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Viewpoint

COVID-19 Crisis in Jordan: Response, Scenarios, Strategies, and Recommendations

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Abstract

As of April 12, 2020, a total of 389 cases of coronavirus disease were confirmed in Jordan. To control this imminent threat, Jordan has enforced public health infection prevention and control measures, called for social distancing, seized all forms of inbound and outbound movement and international travel, and enacted the Defence Law that transferred the authority to the Minister of Defence to work and formulate orders according to the situation. In an effort to support the government in anticipating the requirements of the health system in the upcoming period, an in-depth reflection and examination of different scenarios of the disease spread were developed. This viewpoint suggests different strategies and measures for case detection and contact tracing, clinical management of cases, public health system functioning, and civil society organizations' contribution. It is necessary to accelerate containment of the disease to protect the economy and to maintain the continuity of some activities to mitigate the subsequent social, economic, and financial impacts. This requires finding a coping mechanism for a period that may be prolonged until laboratories develop a vaccine. Specifically, it is strongly recommended to promote community health awareness toward public health prevention and control measures, increase the efficiency and comprehensiveness of the epidemiological investigation and active and passive surveillance, and employ technology and digital health solutions to track cases and contacts. It is also recommended to increase and expand resources of intensive care units including respirators, increase the capacity and the number of trained health staff in the area of public health and epidemiology, ensure continued provision of essential public health programs, and mobilize the resources of nongovernmental sectors and donors to provide services for refugees and vulnerable populations.

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KEYWORDS

infection; prevention; public health; pandemic; Jordan; virus; COVID-19

Introduction

As of April 13, 2020, more than 1.85 million people are confirmed to have coronavirus disease (COVID-19). Although around 429,028 cases are already recovered, the death toll reached over 114,331 worldwide [1]. Most countries recorded variable rates of COVID-19 cases and deaths, instigating a significant burden on their health systems. As a result, some of these national health systems collapsed, lost control, and became unable to provide health services for a large number of COVID-19 cases and others in need.

Jordan's Response to the COVID-19 Pandemic

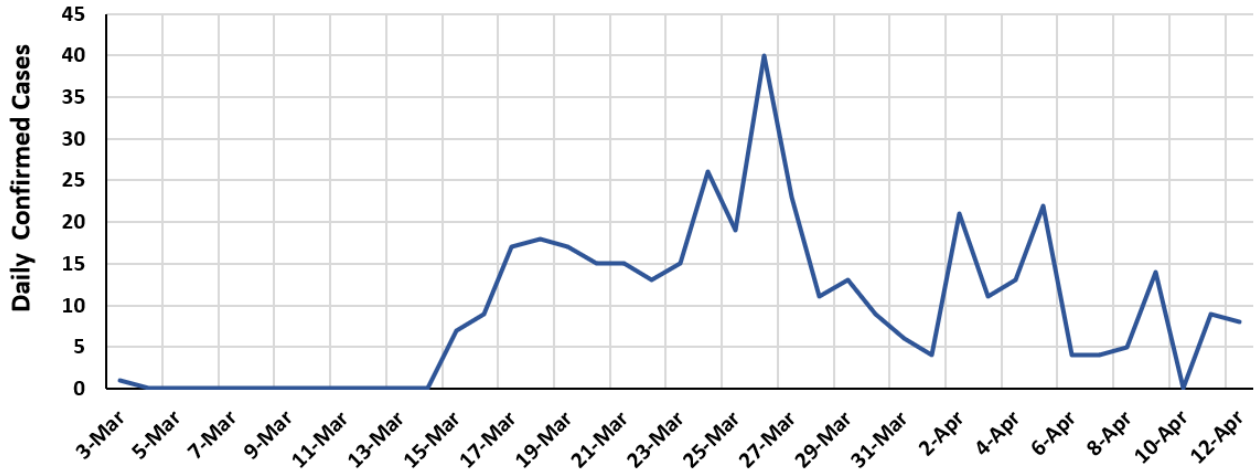
According to Jordan's Ministry of Health data, a total of 389 cases were confirmed across the country as of April 12, 2020. Figure 1 shows the number of daily confirmed COVID-19 cases as of April 12, 2020. The first confirmed case was reported on March 3. However, starting from March 15, the number of cases increased suddenly to 8 cases, and it has been on the rise since then [2]. According to the World Health Organization (WHO) Situation Report 83 released on April 12, 2020, Jordan was classified with a "cluster of cases" transmission for the virus [3]. To control this imminent threat, Jordan has enforced public health infection prevention and control measures. As of March 17, 2020, the government called for social distancing, seized all forms of inbound and outbound movement or international travel, and enacted the Defence Law that transferred the authority to the Minister of Defence to work and formulate orders according to the situation [4]. Consequently, a national curfew was ordered to ensure complete country isolation. It also ordered a lockdown on all border arrivals to the country before March 17 from pandemic countries, and administrative governorates were isolated from each other.

Before embarking on activating the Defense Law, different media channels were used to alert citizens of the seriousness of the virus and its rapid spread. Social media in particular was used heavily in spreading the news about the danger of the disease and groups at high risk of the disease. People were made more aware of the need for social distancing and the importance of personal protection measures. Children and people older than 60 years were the two groups that were specifically addressed by the awareness messages. They were under strict stay-at-home measures, and their care takers were not allowed to accompany them outside of the home except for emergency cases.

Religious leaders, educators, public figures, and opinion leaders were all heavily involved in educating people about the importance of social distancing and infection prevention measures. In addition, the government provided the community, through different channels, with health awareness messages calling for the prevention of the disease and adaptation of healthy behaviors that protect individuals in different social settings. Health awareness was made possible through the Ministry of Health, local and international nongovernmental organizations (NGOs), and academic and research centers. All possible media channels were used including public and private mass communication channels, social media, and religious institutions' preachers [5].

In Jordan, people still value the family and place emphasis on people's strong social relationships. This was used to encourage people and families to enforce social distancing and protection measures not only to save their own lives but also to take care of older adults who live within the families and to protect their beloved ones and those who have comorbidities. Mothers who had to stay at home were heavily involved in facilitating online education of their kids, which made it easier for the government to ensure that curfew measures were not affecting child education.

Figure 1. The number of daily confirmed coronavirus disease cases as of April 12, 2020.



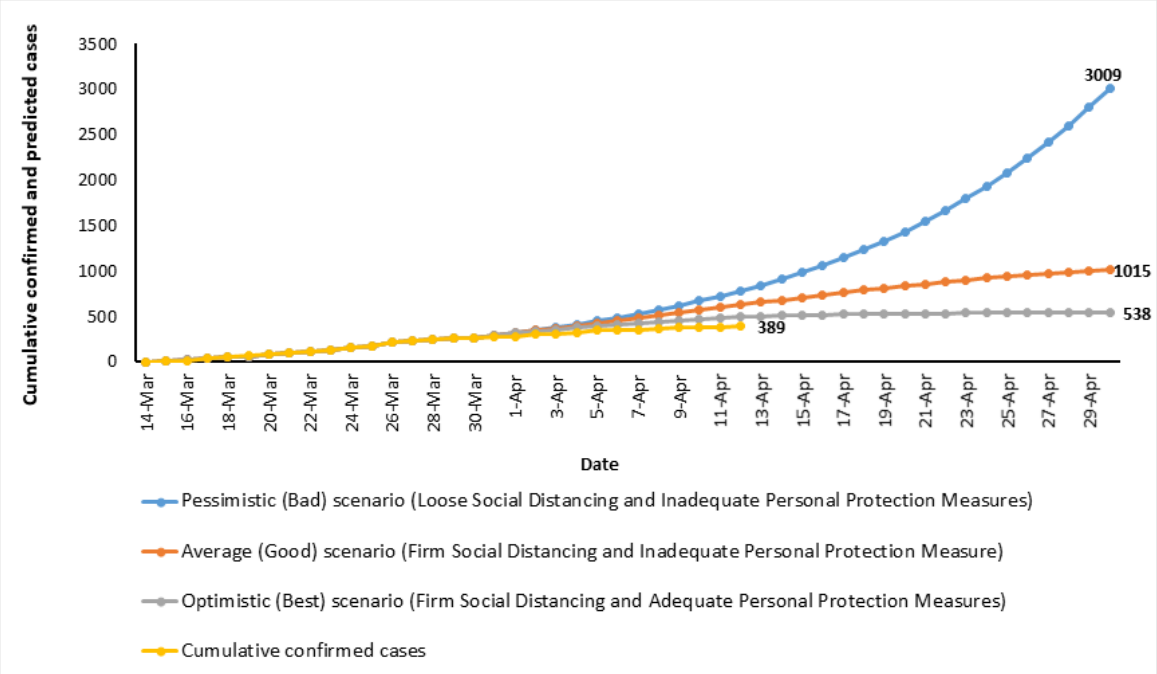
Confirmed and suspected COVID-19 cases from airport arrivals by March 17, 2020, were isolated in hospitals under strict supervision of qualified medical staff. Moreover, the government immediately took measures to ensure preparedness of the health sector. Instantly, the needed equipment and supplies for diagnosis were ordered under the disposal of the National Crises Management Center. Vigorous efforts were exerted to detect and keep track of cases and contacts by outbreak surveillance teams at the national level to contain the spread of the virus and to isolate the cases. The ultimate goal of Jordan was to flatten the disease spread curve to increase the capacity of the health system to absorb new cases.

Projections of COVID-19 Cases in Jordan

About 1 month after the first confirmed case, prolonged national and community-based policies such as isolation, curfews, and social distancing had social and economic implications on individuals and the society at large. In an effort to support the government in anticipating the requirements of the health system in the upcoming period, an in-depth reflection and examination

of different scenarios of the disease incidence and spread were developed (Figure 2).

Figure 2. The cumulative confirmed coronavirus disease cases in Jordan and predicted coronavirus disease cases under different scenarios (March 14-April 29, 2020).



Exponential growth was used for modeling the COVID-19 outbreak in Jordan because epidemiologists have studied those types of outbreaks, and it is well-known that the first period of an epidemic follows exponential growth.

The following exponential growth function (equation 1) was used to predict the number of cases at any given time.

$$x(t) = x_0 * b^t \quad \textbf{(1)}$$

In this equation, x(t) is the number of cases at any given time t; x_0 is the number of cases at the beginning, also called the initial value; and b is the number of people infected by each sick person, or the growth factor.

The first step was to find the real growth factor of the epidemic, by looking at the data from the epidemic spread in Jordan from March 14-30, 2020, after shifting the first case detected to day 0 (March 14). We used a linear regression after logarithmic transformation of the number of cases and then transformed log(b) to "b" by applying the exponential (equation 2). The calculated growth factor (b)=1.074 and x_0=7.313. "t" is the given time.

(2)

The number of predicted cases was calculated for each given time (date) using equation 1 under three different scenarios:

- Pessimistic (bad) scenario (loose social distancing and inadequate personal protection measures): we used the growth factor 1.074 based on the number of reported cases.
- Average (good) scenario (strict social distancing and inadequate personal protection measure): we used a growth factor that is decreasing gradually.
- Optimistic (best) scenario (strict social distancing and adequate personal protection measures): we used a growth factor that is decreasing gradually but at a higher rate compared to the good scenario.

In the interpretation of our projection, one should consider that, although the linear model is the best estimate of the exponential growth function, it has a certain error margin. Moreover, the exponential growth function is not necessarily the perfect representation of the epidemic. The exponential growth will only fit the epidemic at the beginning. At some point, cured people will not spread the virus anymore, and when (almost) everyone is or has been infected, the growth will stop. In addition, one should also consider that the hot spots decrease the predictive power of the model.

Based on these predictions, the requirements to strengthen the health system to adapt to the growing needs and the expected contribution of different players in the system were developed.

Proposed Strategies to Control COVID-19 in Jordan

Case Detection and Contact Tracing

Considering that the country might fall under the (good) scenario where a predicted total cumulative number of cases will reach 1015 by the end of April 2020, all new cases should be timely diagnosed, and all contacts should be actively traced. This requires a high number of public health specialists or epidemiologists and technicians, an adequate number of

laboratory diagnostic tests, and a ready-trained staff to take swaps in-line with standard international practices. Failure to implement this strategy will result in a sharp increase in the number of cases. However, this strategy will place a high burden on the limited number of competent field epidemiologists and on laboratories to carry out tests for cases and potential contacts. To facilitate contact tracing, the government needs to consider the use of information technology and digital initiatives to determine high-spot areas for a better reach of the contacts. Moreover, the government should use the available data on cases and contacts to identify the high-risk geographical areas and high-risk groups to be able to predict the needed resources including intensive care beds and respirators. According to the estimates of the Higher Population Council and considering that around 20% of the population might be symptomatic when affected, 21,684 people are predicted to need hospital care [6]. This will place an unusual burden on the entire health system, which, at best, currently has a hospital bed capacity of 14,701 beds in all health sectors' service providers. Therefore, it is important that the country secure sufficient numbers of filed workers for case screening and adequate testing kits and laboratory equipment to prevent the overload of the hospital beds. In addition, there will be a need for trained staff to collect and analyze the data on cases, disseminate the data, and share the findings with policy makers for proper decision making, as well as with the local community to ensure transparency. In coordination with the WHO, standardized COVID-19 prevention and control training and implementation guidelines are being developed for health staff and institutions. Further development of online training needs to be put in place.

Clinical Management of Cases

If the good scenario applies, the confirmed cases must be transferred to the hospital (secondary care), isolated, and provided with appropriate medical care. Although about 25% of COVID-19 cases are either asymptomatic or mildly symptomatic, symptomatic cases must be provided with several hospital care services by specialized doctors based on the specific condition of the patient. Moreover, there is a special need for:

- Availability of proper human resources such as intensive care unit (ICU) nurses, respiratory therapists, radiologic technicians, laboratory technicians, and microbiologists
- Human resource training: all hospital health staff need to undergo special practice training and be aware of how to protect themselves and others from COVID-19. The training must be consistent with international best practices for service provision, infection control, quality assurance, and personal protection inside the hospital and in ambulances.
- Hospital infrastructure preparation: all hospitals need to secure sufficient numbers of hospital beds, isolation rooms, ICU rooms, ventilators, computed topography scans, and secure medical supplies including supplies for sterilization, infection control, and disinfectants inside and outside the hospital environment.
- Appropriate technology and medicines: appropriate medications (currently on the list of nationally approved treatments) to treat and relieve symptoms, appropriate nutrition to boost immunity, and psychological support are all requirements that should be secured.

This strategy requires a lot of human and material resources. The need for these arrangements is substantial if social distancing has not been strictly practiced and personal protection policies and procedures have not been adequately applied. In this case, it is expected that Jordan will be in need of triple the amount of resources or more to meet the need of the 3009 cumulative total number of cases predicted to take place by the end of April under the pessimistic (bad) scenario.

The government should pay attention to the fact that the optimistic scenario is a somewhat comfortable state where social distancing is practiced and personal protection is applied, albeit not totally. This would result in a relatively small increase in the number of cases at the end of April. The government can then deal with the situation effectively and efficiently.

Public Health System Functioning

The government should use the services of public primary health care centers (PHCs), which are mostly run by the Ministry of Health, by ensuring that centers' staff are timely and properly assigned to the centers' program of work. These centers must continue to provide the essential preventive care to children and pregnant women; immunization; screening programs for newborns; family planning services, communicable disease treatment, and surveillance; and mental health services. It is particularly important also to continue to provide paramedic and emergency services in the health centers. This reduces the load on the hospitals at a time when hospital beds and staff are being prepared for any COVID-19 cases. These arrangements should be complemented by strict measures of infection prevention and control at the PHCs. Moreover, staff should also be able to educate patients on protecting themselves against the virus. Accordingly, there should be personal protection protocols for PHCs' staff members. Care should be provided in a safe context where social distancing is implemented when patients are received, examined, or referred to secondary care (if needed).

The previously mentioned strategies would need a lot of resources for a high-middle income country, which already suffers from a general budget deficit. Within these budget restrictions, the country could develop its partnership with the private sector and give them incentives to possibly modify their production lines such as shifting from garment production to produce masks and needed protection gowns and equipment.

Civil Society Organizations Contributions

The civil society in Jordan includes NGOs and local community-based organizations (CBOs). NGOs are larger in terms of staff, resources, and financing and operate at a national level with wide geographical coverage. NGOs also have strong systems of governance and accountability. CBOs serve local communities in the geographic areas where they operate and are smaller in terms of staff, resources, and funding, and do not have clear systems of governance and accountability. Therefore, the roles of civil society with all its components must be activated in a phasic approach so that it supports government efforts in addressing this pandemic. Their roles include raising awareness and sustaining delivery of health services; protection;

water, sanitation, and hygiene; and social protection services especially in disadvantaged areas as well as marginalized and vulnerable populations including the refugee camps. Civil society can actively contribute to the promotion and activation of social distancing mechanisms and the application of personal protection policy. They can also contribute to facilitating community access and participation. In addition, NGOs can build the capacity of CBOs, unions, political parties, and other community actors on social distancing mechanisms and personal protection policy; provide protection and sterilization kits for staff and clients; and contribute to monitoring cases and contacts, thus supporting the government efforts at local levels.

Recommendations

There is currently an urgent need to control the COVID-19 crisis and protect the economy at the same time. It is necessary to accelerate containment of the disease to protect the economy and to maintain the continuity of some activities to mitigate the subsequent social, economic, and financial impacts. This requires finding a coping mechanism for a period that may be prolonged until laboratories develop a vaccine. Specific recommendations include the following:

- Promote community health awareness toward the best practices of infection prevention and control and other public health measures such as social distancing
- Increase the efficiency and comprehensiveness of the epidemiological investigation or active and passive surveillance
- Employ technology and digital health solutions to track cases and contacts
- Increase and expand resources of ICUs and respirators
- Increase the number of well-trained, specialized, and supportive health personnel
- Increase the capacity and the number of trained health staff in the area of public health and epidemiology
- Develop and disseminate the guidelines and protocols on the best medical practices in the context of COVID-19
- Train health care professionals in hospitals and primary health centers on infection prevention and control measures
- Ensure continued provision of essential public health programs including vaccination, newborn screening tests, family planning services, communicable disease prevention and control, medical services for chronic diseases, and emergency services
- Mobilize the resources of nongovernmental sectors and donors to create awareness and provide services for refugees and vulnerable populations

Conflicts of Interest

None declared.

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Abbreviations

CBO: community-based organization
COVID-19: coronavirus disease
ICU: intensive care unit
NGO: nongovernmental organization
PHC: primary health care center
WHO: World Health Organization

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Original Paper

Contributing to Elimination of Cross-Border Malaria Through a Standardized Solution for Case Surveillance, Data Sharing, and Data Interpretation: Development of a Cross-Border Monitoring System

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Abstract

Background: Cross-border malaria is a significant obstacle to achieving malaria control and elimination worldwide.

Objective: This study aimed to build a cross-border surveillance system that can make comparable and qualified data available to all parties involved in malaria control between French Guiana and Brazil.

Methods: Data reconciliation rules based on expert knowledge were defined and applied to the heterogeneous data provided by the existing malaria surveillance systems of both countries. Visualization dashboards were designed to facilitate progressive data exploration, analysis, and interpretation. Dedicated advanced open source and robust software solutions were chosen to facilitate solution sharing and reuse.

Results: A database gathering the harmonized data on cross-border malaria epidemiology is updated monthly with new individual malaria cases from both countries. Online dashboards permit a progressive and user-friendly visualization of raw data and

epidemiological indicators, in the form of time series, maps, and data quality indexes. The monitoring system was shown to be able to identify changes in time series that are related to control actions, as well as differentiated changes according to space and to population subgroups.

Conclusions: This cross-border monitoring tool could help produce new scientific evidence on cross-border malaria dynamics, implementing cross-border cooperation for malaria control and elimination, and can be quickly adapted to other cross-border contexts.

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KEYWORDS

cross-border malaria; surveillance; data interoperability; data visualization; French Guiana; Brazil

Introduction

The Global Technical Strategy of the World Health Organization (WHO) [1] aims for a 90% reduction in global malaria mortality and incidence by 2030 in comparison with 2015 levels, notably by "transforming malaria surveillance into a core intervention."

However, several obstacles make such a strategy difficult to apply and the elimination target challenging to reach. One of them is *cross-border malaria* [2-7]. Cross-border malaria does not only refer to the malaria cases that cross international borders, but also to all aspects of the disease within cross-border living territories that require actual cross-border visions. However, from one country to another, differences are observed in disease diagnosis and treatment protocols, the epidemiological information collected, database structures, information representations (ie, database attribute names, formats, encoding, etc), data access protocols and rights, and so forth. Such differences prevent the border countries from having a shared and unified view of the cross-border epidemiological situation and, thus, to jointly design and implement efficient control actions. Cross-border epidemiological surveillance systems are required to overcome such obstacles. One solution is to build them into existing national systems, when they exist, by ensuring data interoperability. However, data reconciliation implies dealing with semantic, structural, and syntactic heterogeneities. Moreover, the diversity of recipients of the harmonized data (ie, health actors, health and territory managers, the general public, etc) challenges the actual and advantageous dissemination of cross-border harmonized data and knowledge. In fact, the potential recipients differ notably in their objectives, background knowledge on the disease, technological skills, and languages.

The French Guiana–Brazil border is an endemic malaria region [8]. The Franco-Brazilian cooperation agreement of May 28, 1996, led to the creation of the Joint Commission for Cross-Border Cooperation between French Guiana and Brazil. A subworking group has been working exclusively on health-related issues since 2009. Notably, this resulted in regular epidemiological data exchanges on malaria between French Guianese and Brazilian malaria surveillance authorities. However, differences in data formats, update frequencies, spatial and temporal aggregation units, and nature of information; the lack of contextual information (ie, metadata) and shared frame of reference, notably, a cartographic representation; as well as the limited numbers of recipients of the information on both sides of the border make such a procedure inefficient in providing a unified vision of the malaria situation in the cross-border area. This consequently prevents the design and implementation of concerted control and elimination actions.

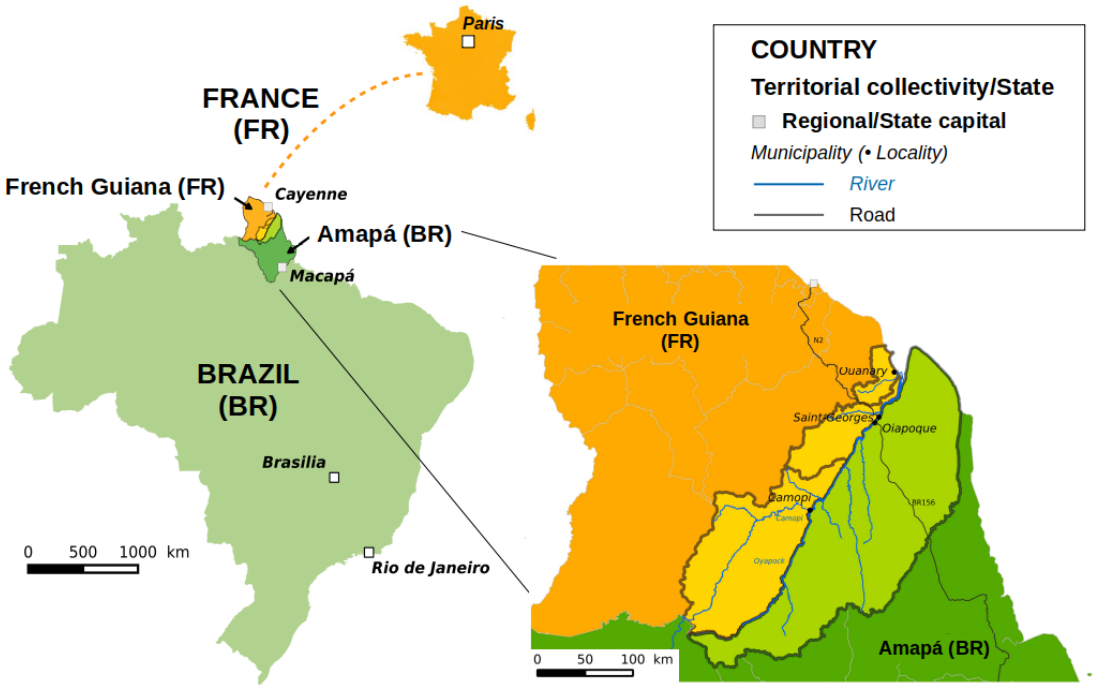
In this context, building a cross-border malaria information system (CBMIS) is needed. This requires specifying easily reproducible methods based on explicit data harmonization rules, free technological solutions, as well as information representation and dissemination good practices. Moreover, data visualization solutions for health actors, health and territory managers, and the general public are necessary to facilitate data and knowledge dissemination. This paper addresses such issues by describing a cross-border system for data harmonization and visualization implemented between French Guiana and Brazil.

Methods

Study Area

French Guiana—83,534 km^2 in area with an estimated 290,691 inhabitants in 2020 [9]—is a French overseas region located in the Amazon, South America. French Guiana consists of 22 municipalities, with four of them bordering Brazil: Maripasoula, Camopi, Saint-Georges de l'Oyapock (hereafter referred to as Saint-Georges), and Ouanary. Amapá—142,829 km^2 in area with an estimated 845,731 inhabitants in 2019 [10]—is one of the 27 states, including the federal district, of the Federative Republic of Brazil. The Amapá state is located in the Brazilian Amazon, bordering French Guiana to the north (see Figure 1).

Figure 1. Cross-border area delimitation and administrative structuration of the region.



For the development of the CBMIS, the cross-border area between French Guiana and Brazil was defined by the border municipalities of both countries, which define a coherent and continuous living territory for local populations (see Figure 1): for French Guiana, this includes Ouanary, Saint-Georges, and Camopi, with 201, 4220, and 1828 inhabitants in 2017, respectively [9]; for Brazil, this includes Oiapoque, with 27,270 inhabitants in 2019 [10]. The population living in this area is distributed over two main urban centers, Saint-Georges and Oiapoque, as well as in villages mainly located along the Oiapoque River, along the BR-156 road in Amapá, and in territories with restricted access (ie, natural parks on both sides of the border and the Brazilian Amerindian Territories).

Data Sources and Definition of Cross-Border Malaria Cases

Concerning French Guiana, anonymized information regarding *individual malaria cases* is collected monthly from the surveillance system of the delocalized Centers for Prevention and Care (Centres Délocalisés de Prévention et de Soins [CDPSs]) operated by the Cayenne Hospital, which has been operating since 2007. Four CDPSs are present in the cross-border area: in Ouanary, Saint-Georges, Camopi, and Trois-Sauts (Camopi municipality). In this system, a malaria case is defined as any positive rapid diagnostic test (RDT) (SD BIOLINE Malaria Ag Pf/Pan in French Guiana). Such tests only distinguish *P falciparum* and non-*P falciparum* species. *New attacks* of malaria (ie, new infections due to new mosquito bites, to be distinguished from malaria notifications related to the follow-up of patients, treatment failures, or *P vivax* relapses) are not explicitly identified in the database. Each patient in the database is identified by a unique coded identifier.

Regarding Brazil, information on *individual malaria cases* is provided by the Malaria Epidemiological Surveillance Information System (Sistema de Informações de Vigilância Epidemiológica da Malaria [SIVEP-Malária]), operated by the information technology department of the unified health system (Departamento de Informática do Sistema Único de Saúde) of the Brazilian Ministry of Health. Brazil mainly uses thick smear microscopy, allowing for the identification of all *Plasmodium* species and development stages, but also the RDT (SD BIOLINE Ag Pf/Pf/Pv).

In the Brazilian database, malaria attacks related to follow-up consultations, treatment failures, and relapses are all referred to as *treatment verification slides* (lâminas de verificação de cura [LVCs]). A malaria case is considered as an LVC for *P vivax* (or for *P falciparum*) if the patient received treatment against *P vivax* (or for *P falciparum*) within the last 60 days (40 days for *P falciparum*) [11]. A non-LVC case is considered a *new case*. Patients are not identified by a unique coded identifier. The SIVEP-Malária supplies anonymized data on a monthly basis to the CBMIS through a partnership with the Oswaldo Cruz Foundation (Fundação Oswaldo Cruz [Fiocruz]). Database fields of the French and Brazilian surveillance systems that were considered in the CBMIS are detailed in Multimedia Appendix 1, Table S1.

A *cross-border malaria case* was defined as any malaria case as defined by the national surveillance systems and that was associated with (1) a notification center, (2) a patient's residential address, *or* (3) a possible transmission location, *located in the previously defined cross-border area*.

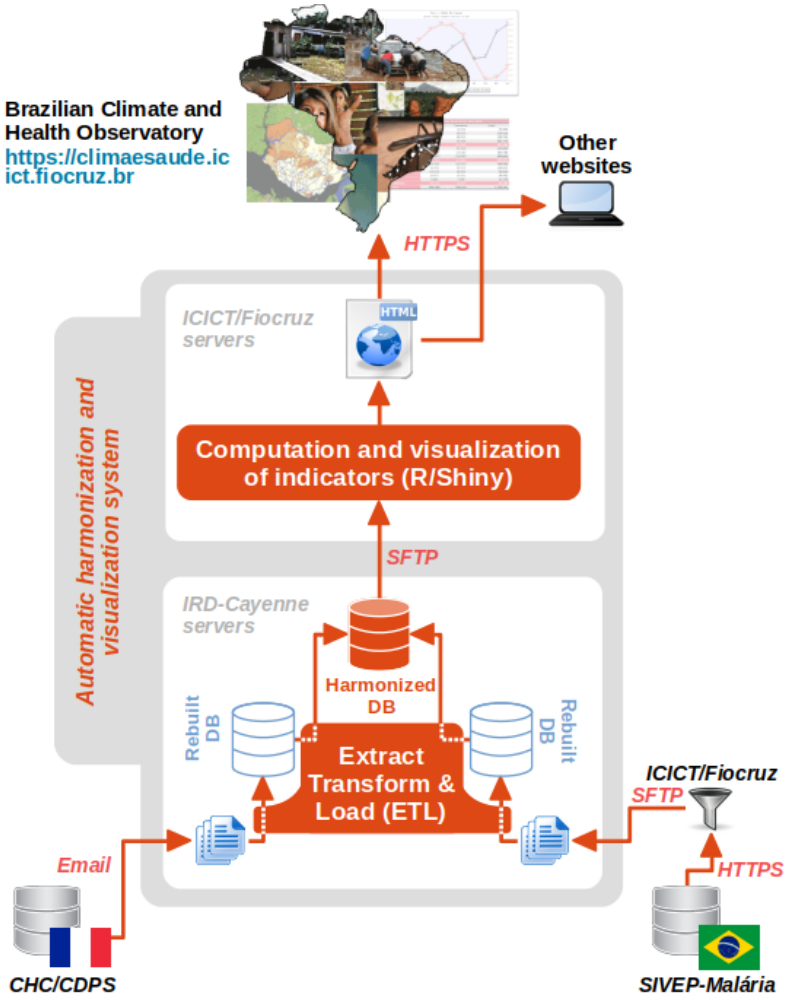
The two surveillance systems report on the locations of notification centers, residences, or putative contamination locations, with respect to predefined and scalable lists of *localities* (ie, a locality being either isolated but inhabited places, villages, or urban neighborhoods), but without systematically providing their geographical coordinates [12]. Thus, geographical coordinates of localities were obtained through various sources: knowledge of the researchers and partners

involved in the project; OpenStreetMap collaborative project; National Indigenous Foundation (for Brazilian Amerindian villages); Google and Bing satellite imagery; and Sentinel-2 satellite images from the European Space Agency, retrieved from the operating platform (Plateforme d'Exploitation des Produits Sentinel) of the Sentinel products developed by the French space agency (Centre National d'Études Spatiales).

Data Harmonization System

Harmonization was aimed at transforming the data from the two national information systems in order to make them satisfy a common harmonized data model; see Figure 2 for a representation of the global data flow, with the main harmonization steps and the data transfer protocols used.

Figure 2. Overall system architecture and data and information flow. CDPS: Service des Centres Délocalisés de Prévention et de Soins (Department of the Centers for Prevention and Care); CHC: Centre Hospitalier de Cayenne (Cayenne Hospital); DB: database; Fiocruz: Fundação Oswaldo Cruz (Oswaldo Cruz Foundation); HTTPS: hypertext transfer protocol secure; ICICT: Instituto de Comunicação e Informação Científica e Tecnológica em Saúde (Institute of Scientific and Technological Communication and Information in Health); IRD: Institut de Recherche pour le Développement (French National Research Institute for Sustainable Development); SFTP: secure shell file transfer protocol; SIVEP-Malária: Sistema de Informações de Vigilância Epidemiológica da Malária (Malaria Epidemiological Surveillance Information System).



This common harmonized data model relied, as much as possible, on existing standards: international standards or, if not available, national ones or even de facto normative representations, due to their extensive and consensual use in the knowledge areas involved in the study. In practice, harmonization consisted of changes in data types (eg, conversion from string type to integer type for the sex field in the SIVEP-Malária database), unit conversions (eg, patient age conversion from days or months to years), and data transformations that required more deep knowledge on malaria surveillance and parasitology, especially regarding *Plasmodium* species specification and new malaria case detection. The information provided by the RDT on *Plasmodium* species was more general and was the only information shared by both countries. In the harmonized database, *Plasmodium* species were consequently coded as "*P falciparum*," "non-*P falciparum*," "mixed infection with *P falciparum*," or "Unspecified" (see Multimedia Appendix 1, Table S2, for details). Eventually, a *new attack* was defined in the CBMIS: for data from the SIVEP-Malária (Brazil), this was defined as any case notification that is *not* an LVC; for data from the CDPS database (French Guiana), this was defined as any *P vivax* (or *P falciparum*) case notification that occurs at least 91 days (41 days for *P falciparum*) after the last *new attack* of *P vivax* (or *P falciparum*). In fact, French epidemiologists consider that a *P vivax* malaria notification can be considered as a *new case* if it occurs more than 90 days after the last contamination [13].

Unique patient identifiers were used to reconstruct the patient notification history and to apply this *new case* detection rule.

The initial data representations within the national systems, the harmonized data model, and associated standards, as well as the harmonization rules, are provided in Multimedia Appendix 1, Table S1.

An *extract, transform, and load* (ETL) process, implemented by the free software Talend Open Studio for Big Data, was used to apply all the transformation rules.

Harmonized Data Visualization and Dissemination

To deal with the previously mentioned barriers to information and knowledge dissemination, progressive access to information was implemented using the Shneiderman et al mantra [14]: "Overview first, zoom and filter, then details-on-demand." Dashboards in three languages—Portuguese, French, and English—accessible to the users via the internet, using any updated browser on a computer or mobile device, were developed. The visualization tool has been implemented in two versions: a *general public* version, accessible without any authentication procedure but with restricted functionalities and data access, and an *expert* version, accessible through log-in and password and with full access to master harmonized data and functionalities. Multimedia Appendix 1, Table S3, details the functionalities of the two versions.

The visualization dashboards were implemented with the R package Shiny (RStudio) [15]. They were made accessible online [16,17]. Access to dashboards was also provided through the Brazilian Climate and Health Observatory [18], more precisely via the webpage dedicated to the Amapá–French Guiana *surveillance area* [19].

Legal and Ethical Considerations

Data on malaria cases are received already anonymized from the CDPS department and the SIVEP-Malária. The CBMIS ensures the automatic processing of patient-related personal data and the transfer of these data to the Brazilian partner. This required the following: (1) the authorization from the French data protection authority (Commission Nationale de l'Informatique et des Libertés [CNIL]), which verifies compliance with the General Data Protection Regulation (EU) 2016/679 (CNIL deliberation No. 2019-025 of 28 February 2019, request for authorization No. 2135363), and (2) the ratification of the *European Union standard contractual clauses for transfers between two data controllers*. In Brazil, all the actions carried out were authorized as part of the Fiocruz public health activities, as per the Brazilian *free access* law 12.527 of November 18, 2011, and in compliance with law 13.709 of August 14, 2018.

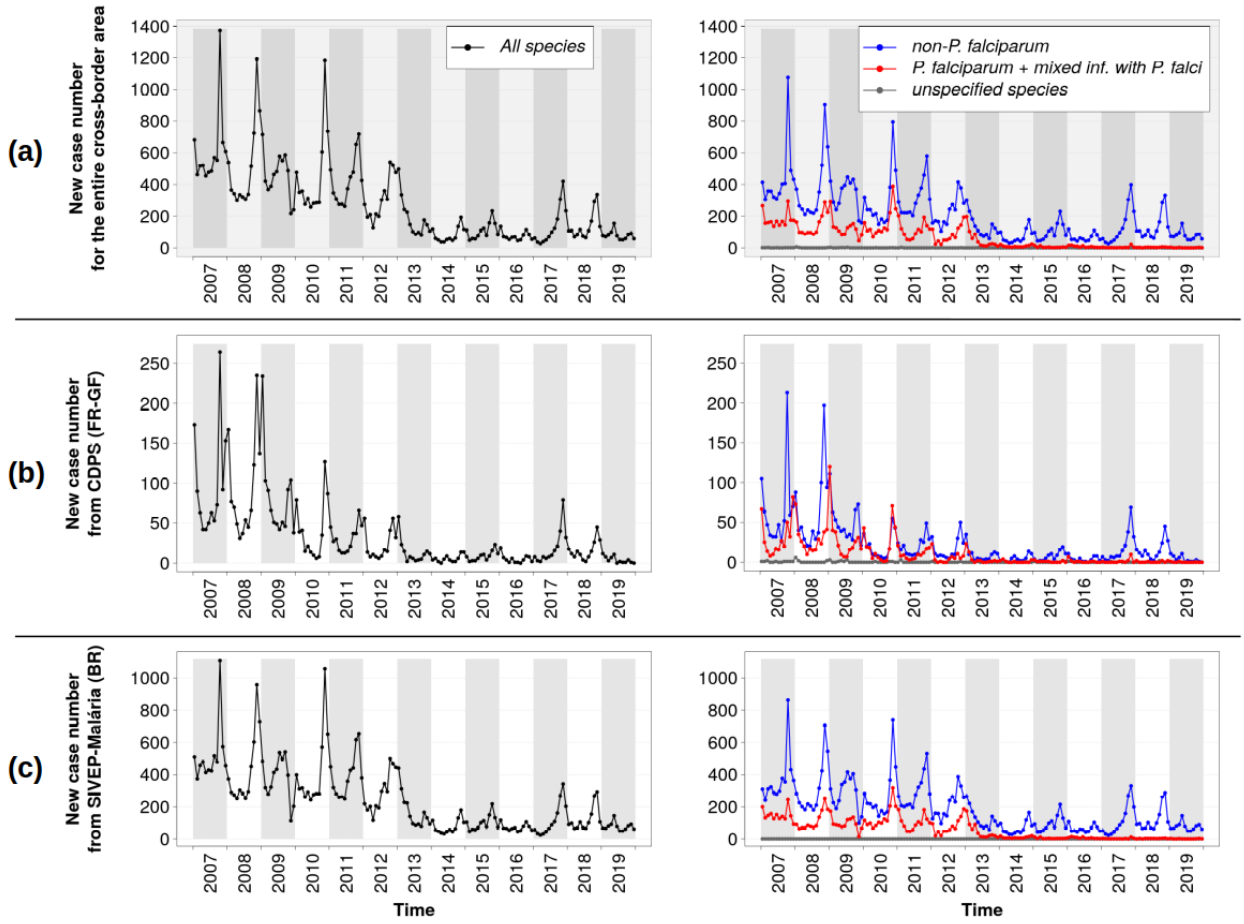
The compliance with legal requirements demanded a specific algorithmic development for new case identification in the French Guiana database, which is detailed in Multimedia Appendix 1, Figure S1.

Results

The CBMIS has been implemented and updated and harmonized data are delivered monthly. Data are available starting from 2003 and 2007 for the SIVEP-Malária Brazilian system and the CDPS French Guiana database, respectively. Some key harmonized database contents for the common period (ie, since 2007) are presented hereafter.

Figure 3 shows the number of new malaria cases in the cross-border area as a whole and as a function of the country of notification.

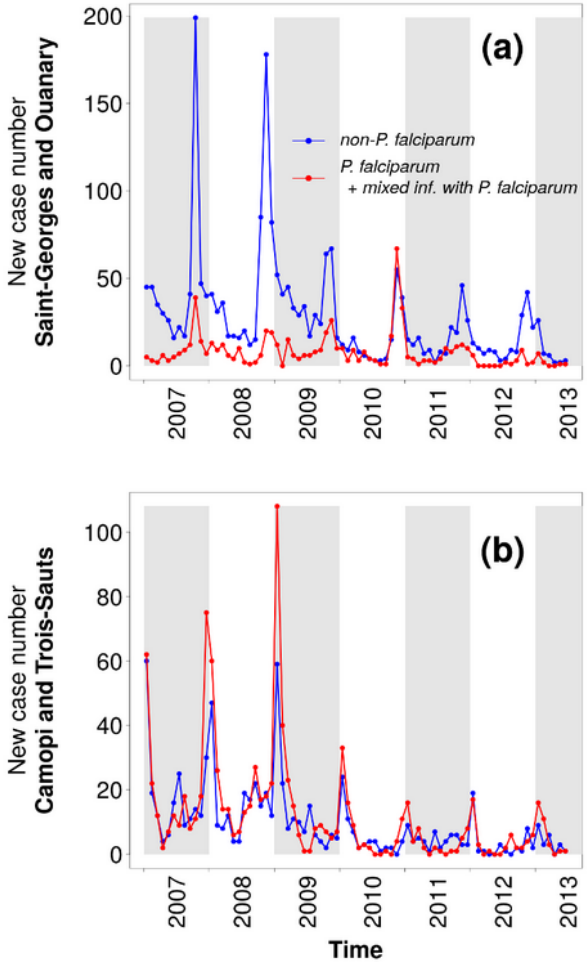
Figure 3. Number of new monthly malaria cases reported in the cross-border area from 2007 to 2019: (a) the cross-border area as a whole; (b) cases recorded in the database of the Department of the Centers for Prevention and Care (Service des Centres Délocalisés de Prévention et de Soins [CDPS]) in French Guiana (FR-GF); (c) cases recorded in the Malaria Epidemiological Surveillance Information System (Sistema de Informações de Vigilância Epidemiológica da Malária [SIVEP-Malária]) in Brazil (BR).



Cases notified by both countries, globally, presented comparable dynamics, with a clear seasonality showing a peak between October and December (ie, at the end of the dry season and the early beginning of the rainy season). Four main phases can be distinguished over the total period:

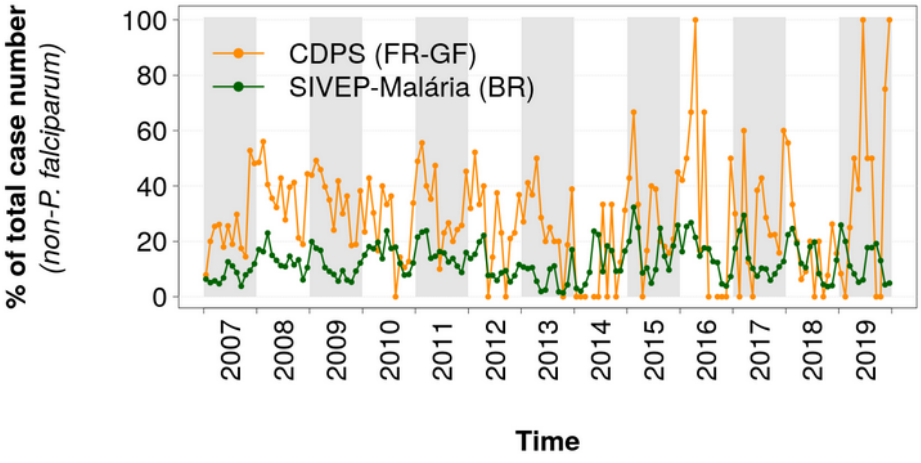
1. January 2007 to June 2013: high but decreasing number of cases. Figure 3 (b) shows a two-peak epidemic curve in cases notified in the CDPS database (French Guiana) for this period, except for the year 2010. These two peaks were associated with different subregions and, to a lesser extent, with different *Plasmodium* species (see Figure 4). The first peak (October to November) corresponded with the lower Oyapock River region (ie, Saint-Georges and Ouanary), with a majority of non-*P falciparum* cases, as seen in Figure 4 (a); the second peak (December to January) corresponded to the upper Oyapock River region (ie, Trois Sauts and Camopi), with a majority of *P falciparum* cases, as seen in Figure 4 (b). Moreover, two subphases can be seen during this period in the cases provided by the CDPS database: a high and quite stable number of cases in 2007 and 2008 and a significant drop in the number of cases in 2009, followed by a progressive decrease up to 2013.
2. July 2013 to December 2016: low number of cases with relative interannual stability, despite a higher number of cases in 2015. The year 2013 particularly corresponded to a significant drop in the number of *P falciparum* cases (see Figure 3).
3. January 2017 to December 2018: recrudescence of *P vivax* cases.
4. January 2019: number of cases comparable with the 2013-2016 period, even lower for CDPS data, with a peak earlier in the year in May, particularly marked in the data provided by the SIVEP-Malária (Brazil).

Figure 4. Monthly reported malaria cases by species at the Centers for Prevention and Care (Centres Délocalisés de Prévention et de Soins [CDPSs]) of (a) Saint Georges de l'Oyapock and Ouanary and (b) Camopi and Trois Sauts, between January 2007 to June 2013.



For non-*P falciparum* species, a significantly higher percentage of cases related to follow-up, treatment failures, and relapses were identified in the CDPS database (see Figure 5). During the whole period, the average percentages were 28.7% and 12.7% in the CDPS database and in the SIVEP-Malária, respectively. As the number of cases became very low in French Guiana in 2016 and 2019, no malaria case was reported for some months; for other months, 100% of the cases were associated with follow-ups, putative treatment failures, or relapses.

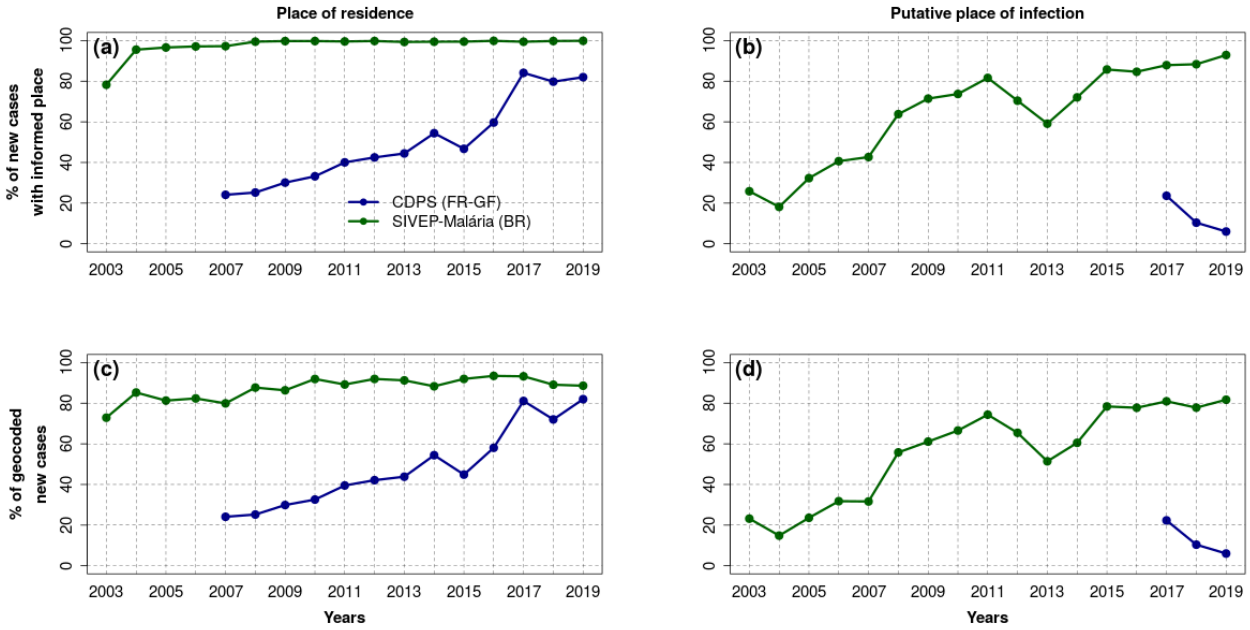
Figure 5. Percentages of cases associated with follow-up, treatment failures, or relapses for non-P falciparum cases in the database of the Department of the Centers for Prevention and Care (Service des Centres Délocalisés de Prévention et de Soins [CDPS]) in French Guiana (FR-GF) and the Malaria Epidemiological Surveillance Information System (Sistema de Informações de Vigilância Epidemiológica da Malária [SIVEP-Malária]) in Brazil (BR).



In the CDPS database, the percentage of cases associated with a place of residence increased from less than 30% in 2007 to more than 80% since 2017, as seen in Figure 6 (a). On the other hand, 100% of the new cases from the SIVEP-Malária database

were associated with a place of residence since 2008, as seen in Figure 6 (a).

Figure 6. Percentage of malaria cases in the database of the Department of the Centers for Prevention and Care (Service des Centres Délocalisés de Prévention et de Soins [CDPS]) in French Guiana (FR-GF) and in the Malaria Epidemiological Surveillance Information System (Sistema de Informações de Vigilância Epidemiológica da Malária [SIVEP-Malária]) in Brazil (BR) associated with (a) a place of residence; (b) a putative place of infection; (c) a geolocalized place of residence; and (d) a geolocalized putative place of infection. Putative places of infection were not stored in the CDPS database before 2017.

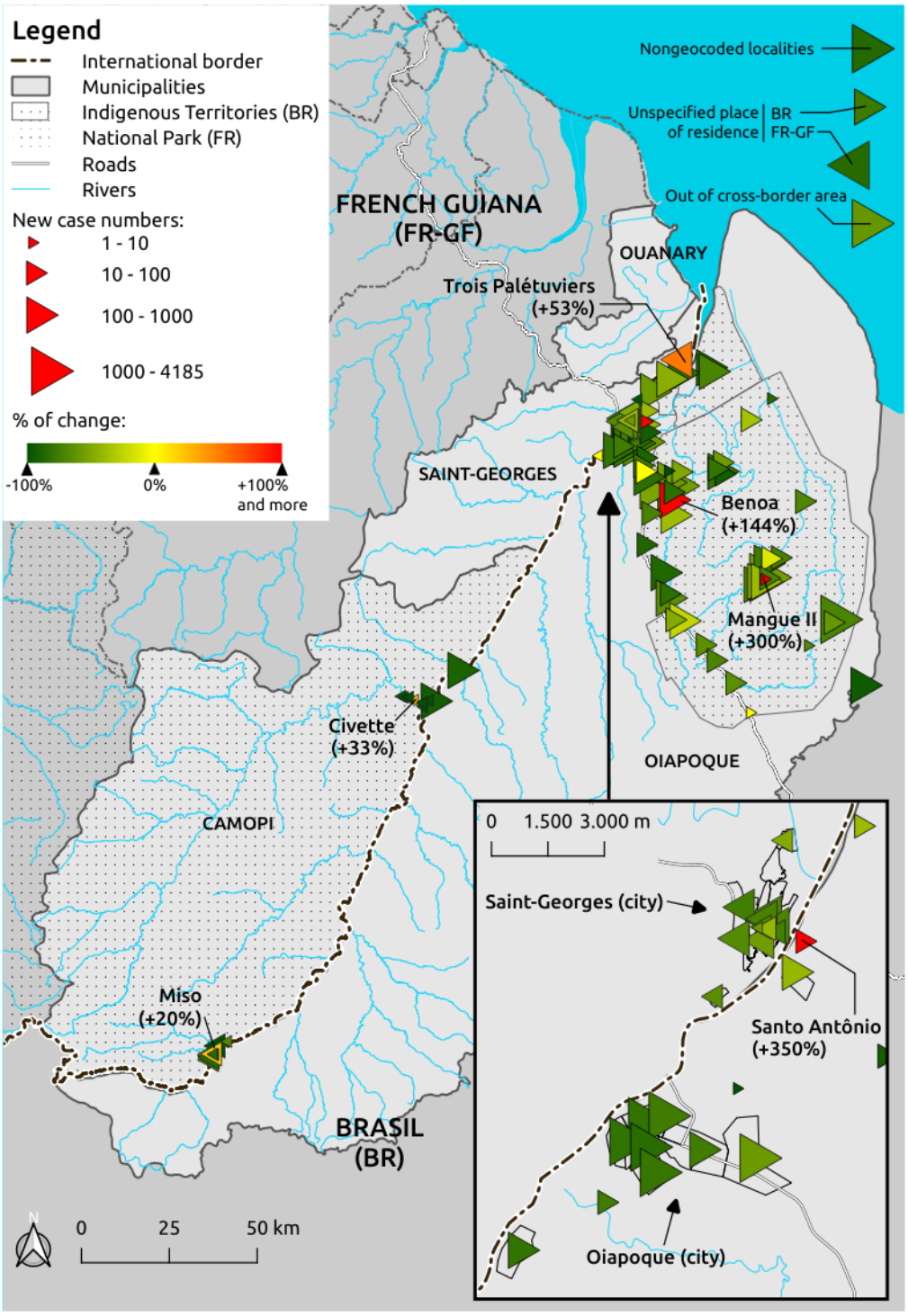


Concerning the putative place of infection of the new cases, the information has only been stored in the CDPS database since 2017. Such information remained rare and even tended to be rarer in the CDPS database, passing from about 20% of the new cases in 2017 to less than 10% in 2019 as seen in Figure 6 (b). In the SIVEP-Malária database, such information was much more present, with more than 80% of the new cases associated with a possible place of infection since 2015 as seen in Figure 6 (b).

The specific work carried out in this study to geolocalize, or geocode, localities resulted in 100% and 52.4% of geolocalized localities of the cross-border area for the French Guiana and Brazilian sides, respectively. However, in the SIVEP-Malária, the relatively small proportion of geolocalized localities (52.4%) had little impact on the number of cases actually geolocalized, with about 90% and 80% of the cases geocoded since 2015 in relation with the places of residence and probable places of infection, respectively, as seen in Figure 6 (c) and (d).

Figure 7 shows an example of a map realized with the harmonized data of the CBMIS. It represents the numbers of new cases as a function of the places of residence of the patients, from January 2007 to December 2019, jointly with the percentage of change in the case numbers between the two main periods previously described: January 2007 to June 2013 and July 2013 to December 2019. The map shows a significant decrease in almost the entire cross-border area. The decrease was very significant in the Camopi municipality and in the urban quarters of the Oiapoque city. The decrease was significant but less important in the Amerindian communities of the Oiapoque municipality and in the Saint-Georges municipality. Some localities experienced an increase in case numbers between the two periods: the two Amerindian localities Benoa and Trois Palétuviers, in Brazil and French Guiana, respectively, had a significant increase from 34 to 84 cases (144%) and 93 to 142 cases (53%), respectively. The Amerindian locality Mangue II (Brazil), the locality Santo Antônio (Brazil), as well as the two Amerindian localities Civette and Miso in the Camopi municipality (French Guiana) experienced a nonsignificant increase in regard to the total number of cases.

Figure 7. Number of reported malaria cases as a function of patients' places of residence. Triangles with apexes oriented to the right correspond to Brazilian localities; triangles with apexes oriented to the left correspond to French localities. The triangle size is a function of the case number. The triangle color is a function of the percentage of change in the case number between the following two periods: January 2007 to June 2013 and July 2013 to December 2019.



Discussion

Principal Findings

The results showed the potential of the CBMIS for the analysis of cross-border malaria dynamics, in both space and time. Such a system also allows for pointing out similarities and differences in the epidemiological situations of both countries. As it is shown hereafter, such similarities and differences can be interpreted in terms of control strategies. In the following paragraphs, methodological aspects of the proposed approach and the previously presented results are discussed. However, specific and deep investigations of cross-border epidemiological issues are out of the scope of this paper.

Definition of Cross-Border Malaria Cases

Human mobility is an important issue when considering border regions [2]. By differentiating between places of residence, notification, and infection, the CBMIS allows an estimation of internal and external flows in the area and facilitates the identification of autochthonous and imported malaria cases. Such differentiation also allows for conducting studies from different viewpoints, notably on environmental determinants of the transmission, population profiles, identification of spatial clusters of malaria cases, provision of and access to care, and activity level of health infrastructures.

General Harmonization Strategy

The chosen approach relies on current national health system data reconciliation and does not require any previous system modifications. Such an approach is comparable to the one in Dell'Erba et al [20], which was developed for the domains of travel and tourism information systems and data, or Zinszer et al [21] for malaria data integration. This approach is likely to facilitate the participation of surveillance agencies in the development of a CBMIS, whereas these agencies would be "reluctant to abandon their own data schemata in favor of a standard schema supplied by someone else" [20]. In that sense, the proposed approach differs from recommendations provided in D'Agostino et al [22] to facilitate data sharing in public health, which include the development of regional frameworks that "can be adopted or adapted by each country through national or subnational policies" as a prerequisite for the realization of data interoperability.

In Al Manir et al [23], the authors developed a set of services to query multisource heterogeneous malaria-related data using standard terminologies and rules to match database fields and controlled vocabularies. They illustrated the functioning of the system by answering thematic questions provided by the Uganda Ministry of Health and by querying two data repositories: the Scalable Data Integration for Disease Surveillance platform [21] and the Global Malaria Mapper from the WHO, now integrated into the Global Health Observatory data [24]. The system was not designed to provide and visualize comparable and qualified raw epidemiological data as in this study. However, it can automatically identify any change in source databases and provides tools to reconfigure the system in order to maintain its integrity, unlike our method. Such functionality would be of interest in applying the approach proposed in this article to a large number of surveillance systems.

Data Completeness, Quality, and Limitations

In French Guiana, CDPSs are not the only malaria notifiers. Nevertheless, given the care pathway of the people living in or frequenting the three border municipalities, the quasi-totality of the malaria cases is retrieved by the system. On the other hand, the three French Guiana border municipalities have only been reporting putative places of infection since 2017, and a lot of missing data are associated with this field. As a consequence, some malaria cases can be omitted by the system if their notifications and places of residence are out of the cross-border area, but the putative places of infection would belong to it. However, we can expect such a number to be negligible. In Brazil, the legal Amazon, whose malaria cases are reported in the SIVEP-Malária, accounts for more than 99% of the Brazilian malaria cases [25,26]. In conclusion, the CBMIS reports reliably on the number of cases within the cross-border area.

Some database attributes exhibit a lot of missing data. Among them, the putative place of contamination, and to a lesser extent the place of residence, is by far the least informed in the CDPS database. However, the information on putative places of contamination has been collected for a long time in French Guiana and has been used for malaria control. The epidemiological bulletins on malaria in French Guiana, published by the national agency for epidemiological surveillance (Santé Publique France), reported that, for the whole French Guiana area and the period between January 2017 and September 2019, the suspected place of contamination is known for 76.9% of cases on average, with a global upward trend (minimum of 54.4% for the first trimester of 2017; maximum of 87% for the first trimester of 2019) (see Multimedia Appendix 1, Table S4). These numbers are comparable with those on the Brazilian side and considerably contrast with those previously shown for French Guiana. In fact, when the CDPS transmits the information on new malaria cases to the local health surveillance authority, the latter requests that the vector control service of the French Guiana territorial collectivity carry out intradomiciliary insecticide spraying and to investigate the context of contamination, in particular, the putative place of contamination. There is currently no back-feeding of the CDPS database with the collected information, which should be considered in the future.

It is worth noting that, despite the difficulties encountered in geocoding all localities on the Brazilian side, the great majority of the new cases reported in Brazil are finally geocoded according to their residence and the place of infection. In fact, only very small localities, and localities that no longer exist, that are associated with very low numbers of cases could not be geocoded. However, efforts are continuing to reach the target of 100% geocoded localities on the Brazilian side.

Some of the missing information in the harmonized database may be due to inadequate coding of the information at the time of notification. However, all possible errors cannot be anticipated and considered within an automatic processing framework unless a highly specific system is built, the functioning of which may become difficult to understand and maintain. The strategy chosen for the CBMIS is instead to provide quality indicators, especially relative to missing information, in order to (1) provide users with the primary interpretation keys in order to let them decide whether an information item is significant or not and (2) give feedback to health actors in charge of surveillance, to allow them to identify surveillance system weaknesses and improve their practice.

The far more difficult point is the interpretation biases derived from differences in country surveillance cultures and practices. Some of these differences are not surmountable, and the harmonization requires making choices and compromises, as with the *new attack* notion discussed above and in Multimedia Appendix 1. Here again, the solution lies in clarifying these differences and the implemented harmonization rules.

Multimedia Appendix 1 gathers complementary discussion points that can help inform interpretation of the harmonized data. Eventually, for complementary knowledge on SIVEP-Malária data quality, readers are encouraged to refer to existing publications on the subject [12,27].

Method Reproducibility

The entire development of the harmonization and visualization applications was carried out with the constant concern that they can be easily and rapidly implemented in other cross-border contexts.

This was ensured by satisfying standards and using existing dedicated and open source tools for data harmonization and visualization. Moreover, the objects of study (ie, patient, consultation, locality, etc) and their properties were formalized by an application knowledge model that currently takes two forms: a dump of the database structure in Structured Query Language (SQL) for its implementation within a database management system such as PostgreSQL, and an ontological formalization in Web Ontology Language (OWL) [28] that enables the knowledge model to be represented according to web data standards and thus ensures its dissemination and reuse by other projects and platforms. Future work will focus on updating and enriching this ontology.

The French Guiana–Brazil cross-border area proved to be an excellent laboratory for the cross-border malaria surveillance issue. It gathers all the specific characteristics of cross-border territories, which make the cross-border malaria issue a major obstacle for the elimination of the disease [2]. The characteristics are as follows: a high diversity of cultures, activities, lifestyles, and languages among the populations; different conceptions, strategies, and means of surveillance, prevention, and control of the disease from one country to another; difficulties in following up with some populations due to their high mobility and possible situations of illegality (ie, undocumented people, illegal activities, etc); and marginalization of border areas with respect to national territorial management and implementation of national public health policies. Moreover, the existing national surveillance systems present significant systemic, syntactic, and semantic differences, and both countries impose different and constraining legal requirements. All the previously listed features make the study area representative of situations we are likely to encounter elsewhere, especially at the international borders of the Brazilian Amazon.

All of the above ensures reproducibility of the method. In fact, the approach was successfully tested at the border between Colombia and Brazil, where a similar monitoring system is currently being developed.

Cross-Border Malaria Dynamics

Interannual dynamics of malaria case numbers result from a conjunction of multiple factors, and it is difficult to state which one is predominant. However, a few suggestions can be made. Thus, the use of RDTs and the introduction of artemisinin-based combination therapies from 2007 in the CDPSs of French Guiana can explain the drop in cases in French Guiana from 2008 [29]. Moreover, in 2008 with the start of the military operation Harpie, which followed operations Anaconda and Toucan, the French army significantly increased pressure on illegal gold mining in French Guiana, expelling more illegal workers, mainly to Brazil, and tending to make illegal gold mining unprofitable. Although there is a delay of one year, this may partly explain the drop in the number of cases reported in French Guiana from 2009 onward, since the gold-miner population represents one of the major *Plasmodium* species reservoirs in French Guiana [30,31].

In 2012, a binational campaign of distribution of long-lasting insecticide-treated mosquito nets (55 mg/m^2 concentration of deltamethrin) was carried out on both sides of the French Guiana–Brazil border, co-conducted by the regional health agency of French Guiana (Agence Régionale de Santé de la Guyane) and the health secretariat of the municipality of Oiapoque in Brazil. This may have contributed to the drop in *P falciparum* cases from 2013.

The recrudescence of the case numbers in 2017 and 2018 is more difficult to explain. In fact, such a recrudescence concerned five countries of the Americas according to the Pan American Health Organization [32]: Brazil, Ecuador, Mexico, Nicaragua, and Venezuela. Brazil reported 174,522 cases between January and November 2017 (ie, 56,690 cases more than for the same period in 2016, which represents a 48% increase) [32]. The Amapá state, meanwhile, has seen the number of cases increase by 23%. French Guiana experienced a significant increase of malaria case numbers for the same period, especially in the municipalities at the border with Brazil [33].

The low number of cases in 2019 can be partly explained by concomitant action-research projects, even if their impacts have still to be evaluated. In 2017 and 2018, the ELIMALAR-PALUSTOP (Elimination of Malaria – Stop Paludisme) project performed an active *Plasmodium* species mass screening by molecular biology—polymerase chain reaction method—among 1566 inhabitants of the Saint-Georges municipality, followed by the treatment of all symptomatic and asymptomatic cases. This should have contributed to the decrease of transmission in this cross-border area. In addition, in 2018 and 2019, the French-Brazilian Malakit project distributed self-diagnosis and self-treatment kits to the gold miners in this cross-border area [34].

Differences in follow-up protocols between French Guiana and Brazil can explain the relatively high number of cases associated with follow-up, possible treatment failures, and relapses in French Guiana. The Brazilian health system involves community health workers who visit patients and help with compliance with treatment. On the other hand, in French Guiana, the health system does not benefit from the action of community health workers. Moreover, Brazil systematically gives primaquine to patients with *P vivax*—except for specific cases including pregnancy—which significantly reduces the risk of relapses, whereas prior glucose-6-phosphate dehydrogenase testing is required in French Guiana, which tends to restrict and delay the use of primaquine [33,35]. This situation makes French Guiana more likely to observe *P vivax* relapses than Brazil. In Brazil, patients with good compliance do not experience relapses; in addition, their follow-up does not require consultations at the health centers and does not generate new notifications in the

Brazilian system. Eventually, such differences can be explained by the fact that the rule for the non-*P falciparum new case* identification implies a longer delay in French Guiana (90 days) than in Brazil (60 days) (see Methods section and Multimedia Appendix 1).

International Cooperation

Partnership was a key factor in the success of the CBMIS development. In fact, an operational multilevel—from local health actors to national organizations—and multidisciplinary partnership, including data science, information systems, epidemiology, parasitology, geography, and geomatics, has been strengthening for about eight years within the framework of several research and regional cooperation programs. Such a partnership is able to mobilize skills and know-how to study other cross-border contexts. The co-construction of the system with all partners ensures its appropriation by health actors so that the system can actually enter into the practice of surveillance and ensure targeted and coordinated public health responses from both countries in order to achieve malaria elimination.

Conclusions

We propose a system that provides comparable and qualified data on the cross-border malaria epidemiological situation. The system is built on technological advances and existing national monitoring systems. Implementing such a system required the application of development good practices, some of which are compulsory, such as those related to privacy, while others contribute to the easy and regular updating of data, facilitate the method's reproducibility, and ensure confidence in the system, thus ensuring the appropriation of results by user communities.

The resulting system is accessible to territory managers, caregivers, researchers, and the general public. The system can notably help in producing new scientific evidence on disease dynamics and determinants, facilitate cross-border cooperation regarding malaria prevention and control, and contribute to citizens' informed participation in public debate and in public authority accountability, in order to achieve malaria elimination.

Acknowledgments

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Authors' Contributions

RS and ER wrote the manuscript, with all coauthors commenting on the drafts of the paper; RS also defined the epidemiological indicators, designed and implemented dashboards, ensured SIVEP-Malária data retrieval, and is contributing to the CBMIS maintenance. EM contributed to the harmonization rule definition, the CBMIS evaluation, and the interpretation of the results. CB contributed to the CBMIS conception, the understanding and use of the SIVEP-Malária, and the French-Brazilian scientific cooperation. AC and BG provided the CDPS surveillance system description and contributed to the CBMIS data retrieval. CC installed and is maintaining the CBMIS on the IRD's servers and participated with the development of the CNIL authorization request. JCD participated in the ETL implementation, knowledge formalization, and the CNIL authorization request development. MDSMG, AMM, and PCP contributed to the understanding and use of the SIVEP-Malária and assisted in the geocoding of Brazilian localities and cross-border cooperation. TM contributed to the ETL method implementation. LM contributed to the interpretation of results. AS and BVG supported the cross-border cooperation and participated in the CBMIS evaluation. ER designed and coordinated the project and contributed to the CBMIS design and implementation, to obtaining the CNIL authorization, to the CBMIS maintenance, and to the French-Brazilian scientific cooperation.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Harmonization rules and algorithm (Tables S1 and S2; Figure S1); online dashboard description (Table S3); and percentage of cases with a specified putative infection location in French Guiana, according to epidemiological bulletins of the interregional epidemiology unit of French Guiana (CIRE [Cellule Inter-Regional d'Epidemiologie; Inter-Regional Epidemiological Center]-Guyane/Santé Publique France) (Table S4).

[PDF File (Adobe PDF File), 227 KB - publichealth_v6i3e15409_app1.pdf]

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Abbreviations

CAPES: Coordenação de Aperfeiçoamento de Pessoal de Nível Superior (Coordination for the Improvement of Higher Education Personnel)
CBMIS: cross-border malaria information system

CDPS: Centre Délocalisé de Prévention et de Soins (Center for Prevention and Care), or Service des Centres Délocalisés de Prévention et de Soins (Department of the Centers for Prevention and Care)
CIRAD: Centre de Coopération Internationale en Recherche Agronomique pour le Développement (French Agricultural Research Centre for International Development)
CNIL: Commission Nationale de l'Informatique et des Libertés (National Commission for Computing and Liberties)
ELIMALAR-PALUSTOP: Elimination of Malaria – Stop Paludisme
ETL: extract, transform, and load
FAPEAM: Fundação de Amparo à Pesquisa do Estado do Amazonas (Amazonas State Research Support Foundation)
FAPEAP: Fundação de Amparo à Pesquisa do Estado do Amapá (Amapá State Research Support Foundation)
FAPEMA: Fundação de Amparo à Pesquisa do Estado do Maranhão (Maranhão State Research Support Foundation)
Fiocruz: Fundação Oswaldo Cruz (Oswaldo Cruz Foundation)
GAPAM-Sentinela: Guyane Française – Amapá – Amazonas – Malária: Sítio Sentinela Transfronteiriça do Observatório Clima e Saúde (French Guiana – Amapá – Amazonas – Malaria: Cross-Border Sentinel Site of the Brazilian Climate and Health Observatory)
IRD: Institut de Recherche pour le Développement (French National Research Institute for Sustainable Development)
LMI: Laboratoire Mixte International (Joint International Laboratory)
LVC: lâmina de verificação de cura (treatment verification slide)
ODYSSEA: Observatory of the Dynamics of Interactions Between Societies and Environment in the Amazon
OWL: Web Ontology Language
PrInt: Programa de Internacionalização (Internationalization Program)
RDT: rapid diagnostic test
SIVEP-Malária: Sistema de Informações de Vigilância Epidemiológica da Malária (Malaria Epidemiological Surveillance Information System)
SQL: Structured Query Language
WHO: World Health Organization

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Original Paper

Potential Early Identification of a Large Campylobacter Outbreak Using Alternative Surveillance Data Sources: Autoregressive Modelling and Spatiotemporal Clustering

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Abstract

Background: Over one-third of the population of Havelock North, New Zealand, approximately 5500 people, were estimated to have been affected by campylobacteriosis in a large waterborne outbreak. Cases reported through the notifiable disease surveillance system (notified case reports) are inevitably delayed by several days, resulting in slowed outbreak recognition and delayed control measures. Early outbreak detection and magnitude prediction are critical to outbreak control. It is therefore important to consider alternative surveillance data sources and evaluate their potential for recognizing outbreaks at the earliest possible time.

Objective: The first objective of this study is to compare and validate the selection of alternative data sources (general practice consultations, consumer helpline, Google Trends, Twitter microblogs, and school absenteeism) for their temporal predictive strength for Campylobacter cases during the Havelock North outbreak. The second objective is to examine spatiotemporal clustering of data from alternative sources to assess the size and geographic extent of the outbreak and to support efforts to attribute its source.

Methods: We combined measures derived from alternative data sources during the 2016 Havelock North campylobacteriosis outbreak with notified case report counts to predict suspected daily Campylobacter case counts up to 5 days before cases reported in the disease surveillance system. Spatiotemporal clustering of the data was analyzed using Local Moran's I statistics to investigate the extent of the outbreak in both space and time within the affected area.

Results: Models that combined consumer helpline data with autoregressive notified case counts had the best out-of-sample predictive accuracy for 1 and 2 days ahead of notified case reports. Models using Google Trends and Twitter typically performed the best 3 and 4 days before case notifications. Spatiotemporal clusters showed spikes in school absenteeism and consumer helpline inquiries that preceded the notified cases in the city primarily affected by the outbreak.

Conclusions: Alternative data sources can provide earlier indications of a large gastroenteritis outbreak compared with conventional case notifications. Spatiotemporal analysis can assist in refining the geographical focus of an outbreak and can potentially support public health source attribution efforts. Further work is required to assess the location of such surveillance data sources and methods in routine public health practice.

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KEYWORDS

Campylobacter; disease outbreaks; forecasting; spatio-temporal analysis

Introduction

Background

In August 2016, Havelock North, one of the 5 cities in the Hawke's Bay region, New Zealand, was the site of a large waterborne outbreak of Campylobacter infection. This outbreak began on August 8, but a large number of cases were not known to the national notifiable disease surveillance system until August 14. By that time, more than a third of Havelock North residents had been infected with Campylobacter. This event led to serious interruption of daily life in the area and large economic costs [1,2].

The surveillance for notifiable diseases in New Zealand is predominantly passive, with laboratories and physicians notifying their local public health service through submission to the national notifiable disease surveillance system, EpiSurv [3]. There are inevitable delays from when people are exposed to an outbreak source (in this outbreak, the source was contaminated drinking water) to when they become ill, seek medical care, are diagnosed, and then notified to health authorities. There are usually further delays before an outbreak is recognized, investigated, and controlled. Therefore, notifiable disease reports are after the fact, and the information is typically delayed due to systematic information flow through traditional channels, for example, from physicians and laboratories.

Interest in considering alternative data sources for early prediction of such outbreaks was motivated by previously published work reporting on the use of data from internet search engines [4-7], crowd-sourced participatory disease surveillance systems [8,9], Twitter microblogs [5,10,11], news stories [12], school absenteeism reports [13,14], general practice (GP) consultations [15], consumer helpline calls [16,17], bank transactions [18], and numerous other sources. Location-aware applications have also been exploited for public and environmental health surveillance and crisis management [19,20] or to provide situational awareness and forecasting for disease outbreaks at the local level [20].

Objectives

This study revisits the Havelock North Campylobacter outbreak to examine signals present in data sources that were not available to the public health team during the response. By analyzing temporal and spatiotemporal patterns in these alternative data sources, the study assesses the relative effectiveness and sensitivity of different data sources in detecting the outbreak earlier. First, we aim to assess the temporal predictive strength of modeled combinations of measures from the following daily alternative data sources: GP consultations, consumer health helpline calls, Google Trends, Twitter microblogs, and school absenteeism records. These models will be measured by the time gained (up to 5 days ahead) compared with the cases notified in the existing disease surveillance system, using multiple evaluation metrics. Second, we will examine city-level spatiotemporal patterns in measures from alternative data sources relative to notified case counts to identify clusters and outliers in both space and time over the outbreak period.

Methods

Ethics

The study protocol was approved by the Health and Disability Ethics Committee, New Zealand, under the protocol number NZ/1/6350114. The Twitter data used in this study were obtained under the Twitter terms and conditions and in agreement with its public privacy settings.

Data Collection and Management

For the greater area affected by the outbreak (Hawkes Bay), we collected daily data for the entire 2016 calendar year from the data sources described in Table 1.

Table 1. Description of data sources used in analysis.

Source	Fields of interest	Data level used in analysis	Counts	References
Notified case count (New Zealand surveillance database EpiSurv)	Date of onset, testing, and notification for confirmed and probable cases of campylobacteriosis	Aggregated by notification date and city of residence in Hawkes Bay	1345	Ministry of Health New Zealand [3]
General practice consultations (HealthStat)	Visits for gastrointestinal complaints	Individual with visit date, age, and sex, for entire Hawkes Bay District Health Board area only	772	Cumming J and Gribben B [21]
Consumer helpline (HealthLine) calls	Consumer calls concerning gastrointestinal complaints	Individual with call date, age, sex, and residential city in Hawkes Bay	1196	St George IM and Cullen MJ [22]
Google Trends	User queries with keywords for gastrointestinal complaints	Normalized counts aggregated by date, query keyword, and Google Trends normalized count for entire Hawkes Bay District Health Board area only	Not applicable	Google Trends [23]
Twitter microblogs (from Gnip Historical PowerTrack service)	Tweets with keywords for gastrointestinal complaints	Individual tweets geocoded to cities in Hawkes Bay	191	Gnip [24]
School absenteeism records (from individual schools)	Absence owing to illness or any valid reason	Aggregated by schools for the 5 schools providing data, areas represented: Havelock North, Napier, and Hastings	23,836	Ministry of Education, New Zealand [25]

Notified Case Count

We extracted confirmed and suspected cases of campylobacteriosis in Hawkes Bay from EpiSurv [3] and aggregated them by report date and city-level locations. EpiSurv is the core surveillance system used for monitoring the occurrence of notifiable infectious diseases such as campylobacteriosis and detecting increases that may indicate an outbreak in New Zealand [26]. We refer to these data as *notified case counts* and use them as the main comparator for assessing the potential value of alternative surveillance data sources.

GP Consultations

Daily data on consultations with GPs were collected through HealthStat. This system automatically monitors the number of people who consult primary care medical practitioners based on automated extracts of GP-coded data from computerized practice management systems [21]. The data we used were the daily counts of those who consulted for gastroenteritis.

Consumer Helpline Calls

Consumer helpline data were collected from HealthLine, which is a free national 24-hour 0800 telephone health advice service funded by the New Zealand Ministry of Health [22]. Calls made to HealthLine are triaged using electronic clinical decision support software. The data collected are a daily count and the city-level location of all phone calls made to HealthLine by people reporting symptoms of gastrointestinal illness. A list of the symptoms used is included in Multimedia Appendix 1.

Google Trends

Google Trends provides a time series index of the volume of queries users enter into Google in a given geographic area [23]. We collected daily Google Trends data for a range of keywords that could be used to search for information regarding any gastrointestinal illness (see Multimedia Appendix 2 for a list of keywords). These Google Trends data were downloaded within a single day, as Google varies the signal display over time. Google Trends data for the selected keywords were assessed for correlation and cross correlation with the notified case counts for up to 10 previous days, and those keywords with correlations over 0.03 were chosen for the further analysis: “campylobacter,” “diarrhoea,” “diarrhea,” “gastro,” “gastroenteritis,” “puke,” and “vomiting.” Pearson correlation and cross correlation (same day and lagged) of these keywords in Google Trends with notified case counts of campylobacteriosis (January 2016 to July 2016) are presented in Multimedia Appendix 3.

Twitter Microblogs

Twitter is a free social networking and microblogging service that enables millions of users to send and read each other's tweets, or short, 140-character messages. Registered users collectively send more than 200 million tweets a day. Twitter accounts are by default public and visible to all (even to unregistered visitors using the Twitter website). Users can restrict their account settings to private, in which case their contents can only be visible to approved followers.

In a previous study, we obtained Twitter data from Gnip, their licensed data provider, through their Historical PowerTrack service [24]. In contrast to the publicly available Twitter data stream (Twitter application programing interface), which provides approximately 1% of all real-time tweets, the Historical PowerTrack provides search access to 100% of all publicly available tweets as well as metadata associated with each tweet. Tweets generated between April 2012 and March 2017 were collected from PowerTrack. They contained one or more gastrointestinal-related keywords and were assigned a country code of New Zealand in the Tweet or in the user profile location. The Gnip Query to collect Twitter data is included in Multimedia Appendix 4. A total of 131,843 records were obtained. These data were first geocoded using the latitude and

longitude of the tweet. If the tweet location was missing, the profile latitude and longitude were used.

Twitter feeds were classified by developing a supervised machine learning classifier using the Naïve Bayes algorithm in Python. A total of 10,000 random tweets were manually labeled as (1) gastrointestinal illness, (2) other infectious illness, and (3) irrelevant tweets. A tweet was labeled "gastrointestinal illness" when its content described a recent account of infectious gastrointestinal illness, "infectious illness" for tweets that described a recent account of other infectious illnesses, and "irrelevant" for tweets that did not fit in the other 2 categories. This training set was used to train the machine learning classifier, which was then used to classify the complete Twitter data. This classifier was evaluated on 1000 randomly selected and manually labeled tweets that were not included in the training set. Precision, recall, and F1 scores were calculated to evaluate the performance of the classifier. Precision is the ratio of observations judged relevant to the total observations predicted as relevant, recall is the ratio of observations judged relevant out of total relevant observations, and F1 is the weighted average of precision and recall [27]. The classification method obtained a precision of 0.813, recall of 0.803, and F1 score of 0.804. We applied this developed supervised classifier to the data from the Hawkes Bay region for the period of January 1, 2016, to December 31, 2016.

School Absenteeism

We collected school absenteeism data from 5 schools in Hawke's Bay: 2 from Havelock North, 2 from Hastings, and 1 from Napier. These included 4 primary schools and 1 secondary school. Primary school data had a reason for absence code, so we included data for codes related to illness and/or any justified absence. Absenteeism codes are listed in Multimedia Appendix 5. For the secondary school, all absenteeism counts were included without any subcoding. Havelock North and Hastings were the areas primarily affected by the outbreak, whereas the Napier school served as a control.

A daily time series with cumulative counts from all the previously mentioned data sources was constructed. For the school data set, days covering the school holidays were removed from the analysis. In all data sources, missing data values were estimated by interpolation of observational data. These adjustments were made to reduce the impact of missing data in the analysis.

Statistical Analysis

Correlation and Cross Correlation

To assess whether the selected data sources could have predicted this Campylobacter outbreak earlier, we used Pearson correlation statistics to calculate correlations between daily counts of these alternative surveillance measures and daily counts of notified cases. Correlations were calculated for the notified case count with the alternative measure on the same day as well as with up to a 10-day negative lag for each alternative measure (ie, correlating the notified case count on day t with the alternative measure on day t−10, t−9, etc; Table 2). Using this method, a significant correlation with the count on the same day indicates that the peak occurs at the same time [28], and the cross correlation at a specific lag of *x* days indicates that the peak in the alternative measure occurs *x* days before the peak in notified cases.

Table 2. Correlation and lagged transformed correlation of alternative predictors with notified case counts of campylobacteriosis.

Data source	Number of days that alternative measures are lagged before notifiable counts										
	0 days	−1 day	−2 days	−3 days	−4 days	−5 days	−6 days	−7 days	−8 days	−9 days	−10 days
GP[a] consultations	0.5[b]	0.43[b]	0.39[b]	0.26[b]	0.17[b]	0.14[b]	0.09	0.05	0.04	0.01	0.01
Consumer helpline	0.44[b]	0.59[b]	0.67[b]	0.64[b]	0.55[b]	0.37[b]	0.2[b]	0.12[b]	0.1	0.07	0.07
Google Trends	0.13[b]	0.16[b]	0.22[b]	0.22[b]	0.21[b]	0.17[b]	0.21[b]	0.21[b]	0.16[b]	0.08	0.02
Twitter microblogs	0.11[b]	0.21[b]	0.31[b]	0.25[b]	0.21[b]	0.07	0	−0.01	0	−0.03	0
School absenteeism	0.3[b]	0.48[b]	0.64[b]	0.7[b]	0.52[b]	0.35[b]	0.21[b]	0.2[b]	0.17[b]	0.18[b]	0.15[b]

[a]GP: general practice.

[b]Statistically significant correlation coefficient >0.1.

Models

To forecast daily suspected cases of campylobacteriosis, a collection of multivariable autoregressive integrated moving average (ARIMA) models were constructed. These models were found to be a good tool for the prediction of communicable disease incidences [5,6,29-32]. These models are denoted as ARIMA(p,d,q), where parameters p, d, and q are non-negative integers; p is the number of autoregressive terms, d is the degree of differencing needed for stationarity, and q is the moving average component of the model. Data from January 1 to July 31, 2016, were used for model development. Model identification for ARIMA was initiated using the R statistical function auto.arima, which uses the Bayes information criterion to determine the orders p and q and the Phillips-Perron unit root test for determining the order d.

These models used the negative lagged (day −1 to day −10) daily counts for each alternative measure (Table 2) and the nonlagged notified case counts as covariates. We computed various permutations using different combinations of covariates and chose the optimal combination of covariates using the root mean square error (RMSE). The autocorrelation and partial autocorrelation plots of the models obtained from auto.arima were examined to further adjust the range of ARIMA (p and q)

parameters. In addition to the models that used the aforementioned data streams as covariates, we built baseline models with only notified case counts for comparison and context. We considered models that only used historical observation of Campylobacter cases to predict cases on the subsequent days and models that incorporated information from the various alternative data streams to compare their predictive abilities during the volatile peak of the outbreak.

Models were thus evaluated for their predictive performance during the test period from July 31 to August 30, 2016. For each model, we report 3 evaluation metrics: the Pearson correlation (ρ), RMSE, and the relative root mean square error (rRMSE) of the predictions. ρ is a measure of the linear dependence between two variables during a period. RMSE is a measure of the difference between the predicted and true values. rRMSE is a measure of the percent difference between the predicted and true values. The equations for these measures are given below:

where y_i denotes the observed value of the notified Campylobacter cases at time t_i, x_i denotes the predicted value by any model at time t_i,  denotes the mean of the observed values, and  denotes the mean of the predicted values.

Spatiotemporal Clustering

Sources that included city-level locations (notified cases, school absenteeism, consumer helpline, and Twitter feeds) were used for spatiotemporal analysis. To understand the spatial and temporal trends of the event data, we broke them up into a series of time snapshots, using the space-time cube method [33]. We applied this method to the data for August 2016 from Havelock North and Hastings, the two largely affected cities in the outbreak.

We used a Local Outlier Analysis tool in ArcGIS (Esri) to identify locations that were statistically different from their neighbors in both space and time. This tool generates Anselin Local Moran's I [34] statistics for each space-time window. These statistics have been used for spatial outlier detection in domains such as emergency management [35,36], epidemiology [37], and economics [38]. A Local Moran's I with a negative value (representing high-low or low-high autocorrelation) suggests dissimilarity with neighbors; hence, an outlier, with a positive value (representing high-high or low-low autocorrelation) suggests similarity and a zero value suggests randomness. A *P* value less than .05 indicates that the cluster or outlier is statistically significant [39]. Twitter was found to be insufficient in terms of spatialized city-level data (with no tweet from Havelock North and only 4 from Hastings during the outbreak period) to generate Local Moran's I statistics and hence was excluded from this analysis. The analysis was performed using ArcGIS Pro version 2.1.

Results

Relationship Between Notified Cases and Alternative Data

All alternative surveillance measures correlated significantly with notified Campylobacter cases on the same day. Many of these alternative surveillance measures also demonstrated strong correlations when lagged 1 to 8 days before notified cases. Indeed, the correlation ranged from 0.14 to 0.43 for up to 5 days of lag for GP consultations, 0.12 to 0.67 for up to 7 days of lag for consumer helpline inquiries, 0.16 to 0.22 for up to 8 days of lag for Google Trends, 0.21 to 0.31 for up to 4 days of lag for Twitter, and 0.15 to 0.7 for up to 10 days of lag for school absenteeism (Table 2).

ARIMA Models

The final ARIMA models and the covariates of alternative data sources with their in-sample error measure of RMSE are summarized in Table 3. We found multiple models suitable for prediction: school absenteeism performed best (average RMSE: 1.00) with ARIMA (5,1,3) for forecasting 1 to 2 days ahead and ARIMA (5,0,2) for forecasting 3 to 5 days ahead, followed by Google Trends (average RMSE: 1.07) with ARIMA (2,0,0) for forecasting up to 5 days ahead. GP consultation was found to have an average RMSE of 1.04, with ARIMA (3,0,1) for forecasting for the following day and ARIMA (2,0,0) for forecasting 2-5 days ahead. Twitter had an average RMSE of 1.08 and HealthLine had an average RMSE of 1.084 when used as the covariates in the models for predicting notified case counts.

Table 3. Autoregressive integrated moving average models with time-lagged covariates used with alternative data sources for forecasting 1 to 5 days ahead.

Alternative data source and forecast step	Time-lagged covariates, days[a]	ARIMA[b] order[c]	RMSE[d]
GP[e] consultations			
1 day	1 to 10	3,0,1	1.01
2 days	2 to 10	2,0,0	1.04
3 days	3 to 10	2,0,0	1.04
4 days	4 to 10	2,0,0	1.05
5 days	5 to 10	2,0,0	1.06
Consumer helpline			
1 day	1, 2, 3, 4, 5, 6, 7, 8, 10	3,0,2	1.08
2 days	2, 3, 5, 6, 7, 8, 10	3,0,2	1.08
3 days	3, 4, 5, 6, 7, 8, 10	3,0,2	1.08
4 days	4, 6, 7, 8, 9, 10	3,0,2	1.09
5 days	6, 7, 8, 9, 10	3,0,2	1.09
Google Trends			
1 day	1 to 10	2,0,0	1.07
2 days	2 to 10	2,0,0	1.08
3 days	3 to 10	2,0,0	1.08
4 days	4 to 10	2,0,0	1.08
5 days	5 to 10	2,0,0	1.08
Twitter			
1 day	1 to 10	4,0,1	1.07
2 days	2 to 10	5,0,2	1.08
3 days	3 to 10	3,0,2	1.08
4 days	4 to 10	2,0,2	1.09
5 days	5 to 10	2,0,2	1.09
School absenteeism			
1 day	1 to 10	5,1,3	0.94
2 days	2 to 10	5,1,3	0.94
3 days	3 to 10	5,1,3	0.94
4 days	4 to 10	5,0,2	1.09
5 days	5 to 10	5,0,2	1.09

[a]Lagged covariates refer to the time-lagged independent variables of alternative data source.

[b]ARIMA: autoregressive integrated moving average.

[c]ARIMA order (p,d,q) refers to the number of autoregressive terms, degree of differencing, and moving average components of the model.

[d]RMSE**:** root mean square error.

[e]GP: general practice.

We produced predictions for 1 to 5 days ahead during the outbreak (ie, the testing period) using the models in Table 3 and with the baseline models that used only autoregressive notified case counts. The daily estimations of the models with autoregressive (AR) information of notified case counts, AR with Google Trends (AR+GT), AR with consumer helpline (AR+CHL), AR with GP consultations (AR+GP), AR with school absenteeism (AR+ABS), and AR with Twitter (AR+Twitter) are presented in Figure 1.

Figure 1. Actual notified case counts and prediction results 1 to 5 days ahead for all developed models, with their prediction errors based on relative root mean square error. The best model performance with the lowest prediction error (relative root mean square error) in each time series is shown as a bold line. ABS: abseentism; AR: autoregressive; CHL: consumer helpline; GP: general practice; GT: Google Trends.

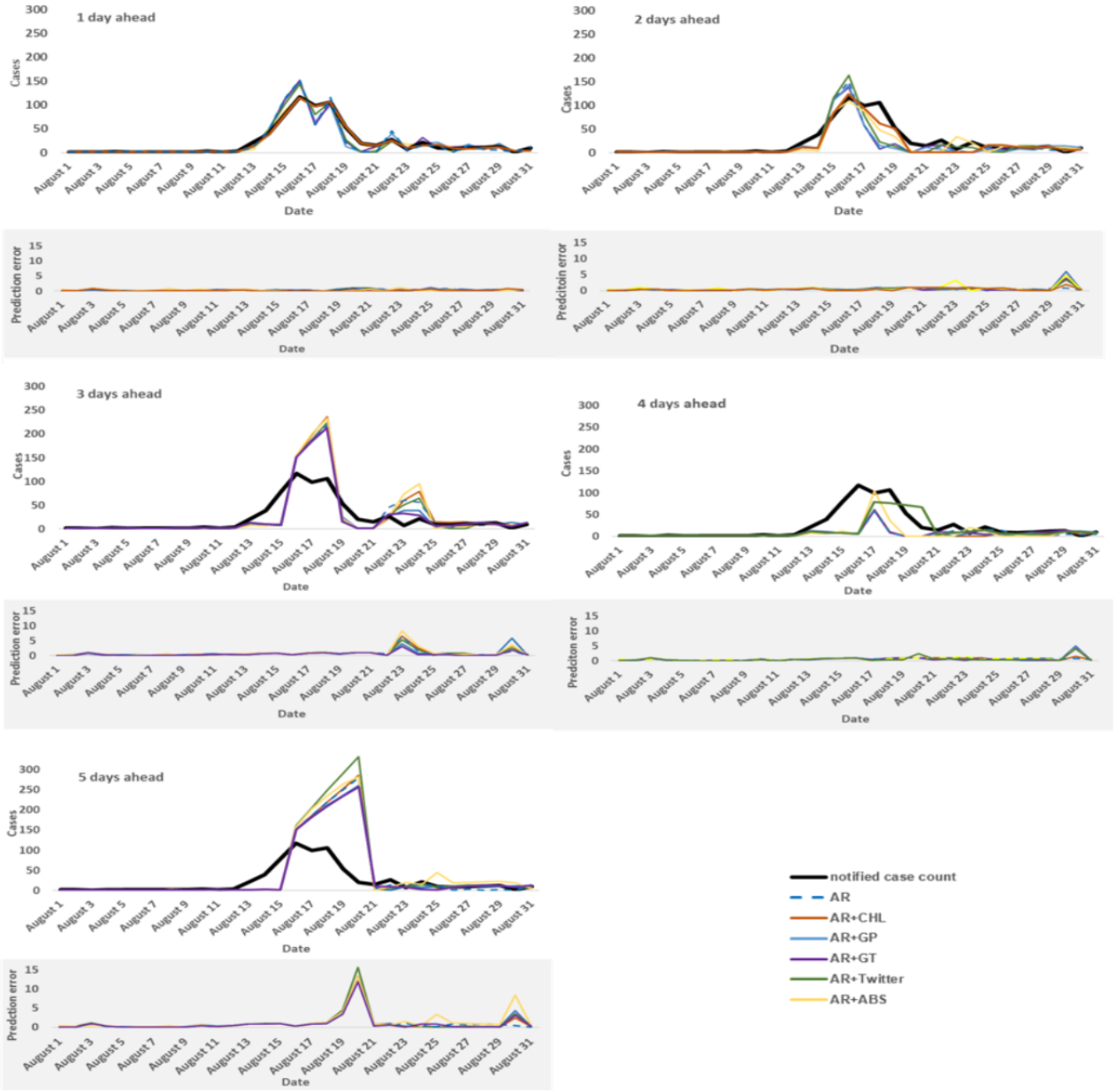


Table 4 summarizes the predictive performance of the models during the test period for each of the 1-, 2-, 3-, 4-, and 5-day ahead predictions, as captured by the 3 evaluation metrics RMSE, rRMSE, and ρ. Although some model's predictions showed good correlation with the notified case counts, their predictions showed large discrepancies from the true number of cases reported, as shown by the rRMSE. The rRMSE provides an estimate of the prediction error relative to the number of actual cases reported in each day over the evaluation period, and from our perspective, it provides a better measure of the quality of model prediction given the short time span of the outbreak.

Table 4. Root mean square error, relative root mean square error, and Pearson correlation for 1-, 2-, 3-, 4-, and 5-day ahead predictions during the test period (August 2016).

Model	1 Day			2 Days			3 Days			4 Days			5 Days		
	RMSE[a]	rRMSE[b]	ρ[c]	RMSE	rRMSE	ρ	RMSE	rRMSE	ρ	RMSE	rRMSE	ρ	RMSE	rRMSE	ρ
AR[d]	15.28	46.9	0.917	23.73	72.8	0.76	33.9	105.3	0.82	38.85	119.2	0.20	67.57	202	0.65
AR+CHL[e]	*2.74* [f]	*8.4* [f]	*0.996* [f]	*15.1* [f]	*46.3* [f]	*0.91* [f]	39.74	123.5	0.79	38.14	117	0.28	68.51	204.8	0.64
AR+GP[g]	15.71	48.2	0.901	23.77	72.9	0.75	31.55	98	0.84	39.59	121.4	0.21	63.21	189	0.66
AR+GT[h]	12.9	39.6	0.933	22.5	69	0.76	*29.86* [f]	*92.8* [f]	*0.85* [f]	37.84	116.1	0.21	*62.41* [f]	*186.6* [f]	*0.66* [f]
AR+Twitter	11.61	35.6	0.951	22.67	69.5	0.80	35.63	110.7	0.81	*26.76* [f]	*82.1* [f]	*0.61* [f]	80.83	241.7	0.62
AR+ABS[i]	4.74	14.5	0.989	15.97	49	0.89	38.68	120.2	0.81	47.26	145	0.28	71.5	213.8	0.65

[a]RMSE: root mean square error.

[b]rRMSE: relative root mean square error.

[c]ρ: Pearson correlation.

[d]AR: autoregressive.

[e]CHL: consumer helpline.

[f]Best performing model for a particular day on basis of the rRMSE.

[g]GP: general practice.

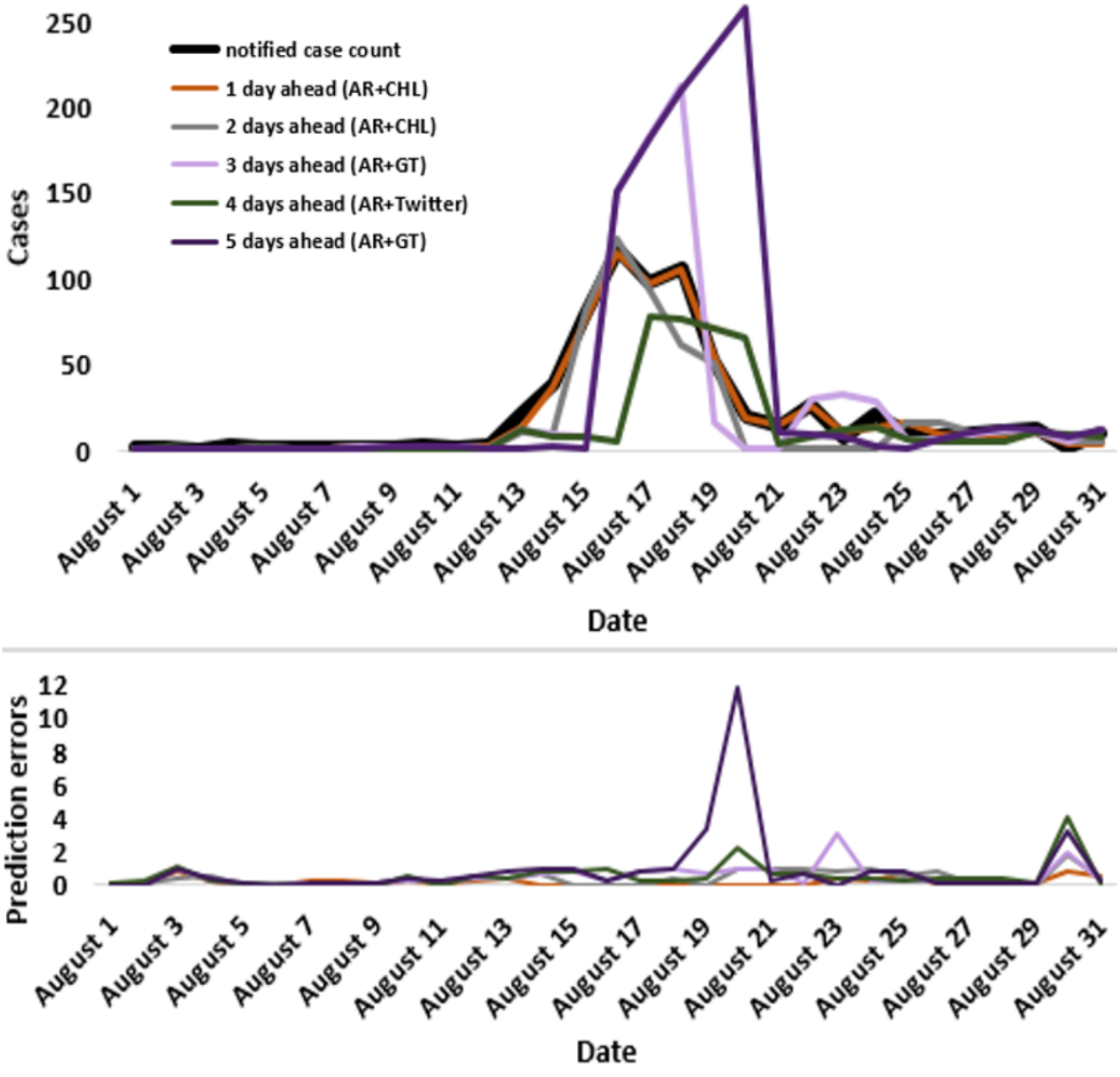
[h]GT: Google Trends.

[i]ABS: school absenteeism.

As seen in the evaluation metric values in Table 4, no model depending on a single data source performed best across all metrics or time periods. On the basis of the rRMSE, models that combined consumer helpline with autoregressive information (AR+CHL) outperformed all other models for 1 day and 2 days ahead predictions (rRMSE=8.4 and 46.3, respectively). Meanwhile, models that combined Twitter with autoregressive information from notified cases (AR+Twitter) performed best for 4-day ahead prediction (rRMSE=82.1), and models that combined Google Trends with autoregressive information (AR+GT) performed best for 3- and 5-day ahead predictions (rRMSE=92.8 and 186.6, respectively). In all time periods, the model using only the historical case counts underperformed all the other models.

The out-of-sample (ie, using the data for the testing period) prediction with the best performing models for the 1, 2, 3, 4, and 5 days ahead time horizons and their prediction errors are shown in Figure 2. Across models, prediction accuracy decreased as predictions were made further days ahead, resulting in increases in rRMSE (and RMSE) and decrease in model correlations across time horizons. For example, for the best models, based on Google Trends, the prediction error nearly doubled from the 3-day to the 5-day forecast.

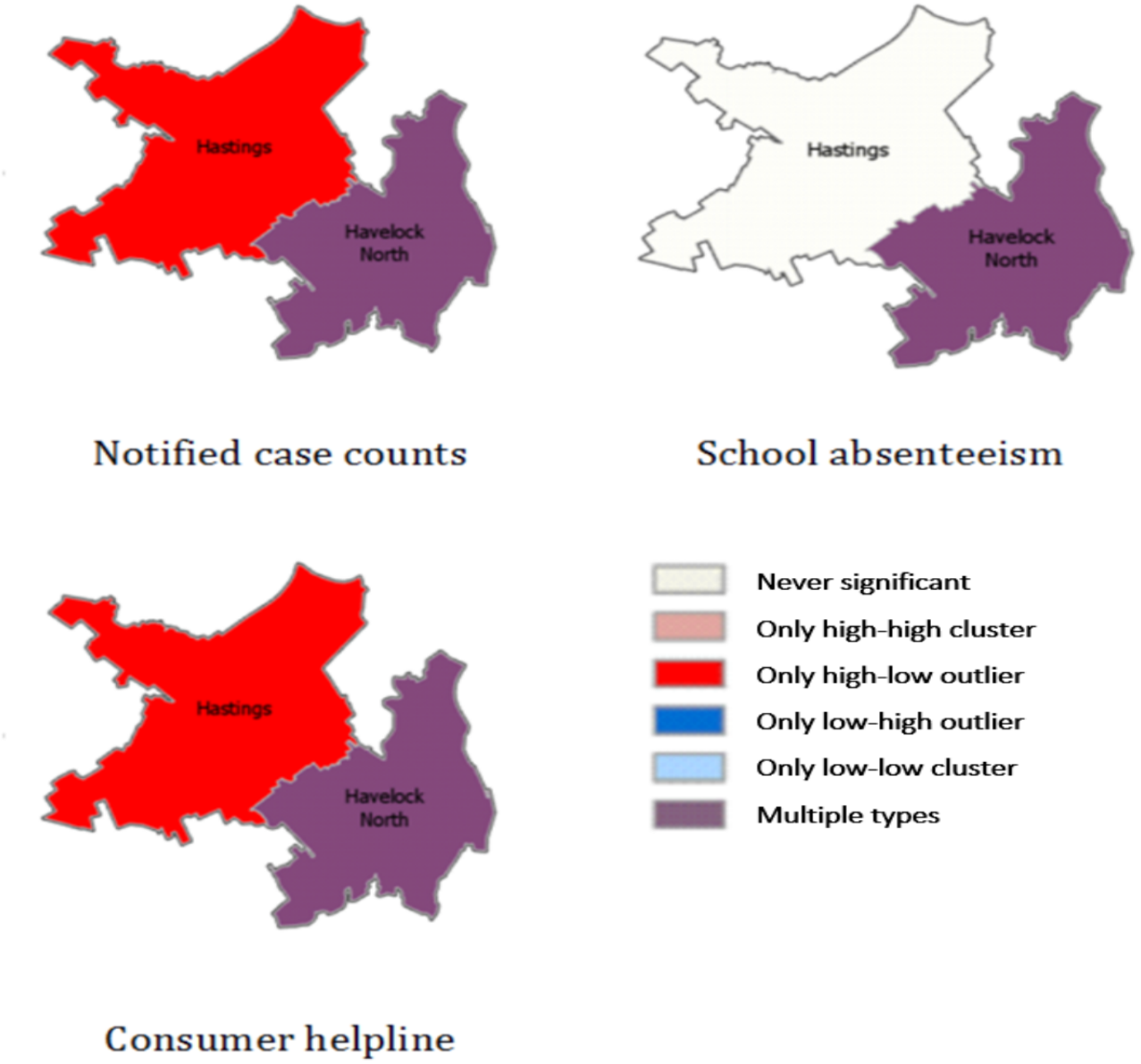
Figure 2. The daily estimations of the best performing models (lowest relative root mean square error) and their prediction errors during the testing period (August 2016). AR: autoregressive; CHL: consumer helpline; GT: Google Trends.



Clustering and Cluster Detection

The summarized cluster types in notified case counts, consumer helpline inquiries, and school absenteeism in Hastings and Havelock North are shown in Figure 3. Both notified case counts and consumer helpline inquiries indicated high-low outliers in Hastings and multiple cluster types (ie, high-high, low-low, high-low, and low-high) in Havelock North throughout the time period. The cluster types could not be identified in the Twitter data because of the limited availability of daily records in all 3 cities in the time period.

Figure 3. Cluster types in notified case counts, consumer helpline inquiries, and school's absenteeism in Hastings and Havelock North. High-high cluster refers to high values surrounded by high values, high-low cluster refers to high values surrounded by low values, low-high cluster refers to low values surrounded by high values, and low-low cluster refers to low values surrounded by low values. Multiple Types refer to multiple cluster-type designations (ie, high high, low low, high low, and low high) through the time period.



The prevalence of the designation Multiple Types did not illuminate trends or clusters in the data set. Therefore, we examined daily Local Moran's I to compare the clustering between 2 cities during the outbreak (Table 5). Comparing the 2 cities, clustering in data sources was very weak in Hastings, compared with Havelock North. On the basis of Local Moran's I, outliers were found in school absenteeism and consumer helpline (Moran's I: −0.40 and −0.77, respectively) in Havelock North on August 11, 2016, which continued to grow in size until August 15, 2016. After 3 days, a stronger outlier appeared in the notified case counts (−2.17) from Havelock North. In Hastings, no significant cluster appeared in school absenteeism, a relatively weak cluster appeared in notified case counts, and a consumer helpline outlier appeared on August 14. These data suggest that the spatiotemporal indicators in consumer helpline and school absenteeism indicated the outbreak in Havelock North 3 days earlier than the notified surveillance data.

Table 5. Daily Local Moran's I in school absenteeism, consumer helpline inquiries, and notified case counts in Havelock North and Hastings cities in August 2016.

Date	Havelock North			Hastings		
	School absenteeism	Consumer helpline	Notified case count	School absenteeism	Consumer helpline	Notified case count
	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score
August 4, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.03 (−0.16)	0.04 (−0.23)	0.08 (−0.29)
August 5, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.04 (−0.23)	0.07 (−0.29)	0.09 (−0.32)
August 6, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 7, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 8, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 9, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 10, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.04 (−0.19)	0.03 (−0.1)	0.09 (−0.29)
August 11, 2016	*−0.40 (1.74)*[a,b]	*−0.77 (2.71)*[a,b]	0 (0.01)	0.03 (−0.15)	0.01 (−0.1)	0.08 (−0.29)
August 12, 2016	−0.40 (−0.23)	-0.77 (−0.29)	0 (−0.32)	0.04 (−0.23)	0.03 (−0.29)	0.09 (−0.32)
August 13, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 14, 2016	−1.62 (7.08)[a]	−1.92 (6.71)[a]	*−2.17 (6.86)*[a,b]	*0.04 (− 0.16)*	*−0.06 (0.22)*[b]	*−0.20 (0.64)*[b]
August 15, 2016	−1.62 (−0.23)	−1.92 (−0.29)	−2.17 (−0.32)	0.03 (−0.17)	-0.01 (−0.04)	0.56 (0.89)
August 16, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.03 (−0.16)	0 (−0.04)	1.20 (1.37)
August 17, 2016	0.05 (0.23)	0.08 (−0.29)	0.10 (−0.32)	0.02 (−0.15)	0 (0.03)	1.20 (0.89)
August 18, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.02 (−0.11)	0 (0.03)	0.31 (0.35)
August 19, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.03 (−0.23)	−0.01 (−0.29)	−0.11 (−0.32)
August 20, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 21, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.03 (−0.13)	0.01 (−0.04)	−0.08 (0.25)
August 22, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.02 (−0.17)	0 (−0.04)	−0.05 (−0.19)
August 23, 2016	−0.10 (0.45)	−0.11 (0.37)	−0.11 (0.34)	0.03 (−0.18)	0 (−0.1)	−0.02(0.13)
August 24, 2016	0.21 (0.46)	0.14 (0.37)	0.12 (0.34)	0.03 (−0.16)	0.02 (−0.16)	−0.03 (−0.23)
August 25, 2016	0.14 (0.3)	0.14 (0.37)	0.23 (0.68)	0.03 (−0.16)	0.04 (−0.23)	0.06 (−0.29)
August 26, 2016	−0.07 (−0.23)	−0.11 (−0.29)	−0.22 (−0.32)	0.04 (−0.23)	0.07 (−0.29)	0.09 (−0.32)

Date	Havelock North			Hastings		
	School absenteeism	Consumer helpline	Notified case count	School absenteeism	Consumer helpline	Notified case count
	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score	Moran's I value, Z score
August 27, 2016	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)
August 28, 2016	−0.05 (0.2)	−0.01 (0.04)	−0.11 (0.34)	0.04 (−0.19)	0.03 (−0.1)	0.03 (−0.1)
August 29, 2016	−0.05 (−0.23)	−0.01 (−0.29)	−0.11 (−0.32)	0.04 (−0.23)	0.03 (−0.29)	0.03 (−0.32)
August 30, 2016	−0.02 (0.11)	−0.11 (0.37)	0.05 (−0.16)	0.05 (−0.23)	0.08 (−0.29)	0.10 (−0.32)

[a]Negative values of the Moran's I value and corresponding Z scores greater than 1.96 indicate that there is a statistically significant spatial outlier.
[b]First day when the data source shows a spatial outlier.

Discussion

Principal Findings

The results show that alternative surveillance data sources can be used to predict an increase in notified Campylobacter cases up to 5 days before the outbreak would be detected via the notifiable disease surveillance system. Importantly, models that relied solely on available time-lagged notified case data were found to be no better than the models based on alternative data sources in predicting near–real-time Campylobacter cases. This finding further underscores the need for alternative real-time data sources such as consumer helpline and Google Trends.

Models that relied on consumer helpline calls provided 1 to 2 days of lead time before an increase in notified cases and consistently performed well, with low error rates. This finding suggests that consumer helpline data have potential utility for earlier detection of outbreaks of acute gastroenteritis. Qualitatively, this result is consistent with our expectations, as the consumer helpline and GP consultations are well-established services for those seeking medical attention in New Zealand [22] and can be expected to provide good predictors of potential cases.

The web data sources (Google Trends and Twitter) were found to be good estimators of Campylobacter cases, even earlier than consumer helpline data. For example, Google Trends reduced the prediction error by less than 6% compared with the next-best model (ie, with GP consultations) for 3-days ahead prediction, as shown in Table 4.

As seen in prediction studies for other diseases [7,31], the quality of predictions decreased as the time horizon of prediction increased. Specifically, for 1-day ahead predictions, we found that the model using consumer helpline combined with autoregressive terms (the AR+CHL model) performed best. The autoregressive terms generally help maintain predictions within a reasonable range, whereas the alternative data sources helped the models to respond more rapidly to sudden changes in the dynamics, a finding that has been documented in previous studies [7,40]. However, for 3- to 5- day ahead predictions, models that used data from Google Trends and Twitter performed best. Google search and Twitter activity appear to respond more rapidly to fluctuations in the dynamics of campylobacteriosis. Evidently, people affected by Campylobacter begin searching for gastrointestinal-related keywords when starting to have symptoms or when they may suspect a risk of exposure. This suggests that monitoring search activity may help track disease incidence.

Spatiotemporal analysis was also retrospectively able to confirm the area impacted by the outbreak. Havelock North and Hastings followed the same clustering in notified case counts and consumer helpline inquiries, whereas Hastings, which was not in the area most affected by the outbreak, had early peaks in consumer helpline inquiries and school absenteeism but fewer overall helpline calls and cases. Aggregating the time series data at the city level may immediately give indications of potential clusters, such as the one identified in Havelock North by Local Moran's I statistics. In particular, primary clusters in school absenteeism and consumer helpline inquiries started on August 11, which was 3 days before the same type of cluster was found in notified case counts and a day earlier than actual public health response actions were initiated. Used prospectively, such spatiotemporal analysis could identify clusters and outbreaks earlier in their course than notification data [41].

Limitations

There are limitations in our approach from inherent biases in the alternative data sources. Users of any of these services are not representative of the general population or those at risk of exposure to pathogens. Google search patterns and care seeking may reflect media coverage and situational awareness rather than the actual impact of the outbreak. Local media in regions with a large outbreak may react differently than the regions where these diseases are fewer in number. Thus, media attention has the potential to dramatically influence our daily predictions [42].

We used the correlation of keywords with notified cases to filter Google Trends data and to classify tweets, which improved the predictive values of these data sources. However, neither of these data sources can distinguish people who search or tweet because of awareness from those with infection. In addition, the static assessment of the predictive power of the included

keywords can impose some limitations. Self-correcting keyword selection by dynamically reassessing the predictive power of each input variable, as discussed by McGough et al [7], could be used in the future to mitigate these limitations. The terms that peak due to high media attention could thus be excluded from the model if their relationship with case count information has weakened.

As mentioned in the Results section, there was insufficient Twitter data to use in the spatiotemporal analysis. However, tweets were only queried in English. With an already low tweet volume, capturing other languages such as Māori might be needed to refine models in the future. Furthermore, we relied on Twitter-generated coordinate information to capture local data. To overcome this limitation, future work could explore ways to geocode the data using location information in the tweet text [43]. For temporal analysis, only limited Twitter and school absenteeism data were available from the entire Hawke's Bay region, presenting a clear limitation to the power of the analysis. It is encouraging that despite the limited school absenteeism data, it was still found to show statistically significant spatiotemporal clusters at the city level.

We are not advocating alternative data sources to replace traditional methods, but rather to complement them. For example, in the Havelock North outbreak, public health officials still required information that suggested an outbreak source (positive bacterial test from local water supply) to start control activities (boil water notice and chlorination of drinking water supply). Early signals from social media and HealthLine calls could have triggered efforts to investigate potential outbreak sources earlier. However, nontraditional surveillance carries with it the workload required to interpret and respond to signals, which can be extensive, as others have noted [44,45].

Comparison With Previous Work

This study shows a number of improvements over previous methodologies using monthly or weekly data from alternative sources to predict disease incidence in the community [4-7,12,14,18], notably by using diverse daily data sources and combining with autoregressive modeling and spatiotemporal clustering to predict the incidence of gastrointestinal illness in a localized outbreak. Many researchers have used internet search queries to build prediction models in recent years. Bahk et al [6] used internet search query data for predicting weekly foodborne illness up to 2 months ahead of increases. Liu et al [4] used internet queries to predict weekly dengue fever outbreaks. Both of these analyses used Spearman r correlation to quantify the strength of associations between disease incidence and internet search queries. Similar to our study, Bahk et al [6] used the seasonal autoregressive integrative moving average (SARIMA) to develop their predictive models. However, Liu et al [4] used regression tree models to assess the threshold effects between the weekly disease incidence and internet search queries. Their results are consistent with those in this study, finding that internet search query data provided a timely data source for predicting the incidence of disease.

In addition to internet search volumes, some studies have used time-lagged data from Twitter to predict the incidence of diseases such as Zika [7] and influenza-like illness [5]. As in our study, McGough et al [7] used ARIMA and rRMSE to select the best model and found that Google typically performed better than Twitter for 2- and 3-week ahead predictions. However, rather than using static keywords, this study used a dynamic keyword selection method. Nagar et al [5] used an Englemen Granger co-integration test to make weekly predictions of influenza-like illness from time-lagged data sets containing Google, Twitter, and notified case counts. However, this study found that Twitter data produced better predictions than Google Trends data. Both of these studies found that time-lagged notified case data were not statistically significant in predicting cases in real time, in line with the results found in our study. In addition to regression models, Nagar et al [5] also used a spatial scan technique to identify areas with relatively higher risk of disease, comparable with the outlier analysis using Local Moran's I, which we used to identify spatial outliers.

Dong et al [14] used diverse data sources including over-the-counter drug sales, search queries, and school absenteeism to estimate the correlation of these data sources with influenza activity. As in our study, they found that 1-week lagged data of internet search queries and school absenteeism showed the strongest correlation with laboratory-confirmed cases. However, they did not attempt to estimate the activity of disease in the community ahead of time. Widerström et al [17] used consumer helpline data and applied SARIMA to develop weekly predictive models for acute gastrointestinal illness and influenza-like illness. As in our study, consumer helpline data proved to be an important source for the early detection of outbreaks of these conditions. Wang et al [18] suggested the possibility of using bank transaction data with a simple moving average to monitor post outbreak disease spread, and they gave the Havelock North outbreak as an example; however, the use of such data for early warning of the outbreak was not very encouraging.

Implications and Further Research

This study has further demonstrated that alternative surveillance data sources can identify large outbreaks of gastrointestinal illness a few days earlier than traditional surveillance methods. The lead time gained depends on the nontraditional surveillance data source used, with onset of symptoms quickly stimulating Google and Twitter activity followed soon after by calls to consumer health helplines, days off from school, and GP consultations.

Such alternative data sources also need to be combined with suitable analytic methods that can be run routinely and easily to identify potential outbreaks, so they can be further investigated and acted on if control measures are needed. This research has identified models with autoregressive information as promising approaches for the analysis of a set of alternative data sources. However, for waterborne outbreaks, as in Havelock North, inclusion of measures from drinking water supply and weather conditions could be included as further data sources for disease surveillance.

This study used the traditional ARIMA models to assess the efficiency of using alternative data sources for the early prediction of a large Campylobacter outbreak. The development of further machine learning models using other techniques to

validate the results of this study will be useful. For example, deep learning–based algorithms have been found to increase the performance of traditional time series forecasting methods [46,47].

The Havelock North outbreak was very large. The signal produced in data sources was therefore easier to detect than would be the case in a smaller outbreak where the signal-to-noise ratio would be lower. It would be useful to repeat the study with outbreaks of smaller magnitude and in different settings to determine whether similar findings apply.

There are multiple operational questions that would need to be resolved before any of the methods identified here could be introduced for routine use by public health agencies in New Zealand or elsewhere. In particular, it is important to identify the range of conditions or syndromes where early detection is important for guiding effective public health action. It is also important to consider the volume of false positives that might be generated and the additional resources required to investigate and rule them out. The range of surveillance modalities also needs to be considered. For example, specific forms of environmental surveillance may be more effective for guiding public health action, for example, improved surveillance of drinking water quality and meteorological data may be more effective in preventing disease rather than focusing on early indicators of illness. Resource issues will also need to be considered, which might favor systems that are already operating on a real-time basis (eg, consumer calls to HealthLine).

Conclusions

This study presents several important conclusions. We tested the use of data from alternative sources in predictive models and showed that they could have provided earlier detection of the Havelock North outbreak. Given the need for early intervention to curb disease transmission, our model predictions could fill a critical time gap in existing surveillance based on notification of cases of disease. These notifications inevitably do not appear until a few days after the occurrence of a communicable disease outbreak. Our results show that models that combine consumer helpline data with autoregressive information of notified case counts performed best for predictions 1 and 2 days ahead, whereas models using Google and Twitter data performed best for predictions 3 and 4 days ahead, although with lower prediction accuracy. Spatiotemporal clusters showed an earlier spike in school absenteeism and consumer helpline inquiries when compared with the notified case counts in the city primarily affected by the outbreak, which suggests that spatiotemporal modeling of alternative data sources could help to identify and locate outbreaks earlier in their development. The methods presented here can potentially be expanded to other regions in the country to signal changes in disease incidence for public health decision makers. However, before doing that, a number of key questions will need to be systematically investigated to establish the practical role of these methods and how they could be most effectively integrated into routine public health practice.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Symptoms classified as gastrointestinal illness in HealthLine calls.
[DOCX File , 12 KB - publichealth_v6i3e18281_app1.docx]

Multimedia Appendix 2
Keywords used to collect Google Trends data.
[DOCX File , 12 KB - publichealth_v6i3e18281_app2.docx]

Multimedia Appendix 3
Correlation and cross correlation of key words in Google Trends with the notified case counts.
[DOCX File , 13 KB - publichealth_v6i3e18281_app3.docx]

Multimedia Appendix 4
Gnip Query to collect Twitter data.
[DOCX File , 12 KB - publichealth_v6i3e18281_app4.docx]

Multimedia Appendix 5
Codes used to collect absenteeism data form primary schools.

[DOCX File , 12 KB - publichealth_v6i3e18281_app5.docx]

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Abbreviations

AR: autoregressive
ARIMA: autoregressive integrated moving average
CHL: consumer helpline
GP: general practice
GT: Google Trends
RMSE: root mean square error
rRMSE: relative root mean square error
SARIMA: seasonal autoregressive integrative moving average

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Original Paper

An Automated Approach for Finding Spatio-Temporal Patterns of Seasonal Influenza in the United States: Algorithm Validation Study

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Abstract

Background: Agencies such as the Centers for Disease Control and Prevention (CDC) currently release influenza-like illness incidence data, along with descriptive summaries of simple spatio-temporal patterns and trends. However, public health researchers, government agencies, as well as the general public, are often interested in deeper patterns and insights into how the disease is spreading, with additional context. Analysis by domain experts is needed for deriving such insights from incidence data.

Objective: Our goal was to develop an automated approach for finding interesting spatio-temporal patterns in the spread of a disease over a large region, such as regions which have specific characteristics (eg, high incidence in a particular week, those which showed a sudden change in incidence) or regions which have significantly different incidence compared to earlier seasons.

Methods: We developed techniques from the area of transactional data mining for characterizing and finding interesting spatio-temporal patterns in disease spread in an automated manner. A key part of our approach involved using the principle of minimum description length for representing a given target set in terms of combinations of attributes (referred to as clauses); we considered both positive and negative clauses, relaxed descriptions which approximately represent the set, and used integer programming to find such descriptions. Finally, we designed an automated approach, which examines a large space of sets corresponding to different spatio-temporal patterns, and ranks them based on the ratio of their size to their description length (referred to as the compression ratio).

Results: We applied our methods using minimum description length to find spatio-temporal patterns in the spread of seasonal influenza in the United States using state level influenza-like illness activity indicator data from the CDC. We observed that the compression ratios were over 2.5 for 50% of the chosen sets, when approximate descriptions and negative clauses were allowed. Sets with high compression ratios (eg, over 2.5) corresponded to interesting patterns in the spatio-temporal dynamics of influenza-like illness. Our approach also outperformed description by solution in terms of the compression ratio.

Conclusions: Our approach, which is an unsupervised machine learning method, can provide new insights into patterns and trends in the disease spread in an automated manner. Our results show that the description complexity is an effective approach for characterizing sets of interest, which can be easily extended to other diseases and regions beyond influenza in the US. Our approach can also be easily adapted for automated generation of narratives.

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KEYWORDS

epidemic data analysis; summarization; spatio-temporal patterns; transactional data mining

Introduction

Large-scale spatio-temporal analyses and forecasts are becoming increasingly common for several diseases, such as influenza [1-4]. There is a lot of public interest in analysis of spatio-temporal trends relating to how these diseases are spreading across the United States—this includes statements about whether the season has officially started, a listing of regions which have differing levels of activity, and the contrast between the current season and earlier seasons. Such analyses have a broad readership and are popular among news media, the general public, and government agencies, as well as public health organizations; this is evidenced by spatio-temporal pattern reports [5,6] about the spread of influenza from news agencies and blogs.

Such patterns are typically identified manually by domain experts who have significant expertise on specific diseases. Data for such analyses often comes from public health agencies, such as the Centers for Disease Control and Prevention (CDC) [7] and World Health Organization. Reports generated by the CDC contain raw surveillance data on metrics (eg, activity level from outpatient visits and rates of hospitalization) across states in the US. In addition, summaries of regions with specific characteristics (eg, those which have high activity levels) are also included in the reports [7,8]. For instance, one CDC report [8] summarizes the states with high influenza-like illness activity for the week ending on March 4, 2017 with the number of states followed by a list of the state names.

Such descriptive listings are easy to construct from raw data but are tedious to read and do not provide deeper insight into the disease spread. In contrast, the analysis by Mashable [6] is a succinct description of the set of states which have widespread activity, namely, all states in the contiguous US, except Oregon. An analysis by the New York Times [5] was also a good and succinct description of the set of states which have reported widespread activity for 3 consecutive weeks. In addition to descriptions of the set of states with a particular activity level, sets exhibiting specific temporal patterns might also be of interest. An example is the set of states which maintained stable high activity for 3 consecutive weeks, ending in the week of January 27, 2018; most states had high influenza-like illness activity level 4 weeks prior, plus the states of New Jersey, New Mexico, Virginia, Washington, and Wyoming. Such descriptions involve identification of features common to these states, which provide additional insights on the outbreak.

The overall objective of our work was to automate the process of identifying interesting spatio-temporal patterns from disease surveillance data and generating succinct descriptions for them. In order to do this, we encoded the incidence data as binary matrices (presence or absence of a feature) and used techniques from pattern mining [9,10] in transactional data to find insights into epidemic spread; we demonstrated its utility using seasonal influenza in the US as a case study.

Methods

Data

We used the state level influenza-like illness activity indicator data available from the CDC [11]. In the data set, each state for each week during a given influenza season is assigned an activity level from 1 to 10 based on the severity of influenza prevalence in that week (measured using the percentage of outpatient visits that show influenza-like symptoms) [12]. These activity levels are also grouped by coarser labels such as minimal (1-3), low (4-5), moderate (6-7), or high (8-10) [13]. We also incorporated the geographic spread index as published by CDC in [14], which categorizes the states based on the internal spatial spread of influenza. We used a number of features associated with each state which are defined by the CDC and can be categorized as follows:

1. Geographical or spatial which included features such as Great Lakes, southeast, mid-Atlantic;

2. Temporal which included features such as activity level (eg, high, moderate, and low) in the *t*th week before the current (at that time) week, geographical spread (eg, widespread or local) in the *t*th week prior, whether the number of infections has crossed a threshold, whether the peak has been reached, and similarity with past season. In the description below, these features are denoted by *was1_high* (states with high influenza-like illness activity 1 week prior), *was2_moderate* (states with moderate influenza-like illness activity 2 weeks prior), *was52_high* (states with high activity 52 weeks prior), and so on. These features capture the spatial, temporal, and severity aspects of the reported cases. A full list of attributes and their description is presented in Multimedia Appendix 1.

We used data corresponding to weeks from 2014 to 2017. To generate narratives for a particular week, we use data from these reports for that week, the previous 3 weeks, and the data from 52 weeks prior to generate the temporal data for each state. This was expressed as a data matrix D containing the characteristics number of regions as rows (n=51 representing 50 states and the District of Columbia) and number of features as columns (m=42 spatial, temporal, or severity features). Therefore, the data matrix for a given week had $m \times n$=2142 entries.

Problem Formulation

Let $D_{n \times m}$ be the data matrix, where each row corresponds to a state and each column to a feature, and D_{ij}=1 if state i has feature j. Let $U=\{e_1,..., e_n\}$ be the universe of elements, in our case, the set of all states. Let $D_j=\{i: D_{ij}=1\}$ denote the set of elements having feature j. Let $S(j_1,..., j_k)=$ $\cap ... \cap$ denote the set of elements that have features $(j_1,..., j_k)$ (denoted by $\boldsymbol{j}$), referred to as a conjunctive clause. The clause S($\boldsymbol{j}$) has length k, meaning that it is formed by the intersection of k features.

Given a target set $T \subseteq U$, we consider expressions of T in terms of unions and differences, ie,

, **(1)**

with an associated cost

 , **(2)**

where and α and β are the constant parameters associated with positive,

 , **(3)**

and negative clauses,

 , **(4)**

respectively, and

 , **(5)**

denotes the number of features involved in a clause

 . **(6)**

The negative clauses describe the elements which need to be removed from the set of positive clauses, in order to exactly cover the elements of *T*.

Given a subset $T \subseteq U$ (referred to as a target set), and a data set *D*, the minimum description length problem involves finding a set of tuples $\boldsymbol{j}^1,...,\boldsymbol{j}^s$, such that *T* is represented in terms of unions and differences and the associated cost (represented by equation 2) is minimized.

In order to make the descriptions interpretable, we will restrict the sizes of these clauses (ie, the number  of columns whose intersection is allowed); herein, we will focus on  ≤2, though our approach extends to any *k*.

Our main idea for finding patterns of interest was to explore the space of all target sets and identify those which have low cost descriptions. This was motivated by the minimum description length principle, that forms the basis of many machine learning methods to find such descriptions; we refer to [15,16] for details on this topic.

In some cases, the target set *T* does not have a small description, but we can find a set *T'* which is close to *T* and has a smaller description than *T*. We model this as finding a representation for a subset *T'* such that *T'*≈*T*, which is formalized as the minimum approximate description length problem. Given a target set $T \subseteq U$, a data set *D*, and constant parameters α, β, γ, the minimum approximate description length problem involves finding a set of tuples $\boldsymbol{j}^1,...,\boldsymbol{j}^s$, for representation of *T'* as unions and differences, such that the symmetric difference of *T* and *T'* is of size at most γ|*T*|, and the associated cost is minimized. Since minimum approximate description length is a generalization of minimum description length, we only consider the minimum approximate description length problem in the rest of the paper. The minimum description length and minimum approximate description length problems are both NP-complete, even when  =1, which corresponds to the set cover problem (refer to [17] for discussion on this topic).

Approach and Implementation

We used an integer programming approach described in Multimedia Appendix 1, which is able to scale well for the problems of interest in epidemic analysis. We used Gurobi optimization software [18] to solve the resulting integer program. The size of the instances encountered results in programs that can be solved very efficiently.

Generate Set Descriptions.

We considered the set of states with a high activity level in a given week, as a target set *T* and prepared the data matrix *D*. These states had value 1 in the column named high in the matrix. Then, we used our method to compute the succinct descriptions for the target set *T* for the parameters (α, β, γ)=(2, 2, 0). From the minimum description length principle, a set *T* was likely to be an interesting pattern if it had a high compression ratio.

We also studied the impact of the parameter γ on the description length. Recall that the parameter controls how accurately we attempt to describe the target set. A larger γ would mean greater error but should lead to a more succinct description. The target set *T* was the set of states with high activity in a given week. We ran our method for the given week with target set *T* and, for each value of γ ∈ (0.1, 0.2, 0.3).

Ranking Set Descriptions

It was not known a priori which target sets would give interesting patterns. We searched from a large space of possible target sets corresponding to all clauses with up to *k* terms (ie, sets formed by intersections of up to *k* columns), computed their minimum description length scores, and ranked them based on their compression ratio, and other characteristics.

Baselines and Evaluation Measures

The work of Xiang et al [19] is directly related to our approach and can be considered as a special case of minimum description length, where only positive clauses are allowed. We referred to this as description by solution. We used the number of clauses used by description by solution and minimum approximate description length for comparison.

We used the compression ratio as a metric for evaluating the performance of our method. The number of clauses used for minimum approximate description length for a target set *T* was *s*. The compression ratio provided by minimum approximate description length was defined as the ratio of the target set size |*T*| to the number of clauses used in the solution to minimum approximate description length, compression ratio=|*T*|/*s*.

We also provided a scoring system to determine the interestingness of a target set. Sets consisting of states with high activity level were likely to be more interesting than those with moderate, low or minimal activity levels; therefore, these were assigned scores of 4, 3, 2, and 1 for high, moderate, low, and minimal activity level, respectively. Next, states exhibiting a sudden change in activity level (eg, from low to high, or vice versa) were considered more interesting than those having no change in activity levels; therefore, we assigned a score of 5 for the former type and 2 for the latter. Then, a set of states with high activity that week and minimal activity 1 week prior had a score of 9, while a set of states with minimal activity that week and minimal activity 1 week prior had a score of 3. This process is described in detail in Multimedia Appendix 1. The score

assigned to each target set or description measured its interestingness.

Results

Generate Set Descriptions

The text descriptions (manually generated), in Table 1 correspond to solutions computed using our method. The mean compression ratio was 2.63. This showed that our method could easily find succinct descriptions for different kinds of target sets.

Qualitatively, some descriptions (Table 1) involved large target sets (eg, February 18, 2017 and January 3, 2015 which correspond to 27 and 29 states, respectively). The CDC descriptions for these weeks were long lists, which were unlikely to give useful insights or identify any patterns. The description for the week of January 3, 2015 was succinct. Almost all the states with high or moderate activity level in the previous week had high activity in that week, 3 new states that were not experiencing high or moderate activity in the previous week had high activity, and Florida and Georgia experienced a sharp decline in activity levels within the week.

We also noted that some of the descriptions may not be insightful. For instance, the description for the week of April 8, 2017 was simply a list of 2 states; it is possible that there were no common characteristics between the 2 states, so this was the most succinct. The description for the week of February 18, 2017 was quite complicated. It combined 3 sets of states with different activity levels in different times in the past. Figure 1 shows that a set of 10 states with high influenza-like illness for the week of January 21, 2017 was represented using 6 clauses. The compression ratio achieved was 1.67 as we only use 6 clauses instead of listing 10 state names. However, automated generation of such descriptions will allow a human expert to filter and select appropriate descriptions, instead of creating them from scratch.

The compression ratio increased as we increased the relaxation factor (Table 2) γ. Figure 2 shows that a set of 29 states with high influenza-like illness for week January 3, 2015 can be represented using only 3 sets per clauses; although 8 out of the 29 states are omitted from the description (shown in the light blue region), as the relaxation parameter is set to 0.3.

Table 1. Description for the set of states with high activity levels.

Week	Descriptions of states with high influenza-like illness activity in the week	Number of clauses	Target set	$\|T\|$	Compression ratio
January 21, 2017	Kansas, New York, Washington, and states with high activity 2 weeks back excluding Oregon and Utah	6	Alabama, Georgia, Kansas, Kentucky, Missouri, New Jersey, New York, Oklahoma, South Carolina, Washington	10	1.67
February 18, 2017	Alaska, Illinois, Maryland, Minnesota, states with high activity a week prior, states with low activity 2 weeks prior, and states with minimal activity 3 weeks prior excluding Wyoming	7	Alabama, Alaska, Arkansas, Connecticut, Georgia, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maryland, Michigan, Minnesota, Mississippi, Missouri, New Jersey, New Mexico, New York, North Carolina, Oklahoma, Pennsylvania, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Virginia	27	3.86
March 25, 2017	States with high activity for last 2 weeks, excluding Louisiana, Mississippi and Texas	4	Alabama, Arkansas, Georgia, Kansas, Kentucky, North Carolina, Oklahoma, South Carolina, Tennessee, Virginia	10	2.50
April 8, 2017	Kentucky, South Carolina	2	Kentucky, South Carolina	2	1.00
January 3, 2015	California, Nevada, New York, and states with high or moderate activity levels a week prior excluding Florida and Georgia	7	Alabama, Arkansas, California, Colorado, Hawaii, Idaho, Illinois, Indiana, Kansas, Kentucky, Louisiana, Maryland, Minnesota, Mississippi, Missouri, Nevada, New Mexico, New York, North Carolina, Ohio, Oklahoma, Pennsylvania, South Carolina, Tennessee, Texas, Utah, Virginia, West Virginia, Wisconsin	29	4.14

Figure 1. The set representation of the description for week of January 21, 2017. Each circle is a set and the states in the set are listed with their respective abbreviations. The states in the blue region correspond to the target set T. Oregon and Utah are the singleton subsets (in dark blue) with high influenza-like illness activity two weeks prior but not in that week. AL: Alabama; GA: Georgia; ILI: influenza-like illness; KY: Kentucky; KS; Kansas; MO: Missouri; NJ: New Jersey; NY: New York; OK: Oklahoma; OR: Oregon; SC: South Carolina; UT: Utah; WA: Washington.

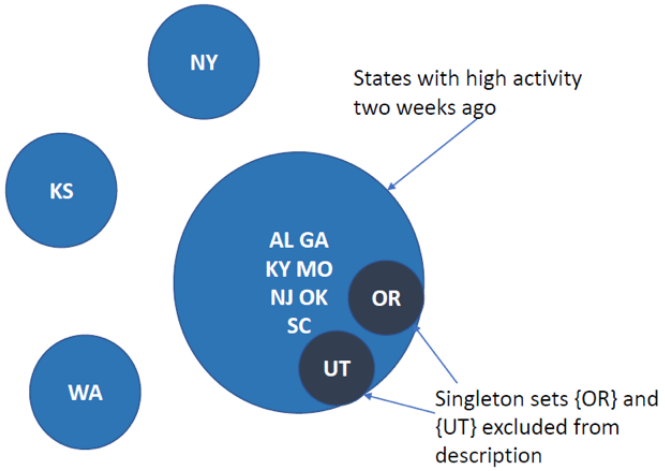
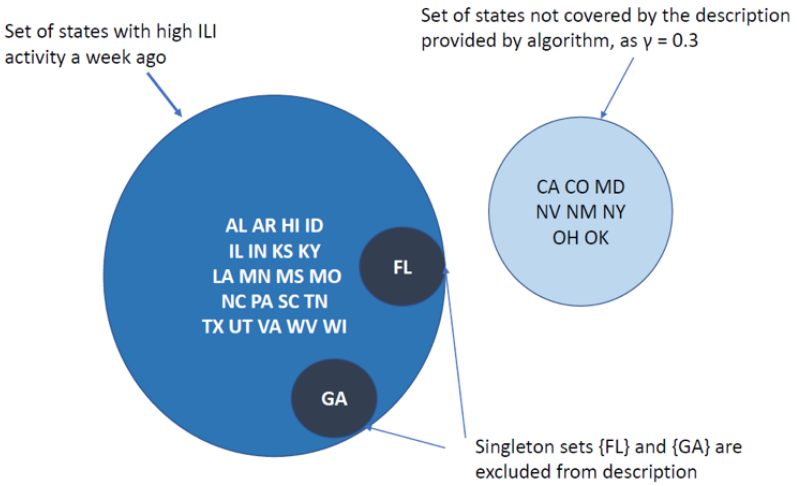


Table 2. Impact of varying relaxation factor γ on the description and compression ratio using 2 examples.

Week, γ	Description	Clauses, number	Compression ratio
January 21, 2017			
0	Kansas, New York, Washington, and states with high activity 2 weeks prior, excluding Oregon and Utah	6	1.67
0.1	Kansas, Washington, and states with high activity 2 weeks prior, excluding Oregon and Utah	5	2
0.2	New York and states with high activity 2 weeks back, excluding Oregon and Utah	4	2.5
0.3	States with high activity 2 weeks back, excluding Oregon and Utah	3	3.33
January 3, 2015			
0	California, Nevada, New York, and states with high or moderate activity levels a week prior, excluding Florida and Georgia	7	4.14
0.1	New York, and states with high or moderate activity levels a week prior, excluding Florida and Georgia	5	5.8
0.2	States with high or moderate activity levels a week prior, excluding Florida and Georgia	4	7.25
0.3	States with high activity level a week prior, excluding Florida and Georgia	3	9.67

Figure 2. The set representation of description of set of states with high influenza-like illness activity on January 3, 2015. The blue set corresponds to the states with high activity 1 week prior. The dark blue colored singletons Florida and Georgia are subsets of the blue set but do not have high activity in the current week. The light blue colored set consists of the states omitted from the description due to relaxation. AL: Alabama; AR: Arkansas; CA: California; CO: Colorado; HI: Hawaii; ID: Idaho; IL: Illinois; IN: Indiana; KS: Kansas; KY: Kentucky; LA: Louisiana; MD: Maryland; MN: Minnesota; MS: Mississippi; MO: Missouri; NV: Nevada; NM: New Mexico; NY: New York; NC: North Carolina; OH: Ohio; OK: Oklahoma; PA: Pennsylvania; SC: South Carolina; TN: Tennessee; TX: Texas; UT: Utah; VA: Virginia; WV: West Virginia; WI: Wisconsin.



Ranking Set Descriptions

We found that the top scoring narratives were generally trends. An example of trend found by our method was a gradual increase in activity levels over consecutive weeks; the states Alabama, Georgia, Mississippi, and Tennessee had high activity in the week of March 12, 2016, had moderate activity the previous week, and had minimal activity 2 weeks prior. Another trend was stable high activity for consecutive weeks; in the week ending January 27, 2018, New Jersey, New Mexico, Virginia, Washington, and Wyoming, and states with high activity 4 weeks earlier, excluding Nebraska and Tennessee, had high activity levels for 3 consecutive weeks. Another trend was a gradual decrease in influenza-like illness activity over consecutive weeks; for the week of February 1, 2014, the activity levels in North Carolina decreased from high to moderate to low in 3 consecutive weeks.

Examples of surprise events identified by our methods were (1) the activity level in North Carolina, New Mexico, South Dakota, and Wyoming jumped from low to high within 1 week, for the week ending February 4, 2017 and (2) the activity level in New Hampshire and Tennessee changed from high to low within 1 week, for the week ending February 2, 2013.

