 shows a sample of agile software requirements planning.

The discovery phase aims to efficiently define requirements via a structured process, with subsequent iterative build and testing during the alpha, beta, and live phases. Aligned with the Service Manual agile framework guidelines [29], the accessibility standards and principles are integrated into the system design and development process. This approach also allows the resulting insights and technology to be replicable, scalable, and transferable to extend the solution to the adjacent problem areas.

Figure 2. Sample of agile software requirements planning.



Evaluation: Study Design

A feasibility study will be initiated and last 12 months; this will include a 1-month evaluation and intervention refinement (ending by June 27, 2020), and an 11-month implementation and follow-up (commencing June 28, 2020, and concluding June 1, 2021). During the implementation period, the research team will prepare for subsequent larger-scale studies should interim results indicate study feasibility, adoption, and usability of the app (by December 31, 2020). The study is centered on the app and excludes the reporting engine; the basis for this is that successful uptake of the app is required for downstream data in the reporting engine to be useful.

The evaluation of the app's feasibility, acceptability, and usability shall be conducted using the following scales and theoretical models and frameworks:

- Public Health England guidance on evaluating digital health products [30]
- Bandura's model of health promotion by social cognitive theory will be used in the measurement of factors impacting the BCW framework development and validity, with specific emphasis on self-efficacy, perceived benefits, and perceived barriers [31].
- The reach effectiveness adoption implementation maintenance framework [32] to include information regarding the target population reach, potential for solution impact, adoption by target users, implementation consistency, and costs made during delivery and maintenance of the intervention
- Long-term adoption and suitability to further trials will be evaluated using the NASSS framework [26].

A total of 6000 (primary app users older than 65 years) will be recruited for evaluation. However, because recruitment will be done via the app store and advertised publicly, it is expected that the number of primary app users will exceed this number. We will randomly select 10% of the primary app users and 10% of secondary app users (adult users aged 18-65 years; participants will be drawn from sets collected at 1, 2, and 3 months poststudy commencement) for further qualitative investigation. A central study objective is to reach demographic saturation (ethnicity, social-economic background, and education) for study participants. Qualitative feedback will be measured through an examination of factors associated with app use and uptake. Participants will use the app online via smartphones at any location for, on average, 15-45 minutes per day during the implementation period. The qualitative evaluation will make use of in-app surveys and interviews. Study participants will be asked to take part in two interviews via Skype or telephone lasting 40-60 minutes conducted by the principal investigator (EM) and trained research staff. Interview questions will be asked within the context of how the participants interpreted the impact of the app. Interviews will be used to evaluate evidence-based strategies for engagement and BCTs, including self-monitoring, goal setting, physical activity and healthy eating support, personalized feedback and motivational strategies (eg, rewards, prompts, or gamification), and social support.

Skype and telephone conferences have been selected as methods of interviewing because participants are distributed regionally and adhering to social distancing regulations, and this is the most accessible means of interviewing participants. We will sample a sufficiently significant number of participants for qualitative interviews to provide sufficient insight into app impact. All those who opt for the study will undergo data analysis to avoid attrition bias. After being given information on the structure of the study to ensure that they understand it, participants will be asked to provide informed consent. Should participants opt not to have interview sessions audio recorded, detailed notes of those sessions will be taken and shared with participants at the end of the interview summarizing discussions. The full study design is under development and will be submitted for review in May 2020.

Results

This paper summarizes the real time development of ADAPT-CAFÉ to share design principles that could be reused or extended by other app developers and scientists. In this section, we summarize the in-progress work plan for the solution.

Work Plan

Phase 1: Discovery Phase

To ensure the build of a fit-for-purpose app, a project initiation document detailing user needs, the current state of the literature, and requirements specific to self-isolation and government policies surrounding the lockdown will be produced and agreed upon by all parties.

User stories and epics surrounding the accessibility requirements of older users and their families will be further developed to enable users with little to no digital skills to use the technology efficiently. Initial wireframes will be produced, and small focus group meetings will be held via Skype or Zoom to validate the defined problem and proposed solution.

This phase's work has already commenced due to the urgent nature of the problem.

Phase 2: Alpha Phase Prototype

Focusing on the self-isolation challenge epic, a prototype participant interaction system and chatbot to aid social connection and physical and mental fitness for older people will be developed. The type and format of the data to be collected will be explored to ensure data interoperability with external data systems.

Concurrently, research ethical approval [33] will be sought at this stage from the University of Oxford to ensure that the solution can be implemented and evaluated in an ethical manner complying with privacy, data security, and other considerations.

Phase 3: Beta Phase Testing

The prototype app will be released to a small group of app testers. Qualitative feedback will be measured using the evaluation protocol designed in the alpha phase through Skype interviews of participants (families or peer groups and associated older stakeholders). Iterations to the app will be made based on

suggestions by users. Iterative data analytics and fine-tuning of the data collection process will be conducted at this phase and aggregated with other data sources outside of the app to allow aggregate data analysis via the GE Healthcare Command Center. This work will continue throughout the development life cycle of the app to allow for continuous improvement of the app.

The technology development will follow a modular approach following the representational state transfer application program interface structure. Backend app databases will be hosted on the Amazon Web Services (AWS) infrastructure, complying with General Data Protection Regulation-compliant levels of data security and enabling big data processing (including voice and video transfer, storage, and analytics) as well as the deployment of machine learning modules.

At the core of the system, implementation is an artificial intelligence (AI)-powered chatbot agent, deployed with an open-source framework such as Amazon Lex, a service that allows the creation of intelligent conversational chatbots and is part of the AWS ecosystem. The integrated machine learning modules will give users a personalized experience to improve the quality of question prediction and response.

To cater to the needs of older adult users, a voice-enabled conversational AI will support accessibility and improve the ease of interaction. The app will use a voice-user interface that interacts with voice servers such as Amazon Alexa and delivers voice recognition, conversational dialogues, entity resolution, and memory.

At the second stage of the process after 1 year, the developed ecosystem will create a basis to further improve the technology for delivering advanced medical and lifestyle assistance for older and isolated people. The core data processing and storage engine are planned to be expanded with electronic health care records (EHR) data exchange gateway to connect with third-party EHR data providers and deliver personalized plans and recommendations, as well as automate schedules and programs for care and interactions. At that stage, the distributed ledger technology component is planned to further augment the work of independent communities via securing data exchange mechanisms and enabling token-based motivational schemes.

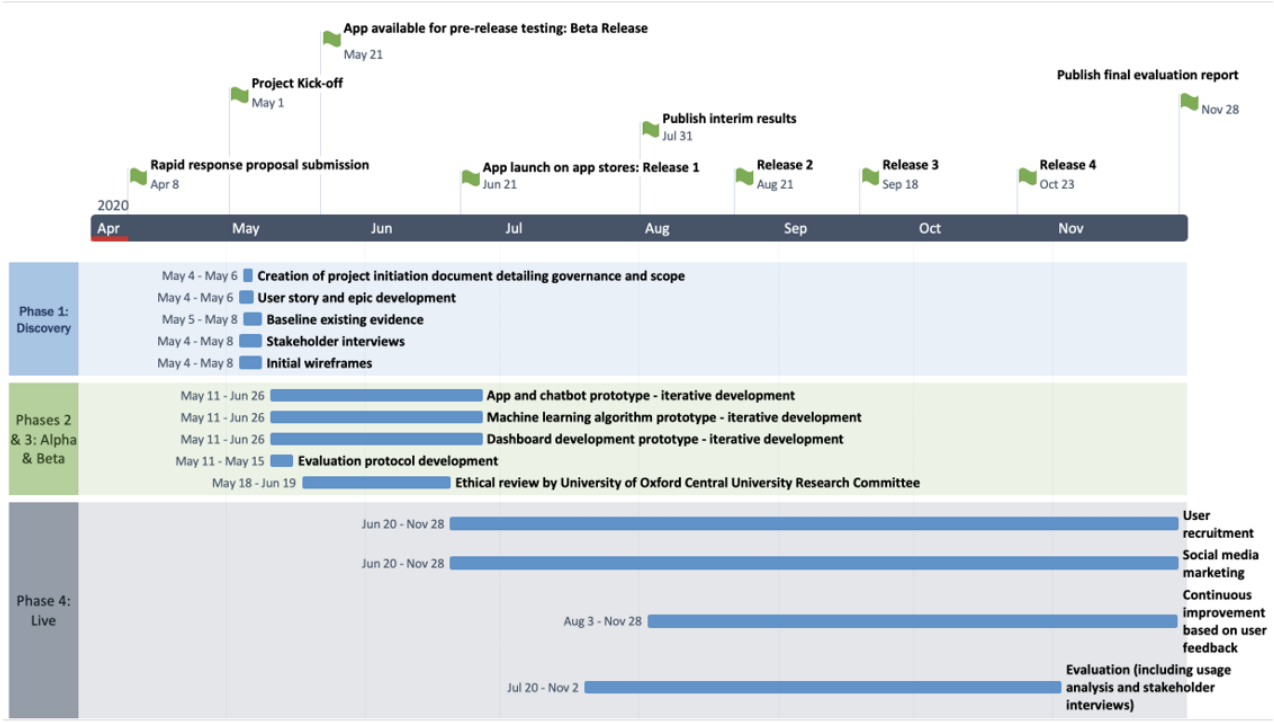
Phase 4: Live Phase

The app will go live on the Apple App store and Google Play store after beta iterations. The app will be marketed through social media channels and paid digital advertising. Continuous support and software updates will be made based on user feedback.

An evaluation study will be conducted using a combination of online surveys and qualitative video call interviews at various time points. A short-term time point will be examined for users after 5 days of app use to understand whether the app is successful in meeting the needs of users and improve and update the app to meet short-term user needs. A longer-term time point will be examined 2 months after the start of live app use to understand the attrition rate and long-term effects of using the app in the pandemic context.

The results will be published in a peer-reviewed journal to share the experience in the development and feedback of the app and contribute to the broader community of researchers tackling the challenges arising from this worldwide pandemic. Figure 3 shows the proposed implementation timeline.

Figure 3. Proposed implementation timeline.



Discussion

Principal Findings

Mobile digital technology enables the capability to rapidly design, build, and deploy solutions with the capacity of connecting vast geographies of individuals. Despite the constraints of social distancing, such digital technology creates a capability for interconnectedness. The critical challenge, however, in the design of digital innovations is to construct them in a way that allows for evaluation and will assure the potential for long-term uptake and use. These issues are even more pressing with the context of this pandemic because resources must be deployed in a way that ensures a promise of effectiveness.

Lessons Learned

This project was the genesis of brainstorming to a rapid-response call, which was developed hours before a submission deadline and subsequent iteration to four other rapid-response requests over 3 weeks. This pandemic has required the development of solutions in real time to respond to a public health emergency of international concern. It is challenging for academic institutions and funders to react responsively, particularly in medicine, because systems are designed to follow structures that ensure safety and evidence-based practice, which by their very design are methodical and time intensive. Despite these institutional barriers, however, the international clinical, academic, and industrial community have responded with speed during this crisis. The key lessons learned will be long-term enablement of what has worked for agile solution delivery and how we can embed these practices in care delivery in the future.

It is also worth considering other ideas that were not funded or unable to be developed due to constraints. A lesson learned for the community is how to channel these efforts and not merely rely on a meritocratic belief that the best solutions always present themselves. In a digital age, we can mobilize people, ideas, and resources in exponential ways, but making use of effort and its deployment is by no means simple.

Strengths and Limitations of the Study

Our app development adopts user-centered design and takes into account evidence-based theories for the implementation of technology interventions in health and care. The composite of consideration for iterative development and system-wide thinking combined with a framework for evaluation during a rapid app development process is a strength of our approach. A limitation of our approach is that, due to the evolving nature of the current problem, it is unfeasible to follow a traditional scientific investigation format where the design would be finalized up-front and research ethics developed and approved before any software development was started. However, analysis of the efficacy and validity of our methods are the reasons we have submitted our work for international peer review while obtaining research funding for our solution.

Further Research

The success and failure of digital solutions used during this pandemic will make valuable contributions to the literature. Lessons learned can be applied to influence future software engineering management of digital health solutions. Whether the authors can achieve the uptake and data sources intended will provide information about the best ways of combining real world and clinical data to inform potential case demand.

Conclusions

This case study outlined a digital health agile requirements engineering approach to tackle a new and urgent issue arising from government measures to combat the COVID-19 worldwide pandemic. The proposed solution is to use a peer-to-peer engagement system and voice AI chatbot to connect older people with their family and friends and promote mental, physical, and social well-being. The testing and evaluation of the app will be reported in future studies.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

ADAPT-CAFÉ: Activating Digital to Support Social Distancing COVID-19 Aware Family Engagement
AI: artificial intelligence
AWS: Amazon Web Services
BCT: behavior change techniques
BCW: behavior change wheel
COVID-19: coronavirus disease
EHR: electronic health care records
NASSS: nonadoption, abandonment, scale-up, spread, and sustainability

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Original Paper

Mathematical Modelling to Assess the Impact of Lockdown on COVID-19 Transmission in India: Model Development and Validation

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Abstract

Background: The World Health Organization has declared the novel coronavirus disease (COVID-19) to be a public health emergency; at present, India is facing a major threat of community spread. We developed a mathematical model for investigating and predicting the effects of lockdown on future COVID-19 cases with a specific focus on India.

Objective: The objective of this work was to develop and validate a mathematical model and to assess the impact of various lockdown scenarios on COVID-19 transmission in India.

Methods: A model consisting of a framework of ordinary differential equations was developed by incorporating the actual reported cases in 14 countries. After validation, the model was applied to predict COVID-19 transmission in India for different intervention scenarios in terms of lockdown for 4, 14, 21, 42, and 60 days. We also assessed the situations of enhanced exposure due to aggregation of individuals in transit stations and shopping malls before the lockdown.

Results: The developed model is efficient in predicting the number of COVID-19 cases compared to the actual reported cases in 14 countries. For India, the model predicted marked reductions in cases for the intervention periods of 14 and 21 days of lockdown and significant reduction for 42 days of lockdown. Such intervention exceeding 42 days does not result in measurable improvement. Finally, for the scenario of "panic shopping" or situations where there is a sudden increase in the factors leading to higher exposure to infection, the model predicted an exponential transmission, resulting in failure of the considered intervention strategy.

Conclusions: Implementation of a strict lockdown for a period of at least 21 days is expected to reduce the transmission of COVID-19. However, a further extension of up to 42 days is required to significantly reduce the transmission of COVID-19 in India. Any relaxation in the lockdown may lead to exponential transmission, resulting in a heavy burden on the health care system in the country.

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KEYWORDS

covid-19; coronavirus; epidemic; mathematical modelling; pandemic; sars

Introduction

The novel coronavirus disease (COVID-19) pandemic spread through 190 countries within 20 weeks from the epicenter of Wuhan in China, affecting 334,000 populations and causing more than 14,500 deaths by mid-March 2020. As of April 6, 2020, the number of infected people has increased to 1,210,956 and the number of associated deaths to 67,594 [1]. While several European countries had gone through stage 3 of the pandemic by the second week of February, India entered into transition

towards stage 3 at this point in time. It is well known that there are differences in behavior regarding the epidemic within the same country and in other countries; mathematical modelling helps to predict the course of the epidemic to determine why there is no uniformity in the infection [2,3]. In addition, the health system can utilize the predictions of such models as an intelligent tool to decide on the types of control measures as well as the time and location of their application. It is also essential to understand the dynamics of the transmission of an infection introduced in a new country or location and to forecast whether the proposed control measures will result in measurable effects [4,5]. The measured effects suggest that alternate interventions should be designed; therefore, it is obvious that predictions must be critically analyzed before applying interventions [6].

India recorded its first case of COVID-19 infection on January 30, 2020, in a student from China's epicenter, Wuhan [7]. The Ministry of Health in India initiated the course of action of screening travelers in airports and then shut down schools during the first week of March 2020. As of March 22, 2020, India reported only 360 positive COVID-19 cases from 23 states across the country [8]. However, compared to the course of the epidemic in western countries, either the epidemic in India progressed through a slow phase or the number of asymptomatic cases in India is higher. The Government of India imposed the Janata Curfew for 24 hours as an initial measure to contain the spread of infection, followed by a lockdown under the Disaster Management Act 2005 for a period of 21 days starting on March 24, 2020 [9]. In the absence of an effective vaccine for COVID-19 prevention, the only remaining options are prevention of further influx of migrant cases at airports and seaports and contact tracing. China learned from its experience that only complete shutdown prevented further spread, and Italy learned from its experience that negligence of communities towards simple public health strategies leads to uncontrolled morbidity and mortality.

It is well known that COVID-19 infection leads to mild and self-limiting respiratory symptoms. However, two betacoronaviruses, severe acute respiratory syndrome coronavirus (SARS-CoV) and Middle East respiratory syndrome coronavirus (MERS-CoV), result in severe forms of pneumonia, causing 10% and 37% mortality, respectively [10,11]. SARS-CoV spread through 26 countries and affected more than 8000 individuals, while the MERS-CoV epidemic was mainly focused in Middle Eastern countries and affected nearly 2500 people.

In recent studies, it has been reported that the maximum time from the onset of coronavirus infection to hospitalization is 10 days, with an incubation period of 2 to 14 days [12,13]. According to the World Health Organization (WHO), the time between the start of symptomatic manifestations and death is approximately 2-8 weeks [14]. Another study reports that the duration of viral shedding is 8-37 days [15]. Further, the effectiveness of the interventions depends on multiple factors, and a recent report recommends estimating the optimal periods to implement each intervention [16]. However, most countries have implemented 14 days of self-quarantine to prevent further spread of the infection. Therefore, it is important to mathematically estimate the lockdown period required to interrupt the transmission of COVID-19 infection with respect to each country because the contact patterns between individuals are highly dynamic and nonhomogeneous across each population. SARS-CoV can survive on inanimate objects such as metal, wood, paper, glass, and cloth for 4-5 days at room temperature [17]. It has been shown that clinically ill patients play a vital role in SARS-CoV transmission [18], as peak viral load in the respiratory tract occurs approximately ten days after the onset of symptoms [19].

Recently, the Government of India took the very intelligent step of implementing a lockdown for a period of 21 days starting at midnight on March 14, 2020. Based on this scenario, we developed a mathematical model to predict the course of the epidemic in India and to determine the impact of the intervention under different possible conditions.

Methods

In this work, a dynamic mathematical model for prediction of the future infected population with COVID-19 was developed. Infected populations in the date range from February 19, 2020 to March 18, 2020 served as inputs for the development of the model. The WHO Situation Reports on COVID19 and updates by the International Society for Infectious Diseases (ISID) were the major sources of the numbers of cases in different countries [20,21]. The infected populations from 14 countries (China, Italy, Germany, France, the United States, the United Kingdom, Sweden, the Netherlands, Austria, Canada, Australia, Malaysia, Singapore, and India) were considered for the development of the model due to the major interactions and travel of infected populations between these countries and India for education and employment. The first case reported in India was related to medical education in Wuhan, China; also, countries such as Italy and Germany admitted groups of students in February 2020. The developed model consists of a framework of first order ordinary differential equations of the form shown in Figure 1.

The model has the constraint $0 \leq x_i(t) \leq TP_i$, where $x_i(t)$, $i = 1, 2, ..., 14$ is the total number of infected people at time t for each country. $\dot{x}_i$, $i = 1, 2, ..., 14$ is the rate of change of the infected population at time t for each country. a_i, $i = 1, 2, ..., 14$ is the parameter that influences the rate of infection in each country. C_i, $i = 1, 2, ..., 14$ is the parameter of the model that is influenced by factors specific to each country, such as population density and cross-antibodies. b is a parameter common to all the considered countries. TP_i, $i = 1, 2, 14$ is the total population in each country, and $r(t)$ is a random change acting on the infection dynamics due to sociological factors. I is the identity matrix. Finally, $k_i(t)$, $i = 1, 2, ..., 14$ is the forcing function that represents the intervention in terms of travel restrictions such as lockdown, medications, and vaccination strategies. However, at present, because travel restrictions are the existing intervention strategy, it was considered appropriate to apply "lockdown" as the intervention. Furthermore, the total population of each country was considered as the maximum susceptible population for COVID-19 infection. We considered

the whole population for the prediction because the rate of RNA positivity is only 1/307 (0.3%) in blood samples, indicating very minimal viremia; the antibody positivity in the community is not known at this point in time, and variable results would be obtained for R_0. The parameters of the model were estimated using the numbers of reported infected cases provided by the WHO, which are available as open source data. A prediction error method [22] was utilized for the estimation of the model parameters using the reported cases. The developed model was validated using the reported infections in the adopted period and was utilized to predict the future infected cases in the 14 considered countries up to a further period of 65 days.

After the validation, the developed model was utilized to determine the impact of the intervention strategy in terms of lockdown for India to contain the infection. Five different intervention strategies with travel lockdown periods of 4 days, 14 days, 21 days, 42 days, and 60 days (Multimedia Appendix 1) were analyzed using the developed model. Further, a random increase in exposure to infection on the day before the implementation of the intervention strategy due to aggregation of the susceptible population in locations such as grocery stores, markets, railway stations, and buses due to panic shopping, etc., was considered, and these scenarios were analyzed. Three different scenarios with increases in infection exposure by factors of 2, 3, and 5 were considered on the day before the start of the lockdown (Multimedia Appendix 2).

Figure 1. Framework of the first order ordinary differential equations used in the model.

$$\begin{bmatrix} \frac{dx_1}{dt} \\ \frac{dx_2}{dt} \\ \frac{dx_3}{dt} \\ \frac{dx_4}{dt} \\ \frac{dx_5}{dt} \\ \frac{dx_6}{dt} \\ \frac{dx_7}{dt} \\ \frac{dx_8}{dt} \\ \frac{dx_9}{dt} \\ \frac{dx_{10}}{dt} \\ \frac{dx_{11}}{dt} \\ \frac{dx_{12}}{dt} \\ \frac{dx_{13}}{dt} \\ \frac{dx_{14}}{dt} \end{bmatrix} = b \begin{bmatrix} a_1 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & a_2 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & a_3 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & a_4 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & a_5 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & a_6 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & a_7 & 0 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_8 & 0 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_9 & 0 & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_{10} & 0 & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_{11} & 0 & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_{12} & 0 & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & a_{13} & 0 \\ 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & 0 & r(t)a_{14} \end{bmatrix} \begin{bmatrix} x_1 \\ x_2 \\ x_3 \\ x_4 \\ x_5 \\ x_6 \\ x_7 \\ x_8 \\ x_9 \\ x_{10} \\ x_{11} \\ x_{12} \\ x_{13} \\ x_{14} \end{bmatrix} - I \begin{bmatrix} x_1 \\ x_2 \\ x_3 \\ x_4 \\ x_5 \\ x_6 \\ x_7 \\ x_8 \\ x_9 \\ x_{10} \\ x_{11} \\ x_{12} \\ x_{13} \\ x_{14} \end{bmatrix} + \begin{bmatrix} C_1 \\ C_2 \\ C_3 \\ C_4 \\ C_5 \\ C_6 \\ C_7 \\ C_8 \\ C_9 \\ C_{10} \\ C_{11} \\ C_{12} \\ C_{13} \\ C_{14} \end{bmatrix} - \begin{bmatrix} k_1 \\ k_2 \\ k_3 \\ k_4 \\ k_5 \\ k_6 \\ k_7 \\ k_8 \\ k_9 \\ k_{10} \\ k_{11} \\ k_{12} \\ k_{13} \\ k_{14} \end{bmatrix}$$

Results

The developed model can capture the infection dynamics in each country to a considerable extent and predict future cases (Multimedia Appendix 3 and 4). Also, the correlation between the reported cases and those obtained using the developed model was found to be high for all 14 countries (China: 0.9763, Italy: 0.9960, Germany: 0.9416, France: 0.9965, USA: 0.9992, UK: 0.9959, Sweden: 0.9615, Netherlands: 0.9976, Austria: 0.9979, Canada: 0.9987, Australia: 0.9971, Malaysia: 0.8769, Singapore: 0.9751, India: 0.9858).

The infected populations predicted using the developed model for the case of India along with the effects of the intervention periods of 4, 14, 21, 42, and 60 days are presented in Figure 2. No significant change was observed in the predicted infected cases with a 4-day intervention period compared to the scenario without intervention. However, there were significant decreases in the number of infected cases with intervention periods of 21, 42, and 60 days. For the 21-day lockdown intervention, the number of predicted cases was reduced from 378,036 (non-intervention) to 70,424 at 110 days. For a 42-day lockdown intervention, the predicted cases were further reduced significantly to 42,950. However, there was no significant

change in the predicted number of infections between the 42-day and 60-day intervention scenarios.

Figure 3 (a-c) shows the effects of the random changes in the infection dynamics on the day before the intervention period with *r*=2, 3, and 5, respectively, on the number of predicted infections. It was observed that even for 2-fold augmentation in transmission (*r*=2), the predicted number of infected people increased exponentially to 450,618 despite the 21-day intervention. The predicted number of infected people further increased exponentially for the 3-fold (*r*=3) and 5-fold (*r*=5) augmentations in transmission.

Figure 2. The effects of the intervention periods on the number of infected cases in India according to the model.

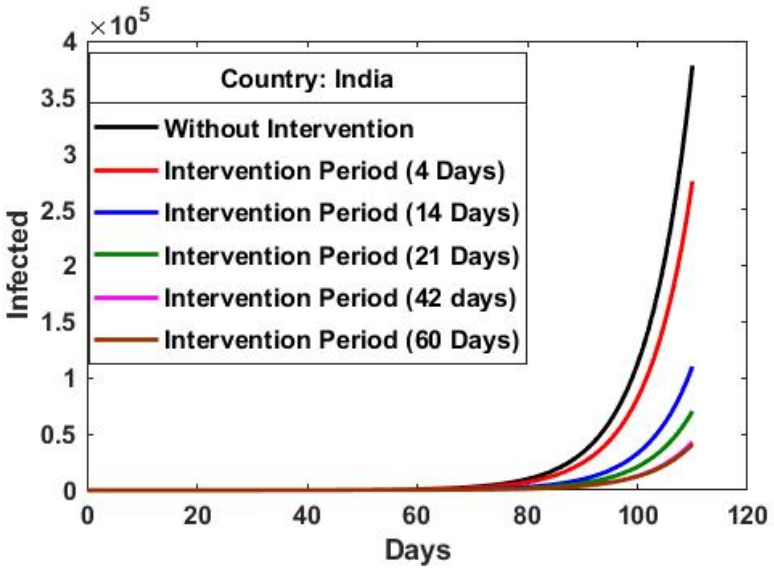
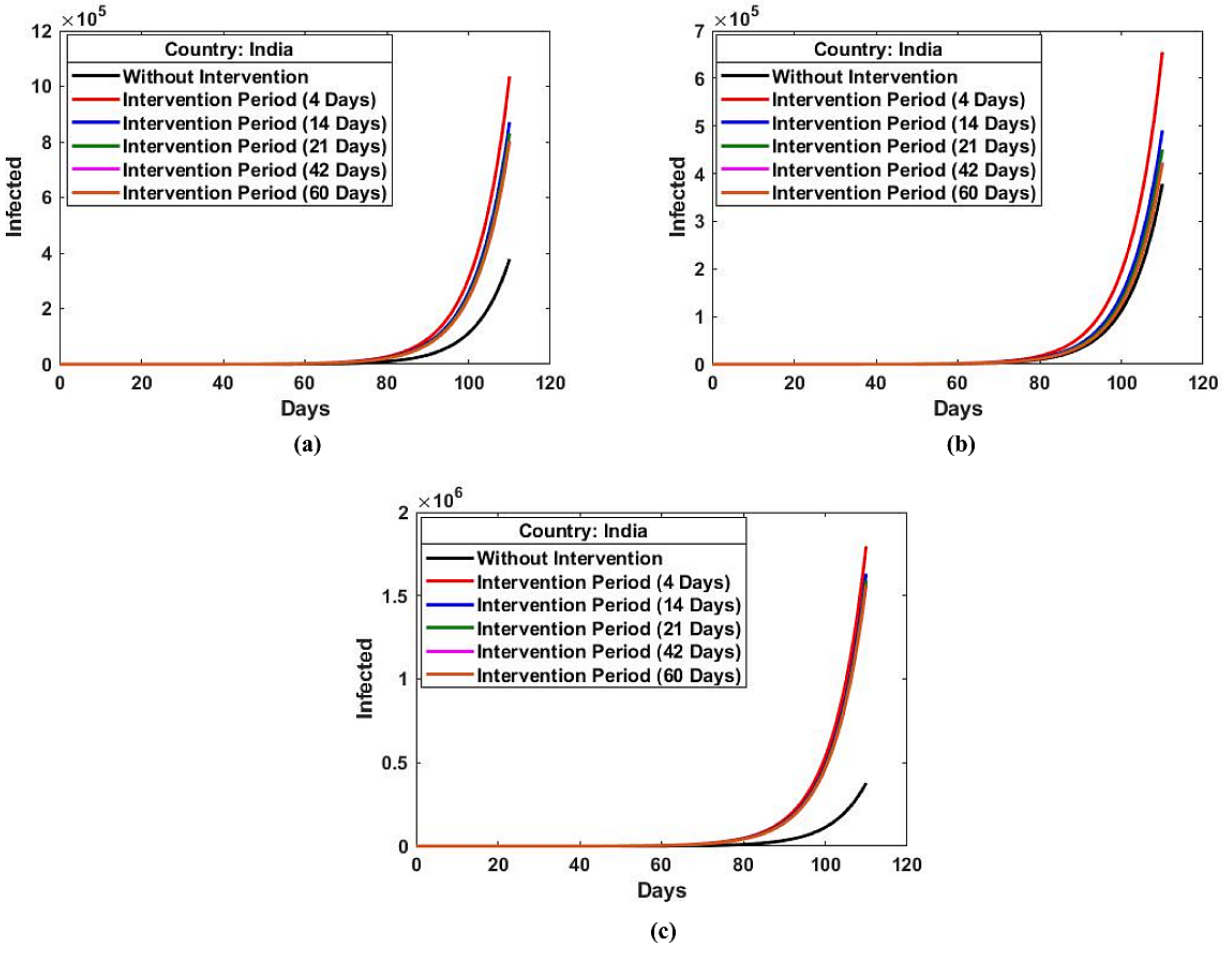


Figure 3. The effects of the random changes in the infection dynamics due to social activity on the day before the intervention period for (a) r=2, (b) r=3, and (c) r=5.



Discussion

Principal Findings

The results obtained using the developed model suggest that the implementation of a 21-day lockdown is necessary to slow the progression of the COVID-19 epidemic in India. An increase in the lockdown period up to 42 days is required to significantly reduce the number of COVID-19 cases in the country. However, the impact of the intervention depends on the extent to which the exposure to COVID-19 was augmented due to aggregations of the susceptible population with the infected population just before the lockdown. Even 2-fold augmentation may result in exponential transmission in different parts of the country.

Although the COVID-19 pandemic has spread to 190 countries worldwide, other than China, 10 European countries have been the most affected [23]. Currently, the epidemic is heading towards stage 3 in the second most populated country in the world, India, and the course of the epidemic in India is expected to determine the global burden of morbidity and mortality as well as the future course of this pandemic. In the present model, we included the cases reported for a period of 45 days from 13 countries that are employment and education hubs for Indians, considering the fact that many exposed people must have migrated to India and escaped screening. However, the epidemic in India did not set in until March 2020, as seen from the number of reported cases [20]. This can be explained by the experiences in the Chinese epidemic, particularly at the epicenter, Wuhan, where it was found that a single case cannot trigger an epidemic and that the introduction of several cases is required to generate a successful epidemic [24]. India started to report additional cases only in the second week of March 2020. This provided an opportunity to construct a model to predict future cases; we preferred to restrict the prediction to a shorter period of 110 days, assuming that other factors will alter the epidemic behavior and affect the long-term prediction capability of the model.

Several models are used to analyze the dynamics of an epidemic. Of these, the Susceptible-Infected-Recovered, Susceptible-Exposed-Infected-Recovered, and Susceptible-Infected-Susceptible models are frequently explored by epidemiologists and public health experts [25-27]. Most of the available epidemiological models assume the network of interactions [28]. Furthermore, there are several challenges and limitations when these models are applied to a new infection of pandemic proportions [29]. To date, the possibility of reinfection due to severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) has not yet been analyzed, and superinfections cannot be described by the Susceptible-Infected-Recovered model. Also, most of the available models are time-invariant [30]. Furthermore, when a very large population is considered, the Susceptible-Infected-Recovered model suffers from numerical errors because the number of susceptible people in the initial days of the epidemic is very high and the numbers of infected and recovered people in the first few days are low.

In the present work, we attempted to predict the progression of the COVID19 epidemic in the first few months of the outbreak. In view of the exponential transmission and almost uniform spread in several countries, we considered a simple mathematical framework consisting of ordinary differential equations due to their higher dynamic prediction capabilities and the ease of applying control forces to the model to find the outcomes. Furthermore, such models have been proved to be highly useful in epidemiological and population modelling for effective prediction of future populations.

Based on the evidence of viral survival on surfaces, incubation period, viral shedding duration by infected persons, and the datewise reported cases from the 14 studied countries, we considered lockdowns for 4, 14, 21, 42, and 60 days as intervention strategies. In addition, we assumed that an intervention approach of adopting only lockdown would have a 30% impact on transmission. With these inputs, our model predicted that with a 21-day lockdown, there will be a significant break in transmission; it also predicted that this can be even further improved with a 42-day lockdown. Further extension to 60 days may not result in a desirable impact on transmission. Therefore, the lockdown imposed by the Government of India is likely to have a significant impact on containing the COVID-19 epidemic in the country. Using the IndiaSim model, Eili Klein et al [31] predicted that sensitivity of the virus to temperature and humidity will result in decreased transmission in India. In IndiaSim, the authors assumed that a 21-day lockdown would have a 25% impact on transmission. In our model, we assumed a 30% reduction of transmission; in addition, the infection rate was considered to influence the transmission at least 10 times more than other parameters, such as temperature and humidity.

Although India has started to implement interventions in the form of travel restrictions, on the day before the implementation of the intervention, an unusual increase in social gatherings was witnessed throughout the country; this must have changed the epidemic dynamics to a great extent. It has been established that the viral droplet nuclei can travel up to 2 meters and that the virus can remain infective in the atmosphere for several hours [32]. In our model, we assumed that even a small number of people newly infected with COVID-19 in such a population would alter the transmission 2-fold, 3-fold, or even 5-fold. For these situations, the model predicts exponential transmission, as seen in other European countries. In real situations, this will be revealed if the testing strategy is extended to screen the asymptomatic population in communities.

Limitations

The first limitation of this study is that it considers the total population in each country as the susceptible population because sufficient evidence of the fraction of each population that is susceptible to SARS-CoV-2 is not yet available. The model was constructed by including the reported cases based on the initial testing strategy adopted in India with the assumption that there was no community spread until the first week of March 2020. Also, the model utilized in this study has limited dynamic prediction range; therefore, the authors restricted the prediction to a window of 110 days. The model will need to be updated with the numbers of reported cases to analyze the future course of the infection after May 21, 2020.

Conclusion

Our model suggests that strict implementation of a country-wide 21-day lockdown in India will reduce community transmission, and an extension of another 21 days (total period of 42 days) will further improve the break in the transmission chain in local communities. This will also provide an opportunity to identify the proportion of SARS and case fatality rates. Health facilities in India can be reorganized to handle SARS and to reduce the case fatality rate. Therefore, the government must impose a lockdown with stringent measures, preferably for at least 42 days. Despite these stringent measures, approximately 40,000 cases will be spread throughout the country. Contact tracing and community screening must be completed during this period, and the lockdown must be lifted in a phased manner at the district level. Any flexibility in implementing the lockdown or sudden release from lockdown and failing to achieve contact tracing may lead to exponential transmission, leading to large numbers of COVID-19 cases that India will not be able to handle with the available health infrastructure and professional staff.

The results derived from the developed model for lockdown intervention strategies in India can provide useful insight into the imposition and release of lockdown to slow the progression of the COVID-19 epidemic in other countries which are currently in stage 1 or stage 2 of the epidemic. As of April 24, 2020, 23077/38522 (59.9%) of the confirmed COVID-19 infections in the WHO-defined South-East Asia region are in India [33], and Indonesia and Bangladesh may enter stage 3 of the epidemic, similar to India, in another 2-4 weeks. These countries must impose intervention strategies well before stage 3 and continue proper testing strategies and contact tracing to contain the epidemic effectively.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary Figure S1.
[PDF File (Adobe PDF File), 98 KB - publichealth_v6i2e19368_app1.pdf]

Multimedia Appendix 2
Supplementary Figure S2.
[PDF File (Adobe PDF File), 96 KB - publichealth_v6i2e19368_app2.pdf]

Multimedia Appendix 3
Supplementary Figure S3.
[PDF File (Adobe PDF File), 222 KB - publichealth_v6i2e19368_app3.pdf]

Multimedia Appendix 4
Supplementary Figure S4.
[PDF File (Adobe PDF File), 169 KB - publichealth_v6i2e19368_app4.pdf]

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Abbreviations

COVID-19: coronavirus disease
ICMR: Indian Council of Medical Research
ISID: International Society for Infectious Diseases
MERS-CoV: Middle East respiratory syndrome coronavirus
SARS-CoV: severe acute respiratory syndrome coronavirus
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
VCRC: Vector Control Research Centre
WHO: World Health Organization

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Viewpoint

Considerations for Postacute Rehabilitation for Survivors of COVID-19

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Abstract

Coronavirus disease (COVID-19), the infection caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was first reported on December 31, 2019. Because it has only been studied for just over three months, our understanding of this disease is still incomplete, particularly regarding its sequelae and long-term outcomes. Moreover, very little has been written about the rehabilitation needs of patients with COVID-19 after discharge from acute care. The objective of this report is to answer the question "What rehabilitation services do survivors of COVID-19 require?" The question was asked within the context of a subacute hospital delivering geriatric inpatient and outpatient rehabilitation services. Three areas relevant to rehabilitation after COVID-19 were identified. First, details of how patients may present have been summarized, including comorbidities, complications from an intensive care unit stay with or without intubation, and the effects of the virus on multiple body systems, including those pertaining to cardiac, neurological, cognitive, and mental health. Second, I have suggested procedures regarding the design of inpatient rehabilitation units for COVID-19 survivors, staffing issues, and considerations for outpatient rehabilitation. Third, guidelines for rehabilitation (physiotherapy, occupational therapy, speech-language pathology) following COVID-19 have been proposed with respect to recovery of the respiratory system as well as recovery of mobility and function. A thorough assessment and an individualized, progressive treatment plan which focuses on function, disability, and return to participation in society will help each patient to maximize their function and quality of life. Careful consideration of the rehabilitation environment will ensure that all patients recover as completely as possible.

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KEYWORDS

covid-19; rehabilitation; subacute care; inpatient rehabilitation; public health; infectious disease; virus; patient outcome; geriatric; treatment; recovery

Introduction

Coronavirus disease (COVID-19), the infection caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was first reported on December 31, 2019. Because it has only been studied for just over three months, our understanding of this disease is still incomplete, particularly its sequelae and long-term outcomes. Knowledge about COVID-19, including its presentation and treatment, is changing very rapidly, and guidelines are quickly being created and updated. Therefore, it is important to remain current by engaging in frequent reviews of new research.

The objective of this report was to answer the question "What rehabilitation services do survivors of COVID-19 require?" The question was asked within the context of a subacute hospital delivering geriatric inpatient and outpatient rehabilitation services. As of April 14, 2020, very little has been written about the rehabilitation needs or outcomes for patients with COVID-19 after discharge from acute care. Upon thoughtful consideration of the question, it appears that the topics of greatest importance to allied health professionals treating patients with COVID-19 are the physical, cognitive, and psychosocial presentation of survivors, the procedures that would be required within a rehabilitation department, and the treatment that should be provided. These three topics are discussed in order below.

Much of what has been published is based on expert opinion but not on direct observation of the actual trajectories of patients with COVID-19. Many of the early papers came from China and Italy , the locations that had the earliest experience with COVID-19; these can potentially provide insight into longer-term outcomes and ongoing patient needs. Organizations such as the World Health Organization (WHO) and physiotherapy organizations have also written acute-care clinical practice guidelines for patients with COVID-19 [1,2]. Some authors have extrapolated based on postacute patient presentations and the rehabilitation needs of patients with similar conditions, such as severe acute respiratory syndrome (SARS), Middle East respiratory syndrome (MERS), and sepsis, and from those requiring intensive care unit (ICU) care and assisted mechanical ventilation for other reasons [1-7]. These suggestions have been included here, and research on these conditions has informed what follows here regarding patient presentation and rehabilitation. However, the physical presentations of SARS and MERS are different than that of COVID-19, and the experiences of patients with these diseases are not necessarily the same as those of COVID-19 patients. SARS mainly causes respiratory symptoms along with diarrhea, while MERS causes more gastrointestinal and kidney symptoms along with respiratory symptoms [4,8]. COVID-19 appears to cause a wider variety of symptoms that are related to many body systems (eg, cardiac, kidney, and nervous systems) [4,9-12]. SARS and MERS are more lethal than COVID-19, with fatality rates of approximately 10% and 36%, respectively, and patients with both diseases are more likely to be hospitalized and require mechanical ventilation [8].

Patient Presentation For COVID-19 Survivors in the Rehabilitation Unit

Comorbidities, direct lung damage from COVID-19, and concurrent injuries to other organs and systems due to COVID-19 are all important considerations when creating a rehabilitation treatment plan for patients recovering from COVID-19. The information below presents several comorbidities and features of COVID-19; however, this knowledge continues to evolve.

Comorbidities

The leading comorbid conditions of patients with COVID-19 are hypertension (55%), coronary artery disease and stroke (32%), and diabetes (31%) [10]. Patients with COVID-19 are less likely to have the following chronic illnesses: liver diseases (9%), chronic obstructive pulmonary disease (7%), malignancy (6%), chronic renal failure (4%), gastrointestinal diseases (3%), central nervous system diseases (<1%), and immunodeficiency (1%) [10]. Therefore, survivors requiring prolonged rehabilitation are more likely to be older and to have preexisting cardiovascular and cerebrovascular disease, which may influence their rehabilitation and outcomes.

Complications of Severe COVID-19

The most likely early complications are acute respiratory distress syndrome (ARDS) and sepsis/septic shock, multi-organ failure, acute kidney injury, and cardiac injury [2,10,13]. These complications contribute to the need for ICU admissions [10].

Critical illness polyneuropathy (CIP) is a mixed sensorimotor neuropathy that leads to axonal degeneration; it may occur after COVID-19 [5,14-16]. In one study of patients hospitalized in the ICU with ARDS, up to 46% of patients presented with CIP [15]. CIP causes difficulty weaning from mechanical ventilation, generalized and symmetrical weakness (distal greater than proximal, but including diaphragmatic weakness), distal sensory loss, atrophy, and decreased or absent deep tendon reflexes [15,16]. It is associated with pain, loss of range of motion, fatigue, incontinence, dysphagia, anxiety, depression, posttraumatic stress disorder (PTSD), and cognitive loss [15]. Muscle biopsies and electromyographic testing can be diagnostic [15,16]; however, it is unclear how often these tests are performed in acute care settings post–COVID-19.

Critical illness myopathy (CIM), which presents in 48%-96% of ICU patients with ARDS, is a non-necrotizing diffuse myopathy with fatty degeneration, fiber atrophy, and fibrosis [5,15,16]. It is associated with exposure to corticosteroids, paralytics, and sepsis. The clinical presentation is similar to CIP but with more proximal than distal weakness and sensory preservation [15,16]. For both CIP and CIM, the cranial nerves and facial muscles are preserved [16]. Patients recover from myopathy more completely and quickly than from polyneuropathy; however, with both conditions, weakness, loss of function and quality of life, and poor endurance may persist for up to two years or even longer [15,16]. These prolonged changes are out of proportion with any residual loss of pulmonary function. Research studies on the effects of postacute care rehabilitation are inconclusive but suggest that comprehensive integrated inpatient rehabilitation is required [14].

Post–intensive care syndrome is described separately from CIP and CIM; it is associated with reduced pulmonary function (restrictive pattern), reduced inspiratory muscle strength, poor knee extension, poor upper extremity and grip strength, and low functional capacity [17]. Improvement occurs over a year or more [17].

Potential Persistence of SARS-CoV-2 Virus

Patients with COVID-19 who have physically recovered and have tested negative for the virus twice are deemed to be cured and noninfectious. However, there are reports of such patients subsequently testing positive 5-13 days later using a different manufacturer's test kit [18]. The virus may also persist in a patient's oropharyngeal cavity and stools for up to 15 days after they are declared cured of COVID-19 (no fever, no respiratory symptoms, 2 negative swab tests) [19]. This is of particular concern for patients who are intended to be discharged to rehabilitation facilities or long-term care because they may still be able to transmit disease, potentially infecting other patients or residents. Because of this, an additional 14 days in quarantine or discharge to a dedicated COVID-19 step-down unit has been recommended [18,20].

Cardiac Sequelae

In one study [13], 20% of hospitalized patients in China with COVID-19 had associated cardiac injury. These patients were more likely to have comorbidities, require mechanical ventilation, and have other complications (eg, ARDS 59%, acute kidney injury 9%, electrolyte disturbances 16%, hypoproteinemia 13% and coagulation disorders 7%) [13]. They also had much higher mortality (51% vs 5%) [13]. The mechanism of cardiac injury is uncertain [13]. Presentations can include arrhythmia, cardiac insufficiency, ejection fraction decline, troponin I elevation, and severe myocarditis with reduced systolic function [4,11]. One brief report profiled a woman with acute myopericarditis/heart failure post–COVID-19 [9]. As the research investigating cardiac injury included either cross-sectional studies or cohort studies with short-term follow-up (4 weeks), long-term outcomes are unknown [4,21]. Persistent tachycardia was common after SARS; however, it tended to resolve itself and was not associated with increased risk of death [4,13]. The presence of cardiac injury and accompanying comorbidities must be taken into consideration for patients entering rehabilitation.

Neurological Sequelae

Acutely, 36.4% of patients with COVID-19 develop neurological symptoms, including headaches, disturbed consciousness, seizures, absence of smell and taste, and paresthesia [5,21]. Posterior reversible encephalopathy syndrome, which causes headache, confusion, seizures and visual loss, is a potential complication of COVID-19 [5]. Viral encephalitis has been reported to be caused by COVID-19, and brain tissue edema and partial neuronal degeneration have been found in deceased patients [12,22]. It is hypothesized that COVID-19 can increase one's risk for acute cerebrovascular events [12]. At least one person has had Guillain-Barré syndrome associated with COVID-19; however, no causal relationship was determined [23].

SARS can induce neurological diseases such as polyneuropathy, viral encephalitis, and aortic ischemic stroke [24]. In MERS, almost one-fifth of patients showed neurological symptoms (altered consciousness, paralysis, ischemic stroke, Guillain-Barré syndrome, infectious neuropathy, or seizures) [25,26].

Other Body Systems

Patients severely affected by COVID-19 are more likely to have acute kidney injury as well as secondary infection [10,11]. Survivors of ARDS with mechanical ventilation have reported complications such as tracheal stenosis, heterotopic ossification, contractures, adhesive capsulitis, decubitus ulcers, hoarseness, tooth loss, sensorineural hearing loss, tinnitus, brachial plexus injuries, and entrapment neuropathies (peroneal and ulnar) [7,15]. They also had concerns regarding scarring and changes in appearance due to a variety of causes [15].

Osteoporosis and avascular necrosis have been reported as sequelae of SARS [27]. These conditions may have arisen due to the use of corticosteroids, which are not a suggested treatment for COVID-19 [10]. The prevalence of the use of corticosteroids to treat COVID-19 in different cities and countries is unknown.

Cognitive Sequelae

In one study of patients with respiratory failure or shock, after ICU admission (91% were mechanically ventilated), median global cognition scores (measured by the Repeatable Battery for the Assessment of Neuropsychological Status) were an average of 1.5 SD below the age-adjusted population mean and similar to those of patients with mild cognitive impairment [28]. Among these patients, 26% had scores 2 SD below the population mean, similar to scores for patients with mild Alzheimer disease [28]. Repeat testing at 12 months did not show much change [28]. The trend was the same for patients regardless of their age [15,28]. Cognitive impairment can persist [15,28]. Cognitive impairment can affect 70%-100% of patients at discharge; 46%-80% still have it one year later, and 20% still have it after 5 years [15]. All components of cognition can be affected, including attention, visual-spatial abilities, memory, executive function, and working memory [15,28]. However, there is a great deal of variation in these effects.

Psychological Sequelae

In research regarding ICU admissions for ARDS, adverse psychological impacts have been reported [15]. Even after 2 years, PTSD (22%-24%), depression (26%-33%), and general anxiety (38%-44%) are prevalent [15]. These have been reported as concerns post–COVID-19 as well, accompanied by a severe reduction in quality of life and function [7]. One of the greatest risk factors for post-ARDS mood disturbances is premorbid psychiatric illness [15]. Other risks include younger age, female sex, unemployment, alcohol use, and greater use of opioid sedation [15]. Family members may also suffer from PTSD, anxiety, and depression, and they may have difficulty managing their new caregiver roles [15].

Suggested Procedures for Post–COVID-19 Rehabilitation

After discharge from acute care, some patients who have recovered from the acute respiratory effects of COVID-19 will need further rehabilitation. How many of these patients may need postacute care? In one study, 30% of patients hospitalized with sepsis (which has a similar mortality rate to COVID-19) required facility-based care; another 20% required home health care [29].

Design and Procedures for an Inpatient Rehabilitation Unit

These suggestions regarding the design of an inpatient rehabilitation unit in this time of COVID-19, and the procedures to be followed, are mostly based on the experiences of China and Italy, who are ahead of Canada on the COVID-19 trajectory [5,21,29-31]. Experience during the SARS epidemic has also informed these suggestions on the provision of rehabilitative care [32]. Considerations for the design and procedures for inpatient rehabilitation after COVID-19 will become more refined as more survivors are treated and facilities learn from experience. Each suggestion from the literature [5,21,29-31], stated below, needs to be evaluated based on the unique circumstances of each rehabilitation unit as well as the needs of the patients and the greater health care community.

- A separate unit or area is suggested for the rehabilitation of patients post–COVID-19 and other patients arriving on the unit.
- Depending on need, it has been suggested that dedicated facilities should be used to treat patients post–COVID-19; examples may include underutilized rural hospitals or retrofitted unused buildings, such as university dormitories.
- It may be necessary to receive patients from acute care earlier than is generally done.
- Patients should stay in their rooms.
- Group therapy and therapy in rehabilitation gyms should be prohibited; therapy should be provided one-on-one in patients' rooms.
- Patients may be discharged to home sooner than usual (as soon as the family is able to take care of the patient) to free space.
- It may be difficult to discharge some patients because long-term care facilities and retirement homes may not be accepting new residents.
- Shared equipment must be decontaminated between patients; single-use equipment should be used where possible (eg, TheraBands rather than hand weights). Particular attention should be paid to electrode sponges, hydrocollator heat packs, gels, topical lotions, items for training manual dexterity, etc.
- Plan therapeutic activities to minimize the number of personnel involved when possible (eg, one therapist with a gait aid rather than a therapist and an assistant).
- Minimize the number of personnel entering a patient's room. Have a single staff member perform most (if not all) of the care and duties for a particular patient (eg, deliver food trays, make the bed, give medication, help with morning care).
- Walking practice should be done in parts of the hospital that are not commonly used.
- Surgical masks should be worn by the patients and the therapists.
- Patients should be kept at least 2 meters apart and avoid talking or eating while facing each other.

Personnel Considerations

Several suggestions for how allied health care professionals can adapt to working with COVID-19 rehabilitation patients are provided here. These suggestions have been informed by early COVID-19 reports and adapted from acute care guidelines [5,21,30,31].

- Health checks for personnel should be done frequently.
- There may be personnel shortages due to staff illness, staff in isolation, or redeployment.
- There may be changes in staff/patient ratios due to the increased number of one-on-one treatments (due to patients not being seen in the rehabilitation gyms).
- Continuous staff training will be required due to changing protocols/guidelines.
- Time should be taken to train and retrain personnel in the use of personal protective equipment (PPE).
- Physiotherapists and speech-language pathologists should wear higher levels of PPE if they may be exposed to aerosols from post–COVID-19 patients (eg, chest physiotherapy and swallowing assessments).
- It is important to seek ongoing input from front line staff to inform others. One group of rehabilitation professionals in Italy has been holding weekly webinars to stay up-to-date with the changing needs of rehabilitation during this time. These are available for an international audience.
- All nonrequired therapies and services should be cancelled, or telecommunication should be used to deliver them.
- The time taken to don PPE and perform infection control measures may decrease work efficiency.
- Allied health professionals should wear scrubs and a T-shirt at work and shower and change into street clothes before going home.
- Rehabilitation staff may be divided into two teams who work independently of each other. If several members of one team become ill, the other team can take over.
- Meetings should be held virtually when possible.

Home-Based Rehabilitation

If patients can be managed at home, this may be a good option, even for patients who might have been admitted to inpatient rehabilitation in the past [29,32]. Isolation is easier at home, and the burden on inpatient services would be lessened [29,32]. However, for this to be a viable choice, enhanced homecare services and outpatient rehabilitation must be available and able to provide a level of care on par with inpatient rehabilitation. This mode of delivery may be difficult to institute if home care staff are restricted from entering patients' homes [33]. However, given the right precautions, home-based care may be safer for patients who have recovered from COVID-19 and for other patients in a rehabilitation unit [33]. Home-based therapy can be provided over the internet and telephone via telerehabilitation [28]. Both assessment and treatment may be provided, either synchronously (ie, in real time) or asynchronously (eg, a prerecorded customized exercise plan). It is important that processes are put in place to ensure that patients and therapists can use this method successfully, given the rehabilitation needs and comfort with technology of the individual patient. One or more in-person visits may be required as well. Telerehabilitation may also be a good choice for patients being discharged from inpatient rehabilitation to continue their treatment and promote further recovery [30,32].

Rehabilitation Guidelines After COVID-19

The importance of rehabilitation after COVID-19 has been emphasized according to the framework of the International Classification of Functioning, Disability and Health [34,35]. The WHO does not have rehabilitation guidelines for patients post–COVID-19 [2]; however, the situation is evolving quickly. Each patient should be fully assessed by all health care staff (physicians, nursing, and allied health care workers), and a suitable treatment plan should be created in conjunction with the patient and the team while considering the patient's wishes and goals. The direct impact of COVID-19 (eg, on the respiratory system and other systems), its sequelae (eg, ICU stay, mechanical ventilation), and its comorbidities (eg, hypertension, diabetes) will inform the treatment plan [3]. The

discharge destination and estimated discharge date will also affect the plan. What follows are some guidelines suggested by health care professionals in China, Italy, and other areas based on their experiences and expert opinions [3,6]. The guidelines are influenced by the prevailing rehabilitation in the regions; however, there is very little actual research on the impact of rehabilitation after COVID-19, with only one randomized controlled trial published to date [36].

Respiratory Rehabilitation

Recommendations from both China and Italy state that to avoid aggravating respiratory distress or dispersing the virus unnecessarily, respiratory rehabilitation should not begin too early [3,37,38]. In the acute phase, diaphragmatic breathing, pursed lip breathing, bronchial hygiene, lung expansion techniques (positive expiratory pressure), incentive spirometry, manual mobilization of the ribcage, respiratory muscle training, and aerobic exercise are not recommended [37]. Secretions are not commonly a problem after COVID-19; however, comorbid conditions such as bronchiectasis, secondary pneumonia, or aspiration may increase secretions [7]. Postural drainage and standing (for gradually increasing periods of time) are suggested for secretion management [39].

In inpatient rehabilitation, respiratory assessment should include dyspnea, thoracic activity, diaphragmatic activity and amplitude, respiratory muscle strength (maximal inspiratory and expiratory pressures), respiratory pattern, and frequency [38,39]. Cardiac status should also be assessed [39].

In the postacute phase, inspiratory muscle training should be included if inspiratory muscles are weak. Deep, slow breathing, thoracic expansion (with shoulder elevation), diaphragmatic breathing, mobilization of respiratory muscles, airway clearance techniques (as needed), and positive expiratory pressure devices can be added based on assessed needs [38,39]. Care must be taken to avoid overloading the respiratory system and causing distress [7]. One randomized controlled trial showed a significant improvement in respiratory function, endurance, quality of life, and depression from 2 sessions of 10 minutes of respiratory rehabilitation per week for 6 weeks following discharge from acute care [36]. Rehabilitation included respiratory muscle training with a positive expiratory pressure device, cough exercises, diaphragmatic training (using 1 to 3 kilograms of weight on the abdomen in supine), chest stretching, and pursed-lip breathing. Patients should be monitored closely for shortness of breath, decreased SaO_2 (<95%), blood pressure <90/60 or >140/90, heart rate >100 beats per minute, temperature >37.2 ºC, excessive fatigue, chest pain, severe cough, blurred vision, dizziness, heart palpitations, sweating, loss of balance, and headache [3,38].

Mobility and Functional Rehabilitation

Functional assessment should include muscle joint range of motion, strength testing, and balance (use of the Berg Balance Scale is suggested) [3,7,38]. Exercise capacity can be assessed with the 6-minute walk test (with continuous oxygen saturation monitoring) and cardiopulmonary exercise testing. Function and disability can be measured with the International Physical Activity Questionnaire, Physical Activity Scale for the Elderly, and the Barthel Index to measure activities of daily living (ADLs).

Physiotherapy should begin in the acute inpatient setting and continue after transfer to inpatient rehabilitation [3,38]. Early mobilization should include frequent posture changes, bed mobility, sit-to-stand, simple bed exercises, and ADLs, while respecting the patient's respiratory and hemodynamic states [1,7]. Active limb exercises should be accompanied by progressive muscle strengthening (suggested program: 8-12 repetition-maximum load for 8-12 repetitions, 1 to 3 sets with 2 minutes rest between sets, 3 sessions a week for 6 weeks) [3,38]. Neuromuscular electrical stimulation can be used to assist with strengthening. Aerobic reconditioning can be accomplished with overland walking, cycle or arm ergometry, or a NuStep cross trainer [7]. Initially, aerobic activity should be kept to less than 3 metabolic equivalents of task. Later, progressive aerobic exercise should be increased to 20-30 minutes, 3-5 times a week. Balance work should be incorporated. Studies on the effectiveness of exercise interventions after SARS showed benefits for endurance, maximum oxygen consumption, and strength [40].

Occupational therapy should focus on ADL and instrumental ADL guidance as well as targeted interventions to facilitate functional independence and prepare patients for discharge [41]. Speech-language pathologists should assess and treat dysphagia and voice impairments resulting from prolonged intubation and may also address respiratory strength and coordination [41]. Occupational therapists should also address cognitive changes, while speech-language pathologists should address communication issues [41]. Chinese medicine techniques such as tai chi, the Qigong 6-character mnemonic, guided breathing, and Baduanjin qigong have been suggested by the Chinese [3,38]. Education on the importance of a healthy lifestyle and participation in family and social activities should be included. Psychological interventions delivered by occupational therapists, social workers or rehabilitation psychologists may be required for patients with depression, anxiety, or PTSD [41].

Conclusions

Rehabilitation after COVID-19 is similar to that provided for many patients in geriatric rehabilitation units who have been affected by illness or injury. Some may present with a variety of sequelae associated with the viral illness and with a prolonged stay in the ICU, possibly including mechanical ventilation. Many will have preexisting comorbidities. A thorough assessment and an individualized, progressive treatment plan which focuses on function, disability, and return to participation in society will help each patient to maximize their function and quality of life.

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The research was unfunded.

Authors' Contributions

LS researched and wrote the paper.

Conflicts of Interest

None declared.

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Abbreviations

ADL: activity of daily living
ARDS: acute respiratory distress syndrome
CIM: critical illness myopathy
CIP: critical illness polyneuropathy
COVID-19: coronavirus disease
ICU: intensive care unit
MERS: Middle East respiratory syndrome
PPE: personal protective equipment
PTSD: posttraumatic stress disorder
SARS: severe acute respiratory syndrome
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Knowledge and Behaviors Toward COVID-19 Among US Residents During the Early Days of the Pandemic: Cross-Sectional Online Questionnaire

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Abstract

Background: The early days of the coronavirus disease (COVID-19) pandemic in the United States brought uncertainty in the knowledge about COVID-19 and what to do about it. It is necessary to understand public knowledge and behaviors if we are to effectively address the pandemic.

Objective: The aim of this study is to test the hypothesis that knowledge about COVID-19 influences participation in different behaviors including self-reports of purchasing more goods than usual, attending large gatherings, and using medical masks.

Methods: This study was funded and approved by the Institutional Review Board on March 17, 2020. The cross-sectional online survey of 1034 US residents aged 18 years or older was conducted on March 17, 2020.

Results: For every point increase in knowledge, the odds of participation in purchasing more goods (odds ratio [OR] 0.88, 95% CI 0.81-0.95), attending large gatherings (OR 0.87, 95% CI 0.81-0.93), and using medical masks (OR 0.56, 95% CI 0.50-0.62) decreased by 12%, 13%, and 44%, respectively. Gen X and millennial participants had 56% and 76% higher odds, respectively, of increased purchasing behavior compared to baby boomers. The results suggest that there is a politicization of response recommendations. Democrats had 30% lower odds of attending large gatherings (OR 0.70, 95% CI 0.50-0.97) and 48% lower odds of using medical masks (OR 0.52, 95% CI 0.34-0.78) compared to Republicans.

Conclusions: This survey is one of the first attempts to study determinants of knowledge and behaviors in response to the COVID-19 pandemic in the United States. A national, coordinated effort toward a pandemic response may ensure better compliance with behavioral recommendations to address this public health emergency.

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KEYWORDS

public health; surveillance; COVID-19; knowledge; behavior; outbreak; infectious disease; health information

Introduction

Some of the most important problems in the world require an understanding and acceptance of science by the general public, including addressing health problems such as the emergence of the novel coronavirus (severe acute respiratory syndrome coronavirus 2 [SARS-Cov-2]) and subsequent disease (coronavirus disease [COVID-19]) transmission. SARS-CoV-2 first emerged in December 2019 in Hubei Province in Wuhan, China [1]. By mid-January 2020, Thailand and Japan were the first countries outside of China to report COVID-19 cases [1]. The Chinese government subsequently quarantined the greater Wuhan area on January 23, 2020, to prevent COVID-19 spread [2].

On January 21, 2020, the first COVID-19 case in the United States was reported in Washington State [3], and it was later reported that public health officials thought the virus was

prevalent in the community for at least several weeks [4]. In the United States, the federal government ordered that certain flights from China be halted and passengers from other locations at different ports of arrival would be screened [5]. The Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) began making recommendations based on the scientific knowledge of the situation to limit social contacts, encourage wise use of medical supplies including masks, and assure the public about the reliability of the food and consumable goods supplies [6]. However, even after these recommendations, there were reports of college students waiting in long lines at bars to celebrate their campuses closing [7], people buying medical-grade masks [8], and people hoarding everything from toilet paper to eggs and milk [9], even as the President sought to reassure the public that the supply of food and goods was secure [10].

Scholarship on the public understanding of science (PUS) aims to explain public understanding of, involvement in, and trust in science. In the face of the current pandemic, this requires the public to understand and trust those who are making recommendations to limit exposure and the spread of the illness. The deficit model of PUS posits that a lack of support for science (and a subsequent rejection of recommendations) is due to a lack of understanding about science, and if scientists can find a way to fill this knowledge deficit, then support for science will increase. A more contemporary view of PUS is that the public's knowledge is not deficient, but rather there is a deficit in trust of science and in scientific experts specifically. Because of an increasing lack of trust in these institutions, Solomon [11] observed that there is an increased personal rejection of science, which then leads to lower levels of scientific literacy and understanding of science. Low literacy and understanding may influence people to not follow recommendations for addressing science-based problems as is evident with the current pandemic.

Much of the PUS literature examines trends in scientific knowledge (albeit self-reported knowledge for the most part) and attitudes about science. Results are mixed as to whether increased knowledge leads to positive attitudes (variously described as trust, support, confidence, and support for funding) about science. Allum et al [12] observed a small positive correlation between knowledge about science and positive attitudes about science, and Miller [13] reports that there is public support for science even in the face of a scientific literacy rate of 20%. The public's support for science is necessary when addressing many important social issues, including an immediate need for the public to understand and trust the science about the novel coronavirus pandemic currently plaguing the world. If the public does not trust the underlying science about these issues and does not trust institutions that are tasked with managing this threat, it will be difficult to count on public support for policies to address these issues.

This paper describes a cross-sectional online survey designed to gauge public knowledge and behaviors about COVID-19 in the United States. Zhong et al [14] conducted a similar study in China, approximately 1 week after the Hubei Province was put on lockdown (approximately 8 weeks after the first case emerged), to determine the level of knowledge and public sentiment about the emerging pandemic in China. This study essentially replicates questions about knowledge from that study while asking about more specific behaviors. The sample was drawn from an online work platform (Amazon's Mechanical Turk) to determine the level of knowledge about COVID-19 and characteristics that influence knowledge and behaviors toward COVID-19. This is among one of the first attempts to investigate determinants of knowledge and behaviors in the public related to COVID-19 in the United States.

The general hypothesis guiding this research is that lower levels of knowledge about the coronavirus pandemic are associated with behaviors that are contrary to current guidelines that suggest against panic buying, large gatherings, and the use of medical masks. Furthermore, there are differences in knowledge and behaviors in different age groups, sex, education level, race, income, and political party identification.

Methods

Participants

This cross-sectional study recruited a convenience sample of respondents from Amazon Mechanical Turk (MTurk). MTurk is an online platform for recruiting remote workers to complete small tasks for small amounts of money. Some studies report that MTurk sample demographics are closer to the US general public than typical university samples [15,16] and tend to be more diverse than other internet samples [17]. MTurk provides a quick, inexpensive method to collect data from a wide cross-section of the general public.

The MTurk interface allows requestors (author JC) to advertise human intelligence tasks (ie, the survey in this case) to workers (survey participants). Although the survey was included on a website that anyone can openly access, JC advertised for workers aged 18 years and older who resided in the United States (thereby, creating a "closed" survey) and offered to pay them US $1 to complete the survey. By using MTurk, JC was unable to report how many potential people saw the advertised survey. The Institutional Review Board at Michigan State University determined that this research was exempt from full board review. Participants provided consent by answering a yes-no question at the start of the survey before they could move to the first question.

Survey

The survey was administered in two parts. Prior to accessing the survey, participants read an informed consent statement that described that participation was voluntary and that they could stop at any time. By clicking on a "next" button, participants were informed that they were providing consent to complete the survey. The first part asked participants basic demographic characteristics including year of birth, which was used to determine age and generational membership (eg, baby boomers, Gen X [18]); education; sex; income; race; political party affiliation; and place of residence (US state). Age was included to determine differences in knowledge and behavioral patterns based on age. Some reports in the United States essentially callout different age groups for ignoring public health recommendations [7,19]. In addition, there are well described patterns of health literacy based on education level [20] and

race [21], which may not be present in a homogeneous society such as China. Political party identification is associated with many attitudes and behaviors in the United States related to science and science-based recommendations [22,23]. Leaders from both major parties in the United States have reacted differently to the COVID-19 pandemic, likely influencing those who follow them [24,25]. No personal identifiers were collected.

The second part of the survey included 12 questions that were adapted from Zhong et al [14] to measure knowledge about COVID-19, including clinical characteristics, transmission, and prevention and control. The knowledge questions were scored with one point for each correct question, and an aggregate score was calculated (range 0-12), with higher scores indicating more knowledge about COVID-19. Three additional questions were asked to determine participation in specific behaviors related to recommendations from the CDC and the NIH, including whether participants had spent more money than usual in the last 2 weeks on cleaning supplies, personal hygiene products, and food (a proxy measure of hoarding); whether they had gone to any place in the last 5 days where there were more than 50 people present (contradicting CDC recommendations to avoid such gatherings); and if they had worn a mask when leaving the home in the last 5 days (contradicting CDC, NIH, and health care official guidance).

Statistical Analyses

Sample characteristics were generated using frequency analysis and other descriptive statistics as appropriate (Table 1). Knowledge scores were compared using two-tailed independent sample *t* tests for differences in mean scores between males and females, as well as groups based on whether people had engaged in hoarding activity or not, had attended large gatherings or not, and had worn masks or not. In addition, two-tailed independent sample *t* tests were used to determine differences in mean age between people who had engaged in these activities or not. An analysis of variance was used to determine differences in mean knowledge scores among groups based on education, race, income, political party, and generational age groups (eg, baby boomers, Gen X; Table 2). A multivariable linear regression was used to determine which demographic characteristics influenced knowledge scores, and a binomial logistic regression was used to determine which characteristics influence participating in hoarding behavior, attending large group events, and using masks (Table 3). All analyses were conducted using SPSS (version 25; IBM Corp). Reporting results followed Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [26].

The use of virtual private network networks allows people from all over the world to mimic US internet protocol (IP) addresses, so each participant was asked for their US state of residence, and this was compared to each IP address location to determine matches. JC then excluded responses from participants whose IP address location did not match their given state. A total of 36 participants were excluded for the final sample size of 1034. The survey was offered to MTurk workers on March 17, 2020, at 4:05 PM Eastern time, and all 1070 responses were completed by 6:13 PM Eastern time. To set the context for the setting of the study, at the time the survey was released, there were 5704 COVID-19 cases reported in the United States and 195,957 worldwide. At the date of this writing (March 24, 2020) there were 46,548 cases in the United States and 396,249 worldwide [27]. It is likely that these numbers vastly underrepresent the actual prevalence.

Table 1. Demographics and COVID-19 knowledge and behaviors of participants (N=1034).

Demographics	Participants
Age (years), mean (SD)	37.11 (11.22)
Age categories, n (%)	
Baby boomers (born 1946-1964)	104 (10.06)
Gen X (born 1965-1976)	140 (13.54)
Millennials (born 1977-1995)	717 (69.34)
Gen Z (born 1996 or later)	73 (7.06)
Education, n (%)	
High school/general equivalency diploma	102 (9.86)
Some college	295 (28.53)
Bachelor degree	469 (45.36)
Graduate/professional degree	168 (16.25)
Race, n (%)	
White	784 (75.82)
Black/African American	145 (14.02)
Asian/Pacific Islander	69 (6.67)
Other	36 (3.48)
Male sex, n (%)	602 (58.22)
Income (US $), n (%)	
0-29,999	232 (22.44)
30,000-59,999	366 (35.40)
60,000-89,999	235 (22.72)
≥90,000	201 (19.44)
Political party, n (%)	
Republican	289 (27.95)
Democrat	487 (47.10)
Independent	258 (24.95)
Behaviors, n (%)	
Participant reported spending more money at a grocery or club store on cleaning supplies, personal hygiene products, or food than normal in the last 2 weeks	649 (62.77)
Participant reported going to any place with more than 50 people in attendance at the same time in the last 5 days	320 (30.95)
Participant reported wearing a mask when leaving home in the last 5 days	244 (23.60)
Knowledge questions answered correctly, n (%)	
The main clinical symptoms of COVID-19[a] are fever, fatigue, and dry cough (true).	948 (91.68)
Unlike the common cold, stuffy nose, runny nose, and sneezing are less common in persons infected with COVID-19 (true).	668 (64.60)
There currently is no effective cure for COVID-19, but early symptomatic and supportive treatment can help most patients recover from the infection (true).	942 (91.10)
Not all persons with COVID-19 will develop severe cases. Those who are elderly and have chronic illnesses are more likely to be severe cases (true).	886 (85.69)
Eating or contacting wild animals would result in infection by the COVID-19 virus (false).	541 (52.32)
Persons with COVID-19 cannot transmit the virus to others when a fever is not present (false).	820 (79.30)
The COVID-19 virus spreads via respiratory droplets of infected individuals (true).	917 (88.68)

Demographics	Participants
Ordinary residents can wear general medical masks to prevent infection by the COVID-19 virus (false; although this knowledge has changed since survey administration).	567 (54.84)
It is not necessary for children/young adults to take measures to prevent infection with COVID-19 (false).	878 (84.91)
To prevent infection with COVID-19, individuals should avoid going to crowded places and avoid public transportation (true).	973 (94.10)
Isolation and treatment of people who are infected with COVID-19 are effective ways to reduce the spread of the virus (true)	957 (92.55)
People who have contact with someone infected with the COVID-19 virus should be immediately isolated. In general, the observation period is 14 days (true).	955 (92.36)

[a]COVID-19: coronavirus disease.

Table 2. Group comparisons of knowledge scores and age comparisons of participants (N=1034).

Groups	Score, mean (SD)	*t* test/*F* test	*P* value
Age categories		*F*=9.184	<.001
Baby boomers (born 1946-1964)	10.55 (1.48)		
Gen X (born 1965-1976)	9.86 (1.74)		
Millennials (born 1977-1995)	9.62 (1.94)		
Gen Z (born 1996 or later)	9.19 (2.40)		
Sex		*t*=4.184	<.001
Male	9.52 (2.07)		
Female	10.01 (1.69)		
Education		*F*=7.513	<.001
High school/general equivalency diploma	9.66 (1.96)		
Some college	10.14 (1.49)		
Bachelor's degree	9.61 (2.01)		
Graduate/professional degree	9.33 (2.24)		
Race		*F*=23.43	<.001
White	9.92 (1.85)		
Black/African American	8.51 (2.11)		
Asian/Pacific Islander	9.91 (1.82)		
Other	9.66 (1.39)		
Income (US $)		*F*=2.861	.04
0-29,999	9.58 (1.85)		
30,000-59,999	9.60 (2.13)		
60,000-89,999	9.76 (1.83)		
≥90,000	10.05 (1.73)		
Political party identification		*F*=21.821	<.001
Republican	9.11 (2.07)		
Democrat	10.04 (1.74)		
Independent	9.79 (1.97)		
Behaviors			
Spent more money on cleaning supplies, personal hygiene products, or food than normal		*t*=4.001	<.001
Yes	9.54 (1.95)		
No	10.02 (1.87)		
Participant reported going to any place with more than 50 people in attendance		*t*=4.787	<.001
Yes	9.26 (2.16)		
No	9.93 (1.79)		
Participant reported wearing a mask when leaving home in the last 5 days		===*t* =16.848	<.001
Yes	8.02 (1.85)		
No	10.25 (1.63)		
Behaviors age comparisons			
Spent more money on cleaning supplies, personal hygiene products, food than normal		*t*=1.231	.22
Yes	36.77 (10.42)		
No	37.70 (12.47)		
Participant reported going to any place with more than 50 people in attendance		*t*=1.895	.05

Groups	Score, mean (SD)	*t* test/*F* test	*P* value
Yes	36.18 (10.02)		
No	37.54 (11.71)		
Participant reported wearing a mask when leaving home in the last 5 days		*t*=4.153	<.001
Yes	34.76 (9.63)		
No	37.84 (11.58)		

Table 3. Determinants of knowledge score and behavior outcomes of participants (N=1034).

Groups	Knowledge score		Bought more goods, OR[a] (95% CI)	Gathering of more than 50 people, OR (95% CI)	Wore mask, OR (95% CI)
	b (SE)	*P* value			
Constant, b (SE)	9.90 (0.29)	<.001	0.69 (0.51)	–0.08 (0.53)	2.99 (0.73)
R^2	0.149	N/A[b]	0.08	0.07	0.45
Knowledge score	N/A	N/A	0.88 (0.81-0.95)	0.87 (0.81-0.93)	0.56 (0.50-0.62)
Age (reference: baby boomers)					
Gen X (born 1965-1976)	–0.53 (0.24)	.02	1.76 (1.03-3.01)	1.23 (0.68-2.23)	1.28 (0.56-2.88)
Millennials (born 1977-1995)	–0.64 (0.19)	.001	1.56 (1.01-2.41)	1.35 (0.82-2.22)	1.27 (0.63-2.54)
Gen Z (born 1996 or later)	–1.28 (0.28)	<.001	0.94 (0.50-1.77)	0.96 (0.46-1.99)	0.83 (0.28-2.42)
Male sex	–0.31 (0.12)	.007	0.88 (0.67-1.15)	0.96 (0.73-1.28)	1.35 (0.92-1.96)
Education (reference: high school/general equivalency diploma)					
Some college	0.36 (0.21)	.09	1.40 (0.88-2.23)	1.62 (0.93-2.81)	1.23 (0.51-2.95)
Bachelor degree	–0.17 (0.20)	.39	1.88 (1.19-2.97)	1.59 (0.93-2.72)	4.47 (2.00-9.97)
Graduate/professional degree	–0.41 (0.24)	.09	2.11 (1.22-3.65)	1.67 (1.46-4.87)	7.41 (3.07-17.9)
Race (reference: white)					
Black/African American	–1.19 (0.17)	<.001	1.28 (0.84-1.95)	1.16 (0.78-1.73)	2.48 (1.52-4.07)
Asian/Pacific Islander	–0.01 (0.23)	.97	1.45 (0.82-2.54)	0.93 (0.53-1.64)	0.62 (0.27-1.42)
Other	–0.19 (0.31)	.54	0.80 (0.40-1.59)	1.11 (0.53-2.33)	1.40 (0.53-3.67)
Income (US $; reference: 0-29,999)					
30,000-59,999	0.26 (0.15)	.09	1.44 (1.02-2.05)	1.13 (0.78-1.66)	0.99 (0.59-1.65)
60,000-89,999	0.40 (0.17)	.02	1.44 (0.97-2.14)	1.04 (0.68-1.59)	1.21 (0.69-2.11)
≥90,000	0.71 (0.18)	<.001	1.54 (1.01-2.36)	1.22 (0.78-1.90)	0.76 (0.42-1.39)
Political party identification (reference: Republican)					
Democrat	0.76 (0.14)	<.001	1.07 (0.77-1.49)	0.70 (0.50-0.97)	0.52 (0.34-0.78)
Independent	0.57 (0.16)	<.001	0.78 (0.54-1.12)	0.84 (0.58-1.23)	0.34 (0.19-0.57)

[a]OR: odds ratio.

[b]Not applicable.

Results

A total of 1070 participants completed the survey. On average it took 4 minutes to complete the survey (equivalent to US $15/hour). Participants were on average 37.11 years of age ranging from 19 to 77. Of the 1034 participants, less than half of the participants completed a bachelor's degree, more than three-fourths reported a white race, over half were male, over one-third reported an income between US $30,000 and US $59,999, and less than half identified as Democrats. Additional demographic information is included in Table 1.

Results for each of the COVID-19 knowledge questions are included in Table 1. Answers for questions ranged from over half to almost all participants answering correctly. The mean knowledge score was 9.72 (SD 1.93, range 0-12) for an overall correct percentage of approximately 80%, which was lower than the 90% correct rate that Zhong at al [14] reported in their

sample of Chinese citizens at approximately 2 months into the outbreak.

Knowledge scores were significantly different between groups based on sex, generational ages, education, race, income, and political party identification. In general, baby boomers, females, those with some college education, and those with higher incomes were more knowledgeable about COVID-19, while black participants and Republicans were less knowledgeable (Table 2).

Regarding behaviors, participants who reported spending more money in the last 2 weeks, going to gatherings with more than 50 people, or wearing masks outside the home, were less knowledgeable about COVID-19 compared to participants who did not report these activities. In addition, participants who reported these behaviors were also significantly younger, except for increased spending, which had no significant difference in age (Table 2).

The multivariable linear regression (Table 3) results suggest several important relationships. First, compared to baby boomers, members of Gen X, millennials, and Gen Z had significantly lower COVID-19 knowledge scores. Exponentiating the unstandardized parameter estimate indicates that predicted mean knowledge scores for Gen X, millennials, and Gen Z were 42%, 53%, and 73%, respectively, lower than baby boomers. Second, black participants had mean knowledge scores that were 70% lower when compared to whites. Third, participants with higher incomes had higher knowledge scores. Fourth, Democrats and independents had mean knowledge scores that were 113% and 76% higher, respectively, than Republicans.

The binary logistic regression analysis (Table 3) results revealed several predictors of each behavior. Self-reports of buying more goods than usual was negatively associated with COVID-19 knowledge. For every point increase in knowledge score, the odds of reporting unusual buying behavior decreased by 12%. In the context of generational groups, the odds of reporting purchasing behavior increased by 76% and 56% for Gen X and millennials, respectively, compared to baby boomers. In addition, people with higher education were associated with increased buying behaviors. The odds of unusual purchasing behavior increased by 88% and 111% for people with bachelor's degrees and graduate or professional degrees, respectively, compared to those with a high school education. Finally, those with higher incomes had increased odds of unusual purchasing behavior.

For every point increase in knowledge scores, the odds of attending large gatherings in the last 5 days decreased by 13%. Participants with graduate or professional degrees had 67% greater odds of attending large gatherings, compared to those with a high school education. Finally, Democrats had 30% lower odds of attending large gatherings compared to Republicans.

For every point increase in knowledge scores, the odds of wearing a mask outside the home decreased by 44%. The largest effect of any of the analyses revealed that those with a bachelor's degree or a graduate or professional degrees had 347% and 641%, respectively, increased odds of wearing masks outside the home compared to respondents with a high school education. Black participants had 148% increased odds of wearing masks outside the home compared to white participants. In addition, Democrats and independents had 48% and 66% lower odds, respectively, of reporting wearing masks compared to Republicans.

Discussion

The PUS literature posits that an increase in knowledge leads people to understand science and trust in the institution of science. Extending this to the current COVID-19 pandemic, JC hypothesized that increased knowledge should lead to willingness to follow public health recommendations. In this sample, lower knowledge is associated with self-reports of engaging in purchasing more goods than necessary, attending gatherings of more than 50 people, and wearing medical masks outside the house. In addition, there were differences in knowledge about COVID-19 based on age group. In fact, contrary to recent US media, baby boomers in this sample were more knowledgeable about COVID-19 than all other age groups and were less likely to engage in purchasing behavior that could be considered hoarding. In general, people who did not engage in these behaviors had significantly higher knowledge scores. Finally, people who reported attending large gatherings and wearing masks in public were younger on average.

The average knowledge score for this entire sample was about 9.72 out of 12 total points (approximately 80%); this was 8 weeks after the first case was diagnosed in the United States. Approximately 8 weeks after the first diagnosis in China, the mean knowledge score for a sample of Chinese citizens was 10.8/12 (approximately 90%) [14], and it was suggested that the knowledge of Chinese citizens was high because of their experiences with the severe acute respiratory syndrome outbreak in the early 2000s and the observation that this sample was relatively affluent and highly educated. In this study, a difference of 1 point (8%) on the knowledge test is equivalent to about one question. This is a small difference, and most of the differences detected as statistically significant were about 1 point or less between groups. The large sample size likely contributes to this observation, but much smaller sample sizes on the order of 50-100 could have also detected these differences as significant. In addition, the knowledge differences detected based on age, race, sex, and political ideology were in agreement with other literature about controversial scientific topics.

In this sample, nearly 30% of people reported attending gatherings or going to places with more than 50 people in the last 5 days, contrary to advice from the CDC since March 12, 2020 (survey conducted on March 17, 2020). In China, only 3.6% of people reported going to crowded places in the previous 2 weeks [14]. It is possible that the coordinated effort and unchecked authority of the Chinese government to lockdown provinces provided most of the motivation for Chinese citizens to obey these mandates. To date, there has not been a coordinated effort by the US government to lockdown the nation. There is some debate whether the federal government even has constitutional authority, so individual states are left to make decisions about "shelter at home" policies and similar

efforts. As of this writing, California, Illinois, New York, Washington, Michigan, Massachusetts, Indiana, Oregon, and West Virginia have issued stay-at-home orders; however, no state had issued a stay-at-home order as of the date of the survey, March 17, 2020. California was the first state in the nation to issue the order on March 19, 2020. Although many citizens all over the country could have anticipated some of these stay-at-home policies, which might have led them to change their purchasing behaviors, it is not possible with this data to determine if there were differences in purchasing behavior based on the presence of a stay-at-home order. With about 1 in 3 US citizens ordered to stay home, it is likely in the coming weeks that fewer people will report attending large gatherings. With recent changes in recommendations about wearing masks, that number is also likely to change.

Use of masks is an evolving and cultural phenomenon. In Asia, people are encouraged and even mandated to wear masks outside the house. In China, only 2.0% of people reported not wearing masks outside the home [14]. In this sample, approximately 76% of people did not wear masks outside the home in the last 5 days, which is perhaps reflective of the CDC and NIH recommendations that the general public not use masks so that they are saved for frontline health care workers [28]. However, it is probably more likely that masks could not be found in the United States because of a lack of supply combined with hoarding behavior [10]. Still, 24% of people reported using masks, indicating that a large section of the US public chose to ignore recommendations. It is important to note that the debate on masks has changed even since this survey was conducted, and the nationwide recommendation now is to wear masks, which has been made based on the understanding that many people with mild symptoms may not even know they are infected with COVID-19. Mask use could prevent infecting others by asymptomatic carriers. Knowledge about COVID-19 is rapidly changing, and what was considered “correct” at the time of this writing may not be “correct” anymore.

Political party identification significantly influenced knowledge about COVID-19 as well as behaviors related to attending large gatherings and wearing medical masks. To summarize, Republicans had lower knowledge and had higher odds of attending large gatherings and wearing masks in public compared to Democrats and independents. These behaviors directly contradict recommendations by both the CDC and NIH. In the United States, there is a widening gap in trust in science and science-based recommendations based on political party [22], which may contribute to the observation here that Republicans are more likely to ignore recommendations about the COVID-19 response. In addition, the results reported here suggest that there continues to be political divisions over the role of scientific experts in policy matters [23]. That is, Democrats want expert involvement and believe scientists should be involved in policy recommendations. Conversely, Republicans believe scientists should stay out of policy debates. These attitudes may be reflected in the results that Republicans have lower knowledge about COVID-19 and have higher odds of participating in behaviors that are not recommended by authorities to stem the tide of the current pandemic. However, to more definitively conclude anything about the involvement of scientists in policy debates, specific questions about this matter could be added to future surveys.

There are some limitations to this research. First, knowledge questions were not validated and scientific knowledge is currently a moving target. For example, although the current consensus is that eating wild animals will not transmit the disease, living and working in close proximity to animals clearly influenced this outbreak and could influence future outbreaks. As such, the argument for banning wet markets in China is gaining momentum, but knowledge about proximity to animals, as opposed to using them as a food source, might be conflated. Second, knowledge regarding who is most at risk for COVID-19 may change as the pandemic proceeds, as well as with experiences in different countries. For instance, fewer younger people in China were infected, while in the United States, a different pattern appears to be emerging [29]. Third, this was a convenience sample of US residents from every state in the country, but people were able to self-select based on their interest and experience with the topic. It is possible that sample demographics may not completely represent the US public. Fourth, although the survey questions were not able to be validated given the fast-moving nature of the pandemic response in the United States, the questions do have face value in the context of the situation at the time the survey was conducted. However, the first question about purchasing behavior (cleaning supplies, hygiene products, and food) might be better asked as three separate questions. Fifth, the theory that PUS and knowledge about science drives behavior is just one theory to study behaviors, attitudes, and beliefs. Future studies could incorporate models based on the theory of planned behavior, social cognitive theory, or even health belief models with questions devised to elicit responses about how desires, needs, and beliefs drive the types of behaviors studied here.

This survey is one of the first attempts to describe determinants of US public knowledge and behavioral response to the emerging COVID-19 pandemic in the United States. Although knowledge about COVID-19 is generally high, there are differences in knowledge based on age, sex, education, income, race, and political party identification. These differences appear to have prevented a coordinated effort at slowing the spread of the pandemic in the United States in the early days of the pandemic. Ignoring official recommendations for crowd avoidance, the use of medical supplies, and purchasing behaviors that signal hoarding of goods, does not bode well for efforts to contain the spread of the virus and limit exposure to vulnerable populations. Without a coordinated national response, it is likely that the United States will experience a longer, more drawn out battle than if such coordination would occur. In addition, it is important for future waves of COVID-19 that we consider implementing specific policies and programs to target groups of people who have been unequally affected by the pandemic. Now is the time for policy makers to address the structural issues in many urban areas that adversely affect minority health care, especially when we observe disparities in mortality based on race. Now is the time for policy makers to ensure that access to care, especially specialized care, in rural areas does not hamper the response to COVID-19, which is likely to hit rural areas in the next wave. Finally, it is time for policy makers to reverse

the decades long decimation of public health funding and infrastructure that has left the United States so vulnerable to the ravages of this pandemic.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
CHERRIES: Checklist for Reporting Results of Internet E-Surveys
COVID-19: coronavirus disease
IP: internet protocol
MTurk: Mechanical Turk
NIH: National Institutes of Health
OR: odds ratio
PUS: public understanding of science
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Viewpoint

Preparation for Quarantine on the Cruise Ship Diamond Princess in Japan due to COVID-19

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Abstract

Background: Japan implemented a large-scale quarantine on the Diamond Princess cruise ship in an attempt to control the spread of the novel coronavirus severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in February 2020.

Objective: We aim to describe the medical activities initiated and difficulties in implementing quarantine on a cruise ship.

Methods: Reverse transcription–polymerase chain reaction (RT-PCR) tests for SARS-CoV-2 were performed for all 3711 people (2666 passengers and 1045 crew) on board.

Results: Of those tested, 696 (18.8%) tested positive for coronavirus disease (COVID-19), of which 410 (58.9%) were asymptomatic. We also confirmed that 54% of the asymptomatic patients with a positive RT-PCR result had lung opacities on chest computed tomography. There were many difficulties in implementing quarantine, such as creating a dividing traffic line between infectious and noninfectious passengers, finding hospitals and transportation providers willing to accept these patients, transporting individuals, language barriers, and supporting daily life. As of March 8, 2020, 31 patients (4.5% of patients with positive RT-PCR results) were hospitalized and required ventilator support or intensive care, and 7 patients (1.0% of patients with positive RT-PCR results) had died.

Conclusions: There were several difficulties in implementing large-scale quarantine and obtaining medical support on the cruise ship. In the future, we need to prepare for patients' transfer and the admitting hospitals when disembarking the passengers. We recommend treating the crew the same way as the passengers to control the infection. We must also draw a plan for the future, to protect travelers and passengers from emerging infectious diseases on cruise ships.

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KEYWORDS

SARS-CoV-2; COVID-19; infectious control; cruise ship quarantine; pandemic; outbreak; surveillance; preparation; infectious disease; public health; quarantine

Introduction

Since severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) was first detected in China on December 31, 2019, it has rapidly spread all over the world and 230,104 people have died from coronavirus disease (COVID-19) in 215 countries as of May 3, 2020 [1]. There have been many infections and related problems on ships worldwide such as the Grand Princess (United States) [2], the Ruby Princess and Ovation of the Seas (Australia), and Costa Luminosa (France). Japan implemented a large-scale quarantine on the Diamond Princess cruise ship, and all passengers including asymptomatic patients were tested for SARS-CoV-2 by using reverse transcription–polymerase chain reaction (RT-PCR); valuable

lessons can be learned from the steps taken for quarantine implementation on the cruise ship. The Diamond Princess had 3711 people (2666 passengers and 1045 crew) on board, and the average age of passengers was 66.0 years [3]. The ship left Yokohama Port on January 20, 2020. A passenger who disembarked from the ship in Hong Kong on January 25 developed a fever on January 30. This passenger was confirmed to be positive for COVID-19 on February 1. The ship arrived at Yokohama earlier than scheduled on February 3, at which time the quarantine began [3].

We, the authors, worked as medical staff at the entrance of the Diamond Princess from February 14 to 17, 2020, when the number of RT-PCR–confirmed COVID-19 cases reached its peak. We supported the transport of people with positive RT-PCR results by coordinating with the hospital and transportation provider, depending on their condition. In addition to scheduling transportation, we arranged for emergency transportation of people whose symptoms worsened. Since February 18, Fujita Medical University Okazaki Medical Center (Shinkaiin Temple) has accepted a large number of patients with mild symptoms and has served as a place for quarantining asymptomatic patients.

We report on the experience of this large-scale quarantine and the passenger room isolation procedures implemented to control COVID-19 aboard a cruise ship. During the quarantine, RT-PCR testing of throat swabs was extended to all passengers in the following order:

1. Symptomatic patients and their close contacts
2. Elderly people aged 80 years or above and people with comorbidities
3. People aged 75 years and above
4. People aged 70 years and above
5. All other passengers
6. All crew members

This report did not contain any personal information, and all information was anonymized before it was added into the report. There was no reward for the research participants, since there are no economic interests that affect the research results. This research paper was approved by the ethics committee of Yodogawa Christian Hospital (Approved No 2020-006). RT-PCR tests were performed for all 3711 passengers and crew of the Diamond Princess; 696 (18.8%) passengers tested positive, of which 410 (58.9%) were asymptomatic (Figure 1, Table 1). As of March 8, 2020, 31 patients (4.5% of those with positive RT-PCR results) were hospitalized with a ventilator or in intensive care units, and 7 patients (1.0% of those with positive RT-PCR results) had died (Figure 2) [4,5]. We transported asymptomatic people to the quarantine location. The criteria for “asymptomatic” status were no fever (body temperature <37.5 °C/99.5 °F as measured by an axillary thermometer), with an SpO_2 (blood oxygen saturation) of 97% or above as measured with a pulse oximeter in room air. Of the 128 people who were transported, 75% (n=96) had positive RT-PCR results while on board the ship. Of the asymptomatic people with RT-PCR–positive results, 13.5% (n=13) required medical intervention after being transported from the ship and were transferred from the quarantine location to a hospital within 24 hours of arrival.

Figure 1. The total number of reverse transcription–polymerase chain reaction (RT-PCR) tests and positive results.

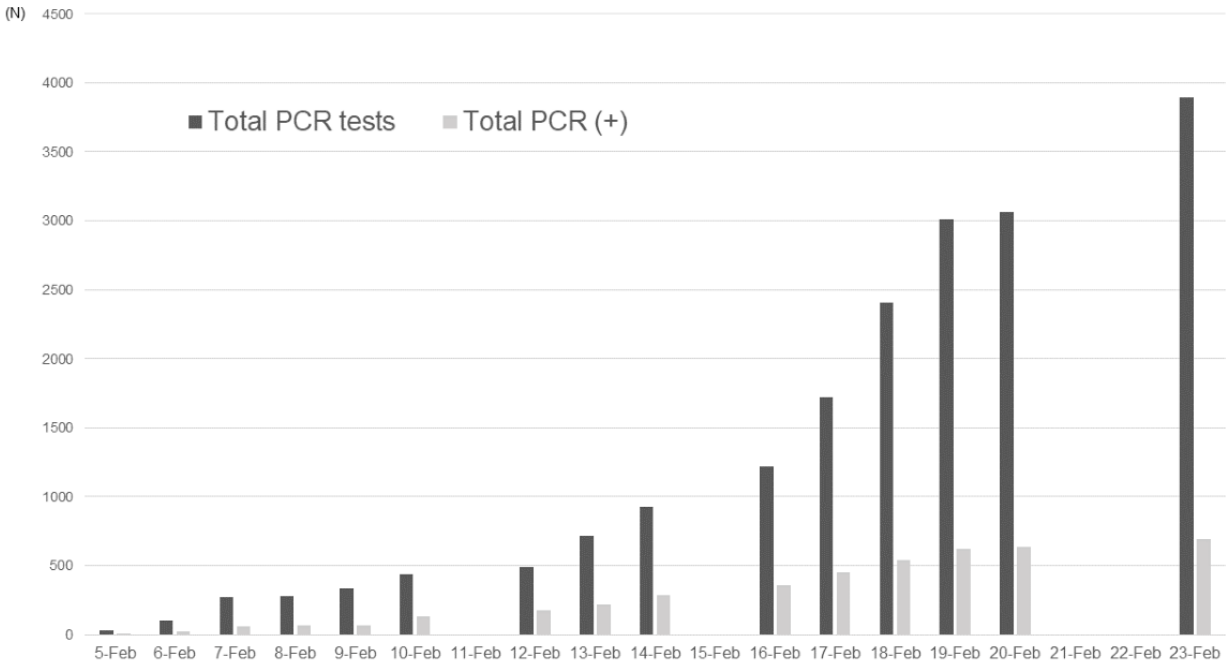


Table 1. Reverse transcription–polymerase chain reaction tests and the results.

Date (year 2020)	RT-PCR[a] tests, n	Positive RT-PCR results, n (%)	Total RT-PCR tests[b], n	Total positive RT-PCR results[c], n (%)
5-Feb	31	10 (32.3)	31	10 (32.3)
6-Feb	71	10 (14.0)	102	20 (19.6)
7-Feb	171	41 (24.0)	273	61 (22.3)
8-Feb	6	3 (50.0)	279	64 (22.9)
9-Feb	57	6 (10.5)	336	70 (20.8)
10-Feb	103	65 (63.1)	439	135 (30.8)
11-Feb	__[d]	—	439	135 (30.8)
12-Feb	53	39 (73.6)	492	174 (35.4)
13-Feb	221	44 (19.9)	713	218 (30.6)
14-Feb	217	67 (30.9)	930	285 (30.6)
15-Feb	—	—	930	285 (30.6)
16-Feb	289	70 (24.2)	1219	355 (29.1)
17-Feb	504	99 (19.6)	1723	454 (26.3)
18-Feb	681	88 (12.9)	2404	542 (22.5)
19-Feb	607	79 (13.0)	3011	621 (20.6)
20-Feb	52	13 (25.0)	3063	634 (20.7)
21-Feb	—	—	3063	634 (20.7)
22-Feb	—	—	3063	634 (20.7)
23-Feb	831	57 (6.9)	3894	691 (17.7)

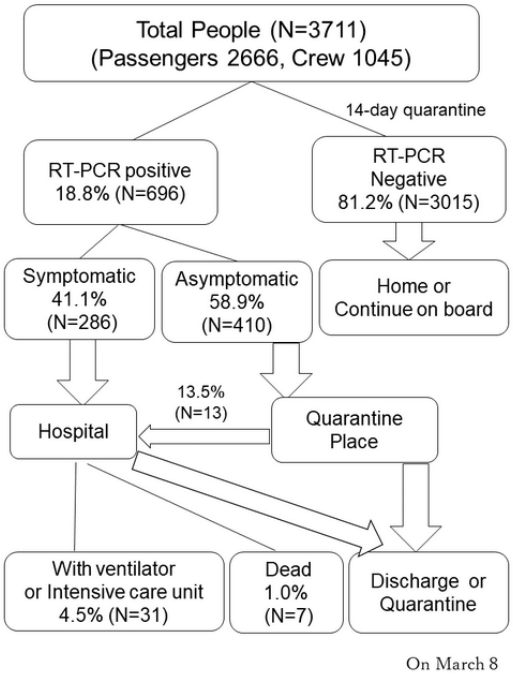
[a]RT-PCR: Reverse transcription–polymerase chain reaction.

[b]The total RT-PCR test number is larger than the number of passengers and crew on board because some people required retesting due to the appearance of new symptoms.

[c]The total number of positive RT-PCR results does not include the people who were transported by emergency disembarkation to the medical institution.

[d]Not available.

Figure 2. The flowchart of a large-scale cruise ship quarantine.



Case fatality ratios and infection fatality ratios on the Diamond Princess ship were reported to be 2.6% (95% CI 0.89-6.7) and 1.3% (95% CI 0.38-3.6), respectively [6]. Mizumoto et al [7] determined that most infections occurred before the quarantine started. However, the environment of a cruise ship is vulnerable to the spread of infection, and the peak reproduction number on the Diamond Princess ship was 12.1 before the quarantine started [8]. We will describe the medical activities and difficulties experienced in infection control on the cruise ship.

Structure of the Cruise Ship

First, the structure of the cruise ship made it difficult to carry out the medical services required for an outbreak of an emerging infectious disease. The situation necessitated onboard quarantine with complete inspection and isolation of RT-PCR–positive persons. Additionally, today's cruise ships are huge. The Diamond Princess had 3706 people on board, including 2706 passengers of many nationalities. The ship began service in 2004; it is 290 meters (951.4 feet) long and 37.5 meters (123.0 feet) wide, with 18 floors [9]. Each room has a toilet and shower. The high-class rooms are large and have balconies. As the class level decreases, the area of the rooms becomes smaller and the rooms are located on lower floors. The lowest class rooms are interior rooms with no windows. Crew rooms are even smaller and have limited personal space. All large cruise ships have many rooms with narrow corridors, and many people gather in small spaces, such as restaurants, theaters, and casinos. The Diamond Princess was anchored at Daikoku Wharf (Yokohama City) and berthed at the quay (Figure 3). The ship has three elevator halls: one near the bow, one near the center, and one near the stern. The opening at the stern is used only for carrying supplies, so we could only use 2 elevators to enter. From the outside of the ship, we passed through a narrow passageway and entered the ship from the opening near the center (Figure 4). Then, we passed through a security check and reached the elevator hall in front of the medical center.

Figure 3. The Diamond Princess was anchored at Daikoku Wharf.

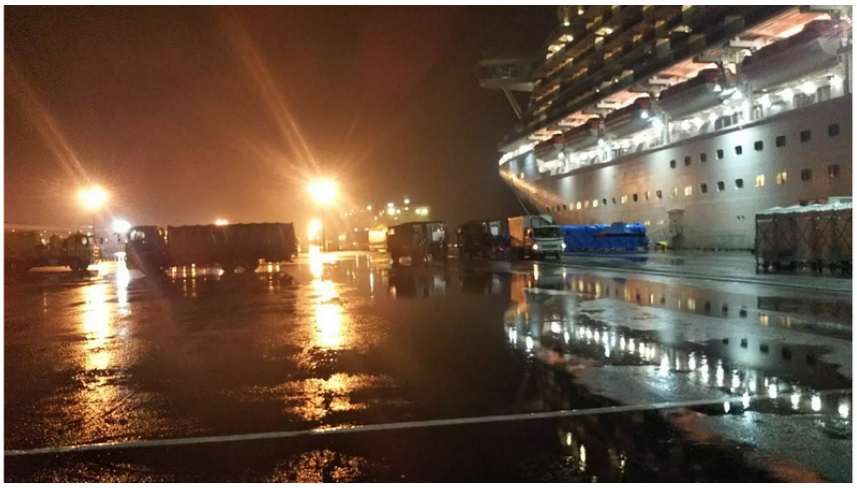


Figure 4. The entrance of the ship.

Emerging Diseases and Cruise Ships

Emerging infectious diseases are novel to humans and the mode of transmission, infectivity (basic reproduction number), severity rate, fatality rate, and long-term prognosis are not known at the time of confirmation. At the beginning of the outbreak in China, it was thought that COVID-19 could not be spread via human-to-human transmission. However, it later became clear that human-to-human infection could occur. The possibility of airborne infection was also raised. At the beginning of implementation of the quarantine, we had to enact measures based on limited information, which is confusing. In general,

when we do not have the exact information, we have to consider the maximum risk possible. During the quarantine of the Diamond Princess, a lot of new information about COVID-19 in China was published; hence, we had to change our practice and attitude accordingly. There might be a gap between the new and old infection control measures.

There were several collaborators in the response to the outbreak on the Diamond Princess, such as the original medical staff; Ministry of Health, Labour and Welfare; quarantine support team; Self-Defense Forces; Disaster Medical Assistance Team (DMAT); Japanese Red Cross Society; Disaster Psychiatric Assistance Team (DPAT); Japan Medical Association Team (JMAT); and National Hospital Organization. Some staff did not have medical qualifications and each organization had different standards.

The Quarantine Strategy of the Japanese Government

On February 3, 2020, when the ship arrived at Yokohama, a quarantine was initiated. All passengers and crew underwent medical examinations. On February 5, the RT-PCR results from the throat swab for symptomatic people and their close contacts revealed that 10 of 31 individuals were positive for SARS-CoV-2. On the same day, the Japanese government decided that all passengers were to be quarantined in their cabins for 14 days [10]. Based on international guidance on infection control, the crew continued to maintain ship functions and support passengers for their food, clothing, and shelter-related needs.

At this point, the RT-PCR testing took about 6 hours, but it took additional time to collect and transport samples and verify the results. To protect the personal information of the people involved, specimens are not managed by name but by individually identified specimen ID. Caution was required when double-checking the test results against the individual ID.

A total of 2666 passengers and 1045 crew members underwent RT-PCR testing [4,5]. We could not isolate the cabin crew since they needed to maintain the ship's functions and provide passengers with food and laundry. Of the cabin crew, those with symptoms or positive RT-PCR results disembarked and were transferred to the appropriate facilities, depending on their condition. Those with negative RT-PCR results were transferred to a residential facility to be observed for 14 days after disembarkation. We were aware that the RT-PCR test was not sensitive enough and might have led to false negatives. Those who tested positive were promptly notified that they were positive before being transferred to the hospital or quarantine facilities, under the Quarantine Law. Since a certain number of false negative RT-PCR test results were expected, the negative results were labeled as “undetermined test results” until the last day of the 14-day quarantine period and the negative result was reported at the time of the disembarkation. The RT-PCR–negative passengers who had not developed any symptoms after 14 days of cabin isolation were discharged and returned to their homes.

Operational Difficulties

The following are 5 difficulties we faced during the quarantine of the cruise ship.

Securing Traffic Lines

Theoretically, we needed to divide the traffic line between infectious (red zone) and noninfectious things (green zone) including humans, but exceptions were made because of the following reasons.

First, there were many elderly people over 75 years old, and some of them could not walk on their own. To separate the traffic line of the infected people from the medical staff, the other opening on the bow side was considered to be the disembarkation port for the infected people. However, it was very hard for aging passengers to walk to the entrance at the bow.

Second, going through the center entrance was the shortest way for the medical staff to get to the headquarters. The shipboard activity headquarters and the medical support headquarters were located in the two dining areas in the center of Deck 5, which is directly above the entrance in the center [9]. In addition, using that entrance meant that we did not need to use an elevator to get to the headquarters. This route minimized contact with the passengers and crew. If the bow side was used as an entrance for the medical staff, people would have had to walk through narrow corridors between cabins for a long time to reach the headquarters.

Looking back, equipped with the current information, it seems that the elevator hall in front of the medical center could have had a higher infection risk because it was not possible for infected and noninfected people to use the elevator separately. The place where the headquarters was located was where it did not overlap with other people's traffic lines.

Coordinating Accepting Facilities and Transport Means

Under the Quarantine Act and the Infectious Diseases Act, people infected with SARS-CoV-2 were to be placed in quarantine. It was very difficult to decide where to isolate the 696 RT-PCR–positive individuals, arrange for transportation, and ensure that each person was transported to the facility. The Kanagawa Prefectural Government and its supporting DMAT were in charge of contacting the hospital to be used as the isolation facility, making inquiries about acceptance, deciding who would be placed in which facility, and securing vehicles for their transport. The DMAT command center, located at the terminal of the Daikoku Wharf, was in charge of deciding which vehicles would be used to transport the RT-PCR–positive patients. The onboard medical headquarters was in charge of checking the medical condition of the people who would disembark and of supporting them to the entrance at the center of the ship. The DMAT at the entrance of the ship was in charge of checking the preparation of the vehicles and their destination and ensuring correct transportation.

At first, we transported the symptomatic patients to the designated medical institutions in that area that were equipped

to handle infectious diseases. However, all the beds in Kanagawa Prefecture were soon filled, and we had to extend transportation to other places in the Kanto region. At the same time, the Japanese government was operating facilities for health observation and quarantine for people who were returning to Japan on flights from Hubei Province. We had to expand the transportation area to Fukushima, Nagano, and even Osaka, which is a 6-hour drive from the ship. On the peak day, we had new 99 RT-PCR–positive patients, and we had to transport family members separately, even though they should have stayed in the same facility. We could not send all family members to the same quarantine place at that time. The Fujita Medical University Okazaki Medical Center offered to accept 170 asymptomatic patients. Since this facility was still in preparation to open as a hospital in April 2020, it was intended to only accept patients who would require no medical treatment. The author was dispatched as a DMAT for logistic support at Okazaki Medical Center and was in charge of ensuring bus transportation, room allocation, arrival confirmation, advice on the transfer to a medical facility, and overall reception. Since the patient lists were sent to the quarantine facility from Yokohama headquarters in advance, we finished the allocation of the name, ID, and room before the arrival of the bus. At the quarantine building, the transport bus was attached to the front entrance, the staff first carried their baggage to the entrance hall, and then the passengers got off the bus. We checked their body temperature and SpO_2 levels while their baggage was picked up and patients were registered. We took face photos and attached the ID registration wristband in the allocated room (Figure 5).

Figure 5. At the entrance of the quarantine building. Body temperature and SpO2 were checked while people were registered and baggage was picked up.

Risk of Deterioration

As previously reported, chest computed tomography (CT) has a high sensitivity (97%; 95% CI 95%-98%) for COVID-19 pneumonia [11]. We also confirmed that 54% (n=221) of the asymptomatic patients with a positive RT-PCR result had observable lung opacities on chest CTs [12]. Some people who were transported from the ship to the Okazaki facility developed mild chest pain during the 6-hour transportation. Based on the results of the CT image, the development of pneumonia may cause pleural pain. The speed at which the patients changed from being asymptomatic or mild to severe was very high. About 10% of asymptomatic people developed symptoms during a 6-hour transport, and 10%-20% of them worsened rapidly to a state in which intubation was considered within 24 hours.

The Complex Transporting Process on the Ship

The following 6 processes were required to transfer a person from self-isolation in the cabin room to another facility:

1. Explanation to the person that his/her RT-PCR test result was positive (on board)
2. Determination of the destination (by the prefectural government)
3. Determination of the vehicle (commander in charge at the wharf)
4. Creation of the medical information report (at the onboard medical headquarters)
5. Packing of baggage (by the individuals)
6. Visiting the toilet before long-distance transportation (by the individuals)

Once the process was completed, the DMAT of the onboard medical headquarters assisted the person in moving from their cabin to the entrance of the ship. Many medical institutions preferred to accept patients in the daytime, so these tasks were concentrated in a very short time.

Unlike the usual disembarkation from a cruise ship, the patients needed to carry their baggage themselves. They had to pass through the quarantine area and customs. Some people had difficulty walking or had a lot of baggage, which meant it took a long time to move. The author was to check each transportation process and the departure of the vehicle and report it to the command center. Many foreign passengers did not understand Japanese or English at all, making the situation unimaginably difficult to manage. Sometimes, we had to ask the crew to interpret the command, even if it increased the risk of infection.

Support for Daily Life on the Ship

We needed to support the daily lives of 3711 people on the ship. Since all passengers were isolated in each cabin, we had to

deliver daily supplies to each room. There were people of various nationalities and religions aboard, and it was necessary to consider religious taboos and allergies. The crew members had to keep working under the risk of infection. The crew dining area was considered the primary area of infection for the crew, since the food service had the most confirmed cases [13]. We recommend treating the crew the same way as the passengers for infection control. In addition, a lot of water is necessary for human life and a lot of sewage was generated. In the beginning, we left the pier to the open ocean offshore once every few days for sewage disposal, but in the latter half of the quarantine period, the government and municipalities facilitated drinking water delivery and sewage water collection while the ship was still alongside the pier. Leaving the pier also became a barrier to the patients' transportation.

We have described the difficulties associated with medical activities in the management of emerging infectious diseases on a cruise ship. Infection control on a cruise ship is very difficult because of environmental factors [14], human factors, and limited medical resources.

On February 24, 2020, the World Health Organization announced an interim guidance for the operational considerations for managing COVID-19 cases and outbreaks on board ships [15]. We learned that a significant number of passengers with positive RT-PCR results had no or mild symptoms. The deterioration of patients with COVID-19 is very fast, suggesting that authorities need to prepare for patients' transfer and the admitting hospital when disembarking the passengers. There were several difficulties on the cruise ship, such as securing traffic lines, coordinating accepting facilities and transport means, risk of deterioration, the complex transporting process on the ship, and support for daily life on the ship. We recommend treating the crew the same way as the passengers for infection control. We must make a plan for the future to protect travelers and passengers from emerging infectious diseases on cruise ships. We strongly hope this report will be helpful to the people who are working to control COVID-19 infections on cruise ships worldwide.

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Authors' Contributions

YY collected the data and wrote the Japanese manuscript. AS translated it and wrote the final manuscript. All authors critically revised the manuscript and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
CT: computed tomography
DMAT: Disaster Medical Assistance Team
DPAT: Disaster Psychiatric Assistance Team
JMAT: Japan Medical Association Team
RT-PCR: reverse transcription–polymerase chain reaction
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Viewpoint

Delivering Benefits at Speed Through Real-World Repurposing of Off-Patent Drugs: The COVID-19 Pandemic as a Case in Point

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Abstract

Real-world drug repurposing—the immediate "off-label" prescribing of drugs to address urgent clinical needs—is a widely overlooked opportunity. Off-label prescribing (ie, for a nonapproved indication) is legal in most countries and tends to shift the burden of liability and cost to physicians and patients, respectively. Nevertheless, health crises may mean that real-world repurposing is the only realistic source for solutions. Optimal real-world repurposing requires a track record of safety, affordability, and access for drug candidates. Although thousands of such drugs are already available, there is no central repository of off-label uses to facilitate immediate identification and selection of potentially useful interventions during public health crises. Using the current coronavirus disease (COVID-19) pandemic as an example, we provide a glimpse of the extensive literature that supports the rationale behind six generic drugs, in four classes, all of which are affordable, supported by decades of safety data, and targeted toward the underlying pathophysiology that makes COVID-19 so deadly. This paper briefly summarizes why cimetidine or famotidine, dipyridamole, fenofibrate or bezafibrate, and sildenafil citrate are worth considering for patients with COVID-19. Clinical trials to assess efficacy are already underway for famotidine, dipyridamole, and sildenafil, and further trials of all these agents will be important in due course. These examples also reveal the unlimited opportunity to future-proof our health care systems by proactively mining, synthesizing, cataloging, and evaluating the off-label treatment opportunities of thousands of safe, well-established, and affordable generic drugs.

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KEYWORDS

COVID-19; drug costs; drug repositioning; drugs, generic; off-label use; public health; severe acute respiratory syndrome coronavirus 2; pandemic; crisis

December 2019 heralded the transformation of modern-day life. A new and lethal disease, now named COVID-19, was emerging in China and was about to change the world as we know it. The same month, in propitious timing, a few hundred of the world's leading physicians, scientists, government agency officials, and nonprofit leaders gathered at an inaugural 2-day conference jointly sponsored by the US Food and Drug Administration (FDA) and National Institutes of Health (NIH) in Washington, DC. The topic of the conference was "Repurposing Off-Patent Drugs," and attendees had convened to discuss how widely used, low-cost, and safe medicines that are approved for one indication might be harnessed to provide additional, novel, and sometimes unexpected therapeutic benefits in other diseases.

Dr Christopher Austin, Director of the National Center for Advancing Translational Sciences at the NIH, opened the conference by welcoming the birth of a new era in human medicine. He asked participants "to skewer some sacred cows," emphasizing the need to embrace controversial thinking to improve patients' lives.

> *Drug repurposing seems tantalizingly simple. Conservatively, there are 6,500 human diseases that*

> *have no regulatory-approved treatments whatsoever. At the current rate of progress, it will be 2,000 years before every human disease is treatable. What percentage of those 6,500 currently untreatable diseases is ameliorable, to some degree, by a drug you can get at [your local pharmacy]? Shame on us if we can't figure out a way to make these available to patients suffering from disabling and lethal diseases. This is an eminently solvable problem.*

If drug repurposing was an obscure subject for experts as well as the public, COVID-19 has changed that forever. The publicity generated by the US president endorsing the antimalarial agents hydroxychloroquine and chloroquine as treatments for COVID-19 jolted regulatory authorities worldwide. The FDA felt compelled to grant emergency-use authorization for these drugs, while the European Medicines Agency held back, urging that they should not be prescribed outside of clinical trials and nationally agreed upon protocols. In the absence of proven treatments, many physicians at the frontlines of the COVID-19 battle prescribed these drugs, resulting in a worldwide shortage. Conflicting clinical trial data have emerged since then regarding use of these antimalarial drugs in COVID-19 [1-7], some of which indicate a lack of benefit or even the potential for harm [6]. This underscores the need for emergency regulatory authorization of unproven treatments, if deemed necessary in a public health crisis, to be based first and foremost on robust evidence of safety. It is also important that the relevant agency issues a statement emphasizing the exploratory nature of the intervention and urgent need for robust clinical trial data to support ongoing use.

Hydroxychloroquine and chloroquine were developed as antimalarial treatments and subsequently repurposed for treating systemic lupus erythematosus and rheumatoid arthritis. Their repurposing for these challenging autoimmune diseases was facilitated by funding from pharmaceutical companies, which recouped their investment through patent-protected revenues until the drugs became available as generics. However, only a small proportion of drug-repurposing discoveries enjoy patent protection and can benefit from the large and costly clinical trials necessary for regulatory approval.

By contrast, real-world repurposing—the immediate "off-label" prescribing of drugs by caring physicians based on their acumen, awareness of pilot studies or case reports, or field experience in the clinical setting—is a widely overlooked opportunity. Prescribing a drug off-label (ie, for a use other than what it was approved for) is legal in almost every country worldwide. However, if there is an unforeseen adverse outcome, the burden of liability shifts from the regulator or pharmaceutical company to the prescribing physician. Additionally, the burden of payment shifts from the insurer or other institutional health care payers to the patient. Nevertheless, when dealing with immediate and urgent health crises, whether at an individual or public level, real-world repurposing is frequently the only realistic solution.

To protect the public from unscrupulous players, the US FDA prohibits pharmaceutical companies from promoting off-label uses of their drugs, which could be used to increase profit while avoiding investment in clinical trials. By contrast, the FDA is supportive of disseminating information about promising off-label uses by independent entities, a point reiterated in March 2020 on the FDA's website [8]. This underscores the importance of vigorous efforts to create reliable, independent evidentiary repositories to disseminate such treatment opportunities, and thereby support the decision making of those in the frontlines, in nearly real time.

Two additional critical elements are prerequisites if real-world repurposing is to deliver health benefits at the public level: safety and affordability. The former calls for a decades-long track record of established safety, and the latter requires the availability of generic low-cost drug candidates. Fortunately, many thousands of such drugs are already available. The challenge is that no central repository of off-label uses exists in a way that enables immediate intervention in times of public health crises.

Taking the COVID-19 pandemic as an example, we have selected four well-established drugs backed by many decades of safety data, widespread use, and affordability, which we believe offer the opportunity to prevent or treat both the viral infection and the disabling and deadly complications that ensue. Although COVID-19 usually presents with respiratory symptoms, infection that spreads beyond the lung contributes significantly to the disease toll through uncontrolled outpouring of immune cells, disturbed clotting, multi-organ failure, and other life-threatening complications. There is extensive clinical support, backed by a solid mechanistic scientific rationale, underpinning the proposed drugs (Multimedia Appendix 1). Each was selected based on safety, affordability, and ability to target multiple aspects of the underlying disease processes that make COVID-19 so deadly. The proposed doses are those that have been shown to achieve the target physiological effects as demonstrated in the supporting references.

Cimetidine and famotidine, which are approved for heartburn caused by reflux disease [9], have been shown to have powerful effects on the immune system [10]. Data indicate that they can suppress a wide variety of common viruses, including herpes and human papillomaviruses [11-13], and boost immune response after vaccination [14-20], with additional immune-modulating effects in a range of cancers and allergic diseases [10]. They have also shown efficacy in protecting the heart from excessive workload, lowering blood pressure, and improving cardiac efficiency [21,22]; reducing inflammation [23]; and inhibiting pathological blood clotting [24,25]. A clinical trial of famotidine in COVID-19 was started recently in New York, following the observation (as yet unpublished) that certain patients in China who were taking it when diagnosed with COVID-19 had better clinical outcomes than those who were not [26]. Data generated from this new study are eagerly awaited.

The antiplatelet agent dipyridamole, which is approved to prevent thrombotic events in at-risk patients [27,28], has also caught the eye of researchers investigating potential treatments for COVID-19. A recently published study in China illustrated its ability to suppress the severe acute respiratory syndrome coronavirus 2 virus that causes COVID-19, leading to marked clinical improvements [29]. A larger study recently launched

in China examines dipyridamole in 460 patients with COVID-19 (ChiCTR2000030055). Beyond these antiviral effects, dipyridamole has shown anti-inflammatory, antioxidant, and vasodilatory activity [30-34], and is one component of a widely used anticoagulant (citrate-theophylline-adenosine-dipyridamole [CTAD]) [35-37]. Clinically, cardioprotective effects have been reported in patients with chronic heart failure [38], and improved renal function is documented in patients with chronic kidney disease, delaying risk of progression to dialysis and reducing mortality [39,40].

The cholesterol-lowering agents fenofibrate and bezafibrate are approved for treatment of dyslipidemias [41]. Although bezafibrate is unavailable in the United States, it is widely used in Europe. Meta-analyses show that they can reduce disability and death from atherosclerotic cardiovascular disease and stroke, independent from their effects on cholesterol [42,43]. Potentially protective effects on kidney function have been reported [44,45], along with antiviral efficacy in patients with a hepatitis C virus infection [46]. In some patients, fibrates have lowered plasma fibrinogen levels to a statistically significant degree [47-52], suggesting the potential to address the dangerous hypercoagulability seen in many patients with COVID-19. Indeed, fibrates have demonstrated anticoagulant and cardiovascular protective effects in patients with metabolic syndrome [53], which represents a hypercoagulable state accompanied by inflammation and endothelial dysfunction.

The phosphodiesterase-5 (PDE-5) inhibitor sildenafil citrate is a vasodilator that was approved in 1998 for treating erectile dysfunction [54] and more recently received an indication for pulmonary arterial hypertension (PAH) [55]. Sildenafil has a wide range of anti-inflammatory, antioxidant, and vasodilatory actions across many body systems, with benefits reported in case studies of patients with type 2 diabetes [56,57] and hematological cancers [58]. Reported cardioprotective effects, stemming from improved pulmonary circulation as well as direct action on the myocardium [59], include improved cardiac contractility and reduced symptoms in patients with a range of cardiac disorders [60-62], with reduction in cardiovascular events and mortality in patients at high risk [63]. Studies demonstrating sildenafil's efficacy and tolerability in PAH continue to accrue, and a recent Cochrane review and meta-analysis concluded that patients with PAH who received PDE-5 inhibitors were significantly less likely to die in the short-term than those receiving a placebo [64]. Sildenafil may also reduce mortality in idiopathic pulmonary fibrosis [65], an interstitial lung disease with high mortality, and preliminary evidence suggests that this drug class is actively renoprotective [62,66]. Sildenafil is currently under investigation in a phase 3 trial in patients with COVID-19 (NCT04304313), which will help clarify its therapeutic potential.

Times of emergency, such as with the COVID-19 pandemic, call for a radical review of the way we practice medicine. As Dr Austin aptly stated, we have to be ready "to skewer some sacred cows." Clinical trials of unprofitable generic drugs sponsored by governments or nonprofit organizations are obviously welcome and important but should not delay the judicious use of well-established, safe, cost-effective, and rationally prescribed therapies.

The race to find a cure for COVID-19 has resulted in unprecedented worldwide research efforts. As of the time of writing, the Milken Foundation has compiled a list of treatments being studied for COVID-19 [67]. Nevertheless, the time to approval and the expected high cost of the majority of these drugs may leave them out of reach for a large portion of the world's population.

The four well-established drugs presented here for consideration, alone or in combination, for at-risk patients with COVID-19 highlight the gems buried in the mountain of hundreds of thousands of clinical studies, inaccessible to physicians battling at the frontlines of clinical medicine. Unbeknownst to most of them, the four drugs selected in this case, officially approved for a handful of indications, have shown efficacy in managing over 100 additional diseases. We do not propose specifically when or how each of these drugs should be used; rather, we aim to provide a pathophysiological rationale for their use, alone or in combination; share our understanding of why and how they may provide benefit; and spur creative thinking about their potential use in this disease while illustrating the untapped potential of therapeutic options that may be hidden in plain sight.

The COVID-19 pandemic represents an unparalleled opportunity to refocus our efforts on mining, synthesizing, and cataloging the body of evidence behind many promising treatment opportunities. This article is an invitation to kindred spirits and curious, bold humanitarians to pool efforts to harness this opportunity to future-proof our health care systems based on robust science. We owe it to ourselves and future generations.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Approved indications and recognized physiological effects of drugs to consider repurposing for patients with COVID-19.

[DOCX File , 15 KB - publichealth_v6i2e19199_app1.docx]

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Abbreviations

COVID-19: coronavirus disease
FDA: Food and Drug Administration
NIH: National Institutes of Health
PAH: pulmonary arterial hypertension
PDE-5: phosphodiesterase-5

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Original Paper

Estimation of the Probability of Reinfection With COVID-19 by the Susceptible-Exposed-Infectious-Removed-Undetectable-Susceptible Model

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Abstract

Background: With the sensitivity of the polymerase chain reaction test used to detect the presence of the virus in the human host, the worldwide health community has been able to record a large number of the recovered population.

Objective: The aim of this study was to evaluate the probability of reinfection in the recovered class and the model equations, which exhibits the disease-free equilibrium state for the coronavirus disease.

Methods: The model differential equation was evaluated for the disease-free equilibrium for the case of reinfection as well as the existence and stability criteria for the disease, using the model proportions. This evaluation shows that the criteria for a local or worldwide asymptotic stability with a basic reproductive number (R_0=0) were satisfied. Hence, there is a chance of no secondary reinfections from the recovered population, as the rate of incidence of the recovered population vanishes (ie, B=0).

Results: With a total of about 900,000 infected cases worldwide, numerical simulations for this study were carried out to complement the analytical results and investigate the effect that the implementation of quarantine and observation procedures has on the projection of further virus spread.

Conclusions: As shown by the results, the proportion of the infected population, in the absence of a curative vaccination, will continue to grow worldwide; meanwhile, the recovery rate will continue slowly, which means that the ratio of infection rate to recovery rate will determine the death rate that is recorded. Most significant for this study is the rate of reinfection by the recovered population, which will decline to zero over time as the virus is cleared clinically from the system of the recovered class.

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KEYWORDS

infectious; disease; reinfection; model; math; COVID-19; coronavirus; pandemic; outbreak; SEIRUS

Introduction

The coronavirus disease (COVID-19) pandemic has had a major impact on the global economy and on behavioral practices of people worldwide. Until its early detection in Wuhan, China in 2019, the virus was unknown to the scientific world, and the extent of its damage was unmeasurable. However, upon its outbreak, various research, including but not limited to Victor [1] and Batista [2], began to predict the scale that the virus would hit the world; the ratio of the death to recovery rate has seemingly been a positive proportion. With the slow but deliberate efforts by governments of developed and developing countries to control, slow, and possibly halt the further spread of the virus, contact tracing and testing has reached millions of people. With the sensitivity of the testing approach, the polymerase chain reaction (PCR), the infected and exposed populations were easily identified for isolation and quarantine, respectively, in a bid to slow the curve of secondary infections and manage the critically affected infected group. Meanwhile, a common trend that seems to show a ray of hope in the fight against the coronavirus was the unattended recovery of infected and exposed patients, and, despite the absence of a Food and

Drug Administration-approved vaccine, this recovery rate seems to be encouraging. However, as the recovery rate and infection rate continues to increase, the question that has eluded health care workers, the Centers for Disease Control and Prevention, and the World Health Organization (WHO) is if there will be reinfection after a patient with COVID-19 has recovered clinically?

In the literature (Victor [1], Nesteruk [3], and Ming et al [4]), focus has been placed on the outbreak, exposure, and the rate of infection for COVID-19 by the use of various models to study the trend of the pandemic. In their studies, Nesteruk [3] and Ming et al [4] used the popular susceptible-infectious-removed (SIR) model to obtain optimal values for the model parameters for use with a statistical approach and, hence, predicted the number of infected, susceptible, and removed persons over time. This model approach by Nesteruk [3] has been a major breakthrough in modelling disease control and has been used by several authors (eg, Ming et al [4] and Victor [1]). However, although there exists a worldwide interest in contact tracing, testing, isolating those that are exposed to COVID-19, and estimating and projecting the rate of worldwide infections, what is more interesting is an estimation that could evaluate the probability of reinfection by those who have recovered from COVID-19. Therefore, in this study, the approach developed by Victor [1] based on an age-structured model developed and used by Victor and Oduwole [5] for HIV/AIDS transmission in Africa was adopted, which is a deterministic endemic susceptible-exposed-infectious-removed-undetectable-susceptible (SEIRUS) model.

The SEIRUS model was used due to the resulting solutions that captured the relevant parameters for the exposed and untransmitable classes, which are not present in the SIR model as used by Nesteruk [3] and Batista [2].

The resulting equations from the SEIRUS model are a system of coupled homogenous differential equations used to capture the susceptible rate, rate of exposure, infectious rate, and the rate of recovery. In addition, the equations capture the rate of reinfection, which is captured in the undetectable class that is clinically ascertained by the PCR testing approach for the recovered population.

Numerical experiments, with relevant simulation showing how the variation of the reproductive number (R_0) affects the number of infected individuals, were carried out as well as a projection for the rate of reinfection by the recovered class. Conscious effort to evaluate the new deterministic SEIRUS model was done to reduce the R_0 to zero and possibly halt the spread of the disease, thereby leading to an endemic equilibrium and eradication of the disease in the future.

The worldwide COVID-19 pandemic and the lack or inefficiency of purposeful and result-based interventions are great calls for other empirical and scientific interventions that seek to review strategic models and recommendations of social and scientific research for disease control. Although previous studies have been tailored toward the epidemiology and the disease-free equilibrium (DFE) where the R_0 of the infectious population is at its bare minimum, this study seeks to evaluate the impact of a new endemic deterministic model on the endemic equilibrium while taking into consideration the possibility of the recovered population being undetectable and fit to be moved to the susceptible class, which will, therefore, imply zero secondary infection of the disease worldwide.

In summary, this study aims to use the new deterministic endemic SEIRUS compartmental model for COVID-19 dynamics, which combines quarantine and observation procedures, and behavioral change and social distancing in the control and eradication of the disease in the most exposed subpopulations to predict the chances of reinfection by the recovered class.

Methods

Model Variables and Parameters

As suggested in Victor [1] and Victor and Oduwole [5], the variables and parameters for the investigation of the stability analysis of the equilibrium state for the new deterministic endemic model are given in Tables 1 and 2.

Table 1. The variables for the new deterministic endemic model.

Variable	Description
$S(t)$	Number of susceptible population at time t
$E(t)$	Number of exposed population at time t
$I(t)$	Number of infected population at time t
$R(t)$	Number of infected population quarantined and expecting recovery at time t
$U(t)$	Number of recovered adults satisfying undetectable criteria at time t

Table 2. The parameters for the new deterministic endemic model.

Parameter	Description
μ	Natural death rate of the population
α_0	Maximum death rate due to coronavirus disease ($\alpha \leq \alpha_0$)
α	Death rate of the infected population due to coronavirus disease
ϕ	Disease induced death rate of infected population not quarantined
ϖ	Disease induced death rate of infected receiving quarantine
T	Maximum lifespan after infection ($T \geq 14$ *days*)
k	Efficacy of quarantine ($0 \leq k \leq 1$)
ρ	Rate of recovery
β	Rate of transmission
σ	Proportion of infected population in quarantine per unit time (treatment rate)
π	Proportion of population from susceptible to exposed/latent class
ε	Proportion of removed population still being observed and being moved to susceptible class
$B(t)$	Incidence rate or force of infection in the population

Model Assumptions

The following assumptions, as suggested in Victor [1] and Victor and Oduwole [5], help in the derivation of the model:

1. There is no emigration from the total population and there is no immigration into the population. A negligible proportion of individuals move in and out of the population at a given time.
2. Maturation (or maturity) is interpreted as the period between infection and symptom observation (days 1-14).
3. The susceptible population are first exposed to a latent class where they can be infected or not.
4. Some infected individuals move to the removed class when they are quarantined for observation procedures.
5. The recruitment from the S class into the E class is through contact with populations in the I class to the S class.
6. The recruitment into the R class from the I class is at a rate of σ.
7. The recruitment into the U class from the R class depends on the effectiveness of the quarantine and observation procedures at a rate of ρ.
8. Death is implicit in the model, and it occurs in all classes at a constant rate μ. However, there is an additional death rate in the I and R classes due to infection for both juvenile and adult subpopulations, denoted by ϕ and ϖ, respectively.

Model Description

This study uses the deterministic endemic model where a susceptible class is a class that is yet to be infected but is open to infection as interactions with members of the *I* class continue. An infected individual is one who has contracted the coronavirus and is at some stage of infection. A removed individual is one that is confirmed to have the virus with its expected symptoms and is under quarantine while following relevant observation procedures. A member of the undetectable class is one that has been removed, does not secrete the virus anymore, and has satisfied the WHO standard to be in the undetectable class.

The following diagram [1] describes the dynamic of the SEIRUS framework and will be useful in the formulation of model equations:

The Model Equations

The following equations are a system of coupled homogenous differential equations for projecting the detection rate of the presence of the virus in the clinically prescribed recovered population based on the assumptions and the flow diagram previously mentioned:

The incidence rate or force of infection at time *t*, denoted by $B(t)$, in the population

is given by:

Model Equations in Proportions

The model equations in proportion according to Victor [1] was adopted for this study as follows:

However, $s + e + i + r + u = 1$

Equations 10-14 are the model equations in proportions, which define the prevalence of infection.

Existence and Uniqueness of a Disease-Free Equilibrium State in the SEIRUS Model

The DFE state of the endemic SEIRUS model is obtained by setting the left-hand sides of equations 10-14 to zero while setting the disease components $e = i = r = u = 0$, leading to equations 15 and 16.

0=*s***(16)**

After substituting equation 16 into 15 we have: , which makes 0=π.

We then take 15, where *s*=0 or:

$0 = \mu - \mu s - s^2$**(17)**

Simplifying this further gives us:

$As^2 + Bs + C\mu = 0$ **(18)**

In equation 18, *A*=1, *B*=*μ*, and *C*=–*μ*.

Therefore, the solution for the equations in 18 are given by:

Ignoring the native values of , and other stringent conditions, there exists a unique, trivial, and DFE state at ( ) given by (0,0). The solution of equation 19 satisfies equation 18 identically.

Stability Analysis of Disease-Free Equilibrium State for the Recovered Population

In the event that patients recover from COVID-19, it is assumed that they are disease free for at least 14 days after their last clinical test shows that they have clinically recovered from the virus. Hence, to study the behavior of the equations 10-14 around the DFE state, E_0=(0,0,0,0,0), we resort to the linearized stability approach from Victor [1], which gives us a Jacobian transformation of the form:

Hence, according to Gerald [6], the determinant of the Jacobian matrix is given by the recursive definition of a 5 x 5 matrix defined as:

From equation 20:

Det( )>0 **(22)**

Similarly from the Trace of the Jacobian matrix given in equation 20, we have:

Hence, since *Def*( )>0 and *Trace*( )<0, which does satisfy the prescribed threshold criteria based on Gerald [6], then the DFE (E_0) for COVID-19 does satisfy the criteria for a local or worldwide asymptotic stability for the recovered population. This implies that the pandemic of COVID-19, as declared by WHO [7], does not have a curative vaccine so far, and precautionary measures are advised through quarantine and observation procedures. Therefore, for the recovered population, the chances of reinfection appear to be uncertain though nearly impossible, unless regular clinical tests are not accurately administered.

Computation of the Basic Reproductive Number of the Model

The basic R_0 is defined as the number of secondary infections that one infectious individual would create over the duration of the infectious period, provided that everyone else is susceptible. R_0=1 is a threshold, and if the number is below it, the generation of secondary cases is insu cient to maintain the infection in human communities. If R_0<1, the number of infected individuals will decrease from one generation to the next, and the disease dies out; if R_0>1 the number of infected individuals will increase from one generation to the next, and the disease will persist.

To compute the basic reproductive number (R_0) of the model with the incidence rate for the recovered population assumed to vanish, such that *B*=0, we employed the next generation method as applied by Deikmann et al [8] and van den Driessche and Watmough [9].

F_i and V_i are the rate of appearances of new infections in compartment *i* and the transfer of individuals into and out of compartment *i* by all means, respectively. Using the linearization method, the associated matrices at DFE (E_0) and after taking partial derivatives as defined by:

F is nonnegative, and *V* is a nonsingular matrix in which both are the *m* x *m* matrices defined by:

Here, 1≤*i*, *j*≤*m*, and *m* is the number of infected classes. In particular, *m*=2, and we have:

The inverse of *V* is given as:

The next matrix will then be denoted by FV^{-1}, given as:

We find the eigenvalues of FV^{-1} by setting the determinant $|FV^{-1} - \gamma I| = 0$

The characteristics polynomial is:

$\rho(\gamma)=\gamma^2$

The characteristics equation is given as:

$\gamma^2=0$

We solve the characteristics equation for the eigenvalues $\gamma_{1,2}$, where R_0 is the maximum of the two eigenvalues $\gamma_{1,2}$. Hence, the basic R_0 is the dominant eigenvalues of FV^{-1}. Thus, we have that:

$R_0=0$ **(26)**

The basic reproductive number ($R_0=0$) of equation 26 shows that, with no incidence rate in the recovered population, there is no chance of a secondary infection by patients with COVID-19 who have been clinically declared negative and free from the virus (ie, the virus is completely cleared from their system). Hence, although there currently exists no clinical vaccine for the cure of COVID-19, with equation 26, there is a high chance of zero cases of reinfection after clinical recovery from the virus.

Results

Description and Validation of Baseline Parameters for Worldwide Cases of COVID-19

According to the WHO [10], the total cases of COVID-19 worldwide stands at about 900,000, with a total of about 190,000 recovered, and the current total deaths is about 44,000 from about 172 countries. Figures 1 and 2 show the cumulative case count per country [11] and worldwide [11], respectively.

Figure 1. A world map showing the number of cases for each country with a coronavirus disease case.

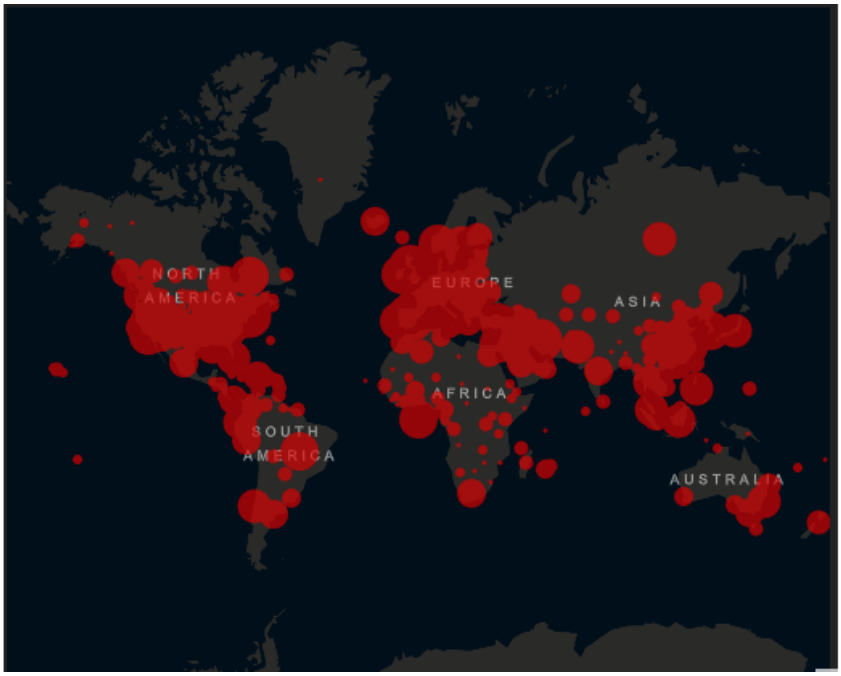
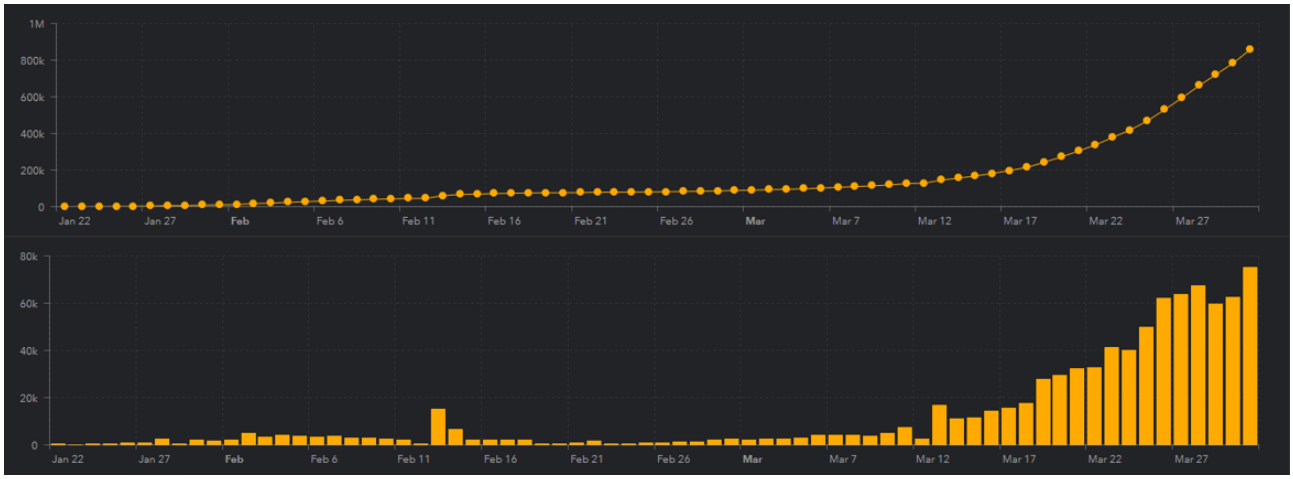


Figure 2. A cumulative case chart showing the number of cases of coronavirus disease.



Numerical Experiments of the Model

The age-structured deterministic model in equations 10-14 was solved numerically using the Runge-Kutta-Fehllberg fourth to fifth order method and implemented using Maple Software (Maplesoft). The model equations were first transformed into proportions, thus, reducing the model equations to 10 differential equations. The parameters used in the implementation of the model are shown in Table 3. Parameters were chosen in consonance with the threshold values obtained in the stability analysis of the DFE state of the model.

Hence from equation 26, the reproductive number R_0=0 means there is a 100% chance of zero secondary reinfections from the recovered compartment of the COVID-19 patient group when a reinfected population interacts by contact with the susceptible population. Figure 3 shows the rate of recovery and rate of infection for COVID-19, and Figure 4 shows the rate of reinfection.

Table 3. Estimated values of the parameters used in the numerical experiments.

Parameters	Values	Data source	Parameters	Values	Data source
N (0)	7.57 billion	WPR[a] [12]	ϕ	0.000005[b]	Assumed
N(1)	845,292	WHO[c] [10]	ϖ	0.0000007	JHU[d] [11]
s(0)	1.0000	Estimation	T	14 days	WHO [10]
e(0)	1.0000	Estimation	k	0.5[b]	Assumed
i (0)	0.00002	WHO [10]	ρ	0.000095	JHU [11]
r(0)	0.000095	JHU [11]	β	0.00002	WHO [10]
u(0)	0.000095	JHU [11]	σ	0.28404[e]	Estimated
μ	0.000001	WPR [12]	π	0.00567[b]	Assumed
α_0	0.000011	Nesteruk [3]	ε	0.000095	JHU [11]
N/A[f]	N/A	N/A	$B(t)$	0.00000	Assumed

[a]WPR: World Population Review.

[b]Assumed: Hypothetical data used for research purposes.

[c]WHO: World Health Organization.

[d]JHU: Johns Hopkins University.

[e]Assumed: Based on Victor [1], Batista [2], and Nesteruk [3].

[f]Not applicable.

Figure 3. Chart of recovered and infectious compartments for coronavirus disease.

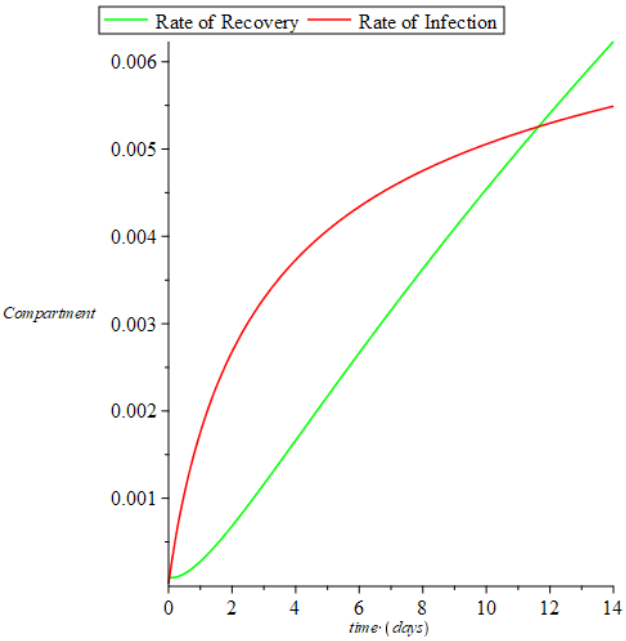
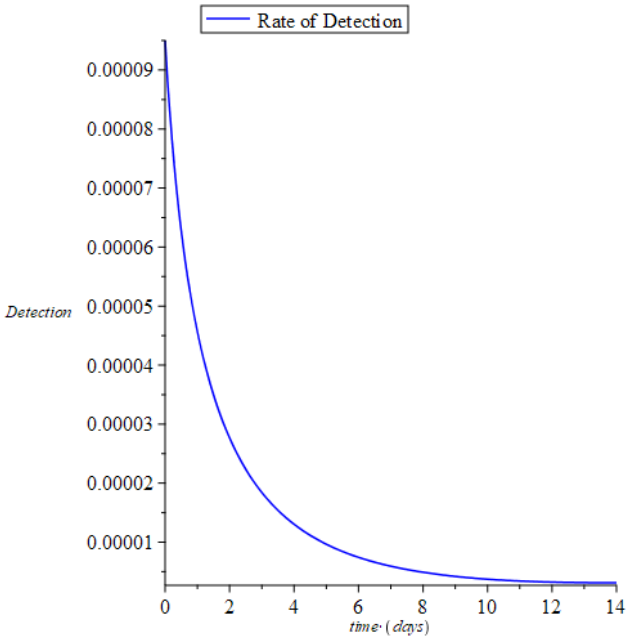


Figure 4. Chart of the rate of reinfection of the recovered compartment from coronavirus disease.



Discussion

Principal Findings

The analysis clearly shows that the secondary infection rate satisfies the local and worldwide stability criteria and the DFE for an endemic situation. Unlike the respiratory syncytial virus, which causes a significant respiratory disease often in those 5 years or younger, COVID-19 is estimated to burden more than 10,000 people worldwide. Although the stability analysis shows that there is no chances of secondary reinfection by the recovered class, the rate of the infectious will continue to rise asymptotically over a long period of time and there after begin to slide in a normal trajectory if no vaccine is available. Batista [2] and Nesteruk [3] focused their study on the impact of the infectious class in the subpopulation with the SIR model and forecasted a rapid geometric growth in the spread of the virus worldwide and a subsequent progression in the rate of recovery among the exposed and infectious groups.

According to Victor [1], the model equations that exhibit the DFE (E_0) state for COVID-19 satisfies the criteria for a local or worldwide asymptotic stability when the basic R_0=0 for an endemic situation. This implies that the COVID-19 pandemic, as declared by WHO [7], does not have a curative vaccine yet, and precautionary measures are advised through quarantine and observation procedures.

However, with the various make shift treatments, social distancing measures, and quarantine strategies being adopted, the recovery rate will keep rising slowly but steadily over a long period of time. Therefore, as the recovery rate continues to grow steadily, the number of recovered patients who have been clinically declared free of the virus by the PCR test are also declared uninfectious as long as the virus is completely cleared from their system, and the rate of detection will vanish, making the rate of secondary infection R_0=0 as long as the incidence rate B=0.

Conclusions

There is a need for a dedicated effort from individual populations, governments, health organizations, policy makers, and stakeholders. The world is hardly rid of COVID-19, and further spread is eminent; the rate of infection will continue to increase despite the increased rate of recovery until a curative vaccine is developed.

With the worldwide health sector in a bid to tackle COVID-19, this study gives encouragement to the policy makers and public health care sectors, as there is zero secondary reinfections by the recovered population. Therefore, the policy makers and public health sectors can enhance contact tracking, tracing, and testing to improve the isolation and quarantine of the infected and exposed classes. In addition, the health sector could use COVID-19 antibodies from the samples of the recovered class to develop effective vaccines for the virus. However, since the hypothesis of zero reinfections has not been clinically proven, further observations should be carried out on the recovered class in clusters to study the progression of the exposed with the re-exposed subpopulations to see, by clinical examination, the possibilities of reinfection and, thereby, promote the use of these antibodies for vaccine creation.

Limitation

This study was limited by the variability of data available at the time of developing this paper. Meanwhile, from the statistics, the infected cases and fatalities were projected to increase geometrically. Therefore, the findings of this study are based on sample data taken at the time of the study.

In addition, with the SEIRUS model and the discovery that the R_0=0, we concluded that there are no secondary reinfections from the recovered population, as the rate of incidence of the recovered population vanishes. However, reports from worldwide public health data have shown that there has been a few rare cases of reinfection of some from the recovered class,

and they are suspected to be reinfected by a rare type of the coronavirus but not COVID-19.

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The data used for this study was made available from John Hopkins University for the total number of infected patients and recovered patients for the entire population. In addition, the data for the worldwide population used to extract the susceptible class was made available from the World Population Review, and the material and methods were adopted from Victor and Oduwole from their work on disease control.

Authors' Contributions

The author's contributions include but were not limited to developing and using the novel SEIRUS model for COVID-19 tracking, using the SEIRUS model to predict the probability of reinfection of COVID-19 worldwide, confirming that there is no secondary spread of the virus after recovery without vaccine with a R_0=0, and evaluating the disease-free equilibrium with local or worldwide asymptomatic cases.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
DFE: disease-free equilibrium
PCR: polymerase chain reaction
R0: reproductive number
SEIRUS: susceptible-exposed-infectious-removed-undetectable-susceptible
SIR: susceptible-infectious-removed
WHO: World Health Organization

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Original Paper

Emergency Response to COVID-19 in Canada: Platform Development and Implementation for eHealth in Crisis Management

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Abstract

Background: Public health emergencies like epidemics put enormous pressure on health care systems while revealing deep structural and functional problems in the organization of care. The current coronavirus disease (COVID-19) pandemic illustrates this at a global level. The sudden increased demand on delivery systems puts unique pressures on pre-established care pathways. These extraordinary times require efficient tools for smart governance and resource allocation.

Objective: The aim of this study is to develop an innovative web-based solution addressing the seemingly insurmountable challenges of triaging, monitoring, and delivering nonhospital services unleashed by the COVID-19 pandemic.

Methods: An adaptable crisis management digital platform was envisioned and designed with the goal of improving the system's response on the basis of the literature; an existing shared health record platform; and discussions between health care providers, decision makers, academia, and the private sector in response to the COVID 19 epidemic.

Results: The Crisis Management Platform was developed and offered to health authorities in Ontario on a nonprofit basis. It has the capability to dramatically streamline patient intake, triage, monitoring, referral, and delivery of nonhospital services. It decentralizes the provision of services (by moving them online) and centralizes data gathering and analysis, maximizing the use of existing human resources, facilitating evidence-based decision making, and minimizing the risk to both users and providers. It has unlimited scale-up possibilities (only constrained by human health risk resource availability) with minimal marginal cost. Similar web-based solutions have the potential to fill an urgent gap in resource allocation, becoming a unique asset for health systems governance and management during critical times. They highlight the potential effectiveness of web-based solutions if built on an outcome-driven architecture.

Conclusions: Data and web-based approaches in response to a public health crisis are key to evidence-driven oversight and management of public health emergencies.

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KEYWORDS

eHealth; digital health; web-based intervention; crisis management; COVID-19; public health; health care system

Introduction

Health care systems development is determined by existing structures and traditions, but they also change rapidly in response to crises, public health threats, or urgent societal needs. The 2009 influenza pandemic and the 2014 Ebola virus disease outbreak had a global impact and revealed gaps in the structure of health care systems in countries around the world [1,2]. Epidemics have always been a time of enormous challenges, causing preventable fatalities that uncover structural and interventional deficits in the system—the coronavirus disease (COVID-19) pandemic is no different. Severe acute respiratory syndrome coronavirus 2 was first reported in Wuhan, Hubei Province, China and has subsequently spread at an alarming rate, becoming a global pandemic and provoking a shutdown for which we were all ill-prepared [3].

Large-scale community containment efforts have been deployed in several countries in an attempt to "flatten the curve," but health care systems are still falling short. In Italy, Spain, and the United States, health care workers are failing to meet the high demand, and patients in critical condition are saturating the intensive care units [4]. In the United Kingdom, the critical care bed demand is expected to be exceeded, with an eventual peak in intensive care unit demand that is over 30 times greater than the maximum supply, despite mitigation strategies [5]. As more cases appear, frontline health care workers are under pressure and called into action at the detriment of their own safety [6,7].

Challenges in reorganizing care during a system crisis are significant. Response teams need and deserve a continuous flow of accessible data to respond effectively to the dynamic of an epidemic. Moreover, the interaction with patients and potentially their social network is critical for the efficacy of crisis response—empowering and engaging patients into any approach can make all the difference [8]. Online communication can facilitate and organize patient involvement while collecting essential data to facilitate efficient use of finite human and nonhuman health care resources [8]. Ideally, such patient interfacing would be set prior to any immediate need of crisis management such as with the current pandemic.

As identified throughout the literature and in experience, major shortcomings in health care crisis management systems can be summarized as the following:

1. Lacking centralized and intelligent screening and triaging [9]: current centralized services that offer medical advice and health information, such as telephone support lines, are not built to scale nor can they handle surges in demand. Although a plethora of single-use screening tools, whether online or not, have been deployed, these tools tend to operate disparate from the existing health care system, do not integrate to primary care, and do not offer intelligent risk stratification that can adapt to changing needs of a pandemic.
2. Difficult referral management and absence of integrated surveillance [10]: rapidly evolving dynamic circumstances require rapid reallocation of health care resources such as health care workers and medical devices based on prioritization. Patient and health care delivery are impacted by existing referral management systems, which lack any meaningful "forward triage." There is no centralized and scalable system able to provide ongoing management of patients and health care delivery, as well as surveillance of the public for symptoms and risk factors.
3. Lack of capacity to seamlessly deliver care [10]: existing tools tend to simply screen or deliver information, rather than provide a seamless pathway to actually deliver care, such as through asynchronous messaging, instant messaging, and video and audio communication tools. The predominant communication methodologies leave patients in limbo and contribute to confusion and a potential worsening of the crisis through a lack of patient flow control.
4. No built-in analytic engine: there is a lack of live visualizations and reporting of data that is collected securely and in real time, leaving little opportunity to act or improve.

All of these points are exaggerated in the context of an infectious pandemic in proportion to the enormous pressure on individuals and systems. Structural and governance problems as well as any existing dysfunctional processes in clinical and logistics pathways become visible at once. The lack of preparedness is notable worldwide, which, among other things, generates lack of confidence and fear in the public. When systems are ineffective and ill-prepared, solutions to address crises can become multiple, fragmented, and ineffective.

The sudden increased demand on delivery systems puts unique pressures on pre-established care pathways. These extraordinary times require efficient tools for smart governance and resource allocation. Web-based solutions in health care represent a paradigm shift in communication and organization of health care [9,11]. Critical to their scalability and interoperability is their architecture and the clinical principles they translate into practice. They are a tool that reflects the underlying treatment and care philosophy [8,12,13].

The objectives of this paper are to describe the obvious needs that must be addressed in the crisis response to an upcoming epidemic and the conceptional framework for a web-based solution addressing these problems. As part of a public health response, we aim to make the design and development process transparent and accessible for further evaluation. The strength of web-based solutions in this context will be reflected in the presentation of a specific solution developed in response to COVID-19. This specific solution will incorporate the functionalities needed to better respond to the needs of the population.

Methods

In response to the COVID-19 pandemic, we hypothesized that web-based solutions represent a paradigm shift in communication and organization of health care, which could address the shortcomings of traditional crisis management systems to manage an infectious pandemic.

We reviewed the current literature on existing web-based solutions and consulted with medical specialists, decision

makers, and policy makers to address the major shortcomings in the current crisis management systems. We then conceptualized how web-based solutions could address these shortcomings.

Using the conceptual framework, we endeavored to develop a web-based, lightweight, and cloud-based crisis management system designed for rapid deployment. As COVID-19 gives new urgency to a long-neglected demand for change in health care paradigms, this crisis management system was aimed to have health care meet people where they are, instead of bringing people to where health care is. The design of such a solution was driven by the need for an urgent, scalable, and efficient set of deliverables, regardless of setting or method. An ideal response would be a rapidly implementable and scalable method for mass screening and continuous monitoring for potentially the majority of the world's population. Only web-based tools can be deployed so rapidly and scaled up to large areas and populations with relatively minimal marginal cost.

Results

Conceptual Framework

The conceptual framework for a crisis management system that addresses the major shortcomings identified includes the following:

1. Centralizing the screening and triage process with a single, shared platform that integrates primary care: screening can happen automatically at scale without absorbing resources and can take place in a manner that is both standardized as well as agile to accommodate the changing screening criteria. Based on data collected from patients, there is an opportunity to triage patients to ensure they are directed to the most appropriate type of care (eg, self-isolation, primary care, emergency department). A cloud-based solution could unite health care providers across the region, providing a single platform to deliver care for patients during a pandemic while also allowing individuals to connect to their own primary care provider where possible. This counteracts substantial silos that exist presently with disparate systems that produce barriers to collaboration.
2. Automated ability to track and follow up with patients: A built-in remote monitoring capability via symptom-tracking questionnaires with automatic alerts would enable providers to manage the majority of patients in their own homes, addressing patient and provider health as well as source control.
3. Integrated and intelligent virtual care: a web-based solution has the ability to provide virtual care and self-management strategies directly through the platform, including secure video, audio, and instant messaging. This can increase access by allowing more health care providers to deliver care to patients, reducing personal protective equipment use, and allowing providers to share tools and resources meant to improve the patient's understanding and improve self-management capabilities.
4. Centralization of data analysis: The combined aggregation of data from screening and triaging as well as clinical data from health care provider interactions and remote symptom tracking could produce a comprehensive data set unlike any other solution. Furthermore, a data analytics engine that allows for real time dashboards of information across the region in a single interface would enable real time responses to a changing pandemic.

Given this conceptual framework, digital health developers designed the Crisis Management Platform (CMP) over a period of 2 weeks. The CMP then had to go through a noncompetitive procurement process run by the provincial government of Ontario, which involved a review of the existing technical, security, and privacy policies and features, before being approved and offered to health authorities in Ontario on a nonprofit basis.

As of the March 23, 2020, the platform was deployed within the province of Ontario, Canada in the London-Middlesex Region and has expanded to other regions including Oxford, Windsor-Essex, Huron, and Perth.

At the time of writing this manuscript, 13,479 patients have been triaged, 401 providers have been onboarded (including 380 medical doctors), and 206 virtual appointments have been conducted [14,15]. As implementation providers are not currently part of our writing group, a follow-up manuscript will describe the experience and review the data in more detail once ethics is established. In the following section, we provide a description of the development and the solution, presented as 6 modules.

Crisis Management Platform

Module 1: Forward Triage Intake

The "forward triage"–oriented CMP initiates patient intake through adaptable branching logic-based questionnaires, which are able to direct or deflect as necessary**.** Initial data collection stratifies patient risk into high, medium, or low risk categories and presents health care access options accordingly based on programable logic: urgent care, emergency department, primary care redirect (Multimedia Appendix 1, page 1). The triage process also supports resource allocation and determines the place in a waiting list or even the immediate necessary crisis response.

Fundamental to the success of the forward triage component of the platform is the ability to rapidly iterate and modify pathways based on new information and data. For example, in the COVID-19 pandemic, it became quickly apparent that travel history was less relevant in screening patient risk when community transmission became predominant. Any platform that is deployed for forward triage must allow for the administrators to control direction and deflection algorithms with ease.

Module 2: Autonomous Patient Booking and Registration

Governments across the world, such as in Canada, were quick to release online self-assessment tools for COVID-19. Indeed, such rapid deployment of technology for government was unprecedented. Beyond the press releases, however, is the acknowledgement of fragmented systems where such triage tools have limited end points such as call 911, go to the hospital,

talk to your family doctor, or stay at home (with no monitoring available). Furthermore, it became quickly apparent that these tools were not easy to modify, as they continued to propagate questions that were irrelevant based on changing guidelines.

The CMP departed from single use, generic online screening tools by providing an opportunity for patients who were risk categorized appropriately to access same-day appointments (Multimedia Appendix 1, page 2). Rather than ask patients to wait in line, it made abundant sense to allocate appointment slots based on risk category.

Module 3: Patient Flow Tracking

A unique innovation in the digital platform is the application of Kanban methodology to patient flow management [16]. Although Kanban was originally designed for manufacturing control in repetitive systems and later adapted more generally to project management, the CMP offers a novel use of the methodology in the management of patient flow. Rather than moving tickets or equipment, the health care provider is able to move patients through customizable clinical pathways, all readily visual through a live-updated online tracking board. Administrators are able to customize the pathways that are possible, as well as the automations that occur following movement between steps (Multimedia Appendix 1, page 3). For example, when a patient is moved into the "Person Under Investigation" category, a monitoring system is immediately activated, which allows them to report on their symptoms from home using the online patient interface app (Multimedia Appendix 1, page 4). Self-assessments via simple questionnaires allow for repeated and effective monitoring of clinical features.

Module 4: Shared, Longitudinal Record

The integrated COVID-19 shared record represents a temporary pandemic longitudinal record. Lack of interoperability between disparate health care systems is an age-old problem. During a time of crisis, we must be less focused on software integrations and more focused on the immediate needs to reduce mortality and morbidity from the terrible onslaught of something like a pandemic. The digital platform provides a lightweight, cloud-based, and secure health record, which serves as the central documentation system for all encounters related to COVID-19.

A new digital workforce can be rapidly onboarded to track patient encounters and supervise patient's open tasks; a collaborative team can then screen the necessary data to provide care to the patient (Multimedia Appendix 1, page 5). Notably, the entirety of the patient's medical history and full chart is not integrated into the solution. Given privacy concerns, the emergency record only facilitates the bare minimal data set to provide care in the context of the crisis at hand. Wherever possible, data is collected discretely through the encouragement of patient-generated data using questionnaires and having minimal free-text data entry. The triage and daily monitoring questionnaires only collect data on risk factors for exposure, age, and sex. All data is available to providers at all times and can be accessed on the patient profile. Clinician inputted data can be facilitated through templates with variables, again avoiding free or narrative text to feed immediately accessible data into the integrated analytics engine. As in most patient-provider interactions, the responsibility is on that provider to appropriately triage and follow up with the patient. Currently the platform does not have integration with radiology, but laboratory results are being integrated based on unique patient identifiers by an onboarded digital task force.

Module 5: Patient App and Virtual Care

Visits with patients are either going to occur physically or virtually. In the context of the COVID-19 pandemic, it is imperative that, wherever possible, the health care system be able to keep patients at home and away from crowded facilities where their attendance could be responsible for getting infected, spreading infection, or infecting health care workers.

As a component within an integrated system, there is an app available for patients to communicate virtually with clinicians using voice-over Internet Protocol technology, video technology, and live chat (Multimedia Appendix 1, page 6). The readily accessible communication capacity through the app provides an efficient way for health care providers to reach patients on demand. If a symptom tracker is going in a negative direction, a clinician could initiate a virtual visit on demand through this integrated technology.

Patients are triaged according to the programmed branching logic, which is provided by their provincial health authority. In Ontario, for example, patients are triaged into same-day virtual visits with automated daily monitoring or immediate emergency care. This is all done based on patient responses and allows patients to self-isolate or social distance easily. Once a same-day virtual visit is requested, an onboarded provider is notified and takes over the patient's management.

Module 6: Integrated Analytics

All data that is collected through the other modules are fed into an analytics engine, which allows for the creation of ad-hoc data visualizations and exportable reports that provide real time data (Multimedia Appendix 1, page 7). Data can be presented in a multitude of fashions such as on aggregate population levels or separated into cohorts. By integrating analytics in this fashion, a tremendous amount of time is saved from the typical data processing that health care systems are used to. Data is not required to be exported out of the platform for analysis. The data pipeline provides the "air traffic control" style views that administrators need to make better decisions, identifying system delays and assessing outcomes.

How This Crisis Management Platform Addresses Our Current System Delivery Flaws

A number of problems identified in current health care and crises management systems are addressed using the proposed system, as summarized in the following bullet points:

- Triage and surveillance happen automatically, "en masse," without absorbing resources and in a scalable and standardized manner.
- Care delivered on a virtual platform is more efficient for patient and provider. Physicians will, therefore, have more time to apply thought to the specific nuances of the problem at hand.

- With a virtual model of screening and daily monitoring via questionnaire with automatic alerts, it is possible to manage the majority of patients in their own homes, addressing patient health as well as source control. The risk to health care workers will be less too.
- Standardization is addressed with questionnaires that are continuously reviewed and adapted if need be to help compare findings and improve the quality of surveillance.
- Patient engagement is inherently improved, as they have a critical role and can become an active part of the solution.
- Built-in analysis is automated, and audit processes will become part of care as usual. An important aspect is patient reported outcomes that will also become routinely generated and tracked longitudinally, identifying continuous opportunities for quality improvement.
- It can provide referral for health concerns related to COVID-19.

Privacy and Security

As with any digital health system involving the capture of large amounts of personal health information, privacy concerns must be considered. This is particularly true in this effort, where a large number of clinical users will be accessing a shared system. Privacy concerns will be dealt by:

- Technical considerations such as per user-level access restrictions and control, ability to generate audit logs, and ability to track unusual access patterns
- Regulatory considerations such as having completed privacy impact assessments on the platform
- Process considerations such as centralized control over the ability to add new users and control permissions, as well as privacy training
- Advisory considerations, including engagement with privacy expertise both on the technology and regional front

Security is paramount when discussing scalable systems in health care. The Google Cloud Platform has been employed to provide several layers of encryption to protect customer data at rest. Multiple third-party security assessments have been completed, and the development team has more than 10 years of experience deploying enterprise projects. In addition, a dedicated team works to ensure security processes are tested and remain updated.

Discussion

Principal Findings

Public health crises are the moments of truth on a systems level. They disclose problems but also provide learning and opportunities for innovation and necessary disruptive changes. Mistakes happen and action driven through anxiety will also occur. Although some flexibility is important for the collaborative efforts of self-organizing and cross-functional teams, rapid and flexible responses to problems brought on by a lack of governance can make the difference [17].

Web-based communication and online resources can be disruptive because they have the potential of changing the whole process of care delivery, from facilitating access (much easier in remote locations) and engaging with patients in an ongoing way (asynchronous communication, motivational enhancement, gamification) to offer quality care with no direct professional involvement (online health promotion, psychoeducation, psychotherapy) [12,13]. These changes build the capacity to increase coverage and improve quality [12,13].

It is clear that telehealth has contributed positively to previous crises; mobile app tracking during the Ebola crisis and video conferencing during the severe acute respiratory syndrome outbreak are examples of this [2]. Similarly, after the Haiti earthquake, a mobile health information technology (IT) platform with over 600 patient entries enabled adequate triaging and improved continuity of care and provider hand offs [18]. For COVID-19, virtual heath care companies across the world have enabled secure communication between providers and patients [2]. In China, the Emergency Telemedicine Consultation System enabled remote monitoring of 63 severe cases and 591 patients with mild cases of respiratory infections, of which 420 cases were cured and discharged [19]. This tool improved outcomes by effectively collecting and evaluating patient health data and efficiently bringing together specialists from different clinical disciplines, thereby avoiding shortages of resources and allowing for comprehensive assessment and treatment [19,20]. The CMP, like many other tools, supports and enables communication and coordination between health care's different disciplines.

Implementation studies are required to confirm whether the CMP can improve outcomes and help deal with limited resources. However, the concept offers some realistic expectations. The online triage, which includes a self-assessment, is serving a big group of concerned citizens in the lineup for testing—over 13,479 patients had been triaged as of March 23, 2020. This is also keeping them away from centralized services that offer medical advice, such as phone lines, which have been notorious for long wait times [21]. Additionally, the self-tracking of symptoms supports health professionals later, as it documents the clinical trajectory of the patient. Finally, the first implementation responses from physicians have been positive, with over 350 medical doctors onboarded in the several weeks it has been active.

The system's use is only expected to increase [22]. Health systems have seen their share of virtual visits grow from less than 1% of all visits (in-person and virtual) to 70% within a 4-week period [22]. This is understandable, given the fact that virtual care facilitates the avoidance of physical contact and prevents the potential transmission of infection [19]. Among health professionals, this is especially critical: almost 10% of all infected cases in Italy have been health care workers [23]. Additionally, physicians are embracing virtual care, as it allows them to monitor and treat patients at a much larger scale and with little risk of infection [20]. On the patient side, acceptance of online treatment has been shown to be increasing, especially if the process is transparent and directly engages them in the management of their care [24,25]. This solution gives access control to the patients, who may use this information while still allowing the most responsible physician to have oversight and coordinate the process.