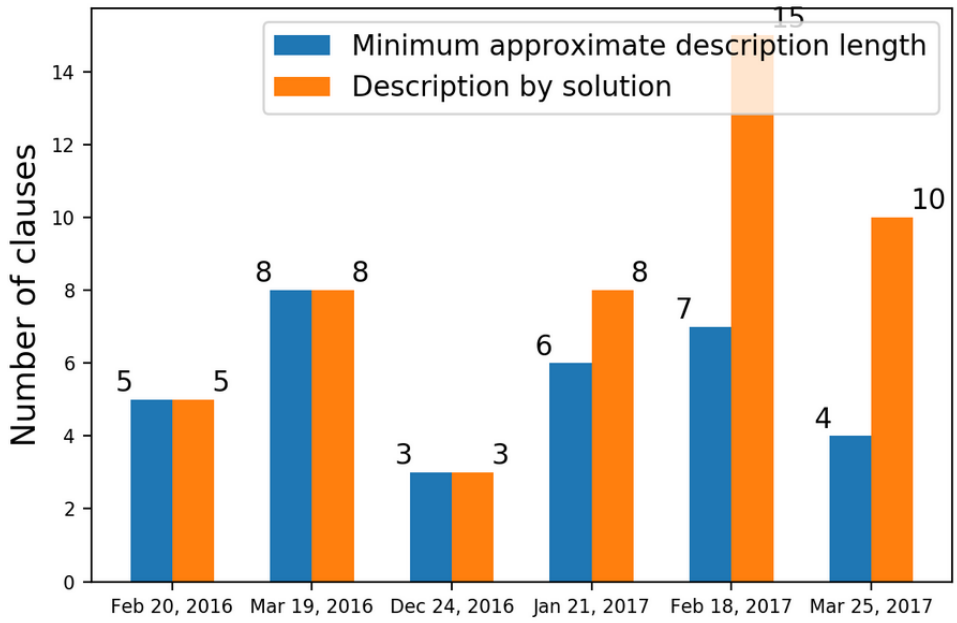
Table 3. Interestingness scores.

Week	α, β, γ	Target set or pattern	Description	Score
January 27, 2018	(0, 2, 2)	States with high activity the specified week, low activity 2 weeks prior, and moderate activity 3 weeks prior	Hawaii, Maryland, North Carolina, Ohio	14
		States with moderate activity 1 week prior, minimal activity 2 weeks prior, and low activity 3 weeks prior	North Dakota	13
		States with low activity 2 weeks prior, moderate activity 3 weeks prior, and minimal activity 4 weeks prior	Maryland, North Carolina, Ohio	7
February 25, 2017	(0.3, 2, 4)	States with high activity 1 week prior, low activity 2 weeks prior, and moderate activity 3 weeks prior	Iowa	14
		States that had moderate activity levels 1 week prior, minimal activity levels 3 weeks prior, and minimal activity levels 4 weeks prior	Massachusetts, Ohio, Wisconsin	8

Comparison With Baselines

Minimum approximate description length provided summaries at less cost than those provided by description by solution for the weeks of January 21, 2017; February 18, 2017; and March 3, 2017 (Figure 3). For the remaining weeks, minimum approximate description length provided summaries at a cost equivalent to those provided by description by solution.

Figure 3. Solution comparison: minimum approximate description length versus description by solution.



Discussion

Principal Findings and Previous Work

There has been a lot of previous work [19-22] on finding spatio-temporal patterns in different data sets. These have typically used unsupervised machine learning methods, and we refer the readers to [20,21] for surveys on different algorithms and their applications to various data sets. As is the case with other unsupervised methods, the specific technique depends on the application. We note that mining patterns from transactional data has been successfully used in many areas, such as analysis of retail transaction data [23], biomedical data analysis [19,24] and information retrieval [25]. The approach of finding patterns based on compression and small description have been found to be useful in many settings [22,26-28]. We found that our description length-based approach gives useful insights into spatio-temporal patterns in incidence of influenza-like illness, especially when negative clauses are allowed. However, no prior methods handle negative clauses, to the best of our knowledge. In addition to negative clauses, we also found that the relaxed versions can also significantly reduce the complexity of descriptions in many cases.

Our ranking method also provides a systematic approach to identify trends and surprises in the spread of influenza-like illness. However, the descriptions of high score are not always intuitive or interesting, which is often the case with unsupervised machine learning methods. Instead, our ranking-based approach (or other variations of it) could help provide new insights to a domain expert, who might be able to find interesting spatio-temporal patterns more easily. Thus, such an approach could be a first step in processing epidemic incidence data. We believe that including more characteristics for the data (ie, more columns in the data matrix D) can help find more succinct descriptions. Furthermore, the integer programming–based approach is quite powerful, and more constraints can be easily added to generate descriptions with specific kinds of properties. Though the descriptions reported here were generated manually based on the outputs, the outputs are well structured and could conceivably be generated using natural language processing techniques easily.

Comparing the performance of our method with 2 other pattern detection methods in the literature, though, as mentioned earlier, which do not consider negative clauses, the first method, called Apriori [23] is a very popular approach for association rule mining and pattern detection in a database containing transactions. Each transaction is seen as a set of items called itemset. The Apriori algorithm finds the frequent item sets in the database, the item sets that appear frequently among the transactions of the database. We observed that the rules generated by Apriori using Weka [29] are trivial in nature and are not highly informative.

The work of Xiang et al [19] (description by solution) can be considered as a special case of minimum description length, where only positive clauses are allowed. Xiang et al [19] give a logarithmic approximation for the description by solution problem for such instances. We implement an integer linear program to solve this problem exactly. By comparing the solutions provided by minimum approximate description length with that of description by solution, we demonstrated the benefit of allowing differences in generating compact descriptions. We note that using additional attributes for the regions might allow for more succinct descriptions.

Our methodology could be easily extended to other diseases and applications involving spatio-temporal data, since the method can handle very general kinds of features and clauses formed by them. The ranking method would have to be designed based on the specific domain. Also, we expect our method could scale to much larger data sets easily.

Limitations

The feature values are real numbers (eg, the similarity with a past season can be a correlation metric) not binary. One way to handle this issue would be to map the nonbinary values to binary using discretization of the weights. Since we limited our focus to only meaningful features, our current approach explores target sets with temporal properties over small time intervals. In the case of an increase in number of features by a few orders of magnitude than we considered, the integer linear program may not be able to scale well. One way to address this problem would be to design scalable heuristics that give some theoretical or experimental guarantees.

Conclusion

Automated generation of interesting spatio-temporal patterns and trends is an important problem, and can be especially useful to public health experts, as well as the general public. Our approach, based on techniques from pattern mining, provide a short-list of patterns in influenza-like illness data from the CDC. We found that sets with high compression ratio tend have common characteristics, which are often interesting. This is, however, an unsupervised machine learning method, and needs to be verified manually. Our ranking method is one way to select interesting patterns in an automated manner. The techniques developed in this paper could potentially be applied for other diseases, and other public health domains.

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Authors' Contributions

PS, PB, BL, and AV designed the study. PS, PB, and AV developed the methods. All authors helped in the evaluation and writing.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Additional material.
[DOCX File , 142 KB - publichealth_v6i3e12842_app1.docx]

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Abbreviations

CDC: Centers for Disease Control and Prevention

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Original Paper

Changes in Health-Risk Behavior, Body Mass Index, Mental Well-Being, and Risk Status Following Participation in a Stepwise Web-Based and Face-to-Face Intervention for Prevention of Lifestyle-Related Diseases: Nonrandomized Follow-Up Cohort Study

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Abstract

Background: Recent evidence suggests the effectiveness of stepwise, targeted approaches for the prevention of lifestyle-related diseases with combinations of web-based and face-to-face interventions showing promising results.

Objective: This paper reports on 1-year changes in health-risk behaviors, BMI, self-rated health, mental well-being, and risk of disease at 1-year follow-up after participation in a stepwise intervention that targeted persons at high risk of disease and persons with health-risk behavior. To this end, we distinguish between participants who took up the full intervention (web-based plus face-to-face) and those who received only the web-based intervention.

Methods: The Early Detection and Prevention (Danish acronym: TOF) pilot study was conducted as a nonrandomized, 1-year follow-up intervention study in two municipalities in the Region of Southern Denmark. A total of 9400 citizens born between 1957 and 1986 (aged 29 to 60 years) were randomly sampled from participating general practitioner (GP) patient-list systems and were invited to take part in the study. Participants were subsequently stratified into risk groups based on their responses to a questionnaire on health-risk behavior and data from their GP's electronic patient record (EPR) system. All participants received a digital personal health profile with individualized information on current health-risk behavior and targeted advice on relevant health-risk behavior changes. In addition, patients at high risk of disease, as indicated by their digital health profile, were offered a targeted intervention at their GP. Patients who were not deemed at high risk of disease but who exhibited health-risk behaviors were offered a targeted intervention at their municipal health center (MHC). At 1-year follow-up, health-risk behaviors, self-rated health, BMI, and mental well-being were reassessed by questionnaire, and current information on diagnoses and medical treatment was retrieved from the EPRs.

Results: Of 598 patients at high risk of disease or with health-risk behavior, 135 took up the targeted intervention at their GP or MHC and 463 received the personal health profile only. From baseline to 1-year follow-up, the number of patients with unhealthy eating habits decreased, mean mental well-being increased, and smoking prevalence decreased in patients who had received the digital personal health profile alone. Among patients who took up the targeted intervention, unhealthy eating habits and sedentary lifestyles decreased and significant reductions in mean BMI were observed. At 1-year follow up, no health-risk behaviors were detected among 17.4% of patients who at baseline had exhibited health-risk behaviors or high risk of disease.

Conclusions: A stepwise targeted preventive approach using web-based and face-to-face elements may lead to favorable lifestyle changes. Specifically, a web-based approach may improve smoking and eating habits and mental well-being, whereas supplementary face-to-face interventions may be necessary to improve exercise habits and BMI.

Trial Registration: ClinicalTrials.gov NCT02797392; https://clinicaltrials.gov/ct2/show/NCT02797392

International Registered Report Identifier (IRRID): RR2-10.1186/s12875-018-0820-8

(JMIR Public Health Surveill 2020;6(3):e16083) doi:10.2196/16083

KEYWORDS

health behavior; noncommunicable diseases; lifestyle-related disease; prevention; patient web portal; primary health care; risk reduction behavior

Introduction

Lifestyle-related diseases such as cardiovascular disease (CVD), type 2 diabetes mellitus, and chronic obstructive pulmonary disease (COPD) constitute a major health problem in most developed countries. A high overall prevalence of lifestyle-related diseases, combined with increases in the number of years lived with the resulting disease-related disabilities [1], represents a significant burden on any given health care system. As such, there is an urgent need to design and implement interventions that facilitate early identification and management of persons at risk of lifestyle-related diseases.

A systematic review from 2012 indicates that preventive health checks offered to the general population have no long-term effects on total mortality above and beyond those associated with standard care [2]. More recent systematic reviews of general practice–based health checks, however, suggest that people at high risk of chronic disease may benefit from targeted health checks [3,4]. In addition, a Cochrane review from 2011 showed that counseling- and education-based interventions targeting health risk behaviors can reduce mortality in the high-risk population [5]. Counseling and education may be delivered face to face, remotely (eg, by phone), or through web-based interventions [6-8], and evidence suggests that supplementing web-based interventions with face-to-face or remote counseling may increase the total effect of prevention programs [8].

In Denmark, the primary care sector is publicly funded and extensive, comprising municipal health centers (MHC) and general practitioner (GP) clinics. Almost all Danish citizens (98% of the population) are registered with a GP clinic [9]. The MHCs provide primary prevention (eg, smoking cessation and alcohol-reduction courses), while GPs are tasked with both primary and secondary prevention (eg, treatment for hypertension and hyperlipidemia) [9]. Targeted preventive actions are therefore an accepted and a well-integrated part of the Danish health care system. Nonetheless, these initiatives are often limited in terms of identifying the at-risk population.

In the Early Detection and Prevention project (TOF is the Danish acronym), we use a stepwise screening procedure to identify the at-risk population (ie, individuals at high risk of type 2 diabetes mellitus, COPD, or CVD and individuals who engage in health-risk behaviors). All screened individuals receive a digital personal health profile containing individualized information on current health-risk behaviors, risk of disease, and relevant preventive health services. In addition, individuals at high risk of the aforementioned diseases and those with health-risk behaviors are offered a targeted intervention at their GP or MHC. The GP intervention comprises a focused clinical examination and health dialog. At the MHC, participants are invited to one or two health dialogs. The overall purpose of the TOF intervention is to encourage and support participants to change their health-risk behavior, initiate preventive treatment if needed, and promote health and longevity. The TOF intervention is described in detail in a study protocol article [10].

In line with the Medical Research Council guidelines on complex interventions, the interventions were pilot-tested for acceptability, feasibility, and short-term effects in two municipalities in 2016 [10,11].

This paper reports on changes in health-risk behaviors, BMI, self-rated health, mental well-being, and risk of disease from baseline to 1-year follow-up among persons at high risk of disease and persons with health-risk behaviors. To this end, we distinguish between persons who take up the targeted interventions at their GP or MHC and those who receive the digital personal health profile but forego the targeted interventions.

Methods

Setting and Design

The TOF pilot study was carried out as a nonrandomized, 1-year follow-up cohort study in two Danish municipalities (Varde and Haderslev; total population, January 2016: 106,318).

Population

The study population comprised patients randomly sampled from participating GPs' patient list system. Almost all Danish citizens are registered with a GP [9,12,13], and each GP has an average of approximately 1600 registered patients. This study included patients born between 1957 and 1986 (age 29 to 60 years). A total of 200 eligible patients were randomly selected per GP. Patients who resided outside of the participating municipalities and patients who did not have a digital mailbox were excluded from the study. A digital mailbox is provided by the Danish government for secure and direct communication between citizens and public authorities. In general, all permanent citizens are obliged to have a digital mailbox, but citizens with low information technology literacy (usually elderly persons),

cognitive impairment, or other complicating factors may opt out of the digital mail system.

Recruitment and Baseline Questionnaire

In January 2016, GPs residing in the two municipalities were invited to take part in the study. In April 2016, the study population was sampled and an invitation and informed consent form were sent to prospective participants by digital mail. The consent form covered participation and the retrieval of relevant diagnoses and medical scripts from the GPs' electronic patient record (EPR) systems. This information was used to identify patients who were registered with International Classification of Primary Care–2 codes or medical scripts related to CVD, type 2 diabetes mellitus, COPD, hypertension, or hyperlipidemia. In September 2016, all participants received a digital questionnaire with items on height, weight, self-rated health, family history of diabetes, known hypertension, COPD-related symptoms, smoking habits, leisure activity level, alcohol intake, and eating habits. The questionnaire items were from the Danish Diabetes Risk model [14], the COPD population screener [15], the HeartScore BMI score for CVD [16], the Swedish National Guidelines on Disease Prevention [17], and the Danish National Health Profile [18]. In addition, mental well-being was assessed using the Short Warwick-Edinburgh Mental Well-Being Scale (SWEMWBS) [19]. Both the initial invitation and questionnaire were sent on behalf of the patients' GP and the MHC.

Stratification of Patients

Based on information from the GPs' EPR systems and the questionnaire results, patients were stratified to one of four groups (see Table 1). Group 1 included patients with preexisting diagnoses and/or treatment for type 2 diabetes mellitus, CVD, hypertension, hyperlipidemia, and/or COPD. These patients were identified solely from the EPR information. Group 2 comprised patients who were deemed at high risk for type 2 diabetes mellitus, CVD, or COPD based on three validated risk scores [14-16]. Next, patients who were not at high risk of disease but who engaged in health-risk behaviors were placed in group 3. Health-risk behaviors included current smoking, consuming more than 14/21 (female/male) standard units of alcohol per week, having an unhealthy diet (diet score ≤4 on a 12-point scale drawn from the Swedish National Guidelines on Disease Prevention) [17], maintaining a BMI ≥35 kg/m^2, and/or engaging in a generally sedentary lifestyle as defined by the Saltin-Grimby Physical Activity Level Scale (primary leisure time activity level during the past year: reading, watching television, or other sedentary activities) [20]. Finally, group 4 comprised patients with no health-risk behaviors and no need for further intervention.

Patients at high risk of disease (group 2) and patients with health-risk behaviors (group 3) were eligible to receive the full TOF intervention. These two groups are therefore the focus of this paper.

TOF Intervention

The TOF intervention included a digital personal health profile and targeted preventive activities at patients' GP or MHC. The digital personal health profile was designed to encourage patients to change their health-risk behavior and follow the tailored advice provided by the system. The health profile included individualized information on current health-risk behaviors and risk of disease, personalized advice on relevant health-risk behavior changes, and information about relevant preventive health services. Participants could access their personal health profile on a password-protected website [10].

The preventive activities at the GPs or MHCs targeted patients with different risk profiles. Patients at high risk of disease (group 2) were offered a clinical examination at their GP, including measurements of glycated hemoglobin, cholesterol, height, weight, and blood pressure, plus lung functions and electrocardiogram, if indicated, and a subsequent health dialog, scheduled in 30-minute time slots. Patients with health-risk behaviors (group 3) were advised to consult their MHC for a 15-minute telephone-based health dialog. The health dialog could be requested by patients on their personal health profile. If necessary, the telephone-based health dialog was followed up with a 1-hour face-to-face consultation at the MHC.

All patients offered a health dialog, either at their GP or at their MHC, were encouraged to prepare by answering questions about known determinants of behavior change (eg, motivation, resources, social network, mental health, former experience with behavior change) [21,22]. This information, along with information about health-risk behavior, was shared with health professionals on separate user interfaces of the digital support system. During the health dialog, the patient and health professional would work together to develop a prevention plan that set a goal for health-risk behavior change and determined the necessary means for achieving that goal. The prevention plan was subsequently registered on the digital support system by the health professional and was thus accessible to both health professional and patient. If relevant and feasible, the patient would be referred to municipal behavior change interventions (such as smoking cessation courses, exercise classes, etc), prescribed medical treatment by their GP, or both.

The design of the digital support system was inspired by the work of Krist and colleagues' research on preventive EPRs and by the results of a Delphi process completed to identify factors for optimal development of health-related websites [23-25]. Details about the digital personal health profile and the digital support system are published elsewhere [10].

The TOF intervention was available from September through December 2016. However, intervention-initiated referrals to municipal health-risk behavior change interventions and prescription of medical treatment continued beyond this time frame.

Table 1. Group characteristics and preventive activities offered to participants in the high-risk of disease group and the health-risk behavior group (groups 2 and 3).

Variables	High risk of disease group	Health-risk behavior group
Group characteristics	Patients at high risk of type 2 diabetes mellitus, CVD[a], or COPD[b]	Patients with health-risk behaviors such as current smoking, high-risk alcohol intake, sedentary lifestyle, unhealthy diet and/or maintaining a BMI ≥35 kg/m^2
Intervention offered	Digital personal health profile, focused clinical examination, and subsequent 30-minute health dialog at the GP[c]	Digital personal health profile, 15-minute telephone-based health dialog, and optional 1-hour face-to-face consultation at the MHC[d]

[a]CVD: cardiovascular disease.

[b]COPD: chronic obstructive pulmonary disease.

[c]GP: general practitioner.

[d]MHC: municipal health center.

Follow-Up Questionnaire and Electronic Patient Record Information

In September 2017, 1 year after baseline assessments, all consenting patients received a follow-up electronic questionnaire that included the same items on weight, health-risk behaviors, self-rated health, COPD-related symptoms, and mental well-being as the baseline questionnaire. In addition, up-to-date EPR information was collected to identify any patients who had been diagnosed with or commenced medical treatment for type 2 diabetes mellitus, CVD, hypertension, hyperlipidemia, or COPD during the 1-year follow-up period.

Outcomes and Statistical Analysis

We report on specific health-risk behavior changes observed between baseline and 1-year follow-up in patients at high risk of disease and patients with health-risk behaviors.

Health-risk behaviors were treated as dichotomous variables (yes/no): current smoking (including daily and occasional smoking), high-risk alcohol intake (ie, above 14/21 [female/male] standard units of alcohol per week), unhealthy diet (ie, diet score ≤4 on a 12-point scale drawn from the Swedish National Guidelines on Disease Prevention) [17], and sedentary lifestyle (according to the Saltin-Grimby Physical Activity Level Scale [20]). We also looked at changes in self-rated health ("In general, how would you rate your health at present?" with response categories excellent, very good, good, fair, and poor, dichotomized into two categories: fair or poor and good, very good, or excellent), BMI, and mental well-being (from SWEMWBS) from baseline to 1-year follow-up [26]. The raw SWEMWBS score was converted to a metric score using a conversion table.

We report on these changes among participants who took up the targeted interventions at their GP or MHC and participants who received only the digital personal health profile. Attending the targeted intervention at the GP was defined as having received the focused clinical examination, whereas attendance at the MHC was defined as having participated at minimum in the telephone-based health dialog.

Changes in health-risk behaviors and self-rated health from baseline to 1-year follow-up were analyzed using a McNemar test. Changes in BMI and SWEMWBS scores were analyzed using paired *t* tests. Analyses were repeated after stratifying by gender.

Finally, we analyzed any changes in individual risk stratification from baseline to 1-year follow-up. Stratification groups at 1-year follow-up were determined from up-to-date data on health-risk behaviors, BMI, diagnoses, and medical scripts from the EPR system. The follow-up calculations were performed as described in the stratification of patients section except we applied baseline age to the three validated risk scores in order to preclude age-related changes in risk groups. That is, we investigated whether patients were reallocated during the study to another risk group than the one at baseline by virtue of changes in diagnoses, health-risk behaviors, or BMI rather than age.

Nonresponse bias was assessed by comparing baseline characteristics of participants answering the 1-year follow-up questionnaire with those who did not. Unadjusted estimates were generated from Fisher exact tests for dichotomous variables and *t* tests for continuous variables. These estimates were adjusted for age and gender differences using logistic and linear regression, respectively. The distribution of SWEMWBS scores and BMI were assessed for normality by visual inspection of histograms. There were no missing values for health-risk behaviors, BMI, or self-rated health as participants responses to these questions were compulsory. Statistical significance was set at $P<.05$. Statistical analyses were performed using Stata 15.1 (StataCorp LLC) statistical software for Windows.

Ethics Approval and Consent to Participate

The study was approved by the Danish Data Protection Agency (J.nr. 2015-57-00089) and registered with the University of Southern Denmark's list of approved studies (J.nr. 10.361) and on ClinicalTrials.gov [NCT02797392]. According to Danish regulations, the study did not need approval from a health research ethics committee. The study complies with the World Medical Association Declaration of Helsinki, including providing informed consent to study participation and disclosure of data from the GP EPRs.

Results

A total of 69% (47/68) of invited GPs agreed to participate in the study, resulting in a source population of 9400 patients. Among these, 586 were excluded because they resided outside

the participating municipalities or did not have a digital mailbox. Of the 8814 patients who received the initial invitation, 3587 patients consented to participate, and 2661 subsequently completed the baseline questionnaire and received a digital personal health profile [27]. Of these, 582 were deemed to be at high risk (group 2) and were offered the targeted intervention at their GP. Another 618 patients engaged in health-risk behaviors (group 3) and were offered the targeted intervention at the MHC [28]. At 1-year follow-up, 56.2% (327/582) of patients from the high-risk group and 43.9% (271/618) from the health-risk behavior group responded to the questionnaire (Figure 1). Of these, 135 (77 women, 58 men) had attended the targeted interventions at their GP or MHC.

Table 2 shows the baseline characteristics of the participants who responded to the follow-up questionnaire and those who did not. The follow-up group was older than the group that did not answer the follow-up questionnaire (48.8 vs 46.5 years, $P<.001$), included more men (52.5% vs 45.7%, $P=.02$), and had fewer current smokers (21.6% vs 31.7%, $P<.001$). The two groups did not differ on any of the other items.

For participants who received the digital personal health profile only, a significant reduction in the number of current smokers and participants with unhealthy eating habits was seen from baseline to 1-year follow-up (Table 3). In addition, the mental well-being score was significantly higher at 1-year follow-up compared with baseline levels. Specifically, 40.0% (183/457) of participants experienced an increase of one or more in their mental well-being score. In subgroup analyses, changes in mental well-being reached statistical significance in women, whereas decreases in current smoking prevalence was statistically significant for men only.

No significant changes in the prevalence of sedentary behavior, high-risk alcohol intake, or fair/poor self-rated health were observed among participants who received only the digital personal health profile. The number of participants with a BMI >30 kg/m^2 decreased from 25.5% (118/463) at baseline to 24.0% (111/463) at 1-year follow-up, but no significant changes in mean BMI were detected.

Among participants who attended the targeted intervention at their GP or MHC, a similar drop in the number of participants with unhealthy eating habits was observed (Table 4). In addition, mean BMI and the number of participants with a sedentary lifestyle had declined at 1-year follow-up, although subgroup analyses were statistically nonsignificant. The number of participants with a BMI >30 kg/m^2 decreased from 34.1% (46/135) at baseline to 27.4% (37/135) at 1-year follow-up. No significant changes were observed in mental well-being, current smoking status, high-risk alcohol intake, or self-rated health.

Figure 2 shows the changes in risk status from baseline to 1-year follow-up. Among 327 participants at high risk of disease and 271 participants with health-risk behaviors, 39 (11.9%) and 65 (24.0%), respectively, had no health-risk behaviors at 1-year follow-up. A total 4.0% (13/327) of participants at high risk of disease and 3.3% (9/271) with health-risk behaviors were diagnosed with or commenced preventive medical treatment for hypertension, hyperlipidemia, CVD, type 2 diabetes mellitus, or COPD between baseline and 1-year follow-up. In addition, 4.1% (11/271) of participants with health-risk behaviors were at high risk of disease at 1-year follow-up, whereas 4.0% (13/327) had reduced their risk status from high risk of disease to health-risk behaviors.

Figure 1. Flowchart of the TOF pilot study.

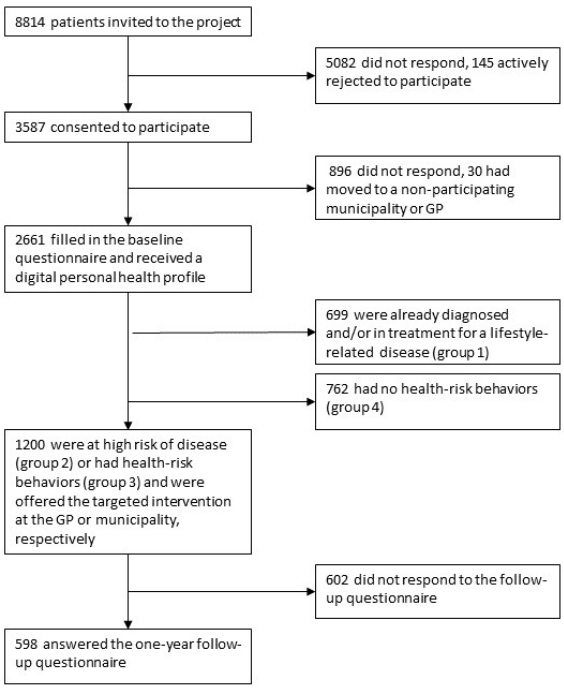


Table 2. Baseline characteristics among high-risk and health-risk behavior participants with and without 1-year follow-up (n=1200).

Variable	High-risk and health-risk behavior participants (groups 2 and 3)				
	With follow-up (n=598)	Without follow-up (n=602)	*P* unadjusted	*P* adjusted[a]	All (n=1200)
Age in years, mean (SD)	48.8 (8.2)	46.5 (8.4)	<.001	N/A[b]	47.7 (8.4)
Gender, male, n (%)	314 (52.5)	275 (45.7)	.02	N/A	589 (49.1)
Current smoker, n (%)	129 (21.6)	191 (31.7)	<.001	.001	320 (26.7)
Unhealthy diet, n (%)	217 (36.3)	252 (41.9)	.05	.41	469 (39.1)
Sedentary lifestyle, n (%)	125 (20.9)	134 (22.3)	.58	.69	259 (21.6)
High-risk alcohol intake, n (%)	19 (3.2)	28 (4.7)	.23	.09	47 (3.9)
BMI (kg/m^2), mean (SD)	27.7 (5.5)	27.6 (5.5)	.63	.50	27.6 (5.5)
Fair or poor self-rated health, n (%)	80 (13.4)	78 (13.0)	.87	.53	158 (13.2)
Mental well-being score[c], mean (SD)	24.2 (3.6)	24.0 (3.7)	.43	.96	24.1 (3.6)

[a]Adjusted for age and gender differences.

[b]Not applicable.

[c]A total of 1176 (591 with follow-up and 585 without) answered the questions on mental well-being.

Table 3. Health-risk behaviors, BMI, self-rated health, and mental well-being at baseline and 1-year follow-up among high-risk and health-risk behavior participants receiving the digital personal health profile only.

Variable	All (n=463)			Women (n=207)			Men (n=256)		
	Baseline	1-year follow-up	*P* value	Baseline	1-year follow-up	*P* value	Baseline	1-year follow-up	*P* value
Current smoker, n (%)	106 (22.9)	93 (20.1)	.003	54 (26.1)	49 (23.7)	.10	52 (20.3)	44 (17.2)	.01
Unhealthy diet, n (%)	161 (34.8)	128 (27.7)	<.001	58 (28.0)	44 (21.3)	.01	103 (40.2)	84 (32.8)	.03
Sedentary lifestyle, n (%)	92 (19.9)	77 (16.6)	.07	51 (24.6)	40 (19.3)	.06	41 (16.0)	37 (14.5)	.48
High-risk alcohol intake, n (%)	15 (3.2)	13 (2.8)	.56	<5	<5	.99	11 (4.3)	9 (3.5)	.48
BMI (kg/m^2), mean (SD)	27.4 (5.5)	27.3 (4.8)	.36	27.6 (6.1)	27.7 (5.8)	.88	27.3 (5.0)	27.0 (3.8)	.19
Fair or poor self-rated health, n (%)	57 (12.3)	62 (13.4)	.51	31 (15.0)	34 (16.4)	.58	26 (10.2)	28 (10.9)	.71
Mental well-being score[a], mean (SD)	24.3 (3.6)	24.7 (4.2)	.01	24.3 (3.9)	24.9 (4.4)	.04	24.3 (3.3)	24.6 (4.0)	.11

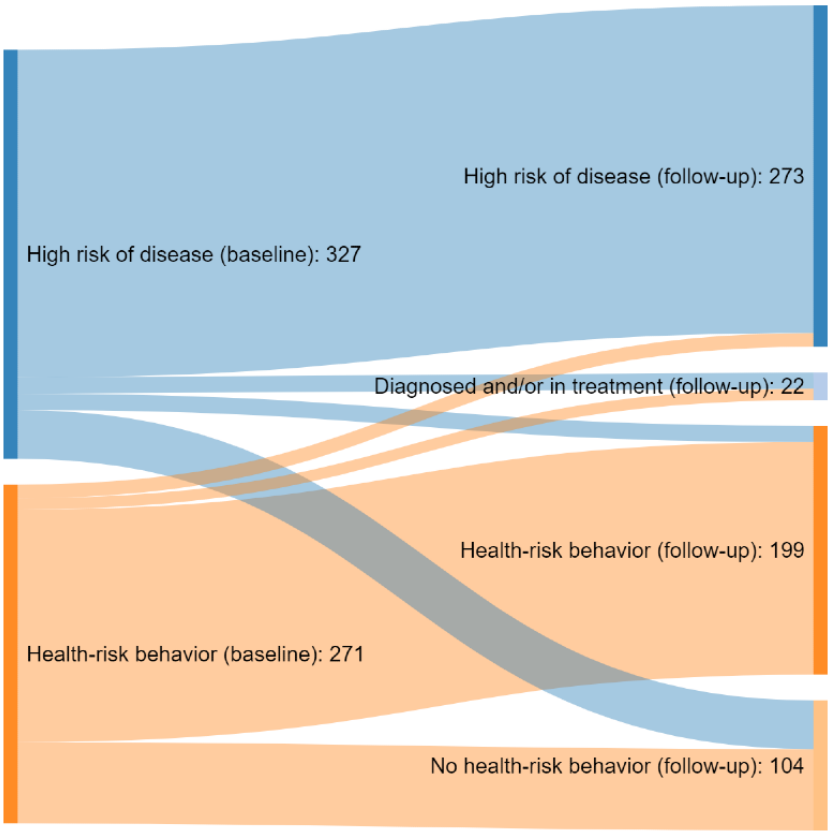
[a]SWEMWBS score: a total of 457 (203 women and 254 men) answered the questions on mental well-being.

Table 4. Health-risk behaviors, BMI, self-rated health, and mental well-being at baseline and 1-year follow-up among high-risk and health-risk behavior participants who received the digital personal health profile and targeted intervention at their general practitioner or municipal health center.

Variable	All (n=135)			Women (n=77)			Men (n=58)		
	Baseline	1-year follow-up	*P* value	Baseline	1-year follow-up	*P* value	Baseline	1-year follow-up	*P* value
Current smoker, n (%)	23 (17.0)	21 (15.6)	.48	12 (15.6)	13 (16.9)	.56	11 (19.0)	8 (13.8)	.18
Unhealthy diet, n (%)	56 (41.5)	39 (29.9)	.001	28 (36.4)	19 (24.7)	.007	28 (48.3)	20 (34.5)	.046
Sedentary lifestyle, n (%)	33 (24.4)	17 (12.6)	.001	21 (27.3)	13 (16.9)	.03	12 (20.7)	n<5	.01
High-risk alcohol intake, n (%)	<5	<5	.65	<5	<5	.32	<5	<5	.32
BMI (kg/m^2), mean (SD)	28.7 (5.5)	28.3 (5.7)	.02	29.6 (5.8)	29.1 (6.1)	.11	27.6 (4.9)	27.2 (4.9)	.05
Fair or poor self-rated health, n (%)	23 (17.0)	21 (15.6)	.64	18 (23.4)	14 (18.2)	.25	5 (8.6)	7 (12.1)	.41
Mental well-being[a], mean (SD)	24.0 (3.6)	24.4 (4.2)	.17	24.0 (3.6)	24.2 (4.4)	.50	24.0 (3.8)	24.7 (3.9)	.20

[a]SWEMWBS score: a total of 134 (77 women and 57 men) answered the questions on mental well-being.

Figure 2. Participant change in risk status from baseline to 1-year follow-up.



Discussion

Principal Findings

Our results suggest that a stepwise and targeted prevention approach focusing on patients at high risk of lifestyle-related diseases and patients with health-risk behaviors may be effective in promoting certain healthy lifestyle changes.

Significant improvements in smoking and eating habits and mental well-being were seen among patients who received the web-based intervention. Supplementary face-to-face intervention, however, appeared to be necessary to significantly improve exercise habits and BMI.

Improvements in dietary habits were observed among participants who attended the targeted interventions at their GPs and MHCs and among participants who got a digital personal health profile only. These findings are in line with previous evidence on the effectiveness of primary-care-based lifestyle interventions [29-32] and exclusively web-based interventions [6].

Similarly, the observed reduction in current smoking status among participants who got a digital personal health profile is consistent with previous evidence from web-based smoking cessation interventions [7]. Although brief smoking interventions delivered in general practice and in the primary care sector have previously been shown to be successful [33,34], smoking prevalence was unchanged at 1-year follow-up in patients who participated in the targeted intervention. This result may in part be attributed to the limited sample size and the low follow-up response rate among baseline current smokers. In addition, more nonsmokers than current smokers took up the targeted intervention at their MHC [28].

The observed improvements in mental well-being and concomitant healthy lifestyle changes are consistent with findings from other lifestyle intervention studies [35,36]. Specifically, a systematic review concluded that smoking cessation was associated with reduced depression, anxiety, and stress as well as improved mood and quality of life [37]. Such results may in part be explained by biological mechanisms, as smoking causes alterations in the nicotine pathways in the brain, which has been associated with depressed mood and anxiety [38]. In addition, epidemiological studies have revealed close associations between fruit and vegetable consumption and mental health [39], with some studies even suggesting a causal relationship [40,41]. Although the changes in mean SWEMWBS score were relatively small in this study, 40.0% of the participants experienced improvements exceeding the suggested threshold for statistically meaningful change at the individual level [42]. Despite improvements in mean SWEMWBS score among participants attending the targeted interventions, the changes did not reach statistical significance. Although possibly attributable to the small sample size, these findings are somewhat surprising as additional human support during targeted interventions should intuitively facilitate mental health. However, participants attending the targeted intervention at their GP had lower baseline self-efficacy than those who received the digital personal health profile alone [28]. This may have influenced the results as self-efficacy is known to be associated with well-being [43].

Significant reductions in BMI were seen among participants attending the targeted intervention but not among those who received only the digital personal health profile. This may be due to higher motivation among those participants who chose to take up the targeted interventions at their GP or MHC. In comparison, a recent systematic review indicated that significant weight reductions could be achieved through web-based interventions alone. However, the review also showed that blended interventions (ie, combination of an internet application and human support) like the one tested in this study were more effective in reducing weight than purely web-based ones [6]. The reduction in BMI fits well with the concurrent improvements in physical activity and dietary habits. Although improved, BMI changes did not reach statistical significance in subgroup analyses. This may be attributable to the small sample size.

The behavior change techniques (BCTs) applied in the TOF study are partially inspired by tried and tested methods from dietary interventions. These include goal setting (outcome), plan social support/social change, social comparison, and barrier identification/problem solving [30,44]. These BCTs might have contributed to the positive effect on dietary habits. In addition, information on the consequences of behavior in general, which has been associated with a positive change in physical activity level, was incorporated into the digital personal health profile [45]. A recent review identified interventions encouraging self-monitoring of behavioral outcomes or using follow-up prompts to be the most effective in maintaining physical activity improvements [46]. Such BCTs were not used in the TOF pilot study but may well be relevant in future effectiveness studies.

Results from a recent systematic review on medium-intensity (31 to 360 minutes) to high-intensity (>360 minutes) behavioral counseling in high-risk populations showed improvements in dietary intake and physical activity as well as concordant reductions in intermediate CVD outcomes such as total cholesterol, low-density lipoprotein cholesterol, blood pressure, fasting glucose, diabetes incidence, and weight outcomes [47]. In our study, 17.4% (104/598) improved their lifestyle to the extent that no health-risk behaviors were present 1 year after entering the study, and 19.6% (117/598) had changed to a lower risk group at 1-year follow-up. We believe such changes are likely to improve intermediate CVD outcomes like the ones described above (not included in this study). Effects in terms of intermediate outcomes such as changes in the level of biomarkers and incidence of disease should be examined further.

Strengths and Limitations

This study used validated questions and risk scores to assess health-risk behaviors and risk of disease and used a longer follow-up period than most lifestyle intervention studies. Health-risk behavior changes were assessed by self-reported outcomes, which may be subject to reporting bias. However, participants were not asked if they had improved their lifestyle but merely responded to the same questions on health-risk behaviors at baseline and at 1-year follow-up. We therefore believe the risk of social desirability bias to be minimal. In this study, the follow-up response rate was 50%, which may affect the generalizability of the results. In addition, responders differed from nonresponders by being older and more often male. Such differences may point to more unfavorable health-risk profiles among responders [48], but the two groups only differed in current smoking status. Finally, the study did not include an untreated control group. Therefore, the observed changes in health-risk behaviors could be partly attributable to factors other than the intervention tested.

Conclusion

Results from this pilot study indicate that persons at high risk of disease and persons with health-risk behaviors may benefit from a stepwise, targeted intervention in terms of favorable lifestyle changes. Specifically, a web-based approach may improve smoking and eating habits and mental well-being, whereas supplementary face-to-face interventions may be necessary to improve physical exercise habits and BMI. While the extent of effects reported here seem to depend on the breadth of intervention received, it is important to note that even a low-cost, web-based intervention alone may be effective in facilitating meaningful health behavior change. Long-term

effects need to be assessed in a large-scale, controlled study design.

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Conflicts of Interest

None declared.

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Abbreviations

BCT: behavior change technique
COPD: chronic obstructive pulmonary disease
CVD: cardiovascular disease
EPR: electronic patient record
GP: general practitioner
MHC: municipal health center
SWEMWBS: Short Warwick-Edinburgh Mental Well-Being Scale
TOF: Early Detection and Protection Project (Danish)

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Original Paper

Evaluation of the Sexual Health Behaviors of Black Male Adolescents and Young Adults Through Social Media Platforms: Web-Based Survey Study

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Abstract

Background: Social media platforms such as Facebook, Instagram, and Twitter, which have millions of users who interact and communicate every day, have been effective in promoting sexual health interventions and in disseminating reproductive health education. They have also been shown to be useful in health promotion and have been used to track several key metrics (eg, comments, posts) among users of all demographics. However, there is a lack of research on the impact and reach of these social media platforms as a community-based tool for disseminating sexual health information and for increasing engagement among Black adolescents and young adults, which is a targeted high-risk population.

Objective: The purpose of this study was to determine the social media platforms and banner advertisements that affected engagement among Black male adolescents and young adults in participating in web-based health surveys.

Methods: A web-based survey was conducted from March 2019 to July 2019 to assess sexual health and health behaviors in a convenience sample of Black male adolescents and young adults in the age range of 18-24 years (N=170). Social media metrics from Facebook, Instagram, and Twitter were monitored. This cross-sectional survey comprised several categories, including basic personal information, drug-related risk behaviors, health care, sexual reproductive health questions, attitudes, norms, and perceived control, mental health, violence-related risk behaviors, and social media preferences.

Results: Social media advertisements on the Black Male Opinion survey reached approximately 146,412 individuals. Our primary finding of the web-based survey engagement was that referral (eg, group chat, indirect social media sharing) led to as the greatest proportion of recruitment, with Twitter and YouTube as the preferred sites to receive sexual health information.

Conclusions: Recognizing the variety of technologies being used among Black male young adults and adolescents can help the community, researchers, and health care providers understand the web-based engagement of this high-risk population. This information may also promote culturally sensitive, customized marketing on sexual health information for this population.

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KEYWORDS

social media; survey; adolescent; young adult; Black; males; sexual health; service delivery

Introduction

Internet and social media use are universal among adolescents and young adults in the United States, with 80% having access to either a smartphone or broadband internet [1]. Moreover, about two-thirds of the Americans claim that internet access is essential for accessing personal health information [2,3]. An increasing number of health care systems are adapting to this new "social media age" and integrating these platforms into their services. Various hospitals use social media to increase engagement, marketing, and their impact on local communities [3,4]. In addition, social media platforms have increasingly become a source of data to the general public and a means of spreading health awareness, promoting screenings, and reducing health disparities [5]. Major health care systems such as the Mayo Clinic have begun beta testing the impact of social media by creating Twitter accounts and by using analytics to track engagement and the impact on their marketing [6]. This shift toward a more social media–friendly approach in the health care system in general, particularly in primary care, is a result of the need to adapt to new technologies and to reach those disproportionately affected by health problems due to socioeconomic factors.

Young Black males, specifically the emerging adulthood population, in the age range of 18-24 years, have a substantially greater need for sexual reproductive health services and are at a higher risk of contracting sexually transmitted infections (STIs) than other adolescents and young adult populations [7-13]. Likewise, the sexual reproductive health needs of this population are often underaddressed and insufficiently understood in clinical settings [7]. One possible cause for these disparities is the lack of access to sexual health resources such as education and condoms. To increase access in hard-to-reach populations, social media platforms have been used to promote health resources and have been slowly incorporated into health care. Addressing disparities in sexual health among young Black males could become more feasible with the use of these platforms [14-16].

Social media platforms such as Facebook, Instagram, and Twitter, which have millions of users who interact and communicate every day, have been effective in promoting sexual health interventions and in the spread of reproductive health education [17,18]; some examples of promoting these interventions are by improving STI knowledge, encouraging people to undergo testing or screening for HIV/STIs, and using social media as a resource for STI education [19]. These platforms have also been shown to be useful in health promotion and have been used to track several key social media metrics (eg, comments, posts) among users of all demographics. However, there is a lack of research on the impact and reach of these social media platforms as a community-based tool for sexual health promotion and on the increasing engagement of social media use among Black adolescents and young adults, which is a targeted high-risk population [20,21]. We recently surveyed young heterosexual Black males across the United States. We sought to learn the extent to which young Black males engage in taking web-based surveys via social media. Thus, the purpose of this study was to determine the social media platforms and banner advertisements that affected the engagement of Black male adolescents and young adults in participating in web-based health surveys. Social media metrics such as "likes," "impressions" (number of times an advertisement is shown on a social media page that may not be unique to individuals), and "link clicks" were used to assess the impact of the engagement. Recognizing the variety of technologies being used by this population can help the community, researchers, and health care providers understand how Black young adults and adolescents can be engaged through web-based services. This information can promote culturally sensitive customized marketing on sexual health information for this population.

Methods

Recruitment

Project Black Male Opinion was a web-based survey disseminated via the study staff through mass email listservs, Facebook, Instagram, and Twitter. Dissemination of the survey was also supported by collaborative partnerships that included a Federally Qualified Health Center Organization in Detroit and the University of Michigan Center for Sexuality and Health Disparities. The data reported here is the first subanalysis of a larger survey to collect information to understand the association between social media use and sexual health care among Black male adolescents and young adults. The goal of the larger study was to (1) determine the optimal social media sites to disseminate sexual health information to this population and (2) build a registry of zip codes to examine cross-sectional data on sexual reproductive health and risk behaviors (eg, substance abuse, violence) in young Black males beyond the local Detroit community. A convenience sample was used to recruit Black male adolescents and young adults who met certain practical criteria (eg, geographic criteria, web-based accessibility, willingness to participate) [22] to participate in the web-based survey. The study advertisements were designed to recruit young Black males between the ages of 18 years and 24 years who expressed a "multicultural affinity" through their profile self-identification or posted content pertaining to being Black and male.

This study used Facebook, Instagram, and Twitter to promote social media advertisement campaigns. A previous study indicated that these sites are best used to promote condom use education among young Black males [23]. Another recent study showed that these sites are frequently used by Black youth and are cost-effective [24]. Facebook analytics were used to track and analyze the audience and their engagement with each post. Since Facebook owns Instagram, the study team was able to review all the posts from both social media platforms simultaneously. On the Facebook page, an insight tab allowed the study team to analyze the "actions" on the page. The actions included the frequency of reviewing or previewing a post, the number of individuals that "liked" the page, user engagement (a combination of likes, comments, and shares), and the number of times the individuals saw the post across their social media timelines (reach) [25,26]. Each week, social media analytics were reviewed for the total reach on each social media platform,

including the number of "impressions" and "likes" and the number of "clicks" on the survey link. The goal of this descriptive study was to collect a maximum of 300 survey responses. This web-based survey was open from March 2019 to July 2019, gathering a total sample response of 170 respondents who answered the survey on their sexual health care and health behavior. Recruitment materials consisted of designed advertisements that used stock images of young Black males on Facebook, Instagram, and Twitter websites (including our community and academic partner websites) and directed participants to the Qualtrics survey tool. The advertisements indicated the purpose of the study and the inclusion criteria for participation. The survey website to which the participants were directed contained additional information about the details of the survey, the contact information of the study staff, and informed consent.

Study Population

Our study included participants who were (1) 18-24 years of age (2) self-identified as Black or African American (3) males, and (4) living in the United States. We excluded participants who did not reside within the United States, who were under the age of 18 years, and did not self-identify as African American or Black.

Survey Development and Analysis

Social media metrics from Facebook, Instagram, and Twitter were monitored. This cross-sectional survey comprised several categories, including basic personal information, drug-related risk behaviors, health care plans (eg, current insurance plan), sexual reproductive health questions (eg, last sexual encounter, number of partners, testing, clinic utilization), attitudes, norms, and perceived control (eg, condom use behaviors, HIV/STI transmission), mental health (eg, opinion of self, safe space), violence-related risk behaviors (eg, fighting, physically threatened), and social media preferences. Questions were selected from the Youth Risk Behavior Surveillance System Survey, the Centers for Disease Control and Prevention, and the National Health and Nutrition Examination Survey [27,28]. The survey was administered using the Qualtrics survey programming software. Before administration, closed beta testing was used to review the content and the clarity of the questions. Participants accessed the survey by clicking on a link in the banners and other photo advertisements targeted at young Black males through a personal social media marketing plan. Web-based electronic consent was obtained at the beginning of the survey. The institutional review board at the sponsoring institution approved all the survey and the study procedures.

For this analysis, we have described the process of recruitment, rates of enrollment, demographics of the eligible participants, and the associated costs across the social media platforms. Our outcome of interest was survey participation through branded social media advertisements. For the purpose of this analysis, participants were categorized as eligible once they provided consent to screen for eligibility, met eligibility criteria, and completed the survey. Additionally, we report the social media metrics (ie, link clicks, reach, and impressions) that generated the participant recruitment of our eligible sample and their demographic characteristics. All additional descriptive analyses were performed using the statistical software, that is, software for statistics and data science 15.0 (StataCorp).

Results

In total, the Black Male Opinion social media advertisements reached approximately 146,412 individuals, generating 187,320 impressions, and resulting in 0.80% (1483/187,320) clicks. Of those individuals who clicked the advertisements, web-based electronic consent to screen for eligibility was obtained from 14.7% (218/1483) of the sample population. Of these individuals, 78.0% (170/218) started the survey, and 47.1% (80/170) of these individuals met the eligibility criteria. The reasons for ineligibility included not identifying as Black or African American (22/90, 24%), age greater than 24 years (47/90, 52%), and not male gender (12/90, 13%) (Table 1). The total cost for all paid advertising was US $1067.90 through a 5-month recruitment period. The cost can be broken down as follows: US $1.39 per click, US $4.90 per consent, and US $13.35 per eligible participant.

Table 1. Descriptive statistics of the participants and the demographic variables (N=170).

Characteristics	Ineligible (n=90)[a], n (%)	Eligible (n=80), n (%)
Age (years)		
Under 18	12 (13)	N/A[b]
18-20	16 (18)	39 (49)
21-22	12 (13)	22 (27)
23-24	3 (3)	19 (24)
25+	47 (52)	N/A
Hispanic or Latino		
Yes	12 (28)	10 (12)
No	31 (72)	70 (87)
Identify as Black or African American		
Yes	21 (49)	80 (100)
No	22 (51)	N/A
Gender		
Male	3 (20)	80 (100)
Female	5 (33)	N/A
Transgender	7 (47)	N/A
Sexual orientation		
Straight	10 (59)	60 (75)
Gay	1 (6)	13 (16)
Bisexual	3 (18)	5 (6)
Preferred not to say	1 (6)	2 (2)
Other	2 (12)	N/A
Has health insurance		
Yes	6 (75)	67 (84)
No	2 (25)	13 (16)
Education		
Up to high school	4 (27)	13 (16)
Some college/technical degree	9 (60)	43 (54)
College/Graduate school	2 (13)	24 (30)

[a]It was not mandatory for the ineligible participants to answer all the questions related to demographics. Therefore, the percentages in this column were calculated on the basis of those who responded.

[b]Not applicable.

The participant age distribution comprised mostly of males aged 18-20 years (39/80, 49%), 21-22 years (22/80, 27%), and 23-24 years (19/80, 24%) years (Table 2). The mean age of the final sample was 21 years old, with a majority of the participants being 19 years old. A smaller proportion of the participants was identified as being Hispanic or Latino (10/80, 12%). The majority of the sample was identified as straight in sexual orientation (60/80, 75%), had health insurance (67/80, 84%), and had some college or technical education (43/80, 54%).

Table 2. Demographics of the eligible participants in each recruitment platform (n=80).

Demographic characteristics	Total, n=80, n (%)	Referral, n=27, n (%)	Facebook, n=14, n (%)	Instagram, n=8, n (%)	Missing, n=18, n (%)	Email, n=9, n (%)	Other[a] (n=2), n (%)
Age (years)							
18-20	39 (49)	13 (48)	4 (29)	7 (87)	8 (44)	5 (56)	2 (100)
21-22	22 (27)	9 (33)	5 (36)	1 (12)	4 (22)	2 (22)	N/A[b]
23-24	19 (24)	5 (18)	5 (36)	0 (0)	6 (33)	2 (22)	N/A
Hispanic or Latino							
Yes	10 (12)	7 (26)	1 (7)	1 (12)	1 (6)	N/A	N/A
No	70 (87)	20 (74)	13 (93)	7 (87)	17 (94)	9 (100)	2 (100)
Sexual orientation							
Straight	60 (75)	19 (70)	9 (64)	6 (75)	15 (83)	8 (89)	2 (100)
Gay	13 (16)	4 (15)	3 (21)	2 (25)	3 (17)	1 (11)	N/A
Bisexual	5 (6)	3 (11)	2 (14)	N/A	N/A	N/A	N/A
Preferred not to say	2 (2)	1 (4)	N/A	N/A	N/A	N/A	N/A
Has health insurance							
Yes	67 (84)	24 (89)	11 (79)	7 (87)	14 (78)	8 (100)	2 (100)
No	13 (16)	3 (11)	3 (21)	1 (12)	4 (22)	N/A	N/A
Education							
Up to high school	13 (16)	2 (7)	4 (29)	1 (12)	4 (22)	1 (11)	1 (50)
Some college/technical degree	43 (54)	15 (56)	7 (50)	5 (62)	10 (56)	5 (56)	N/A
College/Graduate school	24 (30)	10 (37)	3 (21)	2 (25)	4 (22)	3 (33)	1 (50)

[a]Includes 2 more from an unspecified web-based advertisement.

[b]Not applicable.

Across platforms, our primary finding for web-based survey engagement was that referral (eg, group chat, indirect social media sharing) provided the greatest proportion of recruitment (27/80, 34%), while other methods such as web-based spaces that we were not able to capture (2/80, 0%) and Instagram (8/80, 10%) obtained the lowest rate of recruitment. The method of recruitment was missing for individuals who did not provide a response (18/80, 24%). Those with missing recruitment platforms may fall into the other categories, potentially undercounting the frequencies of the other platforms. Users reported Twitter (24/80, 39%) and YouTube (27/80, 34%) as being the best platforms to receive sexual health information. Overall, different sites produced different results in engagement and cost. Table 3 indicates the sample banner advertisement engagement across social media platforms and the associated costs per participant.

Table 3. Subset of recruitment advertisement performance by platform.

Advertisement name	Facebook				Instagram			
	Reach (n)	Impression (n)	Engagement[a] (n)	Cost per engagement (US $)	Reach (n)	Impression (n)	Engagement (n)	Cost per engagement (US $)
Your Opinion Counts	42,958	47,207	252	0.74	N/A	N/A	N/A	N/A
Your Opinion Matters	15,880	21,690	98	0.75	N/A	N/A	N/A	N/A
Be more informed	5788	5865	59	0.64	N/A	N/A	N/A	N/A
Be more visible	1181	1213	377	0.09	15,180	18,768	96	0.87
Help us change	N/A	N/A	N/A	N/A	4402	5388	78	0.45
Be more together	3245	3717	30	0.78	3300	3772	17	1.22
Be more in sync	630	639	59	0.28	416	422	19	0.50

[a]Engagement is defined as any user interaction with an advertisement, and it may include a link click, comment, or like.

[b]Not applicable.

Discussion

Principal Findings

We conducted a web-based survey to determine the social media platforms and the banner advertisements that affected the engagement of self-identified Black adolescents and young adults in participating in web-based surveys. In this web-based survey, 80 eligible individuals completed the Black Male Opinion social media survey. Overall, we found that young Black males who participated in this survey joined via referral through other social media outlets (eg, friends sending links via Facebook Messenger or Instagram Direct Message). Empirically, this population engaged through Facebook most frequently via paid web banner advertisements. However, in the survey responses, participants reported a preference for Twitter and YouTube as venues for receiving sexual health information. The paid banner advertisements resulted in reaching approximately 150,000 individuals within the defined demographic over 5 months.

Previous studies have shown that social media platforms have the potential to promote safe sex practices and STI prevention among adolescents and young adults engaging in high-risk behaviors [20,29]. The response from this engagement in this study shows the possibility of reaching a large untapped population. With these findings, there is also the potential for targeted use of one of the identified social networks that this target audience prefers as well as for a comparison of the distribution and uptake of this survey in other social media campaigns with adolescents and young adults and health behaviors. By using this marketing strategy, more culturally sensitive and customized health information may be created to promote health awareness such as STI-screening locations, accurate sexual health education, and condom availability for this demographic. Moreover, using this type of web-based engagement may be useful in removing barriers such as transportation and face-to-face engagement (eg, distrust in the medical system, stigma, lack of community-based resources, lack of knowledge) [15,30,31]. The social media site that would be best suited as a community-based tool for the generalized population is still unclear in this study. However, from our sample, there is an indication that YouTube and Twitter are viable methods for promoting sexual health information and education to young Black males. Future research would need to affirm these findings by designing a pilot study that directly compares these social media platforms to weigh the benefits that each site would have to offer. This work is one step closer to potentially utilizing a more creative and culturally sensitive approach that may be included in the current health care system, more specifically in primary care. However, the ultimate goal is not only to engage young Black males but also to aid them in finding a safe space for navigating services and participating in conversations that are relevant about their identities and sexual health both in and outside of the clinic.

Limitations

Our study has the following limitations. First, our sample size was small and therefore is not representative of the entire population. Offering an incentive may have enhanced the response rate [32]. Using a multimodal approach such as traditional recruitment methods (eg, word of mouth, flyers) in combination with other social media platforms (eg, Reddit, Snapchat) may have helped to cover broader demographics and reach a larger and more diverse pool of potential respondents [33]. Second, requests from social media sites to update banner advertisements due to incorrect wordings and noncompliance with advertisement policies consumed additional time for running and producing the advertisements. Reviewing advertisement policies before posting, such as Facebook's brand or content that asserts or implies personal attributes such as gender identity or age, can help to create an appropriate user-friendly advertisement [34]. Setting up a personalized marketing plan with a marketing expert for the intended social media site can also help to specify design formats and optimize recruitment campaigns for future studies. Third, owing to budget constraints, it was difficult to use more than 3 types of social media platforms to market the advertisements. Finally, these

data have limited generalizability to a broader population. Nonetheless, our findings from this study contribute to the currently limited information available about this population.

Implications

There is an urgent need for health care researchers to focus on improving the health of adolescents and young adults to better engage vulnerable populations, particularly Black males who have a need for sexual reproductive health services. Since adolescents and young adults universally engage over social media platforms, health care researchers have the opportunity to creatively develop web-based sexual reproductive health services that attract adolescents and young adults. This engagement is defined in different ways such as observation (ie, viewing the advertisement), liking the advertisements, or clicking the links. Reaching communities via methods of web-based social media platforms is often dictated by the advertising policies that each social media site uses such as the advertisement review process, brand assets, steps to take if the advertisement is disapproved, and prohibited content [34]. As social media platforms become more complex in their use and development, so will their policies; thus, health care researchers, the community, and those interested in reaching adolescents and young adults must be flexible and creative in how they attract users and build engagement on these important topics. Black male adolescents and young adults will benefit from the adoption of these evolving platforms into the research methodologies. Providing ongoing evidence of the extensive social media platform use among adolescents and young adults will inform policies and effective primary care and hospital system changes that may improve sexual health access.

Black male adolescents and young adults have an increased rate of STIs and would benefit from adolescent-friendly clinical practices regarding their sexual health [35]. In addition to providing sexual reproductive health care (eg, sexual education, STI screening) to adolescents and young adults in the clinical setting, health care providers have the opportunity to lead this type of innovation of using social media platforms for creating a space to discuss sexual health and to use these platforms to engage in creatively marketing sexual reproductive health resources. Thus, health care providers can become thought leaders in clinical settings to promote change or to ensure that this innovative method is implemented in the face of resistance or among those who do not use these platforms. With this in mind, these platforms can potentially increase engagement in this population by providing web-based information about STI screening in their local communities, obtaining condoms, and about alternative response venues to direct individuals to come into the clinic and to schedule appointments with a health care professional [23].

Conclusion

A critical strategy in the efforts to reduce sexual health disparities is understanding the social media platforms that Black male adolescents and young adults engage in. This includes understanding the difference between the platforms that individuals may access on a regular basis versus the platforms that individuals may access to seek sexual health information for their personal use. This study demonstrates that this population engages through Facebook most frequently via paid web-based banner advertisements and through direct messages on Facebook and Instagram, which is a private form of communication via social media. Additionally, creating sexual reproductive health information on preferred platforms (eg, Twitter, YouTube) could benefit this vulnerable population. As social media platforms evolve and become more integrated into our culture, health care providers and researchers need to find novel ways to improve their marketing efforts and engagement with Black male adolescents and young adults. Creating policies and methodologies aimed at incorporating and utilizing these social media platforms will be vital in increasing sexual reproductive health education, resources, and access for adolescents and young adults, thereby promoting future health equity initiatives in virtual spaces and improved health outcomes for this underserved population.

Conflicts of Interest

None declared.

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Abbreviations

STI: sexually transmitted infection

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Original Paper

Identifying Influential Factors in the Discussion Dynamics of Emerging Health Issues on Social Media: Computational Study

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Abstract

Background: Social media has become a major resource for observing and understanding public opinions using infodemiology and infoveillance methods, especially during emergencies such as disease outbreaks. For public health agencies, understanding the driving forces of web-based discussions will help deliver more effective and efficient information to general users on social media and the web.

Objective: The study aimed to identify the major contributors that drove overall Zika-related tweeting dynamics during the 2016 epidemic. In total, 3 hypothetical drivers were proposed: (1) the underlying Zika epidemic quantified as a time series of case counts; (2) sporadic but critical real-world events such as the 2016 Rio Olympics and World Health Organization's Public Health Emergency of International Concern (PHEIC) announcement, and (3) a few influential users' tweeting activities.

Methods: All tweets and retweets (RTs) containing the keyword Zika posted in 2016 were collected via the Gnip application programming interface (API). We developed an analytical pipeline, EventPeriscope, to identify co-occurring trending events with Zika and quantify the strength of these events. We also retrieved Zika case data and identified the top influencers of the Zika discussion on Twitter. The influence of 3 potential drivers was examined via a multivariate time series analysis, signal processing, a content analysis, and text mining techniques.

Results: Zika-related tweeting dynamics were not significantly correlated with the underlying Zika epidemic in the United States in any of the four quarters in 2016 nor in the entire year. Instead, peaks of Zika-related tweeting activity were strongly associated with a few critical real-world events, both planned, such as the Rio Olympics, and unplanned, such as the PHEIC announcement. The Rio Olympics was mentioned in >15% of all Zika-related tweets and PHEIC occurred in 27% of Zika-related tweets around their respective peaks. In addition, the overall tweeting dynamics of the top 100 most actively tweeting users on the Zika topic, the top 100 users receiving most RTs, and the top 100 users mentioned were the most highly correlated to and preceded the overall tweeting dynamics, making these groups of users the potential drivers of tweeting dynamics. The top 100 users who retweeted the most were not critical in driving the overall tweeting dynamics. There were very few overlaps among these different groups of potentially influential users.

Conclusions: Using our proposed analytical workflow, EventPeriscope, we identified that Zika discussion dynamics on Twitter were decoupled from the actual disease epidemic in the United States but were closely related to and highly influenced by certain sporadic real-world events as well as by a few influential users. This study provided a methodology framework and insights to better understand the driving forces of web-based public discourse during health emergencies. Therefore, health agencies could deliver more effective and efficient web-based communications in emerging crises.

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KEYWORDS

social media; infodemiology; infoveillance; infodemic; health emergency; tweeting dynamics; events detection; online influentials; Zika; public engagement

Introduction

Background

Social media platforms, such as Twitter and Facebook, are attracting a growing number of people with diverse demographic characteristics to share and obtain information on the web. As a result, these platforms have become one of the main targets for practitioners and decision makers across various fields to understand public opinion and, at the same time, disseminate information to the public [1-17]. Many public health agencies and organizations, such as the US Centers for Disease Control and Prevention (CDC), are active on Twitter and other social media platforms as the main channels of communication with the general public, especially during health emergencies such as the 2014 Ebola and 2016 Zika outbreaks. The CDC has 67 officially associated Twitter accounts that cover a wide variety of health- and disease-related topics. In 2016, when Zika caused 5168 confirmed noncongenital cases in 50 states and the District of Columbia in the United States, and a much higher case number across US territories [6], former CDC director Dr Tom Frieden was active on Twitter and hosted live Twitter chats with the general public [18], including a 1-hour live chat session with the public regarding Zika in February 2016.

Nevertheless, there are multiple challenges in utilizing social media platforms as an effective channel of communication. A considerable percentage of users are unfamiliar with the emerging health issue. At the same time, user-posted content does not go through any rigorous fact-checking process, making room for misinformation to take advantage of such a situation. During the 2016 Zika epidemic, despite the CDC's prominent web presence and efforts, inaccurate information regarding Zika proliferated on social media and outperformed CDC (and other legitimate sources such as the World Health Organization [WHO]) by a large margin [7]. Uncertainty about the root cause and transmission route of this virus gave room for the proliferation of rumors and misinformation [19,20].

In addition to the problem of misinformation propagation, the rhetorical aspect of a message, or in other words, crafting it based on the needs and perception of audiences is a critical challenge [21,22]. Studies have shown a substantial topic discrepancy between public concern and the CDC's response to Zika on Twitter [8,9,20,23]. More specifically, the general public was more concerned about the transmission routes of Zika and effective prevention methods, whereas the CDC focused on symptoms to educate the public [24,25]. Glowacki et al [25] argued that this could be seen as failure of the CDC to identify what kind of information the public was looking for and respond accordingly or it could be an on-purpose attempt by the CDC to redirect public attention to what the CDC believed to be more important during the epidemic.

In addition, one important yet overlooked issue in utilizing social media platforms as a communication mechanism with the public is the low rate of user engagement (measured by the number of retweets [RTs] and replies), where social media is an interactive platform for public engagement and interaction [26], in addition to one-directional news outlets [10,27,28]. To better engage the public, it is essential to recognize critical factors that are directing and driving the general discussion dynamics on social media. Such factors can be discovered by observing and analyzing the public's tweeting behaviors on social media [29,30]. Learning about these factors can help health agencies to accurately predict shifts in the public's concern about the health issue and provide the public with useful information accordingly. As a result, systematically collecting and analyzing data related to public discourse of emerging health issues on social media, also referred to as digital public health surveillance, infodemiology, or infoveillance [31], is essential for understanding public concerns and disseminating useful information correspondingly.

Objectives

In this study, we aimed to identify important factors that could potentially drive tweeting dynamics in the 2016 Zika epidemic. We collected and comprehensively analyzed all Zika-related English tweets posted during 2016. We further proposed and evaluated the following 3 testable hypotheses (H):

1. H1: The observed overall tweeting dynamics of Zika was associated with and influenced by the underlying Zika epidemic, defined as the number of case counts per day, especially in the United States.
2. H2: The tweeting dynamics of Zika was associated with and influenced by a few real-world critical events, other than the continuous Zika epidemic.
3. H3: The tweeting dynamics of Zika were driven by a few highly influential users (colloquially referred to as influentials hereafter), which led to the public discourse of Zika on Twitter.

Methods

Data Acquisition

We requested and retrieved more than 6 million English tweets, including the keyword *Zika* from January 1 to December 31, 2016, via the Gnip application programming interface (API) through the Data Science Initiative (DSI), University of North Carolina Charlotte. All associated metadata with these tweets, such as RT counts, posted time, and the verification status of tweeting/retweeting ID, were also included in the data set. This data set represented the complete public discourse about Zika in English and was therefore not as prone to potential selection bias as the common 10% sample provided by the common Twitter API. Therefore, the data set in this study was able to provide an unbiased and comprehensive depiction of the public's

discourse of Zika, the most discussed health topic in 2016 on a major social media platform.

In addition to web-based Twitter data, the complete time series of confirmed noncongenital Zika case counts in 2016 in the United States were obtained from the CDC's database [32]. Both domestic cases (cases in 50 states and District of Columbia) and all cases combined (cases in 50 states, District of Columbia, and overseas territories such as Puerto Rico, Virgin Island, Guam) were acquired.

Association Between the United States Zika Epidemic and Tweeting Dynamics

Zika case counts in 2016 were retrieved from the CDC [32] and then downscaled into standardized daily counts using the cubic spline interpolation method [27]. The time series of the downscaled daily case counts was then compared with daily Zika-related tweet counts. As both time series (cases and tweets) had the same daily resolution and the same length of 366 days, a cross-correlation function (CCF) was applied to quantify potential association and time lags between the two time series. CCF measured the temporal similarity between the two time series, as shown in equation (1). The significance level was set at 0.2 by default in the analytical package in this study. In general, larger absolute values of cross-correlation at time lag L indicate a stronger association between the two time series. Both domestic US Zika cases and all US Zika cases were compared with Zika-related tweet counts in each of the four quarters of 2016 as well as during the entire 2016 period:

In addition, mutual information (MI) between Zika case counts and Zika-related tweets in each of the four quarters as well as in 2016 was quantified to further evaluate the mutual dependence of the two time series. MI was calculated as the expected value of the pointwise MI (PMI) of the two time series. PMI measured the level of dependency between 2 observations [33]. PMI between X and Y was calculated using equation (2):

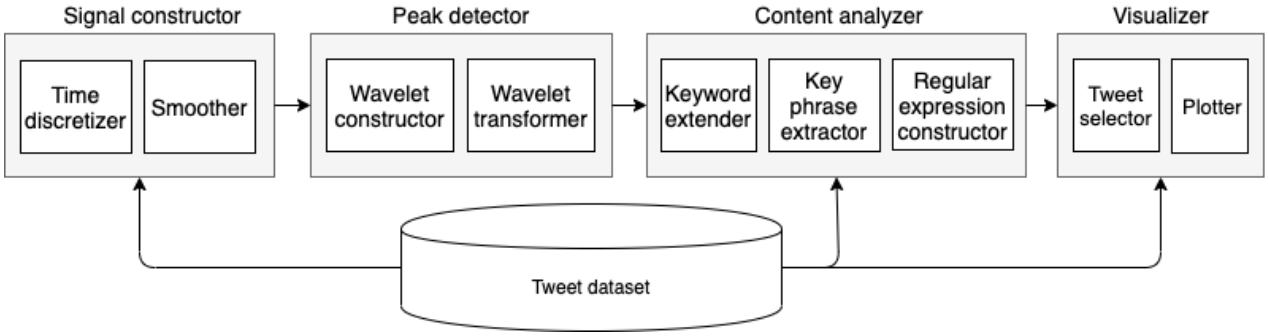
where p (.) is the probability function. The 2 observations that had a high PMI value were strongly associated with each other. In other words, they frequently co-occurred. The average dependency or MI between the 2 random variables X and Y was then calculated using equation (3):

CCF provided an overview of the association between real-world Zika case counts and tweeting activities regarding Zika over a period. A CCF above 0.05 indicated a strong association between the two time series. MI further quantified this association with a value. These two approaches complemented each other.

Association Between Critical Events and Tweeting Dynamics

Health emergencies, such as the Zika epidemic, would never occur in isolation and almost always be intermingled with other health, social, societal, and political events in the real world. We suggest that related and sometimes unrelated real-world events could be potential driving forces of Zika discussions on social media. Unlike the time series of daily Zika case counts, these real-world events were much more discrete and sporadic. Here, we evaluated the second hypothesis (H2) such that Zika-related tweeting activities were substantially influenced by sporadic real-world events. We adopted the definition of an event provided by Hasan et al [18] stating, "An event, in the context of social media, is an occurrence of interest in the real world which instigates a discussion on the event-associated topic by various social media users, either soon after the occurrence or, sometimes, in anticipation of it." We developed an analytical pipeline, EventPeriscope, to explore and quantify the impact of real-world events on the tweeting dynamics of a specific topic (eg, Zika in this study) and to evaluate H2. Figure 1 demonstrates the 4 main components of the EventPeriscope pipeline: signal constructor, peak detector, content analyzer, and visualizer.

Figure 1. EventPeriscope analytical pipeline.



The signal constructor module modeled the number of daily tweets about Zika as a signal to characterize its temporal changes. If a particular real-world event had a significant influence on Twitter discussions, we would expect to see a peak in the time of the event or close to it. Therefore, a sudden rise in the signal indicated the high engagement of Twitter users, which might be linked to a potential real-world event. To identify these peaks, the peak detector module applied the wavelet transform to detect peaks in the constructed signal from the signal constructor module. Nevertheless, a peak at or around the time of a real-world event was only a necessary but not sufficient condition to conclude that the event was the main

driver of the rise in the number of tweets. Overlap of the event and peak of Zika-related tweeting might be coincidental. It would be critical to demonstrate that Zika-related tweets around the event were actually regarding that event. To confirm this relevance, the content analyzer module then analyzed textual contents of the tweets around the real-world event to extract all key phrases that were relevant to the event. Then, the content analyzer created regular expression (regex) rules to automatically capture all variations and combinations of these key phrases. Finally, the visualizer module compared all tweets in the data set against the constructed event-specific regex rules and constructed a new time series from the matched tweets as the signal of a specific event related to Zika. It helped to understand how discussions spanned around the event in a wider time window. To illustrate how all 4 modules worked synergistically in EventPeriscope, we provided case studies of critical real-world events and their impact on Zika-related tweeting dynamics.

Case Studies of Critical Events

Real-world events could be categorized into 2 dichotomized and mutually exclusive types [34]: (1) planned (ad hoc) events that people expected in advance, such as the 2016 Rio Olympics; (2) unplanned (posthoc) events that people would not know beforehand, contrary to planned events. An example of unplanned events was the WHO's Public Health Emergency of International Concern (PHEIC) announcement about Zika on February 1, 2016. In the next section, we have discussed methodological differences in exploring planned (Rio Olympics 2016) and unplanned (WHO-PHEIC) events in detail. Planned events might increase their presence in tweeting around the event, but it could be mentioned throughout the entire year because people were well aware of it beforehand. Unplanned events, however, would not be mentioned in tweets until their occurrence in the real world. In the next section, we examine the impact of these 2 types of real-world events on Twitter discussion dynamics.

Unplanned Event: World Health Organization's Public Health Emergency International Concern Announcement

On February 1, 2016, the director-general of WHO, Margaret Chan, declared a PHEIC of a potential Zika pandemic [35]. In this statement, in addition to raising concerns over the linkage of Zika with microcephaly and other neurological disorders, the WHO provided travel advice in Zika-impacted regions. The WHO-PHEIC announcement was an unplanned event, and the general public did not have any previous knowledge of its occurrence. Therefore, it should only influence tweets posted after the PHEIC announcement. We used EventPeriscope to quantify the influence of the WHO-PHEIC event on Zika-related tweeting as follows.

First, a signal was constructed from all posted Zika-related tweets, which is hereafter referred to as the main tweet signal. The main tweet signal peak in the entire 2016 period occurred almost immediately after the WHO-PHEIC event on day 32 (February 1, 2016), indicating a potential and strong correlation between the event and Zika-related tweeting. Textual contents of tweets were then analyzed to verify the association between Zika-related tweets and the WHO-PHEIC announcement. The set of tweets posted in a 2-day interval, the day of the WHO-PHEIC announcement (February 1) and 1 day after (February 2), were used as the input of the content analyzer (CA) module to construct a regex rule describing the WHO-PHEIC event. In addition, this module was given a set of 2 additional keywords, *WHO* and *PHEIC*, relevant to the WHO-PHEIC announcement event. To find other relevant keywords, the keyword extractor in the CA module used PMI, which was discussed in the previous section, and calculated PMI values between each of these 2 keywords and all the keywords extracted from the input signal. The new keywords were then sorted in descending order based on PMI values, and those with the highest PMI values were selected. In this study, we selected the top 6 keywords from the list.

Using this approach, the additional set of keywords included *emergency*, *public*, *international*, *global*, *world*, and *health*. A single word within a tweet was usually not adequate to reveal the topic of the content. Therefore, to consider the context of a tweet and obtain a more accurate result, the key phrase extractor uses these keywords to synthesize key phrases describing the event. We defined a key phrase as a noun phrase that contained at least one of the keywords. The key phrases relevant to WHO-PHEIC were *public health emergency*, *global emergency*, *international emergency*, and *world health*. On the basis of these key phrases, a regex rule was crafted. Using a similar approach, another regex rule was generated to capture Zika-related tweets relevant to WHO, regardless of whether it was related to WHO-PHEIC. Finally, the visualizer module compares all tweets in the input data set with these regex rules and generated 2 output signals: one for WHO-PHEIC and the other for WHO.

Planned Event: RIO2016

The Rio 2016 Olympic Games were held from August 5 to 21, 2016, in Rio de Janeiro, Brazil, amid global concerns about the Zika outbreak. In November 2015, Brazilian authorities declared a national public health emergency due to a high Zika incidence [26]. As RIO2016 was a planned event, we expected to see tweeting about Zika and RIO2016 before its opening. The CA module of the EventPeriscope pipeline was initialized with tweets posted from August 4 to 6 (days 217 to 219) within plus or minus a 1-day window of the RIO2016 opening. Then, a regex rule was generated to detect the co-occurrence of the Zika and Rio Olympics topics in Twitter discussions. The final keywords and key phrases were *Rio*, *Olympics*, *Rio2016*, *2016 Olympics*, and *Rio Olympics*.

Association Between Web-Based Influentials and Zika-Related Tweeting Dynamics

In this part of the study (H3), we hypothesized that a few influentials on Twitter made a substantial contribution in driving the tweeting dynamics, that is, a noticeable sudden rise in the number of tweets. To evaluate this hypothesis, we defined 4 different types of web-based influentials in 2 major categories: active influentials who posted a large number of original tweets about Zika (top tweeter [TT]) and who retweeted a lot about Zika from other accounts' posts (top retweeter [TR]). These users actively disseminated Zika-related information to the public. In addition, influentials on social media could be passive as well: whose original posts were retweeted a lot (top received

retweets [TRRT]) and who received many mentions (@_userID) from other Twitter users (top mentioned [TM]). These passive influentials, on the other hand, were more reflective of public perception and engagement of Zika discussions on Twitter. We ranked and selected the top 100 users in each of these 4 influential groups: TT, TR, TRRT, and TM. The tweeting dynamics of each user in the TT, TRRT, and TM groups and the retweeting dynamics of each influential in the TR group were extracted as their respective time series signals. These tweeting/retweeting signals were then aggregated and compared with the overall tweeting dynamics using a CCF in each quarter of 2016 as well as the entire year. This step tested the group-level association between types of influential and overall Zika-related tweeting dynamics. In addition, we derived the time lag between each influential's tweeting (or retweeting) dynamics and the main tweet signal to test if these tweeting activities of influentials preceded the overall tweeting dynamics. This step was critical to further reveal if these influentials actually initiated an increasing number of Zika-related tweets, or the other way around, that is, these influentials were actually following and catching up with the general trend on Twitter. We also examined the overlap between the 4 groups of influentials by calculating the intersection of any 2 sets of influentials. This would reveal if certain influential group(s) on Twitter would also be influential in other ways. In particular, we wanted to identify influentials who were both actively disseminating information to the public (ie, in TT or TR groups) and passively receiving attention from the general public on social media (ie, in TRRT or TM groups).

The work was carried out in Python 3.7 (Python Software Foundation) for data retrieving and EventPeriscope pipeline construction. In addition, *R* 3.3.1 was used for the statistical analyses. All codes associated with this study were freely available upon request.

Results

Descriptive Results of the Zika-Related Tweeting Dynamics

A total of more than 6 million English tweets with the keyword *Zika* posted during 2016 were retrieved, of which approximately 4 million were original posts, and the remaining were RTs. More than 70% of the original posts received no RT at all, and only 2% of tweets received at least five RTs. The Gini coefficients of the number of RTs were 0.74 and 0.98 for all original tweets and original tweets that received RTs, respectively. This indicated a very high heterogeneity in the potential influence of individual tweets on social media.

Association Between the Zika Epidemic and Tweeting Dynamics

No significant cross-correlation between domestic Zika cases in the United States and overall discussion dynamics on Twitter was observed in any of the four quarters in 2016 (Figure 2). Although in the first quarter, the CCF was substantially above the threshold, it was distributed almost normally around 0, indicating a lack of time lag between the domestic Zika case and Twitter discussion dynamics. Similarly, no substantial cross-correlation between all Zika cases in the United States (including overseas territories) and Twitter discussion dynamics was prominent in any quarter in 2016 (Figure 3). For all Zika cases, including overseas territories, the highest cross-correlation occurred in the fourth quarter, which was different from the domestic case with the highest correlation in the first quarter. These results demonstrated that Zika-related tweeting dynamics were decoupled from the actual disease epidemic in the United States, indicating that the underlying Zika epidemic did not substantially influence the Zika discussion on Twitter. In fact, the highest peak of Zika-related tweeting occurred around February 1, 2016, where the case counts were low in the United States, both domestically and overseas. Therefore, such prominent peaks in Zika-related tweeting dynamics should be explained by other driving forces than the actual Zika case counts. MI between the two time series, as shown in Table 1, was lower in 2016 but substantially higher in each quarter. The highest MI occurred in the second quarter when the number of new Zika cases was the highest in 2016. However, most Zika-related tweets were tweeted in the first quarter of 2016.

Figure 2. Cross-correlation function between Zika case counts in the domestic United States and tweet counts in 2016. CCF: cross-correlation function.

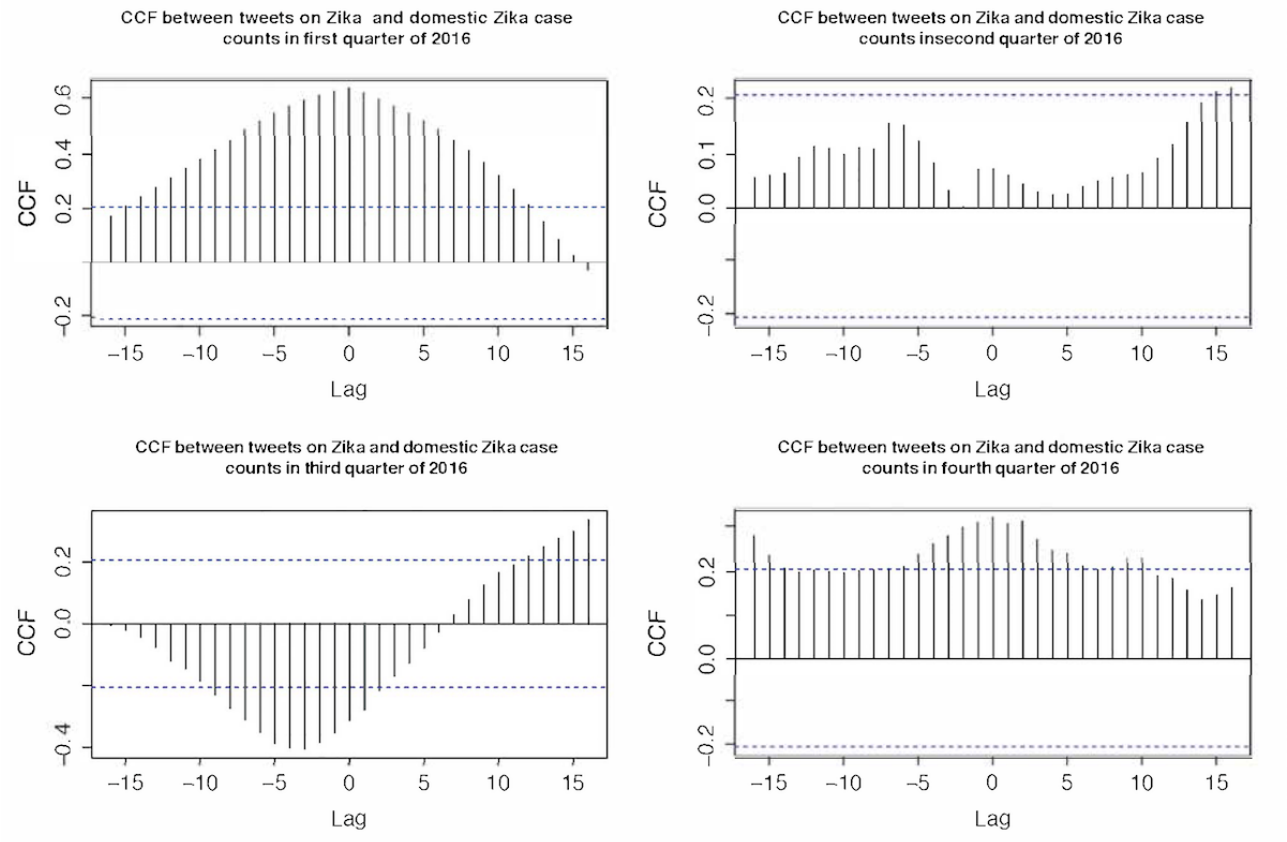


Figure 3. Cross-correlation function between Zika case counts in the domestic United States plus overseas territories and tweet counts in 2016. CCF: cross-correlation function.

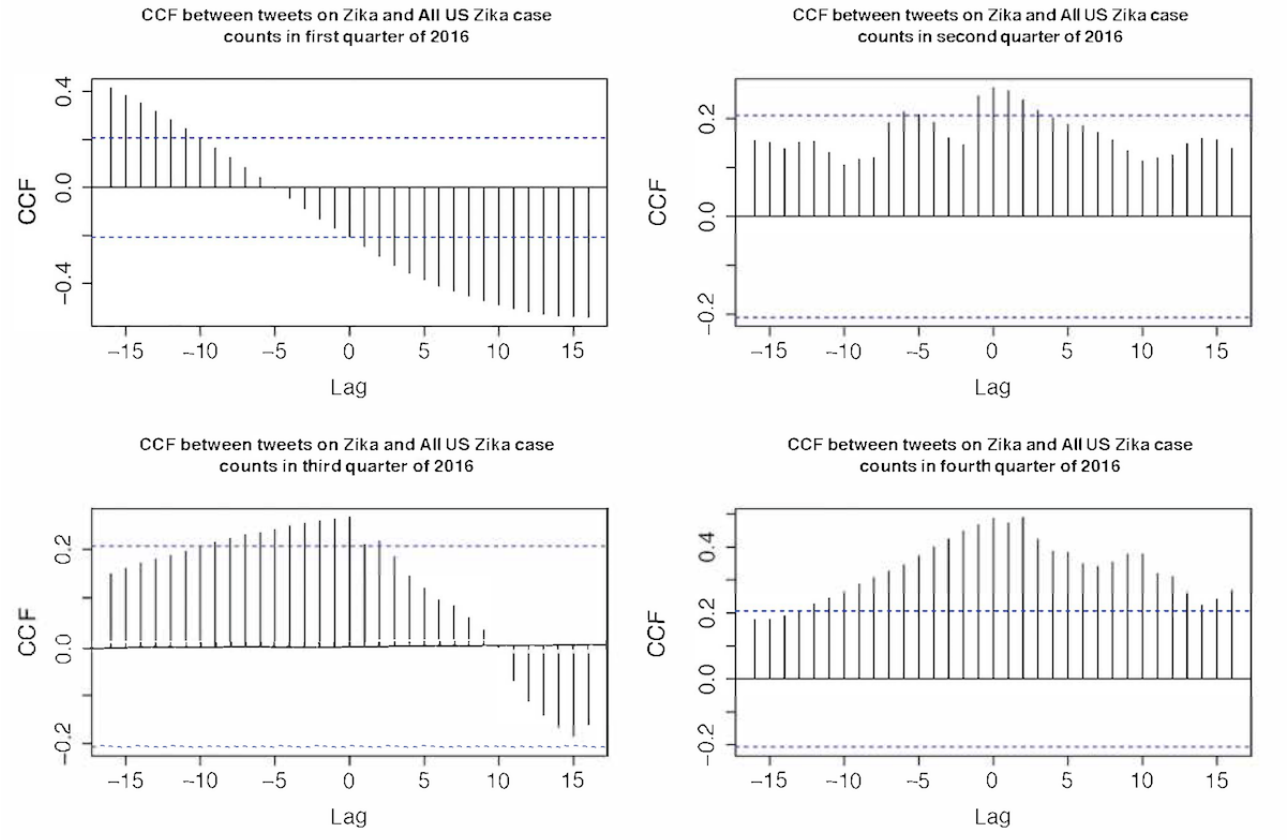


Table 1. Mutual information between Zika case counts and tweet counts in the United States in 2016.

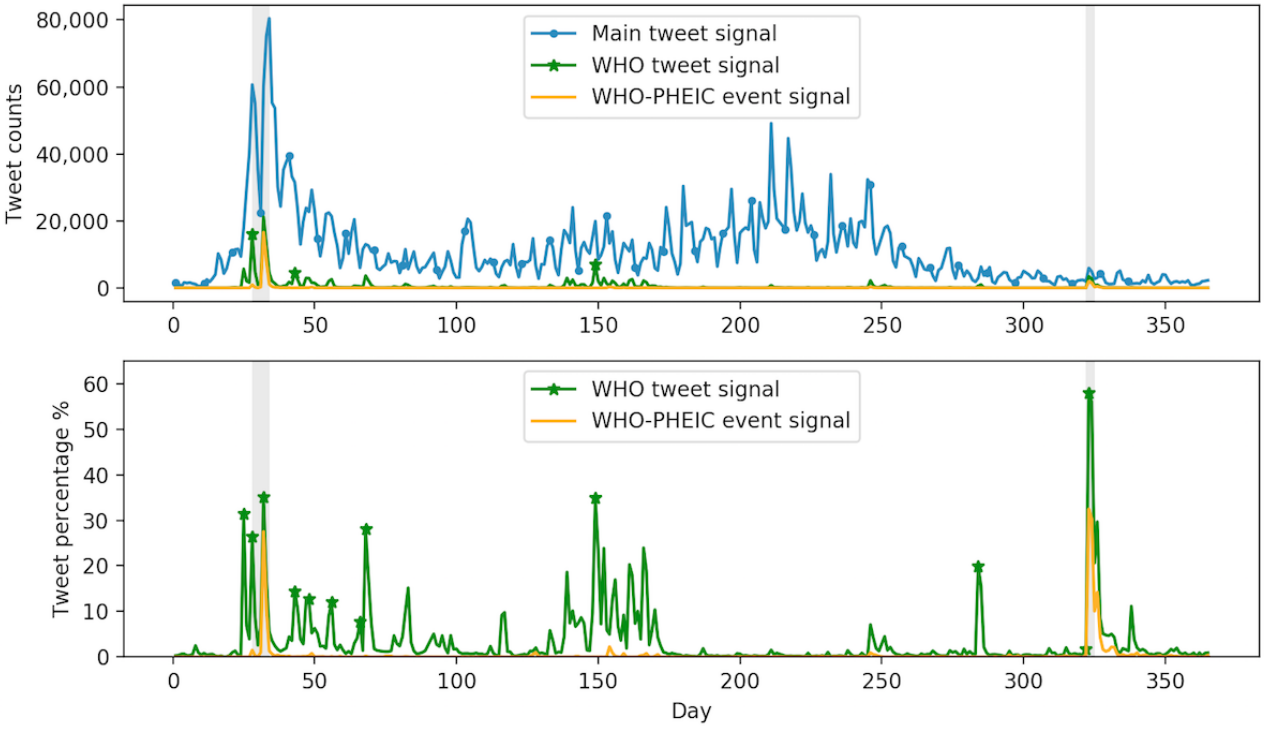
Case counts in the United States	Quarter 1	Quarter 2	Quarter 3	Quarter 4	2016
Domestic	2.15	3.40	2.99	2.51	1.89
Domestic and overseas territories	2.93	3.23	2.45	2.64	1.83

Association Between Sporadic Critical Events and Zika-Related Tweeting Dynamics

The peaks of Zika-related tweets were not synchronized with peaks of Zika counts, as discussed in the previous section. In fact, a large number of Zika-related tweets were associated with a few sporadic real-world events. The association between Zika-related tweets and the unplanned real-world event WHO-PHEIC announcement is shown in Figure 4. WHO and WHO-PHEIC tweets were subsets of all Zika-related tweets. The upper panel of Figure 4 is the absolute number of tweet counts. The blue signal shows all Zika-related tweets in 2016. The green and orange signals represent WHO and WHO-PHEIC signals, respectively. The lower panel of Figure 4 shows the percentage of WHO and WHO-PHEIC tweets relative to all Zika-related tweets. If a tweet had both keywords/key phrases of WHO and PHEIC, then the same tweet would be included in both categories. PHEIC- and WHO-related tweets had a high overlap (>50%), indicating the substantial impact of the WHO-PHEIC announcement on public discourse on social media.

The keyword *WHO* had a strong presence in Zika-related tweeting throughout the first two quarters of 2016. There was a sudden rise in the number of tweets between days 31 and 32 of 2016 (Figure 4); the number of Zika-related tweets increased drastically from 1481 on day 31 (January 31) to 21,171 on day 32 (February 1), when the WHO announced the Zika epidemic as PHEIC. On February 1, 2016, 35% of all Zika-related tweets were relevant to WHO and 27% were about the announcement of PHEIC. This announcement also caused cascading public announcements in countries such as Brazil, Honduras, and the United States. The highest number of tweets (92,000) posted on a single day regarding Zika was observed on day 34, just 2 days after the WHO-PHEIC announcement. Therefore, the unplanned WHO-PHEIC announcement was the driving force of the largest peak of Zika-related tweeting dynamics in 2016. It is worth noting that the discussion about the PHEIC started on January 28, when the director-general of WHO announced that she convened the International Health Regulations emergency committee and would have a meeting on February 1 [35]. In addition to this peak, the WHO-PHEIC signal had another prominent peak around day 323 (November 18, 2016; Figure 4). On November 18, 2016, about 32% of the Zika-related tweets were related to WHO-PHEIC because WHO declared that the Zika epidemic was no longer a PHEIC on that specific day. Therefore, our EventPerisope analytical pipeline was effective in identifying and evaluating the impact of real-world events on tweeting dynamics.

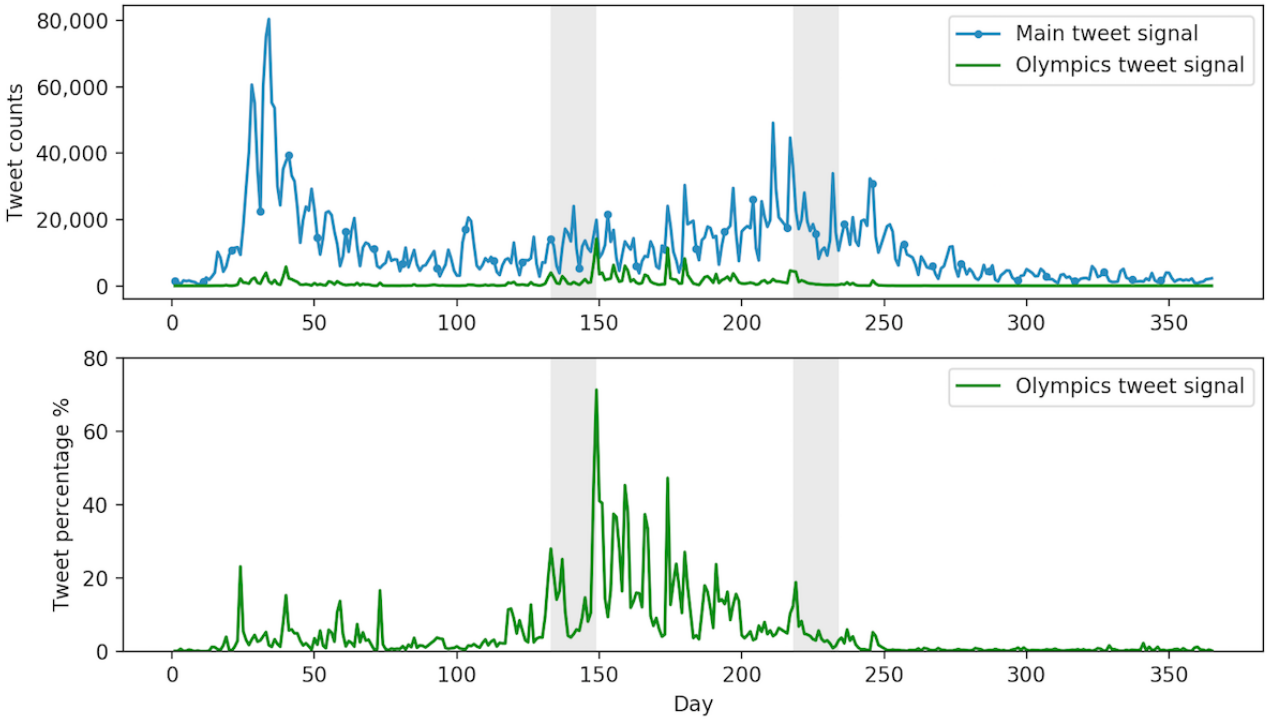
Figure 4. Signals of the main Zika-related tweets, WHO tweets, and WHO-PHEIC tweets. WHO: World Health Organization; PHEIC: Public Health Emergency of International Concerns.



The association between the planned event, RIO2016, and the peaks of Zika-related tweeting are shown in Figure 5. The upper panel shows the absolute number of tweet counts. The blue and green signals showed all Zika-related tweets and RIO2016

Olympics tweets in 2016, respectively. The lower panel shows the percentage of RIO2016-related tweets relative to all Zika-related tweets. In general, discussions about Zika and the RIO2016 Olympics started from the beginning of 2016 all the way through a few days after the Olympics ended. In other words, although the event of the RIO2016 Olympics only lasted for 2 weeks, the discussion of this event with regard to Zika went on throughout the entire year because the Olympics was a planned event. Specifically, on its opening ceremony day (August 5) and on the next day, 12% and up to 18% of all Zika-related tweets were related to RIO2016, respectively.

Figure 5. Signals of the main Zika-related tweets and RIO2016 tweets.



In addition, RIO2016 had a prominent presence in other noticeable peaks of the Zika-related tweeting signal. For example, RIO2016 constituted 71% of all Zika-related tweets on day 149 (May 28). Our further investigation revealed that on day 133 (May 12), a researcher started the debate that RIO2016 should be canceled or at least postponed amid concerns of the Zika outbreak [36]. However, on day 149 (May 28), the WHO released a statement [35] explaining that it was not necessary to take such an action. Owing to the WHO announcement regarding RIO2016 and Zika on day 149, the WHO-Zika signal also had a peak on day 149; WHO/Zika–related tweets comprised 34% of all Zika-related tweets (Figure 4). These results supported H2 that Zika-related tweeting dynamics were triggered by other events in the real world.

Association Between Web-Based Influentials and Zika-Related Tweeting Dynamics

In this section, we present the role of TT, TR, TRRT, and TM influential user groups, as defined previously.

Comparison Between Each Group of Influentials and Zika-Related Tweeting Dynamics

Tweeting dynamics in the TRRT, TT, and TM groups and retweeting dynamics in the TR group were extracted and constructed for the top 100 users in each group. Quarterly association between these groups' tweeting dynamics and overall Zika-related tweeting dynamics is shown in Figures 6-9. Each figure has 3 panels. The upper panel shows the overall tweeting dynamics, the middle panel demonstrates the tweeting dynamics of the particular influential group, and the bottom panel shows the CCF of the 2 signals. Group-level tweeting dynamics in TT, TM, and TRRT groups were highly correlated with and approximated the shape of the overall tweeting dynamics (Figures 6-8). However, the retweeting dynamics of the TR group were not closely associated with the overall Zika-related tweeting dynamics (Figure 9). In the TR group, there were peaks in their retweeting signal on days 170, 173, 265, and 303; however, no noticeable corresponding peaks were identified around these days in the main Zika-related tweeting signal. We conjectured that the TR group, in general, would be more active following certain undetected events, which did not necessarily coincide with the overall Zika-related tweeting dynamics.

Figure 6. Quarterly correlation between the main Zika-related tweeting signals and users' tweeting signals in the TT group. TT: top tweeter.

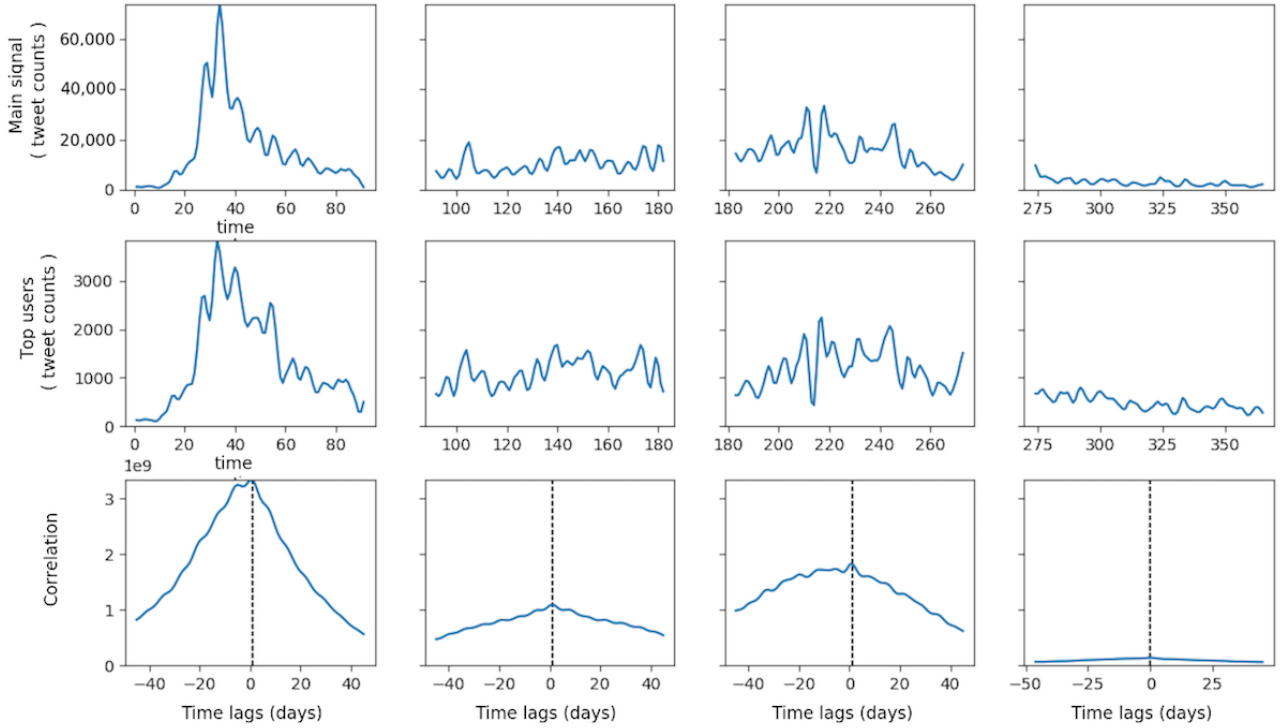


Figure 7. Quarterly correlation between the main signal and users in the TR group. TR: top retweeter.

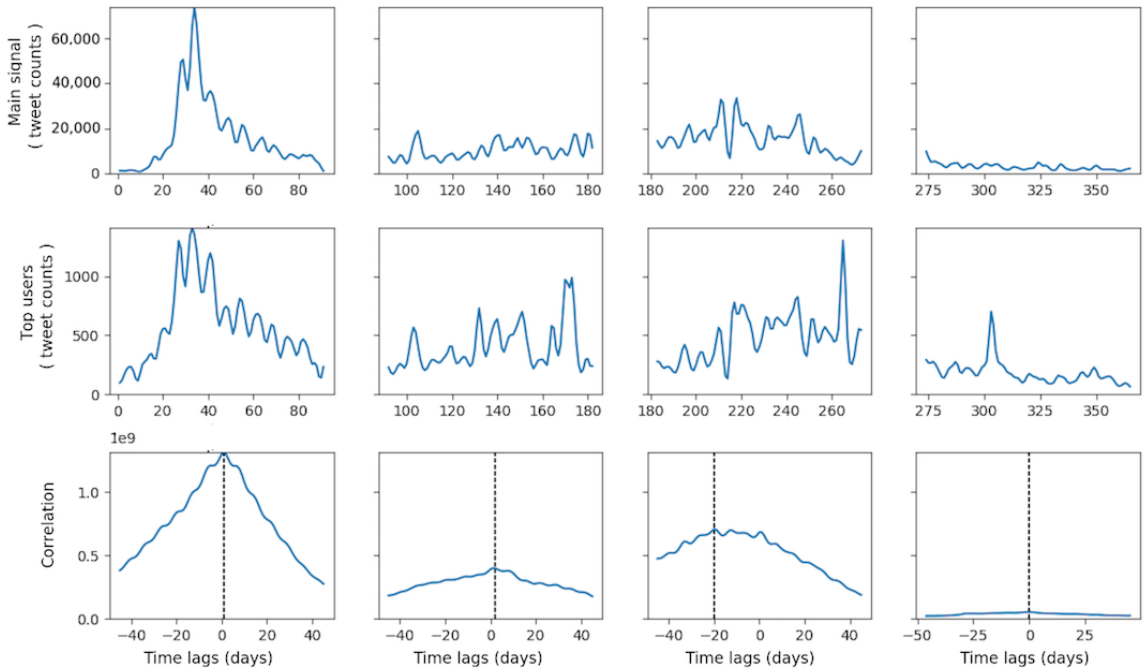


Figure 8. Quarterly correlation between the main signal and users in the TRRT group. TRRT: top received retweets.

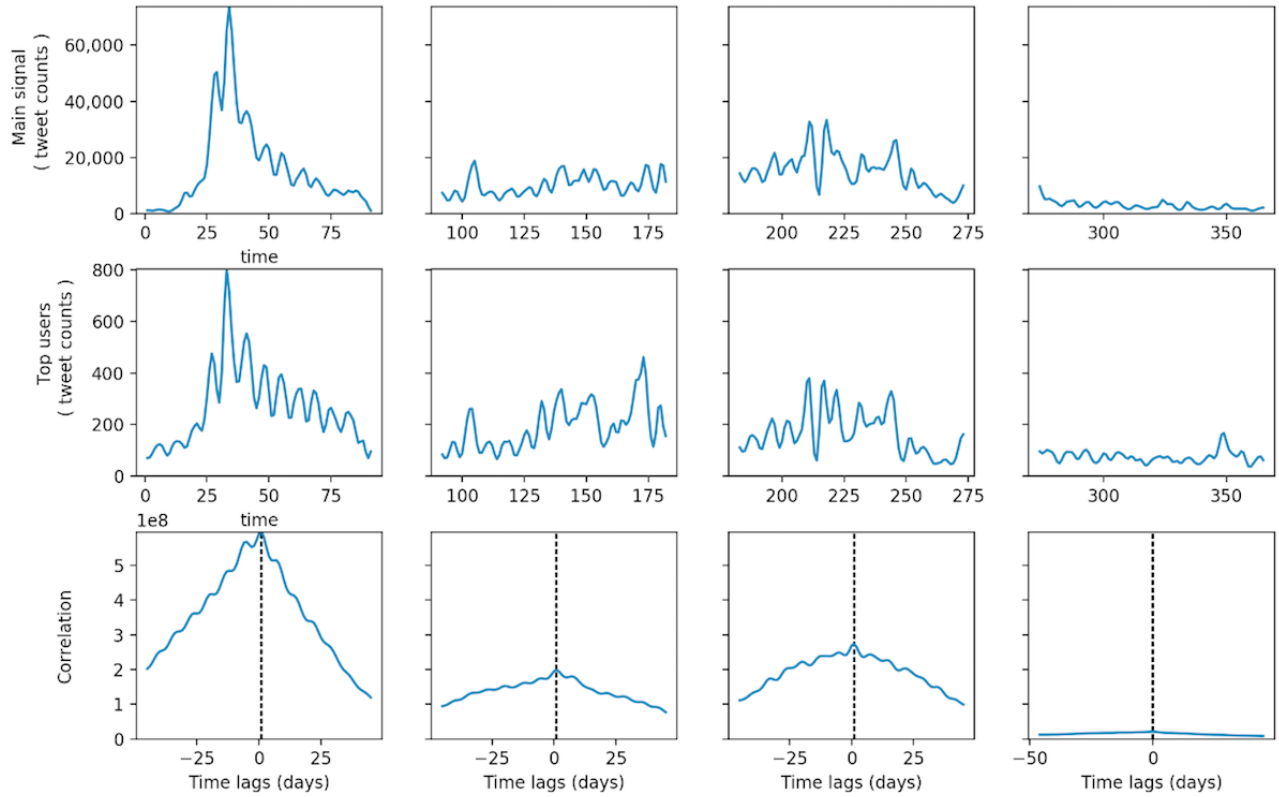
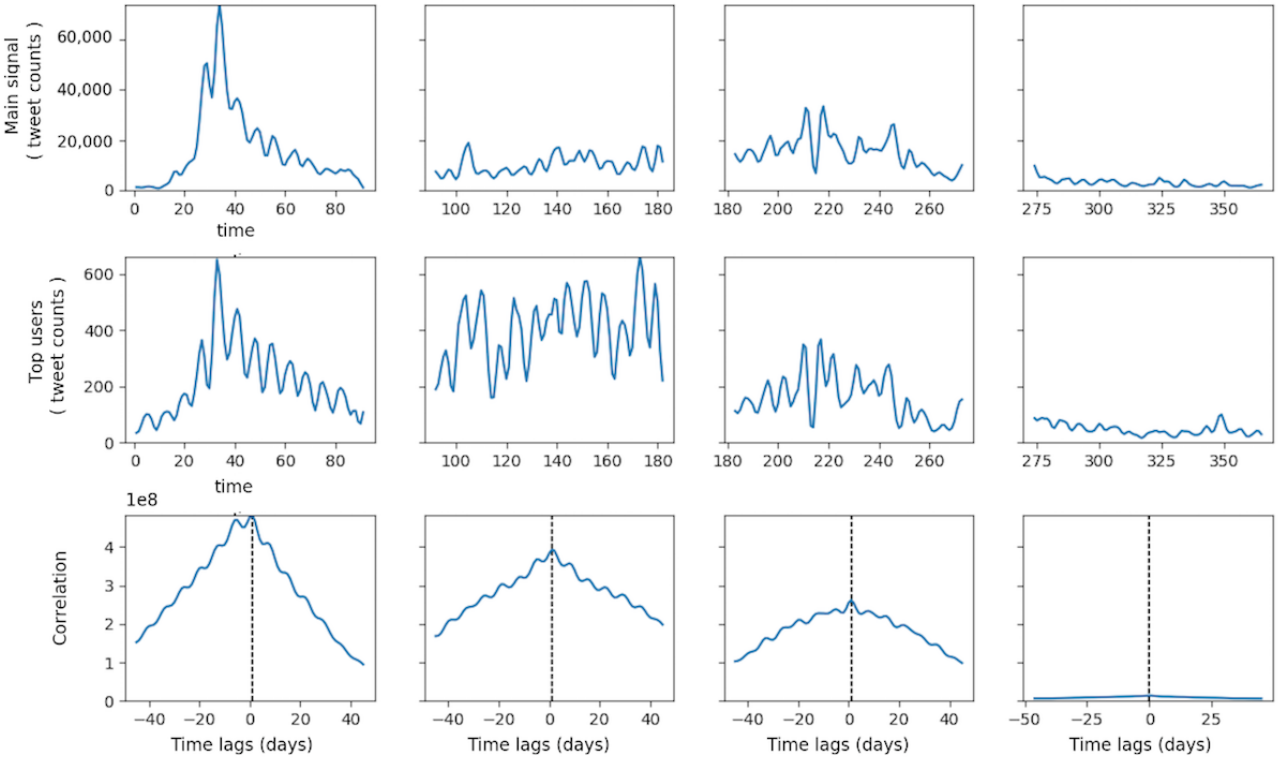


Figure 9. Quarterly correlation between the main signal and users in the TM group. TM: top mentioned.

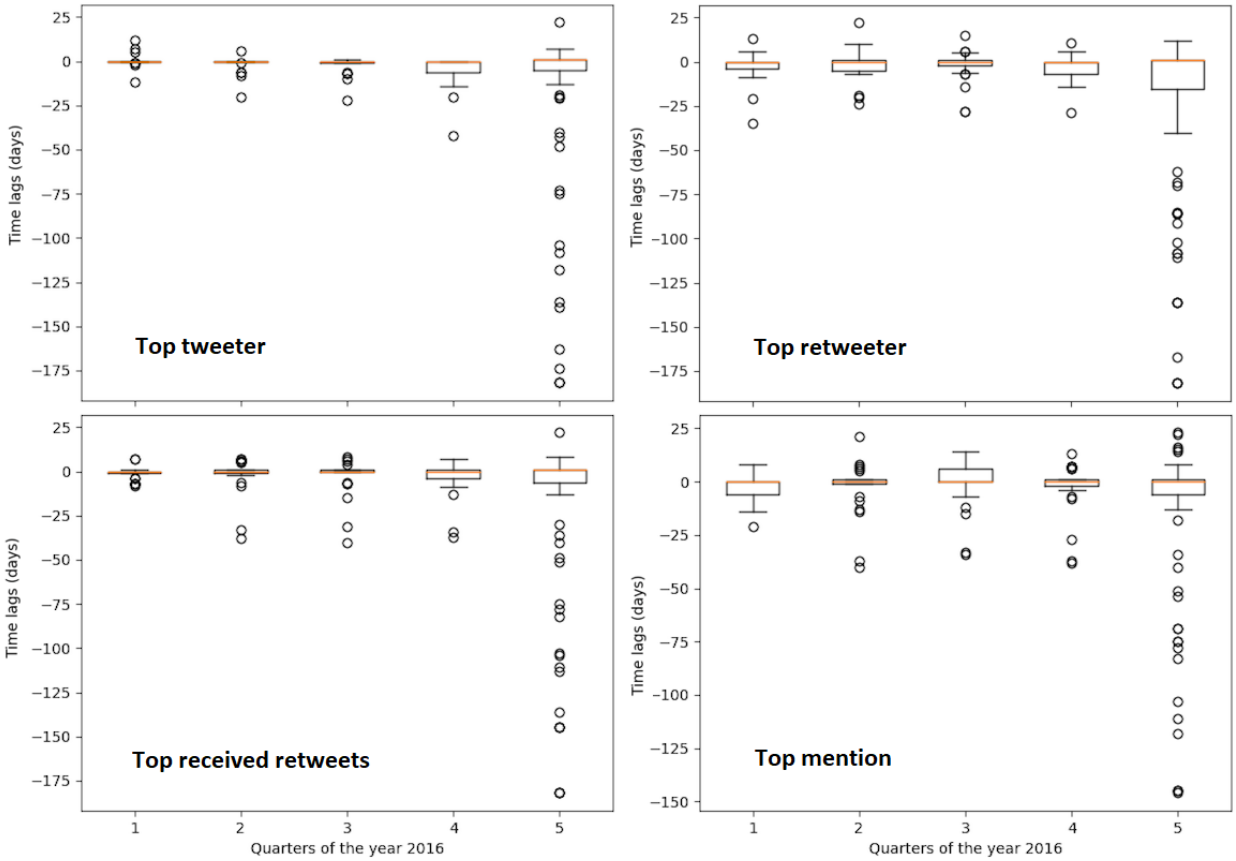


More importantly, for TT, TRRT, and TM groups, the maximum CCF occurred at +1 day lag in the first three quarters of 2016 (Figures 6, 8, and 9), indicating that these groups' tweeting activities were 1 day ahead of the overall discussion on Twitter. For example, the peaks in the overall Zika-related tweeting signal lagging behind the peaks in the TM group by approximately 1 to 2 days. Therefore, these influential groups' tweeting activities were not only highly associated with the overall tweeting dynamics but these influentials were also the potential driving forces of the overall Zika discussions on Twitter. As a result, by observing a few hundred influentials' tweeting activities, we could accurately predict the upcoming

rise and fall in the overall tweeting dynamics. Nevertheless, this lag diminished to zero in the fourth quarter for all 3 influential groups, as the Zika epidemic and PHEIC ended in the fourth quarter of 2016.

In addition, we examined the contributions of individual users in each of these influential groups, TT, TRRT, and TM. We further calculated the CCF between a user's tweeting time series and the overall tweeting dynamics in each quarter as well as in 2016 (Figure 10). Time lags of the majority of influential users were very close to zero, which implies that these users could not be driving the overall discussion of Zika on Twitter, but rather participating in the discussion. However, there were a few users whose time lags were substantially positive, indicating their potential role in driving the overall Zika-related tweeting dynamics. Furthermore, the quarterly results revealed the tweeting dynamics of influentials at a finer temporal resolution than yearly results (Figure 10). Note that in each panel, the first 4 boxplots (labels 1-4 on the x-axis) were quarterly, and the last one (label 5) was for the entire year of 2016. In general, most influentials did not engage in Zika discussions on Twitter constantly and continuously across the entire year of 2016. They might be active and highly influential during certain periods when they were interested in Zika and, hence, participated in discussions on Twitter. As a result, aggregating all individual influential users' tweeting activities in the entire year would undermine each user's temporal dynamics of tweeting and, consequently, its time-specific influence on the overall discussion dynamics on social media.

Figure 10. Comparison of tweeting activity of an individual user in 4 influential groups with the main signal.



Overlap Between Influential Groups

In addition to exploring each potential influential group's role in driving the Zika-related tweeting dynamics, we also investigated if different influential groups had overlaps. Table 2 shows the year-long intersections between any 2 groups of influentials, whereas Table 3 shows the overlap for selected groups on a quarterly basis. The TM group had no member who also belonged to the TM or TRRT groups, and the TT group had no intersection with the TRRT group. These results suggested that being highly active did not necessarily guarantee to receive a lot of mentions and/or RTs from other users on social media. Therefore, active and passive influentials discussing Zika on social media were distinctive users.

On a quarterly basis, there were quite a few influentials who were being mentioned and retweeted extensively at the same time (Table 3, column 2). On the other hand, there were only a few users in the TR group who were also highly mentioned and retweeted (Table 3, columns 1 and 3). These user accounts belonged to health organizations, such as @cdchep and @CDCChronic, and also a few well-known but independent individuals, such as @Laurie_Garrett and @MackayIM. This reinforced our previous finding that active and passive influentials were not the same users. For public health agencies such as the CDC, although they might actively disseminate information to the public on social media, their efforts were not well recognized by the general public users. Therefore, health agencies need to craft more effective strategies to engage public participation and discussion of an emerging health issue on social media.

Table 2. Overlap between the 4 groups of influentials in the entire 2016 period.

Influentials	TM[a], n	TRRT[b], n	TT[c], n	TR[d], n
TM	N/A[e]	47	11	0
TRRT	47	N/A	0	0
TT	11	0	N/A	6
TR	0	0	6	N/A

[a]TM: top mentioned.

[b]TRRT: top received retweets.

[c]TT: top tweeter.

[d]TR: top retweeter.

[e]N/A: not applicable.

Table 3. Quarterly overlap between selected influential groups.

Quarter in 2016	TM[a]-TR[b]	TM-TRRT[c]	TR-TRRT
1	4	49	3
2	4	43	5
3	3	44	2
4	6	45	8

[a]TM: top mentioned.

[b]TR: top retweeter.

[c]TRRT: top received retweets.

Discussion

Principal Findings and Future Work

Communicating with the general public is essential in risk communication during public health emergencies [37]. Hosting a large and diverse population, social media platforms such as Twitter are valuable resources for public health professionals to understand and analyze public opinions on emerging health issues [23,38-41]. During the 2016 Zika epidemic, Twitter was demonstrated to be an ideal place to explore public concerns and interests about the disease through time and across different locations [23,25,27,42-44]. In addition as a means of understanding public opinions, social media platforms are utilized by health professionals to communicate with the public and disseminate accurate and timely information regarding an ongoing health emergency [45]. For example, our previous study evaluated the role of CDC in disseminating Zika-related information on Twitter during the Zika outbreak. We revealed that the CDC played a critical role in tweeting Zika-related information during the first quarter of 2016 when the actual disease counts were still relatively low. However, the CDC's Zika-related tweets quickly and drastically decreased after the first quarter of 2016, when the Zika case counts increased [27]. One important yet underexplored aspect of web-based discussions of health emergencies is to identify potential driving forces that can lead and change the dynamics of discussions on social media. Identifying such influential factors/contributors is critical for devising effective strategies in health crisis management and risk communication. Studies have shown that monitoring discussions on social media or search queries through infodemiology and infoveillance methods can help estimate or predict disease burden [28,31,46,47]. However, it is unclear if and how the actual situation of a health issue influences the public's perception and discourse on social media. Moreover, the correlation between real-world events and their potential impact on web-based discussions of health emergencies is not well investigated and understood. In addition to investigating the impact of *what happened*, it is critical to evaluate the role of web-based influential actors, that is, those who would be web-based opinion leaders who drive web-based discussions.

These 3 research questions correspond to the 3 hypotheses investigated in this study. Our systematic and comprehensive analyses have provided a novel and holistic view of different factors impacting discussions about a health emergency on social media. This new perspective will help us better understand the complexity of such discussions.

In the future, there are a number of directions that we could pursue to further improve and expand this work. As an example, the last hypothesis that investigates the role of web-based influentials is not mutually exclusive from the first 2 hypotheses. For instance, our preliminary study has shown that during and immediately after the WHO-PHEIC announcement on February 1, 2016, many news agencies' Twitter accounts helped disseminate this announcement on Twitter. Therefore, both the critical real-world event (WHO-PHEIC announcement) and web-based influentials (news agencies' accounts) simultaneously drove Zika-related tweeting dynamics. In the future, we plan to further explore changes in the dynamics of discussions by constituent contributors.

In this study, we demonstrated a high association and temporal precedence between the tweeting activity of influentials and overall tweeting dynamics. The web-based tweeting signals of influentials preceded the overall tweeting signal regarding Zika, which were strong indicators of potential causality. Our results suggest that the tweeting activities of the TRRT, TT, and TM groups are good representatives of the overall tweeting dynamics. Therefore, their tweeting dynamics can be used to accurately approximate overall discussion dynamics on social media and to further predict the upcoming changes in discussion dynamics effectively.

To investigate discussion dynamics on Twitter, a highly sophisticated and complicated social media platform with millions of tweets, we utilized an array of different computational methods, including a time series analysis, signal processing, a content analysis, and information theory computations. In particular, we developed an analytical pipeline, EventPeriscope, to integrate and consolidate these different computations. The EventPeriscope pipeline is the practical outcome and contribution of this study. Compared with other similar analytical frameworks, EventPeriscope has the advantage of detecting both planned and unplanned events related to a specific discussion topic. This analytical pipeline can be readily transferred and applied to investigate other emerging or nonemerging issues on social media, such as the general discussion of health issues, identifying potential driving forces of the discussion, and evaluating their influence.

It should be noted that the 3 major drivers on tweeting dynamics mentioned in this study are not an exhaustive list of possible drivers. Further potential drivers, such as individual users or organization users and verified or unverified user status, will also be investigated in the future. In addition, we can also use EventPeriscope to detect other concurrent issues that might also influence Zika-related tweeting dynamics, such as the 2016 US presidential election. In addition, Zika case counts outside the United States could also be a potential driver, especially web-based discussions in Spanish and Portuguese.

Conclusions

This study analyzed Zika-related tweeting dynamics in 2016 when Zika became a global concern. We revealed the potential drivers of Zika discussions on social media by testing 3 hypotheses. First, we demonstrated that Zika-related tweeting dynamics, that is, the time series of the daily number of Zika-related tweets, were not substantially associated with the underlying Zika epidemic (the time series of downscaled daily case counts) in the United States in any of the four quarters in 2016 as well as in the entire 2016 period. We then showed that peaks of Zika-related tweeting dynamics were significantly influenced by and associated with critical real-world events, both planned, such as the Rio Olympics, and unplanned, such as the WHO-PHEIC announcement. We further evaluated the role of potential web-based influentials and demonstrated that the TT, TM, and top users whose tweets were retweeted many times (TRRT) groups were potential drivers of the overall discussion of Zika on Twitter. Through these careful analyses of tweeting dynamics, our study revealed the potential contributors and drivers of a discussion on an emerging health topic. Insights gained from this study could be applied to other emerging health topics in the future. More importantly, we demonstrated the feasibility of our comprehensive analytical approach and the EventPeriscope framework to investigate web-based discussion dynamics of health emergencies and to identify the potential driving forces of these discussions.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

CA: content analyzer
CCF: cross-correlation function
CDC: Centers for Disease Control and Prevention
DSI: Data Science Initiative

MI: mutual information
PHEIC: Public Health Emergency of International Concern
PMI: pointwise mutual information
Regex: regular expression
RTs: retweets
TM: top mentioned
TR: top retweeter
TRRT: top received retweets
TT: top tweeter
WHO: World Health Organization

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Original Paper

General Public's Information-Seeking Patterns of Topics Related to Obesity: Google Trends Analysis

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Abstract

Background: Obesity is a major public health challenge, and recent literature sheds light on the concept of "normalization" of obesity.

Objective: We aimed to study the worldwide pattern of web-based information seeking by public on obesity and on its related terms and topics using Google Trends.

Methods: We compared the relative frequency of obesity-related search terms and topics between 2004 and 2019 on Google Trends. The mean relative interest scores for these terms over the 4-year quartiles were compared.

Results: The mean relative interest score of the search term "obesity" consistently decreased with time in all four quartiles (2004-2019), whereas the relative interest scores of the search topics "weight loss" and "abdominal obesity" increased. The topic "weight loss" was popular during the month of January, and its median relative interest score for January was higher than that for other months for the entire study period (P<.001). The relative interest score for the search term "obese" decreased over time, whereas those scores for the terms "body positivity" and "self-love" increased after 2013.

Conclusions: Despite a worldwide increase in the prevalence of obesity, its popularity as an internet search term diminished over time. The reason for peaks in months should be explored and applied to the awareness campaigns for better effectiveness. These patterns suggest normalization of obesity in society and a rise of public curiosity about image-related obesity rather than its medical implications and harm.

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KEYWORDS

obesity; normalization; public awareness; infodemiology; infoveillance

Introduction

The prevalence of obesity worldwide has consistently increased in the past decades, with a third of the world population now falling under the category of overweight or obese [1,2]. Importantly, obesity increases the risk of several diseases and health conditions, including hypertension, type 2 diabetes, and cardiovascular disease [3]. Worldwide, organizations are using a multifaceted approach to increase population awareness and foster an environment supporting healthy lifestyle by involving stakeholders such as policy makers, community leaders, health care professionals, and school officials.

An important step in addressing the obesity epidemic is acknowledging it as a problem. However, health surveys among the population with obesity and overweight have shown that a significant number of individuals perceived their weight to be "normal" [4]. Underestimation of excessive body weight, or the "normalization" of obesity, is a concern, as it can undermine a serious public health challenge. Public perception of weight and obesity may be influenced by an increase in their prevalence,

and therefore, being overweight and obese may become the new normal. Furthermore, individuals with obesity, especially women are affected by its social implications, including discrimination and weight stigma in various walks of life [5-7]. This stigma extends to the health care settings and has been observed among physicians, nurses, medical students, and dietitians [6,8]. Social movements such as "body positivity" and "self-love" encourage inclusive and positive conceptualization of body image [7,9] with the principle to foster acceptance and appreciation of all body shapes, sizes, and appearances [10].

Historically, mass media has had an important role in shaping and influencing public health-related beliefs and behaviors [11,12]. The media interest in obesity has been growing, with frequent discussions and articles in the mass media [13,14]. Whether this trend toward increased mass media interest percolates into the public perception of the growing problem of obesity is currently unknown. In the past years, we have seen a change in the media landscape of health information access; it has shifted from television, radio, and print to digital platforms [15].

Health awareness campaigns have shown to increase information-seeking behavior of public pertaining to the agenda of the campaign. The effectiveness of such campaigns can be evaluated using Google Trends, a website by Google that analyzes the popularity of search queries on Google Search across various regions and languages [16]. Public web-based information-seeking trends related to obesity remain unknown. Using Google Trends as a surrogate for public interest, we aimed to study the worldwide patterns of information-seeking by public on obesity and the related terms and topics over the last 16 years.

Methods

All data used in this paper are publicly available and did not require an institutional review board approval. Google Trends search criteria are reported in Textbox 1.

Textbox 1. Google Trends search criteria.

- Access date: April 15, 2020.
- Time period of search: January 1, 2004, to December 31, 2019.
- Search syntax: obesity, obese, weight loss, abdominal obesity, body positivity, self-love.
- Geographic region of search: worldwide.
- Query category: global (web search). All available categories on Google Trends were included.
- Quantification of data: monthly and then divided into 4-year quartiles.

We evaluated search activity of the MeSH (Medical Subject Headings) terms related to obesity (obesity, weight loss, obese, and abdominal obesity) and body image (body positivity and self-love) using Google Trends from January 1, 2004, to December 31, 2019, (n=192 months) worldwide using the method recommended by Nuti et al [17]. To assess the impact of terms related to obesity in our multilingual world, we also explored "search topics," which include Google Trends searches in different languages such as Spanish, Portuguese, Persian, Ukrainian, and Thai [18]. Search terms and topics were chosen from the National Institute of Diabetes and Digestive and Kidney Disease's glossary of terms related to obesity, as these words are commonly used when people talk or write about obesity [19]. Google Trends is a public web facility of Google Inc, which has been aggregating data on the Google search queries since 2004 [20]. It analyzes web searches to determine their quantity over a period of time and assigns a number between 0 and 100, which reflects the quantity of searches done for a particular term or topic relative to the total number of searches done on Google. This number does not represent an absolute search volume, but rather a normalized value reflected on a scale from 0 to 100, where 100 is the point of maximum popularity among the search terms or topics over a specified time frame. Relative monthly scores for all search terms and topics are expressed as relative interest scores, which are surrogates for the relative popularity of a particular search term and topic over that time frame.

Additionally, Google Trends provides information on the popularity of search terms and topics based on the geographical region, time, and search-related queries. Google trends excludes certain data, such as duplicate searches and search terms and topics with low volume. It filters out queries with special characters such as apostrophes [21]. Similar application of infoveillance in the investigation of health campaign effectiveness has been described previously [16,22]. Mean relative interest scores of search terms and topics were extracted from Google Trends and compared.

The mean relative interest scores were compared across the 4-year quartiles (Quartile 1, 2, 3, and 4) from January 1, 2004, to December 31, 2019. Means were then compared using the Kruskal-Wallis test for the 4 subgroups, as each had 16 observations. A P value <.05 was considered significant.

Results

Obesity-Related Search Terms and Topics

Table 1 compares the relative interest scores of the obesity-related search terms and topics.

The mean relative interest score of the search term "obesity" consistently decreased with each quartile (Figure 1A).

Thailand, Iran, and Afghanistan had the highest search volume during our study period (Figure 2A).

Table 1. Relative interest scores of search terms and topics.

Search terms and topics	Quartile 1[a] Mean (SD)	Quartile 2[b] Mean (SD)	Quartile 3[c] Mean (SD)	Quartile 4[d] Mean (SD)	*P* value
Obesity	75.9 (SD 12.0)	63.7 (SD 6.9)	63.7 (SD 4.7)	61.7 (SD 44.0)	<.001
Weight loss	55.4 (SD 6.2)	78.5 (SD 10.8)	87.4 (SD 8.5)	79.5 (SD 13.1)	<.001
Obese	77.1 (SD 9.9)	67.9 (SD 8.5)	69.8 (SD 5.5)	62.9 (SD 4.9)	<.001
Abdominal obesity	23.7 (SD 4.3)	57.2 (SD 13.9)	83.4 (SD 10.4)	78.6 (SD 10.1)	<.001
Self-love	9.0 (SD 3.3)	14.3 (SD 2.8)	27.1 (SD 7.7)	79.5 (SD 13.1)	<.001
Body-positivity	17.9 (SD 11.8)	9.2 (SD 4.9)	19.7 (SD 11.6)	77.1 (SD 17.6)	<.001

[a]Quartile 1: January 1, 2004, to December 31, 2007.

[b]Quartile 2: January 1, 2008, to December 31, 2011.

[c]Quartile 3: January 1, 2012, to December 31, 2015.

[d]Quartile 4: January 1, 2016, to December 31, 2019.

Figure 1. Comparison of the relative interest scores of the obesity-related search terms and topics during the study period.

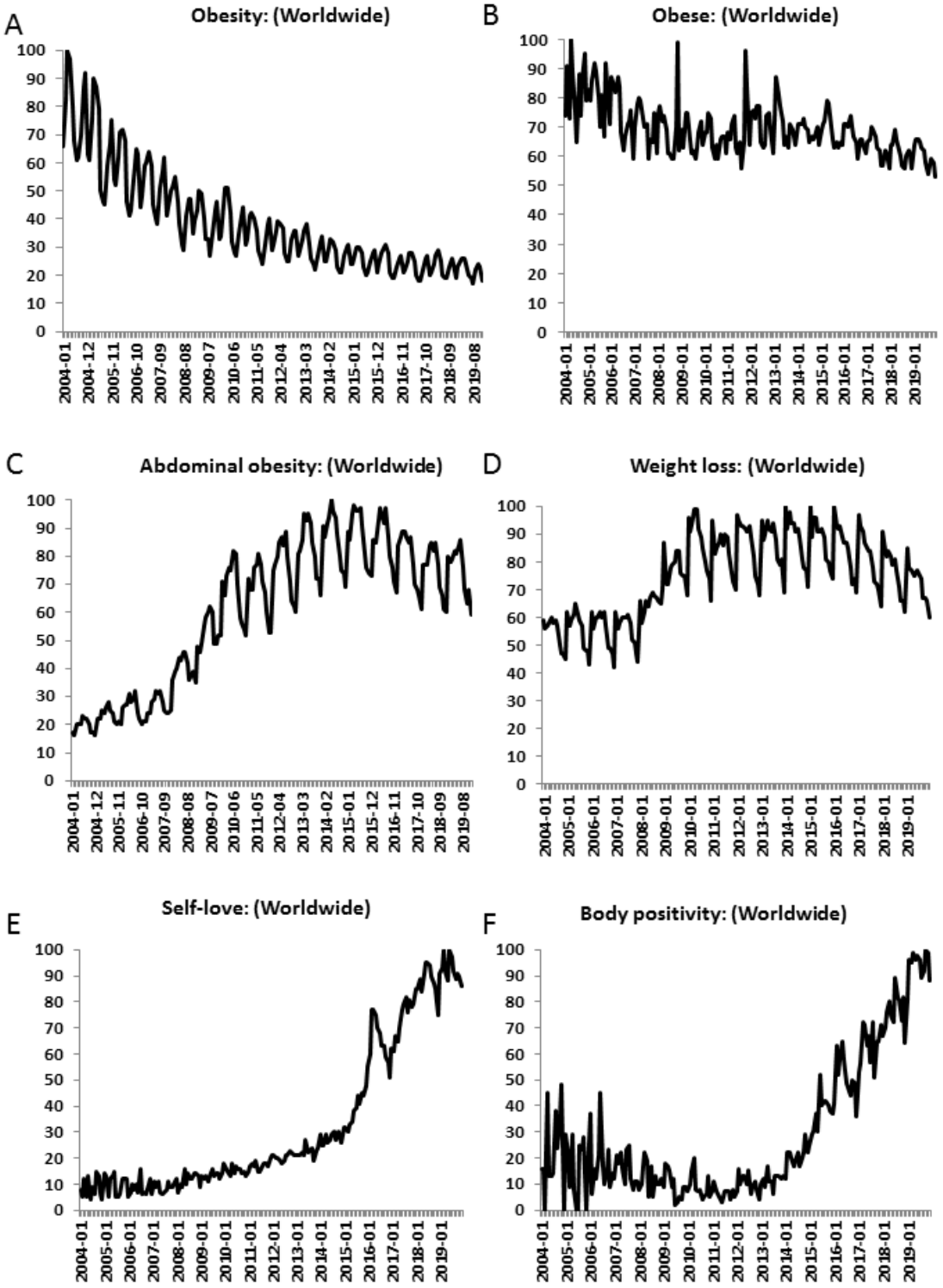
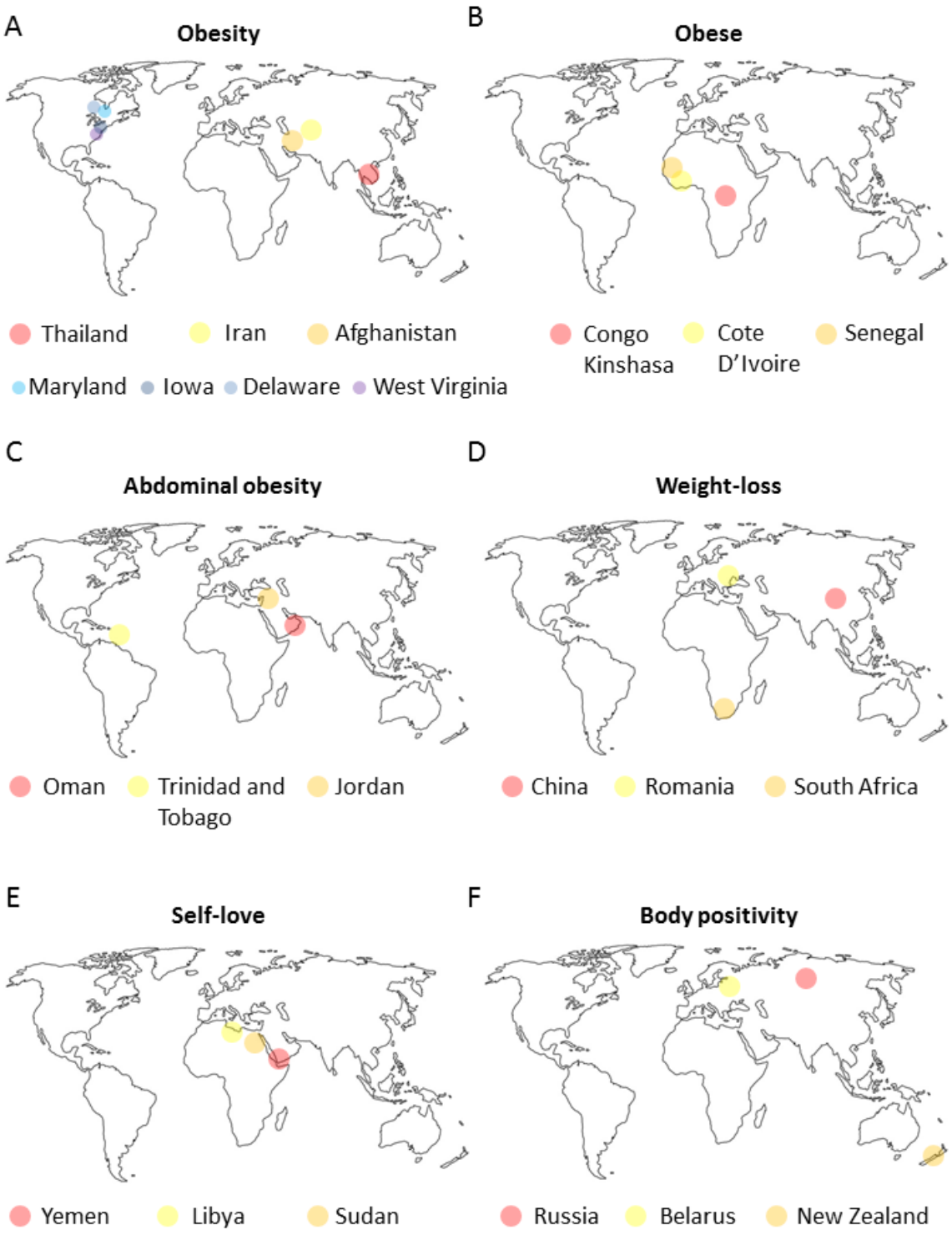


Figure 2. Worldwide distribution of the obesity-related search terms and topics and the top 3 countries with the highest search volume during the study period.



In the United States (28th country in ranking), highest searches were performed in West Virginia, Maryland, Iowa, and Delaware. The relative interest score for the search term "obese" decreased over time (Figure 1B) with most volume of searches in Congo Kinshasa, Côte D'Ivoire and Senegal (Figure 2B). Contrarily, the relative interest score of "abdominal obesity" increased over time (Figure 1C) with greatest popularity in Oman, Trinidad and Tobago, and Jordan (Figure 2C). The relative interest score of the search topic "weight-loss" consistently increased within the search period with fluctuating popularity. The term appeared to be particularly popular during the month of January. Its median relative interest score for January (n=16) was significantly higher than that for the other months (n=176) during the entire study period (Figure 1D). China, Romania, and South Africa had the most search volumes for the search term "weight loss" (Figure 2D). This study evaluated the queries associated with the obesity-related search topics and terms. Textbox 2 reports the top five queries. There does not seem to be any overlap between the search topics based

on the queries, and the reported queries highlight the context behind the search of a particular topic.

Textbox 2. Top 5 queries associated with the obesity-related search topics.

- Obesity: obesity,  (fat in Thai), obese, obesidad (obesity in Spanish),  (obese in Persian).
- Obese: obese people, fat, obesity, obese weight, morbidly obese.
- Weight loss: weight loss, lose weight, adelgazar (slim down in Spanish), how to lose weight, emagrecer (lose weight in Portugese).
- Abdominal obesity: fat belly, lose belly fat, how lose belly fat, how to lose belly fat, love handles.
- Self-love: amor (love in Spanish), amor proprio (love self in Spanish, frases amor (phrases love in Spanish), frases (phrases in Spanish), frases amor proprio (phrases self-love in Spanish).
- Body positivity: body, positive body, body positivity,  (body positive in Ukrainian), the body positive.

Body Positivity–Related Topics

The topics of "Self-love" and "body positivity" have had a consistently increasing interest during the study period (Figure 1E and F). After quartile 3 (2013), there was a steep rise in their relative interest scores. "Body positivity" was most popular in Russia, Belarus, and New Zealand (Figure 2E), whereas "self-love" was most popular in Yemen, Libya, and Sudan (Figure 2F).

Discussion

As suggested by relative interest scores of the search topics obesity and obese, information-seeking on terms and topics related to obesity on the internet may be declining despite an increase in the prevalence of obesity worldwide. This may indicate rising normalization of obesity in the society. However, this downward trend in searches is limited to obesity as a disease entity, with a contrary increase in search trends and topics related to perception of body image related to obesity, weight loss, and positive acceptance of body image.

Misperception of one's own weight as normal among the population with overweight and obesity has been described before and termed as normalization of obesity [4]. As one of the major public health challenges worldwide, obesity has significant ramifications on population health with an economic burden on nations, families, and individuals. It poses an additional risk for other diseases and has been well recognized by health professionals as well as public policy makers. Obesity leads to substantial economic impact on medical, productivity, transportation and human capital accumulation cost with reported total annual income loss in excess of US $251 billion in the United States alone [23]. With growing normalization, it is challenging for the public to realize this epidemic and to encourage healthy environment and discussion in addressing obesity. The public needs to be aware of this problem. Medical settings such as health care provider's office are an ideal place for discussing medical implications of obesity. When done with simple and sensitive language and techniques, these discussions can have positive outcomes and are associated with significant weight loss [24,25]. This approach increases the public curiosity and understanding of medical implications of obesity. The rate of counseling on obesity seems to be declining in the primary care setting [26] especially for patients with obesity and weight-related comorbidities [27]. Primary care providers often have to address several problems within a limited period of time, and weight loss becomes a lower priority [28,29]. Health care professionals are prone to normalizing obesity similar to the general public and may hold a critical negative view of patients with obesity, which leads to fewer interactions with those patients regarding weight management. Further studies are required to explore whether more interactions between medical professionals, patients, and the community about obesity can increase the public interest and internet search activity on obesity, leading to healthy lifestyle and obesity management. Additionally, it is unknown whether normalization of obesity has also affected care providers wherein patients who are overweight and obese might not be counseled because they are considered to be the new normal.

Frequency of internet searches related to weight loss showed an upward trend with peaks in the month of January. This may be due to the end of the holiday season and New Year resolutions. The specific reasons for this increased interest in certain months should be explored and applied to awareness campaigns for better effectiveness. Interestingly, increased peaks in popularity of weight loss also coincide with the search topic of abdominal obesity. It is encouraging that weight loss had the highest volume of search compared to other topics evaluated in this study. A survey of 1000 US adults in November 2017 determined that 45% of Americans share a common New Year's resolution of weight loss and getting in shape [30]. However, tracking the sustainability of New Year's resolutions over a 2-year period showed that 77% maintained their pledges for 1 week and only 19% for 2 years [31]. Furthermore, public health strategies to tackle weight loss and information sharing on statistics related to obesity seem to correlate with certain peaks in the relative interest scores of weight loss and abdominal obesity [32,33].

Obesity has a well-known psychosocial impact. This impact stems from weight-based discrimination and frequently leads to loss of self-esteem, which may be counterproductive to obesity alleviation. In the 1960s, this led to the body positive movement, with a goal to encourage self-acceptance of one's own body with an emphasis on self-worth as an individual, rather than on physical appearance [34]. Reassuringly, we found increased search interest in topics involving body positivity and self-love, with a steep rise after year 2013. This may be a result of social media influencers with an emphasis on promotion of

body positivity through various outlets [35]. However, social media can be a double-edged sword. It can have a positive impact on body image when consumers imitate role models and accept the help of support groups. However, the same concept can be used for maladaptive body comparison as well [36]. Counseling on obesity and body positivity is a sensitive topic. There is a fine line that differentiates counseling to improve health outcomes in individuals with overweight and obesity from offending them and leading to a worse outcome. Whether intervention from trained weight counselors toward the public would increase public interest in obesity pertaining to medical benefits is currently unknown.

Limitations

This study is subject to several limitations as with all search trend studies. Currently, Google Trends is the only search engine that offers a data analytics tool, yet Google is the most popular search engine at present. Second, the average user of Google is younger with a higher income and therefore may not be representative of all the population, especially as use of Google requires skills, computer, and internet access. Another limitation of the study is that Google does not provide methodological details of calculating relative search volume. However, we followed methods standardized by Nuti et al [17]. Third, it is difficult to know the intention of an individual searching a particular topic. For example, the topic "fat" could be associated with obesity or as an ingredient in food items. To tackle this problem, we explored related queries to the search topics, which clarify the intentions of the query to some extent; for example, whether they are medical or body image-related. Similarly, this delineates an overlap between the search topics, if any. However, even with the abovementioned limitations, our study has multiple strengths and provides information and generates a hypothesis that the public may be normalizing obesity, and their curiosity towards obesity may be shifting toward the body image more than the negative implications of obesity on health.

Conclusions

In summary, this study explored the patterns of obesity-related information seeking by general public, suggesting an increase in the normalization of obesity in the society. Furthermore, these data may indicate a shift of search interest from obesity as a medical condition to that as a more body image-related entity. This may have an impact on public health awareness campaigns and may be of interest to policy makers and governments to better address the problem. There is an increased interest in body positivity, which may suggest an increase in positive encouragement in identifying self-worth not based on body weight. It is difficult to delineate whether this stems from increased awareness or negative psychosocial impact leading to curiosity into body positivity. Similarly, it would be helpful for obesity prevention programs to consider these concepts. While more empirical studies are required to characterize these phenomena, the use of Google Trends certainly provides valuable data to assess the public awareness and possibly, health-related campaigns, which are vital to the success of managing obesity at the global level.

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Conflicts of Interest

LOL receives grant funding from Novo Nordisk and is an advisor to Weijian Technologies and AstraZeneca.

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Abbreviations

MeSH: Medical Subject Headings

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Original Paper

Willingness of Adults in the United States to Receive HIV Testing in Dental Care Settings: Cross-Sectional Web-Based Study

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Abstract

Background: The Centers for Disease Control and Prevention estimates that 1.1 million people in the United States are living with HIV and 1 in 8 are estimated to be unaware of their serostatus. Little is known about whether individuals would consider being tested for HIV in nontraditional health care settings such as a dentist's office. Studies in selected US cities have indicated high acceptability of receiving an HIV test among people attending dental clinics. However, we are not aware of studies that have assessed willingness to receive HIV testing in dental care settings at a national level.

Objective: Using a web-based sample of adult residents of the United States, we sought to assess the self-reported willingness to receive any type of HIV testing (ie, oral fluid rapid testing, finger-stick blood rapid testing, or venipuncture blood testing) in a dental care setting and evaluate independent associations of willingness with the extent to which dental care providers were perceived as knowledgeable about HIV and how comfortable participants felt discussing HIV with their dental care providers.

Methods: Participants were recruited using banner advertisements featured on social networking platforms (Facebook and Instagram) from December 2018 to February 2019. Demographic and behavioral data including information on sexual behaviors in the past 6 months, HIV testing history, and dental/health care–seeking history were collected using an anonymous web-based survey. Willingness to receive any type of HIV testing in a dental care setting was assessed on 4-point scale from very willing to very unwilling. Factors independently associated with participants' willingness were identified using a multivariable logistic regression model.

Results: Of the 421 participants in our study aged 18 to 73 years, 271 (64.4%) reported having oral sex, 197 (46.8%) reported having vaginal sex, and 136 (32.3%) reported having anal sex in the past 6 months. Approximately one-third had never been tested for HIV (137/421, 32.5%), and the same proportion had not been tested in the past year (137/421, 32.5%). Most participants had dental insurance coverage (356/421, 84.6%), and more than three-fourths reported being very or somewhat willing (326/421, 77.4%) to receive any type of HIV testing in a dental care setting. Higher levels of willingness were associated with being 18 to 24 years versus ≥35 years (aOR 3.22, 95% CI 1.48-6.98), 25 to 34 years versus ≥35 years (aOR 5.26, 95% CI 2.52-10.98), believing that one's dental care provider is knowledgeable about HIV (aOR 2.04, 95% CI 1.06-3.92), and feeling comfortable discussing HIV with one's dental care provider (aOR 9.84, 95% CI 3.99-24.27).

Conclusions: Our data indicate high acceptability of receiving HIV testing in a dental care setting, especially among those who report having a positive patient-provider relationship. Future research should focus on assessing dental care providers' attitudes, self-efficacy, and beliefs about whether HIV testing fits into the scope of dentistry.

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KEYWORDS

HIV testing; HIV prevention; dental care settings

Introduction

The US Centers for Disease Control and Prevention (CDC) estimates that 1.1 million people in the United States are living with HIV and that 1 in 8 are unaware of their serostatus [1]. Decreasing the number of HIV-positive persons who are unaware of their infection is critical to advancing HIV prevention efforts [2]. The US Preventive Services Task Force recommends that clinicians screen all adolescents and adults aged 15 to 65 years at least once in their lifetime in order to identify those who are HIV positive and repeatedly screen those who are known to be at risk for HIV infection, those who actively engage in risky behaviors, and those who live in or receive medical care in high-prevalence settings [3]. Although HIV testing levels in the general US population have increased over time (from 38% in 2005 [4] to 46% in 2017 [5]), more than half of all nonelderly Americans report never having been tested for HIV [5].

Rapid HIV testing using an oral fluid specimen (20-minute test) was approved by the US Food and Drug Administration (FDA) for professional use in 1996 [6] and for home use in 2012 [7]. Similarly, rapid HIV testing using a finger-stick blood specimen (1-minute test) was approved for professional use by the FDA in 2015 [8]. Given the ease of oral fluid and finger-stick blood specimen collection and the short wait time for test results, it is worth exploring nontraditional settings in which such tests could be offered. Currently, rapid HIV testing is performed in community health centers [9], domestic violence shelters [10], emergency departments [11], large urban jails [12], pharmacies [13], and primary care offices [14]. Dental clinics represent another potential setting that offers the advantage of being able to reach a large proportion of the general US population. According to the CDC, in 2015, 64% of adults aged 18 to 64 years and 63% of adults aged 65 years and over had visited a dentist in the preceding year [15]. Additionally, dental care providers regularly screen their patients for manifestations of systemic diseases [16], and their training includes a thorough foundation in communicable diseases, which could establish them as potential providers of rapid HIV testing [17,18].

Previous research studies from Kansas City [19], Los Angeles [20], and New York City [21] have indicated a high acceptance of potentially receiving an HIV test among people attending dental clinics. Specifically, 73% of 150 respondents in the Kansas City study reported they would be willing to receive free HIV testing during their dental visit [19], 71% of 383 respondents in the Los Angeles study indicated being willing to receive HIV testing at their dentist's office [20], and 72% of 426 respondents in the New York City study reported being willing to get tested for HIV in a dental care setting (85% preferred an oral fluid rapid test, 5% preferred a finger-stick blood rapid test, 9% preferred a venipuncture blood test) [21]. Each of these studies included convenience samples drawn from local clinics, and their results cannot be generalized to other cities in the United States. We are not aware of any studies that have assessed patient willingness to receive HIV testing in dental care settings at a national level.

Using a web-based sample of adult residents of the United States who reported an HIV-negative or unknown serostatus, we sought to assess the willingness to receive any type of HIV testing in dental care settings and describe variations across strata of demographic characteristics and dental care-seeking history. We also sought to evaluate independent associations of willingness to receive HIV testing in dental care settings with the extent to which providers were perceived as knowledgeable about HIV and how comfortable respondents felt discussing HIV with their dental care providers. Understanding these issues can help guide future HIV education programs and prevention efforts, particularly an exploration of the facilitators and barriers to offering HIV testing in nontraditional settings such as dentists' offices.

Methods

Participants were recruited using banner advertisements featured on social networking platforms (Facebook and Instagram) from December 2018 to February 2019. Recruitment was targeted toward user profiles of those aged 18 years or older and residents of the United States and its dependent areas. The advertisements included diverse images of patients and dental care providers in clinical settings, the study title (Project Viva), as well as the following call-to-action text: "Would you be willing to take an HIV test at your dentist's office? Tell us on this short University of Michigan survey!" Individuals who clicked through the banner advertisements were directed to an informed consent page programmed in Qualtrics, a web-based survey platform, and those who consented were screened to determine eligibility. The eligibility criteria included being at least 18 years of age, currently residing in the United States or its dependent areas, and reporting HIV-negative or unknown serostatus. Eligible individuals were directed to a voluntary web-based survey, which had an estimated time to completion of 15 minutes. No monetary incentives were provided to the participants for completing our survey. Ethical approval for this study was obtained from the University of Michigan's institutional review board (HUM00153814).

Demographic information collected from participants included their age, race and ethnicity, highest level of education, gender identity, sexual orientation, and relationship status. Those who were partnered were asked about whether they were in a closed relationship (ie, sex with outside partners was not allowed), an open relationship in which sex with outside partners was allowed with certain rules or restrictions, or an open relationship in which sex with outside partners was allowed without any rules or restrictions. State of current residence could be selected from a drop-down list, and this information was used to create regional categories (Northeast, Midwest, South, West). Participants were also asked about their sexual behaviors in the past 6 months (oral sex, vaginal sex, and anal sex), and their HIV testing history. Several questions were used to elicit information on participant's use of and experiences with seeking dental care services. Dental insurance coverage was assessed using the question: "What type of dental insurance do you currently have?" (Response options: private/work-based insurance, school-based insurance, Affordable Care Act, Medicaid/Medicare, Veterans Administration benefits, some

other insurance, I do not have dental insurance.) Frequency of visiting a dental care provider was assessed using the question: "How many times did you see a dental care provider in the past year?" (Response options: 0, 1, ≥2.) Location of seeking dental care services was assessed using the question: "Where do you usually seek dental care services?" (Response options: private practice/clinic, community dental clinic, dental school clinic, mobile dental clinic, some other location, I do not have a source of dental care.) Perception regarding whether one's dental care provider was knowledgeable about HIV was assessed using a 4-point Likert item asking participants the extent to which they agreed or disagreed with the following statement: "The provider where I usually seek dental care services is knowledgeable about HIV." (Response options: strongly agree, somewhat agree, somewhat disagree, strongly disagree.) Similarly, participants' level of comfort around discussing HIV with their dental care provider was assessed using the following 4-point Likert item question: "How comfortable do you feel discussing HIV with your dental care provider?" (Response options: very comfortable, somewhat comfortable, somewhat uncomfortable, very uncomfortable.)

Willingness to receive any type of HIV test in a dental care setting was assessed using the following question: "Did you know there are multiple ways to test for HIV? These include: 1. A traditional HIV test performed on blood, drawn using a syringe; 2. A rapid HIV test performed on blood, collected from a finger prick; 3. A rapid HIV test performed on an oral fluid sample, collected by swabbing your gums. If any of these tests could be offered by a dental care provider, would you be willing to have one in a dental care setting?" (Response options: very willing, somewhat willing, somewhat unwilling, very unwilling.) For analytical purposes, participants' responses to this question were combined to construct a dichotomous variable for our outcome of interest: Willing to receive any type of HIV testing in a dental care setting—yes or no. Participants who responded being very or somewhat willing to receive any type of HIV testing were also asked to indicate their most preferred of the three options.

Statistical analyses were conducted using SAS version 9.4 (SAS Institute Inc). Because of our primary focus on the willingness to receive HIV testing in dental care settings, we restricted our analyses to participants who reported having a source of dental care and answered this question. The demographic and behavioral characteristics of the sample were summarized using descriptive statistics. Factors independently associated with participants' willingness to receive any type of HIV testing in a dental care setting (ie, oral fluid rapid testing, finger-stick blood rapid testing, or venipuncture blood testing) were identified using a multivariable logistic regression model. Estimated logit plots were produced to determine whether age, collected as a continuous measure, should be treated as a continuous or categorical variable. Because age demonstrated a nonlinear relationship with our outcome of interest (willingness to receive any type of HIV testing in a dental care setting), it was treated as a categorical measure. An examination of the condition indices and variance decomposition proportions did not reveal any collinearity problems. Results from the model are presented as adjusted odds ratios (aORs) with their 95% confidence intervals.

Results

Overall, 680,290 advertising impressions (ie, the number of times an advertisement displayed on a user's screen within Facebook or Instagram) resulted in 3849 link clicks (ie, the number of users who clicked on the advertisements) to the survey landing page over an 8-week period. Of these, 548 individuals provided informed consent, 509 of whom were eligible to participate. Our final analytical sample was restricted to 421 of 509 study participants who reported having a source of dental care and provided data on their willingness to receive an HIV test in a dental care setting. Excluded participants were similar in demographic and behavioral characteristics to those whose data were analyzed.

Table 1 summarizes the descriptive characteristics of the 421 participants. The majority were younger than 35 years (mean 33 years, median 29 years), non-Hispanic white, had an associate's or bachelor's degree, and identified as cisgender. Over half (221/421, 52.5%) reported their orientation as either homosexual/gay, bisexual, queer, or questioning/unsure. A total of 255 (60.6%) reported having a primary partner (described to the participants as "Someone you feel committed to above all others. You might call this person your boyfriend/girlfriend, partner, significant other, spouse, or husband/wife"). Of these, 207 (81.2%) reported being in a closed relationship, 36 (14.1%) reported being in an open relationship with certain rules or restrictions, and 11 (4.3%) reported being in an open relationship without any rules or restrictions (1 participant did not respond to this question). Our sample included participants residing all across the United States—108 (25.7%) in the Northeast, 72 (17.1%) in the Midwest, 129 (30.6%) in the South, and 112 (26.6%) in the West.

Regarding sexual activity in the past 6 months, 271 of 421 participants (64.4%) reported engaging in oral sex, 197 (46.8%) reported engaging in vaginal sex, and 136 (32.3%) reported engaging in anal sex. Regarding number of sexual partners, 104 of 421 participants (24.7%) that reported oral sex, 39 (9.3%) that reported vaginal sex, and 49 (11.6%) that reported anal sex did so with ≥2 partners. With respect to participants' HIV testing history, two-thirds (284/421, 67.5%) reported having ever been tested for HIV, 147 (34.9%) of whom had been tested in the past year. Of the 421 participants, 137 (32.5%) had never been tested for HIV.

Table 1. Demographic and behavioral characteristics of study participants, United States, December 2018 to February 2019.

Characteristic	Willing to receive any type of HIV testing in a dental care setting		Total (n=421) n (%)
	Yes (n=326)[a] n (%)	No (n=95)[b] n (%)	
Age in years[c]			
18-24	105 (32.21)	29 (30.53)	134 (31.83)
25-34	132 (40.49)	26 (27.37)	158 (37.53)
≥35	89 (27.30)	40 (42.11)	129 (30.64)
Race/ethnicity			
Hispanic	20 (6.13)	6 (6.32)	26 (6.18)
Non-Hispanic, nonwhite[d]	60 (18.40)	10 (10.53)	70 (16.63)
Non-Hispanic, white	246 (75.46)	79 (83.16)	325 (77.22)
Educational level			
Associate's degree or lower[e]	129 (39.57)	30 (31.58)	159 (37.77)
Bachelor's degree	118 (36.20)	34 (35.79)	152 (36.10)
Master's degree or higher[f]	79 (24.23)	31 (32.63)	110 (26.13)
Gender identity			
Cisgender male	128 (39.26)	40 (42.11)	168 (39.90)
Cisgender female	171 (52.45)	49 (51.58)	220 (52.26)
Other[g]	27 (8.28)	6 (6.32)	33 (7.84)
Sexual orientation			
Heterosexual/straight	152 (46.63)	48 (50.53)	200 (47.51)
Homosexual/gay	80 (24.54)	30 (31.58)	110 (26.13)
Other[h]	94 (28.83)	17 (17.89)	111 (26.37)
Relationship status			
Single	129 (39.57)	37 (38.95)	166 (39.43)
Partnered[i]	197 (60.43)	58 (61.05)	255 (60.57)
Region			
Northeast	83 (25.46)	25 (26.32)	108 (25.65)
Midwest	56 (17.18)	16 (16.84)	72 (17.10)
South	102 (31.29)	27 (28.42)	129 (30.64)
West	85 (26.07)	27 (28.42)	112 (26.60)
Engaged in oral sex in the past 6 months			
Yes, with ≥2 partners	86 (26.38)	18 (18.95)	104 (24.70)
Yes, with 1 partner	132 (40.49)	35 (36.84)	167 (39.67)
No	108 (33.13)	42 (44.21)	150 (35.63)
Engaged in vaginal sex in the past 6 months			
Yes, with ≥2 partners	36 (11.04)	3 (3.16)	39 (9.26)
Yes, with 1 partner	122 (37.42)	36 (37.89)	158 (37.53)
No	168 (51.53)	56 (58.95)	224 (53.21)
Engaged in anal sex in the past 6 months			
Yes, with ≥2 partners	38 (11.66)	11 (11.58)	49 (11.64)
Yes, with 1 partner	67 (20.55)	20 (21.05)	87 (20.67)

Characteristic	Willing to receive any type of HIV testing in a dental care setting		Total (n=421) n (%)
	Yes (n=326)[a] n (%)	No (n=95)[b] n (%)	
No	221 (67.79)	64 (67.37)	285 (67.70)
HIV testing history			
Tested in past year	119 (36.50)	28 (29.47)	147 (34.92)
Tested more than a year ago	101 (30.98)	36 (37.89)	137 (32.54)
Never been tested	106 (32.52)	31 (32.63)	137 (32.54)

[a]Includes 204 who were very willing and 122 who were somewhat willing.

[b]Includes 53 who were somewhat unwilling and 42 who were very unwilling.

[c]Age: mean 33 years, median 29 years, range 18 to 73 years.

[d]Includes 27 non-Hispanic black/African American, 14 Asian, 4 Native American/Alaskan Native, 1 Middle Eastern/Arab American, 20 mixed, and 4 other.

[e]Includes 26 with an Associate's degree, 110 with some college education, 19 with a high school diploma, 3 with some high school education, and 1 who never went to high school.

[f]Includes 84 with a Master's degree and 26 with a doctoral degree.

[g]Includes 12 transgender male, 1 transgender female, 13 genderqueer/nonbinary, 5 gender fluid, and 2 other.

[h]Includes 68 bisexual, 25 queer, 11 questioning/unsure, and 7 other.

[i]Includes 207 who reported being in a closed relationship (ie, sex with outside partners was not allowed), 36 who reported being in an open relationship in which sex with outside partners was allowed with certain rules or restrictions, 11 who reported being in an open relationship in which sex with outside partners was allowed without any rules or restrictions, and 1 who did not respond to this question.

Table 2 summarizes the previous use of and experiences with seeking dental care services among our study participants. Most participants had dental insurance coverage (356/421, 84.6%), saw a dental care provider at least once in the past year (340/421, 80.8%), and usually sought dental care services at a private practice or clinic (388/421, 92.2%). Slightly over a third (162/421, 38.5%) strongly or somewhat agreed that their dental care provider was knowledgeable about HIV, and a smaller proportion (137/421, 32.5%) felt very or somewhat comfortable discussing HIV with their dental care provider.

Acceptability of receiving any kind of HIV testing in a dental care setting was high, with more than three-fourths being very or somewhat willing (326/421, 77.4%). Of these participants, most were between the ages of 18 and 34 years (237/326, 72.7%), cisgender female (171/326, 52.5%), homosexual/gay, bisexual, queer, or questioning/unsure (174/326, 53.4%), partnered (197/326, 60.4%), and had been tested for HIV at least once in their lifetime (220/326, 67.5%). Most of the participants who reported being very or somewhat willing to receive HIV testing in a dental care setting had dental insurance (276/326, 84.7%) and had seen a dental care provider at least once in the past year (261/326, 80.1%). The majority strongly or somewhat disagreed that their dental care provider was knowledgeable about HIV (184/326, 56.4%) and felt very or somewhat uncomfortable discussing HIV with their dental care provider (195/326, 59.8%). Regarding the type of HIV test that would be most preferred, 79.9% (259/326) reported they would prefer receiving an oral fluid rapid test, 9.9% (32/326) reported they would prefer receiving a finger-stick blood rapid test, and 10.2% (33/326) reported they would prefer receiving a venipuncture blood test (2 participants did not respond to this question).

Results from our multivariable logistic regression model used to identify factors independently associated with willingness to receive any type of HIV testing in a dental care setting are summarized in Table 3. Participants aged 18 to 24 years (aOR 3.22, 95% CI 1.48-6.98) and 25 to 34 years (aOR 5.26, 95% CI 2.52-10.98) were significantly more willing compared with those who were ≥35 years. Believing that one's dental care provider was knowledgeable about HIV (aOR 2.04, 95% CI 1.06-3.92) and feeling comfortable discussing HIV with one's dental care provider (aOR 9.84, 95% CI 3.99-24.27) were also positively associated with willingness to receive any type of HIV testing in a dental care setting. Given that 259 of 326 (79.9%) willing participants reported they would prefer receiving an oral fluid rapid test, we performed a sensitivity analysis using a subsample of 354 participants to identify factors independently associated with willingness to receive oral fluid rapid HIV testing in a dental care setting. The results of this multivariable logistic regression model were similar. Participants aged 18 to 24 years (aOR 3.48, 95% CI 1.54-7.85) and 25 to 34 years (aOR 5.57, 95% CI 2.58-12.03) were significantly more willing compared with those who were ≥35 years, as were non-Hispanic nonwhite participants (aOR 2.34, 95% CI 1.03-5.33) compared with non-Hispanic white participants. Feeling comfortable discussing HIV with one's dental care provider (aOR 10.03, 95% CI 3.94-25.50) was also positively associated with willingness to receive oral fluid rapid HIV testing.

Table 2. Use of and experiences with seeking dental care services among study participants, United States, December 2018 to February 2019.

Characteristic	Willing to receive any type of HIV testing in a dental care setting		Total (n=421) n (%)
	Yes (n=326)[a] n (%)	No (n=95)[b] n (%)	
Dental insurance coverage			
Insured[c]	276 (84.66)	80 (84.21)	356 (84.56)
Uninsured	50 (15.34)	15 (15.79)	65 (15.44)
Number of visits to a dental care provider in the past year			
≥2	177 (54.29)	48 (50.53)	225 (53.44)
1	84 (25.77)	31 (32.63)	115 (27.32)
0	65 (19.94)	16 (16.84)	81 (19.24)
Usual location of seeking dental care services			
Private practice/clinic	296 (90.80)	92 (96.84)	388 (92.16)
Other[d]	30 (9.20)	3 (3.16)	33 (7.84)
Level of agreement regarding whether one's dental care provider is knowledgeable about HIV[e]			
Strongly agree	44 (13.58)	2 (2.13)	46 (11.00)
Somewhat agree	96 (29.63)	20 (21.28)	116 (27.75)
Somewhat disagree	128 (39.51)	36 (38.30)	164 (39.24)
Strongly disagree	56 (17.28)	36 (38.30)	92 (22.01)
Level of comfort around discussing HIV with one's dental care provider[f]			
Very comfortable	50 (15.38)	3 (3.16)	53 (12.62)
Somewhat comfortable	80 (24.62)	4 (4.21)	84 (20.00)
Somewhat uncomfortable	115 (35.38)	21 (22.11)	136 (32.38)
Very uncomfortable	80 (24.62)	67 (70.53)	147 (35.00)

[a]Includes 204 who were very willing and 122 who were somewhat willing.

[b]Includes 53 who were somewhat unwilling and 42 who were very unwilling.

[c]Includes 293 with private/work-based insurance, 37 with Medicaid/Medicare, 9 with Affordable Care Act insurance, 8 with school-based insurance, 2 with Veterans Administration benefits, and 7 with some other insurance.

[d]Includes 15 at a community dental clinic, 14 at a dental school clinic, 1 at a mobile dental clinic, and 3 at some other location.

[e]Numbers do not add to total because 3 participants did not respond to this question.

[f]Numbers do not add to total because 1 participant did not respond to this question.

Table 3. Factors associated with willingness to receive any type of HIV testing in a dental care setting, United States, December 2018 to February 2019.

Characteristic	Willing to receive any type of HIV testing in a dental care setting, Adjusted odds ratio (95% CI)	*P* value
Age in years[a]		<.001
18-24	3.22 (1.48-6.98)	
25-34	5.26 (2.52-10.98)	
≥35	referent	
Race/ethnicity		.07
Hispanic	0.51 (0.17-1.56)	
Non-Hispanic, nonwhite[b]	2.16 (0.96-4.83)	
Non-Hispanic, white	referent	
Educational level		.12
Associate's degree or lower[c]	2.14 (1.00-4.52)	
Bachelor's degree	1.32 (0.67-2.61)	
Master's degree or higher[d]	referent	
Gender identity		.44
Cisgender male	0.62 (0.19-2.00)	
Cisgender female	0.95 (0.31-2.97)	
Other[e]	referent	
Sexual orientation		.80
Heterosexual/straight	0.78 (0.36-1.66)	
Homosexual/gay	0.79 (0.31-2.97)	
Other[f]	referent	
Relationship status		.84
Single	1.06 (0.61-1.83)	
Partnered[g]	referent	
Engaged in oral, sex with ≥2 partners in the past 6 months		.29
Yes	1.73 (0.62-4.81)	
No	referent	
Engaged in vaginal sex with ≥2 partners in the past 6 months		.40
Yes	1.94 (0.42-9.05)	
No	referent	
Engaged in anal sex with ≥2 partners in the past 6 months		.83
Yes	0.88 (0.58-2.95)	
No	referent	
HIV testing history		.82
Tested in the past year	1.23 (0.58-2.58)	
Tested more than a year ago	0.98 (0.50-1.92)	
Never been tested	referent	
Dental insurance coverage		.87
Insured[h]	0.95 (0.46-1.97)	
Uninsured	referent	

Characteristic	Willing to receive any type of HIV testing in a dental care setting, Adjusted odds ratio (95% CI)	*P* value
Number of visits to a dental care provider in the past year		.25
≥2	0.96 (0.46-2.00)	
1	0.58 (0.26-1.31)	
0	referent	
Agree that one's dental care provider is knowledgeable about HIV		.03
Yes[i]	2.04 (1.06-3.92)	
No[j]	referent	
Feel comfortable discussing HIV with one's dental care provider		<.001
Yes[k]	9.84 (3.99-24.27)	
No[l]	referent	

[a]Age: mean 33 years, median 29 years, range 18 to 73 years.

[b]Includes 27 non-Hispanic black/African American, 14 Asian, 4 Native American/Alaskan Native, 1 Middle Eastern/Arab American, 20 mixed, and 4 other.

[c]Includes 26 with an Associate's degree, 110 with some college education, 19 with a high school diploma, 3 with some high school education, and 1 who never went to high school.

[d]Includes 84 with a Master's degree and 26 with a doctoral degree.

[e]Includes 12 transgender male, 1 transgender female, 13 genderqueer/nonbinary, 5 gender fluid, and 2 other.

[f]Includes 68 bisexual, 25 queer, 11 questioning/unsure, and 7 other.

[g]Includes 207 who reported being in a closed relationship (ie, sex with outside partners was not allowed), 36 who reported being in an open relationship in which sex with outside partners was allowed with certain rules or restrictions, 11 who reported being in an open relationship in which sex with outside partners was allowed without any rules or restrictions, and 1 who did not respond to this question.

[h]Includes 293 with private/work-based insurance, 37 with Medicaid/Medicare, 9 with Affordable Care Act insurance, 8 with school-based insurance, 2 with Veterans Administration benefits, and 7 with some other insurance.

[i]Includes 46 who strongly agree and 116 who somewhat agree.

[j]Includes 92 who strongly disagree and 164 who somewhat disagree.

[k]Includes 53 who feel very comfortable and 84 who feel somewhat comfortable.

[l]Includes 147 who feel very uncomfortable and 136 who feel somewhat uncomfortable.

Discussion

Principal Findings

Our study found high levels of willingness to receive any type of HIV testing (ie, oral fluid rapid testing, finger-stick blood rapid testing, or venipuncture blood testing) in a dental care setting across selected strata of web-using adults in the United States. Higher levels of willingness were associated with being younger than 35 years, believing that one's dental care provider is knowledgeable about HIV, and feeling comfortable discussing HIV with one's dental care provider. Given that more than three-fourths of our sample expressed a favorable attitude toward this approach, a third of whom had never been tested for HIV, it might be useful to explore whether HIV prevention efforts could be expanded to include dental care settings and optimal ways of potentially initiating the process. Our results also suggest that efforts to improve patients' perceptions of whether their dental care providers are knowledgeable about HIV and their comfort levels around discussing HIV could be an important consideration for successfully implementing HIV testing in this nontraditional setting.

First, we focus our discussion on the demographic characteristics associated with willingness to receive any type of HIV testing in a dental care setting. Participants aged 18 to 24 years were more than 3 times as likely to report being willing and those aged 25 to 34 years were more than 5 times as likely to report being willing compared with those aged ≥35 years. Although not statistically significant at an α level of .05, non-Hispanic, nonwhite participants were twice as likely to report being willing to receive any type of HIV test in a dental care setting compared with non-Hispanic white participants. However, this association was significant in the subsample of 354 participants in which we examined associations with willingness to receive oral fluid rapid HIV testing. These results are important in light of the disproportionate burden of HIV among people under the age of 35 years and black/African American individuals [22]. The latest CDC models estimate that 44% of HIV-positive individuals younger than 25 years and 29% of HIV-positive individuals aged 25 to 34 years are unaware of their serostatus [23]. In addition, 15% of blacks/African Americans currently living with HIV are unaware of their infection [23]. This is despite the fact that in 2017, the majority of CDC-funded HIV tests were received by people in their twenties and thirties, and black/African American individuals got tested at much higher rates than any other racial/ethnic group [24]. Collectively, our results indicate that although not everyone would be willing to

undergo HIV testing at their dental care providers' offices, certain high-risk subgroups may benefit from this strategy.

Turning to focus on how patients' perceptions of dental care provider knowledge about HIV and their comfort levels around discussing HIV with their dental care providers might influence willingness to receive HIV testing, our study found some noteworthy associations. Participants who believed that their dental care provider was knowledgeable about HIV were more than twice as likely to report being willing to receive any type of HIV testing in a dental care setting versus those who did not. Only 38% of our sample believed that their dental care provider was knowledgeable about HIV. Participants who felt comfortable discussing HIV with their dental care provider were approximately 10 times as likely to report being willing to receive any type of HIV testing in a dental care setting versus whose who did not. Only 33% of our sample felt comfortable discussing HIV with their dental care provider. These findings highlight the role that constructs such as perceived knowledge and comfort around discussing sensitive topics could play in influencing health promoting behaviors. Typically, patients do not engage in conversations about their sexual health with dental care providers, which might negatively influence their perceptions about provider knowledge pertaining to HIV prevention and treatment. Individuals are also unlikely to be aware of the nature and extent of HIV-related training received by dental care providers. In a qualitative study involving 19 attendees of a low-cost dental clinic in New York City, participants raised concerns about the negative psychological impact a positive HIV test result could have not just on patients, but also on providers who might not be trained to handle the situation [25]. Approximately a third of these participants stated they believed there was a need for professional counseling and linkage to care for anyone testing HIV positive. Informing patients that dental care providers receive education on HIV (as oral lesions are one of the first overt clinical features of infection) and are skilled in delivering potentially concerning news to facilitate referral for appropriate management (eg, in the case of suspected oropharyngeal cancer) might help improve perceptions. Good interpersonal and communication skills in dentistry are known to foster a positive provider-patient relationship [26,27]. Active communication strategies, assessing the emotional states of patients, and demonstrating empathy might help create rapport and a trusting relationship between dental care providers and their patients.

Our findings pertaining to patients' perceptions of provider knowledge about HIV and their comfort levels around discussing HIV along with the literature on dental care providers' attitudes toward and knowledge of HIV testing highlight several challenges to a potential large-scale implementation of HIV testing in dental care settings. One large national study that assessed 1802 dentists' attitudes toward HIV testing found that only 57% were willing to offer HIV testing and even fewer (40%) believed that HIV testing is part of their role [28]. Only 14 participants in that study reported they were currently offering HIV testing, and less than 1 in 8 were familiar with the CDC guidelines that recommend routine HIV screening of US adults in outpatient health care settings [3]. Nonetheless, recent qualitative research with dentists who are currently offering HIV testing lends support for the notion that dental care providers could take an expanded role in patients' overall well-being. Participants in one study recognized the public health value in identifying undiagnosed persons in a timely manner and linking them to medical care and believed that dentists should start functioning as "total health providers, not just providers of the mouth" [29]. However, they also cited several barriers to the mainstream incorporation of HIV testing into dental care settings. These include the lack of an American Dental Association reimbursement code, perceived time constraints, feeling ill-equipped to deliver positive HIV test results, and concerns about the appropriateness of HIV testing in dentistry, a profession that has historically been characterized as generating more fear and anxiety than other forms of health care.

Strengths and Limitations

Strengths of our study include examining variations in the willingness to receive any type of HIV testing in a dental care setting across demographic strata of a diverse sample of adults recruited from across the United States. The use of social media platforms allowed us to collect data in a time- and resource-efficient manner from a large number of individuals who had not visited a dental care provider in the past year (81/421, 19.2%). Our survey was voluntary and could only be accessed by clicking on our banner advertisements, so it is unlikely that the same individual would have responded more than once. Because the web might offer opportunities to create and maintain networks of relationships from which people could potentially draw health and social support resources [30], it is important to explore how to best harness its full potential to improve people's health, particularly with regard to HIV testing. Notably, over half of our sample identified as either gay, bisexual, queer, or questioning, which is considerably higher than the proportion of these demographic subgroups in the general US population [31]. Given that sexual and gender minorities are disproportionately impacted by the HIV epidemic [32], it is encouraging that individuals responded to our Facebook and Instagram advertisements that suggested the potential for HIV testing in a nontraditional setting.

However, we acknowledge that our study is not without limitations. Our convenience sampling process yielded a group that was predominately non-Hispanic white. The underrepresentation of racial and ethnic minorities in our sample is comparable to previous web-based research studies [33]. The majority of our participants had dental insurance coverage, and more than three-fourths saw a dental care provider at least once in past year. These estimates are higher than the most recent available data from the US National Center for Health Statistics, in which only 50% adults aged 18 to 64 years had dental insurance coverage [34] and only 64% had visited a dental care provider in the past year [35]. Therefore, our results cannot be generalized to adults across the country. Finally, recent data management and security concerns at Facebook might have influenced the extent to which potential or actual participants felt comfortable responding to questions from an online source regarding their personal health information [36].

Conclusions

Despite these limitations, our study adds to the growing body of literature on the willingness to receive HIV testing in dental care settings. Thus far, the data suggest that patients are highly willing to receive HIV testing (particularly an oral fluid rapid test), and in our study, this willingness varied across age, perceived dental care provider knowledge of HIV, and comfort levels discussing HIV with providers. Novel strategies are needed to encourage adults in the United States who might be at risk for acquiring HIV to discuss their risk with providers in all outpatient care settings. Future research should focus on assessing dental care providers' attitudes, self-efficacy, and beliefs about whether HIV testing fits into the scope of dentistry. Trainings and interventions to enhance dental care provider education, including those that incorporate evidence-based practices in HIV prevention such as patient-centered care, harm reduction, and motivational interviewing [37,38], could prove beneficial.

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Conflicts of Interest

None declared.

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Abbreviations

aOR: adjusted odds ratio
CDC: US Centers for Disease Control and Prevention
FDA: US Food and Drug Administration

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Original Paper

Practical and Ethical Concerns in Implementing Enhanced Surveillance Methods to Improve Continuity of HIV Care: Qualitative Expert Stakeholder Study

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Abstract

Background: Retention in HIV care is critical to maintaining viral suppression and preventing further transmission, yet less than 50% of people living with HIV in the United States are engaged in care. All US states have a funding mandate to implement Data-to-Care (D2C) programs, which use surveillance data (eg, laboratory, Medicaid billing) to identify out-of-care HIV-positive persons and relink them to treatment.

Objective: The purpose of this qualitative study was to identify and describe practical and ethical considerations that arise in planning for and implementing D2C.

Methods: Via purposive sampling, we recruited 43 expert stakeholders—including ethicists, privacy experts, researchers, public health personnel, HIV medical providers, legal experts, and community advocates—to participate in audio-recorded semistructured interviews to share their perspectives on D2C. Interview transcripts were analyzed across a priori and inductively derived thematic categories.

Results: Stakeholders reported practical and ethical concerns in seven key domains: permission and consent, government assistance versus overreach, privacy and confidentiality, stigma, HIV exceptionalism, criminalization, and data integrity and sharing.

Conclusions: Participants expressed a great deal of support for D2C, yet also stressed the role of public trust and transparency in addressing the practical and ethical concerns they identified.

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KEYWORDS

HIV surveillance; retention in HIV care; qualitative research; public health ethics

Introduction

Retention in HIV care is critical to maintaining viral suppression and preventing further transmission, yet less than 50% of people living with HIV in the United States are engaged in care, and only 56% are virally suppressed [1]. Common barriers to remaining in care include: feeling depressed or stigmatized; substance use; low literacy; day-to-day responsibilities, including work or school; inadequate housing, insurance, and related financial problems; lack of reliable transportation, particularly for rural populations; and institutional variability in attempts to contact and locate patients who miss appointments [2-6]. Low care engagement results in excess morbidity and mortality among people living with HIV and fuels HIV transmission [7]. Accordingly, identifying out-of-care people living with HIV and linking them to sustainable care is essential to addressing the HIV epidemic.

As interconnecting sources of electronic data expand, state and local health departments are increasingly pursuing novel strategies, including health information technologies, to re-engage out-of-care people living with HIV in care [8,9]. All states in the US have a funding mandate to implement Data-to-Care (D2C) programs, which use surveillance data such as HIV viral load test results, Medicaid claims records, or electronic health records from private or state-run systems to identify out-of-care HIV-positive persons and re-link them to treatment. Because HIV viral load test results are mandatorily reported to public departments of health (DOH), they can be used to assess retention in care.

In the DOH model of D2C, which we focus on here, the first step is for a state or local DOH to use its surveillance data to generate a list of people living with HIV identified as being out of care. Typically, this is defined as someone who has not had a viral load laboratory test reported in the previous 12 months. Because misclassification of care status can occur while using reported viral load test results due to delays and incomplete reporting [10], additional data sources, such as state Medicaid records, electronic health records, or mortality records, may be checked to verify whether a person is not in care. Public health personnel can then contact the patient's last known HIV provider. If the patient is confirmed to be out of care, the health care provider may try to contact the patient, or a specially trained public health outreach worker employed by the DOH may reach out to the patient, either by telephone or in-person. The outreach worker or health care provider will then assess whether the patient is indeed out of care, and if so, why. The goal of this contact is to help patients overcome any barriers so that they can resume care [11].

Preliminary research suggests that D2C activities are effective at re-engaging out-of-care individuals in care [12-14], yet few studies have examined the practical and ethical issues raised by such novel applications of health information technologies [15-17]. For example, physicians have expressed concerns about DOH personnel intruding on patient privacy and the physician-patient relationship [18]. The purpose of this study was to identify and describe practical and ethical considerations that arise in planning for and implementing D2C.

Methods

Overview

This article reports findings from a larger qualitative study of expert stakeholders' perspectives on the potential to use criminal justice system data to enhance surveillance and D2C to understand and improve continuity of care among people living with HIV/AIDS in North Carolina who have spent time in county jails. For this sub-study, we focus on stakeholders' reported views on the current use of D2C in the general population. The Institutional Review Board of the University of North Carolina at Chapel Hill approved the study. Below we describe our methods for recruitment, data collection, and analysis. A full description of the parent study, data collection, and analysis are provided elsewhere [19].

Data Collection

Expert stakeholders were recruited via a purposive sampling strategy in which we aimed to recruit three to five participants in several categories of professional expertise (public health, ethics and privacy, legal experts and criminal justice personnel, and community advocates). Potential participants were identified using a combination of methods, including the research team's professional network, literature review and online searches, and snowball sampling. Because the larger study was focused on applications of enhanced surveillance methods and D2C to North Carolina jails, we oversampled expert stakeholders located in North Carolina. Prospective participants were invited over email to participate in the study.

Semistructured interview guides included questions about the participant's professional background and perspectives on HIV surveillance and D2C in the general population, the potential use of HIV surveillance and D2C in North Carolina jails, privacy, community engagement, data governance, and research practices. In some cases, guides were further tailored to stakeholder categories to collect specific information. For example, DOH personnel were asked additional questions about D2C operations. This article focuses on participants' responses to questions about HIV surveillance and D2C in the general population. Three members of the research team with training in qualitative interviewing conducted all interviews after obtaining informed consent. Except for one participant, interviews were audio-recorded and conducted either in person (n=28) or via videoconference (n=12) or telephone (n=3). Interviews were conducted between April 2018 and August 2019 and lasted between 40 and 107 minutes.

Data Analysis

We used Dedoose software to analyze interview transcripts across twenty-two thematic codes. After coding was completed using a set of procedures reported elsewhere [19], we identified salient themes for further analysis and further examined coding reports from each coding category to identify patterns across the larger dataset. For this article, we focused on stakeholders' responses in seven thematic domains relevant to practical and ethical concerns in implementing D2C: permission and consent, government assistance vs overreach, privacy and confidentiality, HIV stigma, HIV exceptionalism, HIV criminalization, and data

integrity and sharing. For this substudy, we excluded responses from four jail administrators, whose expertise was not relevant to this analysis.

Results

Forty-three expert stakeholders—including ethicists, privacy experts, researchers, public health personnel, HIV medical providers, legal experts, and community advocates—participated in this sub-study (see Table 1). The majority of participants came from North Carolina (26/43); the remainder lived in other states (n=15) or outside the United States (n=2). Participants universally acknowledged the public health needs that DOH-based D2C programs aim to address, and most expressed support for the public health goals such programs fulfill. As one participant put it, “I feel if you have a public health imperative and you can do things about that, and you can treat and basically save people’s lives, that you have a responsibility to try to do that.” In discussing the practical and ethical considerations of implementing such programs, however, participants qualified their support with a range of significant concerns, which clustered into the seven themes identified above. Below, we describe findings from each theme in more detail. We offer illustrative quotations from stakeholders in Table 2.

Table 1. Stakeholder type (N=43).

Stakeholder categories	Count, n
Ethics and privacy	
Ethicists	4
Privacy experts	5
Public health	
Public health researchers	8
Federal, state, and local public health personnel	8
HIV linkage staff	4
Community HIV providers	4
Legal experts	3
Community advocates	
Criminal justice advocates	3
HIV community advocates	4

Table 2. Illustrative quotations.

Concept	Participant comments
Permission and consent	• *Permission should be obtained*: "Absolutely they should have permission…People might not even know that they're in a surveillance system. And given the potentially adverse consequences of the use of that data, there might be cause for concern there for those folks." (1010, privacy expert) • *Obtaining permission would impede public health objectives*: "Probably hard to have a program like this that's opt in. When you do that, either no one does or the only people who do are people getting treatment already." (1035, privacy expert)
Government assistance vs overreach	• *D2C*[a]*is justified assistance*: "So, for HIV we intercede, we stick our noses into people's medical records extensively with the practical goal of making sure people receive treatment, which is not ethically a bad goal, but it can be highly intrusive, although we try to do it sensitively, and is not everybody's personal goal." (1002, public health employee) • *D2C is government overreach*: "There are a lot of things that people do or don't do that affect health or wellbeing or whatever and the state could intervene with them to say do better…Kind of a nanny state." (1035, privacy expert)
Privacy and confidentiality	• *Health worker showing up could breach confidentiality*: "[A] state health official showing up could alert family members, could alert folks in the neighborhood, could alert others in the household. Hey, there's something. We're not sure what, but there's something going on." (1011, researcher) • *People may not want to be contacted*: "[There's] reasons people are not in this care continuum. And they may not want to be found. They may think finding them will bring other kinds of surveillance that they're not interested in having." (1013, ethicist)
HIV stigma	• *D2C could exacerbate stigma*: "The way that [the D2C] system works, I don't see that as helpful, because you've got these strange people knocking on your door looking for you, and you don't really understand who these strange people are. And because these people are appropriately afraid of the system they always think somebody's coming after them to incarcerate them, to take them to court. So that deepens the stigma." (1036, HIV Provider)
HIV exceptionalism	• *Not problematic that D2C is focused on HIV*: "HIV is exceptional because HIV is different. And it's exceptional in lots of ways. So, our response to it has to be exceptional in some ways." (1030, ethicist) • *D2C focus on HIV is stigmatizing*: "It almost seems stigmatizing in the way that [HIV] is so singled out and so hyper focused on. Not that it doesn't deserve that amount of focus and resources, but that it's to the exclusion of other things…A job, etc." (1033, criminal justice advocate)
HIV criminalization	• *D2C could lead to punitive measures for PLWH*: "The community doesn't see it that way. They see [D2C] as a way that will create opportunities for criminalization, that it can be used against people. (1021, HIV advocate)
Data integrity and sharing	• *D2C increases risk of data reaching "the wrong hands"*: "I would say that there are probably potentially more risks because, as more data changes hands, there's always the possibility that it could end up in the wrong place or in the wrong hands." (1031, public health personnel) • *Data could be misused*: "I think that the fears that the individuals have that the data will be used in some other way that the—I don't want to say criminal, but certainly the people in government might start misusing those data in ways that were not intended from big data work for that. And then the current environment, governmental environment in the country I think that that fear is incredibly reasonable." (1047, HIV advocate)

[a]D2C: data-to-care.

Permission and Consent

Stakeholders were largely divided by stakeholder type on whether permission and consent for D2C should be obtained. Those in favor of obtaining consent for future contact associated with D2C at the time of diagnosis—including most privacy and legal experts, community advocates, and some ethicists—argued that doing so would demonstrate respect and dignity, improve the government's credibility, and that the risks of public harm created by potential refusals were too low to justify overriding consent on public health grounds. However, even those who thought consent should be obtained acknowledged the practical challenges of doing so, and that permitting people to opt out would potentially impede the efficacy of D2C. Others—including most public health personnel, researchers, and some ethicists—argued that forgoing consent was justified because D2C is a core component of public health surveillance, which does not require consent. They argued that obtaining consent would limit the state DOH's ability to intervene and that the state should act on this information to return out-of-care patients to care rather than do nothing. One public health employee noted that if surveillance is to proceed without informed consent, treatment must be non-coercive. Several others suggested that in lieu of consent, the DOH should inform people that D2C is occurring, ideally through providers' offices. One researcher suggested this is best framed as a way to support people living with HIV, rather than a response to "falling out of care."

Government Assistance Versus Overreach

Five public health personnel emphasized that the state DOH has a responsibility to the public to implement D2C, even at the expense of some individual privacy. They argued that the agency's public health mission and legal authority provide adequate justification for the level of state intrusion required for D2C, as long as the right to refuse care is ultimately preserved. On the other hand, 11 stakeholders, particularly ethicists, researchers, privacy experts, and some public health

personnel, thought that people would object to the state tracking them or contacting them about their healthcare through surveillance and D2C, and some thought that this might constitute an unwelcome form of government intrusion. Six of them explicitly suggested that such activities reflected the work of "Big Brother" or a "nanny state." Overall, participants expressed concerns about the potential for government overreach more frequently than they defended the necessity of this type of assistance. Nevertheless, ten stakeholders still thought the benefits of D2C outweighed the risks of government overreach, and several had suggestions for how to mitigate these concerns through implementation procedures.

Privacy and Confidentiality

Stakeholders uniformly acknowledged that a health worker showing up at someone's home as a result of D2C activities could constitute an unwanted invasion of privacy by alerting family members or neighbors to a potential problem. Four noted that these types of privacy concerns might be more pronounced in areas with heightened HIV stigma (see below), particularly in rural areas, and that these violations could have serious ramifications for trust in government. Eight stakeholders saw such intrusions into private space as a more significant violation because people living with HIV may not want to be contacted for linkage to care and have a legal and ethical right to refuse care. One public health employee suggested that this type of privacy violation is especially significant in the D2C context because informed consent is not obtained, and HIV surveillance data is being used differently from its initial authorized purpose, which was purely for tracking rather than recontacts and linkage to care.

The potential for inadvertent disclosure was the biggest concern associated with D2C. Stakeholders displayed different levels of trust that private health information collected as a result of D2C will remain confidential. DOH personnel noted that community health workers are very well-trained, suggesting a low probability for disclosure, while privacy experts averred that the risk of a breach increases with more people accessing confidential information, regardless of the context. Several HIV providers reported that their patients had had negative experiences with disease intervention specialists (DOH employees who contact people newly diagnosed with HIV to collect information about potential contacts and risk factors and to help connect them to care) at the time of diagnosis. These experiences suggested to these HIV providers the potential for a breach of confidentiality by DOH outreach workers engaged in D2C. One researcher viewed sharing confidential information with health workers as a breach in itself. Four stakeholders suggested that the risk of a breach may be greater in rural communities where there may be a greater risk of overlap in the social networks of health workers and the communities they serve.

HIV Stigma

Many stakeholders suggested that the public response to D2C depended in part on HIV stigma. While some stakeholders believed that HIV stigma has decreased over time, others—particularly HIV providers—still see evidence of substantial stigma (eg, patients traveling far away from their home communities to access HIV care or choosing to forego care). Fourteen participants mentioned that D2C could potentially heighten HIV stigma through unwanted attention from state health workers, privacy violations, and inadvertent disclosure, yet varied in terms of how likely they viewed this scenario. Concerns about this possibility were embedded in broader concerns related to the marginalization of vulnerable groups (eg, African Americans, men who have sex with men, and transgender people) and HIV exceptionalism (discussed further below). Three stakeholders cautioned that D2C could be implemented in a way that alienates people from systems of care, produces panic, or overlooks the circumstances of people's lives in ways that reinforce stigma.

HIV Exceptionalism

HIV exceptionalism is the view that, for a variety of reasons, HIV is or should be treated differently than other communicable diseases or conditions that may result in death if untreated. D2C may be an example of HIV exceptionalism because it is used widely for HIV, but much less commonly for other conditions. Stakeholders were overall split regarding whether it is problematic for D2C to focus on HIV, with many people remaining uncertain. Six participants raised the possibility that HIV exceptionalism heightens stigma, and four suggested that if there were similar surveillance-based interventions for other conditions, it might reduce some of the stigmas around HIV because people would not feel singled out for their HIV status. Ten participants indicated that D2C should be used for other conditions, especially infectious or sexually transmitted diseases.

HIV Criminalization

When asked about possible risks or harms of HIV surveillance and D2C, 12 stakeholders mentioned the possibility that D2C could lead to punitive measures for people living with HIV. Some state laws require people living with HIV to disclose their HIV status to partners if they are not virally suppressed. One ethicist stated that HIV surveillance is necessarily problematic in a context in which HIV is criminalized. At the same time, a community HIV advocate noted that the potential for criminalization could be used to try to persuade people living with HIV who have fallen out of care to re-establish care.

Data Integrity and Sharing

Data integrity is a basic tenet of public health surveillance because there are always increased security risks when using and sharing data. Many participants expressed concerns that D2C programs could inadvertently result in sensitive personal information reaching the "wrong hands," particularly in rural areas. Possible risks of someone outside of DOH personnel illegally obtaining data include data breaches and malware attacks. Four stakeholders, including a privacy expert, community advocate, and two legal experts, raised concerns about the possible harms that might occur if D2C personnel obtained erroneous data. For example, incorrect data could lead state health workers to contact the wrong person for re-engagement in care. Nevertheless, public health personnel reported that wrongful identification, although possible, was rare due to rigorous data cleaning and matching before field contacts are attempted.

Four stakeholders mentioned concerns about possible misuse of the data by the government—for example, suggesting that the information might be shared with legislators to enhance criminalization laws. Several stakeholders noted that many people do not understand or trust data protections and that the government sponsorship of D2C increases mistrust, especially among African American communities. Stakeholder recommendations included: creating oversight for how data is collected, used, and shared, including necessary safeguards to protect against breach or misuse, checks and balances to ensure the data is accurate, and strong security measures.

Discussion

Expert stakeholders expressed a range of ethical and practical concerns related to the use of D2C to improve the continuity of HIV care. Most stakeholders acknowledged that using big data methods to re-engage patients in care is a logical extension of public health surveillance that is justified by the mission of state and local health departments to reduce HIV transmission and promote public health. At the same time, D2C also represents a new application of existing surveillance data that may raise the suspicions of some community members [20,21]. The tension between government assistance and government overreach encapsulates the promise and pitfalls of using D2C and other big data technologies in public health interventions.

Responses from expert stakeholders emphasized that context matters greatly to the ethics of D2C. Many stakeholders suggested that privacy and stigma concerns are more pronounced in areas of the rural south where many study participants are located and among vulnerable groups such as racial, ethnic, and gender and sexual minorities. Our findings lend additional support to previous studies suggesting that stakeholder engagement in program implementation is critical for ensuring that D2C programs and other public health surveillance programs are designed in contextually sensitive ways [22,23], particularly given the high degree of support for the notion that D2C could heighten stigma. The public response to digital surveillance has demonstrated this point during the COVID-19 pandemic, which may reinforce the distrust of public health authorities [24].

At the same time, a few stakeholders expressed caution about community engagement. Two participants noted that some people might feel exploited if the motivations for engagement are not genuine, and one suggested that community engagement may inadvertently lead to the spread of misinformation. These findings suggest that care must likewise be taken concerning data protection and data stewardship, both to safeguard against potential breaches and to ensure the trust of the community. Such efforts can mitigate potential mistrust of government motives regarding D2C and the necessary privacy violations entailed. While conducting HIV surveillance without individual informed consent has been ethically justified [15,16,25], the strength of concerns expressed by several stakeholder groups (eg, community advocates, privacy and legal experts) about the lack of informed consent highlight the importance of making communities aware of these public health activities and the reasons for forgoing consent. Such public transparency is a critical component of stakeholder engagement as D2C continues to evolve.

The strengths of this study include its qualitative design, which is well equipped for capturing rich descriptive information regarding practical and ethical challenges in implementing new surveillance methods. Interviews captured nuanced expert perspectives from a wide range of disciplinary backgrounds. The primary limitation is that the purposive sample may not reflect the breadth of views about D2C from all relevant stakeholders. Because the majority of participants came from North Carolina, and public health resources vary widely by state, studies based in other locations may raise different issues. Our interviews focused on the DOH model of D2C. Thus, findings may not be generalizable to other models, such as the use of patient registries generated by specific health care systems.

Conclusions

This qualitative, descriptive study contributes valuable information that will be useful for understanding future applications of D2C and related surveillance methods. Participants expressed a great deal of support for D2C, yet also stressed the role of public trust and transparency in addressing the practical and ethical concerns they identified. The next steps for the ongoing expansion of D2C programs are pre-implementation community engagement efforts to foster public trust and transparency.

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Conflicts of Interest

None declared

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Abbreviations

D2C: data-to-care
DOH: department of health

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Original Paper

Investigating the Attitudes of Adolescents and Young Adults Towards JUUL: Computational Study Using Twitter Data

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Abstract

Background: Increases in electronic nicotine delivery system (ENDS) use among high school students from 2017 to 2019 appear to be associated with the increasing popularity of the ENDS device JUUL.

Objective: We employed a content analysis approach in conjunction with natural language processing methods using Twitter data to understand salient themes regarding JUUL use on Twitter, sentiment towards JUUL, and underage JUUL use.

Methods: Between July 2018 and August 2019, 11,556 unique tweets containing a JUUL-related keyword were collected. We manually annotated 4000 tweets for JUUL-related themes of use and sentiment. We used 3 machine learning algorithms to classify positive and negative JUUL sentiments as well as underage JUUL mentions.

Results: Of the annotated tweets, 78.80% (3152/4000) contained a specific mention of JUUL. Only 1.43% (45/3152) of tweets mentioned using JUUL as a method of smoking cessation, and only 6.85% (216/3152) of tweets mentioned the potential health effects of JUUL use. Of the machine learning methods used, the random forest classifier was the best performing algorithm among all 3 classification tasks (ie, positive sentiment, negative sentiment, and underage JUUL mentions).

Conclusions: Our findings suggest that a vast majority of Twitter users are not using JUUL to aid in smoking cessation nor do they mention the potential health benefits or detriments of JUUL use. Using machine learning algorithms to identify tweets containing underage JUUL mentions can support the timely surveillance of JUUL habits and opinions, further assisting youth-targeted public health intervention strategies.

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KEYWORDS

JUUL; electronic cigarettes; smoking cessation; natural language processing; NLP; Twitter; underage tobacco use; tobacco; e-cig; ENDS; electronic nicotine delivery system; machine learning; infodemiology; infoveillance; social media; public health

Introduction

Background

Although the overall use of any tobacco product among high school students decreased from 24.2% in 2011 to 19.6% in 2017 [1], overall use increased to 27.1% in 2018 [2] and further to 31.2% in 2019. This increase was primarily influenced by the use of electronic nicotine delivery systems (ENDS). Current use of ENDS among high school students increased from approximately 1.5% in 2011 [1] to approximately 27.5% in 2019 [3]. This rise in ENDS usage appears to be associated with the increasing popularity of the brand JUUL, a compact pod

mod device with a disposable or refillable pod typically containing artificial flavors, nicotine salts, and either vegetable glycerin or propylene glycol and whose sales represented 76% of the ENDS market at the end of 2018 [4].

JUUL's popularity stems from 3 main features of the product: appearance, flavors, and nicotine delivery [5,6]. JUUL's sleek "USB-like" design has assisted in the normalization of public ENDS usage and serves to facilitate inconspicuous use in smoking-prohibited areas such as schools and other public places [7]. JUUL was previously available in a variety of youth-appealing flavors, including but not limited to mango, mint, Crème brûlée, and menthol [8]. As of October 2019, JUUL Labs had removed all flavors except for the classic tobacco, Virginia tobacco, and menthol flavors in an attempt to address concerns regarding the appeal of the product to underage users [9].

Where the nicotine concentrations of combustible tobacco products range from 1.5% to 2.5% by weight [10,11], nicotine concentrations in JUUL pods range from 3% (35 mg/mL) to 5% (59 mg/mL) by weight. Although JUUL pods contain a fraction of the total nicotine that a pack of cigarettes does, JUUL users absorb roughly the same amount of nicotine in a single pod as a pack of cigarettes [12]. This suggests that nicotine is being absorbed more efficiently through JUUL pods than through combustible cigarettes — likely a result of cigarette nicotine being combusted into sidestream smoke and JUUL pods' nicotinic formulation [13]. JUUL pods contain a protonated form of nicotine known as nicotine salts [14], of which the absorption resembles freebase nicotine seen in cigarettes [15,16] but has a smoother feel when inhaled and does not taste as bitter [13,17].

A recent study on youth awareness of JUUL's nicotine strength demonstrated that 37.4% of adolescents believed JUUL to contain low or medium nicotine strength and 31.4% were unaware of the nicotine strength [18]. These findings suggest that adolescents are unaware of the relatively high nicotine content in a single JUUL pod. Additional research has documented the emergence of JUUL-compatible pods, some containing nicotine concentrations as high as 6.5% [13]. With approximately 90% of adult daily ever smokers beginning before 18 years of age [19] and a lack of public understanding regarding JUUL's highly concentrated nicotine levels [20], it has been hypothesized that JUUL poses a risk to younger populations for developing nicotine dependency [21,22]. Consequently, nicotine dependency developed in adolescence may result in addiction and potentially a later transition to traditional combustible cigarettes [23]. With the ENDS market rapidly changing in terms of products and patterns of use (ie, pod mods, box mods, vape pens), there are crucial knowledge gaps in understanding underage ENDS use and its consequences [24].

Studies of JUUL Use Using Social Media

Free and publicly available data obtained from Twitter can provide insight into public perceptions and knowledge of health behaviors. As reported in 2018 and 2019 Pew Research Center surveys, 32% of teenagers between the ages of 13 and 17 years [25] and 44% of adults between the ages of 18 and 24 years [26] use Twitter. Given this age distribution, the platform serves as a promising source of data for understanding adolescent and young adult JUUL use. Previous studies that have utilized Twitter data on JUUL have identified a number of experiences and insights into the product and its users such as the use of JUUL in prohibited environments (eg, schools) [27], the acquisition of JUUL devices and JUUL pods [28], and the correlation between JUUL mentions on Twitter and JUUL sales [29]. In addition to these studies, there is a growing body of work assessing how JUUL is promoted and used by underage individuals on various social media platforms. Not only does the literature suggest a heavy presence of youth JUUL-related content [30], but younger users are also sharing their opinions and experiences with other users and are talking about the various aspects associated with JUUL use [31-33]. However, a large-scale analysis of JUUL-related tweets that utilizes computational methods has, to the best of our knowledge, not been conducted to understand underage patterns of use and perceptions towards JUUL. Using machine learning algorithms to classify tweets allows for the automatic categorization of tweets and eliminates the time-consuming and resource-consuming burden that comes with the labor-intensive manual annotation process. While the application of machine learning to tweets has shown promise in several public health subdisciplines [34,35], these methods are greatly underutilized in ENDS research.

Objectives

Our primary objective was to further understand salient themes and topics related to JUUL use on Twitter with particular foci on underage JUUL use and health perceptions. Our secondary objective was to use natural language processing (NLP) methods to develop machine learning–based classifiers capable of automatically identifying and evaluating underage-related JUUL mentions as well as positive and negative sentiments towards JUUL. In doing so, we hoped to provide optimally performing classifiers to be further validated and applied to additional work relating to underage JUUL use and its representation on Twitter.

Methods

Data Collection

Using the free Twitter application programming interface (API) [36], we collected a sample of 28,590 tweets from July 2018 to August 2019. To query the Twitter API, appropriate JUUL-related keywords were determined with the aid of a tobacco control researcher (SZ). We used the case-insensitive keywords JUUL, Phix, Sourin, myblu, Aspire Breeze, vaping pod, pod mod, and vape pod, as these terms are all common to pod mod ENDS devices. As we were primarily interested in the organic perspective of individuals regarding JUUL use, we removed all retweets from the dataset. After retweet removal, our dataset was comprised of 11,556 unique English language tweets.

Ethical Considerations

This study was determined to be exempt from review by the University of Utah Institutional Review Board (IRB#00076188). To protect user privacy, we refrained from including usernames

in this paper. Further, all quotations used are synthesized from multiple examples.

Manual Twitter Content Analysis

To analyze the various themes of our collected tweets, we carried out a manual annotation process in which we categorized each tweet according to its content. We used the classification scheme developed by Myslin et al [34] for emerging tobacco product Twitter surveillance as a starting point, modifying the classification categories to more appropriately reflect our scope of interest in JUUL. We initially included 39 categories to code for tweet relevancy (ie, whether the tweet was JUUL-related), type, content, and sentiment. At this point, an initial annotation coding round was carried out on 200 tweets to determine the interrater agreement between 2 annotators (RB and MC) and refine the annotation scheme. With consensus among annotators, categories deemed extraneous and irrelevant to our analysis of JUUL (eg, hookah) were excluded from the annotation scheme. Additionally, categories deemed too specific were consolidated with closely related categories. For instance, the separate categories "Industry" and "Policy" were combined to form a singular "Industry and Regulation" category. The final annotation scheme was comprised of 22 categories related to themes of JUUL use, its perceptions among users, and an "Unrelated" category. Our final annotation scheme is available in Multimedia Appendix 1, and synthetic examples of these annotation categories are presented in Figure 1. In an attempt to limit our analysis to JUUL use exclusively, tweets that contained keywords other than JUUL were annotated as "Unrelated" unless the tweet also contained the keyword "JUUL." Further, we restricted the underage label to those tweets that contained explicit contextual evidence regarding underage elements (eg, "My parents still don't know I JUUL at school," "FDA warns of JUUL use in high school," "For my 16th birthday, I want mango JUUL pods").

Figure 1. Final categories and synthetic tweet examples, as seen in the manual annotation.

Tweet Category	Synthetic Tweet Examples
First Person Experience	"I left my juul at the party…"
Experience: Other	"My sister threw her juul out the window"
Humor	"My dad thought my Juul was a USB"
News/Media	"The FDA is cracking down on JUUL."
Marketing	"Pods now 40% off with JUUL purchase"
Opinion	"Juul is way better than Suorin"
Cessation	"Thanks to Juul, I haven't smoked in 3 weeks."
Starting	"Bought a juul starter kit at the vape shop"
Health	"Ugh, I need to hit the juul. My head hurts"
Commodity	"Just bought mango JUUL pods :) "
JUUL	"Wheres my juul?"
Suorin	"Suorin>>>>juul"
Flavor/JUUL Pods	"Nothing better than menthol Juul pods."
Pleasure	"On cloud 9 with my juul rn"
Craving	"I haven't hit my juul in 3hrs…dying"
Disgust	"Tobacco flavored juul pods are awful!"
Other Substances	"Where can I get an MJ juul pod?"
Underage	"Got caught with my Juul in third period"
Industry/Regulation	"The FDA has banned most flavored pods"
Positive Sentiment	"I would die without my juul!"
Negative Sentiment	"I will never touch a JUUL ever again"
Neutral Sentiment	"Juul comprises most of the e-cig market"

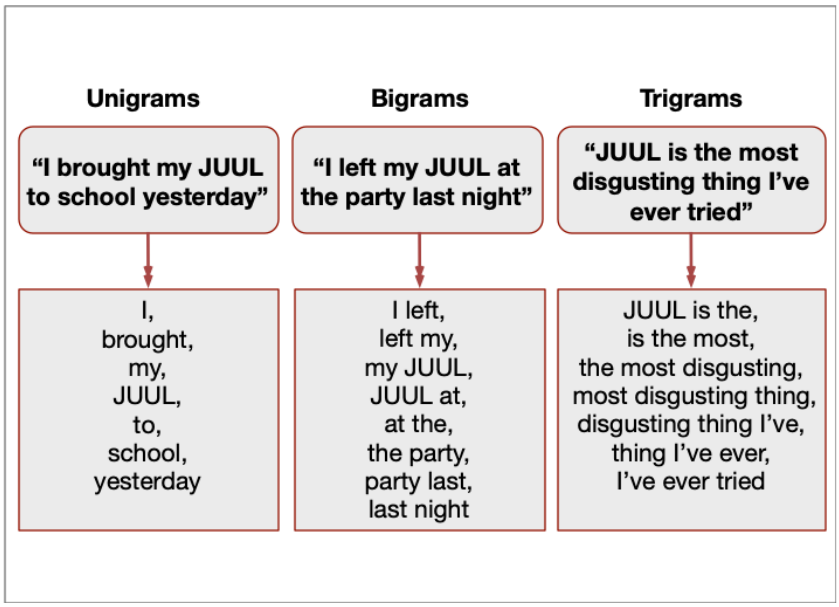
Once the interrater agreement exceeded an acceptable Cohen kappa level [37] (ie, >0.7 [38]), the remaining manual annotation process was carried out by one annotator (RB). Excluding the tweets used for interrater agreement, a total of 4000 tweets were annotated during the manual annotation to ensure there was a sufficient number of tweets for training the machine learning classifiers.

Data Preprocessing

Using the Natural Language Toolkit (NLTK) [39] – a widely used Python toolkit for analyzing text data – our manually annotated tweets were tokenized using the TweetTokenizer tool. This tool splits characters into individual tokens while also removing punctuation, @ characters, and other extraneous characters. TweetTokenizer is also capable of handling and tokenizing emojis and emoticons. Since these characters are often used in modern text when conveying emotion and sentiment, they are imperative in understanding tweet content. Consequently, we retained emojis and emoticons in the tweets, and they were tokenized as if they were words themselves.

All tokens were then converted into n-gram text sequences. An n-gram (ie, unigram, bigram, trigram) is a contiguous sequence of *n* features used in NLP to transform raw text into features that can be readily processed by a machine learning algorithm (Figure 2).

Figure 2. Visualization of n-grams. n-grams can be described as a sequence of n-items, can encode additional semantic content beyond individual words, and once vectorized, can be used as features in machine learning algorithms.



Machine Learning Classification

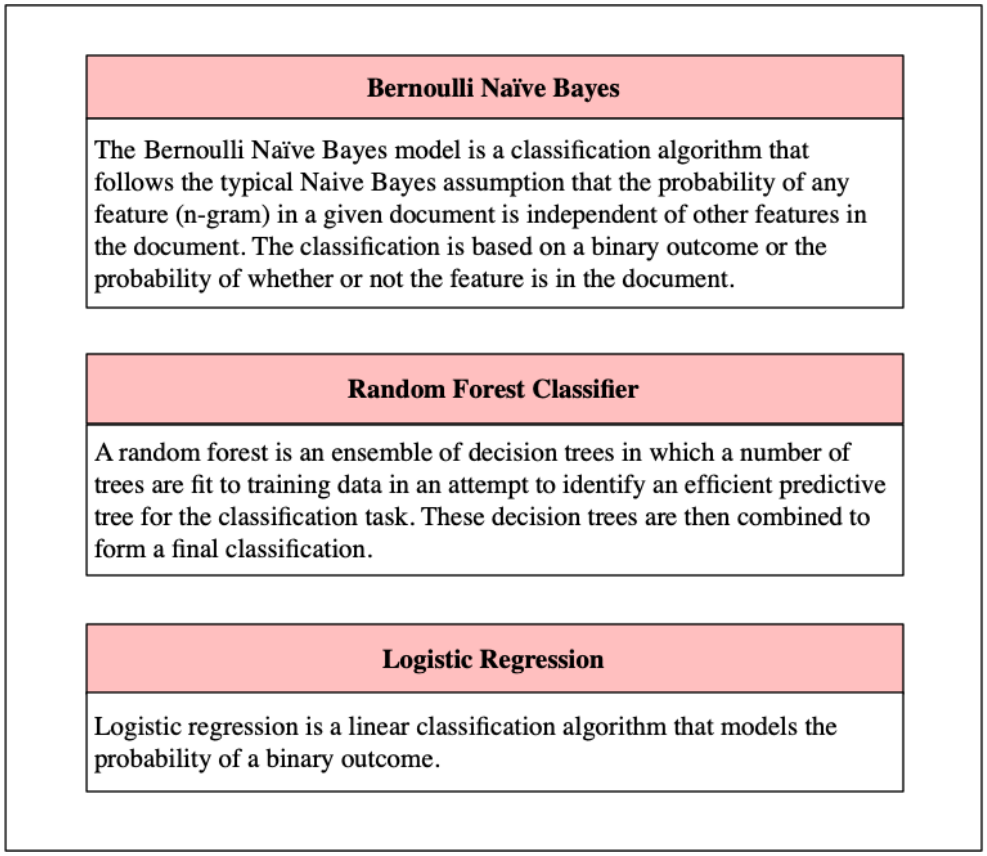
In an attempt to automatically classify JUUL related tweets, we applied supervised machine learning algorithms to identify tweets related to underage JUUL use, positive sentiment, and negative sentiment. The goal of this machine learning–based approach was to identify a predictive function of the data in which unseen data can be accurately classified as containing either underage JUUL use, positive sentiment, or negative sentiment. The efficient and automatic classification of JUUL-related tweets provides a snapshot into the perceptions and use patterns of JUUL and the potential to scale up the analysis beyond what can be realistically performed by manual annotation alone. The algorithms we used for classification were a logistic regression, Bernoulli naïve Bayes, and random forest classifier. Descriptions of the 3 classification algorithms are available in Figure 3.

These models were selected because of their computational simplicity and efficiency in Twitter-based classification tasks [34,40-42]. The input of each classifier consisted of the most salient features determined by feature selection (ie, a process in which the essential terms for model performance are identified automatically, with the rest being discarded).

This feature selection was carried out using Sci-Kit Learn (sklearn) [43], another Python toolkit that is frequently used for text analysis. The tool SelectKBest was used to compare chi-square statistics for each feature and retain the most discerning features of the dataset. In addition to reducing the chance of overfitting the models, feature selection improves model performance due to the removal of features deemed irrelevant. Once a range of suitable features had been selected, the hyperparameters for each algorithm were optimized. This hyperparameter optimization was carried out with sklearn's GridSearchCV tool, which iterates through specified model parameters and determines the optimally performing model using 10-fold cross-validation. Finally, we applied the optimally performing model to the remaining unannotated tweets.

The following 4 metrics were used to evaluate the performance of the various models: accuracy, precision (positive predictive value), recall (sensitivity), and F1 score (the harmonic mean of precision and recall). These metrics are standard in NLP and reflect a classifier's ability to classify the task at hand effectively [44,45]. Our goal was to develop classifiers capable of performing well across all 4 metrics, and all 4 metrics were considered when evaluating overall performance.

Figure 3. Brief descriptions of the 3 machine learning algorithms used to classify our annotated tweets.



Results

Manual Twitter Content Analysis

Of the 4000 tweets analyzed during the annotation process, 3152 (78.80%) were relevant to JUUL and explicitly mentioned JUUL or JUUL-related accessories such as JUUL pods and chargers. Of the relevant tweets, the most prevalent category was first person usage or experience (1792/3152, 56.85%). The least prevalent categories were using JUUL as a cessation method (45/3152, 1.43%) and using JUUL for the first time (38/3152, 1.21%). Overall sentiment towards JUUL was more positive (1052/3152, 33.38%) than negative (683/3152, 21.67%), and 1416 tweets (1416/3152, 44.92%) demonstrated neutral sentiment. When excluding news, media, and marketing tweets, positive sentiment towards JUUL slightly increased to 33.91% (941/2775) compared to 19.14% (531/2775) for negative sentiment. Lastly, 216 tweets (216/3152, 6.85%) mentioned potential health benefits or detriments of JUUL usage, and 586 tweets (586/3152, 18.59%) mentioned JUUL pods or flavors. See Table 1 for the proportions and frequencies obtained in the manual annotation.

Table 1. Category proportions and frequencies from the manual annotation of tweets (n=3152).

Category[a]	Proportion, %	Frequency
First-person experience	56.85	1792
Neutral sentiment	44.92	1416
Positive sentiment	33.38	1052
Negative sentiment	21.67	683
Flavor/JUUL pods	18.59	586
Opinion	15.96	503
News/media	9.58	302
Other substances	9.55	301
Industry/regulation	8.95	292
Experience: other	7.99	252
Health effects	6.85	216
Underage	6.03	190
Commodity	4.89	154
Humor	3.20	101
Suorin	2.54	80
Marketing	2.38	75
Pleasure	2.09	66
Disgust	1.71	54
Craving	1.46	46
Cessation	1.43	45
Starting	1.21	38

[a]Categories are not mutually exclusive.

Machine Learning Classification of Underage JUUL Mentions and Sentiment

Using supervised machine learning algorithms, we created models to classify underage JUUL mentions and sentiment towards JUUL among Twitter users. To evaluate the different models, we compared the test metrics for all 3 algorithms using the 500 most relevant features for each model (Table 2). In all 3 classification tasks, the random forest model outperformed the logistic regression and Bernoulli naïve Bayes models. When classifying tweets related to underage usage of JUUL, the random forest model yielded a higher accuracy (99% accuracy) when compared to the logistic regression model (94% accuracy) and substantially higher accuracy than the Bernoulli naïve Bayes model (78% accuracy; Figure 4). When comparing the models' performance for classifying positive and negative tweet sentiment, the random forest model performed considerably better (82% and 91% accuracy, respectively) than the logistic regression model (72% and 78% accuracy, respectively) and the Bernoulli naïve Bayes model (69% and 62% accuracy, respectively). When applying our random forest classifier to additional unseen data (7356 unannotated tweets), our model classified 109 of 7356 tweets as underage-related (1.48%). This proportion is lower than that of the tweets classified as underage-related during the manual annotation process (190/3152, 6.03%), perhaps due to the presence of previously unseen terms related to underage JUUL use.

Table 2. Test metrics of the 3 algorithms for all 3 classification tasks as well as average model performance at 500 features for each classification task.

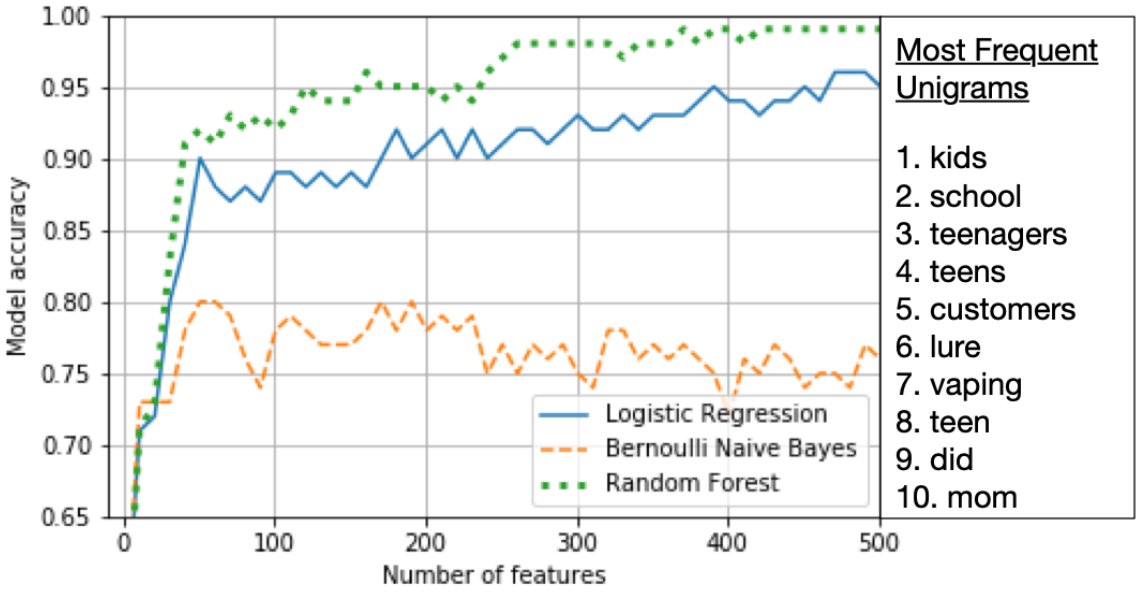
Test metrics and performance	Logistic regression				Bernoulli naïve Bayes				Random forest			
	Acc[a]	*F*	Prec[b]	Rec[c]	Acc	*F*	Prec	Rec	Acc	*F*	Prec	Rec
Underage JUUL use	0.94	0.94	0.95	0.92	0.78	0.71	0.99	0.57	0.99	0.99	0.99	0.99
Positive sentiment	0.72	0.69	0.82	0.69	0.69	0.63	0.83	0.53	0.82	0.82	0.80	0.75
Negative sentiment	0.78	0.77	0.85	0.73	0.72	0.66	0.98	0.50	0.91	0.91	0.90	0.94
Average model performance	0.81	0.80	0.87	0.78	0.73	0.67	0.93	0.53	0.91	0.91	0.90	0.89

[a]Acc: accuracy

[b]Prec: precision

[c]Rec: recall

Figure 4. Line plot of model performance at 500 features in classifying underage tweets and the top 10 most discerning features of the underage tweets.



Discussion

Principal Findings

In addition to supporting previous JUUL research using Twitter [27-29], our findings identified critical factors in the understanding and usage of JUUL among Twitter users. In our study, only 1.43% (45/3152) of annotated tweets mentioned using JUUL as a method of smoking cessation. This finding seems incongruent with JUUL's stated mission of improving the lives of smokers by eliminating combustible cigarette use and replacing it with the — purportedly less harmful — JUUL product [46]. This observation is also inconsistent with the results of a 2019 survey reporting that around 20% of individuals aged 18-24 years initiated JUUL use in an attempt to quit combustible tobacco [47]. Additional research has suggested that youth not only appear to be experimenting with JUUL but are also habitually using the device [48]. Such results, in addition to our findings, suggest that Twitter may be seen as a method of obtaining information to facilitate JUUL use and procurement among youth.

Additionally, only 6.85% (216/3152) of our annotated tweets mention the potential health benefits or detriments of using JUUL, a result consistent with that found by Morean et al [18] and poses the question of whether JUUL users recognize the known effects of high-level nicotine exposure and the potential for developing nicotine dependency and subsequent nicotine addiction. While the long-term effects of JUUL use are yet to be ascertained, there is evidence to support the view that adolescent nicotine exposure may play a significant role in the detrimental alteration of neurochemical, structural, cognitive, and behavioral processes [49].

After removing underage tweets that contained news and media related content, 47% (56/118) of the remaining underage tweets mentioned first-person experiences with JUUL, with 21% (12/56) of those tweets mentioning JUUL pods and flavors — findings consistent with previous literature [28]. Moreover, of those underage first-person mentions, 32% (18/56) contained positive sentiment (eg, "I love my JUUL so much"), compared to 23% (13/56) containing negative sentiment (eg, "Juul is so disgusting") — a finding that we expected due to the popularity

of the pod mod device among youth as compared to other ENDS devices [50].

Although a majority of the tweets that we annotated contained a neutral sentiment towards JUUL (1416/3152, 44.92%), overall tweets contained a more positive sentiment (1052/3152, 33.37%) than negative sentiment (683/3152, 21.67%). And with nearly 20% (586/3152, 18.59%) of the JUUL-related tweets mentioning JUUL pods or flavors, Twitter appears to be regularly used for sharing opinions on various JUUL accessories such as pods or flavors as well as a means to gather information regarding the procurement of such accessories. At face value, it appears that Twitter may be used by individuals to share information about JUUL, thus facilitating its use; additional qualitative research would be necessary to understand the level of exposure of individuals to this content. This finding also suggests the potential for educational campaigns employing Twitter to inform the public about JUUL use, as noted in prior work [16].

Of all the machine learning models we developed, our random forest model performed best in all 3 classification tasks. The performance of the random forest can be primarily attributed to the nature of the algorithm itself. Because a random forest is an ensemble of decision trees containing random subsets of the input features, this algorithm is resilient to outlier data, and the final classification is based on the "majority vote" of the constituent decision trees [51]. Additionally, the random forest's relatively easy implementation and computational simplicity make it a viable candidate for tobacco control researchers to use in Twitter-based ENDS surveillance.

Limitations

Our work has some limitations to be considered. First, our data were obtained via the free 1% Twitter API using keyword search rather than the entire Twitter "firehose" dataset; therefore, there is the possibility that not all JUUL-related tweets in the study period were collected. Additionally, our list of keywords (JUUL, Phix, Sourin, myblu, Aspire Breeze, vaping pod, pod mod, and vape pod) is not exhaustive and does not include all pod mod devices available in the United States. We also cannot assume that Twitter users nor their tweets are entirely representative of the general population regarding personal health behaviors.

Second, the frequency of some annotation categories is relatively low, and our models may risk overfitting. In machine learning, overfitting can be described as a model that accurately recognizes patterns and performs well on the training data, but performance decreases when applied to previously unseen data [52]. For instance, our algorithms may fit the data that it was trained on, but if presented with data it has never seen before, it may not be able to maintain this accuracy as the algorithm cannot recognize patterns in the new data.

Additionally, the interpretation of tweet content during the manual annotation process is often subjective due to the brevity of tweet content, lack of grammatical structure, and usage of hyperbole, idioms, and so on. With manual annotation being an inherently interpretive task, we attempted to retain the consistency among our annotations by calculating interrater agreement between annotators, while also focusing on explicit contextual language when assigning labels to tweets.

Finally, the results of this study are preliminary, and in order to derive policy implications from our work, these classification algorithms should be further studied and validated using additional unseen data. Future work should look to apply these classifiers on unlabeled data, conduct error analysis, and refine the algorithms as needed. Pending further validation, these classifiers can be used to automatically categorize large quantities of tweets, allowing researchers to further understand how JUUL is disseminated among youth populations and propose policy change to combat underage ENDS use.

Conclusions

Our analysis provides a snapshot of the representation of JUUL on Twitter and brings forth several interesting observations for future research endeavors. Our work suggests that the majority of JUUL users on Twitter do not use JUUL as a method of smoking cessation. Additionally, there is a paucity of tweets in which users talk about the potential health effects of using JUUL. Using this manually annotated corpus as training data, we developed 3 supervised machine learning models to accurately classify tweets related to underage JUUL use as well as sentiment towards JUUL. Of the 3 models, our random forest classifier most accurately predicted underage JUUL-related tweets and their sentiment. The application of this algorithm is a novel analytic approach to understanding underage JUUL use on Twitter and, with further research and validation, can promote future research on underage JUUL use patterns as manifested on Twitter.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
JUUL-related tweet Annotation Scheme.
[PDF File (Adobe PDF File), 168 KB - publichealth_v6i3e19975_app1.pdf]

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Abbreviations

Acc: accuracy
API: application programming interface
ENDS: electronic nicotine delivery systems
NLP: natural language processing
Prec: precision
Rec: recall

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Protocol

The Oxford Royal College of General Practitioners Clinical Informatics Digital Hub: Protocol to Develop Extended COVID-19 Surveillance and Trial Platforms

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Abstract

Background: Routinely recorded primary care data have been used for many years by sentinel networks for surveillance. More recently, real world data have been used for a wider range of research projects to support rapid, inexpensive clinical trials. Because the partial national lockdown in the United Kingdom due to the coronavirus disease (COVID-19) pandemic has resulted in decreasing community disease incidence, much larger numbers of general practices are needed to deliver effective COVID-19 surveillance and contribute to in-pandemic clinical trials.

Objective: The aim of this protocol is to describe the rapid design and development of the Oxford Royal College of General Practitioners Clinical Informatics Digital Hub (ORCHID) and its first two platforms. The Surveillance Platform will provide extended primary care surveillance, while the Trials Platform is a streamlined clinical trials platform that will be integrated into routine primary care practice.

Methods: We will apply the FAIR (Findable, Accessible, Interoperable, and Reusable) metadata principles to a new, integrated digital health hub that will extract routinely collected general practice electronic health data for use in clinical trials and provide enhanced communicable disease surveillance. The hub will be findable through membership in Health Data Research UK and European metadata repositories. Accessibility through an online application system will provide access to study-ready data sets or developed custom data sets. Interoperability will be facilitated by fixed linkage to other key sources such as Hospital Episodes Statistics and the Office of National Statistics using pseudonymized data. All semantic descriptors (ie, ontologies) and code used

for analysis will be made available to accelerate analyses. We will also make data available using common data models, starting with the US Food and Drug Administration Sentinel and Observational Medical Outcomes Partnership approaches, to facilitate international studies. The Surveillance Platform will provide access to data for health protection and promotion work as authorized through agreements between Oxford, the Royal College of General Practitioners, and Public Health England. All studies using the Trials Platform will go through appropriate ethical and other regulatory approval processes.

Results: The hub will be a bottom-up, professionally led network that will provide benefits for member practices, our health service, and the population served. Data will only be used for SQUIRE (surveillance, quality improvement, research, and education) purposes. We have already received positive responses from practices, and the number of practices in the network has doubled to over 1150 since February 2020. COVID-19 surveillance has resulted in tripling of the number of virology sites to 293 (target 300), which has aided the collection of the largest ever weekly total of surveillance swabs in the United Kingdom as well as over 3000 severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) serology samples. Practices are recruiting to the PRINCIPLE (Platform Randomised trial of INterventions against COVID-19 In older PeopLE) trial, and these participants will be followed up through ORCHID. These initial outputs demonstrate the feasibility of ORCHID to provide an extended national digital health hub.

Conclusions: ORCHID will provide equitable and innovative use of big data through a professionally led national primary care network and the application of FAIR principles. The secure data hub will host routinely collected general practice data linked to other key health care repositories for clinical trials and support enhanced in situ surveillance without always requiring large volume data extracts. ORCHID will support rapid data extraction, analysis, and dissemination with the aim of improving future research and development in general practice to positively impact patient care.

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KEYWORDS

primary health care; general practice; medical record systems, computerized; sentinel surveillance; public health surveillance; clinical trials as a topic; adaptive clinical trials; severe acute respiratory syndrome coronavirus 2; COVID-19

Introduction

Background and Rationale for the Study

The Oxford Royal College of General Practitioners Research and Surveillance Centre (RCGP RSC), in close partnership with Public Health England (PHE), has been using routinely collected primary care data for surveillance of influenza and vaccine effectiveness for over 50 years [1]. The RCGP RSC works in collaboration with primary care software providers, such as Egton Medical Information Systems (EMIS) and The Phoenix Partnership (TPP). As medical records and health information have become increasingly digitalized, the Oxford RCGP RSC has developed clinical informatics expertise enabling a wider range of research projects while providing audit-based education and novel digital feedback to practices to improve practice data quality and build research capability. Due to these advances, the Oxford RCGP RSC offers a unique opportunity to accurately measure clinical outcomes using routine patient-level data in a time-sensitive manner. This opens the possibility for enhanced public health surveillance of communicable and noncommunicable diseases as well as integrated observational and interventional research in primary care practice.

In 2017, Professor Sir John Bell highlighted potential opportunities to improve the collection of real world health data, including digital innovations to modernize trials and measure clinical and cost-effectiveness outcomes [2]. The United Kingdom Life Sciences Industrial Strategy Report suggested that this can be achieved through collaboration between the National Health Service (NHS) and key partner organizations, including academia and industry [2]. Clinical trial costs could be reduced by streamlining the process for data monitoring and follow-up, while information feedback and reimbursement to practices could be faster, more specific, and more flexible. This would allow the health care system to bring innovative product use into clinical practice at scale and pace for the benefit of patients. Real world data has additional importance for regulatory bodies to monitor postmarket drug efficacy and safety, informing regulatory decisions and guidelines.

Existing clinical databases in the United Kingdom provide important resources for observational research, including the Oxford RCGP RSC, the QResearch Database, and the Clinical Practice Research Datalink. However, these databases share limitations, such as a time lag of up to several weeks between data input in practice to availability for research analysis and the need to apply for access to linked data on a study-by-study basis.

With the current coronavirus disease (COVID-19) pandemic, the need for adaptive, real-time surveillance and rapid, inexpensive clinical trials has rarely been more pressing [3]. Identified in Wuhan, China, in late 2019, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which causes COVID-19, has rapidly spread to become a global pandemic, with 267,240 confirmed cases and 37,460 deaths in the United Kingdom alone at the time of writing. The COVID-19 outbreak demonstrates the need for more rapid, large-scale UK surveillance networks that are “pandemic-ready” and provide data on disease epidemiology, including infection rates and severity, to enable monitoring of the impact of public health measures such as containment. Furthermore, clinical trials to establish effective treatments for this novel pathogen need to

be rapidly developed "in-pandemic" within a health care system under strain [3,4].

In this protocol, we outline the proposed approach to delivering the Oxford RCGP Clinical Informatics Digital (ORCHID) Hub and its first two platforms, the Surveillance Platform and the Trials Platform. At the time of writing, ORCHID is in the advanced stages of development and is undergoing regulatory assessment but is not yet operational. The hub will integrate general practice records at a national level to support integrated clinical trials in routine practice and provide platforms for extended community surveillance that can be delivered in situ without always requiring large volume data extracts. This work will draw on the experience and stewardship of general practitioners in a bottom-up approach, informing the structure, interface, and ideology of the hub. We will outline how the platform will adhere to the Findable, Accessible, Interoperable, and Reusable (FAIR) principles of metadata [5] and will align with the wider principles of open science.

While this technical innovation was not originally developed as a specific response to the COVID-19 pandemic, it is timely given the emphasis on surveillance and integrated clinical trials and the reduced direct patient contacts with trial teams. The community incidence of respiratory infections presenting to primary care has fallen to around one-third of usual levels since the lockdown in the United Kingdom [6,7]. Therefore, ORCHID will need to be implemented rapidly alongside a threefold expansion in the number of surveillance practices to meet requirements for COVID-19 surveillance and to support in-pandemic trials. For example, before the lockdown, it was estimated that 300 practices would be needed to recruit sufficient volunteers to the PRINCIPLE (Platform Randomised trial of INterventions against COVID-19 In older PeopLE) [8]. This number has now risen to 900 and may rise further if community incidence falls. This "in-pandemic" implementation will offer an early opportunity to test the approach to the Trials Platform, provide learning for its long-term development and understanding of its value, and inform longer-term resourcing agreements between Oxford University and the RCGP.

Aim

The aim of ORCHID is to rapidly deliver integrated digital health platforms that operate using FAIR principles and are integrated across health services, including primary and secondary care. The initial platforms aim to improve the surveillance of communicable disease and to incorporate clinical trials into routine primary care practice.

Purpose

The hub is being developed at pace for the following purposes, in accordance with applicable information governance and data security requirements:

- Establish a large, near–real time primary care health informatics hub for the use of data from consenting patients in clinical trials and supplement existing disease surveillance using in situ network data without large-scale data extraction.
- Integrate UK general practice data from a network of over 1000 practices, linked with secondary care and other affiliated health care data sets, including national mortality.
- Develop systems for rapid data extraction, analysis, and dissemination using data sets that are findable, accessible, interoperable, and reusable in accordance with FAIR principles.
- Provide a bottom-up professional network and support system for participating general practices, incorporating continuing education and local level service improvement.
- Establish sustainable partnerships with general practices, NHS informatics organizations, UK public health institutions, and universities to maximize the benefits of NHS data analysis for the UK public.
- Provide a trials platform that can deliver commercial trials and, subject to resourcing discussions with the RCGP, ensure direct financial benefit to participating practices and investment in the development of other operational improvements, member benefits, and policy research that support sector priorities.

Methods

Study Design

ORCHID will be an integrated digital health system that will be developed using the FAIR data principles (Table 1) [9]. It will be developed through five work streams: (1) Data export, transformation and loading as well as in situ analysis for surveillance, (2) information governance, (3) database management and analysis, (4) recruitment and benefits for practices, and (5) project management. Each of these five workstreams underpins the development of distinct digital platforms, with data set releases that will be *findable* using digital object identifiers (DOIs). The initial platforms will include the Surveillance Platform and the Trials Platform; however, further platforms are planned, including a Diagnostics Platform. The hub will be *findable* through membership in the Health Data Research UK and the European Health Data & Evidence Network (EDHEN) metadata repositories. Here, we describe the five main workstreams that will deliver this program (Figure 1) and how they will follow the FAIR principles (Table 1) [9].

Table 1. FAIR principles (adapted from [5]) and ORCHID compliance.

Principle	Description	ORCHID[a] compliance
Findable	Metadata and data should be easy to find by both humans and computers. Machine-readable metadata are essential for automatic discovery of data sets and services.	ORCHID will provide a single access portal for linked primary and secondary care data sets to facilitate metadata research. ORCHID will be a member of the Health Data Research UK and EDHEN[b] metadata repositories. Data set releases issued by the ORCHID-Surveillance and ORCHID-Trials platforms will each have a DOI[c]. This will be a globally unique and persistent identifier linked to the metadata description. The description will contain information about how to apply for data access. Metadata for the latest bulk release will be published in standard metadata registers (ie, FAIRsharing.org, re3data.org).
Accessible	Once the user finds the required data, they need to know how they can be accessed, possibly including authentication and authorization.	There will be a standardized online application process for use of the data for SQUIRE[d] purposes. Metadata for the bulk data releases will be universally accessible using standard internet tools. We will maintain historic metadata even when data is no longer available (data can be requested from bulk data releases up to three years back).
Interoperable	Data usually need to be integrated with other data. In addition, the data need to interoperate with applications or workflows for analysis, storage, and processing.	Facilitating interoperability between general practice and HES[e]/ONS[f] data using a common data model and HL7[g] Standards is a key component of ORCHID. Data releases will also facilitate interoperability using the FDA[h] Sentinel and OMOP[i] common data models.
Reusable	Metadata and data should be well described so that they can be replicated and combined in different settings.	Our validated case definitions will be published as ontologies in biomedical ontology repositories. We will prepare patient-level synthetic data that will simulate properties of a defined subset of the RCGP RSC[j] database. The metadata will provide detailed information about the provenance of the data. The bulk data releases will be issued with a clear data usage license.

[a]ORCHID: Oxford Royal College of General Practitioners Clinical Informatics Digital Hub.

[b]EDHEN: European Health Data & Evidence Network.

[c]DOI: Digital Object Identifier.

[d]SQUIRE: Surveillance, Quality Improvement, Research, and Education

[e]HES: Hospital Episode Statistics.

[f]ONS: Office of National Statistics.

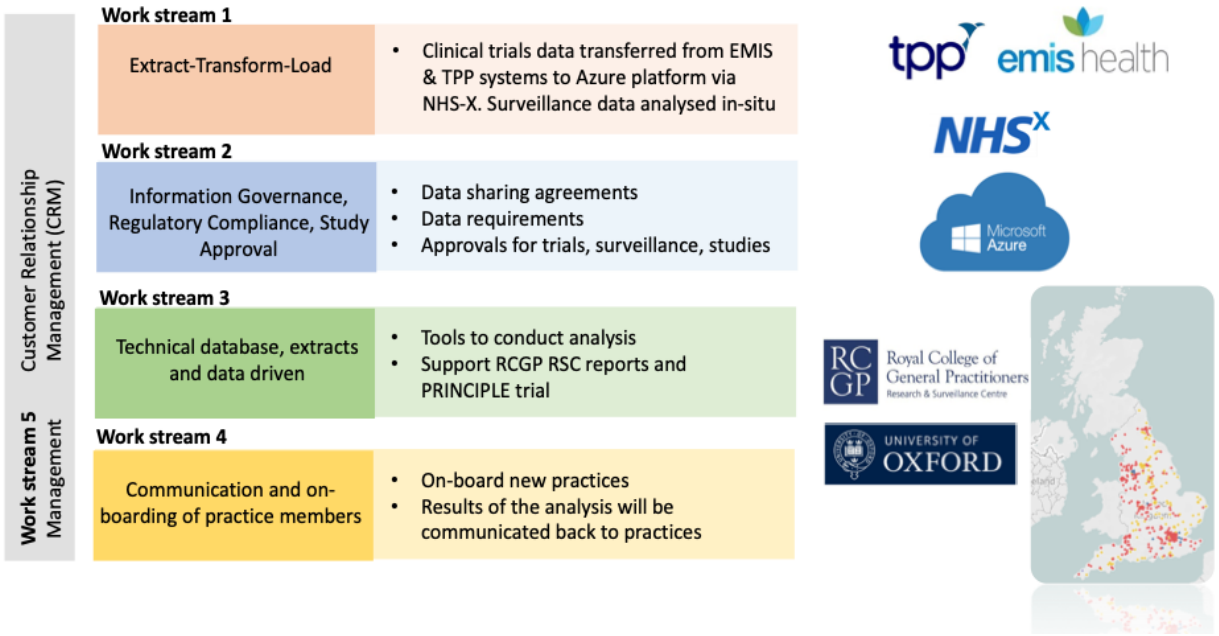
[g]HL7: Health Level 7.

[h]FDA: US Food and Drug Administration.

[i]OMOP: Observational Medical Outcomes Partnership.

[j]RCGP RSC: Royal College of General Practitioners Research and Surveillance Centre.

Figure 1. ORCHID hub work streams.



Data Export, Transformation, and Loading (Work Stream 1)

The aim of this program is to transform routine clinical data from individual patient records at practice level into an *accessible* repository of data for health research. The hub will use computerized medical record (CMR) data from the Oxford RCGP RSC, whose membership currently includes over 1200 general practices in England covering approximately 8 million patients who are broadly representative of the English general population [10,11]. The emergent COVID-19 pandemic has seen a rapid increase in the number of new practices joining the network to support the national surveillance program. The aspiration is to expand the RCGP RSC to approximately 2000 practices, or 16 million patients, by 2021, representing close to 25% of the UK population.

Pseudonymized patient level data will be extracted from general practice CMR systems such as EMIS and TPP SystmOne for consenting patients enrolled in active clinical trials. This will include demographic data, clinical event data coded with Systematized Nomenclature of Medicine (SNOMED) CT (SNOMED International), medication data coded with the Dictionary of Medicines and Devices (dm+d), and free text entries. Encrypted data will be transported securely to the protected hub, initially through providers such as the Azure environment (Microsoft Corporation) hosted by NHSX. In this environment, we will create an extract, transform, and load (ETL) process that will convert the EMIS and TPP data into the Observational Medical Outcomes Partnership (OMOP) common data model and map to the Standardized Vocabularies [12]. The implementation will be carried out using a collection of automated scripts (ie, SQL) to enable the ETL process to be repeatable.

Different CMR vendors vary in the data extractions they allow. TPP has agreed to allow individual consented patient record extracts to support trials; more complete practice level extracts, whether for research or surveillance, would be performed using Apollo Data Management Services (which RCGP RSC currently uses to manage data extractions). TPP and RCGP RSC are also exploring the new possibility of in situ analytics, using a similar paradigm to the OpenSAFELY approach. However, we will be able to receive customized aggregated public health data extractions.

To facilitate *interoperability*, Fast Healthcare Interoperability Resources (FHIR), data schemas, and HL7 standards will be used to transform data [12,13]. Crucially, within the hub, pseudonymized data linkage will link primary care data to other CMR data sources. These sources include hospital data, such as Hospital Episode Statistics (HES) Admitted Patient Care, HES Outpatient, HES Accident and Emergency, and the Office for National Statistics (ONS) for mortality data and cancer registry data. When a unique identifier is not available, we will use geographical, deterministic, and probabilistic linkage processes. These data schema will enable enhanced in situ communicable disease surveillance without requiring large scale data extracts for analysis.

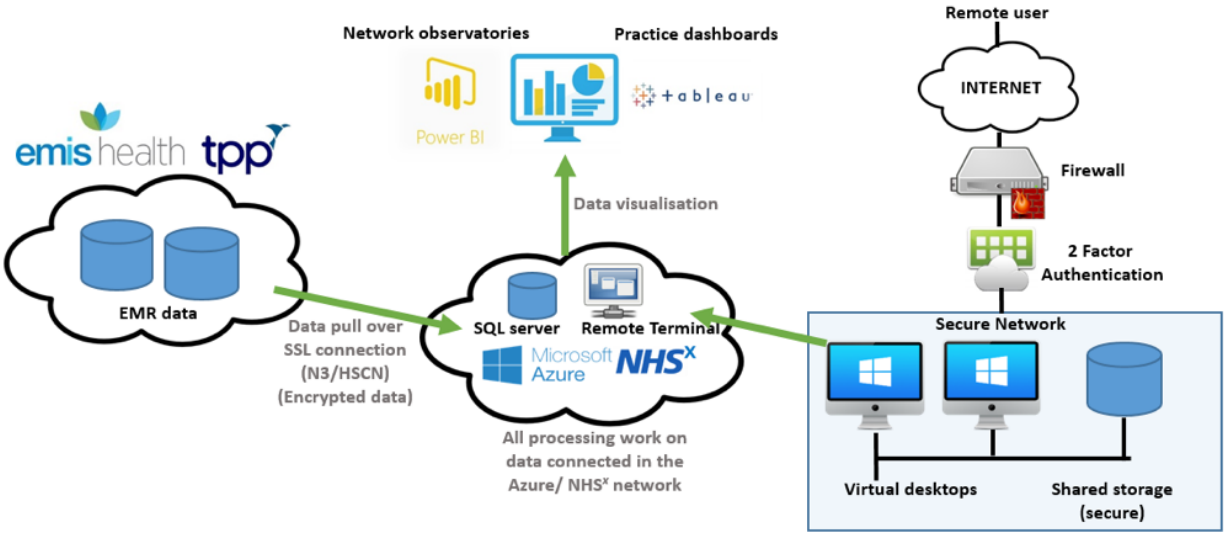
Successful data linkage is generally straightforward; it is based on the patient's NHS number and works well in most cases. However, this may not always be possible, such as when a patient does not have a NHS number (eg, homeless people, migrants, or members of the traveller community); thus, the study of these groups is more challenging. Some relevant data we may wish to link to may not mandate NHS number use (eg, psychological therapies) or may not be recorded (eg, social care data). We have developed techniques to use in these circumstances [14]. The clinical informatics community generally shares expertise in these areas.

Data linkage will provide researchers with the ability to identify important clinical outcomes, such as hospital admission or mortality, across the primary and secondary care interface within

a single platform. Bringing these different data sets into a single repository for health researchers will help make the data both accessible and more easily findable. The data flows are outlined in Figure 2.

The major CMR suppliers have recently launched COVID-19 surveillance tools for patient completion. By accessing patient-facing parts of their CMR system, patients are given the option to provide details about their symptoms if they think they may have COVID-19. This information can be supplied (with appropriate governance), pseudonymized, and linked to a patient's records. This would provide potentially useful information about the size of the epidemiological iceberg and enable the capture of more structured information regarding symptoms [15]. There is also potential to message patients about relevant studies and for patients to consent to participate.

Figure 2. Flow of data for clinical trials in the ORCHID platform.



Information Governance and Contracting (Work Stream 2)

This work stream will incorporate guidance from both information governance and contracting as supported by the University of Oxford Nuffield Department of Primary Care Health Sciences Department of Information Technology and Governance team as well as the University of Oxford Information Compliance, Research Services, and Legal Services teams, respectively.

Regulatory Compliance

Data security and information governance are fundamental to protecting the privacy of individual patients while providing data in a format that can be analyzed for public health or research purposes. ORCHID is undergoing an internal review to confirm which data Oxford would process and the legal basis for doing so. This review will also confirm that the necessary safeguards are in place to minimize and prevent any risks or potential for harm that could accrue to individuals arising from the processing.

ORCHID will be compliant with data protection legislation, including the Data Protection Act 1998 and EC Directive 95/46/EC, the subsequent General Data Protection Regulation ((EU) 2016/679), and the NHS Digital Data Security and Privacy Policy. It will also be subject to data sharing and other required agreements with all parties (eg, NHSX). Both the University of Oxford and the University of Surrey (where the RSC data has historically been held) are compliant with the Data Security and Privacy toolkit.

All participating general practices will be required to sign an agreement setting out the nature of their involvement in the RCGP Clinical Informatics Digital Hub. Data transfers between primary care CMR providers such as EMIS and TPP will be governed by data sharing agreements subject to the laws and regulations of the United Kingdom. All clinical trials using the hub will require research ethics committee approval as well as approval by other regulatory authorities such as the Medicines and Healthcare Products Regulatory Agency. Where not otherwise governed by data protection legislation and NHS policy, the proposed surveillance work will be performed on the instructions of PHE in accordance with Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002 for health protection and Regulation 5 for health promotion activities [16]. These activities are reviewed annually by the Caldicott Guardian of PHE. Any work not falling under these categories will require appropriate ethical approval.

Accessibility of Data

ORCHID allows researchers and organizations wishing to access data for SQUIRE (Surveillance, Quality Improvement, Research, and Education) purposes to do so via a single, standard online application, available from the RCGP RSC [17]. The request will include the data set required according to the RSC standard data configurations as well as any custom requirements defined by the applicant. Requests will be reviewed by the RCGP RSC approval committee, who will also assess whether the necessary research ethics committee approvals have been obtained where appropriate. Once approval has been granted, the data will be subject to recognized statistical disclosure control processes. Data will be available in study-ready RSC standard data

configurations as well as with any custom requirements defined by the applicant. The metadata describing the latest releases of RCGP RSC data will be frequently updated on standard metadata repositories. The metadata will be available in the DataCite Metadata Schema (a schema featuring a list of core metadata properties defined by the Metadata Working Group) [18]. We will also use the US Food and Drug Administration (FDA) Sentinel and OMOP common data models to increase *interoperability* and *reusability* of the data in international studies, with comprehensive open access metadata and clear data usage licensing. Data will be available at cost to NHS-based or UK-based academic institutions and researchers.

Database Management and Analysis (Work Stream 3)

Database Management

Currently, the hub will be hosted by NHSX in the Azure environment, although secure alternatives may be considered should the need arise in future. This hub will initially host pseudonymized EMIS data and data extracted by Apollo Medical Services. The platform enables rapid implementation of both storage and computing power while ensuring data integrity through network segmentation and encryption. This has the advantage of allowing the service to be flexible in reacting to the demands of the data flows and compute requirements through bringing on additional servers to improve data processing throughput. Within the hub, separate platforms will be hosted for each respective end use; initially, these platforms will contain clinical trial data and in situ communicable disease surveillance. The data schema from all data inputs will be used to identify the necessary information that will be available in each platform. Data will be cleaned and checked by members of the Clinical Informatics group. The schema will be used to identify opt-outs and confidential information. It will also confirm that researchers are only provided with the required data sets and suppress opt-outs and confidential information. RCGP RSC will access the data through its existing secure network to restrict access to the cloud solution only to authorized users and require induction for new users.

Data Analysis

This integrated data platform will enable a broad range of analyses to be performed. The ORCHID team will transform data to the standard RSC population configuration (based on age band, ethnicity, index of multiple deprivation, and rurality), clinical case definitions (generally ontological), covariates, and outcomes. These will be automatically benchmarked to ONS standard populations to enable rapid comparisons between the study and national populations. Demographic data will be available where strictly necessary from general practice registration data (eg, for health protection purposes in the case of communicable disease surveillance). Relevant SNOMED CT codes will be searchable, while linked HES and ONS data will be available to provide information on hospital admissions and deaths. Data will be analyzed using packages such as SQL, R, and PowerBI. All code and ontologies will be made shareable to facilitate *reusability* of the data.

The first two platforms will be the Surveillance Platform and the Trials Platform, which are being urgently implemented to support the national response to COVID-19. These platforms provide examples of how ORCHID will be operationalized to respond to pressing public health needs. Further platforms are planned, including a dedicated Diagnostics Platform.

The Surveillance Platform will provide near–real time data regarding clinical diagnoses of upper and lower respiratory infections, influenza-like illness, suspected and confirmed COVID-19 cases, and related hospital admissions at participating practices, including new cases detected via population screening approaches (Table 2). Information from this clinical and virological surveillance system will be vital to understand the spread of COVID-19 and inform responsive and evidence-based public health COVID-19 policy. Surveillance outcomes will be reported and updated on a daily to weekly basis on a publicly accessible website [19], and relevant data extracts will be provided directly to PHE to feed into the national COVID-19 response data hub. Clinical and virological data will also be valuable for other pressing analyses of clinical significance, such as the sensitivity of clinical symptom sets to predict COVID-19 infection and the influences of smoking, comorbidities, ibuprofen, angiotensin-converting enzyme (ACE) inhibitors, and angiotensin II receptor blockers on COVID-19 outcomes. The ORCHID team will work with PHE in a complementary fashion, sharing expertise on real time surveillance, daily analysis, and direct links to the public health effector organization.

The Trials Platform will support the PRINCIPLE, a large, adaptive platform, randomized clinical trial of interventions to treat COVID-19 in general practice (eg, hydroxychloroquine and azithromycin) [8,20]. PRINCIPLE will be used as a test case to assess the success of the trial platform at identifying study participants and key health care outcomes. This validation process may present opportunities for improving the data management system before it is made more widely available. The ORCHID Trials Platform will provide routinely collected data that will complement and enhance the recording of adverse events and key trial outcomes, thereby reducing trial workload. Beyond the COVID-19 response, data from ORCHID will be used for additional analysis to support further infectious disease surveillance, clinical trials (including vaccine trials), and other public health analyses.

Table 2. Examples of clinical outcomes available in ORCHID.

Outcome	Data source
PRINCIPLE[a]	
Hospital admission related to suspected COVID-19[b]	Primary care medical record or HES[c] data
In-hospital oxygen administration, intensive care unit admission, and mechanical ventilation	Primary care medical record or HES data
Death related to suspected COVID-19	Primary care medical record, HES or ONS[d] data
Contacts with health services	Primary care medical record
Consumption of antibiotics	Primary care medical record
Positive COVID-19 test	Trial-specific testing and primary care medical record
RGP RSC[e] surveillance	
Clinical symptoms of upper and lower respiratory tract infections and influenza-like illness	Primary care medical record
Excluded, exposed, suspected, tested, or confirmed COVID-19 infection	Primary care medical record and specific surveillance testing
Covariates of interest for observational analyses of the COVID-19 pandemic	
Smoking status	Primary care medical record
Medical comorbidities that may worsen COVID-19 outcomes (eg, diabetes, cardiovascular disease)	Primary care medical record
Concurrent medication that may influence COVID-19 outcomes (eg, ACE[f] inhibitors, ibuprofen)	Primary care medical record

[a]PRINCIPLE: Platform Randomised trial of INterventions against COVID-19 In older PeopLE.

[b]COVID-19: coronavirus disease.

[c]HES: Hospital Episode Statistics.

[d]ONS: Office of National Statistics.

[e]RCGP RSC: Royal College of General Practitioners Research and Surveillance Centre.

[f]ACE: angiotensin-converting enzyme.

Recruitment and Benefits for General Practices in ORCHID (Work Stream 4)

Recruitment

All general practices in England using a supported primary care CMR system will be eligible to participate in ORCHID through the Oxford RCGP RSC network. We aim to expand to all four nations of the United Kingdom in the near future. Existing members of the RCGP RSC will be automatically migrated to the new hub. For current nonmembers, invitations to all EMIS practices in England have been sent out, and further invitations to general practices using TPP and other CMR systems will be distributed once the infrastructure design has been finalized and the platforms are operational. To facilitate ease of signup, practices can complete and submit agreements electronically and can easily activate data to allow ongoing automatic data extraction. Involvement in the Oxford RCGP RSC network can be at three levels, namely sharing patient data, virology sampling, and clinical trial participation (Table 3).

Table 3. Levels of involvement for general practices in the Oxford RCGP RSC and ORCHID Platform.

Level of involvement	Description
Member	Practices provide data and undergo data quality assessments.
Microbiological sample–providing practices	These practices provide microbiological samples as part of our surveillance programs as well as high quality data. Most will be providing nasal and throat swabs. Members of these programs will have completed the web-based learning relevant to the programs they are participating in.
Clinical trial participation	These practices will be ready to take part on clinical trials organized through ORCHID[a].

[a]ORCHID: Oxford Royal College of General Practitioners Clinical Informatics Digital Hub.

Benefits of Participating in ORCHID

We are committed to developing our bottom-up, professionally led network, which increases the value of high-quality CMRs for patients and practices. Each contributing practice will receive regular feedback via “Weekly Updates” on the latest surveillance and research findings, developments within the hub, and tips to improve data quality. Each practice will have access to its own dashboard, which provides a graphical representation displaying practice workload and statistics alongside

comparisons with other practices in the network to improve data quality, clinical care, and patient safety. These dashboards can also highlight areas where practices can increase revenue streams through improving Quality and Outcomes Framework and Direct Enhanced Services income. Practices in the Oxford RCGP RSC network will have the opportunity to participate in research and contribute to COVID-19 pandemic surveillance by contributing data. Payments for clinical trial participation will provide additional opportunities to increase practice funding. Practice members are incentivized to perform online training regarding data collection, information governance, and data quality processes, including accurate coding for clinicians. This training will be recognized with Continuing Professional Development credit. Patients in member practices may also benefit from the opportunity to participate in primary care clinical trials and be granted increased access to testing (such as influenza or COVID-19 testing) through surveillance programs. Overall, providing more joined-up national level data will enable skilled research teams to provide data analysis and feedback in a manner that is both meaningful and accessible to clinicians in practice.

Project Management (Work Stream 5)

Resources and Management

Each of the five workflows has a dedicated team lead who is supported by a range of data analysts, research officers, and administrative staff. Additional teams will support relevant platforms, such as the University of Oxford Nuffield Department of Primary Care Health Sciences Clinical Trials Unit for the Trials platform and dedicated data curators and statisticians for the Surveillance Platform. The team has a number of clinical academics with experience working in general practice across the United Kingdom who will support the process of practice feedback and integrated research. Funding to maintain the ORCHID management system and long-term infrastructure development will be provided through grants and commercial investment (eg, clinical trials). To ensure the data is findable and accessible, the secure hub will be accessed through a single portal entry for authorized external users, which will be monitored and run by a Customer Relationship Manager. The Customer Relationship Manager will act as a liaison for external teams, offering support on navigating the interface and responding to feedback to drive service improvement. Applications for data access will be triaged; those seeking to access the data set will be given the opportunity to flag requests they consider priorities for fast-track approval.

Patient and Public Involvement (PPI)

The RCGP RSC draws on the experience and feedback of a patient and public involvement (PPI) group, who provided input on the need for and safe running of the Surveillance and Trials Platforms. The ORCHID team will appoint an independent steering committee and chairman. As the hub develops, we anticipate increasing the number of members to reflect the wider scope of work compared to the existing RSC platform. PPI members will support the hub team across a range of areas, including decision-making around research governance, ethics applications, dissemination of results from linked studies, and the best approaches to involving patients directly in research and ensuring informative feedback. We will also develop materials to support integrated PPI in Workstream 4, including practice websites and patient participation groups.

Partnerships

The ORCHID project is hosted by the University of Oxford within the Nuffield Department of Primary Care Health Sciences. The RCGP is a key partner and provides support in terms of practice recruitment and retention for the RSC. An RSC National Clinical Champion supports local patient and public communication. We will partner with PHE to extend and enhance the national surveillance of communicable diseases, with COVID-19 an immediate priority; however, future workflows are planned to include influenza-like illness, respiratory disease, vaccine-preventable disease, and gastrointestinal and sexually transmitted infections. Potential for surveillance of noncommunicable diseases and conditions sensitive to environmental conditions, such as cardiovascular disease, injuries, and mental health, and their related morbidity and mortality will also be explored. Greater synergy with the PHE Syndromic Surveillance Unit, with their expertise in daily analysis and interpretation, could allow complementary work on near–real time surveillance and provide a direct link to the public health effector organization. NHS Digital and NHSX are the units responsible for supporting the advancement and safe handling of data within the NHS as a whole.

Discussion

General Considerations

Rapid technical innovation will deliver the ORCHID and its surveillance and trial platforms, which are readily scalable to respond to the COVID-19 pandemic through enhanced disease surveillance, streamlined, large-scale clinical trials, and observational analyses of the impact of public health measures, such as community lockdown. The hub will host integrated data from routine general practice records linked to HES and ONS data. This will improve on existing large-scale health care databases in the United Kingdom by providing continuous uploads of high-quality primary care data for analysis and clinical trials. The near–real time data access will improve national surveillance infrastructure, providing data to PHE and the NHS to support flexible and adaptive public health interventions, initially in the context of COVID-19. Uniquely, it will become possible to embed streamlined clinical trials into routine general practice, enabling trial monitoring as well as direct feedback of patient safety and outcome data to patients. This information can reduce workload pressures in general practice but can also benefit practices and their patients by enabling innovations in health research to be implemented at scale and at pace.

Strengths

Improving the United Kingdom's digital health care data and clinical trial capabilities through translational science and collaboration with key industry partners are key components of the government's Life Sciences Industrial Strategy [2]. The positive impacts of such changes will benefit population health, economic growth, and future investment in health sciences. The

need to transform public health data into political action and policy change has also been highlighted in other key documents, such as The Marmot Report [21].

The United Kingdom is in a unique position to develop an integrated digital research platform. Primary care CMRs were first developed in the United Kingdom, and all practices in the United Kingdom record data in this way. Because the health service is nationalized, almost the entire population are registered with local general practitioners; therefore, disease surveillance through a single platform is possible. Other initiatives are underway to develop integrated big data networks and analytics platforms, including OpenSAFELY [22]. Similarities exist between OpenSAFELY and ORCHID in terms of data linkage and governance; however, ORCHID benefits from developing the existing Oxford RCGP RSC infrastructure and long-term relationships with practices, including an established system of communicable disease monitoring that is delivered in partnership with PHE and the RCGP.

ORCHID will evolve the existing Oxford RCGP RSC infrastructure to provide these data in a timeframe that enables a more rapid response to communicable disease outbreaks. Because ORCHID is a member of the Health Data Research UK and EDHEN metadata repositories, its data will be findable and searchable via unique DOIs for data set releases. Data downloads will be provided in a research-ready format with linkage to secondary care, trial, and mortality repositories; thus, data will be both interoperable and accessible [23]. Our validated case definitions will be published as ontologies in open platforms to allow them to be used by other researchers and replicated across data platforms.

Cloud computing, which we plan to implement within work stream 3, will facilitate collaborative work and enable us to deploy the computing power needed in the future to work with genetic data. The latter is essential if we are to ultimately move to the delivery of more personalized medicine [24]. Plans are well advanced for these approaches in cardiovascular disease and diabetes, but not yet in infections [25,26].

The ORCHID team will use established standard operating procedures and data security arrangements from the Oxford RCGP RSC to rapidly upscale work into the new hub. Funding streams from commercial revenue and research grants can sustain and enhance the management structures within ORCHID to offer rapid and equitable access to data. Existing mechanisms of feedback to participating practices are well-established and have been refined over previous iterations to provide data in a manner that is useful for practice-level quality improvement. Feedback to local practices can provide important data to inform and improve clinical care and is a valuable educational resource. There are recognized problems in terms of variation in provision of health care across the United Kingdom; this improvement in data quality may help identify and address these problems [27].

Establishing a readily scalable national near–real time data platform to collect and collate primary care health records offers enormous opportunities for future research. Implementation of clinical trials in general practice currently requires data reporting from individual practice sites to a centralized trial team. The ability of a platform to provide outputs in near–real time will enable more streamlined, integrated clinical trials with direct monitoring from the trial team. One such trial is PRINCIPLE, a collaboration between the Oxford Primary Care Clinical Trials Unit and the Oxford RCGP RSC 19. This is a platform randomized trial of interventions such as hydroxychloroquine and azithromycin to treat COVID-19 in general practice that was established in-pandemic. PRINCIPLE will use the RCGP RSC's network of research-ready practices to implement the trial and allow remote follow-up of participants to directly ascertain key outcomes recorded in routine data, including hospital admission, mortality, and adverse events. PRINCIPLE offers an opportunity to validate and refine the data management and analysis systems before widespread access to ORCHID is operational. The Trials Platform will enable researchers to use this approach in future trials to search and record outcomes at a higher population level, helping to reduce workload, improve event recording, and facilitate large-scale, high-quality clinical trials based in primary care. Lower cost research with faster outputs will enable the results of the trials to feed back into practice more quickly for the benefit of patients.

There are plans to add further platforms to the hub in the near future. The next platform may be a Diagnostics Platform, which will support implementation of a range of new diagnostic tests in primary care [28]. Rapid point of care tests for influenza have previously been piloted in the RCGP sentinel network [29]. These tests promise to reduce clinical uncertainty [30], enabling decisions to be made by primary care clinicians closer to the onset of symptoms. Within the context of COVID-19, the Diagnostic Platform could support new point of care tests in general practice surgeries, provide research data to compare the diagnostic performance of swab-based versus serology-based testing, or facilitate novel tests and treatment trials that may pave the way for the widespread introduction of newer antiviral medications that require laboratory-confirmed diagnoses [31]. The links to surveillance and trial platforms would enable joined-up follow-up of participants, reducing costs and shortening the time for new diagnostic equipment to be brought into practice.

Limitations

Information governance is a crucial component of the planned ORCHID. The Surveillance Platform with PHE comes under Regulation 3 of the Health Service (Control of Patient Information) Regulations 2002, including the more recent COVID-19 notices. Therefore, in some cases, identifiable patient data will be included on the platform, and individuals whose data reside there will not have the choice to opt out of providing their pseudonymized data for health protection purposes. While this does not allow the usual autonomy of personal data that health care records afford, there is tension between individual privacy and data protection and the need for national surveillance of communicable disease and the potential public health benefit of monitoring the population to determine the impact of health interventions. By providing a secure, trusted database with limited access to researchers and health commissioners, we would ensure that any access to data conforms with ethical guidance and data security regulations. Patients will retain the right to opt out of providing their data for any other research purpose. There is evidence to suggest

that patients who opt out may be different from the wider population, with young people particularly likely to decline access to their data. This may lead to selection bias and an unrepresentative sample, particularly in studies focused on younger people. Missing or incomplete data may also impact the data linkage process. As with all routinely collected data, data quality relies on accurate coding in clinical practice. Our systems will be able to provide feedback to member practices on their quality of coding to promote change, such as highlighting possible financial benefits from improved coding through Quality and Outcomes Framework payments. Trust and professionalism are key to delivering a project of this type, particularly when done at pace. We are mindful of this and include active communication in work streams 4 and 5 [32-34].

Conclusion

Equitable, innovative use of big data is recognized as an implementation priority in the UK government's Life Sciences Industrial Strategy. ORCHID addresses this need by applying FAIR metadata principles to provide a unique, secure data hub that supports routinely collected primary care data linked to other key health care repositories. The hub is designed to support rapid data access, analysis, and dissemination. Dedicated platforms will initially support national enhanced surveillance of communicable disease and integrated, streamlined, large-scale clinical trials with future platforms to follow, including for diagnostics. This hub will support a professional network of clinicians to create sustainable partnerships, promoting future research and development in general practice, the point of most contacts for patients with the health care system. Practices can join or request further information by emailing the Oxford RCGP RSC Practice liaison team at practiceenquiries@phc.ox.ac.uk.

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Authors' Contributions

SdL and RH conceived the idea for the paper. NJ and JD wrote the first draft. RB, HL, JB, FF, PN, and JW all contributed to the individual workflow stream questions. All authors reviewed the draft manuscript and provided comments.

Conflicts of Interest

CB and JP are employees of TPP, and that AE, IW, and SH are employees of EMIS. Both TPP and EMIS are commercial partner organisations for this project.

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Abbreviations

ACE: angiotensin-converting enzyme
CMR: computerized medical record
COVID-19: coronavirus disease
dm+d: Dictionary of Medicines and Devices
DOI: digital object identifier
EDHEN: European Health Data & Evidence Network
EMIS: Egton Medical Information Systems
FAIR: Findable, Accessible, Interoperable, and Reusable
FDA: US Food and Drug Administration
FHIR: Fast Healthcare Interoperability Resources
HES: Hospital Episode Statistics
HL7: Health Level 7
NHS: National Health Service
OMOP: Observational Medical Outcomes Partnership
ONS: Office of National Statistics
ORCHID: Oxford Royal College of General Practitioners Clinical Informatics Digital Hub
PHE: Public Health England
PPI: patient and public involvement
PRINCIPLE: Platform Randomised trial of INterventions against COVID-19 In older PeopLE
RCGP RSC: Royal College of General Practitioners Research and Surveillance Centre
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
SNOMED: Systematized Nomenclature of Medicine
SQUIRE: surveillance, quality improvement, research, and education
TPP: The Phoenix Partnership

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Original Paper

Complementing the US Food and Drug Administration Adverse Event Reporting System With Adverse Drug Reaction Reporting From Social Media: Comparative Analysis

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Abstract

Background: Adverse drug reactions (ADRs) can occur any time someone uses a medication. ADRs are systematically tracked and cataloged, with varying degrees of success, in order to better understand their etiology and develop methods of prevention. The US Food and Drug Administration (FDA) has developed the FDA Adverse Event Reporting System (FAERS) for this purpose. FAERS collects information from myriad sources, but the primary reporters have traditionally been medical professionals and pharmacovigilance data from manufacturers. Recent studies suggest that information shared publicly on social media platforms related to medication use could be of benefit in complementing FAERS data in order to have a richer picture of how medications are actually being used and the experiences people are having across large populations.

Objective: The aim of this study is to validate the accuracy and precision of social media methodology and conduct evaluations of Twitter ADR reporting for commonly used pharmaceutical agents.

Methods: ADR data from the 10 most prescribed medications according to pharmacy claims data were collected from both FAERS and Twitter. In order to obtain data from FAERS, the SafeRx database, a curated collection of FAERS data, was used to collect data from March 1, 2016, to March 31, 2017. Twitter data were manually scraped during the same time period to extract similar data using an algorithm designed to minimize noise and false signals in social media data.

Results: A total of 40,539 FAERS ADR reports were obtained via SafeRx and more than 40,000 tweets containing the drug names were obtained from Twitter's Advanced Search engine. While the FAERS data were specific to ADRs, the Twitter data were more limited. Only hydrocodone/acetaminophen, prednisone, amoxicillin, gabapentin, and metformin had a sufficient volume of ADR content for review and comparison. For metformin, diarrhea was the side effect that resulted in no difference between the two platforms (P=.30). For hydrocodone/acetaminophen, ineffectiveness as an ADR that resulted in no difference (P=.60). For gabapentin, there were no differences in terms of the ADRs ineffectiveness and fatigue (P=.15 and P=.67, respectively). For amoxicillin, hypersensitivity, nausea, and rash shared similar profiles between platforms (P=.35, P=.05, and P=.31, respectively).

Conclusions: FAERS and Twitter shared similarities in types of data reported and a few unique items to each data set as well. The use of Twitter as an ADR pharmacovigilance platform should continue to be studied as a unique and complementary source of information rather than a validation tool of existing ADR databases.

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KEYWORDS

adverse drug reactions; FAERS; social media reporting; pharmacovigilance

Introduction

Background

Adverse drug reactions (ADRs) are the unintended effect of medicine at doses used for prophylaxis, diagnosis, or treatment [1]. ADRs can occur anytime when a patient takes a medication. Factors including drug and food interactions, medication errors, allergies, and metabolism contribute to the occurrence of ADRs. ADRs have been identified as one of the leading causes of death in the United States. ADRs resulted in more deaths than the pulmonary diseases, diabetes, HIV/AIDS, and pneumonia [2,3]. A systematic review on ADR-induced hospital admissions found that 5.3% of hospital admissions were associated with ADRs [4]. New drug therapies, the aging population, and polypharmacy expose the population to increased risks of ADRs [5]. The burden of ADRs necessitates appropriate detection and assessment, and reporting is fundamental to successful pharmacovigilance systems.

The US Food and Drug Administration (FDA) Adverse Event Reporting System (FAERS) is a database for reports of adverse events, medication errors, and product quality complaints [6]. Although FAERS serves as a valuable data source for postmarket pharmacovigilance, only drug manufacturers are required to send reports received from health care professionals and consumers to the FDA. Health care professionals and consumers may voluntarily submit reports, which may lead to incomplete data in FAERS. In order to obtain more comprehensive information on drug products, multiple data sources should be used to fill the information gap.

Social media has been proposed as a potential data source as it allows an easily accessible information sharing platform with almost no chronological and geographical constraints. A systematic review of 51 studies compared ADR reports on social media and other pharmacovigilance systems, and the review noted that the prevalence of all ADR reports ranged from 0.2% to 8% and social media contained more reports of mild ADRs than severe ADRs [7]. Previous studies showed that ADRs were underrepresented in clinical trial data, and less severe ADRs were more frequently reported on social media. Social media ADR reports reflected the ADRs reported on FAERS on average 11 months earlier [8,9]. Comparative studies suggested the practicality of using social media as a complementary resource and demonstrated a moderate agreement on ADR data between social media and FAERS [10,11]. These studies have shed light on the role of social media in ADR reporting. However, many studies only examined one or two less commonly used pharmaceutical agents, and some included more than 1000 drugs. While the inclusion tested a general scheme of social media reporting, it overlooked the role of social media reporting for common drugs.

The Center for Medication Safety Advancement (CMSA) at Purdue University College of Pharmacy aims to adopt previous research strategies and compare ADR reports in social media and FAERS. Twitter was selected as the social media for evaluation thanks to its simplicity and timeliness in information sharing and access. Twitter users can report an ADR in one tweet pursuant to the FDA guideline, which requires as a minimum dataset to constitute a viable report an identifiable patient, an identifiable reporter, a product exposure, and an adverse event [12]. Additionally, the FDA does not require reports to demonstrate causation or to be specific regarding the type of error. All suspected medication errors, ADRs, or adverse events are accepted as reports. Given the advantage of the Twitter database, the objective of this study is to validate the accuracy and precision of the research methodology and conduct evaluations of social media ADR reporting via tweets for commonly used pharmaceutical agents.

Ethics Statement

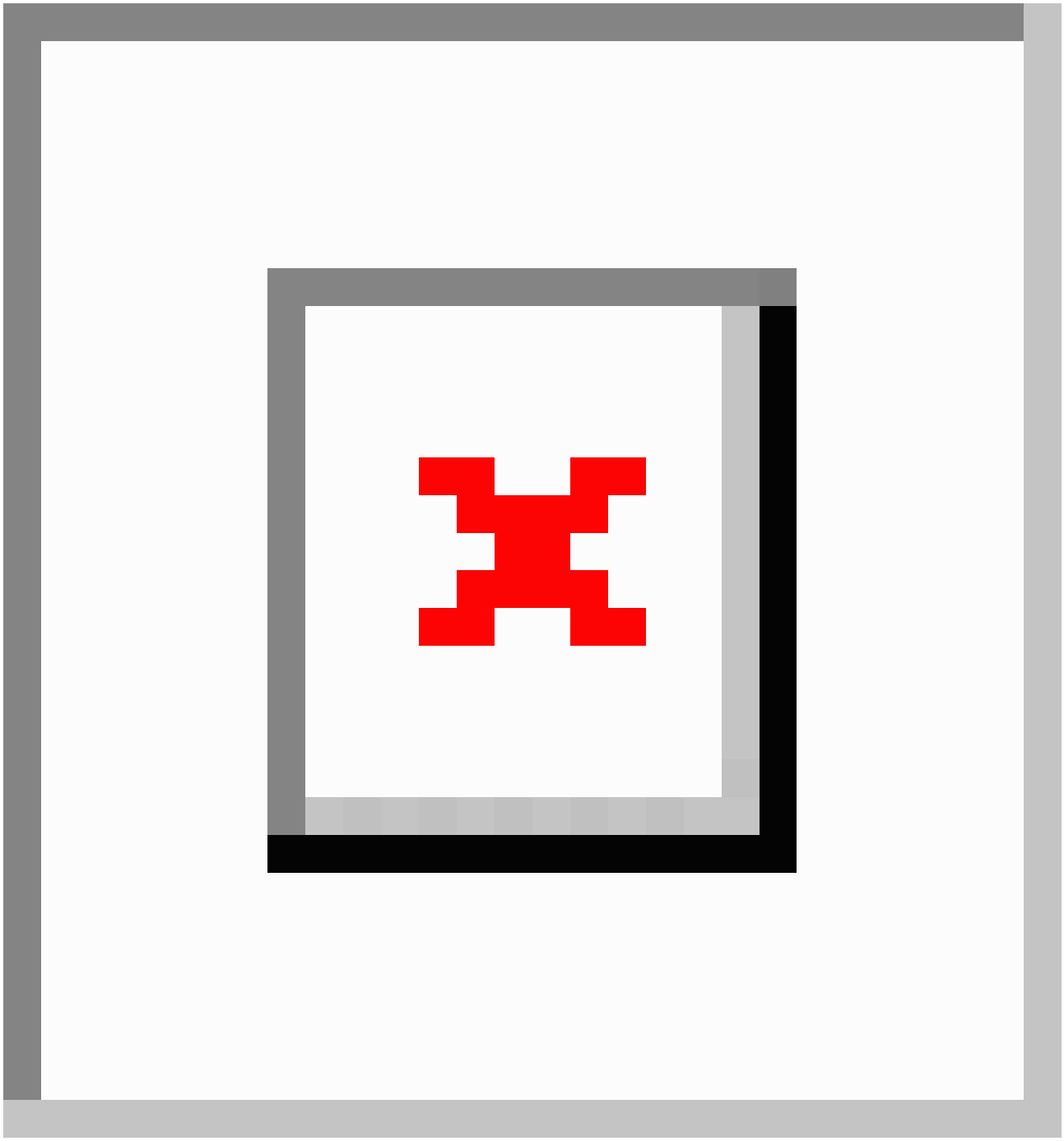
All social media data used in data collection and analysis were extracted from public sources. Example tweets were paraphrased and edited to prevent unmasking through a reverse search on Twitter. FAERS reports on SafeRx were also anonymized. As data used in this study were publicly available, no institutional review board approval was sought.

Methods

Overview

This study was divided into 3 sections: drug selection, FAERS data collection, and Twitter data collection. Collecting FAERS data included searching for ADR reports of a pharmaceutical agent and calculating relative frequencies of the 5 most frequently reported ADRs, whereas Twitter data collection required an additional step to identify relevant tweets according to inclusion and exclusion criteria. Figure 1 demonstrates the overall scheme for the methodology of this study.

Figure 1. Methodology scheme. ADR: adverse drug reaction; FAERS: FDA Adverse Event Reporting System.



Pharmaceutical Agents

To identify the 10 most popular prescribed medications, prescription data were used from GoodRx, a health care company that operates a telemedicine platform. GoodRx generates a list of the top 10 drugs from monthly claims submitted by pharmacies in the United States; in November 2017, those drugs were hydrocodone/acetaminophen, levothyroxine, prednisone, lisinopril, amoxicillin, gabapentin, metformin, atorvastatin, alprazolam, and amlodipine [13]. Previous studies included both brand and generic names in data collection to expand the data that could be obtained [10,14]. Some studies further suggested that patients tended to use the most common brand name in social media if a drug had multiple brand names [15,16]. Accordingly, this study included common brand names in the searching criteria as Twitter users could be discussing ADRs using common brand names. For the data collection purpose of this study, the most commonly used brand name for each selected drug was identified according to Micromedex: Norco for hydrocodone/acetaminophen, Synthroid for levothyroxine, Deltasone for prednisone, Prinivil for lisinopril, Amoxil for amoxicillin, Neurontin for gabapentin, Glucophage for metformin, Lipitor for atorvastatin, Xanax for alprazolam, and Norvasc for amlodipine.

US Food and Drug Administration Adverse Event Reporting System Data

Purdue University College of Pharmacy's CMSA designed and maintained a searchable database for all published FAERS reports since 2012 under SafeRx. SafeRx enables large-scale studies to improve prescription medication safety as the database contains a collection of 4,935,048 ADRs, representing 294,652 different drugs from the fourth quarter of 2012 through December 2016. ADR reports were obtained via the FAERS Data Explore function in SafeRx. The search criteria were set to display data from March 1, 2016, to March 31, 2017, and the data included both brand and generic names of selected drugs as the primary suspect and the secondary suspect drug. After obtaining all ADR reports from SafeRx, the 5 most reported ADRs for each selected drug were recorded for data analysis.

Twitter Data

Searchability and generalizability were the main factors in selecting Twitter as the social media platform. Twitter's search engine enabled keyword-based searching within a predetermined time frame, and all public tweets containing the keyword could be displayed. According to the Pew Research Center, Twitter users were diverse in terms of age distribution and well balanced in terms of gender and geographic areas at the time of study in 2016 [17]. As medications including hydrocodone/acetaminophen, prednisone, levothyroxine could be prescribed to individuals from all age groups regardless of gender and geographic areas, Twitter's population represented a robust data source for generalizability.

Tweets were obtained from the Advanced Search webpage on Twitter's website [18]. Both generic and brand names of the selected medication were entered as keywords into the "any of these words" field in the Advanced Search engine. To exclude tweets containing advertisements, hyperlinks to external webpages, and retweets, characters including "rt" for retweets, "http," and ".com" were entered into the "none of these words" field. By eliminating tweets from pharmaceutical companies, health care marketers, and agencies, Twitter data became more comparative to the FAERS data. Table 1 describes additional exclusion criteria in the selection of tweets. The "written in" field was set so that only tweets in the English language would be displayed. The time frame was chosen to be from March 2016 to March 2017 in order to correspond with the FAERS data obtained from CMSA's SafeRx database. All tweets displayed were subsequently reviewed to include only those that described ADRs after consuming the medication. Those tweets served as the final source for data recording, which included the username, offending medication, content of the tweet, and types of ADRs. At the time of data collection, the number of tweets was benchmarked at 100 for analysis.

Table 1. Additional exclusion criteria in the collection of tweets.

Exclusion criteria	Examples
ADRs[a] described a metaphorical narration instead of a true patient experience.	"He slept for a whole night like he took 20 Xanax"
ADRs occurred long before the date of tweeting.	"Lipitor gave me muscle aches when I took it 10 years ago"
Tweet was a part of copied lyrics, lines from books, and other forms of literature.	"Xanax got me sleeper. Leanin' by the liter"
Tweet did not include the 4 minimal requirements to construct a report.	Tweets lacking the person who was reporting, the person who experienced the ADR, name of the drug, and the actual ADR.

[a]ADR: adverse drug reaction.

Statistical Analysis

The analysis of ADR data from SafeRx and Twitter included the following components: calculation of relative frequencies, examination of ADR distribution, and test for association and independence. A chi-square test was used to statistically quantify the difference in ADRs between the FAERS data and Twitter data. It was appropriate to use the chi-square test as no cell in the cross-tabulation contained an expected value of 5 or below. The sample size required to achieve an a priori $\alpha<.01$ was 96, and samples from both sources exceeded the threshold. The null hypothesis (H0) was "there is no significant difference between FAERS data and Twitter data on common ADRs." The failure to reject H0 would signify that Twitter data were similar to and independent from the FAERS data. The statistical analysis in this study was conducted using SAS version 9.4 (SAS Institute Inc).