The rapid deployment of the solution does not address its integration into existing electronic medical record (EMR) systems (whether hospital- or clinic-based). In fact, the digital platform, which has pre-existing Health Level 7– and Fast Healthcare Interoperability Resources–based architecture, is not able to easily integrate with the existing systems at the velocity that would be required for deployment in the context of a crisis [26,27]. The restrictions are not based on developer or technology constraints, but rather the lack of any expedited process such as privacy impact assessments for third-party integrations into central or core health information systems. Despite billions and billions of dollars of investment in health IT infrastructure, the existing heath information systems are rigid, disparate, and fragmented, an even more intolerable state of affairs in a time of crisis [21,28]. In effect, the development of a separate independent solution for the epidemic, despite the fact that there are already established EMR systems, is due to the inability of the current solution to address the described problems with triaging, tracking, and disease management due to COVID-19 [29]. This is an issue of critical importance given the fact that the Canadian government provided IBM, the multinational technology company, with a multimillion-dollar budget to develop a tracking system as part of epidemic preparedness, which turned out not to be functional [28]. Finally, all other solutions interact with health care professionals without providing users with direct access to their own data. However, patient portals tethered to EMR systems improve patient engagement and health outcomes [8]. Therefore, developing a separate standalone platform was a more feasible approach to integrating an existing system, given the time pressure and pre-existing structural and regulatory problems on a system level.

It is apparent that the deployment of new digital systems may fragment and isolate care pathways, even further than they already are [7,19]. One way the CMP addresses this is by identifying patients that are attached versus unattached to primary care during their registration. Attached patients are put into a pathway that makes it easy for their own primary care provider to access the system and manage their care, where available. Unattached patients are seen by a virtual physician workforce that is acting more in a walk-in style model during this time of crisis.

Limitations

There are limitations to this approach. First, the platform was purposefully deployed in a standalone fashion, not integrated through any meaningful application program interface (API) into existing infrastructure. This was done to avoid delays related to developing said APIs and other issues of compatibility but could be reversed if and when that becomes desirable. Due to the lack of such integrations, certain actions like hospitalization of the patient require manual data reconciliation as opposed to the ideal automated state triggered through software. Second, although online technology is quite ubiquitous in most societies, those that are most vulnerable and marginalized in society are often the ones who have no access. Although proxy people can facilitate technology on their behalf, it is important to not isolate them or worsen their outcomes through further neglect. Voice-based systems (notably scaled down) need to be maintained to serve these patients. Third, rapid privacy impact assessments are needed in a time of crisis. There is no defined methodology, and a rapid rollout of technology could compromise patient privacy if not governed in an intelligent and streamlined fashion.

Assets of the Crisis Management Platform

Based on correspondences with the implementation team including providers, decision makers, researchers, and health care workers, several specific theoretical advantages can be conceptualized.

The assets from a health system's perspective are:

- Integrated population health tool that can efficiently track patients and identify what's going on, where it is happening, and how to reduce the spread in real time
- Patients can enter data points themselves, and doctors have the opportunity to confirm the data inputted and can then apply it to the patient's profile. This will attempt to increase the efficiency of our health care system in the context of a surge in volume and allows patients to become a part of the solution.
- The system can send mass questionnaires to the whole patient load, with the ability to modify different filters to target specific patient demographics. When those questionnaires come back answered, we can also screen for specific things and send specific individuals different questionnaires depending on different risks, which points to efficiency and scalability.
- Positive test tracking: data inputted from any active lab results in the system or patient data points flagged in a chart as being positive goes into an analytic visualization that allows users to see how tests change overtime and can use heatmaps and report by age, gender, sex, etc, providing automatic analysis.

The assets from a health care worker's perspective are:

- The questionnaire builder can produce any type of branching logic-based questionnaire with a way to distribute these questionnaires directly to patients using smartphones through text messaging and email. As this screening and surveillance program grows, we would build a few different collections of these screening tools, which would be available and distributable. Crises require logical thought and flow. We need a thought-out structure to work efficiently, and questionnaires provide this.
- The custom data system can produce a data dictionary from answers, organically building a registry of patients with data coming directly from the patients themselves. Mandatory fields ensure capturing of the most important data points and limit missing data.
- Full workflow management system: the dashboard allows providers to create pathways for patients, moving them across the different phases, which allows them to actually track the activity live. This system also tracks all interactions so that problems in the supply chain can be identified. It also tracks the amount of time people spend on these individual stages, so from a population and community perspective, this allows for quality assurance

or allows us to understand the metrics around the different stages of care.

The assets from a patient's perspective are:

- Booking and registration: patients can self-register into shared EMRs and self-book appointments with available physicians. Prescreening questionnaires can classify their risk based on their answers and prioritize them in the booking queue. An alert system for the health care professionals becomes activated if the patient is at a very high risk and initiates immediate action.
- Push notifications for confirmation and reminders make the communication with providers convenient and easy. Automatically queued actions and questionnaires are based on transitions and assigned tasks. Self-management strategies such as references and tools can be automatically queued (eg, being transitioned to quarantine could automatically queue videos for hand-washing and daily questionnaires for symptoms). Patients can fill in an active daily monitoring questionnaire, which updates us on symptom progression, tracks whether the patient is getting worse, or whether they need to get to a hospital, etc. Compliance to these tasks are tracked to engage with patients and support them with appropriate measures.
- The system supports all ways of communication (chat, video, secure message) with physicians, and health institutions try to make access as easy as possible.

Web-based solutions can be a significant asset in the crisis response to a public health threat [30]. Best case would be to have an appropriate system in place with the necessary functionalities. The slowest part is the decision making; after that, solutions can be developed and built up to work quickly. The current solution is an example, which needs further research. It provides important learnings about process and outcomes for the future of crisis management. The next steps include evaluating its implementation within the community and adapting the system in response to the needs of the health care system and to the evolving crisis.

Conclusion

A paradigm shift toward eHealth requires a change in mindset, but many systemic health problems can be better managed in this manner—COVID-19 just happens to be a perfect example of such a change. The pandemic has generated a sense of urgency that will allow the adoption of innovation without the logistical barriers and path dependencies that we have become accustomed to.

Web-based solutions like the CMP can fill a critical gap for health care resource allocation. It demonstrates the potential effectiveness of patient-centered, web-based solutions built on outcome-driven architecture, which needs to be proven by further evaluation and research. Data- and web-based approaches are key to evidence-driven oversight and management of health care systems during public health crises.

Conflicts of Interest

DR is the CEO and cofounder of InputHealth. RS is a clinical consultant for InputHealth.

Multimedia Appendix 1
Crisis Management Platform functionalities.
[PDF File (Adobe PDF File), 10505 KB - publichealth_v6i2e18995_app1.pdf]

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Abbreviations

API: application program interface
CMP: Crisis Management Platform
COVID-19: coronavirus disease
EMR: electronic medical record
IT: information technology

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Original Paper

Correlations of Online Search Engine Trends With Coronavirus Disease (COVID-19) Incidence: Infodemiology Study

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Abstract

Background: The coronavirus disease (COVID-19) is the latest pandemic of the digital age. With the internet harvesting large amounts of data from the general population in real time, public databases such as Google Trends (GT) and the Baidu Index (BI) can be an expedient tool to assist public health efforts.

Objective: The aim of this study is to apply digital epidemiology to the current COVID-19 pandemic to determine the utility of providing adjunctive epidemiologic information on outbreaks of this disease and evaluate this methodology in the case of future pandemics.

Methods: An epidemiologic time series analysis of online search trends relating to the COVID-19 pandemic was performed from January 9, 2020, to April 6, 2020. BI was used to obtain online search data for China, while GT was used for worldwide data, the countries of Italy and Spain, and the US states of New York and Washington. These data were compared to real-world confirmed cases and deaths of COVID-19. Chronologic patterns were assessed in relation to disease patterns, significant events, and media reports.

Results: Worldwide search terms for shortness of breath, anosmia, dysgeusia and ageusia, headache, chest pain, and sneezing had strong correlations (r>0.60, P<.001) to both new daily confirmed cases and deaths from COVID-19. GT COVID-19 (search term) and GT coronavirus (virus) searches predated real-world confirmed cases by 12 days (r=0.85, SD 0.10 and r=0.76, SD 0.09, respectively, P<.001). Searches for symptoms of diarrhea, fever, shortness of breath, cough, nasal obstruction, and rhinorrhea all had a negative lag greater than 1 week compared to new daily cases, while searches for anosmia and dysgeusia peaked worldwide and in China with positive lags of 5 days and 6 weeks, respectively, corresponding with widespread media coverage of these symptoms in COVID-19.

Conclusions: This study demonstrates the utility of digital epidemiology in providing helpful surveillance data of disease outbreaks like COVID-19. Although certain online search trends for this disease were influenced by media coverage, many search terms reflected clinical manifestations of the disease and showed strong correlations with real-world cases and deaths.

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KEYWORDS

COVID-19; coronavirus; big data; infodemiology; infoveillance; Baidu; SARS-CoV-2; Google Trends; digital health; epidemiology; China; Italy; Spain; New York; Washington

Introduction

The coronavirus disease (COVID-19) is the most recent pandemic to occur in the digital age. The zoonotic infections influenza H5H1 in 1997 and severe acute respiratory syndrome (SARS) in 2002 led to significant interests in using advances in technology and data harvesting to assist in disease prediction, surveillance, and mitigation [1]. In 2003, Eysenbach discussed the use of population health tools and technologies, including the internet, during the 2002-2004 SARS outbreak. His work in the field has led to the concept of information epidemiology, which has been termed infodemiology [2,3]. With online search engines harvesting large amounts of data from the general population in real time and providing the information publicly, interest has risen in the potential for public health use of these data during impending outbreaks [4-10].

Google Trends (GT) and the Baidu Index (BI) are examples of Big Data surveillance tools that were developed to help researchers analyze temporal and geographical trends in online search terms or topics through the Google and Baidu search engines, respectively [11,12]. In a recent systematic review, Mavragani et al [13] identified over 100 peer-reviewed papers studying health-related phenomena using GT data, demonstrating trending in search volumes with time related to the population's increased use of the internet search engines in seeking information regarding their health. In 2010, Zhou and Shen [14] reported that Baidu search queries and news articles were 10-40 days ahead of official epidemiology for several infectious diseases in China.

With the time stamping of these searches, we can also correlate timing of searches to major public events, media coverage, and confirmed disease spread, and possibly forecast dissemination of disease from these events. The purpose of this study was to apply this type of digital epidemiology to the current COVID-19 pandemic to determine its utility to public health surveillance efforts.

Methods

Region Selection

In selecting the regions, the authors chose the initial epicenter of the pandemic (China) as well as the most severely affected regions in Europe and the United States. Up to April 6, 2020, the two most affected countries in Europe were Italy and Spain with 130,759 and 128,948 confirmed cases and 15,889 and 12,418 confirmed deaths, respectively.

Real-World Databases

Real-world data for daily confirmed cases and deaths were obtained using the World Health Organization's (WHO) COVID-19 Dashboard for worldwide, China, Italy, and Spain, and the corresponding state department's databases for the states of Washington and New York [15-17]. These data were normalized to a scale from 0 to 100 to allow comparisons with the search terms.

Search Query Databases

GT [11] is a public sampling database of actual search requests performed using the Google search engine [18] that are anonymized, categorized, and aggregated. According to Google [19]: "GT normalizes search data to make comparisons between terms easier. Each data point is divided by the total searches of the geography and time range it represents to compare relative popularity. The resulting numbers are then scaled on a range of 0 to 100 based on a topic's proportion to all searches on all topics." Therefore, a value of 100 means the maximum search interest for the time and location selected.

The BI [12] is a public sampling database of search queries users entered into the Baidu search engine [20], the predominant search engine in China. BI is catered towards an exclusively Mandarin speaking and reading clientele, as there are no options to change language. Unlike GT, BI results are not displayed as normalized values and, instead, reflect the absolute Baidu search volume but are not equivalent to it [21]. Because of this function, results for different terms can be compared to each other for relative frequency, even across different time periods. Search terms were translated into traditional Chinese characters. BI allows for combined searches that display the results of multiple search terms added together, which can be accomplished in the search bar using "+" or by using the advanced search option. This was used when there were multiple potential words or phrases for symptoms. Unfortunately, data cannot be as conveniently extracted from BI as from GT; there is no way to download data files for search queries. However, scrolling over the search trend curve yields daily search volumes, and these search volumes were manually recorded for each search term over the studied time period.

Disease Nomenclature and Symptom Search Term Selection

The authors selected search terms for the database query using a systematic approach. Key concepts were presented to the research group, and a preliminary list of search terms was compiled using COVID-19 nomenclature and symptomatology [22-27].

The authors used a combination of literature review, clinical experience, google searches, and news resources to compile a list of potential symptomatology associated with COVID-19. Since multiple iterations of a word may be used to search the same condition or symptom (eg, myalgia and muscle ache), GT groups a cluster of search terms as a topic or disease [28]. Therefore, topics or diseases were used over an individual search term when applicable. The list of symptom terminology considered were: fever (medical condition), shortness of breath (disease), cough (disease), anosmia (topic), fatigue (medical condition), rhinorrhea (medical condition), nasal congestion (syndrome), sneeze (topic), myalgia (topic), sore throat (topic), diarrhea (topic), anorexia (symptom), chest pain (syndrome), sputum (sputum), headache (medical condition), nausea (disorder), ageusia (topic), abdominal pain (syndrome), dizziness (medical condition), vomiting (ailment), and eye pain (topic).

Disease terminology assessed included coronavirus (virus), coronavirus (search term), COVID-19 (search term),

SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2; search term), and severe acute respiratory syndrome (disease). Because the timing of the nomenclature designations overlapped with the study period, we elected to study both clustered terms and individual search terms for COVID-19. The period studied was set from January 9, 2020, to April 6, 2020, to capture the last 3 months.

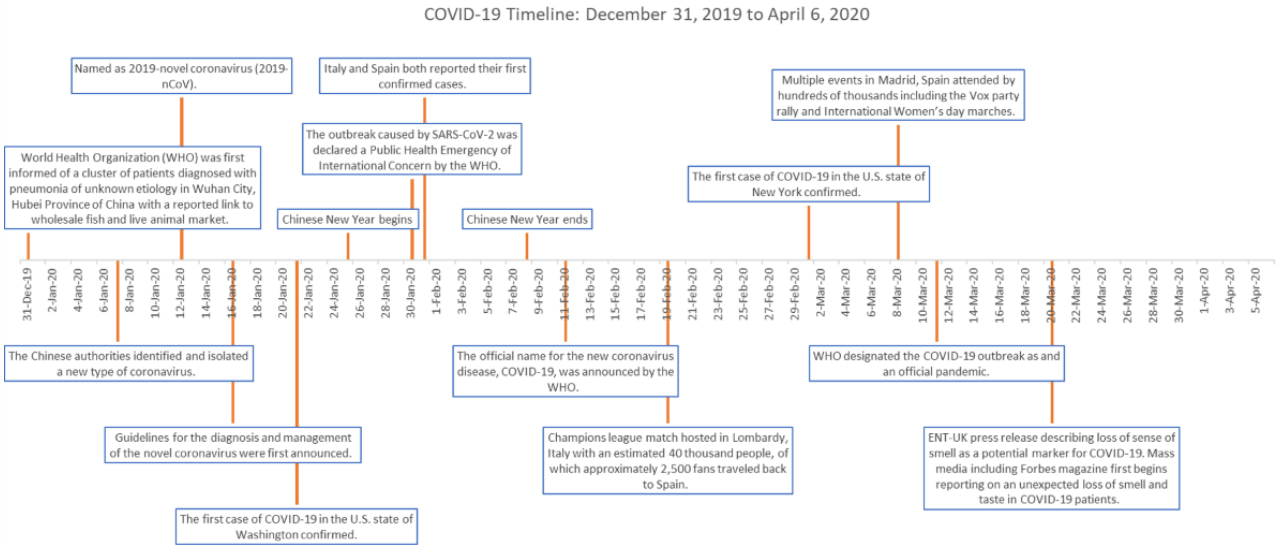
GT data for each symptom were obtained and compared using a Pearson correlation with the disease terms. Those terms reaching statistically significant correlations were then used in the final modeling. Two physicians fluent in Chinese determined search terms related to COVID-19 nomenclature and symptomatology for use in the BI.

Locations chosen for analysis were selected from early epicenters of the COVID-19 pandemic with reported internet search data, reported cases, and deaths available during this period. China, Wuhan (China), Italy, Spain, Washington State (United States), and New York State (United States) were selected for regional analysis. The WHO was first informed of a pneumonia-like illness outbreak in Wuhan, China on December 31, 2020. Other regions of the world then gradually started reporting their first confirmed cases, including the state of Washington (United States) on January 21, 2020, Italy and Spain on January 31, 2020, and the state of New York (United States) on March 1, 2020. Regional GT data were collected from the date of the first confirmed case.

Significant Events

The timeline of the pandemic was then outlined based upon WHO reporting of global cases around the world, as well as identification of large public events and media publications on COVID-19-related topics (Figure 1) [27,29-33]. These important dates were then compared to GT and Baidu search trends, to identify possible "super-spreader" events, media influence, and context for the trends.

Figure 1. Timeline of real-world COVID-19 significant events. COVID-19: coronavirus disease; ENT-UK: British Association of Otolaryngologists; SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.



Analyses

Analyses were performed using SPSS Statistics for Windows (Version 26.0, IBM Corp). A Pearson correlation was used to compare volumes of real-world confirmed cases, real-world deaths, COVID-19 disease nomenclature searches, and symptom terms searches. Associations across time series were assessed by fitting autoregressive integrated moving average (ARIMA) models to the individual search volumes and real-world time series, based on the methods of Box and Jenkins [34]. The models were created with assessments of trend, seasonal differencing, and outliers. Autocorrelation functions and partial autocorrelation functions were assessed, and the Ljung-Box statistic was used to examine the residuals from the time series models to evaluate the lack of fit [35]. Sample cross-correlation functions (CCF) were then used to compare the time series models to assess the correlation between the explanatory and dependent time series. Lags of the time series were determined by comparing asynchronous cross-correlations and synchronous cross-correlations [36]. Significance was determined using a two-tailed $P<.05$.

Results

Worldwide Real-World COVID-19 Data and GT

Figure 2 shows a geographic heat map of online Google searches for coronavirus (virus) during the study period of January 9, 2020, to April 6, 2020, which demonstrates the highest search volumes in Italy with high search volumes in Spain and the United States. The corresponding worldwide geographic heat maps of real-world COVID-19 confirmed cases (Figure 3) and deaths (Figure 4) provide visual comparative representations of these observations with the GT results. Figure 5A shows the sequence charts for the disease nomenclature searches. Of the GT disease nomenclature evaluated, the real-world (RW) confirmed cases and deaths were strongly correlated with COVID-19, coronavirus (virus; $r=0.62$, $r=0.57$, respectively), coronavirus (search term), and SARS-CoV-2 (search term; $r=0.73$, $r=0.67$, respectively). All these correlations demonstrated $P<.001$. Worldwide RW data were not statistically significantly correlated with severe acute respiratory syndrome (disease).

A total of 15 of the symptom search terms had statistically significant correlation coefficients with worldwide GT COVID-19, GT coronavirus (disease), and RW confirmed cases (Table 1). Of the included terms, only diarrhea failed to reach statistically significant correlation with RW deaths of COVID-19. The symptoms of shortness of breath (SOB), anosmia, ageusia, headache, chest pain, and sneezing all had strong correlations (r>0.60) to both new cases and deaths.

Figure 2. Geographic heat map of worldwide online Google searches for coronavirus (virus) between January 9, 2020, and April 6, 2020.

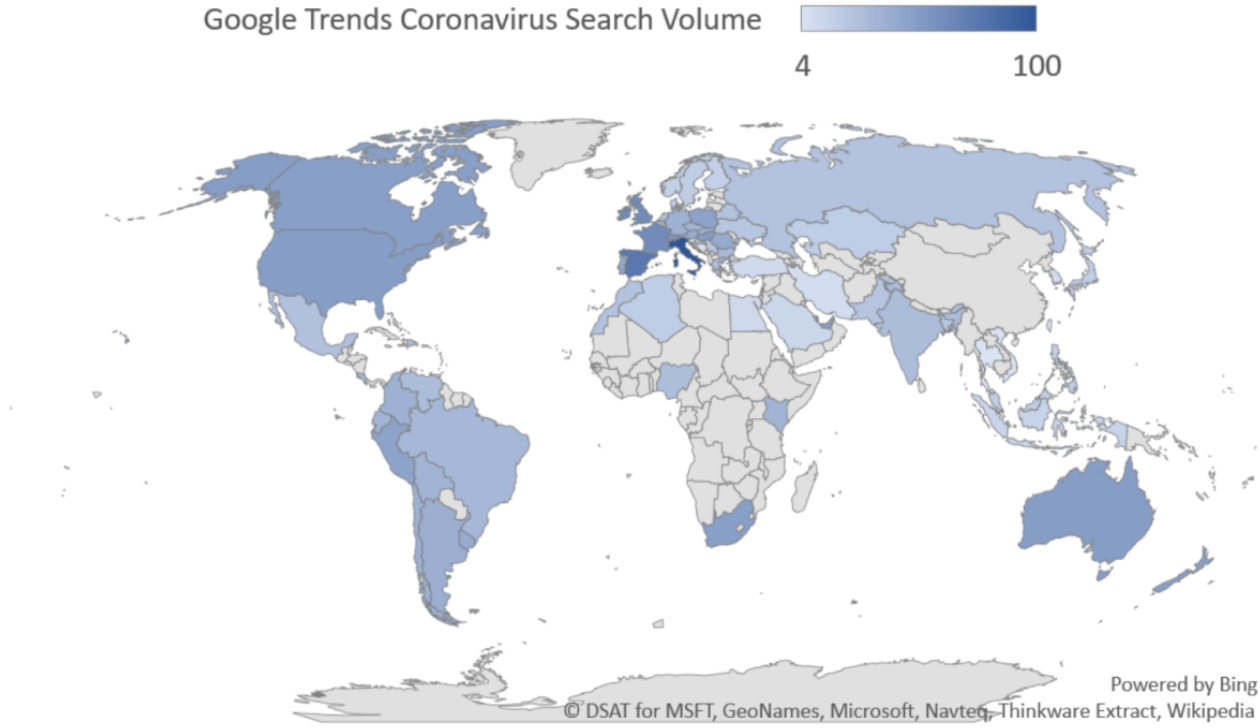


Figure 3. Geographic heat map of worldwide real-world confirmed cases of COVID-19 as of April 6, 2020. COVID-19: coronavirus disease.

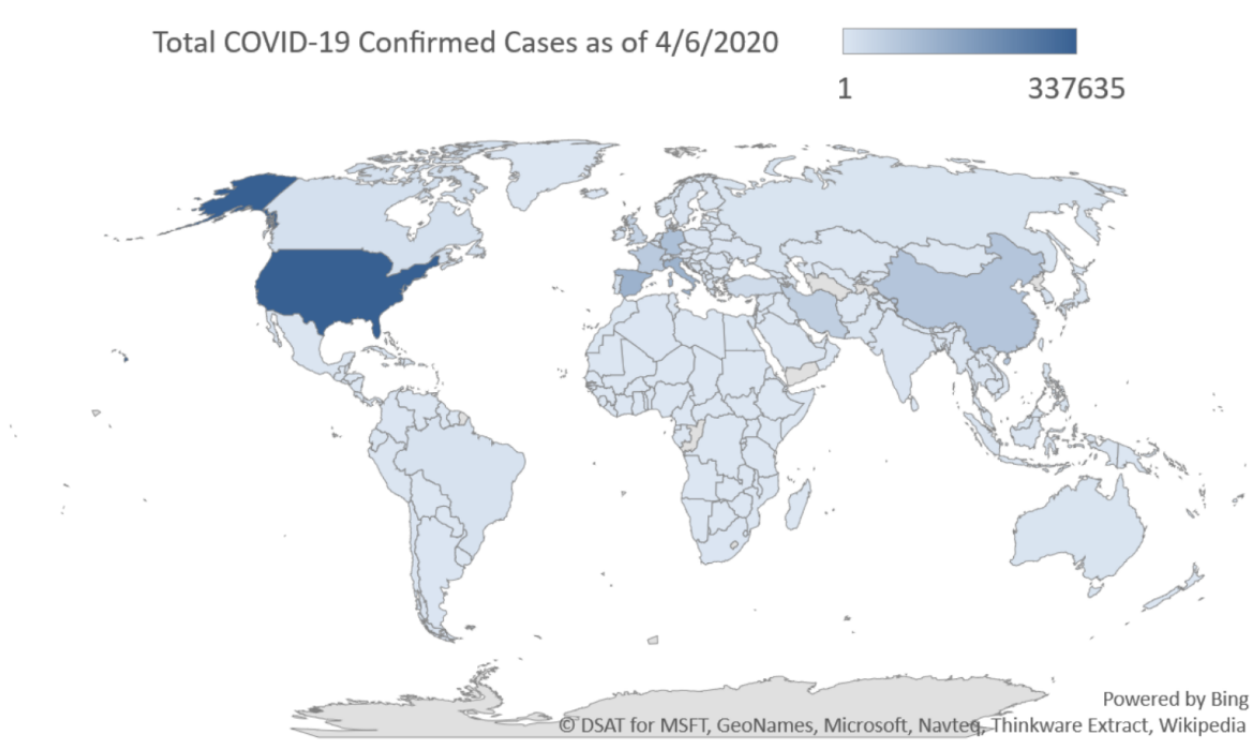


Figure 4. Geographic heat map of worldwide real-world deaths from COVID-19 as of April 6, 2020. COVID-19: coronavirus disease.

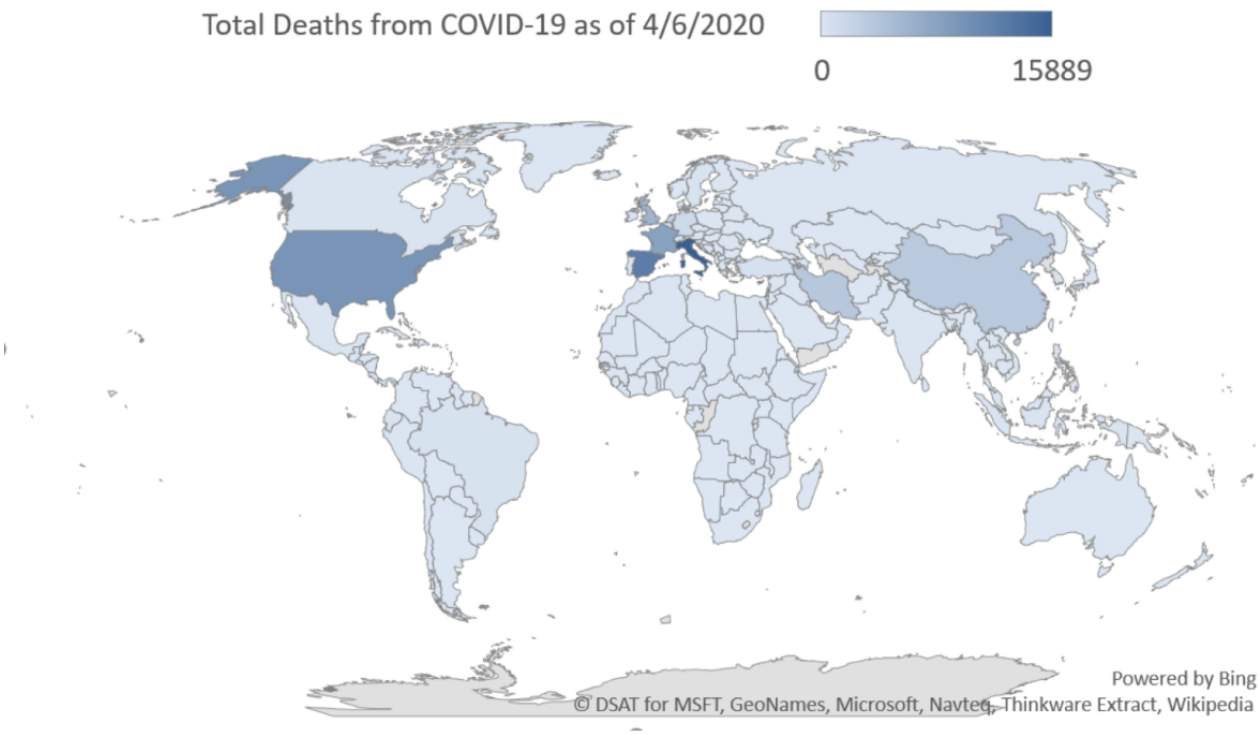


Figure 5. Normalized Google Trends and Baidu Index search terms by date compared to real-world new confirmed cases and deaths from COVID-19: (A) RW worldwide data and GT COVID-19 search terms, (B) China RW data and Baidu Index COVID-19 search terms, and (C) GT search for coronavirus (virus) by geographic region. B: Baidu Index; COVID-19: coronavirus disease; GT: Google Trends; RW: real-world; SARS: severe acute respiratory syndrome; SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.

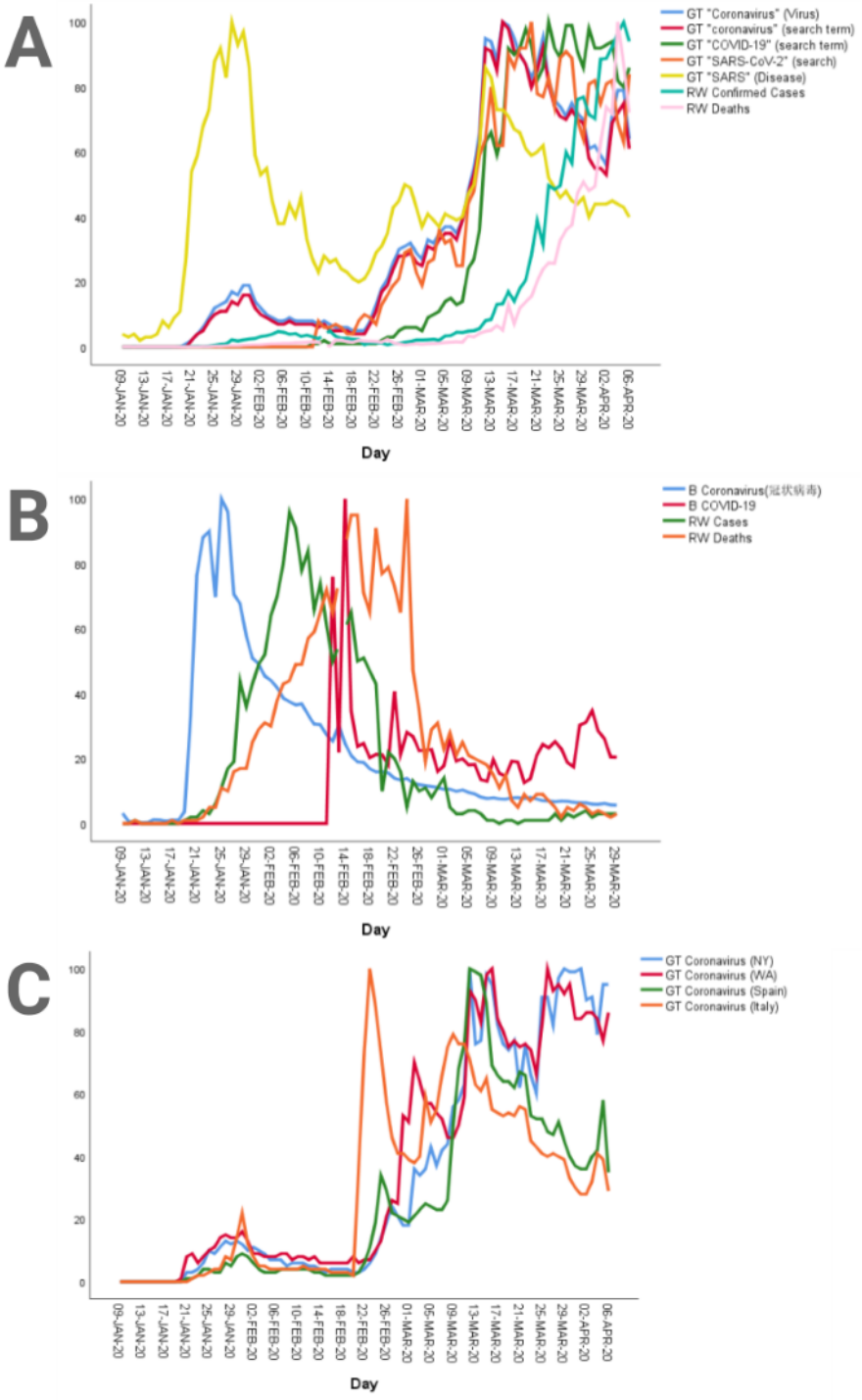


Table 1. Correlations among Google and Baidu search engines and real-world cases and deaths of COVID-19.

Search term[a]	WW[b] cases	WW deaths	China cases	China deaths	Italy cases	Italy deaths	Spain cases	Spain deaths	WA cases	WA deaths	NY cases	NY deaths
Real world deaths												
r	*0.87*[c]	N/A[d]	0.63	N/A	*0.95*	N/A	*0.97*	N/A	*0.92*	N/A	*0.87*	N/A
P value	<.001	N/A	<.001	N/A	<.001	N/A	<.001	N/A	<.001	N/A	<.001	N/A
Coronavirus												
r	*0.61*	0.56	0.35	0.049	0.33	0.19	0.44	0.32	*0.92*	*0.85*	*0.62*	0.51
P value	<.001	<.001	.002	.67	.006	.12	<.001	<.001	<.001	<.001	<.001	<.001
COVID-19 [e]												
r	*0.82*	*0.75*	–0.20	–0.34	*0.95*	*0.87*	*0.86*	*0.77*	*0.89*	*0.84*	0.56	0.27
P value	<.001	<.001	.08	.002	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.11
Fever												
r	0.41	0.33	0.47	–0.065	0.28	0.07	0.21	0.06	*0.83*	*0.84*	0.49	0.20
P value	<.001	<.001	<.001	.57	.02	.56	.09	.62	<.001	<.001	<.001	.23
SOB [f]												
r	*0.73*	*0.65*	0.38	0.053	0.26	0.13	0.51	0.37	*0.76*	*0.73*	–0.11	–0.37
P value	<.001	<.001	<.001	.65	.04	.31	<.001	<.001	<.001	<.001	.53	.03
Cough												
r	0.35	0.26	0.56	0.33	–0.19	–0.37	0.21	0.05	0.46	0.54	–0.51	–0.65
P value	<.001	.02	<.001	.003	.13	<.001	.08	.67	<.001	<.001	<.001	<.001
Sputum												
r	0.48	0.39	0.48	0.32	0.05	–0.01	0.17	0.07	0.43	0.41	*0.63*	0.55
P value	<.001	<.001	<.001	.005	.72	.92	.17	.58	<.001	<.001	<.001	<.001
Anosmia												
r	*0.70*	*0.61*	–0.16	–0.21	*0.83*	*0.77*	0.58	0.47	*0.69*	0.58	*0.83*	0.53
P value	<.001	<.001	.15	.06	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001
Dys/ageusia [g]												
r	*0.75*	*0.66*	0.060	0.003	*0.68*	*0.64*	*0.69*	*0.58*	0.57	0.48	*0.94*	*0.73*
P value	<.001	<.001	.60	.98	<.001	<.001	<.001	<.001	<.001	<.001	<.001	<.001
Nasal congestion												
r	0.41	0.32	0.59	0.14	0.02	–0.04	0.08	–0.08	0.26	0.25	0.27	–0.05
P value	<.001	.002	<.001	.24	.88	.74	.51	.53	.03	.03	.11	.77
Rhinorrhea												
r	0.34	0.26	0.52	0.016	*0.64*	0.48	0.09	–0.02	*0.60*	0.57	0.50	0.40
P value	<.001	.02	<.001	.16	<.001	<.001	.49	.86	<.001	<.001	<.001	.01
Sneezing												
r	0.65	0.58	*0.78*	*0.73*	0.16	0.03	0.27	0.17	*0.65*	*0.69*	0.22	–0.04
P value	<.001	<.001	<.001	<.001	.21	.81	.03	.18	<.001	<.001	.19	.82
Sore throat												
r	0.49	0.41	*0.63*	0.34	–0.08	–0.17	0.27	0.11	0.29	0.38	–0.23	–0.32
P value	<.001	<.001	<.001	.003	.55	.17	.03	.36	.01	<.001	.18	.05
Headache												

Search term[a]	WW[b] cases	WW deaths	China cases	China deaths	Italy cases	Italy deaths	Spain cases	Spain deaths	WA cases	WA deaths	NY cases	NY deaths
r	*0.82*	*0.77*	0.56	*0.66*	0.16	0.09	0.46	0.35	0.18	0.20	–0.18	–0.43
P value	<.001	<.001	<.001	<.001	.20	.46	<.001	<.001	.12	.08	.30	<.001
Myalgia												
r	0.47	0.42	*0.64*	0.32	0.07	–0.07	0.42	0.31	0.24	0.17	–0.35	0.24
P value	<.001	<.001	<.001	.005	.60	.56	<.001	.01	.04	.14	.03	.15
Chest pain												
r	*0.83*	*0.75*	*0.80*	0.53	0.59	0.43	0.44	0.28	0.58	0.41	0.55	0.26
P value	<.001	<.001	<.001	<.001	<.001	<.001	<.001	.02	<.001	<.001	<.001	.12
Eye pain												
r	0.35	0.29	0.15	0.24	0.06	0.08	–0.05	–0.07	–0.12	–0.05	*0.81*	*0.61*
P value	<.001	.006	.19	.03	.66	.50	.68	.57	.30	.64	<.001	<.001
Diarrhea												
r	0.28	0.21	0.47	0.14	0.35	0.23	0.40	0.26	0.40	0.43	0.33	0.05
P value	.008	.05	<.001	.21	.004	.06	<.001	.03	<.001	<.001	.05	.76

[a]Google Trends used for all regions excluding China. Baidu Index used for China.

[b]WW: worldwide.

[c]Italics denotes strong correlation of $r>0.60$.

[d]Not applicable.

[e]COVID-19: coronavirus disease.

[f]SOB: shortness of breath.

[g]Dysgeusia used for China and Baidu Index search. Ageusia used for all Google Trends searches.

Chinese COVID-19 Data With Baidu Index

In China, the written phrase for coronavirus (冠状病毒) was the predominant term used for searches during the COVID-19 crisis. Searches for “coronavirus” were correlated with new Chinese cases of COVID-19 but were not correlated with deaths (Table 1). The term COVID-19 was introduced by the World Health Organization (WHO) on February 11, 2020, so searches for this term only started after the outbreak in China was well underway. Figure 5B plots the Baidu search volumes along with the RW Chinese confirmed cases and deaths. The symptoms that correlated with both new daily Chinese cases and deaths were cough (咳嗽), sputum (痰, 黏液), sneezing (喷嚏), sore throat (咽喉痛), myalgia (肌肉酸痛), chest pain (胸痛), and headache (头痛). Symptoms that correlated to new Chinese cases but not deaths were fever (发热, 发烧), shortness of breath (呼吸急促, 呼吸困难, 呼吸短难), nasal congestion (鼻塞), rhinorrhea (流鼻涕), and diarrhea (腹泻). Eye pain (眼痛) was the only symptom that correlated to deaths but not cases (Table 1). The symptoms with strong correlations ($r>0.60$) to new Chinese cases were sneezing, sore throat, myalgia, and chest pain. The symptoms with strong correlations to deaths in China were sneezing and headache.

Italian and Spanish COVID-19 Data With Google Trends

Figure 5C is a sequence chart showing the geographic regional data. Spanish and Italian GT correlations are also displayed in Table 1. Symptoms strongly associated with new Italian cases ($r>0.60$) were anosmia, ageusia, rhinorrhea, and chest pain. Symptoms strongly correlated to Italian deaths ($r>0.60$) were anosmia and ageusia. Symptoms strongly associated with new Spanish cases ($r>0.60$) were anosmia and ageusia. The only symptom strongly correlated to Spanish deaths ($r>0.60$) was ageusia, though anosmia was the next closest ($r=0.50$).

Washington and New York, United States COVID-19 Data With Google Trends

GT correlations with new daily cases are shown in Table 1. For Washington, fever, SOB, anosmia, rhinorrhea, and sneezing were strongly correlated with new in-state cases ($r>0.60$) though ageusia was close ($r=0.58$). Fever, SOB, rhinorrhea, and sneezing were strongly correlated with in-state deaths ($r>0.60$), though anosmia and ageusia were close with moderate correlations ($r=0.58$ and $r=0.51$, respectively). In New York, fever, sputum, anosmia, ageusia, rhinorrhea, chest pain, and eye pain correlated strongly with new in-state cases. Symptoms that correlated strongly to New York state deaths ($r>0.60$) were sputum, anosmia, and ageusia.

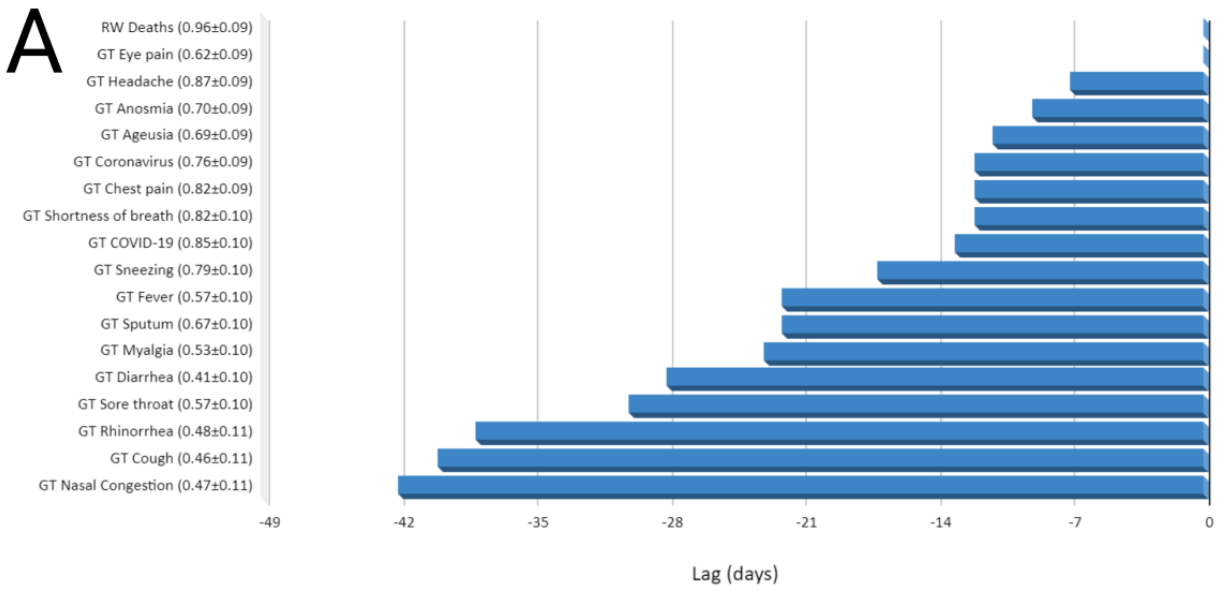
Time Series Cross-Correlations With Lag

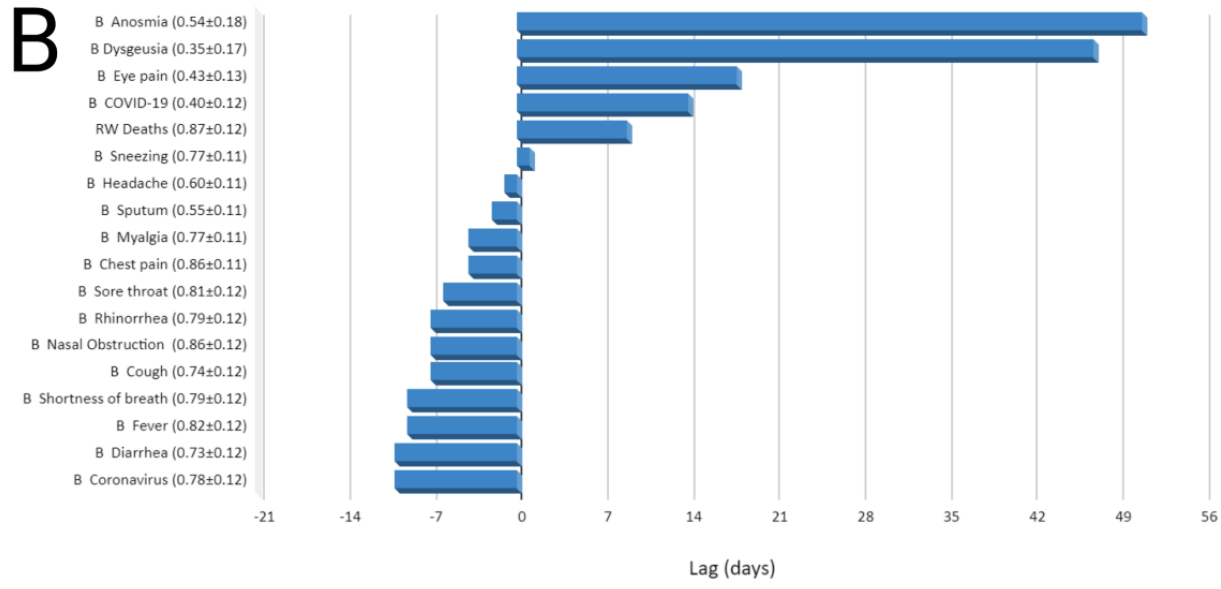
All time series were fit for the ARIMA models. Outliers were removed prior to the analysis from the worldwide and China's RW confirmed COVID-19 cases and deaths corresponding to February 13, 2020, in which a large amount of previously unreported cases was provided to the WHO on a single day [12].

Figure 6 summarizes the lagged correlations in CCFs of the ARIMA models. As shown in Figure 6A, GT coronavirus (virus) and GT COVID-19 (search term) searches predated RW confirmed cases by approximately 12 days with strong correlations (r=0.79, SE 0.09 and r=0.84, SE 0.10, respectively) predating them by 19 days. Figure 6B shows a visual representation of lag correlations of RW confirmed cases compared to BI searches in China. Searches for BI coronavirus had a strong correlation with RW confirmed cases with a negative lag of 10 days (r=0.78, SE 0.12), while BI COVID-19 had a moderate correlation with a positive lag of 14 days (r=0.40, SE 0.12). Lag correlation of the various search terms and real-world cases demonstrated significant correlations with all terms (Figure 6B). Searches for symptoms of diarrhea, fever, shortness of breath, cough, nasal obstruction, and rhinorrhea all had negative lag >1 week compared to new daily cases.

GT anosmia and ageusia demonstrated very strong correlations with RW COVID-19 confirmed cases worldwide at a lag of 5 days, while Baidu searches for anosmia and dysgeusia had moderate to high correlations with RW COVID-19 confirmed cases in China at an extended lag of 64 and 57 days, respectively.

Figure 6. Lag correlations of online search terms worldwide to RW COVID-19 daily cases from January 9, 2020, to April 6, 2020. Note that a negative lag time means online searches preceded the daily RW cases. In parenthesis next to each search term is r±SE. (A) Lag-time of GT search terms, including GT coronavirus (virus), GT COVID-19 (search term), symptom term searches, and RW deaths compared to RW confirmed COVID-19 cases worldwide. (B) Lag time of Baidu Index search terms, including Baidu Index coronavirus (search term), Baidu Index COVID-19 (search term), symptom term searches, and RW Chinese deaths compared to RW confirmed COVID-19 cases in China. B: Baidu Index; COVID-19: coronavirus disease; GT: Google Trends; RW: real-world.





Discussion

Principal Findings

Our study demonstrates that digital epidemiology of the COVID-19 pandemic accurately correlated symptom searches around the globe with real-world cases and deaths, with internet searches preceding real-world cases and deaths by several days to a few weeks (Figure 6A). This lag time may represent a reporting bias, rooted in delays in testing [37]. Peaks of confirmed cases and deaths were similar, possibly due to the confirmation of COVID-19 status late in the disease course, closer to time of death. This lag time bias further justifies the importance of pursuing more real time assessments of disease development, ostensibly when people turn to the internet as they develop symptoms [24]. Previous epidemics have supported the use of internet searches for outbreak surveillance, suggesting that this method of surveillance may deserve more investment by public health agencies with development for the sole purposes of health care [4-7,9].

As SARS-CoV-2 is a novel virus, symptom constellation was poorly defined at the beginning of the outbreak. Symptoms evolved to include nasal congestion, sore throat, diarrhea, dysgeusia, and anosmia. Conceivably, digital epidemiology could assess these trended disease symptom searches in real time, actively correlating searches with real-world cases and deaths. Focusing on symptoms with strong correlations could then be emphasized in screening exams and public health campaigns.

With the evolution of anosmia as a recognized symptom, media influence was readily apparent. The first report on anosmia coinciding with the outbreak was published by Iran on March 9, 2020, though it did not disseminate internationally [30]. It was not until March 20, 2020 that the international medical community and mass media both began circulating press releases on the loss of smell as a potential marker for the COVID-19 infection [32,33]. GT searches for anosmia and ageusia were strongly correlated with RW COVID-19 confirmed cases worldwide at a lag of 5 days, while Baidu anosmia and dysgeusia searches had moderate to high correlations with RW confirmed cases in China at an extended lag of 64 and 57 days, respectively. These findings suggest that the search volumes of these terms were related to an index event, in this case after the scientific and journalistic media announced anosmia as a symptom on March 20, 2020. Within this atmosphere of constant and increasing media coverage, it is important to recognize the effect the media has on public interest. Cervellin et al [38] evaluated Google Trends in 2017 in an effort to determine its reliability as a tool for epidemiology. They found that, although reliable, it is certainly influenced by media coverage, which raises concerns for the true impact of these disease symptoms. This is matched by our data seen with anosmia peaking much later than other symptoms (Figure 6A), around the time of this mass media coverage (Figure 1).

Both search terms for loss of smell and taste had positive lag in our ARIMA models for both worldwide and Chinese data (Figure 6B), meaning that peaks in searches occurred after peaks in new cases. Our data show an enormous spike in these searches right after the time the international news media began to produce articles detailing these previously rare symptoms. It is important to consider that, although some of these searches may derive from patients with symptoms, they were accentuated by media attention.

As researchers learned more about COVID-19, other symptoms lesser known to the lay public were also being discussed among the medical community. Chest pain, myalgia, headache, and eye pain have all been reported. Although these symptoms have not received wide media coverage, they are consistent with recently discovered clinical manifestations of the disease, such as cardiac injury, embolic events, and neurologic sequelae [25,39,40]. In this study, these lesser known symptoms had similar lag times without the concern for media bias as seen with anosmia and other publicized symptoms. These symptoms may better represent patients developing disease, rather than those simply curious about the virus and its symptoms [41,42].

Though worldwide evaluation of cases and deaths provides data regarding the symptom profile of the disease, isolating regional data yields information about cultural differences, effects of the media, and of possible “super-spreader” events that could be used by public health officials as a form of contact tracing. The analysis of the Chinese BI data allows us to analyze the COVID-19 pandemic before the international medical community and media attention had the potential to distort search trends. The two symptoms that were correlated with new cases and deaths in China, sneezing and chest pain, were the two most frequently correlated symptoms to new cases and deaths in all regions studied. Dysgeusia was not found to be significantly correlated when analyzing China as a whole but was significantly correlated with new cases in Wuhan, the epicenter of the pandemic (r=0.22, P=.49). The significance of this finding, which manifested well before any known association between smell and taste loss with COVID-19, highlights the ability for informatics to identify the spread of disease using novel symptoms.

Lag correlation with ARIMA modeling did demonstrate significant correlation between new daily cases in China with anosmia and dysgeusia, but the lag was 64 and 57 days, respectively. This precisely corresponds to the increase in searches spurred from the announcement of these symptoms’ associations with COVID-19 in the media in late March [32,33,43,44]. This further highlights the potential for the media’s effects on this type of methodology.

Symptoms with negative lag have the potential for predicting location or size of disease outbreaks before they happen. In China, symptoms of rhinorrhea, nasal congestion, cough, shortness of breath, fever, and diarrhea all had significant lags of a week or more when correlated with new cases (Figure 6B). The media and medical community have paid significant attention to certain symptoms like fever, cough, and SOB, and these symptoms showed strong correlation (r>0.60) in the ARIMA modeling, confirming they could be good predictors for outbreaks. Interestingly, diarrhea is also a strongly correlated symptom with longer negative lag, indicating the potential for predictive values. Italy and Spain had their first confirmed cases of COVID-19 on January 31, 2020, and by mid-March, both

countries were in full quarantine and had ceased all nonessential activity. The symptoms found to correlate to new cases and deaths in these two regions (Table 1) match well with our findings that the symptoms that most correlate with worldwide cases and deaths include headache, chest pain, sneezing, anosmia, and ageusia. Interestingly, our data also showed a direct correlation of search volume with major events within Italy and Spain. On February 19 in the Lombardy Region of Italy, 40,000 people attended a Champions league soccer match [27,29]. Similarly, on March 8, both an International Women's Day March and a Vox party rally were taking place with thousands of people in attendance. As is apparent in Figure 5C, a peak in searches is seen directly after these dates.

In the United States, Washington was the first state to announce a COVID-19 case on January 21, 2020, and peaked with daily confirmed cases on March 23. New York then became the epicenter of the COVID-19 pandemic in the United States with one-third of the country's cases. GT coronavirus (virus) and GT COVID-19 (search term) searches in these regions were strongly correlated with their respective regional RW confirmed cases and RW deaths. Analysis of GT for New York showed very strong correlations for both anosmia and ageusia with regard to daily confirmed cases and deaths, respectively. In this novel pandemic, this finding may demonstrate that, although media coverage may have the potential to distort the prevalence of certain disease characteristics, it may also be able to emphasize certain unique qualities of a disease once they have been identified. Interestingly, eye pain was a symptom that was found to be strongly correlated with new cases in New York, and this symptom was one that was found to correlate with new cases worldwide as well [25]. Eye pain has not had nearly as much media attention as loss of smell or taste, and it was added to a list of potential symptoms from less disseminated publications [25]. This may imply that further attention be paid to ophthalmologic complaints (eg, conjunctivitis) or headaches in this outbreak. With the use of Big Data such as Baidu and GT, there are limitations that must be acknowledged. Both platforms do not provide the exact methodology by which they generate search data, and the study population responsible for the searches cannot be determined [21]. The most widely discussed limitation is that search volumes can be heavily influenced by the dissemination of information through the internet or news media. Previous studies have also highlighted this limitation, and GT and BI may have better reliability defining the epidemiology for common diseases with minor media coverage or rare diseases and conditions with higher audiences. This was observed in our study with better reliability seen in those symptoms of COVID-19 with less media coverage [38,45].

Conclusion

This study demonstrates the utility of digital epidemiology in providing helpful surveillance data of disease outbreaks like COVID-19. Although certain online search trends for this disease were influenced by media coverage, many search terms reflected clinical manifestations of the disease and showed strong correlations with RW cases and deaths.

Authors' Contributions

Each named author has substantially contributed to conducting the underlying research and drafting this manuscript. The authors have not published, posted, or submitted any related papers from the same study. This study received no funding.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Complete list of considered search terms.
[PDF File (Adobe PDF File), 401 KB - publichealth_v6i2e19702_app1.pdf]

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Abbreviations

ARIMA: autoregressive integrated moving average
BI: Baidu Index
CCF: cross-correlation functions
COVID-19: coronavirus disease
GT: Google Trends
RW: real-world
SARS: severe acute respiratory syndrome
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
SOB: shortness of breath
WHO: World Health Organization

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Original Paper

Global Sentiments Surrounding the COVID-19 Pandemic on Twitter: Analysis of Twitter Trends

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Abstract

Background: With the World Health Organization's pandemic declaration and government-initiated actions against coronavirus disease (COVID-19), sentiments surrounding COVID-19 have evolved rapidly.

Objective: This study aimed to examine worldwide trends of four emotions—fear, anger, sadness, and joy—and the narratives underlying those emotions during the COVID-19 pandemic.

Methods: Over 20 million social media twitter posts made during the early phases of the COVID-19 outbreak from January 28 to April 9, 2020, were collected using "wuhan," "corona," "nCov," and "covid" as search keywords.

Results: Public emotions shifted strongly from fear to anger over the course of the pandemic, while sadness and joy also surfaced. Findings from word clouds suggest that fears around shortages of COVID-19 tests and medical supplies became increasingly widespread discussion points. Anger shifted from xenophobia at the beginning of the pandemic to discourse around the stay-at-home notices. Sadness was highlighted by the topics of losing friends and family members, while topics related to joy included words of gratitude and good health.

Conclusions: Overall, global COVID-19 sentiments have shown rapid evolutions within just the span of a few weeks. Findings suggest that emotion-driven collective issues around shared public distress experiences of the COVID-19 pandemic are developing and include large-scale social isolation and the loss of human lives. The steady rise of societal concerns indicated by negative emotions needs to be monitored and controlled by complementing regular crisis communication with strategic public health communication that aims to balance public psychological wellbeing.

(JMIR Public Health Surveill 2020;6(2):e19447) doi:10.2196/19447

KEYWORDS

COVID-19; Twitter; pandemic; social sentiments; emotions; infodemic

Introduction

The coronavirus disease (COVID-19) pandemic has infected individuals in more than 200 countries and resulted in many deaths [1]. With the World Health Organization's (WHO's) pandemic declaration and government-initiated actions against the disease, sentiments about COVID-19 are rapidly evolving. In the past decade, social media analytic tools have been utilized to monitor public sentiments and communication patterns of public health emergencies like the Ebola and Zika epidemics. Although many studies have investigated general sentiment valences and discourse topics [2,3], specific emotions have been

found to be more closely linked to psychological processes and behaviors than the overall positive and negative valences [4]. Therefore, we postulate that distinct emotions emerging from social media and their underlying narratives are highly relevant to the current COVID-19 crisis and can provide actionable insights into the efficacy of public health messaging.

Particularly, we focused on four emotions: fear, anger, sadness, and joy. According to Plutchik's Wheel of Emotions [5], fear-anger and sadness-joy are the basic emotion pairs of opposite experiences. Fear is an unpleasant emotion typically arising from danger or uncertainties caused by circumstances, while anger results from uncertainties caused by others [6]. Sadness is a negative emotion experienced typically after unpleasant circumstances that are out of one's control, and joy is a positive feeling after pleasant events that are appraised as certain and under control [6]. Investigating the evolution of these four basic emotions can demonstrate the changing dynamics of the public's experience to the crisis.

In this report, we present the results of Twitter users' public emotional responses to the pandemic. Trends of the four basic emotions and the narratives underlying those emotions were examined.

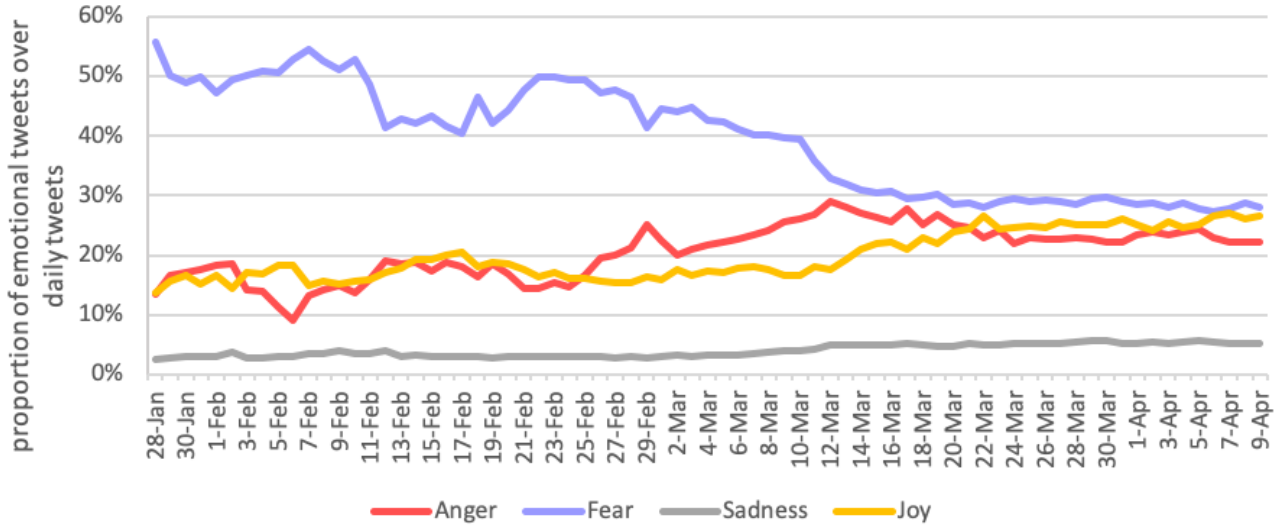
Methods

English tweets related to COVID-19 worldwide posted from January 28 to April 9, 2020, were collected from Twitter's standard search application programming interface using "wuhan," "corona," "nCov," and "covid" as search keywords. These keywords were selected because they were widely used during the early assessment of the COVID-19 situation. Publicly accessible tweets from any type of account that contained any of the keywords were collected. The underlying emotions of tweets were analyzed using the algorithm *CrystalFeel*, a sentiment analytic technology whose accuracy had been demonstrated (see details and examples in Multimedia Appendix 1) [7]. Pearson *r* correlations were conducted between emotions and date to demonstrate the trends of emotions across time statistically. Word clouds were generated for each of the four emotions based on the top frequent unigrams and bigrams.

Results

A total of 20,325,929 tweets were collected, including 7,033,158 unique users from more than 170 countries. The daily proportion of tweets stratified by emotion were plotted across time (Figure 1).

Figure 1. Emotions trends during the early stages of the COVID-19 pandemic.



Expectedly, fear was the dominant emotion at the end of January when the disease first surfaced. The prominence of fear gradually dropped to less than 30% of daily tweets in early April as the crisis developed (r_{71}=–0.92; P<.001). In contrast, tweets on anger progressively increased from late January to early March, peaking at 29% on March 12, a day after the pandemic declaration by the WHO. Tweets on anger slightly decreased since then, but remains at a relatively high level (r_{71}=0.75; P<.001). Coinciding with the decrease of tweets on both fear and anger after the pandemic announcement, tweets on sadness, although proportionally lower than those of the other emotions, doubled since the WHO declaration (r_{71}=0.88; P<.001). Similarly, tweets on joy, suggesting a sense of pride, gratitude, hope, and happiness [7], also increased (r_{71}=0.86; P<.001).

Further analyses using word clouds suggest that narratives underlying those emotions evolved as the pandemic developed (Multimedia Appendix 2). In late January, fear was possibly related to the emergence of COVID-19 and its unknown nature, causing uncertainty about containment and spread, indicated by words such as "first case" and "outbreak." However, as the pandemic escalated, the narratives suggested fear about shortages of COVID-19 tests and medical supplies indicated by words such as "test shortages" and "uncounted." The anger word clouds suggest xenophobia at the beginning of the pandemic when the disease was predominantly localized to China and Asia, indicated by words such as "racist" and "Chinese people." Anger then shifted to discourse around isolation fatigue that can occur from social seclusion, indicated by words such as "stay home" and several swear words. Narratives of recent sadness surrounding the topics of losing

friends and family members are surfacing, with words relating to "loved one" and "passed away," highlighting potential social concerns arising from personal traumatic experiences of the pandemic. The world has also seen a concurrent increase in the sense of joy encompassing hope, gratitude, and human resilience with words such as "Thank," "good news," and "feel good."

Discussion

Our initial findings suggest that global online discourse is swiftly evolving. The discourse is driven by shared public experiences of the COVID-19 pandemic, including large-scale social isolation and the loss of human lives. Although existing studies have demonstrated the immediate psychological reactions to COVID-19 [8,9], our study is the first to demonstrate the evolution of responses across time.

Our findings reveal that negative emotions are dominant during the COVID-19 pandemic, supporting the recent call for action to maintain the public's mental wellbeing for this unprecedented crisis [10]. Negative emotions such as anger and sadness, which are increasing, need to be heeded and counterbalanced by complementing regular crisis communication with strategic public health communication that aims to balance public psychological wellbeing [2]. If such overbearing public emotions are not addressed, there is potential for the emergence of unintended outcomes such as breeding mistrust in the handling of the disease and a belief in online falsehoods that could hinder the ongoing control of the disease [11,12].

Although the data, collected from Twitter's standard application programming interface, looks at only public tweets surrounding the four selected keywords, the estimation is appropriate for the public discourse surrounding the pandemic at present that abides to ethnical guidelines. Future studies should further investigate sentiments by examining specific countries and expanding the scope to include other media platforms such as Facebook and Weibo.

Acknowledgments

MOL conceptualized, initiated, and led the manuscript; JL and AS drafted the manuscript; PJS and WS provided discussions surrounding global results; RG and YY provided data analysis. All authors contributed to the manuscript writing, reviewed the content, and agreed with the submission.

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Conflicts of Interest

RG and YY are co-inventors of the CrystalFeel algorithm. No other conditions or circumstances present a potential conflict of interest for the other authors.

Multimedia Appendix 1
Extended details on methods and data analysis.
[DOCX File , 209 KB - publichealth_v6i2e19447_app1.docx]

Multimedia Appendix 2
Narratives of emotions during the COVID-19 pandemic.
[DOCX File , 1913 KB - publichealth_v6i2e19447_app2.docx]

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Abbreviations

COVID-19: coronavirus disease
WHO: World Health Organization

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Original Paper

Mathematical Modeling of COVID-19 Control and Prevention Based on Immigration Population Data in China: Model Development and Validation

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Abstract

Background: At the end of February 2020, the spread of coronavirus disease (COVID-19) in China had drastically slowed and appeared to be under control compared to the peak data in early February of that year. However, the outcomes of COVID-19 control and prevention measures varied between regions (ie, provinces and municipalities) in China; moreover, COVID-19 has become a global pandemic, and the spread of the disease has accelerated in countries outside China.

Objective: This study aimed to establish valid models to evaluate the effectiveness of COVID-19 control and prevention among various regions in China. These models also targeted regions with control and prevention problems by issuing immediate warnings.

Methods: We built a mathematical model, the Epidemic Risk Time Series Model, and used it to analyze two sets of data, including the daily COVID-19 incidence (ie, newly diagnosed cases) as well as the daily immigration population size.

Results: Based on the results of the model evaluation, some regions, such as Shanghai and Zhejiang, were successful in COVID-19 control and prevention, whereas other regions, such as Heilongjiang, yielded poor performance. The evaluation result was highly correlated with the basic reproduction number (R_0) value, and the result was evaluated in a timely manner at the beginning of the disease outbreak.

Conclusions: The Epidemic Risk Time Series Model was designed to evaluate the effectiveness of COVID-19 control and prevention in different regions in China based on analysis of immigration population data. Compared to other methods, such as R_0, this model enabled more prompt issue of early warnings. This model can be generalized and applied to other countries to evaluate their COVID-19 control and prevention.

(JMIR Public Health Surveill 2020;6(2):e18638) doi:10.2196/18638

KEYWORDS

COVID-19; 2019-ncov; epidemic control and prevention; epidemic risk time series model; incoming immigration population; new diagnoses per day

Introduction

The first case of coronavirus disease (COVID-19) was diagnosed in December 2019 in Wuhan, Hubei, China. Despite the spread of COVID-19, few prevention actions were reinforced at the beginning of the disease outbreak in China. For example, a celebration banquet with tens of thousands of people was held in Wuhan on January 18, 2020; this event accelerated the spread of COVID-19 in that region [1]. Gradually, more prevention actions were taken, including investigation and control of incoming immigration populations from other regions; closing some densely populated areas; and requiring face masks to be worn in public [2,3].

In addition to the traditional methods of COVID-19 prevention and control, supplemental measures are considered to be necessary, particularly to address the issue of people who have no symptoms but may be infectious during the incubation period [4]. Specifically, the screening mechanism of taking people's temperature before they enter public areas can only detect some COVID-19 cases [4].

Given the recent pandemic development, limited studies have utilized COVID-19-related data to investigate the effectiveness of COVID-19 control and prevention [5]. Some studies have collected media reports regarding COVID-19 to examine the role that the media has played in the current epidemic in China [6]. Similarly, researchers previously investigated norovirus epidemics via internet surveillance and built a model to predict potential disease infections in China [7].

The effectiveness of epidemic prevention and control can be estimated from statistical data, such as the daily number of newly diagnosed patients in the provinces or municipalities of China [8-10]. However, this method does not evaluate the effectiveness of prevention and control in regions (including provinces or municipalities) of China because the newly diagnosed case data are not analyzed in combination with the immigration population information during the outbreak. For example, when comparing two provinces A and B with the same numbers of newly diagnosed patients during the outbreak period, the new cases in Province A may mainly immigrate from outside the province, and most of these cases may be confirmed on the day of entrance; meanwhile, Province B may mainly consist of local residents, and most incoming cases may be confirmed one week after their entrance. All confirmed cases in both Province A and B are quarantined until being diagnosed. Therefore, the epidemic prevention and control measures in Province A should be considered to be more effective than those in Province B because the virus spread more severely in Province B despite its lower number of immigrating residents.

The Chinese government has been emphasizing the analysis of big data, especially immigration population data, in COVID-19 prevention and control since mid-February 2020 [11,12]. Immigration population data analysis is an approach to disease prevention. Particularly, the Health Code app was created [13] and applied in various regions [14-17]. The Health Code is a mobile application that detects individuals' prior travel histories, such as in epidemic zones, before they enter a public area. Hence, to detect infected individuals prior to their entrance into public areas, it is more effective to combine this mobile application with body temperature measurements.

Several reports have analyzed the trend of population movement during the COVID-19 pandemic based on immigration population data from Baidu, Inc [18,19]. However, at present, very few COVID-19 control and prevention studies have used the dataset of the daily incoming immigration population in each region.

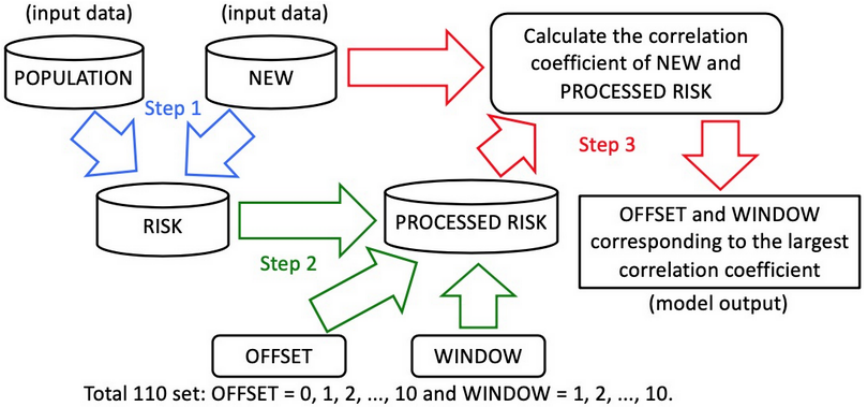
In this study, we analyzed immigration population data to evaluate the risk posed by the daily incoming immigration population in various regions of China. The risk output presents similar indications to the Health Code app, which evaluates the immigration risk from relevant data sources. Moreover, we built an Epidemic Risk Time Series Model to evaluate the effectiveness of COVID-19 control and prevention across different regions. Using this evaluation, regions with poor prevention performance can be detected as soon as possible.

Methods

Overview

In the Epidemic Risk Time Series Model, two decision variables, the OFFSET and WINDOW parameters, were used to reveal the delayed days of the risk (RISK) of the daily incoming immigration population (POPULATION) in each region (REGION) converting to new cases (NEW). More days indicates less effective disease control and prevention. The model workflow is shown in Figure 1. According to this model, there were three major steps to evaluate a REGION in a period of days. Specifically, first, the RISK data were constructed from POPULATION and NEW data; second, the RISK data were processed into PROCESSED RISK data using the OFFSET and WINDOW variables; last, the OFFSET and WINDOW variables that yielded the highest correlation coefficients of NEW and PROCESSED RISK data were chosen as the outputs of the model.

Figure 1. Flowchart showing the three steps of the Epidemic Risk Time Series Model.



Data Sources

Model Input Data 1: NEW

Since January 17, 2020, various REGIONs have released NEW data. The NEW data were crawled from [8].

Model Input Data 2: POPULATION

To detect ongoing trends of the COVID-19 epidemic, the daily incoming immigration population data, which were distinguished from different source REGIONs, were crawled from [20]. Since there were no data sources regarding immigration population data in regions such as Hong Kong, Macao, and Taiwan, and interstate traffic from Hubei has been shut down since late January, these regions were excluded from this analysis. However, the immigration populations emigrating from Hubei to other REGIONs were included in this study. All statistical analyses were conducted using Python version 3.7 (Python Software Foundation).

Analytical Methods

Calculation of RISK

Incoming immigration populations of the same size exposed to different factors were at different levels of risk of contracting COVID-19. For example, individuals with prior residence in Hubei during the spread of COVID-19 experienced higher risks of being infected than individuals in other immigration populations with the same size. Hence, POPULATION was processed using Equation 1, and the RISK data were constructed.

In Equation 1, all the values of RISK, POPULATION, and ACCUMULATED NEW are for a single day. The $RISK_i$ value is the daily immigration risk of REGION i in one day. i can be 1, 2, 3, …, n, where n is a fixed number. In this study, n was 31 because we analyzed 31 REGIONs, including Hubei. The i value in this study cannot be the number of Hubei for the reason mentioned. The $POPULATION_j$ was the POPULATION of source REGION j, where j can be 1, 2, 3, …, n, and j cannot be the same as i. $ACCUMULATED\_NEW_j$ was the sum of NEW in immigration source REGION j in the last 3 days (ACCUMULATED NEW), and it was calculated with Equation 2. $ACCUMULATED\_NEW_d$ is the ACCUMULATED NEW value on date d.

$$ACCUMULATED\_NEW_d = NEW_d + NEW_{d-1} + NEW_{d-2}$$

OFFSET

The OFFSET variable was used to evaluate the control of the incoming immigration population. Among the incoming immigration populations, disease control and prevention were varied at different times or in different regions. Specifically, some regions implemented strict screening mechanisms, such as measuring temperature and examining cough symptoms, to detect infected immigrants and to reinforce quarantine immediately. Therefore, NEW increased simultaneously with the sudden increase of RISK on the same day, whereas infected individuals were diagnosed and confirmed relatively late if they had been infected before entering the REGION. The OFFSET was the number of days that the RISK was shifted. For example, if OFFSET was 3, the RISK of each day was processed as the RISK of 3 days ago.

WINDOW

The WINDOW variable was used to evaluate the control for domestic/local residents. The control and spread among the local people as well as their awareness of prevention would affect the spread of the epidemic. In some regions, immigrants were strictly home-quarantined for 14 days [21]. These rigorous measures prevented potentially infected people from spreading the virus when entering that region.

According to this model, hypothetically, when only deals with externally infected individuals, there will only include the OFFSET. On the other hand, other conditions may contribute to the spread of COVID-19 and have prolonged impact on the RISK. For instance, an infected individual who travels to the REGION, whether sick or incubating the virus, may not seek immediate medical treatment; also, local residents may have poor disease awareness and may not wear a face mask in public areas. Therefore, the WINDOW concept was introduced to the model. For example, when the WINDOW is 10, the total RISK of 10 consecutive days will affect the NEW value on the 10th day. Moreover, the incubation period with a 95% confidence interval was between 4.1 and 7.0 days. Hence, the infected person who entered the REGION 10 days ago could still affect the REGION by spreading the disease from person to person [22].

Processing RISK by OFFSET and WINDOW

RISK can be processed by OFFSET and WINDOW, as in Equation 3.

In Equation 3, all the PROCESSED RISK and RISK values are for the same REGION. $PROCESSED\_RISK_d$ is the value of PROCESSED RISK by OFFSET and WINDOW on date d. $RISK_{d\text{-}w\text{-}OFFSET}$ is the value of RISK on the date d-w-OFFSET. Specifically, if it is necessary to calculate the value of PROCESSED RISK on February 11, 2020, when OFFSET is 3, WINDOW is 2. The equation is as follows:

$$PROCESSED\_RISK_{02/11/2020} = RISK_{02/08/2020} + RISK_{02/07/2020} \text{ (if OFFSET = 3, WINDOW = 2)}$$

When OFFSET equals 0, WINDOW is 1. $PROCESSED\_RISK_d$ is simply $RISK_d$ without any process:

$$PROCESSED\_RISK_{d0} = RISK_d \text{ (if OFFSET = 0, WINDOW = 1)}$$

Correlation Coefficients Between NEW and PROCESSED RISK and Model Outputs

The final step of this model was to find a set of OFFSET and WINDOW that was the best fit for the NEW and PROCESSED RISK values of each REGION on a daily basis.

For each REGION on a daily basis, starting from January 17, 2020, which was the first day of NEW data collection, the OFFSET was calculated from 0 to 10 and the WINDOW was calculated from 1 to 10. There were 110 different OFFSET and WINDOW sets, and the 110 sets were used to process RISK accordingly to calculate the 110 correlation coefficients with NEW and PROCESSED RISK. Finally, the set of OFFSET and WINDOW data corresponding to the maximum correlation coefficient (CORR) was the model output for the REGION on that day.

Results

Processing POPULATION and NEW Into RISK

Based on Equation 2, ACCUMULATED NEW was processed from NEW. As an example, the process for Hubei in the first 6 days is shown in Table 1. Accurate data were released starting on January 17; the values before that day were set to 0. Similar calculations were performed in the other 30 REGIONs on a daily basis.

Table 1. The NEW and ACCUMULATED NEW data in Hubei Province from January 17-22, 2020.

Date	NEW in Hubei	ACCUMULATED NEW in Hubei
01/17/2020	17	17
01/18/2020	59	76
01/19/2020	77	153
01/20/2020	72	208
01/21/2020	105	254
01/22/2020	69	246

Based on Equation 1, RISK was processed from POPULATION and ACCUMULATED NEW. For example, the total POPULATION travelling to Jiangsu and Heilongjiang Province and the total ACCUMULATED NEW of source REGIONS on a daily basis are compared with their RISK in Figure 2 and Figure 3. Meanwhile, according to Equation 1, there were 30 incoming POPULATION and ACCUMULATED NEW values for every targeted REGION. To avoid plotting too many polylines in the chart, the total POPULATION and ACCUMULATED NEW polylines were plotted.

Figure 2. RISK of Jiangsu Province from January 17, 2020 to February 11, 2020.

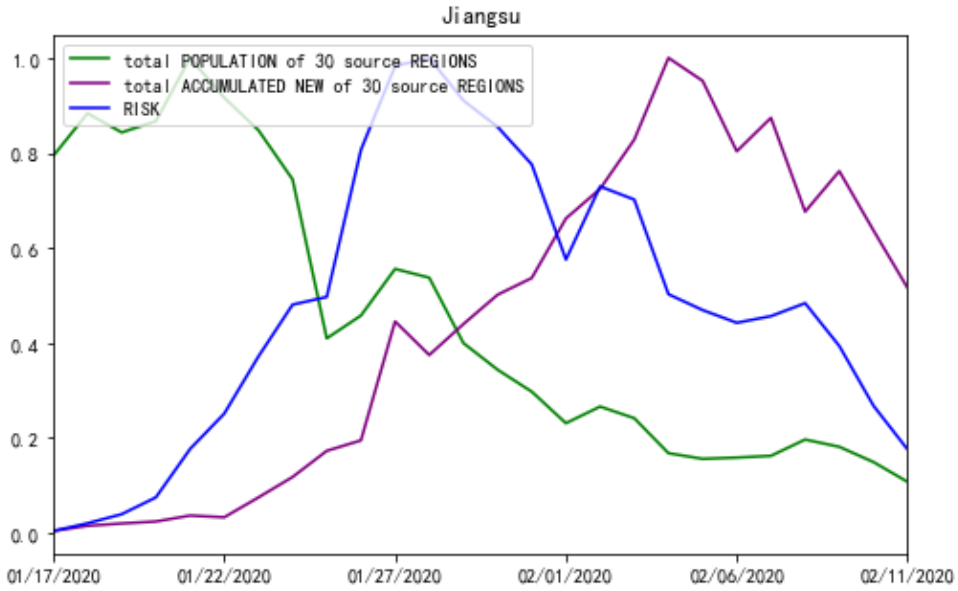
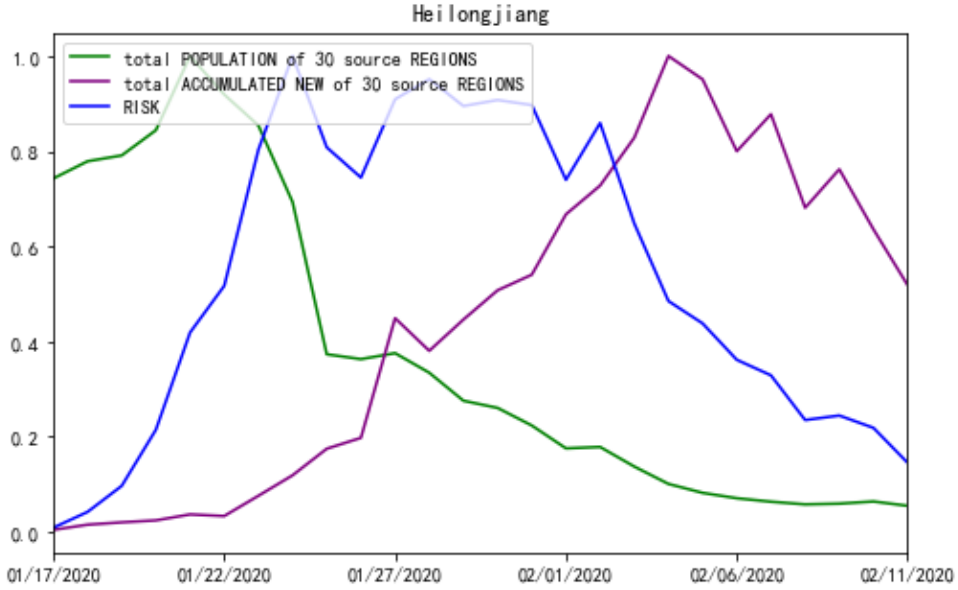


Figure 3. RISK of Heilongjiang Province from January 17, 2020 to February 11, 2020.



Moreover, we only analyzed the correlation among the 3 variables POPULATION, ACCUMULATED NEW, and RISK within the same region; therefore, we merged the effects and set the range of the 3 lines to zero and one.

PROCESSED RISK and the Correlation Coefficient

In each REGION, 110 sets of OFFSET and WINDOW data were used to generate RISK on a daily basis. Due to the large amounts of data, line charts of the NEW, RISK, and PROCESSED RISK processed by the model outputs in Jiangsu and Heilongjiang from January 17 to February 11 are used here to illustrate the roles of the OFFSET and WINDOW parameters.

As illustrated in Figures 4 and 5, only the absolute values of NEW and RISK were collected from the same REGION to calculate the relative indices. Hence, we defined the range of variable values to be between 0 and 1. The correlation coefficients between NEW and RISK of Jiangsu and Heilongjiang were 0.684 and –0.014, respectively. The value of Jiangsu was not high, and that of Heilongjiang was nearly uncorrelated (Figures 4 and 5). When we used PROCESSED RISK instead of RISK to draw the polyline chart, the polylines were more fitted, as illustrated in Figures 6 and 7. The correlation coefficient values increased to 0.979 and 0.874, respectively (Figures 6 and 7).

Figure 4. The polyline chart of NEW and RISK for Jiangsu Province from January 17, 2020 to February 11, 2020.

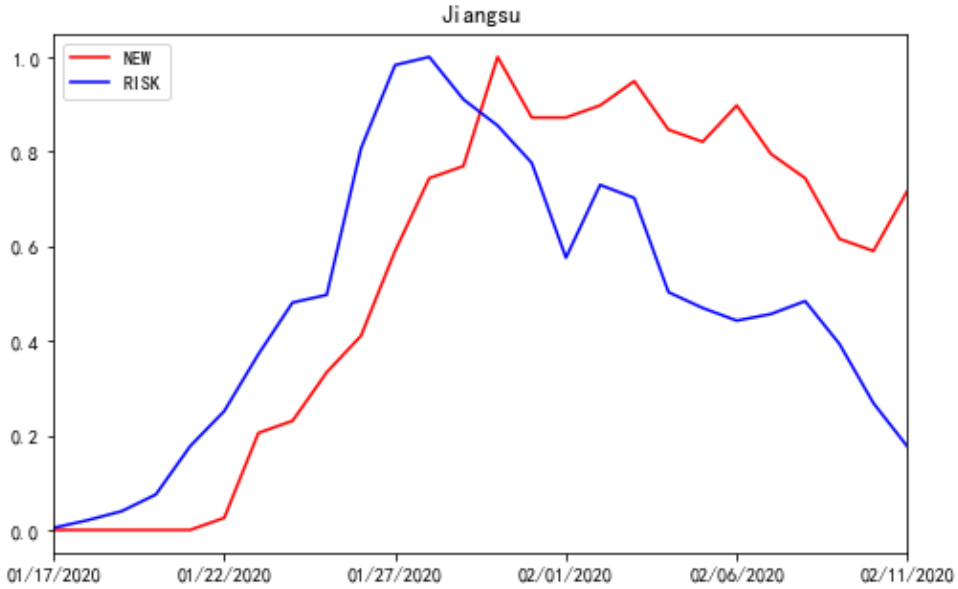


Figure 5. The polyline chart of NEW and RISK for Heilongjiang Province from January 17, 2020 to February 11, 2020.

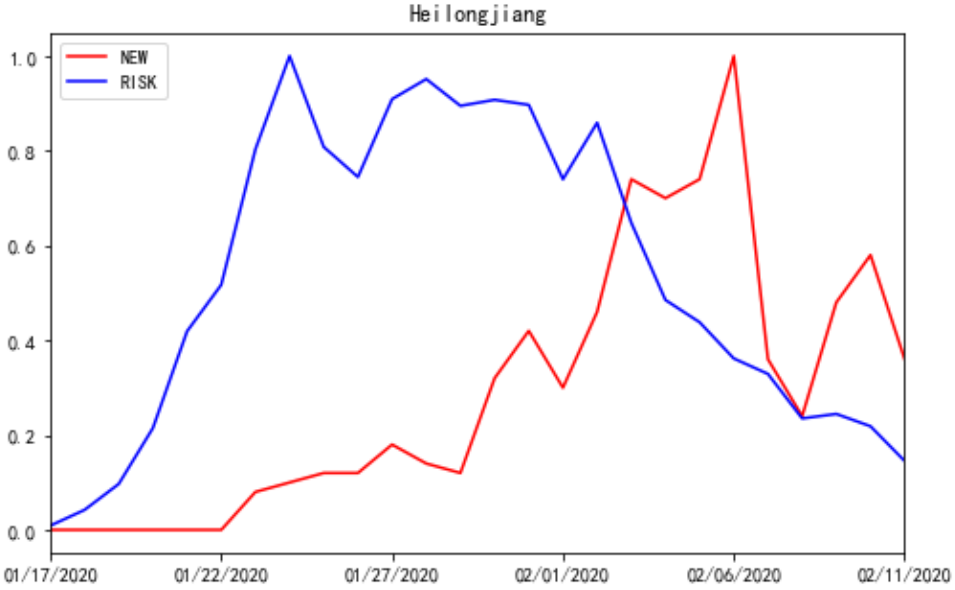


Figure 6. The polyline chart of NEW and PROCESSED RISK for Jiangsu Province from January 17, 2020 to February 11, 2020 when OFFSET=0 and WINDOW=9.

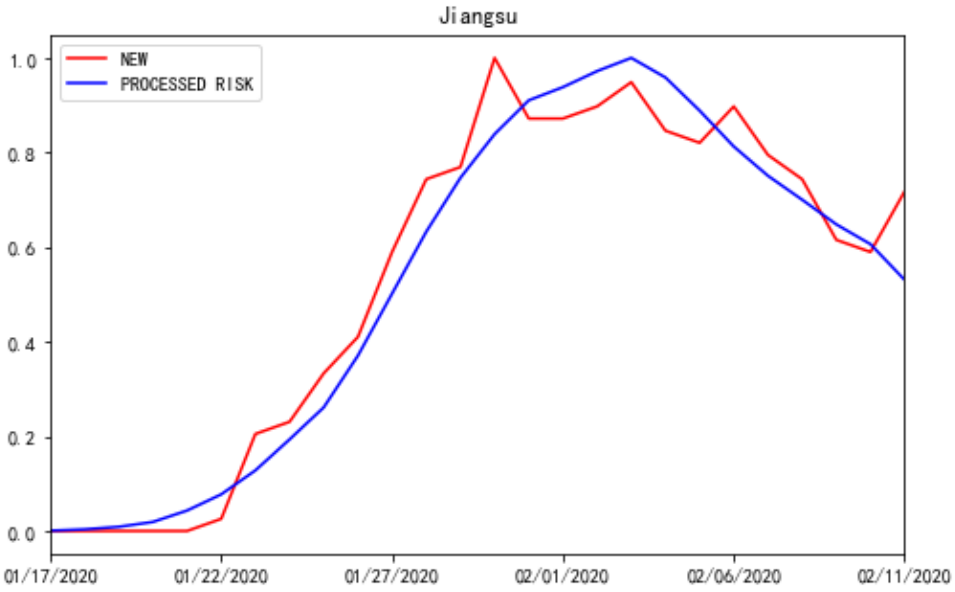
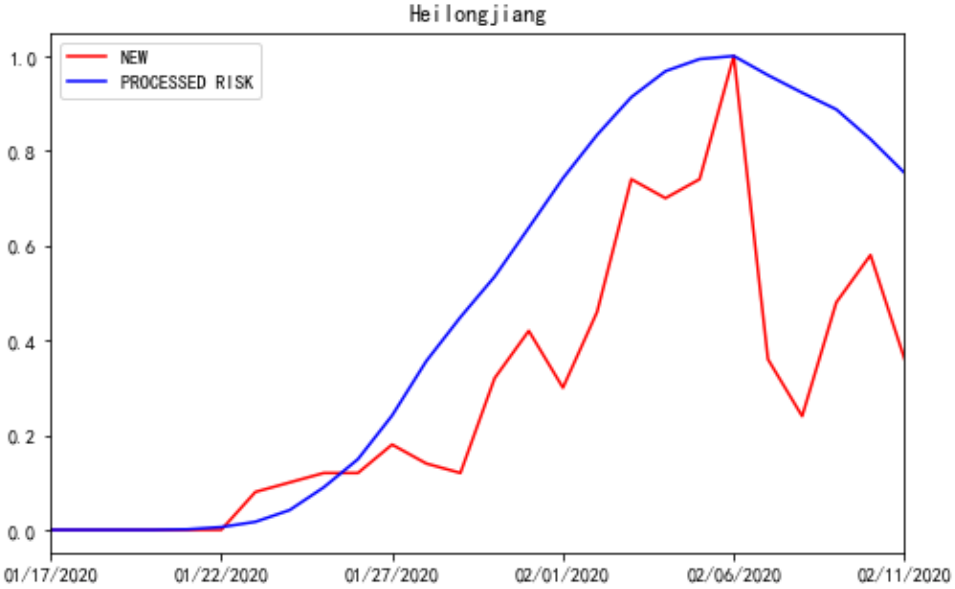


Figure 7. The polyline chart of NEW and PROCESSED RISK for Heilongjiang Province from January 17, 2020 to February 11, 2020 when OFFSET=4 and WINDOW=10.



As illustrated in Figures 4-7, the OFFSET and WINDOW variables revealed the delayed days before RISK converted to NEW. In theory, if all infected individuals entering the REGION could be immediately detected and quarantined, the polylines of NEW and RISK would be fully fitted. Moreover, under this condition, the value of OFFSET would be 0, that of WINDOW would be 1, and that of CORR would be 1. On the other hand, if the infected people entering the REGION were not detected promptly and spread the virus after entering, RISK would affect NEW in the next few days. The delayed days were evaluated by the values of OFFSET and WINDOW.

Model Output

The original size of the dataset was large; therefore, we only included the sample results from every three days between January 21, 2020 and February 11, 2020 from 11 REGIONs (Table 2), which were compared to actual data released from news reports. The study period was chosen based on the severity of the COVID-19 spread in China: the early spread of COVID-19 from Hubei Province to other REGIONs in the country to NEW was gradually decreasing in most of the REGIONs. The complete outputs are included as an appendix to this paper (Multimedia Appendix 1).

Table 2 can be used to evaluate the effectiveness of the COVID-19 control and prevention efforts in each REGION on a daily basis. The value NN indicates no confirmed cases in the REGION during the study period. The REGIONs were sorted by the values of OFFSET+WINDOW on February 11, 2020 in ascending order, which also indicated the sorting order of control and prevention effectiveness. Based on the evaluation results, Shanghai presented the lowest OFFSET and WINDOW values among the 11 REGIONs, which indicated the highest effectiveness in COVID-19 control and prevention. In contrast, Heilongjiang was the least effective REGION in COVID-19 control and prevention.

Confirmation of the Model Outputs With Related News Reports

Limited data has been released that can be used to compare the effectiveness of disease control and prevention in the different REGIONs. However, we were able to collect data and news reports from 11 REGIONs to compare and confirm the model outputs.

First, according to the data released by the DXY Doctor Network up to February 11, 2020, the cumulative confirmed cases were grouped by incoming immigrants and local residents from three REGIONs: Shanghai, Beijing, and Tianjin (Table 3).

We then compared the cumulative confirmed cases with the OFFSET and WINDOW values in Table 2. Shanghai generated the lowest OFFSET+WINDOW value, and it performed best in COVID-19 control and prevention; also, the local residents' infection rate in Shanghai was the lowest among the REGIONs. Beijing ranked second in performance evaluation. Tianjin demonstrated the highest OFFSET+WINDOW value; therefore, it ranked the lowest in performance (Table 2).

Second, basic reproduction number (R_0) data for Shanghai, Zhejiang, Sichuan, Jiangsu, Henan, and Anhui were collected [23]. The R_0 values on February 10, 2020, are shown in Table 4. Compared with Table 2, the relative values and rankings of R_0 and OFFSET+WINDOW during the time around February 10, 2020 are nearly identical.

Table 2. OFFSET (O) and WINDOW (W) values from 11 REGIONs between January 21, 2020 and February 11, 2020.

	01/21		01/24		01/27		01/30		02/02		02/05		02/08		02/11	
REGION	O	W	O	W	O	W	O	W	O	W	O	W	O	W	O	W
Shanghai	3	1	3	1	6	1	6	1	1	1	0	3	1	1	0	1
Liaoning	NN[a]	NN	7	3	1	1	1	1	1	1	1	1	1	1	1	1
Zhejiang	4	1	2	1	2	1	2	1	1	2	1	2	1	3	1	3
Beijing	1	2	2	1	4	2	0	1	0	8	1	4	1	3	0	5
Jilin	NN	NN	2	1	0	1	2	1	8	9	6	6	6	3	6	1
Tianjin	4	1	1	1	1	1	0	1	6	1	6	1	6	1	6	2
Sichuan	NN	NN	1	4	2	1	0	10	1	6	1	6	1	6	1	7
Jiangsu	NN	NN	2	1	1	4	1	4	0	6	0	7	0	8	0	9
Anhui	NN	NN	3	2	0	10	4	2	2	10	3	10	3	10	3	10
Henan	4	1	6	7	4	1	2	10	2	10	4	10	3	10	3	10
Heilongjiang	NN	NN	2	5	0	10	0	10	3	10	6	10	4	10	4	10

[a]NN: values indicate no confirmed diagnosis until that day.

Table 3. Confirmed cases and infection rates in incoming immigrants and local residents in three of the studied REGIONs.

REGION	Incoming immigrants (n)	Local residents (n)	Local infection rate (%)
Shanghai	99	207	67.6
Beijing	25	352	93.4
Tianjin	6	106	94.6

Table 4. Basic reproduction numbers for 6 REGIONs on February 10, 2020.

REGION	R_0[a] value
Shanghai	0.46
Zhejiang	0.52
Sichuan	0.81
Jiangsu	0.82
Henan	0.75
Anhui	0.98

[a]R_0: basic reproduction number.

The model output was confirmed by related news outlets as follows: in late January, a large group of infected businessmen returned to Wenzhou, Zhejiang from Wuhan, Hubei [24]. On February 1, 2020, the municipal government of Wenzhou, Zhejiang issued 25 control and prevention measures in a timely manner [25,26]. On February 22, 2020, after the Wenzhou epidemic was completely under control, the Chinese government newspaper published an article strongly affirming Wenzhou's achievements in epidemic control and prevention [27]. With the outbreak of COVID-19 in Wenzhou City, its province, Zhejiang, performed well in COVID-19 control and prevention. Our model confirmed this evaluation result by presenting relatively low values of OFFSET and WINDOW in Zhejiang (Table 2).

In addition, according to survey data, Heilongjiang did not pay sufficient attention to the epidemic and showed poor prevention awareness [28]. This was also confirmed by our study results, with high OFFSET and WINDOW values (Table 2). Particularly, an online survey was conducted on January 31, 2020 that targeted 10,304 residents of three provinces in Northeastern China, namely Heilongjiang, Jilin, and Liaoning. This survey examined people's feelings of being "confident," "alert," and "scared" during the COVID-19 outbreak. The level of feeling was ranked between 0 and 5, with 5 being the strongest feeling. Based on this survey, Heilongjiang demonstrated the lowest level of awareness of disease control and prevention; meanwhile, Liaoning demonstrated the highest level, and Jilin ranked second in awareness (Table 5). The survey results were also confirmed by our model (Table 2).

Table 5. Online survey results regarding awareness of COVID-19 control and prevention from three provinces in northeastern China. Participants ranked their feelings from 0-5, where 5 was the strongest feeling.

	Feelings toward the COVID-19[a] outbreak		
REGION	Confident	Alert	Scared
Heilongjiang	4.1	3.8	2.1
Jilin	3.9	3.9	2.2
Liaoning	3.7	3.9	2.3

[a]COVID-19: coronavirus disease.

Using the hypothesis-testing approach described above [29], the data in Table 2, Table 3, Table 4, and Table 5 were tested based on our hypotheses. First, the correlation coefficient between the internal infection rates of the three REGIONs in Table 3 and the corresponding OFFSET+WINDOW values of these three REGIONs in Table 2 on February 11 was 0.9216, and the original hypothesis H_0, the correlation between the local infection rate and the OFFSET+WINDOW value, was not statistically significant. For the alternative hypothesis H_a, the correlation coefficient between the local infection rate and the OFFSET+WINDOW value was correlated; we obtained a *t* value of 2.374, and the two-tailed *P* value was .254.

The correlation coefficient between the R_0 values of the six REGIONs in Table 4 and the corresponding OFFSET+WINDOW values of these 6 REGIONs in Table 2 on February 11, 2020 was 0.8787. The original hypothesis H_0 assumed that the correlation between the R_0 value and OFFSET+WINDOW value was not statistically significant; meanwhile, the alternative assumption was that the H_a:R_0 value and OFFSET+WINDOW value were correlated. The *t* value was calculated to be 3.682, aand the two-tailed *P* value was .021.

Finally, for the three REGIONs in Table 5, the correlation coefficient between the "alert+scared–confident" values and the corresponding "OFFSET+WINDOW" values for the three REGIONs in Table 2 on February 11 was –.9999. Specifically, the sizes of the alert and scared values were correlated to the "alert," so the correlation coefficient was positive; meanwhile, the "confidence" and "alert" values were inversely correlated, so the correlation coefficient was negative. In addition, we proposed the hypothesis H_0 that the correlation coefficient between the "alert+scared–confident" value and the OFFSET+WINDOW value was not significant. The alternative hypothesis H_a was that the "alert+scared–confident" value and the OFFSET+WINDOW value were correlated; the *t* value was –73.32 and the two-tailed *P* value was .009.

In summary, based on the 3 *P* values, the model results were highly correlated with the three datasets; this confirmed the validity of the model.

Discussion

Principal Findings

In this paper, the effectiveness of COVID-19 outbreak control and prevention across China was evaluated using population movement data between regions and daily new confirmed cases. Moreover, the comparison of the model output (Table 2) through the infection rate among local residents (Table 3), R_0 value (Table 4), and vigilance survey (Table 5) confirmed the correctness of the Epidemic Risk Time Series Model; that is, when a region was evaluated by the model to perform better in control and prevention, the R_0 value was smaller, the infection rate of local residents was lower, and residents' vigilance regarding the COVID-19 outbreak was stronger.

Early Warning by the Epidemic Risk Time Series Model in Epidemic Control and Prevention

According to Figure 5, the peak day of new cases (NEW) in Heilongjiang was February 6, 2020. The peak day of RISK in Heilongjiang was January 24, 2020, which was 13 days prior to the peak day of NEW. Based on Table 3, the values of OFFSET and WINDOW in Heilongjiang rose gradually from the first day. Therefore, the current daily incidence (newly diagnosed cases) could have been lower in Heilongjiang if the control and prevention measures had been stricter in Heilongjiang from the end of January 2020.

Based on our model, the warning threshold should be triggered as "problematic" when the value of OFFSET+WINDOW is ≥ 5 (Table 3); when the combined value of OFFSET+WINDOW is ≥ 10, the situation should be considered "serious." The warning level may be affected by factors such as the incubation period. Hence, when this model is used to evaluate the effectiveness of control and prevention for other epidemics, the warning values should be modified accordingly.

The Epidemic Risk Time Series Model vs the R_0 Method

Compared to the R_0 evaluation method [23], the Epidemic Risk Time Series Model was able to detect the "warning threshold" more promptly. For example, the first confirmed case in Heilongjiang was diagnosed on January 23, 2020. According to our model, the OFFSET+WINDOW values of Heilongjiang on that day were 6 and 7; the value of OFFSET+WINDOW continued to increase gradually since then (Table 3). On the other hand, the R_0 method can only be used at least 5 days after the first confirmed cases in that REGION, which is the average incubation period [22].

The Formula for Calculating RISK

In Equation 2, the "recent 3 days" in ACCUMULATED NEW_j is derived from the following considerations. Based on this study, the lower the number of days used in the calculation, the

greater the CORR value generated in the later step of the model. The number of diagnoses after a long-term incubation period did not readily reflect the current RISK from its original REGION. The NEW value may vary greatly on a daily basis. Moreover, the days of suspected cases converting into confirmed cases may vary by day. Therefore, “recent 3 days” was used to calculate RISK in this model.

In Equation 1, we categorized the total population of the source REGION before calculating the cumulative cases. The values of ACCUMULATED NEW_j grouped by the two source REGIONs were equal. Particularly, the people in a REGION with a smaller population size presented greater probability than the infected patients traveling to the destination REGION. The CORR values remained constant, whereas the values of OFFSET+WINDOW increased to fit similar CORR values. Compared to local residents, immigrating individuals were more likely to be infected with the virus. Hence, Equation 1 was used when calculating RISK.

Conclusion

In this study, a mathematical model was built using the number of daily confirmed cases and the daily immigration population size; the effectiveness of epidemic control and prevention, evaluated by OFFSET+WINDOW, were the outputs of the model. The results indicated that the OFFSET+WINDOW values may change daily with effective control and prevention. For REGIONs with poor performance, warning systems were triggered by the OFFSET+WINDOW values 2 weeks prior to their peak days of cases. Compared to the R_0 method, the Epidemic Risk Time Series Model is more prompt in aiding disease control and prevention.

Although the POPULATION data may have different statistical units in other countries, we utilized the relative values of the POPULATION to calculate the correlation coefficient. Therefore, the model does not only apply to Chinese data. Theoretically, the method in this study can be generalized to other countries to evaluate the effectiveness of their COVID-19 control and prevention measures.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional input and output data and figures for the Epidemic Risk Time Series Model.
[ZIP File (Zip Archive), 1311 KB - publichealth_v6i2e18638_app1.zip]

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Abbreviations

CORR: correlation coefficient
COVID-19: coronavirus disease
H_0: original hypothesis
H_a: alternative hypothesis
R_0: basic reproduction number

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Original Paper

Online National Health Agency Mask Guidance for the Public in Light of COVID-19: Content Analysis

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Abstract

Background: The rapid global spread of the coronavirus disease (COVID-19) has compelled national governments to issue guidance on the use of face masks for members of the general public. To date, no work has assessed how this guidance differs across governments.

Objective: This study seeks to contribute to a rational and consistent global response to infectious disease by determining how guidelines differ across nations and regions.

Methods: A content analysis of health agency mask guidelines on agency websites was performed in late March 2020 among 25 countries and regions with large numbers of COVID-19 cases. Countries and regions were assigned across the coding team by language proficiency, with Google Translate used as needed. When available, both the original and English language version of guidance were reviewed.

Results: All examined countries and regions had some form of guidance online, although detail and clarity differed. Although 9 countries and regions recommended surgical, medical, or unspecified masks in public and poorly ventilated places, 16 recommended against people wearing masks in public. There were 2 countries that explicitly recommended against fabric masks. In addition, 12 failed to outline the minimum basic World Health Organization guidance for masks.

Conclusions: Online guidelines for face mask use to prevent COVID-19 in the general public are currently inconsistent across nations and regions, and have been changing often. Efforts to create greater standardization and clarity should be explored in light of the status of COVID-19 as a global pandemic.

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KEYWORDS

public health policy; infectious disease; personal protective equipment; public health; COVID-19; pandemic; online health information; content analysis

Introduction

The rapid global spread of the coronavirus disease (COVID-19) has compelled national governments to issue guidance on the use of face masks for members of the public. Growing evidence of transmission from asymptomatic and presymptomatic individuals makes the development of these guidelines increasingly pressing [1-3]. Recent research suggests that surgical masks could help prevent transmission of human coronaviruses by reducing emissions of coronavirus RNA in respiratory droplets and aerosols [4]. Although N95 respirators have the potential for even greater protection when compared

to surgical masks [5,6], they also require fit testing that make them unsuitable for the public at large [7]. Currently, both surgical masks and N95 respirators are in short supply, with health care workers continuing to face shortages of personal protective equipment (PPE). In light of this, fabric masks have become a third masking option, although current evidence on their efficacy is limited. Prior studies suggest that fabric masks are significantly less effective than surgical masks, both for protecting health care workers and for reducing spread among the general public [8,9]. Even with lower efficacy, however, all masking options appear to hold value. Recent modeling suggests that widespread public adoption of even relatively ineffective masks would be able to help curtail community transmission of COVID-19, although more effective masks yield greater reductions in mortality [10].

Despite growing evidence on the value of masking and calls for public use of masks as part of a broader strategy that also includes social distancing and hand washing [10,11], recent commentary suggests that public guidance on masks may be inconsistent across nations [12], and the World Health Organization (WHO) maintains, as of May 2020, that masks are only needed for healthy individuals when they are taking care of someone with suspected COVID-19 [13]. Given the pandemic status of COVID-19, it is critical to establish a baseline understanding of current government guidelines on mask use for the general public. To date, no studies have conducted a systematic analysis of mask guidelines aimed at the public. Public-facing guidelines are critical to compliance since government provision of cues is an important driver of mask use [14]. Agency websites are a particularly critical way to disseminate these types of guidelines, as the public increasingly turns to the internet for health information.

To inform this discussion and help health agencies to "adopt rational recommendations on appropriate face mask use" [12], this paper presents a content analysis of health agency mask guidelines in March 2020 among countries and regions with large numbers of COVID-19 cases.

Methods

The 25 countries and regions with the highest number of confirmed COVID-19 cases were drawn from the Johns Hopkins Center for Systems Science and Engineering Coronavirus COVID-19 Global Cases tracker on March 9, 2020 [15]. These countries and regions are listed in Table 1. To replicate the experience of someone looking for guidance, we visited national health agency websites for each country and region seeking mask guidelines (medical, surgical, and unspecified mask types) aimed at the public. Given limited evidence for their efficacy relative to surgical and medical masks [8,9], we considered fabric masks separately. Specifically, we sought to find both recommendations for or against fabric masks for primary use and recommendations for fabric masks only when other more effective masks are unavailable. A content analysis approach was used [16], and a codebook was developed in Excel (Microsoft Corporation) to track guidance on when masks are recommended or not recommended. Initial coding suggested that several nations indicated that masks were not recommended because they may increase risks or create a false sense of safety. A code was also added to track these statements. Countries were assigned across the coding team by language proficiency, with Google Translate used as needed. When available, both the original and English language version of guidance were reviewed. All relevant webpages and documents were downloaded to create a static record. Websites were coded between March 13 and March 23, 2020, with all coding verified by a second coder the following week. Any coding discrepancies were discussed among authors and resolved. All websites were revisited a final time on March 30 to look for updated materials, and coding was updated as needed.

Table 1. Health agency guidance for public use of surgical, medical, and unspecified masks for coronavirus disease as of March 30, 2020.

Country/region	Public should wear masks when symptomatic	Public should wear masks when caring for/in proximity of symptomatic people	Public should wear masks when in public places/places with poor ventilation	Masks are explicitly not recommended for the public at large	Masks may pose health risks or create a false sense of security
Australia	✓[a]	X[b]	X	✓	X
Austria	✓	✓	✓	X	X
Bahrain	✓[c]	X	X	X	X
Belgium	✓	X[d]	X	✓	X
Canada	✓	✓	X	✓	✓
France	✓	X	X	✓	X
Germany	✓	X	X	✓	✓
Greece	✓	✓	X	✓	X
Hong Kong	✓	✓	✓	X	X
Iran	✓	✓	✓	✓[e]	✓[e]
Iraq	X	X	✓[f]	X	X
Italy	✓	✓	X	✓	✓
Japan	✓	✓	✓	X	X
Kuwait	✓	✓	✓	X	X
Mainland China	✓	✓	✓	X	X
Malaysia	✓	✓	✓	X	X
Netherlands	X	X	X	✓	✓
Norway	✓	✓	X	✓	✓
Singapore	✓	X	X	✓	X
South Korea	✓[g]	✓[h]	✓	X	X
Spain	✓	X	X	✓	X
Sweden	X	X	X	✓	X
Switzerland	✓	X	X	✓	✓
United Kingdom	X	X	X	✓	X
United States	✓	✓	X[i]	✓	X

[a]✓: guidelines were identified on the website.

[b]X: guidelines were absent on the website.

[c]Bahrain requires masks when in self-isolation for 14 days following a return from a country with a high volume of coronavirus disease cases.

[d]Belgium indicates that "wearing face masks to prevent coronavirus infection only makes sense in hospitals where patients with Coronavirus are treated."

[e]Iran's newer guidelines recommend masks, but the old document discouraging public mask use still remains active on the health agency website.

[f]Iraq lacks formal guidelines but featured a press release about the importance of wearing masks when shopping.

[g]South Korea recommends a KF94 or higher respirator rather than a surgical or unspecified medical mask when caring for coronavirus disease cases.

[h]South Korea recommends a KF80 or higher respirator when symptomatic.

[i]The United States recommends the use of fabric masks in public places as of April 3, 2020, but explicitly does not recommend surgical mask use.

Results

All 25 countries and regions had some form of publicly available information about masks on their health agency websites aimed at the public. Format and level of detail ranged greatly and included infographics (eg, Malaysia) and short responses in a frequently asked questions format (eg, Netherlands). Iraq had the vaguest guidance, which the coding team inferred from news stories and press releases about mask use rather than the existence of a formal page or document with public COVID-19 prevention guidance. A total of 4 (16%) countries and regions lacked recommendations for wearing surgical, medical, or unspecified masks when symptomatic, and 12 (48%) countries did not mention use by individuals providing care during home quarantine (Table 1). Although 9 (36%) countries and regions recommended surgical, medical, or unspecified masks in public

or poorly ventilated places, 16 (64%) explicitly recommended against the general public wearing masks. A total of 7 (28%) also noted that surgical, medical, or unspecified masks were not recommended because they could increase health risks to the wearer or give a false sense of security.

With regard to fabric masks, no countries or regions recommended this mask type as preferable to surgical or medical masks in the Table 1 scenarios. Out of the 25 countries and regions, there was a country and a region (n=2, 8%) that explicitly recommended against them due to their protective capacity being either unknown (Italy) or inadequate (Hong Kong). South Korea and Mainland China recommended fabric masks as part of a broader guidance of different mask types being appropriate for different risk scenarios. South Korea, for example, noted: "In cases where there is not a high risk of infection or there is no health mask, it is helpful to use a cotton mask (including replacing the electrostatic filter) to avoid droplets directly from coughing or sneezing." Germany, the United States, and Japan recommended some form of fabric mouth covering (including scarves and handkerchiefs) only when other options were unavailable. Austria was the only country or region at the time of analysis to recommend fabric masks interchangeably with other types of masks, noting that a "textile mouth-nose guard can also be used" as part of guidance on mask use in public spaces. The remaining 17 (68%) countries and regions did not explicitly address fabric masks in their guidance.

In some cases, countries or regions updated their guidance during the study period. For example, Iranian guidance initially recommended asymptomatic individuals not wear masks. By March 29, 2020, additional guidance was posted recommending masks at the park, gym, or when engaging in urban travel. On March 30, Austria removed guidelines referencing the WHO that stated that "disposable face masks are not an effective protection" and instead recommended "protective mask[s] in public spaces where there may be close contact with other people, e.g. in supermarkets." By contrast, Sweden scaled back guidance during the study period, removing language that masks could help prevent spread from symptomatic individuals.

Discussion

Principal Findings

As of late March 2020, there was little consistency in guidance on face mask use for the public, despite COVID-19 being declared a global pandemic. Although the countries and regions analyzed were chosen in light of having the highest number of confirmed cases in early March 2020, per-capita rates varied considerably. Accordingly, some of the variation in guidance could be due to countries or regions being in different stages of pandemic response. Guidance may also be informed by strategic considerations related to PPE shortages and a desire to reserve masks for health care providers. However, variation in statements regarding mask risks suggest a more fundamental difference in assessments of masks as an appropriate approach for reducing community spread of COVID-19. Many differences also appear to be regional. With the exception of Austria, only Asian and Middle Eastern nations and regions recommend masks of any type in public as of March 30, 2020. This is also broadly consistent with greater mask use in Asian nations during previous outbreaks such as H1N1 and severe acute respiratory syndrome [17,18]. Several European countries also failed to outline guidelines consistent with the WHO recommendation that symptomatic individuals and those who care for them should wear masks.

The United States in particular has struggled with face mask guidelines. In early March 2020, the US Surgeon General issued a strongly worded tweet indicating that members of the public should not purchase masks in response to the spread of COVID-19, suggesting both that masks would be ineffective and that they are needed by health care providers [19]. The US Centers for Disease Control and Prevention (CDC) also consistently advised the public not to use face masks unless sick or caring for someone sick and denied that any updated mask guidance was scheduled as of March 28, 2020 [20]. On April 3, 2020, the CDC updated its website guidance to recommend that the public wear fabric masks in public settings where social distancing is a challenge [21]. The following day the US Surgeon General posted a video on Twitter demonstrating how to make a face mask out of a T-shirt [22]. Guidelines also specify that they are not recommending surgical masks, as these "are critical supplies that must continue to be reserved for health care workers and other medical first responders" [21]. At the time of writing, US states continue to face shortages of PPE [23], and the CDC recommends medical use of bandanas and scarves as a last resort [24]. The United States should monitor the efficacy of its guidelines relative to those in other nations and regions.

As illustrated by the US example, guidelines are constantly evolving in light of new risk information and mask availability. Although the ability to shift guidelines is critical to ensure that they reflect current evidence, changes also pose distinct health communication challenges. For example, some members of the public may struggle to understand why universal mask use is encouraged if the previous message focused on masks posing a health risk. Misinformation about mask use already appears to be circulating on social media [25]. Research on understanding and receptivity to mask guidance will be critical. Most recently, several countries in addition to the United States appear to be rethinking the value of fabric masks. For example, both Iran and Greece now provide online instructions for how to create a fabric mask at home [26,27]. It will remain important to maintain awareness of developments in mask guidelines across regions and nations given that COVID-19 is not bound by political and legal borders. It is also imperative that mask guidelines are clearly communicated to the public with messages explaining any guideline changes.

Limitations

Findings on mask guidance should be interpreted in the context of their limitations and recognition that the sample focused on countries and regions with high levels of COVID-19 in early March 2020. Although we sought to assign coding based on language proficiency, some countries and regions necessitated more reliance on Google Translate than others. This may have introduced some translation errors. Some nations and regions

may have communicated information via social media that was not present on their website and, therefore, not included in this analysis. Finally, mask guidance does not necessarily imply mask access, and the availability of masks for public use is a separate question that warrants significant attention from researchers and policy makers.

Conclusions

Although COVID-19 was declared a pandemic by the WHO on March 11, 2020 [28], guidelines for face mask use to prevent COVID-19 in the public remained broadly inconsistent across nations and regions at the end of March 2020. Efforts should be made to continue to monitor mask recommendations and create greater standardization based on scientific evidence. Furthermore, there is a strong need for additional research on the efficacy of different mask types in community settings. Although not the primary focus of this study, the clarity of guidelines was also a source of concern, with some guidelines spread across multiple pages and sometimes not specifying the type of mask recommended. Further, as mask use begins to increase in nations and regions where face masks have not experienced "cultural assimilation"[18], it will be critical to expand guidelines to include not just *when* masks should be worn but also *how* they should be worn. Future research should consider how to best communicate such guidelines to the public, particularly as guidelines continue to change over time.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
PPE: personal protective equipment
WHO: World Health Organization

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Original Paper

Comparison of Transmissibility of Coronavirus Between Symptomatic and Asymptomatic Patients: Reanalysis of the Ningbo COVID-19 Data

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Abstract

Background: Since the outbreak of the novel coronavirus disease (COVID-19) in December 2019, the coronavirus has spread all over the world at an unprecedented rate. The transmissibility of the coronavirus from asymptomatic patients to healthy individuals has received enormous attention. An important study using COVID-19 data from the city of Ningbo, China, was carried out to estimate and compare the transmission rates of the coronavirus by the symptomatic and asymptomatic patients. However, in the original analysis, the usual chi-square tests were unduly used for some contingency tables with small cell counts including zero, which may violate the assumptions for the chi-square test.

Objective: We reanalyze the data from the city of Ningbo with more appropriate statistical methods to draw more reliable and sound conclusions on the transmission rates of the coronavirus by the symptomatic and asymptomatic patients.

Methods: We excluded the cases associated with the super-spreader and adopted a more appropriate statistical method, including the permutation test and the Fisher exact test, to reanalyze the COVID-19 data from the city of Ningbo.

Results: After excluding the cases related to the super-spreader, the Fisher exact test yields a *P* value of .84, which indicates stronger evidence of no difference in the transmission rates compared with the original analysis. The odds ratio of the coronavirus transmission rates between the symptomatic and asymptomatic patients is 1.2 with a 95% confidence interval 0.5-2.8.

Conclusions: Through a more in-depth and comprehensive statistical analysis of the Ningbo data, we concluded that there is no difference in the transmission rates of coronavirus between symptomatic and asymptomatic patients.

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KEYWORDS

asymptomatic case; close contact; coronavirus; COVID-19; Fisher exact test; transmission rate; transmission; virus; immunology; analysis

Introduction

Since the outbreak of the novel coronavirus disease (COVID-19) in December 2019, the coronavirus has spread all over the world at an unprecedented rate. By May 21, 2020, more than 200 countries and territories have been affected by COVID-19, with a total of more than 5 million confirmed cases and over 330,000 deaths [1]. In addition, both the numbers of cases and deaths continue to climb up quickly. On March 11, 2020, COVID-19 was declared an international public health emergency by the World Health Organization [2]. Many countries have taken the most restrictive travel bans and quarantine policies in an attempt to stop the coronavirus from infecting their healthy populations. The worldwide economy has also been greatly set back.

During the disease incubation period, a percentage of coronavirus carriers may have no symptoms or minimal symptoms and thus often go undetected. These covert coronavirus carriers may not even be aware of the infection themselves but would be confirmed as positive cases if tested

using the reverse transcriptase polymerase chain reaction (RT-PCR). If the percentage of asymptomatic carriers is large and if their transmissibility of coronavirus is as high as the symptomatic cases, this would pose a great threat to the public health worldwide. Therefore, it is critical to determine the percentage and the transmissibility of asymptomatic coronavirus carriers in the population.

There has been some work in the literature on the estimation of the asymptomatic proportion of COVID-19 cases. Based on the infected cases on the Diamond Princess cruise ship, the asymptomatic ratio was estimated to be 0.179 with a 95% Bayesian credible interval of 0.155-0.202 [3]. Another study [4] indicated that the asymptomatic ratio could be as high as 0.416 by using the information on Japanese nationals who were evacuated from Wuhan, China on charter flights. An analysis on the COVID-19 infected cases from Tibetan Autonomous Prefecture [5] found that the proportion of asymptomatic carriers was 0.217. In a study with 36 children with COVID-19 in Zhejiang, China [6], it was found that there were 10 asymptomatic cases out of 36 infections (27.7%). Another investigation in a skilled nursing facility in King County, Washington identified that, out of 48 residents that tested positive for COVID-19, 27 (56%) were asymptomatic at the time of testing [7]. The aforementioned studies indicate that the proportion of asymptomatic carriers in the total infected cases is considerably high, but the sample sizes of these studies are rather small.

There has been evidence for transmission of coronavirus from asymptomatic carriers. It was reported that the viral load detected in the asymptomatic patients was similar to that in the symptomatic patients, which suggests the potential transmissibility of asymptomatic carriers [8]. A familial cluster of 5 patients in Anyang, China demonstrated transmission of the coronavirus from an asymptomatic carrier with normal chest computed tomography but tested positive after all 5 contacted family members had shown symptoms and confirmed positive RT-PCR test results [9]. A similar case of the familial cluster of 5 members associated with COVID-19 in Luzhou, China also suggested that coronavirus can be transmitted by asymptomatic carriers [10]. Another example of coronavirus infection by an asymptomatic patient was a German case through the usual contact in business meetings [11]. Moreover, the mathematical model developed to estimate the basic reproductive number of COVID-19 and quantify the contribution of different transmission routes also indicated the transmissibility of the asymptomatic individuals [12]. In a study on a cluster of 22 close contacts of a male 22 years of age with COVID-19 [13], the asymptomatic patient showed the rapid human-to-human transmissibility. Via a detailed literature review conducted at the Centers for Disease Control and Prevention [14], it was demonstrated from the epidemiologic, virologic, and modeling studies that COVID-19 is transmittable by persons with presymptomatic or asymptomatic infection.

Chen et al [15] carried out an important study using the COVID-19 data from Ningbo, China to estimate the transmission rates of the coronavirus by the symptomatic and asymptomatic cases. The estimated transmission rates for the symptomatic and asymptomatic patients were 0.063 and 0.041, respectively, and the chi-square test yielded a *P* value of .29, which indicates that there is no statistically significant difference between the two transmission rates. They further investigated the transmission rates for different relationships and different types of contact with the infected patients including both symptomatic and asymptomatic cases. The conclusions were that there are statistically significant differences in the transmission rates across different relationships and different types of contact. As expected, the closer the contact is with the infected patients, the higher the chance of infection.

The following is the permutation test algorithm:

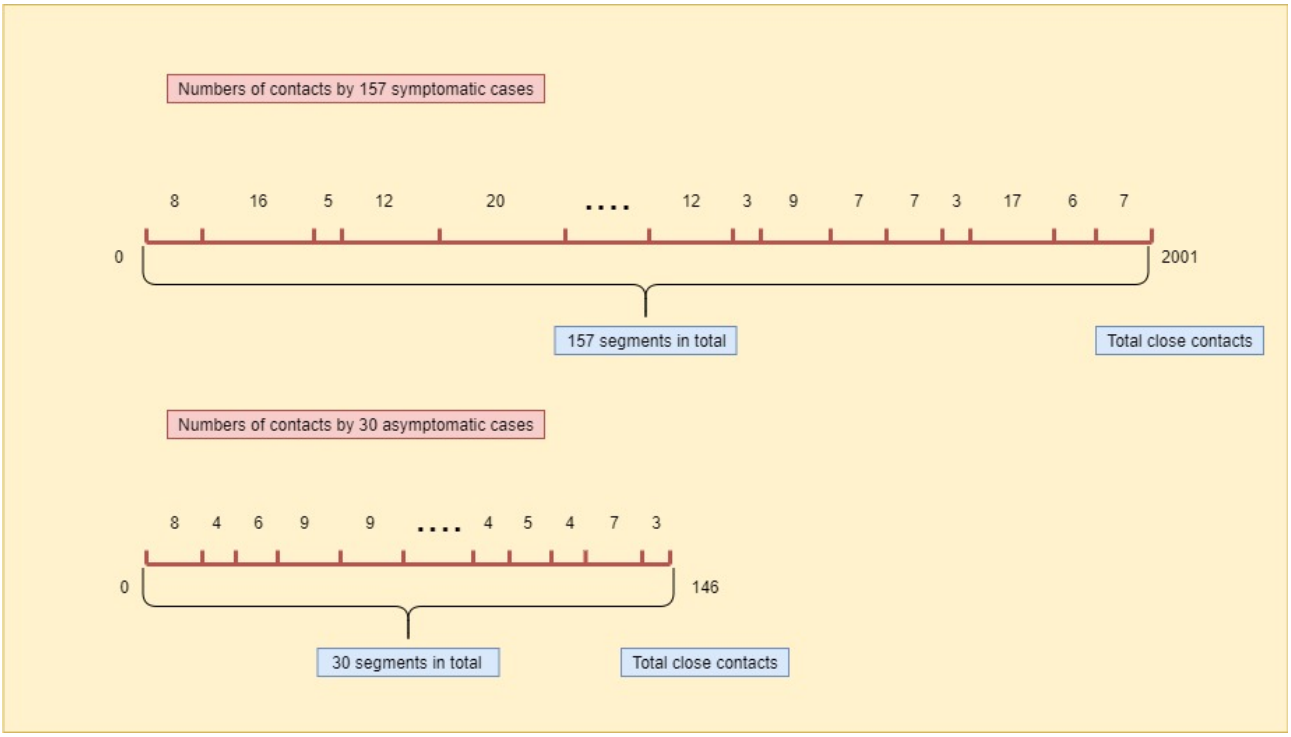
However, in their original statistical analysis [15], the chi-square tests were unduly used because the counts in some cells of the contingency tables were rather small and sometimes even zero, which violates the assumptions of a chi-square test and thus casts doubt on the validity of the hypothesis test. Moreover, when comparing the transmission rates of symptomatic and asymptomatic cases, Chen et al [15] included the cases associated with a super-spreader who mainly transmitted the disease in an air-conditioned bus and a Buddhism activity gathering. However, this may reduce the generalization of the findings, as the super-spreader should be regarded as an outlier and removed from the primary analysis.

Methods

Permutation Test

We adopted a permutation test to determine the difference in the average numbers of contacts by the symptomatic and asymptomatic cases. The permutation test algorithm gives the details of the permutation test, and Figure 1 provides the diagram for the resampling step in the permutation test. Note that the permutation test requires no assumptions on the data, which simply permutes the data to simulate the null distribution.

Figure 1. The diagram for the resampling step in the permutation test, where the lengths of segments are randomly generated corresponding to the number of close contacts for each individual patient.



Fisher Exact Test

To allow for small cell counts including zero in the contingency table, the Fisher exact tests [16] were used to investigate the difference in the transmission rates between the symptomatic and asymptomatic patients wherever small cell counts were present (eg, less than 5 as a rule of thumb).

Without making any assumptions on the data, the Fisher exact test simply adopts the hypergeometric distribution to calculate the exact probability of the observed data in the table. For example, as shown in Table 1, suppose that there are *a* infected cases and *b* uninfected individuals in the close contacts of the symptomatic cases, while there are *c* infected cases and *d* uninfected individuals in the close contacts of the asymptomatic cases. The probability of observing such data is given by:

The *P* value of the Fisher exact test is calculated by summing up all the probabilities of obtaining data as or more extreme than the observed under the null hypothesis (ie, there is no difference between the two groups).

Table 1. A typical 2×2 contingency table.

Group	Infected	Uninfected
Number of close contacts of symptomatic cases	*a*	*b*
Number of close contacts of asymptomatic cases	*c*	*d*

Odds Ratio and Related Confidence Intervals

To gain more insight into the Ningbo data, we further calculated the odds ratio between the symptomatic and asymptomatic groups as well as the corresponding confidence interval. For a 2×2 contingency table with cell counts (*a*, *b*, *c*, *d*) as shown in Table 1, the odds ratio is *ad*/*bc*, and the corresponding 95% confidence interval is given by:

If the estimated transmission rate with sample size *n* is denoted by  , the 95% confidence interval of the transmission rate is:

Both confidence intervals for the odds ratio and the transmission rate are based on normal approximation, and in the Ningbo data, the sample sizes for computation of these confidence intervals are reasonably large.

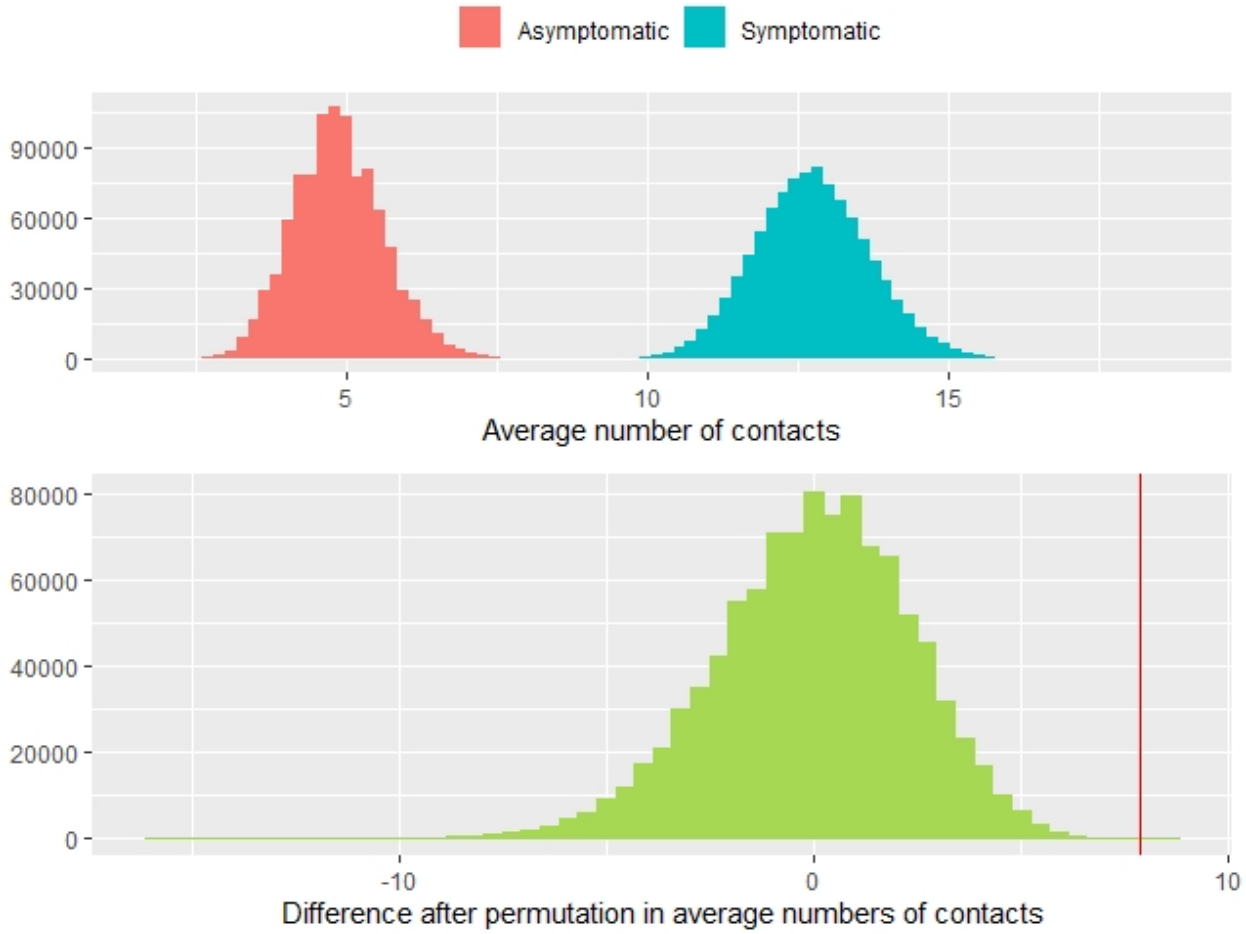
Results

Results of the Permutation Test

From January 21 to March 6, 2020, there were 157 symptomatic cases and 30 asymptomatic cases in the Ningbo COVID-19 data [15]. These infected cases resulted in 2147 close contacts with them, of which 2001 exposures were caused by the symptomatic cases and 146 by the asymptomatic cases. The average number of close contacts by a symptomatic case was 13 and for an asymptomatic case was 5, and the difference is statistically significant with $P<.001$ from the permutation test. Figure 2

presents the histograms of the average numbers of contacts by the symptomatic and asymptomatic cases as well as the differences after the permutation (ie, under the null distribution) in the average numbers of contacts by the symptomatic and asymptomatic cases in the permutation test. The larger number of close contacts by the symptomatic cases may be due to the medical attention they received after they had the confirmation of a COVID-19 positive test.

Figure 2. The histograms of the average numbers of contacts by the symptomatic and asymptomatic cases (top panel) and the difference after the permutation in the average numbers of contacts by the symptomatic and asymptomatic cases in the permutation test (bottom panel). The red vertical line indicates the observed difference in the average number of contacts between symptomatic and asymptomatic cases, which lies at the far end of the null distribution.



Results of the Fisher Exact Test

Under the Fisher exact test, we consider two scenarios: (1) to combine the numbers of symptomatic and asymptomatic cases as the total number of infected patients, leading to a 2×2 table; or (2) to separate them, leading to a 2×3 table, as shown in the primary analysis of close contacts section of Table 2.

From the results summarized in Table 2, we concluded that there was no significant difference in the transmission rates between the symptomatic and asymptomatic cases, either including or excluding the cases associated with the super-spreader. However, the tests excluding the cases associated with the super-spreader yielded larger *P* values: *P*=.84 when combining the numbers of symptomatic and asymptomatic cases, and *P*=.11 when separating them. As a result, there is no statistical evidence in the data to rule out the transmissibility of asymptotic carriers in comparison with symptomatic cases.

Table 2. Analysis of the transmission rates through close contacts by the symptomatic and asymptomatic cases of the coronavirus disease in Ningbo after removing all the cases associated with the super-spreader.

Analysis	Close contacts, n	Infected		Uninfected, n	*P* value	
		Symptomatic cases, n	Asymptomatic cases, n		Combined[a]	Separate[b]
Primary analysis of close contacts by symptomatic and asymptomatic cases					.84 (.37)[d]	.11 (.08)
Symptomatic cases	1904 (97)[c]	79 (28)	15 (4)	1810 (65)		
Asymptomatic cases	146	3	3	140		
Total	2050 (97)	82 (28)	18 (4)	1950 (65)		
Subgroup analysis by different relationships with infected cases					<.001	<.001
Family	268	37	10	221		
Relatives	400	13	6	381		
Friends	153	23	1	129		
Coworkers	57	2	0	55		
Medical	79	0	0	79		
Others	1093	7	1	1085		
Total	2050	82	18	1950		
Subgroup analysis by different types of contact with infected cases					<.001	<.001
Daily activities	1048	69	14	965		
Transportation	167	1	2	164		
Medical contact	297	4	0	293		
Other contact	538	8	2	528		
Total	2050	82	18	1950		

[a]Combined means *P* values were obtained by pooling the numbers of symptomatic and asymptomatic cases together.

[b]Separate means *P* values were obtained by separating the numbers of symptomatic and asymptomatic cases.

[c]The numbers in the parentheses are associated with the super-spreader.

[d]*P* values in the parentheses were obtained when including the cases associated with the super-spreader.

Estimation of the Odds Ratio

The estimated odds ratio, transmission rates, and their difference between symptomatic and asymptomatic cases as well as the corresponding 95% confidence intervals are all presented in Table 3. The odds of transmitting the coronavirus to a healthy individual by a symptomatic patient is 1.2 times more than that by an asymptomatic patient, which was not statistically significant as the 95% confidence interval covers one. Furthermore, as the 95% confidence intervals for the difference of transmission rates cover zero, we concluded that there is no difference in the transmissibility of the coronavirus through close contacts between symptomatic and asymptomatic cases, which is consistent with the findings using the Fisher exact tests.

The transmission rates under different relationships with the infected cases are significantly different with both *P* values<.001 whether combining the symptomatic and asymptomatic cases or not. With regard to different types of contact, the transmission rates are also significantly different with *P* values<.001. As expected, the more close contacts with the infected cases, the higher the likelihood of contracting the coronavirus.

Table 3. Primary analysis with the estimated rates and 95% CIs.

Variable	Odds ratio (95% CI)	Transmission rate of symptomatic cases, (95% CI)	Transmission rate of asymptomatic cases (95% CI)	Difference of transmission rates (95% CI)
With super-spreader cases	1.568 (0.679-3.620)	0.063 (0.053-0.075)	0.041 (0.017-0.091)	0.022 (–0.016 to 0.059)
Without super-spreader cases	1.212 (0.522-2.815)	0.049 (0.040-0.060)	0.041 (0.017-0.091)	0.008 (–0.029 to 0.046)

Discussion

In summary, we provided a more in-depth analysis of the Ningbo COVID-19 data to examine the difference in the transmissibility of the coronavirus for symptomatic and asymptomatic patients. The conclusion remains the same, that there is no statistically significant difference in the transmissibility of the coronavirus between symptomatic and asymptomatic patients, but our evidence for no difference appears to be stronger with larger *P* values than the original analysis [15].

As the proportion of asymptomatic carriers in the total infected cases is considerably high [3-7], such findings are crucial to the public health and can help to guide the relevant government agencies on policy making about the asymptomatic cases.

However, our analysis only focuses on the data from the city of Ningbo, China, and the sample size is small. Therefore, the generalization of our findings to a larger and more diverse population is limited. More work is warranted to study the transmissibility of coronavirus by the asymptomatic coronavirus carriers.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
RT-PCR: reverse transcriptase polymerase chain reaction

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Original Paper

No Place Like Home: Cross-National Data Analysis of the Efficacy of Social Distancing During the COVID-19 Pandemic

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Abstract

Background: In the absence of a cure in the time of a pandemic, social distancing measures seem to be the most effective intervention to slow the spread of disease. Various simulation-based studies have been conducted to investigate the effectiveness of these measures. While those studies unanimously confirm the mitigating effect of social distancing on disease spread, the reported effectiveness varies from 10% to more than 90% reduction in the number of infections. This level of uncertainty is mostly due to the complex dynamics of epidemics and their time-variant parameters. However, real transactional data can reduce uncertainty and provide a less noisy picture of the effectiveness of social distancing.

Objective: The aim of this paper was to integrate multiple transactional data sets (GPS mobility data from Google and Apple as well as disease statistics from the European Centre for Disease Prevention and Control) to study the role of social distancing policies in 26 countries and analyze the transmission rate of the coronavirus disease (COVID-19) pandemic over the course of 5 weeks.

Methods: Relying on the susceptible-infected-recovered (SIR) model and official COVID-19 reports, we first calculated the weekly transmission rate (β) of COVID-19 in 26 countries for 5 consecutive weeks. Then, we integrated these data with the Google and Apple mobility data sets for the same time frame and used a machine learning approach to investigate the relationship between the mobility factors and β values.

Results: Gradient boosted trees regression analysis showed that changes in mobility patterns resulting from social distancing policies explain approximately 47% of the variation in the disease transmission rates.

Conclusions: Consistent with simulation-based studies, real cross-national transactional data confirms the effectiveness of social distancing interventions in slowing the spread of COVID-19. In addition to providing less noisy and more generalizable support for the idea of social distancing, we provide specific insights for public health policy makers regarding locations that should be given higher priority for enforcing social distancing measures.

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KEYWORDS

COVID-19; public health; social distancing; machine learning; pandemic

Introduction

As of mid-May 2020, approximately 4.5 million people worldwide have been infected by the new deadly coronavirus disease (COVID-19) [1]. In the absence of a vaccine or effective medication, public health experts and epidemiologists suggest that social distancing is the most effective intervention to control the spread of the disease or "flatten the curve" [2,3]. Based on this concept, some serious restrictive policies (eg, shutting down businesses and closing schools) have been enacted by the governments of the affected countries to encourage (and, in some countries, to force) people to stay at home.

The effectiveness of social distancing in response to an epidemic has been widely studied, mostly using simulation-based methods. For example, using a differential game approach, Reluga [4] argues that optimal social distancing can only reduce the chance of infection by less than 30%. In another agent-based simulation study using a small population, Kelso et al [5] showed that depending on the initial reproduction number (R_0) of the epidemic and the delay from the first case until the introduction of social distancing measures, the attack rate of the disease can be reduced by between 10% and 73%. Ahmed et al [6], in a systematic review of prior research, stated that social distancing measures in workplaces caused a median reduction of 23% in the cumulative H1N1 influenza attack rate during the 2009 pandemic. In another study, Earn et al [7] showed that school closure had a considerable mitigating effect on the incidence of pandemic influenza in Alberta, Canada. Also, multiple studies have discussed the effects of social distancing on the 1918 influenza pandemic [8-10].

With respect to the COVID-19 pandemic, some recent studies have discussed the effects, challenges, and consequences of social distancing policies. Andersen [11], for instance, shows that mandatory social distancing measures have been effective in reducing visits to public locations. Additionally, Kissler et al [12] maintain that while social distancing is effective, intermittent social distancing should be continued until 2022 to fully control the epidemic. Similarly, Singh and Adhikari [13] propose that a 3-week lockdown is insufficient for controlling the disease in India and that intermittent social distancing should remain in place. In a simulation-based study, Koo et al [14] showed that under scenarios of different R_0 values of COVID-19 (1.5, 2, or 2.5) and social distancing interventions (combinations of quarantine, school closure, and distance working), the number of infections may be reduced by 78.2%-99.3%. Another simulation study in Australia shows that infected case isolation is the most effective social distancing intervention among others (ie, school closure, distance working, and community contact reduction) [15]. Using an online questionnaire approach, Luo et al [16] showed that social distancing policies were effective in containing the spread of COVID-19 from Wuhan City to other areas of China. Greenstone and Nigam [17] estimated that social distancing measures in the United States would save 1.7 million lives by October 2020, and the monetary mortality benefit involved is around US $8 trillion.

Recently, particularly since the spread of COVID-19, researchers have begun to utilize geolocation data obtained from navigation and tracking information systems to analyze the consequences of social distancing policies. For example, using GPS data, Engle et al [18] showed that a higher perceived prevalence of COVID-19 in a small US community (from 0% to 0.003%) reduced mobility by 2.31%. Additionally, Queiroz et al [19] used cell phone navigation data of millions of people in Sao Paulo to show that mandatory social distancing measures have effectively changed the mobility patterns of people in the largest city in Brazil. A similar study was performed by Warren and Skillman [20] to study mobility changes in the United States in response to COVID-19. In another study, Gibson and Rush [21] used data from a geographic information system to discuss the feasibility of implementing social distancing in informal settlements in Cape Town.

Simulation-based studies have consistently shown the overall mitigating role of various social distancing interventions in the spread of epidemics. However, due to the complexity and time-variant nature of diseases, the reported effectiveness of interventions in these studies varies greatly and, in most cases, relies on local assumptions; hence, the results are not generalizable.

Recently, Google LCC [22] and Apple Inc [23] published data sets indicating changes in mobility (compared to an average baseline before the COVID-19 pandemic) of people in different categories of places (eg, transit stations and grocery stores) and different types of activities (eg, driving and walking) based on GPS data collected from users of their navigation applications around the world. These reports confirm the effectiveness of government incentives and restrictive policies to make people stay at home by indicating considerable decreases in mobility within public places (and, in turn, increases in mobility within residential areas); however, the effectiveness of these measures in slowing the disease spread is not apparent. Particularly, many countries are still experiencing increasing numbers of confirmed COVID-19 cases despite having social distancing policies in effect for several weeks; this raises the question of to what extent, if any, the changes in mobility patterns resulting from these policies were effective in managing the disease spread. In this study, we seek to clarify this issue.

To this end, we relied on the susceptible-infected-recovered (SIR) model, one of the most common compartmental models in studying epidemics, along with official reports on the number of COVID-19 cases in different countries to estimate the average transmission rate (β) of the disease. While the original SIR model considers a time-invariant β value, intuitively, the speed of the epidemic can be at least partially manipulated over time; thus, the magnitude of the parameter β can be time-variant (Katriel and Stone [24]; Liu et al [25]). Therefore, each estimation pertaining to a different time section (weeks, in our study) may yield a different β value. In our study, these varying β values correspond to the weekly mobility statistics with a 7-day lag (considered to reflect the effect of mobility changes on the disease transmission rate). The resulting data set was used to train a machine learning regression algorithm to investigate the relationship between mobility and disease transmission. To the best of our knowledge, this is the first study that uses real transactional data to investigate the actual

contribution of social distancing policies (through mobility reduction) in controlling the spread of a pandemic.

Methods

Data Sources

Google and Apple Mobility Data Sets

In April 2020, Google LLC [22] and Apple Inc [23] started sharing daily mobility data from select regions and select countries in the world. The Google data set incorporates five different mobility trend variables: grocery and pharmacy (supermarkets, farmer's markets, drug stores, and pharmacies), parks (national/local parks, public beaches, and gardens), transit stations (public transport hubs, including train, bus, and subway stations), retail and recreation (restaurants, cafés, shopping centers, movie theaters), residential (places of residence), and workplaces. The data sets show trends from prior to the outbreak (Google does not provide any specific benchmark date) onward. The Apple data set also shows the relative volume of requests for directions compared to a specific baseline volume of January 13, 2020. Google and Apple do not include mobility data on some countries in the top 30 in terms of cumulative cases of COVID-19, such as Russia, China, the United Kingdom, Iran, and Algeria. Therefore, our analysis is limited to the countries included in both the European Centre for Disease Prevention and Control (ECDC) and mobility data sets.

To control COVID-19, many governments have declared mandatory or optional quarantines or are employing other policies. For simplicity, we used a 7-day window and transformed our daily mobility data into weekly data. We also performed missing value imputation using linear interpolation during this transformation. Our mobility data started on February 28, 2020 and ended on April 17, 2020, covering a total of 7 weeks in 26 countries (7 × 26 = 182 rows). For each country, using consecutive day pairs, we estimated the mobility averages of 9 variables (see Table 1).

Table 1. Mobility data obtained from Apple and Google.

Data	Google	Apple
Starting date	February 15, 2020	January 13, 2020
Ending date	April 11, 2020	April 21, 2020
Countries (n)	131	63
Subregions (n)	1710	89
Variables		
1	Retail and recreation	Driving
2	Grocery and pharmacy	Walking
3	Parks	Transit
4	Transit stations	N/A[a]
5	Workplaces	N/A
6	Residential	N/A

[a]Not applicable.

ECDC COVID-19 Data

In this study, our aim was to understand the relationships between reported mobilities and the dynamics of the COVID-19 outbreak. Several agencies, including the European Union, World Health Organization, and Johns Hopkins, offer up-to-date data aggregations of the number of cases as well as the number of deaths from over 150 countries. As one source of data, we used the ECDC data, which is updated daily on their website [26]. The data coverage was limited (no gender or age breakdowns, no data on the number of recovered patients or the number of tests conducted). We limited our analysis to the top 30 countries in terms of the number of cumulative cases. After the data transformations, we trimmed our data according to the starting and ending dates in Table 1.

Other Data Sets

During our study, to overcome the limitations of the ECDC COVID-19 data set (or similar data set providers), we also used several other data sets provided by individual countries such as the United States (the COVID tracking project by *The Atlantic* [27]), Belgium (the ECDC website [26]), and Turkey (the National Ministry of Health [28]). These data sets include the number of recovered patients on a daily basis.

Methodology

To understand the relationships between limited mobility and the spread of COVID-19, we first established a target variable depicting the speed of the spread of the virus. The use of variables such as "number of daily cases" or "number of daily fatalities" was driven by many forces, such as "natural course of the spread of the virus" and "limited mobility and other controllable effects." Because we were interested in measuring the actual changes in the diffusion of the spread, we decided to employ one of the most frequently used endemic models, the SIR model. Instead of looking at the case and fatality data, we investigated the relationship between the parameter changes of the SIR model and the changes in the mobility data set.

The SIR Model

Pandemics are first characterized by a number referred to as the reproduction number, R_0. This number approximately indicates the expected number of new infections caused by a single infection; hence, it has no unit. This is especially important during the early days of the spread of an infection. While $R_0<1$ implies no epidemic, a greater R_0 may indicate a pandemic of a larger scale. For instance, while seasonal influenza has an R_0 of 1.3 [29], the R_0 for COVID-19 is speculated to be around 2.2 [30,31]. During an outbreak, the trajectory of the number of infected people over time follows an approximately bell-shaped curve. Depending on the severity of the infection, health care systems are concerned with the peak of this curve to provide adequate health care services. The number R_0 is simply obtained by multiplying the transmissibility per contact, the contacts per time unit, and the recovery rate.

Perhaps the most frequently used model in epidemic models is the SIR model. The model categorizes individuals into three different compartments: susceptible (*S*), infected (*I*), and recovered (*R*). Therefore, it is called a compartmental model. Within the SIR model, the effective contact rate β controls the transition from compartment *S* to compartment *I*. This rate, which measures the number of new infections over time, may be influenced by interventions such as social distancing, wearing protective gear, or handwashing. The term γ, on the other hand, refers to the effective recovery rate. Therefore, a shorter average infectious period (1/γ) translates into a larger γ recovery rate. γ is strongly linked to the duration of the disease rather than to policy changes. Within the SIR compartment model, this value controls the move from compartment *I* to compartment *R*. The rates corresponding to intercompartment transitions can be written as a set of differential equations, as in equations 2-4 [32].

$$dS/dt = -\beta SI/N \quad (2)$$

$$dI/dt = \beta SI/N - \gamma I \quad (3)$$

$$dR/dt = \gamma I \quad (4)$$

While this set of differential equations is self-explanatory, the parameter estimations, especially at the beginning of an outbreak, are usually not quite as straightforward. At the beginning of an outbreak, everyone may be considered as susceptible ($S \approx N$), and R_0 becomes β/γ. However, at later stages, R_0 determines the size of the compartment *S* ($S \neq N$); thus, it becomes numerically more challenging to calculate an estimate.

Calculating γ

To determine a good approximation of the rate of recovery, we estimated the average number of days from case report to recovery. We used reported data available from three different countries: Turkey, Belgium, and the United States. By using a sliding window to investigate the correlation between the number of recovered cases and the number of new cases using a lag variable, we estimated the slide amount that maximizes the correlation between these two sets of numbers. While the results may depend on individual practices of the countries, our analysis consistently yielded a lag time of 7-8 days regardless of the country (see Multimedia Appendix 1 and Multimedia Appendix 3 for more details). Therefore, we chose to set γ at 1/7.5 = 0.133.

Aggregating Reported Case Numbers for Analysis

ECDC reports the number of daily cases. Cases do represent infection; however, the number of infected cases on a given day does not simply equal the number of daily reported cases. While it may be more convenient to simply run the SIR model using daily case data, a more accurate approach involves estimating the number of infected individuals at a given time. Using our γ estimation of a 7.5-day average treatment window, we aggregated the daily case data to obtain an estimate of the number of active infections on each day.

Fitting the SIR Model

Fitting a compartment model such as SIR is a numerical challenge. The curve fitting is usually achieved by solving a set of differential equations using the Runge-Kutta algorithm [33,34]. In our study, we were interested in how the effective contact rate of the infection, β, changes according to mobility. By fixing γ = 1/7.5, we sought to determine the value of β that minimizes the sum of squared errors.

Our mobility data started on February 28, 2020 and ended on April 17, 2020, covering a total of 7 weeks. For each country, using consecutive starting and ending weeks, we estimated the corresponding β of the SIR model (182 β values).

When estimating the β values, we used multilevel single linkage [35], Subplex (Nelder-Mead algorithm on the sequence of subspaces) [36], and Broyden–Fletcher–Goldfarb–Shanno quasi-Newton method [37] algorithms to check the consistency of the error-minimizing β parameter, and we reported the best value in terms of the mean squared error. All methods yielded identical β values, indicating the numerical stability of the fitted curve.

Machine Learning Setup

As the last step of the extract, transform, load process, we merged the mobility data with the SIR model fits (β values) by adding a 1-week delay period to measure the effects of mobility on the overall fit of the model. Larger β values indicate a larger, faster spread (). A graphical summary of the data merging and the study methodology is provided in Multimedia Appendix 2.

We investigated the relationship between β and the mobility factors by examining the predictive power of mobility with respect to β. Since the mobility factors were highly correlated, instead of training ordinary least squares regression models, which may raise multicollinearity concerns, we used the data to train a gradient boosted trees (GBT) model for regression.

GBT is a boosting ensemble machine learning approach that sequentially constructs a large number of decision trees; in each sequence, the algorithm reweights the training data based on the model performance in the previous sequence (giving a higher weight to instances with a more substantial error term).

According to Hastie et al [38], GBT automatically disregards redundant features at any step due to its stepwise greedy strategy for selecting features in growing trees; hence, it is robust to multicollinearity.

Due to our limited sample size (N=130; 26 countries, 5 weeks per country), we employed a leave-one-out strategy to validate the GBT models. Each time, we used the algorithm to sequentially grow 2000 trees with a learning rate of 0.01 using 129 data points and tested the model on the remaining data point.

Moreover, to assess the importance of each single mobility variable in determining changes in β, we then examined the feature importance report provided by the GBT algorithm. For each predictor variable, the report provides a score indicating how valuable that variable was in the construction of the decision trees within the model. The more a feature is used to split the tree nodes, the higher its relative importance. A detailed discussion on how each score was calculated is provided in [38]. The results are described in the next section.

Results

While the mobility trends indicate lower mobilities, limiting mobilities resulted in increased residential mobilities across almost all countries. Figures 1 and 2 show a graphical depiction of our expected results. It can be observed that the β values mimic the mobilities of the earlier weeks. In the United Kingdom, for instance, while reduced mobility in earlier weeks resulted in a slower spread, a slight increase in mobility resulted in the growth of spread speed (larger β).

The GBT regression analysis results suggest that changes in mobility factors were able to explain around 47% of the variation in the COVID-19 transmission rate (β). The mean absolute error, mean squared error, and root mean squared error of the β predictions were 0.06, 0.005, and 0.072, respectively.

Figure 3 indicates the relative importance score of each mobility feature obtained from the GBT algorithm.

Figure 1. Mobility and spready in Turkey after lag is taken into account (the β values correspond to the week after the indicated date on the x-axis).

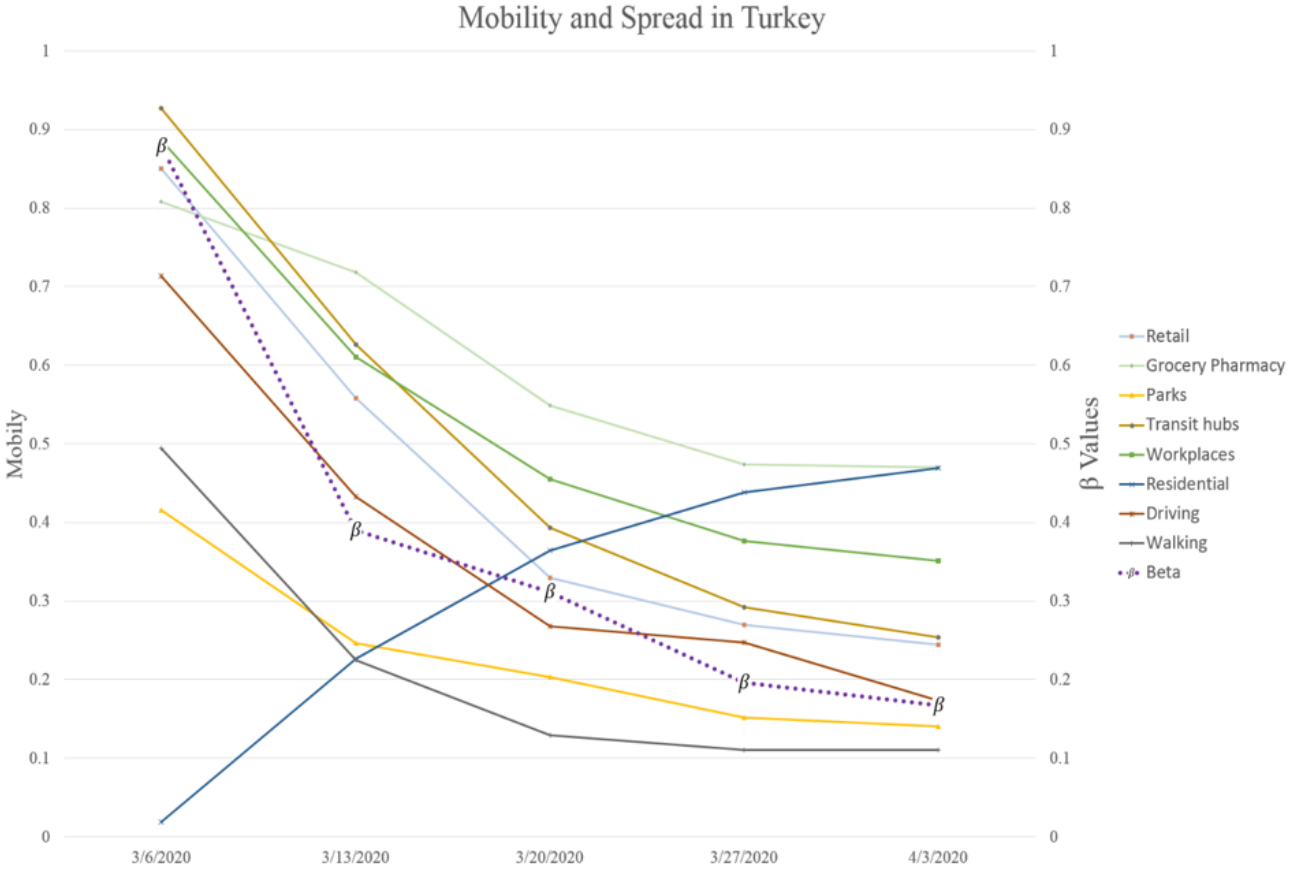


Figure 2. Mobility and spread in Italy after lag is taken into account (the β values correspond to the week after the indicated date on the x-axis).

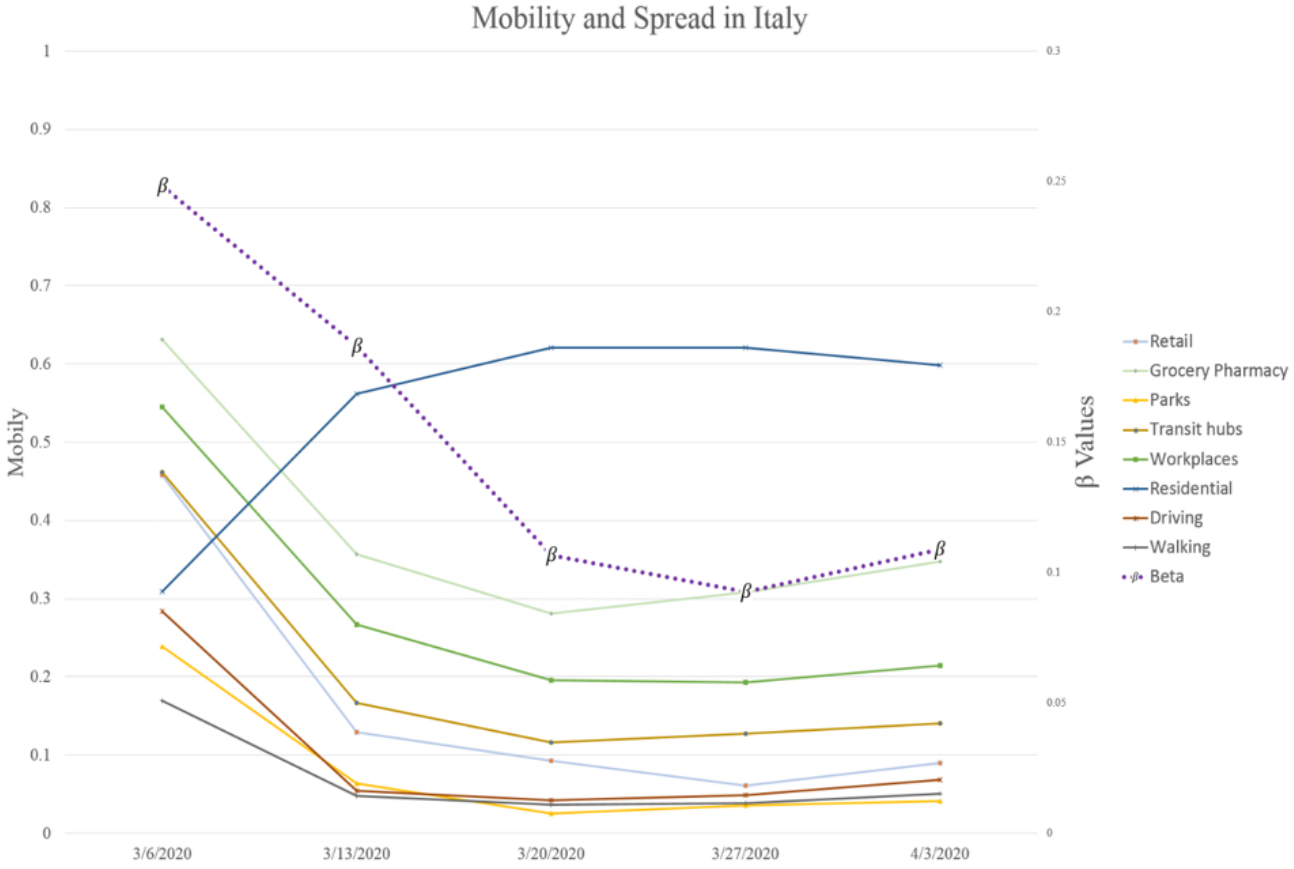
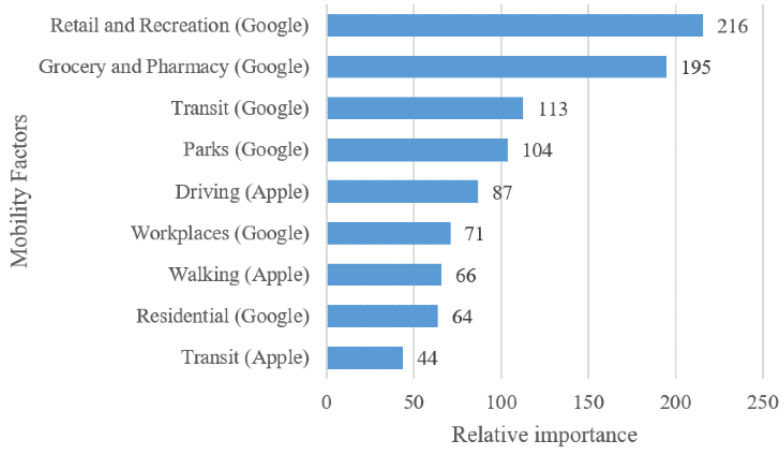


Figure 3. Relative importance of mobility factors in determining the COVID-19 transmission rate.



Discussion

Principal Findings

This study seeks to provide a more realistic and generalizable assessment of the effectiveness of social distancing interventions (reflected in mobility pattern changes) in controlling the spread of disease during a pandemic. Our results show that around 47% of the variation in the disease transmission rates is explainable by changes in mobility patterns resulting from enforcing of social distancing policies in the studied countries.

Also, as shown in Figure 3, changes of mobility in public places such as retail and recreation centers (eg, restaurants, cafes, theaters), grocery stores and pharmacies, transit hubs (eg, airports, bus stations, subways), and parks are the most important determinants of the disease transition rate. Additionally, interestingly, mobility in residential areas (the least public area) were found to be the second least relevant factor in predicting β. It should be noted that the transit mobility variable from the Apple data contained only zero values for 8/26 countries (31%). Because these values were not marked as missing in the original data set, we used them as provided. However, it is highly likely that these values were actually missing, in which case the Residential mobility variable would probably be the least important predictor of β. Overall, this justifies the government policies to enforce restrictions on travel,

restaurants, and public events with the aim of controlling the spread of the disease.

Social distancing is an umbrella term that involves several different types of interventions, including case isolation, school closure, quarantine, distance working, and contact reduction in public places. Changes in mobility patterns, the effects of which were investigated in this research, can be considered as a surrogate measure of multiple social distancing interventions at the same time. The focus of other similar studies (mostly simulation-based) is on different combinations of these interventions, and different criteria were used to report the effects in those studies; therefore, comparing our results to theirs is challenging. For instance, Koo et al [14] used different combinations of R_0 values and interventions and reported the mitigating effects in terms of the reduction in the number of infections (78%-99%), while Milne and Xie [15] examined several interventions sequentially and reported the mitigation role in terms of the reduction in the proportion of population infected (66%-24%). This study, meanwhile, uses the disease transmission rate β as the criterion to report the efficacy of social distancing.

From a theoretical viewpoint, this study contributes to the literature by proposing an approach for utilizing real data, as opposed to simulated numbers, to study the effects of various interventions at the time of an epidemic. We acknowledge that our results are highly affected by the lack of sufficient data (primarily due to the recency of the COVID-19 pandemic and the enforcement of social distancing policies); however, it still provides solid evidence of the effectiveness of social distancing. We argue that our results involve a considerably lower degree of uncertainty due to their reliance on real transactional data, which have already captured the complex dynamics of the epidemic. Also, since our data are not limited to a specific geographical area, our results should be more generalizable than those of similar studies, which are mostly limited to a certain area.

Different countries, due to differences in their public health policies and health care infrastructures, may be inconsistent in terms of the number of tests they perform and, consequently, in their reporting of the number of infections. However, we argue that since our approach only considers within-country changes for estimating the transmission rates, it is fairly robust to such inconsistencies. Also, we obtained identical β estimates from three different optimization algorithms, which shows that our estimates are robust with regard to the estimation methods as well.

Because we relied on real transactional data, we argue that this study provides a less noisy assessment of the efficacy of social distancing interventions than similar simulation-based studies. This is especially due to the complex nature of epidemics, which requires researchers who take a simulation approach to estimate several dependent parameters (eg, estimating the mortality rate depends on the number of infections, which itself depends on the transmission rate and the susceptible population), each of which are based on a set of assumptions that may be too simplistic in some cases; because each of those estimations may involve a reasonable error, this dependency leads to the introduction of a relatively high accumulated error in the whole study. Due to this complexity, most simulation-based studies only focus on the efficacy of a single social distancing policy (e.g., Earn et al [7] only examined school closure). Using real data, on the other hand, eliminates some sources of error by reducing the need for multiple estimations.

Moreover, due to the cross-national nature of the data, our results are more generalizable than those of similar studies that were mostly conducted in a single geographical area. Whereas countries may prefer to study the effects of their policies in their own situations, we argue that by fitting a single model to a multicountry data set, we mitigated the country-level idiosyncrasies in data; this provides policy makers with a clearer picture of how mobility is linked to the speed of disease spread.

From an empirical standpoint, in addition to providing supporting evidence for the effectiveness of social distancing policies, our study provides specific insights for policy makers as to which categories of locations and activities should be considered as top priorities for enforcing social distancing measures. Notably, our investigation revealed that mobility changes in highly public places such as restaurants, cafés, grocery stores, transit stations, and parks play more important roles in decreasing disease spread compared with workplaces or residential areas.

Additionally, our results suggest that reductions in driving mobility are relatively more important than changes in walking patterns in determining (decreasing) disease spread. This is also reasonable because the geographical span of driving mobility is normally far wider than that of walks; therefore, a susceptible person is subject to a higher risk of infection due to the potentially larger infected population residing in a wider area. This suggests that governmental restrictions on driving (especially long distances) can effectively reduce the number of new infections.

In addition to the relatively small sample size, another limitation of the present study is its reliance on highly aggregated data at the country level. Whereas this limitation is mainly due to the unavailability of granular mobility and COVID-19 data at the present time, we believe that replicating the proposed approach using a more granular mobility data set (in terms of the types of activities and categories of places) could reveal more interesting facts with regard to the effectiveness of specific social distancing policies. Therefore, we encourage future researchers to extend the present study as such data become available.

In the end, we believe that this study sheds light on the high potential of technology innovations in studying pandemics. Whereas we only took a retrospective approach by using historical geolocation data, a proactive approach that uses tracking technologies to identify people and locations at high risk could help governments and public health policy makers prepare for similar pandemics in the future. As a very recent effort, Google and Apple have announced a collaboration to implement a contact tracing system to send automatic mobile phone alerts to people who have recently been in close contact with people who tested positive for COVID-19 [39].