Results

US Food and Drug Administration Adverse Event Reporting System Data Result

A total of 40,539 FAERS ADR reports from March 1, 2016, to March 31, 2017, were obtained via SafeRx. Table 2 summarizes the 5 most reported ADRs for each of the 10 drugs.

Table 2. Five most frequently reported FDA Adverse Event Reporting System adverse drug reactions from March 1, 2016, to March 31, 2017, for each selected drug on SafeRx.

Drug and the top 5 adverse drug reactions	n (%)
Hydrocodone/acetaminophen (Norco, n=1765)	
Ineffectiveness	429 (24.31)
Nausea	371 (21.02)
Fatigue	353 (20.00)
Pain	345 (19.55)
Headache	267 (15.13)
Levothyroxine (Synthroid, n=3728)	
Fatigue	881 (23.63)
Ineffectiveness	828 (22.21)
Nausea	733 (19.66)
Headache	664 (17.81)
Diarrhea	622 (16.68)
Prednisone (Deltasone, n=5689)	
Ineffectiveness	1423 (25.01)
Fatigue	1332 (23.41)
Dyspnea	1067 (18.76)
Nausea	976 (17.16)
Diarrhea	900 (15.82)
Lisinopril (Prinivil, n=5386)	
Ineffectiveness	1243 (23.08)
Fatigue	1172 (21.76)
Diarrhea	1136 (21.09)
Nausea	1062 (19.72)
Dyspnea	773 (14.35)
Amoxicillin (Amoxil, n=797)	
Hypersensitivity	328 (41.15)
Fatigue	126 (15.81)
Diarrhea	123 (15.43)
Nausea	121 (15.18)
Rash	99 (12.42)
Gabapentin (Neurontin, n=5734)	
Ineffectiveness	1637 (28.55)
Fatigue	1220 (21.28)
Nausea	997 (17.40)
Pain	966 (16.85)
Diarrhea	914 (15.94)
Metformin (Glucophage, n=5109)	
Hyperglycemia	1311 (25.66)
Nausea	1111 (21.75)
Ineffectiveness	973 (19.04)
Diarrhea	919 (18.00)

Drug and the top 5 adverse drug reactions	n (%)
Fatigue	795 (15.56)
Atorvastatin (Lipitor, n=6588)	
Type 2 diabetes	4601 (69.84)
Hypersensitivity	586 (8.89)
Fatigue	537 (8.15)
Ineffectiveness	445 (6.75)
Nausea	419 (6.36)
Alprazolam (Xanax, n=2551)	
Ineffectiveness	561 (21.99)
Fatigue	548 (21.48)
Nausea	547 (21.44)
Anxiety	451 (17.68)
Headache	444 (17.40)
Amlodipine (Norvasc, n=3192)	
Diarrhea	696 (21.80)
Fatigue	682 (21.37)
Ineffectiveness	636 (19.92)
Nausea	611 (19.14)
Dyspnea	567 (17.76)

Twitter Data Result

More than 40,000 tweets containing the drug names as keywords from March 1, 2016, to March 31, 2017, were obtained from Twitter's Advanced Search engine. Although searching on Twitter yielded an overall large quantity of tweets, ADRs of some drugs were simply not mentioned in enough tweets. Within the study period, searching keywords levothyroxine and Synthroid yielded 50 relevant tweets, keywords alprazolam and Xanax resulted in 35 relevant tweets, lisinopril and Prinivil were found in 33 relevant tweets, and only 3 relevant tweets were found for atorvastatin and Lipitor. No relevant tweets were found for keywords amlodipine and Norvasc. Due to the insufficiency of relevant tweets to meet the benchmark, the final Twitter data analysis did not include levothyroxine, alprazolam, lisinopril, atorvastatin, and amlodipine. Table 3 presents the ADRs reported for the remaining 5 drugs.

Table 3. Reported adverse drug reactions on Twitter from March 1, 2016, to March 31, 2017, for 5 drugs.

Drugs and adverse drug reactions	Value %
Hydrocodone/acetaminophen	
Fatigue	36
Ineffectiveness	22
Pruritus	10
Nausea	9
Mood changes	5
Vivid dreams	3
Insomnia	3
Headache	2
Constipation	2
Dizziness	2
Chest tightness	1
Delusion	1
Hallucination	1
Singultus	1
Inattention	1
Short-term amnesia	1
Sweating	1
Vomiting	1
Prednisone	
Insomnia	25
Increased appetite	23
Mood changes	10
Moon face	8
Weight gain	8
Fatigue	5
Muscle weakness	4
Jitteriness	3
Diaphoresis	2
Tachycardia	2
Anxiety	2
Bradycardia	1
Cataracts	1
Xerostomia	1
Dyspnea	1
Heartburn	1
Osteoporosis	1
Stomachache	1
Visual hallucination	1
Thirst	1
Amoxicillin	
Hypersensitivity	46

Drugs and adverse drug reactions	Value %
Rash	16
Ineffectiveness	15
Nausea	8
Diarrhea	5
Fatigue	3
Pruritus	3
Vomiting	3
Stomachache	1
Gabapentin	
Drowsiness	31
Fatigue	24
Ineffectiveness	23
Weight gain	8
Dizziness	5
Nausea	2
Blurred vision	1
Dysphasia	1
Confusion	1
Headache	1
Jitteriness	1
Mood changes	1
Vivid dreams	1
Metformin	
Nausea	57
Diarrhea	22
Ineffectiveness	5
Fatigue	3
Renal dysfunction	3
Bloating	2
Headache	2
Hypersensitivity	1
Heartburn	1
Hypoglycemia	1
Mood changes	1
Vomiting	1

Drug and Adverse Drug Reaction Matching

The process was completed through consolidating the ADRs reported in the Twitter dataset to match the top 5 ADRs from SafeRx. Following the matching, a chi-square test was performed to test nonsignificant differences in the relative frequencies of an ADR between FAERS data and Twitter data. In order to demonstrate the similarity of Twitter's ADR profile with that of FAERS, one should fail to reject H0 according to the *P* value from the chi-square test. Table 4 shows matched ADRs between the two data sources, relative frequencies of ADRs of each drug, and the results of chi-square test.

Table 4. Matched adverse drug reactions and chi-square test results for 5 drugs.

Drug and adverse drug events	Relative frequencies, FAERS[a] data (%)	Relative frequencies, Twitter data (%)	Chi-square	*P* value
Hydrocodone/acetaminophen				
Ineffectiveness	24.31	22.00	0.3	.60[b]
Nausea	21.02	9.00	5.3	.02
Fatigue	20.00	36.00	14.7	<.001
Headache	15.13	2.00	13.2	<.001
Prednisone				
Fatigue	23.41	5.00	18.8	<.001
Dyspnea	18.76	1.00	47.0	<.001
Amoxicillin				
Hypersensitivity	41.15	46.00	0.9	.35[b]
Diarrhea	15.43	5.00	7.9	.005
Nausea	15.18	8.00	3.8	.05[b]
Fatigue	15.81	3.00	11.8	<.001
Rash	12.42	16.00	1.0	.31[b]
Gabapentin				
Ineffectiveness	28.55	22.00	2.1	.15[b]
Fatigue	21.28	23.00	0.2	.68[b]
Nausea	17.40	2.00	16.4	<.001
Metformin				
Nausea	21.75	57.00	70.1	<.001
Ineffectiveness	19.04	5.00	12.7	<.001
Diarrhea	18.00	22.00	1.1	.30[b]
Fatigue	15.56	3.00	11.9	<.001

[a]FAERS: US Food and Drug Administration Adverse Event Reporting System.

[b]Indicates a *P* value above .05, leading to the failure of rejecting the null hypothesis and indicating that there is no difference in ADR frequency reported between FAERS and Twitter.

Discussion

Principal Findings

Among the 5 drugs in the final analysis, a number of Twitter ADR relative frequencies were not significantly different from those of FAERS ADRs. For metformin, diarrhea was one of the side effects. As no significant difference was detected between FAERS and Twitter data on diarrhea (*P*=.30), it showed that Twitter ADR reports could be further studied for their use as a complementary ADR dataset. In the hydrocodone/acetaminophen group, there were no significant differences in ineffectiveness between sources (*P*=.60). Gabapentin was shown to comparatively result in ineffectiveness and fatigue according to FAERS and Twitter (*P*=.15 and *P*=.67, respectively). Three ADRs of amoxicillin, hypersensitivity, nausea, and rash, shared similar profiles on FAERS and Twitter (*P*=.35, *P*=.05, and *P*=.31, respectively).

ADRs remain one of the leading causes for preventable hospital admissions, reduced quality of life, increased financial burdens in the society, and mortality [19]. Prevention relies on adherence to evidence-based medicine, monitoring, medication therapy management, and pharmacogenomic testing [20]. Management of ADRs should emphasize effective prevention and timely detection, yet the current ADR reporting mechanism has shown delays in detection [21]. The cause for delays is multifactorial. Consumers might not know about such a reporting system, and the reporting steps could be troublesome. Further, as clinicians and patients are not required to report ADRs, many could be underreported. Social media and online resources have been proposed as additional resources for pharmacovigilance. In 2017, MacKinlay et al [22] evaluated ADRs of 3055 drugs on Twitter and found that Twitter had up to 72% precision of ADR detection. By extracting ADRs of erlotinib, nivolumab, and pembrolizumab through social health networks, Nikfarjam et al [23] detected that social media ADRs were comparable and 7 months ahead of ADRs from literature reports. Along with

numerous major publications on validating ADR reports across different social media platforms, Hoang et al [24] took a step further and incorporated content authenticity and user credibility to improve ADR detection on Twitter. With more advanced technology for data mining and ADR detection, social media can serve as an additional channel for monitoring ADRs.

In this study, 10 drugs were identified, and ADR reports of these drugs on Twitter were retrospectively obtained by searching for tweets containing the drug names that mentioned ADR experiences. While adopting comparative methods used in previous studies, this study specifically focused on the 10 most commonly prescribed drugs to investigate if discrepancies existed pursuant to different drugs. Based on the results of this study, FAERS data and Twitter data showed some similar ADR profiles for hydrocodone/acetaminophen, amoxicillin, gabapentin, and metformin. In the data collection process, levothyroxine, alprazolam, lisinopril, and atorvastatin did not appear as keywords in sufficient tweets from March 1, 2016, to March 31, 2017. A possible explanation of the low number of tweets is the demographics of patients taking these medications. Atorvastatin, a lipid-lowering agent, is usually initiated for elderly patients, as are the antihypertensive agents lisinopril and amlodipine. Individuals aged 50 to 64 years and those older than 65 years represented 21% and 10% of all Twitter users, respectively [16]. Fewer Twitter users in these age ranges could potentially explain the low number of tweets for those drugs. The number of reports of these 3 drugs on FAERS further demonstrates that the lack of tweets was due to fewer users, as atorvastatin, lisinopril, and amlodipine had 6588, 5386, and 3192 reports on FAERS. Other social media–based studies have also experienced this challenge and achieved opposite conclusions due to inactivity for most of the drugs studied on social media [25,26]. Nevertheless, data from the remaining drugs indicates the potential role of Twitter as a complementary source of ADR reporting to FAERS.

The similarities observed for some ADRs between Twitter and FAERS data were disparate across the individual drugs studied. This variability further suggests that patients' actual experiences with medications are not being shared with their providers or that providers have not reported these experiences to national ADR repositories at a similar rate. Moreover, the insufficiency of tweets for some drugs may indicate that social media ADR reporting should consider drug classes and the demographics of patients taking them. One recommendation is to further investigate social media ADR reporting for drugs that are consumed by a population that represents a large share of social media users and drugs that require early ADR detection.

In addition to being a supplementary data source for pharmacovigilance services, social media can also serve as a resource for pharmaceutical companies, regulatory bodies, researchers, health care professionals, patients, and policymakers. In this study, ineffectiveness appeared as an ADR for hydrocodone/acetaminophen, gabapentin, and metformin on both data sources. Gabapentin, for example, takes time to exert its full effect in controlling neurological pain. As 23.00% of Twitter ADRs and 28.55% of FAERS ADRs for gabapentin were ineffectiveness, it should encourage prescribers and pharmacists to consult patients on the time lag between taking the medication and seeing its effect. This study result should also prompt patient education on regular monitoring and diet adjustment when managing diabetes, as ineffectiveness for an antidiabetic drug, metformin, was 19.04% and 5.00% of all ADRs on FAERS and Twitter, respectively. Data mining to track ineffectiveness for hydrocodone/acetaminophen may offer a potential avenue for regulatory bodies in examining opioid use patterns.

Limitations

This study does have two prominent limitations: sample size and search methodology. Among multiple social media platforms, only Twitter was selected as the data source. Despite Twitter's users being from multiple age groups, patients may choose to share their ADR experiences on other sites such as Facebook, Instagram, Reddit, and online forums, which prevented this study from examining social media data across different platforms. Additionally, due to Twitter's privacy setting, private tweets are not searchable, which can reduce the number of tweets for data collection. The sample size of tweets obtained for the drugs was relatively small compared with that of FAERS reports from March 1, 2016, to March 31, 2017. The sample size could be largely increased in future studies as Twitter contains a large collection of tweets. During the search process, the keywords hydrocodone/acetaminophen and Norco yielded more than 100 tweets in the time period, which could potentially improve the accuracy of Twitter ADR data. However, there was a lack of relevant tweets for 4 of the 10 drugs, even with the benchmark of 100 tweets. This situation could potentially be resolved by extending the time frame to more than 1 year; however, the extent of sample size improvement might not be significant given the low number of social media users when studying specific drugs such as atorvastatin and amlodipine.

Regarding the search mechanism, only one common brand name per drug was used to search for tweets, yet many drugs have multiple brand names. Lisinopril is sold under the brand names Prinivil and Zestril, and levothyroxine has brand names Synthroid, Levoxyl, and Thyrax. Using only one brand name in the study could limit the number of tweets obtained in this study, as patients might have shared their ADRs by using the brand names that were not included in this study. Other challenges to gathering all tweets through keywords include typographical errors, abbreviations, and unstructured lexicons. Furthermore, social media intrinsically bears a limitation in terms of patient follow-up. So far, research methodology involving social media pharmacovigilance has yet to be capable of investigating the causes of ADRs, the consequences of ADRs, and the actions taken to resolve ADRs. Some challenges are being tackled by computational technologies. For example, text normalization and classification through machine learning have been investigated by Sarker et al [27], and they offered insights into processing text data on social media. Other challenges of social media ADR reporting may continue to be barriers for taking full advantage of this data source.

Although social media cannot replace professional reporting systems such as FAERS at this stage, studies including this analysis have indicated the role of social media as a tool for

early detection and a reporting system for mild symptoms. To demonstrate the accuracy and usability of social media ADR data in complementing FAERS, future studies may benefit by using a larger sample of data, including specific drugs, and assessing multiple social media platforms. It is also important to apply technology, along with structured reporting systems, to avoid arbitrary entries to better provide health care professionals, regulatory bodies, patients, and pharmaceutical companies with robust ADR data.

Conclusion

While the use of Twitter as an ADR reporting platform has limitations, should be considered as a unique and complementary source of information rather than a validation tool of an existing ADR database. Future research should focus on validating Twitter and other social media platforms using involving larger sample sizes and different medications. Additionally, evaluating the types of ADRs on social media that share the most similarity with those on FAERS would be helpful to promote effective use of this source of information.

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Conflicts of Interest

None declared.

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Abbreviations

ADR: adverse drug reaction
CMSA: Center for Medication Safety Advancement
FAERS: FDA Adverse Event Reporting System
FDA: US Food and Drug Administration

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Original Paper

Text Mining of United States Obesity-Related Public Policies: Systematic Document Search

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Abstract

Background: Obesity has become a worldwide health problem, caused by multiple and complex factors. To face this challenge, governments have played a central role in combating its rise. Considering this, public policies are introduced or enacted for the benefit of whole populations, taking into account the perspective of multiverse social stakeholders based on solid scientific fundamentals.

Objective: The aim of this study was to examine obesity-related public policies in the United States and the District of Columbia, in order to understand their scientific basis.

Methods: We analyzed the public policies implemented in the United States from 2003 to 2013, during which time the largest number of obesity-related public policies were introduced, using text mining.

Results: In total, 1592 obesity-related public policies were retrieved from the Centers for Disease Control and Prevention. Multidisciplinary policies were predominant in the documents analyzed (533/1592, 33.5%), followed by health sciences (454/1592, 28.5%), social sciences (330/1592, 20.7%), life sciences (240/1592, 15.1%), and physical sciences (35/1592, 2.2%). Throughout the country, most policies were community oriented (1082/1865, 58.0%) and many of them were related to school and family environments (447/1865, 24.0%), early care and education (75/1865, 4.0%), hospitals (63/1865, 3.4%), and workplaces (47/1865, 2.5%).

Conclusions: The contents of obesity-related public policies were generally uniformly framed across the United States. They were generally based on scientific references, in which there was a predominance of multidisciplinary research. These findings are consistent with what is known about the multiple factors causing obesity and about the methods being developed to control the epidemic.

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KEYWORDS

government; data mining; school; health policy

Introduction

Obesity is the result of a complex set of interactions among multiple factors, and it is considered a worldwide problem. Due to its established health risks and substantial increases in its prevalence, obesity has become a global health challenge. Based on data from the Organization for Economic Co-operation and Development, across the globe, 19.5% of the adult population was obese in 2015. This rate ranged from less than 6.0% in

Korea and Japan to more than 30.0% in Hungary, New Zealand, Mexico, and the United States [1,2].

Projections made by the Organization for Economic Co-operation and Development [1] show that, in the US, Mexico, and England, 47.0%, 39.0%, and 35.0% of the population, respectively, will be obese by 2030. Considering the high obesity rates around the world, many stakeholders, including the public, scientific communities, media, and governments have been involved in finding ways to prevent and control obesity. The growing number of scientific publications on this topic shows its importance. There is an increasing consensus regarding the importance of and urgency in searching for solutions to obesity, which has placed the issue on many countries' political agendas, as is the case in the US [3].

Nutrition is presented as a challenging issue, requiring an expanded view that demands different theoretical references for its exploration [4]. Obesity also requires broad interdisciplinary analysis and a sustained response from society [5]. Considering these aspects, the formulation of policies is considered more complex due to the multidimensionality of obesity. In order to overcome this difficulty, the scientific basis used in the development of those policies can be studied.

Researchers generally share the view that science should support the elaboration of policies [6-9]. Science should be used to respond to the demands of society and industry as well as to support the government and its political decisions [10,11]. In order to succeed in nutrition-related policies, it is important to have an adequate level of scientific evidence with the objective of avoiding unintended consequences. Scientific inquiry has been used to contribute to the process of nutrition policy making [12].

The US government plays an important role in health promotion and disease prevention among the US population. The states have legislative and regulatory interests that encourage individuals to eat healthy foods and lead active lives; therefore, the state and local governments implement comprehensive and multisectoral solutions to improve the health of their citizens and prevent obesity [13].

The aim of this study was to examine the official obesity-related public policies in all the states and in the District of Columbia using text mining, in order to identify which areas of knowledge have guided the development of these policies. Text mining is a knowledge discovery process that uses data extraction and analysis techniques from texts, phrases, or words. It involves the application of computational algorithms that process text and identify useful and implicit information that could not normally be retrieved using traditional query methods, since they are usually in an unstructured form [14].

In the last few years, technology has improved information readability and accessibility for researchers, patients, governments, health care professionals, and other information consumers.

> *These technologies can support not only healthcare professionals and patients' situational awareness and decision making but also knowledge discovery in health science (p 128)* [15]

Considering these arguments, this study aims to have two main contributions; it will demonstrate a useful analytical framework for identifying patterns and information from a large volume of documents and that the results obtained can guide government investments in science for its potential contribution to the development of policies related to obesity.

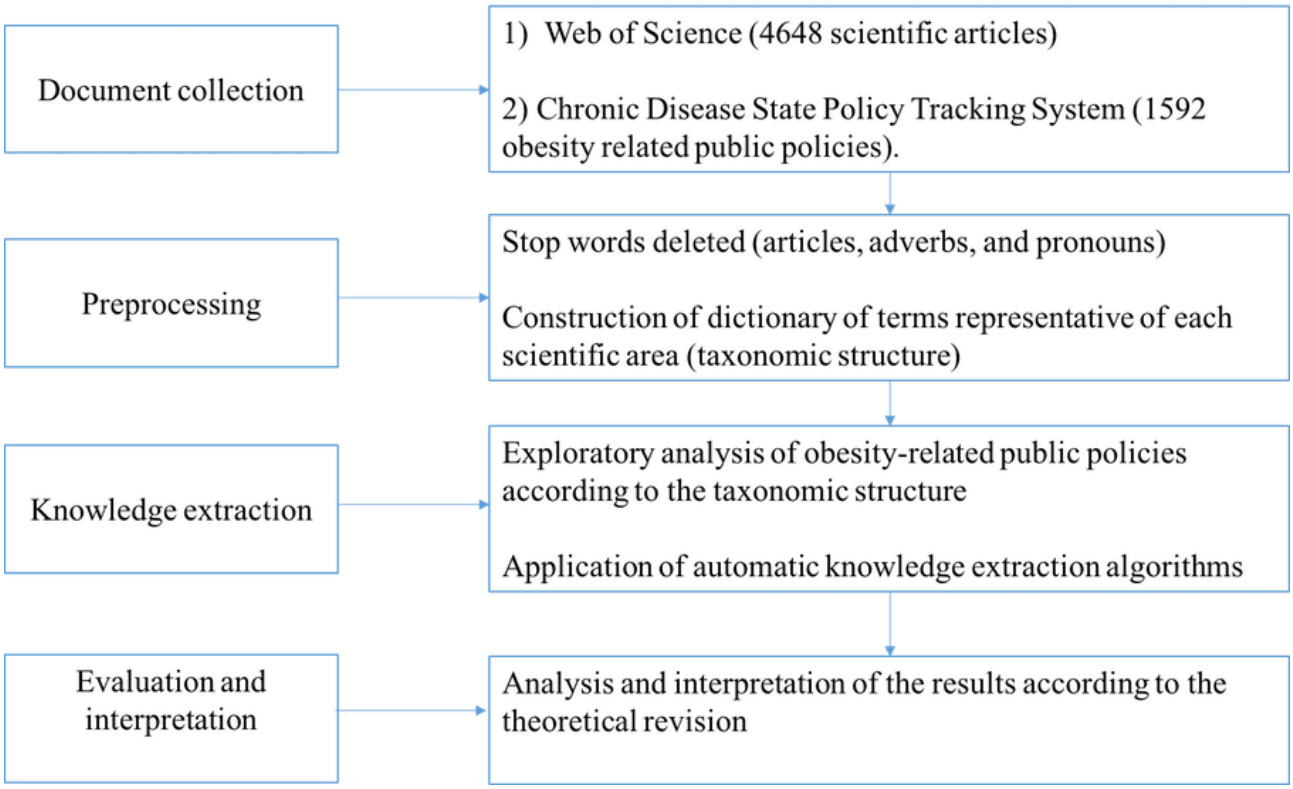
Methods

Text Mining

Text mining, which involved information retrieval, textual analysis, information extraction, clustering, categorization, visualization, database technology, and data mining, was used [16]. Many studies [17-23] have also used text mining in researching different subjects, including health topics. For example, one study [23] analyzed the characteristics of general public opinion in relation to diabetes, diet, exercise, and obesity expressed on Twitter using a multicomponent semantic and linguistic framework.

Text mining can contain several stages; however, some steps are basic in all processes—document collection, preprocessing, knowledge extraction, and evaluation and interpretation of results [24] (Figure 1).

Figure 1. Methodological design.



Document Collection

In the document collection stage, two databases were used. The first was the Web of Science database to search scientific documents. The second was the Chronic Disease State Policy Tracking System to search the summaries of all the obesity-related public policies introduced or established in all states during the period from 2003 to 2013. In that period, we observed greater governmental concern with obesity, and an increased number of public policies.

For scientific articles, we used the set of keywords *food* AND *consumption* AND *obesity* OR *obesogen** in Web of Science to search the scientific documents for the period of 2003 to 2013. The words *food* AND *consumption* were chosen in order to capture articles that deal with diets, food consumption, and eating habits. The words *obesity* OR *obesogen** were chosen because they were directly related to the research object. In addition, this set of words was submitted for validation by experts on this subject. Content validity was a subjective assessment, usually involving consultation with a small sample of experts to judge the appropriateness of the indicators [25].

For obesity-related public policies, we used the search filters available in the Chronic Disease State Policy Tracking System and selected policies related to nutrition, obesity, and physical activity.

Preprocessing

In the preprocessing stage, the terms that would be used for the extraction of knowledge were defined. For that, the stop words, terms with no relevant meaning for the research such as articles, adverbs and pronouns were eliminated. In addition, morphological variations were identified using lemmatization.

Knowledge Extraction

In defining the terms used in the extraction of knowledge, we constructed a taxonomic structure starting with the identification of scientific areas that were found in the obesity-related scientific literature. We organized all the scientific articles according to the journal in which they were published. These journals were subsequently classified according to the scientific area to which they belonged, based on the editorial scope of the journal and established categories in the Web of Science Multimedia Appendix 1. Results were classified into five scientific areas—health sciences, life sciences, physical sciences, social sciences, and multidisciplinary. Complex problems that reached the contemporary scientific agenda generally involved more than one discipline. In this regard, *multidisciplinary* was understood as the possibility of tackling a given subject from multiple viewpoints, encompassing its inherent complexity and extrapolating restrictions related to disciplines [26]. The multidisciplinary approach presented perceptions of two or more disciplines to investigate and solve complex problems [27]. The decision to use these major areas of knowledge was based on the need to improve the explanatory power of the model, namely the taxonomic structure. Thus, we decided to group specific areas (such as pediatrics, general medicine, nursing, etc) due to their similarity, since they belong to the same wide field of health sciences. From that perspective, we considered that a major area of knowledge is made up of disciplines which are similar to each other, but different from other areas.

The next step involved the construction of the dictionary of terms, representative of each scientific area. The list of terms, called *d-words*, was composed of the most relevant keywords that best described the scientific area Multimedia Appendix 2. Each scientific area required a specific list of d-words. Titles,

abstracts, and keywords of the scientific articles were inserted in the QDA Miner software (version 3.2; Provalis Research). In order to determine the list of representative words for each scientific area, we identified words that had a higher term frequency–inverse document frequency product. The *term frequency–inverse document frequency product* was used to evaluate how important a word was to a document in a collection. A high term frequency–inverse document frequency product strongly implied relevance of the word to the document and of the document to the scientific area [28]. The term frequency–inverse document frequency product is composed of the normalized *term frequency,* the number of times a word appears in a document divided by the total number of words in that document, and the *inverse document frequency*, the logarithm of the number of documents in the corpus divided by the number of documents where the specific term appears [29].

We ordered the d-words of each scientific area in decreasing value of term frequency–inverse document frequency product and used the first percentile ranking to select the number of specialized words that best characterized the disciplinary dimension. The resulting number of words depended on the criteria established (which were based on our research objectives) [30].

We identified similar words belonging to different subject dimensions. In order to differentiate the similar terms, we used Jaccard coefficients to find the next two terms, which contextualized them in the respective scientific area. This coefficient ranges from 0 to 1 (ie, the closer to 1, the greater the similarity).

The next step was to insert all the obesity-related public policies into the software for knowledge extraction to be performed following the taxonomic structure described. At this step, an exploratory analysis of the data was performed, based on the frequency of words and word expressions. Automatic knowledge extraction algorithms were applied to search for unknown information [22]. The algorithms were used to group similar objects through a measure of proximity. The last step consisted of evaluation and interpretation.

Evaluation and Interpretation

An exploratory analysis when combined with clustering, allows identifying functional relationships between specific keywords and categories defined by the values of the independent variable. This allows for the visualization of groups of cells with high and low relative frequencies [31].

Clustering analyses were performed directly on the cross-tabulation tables. As a consequence, the similarity index, computed for two keywords or categories and used for clustering, measured the similarity of their distribution among the various groups of the independent variable. A dendrogram was used to visualize how keywords were distributed across the various subgroups such that similar distributions would tend to be grouped under the same cluster [31]. WordStat (Provalis Research) used an average-linkage hierarchical clustering method to create clusters from a similarity matrix. Words or categories that tended to appear together were combined at an early stage, while those that were independent of one another tended to be combined at the end of the agglomeration process [31].

Results

We obtained 131 d-words for health sciences, 92 d-words for life sciences, 72 d-words for multidisciplinary sciences, 55 d-words for social sciences, and 28 d-words for physical sciences. In total, 4648 scientific articles and 1592 obesity-related public policies were analyzed.

The Call to Action to Prevent and Decrease Overweight and Obesity, promoted by the US Surgeon General in 2001, identified obesity as a key public health priority for the US [32]. Most of the policies were concentrated in the years 2009, 2010, and 2011, representing 62.8% (1000/1592) of the total obesity-related public policies analyzed. For example, one of the topics was improving food environments in schools and childcare settings. After 2009, we noted the inclusion of different topics dealing with obesity. These were associated with governmental priorities in this period [33-35].

During the period from 2003 to 2013, the analysis by state showed that Texas had the highest number of obesity-related public policies (101/1592, 6.3%), followed by California (82/1592, 5.2%), Illinois (79/1592, 5.0%), Maryland (70/1592, 4.4%), Arkansas (52/1592, 3.3%), and New York (51/1592, 3.2%), while South Carolina (9/1592, 0.6%), Kansas (8/1592, 0.5%), Alaska (8/1592, 0.5%), Wyoming (7/1592, 0.4%), and South Dakota (5/1592, 0.3%) were among the states that had the lowest number of policies related to obesity.

According to Behavioral Risk Factor Surveillance System data published in 2018 [34], adult obesity rates exceeded 35.0% in 7 US States—Iowa, Oklahoma, Arkansas, Louisiana, Mississippi, Alabama, and West Virginia. Considering the number of obesity-related public policies, these states did not have a large number of policies from 2003 to 2013; Iowa (23/1592, 1.4%), Oklahoma (37/1592, 2.3%), Mississippi (43/1592, 2.7%), Alabama (14/1592, 0.9%), and West Virginia (20/1592, 1.3%) had relatively low numbers of policies. Only Arkansas (52/1592, 3.3%), Louisiana (51/1592, 3.2%), and New York (51/1592, 3.2%) had more than 50 obesity-related public policies. Even the states with the highest number of obesity-related public policies had high rates of obesity. For example, in Texas (highest number of policies), Illinois (third highest number of policies), Maryland (fourth highest number of policies), and Arkansas (fifth highest number of policies), adult obesity rates exceeded 30.0% [36].

In order to understand the complexity and multidimensionality of this issue, it was necessary to know the content and amount of obesity-related public policies. Table 1 shows that most obesity-related public policies were community oriented, followed by those related to school and after school environments, restaurants and food retail, early care and education, medical facilities and hospitals, and lastly, workplace environments.

Table 1. Number of obesity-related public policies in US states (2003-2013).

Setting[a]	Number of policies
Community	1082
School and after school	447
Restaurant and food retail	151
Early care and education	75
Medical facilities and hospital	63
Workplace	47
Total[b]	1865

[a]Elaborated by the authors based on Centers for Disease Control and Prevention [37].

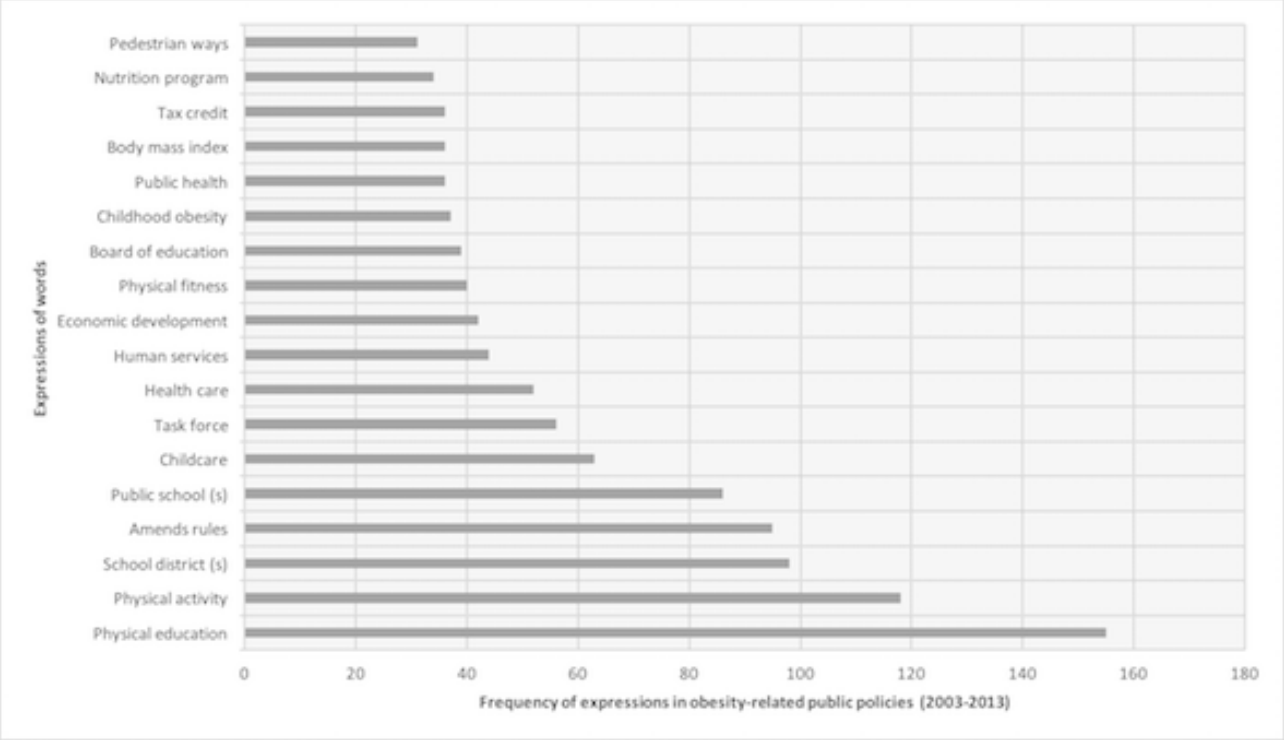
[b]The sum is greater than the number of obesity-related public policies analyzed (1592) because the Centers for Disease Control and Prevention has framed some policies in more than one category.

Most policies were concentrated within the community setting, which included different environments in which people live such as neighborhoods, schools, workplaces, play areas, and places of worship. The content of policies directed to restaurants or food retail locations included menu labeling, access to healthy foods, and food produced locally.

Most of the policies that were analyzed were directed toward modifying environmental factors with the aim of making the environment less obesogenic. We noted that many studies and reports from influential health organizations call on policy and population-based approaches to change the obesogenic environment to combat the obesity epidemic [38]. A number of authors have investigated the influence of the environment on obesity, with some mentioning the influence of fast food in food habits and weight gain [39-41].

With the objective of identifying the most frequent expressions of words in policy content, we selected frequent expressions with a minimum of two and a maximum of four words. This showed which words were more frequent in the set of documents and their focus over time. The most frequent expressions in obesity related public policies included: “physical education” (155/1592, 9.73%), “physical activity” (118/1592, 7.41%), “school district(s)” (98/1592, 6.15%), “amends rules” (95/1592, 5.96%), and “public school(s)” (86/1592, 5.4%). Expressions oriented to early childhood care were also highlighted, as evidenced by the presence of expressions such as “childcare” (63/1592, 3.95%) and “childhood obesity” (37/1592, 2.32%). Moreover, we found expressions related to the practice of physical activities such as “physical fitness” (40/1592, 2.51%) and “pedestrian ways” (31/1592, 1.94%) (Figure 2).

Figure 2. The most frequent obesity-related public policy expressions in US states and the District of Columbia.



We noted that the expression “amends rules” started to appear (2/1592, 0.12%) in 2008. Similar behavior was observed in the expressions “nutrition program” (11/1592, 0.69%) and “pedestrian ways” (1/1592, 0.06%) in 2007. “Childcare”

appeared with more frequency (17/1592, 1.06%) in 2010. On the other hand, the expressions “physical activity” (mean 10.72, range 1-18) and “physical education” (mean 14.09, range 5-27%) have been used since 2003.

After identifying the most relevant expressions in obesity-related public policies, we attempted to identify how science was expressed in the content of these policies. Using the taxonomic structure, the multidisciplinary sciences represented 33.5% (533/1592) of the content of the documents analyzed, followed by health sciences (454/1592, 28.5%), social sciences (330/1592, 20.7%), life sciences (240/1592, 15.1%), and physical sciences (35/1592, 2.2%).

A detailed analysis of the clusters using the Jaccard coefficient (Table 2) showed the existence of a greater similarity between health sciences and life sciences (Jaccard coefficient 0.672) and between multidisciplinary sciences and health sciences (Jaccard coefficient 0.649). It may be explained by the fact that knowledge produced by life sciences is applied in health sciences. The multidisciplinary sciences area is closer to health sciences and life sciences because it gathers knowledge from both areas. Social sciences have a moderated similarity with health sciences and life sciences, whereas physical sciences have a lower similarity between all areas.

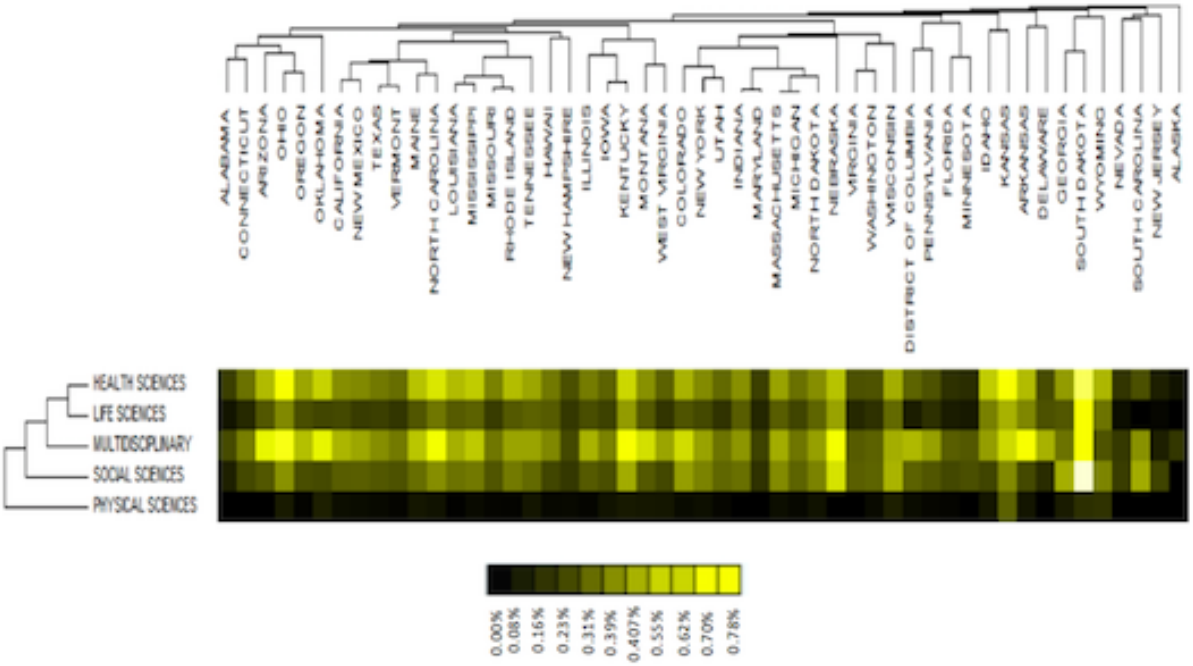
Table 2. Jaccard coefficient between the scientific areas expressed in obesity-related public policies in the US.

Scientific areas	Health sciences	Life sciences	Multidisciplinary sciences	Physical sciences	Social sciences
Health sciences	1	0.672	0.649	0.134	0.591
Life sciences	0.672	1	0.561	0.180	0.572
Multidisciplinary sciences	0.649	0.561	1	0.116	0.508
Physical sciences	0.134	0.180	0.116	1	0.124
Social sciences	0.591	0.572	0.508	0.124	1

The relative frequency results of the taxonomic classification by state are shown using heatmaps with a clustering of rows and columns. The brightest colors represent the highest frequencies (Figure 3). This analysis in Figure 3 also shows that all the states responded to obesity in a similar way, with few differences in the scientific frameworks adopted by local specificities. In some states, multidisciplinary sciences predominated with Nebraska, Montana, Ohio, and Oregon as examples. The health sciences category appeared more frequently in Kansas, Oklahoma, Idaho, and North Carolina. The social sciences category predominated in South Dakota, Wisconsin, and Nebraska. Kansas and Indiana were among the states with the greatest number of policies focused on life sciences. On the other hand, the physical sciences category was the scientific area with the lowest relative frequency in the US.

The results in Figure 3 also showed high similarity in the obesity-related public policy content of most states analyzed, such Texas and Vermont, Louisiana and Mississippi, New York and Utah, Indiana and Maryland, Massachusetts and Michigan, and Missouri and Rhode Island. In other words, the content of policies in these states was made in a similar way, considering the scientific fundamentals.

Figure 3. Relationships between obesity-related public policies in US states and scientific areas.



Discussion

The results showed that obesity-related public policy contents were generally uniformly framed across the US. They were approximately based on the same scientific references in which there was a predominance of the multidisciplinary area. These findings were consistent with what has been discussed with respect to the multifactorial causes of obesity as well as the means to control the epidemic. The high frequency of multidisciplinary sciences in the content of obesity-related public policies (533/1592, 33.5%) supports the findings of various previous studies [4,9,42,43]. In these studies, the authors highlighted that obesity requires a multidisciplinary analysis to be understood and our study shows that the government has used multidisciplinary sciences to address obesity.

We observed that the US obesity-related public policies varied in number, but had similar scientific content. Policies based on advances in scientific knowledge can influence the improvement of well-being and the reduction of population obesity and health expenditures; however, the implementation of public policies can be affected by a wide range of factors that challenge their effectiveness. For example, government influences, other interest groups, limitations imposed by the legislative body, the media, or the public [6]. Based on this, we suggest that new studies should be developed to better understand the factors that may limit the effectiveness of health-related public policy.

We also suggest scanning policies for other d-words, with the intention of verifying the intensity of use and the evolution of use of certain expressions within the policies. Associated with this, the elaboration of indicators to measure the influence of this content on obesity indices would allow for a more in-depth view of the functioning and impact of the content. The use of this methodology, combined with other research techniques, may offer a relevant understanding of how science and government are interrelated. Studies that aim to analyze the association between the number of public policies and the rates of obesity in different states can be useful in the identification of policy effectiveness.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Distribution of scientific papers according to the major scientific areas (2003-2013).
[DOCX File , 66 KB - publichealth_v6i3e13235_app1.docx]

Multimedia Appendix 2
D-words corresponding to the major scientific areas contextualized by the respective associated terms.
[DOCX File , 40 KB - publichealth_v6i3e13235_app2.docx]

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Original Paper

An Online Influenza Surveillance System for Primary Care Workers in Switzerland: Observational Prospective Pilot Study

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Abstract

Background: A better understanding of the influenza epidemiology among primary care workers could guide future recommendations to prevent transmission in primary care practices. Therefore, we designed a pilot study to assess the feasibility of using a work-based online influenza surveillance system among primary care workers. Such an approach is of particular relevance in the context of the coronavirus disease (COVID-19) pandemic, as its findings could apply to other infectious diseases with similar mechanisms of transmission.

Objective: This study aims to determine the feasibility of using a work-based online influenza surveillance system for primary care workers in Switzerland.

Methods: Physicians and staff of one walk-in clinic and two selected primary care practices were enrolled in this observational prospective pilot study during the 2017-2018 influenza season. They were invited to record symptoms of influenza-like illness in a weekly online survey sent by email and to self-collect a nasopharyngeal swab in case any symptoms were recorded. Samples were tested by real-time polymerase chain reaction for influenza A, influenza B, and a panel of respiratory pathogens.

Results: Among 67 eligible staff members, 58% (n=39) consented to the study and 53% (n=36) provided data. From the time all participants were included, the weekly survey response rate stayed close to 100% until the end of the study. Of 79 symptomatic episodes (mean 2.2 episodes per participant), 10 episodes in 7 participants fitted the definition of an influenza-like illness case (attack rate: 7/36, 19%). One swab tested positive for influenza A H1N1 (attack rate: 3%, 95% CI 0%-18%). Swabbing was considered relatively easy.

Conclusions: A work-based online influenza surveillance system is feasible for use among primary care workers. This promising methodology could be broadly used in future studies to improve the understanding of influenza epidemiology and other diseases such as COVID-19. This could prove to be highly useful in primary care settings and guide future recommendations to prevent transmission. A larger study will also help to assess asymptomatic infections.

(JMIR Public Health Surveill 2020;6(3):e17242) doi:10.2196/17242

KEYWORDS

influenza; surveillance system; primary care; online; nosocomial; transmission

Introduction

Available estimates suggest that 5%-20% of the global population is affected by influenza annually [1]. In Europe, seasonal influenza epidemics have the largest disease burden among all communicable disease in terms of disability-adjusted life years, mainly because of their large contribution to premature mortality [2].

Primary care physicians play a key role during seasonal influenza epidemics, even though most individuals presenting influenza-like symptoms do not seek a medical consultation [3]. In Switzerland, for example, influenza-like illnesses drive 1.4%-3.4% of the general population to consult a primary care physician per influenza season [4]. In addition, primary care physicians are responsible for vaccinating the population, especially vulnerable groups such as older patients and patients with comorbidities. Finally, primary care physicians are at the epicenter of the influenza sentinel networks that exist in many countries, which are used by public health authorities to officially declare national influenza epidemics.

Primary care physicians and staff working in primary care practices (collectively referred to as "primary care workers" hereafter) have a central role in patient care during the seasonal epidemics. For these reasons, they could potentially play a role in the influenza transmission chain. Indeed, primary care physicians were shown to have high levels of influenza antibody titers [5], and health care workers, in general, are at higher risk of influenza compared to adults working in non–health care settings [6-8].

However, the role of primary care practices in the transmission chain is largely unknown. Patients visiting the emergency department during the influenza season were found to have a higher risk of influenza-like illnesses compared with community controls [9]. Similarly, children visiting a pediatric clinic were at increased risk of presenting with influenza-like illnesses in the following days [10]. To prevent nosocomial transmission of influenza, vaccination of health care workers is recommended, and there is some evidence of the effectiveness of this strategy in preventing influenza infection among primary care physicians [11]. However, most of the work on nosocomial influenza has been conducted in hospitals or long-term care facilities [8,12,13]. Indeed, the data on the epidemiology of influenza among health care workers is very rarely described, particularly in primary care practices. Furthermore, evidence on interventions that reduce influenza transmission in primary care practices is particularly scarce [14]. Therefore, a better understanding of influenza epidemiology among primary care workers could guide future recommendations to prevent influenza transmission in this setting. This issue is of particular interest in contemporary times, as it also concerns other infectious diseases with transmission mechanisms similar to those of influenza, such as the coronavirus disease (COVID-19), for which transmission by primary care workers could play an important role.

The wide availability of the internet and the growth of digital communication technologies has led to the increasing use of these resources in public health surveillance. Online systems to monitor the activity of influenza in the general population have been developed previously, based on data provided by volunteers who self-report their symptoms via the internet throughout the influenza season [15,16]. More recently, such systems have included self-swabbing from participants [17,18]. The interest and feasibility of such an online system among health care workers are being evaluated in a hospital setting, but no results have been published to date [19].

As part of a longer-term national project to clarify the role of primary care practices in the transmission of influenza, we conducted a pilot study to assess the feasibility of a prospective work-based online influenza surveillance system among primary care workers [9]. The main objectives of this pilot study were to assess the participation of primary care workers in a weekly online influenza surveillance system as well as to examine the sustainability and feasibility of self-administration of nasopharyngeal swabs among study participants in such a system. We also monitored the influenza-like illnesses attack rate and the confirmed influenza cases over the entire influenza season of 2017-2018 among primary care workers.

Methods

We conducted a prospective observational study in three medical centers: one public walk-in clinic in Lausanne and two private family medicine practices purposively selected due to their regular collaboration with our department.

Recruitment

Data collection took place from October 2017 to April 2018. The study population corresponded to the primary care workers active in the medical centers during the pilot study. Inclusion criteria for medical centers included any family medicine practices or walk-in clinics providing primary care in the canton of Vaud, that were willing to participate in the project. For individual participants, inclusion criteria were age≥18 years and the presence of an employment contract during the study period. Members of the Swiss influenza sentinel medical practice network (Sentinelled) were excluded as participant centers, and staff members without contact with patients were excluded as individual participants. Enrollment was open between the beginning of the influenza surveillance season in Switzerland (week 40) and the beginning of the influenza epidemic as declared by the national influenza surveillance system (week 51 in the 2017-2018 season).

The staff was invited to participate in the survey by one of the medical center's head physicians (center manager). After receiving a numbered information sheet, each staff member was asked to provide information about the inclusion criteria; respond about their intention to participate in the study; and, if applicable, sign an informed consent form. This action was reinforced by verbal reminders during a team meeting. For this pilot study, a convenience sample of 50 subjects was considered appropriate.

The outline of the study is presented in Figure 1. The center manager had to complete a basic questionnaire about the number of employees, their duties, activity rate, and contacts with patients. He was also asked to provide information about staff

vaccination and the use of other preventive measures at the practice (handwashing and disinfection, mask-wearing, isolation of patients, frequency of disinfection, and ventilation of waiting room). He then had to answer a weekly questionnaire about the number absent days of the staff, the number of vaccinations among staff since the previous week, the changes in preventive measures, and the number of patients with influenza syndrome seen daily as a proportion of the total number of patients visiting during the previous week. At the end of the study, he was asked to answer a final questionnaire about the feasibility of the weekly questionnaire.

The study participants were asked to complete a basic questionnaire about demographics, their function at the study site, type of contacts with patients, and compliance with vaccination protocols and other preventive measures. Subsequently, they had to answer a weekly questionnaire about influenza-like illnesses symptoms during the past week (or since the last completed questionnaire if the previous week's data were missing), similar to the one used by the Vinylbenzene questionnaire [16,20] (Figure 2). In the case of influenza-like illnesses symptoms, defined by a history of fever, usually with acute onset (temperature>38 °C), and a cough or sore throat, the participants were asked to provide the exact symptoms start date and the number of missed working days. They were then invited to perform a nasopharyngeal swab and asked about the tolerance and feasibility of a self-administered swab. At the end of the study, they were asked to answer a final questionnaire about the feasibility of the weekly questionnaire, estimated time required to complete it, and suggestions for improving the study procedures. Finally, they were asked about their willingness to perform a serological test for influenza at the beginning and end of the investigation or to conduct a self-administered nasopharyngeal swab in the absence of symptoms.

Data were collected online using RedCap (Research Electronic Data Capture) software (Vanderbilt University), with a link sent to participants by email every Monday. The link was sent to the participant's private or professional email address according to their preference. The questionnaire could be completed until the following Friday. One email reminder was sent if the questionnaire was not completed after 3 days. Participants with influenza-like illnesses symptoms who did not provide a nasopharyngeal swab within 3 weeks were asked about their reasons for not performing a nasopharyngeal swab. The evaluation of missing results and interrupted follow-ups was an integral part of the pilot study.

Nasopharyngeal swabs were sent to the National Reference Centre of Influenza (Geneva, Switzerland). They were tested weekly for influenza A and B by reverse transcriptase real-time polymerase chain reaction (rRT-PCR). Twice during the season, on weeks 3 and 16, samples were tested by rRT-PCR for a panel of respiratory pathogens including influenza A; influenza A (subtype H1N1); influenza B; rhinovirus; coronavirus species NL63, 229E, OC43, and HKU1; parainfluenza 1-4; human metapneumovirus A/B; bocavirus; respiratory syncytial virus A/B; adenovirus; enterovirus; parechovirus; and *Mycoplasma pneumoniae*.

To preserve participants' privacy, no participants' study data were provided to center managers. This point was specified in the participants' information sheet. The study was conducted in accordance with the principles of the Helsinki Declaration. Each study participant signed an informed consent form, and the human research ethics committee of the canton of Vaud approved the study (CER-VD2017-01519).

Figure 1. Outline of the study. ILI: influenza-like illness; PCR: polymerase chain reaction.

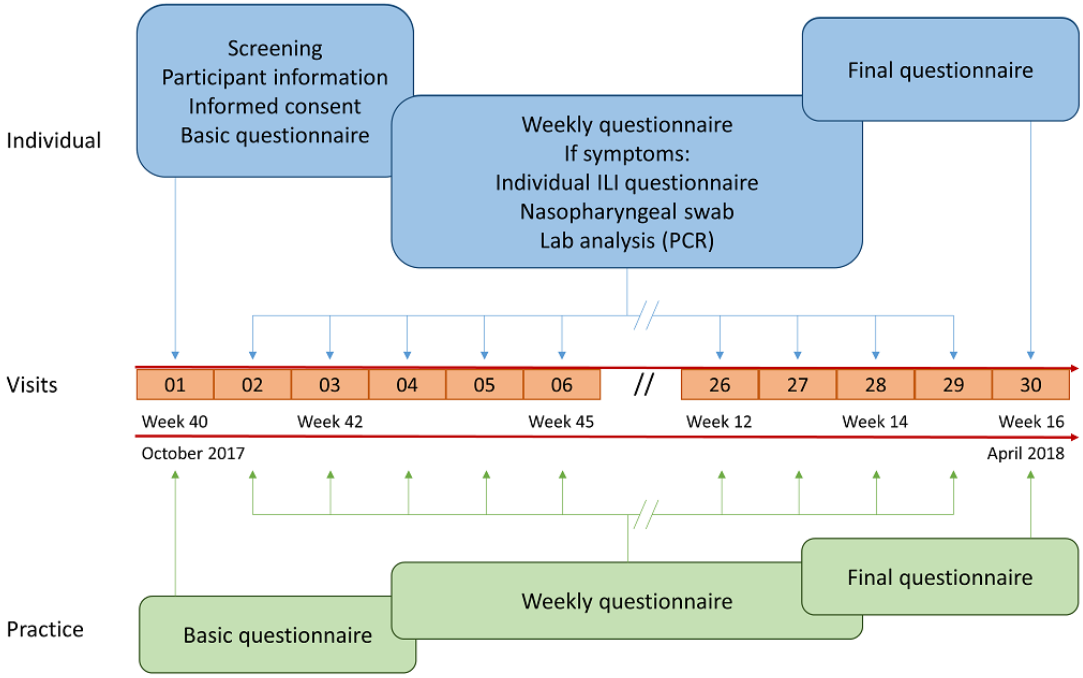
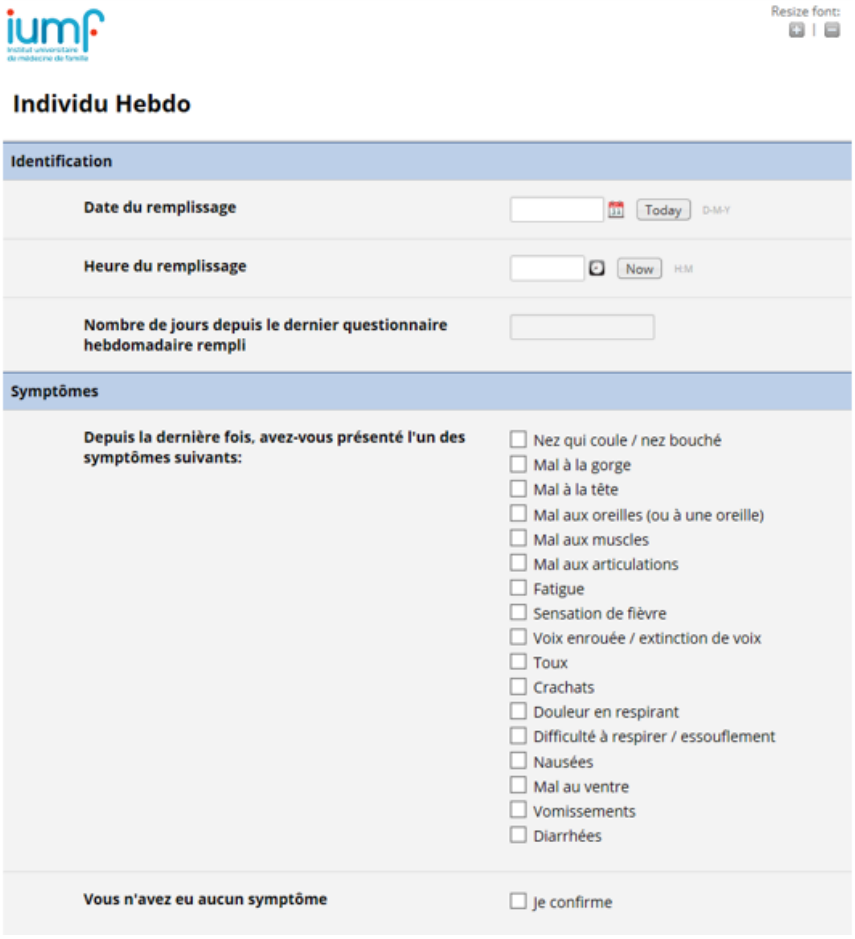


Figure 2. Weekly online questionnaire for study participants.



Statistical Analysis

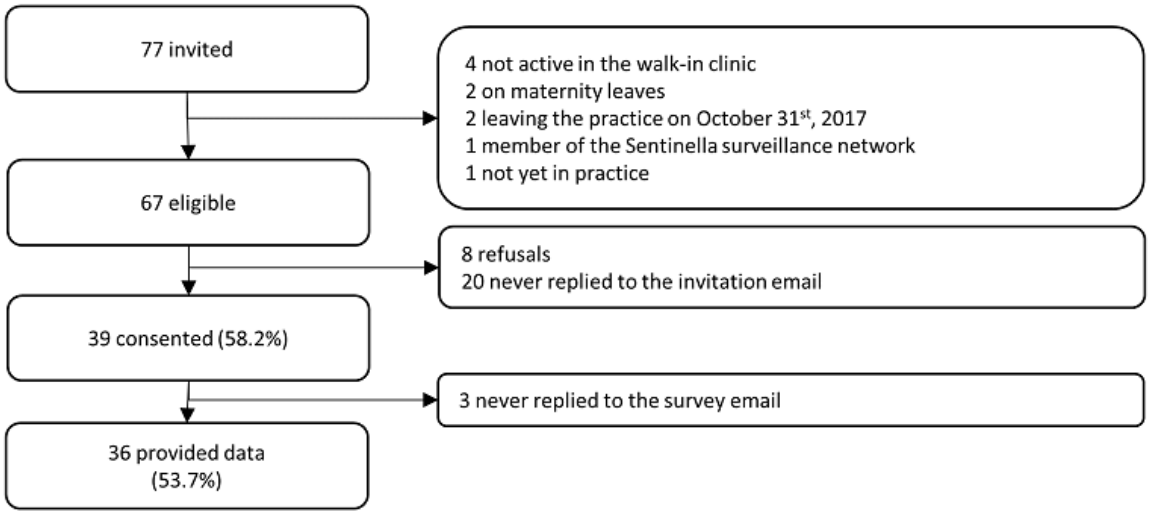
Data were analyzed using Stata 13 statistical software (StataCorp). Results for primary and secondary outcomes were presented as proportion, incidence rates, and attack rates for the total study population. The chi-square and Wilcoxon rank-sum tests were used to compare proportions and medians, respectively, between categories (practices, professions, auto- vs hetero-swab). The significance level was set at P value<.05.

Results

Participation

A total of 77 primary care workers from the three centers were invited to participate in our study. Of the 67 eligible persons based on the inclusion and exclusion criteria, 39 (58%) participants, comprising 22 physicians and 17 medical assistants, consented to the study. The distribution of 39 participants was as follows: 19 of the available 47 (40%) primary care workers from the walk-in clinic and 20 of the available 20 (100%) from two private practices enrolled in the study. Of the 39 participants, 36 (92%) finally provided data (Figure 3). All 28 who did not consent to the study were working in the walk-in clinic. The distribution of nonparticipants corresponded to 10 of the eligible 18 (55%) external medical supervisors, 10 of the 14 (71%) physicians in postgraduate training, 8 of the 15 (53%) eligible medical assistants, and 5 of the 5 (100%) eligible secretaries. The mean age of participants was 42.2 (SD 12.1) years, and 22 (61%) participants were women. The median number of years working in the same practice was 3 (range 2-12 years). In total, 22/36 (61%; missing 1 participant's data) participants were vaccinated against influenza. The proportion of participants that were vaccinated was 18/21 (85%) for physicians and 4/14 (28%, 1 missing data point) for medical assistants (χ^2_1=11.7; P=.001).

Figure 3. Participant flow chart, feasibility study of an online influenza surveillance system among primary care workers of three clinics in Switzerland, 2017-2018.

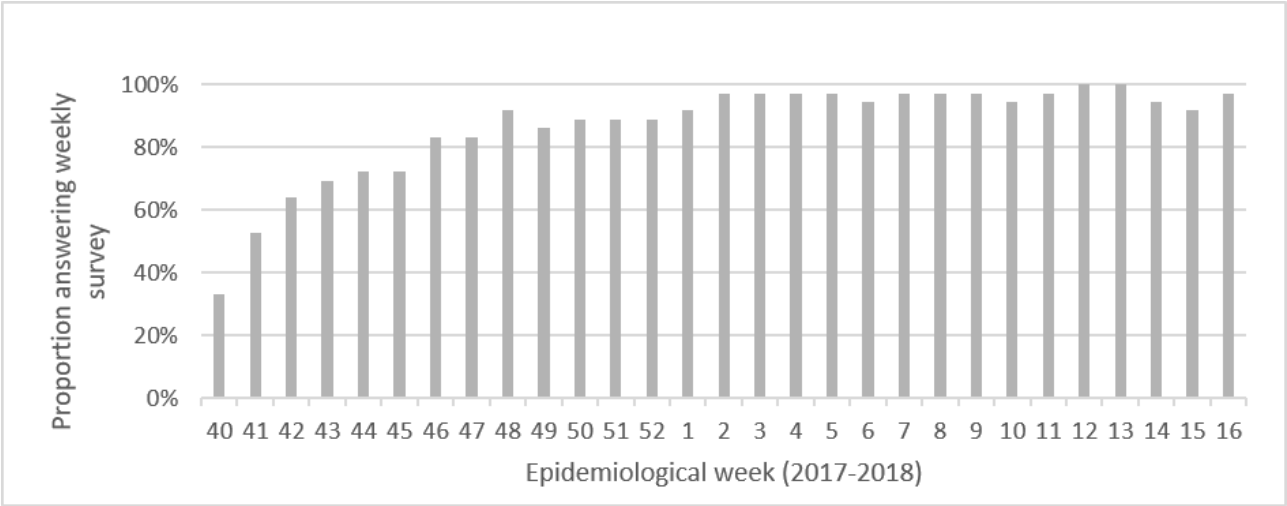


Feasibility

The proportion of workers responding to the weekly online survey per week increased during the first weeks of the study with progressive enrollment. From the time all participants were included, the response rate stayed close to 100% until the end of the study (Figure 4). Among the 36 participants, 25 (69%) primary care workers completed at least 80% of the weekly online surveys.

In the context of survey responses, 23 (63%) participants answered the questionnaires mainly at work, and 12 (33.3%) mainly at home. In terms of access, 20 (55.6%) participants accessed the surveys using the workplace computer, 8 (22%) accessed them through their smartphone, and 7 (19%) accessed them through their private computer. The median time to complete the initial individual questionnaire was 3.0 (IQR 2.0-4.0) minutes and the median time to complete the final individual questionnaire was 2.5 (IQR 2.0-4.0) minutes. Completing the weekly survey took 10 seconds on average in the absence of symptoms and 2 minutes and 17 seconds in case of symptoms. All participants completed questionnaires until the end.

Figure 4. Proportions of participants answering to weekly online survey (n=36).



Acceptability of Swabbing

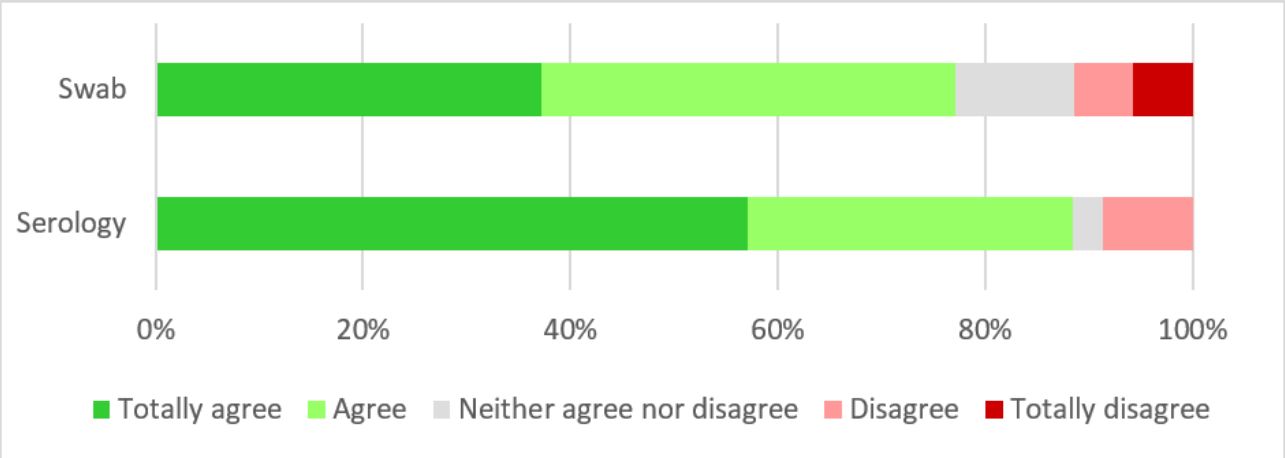
Of the 15 nasopharyngeal swabs (2 pharyngeal, 3 with missing data), 6 (40.0%) were autoswabs, of which 5 were performed by physicians and 1 by a medical assistant. The remaining were heteroswabs. In terms of preference for methods, 9 of 10 medical assistants preferred a heteroswab instead of an autoswab. The median depth of the swab was 8.5 cm (range 6-10 cm, 2 participants with missing data). Two participants (13.3%) mentioned nonsevere adverse effects of the swab (itchy nose, burning sensation). Median discomfort was estimated at 6 on a 10-point pain scale (IQR 4-8, n=15). The level of discomfort was significantly higher among medical assistants than among physicians (median 7.5, IQR 6.5-8, vs median 4, IQR 3-4;

rank-sum *P*=.02), whereas no significant difference in discomfort was observed between heteroswabs and autoswabs (median 7, IQR 4-8 vs median 4, IQR 3-7; rank-sum *P*=.13).

Overall, swabbing was considered relatively easy and most participants "agreed" or "totally agreed" that swabbing explanations were clear and sufficient (Figure 5).

The main reasons for not performing a swab in case of influenza-like symptoms were that participants believed that symptoms were too light or already over (n=21), the diagnosis was not influenza (n=17), they already had taken a swab for that episode (n=5), a swab was unnecessary (n=3), a swab would be negative (n=1), or their symptoms did not fit the influenza-like illnesses case definition (n=1).

Figure 5. Willingness to perform a serological test or a self-administered nasopharyngeal swab in the absence of symptoms (n=35).



Attack Rate of Influenza

Of 79 symptomatic episodes (mean 2.2 per participant), 10 fitted the influenza-like illnesses case definition. Five participants said that they missed work for an average of 2 (range 1-5) days, and 9 participants reduced their daily activities for an average of 3.3 (range 1-10) days. For 31 of the 79 (39%) episodes, participants said they had worked without difference by practice while having symptoms of fever, sore throat, or cough (χ^2_3=2.2; *P*=.53).

In total, 20 swabs were performed for 19 symptomatic episodes (2 swabs for the same influenza A episode) occurring in 16 participants, including 8 of the 10 influenza-like illnesses episodes. The swabs were performed a median of 3 days after the start of symptoms (IQR 1-5) and were received in the lab a median of 2 (IQR 1-3) days later. More than half of the initial symptomatic episodes were swabbed (15/29, 51%), compared to only 10% of the subsequent 40 episodes (4/40, 10%).

A virus was identified in 10 of 19 (52%) symptomatic episodes and 4 of 8 (50%) influenza-like illnesses episodes, respectively. One swab was positive for influenza A H1N1 (attack rate: 2.8%, 95% CI 0.4%-18.3%; Table 1). In addition, 2 cases of coronaviruses HKU1 were identified among the 12 swabbed participants with symptoms not fitting the influenza-like illnesses case definition (data not shown).

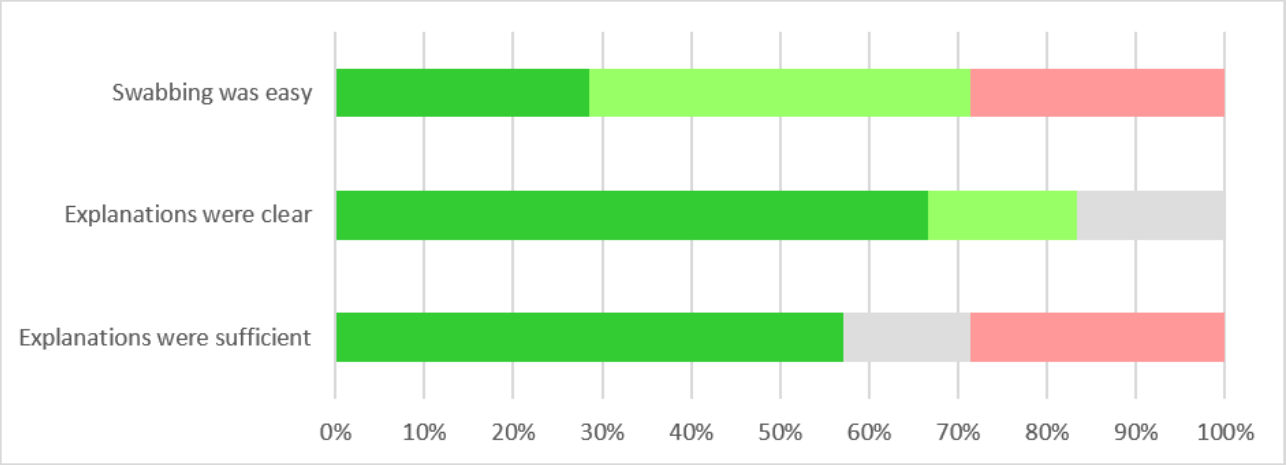
In case of a future study that would also target asymptomatic influenza, most participants "agreed" or "totally agreed" to perform a serological test for influenza at the beginning and end of the surveillance season or to self-administer a nasopharyngeal smear in the absence of symptoms (Figure 6). Participants preferred serological tests over other methods (54% vs 28%; for no preference: 17%).

Table 1. Clinical characteristics and swab results of 10 influenza-like illness episodes reported by practice staff.

Month	Temperature (°C)	Fever history	Sore throat	Cough	Swab	Result
November 2017	38	Yes	Yes	No	Yes	Negative
November 2017	37	Yes	Yes	Yes	Yes	Rhinovirus
December 2017	37	Yes	Yes	Yes	Yes	Coronavirus OC43
January 2018	N/A[a]	Yes	No	Yes	Yes	Negative
January 2018	37	Yes	Yes	Yes	Yes	Influenza A H1N1
January 2018	39	Yes	Yes	Yes	No	N/A
February 2018	N/A	Yes	Yes	Yes	Yes	Negative
February 2018	38	No	Yes	No	Yes	Negative
February 2018	38	Yes	Yes	Yes	Yes	Rhinovirus
February 2018	37	Yes	Yes	Yes	No	N/A

[a]N/A: not applicable.

Figure 6. Acceptability of nasopharyngeal swab (n=15).



Discussion

Principal Results

To prevent influenza transmission to vulnerable patients consulted in primary care practices, it is important to understand the influenza epidemiology among primary care workers. Although surveillance studies among cohorts of health care workers have been conducted in hospital settings, our pilot study is the first one to set up a prospective online influenza surveillance system among the staff of primary care practices. It successfully demonstrated the feasibility of a work-based online influenza surveillance system combined with self-administrated nasopharyngeal swabs in participants with influenza-like illnesses. It also provided detailed information about the feasibility and the level of participation of primary care workers in such a surveillance system. Primary care workers were willing to participate in such a system, with more than half of all eligible workers giving their consent and providing data. Maintaining a sufficient level of participation over time is an important factor in guaranteeing the representativeness of a monitoring system. In our study, almost all participants that provided initial consent maintained their participation and the majority completed most of the weekly online surveys. Furthermore, few nonserious side effects of nasopharyngeal swabbing were mentioned. The discomfort was acceptable, and swabbing was considered relatively easy regardless of the swabbing procedure (autoswab or heteroswab).

Participation was much better in smaller private practices than in the public walk-in patient clinic. Moreover, participation was better among regular staff than among rotating staff (external medical supervisors and physicians in postgraduate training) and administrative staff (secretaries), suggesting that permanent staff are more readily involved in a research project that extends over several months than rotating staff. These findings can also be related to the size of the facility, which allows for more personalized contacts with participants when presenting the study and answering their questions. From the perspective of a future larger-scale study in Switzerland, this observation represents an advantage, as the size of the two practices included in the study closely matches the size of the majority of Swiss primary care practices.

The time spent in providing data and the impact on the privacy of participants can influence the feasibility as well as the participation in a surveillance system. In our study, the median time needed to complete the questionnaires was noticeably short. In addition, most of the participants answered the questionnaires on their workplace and accessed the surveys using the workplace computer.

During an influenza episode, the affected person can be expected to stay at home. For this reason, we decided to distribute swab material to all participants and gave them the freedom to either self-administer the swab or ask a colleague to administer it to them when they fitted the influenza-like illnesses case definition, thereby maximizing the chances of a swab to be performed when indicated. Providing a choice to perform an autoswab or a heteroswab was an effective strategy, as nearly half of the smears taken were autoswabs that did not seem to have caused any problems for physicians, while a little more than half were heteroswabs, mainly among medical assistants. To maximize the number of swabs performed by participants and to study their feasibility under the best possible conditions, we used a less restrictive influenza-like illness case definition than official definitions [21]. In some cases, participants waived the need to perform a swab even if the criteria were met, mostly because they judged it unnecessary, or because they had already taken a swab previously. These results highlight the need for clearer explanations and a clearer framework about the indication for a swabbing in further studies.

In such a study, addressing the issue of privacy is important, as it could lead to underreported episodes by participants because of the risk of being absent from work or being penalized for not staying home in case of symptoms. For this reason, it was made clear to participants that employers were not receiving any information about their employees' study data. During terminal team meetings at the end of the study conducted to present and discuss the results, participants did not identify any privacy issues.

In our study, the attack rate of influenza during the 2017-2018 season was low, but considering the large confidence interval, it was within the range of that estimated by other studies conducted either in the general population or among health care workers [22,23]. This finding leads to the question of

asymptomatic influenza episodes among vaccinated health care workers. Recent studies showed that a significant number of health care workers with respiratory symptoms were afebrile prior to their diagnosis and may pose a risk of influenza transmission to patients and coworkers [23]. To quantify this phenomenon, future studies should be able to assess asymptomatic infections among participants by performing either serological tests before and after the annual influenza epidemic or a self-administered nasopharyngeal swab in the absence of symptoms. The results of our study show that both serologies and swabs would be accepted by participants, with a preference for serological testing.

Limitations

The inclusion of only three practices is not sufficiently representative. However, they are typical of the most frequent type of medical practices in Switzerland, due to their location in a suburban region and their organization as a team of doctors and medical assistants [24]. The walk-in clinic, for its part, is representative of a model of larger medical centers that are currently emerging in Switzerland. We believe that our data on participation are sufficient for planning a larger study. Finally, the size of the sample was too limited to assess the attack rate of influenza among primary care workers, but this was not the main objective of our study.

Conclusion

A work-based online influenza surveillance system among primary care workers, combined by self-administrated nasopharyngeal swabs performed by participants, is a promising methodology for conducting a large-scale study that combines data on staff and patients. Precise estimation of the influenza attack rate among primary care workers, of both symptomatic and asymptomatic infections, will make it possible to recommend preventive measures for primary care practices. This could be immensely useful in guiding future recommendations for preventing nosocomial transmission.

In infectious diseases, including the recent COVID-19 outbreak that displays a high risk of spread with a similar nosocomial transmission, applying such a surveillance system among primary care workers could limit virus spread. Symptomatic primary care workers could be isolated quickly, limiting the risk of contamination. In the context of infectious disease where transmission by asymptomatic carriers is important, surveillance could include systematic testing to identify healthy carriers among primary care workers.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
RedCap: Research Electronic Data Capture
rprt-PCR: real-time polymerase chain reaction

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Corrigenda and Addenda

Correction: A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis

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Related Article:

Correction of: http://publichealth.jmir.org/2020/2/e19170/

(JMIR Public Health Surveill 2020;6(3):e22853) doi:10.2196/22853

In "A Snapshot of SARS-CoV-2 Genome Availability up to April 2020 and its Implications: Data Analysis" (JMIR Public Health Surveill 2020;6(2):e19170) the authors noted errors in the supplementary material files. The previous Multimedia Appendix 3 file included outdated versions of Figure S5 and Figure S8.

The replacement version can be seen in the attached file and will appear in the online version of the paper on the JMIR Publications website on August 10, 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.

Multimedia Appendix 3
Supplementary Figures.
[DOCX File , 2558 KB - publichealth_v6i3e22853_app3.doc]

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Original Paper

Rapid Deployment of a Free, Privacy-Assured COVID-19 Symptom Tracker for Public Safety During Reopening: System Development and Feasibility Study

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Abstract

Background: Since the emergence of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the number of cases of coronavirus disease (COVID-19) in the United States has exponentially increased. Identifying and monitoring individuals with COVID-19 and individuals who have been exposed to the disease is critical to prevent transmission. Traditional contact tracing mechanisms are not structured on the scale needed to address this pandemic. As businesses reopen, institutions and agencies not traditionally engaged in disease prevention are being tasked with ensuring public safety. Systems to support organizations facing these new challenges are critically needed. Most currently available symptom trackers use a direct-to-consumer approach and use personal identifiers, which raises privacy concerns.

Objective: Our aim was to develop a monitoring and reporting system for COVID-19 to support institutions conducting monitoring activities without compromising privacy.

Methods: Our multidisciplinary team designed a symptom tracking system after consultation with experts. The system was designed in the Georgetown University AvesTerra knowledge management environment, which supports data integration and synthesis to identify actionable events and maintain privacy. We conducted a beta test for functionality among consenting Georgetown University medical students.

Results: The symptom tracker system was designed based on guiding principles developed during peer consultations. Institutions are provided access to the system through an efficient onboarding process that uses clickwrap technology to document agreement to limited terms of use to rapidly enable free access. Institutions provide their constituents with a unique identifier to enter data through a web-based user interface to collect vetted symptoms as well as clinical and epidemiologic data. The website also provides individuals with educational information through links to the COVID-19 prevention recommendations from the US Centers for Disease Control and Prevention. Safety features include instructions for people with new or worsening symptoms to seek care. No personal identifiers are collected in the system. The reporter mechanism safeguards data access so that institutions can only access their own data, and it provides institutions with on-demand access to the data entered by their constituents, organized in summary reports that highlight actionable data. Development of the system began on March 15, 2020, and it was launched on March 20, 2020. In the beta test, 48 Georgetown University School of Medicine students or their social contacts entered data into the system from March 31 to April 5, 2020. One of the 48 users (2%) reported active COVID-19 infection and had no symptoms by the end of the monitoring period. No other participants reported symptoms. Only data with the unique entity identifier for our beta test were generated in our summary reports.

Conclusions: This system harnesses insights into privacy and data sharing to avoid regulatory and legal hurdles to rapid adaption by entities tasked with maintaining public safety. Our pilot study demonstrated feasibility and ease of use. Refinements based on feedback from early adapters included release of a Spanish language version. These systems provide technological advances to complement the traditional contact tracing and digital tracing applications being implemented to limit SARS-CoV-2 transmission during reopening.

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KEYWORDS

COVID-19; SARS-CoV-2; home isolation; quarantine; symptom monitoring; information systems; privacy; contact tracing; virus; transmission; public health; eHealth

Introduction

The emergence of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and the resulting coronavirus disease (COVID-19) pandemic have led to significant morbidity and mortality worldwide, with over 9,473,214 confirmed infections and 484,249 deaths by June 26, 2020 [1]. The first travel-related case of COVID-19 in the United States was reported to the US Centers for Disease Control and Prevention (CDC) on January 21, 2020; the United States has since contributed the majority of COVID-19 cases globally, with 2,367,064 cases and 121,645 deaths reported by June 26, 2020 [1]. This has led to tremendous strain on institutions and agencies working to treat infection and prevent viral transmission [2,3]. Most jurisdictions implemented social distancing and stay-at-home orders; these mitigation strategies have been applied with positive effect in multiple settings [4,5]. In the United States, the daily rate of new diagnoses of infection peaked on April 22, 2020, with 31,994 cases reported on April 12, 2020, then declined to below 14,000 cases daily by mid-May; this rate then began to rise again as stay-at-home restrictions were lifted based on federal guidance, with almost 40,000 cases reported on June 24, 2020 [6-8]. Multidimensional approaches to limit SARS-CoV-2 transmission are critical during the reopening of educational, social, and business entities.

COVID-19 causes a spectrum of disease severity, and up to one-fifth of individuals with COVID-19 infection develop severe disease that requires hospitalization [6,9,10]. Critical components to address the SARS-CoV-2 pandemic and break transmission chains is to identify infected individuals through testing, isolate those with infection, and perform contact tracing to identify and quarantine individuals exposed to active COVID-19 cases. Most individuals with COVID-19 do not require hospitalization; monitoring people who have the illness under home isolation is important to detect persistent or worsening disease that may warrant evaluation. In addition, individuals who have been exposed require quarantine during the potential incubation period; also, based on current guidance, individuals exposed to COVID-19 cases should be monitored in home quarantine for up to 14 days to limit transmission during the asymptomatic or pre-symptomatic period, when transmission may also occur [11,12].

These routine public health strategies limit community spread of infection. However, traditional contact tracing mechanisms in the context of the SARS-CoV-2 pandemic with large numbers of cases in the setting of low community immunity requires great resources [13]. Monitoring a multitude of individuals can quickly exceed institutional capacity, and traditional contact tracing lacks the required speed to identify and reach contacts at high risk of becoming infected and transmitting infection [14]. Given the scale of the response required, technological advances can complement traditional contact tracing methods to introduce efficiencies needed to successfully avert ongoing transmission [15]. Digital contact tracing using real-time locator systems, including downloadable apps, has gained traction as a direct-to-consumer approach to efficiently identify individuals who may have come into close contact with persons diagnosed with COVID-19 [16,17]. These systems require broad community acceptance and usage to provide sufficient population-wide coverage, as mathematical modelling estimates suggest that high population coverage is needed to effectively reduce transmission [18,19]. These data further suggest that a combination of direct contact tracing with a digital approach has the highest yield in identifying cases that warrant isolation or quarantine to successfully mitigate ongoing transmission [16]. However, digital privacy remains a concern, and limited voluntary use of contact tracing approaches hampers the utility of these systems [20].

Our multidisciplinary team has implemented systems using Georgetown University's AvesTerra framework for privacy-assured technology for HIV surveillance [21-23]. We then sought to design a user-friendly system to efficiently track symptoms associated with COVID-19 infection to complement existing and evolving contact tracing approaches. We conducted a beta test of the symptom tracker to determine the usability of the system and reporter and evaluate the system's functionality to provide institutions and agencies with summary reports to identify individuals with changing health status during isolation or quarantine.

Methods

Background

We identified the need for a symptom tracking system after consultation with experts responding to the evolving pandemic in metropolitan Washington, DC. The overarching purpose was to provide institutions and agencies that were tasked with tracking and monitoring a set constituency with technology-based options that could accommodate exponential increases in use in the event of large-scale COVID-19 outbreaks. We established a multidisciplinary team with expertise in clinical infectious diseases, epidemiology and public health, computer science and systems development, ethics and privacy,

and organizational strategy. We identified key data elements that are important for COVID-19 tracking, including epidemiology and exposure, clinical signs and symptoms, risk factors for severe disease, and SARS-CoV-2 testing and results, based on emerging reports and scientific literature at the time of development [24-26].

The system was designed in the Georgetown University AvesTerra knowledge management environment, which supports integration and synthesis of data to identify actionable events. The proposed use, design, and content of the tracker were reviewed by the University General Counsel to guide the development of the Terms of Use and the modality whereby users interface with the system. The design considerations included the following features to increase the usability and acceptability of the system. The system is directed to institutions and agencies to provide access to their populations using unique identifiers known only to the originating institute or agency; no personal identifiers are collected, which limits regulatory hurdles and personal inhibitions to using the system; the Terms of Use are streamlined to avoid legal barriers and the need for arduous and time-consuming data sharing agreement processes; immediate and on-demand access is provided to reports by institutions and agencies reflecting data collected from their population only, with built-in safeguards that limit their access to data from their own population; the development team is willing to customize the system to accommodate the unique needs of individual institutions and agencies; and the system is scalable to millions of users.

We beta-tested the COVID-19 Symptom Tracker under a protocol deemed exempt by the Georgetown University Institutional Review Board. Georgetown University medical students were invited to participate by email, with a link to a Qualtrics survey used to describe the project, provide instructions, and document consent. A random unique ID number was directly generated in Qualtrics for each consenting individual. Participants were asked to enter data twice daily for 3 days. The research team downloaded an aggregate summary report. No personal identifiers were available to the study team.

Target Audience

The system is directed to institutions and agencies that are tasked with monitoring individuals in home isolation or quarantine. Participating institutions are provided with a link to a page outlining the Terms of Use (Multimedia Appendix 1). These Terms of Use describe the intended use of the system and provide guidance on accessing the system, with emphasis on ensuring collection of deidentified data. The system uses a clickwrap agreement to indicate acknowledgement of the Terms of Use. Once enrolled, the institution can provide their selected constituent population with access to the system. Institutions are assigned a unique 5-digit institution code. The institution is instructed to provide each person entering data with a unique identifier using the 5-digit prefix followed by 6 additional digits. The originating institution maintains the link between the assigned unique identifier and the individual who is being asked to enter symptom data. With this design, no personal identifiers are collected in the system. Participating institutions and agencies are provided with a Reporter executable file and unique authorization code to access data linked to their own entity. The institutions and agencies maintain access to the unique identifiers assigned to the individuals they ask to enter data into the system, thereby maintaining privacy and confidentiality with respect to our development team and other system users. The system is designed to accommodate data from millions of unique individuals.

Symptom Selection

We selected the two most common symptoms that were reported in early large population–based epidemiology studies: fever (88% to 89%) and cough (68% to 72%) [25]. We selected two additional symptoms that had lower and variable incidence in different publications that we deemed important to capture based on relative frequency or as a potential indicator of disease severity: shortness of breath (18.7%), and sore throat (13.9%) [24]. The option to include additional symptoms using free text was also included in the database design to allow for future iterations and adaptations depending on frequency of reporting.

Exposure, Epidemiology, and Risk Data

We included elements that were deemed critical to risk-stratify individuals for disease based on emerging epidemiology. The symptom tracker collects data on known exposures to individuals with COVID-19, whether in the household or in a health care setting. Information about potential work exposure is gathered, such as whether the user is a health care worker, first responder, or in other at-risk categories. International and domestic travel history is also elicited. Information on underlying health conditions that are associated with worse COVID-19 outcomes is collected; the individual is prompted to enter a categorical response (yes or no) to whether they have any comorbidities of concern. These comorbidities include underlying hypertension, cardiovascular disease, pulmonary disease, and primary or secondary immunodeficiency.

End User Safety

The user interface was designed to provide educational information and links to published COVID-19 prevention recommendations from the CDC. The documentation on the user interface also clearly directs individuals who are entering symptom data to seek additional care if they have new signs or symptoms suggestive of incident or worsening infection.

System Reports

Institutions were provided with an 8-digit authorization code linked to their 5-digit institution identifier during initial enrollment. Agencies and institutions can automatically generate reports that include only their institution-specific data. Actionable information such as the ID number alert for a person with new symptoms is provided to guide institutional decision making and need for follow-up with the individual, who may require testing. Other information provided in the reports includes cessation of symptoms and duration of monitoring, which may trigger removal from isolation for individuals who no longer have symptoms or have met the minimum required period of quarantine. Information on individuals who have not submitted data for the past 24 hours is also generated, which allows institutions to identify subgroups of individuals who may need to be contacted to prompt continued engagement and

entry of symptoms into the system or to determine whether the individual has worsening symptoms that may have led to hospitalization or that warrant referral.

Privacy

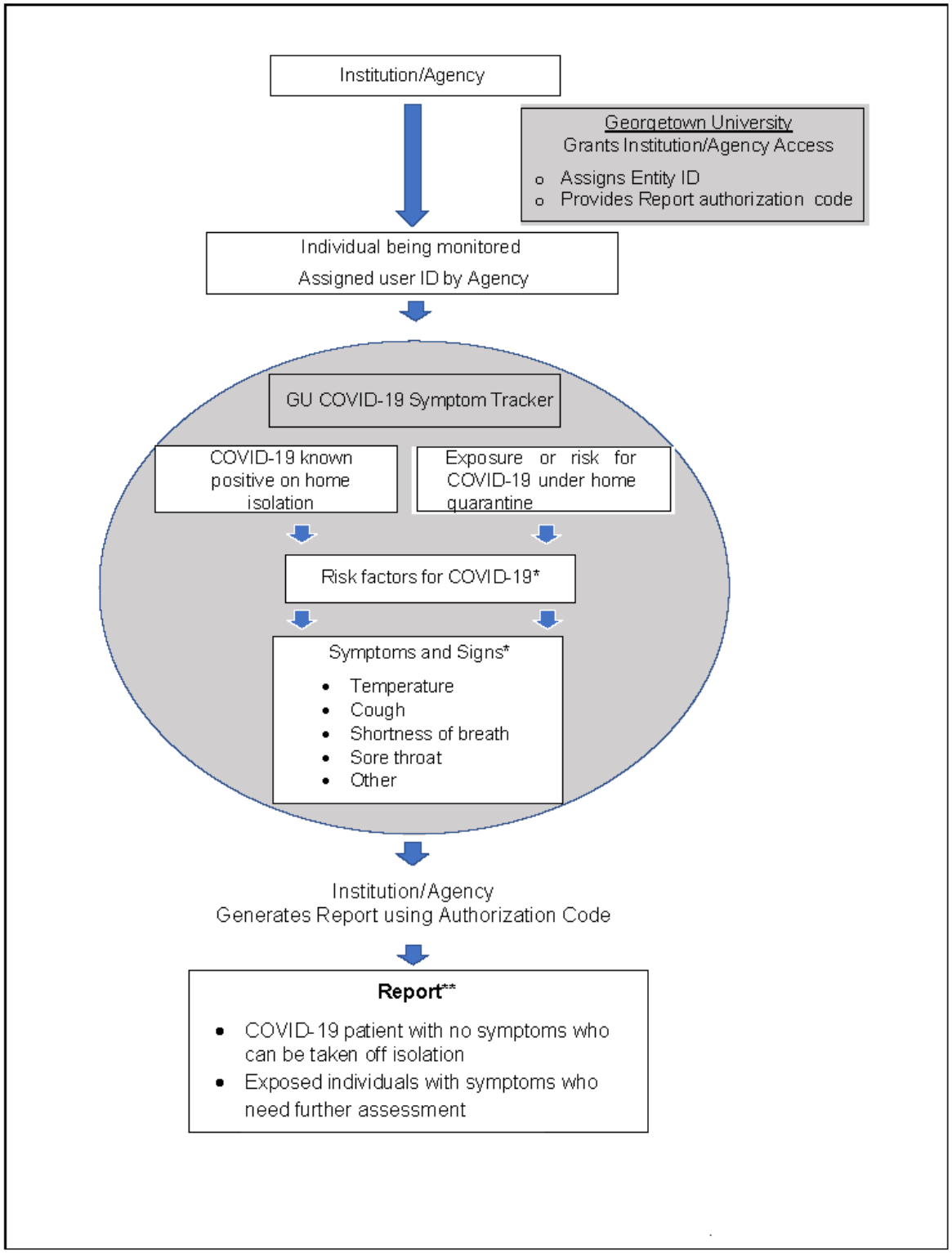
Privacy considerations were a critical design element. As the COVID-19 Symptom Tracker is not a direct-to-consumer app, the enrolled institutions and agencies were instructed to provide unique identifiers that were not linkable to individuals. Only enrolled institutions can provide unique identifiers, which contain the prefix assigned to that institution. Thus, only the enrolled institution or agency knows the identity of an individual user. The system provides instructions to individuals to not include or upload personal identifiers when entering data. In addition, periodic scans of uploaded data are performed to ensure that possible personal identifiers are not being entered in the sections that allow free text, and unstructured data that fit the format of a phone number or date of birth are terminally deleted from the free text sections. Deidentified data entered by an individual are only accessible in reports to the institution that provided the user identifier to the individual, thus protecting the data from access by other institutions or agencies. The development team provided a clear statement about the intended use of the data in the Terms of Use, which is accessible to both institutions and users for review. The text was written in simple language with a twelfth grade readability score using the Flesch Kincaid Grade tool. Data can be released to an institution for users who entered data using the institution's unique 5-digit code. Otherwise, data will only be released if required under subpoena or another legal process.

Results

Symptom Tracker System

The symptom tracker system was designed to encompass functionality to ensure privacy without compromising utility while fulfilling the core guiding principles that were developed during peer consultations. We incorporated several distinguishing features into the system design to increase the usability and acceptability of the system; these are summarized in Figure 1. System development began on March 15, 2020, and the symptom tracker was launched on March 20, 2020 [27]; subsequent iterative improvements were made based on requests from early adapters (including a Spanish language version).

Figure 1. Schema of enrollment in and use of the COVID-19 Symptom Tracker system. COVID-19: coronavirus disease. GU: Georgetown University. *Individuals enter data without personal identifiers based on instructions from the institution or agency. The instructions provided on the website direct individuals with new or worsening symptoms to contact their health care providers. **Institutions and agencies can determine the frequency at which they generate reports.



System Beta Test

A total of 48 users from the Georgetown University School of Medicine participated in beta testing conducted between March 31 and April 5, 2020 (Table 1). One of the 48 users (2%) reported active COVID-19 infection, and 47 individuals (98%) were not infected. On the last day of monitoring, the individual with COVID-19 infection was asymptomatic. None of the 47 other participants reported symptoms of COVID-19 infection. By the end of follow-up, 38 of the 47 individuals (81%) had completed three days of data uploads.

Table 1. Report from the beta test from March 31 to April 5, 2020 obtained at 5:49 PM on April 5 (N=48).

Characteristic	Value (%)
COVID-19[a] infection, n (%)	
Infected	1 (2)
Infected with temperature lower than 99.3 ºF[b]	1 (2)
Infected with no cough	1 (2)
Infected with no shortness of breath	1 (2)
Infected without data in last 24 hours	0 (0)
Exposure, n (%)	
Exposed but not known to be infected	47 (98)
Exposed with temperature greater than 99.5 ºF	0 (0)
Exposed with temperature greater than 100.0 ºF	0 (0)
Exposed with cough	0 (0)
Exposed with shortness of breath	0 (0)
Exposed without data in the last 24 hours	38 (79)
Infection source, n (%)	
Infected, exposed by close contact	0 (0)
Infected, exposed by health care worker	1 (2)
Health care workers infected	1 (2)
Infected users, ID number[c]	
Infected with temperature lower than 99.3 ºF	GUTST_001111
Infected with no cough	GUTST_001111
Infected with no shortness of breath	GUTST_001111

[a]COVID-19: coronavirus disease.

[b]ºF: degrees Fahrenheit.

[c]ID numbers have been altered for publication purposes.

Discussion

Principal Findings

The first diagnosed case of COVID-19 infection in Washington, DC was associated with hundreds of potentially exposed individuals who were required to self-quarantine in early March. The patient was a church rector who revealed his COVID-19 infection status to his congregation and the media. At least five individuals from the rector's parish subsequently tested positive for COVID-19 [28,29]. This case demonstrated the emerging public health challenges and demands on contact tracing that would result as the pandemic unfolded, and it was a driving motivator in the development of this system for use by institutions and agencies tasked with monitoring individuals under home isolation or quarantine. The resulting product, which we have since deployed, is a user-friendly and scalable rapid response system to efficiently monitor individuals who have or have been exposed to COVID-19 while maintaining their privacy.

Our product was intended to support public health agencies and occupational health teams. With this in mind, we incorporated several distinguishing features from existing products into the system design to increase the usability and acceptability of the system. We developed a streamlined onboarding process and designed a system that would not collect personal identifiers, as standard procedures to execute data use agreements that are required when identifiers are included are arduous and impractical during public health emergencies. As health agencies are potential intended users, we included a link to the recently introduced limited waiver of Health Insurance Portability and Accountability Act (HIPAA) sanctions that were passed in the context of the SARS-CoV-2 pandemic in case these concerns would result in institutional reluctance to use the system [30]. The overall design and reassurances in the Terms of Use thereby limit regulatory hurdles to usage by institutions and agencies that are typically bound by privacy regulations related to health data.

The lack of collection of identifying data in the system should also reassure individual users and alleviate personal inhibitions that appear to be the main weak point limiting the success of other digital contact tracing apps that require identifying information to be functional. Voluntarism is an important component of the success of these technologies, and the individual entering data must be willing to use the system. In the United States, surveys have found age differences in

willingness to share SARS-CoV-2 testing results, ranging from 28% of people aged 18-29 years to 63% of people over 65 years of age [31]. However, a much lower percentage of people (50%) were willing to download an app that would alert them upon detecting proximity to a COVID-19 case, and even fewer (45%) were willing to download an app if their data were to be used by public health professionals for disease tracking [31]. These findings suggest that individuals are swayed in their willingness to use contact tracing apps based on who manages their data, with the highest confidence in data residing with and used by health departments [31]. In our design, unlike most other direct-to-consumer models, a specific institution or agency needs to request use of the system by the individual. Given potential sensitivities around monitoring, it is important to engage communities and populations to support the use of these monitoring and tracking systems and to provide guaranteed protections for users. This ethical guidance on best practices for the use of digital contact tracing and symptom monitoring is evolving and should be considered in the design and implementation phase of technology-based contact tracing adjuncts [32].

Contact tracing and monitoring has previously rested firmly in the realm of public health agencies. However, the current situation has documented outbreaks across a swath of occupations [33,34]. With the phased reopening strategy that is currently being rolled out across the United States, the number of cases is rising [7]. It is becoming increasingly apparent that institutions will need to engage in active monitoring for signs and symptoms of COVID-19 as part of their business practice to prevent local outbreaks. These data suggest that implementation of tracing and monitoring systems will be more acceptable when used in the context of reopening to reinvigorate businesses and support employment opportunities [31]. Thus, it is also important to obtain buy-in from employers and small businesses that may choose to use technologically advanced systems such as the system we designed to conduct local active monitoring to ensure the safety of their employees and customers. As this system is available for free, immediate cost would not be a concern; however, use of the system would require introduction of processes to implement it and track responses that are entered by personnel. Given the high burden of COVID-19 among minority populations, we have also provided a Spanish language version to ensure access to this important demographic [35].

Our beta test demonstrated the usability of the Georgetown University COVID-19 Symptom Tracker. We requested a limited duration of reporting as part of this beta test, primarily to ensure functionality of the reporting system as envisioned. Students responded rapidly when asked to participate, and most of them (38/47, 81%) completed three days of symptom updates. Very few of the medical students reported symptoms; this is likely due to the relative youth and low risk of the students, who were distance-learning from their homes. It is also notable that among over 800 students in the School of Medicine, only 48 chose to participate. This demonstrates potential challenges to voluntary usage of this or any other digital contact tracing or monitoring approach. Because this beta test was portrayed to the students as a feasibility study, the lack of uptake is not generalizable to a scenario where the students would be asked to participate in this monitoring system as a condition to safely restart in-person academic instruction in the fall. Our initial beta testing had limited scope to demonstrate feasibility prior to the rapid deployment of the system. Additional in-depth end user feedback to ensure accessibility, ease of use, and willingness and durability of engagement will also be important to assess. Targeted instruction of thought leaders and the target community are needed to ensure understanding of the scope and purpose of the monitoring system to address any reservations and promote use of the system as a social responsibility for public safety and the greater good of the community.

Limitations

The selected symptoms were based on reports of hospitalized patients in the early part of the pandemic [24,25]. Since that time, additional symptoms have been recognized as being associated with COVID-19. While the symptom tracker in its current form does not explicitly ask about every possible symptom that we now associate with COVID-19 infection, the most frequent and clinically important symptoms are represented. This limitation can be easily addressed, as the database enables reporting of additional symptoms; in time, this information can be used to guide iterative changes to the database to capture true incident symptoms as they emerge. Our design also decreases the likelihood of user fatigue in entering data that would be further exacerbated if the list of symptoms was further extended, given the limited yield and additionality of symptoms beyond those we selected guided by the literature.

The system currently requires internet access to enter data using the web interface. Having this system available on smartphones and mobile devices using downloadable apps would increase access and improve functionality and flexibility. This may be key to ensuring durable use of the system to maximize effectiveness. Additional customizable prompts (eg, reminders to enter symptoms at a selected frequency) and alerts can also be built in to provide immediate feedback to individuals and to the institution to improve the current functionality and safety features.

Conclusions

Symptom monitoring systems such as the one we devised and made available for all to use provide technological solutions to support contact tracing and safe reopening in the context of the SARS-CoV-2 pandemic. Privacy issues are addressed, as no personal identifiers are collected. Important health and epidemiologic data are gathered, and the use of these data for purposes of public health and safety is legally permissible and supported. As institutions assume responsibility for monitoring symptoms to protect their constituents, we provide a technological solution to promote efficiency without compromising privacy. With such transparency and assurances, hurdles to large-scale symptom monitoring could be obviated and allow for increased public safety in concert with large-scale contact tracing activities that are already underway. Georgetown University is now applying this privacy-assured technology to an anonymous automated contact tracing system. Public health agencies and occupational health programs should consider using this or another such system as an adjunct to traditional or

novel contact tracing approaches to improve efficiency in the race to contain this burgeoning pandemic. We are providing free access to this system, which is scalable to millions of users, to support institutions and organizations within the global community who need to engage in symptom monitoring for public safety.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Georgetown University COVID-19 Symptom Tracker Terms of Use.
[DOCX File , 154 KB - publichealth_v6i3e19399_app1.docx]

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Abbreviations

CDC: US Centers for Disease Control and Prevention
COVID-19: coronavirus disease
HIPAA: Health Insurance Portability and Accountability Act
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Twitter-Derived Social Neighborhood Characteristics and Individual-Level Cardiometabolic Outcomes: Cross-Sectional Study in a Nationally Representative Sample

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Abstract

Background: Social media platforms such as Twitter can serve as a potential data source for public health research to characterize the social neighborhood environment. Few studies have linked Twitter-derived characteristics to individual-level health outcomes.

Objective: This study aims to assess the association between Twitter-derived social neighborhood characteristics, including happiness, food, and physical activity mentions, with individual cardiometabolic outcomes using a nationally representative sample.

Methods: We collected a random 1% of the geotagged tweets from April 2015 to March 2016 using Twitter's Streaming Application Interface (API). Twitter-derived zip code characteristics on happiness, food, and physical activity were merged to individual outcomes from restricted-use National Health and Nutrition Examination Survey (NHANES) with residential zip codes. Separate regression analyses were performed for each of the neighborhood characteristics using NHANES 2011-2016 and 2007-2016.

Results: Individuals living in the zip codes with the two highest tertiles of happy tweets reported BMI of 0.65 (95% CI –1.10 to –0.20) and 0.85 kg/m^2 (95% CI –1.48 to –0.21) lower than those living in zip codes with the lowest frequency of happy tweets. Happy tweets were also associated with a 6%-8% lower prevalence of hypertension. A higher prevalence of healthy food tweets was linked with an 11% (95% CI 2% to 21%) lower prevalence of obesity. Those living in areas with the highest and medium tertiles of physical activity tweets were associated with a lower prevalence of hypertension by 10% (95% CI 4% to 15%) and 8% (95% CI 2% to 14%), respectively.

Conclusions: Twitter-derived social neighborhood characteristics were associated with individual-level obesity and hypertension in a nationally representative sample of US adults. Twitter data could be used for capturing neighborhood sociocultural influences on chronic conditions and may be used as a platform for chronic outcomes prevention.

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KEYWORDS

neighborhood study; cardiometabolic outcomes; Twitter

Introduction

The neighborhood environment has been recognized as an important determinant of health. Previous studies have identified associations between neighborhood characteristics and health behaviors [1,2], chronic conditions [3,4], and mental health outcomes [5,6]. Access to healthy food, proximity to parks, recreational facilities, and neighborhood walkability are protective factors of obesity, diabetes, and hypertension [7-10]. Conversely, neighborhood disadvantage and neighborhood-level stressors are associated with higher prevalence of obesity and hypertension [3,11-13].

In addition to the physical environment, social contextual factors are also associated with a variety of health outcomes. The Roseto Effect describes the phenomenon in which members of a close-knit community experience a lower heart rate than members of a neighborhood community and is an example of the potential influence of the social environment [14]. Research has shown that greater community happiness is associated with decreased prevalence of obesity, hypertension, and suicide, as well as increased life expectancy [15-17]. Greater social cohesion has been linked with lower hypertension [7,11], and social capital has been linked with lower prevalence of obesity, hypertension, and mental health conditions [18,19]. Social media, such as Twitter, can serve as a data source to characterize the social neighborhood environment. Previous studies using Twitter data have validated the approach for assessing dietary choices, measuring happiness, and examining community levels of physical activity [20-22]. Unlike traditional indicators of neighborhood environment, Twitter indicators reflect an individual's perception and attitude towards the neighborhood environment, as well as an individual's use of neighborhood resources [23]. Traditional neighborhood studies mainly rely on time-consuming neighborhood data collection within limited geographical areas. In comparison, Twitter-derived indicators as proxy measures for neighborhood factors provide low-cost opportunities to conduct neighborhood studies at the national level and to study the association between geographic factors and health outcomes. We hypothesize that neighborhood-level factors, as estimated by aggregating information from tweets, influence individual-level health.

Underlying Mechanism

According to social learning theory, learning occurs in a social context [24]. Social context influences individual health behaviors through reciprocal interactions between people, as well as between people and the environment, through observational learning of modeled behaviors, self-initiated reinforcement, or external positive or negative reinforcement, and socially communicated expectations of particular health behaviors [24]. For instance, communities that tweet more about physical activity may culturally support such activity more than other communities, thus reinforcing the decision of a given resident to engage in similar activity. Communities might also differ in the foods they prefer; therefore, utilizing Twitter data, we can estimate food preferences and norms and determine whether these relate to health outcomes on an individual level.

Study Aim and Hypothesis

In this study, we utilized Twitter-derived characteristics, including happiness, food, and physical activity, as social neighborhood predictors. We assessed the associations between the Twitter-derived characteristics and cardiometabolic outcomes, including obesity, diabetes, and hypertension, using a nationally representative sample from the National Health and Nutrition Examination Survey (NHANES). We hypothesized that people living in zip codes with high levels of Twitter-derived neighborhood happiness, healthy diet, and physical activity have lower mean BMI and lower prevalence of obesity, diabetes, and hypertension, respectively.

Methods

Study Population and Outcomes

Individual-level health data were obtained from the NHANES 2007-2008, 2009-2010, 2011-2012, 2013-2014, and 2015-2016. We received approval to access the restricted, geocoded data from the National Center for Health Statistics (NCHS) Restricted Data Center (RDC). NHANES data and Twitter-derived predictors were merged via zip code linkages by an NCHS analyst. Zip codes were masked after data linkage. All statistical analyses were performed at the Maryland Federal Statistical Research Data Center, and all output was reviewed by an RDC staff member to avoid information disclosure. We followed the RDC confidentiality and disclosure review policies to protect the confidentiality of the NCHS study participants.

NHANES data consist of interview data (demographic, socioeconomic, and health-related questions) and examination data (physiological checks as well as laboratory tests). Data collection for NHANES was approved by the NCHS Research Ethics Review Board (ERB). Analysis of deidentified data from the survey is exempt from the federal regulations for the protection of human research participants. Analysis of restricted data through the NCHS RDC is also approved by the NCHS ERB. The study was approved by the University of Maryland Institutional Review Board (IRB).

We examined the following cardiometabolic outcomes: BMI, obesity, diabetes, and hypertension. NHANES measured weight and height data were used to calculate BMI. Obesity was defined as BMI≥30 kg/m^2. BMI and obesity are interdependent outcomes. Given BMI is a continuous variable, it provides more statistical power to detect differences, enabling readers to assess how much Twitter-derived variables might shift the distribution of BMI values. However, obesity is a clinically important health outcome. We present analyses with both to provide a more comprehensive examination of associations between Twitter-derived community variables and health outcomes. Hypertension was defined as having elevated blood pressure or self-report of taking medications for hypertension. A mean systolic blood pressure >130 mm Hg or mean diastolic blood pressure >80 mm Hg was defined as elevated blood pressure [25]. Diabetes was defined as having a glycohemoglobin (%) value ≥6.5% or self-reported diagnoses of diabetes [26].

We included both individual-level and zip code-level covariates to account for confounding. Individual-level covariates from

NHANES included age, sex, race/ethnicity, and annual household income. Zip code level characteristics included the following: percent of non-Hispanic white, median household income, population density, and median age obtained from the 2011-2015 American Community Survey 5-year estimates [27]. To avoid disclosure of zip codes, we replaced continuous percent non-Hispanic white, median age, and population density with the corresponding median value in each 20-quantile group. We replaced continuous median household income with the corresponding log-transformed median value for each 20-quantile group as requested by the RDC.

Twitter-Derived Social Neighborhood Characteristics

A random 1% of the geotagged tweets that are publicly available were collected through Twitter's streaming application programming interface (API) from February 2015 to March 2016. Geotagged tweets have the latitude and longitude coordinates of the location from which they were sent. We collected 79,848,992 geotagged tweets across the contiguous United States (including Washington, DC) and identified 603,363 unique Twitter users. Duplicated tweets and tweets identified as job postings through hashtags were removed. Each tweet was linked to the corresponding zip code through spatial join using Python (Python Software Foundation) [28].

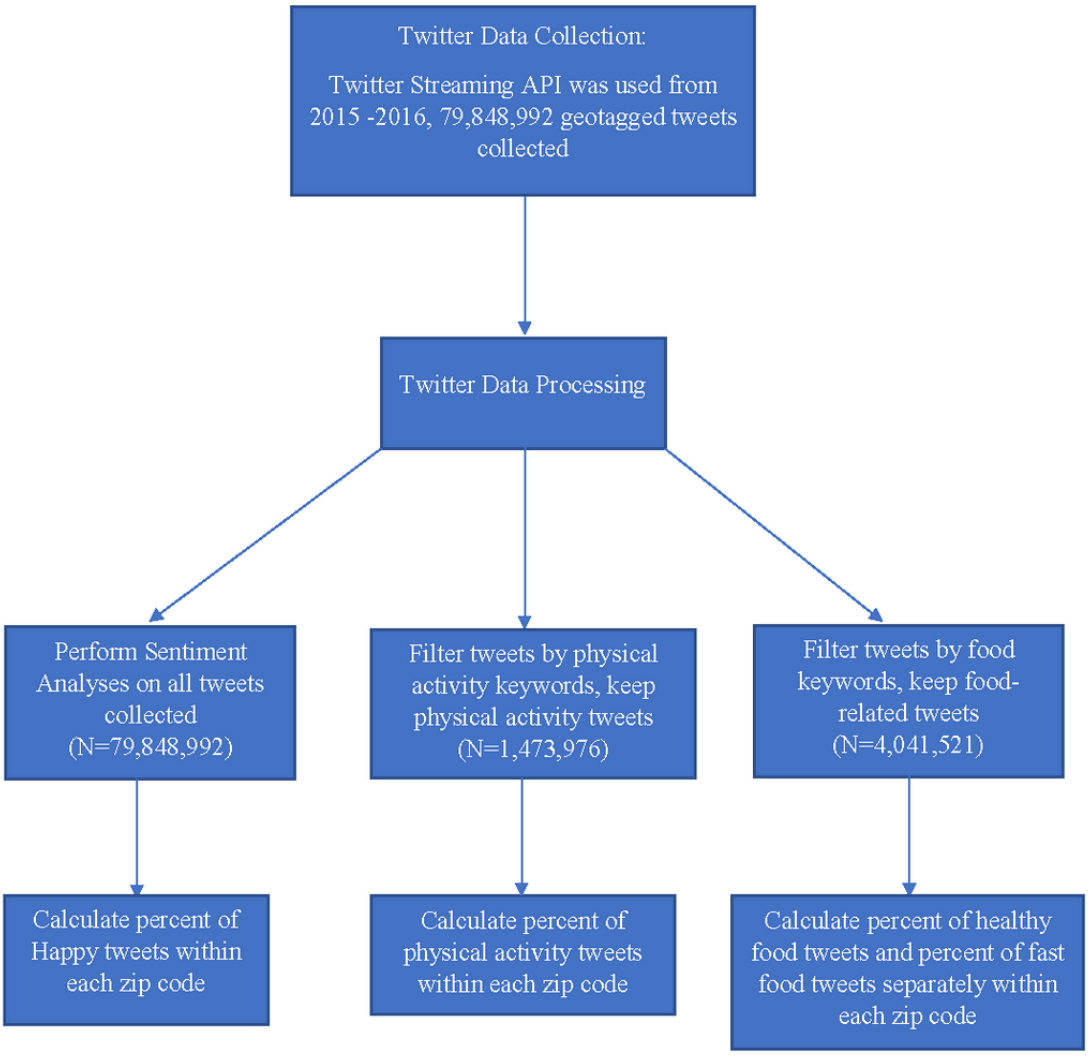
Detailed information on the construction and validation of Twitter characteristics can be found in a previously published article [20]. Figure 1 is a flowchart of Twitter data collection and the construction of Twitter characteristics. Here, we briefly summarized the process to construct Twitter characteristics. We implemented sentiment analysis with the Machine Learning for Language Toolkit (MALLET) [29] to compute the happiness score (range from 0 to 1) for each tweet. We included diverse sources of training data such as Sentiment140 [30], Sanders Analytics [31], and Kaggle [32]. A binary variable of happiness was created for each tweet based on the MALLET score, where a rating >0.8 was defined as happy. The cut-off point of 0.8 reached the highest accuracy of classifying happy tweets and maintained the same prevalence of happy tweets identified in the human-labeled dataset [20]. After identifying each tweet as "happy" versus "not happy," we calculated the percent of happy tweets within each zip code [33].

For food analysis, we created a list of over 1430 popular food words from the US Department of Agriculture's National Nutrient Database [34]. Fruits, vegetables, nuts, and lean proteins were labeled as healthy food (n=340), and fast food labels were also used (n=154). We identified 4,041,521 food-related tweets and filtered each tweet by items on the food list to categorize them as mentions of healthy or fast food. The percentages of healthy and fast food tweets were calculated at the zip code level.

Similar to our food analysis, we created a list of physical activities using the published list of physical activity terms collected from physical activity questionnaires, a compendium of physical activities, and popular fitness programs [35-37]. A total of 376 items were gathered and included activities from gym exercise, sports, recreational activities, and household chores. Expressions such as "running late" and "walk away" were excluded. To avoid including tweets about passively watching sports, we excluded tweets with the verbs "watch/watching/watches/watched" and "attend/attends/attending/attending" and only included team sports tweets when there was the word "play/plays/playing/played." We collected 1,473,976 geotagged tweets associated with physical activity. The percentage of physical activity tweets was aggregated at the zip code level.

To comply with RDC confidentiality and disclosure review policies, we were unable to use continuous percent Twitter characteristics at the zip code level, since the data may serve as geo-identifiers. We categorized Twitter characteristics at the zip code level into tertiles (high, medium, low) as predictors.

Figure 1. Twitter data collection and construction of Twitter characteristics.



Statistical Analysis

We implemented separate regression analyses for each of the outcomes. Linear regression was used for continuous outcomes such as BMI; Poisson regression was used for binary outcomes including obesity, diabetes, and hypertension, to estimate prevalence ratios [38]. All models controlled for individual-level demographics and zip code-level characteristics. We analyzed health outcomes for the NHANES 2011-2016 subcohort, which is closer in time to the Twitter data (2015-2016). As a supplement, we analyzed NHANES data from the most recent five survey cycles from 2007 to 2016 (described below as the "full cohort") to obtain a sample with a higher diversity of zip codes (2116 zip codes in the full cohort and 1384 zip codes for the subcohort). A 10-year Mobile Examination Center (MEC) weight was used for NHANES data from 2007 to 2016, and a 6-year MEC weight was used for NHANES data from 2011 to 2016 [39,40]. Analyses were performed in Stata MP15 (StataCorp LP).

Results

Descriptive Statistics

Descriptive statistics are shown in Tables 1 and 2. The zip code–level Twitter characteristics were calculated for all zip codes in the United States. Of these, 19% were happy (n=29,606), 2.2% mentioned physical activity, and 5.0% mentioned food. There were fewer tweets about healthy foods (1.0%) and fast food (0.3%). Examples of each Twitter-derived characteristic are listed in Table 3.

For the full cohort, the mean age was 47 years, and 15,040 of 29,201 participants (51.9%) were female. Reported participant race and ethnicity included 12,113 (66.6%) non-Hispanic white, 7627 (14%) Hispanic, 6179 (11%) non-Hispanic black, and 3282 (8%) identified as other races. The mean BMI was 29 kg/m^2, and the prevalence of obesity was 36.5% (10,478 participants). The mean glycohemoglobin level was 5.6%, and the prevalence of diabetes was 12.1% (n=4603). Hypertension was reported in 14,336 participants (48.1%). Individual demographic characteristics in the subcohort were similar to those in the full cohort.

Table 1. Descriptive characteristics for Twitter social neighborhood characteristics.

Zip code level Twitter characteristics	Number of zip codes with Twitter characteristics	Mean percentage (SE)
Happy tweets	29,606	19.0 (0.06)
Tweets about physical activity	29,604	2.2 (0.02)
Tweets about food	24,177	5.0 (0.03)
Tweets about healthy food	24,173	1.0 (0.02)
Tweets about fast food	24,174	0.3 (0.01)

Table 2. Descriptive characteristics for individual characteristics from the National Health and Nutrition Examination Survey.

Individual-level characteristics	NHANES[a] 2007-2016[b]		NHANES 2011-2016[c]	
	Total participants, n	Mean, % (SE)	Total participants, n	Mean, % (SE)
Age (years), mean (SE)	29,201	47.3 (0.25)	17,048	47.6 (0.36)
Female, % (SE)	15,040	51.9 (0.28)	8803	52.0 (0.40)
Married, % (SE)	14,836	55.0 (0.72)	8534	54.2 (1.02)
Race/Ethnicity, % (SE)				
Black, non-Hispanic, % (SE)	6179	11.4 (0.82)	3830	11.4 (1.17)
White, non-Hispanic, % (SE)	12,113	66.6 (1.62)	6376	65.4 (2.13)
Hispanic, % (SE)	7627	14.3 (1.11)	4156	14.8 (1.45)
Education, % (SE)				
Less than high school	7579	17.2 (0.70)	3942	15.5 (0.97)
High school	6596	22.1 (0.55)	3708	20.9 (0.71)
Some college	8366	31.4 (0.52)	5119	32.5 (0.76)
College or greater	6621	29.3 (1.02)	4262	31.2 (1.45)
Total annual household income (US$), % (SE)				
<20,000	6247	15.0 (0.61)	3593	14.9 (0.85)
20,000-55,000	11,518	37.1 (0.67)	6453	36.1 (0.97)
55,000-75,000	2965	12.6 (0.44)	1709	12.3 (0.59)
75,000-100,000	2503	11.4 (0.38)	1437	10.8 (0.41)
≥100,000	4399	23.9 (1.09)	2861	25.9 (1.61)
BMI (kg/m^2), mean (SE)	28,818	28.9 (0.09)	16,830	29.1 (0.12)
Obesity, % (SE)	10,478	36.5 (0.54)	6144	37.6 (0.76)
Hemoglobin A_{1c}, % (SE)	27,775	5.6 (0.01)	16,280	5.6 (0.01)
Diabetes prevalence, % (SE)	4603	12.1 (0.32)	2741	12.6 (0.42)
Hypertension, % (SE)	14,336	48.1 (0.59)	8411	48.8 (0.77)

[a]NHANES: National Health and Nutrition Examination Survey.

[b]Descriptive statistics were weighted using the Mobile Examination Center 10-year weight.

[c]Descriptive statistics were weighted using Mobile Examination Center 6-year weight.

Table 3. Examples of each Twitter characteristic[a].

Example number	Happy tweets	Fast food tweets	Healthy food tweets	Physical activity
Example 1	"I am so blessed that my family is healthy – it is all it matters!"	"I just left pizzahut with my mother!"	"collard greens are so delicious"	"gotta get up and workout in a couple hours hopefully I can get up"
Example 2	"Me & my bestie celebrating her bachelorette trip. We are having a blast!"	"The perfect afternoon work spot @starbucks"	"Today woke up at 8 am to eat a kale salad"	"I just finished running 6.02 miles in 50m:44s"
Example 3	"Wednesday night with the best people!"	"Taco Bell run"	"I cooked for lunch today! Brown rice with roast beef, broccoli, and green beans – yummm!"	"A fun seven-mile hike at Shenandoah"
Example 4	"Brunch after the hike!!!#food-porn"	"Chipotle line mad long but I am not leaving!"	"Turkey, broccoli, spinach, and tomatoes! This is breakfast yay"	"hiked to the summit of a mountain today!"

[a]Example tweets were slightly modified to mask the original tweets. Specific time, location, and names were changed to avoid identity disclosure.

Regression Results

Zip code-level happiness was associated with lower mean BMI, as well as a lower prevalence of hypertension (Table 4). Comparing individuals living in the medium (second tertile) and the highest (third tertile) to the lowest level (first tertile) of happy tweets, mean BMI decreased by 0.65 kg/m^2 (95% CI –1.10 to –0.20) and 0.85 kg/m^2 (95% CI –1.48 to –0.21), respectively. The prevalence of hypertension was lower by 8% (prevalence ratio [PR] 0.92; 95% CI 0.86 to 0.98) and 6% (PR 0.94; 95% CI 0.88 to 1.00) in the medium and highest tertiles versus the lowest tertile (Table 4). Associations between happy tweets and obesity and diabetes bordered on statistical significance in the subcohort analyses, but were statistically significant in the full cohort analyses.

High levels of Twitter-derived physical activity were associated with a lower prevalence of hypertension. In a comparison of individuals living in zip codes in the medium and highest levels of physical activity tweets to those with the lowest level, hypertension decreased by 8% (PR 0.92, 95% CI 0.87 to 0.98) and 10% (PR 0.90, 95% CI 0.85 to 0.96), respectively. Physical activity tweets were not associated with BMI, obesity, and diabetes.

Healthy food tweets were linked to BMI, obesity, and hypertension. Individuals living in zip codes with medium and high levels of healthy food tweets had mean BMI values that were 0.73 kg/m^2 lower (95% CI –1.39 to –0.07) and 1.02 kg/m^2 lower (95% CI –1.39 to –0.07). The prevalence of obesity was 5% (PR 0.95, 95% CI 0.86 to 1.04) and 11% lower (PR 0.88, 95% CI 0.79 to 0.98) and the prevalence of hypertension was 6% (PR 0.94, 95% CI 0.88 to 1.00) and 1% (PR 0.99, 95% CI 0.91 to 1.06) lower. Fast food tweets were not associated with BMI, obesity, hypertension, and diabetes. Table 4 shows the number of study participants with given characteristics.

In supplemental analyses using NHANES 2007-2016 (Table 5), we observed associations that exhibited similar patterns as the regression results using the subcohort, with some stronger associations. Table 5 shows the number of study participants with given characteristics.

Table 4. Twitter-derived neighborhood characteristics and adult health outcomes in the NHANES 2011-2016 subcohort[a].

Zip code-level Twitter predictors and tertiles	BMI (kg/m^2), b (95% CI)[b]	Obesity, prevalence ratio (95% CI)[b]	Hypertension, prevalence ratio (95% CI)[b]	Diabetes, prevalence ratio (95% CI)[b]
Happy tweets				
Third tertile (highest)	–0.85 (–1.48 to –0.21)	0.92 (0.82 to 1.04)	0.94 (0.88 to 1.00)	0.90 (0.76 to 1.05)
Second tertile	–0.65 (–1.10 to –0.20)	0.95 (0.86 to 1.04)	0.92 (0.86 to 0.98)	1.02 (0.90 to 1.15)
Physical activity tweets				
Third tertile (highest)	–0.57 (–1.27 to 0.12)	0.94 (0.85 to 1.04)	0.90 (0.85 to 0.96)	1.09 (0.87 to 1.37)
Second tertile	–0.18 (–0.83 to 0.47)	1.00 (0.91 to 1.09)	0.92 (0.87 to 0.98)	1.09 (0.91 to 1.32)
Fast food tweets				
Third tertile (highest)	–0.37 (–0.84 to 0.11)	0.98 (0.90 to 1.07)	0.96 (0.88 to 1.04)	1.00 (0.84 to 1.19)
Second tertile	–0.47 (–1.04 to 0.10)	0.99 (0.89 to 1.10)	0.95 (0.89 to 1.02)	1.00 (0.83 to 1.21)
Healthy food tweets				
Third tertile (highest)	–1.02 (–1.75 to –0.28)	0.88 (0.79 to 0.98)	0.99 (0.91 to 1.06)	1.00 (0.83 to 1.21)
Second tertile	–0.73 (–1.39 to –0.07)	0.95 (0.86 to 1.04)	0.94 (0.88 to 1.00)	1.00 (0.85 to 1.16)
NHANES participants - 1[c,d]	15,897	15,897	15,412	15,473
NHANES participants - 2[e]	15,774	15,774	15,291	15,353

[a]NHANES 2011-2016 among adults 20 years and older.

[b]Adjusted regression models were run for each outcome. For dichotomous outcomes such as obesity and diabetes (0=no; 1=yes), Poisson models were utilized. For continuous variables like body mass index, linear regression was used. Models controlled for individual-level demographics including age, gender, race/ethnicity, annual household income, as well as zip code–level characteristics such as population density, percent white, median age, and median household income. Twitter-derived characteristics were categorized into tertiles, with the lowest tertile serving as the reference group. Analyses accounted for survey weights and complex survey design to produce nationally representative estimates.

[c]NHANES: National Health and Nutrition Examination Survey.

[d]Number of NHANES participants included in models with zip code–level happy tweets or physical activity tweets as the predictor variable.

[e]Number of NHANES participants included in models with zip code–level healthy food tweets or fast food tweets as the predictor variable.

Table 5. Twitter-derived neighborhood characteristics and adult health outcomes in full cohort[a].

Zip code–level Twitter predictors and tertiles	BMI (kg/m^2), b (95% CI)[b]	Obesity, prevalence ratio (95% CI)[b]	Hypertension, prevalence ratio (95% CI)[b]	Diabetes, prevalence ratio (95% CI)[b]
Happy tweets				
Third tertile (highest)	–0.79 (–1.25 to –0.33)	0.90 (0.82 to 0.98)	0.94 (0.89 to 0.99)	0.87 (0.77 to 0.99)
Second tertile	–0.53 (–0.81 to –0.24)	0.93 (0.88 to 0.99)	0.94 (0.89 to 0.98)	0.99 (0.90 to 1.09)
Physical activity tweets				
Third tertile (highest)	–0.69 (–1.19 to –0.19)	0.89 (0.82 to 0.97)	0.91 (0.87 to 0.96)	1.04 (0.87 to 1.24)
Second tertile	–0.34 (–0.80 to 0.12)	0.95 (0.89 to 1.02)	0.93 (0.89 to 0.97)	1.03 (0.90 to 1.18)
Fast food tweets				
Third tertile (highest)	–0.19 (–0.60 to 0.22)	1.00 (0.93 to 1.08)	0.95 (0.89 to 1.01)	1.05 (0.91 to 1.23)
Second tertile	–0.26 (–0.71 to 0.18)	1.01 (0.94 to 1.10)	0.96 (0.91 to 1.02)	1.05 (0.90 to 1.23)
Healthy food tweets				
Third tertile (highest)	–1.02 (–1.54 to –0.51)	0.87 (0.80 to 0.94)	0.96 (0.91 to 1.01)	0.93 (0.80 to 1.09)
Second tertile	–0.80 (–1.26, –0.33)	0.92 (0.86, 0.98)	0.93 (0.89, 0.97)	0.94 (0.83, 1.07)
NHANES participants[c,d]	27,222	27,222	26,151	26,429
NHANES participants[e]	26,814	26,814	25,752	26,029

[a]Data source for health outcome: NHANES 2007-2016 among adults 20 years and older.

[b]Adjusted regression models were run for each outcome separately. For dichotomous outcomes such as obesity and diabetes (0=no; 1=yes), Poisson models were utilized. For continuous variables like body mass index, linear regression was used. Models controlled for individual-level demographics including age, gender, race/ethnicity, annual household income, as well as zip code level characteristics including population density, percent of White, median age and median household income. Twitter-derived characteristics were categorized into tertiles, with the lowest tertile serving as the referent group. Analyses accounted for survey weights and complex survey design to produce nationally representative estimates.

[c]NHANES: National Health and Nutrition Examination Survey.

[d]Number of NHANES participants included in models with zip code–level happy tweets or physical activity tweets as the predictor variable.

[e]Number of NHANES participants included in models with zip code–level healthy food tweets or fast food tweets as the predictor variable.

Discussion

This study is one of the first to investigate the relationship between Twitter-derived social neighborhood characteristics and individual cardiometabolic outcomes utilizing a nationally representative population. We found that healthy food was associated with lower mean BMI and lower prevalence of hypertension, and Twitter-derived physical activity was associated with a lower prevalence of hypertension. Associations between happy tweets and obesity and diabetes bordered statistical significance in the subcohort analyses (NHANES 2011-2016) but were statistically significant in the full cohort (NHANES 2007-2016). The associations between Twitter-derived characteristics and obesity were more evident in the full cohort than in the subcohort, possibly due to the larger sample size and higher statistical power.

Twitter-derived happiness was associated with lower mean BMI and lower prevalence of obesity and hypertension, suggesting the protective effect of positive emotion on obesity and hypertension. Results have also shown that neighborhoods with high and medium happiness tertiles have similar prevalence of obesity and hypertension, which indicates that the percent happiness in a neighborhood may not have any additional impact on cardiometabolic prevalence once it reaches a threshold. We included both continuous BMI and binary obesity as outcomes. Our study results suggest that higher neighborhood happiness values shift BMI distributions lower. Individuals living in the third tertile have 0.85 kg/m^2 lower BMI than those living in the lowest tertile of neighborhood happiness. For obesity, this translates to an 8% lower relative risk. Although obesity is clinically important, the result of BMI provided insights for potential community interventions.

In our study, we focused on neighborhood-level happiness derived from Twitter, which is different from individual-level happiness. However, social networks spread happiness, and an individual's happiness is correlated to that of their neighbors, friends, and families [41]. The influence of affective state on outcomes via health behaviors could explain the link between happiness and a lower prevalence of health outcomes. Prior studies found negative emotions, including anger, depression, and anxiety, as well as stress, were associated with overeating, sedentary lifestyle, and physical inactivity [42-44]. Negative emotions and chronic stress may induce hemodynamic responses that lead to sustained elevation of blood pressure [45]. Although greater happiness is associated with lower cortisol and reduced plasma fibrinogen stress responses, indicating a lower risk for cardiovascular disease [46].

Associations between Twitter-derived physical activity mentions and lower hypertension suggest social learning of physical activity through Twitter may be effective at promoting the

prevention of this condition. Health behaviors, including physical activity, occur in clusters rather than independently [47,48]. Information on physical activity and exercise behaviors may spread over the social network [49], and social network users are more likely to exercise if receiving repetitive messages on physical activity [50]. We also found Twitter-derived healthy food was associated with lower mean BMI and lower prevalence of obesity and hypertension. Social learning of healthy eating behaviors may help in shaping eating behaviors and consequently contribute to a lower prevalence of chronic health outcomes. Our results indicate the potential utility of Twitter as a platform to impact chronic disease prevention via behavioral changes.

Although not statistically significant, we observed associations between Twitter-derived social neighborhood characteristics and outcomes in unexpected directions. More fast food tweets were associated with lower mean BMI and lower prevalence of hypertension. Fast food consumption may be less affected by the local food environment but more affected by individual-level characteristics, including gender, socioeconomic status, and personal preferences [23,51-53]. Some fast-food tweets may come from advertisers rather than individual users. Healthy food tweets are generally sent by individual users, which may partially explain why healthy food tweets are significantly associated with certain community-level health outcomes, while fast food tweets are not. We also found a non-significant association between physical activity tweets and the prevalence of diabetes. We postulate that because diabetes is a complex condition affected by both genetics and environmental factors, the disease is unlikely to change swiftly or reflect the effect of the neighborhood environment.

It is important to note that this study is subject to several limitations. While Twitter does not record user demographics, Twitter users are generally younger [54], and there are more male Twitter users than females [55]. Twitter users are not a representative sample of the general population. Nonetheless, we argue that Twitter data, while imperfect, provides useful information about the social environment that corresponds with differentials in health outcomes [56]. In addition, we only collected geotagged tweets that had the latitude and longitude coordinates, representing a small fraction of all publicly available tweets. Thus, geotagged tweets may not fully capture the social environment for all Twitter users. Moreover, our keyword list approach to classification may not capture all tweets that fall within each topic or misidentify irrelevant tweets. However, we anticipate that misclassified tweets will comprise an insignificantly small portion of all tweets. Misclassification could also occur when assigning the sentiment score to a tweet due to the difficulty in recognizing and differentiating sarcastic expressions and humor. We performed validation for sentiment analysis comparing machine-labeled and manually labeled tweets and observed a high agreement between machine and manually labeled data [20].

Additionally, the study is observational and cross-sectional, which inhibits causal inference. We were unable to establish the temporality between Twitter-derived social neighborhood characteristics and cardiometabolic outcomes. To lessen discordance in the time frame and reduce the potential bias introduced from changing social environments, we implemented separate regression analyses for NHANES data from 2011 to 2016 and from 2007 to 2016. Results generally followed the same pattern for the two time periods, and we observed associations between Twitter-derived characteristics with obesity and hypertension.

We did not account for local resources that might influence cardiometabolic outcomes, for instance, the availability of grocery stores and local sources of healthy foods. However, we controlled for zip code-level characteristics, including percent non-Hispanic white, median age, population density, and median household income in the regression analyses.

Our study has several advantages. We utilize a publicly available big data source, allowing us to create neighborhood characteristics for small areas across the entire contiguous United States. This approach differs significantly from the majority of neighborhood studies that are restricted to local geography, given the time-consuming and expensive nature of gathering neighborhood data. Our study advances the use of social media in health research by constructing social neighborhood characteristics and applied these characteristics at individual-level quantitative analyses. Although researchers have been increasingly aware of the value of using social media data in health research, the majority of existing health studies are content analyses. We are not aware of any studies that used quantitative Twitter characteristics in individual-level outcome research. Additionally, leveraging individual data from NHANES allowed us to incorporate objective health assessments and extensive individual-level demographic information.

Our study investigated the relationships between Twitter-derived social neighborhood features and individual cardiometabolic outcomes in a nationally representative population. Our findings show Twitter as an emerging and cost-effective data source for public health that could be used to understand the potential influence of social context on important chronic health conditions. Researchers and public health practitioners may use Twitter as a public health surveillance tool to identify communities with greater risk of cardiometabolic outcomes. Practitioners could also utilize Twitter as a platform for health education and the social promotion of healthy behaviors aimed at reducing the burden for cardiometabolic outcomes.

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Authors' Contributions

Conceptualization and methodology – QCN; data collection – SK and PD; formal analysis – DH; writing (original draft preparation) – DH, review and editing – DH, QCN, YH, NS, KMG, XH, RP; funding acquisition – QCN.

Conflicts of Interest

None declared.

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Abbreviations

API: application programming interface
MEC: Mobile Examination Center
NCHS: National Center for Health Statistics
NHANES: National Health and Nutrition Examination Survey
RDC: Restricted Data Center

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Original Paper

The Impact of Receiving Pretravel Health Advice on the Prevention of Hajj-Related Illnesses Among Australian Pilgrims: Cohort Study

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Abstract

Background: Pretravel health advice can play a crucial role in improving both travelers' awareness about disease risk and compliance with preventive measures. General practitioners (GPs) and the internet have been reported internationally to be the main sources of health advice for travelers to non–mass gathering (MG) destinations. However, few studies have attempted to investigate the sources of health advice among travelers to MGs including the Hajj pilgrimage, and none of these studies further investigated the impact of pretravel advice on pilgrims' health behaviors.

Objective: The objective of this study was to investigate the impact of the source of pretravel health advice (from GPs and specialized Hajj travel agents) on Hajj pilgrims' awareness of and compliance with health recommendations, and the incidence of Hajj-associated illnesses.

Methods: A prospective cohort study (before and during Hajj) was conducted among Australian pilgrims aged ≥18 years in 2015.

Results: A total of 421 pilgrims participated prior to Hajj, and 391 (93%) provided follow-up data during Hajj. All participants obtained pretravel health advice from one or more sources, with Hajj travel agents (46%) and general practitioners (GPs; 40%) the most commonly reported sources. In total, 288 (74%) participants reported Hajj-related symptoms, of which 86% (248/288) were respiratory symptoms. Participants who obtained pretravel health advice from travel agents were more likely to be aware of the official Saudi recommendations (adjusted odds ratio [aOR] 2.1, 95% CI 1.2-3.8; *P*=.01), receive recommended vaccines before travel (aOR 2.4, 95% CI 1.4-3.9; *P*=.01), use hand sanitizers including soap (aOR 2.5, 95% CI 1.1-6.1; *P*=.03), and wash their hands after touching an ill person during Hajj (aOR 2.9, 95% CI 1.1-7.1; *P*=.01), compared to those who sought advice from GPs. However, neither advice from travel agents nor GPs was associated with a lower incidence of Hajj-related illnesses.

Conclusions: Advice from travel agents appeared to be accessed by more travelers than that from GPs, and was associated with an increased likelihood of positive travel health behaviors.

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KEYWORDS

Hajj; health behavior; mass gathering; pretravel health advice; travelers

Introduction

As more and more people travel each year, the spread of infectious diseases via international travel presents an increasing challenge to disease control globally [1]. Travelers to mass gatherings (MGs) play a significant role in the spread of infectious diseases across international borders due to their unique travel patterns and behaviors [2,3]. An MG has been defined as an event involving large number of participants (≥1000 attendees) at a specific location for a specific purpose for a defined period of time [4]. Hajj pilgrimage to Makkah, Saudi Arabia, is a noteworthy example of an MG. With 2 to 3 million attendees from about 185 countries attending annually, it is considered to be one of the largest annual MGs in the world. The Ministry of Health (MoH) in Saudi Arabia requires that all pilgrims are vaccinated against meningococcal disease, and that pilgrims from endemic countries are vaccinated against polio and yellow fever (Textbox 1) [5,6]. Moreover, vaccines against influenza, pertussis, mumps, and measles are also recommended, as well as other infection control measures, including the use of face masks and hand hygiene. Health authorities in travelers' countries of origin are also encouraged to provide health education to the pilgrims [5,6].

Textbox 1. Health recommendations and preventive measures for travelers to Saudi Arabia for Hajj 2016.

Compulsory vaccines

- Quadrivalent meningococcal vaccine (ACYW135): Compulsory for all pilgrims. Administered not less than 10 days before arrival.
- Oral polio vaccine (OPV) or inactivated polio vaccine (IPV): Compulsory for pilgrims from endemic countries. Administered at least 4 weeks before arrival. Other pilgrims should remain up-to-date.
- Yellow fever vaccine: Compulsory for pilgrims from endemic countries or those transiting through endemic countries. Administered at least 10 days before arrival.

Recommended vaccines

- Seasonal influenza vaccine: Recommended for all, in particular at-risk pilgrims.
- Diphtheria vaccine: Remaining up to date.
- Pertussis vaccine: Remaining up to date.
- Measles vaccine: Remaining up to date.
- Mumps vaccine: Remaining up to date.
- Tetanus vaccine: Remaining up to date.

Nonpharmaceutical measures

- Wash hands with soap and water or disinfectant, especially after coughing and sneezing, after using the toilet, before handling and consuming food, and after touching animals.
- Use disposable tissues when coughing or sneezing and dispose of them afterwards in waste baskets.
- Avoid hand contact with the eyes, nose, and mouth.
- Wear face masks, especially in crowded places.
- Avoid direct contact with persons who appear to be ill with coughing, sneezing, expectorating, vomiting, diarrhea, and do not share personal belongings.
- Maintain good personal hygiene.
- Avoid contact with sick animals.
- Avoid drinking raw camel milk or camel urine or eating meat that has not been properly cooked.
- Take insect bite avoidance measures during daytime and nighttime hours to reduce the risk of infection with dengue and other mosquito-borne diseases.

Health education

- Health authorities in countries of origin are required to provide health information to pilgrims on infectious disease symptoms, transmission mode, and preventive measures.

Pretravel health advice can play a crucial role in improving both travelers' awareness about disease risk and compliance with preventive measures. General practitioners (GPs) and the internet have been reported internationally as the main sources of health advice for travelers to non-MG destinations [7-12]. However, the few studies which have investigated the sources

of health advice among travelers to Hajj found that about two-thirds of Hajj pilgrims sought pretravel health advice [13]. In an Australian setting, most Hajj pilgrims (88%) receive the vaccines (eg, meningococcal, influenza, and other travel vaccines) from GPs and a small proportion receive them from other sources including hospitals, workplaces, and travel clinics [13,14]. No study has yet investigated the impact of pretravel health advice on Hajj pilgrims' awareness of official health recommendations, compliance with preventive measures during Hajj, or incidence of illness symptoms such as cough, sore throat, rhinorrhea, fever, vomiting, and diarrhea. To this end, we conducted a prospective cohort study among Australian Hajj pilgrims, before and during the Hajj in 2015.

Methods

Study Design and Targeted Population

Between August and December 2015, a prospective cohort study was conducted among Australian Hajj pilgrims aged ≥18 years planning to attend Hajj 2015, held in the last week of September 2015. Potential participants living in the Greater Sydney region of New South Wales (NSW) were approached. NSW has the largest Muslim population in Australia (50% of the Australian Muslim population), with the majority living in Greater Sydney [15]. Potential participants were approached through their Hajj tour operators during pre-Hajj seminars. As a Hajj requirement, all overseas "would-be" pilgrims must travel on Hajj via an accredited travel agent. The list of accredited Hajj travel agents in Australia, including their addresses, was obtained from the Saudi Arabian Embassy in Canberra, Australia. For accreditation, the travel agents need to demonstrate the ability to organize and manage the Hajj trip, but no formal training is required. Typically, a few months before Hajj, travel agencies run pretravel seminars for the "would be" pilgrims. The frequency, duration, and talk content of these seminars vary by agency: some run several sessions, each lasting one or more days, while others run only one session lasting a few hours. The content of these seminars typically includes spiritual preparation for Hajj, travel itineraries and logistics, and information about the health requirements of the travel, such as vaccinations. The seminars are typically run in a language spoken by the majority of the travelers, or are bilingual.

For this survey, travel agents with the highest quota for Hajj visas were approached first, and the travel agents running their businesses in locations with diverse ethnic groups were prioritized to ensure a diverse sample.

This study was reviewed and approved by the Human Research Ethics Committee (HREC) at The University of Sydney (project number 2014/599).

Recruitment Methods and Study Variables

Overview

This study involved the use of 2 questionnaires: (1) a pre-Hajj questionnaire where the participants were recruited through face-to-face interviews, and (2) self-administrated questionnaires of 6 identical cards of "Hajj" to be completed by the pilgrims daily within a week during the peak Hajj period (from September 21 to 26, 2015). The surveys were primarily in English, and Arabic translations were available for those who preferred it. Data collected before and during Hajj were linked by a unique barcode.

Pre-Hajj Survey

The researchers attended 11 seminars held by Hajj travel agents in Sydney from August 1 to September 6, 2015. All attendees at the pre-Hajj seminars were invited to participate, and the surveys were conducted before the seminars to ensure assessment of only pre-existing knowledge. After pilgrims consented to participate in the study, data on their demographic characteristics were obtained using a self-administered questionnaire. Data on the receipt of pretravel health advice were also collected and stratified into 2 major groups: (1) professional medical sources, including advice from GPs and specialist travel clinics; and (2) nonmedical sources, including Hajj travel agencies (tour group leaders), family and friends who had previous experience of Hajj, and the internet. The respondents who obtained advice from professional medical sources were asked about the barriers to receiving pretravel medical advice and their satisfaction regarding the advice they received. The respondents typically completed the questionnaires themselves but the researchers were available on-site, ready to clarify any question that was not clear or to fill out the questionnaire as dictated by the respondent.

During Hajj Survey

The researchers travelled to Makkah, Saudi Arabia during the Hajj period and met the study participants (recruited in the pretravel survey) upon their arrival in Mina, Greater Makkah. Each participant was asked to record the following details in the diary (self-reported) for each day: actual use of preventive measures including wearing a face mask, using hand sanitizer (ie, use of soap or alcoholic hand rub), hand washing after touching an ill person, and using disposable handkerchiefs. This diary was completed by the respondents themselves during leisure time; however, a researcher was around to remind them to fill in the questionnaire and provide help if needed. Any respondent who used a preventive measure almost every day (≥5 of 6 days) during the peak Hajj days was considered to be "frequently compliant" with the preventive measure; those who used the preventive measures <5 days were considered to be "infrequently compliant;" and those who did not use the preventive measure at all were considered as "noncompliant." Self-reported development of symptoms suggestive of a respiratory infection (including cough, sore throat, runny nose, and fever) and other symptoms (including vomiting, diarrhea, and nausea) were also collected. We considered those who reported the presence of a cough, sore throat, and subjective fever to meet the definition of influenza-like illness (ILI) [16].

Sample Size

A consecutive convenience sampling plan was used to ensure a sample that was representative of Hajj pilgrims residing in NSW. Based on results from our 2014 study [13], and considering an error margin of 5% to be acceptable for this survey, a sample size of 350 pilgrims was deemed sufficient for this survey; this was inflated to 420 to account for loss to

follow-up. The targeted sample represented about 12% of Australian pilgrims attending Hajj in 2015.

Data Analysis

Statistical analysis was performed using SPSS (version 23.0; SPSS Inc). Chi-square tests were used to compare categorical variables. Bivariate analysis with *P* values <.25 were entered into multivariable regression models. Binary logistic regression using the backward Wald method (controlling for factors such as age, gender, chronic medical conditions, educational level, employment status, and undertaken Hajj times) was used to investigate variables related to pretravel health advice–seeking behavior. To study the impact of pretravel health advice sources on pilgrims' health behaviors (such as face mask use and hand hygiene) and the occurrence of respiratory infections including ILI during Hajj, we compared their behavior according to the most commonly used sources of pretravel health advice among pilgrims: medical (GPs) and nonmedical (Hajj travel agent). We used a logistic regression model (backward Wald method); a two-tailed *P* value of <.05 was considered statistically significant in multivariate models.

Results

Overview

A total of 421 pilgrims were recruited before Hajj, and 391 (93%) were followed during Hajj. Of 421 participants aged 18 to 74 (median 41, mean 42.2) years, 54% were male and 28% reported having one or more chronic medical conditions. Over half of participants (225/421, 54%) had up to university level education. In total, 341 pilgrims (81%) were travelling to Hajj for the first time, and pilgrims planned to stay in Saudi Arabia for a median of 25 days (range 10-45 days). Additional participant details are presented in Table 1.

Table 1. Demographic characteristics of surveyed participants (N=421).

Demographics	Participants, n (%)
Gender	
Male	229 (54)
Female	192 (46)
Education level	
University level and higher degree	164 (39)
Certificate/diploma	61 (15)
High school certificate (Year 12 equivalent)	98 (23)
School certificate (Year 10 equivalent)	75 (18)
No formal education	23 (5)
Country of birth	
Australia	128 (30)
Middle Eastern countries	113 (27)
Indian subcontinent	101 (24)
Southeast Asian countries	32 (8)
Others	42 (10)
Median years of stay in Australia[a]	21.5
Chronic diseases	
No	303 (72)
Yes[b]	118 (28)
Diabetes	41 (35)
Asthma	33 (28)
High cholesterol	30 (25)
Hypertension	28 (24)
Overall pretravel health advice–seeking behavior	
Sought advice from professional medical health sources	177 (42)
Sought advice from nonmedical sources	244 (58)
Professional sources	
General practitioners	169 (40)
Specialist travel clinic	8 (2)
Nonprofessional sources	
Hajj travel agency	192 (46)
Family and friends (who have previous Hajj experience)	38 (9)
Internet	14 (3)

[a]This value only includes those who were born overseas.

[b]Multiple responses were permitted.

Awareness of Official Hajj Health Recommendations

Over one-third (147/421, 35%) of respondents were aware of the annual Hajj health recommendations issued by the Saudi Arabian MoH; no demographic characteristics were significantly associated with awareness of MoH recommendations. Using multivariable logistic regression analysis, controlling for all other potential variables (pilgrims' health behaviors including face mask use and hand hygiene with soap and alcoholic hand rub), we found that awareness of official health recommendations was significantly associated only with frequent compliance with hand washing after touching an ill person (adjusted odds ratio [aOR] 2.1, 95% CI 1.1-3.8; *P*=.02).

Pretravel Advice-Seeking Behavior

All participants obtained some form of pretravel health information before Hajj; in total, 42% (177/421) received

pretravel health advice from medical sources and 58% (244/421) received advice solely from nonmedical sources (Table 2).

Table 2. Multivariate analysis of the association between receiving pretravel health advice from a medical (general practitioner) or nonmedical source (travel agency) and pilgrims' health behavior during Hajj.

Health behavior and source of advice	Yes, n (%)	aOR (95% CI)[a,b]	*P* value[a,b]
Awareness of official Hajj recommendations			
General practitioner	76 (52)	0.4 (0.2-0.9)	.03
Travel agency	98 (67)	2.1 (1.2-3.8)	.01
Received ≥1 recommended vaccines			
General practitioner	177 (54)	0.5 (0.2-1.1)	.1
Travel agency	203 (62)	2.4 (1.4-3.9)	.01
Face mask use			
General practitioner	52 (54)	1.0 (0.4-2.1)	.9
Travel agency	52 (54)	0.6 (0.3-1.3)	.2
Hand washing with soap			
General practitioner	170 (50)	1.3 (0.4-3.8)	.6
Travel agency	200 (59)	2.5 (1.1-6.1)	.03
Hand washing with alcoholic hand rubs			
General practitioner	37 (54)	1.8 (0.6-5.1)	.2
Travel agency	39 (57)	1.5 (0.7-3.2)	.2
Hand washing after touching an ill person			
General practitioner	33 (56)	1.1 (0.4-2.9)	.7
Travel agency	44 (75)	2.9 (1.1-7.1)	.01
Use of disposable handkerchiefs			
General practitioner	94 (54)	1.1 (0.5-2.3)	.6
Travel agency	97 (56)	0.7 (0.4-1.4)	.4

[a]aOR: adjusted odds ratio (binary logistic regression model).

[b]The reference group is the No group (ie, the group who said "no").

Professional Medical Sources

In total, 40% (169/421) of participants sought advice from GPs, while 2% (8/421) received advice from a specialized travel clinic. The majority of participants (153/177, 86%) who received professional medical pretravel advice reported that they were satisfied with the advice. In multivariable analysis, those who have diabetes were more likely to receive professional advice (aOR 2.4, 95% CI 1.05-5.9; *P*=.03) than those who did not have diabetes. However, those who were employed were less likely to seek medical pretravel advice than those who were not (aOR 0.5, 95% CI 0.3-0.8; *P*=.01).

Conversely, 58% (244/421) did not seek any professional medical pretravel advice before travelling to Hajj. Reasons for not seeking this advice included the following: preference for other sources (eg, travel agents, friends, and family members; 103/244, 42%), not seeing the need to seek pretravel health advice (96/244; 39%), being too busy (29/244; 12%), and reliance on prior experience or knowledge (16/244; 7%).

Nonmedical Sources

The most common nonmedical sources pilgrims sought health advice from were Hajj travel agents (192/421; 46%), family and friends who have previous Hajj experience (38/421; 9%), and the internet (14/421, 3%; Table 1).

Multivariable analysis revealed that those who were aged >64 years (aOR 11.1, 95% CI 1.5-81.8; *P*=.01) or employed (aOR 1.5, 95% CI 1.03-2.4; *P*=.03) were more likely to seek advice from nonmedical sources compared to their counterparts.

The Impact of Pretravel Health Advice on Pilgrims' Vaccine Uptake, Health Behavior, and the Occurrence of Symptoms During Hajj

Participants who received the recommended vaccines reported various sources of vaccination advice including Hajj travel agents (57%; 189/329), GPs (27%; 90/329), friends and family members with previous Hajj experience (13%; 44/329), and the internet (2%; 6/329). Among all the sources of pretravel health advice, participants who obtained advice from a travel agent were twice as likely to receive the recommended vaccines (aOR 2.4, 95% CI 1.4-3.9; *P*=.01). Additionally, they were more likely

to be aware of the official health recommendations (aOR 2.1; 95% CI 1.2-3.8; *P*=.01), wash hands with soap (aOR 2.5, 95% CI 1.1-6.1; *P*=.03), and wash their hands after touching an ill person during Hajj (aOR 2.9, 95% CI 1.1-7.1; *P*=.01) compared to those who sought advice from GPs (Table 2).

In total, 288 (74%) participants reported one or more illness symptoms during Hajj; these were mostly respiratory symptoms, including cough (45%; 176/391), sore throat (44%; 171/391), runny nose (26%; 103/391), and fever (15%; 59/391). ILI was only reported among 10% (40/391) of participants. Nonetheless, the source of the advice was not associated with any reported symptom (Table 3).

Table 3. Multivariate analysis of the association between receiving pretravel health advice from a medical (general practitioner) or nonmedical source (travel agency) and the incidence of Hajj-related illness.

Symptom and source of advice	Participants, n (%)	aOR (95% CI)[a,b]	*P* value[a,b]
Fever			
General practitioner	18 (31)	0.8 (0.4-1.6)	.6
Travel agency	22 (37)	0.7 (0.7-1.4)	.3
Cough			
General practitioner	71 (40)	0.5 (0.2-1.1)	.05
Travel agency	84 (48)	1.04 (0.6-1.5)	.8
Sore throat			
General practitioner	47 (27)	0.7 (0.3-1.5)	.4
Travel agency	95 (56)	0.9 (0.6-1.4)	.8
Runny nose			
General practitioner	45 (44)	0.5 (0.2-1.1)	.08
Travel agency	58 (56)	2.5 (1.1-6.1)	.9
ILI[c]			
General practitioner	17 (41)	0.9 (0.5-1.5)	.7
Travel agency	21 (52)	0.7 (0.3-1.3)	.3
Diarrhea			
General practitioner	30 (47)	0.7 (0.3-1.8)	.5
Travel agency	38 (59)	1.5 (0.8-2.8)	.1
Vomiting			
General practitioner	8 (38)	0.8 (0.1-4.1)	.8
Travel agency	6 (29)	0.5 (0.1-1.6)	.3

[a]aOR: adjusted odds ratio (binary logistic regression model).

[b]The reference group is those who did not seek advice from general practitioners or a travel agency (“No” group).

[c]ILI: influenza-like illness; ILI was defined as cough, sore throat, and subjective fever.

Discussion

This study shows that travel agencies and GPs were the most commonly sought sources for pretravel advice. Hajj pilgrims who obtained advice from travel agents were more likely to be aware of the official health recommendations, receive recommended vaccines, use hand soaps, and wash their hands after touching an ill person during Hajj compared to those who sought advice from GPs.

This study showed that 42% (177/421) of pilgrims obtained pretravel health advice from professional medical sources; this was somewhat lower than a previous survey among Australian Hajj pilgrims in 2014, which showed that 66% of respondents sought pretravel advice from medical sources [13]. In this study, although GPs were the most commonly sought source of professional advice (169/421, 40%), a small proportion (8/421, 2%) of the respondents sought advice from specialist travel clinics. This contrasts with another Australian survey, which found that 24% of pilgrims sought pretravel advice from specialist travel clinics before Hajj 2014, indicating annual variation or a real decline in the use of specialist travel clinic services [13].

This study found that seeking advice from GPs appeared to have no significant positive impact on vaccination uptake or the use of preventive measures during Hajj. The role of the GP in travel advice is challenging; providing accurate and tailored travel advice during consultations can be affected by limited time and resources. Studies focusing on non–Hajj-related travel found that travel health practitioners and GPs with travel medicine

training had higher knowledge of travel advice [17,18], and were more likely to provide written educational materials than primary care physicians without travel medicine training [19,20]. It is noteworthy that in a standard pretravel consultation setting, the common topics of pretravel health advice are travel vaccines (eg, against hepatitis A, typhoid, and yellow fever); malaria prophylaxis; and personal protective measures against insect bites, geographically endemic diseases, food- and water-borne illnesses, and sexually transmitted infections [20-22]. Airborne infections such as influenza, meningococcal disease, and measles, which are the most commonly identified infectious diseases during MGs including Hajj, require a special set of vaccines and preventive measures not typically considered for ordinary travelers [23,24]. Therefore, attempts should be made to encourage GPs and travel practitioners to remain up-to-date with the latest recommendations for specific MGs. This could be achieved by providing accessible educational programs for healthcare providers that are specific to MG travel medicine and coordinated with the timing of events [25]. Uniquely, this study found that not recognizing the need to seek pretravel health advice from medical sources was the main barrier to seeking professional pretravel advice. Therefore, Hajj travelers need to be informed that they need travel health advice and this advice should be sought at least 6 to 8 weeks prior to Hajj [26]. This could be achieved by launching awareness campaigns prior to Hajj about the importance of seeking health advice [27].

This study shows that over half of Australian pilgrims (244/421, 58%) sought health advice from nonprofessional sources, mostly travel agents (192/421, 46%). These results may be due to a high level of confidence in advice from travel agents, and family and friends who had previous Hajj experience, as was also demonstrated in a qualitative study among Australian Hajj pilgrims between 2009 and 2012 [28]. In addition, this study found that receipt of pretravel health advice from specialist travel agents (tour group leaders) was significantly associated with travelers' health knowledge and behaviors, including being more aware of the health recommendations of the destination country and better compliance with preventive measures. A previous study among Australian Hajj pilgrims in 2014 found that those who obtained health advice from a Hajj travel agency were more likely to be aware of the emerging infectious diseases in Saudi Arabia and receive vaccines than those who did not [13,29]. Similarly, Barasheed et al [14] found that receiving advice from Hajj tour group leaders was the main motivator for the uptake of influenza vaccination among Australian Hajj pilgrims in 2012. Hajj is not the only travel situation where travelers seek advice from tour operators; there are reports of other travelers (eg, tourists, and travelers visiting friends and relatives) seeking advice from travel agents [7-9,11]. Therefore, supplying travel agents with up-to-date, culturally appropriate health information may improve the health awareness and uptake of preventive measures among travelers, including Hajj pilgrims.

In this study, only 35% (147/421) of pilgrims were aware of the annual Hajj health recommendations issued by the Saudi Arabian MoH. Awareness was lower than that found by a previous study that surveyed Australian Hajj pilgrims in 2014, in which 46% of respondents were aware of the health recommendations [13]. Similarly, another study found that only 23% of European attendees at the Union of European Football Associations (UEFA)'s EURO 2012 were aware of the recommendations regarding measles vaccination before the event [30]. This indicates that published official guidelines may not uniformly reach all pilgrims across the world. Importantly, there are no studies that have assessed the usefulness of the official information from health authorities regarding Hajj or any other MGs; however, this study found that awareness of the official health recommendations was, curiously, not associated with pilgrims' compliance with preventive health measures.

The Saudi Arabian health authority requires that health authorities in pilgrims' countries of origin provide health education to their pilgrims before the pilgrims travel to Hajj [5]. Several studies found that health education delivered to pilgrims is an effective way of improving their knowledge of infectious diseases as well as the uptake of preventive measures [13,27,31,32]. However, uptake of preventive measures, including vaccination, varies among pilgrims by country of residence [33,34]. For instance, influenza vaccine uptake rates among Australian, French, and Egyptian pilgrims in 2012 were 89%, 46%, and 19.7%, respectively [14,35,36]. Lack of knowledge (particularly of the availability of a vaccine) was the main barrier to vaccine uptake and the use of measures to prevent diseases among pilgrims [13,14,28,37]. Theoretically, health agencies assume that health recommendations will reach Hajj pilgrims through their home country health authority, via health care providers. However, there is no evidence to identify the pathway and link between the issue of the annual Hajj health recommendations from Saudi Arabian health authorities, and how these recommendations are delivered to Hajj pilgrims in their countries. In this study, we identified that Hajj travel agents play an important role in this pathway. More detailed knowledge of this pathway and the dissemination of health advice may improve the promotion of Hajj health recommendations and the uptake of preventive measures among Australian pilgrims.

To our knowledge, this is the first in-depth cohort study investigating the impact of receiving pretravel health advice on travelers' health behavior during an MG. However, there are some limitations. First, the findings from this survey cannot be widely generalized; the collected data relied on self-reporting and the quality of the health advice could not be evaluated directly. A study of travel agents is needed to complement this study. To this end, we have undertaken a qualitative study among Australian tour operators that assesses their understanding, practice, and advice on infectious disease prevention at Hajj; this study will be reported separately. Second, the "during Hajj" survey, which was conducted consecutively over 6 days by using the same questionnaire diary, may have actually served as a daily reminder for the preventive measures. Third, this being a self-reported survey, it was not possible for us to validate the information the respondents provided; for instance, we could not check if the GPs recorded their pretravel consultations, as is typically done by a trained travel physician. Fourth, it is noteworthy that in this study we could not evaluate the difference in impact between those who sought pre-Hajj advice and those who did not seek advice because all participants obtained some sort of pretravel advice.

Finally, travel agents with larger quotas and those with pilgrims from multiple ethnic backgrounds were targeted first, which may have led to some selection bias.

In conclusion, this study has uniquely identified that advice from travel agencies (tour group leaders) reached more travelers than that of GPs or travel health practitioners, and was more strongly associated with travelers' positive health behaviors. Travel agents are more easily accessible, experienced, inexpensive, and sensitive to culture. However, they do not have specialist medical knowledge and their advice did not appear to result in decreasing the incidence of symptoms of Hajj-related illnesses. This could be potentially addressed by educating agents and tour operators on basic travel health needs.

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Authors' Contributions

ASA designed the study, collected data, analyzed data, and drafted the manuscript. SA, MG, and MT collected data. NFB designed the computer-aided telephone interview page. HR, KW, AH, and RB supervised data analysis and revised all versions of the manuscript. All the authors substantially contributed to editing the manuscript.

Conflicts of Interest

RB has received funding from Baxter, CSL, GSK, Merck, Novartis, Pfizer, Roche, Romark, and Sanofi Pasteur for conducting this research, travel to conferences, or consultancy work; all funding received is directed to research accounts at The Children's Hospital at Westmead. AEH has received grant funding from GSK and Sanofi Pasteur for investigator-driven research. HR has received fees from Pfizer and Novartis for consulting or serving on an advisory board. KW has received travel support from Fondation Mérieux for conference attendance. The other authors have no competing interests to declare.

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Abbreviations

aOR: adjusted odds ratio
GP: general practitioner
ILI: influenza-like illness
MG: mass gathering
MoH: Ministry of Health
NSW: New South Wales

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Original Paper

General Model for COVID-19 Spreading With Consideration of Intercity Migration, Insufficient Testing, and Active Intervention: Modeling Study of Pandemic Progression in Japan and the United States

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Abstract

Background: The coronavirus disease (COVID-19) began to spread in mid-December 2019 from Wuhan, China, to most provinces in China and over 200 other countries through an active travel network. Limited by the ability of the country or city to perform tests, the officially reported number of confirmed cases is expected to be much smaller than the true number of infected cases.

Objective: This study aims to develop a new susceptible-exposed-infected-confirmed-removed (SEICR) model for predicting the spreading progression of COVID-19 with consideration of intercity travel and the difference between the number of confirmed cases and actual infected cases, and to apply the model to provide a realistic prediction for the United States and Japan under different scenarios of active intervention.

Methods: The model introduces a new state variable corresponding to the actual number of infected cases, integrates intercity travel data to track the movement of exposed and infected individuals among cities, and allows different levels of active intervention to be considered so that a realistic prediction of the number of infected individuals can be performed. Moreover, the model generates future progression profiles for different levels of intervention by setting the parameters relative to the values found from the data fitting.

Results: By fitting the model with the data of the COVID-19 infection cases and the intercity travel data for Japan (January 15 to March 20, 2020) and the United States (February 20 to March 20, 2020), model parameters were found and then used to predict the pandemic progression in 47 regions of Japan and 50 states (plus a federal district) in the United States. The model revealed that, as of March 19, 2020, the number of infected individuals in Japan and the United States could be 20-fold and 5-fold as many as the number of confirmed cases, respectively. The results showed that, without tightening the implementation of active intervention, Japan and the United States will see about 6.55% and 18.2% of the population eventually infected, respectively, and with a drastic 10-fold elevated active intervention, the number of people eventually infected can be reduced by up to 95% in Japan and 70% in the United States.

Conclusions: The new SEICR model has revealed the effectiveness of active intervention for controlling the spread of COVID-19. Stepping up active intervention would be more effective for Japan, and raising the level of public vigilance in maintaining personal hygiene and social distancing is comparatively more important for the United States.

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KEYWORDS

pandemic spreading; SEICR model; COVID-19; prediction; effect of intervention

Introduction

Background

The global spread of the coronavirus disease (COVID-19) has shown no sign of subsiding since its emergence in Wuhan, China, in December 2019 [1]. As of March 21, 2020, a total of 276,472 cases of COVID-19 infection have been confirmed in over 185 countries, with a death toll of 11,417 [2]. Different control strategies at different levels of stringency have been applied to slow the spread of the virus in different countries [3]. Although some countries have seen peaks of infected cases and have observed significant reductions in the number of new infections in the local communities [2,4], the spread has continued in many countries, and surges in infected cases have been observed in Europe, the United States, and Australia. Intercity travel has been found to be a contributing factor to the rapid spread of the virus [5,6]. Thus, effective models for describing the pandemic progression in different cities should take into consideration the volume of intercity travel [4,7]. Additionally, the virus spread from one country to another through the air transportation network [8-10]. Hence, population flow is expected to play an important role in the transmission of COVID-19, and travel restrictions would effectively slow the transmission of COVID-19 [11]. Furthermore, the rapid spread of the virus in a population has often been a result of delayed information or unawareness of the real situation in that population, despite the wide dissemination of information related to COVID-19 outbreaks in other parts of the world. The most notable information latency lies in the number of confirmed cases reported, which depends on the ability of the particular country or city to perform tests as well as the possible bureaucracy in the local system of reporting. Thus, the number of confirmed cases is almost certainly not the true number of infected individuals at any given time [12], and an improved model for predicting the spreading progression should incorporate the latency associated with the reporting system as well as the possible missing cases leading to delay and loss of information. The traditional susceptible-exposed-infectious-recovered (SEIR) model [13,14] thus has obvious shortfalls in describing the spreading dynamics of the COVID-19 pandemic. In this work, we attempt to fill the main gap between the number of confirmed cases and the actual number of infected cases. Specifically, in the proposed model, an infected individual may become a confirmed case and then recovered or removed. Moreover, an infected individual may also be recovered or removed without being confirmed as infected. In other words, the basic model proposed here is a susceptible exposed infected confirmed removed (SEICR) model, which has an additional state corresponding to an individual having been confirmed by the authority as being infected.

On the basis of an SEICR model, we developed a model incorporating intercity travel data that accounts for any increase or decrease in the number of exposed and infected individuals in a city due to intercity migration. Furthermore, the level of intervention in the form of travel restriction, regional lockdown, or other active control measures would profoundly influence the rapidity of the virus spread and the eventual number of infected cases. The model should, therefore, allow the level of active intervention to be included as a control parameter and produce the appropriate progression profile. A specific parameter was used to adjust the level of active intervention in the simulation of future progression profiles, which corresponds quantitatively to the increase in the number of individuals eventually infected due to an additional infected individual at any given time. In this work, we apply the model to study the COVID-19 spreading progression in Japan and the United States. Data of confirmed and recovered cases in 47 Japanese prefectures or regions (January 15 to March 20, 2020) and 50 US states plus Washington, DC (February 20 to March 20, 2020) were used for fitting with the model and retrieval of parameter values. The parameters found were then adjusted to produce future progression trajectories corresponding to the implementation of different levels of active intervention.

Data

The World Health Organization has currently set the alert level of COVID-19 to the highest and has made data related to the pandemic available to the public in a series of situation reports as well as other formats [15]. Our data include the number of confirmed infected cases, the cumulative number of confirmed infected cases, the number of recovered cases, and death tolls for 47 individual prefectures and regions in Japan, from January 15 to March 20, 2020, and for 50 states and a federal district (Washington, DC) in the United States from February 20 to March 20, 2020. Data organized in convenient formats are also available elsewhere [12,16,17]. Moreover, the monthly intercity migration data for February 2020 are available from official statistics provided by the Japanese government [18] and are used as indicative migration strengths between prefectures or regions in Japan. For the United States, annual data for the volume of interstate travelers are available from the Census Bureau [19] and the Bureau of Transportation Statistics [20].

Methods

Migration-Data Augmented SEICR Model

In the proposed SEICR model, every individual would assume one of five possible states at any time, namely, susceptible (*S*), exposed (*E*), infected (*I*), confirmed (*C*), and recovered or removed (*R*). Compared to the traditional SEIR model [13,14], the new SEICR model has an additional *C* state, corresponding to an individual that has been confirmed by the authority as infected. Thus, not all infected individuals will become confirmed, and some infected individuals will transit to the recovered state without going through the confirmed state. For city or region *j*, the number of individuals in the five states are $S_j(t)$, $E_j(t)$, $I_j(t)$, $C_j(t)$, and $R_j(t)$ at time *t*. The transitions of the five states are illustrated in Figure 1.

In addition, $P_j(t)$ stands for the population of region j. Furthermore, to account for intercity movement, we introduce a migration strength, $m_{ij}(t)$, which represents an indicative volume of people moving from region i to region j at time t [4]. The augmented SEICR model is given as follows:

(1)

$\Delta I_j(t) = I_j(t+1) - I_j(t)$, $\Delta E_j(t) = E_j(t+1) - E_j(t)$, $\Delta S_j(t) = S_j(t+1) - S_j(t)$, $\Delta C_j(t) = C_j(t+1) - C_j(t)$, $\Delta R_j(t) = R_j(t+1) - R_j(t)$, $\Delta N_j^s(t) = N_j^s(t+1) - N_j^s(t)$, and $\Delta P_j(t) = P_j(t+1) - P_j(t)$.

The meaning of each parameter is given in Textbox 1. In addition, we assumed that the recovered and confirmed individuals would stay in region j.

In this SEICR model, the number of individuals eventually infected is set initially at $N_j^s(t_0) = \delta_j P_j$ (δ_j being constant), implying that some effective measures have been taken by the authorities to limit the upper bound of the susceptible population. Moreover, in the case of inactive or less effective intervention, or even unchecked spread, the growth in the number of infected cases will add to the eventual infected number. Hence, the number of eventually infected individuals should increase for each additional infected or exposed individual at time t. This is equivalent to adding an extra term (the boxed term below) to $\Delta S_j(t)$ and $\Delta N_j^s(t)$. Furthermore, as the number of infected cases increases and approaches a saturating percentage k_h (such as a herd-immunity condition), the spreading is expected to slow down significantly (ie, α_j and β_j will drop as N_j^s approaches $k_h P_j$, where $0<k_h<1$). Thus, we have:

(2)

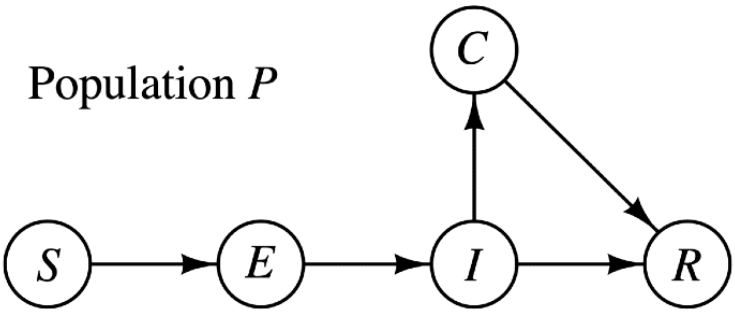
$k_j^{(c)}$ is an inverse indicator of the level of active intervention implemented, and corresponds quantitatively to an increase in the number of eventual infected individuals for each additional infected or exposed individual in region j, and the added term in $\Delta S_j(t)$ and $\Delta N_j^s(t)$ will approach zero as $N_j^s \to k_h P_j$. The meanings of other parameters are given in Textbox 1. Again, the recovered and confirmed individuals are assumed to stay in region j.

The model given in (1) and (2) is general in the sense that it applies to populations with varied effectiveness levels of active intervention during the outbreak. To further facilitate the assessment of control measures implemented in region j, we defined the level of active intervention as:

(3)

Thus, if $\psi_j>1$, the control measures are effective and the progression is limited such that $k_j^{(c)}<1$. The total number of eventually infected individuals is equal to  . However, in the case of less effective or ineffective control (ie, $\psi_j<1$), infected and exposed individuals continue to spread the disease, and for each additional infected individual, there will be $k_j^{(c)}$ more eventual infected individuals, and the pandemic progresses until the number of infected cases reaches $k_h P_j$.

Figure 1. State transition flow chart. C: confirmed; E: exposed; I: infected; R: removed; S: susceptible.



Textbox 1. Parameters of the migration-data augmented susceptible-exposed-infected-confirmed-removed model.

α_j

Rate of infecting a susceptible individual by an exposed individual in region *j*

β_j

rate of infecting a susceptible individual by an infected individual in region *j*

ρ_j

rate of infecting a susceptible individual by a confirmed individual in region *j*

λ_j

confirmed rate of infected individuals in region *j*

κ_j

rate of an exposed individual becoming infected

$\gamma_j^{(I)}$

recovery rate of an infected but not confirmed individual in region *j*

$\gamma_j^{(C)}$

recovery rate of a confirmed individual in region *j*

k_I

possibility of an infected individual moving from one region to another

$k_j^{(c)}$

increase in number of individuals eventually infected for each additional infected or exposed individual in region *j*

ψ_j

level of active intervention, $\psi_j = 1/k_j^{(c)}$

k_h

proportion of population infected achieving no further spreading (ie, absolute upper bound for N_j^S for all *j*)

δ_j

initial percentage of eventual infected individuals in region *j*

$I_{j\,0}$

initial number of infected individuals in region *j*

$E_{j\,0}$

initial number of individuals in region *j*

$C_{j\,0}$

initial number of confirmed infected individuals in region *j*

Parameter Identification

The model represented by (1) and (2) describes the dynamics of the pandemic propagation with consideration of human migration dynamics and the reality of insufficient testing that leads to confirmed infected cases being fewer than the actual infected cases. The parameters in (1) and (2) are unknown and to be estimated from historical data of *C* and *R*. We solve this parameter identification problem via constrained nonlinear programming with the objective of finding an estimated growth trajectory that fits the data. An estimated number of infected cases of each city can be generated from (1) and (2) with unknown set θ_j given by:

$$\theta_j = \{\alpha_j, \beta_j, \gamma_j, \delta_j, \lambda_j, \gamma_j^{(I)}, \gamma_j^{(C)}, k_j^{(c)}, I_{j,0}, E_{j,0}\} \quad \textbf{(4)}$$

$I_{j,0}(t) = I_j(t_0)$ and $E_{j,0}(t) = E_j(t_0)$ are the initial numbers of infected and exposed individuals in region *j*, and $\{\alpha_j, \beta_j, \gamma_j, \delta_j, \lambda_j, \gamma_j^{(I)}, \gamma_j^{(C)}, k_j^{(c)}\}$ are the model parameters of region *j*. Here, we assume that all confirmed cases are either quarantined or hospitalized and, hence, not infectious (ie, ρ_j=0). The unknown set is then $\Theta = \{\theta_1, \theta_2, \ldots, \theta_K, \kappa, k_I, k_h\}$, which essentially has $8K + 3$ unknowns, where *K* is the number of regions in the entire

population under study. The identification of unknown parameters would require a considerable effort of computation.

Specifically, the parameter estimation problem can be formulated as the following constrained nonlinear optimization problem:

(5)

$F(.)$ represents the model given by (1) and (2), $\omega_j^{(C)}$ and $\omega_j^{(R)}$ are the weighting coefficients, and  is the set of estimated variables, with unknown set Θ being bounded between Θ_L and Θ_U. In this work, an inverse approach is taken to find the unknown parameters and states by solving (5).

Prediction

The model parameters characterize the spreading dynamics, and once the set of parameters has been identified using the previously mentioned optimization procedure, we may generate future progression profiles by using the same set of parameters. Moreover, we may also adjust some of the parameters to examine different possible scenarios, corresponding to varying levels of active intervention $\psi_j = 1/k_j^{(c)}$, including travel restriction, mandatory quarantine, and other control measures. If the level of active intervention stays with the status quo, we will use the same value of $k_j^{(c)}$ for generating future progression profiles. Future paths under more active intervention can be predicted by reducing the value of $k_j^{(c)}$. In our study, by extending each simulation run to the forthcoming 200 days, we obtain a set of predicted progression profiles for each region in Japan and the United States. Moreover, different levels of active intervention can be assessed by adjusting parameter $k_j^{(c)}$ relative to the values found in each candidate set. For instance, by reducing $k_j^{(c)}$ and rerunning the simulation, we may assess the effect of tightening the control measures. In particular, we will consider three levels of active intervention: (1) staying with the status quo, corresponding to the same value of ψ_j or $k_j^{(c)}$; (2) 2-fold step-up of active intervention, corresponding to $2\psi_j$ or $0.5k_j^{(c)}$; and (3) 4-fold step-up of active intervention, corresponding to $4\psi_j$ or $0.25k_j^{(c)}$

The pandemic progression profiles of 47 Japanese prefectures or regions were examined. We perform data fitting of the model, described by (1) and (2), using historical daily data of confirmed and recovered cases. For the United States, the pandemic progression profiles of 50 states and a federal district were examined. We again performed data fitting of the model using historical daily data of confirmed and recovered cases from February 20 to March 20, 2020, and obtained 100 candidate sets of parameters that satisfy the fitting criteria.

The level of public vigilance in exercising personal protective measures can also be incorporated in our model through adjusting infection rates α_j and β_j. We can, therefore, assess the combined effectiveness of active intervention and practicing protective measures in controlling the pandemic. Here, we varied α_j, β_j, and $k_j^{(c)}$ from 10% to 100% of the originally identified values in 10 intervals, corresponding to 10 different levels of public vigilance and active intervention by the authorities. In particular, we assess α_j and β_j as one property and $k_j^{(c)}$ as another (ie, varying α_j and β_j in synchrony). Specifically, for each candidate parameter set, we perform 100 simulation runs for each combination of α_j, β_j, and $k_j^{(c)}$, where α_j, β_j, and $k_j^{(c)}$ vary from 10% to 100% of the original values in 10 steps. We then investigate the percentage of the population eventually infected in Japan and the United States.

Results

Parameters and Prediction for Japan

A typical candidate set of parameter values that fit well with the data from January 15, 2020, to March 20, 2020, is as follows: $1.3941<k_j^{(c)}<1.5979$; $0.0982<\alpha_j<0.1158$; $0.3895\ \beta_j<0.5163$; $0.0098<\gamma_j^{(I)}<0.0128$; $0.0027<\gamma_j^{(C)}<0.0047$; $0.0019<\lambda_j<0.0052$; $\kappa=0.1861$; $k_h=0.6514$. This set of parameters reflects an inadequate level of control to slow the spread of the disease, as indicated by the value of $k_j^{(c)}$ being larger than 1. Specifically, for each additional infected or exposed individual, the number of eventual infected individuals would increase by around 1.5 on average. The number of individuals eventually infected will approach a saturating percentage k_h.

We have identified 100 candidate sets of parameters that satisfy the fitting criteria, and for each set of parameters, we perform a separate simulation run. Figure 2 shows one particular simulation run of a well-fitted candidate set of parameters for 8 selected prefectures in Japan. The averaged results of all simulation runs are consolidated in the charts shown in Figure 2. Based on the data up to March 20, 2020, our model estimates that less than 3% of the infected cases are confirmed, with Hokkaido having the highest percentage (6.9%) and Hyogo-ken the least (1.5%), as shown in Figure 3(a). In other words, the actual number of infected individuals could be 20 times as many as the official confirmed number. Statistics of percentages for the population of confirmed and infected with the disease up to March 20, 2020, are shown in Figure 3(b).

We examine three cases corresponding to the level of active intervention being unchanged, 2-fold elevated, and 4-fold elevated. First, staying with the status quo ($k_j^{(c)}$ unchanged), if there is no further tightening of control aiming to slow the spread, all parameters of the candidate sets will remain unchanged. The total number of individuals eventually infected until September 23, 2020, in each region is shown in Figure 3(c). In this case, the number of infected individuals in Osaka-fu and Tokyo-to will reach about 2,300,000 and 600,000 (12% and 4.2% of the population), respectively, while most other regions will have around 5% of the population eventually infected by September 23, 2020, as shown in Figure 3(d). In total, about 6.55% of the population in Japan will be infected.

Second, with two-fold elevated active intervention ($k_j^{(c)} \rightarrow 0.5k_j^{(c)}$), if active intervention is stepped up to twice the current

level (ie, the value of $k_j^{(c)}$ is set to half of the original value in each simulation run), we observe a significant drop in the number of individuals eventually infected, as given in Figure 3(c). Specifically, the percentage of the population eventually infected by September 23, 2020, in Osaka-fu and Tokyo-to would drop to about 6.8% and 2.3%, respectively, while most other regions would drop to less than 2%, as shown in Figure 3(d). In total, about 4.14% of the population in Japan will be infected.

Third, with 4-fold elevated active intervention ($k_j^{(c)} \rightarrow 0.25k_j^{(c)}$), if active intervention is stepped up to four times the current level (ie, the value of $k_j^{(c)}$ set to a quarter of the original value in each simulation run), we observe a drastic drop in the number of individuals eventually infected, as given in Figure 3(c). Specifically, the percentage of the population eventually infected by September 23, 2020, in Osaka-fu and Tokyo-to would drop to about 4.1% and 2.3%, respectively, while most other regions would drop to less than 1%, as shown in Figure 3(d). In total, about 1.54% of the population in Japan will be infected.

In addition, our model estimates that the number of infected individuals could be 20 times as many as the currently confirmed number due to various reasons such as insufficient testing. Based on the data collected so far and assuming no further tightening of control, our model estimates about 6.65% of the population will be eventually infected, and a 4-fold elevation in control efforts may bring it down to 1.54% (about a 75% reduction) and end the pandemic sooner.

Figure 2. Official and estimated number of infected individuals in 8 selected prefectures in Japan (upper), the estimated number of infected individuals (not confirmed; middle), and the estimated number of exposed individuals (lower).

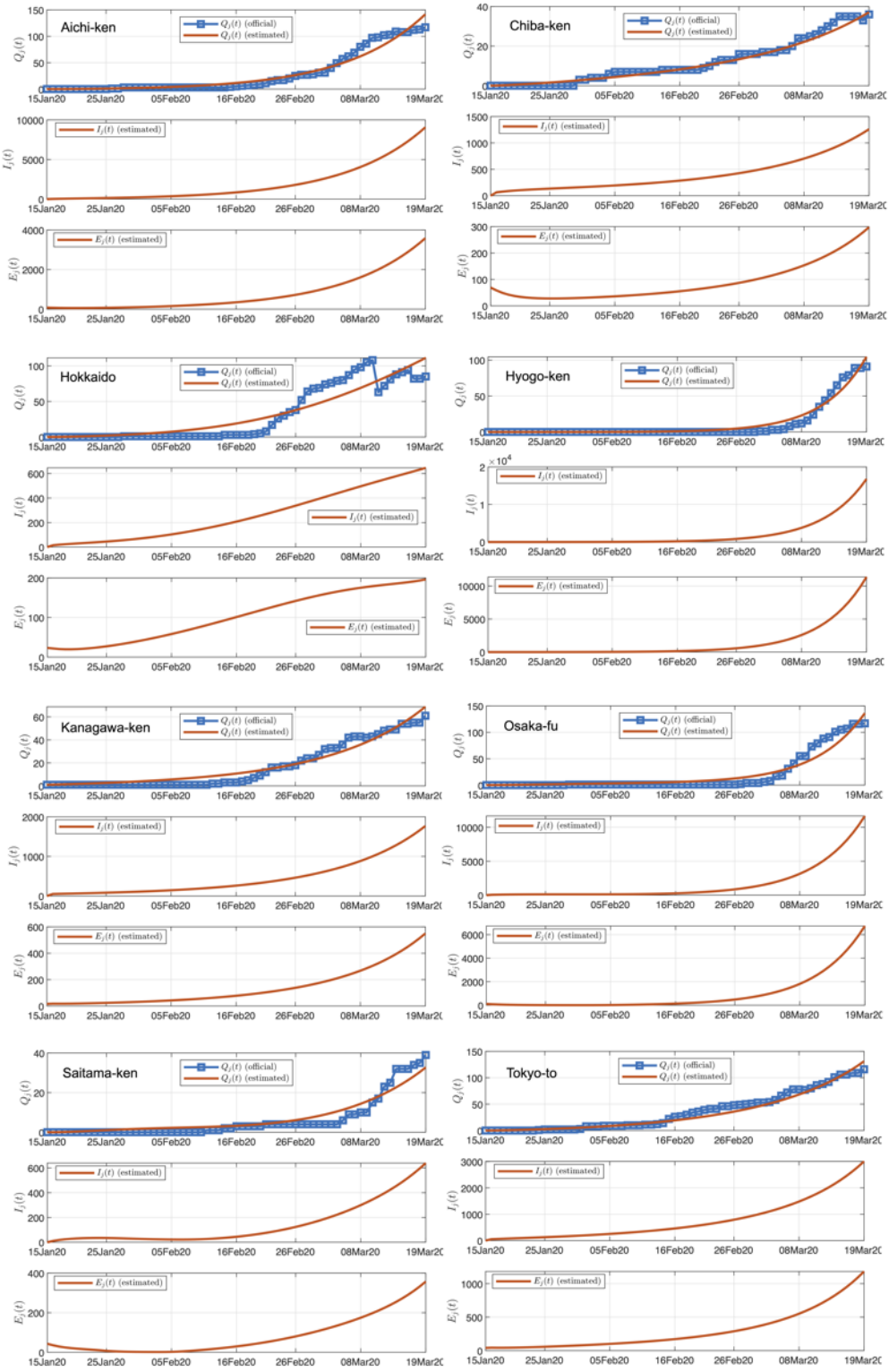
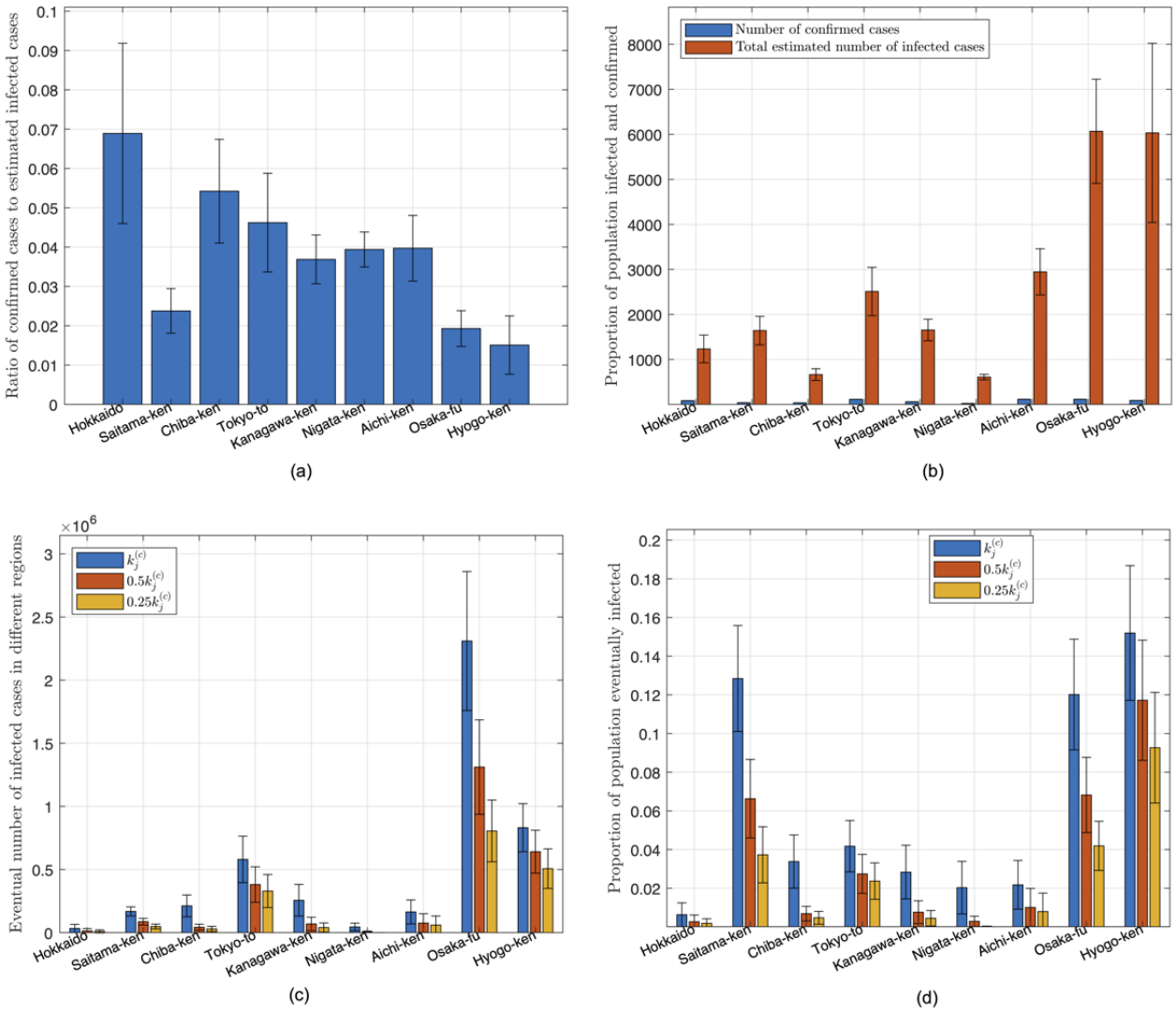


Figure 3. Statistics of data and predicted results for Japan. (a) Proportion of infected cases that are confirmed as of March 20, 2020; (b) number of confirmed cases and estimated number of infected cases as of March 20, 2020; (c) number of individuals eventually infected under three levels of active intervention; (d) proportion of population eventually infected under three levels of active intervention.



Parameters and Prediction for United States

We present here the results for eight selected states having significant numbers of infected individuals as of March 20, 2020. Figure 4 shows one typical simulation run, showing the number of confirmed cases, the estimated number of infected individuals (not confirmed), and the estimated number of exposed individuals.

As of March 19, 2020, our model showed that less than 20% of the infected cases are confirmed, with Washington, DC having the highest percentage (36%) and Michigan state the least (0.7%), as shown in Figure 5(a). In other words, the actual number of infected individuals in the United States could be 5 times as many as the confirmed number. Statistics of percentages for the population of confirmed and infected with the disease up to March 19, 2020, are shown in Figure 5(b).

The key results for the three cases corresponding to three different levels of active intervention are as follows. First, staying with the status quo ($k_j^{(c)}$ unchanged), if there is no further tightening of control aiming to slow the spread, all parameters of the candidate sets will remain unchanged. The total number of individuals eventually infected until September 23, 2020, in each state is shown in Figure 5(c). In this case, the number of infected individuals in California and New York State will reach about 5,800,000 and 7,300,000 (15% and 37.5% of population), respectively, while most other states will have less than 20% of the population eventually infected by September 23, 2020, as shown in Figure 5(d). In total, about 18.2% of the population in the United States will be infected.

Second, with 2-fold elevated active intervention ($k_j^{(c)} \rightarrow 0.5k_j^{(c)}$), if active intervention is stepped up to twice the current level (ie, the value of $k_j^{(c)}$ set to half of the original value in each simulation run), we observe a significant drop in the number of individuals eventually infected, as given in Figure 5(c). Specifically, the percentage of the population eventually infected by September 23, 2020, in California and New York State would drop to about 4.5% and 29.5%, respectively, while most other states would drop to less than 10%, as shown in Figure 5(d). In total, about 14% of the population in the United States will be infected.

Third, with 4-fold elevated active intervention ($k_j^{(c)} \rightarrow 0.5k_j^{(c)}$), if active intervention is stepped up to four times the current level (ie, the value of $k_j^{(c)}$ set to a quarter of the original value in each simulation run), we observe further reduction in the number of individuals eventually infected, as given in Figure 5(c). Specifically, the percentage of the population eventually infected by September 23, 2020, in California and New York State would drop to about 2.5% and 23%, respectively, while most other states would drop to less than 3%, as shown in Figure 5(d). In total, about 9.32% of the population in the United States will be infected.

The results of assessing the combined effectiveness of active intervention and practicing protective measures in controlling the pandemic through adjusting parameters α_j, β_j, and $k_j^{(c)}$ are shown in Figure 6(a) and 6(b).

Figure 4. Official and estimated number of infected individuals in 8 selected states in the United States (upper), the estimated number of infected individuals (not confirmed; middle), and the estimated number of exposed individuals (lower).

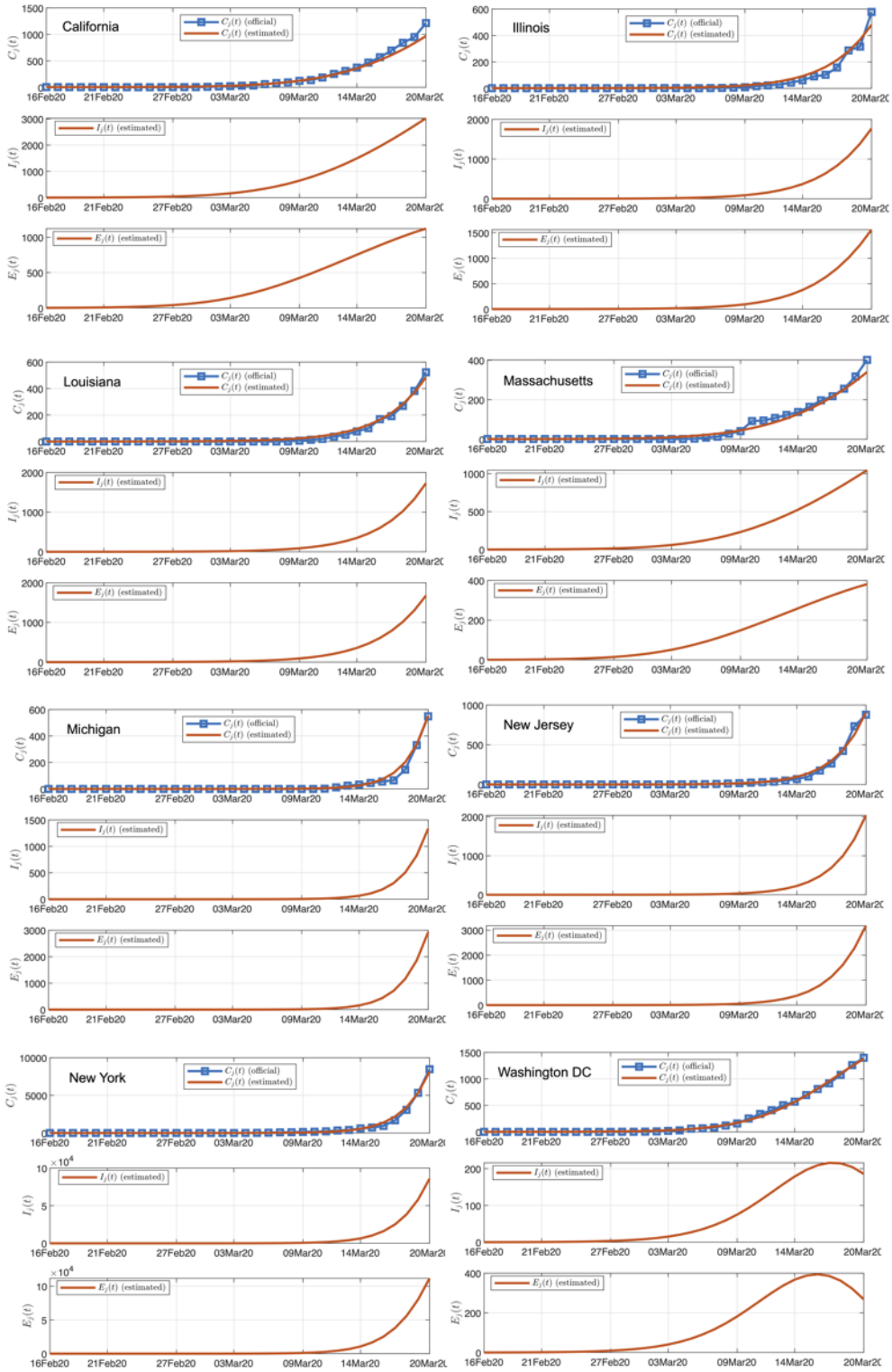


Figure 5. Statistics of data and predicted results for the United States. (a) Proportion of infected cases that are confirmed as of March 19, 2020; (b) number of confirmed cases and estimated number of infected cases as of March 19, 2020; (c) number of individuals eventually infected under three levels of active intervention; (d) proportion of population eventually infected under three levels of active intervention.

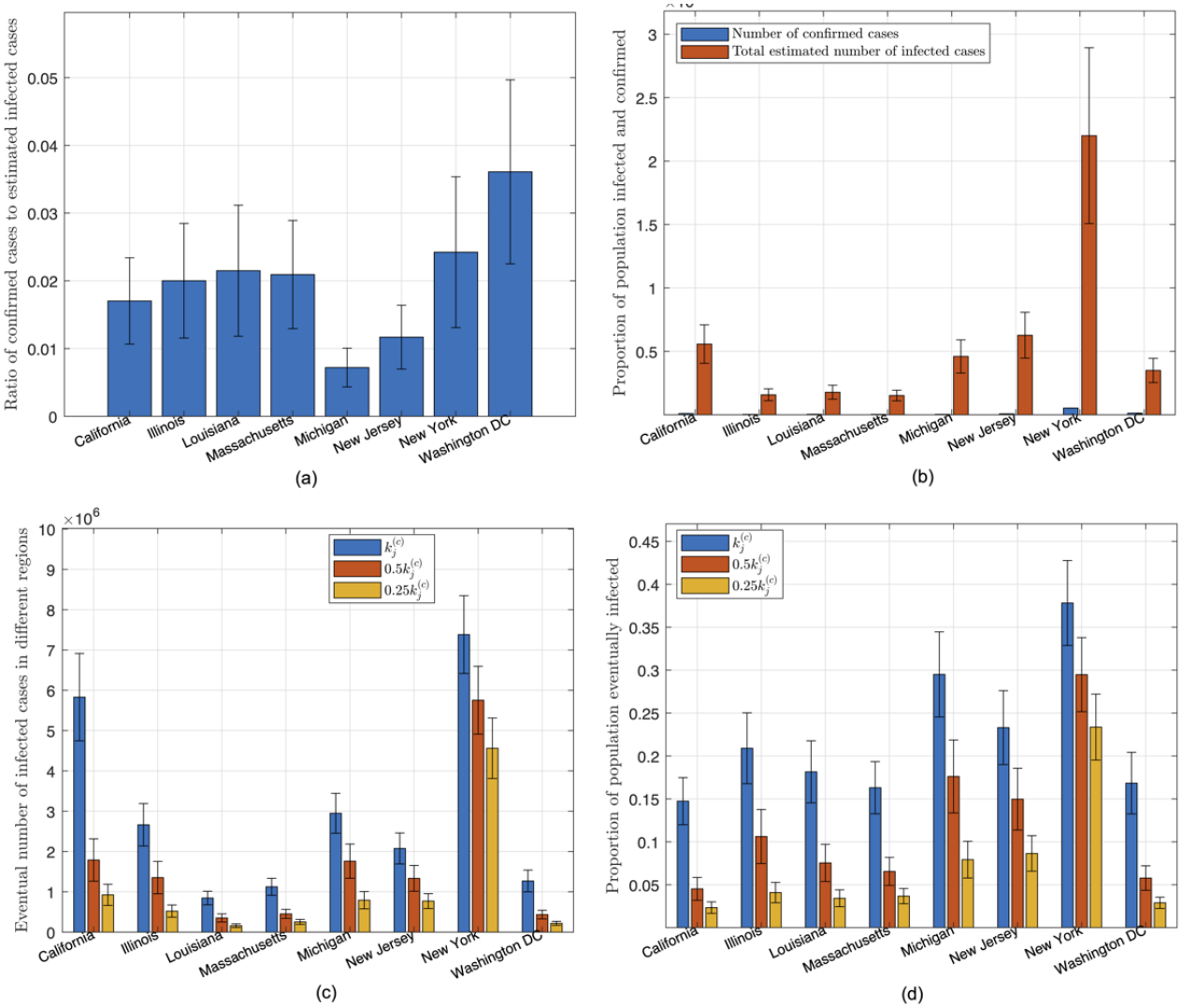


Figure 6. The proportion of the population eventually infected under different levels of the active intervention indicated by kj(c) (smaller the stronger) and maintaining personal hygiene and exercising protective measures indicated by αj, βj (smaller the stronger). (a) Japan; (b) the United States.

Discussion

Principal Findings

A significant step-up in the level of active intervention is necessary to slow the spread of the virus, especially for the United States. Based on the data collected up to March 20, 2020, and assuming no further tightening of the governments' control, our model estimates that about 6.55% and 18.2% of the population would eventually be infected in Japan and the United States, respectively, and a drastic 10-fold elevated active control may bring it down further to 0.24% and 5.24% for Japan and the United States, respectively.

Our results have highlighted the ability of the model in assessing the impact of active intervention through adjusting one of the parameters, namely, $\psi_j = 1/k_j^{(c)}$. Moreover, it has been widely

disseminated that maintaining personal hygiene is equally important in curbing the spread of the virus. The World Health Organization recommends several specific protective measures to be practiced by the public including frequent hand washing; maintaining social distancing, avoiding touching one's eyes, nose, and mouth; and practicing respiratory hygiene [21]. Recent studies have also shown that wearing surgical masks would help in some cases [22,23]. The level of public vigilance in exercising personal protective measures can also be incorporated in our model through adjusting infection rates α_j and β_j. We can, therefore, assess the combined effectiveness of active intervention and practicing protective measures in controlling the pandemic. Here, we varied α_j, β_j, and $k_j^{(c)}$ from 10% to 100% of the originally identified values in 10 intervals, corresponding to 10 different levels of public vigilance and active intervention by the authorities. In particular, we assess α_j and β_j as one property and $k_j^{(c)}$ as another (ie, varying α_j and β_j in synchrony). Specifically, for each candidate parameter set, we performed 100 simulation runs for each combination of α_j, β_j, and $k_j^{(c)}$, where α_j, β_j, and $k_j^{(c)}$ varied from 10% to 100% of the original values in 10 steps. We then investigated the percentage of the population eventually infected in Japan and the United States. The results are shown in Figure 6(a) and (b).

The mean percentage of the population eventually infected under different combinations of parameter values for Japan and the United States are given in the charts shown in Figure 6(a) and (b), respectively. For instance, suppose the level of public vigilance has dramatically raised and the level of active intervention has been stepped up, resulting in a 90% reduction in the infected rates and a 90% reduction in $k_j^{(c)}$ (ie, parameters changed to $0.1\alpha_j$, $0.1\beta_j$, and $0.1k_j^{(c)}$). Referring to Figure 6(a) and (b), the percentage of the population eventually infected can be dramatically reduced to 0.23% for Japan and 2.7% for the United States. Similar interpretations can be taken for any other combination of public vigilance levels and active intervention.

Our results have highlighted an interesting difference between the effectiveness of government's active intervention and maintaining personal hygiene by the public for Japan and the United States. For Japan, we observed a 27-fold reduction (from 6.55% to 0.24%) in the percentage of individuals eventually infected upon a drastic 10-fold step-up of active intervention ($k_j^{(c)}$ changed to $0.1k_j^{(c)}$), whereas less than 3-fold reduction (from 6.55% to 2.16%) is observed in the percentage of individuals eventually infected upon the same 10-fold improvement in personal hygiene (values of α_j and β_j reduced by a factor of 0.1). Thus, government's active intervention seems to be more important for Japan. Moreover, for the United States, we see the opposite. Specifically, only about 4-fold reduction in the percentage of individuals eventually infected is observed upon a drastic 10-fold step-up of active intervention, whereas a 6-fold reduction is observed upon a 10-fold improvement in maintaining personal hygiene by the public. Thus, raising the level of public vigilance in exercising personal protective measures is comparatively more important for the United States. The reason for the difference between Japan and the United States is that the United States has higher infection rates compared to Japan. Reducing $k_j^{(c)}$ for the US case is thus less effective at such high infection rates (ie, a smaller eventual infected number per additional infected individual would not help too much). In contrast, the parameter sets for Japan already have relatively lower infection rates, and further improvement by reducing the infection rates would be limited. As a final remark, combining a very high level of pubic vigilance in exercising strict protective measures and a drastic step-up of government intervention, the percentage of the population getting infected can be reduced to 0.23% in Japan and 2.7% in the United States.

As this study was conducted during the early phase of the pandemic for Japan and the United States, the amount of data used was moderate, though adequate in generating sets of parameter values that fit the data with sufficiently small errors. With more data available, the accuracy of the parameters obtained is expected to improve, and the prediction henceforth would also be more accurate. However, in predicting the pandemic progression, especially during the early phase of an outbreak, we are often confronted with limited data, and the results in this study did demonstrate the application of the proposed model and data fitting method in offering highly consistent prediction of the extent of the pandemic (eg, percentage of the population infected) for Japan and the United States.

Several limitations of the model presented here are worth noting. First, we observed that the actual epidemic trajectory deviates above or below the estimated trajectory due to the varying levels of public health measures applied at particular times, which cause parameters $k_j^{(c)}$, α_j, and β_j to vary with time. Thus, if a city or region has implemented highly successful public health measures, then the actual values of $k_j^{(c)}$, α_j, and β_j would be less than their estimated values. The number of confirmed cases would be less than that estimated by the model and vice versa. Furthermore, the number of confirmed cases is highly related to the number of patients who have been tested [23,24]. The value of λ_j is thus also time varying as the test capacity varies in time. In our model, we take the parameters as constants for simplicity. Using constant parameters, the model can only give an average profile prediction. Second, expanding the parameter set would improve the ability of the model to isolate the different causes that contribute to the pandemic progression profile. For instance, we may introduce a parameter corresponding to the testing capacity of a city or region instead of integrating it with λ_j, which may blur the key factor affecting λ_j. However, with more parameters, the parameter extraction process will become more time-consuming and computationally more intensive. Thus, a right balance should be sought to achieve an adequate coverage of interpretation for physical causes by the parameter set while maintaining a reasonable computational efficiency. Finally, the model has a large set of parameters, and the relative importance of each parameter is not identical [25,26]. A detailed sensitivity analysis can be performed to identify the set of crucial parameters so that resources can be directed to specific kinds

of active measures to slow the pandemic progression more effectively.

Conclusion

One of the key challenges in data-driven modelling and analysis is the delayed and missing information that makes fitting of models either difficult or unreliable, resulting in inconsistent or even erroneous dynamical profiles generated by a poorly parameterized model. The traditional SEIR model provides a general dynamical description of the disease spread in a population and involves a series of transitional processes that describe how a healthy individual becomes exposed, infected, and eventually recovered or removed from the population. However, the data of infected and recovered cases reported by different cities and regions have been found unreliable or incomplete, as they are subject to the availability of test facilities as well as other factors related to the bureaucracy of reporting and the operation mode of the medical systems. In this paper, we propose a new disease spreading model with consideration of the delayed and missing data of infected cases, intercity travel, and the level of active intervention. The model, which estimates the actual number of infected cases after identifying the best parameter sets, was applied to study the COVID-19 pandemic progression in Japan and the United States. Results reveal that the actual number of infected individuals could be up to 20-fold and 10-fold as many as the confirmed numbers in Japan and the United States, respectively, as of March 19, 2020. Our model also allows assessment of varying levels of active intervention implemented by the government, and the results showed that the current level of control by the Japanese and US governments may be inadequate, and a significant step-up in the level of active intervention is necessary to slow the aggressive progression trend in both countries. For Japan, based on the data collected so far and assuming no further tightening of control, our model estimates about 6.55% of the population eventually infected, and a 4-fold elevation in control efforts may bring it down to 1.54%. For the United States, our model estimates about 18.2% of population will eventually be infected if the government does not step up its control, and a 4-fold elevation in active intervention may bring it down to 9.32%. Finally, adjusting the infection rates permits assessing the effectiveness of practicing protective measures and maintaining personal hygiene. Our results show that stepping up government's active intervention would be more effective for Japan, while raising the level of public vigilance in maintaining personal hygiene and social distancing is comparatively more important for the United States.

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Conflicts of Interest

None declared.

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Abbreviations

C: confirmed
COVID-19: coronavirus disease
E: exposed
I: infected
R: recovered or removed
S: susceptible
SEICR: susceptible-exposed-infected-confirmed-removed
SEIR: susceptible-exposed-infectious-recovered

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Original Paper

Statistical Issues and Lessons Learned From COVID-19 Clinical Trials With Lopinavir-Ritonavir and Remdesivir

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Abstract

Background: Recently, three randomized clinical trials on coronavirus disease (COVID-19) treatments were completed: one for lopinavir-ritonavir and two for remdesivir. One trial reported that remdesivir was superior to placebo in shortening the time to recovery, while the other two showed no benefit of the treatment under investigation.

Objective: The aim of this paper is to, from a statistical perspective, identify several key issues in the design and analysis of three COVID-19 trials and reanalyze the data from the cumulative incidence curves in the three trials using more appropriate statistical methods.

Methods: The lopinavir-ritonavir trial enrolled 39 additional patients due to insignificant results after the sample size reached the planned number, which led to inflation of the type I error rate. The remdesivir trial of Wang et al failed to reach the planned sample size due to a lack of eligible patients, and the bootstrap method was used to predict the quantity of clinical interest conditionally and unconditionally if the trial had continued to reach the originally planned sample size. Moreover, we used a terminal (or cure) rate model and a model-free metric known as the restricted mean survival time or the restricted mean time to improvement (RMTI) to analyze the reconstructed data. The remdesivir trial of Beigel et al reported the median recovery time of the remdesivir and placebo groups, and the rate ratio for recovery, while both quantities depend on a particular time point representing local information. We use the restricted mean time to recovery (RMTR) as a global and robust measure for efficacy.

Results: For the lopinavir-ritonavir trial, with the increase of sample size from 160 to 199, the type I error rate was inflated from 0.05 to 0.071. The difference of RMTIs between the two groups evaluated at day 28 was –1.67 days (95% CI –3.62 to 0.28; *P*=.09) in favor of lopinavir-ritonavir but not statistically significant. For the remdesivir trial of Wang et al, the difference of RMTIs at day 28 was –0.89 days (95% CI –2.84 to 1.06; *P*=.37). The planned sample size was 453, yet only 236 patients were enrolled. The conditional prediction shows that the hazard ratio estimates would reach statistical significance if the target sample size had been maintained. For the remdesivir trial of Beigel et al, the difference of RMTRs between the remdesivir and placebo groups at day 30 was –2.7 days (95% CI –4.0 to –1.2; *P*<.001), confirming the superiority of remdesivir. The difference in the recovery time at the 25th percentile (95% CI –3 to 0; *P*=.65) was insignificant, while the differences became more statistically significant at larger percentiles.

Conclusions: Based on the statistical issues and lessons learned from the recent three clinical trials on COVID-19 treatments, we suggest more appropriate approaches for the design and analysis of ongoing and future COVID-19 trials.

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KEYWORDS

coronavirus; COVID-19; cure rate model; sample size adjustment; terminal event; type I error rate; restricted mean survival time

Introduction

Background

The novel coronavirus disease (COVID-19) has spread all over the world at an unprecedented rate since its outbreak in December 2019. More than 200 countries or territories have confirmed cases, and over 8.4 million individuals have been infected, leading to more than 45,0000 deaths as of June 18, 2020. COVID-19 was declared a Public Health Emergency of International Concern by the World Health Organization (WHO) on January 30 and declared a pandemic on March 11, 2020.

As recommended by the WHO R&D Blueprint expert group, clinical improvements for patients with COVID-19 can be classified in a seven-category ordinal scale [1]:

1. Not hospitalized with resumption of normal activities
2. Not hospitalized, but unable to resume normal activities
3. Hospitalized, not requiring supplemental oxygen
4. Hospitalized, requiring supplemental oxygen
5. Hospitalized, requiring nasal high-flow oxygen therapy, noninvasive mechanical ventilation, or both
6. Hospitalized, requiring extracorporeal membrane oxygenation, invasive mechanical ventilation, or both
7. Death

So far, there are only eight clinical trials for COVID-19 completed with results published. Among them, two trials were for hydroxychloroquine with relatively small sample sizes (30 patients for the trial of Chen et al [2] and 36 patients for the trial of Gautret et al [3]). Although the trial conducted by Gautret et al [3] yielded a significant result, the sample size was too small to draw any convincing conclusion. The trial of Cai et al [4] compared favipiravir and lopinavir-ritonavir with a total sample size of 80 patients, leading to a significant result (P=.004). Chen et al [5] conducted a trial comparing favipiravir with arbidol, which had a total sample size of 240 patients and yielded an insignificant result. The trial of Grein et al [6] was a single-arm trial for remdesivir, and the estimated clinical improvement rate at day 18 was 0.68. To determine the efficacy of Lianhuaqingwen (LHQW) capsule, a compounded Chinese herb medicine, Hu et al [7] conducted an open-label randomized controlled trial and reported a statistically significant difference in the symptom (fever, fatigue, coughing) recovery rate between the treatment group and the control group (91.5% vs 82.4%; P=.022). However, the trial did not include a placebo in the control group to implement a double-blinding scheme. Despite the urgency nature of the pandemic, their argument for unblinding due to ethical reasons seems to be unsound. Due to the conscious and subconscious psychological tendencies of humans including both clinicians and patients, bias often arises in an open-label study. Not only does unblinding lead to potential selection bias, but it may also cause placebo effects for patients who took LHQW [8-11], which thus shed doubts on the clinical benefits of LHQW. In particular, the rate of symptom recovery is related to disease relief or symptomatic manifestations such as fever, fatigue, and coughing (“soft” end points), for which placebo effects are known to be strong and more discernible [10]. However, the LHQW and control groups did not differ in the rate of conversion to severe cases or viral assay findings (“hard” end points), for which placebo effects are less perceptible because generally placebos can neither alter the pathophysiology of the disease nor cure it. We take the three randomized clinical trials conducted by Cao et al [12] on lopinavir-ritonavir and by Wang et al [13] and Beigel et al [14] on remdesivir as examples to illustrate statistical issues and lessons learned, as they have drawn great attention in the clinical community.

Lopinavir-Ritonavir Trial

The Lopinavir Trial for Suppression of Severe Acute Respiratory Syndrome Coronavirus 2 in China [12] was conducted with record speed from January 18 to February 3, 2020 (the date of enrollment of the last patient). Patient recruitment up to a planned sample size is often the bottle neck of trial conduct. This was not the case with severe COVID-19 due to the abundance of hospitalized patients during that period of time. In this trial, eligible patients were randomized at a 1:1 ratio to either the lopinavir-ritonavir treatment group (400 mg and 100 mg orally, twice daily) plus the standard care or the standard care alone for 14 days. No placebo was used for blinding because no placebo was prepared due to the urgency of the trial; therefore, both patients and investigators were aware of the treatment identity each patient received. Following the WHO seven-ordinal scale [1], the primary end point adopted by the trial [12] was the time to clinical improvement, which was defined as the time from randomization to an improvement of two points from the status at randomization (eg, from point 6 to point 4 or from point 5 to point 3) or live discharge from the hospital, whichever came first. The sample size was increased from 160 to 199 since the result with the enrolled 160 patients did not reach statistical significance. As a final conclusion, Cao et al [12] reported no benefit with the lopinavir-ritonavir treatment beyond the standard care with a hazard ratio (HR) of 1.24 and the associated 95% CI 0.90-1.72.

Remdesivir Trial 1

Wang et al [13] conducted a randomized, double-blind, placebo-controlled, multicenter trial with remdesivir at ten hospitals in Hubei, China. Overall, 236 patients were enrolled from February 6 to March 12, 2020, and were randomly assigned to the remdesivir group (200 mg on day 1 followed by 100 mg on days 2-10) and the placebo group at a 2:1 ratio. In the original design, the trial planned to recruit 453 patients with 302 to remdesivir and 151 to placebo, but no patients were enrolled after March 12 due to no eligible patients being available in the Hubei Province. As a consequence, the statistical power of the study was reduced from 80% to 58%. The primary clinical end point was the time to improvement within 28 days. Clinical improvement was defined as a two-point improvement from an adjusted six-category ordinal scale from the WHO seven-category ordinal scale. In conclusion, remdesivir did not show statistically significant clinical benefit compared with the placebo in terms of the HR 1.23 (95% CI 0.87-1.75).

Remdesivir Trial 2

Beigel et al [14] reported a randomized, double-blind, placebo-controlled trial of intravenous remdesivir in adults hospitalized with COVID-19 and evidence of lower respiratory

tract infection. This trial had a total sample size of 1059 patients (538 assigned to remdesivir and 521 to placebo). The median recovery time of the remdesivir group was 11 (95% CI 9-12) days and 15 (95% CI 13-19) days for the placebo group. The rate ratio for recovery was 1.32 (95% CI 0.47-1.04; P<.001), which was statistically significant in favor of remdesivir. The Kaplan-Meier estimates of mortality at 14 days were 7.1% with remdesivir and 11.9% with the placebo, and the HR for death was 0.70 (95% CI 0.47-1.04). Remdesivir was shown to be superior to the placebo in shortening the time to recovery in adults hospitalized with COVID-19, and, in terms of the HR for death, there was no significant difference between the two groups.

So far, only one treatment, remdesivir, has been shown to be effective by a randomized clinical trial, but the other remdesivir trial failed to demonstrate its superiority over the placebo. As the pandemic of COVID-19 will not be controlled anytime soon, the aforementioned three clinical trials [12-14] provide extremely valuable information on the treatments of COVID-19 and the corresponding trial design and analysis. However, several important issues have been identified in the statistical analysis, design, and implementation of the three trials. We point out the statistical problems that arose in the three trials [12-14] and reanalyze the data from the cumulative incidence curves for the time to improvement or recovery using more appropriate approaches. Our in-depth and comprehensive analyses yield new insights on the design and analysis for ongoing and future COVID-19 clinical trials.

Methods

Inflation of the Type I Error

The log-rank test [15] is the most commonly used method in survival analysis and clinical trial design to compare the survival benefit of two arms. Consider a randomized clinical trial with a planned sample size N_1 using a two-sided log-rank test. If the hypothesis test indicates no significant survival difference between the two groups under the significance level α but the trial decides to continue to enroll more patients up to a larger sample size N_2, this would inflate the overall type I error of the trial. Any adjustment to the sample size during the trial should be planned and evaluated in advance to maintain the overall type I error rate.

Let Z_1 and Z_2 denote the log-rank test statistics with sample sizes N_1 and N_2, respectively. It holds that under the null hypothesis [16,17] Z_1 and Z_2 jointly follow a multivariate normal distribution:

(1)

$D_1 = dN_1$ and $D_2 = dN_2$ are the expected numbers of events with sample sizes N_1 and N_2, and d is the proportion of patients experiencing the event. Thus, the overall type I error rate α overall with the significance level α is:

(2)

 is the (1 – )th quantile of the standard normal distribution.

Terminal (or Cure) Rate Model

For clinical studies with a survival end point, we are interested in the distribution of event time T. In general, patients will eventually experience the event with a long enough follow-up; although, the exact event time might not be observed due to censoring. However, for some diseases with long-term survivors, it may happen that the event will never occur in a fraction of subjects (ie, the event time for cured subjects is infinity [18-21]). Under this situation, patients can be divided into two groups: the terminal (or cure) group (the specified event would never occur) and the nonterminal group (the specified event would occur but possibly censored due to the end time of the study). Thus, the distribution of the event time T has a point probability mass η at ∞:

$$T = (1 - \eta)T^* + \eta\infty \quad (3)$$

η is the group label taking a value of 1 if the individual is in the terminal group and 0 otherwise; $\gamma = P(\eta = 1) = P(T = \infty)$ is the terminal rate and T^* follows a proper distribution with $P(T^* < \infty) = 1$. For the COVID-19 trials [12,13], the cumulative incidence curve of T can be expressed by

(4)

F_T and F_{T^*} are the cumulative distribution functions of T and T^*, respectively. Note that $P(T < \infty) = 1 - \gamma < 1$.

Restricted Mean Survival Time

Restricted mean survival time (RMST) [16,22-26] is an alternative measure for the mean survival time that is not estimable due to the presence of censoring. The RMST is equal to the expectation of the minimum value of event time T and the specified time point τ, which can be calculated as the area under the survival curve from 0 to τ. It can be estimated by the area under the Kaplan-Meier survival curve, which has gained enormous popularity due to its robustness feature.

Although the HR is the most popular statistic to quantify the survival difference in randomized clinical trials, it is no longer an interpretable quantity if the proportional hazards (PH) assumption is violated [25]. By contrast, the RMST has the advantages of being nonparametric and model-free yet carrying clinically meaningful interpretations. Given the prespecified time point τ, the estimate of the RMST difference between two groups can be interpreted as the extra survival gain on average during the time τ follow-up period.

Predicted Trial Outcome With Sample Size Projection

Clinical trials during the epidemic of an infectious disease might fail to reach the planned sample size due to a lack of eligible patients if the outbreak can be quickly controlled [27]. However, early termination of a clinical trial would inevitably lead to loss of power and thus unconvincing findings. Based on the collected data, the bootstrap method can be used to predict what would happen if the trial had continued to reach the desired sample

size. Let N denote the desired sample size and N_0 ($N_0 < N$) the actual number of patients enrolled. The statistic of interest prediction can be conducted under either conditional or unconditional schemes. The unconditional prediction draws N samples (sampling with replacement from the original data with N_0 observations), while the conditional prediction draws $N - N_0$ samples from the original N_0 observations and keeps the original N_0 samples intact. By repeating the sampling procedure for a large number of times, one can estimate the predicted mean and the corresponding confidence interval for the statistic of interest if the trial had continued to reach the sample size of N.

Results

Lopinavir-Ritonavir Trial of Cao et al

In the original analysis of Cao et al [12], the time to clinical improvement was assessed after all patients had reached day 28, and failure to reach clinical improvement or death before day 28 were considered as right-censored at day 28. In contrast to the usual survival analysis where death (or a bad event such as disease progression) is used as the event of interest, a good event (clinical improvement) was adopted as the end point in this trial. As a result, the shorter time to reach clinical improvement, the better. Cao et al [12] concluded no benefit of using the lopinavir-ritonavir treatment beyond the standard care with an HR of 1.24 (95% CI 0.90-1.72).

We carried out an in-depth and comprehensive investigation of the trial design in Cao et al [12] and identified several key issues with the trial that might have hindered its success. First, the unplanned sample size increment from 160 to 199 would inflate the type I error rate. For this trial, we have N_1=160, N_2=199, d=0.75, $D_1 = 160 \times 0.75 = 120$, $D_2 = 199 \times 0.75 = 149.25$, and based on equation 2, $\alpha_{overall}$=.071 when the nominal significance level is set as α=.05. That is, the false-positive rate for this trial increased as high as 7.1% in contrast to the nominal level of 5%. Any sample size alteration or re-estimation should be planned in advance to control the type I error rate and maintain the integrity of a trial. When the sample size reached 199, the trial was halted for enrollment because of the availability of another treatment, remdesivir. Such termination of a trial was again unplanned and immature; if there were not another agent available, would the trial continue recruitment? Interestingly, the remdesivir trial by Wang et al [13] (the same group of investigators as the lopinavir-ritonavir trial) started 3 days later after the lopinavir-ritonavir trial was terminated.

In terms of the primary end point, clinical improvement using two-level increment on a seven-category ordinal scale from baseline is ad hoc due to uneven clinical differences between adjacent scales. For example, it is ambiguous whether the status of a patient changing from point 5 to point 3 is equivalent to that of changing from point 6 to point 4. In addition, live discharge from the hospital may occur from point 3 to point 2 or point 4 to point 2, which cannot be considered equivalent either. Thus, choosing 2-point improvement on the clinical outcome scale is not a precise end point, which ignores the 1-point improvement and the difference between 2-point and 3-point improvement. Instead, we recommend death as a single and clean end point for such trials, given the mortality rate was not low with patients who were hospitalized with severe COVID-19 (19.2% in the lopinavir-ritonavir group and 25.0% in the standard care group).

The original analysis [12] treated death before day 28 as right-censored at day 28, no matter when death had occurred. This may cause ambiguity because it cannot distinguish the situations where all deaths in one group occurred earlier while those in the other group occurred later. As death is a terminal event, a terminal (or cure) rate model would be more appropriate for analysis of such data. A terminal rate model can be viewed as the counterpart of the traditional mixture cure rate model [18-21], which can be developed by slight modifications. As death is a terminal event, patients who died during the 28-day follow-up period would never reach the clinical improvement (ie, the time to clinical improvement was infinity) denoted as ∞. Death can also be viewed as a competing risk for clinical improvement.

The upper panel of Table 1 shows that there was neither any significant difference in the terminal rates between the lopinavir-ritonavir and standard care groups or in the HR (after excluding the terminal subjects who would eventually be absorbed in the death state) from the mixture terminal rate model. In particular, the terminal rates (including observed deaths as well as unobserved deaths that would occur after day 28 but were censored at day 28) were 21.17% for the lopinavir-ritonavir group and 29.91% for the standard care group with P=.16, and the HR for nonterminal subjects was 1.05 (95% CI 0.78-1.42; P=.74).

Moreover, the crossings of the cumulative event curves for the lopinavir-ritonavir and standard care groups at days 10 and 16 in the second figure of Cao et al [12] imply possible violation of the PH assumption. When the PH assumption is not satisfied, the HR from a Cox model [29] is not clinically meaningful. As an alternative, the area above the curve in the second figure of Cao et al [12] or the area under the inverted curve as shown in our Figure 1, referred to as the restricted mean time to improvement (RMTI), can be used to quantify treatment effect that requires no assumption such as PH [16,22-26]. As a model-free quantity, the RMTI up to 28 days can be interpreted as the average time to reach improvement in 28 days, for which the shorter is the better. The 28-day RMTI difference between the two groups was 1.67 days (95% CI –3.62 to 0.28; P=.09) in favor of lopinavir-ritonavir but not statistically significant. The 7-day and 14-day RMTIs are also presented in the lower panel of Table 1, where the 14-day RMTI showed some promising results for lopinavir-ritonavir, yet further confirmation is needed.

Tables 2 and 3 show the numbers on mortality and clinical improvement by day 28 across the two treatment groups, respectively. We carried out chi-square tests (or Fisher exact tests if some of the cell counts were smaller than 5) to examine any association between the outcomes and treatments. For Table 2 with 2×3 cells, there is no association with P=.53, and if combining deaths in both earlier and later stages, this leads to 2×2 cells with P=.32 and odds ratio 0.71 (95% CI 0.36-1.40). Patients treated with lopinavir-ritonavir had 0.71 times odds to

die by day 28 in comparison to those in the standard care group. For Table 3 with 2×4 cells, there is no association with *P*=.11, and if combining all clinical improvement cases, this leads to 2×2 cells with *P*=.53 and odds ratio 1.24 (95% CI 0.64-2.40). Patients treated with lopinavir-ritonavir had 1.24 times odds to achieve clinical improvement by day 28 in comparison to those in the standard care group. However, none of the results are statistically significant.

Table 1. Comparisons of estimates from the mixture terminal (or cure) model and the RMTI based on the reconstructed data from the second figure in Cao et al [12].[a]

Terminal rate model[b]	Lopinavir-ritonavir	Standard care	Difference	*P* value	Hazard ratio (95% CI)	*P* value
Terminal rate, % (95% CI)	21.17 (15.77-28.42)	29.91 (4.40-36.66)	–8.74 (–21.04 to 3.55)	.16	1.05 (0.78-1.42)	.74
RMTI[c] (95% CI)						
Day 7	6.91 (6.79-7.00)	6.98 (6.94-7.00)	–0.07 (–0.19 to 0.05)	.26	N/A[d]	N/A
Day 14	12.58 (12.11-13.04)	13.25 (12.92-13.58)	–0.67 (–1.24 to –0.11)	.02	N/A	N/A
Day 28	17.19 (15.78-18.60)	18.86 (17.51-20.21)	–1.67 (3.62 to 0.28)	.09	N/A	N/A

[a]Cumulative incidence curves were extracted and reconstructed from the second figure in Cao et al [12] using the "digitize" package [28] in R software (R Foundation for Statistical Computing).

[b]The mixture terminal rate model was performed using the "smcure" package.

[c]The RMTI (restricted mean time to improvement) was estimated by calculating the area above the cumulative incidence curve using the "survRM2" package.

[d]Not applicable.

Figure 1. The restricted mean time to improvement corresponding to the area under the curves for the lopinavir-ritonavir group and the standard care group evaluated at days 7, 14, and 28 in Cao et al [12].

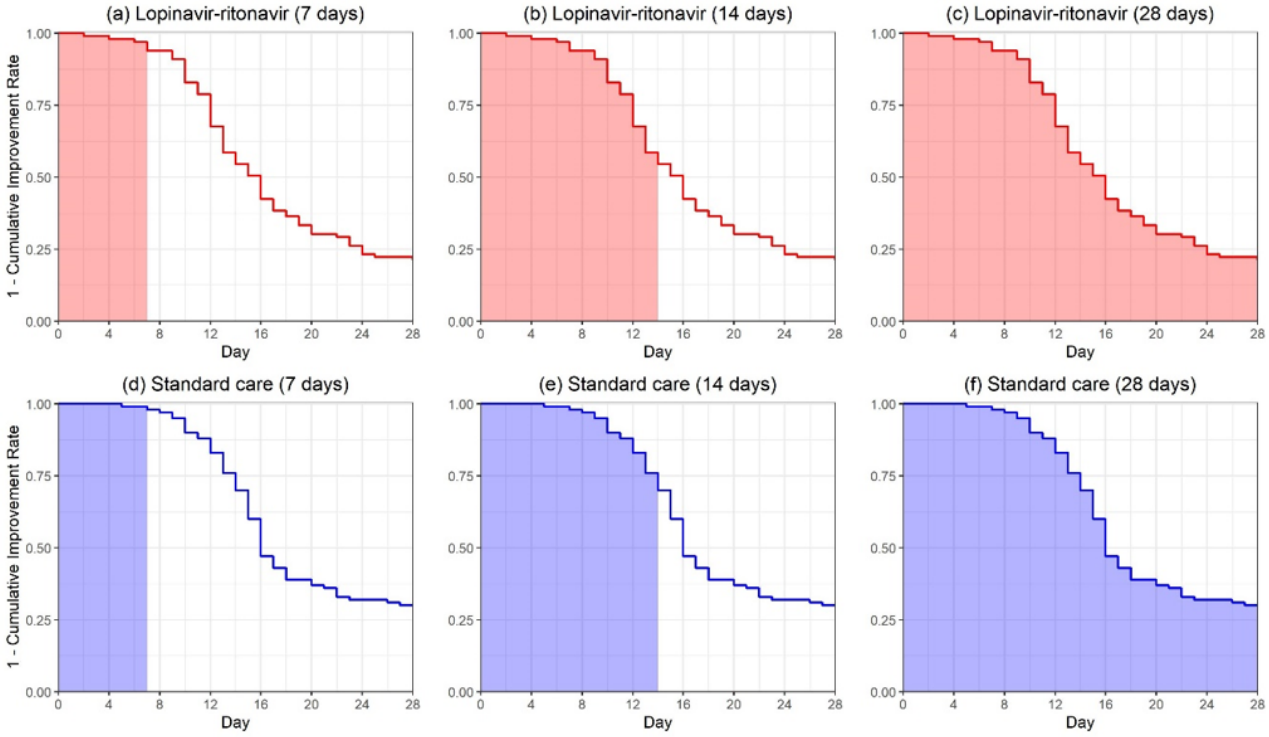

Table 2. Counts of deaths for the earlier stage (≤12 days after onset of symptoms) and later stage (>12 days after onset of symptoms), and survivors.

Treatment	Deaths		Survivors, n
	Earlier, n	Later, n	
Lopinavir-ritonavir	8	11	80
Standard care	13	12	75

Table 3. Counts of clinical improvement cases in days 1-7, 8-14, and 15-28, and nonimprovement cases.

Treatment	Clinical Improvement			No improvement, n
	Days 1-7, n	Days 8-14, n	Days 15-28, n	
Lopinavir-ritonavir	6	39	33	22
Standard care	2	28	40	30

Remdesivir Trial of Wang et al

Wang et al [13] reported a randomized, double-blind, placebo-controlled remdesivir trial for patients with severe COVID-19. Based on an adjusted six-point ordinal scale of clinical status, the primary end point was the time to clinical improvement, defined as a 2-level decline from randomization (similar to that in Cao et al [12]; in fact, the two trials were conducted by the same group of investigators), for which the shorter is the better. Patients were permitted concomitant use of lopinavir-ritonavir, interferons, and corticosteroids. The HR between the remdesivir and placebo groups was 1.23 (95% CI 0.87-1.75), indicating no significant difference. Overall, 237 eligible patients were enrolled, with 158 patients assigned to the remdesivir group and 78 patients to the placebo group under the intent-to-treat (ITT) scheme. The trial was stopped early and thus failed to reach the designated sample size 453 due to a lack of eligible patients.

Similar to the trial by Cao et al [12], deaths before day 28 were treated as right-censored observations at day 28, regardless of the actual occurrence time of deaths in Wang et al [13]. Moreover, a clinical improvement might not be observed due to death (ie, death is a terminal event), and thus, the terminal or cure rate model introduced earlier should be recommended for the survival analysis rather than the standard Cox model.

The upper panel of Table 4 indicates no significant difference in the terminal rates between the remdesivir and placebo groups. In particular, the terminal rates were 31.49% for the remdesivir group and 40.71% for the placebo group with P=.19. With the terminal subjects excluded, the HR from the mixture terminal rate model was 0.92 (95% CI 0.63-1.35; P=.67), which also showed no significant difference between the two groups.

Due to the competing risk from death, the end point might not be observed, and thus, the standard hazard concept is ambiguous, and the HR does not have a meaningful interpretation anymore [30]. In the second figure in Wang et al [13], the curve for the cumulative improvement event of remdesivir is uniformly higher than that of the control, indicating patients with remdesivir reached improvement faster than those in the control group. The area above the cumulative incidence curve or, equivalently, the area under the survival curve up to 28 days in our Figure 2 would be a reasonable quantity for evaluating the treatment efficacy. Using the reconstructed data from the second figure in Wang et al [13], the RMTI evaluated at day 28 was 20.42 (95% CI 19.26-21.57) days for the remdesivir group and 21.31 (95% CI 19.73-22.88) days for the placebo group. As shown in the lower panel of Table 4, the difference in RMTIs was –0.89 days (95% CI –2.84 to 1.06), numerically favoring remdesivir but not statistically significant. It can be interpreted that patients treated by remdesivir on average had an extra 0.89 days of improvement during the 28-day follow-up compared with those in the placebo group. The 7-day and 14-day RMTIs are also presented in the lower panel of Table 4, and neither showed statistically significant results.

The trial was terminated without reaching the originally planned sample size, 453, due to a lack of eligible patients. With only 236 patients in the ITT analysis, the estimated HR was 1.23 (95% CI 0.87-1.75), numerically favoring remdesivir, which might not be reliable due to the underpowered study. Using the bootstrap method, we can predict what would happen if the trial had continued to reach the full sample size or double the planned sample size. Table 5 shows both the unconditional and conditional predictions of the HR, similar to sample size re-estimation using conditional power [31] in a two-stage design. If the trial could have reached the designated sample size, the HR from the conditional prediction shows the significant treatment effect of remdesivir with P=.02, and if the trial had enrolled twice of the target sample size, both conditional and unconditional approaches result in significant differences under the 5% significance level. Thus, a larger sample size may be needed to show the significant difference between remdesivir and placebo.

Table 4. Comparisons of the estimates from the mixture terminal (or cure) rate model and the RMTI based on the reconstructed data from the second figure in Wang et al [13].

Terminal rate model	Remdesivir	Placebo	Difference	*P* Value	Hazard ratio (95% CI)	*P* value
Terminal rate, % (95% CI)	0.31 (0.27-0.37)	0.41 (0.32-0.51)	–9.22 (–22.9 to 4.45)	.19	0.92 (0.63-1.35)	.67
RMTI[a]						
Day 7	6.95 (6.90-7.00)	6.97 (6.92-7.00)	–0.03 (–0.10 to 0.05)	.49	N/A[b]	N/A
Day 14	13.09 (12.78-13.40)	13.29 (12.92-13.67)	–0.20 (–0.69 to 0.29)	.42	N/A	N/A
Day 28	20.42 (19.26-21.57)	21.31 (19.73-22.88)	–0.89 (–2.84 to 1.06)	.37	N/A	N/A

[a]RMTI: restricted mean time to improvement.

[b]Not applicable.

Figure 2. The restricted mean time to improvement corresponding to the area under the curves for the remdesivir group and the placebo group evaluated at days 7, 14, and 28 in Wang et al [13].

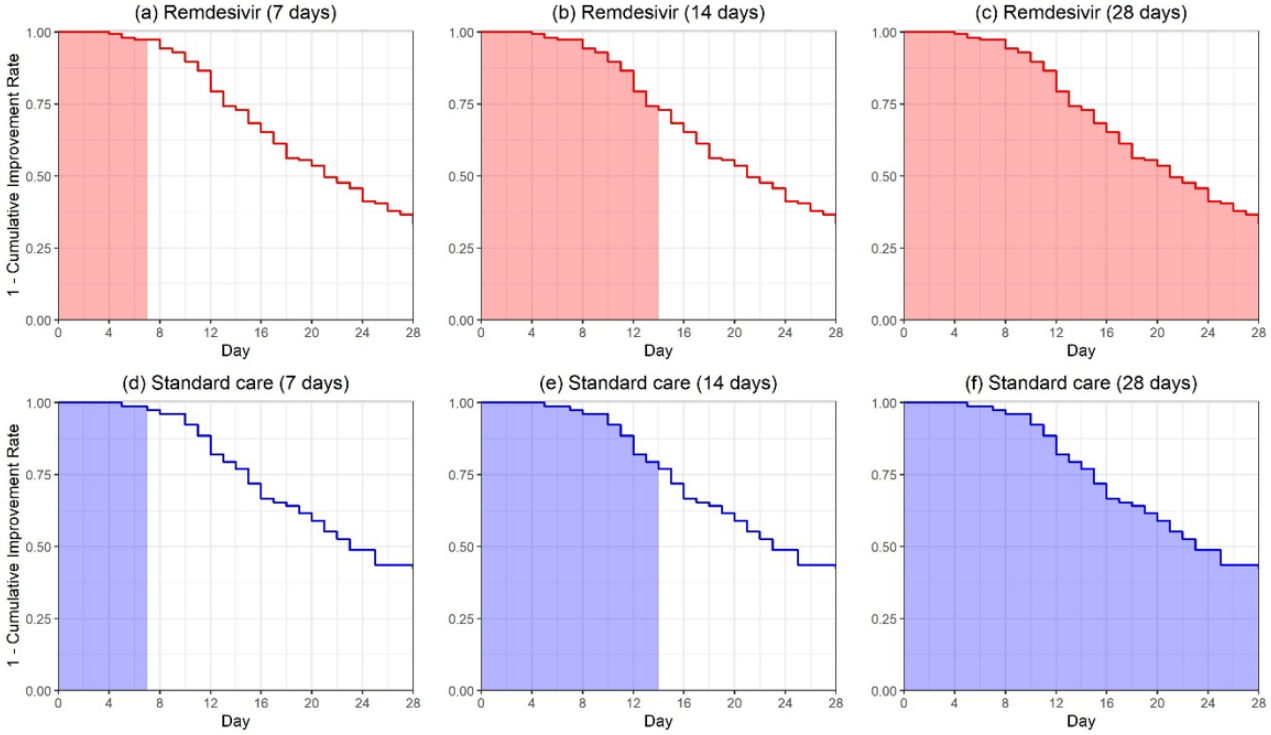

Table 5. Predicted hazard ratios (with 95% CIs) and *P* values at the actual, target, and double target sample sizes using 50,000 bootstrap samples based on the reconstructed data from the second figure in Wang et al [13].

Sample size	Sample size in each arm		Unconditional prediction		Conditional prediction	
	Remdesivir, n	Placebo, n	HR[a] (95% CI)	*P* value	HR (95% CI)	*P* value
Actual	158	78	1.23 (0.87-1.75)	.24	N/A[b]	N/A
Target	302	151	1.24 (0.96-1.60)	.10	1.24 (1.03-1.48)	.02
Target×2	604	302	1.24 (1.03-1.48)	.02	1.24 (1.06-1.44)	.01

[a]HR: hazard ratio.

[b]Not applicable.

Remdesivir Trial of Beigel et al

Beigel et al [14] presented a preliminary report of the NCT04280705 trial, which is a randomized, double-blind, placebo-controlled trial of intravenous remdesivir in adults hospitalized with COVID-19 and evidence of lower respiratory tract involvement. This trial enrolled 1059 patients (538 assigned to remdesivir and 521 to placebo). The primary end point of the

original analysis was the recovery time, defined by either discharge from the hospital or hospitalization for infection-control purposes only. The median recovery time of the remdesivir group was 11 (95% CI 9-12) days and that of the placebo group was 15 (95% CI 13-19) days. The rate ratio of recovery for remdesivir vs placebo was 1.32 (95% CI 1.12-1.55; *P*<.001), which demonstrated the superiority of remdesivir. In terms of the HR for death, there was no significant difference between the remdesivir and placebo groups with an HR of 0.70 (95% CI 0.47-1.04).

The remdesivir trial of Beigel et al [14] is essential to evaluate the efficacy of remdesivir, as it had a large sample size of 1059 patients under a well-designed randomized controlled trial scheme. In terms of the data analysis, Beigel et al [14] only reported the median recovery time without a *P* value. From the second figure in Beigel et al [14], the Kaplan-Meier curves of cumulative recoveries are initially intertwined and then diverge, so other percentiles of the time to recovery would provide more information on the efficacy of remdesivir. Meanwhile, a global and robust measurement, the restricted mean time to recovery (RMTR), can help to quantify the treatment efficacy in a more comprehensive way [16,22-26].

The upper panel of Table 6 presents the RMTRs up to day 30 for both the remdesivir and placebo groups. The RMTRs were 14.5 days and 17.2 days for remdesivir and placebo, respectively, indicating that patients with remdesivir on average had 2.7-day gains of recovery with 30-day follow-ups. The difference in RMTRs was statistically significant with *P*<.001, demonstrating the superiority of remdesivir. This is consistent with the original analysis in terms of the rate ratio of recovery [14]. Meanwhile in the bottom panel of Table 6, more percentiles of the time to recovery were reported with *P* values. The early difference for remdesivir vs placebo in the recovery time at the 25th percentile was –1 (95% CI –3 to 0; *P*=.65), which was not statistically significant. However, the differences manifested to be statistically significant later; for example, the 30th to 60th percentiles of the recovery time in the remdesivir group were all significantly shorter than those in the placebo group. It is reasonable for the treatment to take effect after a certain length of follow-up.

Table 6. The RMTR and percentiles of the time to recovery based on the reconstructed data from the second figure in Beigel et al [14].

Statistical measure	Remdesivir	Placebo	Difference (95% CI)	*P* value
RMTR[a] (up to day 30)	14.5 (13.6-15.5)	17.2 (16.1-18.2)	–2.7 (–4.0 to –1.2)	<.001
Percentiles of the time to recovery (95% CI)				
25th	5 (4-5)	6 (6-7)	–1 (–3 to 0)	.65
30th	6 (5-6)	8 (7-9)	–2 (–4 to –1)	.002
40th	8 (7-9)	11 (9-13)	–3 (–5 to –1)	.007
50th (median)	11 (9-12)	15 (13-19)	–4 (–9 to –2)	.01
60th	15 (13-19)	22 (20-27)	–7 (–12 to –3)	.004

[a]RMTR: restricted mean time to recovery.

Discussion

When designing and conducting a clinical trial for new treatment, particularly for the COVID-19 pandemic without knowing much about the clinical outcomes, many things can go wrong if the design is not well thought out, the trial is not carefully conducted following the protocol, or the analysis is not properly carried out. Critical issues with such trials include but are not limited to the end point selection, the type I error rate control, double blinding or open label, early termination of a trial, the validity of the PH assumption in a Cox model, and assumptions for statistical tests and models. In contrast to searching for a needle in a haystack, the trial design should be more targeted, focused, and tailored for specific needs of patients with COVID-19 and particular disease characteristics and severities [32].

Given the emergency and the fast spread of the coronavirus around the world, it is crucial to design the right clinical trial and accelerate the development of a new treatment. With the high speed of enrollment and urgency of the trial outcome, it appears to be difficult to carry out any adaptation during the trial conduct. The trial outcomes unfold so fast that any adaptation may not be able to catch up with the speed of recruitment.

As a summary, our recommendations for COVID-19 trials are:

1. Adopt death as a single end point for patients hospitalized with severe COVID-19 or live discharge from the hospital for patients with moderately severe COVID-19
2. Conduct the gold standard trial scheme: a randomized, double-blind, controlled trial with equal randomization; 1:2 or 1:3 allocation ratio for control vs treatment
3. With multiple agents tested in one trial, allow the trial to drop certain treatment due to futility or toxicity
4. Adopt the RMST as the metric to quantify the treatment effect when the PH assumption is not satisfied; otherwise, standard approaches using the HRs and log-rank tests should be used
5. Control the type I error rate: Any sample size alternation during the trial must be planned and evaluated in advance with a strict control of the false-positive rate.
6. ITT analysis (or its modified version) is recommended for the final analysis.

Although adaptive design has gained much popularity and is playing an increasingly important role in clinical trials,

particularly in oncology, the advantages of adaptive design may be mitigated to a large extent under such a fast patient enrollment because the impact of any adaptation may be too slow to manifest before the trial is completed. In such cases, the CONSORT (Consolidated Standards of Reporting Trials) statement [33,34] can provide a general guideline for the trial design and conduct. As a result, our recommendations follow the gold standard scheme of conventional trial design without much adaptation ingredient, which may help investigators to discriminate different treatments and identify the effective ones in an efficient way.

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Conflicts of Interest

None declared.

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Abbreviations

CONSORT: Consolidated Standards of Reporting Trials
COVID-19: coronavirus disease
HR: hazard ratio
ITT: intent-to-treat
PH: proportional hazards
RMST: restricted mean survival time
RMTI: restricted mean time to improvement
RMTR: restricted mean time to recovery
WHO: World Health Organization

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Original Paper

Use of Health Belief Model–Based Deep Learning Classifiers for COVID-19 Social Media Content to Examine Public Perceptions of Physical Distancing: Model Development and Case Study

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Abstract

Background: Public health authorities have been recommending interventions such as physical distancing and face masks, to curtail the transmission of coronavirus disease (COVID-19) within the community. Public perceptions toward such interventions should be identified to enable public health authorities to effectively address valid concerns. The Health Belief Model (HBM) has been used to characterize user-generated content from social media during previous outbreaks, with the aim of understanding the health behaviors of the public.

Objective: This study is aimed at developing and evaluating deep learning–based text classification models for classifying social media content posted during the COVID-19 outbreak, using the four key constructs of the HBM. We will specifically focus on content related to the physical distancing interventions put forth by public health authorities. We intend to test the model with a real-world case study.

Methods: The data set for this study was prepared by analyzing Facebook comments that were posted by the public in response to the COVID-19–related posts of three public health authorities: the Ministry of Health of Singapore (MOH), the Centers for Disease Control and Prevention, and Public Health England. The comments made in the context of physical distancing were manually classified with a Yes/No flag for each of the four HBM constructs: perceived severity, perceived susceptibility, perceived barriers, and perceived benefits. Using a curated data set of 16,752 comments, gated recurrent unit–based recurrent neural network models were trained and validated for text classification. Accuracy and binary cross-entropy loss were used to evaluate the model. Specificity, sensitivity, and balanced accuracy were used to evaluate the classification results in the MOH case study.

Results: The HBM text classification models achieved mean accuracy rates of 0.92, 0.95, 0.91, and 0.94 for the constructs of perceived susceptibility, perceived severity, perceived benefits, and perceived barriers, respectively. In the case study with MOH Facebook comments, specificity was above 96% for all HBM constructs. Sensitivity was 94.3% and 90.9% for perceived severity and perceived benefits, respectively. In addition, sensitivity was 79.6% and 81.5% for perceived susceptibility and perceived barriers, respectively. The classification models were able to accurately predict trends in the prevalence of the constructs for the time period examined in the case study.

Conclusions: The deep learning–based text classifiers developed in this study help to determine public perceptions toward physical distancing, using the four key constructs of HBM. Health officials can make use of the classification model to characterize the health behaviors of the public through the lens of social media. In future studies, we intend to extend the model to study public perceptions of other important interventions by public health authorities.

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KEYWORDS

health belief model; physical distancing; COVID-19; text classification; deep learning; recurrent neural network; social media

Introduction

Background

The Health Belief Model (HBM) is a theoretical model constructed based on psychological and social theory [1]. It has been widely used as a conceptual framework in behavioral research to understand the health behavior of individuals. The HBM attempts to explain and predict behavioral outcomes based on two main aspects: the desire to avoid a health threat (ie, infection or illness) and the perception of the effectiveness of the behavior adopted to counteract that threat. The perception of threat is composed of an individual's perceived susceptibility and perceived severity to a specific illness or threat. The effectiveness of a specific health behavior is dependent on the interaction between the perceived benefit of the behavior and the perceived barriers to taking action to mitigate the threat or illness [2]. In addition, cues to action are prompts or events that trigger the health behavior of interest. Cues to action can be divided into internal (eg, physical symptoms) or external (eg, mass media, reminders, advice) triggers. Lastly, health motivation (or self-efficacy) explains how predisposed an individual is to respond to cues to action based on the value of their health. The HBM has been adopted as an explanatory model of the communication process [3]. Constructs of the HBM have been used to study the health beliefs of the public on the social media platform Twitter [4] and analyze responses to outbreak communication campaigns on Instagram [5].

In the context of the ongoing coronavirus disease (COVID-19) outbreak, the constructs of the HBM will be influenced by the interaction of information from news and media reports, government policy actions, and feedback from the public throughout the course of the outbreak. These messages will alter an individual's behavior if it targets perceived barriers, benefits, self-efficacy, and threat. One such example is the physical distancing measures put forth by public health authorities across the globe. Physical distancing measures constitute a combination of measures that aim to increase the physical distance between individuals and reduce the frequency of close contact, which results in lower community transmission of the virus. We note the distinction between physical distancing and self-isolation measures and quarantine orders. Isolation and quarantine measures are for individuals who display COVID-19–related respiratory symptoms or have had close contact with confirmed or suspected cases [6]. For the physical distancing measure, public behavior can either be supportive (desired) or critical (undesired).

The perceptions of the public toward physical distancing can be ascertained by mining the relevant content from social media platforms. Public health authorities have been using Facebook and Twitter to post regular updates about COVID-19 through their official pages or accounts [7]. Members of the public respond to these updates through comments or tweets. Their opinions may be neutral, supportive, or critical. It is practically difficult for public health authority officials to manually analyze the content on social media on a periodic basis. Automated analysis of textual content can be facilitated through machine learning methods such as text classification or categorization. Such methods can be used to dynamically classify bulk social media content for real-time analysis so that public health authority officials can gauge the public response to their health messages. In a related study, a deep learning–based text classification model was used to classify tweets about the human papillomavirus vaccine with the HBM constructs [4]. Through the study, it was possible to identify the time periods during which the different HBM constructs were prevalent.

Study Overview

In this study, using the constructs of the HBM, we aimed to develop deep learning–based text classification models for classifying social media content posted in response to the COVID-19 updates of public health authorities. The models were tailored specifically for content related to the physical distancing intervention. We used the gated recurrent unit (GRU) variant of the recurrent neural network (RNN) [8] to build the text classification models. The models were trained and validated with a data set of 16,752 comments primarily extracted from the Facebook pages maintained by public health authorities in Singapore, the United States, and England. As a demonstrative case study for testing, we used the model to classify all Facebook comments received in response to the COVID-19 Facebook posts of the Ministry of Health, Singapore (MOH) during the first quarter of 2020. In addition, we created an online demo webpage for bulk classification of social media data (Facebook comments, tweets) related to physical distancing using the models developed in this study.

Methods

Data Set Preparation

Data for this study were extracted from three Facebook pages using the Facepager tool [9] for the time period from January 1 to March 31, 2020. The three Facebook pages are officially managed by MOH Singapore [10], the Centers for Disease Control and Prevention (CDC) in the United States [11], and Public Health England (PHE) [12]. Extracted data included posts by public health authorities and comments on those posts. From the extracted posts, COVID-19 posts were identified by searching the posts for the existence of at least one of the keywords "wuhan virus," "coronavirus," "ncov," "ncov-2019," "covid," and "covid-19." The comments received on the filtered COVID-19 posts were subsequently classified using four key HBM constructs: perceived susceptibility, severity, benefits, and barriers. We focused on the physical distancing intervention as the preventive behavior of interest. In Table 1, definitions and sample comments for the HBM constructs are provided in the context of this study.

Table 1. Definition of the Health Belief Model constructs examined and sample comments in relation to coronavirus disease.

Construct	Definition
Perceived susceptibility	Comments that indicated an assessment of the increased likelihood of contracting coronavirus disease, highlighting increasing local prevalence and the high number of imported cases
Perceived severity	Comments that indicated an assessment of an increase in the perceived seriousness and consequences of contracting coronavirus disease (eg, hospitalization, pneumonia, death, mortality risk)
Perceived benefits	Comments that supported physical distancing measures (eg, school closure, working from home, cancellation of events and mass gatherings) to reduce the transmission of coronavirus disease
Perceived barriers	Comments that mentioned the difficulties, challenges, and negative effects of physical distancing (eg, loss of freedom, violation of individual rights, inconvenience, loss of income), as well as the perceived ineffectiveness of physical distancing

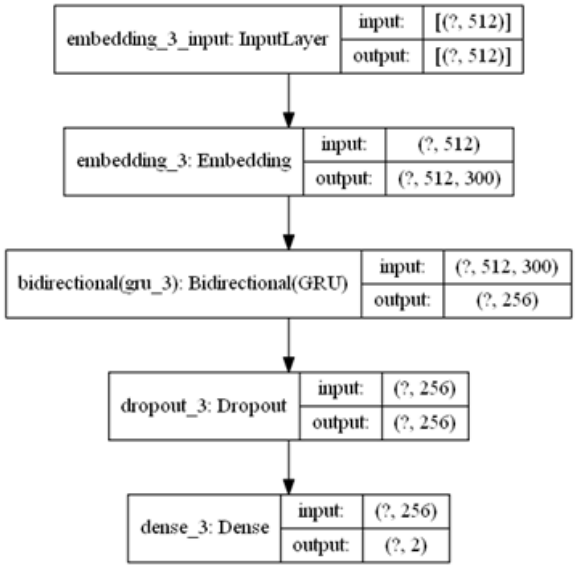
The classification of comments for perceived susceptibility and perceived severity was performed using a rule-based filtering method where we used a set of candidate keywords that accurately represented these two constructs. Comments that met the filtering criteria were flagged accordingly. However, this approach did not work well for perceived barriers and perceived benefits as we could not find an accurate set of keywords that represented these constructs. Hence, the comments were manually classified with the help of two coders. All comments were manually validated using the abovementioned approaches. Interrater agreement between the two coders was strong. Cohen scores were 0.91, 0.86, 0.89, and 0.91 for the four HBM constructs of perceived susceptibility, perceived severity, perceived benefits, and perceived barriers, respectively. After eliminating blank comments and comments with images, we arrived at a total of 99,197 comments. However, only 8376 comments (8.44%) represented at least one of the four HBM constructs.

The next step was to prepare a balanced data set from the analyzed comments to train and validate the text classification models. All 8376 comments that represented at least one of the four HBM constructs were first added to the data set. Next, another 8376 comments which did not represent any of the four HBM constructs were added. As a result, the final data set was comprised of 16,752 comments with 50% of the comments representing preventive behavior (any of the HBM constructs). The comments from this data set were randomly divided into training (n=13,401) and validation (n=3351) sets using the traditional 80/20 split method. Sample comments representing the HBM constructs are provided in Multimedia Appendix 1.

Text Classification Model

For the first time, we used a GRU-based RNN model [8] to classify content using the HBM constructs. The GRU model is considered an improvement over the basic RNN model [13] as it addresses the vanishing gradient problem. The gradients carry information used in the updates to the RNN parameter; when the gradients become progressively smaller, the parameter updates become insignificant. As a result, no real learning is performed. Hence, the learning of long data sequences is hampered due to vanishing gradients. Conversely, GRU makes use of the update gate and reset gate to solve this issue [8]. RNN was previously used in HBM-based models to study tweets [4]. A bidirectional structure was set for the GRU model as it helps record information from both backward and forward states in the neural network [14]. An embedding layer was used as the first layer of the model. The embedding layer is useful for mapping words to a vector of continuous numbers. For this purpose, we used pretrained GloVe (Global Vectors for Word Representation) word vectors [15], which map each word to a vector of a specific size. The classification models were implemented in TensorFlow 2.0 (Google Brain, Google Inc) [16] and comprised five layers, as well as a dropout layer added to avoid overfitting [17]. Accuracy and binary cross-entropy loss were the metrics used to evaluate the performance of the models. Other parameters set for the models were as follows. Sequence length, embedding size, vocabulary size, and number of units were set to 512, 300, 50,000, and 128, respectively. Adam optimizer was used as the optimization algorithm in the models [18]. In Figure 1, the common architecture of the classification models is illustrated. For each of the four HBM constructs, the model was separately trained and validated. As a result, we obtained four binary classification models with a common design.

Figure 1. Health Belief Model text classifier neural network architecture. GRU: gated recurrent unit.



Results

Classification Performance

In Table 2, the training and validation performance of the models are depicted in the form of mean accuracy and mean loss calculated from six epochs, along with the standard deviation values. All four models had an accuracy above 0.91 for both the training and validation sets. In the training set, perceived severity had the best accuracy (μ=0.95), followed by perceived barrier (μ=0.94), perceived susceptibility (μ=0.93), and perceived benefit (μ=0.91). The validation accuracy values were similar; perceived susceptibility (μ=0.92) was the exception. Through the epochs, the losses gradually reduced for the constructs in both the training and validation cycles. Multimedia Appendix 2 illustrates the loss values by epoch for training and validation.

Table 2. Health Belief Model classification models' performance statistics.

Health Belief Model construct	Training accuracy, mean (SD)	Training loss, mean (SD)	Validation accuracy, mean (SD)	Validation loss, mean (SD)
Perceived susceptibility	0.93 (0.04)	0.17 (0.09)	0.92 (0.03)	0.23 (0.15)
Perceived severity	0.95 (0.02)	0.14 (0.07)	0.95 (0.02)	0.11 (0.03)
Perceived benefit	0.91 (0.03)	0.20 (0.07)	0.91 (0.01)	0.22 (0.01)
Perceived barrier	0.94 (0.01)	0.15 (0.04)	0.94 (0.00)	0.15 (0.01)

MOH Case Study

The HBM classification models were used to classify all comments received on COVID-19 posts by the MOH in the first quarter of 2020. We chose the MOH as a case study because it was the most active in posting on Facebook among the three public health authorities discussed in this study. In total, 9053 comments were classified as part of this exercise. In Table 3, the specificity, sensitivity, and balanced accuracy percentages are listed for the four HBM constructs. Specificities were above 96% for all four constructs, and perceived susceptibility and perceived barrier had the highest values (99.7% and 99.0%, respectively). However, these two constructs had the lowest sensitivities (79.6% and 81.5%) among the four constructs, indicating that the corresponding models overpredicted false-negative cases. Due to skewed specificities, the models for classifying perceived susceptibility and perceived barrier achieved a balanced accuracy of 89.6% and 90.3%, respectively. On the other hand, both sensitivity and specificity were above 90.0% for perceived severity and perceived benefit. Hence, the balanced accuracy for these two constructs was high, with values of 96.5% and 93.7%.

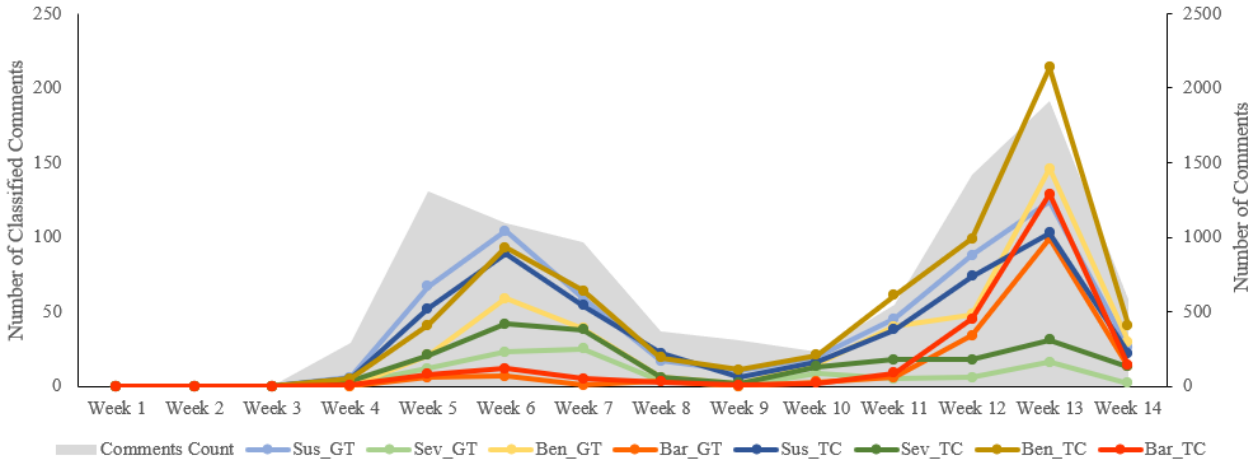
The performance of the classification models was calculated with the following equations: SP=TP/(TP+FN); SE=TN/(TN+FP); and BA=(SP+SE)/2, where SP is specificity, TP is true positives, FN is false negatives, SE is sensitivity, TN is true negatives, FP is false positives, and BA is balanced accuracy.

Table 3. Performance of the Health Belief Model classification models with MOH Facebook comments.

Health Belief Model construct	Specificity, %	Sensitivity, %	Balanced accuracy, %
Perceived susceptibility	99.7	79.6	89.6
Perceived severity	98.8	94.3	96.5
Perceived benefit	96.5	90.9	93.7
Perceived barrier	99.0	81.5	90.3

In Figure 2, the number of classified comments per HBM construct is plotted as a line graph to compare the ground truth (manually classified comments) with the deep learning classification results for the HBM constructs. The total number of comments is plotted as an area graph to facilitate the interpretation of the prevalence of the HBM constructs. The data has been aggregated at the week level to facilitate interpretation. Until the end of Week 4 (January 25, 2020), the number of comments representing the four HBM constructs was low. This is primarily because the total comments were also low. There were two peaks periods in the prevalence of the HBM constructs, one in Week 6 (February 2-8) and the other in Week 13 (March 22-28). Except for perceived susceptibility, the classification models seem to overpredict compared to the ground truth. The gap between the actual results and predicted results is evident for perceived benefits in both peak periods. Overall, the proportion of comments on perceived severity and perceived barriers was low, with only 12.4% and 6.3% prevalence, respectively. Conversely, perceived benefits and perceived susceptibility accounted for 20.5% and 17.5% of the total comments, respectively.

Figure 2. Classification of Ministry of Health comments with Health Belief Model constructs. The primary x-axis is for the classified comments count for the Health Belief Model constructs, while the secondary x-axis is for the total comments count. Sus refers to perceived susceptibility, Sev refers to perceived severity, Ben refers to perceived benefit, and Bar refers to perceived barrier. Suffixes GT and TC refer to ground truth and text classification, respectively.



Discussion

The similarity in training and validation mean accuracy rates indicates that overfitting and underfitting aspects were minimal, thereby supporting our strategy of creating a data set with equal percentages of preventive behavior comments and nonpreventive behavior comments. The variable length of comments could be an issue, as we noticed that models performed well with longer comments as the context is more discernable. In the case study with MOH Facebook comments, the developed classification models achieved better specificities, sensitivities and accuracies than were achieved in a previous study [4] where a deep learning model was used to classify tweets with HBM constructs. However, the slightly lower sensitivities of perceived susceptibility and perceived barriers resulted in more false-negative cases during classification. The high specificities for all four models were a result of the skewed nature of the data, since only 8.4% of comments in the base set represented at least one of the HBM constructs. Sensitivity is more important than specificity in this study since positive cases need to be more accurately predicted.

The comparison of ground truth with the classification results at the week level indicates that the classification models predict upward and downtrend trends in a precise manner. There are two peak periods in the prevalence of HBM constructs among comments. The first peak period corresponded to the week when Singapore shifted to Disease Outbreak Response System Condition (DORSCON) orange, the second-highest level of alert for disease outbreaks in Singapore, on February 7, 2020 [19]. However, the prevalence of perceived barrier comments did not resemble the other three HBM constructs in this first peak period. The second peak in the prevalence of HBM constructs did not correspond to any discernible real-world event; we speculate that MOH Facebook page followers started commenting at a higher frequency from this week. Since our data collection period ended on March 31, 2020, Week 14 does not include a full week of data. In this second peak, the prevalence of perceived barriers increases considerably to

indicate that the public started talking about barriers to physical distancing at a discernible level during this period. At the same time, the prevalence of perceived severity remained consistently low and did not increase during the second peak.

In the first 13 weeks of 2020, it can be deduced that people talked more about susceptibility and the benefits of physical distancing than severity and barriers. Overall, the prediction results closely followed the ground truth with no outlying trends, thereby indicating that the classification models can be used to predict trends in the HBM constructs in the upcoming months in the context of physical distancing interventions. We have created an online demonstration webpage to showcase the bulk classification of social media content using the developed models [20]. We converted the text classification models to the TensforFlow.js format for this purpose [21]. To enable programmatic usage and retraining with new data, the original and converted files of the four classification models have been made available in the HDF5 (Hierarchical Data Format version 5) and TensorFlow.js formats, respectively [22].

This study has certain limitations. The comments analyzed in this study should be considered a snapshot of the overall public response, as users can delete comments from Facebook retrospectively. The opinions of Facebook users regarding physical distancing could be different on Facebook pages other than the public health authority page of their respective country. Those opinions are not covered in this study. The rule-based filtering approach for the manual classification of comments may not be able to accurately capture all the comments under each of the respective HBM constructs. Spelling mistakes, memes, colloquial words, and non-English comments expressing a certain health belief may not be captured.

In conclusion, this study showed that our deep learning–based text classifiers successfully yielded accurate classifications of COVID-19 Facebook comments using the HBM constructs, in the context of the physical distancing intervention. This further demonstrates the potential for developing deep learning prediction systems to classify big data from social media using behavioral models and frameworks. We hope that the classification model files from this study and the bulk classifier demonstration webpage are of practical use for public health officials and the scientific community. In future work, we intend to further improve the classification models and extend our study through various approaches. First, variable-length comments should be handled more efficiently. Second, we intend to experiment with a two-stage classification approach, where the first-stage classification predicts whether a comment represents a preventive behavior or not. The second-stage classification would then predict whether a filtered comment represents any of the four HBM constructs. Third, we intend to study social media users' perceptions toward other public health authority interventions, such as wearing face masks.

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Authors' Contributions

WHL conceptualized the study, interpreted the data, critically revised the manuscript for important intellectual content, and provided supervision. SRA designed the study; acquired, analyzed, and interpreted the data; developed the text classification model, drafted the manuscript, and critically revised the manuscript for important intellectual content. TSG annotated, analyzed, and interpreted the data, and critically revised the manuscript for important intellectual content. All authors approved the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Sample comments representing the Health Belief Model constructs.
[DOCX File , 20 KB - publichealth_v6i3e20493_app1.docx]

Multimedia Appendix 2
Loss values of the training and validation models for the four HBM constructs. Sus refers to perceived susceptibility, Sev refers to perceived severity, Ben refers to perceived benefit, and Bar refers to perceived barrier. Suffixes T and V refer to training and validation sets, respectively. HBM: Health Belief Model.

[PNG File , 35 KB - publichealth_v6i3e20493_app2.PNG]

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Abbreviations

CDC: Centers for Disease Control and Prevention (United States of America)
COVID-19: coronavirus disease
DORSCON: Disease Outbreak Response System Condition
GloVe: Global Vectors for Word Representation
GRU: gated recurrent unit
HBM: Health Belief Model
MOH: Ministry of Health (Singapore)

PHE: Public Health England
RNN: recurrent neural network

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Short Paper

Association of Search Query Interest in Gastrointestinal Symptoms With COVID-19 Diagnosis in the United States: Infodemiology Study

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Abstract

Background: Coronavirus disease (COVID-19) is a novel viral illness that has rapidly spread worldwide. While the disease primarily presents as a respiratory illness, gastrointestinal symptoms such as diarrhea have been reported in up to one-third of confirmed cases, and patients may have mild symptoms that do not prompt them to seek medical attention. Internet-based infodemiology offers an approach to studying symptoms at a population level, even in individuals who do not seek medical care.

Objective: This study aimed to determine if a correlation exists between internet searches for gastrointestinal symptoms and the confirmed case count of COVID-19 in the United States.

Methods: The search terms chosen for analysis in this study included common gastrointestinal symptoms such as *diarrhea*, *nausea*, *vomiting*, and *abdominal pain*. Furthermore, the search terms *fever* and *cough* were used as positive controls, and *constipation* was used as a negative control. Daily query shares for the selected symptoms were obtained from Google Trends between October 1, 2019 and June 15, 2020 for all US states. These shares were divided into two time periods: pre–COVID-19 (prior to March 1) and post–COVID-19 (March 1-June 15). Confirmed COVID-19 case numbers were obtained from the Johns Hopkins University Center for Systems Science and Engineering data repository. Moving averages of the daily query shares (normalized to baseline pre–COVID-19) were then analyzed against the confirmed disease case count and daily new cases to establish a temporal relationship.

Results: The relative search query shares of many symptoms, including *nausea*, *vomiting*, *abdominal pain*, and *constipation*, remained near or below baseline throughout the time period studied; however, there were notable increases in searches for the positive control symptoms of *fever* and *cough* as well as for *diarrhea*. These increases in daily search queries for *fever*, *cough*, and *diarrhea* preceded the rapid rise in number of cases by approximately 10 to 14 days. The search volumes for these terms began declining after mid-March despite the continued rises in cumulative cases and daily new case counts.

Conclusions: Google searches for symptoms may precede the actual rises in cases and hospitalizations during pandemics. During the current COVID-19 pandemic, this study demonstrates that internet search queries for *fever*, *cough*, and *diarrhea* increased prior to the increased confirmed case count by available testing during the early weeks of the pandemic in the United States. While the search volumes eventually decreased significantly as the number of cases continued to rise, internet query search data may still be a useful tool at a population level to identify areas of active disease transmission at the cusp of new outbreaks.

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KEYWORDS

COVID-19; diarrhea; internet search queries; Google Trends; gastrointestinal; symptom; health information; pandemic; infectious disease; virus

Introduction

The coronavirus disease (COVID-19) pandemic has resulted in over 10.3 million cases and over 508,000 deaths to date worldwide [1]. Almost all known information regarding symptoms of COVID-19 has been obtained from studies of patients who seek medical care; fever, cough, fatigue, and dyspnea are the predominant symptoms [2,3]. Early reports have suggested that gastrointestinal symptoms are also a primary manifestation in 3% to 37% of patients, and these symptoms may precede clinical diagnosis [2,4,5]. To study the presentation of COVID-19, clinicians have primarily used the traditional approach of identifying symptom prevalence among confirmed cases [6]. However, due to limited testing availability and the high occurrence of subclinical and minimally symptomatic disease, innovative uses of internet-based approaches may have increased utility in examining symptom manifestations in the general population.

Infodemiology is an emerging field that involves analyzing information from internet sources to obtain insight into changes in population health that may ultimately inform public health and policy, especially during outbreaks and epidemics [7]. Examples of such metrics include dissecting content from Twitter to understand attitudes and behaviors during the Zika virus and Ebola virus outbreaks and exploring the role of media awareness of Middle Eastern respiratory syndrome coronavirus (MERS-CoV) and case management [8-10]. One validated approach includes analyzing internet search queries that reflect the health information–seeking activity of users. This methodology has correlated antecedent symptoms with norovirus outbreaks and has accurately predicted symptom-based patterns of influenza spread and incidence [11-13]. The aim of this infodemiology study was to examine trends of internet search queries for gastrointestinal symptoms during a period of COVID-19 case confirmation within the US population.

Methods

Data Sources

Google Trends provides access to an unbiased sample of Google searches. The Google Trends interface reports a "query share," calculated by dividing the number of queries of interest by the total number of queries for all search terms over the same time period and region. Each query share is normalized on a scale of 0 to 100, with 100 representing the maximum value of the share for the period and region selected [14]. The scaled query share values are plotted daily, generating a time series.

The chosen search terms were gastrointestinal symptoms that have previously been reported to be associated with COVID-19 infection in the literature, including *diarrhea*, *nausea*, *vomiting*, and *abdominal pain*. The terms *fever* and *cough* were included as positive controls. The term *constipation* was included as a negative control, as we felt this symptom was unlikely to be associated with COVID-19. The terms *anosmia*, *dysgeusia*, *loss of appetite*, *loss of taste*, and *loss of smell* were considered; however, due to the low frequency of searches for these terms, analysis was limited by missing data. The default "All categories" and "Web search" settings were selected for the Google Trends query.

Daily case counts of confirmed COVID-19 cases for each US state were obtained from the Johns Hopkins University Center for Systems Science and Engineering data repository [15].

Data Analysis

Daily query shares for the selected symptoms were obtained from October 1, 2019 to June 15, 2020 for the United States. The full data set of search query shares is provided in Multimedia Appendix 1. The data were divided into two time periods for comparison: a baseline period during which the COVID-19 case burden was low (October 1 to February 29) and a post–COVID-19 period (March 1 to June 15). The query share for each symptom was divided by its average for the pre–COVID-19 period to generate a curve of search interest relative to the pre–COVID-19 baseline. To examine longer-term patterns, the search query shares for the 5-year period preceding the COVID-19 pandemic were plotted. A 3-day moving average smoother was applied to reduce day-to-day variation. Cumulative and new COVID-19 cases from the United States were superimposed on Google search data to assess their temporal relationship with the symptoms. All analyses were performed with Stata 13.0 (StataCorp LP).

Results

2.1 million cases of COVID-19 were reported within the United States through June 15, 2020. Figure 1 demonstrates a sharp increase relative to the pre–COVID-19 baseline in search query shares for *fever* and *cough* starting on March 7. This trend precedes the rise in reporting of confirmed COVID-19 cases that occurs 10 to 14 days afterward. Notably, the *diarrhea* search query share also increases at the same time or slightly after those for *fever* and *cough*. The search query shares for the remaining gastrointestinal symptoms are either only very slightly above baseline (*nausea* and *vomiting*) or below baseline (*abdominal pain* and *constipation*). The search query shares for *fever*, *cough*, and *diarrhea* all appear to decline after March 20 despite a continued steady rise in cumulative cases through June 15.

Figure 1. Google search query shares for gastrointestinal symptoms, fever, and cough relative to the pre-March 1, 2020 baseline and their relationships to the cumulative confirmed COVID-19 case count in the United States from October 2019 through June 2020. m: million.

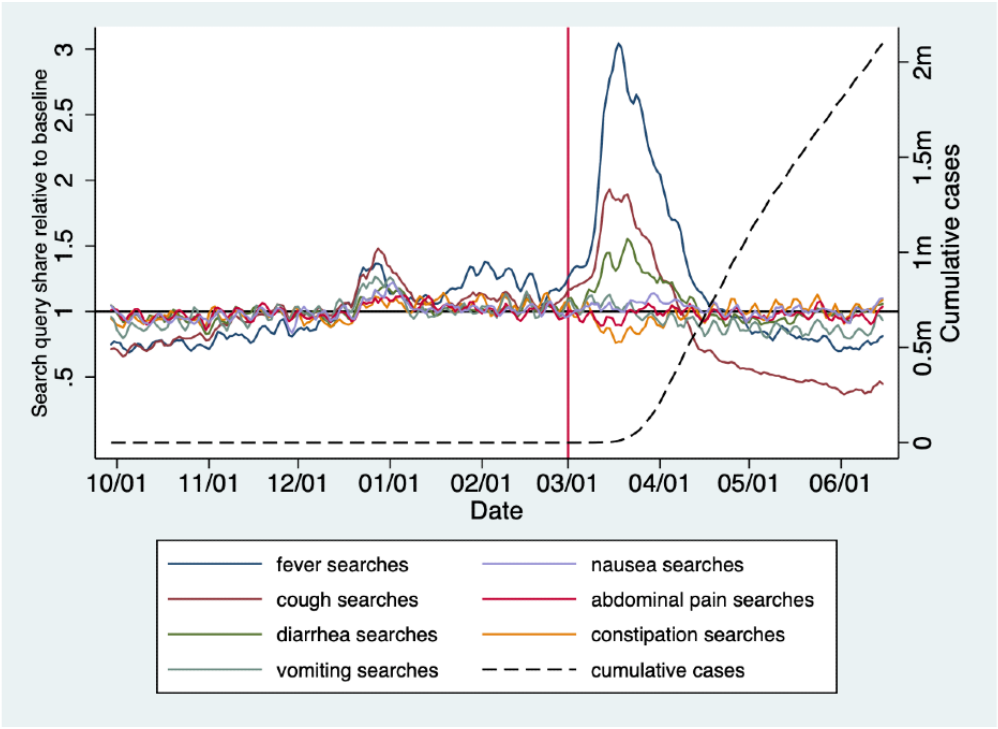
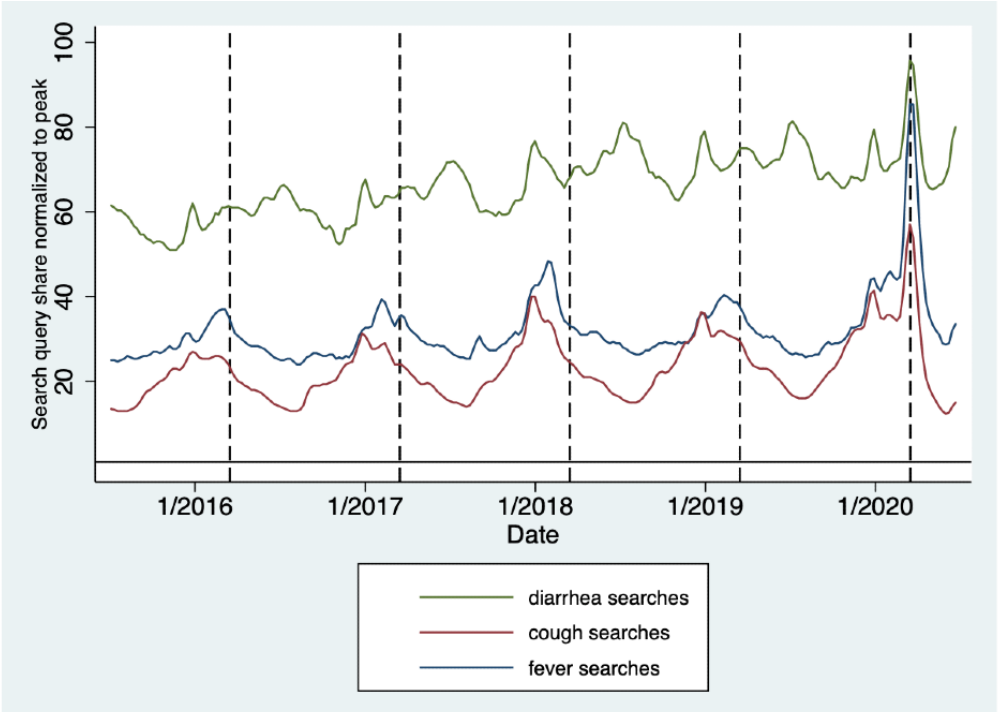


Figure 2 depicts long-term trends in the query shares for the *fever*, *cough*, and *diarrhea* search terms over a 5-year period. Winter seasonality in the search query shares for all terms is apparent; however, the mid-March peak seen in 2020 in the setting of the COVID-19 pandemic deviates from the decreasing trend at the same point in prior years. As shown in Multimedia Appendix 2, when the new case rate began to trend downward in the first week of April, relative query shares for *fever*, *cough*, and *diarrhea* were already declining, and they returned to or decreased below baseline by mid-April.

Figure 2. Seasonal trends in Google search query shares for *fever*, *cough*, and *diarrhea* over the last five years as percentages of peak interest.



Discussion

Principal Findings

Our analysis of aggregate internet search query data reveals that the search query shares for symptoms associated with COVID-19 rose in advance of the substantial increase in identified cases that occurred with the first wave of the pandemic in the United States in early March 2020. The data suggest that symptoms of fever, cough, and diarrhea may occur contemporaneously and precede case identifications by up to two weeks in the United States, particularly during the early weeks of the pandemic. This study validates the findings of Higgins et al [16] that COVID-19–related internet searches preceded case identification by over a week in China, Italy, Spain, Washington, and New York.

This study also suggests that there was no significant increase in abdominal pain or constipation queries, which may provide reassurance to clinicians who are faced with these very common complaints in the setting of a new and uncertain pandemic.

The seasonal increase in search query shares for *fever*, *cough*, and *diarrhea* in December 2019 and at the same time in prior years can be attributed to increased search interest during the typical cold and influenza season in the winter. These query shares are much lower than those seen during the post–COVID-19 time range in this study.

Despite the consistent increase in cumulative case count throughout April and May, our findings show that search queries for *fever*, *cough*, and *diarrhea* begin decreasing in mid-March, when the new daily case rate was over 5000 and continuing to rise. There are several possible explanations for the decoupling of COVID-19 cases and search query interest. One explanation is that users sought information via the internet early in the pandemic when there was less public knowledge regarding the virus and its manifestations and that by April, the demand for further information was saturated. During the early weeks of the pandemic, access to outpatient medical care and COVID-19 testing were limited; however, later in the pandemic, both testing and access to telehealth visits became more common, and individuals may thus have relied on alternative sources of information. Our study suggests that internet search query data can provide early clues to the start of an outbreak but may have less utility as the course of the pandemic extends.

Limitations

There are many limitations and assumptions that must temper our interpretation of these data. Through this infodemiological approach, data were only gathered from internet users, who may not reflect the entire population, such as younger or older persons. Moreover, individuals may be searching for these terms for reasons other than being symptomatic themselves. The role of media attention in influencing user behavior should also be considered. However, public knowledge of the gastrointestinal symptoms associated with COVID-19 was minimal during the period in which the search volumes rose and peaked, which suggests that search interest in diarrhea was less likely to be influenced by media reporting of diarrhea as a manifestation of the disease.

Conclusions

This study demonstrates sharp increases in internet search interest in fever, cough, and diarrhea at the onset of the COVID-19 pandemic in the United States preceding case identification. Further work is warranted to determine if infodemiological approaches can contribute to population-based surveillance of early outbreaks.