Conclusion

Our analyses of real mobility and COVID-19 data provide substantial evidence of the significant mitigating role of social distancing interventions on disease transmission rates. Particularly, we have shown that controlling people's attendance and mobility in highly public places as well as enforcing driving restrictions are effective public health policies to help flatten the curve.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Merging mobility features and SIR model fits with a 7-day lag.
[PNG File , 36 KB - publichealth_v6i2e19862_app1.png]

Multimedia Appendix 2
Graphical depiction of the data integration and analysis procedures.
[PNG File , 84 KB - publichealth_v6i2e19862_app2.png]

Multimedia Appendix 3
Table S1. Determining the value of γ using a sliding lag window.
[DOCX File , 14 KB - publichealth_v6i2e19862_app3.docx]

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Abbreviations

β: average transmission rate
COVID-19: coronavirus disease
R_0: reproduction number
SIR: susceptible-infected-recovered
ECDC: European Centre for Disease Prevention and Control

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Viewpoint

COVID-19: Putting the General Data Protection Regulation to the Test

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Abstract

The coronavirus disease (COVID-19) pandemic is very much a global health issue and requires collaborative, international health research efforts to address it. A valuable source of information for researchers is the large amount of digital health data that are continuously collected by electronic health record systems at health care organizations. The European Union's General Data Protection Regulation (GDPR) will be the key legal framework with regard to using and sharing European digital health data for research purposes. However, concerns persist that the GDPR has made many organizations very risk-averse in terms of data sharing, even if the regulation permits such sharing. Health care organizations focusing on individual risk minimization threaten to undermine COVID-19 research efforts. In our opinion, there is an ethical obligation to use the research exemption clause of the GDPR during the COVID-19 pandemic to support global collaborative health research efforts. Solidarity is a European value, and here is a chance to exemplify it by using the GDPR regulatory framework in a way that does not hinder but actually fosters solidarity during the COVID-19 pandemic.

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KEYWORDS

COVID-19; data sharing; GDPR; research exemption; global health; public health; research; digital health; electronic health records; EHR

As the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) continues to spread around the globe, researchers are racing to understand and contain the pandemic, learn how to best treat patients with SARS-CoV-2 infection and the resulting coronavirus disease (COVID-19), and develop a vaccine. The COVID-19 pandemic is also very much a global health issue and requires collaborative, international health research efforts to address it. A valuable source of information for researchers is the large amount of digital health data that are continuously collected by the electronic health record systems of health care organizations. However, such digital health data typically exists in separate systems and researchers in many countries are currently severely hamstrung by the lack of integrated and comprehensive, publicly available, patient-level data regarding COVID-19. They are having to derive answers from limited analyses of small case series, while large amounts of relevant digital health data sits unexamined on hospital servers around the world. This situation has led to calls for a common, multinational, COVID-19 database to be created, pointing to the Medical Information Mart for Intensive Care (MIMIC) database at the Beth Israel Deaconess Medical Center in Boston as a model for publicly sharing deidentified electronic health data [1].

While setting up COVID-19-related databases for research makes obvious sense from a research perspective, there is also currently a broader societal reason why this is a good idea. Indeed, the COVID-19 pandemic has put solidarity into strong focus; many ongoing measures to contain the spread have been described as solidarity practices—that is, as prosocial behaviors to help and/or protect others, or collective resources such as health care systems, that are based on the recognition of a shared

interest. Health databases and biobanks have also previously been framed as solidarity-based endeavors, and solidarity-based governance models have been proposed to reflect the prosocial motivation many people have toward such resources, which at the same time avoid some of the burden of the usual restrictive, autonomy-based governance models [2].

As the total deaths from COVID-19 continues to increase globally, the ethical and social imperative to quickly curtail the pandemic is clear. However, this does not negate the need for the use of digital health data to respect data protection regulations and patient privacy and confidentiality [3]. In fact, although the scale of COVID-19 is clearly new, the ethical challenge of balancing confidentiality with public health has been well discussed [4-7].

With the epicenter of the pandemic currently shifting from Europe to the United States, the European Union's (EU) General Data Protection Regulation (GDPR) will be the key legal framework with regard to using and sharing European digital health data for research purposes [8]. However, concerns persist that the GDPR has made many organizations very risk-averse in terms of data sharing, even if the regulation permits such sharing. Health care organizations focusing on individual risk minimization threaten to undermine COVID-19 research efforts.

The European Data Protection Board has stressed the importance of protecting personal data during the COVID-19 pandemic. However, it has also noted: "Data protection rules (such as GDPR) do not hinder measures taken in the fight against the coronavirus pandemic" [9]. Indeed, article 9(2)(i) of the GDPR explicitly allows the processing of sensitive personal data (including genetic data, biometric data, and data concerning health) if it is "necessary for reasons of public interest in the area of public health." Recitals 46, 52, 53, and 54 also explicitly acknowledge the need to sometimes process special categories of personal data for reasons of public interest in the area of public health.

Furthermore, article 9(2)(j) sets out a scientific research exemption for the processing of sensitive personal data, which could occur without consent if subject to appropriate safeguards, which may include pseudonymization (deidentification) (see article 89(1)) (Table 1). Researchers and health care organizations wanting to utilize and share patient-level data regarding COVID-19 from data subjects residing in the EU will need to be aware of the following:

- The GDPR applies to any personal data concerning an identified or identifiable natural person, but not to anonymous information. As the GDPR does not distinguish between anonymized and anonymous data, databases collecting identifiable data for research purposes will be excluded from the scope of the GDPR if the data are later rendered anonymized [8,10].
- Pseudonymized data is now recognized as personal data if it could be attributed to a natural person by the use of additional information. Given pseudonymized health data is what health care databases typically use, recognizing pseudonymized data as personal data may result in more bureaucracy, particularly for those countries that currently consider pseudonymized data to fall outside the scope of personal data [8,10].
- The processing of special categories of personal data ("sensitive personal data"), including genetic data, biometric data, and data concerning health, shall be prohibited under the GDPR unless certain conditions applies. Health care databases using pseudonymized sensitive personal data will need to either obtain explicit consent from the data subject or for the data to be processed under the scientific research exemption set out in the GDPR, which could occur without consent if subject to appropriate technical and organizational safeguards [8,10].

In our opinion, there is an ethical obligation to use the GDPR scientific research exemption clause during the COVID-19 pandemic to support global collaborative health research efforts. However, while the provision is there, researchers and research institutions in Europe have been reluctant to use it, likely due to fear of the difficulties that may be caused by their national bodies. In fact, consortia funded in the current H2020 funding scheme by the European Commission have overwhelmingly used other more burdensome legal justifications, such as informed consent, than the research exemption.

This is not sufficient for the current situation. COVID-19 is a real test for the GDPR. There is a strong ethical case that countries use the regulatory leeway the GDPR provides for enabling health data to be used for research purposes and that they support health care organizations and investigators to invoke the research exemption confidently in the context of a global pandemic. Recent research in some European countries also suggests that many people would accept the secondary use of their data for health-related research under the research exemption, based on prosocial motivations such as solidarity [11]. Solidarity is a European value, and here is a chance to exemplify it by using the GDPR regulatory framework in a way that does not hinder but actually fosters solidarity during the COVID-19 pandemic.

Table 1. Scientific research exemption provisions of the European Union's General Data Protection Regulation (GDPR).

GDPR article	Relevant sections
Article 9: Processing of special categories of personal data	Section 1: Processing of personal data revealing racial or ethnic origin, political opinions, religious or philosophical beliefs, or trade union membership, and the processing of genetic data, biometric data for the purpose of uniquely identifying a natural person, data concerning health or data concerning a natural person's sex life or sexual orientation shall be prohibited. Section 2: Paragraph 1 shall not apply if one of the following applies: • The data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law states that the prohibition referred to in paragraph 1 may not be lifted by the data subject; …. • Processing is necessary for reasons of public interest in the area of public health, such as protecting against serious cross-border threats to health or ensuring high standards of quality and safety of health care and of medicinal products or medical devices, on the basis of Union or Member State law which provides for suitable and specific measures to safeguard the rights and freedoms of the data subject, in particular professional secrecy; • (j) Processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject.
Article 89: Safeguards and derogations relating to processing for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes	Section 1: Processing for archiving purposes in the public interest, scientific or historical research purposes, or statistical purposes shall be subject to appropriate safeguards, in accordance with this Regulation, for the rights and freedoms of the data subject. Those safeguards shall ensure that technical and organisational measures are in place in particular in order to ensure respect for the principle of data minimisation. Those measures may include pseudonymisation provided that those purposes can be fulfilled in that manner. Where those purposes can be fulfilled by further processing which does not permit or no longer permits the identification of data subjects, those purposes shall be fulfilled in that manner.

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Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
EU: European Union
GDPR: coronavirus disease
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Tracking Social Media Discourse About the COVID-19 Pandemic: Development of a Public Coronavirus Twitter Data Set

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Abstract

Background: At the time of this writing, the coronavirus disease (COVID-19) pandemic outbreak has already put tremendous strain on many countries' citizens, resources, and economies around the world. Social distancing measures, travel bans, self-quarantines, and business closures are changing the very fabric of societies worldwide. With people forced out of public spaces, much of the conversation about these phenomena now occurs online on social media platforms like Twitter.

Objective: In this paper, we describe a multilingual COVID-19 Twitter data set that we are making available to the research community via our COVID-19-TweetIDs GitHub repository.

Methods: We started this ongoing data collection on January 28, 2020, leveraging Twitter's streaming application programming interface (API) and Tweepy to follow certain keywords and accounts that were trending at the time data collection began. We used Twitter's search API to query for past tweets, resulting in the earliest tweets in our collection dating back to January 21, 2020.

Results: Since the inception of our collection, we have actively maintained and updated our GitHub repository on a weekly basis. We have published over 123 million tweets, with over 60% of the tweets in English. This paper also presents basic statistics that show that Twitter activity responds and reacts to COVID-19-related events.

Conclusions: It is our hope that our contribution will enable the study of online conversation dynamics in the context of a planetary-scale epidemic outbreak of unprecedented proportions and implications. This data set could also help track COVID-19-related misinformation and unverified rumors or enable the understanding of fear and panic—and undoubtedly more.

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KEYWORDS

COVID-19; SARS-CoV-2; social media; network analysis; computational social sciences

Introduction

The first cases of coronavirus disease (officially named COVID-19 by the World Health Organization [WHO] on February 11, 2020) were reported in Wuhan, China, in late December 2019; the first fatalities were reported in early 2020 [1]. The fast-rising infections and death toll led the Chinese government to quarantine the city of Wuhan on January 23, 2020 [1]. During this period, other countries began reporting their first confirmed cases of the disease, and on January 30, 2020, the WHO announced a Public Health Emergency of International Concern. With more countries reporting cases of the disease, and infections rapidly escalating in some regions of the world, including South Korea, Iran, and Italy, the WHO declared COVID-19 a pandemic [2]. At the time of this writing, COVID-19 has been reported in 185 countries, leaving governments all over the world scrambling for ways to contain the disease and lessen its adverse consequences to their people's health and economy [3].

Preventative measures implemented by national, state, and local governments now affect the daily routines of millions of people worldwide [4]. *Social distancing*, the most widely used of such

measures, aims to curtail new infections by reducing physical contact between people [5]. Social distancing measures have led to the cancellation of sporting events and conferences [6], closures of schools and colleges [7], and has forced many businesses to require their employees to work from home [8]. As more and more social interactions move online, the conversation around COVID-19 has continued to expand, with growing numbers turning to social media for both information and company [9,10]. Platforms such as Twitter have become central to the technological and social infrastructure that allows us to stay connected even during crises.

We describe a Twitter data set about COVID-19-related online conversations that we are sharing with the research community. People all over the world take to Twitter to express opinions and engage in dialogue in a public forum, and, with Twitter's open application programming interface (API), has proven to be an invaluable resource for studying a wide range of topics. Twitter has long been used by the research community as a means to understand dynamics observable in online social networks, from information dissemination [11,12] to the prevalence and influence of bots and misinformation [13,14]. More importantly during the current COVID-19 pandemic, Twitter provides researchers the ability to study the role social media plays in the global health crisis [15-19]. We hope that this data will spur new research about the social dimensions of the pandemic.

We began collecting data in real time from Twitter, with the earliest tweets dating to January 21, 2020, by tracking COVID-19-related keywords and accounts. Here, we describe the data collection methods, document initial data statistics, and provide information about how to obtain and use the data.

Methods

Overview

We have been actively collecting tweets since January 28, 2020, leveraging Twitter's streaming API [20] and Tweepy [21] to follow specific keywords and accounts that were trending at the time. When we started collecting tweets, we also used Twitter's search API [22] on the same keywords to gather related historical tweets. Thus, the earliest tweets in our collection date back to January 21, 2020. Since then, we have incrementally added keywords and accounts to follow based on the conversations occurring on Twitter at any time. We have collected over 72 million tweets from inception to March 21, 2020, constituting roughly 600 GB of raw data, and are still collecting data to this day.

Our collection relies upon publicly available data and is hence registered as IRB (institutional review board) exempt by the University of Southern California IRB (approved protocol UP-17-00610). We release the data set with the stipulation that those who use it must comply with Twitter's Terms and Conditions [23].

Tracked Keywords and Accounts

By continuously monitoring Twitter's trending topics, keywords, and sources associated with COVID-19, we did our best to capture conversations related to the outbreak.

Twitter's streaming API returns any tweet containing the keyword(s) in the text of the tweet, as well as in its metadata; therefore, it is not always necessary to have each permutation of a specific keyword in the tracking list. For example, the keyword "Covid" will return tweets that contain both "Covid19" and "Covid-19." We list a subset of the keywords and accounts that we are following in Tables 1 and 2, respectively, along with the date we began tracking them. There are some keywords that overlap due to an included keyword being a substring of another, but we included both for good measure. The keyword choices in the current data set are all in English, so there is a heavy bias toward English tweets and events related to English-speaking countries. Due to the evolving nature of the pandemic and online conversations, these tables will expand as we continue to monitor Twitter for additional keywords and accounts to add to our tracking list.

Table 1. A sample of the keywords that we are actively tracking in our Twitter collection; see the GitHub repository for a full list of all tracked keywords (v1.8—May 8, 2020) [24].

Tracked since	Keyword
1/21/2020	Coronavirus; Corona; CDC; Ncov; Wuhan; Outbreak; China
1/22/2020	Koronavirus; Wuhancoronavirus; Wuhanlockdown; N95; Kungflu; Epidemic; Sinophobia
2/16/2020	Covid-19
3/2/2020	Corona virus
3/6/2020	Covid19; Sars-cov-2
3/8/2020	COVID–19
3/12/2020	COVD; Pandemic
3/13/2020	Coronapocalypse; CancelEverything; Coronials; SocialDistancing
3/14/2020	Panic buying; DuringMy14DayQuarantine; Panic shopping; InMyQuarantineSurvivalKit
3/16/2020	chinese virus; stayhomechallenge; DontBeASpreader; lockdown
3/18/2020	shelteringinplace; staysafestayhome; trumppandemic; flatten the curve
3/19/2020	PPEshortage; saferathome; stayathome
3/21/2020	GetMePPE
3/26/2020	covidiot
3/28/2020	epitwitter
3/31/2020	Pandemie

Table 2. Account names that we are actively tracking in our Twitter collection (v1.8—May 8, 2020).

Tracked since	Account name
1/22/2020	PneumoniaWuhan; CoronaVirusInfo; V2019N; CDCemergency; CDCgov; WHO; HHSGov; NIAIDNews
3/15/2020	DrTedros

Results

Releases

Our data collection will continue uninterrupted for the foreseeable future. As the pandemic continues to run its course, we anticipate that the amount of data will grow significantly. The data set is available on GitHub [24] and is released in compliance with the Twitter's Terms and Conditions, under which we are unable to publicly release the text of the collected tweets. We are, therefore, releasing the Tweet IDs, which are unique identifiers tied to specific tweets. The Tweet IDs can be used by researchers to query Twitter's API and obtain the complete tweet object, including tweet content (text, URLs, hashtags, etc) and authors' metadata. This process to retrieve the full tweet object from Twitter starting from a Tweet ID is referred to as *hydration*. There are several easy-to-use tools that have been developed for such purposes, including the *Hydrator* [25] and *Twarc* [26], but one could also directly use Twitter's API to retrieve the desired data. This data set can also be found on Harvard Dataverse [27]. Table 3 displays basic statistics, including collection period and number of tweets in that respective release, for all current releases (as of May 15, 2020).

There are a few known gaps in the data, which are listed in Table 4. Due to Twitter API restrictions on free data access, we were unable to recover data from the listed times, as Twitter only provides free access to tweets returned from their streaming API from the past week. To request access, interested researchers will need to agree upon the terms of usage dictated by the chosen license.

All of the Tweet ID files are stored in folders that indicate the year and month the tweet was posted (YEAR-MONTH). The individual Tweet ID files each contain a collection of Tweet IDs, with the file names all beginning with the prefix "coronavirus-tweet-id-" followed by the year, month, date, and hour the tweet was posted (YEAR-MONTH-DATE-HOUR).

We note that if a tweet has been removed from the platform, researchers will not be able to obtain the original Tweet.

Table 3. List of all releases and their statistics.

Release version	Release date	Data collection period	Tweets, n
v1.0	3/17/2020	3/05/2020 - 3/12/2020	8,919,411
v1.1	3/23/2020	1/21/2020 - 3/12/2020	63,616,072
v1.2	3/31/2020	1/21/2020 - 3/21/2020	72,403,796
v1.3	4/11/2020	1/21/2020 - 4/03/2020	87,209,465
v1.4	4/13/2020	1/21/2020 - 4/10/2020	94,671,486
v1.5	4/20/2020	1/21/2020 - 4/17/2020	101,771,227
v1.6	4/26/2020	1/21/2020 - 4/24/2020	109,013,655
v1.7	5/04/2020	1/21/2020 - 5/01/2020	115,929,358
v1.8	5/11/2020	1/21/2020 - 5/08/2020	123,113,914

Table 4. Known gaps in the data set in UTC (v1.8—May 8, 2020).

Date	Time
2/1/2020	4:00 - 9:00 UTC
2/8/2020	6:00 - 7:00 UTC
2/22/2020	21:00 - 24:00 UTC
2/23/2020	0:00 - 24:00 UTC
2/24/2020	0:00 - 4:00 UTC
2/25/2020	0:00 - 3:00 UTC
3/2/2020	Intermittent internet connectivity issues

The Most Recent Release (Release v1.8—May 11, 2020)

Our 9th release spans January 21, 2020, through May 8, 2020. The data set available now contains tweets from January 21, 2020 (22:00 UTC), through May 8, 2020 (21:00 UTC), with 123,113,914 tweets. The language breakdown of the tweets can be found in Table 5. A subset of the keywords and accounts that were followed during this timeframe can be identified by referencing Tables 1 and 2. For a full and up-to-date list of the keywords we are tracking, please see the "keywords.txt" file in the GitHub repository (a list of the accounts we are tracking can be found in the "accounts.txt" file) [24]. Some of the keywords may appear earlier than the initial listed track date in Table 1, as we systematically ran the same keywords through Twitter's search API to collect past instances of the keywords shortly after adding the keywords to be tracked in real time.

Table 5. Breakdown of the most popular languages and the number of associated tweets (v1.8—May 8, 2020).

Language	ISO[a]	Tweets (N=123,113,914), n (%)
English	en	80,698,556 (65.55)
Spanish	es	13,848,449 (11.25)
Indonesian	in	4,196,591 (3.41)
French	fr	3,762,601 (3.06)
Portuguese	pt	3,451,196 (2.80)
Japanese	ja	2,897,046 (2.35)
Thai	th	2,754,627 (2.24)
(undefined)	und	2,711,649 (2.20)
Italian	it	1,615,916 (1.31)
Turkish	tr	1,308,989 (1.06)

[a]ISO: International Organization for Standardization.

General Release Notes

In order to use any Twitter-facing libraries, including hydration software, users must first apply for a Twitter developer account and obtain the necessary authentication tokens [28].

The GitHub community has also generously contributed scripts to enable researchers to hydrate the Tweet IDs using *Twarc* [26].

Discussion

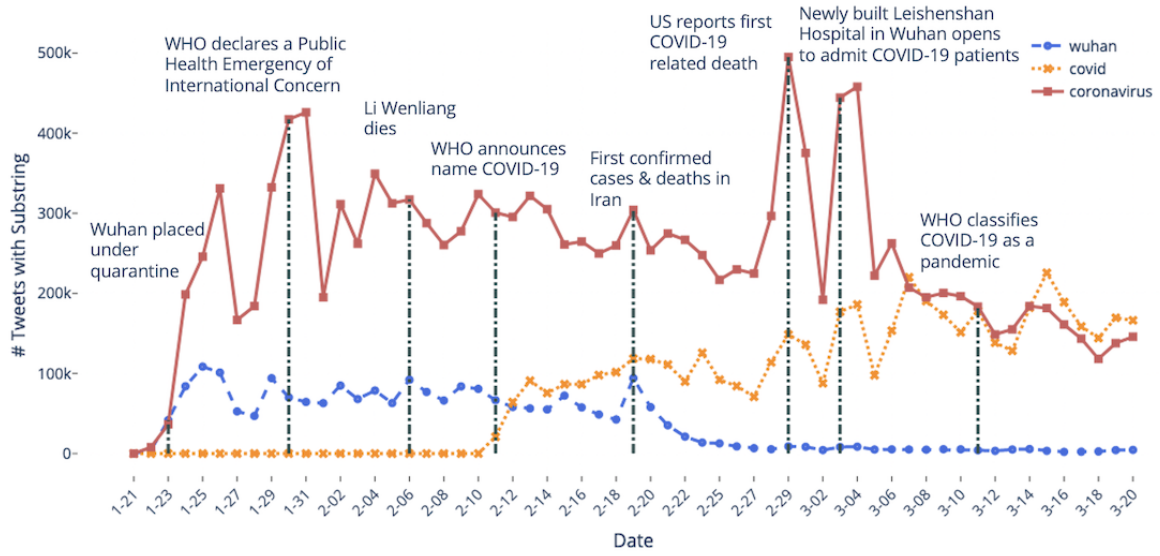
Overview

We present an initial analysis of our collected data set that verifies that Twitter discourse statistics reflect major events at the time, and leverage Business Insider [29], NBC [30], and CNN [31] released timelines to identify these events of interest during the development of the COVID-19 pandemic. In some of these analyses, there is a dip on March 2, 2020—this was due to internet connectivity failures throughout that specific day. Our discussion is based on analysis done on tweets from release v1.2 (January 21, 2020 to March 31, 2020), while the most recent release is v1.8.

Hashtags

We tracked the frequency of COVID-19-related hashtags, specifically those that contain the substrings "wuhan," "coronavirus," and "covid" throughout our collection period (Figure 1). We can see that while hashtags with the substring "coronavirus" consistently remain a more heavily used hashtag in our data set, the hashtag usage spiked on the day the WHO declared COVID-19 a global public health emergency; it also spiked on the day the United States announced the first COVID-19-related death [2]. We also did not see hashtags referencing "covid" being used until February 11, 2020, when the WHO announced "COVID-19" as the official name for the novel coronavirus disease. The keyword "wuhan" in hashtags experienced consistent usage until late February, then steadily declined, which reflects the decrease in cases in China and the global spread of the virus.

Figure 1. Usage of hashtags containing the substrings "wuhan," "covid," and "coronavirus" over time. COVID-19: coronavirus disease; WHO: World Health Organization.

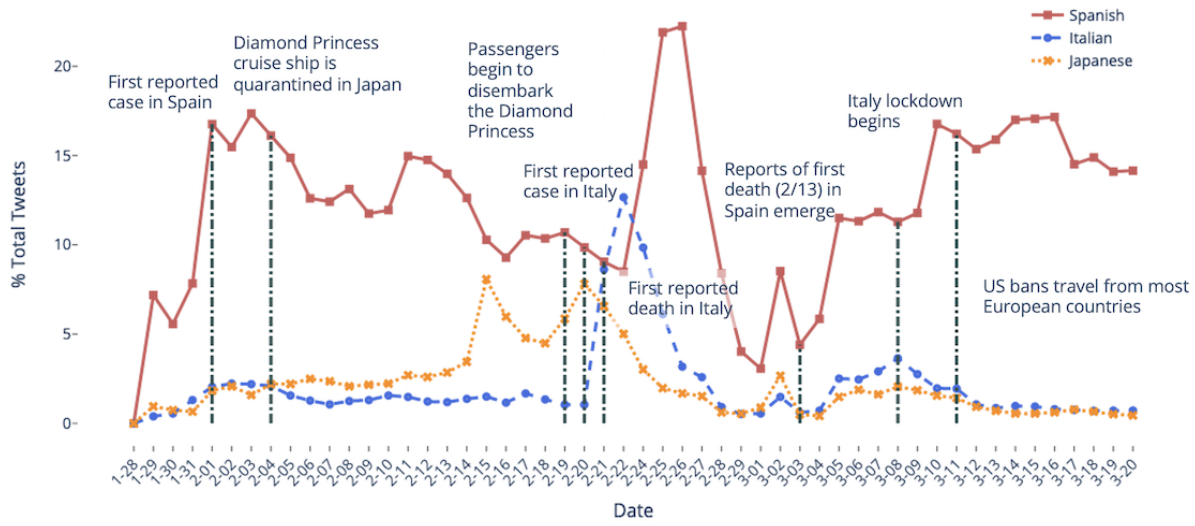


Languages

We then examined the percentage of total tweets posted in different languages (Figure 2). Although English is the most prominent language in our data set, we excluded English from this analysis to better visualize tweet activity in countries that experienced COVID-19 outbreaks earlier in the timeline. In particular, we found that Japanese tweet activity increased steadily after the cruise ship Diamond Princess was quarantined off the coast of Yokohama, Japan, with a peak around the time when passengers began to disembark [32].

There was also a significant spike in tweets from Italy when the first case related to COVID-19 was reported in Lodi, Italy, and first death was seen in Veneto [33]. We also observed a peak in the percentage of Spanish tweets after the first COVID-19 case in Spain was announced on February 1, 2020 [34] and a steady increase in the percentage of Spanish tweets after reports of the first COVID-19-related death began to emerge (the death itself occurred on February 13th, but the cause was diagnosed postmortem) [35].

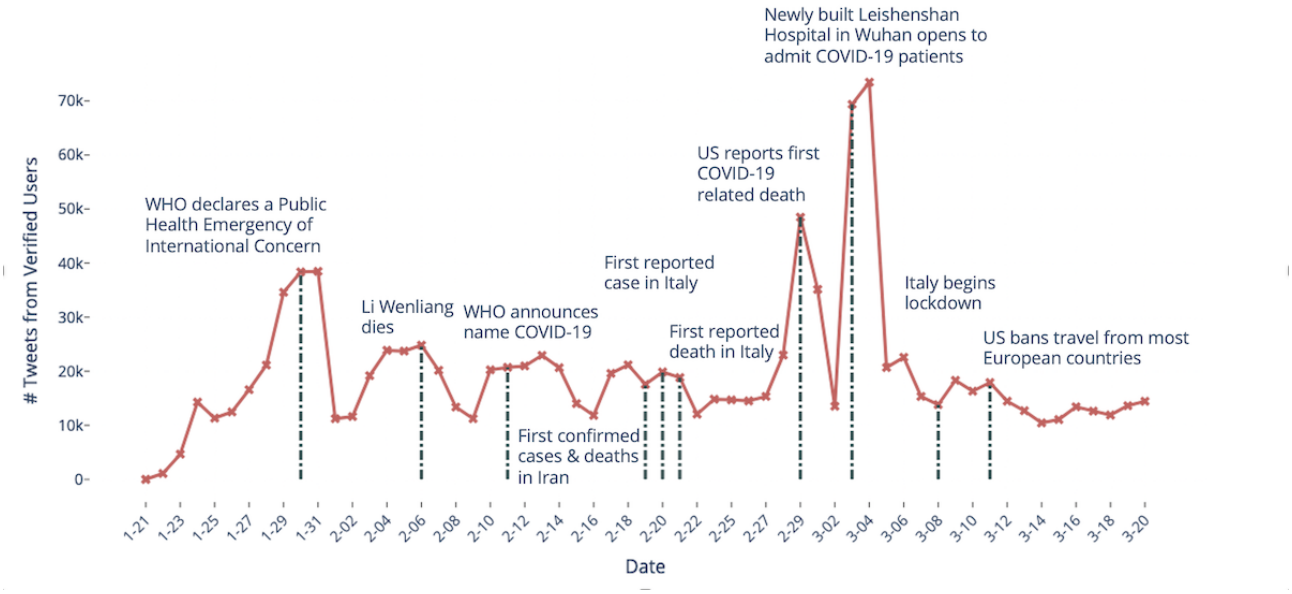
Figure 2. Tweets in Spanish, Italian, and Japanese over time (our multilingual database began data collection after January 28, 2020).



Verified Users

Verified users on Twitter have been identified by Twitter as accounts of public interest and are verified to be authentic accounts [36]. We observed that the verified accounts, which include news sources and political figures, are the most active when major events occur, as seen in Figure 3. This is to be expected since influential figures and news sources often weigh in and report on breaking news in real time using Twitter as a platform to amplify their messaging. As the United States also drives much of the discourse on Twitter, it is therefore unsurprising that there is a major spike in activity from verified users when the country experienced its first COVID-19-related death.

Figure 3. Number of tweets from verified users over time. COVID-19: coronavirus disease; WHO: World Health Organization.



Limitations

There are several limitations to our data set. We collect our data set leveraging Twitter's free streaming API, which only returns 1% of the total Twitter volume, and the volume of tweets we collected continues to be dependent on our filter endpoint and network connection [37].

While our data set is a multilingual data set, containing tweets in over 67 languages, the keywords and accounts we have been tracking and continue to track have been mostly English keywords and accounts. Thus, there is a significant bias in favor of English tweets in our data set over tweets in other languages.

Despite these limitations, our data collection gathers over 1 million tweets a day from the 1% of tweets available to us through Twitter's API, and our data set contains on average

35% non-English tweets. Our collection begins in late January, capturing tweets during many major developments, and we plan on continuing collecting tweets for the foreseeable future.

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Authors' Contributions

EC was responsible for data curation. All authors contributed to the writing of this manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
COVID-19: coronavirus disease
IRB: institutional review board
WHO: World Health Organization

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Original Paper

A Web- and App-Based Connected Care Solution for COVID-19 In- and Outpatient Care: Qualitative Study and Application Development

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Abstract

Background: From the perspective of health care professionals, coronavirus disease (COVID-19) brings many challenges as well as opportunities for digital health care. One challenge is that health care professionals are at high risk of infection themselves. Therefore, in-person visits need to be reduced to an absolute minimum. Connected care solutions, including telehealth, remote patient monitoring, and secure communications between clinicians and their patients, may rapidly become the first choice in such public health emergencies.

Objective: The aim of the COVID-19 Caregiver Cockpit (C19CC) was to implement a free-of-charge, web- and app-based tool for patient assessment to assist health care professionals working in the COVID-19 environment.

Methods: Physicians in Argentina, Germany, Iran, Italy, Portugal, Switzerland, and the United States explained their challenges with COVID-19 patient care through unstructured interviews. Based on the collected feedback, the first version of the C19CC was built. In the second round of interviews, the application was presented to physicians, and more feedback was obtained.

Results: Physicians identified a number of different scenarios where telemedicine or connected care solutions could rapidly improve patient care. These scenarios included outpatient care, discharge management, remote tracking of patients with chronic diseases, as well as incorporating infected physicians under quarantine into telehealth services.

Conclusions: The C19CC is the result of an agile and iterative development process that complements the work of physicians. It aims to improve the care and safety of people who are infected by COVID-19.

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KEYWORDS

COVID-19; eHealth; connected care; telecare; cloud solution; telehealth; public health; infectious disease; pandemic; outbreak

Introduction

Health systems around the world face an unprecedented new challenge with the rapid and unexpected spread of coronavirus disease (COVID-19), where limited physical interactions and self-isolation are needed to prevent and reduce infection rates. COVID-19 has become a primary concern for people worldwide. Without the establishment of isolation policies and practices of self-disinfecting and avoidance of interpersonal physical contact, potential infections would have reached 7 billion people, with

40 million deaths around the world [1]. With some exceptions, countries have adopted strict policies so that the expected number of deaths for 2020 will be much less than projected. However, living in these conditions brings forth different levels of discomfort and distress. Half of noninfected persons is feeling a moderate-to-severe psychological impact, and one-third have moderate-to-severe anxiety [2]. Electronic health (eHealth) technology can be a useful tool for supporting the everyday care of patients as well as healthy people. The emergence of COVID-19 in 2019 may, therefore, propel significant steps toward the largescale implementation of digital support in medicine, and experiences of population surveillance and disease monitoring at a population level can be seen.

From the perspective of health care professionals (HCPs), COVID-19 brings many challenges but also rapidly increases the need for digital health care. Because HCPs are also at risk of infection themselves, in-person visits need to be reduced to an absolute minimum. Connected care solutions, including telehealth, remote patient monitoring, and secure communications between clinicians and their patients, may thus rapidly become a significant tool during public health emergencies [3].

Many health centers experience an influx of anxious and infected people. A contact-free prescreening tool is needed to optimize patient control. In another perspective, care management of patients with chronic diseases who are under treatment or observation is also challenging. The risk of getting infected while visiting outpatient departments should be minimized as much as possible.

Another problem is observed in the quickly established departments for COVID-19 care. Under normal circumstances, vital data are usually sent automatically to a centralized monitor; in these units, however, vital data exchange is missing. Since inpatient resources are limited, both early discharge and assurance of patient safety with remote monitoring are needed. Patients can be discharged but need to remain connected via real-time, electronic communication to a remote medical team until full recovery. Another use-case would be physicians who are themselves under COVID-19 quarantine. They cannot do in-person visits, but they can support patients via an easily accessible connected care platform.

The idea of the COVID-19 Caregiver Cockpit (C19CC) was to build a free-of-charge, web- and app-based solution where all these different scenarios (ie, patient screening and visit preparation; remote monitoring; hospital ward cockpit) are supported within a single platform [4].

Methods

The COVID-19 Caregiver Cockpit

The C19CC is based on the existing CANKADO environment. The underlying architecture of the multilingual CANKADO is a cloud-based electronic health record (EHR) system with access rights management and function-based access options [5]. Feature packages can be enabled and disabled according to the patient's illness (eg, diabetes, cancer, etc) and HCP type (eg, oncologist, cardiologist, nurse, psychologist, etc). Information is stored and encoded, allowing physicians and patients to see the EHR in their preferred language.

The CANKADO solution has been developed and operates according to ISO 27001 and ISO 13485. Continuous penetration tests are performed according to the Open Web Application Security Project guidelines.

CANKADO is available through the web or as an app. Patients log in through the CANKADO website or the CANKADO Patient App [6,7] to access their data. HCPs can also use the web access or the HCP Pro App [8,9]. Other connected apps do exist but are not related to the COVID-19 module.

This Study

Unstructured interviews with physicians in different countries involved in COVID-19 patient care were conducted to identify all the scenarios where telemedicine or connected care solutions could improve patient care. During the first round, physicians in Argentina, Germany, Iran, Italy, Portugal, Switzerland, and the United States explained their challenges with COVID-19 patient care, followed by questions regarding opportunities to improve care using telemedicine or connected care. Based on the feedback collection during round one interviews, the first version of the C19CC was built. In the second round of interviews, the application was presented to the doctors, and their feedback was obtained.

Results

Physicians' Needs

During the first round of interviews, physicians disclosed the following primary needs: an overview of patients housed within provisionary COVID-19 wards, prescreening larger groups of outpatients, keeping close and continuous contact with patients with chronic diseases (mainly cancer patients), improving discharge management, and involving infected physicians in quarantine in patient care.

During the second round of interviews, the most crucial changes requested were to simplify the enrollment process, reduce HCPs' workload, and implement ways of contact-free interactions between physicians and patients (or separated by a window) with a smartphone app for ward doctors with immediate push notifications. After implementing these additional requests, the application underwent an additional round of review, of which the final results are described in the following sections.

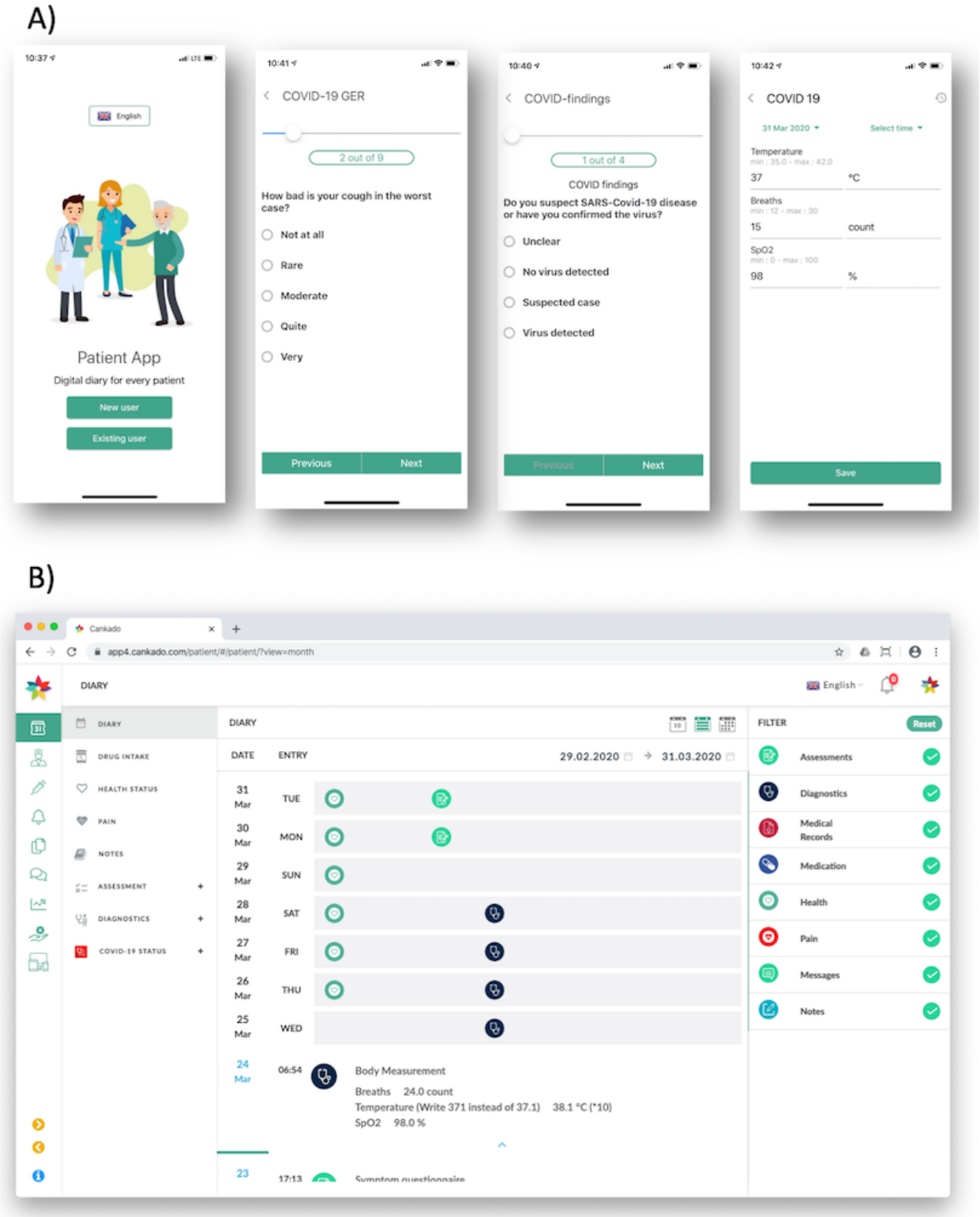
The Personal Diary

Patients who want to track personal observations that may be related to COVID-19 can use the system as a personal diary. To do so, they have to download the app and select the COVID-19 extension during the registration process.

Features are categorized into three groups. After the registration process is completed, patients will receive a questionnaire as a primary assessment to clarify general risk factors and relevant comorbidities. A second questionnaire asks for all cold symptoms according to the validated PRO-CTCAE (Patient Reported Outcomes–Common Terminology Criteria for Adverse Events) questions [10]. This questionnaire is triggered once

daily to ensure regular updates from the patient. A third questionnaire is for continuously tracking necessary vital parameters like body temperature and respiratory rate. For those who have a pulse oximeter, oxygen saturation can also be documented. Furthermore, other COVID-19 findings can also be reported via the system (Figure 1).

Figure 1. Screenshot examples from the patients' app for login and data entry (A) and web view of the patient diary (B).

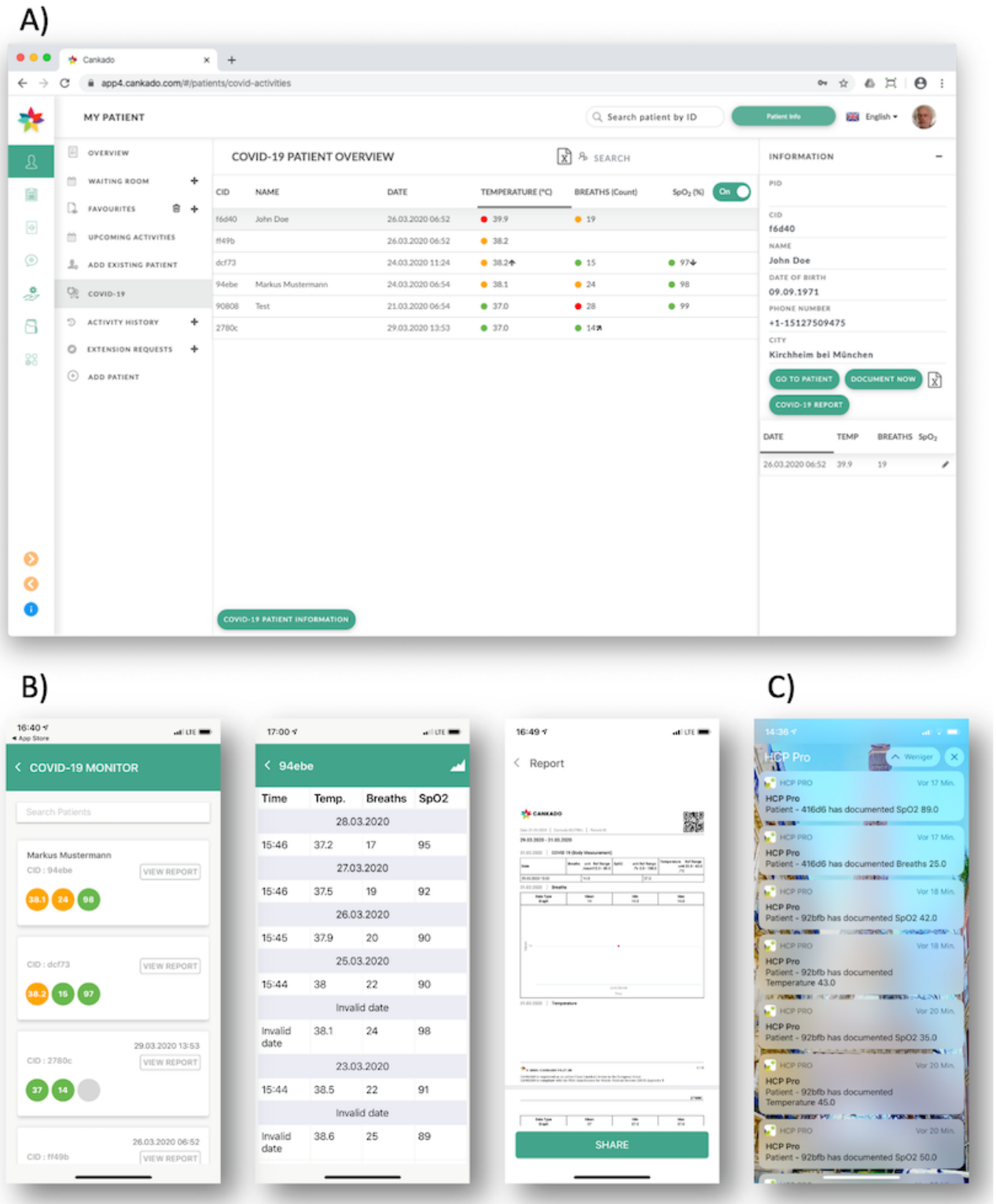


The Health Care Professional Cockpit

If patients and HCPs are connected, the HCPs can see all their COVID-19 patients in a separate cockpit. A fast and accessible overview of all patients is the main intention of the system. The central window provides the patient list with the latest vital parameters, color coded for severity, with arrows indicating changes compared to the day before. Two export features allow data transfer either from the patient list or from an individual patient history into a table format. The "COVID-19 Report" generates a single PDF file with the entire COVID-19-related

history of a patient, and the "COVID-19 Patient Information" button creates a printout for easy patient linkage (Figure 2).

Figure 2. The COVID-19 cockpit view for health care professionals (A); patient list, patient details, and a PDF report preview using the HCP Pro App (B); push notification alerts for health care professionals if a patient's condition deteriorates (C).



Contact-Free Linkage

The system provides several ways to link or connect patients and doctors without having physical contact. The connecting process can be initiated by both the patient and the doctor.

Patients have three options for connecting with their physicians. After launching the app, the patient can rotate the smartphone into landscape orientation. The screen automatically switches to an identifier page like a business card (Figure 3A). This identifier contains a QR (Quick Response) code for direct scanning and invitation code. The QR code can be scanned by the physician through the HCP Pro App. This scanning procedure can also be performed through a closed glass door. The invitation code is intended for transmission by telephone.

To do this, the doctor must select the function “Add Existing Patient” in the web portal. For those patients who prefer not to use the app, an invitation letter can be generated in the web portal by selecting the “Invite Physician” feature. This function creates a PDF document that is intended for use via fax, email, or regular mail.

To connect the other way around, physicians can generate a patient information page by selecting “COVID-19 Patient Information.” This printout contains instructions for patients as well as a center-specific extension code (Figure 3B). This extension code can be used for an unlimited number of patients. Patients who are using this code will receive the COVID-19 extension and are automatically connected to the health center that generated the printout.

Figure 3. Invitation code using the patient app for a contact-free meeting with their physician (A); patient instruction for self-linking to a center (B).

Scenario 1: Patient Screening and Visit Preparation

Once a patient is linked to a health center and has completed the assessments, all information can be printed at once using the "COVID-19 Report" feature in the cockpit view. Within a single click, a PDF is generated, which contains all COVID-19-related information, including a graphical view of vital parameters. To link patients with their HCP, all previously described methods can be used.

Scenario 2: Remote Monitoring

Remote monitoring is intended for several use-cases. For example, patients can continue to be observed after discharge, or physicians who are under quarantine can take care of their patients remotely. For this purpose, the C19CC provides real-time access to all documented data. In case data are asked and provided via phone, doctors have the chance to enter the data immediately; should errors occur on the patient's side, the data can be edited.

Scenario 3: Use in a Hospital Ward

The provisional COVID-19 wards cannot often monitor patient data centrally. In these situations, the C19CC, in combination with the HCP Pro App for physicians, can be used. If a patient documents worsening vital parameters, connected doctors immediately get a push notification via the app and can review the patient's history (Figure 2C). The web view also supports real-time monitoring.

Discussion

The C19CC is the connected care, solution-driven result of a joint international collaboration between physicians who are taking care of COVID-19 patients. It includes several scenarios in routine care.

The most critical use-cases are undoubtedly in the outpatient departments, which are overrun by patients. Here, the application helps to prescreen patients in a contact-free manner and to get a fast overview of those patients who most urgently need help. Improving workflows and reducing workload in provisional COVID-19 wards constitute another vital application to help relieve some of the overburdened human resources while ensuring patient safety at the same time.

As of February 20, 2020, 20% of all HCPs in Italy taking care of COVID-19 patients have become infected themselves [11]. Physicians who are infected or who had close contact with infected persons have to remain under quarantine. However, these medical resources often remain unused during the quarantine period. Enabling these doctors to take care of patients remotely helps to keep them integrated with the delivery of medical care in a time when resources are scarce.

One very vulnerable group is patients with chronic diseases. Cancer patients, in particular, are at increased risk for severe events compared to noncancer patients [12]. The same seems to apply to patients suffering from hypertension, diabetes mellitus, fatty liver/abnormal liver function, chronic gastritis/gastric ulcer, coronary heart disease, hyperlipidemia, cholelithiasis, arrhythmia, thyroid diseases, electrolyte imbalance, urolithiasis, stroke, chronic renal insufficiency, aorta sclerosis, secondary pulmonary tuberculosis, or chronic obstructive pulmonary disease [13]. These patients should only go to the outpatient clinic if it is unavoidable in order to minimize their risk of infection. The described system can now support their care by real-time, electronic communication between a patient and their physician, including telehealth, remote patient monitoring, and secure communication between clinicians and their patients.

In conclusion, the C19CC demonstrates how eHealth technology can quickly adapt to actual changing needs in the health care environment and implement a system that can aid HCPs in patient care and ensure patient safety at the same time. The C19CC is registered as an active medical device in the European Union and compliant with the FDA classification for Mobile Medical Devices (2015) Appendix B.

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Conflicts of Interest

TS is the owner and managing director of the CANKADO companies. MRG is the managing director of CANKADO Latin America.

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Abbreviations

C19CC: COVID-19 Caregiver Cockpit
COVID-19: coronavirus disease
eHealth: electronic health
EHR: electronic health record
HCP: health care professional
PRO-CTCAE: Patient Reported Outcomes–Common Terminology Criteria for Adverse Events
QR: Quick Response

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Original Paper

A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis

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Related Article:

This is a corrected version. See correction statement: http://publichealth.jmir.org/2020/3/e22853/

Abstract

Background: The severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) pandemic has been growing exponentially, affecting over 4 million people and causing enormous distress to economies and societies worldwide. A plethora of analyses based on viral sequences has already been published both in scientific journals and through non–peer-reviewed channels to investigate the genetic heterogeneity and spatiotemporal dissemination of SARS-CoV-2. However, a systematic investigation of phylogenetic information and sampling bias in the available data is lacking. Although the number of available genome sequences of SARS-CoV-2 is growing daily and the sequences show increasing phylogenetic information, country-specific data still present severe limitations and should be interpreted with caution.

Objective: The objective of this study was to determine the quality of the currently available SARS-CoV-2 full genome data in terms of sampling bias as well as phylogenetic and temporal signals to inform and guide the scientific community.

Methods: We used maximum likelihood–based methods to assess the presence of sufficient information for robust phylogenetic and phylogeographic studies in several SARS-CoV-2 sequence alignments assembled from GISAID (Global Initiative on Sharing All Influenza Data) data released between March and April 2020.

Results: Although the number of high-quality full genomes is growing daily, and sequence data released in April 2020 contain sufficient phylogenetic information to allow reliable inference of phylogenetic relationships, country-specific SARS-CoV-2 data sets still present severe limitations.

Conclusions: At the present time, studies assessing within-country spread or transmission clusters should be considered preliminary or hypothesis-generating at best. Hence, current reports should be interpreted with caution, and concerted efforts should continue to increase the number and quality of sequences required for robust tracing of the epidemic.

(JMIR Public Health Surveill 2020;6(2):e19170) doi:10.2196/19170

KEYWORDS

covid-19; sars-cov-2; phylogenetics; genome; evolution; genetics; pandemic; infectious disease; virus; sequence; transmission; tracing; tracking

Introduction

In December 2019, a novel coronavirus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), was identified in Wuhan, China, as the etiologic agent of coronavirus disease (COVID-19); as of May 2020, this virus had spread to more than 187 countries [1,2]. Common symptoms of infection include fever, cough, and shortness of breath, while severe cases are characterized by advanced respiratory distress and pneumonia, often resulting in death [3]. It is still unknown how many infected people who present mild or no symptoms can spread the virus; however, a recent study showed that in Wuhan, roughly 60% of all infections were spread by asymptomatic people [4]. This characteristic significantly thwarts the work of public health officials who are attempting to detect transmission clusters, such as the ones identified in China [5,6] and Singapore [7], through epidemiological contact tracing.

Soon after the first epidemiological and genetic sequence data of SARS-CoV-2 were made available, a glut of phylogeny-based analyses began to circulate, in scientific papers as well as on social media, discussing the origin and variants of the virus as well as the countries that may have fueled its spread [8-10]. The implications of misunderstanding the real dynamics of the COVID-19 pandemic are extremely dangerous. Ethnic or social discrimination resulting from unsupported assumptions on viral contagion—which are often amplified by irresponsible, uncontrollable communications—can be highly damaging for people and countries. Although social media platforms are often vehicles for "fake news" and hype, tremendous efforts are being made by the scientific community to provide free, up-to-date information on ongoing studies as well as critical evaluations. In particular, the US-based NextStrain [11] team has been posting real-time updates on the tracing of the epidemic by molecular analyses. Several discussions and evidence-based debates on controversial hypotheses on the epidemic have ensued (eg, the number of untraced infections in the US, the putative introduction of the virus to Italy through Germany [12], and the alleged lineage diversification in China [13], which was later criticized [14]). Another example is a recent study that identified three geographically separated variants of SARS-CoV-2 based on a phylogenetic network inferred from 160 full genomes available on March 3, 2020 [10]. This work was widely covered by the news media [15]; however, it was also highly criticized by experts in the field for its inaccurate use of phylogenetic methods, incorrect rooting of the phylogeny, and significant sampling bias [16-18]. An editorial published in *Science* [19] also highlighted how unsupported or misleading claims circulating in forums, social media, and even peer-reviewed articles have resulted from substantial overinterpretation of the available data. Hence, there is an urgent need to reframe the current debate in more rigorous scientific terms and quantitatively evaluate whether sufficient information for reliable phylogenetic and phylogeographic studies currently exists or whether gaps need to be addressed. Here, we present an in-depth longitudinal analysis of the phylogenetic information on SARS-CoV-2 genomes that became available between March and April 2020 to assess their reliability for molecular epidemiology studies.

Methods

Data

The GISAID (Global Initiative on Sharing All Influenza Data) database [20] was accessed on March 18, March 25, March 30, and April 24, 2020 (Table S1 in Multimedia Appendix 1 and Table S2 in Multimedia Appendix 2). Our main analyses compared the March 30 data set with the April 24 data set. After quality control of sequences that were not full genomes or contained extensive stretches of unknown nucleotides, separate sequence alignments were generated using MAFFT alignment software [21]. Each sequence alignment included all sequences collected on a given date: March 18, 794 genome sequences from 35 countries; March 25, 1662 genome sequences from 42 countries; March 30, 2608 genome sequences from 55 countries; and April 24, 8992 genome sequences from 63 countries.

Phylogenetic Signal and Maximum Likelihood Phylogeny Inference

Before carrying out any phylogeny-based analysis of virus evolution and spatiotemporal spread, it is crucial to test the quality of the sequence data, since uneven sampling, the presence of phylogenetic noise, and the absence of a temporal signal can affect the reliability of the results (eg, ancestral state reconstructions, molecular clock calibrations) [22]. SARS-CoV-2 full genome alignments generated from sequences in GISAID [23] at different time points were analyzed as follows. Transition/transversions vs genetic distance plots were generated using DAMBE6 [24]. The presence of phylogenetic signals satisfying resolved phylogenetic relationships among sequences was evaluated by likelihood mapping analysis [25] using IQ-TREE and allowing the software to search for all possible quartets using the best-fitting nucleotide substitution model [25]. Likelihood mapping analysis estimates the likelihood of each of possible tree topology for any group of four sequences (quartet), randomly chosen from an alignment, and reports them inside an equilateral triangle (the likelihood map) where the corners represent distinct tree topologies and the center represents star-like trees. Quartets are considered to be resolved when the three likelihoods are significantly different (ie, a phylogenetic signal and most dots equally distributed in the corners indicate that the data are suitable for robust phylogeny inference). Quartets are considered to be unresolved or partially resolved when two or all three of the likelihood values are not significantly different (ie, phylogenetic noise and most dots distributed in the side or center areas indicate that the data may not be sufficient for robust phylogeny inference). Extensive simulation studies have shown that for sequences to be considered robust in terms of the phylogenetic signal, the side/center areas of the likelihood mapping must include <40% of the unresolved quartets [26]. Maximum likelihood tree reconstruction was performed in IQ-TREE based on the best-fit model chosen according to the Bayesian information criterion [27,28]. Exploration of the temporal structure (ie, the presence of a molecular clock in the data) was assessed by regression of divergence (root-to-tip genetic distance) vs sampling time using TempEst [29]. In this case, the absence of a linear trend indicates that the data do not contain a temporal signal and that the data

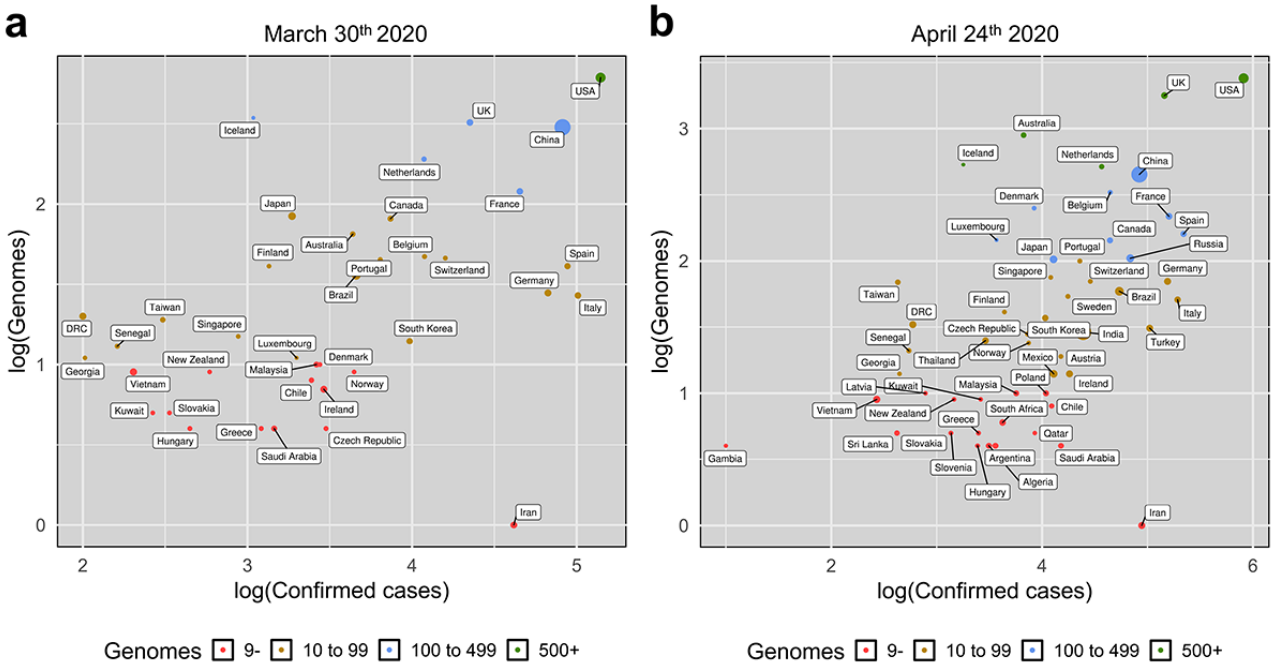
are not appropriate for phylogenetic inference using molecular clock models. The recently developed TransPhylo software package was employed to estimate how many intermediates in the putative transmission chain connected each pair of viral sequences from two infected individuals using a transmission matrix [30]. The TransPhylo R package was used to infer the transmission matrices of SARS-CoV-2 [30].

Results

Sampling and Phylogeographic Uncertainty

As of March 30, 2020, we compared the number of full genomes sampled per country with the number of confirmed cases at the time of sampling, as well as with the country's total population (Figure 1). We obtained 2608 full genomes from 55 countries. During the pandemic, the number of full genomes with high coverage has been steeply increasing. By considering countries with at least 25,000 confirmed cases or 3 or more genomes in our set, we found the Spearman (rank) correlations between confirmed cases (a proxy for sampling homogeneity) and genomes per country to be fairly weak: 0.47 on March 30 and 0.52 on April 24. However, correlation could only be investigated with confirmed cases, since not all affected countries have publicly reported the total number of coronavirus tests performed. As of March 30, within the same country, sequenced genomes were usually sampled from a few hotspots; thus, these data are not necessarily representative of the whole epidemic in that country. SARS-CoV-2 full genome sequences available from patients in the United States, the country with the highest number of confirmed cases, were mainly sampled in Washington State (66%) during the early epidemic, while less than one-third (32%) available from the epicenter of the US epidemic, the state of New York. Italy, the country with the second highest number of confirmed cases, uploaded 26 genomes, 1 of which came from the Marche region, 4 from Friuli Venezia Giulia, 7 from Abruzzo, 9 from Lazio, and only 5 from Lombardy, which is the epicenter of the Italian epidemic [31] (Table S1). As of March 30, 2020, the top 10 contributors per number of genomes were the United States (n=612), Iceland (n=343), UK (n=321), China (n=300), the Netherlands (n=190), France (n=119), Japan (n=83), Canada (n=80), Australia (n=64), Spain (n=40), and Belgium (n=46). Notably, some countries uploaded a high number of genomes despite having a relatively low number of cases (eg, Georgia, Iceland, Senegal, and the Democractic Republic of the Congo). As of April 24, 2020, the top 10 contributors per number of genomes were the United States (n=2413), the United Kingdom (n=1779), Australia (n=891), Iceland (n=533), the Netherlands (n=514), China (n=449), Belgium (n=329), Denmark (n=250), France (n=217), and Spain (n=159; Table S2 in Multimedia Appendix 2).

Figure 1. Snapshots of genomes and confirmed cases on March 30, 2020 (panel a) and April 24, 2020 (panel b). On a logarithmic scale, the x-axis reports the confirmed cases, while the y-axis reports the number of genomes +1. Each dot represents a country; the dot color indicates the number of genomes, and the dot size is proportional to the country population.



Phylogenetic Noise in Sequence Data

Lack of resolution and uncertainty in the SARS-CoV-2 phylogenetic tree is to be expected, considering that relatively little genetic diversity can be accumulated during the first 3 months of an epidemic, even for an exponentially spreading and rapidly evolving RNA virus. Overall, the phylogenetic signal of the current data has been increasing with the number of genomes released. The percentages of unresolved quartets detected in the SARS-CoV-2 full genome alignments on March 3 and March 10 were still too high to allow reliable inferences (Figure S1 in Multimedia Appendix 3). In other words, this lack of phylogenetic signal likely resulted in overall unreliable topologies of any SARS-CoV-2 trees obtained using these data, and even clades with high bootstrap values should be interpreted with extreme caution. A preliminary maximum likelihood tree,

inferred from the full genome viral sequences available on March 3, 2020, showed a well-supported cluster of European and Asian sequences (reported in Figure S2 in Multimedia Appendix 3), which contained a subclade (Subclade A, Figure 2a) including a sequence isolated in Germany that appeared to be paraphyletic (with strong bootstrap support) to an Italian sequence clustering in turn with sequences from Finland, Mexico, Germany, and Switzerland. Based on this observation (which is available on NextStrain), a heated discussion circulated on social media about a transmission event from Germany to Italy followed by further spread from Italy to other countries. However, in a new tree inferred just one week later, when more than 135 new full genome sequences were made available on GISAID [23], the direct link between Germany and Italy in Subclade A disappeared due to additional clustering of previously unsampled sequences from Portugal, Brazil, Wales, and the Netherlands (Figure 2b). In addition, the likelihood that alternative tree topologies generated arbitrarily switching branches in the tree (arrows in Figure 2b), implying different dissemination scenarios, was not significantly different (Shimodaira-Hasegawa test, Table 1) than the likelihood of the tree inferred from the real data. In other words, it is not possible with the present data to decide which branching pattern (and, therefore, which phylogeographic reconstruction) most likely represents actual dissemination routes among European countries.

As the number of available genome sequences is rapidly growing, SARS-CoV-2 full genome data sets are steadily showing less than 40% unresolved quartets in the center: 38.6% on March 18 (Figure S1c in Multimedia Appendix 3), 32.3% on March 25 (Figure S1d in Multimedia Appendix 3), 28.9% on March 30th (Figure S1e in Multimedia Appendix 3), and 27.6% on April 24 (Figure S1f in Multimedia Appendix 3). This indicates that the amount of phylogenetic information can now potentially be used to define phylogenetic relationships among strains. By plotting the mean genetic distance of each sequence from the root of a phylogeny versus the sequence sampling time, we can test for a significant linear correlation, which is necessary to calibrate a reliable molecular clock [29] (Figure S3 in Multimedia Appendix 3). As expected in genomes obtained over a very short period of time (approximately 3 months) since the beginning of the outbreak, the correlation in the current data is fairly weak (Table 1). Reconstructing the phylogenetic relationships of the same European sub-clade A discussed above with the sequences available on March 18, 2020 showed a much more complex snapshot of the spread of SARS-CoV-2 (Figure S4 in Multimedia Appendix 3). A closer look at subclade A reveals that even with more genomes available, inference is biased by oversampling of some countries and undersampling of others (Figure S4 in Multimedia Appendix 3). Moreover, when estimating the number of intermediates in the putative transmission chain, we found that numerous links among samples were still missing (Figure S5 in Multimedia Appendix 3). In such a scenario, it is not advisable to extrapolate conclusions on the origin and dissemination of strains.

The phylogenetic signal is increasing in the global alignment; however, likelihood mapping per country using data from countries reporting the highest numbers of cases (United States, Italy, Spain, Germany, and France) indicates that some local data sets lacked sufficient signals up to March 30, 2020 (Figure S6 in Multimedia Appendix 3). In particular, a lack of signal was found in sequence sets from Italy (26 genomes, 45 variant sites, 0.2% of total sites in the genome, 11 parsimony informative), the United States (612 genomes, 675 variant sites, 2.3% of total sites in the genome, 158 parsimony informative) and China (300 genomes, 742 variant sites, 2.5% of total sites in the genome, 98 parsimony informative). The top 5 contributing states in the United States are Washington (405/612, 66.2%), California (45/612, 7.4%), Minnesota (33/612, 5.4%), Wisconsin (29/612, 4.7%), and Utah (22/612, 3.6%); 42 genomes (6.9%) are not labeled with a state or city. The United States data set comprised mostly sequences collected in Washington State (423/612 genomes, 69.1%). The top 5 contributing provinces in China are Shanghai (96/300, 32.0%), Guangdong (80/300, 26.7%), Hong Kong (30/300, 10.0%), Hubei (31/300, 10.3%), Hangzhou (9/300, 3.0%), and Shandong (9/300, 3.0%); 20 genomes (6.7%) are not labeled with a province or city. Neither China nor the United States showed a phylogenetic signal despite the high number of genome sequences available (Figure S6 in Multimedia Appendix 3). Contrastingly, and unexpectedly, countries with low numbers of genome sequences (Germany, Spain, and France) did show a phylogenetic signal (Figure S6 in Multimedia Appendix 3). The presence of a phylogenetic signal (<40% unresolved quartets in the center) was detected only for Germany (27 genomes, 34 variant sites, 0.2% of total sites in the genome, 15 parsimony informative), with Düsseldorf and North Rhine Westphalia being the highest contributing regions (12 and 11 genomes, respectively); Spain (40 genomes, 60 variant sites, 0.2% of total sites in the genome, 23 parsimony informative), with Madrid and Comunidad Valenciana being the highest contributing regions (18 and 10 genomes, respectively); and France (119 genomes, 155 variant sites, 0.5% of total sites in the genome, 44 parsimony informative), with Auvergne-Rhône-Alpes, Hauts de France, and Bretagne being the highest contributing regions (42, 30, and 13 genomes, respectively). Despite the presence of a phylogenetic signal in these countries, only the genomes from France also showed a temporal signal that would allow the calibration of a molecular clock and reframing of the phylogenetic and phylogeographic inferences in the spatiotemporal dimension (Figure S7 in Multimedia Appendix 3). On the other hand, the transmission matrix for France indicates that considerable links are still missing due to unsampled infected individuals, limiting the reliability of transmission cluster studies based on the sequence data (Figure S8 in Multimedia Appendix 3). When we looked almost a month later at the phylogenetic signals for the countries that reported the highest numbers of confirmed cases as of April 24, 2020, we found that these countries showed sufficient phylogenetic signals (Figure S9 in Multimedia Appendix 3). However, while France and Germany also displayed sufficient temporal signals to allow in-depth molecular epidemiology studies, at least in principle, data sets from the United States (3.9-fold increase on April 24 with respect to March 30), the United Kingdom (5.5-fold increase), and Spain (3.9-fold increase), still showed weak or no temporal signals (Figure S10

in Multimedia Appendix 3) despite the substantial increases in the number of available sequences.

Figure 2. Cladograms of SARS-CoV-2 subclades. Cladograms were extracted from maximum likelihood phylogenies rooted by enforcing a molecular clock. The colored branches represent the country of origin of the sampled sequences (tip branches) and the ancestral lineages (internal branches). The numbers at the nodes indicate ultrafast bootstrap support (only >90% values are shown). (a) Cladogram of a monophyletic clade within the SARS-CoV-2 maximum likelihood tree inferred from sequences available on March 3, 2020 (Figure S1 in Multimedia Appendix 3). The subclade including sequences from Italy and Germany, named Subclade A, is highlighted. (b) Cladogram of sub-clade A of the SARS-CoV-2 maximum likelihood tree including additional sequences that became available on March 10, 2020 (Figure S2 in Multimedia Appendix 3). Each bidirectional arrow and corresponding number connects two tip branches that were switched to generate an alternative tree topology to be tested (Table 1).

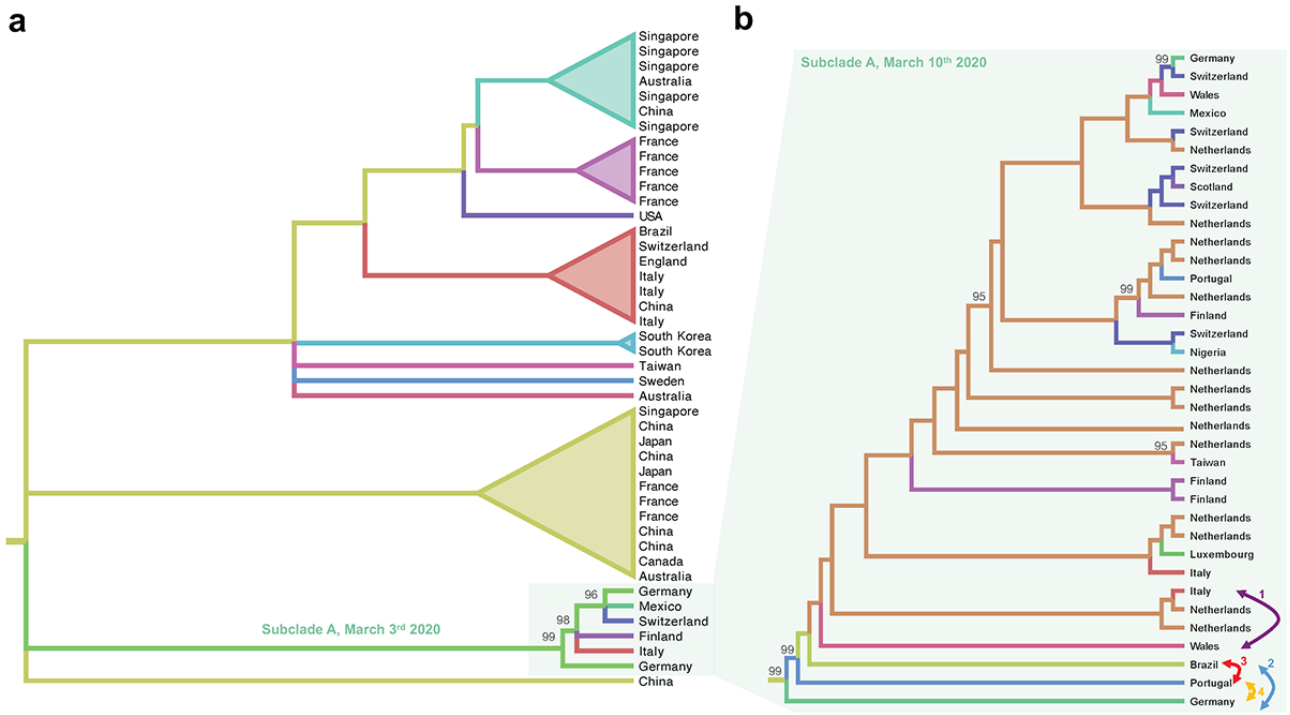


Table 1. Testing of alternative topologies.

Alternative topology[a]	Switched branches	LogL[b]	ΔL[c]	*P* value[d]
1	Italy with Wales	–45443.2	0.0000	.24
2	Germany with Brazil	–45451.5	8.3554	.16
3	Portugal with Brazil	–45443.2	0.0002	.75
4	Germany with Portugal	–45451.5	8.3197	.16

[a]Alternative topologies were obtained by switching branches in the maximum likelihood tree inferred from SARS-CoV-2 full genome sequences. 1) Italy (EPI_ISL_412973) switched with Wales (EPI_ISL_413555); 2) Germany (EPI_ISL_406862) with Brazil (EPI_ISL_412964); 3) Portugal (EPI_ISL_413648) with Brazil (EPI_ISL_412964); 4) Germany (EPI_ISL_406862) with Portugal (EPI_ISL_413648).

[b]LogL: log likelihood estimated for each alternative topology.

[c]ΔL: difference between LogL and the log likelihood of the original tree.

[d]Calculated with the Shimodaira-Hasegawa test [32].

Discussion

Characterization of transmission events is fundamental to understand the dynamics of any infectious disease. From a public health standpoint, it is crucial to be able to trace transmissions at the local level. Within-country identification of active transmission clusters would open the way to more effective public health interventions. The most optimal inference of transmission events would contain a combination of genetic and epidemiological data for a joint analysis. Indeed, transmission investigations that have been performed to date have been based on contact-tracing, epidemiological, and clinical data [33,34]. Bayesian analysis [35], which infers phylogenetic and phylogeographic patterns from a posterior distribution of trees, can facilitate comparisons of different evolutionary scenarios, aid retrieval of the correct topology, and estimate an accurate evolutionary rate using relaxed clock methods [36]. More genome sequences, sampled at different time points and from diverse geographic areas, are becoming available daily; therefore, in-depth Bayesian phylodynamic and phylogeographic analyses of the COVID-19 pandemic will soon be a viable option. However, it is important to consider the dramatic effects of inhomogeneous sampling, lack of phylogenetic signal, and missing data on phylogeographic reconstructions [37].

Published scientific data and media are currently easily accessible to a worldwide audience; proper weighing of the information being shared is more important than ever. In the first months of the epidemic, many researchers rushed to study local dynamics and to publish their findings without assessing the bias in sampling or the presence of a phylogenetic or temporal signal. As shown by our analysis, as of March 2020, the United States and Italy, the two countries with the highest numbers of confirmed cases, did not show sufficiently large or representative sampling. This finding is extremely worrisome and raises questions regarding the generalizability of the results of studies investigating the origin of the introduction of SARS-CoV-2 in Italy [8,12] or of the circulation of SARS-CoV-2 in the state of Washington in early March 2020 [9]. Rushed studies [10,13] that are acclaimed by news media despite being criticized in the literature [16-18] and on social media [14] may do more harm than good. To recapitulate the importance of examining phylogenetic information in available data before performing phylogenetic inferences that may lead to erroneous or unreliable conclusions, we propose the use of a well-established phylogenetic checkpoint pipeline (Figure S11 in Multimedia Appendix 3) [22]. The first step that researchers must take before they complete their phylogenetic studies is determining whether the data set is biased in terms of the number of genomes per given location, host, source, etc. In the specific case of SARS-CoV-2, it would be advisable to calculate the correlations between the confirmed cases and genomes per country. If this first step is completed, the second step is to build a proper codon-based alignment while ensuring that the alignment is in frame; this is extremely important when researchers study selective pressures. The third step consists of assessing the presence of a sufficient phylogenetic signal and the absence of nucleotide substitution saturation, which decreases the phylogenetic information contained in the sequences [38]. The analysis can proceed to the fourth step, determining the presence or absence of recombination, only if the previous criteria are met. Recombination can impair the phylogenetic signal [39,40] and this is another important checkpoint before inferring a phylogeny. In this study, we did not test for recombination for the SARS-CoV-2 data set, as absence of recombination in the human lineage has previously been shown [41]; however, because coronaviruses are prone to recombination events, this step should be performed as more sequences become available. Detecting the presence of a temporal signal is an additional step that must be performed before the inference of a phylogeny scaled in time. Without a correlation between genetic divergence and time, it is not possible to calibrate a molecular clock and therefore to obtain a phylogeny scaled in time, regardless of whether the method employed to date the phylogeny is Bayesian [35], maximum likelihood [42], or least-squares dating [43]. Only when all these checkpoints have been considered and given proper weight should subsequent analyses be considered by choosing adequate phylogeny inference methods.

The genomic data set available on GISAID is rapidly growing; thus, a limitation of our study is that we can only provide a snapshot of the past, and this may not reflect the most current situation. We have already shown an increase in phylogenetic and temporal signals that may allow researchers to attempt to estimate the origin and spatiotemporal dissemination of SARS-CoV-2 as long as sampling bias is properly taken into account. However, it is important to reiterate that during the month of March 2020, we deem that the molecular epidemiology data and studies were not sufficiently solid to provide a scientifically sound analysis of SARS-CoV-2 spread. Thus, we suggest that any conclusions drawn about existing lineages and the direction of viral spread that were based on the sequence data available up to March 30, 2020 should be considered preliminary and hypothesis-generating at best. The evolutionary dynamics of SARS-CoV-2 spread is revealing an unprecedented amount of information, which is essential to make policy decisions. The whole of humanity is threatened by the current pandemic, and policymakers must adjust their mitigation measures while the pandemic itself is developing. Some of the urgent answers required lie in the timely availability of abundant, high-quality genetic data not only from countries experiencing a high number of reported cases but also from countries that appear to be experiencing, at least currently, a lower number of infections.

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Authors' Contributions

CM and MS contributed equally as corresponding authors; CM and SM contributed equally as first authors.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Table S1. GISAID IDs of genome sequences downloaded from GISAID on March 30, 2020.
[XLS File (Microsoft Excel File), 164 KB - publichealth_v6i2e19170_app1.xls]

Multimedia Appendix 2
Table S2. GISAID IDs of genome sequences downloaded from GISAID on April 24, 2020.
[XLS File (Microsoft Excel File), 489 KB - publichealth_v6i2e19170_app2.xls]

Multimedia Appendix 3
Supplementary Figures.
[DOC File , 3442 KB - publichealth_v6i2e19170_app3.doc]

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Original Paper

Primary Health Care Facility Preparedness for Outpatient Service Provision During the COVID-19 Pandemic in India: Cross-Sectional Study

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Abstract

Background: Primary health centers (PHCs) represent the first tier of the Indian health care system, providing a range of essential outpatient services to people living in the rural, suburban, and hard-to-reach areas. Diversion of health care resources for containing the coronavirus disease (COVID-19) pandemic has significantly undermined the accessibility and availability of essential health services. Under these circumstances, the preparedness of PHCs in providing safe patient-centered care and meeting the current health needs of the population while preventing further transmission of the severe acute respiratory syndrome coronavirus 2 infection is crucial.

Objective: The aim of this study was to determine the primary health care facility preparedness toward the provision of safe outpatient services during the COVID-19 pandemic in India.

Methods: We conducted a cross-sectional study among supervisors and managers of primary health care facilities attached to medical colleges and institutions in India. A list of 60 faculties involved in the management and supervision of PHCs affiliated with the community medicine departments of medical colleges and institutes across India was compiled from an accessible private organization member database. We collected the data through a rapid survey from April 24 to 30, 2020, using a Google Forms online digital questionnaire that evaluated preparedness parameters based on self-assessment by the participants. The preparedness domains assessed were infrastructure availability, health worker safety, and patient care.

Results: A total of 51 faculties responded to the survey. Each medical college and institution had on average a total of 2.94 (SD 1.7) PHCs under its jurisdiction. Infrastructural and infection control deficits at the PHC were reported in terms of limited physical space and queuing capacity, lack of separate entry and exit gates (n=25, 49%), inadequate ventilation (n=29, 57%), and negligible airborne infection control measures (n=38, 75.5%). N95 masks were available at 26 (50.9%) sites. Infection prevention and control measures were also suboptimal with inadequate facilities for handwashing and hand hygiene reported in 23.5% (n=12) and 27.4% (n=14) of sites, respectively. The operation of outpatient services, particularly related to maternal and child health, was significantly disrupted (P<.001) during the COVID-19 pandemic.

Conclusions: Existing PHC facilities in India providing outpatient services are constrained in their functioning during the COVID-19 pandemic due to weak infrastructure contributing to suboptimal patient safety and infection control measures. Furthermore, there is a need for effective planning, communication, and coordination between the centralized health policy makers and health managers working at primary health care facilities to ensure overall preparedness during public health emergencies.

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KEYWORDS

primary health care; COVID-19; pandemic; health systems; India

Introduction

The coronavirus disease (COVID-19), which is caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), has resulted in an unprecedented global health crisis [1]. The COVID-19 pandemic in India has already recorded more than 118,446 cases and 3583 deaths (as of May 23, 2020), with cases reported in every state of the country [2].

Healthy systems in lower and lower-middle income countries are experiencing major challenges in coping with the COVID-19 pandemic due to the high pre-existing vulnerability from the limited public health infrastructure combined with the diversion of essential medical resources for the provision of dedicated care and management to presumptive COVID-19 cases [3-5]. In India, the second-most populous country in the world, several secondary and tertiary care hospitals that cater to millions of daily outpatients have been converted into temporary dedicated COVID-19 hospitals to provide care to the patients with moderate and severe COVID-19 as per the designated clinical criteria [6,7]. Consequently, the health care needs of patients with chronic diseases and maternal and child health requires alternative primary care service delivery. The World Health Organization (WHO) has also warned of the increased likelihood of resurgence in outbreaks of vaccine-preventable diseases due to the subversion of routine immunization services during the COVID-19 pandemic [8]. In addition, pandemic preparedness at primary care facilities that enable the early management of novel infectious diseases in communities with the reduction in their potential morbidity and mortality is well-established [9,10]. In India, a network of over 25,000 primary health centers (PHCs), the first and lowest health tier, provide essential preventive, promotive, and curative health services such as maternal and child health, essential drugs, and health education in the rural, suburban, and underserved hard-to-reach areas [11]. Furthermore, all medical colleges and institutions in India, as per the mandate of the reorientation of medical education scheme, are linked to primary health facilities in rural and urban areas through the community medicine department [12]. Hence, the preparedness of PHCs in providing safe patient-centered care for meeting the current health needs of the population and preventing further transmission of the SARS-CoV-2 infection is crucial.

The study objective was to determine the primary health care facility preparedness toward the provision of safe outpatient services during the COVID-19 pandemic in India

Methods

Design and Settings

We conducted a cross-sectional study among supervisors and managers of primary health care facilities attached to medical colleges and institutions anywhere in India, either in the government or private setting. We collected the data for 7 days from April 24 to 30, 2020, through means of a web-based survey for self-assessment by PHC managers and supervisors. The preparedness domains assessed were infrastructure availability, health worker safety, and patient care [13].

Procedure

We collected data through a rapid survey using a pretested Google Forms online digital questionnaire (Multimedia Appendix 1). A nonrandom convenient sampling method was used to select the study participants. A list of 60 faculty involved in the management and supervision of PHCs affiliated to the community medicine departments of medical colleges and institutes across India was compiled from an accessible private organization member database. These members were sent an invitation to participate in the study through email and instant messages containing the Google Form survey link. Since the sampling unit was a medical college or institution, we selected only one potential respondent from each site to prevent duplication.

Operational Definitions

Operations (functionality) of any specific health service through outpatient clinics conducted at the PHCs was assessed in terms of continuity of service provision to patients and beneficiaries at the time of the survey. Pre-COVID-2019 refers to the period of service delivery at the PHCs until February 2020. Post-COVID-2019 refers to the period of PHC service delivery at the time of the survey. Adequate ventilation refers to the availability of cross-ventilation with separate doors and windows at the site of service provision to the patients. Adequate handwashing facilities refers to the availability of running water and soap for patients. Adequate hand hygiene facilities refers to the availability of alcohol-based hand sanitizer for health staff.

Statistical Analysis

The Google Form data was exported into Microsoft Excel 2013 (Microsoft Corporation) software and cleaned and analyzed using SPSS version 25 (IBM Corp). Results were expressed in frequency, proportions, and 95% confidence intervals for categorical variables, and mean for continuous variables. The significance of the difference between proportions was assessed using the chi-square test. A $P<.05$ was considered statistically significant.