Acknowledgments

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Authors' Contributions

SM planned the study, performed the analysis, co-wrote the manuscript, and critically edited the manuscript. AR extracted data, analyzed data, and co-wrote the manuscript. RS, RSB, RZS, and BL co-wrote and critically edited the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Data set of daily search query shares for the selected symptoms and cumulative and daily case counts.
[PDF File (Adobe PDF File), 82 KB - publichealth_v6i3e19354_app1.pdf]

Multimedia Appendix 2
Google search query shares for gastrointestinal symptoms, fever, and cough relative to the pre-March 1 baseline and their relationships with the daily new case count in the United States.
[PNG File , 584 KB - publichealth_v6i3e19354_app2.png]

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Abbreviations

COVID-19: coronavirus disease
MERS-CoV: Middle Eastern respiratory syndrome coronavirus

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Original Paper

Fluctuation of Public Interest in COVID-19 in the United States: Retrospective Analysis of Google Trends Search Data

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Abstract

Background: In the absence of vaccines and established treatments, nonpharmaceutical interventions (NPIs) are fundamental tools to control coronavirus disease (COVID-19) transmission. NPIs require public interest to be successful. In the United States, there is a lack of published research on the factors that influence public interest in COVID-19. Using Google Trends, we examined the US level of public interest in COVID-19 and how it correlated to testing and with other countries.

Objective: The aim of this study was to determine how public interest in COVID-19 in the United States changed over time and the key factors that drove this change, such as testing. US public interest in COVID-19 was compared to that in countries that have been more successful in their containment and mitigation strategies.

Methods: In this retrospective study, Google Trends was used to analyze the volume of internet searches within the United States relating to COVID-19, focusing on dates between December 31, 2019, and March 24, 2020. The volume of internet searches related to COVID-19 was compared to that in other countries.

Results: Throughout January and February 2020, there was limited search interest in COVID-19 within the United States. Interest declined for the first 21 days of February. A similar decline was seen in geographical regions that were later found to be experiencing undetected community transmission in February. Between March 9 and March 12, 2020, there was a rapid rise in search interest. This rise in search interest was positively correlated with the rise of positive tests for SARS-CoV-2 (6.3, 95% CI −2.9 to 9.7; $P<.001$). Within the United States, it took 52 days for search interest to rise substantially after the first positive case; in countries with more successful outbreak control, search interest rose in less than 15 days.

Conclusions: Containment and mitigation strategies require public interest to be successful. The initial level of COVID-19 public interest in the United States was limited and even decreased during a time when containment and mitigation strategies were being established. A lack of public interest in COVID-19 existed in the United States when containment and mitigation policies were in place. Based on our analysis, it is clear that US policy makers need to develop novel methods of communicating COVID-19 public health initiatives.

(JMIR Public Health Surveill 2020;6(3):e19969) doi:10.2196/19969

KEYWORDS

Infodemiology; COVID-19; SARS-CoV-2; digital health; Google Trends; trend; internet; public health

Introduction

Over the past 20 years, two pathologic human coronaviruses (HCoVs) emerged that cause significant morbidity and mortality: severe acute respiratory syndrome coronavirus (SARS-CoV) and Middle East respiratory syndrome coronavirus (MERS-CoV). In December 2019, another pathologic HCoV, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2),

emerged in Wuhan, China, causing coronavirus disease (COVID-19) [1-3]. During the severe acute respiratory syndrome (SARS) epidemic in 2003, 8098 cases and 774 deaths were reported. The cases were concentrated in five countries and regions: China, Taiwan, Hong Kong, Singapore, and Canada. SARS was brought under control in 8 months through syndromic surveillance, prompt isolation of patients, strict quarantine, and community-level quarantine. In contrast, in just 3 months, COVID-19 resulted in more than 2800 deaths and 82000 confirmed cases, and more than 46 countries were affected [4]. COVID-19 is associated with significant morbidity and mortality, with a reported case fatality rate as high as 7.2% [5].

Unfortunately, the epidemiological trajectory of SARS-CoV was a poor predictor of its worldwide impact. While many similarities exist between SARS and COVID-19, clear differences in their transmissibility and severity pyramids alter their epidemiologic trajectories. As many as 81% of patients with confirmed COVID-19 have been reported to have mild disease [6]. This contributes to greater community transmission; thus, the application of traditional public health measures for halting human-to-human transmission is more challenging [5].

In the absence of vaccines and established treatments, nonpharmaceutical interventions (NPIs) such as isolation, quarantine, social distancing, and community containment tools are fundamental tools to control human-to-human transmission [7]. Early and sustained response with NPIs has been shown to reduce transmission of a new contagious pathogen [8]. NPIs achieved improved control of COVID-19 in the Republic of Korea, Hong Kong, and Singapore [9,10].

Implementation of containment strategies for COVID-19 began in the United States in January 2020, with travel restrictions, removal of persons with COVID-19 from the community and into medical facilities, and instructions on mandatory quarantine for people traveling from endemic areas. Once community transmission became evident, the United States shifted from containment to a mitigation strategy in early March [11,12]. Public interest is critical to the effectiveness of containment and mitigation strategies alike; indeed, the first confirmed patient with COVID-19 in the US did not have severe symptoms initially but sought evaluation on January 19 after seeing a health alert from the US Centers for Disease Control and Prevention (CDC) [13].

While studies have been performed on public interest within China and Taiwan in the early days of their respective outbreaks, there is a lack of published research of US public interest in COVID-19 during the early containment and mitigation periods [14,15].

When discussing public interest, communication platforms are at the forefront. Since the 1990s, digital media has become the dominant means of communication worldwide [16]. More than 90% of the US population actively uses the internet in their daily lives. Google is the most popular internet search engine in the world. It is also the most popular search engine within the United States, with a search engine market share of 88.2% [17]. Google Trends, a real-time sample of Google search data, has been publicly available since 2006. Several health-related studies have used Google Trends to measure the interest in infectious diseases and the disease awareness of the general public [18-21]. Google Trends has played a major role in the emerging field of infodemiology, the study of electronically transmitted medical information for the purpose of public health [22]. While there is no absolute method to measure public interest in COVID-19, Google search data has been leveraged in prior research studies as a correlate [14,23,24].

Countries that had prior experience with SARS (and have largely contained COVID-19) instituted robust public health campaigns. These campaigns were targeted to increase public interest in containment and mitigation policies. Increased public interest is thought to be correlated with increased attention and willingness to participate in strategies to reduce person-to-person transmission [9,10,25].

Using Google Trends search queries as a proxy, we examined the US level of interest in COVID-19 during the critical time when containment and mitigation strategies were first being employed. We analyzed how the number of positive SARS-CoV-2 cases affected Google searches in the United States. Lastly, we compared public interest in COVID-19 in the US and Italy to that in countries and regions that have focused on public education as a key strategy, namely Singapore, Hong Kong, and the Republic of Korea, who delivered guidance through traditional print media, broadcast media, social media, and other novel methods [25,26].

Methods

Study Tools

This was a retrospective study of the public online search interest in COVID-19 in the early months of 2020 within the United States during the periods of changing case numbers, major news headlines, and implementation of NPIs. Subsections of the United States and other countries and regions were further examined. A variety of tools were used to obtain this understanding.

Google Trends is a publicly available website [27] that allows users to gain an understanding of what the general population is searching for using Google's search engine. Google searches are stored, anonymized, and processed, and repeat searches are removed [16]. When a user accesses Google Trends, they can extract a value for the search volume of keywords and phrases across specific geographical areas. The output from the tool is converted from the absolute search volume and is reported as a relative volume named "search interest," which is assigned a numerical value between 0 and 100. We refer to this value as the relative search volume (RSV) [20,28]. An elevated RSV is indicative of a higher proportion of users searching a topic within a set location and time period.

The COVID Tracking Project [29] is a website that aggregates all available COVID-19 testing information in the US for each day. This website collects information from the Department of Health and Human Services in each state. The COVID Tracking Project has been cited by many major news organizations [30,31]. It originally began reporting data on March 4, 2020. Our results were collected by referencing the "US daily 4pm

ET" datasheet and using the copy function for the Date and Positive sections. This information was saved as confirmed cases of COVID-19 (Appendix Table 1, Multimedia Appendix 1).

Other tools were used to achieve context in the form of the timeline and major cultural events that surrounded the rise of COVID-19 within the United States. In order to provide societal context, news stories were extracted from the *New York Times* article "A Timeline of the Coronavirus Pandemic" [32] (Appendix Table 2, Multimedia Appendix 1). Google Daily Trends was used to elucidate what drew the attention of the US population in early March. This tool displays the 20 most searched topics daily in the United States, with the ability to review data up to the last 28 days.

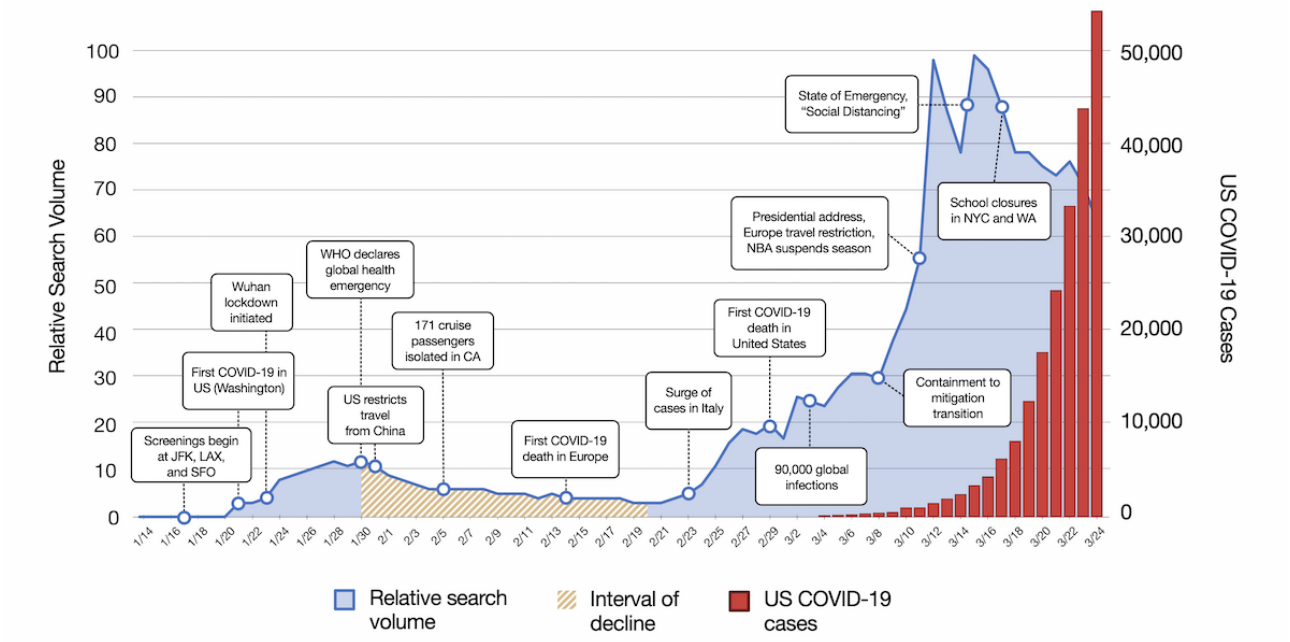
Selection Criteria

The starting date of December 31, 2019, was chosen because a major news headline from Wuhan about an unknown pneumonia appeared on this day [32]. The end date of March 24, 2020, was chosen because this was the most recently accessible date when this project started.

Study Design

The main topic explored was the search interest in COVID-19. The most commonly searched keyword was chosen to represent this topic. To identify the most searched keyword, on March 30, 2020, we accessed and queried Google Trends for *coronavirus*, *COVID-19*, *COVID*, *SARS*, and *SARS-COV-2*. Filters were used to set a timeline from December 31, 2019, to March 24, 2020, and an additional filter limited the search to the United States. No filter was set for category or search type. The results were graphed over time (Appendix Figure 1, Multimedia Appendix 1). The most searched term, *coronavirus*, was selected for further analysis.

Figure 1. Google Trends RSV (0-100) of the keyword *coronavirus* in the United States graphed over time and during the period of rising COVID-19 cases. Key events are shown on the timeline between January 14, 2020 and March 24, 2020, and the interval decline in search interest is highlighted. COVID-19: coronavirus disease. CA: California. COVID-19: coronavirus disease. JFK: John F. Kennedy International Airport. LAX: Los Angeles International Airport. NBA: National Basketball Association. NYC: New York City. SFO: San Francisco International Airport. US: United States. WA: Washington. WHO: World Health Organization.



Subgroup Design

A secondary analysis of the relationship between the RSV of *coronavirus* over time in areas with significant outbreaks was performed. Throughout early 2020, New York City, NY, and Seattle-Tacoma, WA, experienced high levels of disease burden within the United States [33-36]. On March 31, 2020, we accessed and queried Google Trends for *coronavirus*. Filters were set for the above timeline, and the location filter was set to New York City, NY. No other filters were set, and the results were downloaded. The same process was repeated with the location filter for Seattle-Tacoma, WA. For another comparison, countries and regions with similar first case dates were chosen for comparison, including Italy, Singapore, Republic of Korea, and Hong Kong. Using the same steps as above with the respective location filters set, the keyword was searched in the local language (Appendix Table 3, Multimedia Appendix 1), and the results were downloaded. In the Daily Search Trends section, we extracted information on the most popular searches from March 3 to March 14.

Outcome Measures

The primary outcome measure was evaluating the relationship between search interest in COVID-19, major news events, and positive cases of SARS-CoV-2 (Figure 1). Secondary outcome measures included an analysis of the search interest within areas of the United States experiencing high disease burden, an analysis of search interest in specific foreign countries, and an examination of the major search topics in the United States in early March.

Study Analysis

The RSVs for *coronavirus* were tabled alongside the numbers of COVID-19 cases (Appendix Table 1, Multimedia Appendix 1). The RSV for *coronavirus* was graphed alongside major COVID-19 news headlines and cases of COVID-19 to examine the relationship between the RSV and major events as the number of COVID-19 cases increased (Figure 1). To further analyze the relationship between the number of COVID-19 cases and the RSV of *coronavirus*, the cases of COVID-19 data were linearized using logarithmic transformation with a base of 2. Log2(cases of COVID-19) was then graphed against the RSV for *coronavirus*. A linear relationship was assumed, and a model was fit. Using the Excel data analysis toolkit (Microsoft Corporation), the relationship was analyzed via linear regression. To describe the linear regression, descriptive statistics, including the Pearson coefficient, mean, standard error, and 95% CI, were calculated.

Subgroup Analysis

The results of the RSV of *coronavirus* over time were graphed for New York City and Seattle-Tacoma (Figure 2) as well as for foreign countries (Figure 3). The first date that the RSV was >90 was recorded alongside the date on which the first case was reported and the time between those two dates (Appendix Table 4, Multimedia Appendix 1). The time between the first case and RSV >90 in each location was then graphed (Figure 4). Top searches for every day leading up to and following March 11 were recorded in a table (Appendix Table 5, Multimedia Appendix 1). Top 5 searches on March 11 were also recorded (Appendix Table 6, Multimedia Appendix 1).

Figure 2. Google Trends RSV (0-100) of the keyword *coronavirus* in New York City, NY and Seattle-Tacoma, WA from December 31, 2019 to March 24, 2020. RSV: relative search volume.

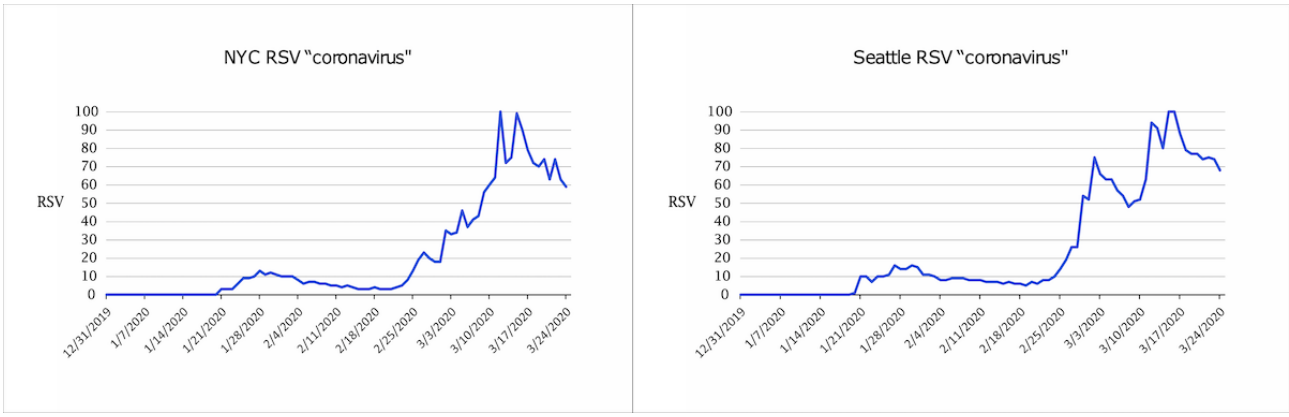


Figure 3. Graphs of Google Trends RSVs (0-100) for the keyword *coronavirus* vs time from December 31, 2019 to March 24, 2020 in Italy, Singapore, South Korea, and Hong Kong. RSV: relative search volume.

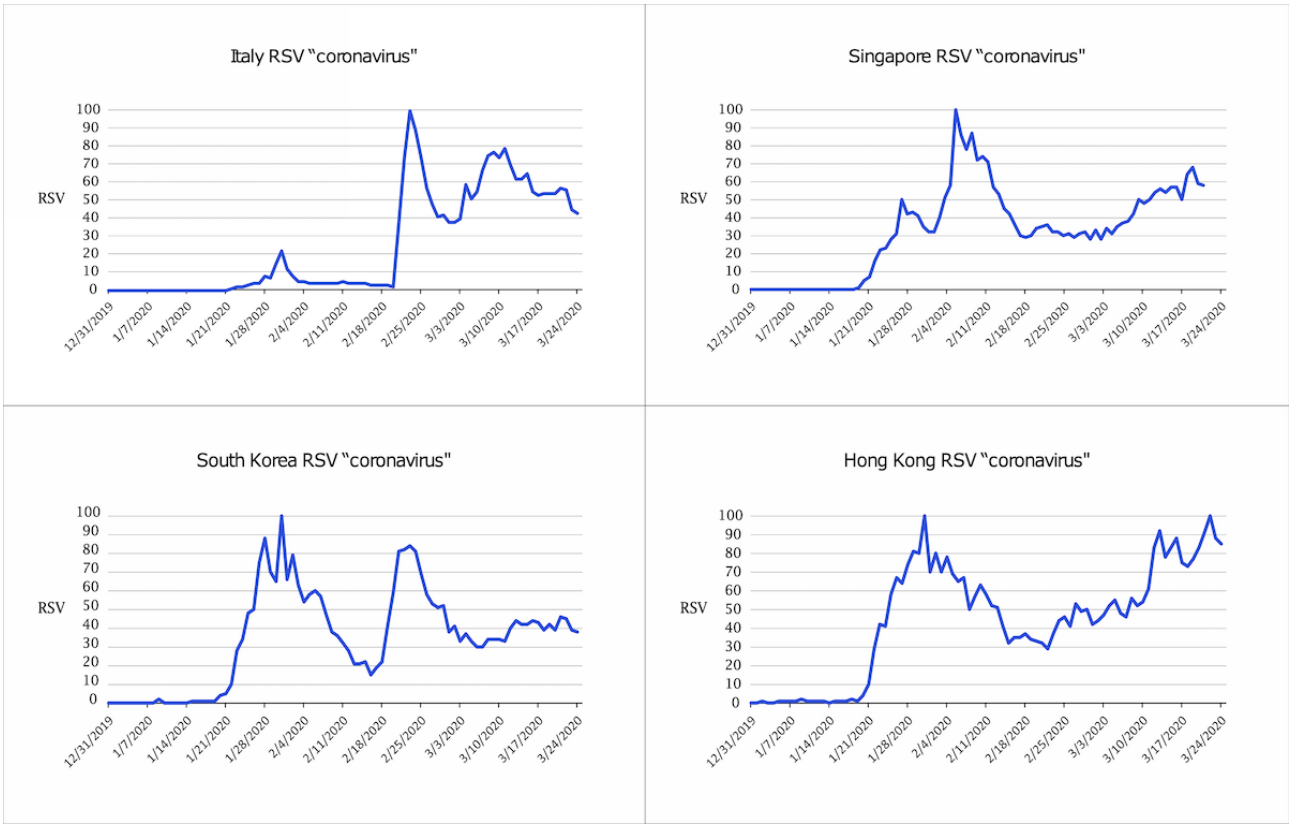
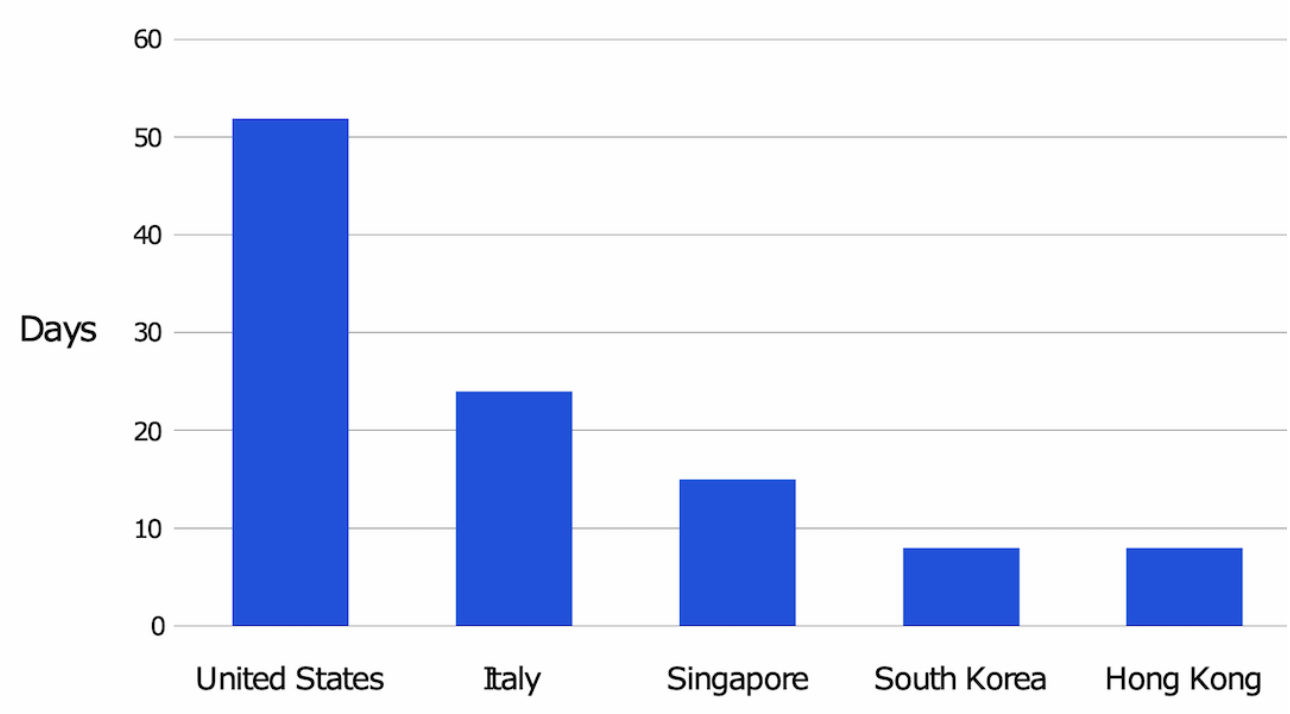


Figure 4. Number of days from the first COVID-19 case until the relative search volume on Google Trends for the search term *coronavirus* reached >90 in the United States, Italy, Singapore, South Korea, and Hong Kong.



Results

Primary Results

The RSV for coronavirus remained below 12 throughout all of January and most of February 2020. It began to rise at the end of February and rose further between March 9 and March 12; Figure 1 demonstrates an increase in the RSV for *coronavirus* within the United States to 99. Figure 5 shows the relationship between Log2(cases of COVID-19) and the RSV for *coronavirus*.

To describe the linear regression, descriptive statistics including Pearson coefficient, t-statistics, standard error, and 95% confidence intervals were calculated (Table 1). There is a significant positive correlation between the two with the equation F(RSV(coronavirus)) = 6.32(Log2(cases of COVID-19)) – 6.97 and R^2=0.445. The X variable has a *P* value <.001 and a 95% CI of 2.93-9.71.

Figure 5. Cases of COVID-19 data linearized using logarithmic transformation with base of 2 graphed against the RSV for the Google search term *coronavirus*. A linear relationship was assumed, and a model was fit. RSV: relative search volume.

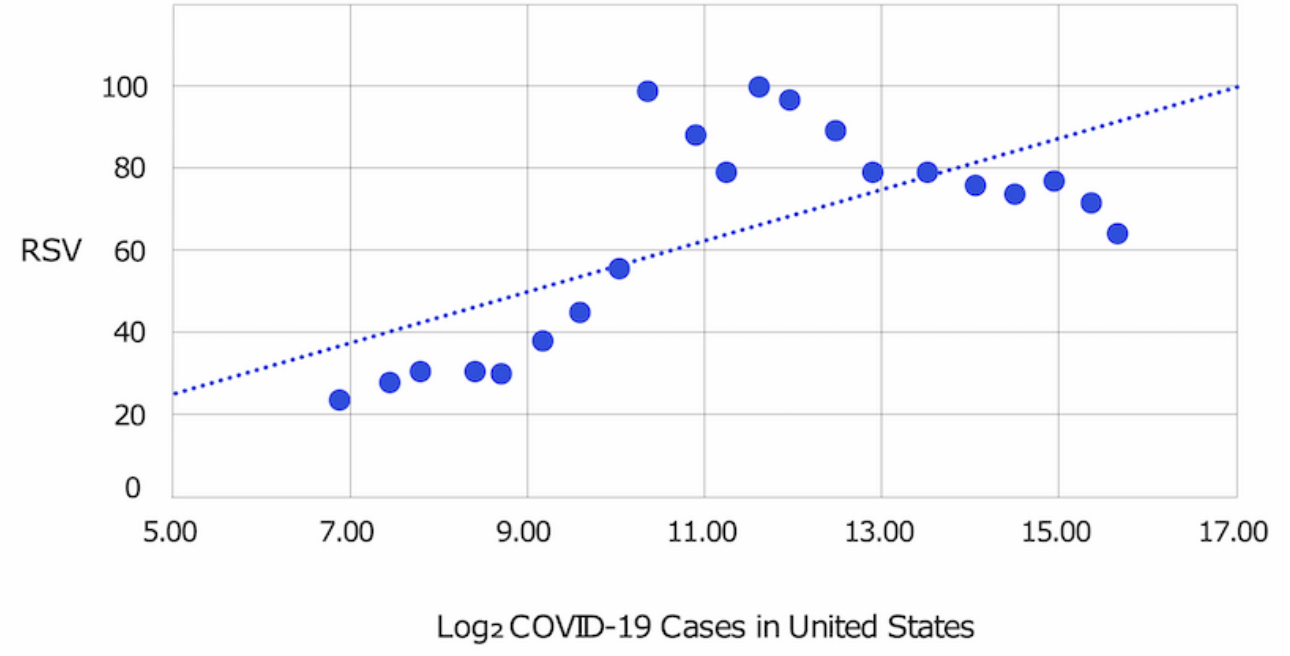


Table 1. Descriptive statistics of the linear regression of Log2(cases of COVID-19) and the RSV for the search term coronavirus.

Variable	Pearson coefficient (SE)	*t* value	*P* value	95% CI
Intercept	–6.974 (18.846)	–0.370	.715	–46.418 to 32.471
X variable 1	6.321 (1.621)	3.899	<.001	2.928 to 9.714

Subgroup Results

Figure 2 shows that in both New York City and Seattle, a small increase in interest occurred in January 2020, followed by a decrease in interest throughout February before reaching an RSV of 100 in mid-March. Figure 4 shows the RSV trend for the search term *coronavirus* over time in other countries. Italy showed lower interest throughout January and February 2020 than Singapore, the Republic of Korea, or Hong Kong. Figure 5 shows the time from the first confirmed case until high levels of public interest were reached, reflected by RSV >90. Appendix tables 5 and 6 (Multimedia Appendix 1) show that March 11, 2020 was the day when the most popular daily search topics in the United States reflected COVID-19–related queries.

Discussion

Principal Findings

Using Google Trends data, our results indicate that the initial US level of public interest in COVID-19 was limited and even decreased during a time when containment and mitigation strategies were being implemented. On January 17, 2020, the CDC implemented public health airport entry screenings at airports in San Francisco (San Francisco International Airport), New York (John F. Kennedy International Airport), and Los Angeles (Los Angeles International Airport), with announcements of other international airports to follow [37]. The CDC activated its Emergency Operations Center on January 20 [38]. Despite these measures, until January 21, the RSV for *coronavirus* remained at 0, indicating that the US public had low interest in COVID-19.

On January 21, 2020, the CDC reported the first case of COVID-19 in the state of Washington [39]. By the end of January, the World Health Organization had declared COVID-19 a “public health emergency of international concern,” and the United States had implemented aggressive travel restrictions from countries with significant spread [40]. These announcements resulted in the first modest upward movement of public interest. In February, there was actually a relative decline in public interest from February 1 to February 21. This is surprising considering the events that occurred during that time. The *Diamond Princess* cruise ship, with 428 US citizens on board, was found to have hundreds of cases. European deaths were being reported from COVID-19, and multiple countries started to report outbreaks [41,42].

Even more surprisingly, this February decline in public interest was observed in the Seattle and NYC geographical areas, although both areas were experiencing undetected community transmission during this time [33-36]. A similar February downward trend of public interest in COVID-19 was experienced in Italy, a country that experienced a high epidemiologic trajectory of COVID-19 [24]. We suspect this downward trend in public interest in February contributed to the community transmission that occurred in New York City, Seattle, and Italy in February. The reason for this downward trend of COVID-19 public interest should concern policy makers, as this was a critical time for containment measures requiring the public’s attention.

A dramatic increase of public interest in COVID-19 occurred from March 9 to 12, 2020. Several events could explain this. We discovered that the top searched keywords on March 11 related to *Tom Hanks* and *NBA*, each yielding more than ten million searches each. That day, it was reported that actor Tom Hanks had tested positive for SARS-CoV-2 [43]. Additionally, the National Basketball Association (NBA) suspended all games when one of its players tested positive [44]. The third highest search term for the day was related to *coronavirus symptoms*, yielding more than five million searches. That evening, the President of the United States announced travel restrictions from Europe in his first prime time television address of the pandemic [45]. The President’s name was the top search term the following day, with over five million searches on March 12. It is interesting that societal events were associated with sharp increases in COVID-19 public interest. Based on our compiled search term histories, these events and the accompanying media coverage may have contributed to the culmination of public interest in COVID-19.

A strong correlation exists between positive SARS-CoV-2 cases and increasing RSV. We interpret that COVID-19 public interest increased as more cases were discovered. This correlation shows the importance of diagnostic testing. The delays in diagnostic testing that occurred in the United States were a contributor to delaying public interest [46,47]. However, this does not fully explain the substantial lack of public interest. Before the United States developed a high level of public interest (RSV >90), more than 50 days had passed since the first US case of COVID-19, and there had been thousands of positive cases with multiple deaths [30,31].

One of the most interesting and concerning findings was the lack of early public interest in the United States and Italy compared to countries that were able to contain COVID-19 more effectively. From the first cases of COVID-19 in the United States and Italy, 52 and 24 days passed, respectively, before public interest reached high levels. In Singapore, Republic of Korea, and Hong Kong, public interest reached high levels within 15 days of the first positive COVID-19 case.

An important aspect of containment is isolation and quarantine. These both require significant public education and interest for compliance. One of the main goals of modern quarantine is to reduce transmission by increasing the social distance between persons. This requires the general public to understand the actions to take when they are exposed to a disease or develop symptoms, such as effective separation and duration of

quarantine [48]. Policy makers should consider partnering with existing popular digital platforms (Facebook, Twitter, Google, and others) not only to monitor interest but to engage the general public when messaging is rapidly changing.

Limitations

There are several limitations associated with this analysis. First, the exclusive use of Google Trends as a data set does not comprise all internet search traffic. Google constitutes 72% of search engine activity [15]. The remaining internet search activity is conducted on other search engine platforms and is not represented in our analysis. Second, the presumptive association between RSV and public interest has limitations. While RSV offers an innovative method to approximate public interest and has been utilized in prior research, its accuracy in measuring public interest has not been validated [14,23,24]. Third, given the anonymity of the data that Google Trends makes available to the public, it is difficult to determine which segments of the population may be underrepresented in or excluded from the analysis [49]. Fourth, the search criteria used in this analysis are not standardized and may not encompass all search phrases used by the public, including countries that have different platforms and different communication channels. Finally, with 3 months of search information included, conclusions drawn from this data set must be considered in the context of a longer and continually evolving pandemic event, especially within the context of different SARS-CoV-2 timelines.

Conclusion

Public interest in COVID-19 was limited until March 12, 2020, when a rapid succession of events brought the disease into full public view. Surprisingly, public interest declined into most of February, even in geographic areas that were experiencing undetected community transmission and during a time when containment strategies were in place. While an inability to perform aggressive testing likely contributed to the low level of interest, other countries with improved control of COVID-19 showed accelerated levels of public interest after their first positive cases.

SARS-CoV-2 is now the third novel pathological HCoV to emerge in a relatively short course of time. At this time, there is no proven vaccine or pharmacological treatment available; therefore, adoption of public health initiatives is critical to curtail spread. Based on our analysis, it is clear that policy makers need to develop novel methods of communicating with the public regarding not only SARS-CoV-2 but other emerging infectious diseases. As popular digital tools continue to become ubiquitous, we propose that policy makers should use them not only to understand public interest but to tailor targeted messaging towards the public.

Acknowledgments

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Conflicts of Interest

JPS has received research funding from Abbott Point of Care and Roche Diagnostics. IH is a cofounder of Impathiq Inc and iMedicalApps.com. SG is a cofounder of Impathiq Inc.

Multimedia Appendix 1
Supplementary information.
[DOCX File , 367 KB - publichealth_v6i3e19969_app1.docx]

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
HCoV: human coronavirus
MERS-CoV: Middle East respiratory syndrome coronavirus
NBA: National Basketball Association
NPI: nonpharmaceutical intervention
RSV: relative search volume
SARS: severe acute respiratory syndrome
SARS-CoV: severe acute respiratory syndrome coronavirus
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

COVIDApp as an Innovative Strategy for the Management and Follow-Up of COVID-19 Cases in Long-Term Care Facilities in Catalonia: Implementation Study

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Abstract

Background: The coronavirus disease (COVID-19) pandemic has caused an unprecedented worldwide public health crisis that requires new management approaches. COVIDApp is a mobile app that was adapted for the management of institutionalized individuals in long-term care facilities.

Objective: The aim of this paper is to report the implementation of this innovative tool for the management of long-term care facility residents as a high-risk population, specifically for early identification and self-isolation of suspected cases, remote monitoring of mild cases, and real-time monitoring of the progression of the infection.

Methods: COVIDApp was implemented in 196 care centers in collaboration with 64 primary care teams. The following parameters of COVID-19 were reported daily: signs/symptoms; diagnosis by reverse transcriptase–polymerase chain reaction; absence of symptoms for ≥14 days; total deaths; and number of health care workers isolated with suspected COVID-19. The number of at-risk centers was also described.

Results: Data were recorded from 10,347 institutionalized individuals and up to 4000 health care workers between April 1 and 30, 2020. A rapid increase in suspected cases was seen until day 6 but decreased during the last two weeks (from 1084 to 282 cases). The number of confirmed cases increased from 419 (day 6) to 1293 (day 22) and remained stable during the last week. Of the 10,347 institutionalized individuals, 5,090 (49,2%) remained asymptomatic for ≥14 days. A total of 854/10,347 deaths (8.3%) were reported; 383 of these deaths (44.8%) were suspected/confirmed cases. The number of isolated health care workers

remained high over the 30 days, while the number of suspected cases decreased during the last 2 weeks. The number of high-risk long-term care facilities decreased from 19/196 (9.5%) to 3/196 (1.5%).

Conclusions: COVIDApp can help clinicians rapidly detect and remotely monitor suspected and confirmed cases of COVID-19 among institutionalized individuals, thus limiting the risk of spreading the virus. The platform shows the progression of infection in real time and can aid in designing new monitoring strategies.

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KEYWORDS

COVID-19; mobile health; app; COVIDApp; long-term care facilities; institutionalized individuals; mHealth; elderly; long-term; care; public health; management; surveillance

Introduction

The disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), called coronavirus disease (COVID-19), was initially identified in December 2019 as a case of pneumonia in Wuhan, China [1,2]. COVID-19 has since become a global pandemic that is affecting more than 200 countries worldwide, with more than 3.5 million people infected globally and more than 240,000 related deaths as of April 30, 2020 [3]. The World Health Organization declared COVID-19 a pandemic on March 11, 2020, and called for coordinated mechanisms to provide a response to the infection across various health sectors [4]. On March 14, the Spanish authorities declared the pandemic to be a national emergency [5].

The rapid spread of the infection and its severity in a considerable percentage of patients has necessitated unprecedented public health measures. Health systems worldwide are working against the clock and taking exceptional measures to address the crisis. Health professionals require methods to detect, treat, and monitor patients with COVID-19 effectively and efficiently and to prevent further transmission of the disease.

The health crisis generated by COVID-19 requires new approaches to disease management, especially in the case of older individuals, as this population is especially vulnerable to severe illnesses and early data point to higher mortality from COVID-19 in this population than in young and middle-aged patients [6,7]. In addition, the high risk of transmission of COVID-19 in long-term care facilities (nursing homes and other institutions) with vulnerable populations and the resulting challenge of controlling the epidemic in these settings have necessitated innovative responses [8,9]. In this sense, expert recommendations indicate that medical decisions should include rapid screening to identify suspected cases early and to facilitate on-site management or transfer to hospital, as applicable [10].

Given this scenario, we adapted a mobile health app that was designed in 2015 [11] and that has since been used for the clinical management of HIV-infected persons in our HIV Unit (+Approp). For the last two years, the app has been used in additional scenarios, such as clinical management of the general population and of patients with chronic conditions (Doole Health). COVIDApp is an adapted version of this app that aims to address the current COVID-19 crisis by closely monitoring institutionalized subjects and their contacts through providing remote medical attention. The objective of this paper is to report the use of this innovative tool for the management of long-term care facility residents as a high-risk population, specifically for early identification and self-isolation of suspected cases, remote monitoring of mild cases, and real-time monitoring of the progression of the infection.

Methods

Study Design, Objectives, and Population

We describe the implementation of a mobile app (COVIDApp) for the management of COVID-19 in institutionalized persons in long-term care facilities (older residents and individuals with physical and mental disabilities). This innovative strategy addresses the COVID-19 pandemic by intervening in prevention, care, and epidemiology.

The COVIDApp tool was optimized to meet the following objectives: early identification and self-isolation of persons suspected of having COVID-19 for rapid diagnosis of positive cases by real-time reverse transcriptase–polymerase chain reaction (RT-PCR), thus minimizing the risk of transmission in long-term care facilities; remote treatment and monitoring of mild cases of COVID-19 self-isolating at nursing homes when indicated; and real-time monitoring of the progression of the infection and its consequences in these at-risk facilities.

A total of 196 care centers (169 nursing homes and 27 institutions for people with physical and mental disabilities) participated in collaboration with 64 primary care teams from the northern area of Barcelona, Catalonia (Barcelonès Nord, Maresme, Vallès Oriental, and Vallès Occidental Valles), which has a reference population of 1,986,032 inhabitants. In Catalonia, the entire population is covered by publicly financed health services, and universal care is provided by primary care teams and hospitals. Regarding long-term care facilities, although some of these facilities are private, all citizens are covered by public health services. For that reason, each long-term care facility has a primary care team of reference.

We began using COVIDApp as a support tool for the clinical response of primary care teams to the epidemiological crisis on April 1, 2020. The data reported in this paper were registered on the platform between April 1 and 30, 2020.

Endpoints

The parameters reported by health care staff at each institution with respect to all residents and caregivers were the number of persons with signs and/or symptoms of COVID-19

(suspected/symptomatic cases), number of persons with a diagnosis of SARS-CoV-2 by RT-PCR, number of residents remaining asymptomatic for more than 14 days, total number of deaths and deaths in suspected cases, number of suspected cases in health care workers, and number of isolated health care workers (confirmed cases, suspected cases, or contacts).

The number of high-risk facilities was also described. We categorized a long-term care facility as a high-risk center if it presented one or more of the following risk factors for two or more consecutive days: reporting by long-term care facility managers of difficulties managing the crisis (requiring action from local or regional authorities), reduced number of available health care professionals due to suspected or confirmed infection, lack of personal protective equipment (PPE) or need to disinfect the area, and situations where primary care teams detected that long-term care facility staff experienced difficulties complying with clinical recommendations or understanding epidemiological recommendations for prevention of new infections.

COVIDApp Functions

COVIDApp is an easily accessible mobile health app that is available in the Google Play Store for the Android platform and in the Apple Store in iOS format; the app facilitates direct communication between long-term care facilities and primary care teams. Health personnel can access the app from any computer through a webpage. However, only authorized personnel can access the back office of the app to upload patients' information.

COVIDApp provides information on facility residents in real time, including vital signs (eg, temperature, heart and respiratory rate, blood pressure, and oxygen saturation rate) and symptoms (eg, cough, expectoration, dyspnea, vomiting, diarrhea, or confusion). The platform provides a daily report of the numbers of suspected or confirmed COVID-19 cases, isolated cases, people remaining asymptomatic for more than 14 days, and deaths. COVIDApp also enables communication via chat or video between the health care team and the patient's family and can be used to send different types of messages (eg, recommendations or treatment protocols), although this tool has not yet been activated. The app is implemented using redundant servers, periodic and encrypted backups, information encrypted via transport layer security (TLS) and HTTPS, and an Amazon Web Services global cloud infrastructure.

COVIDApp functions in various stages. First, vital signs and symptoms from all suspected cases are monitored daily at an individualized frequency (1 to 3 times per day) by health personnel at the institutions and are collected in the platform in real time. An immediate alert is sent to the primary care team through activation of an alarm via the app when people develop signs or symptoms related to COVID-19. Second, following an alarm, a clinical assessment by the primary care team is planned within 12 to 24 hours. Third, after the initial assessment, several measures are recommended, as follows: preventive epidemiological recommendations such as compartmentalization of specific areas and isolation of suspected cases and contacts; measures for staff to prevent infection, including PPE; RT-PCR testing; and reassessment of isolation measures based on test results. Fourth, suspected cases are isolated until the RT-PCR test result is available (within 24 hours), and cases who test positive for SARS-CoV-2 remain isolated and quarantined, receive appropriate treatment, and are monitored twice daily. Fifth, clinical progress (vital signs, symptoms, and clinical opinion) is reported daily by the long-term care facility staff via the app. Finally, clinical treatment is provided based on an individualized care plan: mild cases receive acute and supportive treatment, severe cases are transferred to hospital, and more severe cases may receive end-of-life palliative care. All patients remain in the center, except for severe cases, who are transferred to hospital.

Results

During 30 days of follow-up using the platform, we managed data from more than 10,000 institutionalized individuals and up to 4000 health care workers. These data are a key element of the project and are shown in Table 1. The table shows the number of residents along with the percentages of centers that reported data on the platform each week. Because the numbers varied over the 30 days depending on the mobility of some residents, the number of deaths, and the number of centers reporting data daily on the platform, we present the data available at the end of each week throughout the 30-day period. The percentage of the 196 institutions that reported data was very high and increased over time, from 174 (88.8%) at day 9 to 190 (96.9%) at day 30.

Figure 1 shows the information provided by long-term care facility staff on suspected/symptomatic and confirmed COVID-19 cases over time. A rapid increase in the number of suspected cases was seen until day 6; this number remained stable until day 14 and decreased during the last 2 weeks.

In contrast, the number of confirmed COVID-19 individuals increased progressively until day 22 and remained stable during the last week. Over the 30 days, the number of residents asymptomatic for more than 14 days was stable (5,090 of 10,347 (49.2%), Figure 2).

Long-term care facilities reported a total of 854/10,347 (8.3%) institutionalized deaths during the 30 days; of these, 383 (44.8%) were suspected/confirmed cases. Figure 3 shows the progress of the deaths over the 30 days; increases were observed in both the total number of deaths and the deaths among suspected/confirmed cases during the first 2 weeks, followed by a progressive decrease. This decrease was more marked from the third week onward.

Figure 4 shows the progress of suspected cases and isolated cases by center among health care staff working in long-term care facilities. The number of isolated health care workers (suspected or confirmed cases or contact with a confirmed case) remained high over the 30 days, although the number of suspected cases decreased during the last 2 weeks; this decrease became more apparent during the last week.

The number of long-term care facilities considered to be high-risk for COVID-19 decreased progressively from 19/196 (9.7%) to 3/196 (1.5%).

Table 1. Weekly data on the number of institutionalized residents, percentages of centers that reported data on the COVIDApp platform, and number of facilities considered to be high-risk.

Week (2020)	Residents, n	Centers that reported data, n (%)	High-risk centers, n (%)
April 9	10,347	174 (88.8)	19 (9.7)
April 16	10,089	177 (90.3)	8 (4.0)
April 23	9909	187 (95.4)	5 (2.5)
April 30	9785	190 (96.9)	3 (1.5)

Figure 1. Numbers of suspected/symptomatic cases and confirmed cases of coronavirus disease among residents as reported by long-term care facility health care staff through COVIDApp over 30 days.

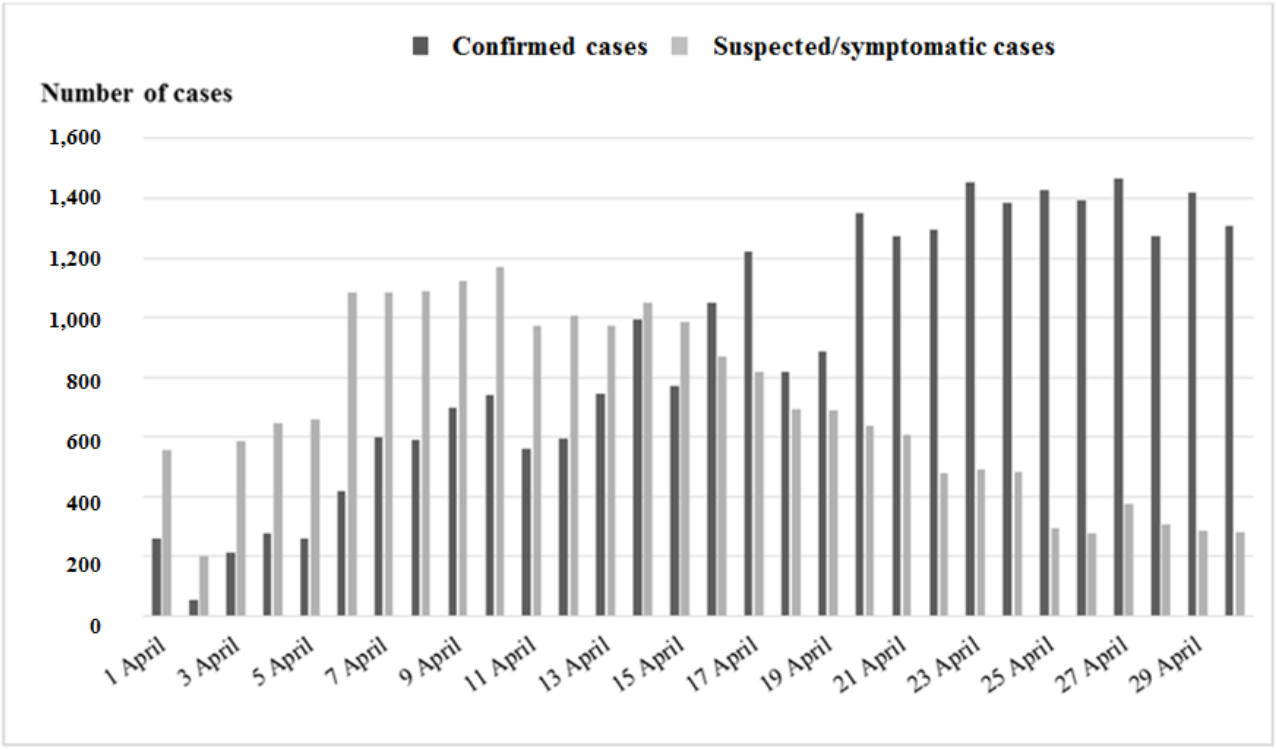


Figure 2. Numbers of residents who were asymptomatic for coronavirus disease for more than 14 days as reported by long-term care facility health care staff through COVIDApp over 30 days.

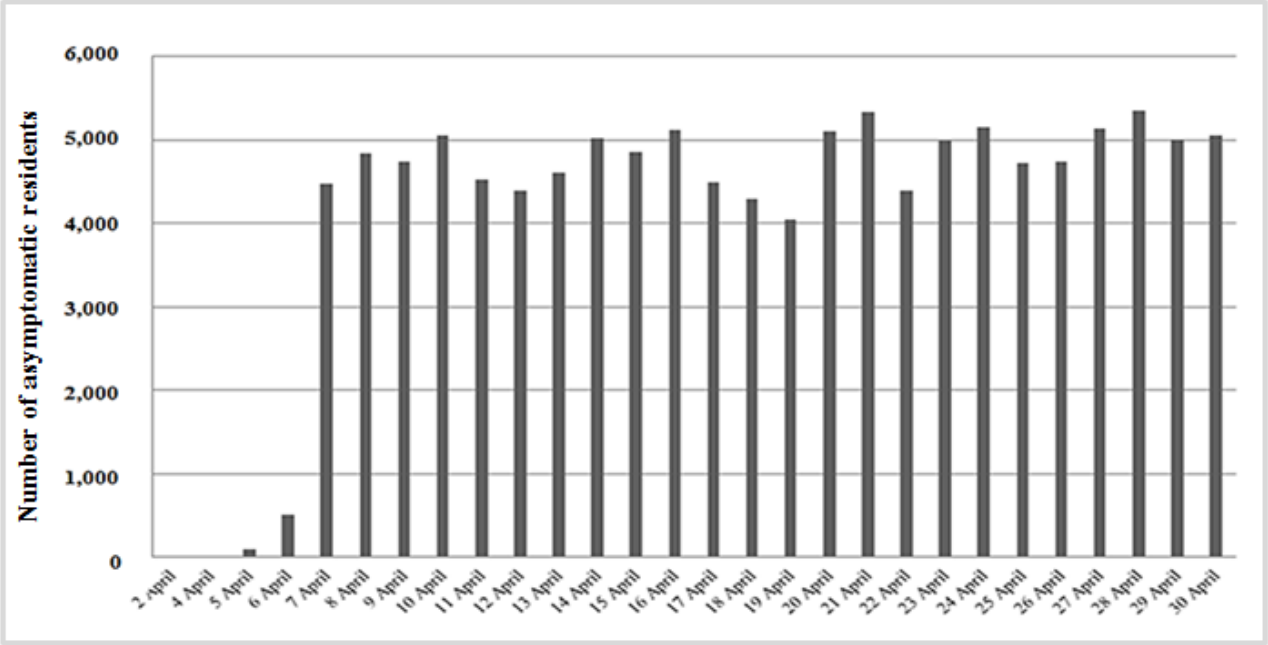


Figure 3. Total number of deaths and deaths in suspected/confirmed cases among residents, as reported by LTCF health care staff over 30 days.

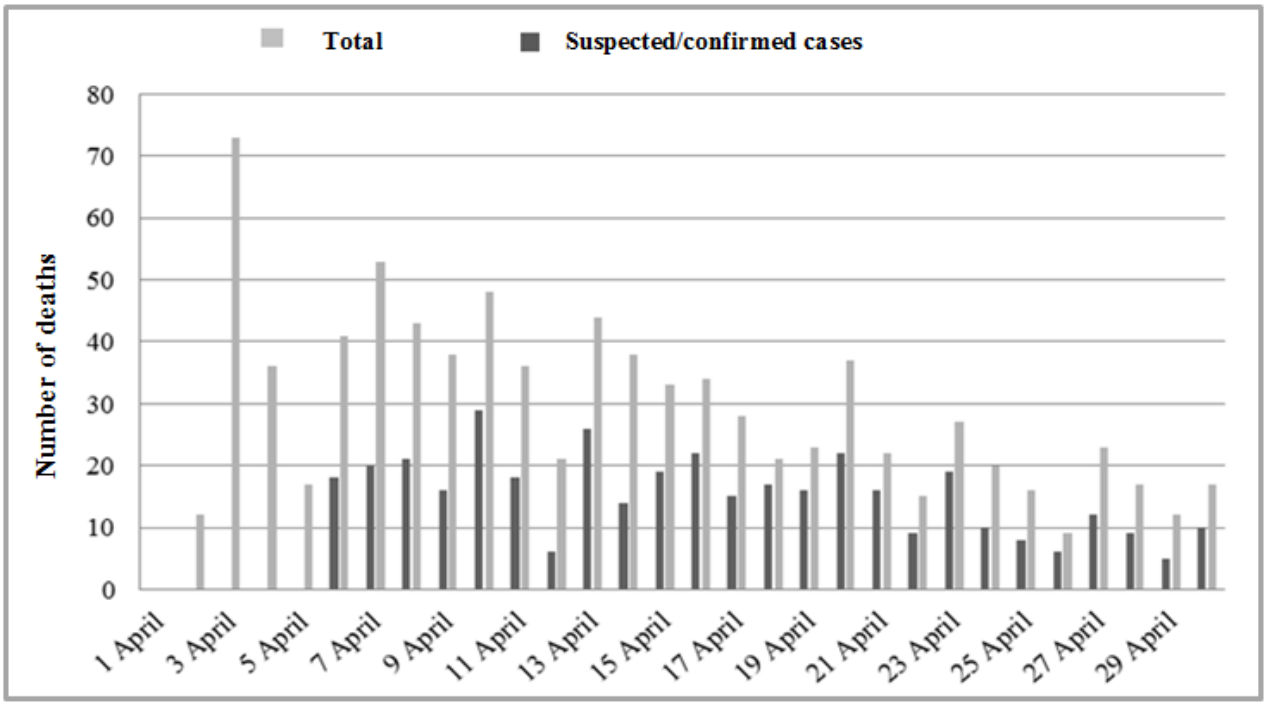
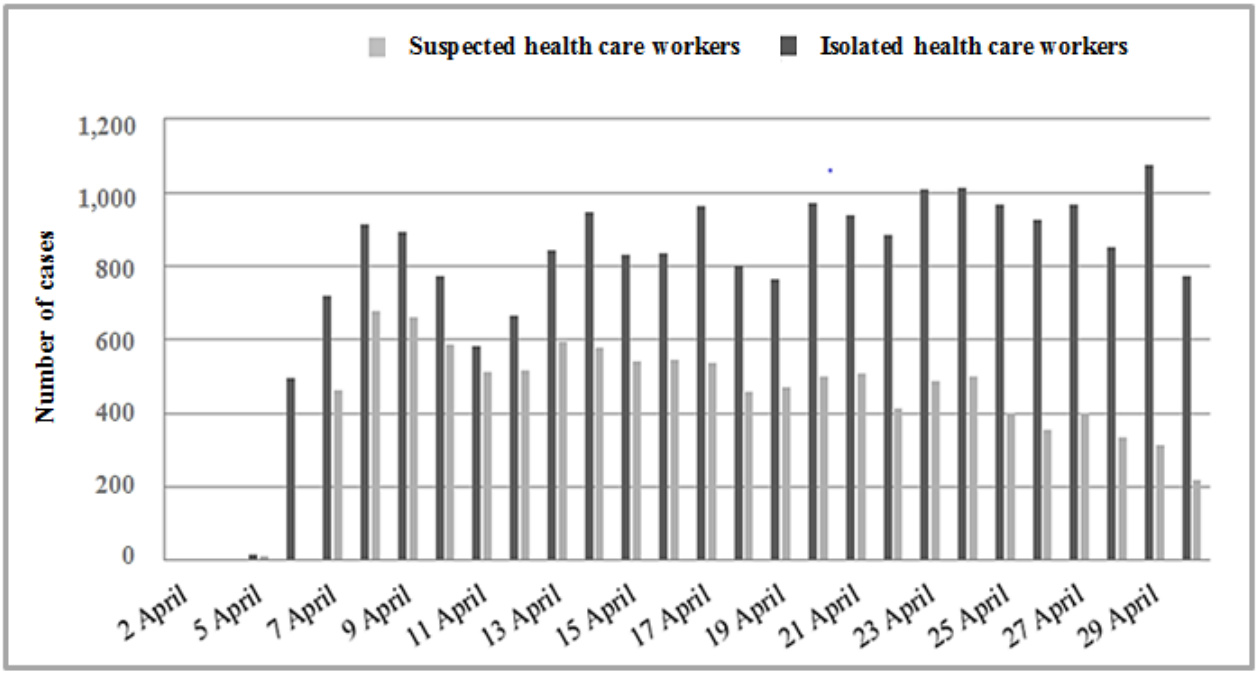


Figure 4. Number of suspected cases in health care workers and number of isolated health care workers, as reported by LTCF healthcare staff over 30 days.



Discussion

Principal Findings

Our app helped institutional staff from long-term care facilities and primary care clinicians address the COVID-19 pandemic by providing a new channel for real-time communication. The strategy was focused on 3 actions: first, early detection of suspected COVID-19 cases and rapid development of epidemiological actions such as self-isolation of suspected cases and contacts and relocation after positive or negative results; second, remote management of mild COVID-19 cases treated in institutions; and third, knowledge of progression of the infection in long-term care facilities (progress of confirmed cases, isolated and asymptomatic residents, number of isolated health care workers, and management of risk of spreading the infection in LTCF with a high number of risk factors for negative outcomes).

With data and guidelines still in development, health care professionals are fighting the COVID-19 pandemic on multiple fronts, and support tools are needed to manage the situation due to the complete saturation of national health systems (both primary and hospital care). In this context, telemedicine could be promoted for early diagnosis, patient isolation, and contact tracing. However, few data have been reported to date with respect to the use of technological platforms in the management of the COVID-19 pandemic [12-16]. Preliminary data indicates that telemedicine technologies, particularly video consultations, have been enhanced and scaled up to reduce the risk of transmission by monitoring symptomatic individuals in the United Kingdom [13] and the United States [14,15]. In France, Rolland et al [17] described the use of telemedicine to advise and support older people in nursing homes through a website that enables direct contact between a senior geriatrician and centers for older people. Much like our system, this approach enables diagnosis and monitoring of cases with COVID-19 in a care setting by mobile teams. However, no epidemiological data have yet become available from these studies.

Despite the limitations imposed by the COVID-19 pandemic, we were able to monitor the progress of the infection over 4 weeks of the pandemic in our area. We observed an initial gradual increase in the number of suspected and confirmed cases of COVID-19 with subsequent stabilization, together with a decrease in the number of deaths and an increase in the number of residents without symptoms for more than 14 days. Among health care workers, the number of suspected cases decreased during the last weeks of the study. COVIDApp enabled us to intervene proactively by isolating residents with suspected infection early and by monitoring contacts, not only among residents but also among health care workers, who are at high risk of COVID-19 infection. In this sense, the app proved to be a powerful tool for monitoring individuals living in health care institutions and the status of long-term care facilities and their health care workers during the COVID-19 pandemic. Consequently, the number of high-risk centers decreased during the study period. Monitoring centers at high risk of infection by detecting key risk factors appears to be essential if we are to minimize the spread of COVID-19 in long-term care facilities. The factors contributing to the vulnerability of these facilities were summarized by McMichael et al [18] as follows: working while symptomatic or working in more than one facility; inadequate familiarity with and adherence to standard, droplet, and contact precautions and eye protection recommendations; difficulty implementing infection control practices, including inadequate supplies of PPE and other items (eg, alcohol-based hand sanitizer); delayed recognition of cases because of a low index of suspicion, limited testing availability, and difficulty identifying persons with COVID-19 based on signs and symptoms alone.

Our strategy was based on detection and monitoring of suspected cases but also has a double epidemiological objective: to reduce transmission in a vulnerable population (residents and long-term care facility health care workers) and to monitor the progress of the infection in these centers [8,10,19]. Several authors have suggested that the consequences of insufficient response to epidemics in long-term care facilities could be severe in older persons, who are by definition frail and immunologically naïve to the virus [9,20].

Limitations

Our tool was implemented in the midst of a pandemic, which necessarily implies a series of limitations. First, data must be interpreted with caution because they are reported and registered by long-term care facility staff for use in clinical care planning, although the data were validated by the primary care teams. Second, despite our conviction of the usefulness of the tool, implementation was difficult to consolidate due to the complexity of reporting the clinical status of individuals, especially in long-term care facilities experiencing multiple difficulties managing the crisis. In the near future, it will be necessary to work more closely with the staff of these facilities to improve individual reporting of signs, symptoms, and other clinical information as well as to introduce additional functionalities of the app. The need for rapid implementation of the app resulting from the urgency of the situation enabled us to manage COVID-19 in these centers; however, continuous changes in the platform have been necessary to ensure universal implementation and to optimize clinical data (monitoring of symptoms and vital signs and inclusion of additional clinical and epidemiological data). In addition, other aspects (eg, laboratory data, adherence to treatment, and adverse events) must be tested in future analyses under conditions of clinical practice.

Conclusion

The COVID-19 pandemic has highlighted the need to optimize existing resources to prevent the collapse of health systems. COVIDApp is an innovative tool that can help clinicians rapidly detect and remotely monitor suspected and confirmed cases of COVID-19 in institutions, thus limiting the risk of spreading the virus. In addition, the platform shows the characteristics and progression of the situation in real time, thus facilitating the design of strategies tailored to a specific setting. Cost-benefit studies are necessary to measure the real benefits of such strategies.

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Authors' Contributions

PE, MAM, JP, BC, and EN participated in the conception and design of the study; MI, MM, MV, RP, YO, SP, UMP, IM, and BD participated in the acquisition of data; and all authors participated in the drafting and critical review of the submitted manuscript. All authors read and approved the final manuscript. The authors would like to specially thank JMR and JH for the development of the app and data analysis.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
PPE: personal protective equipment
RT-PCR: reverse transcriptase–polymerase chain reaction
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
TLS: transport layer security

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Original Paper

Belief in a COVID-19 Conspiracy Theory as a Predictor of Mental Health and Well-Being of Health Care Workers in Ecuador: Cross-Sectional Survey Study

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Abstract

Background: During the coronavirus disease (COVID-19) pandemic, social media platforms have become active sites for the dissemination of conspiracy theories that provide alternative explanations of the cause of the pandemic, such as secret plots by powerful and malicious groups. However, the association of individuals' beliefs in conspiracy theories about COVID-19 with mental health and well-being issues has not been investigated. This association creates an assessable channel to identify and provide assistance to people with mental health and well-being issues during the pandemic.

Objective: Our aim was to provide the first evidence that belief in conspiracy theories regarding the COVID-19 pandemic is a predictor of the mental health and well-being of health care workers.

Methods: We conducted a survey of 252 health care workers in Ecuador from April 10 to May 2, 2020. We analyzed the data regarding distress and anxiety caseness with logistic regression and the data regarding life and job satisfaction with linear regression.

Results: Among the 252 sampled health care workers in Ecuador, 61 (24.2%) believed that the virus was developed intentionally in a lab; 82 (32.5%) experienced psychological distress, and 71 (28.2%) had anxiety disorder. Compared to health care workers who were not sure where the virus originated, those who believed the virus was developed intentionally in a lab were more likely to report psychological distress and anxiety disorder and to have lower levels of job satisfaction and life satisfaction.

Conclusions: This paper identifies belief in COVID-19 conspiracy theories as an important predictor of distress, anxiety, and job and life satisfaction among health care workers. This finding will enable mental health services to better target and provide help to mentally vulnerable health care workers during the ongoing COVID-19 pandemic.

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KEYWORDS

coronavirus; 2019-nCoV; mental health; psychiatric identification; Latin America; COVID-19; conspiracy; well-being; health care worker; social media; prediction

Introduction

During the coronavirus disease (COVID-19) pandemic, social media platforms have become populated with conspiracy theories, which are attempts to explain the ultimate causes of significant social events as secret plots by powerful and malicious groups [1,2]. The most popular examples related to the pandemic include "COVID-19 was developed in a lab," "people developed COVID-19 to destroy Donald Trump's presidency," "COVID-19 is caused by 5G and is a form of radiation poisoning transmitted through radio waves," and "COVID-19 is Bill Gates's attempt to take over the medical industry" [3-5]. The latter conspiracy theory alone was mentioned 295,052 times across social media, broadcast media, traditional media, and websites during one week in May 2020 [6]. A national survey in the United Kingdom found that approximately 50% of the population endorsed conspiracy theories to some degree [5].

Individuals' belief in conspiracy theories has been linked to maladaptive personality traits [7], mental disorders, and lower well-being [8]. However, no research has studied whether a belief in conspiracies about COVID-19 is associated with mental health and well-being. This association is important because posts on social media related to specific COVID-19 conspiracy beliefs are directly assessable; hence, this information is useful to identify people with mental health and well-being issues during the pandemic. In this paper, we explore whether belief in a COVID-19–specific conspiracy theory that the disease was developed intentionally in a lab is a predictor of individuals' mental health and well-being during the pandemic. In particular, we focus on the mental health and well-being of health care workers, which is a prevalent and emergent issue during the COVID-19 pandemic [9]. The identification of belief in COVID-19 conspiracy theories as a marker of mental health issues in health care workers reveals a new channel for psychiatric screening and health communication [10], opening new avenues of research for medical informatics.

Previous research on COVID-19 has been primarily conducted in the United States, China, and European countries, and there is a need for research in low-and-middle-income countries [11]. This study focuses on Ecuador, where the COVID-19 crisis presents a particularly serious threat for health care workers given the country's scarce health care resources [12]. We surveyed health care workers in Ecuador from April 10 to May 2, 2020. During this period, there were 26,336 confirmed cases of COVID-19 and 1063 deaths; thus, the small country of Ecuador is among the countries with the highest numbers of cases and deaths per capita in the world [13].

Methods

Sample and Procedure

We conducted a web-based survey with a convenience sample that included health care workers in both urban and rural areas. We approached 401 health care workers who worked in hospitals, clinics, emergency response units, medical wards, nursing homes, dental clinics, and pharmacies in the 24 provinces of Ecuador. We received 252 completed surveys (response rate: 62.8%) from 54 health care facilities in 13 provinces (29 facilities in Carchi, 9 facilities in Quito, and 16 facilities from 11 other provinces). Therefore, our sample covered a wide range of provinces in which the severity of the COVID-19 crisis varied.

Ethical approval (20200322) was obtained from Tsinghua University. All participants provided their informed consent, participated voluntarily, and could terminate the survey at any time. The survey was anonymous, and confidentiality of information was ensured.

Measurements

We assessed the participants' sociodemographic characteristics, including gender, age, educational level, marriage status, and number of hours of exercise per day during the past week. COVID-19 status was measured by asking "Are you infected with COVID-19?" with answer options of No, Unsure, or Yes. We measured belief in a conspiracy theory specific to COVID-19 by asking participants "From what you've seen or heard, what do you think is most likely the origin of the coronavirus?" The four possible responses were 1) It came about naturally; 2) It was developed intentionally in a lab (conspiracy theory belief); 3) It was most likely made accidentally in a lab; 4) I am not sure where the virus originated [14].

We used a brief measure of generalized anxiety disorder, the GAD-7, which has been used broadly to measure anxiety [15]. The GAD-7 consists of seven questions, with a score of 10 or greater indicating generalized anxiety disorder caseness (α=.87). Psychological distress was measured with the 6-item K6 screening scale (α=.90) [16], with a score of 13 representing psychological distress caseness. We conducted logistic regression to analyze the anxiety and psychological distress caseness.

Following the example of previous research [17,18], we used life satisfaction and job satisfaction to measure health care workers' well-being. Life satisfaction was measured by a satisfaction with life scale containing five items, including "In most ways, my life is close to my ideal" (1=strongly disagree, 7=strongly agree; α=.81) [19]. Job satisfaction was measured with five items, including "I feel fairly satisfied with my present job" (1=strongly disagree, 7=strongly agree; α=.78) [20]. We used linear regression to analyze the participants' life satisfaction and job satisfaction.

Results

Descriptive Findings

Table 1 presents the descriptive findings for the survey responses of the sampled health care workers. Of the 252 health care workers who completed the survey, 61 (24.2%) believed that COVID-19 was developed intentionally in a lab; 52 (20.6%) believed that the virus came about naturally; 35 (13.9%) believed that it was created accidentally in a lab; and the remaining 104 (41.3%) were unsure where it originated.

Table 1. Descriptive findings and predictors of health care workers' mental health and well-being by regression analyses (N=252).

Variable	n (%)	Anxiety		Psychological distress		Life satisfaction		Job satisfaction	
		OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	β (95% CI)	*P* value	β (95% CI)	*P* value
Belief in the origin of COVID-19[b]									
Not sure	104 (41.3)	Reference	N/A[c]	Reference	N/A	Reference	N/A	Reference	N/A
Developed intentionally	61 (24.2)	4.76 (2.29 to 9.90)	0.000	2.44 (1.20 to 4.98)	0.014	–0.20 (–0.34 to –0.07)	0.004	–0.15 (–0.29 to 0.00)	0.036
Occurred naturally	52 (20.6)	1.62 (0.73 to 3.59)	0.239	1.08 (0.51 to 2.29)	0.834	0.01 (–0.10 to 0.13)	0.839	0.00 (–0.13 to 0.13)	0.944
Created accidentally	35 (13.9)	1.12 (0.42 to 3.00)	0.827	0.93 (0.39 to 2.21)	0.877	–0.08 (–0.21 to 0.05)	0.216	–0.09 (–0.23 to 0.06)	0.213
Marital status									
Not married	137 (54.4)	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Married	115 (45.6)	1.16 (0.63 to 2.14)	0.636	0.74 (0.41 to 1.32)	0.307	0.15 (0.04 to 0.27)	0.010	0.04 (–0.09 to 0.17)	0.522
Education		1.27 (0.91 to 1.76)	0.163	1.24 (0.89 to 1.71)	0.202	0.12 (–0.01 to 0.24)	0.076	0.04 (–0.10 to 0.19)	0.533
High school	11 (4.4)								
Technical	9 (3.6)								
Undergraduate	159 (63.1)								
Master	43 (17.1)								
Specialty	30 (11.9)								
Age (years)		0.98 (0.94 to 1.01)	0.237	0.97 (0.94 to 1.01)	0.127	0.09 (–0.06 to 0.25)	0.233	0.21 (0.05 to 0.36)	0.006
18-24	26 (10.3)								
25-34	125 (49.6)								
35-44	61 (24.2)								
45-54	32 (12.7)								
55-69	8 (3.2)								
Gender									
Female	165 (65.5)	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Male	87 (34.5)	1.44 (0.78 to 2.65)	0.244	0.96 (0.55 to 1.70)	0.897	0.10 (–0.02 to 0.22)	0.089	0.02 (–0.11 to 0.15)	0.751
Daily hours of exercise in the previous week		0.84 (0.69 to 1.01)	0.069	0.91 (0.77 to 1.07)	0.234	0.15 (0.04 to 0.26)	0.009	0.11 (–0.02 to 0.24)	0.075
0	90 (35.7)								
1	78 (31.0)								
2	27 (10.7)								
3	24 (9.5)								
4	8 (3.2)								
5	10 (4.0)								
≥6	15 (6.0)								
Infected with COVID-19									
Unsure	70 (27.8)	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No	181 (71.8)	0.60 (0.31 to 1.31)	0.113	0.60 (0.33 to 1.12)	0.110	0.14 (0.03 to 0.26)	0.016	0.11 (–0.03 to 0.25)	0.096

Variable	n (%)	Anxiety		Psychological distress		Life satisfaction		Job satisfaction	
		OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	β (95% CI)	*P* value	β (95% CI)	*P* value
Yes	1 (0.4)	N/A	N/A	N/A	N/A	–0.02 (–0.04 to 0.00)	0.084	–0.06 (–0.09 to –0.03)	0.000

[a]OR: odds ratio.

[b]COVID-19: coronavirus disease.

[c]N/A: not applicable.

Predictors of Health Care Workers' Mental Health

As presented in Table 1 and further illustrated in Multimedia Appendix 1, health care workers who believed that the virus was developed intentionally in a lab were more likely to experience psychological distress than those who were unsure of the origin of the virus. The Wald test showed that these health care workers were also more likely to experience psychological distress than those who believed the virus was created accidentally (χ^2_1=4.24, *P*=.039).

Health care workers who believed that the virus was developed intentionally in a lab were more likely to have anxiety disorder than those who were unsure how the virus originated. The Wald test showed that these health care workers were also more likely to have anxiety disorder than those who believed the virus came about naturally (χ^2_1=6.42, *P*=.011) and those who believed the virus was made accidentally (χ^2_1=8.11, *P*=.004).

Predictors of Health Care Workers' Well-Being

Health care workers who were married or who exercised for more hours in the previous week reported higher life satisfaction. Those who were not affected by COVID-19 were more satisfied with life than those who were unsure. Health care workers who believed the virus was developed intentionally in a lab had lower life satisfaction than those who were unsure how the virus originated. The Wald test showed that the life satisfaction of these health care workers was also lower than that of health care workers who believed the virus came about naturally (χ^2_1=7.80, *P*=.006).

Older health care workers had higher job satisfaction. Health care workers who believed that the virus was developed intentionally in a lab had lower job satisfaction than those who were unsure how the virus originated.

Discussion

Principal Findings

First, this study revealed that health care professionals can believe in conspiracy theories (61/252 in this sample, 24.2%). A prevalent belief in a conspiracy theory is related to high anxiety and distress of health care workers in Ecuador. Almost one-third (n=82, 32.5%) of the 252 health care workers passed the cutoff for psychological distress, and 71 (28.2%) had anxiety disorder. The proportion of psychologically distressed health care workers in Ecuador was significantly higher than that of health care workers in Iran surveyed from February 28 to 30, 2020 (20.1%, N=304) [21]. The prevalence of anxiety disorder was similar to that in a sample of 5062 health care workers (24.1%) in Wuhan, China, from February 8 to 10, 2020 [22], and higher than that in a sample of 4872 individuals (22.6%) in China surveyed from January 31 to February 2, 2020 [23].

In this study, we found that belief in a conspiracy theory regarding the origin of COVID-19 was associated with lower mental health, life satisfaction, and job satisfaction of health care workers. From a health informatics perspective, belief in a COVID-19–related conspiracy theory provides a marker to identify mentally vulnerable people, who may browse, search, follow, like, discuss, and disseminate COVID-19–related conspiracy theories via social media and other channels. This information can serve as a risk factor to identify individuals who are more susceptible to mental disorders through psychiatric screening via social media [24] at a time when psychological screening, diagnosis, and intervention are rapidly becoming web-based [25].

In addition, this study has important implications for the dissemination of scientific and health information. Previous research has recognized the important role of web-based scientific communication in combating conspiracy theories [1,26]. This study suggests that such communication should acknowledge recipients' psychological states, such as anxiety and distress, while introducing scientific hypotheses about the origin of the virus [27]. Given that people who believe in conspiracy theories tend to form clusters [4], followers of COVID-19–related conspiracy theories also provide targeted groups for scientific communication and dissemination of mental health information [10].

Finally, belief in the conspiracy theory that COVID-19 was developed intentionally in a lab was associated with reduced job satisfaction of health care workers. Given that the mental health of health care workers is important to sustain their employment and job performance [28], this study highlights the important role of conspiracy theories in assessing the mental health of health care workers, which has profound implications for their overall performance. This is especially important in settings where health care resources are already constrained, such as the COVID-19 pandemic.

Limitations and Future Research

This study has several limitations. First, the cross-sectional design limits our ability to make causal arguments about the relationship between belief in conspiracy theories and mental health. In future research, experimental designs should be adopted to establish a causal relationship between conspiracy theory belief and mental health. Second, we only focused on health care workers, whose role is especially important during

the ongoing COVID-19 pandemic in Ecuador. It is worth investigating whether the effects of belief in conspiracy theories generalize to the general population. Finally, Ecuador is a country that has been severely affected by the pandemic. The extent to which these findings are generalizable to other countries, which face different degrees of threat from the pandemic, remains to be determined. For instance, it may be interesting to investigate whether belief in conspiracy theories about COVID-19 predicts mental health in countries where the social and political systems are severely threatened by the pandemic, because system identity threat is an important cause of adoption of conspiracy theories [29].

Conclusion

This study provides the first empirical evidence that belief in COVID-19–related conspiracy theories is associated with the mental health and well-being of health care workers. Hence, belief in COVID-19–related conspiracy theories expressed on social media and in interest groups may help identify mentally vulnerable people to enable more targeted identification and communication from a health informatics perspective.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Predicted values and 95% CIs of health care workers' anxiety (GAD-7 score≥10), distress (K6 score≥13), life satisfaction, and job satisfaction.
[PNG File , 289 KB - publichealth_v6i3e20737_app1.png]

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Abbreviations

COVID-19: coronavirus disease

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Original Paper

Emergency Center Curbside Screening During the COVID-19 Pandemic: Retrospective Cohort Study

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Abstract

Background: Coronavirus disease (COVID-19) is a global pandemic that has placed a significant burden on health care systems in the United States. Michigan has been one of the top states affected by COVID-19.

Objective: We describe the emergency center curbside testing procedure implemented at Beaumont Hospital, a large hospital in Royal Oak, MI, and aim to evaluate its safety and efficiency.

Methods: Anticipating a surge in patients requiring testing, Beaumont Health implemented curbside testing, operated by a multidisciplinary team of health care workers, including physicians, advanced practice providers, residents, nurses, technicians, and registration staff. We report on the following outcomes over a period of 26 days (March 12, 2020, to April 6, 2020): time to medical decision, time spent documenting electronic medical records, overall screening time, and emergency center return evaluations.

Results: In total, 2782 patients received curbside services. A nasopharyngeal swab was performed on 1176 patients (41%), out of whom 348 (29.6%) tested positive. The median time for the entire process (from registration to discharge) was 28 minutes (IQR 17-44). The median time to final medical decision was 15 minutes (IQR 8-27). The median time from medical decision to discharge was 9 minutes (IQR 5-16). Only 257 patients (9.2%) returned to the emergency center for an evaluation within 7 or more days, of whom 64 were admitted to the hospital, 11 remained admitted, and 4 expired.

Conclusions: Our curbside testing model encourages the incorporation of this model at other high-volume facilities during an infectious disease pandemic.

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KEYWORDS

COVID-19; emergency center; curbside testing; drive-through testing; pandemic; public health

Introduction

The first case of human-to-human transmission of coronavirus disease (COVID-19) in the United States was reported on January 30, 2020 [1]. Soon after, in March 2020, the World Health Organization (WHO) declared COVID-19 a pandemic [2]. As of May 25, 2020, there have been 54,679 cases and 5228 deaths across all counties in Michigan [3]. Beaumont Health, the largest 8-hospital health system in Southeast Michigan, has diagnosed more than 7000 COVID-19 patients.

In light of this, as of March 2020, potentially overwhelming numbers of patients were expected to seek care at emergency centers (EC). In the setting of an infectious disease pandemic, this would have resulted in two major problems: (1) cross-infection and (2) additional stress on already overburdened ECs [4]. Accordingly, Beaumont Health set up one of the first EC curbside screening sites early in March 2020 in response to the COVID-19 pandemic.

There is no data yet about the curbside experience in the United States. We describe in detail the curbside screening process and

patient outcomes, including EC visits for evaluation, admissions, and mortality. We hope that this information will help other health systems implement similar processes early, safely, and efficiently.

Methods

EC curbside services were implemented at all 8 hospitals at Beaumont Health during the COVID-19 pandemic. We report the curbside experience from the largest hospital in the system, Beaumont Hospital, in Royal Oak, MI, from March 12, 2020, to April 6, 2020.

The study protocol was approved by the Institutional Review Board at Beaumont Health System.

Preparation Phase: Project Planning

Beaumont Health anticipated a surge of patients, so the implementation of a screening process became a priority for the health system. We obtained the appropriate approvals within 24 hours and created a multidisciplinary team of health care workers predominantly from the EC, including physicians, advanced practice providers (APPs), residents, nurses, technicians, and registration staff. Additional redeployment of APPs from the inpatient setting helped supplement staffing as needed. An organizational structure for traffic control and security was developed. We chose the EC location as we knew that many patients would be driving up to the EC to seek care. Patients were registered as active EC patients, and documentation was done via the electronic medical record (EMR), including a provider note. All aspects of this process were compliant with the Emergency Medical Treatment and Labor Act and adhered to the Centers for Medicare & Medicaid Services guidelines [5] regarding medical screening exams conducted in an alternate site of care. Data were automatically extracted from the EMR.

Implementation Phase

Pilot Phase

Beaumont Health began curbside testing on March 12, 2020, at its largest campus in Royal Oak, MI. The service was then expanded to the other hospital-based ECs in the health system. Testing was done with real-time reverse transcriptase–polymerase chain reaction (RT-PCR) assay of nasopharyngeal swab. A website was developed to better inform patients about curbside testing and its process and to display patient wait times at each location [6].

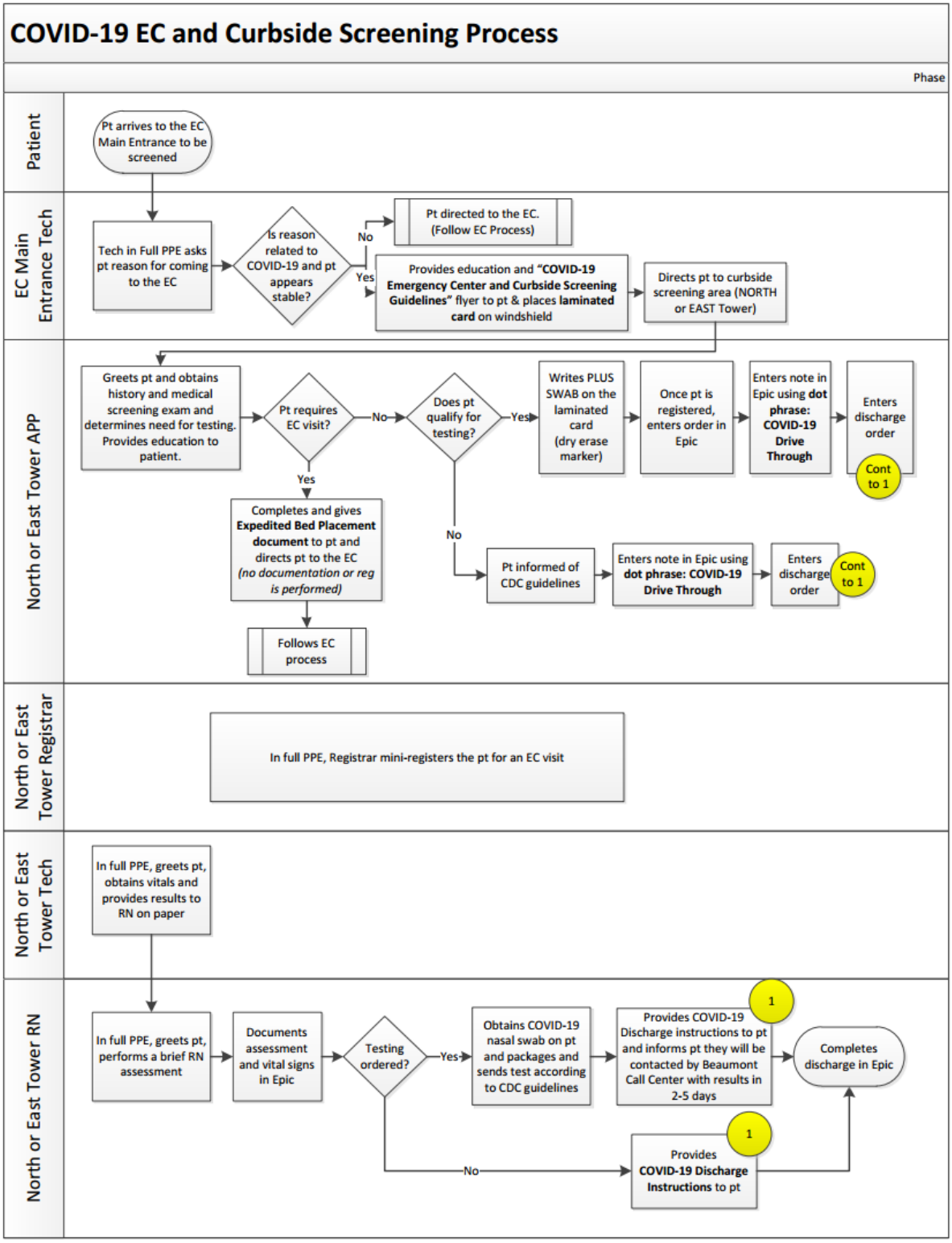
Curbside Experience at Beaumont Hospital

Patients required no referral and remained in their vehicle during the entire curbside screening process. In summary, patient flow (Figure 1) started with the EC main entrance tech personnel, who directed patients to a designated curbside location (East or North Tower). The patient would then see an APP, registrar staff, tech staff, and finally a registered nurse, who would eventually discharge the patient. All patients seeking emergency care were initially asked by the EC tech personnel if testing was the purpose of their visit, and if so, they were sent to the curbside location. After a few days, the EC tech personnel was replaced by a midlevel provider or a resident who stayed at the front door and triaged patients to either curbside screening or EC admission. A laminated card was placed on the windshield. APPs carried a dry erasable marker and marked initials on the laminated sheet to indicate who was caring for which patient as registration was occurring simultaneously.

Testing was done based on system capabilities. Initially tests were readily available. Later on, as testing capacity became scarce, we were only able to perform screening for a higher level of care, which meant, based on the Michigan Department of Health instructions [3], that testing was offered if patients experienced moderate cough or fever over 100.4°F, and if the patients had chronic kidney disease; heart disease; diabetes; chronic lung disease; were receiving immunosuppression medication, or were immunocompromised due to cancer treatment, recent surgeries, or other conditions, suggesting high risk for severe disease. As volumes grew rapidly, we moved the location to a main hospital entrance that was not being used during the COVID-19 outbreak, which allowed a reprieve from the weather and increased operational capacity (hot, warm, cold zones; electrical access, etc). We were able to see a large volume of patients without backing up the main emergency department entrance. Also, to avoid long wait times, we opened multiple triage and screening locations based on the surge of patients and also streamlined documentation, increased staffing, and processed in parallel instead of serially.

All patients were discharged home with instructions pertaining to COVID-19. Initially physicians called patients to provide test results, but later the process was transferred to a central location within the health system. During peak volume, there was a 7-hour wait to reach the front of the curbside line until further improvements were made to the process.

Figure 1. Layout of the emergency center curbside screening process at Beaumont Hospital in Royal Oak, MI. EC: emergency center; CDC: Centers for Disease Control and Prevention; PPE: personal protective equipment; COVID-19: coronavirus disease; APP: advanced practice provider; RN: registered nurse.



Personnel Duties, Personal Protective Equipment, and Hygiene Rules

APPs did not come into contact with patients but screened them from outside the car for history and general appearance and reviewed vital signs. Gloves were removed and hand hygiene performed before entering the warm zone for documentation; hand hygiene and new gloves were used before returning to the outdoor area. Personal protective equipment (PPE) comprised the following: N95 mask, face shield, surgical mask, gown, and gloves. Nursing personnel only came into contact with patients if performing nasopharyngeal swab. Proper doffing after swab was obtained and all PPE was changed except for the N95 mask. Of note, at peak volume times, we had 1-2 nurses dedicated to

doing swabs. PPE comprised the following: N95 mask, face shield, surgical mask, gown, and gloves. Tech staff performed vitals. Hand hygiene and changing of gloves were performed in between patients. PPE comprised the following: N95 mask, surgical mask, gown, and gloves. Registration staff changed gloves and performed hand hygiene in between patients. PPE comprised the following: N95 mask, surgical mask, gown and gloves.

Results

Process Analysis

A total of 2782 patients were seen through the EC curbside at the Royal Oak campus during a period of 26 days. A nasopharyngeal swab was performed on 1176 patients (41%), which came back positive for 348 patients (29.6%). The median time for the entire process (from registration to discharge from the electronic medical system) was 28 minutes (IQR 17-44). The median time from when the medical diagnosis and disposition decision were made to completion of EMR documentation was 9 minutes (IQR 5-16). The median time spent per patient from registration to final medical decision was 15 minutes (IQR 8-27). The overall potential EC burden was decreased significantly by 90.8%.

Patient Outcomes

Outcomes were assessed as of April 13, 2020. Only 257 patients (9.2%) returned to the EC for an evaluation within 7 or more days, out of which 64 patients (24.9%) were admitted to the hospital. In total, 11 (17.2%) patients are still currently admitted, and 4 (6.2%) admitted patients have expired.

Discussion

Principal Findings

Based on our experience and previous published literature [7], we worked to address process limitations as they became apparent during curbside testing implementation. An important limitation that many facilities across the nation also faced was limited testing availability [8]. We developed educational materials, with information on when to get tested, that were available on our website. We also had phone and online screening questionnaires that were used to determine if a person needed to present for curbside testing. A facility should address this limitation by working to inform the population about limitations in resources and selective testing capabilities with focus on patients who are considered at increased risk of developing severe disease [5]. We anticipate that this problem will be mitigated as testing becomes more readily available. While we initially had long wait times for testing, we opened multiple triage and screening locations based on the surge of patients and also streamlined the documentation process, increased staffing, and processed in parallel instead of serially in order to address this issue. We also had to create solutions to caring for medically unstable patients. We recommend having a separate triaging location from the screening location in order to identify patients at high risk for severe disease and direct them in a timely manner to receive traditional EC care. In addition, we tested patients in early spring, which is often associated with cold temperatures in Michigan. A large outdoor space was required for this curbside model in order to mitigate the high risk of contagiousness. However, an area with warming potential needs to be chosen to ensure the protection of personnel from the outdoor conditions. This will become relevant if another wave of COVID-19 occurs this upcoming fall and winter. We did not record and quantify the number of patients that were triaged and sent straight to the EC to be evaluated; therefore, we cannot report on the actual number of patients who sought EC curbside testing in the first place.

Conclusion

Curbside screening has been shown to be safe for COVID-19 patients. The process is also efficient, with a median of 15 minutes spent per patient from registration to final medical decision. Our findings support the incorporation of this model at other high-volume facilities during an infectious disease pandemic.

Acknowledgments

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Conflicts of Interest

None declared.

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Abbreviations

APP: advanced practice provider
CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
EC: emergency center
EMR: electronic medical record
PPE: personal protective equipment
RT-PCR: reverse transcriptase–polymerase chain reaction
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Viewpoint

Public Health Strategies for the Gradual Lifting of the Public Sector Lockdown in Jordan and the United Arab Emirates During the COVID-19 Crisis

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Abstract

In this viewpoint, we present public policies and public health strategies for a gradual lockdown lifting during the coronavirus disease (COVID-19) crisis in two country cases, Jordan and the United Arab Emirates. While managing pandemics is critical in terms of preparedness, response, and recovery, it is equally vital to ensure that the measures for a lockdown exit are both efficient and effective. It is critical to learn from first-wave lessons to systematize responses during times of crisis and execute appropriate public policies and public health strategies. This viewpoint highlights the importance of the following during lockdown lifting: pandemic control, health care capacity, training, scaling up of resources and systems, and priority setting of public policies by acknowledging challenges, developing policy insights, and setting the policy direction. The systematic approaches and leadership thinking required for lifting lockdowns during a crisis include the three Rs: *Readiness, Responses,* and *Resilience & Recovery.*

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KEYWORDS

COVID-19; health policies; lockdown; recovery; exit strategy; public sector; Jordan; United Arab Emirates

Introduction

About 5 million people have been infected with coronavirus disease (COVID-19) worldwide, with over 324,000 deaths as of May 20, 2020 [1]. According to the latest World Health Organization (WHO) situation report, the United Arab Emirates (UAE) has entered the community transmission phase of the pandemic with 25,063 confirmed cases and 227 deaths as of May 20, 2020, while Jordan has contained clusters of cases with 649 confirmed and 9 deaths [1]. The overall goal while lifting the lockdown is a continued reduction in the incidence of COVID-19 cases in the absence of a pharmaceutical intervention such as vaccine and medical treatment. It is critical to learn from first-wave experiences to systematize responses during times of crisis. As the situation continues to evolve, public policies will similarly have to adapt to accommodate and mitigate this change and better serve their purpose of protecting the well-being of the population [2]. Reorienting health system priorities and public sector systems to be proactive, preventive, and protective [2-4] will allow us to stay ahead of the curve, not just attempt to flatten it. Most countries, including Jordan and the UAE, have been recently moving from the "response" phase of epidemic management to the "recovery" phase; therefore, one of the many strategies for consideration is the lifting of the public sector lockdown. The approach of this viewpoint on lockdown exit strategies and recommendations for public sector institutions is based on a review of current practices, initiatives, and studies in Jordan and the UAE.

The COVID-19 Situation in Jordan and the UAE

According to the Ministry of Health in Jordan, the first confirmed case was reported on March 2, 2020 [5]. The number of cases suddenly increased to 8 starting on March 15 and has been rising since then. According to the World Health Organization (WHO) Situation Report #83 released on April 12, 2020, Jordan was classified as having a "cluster of cases" transmission for the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) [6]. To control this imminent threat, Jordan has enforced infection prevention and control measures and activated the National Epidemiology Committee. As of March 17, 2020, the government called for social distancing, halted all forms of inbound and outbound movement/international travel, and enacted the Defence Law, which transferred the authority to the Minister of Defence to work and formulate orders in response to the situation [3,4]. The National Crises Management Center in coordination with government bodies took over the enforcement, follow-up, and implementation of the Defence Law orders. Consequently, a national curfew was ordered to ensure complete country isolation [3,4]. It also ordered a lockdown on all border arrivals to the country before March 17 from pandemic countries, and administrative governorates were isolated from each other. Awareness messages were targeted at children and adults older than 60 years [3,4]; they were placed under strict stay-at-home measures and their caretakers were not permitted to accompany them outside the home for any reason except in an emergency. Confirmed and suspected COVID-19 cases from airport arrivals by March 17 were isolated in hospitals under the strict supervision of qualified medical staff [3,4]. Moreover, the government immediately took measures to ensure the preparedness of the health sector. Instantly, equipment and supplies necessary for diagnosis were ordered and put at the disposal of the National Crises Management Center [3,4]. Vigorous efforts were exerted to detect and track cases and contacts by outbreak surveillance teams at the national and governorate levels in order to contain the spread of the virus and to isolate cases. The ultimate goal of Jordan was to flatten the disease spread curve in order to increase the capacity of the health system to absorb new cases [3,4].

In the UAE, the current widespread physical distancing and lockdown measures taken and the ramping up of testing have been successful in identifying new cases of COVID-19. However, the average number of new cases (from April to May) is estimated at 300-500 per day and rising [1,2,7]; it may still prove early for the country to ease its restriction measures. At this point, planning a cautious and responsive "exit strategy" is appropriate, but there remains a need for an even stronger capacity to test, retest, identify, quarantine, trace, and isolate contacts. In order to suppress transmission, public health and social measures should continue both at the individual and community levels. Individuals will need to maintain movement restriction measures at their own discretion, wear masks in public places, and maintain a 2-meter distance; international travel restrictions will continue to be implemented [1,2,7]. It is unknown how long this pandemic will continue, and the possibility of a surge in COVID-19 cases once restrictions are lifted is likely. It is advised that the government consider lifting restrictions when the number of new cases drops to 40-50 per day, with strict surveillance controls and 14-day intervals to identify the effects of loosening lockdown measures [1,2,7]. In reality, even the best plan may be insufficient, such as in the case of Singapore where lockdown measures were lifted after initial success and then reinstated due to a surge in cases [1,2,7]. Until effective pharmaceutical interventions (therapies and vaccines) are made widely available, the UAE will need to continue alternating between loosening and reinstating measures throughout this pandemic [1,2,7].

Lockdown Lifting Overview

In an ideal situation, the requirements for lifting the lockdown would include the following:

1. Control the spread of the virus in a way that ensures a continuous reduction in new cases and a decrease in reproduction rate (R0) to less than one (ie, on average, each COVID-19–infected person may infect one other person or less over the most extended possible period) [8]
2. Preparedness of public health and curative services to contain all new cases and the contact spread chain, whether from a local source or for those who come from abroad, through the following measures [9]:
   - The ability to epidemiologically detect suspected cases within 48 hours of the appearance of symptoms
   - The ability to effectively isolate all diagnosed cases in hospitals or identified facilities
   - The ability to detect, trace, quarantine, and monitor the close contacts of suspected or confirmed COVID-19 cases
3. The reduction of the potential spread of COVID-19 in congregated settings with a large number of people that are in close contact in the most vulnerable populations and areas such as nursing homes, nurseries, kindergartens, schools, universities, restaurants, religious or entertainment events (ie, minimizing outbreak risk in these settings)
4. The ability to manage evacuated returnees and those crossing the border (eg, shipments) to minimize the risk of spreading the epidemic (importation risk management)
5. The community and citizens should be aware of the measures to be taken when responding to the lockdown lifting; commitment and collaboration by identifying and reporting any new cases and cooperating to prevent the spread of the disease in large numbers is needed [8].

It is paramount to consider the notions of priority setting of public policies when it comes to lifting the lockdown via acknowledging the challenges, developing policy insights, and setting the policy direction [7,10].

Strategies for Lifting the Public Sector Lockdown

Jordan and the UAE have already started the gradual lifting of the lockdown for private businesses and in some industries and

local communities. The timing of movement regulations during the lockdown implementation is a critical element since access to public services and offices were restricted. As an effort to partially lift the lockdown measures, movement was allowed during specific times in both countries. During the lockdown, there were restrictions in terms of moving to and from public sector offices; only essential employees were permitted to move during the usual working hours of the public sector. In Jordan, the public sector lockdown exit began by permitting citizens to leave homes between 10 AM to 6 PM for reasons including visits to essential public offices (eg, to obtain medications for chronic patients). Meanwhile, in the UAE residents are allowed to leave their homes between 6 AM and 10 PM without a permit, which includes visits to essential public offices (eg, justice, foreign affairs, education, health, residency, infrastructures, municipalities, and judiciary).

It may not be necessary to wait for all the ideal requirements for lifting the lockdown to exist to open up public sector institutions. Accordingly, we provide our perspective on the most important strategies that may enable the opening process to achieve the overall goal of continuous reduction in the spread of the disease (case incidence) while gradually restoring normal life for society and the economy. The proposed strategies should be implemented slowly in stages, and an epidemic situational assessment should be completed at each stage to ensure there are no new cases detected. Once the stage proves successful, the next step can be implemented. If the epidemic situation were to worsen, it will be possible to resume lockdown measures.

What Strategies Need to Be in Place?

The lockdown, which was initiated around mid-March and has lasted strictly until about the end of April, has caused much economic and social suffering, especially for the self-employed sector, big businesses, private clinics, and disadvantaged groups. Many have demanded a rapid lifting of the lockdown, which was considered and done gradually. However, the public sector, including health, higher education and vocational training, transport, etc, remained almost completely inaccessible. This viewpoint addresses the public health strategies and recommendations for the gradual lifting of the lockdown in these sectors.

The systematic approaches and leadership thinking required for lifting lockdowns in times of crisis include the three Rs: *Readiness*, *Responses*, and *Resilience & Recovery* (Figure 1). The first phase, *Readiness*, focuses on coordination, training, and preparedness; the second phase, *Responses*, refers to laws, engagement with the public, communities and civil society, and policing; and the third phase, *Resilience & Recovery*, involves documenting lessons learned and building resilience plans for the future. Below, we outline 12 recommendations and strategies for lifting the lockdowns with examples from Jordan and the UAE.

Figure 1. The 3 Rs of systematic approaches and leadership thinking required for lifting lockdowns.

Phase 1: Readiness

1. Coordination of Emergency Task Forces

This step involves coordination between the local COVID-19 National Disaster Management Committee and the National Infection Control Committee in addition to the various ministerial government departments in order to manage and coordinate the opening process and public sector lockdown lifting nationally.

2. Training and Capacity Skills Building

This involves the provision and training of sufficient numbers of COVID-19 investigation teams qualified to [9,11]:

- Conduct random COVID-19 testing of high-risk groups, in hot spots, and in different institutions that have a high population density (eg, nursing homes, institutional homes, refugee camps, labor accommodations, and labor camps)
- Scale up and continue contact tracing
- Carry out random testing of communities, industries, and institutions to detect asymptomatic cases
- Conduct sentinel surveillance of the workforce at different workplaces

These measures aim to ensure that the spread of the virus is under control and that there is an ability to detect and isolate new cases that may arise due to rapid reopening and to quarantine their contacts. It also will provide insight into how much herd immunity has been achieved. The most important criteria that should be monitored while applying this strategy are:

- The occurrence of an unexpected spike in new cases
- Continued reduction in the number of cases from unknown sources
- Rapid identification and control of hot spots and proper control of cases and their contacts

3. Increase Preparedness for Health Resources

This involves raising the preparedness of available public laboratories and their technical and working staff and, when necessary, train and seek assistance from the private sector, retirees, and relevant, unemployed laboratory science graduates to accommodate the expected increasing number of COVID-19 polymerase chain reaction (PCR) diagnostic tests needed. The customary protocol requires conducting 152 screening tests per 100,000 people daily [12,13], which may be difficult to carry out in low-resource settings such as Jordan; however, over 140,000 COVID-19 tests have been completed with a ratio of 13,760 tests to 1 million people conducted throughout the crisis period [13]. In the UAE, there are over 1.5 million completed COVID-19 tests with a 158,000 to 1 million people test ratio [14-17]. However, these figures indicate the large effort and burden needed to apply this strategy, including:

- Providing large numbers of test kits
- Training the field infection investigation team staff on COVID-19 field sample collection protocol and other laboratory technicians on the procedures associated with running COVID-19 test in laboratories
- Ensuring safety and personal protection measures for staff

4. Increase Preparedness for Health Services

This entails increasing the preparedness of hospitals and other curative service delivery posts by at least 20% to accommodate possible increases in the number of new cases requiring medical care at the national level. The construction of field hospitals is evident with a bed capacity of up to 3000 in the case of the UAE [7].

Phase 2: Responses

5. Legislation and Laws

This involves managing reopening at the provincial level by promoting the activation of the Decentralization Law or any relevant local government legislation. The experience of Jordan in managing the COVID-19 crisis in some governorates such as Irbid and Alaqaba was proven to be successful through contact tracing. This experience can be expanded to delegate the management of the opening-up measures at local levels to the local government and local executive boards. A thorough involvement of local community stakeholders who know which sectors have the highest priority to be opened is needed. Depending on the situation in each province, brigade, and locality in Jordan, and with continuous daily coordination at the national level, a more community-oriented lifting strategy may need to be achieved. Therefore, the roll-out strategy is to gradually increase the percentage of employees returning to public offices. Recently, in the UAE, a small number of public sector staff were allowed to work from the office, but this should not exceed 30% of the total number of employees [14].

6. Public Engagement

The effective involvement of the communities, stakeholders, and individuals in the opening-up strategies across the public sectors is paramount. This strategy will encourage their serious buy-in commitment to reduce the number of new cases. They can be empowered to be actively involved in monitoring the case incidence by providing and encouraging innovative methods to report on suspected cases in person through private electronic platforms or to report on suspected cases in the workplace or among friends and family via other methods such as social media communication and different modes (event-based surveillance) and public information [16].

7. Public Awareness and Education

It is paramount to effectively communicate with the public about the situation and policy measures in a timely manner to raise awareness levels. In addition, increasing health awareness by providing health education and public safety information to the public is needed. This responsibility falls on public, private, and civil society institutions alike (a holistic government-society approach) [18]. While it is expected that the leading role of raising health awareness of the disease and methods of social distancing lies on the shoulders of the Ministry of Health, all the public institutions that will open up have a significant role in raising awareness about the disease, and implementing social distancing measures [19] and personal protection measures using scientific models such as the Health Behavior Model. All institutions should be aware of their role in providing guidance on personal protection measures, social distancing, and in identifying the most critical symptoms of the disease and reporting suspected cases or their contacts, implementing self-isolation for a minimum of 14 days, and carrying out further tests to ensure negative results. For instance, citizens in Jordan and the UAE during the postlockdown period were required to not leave the house, with exceptions made for daily walking (Jordan) and exercise (UAE), grocery shopping, and other essential trips. Furthermore, there is evidence of coordinated public information campaigns (eg, across traditional and social media) [14,16]. Health awareness and promotion can be done in a comic way, a method that has proven to be effective in changing health behavior, especially in men (humorous persuasion) [20]. It can also be done by using religious symbols

meaningful to some groups of society to reach most social classes, geographical areas, and working environments and institutions.

8. Civil Society Institutional Awareness

This consists of involving civil society institutions in all phases of the opening process. The public sector is an essential partner in this crisis either in terms of raising awareness and field education for families and local communities or by involving them in infection field investigation measures. However, in the latter, they should receive adequate training in reporting suspected cases and in tracing their contacts. Civil society can also contribute to providing essential services to vulnerable populations in Jordan and the UAE, such as refugees, people with special needs, the elderly, orphanages, and other workers. According to the latest reports from the UAE's Ministry of Health & Prevention [13], more than 97,645 workers from 31 labor accommodations were tested, and contact tracing for COVID-19 was implemented; a few of these cases were found to be positive.

9. Judicial Policing

This involves activating the role of the "judicial police" and giving them the authority to refer establishments, institutions, or individuals who do not comply with personal protection measures and social distancing to the relevant authorities under the activated emergency legislation. Strict government policy adherence in Jordan and the UAE is vital, especially those related to school closures, workplace closures, cancellation of public events, restrictions on public gatherings, closures of public transport, stay-at-home requirements, general information campaigns, restrictions on internal movements, and international travel bans [16]. For instance, according to local UAE reports, Sharjah Police recently issued 3901 fines for violating movement restrictions, and in Dubai fines amounted to 52,000 for violating restrictions [21]. Such measures will make lifting the lockdown easier as they will ultimately reduce the case incidence and help the government to resume its activities gradually in a safe environment.

Phase 3: Resilience & Recovery

10. Resume Life and Document Lessons Learned

This step involves taking advantage of the comprehensive database found in some public and private institutions that show population data at the level of neighborhoods to document lessons to be learned [4]. In addition, it is essential to highlight how different services are distributed in each area, in addition to the resources available in local communities and at institutions, so that each area can function independently and facilitate the use of health and nonhealth services to detect and isolate cases, trace contacts [15], and quarantine suspected cases easily [7].

11. Health Resilience and Surveillance Assessments

This strategy involves restarting the provision of public services at the national and local levels. This will decrease the burden on the secondary care level, which needs to be ready for a possible increase in the number of COVID-19 cases [19]. In the UAE, telehealth services have been implemented during the COVID-19 outbreak; such telehealth services should be continued in order to lessen the burden of health care services if confirmed cases were to increase [7].

12. Public Policy and Priority Setting

This involves setting criteria for lifting the lockdown beginning with vital public sectors such as health and food security followed by other sectors in a gradual manner that provides enough time after reopening to detect any new or suspected cases and their contacts [7,9]. The standard strategy is to resume lockdown procedures if the epidemic situation worsens. The proposed criteria that may be used depends on:

- The contact intensity and density; that is, either high-risk exposure contacts who have spent 15 minutes or more in close proximity (≤2 meters) or in a closed environment; or low-risk exposure contacts who are still at risk but who have not been exposed to a confirmed case for as long;
- The number of persons or crowd number (contact number), which is given a value that ranges between high, medium, and low [7,21]; and
- Crowd reduction (risk modifying likelihood ability), which describes the institution's ability to introduce measures such as spatial or physical distancing into a space that will control the number of people in contact within a distance of 2 meters. These criteria are also given a value that ranges between high, medium, or low.

Based on the assessment of these three criteria and consensus on the value, vital sectors can initiate reopening while active monitoring and case detection are continuously exercised and kept in line with the criteria mentioned above.

The Way Forward

It is critical to reinforce the notions of priority setting of public policies and public health strategies when it comes to lockdown lifting nationwide and keep in mind the challenges that may lie ahead. Thus, it is important to have mobilized teams in place for developing policy insights and setting the policy direction [22] and execution. Once the lockdown is lifted, the way forward for Jordan as well as the UAE would be to have policies in place to increase public awareness and implementation of the most important public health measures with a focus on physical distancing and personal protective equipment. Both countries should also increase the number of PCR tests, particularly for vulnerable populations and areas, and strengthen contact tracing measures. Preparation in terms of health system secondary care facilities, equipment, and supplies, in addition to an adequate number of trained and skilled health workers, is a must in light of a potential COVID-19 resurgence.

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Authors' Contributions

RAQ and IAM conceptualized and led the study as the primary investigators and wrote the manuscript. MRT, MAN, and YK conceptualized the study, reviewed the literature, and contributed to the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
PCR: polymerase chain reaction
R0: reproduction rate
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
UAE: United Arab Emirates
WHO: World Health Organization

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Viewpoint

Digital or Digitally Delivered Responses to Domestic and Intimate Partner Violence During COVID-19

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Abstract

Before the coronavirus disease (COVID-19), 1 in 3 women and girls, globally, were victimized by an abusive partner in intimate relationships. However, the current pandemic has amplified cases of domestic violence (DV) against women and girls, with up to thrice the prevalence in DV cases compared to the same time last year. Evidence of the adverse effects of the pandemic on DV is still emerging, even as violence prevention strategies are iteratively being refined by service providers, advocacy agencies, and survivors to meet stay-at-home mandates. Emotional and material support for survivors is a critical resource increasingly delivered using digital and technology-based modalities, which offer several advantages and challenges. This paper rapidly describes current DV mitigation approaches using digital solutions, signaling emerging best practices to support survivors, their children, and abusers during stay-at-home advisories. Some examples of technology-based strategies and solutions are presented. An immediate priority is mapping out current digital solutions in response to COVID-19–related DV and outlining issues with uptake, coverage, and meaningful use of digital solutions.

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KEYWORDS

COVID-19; pandemic; mental health; digital interventions; technology; coronavirus; domestic violence; prevention; abuse; intimate partner violence

Domestic Violence and COVID-19

Violence against women and girls remains a social justice, human rights, and public health issue. Domestic violence during the coronavirus disease (COVID-19) pandemic has been aptly described as a "shadow pandemic," by the Executive Director of United Nations (UN) Women. This is in light of local and global emerging statistics that show exponential spikes in domestic violence (DV) incidents (compared with the same period last year) [1-5]. From high-tech cities to low-tech rural areas across the world, there have been noted COVID-19–related upsurges in crisis calls to law enforcement and DV hotlines since the first week of the lockdowns [1-5]. The usual channels of support are now jeopardized by stay-at-home and social distancing mandates, so DV victims, many of whom are sequestered with their abusers, must find alternative means of support and safety, hence the focus on digital and technology-based DV mitigation strategies.

Accordingly, this perspective piece rapidly reviews evolving digital responses to DV in the wake of the COVID-19 pandemic. Specifically, this paper describes emerging best practices to support survivors, their children, and even abusive partners during stay-at-home advisories. Some examples of technology-based strategies and solutions are presented, and the paper concludes with emergent priorities including the need to map out current digital solutions in response to COVID-19–related DV, even as we outline new and old issues with the uptake, scope, and meaningful use of these digital solutions.

Before COVID-19, 1 in 3 (or 243 million) women and girls, globally, experienced violence by an abusive partner in intimate and casual relationships [6,7]. However, this pandemic has amplified domestic and intimate partner violence against women and girls, with increasing spates of physical, psychological, and sexual violence, and other co-occurring violence typologies (eg, child abuse, elder abuse, pet abuse, femicide, cyberviolence,

stalking, and financial abuse) [8-10]. Besides, a current proliferation of gun and ammunition sales as families brace for COVID-19–related uncertainties have led to worrying fears of increased femicide (the intentional murder of female partners) since lockdown mandates were established [2,3]. Newer forms of partner abuse have also emerged, including reports of violent abusers threatening to infect a partner or their children in the home with the coronavirus.

No doubt, although DV survivors and victims are now dangerously sequestered with an abusive partner and are enduring adverse physical, psychological, social, and economic conditions [11-15], emergent mental health outcomes will be exacerbated by lockdown mandates. Current social distancing and stay-at-home mandates will also amplify pre-existing depression, anxiety disorders, suicidal ideation [12,15,16], panic disorders, posttraumatic stress disorder [17], as well as other mental and psychosomatic distress reactions (eg, insomnia, hyperarousal, avoidance, numbing, obsessive-compulsive disorder, and personality disorders) [18]. Within communities, epidemiologic evidence shows an intensification (ie, increased prevalence and severity) of other forms of gender-based violence including rape, sex trafficking, female genital mutilation or cutting, and early or child marriages during and immediately after catastrophic events of this magnitude [2,3,9,19-22]. The usual support networks for survivors have been compromised, as DV service providers contend with new and extraordinary challenges related to this pandemic. This disruption in the delivery of essential services has prompted growing calls for evidence-based, free, low-burden, and scalable digital solutions that reach survivors where they are in response to the rising shadow pandemic of DV and its projected residual effects.

Prepandemic Digital Interventions for Domestic and Intimate Partner Violence

Current Digital Interventions

Before this pandemic, the delivery of digital health interventions via mobile devices (mobile health), web-based, and electronic health platforms (such as online and social media modalities) had become prominent. Likewise, with those who experience DV, there is growing evidence of the acceptability and feasibility of trauma-informed digital or digitally delivered interventions that prevent violence, increase the safety and decision-making of persons in an abusive relationship, and ultimately link them to trusted support [23-27]. Evidence shows some DV survivors prefer the practicality and confidentiality of technology-enabled interventions and guided online support (as opposed to in-person face-to-face services such as group counseling and individual therapy), making this a highly acceptable form of intervention delivery [23-28]. To their merit, technology-based interventions prioritize survivor privacy and safety, and offer personalized real-time access to DV screening, risk awareness, and support services [24,25]. Substantively, digital interventions provide safer options for leaving or navigating an abusive relationship (ie, safety planning). These interventions also offer risk and danger assessment, psychoeducation, referral to trusted care, and can be tailored to unique social ecologies in ways that mitigate user burden and maximize safety [25]. In this COVID-19 era, these digital interventions have become of value to socially and physically isolated people who experience abuse, especially while survivors are sequestered at home with abusive partners.

Examples of pre–COVID-19 evidence-based digital interventions and safety decision aids include the myPlan app [25,29], I-DECIDE [30], and *iSafe* [26]. These web- and app-based digital tools are free and easy to access, and have been tested for efficacy and effectiveness (using randomized controlled trials), and with several survivor cohorts. These apps have been used successfully with some Indigenous; immigrant; same-sex; lesbian, gay, bisexual, transgender, and queer+; college; pregnant; and rural female survivors [25-27,31-33].

How They Work: Digital Interventions for Domestic and Intimate Partner Violence

As an example, the myPlan app [34]—first designed as a computer-based intervention—serves primarily as a decision aid to help survivors make informed decisions about their safety and well-being. Leveraging a strength-based and empowerment-focused approach (ie, Dutton's empowerment model), the authors of the app suggest it increases the survivor's autonomy and agency. Specifically, the myPlan app—similar to most DV digital interventions—seeks to educate survivors on relationship red flags and fatality risk using a danger assessment component [35]. The myPlan app also estimates survivor priorities for safety, creates a checklist of survivor-specific safety behaviors, and designs a tailored safety plan based on the survivor's level of danger and achievable safety behaviors [25]. The goal is to connect survivors to meaningful support as they see fit. A 12-month follow-up of a US study showed the myPlan app reduced total decisional conflict (P=.01), increased feelings of being supported in deciding what to do in an abusive relationship (P=.01), and increased the likelihood of creating a safety plan [25]. Similarly, a New Zealand study using the web-based *iSafe* intervention with Māori Indigenous women showed a reduction in violence exposure for Māori survivors (adjusted intervention estimate −14.19; 95% CI −24 to −4.37) at 6 months and at 12 months (adjusted intervention estimate −12.44; 95% CI −23.35 to −1.54) compared to non-Māori survivors (adjusted intervention estimate 0.76; 95% CI −5.57 to 7.09) in the same period. The *iSafe* intervention also reduced depression for Māori survivors at 3 months only (adjusted intervention estimate −7.75; 95% CI −15.57 to 0.07) compared to non-Māori survivors (adjusted intervention estimate 1.36; 95% CI −3.16 to 5.88) [26]. Building on this efficacy, several country-specific adaptations and clinical trials are now in progress. Qualitative studies also show wide acceptance and satisfaction with these digital tools by survivors [25,30].

These digital interventions are of benefit now more than ever, as they support hard-to-reach low-income survivors of partner violence [33], especially in health provider shortage areas, where victimization may intersect with other determinants of violence [24,25,29,36]. However, these digital interventions preclude the unique circumstances of a global pandemic.

Current Technology-Based Strategies

Remotely Working With Survivors

According to a report by UN Women [10], free, round-the-clock digital solutions such as 24/7 hotlines have become a treasured resource during the lockdowns. Consequently, several countries have expanded online web-based services for victims of violence, with 24/7 digitalized responses prioritizing the uniqueness of social and physical isolation [37]. Specific digital responses include the use of DV hotlines, web-services (eg, tele-counseling and telepsychiatry), and a growing corpus of recommendations to guide the selection of prepandemic proprietary smartphone apps. Issues like user safety, user burden, gender digital divides, data privacy, and confidentiality have become paramount priorities and challenges of digital DV intervention. Digital solutions now attempt to augment but not compete with nondigital traditional services [23-28,38]. However, they pose complex challenges as digital responses strive to be convenient but inconspicuous, given that abusers are likely to intercept them in close quarters, further compromising the safety of survivors and their children. At a macrolevel, there have been several published tech safety guidelines by mainstream DV agencies, including the National Network to End Domestic Violence (NNEDV), the National Coalition Against Domestic Violence, the National Domestic Violence Hotline, the Sexual Violence Research Initiative (SVRI), and the Center for Court Innovation. These tech safety guidelines have become useful evaluative tools as survivors, service providers, bystanders, and advocates decide on which digital solution is best for whom, signaling emerging best practices.

In low- and middle-income settings, there are media reports of pragmatic support services delivered via low-data messaging platforms (eg, WhatsApp, WeChat, Sina Weibo) with on- and offline capabilities. Specifically, DV agencies use these platforms to send and receive confidential information during client check-ins and meetings. Besides, online support groups provide a platform for survivors to disclose and document their abuse. These social media platforms also help survivors participate in asynchronous real-time chat forums and virtual meetups with other survivors. With concerns for safety, several guidelines are in place to ensure these online spaces remain confidential, private, and secure. For example, the TechSafety webpage of NNEDV provides several comprehensive guidelines for online, social media, device, and browser safety.

Since awareness is a key prevention strategy, social media users around the world are showing solidarity with survivors by using hashtags to call attention to COVID-19–related spikes in DV. A precursory infoveillance of internet and social media ecosystems using basic data extraction methods (eg, Twitter mining, web searching) revealed hashtags referencing the rise of DV since January 2020. In addition to other trending hashtags (#FlattenTheCurve, #StayHomeSaveLives), DV hashtags like #YouAreNotAlone (launched as an official campaign hashtag by the UK government) and #AntiDomesticViolenceDuringEpidemic (searched more than 3000 times on the Weibo app alone) have become essential tools of digital protest, social activism, and DV consciousness-raising on social media [4,39].

These digital efforts also include men and boys who are abusive or at-risk for becoming abusers. DV social media campaigns (such as the MenEngage campaign) target men and fathers at home, stressing the benefits of healthy relationships, role modeling, and positive masculinity. Long before the pandemic, the MenEngage campaign has been a popular international men's program with over 700 nongovernment organizations and country partners all over the world. However, DV spikes have underscored this as a crucial digital strategy among men and boys. This tactic is critically important, as current spates of furloughs and job losses are predictive of economic stressors, which can lead to feelings of helplessness, anger, worries of infection, and emotional dysregulation—all likely to increase the frequency, volatility, and severity of DV among families with an abuser already present [3,4].

Remotely Working With Perpetrators and Abusers

Family court and Family Justice Center proceedings have also ground to a halt, slowing down filing and sentencing procedures. This is a crucial impediment, as orders of protection through the family court are a vital resource for survivors seeking to hold their abusers accountable, especially those in underserved areas [40,41]. Court systems experiencing delays in usual court processes (physical appearances at court, processing bail, bonds, and warrants) are now fast-tracking lockdown-related case management by switching to digital and virtual procedures (eg, remote hearings). Some courts are putting aside "non-urgent court matters" for the groundswell of DV-related cases [42]. Continuing Operations Plans from court systems have been amended to ensure the uninterrupted continuance of court events to allow for virtual and remote procedures. Some digital responses include implementing electronic monitoring of bail and sentencing procedures, keeping and tracking attendance records using digital devices, court appearances and child custody hearings via telepresence, and digital filing of restraining orders. Other pragmatic solutions include extending the duration for restraining orders to assure the protection of survivors; providing extra notice of hearings; making backup plans for technology- and internet-impaired clients; training judges, attorneys, and court staff; using video conferenced interpreters; and publishing best practices and how-tos for remote hearings [4,37]. For example, some courts in California now use emergency civil orders of protection requested via drop box, online request forms, email, and fax, issued for 30 days any time of the day. However, court systems that are not already technology-enabled (with audiovisual, text, screen-sharing, and file transfer functions) may find it challenging to pivot to digital methods. Besides, court systems may find it challenging to secure funding to procure telecommunication equipment to facilitate remote court proceedings [43]. This pandemic has highlighted the usefulness of digital interventions with abusers, however, these digital strategies are not without issues, as security, privacy, and access problems remain prevalent.

Batterer rehabilitation programs have always offered online classes to deliver program curricula to abusers. However, rehabilitation programs may now fully use digital modalities

for remote offender counseling, group or individual sessions, intake processing for new abusers, and monitoring completion of assignments as part of their rehabilitation program. Digital modalities may also be of use for other urgent legal proceedings such as filing disputes for divorce and child custody. In some areas, parole officers are encouraged to use digital tactics such as on-site but socially distanced phone calls to parolees to minimize exposure to the coronavirus. Of note, although vital to abuser accountability, it is likely these digital solutions may compromise effective monitoring of DV and fail to detect recidivist behaviors with abusers [43]. Another way that technology is used is with the early and supervised release programs of low-level, aging, pregnant, and at-risk offenders to curtail the spread of COVID-19 in prisons and jails. Victim notification apps such as VINEmobile [44] are now being leveraged to notify survivors of changes in their abuser's custody status, case details, arrests, bond hearings, and other legal activities.

Others Responding to COVID-19–Related Domestic Violence

The NNEDV published a Digital Services Toolkit in response to COVID-19 [45]. Some topics covered include "Using Technology to Communicate with Survivors During a Public Health Crisis," and "Step-by-Step Guide to Choosing Tools for Digital Services" [45]. Service providers, advocates, and clinicians can use these digital compendia as a checklist to gauge the credibility, usefulness, and safety of digital interventions for survivors. Similar best practices for technology use are being used around the world. For example, in Beijing, China, the Yuanzhong Family and Community Development Service Center published an online legal aid of special manuals (translatable to English) for survivors and service providers [39]. The American Psychiatric Association's "*Hierarchical framework for evaluation and informed decision-making regarding smartphone apps for clinical care*" is also a suggested checklist for checking the credibility of digital interventions that specifically target mental health outcomes [46].

Information on how to continue research with DV survivors in light of COVID-19 is also emerging. On the one hand, data collection to support vulnerable survivors is critical information; however, data collection is threatened by the heightened risk of doing so with the added insecurities brought on by COVID-19. Considering this conundrum, Elizabeth Dartnall (Executive Director of the SVRI) and Ellen Bates-Jefferys (Senior Research Associate at Innovations for Poverty Action) have recommended tools for remotely gathering research data during the lockdown [47]. Some strategies involve replacing face-to-face data gathering methods with computer- and mobile phone–assisted surveys, websites such as SurveyMonkey [48], and instant messaging platforms such as WhatsApp. This comes as DV researchers are forced to change their research and survey protocols by switching to phone call protocols and online consenting processes using enhanced data management plans after research review board amendments [47]. Although it is crucial to understand the scope of COVID-19–related DV, data collectors raise essential concerns about ethicality, data quality, survivor safety, retraumatization, confidentiality, and data ownership during this period [47].

Spurred by DV advocate organizations and human rights activists, service providers are recommending digital platforms to reach *all* survivors. For instance, the National Domestic Violence Hotline and the National Teen Dating Abuse Helpline continue to publish their 1-800-799-SAFE (7233) and 1-866-331-9474 numbers, respectively, offering free and real-time talk and chat services in English and Spanish. Similar local and global efforts have inspired the innovative use of emergency websites and crisis numbers responsive to sexual and gender minority groups, including male survivors—who also face violence from male or female abusers. For instance, Futures Without Violence published a list that includes the Trans Lifeline (1-877-565-8860) staffed by trans facilitators for trans and questioning folks, as well as the Deaf Hotline—an around-the-clock video phone (1-855-812-1001), email, and chat service for deaf and hard of hearing survivors. At the grassroots level, online antiviolence coalition-building, social media consciousness-raising, online crowdfunding, electronic filing services for court services and proceedings have become welcome digital strategies to support survivors, prevent abuse, and even hold abusers accountable.

At the governmental level, key leaders and heads of government met at the Women Leaders' Virtual Roundtable on COVID-19 to re-emphasize the short- and long-term detrimental effect of the COVID-19 pandemic on women and girls. Findings from this meeting identified priority policy measures to facilitate "a more gender-inclusive recovery path" [10]. Governments are advised to use coordinated multi-sector community-led responses to exempt survivors from shelter-in-place orders and to sustain much-needed funding to key agencies. Other recommendations include efforts to classify DV shelters as essential services and increase necessary resources to DV and allied services for gender-diverse victim groups, including trans men and women who face exponential levels of partner or nonpartner violence.

Challenges With Using Technology

However, novel digital modalities are not without their shortcomings. For example, survivors (and even abusers in treatment) may face inherent structural and practical barriers to accessing digitalized services while sheltered in-place. Specific challenges may include internet connectivity issues (in low- or dead-zone internet coverage areas) and in no-tech and low-tech situations, leading to high-data burden and accessibility issues. These barriers can significantly impair help-seeking and are pronounced in unincorporated rural communities, among low-income users, and among older adult users (so-called "digital immigrants") who may be unfamiliar with new technologies. Survivors also worry about their rights and choices when using impersonal digital technologies to discuss such a sensitive and dangerous issue [24,26,38]. In low- and middle-income countries, reduced use of counseling services by phone, SMS, and email is linked to profound gender digital divides, technical illiteracy, and device disparities, making digital resources supplementary at best [10,49]. Not to mention

the challenges service providers face in meeting the cultural needs of some vulnerable cohorts (eg, immigrant and minority groups) [50].

In addition, there are practical barriers in the home. Abusers are known to use a recipe of digital trackers, GPS, and spyware to covertly and overtly monitor the online presence of the person they are abusing to maintain coercive and even deadly control [51]. Abusers may impersonate the person they are abusing and gain entrée into what is supposed to be a safe space, particularly online fora, using fake social media accounts, and under false pretexts, armed with intimate details of the person they abuse [51]. In the wake of this pandemic, emerging forms of technology-based abuse have also spiked. These include online stalking, zoombombing, cyberbullying, doxing (disclosing personal information online in retaliation), sexualized trolling, nonconsensual pornography (or revenge porn), and coercive behaviors with adverse implications for victims of online abuse, including children and adolescents [49]. In addition, stay-at-home directives will facilitate the interception and strict round-the-clock surveillance of social media and mobile devices by abusers. This will further limit known and free avenues for help-seeking and abuse disclosure [2].

To reduce this type of online abuse and surveillance, Freed et al [51] recommends that app designers and vendors set up interface-level security measures that can distinguish the abuser from the victim based on behavioral, keystroke, or contextual cues. They also recommend covert authentication and verification protocols (eg, emergency exit buttons, app lockdown, or data dump after failed password entry) integrated into DV apps and websites. Other strategies include passcodes for mobile apps, one-click access to DV hotlines, and the use of evidence-based and tailored content for unique users. As a preemptive measure, Eterovic-Soric and colleagues [52] suggest some antiviolence technologies can be used against stalkers. These include specialized stalker detection software, Tor anonymity network set-up for private online communication, and device encryption [52]. On the TechSafety webpage, NNEDV provides comprehensive pros and cons reviews on some of these apps [45]. In partnership with Facebook, NNEDV has also published a resource on "Tips for Helping a Friend Experiencing Domestic Abuse During COVID-19," along with other COVID-19–specific guidelines for survivors, friends and family of survivors, and service providers [53].

Challenges for DV Agencies

At the agency level, there are noted barriers to the uptake of digital solutions during social distancing and lockdown restrictions, including the burden on agency staff to appraise and become familiar with the safe use of new technologies. Nonprofit agencies on shoestring budgets also contend with overextended bandwidth, device or subscription requirements, information technology (IT) troubleshooting issues, data privacy, and data mining worries.

Even as DV agencies grapple with the learning curve of digital interventions, DV shelters expectedly get more shelter-seekers during natural disasters [9,19,21]. With COVID-19, shelters are surpassing their maximum capacity, prompting alternative sheltering options such as Hotel Assistance Programs using vacant hotel rooms and dormitories as makeshift shelters for survivors. In past disasters, survivors (mothers and children) have been turned away [19]. Still, this pandemic poses a unique complexity as DV shelters are doubly burdened with monitoring clients for symptoms of the coronavirus to enact infection control protocols.

Nonprofit DV service providers contend with funding cuts such as grant matching stipulations; overburdened services; even as their staff are exposed to their own violence online, in person, and within antiviolence spaces. Overall, funding cuts are heightened now, as cuts in government relief funding are diverted to meet other emergent needs. Fortunately, the Coronavirus Aide, Relief and Economic Security (or CARES Act) provided $45 million for programs under the Family Violence Prevention and Services Act that offers DV survivors emergency housing and other critical services during this time. The CARES Act also provides $2 million for the National Domestic Violence Hotline—a much needed digital resource. However, additional support is still needed for sexual assault programs, even as shelter and service providers continue to contend with upsurges.

In light of these, DV agency staff working under these militating conditions also face adverse psychological stress, compassion fatigue, and burnout, and may need to be intentional in acts of self-care and separation from work to continue contributing their expertise and emotional labor in support of survivors. This process is contingent on unimpeded material and moral support from us all, as supporting DV survivors and DV-impacted families is a responsibility not limited to the government, agency heads, and advocates.

Conclusion: What Now?

Going forward, Fisher [20] emphasizes prioritizing survivor voices, rights, and perspectives in the design of trauma-informed digital intervention. Digital intervention planners are advised to use "gender mainstreaming," feminist, and socio-ecological lenses as guiding praxis for pre- and postdisaster preparedness to respond to DV and its intersectional issues [54]. A specific example may be the use of gender-disaggregated data to understand the gendered effects of DV during and after a disaster. Emerging research must focus on understanding the residual impact of the coronavirus pandemic on family functioning in the context of DV, with specific emphasis on protective factors, resiliency, resistance, coping, and safety. Knowing the importance and value of digital interventions, DV researchers and advocates must quickly form cross-collaborations with other professionals such as app developers, using tested coordinated community networks to capitalize on current research infrastructure and expertise [55]. Peterman et al [33] recommend other strategies including training health care providers to better identify and use DV digital tools, and reinforcing digital safety nets for survivors and service providers, including digitized cash transfers, digital resources listing employment benefits, legal, health, childcare, shelter or transitional housing, and trusted psychosocial services for survivors and their families.

DV researchers must also build emergency preparedness into future service delivery protocols, building on lessons learned so far. Interventionists and disaster planners are now tasked with fully understanding the psychological consequences of social isolation on survivors and the abuse tactics of perpetrators in social isolation, and developing urgent strategies in creating, testing, and mapping out digital and digitally delivered responses for our complex digital ecosphere. As the tech sector continues to innovate digital tools and the government continues to facilitate the accelerated IT modernization of our digital infrastructure, partnerships between researchers, advocates, survivors, and community-based organizations have become pertinent. These collaboratives can help improve policies, regulatory mechanisms, and funding systems that advance the design, testing, and upscaling of digital interventions in DV spaces while anticipating the unintended effects these interventions may have on the health and well-being of survivors and their families. These public-private partnerships are necessary to invest in critical digital tools that streamline access to evidence-based but pragmatic digitalized services.

Last, per the gender and disaster literature, the outcomes of natural disasters are highly gendered. This disproportionately impacts women and girls by increasing their invisibility and vulnerability to gender-based forms of violence—much unlike men and boys [20]. Although the effects of disasters are felt more so at the individual level, social and economic recovery efforts will depend primarily on pre-existing socio-ecological systems and systemic vulnerabilities among at-risk groups [19,20]. These vulnerabilities are intersectional and should form the basis of disaster and vulnerability praxis, as we continue to design and fine-tune digital and digitally delivered responses to DV during disruptive events such as pandemics.

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Conflicts of Interest

None declared.

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Abbreviations

CARES: Coronavirus Aide, Relief and Economic Security
COVID-19: coronavirus disease
DV: domestic violence
IT: information technology
NNEDV: National Network to End Domestic Violence
SVRI: Sexual Violence Research Initiative
UN: United Nations

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Viewpoint

Notes From the Field: Use of Emergency Medical Service Data to Augment COVID-19 Public Health Surveillance in Montgomery County, Maryland, From March to June 2020

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Abstract

Epidemiologic and syndromic surveillance metrics traditionally used by public health departments can be enhanced to better predict hospitalization for coronavirus disease (COVID-19). In Montgomery County, Maryland, measurements of oxygen saturation (SpO_2) by pulse oximetry obtained by the emergency medical service (EMS) were added to these traditional metrics to enhance the public health picture for decision makers. During a 78-day period, the rolling 7-day average of the percentage of EMS patients with SpO_2 <94% had a stronger correlation with next-day hospital bed occupancy (Spearman ρ=0.58, 95% CI 0.40-0.71) than either the rolling 7-day average of the percentage of positive tests (ρ=0.55, 95% CI: 0.37-0.69) or the rolling 7-day average of the percentage of emergency department visits for COVID-19–like illness (ρ=0.49, 95% CI: 0.30-0.64). Health departments should consider adding EMS data to augment COVID-19 surveillance and thus improve resource allocation.

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KEYWORDS

SARS-CoV-2; COVID-19; public health; surveillance; prediction; emergency medical service; EMS; pulse oximetry; testing

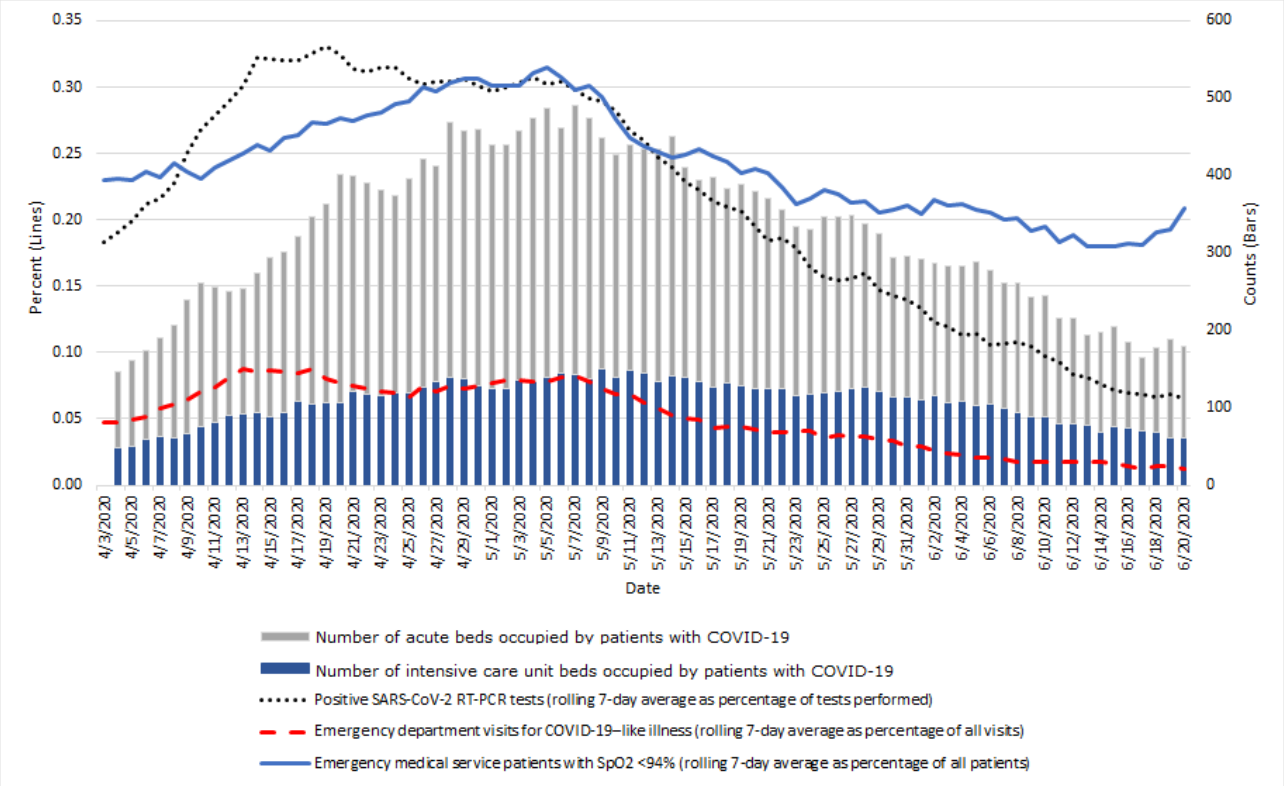
Introduction

On March 5, 2020, Montgomery County, Maryland, a densely populated county neighboring Washington, DC, reported its first cases of coronavirus disease (COVID-19); this prompted the county health department to develop a daily surveillance report [1]. By March 27, this report included the following information: daily and cumulative confirmed COVID-19 cases; percentage of reverse transcription polymerase chain reaction (RT-PCR) tests positive for severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus that causes COVID-19; acute and intensive care unit beds occupied in the county's seven hospitals; daily emergency department encounters for COVID-19–like illness; and daily emergency medical service (EMS) calls and acuity indicators, including the number of patients with a pre-hospital pulse oximetry value (SpO_2) below 94% [2]. Epidemiologic data were retrieved from the Maryland Department of Health. Emergency department syndromic data were retrieved from the Montgomery County Electronic Surveillance System for the Early Notification of Community-based Epidemics (ESSENCE) using the COVID-19–like illness query published by the National Syndrome Surveillance Program; this query is defined as fever plus cough, difficulty breathing, or shortness of breath, and it includes International Statistical Classification of Diseases, Tenth Revision (ICD-10) codes for COVID-19 [3]. EMS data were provided by the Montgomery County Fire and Rescue Service.

As the situation unfolded, it was noted that the percentage of EMS patients with SpO_2 <94% tracked closely with the number of hospital beds occupied by patients with COVID-19 in the county (Figure 1). It was postulated that this metric, in addition

to typical epidemiologic and syndromic surveillance data, may be beneficial for hospital utilization forecasting.

Figure 1. Metrics associated with hospital bed occupancy for COVID-19 in Montgomery County, Maryland, from April 3 to June 20, 2020.



Methods

The relationship between prehospital hypoxemia and next-day hospital bed occupancy for COVID-19 was assessed using the Spearman rank-order correlation. Prehospital hypoxemia was defined as the rolling 7-day average of the percentage of EMS patients with SpO_2 <94%. The Spearman rank-order correlation was also used to assess the correlation between the rolling 7-day average of the percentage of RT-PCR tests that were positive for SARS-CoV-2 and next-day hospital bed occupancy, as well as the correlation between the rolling 7-day average of the percentage of emergency department visits for COVID-19–like illness and next-day hospital bed occupancy. Correlations were computed using SAS 9.4 (SAS Institute) with 95% CIs based on the Fisher z transformation. This study was approved as exempt research by the Maryland Department of Health Institutional Review Board (protocol #20-32).

Results

During the 78-day period from April 3 to June 19, 2020, the correlation coefficient (ρ) between the rolling 7-day average of the percentage of EMS patients with SpO_2 <94% and the total hospital bed occupancy on the following day (ie, from April 4 to June 20) was 0.58 (95% CI 0.40-0.71). This correlation was stronger than those for the two other metrics commonly used to assess COVID-19 trajectory in a community: the rolling 7-day average of the percentage of positive tests (ρ=0.55, 95% CI 0.37-0.69) and the rolling 7-day average of the percentage of emergency department visits for COVID-19–like illness (ρ=0.49, 95% CI 0.30-0.64).

Discussion

To reduce morbidity and mortality associated with the ongoing pandemic, government authorities and health care administrators must anticipate demands for hospital beds, equipment, and treatments [4]. These leaders will continue to rely on public health metrics to anticipate surges in the number of patients with COVID-19. The value of these metrics increases with their predictive ability and their nearness to real time [3,5]; ideally, extant metrics can be adopted without implementing novel data collection infrastructure [6].

Prehospital pulse oximetry may meet these requirements and surpass traditional surveillance measures for predicting COVID-19 hospitalizations for at least four reasons. First, by requiring two sets of vital signs and by documenting SpO_2 for nearly every patient encounter regardless of presentation or working diagnosis, EMS has established a metric that is comprehensively ascertained and internally valid. Second, these data are usually generated before those from traditional health care sources, such as emergency department assessments and RT-PCR test results. Third, because hypoxemic patients are more likely than asymptomatic or mildly symptomatic patients to be hospitalized, the predictive criterion validity of SpO_2 may surpass that of RT-PCR test positivity [7]. Fourth, although syndromic surveillance provides some information on disease severity, patient acuity indicators are not consistently populated in the Montgomery County syndromic system, and emergency department pulse oximetry measurements may be affected by oxygen administration in the prehospital environment.

In Montgomery County, Maryland, the 7-day rolling average of the percentage of EMS patients with SpO_2 <94% correlated well with next-day hospitalizations for COVID-19. State and county health departments should consider tracking the hypoxemia status of prehospital patients by using EMS data to augment surveillance and improve their COVID-19 response.

Acknowledgments

The views expressed in this article are those of the authors and do not necessarily reflect the official policy or position of the Air Force, the Department of Defense, or the US Government.

Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
EMS: emergency medical service
ESSENCE: Electronic Surveillance System for the Early Notification of Community-based Epidemics
ICD-10: International Statistical Classification of Diseases, Tenth Revision
RT-PCR: reverse transcription–polymerase chain reaction
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

COVID-19 in India: Statewise Analysis and Prediction

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Abstract

Background: The highly infectious coronavirus disease (COVID-19) was first detected in Wuhan, China in December 2019 and subsequently spread to 212 countries and territories around the world, infecting millions of people. In India, a large country of about 1.3 billion people, the disease was first detected on January 30, 2020, in a student returning from Wuhan. The total number of confirmed infections in India as of May 3, 2020, is more than 37,000 and is currently growing fast.

Objective: Most of the prior research and media coverage focused on the number of infections in the entire country. However, given the size and diversity of India, it is important to look at the spread of the disease in each state separately, wherein the situations are quite different. In this paper, we aim to analyze data on the number of infected people in each Indian state (restricted to only those states with enough data for prediction) and predict the number of infections for that state in the next 30 days. We hope that such statewise predictions would help the state governments better channelize their limited health care resources.

Methods: Since predictions from any one model can potentially be misleading, we considered three growth models, namely, the logistic, the exponential, and the susceptible-infectious-susceptible models, and finally developed a data-driven ensemble of predictions from the logistic and the exponential models using functions of the model-free maximum daily infection rate (DIR) over the last 2 weeks (a measure of recent trend) as weights. The DIR is used to measure the success of the nationwide lockdown. We jointly interpreted the results from all models along with the recent DIR values for each state and categorized the states as severe, moderate, or controlled.

Results: We found that 7 states, namely, Maharashtra, Delhi, Gujarat, Madhya Pradesh, Andhra Pradesh, Uttar Pradesh, and West Bengal are in the severe category. Among the remaining states, Tamil Nadu, Rajasthan, Punjab, and Bihar are in the moderate category, whereas Kerala, Haryana, Jammu and Kashmir, Karnataka, and Telangana are in the controlled category. We also tabulated actual predicted numbers from various models for each state. All the R^2 values corresponding to the logistic and the exponential models are above 0.90, indicating a reasonable goodness of fit. We also provide a web application to see the forecast based on recent data that is updated regularly.

Conclusions: States with nondecreasing DIR values need to immediately ramp up the preventive measures to combat the COVID-19 pandemic. On the other hand, the states with decreasing DIR can maintain the same status to see the DIR slowly become zero or negative for a consecutive 14 days to be able to declare the end of the pandemic.

(JMIR Public Health Surveill 2020;6(3):e20341) doi:10.2196/20341

KEYWORDS

COVID-19; disease modeling; 30-day prediction; logistic model; exponential model; SIS model; daily infection rate

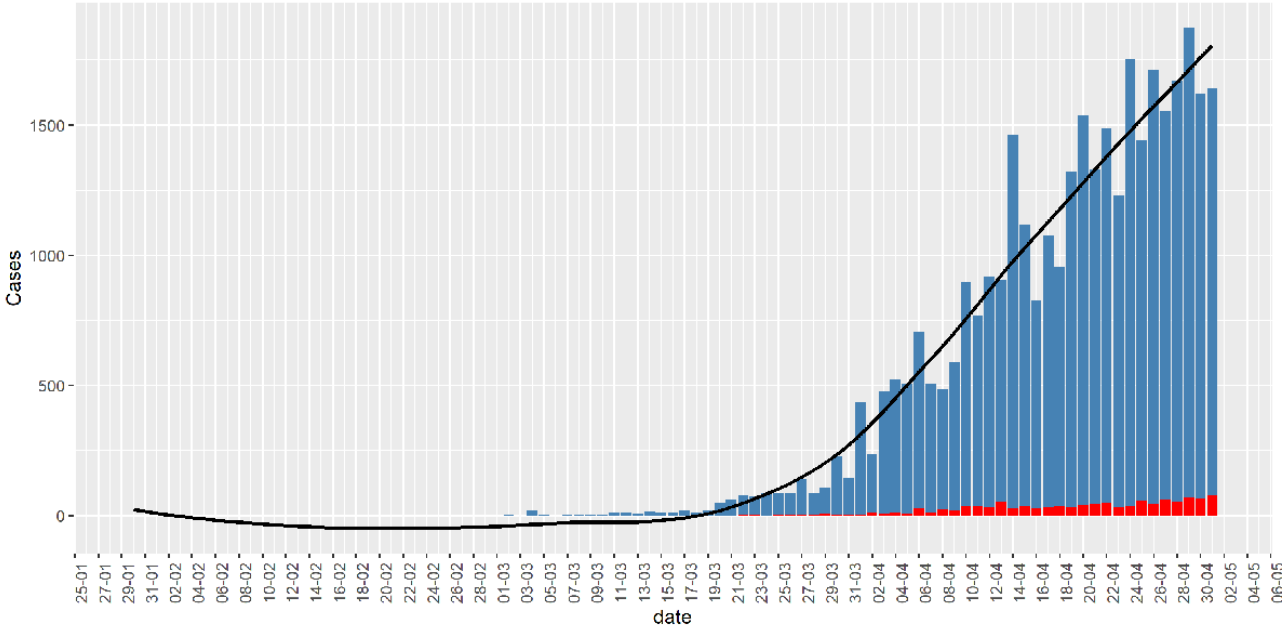
Introduction

Background

The world is now facing an unprecedented crisis due to the novel coronavirus, first detected in Wuhan, China in December 2019 [1]. The World Health Organization (WHO) defined coronavirus as a family of viruses that range from the common cold to the Middle East respiratory syndrome coronavirus and the severe acute respiratory syndrome coronavirus [2]. Coronaviruses circulate in some wild animals and have the capability to transmit from animals to humans. These viruses can cause respiratory symptoms in humans, along with other symptoms of the common cold and fever [3]. There are no specific treatments for coronaviruses to date. However, one can avoid infection by maintaining basic personal hygiene and social distancing from infected persons.

The WHO declared the coronavirus disease (COVID-19) as a global pandemic on March 11, 2020 [4]. The disease has spread across 212 countries and territories around the world, with a total of more than 3 million confirmed cases [5,6]. In India, the disease was first detected on January 30, 2020, in Kerala in a student who returned from Wuhan [7,8]. The total (cumulative) number of confirmed infected people is more than 37,000 to date (May 3, 2020) across India. The bar chart in Figure 1 shows the daily growth of the COVID-19 cases in India. After the first 3 cases from January 30 to February 3, 2020, there were no confirmed COVID-19 cases for about a month. The COVID-19 cases appeared again from March 2, 2020, onwards. These cases are related to people who have been evacuated or have arrived from COVID-19–affected countries. From March 20, 2020, onwards, there is an exponential growth in the daily number of COVID-19 cases at the pan-India level.

Figure 1. Bar chart of daily infected cases (blue) in India. Red bar denotes death. The black curve is a fitted smooth curve on the daily cases.



There are four stages of COVID-19 depending on the types of virus transmission [9,10]. During the first stage, a country or region experiences imported infected cases with travel history from virus-hit countries. During the second stage, a country or region gets new infections from persons who did not have a travel history but came in contact with persons defined in stage 1. Stage 3 is community transmission; in this period, new infection occurs in a person who has not been in contact with an infected person or anyone with a travel history of virus-hit countries. At stage 4, the virus spread is practically uncontrollable, and the country can have many major clusters of infection.

Many news agencies are repeatedly saying or questioning whether India is now at stage 3 [9,11,12]. In reality, different Indian states are or will be at various stages of infection at different points in time. Labeling a COVID-19 stage at the pan-India level is problematic. It will spread misinformation to common people. Those states that are at stage 3 require more rapid action compared to others. On the other hand, states that are in stages 1 and 2 need to focus on stopping the community spread of COVID-19.

In this paper, we first discuss the importance of statewise consideration, contemplating all the states together. Second, we will focus on the infected people in each state (considering only those states with enough data for prediction) and build growth models to predict infected people for that state in the next 30 days.

Why Statewise Consideration?

India is a vast country with a geographic area of 3,287,240 square kilometers and a total population of about 1.3 billion [13]. Most of the Indian states are quite large in geographic area and population. Analyzing coronavirus infection data, considering the entirety of India to be on the same page may not provide us the right picture. This is because the first infection, new infection rate, progression over time, and preventive measures taken by state governments and the common public for each state are different. We need to address each state separately. It will enable the government to use the

limited available resources optimally. For example, currently, Maharashtra already has more than 10,000 confirmed infected cases, whereas West Bengal has less than 800 confirmed cases (May 1, 2020). The approaches to addressing the two states must be different due to limited resources. One way to separate the statewise trajectories is to look at when each state was first infected.

In Figure 2, we present the first infection date along with the infected person's travel history in each of the Indian states. All the states and the union territories, except Assam, Tripura, Nagaland, Meghalaya, and Arunachal Pradesh, observed their first confirmed infected case from a person who had travel history from one or more already COVID-19–infected countries. The Indian government imposed a complete ban on international flights to India on March 22, 2020 [14]. Figure 2 justifies government action to international flight suspension. Had it been taken earlier, we could have restricted the disease to only a few states compared to the current scenario.

Figure 2. When the first case in each state happened with their travel histories. UAE: United Arab Emirates.

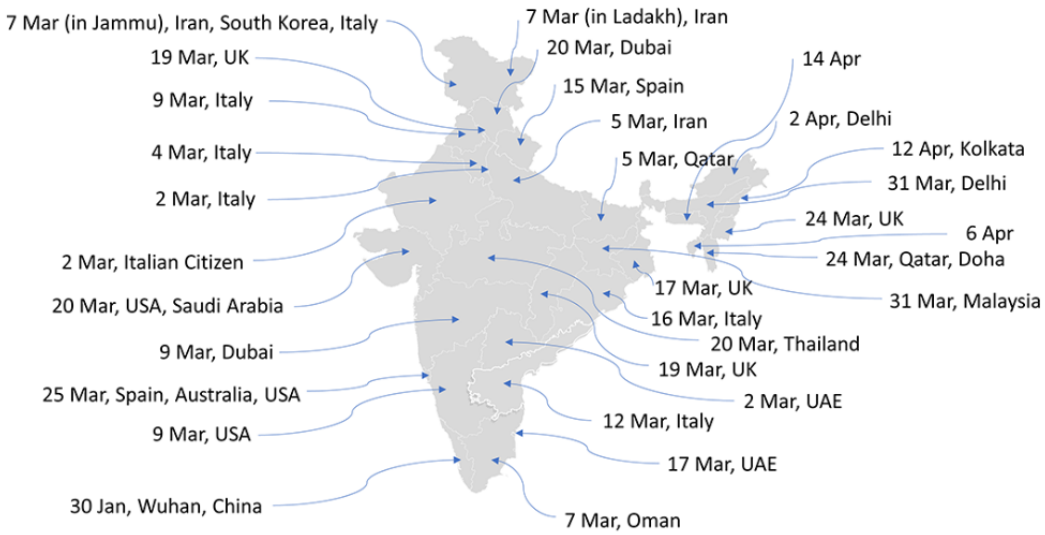
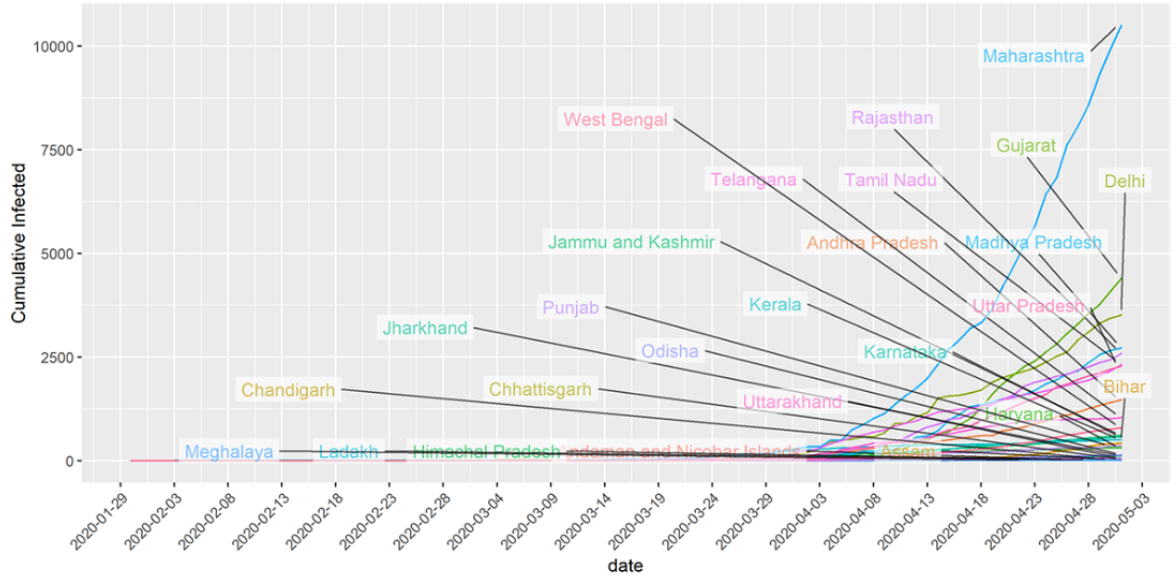


Figure 3 shows the curve of the cumulative number of infected people in those Indian states having at least 10 total infected people. Currently, Maharashtra, Delhi, Gujarat, Tamil Nadu, Madhya Pradesh, Rajasthan, and Uttar Pradesh are the states where the cumulative number of infected people have crossed the 2000 mark, with Maharashtra having more than 10,000 cases. Kerala, the first state to have a COVID-19 confirmed case, seems to have restricted the growth rate. There are few states with cumulative infected people in the range of 500-1500. Depending on how those states strictly follow the preventive measures, we may see a rise in the confirmed cases.

Figure 3. Cumulative number of infected people over time in states with at least 10 infected cases.



Preventive Measures

In Textbox 1, we list the major preventive measures taken by the Indian Government [15].

Textbox 1. List of major preventive measures taken by the Indian Government.

January 25-March 13, 2020

Health screenings at airports and border crossings

February 26-March 20, 2020

Introduction of quarantine policies: gradually for passengers coming from different countries

February 26-March 13, 2020

Visa restrictions: gradually for different countries

March 5, 2020

Limit public gatherings (closure of some selected public institutions like museums, religious places, and postponing of several local elections to stop public gatherings)

March 11, 2020

Border checks

March 13-15, 2020

Border closure

March 16, 2020

Limit public gatherings (ban on all sorts of public gatherings and meetings, and stopping people from making any congregation)

March 18, 2020

Travel restrictions

March 20, 2020

Testing for the coronavirus disease (before this point, only people who had traveled from abroad were tested; this point onwards, testing was also introduced for symptomatic contacts of laboratory-confirmed cases, symptomatic health care workers, and all hospitalized patients with severe acute respiratory illness)

March 22, 2020

Flight suspensions

March 22, 2020

Cancellation of passenger train services until March 31, 2020

March 24, 2020

Suspension of domestic airplane operations

March 25, 2020

21-day lockdown of entire country

March 25, 2020

Cancellation of passenger train services extended to April 14, 2020

March 30, 2020

Increase of quarantine/isolation facilities

April 14, 2020

Extension of lockdown until May 3, 2020

May 1, 2020

Extension of lockdown until May 17, 2020

Methods

Data Source

We have used Indian COVID-19 data available publicly. The three primary sources of the data are the Ministry of Health and Family Welfare, India [16]; COVID-19 India [17]; and Wikipedia [18].

Statistical Models

In this paper, we consider the exponential model, the logistic model, and the susceptible-infectious-susceptible (SIS) model

for COVID-19 pandemic prediction at the state level. These models have already been used to predict epidemics like COVID-19 around the world, including in China, and for the Ebola outbreak in Bomi, Liberia in 2014 [19-21]. See Multimedia Appendix 1 [20-22] for details about the models.

Using the Models in State-Level Data

The previously mentioned three models will provide a different prediction perspective for each state. The exponential model–based prediction will give a picture of what could be the cumulative number of infected people in the next 30 days if we do not take any preventive measures. We can consider the forecast from the exponential model as an estimate of the upper bound of the total number of infected people in the next 30 days. The logistic model–based prediction will capture the effect of preventive measures that have already been taken by the respective state governments as well as the central government. The logistic model assumes that the infection rate will slow down in the future with an overall "S" type growth curve. In other words, the logistic model tries to explore a situation where there is a full lockdown in the country, leading to an extreme restraint on the people's movement, hence reducing the rate of infection considerably. Under the effective implementation of the lockdown, it is appropriate to use a logistic model. In this scenario, many people have already been infected; the virus may find it hard to spot more susceptible people. Thus, the virus slows down its spread, causing the flattening in the S-curve at a later stage. Several research papers have used the logistic model in the context of COVID-19 [23-26].

The purpose of the SIS model is to reflect the effect of the major preventive measure like the nationwide 21-day lockdown from March 25 to April 14, 2020. The lockdown was extended in two phases: (1) until May 3 and (2) then until May 17, 2020, with some relaxation [27,28]. The SIS model is critically dependent on the infection-rate parameter (β). It is defined as the number of people infected per unit time from an infected person. Note that this parameter is subject to change due to the effect of lockdown and other preventive measures to ensure social distancing. When people are at home, the infection rate is expected to be on the lower side. The other parameter in the SIS model is  with *D* being the recovery time. We have considered  = 14 days [29,30]. In this study, to make the SIS model simple, we assumed that the number of births and deaths in a state are the same.

Study the Effect of Lockdown Using the Daily Infection Rate and SIS Model

Kumar et al [31] reported the estimated number of people that a person may *come in contact with within* a day (24 hours) in a rural community in Haryana, India to be 17. They defined *contact* as having a face-to-face conversation within 3 feet, which may or may not have included physical contact. The estimate of the contact-rate parameter from their paper is 0.70. In practice, only some of all the people who come in *contact* with a person infected with COVID-19 may be actually infected by the virus. Note that India has already taken many preventive measures to ensure social distancing. In the current scenario, the infection rate based on Kumar et al's [31] study could be an overestimate of its present value. However, despite nationwide lockdown, banks, hospitals, and grocery stores are still open to cater to the essential needs of people. We consider here two approaches to study the effect of lockdown and other preventive measures jointly in each state. *First*, we plot the daily infection rates (DIRs) for each state. The DIR for a given day is defined as:

The DIR takes a positive value when we see an increase in active COVID-19 cases from yesterday, the zero value in case of no change in the number of active cases from yesterday, and a negative value when the total number of active cases decreases from the previous day. A DIR value can be more than 1 also, particularly during initial days of infection in a state. For example, when the total number of active cases increases from 5 yesterday to 20 today, then the DIR value is (20 – 5) / 5 = 3. The visual trends in infection rates can explain whether the COVID-19 situation is under control or not in a specific state. A state where DIRs are declining for the last few days indicates that the situation is improving. However, a certain jump in infection rates could inform us that there could be cases of COVID-19 that are underreported. We need to search for infected clusters as quickly as possible. *Second*, we have incorporated a fitted SIS curve (fitted via a nonlinear least squares approach), a close representation of the observed number of cases (red curve) for each state. The estimated values of the basic reproduction number (R_0) from the SIS model are also reported for each state. Here,  from the SIS model. Using the SIS model, we have also considered four predicted curves of active infected patients with different infection rates. The four different infection rates used in the SIS model for prediction are the 25th, 50th, 75th, and 80th percentiles of the observed DIRs. We also plotted the observed active infected patients over time. A declining curve of observed active infected patients (red curve) can ensure that measures like lockdown and social distancing are working when all the infected cases are reported and tested. The different predicted lines, using the SIS model, may serve as reference frames to indicate whether the government needs to enforce the social distancing more stringently. For example, if the current part of the graph of observed active infected patients (red curve) is above the 75th percentile line, then there is a major concern for that state. We may need to increase the lockdown period in a state if we do not see a declining trend of observed active infected patients (red curve).

India implemented a nationwide lockdown on March 25, 2020. We first considered the incubation period of the novel coronavirus to study the effect of the lockdown. The incubation period of an infectious disease is defined as the time between infection and the first appearance of signs and symptoms [32]. Using the incubation period, health researchers can decide on the quarantine periods and halt a potential pandemic without the aid of a vaccine or treatment [33]. The estimated median incubation period for COVID-19 is 5.1 (95% CI 4.5-5.8) days, and 97.5% of those who develop symptoms will do so within 11.5 (95% CI 8.2-15.6) days of infection [34]. The WHO recommends that a person with laboratory-confirmed COVID-19

be quarantined for 14 days from the last time they were exposed to the patient [35]. Therefore, if a person was infected before the lockdown (March 25, 2020), they should not infect others except their family members if that person is entirely inside their house for more than 14 days. The WHO also recommends common people to maintain a distance of at least 1 meter from each other in a public place to avoid COVID-19 infection. The effective implementation of social distancing can stop the spread of the virus from an infected person, even when they are outside for some essential business. However, given a highly dense population in most of India, particularly in cities, it may not always be possible to maintain adequate social distance.

Results

Statewise Analysis and Prediction Report

In this section, we depend on inputs from the exponential, logistic, and SIS models along with DIRs for each state. Remembering the words of the famous statistician George Box "All models are wrong, but some are useful," we interpreted the results from different models jointly. We consider different states with at least 300 cumulative infected cases. For each state, we present four graphs. We have used the state-level data until May 1, 2020. The first and second graphs are based on the logistic and the exponential models, respectively, with the next 30-day predictions. The third graph is the plot of DIRs for a state. Finally, the fourth graph is showing the growth of the active infected patients using SIS model prediction ("*pred*") along with the observed active infected patients. Table 1 represents the 30-day prediction of the cumulative infected number of people for each state using the logistic model, the exponential model, and a data-driven combination of the two. The corresponding measures of goodness of fit (R^2 and deviance) are presented in the table in Multimedia Appendix 1.

Table 1. Data-driven assessment and 30-day prediction using the logistic and exponential models, and their linear combination.

State	Observed cumulative cases (May 1, 2020)	Maximum DIR[a] in the last 2 weeks	Estimated R_0[b] from SIS[c] model (data until May 1, 2020)	Data driven assessment of COVID-19[d] situation	30-day prediction (May 31, 2020)			Observed cumulative cases (May 31, 2020)	Assessment of observed cumulative cases with respect to (LC_{pred}[e], exponential)
					Logistic	Linear combination of logistic and exponential (LC_{pred})	Exponential (applicable only if the situation is severe)		
Andhra Pradesh	1463	0.17	3.22	Severe	2313	4725	16,502	3571	Below
Bihar	426	0.39	3.08	Moderate	16,452	16,472	16,502	3807	Below
Delhi	3515	0.17	2.94	Severe	4262	9650	35,957	19,844	Between
Gujarat	4395	0.27	3.50	Severe	5206	33,736	110,874	16,794	Below
Haryana	313	0.18	1.82	Controlled	321	590	1815	2091	Above
Jammu and Kashmir	614	0.09	2.66	Controlled	724	1124	5170	2446	Between
Karnataka	576	0.06	2.38	Controlled	3711	3711	3713	3221	Below
Kerala	497	0.18	1.96	Controlled	455	740	2040	1270	Between
Madhya Pradesh	2719	0.10	3.36	Severe	3030	6521	37,935	8089	Between
Maharashtra	10,498	0.15	3.50	Severe	17,115	43,963	196,103	67,655	Between
Punjab	357	0.14	2.52	Moderate	419	713	2517	2263	Between
Rajasthan	2584	0.12	2.94	Moderate	2821	6125	30,356	8831	Between
Tamil Nadu	2323	0.12	3.22	Moderate	2241	3967	16,624	22,333	Above
Telangana	1039	0.09	2.66	Controlled	1063	1631	7373	2698	Between
Uttar Pradesh	2281	0.13	2.52	Severe	3016	6566	30,326	8075	Between
West Bengal	795	0.17	3.22	Severe	1261	3225	12,815	5501	Between

[a]DIR: daily infection rate.

[b]R_0: basic reproduction number.

[c]SIS: susceptible-infectious-susceptible.

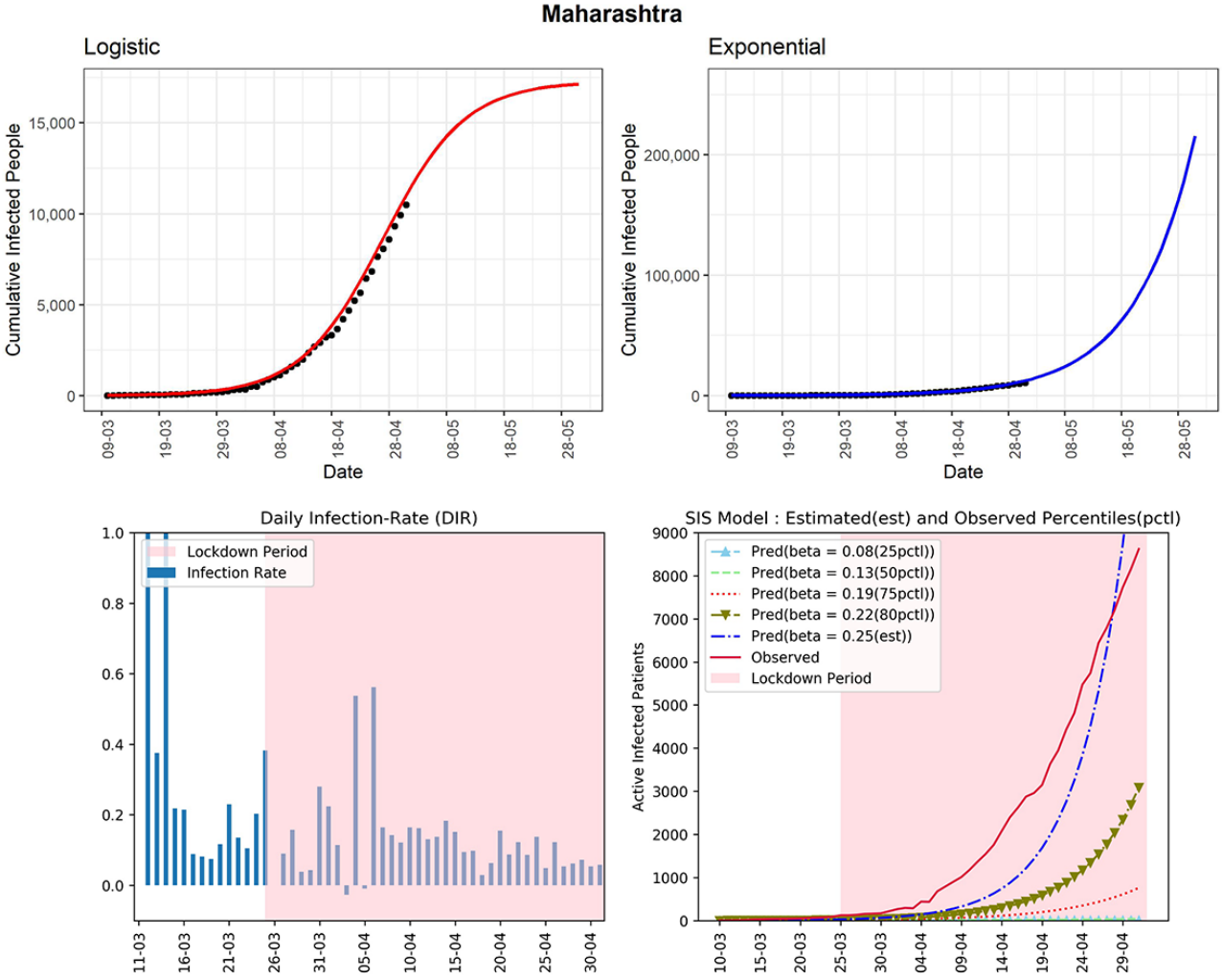
[d]COVID-19: coronavirus disease.

[e]LC_{pred}: linear combination prediction.

Maharashtra

The situation in Maharashtra is currently very severe with respect to the active number of cases (see Figure 4). As of May 1, 2020, the total number of infected cases is 10,498. The logistic model indicates that, in another 30 days from now, the state could observe around 17,100 cumulative infected cases. The DIRs for this state were between 0.03 and 0.15 in the last 2 weeks, and it was more than 0.4 for 2 days at the beginning of April. Note that, for Maharashtra, the lower DIR values of 0.03 may not indicate a good sign since the total number of *active infected cases* is above 8000. Thus, a DIR value of 0.03 for a day implies 8000 x 0.03 = 240 new infected cases. The curves from the SIS model are alarming as the observed active infected patients (red line, fourth panel) line is far above the predicted line with estimated infection rate at the 80th percentile of observed DIRs (β=0.22). It is apparent from the graphs that even after 30 days of lockdown, Maharashtra has not seen any decline in the number of active cases. The estimated R_0 for Maharashtra obtained from the fitted SIS model is 3.5, which is the highest among all the states. This may also indicate that there could be a large number of people who are in the community without knowing that they are carrying the virus. The state can be considered to be in stage 3.

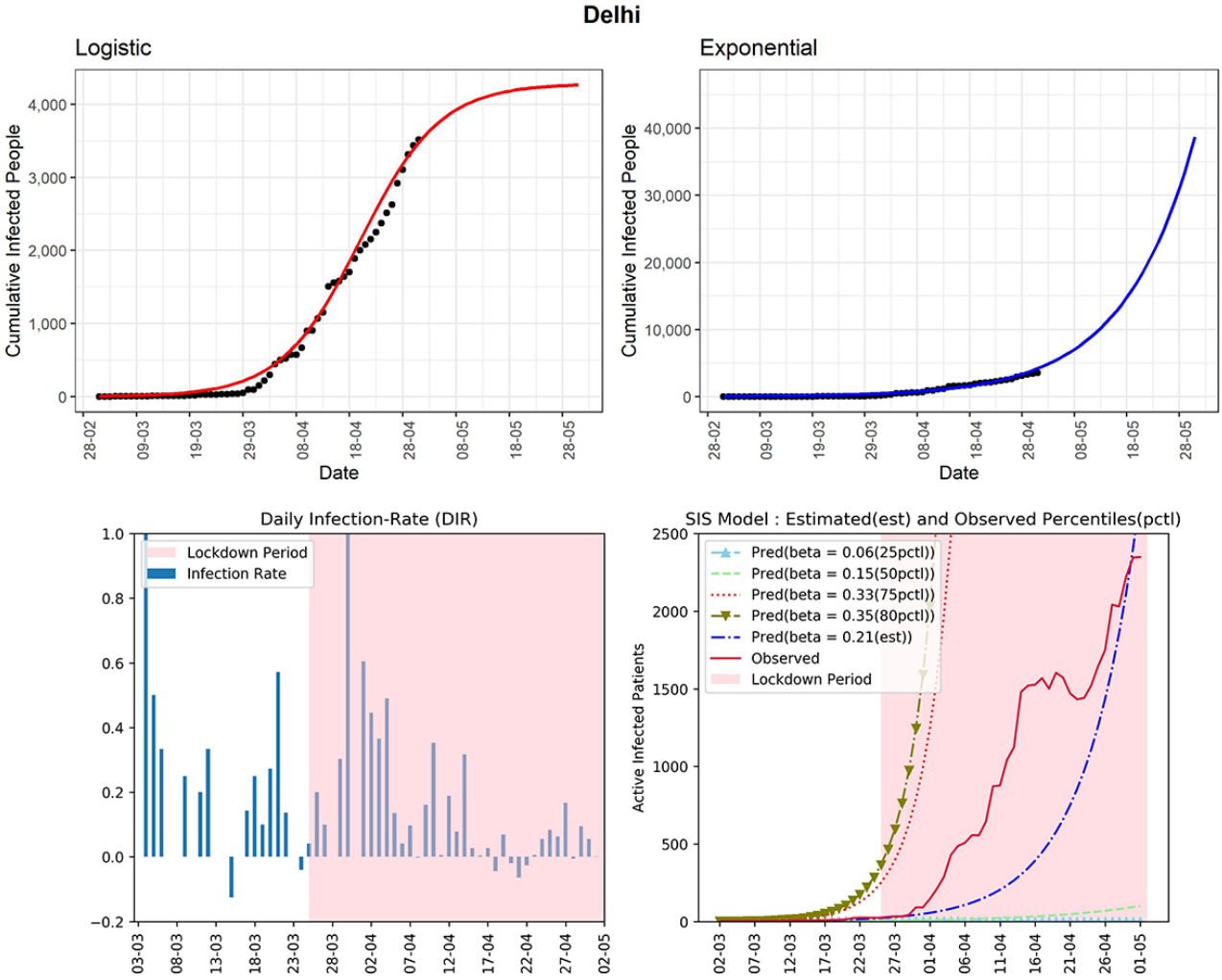
Figure 4. Graphs for the state of Maharashtra. SIS: susceptible-infectious-susceptible.



Delhi

Delhi, being a state of high population density, has already observed 3515 confirmed COVID-19 cases (see Figure 5). Based on the logistic model, the predicted number of cumulative infected cases could reach around 4200 in the next 30 days. The DIR has not seen a downward trend in the past few days. The curve (red line, fourth panel) of observed active infected patients was showing a downward trend from April 20 to April 23, 2020. However, the same graph has picked up exponential growth in the last few days. This is an important observation that illustrates why we need a continuous downward trend of active cases for at least 14 days and that a slight relaxation may put a state in the same severe condition where it was earlier. The estimated R_0 for the state obtained from the fitted SIS model being 2.94 is quite alarming. The observed DIR has been currently fluctuating between –0.06 and 0.17 in the last 2 weeks. The occasional high DIR may suggest that there could be many people who are in the community without knowing that they are already infected with COVID-19. The state could be heading to community spread of COVID-19 (stage 3).

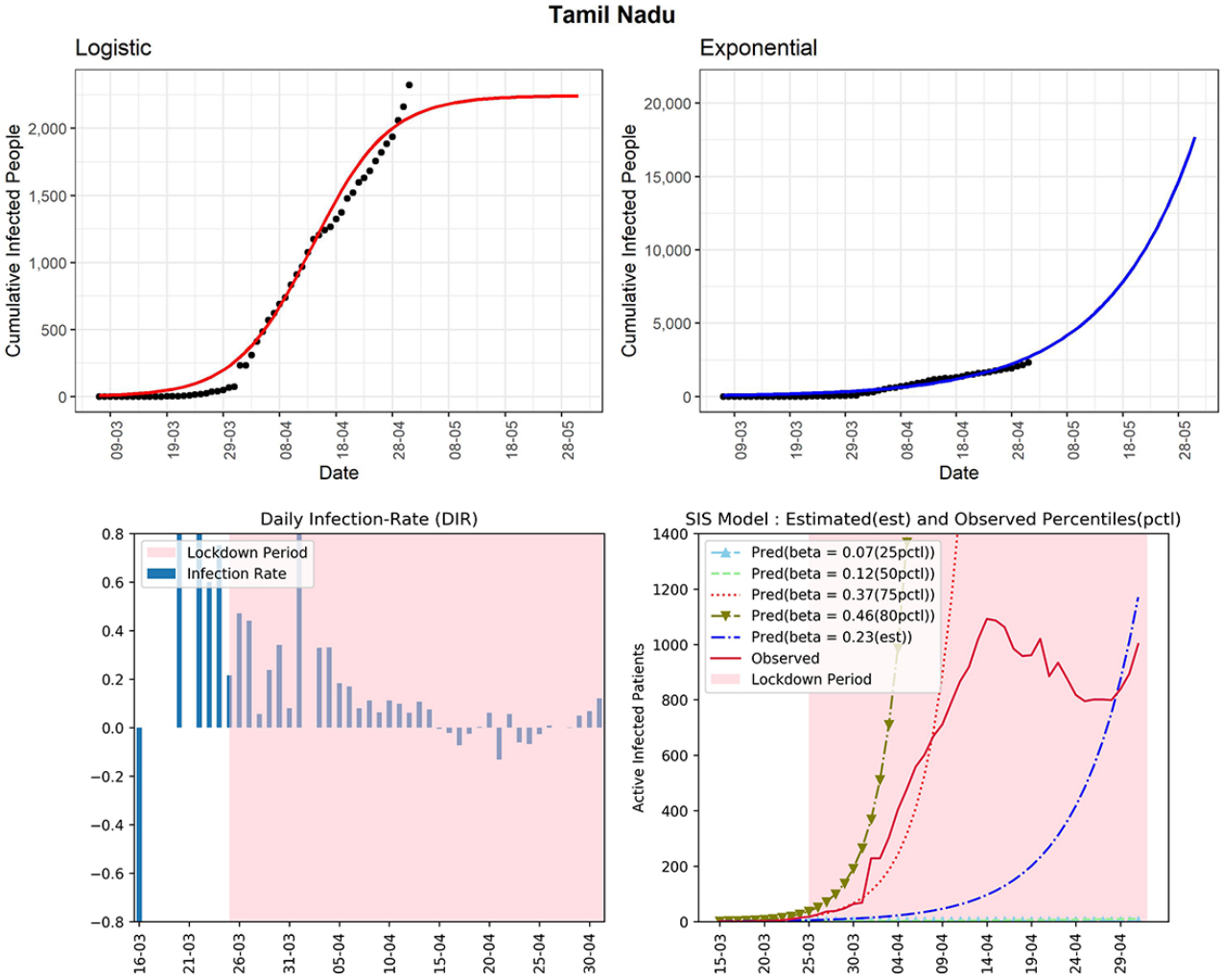
Figure 5. Graphs for the state of Delhi. SIS: susceptible-infectious-susceptible.



Tamil Nadu

The cumulative infected cases in Tamil Nadu is 2323 (see Figure 6). The state has observed a high DIR of more than 0.7 for some days in March. Tamil Nadu is one of the states where the effect of lockdown is visible from the declining DIRs from the beginning to the end of April. However, there was again an increasing trend in DIR over the last 3 days. The DIRs were between –0.13 and 0.12 over the previous 2 weeks. The latter part of the curve (red line, fourth panel) of observed active infected patients is showing a decreasing trend first but then an increasing trend again. The estimated R_0 for this southern state obtained from the fitted SIS model is 3.22, which is quite high. The preventive measures need to be maintained to bring down the active cases as well as to stop new infections in this state.

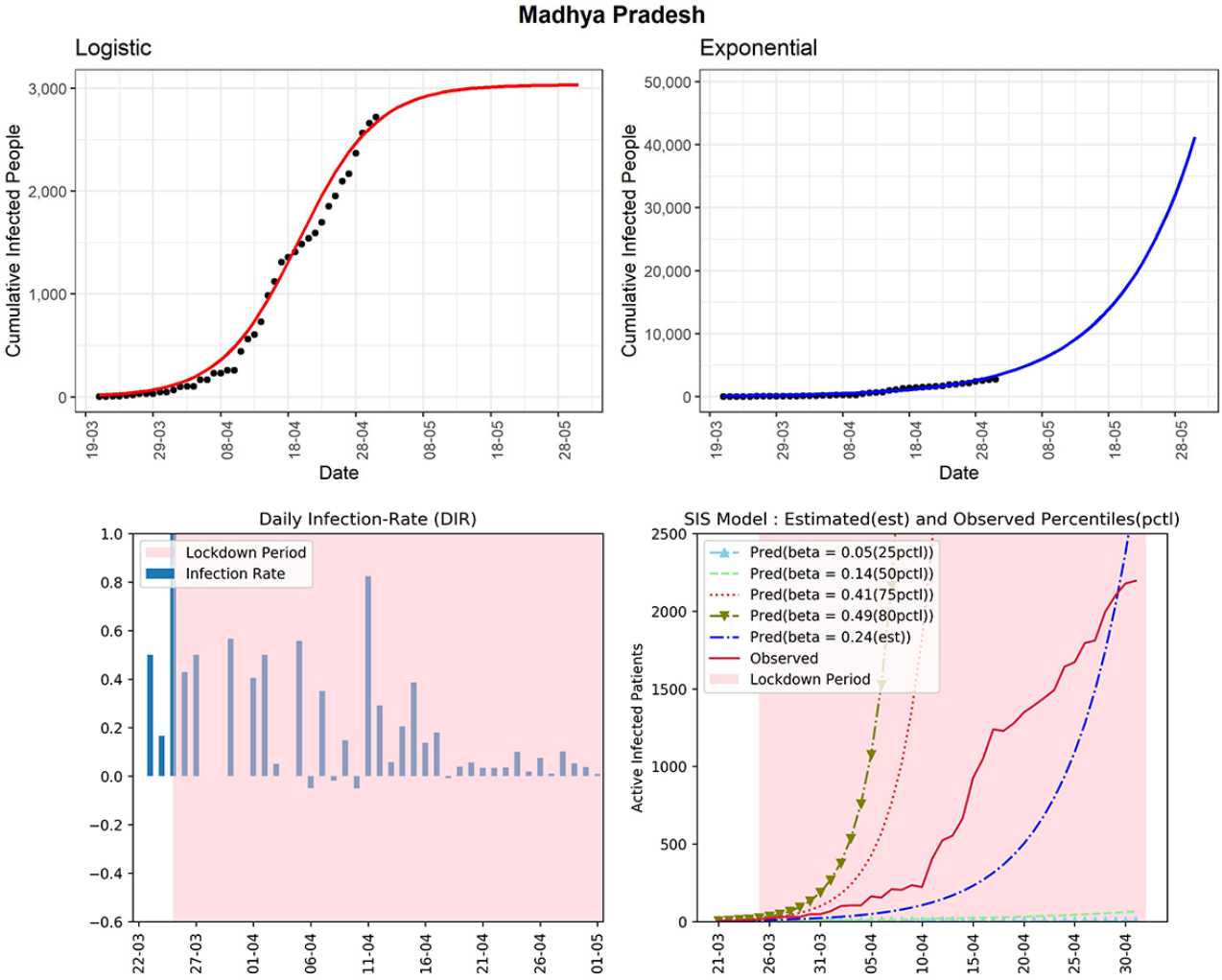
Figure 6. Graphs for the state of Tamil Nadu. SIS: susceptible-infectious-susceptible.



Madhya Pradesh

This state currently has 2719 cumulative COVID-19 cases (see Figure 7). In the later part of the lockdown, after April 10, 2020, the state observed a few days with a DIR more than 0.4. Until now, there is no sight of a declining trend in the DIRs. The same type of conclusion can be drawn from the curves of the SIS model. The curve (red line, fourth panel) of observed active infected patients is in between the curves of the SIS model corresponding to the 50th-75th percentiles' curves. The same curve is maintaining an exponential growth after April 10. Note that, for Madhya Pradesh, the 50th percentile of observed DIRs was 0.14, which is higher than the 50th percentile of some other states. The estimated R_0 for this state obtained from the fitted SIS model was 3.36, which is pretty high. The high growth of active cases in the latter part of the lockdown is a major concern for this state. It could be a signal of a community spread of COVID-19.

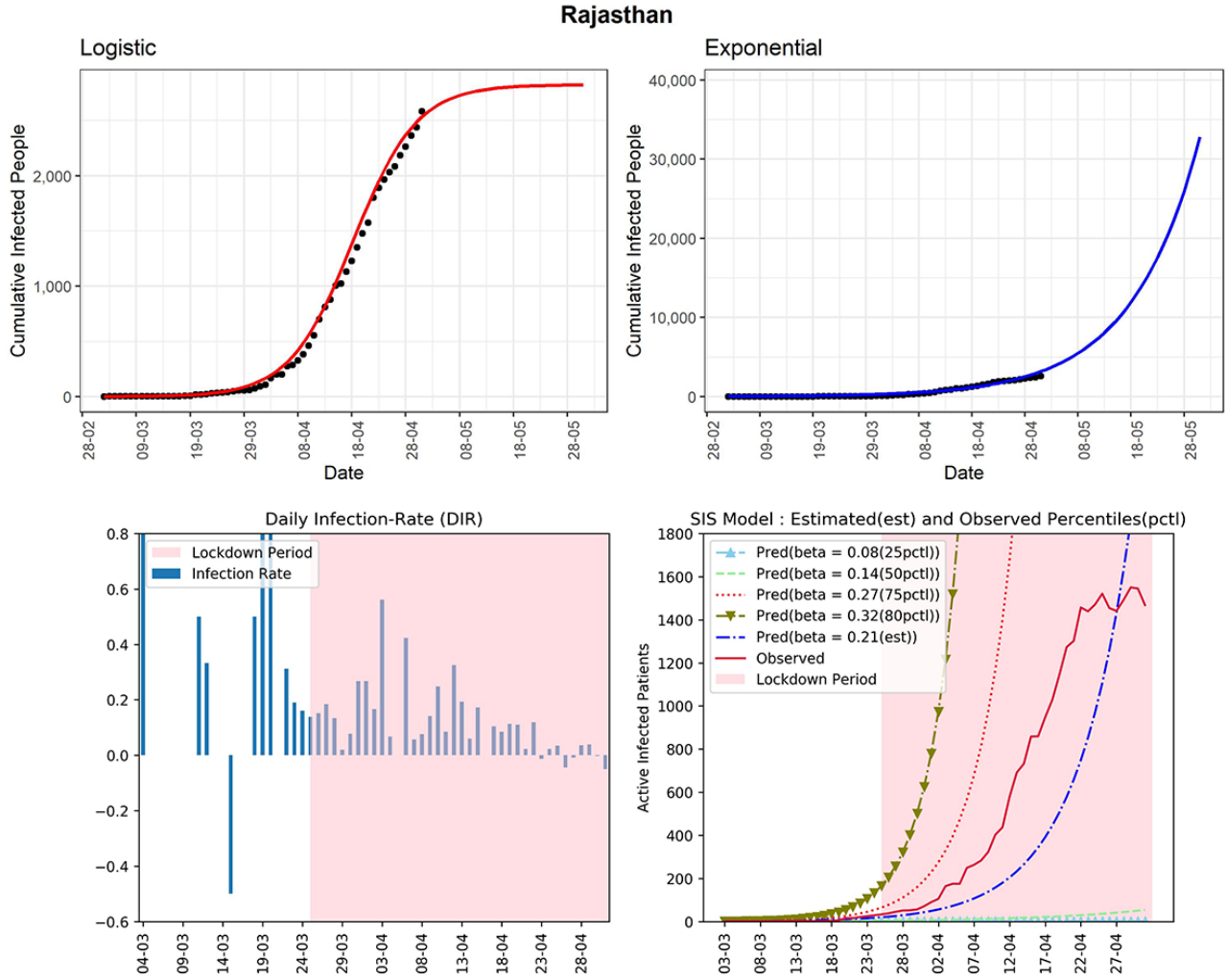
Figure 7. Graphs for the state of Madhya Pradesh. SIS: susceptible-infectious-susceptible.



Rajasthan

The western state of India, Rajasthan, reported 2584 cumulative infected COVID-19 cases (see Figure 8). The logistic model indicates that in another 30 days from now, the state could observe around 2800 cumulative infected cases. The state has seen a declining trend in the DIRs during the last part of April. The curve (red line, fourth panel) of observed active infected patients is increasing and is in between the curves of the SIS model corresponding to the 50th-75th percentiles of observed DIRs (0.14-0.27) using the SIS model. In the last 2 weeks, the DIRs for Rajasthan have been fluctuating between –0.05 and 0.12. The active cases in this state have not increased too much in the latter part of April. An increase in recovery cases is one of the reasons. The estimated R_0 for Rajasthan obtained from the fitted SIS model was 2.94. Therefore, the current COVID-19 situation in the state is not controlled yet.

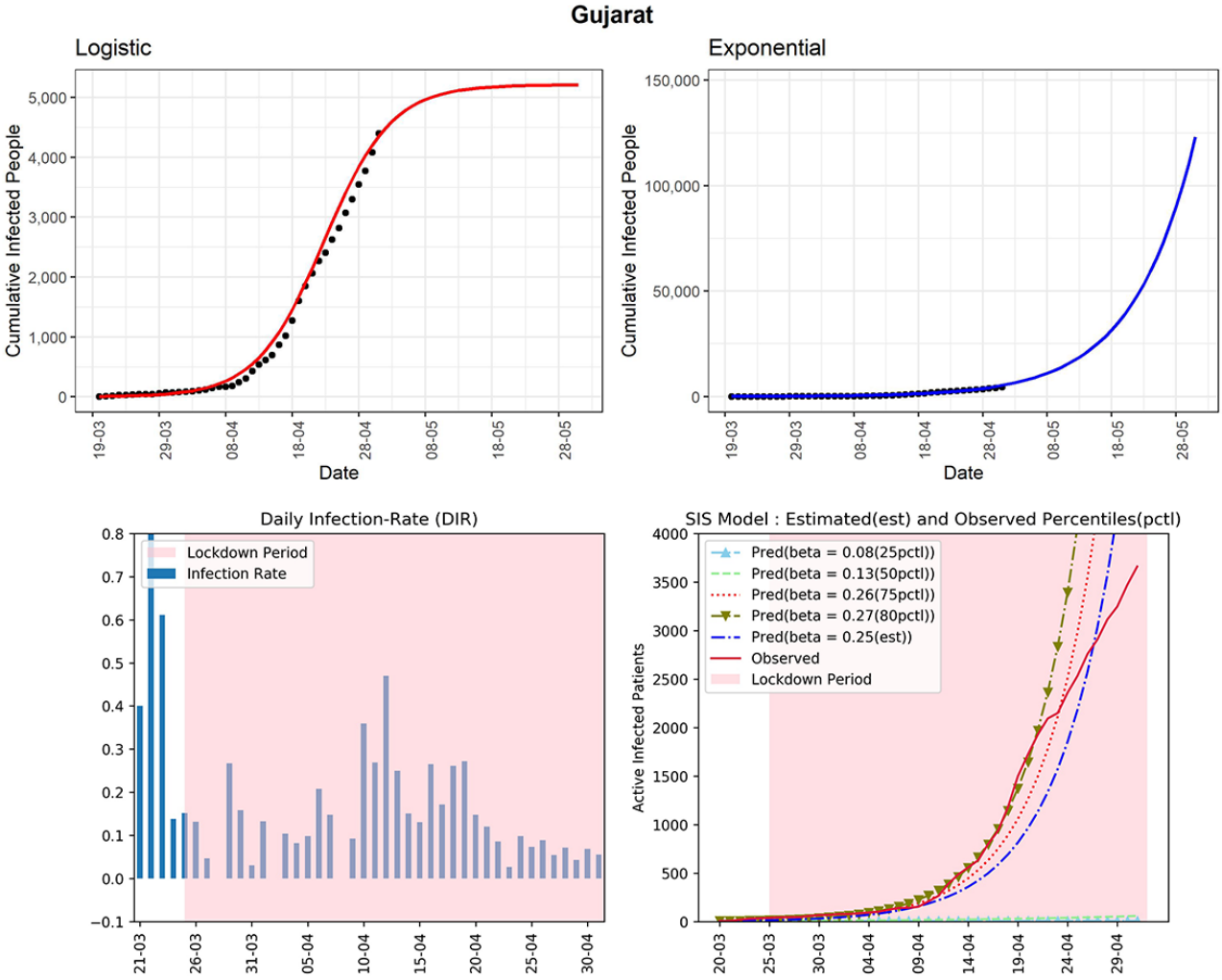
Figure 8. Graphs for the state of Rajasthan. SIS: susceptible-infectious-susceptible.



Gujarat

The state is currently experiencing exponential growth with 4395 as the cumulative number of COVID-19 cases (see Figure 9). Using the logistic model, the cumulative infected cases could reach around 5206 in the next 30 days. There is apparently a stable rather than a declining trend in the DIRs in the last few days. The DIRs were in the range of 0.03-0.27 in the last 2 weeks, which are on the higher side. The curve (redline, fourth panel) of observed active infected patients is close to the curve of the SIS model corresponding to the estimated 75th percentile of observed DIR (β=.26). Surprisingly, in the latter part of the lockdown, the red line is experiencing exponential growth. The estimated R_0 for Gujarat obtained from the fitted SIS model was 3.5, which is one of the highest. This state needs immediate intervention to implement all the preventive measures already taken by the Government strictly.

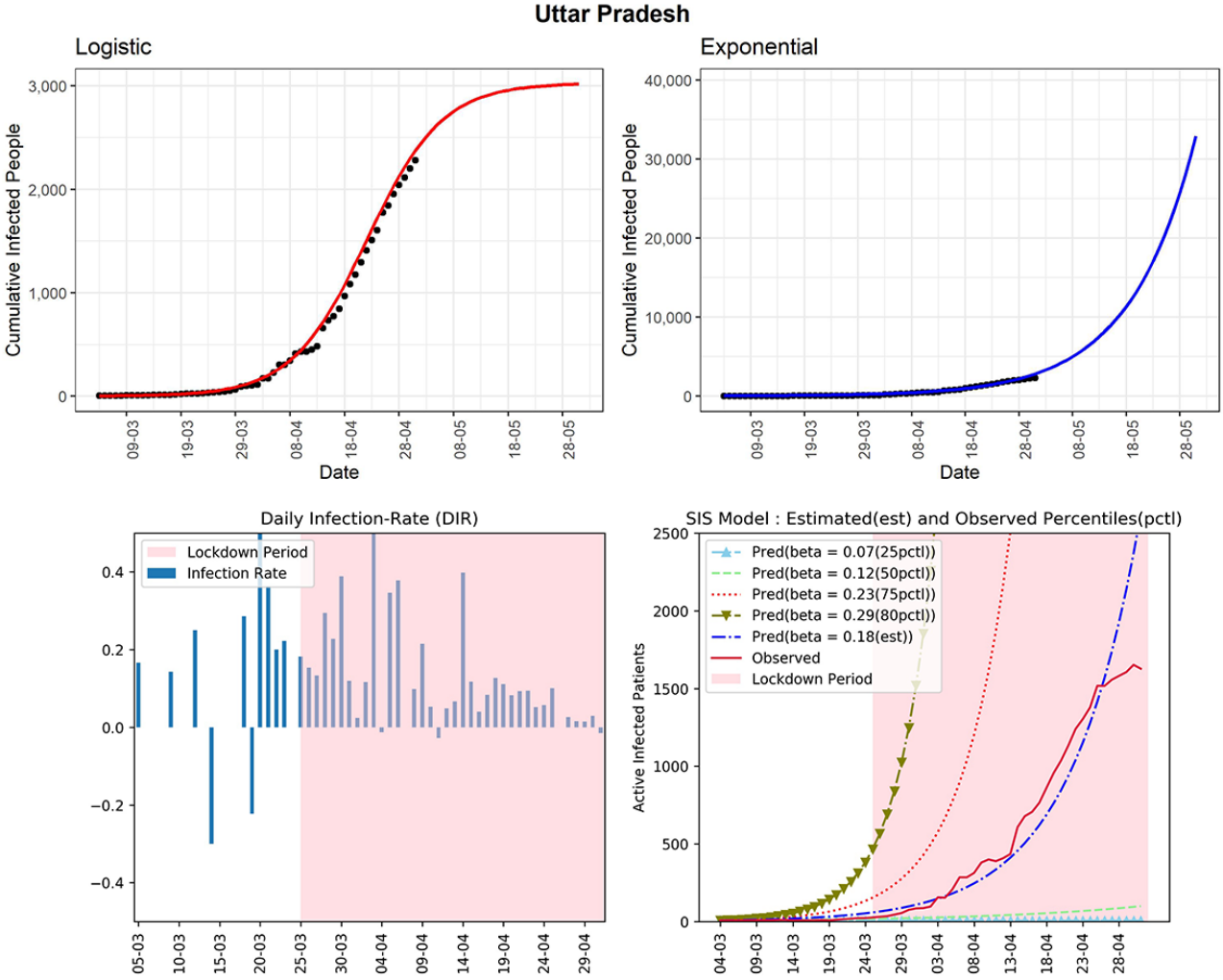
Figure 9. Graphs for the state of Gujarat. SIS: susceptible-infectious-susceptible.



Uttar Pradesh

This northern state of India has experienced 2281 cumulative COVID-19 cases (see Figure 10). Using the logistic model, the predicted number of cumulative confirmed cases could be around 3000 in the next 30 days. The curve (red line, fourth panel) of observed active infected patients was in between the curves of the SIS model corresponding to the 50th and 75th percentiles of observed DIRs (β=0.12 and 0.23, respectively). The DIR was in the range of –0.02 to 0.13 without a moderately decreasing trend in the last 2 weeks. The overall growth of active cases was still exponential, which is a major concern for the state. The estimated R_0 for the state obtained from the fitted SIS model was 2.52. There could be many unreported cases in the state. In the absence of preventive measures, unreported cases can contribute to spreading the virus in the community.

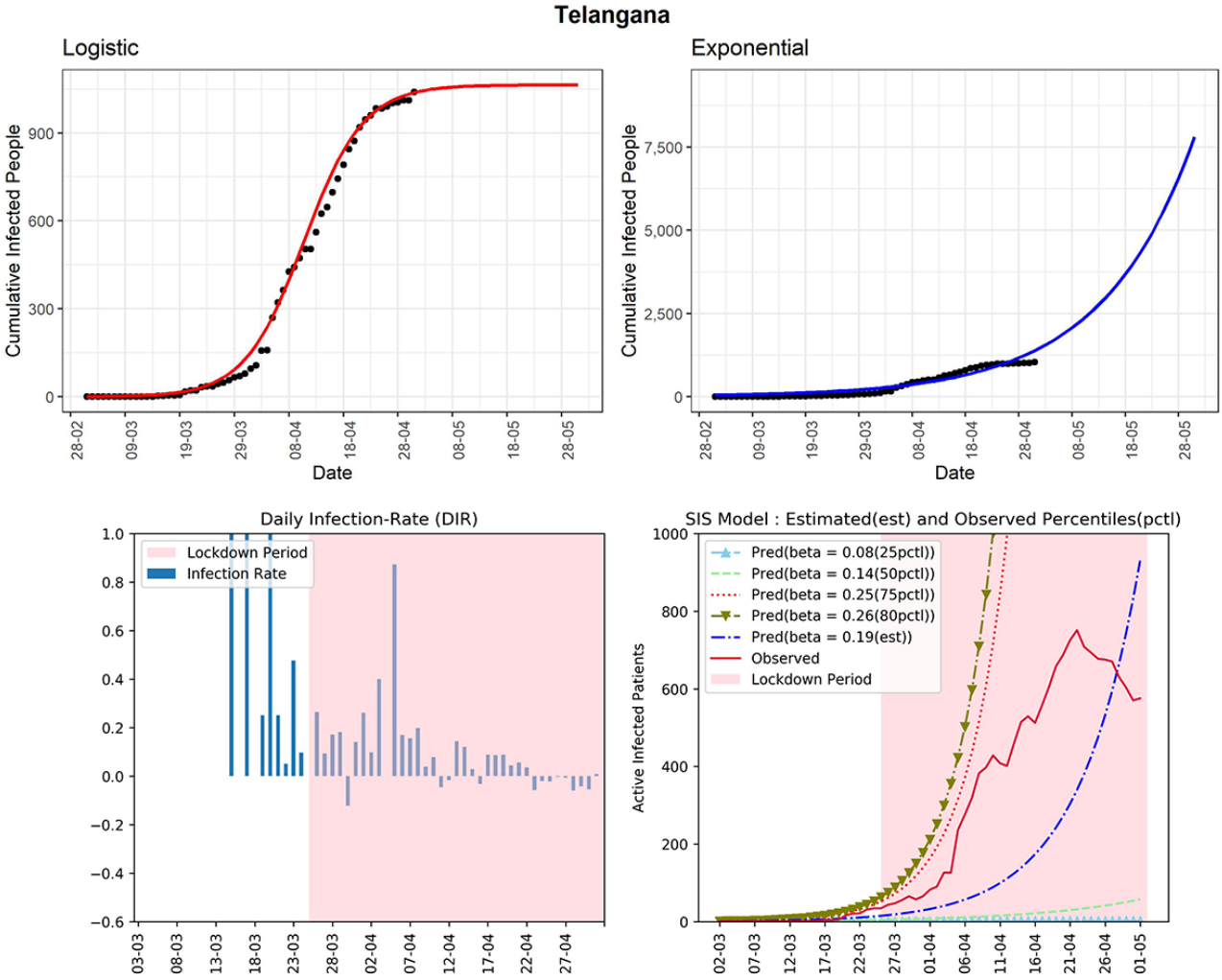
Figure 10. Graphs for the state of Uttar Pradesh. SIS: susceptible-infectious-susceptible.



Telangana

The southern Indian state of Telangana has reported 1039 cumulative infected cases until now (see Figure 11). The logistic model predicts that the number of cases for the state will be around 1063 in the next 30 days. In the fourth graph, the curve (red line, fourth panel) shows that the active number of cases has continuously remained below the curve of the SIS model corresponding to the 75th percentile of the observed DIRs (β=0.25). The estimated R_0 for Telangana obtained from the fitted SIS model was 2.66. From April 23, 2020, onwards, there is a visible downward trend in the same line graph. This evidence is also supported by a clear decreasing trend in the DIR for more than 2 weeks. The state is going in the right direction to control the COVID-19 pandemic. However, preventive measures need to be in place to see long-term success against the virus.

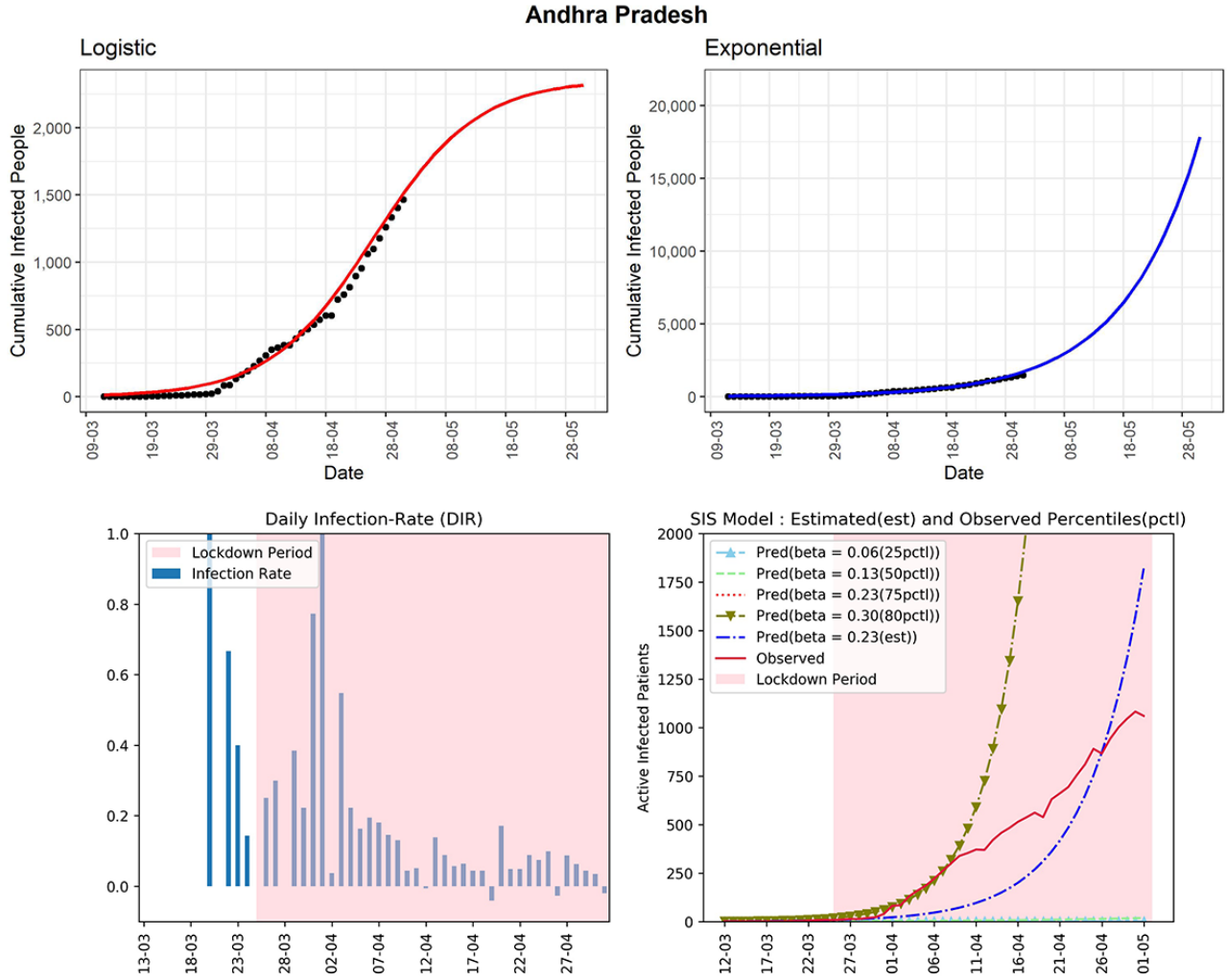
Figure 11. Graphs for the state of Telangana. SIS: susceptible-infectious-susceptible.



Andhra Pradesh

This state has observed 1463 confirmed cumulative infected cases so far (see Figure 12). The curve (red line, fourth panel) shows that the number of active cases is now below and close to the curve of the SIS model corresponding to the 75th percentile of the observed DIR (β=0.23). The logistic model predicted that the maximum number of cumulative infected people will be around 2313 in the next 30 days. Despite showing good progress in mid-April, the state is again showing an exponential type growth rate. This state has seen DIRs between –0.04 and 0.17 during the last 2 weeks. The estimated R_0 for this state obtained from the fitted SIS model was 3.22, which is quite high. The state has shown a few short declining trends, without any long-term declining trend in the DIR values. It could be due to many unreported infected cases in the community that is spreading the virus.

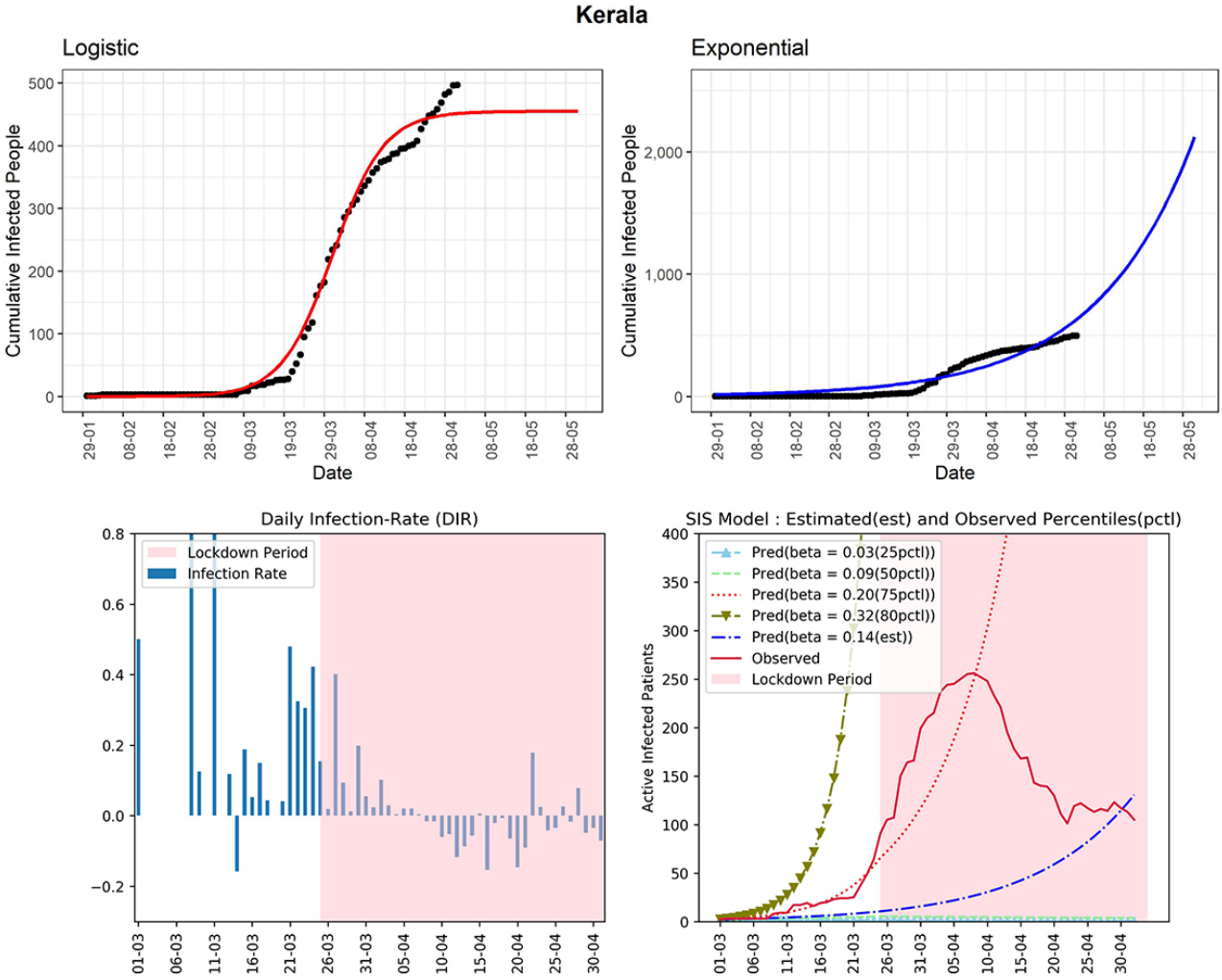
Figure 12. Graphs for the state of Andhra Pradesh. SIS: susceptible-infectious-susceptible.



Kerala

The southern state of Kerala is one of the few states of India where the effect of the lockdown is observed strongly. The state reported the first COVID-19 case in India. However, Kerala has been able to control the spread of the virus to a large extent to date. The cumulative number of cases reported until now is 497 (see Figure 13). It is a state where the curve (red line, fourth panel) of observed active infected patients is going down, which shows that the lockdown and other preventive measures have been effective for this state. The DIR has declined steadily from positive to negative values. However, some spikes in the DIR values can be noticed in the last few days. The estimated R_0 for Kerala obtained from the fitted SIS model was 1.96, which is quite low compared to other states. It can be expected that with the present scenario of the extended lockdown the number of active cases will be few at the end of May.

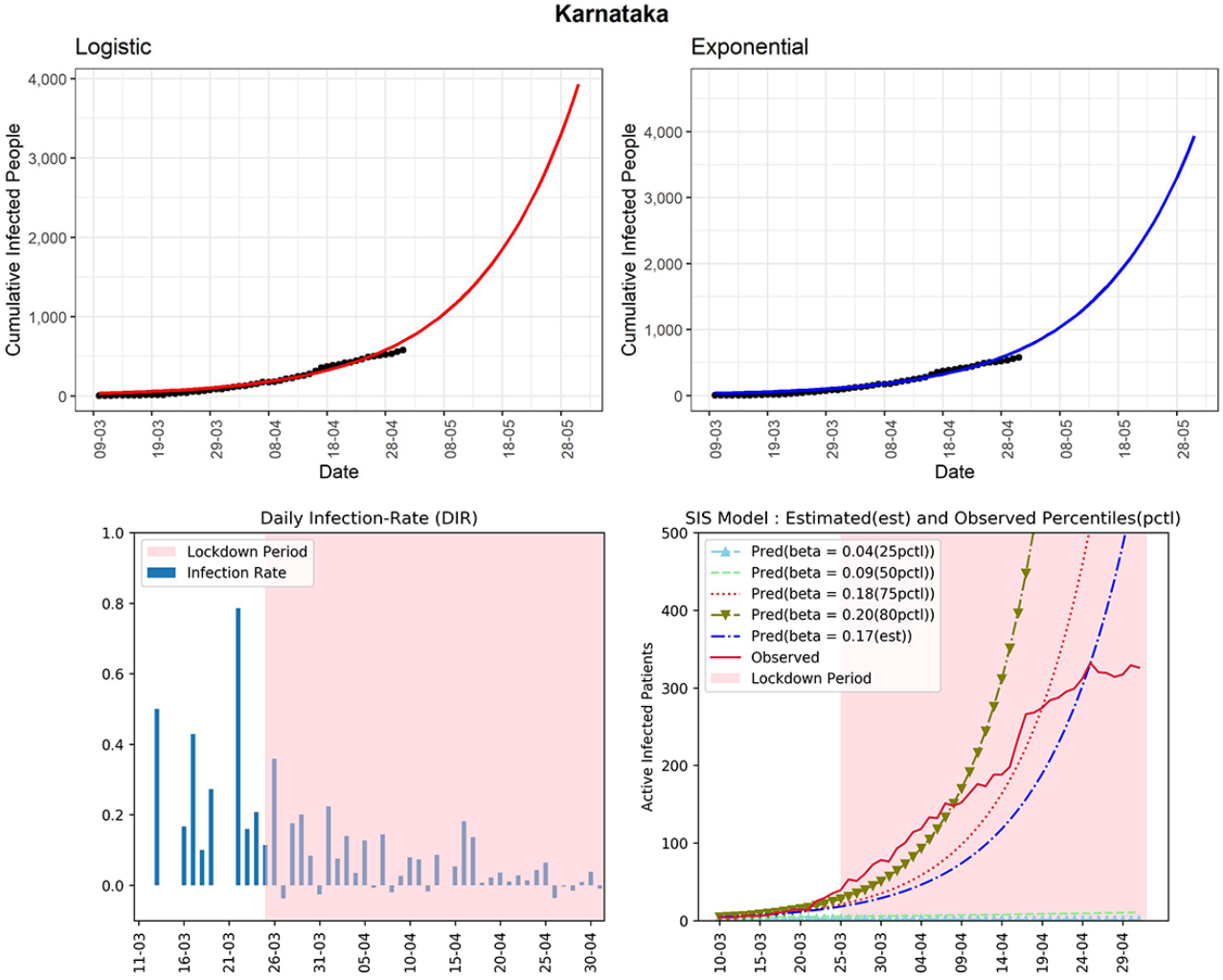
Figure 13. Graphs for the state of Kerala. SIS: susceptible-infectious-susceptible.



Karnataka

The state has managed to restrict the cumulative infected cases to 576 until now (see Figure 14). The curve (red line, fourth panel) of observed active infected patients is now below the curve of the SIS model corresponding to the 75th percentile of the observed DIRs (β=0.18). Compared to other states, the 75th percentile DIR is on the lower side. The estimated R_0 for the state obtained from the fitted SIS model was 2.38. We can observe the ups and downs of the DIR with an upper bound of 0.2 from early April. This state has seen DIRs between –0.04 and 0.06 during the last 2 weeks. However, the preventive measures need to be maintained to control the spread of the virus.

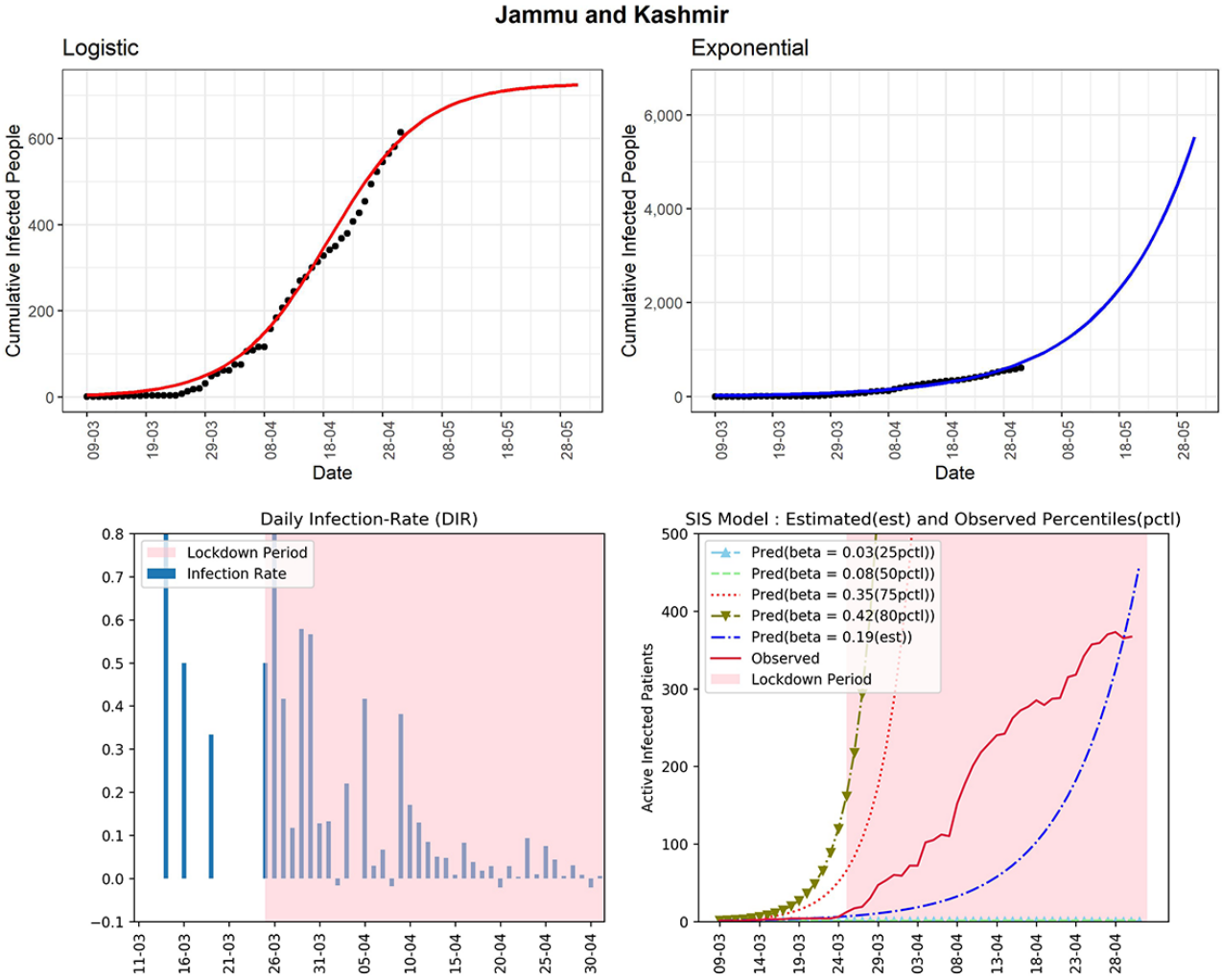
Figure 14. Graphs for the state of Karnataka. SIS: susceptible-infectious-susceptible.



Jammu and Kashmir

The northernmost state of Jammu and Kashmir has seen 614 cumulative infected cases so far (see Figure 15). The curve (red line, fourth panel) of observed active infected patients has been far below the curve of the SIS model corresponding to the 75th percentile of the observed DIR (β=0.35). The estimated R_0 for the state obtained from the fitted SIS model was 2.66. From April 9, 2020, onwards, the DIR was apparently decreasing. There are some spikes in DIR values occasionally. It could be due to many unreported cases, which are allowing the infection to spread even during the lockdown period. The DIR was in the range of –0.02 to 0.09 in the last 2 weeks.

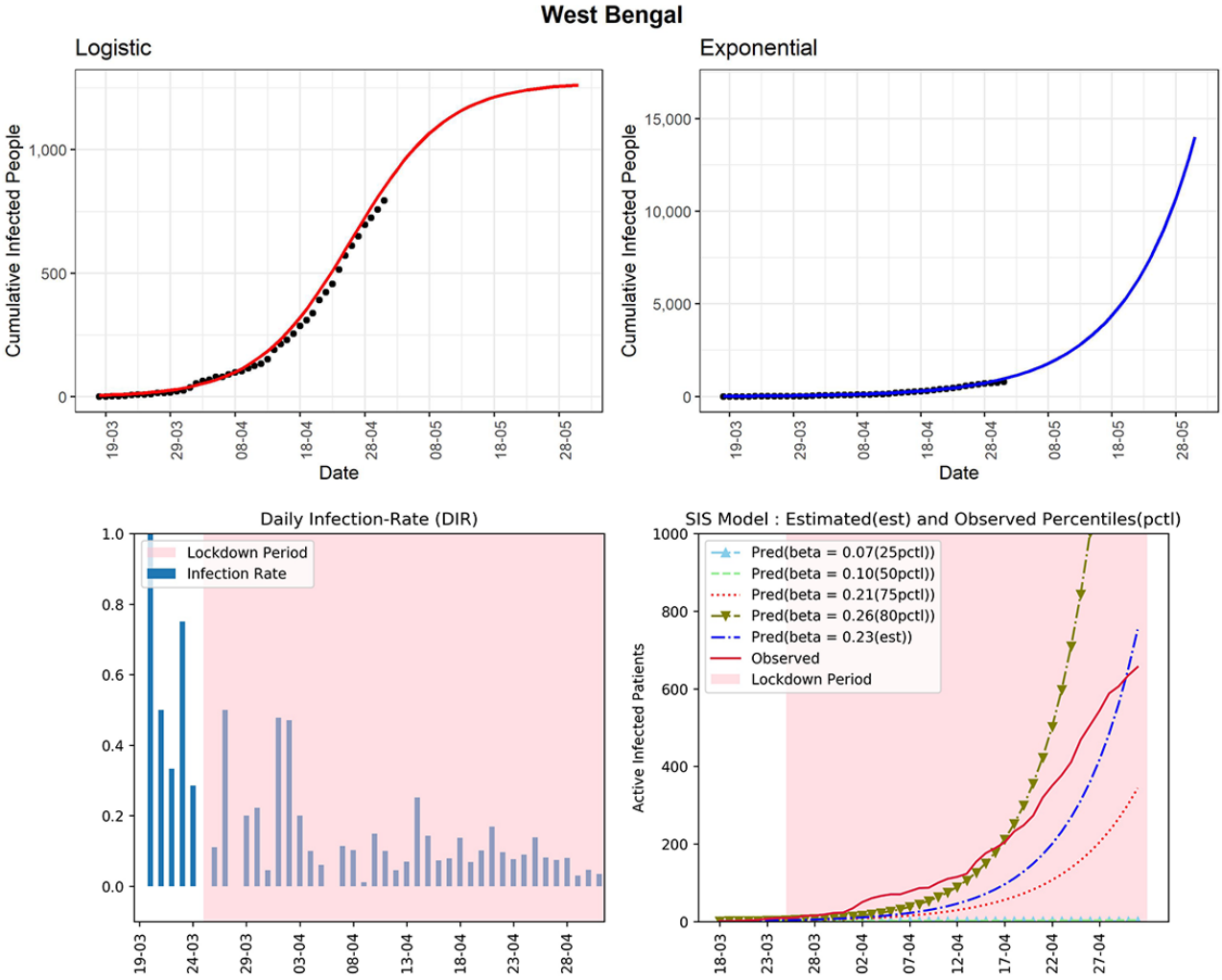
Figure 15. Graphs for the state of Jammu and Kashmir. SIS: susceptible-infectious-susceptible.



West Bengal

The state of West Bengal is standing at 795 cumulative infected cases as of now (see Figure 16). The DIR values do not show any trend of slowing down in recent times. Based on the logistic model, the predicted cumulative infected cases could be around 1261 in the next 30 days. The curve (red line, fourth panel) of observed active infected patients was above the curve of the SIS model corresponding to the 75th percentile of the DIR (β=0.21). The DIRs were between 0.03 and 0.17 in the last 2 weeks. The cumulative infected cases graphs based on logistic and exponential models (first and second panels), as well as the active cases–based curve (red line, fourth panel) were all showing exponential type growth rates. The estimated R_0 for West Bengal obtained from the fitted SIS model was 3.22, which is quite high. Strict implementation of preventive measures is needed to control the spread of COVID-19 in the state.

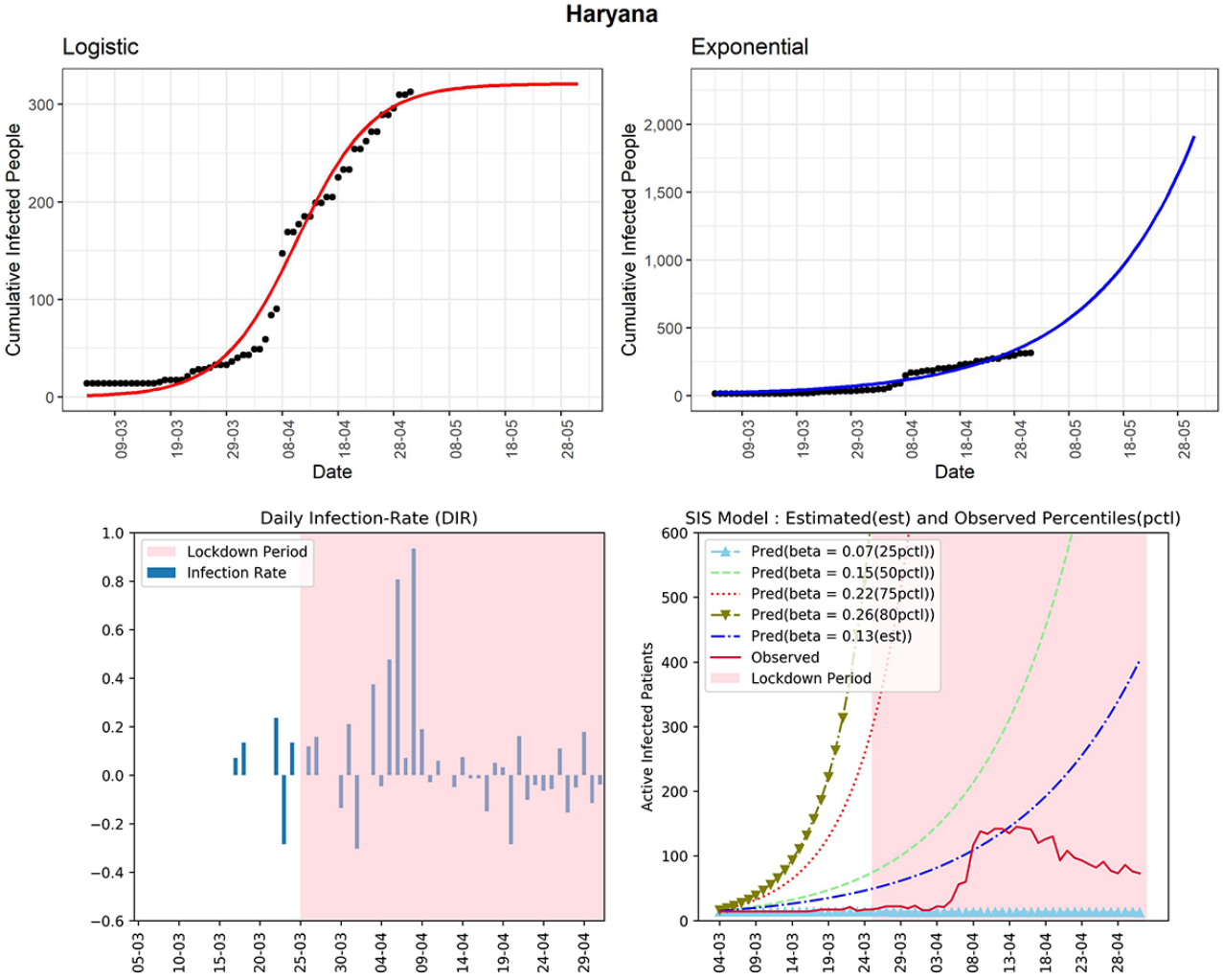
Figure 16. Graphs for the state of West Bengal. SIS: susceptible-infectious-susceptible.



Haryana

The state of Haryana has observed 313 cumulative infected COVID-19 cases so far (see Figure 17). It has reported a very low rate of infection in the latter part of the lockdown except for the last reported day. In the fourth panel, the curve (red line) of observed active infected patients is now far below the curve of the SIS model corresponding to the 50th percentile of observed DIRs (β=0.15) and is showing a decreasing trend in the latter part. The estimated R_0 for the state obtained from the fitted SIS model was 1.82, which is on the lower side. The DIRs were between –0.28 and 0.18 in the last 2 weeks. Under the assumption that there are not too many unreported cases, the situation in Haryana seems to be under control.

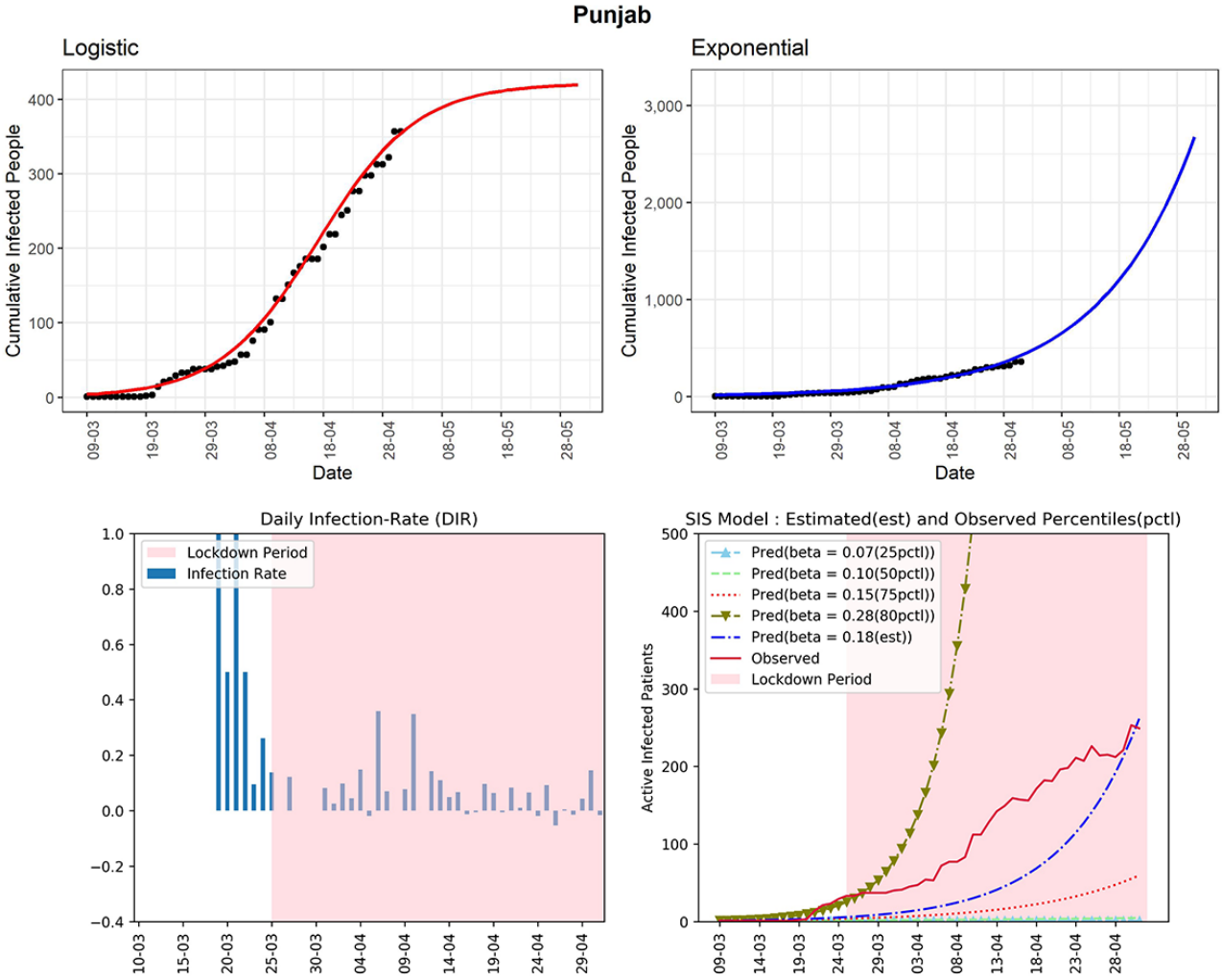
Figure 17. Graphs for the state of Haryana. SIS: susceptible-infectious-susceptible.



Punjab

The state of Punjab has reported 357 cumulative infected cases until now (see Figure 18). Based on the logistic model, the predicted cumulative confirmed cases could be around 419 in the next 30 days. The curve (red line) of observed active infected patients was in between the SIS model curves corresponding to the estimated 75th and 80th percentiles of observed DIRs (β=0.15 and 0.28, respectively). The estimated R_0 for Punjab obtained from the fitted SIS model was 2.52. The DIRs were between –0.05 and 0.14 in the last 2 weeks, which is good given the low number of active infected cases in the state.

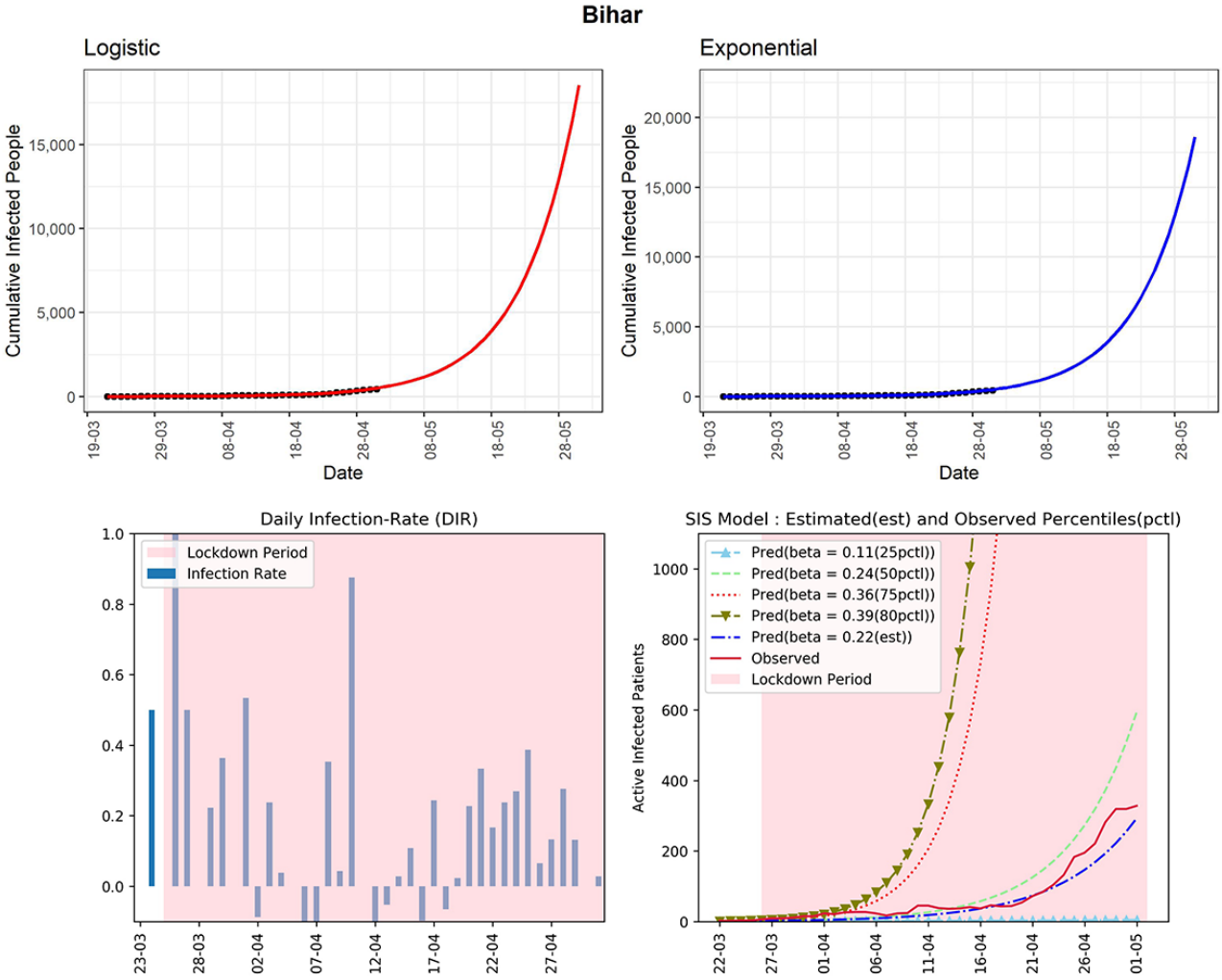
Figure 18. Graphs for the state of Punjab. SIS: susceptible-infectious-susceptible.



Bihar

The state has reported 426 cumulative infected cases until now (see Figure 19). Based on the logistic model, Bihar could see 16,452 total infected cases in the next 30 days. The estimated R_0 for the state obtained from the fitted SIS model was 3.08. It may be an overestimate. However, the DIRs showed no sign to decline in the last 2 weeks, with the highest reported value of 0.39. It may indicate many unreported cases in the state. However, the cumulative infected cases are still low for this state. Effective implementation of preventive measures is needed for the state.

Figure 19. Graphs for the state of Bihar. SIS: susceptible-infectious-susceptible.



Joint Interpretation of Results From all Models

We consider a data-driven assessment of the COVID-19 situation based on the growth of active cases in recent times (red line, fourth panel in each state plot) along with the DIR values for each state (see Table 1). We labeled the condition of a state as *severe* if we observed a nondecreasing trend in DIR values over the last 2 weeks and a near exponential growth in active infected cases, as *moderate* if we observed an almost decreasing trend in DIR values over the last 2 weeks and neither increasing nor decreasing growth in active infected cases, and as *controlled* if we observed a decreasing trend in the last 2 weeks' DIR values and a decreasing growth in active infected cases. It can be noticed that the logistic model is underpredicting the next 30-day prediction, whereas the exponential model is overpredicting the same. As we have argued earlier, despite nationwide lockdown, people are out of their homes for essential businesses, which can contribute to the spreading of the virus. The maximum value of DIR in the last 2 weeks can capture how severely COVID-19 is spreading in recent times. Note that, for example, a DIR value of 0.10 cannot be interpreted in the same way for two different states with, for example, 500 and 5000 active cases. For the first state, we see 500 x 0.10 = 50 new cases, and for the second state, we observe 5000 x 0.10 = 500 new cases. In an attempt to capture these various subtleties in a realistic prediction, we propose a linear combination prediction (LC_{pred}) of the logistic and the exponential predictions using the maximum value of DIR over the last 2 weeks (DIR_{max}) as a weighting coefficient (tuning parameter) as follows:

LC_{pred} = Logistic-prediction × (1 – λ) + Exponential-prediction × λ, where λ = max {0, min {1, DIR_{max}}}

Such a choice of the tuning parameter λ makes the LC_{pred} equal to the logistic prediction when DIR_{max} is negative with λ=0. On the other hand, the LC_{pred} is equal to the exponential prediction when DIR_{max} is more than 1 with λ=1. When DIR_{max} is in between 0 and 1, the LC_{pred} is a combination of the predictions from the logistic and the exponential models. Given the situation in the entirety India, we recommend LC_{pred} along with the exponential predictions (particularly for states in severe condition) to be used for assessment purposes in each state.

Extensive testing may not be logistically feasible given India's large population and limited health care budget. The undertesting can significantly impact the logistic prediction and less so the exponential prediction since the first one is underforecasting and the second one is overforecasting. The DIR indirectly captures the undertesting phenomenon. Thus, the LC_{pred} with

(a truncated version of) DIR as the weight (λ) can be thought of as a treatment for undertesting, albeit in a limited fashion.

From Table 1, we can see that out of 16 states for which we have predictions, 10 states lay between the linear combination (LC_{pred}) and the exponential predictions, 4 states are below the LC_{preds}, and 2 states are above the exponential predictions.

Discussion

India, a country of approximately 1.3 billion people, has reported 17,615 confirmed COVID-19 cases after 80 days (from January 30, 2020) from the first reported case in Kerala [36]. In a similar duration from the first case, the United States reported more than 400,000 cases, and both Spain and Italy reported more than 150,000 confirmed COVID-19 cases. To gain some more perspective, note that, the United States has around one-fourth of the Indian population size. Therefore, according to the reported data so far, India seems to have managed the COVID-19 pandemic better compared to many other countries. One can argue that India has conducted too few tests compared to its population size [37]. However, a smaller number of testing may not be the only reason behind the low number of COVID-19–confirmed cases in India so far. India has taken many preventive measures to combat COVID-19 in much earlier stages compared to other countries, including a nationwide lockdown from March 25, 2020. Apart from the lockdown, people have certain conjectures about possible reasons behind India's relative success (eg, measures like the travel ban relatively early, use of Bacille Calmette-Guerin vaccination to combat tuberculosis in the population that may have secondary effects against COVID-19 [38,39], exposure to malaria and antimalarial drugs [40], and hot and humid weather slowing the transmission [41,42]). However, as of now, there is no concrete evidence to support these conjectures, although some clinical trials are currently underway to investigate some of these [43].

Note that India may have seen fewer COVID-19 cases until now, but the war is not over yet. There are many states like Maharashtra, Delhi, Madhya Pradesh, Rajasthan, Gujarat, Uttar Pradesh, and West Bengal who are still at high risk. These states may see a significant increase in confirmed COVID-19 cases in the coming days if preventive measures are not implemented properly. On the positive side, Kerala has shown how to effectively "flatten" or even "crush the curve" of COVID-19 cases. We hope India can limit the spread and impact of COVID-19 with a strong determination in policies as already shown by the central and state governments.

There are a few other works that are based explicitly on Indian COVID-19 data. Das [30] has used the epidemiological model to estimate the R_0 at national and some state levels. Ray et al [44] used a predictive model for case counts in India. They also discussed hypothetical interventions with various intensities and provided projections over a time horizon. Both the papers have used the susceptible-infected-recovered model (or some extension) for their analysis and prediction. As we discussed earlier, considering the great diversity in every aspect of India, along with its vast population, it would be a better idea to look at each of the states individually. The study of each of the states individually would help decide further actions to contain the spread of the disease, which can be crucial for the specific states only. In this paper, we have mainly focused on the SIS model along with the logistic and the exponential models at each state (restricting to only those states with enough data for prediction). The SIS model takes into account the possibility that an infected individual can return to the susceptible class on recovery because the disease confers no long-standing immunity against reinfection. In South Korea, the health authorities discovered 163 patients who tested positive again after a full recovery [45,46]. The WHO is aware of these reports of patients who were first tested negative for COVID-19 using polymerase chain reaction testing and then after some days, tested positive again [47]. In a scientific brief, dated April 24, 2020, the WHO said, "there is currently no evidence that people who have recovered from COVID-19 and have antibodies are protected from a second infection" [48]. Several research papers have reported that, even though being infected by the virus may build immunity against the disease in the short-term, it is not a guaranteed fact, and it may not be long-lasting protection [49-51].

A report based on one particular model can mislead us. Here, we have considered the exponential, the logistic, and the SIS models along with the DIR. We have interpreted the results jointly from all models rather than individually. We expect the DIR to be zero or negative to conclude that COVID-19 is not spreading in a certain state. Even a small positive DIR such as 0.01 indicates that the virus is still spreading in the community and can potentially increase the DIR anytime. The states without a decreasing trend in DIR and near exponential growth in active infected cases are Maharashtra, Delhi, Gujarat, Madhya Pradesh, Andhra Pradesh, Uttar Pradesh, and West Bengal. The states with an almost decreasing trend in DIR and nonincreasing growth in active infected cases are Tamil Nadu, Rajasthan, Punjab, and Bihar. The states with a decreasing trend in DIR and decreasing growth in active infected cases in the last few days are Kerala, Haryana, Jammu and Kashmir, Karnataka, and Telangana. States with nondecreasing DIR need to do much more in terms of the preventive measures immediately to combat the COVID-19 pandemic. On the other hand, the states with decreasing DIR can maintain the same status to see the DIR become zero or negative for a consecutive 14 days to be able to declare the end of the pandemic.

Based on the modeling approaches presented in this paper, we have developed a web application [52] to see the Indian statewise forecast based on recent data that is updated regularly. The web application also offers a 30-day prediction of cumulative cases at the pan-India level by summing up the predicted cumulative cases of considered states.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Supplementary material.
[DOCX File , 20 KB - publichealth_v6i3e20341_app1.docx]

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Abbreviations

COVID-19: coronavirus disease
DIR: daily infection rate
DIR_{max}: maximum value of daily infection rate over the last 2 weeks
LC_{pred}: linear combination prediction
R_0: basic reproduction number
SIS: susceptible-infectious-susceptible
WHO: World Health Organization

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Original Paper

Real-Time Digital Contact Tracing: Development of a System to Control COVID-19 Outbreaks in Nursing Homes and Long-Term Care Facilities

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Abstract

Background: Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) can spread rapidly in nursing homes and long-term care (LTC) facilities. Symptoms-based screening and manual contact tracing have limitations that render them ineffective for containing the viral spread in LTC facilities. Symptoms-based screening alone cannot identify asymptomatic people who are infected, and the viral spread is too fast in confined living quarters to be contained by slow manual contact tracing processes.

Objective: We describe the development of a digital contact tracing system that LTC facilities can use to rapidly identify and contain asymptomatic and symptomatic SARS-CoV-2 infected contacts. A compartmental model was also developed to simulate disease transmission dynamics and to assess system performance versus conventional methods.

Methods: We developed a compartmental model parameterized specifically to assess the coronavirus disease (COVID-19) transmission in LTC facilities. The model was used to quantify the impact of asymptomatic transmission and to assess the performance of several intervention groups to control outbreaks: no intervention, symptom mapping, polymerase chain reaction testing, and manual and digital contact tracing.

Results: Our digital contact tracing system allows users to rapidly identify and then isolate close contacts, store and track infection data in a respiratory line listing tool, and identify contaminated rooms. Our simulation results indicate that the speed and efficiency of digital contact tracing contributed to superior control performance, yielding up to 52% fewer cases than conventional methods.

Conclusions: Digital contact tracing systems show promise as an effective tool to control COVID-19 outbreaks in LTC facilities. As facilities prepare to relax restrictions and reopen to outside visitors, such tools will allow them to do so in a surgical, cost-effective manner that controls outbreaks while safely giving residents back the life they once had before this pandemic hit.

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KEYWORDS

COVID-19; SARS-CoV-2; contact tracing; nursing homes; long term care; care homes; digital contact tracing

Introduction

The coronavirus disease (COVID-19) is a rapidly spreading infectious disease caused by severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) [1]. A total of 4.0 million cases and 143,000 COVID-19–associated fatalities have been reported in the United States as of July 25, 2020 [2]. Residents of nursing homes and long-term care (LTC) facilities represent only 0.7%

of the total US population yet account for 8% of cases and 47% of all COVID-19 fatalities in the United States [2,3]. LTC residents also exhibit an infection fatality rate of 18.6%—a rate that is 13 times higher than for the total population [2-8].

The vulnerability of LTC facilities to respiratory disease outbreaks is well documented, and several factors have contributed to the recent COVID-19 outcomes: high-risk population (the majority of LTC residents are advanced in age and have one or more underlying conditions), high-risk setting (the frequency, type, and duration of close contact between the residents and staff), and epidemiological features and transmission dynamics (people infected with SARS-CoV-2 can be infectious before showing symptoms and 40% of new COVID-19 cases are transmitted by asymptomatic cases) [9,10]. Due to these factors, symptoms-based monitoring and slow manual contact tracing methods presently used by LTC facilities have proven inadequate, and new tools are needed to better control COVID-19 outbreaks [11-13].

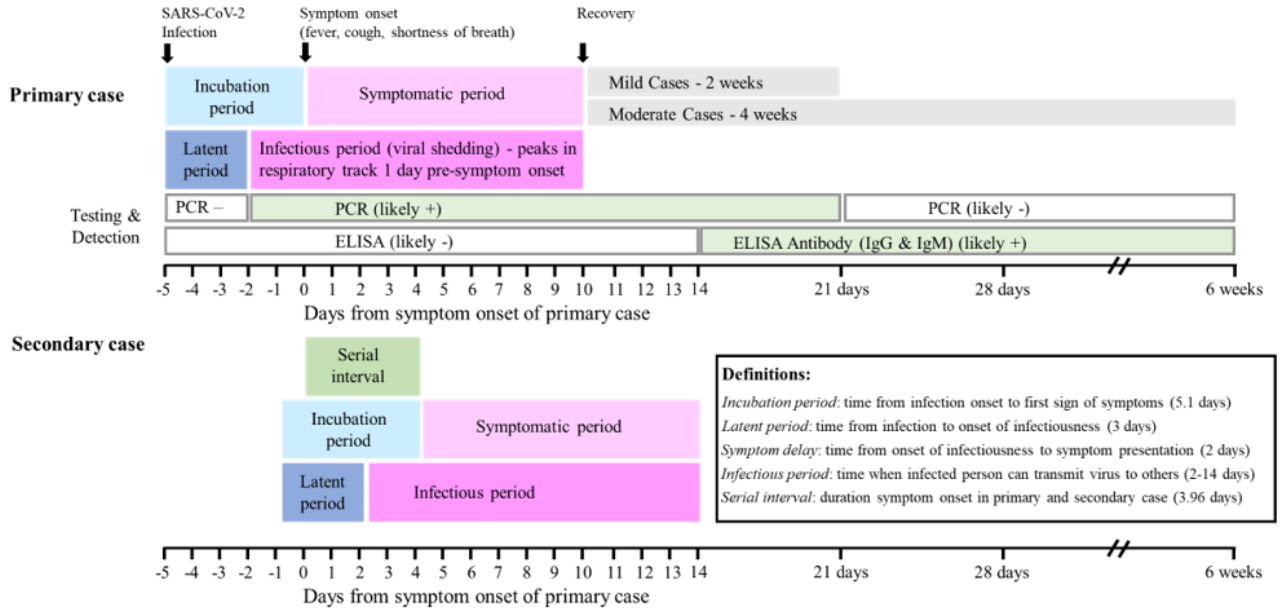
Advanced age and underlying comorbidities are well-established risk factors for severe COVID-19–associated illness, hospitalization, and death [14,15]. Adults 85 years and older represent 2% of the US population but have contributed to 33% of all COVID-19 deaths (Multimedia Appendix 1) [2,3,16,17]. This death rate is 613.1 (per 100,000 population), 14 times higher than the overall population rate [2,18]. The average COVID-19–associated hospitalization rate for adults 85 years and older is 607.3 (per 100,000 population), roughly 6 times higher than for the overall population [2,18]. Older adults are also disproportionally affected by chronic conditions, where 60% have two or more conditions, and such persons are known to be at an elevated risk for severe COVID-19–associated illness [19,20]. Richardson et al [21] found that 94% of patients hospitalized with COVID-19 exhibited one comorbidity, and 88% of patients exhibited two or more.

In addition to housing vulnerable residents, LTC facilities exhibit several intrinsic characteristics that make them high-risk settings conducive for the rapid spread of SARS-CoV-2 [22]. First, in LTC facilities, residents live together in close quarters, eat communal meals, and participate in many group social activities. Second, caregiving staff frequently assist residents with their activities of daily living (ADL) such as bathing, dressing, and eating. ADL assistance requires intimate resident contact, which increases the probability for transmission from an infected staff member or resident. Third, during the course of a work day, facility staff move from room-to-room to provide care for many different residents. In addition, many staff members may work at multiple facilities or home care agencies; thus, if they become infected, they can serve as potential vectors between facilities [11,12,23]. Overall, the frequency, type, and duration of contact between residents and staff has contributed to increased SARS-CoV-2 transmission both within and between facilities.

The epidemiological features, infection progression characteristics, and transmission dynamics of SARS-CoV-2 and COVID-19 have also contributed to the difficulties faced by LTC facilities to contain outbreaks. Such parameters are also fundamental to the development of accurate mathematical models, control systems, and effective infection control policies [9,14,24-27]. The SARS-CoV-2 virus is known to spread primarily person-to-person through large respiratory droplets (>5 μm) expelled when an infected symptomatic or asymptomatic person coughs, sneezes, or breathes [9,10]. Airborne virus transmission is also possible in confined, poorly ventilated environments such as LTC facilities because when an infected person speaks they can expel aerosols, tiny virus containing droplet nuclei (≤5 μm), that can linger in the air for up to 14 minutes [28-32]. SARS-CoV-2 is also believed to be viable and infectious on surfaces for hours; therefore, transmission may occur indirectly via *fomites*, contamination of surfaces in the environment [33,34].

Isolation of confirmed and suspected cases, and identification of contacts via contact tracing are crucial to effective control efforts. These methods hinge on three key epidemiological parameters: (1) basic reproduction number (R_0), the average number of secondary infections generated by each infection; (2) serial interval, duration between successive infections and speed of viral spread; and (3) proportion of asymptomatic transmission. Best estimates indicate that the R_0 for SARS-CoV-2 causing COVID-19 is 2.5, which is significantly higher than the flu [35]. The serial interval, duration between symptom onset in a primary and secondary case, is estimated to be 3.96 days, which is almost twice as fast as SARS-CoV-1 [26,27]. The mean latent period, time from infection to onset of infectiousness, is estimated to be 3 days, which is shorter than the 5.1 day incubation period, time between infection and onset of symptoms (fever, cough, shortness of breath; Figure 1) [9,14,24-27]. Consequently, people infected with SARS-CoV-2 are most infectious 1-3 days before showing symptoms and up to 10 days after symptom onset [14,25]. SARS-CoV-2 is transmitted via symptomatic, asymptomatic, and presymptomatic routes, and current best estimates indicate the following: 25%-81% of cases are asymptomatic [36-38], symptomatic and asymptomatic cases are equally infectious [35], and 40%-44% of new COVID-19 cases are transmitted from presymptomatic individuals [14,35,36,39,40]. These features are consistent with early reports from LTC facilities, where 56%-73% of residents that tested positive for COVID-19 were asymptomatic at the time of testing [11,12,41] and that both presymptomatic and asymptomatic cases contributed to rapid facility spread [11-13]. Thus, symptom-based screening alone failed to detect asymptomatic infectious cases, and Arons et al [11] posited that conventional screening approaches in LTC facilities are inadequate because symptoms-based screening and polymerase chain reaction (PCR) tests are only being performed on symptomatic persons [12,13]. LTC facilities need contact tracing systems to rapidly identify, contain, and then broadly test asymptomatic infectious contacts [42].

Figure 1. Overview of current estimates on key epidemiological features, infection characteristics, transmission dynamics, and testing methods for SARS-CoV-2 and the coronavirus disease. ELISA: enzyme-linked immunosorbent assay; IgG: immunoglobulin G; IgM: immunoglobulin M; PCR: polymerase chain reaction; SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.



Contact tracing, a core disease control measure used by public health authorities (PHAs) to prevent the spread of infectious diseases, is now being employed to identify and isolate individuals that came in close contact with a person infected with SARS-CoV-2 [43]. The manual contact tracing process is slow and has inherent time delays between confirming a case and finding a person's contacts [9,44,45]. These time delays give secondary contacts more time to transmit the virus even further in the facility. Manual contact tracing also relies on humans both for data collection and data entry, which increases the potential for inaccurate or incomplete results due to human error. For the tracing process, a case needs to remember and report all contacts made over the past 14 days. In the LTC setting, an infected resident may have 10-30 close contacts, and older adults that may be experiencing memory impairment or dementia may forget their close contacts. Since more than 70% of contacts must be traced to control an outbreak [46], this may be difficult to achieve using manual contact tracing in a LTC facility.

Since SARS-CoV-2 spreads too fast to be contained by slow manual contact tracing, several digital contact tracing tools using smartphone-based apps have been developed [47,48]. If widely adopted, these apps show promise to effectively mitigate the spread of SARS-CoV-2 for the general population; however, smartphone-based contact tracing may have limited utility in LTC facilities for several reasons. First, LTC residents are typically older adults, and only 17% of adults 80 years and older own a smartphone [49]. Second, staff in many LTC facilities are not permitted to use a smartphone during the work day. Finally, smartphone-based approaches use Bluetooth technology, which transmits through thin walls in a facility and can result in false positives. Due to these limitations, there is benefit to having a digital contact tracing system built specifically for use in LTC facilities.

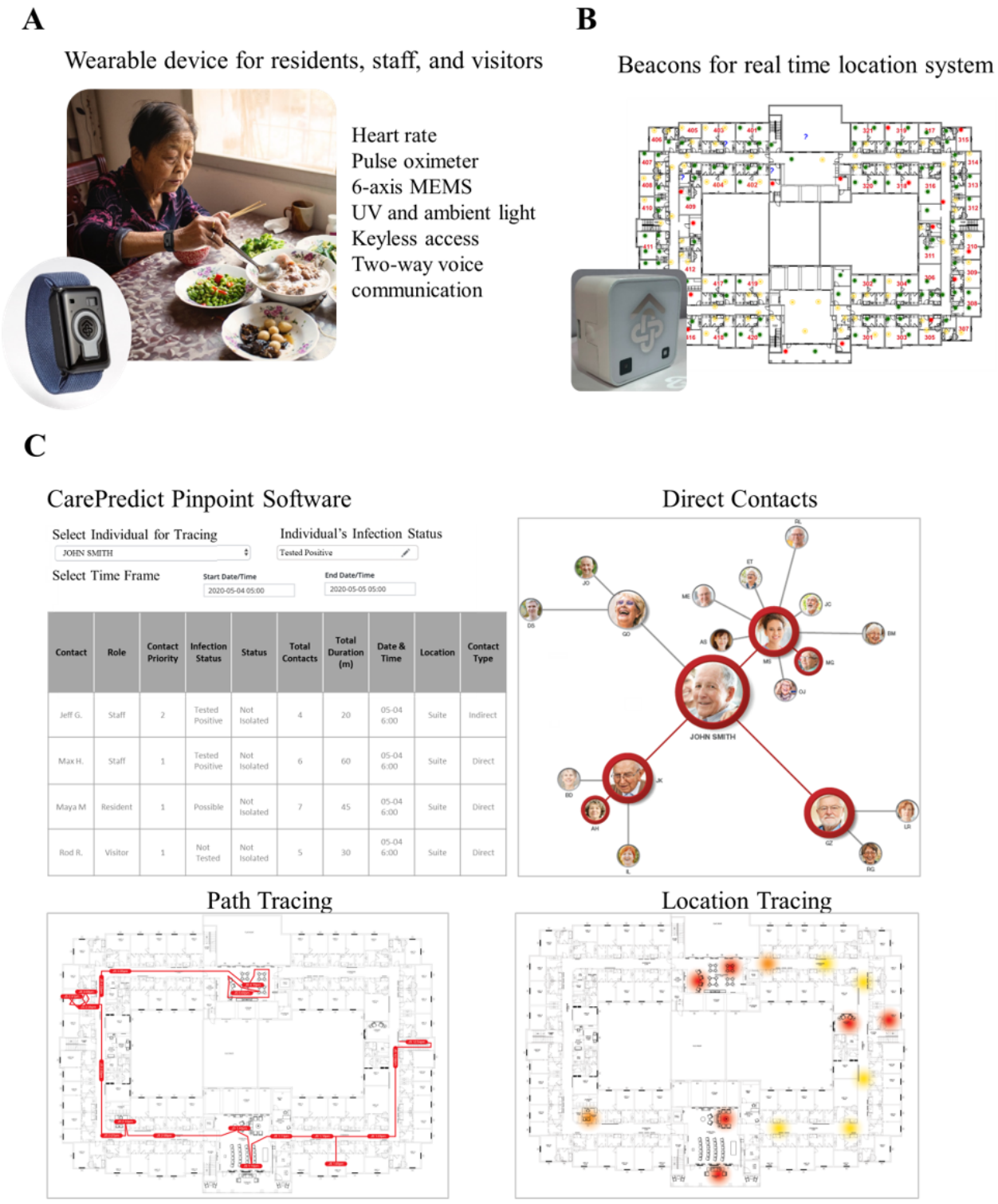
In this study we describe the development and implementation of a real-time digital contact tracing system designed specifically for LTC facilities to mitigate the spread of SARS-CoV-2 infections. Additionally, we developed a new susceptible-exposed-infectious-recovered (SEIR)–type infectious model that was adopted and parameterized specifically to describe propagation of COVID-19 in LTC facilities. The model was also used to simulate and assess the interventional performance of digital contact tracing compared to symptom-based mapping, manual contact tracing, and PCR testing.

Methods

Real-Time Digital Contact Tracing System

The CarePredict PinPoint is a real-time digital contact tracing system designed for use in an LTC facility. The system is used to rapidly identify and categorize individuals (staff, residents, and visitors) that may have been exposed to a person infected with COVID-19. The system consists of a wrist-worn wearable device (Tempo), beacons for real-time location tracking, and a cloud-based software application for visualization of egocentric contact networks (Figure 2) [50].

Figure 2. Digital contact tracing system: wearable device, real-time location tracking, and software. A: wearable device; B: real-time location system for retrospective contact tracing; C: PinPoint software. MEMS: microelectromechanical systems.



The wearable is worn on the dominant arm of residents, staff, and visitors. The wearable recognizes gestures according to the changes in the user's wrist kinematics and autonomously provides outputs on the user's ADL such as eating, bathing, walking, bathroom visits, and sleep duration. The wearable houses the following sensors for detection of the user's heart rate, blood oxygenation (via pulse oximetry), 6-axis microelectromechanical systems sensor, and UV and ambient light sensors (Figure 2A). When coupled with data from context beacons, indoor positioning information is obtained such as the type of room in which the person is located (Figure 2B). The wearable uses Wi-Fi to communicate data to the cloud over an encrypted connection and supports two-way audio so the wearer can communicate via mobile apps on iOS and Android devices. The device supports radio-frequency identification (RFID) protocols for integration with electronic door access systems. The wearable measures 50 x 33 x 17.7 mm; weighs 40 grams; and includes a microprocessor, RFID, Bluetooth 4, and Wi-Fi

802.11 b/g/n. The wearable uses a 380mAH Li-ion 10.6g polymer battery, which has 50-100 hours of battery life. The device uses a swappable battery design so the user does not have to take off the device for charging. The wearable has an operational temperature range of –20 °C to 55 °C, water-resistant to IP67, and has the following certifications: FCC (Federal Communications Commission), CE (Conformité Européenne), TELEC (Telecom Engineering Center), and Bluetooth.

The real-time location system uses beacons to determine the room-level indoor location of the wearable, and the duration of contact with other wearable devices. The beacon measures 52.1 x 52.1 x 28.0 mm, weighs 78 g, and uses Lithium CR123A batteries. A patented line-of-sight technology is used for multi-floor level indoor positioning with room-level accuracy and no bleed-throughs.

The PinPoint software consists of three tools (Figure 2C):

1. Contact tracing workspace: direct—identify all individuals the infected person (person under investigation [PUI]) had direct contact with in the facility; secondary or indirect contacts (individuals who subsequently came in contact with the PUIs direct contacts); and environmental (individuals who spent time in facility rooms that may have been contaminated by the PUI [ie, possible fomite or aerosol transmission]). Each unique interaction is summarized regarding the time of day, duration, and location. All three types of contacts are then classified as priority 1 or priority 2 contacts (Figure 2C).
2. Line listing tool: digitized respiratory line listing tool to store and track infection data
3. Decontamination tool: identify all of the confined areas (suites, bathrooms, offices) and common areas that the PUI visited in the facility—including the day, time, and duration. The high-touch surfaces in these rooms can then be cleaned and disinfected.

Simulation Model

We developed a specialized *SEIR*-type compartmental model to simulate the dynamics of propagation, disease transmission, and containment of SARS-CoV-2 cases in LTC facilities [51,52]. In this model, individuals within the LTC facility (residents and staff) are separated into mutually exclusive groups, or compartments, based on their disease state: susceptible (*S*), exposed (*E*), infected (*I*), quarantined (*Q*), recovered (*R*), and deceased (*D*). Infected individuals were further segmented into two distinct groups: presymptomatic (I_P) and symptomatic infectious individuals (I_S). The decoupled compartments include deceased (*D*) and quarantined individuals (*Q*) from the (*E*, I_P, *or* I_S) compartments. The model assumes no demography, such that the population size is constant, denoted by *N*. The facility was assumed to have a population of 120 persons, consisting of 80 residents and 40 staff. A schematic representation of the model is provided in Multimedia Appendix 2 [51]. The population dynamics are modeled by the following system of differential equations:

where $N = S + E + I_P + I_S + Q + R + D$.

The transmission parameters, β_p and β_s, represent the transmission rate for presymptomatic and symptomatic individuals; τ is the mean latent period; α is the difference in latent and incubation period, where α = (incubation period – τ). The following parameters varied depending on the intervention approach: Ω_i is an intervention on/off parameter; ω is the intervention traced contact probability; δ is the time delay to trace, where ω/δ is the rate at which a contact trace is quarantined; and μ is the death rate. For this model, we assumed that once an individual is quarantined, all staff wear personal protective equipment when interacting with residents, and thus, no further transmission would occur between quarantined and susceptible individuals.

The model was developed to assess the performance, defined as the number of cases and resultant deaths, for several intervention types: digital contact tracing, manual contact tracing, symptom-based mapping, PCR testing, and no intervention. Table 1 contains the intervention parameters and assumptions used in the model. For no intervention, β is set to average contacts per day from the facility. For intervention, $\beta_s = \beta_p/2$. For symptom mapping, we assume that only symptomatic individuals are quarantined but presymptomatic individuals are not (Ω=0). The initial time delays (δ) for each intervention method were as follows: symptom-based mapping (1 day), manual contact tracing (2 days), swab PCR (1 day), and digital contact tracing (0.1 days). Simulations were also conducted where the time delay parameter was adjusted to assess the impact that time delay has on interventional performance.

Table 1. Parameters for compartmental infection and intervention model.

Name and symbol	Description	Central value	Range	References
Transmission rate (presymptomatic) (β_p)	Infectious transmission rate for presymptomatic individuals	0.52 day^{-1}	0.5-1.5 day^{-1}	[53], fit data [13], [35]
Transmission rate (symptomatic) (β_s)	Infectious transmission rate for symptomatic individuals. Assume half the contacts.	β_p/2 day^{-1}	0.5-1.5 day^{-1}	[13,53], [35]
Latency period (τ)	Time from infection to infectious	4 days	3-5 days	[9,14,24-27]
Incubation period (α)	Time from infection to symptomatic	8 days	2-14 days	[9,14,24-27]
Death rate (μ)	Death rate	0.02 days	0.001-0.1	[35]
Intervention function target (Ω_i)				
Manual contact tracing		1	N/A[a]	N/A
Swab PCR[b] testing		1: I_P& I_S, 0: E	N/A	N/A
Digital contact tracing		1	N/A	N/A
Symptom mapping		0	N/A	N/A
No intervention		0	N/A	N/A
Symptom mapping trace rate (ω_s)	Probability of traced contact by tracing symptomatic individuals	0.6	N/A	[35]
Manual contact tracing rate (Ω_m)	Probability of traced contact by tracing symptomatic individuals	0.7	N/A	[54]
Swab PCR testing rate (Ω_m)	Probability of traced contact by tracing symptomatic individuals	0.7	N/A	[35]
Digital contact tracing rate (ω_d)	Probability of traced contact individuals	0.9	N/A	This study
Time delay to trace (δ)				
Symptom-based mapping		1 day	1-4 days	[11-13]
Manual contact tracing		2 days	1-4 days	[44]
PCR test		1 days	1-6 days	[24]
Digital contact tracing		2.4 hours	N/A	This study

[a]N/A: not applicable.

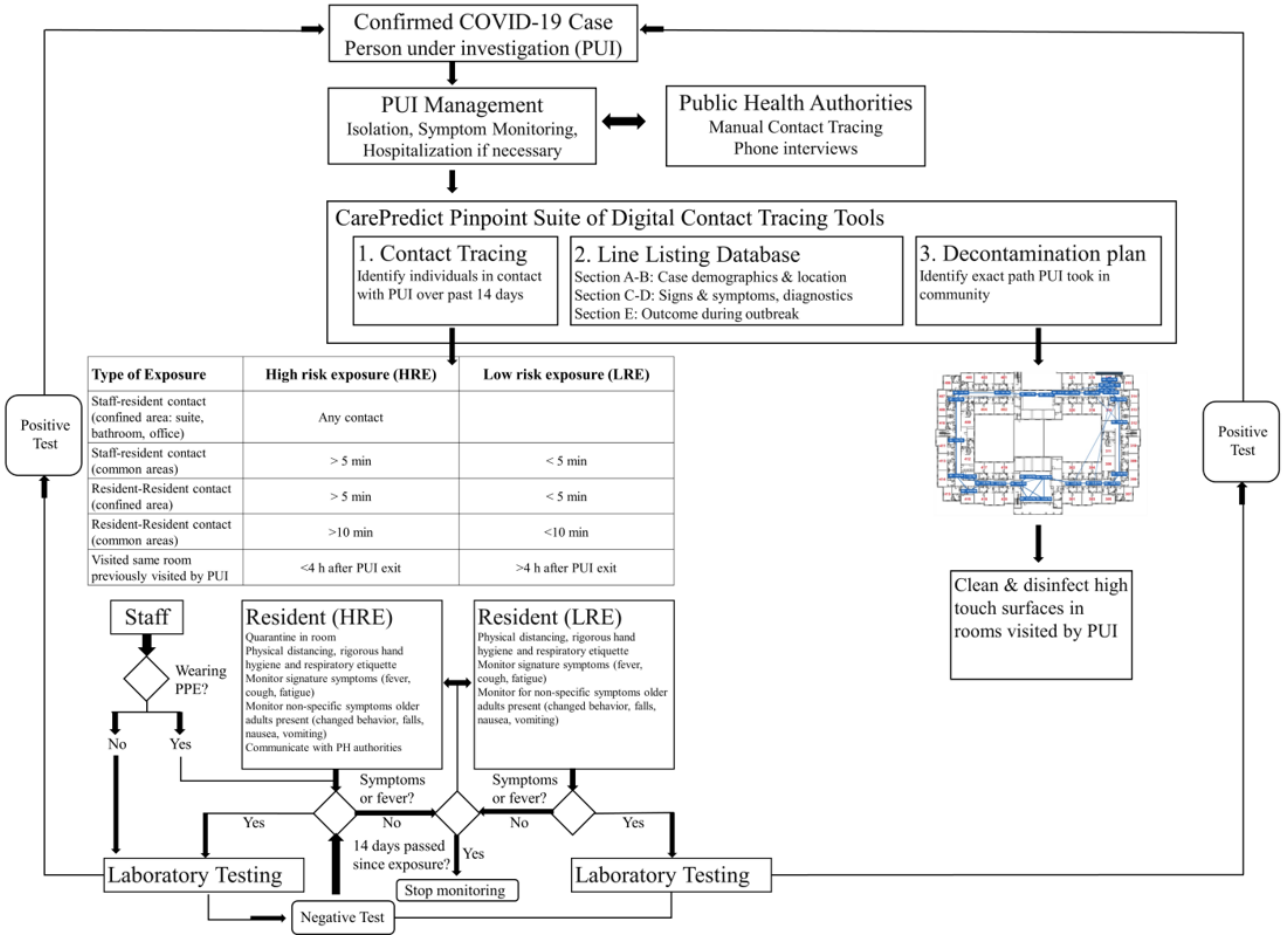
[b]PCR: polymerase chain reaction,

Results

System Implementation

An example of implementation and workflow for the CarePredict PinPoint digital contact tracing system is provided in Figure 3 [44]. The process could work in the following manner. First, a positive COVID-19 case, defined as a PUI is confirmed, immediately isolated, has symptoms monitored, and is hospitalized if necessary. Data for the PUI would then be inputted into the Pinpoint software respiratory line listing tool: A. case demographic; B. case location; C. signs and symptoms; D. diagnostics; and E. outcome during outbreak. This line list date is then provided to the PHAs so they can begin manual contact tracing processes. The digital contact tracing tool would then be executed to identify the individuals that came in contact with the PUI over the past 14 days. The contacts are classified as either priority 1 (high-risk exposures) or priority 2 (low-risk exposures), and staff would provide the necessary next steps of care. The priority 1 contacts would be immediately quarantined and their symptoms monitored, and the priority 2 contacts would be monitored and provided safety instructions regarding physical distancing, rigorous hand hygiene, and respiratory etiquette. For safety precautions, the temperature of all contacts would be measured to see if the person had a fever [55]. If signature or nonspecific symptoms are not observed for 14 days then monitoring is stopped. PCR testing should be conducted on all exposed contacts (both symptomatic and asymptomatic) to determine if infected by SARS-CoV-2 or another pathogen. After completing the contact tracing runs, the decontamination tool would be used to determine the rooms and areas in the facility that may be in infected and require cleaning.

Figure 3. Sample representation for integrating CarePredict's PinPoint system and software into a long-term care facility's COVID-19 risk assessment workflow. General workflow diagram developed to be consistent with those proposed by the European Centre for Disease Prevention and Control. COVID-19: coronavirus disease; PH: public health; PPE: personal protective equipment; PUI: person under investigation.

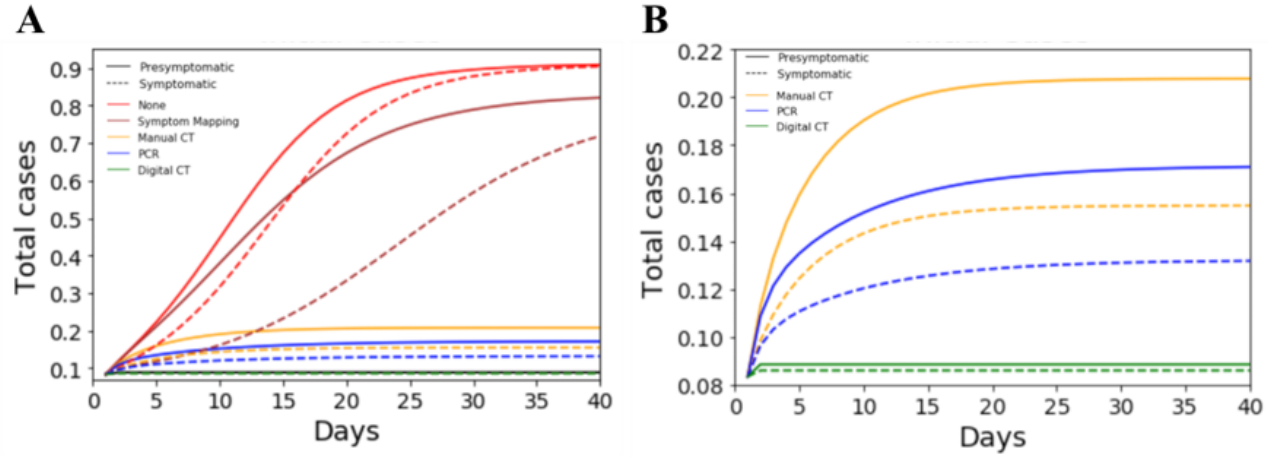


Type of Exposure	High risk exposure (HRE)	Low risk exposure (LRE)
Staff-resident contact (confined area: suite, bathroom, office)	Any contact	
Staff-resident contact (common areas)	> 5 min	< 5 min
Resident-Resident contact (confined area)	> 5 min	< 5 min
Resident-Resident contact (common areas)	>10 min	<10 min
Visited same room previously visited by PUI	<4 h after PUI exit	>4 h after PUI exit

Simulation Model

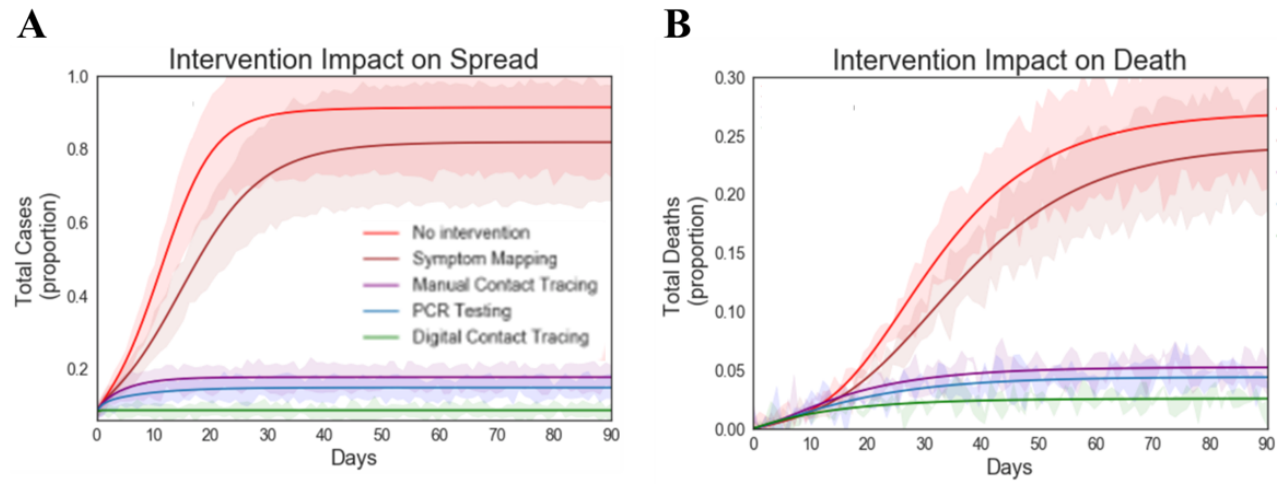
Asymptomatic SARS-CoV-2 infected cases contributed to the rapid spread in several LTC facilities, and conventional methods were inadequate to control those outbreaks [11,12]. To assess the impact that presymptomatic cases have on facility spread, we used our model to simulate and compare community transmission for two initial conditions: one seeded with 10 presymptomatic cases and the other seeded with 10 symptomatic cases. Simulation results for each intervention group are presented in Figure 4A. For all intervention groups, the seeding of presymptomatic cases (full lines) resulted in 6%-10% more total cases (ie, greater infection spread) than the group seeded with symptomatic cases (dotted lines). Symptom-based monitoring alone was the least effective control method, yielding 60%-71% more cases than the other interventional groups. Digital contact tracing provided the most effective intervention control. Five days after presymptomatic seeding, digital contact tracing yielded 5% and 7% fewer cases than PCR testing and manual contact tracing, respectively. After 40 days, the digital contact tracing provided 6% and 12% fewer cases than PCR testing and manual contact tracing, respectively (Figure 4B).

Figure 4. Assessing the impact of presymptomatic cases on facility spread. Simulations were performed to compare transmission and interventional control for two initial seeding conditions: presymptomatic (filled colored lines: 10 presymptomatic and 0 symptomatic cases) and symptomatic (dotted colored lines: 0 presymptomatic and 10 symptomatic cases). Simulations were performed to measure the number of total cases as a function of time for each intervention group: digital contact tracing, PCR testing, manual contact tracing, symptom-based monitoring, and no intervention. A: total cases over time for each intervention group and initial seeding condition. B. Total cases over time for manual contact tracing, PCR testing, and digital contact tracing. CT: contact tracing; PCR: polymerase chain reaction.



To quantify control success for each intervention group, simulations were performed using an initial seeding condition of 10 cases, 40% asymptomatic and 60% symptomatic cases [35]. These conditions were selected based on current best estimates provided by the Centers for Disease Control and Prevention [35]. The simulation results for each intervention group are presented in Figure 5. Symptom-based monitoring alone was the least effective intervention method, resulting in nearly 60% more cases than the other interventional groups (Figure 5A). Digital contact tracing provided the most effective intervention control, resulting in the fewest number of new cases and deaths (Figure 5B). Direct contact tracing achieved 22%, 3%, and 2% fewer deaths than symptom-based monitoring, manual contact tracing, and PCR testing methods, respectively. The data shows that with no intervention, 26% of the total cases result in death, which is consistent with observed case infection fatalities in LTC facilities [3].

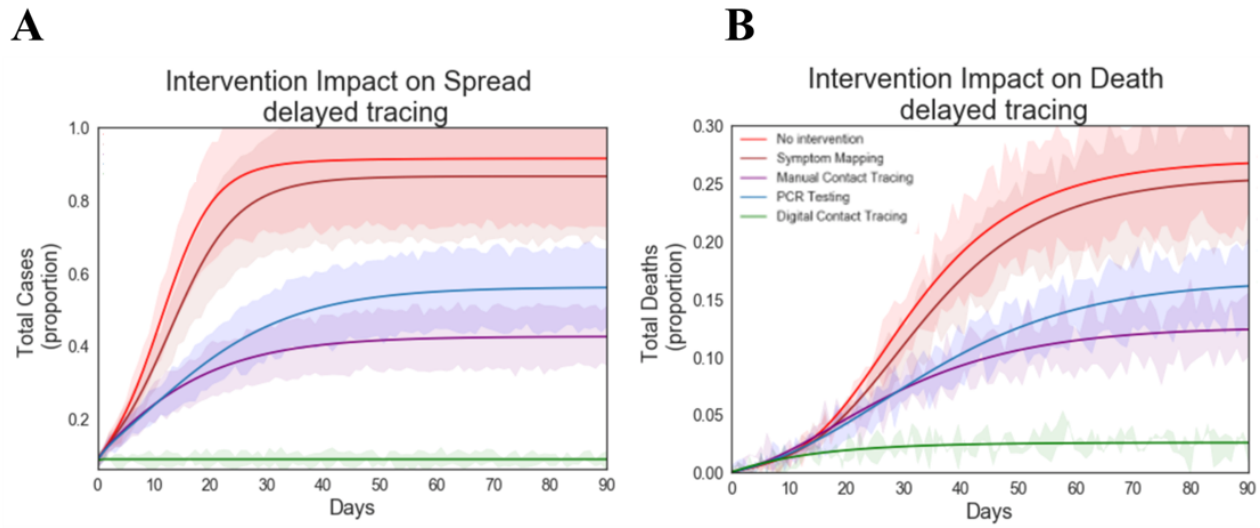
Figure 5. Quantifying control success for each intervention group. A: total cases (proportion) over time. B: total deaths (proportion) over time. Simulations were performed for all intervention groups using initial seeding conditions: 10 cases (40% presymptomatic and 60% symptomatic cases). Time delay to trace for digital contact tracing (0.1 days), symptom-based mapping (1 day), manual contact tracing (2 days), and PCR testing (1 day). Simulations were performed to measure the total cases and deaths as a function of time for each intervention group: digital contact tracing, PCR testing, manual contact tracing, symptom-based monitoring, and no intervention. PCR: polymerase chain reaction.