Ethical Considerations

The study was approved and exempted from full review by the Institutional Ethics Committee (F.1/IEC/MAMC/(73/01/2020/No68). The consent of the participants was implied as participation in the study was voluntary.

Results

A total of 51 faculty from various medical institutions and colleges across India responded to the survey for a net response rate of 85% (n=51/60). The participants were from Northern India (n=31, 60.7%), Southern India (n=6, 11.7%), Western India (n=7, 13.7%), and Eastern and Northeastern India (n=7, 13.7%).

Infrastructure preparedness of the primary health facilities was assessed in terms of the total number of rooms that were available for service provision. Each medical college or institution had on average a total of 2.94 (SD 1.7) PHCs under its jurisdiction. The median number of both urban and rural

PHCs attached to each of the medical colleges and institutions was 1. The average number of rooms in the largest and the smallest PHC for patient-care purposes was 3.37 and 1.77, respectively. Furthermore, each PHC was equipped on average with 2.71 rooms for the provision of various health care services.

Patient care and service provision preparedness were evaluated by comparing the outpatient department (OPD) clinic functionality and the number of patients and beneficiary services. Before the onset of the COVID-19 epidemic in India, the participant colleges and institutions were providing on average antenatal care (ANC) and immunization services at their sites to 26.5 and 41.4 clients, respectively. However, outpatient services were significantly disrupted during the COVID-19 epidemic. Among the OPD clinics at the PHC sites, the maximum reduction in clinic operations was reported for the noncommunicable diseases (NCD) and the immunization clinics; ANC services were less disrupted. In contrast, the general OPDs were least disrupted (Table 1). Furthermore, fever (flu) clinics had been started at 72.4% (n=37) of the sites to screen patients reporting with symptoms of influenza-like illnesses (fever, dry cough, or respiratory difficulties) for suspected COVID-19 and initiate appropriate referral services when necessary. On average, 30 patients attended these fever clinics each day in the sites where such dedicated clinics were available.

Table 1. Comparison of outpatient services (N=51) functionality during the COVID-19 epidemic in India during the study period (April 24-30, 2020).

OPD[a] facility	Pre-COVID-19[b]		Post-COVID-19		*P* value
	n (%)	95% CI	n (%)	95% CI	
ANC[c]	48 (94.1)	83.8-98.8	33 (67.3)	50.1-77.6	<.001
Immunization	48 (94.1)	83.8-98.8	26 (53.1)	36.6-65.2	<.001
Animal bite	23 (45.1)	31.1-59.7	14 (27.4)	15.9-41.7	.06
NCD[d]	47 (92.1)	81.1-97.8	21 (41.1)	27.6-55.8	<.001
General	51 (100.0)	0.93-100	42 (82.3)	36.5-46.0	.002

[a]OPD: outpatient department.

[b]COVID-19: coronavirus disease.

[c]ANC: antenatal care.

[d]NCD: noncommunicable diseases.

Safety and infection control in the PHCs was assessed in terms of space for patient queuing, availability of cross ventilation through separate doors and windows, type of entries and exits, and the existing protocol for conducting disinfection measures. Each site, on average, reported a patient queuing capacity of 14.1 persons subject to maintaining minimum physical distancing requirements to reduce the chances of SARS-CoV-2 transmission. Moreover, nearly half (n=25, 49%) of the sites were missing separate or multiple entries and exits (n=27, 52.9%). A majority (n=29, 57%) of the participants reported inadequate ventilation at their PHC sites. Airborne infection control measures were reported as absent in 75.5% (n=38) of sites. Nevertheless, chemical disinfection of the PHCs was being undertaken at most (n=42, 82.4%) sites with daily, alternate day, and less frequent disinfection reportedly conducted in 52.9% (n=27), 13.7% (n=7), and 19.6% (n=10) of the sites, respectively. However, adequate handwashing services for patients were unavailable at 12 (23.5%) sites.

A majority of respondents (n=34, 66.7%) supervising their respective PHC sites lacked adequate confidence in achieving effective segregation of patients with presumptive COVID-19 from other routine beneficiaries for preventing nosocomial transmission of the SARS-CoV-2 infection at their sites. For this reason, a majority (n=30, 58.8%) of the participants were disinclined toward operating dedicated fever clinics simultaneously with any special OPD clinics.

The safety of health workers was evaluated in terms of the provision of personal protective equipment (PPE) to the health staff and access to hand hygiene facilities. PPE suits were available at 14 (27.4%) sites, N95 masks at 26 (50.9%) sites, and only surgical masks were available at 19 (39.3%) sites. Hand hygiene facilities for PHCs were considered inadequate at 14 (27.4%) sites. Training related to the safe and effective management of patients with presumptive COVID-19 had been previously provided at 40 (78.4%) of the sites to their health staff.

Discussion

Principal Findings

The maintenance of essential care health services on an outpatient basis during the aftermath of the COVID-19 pandemic is a major public health challenge. Our study findings indicate that the provision of essential outpatient health care service were disrupted in a significant proportion of PHCs across India with the onset of the COVID-19 pandemic and the rapid escalation of cases. Furthermore, suboptimal infrastructural capacity at most PHCs, poor ventilation, negligible airborne infection control measures, and constraints in achieving minimum physical distancing requirements among patients needed to reduce the risk of COVID-19 transmission [14] possibly precluded the expansion of screening and referral of presumptive COVID-19 cases at these sites.

The public health measures undertaken for containing the COVID-19 epidemic in India significantly contributed to the decline in the provision of essential services at the PHCs. First,

India enforced a strict nationwide lockdown from March 23, 2020, onwards (which is continuing at the time of writing), including ceasing all public transport, resulting in diminished health care accessibility [15]. Second, there was a diversion of health care staff, especially doctors and nurses, for COVID-19–related duties. Moreover, even frontline community health workers, including the accredited social health activists, were engaged in the surveillance and contact tracing activities related to COVID-19 [16]. This resulted in the absence of community mobilization of women and caregivers for continuing with immunization and regular ANC services at the PHCs. Third, the feasibility of separating waiting areas for immunization services from curative services and adherence to physical distancing at the health facilities as recommended by the WHO [17] was not possible at several sites due to infrastructural limitations. Fourth, parents of immunization eligible children and antenatal women possibly refrained from visiting primary health facilities due to increased risk perception of contracting the coronavirus infection from other patients.

Primary care providers are known to be at increased risk of getting infected with new infectious diseases, especially when handling patients with acute respiratory illnesses during epidemics [18,19]. The inadequate availability of PPE for health care providers during the COVID-19 pandemic has also been observed worldwide [20]. Under these circumstances, the allocation of PPE has been subject to expert criteria that recommend limiting the provision of N95 masks to only those health care providers who are directly involved in the management of confirmed COVID-19 cases [21]. Consequently, primary care providers in resource-constrained settings, working in enclosed small clinic spaces that lack adequate ventilation and are likely overcrowded, are rendered highly vulnerable to COVID-19 in the absence of effective PPE provision. In our analysis, we found that only 1 in 2 medical colleges and institutions were able to provide N95 masks to the health care providers at their primary health care facilities. However, the adequacy of the supply of N95 masks was not assessed in this study.

According to the report of the National Health Policy (2017), only 1 in 5 Indians in rural India use outpatient services at public (government) health facilities due to perceived deficiencies in standards of care arising from dilapidated infrastructure and nonavailability of essential services and drugs [22]. Considering the deficiencies in physical infrastructure at PHC sites combined with the ubiquitous availability of cheap mobile telecommunication services, the potential role of telemedicine services to maintain continuity of care should be considered in such settings [23].

Finally, the functionality of fever or flu clinics is considered a crucial primary care role in the preliminary assessment, counseling and reassurance, and referral of patients reporting with influenza-like illness during pandemics similar to COVID-19. However, in India, government guidelines have stipulated the functioning of fever clinics at primary care facilities subject to the availability of adequate space [7]. Nevertheless, in this study, we found nearly 3 in 4 institutions were operating fever clinics at their PHC facilities despite the obvious infrastructural limitations.

Study Limitations

First, due to the convenient sample, representativeness was limited as a majority of sites were restricted to Northern India. Second, the survey was based on self-assessment, which can be subject to bias. Third, we conducted a cross-sectional survey and did not assess prospective change in the OPD clinic operations and service provisions during the COVID-19 epidemic in India. Fourth, we did not consider factors related to facility preparedness like health education and the monitoring and surveillance of health events due to the absence of objective evaluation through an external observer. Fifth, reasons for nonfunctionality of the OPD clinics, which were either due to logistical constraints or because of nonreporting by patients and beneficiaries were not ascertained in this survey.

Conclusion

Existing PHC facilities in India providing outpatient care during the COVID-19 epidemic are constrained in their functioning by weak infrastructure contributing to suboptimal patient safety and infection control measures. Most PHCs reduced essential OPD services and instead were running dedicated clinics for screening and referral of patients with suspected COVID-19 reporting with symptoms of influenza-like illnesses. However, health care managers must address the risks of nosocomial infection in these settings when operationalizing simultaneous COVID-19 screening and special OPD clinics for NCDs, ANC, and care for children younger than 5 years that cater to populations highly susceptible to COVID-19 [24].

Recommendations

The COVID-19 pandemic is still ensuing, and there are projected second waves and considerable time until development of any effective vaccine, generation of herd immunity, and ultimate pandemic resolution [25]. Findings from this study emphasize the need for effective planning, communication, and coordination between the centralized health policy makers and health managers working at primary care settings to ensure overall preparedness. For instance, the government of India, after 3 weeks of lockdown (April 14, 2020), issued a general guideline to the states to make best efforts toward continuing with essential health services at peripheral health facilities as per their feasibility [26]. Subsequently, on May 20, 2020, the government of India issued a comprehensive guidance note that re-emphasized the need for continuing both facility and outreach immunization services except in the containment zones (areas having a relatively higher number of COVID-19 cases and shorter time to doubling of cases) [27,28]. These lessons are suggestive of the need for maintaining effective channels of health communication between various stakeholders for ensuring continuity of essential services during any future waves of the COVID-19 pandemic.

In the medium- and long-term, governments both at the state and center should considerably invest in infrastructure, capacity building, and the strengthening of primary health care services to ensure their effective functioning during public health emergencies [29]. Under the Ayushman Bharat National Health Protection, the government of India has envisaged the upgrading and developing of 150,000 primary care facilities throughout

India [30]. Nevertheless, to strengthen PHC in India and significantly augment their capacities and roles during pandemics, an emphatic focus on infrastructure development, especially in terms of spacing, ventilation, and infection control, warrants high prioritization.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questionnaire.
[PDF File (Adobe PDF File), 192 KB - publichealth_v6i2e19927_app1.pdf]

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Abbreviations

ANC: antenatal care
COVID-19: coronavirus disease
PHC: primary health center
NCD: noncommunicable diseases
OPD: outpatient department
PPE: personal protective equipment
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Machine Learning to Detect Self-Reporting of Symptoms, Testing Access, and Recovery Associated With COVID-19 on Twitter: Retrospective Big Data Infoveillance Study

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Abstract

Background: The coronavirus disease (COVID-19) pandemic is a global health emergency with over 6 million cases worldwide as of the beginning of June 2020. The pandemic is historic in scope and precedent given its emergence in an increasingly digital era. Importantly, there have been concerns about the accuracy of COVID-19 case counts due to issues such as lack of access to testing and difficulty in measuring recoveries.

Objective: The aims of this study were to detect and characterize user-generated conversations that could be associated with COVID-19-related symptoms, experiences with access to testing, and mentions of disease recovery using an unsupervised machine learning approach.

Methods: Tweets were collected from the Twitter public streaming application programming interface from March 3-20, 2020, filtered for general COVID-19-related keywords and then further filtered for terms that could be related to COVID-19 symptoms as self-reported by users. Tweets were analyzed using an unsupervised machine learning approach called the biterm topic model (BTM), where groups of tweets containing the same word-related themes were separated into topic clusters that included conversations about symptoms, testing, and recovery. Tweets in these clusters were then extracted and manually annotated for content analysis and assessed for their statistical and geographic characteristics.

Results: A total of 4,492,954 tweets were collected that contained terms that could be related to COVID-19 symptoms. After using BTM to identify relevant topic clusters and removing duplicate tweets, we identified a total of 3465 (<1%) tweets that included user-generated conversations about experiences that users associated with possible COVID-19 symptoms and other disease experiences. These tweets were grouped into five main categories including first- and secondhand reports of symptoms, symptom reporting concurrent with lack of testing, discussion of recovery, confirmation of negative COVID-19 diagnosis after receiving testing, and users recalling symptoms and questioning whether they might have been previously infected with COVID-19.

The co-occurrence of tweets for these themes was statistically significant for users reporting symptoms with a lack of testing and with a discussion of recovery. A total of 63% (n=1112) of the geotagged tweets were located in the United States.

Conclusions: This study used unsupervised machine learning for the purposes of characterizing self-reporting of symptoms, experiences with testing, and mentions of recovery related to COVID-19. Many users reported symptoms they thought were related to COVID-19, but they were not able to get tested to confirm their concerns. In the absence of testing availability and confirmation, accurate case estimations for this period of the outbreak may never be known. Future studies should continue to explore the utility of infoveillance approaches to estimate COVID-19 disease severity.

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KEYWORDS

infoveillance; COVID-19; Twitter; machine learning; surveillance

Introduction

As of the beginning of June 2020, the novel coronavirus disease (COVID-19) pandemic has now reached over 6 million confirmed cases worldwide (over 1.7 million in the United States alone) and approximately 370,000 deaths worldwide according to the Johns Hopkins University Coronavirus Resource Center. COVID-19 case counts are alarming in both their volume and widening geographic scope. There are also concerns about the accuracy of reported COVID-19 case counts, particularly at earlier stages of the pandemic, and whether underreporting may have obscured the true extent of the outbreak, its underlining epidemiological characteristics, and its overall health and societal impact [1-3].

Specifically, concerns regarding COVID-19 underreporting are influenced by factors such as lack of access to testing kits; a lag in reporting and registering cases due to overburdened health systems; failure to report or test before or after a COVID-19-suspected death; variation in testing administration or decision making (eg, foregoing testing when it would not change the course of treatment for a patient); and uncomplicated, mild, or asymptomatic cases simply never being tested or seeking care [4,5]. Concerns about underreporting have been pervasive, with media reports highlighting challenges in countries with outbreaks of different scale and at varying time periods, including the United States, China, Iran, and Russia, to name a few [6-9].

Accurate estimations of the number of people who have recovered from COVID-19 are also difficult to ascertain. The John Hopkins University Coronavirus Resource Center COVID-19 data dashboard is one source that aggregates the number of reported COVID-19 recovered cases, which now stands at over 2.6 million worldwide. However, case reporting on recoveries can be difficult to measure and define, leading to potential overestimation of the mortality rate and underestimation of community spread that can complicate efforts toward estimating population immunity [5]. Reflecting these challenges, COVID-19 recovered cases are often limited to data aggregated at the country or national level, are derived only from confirmed cases, and may differ based on the definition of "recovery" or method of confirmation [5,10].

In response, this study sought to better understand the characteristics of publicly available self-reported user-generated conversations associated with terms that could be related to COVID-19 symptoms, recoveries, and testing experiences. This was accomplished using a retrospective observational infoveillance study during earlier stages of the global pandemic. Infoveillance studies, which use data from the internet, social media, and other information in an electronic medium for disease surveillance purposes, have been used in prior outbreaks (eg, H1N1, Ebola) [11-15]. There is also an emerging base of literature using social media and website search results to explore the COVID-19 pandemic [16-21].

Methods

This retrospective infoveillance study was conducted in two phases: (1) data collection using the public streaming Twitter application programming interface (API) for COVID-19-related keywords; and (2) data cleaning, processing, and analysis of tweets using an unsupervised machine learning approach by means of natural language processing, followed by subsequent statistical and geospatial analysis of twitter message characteristics.

We first collected tweets by filtering for general COVID-19-related keywords including: "covid19," "corona," "coronavirus," "coronavid19." Following the collection of a corpus of general COVID-19 tweets, we further filtered this corpus for terms that could be associated with COVID-19 symptoms, testing, and recovery conversations. These additional terms included: "diagnosed," "pneumonia," "fever," "test," "testing kit," "sharing," "symptoms," "isolating," "cough," "ER" (emergency room), and "emergency room." The COVID-19-related keywords were chosen based on relevance to general COVID-19 social media conversations as used in prior studies [16,18,22]. Filtered terms were chosen based on manual searches conducted by the study team prior to the commencement of the study, where user-generated tweets associated with COVID-19 symptoms were detected and the terms used were assessed.

Data was collected from the Twitter public API from March 3-20, 2020. For data processing, we first removed hashtags, stop words, and the top 100 news Twitter handles or accounts. We removed the top news accounts as the focus of this study was on user-generated content, both first- and secondhand accounts, of COVID-19 experiences, not COVID-19 news and media sources of information.

For data analysis, we used the biterm topic model (BTM), an unsupervised machine learning approach to extract themes from

groups of texts as used in prior studies to detect substance abuse disorder and other public health issues [23-25]. Groups of messages or text containing the same word-related themes are categorized into clusters; the main themes of those clusters are considered as the topic of the text aggregation, which is then split into a bag of words where a discrete probability distribution for each theme is generated [26]. Using BTM, we identified topic clusters with word groupings, frequencies, and characteristics that appeared to be related to symptoms, recovery, and testing experiences with COVID-19 ("signal") and then extracted tweets from these topic clusters for manual annotation.

The number of topic clusters we chose to extract (k) can affect the results associated with these topics. Too many clusters could lead to diffusion of signal, while too few clusters may conceal possible signals in the topics. To address this, we used a coherence score to measure the quality of the number of topics we chose by measuring how correlated the texts are in the same clusters. A higher coherence score means the text in the cluster are more correlated to each other. We chose five different k values for the number of clusters (k=5,10,15,20,25), then we calculated the coherence score and identified the k value with the highest score as a parameter for BTM.

Here is how we calculate the u-mass coherence score $C(t;v^t)$. We let D(v) be the document frequency of the word type v (ie, the number of documents containing at least one token of type v) and D(v, v0) be the codocument frequency of word types v and v0 (ie, the number of documents containing one or more tokens of type v and at least one token of type v0). We define topic coherence as:

V(t) =  is a list of the M most probable words in topic t. A smoothing count of 1 is included to avoid taking the logarithm of zero.

Manual annotation of tweets was conducted by authors VP, NS, MN, and CB. Coding was focused on content analysis using an inductive coding scheme, including a binary classification of whether the tweet discussed symptoms that could be related to COVID-19 (including firsthand or secondhand accounts), experiences with seeking COVID-19 testing access, or disease recovery, and the co-occurrence of these themes (see Multimedia Appendix 1 for description of coding schema). VP, NS, MN, and CB coded posts independently and achieved high intercoder reliability (kappa=0.98). For inconsistent results, authors reviewed and conferred on correct classification with author TM.

Data collection and analysis was conducted using the Python (Python Software Foundation) programming language and associated package Tweepy. Statistical and geospatial analysis was carried out using RStudio 3.6.1 (RStudio, Inc) and ArcGIS (Esri). For statistical analysis and geospatial visualization, COVID-19 cases from March 20, 2020, were obtained from the JHU GitHub CSSEGISandData file.

Ethics approval and consent to participate was not required for this study. All information collected from this study was from the public domain, and the study did not involve any interaction with users. Users' indefinable information was removed from the study results.

Results

A total of 72,922,211 tweets were collected from March 3-20, 2020, from the Twitter public API filtered for general COVID-19-related keywords. From this entire corpus, we filtered for the previously mentioned additional terms associated with COVID-19 symptoms, testing, and recovery conversations, resulting in a filtered data set of 4,492,954 tweets (ie, this data set included tweets with both COVID-19 general terms and at least one additional term). BTM was then used to analyze the filtered data set to identify relevant topic clusters. After identifying topic clusters that had characteristics related to signal, we extracted 35,786 tweets contained in these BTM topic clusters for the purposes of manual annotation (ie, this data set represents all tweets that were contained in relevant BTM topic clusters selected for manual labelling). After removing duplicates and manually annotating tweets, 3465 (0.00077% of the filtered data set) posts from 2812 unique users were confirmed and identified as signal conversations related to symptoms, testing experiences, or recovery that users associated with COVID-19 (ie, this data set represents true positives that were identified by manual annotation).

Signal tweets were grouped into five main thematic categories: (1) firsthand and secondhand (eg, family, friends) reporting of suspected symptoms that users associated with COVID-19 (eg, fever, cough, shortness of breath, chills); (2) symptom reporting with concurrent discussion of lack of access to COVID-19 testing, mostly due to rigorous criteria to qualify for testing (eg, symptom severity, fever, travel history, insurance) and with no confirmatory diagnosis; (3) user discussion of recovery from suspected COVID-19 symptoms; (4) user confirmation of a negative COVID-19 diagnosis after receiving testing; and (5) users recalling symptoms in the past 5 months that they suspected as possibly associated with a COVID-19 infection (see deidentified examples in Table 1).

Metadata associated with users from these signal tweets indicated that the majority of these conversations were most likely organic (ie, originating and consisting of user-generated content). Though we did not explicitly filter our tweets for bot or spam traffic, the average ratio of users' followers to following was 1607:78, and only 111 users had accounts created recently in 2020. We also observed during our manual coding that these accounts generally included longer interactions with other users, original content, and profile information that had individually identifiable information or biographies. Generally, these user metadata characteristics are reflective of organic content versus automated and social bot-based content.

Table 1. Numbers and examples of posts related to COVID-19 symptoms, access to testing, and recovery (modified for deidentification; n=3465).

Theme[a]	Posts, n (%)[b]	Example conversation[c]
Conversations about symptoms		
• Self-reporting of symptoms (firsthand) • Secondhand reporting of symptoms	3465 (100)	• *"1/I went to ER[d] day before Asked by Dr why I was there I said "I have Coronavirus symptoms." (I really do.) He laughed; asked what symptoms were. I gave all the Coronavirus symptoms. He said "I believe you have an upper respiratory virus. Let's give you a steroid shot."* • *"Contacted the er and [FACILITY NAME] in [CITY] because my daughter has a runny nose fever and a sore throat. I was told they're testing for everything else before testing for coronavirus. Is that backwards or am I trippin? #CoronaVirusSeattle"*
Conversations about symptoms concurrent with other themes		
• Symptom reporting and lack of access to testing	512 (14.8)	• *"Hey [NAME] why can't we get tested for COVID-19[e] in [LOCATION]? My wife has all the symptoms but ER said no testing unless you're admitted."*
• Conversations about symptom and recovery • User confirmation not COVID-19 case after testing • User recalling past COVID-19 suspected symptoms	780 (22.5)	• *"My spouse, 4 yr old and I are almost better now. We were sick about ten days. Don't know if it is Corona because we could not get a test. Fever lasted 3 to 4 days. No cough for us. Consistent headache, chills, sore throat. Reduced appetite for a few days Hydrate! Nap! "* • *"I went to the doctor and they contacted the CDC[f] thinking it was Coronavirus and tried to quarantine me when it was just the flu (I was tested at the ER and it's NOT) thank you to the [NAME] nurse and clinic for being very misinformed & freaking me out"* • *"Just before Christmas I was diagnosed with pneumonia. In acute pain breathing I had cough that wouldn't go away for weeks &; was so fatigued I slept for hours every day. I had no appetite or the strength. It lasted for approx 2 weeks. Was it #coronavirus"*

[a]Discrete or concurrent signal.

[b]Number of posts and the percentage of total signal posts that contained the theme.

[c]Twitter posts or comments with signal.

[d]ER: emergency room.

[e]COVID-19: coronavirus disease.

[f]CDC: Centers for Disease Control and Prevention.

In addition to content analysis, we assessed posts for descriptive longitudinal and geospatial trends by analyzing time stamps and location for the subset of tweets that were geotagged. Posts exhibited longitudinal trends with an overall increase during the study period, with noticeable rapid increases from March 3-6, 2020, and an uneven but gradual increase thereafter (Figures 1 and 2). Out of the 35,786 extracted tweets from the BTM topic clusters, 1769 (4.94%) included geospatial coordinates compared to 522,958 (0.71%) and 22,048 (0.49%) tweets that had coordinates in the entire corpus and the term-filtered data set, respectively. Hence, our total corpus is similar to other studies, reporting that approximately 1% of all tweets were geotagged, and our BTM topic cluster output had an overall higher volume of geolocated tweets in its sample [27,28]. From a global standpoint, 64.9% (n=1125) originated from the United States, followed by the United Kingdom (n=228, 13.2%), Canada (n=52, 3.0%), India (n=52, 3.0%), and Australia (n=43, 2.5%).

The high presence of US-based tweets and tweets from countries where the majority language is English (with the exception of India) is likely reflective of our sampling methodology, which focused on English-language tweets, and the fact that the highest proportion of Twitter users are located in the United States. This skewed geographic global distribution of tweets has also been explored in other studies that found a small number of countries (led by the United States) that account for a large share of the total Twitter user population [29]. The practical implications of this US-skewed geotagging mean that it is likely difficult to infer geospatial trends for tweets on specific COVID-19-related topics for other countries unless data collection is more targeted (eg, collection of tweets in foreign languages, in a specific time zone, or targeting geotagging for country or region-specific shapefiles).

From a national perspective, the US states with the most tweets associated with COVID-19 symptoms and disease experiences were California (n=165), Texas (n=126), New York (n=88), and Illinois (n=54), which largely follows the most populous states in the country (with the exception of Florida). Manual coding revealed a similar ranking of symptom-related tweets that mentioned a state or city as self-reported by the user: California (n=43), New York (n=33), Texas (n=31), and Georgia (n=16). Even though these tweets had the highest frequency in larger states, smaller states and states that had reported confirmed COVID-19 cases (eg, Washington State) were also detected. Overall, COVID-19 associated symptom tweets exhibited wide distribution of Twitter user locations, including

many in areas with high levels of population-normalized COVID-19 confirmed case counts (Figure 3).

Spearman correlations were also computed between the following variables associated with tweets collected: conversations about symptom reporting, experiences with lack of testing, recovery from suspected symptoms, and US location to assess co-occurrence of detected themes. Statistically significant positive correlations exceeding r=0.3 were observed between tweets that included users self-reporting symptoms and experiences with lack of testing (r=0.33, P<.001), as well as self-reporting of symptoms and self-reported recovery from reported symptoms (r=0.45, P<.001).

Figure 1. Volume of total signal Twitter posts filtered for the coronavirus disease symptom terms plotted over the study period (March 3-20, 2020).

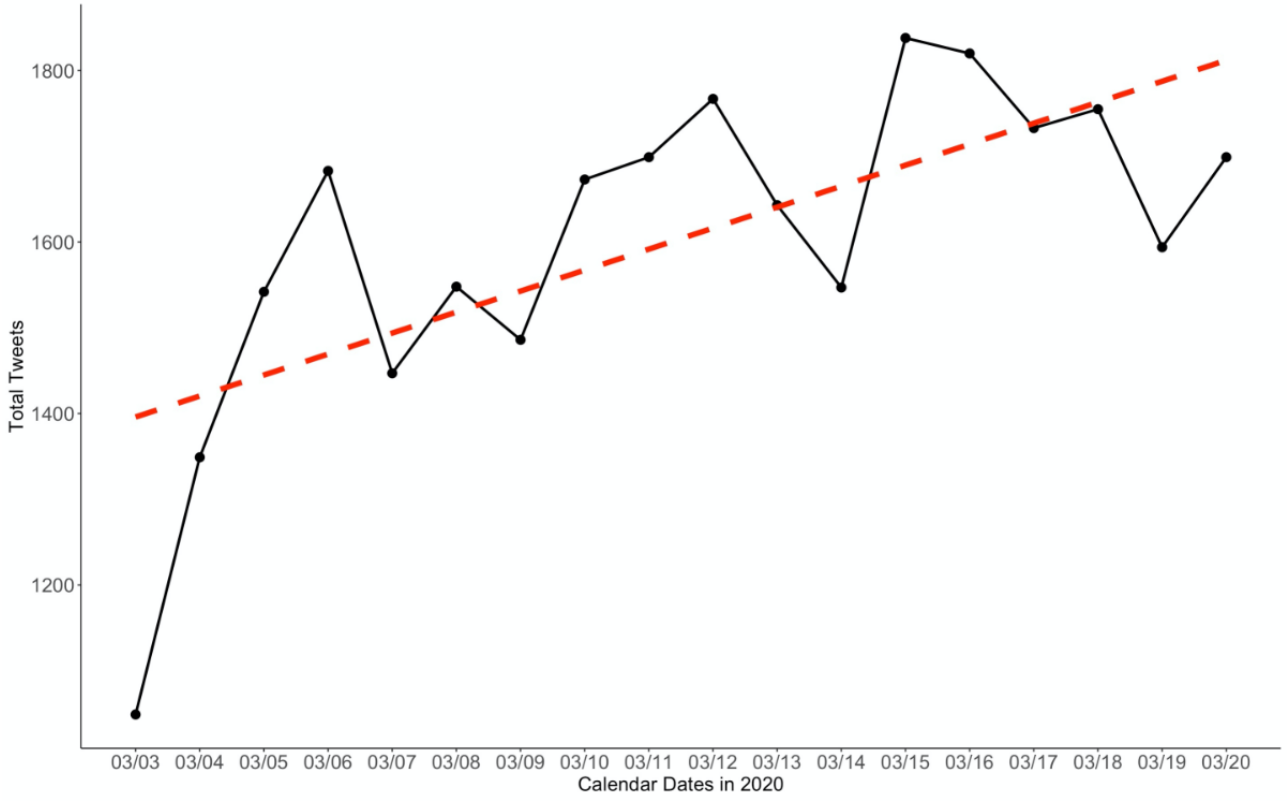


Figure 2. Volume of confirmed symptom tweets plotted over the study period (March 3-20, 2020).

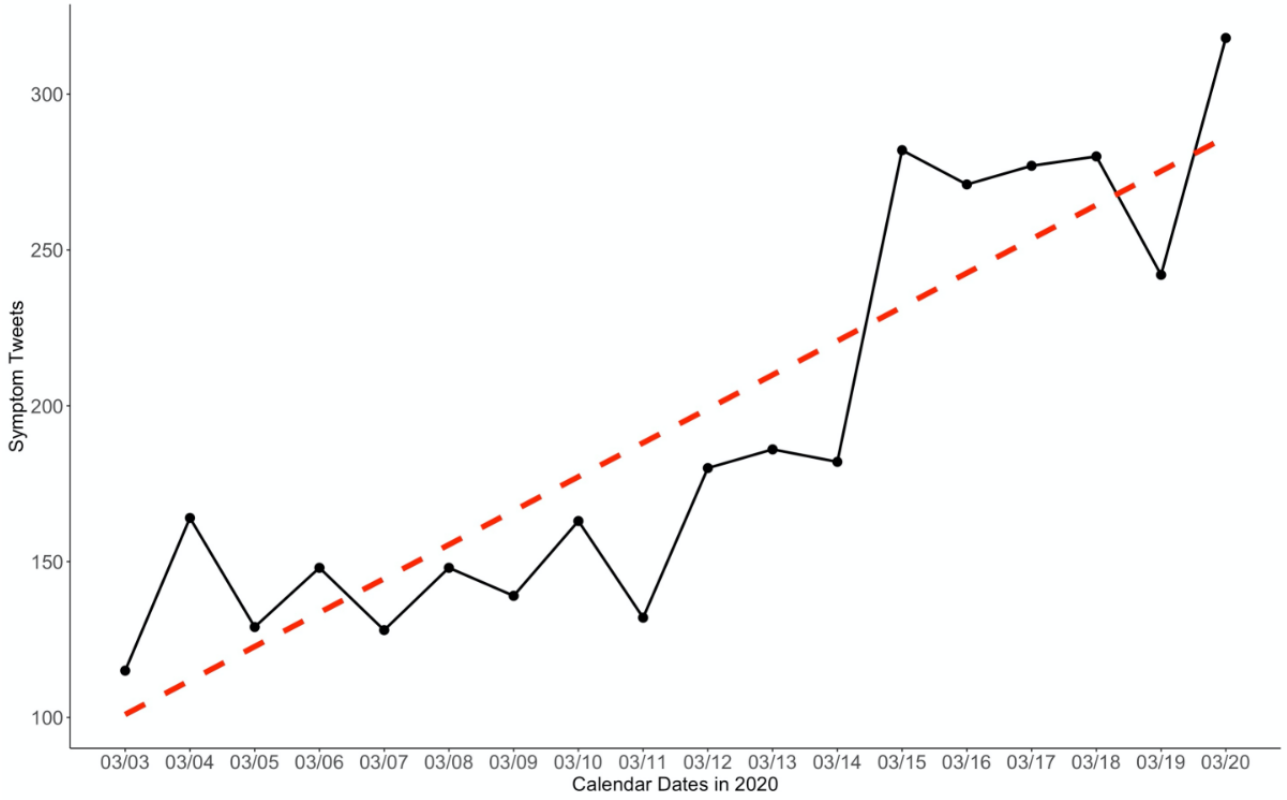
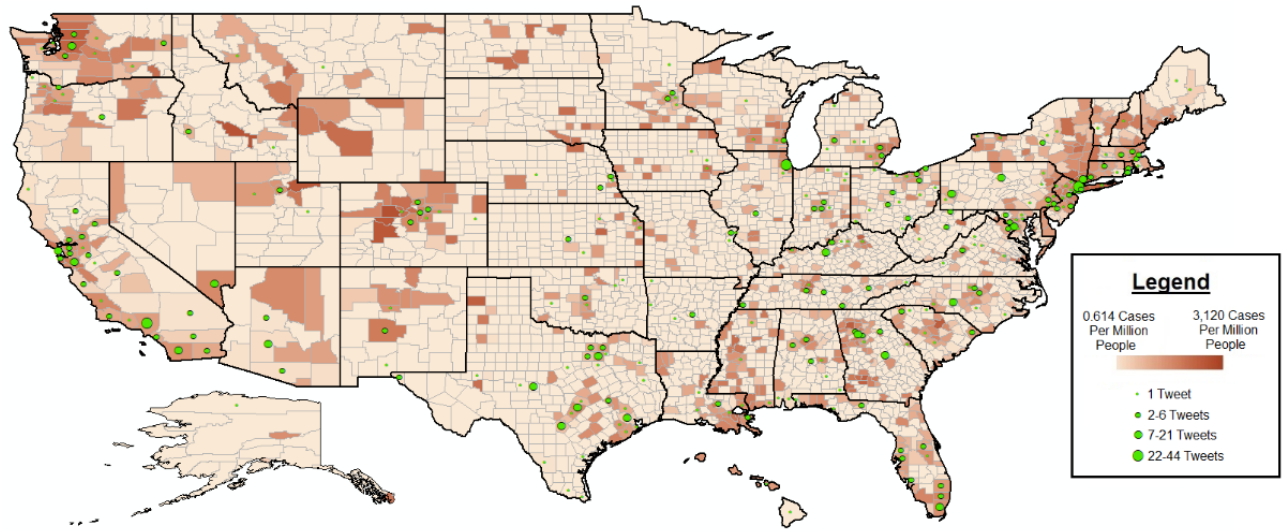


Figure 3. Distribution of tweets originating from the United States as point coordinates overlaid on a choropleth gradient denoting population-normalized coronavirus disease cases on March 20, 2020 (final day of data collection).



Discussion

Principal Findings

This study identified tweets that included both first- and secondhand self-reporting of symptoms, lack of access to testing, and discussion of recovery that users associated with possible COVID-19. The total volume of these COVID-19 conversations increased over the time of the study (particularly between March 3 and March 6, 2020), also corresponding with a period that saw an increase in the number of confirmed cases in the United States. The majority of these conversations related to first- or secondhand reporting of symptoms users associated with COVID-19, with a subset of this group concurrently reporting that they could not get access to testing despite having COVID-19-related symptoms. Other topics that occurred in lower frequency included self-reported recovery from symptoms, users confirming they were not COVID-19 positive, and past accounts of symptoms users believed could have been undetected cases of COVID-19 (dating back as early as November 2019).

Correlation analysis of themes generated by different tweets analyzed for this study found that it was more likely that users who self-reported symptoms they associated with COVID-19 would also concurrently report experiences with lack of access

to testing or recovery from said symptoms. These results indicate that the public's lived experience with COVID-19 included uncertainty about whether they or others were infected with COVID-19, frustration that they could not get tested to confirm these concerns, and sometimes their recovery experience from these symptoms. However, this study was not able to confirm if users reporting these experiences were actually COVID-19 cases, and users may similarly have not tweeted if they had eventually received confirmatory testing or otherwise if there was a change in their condition.

Importantly, ascertaining accurate case estimations of the COVID-19 outbreak is critical to ensuring health care system capacity is not overburdened; evaluating the impact of public health interventions; better enabling comprehensive contact tracing (including methods of digital contact tracing); ensuring the accuracy and predictability of COVID-19 disease mathematical modeling; and assessing the real-world needs for COVID-19 treatment, medical equipment, diagnostics, and other supplies [30,31]. Other online tools, such as the website COVID Near You [32], have collected self-reported symptom and testing access data directly from the public to better inform these case estimations.

Relatedly, the value of our study is in its innovative approach using data mining in combination with modeling to sift through a large volume of unstructured data to detect and characterize potential underreported cases of COVID-19. The methodology has particular utility for new and emerging topics such as a novel infectious disease outbreak where an existing training or labelled data set is not available for machine learning classification tasks. Specifically, our study tapped into an existing publicly available data source to help characterize conversations from Twitter users about their self-reported experiences with COVID-19 and provides insight into one period of this evolving and rapidly spreading global pandemic. It is our hope that this study can help inform future infoveillance efforts, supplement traditional disease surveillance approaches, and advance needed innovation to improve the scope and accuracy of future disease outbreak case estimations for COVID-19 and future health emergencies.

Limitations

This study has limitations. We only collected data from one social media platform and limited study keywords and additional filtered terms to the English language. This likely biased study results to English speakers and primarily English-speaking countries, particularly since the highest number of Twitter users are already located in the United States. In fact, in our final data set of signal tweets, we did not observe any conversations in languages other than English. Our keywords and filtered terms were also chosen on the basis of our own manual searches on the platform but may not have been inclusive of all Twitter conversations related to the study aims. Future studies should expand data collection and analysis approaches to different languages and phrases associated with COVID-19 symptoms, testing, and recovery to obtain a more worldwide representative corpus of social media conversations. We also did not cross-validate the veracity of user-generated comments with other data sources (eg, confirmed case reports, additional survey data, death certificates, data on other diseases with similar symptoms, or electronic medical records). Future studies should explore combining multiple data layers from different sources to better validate whether user-generated self-reporting is highly associated with confirmed cases, case clusters, and disease transmission trends using traditional, syndromic, and other infoveillance approaches while also controlling for seasonal incidence of symptomatically similar diseases (upper respiratory infections, pneumonia, and flu or influenza). Additionally, though we used data filtering and BTM to more efficiently analyze a large corpus of tweets, we nevertheless relied on manual annotation to confirm whether tweets contained a signal. This was particularly important to remove false positives generated by our BTM outputs (ie, the word "testing" can take on different meaning depending on the context of a conversation). Future studies should also focus on developing feature-based supervised machine learning classifiers based on identified conversation characteristics reported in this study to detect self-reported COVID-19 experiences with symptoms, testing, and recovery. Specifically, supervised models that can leverage validated training sets are likely to have a much higher performance in terms of precision and recall compared to the use of topic models used in this study and could likely achieve classification closer to real time. Given that accurate case estimations are more effective when they are timely and can be acted upon quickly, these future approaches would likely have more utility in aiding with unreported case detection, identifying potentially vulnerable or at-risk populations, and better elucidating the public's lived experiences with COVID-19.

Authors' Contributions

JL and MC collected the data; all authors designed the study, conducted the data analyses, wrote the manuscript, and approved the final version of the manuscript.

Conflicts of Interest

TM, JL, MN, MC, and BL are employees of the start-up company S-3 Research LLC. S-3 Research is a start-up funded and currently supported by the National Institutes of Health – National Institute on Drug Abuse through a Small Business Innovation and Research contract for opioid-related social media research and technology commercialization. Authors report no other conflicts of interest associated with this manuscript.

Multimedia Appendix 1
Coding methodology for content analysis.

[DOCX File , 16 KB - publichealth_v6i2e19509_app1.docx]

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Abbreviations

API: application programming interface
BTM: biterm topic model
COVID-19: coronavirus disease
ER: emergency room

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Original Paper

Mining Physicians' Opinions on Social Media to Obtain Insights Into COVID-19: Mixed Methods Analysis

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Abstract

Background: The coronavirus disease (COVID-19) pandemic is considered to be the most daunting public health challenge in decades. With no effective treatments and with time needed to develop a vaccine, alternative approaches are being used to control this pandemic.

Objective: The objective of this paper was to identify topics, opinions, and recommendations about the COVID-19 pandemic discussed by medical professionals on the Twitter social medial platform.

Methods: Using a mixed methods approach blending the capabilities of social media analytics and qualitative analysis, we analyzed COVID-19–related tweets posted by medical professionals and examined their content. We used qualitative analysis to explore the collected data to identify relevant tweets and uncover important concepts about the pandemic using qualitative coding. Unsupervised and supervised machine learning techniques and text analysis were used to identify topics and opinions.

Results: Data were collected from 119 medical professionals on Twitter about the coronavirus pandemic. A total of 10,096 English tweets were collected from the identified medical professionals between December 1, 2019 and April 1, 2020. We identified eight topics, namely actions and recommendations, fighting misinformation, information and knowledge, the health care system, symptoms and illness, immunity, testing, and infection and transmission. The tweets mainly focused on needed actions and recommendations (2827/10,096, 28%) to control the pandemic. Many tweets warned about misleading information (2019/10,096, 20%) that could lead to infection of more people with the virus. Other tweets discussed general knowledge and information (911/10,096, 9%) about the virus as well as concerns about the health care systems and workers (909/10,096, 9%). The remaining tweets discussed information about symptoms associated with COVID-19 (810/10,096, 8%), immunity (707/10,096, 7%), testing (605/10,096, 6%), and virus infection and transmission (503/10,096, 5%).

Conclusions: Our findings indicate that Twitter and social media platforms can help identify important and useful knowledge shared by medical professionals during a pandemic.

(JMIR Public Health Surveill 2020;6(2):e19276) doi:10.2196/19276

KEYWORDS

pandemic; coronavirus; COVID-19; social media; infodemiology; infoveillance; medical professionals; opinion analysis

Introduction

The rapid spread of the novel coronavirus disease (COVID-19) has sparked alarm worldwide. The World Health Organization (WHO) has declared the rapidly spreading COVID-19 outbreak to be a pandemic, and countries around the world are grappling with surges in confirmed cases [1]. This outbreak has changed the lives of many people in many countries. With millions of people forced out of public spaces, many conversations about these phenomena now take place on social media [2].

However, the accuracy and credibility of this conversation is often concerning and challenging for public health officials [3], especially because the authors of this information are often unknown [4]. In addition, data available on public platforms such as Twitter provide unique insights that are challenging to identify due to data size, recentness, and geographic scale [5,6]. Misinformation is spreading rapidly as people struggle to understand how best to protect themselves and the people around them [7]. Therefore, it is important to ensure that people seek information from proper sources on social media platforms. Seeking information from these outlets ensures the flow of relevant, accurate, and high-quality information about the COVID-19 pandemic outbreak, which can help control the pandemic [8]. An example of a proper source is a medical professional.

Currently, social media platforms such as Twitter and Facebook are being used by medical professionals around the world and have become important players in the COVID-19 pandemic. These platforms are used by medical professionals to provide patient care and education [4], increase personal awareness of news and discoveries, and provide health information to the community [9]. Furthermore, these platforms are increasingly popular for sharing and debating scientific information [10,11]. For example, Glowacki et al [3] analyzed tweets about electronic cigarettes posted by physicians from two countries, the United Kingdom and the United States; they found that physicians discussed important topics such as the likelihood of electronic cigarette use among teenagers, Food and Drug Administration regulations on tobacco, measures of the sources of harm inherent to any kind of tobacco use, and references to a Harvard study on the effects of flavoring chemicals on the lungs. In addition, Alpert and Womble [12] addressed how physicians navigate Twitter and their challenges and benefits of using the platform. The results showed that physicians used Twitter for reach and presence, to express concerns and apprehension, for networking, news, and education, for patient engagement, and to advocate against misinformation. Finally, Chaudhry et al [13] addressed the extent to which oncologists used Twitter during annual meetings. The results showed that physicians mainly used Twitter to report clinical news from scientific sessions, discuss treatment issues, for promotion, and to provide social commentary.

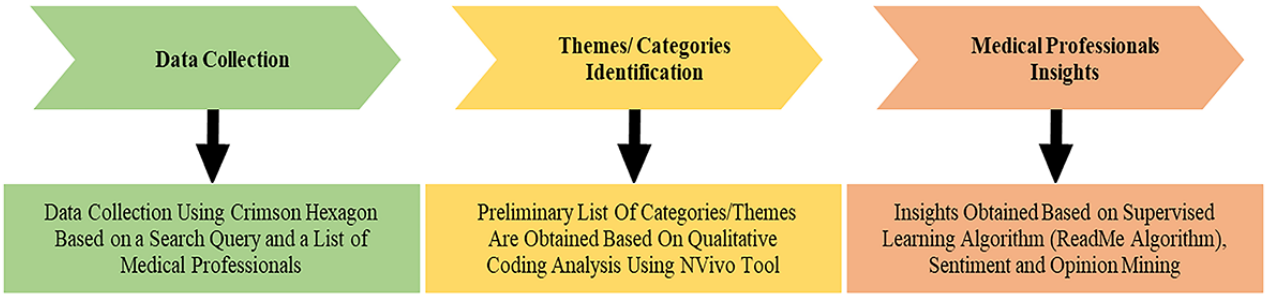
In summary, prior research demonstrates the potential of mining social media to uncover useful information regarding a variety of health care–related issues. However, no study to date has examined communities of medical professionals on social media to identify themes and discussion topics about the COVID-19 pandemic. These posts can help identify topics that are important to the community and can serve as a gauge for measuring concerns about potential threats [3]. With the rapid outbreak of the COVID-19 pandemic and the global effort to fight it, this research aims to extract medical professionals' insights about the coronavirus pandemic. From a practical perspective, the research identifies proactive actions, recommendations, and knowledge that can help control the pandemic.

Methods

Methodology

To analyze posts by medical professionals on social media, we used a mixed methods approach blending the capabilities of a social media analytics tool, Crimson Hexagon, with the capabilities of a qualitative analysis tool, NVivo (QSR International), for data collection and analysis (Figure 1).

Figure 1. Research methodology.



In general, the methodology started with data collection. The researchers agreed on a data range of interest, target social media platform, target users, keywords used to search for online posts, and restrictions to impose. Second, qualitative analysis was conducted using NVivo to explore the collected data to identify relevant tweets, infer prominent concepts, and then identify the main themes in the data. Qualitative analysis can be used to uncover important concepts and develop an understanding about a phenomenon [14]. A popular method for qualitative analysis is qualitative coding [15], which was adopted in this study. Qualitative coding is the process of assigning descriptive or inferential labels to chunks of data, which may assist concept development [16,17]. Third, a data analytics tool, Crimson Hexagon, was used for opinion analysis of the predefined categories. Crimson Hexagon, a social media analytics company that is now part of Brandwatch, employs unsupervised and

supervised machine learning techniques and a text analysis model developed by Hopkins and King [18].

Data Collection

Our target social media platform for data collection was Twitter. Initially, we identified 119 medical professionals who were actively discussing the COVID-19 pandemic on Twitter. The medical professionals were identified by searching the Onalytica website, which specializes in providing influencer marketing software, and finding a list of top health care professionals ranked by influence score [19]. Also, we used the Johns Hopkins Coronavirus Resource Center [1], which provides a comprehensive COVID-19 case tracker as well as other useful information about COVID-19, including the Johns Hopkins COVID-19 Experts/Centers account on Twitter. The Twitter IDs of the medical professionals were used to identify the target users. Next, using Crimson Hexagon with the search query shown in Figure 2, we extracted all tweets for the identified medical professionals between December 1, 2019 and April 1, 2020. A total of 10,096 English tweets were collected. The key advantage of using a social media analytics platform such as Crimson Hexagon is that it provides access to the "Twitter firehose" (ie, every public tweet ever posted on Twitter in any language and from any geographic location that meets the search criteria).

Figure 2. Search query used with Crimson Hexagon.

```
(Coronav* OR Covid* OR #covid* OR #corona* OR #SARSCoV2 OR #nCoV2019 OR "SARS-CoV-2"
 OR #nCoV2019 OR #2019nCoV OR #2019nCoV) AND - (RT OR http OR https)
```

Data Analysis

For the data analysis, we started by identifying relevant tweets. To do this, a random subset of 250 tweets were analyzed by three researchers to determine which tweets were relevant to the COVID-19 pandemic. Three researchers independently labeled the tweets as relevant or not relevant. To ensure that the obtained results were reliable and consistent, we followed a case study protocol and established interrater reliability. We obtained a Fleiss κ value of 0.628, which is at the bottom of the range that reflects substantial agreement (0.61-0.80) and is just above the range that reflects moderate agreement (0.41-0.60) [20].

Next, we performed automatic coding of the relevant tweets using NVivo, a tool that helps organize and analyze a wide variety of data, including but not limited to documents, images, audio, video, and social medial content [21]. Automatic coding was used to assist the process of concept development related to the COVID-19 pandemic. The results of the automatic coding process are shown in Multimedia Appendix 1. Once the main codes and subcodes were identified, three researchers worked together via a combination of inductive and deductive thinking to identify conceptual categories [22]. The goal was to build a descriptive, multi-dimensional preliminary framework for later analysis. Based on the main code and subcode analysis, we were able to identify eight main categories/themes, namely information and knowledge, symptoms and illness, fighting misinformation, infection and transmission, testing, actions and recommendations, the health care system, and immunity.

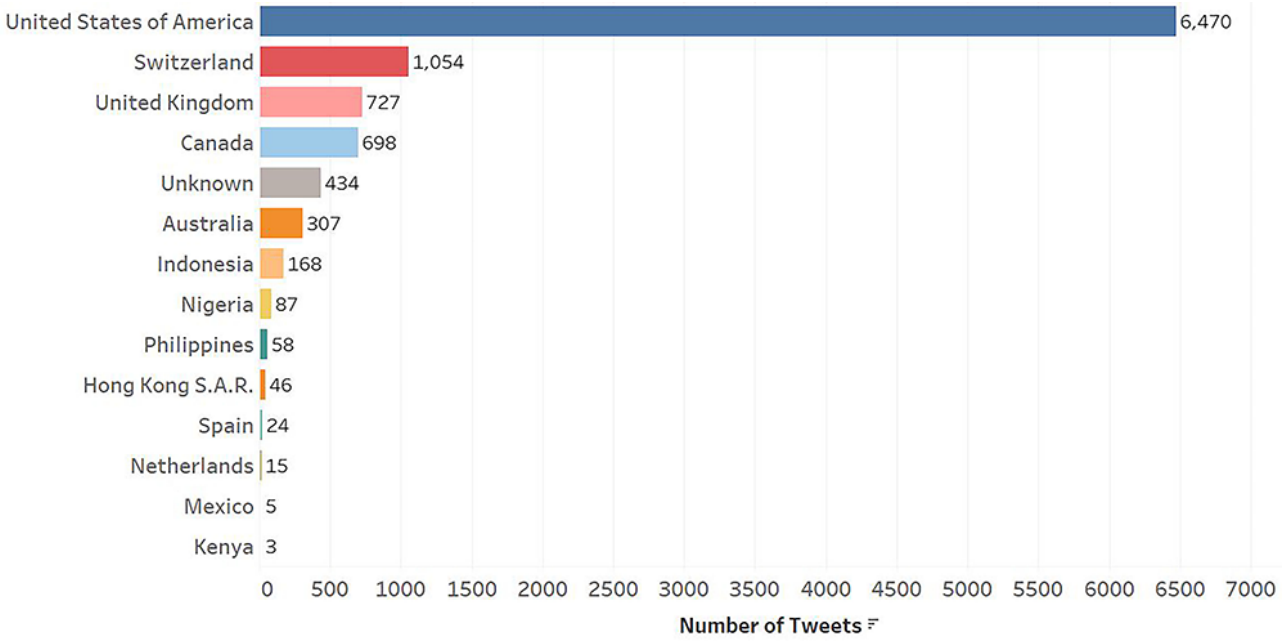
We initially used Crimson Hexagon to define the categories from the qualitative analysis and the associated trained algorithm to explore the medical professional opinion surrounding the COVID-19 pandemic outbreak. Multimedia Appendix 1 describes each of the categories, lists the keywords delineating each of the categories, and provides a representative tweet for each. Using Multimedia Appendix 1 as a codebook, we manually labeled the categories and automatically distributed 10,096 tweets over 9 categories: the 8 categories from qualitative analysis and 1 additional category for irrelevant tweets. The training was an iterative process, ensuring that each category was clearly outlined by the examples. The number of coded tweets increased over several runs of the model as we reviewed the categories and coded more tweets.

Results

Tweet Distribution and Categories

A total of 10,096 English tweets were collected between December 1, 2019 and April 1, 2020 from a total of 119 providers, of which 29 (24.4%) were female, 59 (49.6%) were male, and 31 (26.0%) were of unknown gender. The average number of tweets per provider was 84.8. The distribution of tweets per country is shown in Figure 3; the majority of tweets were from medical professionals located in the United States.

Figure 3. Distribution of tweets by country.



The distribution of the tweets over the categories identified using qualitative analysis is shown in Figure 4. Overall, the results demonstrate that relevant tweets account for 92% of the collected tweets, and irrelevant tweets account for 8%. Irrelevant tweets are tweets posted by medical professionals that do not discuss COVID-19. For example, tweets that reference websites links, such as "words have never been more well-spoken. #coronavirus #coronavirusoutbreak #covid19" or tweets that make announcements about TV interviews, such as "I gave interview last month where I was asked "Is COVID-19 going to be like Zika, where nobody was really affected in the end?" and "It's great to see the media interviewing actual experts on epidemics about #COVID19!" The distribution of the relevant tweets was as follows: actions and recommendations (2827/10,096, 28%), fighting misinformation (2019/10,096, 20%), information and knowledge (911/10,096, 9%), health care system (909/10,096, 9%), symptoms and illness (810/10,096, 8%), immunity (707/10,096, 7%), testing (605/10,096, 6%), and infection and transmission (503/10,096, 5%).

Figure 4. Percentages of tweets per category.

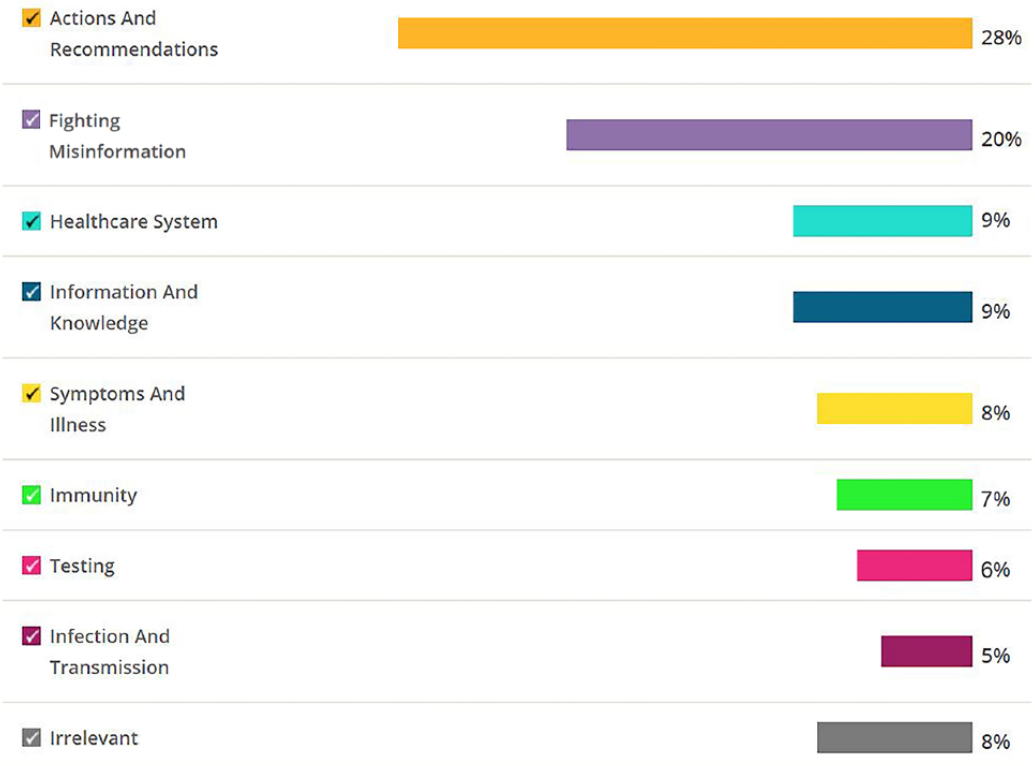
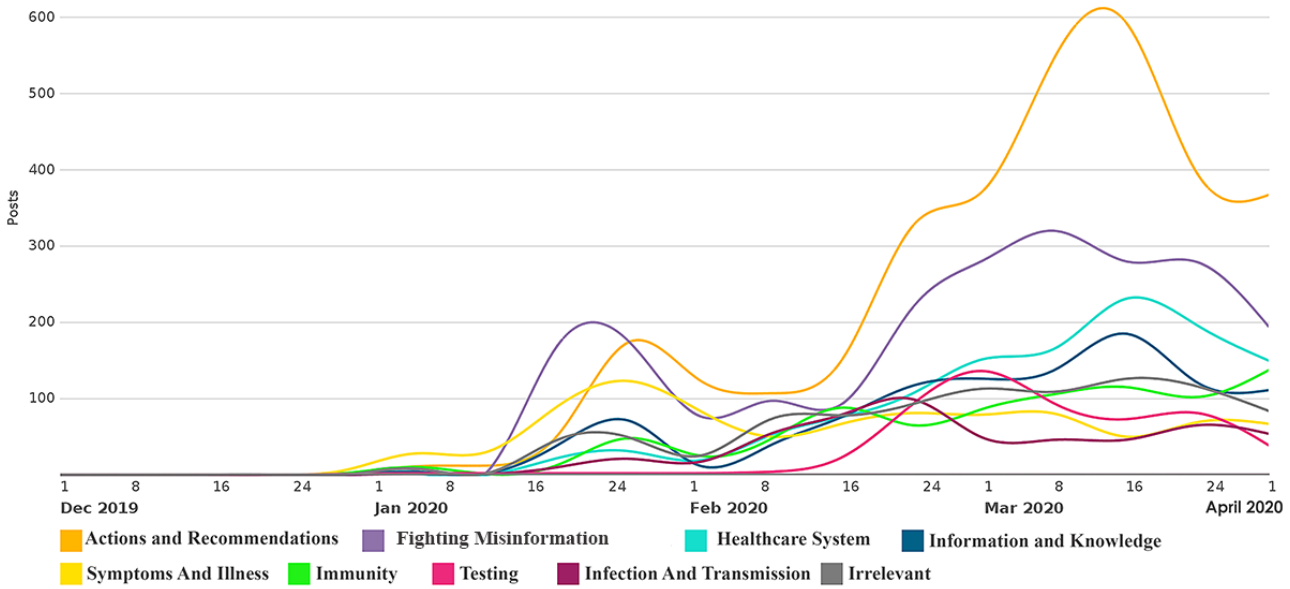


Figure 5 shows the volume of tweets over time by category. As shown in the figure, the number of posted tweets increased with time. More tweets were posted as the number of COVID-19 cases increased. The number of tweets posted about actions and recommendations increased noticeably, followed by tweets posted about fighting misinformation.

Figure 5. Trends of tweets per category from December 2019 to April 2020.



Actions and Recommendations

Overall, the tweets revealed the important topics about the COVID-19 pandemic that medical professionals discussed during the period of the study. Medical professionals provided a wide range of actions and recommendations that must be considered by the government, public health officials, and individuals. These actions and recommendations mainly focused on flattening the curve, quarantine, self-isolation, social distancing, staying at home, and personal self-care. According to Multimedia Appendix 2, tweets related to "must quarantine," "social distancing," "flattening," and "curve" dominated this category. Example tweet:

> *This is the time to #preparenotpanic for #COVID2019 Here are my tips 1. good hand hygiene (wash hands with soap and water or use alcohol-based hand gel) 2. cover your cough and sneeze 3. if sick stay at home 4. discuss sick leave rules with work.*

Fighting Misinformation

Medical professionals also discussed concerns related to misinformation and how dangerous and misleading it is to share and report such information. Furthermore, they encouraged the public to seek updates from government officials and trusted sources. According to Multimedia Appendix 3, tweets related to "misinformation" and "disinformation" dominated this category. Medical professionals discussed information related to the virus infection and transmission. Example tweet:

> *Along with infectious disease epidemics come misinformation/hysteria epidemics. The latter spreads faster and is just as dangerous. We need responsible reporting; accurate information; and the media needs to avoid using panic/fear to sell headlines. #coronavirus #nCoV2019*

Health Care System

Medical professionals shared their opinions regarding the health care system during the COVID-19 pandemic. They shared information and concerns regarding health care workers and their safety and whether the health care system can accommodate the increasing numbers of patients with COVID-19. According to Multimedia Appendix 4, tweets related to "healthcare," "hospitals," "system," "patients," and "workers" dominated this category. Example tweet:

> *We will need LOTS of help, including delivery of food and medicine, support of health care facilities, or direct patient care.*

Information and Knowledge

Medical professionals posted tweets about general COVID-19 pandemic information and knowledge. This information and knowledge included recent statistics and comparisons between countries and general information about the virus not directly related to any of the other categories. According to Multimedia Appendix 5, tweets related to "information," "important," and "knowledge" dominated this category. Example tweet:

> *#coronaviruses are enveloped viruses, meaning they are coated with a membrane derived from the host cell.*

Symptoms and Illness

Medical professionals also shared their knowledge about the symptoms and illnesses associated with COVID-19. According to the tweets in this category, people infected with COVID-19 can have a range of symptoms, from none to severe. The tweets indicated that some patients with COVID-19 can have no immediate symptoms or no symptoms at all (asymptomatic), most patients seem to have no or mild symptoms, and some

patients have pneumonia or breathing issues. According to Multimedia Appendix 6, tweets related to "symptoms," "asymptomatic," "illness," "mild," and "severe" dominated this category. Example tweet:

> *People who have contracted new #coronavirus are showing a wide range of symptoms. Of known cases, most people exhibit milder symptoms, but about 1 in 5 people have severe illness, including #pneumonia and respiratory failure.*

Immunity

Medical professionals shared thoughts and opinions about how our immune systems respond and react to the virus as well as theories related to immunity. According to Multimedia Appendix 7, tweets related to "immunity," "herd," "strategy," and "immune" dominated this category. Example tweet:

> *Collecting antibodies from those who recover from coronavirus infections is certainly a strategy to consider, & various countries are looking at this. Personally, I would prefer to give convalescent plasma to a patient with knowledge that it contains a decent amount of antibodies.*

Testing

The medical professionals also discussed testing in their tweets. These discussions were mainly about testing as the most viable option to control the disease, concerns about testing, and the need to scale up testing and expand testing capabilities. According to Multimedia Appendix 8, tweets related to "testing," "test," "kits," "lab," "mild," and "severe" dominated this category. Example tweet:

> *We need to be thinking outside the box: drive-thru testing & home-based testing. This will help expand testing options for patients.*

Infection and Transmission

Medical professionals also discussed information related to virus infection and transmission. According to Multimedia Appendix 9, tweets related to "transmission," "spread," "outbreak," and "infected" dominated this category. Example tweet:

> *Its good news that young children appear not to suffer severe #COVID19 illness. Unfortunately, the bad news is that these kids can readily spread the #coronavirus to others who are at much higher risk for serious illness.*

Discussion

Principal Findings

The collected data and analysis show that social media content reveals important topics that medical professionals perceive as relevant to the ongoing discourse about the COVID-19 pandemic. These topics are mainly related to actions and recommendations, fighting misinformation, the health care system, information and knowledge, symptoms and illness, immunity, testing, and infection and transmission. Interestingly, tweets relating to actions and recommendations and concerns about misinformation accounted for more than 50% of relevant tweets, while health care system–related tweets accounted for less than 10% of relevant tweets. This is revealing given that discussion of shortages of medical supplies and limitations of the health care system seems to dominate mainstream media. However, while medical professionals are concerned about the health care system, from their perspective, the importance of actions and recommendations reflects a proactive stance to combat a pandemic that currently has no effective treatment and for which a vaccine will not be available for a long time. Tweets in this category peaked around mid-March, coinciding with the ongoing effort to curtail the pandemic, and included extensive references to approaches such as social distancing, quarantining, and contact tracing. These approaches are considered to be the first response to new infectious diseases [23]. While the volume of tweets has declined since mid-March, there was an uptick toward early April, potentially coinciding with conversations associated with the appropriate timing for "opening" the economy and associated measures that may be needed to keep the pandemic in check.

Furthermore, misinformation is a major concern for medical professionals; this was addressed in many tweets, which emphasized how this misleading information could lead to infection of more people with the virus. In a sense, some tweets suggested that the spread of misinformation was equally as disconcerting as the spread of COVID-19. Although the actual process by which such infection and spread could occur due to misleading information is not clear, there is ongoing effort by government and public health organizations such as the Centers for Disease Control and Prevention (CDC) and WHO to disseminate credible information about the state of the pandemic. This effort is imperative to develop interventions to fight misinformation in cases where high quality information may literally be a life-and-death concern [24]. As of April 1, 2020, this topic remained second with respect to tweet volume, indicating continued concern. Implications for public health include the need to expand the reach of credible information about various aspects of the virus, including symptoms, treatment, testing, vaccination, and progression. It is also important to increase public awareness about the duty to share information wisely and the importance of seeking information from trusted sources such as medical professionals.

Concerns were also shared about health care systems and health care workers. Medical professionals expressed concern that the increase in the number of cases will lead to collapse of the health care system and that the shortage of medical personal protective equipment (PPE) will increase the likelihood that health care workers will be infected. According to the CDC [25], it is critical to make every effort to protect the essential national workforce of health care providers, both at work and in the community. Also, CDC data show that PPE shortages are posing challenges to the health care system because of the COVID-19 pandemic [26]. Examples of suggested measures include scaling up existing facilities, provisioning field hospitals, and directing resources to support ailing health care infrastructure in a timely and proactive manner. Interestingly, the number of tweets showed a declining trend toward the end of the analysis period, potentially reflecting the global effort to ramp up health care

infrastructure and the adaption of health care providers to the fledging health crisis.

In addition, medical professionals shared their knowledge and information about the symptoms associated with COVID-19; they stated that a person with COVID-19 can show a wide range of symptoms and it is even possible that they will show no symptoms at all. This is aligned with the existing literature, where accumulating evidence is indicating that a substantial fraction of people infected with COVID-19 are asymptomatic [27]. These posts reflect less than 20% of all relevant posts; however, they reflect another opportunity for medical professionals to influence the course of the pandemic by helping to disseminate credible and accurate information about the disease. This role can also extend to proactively debunking misinformation. While the volume of tweets showed a declining trend after mid-March, it is encouraging to note that there was an uptick toward the end of the analysis period.

Issues related to how the human immune system acts and reacts with the virus were also discussed. Most notably, medical professionals were concerned about the fact that some countries are considering herd immunity as an option to address the COVID-19 pandemic. This option is criticized because it is practically impossible to perfectly tune actual interventions without exceeding or undershooting the capacity of the health care system [28]. Interestingly, immunity shows a consistent upward trend during the analysis period among all topics. This trend is likely to continue as health care professionals, policymakers, and communities attempt to determine the role of the immune system (particularly post-infection) in suppressing the likelihood of future infections and how these findings can impact future courses of action.

Medical professionals tweeted about testing as the most urgent and efficient option to control the spread of COVID-19 while there is no effective treatment or vaccine. Given the magnitude of the COVID-19 pandemic, effective testing can reduce or prevent the need for much greater intrusions [29]. Suggested measures included increasing testing, surveillance, and detection as much as possible, adopting drive-through testing, and rapid scaleup of diagnostic testing outside of hospitals.

Finally, information about how the virus infects people, transmits from person to person, and spreads in communities was shared by different medical professionals. In this category, there was a significant emphasis on the role of the public in stemming the transmission of the infection. This information included the need to practice social distancing, basic personal hygiene, and self-quarantining after potential exposure to COVID-19.

Limitations

This research has a number of limitations due to its reliance on social media. For example, despite the breadth of tweets collected, not all medical professionals use Twitter, and those who do use Twitter use a significant amount of discretion with respect to their level of engagement with the platform. There are also temporal and geographic dimensions [5,6] that are not necessarily captured. The findings from the analysis could be improved through additional refinement of the defined categories and by focusing on specific categories (eg, actions and recommendations). In addition, the data collection could be complemented with surveys of medical professionals with more focused and specific questions to better understand their specific concerns and experience.

Conclusions

In this research, we analyzed tweets by medical professionals on social media to understand topics, insights, and information about the COVID-19 pandemic outbreak. Using a mixed methods approach that blended social media analytics and qualitative analysis, this research revealed trending themes and topics of concern by medical professionals about the novel coronavirus. While this health crisis is still unfolding, this study provides a unique perspective of medical professionals during the early stages of the pandemic outside of China. At this stage, a sizeable volume of tweets pertained to proactive actions to combat the virus and to recognition of the scale of the spread of misinformation as well as its adverse effects on the ongoing effort to fight the pandemic. Other issues characterizing this stage included concern about the current status of the health care system, the dissemination of information about the disease, the role of testing to better assess the scope of the crisis and properly target mitigation efforts, and the potential response of the human immune system.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Hierarchy Chart from Automatic Coding and Codebook for Labeling Categories.
[DOC File , 250 KB - publichealth_v6i2e19276_app1.doc]

Multimedia Appendix 2
Topics of tweets in the Actions and Recommendations category.
[PNG File , 1055 KB - publichealth_v6i2e19276_app2.png]

Multimedia Appendix 3
Topics of tweets in the Fighting Misinformation category.

[PNG File , 613 KB - publichealth_v6i2e19276_app3.png]

Multimedia Appendix 4
Topics of tweets in the Health Care System category.
[PNG File , 528 KB - publichealth_v6i2e19276_app4.png]

Multimedia Appendix 5
Topics of tweets in the Information and Knowledge category.
[PNG File , 527 KB - publichealth_v6i2e19276_app5.png]

Multimedia Appendix 6
Topics of tweets in the Symptoms and Illness category.
[PNG File , 408 KB - publichealth_v6i2e19276_app6.png]

Multimedia Appendix 7
Topics of tweets in the Immunity category.
[PNG File , 598 KB - publichealth_v6i2e19276_app7.png]

Multimedia Appendix 8
Topics of tweets in the Testing category.
[PNG File , 889 KB - publichealth_v6i2e19276_app8.png]

Multimedia Appendix 9
Topics of tweets in the Infection and Transmission category.
[PNG File , 573 KB - publichealth_v6i2e19276_app9.png]

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
PPE: personal protective equipment
WHO: World Health Organization

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Original Paper

Distribution of Patients at Risk for Complications Related to COVID-19 in the United States: Model Development Study

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Abstract

Background: Coronavirus disease (COVID-19) has spread exponentially across the United States. Older adults with underlying health conditions are at an especially high risk of developing life-threatening complications if infected. Most intensive care unit (ICU) admissions and non-ICU hospitalizations have been among patients with at least one underlying health condition.

Objective: The aim of this study was to develop a model to estimate the risk status of the patients of a nationwide pharmacy chain in the United States, and to identify the geographic distribution of patients who have the highest risk of severe COVID-19 complications.

Methods: A risk model was developed using a training test split approach to identify patients who are at high risk of developing serious complications from COVID-19. Adult patients (aged ≥18 years) were identified from the Walgreens pharmacy electronic data warehouse. Patients were considered eligible to contribute data to the model if they had at least one prescription filled at a Walgreens location between October 27, 2019, and March 25, 2020. Risk parameters included age, whether the patient is being treated for a serious or chronic condition, and urban density classification. Parameters were differentially weighted based on their association with severe complications, as reported in earlier cases. An at-risk rate per 1000 people was calculated at the county level, and ArcMap was used to depict the rate of patients at high risk for severe complications from COVID-19. Real-time COVID-19 cases captured by the Johns Hopkins University Center for Systems Science and Engineering (CSSE) were layered in the risk map to show where cases exist relative to the high-risk populations.

Results: Of the 30,100,826 adults included in this study, the average age is 50 years, 15% have at least one specialty medication, and the average patient has 2 to 3 comorbidities. Nearly 28% of patients have the greatest risk score, and an additional 34.64% of patients are considered high-risk, with scores ranging from 8 to 10. Age accounts for 53% of a patient's total risk, followed by the number of comorbidities (29%); inferred chronic obstructive pulmonary disease, hypertension, or diabetes (15%); and urban density classification (5%).

Conclusions: This risk model utilizes data from approximately 10% of the US population. Currently, this is the most comprehensive US model to estimate and depict the county-level prognosis of COVID-19 infection. This study shows that there are counties across the United States whose residents are at high risk of developing severe complications from COVID-19. Our county-level risk estimates may be used alongside other data sets to improve the accuracy of anticipated health care resource needs. The interactive map can also aid in proactive planning and preparations among employers that are deemed critical, such as pharmacies and grocery stores, to prevent the spread of COVID-19 within their facilities.

(JMIR Public Health Surveill 2020;6(2):e19606) doi:10.2196/19606

KEYWORDS

COVID-19; modeling; chronic conditions; older adults

Introduction

The first case of coronavirus disease (COVID-19) was detected in the United States on January 20, 2020 [1]. The spread of the virus increased exponentially across the United States during the subsequent two months, with large outbreaks occurring in urban localities including New York City, the San Francisco Bay Area, Detroit, and New Orleans [2].

The Centers for Disease Control and Prevention (CDC) analyzed data from lab-confirmed COVID-19 cases in the United States from February 12 to March 28, 2020. This analysis found that older adults and individuals with underlying health conditions are at higher risk of developing life-threatening complications from COVID-19 [3]. Among COVID-19 patients, 38% had one or more underlying health conditions, and the rates of hospitalization among these patients was disproportionately high. The majority of intensive care unit (ICU) admissions (78%) and non-ICU hospitalizations (71%) were patients with at least one underlying health condition.

Efforts to reduce mortality due to COVID-19 should include identifying and protecting patients who have the highest risk of developing severe complications from the disease. The purpose of this study was to develop a risk model to estimate the risk status for patients of a nationwide pharmacy chain in the United States and to identify the geographic distribution of patients who have the highest risk of severe COVID-19 complications.

Methods

Data Inputs and Sources

Pharmacy Data

Adult patients (aged ≥18 years) were identified from the Walgreens electronic data warehouse. Patients were considered eligible to contribute data to the model if they had at least one prescription filled at a Walgreens location between October 27, 2019, and March 25, 2020. Eligible patients were assigned a risk score based on the sum of each patient's risk parameters including the following: an inferred diagnosis of a serious chronic condition based on a prescription fill within this period for certain specialty medications (Multimedia Appendix 1), an inferred diagnosis of a chronic condition that is deemed to put the patient at high risk of severe COVID-19 complications based on a prescription fill to treat these conditions (Multimedia Appendix 2), prescription fills which infer diagnosis of other chronic conditions, age, and urban density classification. Ethical approval was received from the Advarra Institutional Review Board (protocol number 35300).

Our team assigned a risk value to each parameter based on findings from recent COVID-19 studies [3,4]. The risk score algorithm weighted parameters based on their association with complications from COVID-19 infection, such as hospitalization and death. Parameters shown to be associated with the greatest risk of severe COVID-19 complications were assigned the highest value possible, regardless of the presence of other risk factors. The highest risk parameters included a prescription fill within the study period for one of the high-risk specialty medications and being aged 80 years and above.

Prescription fills to treat high-risk chronic conditions and other chronic conditions not deemed high-risk were assigned a value based on hazard ratios published in the European Respiratory Journal [5]. Patients with specific underlying health conditions are at high risk of developing severe complications from COVID-19 [3]. The risk score for patients with chronic lung disease, diabetes mellitus, and cardiovascular disease was weighted higher than the risk for patients being treated for other chronic conditions that do not fall into one of these three disease states. Baseline risk is determined by the number of medications the patient is on, and whether that medication is for treatment of any chronic condition. Patients treated with medication for one or more of the three high-risk conditions in addition to being treated with additional chronic condition medications received a cumulative value for each category. For instance, a patient being treated for chronic lung disease, diabetes mellitus, and one additional high-risk maintenance medication would receive the following values for these conditions: 2.681 + 1.586 + 2.592 = 6.459.

Compounding evidence shows that the risk of developing severe complications from COVID-19 increases exponentially with age; therefore, the risk score was weighted more heavily for older patients. Observational evidence shows that the spread of COVID-19 occurs most rapidly in urban areas. For this reason, we weighted patients who live in densely populated urban areas with the greatest risk, followed by those in less dense urban, suburban, and rural settings. Counties categorized as rural contain a population density of <400 people per square mile, suburban encompasses population density between 400 and 5000 people per square mile, less dense urban includes counties with 5000 to 12,500 people per square mile, and urban encompasses population density over 12,500 people per square mile. Population data were acquired from Popstats 2019 (Syergos Technologies Inc).

The risk model was developed using a training test split approach. The model was tested and validated using data for patients residing in one state (Georgia), and then applied to the full United States study cohort. Once cumulative risk values were calculated for each patient, the values were transformed to a maximum risk score of 10 to aid with interpretation using the following formula:

COVID-19 Surveillance Data

Real-time data of COVID-19 cases captured by the Johns Hopkins University Center for Systems Science and Engineering (CSSE) [2] was layered in the risk map to show where cases exist relative to the populations identified as being at high risk of severe complications from COVID-19.

Model Validation

The model was compared with current trends in COVID-19 cases. Without the availability of confirmed cases, the predictive value of this model is unknown [6].

Mapping

ArcMap (Esri) was used to depict the presence of patients identified as being at high risk for severe complications from COVID-19 and real-time COVID-19 cases. The at-risk rate per 1000 people is provided at the county level. County populations of fewer than 100 residents or fewer than 10 patients were excluded from the data set. The combined view shows where cases exist relative to the populations identified as high-risk. Additionally, testing locations, Walgreens store, and clinic locations are seen with a zoomed in view. The ArcGIS Online platform (Esri) was used to distribute this map publicly beginning April 16, 2020.

Results

The study included 30,100,826 adults filling at least one specialty or maintenance medication during the study period. Table 1 shows the model inputs and parameters. Using a training test split approach, the model was tested and validated on 623,972 patients residing in Georgia and applied to the full US study cohort (N=30,100,826).

The average age of patients is 50 years, and the average patient has 2 to 3 comorbidities. Nearly 28% (8,285,408) of patients have the greatest risk score, and 10,426,683 (34.64%) of patients are considered high-risk (a score of at least 8; Table 2). The mean risk score before standardization is 7.81. Age accounts for 52% (4.04) of a patient's total risk, followed by the number of inferred comorbidities (29%; 2.23); inferred chronic obstructive pulmonary disease, hypertension, or diabetes (15%; 1.21); and the urban density classification (5%; 0.38).

The risk assigned is most heavily weighted for adults aged ≥80 years (maximum value assigned), followed by adults aged 65 to 79 years [(7 + age/100)], 50 to 64 years [$(1 + age/100)^3$], and 18 to 49 years [$(1 + age/100)^2$].

Table 1. Model inputs and values.

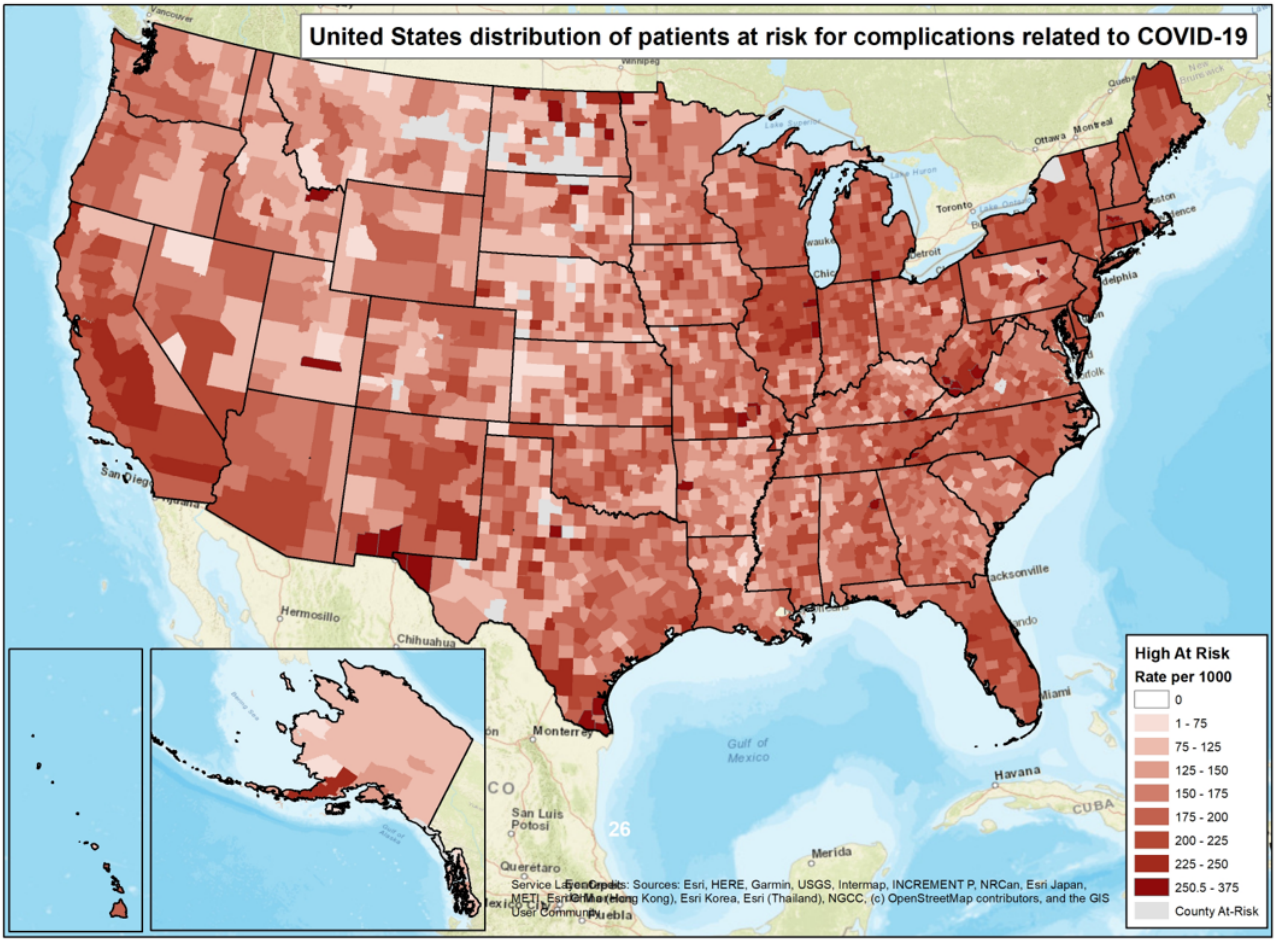
Risk factor	Risk value
Baseline risk	
Maintenance medications for a non–high-risk chronic condition	1.789
Maintenance medications for a high-risk chronic condition	2.289
Maintenance medications (≥2)	2.592
Known disease states for risk	
Specific specialty medications	Maximum
Chronic lung disease medications	2.681
Diabetes mellitus medications	1.586
Cardiovascular disease medications	1.575
Age-related risk	
Age of 18-49 years	$(1 + age/100)^2$
Age of 50-64 years	$(1 + age/100)^3$
Age of 65-79 years	(7 + age/100)
Age of ≥80 years	Maximum
Urban density classification risk	
Urban	1
Less dense urban	0.75
Suburban	0.5
Rural	0

Table 2. Risk category summary (N=30,100,826).

Risk category	Patients, n (%)
≤1	765,867 (2.54)
≤3	6,598,930 (21.92)
≤4	4,594,748 (15.26)
≤5	2,999,058 (9.96)
≤6	2,374,706 (7.89)
≤7	2,340,834 (7.78)
≤8	1,679,440 (5.58)
≤9	447,802 (1.49)
<10	14,033 (0.05)
10	8,285,408 (27.53)

Patient addresses were used to depict the distribution of risk status across the United States. These data were then compiled to depict a county-level risk status for each county for which we had sufficient data. A county-level at-risk rate was calculated per 1000 residents. The highest county-level risk category ranged from 265.1 to 375.0 high-risk residents per 1000. Furthermore, 8 risk ranges were assembled and color coded onto a county-level US map (Figure 1). The real-time Johns Hopkins University CSSE COVID-19 cases data are layered on top of the county-level risk status to facilitate a visual depiction of the presence of cases in relation to the county-level risk of residents at risk of suffering severe complications from COVID-19 [2]. At the time of publication, the map depicts numerous counties, principally in less densely populated regions of the United States that have a high rate of vulnerable residents but have not yet had large numbers of COVID-19 cases. The interactive map depicting the US distribution of patients at risk for complications related to COVID-19 is publicly available for viewing [7]. The county-level risk rates are recalculated and refreshed weekly, whereas the Johns Hopkins University CSSE case numbers are uploaded in real time.

Figure 1. Distribution of patients at risk for complications related to coronavirus disease (COVID-19) in the United States.



Discussion

Overview

This study shows that there are counties across the United States whose residents are at high risk of developing severe complications from COVID-19; many of these counties had not yet recorded many COVID-19 cases when the interactive map was released. Although transmission rates may differ among rural and urban areas, it is often the case that residents of rural counties have higher risk statuses and less access to health care resources. If disease transmission becomes rampant in a rural county with a high risk status, health care resources may become depleted quickly if a disproportionate number of its residents experience severe complications from the disease.

This risk model utilizes data from approximately 10% of the US population. At the time of publication, this is the most comprehensive US model to depict county-level prognosis of COVID-19 infection [8]. DeCaprio et al [9] modeled rates of COVID-19–related pneumonia and hospital admission using 1.5 million records from Medicare claims data from 2015 to 2016. Unlike medical claims data, our pharmacy claims data is accessible at a near real-time rate, which likely improves the precision of the model. Moreover, our data includes US adults aged 18 years and above, making our population estimates broader and more generalizable.

With the core data, Walgreens was able to implement proactive community outreach by pharmacists who offered home delivery to high-risk patients to ensure they had a sufficient supply of their medications without having to leave their homes. The pharmacists also inquired about patients' wellbeing during the pandemic and shelter-in-place orders, and they referred patients to community services as needed. Additionally, by publicly sharing deidentified county-level risk distributions, Walgreens and other organizations are able to plan and respond as COVID-19 begins to spread to areas that previously experienced little impact.

More importantly, our interactive map will serve to inform public officials and health care leaders of where there are highly vulnerable pockets of the population so that they may proactively prepare for the possibility of a disproportionately high number of patients with severe complications due to COVID-19. Many of these high-risk populations are in rural areas that have limited access to advanced health care services such as a hospital with respirators. Other maps have depicted the current availability of health care resources, such as ICU beds, compared to the amount that will be required in the event of a regional COVID-19 outbreak [10]. Our county-level risk estimates may be used alongside data sets such as that produced by Moghadas et al [10] to improve the accuracy of anticipated health care resource needs.

Our interactive map will also aid in proactive planning and preparations among employers that are deemed critical, such as pharmacies and grocery stores, to prevent the spread of COVID-19 within their facilities. At the time of publication, the interactive map showed that it is relatively uncommon to see a county with a low rate of patients at risk for complications related to COVID-19, but a high rate of COVID-19 cases. This may be evidence of the differential presentation of SARS-CoV-2 (severe acute respiratory syndrome coronavirus 2) in individuals who are younger and have few comorbidities as compared to their counterparts.

Limitations

There is potential bias in the data source as it only includes Americans who have access to health care and can afford to purchase medication. The model would likely be strengthened if it represented less-advantaged individuals who are uninsured or underinsured, as well as those who are financially unable to afford their medications. Moreover, since our model relied on pharmacy data, not medical claims data, patient diagnoses were assumed based on the pharmaceutical treatment regimen. Finally, the model could not be externally validated because we did not have access to patient-level COVID-19 case data, which limited our ability to calculate the sensitivity and specificity of the risk model.

While the interactive map will be useful for multiple purposes, it is for informational purposes only and is not intended to provide medical advice or discourage social distancing or other health-related recommendations. Although Walgreens will take reasonable steps to update this map routinely with the latest available information, SARS-CoV-2 is a novel virus and its spread is rapid and unpredictable. We encourage everyone to visit the CDC's Coronavirus (COVID-19) webpage for the latest information and recommendations [11]. We encourage the public to contact their health care provider to address any concerns and before taking any personal action in response to the information provided by the model or map.

Authors' Contributions

RLSR, EER, TS, and MT designed and performed the research; EER wrote the code and developed the weighting for the risk model; RLSR, TS, and MT reviewed the model output and worked with EER to refine the model parameters; DEL developed the map, including the uploading of both data sources; TS reviewed and performed quality checks of the interactive map; RLSR, EER, DEL, TS, and MT wrote the paper.

Conflicts of Interest

All authors are employees of Walgreen Co.

Multimedia Appendix 1
Specialty medications included in the coronavirus disease (COVID-19) risk calculation.

[DOCX File , 53 KB - publichealth_v6i2e19606_app1.docx]

Multimedia Appendix 2
Maintenance medications included in the coronavirus disease (COVID-19) risk calculation.
[DOCX File , 14 KB - publichealth_v6i2e19606_app2.docx]

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
CSSE: Center for Systems Science and Engineering
ICU: intensive care unit
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Modeling COVID-19 Latent Prevalence to Assess a Public Health Intervention at a State and Regional Scale: Retrospective Cohort Study

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Abstract

Background: Emergence of the coronavirus disease (COVID-19) caught the world off guard and unprepared, initiating a global pandemic. In the absence of evidence, individual communities had to take timely action to reduce the rate of disease spread and avoid overburdening their health care systems. Although a few predictive models have been published to guide these decisions, most have not taken into account spatial differences and have included assumptions that do not match the local realities. Access to reliable information that is adapted to local context is critical for policy makers to make informed decisions during a rapidly evolving pandemic.

Objective: The goal of this study was to develop an adapted susceptible-infected-removed (SIR) model to predict the trajectory of the COVID-19 pandemic in North Carolina and the Charlotte Metropolitan Region, and to incorporate the effect of a public health intervention to reduce disease spread while accounting for unique regional features and imperfect detection.

Methods: Three SIR models were fit to infection prevalence data from North Carolina and the greater Charlotte Region and then rigorously compared. One of these models (SIR-int) accounted for a stay-at-home intervention and imperfect detection of COVID-19 cases. We computed longitudinal total estimates of the susceptible, infected, and removed compartments of both populations, along with other pandemic characteristics such as the basic reproduction number.

Results: Prior to March 26, disease spread was rapid at the pandemic onset with the Charlotte Region doubling time of 2.56 days (95% CI 2.11-3.25) and in North Carolina 2.94 days (95% CI 2.33-4.00). Subsequently, disease spread significantly slowed with doubling times increased in the Charlotte Region to 4.70 days (95% CI 3.77-6.22) and in North Carolina to 4.01 days (95% CI 3.43-4.83). Reflecting spatial differences, this deceleration favored the greater Charlotte Region compared to North Carolina as a whole. A comparison of the efficacy of intervention, defined as 1 – the hazard ratio of infection, gave 0.25 for North Carolina and 0.43 for the Charlotte Region. In addition, early in the pandemic, the initial basic SIR model had good fit to the data; however, as the pandemic and local conditions evolved, the SIR-int model emerged as the model with better fit.

Conclusions: Using local data and continuous attention to model adaptation, our findings have enabled policy makers, public health officials, and health systems to proactively plan capacity and evaluate the impact of a public health intervention. Our SIR-int model for estimated latent prevalence was reasonably flexible, highly accurate, and demonstrated efficacy of a stay-at-home order at both the state and regional level. Our results highlight the importance of incorporating local context into pandemic forecast modeling, as well as the need to remain vigilant and informed by the data as we enter into a critical period of the outbreak.

(JMIR Public Health Surveill 2020;6(2):e19353) doi:10.2196/19353

KEYWORDS

COVID-19; public health surveillance; novel coronavirus 2019; pandemic; forecasting; SIR model; detection probability; latent prevalence

Introduction

In December 2019, a novel coronavirus emerged in Wuhan, Hubei Province, China [1]. The pathogen causes a respiratory illness, now known as the coronavirus disease (COVID-19) [2,3]. From its original epicenter in Wuhan, the virus spread rapidly within 30 days to other parts of Mainland China and exported to other countries [4-8]. As of April 10, 2020, 210 countries and territories have reported 1,673,423 confirmed cases of COVID-19 and 101,526 deaths [9]. Due to the spread across multiple countries and the large number of people impacted, on March 11 the World Health Organization recognized the novel severe acute respiratory syndrome (SARS) coronavirus 2 as a pandemic that poses a major global public health threat [10,11].

Although the effects of the COVID-19 pandemic are experienced worldwide, many key health policy decisions designed to reduce transmissions are determined at national and regional levels. These critical policy decisions must be implemented quickly and evaluated continuously so they can be adapted to the local context, recognizing the clear effect that geography, community context, density, and social determinants of health have on COVID-19 outcomes. In North Carolina, the first COVID-19 case was reported on March 2, 2020, and cases increased to 3,963 total confirmed cases as of April 10 [12]. To slow the rapidly increasing transmission rate, within a few weeks after the first case was detected, North Carolina state officials promoted social distancing strategies (ie, deliberately increasing physical space), banned large social gatherings, and closed public schools and universities. Subsequently, a stay-at-home order, which only allows for essential travel outside the home, was issued in the southwestern part of the state by Mecklenburg County effective at 8 am, March 26, lasting through April 16 (since extended to April 29), while a statewide stay-at-home order was issued effective at 5 pm, March 30, lasting to April 29.

Because the COVID-19 landscape evolves rapidly due to the confluence of locally relevant factors, appropriate modeling using timely infection prevalence to drive decision making around containment, treatment, and resource planning is critical. Forecasting models are used to generate early warnings to identify how a pandemic might evolve. During the early stages of the COVID-19 pandemic, forecasting was frequently applied to predict national and international infection transmission trends [13,14]. Local communities and health systems turned to these national and international models for their own planning; however, the generalizability of such models to the local situation is limited and ignores important community-level population characteristics and transmission dynamics [3,15-17]. An objective of this study was to understand how spatial differences impact model results and their interpretation.

In response to the need for actionable data insights in our community and health system, investigators from the Atrium Health Center for Outcomes Research and Evaluation developed a series of COVID-19 forecasting models, which were used to guide Atrium Health's initial proactive response to ensure sufficient capacity to treat the expected surge in patient care demands. In this study, we present an initial susceptible-infected-removed (SIR) epidemic model and its evolution to the susceptible-infected-removed-social distancing-detection rate (SIR-int) model. In this paper, we describe and compare these models, the spatial differences in a pandemic, the significance of observed cases versus actual prevalence in the setting of rapidly evolving testing strategies, the current epidemiological trends, and the potential effects of nonpharmaceutical interventions applied locally (eg, social distancing).

Methods

The observed cumulative case and death counts were obtained daily at noon starting March 2, 2020, when the first COVID-19 case was reported, from the North Carolina Department of Health and Human Services website for all 100 counties [12]. Data collection for this manuscript ended on April 7, just prior to submission. To accurately estimate the actual latent prevalence at time *t*, the cumulative case counts were adjusted for imperfect detection by dividing them by 0.14. Although estimates of detection probability for the coronavirus, also known as the ascertainment rate, vary in the literature, ours is in line with those reported [18-22]. Modeling only the observed prevalence will give an inaccurate timeline of pandemic behavior. Cumulative deaths were then subtracted from adjusted cumulative cases. We also adjusted cumulative cases for recoveries by removing cases after 20 days, the estimated median duration of viral shedding from illness onset [23]. Daily incremental incidence was obtained by subtracting the estimated latent prevalence at time $t-1$ from that at time t. Crucially, in our research, we model estimated latent prevalence as constructed here, not observed prevalence. For the sake of brevity moving forward, we use the terms "latent prevalence" and "prevalence" interchangeably.

In addition to North Carolina, interest also lay in the subpopulation served by Atrium Health's greater Charlotte market. For convenience, we make use of a designation of a group of counties that constitute the greater Charlotte area used by the North Carolina Department of Health and Human Services. Specifically, the US Centers for Disease Control and Prevention's Cities Readiness Initiative (CRI) is a federally funded program designed to enhance preparedness in the nation's largest population centers to rapidly and effectively respond to large public health emergencies such as an act of bioterrorism. This also allowed us to model on a region that harmonized with the state's approach to disaster planning in case statewide coordination of resources would be required. Within North Carolina, 11 counties are grouped into a CRI region that includes Anson, Cabarrus, Catawba, Cleveland, Gaston, Iredell, Lincoln, Mecklenburg, Rowan, Stanly, and Union. Collectively, we henceforth refer to these counties as "the CRI" (Figure 1). Because the CRI closely mirrors the large area served by Atrium Health's greater Charlotte market, we used this population base for our local modeling efforts. The CRI includes over 2.5 million residents (24% of the North Carolina population) and ranges from rural settings like Anson County to Mecklenburg County, which contains North Carolina's largest city, Charlotte [24]. To understand how spatial

differences impact model results and their interpretation, we compared the CRI to North Carolina throughout the early phases of this pandemic.

We introduce the SIR deterministic compartmental model originally described by Kermack and McKendrick [25] and depict it in Figure 2.

Figure 1. Map of North Carolina showing the Cities Readiness Initiative region.

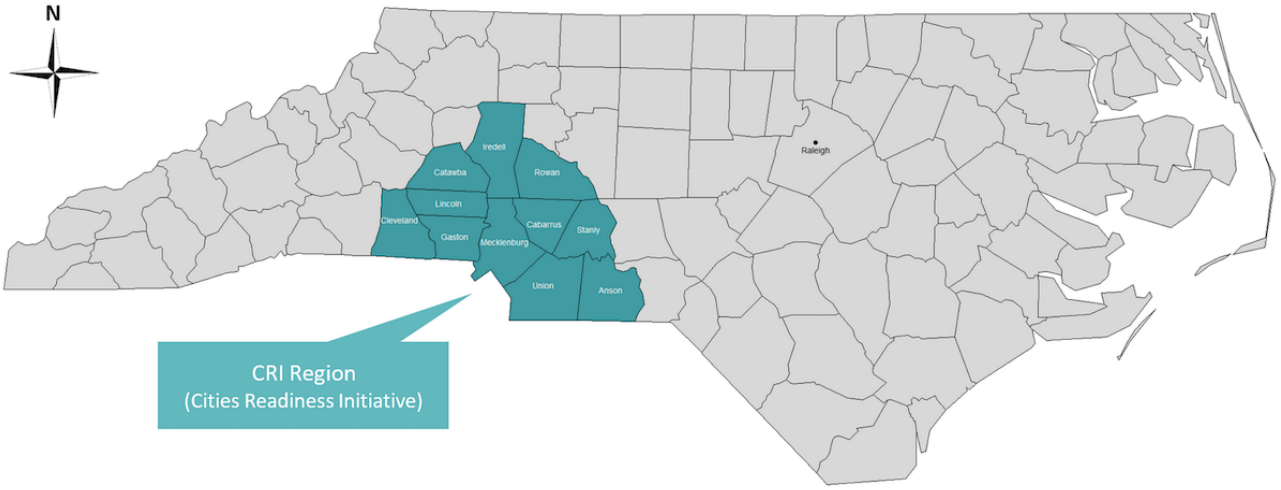
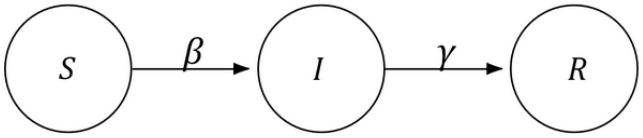


Figure 2. Susceptible-infected-removed model diagram showing compartments and flow. I: infected; R: removed; S: susceptible.



S is the number of individuals that are *susceptible* to infection in the population; *I* is the number of individuals that are *infected*; *R* is the number of individuals that are *removed* from the population via recovery and subsequent immunity or death from infection. This mutually exclusive and exhaustive partition is such that $S + I + R = N$, where N is the closed population size. We further assume all uninfected individuals are susceptible to infection. The transition flow is described by the arrows in the figure labeled with two rates. The parameter β is the infection rate and can be further decomposed as the product of the probability of transmission per contact and the rate of contact per person per unit time. γ is the removal rate.

More formally, the SIR model is a system of three ordinary differential equations (ODEs) involving two unknown parameters.

Note that all of *S*, *I*, and *R*, and their derivatives are functions of time *t*, such as $S = S(t)$, although we do not denote this notationally here. By how the model is constructed, the first equation in the system returns a number less than or equal to zero, the second equation returns any real number, and the third equation returns a number greater than or equal to zero.

All data analysis was done using R statistical software, version 3.6.2 (R Foundation for Statistical Computing). As described in Churches [26], we used the ode() default solver from the desolve package to solve the system of ODEs defining the SIR model. Next, we used a quasi-Newton method with constraints to find the optimal values for β and γ on (0, 1) by minimizing the square root of the sum of the squared differences between *I*, which is our prevalence, and its prediction $\hat{I}$ over all time *t* [27]. To establish initial conditions for model fitting, we estimate the population size of North Carolina and the CRI to be 10,488,084 and 2,544,041, respectively, using information taken from census estimates [24]. After obtaining the estimates  and  , to help assess model goodness-of-fit, we define the following statistic:

Time is indexed from *i* 1, ... , *n*, and *n* is the number of prevalences in the sample. Note that $\bar{I}$ is the average of the I_i's.

To compare different scenarios for both North Carolina and the CRI, we define an SIR model (SIR-pre) fit to the data from the time of the outbreak until the time of the March 26, 2020, Mecklenburg County stay-at-home order. Since Mecklenburg County is the state's second largest county, this could have a strong effect on the pandemic trajectory, both in the CRI and the state; therefore, we have used this date to delineate the date of the significant public health intervention. We further define an SIR model (SIR-post) fit to the data from the time of the outbreak until the end of data collection.

Given the major public health intervention implemented on March 26, 2020, we modified the SIR model for both the CRI and North Carolina to accommodate this (denoted SIR-int). SIR models with interventions can be simulated using the EpiModel

package. This package provides tools for building, simulating, and analyzing several classes of models for the population dynamics of infectious disease transmission in epidemics. These include not only deterministic compartmental models, but stochastic individual contact models and network models. We first fitted the SIR model as before to the data up until March 26 and extracted the estimates of β and γ. After March 26, we retained the removal rate but modified the infection rate. We set the preintervention probability of transmission equal to 0.015, which is consistent with other viral infectious diseases like SARS and AIDS [28,29]. We then set the rate of contact so that the probability of transmission multiplied by the rate of contact equaled  . To simulate the observed intervention, using the default fourth-order Runge-Kutta Method (RK4) ODE solver, we affected the probability of transmission by iteratively decreasing the hazard ratio of infection, given exposure to the intervention (step size of 0.0001) compared to no exposure, until the fitted infection curve yielded a maximum  .

For exploratory data analysis, we generated time plots for prevalence, incidence, and both daily and cumulative deaths. The basic reproduction number R_0 is the average number of secondary cases of disease caused by a single infected individual over his or her infectious period in a population where all individuals are susceptible to infection. To estimate R_0, we compute:

 and  are estimates taken from the model fit. Since the SIR model is fully parameterized by β and γ, we also obtain predictions  and  over all time *t*. The percentage of infected at peak prevalence was computed by dividing the maximum $\hat{I}$ by the population size *N*, while the final percentage of infected was computed as the limit 1 −  (∞)/*N*. To estimate doubling time and compute a 95% confidence interval, we modeled incidence growth by fitting a loglinear model as a function of time *t* using the incidence package.

Results

Figure 3 shows time plots of prevalence, cumulative deaths, incidence, and daily deaths for North Carolina from the start of the outbreak on March 2 up to and including April 7, 2020. The first death was recorded in North Carolina on March 24.

Figure 4 shows time plots of prevalence, cumulative deaths, incidence, and daily deaths for the CRI from the start of the outbreak on March 11 up to and including April 7, 2020. The first death was recorded in the CRI on March 25.

Notably, the prevalence and cumulative death curves for both figures look exponential. Although both incidence curves are increasing, the incidence curves become volatile after the stay-at-home order went into effect. Prior to March 26, 2020, doubling time was estimated to be 2.56 days in the CRI (95% CI 2.11-3.25) and 2.94 days in North Carolina (95% CI 2.33-4.00). Once data after March 26 were included, the doubling times increased and were estimated to be 4.70 days in the CRI (95% CI 3.77-6.22) and 4.01 days in North Carolina (95% CI 3.43-4.83).

Figure 3. Time plots for NC. COVID-19: coronavirus disease; NC: North Carolina.

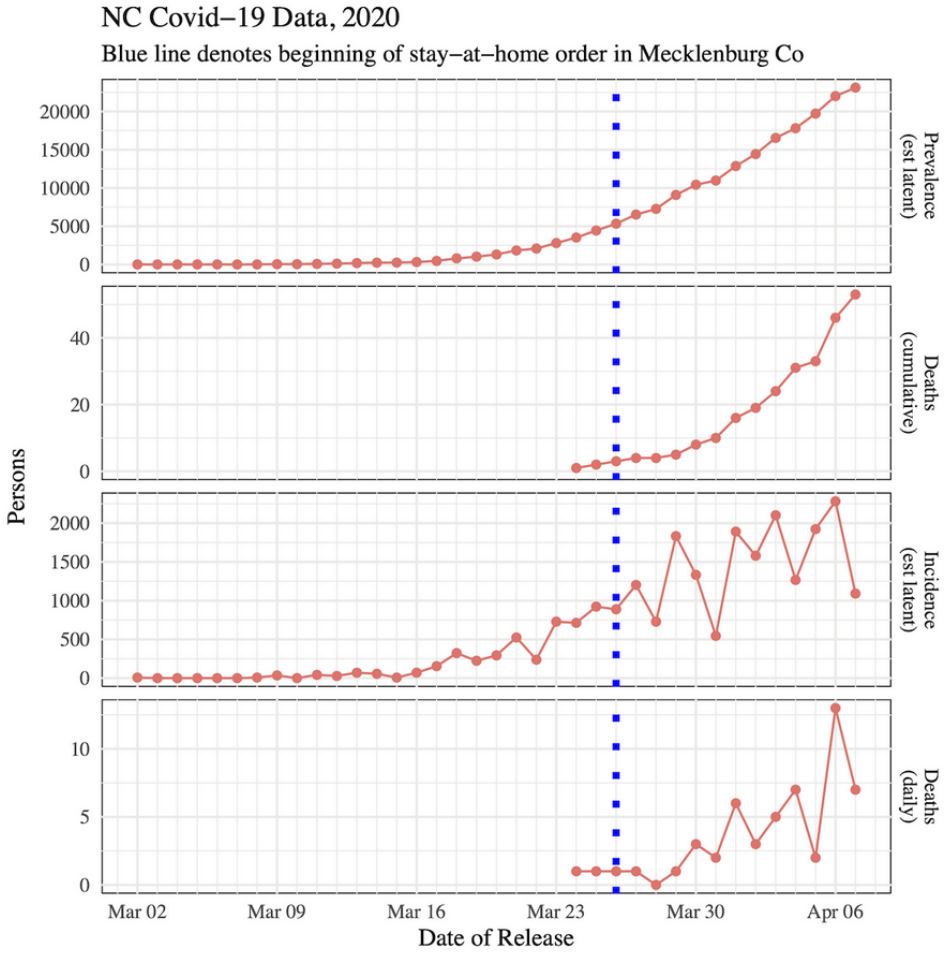
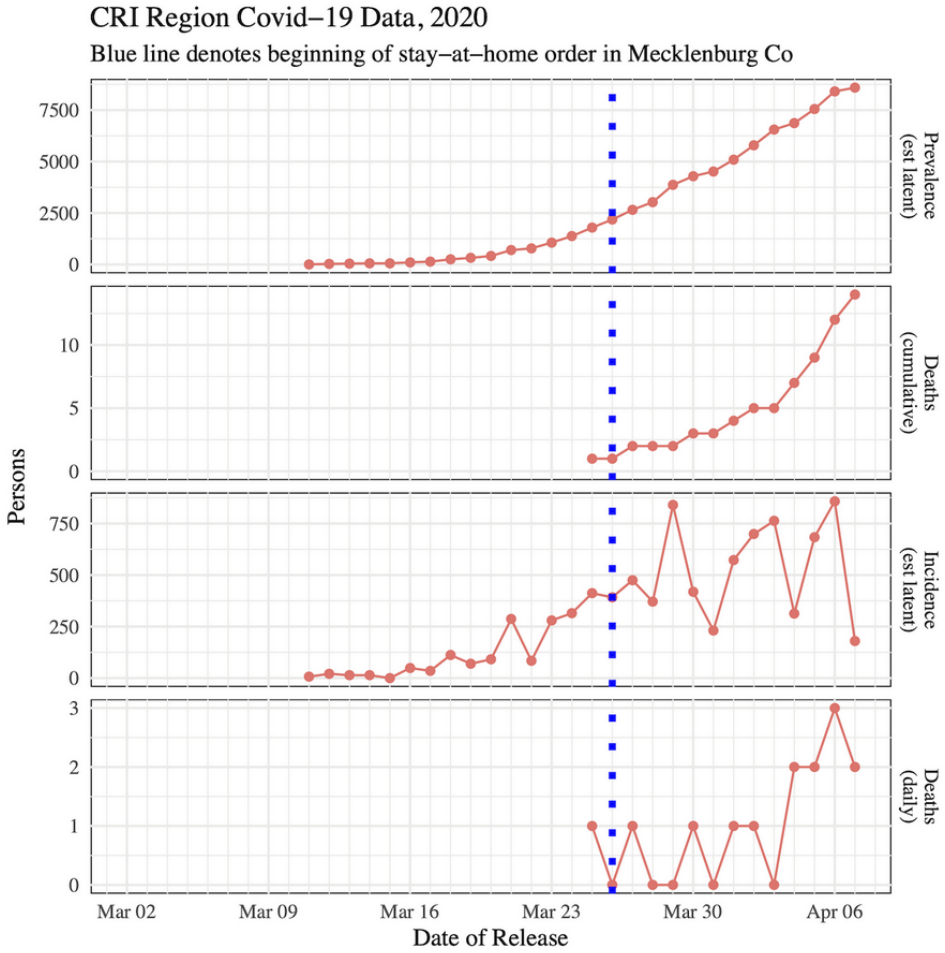


Figure 4. Time plots for the CRI. COVID-19: coronavirus disease; CRI: Cities Readiness Initiative.



Tables 1 and 2 gives a synopsis of the model fits for each location and model type. The estimated R_0 of 2.36 for the CRI prior to March 26, 2020, is more typical of the range of R_0 values given in the literature for COVID-19, while the value of 1.79 for North Carolina is substantially lower [5,30]. After the intervention, the estimated R_0 values for both locations drop to a similar value, although this result was affected by a reduced model fit. A comparison of the efficacy of intervention, defined as 1 – the hazard ratio of infection, gives 0.25 for North Carolina and 0.43 for the CRI. Using these hazard ratios to compute estimates of R_0 from March 26 onward ($R_{0,\,post}$), we derive 1.34 and 1.33 for North Carolina and the CRI, respectively. This suggests that the COVID-19 outbreak is rapidly decelerating in North Carolina and the CRI after the aggressive public health intervention.

Table 1. Summary table of model fit for SIR-pre and SIR-post models in NC and the CRI.

Location	Model			R_0	
NC[a]	SIR[b]-pre	0.6415	0.3585	1.79	0.99
NC	SIR-post	0.6165	0.3835	1.61	0.84
CRI[c]	SIR-pre	0.7020	0.2980	2.36	0.94
CRI	SIR-post	0.6381	0.3619	1.76	0.65

[a]NC: North Carolina.

[b]SIR: susceptible-infected-removed.

[c]CRI: Cities Readiness Initiative.

Table 2. Summary table of model fit for susceptible-infected-removed–int model in NC and the CRI.

Location	Hazard ratio	β_0	$\beta_{0,\text{post}}$
NC[a]	0.75	0.99	1.34
CRI[b]	0.57	0.99	1.33

[a]NC: North Carolina.

[b]CRI: Cities Readiness Initiative.

Figures 5 and 6 show plots of the three fitted models' infection curves for North Carolina and the CRI, respectively, out to April 7, 2020. The behavior in the two plots is the same. The SIR-post model clearly demonstrates a lack-of-fit to the data. For the SIR-int model, we noted the hinge point induces a change of behavior from March 26 onward. The dotted orange line represents the SIR-pre forecast projections from March 26 onward. They are much larger than the actual data.

Figure 5. Infection prevalence prediction curves for NC up to April 7, 2020. COVID-19: coronavirus disease; NC: North Carolina; SIR: susceptible-infected-removed.

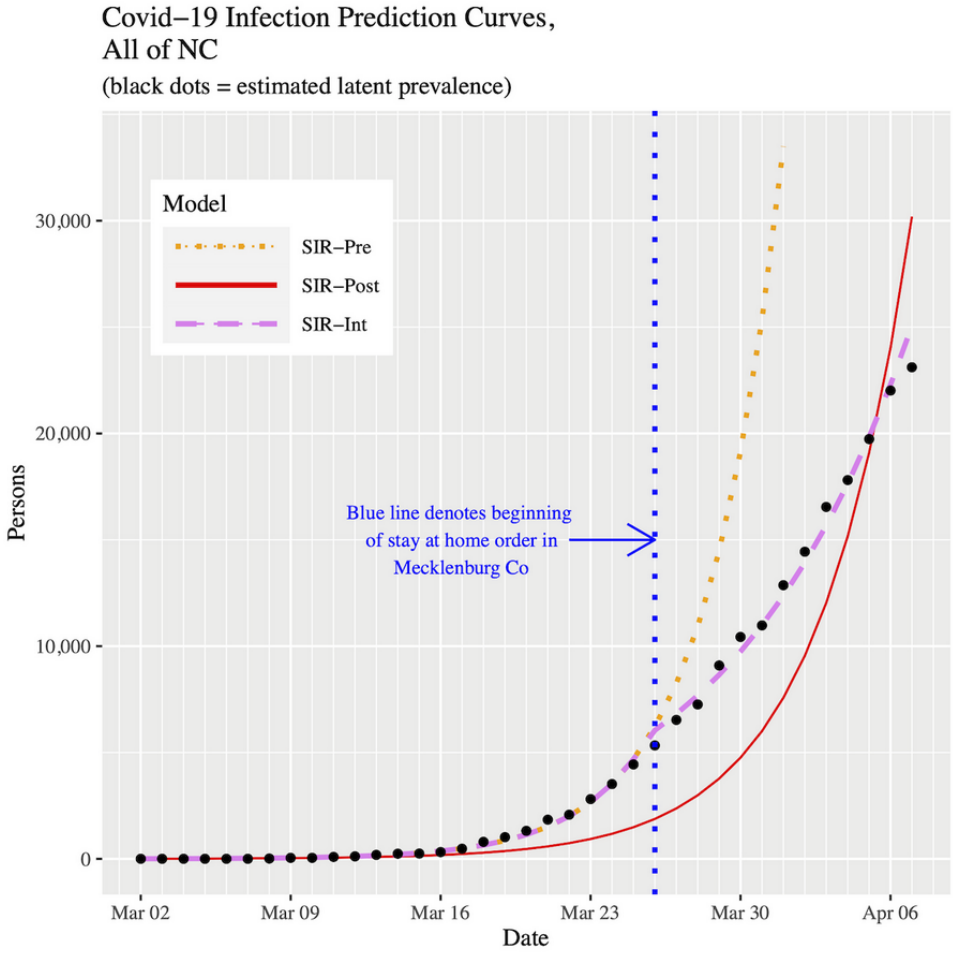
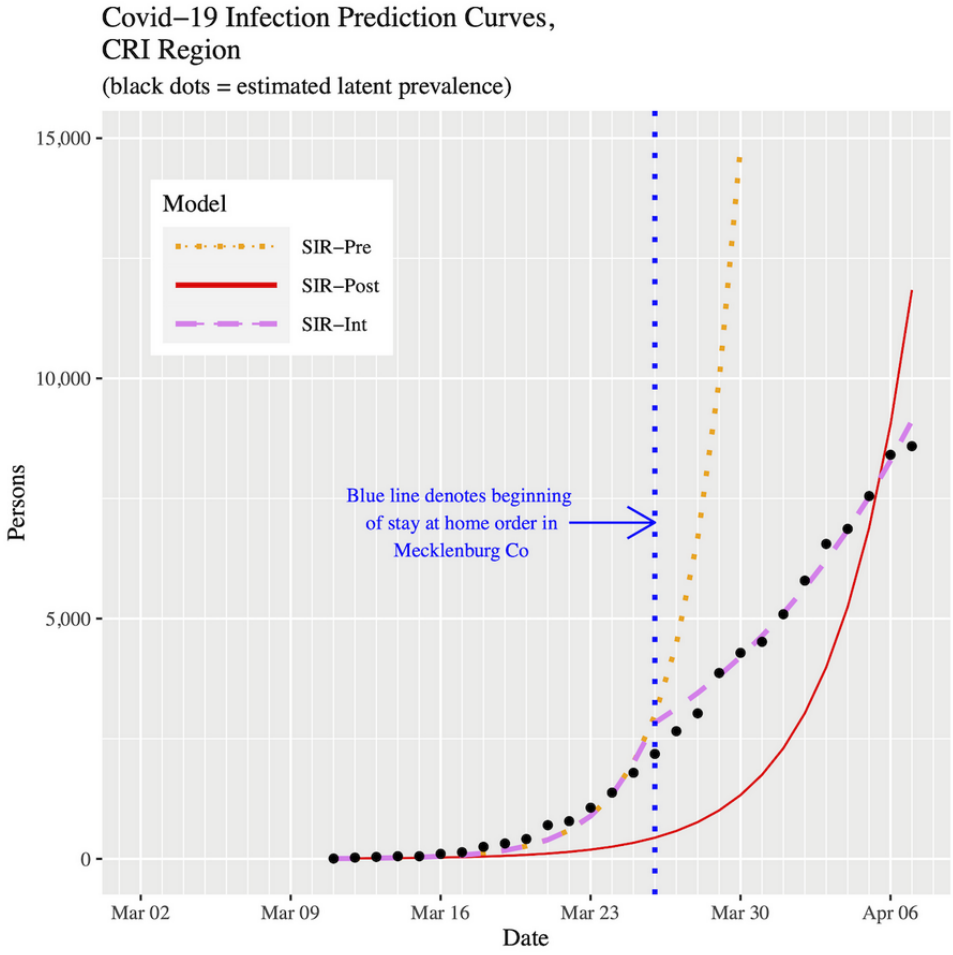


Figure 6. Infection prevalence prediction curves for the CRI up to April 7, 2020. COVID-19: coronavirus disease; CRI: Cities Readiness Initiative; SIR: susceptible-infected-removed.



Figures 7 and 8 show plots of the three fitted models' infection curves for North Carolina and the CRI, respectively, projected out to the beginning of August. In both plots, we see the dramatic effect of the public health intervention; that is, the so-called "flattening of the curve." There are two important differences to note between North Carolina and the CRI region. First, the CRI visibly shows relatively more flattening. This effect can be best observed in Table 3 in the peak infected and final infected columns. Moving from the pre to post to int models within a location, the drop in percentage infected is more pronounced in the CRI. In fact, for the SIR-int model, the percentages are virtually the same for both locations; that is, the CRI has "slowed down" to the state as a whole. Second, the date of peak prevalence was initially 8 days earlier for the CRI compared to North Carolina. However, using the current SIR-int model, although both locations showed their infection curves shifting forward in time, the date of peak prevalence is now 3 days later in the CRI (Table 3). To put this into context, for North Carolina, the time duration from the start of the outbreak to the peak prevalence has gone from 49 days to 70 days (43% increase). However, for the CRI, the time duration from the start of the outbreak to the peak prevalence has gone from 32 days to 64 days (100% increase).

Figures 9 and 10 show plots of the three fitted models' removal curves for North Carolina and the CRI, respectively, projected out to the beginning of August. These plots support what we have observed so far. With the continued intervention, the removal curves are beginning to collapse, which is a behavior we would expect. For the SIR-int model, both locations show a removal plateau being reached roughly around the beginning of July.

Figure 7. Infection prevalence prediction curves for NC up to August 1, 2020. COVID-19: coronavirus disease; NC: North Carolina; SIR: susceptible-infected-removed.

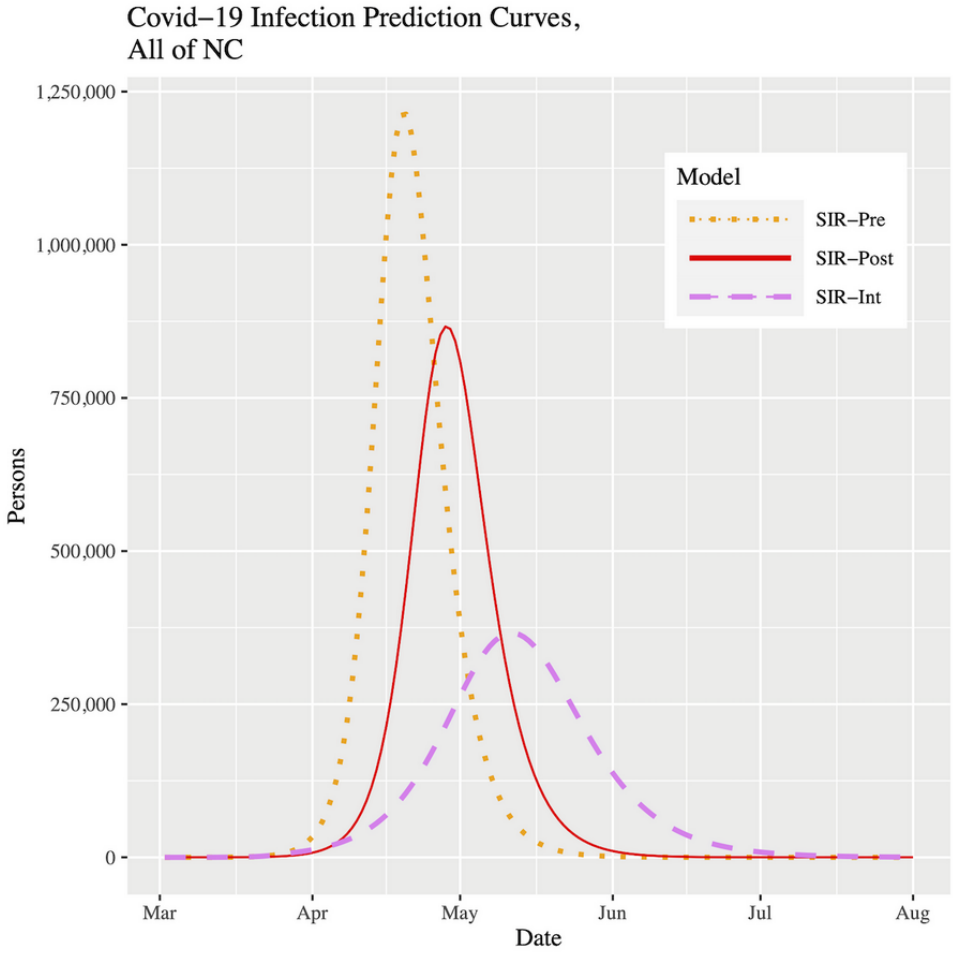


Figure 8. Infection prevalence prediction curves for the CRI up to August 1, 2020. COVID-19: coronavirus disease; CRI: Cities Readiness Initiative; SIR: susceptible-infected-removed.

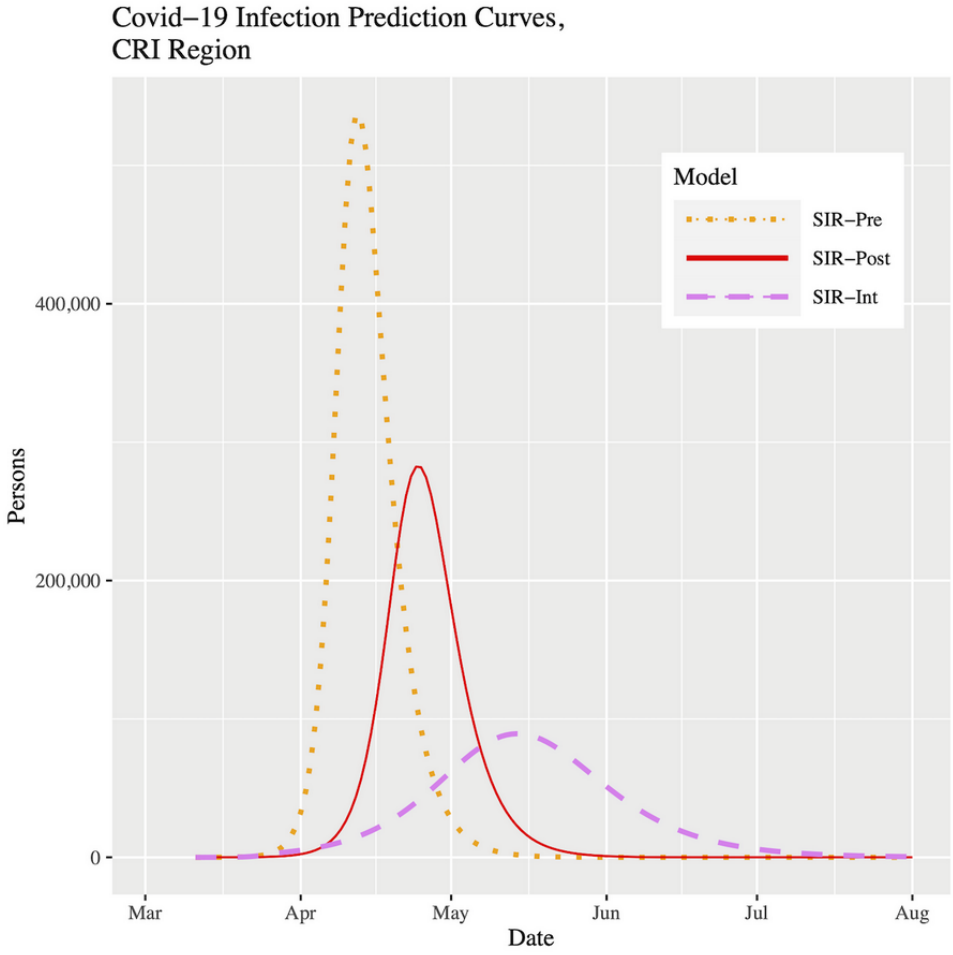


Table 3. Summary table describing infection under three different models in NC and the CRI.

Peak Kinetics							Final infected, n (%)
Location	Model	2020 date	[illegible]	$\hat{I}$	[illegible]	Peak infected, %	
NC[a] (n=10,488,084)	SIR[b]-pre	Apr 20	5,673,270	1,213,190	3,601,625	12	7,639,271 (73)
NC (n=10,488,084)	SIR-post	Apr 28	6,614,437	866,404	3,007,244	8	6,776,491 (65)
NC (n=10,488,084)	SIR-int	May 11	7,913,011	366,037	2,209,037	3	4,798,450 (46)
CRI[c] (n=2,544,041)	SIR-pre	Apr 12	1,142,320	537,031	864,690	21	2,217,696 (87)
CRI (n=2,544,041)	SIR-post	Apr 24	1,488,530	282,257	773,254	11	1,826,953 (72)
CRI (n=2,544,041)	SIR-int	May 14	1,911,343	89,324	543,374	4	1,163,824 (46)

[a]NC: North Carolina.

[b]SIR: susceptible-infected-removed.

[c]CRI: Cities Readiness Initiative.

Figure 9. Removal prevalence prediction curves for NC up to August 1, 2020. COVID-19: coronavirus disease; NC: North Carolina; SIR: susceptible-infected-removed.

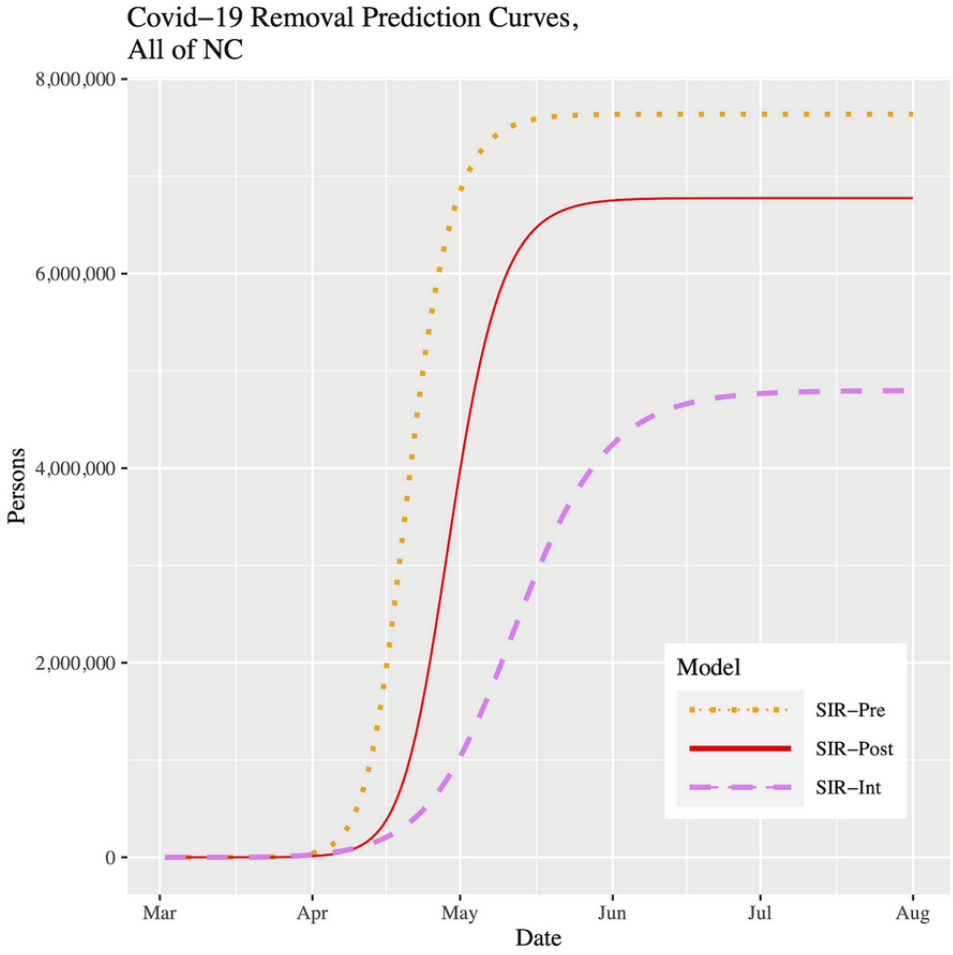
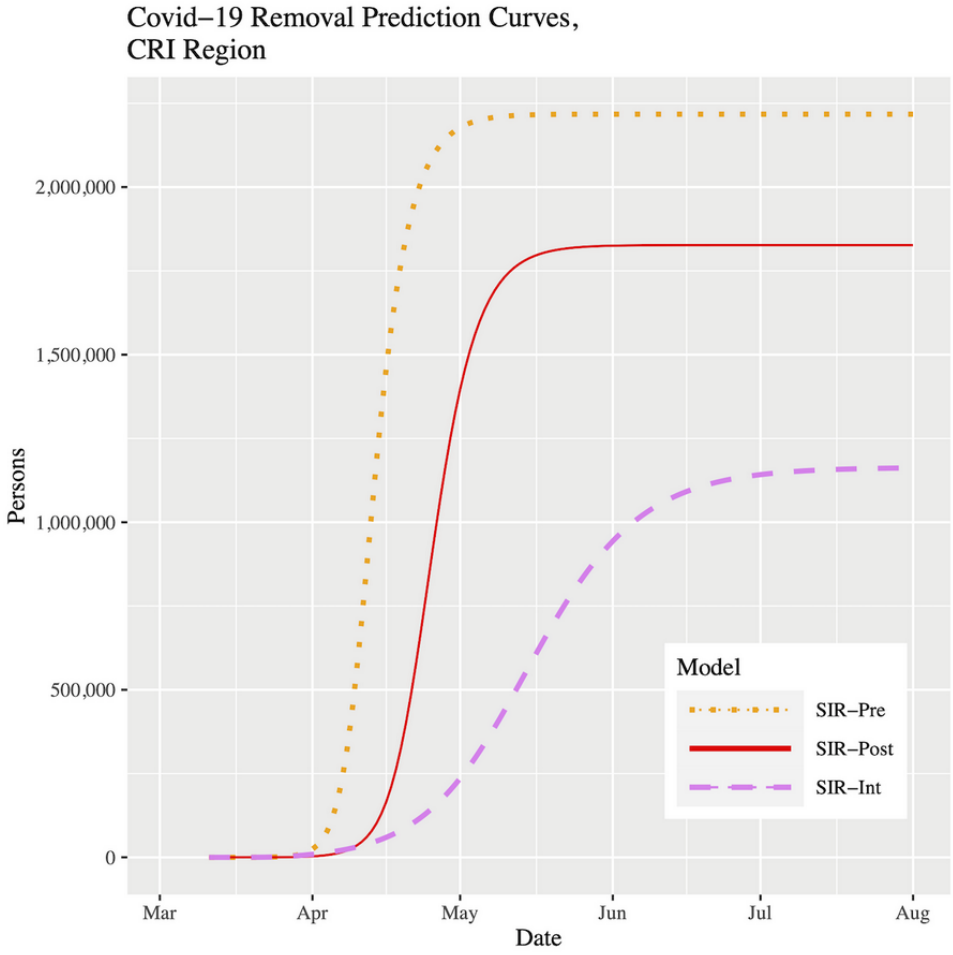


Figure 10. Removal prevalence prediction curves for the CRI up to August 1, 2020. COVID-19: coronavirus disease; CRI: Cities Readiness Initiative; SRI: susceptible-infected-removed.



Discussion

Principal Results

In terms of model fitting, we state several observations. The SIR-pre model represents a "worst case" scenario, as if the disease were allowed to run its course. Hence, early in a pandemic like this, it serves a useful purpose to help leaders understand the consequences of taking no action, or delayed action on implementing public health interventions. Beyond that, a basic SIR model, especially one that is used after being fit only to early pandemic data, imparts no further value for informing pandemic response planning, and indeed may provide errant forecasts. This diminished value also holds true when a basic SIR model is fit to contemporary data, yet ignores the effect of a public health intervention, as demonstrated by the SIR-post model. Eventually, both such models will provide a poor fit to the data. Because the behavior of any epidemic is dynamic, any model requires constant monitoring, assessment of fit to local data, and evaluation of efficacy as new data are collected or additional research becomes available. Our SIR-int model provides an example where this attention to model fit and incorporation of regional influences allows for appropriate model adaption and careful calibration thus generating the most accurate predictions available to guide regional decision making at the time.

Summarizing the effect of the intervention, the doubling time for both locations is substantially slower after the intervention, with the CRI doubling time estimate (4.70 days) now being greater than North Carolina (4.01 days). The stay-at-home orders strongly appear to be working as intended as the infection curves for both locations are now becoming flatter (and *shrinking*), with peak infection prevalence now being pushed towards mid-May, both location's recovery curves starting to fall, and measurable intervention effects on the hazard ratio and R_0. It is interesting to note that our results match rigorous Monte Carlo simulation studies we conducted weeks beforehand.

If we compare the two locations, the estimated R_0 of 2.36 for the CRI prior to March 26, 2020, is more typical of the range of R_0 values in the literature for COVID-19, while the value of 1.79 for North Carolina is substantially lower. This could be attributed to the fact that the CRI contains the largest city in North Carolina, and one of the United States' busiest airports, setting the stage for this region to have become another COVID-19 hot spot. It is interesting to note that the North Carolina SIR-int model showed a better fit when the changepoint was also set to March 26, rather than March 30 when the statewide stay-at-home order went into place. One possible explanation for this could be that as the pandemic began in earnest, the general population's fear of the virus also increased, perhaps causing most North Carolina citizens to shelter-in-place

prior to the order going into effect. Another explanation is that Mecklenburg County accounts for almost 11% of the North Carolina population and so the effect of the county order directly impacted adjoining counties in the CRI, thus influencing the observed effect at the state level. Two additional interesting observations highlight the critical influence of spatial variation. First, the CRI infection curve evidences relatively more flattening and a later peak infection date. Second, the intervention effect in the CRI also appears stronger. The likely explanations for these differences are the Mecklenburg County stay-at-home policy going into effect 5 days before the state order, the different reaction of the local population to the order and its related messaging, and innumerable other unknown covariates such as early canceling of religious services, public gathering policies, and canceling of elective medical visits and procedures.

Limitations

There are limitations to the SIR model. Some take issue with its deterministic form, although one could fit a Bayesian SIR model to make it stochastic. Perhaps the biggest limitation is that β and γ could be time-varying due to different forms of intervention (enhanced personal protective measures and social distancing). However, as we have shown in this paper, we can easily leverage pre-existing R functions to incorporate a changepoint that modifies the probability of transmission to acknowledge an important public health intervention. It is also possible to customize the SIR model within R to define more advanced and different transition processes, and then parameterize and simulate those models to accommodate insights from additional research. In this way, one can also examine "what if" scenarios or assess model robustness through sensitivity analysis. The SIR model is simple to understand and easier to fit, as opposed to other deterministic compartmental models, such as SEIR, or stochastic individual contact models [31]. However, these more advanced models will play an increasingly important role in forecasting and understanding the dynamics of this evolving pandemic.

The lack of widespread COVID-19 testing, both for symptomatic and asymptomatic individuals, presents a major limitation of unknown scale and implications to forecasting models [32,33]. Data sources are known to undercount cases, only include asymptomatic illness by chance, and define cases inconsistently based on variable testing criteria between and within geographies. Collectively, these contribute to imperfect detection. As a result, high-level models may not comprehend the full extent of the outbreak, creating challenges in producing accurate forecasts. Our decision to base our modeling strategy on estimated latent prevalence addresses this inconsistency by adjusting observed prevalence counts. Modeling only the observed prevalence has the effect of shifting the SIR curves ahead in time by several days or more. Although our estimate of the detection probability (0.14) is heuristically motivated, a thorough search of the literature supports our use of this estimate as reasonable. Future work will focus on refining this estimate as new research appears and allowing it to vary as a function of time.

Comparison With Prior Work

Although there is a plethora of models that estimate the impact of COVID-19 in the United States, there are far fewer that give localized projections. We note that our mid-May date for the peak infection curve is roughly 3-4 weeks later than the projection from the often-cited model from the Institute for Health Metrics and Evaluation [34]. The latter uses a Bayesian generalized nonlinear mixed model to examine cumulative death rates and assumes a strict social distancing policy is in place. Using data up until March 13, 2020, Columbia University reported a mid-May peak time for North Carolina under no control measures and a start of July peak time under some control measures [35]. The authors caution that their metapopulation SEIR model is designed to capture national trends, and local projections should be viewed as broad estimates. Other models, such as the CHIME model from the University of Pennsylvania Health System, relied on data from three Pennsylvania hospitals to estimate hospital capacity and clinical demand and was not designed to capture changing regional mitigation strategies [36].

Policy and Practice Implications

In the context of limited national policy guidelines to reduce COVID-19 transmission, provide resources for health care system pandemic preparedness, and mitigate health consequences, state and local authorities must have reliable, timely, and geographically specific models to manage the unfolding crisis. We provided our local forecasts to health system leaders and public health officials to help guide regional planning. Because we regularly refit our models to local data, these served as a flexible tool enabling first proactive preparedness based on the initial pandemic trajectory, followed by timely pivoting of capacity planning to match the observed disease deceleration. Furthermore, locally accurate forecasts enhance the relevance of forecasting's role in public health communication [37]. For example, the potential disease impact on local health system capacity may help communities understand the rationale for public health interventions, whereas the positive effects of community mitigation may provide reinforcement for maintaining strategies like social distancing and enhanced hygiene.

Using regional and state data, we demonstrate how epidemiological modeling based on local context is critically important to informing pandemic preparedness for health systems and policy leaders. The results highlight the importance for such models to be created using local data, as opposed to running a simulation that makes many assumptions about the truth of parameter values. All models should be continuously recalibrated and adapted to the rapid, continuously changing situations inherent to a pandemic. A one-size-fits-all approach to the underpinning forecasting model or reliance on data that does not incorporate local context, sets the stage for misguided forecasting. Additionally, our study shows that, although a classic SIR model may perform well in the early days of the pandemic, it begins to lose relevance with the emergence of additional influences like social distancing and enhanced awareness of personal hygiene.

The SIR-int model has high predictive accuracy based on data collected from March 2 to April 7, 2020, for both North Carolina and the CRI and is able to demonstrate clear, compelling evidence of the efficacy of a stay-at-home order. By modeling estimated latent prevalence as we have done in this paper, instead of observed prevalence, a lag delay in projecting peak infection can be avoided, reducing the consequences to leaders who require an accurate timeline for planning purposes (eg, surge planning of hospital beds, supplies, and personnel).

Conclusions

All other things being equal, if residents continue to observe the stay-at-home orders, maintain attention to social distancing, and increase personal hygiene, then this wave of the COVID-19 outbreak would essentially be over by mid-July. It is possible that we could see continued flattening and shrinking of the infection curve in which case our forecast results would adapt commensurately. It is also possible that infection prevalence could oscillate at a low level over time, in which case more advanced modeling and methods would be needed. Our results highlight the importance of incorporating local context into pandemic forecast modeling, as well as the need to remain vigilant and informed by the data as we enter into a critical period of the outbreak. Although there will regrettably still be tragic loss of life and many North Carolina citizens infected by the coronavirus, this scenario pales in comparison to what could have been a far worse conclusion.

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PT takes full responsibility for the integrity and accuracy of the statistical analysis and assembling the manuscript; SHC generated the map and was involved in discussions on statistical analysis; YT and MS drafted the abstract and discussion; MK and JP drafted the introduction; PT drafted the methods, results, and part of the discussion; MK, MS, YT, and PT assembled references; YT, SHC, MS, and AW performed critical revision of the manuscript for important intellectual content; PP collected the data and drafted the bibliography; and AW supervised the study.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
CRI: Cities Readiness Initiative
ODE: ordinary differential equations
RK4: fourth-order Runge-Kutta method
SARS: severe acute respiratory syndrome
SIR: susceptible-infected-removed

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Original Paper

Perspective of Medical Students on the COVID-19 Pandemic: Survey of Nine Medical Schools in Uganda

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Abstract

Background: The coronavirus disease (COVID-19) pandemic is a global public health concern affecting over 5 million people and posing a great burden on health care systems worldwide.

Objective: The aim of this study is to determine the knowledge, attitude, and practices of medical students in Uganda on the COVID-19 pandemic.

Methods: We conducted an online, descriptive cross-sectional study in mid-April 2020, using WhatsApp Messenger. Medical students in 9 of the 10 medical schools in Uganda were approached through convenience sampling. Bloom's cut-off of 80% was used to determine good knowledge (≥12 out of 15), positive attitude (≥20 out of 25), and good practice (≥12 out of 15).

Results: The data of 741 first- to fifth-year medical students, consisting of 468 (63%) males with a mean age of 24 (SD 4) years, were analyzed. The majority (n=626, 84%) were pursuing Bachelor of Medicine and Bachelor of Surgery degrees. Overall, 671 (91%) had good knowledge, 550 (74%) had a positive attitude, and 426 (57%) had good practices. Knowledge was associated with the 4th year of study (adjusted odds ratio [aOR] 4.1, 95% CI 1.6-10.3; *P*<.001). Attitude was associated with the female sex (aOR 0.7, 95% CI 0.5-1; *P*=.04) and TV or radio shows (aOR 1.1, 95% CI 0.6-2.1; *P*=.01). Practices were associated with the ≥24 years age category (aOR 1.5, 95% CI 1.1-2.1; *P*=.02) and online courses (aOR 1.8, 95% CI 1.1-3.2; *P*=.03). In total, 592 (80%) medical students were willing to participate in frontline care if called upon.

Conclusions: Medical students in Uganda have sufficient knowledge of COVID-19 and will be a large reservoir for health care response when the need arises.

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KEYWORDS

knowledge; attitude; practices; COVID-19; medical students; Uganda; medical education; perspective

Introduction

In late December 2019, a pneumonia of unknown cause was first reported in Wuhan City, China [1]. The World Health Organization (WHO) later named the disease the coronavirus disease (COVID-19). COVID-19 caused by the novel coronavirus, also known as severe acute respiratory syndrome coronavirus 2 was linked to a seafood and wild animal wholesale market in Wuhan, Hubei Province, China [2]. COVID-19 has since rapidly spread across the world with multiple countries and was declared a global pandemic on March 11, 2020, by the WHO [3].

Over 5.5 million cases and 350,000 deaths have been reported worldwide [4]. Over 30% of the confirmed cases and 25% of COVID-19 deaths worldwide are in the United States alone [5]. As of May 27, 2020, Africa has over 83,000 confirmed cases and 2000 deaths [5]. The strategies established worldwide to reduce the transmission are mostly behavioral (eg, social distancing, regular washing of hands), largely depending on rapid change in behavior, which relies on one's knowledge about the problem, ability to perceive the risk, and willingness to change their attitude [6]. So far, over 10,000 health care workers have been infected with the virus and over 100 have died from COVID-19 [7]. In countries with large amounts of COVID-19 cases such as Italy, the United States, and the United Kingdom, final year medical students and foundation year doctors were fast-tracked into the next level of their career with expedited assessment to help the severely overwhelmed health workforce [8,9]. Empowering medical students with adequate knowledge will place them at the forefront of health education to give the public correct information and refute myths and false information about COVID- 19 [10].

A recent study among Iranian medical students spending their clinical courses in university teaching hospitals all over Iran, found a significantly negative correlation between self-reported preventive behaviors and risk perception, which is needed to reduce stress, anxiety, and risk perception, which are the major problems in disease outbreaks [11]. To our knowledge, no study has been published assessing the knowledge, attitude, and practices (KAP) of medical students in Uganda and Africa at large toward COVID-19, necessitating this study. We, therefore, aimed to assess the KAP of medical students in Uganda toward the COVID-19 pandemic.

Methods

Study Design

We conducted an online, descriptive cross-sectional study between Monday, April 13 and Sunday, April 19, 2020. A quantitative analysis approached was used.

Study Settings

There are 10 universities in Uganda offering undergraduate medical degrees, namely, Makerere University (Mak), Mbarara University of Science and Technology (MUST), Gulu University (GU), Kampala International University (KIU), Kabale University (KU), Busitema University (BU), Islamic University in Uganda, Soroti University (SU), King Caesar International University, and Uganda Christian University (UCU). Mak, GU, MUST, BU, KU, and SU are public universities, and the remaining universities are private. UCU was not included in this survey because of a lack of a representative. The combined population size of all these medical schools is about 6000-8000 students.

Study Population

Medical students pursuing the following undergraduate degree programs in various universities were targeted: Bachelor of Medicine and Bachelor of Surgery (MBChB), Bachelor of Dental Surgery (BDS), Bachelor of Nursing (BNUR), and Bachelor of Pharmacy (BPHARM).

Inclusion and Exclusion Criteria

Individuals 18 years or older were included in the study after an informed consent was obtained. Students who were too ill to participate were excluded.

Sampling Procedure and Data Collection

At the time of data collection, Uganda was in a total lockdown; all schools, universities, and institutions were closed. Therefore, we opted to use WhatsApp Messenger (Facebook Inc) for enrolling potential participants. By employing a convenience sampling method, we identified all the existing WhatsApp groups of medical students in the various universities. The Google Form link to the questionnaire was sent to the enrolled participants via the identified WhatsApp groups with approximately 2500 students.

Study Variables

Independent variables were the demographic characteristics sex, age, education institution, and sources of information on COVID-19, and dependent variables were knowledge, attitude, and practices toward COVID-19.

Bloom's cut-off of 80% was used to determine whether a medical student had good knowledge, positive attitude, and good practice or not [12].

Knowledge was assessed using a 12-item questionnaire adapted from Zhong et al [13] and modified to suit medical students, each correct answer weighing one point. The questions were about clinical presentations, transmission, prevention, and control of COVID-19. Each correct response was weighted as 1 point and 0 for incorrect responses. The total score was 15, and ≥12 (ie, 80%) correct responses was considered good knowledge.

Attitudes were assessed using 5 Likert-item questions that have been adopted from Goni et al [14] and modified appropriately for COVID-19 by the authors. The responses were strongly disagree, disagree, neutral, agree, and strongly agree, each weighing 1-5 for each positive statement. Some questions were reversed to eliminate biases of giving a single similar response in all the items. The total score was 25, and ≥20 (ie, 80%) correct responses was considered a positive attitude.

Practices were assessed using 5 Likert-item questions that have been developed from the WHO and Ministry of Health Uganda recommended practices for prevention of COVID-19 transmission (ie, hand washing, avoiding crowded places, keeping social distance [1 meter apart], avoiding touching of face, and avoiding handshakes). The responses were always, occasional, and never, each weighing 3, 2, and 1 point for a good practice. The total score was 15, and ≥12 (ie, 80%) correct responses were considered good practices.

The questionnaire can be accessed in Multimedia Appendix 1.

Data Management and Analyses

Fully completed questionnaires were extracted from Google Forms and exported to Microsoft Excel 2016 (Microsoft Corporation) for cleaning and coding. The cleaned data was exported to Stata (StataCorp) version 15.1 for analyses. Numerical data was summarized as means and standard deviations. Categorical data was summarized as frequencies and proportions. Associations between independent variables and dependent variables were assessed using chi-square test and multivariate analysis in Stata 15.1 software. A $P<.05$ is considered statistically significant.

Ethical Consideration

The study was cleared by Mulago Hospital Research Ethics Committee, protocol number MHREC 1866. All participants consented to the study, and it was conducted according to the *Declaration of Helsinki.*

Results

Sociodemographic Characteristics of the Participants

Overall, 806 participants responded to the study. After cleaning and validating the data, 741 valid responses were exported for analysis. The vast majority of the participants were male (n=468, 63%) and pursuing MBChB degree (n=626, 84%). Up to 24% (n=177) were from Makerere University College of Health Sciences, the oldest medical school in Uganda. The majority of the participants used mass media like televisions and social media to access information on COVID-19 (79% vs 76%, respectively). Only 2% (n=18) of the participants were from Soroti University School of Health Sciences, the youngest medical school in Uganda. Table 1 summarizes the characteristics of participants.

Knowledge of Medical Students on COVID-19

The majority of medical students identified fever, cough, and difficulty in breathing as the main clinical symptoms of COVID-19 (95%, 85%, and 88%, respectively). However, only 19% knew that myalgia was a main clinical symptom of COVID-19 (Table 2).

The mean knowledge score of the participants was 13.1 (SD 1.2) indicating a good overall knowledge among medical students. The vast number of the medical students had sufficient knowledge (score≥12, n=671/741, 91%) on COVID-19 main clinical symptoms, transmission, and prevention. Table 3 summarizes the mean knowledge score of participants.

Table 1. Sociodemographic characteristics of the participants (N=741).

Variables	Participants
Sex, n (%)	
Male	468 (63)
Female	273 (37)
Age (years), mean (SD)	24.0 (4)
18-23, n (%)	425 (57)
≥24, n (%)	316 (43)
University, n (%)	
Busitema University	94 (13)
Gulu University	67 (9)
Islamic University in Uganda	128 (17)
Kabale University	88 (12)
Kampala International University	76 (10)
King Caesar University	29 (4)
Makerere University	177 (24)
Mbarara University of Science and Technology	64 (9)
Soroti University	18 (2)
Program, n (%)	
Bachelor of Medicine and Bachelor of Surgery	626 (84)
Bachelor of Dental Surgery	20 (3)
Bachelor of Nursing	63 (9)
Bachelor of Pharmacy	32 (4)
Year of study, n (%)	
1st	109 (15)
2nd	150 (20)
3rd	168 (23)
4th	221 (30)
5th	93 (13)
Source of information on the coronavirus disease, n (%)	
Webinar	107 (14)
TV or radio	583 (79)
Journal and articles	292 (39)
Social media	565 (76)
Websites	354 (48)
Online courses	77 (10)

Table 2. Responses of Ugandan medical students (N=741) to questions on knowledge about COVID-19.

Question	Response, n (%)	
	True	False
SARS-COV-2[a] the virus that cause COVID-19[b] is a DNA virus (*false*)	240 (32)	501 (68)
The main clinical symptoms of COVID-19 are (tick all that apply)		
Cough (*true*)	631 (85)	110 (15)
Fever *(true*)	703 (95)	38 (5)
Myalgia (*true*)	143 (19)	598 (81)
Dyspnea (*true*)	649 (88)	92 (12)
Sore throat	551 (74)	190 (26)
Runny nose	358 (48)	383 (52)
Headache	258 (35)	483 (65)
Sneezing	546 (74)	195 (26)
Confusion	13 (2)	728 (98)
Diarrhea	67 (9)	674 (91)
There is currently no effective cure for COVID-19, but early symptomatic and supportive treatment can help most patients recover from the infection (*true*)	738 (100)	3 (0)
Not all persons with COVID-19 will develop severe cases. Only those who are elderly, have chronic illnesses, and are obese are more likely to be severe cases (*true*)	669 (90)	72 (10)
Persons with COVID-2019 cannot transmit the virus to others when a fever is not present (*false*)	23 (3)	718 (97)
The COVID-19 virus spreads via respiratory droplets of infected individuals. (*true*)	734 (99)	7 (1)
SARS-COV-2 the virus that causes COVID-19 cannot persist on surfaces of objects for hours (*false*)	74 (10)	667 (90)
Wearing general medical masks can prevent one from acquiring infection by the COVID-19 virus (*true*)	642 (87)	99 (13)
It is not necessary for children and young adults to take measures to prevent the infection by the COVID-19 virus (*false*)	22 (3)	719 (97)
To prevent the infection by COVID-19, individuals should avoid going to crowded places such as bus parks and avoid taking public transportations (*true*)	735 (99)	6 (1)
Isolation and treatment of people who are infected with the COVID-19 virus are effective ways to reduce the spread of the virus (*true*)	739 (100)	2 (0)
People who have contact with someone infected with the COVID-19 virus should be immediately isolated in a proper place. In general, the observation period is 14 days (*true*)	738 (100)	3 (0)

[a]SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.

[b]COVID-19: coronavirus disease.

Age, year of study, and source of information were significant predictors of knowledge on bivariate analysis, however, they lost significance in the multivariate analysis. Medical students who used journals or articles (P=.03) and websites (P=.03) as a source of information significantly had sufficient knowledge than others (Table 3). On multivariate analysis, fourth year medical students in Uganda significantly had more sufficient knowledge than their first year counterparts (adjusted odds ratio [aOR] 4.1, 95% CI 1.6-10.3, P<.01). Age, sex, university, program, and source of information on COVID-19 were not statistically significant in the multivariate analysis (Table 4).

Table 3. Mean scores and chi-square test showing knowledge, attitude, and practices of medical students in Uganda toward COVID-19.

Variables (N=741)	Knowledge			Attitude			Practice		
	Mean (SD)	Sufficient, n (%)	*P* value	Mean (SD)	Positive, n (%)	*P* value	Mean (SD)	Good, n (%)	*P* value
Overall	13.1 (1.2)	671 (91)	N/A[a]	20.8 (3.2)	550 (74)	N/A	11.8 (1.9)	426 (57)	N/A
Sex			.06			.04			.99
Male	13.2 (1.1)	431 (92)		21 (3.3)	359 (77)		11.8 (2)	269 (57)	
Female	13 (1.3)	240 (88)		20.4 (3)	191 (70)		11.8 (1.7)	157 (58)	
Age (years)			.046			.55			.01
18-23	13 (1.2)	377 (89)		20.9 (2.7)	319 (75)		11.7 (1.8)	228 (54)	
≥24	13.3 (1.2)	294 (93)		20.6 (3.8)	231 (73)		12 (1.9)	198 (63)	
University			.30			.20			.05
Busitema University	13.3 (1.1)	89 (95)		20.9 (3.6)	68 (72)		11.7 (1.8)	54 (57)	
Gulu University	13.1 (1.2)	59 (88)		20.7 (3.6)	52 (78)		11.4 (1.9)	32 (48)	
Islamic University in Uganda	12.9 (1.3)	109 (85)		20.6 (2.8)	94 (73)		11.9 (2)	76 (59)	
Kabale University	13.1 (1.3)	78 (89)		21.7 (2.2)	73 (83)		12.1 (1.5)	58 (66)	
Kampala International University	13.1 (1)	70 (92)		21 (3.1)	61 (80)		12.5 (1.7)	53 (70)	
King Caesar University	13.2 (1)	27 (93)		20.9 (2.5)	24 (83)		12.2 (1.6)	19 (66)	
Makerere University	13.2 (1.2)	165 (93)		20.2 (3.6)	120 (68)		11.5 (2.1)	88 (50)	
Mbarara University of Science and Technology	13.1 (1.2)	57 (89)		20.8 (3.2)	45 (70)		11.8 (1.7)	35 (55)	
Soroti University	13.2 (1.2)	17 (94)		21 (2.6)	13 (72)		12.2 (1.9)	11 (61)	
Program			.11			.04			.06
Bachelor of Medicine and Bachelor of Surgery	13.2 (1.1)	574 (92)		20.9 (3)	476 (76)		11.8 (1.8)	354 (57)	
Bachelor of Dental Surgery	12.8 (1.4)	17 (85)		19.3 (5.2)	11 (55)		11.1 (2.9)	9 (45)	
Bachelor of Nursing	13 (1.7)	53 (84)		20.4 (4.2)	41 (65)		11.9 (1.8)	38 (60)	
Bachelor of Pharmacy	12.9 (1.4)	27 (84)		20.5 (3.7)	22 (69)		12.5 (1.9)	25 (78)	
Year of study			<.001			.78			.98
1st	12.8 (1.3)	91 (83)		20.6 (3)	83 (76)		11.8 (1.9)	63 (58)	
2nd	12.8 (1.3)	131 (87)		20.9 (2.9)	112 (75)		11.8 (1.9)	87 (58)	
3rd	13.1 (1.1)	150 (89)		20.9 (2.8)	122 (73)		11.8 (1.8)	93 (55)	
4th	13.4 (1.1)	212 (96)		20.9 (3.2)	168 (76)		11.9 (1.8)	128 (58)	
5th	13.3 (1.1)	87 (94)		20.3 (4.3)	65 (70)		11.8 (2.1)	55 (59)	
Source of information on COVID-19[b]									
Webinar	13 (1.3)	96 (90)	.75	20.7 (3.7)	77 (72)	.56	12.1 (2.3)	71 (66)	.04
TV or radio	13.2 (1.1)	531 (91)	.35	20.9 (3.1)	445 (76)	.01	11.8 (1.9)	332 (57)	.57
Journal and articles	13.2 (1.1)	273 (93)	.03	20.9 (2.9)	226 (77)	.11	12.1 (1.8)	185 (63)	.01
Social media	13.2 (1.2)	518 (92)	.06	20.9 (3.1)	425 (75)	.27	11.8 (1.8)	327 (58)	.70
Websites	13.2 (1.1)	329 (93)	.03	20.7 (3.1)	261 (74)	.77	11.8 (1.8)	216 (61)	.06
Online courses	13.2 (1.2)	73 (95)	.18	20.9 (3.4)	58 (75)	.82	12.4 (1.8)	56 (73)	<.001

[a]Not applicable.

[b]COVID-19: coronavirus disease.

Table 4. Multivariate analysis showing factors associated with knowledge, attitude, and practices toward COVID-19 among Ugandan medical students.

Variable	Knowledge		Attitude		Practices	
	aOR[a] (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value
Sex						
Male	1	N/A[b]	1	N/A	1	N/A
Female	0.7 (0.4-1.2)	.18	0.7 (0.5-1)	.04	1.1 (0.8-1.5)	.61
Age (years)						
18-23	1	N/A	1	N/A	1	N/A
≥24	1.1 (0.6-2.1)	.66	0.9 (0.6-1.3)	.49	1.5 (1.1-2.1)	.02
University						
Busitema University	1.1 (0.3-3.6)	.88	1.2 (0.7-2.2)	.56	1.4 (0.8-2.4)	.25
Gulu University	0.3 (0.1-1)	.05	1.5 (0.7-3.1)	.29	1 (0.5-1.9)	.98
Islamic University in Uganda	0.4 (0.2-1.1)	.07	1.3 (0.7-2.3)	.38	1.7 (1-2.8)	.06
Kabale University	0.5 (0.2-1.3)	.14	2.1 (1.1-4.1)	.03	2.2 (1.3-3.9)	.01
Kampala International University	0.6 (0.2-1.9)	.40	1.9 (0.9-3.6)	.07	2.4 (1.3-4.5)	<.001
King Caesar University	0.7 (0.1-3.5)	.64	2.1 (0.7-6.1)	.16	2.3 (1-5.4)	.06
Makerere University	1	N/A	1	N/A	1	N/A
Mbarara University of Science and Technology	0.5 (0.2-1.6)	.25	1 (0.5-1.9)	>.99	1.4 (0.8-2.6)	.25
Soroti University	2.8 (0.3-27.4)	.38	1.3 (0.4-4.4)	.72	1.6 (0.5-5.1)	.41
Program						
Bachelor of Medicine and Bachelor of Surgery	1	N/A	1	N/A	1	N/A
Bachelor of Dental Surgery	0.3 (0.1-1.3)	.10	0.5 (0.2-1.2)	.12	0.9 (0.4-2.4)	.87
Bachelor of Nursing	0.5 (0.2-1.1)	.07	0.7 (0.4-1.3)	.25	1.2 (0.7-2.1)	.57
Bachelor of Pharmacy	0.3 (0.1-1.1)	.06	0.7 (0.3-1.6)	.35	2.9 (1.2-7.1)	.02
Year of study						
1st	1	N/A	1	N/A	1	N/A
2nd	1.4 (0.7-3)	.39	0.9 (0.5-1.8)	.86	1 (0.6-1.7)	>.99
3rd	1.5 (0.7-3.4)	.33	0.8 (0.4-1.6)	.60	1 (0.5-1.7)	.91
4th	4.1 (1.6-10.3)	<.001	1 (0.5-1.9)	.96	0.8 (0.5-1.5)	.55
5th	2.5 (0.8-8)	.12	0.7 (0.3-1.5)	.38	1 (0.5-2)	.94
Source of information on COVID-19[c]						
Webinar	0.7 (0.3-1.6)	.44	0.8 (0.5-1.4)	.50	1.2 (0.8-2)	.37
TV or radio	1.1 (0.6-2.1)	.67	1.7 (1.1-2.6)	.01	0.9 (0.6-1.3)	.47
Journal and articles	1.3 (0.7-2.5)	.36	1.3 (0.9-1.9)	.20	1.4 (1-2)	.06
Social media	1.6 (0.9-2.8)	.13	1.1 (0.7-1.7)	.58	1.1 (0.8-1.6)	.66
Websites	1.3 (0.7-2.2)	.40	0.8 (0.5-1.1)	.22	1.1 (0.8-1.6)	.44
Online courses	2.1 (0.7-6.4)	.20	1.2 (0.7-2.1)	.56	1.8 (1.1-3.2)	.03

[a]aOR: adjusted odds ratio.

[b]Not applicable.

[c]COVID-19: coronavirus disease.

Attitudes of Medical Students on COVID-19

Of the 741 medical students in Uganda, 74% (n=550) had a positive attitude toward COVID-19 prevention. The mean attitude score was 20.8 (SD 3.2; Table 3). Most of the participants agreed that they would go for institutional quarantine if they had contact with patients with COVID-19. A total of 80% (n=592) were willing to participate in the management of patients with COVID-19 when called upon. However, 32% (n=236) of Ugandan medical students were not confident that Uganda would contain the pandemic (Table 5).

Table 5. Responses of Ugandan medical students (N=741) to questions on attitude toward COVID-19.

Questions	Strongly disagree, n (%)	Disagree, n (%)	Neutral, n (%)	Agree, n (%)	Strongly agree, n (%)
Frequently washing my hands using soap or alcohol-based sanitizers can prevent me from getting COVID-19[a]	32 (4)	6 (1)	4 (1)	253 (34)	446 (60)
Wearing a facemask can protect me from getting COVID-19 infection	20 (3)	42 (6)	24 (3)	441 (60)	214 (29)
I will go into institutional quarantine if I come into contact with a patient with COVID-19	27 (4)	18 (2)	23 (3)	252 (34)	421 (57)
When called upon, I will willingly participate in the frontline of COVID-19 pandemic response	29 (4)	26 (4)	94 (13)	250 (34)	342 (46)
Uganda is in a good position to contain COVID-19 pandemic	39 (5)	74 (10)	123 (17)	322 (43)	183 (25)

[a]COVID-19: coronavirus disease.

On bivariate analysis, sex (*P*=.04), academic program (*P*=.04), and mass media like television and radios (*P*=.01) significantly affected attitudes of medical students on COVID-19 prevention (Table 3). After adjusting the effects of independent variables on attitudes, medical students from Kabale University were 2 times more likely to have a better attitude compared to Makerere University (aOR 2.1, 95% CI 1.1-4.1; *P*=.03; Table 4). Those who obtained information on COVID-19 using mass media (television and radios) were twice more likely to have a positive attitude than their counterparts who used other sources (aOR 1.7, 95% CI 1.1-2.6; *P*=.01; Table 4). Female medical students also significantly had more negative attitudes (aOR 0.7, 95% CI 0.5-1.0; *P*=.04) toward COVD-19 prevention than male students (Table 4).

COVID-19 Prevention Practices Among Medical Students

Of the 741 students, only 57% (n=426) had good practices toward the prevention of COVID-19. The mean practice score was 11.8 (SD 1.9) indicating moderately good practices (Table 3). The majority of the students had maintained a social distance, refrained from shaking hands, and washed hands before touching their face (Table 6). It is notable that over four-fifths of the medical students had engaged in health education aimed at improving the public's understanding of COVID-19 (Table 6). Older medical students (aOR 1.5, 95% CI 1.1-2.1; *P*=.02), pharmacy students (aOR 2.9, 95% CI 1.2-7.1; *P*=.02), and KU (aOR 2.2, 95% CI 1.3-3.9; *P*=.01), and KIU (aOR 2.4, 95% CI 1.3-4.5; *P*<.001) students all significantly had better practices compared to students younger than 24 years, MBChB students, and Makerere University medical students, respectively (Table 4). Students who took online courses on COVID-19 also significantly had better practices than others on multivariate analysis (Table 4).

Table 6. Responses of Ugandan medical students (N=741) to questions on practices toward COVID-19.

Questions	Always, n (%)	Occasional, n (%)	Never, n (%)
In recent days, I have maintained a social distance of 1 meter with anyone coughing or sneezing	449 (61)	260 (35)	32 (4)
In recent days, I have worn a mask when getting outside home	170 (23)	285 (38)	286 (39)
In recent days, I have refrained from shaking hands	631 (85)	96 (13)	14 (2)
In recent days, I have washed my hands before touching my face	359 (48)	354 (48)	28 (4)
In recent days, I have engaged in health information campaigns on COVID-19[a]	235 (32)	367 (50)	139 (19)

[a]COVID-19: coronavirus disease.

Discussion

The rapid spread of the COVID-19 pandemic has greatly impacted public health and significantly strained health care systems, especially the medical workers [15]. COVID-19 has also impaired the training of medical students across the world as a result of the closure of schools during the lockdown.

This study sought to determine the perspective of medical students in Uganda toward the COVID-19 pandemic. To the best of our knowledge, this is the first study in Uganda and Africa at-large to examine the perspective toward COVID-19 among health sciences students.

We found that at least 9 in 10 of the medical students had sufficient knowledge, irrespective of their age, sex, university of study, and the course they were pursuing. This level of knowledge is higher than that demonstrated among Iranian medical students (86.96%) [11], Indian health care professionals, students and nonmedical health staff (71%) [16], and Bangladesh students (10.5%) [17]. The study program (MBChB, BDS, BPHARM, and BNUR) and university did not significantly affect knowledge on COVID-19. Fourth year students were 4 times more likely to have good knowledge compared to first year counterparts. Fourth year students in all medical schools in Uganda have at least undergone a junior clerkship in medical wards and have better understanding of disease aspects. This puts them and other medical students who have experienced ward rotations at a good position to participate in the management of patients with COVID-19 once the need arises. However, this cannot explain why they had better knowledge compared to their senior colleagues in 5th year. Perhaps this could be due to the fact that 4th years constituted up to nearly one-third of the study population. Although the majority of the students used mass media to obtain their information, those who used journals or articles and websites significantly had sufficient knowledge more than others. This demonstrates that journal articles and websites are comparatively better reserves for medical knowledge on COVID-19. Peer-reviewed journal articles have been the main stay for dissemination of up-to-date and credible scientific information regarding all aspects of COVID-19. Furthermore, social media although convenient and widely preferred especially by youth, may have a lot of other false content and is not the best portal to relay medical knowledge to students. However, its wide use could be leveraged to convey messages especially on preventive health measures to the public.

In our study, 74% of all participants had positive attitudes compared to 65.4% of participants in a similar Pakistani study [18] who had positive attitudes. However, students who watched TV or heard radio talk shows were 10% more likely to have a good attitude. These sources provide more censored information given that their operations are binding to regulatory guidelines from government agencies like Uganda Communications Commission compared to sources like social media and websites that are less regulated and have had an onslaught of conspiracy theories and misinformation that can ably bias one's picture of the pandemic. Academic program significantly affected attitude; MBChB students had the most positive attitude probably because they act as frontline health workers and directly interact with patients in most regional referral teaching hospitals during their clinical years on a routine basis. However, this finding could be biased by the disproportionate representation among respondents from different medical courses.

With regard to practices, Iranian medical students had a high rate of preventive practice behaviors compared to their Ugandan counterparts (95% vs 57%). This could be due to recruitment of more senior students in their clinical years (5th to 7th year medical students) in the Iran study compared to our study where we enrolled 1st to 5th year medical students. KU and KIU students were twice more likely to have better practices than MUK students. These two medical schools are all located in Western Uganda. Western Uganda is known for outbreaks of viral hemorrhagic fevers hence priming the health care professionals and trainees on the heightened need for appropriate preventive practices. Pharmacy students also significantly had better practices than MBChB students calling for increased sensitization. Of interest, we also found that over 80% of the medical students in Uganda were willing to participate in frontline care response to COVID-19 if called upon. This finding, combined with the fact that over 80% of the medical students had already engaged in health education aimed at improving the public's understanding of COVID-19 despite being in lockdown, underscores the enthusiasm medical students have toward providing health services and would effortlessly engage in frontline care if the situation warranted. This is in consonance with a study that reported great willingness by medicine, nursing, and pharmacy students to work during infectious disease outbreaks despite their fears [19]. The health ministry in India also proposed provisional permission of medical undergraduates of senior grades to treat patients with COVID-19 [16]. Therefore, we have a generation of enthusiastic future health care professionals and there is surely widespread consensus that they can play an active role in the pandemic.

Medical students who may wish to join hospital teams managing the COVID-19 outbreaks have a high risk of exposure to the infection given their limited clinical experience. It has been shown among medical students that having and enhancing knowledge about a new infectious disease by fostering cooperation between hospitals and universities will help improve the students' perceptions of the disease and preventive behaviors [20]. The risk of medical students acquiring coronavirus infection due to lack of enough knowledge about COVID-19 is increased by the fact that there is asymptomatic carrier transmission of the coronavirus, which has been reported [21,22].

The limitation of our study lies on the nonavailability of a validated KAP assessment tool among this population. Sending daily reminders to the eligible participants on the targeted WhatsApp groups lessened possible response bias associated with online surveys. Sampling bias due to convenience sampling used in the study limits the representativeness of the study. However, the relatively large sample size reduces the effect of sampling bias. The study also involved nearly all medical schools across the country.

In conclusion, we were able to demonstrate that Ugandan medical students have sufficient knowledge on COVID-19 and the majority are willing to join the frontline health care response when called upon. Therefore, in the event of escalation in COVID-19 cases in Uganda, medical students, especially those in the clinical years, may be harnessed to work alongside qualified health care professionals in the COVID-19 response. Continued access to online health information resources like free courses, clinical management guidelines, and webinars on COVID-19 offered internationally (eg, by the International Federation of Medical Students Association [23], the CDC [24], and the WHO [25,26]) and nationally (eg, by Ministry of Health-Uganda [27]) may help improve knowledge, attitude, and practices among medical students.

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Authors' Contributions

JK (MUST), RO, and FB conceptualized the study. RO and FB designed the study protocol. RO, FB, GC, JK (MUST), JK (Gulu), LN, PM, OKM, AMK, LM, AA, GW, and DRN participated in data collection. RO and FB analyzed the data. RO, JK (MUST), GC, GW, AMK, LN, and FB drafted the original manuscript. All authors reviewed and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data collection questionnaire.
[PDF File (Adobe PDF File), 330 KB - publichealth_v6i2e19847_app1.pdf]

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Abbreviations

aOR: adjusted odds ratio
BDS: Bachelor of Dental Surgery
BNUR: Bachelor of Nursing
BPHARM: Bachelor of Pharmacy
BU: Busitema University
COVID-19: coronavirus disease
GU: Gulu University
KAP: knowledge, attitude, and practices
KIU: Kampala International University
KU: Kabale University
Mak: Makerere University
MBChB: Bachelor of Medicine and Bachelor of Surgery
MUST: Mbarara University of Science and Technology
SU: Soroti University
UCU: Uganda Christian University
WHO: World Health Organization

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Review

COVID-19 and Laparoscopic Surgery: Scoping Review of Current Literature and Local Expertise

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Abstract

Background: The current coronavirus disease (COVID-19) pandemic is holding the world in its grip. Epidemiologists have shown that the mortality risks are higher when the health care system is subjected to pressure from COVID-19. It is therefore of great importance to maintain the health of health care providers and prevent contamination. An important group who will be required to treat patients with COVID-19 are health care providers during semiacute surgery. There are concerns that laparoscopic surgery increases the risk of contamination more than open surgery; therefore, balancing the safety of health care providers with the benefit of laparoscopic surgery for the patient is vital.

Objective: We aimed to provide an overview of potential contamination routes and possible risks for health care providers; we also aimed to propose research questions based on current literature and expert opinions about performing laparoscopic surgery on patients with COVID-19.

Methods: We performed a scoping review, adding five additional questions concerning possible contaminating routes. A systematic search was performed on the PubMed, CINAHL, and Embase databases, adding results from gray literature as well. The search not only included COVID-19 but was extended to virus contamination in general. We excluded society and professional association statements about COVID-19 if they did not add new insights to the available literature.

Results: The initial search provided 2007 records, after which 267 full-text papers were considered. Finally, we used 84 papers, of which 14 discussed severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2). Eight papers discussed the added value of performing intubation in a low-pressure operating room, mainly based on the SARS outbreak experience in 2003. Thirteen papers elaborated on the risks of intubation for health care providers and SARS-CoV-2, and 19 papers discussed this situation with other viruses. They conclude that there is significant evidence that intubation and extubation is a high-risk aerosol-producing procedure. No papers were found on the risk of SARS-CoV-2 and surgical smoke, although 25 papers did provide conflicting evidence on the infection risk of human papillomavirus, hepatitis B, polio, and rabies. No papers were found discussing tissue extraction or the deflation risk of the pneumoperitoneum after laparoscopic surgery.

Conclusions: There seems to be consensus in the literature that intubation and extubation are high-risk procedures for health care providers and that maximum protective equipment is needed. On the other hand, minimal evidence is available of the actual risk of contamination of health care providers during laparoscopy itself, nor of operating room pressure, surgical smoke, tissue extraction, or CO_2 deflation. However, new studies are being published daily from current experiences, and society statements are continuously updated. There seems to be no reason to abandon laparoscopic surgery in favor of open surgery. However, the risks should not be underestimated, surgery should be performed on patients with COVID-19 only when necessary, and health care providers should use logic and common sense to protect themselves and others by performing surgery in a safe and protected environment.

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KEYWORDS

laparoscopy; COVID-19; surgical procedures, operative; corona 2019; surgery; pandemic; outbreak; infectious disease; health care provider; physician

Introduction

Background

Coronavirus disease (COVID-19) is spreading worldwide, and all health care workers are affected by it [1]. At the moment of writing, the World Health Organization estimated over 2.5 million confirmed cases of COVID-19 and over 175 thousand deaths [2]. It is estimated from the Chinese outbreak that the risk of death is as high as 12% in epicenters of the epidemic and as low as 1% in less severely affected areas. This large difference may be due to a breakdown of the health care system in the epicenter, enhanced public health interventions, and enhanced hygienic measures [3].

According to Médecins Sans Frontières, nearly 1700 healthcare providers have been infected, representing 8% of the total COVID-19 cases in Italy, despite all preventive measures [4]. Therefore, health care providers are the highest risk group for infection, severe illness, and intensive care admission. This stresses the incredible importance of protecting this group.

Due to the combination of increased risk of individual infection and the effects of a breakdown of the healthcare system, it is even more relevant to discuss how to properly protect health care providers. If no personal protective equipment is available, health care workers will be jeopardized [5,6]. Moreover, the shortage of supplies is forcing management to make difficult decisions as to where supplies should be allocated and who needs them most in a hospital.

So, who is at risk? According to the US Centers for Disease Control and Prevention, all health care providers that are in direct contact with infectious secretions from a patient with COVID-19 are at risk. Secretions at risk for viral transmission include sputum, serum, blood, feces, and especially respiratory droplets [7,8]. Health care providers are all recommended to wear personal protective equipment (PPE). The risk increases with exposure to aerosol-generating procedures for at least 10 minutes at a distance of fewer than 2 meters from the patient [9]. Studies have shown that procedures such as endotracheal intubation, extubation, noninvasive ventilation, and exposure to aerosols in an open circuit are associated with high risk of viral transmission. Guidelines about the PPE needed in these situations are receiving increasing attention [10].

According to Wong et al [11], the main risk groups in the operating theater are those who cannot cancel or delay elective procedures. Foremost, of course, are anesthesiologists; however, departments such as intervention radiology, obstetrics, and cardiothoracic surgery are also at risk. Many acute surgical interventions are performed by laparoscopy; however, very little is written about the risks for health care providers of performing laparoscopic surgery on a patient with COVID-19. There is a debate in the literature whether open surgery is safer for health care providers compared to laparoscopic surgery [12,13].

The objective of this study is to provide an overview of potential contamination routes and possible risks for health care providers, and propose research questions based on current literature and expert opinions about laparoscopic surgery on patients with COVID-19.

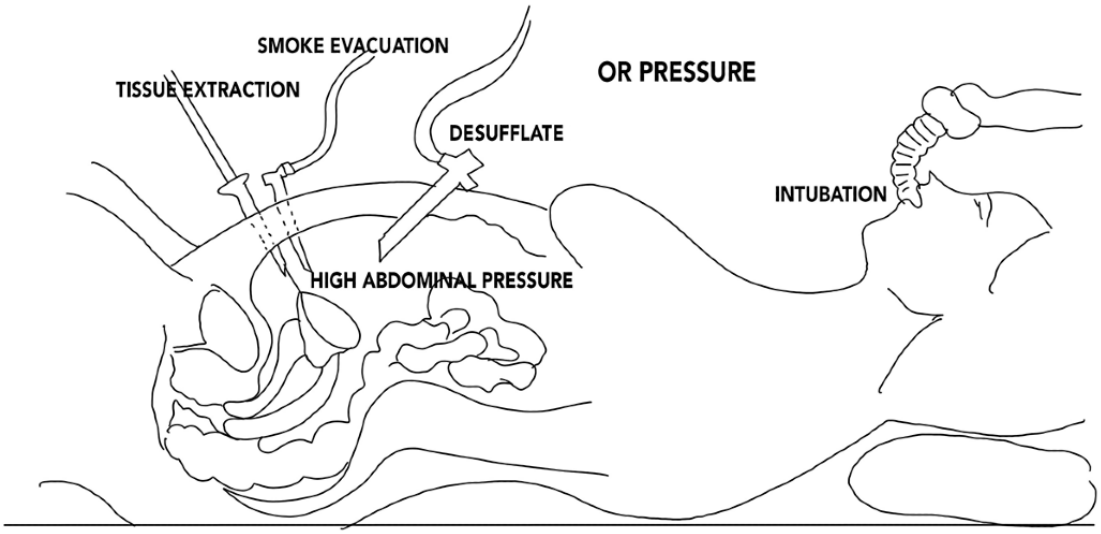
Theoretical Contamination Routes During Laparoscopic Surgery

Before we can elaborate on the theoretical contamination routes, we must first discuss the contamination agents. The agents of contamination can be divided into three groups: those with proven infectious transmission, such as droplets, close contact, and aerosol transmission [14]; those with proven RNA presence, but no proven contamination yet, such as feces, inanimate surfaces, and blood [8,15,16]; and unknown or highly debated agents or even the presence of RNA, such as urine and amniotic fluid [8]. It should be noted that many studies are underway to determine which of these agents are, in addition to containing virus RNA, are also infectious. Taking these agents into consideration, there are several theoretical contamination routes by which health care providers can be infected by a COVID-19 positive patient.

Figure 1 shows potential viral contamination routes in the IR during laparoscopic surgery. The first and most discussed contamination route is intubation and extubation [17]. At this moment, the patient will excrete the most virulent respiratory secretions. The second risk is smoke and air evacuation during surgery [18]. During laparoscopy, smoke and aerosols are generated, not only by cauterization of blood vessels but also by dissection. This smoke can contain virulent DNA and RNA and is sometimes evacuated directly into the overpressured operating room (OR) by opening a valve on a trocar. The third contamination risk is tissue extraction [19]. Removing tissue,

such as an appendix, bowel segment, gallbladder, cyst, or ectopic pregnancy, can cause excretions to be expelled from the body; the higher abdominal pressure from laparoscopy creates aerosols from excretions such as blood and mucus. The fourth moment at risk for contamination is at the end of the surgery, when the abdominal pressure is released by desufflation [19]. All the air, possibly filled with virulent DNA and RNA, is released into the air of the OR, usually under relatively high pressure. A fifth risk factor can be the positive air pressure in the OR, which pushes aerosols out of the OR into hallways and other ORs [17].

Figure 1. Contamination routes during laparoscopy. OR: operating room.



Methods

To provide insight into the possible risks of the abovementioned contaminating routes, we believe a scoping review is most suited. A scoping review allows a broader search and answers multiple questions while still performing a systematic search [20]. Because we expected few results from a search on COVID-19 and laparoscopy, we performed five additional searches for the contamination route and viruses in general.

Systematic Search

The literature search was performed on April 24, 2020, by searching the PubMed, CINAHL, and Embase databases. We then added gray literature from Google Scholar and local expertise and handbooks from the authors themselves from China, Italy, Spain, the United Kingdom, and the Netherlands. The search string can be found in Multimedia Appendix 1. The five additional questions were:

1. What is the effect of operating room pressure on the contamination risk of COVID-19?
2. What is known about the additional risk during intubation and extubation?
3. Does smoke evacuation during laparoscopic surgery increase the risk of the spread of COVID-19 particles?
4. Is anything known about tissue extraction during laparoscopic surgery on a patient with COVID-19?
5. Does desufflation of the abdomen after laparoscopic surgery create airborne aerosols that endanger health care providers?

Inclusion Criteria

Types of studies included were trials, reviews, case studies or series, and other descriptive studies concerning contamination of health care providers during (laparoscopic) surgery in the operating theater. We also included expert opinions if they added additional insight to the current literature.

Exclusion Criteria

We excluded society and professional association statements about COVID-19 if they did not add any new information. We did use them to snowball their references. We also excluded commentaries such as letters to the editor and papers not written in English.

Study Selection

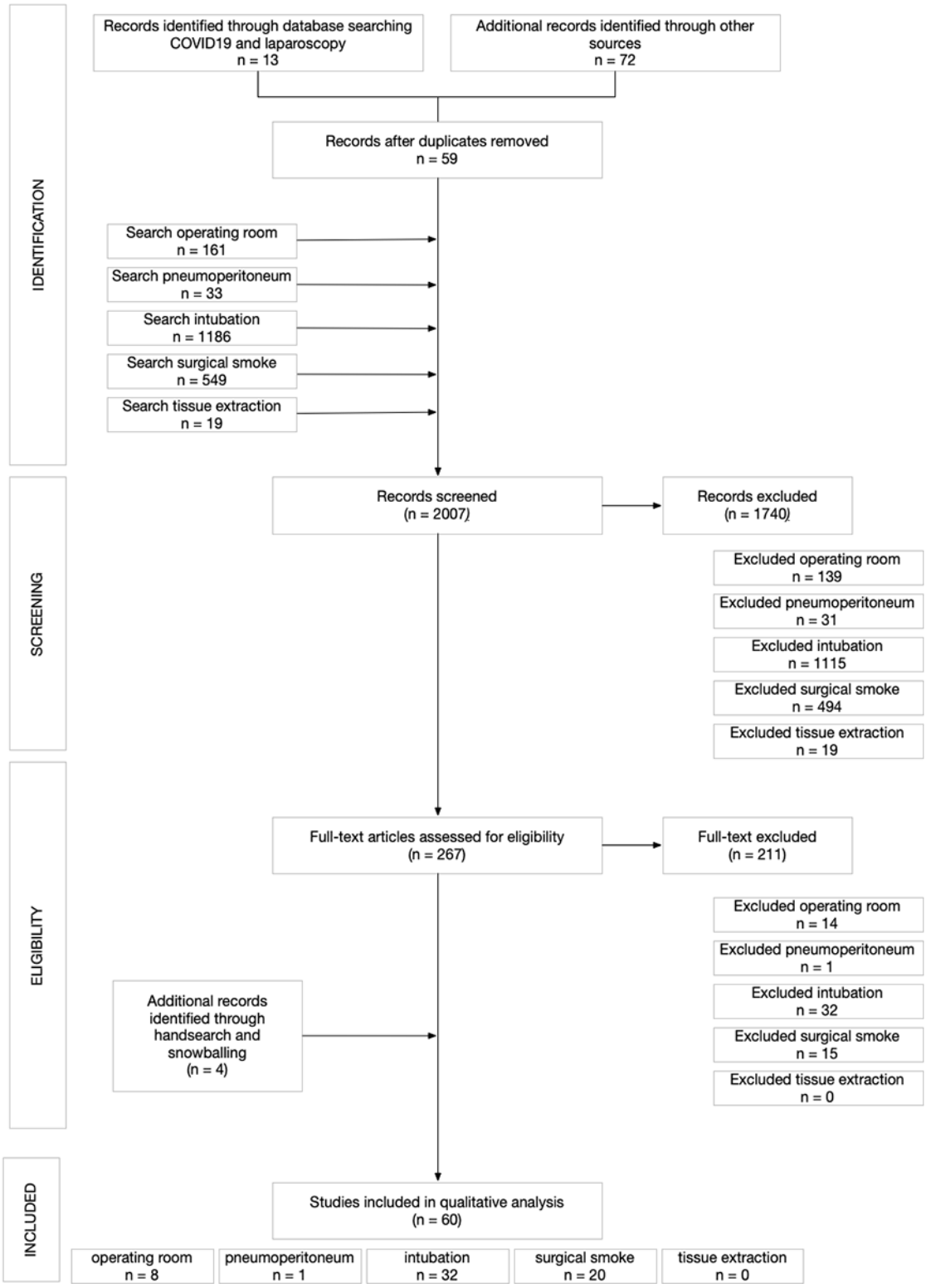
Working independently and in duplicate, reviewers RDL and NB screened all record titles and abstracts. Potentially eligible abstracts and abstracts with disagreement or insufficient information were screened in full text. Disagreements were addressed by discussion of the full text.

Results

Literature Search

Figure 2 shows a flowchart of the literature search and results. The initial search identified 2007 records, of which 59 concerned COVID-19. After excluding 1740 records based on their title and abstract, we assessed 267 full-text papers for eligibility. Papers were excluded because they discussed a treatment therapy or diagnostic method (118/267, 44.2%), did not provide any new information (society statements, letters to the editor and others) (30/267, 11.2%), were not related to our question (12/267, 4.5%) or were not available in English (9/267, 3.4%). After hand-searching the papers and society statements, we were left with 60 papers for this review. Of these 60 papers, 21 (35%) concerned COVID-19, and 39 (65%) discussed our questions in regard to other viral transmissions. We will now discuss the results for each of the five proposed questions.

Figure 2. Preferred Reporting Items for Systematic Reviews and Meta-Analyses flow diagram of the literature search and results.



1. What is the Effect of Operating Room Pressure on the Contamination Risk of COVID-19?

We found 8 papers discussing the effects of OR safety and the spread of virus DNA. Only 1 paper actually discussed the experience with COVID-19 in Wuhan [11], and all studies were based on theoretical risks (see Table 1).

Table 1. Literature reports concerning viral transmission in operating rooms.

Study	Country of study	Design	Location and year of evaluation	Pathogen evaluated	Study quality (GRADE[a])
Zhao et al [21]	China	Retrospective cohort study	Wuhan 2020	SARS-CoV-2[b]	Low
Pei et al [22]	China	Case-control study	Peking 2003	SARS[c]	Low
Kamming et al [23]	Canada	Experience paper	Toronto 2003	SARS	Low
Chee et al [24]	Singapore	Experience paper	Singapore 2003	SARS	Low
Tien et al [25]	Canada	Case series	Toronto 2003	SARS	Low
Park et al [26]	South Korea	Experience paper	Sungkyunjkwan 2015	MERS[d]	Low
Beasley et al [27]	United States	Opinion paper	Washington 2004	Smallpox	Low
Santos de Silva et al [28]	Brazil	Case report	Vale dos Sinos 2014	Adenovirus	Low

[a]GRADE: Grading of Recommendations, Assessment, Development, and Evaluations.

[b]SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.

[c]SARS: severe acute respiratory syndrome.

[d]MERS: Middle Eastern respiratory syndrome.

An OR with a negative pressure environment is ideal to reduce dissemination of the virus by preventing air from escaping the OR [11]. Both the Society of American Gastrointestinal and Endoscopic Surgeons (SAGAS) and the American Society of Gastrointestinal Endoscopy advise that surgery be performed in negative pressure ORs [29,30]. However, a standard OR is usually designed to be at positive pressure relative to the surrounding air. Tien et al [25] reported that during the severe acute respiratory syndrome (SARS) outbreak, surgical procedures were performed within airborne isolation Intensive Care Unit rooms and with additional PPE precautions. This eliminated the risk of intrafacility transport and avoided the need to make environmental modifications to the operating room. Other papers discuss the same contamination route with SARS and Middle Eastern respiratory syndrome (MERS) [22-24,26]. Beasley et al [27] discussed even more isolation strategies in the case of surgery on patients with smallpox.

In Singapore, dedicated separate ORs for surgery on patients with COVID-19 have been installed. The aim was to reduce the risk of contamination of other ORs and patients. Each OR had its own ventilation system with an integrated high-efficiency particulate air (HEPA) filter. The traffic and flow of contaminated air were minimized by locking all doors to the OR during surgery, with only one possible route for entry and exit via the scrub room [11].

Wax et al [31] provided practical recommendations to decrease viral spread when managing a patient infected with COVID-19. Their advice is to convert operating rooms to negative pressure environments with airflow changes.

2. What is Known About the Additional Risk During Intubation and Extubation?

Thirteen papers were found discussing intubation and extubation of patients with COVID-19 (see Table 2). Another 19 papers discuss the risk of intubation for health care providers for viruses other than severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2, Multimedia Appendix 2).

Table 2. Literature concerning intubation and SARS-CoV-2 virus in 2020.

Study	Region	Design	Main topic or result
Cook [32]	United Kingdom	Narrative review	Purpose and use of PPE[a]
Wax [31]	Canada	Review	Anesthesia guidelines
Heinzerling [33]	United States	Case series	3/121 (24.8%) of health care professionals tested positive
Meng [34]	China	Experience paper	29% of hospitalized COVID-19[b] patients were health care providers
Sorbello [35]	Italy	Experience paper	High level PPE for aerosol-generating procedures
Yao [36]	China	Experience paper	Anesthesia advice for intubation
Zhao [21]	China	Retrospective cohort study	Anesthetic management guidelines
Zuo [37]	China	Experience paper	Anesthesia guidelines
Giwa [38]	Italy	Experience paper	Complete COVID-19 overview
Greenland [39]	United States	Review	Intubation advice
Kim [40]	South Korea	Expert opinion	Anesthesia advice
Au Yong [41]	Singapore	Experience paper	Intubation advice
Zhang [42]	China	Case series	No health care providers infected

[a]PPE: personal protective equipment.

[b]COVID-19: coronavirus disease.

Two reviews from Cook et al [32] and Wax et al [31] provide a great overview of current knowledge and stress the increased risk to health care providers during intubation and extubation. A case series by van Heinzerling [33] shows that 3/121 health care providers (2.5%) tested positive after assisting intubation.

Zucco at al [43] warn that the anesthesia professionals and intensivists have the highest risk of exposure to respiratory droplets during intubation and extubation. They provide a 10-point list of precautions that should be taken into account when intubating or extubating patients with COVID-19 [44]. Again, Wax et al [31] advise that high-risk aerosol-generating procedures, such as intubation, not be performed in a positive pressure environment. Won et al [11] advise the use of at least a National Institute for Occupational Safety and Health (NIOSH)-certified N95 respirator, eye protection (either goggles or a full face shield), cap, gown, and gloves. As transmission remains possible despite N95 protection, staff participating in aerosol-generating procedures can wear a powered air purifying respirator (PAPR). Repici et al [45] suggest additional PPE during endoscopic procedures but does not provide additional insight into the risks of intubation.

Learning from other experiences, 16 studies stress the increased risk for health care providers during intubation from the 2003 SARS period (Multimedia Appendix 2). Pei et al [22] show that the odds ratio (OR) that a health care provider will be infected is 30.8. While others show lower numbers (Rabout et al [46] 2.79 and Tran et al [47] 6.6), they all label intubation as a very high-risk procedure for health care providers.

3. Does Smoke Evacuation During Laparoscopic Surgery Increase the Risk of the Spread of COVID-19 Particles?

We found 25 papers discussing the effects of surgical smoke on health care providers. However, none of these papers is specific to COVID-19. A review from Mowbay et al [48] from 2013 included 20 studies and showed the diverse outcomes of these studies; they concluded that infective virus DNA can be found in the smoke plume, but the risk to OR staff is unproven. We found 19 studies not mentioned in the Mowbay review (see Table 3) that also showed diverse results. In Korea, Kwak et al [49] found hepatitis B DNA in surgical smoke in 10/11 cases; however, Waynandt [50] did not find any human papillomavirus (HPV) in 28 cases of CO_2 laser plume. However, another study [51] shows that laparoscopic surgery is associated with better preservation of the immune system than open surgery. This results in a decreased incidence of infectious complications. A systematic review concerning surgical smoke during open surgery [48] shows that in terms of infection risk, 6/20 (30%) of the studies assessed surgical smoke for the presence of viruses, with only 1 study (5%) positively identifying viral DNA in laser-derived smoke. This has been shown for HPV DNA [52,53].

Table 3. Literature concerning surgical smoke plumes.

Study	Country, year	Design	Pathogen evaluated	Type of smoke	Positive results
Mowbray et al [48]	Multiple, 2013	Systematic review	HPV[a], compounds, cells, particles	Diathermy, laser, ultrasonic-derived smoke	20 studies included
Subbarayan et al [54]	United States, 2019	Case series	HPV16	Laparoscopic electrosurgery	0/6 cases
Neumann et al [55]	Germany, 2017	Prospective pilot series	HPV	Loop electrosurgical excision procedure	4/24 cases
Dodhia et al [56]	United States, 2017	Case series	HPV	KTP laser	0/12 fibers
Kashima et al [57]	United States, 2016	Case series	HPV	CO_2 laser	17/30 cases
Garden et al [58]	United States, 2015	Animal study	Papillomavirus	CO_2 laser	3/3 cases
Kwak et al [49]	Korea, 2014	Case series	Hepatitis B	Laparoscopic electrosurgery	10/11 cases
Manson [59]	United States, 2013	Review	HPV	CO_2 laser	4 studies included
Weynandt et al [50]	Germany 2010	Case series	HPV	CO_2 laser, argon plasma	0/28 cases
Taravella et al [60]	United States, 1998	Experiment	Polio virus	Excimer laser	2/2 cases
Hughes et al [61]	United States, 1997	Case series	HPV	Erbium YAG laser	0/5 cases
Hagen et al [62]	United States, 1997	Experiment	Pseudorabies virus	Excimer laser	0/20 cases
Gloster et al [63]	United States, 1995	Survey	HPV	CO_2 laser	31/570 reports
Jewett et al [64]	United States, 1992	Experiment	Hemoglobin	Drill aerosols	5 of 5 cases
Starr et al [65]	United States, 1992	Experiment	Simian immunodeficiency virus	CO_2 laser	0 of 5 cases
Baggish et al [52]	United States, 1991	Case series	HIV	CO_2 laser	0 of 12 cases
Hallmo et al [66]	Norway, 1990	Case report	HPV	Erbium YAG laser	1 of 1 cases
Andre et al [67]	France, 1990	Case report	HPV	CO_2 laser	2 of 2 cases
Sawchuk et al [68]	United States, 1988	Case series	HPV	CO_2 laser	4 of 8 cases
Bellina et al [69]	United States, 1982	Experiment	HPV	CO_2 laser	No viable virus

[a]HPV: human papillomavirus.

4. Is Anything Known About Tissue Extraction During Laparoscopic Surgery on a Patient With COVID-19?

We found no studies found concerning this subject. The only studies that we found concerned malignant cells; however, those were out of the scope of this review. One study [70] showed that during laparoscopic surgery, 48.5% of surgeons' masks, 29.5% of assisting surgeons' masks, and 31.8% of scrub nurses' masks were positive for either visible or visually enhanced blood contamination. This demonstrates that wearing masks is of great importance, even when performing laparoscopic surgery.

5. Does Desufflation of the Abdomen After Laparoscopic Surgery Create Airborne Aerosols That Endanger Health Care Providers?

One case study discussed the desufflation of CO_2 gas used during laparoscopic rectal surgery [71]. SAGES recently stated that there is a good possibility of viral contamination during laparoscopy; they added, "While it is unknown whether coronavirus shares these properties, it has been established that other viruses can be released during laparoscopy with carbon dioxide." However, this has only been shown in smoke, not clear CO_2 [72].

In one study, the effects of COVID-19 on the strategy for colorectal cancer patients is discussed. The authors especially recommend that natural orifice specimen extraction surgery and transanal total mesorectal excision should be performed with caution during the epidemic period because fecal-oral transmission and aerosol transmission during this type of surgery have not been excluded. A protective stoma should reasonably be carried out, and the protection of OR personnel should be strengthened [73].

Discussion

There is some existential consensus in the literature that intubation and extubation are high-risk procedures for health care providers. Studies have shown ORs as high as 30, stressing the importance of proper PPE during those procedures [22]. Literature suggests that intubation and extubation should preferably be performed in a low-pressure environment with protective gear for the health care providers. A reasonable number of studies show that surgical smoke contains viral DNA

and that health care providers should avoid inhaling it. The infectiousness of tissue extraction and the insufflation gas itself is absolutely unknown, and all advice is at least "arguable" (see Table 4).

When current knowledge does not help us any further, we are faced with a dilemma. Should we follow the conservative route and provide extensive PPE and prevent surgery at all costs? This may sound like the safe option; however, performing surgery wearing a PAPR [11] may not even be possible. In addition, delaying surgery may cause a patient more harm due to disease progression. Also, as COVID-19 continues to spread, resources are getting low, and it might not be possible to provide each health care provider with proper PPE. In that case, we should start to distribute resources where they are needed most, but also where the evidence provides insight into their effectiveness.

Table 4. Overview of proposed questions and evidence.

Transmission route	Available evidence	Advice
Positive pressure OR[a]	Minimal	Turn off positive pressure, prepare several negative pressure ORs
Intubation/extubation	Minimal	Level III protection, should not be performed in positive pressure OR
Smoke evacuation	Minimal	Use a proper filter in a closed vacuum system
Tissue extraction	None	Use masks and screens/goggles at minimum
Desufflation of abdomen	None	Use a proper filter and a closed system

[a]OR: operating room.

The Handbook of COVID-19 Prevention and Treatment compiled by the First Affiliated Hospital, Zehjang University School of Medicine [74], has not been peer-reviewed and published in the literature; however, it does provide important lessons from previous outbreaks. The authors consider any kind of surgery to be high risk and advise level III protection during surgery (ie, surgical cap, N95 protective mask, work uniform, disposable medical protective uniform, disposable latex gloves, and a full-face PAPR device), negative pressure operating rooms and several other hygiene precautions [74].

Textbox 1 provides a summary of our recommendations.

Textbox 1. Summary of care advice for laparoscopic surgery during the COVID-19 pandemic. COVID-19: coronavirus disease. CT: computerized tomography. PCR: polymerase chain reaction. PPE: personal protective equipment.

- Postpone elective surgery.
- Consider screening every patient who needs emergency surgery for COVID-19 either by PCR swab or CT scan of the thorax.
- Dedicate specific operating rooms to patients with COVID-19.
- Turn off positive pressure/create negative pressure ORs.
- Use Level III personal protective equipment during intubation and extubation.
- Consider Level III PPE but at least provide adequate mouth, face, and eye protection during surgery.
- Use proper filters and closed systems for smoke evacuation.
- Use proper filters and closed systems for CO_2 desufflation.
- Do not perform transanal surgery.
- Consider faces as contaminated fluids.

Comparing Open Surgery With Laparoscopic Surgery

Surgery cannot always be avoided or delayed. Should we then perform open surgery instead of laparoscopic surgery? Evidence has shown the benefits of laparoscopic surgery in many cases and for multiple indications. Should we abandon these benefits for the patient in favor of lowering the risks for health care providers? The risks related to increased OR pressure and intubation are not changed during open surgery. The smoke evacuation may be even better controlled by laparoscopy then by open surgery, and the effects of tissue extraction and desufflation are completely unknown. Cauterization may be comparable; however, dissection by sharp instruments such as scissors and use of ligatures to prevent bleeding is more common during open surgery. Blood splash risks are estimated to be 48.5% [70] in laparoscopy and 45% in open surgery [75]. Northern Italian surgeons [76] prefer laparoscopy over laparotomy, making a case for a more controlled splatter and smoke environment. In their opinion, there is no reason to perform open surgery where laparoscopy is the first choice [76].

Preventive Measures

All studies emphasize the importance of protecting health care providers with adequate PPE whether they are performing surgery or a physical examination. However, there are diverse interpretations of how to use PPE. There are many studies examining, for example, face masks [77-79]. The debate is focused on the added value of giving the patient a mask [78] or which mask to use [79,80]. Some studies provide hospital-made protective gear solutions in case of limited resources [81] or

show the added value of salt-covered masks [82]. Finally, studies that show the influence of transocular infection of influence advise the use of N95 protective gear for the eyes as well [83].

Focusing on other contamination routes, Hahn et al [84] showed that a built-in-filter trocar removes >60% of hazardous molecules during laparoscopic rectal resection, and companies are registering these trocars. SAGAS and others advise that the use of devices to filter aerosolized particles in released CO_2 should be strongly considered and that the high pressure in the OR should be turned off or, even better, low pressure ORs should be created. A few dedicated ORs should be created for the purpose of performing emergency surgery on patients who have or are at high risk for COVID-19.

Health care providers should think logically about tissue extraction, protect themselves and OR staff, desufflate the abdomen first, and not hesitate to increase the incision slightly rather than increasing the risk of the spread of aerosols. Finally, when desufflating, use of a filter should be considered or the same system as the smoke evacuation should be used.

Conclusions

To conclude, we would like to look forward. There is ongoing debate on the preoperative screening of asymptomatic patients and how to proceed when the peak of the crisis is over and elective surgeries can be performed again. To screen patients who are asymptomatic for COVID-19, earlier SARS-CoV-2 outbreak studies show higher sensitivity of computerized tomography (CT) scanning compared to polymerase chain reaction (PCR) swabbing [85,86]. However, more recent studies debate the actual added value in absolute numbers and the risks of false-positive outcomes even when using new classification systems [87,88]. Future studies are needed to provide proper advice about COVID-19 screening. Most of all, health care providers should use logic and common sense to protect themselves and others by performing surgery in a safe and protected environment. A global effort is being made to report on the experience and outcomes of surgical patients with COVID-19. The study protocol, registration, and details can be found at the website [89].

Authors' Contributions

The search was performed by RAdL and JH. Additional papers were added by JT, JZ, and PA. Local expertise was provided by MM, PB, JB, and MC. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Search string.
[DOCX File , 682 KB - publichealth_v6i2e18928_app1.docx]

Multimedia Appendix 2
Study results for anesthesia and viral infection risk.
[DOCX File , 64 KB - publichealth_v6i2e18928_app2.docx]

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Abbreviations

COVID-19: coronavirus disease
CT: computerized tomography
GRADE: Grading of Recommendations, Assessment, Development, and Evaluations
HEPA: integrated high-efficiency particulate air
HPV: human papillomavirus
MERS: Middle Eastern respiratory syndrome
OR: operating room
PCR: polymerase chain reaction
PPE: personal protective equipment
SAGAS: Society of American Gastrointestinal and Endoscopic Surgeons

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Original Paper

Telehealth as a Bright Spot of the COVID-19 Pandemic: Recommendations From the Virtual Frontlines ("Frontweb")

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Abstract

The coronavirus disease (COVID-19) pandemic has accelerated the telehealth tipping point in the practice of family medicine and primary care in the United States, making telehealth not just a novel approach to care but also a necessary one for public health safety. Social distancing requirements and stay-at-home orders have shifted patient care from face-to-face consultations in primary care offices to virtual care from clinicians' homes or offices, moving to a new frontline, which we call the "frontweb." Our telehealth workgroup employed the Clinical Transformation in Technology implementation framework to accelerate telehealth expansion and to develop a consensus document for clinician recommendations in providing remote virtual care during the pandemic. In a few weeks, telehealth went from under 5% of patient visits to almost 93%, while maintaining high levels of patient satisfaction. In this paper, we share clinician recommendations and guidance gleaned from this transition to the frontweb and offer a systematic approach for ensuring "webside" success.

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KEYWORDS

telehealth; telemedicine; primary care; COVID-19; pandemic; outbreak; public health; infectious disease

Introduction

> *If I knew I could see you this way, I would have done this a long time ago. I don't wanna come to your office with my baby and put him at risk for Corona.* [Family Medicine telehealth patient]

Six months ago, the Ohio State University Wexner Medical Center launched an all-encompassing virtual health initiative for primary care clinicians (in the Departments of Family Medicine and General Internal Medicine) and their teams, allowing them to provide telehealth to their patients via a variety of modalities and options. For Family Medicine, this meant delivering virtual health to patients in 9 primary care locations across Central Ohio. This expanded the health reach of Wexner Medical Center's previous offerings in various telehealth initiatives that had been suboptimal but which were ready for expansion. With a new department chair as a passionate telehealth proponent and a new chancellor that articulated a visionary blueprint for the adoption of virtual care, the department was highly motivated, setting a goal of transitioning 30% or more of its routine primary care visits for over 90,000 patients to virtual visits over the next 3-5 years. The department formed a telehealth workgroup within its new Center for Primary Care Innovation and Transformation, and this team applied accepted principles for technology integration in primary care [1] to achieve this goal. At this time, it was known that at least 42% of hospital systems and medical centers had some sort of telehealth capability [2], but adoption had generally been limited by payor reimbursement, regulatory and licensing policy, geography, and institutional readiness [2]. It was also understood

that despite the benefits of telehealth in improving access, quality, efficiency, and cost of care [3], telehealth innovation in primary care has often failed for a number of other reasons as well, including lack of dedicated project management, limited patient engagement and support, and insufficient training [4].

In this initiative, we defined virtual health as any form of health care delivered without the patient and the clinician being present in the same physical location, and telehealth as the various digital communication modalities and applications that empower care to be delivered irrespective of space and time. Broadly, this includes remote monitoring, store-and-forward technology, mobile health applications, and direct patient care.

Primary care clinicians (PCCs) were trained in the use of four modalities of telehealth care, including:

- eVisits: electronic visits between the clinician and the patient, initiated by the patient through a patient portal for select complaints
- tVisits: telephone visits between the clinician and the patient, scheduled by the practice team or initiated by the patient, with documentation in the patient's record
- vVisits: video visits between the clinician and the patient, scheduled by the practice team and conducted securely through an integrated video platform with documentation in the patient's record
- eConsults: electronic consults between the primary care clinician and a subspecialist-clinician that allow clinician-to-clinician communication for specialty care–related consultation

Initially, adoption was primarily by self-selected or chair-appointed champions. Uptake was slow for myriad reasons—less than 5% of patient visits were conducted through telehealth in early 2020. The workgroup focused on removing known and identified barriers to widespread uptake and focused on a phased approach to training and securing buy-in from the clinician workforce.

The COVID-19 Pandemic

On March 9, 2020, the first cases of coronavirus disease (COVID-19) were reported in Ohio and a state of emergency was immediately declared by the Governor. The first diagnoses of community spread in Ohio were reported on March 11, 2020, and by the end of that week, K-12 schools were closed across the state; medical centers, COVID-19 call centers, and swabbing stations were opened. The community and health care landscape had changed dramatically in just 7 days. The following week, our department enacted swift measures to convert as much nonemergent care to telehealth care for patients across the region, working to drastically reduce the volume of patients at-risk in busy waiting rooms to create a safer environment for employees, clinicians, patients, and communities. In a matter of days, we experienced a significant surge in requests by our PCCs to have medical center–issued laptops, video capability, secure telephone tools, resources for telehealth and training, office and home connectivity, and more. PCCs who were reluctant to embrace telehealth were now actively seeking it as a solution. Across the nation, many other health care systems needed to do the same.

As social distancing became increasingly paramount, the Governor closed all restaurants and bars, then public centers, gyms, movie theatres, and more on March 15 and 16, respectively. Within a few days, we rescheduled nonurgent care appointments scheduled for the rest of April to later dates and asked our medical assistants to call patients from every practice to reschedule their visits and check in on their well-being, while also inquiring about their readiness to receive care via telehealth. In the initial calls with approximately 400 patients, our patients expressed that this mode of health care delivery was new for them and posed a number of questions regarding technical requirements, virtual visit preparation, and what would be covered in these visits. Nevertheless, most were open and willing to engage in virtual care for their safety and that of their families, especially since some in-person care would still be provided as needed. However, to be able to deliver telehealth to the majority of patients and minimize the fiscal impact to the practice, there remained significant financial and regulatory barriers to overcome. On March 17, a number of major telehealth regulatory changes in response to the COVID-19 pandemic addressed the most substantial roadblocks to telehealth acceleration and adoption, including the Centers for Medicare and Medicaid broadening access to telehealth by authorizing reimbursement for video visits as well as increased flexibility around state licensure requirements for Medicare patients [5]. In addition, the Office for Civil Rights relaxed strict HIPAA (Health Insurance Portability and Accountability Act) rules around telehealth vendors, covered health care providers, location of service, and modality of communication [6]. On March 20, the American Board of Family Medicine issued an emergency decision to allow telehealth visits for resident physicians to count toward their required graduation ambulatory visit targets [7]. We rapidly scaled training for PCCs, including our resident physicians and their attending faculty, to become proficient in the delivery of virtual care, as well as guidance on important "webside" manners between patients at home and remotely stationed clinicians. Almost overnight, the increased use of telehealth became a bright spot of the pandemic [8].

Approach

Development of Recommendations

An increasing number of Ohioans affected by COVID-19 resulted in the need for enhanced social distancing and containment. Our department transitioned nearly all of its clinical employees to remote operations by March 23, 2020. It was quickly recognized that PCCs and clinical support staff needed detailed guidance as they moved from numerous clinical practice settings to the "frontlines," or as we call it, the "frontweb" of the COVID-19 pandemic. In this process, numerous questions, worries, challenges, and opportunities were expressed by PCCs moving to the frontweb of this pandemic.

It was essential that the PCCs received clear and direct recommendations to optimize newer care delivery models, so the workgroup convened a multidisciplinary subset of experts to draw consensus on appropriate guidance. This team consisted

of physicians, electronic health record (EHR) and information technology (IT) professionals, process improvement and ambulatory leadership, communications experts, and patient experience advocates. The group subsequently developed a concise set of recommended practices, specifically focusing on telephone and video visits toward which the bulk of our care was shifting. These recommendations include: understanding evolving federal, state, and institutional guidelines, as these change in response to the pandemic; seeking additional necessary environment training and experiential learning or various modalities and platforms; creating an ideal virtual office space and testing the technology in advance; communicating with patients about the changes while also planning to accommodate their language, disability, technical, and literacy needs; bringing a thoughtful webside manner to the visits; and suggestions for obtaining additional assistance related to technology, specialty care, personal emotional health, or complex patient needs. A summary of these recommendations can be found in Multimedia Appendix 1.

Applying an Implementation Framework

To ensure the scalability and sustainability of these rapidly emerging changes, the workgroup applied the Clinical Transformation in Technology (CTT) implementation science-based framework, which is an established 5-component change model that enables primary care settings to be successful in technology adoption, implementation, or expansion [1]. The 5 components, or 5L phases, include *Logistics*, *Landscaping*, *Looping* (feedback), *Launching*, and *Leading and Leveraging* (learnings). Without the luxury of extended time, activities in these different components were enacted in synchrony during the pandemic response.

The following sections highlight some of the key actions, activities, barriers, and solutions in each of the 5L phases.

Logistics

The *Logistics* phase of the CTT framework involves legal, technical, security, identifying, anticipating, and mitigating roadblocks, as well as privacy considerations and preparation. Important activities completed by our medical center and department's telehealth workgroups during this phase included: vetting a host of telehealth platforms and third-party solutions that could be supported, in addition to those offered in our EHR system, as well as securing the necessary agreements and support to utilize them; creating a strategy for deployment of software and hardware to the PCCs and other members of the care team; devising solutions for integration of third-party solutions with our EHR system; and ensuring ongoing HIPAA protections with all technical solutions.

Landscaping

The *Landscaping* phase of the CTT framework involves understanding and improving clinical, human resource or process gaps, existing workflows, and systems and setting–specific, actionable goals for success. Important activities that were undertaken to re-engineer processes and workflows during this phase included: revising schedule templates and expanding visit type architecture; creating specific scheduling workflows for various clinician and care team member roles; ensuring device and software compatibility with various telehealth platforms; developing virtual patient check-in and check-out procedures; updating billing protocols, including modifiers, CPT (Current Procedural Terminology) codes and time documentation; building in-person care teams and articulating appropriate clinical conditions for patients requiring a physical visit; setting agreed upon SMART (Specific, Measurable, Actionable/Achievable, Relevant/Realistic and Time-Bound) goals and timelines; and consistently aligning patient communication and support to assist patients with the transition and technology.

Looping

As technical, security, workflow, clinical, communication, training, and process activities occurred, the *Looping* phase of the CTT framework became critical. In this phase, learnings, feedback, and the results of previous changes are used to drive and inform improvement and iteration. Applying rapid-cycle improvements in real time significantly accelerated our ability to scale.

Launching and Leading

The *Launching and Leading* phase involves adequate training, retraining, and structuring telehealth initiatives for optimal impact. Because our clinicians had been previously trained in most telehealth modalities, we were able to provide focused training online to fill in gaps, refresh previous training, and create practical tip sheets. Important activities during this phase included the establishment of regular, frequent department telehealth workgroup office hours to allow clinicians and staff to be able to troubleshoot issues in real time; optimization of patient communication materials; advancing the patient scheduling process to accommodate patient visit modality preferences; revisiting appropriate documentation workflows and virtual visit amenable complaints or conditions; applying protocols for home-based monitoring and patient-initiated reporting; and streamlining the use of internal and third-party telehealth solutions.

Leveraging

Finally, in the *Leveraging* phase, all previous learnings are used to drive scale and spread. Activities we have embarked on during this phase include the development of performance and operational dashboards that align with SMART goals; creating a mechanism through which actionable department-, practice-, and clinician-level data are monitored and shared on a weekly basis with department and clinical leadership; and ensuring that patient preference, experience, comfort, and well-being are systematically assessed.

Results

As PCCs moved from the primary care office to the frontweb of the pandemic, we provided over 1500 telehealth visits within the first few days (Table 1). Over the following few weeks, we experienced a considerable increase in telehealth engagement, with nearly 93% of current care being delivered through telehealth/virtual care, while the ongoing provision of in-person care when it is necessary or preferred by patients continued (Table 1). In the same period, patient satisfaction has remained

at prepandemic high levels, per very preliminary internal patient experience data.

With this level of acceleration, it became imperative that our telehealth workgroup continue leveraging learnings and looping feedback as part of the CTT framework. The workgroup continues to actively work to revise and improve processes and workflows, based on patient technical and connectivity challenges, clinician feedback and technical questions, software and third-party solution differences, state and federal guidance, and institutional recommendations and algorithms. The majority of primary care video visits has been conducted through a platform called Updox, while additional video visits have been completed through Epic MyChart and Doximity. Options for using FaceTime, Skype, and Zoom have also been made available.

Table 1. Summary of COVID-19 telehealth visit acceleration in the Department of Family Medicine, Ohio State University Wexner Medical Center (the denominator for all percentages is defined as the number of total visits [in person + video + telephone]).

Week[a,b]	Visits, N	Telehealth visits[c], n (%)	In-person visits, n (%)	Video visits, n (%)	Telephone visits, n (%)
03/01/20	2822	4 (0.1)	2818 (99.9)	4 (0.1)	0 (0)
03/29/20	1814	1666 (91.8)	148 (8.2)	386 (21.3)	1280 (70.5)
04/26/20	2104	1947 (92.5)	157 (7.5)	1481 (70.4)	466 (22.1)

[a]Data shown here represent 4-week intervals.

[b]Week 03/01 represents pre-COVID operations data. Week 3/29 represents the official launch of video visits across the entire medical center. Weeks 03/01 to 03/29 represents a shift from majority in-person visits to majority virtual telehealth visits overall (phone and video). Weeks 03/29 to 04/26 represents a shift from majority phone visits to majority video visits for all virtual telehealth visits overall.

[c]Telehealth visits include patient visits conducted by Family Medicine physicians and nurse practitioners through tVisits or vVisits (telephone or video); does not include data from Behavioral Health, Clinical Pharmacy, Nutrition or other clinicians.

Telehealth care has been applied for a wide range of primary care needs, such as chronic disease management, well-person care (encompassing physical exams and well-child visits) and wellness checks, mental health follow-up, medication management, new patient encounters, acute nonemergent complaints such as back pain, headache, and rash, and lifestyle counseling. Options for subspecialty consultation, diagnostic testing (lab or radiology), and urgent and emergent care remain available.

Conclusion

Academic medical centers and health systems across the nation have done a tremendous job in responding to an unprecedented pandemic with a panoply of tools to provide high-quality clinical care while keeping their employees, patients, and communities as safe as possible [8]. Rapid adoption or expansion of telehealth care has become one of the central components of the pandemic response [8-10]. As the nation continues to confront its post-COVID-19 future and anticipates its new norm, the fate of primary care telehealth will be determined by (1) which system, regulatory, financial, policy, and clinical adaptations continue to stand; (2) institutional propensity to scale and sustain efforts; and (3) the desire of patients to engage in new modalities of care [8]. We believe that PCCs will maintain some sort of permanency on the frontweb of care and that many patients will appreciate the convenience that telehealth has brought them. However, these are areas for future study. Sharing recommendations, best practices, lessons learned, and strategies to thrive in an ever-changing landscape will become core to the new norm in primary care.

Conflicts of Interest

None declared.

Multimedia Appendix 1
The Primary Care Clinician Recommendation Checklist for delivering telehealth remotely.
[PDF File (Adobe PDF File), 591 KB - publichealth_v6i2e19045_app1.pdf]

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Abbreviations

COVID-19: coronavirus disease
CPT: Current Procedural Terminology
CTT: Clinical Transformation in Technology
EHR: electronic health record
eConsult: electronic consult
eVisit: electronic visit
HIPAA: Health Insurance Portability and Accountability Act
IT: information technology
PCC: primary care clinician
SMART: Specific, Measurable, Actionable/Achievable, Relevant/Realistic and Time-Bound
tVisit: telephone visit
vVisit: video visit

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Original Paper

Suitability and Sufficiency of Telehealth Clinician-Observed, Participant-Collected Samples for SARS-CoV-2 Testing: The iCollect Cohort Pilot Study

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Abstract

Background: The severe acute respiratory coronavirus 2 (SARS-CoV-2) pandemic calls for expanded opportunities for testing, including novel testing strategies such as home-collected specimens.

Objective: We aimed to understand whether oropharyngeal swab (OPS), saliva, and dried blood spot (DBS) specimens collected by participants at home and mailed to a laboratory were sufficient for use in diagnostic and serology tests of SARS-CoV-2.

Methods: Eligible participants consented online and were mailed a participant-collection kit to support collection of three specimens for SARS-CoV-2 testing: saliva, OPS, and DBS. Participants performed the specimen collection procedures during a telehealth video appointment while clinical observers watched and documented the suitability of the collection. The biological sufficiency of the specimens for detection of SARS-CoV-2 by reverse transcriptase–polymerase chain reaction and serology testing was assessed by laboratorians using visual inspection and quantification of the nucleic acid contents of the samples by ribonuclease P (RNase P) measurements.

Results: Of the enrolled participants,153/159 (96.2%) returned their kits, which were included in this analysis. All these participants attended their video appointments. Clinical observers assessed that of the samples collected, 147/153 (96.1%) of the saliva samples, 146/151 (96.7%) of the oropharyngeal samples, and 135/145 (93.1%) of the DBS samples were of sufficient quality for submission for laboratory testing; 100% of the OPS samples and 98% of the saliva samples had cycle threshold values for RNase P <30, indicating that the samples contained sufficient nucleic acid for RNA-PCR testing for SARS-CoV-2.

Conclusions: These pilot data indicate that most participant-collected OPS, saliva, and DBS specimens are suitable and sufficient for testing for SARS-CoV-2 RNA and serology. Clinical observers rated the collection of specimens as suitable for testing, and visual and quantitative laboratory assessment indicated that the specimens were biologically sufficient. These data support the utility of participant-collected and mailed-in specimens for SARS-CoV-2 testing.

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KEYWORDS

COVID-19; testing; home testing; telehealth; pilot study; diagnostic; diagnosis

Introduction

The United States is experiencing expansive spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) as part of a global pandemic of the virus [1]. The rapid rise in the number of cases of infection in the United States has taxed multiple aspects of our health care systems, including capacity for testing for the virus and supply chains for personal protective equipment (PPE), specimen collection swabs, and supplies and equipment for people requiring hospital care. There is a national call to expand opportunities for testing for SARS-CoV-2, to reduce the need for PPE and specimen collection swabs currently required for testing of SARS-CoV-2, and to test for SARS-CoV-2 outside of health care facilities [2-4].

Decisions about coronavirus disease (COVID-19) mitigation policies must be informed by the best epidemiologic information, which requires rapid scaleup of SARS-CoV-2 testing. Currently, testing is limited, and many people with clinical indications cannot receive a test [5]. For instance, as of April 8, 2020, the US rate of SARS-CoV-2 testing was 7131 tests per 1 million people, or 2,360,512 overall since January 10, 2020 [6]. Testing has mainly focused on those most severely ill and requiring hospitalization; this low testing rate and targeted testing provides undercounted and biased estimates that do not inform an understanding of the epidemiology of SARS-CoV-2 infection or enable optimal recommendation of control measures [7]. South Korea currently has the highest rate of testing in the world; this has likely contributed to their successful mitigation of their COVID-19 disease epidemic [6,8]. Based on data from the COVID Tracking Project, at least 1 million US residents should be tested every week (0.3% of the population) during this phase of the pandemic [6,9].

We must find scalable and acceptable ways of reaching more people with testing without overburdening our already taxed health care systems. Novel testing strategies such as rapid diagnostic tests, serological tests, and participant-collected specimens could improve our ability to screen large numbers of people quickly and provide new understanding of the extent of exposure, disease, and recovery without compounding the need for health care personnel and PPE to collect the specimens. The US Food and Drug Administration (FDA) has approved self-collection of midturbinate swabs and anterior nares swabs for reverse transcriptase–polymerase chain reaction (RT-PCR) testing under the supervision of a health care provider in health care settings [10]; however, as of April 11, 2020, there are no FDA-approved options for unsupervised participant collection of specimens for SARS-CoV-2 RT-PCR or testing for antibodies to SARS-CoV-2. These options would be important in the response to the epidemic because they would provide efficient methods to conduct large-scale epidemiologic studies, provide options for testing people without causing crowding in provider offices, and enable testing without requiring the use of the scarce PPE required for providers administering in-person tests.

Commercial HIV test kits using self-collection of specimens have been on the market in the United States since 1996. Concerns were reported for these tests regarding self-collection of samples for HIV testing, including having to wait for results, potential mixup of mailed specimens, and cost [11,12]. However, the benefit assessment for the kit showed that these concerns were offset by the convenience and privacy of specimen collection at home and strong public interest [11-16]. The FDA has approved tests of home-collected specimens for a wide variety of analytes and infectious diseases, including HIV, hepatitis C, and sexually transmitted infections. These are typically marketed through a company that provides a clinician who orders the test, discusses the results with the patient if needed, and assumes regulatory responsibility for infectious disease reporting requirements.

A primary concern with at-home tests is the ability of users to correctly conduct the tests. Several studies have examined how well untrained users can conduct HIV self-tests with oral fluid or whole blood fingersticks; most of these studies concluded that participants were able to conduct the tests successfully [17-22]. The Pre-Exposure Prophylaxis at Home (PrEP@Home) system was developed to allow people to mail in home-collected specimens and to provide the remote laboratory testing needed for HIV PrEP use while removing the substantial burden of in-person laboratory visits [7]. Based on the high acceptability of and preference for PrEP@Home specimen collection relative to laboratory collection, we anticipate that home sample collection kits for SARS-CoV-2 would be well utilized despite requiring participant collection of multiple specimens at multiple sites.

Given the ongoing pace of SARS-CoV-2 transmission with inadequate testing, the iCollect study aimed to understand the viability of home collection of specimens as a pathway to increase SARS-CoV-2 testing for people who may not otherwise require immediate medical attention, who may need to obtain follow-up testing while they are convalescent, or who may be assessed as part of an epidemiological study.

We observed and evaluated the ability of a convenience sample of adults in the continental United States to collect a dried blood spot (DBS) card specimen, a saliva tube specimen, and an oropharyngeal swab (OPS) specimen at home that were all suitable and sufficient for laboratory testing for SARS-CoV-2 RNA and serology. DBS specimens have been used for other infectious disease serology tests [23]. Saliva specimens are a plausible specimen type for SARS-CoV-2 testing because salivary glands have been described as a possible reservoir for viral persistence [24] and viral shedding in saliva or sputum can persist for weeks after infection [25]. Saliva may also have diagnostic utility because it can be a vehicle for oral mucosal cells [26]. The FDA has currently issued emergency use authorization (EUA) approvals for two saliva tests, although both tests involve saliva or oral fluid collection by a health care provider [27,28].

To assess the suitability of the specimens, the specimen collection was observed through a telehealth session with clinician observers, including physicians, nurses, and MD candidates working under the supervision of a physician. To assess biological sufficiency, laboratorians evaluated the specimens through laboratory accession screening and RNA-PCR testing. We report the suitability (by clinician observation) and sufficiency (by laboratory assessment of

specimens) of the participant-collected samples to be analyzed for SARS-CoV-2 RNA and serology.

Methods

Participants, Setting, and Eligibility

The methods for the study have been previously described [29]. Briefly, participants were eligible if they were ≥18 years of age, resided in the United States, had never been diagnosed with a bleeding disorder, were able to read and understand English without assistance, were willing to provide valid contact information so that study testing kits could be mailed to participants, had access to a mobile phone, tablet, or computer with a camera, and were willing to be observed by a clinician while completing the specimen collection processes.

Recruitment

Participants were recruited through two methods. First, we offered enrollment to people who had participated in a previous research study of willingness to self-test for SARS-CoV-2 infection and who agreed to be contacted for participation in future research studies [30]. Second, we shared a link with information about the study within networks of people symptomatic for COVID-19 or at risk for SARS-CoV-2 infection, including through networks of first responders. Participants who accessed the link to the information about the study were offered the opportunity to consent to online screening. Those who consented were screened for eligibility, and those who were eligible were provided with informed consent documents and a contact telephone number and email address to ask questions about the study. Participants were offered US $50 for completion of all study activities (eg, baseline survey, observed participant-collection session, return of specimens by mail, and post-collection survey).

Data Sources and Collection

Participant-Collection Specimen Kit

All participants were mailed a study participant-collection specimen kit composed of a cardboard mailing box, instruction sheets for self-collection of specimens (available in [29]), a saliva collection tube, a specimen collection swab, a vial of viral transport medium, a self-retracting lancet, an alcohol pad, a Whatman dried blood spot collection card, a gauze pad, a small self-adhesive bandage, a biohazard bag, and a prepaid return mailing label.

Clinician-Observed Participant Collection Video Appointment

Participants were sent a link by email to schedule their specimen collection video appointment using a Health Insurance Portability and Accountability Act (HIPPA)-compliant videoconference service. During the video/specimen collection appointment, the clinical observers did not instruct the participants, instead directing them to perform the specimen collection procedures using the instruction sheets [29] in the test kit as if they had been provided the kit and instructions without external observation. The clinical observers documented their observations while the participant collected the specimens and recorded their determination of whether the collection appeared to be suitable for submission for laboratory testing and clinical decision making. Clinical observers were instructed not to respond to questions about how to collect the samples but to redirect participants to the written instructions provided. Clinical observers were instructed to intervene only if the participant was performing an action that might pose a risk to themselves. Study case report forms provided space for the clinician to document whether questions were asked during the collection and the provider's observations about the collection [29].

In addition to the provider's overall assessment of the suitability of the specimen, three specimen-specific checklists of items were used by the clinician to document adherence to directions (eg, whether each step in the instructions was followed and completed by the participant; see Multimedia Appendix 1 in [29]). After completing the at-home collection, participants were asked to package the specimens and mail the completed specimens directly to the central study laboratory using the provided mailer.

Laboratory Assessment of Biological Sufficiency

The main outcome of interest was the biological sufficiency of the specimens for testing by RT-PCR and for detection of antibodies by serology testing. The biological sufficiency of the OPS specimens for PCR was assessed by evaluating the total nucleic acid in the specimen using ribonuclease P (RNase P) measurements as previously described [31]. Briefly, saliva and OPS specimens were subjected to nucleic acid extraction using the Thermo Kingfisher platform (Thermo Fisher Scientific). Extracts were tested for human RNase P by RT-PCR with the Thermo SARS CoV-2 testing kit v1. We considered saliva and OPS with cycle threshold (C_t) values <30 to contain sufficient collections of nucleic acid (as a proxy for collection of biological material) [29]. We compared the C_t values of the participant-collected and shipped saliva and OPS specimens to a laboratory reference set of 100 saliva specimens and 100 clinician-collected OPS specimens that were transported directly to the laboratory on ice after collection from a separate clinical population, and we described the differences in the median C_t value between the clinician-collected specimens and the clinician-observed, participant-collected specimens. To assess the biological sufficiency of the DBS cards, we performed a three-point quality check on the cards, assessing the visual appearance of the blood spot, whether the blood had soaked through the paper, and whether the circles were filled, according to our previously reported method for other DBS specimens [29].

Ethical Approval

Approval for this study was obtained from the Institutional Review Board at Emory University, and the specifics of the protocol have been previously published [29].

Results

Participants

We enrolled 159 participants in the iCollect cohort pilot study; 61 (38.4%) were male, 91 (57.2%) were female, 1 (0.6%) was

genderqueer, and 1 (0.6%) was multiple gender (Table 1). Most were non-Hispanic white/Caucasian (110/159, 69.2%) and were less than 40 years of age (99/159, 62.3%); 13/159 (8.2%) were 60 years or older. The 159 participants reported residence in the US regions of South/Southeast (57, 35.8%), Northeast (43, 28.3%), Midwest (27, 17.0%), West (14, 15.1%), and Northwest (8, 5.0%). Most reported at least one symptom of COVID-19 at the time of the survey: 51 of the 159 enrolled participants (32.1%) reported no symptoms, 56 (35.2%) had 1-3 relevant symptoms, 29 (17.6%) had 4-5 symptoms, and 9 (5.7%) reported 6-8 of the listed symptoms (Table 1).

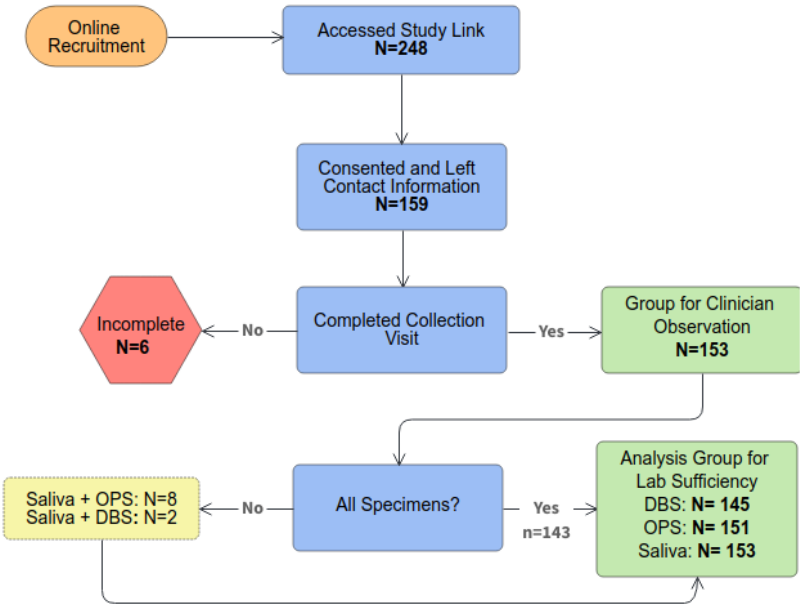
A total of 228 respondents accessed the registration link. A total of 159 participants were eligible (Figure 1), gave consent, and provided contact information for the kit mailing. We mailed kits to 159 participants; 153 (96.2%) of these participants scheduled a video appointment, and all 153 (100.0%) completed that appointment. The mean time for all video appointments was 32 minutes (median 29 minutes, range 13-143 minutes). Of the 153 participants who attended a video appointment, 143 (93%) completed collections of all three samples (Figure 1). DBS was the most commonly uncollected sample; however, only 8 participants did not collect a DBS card. Thus, the analytic sample for clinician assessment of suitability and the laboratory assessment of sufficiency was 153 saliva specimens, 151 OPSs, and 145 DBS cards (Figure 1).

Table 1. Characteristics of the iCollect pilot study participants (N=159).

Characteristic	n (%)
Age (years)	
18-21	7 (4.4)
22-29	56 (35.2)
30-39	36 (22.6)
40-49	23 (14.5)
50-59	24 (15.1)
60-69	8 (5.0)
≥70	5 (3.1)
Race/ethnicity	
White/Caucasian, non-Hispanic	110 (69.2)
Black/African American, non-Hispanic	12 (7.5)
Latino/Hispanic	22 (13.8)
Asian/Pacific Islander, non-Hispanic	8 (5.0)
Native American/Alaska native	0 (0.0)
Mixed race, non-Hispanic	2 (1.2)
Not reported	5 (3.1)
Current gender	
Female	91 (57.2)
Male	61 (38.4)
Genderqueer	1 (0.6)
Multiple	1 (0.6)
Not reported	5 (3.1)
Residence (US region)	
Northeast	43 (28.3)
Midwest	27 (17.0)
South/Southeast	57 (35.8)
Northwest	8 (5.0)
West	24 (15.1)
Symptoms	
Shortness of breath	24 (15.1)
Fever	9 (5.7)
Cough	58 (36.5)
Sneezing	36 (22.6)
Sore throat	34 (21.4)
Headache	49 (30.8)
Diarrhea	18 (11.3)
Myalgia	15 (9.4)
Feeling of being unwell	41 (25.8)
None	51 (32.1)
Not reported	5 (3.1)
Number of symptoms	
0	51 (32.1)

Characteristic	n (%)
1	21 (13.2)
2	20 (12.6)
3	15 (9.4)
4	22 (13.8)
5	6 (3.8)
6	4 (2.5)
7	4 (2.5)
8	1 (0.6)
Not reported	15 (9.4)

Figure 1. Participant and specimen flow of the iCollect study. DBS: dried blood spot. OPS: oropharyngeal swab.



Clinical Observer Assessment of Suitability for Laboratory Testing

Clinical observers assessed that 147/153 (96%) of the saliva samples, 146/151 (96.7%) of the oropharyngeal samples, and 135/145 (93.1%) of the DBS samples were of sufficient quality to be submitted for laboratory testing (Tables 2 and 3). Clinician reasons for lack of suitability are also reported in Tables 2 and 3.

Table 2. Numbers of samples collected in the iCollect study with clinician assessment of the suitability of the collection procedures (n=153).

Sample	Total attempted collections observed, n (%)	Total samples collected, n (%)
DBS[a]	148[b] (96.7)	145[c] (94.8)
Saliva	153 (100.0)	153 (100.0)
OPS[d]	152[e] (99.3)	151[f], 98.7

[a]DBS: dried blood spot.

[b]Five DBS collections were not observed: 2 participants did not see the instructions, 2 did not have the instructions, and 1 experienced anxiety/fainting when drawing blood and did not complete the process.

[c]Three DBS samples were not collected: no blood.

[d]OPS: oropharyngeal swab.

[e]One OPS collection was not observed: no swab in the kit.

[f]One OPS sample was not collected: the participant vomited while attempting to collect it.

Table 3. Numbers of samples assessed as suitable and unsuitable for laboratory testing.

Sample	Clinician assessed as suitable, n (%)	Clinician assessed as unsuitable, n (%)
DBS[a] (n=145)	135 (93.1)	10[b] (6.9)
Saliva (n=153)	147 (96.1)	6[c] (3.9)
OPS[d] (n=151)	146 (96.7)	5[e] (3.3)

[a]DBS: dried blood spot.

[b]Ten DBS samples were unsuitable: 3 had <3 spots, 3 participants pressed their finger into the paper, 2 participants did not fill the spots completely, 1 unknown, and 1 participant did not wash their hands.

[c]Six saliva samples were insufficient: 4 did not invert the tube, 1 did not use the instructions and missed steps, 1 contained lots of foam.

[d]OPS: oropharyngeal swab.

[e]Five oropharyngeal swabs were insufficient: 3 participant did not swab long enough (<20 seconds), 1 participant only held the swab against the roof of the mouth, and 1 participant swabbed their cheeks.

Clinical observers also documented compliance with specific steps in the instructions for each specimen type; these data are presented in Tables 4-6. For DBS collection, the most common errors were touching the specimen collection paper when making the spots (29/148,19.6%) and not completely filling all the circles (52/148, 35.1%). The median number of filled spots was 5; 3 filled spots are required for standard serology assessments in our laboratory, and 137/148 (92.6%) of participants filled at least 3 spots.

Table 4. Clinician-documented participant actions when collecting DBS samples and conducting COVID-19 self-testing during the iCollect study (n=148).

Participant action	n (%)
Labeled DBS[a] card, including name, date of birth, and date of collection	145[b] (98.0)
Did not touch blood collection paper	136[c] (91.9)
Washed hands before collection	143 (96.6)
Cleaned finger with alcohol pad	143 (96.6)
Used lancet on side of finger	133 (89.9)
Did not touch paper while making spots	119[b] (80.4)
Filled spots completely	
All spots	96 (64.9)
Some spots	38 (25.7)
No spots	14 (9.5)
Set the card aside to dry	142[d] (95.9)
Number of spots filled	
0	4 (2.7)
1	2 (1.3)
2	5 (3.4)
3	9 (6.1)
4	15 (10.1)
5	113 (76.4)

[a]DBS: dried blood spot.

[b]One assessment missing.

[c]Four assessments missing.

[d]Three assessments missing.

Table 5. Clinician-documented participant actions when collecting saliva samples and conducting COVID-19 self-testing during the iCollect study (n=153).

Participant action	n (%)
Did not drink, eat, or smoke immediately before or during collection	152[a] (99.3)
Washed hands before collection	135 (88.2)
Rinsed their mouth with water before collection	112[a] (73.2)
Placed their lips over the funnel when providing the saliva sample	145[a] (94.8)
Filled the tube to the red indicator line	146[b] (95.4)
Unscrewed the funnel and put on the cap	152[a] (99.3)
Inverted the vial 20 times	134[a] (87.6)
Removed the barcode label and applied it to the tube	145[a] (94.8)
Wrote their date of birth on the barcode label	140[b] (91.5)
Placed the specimen in the biohazard bag and sealed the bag	150[b] (98.0)

[a]One assessment missing.

[b]Two assessments missing.

Table 6. Clinician-documented participant actions when collecting oropharyngeal swabs and conducting COVID-19 self-testing in the iCollect study (n=152).

Participant action	n (%)
Did not drink, eat, or smoke immediately before or during collection	151[a] (99.3)
Washed hands before collection	135 (88.8)
Did not let the swab touch anything before or after collection	148[a] (97.4)
Inserted the swab in their mouth and swabbed each side for approximately 20 seconds	137[a] (90.1)
Placed the swab in the collection tube	150[a] (98.7)
Broke the swab at the score line	151[a] (99.3)
Placed the lid on the collection tube and tightened it	150[a] (98.7)
Wrote their date of birth on the tube	141[b] (92.8)
Placed the specimen in the biohazard bag and sealed the bag	150[a] (98.7)

[a]One assessment missing.

[b]Two assessments missing.

Laboratory Staff Assessment of Biological Sufficiency for Biological Testing

Data are presented for the first 101 OPSs, first 123 saliva specimens, and first 137 DBS cards processed by the laboratory. For the saliva specimens, all specimens except three had C_t values for RNase P <30 (the value of one specimen was 30.6; 98% of specimens met our pre-specified threshold [29] for sufficient nucleic acid for detection of target RNA). The median C_t for the saliva specimens was 19.5 (IQR 18.8-20.8). For oropharyngeal swabs, all specimens had C_t values for RNase P <30, meeting our pre-specified threshold [29] for sufficient nucleic acid for detection of target RNA. The median C_t for the OPS specimens was 23.9 (IQR 21.0-25.3). We compared the median C_t for OPS patient-collected specimens under clinician observation to the C_t values of 18 clinician-collected OPS swabs processed in the same central laboratory by the Wilcoxon rank sum test. The results indicated that there was no significant difference in the C_t (and, by inference, no difference in the concentrations of nucleic acid in the specimens) between participant-collected and clinician-collected OPS (median self-collected 23.9; median provider-collected 23.7; P=.70). For the 140 DBS cards evaluated, the median number of usable 6 millimeter punches was 3 (IQR 1-5). In terms of saturation, 70/140 (50.0%) were classified as good, 31/140 (22.1%) were classified as fair, and 38/140 (27.1%) were classified as poor; 1 card (0.7%) was assessed as having no blood. In terms of dryness (1=wet, 10=dry), the median dryness was 10 (IQR 9-10). The minimum dryness was 4.

Discussion

Principal Findings

US and global response to the SARS-CoV-2 pandemic desperately requires at-home sample collection both to detect people who are infected with the SARS-CoV-2 virus and for the measurement and monitoring of antibody response to the infection. Unlike nasopharyngeal swab collection, OPS, saliva, and DBS collections do not require any medical training. The level of testing that has been performed to date in the United States is limited for multiple reasons; important solutions are to diversify the types of specimens that have sufficient biological material to be accurately evaluated for SARS-CoV-2 infection (as assessed by RNase P) and immune response (as assessed by saturation and number of usable blood spots) and to diversify the locations in which these specimens can be collected. This study aimed to provide evidence of whether specimens collected at home for SARS-CoV-2 diagnosis are suitable (as assessed by clinical observers) and are sufficient (as assessed by laboratorians). Our results indicate that the collection of the specimens by the participants at home for the diagnosis of SARS-CoV-2 infection and serologic response was suitable as judged by clinical observers. Additionally, the OPS and saliva specimens were judged by objective measures to be sufficient for analysis of SARS-CoV-2 PCR by laboratorians. Most DBS cards contained sufficient samples for testing; however, the laboratorian-rated quality of saturation was variable. Our assessment did not validate these specimens as appropriate specimen types for use for SARS-CoV-2 testing; however, we did assess that the samples had adequate biological material to support testing. Both OPS and saliva have been determined by the FDA to be suitable specimen types for SARS-CoV-2 detection assays [32,33]. Specimens were tested for SARS-CoV-2 RNA by RT-PCR (saliva, oropharyngeal swab) and for IgG and IgM antibodies (dried blood spot, saliva) and IgA antibody (saliva); however, the results are not reported here because the primary intent of this analysis was to describe whether home-collected specimens were suitable and sufficient for RT-PCR and serology testing.

A major finding of our study was that home collection of specimens returned by mail is highly acceptable as a means of submitting specimens for testing for SARS-CoV-2; 143/153 (93.5%) of the participants who were sent kits completed collection of all the specimens and returned the kits. These data confirm findings from a separate study assessing the willingness of people to collect and return specimens for SARS-CoV-2–related testing [30]. In that study, participants were very willing to submit saliva and oropharyngeal swab specimens but were slightly less likely to report willingness to submit dried blood spot specimens. Our study suggests that the extent to which participants actually collect specimens is consistent with previous reports of their willingness to do so, as reported by different participants in an online survey (eg, the saliva collection was the most complete, and participants in a separate study reported being most willing to provide saliva specimens) [30] These data are also consistent with the acceptability of at-home specimen collection for other health conditions, including a long history of the use of at-home dried blood spot collection for HIV diagnosis [34,35]. In our prior work, we found that video instructions may be helpful in increasing the successful collection of specimens, including DBS specimens. We will consider evaluating video instructions as a complement to printed instructions, and we will continue to evaluate the quality of the collected specimens, especially the saturation and completed number of dried blood spot specimens.

To our knowledge, our study is unique in that we used both telehealth to provide clinician observation of participant-collected specimens and rigorous laboratory assessment to determine the sufficiency of those same specimens. We intend that these data will help create a bridge between current regulatory approvals for self-collection of specimens for SARS-CoV-2 diagnosis in clinical settings (eg, OPS; and participant-collected anterior nares swabs, participant-collected OPS, and participant-collected saliva when those specimens are collected under the supervision of a health care provider) and eventual regulatory review of at-home self-collection specimens for laboratory testing. We believe that this study addresses one important component that would support a transition from clinician-observed collection of these specimens to fully unobserved self-collection of specimens that are returned by mail: that the quality of the specimens for diagnostic purposes must be equivalent to clinician-collected specimens. Our evidence in this regard is strong because we incorporated both the professional opinions of clinical observers and objective assessment of the sufficiency of the samples by laboratorians.

However, we recognize that ultimate implementation of at-home self-collection of specimens for diagnosis of SARS-CoV-2 will also be dependent on other important factors. First, it is important that the materials that are sent out in at-home kits are safe, including consideration of the safety of the components of those kits even if they are not used as directed in the test kit instructions. We believe that this can be addressed by review of the material safety data sheets for the components of the kits and by considering modifications of the kits (eg, providing viral transport media in child-resistant tubes) to further improve the safety of the kit components in diverse household settings. Second, stability tests will be required to indicate whether the diagnostic sufficiency of specimens is compromised by conventional shipping processes, delayed shipping, or shipping in extreme environmental conditions. There are well-characterized protocols for such stability studies [36]; ensuring that the test performs as expected under a variety of environmental conditions and after shipping delays is an important part of assuring the diagnostic integrity of the task and, ultimately, the overall performance of the testing approach.

It is also important to view the consideration of deploying at-home participant-collection specimen kits through a broader lens to examine the potential risks and benefits of implementing such a system. We note that Siegler et al [30] documented that a substantial proportion of US respondents indicated they would they would be willing to submit participant-collected diagnostic specimens but were less willing to go to a drive-through, laboratory, or clinical setting to provide specimens. Therefore, the availability of at-home testing may increase our ability to

test large numbers of people, including some who may be unwilling to go into clinical settings where they perceive themselves to be at risk for acquiring SARS-CoV-2 infection. Other countries have similar laboratory capacities, and some already use mailout specimens in public health programs: Public Health England uses mailout specimen collection and specimens returned by mail to screen asymptomatic people for sexually transmitted infections [37]. The ability to test people who have no or mild symptoms or are not willing to be tested in clinical settings can also reduce bias in estimates of SARS-CoV-2 prevalence that are generated from testing cohorts that are largely selected for symptomatic disease or the severity of that disease. Finally, there is a substantial benefit to developing and deploying testing methods for SARS-CoV-2 that are not reliant on supplies of rigid swabs, viral transport media, or PPE, all of which have substantial supply chain limitations. The self-collection of specimens at home thus limits the risk of exposure to health care providers, limits the extent to which PPE is used for diagnostic rather than care purposes, and reduces the congregation of people presenting for SARS-CoV-2 testing in clinics, where they run the risk of being exposed to other infectious patients.

Limitations

Our study has important limitations. Our participants represent a biased group relative to the US population because they were included in the study based on their willingness to self-collect and return specimens. However, most of the 1435 respondents to an online survey reported willingness to collect and submit these specimens [30]; therefore, the extent of this bias may be minimal. We also acknowledge that the behavior of participants when collecting their specimens may have been influenced by the fact that they were being observed by a clinician (eg, a Hawthorne effect [38]). There are potential concerns about the shipping of boxes handled by participants who may be infected with SARS-CoV-2; however, the Centers for Disease Control and Prevention (CDC), the World Health Organization, and the US Surgeon General have indicated that there is no evidence for the spread of the virus that causes COVID-19 through the mail [32]. Our conclusion is that the specimens collected by the participants contained sufficient biological materials to support testing for RNA and antibodies; however, we do not report the results of our testing for SARS-CoV-2 RNA or serology. The CDC considers OPS to be a suitable specimen type if a nasopharyngeal swab is not available [33], and the FDA has granted an EUA for the use of saliva specimens [32].

There are important next steps to realize the promise of participant-collected specimens as one part of a suite of testing options available to address the current global pandemic of SARS-CoV-2. As noted above, it is important to conduct stability testing and to characterize the safety of the kit components before they are sent out to be used for self-collection without clinician observation. There is also a need for further studies to characterize the performance of serology testing for antibodies to SARS-CoV-2, and there are gaps in knowledge about the interpretation of those results. For example, we do not yet know the extent to which antibody responses confer partial, full, or no protection against reinfection. However, the possibility of new mechanisms to collect large numbers of samples from populations in difficult-to-reach places (eg, rural areas, during stay-at-home guidance) and from patients who are not symptomatic could have a practical public health impact. Potential applications of this technology include enabling the collection of specimens from large probability samples, monitoring the antibody status of communities through community sampling, establishing data on antibody kinetics by collecting serial (eg, daily) DBS collections mailed in by people who have been diagnosed with SARS-CoV-2 infection, and conducting screening of populations where it may be impractical to perform frequent health care visits.

Conclusion

We collected and evaluated specimens that were collected by participants observed by clinical observers that can be used for diagnostic testing related to SARS-CoV-2 infection. Our data indicate that participants were willing to collect specimens and that clinical observers believe that the specimens collected only with reference to the provided instructions were suitable for laboratory testing. We believe that these data are generalizable to any participants who need to be tested for SARS-CoV-2 who have access to mail. Additionally, the laboratory assessment indicated that the DBS specimens were sufficient for testing and that the total nucleic acid content of the saliva samples and pharyngeal swabs were sufficient for testing and were consistent with the amounts of nucleic acid in physician-collected pharyngeal swabs and physician-observed saliva specimens. We believe that the potential benefits of the broad availability of participant-collected and mailed-in specimens for clinical purposes and for epidemiological monitoring of the COVID-19 epidemic in the United States outweigh the concerns about whether clinician-collected or clinician-observed at-home specimen collection will produce superior samples. One important issue from a workforce standpoint is defining the level of health care professional who should be recommended to observe self-specimen collection if telehealth-observed self-collection is implemented as a specimen collection method. Based on our observations of the specimen collection behaviors, and bearing in mind that clinicians did not intervene to correct participants who made mistakes, we believe that a broad range of medical professionals, including medical assistants, would be well prepared to fill this role. A final recommendation is to consider feedback from the test kit users; we collected this feedback but did not summarize it as part of this report. Further studies are needed to establish the safety and stability of the specimens during shipment. If procedures can be created that demonstrate safety and stability, we urge consideration of FDA review and approval of the use of participant-collected mail-in specimens for SARS-CoV-2–related diagnostics.

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Conflicts of Interest

THS is editor-in-chief of JMIR Public Health and Surveillance. For this reason, he was not involved in the editorial handling or peer review of the paper.

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
C_t: cycle threshold
DBS: dried blood spot
EUA: emergency use authorization
FDA: Food and Drug Administration
OPS: oropharyngeal swab
PPE: personal protective equipment
PrEP@Home: Pre-Exposure Prophylaxis at Home
RNase P: ribonuclease P
RT-PCR: reverse transcriptase–polymerase chain reaction
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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