Digital contact tracing software has negligible time delays as it requires minimal human resources to instantaneously execute. However, symptom-based mapping, manual contact tracing, and PCR testing are labor intensive and have intrinsic time delays. In previous simulations, we optimistically assumed that symptom-based mapping, manual contact tracing, and PCR testing could be performed quickly with time delays of 1 day, 2 days, and 1 day, respectively. To assess the impact that delayed tracing has on intervention success, we conducted simulations where we delayed the tracing time for each group by 2 days (Figure 6). The data shows that the increased delays in time to trace resulted in increases in cases and deaths for all intervention groups. Due to the increased delays, PCR testing is now less effective than manual contact tracing. This result underscores the importance of speed and rapid turnaround times. Exposed individuals' PCR tests typically are not positive during

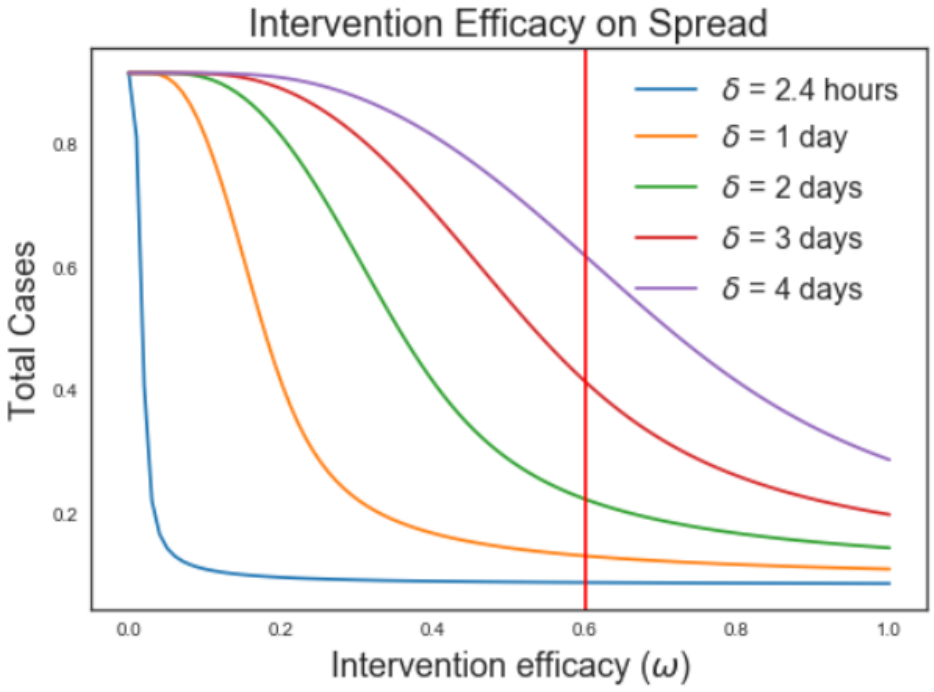
their latency period; thus, multiple follow-up tests must be performed to ensure they are positive COVID-19 cases. Thus, if only individuals with positive PCR test results are being isolated, then the cases that are infected, not yet infectious, and not quarantined could continue to infect others in the facility.

Figure 6. Effect of tracing delays on intervention performance. A: total cases (proportion) over time. B: total deaths (proportion) over time. Simulations were performed for all intervention groups using initial seeding conditions: 10 cases (40% presymptomatic and 60% symptomatic cases). Time delay to trace for digital contact tracing (0.1 days), symptom-based mapping (3 days), manual contact tracing (4 days), and PCR testing (3 days). Simulations were performed to measure the number of total cases and deaths as a function of time for all intervention groups: digital contact tracing, PCR testing, manual contact tracing, symptom-based monitoring, and no intervention. PCR: polymerase chain reaction.



A series of simulations were performed to understand the impact that intervention efficacy (probability of tracing a contact) and delay have on control success (Figure 7). The data shows that as the intervention efficacy (Ω) increases from 0 to 0.6, the number of cases drops sharply from 1.0 to 0.15. The data shows that once an efficacy of 60% is achieved, only modest improvements in control can be achieved by improving the intervention efficacy. To assess the impact that intervention delay has on spread, simulations were conducted varying the time delay from 2.4 hours to 4 days and assuming all interventions had an intervention efficacy of 60%. The data shows that increases in delay intervention time result in sharp increases in the number of total cases. Increasing the delay time from 2.4 hours to 1 day, 2 days, 3 days, and 4 days resulted in increases in total cases by 4%, 13%, 32%, and 52%, respectively. Clearly the delay time has significantly more impact on performance than interventional efficacy.

Figure 7. Impact of intervention efficacy and delay time on intervention success.



Discussion

Between March and July 2020, over 13,000 LTC facilities in the United States reported COVID-19 cases [56]. Many of these LTC facilities have experienced uncontrollable outbreaks resulting from the rapid and widespread transmission of SARS-CoV-2 [11,12,23,57]. As a result, residents of LTC facilities have been disproportionally impacted by SARS-CoV-2 and have accounted for over 40% of all COVID-19 fatalities worldwide [3,16]. Symptoms-based monitoring including temperature assessment [58] fails to identify asymptomatic infectious cases, and slow manual contact tracing methods have proven inadequate for controlling SARS-CoV-2 transmission in LTC facilities [11-13,23,42,59]. In this study, we describe the development of a new digital contact tracing system designed for use in LTC facilities. Our computer simulation results comparing different intervention approaches suggests that this system shows promise to be an effective tool to control COVID-19 outbreaks in LTC facilities.

In this study, we developed an epidemic compartmental model that was specifically parameterized to quantify SARS-CoV-2 transmission and control in LTC facilities. We used the model and considered various scenarios to assess the effectiveness of several intervention groups to control outbreaks: no intervention, symptom-based monitoring, PCR testing, manual contact tracing, and digital contact tracing. Under all conditions tested, the digital contact tracing system outperformed all intervention groups, achieving reduced SARS-CoV-2 spread, fewer total cases, and fewer fatalities. Most importantly, we show that the time delay is the most critical and sensitive parameter of the model. All conventional control methods (symptom-based monitoring, manual contact tracing, and PCR testing) except digital contact tracing have intrinsic time delays that cannot be compensated for with increases in efficiency. We conducted several simulations where we increased each interventional group's probability of tracing a contact, and the results indicated that the control performance still could not reach the level achieved by digital contact tracing. Thus, the primary advantage of automated digital contact tracing methods is the speed at which potentially infectious contacts (both symptomatic and asymptomatic) can be instantly identified, classified, isolated, and tested. Given the high proportion of asymptomatic infections, the ability to quickly identify and test potentially infected persons before they show symptoms is key to preventing future transmission in LTC facilities.

Results from our simulations indicate that symptom-based screening alone was the least effective intervention group, resulting in 60%-71% greater cases and 10%-20% more deaths than the other methods. A limitation of symptoms-based monitoring methods such as temperature monitoring for a fever is that subclinical or presymptomatic secondary cases are missed. In LTC facilities, asymptomatic cases are equally prevalent and infectious as symptomatic cases and, thus, can be major contributors to COVID-19 outbreaks in LTC facilities [11,12,14,25,41]. Our data also suggests that symptom-based monitoring alone has intrinsic time delays due to the time required for people who are infected to both exhibit symptoms and then be identified by facility staff. To complicate matters, evidence is emerging that many older adults may not actually present the signature COVID-19 symptoms (ie, fever, cough, shortness of breath) [12,15,60]. Due to their blunted immune response systems or underlying chronic conditions, which may mask fever and acute illness, older adults may present atypical, nonspecific symptoms when ill with COVID-19, including increased falls, changes in activity and behavior (such as sleeping more and eating less), impaired mobility, malaise, fatigue, nausea, and even vomiting [12,15]. Thus, staff may require more time and use lower thresholds for suspicion to identify infected older adults that exhibit subtle symptoms. Such delays may translate into further spread of infection in the facility.

Manual contact tracing is a useful core disease control that is a key part of our country's multipronged approach to mitigate COVID-19 transmission [43]. Estimates indicate that a large workforce of 300,000 tracers will be required for adequate tracing in the United States (nearly 1 tracer per 1000 people) [61]. The manual tracing process is error prone and slow because it requires a human tracer to interview new cases (~2 hours/interview) and then list, classify, and follow up with each contact (~1 hour/call/contact). Results from our simulations indicate that the time delays created by manual processes render the method less effective in LTC facilities than digital contact tracing methods. We found that digital contact tracing methods resulted in 12% fewer cases and 3% fewer deaths than manual contact tracing. As a result, manual contact tracing approaches will need to be supplemented with other rapid and efficient control measures. There are several additional challenges with using manual contact tracing alone in the LTC setting. First, an infected resident or staff member may have 10-30 close contacts, and estimates indicate that between 6 and 15 tracers require 12-24 hours to fully trace one case [44,45,62]. The delays created by this process give secondary contacts more time to transmit the virus even further in the facility. Second, manual contact tracing relies on humans both for data collection and data entry. This increases the potential for inaccurate or incomplete results due to human error. Accurate manual contact tracing requires the case to remember and report all contacts made over the past 14 days. In the LTC setting, many of the residents may have memory impairment or dementia, and thus, they may forget their contacts. The digital contact tracing system described in this study can automatically identify all of the contacts for a case and can be used to help augment manual contact tracing efforts performed by PHAs.

The most commonly used and reliable test for diagnosing SARS-CoV-2 infected cases is the reverse transcription-PCR (RT-PCR) test. PCR tests measure viral RNA and are performed using a nasopharyngeal, throat or saliva swabs, and take 1-2 days to process. PCR tests can effectively measure infection in people who are symptomatic with COVID-19 but are less likely to detect infection during the case's latent period when they are presymptomatic [14,24]. The results from our simulation indicate that PCR testing can be an effective control method for rapidly identifying infection and minimizing transmission. However, for PCR testing to be effective, testing needs to be implemented on both symptomatic and asymptomatic exposed contacts on a universal and serial (weekly or daily) basis. In a

recent study, Dora et al [41] investigated the benefit of serial RT-PCR testing of residents and staff at an LTC facility after an initial COVID-19 case was diagnosed. In this study, they found that after the first positive case was identified, 19 residents tested positive for SARS-CoV-2 and 73% were asymptomatic. All of the positive cases were rapidly transferred to an isolated ward to successfully break the chain of transmission [41]. One issue with daily universal testing at a LTC facility is the expense. PCR tests are expensive (US $150 per test), so daily testing at a 120 bed facility would cost US $18,000. Frequent PCR testing for all nursing home and LTC residents is reported to be unsustainable, where one-time tests would cost the industry US $672 million [63]. To address this challenge, many LTC facilities to date have performed PCR tests only on symptomatic COVID-19 cases. Given the high proportion of asymptomatic cases, we propose that digital contact tracing systems could be used to identify all high priority possibly infectious contacts that should be selected for PCR testing. This approach would be a cost-effective and effective method to control COVID-19 outbreaks.

Limitations

There are several limitations of this study. First, the computational models that we developed did not incorporate the potential contribution that an individual's underlying health conditions may have on SARS-COV-2 infection, transmission parameters, and death rate. Since the impact of such conditions is not well characterized, and empirical data is currently not available, we were unable to include these impacts in the model. However, it is well established that older adults are disproportionally affected by chronic conditions, and when such persons are infected, they have more severe COVID-19–associated illness [19,20]. Richardson et al [21] found that 94% of patients hospitalized with COVID-19 exhibited one comorbidity, and studies indicate that 94% of COVID-19 patient deaths, 78% of intensive care unit (ICU) admissions, and 71% of non-ICU hospitalizations had at least one comorbidity [64]. The most common comorbidities contributing to hospitalization were hypertension (56.6%), obesity (41.7%), and diabetes (33.8%) [21]. Studies on the effect of multiple comorbidities on adults 85 years and older indicated the following: for COVID-19 hospitalizations, comorbidities included hypertension (38%), diabetes and hypertension (22%), and chronic obstructive pulmonary disease (COPD) and hypertension (10%), and for COVID-19 deaths, comorbities included hypertension (37%); diabetes and hypertension (23%); COPD and hypertension (9%); and COPD, diabetes, and hypertension (8%) [65]. It is entirely possible that older adults with specific underlying comorbidities or a combination of particular comorbidities may exhibit varying infection, transmission, and death rates. As more data becomes available and these relationships are better characterized, we plan to incorporate these relationships into the models that we develop and test in future studies.

Second, the digital contact tracing system described in this paper is currently in use by several LTC facilities in the United States. These facilities are reporting early control success with the system [66]; however, a large enough sample size of empirical data has not been collected to date. Thus, the preliminary empirical results were not compared to those generated with our computer simulation models. Once a sufficient sample size of empirical data is collected using this system at various LTC facilities, we plan to conduct future studies to compare these findings versus the results generated by computer simulation models.

Conclusion

Our digital contact tracing system allows users to rapidly identify and then isolate close contacts, to store and track infection data in a respiratory line listing tool, and to identify contaminated rooms. Our simulation results suggest that digital contact tracing allows for rapid and effective identification and containment of potentially infected close contacts. This digital contact tracing system shows promise as an effective tool to control COVID-19 outbreaks. At the beginning of this pandemic, many facilities implemented strict lockdown measures, which included prohibiting outside family visitors, closing community dining rooms, and reducing social activities and events. These measures were required at the time, but they negatively impacted many resident's physical, social, psychological, and emotional health. As facilities prepare to reopen to outside visitors in the upcoming months, digital contact tracing systems will allow them to do so in a surgical, cost-effective manner that both controls outbreaks while safely giving residents back the life they once had before this pandemic hit.

Conflicts of Interest

GW, IS, DM, JG, GZ, SS, and SM are employees of CarePredict. HF serves as an advisor to CarePredict corporation.

Multimedia Appendix 1
Coronavirus disease (COVID-19) deaths. A: percentage of COVID-19 deaths by age group. B: percentage of COVID-19 deaths per state in long-term care. C: percentage of COVID-19 deaths per country in long-term care. Data as of July 24, 2020.
[PNG File , 147 KB - publichealth_v6i3e20828_app1.png]

Multimedia Appendix 2
Schematic representation of the infection and intervention model for the coronavirus disease in long-term care facilities.
[PNG File , 28 KB - publichealth_v6i3e20828_app2.png]

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Abbreviations

ADL: activities of daily living
CE: Conformité Européenne
COPD: chronic obstructive pulmonary disease
COVID-19: coronavirus disease
D: deceased
E: exposed
FCC: Federal Communications Commission
I: infected
ICU: intensive care unit
I_P: presymptomatic
I_S: symptomatic infectious individuals
LTC: long-term care
MEMS: microelectromechanical systems
PCR: polymerase chain reaction
PHA: public health authorities

PUI: person under investigation
Q: quarantined
R: recovered
RFID: radio-frequency identification
RT-PCR: reverse transcription-polymerase chain reaction
R_0: basic reproduction number
S: susceptible
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
SEIR: susceptible-exposed-infectious-recovered
TELEC: Telecom Engineering Center

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Original Paper

What Factors Increase the Risk of Complications in SARS-CoV-2–Infected Patients? A Cohort Study in a Nationwide Israeli Health Organization

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Abstract

Background: Reliably identifying patients at increased risk for coronavirus disease (COVID-19) complications could guide clinical decisions, public health policies, and preparedness efforts. Multiple studies have attempted to characterize at-risk patients, using various data sources and methodologies. Most of these studies, however, explored condition-specific patient cohorts (eg, hospitalized patients) or had limited access to patients' medical history, thus, investigating related questions and, potentially, obtaining biased results.

Objective: This study aimed to identify factors associated with COVID-19 complications from the complete medical records of a nationally representative cohort of patients, with severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection.

Methods: We studied a cohort of *all* SARS-CoV-2–positive individuals, confirmed by polymerase chain reaction testing of either nasopharyngeal or saliva samples, in a nationwide health organization (covering 2.3 million individuals) and identified those who suffered from serious complications (ie, experienced moderate or severe symptoms of COVID-19, admitted to the intensive care unit, or died). We then compared the prevalence of pre-existing conditions, extracted from electronic health records, between complicated and noncomplicated COVID-19 patient cohorts to identify the conditions that significantly increase the risk of disease complications, in various age and sex strata.

Results: Of the 4353 SARS-CoV-2–positive individuals, 173 (4%) patients suffered from COVID-19 complications (all age ≥18 years). Our analysis suggests that cardiovascular and kidney diseases, obesity, and hypertension are significant risk factors for COVID-19 complications. It also indicates that depression (eg, males ≥65 years: odds ratio [OR] 2.94, 95% CI 1.55-5.58; P=.01) as well as cognitive and neurological disorders (eg, individuals ≥65 years old: OR 2.65, 95% CI 1.69-4.17; P<.001) are significant risk factors. Smoking and presence of respiratory diseases do not significantly increase the risk of complications.

Conclusions: Our analysis agrees with previous studies on multiple risk factors, including hypertension and obesity. It also finds depression as well as cognitive and neurological disorders, but not smoking and respiratory diseases, to be significantly associated with COVID-19 complications. Adjusting existing risk definitions following these observations may improve their accuracy and impact the global pandemic containment and recovery efforts.

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KEYWORDS

SARS-CoV-2; COVID-19; risk factors; complications

Introduction

As of April 30, 2020, more than 3 million people worldwide contracted severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) and close to 250,000 people died of coronavirus disease (COVID-19) complications. In Israel, by that date, 16,004 individuals had been infected by the virus and 223 died from the disease. This pandemic poses grave challenges to patients, health care providers, and policy makers. Many of these challenges may be better addressed with timely stratification of patients to risk groups, based on their past and current medical characteristics. For example, reliably identifying patients at increased (or decreased) risk could guide clinical decisions (eg, hospitalization vs home care), public health policies (eg, risk-based quarantine), and preparedness efforts (eg, expected medical equipment required).

Various algorithms for identifying patients at risk for COVID-19 (severe) complications have been proposed. The Centers for Disease Control and Prevention (CDC) identified individuals 65 years and older, living in a nursing home or long-term care facility, or suffering from underlying medical conditions, particularly if not well controlled, as being at high risk for severe illness from COVID-19 [1]. Similarly, the European Centre for Disease Prevention and Control (ECDC) lists the age category >70 years and some underlying conditions as risk factors for critical illness [2]. The United Kingdom National Health Service (NHS) included solid organ transplant recipients, patients with specific cancers or severe respiratory conditions, pregnant women with significant heart disease, and those with increased risk of infection (eg, due to immunosuppressive therapies) in the highest clinical COVID-19 risk group [3]. In April 2020, approximately 1.3 million people in this group were asked to "shield" by staying at home for a period of at least 12 weeks. In addition, patients >70 years and those suffering from some underlying health conditions (eg, chronic respiratory diseases, BMI ≥40, and pregnant women) were considered in a wider vulnerable group (also referred to as the "flu group"). Finally, a more quantitative risk model (derived from Barda et al [4]) was adopted by the Israeli Ministry of Health (MoH), assigning a point for each underlying condition from a predefined list, then considering age group and point count to identify high-risk patients.

Initially, these algorithms were derived from a quickly growing number of epidemiological characterization studies (eg, [5,6]), which report the prevalence of various conditions in a population of interest, typically severe, hospitalized COVID-19 patients. These studies provide timely and important information; however, identifying risk factors calls for a comparative analysis, contrasting the prevalence of conditions in case and control populations. To date, only a handful of studies implemented such an approach, using, for example, the general population [7] or a confirmed (and symptomatic) COVID-19 patient cohort [8]. Similar to these efforts, we analyze here the medical records of all SARS-CoV-2–positive patients in a nationwide health organization (covering 2.3 million individuals). We compare the prevalence of existing conditions in complicated and noncomplicated cohorts and identify those conditions associated with COVID-19 complications in various age and sex strata. Our analysis highlights stratum-specific risk factors and may allow better identification of patients at risk in different subpopulations.

Methods

Data Source

Maccabi Health Services (MHS) is a nationwide health plan (payer-provider), representing a quarter of the Israeli population. The MHS database contains longitudinal data on a stable population of over 2.3 million people since 1993 (with an annual attrition rate lower than 1%). Data are automatically collected and include comprehensive laboratory data from a single central lab, full pharmacy prescription and purchase data, and extensive demographic information on each patient.

Data are available upon reasonable request. According to Israeli regulations, no patient-level secondary use medical data can be publicly shared.

Study Design and Setting

SARS-CoV-2 polymerase chain reaction testing in Israel uses both nasopharyngeal and saliva samples. Individuals with a positive test result (as of April 22, 2020) were included in the *SARS-CoV-2–positive cohort*. Positive patients whose disease status, as updated by Israeli hospitals, deteriorated to moderate or severe (at any point in time), admitted to the intensive care unit, or died constitute the *complicated COVID-19 cohort*. Initially, the definition of disease status varied, to some extent, between hospitals but was largely based on the severity of lower respiratory tract symptoms, including pneumonia, respiratory distress, and artificial respiration, as well as shock and system failure. The remaining SARS-CoV-2–positive patients (including asymptomatic, mild COVID-19 patients, or those with unknown status) constitute the *noncomplicated COVID-19 cohort*. The follow-up period ended on April 30, 2020 (or upon patient's death).

Patients nor the public were involved in the design, or conduct, or reporting, or dissemination plans of our research.

Patient Characteristics

Apart from age and sex, we considered a set of existing conditions, comprising those included in the CDC, NHS, and Israeli MoH at-risk definitions, as well as a set of conditions showing significant association with flu and flu-like complications.

To identify each individual's existing conditions, we used, when available, registries created and maintained by MHS. These registries are based on validated inclusion and exclusion criteria (considering coded diagnoses, treatments, labs, and imaging, as applicable). The registries are continuously and retrospectively (since 1998) updated based on each patient's central medical record. Patients may be excluded from a registry when deemed misclassified by their primary physician. Linkage across registries and with other sources of information is performed via a unique national identification number. MHS registries used are: cardiovascular diseases (specifically, ischemic heart disease, congestive heart failure, peripheral vascular disease, cerebrovascular disease, and other

cardiovascular diseases) [9], diabetes [10,11], hypertension [12], osteoporosis [13], chronic kidney disease [14], cognitive disorders, mental illness [15], cancer, immunosuppression (including advanced kidney disease, immunosuppressive treatment, asplenia, and organ transplant), weight disorders (obesity, overweight, and underweight), smoking, hospitalization (in the last 3 years), nursing home, and home care (home visits, home respiratory care, respiratory and feeding equipment). For other conditions, we relied on previously grouped lists of diagnosis codes (Read codes or International Classification of Diseases codes, 9th revision) [16-18]: deficiency anemia, fluid and electrolyte disorders, respiratory diseases (specifically, chronic obstructive pulmonary disease, chronic pulmonary disease, pleural effusion, aspiration pneumonia, and bronchiectasis), neurological disorders, end stage renal disease, rheumatoid arthritis, paralysis, hip fracture, lymphoma, and alcohol consumption.

Statistical Analysis

We extracted the prevalence of the studied conditions (excluding ones with less than 20 occurrences) in the noncomplicated and complicated COVID-19 cohorts and measured the association between each condition and disease complication by computing the corresponding odds ratio (OR) and its estimated statistical significance (using Fisher exact test). We conducted the analysis separately in three age groups (18-50 years, 50-65 years, and ≥65 years), as well as four (age, sex) strata (male or female; younger or older than 65 years). Using different age groups (as sensitivity analysis) obtained similar results. Finally, to account for multiple testing, we controlled for the false discovery rate using Benjamini and Hochberg's method [19]. All analyses were performed using version 4.0.0 of the R programming language (R Project for Statistical Computing; R Foundation). We used the STROBE (Strengthening The Reporting of OBservational Studies in Epidemiology) cohort checklist when writing our report [20].

Ethical Approval

The study was approved by the institutional review board of MHS (0024-20-MHS).

Results

The MHS SARS-CoV-2–positive cohort included 4353 individuals, of whom 173 deteriorated to moderate (n=87, 50%) or severe condition (n=45, 26%), were admitted to the intensive care unit (n=66, 38%, partly overlapping with other conditions), or died (n=21, 12%). This group of patients make up the complicated COVID-19 cohort. Overall, patients in the complicated COVID-19 cohort were older, suffered from more comorbidities, and were predominantly male (Table 1). Moreover, the prevalence of COVID-19 complications increased with age and more steeply for men than for women (Table 2). The risk of COVID-19 complications in men <70 years was significantly higher than in women (eg, *P*=.01 for patients 60-70 years old; see Table 2).

Table 1. Characteristics of the severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2)–positive, complicated, and noncomplicated coronavirus disease (COVID-19) patient cohorts.

Characteristic	SARS-CoV-2 positive (n=4353)	Complicated COVID-19 (n=173)	Noncomplicated COVID-19 (n=4180)
Demographic information			
Age (years), median (IQR)	35 (22-54)	70 (58-80)	34 (22-52)
<18, n (%)	647 (15)	0 (0)	647 (15.6)
18-50, n (%)	2354 (54.5)	21 (12.1)	2333 (56.3)
50-60, n (%)	609 (14.1)	29 (16.8)	580 (14)
60-70, n (%)	376 (8.7)	35 (20.2)	341 (8.2)
70-80, n (%)	232 (5.4)	42 (24.3)	190 (4.6)
≤80, n (%)	135 (3.1)	46 (26.6)	89 (2.1)
Female, n (%)	1939 (44.5)	50 (28.9)	1889 (45.2)
Follow-up days, median (IQR)	30 (24-36)	28 (21-33)	30 (24-36)
Comorbidities, n (%)			
Chronic respiratory diseases	481 (11)	39 (22.5)	442 (10.6)
Chronic obstructive pulmonary disease	310 (7.1)	24 (13.9)	286 (6.8)
Other chronic pulmonary disease	153 (3.5)	10 (5.8)	143 (3.4)
Pleural effusion	41 (0.9)	4 (2.3)	37 (0.9)
Cardiovascular diseases	310 (7.1)	57 (32.9)	253 (6.1)
Ischemic heart disease	132 (3)	27 (15.6)	105 (2.5)
Congestive heart failure	30 (0.7)	11 (6.4)	19 (0.5)
Cerebrovascular disease	57 (1.3)	15 (8.7)	42 (1)
Peripheral vascular disease	23 (0.5)	7 (4)	16 (0.4)
Other cardiovascular diseases	199 (4.6)	41 (23.7)	158 (3.8)
Hypertension	627 (14.4)	102 (59)	525 (12.6)
Immunosuppression	164 (3.8)	31 (17.9)	133 (3.2)
Cancer	205 (4.7)	33 (19.1)	172 (4.1)
Deficiency anemia	423 (9.7)	18 (10.4)	405 (9.7)
Liver and kidney diseases			
Liver disease	404 (9.3)	28 (16.2)	376 (9)
Chronic kidney disease	384 (8.8)	86 (49.7)	298 (7.1)
End stage renal disease	85 (2)	26 (15)	59 (1.4)
Fluid and electrolyte disorders	394 (9.1)	37 (21.4)	357 (8.5)
Metabolic diseases			
Diabetes	362 (8.3)	58 (33.5)	304 (7.3)
Obesity (BMI≥30)	874 (20.1)	73 (42.2)	801 (19.2)
Neurological and cognitive disorders			
Neurological disorders	294 (6.8)	57 (32.9)	237 (5.7)
Paralysis	53 (1.2)	12 (6.9)	41 (1)
Depression	578 (13.3)	53 (30.6)	525 (12.6)
Cognitive impairment	87 (2)	28 (16.2)	59 (1.4)
Other			
Hospitalization	931 (21.4)	92 (53.2)	839 (20.1)
Smoking	643 (14.8)	41 (23.7)	602 (14.4)

Characteristic	SARS-CoV-2 positive (n=4353)	Complicated COVID-19 (n=173)	Noncomplicated COVID-19 (n=4180)
Current smoker	514 (11.8)	30 (17.3)	484 (11.6)
Past smoker	129 (3)	11 (6.4)	118 (2.8)
Nursing home	67 (1.5)	23 (13.3)	44 (1.1)
Home care	44 (1)	17 (9.8)	27 (0.6)

Table 2. Association of male sex and coronavirus disease (COVID-19) complications across age groups.

Age group	Patient counts, n (%)				OR[a] (95% CI)	*P* value[b]
	Male		Female			
	Complicated	Noncomplicated	Complicated	Noncomplicated		
18-50 years	18 (1)	1300 (99)	3 (0.3)	1033 (99.7)	4.77 (1.39-25.32)	.01
50-60 years	25 (7)	314 (93)	4 (1)	266 (99)	5.28 (1.79-21.15)	.003
60-70 years	29 (13)	202 (87)	6 (4)	139 (96)	3.32 (1.31-10.03)	.01
70-80 years	27 (20)	108 (80)	15 (15)	82 (85)	1.36 (0.65-2.95)	.47
≥80 years	24 (43)	32 (57)	22 (28)	57 (72)	1.93 (0.89-4.26)	.15

[a]OR: odds ratio. ORs greater than 1 suggest an increased risk for COVID-19 complications in males.

[b]*P* values adjusted for multiple testing using Benjamini and Hochberg's method [19].

Comparing the prevalence of existing conditions in the three age groups between the complicated and noncomplicated COVID-19 cohorts revealed multiple risk factors, including obesity for patients 18-50 years old (OR 11.09, 95% CI 4.15-32.67; *P*<.001), chronic kidney disease for patients 50-65 years (OR 4.06, 95% CI 1.89-8.38; *P*=.005), and neurological disorders (OR 2.65, 95% CI 1.69-4.17; *P*<.001) for patients ≥65 years (for a complete list, see Table 3 and Multimedia Appendix 1).

Stratifying by age (below and above 65 years) and sex (Table 4 and Multimedia Appendix 1), we observed that kidney diseases are a risk factor in all strata (eg, OR 3.45, 95% CI 1.57-8.06; *P*=.02 in women ≥65 years). Additional risk factors included hypertension in males under 65 years (OR 4.56, 95% CI 2.35-8.55; *P*<.001); neurological disorders in females ≥65 years (OR 3.55, 95% CI 1.68-7.74; *P*=.008); cognitive impairment (OR 4.18, 95% CI 1.81-9.72; *P*=.009) and depression (OR 2.94, 95% CI 1.55-5.58; *P*=.01) in males ≥65 years. Respiratory diseases and smoking, while typically more prevalent in complicated COVID-19 patients, were not identified as significant risk factors (eg, chronic obstructive pulmonary disease in patients ≥65 years: OR 1.36, 95% CI 0.75-2.4; *P*=.63) (see Multimedia Appendix 1).

Table 3. Most statistically significant conditions associated with increased risk of coronavirus disease (COVID-19) complications in age-stratified patient groups.

Condition	Age group	Patient counts, n				OR[a] (95% CI)	*P* value[b]
		With condition		Without condition			
		Complicated	Noncomplicated	Complicated	Noncomplicated		
Obesity	18-50 years	14	356	7	1977	11.09 (4.15-32.67)	<.001
Depression	18-50 years	7	229	14	2104	4.59 (1.55-12.3)	.03
Hypertension	18-50 years	4	72	17	2261	7.37 (1.76-23.41)	.04
Liver disease	18-50 years	5	125	16	2208	5.51 (1.55-16.07)	.04
Chronic kidney disease	50-65 years	14	87	27	683	4.06 (1.89-8.38)	.005
End stage renal disease	50-65 years	5	8	36	762	13.11 (3.21-48.19)	.006
Neurological disorders	≥65 years	54	113	57	317	2.65 (1.69-4.17)	<.001
Chronic kidney disease	≥65 years	70	174	41	256	2.51 (1.6-3.97)	.001
Other cardiovascular diseases	≥65 years	36	70	75	360	2.46 (1.49-4.05)	.006
Cognitive impairment	≥65 years	28	52	83	378	2.45 (1.4-4.22)	.02
Home care	≥65 years	16	22	95	408	3.12 (1.47-6.48)	.02
Hypertension	≥65 years	82	249	29	181	2.05 (1.27-3.4)	.03
Cardiovascular diseases	≥65 years	50	129	61	301	1.91 (1.22-2.99)	.03
Nursing home	≥65 years	20	35	91	395	2.48 (1.29-4.65)	.04

[a]OR: odds ratio. ORs greater than 1 suggest an increased risk for COVID-19 complications in patients with the noted condition.

[b]In each stratum, rows are sorted ascendingly by *P* value.

Table 4. Most statistically significant conditions associated with increased risk of COVID-19 complications in age- and sex-stratified patient groups.

Condition	Age, sex group	Patient counts				OR[a]	*P* value[b]
		With condition		Without condition			
		Complicated	Noncomplicated	Complicated	Noncomplicated		
End stage renal disease	<65 years; female	2	5	7	1370	75.7 (6.23-570.01)	.01
Immunosuppression	<65 years; female	3	46	6	1329	14.35 (2.25-69.89)	.03
Chronic kidney disease	<65 years; female	3	58	6	1317	11.3 (1.78-54.41)	.04
Chronic kidney disease	<65 years; male	13	66	40	1662	8.16 (3.82-16.5)	<.001
Hypertension	<65 years; male	17	162	36	1566	4.56 (2.35-8.55)	<.001
Obesity	<65 years; male	25	359	28	1369	3.4 (1.88-6.14)	.001
Hospitalization	<65 years; male	21	285	32	1443	3.32 (1.79-6.04)	.004
End stage renal disease	<65 years; male	3	7	50	1721	14.67 (2.38-66.53)	.03
Diabetes	<65 years; male	9	105	44	1623	3.16 (1.32-6.79)	.04
Neurological disorders	≥65 years; female	26	66	15	136	3.55 (1.68-7.74)	.008
Chronic kidney disease	≥65 years; female	30	89	11	113	3.45 (1.57-8.06)	.02
Home care	≥65 years; female	10	16	31	186	3.72 (1.38-9.69)	.04
Other cardiovascular diseases	≥65 years; female	15	33	26	169	2.94 (1.3-6.51)	.04
Cardiovascular diseases	≥65; female	19	48	22	154	2.76 (1.29-5.85)	.045
Cognitive impairment	≥65 years; male	16	15	54	213	4.18 (1.81-9.72)	.009
Depression	≥65 years; male	26	38	44	190	2.94 (1.55-5.58)	.01
Neurological disorders	≥65 years; male	28	47	42	181	2.56 (1.38-4.73)	.02
End stage renal disease	≥65 years; male	19	26	51	202	2.88 (1.39-5.9)	.03
Chronic kidney disease	≥65 years; male	40	85	30	143	2.24 (1.26-4.02)	.03
Fluid and electrolyte disorders	≥65 years; male	17	22	53	206	2.99 (1.39-6.38)	.03

[a]OR: odds ratio. ORs greater than 1 suggest an increased risk for COVID-19 complications in patients with the noted condition.

[b]In each stratum, rows are sorted ascendingly by *P* value.

Discussion

We compared the prevalence of dozens of existing conditions in Israeli SARS-CoV-2–positive and complicated COVID-19 patient cohorts to highlight conditions associated with a high risk of complications. A few other studies have employed a similar study design to identify risk factors for COVID-19 complications. For example, Ebinger et al [8] studied a cohort of symptomatic COVID-19 individuals (N=442) and examined the association of existing conditions with disease severity; and the OpenSAFELY Collaborative explored the risk of COVID-19–related hospital death in the general population

(N>17 million). We emphasize that cohort composition dictates the research question it can address: our analysis focuses on SARS-CoV-2–positive individuals, hence searches for risk factors of complications in patients who already contracted the virus (but are potentially asymptomatic), while studying the general population may combine risk factors for infection and severe COVID-19 outcome. Additionally, cohorts that consider only a subset of patients, defined based on disease outcome (eg, symptomatic or hospitalized) or otherwise nonrepresentative of the entire population (eg, demographically skewed) may introduce biases to the analysis [21]; instead, we study here all SARS-CoV-2–infected patients in a large, nationwide health organization.

Multiple studies (eg, [7,22]) have shown that COVID-19 complications are most strongly associated with age and sex. Stratifying by these factors provides readily interpretable insights on the supplemental associations (in addition to older age and male sex) between pre-existing conditions and disease complications.

Many conditions highlighted by our analysis have been previously reported [5,6,8] and are part of commonly used at-risk definitions [1,3], including hypertension, obesity, as well as kidney and cardiovascular diseases. We do, however, identify a few additional risk factors, notably depression in patients aged 18-50 years and males ≥65 years; and cognitive and neurological disorders in patients ≥65 years. These additions may be, in part, associated with the different age distribution in the ≥65 years group (median 76 years, IQR 70-83.5 years versus 72 years, IQR 68-78 years, in the complicated and noncomplicated COVID-19 cohorts, respectively) and rely on small sample size (only 7 patients aged 18-50 years with depression in the complicated COVID-19 cohort; Table 3). Nonetheless, with some preliminary support [7], they may deserve more consideration in future studies. Our analysis also points out to the reduced importance of respiratory diseases and smoking. Both conditions appear as factors in most at-risk definitions [3,5]: chronic obstructive pulmonary disease has been associated with severe COVID-19 in multiple studies [23] (though not all [6]), while the role of smoking has been somewhat controversial [23,24]. The discrepancies between our analysis and previous reports likely stem from the different cohorts analyzed: SARS-CoV-2–positive individuals, ranging from asymptomatic to severe COVID-19 versus hospitalized COVID-19 patients, respectively. Other study-related attributes (eg, country-specific characteristics) may also contribute to the varying importance of the studied risk factors.

In parallel to the COVID-19 epidemiological characterization efforts, researchers have also attempted to use retrospective observational data to derive risk models for severe COVID-19 patients [25]. Such models require ample data of COVID-19 patients for both model training and performance assessment. As such data are scarce at present, some models compromised on using data for other diseases with, supposedly, similar clinical trajectory and complications. For example, DeCapprio et al [26] trained models on US Medicare claims data to predict inpatient visits with a primary diagnosis of either pneumonia, influenza, acute bronchitis, or other specified upper respiratory infections as proxy for COVID-19 complications. However, as previously reported (eg, [27]), and in agreement with our analysis, severe COVID-19 patient characteristics differ considerably from that of other diseases, thus limiting the generalizability of such models to COVID-19 and requiring adjustments to their parameters [4].

Our study has several limitations. First and foremost, it relies on routinely maintained electronic health records, which may be inaccurate and incomplete [28]. Second, the number of complicated COVID-19 patients in the MHS data is below 200, limiting the statistical power of our analysis. Third, health care policies and, in particular, testing criteria, may systematically bias the composition of the SARS-CoV-2–positive cohort. Fourth, asymptomatic and patients with mild symptoms of COVID-19 (currently in the noncomplicated cohort) may deteriorate and eventually be part of the complicated cohort, potentially modifying the results of the analysis. Fifth, our analysis is univariate in nature, testing the association of individual conditions with COVID-19 complications; as such, it is unable to uncover more complex relations (eg, interdependencies between existing conditions and COVID-19 complications), which may be discovered by multivariate analysis. Finally, we focused on data from Israel; characteristics in other geographies may differ [27]. We attempted to mitigate some of these limitations by age and sex stratification and robust estimations of statistical significance. We also note that, at the current point in time, many of these shortcomings are shared by all published research on COVID-19.

Notwithstanding these limitations, our work adopts a novel vantage point to the problem of identifying patients at increased risk for COVID-19 complications. Importantly, as SARS-CoV-2 containment efforts focus on patients at risk for severe complications (eg, shielding vulnerable population in the United Kingdom [3]), changes in the list of considered conditions may have a substantial effect on a large number of individuals, thus calling for continuous fine-tuning of the corresponding definitions.

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Authors' Contributions

NK was responsible for study conceptualization; BM, KM, and YB for data curation; CY, BM, and NK for investigation and methodology; PA and VS for project administration; CY for original draft preparation; CY, BM, KM, PA, YB, and GC reviewed and edited the manuscript.

Conflicts of Interest

PA reports personal and other fees from Medial Research, unrelated to the submitted work.

Multimedia Appendix 1
Odds ratio analysis.
[XLSX File (Microsoft Excel File), 29 KB - publichealth_v6i3e20872_app1.xlsx]

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Abbreviations

CDC: Centers for Disease Control and Prevention
COVID-19: coronavirus disease
ECDC: European Centre for Disease Prevention and Control
MHS: Maccabi Health Services
MoH: Ministry of Health
NHS: National Health Service
OR: odds ratio
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
STROBE: Strengthening The Reporting of OBservational Studies in Epidemiology

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Original Paper

Big Data, Natural Language Processing, and Deep Learning to Detect and Characterize Illicit COVID-19 Product Sales: Infoveillance Study on Twitter and Instagram

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Abstract

Background: The coronavirus disease (COVID-19) pandemic is perhaps the greatest global health challenge of the last century. Accompanying this pandemic is a parallel "infodemic," including the online marketing and sale of unapproved, illegal, and counterfeit COVID-19 health products including testing kits, treatments, and other questionable "cures." Enabling the proliferation of this content is the growing ubiquity of internet-based technologies, including popular social media platforms that now have billions of global users.

Objective: This study aims to collect, analyze, identify, and enable reporting of suspected fake, counterfeit, and unapproved COVID-19–related health care products from Twitter and Instagram.

Methods: This study is conducted in two phases beginning with the collection of COVID-19–related Twitter and Instagram posts using a combination of web scraping on Instagram and filtering the public streaming Twitter application programming interface for keywords associated with suspect marketing and sale of COVID-19 products. The second phase involved data analysis using natural language processing (NLP) and deep learning to identify potential sellers that were then manually annotated for characteristics of interest. We also visualized illegal selling posts on a customized data dashboard to enable public health intelligence.

Results: We collected a total of 6,029,323 tweets and 204,597 Instagram posts filtered for terms associated with suspect marketing and sale of COVID-19 health products from March to April for Twitter and February to May for Instagram. After applying our NLP and deep learning approaches, we identified 1271 tweets and 596 Instagram posts associated with questionable sales of COVID-19–related products. Generally, product introduction came in two waves, with the first consisting of questionable immunity-boosting treatments and a second involving suspect testing kits. We also detected a low volume of pharmaceuticals that have not been approved for COVID-19 treatment. Other major themes detected included products offered in different languages, various claims of product credibility, completely unsubstantiated products, unapproved testing modalities, and different payment and seller contact methods.

Conclusions: Results from this study provide initial insight into one front of the "infodemic" fight against COVID-19 by characterizing what types of health products, selling claims, and types of sellers were active on two popular social media platforms at earlier stages of the pandemic. This cybercrime challenge is likely to continue as the pandemic progresses and more people seek access to COVID-19 testing and treatment. This data intelligence can help public health agencies, regulatory authorities, legitimate manufacturers, and technology platforms better remove and prevent this content from harming the public.

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KEYWORDS

COVID-19; coronavirus; infectious disease; social media; surveillance; infoveillance; infodemiology; infodemic; fraud; cybercrime

Introduction

The novel coronavirus (2019-nCoV; also known as severe acute respiratory syndrome coronavirus 2 [SARS-Cov-2]) and associated diagnosis, the coronavirus disease (COVID-19), has created a global crisis. Its broad effect has not been seen since the days of the 1918 influenza pandemic that impacted 200-700 million people (1/3 of the world's population at the time) and resulted in global mortality of 50-100 million [1]. Impacting virtually every corner of the world after initially appearing in Wuhan, China, COVID-19's threat to humanity is broad [2]. Measures to fight the threat, including social distancing, quarantine, and limited commercial activity, are now the global norm, along with travel restrictions and other measures put into place in an effort to contain the pandemic [3].

With the advent of social media, an information-sharing culture, and technological dispersion throughout the world to access these platforms (ie, mobile, broadband access) the more than 2.9 billion global social media users now have more information resources to help them understand and protect themselves against the coronavirus [4]. Indeed, social media platforms represent one of the most accessible sources of health information and are now being used by agencies such as the World Health Organization (WHO), US Centers for Disease Control and Prevention, US Food and Drug Administration (FDA), and others [5,6]. Social media conversations are also important for understanding public sentiment, user behavior, and disease transmission dynamics during outbreaks. For example, Twitter has been used extensively for "infoveillance" approaches to assess past outbreaks such as H1N1, Zika virus, and the Ebola outbreak [7-10].

Yet accompanying the strong utility of internet technologies and social media to positively impact outbreak response and communication is a nefarious underpinning: a criminal element that is now across and within social media seeking to capitalize on confusion, fears, and the acute needs of the public. Labeled by the WHO as an "infodemic," where there is an overabundance of information, some of which includes misinformation and enables COVID-19–related cybercrime, this parallel information epidemic is now a serious challenge to ensuring the success of public health objectives of mitigating the spread of COVID-19 [11,12]. Beyond misinformation about the etiology and basic facts of COVID-19, which the WHO is trying to counter with its COVID-19 "Myth Busters" website, other forms of COVID-19–related cybercrime are now widespread [13].

Documented COVID-19–related cybercrimes include fake coronavirus applications that are actually malware, phishing scams using email, text message campaigns and robocalls, economic scams regarding government assistance or relief, and a host of suspect and counterfeit COVID-19 products now sold online [14,15]. Numerous news outlets have reported the use of online platforms including popular social media sites as a source for suspect COVID-19–related health products [16]. For example, COVID-19 "cures" have appeared across major electronic commerce (e-commerce) sites including Amazon.com (which reported removing a million fake COVID-19 product listings), Shopify store vendors, and other reselling and auction platforms such as eBay [17,18]. Unapproved COVID-19 test kits, both serologic as well as reverse transcriptase polymerase chain reaction tests, are being sold by multiple sources including Twitter, Instagram, and Reddit [19]. Finally, the dark web has been identified as a source for counterfeit COVID-19 therapeutics, including biological products such as blood plasma [20].

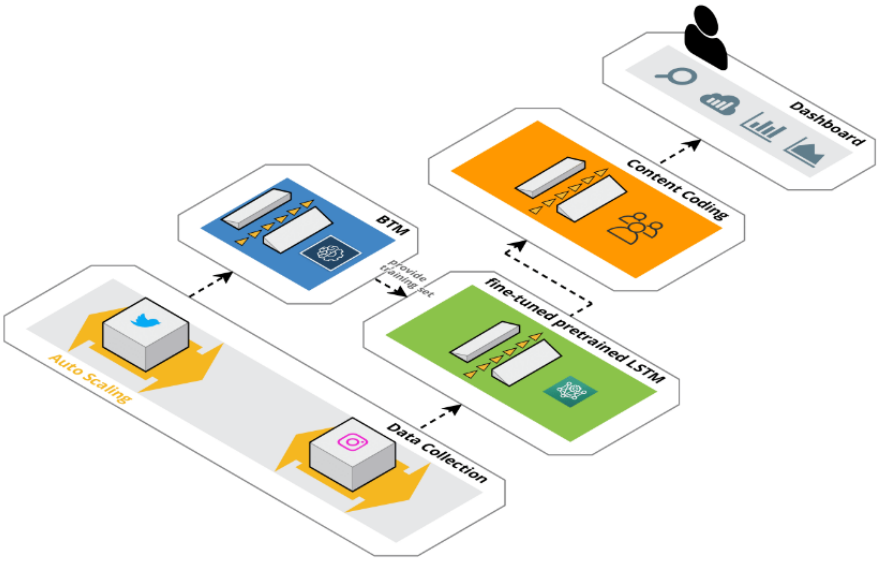
Hence, there is significant need to assess the characteristics of illegal online COVID-19 product marketing and sale at different stages of the pandemic. In response, this study used big data, natural language processing (NLP), and machine learning to identify the marketing and sale of suspect and unapproved COVID-19 cures, testing kits, and other questionable treatments at earlier stages of the pandemic on two popular social media platforms: Twitter and Instagram. We also describe an approach to visualize findings in a customized data dashboard to enable public health intelligence and reporting to authorities.

Methods

Overview

This retrospective big data study was conducted in two phases: (1) data collection using the public streaming Twitter application programming interface (API) and the use of web scraping on Instagram to collect social media posts filtered for COVID-19–related keywords and (2) data analysis using NLP to isolate topic clusters related to COVID-19 product sales combined with a deep learning algorithm to classify a larger volume of social media posts for classification of "signal" posts (ie, posts confirmed as associated with COVID-19 product marketing and selling; see Figure 1 for summary). Data storage and analysis was conducted on an on-premise deep learning workstation in combination with a series of virtual machines deployed on Amazon Web Service cloud-computing. Additional details of the data collection, processing, and analysis are available in Multimedia Appendix 1.

Figure 1. Summary of study methodology. The first phase (yellow) is collection of data from the public streaming Twitter application programming interface and using a web scraper on Instagram to collect social media posts filtered for COVID-19–related keywords; the second phase (blue) used BTM to isolate topic clusters related to COVID-19 product sales to develop an initial training set for classification of posts using a deep learning algorithm (green). Data output by the deep learning classifier was then manually coded for true signals and selling characteristics (orange). Finally, the visualization of labeled data on a customized dashboard to enable public health intelligence and reporting to public health agencies was conducted (grey). BTM: biterm topic model; COVID-19: coronavirus disease; LSTM: long short-term memory.



Data Collection

This study first applied a systematic approach to conduct data mining on Twitter by filtering the public streaming API for keywords associated with COVID-19 to collect a large corpus of general COVID-19–related conversations from March 3 to April 11, 2020. The same set of keywords were used to collect data from Instagram using a web scraper built in the programming language Python. We identified general COVID-19–related keywords based on manual searches on each of the platforms, which included different iterations of "COVID-19" (eg, "covid19," "corona," "coronavirus," "coronavid19"), with these keywords converted into hashtags to conduct searches on Instagram. Text of tweets and Instagram posts were captured, as well as retweets and other metadata including likes; favorites; comments; replies; use of similar hashtags; and associated media, hyperlinks, and metadata of posts (eg, time stamp, geolocation, and account information). This metadata was primarily used to identify any potential temporal trends associated with selling posts, account characteristics of sellers, interaction of posts with other users, geospatial information, and to characterize hyperlinks to external websites that were imbedded in selling posts.

After collecting an initial corpus of tweets and Instagram posts using general COVID-19 keywords, we then filtered the corpus for additional terms we believed to be associated with the marketing and sale of illegal, suspect, counterfeit, and otherwise misleading COVID-19–related products and treatments as first identified in manual searches. A full list of all filtered terms used in this study is available in Multimedia Appendix 1.

Data Analysis Using Unsupervised and Supervised Machine Learning Approaches

After collecting Twitter and Instagram posts, and then filtering for illegal marketing and sales terms, we processed the data by removing hashtags and stop words prior to textual analysis. To our knowledge, there is no existing training set related to detecting suspect COVID-19 products in the context of the current pandemic. This necessitated using a combination of unsupervised and supervised machine learning approaches to detect an initial training set of "signal" posts from each platform that were then used to train a supervised machine learning classifier using a deep learning model.

We first used an "unsupervised" NLP approach to group and summarize all the content of filtered social media data stratified by different product groups of filtered terms. This was accomplished by assessing the entire corpora of COVID-19 filtered data using the biterm topic model (BTM) to both identify initial signal posts in the absence of labelled data and to curate an initial labelled training set for supervised machine learning purposes (see Multimedia Appendix 1 for additional details). We have used BTM in prior published studies to detect social media conversations related to substance use behavior, illicit drug diversion, online wildlife trafficking, and corruption-related activities [21-23].

Signal posts detected in our BTM phase were then used as our training set for a deep learning classifier designed to conduct supervised classification on the entire corpus of filtered social media posts. For this study, we adopted an existing deep learning model used to detect online controlled substance and illicit drug

sales as previously published by authors [24]. Although the original deep learning model was trained on social media posts labelled for illegal online drug sales, the signal texts of these two data sets contained very similar features (eg, specific "seller information" and "product information" features). Hence, the pretrained model helped us detect these specific "selling" features targeted for COVID-19 sellers and products. This was due to the fact that our corpus of social media posts was already purposely filtered for COVID-19 keywords (ie, not illicit drug-related terms).

Hence, this combination of unsupervised and supervised machine learning approaches enabled us to quickly develop a data collection and analysis approach for an emerging infoveillance challenge given the rapidity and large volume of COVID-19–related data and the evolving nature of the pandemic itself.

Content Coding

After classification by our deep learning algorithm, posts that were output by the model and classified as possible "signal" were then manually annotated to confirm if they were associated with illegal marketing and sales of COVID-19 health-related products (see Multimedia Appendix 2 for coding scheme details). First, coders independently used a binary coding approach (ie, signal vs nonsignal) to verify if posts included the sale of a COVID-19 health product and if a contact or purchase method was made available. The purpose of this binary coding scheme was to eliminate "noise" in the data set, including COVID-19 news, regulatory product announcements, user discussions about treatments and testing, and legitimate warnings from public health, law enforcement, and other sources about COVID-19 fraud and cybercrime that were not related to product marketing or sales.

Second, we classified signal posts based on what specific COVID-19 product was being offered individually or concurrently (eg, testing kits, protective equipment, masks, and pharmaceuticals). We also conducted content analysis to characterize strategies used to market and sell products using an open inductive coding scheme based on previous work characterizing online drug sellers [22,24-27]. These characteristics included the method of contacting seller, method of payment (if reported), purported modality of order or purchase, and availability of hyperlinks to other internet sources enabling sale.

Coders individually selected parent topic classifications, removed duplicate topics, and evaluated thematic concurrence by independently coding the entire sample of output posts from our machine learning phase. The third, fourth, fifth, and sixth authors coded posts independently and achieved high intercoder reliability (κ=0.92). In case of inconsistent results, authors reviewed and conferred on the correct classification with the first and last authors who have previously published on the subject.

Availability of Data and Materials

Data collected on social media platforms is available on request from authors, subject to appropriate deidentification.

Ethics Approval and Consent to Participate

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. Indefinable user information was removed from the study results.

Results

Collected Data

Data was collected from March 3 to April 11, 2020, via the Twitter public API stream and from February 5 to May 7 via the web scrapper built for Instagram. During this period, we collected a total of 6,029,323 tweets and 204,597 Instagram posts that included a COVID-19 general term and that were also filtered for terms associated with suspect marketing and sale of COVID-19 products. After using our deep learning algorithm to classify all posts filtered for marketing and sales terms, we manually annotated and confirmed 1271 tweets of which 1042 were unique (see Textbox 1 for Twitter examples) and 596 Instagram posts (see Textbox 2 for Instagram examples) associated with questionable sales of COVID-19–related products.

Textbox 1. Product categories and example signal posts for suspect coronavirus disease–related products on Twitter.

Immunity boosting kits

*"****** is safe for the whole family. Support your immune system with #****** at app.elify.com/vbc/6pf3pvak44…*

*#COVID-19 #coronavirus #FluSeason #ImmuneSystem #immunebooster #hydrosolsilver #antiviral #antivirus" - March 16, 2020 @******

Coronavirus disease (COVID-19) testing kit

*"Negative Test Results Product: Fast SARS-CoV-2 Detection Igm/IgG Bioassay disposable one time use kit 4 minute screening." - March 25, 2020 @******

COVID-19 IgG/IgM antibody detection kits

*"SARS-CoV-2 (COVID-19) IgM / IgG Antibody Fast Detection Kit (Colloidal Gold) New Coronavirus IgM / IgG Antibody Rapid Detection Kit (colloidal gold method)" - March 21, 2020 @******

Personal protection equipment (PPE)/masks/gloves

*"10/50/100pcs Antiviral Disposable Face Mask Anti Dust Anti Influenza Face Mouth Mask For Coronavirus Clear Viruses Tool dropship kawaicorner.com/product/10-50-..." - March 13, 2020 @******

Alleged COVID-19 cures

*"#COVID19 #CoronaOutbreak #Coronavirustexas #Coronachina #ChinaCoronaVirus #coronavirusnigeria found out COVID19 can be cured by the mixture of salivary water extracted from plantain stem, pawpaw tree, scent leaf and Garlic. @****** @WHO @Fmohnigeria @realDonaldTrump @ChinaDaily" - March 2, 2020 @******

Multiple products (PPE, testing kits, etc)

"All available. #COVID19 RNA Preservation Kit (with Swab) COVID-19 IgG/IgM Rapid Test Cassette #Disposable protection suits Infrared forehead thermometer. Disposable Protective mask Pls contact me:

*Whatsapp: ******

*Email: ******" - March 23, 2020 @******

Textbox 2. Product categories and example signal posts for suspect coronavirus disease–related products on Instagram.

Immunity boosting kits

"Happy Monday! ****** is a perfect immune boost for winter illnesses. Get yours before stock runs out.

#killgerms #germs #nhs #coronavirus #covid #covid2019 #vitaminc #zinc #lambertshealthcare #antibacterial #hillcrestpharmacy #hollandpark #nottinghill #w11"

Coronavirus disease (COVID-19) testing kit

"Antibody Rapid Test Coronavirus (COVID-19) ******

Test in 4 Easy Steps

FAST Testing time: 15 min

Accuracy: 92%

Certifications: CE.

Package content = 100 Units

For quantity discounts Please call : ******

#covid #covidtest #coronavirus #rapidtest #covidtestkit #coronatest #covidrapid #workingwear #protectionwear #jumpsuit #hazmat #hazmatsuit #covidrecovery #covidrapidtest #apd #protection #rapidtestkit #rapidtestcorona #rapidtestcovid #rapidtestkits #healthcare #safety #a #s #covidtesting #coronavir #sifsof"

COVID-19 IgG/IgM antibody detection kits

"coronavirus IgM/IgG Test Kit.

1. One box of 25 kits, one box of $192
2. Mode of transport ups plan express. About 3-7 days arrived all over the world.
3. Division I provide certificate and provide clear customs clearance, tax paying. All you have to do is give us the receiving address.
4. The delivery time is 3-5 days.
5. Support 100% payment method: PayPal Western Union or Telegraphic. #covid_19 #testkits #corona #coronavirus #covid19"

Personal protection equipment (PPE)/masks/gloves

"All of these PPE materials are available, welcome to contact !#facemasks #KN95masks #ffp2mask #sanitizers #gloves #testkit #protectiveclothing #temperaturegun"

Multiple products (PPE, testing kits, etc)

"Disposable surgical face mask

****** for coronavirus vaccines and tablets available at very affordable prices hand sanitizer thermometers test kits also available just inbox for your order

#testkit #facemask #thermometer #foreheadthermometer #n95 #3m #8210 #1860 #3plyfacemask #3plymask #/3ply #surgicalfacemask #coronavirus #coronacure #coronavaccine #"

Based on the periods of data collection and terms used, we generally observed that there was a first spike or "wave" of social media posts related to fake cures and unproven treatments including home remedies, traditional medicines, supplements, essential oils, and other unproven products. This was followed by a second and much larger wave of posts, including offers for sale of suspect COVID-19 testing, screening, and diagnostic products (see Figure 2 for timeline). Hence, we observed that the volume of suspect COVID-19 products on Twitter and Instagram appeared to materialize in two distinct infodemic waves during this relatively early period of the pandemic, with the volume of topics changing over time as news, misinformation, and rumors regarding potential COVID-19 treatments, supplies, testing availability, and other conversations evolved (see Table 1).

Figure 2. Timeline for volume and topics of signal posts related to suspect coronavirus disease products on Twitter and Instagram. PPE: personal protective equipment.

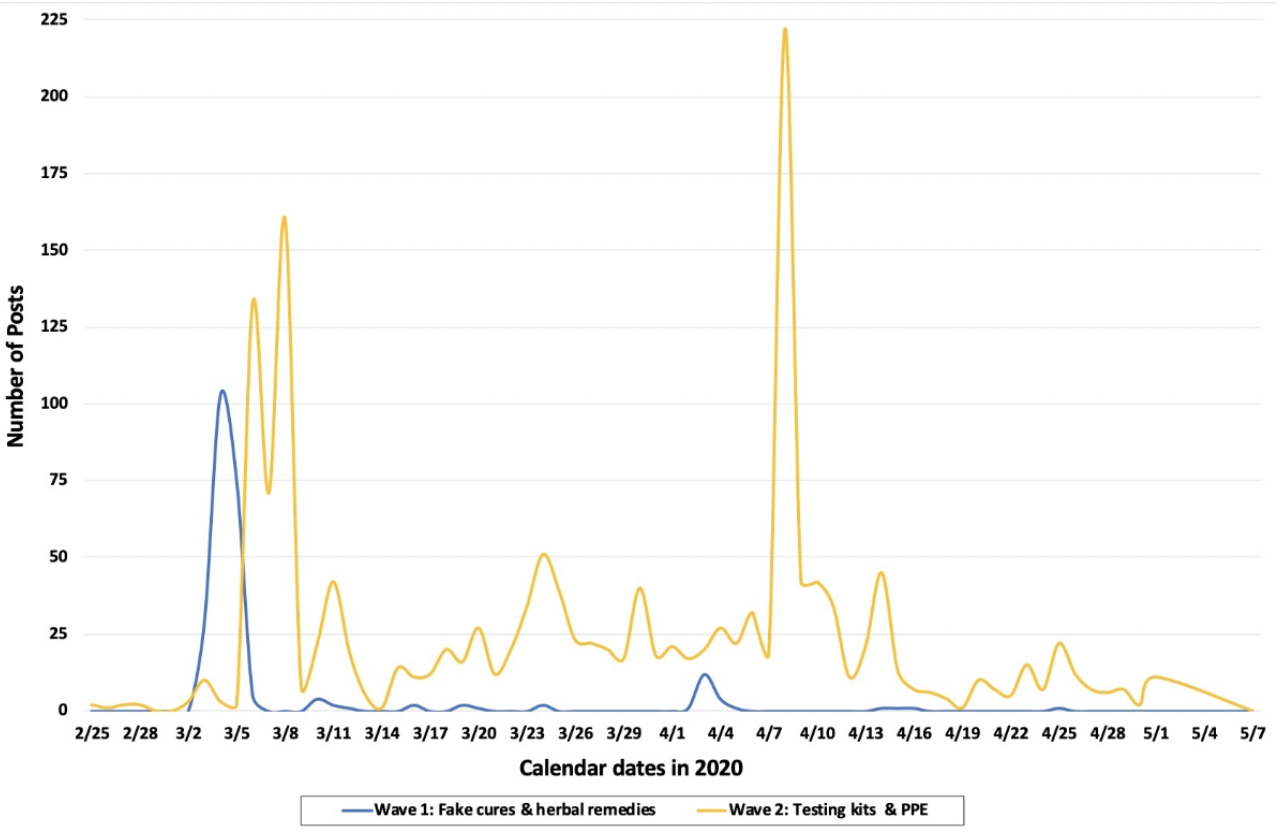


Table 1. Twitter and Instagram posts associated with questionable sales of COVID-19–related products.

Infodemic wave and COVID-19[a]–related product	Posts, n	
	Twitter (n=1271)[b]	Instagram (n=596)[b]
Wave 1		
Fake cures	209	0
Herbal medicines	33	6
Wave 2		
Testing kits and PPE[c]	1028	571
Testing kits	970	410
PPE	112	181
Wave 3		
Pharmaceuticals	5	22

[a]COVID-19: coronavirus disease.

[b]Total does not add up to sum of posts in waves due to some posts having co-occurring COVID-19–related products.

[c]PPE: personal protective equipment.

The first infodemic wave involved posts related to a variety of unproven treatments (eg, including posts with terms such as “antiviral,” “antibiotic,” and products claiming “immunity boosting” benefits) along with products that were subject to regulatory warnings by the FDA (eg, silver colloidal and chlorine). During this time period of observed fake cures and unproven treatments, news events including claims by InfoWars founder Alex Jones and televangelist Jim Bakker that colloidal silver could treat COVID-19 were followed by regulatory warnings by the FDA, likely leading to increased interest and selling activity on social media for similar products. Other similar rumors regarding preventative measures and COVID-19 treatments were also circulating on the internet and social media at the time [28].

The second wave included terms and posts primarily selling COVID-19 testing kits (eg, terms included “IgM/IgG,” “rapidtest,” and “detectionkit”) in combination with other supplies (eg, masks, protective personal equipment, gloves, and

miscellaneous protective gear). During this second wave we observed two distinct spikes of increased volume of posts on or around March 5-10 and April 7-10, 2020. The first spike in March coincided with widespread news coverage about increasing numbers of COVID-19 cases; discussion from state governments about where to get access to testing; press releases from companies discussing development of testing services, such as Quest Diagnostics announcement on March 5, 2020, about new testing services it was developing; and news about testing products undergoing evaluation by the FDA (including under emergency use authorization). The second peak in April coincided with news about testing sites opening and expanding, concerns about a US nationwide shortage of testing capacity, and possible underreporting due to testing backlogs.

Finally, we analyzed the data set for terms associated with promising therapeutics that at the time were announced as possible off-label treatments or were undergoing testing and clinical validation. This included the drugs hydroxychloroquine, chloroquine, remdesivir (proprietary name Veklury, Gilead Sciences), favipiravir (proprietary names Avigan, Abigan, FabiFlu), lopinavir/ritonavir (proprietary name Aluvia, Kaletra, AbbVie Inc), that collectively represent a mix of both proprietary and nonproprietary pharmaceutical treatments, including those that had already been approved by the FDA for non–COVID-19 indications (eg, hydroxychloroquine is approved by the FDA to treat malaria and lupus) and those that are experimental and unapproved drugs. Though we detected some posts in this category, the volume was low relative to waves 1 and 2.

COVID-19 Product Characteristics

In the first wave, which was detected in the earliest stages of the study period from March 3 to April 4, 2020, 242 tweets and 6 Instagram posts (248/1867, 13.28% of all signal posts) advertised the sale of or promoted the use of immune-boosting COVID-19 prevention and treatment products. Herbal products included three general categories: (1) premade herbal or nontraditional remedies; (2) instructions on how to create herbal concoctions and cocktails with purported immunoprotective benefits specific to COVID-19; (3) and other posts including dietary supplements and food products claiming to prevent COVID-19, such as colloidal silver. Other highly questionable products that did not fit into a specific category included a “portable hospital” device that claimed to use a negative ion current to treat COVID-19 and other viruses (see Figure 3 for screenshots).

Premade herbal remedies included products represented as traditional herbal Eastern medicines and compounds but also included consumer items such as lavender spray, pawpaw trees, xylitol, and cow dung with claims of immunoprotective benefits for COVID-19. Sellers of herbal remedies tended to market themselves as doctors or healers with specific reference to Ayurvedic, Eastern, or nontraditional medicine. The descriptive text in some of these posts had misleading claims that combinations of herbal remedies could cure the virus. Moreover, other posts claimed that consumption or proximity to garlic or lomatium could treat COVID-19. Some of the posts used misleading marketing claims such as “approved” or “authorized,” despite these products having no known formal approval for COVID-19 uses.

The second wave included the majority of signal posts detected in this study (1028 tweets and 571 Instagram posts, 73.86%) involving the marketing, sale, and distribution of unapproved COVID-19 testing kits (see Figure 4) and were detected from March 6 to April 10, 2020. Most of these posts advertised their testing products as IgM/IgG tests, generally a type of test that detects fluctuating antibody concentrations to determine the presence or absence of SARS-CoV-2. These products were mainly advertised as “rapid test” kits or testing supplies containing colloidal gold. Though there are official commercial rapid lab-based tests to detect IgM/IgG antibodies, in the United States, none are authorized to be sold direct-to-consumer.

Figure 3. Twitter and Instagram posts related to suspected COVID-19 treatments and remedies. COVID-19: coronavirus disease; WHO: World Health Organization.

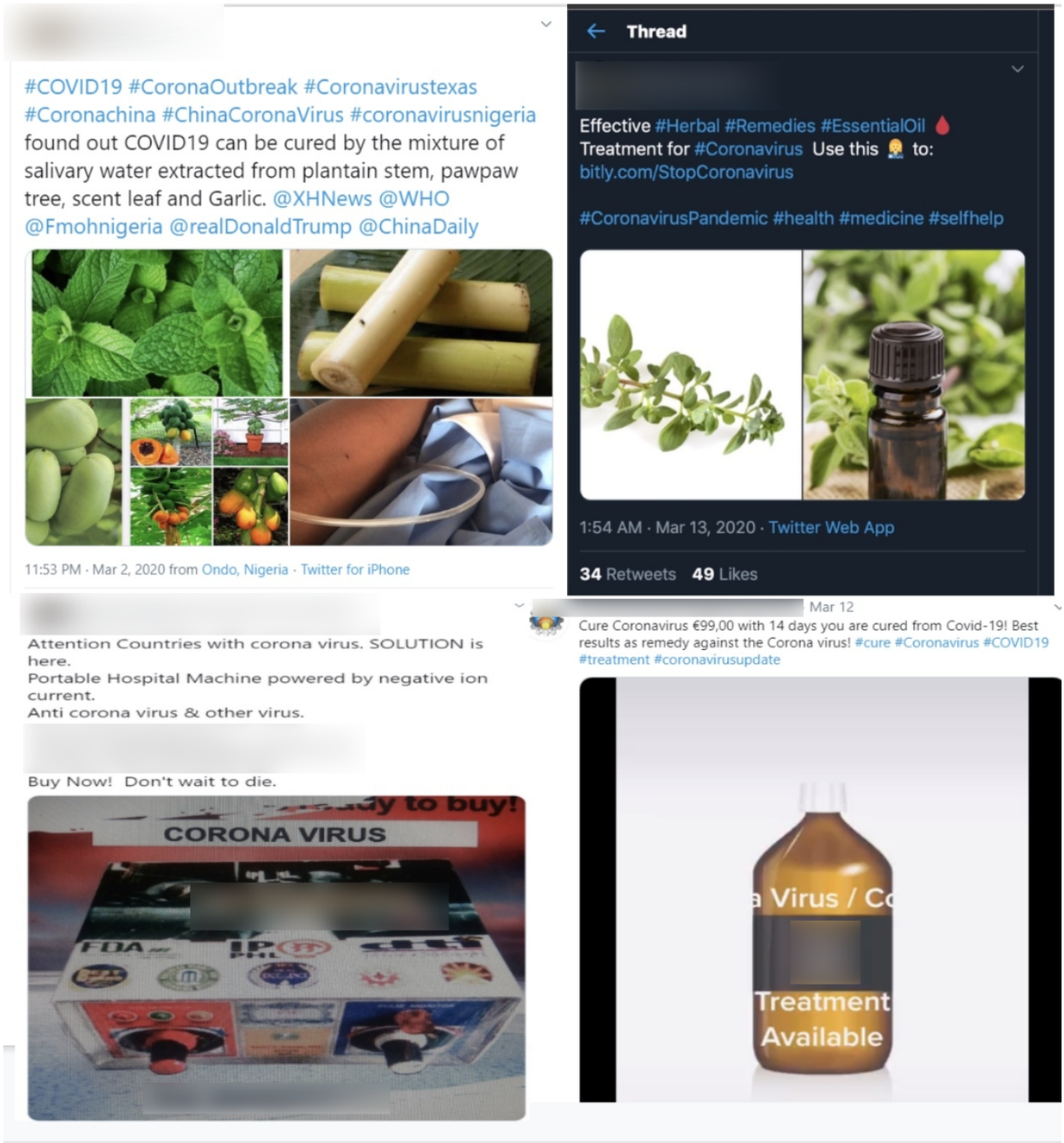
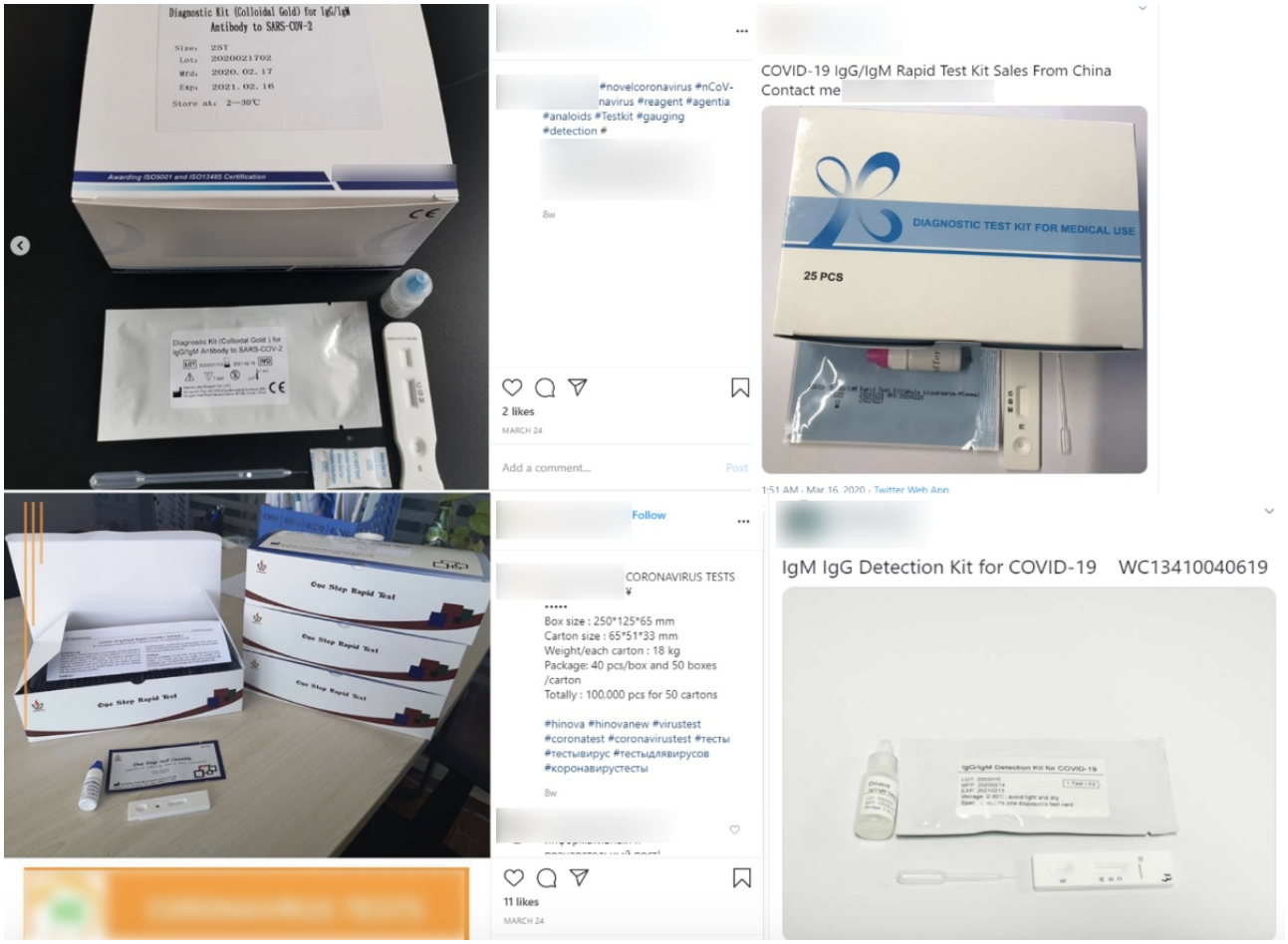


Figure 4. Twitter and Instagram posts related to suspected COVID-19 testing kits. COVID-19: coronavirus disease; SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.



An additional category of testing kit posts included products purportedly approved as at-home kits or "DIY." However, it should be noted that as of April 21, 2020, only one home testing kit had been approved by the FDA, a home sample collection kit named Pixel by LabCorp (Laboratory Corporation of America). The Pixel kit is only for sample collection at home and the swab samples must be sent to LabCorp processing centers to process COVID-19 results. Other examples of questionable products included those that claimed they could detect COVID-19 by using a fingerstick test or through saliva and urine. Some of the rapid testing kit posts detected in this study also alleged COVID-19 results within minutes using at-home testing and even included questionable claims about the percent accuracy of their tests.

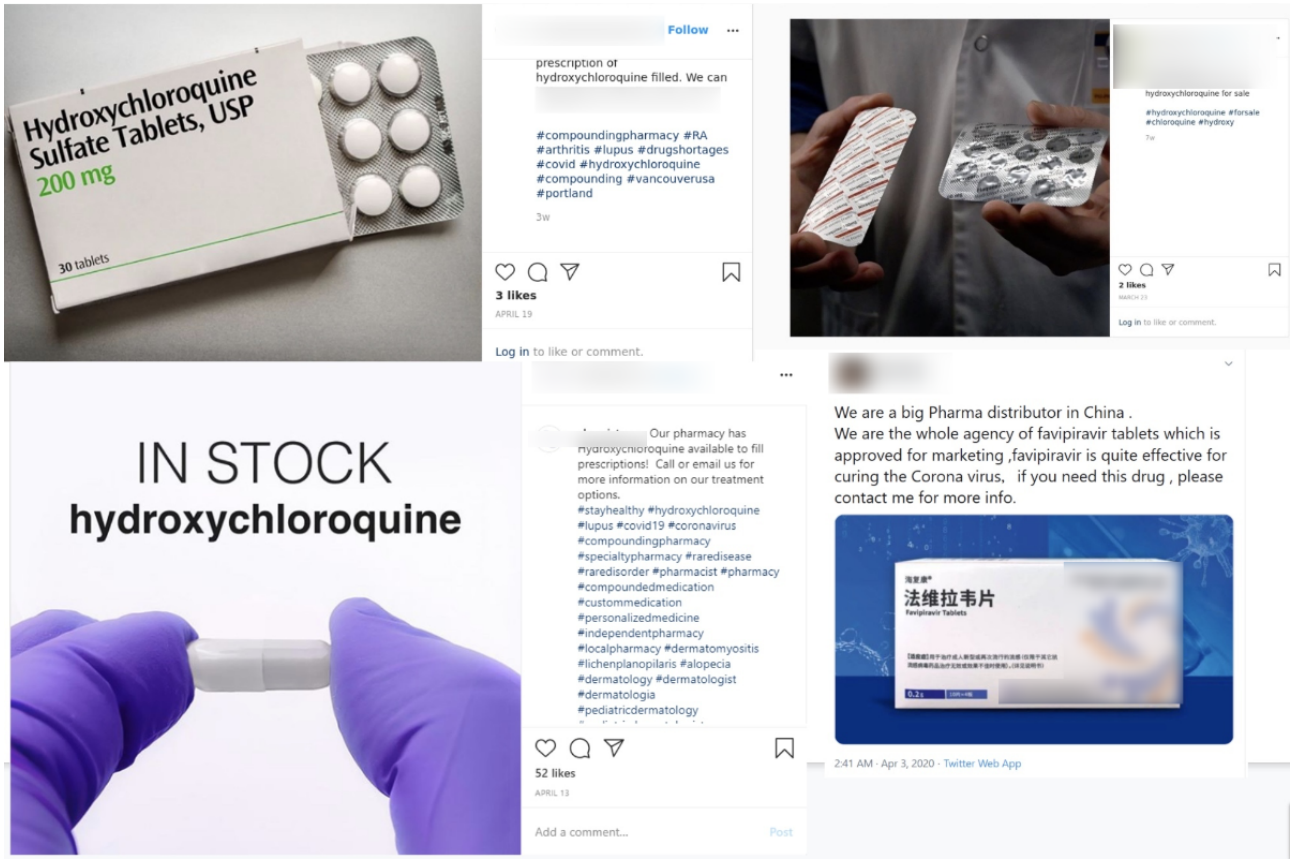
Overall, social media posts involving suspect COVID-19 testing products exhibited similar and identifiable patterns including a picture and description of the specific type of COVID-19 test, the contact information of how to purchase the test kits, and pricing information. Many posts included a claim and mark for a "CE marking," which is a certification mark that a product conforms with applicable health, safety, and environmental protection standards for the European Economic Area but does not mean the product has been approved by regulatory authorities for COVID-19 screening or diagnosis. Some posts also included users claiming to sell FDA-approved COVID-19 testing equipment (with some products that included spurious FDA labelling in images). Pictures of specific COVID-19 testing kits included variations of the labeled box and materials of the testing kit itself, stock photos of a testing kit, or testing kit packaging. For some posts, the labeling on purported testing kits were written in different languages. Additionally, sellers advertised bundled packages that included COVID-19 tests offered concurrently with personal protective equipment (PPE).

Specific to PPE, we detected 535 out of 1867 (28.66%) posts that offered the sale of masks, gloves, and other protective gear in conjunction with tests. Posts mentioned sales available via individual purchases, wholesale, or in bundles with equipment such as temperature gauges, protective suits, hand sanitizers, and immunity boosting kits. Additionally, compounds such as silver hydrosol, colloidal silver, and antimicrobial copper were advertised as medical supplies that could confer immune boosting benefits and help with COVID-19 prevention in a variety of ways. PPE and supply posts often included the cost and approximate shipping time, with some linked to an external medical supply company e-commerce site.

Finally, we detected a small volume of posts offering the sale of COVID-19–related therapeutics, none that, at the time, had been approved for the treatment of COVID-19 (see Figure 5), which were detected from March 5, 2020, to April 13, 2020. The majority of posts reviewed for these therapeutic-related filtered terms contained noise and were not engaged in the online sale of actual pharmaceuticals. On Instagram, we only detected 19 posts purportedly selling hydroxychloroquine and

chloroquine, 2 posts selling remdesivir, and 1 post selling favipiravir. For Twitter, we detected 5 tweets selling hydroxychloroquine. All tweets selling hydroxychloroquine also concurrently sold PPE.

Figure 5. Twitter and Instagram posts related to suspected COVID-19 pharmaceutical drugs. COVID-19: coronavirus disease.



COVID-19 Seller Metadata Characteristics

Sellers used key selling arguments common in e-commerce marketing that included offers of home delivery, free shipping, or discount codes to lower the price of COVID-19 testing kits and other products identified. Marketing tactics also included key selling argument terms such as “great news,” “flash sale,” “reliable,” “rapid,” “bulk sale,” and “immediate response” to give prospective buyers a sense of urgency and promote availability of products that were generally in scarcity in the legitimate supply chain during the study period. Other keywords included product descriptions that users could easily understand and identify including “immunity spray,” “Corona Kit,” and “IgM/IgG.” Because hashtags provide a way for users to curate topics of common interest, many posts included hashtags of the specific product they were selling (eg, #hydroxychloroquine, #IgM/IgG #test, and #testkit) in combination with general COVID-19 tags (eg, #coronavirus, #COVID9, and #rapidtest).

Generally, profiles of sellers included metadata and images that made them appear to originate from individual users. However, upon closer inspection, some of these accounts appeared to be cloned accounts with identical profile pictures and similar usernames that varied by only one or more characters to another more established and likely legitimate social media account. Accounts that were not represented as individuals or had affiliations were generally represented as medical supply or pharmaceutical companies. Individual and organizational accounts claimed to carry inventory of various COVID-19 testing kits and PPE, with alternative medicine–related accounts also selling various herbal remedies. Most posts contained pictures that included the product package, contents of the package and additional text, or had a general illustration of the SARS-CoV-2 virus. Some posts also included hyperlinks to external sites selling COVID-19 products, including 124 twitter posts (90 unique hyperlinks) and 41 Instagram posts (25 unique hyperlinks).

Contact information to enter into a transaction generally included instructions and details for direct messaging, WhatsApp numbers, email addresses, WeChat, and Skype for direct contact with seller. Some posts for testing kits also included hyperlinks to external e-commerce sites for purchase. Still other posts had descriptive text that linked to the user profile for additional contact information. A number of different languages were identified in the descriptive text of selling posts including English, Chinese, Japanese, Spanish, German, Arabic, Hindi, Russian, Ukrainian, Thai, and some others. For posts in a non-English language, coders self-translated those in Chinese, Japanese, Spanish, and Hindi, as coauthors spoke and read these languages. For other languages, the study team relied on Google Translate to assess the content of posts and if they were signals.

We noted that our deep learning classifier focuses on the detection of “selling” arguments (in the English language) and the presence of contact information from a seller. Hence, it is possible that not all non-English COVID-19 selling posts were detected, though non-English signal posts may contain the

features subject to classification. The presence of non-English language posts and characters likely indicates that signal posts targeted non-US audiences and social media users, even though the majority of users on both of these platforms are located in the United States [29-31]. However, determining more precise geolocation of users was difficult as only 87 tweets and 134 Instagram posts had geotagged information available.

Generally, the metadata associated with the majority of signal posts indicated that there was medium to low levels of interaction with other social media users based on the number of likes, favorites, or retweets (the general metric of how much sharing and dissemination a post is getting on social media). The majority of tweets or Instagram posts had few likes, retweets, and followers. No signal posts were retweeted more than 50 times; 9 (0.86%) were retweeted more than 10 times, and 1033 (99.13% of unique tweets) were retweeted less than 10 times. For Instagram posts, the average number of "likes" for a signal post was 12.5, with 87 (15.5%) having more than 10 likes and 473 (84.4%) posts having less than 10 likes. For the interaction that was observed, we noticed that there was more interaction between sellers and other users in the comments section on Instagram compared to replies on Twitter. There were exceptions, with one detected twitter post from an account with over 97,000 Twitter followers and 1.5 million Instagram followers advertising sale of COVID-19 at-home finger stick IgG/IgM test on both Twitter and Instagram from what was characterized as a "LEGIT" supplier.

Although the majority of signal posts included contact information and instructions on purchasing the product, pricing information was included for less than 30 posts, primarily advertising sales of COVID-19 testing kits. The prices of testing kits ranged from US $4-$398 (all currencies converted to US dollars) for offers of individual kits as well as bulk orders. Individual kits were priced as low as US $4 to a maximum of US $375 with a mean cost of US $64.63 (SD $92.96) and a median cost of US $20.61/kit. Bulk kits were priced in the range of US $30.76-$398 for 25-50 kits/box with a mean cost of US $168.70 (SD $175.88). A questionable product described as a "portable hospital" device that claimed to use a negative ion current to treat COVID-19 and other viruses was priced at US $6000 (see Figure 3 for screenshots). Posts advertising availability of large quantities of testing kits also mentioned kits could be purchased at a cheaper price if ordered in bulk (hundreds to thousands). A few posts also included links to major e-commerce platforms such as eBay or AliExpress. Fiat currency was not limited to US dollars but included Euros, Pound Sterling, Indian Rupee, Philippine Peso, and other currencies. Additionally, payment transactions could be effectuated through PayPal or cryptocurrency such as Bitcoin.

Discussion

Principal Findings

This study used big data and machine learning approaches to detect and characterize illegal offers of sale for COVID-19 products on Twitter and Instagram. Overall, the total volume of illegal selling posts detected was low relative to the total volume of COVID-19 conversations collected (our nonfiltered general COVID-19 data set over this time period had over 165 million tweets and more than 272,000 Instagram posts), though the number of tweets and Instagram posts collectively were over 1000 representing a clear risk to patient safety. A possible reason for the small percentage of signal posts was that our data collection approach started with general COVID-19–related social media posts that were not specific to illegal sales but instead filtered for these terms after data collection was complete. As the overall volume of COVID-19 social media posts was extremely high, a more purposeful sampling approach focused on COVID-19–related health products or testing kits may have yielded a corpus with more signal.

Despite these limitations, we nevertheless identified over 1000 suspect selling posts, with the majority related to unapproved COVID-19 testing kits, which were detected at a time when access to legitimate COVID-19 testing in countries like the United States was extremely limited [32,33]. Based on the language, currency, and content of these posts, this infoveillance challenge also appears to be global, though the majority of posts detected were in the English language, reflecting the fact that most social media users on Twitter and Instagram are located in the United States. Far fewer posts were detected for therapeutic products, though separate research conducted by our own group and others have turned up various drugs (including hydroxychloroquine, chloroquine, and favipiravir), vaccines, and even blood plasma offered for sale via illegal online pharmacies, e-commerce sites, and on the dark web [34,35].

The lack of signal posts for COVID-19 therapeutics may indicate that product segmentation on different parts of the internet is occurring. Specifically, illegal online pharmacies and dark web marketplaces may have already been selling these products outside of the context of treating COVID-19, as many of these drugs are already approved for other indications, diminishing the opportunity or need for direct sales to consumers via social media. Consumer demand for drugs may have also been muted as the number of confirmed COVID-19 cases at the time was relatively low and there was limited evidence regarding the efficacy of these products or their given active pharmaceutical ingredient to treat COVID-19. Instead, a widespread lack of access to testing may have made getting a COVID-19 diagnosis a priority before seeking treatment, reflected in our high detection of suspect COVID-19 testing kits.

Some posts detected by our data collection process had already been taken down from the platforms at the time of manual inspection, indicating that platforms may have been self-policing and removing this content given that it violates their existing terms of use or specific content moderation policies related to COVID-19 [36,37]. In fact, many social media platforms indicate they are attempting to address the concern of both COVID-19–related misinformation and cybercrime [38,39]. Yet at present, it is difficult to assess the effectiveness of platform self-regulation. Despite detecting that certain signal posts had been removed (such as those with obvious coronavirus-related account names or descriptions), other detected posts nevertheless remained active and accessible to users after our study was completed, evidencing that more work

needs to be done to reign in this part of the COVID-19 infodemic.

Importantly, the presence of this type of criminal activity and fraud on social media is not a new phenomenon, as cybercriminals are keen to take advantage of the anonymity, convenience, and accessibility to the public that these platforms offer to advance crimes of opportunity. In the case of COVID-19, we are arguably in the midst of a "cyber syndemic," where the public health consequences of COVID-19 simultaneously interact with the unique risks associated with the internet and social media together, which can worsen the spread of the disease. Specifically, the posts detected in this study can bring both economic and health harm by introducing unproven, substandard, falsified, and counterfeit health products to those afflicted by COVID-19, leading to financial loss while also increasing the risk of disease spread by negatively influencing health behaviors [40].

Reflecting the real-world consequences of COVID-19–related crimes, the US Federal Trade Commission estimates that there have already been US $40 million in losses due to COVID-19 fraud [41]. Law enforcement groups such as the US Customs and Border Protection have intercepted hundreds of fake COVID-19–related products at borders and have launched several initiatives such as Homeland Security Investigations' "Operation Stolen Promise" and the S.T.O.P COVID-19 Fraud Campaign [42]. The US Federal Bureau of Investigation reported a 300% increase in fraud and cybercrime scams since 2019-nCoV appeared [43]. Operation Pangea, an Interpol-led takedown of illicit internet sites, focused its March 2020 activities on COVID-19 scams [44]. It found extensive and growing fraud for coronavirus medical "treatments," cures, and protective equipment as well as, more recently, sales of all forms of chloroquine [45]. The European Anti-Fraud Office also announced that the European Union will dedicate resources to target fake coronavirus medical and protection products being sold online.

However, combatting COVID-19 cybercrime, and more specifically illegal online sales of COVID-19 health products, is a dynamic challenge. Existing difficulties of interdicting the global illegal online trafficking of counterfeit and falsified products are accelerated and accentuated during a pandemic, as information rapidly changes, misinformation proliferates, and platforms struggle to self-regulate large and diverse volumes of content on the pandemic. In contrast, black markets can be adaptive to these types of crises, with scammers seeking to take advantage of confusion and heightened concerns about safety and health risks to target vulnerable consumers with fake products and treatments [46].

To address these challenges, a data-driven public health intelligence approach is needed. Specifically, although the results of this study are informative to the characteristics of illegal COVID-19 online sales during early stages of the outbreak, they are nevertheless static, only reflecting the degree of risk to the public at a single point-of-time. Instead, active surveillance of illegal COVID-19 digital marketplaces is needed, along with the use of visualization tools that can provide needed data intelligence to understand the constantly changing dynamics of this infodemic threat. Recognizing this need, we have developed a prototype data dashboard on the open source platform Redash that can be used by public health officials, drug regulatory authorities, and law enforcement agencies that visualizes our ongoing big data digital surveillance work to detect and classify illegal marketing, sales, and trafficking of COVID-19–related products on social media platforms and other parts of the internet. The public version of the dashboard can be viewed at [47]. The dashboard reports and visualizes characteristics of illegal selling posts including location (if available), generates a list of top-related hashtags, captures images of suspect products, and analyzes other metadata about selling activity. We have shared a version of this dashboard with colleagues at the WHO and FDA in hopes that it can help improve and accelerate content removal, increase awareness of the risks to consumers, and lead to a safer online environment in the midst of this ongoing pandemic.

Limitations

Our study has certain limitations. First, it was limited to a relatively short period of data collection, which limits the generalizability of the results to overall illegal COVID-19 social media–based offers for sale. Our corpus of social media posts included general COVID-19 keywords and filtered terms, but it is possible that some COVID-19 sellers do not include these terms in their posts. Hence, we may have failed to collect posts with suspect COVID-19 sales. We did not engage sellers or other social media users to verify if COVID-19 products were actually available, so we cannot say with certainty that advertised products were being sold, whether they were economic frauds and scams, or if they were products approved outside the United States. We relied on textual analysis to identify selling posts and did not use multimodal approaches that could analyze and classify both text and images, a method that could potentially improve classification [48-51]. Finally, due to the time lag in collecting social media messages, conducting our topic modeling, and then classifying posts using our machine learning inference phase, some posts were no longer available for manual inspection as they had been removed from platforms, so we could not further validate their content. These posts may have been self-deleted posts or removed as they violated the terms of use for these platforms.

Conclusion

Our study provides a snapshot of the characteristics of illegal online sales of COVID-19–related health products on two popular social media platforms: Twitter and Instagram. It also details an innovative methodology using a combination of unsupervised and supervised machine learning to detect illegal sales during a global pandemic. Unfortunately, illegal online sales of COVID-19 health products are likely to continue and possibly accelerate as this health emergency continues to progress. A "flattening of the curve" will not halt the progression of this parallel infodemic, as the public continues to desperately seek access to COVID-19 testing, therapeutics, and an eventual vaccine. As legitimate news about promising and new COVID-19 treatments and countermeasures becomes available, scammers and counterfeiters will inevitably seek to capitalize on desperation and high demand from global citizens who

simply want to be safe and prepared against this historic disease. Future studies should continue to explore the dynamic nature of the COVID-19 cyber syndemic and build solutions to prevent its digital spread.

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

TM, JL, MN, and MC 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 conflict of interest associated with this manuscript.

Multimedia Appendix 1
Additional details regarding study methods.
[DOCX File , 116 KB - publichealth_v6i3e20794_app1.docx]

Multimedia Appendix 2
Coding scheme for social media posts.
[DOCX File , 17 KB - publichealth_v6i3e20794_app2.docx]

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Abbreviations

API: application programming interface
BTM: biterm topic model
COVID-19: coronavirus disease
e-commerce: electronic commerce
FDA: Food and Drug Administration
NLP: natural language processing
PPE: personal protective equipment
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization
2019-nCoV: novel coronavirus

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Original Paper

Early Stage Machine Learning–Based Prediction of US County Vulnerability to the COVID-19 Pandemic: Machine Learning Approach

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Abstract

Background: The rapid spread of COVID-19 means that government and health services providers have little time to plan and design effective response policies. It is therefore important to quickly provide accurate predictions of how vulnerable geographic regions such as counties are to the spread of this virus.

Objective: The aim of this study is to develop county-level prediction around near future disease movement for COVID-19 occurrences using publicly available data.

Methods: We estimated county-level COVID-19 occurrences for the period March 14 to 31, 2020, based on data fused from multiple publicly available sources inclusive of health statistics, demographics, and geographical features. We developed a three-stage model using XGBoost, a machine learning algorithm, to quantify the probability of COVID-19 occurrence and estimate the number of potential occurrences for unaffected counties. Finally, these results were combined to predict the county-level risk. This risk was then used as an estimated after-five-day-vulnerability of the county.

Results: The model predictions showed a sensitivity over 71% and specificity over 94% for models built using data from March 14 to 31, 2020. We found that population, population density, percentage of people aged >70 years, and prevalence of comorbidities play an important role in predicting COVID-19 occurrences. We observed a positive association at the county level between urbanicity and vulnerability to COVID-19.

Conclusions: The developed model can be used for identification of vulnerable counties and potential data discrepancies. Limited testing facilities and delayed results introduce significant variation in reported cases, which produces a bias in the model.

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KEYWORDS

COVID-19; coronavirus; prediction model; county-level vulnerability; machine learning; XGBoost

Introduction

The continued spread of confirmed cases of COVID-19, absence of a vaccine, limited resources for testing, and assisting people with confirmed cases have presented a great challenge for our public health and health care provider systems. To this point, nonpharmaceutical interventions such as social distancing are the only effective mitigation measures. The rapid spread of the disease means that government and health services have very little time to plan and design effective response policies such as resource and workforce planning. Accurately predicting the near future COVID-19 spread at sufficient granularity would provide these organizations with better information and more time to appropriately plan and respond.

We have developed a three-stage machine learning model to estimate COVID-19 spread outcomes at the county level in the United States. In the first stage, we estimate the probability that a county has at least one confirmed COVID-19 case. In the

second stage, we estimate the number of COVID-19 occurrences given a county has at least one case. Finally, we combine the results from the two stages to estimate those counties that have the greatest and least vulnerability for changes in disease prevalence for the next five-day period.

There has been significant epidemiological work for previous coronavirus pandemics such as Middle East respiratory syndrome (MERS) and severe acute respiratory syndrome (SARS) [1]. For example, Badawi et al [2] performed a systematic analysis of prevalence of comorbidities in MERS using data from 12 studies and found that diabetes and hypertension were present in 50% of the cases. Matsuyama et al [3] systematically reviewed studies involving laboratory-confirmed MERS cases to measure both the risk of admission to the intensive care unit (ICU) and death. They compared risks by age, gender, and underlying comorbidities. Park et al [4] reviewed characteristics and associated risk factors of MERS. Bauch et al [5] surveyed SARS modeling literature focused on understanding the basic epidemiology of the disease and evaluating control strategies. Surveyed SARS models varied in terms of population studied and geographical characteristics [6,7]. Different designs were used for SARS modeling, including deterministic compartmental models [7], stochastic compartmental models [6], a combination of stochastic and deterministic compartmental models [8], discrete-time models [9], logistics curve-fitting models [10], contact network models [11], and likelihood-based models [12]. Studies associated with risk factors for SARS [13] and MERS [3,14-20] have found an association between comorbidities and infected cases.

MERS and SARS epidemiological modeling has been done at different granularities such as the country [21,22], specific region [23], and case clusters [6]. Given the much broader reach of COVID-19 compared to MERS and SARS, it is very important to make predictions at a sufficiently high level of granularity. This is particularly important since previous studies have shown that there is considerable heterogeneity in space, transmissibility, and susceptibility [5]. Our approach is developed at the county level with the inclusion of a variety of health statistics, demographics, and geographical features of counties. Further, we use publicly available data so that any organization can leverage the model. To the best of our knowledge, no work has been done to predict near future infection risk at the county level using a combination of health statistics, demographics, and geographical features of counties.

Methods

Recruitment

We performed an epidemiological study at the US county level using publicly available data to develop a machine learning predictive model. Data analysis was performed from February 15 to April 3, 2020. The study was reviewed by the Penn State Integrated Research Ethics Board and deemed exempt because it was a deidentified, secondary data analysis. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) reporting guideline [24].

We used US Census data to obtain county-level population statistics for age, gender, and density [25,26]. We obtained county-level data for diagnosed adult diabetics percentage and cancer crude rate statistics from the Centers for Disease Control and Prevention (CDC) [27,28]. We used county-level hypertension estimates and chronic respiratory disease mortality rates obtained from the Global Heath Data Exchange (GHDx) [29,30] website, provided by the Institute for Health Metrics and Evaluation. We obtained the centroids for each county from ArcGIS [31]. Finally, we obtained US Census Cartographic Boundary files for each county in JSON format [32] and county-level COVID-19 daily occurrences data (confirmed cases) from the NYTimes GitHub page [33,34].

Statistical Analysis

There are three primary outcomes for our predictive model: (1) the probability that a county has at least one confirmed case of COVID-19, which we define as a positive instance; (2) the number of confirmed COVID-19 cases within a county, which we define as occurrences; and (3) vulnerability of the county.

Previous studies have shown angiotensin-converting enzyme 2 (ACE2) facilitates infection by COVID-19 [35-37], and that patients with diabetes, hypertension, and cardiovascular diseases have an increased expression of ACE2 [35]. County population factors such as density, age, and sex have a significant impact on the spread of an epidemic [38]. Cancer and chronic respiratory diseases have also been shown to increase mortality risk for COVID-19 [39]. The data set used for our three-stage model contains correlated variables. For example, diabetes and hypertension prevalence, cancer crude rate, and older adult population. Additionally, the underlying relationship between variables was assumed to be nonlinear.

Precursor to the Prediction Model

Machine learning techniques help us to derive insights and predict trends using data without the explicit need for programming. They are mainly divided into two types based on the explicit availability of outcomes for a given set of observations: supervised and unsupervised techniques. In supervised techniques, the outcome or dependent variable is available for a given set of observations. Supervised techniques are further divided into regression or classification techniques depending upon the data type of the outcome variable: continuous or categorical [40]. In the literature, artificial neural network–based deep learning and tree-based gradient tree–boosting techniques have demonstrated better prediction capabilities in exploring nonlinear relationships among correlated predictors [41-49].

XGBoost (Extreme Gradient Boosting) [50] is a gradient tree–based supervised machine learning technique capable of performing both regression and classification tasks. The underlying algorithm combines the results from multiple individual trees with weak predictions (weak learners) to yield accurate final predictions. During the combining process, the algorithm prevents overfitting by regularizing objective function. The performance of this technique depends upon effective tuning of multiple hyperparameters such as learning rate and maximum depth with respect to underlying data distribution. These

hyperparameters can be tuned with the help of random or exhaustive search as well as by using Bayesian optimization. The Bayesian optimization method has shown efficiency in terms of accuracy and time [51].

Developing the Prediction Model

To predict COVID-19 outcomes, we divided the problem into three stages. In the first stage, we classified each county either as a positive or negative instance and used the same as a dependent variable. Hence, we built an XGBoost classifier model to learn from the data.

In the second stage, to predict number of occurrences (a continuous variable), we leveraged an XGBoost regression model that included data only for positive instances with the number of occurrences as the response.

In the last stage, we combined results from the first two stages and calculated the expected occurrences for counties as a measure of county vulnerability. For the calculation of expected occurrences, we multiplied the probability of a county belonging to the positive instances derived using the classification model, with potential occurrences the same county will have if it becomes a positive instance derived using the regression model.

Evaluating the Prediction Model

The evaluation process is illustrated with an example for the date March 14, 2020. For this date, modeling data comprised of COVID-19 cases reported at a county level at the end of March 14 along with all other variables were obtained from fusion process.

In the first stage (classification problem), this data was divided into an 80:20 ratio for training and testing, simultaneously ensuring equivalent representation of both classes (positive and negative instance). With this setup and leveraging the HyperOpt package, multiple hyperparameters of the model were tuned using area under the receiver operating characteristic curve (AUC) and accuracy values as the evaluation criteria. The resultant model was used to compute county-level probability score.

In the second stage (regression problem), the data set was filtered to include only positive instance counties as of March 14 with number of occurrences being a dependent variable. Like the first stage, this data was divided into an 80:20 proportion for testing and training and hyperparameters were optimized by leveraging the HyperOpt package. The regression problem used the root mean squared error (RMSE) value as an evaluation criterion. The best model was used to calculate the number of occurrences associated with counties.

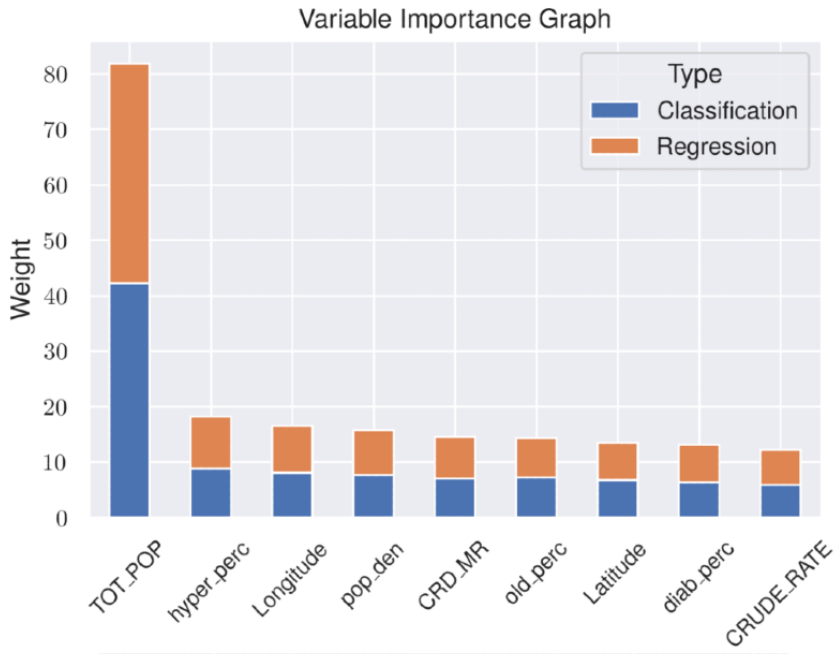
In the final stage, the vulnerability of a county was determined by multiplying the stage one probability score with the stage two number of occurrences. This calculated value was used to identify the riskiest and safest counties. The model is serving as a proxy for estimating after-five-day-vulnerability, the third stage outcome that was evaluated using actual COVID-19 numbers observed 5 days later, on March 19, 2020. To measure sensitivity among the top 5% riskiest counties estimated at the end of the third stage of the model, the number of counties that were observed to be positive as of March 19 were identified (Multimedia Appendix 1). The corresponding fraction was defined as sensitivity. Similarly, the specificity among the top 10% least vulnerable counties was estimated by the third stage of the model (Multimedia Appendix 2). The number of counties that continued to be observed as a negative instance were identified and the corresponding fraction was reported as specificity. The third stage model was assessed for both sensitivity and specificity.

Finally, the consistency of the three-stage modeling process was verified by repeating this process daily from March 14 to March 26 and assessing the same from March 19 to March 31.

Results

The variable importance of the overlapping predictors between the final classification and regression models for March 16 is shown in Figure 1. Total population (TOT_POP) was the most important variable for both the classification and regression models. Other important variables included population density, longitude, hypertension prevalence, chronic respiratory mortality rate, cancer crude rate, and diabetes prevalence. Latitude (we use this to identify neighboring counties and the presence or absence of positive cases in the neighborhood) and the percentage of the population aged >70 years were found to be the least important features of those considered, though they still played a role.

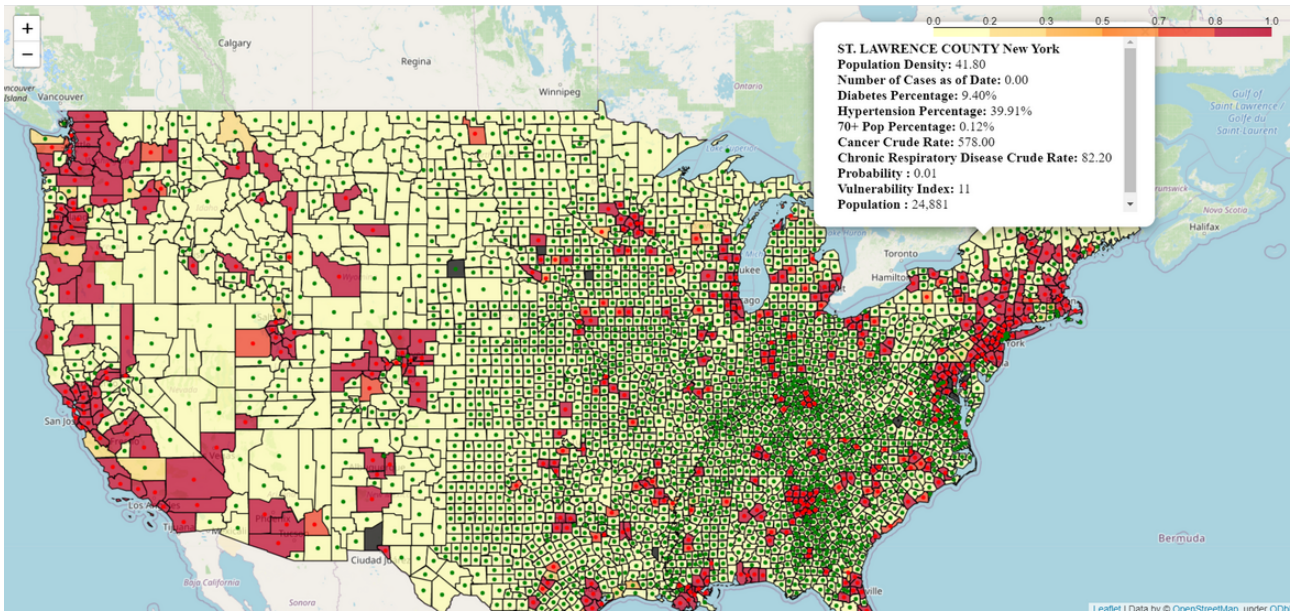
Figure 1. Variable importance for the classification and regression models.



Acronym	Name
TOT_POP	Total Population
hyper_perc	Hypertension Prevalence Percentage
pop_den	Population Density Per Mile
CRD_MR	Chronic Respiratory Diseases Mortality Crude Rate
old_perc	Old Population (70 and above) Percentage
diab_perc	Adult Diabetes Prevalence Percentage
CRUDE_RATE	Cancer Mortality Crude Rate

Figure 2 shows a map of the United States with the predicted probability of a given county being a positive instance visualized as a color gradient. Within the software, county-level statistics can be viewed by moving the cursor over the county of interest. The example of New York County as of March 14 is shown in the Figure 2.

Figure 2. Predicted probability of there being a positive instance for each county in the United States.



Accuracy and AUC for the first-stage model is shown in Table 1. Predictions of the model for all US counties are consistent over 18 days with little variation in AUC and accuracy values. Similarly, RMSE for the second-stage model for all US counties is presented in Multimedia Appendix 3. The results for first two stages of the model were evaluated until March 31.

Table 1. XGBoost classification training and testing details.

Data set and evaluation metrics	Mean value, %	Minimum value, %	Maximum value, %	Standard deviation, %	Number of days
Test					
Accuracy	83	77	92	5	18
Area under the curve	78	71	83	3	18
Train					
Accuracy	94	82	100	5	18
Area under the curve	91	80	100	6	18

The sensitivities and specificities for the vulnerability predictions for the three-stage model trained on data from March 14 to March 26 are shown in Tables 2 and 3. The values are given for each day. The sensitivity (Table 2) is given by the percentage of counties that had no confirmed cases but were identified as being among the 5% most vulnerable and had at least one confirmed COVID-19 case 5 days later. The specificity (Table 3) is given by the percentage of counties identified as being among the 10% least vulnerable with no confirmed cases that still had no confirmed cases 5 days later.

Table 2. Sensitivity of the three-stage model.

Date	Number of 5% most vulnerable counties identified on a given date (with 0 confirmed cases)	Number of counties that reported cases after 5 days	Sensitivity, %
14/3/2020	92	61	66.30
15/3/2020	119	90	75.63
16/3/2020	151	99	65.56
17/3/2020	199	144	72.36
18/3/2020	144	110	76.39
19/3/2020	176	115	65.34
20/3/2020	198	146	73.74
21/3/2020	166	125	75.30
22/3/2020	158	120	75.95
23/3/2020	84	66	78.57
24/3/2020	89	65	73.03
25/3/2020	336	208	61.90
26/3/2020	104	72	69.23

Table 3. Specificity of the three-stage model.

Date	Number of top 10% least vulnerable counties identified on a given date (0 confirmed cases)	Number of counties with 0 cases after 5 days	Specificity, %
14/3/2020	276	274	99.28
15/3/2020	282	276	97.87
16/3/2020	46	44	95.65
17/3/2020	313	304	97.12
18/3/2020	297	281	94.61
19/3/2020	214	198	92.52
20/3/2020	295	266	90.17
21/3/2020	312	291	93.27
22/3/2020	15	14	93.33
23/3/2020	310	289	93.23
24/3/2020	303	270	89.11
25/3/2020	214	197	92.06
26/3/2020	231	218	94.37

The data set is comprised of 37% urban and 63% rural counties based on the urban and rural county definition for 2013 [52]. To determine if there is an association between urbanicity and vulnerability, we performed a set of one-sided *t* tests. The null hypothesis that the 10% least vulnerable counties would have the same proportion of rural counties as the actual proportion of rural counties in the data set was rejected for every day from March 14 to 26. Additionally, the null hypothesis that the actual positive instances counties would have the same proportion of urban counties as the actual proportion of urban counties in the data set was also rejected for every day over the analysis period. It can therefore be concluded that there is a positive association between urban and the most vulnerable counties as well as rural and the least vulnerable counties. The continuous decreasing trend in the confidence interval of the urban counties proportion estimate within actual positive-instance counties can be used to infer that COVID-19 is propagating from urban counties to rural counties.

Discussion

Principal Findings

We developed a three-stage machine learning model using publicly available data to predict the 5-day vulnerability of a given US county. The model estimates the likelihood and impact that a county with no documented COVID-19 cases will have within a 5-day period and a vulnerability prediction for a county is made using those estimates. Using data from March 14 to 31, 2020, the model showed a sensitivity over 71.5% and specificity over 94%. We found a positive association between affected counties and urban counties as well as top 10% least vulnerable counties and rural counties. Further, counties with higher population density, a greater percentage of people aged >70 years, as well as higher diabetes, cardiac illness, and respiratory diseases prevalence are more vulnerable to COVID-19 than their counterparts.

Our model serves multiple purposes. First, it can help in identifying potentially vulnerable counties. This prediction would be a vital component in managing COVID-19 spread by providing vulnerability information based on the likelihood and magnitude of change within 5 days. That can help health organizations to effectively plan the management of hospital resources and the workforce, rapid response teams, COVID-19 testing kits, and COVID-19 testing locations. In addition, there are multiple counties with limited testing facilities, and with current swab-based testing, it takes multiple days to get the results. Thus, occurrences associated with each county fluctuate rapidly daily.

Limitations

There are multiple limitations to our work. First, there are several predictors that we did not include in the model that have known associations with COVID-19. However, one of our goals was to make sure that any organization could use our model by only including data that is publicly available. Second, our analysis (Multimedia Appendix 4) found that there is an increasing trend for the coefficient of variation (CV) for occurrences associated with positive-instance counties. Note that CV is a proxy for economic inequality [53-56]. Hence, there is a bias in the response variable, which can reduce the accuracy of the prediction. As testing facilities improve in terms of numbers and efficiency, this bias would be minimized and would be reflected in the model. Given this point, it would useful to look at the riskiest and safest counties predicted by the three-stage model and examine the data for potential discrepancies. Finally, additional feature engineering and stacking methods can be used to enhance the prediction capabilities of existing models.

Our work uses open source programming and publicly available data. The full data set, sample modeling, and result outputs are available, with instructions for use [57].

Commentary on Present Models

Presently, multiple research groups are providing COVID-19 projections on death and hospitalization case numbers. In the United States, the CDC website maintains a list of projection-providing research groups. These projections are available along with an ensemble projection. As COVID-19 approached a flattened curve stage, states deployed varied levels of easing of restrictions. Thus, these restrictions are expected to alter the presently observed dynamics of disease spread. Hence, they play an important factor in projections. To account for the same, some of these models assume stationary parameters during the projection period, while others assume some form of dynamic nature [58]. These projections are provided at different levels: country level [59], states level [60], metropolitan area level [61], and at the county level [62,63]. These projections are developed using variants of SEIR models [63], deep learning models [64], agent-based models [65], variants of mechanistic disease transmission models [66], renewal equations-based models [67], and statistical models [62]. In all these models, Columbia University's Meta-Population SEIR Model [63] and the University of Iowa's [62] nonparametric spatial-temporal model provide projections at a county level. Columbia University's initial model leveraged US Census county-level daily commute data during daytime and nighttime to account for the movement of the disease. However, this model does not account for county-level population heterogeneity. The University of Iowa's approach was developed using a combination of statistical and mathematical modeling techniques with an assumption of parameter-agnostic exponential family–based conditional distribution of COVID-19 cases and deaths. This model leverages county-level data on intervention policies, demographic characteristics, health care infrastructure, socioeconomic factors, urban rate, and geographical information. However, their model does not account for county-level prevalence of comorbidities. Finally, The University of Texas at Austin [61] model provides projections at the metropolitan area level using mobile-based data. With the better availability of data and information about COVID-19, current models can forecast projections for a longer period with better accuracy than our model. However, our model still presents a unique assumption-free county-level modeling approach accounting for heterogeneity using demographic, health, and geographical features.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Samples of counties from the top 5% riskiest counties, March 14, 2020.
[DOCX File , 13 KB - publichealth_v6i3e19446_app1.docx]

Multimedia Appendix 2
Samples of counties from the top 10% safest counties, March 14, 2020.
[DOCX File , 13 KB - publichealth_v6i3e19446_app2.docx]

Multimedia Appendix 3
XGBoost regression training and testing details.
[DOCX File , 13 KB - publichealth_v6i3e19446_app3.docx]

Multimedia Appendix 4
COVID-19 daily positive occurrences descriptive statistics.
[DOCX File , 14 KB - publichealth_v6i3e19446_app4.docx]

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Abbreviations

ACE2: angiotensin-converting enzyme 2
AUC: area under the receiver operating characteristic curve
CDC: Centers for Disease Control and Prevention
ICU: intensive care unit
MERS: Middle East respiratory syndrome
RMSE: root mean squared error
SARS: severe acute respiratory syndrome
STROBE: Strengthening the Reporting of Observational Studies in Epidemiology
XGBoost: Extreme Gradient Boosting

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Original Paper

Consumer Reported Care Deferrals Due to the COVID-19 Pandemic, and the Role and Potential of Telemedicine: Cross-Sectional Analysis

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Abstract

Background: The COVID-19 pandemic forced many health systems to proactively reduce care delivery to prepare for an expected surge in hospitalizations. There have been concerns that care deferral may have negative health effects, but it is hoped that telemedicine can provide a viable alternative.

Objective: This study aimed to understand what type of health care services were being deferred during the COVID-19 pandemic lockdown, the role played by telemedicine to fill in care gaps, and changes in attitudes toward telemedicine.

Methods: We conducted a cross-sectional analysis of survey responses from 1694 primary care patients in a mid-sized northeastern city. Our main outcomes were use of telemedicine and reports of care deferral during the shutdown.

Results: Deferred care was widespread—48% (n=812) of respondents deferred care—but it was largely for preventive services, particularly dental and primary care, and did not cause concerns about negative health effects. In total, 30.2% (n=242) of those who delayed care were concerned about health effects, with needs centered around orthopedics and surgery. Telemedicine was viewed more positively than prior to the pandemic; it was seen as a viable option to deliver deferred care, particularly by respondents who were over 65 years of age, female, and college educated. Mental health services stood out for having high levels of deferred care.

Conclusions: Temporary health system shutdowns will give rise to deferred care. However, much of the deferrals will be for preventive services. The effect of this on patient health can be moderated by prioritizing surgical and orthopedic services and delivering other services through telemedicine. Having telemedicine as an option is particularly crucial for mental health services.

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KEYWORDS

COVID-19; telemedicine; deferred care; mental health; alternative; health effect; viability

Introduction

The COVID-19 pandemic led to an unprecedented worldwide economic and health system shutdown. COVID-19 is caused by the novel SARS-CoV-2, which first emerged in December 2019 in Wuhan, China [1]. As of July 1, 2020, COVID-19 cases have been reported in more than 200 countries with more than half a million confirmed deaths [2]. The first case in Vermont (the region of this study) was reported on March 7, 2020, and the number of cases in Vermont peaked in late April 2020.

One effect of the pandemic was a widespread temporary shutdown of health care services to prepare the health care system for an expected increase in COVID-19 cases. One unintended consequence of this temporary shutdown is that many types of health care services were deferred until after the "peak" of COVID-19 cases [3-5]. A recent report found that nearly half of all adults reported that either they or someone in their household deferred medical care due to the coronavirus outbreak [6].

As health care systems begin their gradual reopening, the backlog of cases is beginning to be resolved. Yet there is controversy about which services should be reopened and prioritized, with dental care services being a particular flashpoint [7,8]. Health care leaders are trying to balance patient needs and the risk of COVID-19 infection as they consider what health care service lines should be prioritized. Yet little is known about what proportion of patients had deferred care during the pandemic or what types of services are most needed from the patient perspective.

Another unintended consequence of the shutdown is the sudden prominence of telemedicine. Telemedicine is not new, but the ability to deliver care remotely without asking patients to increase their risk of infection has brought telemedicine to new prominence during the pandemic. One of the first administrative acts by the Trump administration was to temporarily relax restrictions on telemedicine delivery [9]. Beginning in early March 2020, Medicare began paying for telehealth visits for a broader set of services, locations, modalities, and professions, as well as waiving requirements such as having an established patient-provider relationship [10]. These changes were intended to allow the emergency expansion of telehealth services during the height of the pandemic from April to June 2020.

One approach that can safely deliver nonemergency care can be telemedicine use for routine care. Much of the nonemergency care that occurred during the peak of the crisis was delivered via telemedicine. This created a sudden introduction to telemedicine for both patients and (some) health care professionals. It has been suggested that the pandemic may permanently change the role of telemedicine in America [11], yet whether views on telemedicine have actually changed is unknown.

Our objective was to present the findings from a recent survey of primary care patients in Vermont about both deferred care and telemedicine. We describe for what services care was deferred and where patient concerns about deferred care are highest. We then explore attitudes toward telemedicine, whether those attitudes have changed, and how telemedicine may be used for deferred care if there is another health care system shutdown. Our data were drawn at a unique time to measure care deferral—while it was happening. The results of this study can provide guidance on what is likely to happen in the future if a similar lockdown of health services occurs.

Methods

The study design is a cross-sectional analysis of the primary care population of the greater Burlington area in Vermont. A random sample of 12,000 individuals over 18 years with at least one primary care visit during the preceding 3 years was drawn from University of Vermont Medical Center patients, stratified by age cohort. Within each 10-year age cohort, a random number generator was used to select the sample. The unit of observation was the individual patient.

Individuals were contacted in two waves between April 30 and May 13, 2020, and asked to consent to participate in the survey. All individuals were provided with an opportunity to opt out of the survey. A total of three follow-up reminders was sent. The survey took an estimated 16-20 minutes to complete and covered a number of different topic areas. These topics included sociodemographic data (eg, age, gender, income, household type and composition, etc), general health status and risk factors (eg, pre-existing health conditions; smoking; COVID-19 symptoms, testing, and diagnosis), exposure to COVID-19 and prevention actions undertaken by the individual, economic impact of the shutdown, beliefs about and preferences for public interventions, telemedicine, and delayed care.

Key variables for our analysis on deferred care included whether the respondent had deferred care due to COVID-19 (yes/no) ("Have you had to defer needed health care because of the COVID-19 outbreak and response?"). For those who answered yes to deferring care, we asked how concerned they were that the delay would harm their health (on a 5-point Likert scale, from *very concerned* to *very unconcerned*); we also asked them to specify the type of health service deferred (eg, primary care, dental, oncology, etc). For telemedicine, individuals were asked if they had ever used telemedicine (yes/no), whether they were more or less likely to use telemedicine now versus before the pandemic, and whether they would consider using telemedicine for deferred care.

Key control variables include age (in categories), income (in categories), gender, education (college: yes/no), and presence of chronic illnesses (yes/no from a list including conditions identified by the Centers for Disease Control and Prevention as increasing the risk of COVID-19 complications) [12]. We also included variables indicating whether the person had lost their job due to COVID-19. For those who had an income reduction due to COVID-19, we asked by how much their income had declined.

Means and frequencies from the data were calculated. For our analysis of reasons for deferred care, the denominator is individuals who reported deferring care. For the telemedicine analysis, the denominator is the entire sample. For dichotomous variables (*increased interest in telemedicine* and *willingness to use telemedicine for deferred care*), we performed a multivariate analysis using a logit model, with the coefficients calculated as odds ratios. Variables were considered to be statistically significant with a P value <.05.

The study was approved by the Institutional Review Board of the University of Vermont. Participants were not compensated for study participation.

Results

The initial sample comprised 12,000 individuals. Of these, 11,700 (98%) had a functioning email address. We had a total of 2275 responses (19.4%), and 1961 (16.3%) individuals both read the consent form and agreed to participate. Of these, 1694 (14.1%) people completed the survey.

Overall, 48% of the sample (803 out of 1694 completed responses) reported deferring care due to COVID-19. Of these 803 individuals who reported deferred care, 78% (n=626) reported that the care was deferred due to a cancellation of the appointment by the health care provider rather than due to a decision by the respondent, while in 22% (n=177) of cases the respondent decided to cancel. The sample was relatively evenly distributed by age (Table 1).

Table 1. Descriptive statistics from the sample of 1681 observations showing frequencies and percentages in different categories.

Variable	Respondents, n (%)
Age group (years)	
18-24	62 (3.69)
25-34	285 (16.95)
35-44	327 (19.45)
45-55	365 (21.71)
55-64	412 (24.51)
65-75	230 (13.68)
Income ($ USD)	
Prefer not to answer	100 (5.95)
$1000-$25,000	50 (2.97)
$25,001-$50,000	145 (8.63)
$50,001-$75,000	241 (14.34)
$75,001-$100,000	338 (20.11)
>$100,001	807 (48.01)
Education	
Less than college	401 (23.85)
College graduate	1280 (76.15)
Location	
Urban	501 (29.8)
Semiurban/suburban	841 (50.03)
Rural	339 (20.17)
Live alone	
No	1465 (87.15)
Yes	216 (12.85)
Sex	
Male	691 (41.11)
Female	990 (58.89)
Presence of chronic illness	
No	765 (45.51)
Yes	916 (54.49)

The top reported service line for deferred care was dental services, with 27% (n=219) of the sample reporting deferred care for dental services (Table 2). Dental care was followed by primary care (n=183, 23%) and other services (n=140, 18%). Considerably fewer respondents reported deferring care for orthopedics (n=65, 8%), women's health (n=56, 7%), and radiology/imaging (n=45, 6%).

Table 2. Delayed care by service line among 803 survey respondents in Vermont between April 30 and May 13, 2020, who reported deferring care due to the COVID-19 pandemic medical services shutdown.

Health care service	Respondents, n (%)
Dental services	219 (27)
Primary care	183 (23)
Other	140 (18)
Orthopedics	65 (8)
Women's health/obstetrics and gynecology	56 (7)
Radiology/imaging	45 (6)
Surgery	22 (3)
Internal medicine	20 (2)
Mental health	17 (2)
Cancer	10 (1)
Neurology	10 (1)
Pediatrics	8 (1)
Cardiovascular	7 (1)

Overall, 68% (n=546) of those who deferred care reported that the purpose of the intended services was preventive care (Table 3). Only 38% (n=305) reported deferring care for existing problems and 29% for newly emergent problems (n=233), which varied across service type. Dental services had the highest level of deferred care overall. Of those who deferred dental care, it had the highest level of deferred care for preventive services (n=184, 84%) and the lowest level of deferred care for ongoing (n=45, 21%) and newly emergent problems (n=37, 17%). In contrast, of those who deferred care for surgery, 68% (n=15) were for newly emergent issues and 45% (n=10) for ongoing issues. Orthopedics also stands out for high levels of deferred care for newly emergent (n=33, 51%) and ongoing (n=41, 63%) care. Note that these percentages do not necessarily add to 100% because respondents could check multiple categories.

Table 3. Reasons for delayed care, by service line and problem type, among 803 survey respondents in Vermont between April 30 and May 13, 2020, who reported deferring care due to the COVID-19 pandemic medical services shutdown.

Health care service	New developed problem, n (%)	Care for ongoing problems, n (%)	Preventive care, n (%)
Dental services	37 (17)	45 (21)	184 (84)
Primary care	52 (29)	56 (30)	137 (75)
Orthopedics	33 (51)	41 (63)	23 (35)
Women's health/obstetrics and gynecology	18 (32)	21 (38)	40 (71)
Radiology/imaging	14 (30)	14 (30)	33 (74)
Surgery	15 (68)	10 (45)	6 (27)
Internal medicine	8 (40)	10 (50)	13 (65)
Mental health	4 (24)	13 (76)	7 (41)
Cardiovascular	3 (43)	4 (57)	6 (86)
Other	38 (27)	78 (55)	80 (57)
Total	229 (29)	309 (38)	547 (68)

Overall, most respondents who deferred care reported relatively low levels of concern about the health effects of the delay (Table 4). Overall, only 5.1% (n=41) of those who deferred care were *very concerned* about the health effect of the delay, 25.0% (n=201) were *concerned*, 30% (n=241) were *neutral* about the effect, and 40% (n=320) were either *unconcerned* or *very unconcerned*. However, the level of concern reported by the survey respondents also varied across service lines. The highest level of concern was for mental health services (*very concerned* / *concerned*: n=10, 59%), followed by surgery (n=12, 55%) and orthopedics (n=32, 50%). The lowest level of concern was for primary care (n=35, 19%) and dental services (n=60, 28%), which were also the most common services for which care was deferred.

Table 4. Level of concern about care delays overall and by service line among 803 survey respondents in Vermont between April 30 and May 13, 2020, who reported deferring care due to the COVID-19 pandemic medical services shutdown.

Health care service	Level of concern, n (%)				
	Very concerned	Concerned	Neutral	Unconcerned	Very unconcerned
Dental services	4 (1.8)	56 (25.8)	56 (24.9)	79 (36.4)	24 (11.1)
Primary care	7 (3.3)	28 (15.4)	64 (35.2)	62 (34.1)	22 (12.1)
Orthopedics	11 (16.9)	21 (32.3)	15 (23.1)	11 (16.9)	7 (10.8)
Women's health/obstetrics and gynecology	4 (7.1)	11 (19.6)	23 (41.1)	10 (17.9)	8 (14.3)
Radiology/imaging	5 (11.6)	11 (23.3)	17 (37.2)	10 (23.3)	2 (4.7)
Surgery	1 (4.6)	11 (50.0)	8 (36.4)	0 (0.0)	2 (9.1)
Internal medicine	1 (5.0)	7 (35.0)	5 (25.0)	2 (10.0)	5 (25.0)
Mental health	1 (5.9)	9 (52.9)	3 (17.7)	3 (17.7)	1 (5.9)
Other	5 (3.6)	35 (25.0)	39 (27.9)	46 (32.9)	15 (10.7)
Total	42 (5.1)	200 (25.0)	242 (30.0)	229 (28.7)	89 (11.2)

Turning to telemedicine, our analysis now includes the entire sample (N=1861). Overall, a minority of the sample had used telemedicine (n=837, 45%), but a strong majority reported that they were more likely to use telemedicine now than before the pandemic (n=1470, 79%) (Table 5). A majority was willing to use it for deferred care (n=1359, 73%), but those respondents were much smaller among individuals who actually deferred care. Among those who deferred care and were concerned about the health effect of the deferral, 59% (n=189) were willing to use telemedicine for the services. Among those who deferred care and were not concerned about the health effect, only 54% (n=261) were willing to use telemedicine to resolve the problem.

Table 5. Experience with and willingness to use telemedicine among 1861 survey respondents in Vermont between April 30 and May 13, 2020.

Question	Respondents, n (%)
Have you ever used telemedicine for health care?	
Yes	760 (46)
No	921 (55)
Are you more likely to use telemedicine now than before the pandemic?	
Yes	1332 (79)
No	332 (20)
Would you consider using telemedicine for deferred care?	
Yes	1226 (73)
No	433 (26)
For those with deferred care and are concerned about health effects: would you use telemedicine for deferred care?	
Yes (concerned about health effects)	130 (59)
Yes (not concerned about health effects)	331 (54)
No (concerned about health effects)	110 (40)
No (not concerned about health effects)	226 (45)

The logit analysis of factors explaining factors associated with increases in willingness to use telemedicine tells a similar story (Table 6). The odds ratio (OR) for persons willing to use telemedicine who were *very concerned*/*concerned* about the health effect of deferred care due to the pandemic was 0.34 *(P*=.02) compared to those who were *neutral* or *unconcerned*/*very unconcerned*. However, college graduates (OR 2.15, *P*<.001) and females *(*OR 1.73, *P*<.001) were more likely to use telemedicine (reference groups: noncollege graduates and males), as were those with a chronic illness (OR 1.4, *P*=.009) (reference group: no chronic illness). The largest age effect was in the oldest population (persons ≥65 years: OR 2.29, *P*=.02) (reference group: <25 years). By service line, mental health was the service with the largest increase, although the effect was not statistically significant *(P*=.12).

Table 6. Logit regression explaining factors predicting increased willingness to use telemedicine among 1861 survey respondents in Vermont between April 30 and May 13, 2020, with coefficients representing percentage point increases.

Variable	Odds Ratio	SE	z	*P* value	95% CI
Had deferred care	0.341	0.251	–1.460	.143	0.081-1.439
Concerned / very concerned about deferred care	0.629	0.123	–2.370	.018	0.429-0.922
Age group (years) (reference: 18-24 years)					
25-34	1.439	0.474	1.100	.269	0.754-2.744
35-44	1.732	0.576	1.650	.099	0.902-3.325
45-54	1.571	0.518	1.370	.171	0.823-2.998
55-64	1.589	0.513	1.440	.151	0.845-2.990
≥65	2.290	0.814	2.330	.020	1.141-4.595
Income (reference: >$100,001)					
Prefer not to answer	0.375	0.091	–4.030	<.001	0.232-0.604
$1000-$25,000	1.017	0.386	0.040	.965	0.484-2.138
$25,001-$50,000	1.251	0.332	0.840	.400	0.743-2.104
$50,001-$75,000	0.994	0.205	–0.030	.976	0.664-1.488
$75,001-$100,000	0.716	0.119	–2.010	.045	0.517-0.992
College graduate	2.146	0.309	5.300	<.001	1.618-2.846
Income decline (reference: no income decline)					
Less than 25%	1.069	0.196	0.360	.718	0.746-1.531
50%	0.816	0.200	–0.830	.409	0.505-1.321
75%	0.845	0.372	–0.380	.703	0.357-2.003
100% (I have lost all my income)	1.446	0.505	1.060	.291	0.729-2.866
Currently unemployed	0.871	0.171	–0.700	.482	0.594-1.279
Location (reference: urban area)					
Semiurban/suburban	1.203	0.176	1.270	.205	0.904-1.602
Rural	1.287	0.235	1.380	.168	0.899-1.840
Sex: female	1.727	0.225	4.200	<.001	1.339-2.229
Live alone	0.748	0.144	–1.510	.131	0.513-1.091
Have chronic illness	1.400	0.181	2.600	.009	1.086-1.804
Deferred care in					
Orthopedics	2.810	2.230	1.300	.193	0.593-13.309
Mental health	4.647	4.561	1.570	.117	0.679-31.812
Neurology	1.455	1.489	0.370	.714	0.196-10.808
Pediatrics	0.963	1.004	–0.040	.971	0.125-7.439
Radiology/imaging	2.600	2.143	1.160	.247	0.517-13.083
Surgery	3.534	3.314	1.350	.178	0.562-22.211
Primary care	2.688	2.016	1.320	.188	0.618-11.692
Cancer	2.540	2.754	0.860	.390	0.303-21.268
Cardiovascular	4.071	5.400	1.060	.290	0.303-54.792
Internal medicine	1.940	1.729	0.740	.457	0.338-11.132
Women’s health/obstetrics and gynecology	2.562	2.067	1.170	.244	0.527-12.458
Dental services	2.372	1.768	1.160	.247	0.550-10.223
Other	3.830	2.934	1.750	.080	0.853-17.188

These results are consistent with factors associated with a willingness to use telemedicine for deferred care (Table 7). In this model, having actually deferred care has a strong negative association with willingness to use telemedicine for deferred care (b=0.18, *P*=.02), but the level of concern was not significantly related. This model again shows a strong age effect, with the 45-55, 55-64, and ≥65 age groups all showing ORs significantly greater than 1 versus the reference group (<25 years), with the largest coefficient observed in the ≥65 years group. College graduates, females, and persons with chronic illnesses again had a higher odds, although some of the coefficients were only marginally significant. Location (suburban) was statistically significant (OR 1.42, *P*=.02) and positive compared to urban although rural was not.

Table 7. Logit regression explaining factors predicting willingness to use telemedicine for deferred care among 1861 survey respondents in Vermont between April 30 and May 13, 2020 with coefficients representing percentage point increases.

Variable	Coefficient	SE	z	*P* value	95% CI
Had deferred care	0.183	0.135	–2.290	.022	0.043-0.781
Concerned / very concerned about deferred care	0.856	0.144	–0.930	.353	0.616-1.189
Age group (years) (reference: 18-24 years)					
25-34	1.211	0.400	0.580	.562	0.634-2.312
35-44	2.048	0.682	2.150	.031	1.066-3.934
45-54	2.241	0.747	2.420	.015	1.166-4.306
55-64	2.328	0.762	2.580	.010	1.226-4.420
≥65	2.802	0.989	2.920	.004	1.403-5.596
Income (reference: >$100,001)					
Prefer not to answer	0.688	0.182	–1.410	.158	0.409-1.156
$1000-$25,000	1.114	0.441	0.270	.785	0.513-2.422
$25,001-$50,000	0.952	0.232	–0.200	.840	0.591-1.535
$50,001-$75,000	0.868	0.166	–0.740	.458	0.597-1.262
$75,001-$100,000	0.960	0.159	–0.250	.806	0.694-1.328
College graduate	1.307	0.196	1.790	.073	0.975-1.753
Income decline (reference: no income decline)					
Less than 25%	0.853	0.146	–0.930	.352	0.610-1.193
50%	0.812	0.195	–0.870	.386	0.507-1.300
75%	0.593	0.233	–1.330	.184	0.274-1.281
100% (I have lost all my income)	1.078	0.350	0.230	.818	0.570-2.038
Currently unemployed	0.973	0.187	–0.140	.885	0.667-1.418
Location (reference: urban area)					
Semiurban/suburban	1.421	0.205	2.430	.015	1.071-1.887
Rural	0.955	0.166	–0.260	.792	0.680-1.342
Sex: female	1.270	0.164	1.860	.063	0.987-1.635
Live alone	1.131	0.222	0.630	.529	0.771-1.662
Have chronic illness	1.218	0.153	1.570	.117	0.952-1.559
Deferred care in					
Orthopedics	0.998	0.777	0.000	.998	0.217-4.591
Mental health	4.551	4.483	1.540	.124	0.660-31.373
Neurology	0.788	0.778	–0.240	.809	0.114-5.454
Pediatrics	1.328	1.380	0.270	.785	0.173-10.176
Radiology/imaging	0.699	0.557	–0.450	.653	0.147-3.330
Surgery	0.545	0.467	–0.710	.479	0.102-2.925
Primary care	1.840	1.382	0.810	.417	0.422-8.023
Cancer	0.996	0.983	0.000	.997	0.144-6.894
Cardiovascular	0.930	1.003	–0.070	.947	0.113-7.688
Internal medicine	1.654	1.466	0.570	.570	0.291-9.395
Women’s health/obstetrics and gynecology	1.032	0.811	0.040	.968	0.222-4.810
Dental services	0.538	0.401	–0.830	.406	0.124-2.321
Other	1.005	0.758	0.010	.995	0.229-4.407

Discussion

The COVID-19 pandemic created an immediate problem with patients being unable to access care as they normally would, but it also presented an opportunity for telemedicine. In terms of how much of a problem deferred care is, our data present a nuanced interpretation. On the one hand, nearly half the sample deferred care, suggesting that deferred care is a substantial problem. On the other hand, respondents were highly unconcerned about the health effect associated with care deferral and report that it was largely for preventive care, with preventive dental services being the top deferred service. However, there was a subgroup—about a quarter of those who deferred care—who were very concerned about the health effects of the deferral; this group was more likely to defer care in areas like surgery and orthopedics.

Telemedicine has still not been used by the majority of the sample, but respondents indicated a strongly increased willingness to try, particularly for deferred care. This effect was especially significant in older females and more educated respondents, but lower for persons who actually had deferred care. A recent review of barriers to telemedicine adoption identified the top six barriers as technically challenged staff (11%), resistance to change (8%), cost (8%), reimbursement (5%), patient age (5%), and level of education of the patient (5%) [13]. The pandemic may have loosened resistance to change, while policy changes altered cost and reimbursement issues. Our findings suggest that age may be less of a factor than suggested by previous research; this is likely due to the lack of alternatives for older persons to receive needed care. This suggests the potential for a permanent shift to telemedicine, assuming reimbursement policies remain in place.

We examined deferred care in the context of an unusual circumstance—the COVID-19–related medical care shutdown. Previous research on deferred care has tended to focus on particular locations such as the emergency room [14], specific populations such as Medicaid enrollees [15] or lower income persons [16], or even particular countries [17]. None of these examples are fully analogous to the situation reported in this paper, where widespread care deferral is seen in a higher income country. The applicability of these findings is most relevant to other high-income countries facing broad pandemic-related shutdowns.

This study has a number of potential limitations. First, the study sample is the primary care population of the Burlington area, and the study was conducted in late March / early April of 2020. The location is a semiurban area with limited racial diversity, extremely high insurance coverage, and relatively high levels of internet access and education. Generalizing to other locations, including other countries and areas that are either more or less urban should be done with caution. The survey was also (purposely) conducted during a time when usual medical care was unavailable. Whether the sentiments expressed in this survey would be true in the future is unknown. The sample also was already engaged to some extent with the health care system (at least one visit in the previous 3 years), so individuals without contact with the health care system may react differently. Finally, the sample was somewhat more educated, wealthier, and comprised more females than the overall population, with 48% of the sample reporting an income of over $100,000 and 76% having completed college. This somewhat reflects the community, which tends have both a higher income and more education than the United States as a whole [18].

Given the variation in COVID-19 impact across the United States and uncertainties about pandemic duration and potential new waves of infection, our data support potential increased use of telemedicine to support access to health care. We observed evidence of increased acceptance, particularly among older and female respondents. Mental health services had a high level of deferred ongoing care and a high willingness to resolve care deferral through telemedicine. This presents an opportunity for health systems as they prepare for a potential second wave. Additionally, our findings suggest that the pandemic may have permanently changed consumers' willingness to use telemedicine for health care, particularly among older individuals. This newfound acceptance of telemedicine, coupled with insurers' decision to continue reimbursing telemedicine at levels consummate with in-person care, suggest that higher levels of telemedicine in health care may be an enduring change.

Conflicts of Interest

JC is the author of and receives annual royalties from the textbook Controversies in Public Health and Health Policy, Jones & Bartlett Learning, 2016.

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Abbreviations

OR: odds ratio

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Original Paper

Association Between Public Knowledge About COVID-19, Trust in Information Sources, and Adherence to Social Distancing: Cross-Sectional Survey

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Abstract

Background: The success of behavioral interventions and policies designed to reduce the impact of the COVID-19 pandemic depends on how well individuals are informed about both the consequences of infection and the steps that should be taken to reduce the impact of the disease.

Objective: The aim of this study was to investigate associations between public knowledge about COVID-19, adherence to social distancing, and public trust in government information sources (eg, the US Centers for Disease Control and Prevention), private sources (eg, FOX and CNN), and social networks (eg, Facebook and Twitter) to inform future policies related to critical information distribution.

Methods: We conducted a cross-sectional survey (N=1243) between April 10 and 14, 2020. Data collection was stratified by US region and other demographics to ensure representativeness of the sample.

Results: Government information sources were the most trusted among the public. However, we observed trends in the data that suggested variations in trust by age and gender. White and older populations generally expressed higher trust in government sources, while non-White and younger populations expressed higher trust in private sources (eg, CNN) and social networks (eg, Twitter). Trust in government sources was positively associated with accurate knowledge about COVID-19 and adherence to social distancing. However, trust in private sources (eg, FOX and CNN) was negatively associated with knowledge about COVID-19. Similarly, trust in social networks (eg, Facebook and Twitter) was negatively associated with both knowledge and adherence to social distancing.

Conclusions: During pandemics such as the COVID-19 outbreak, policy makers should carefully consider the quality of information disseminated through private sources and social networks. Furthermore, when disseminating urgent health information, a variety of information sources should be used to ensure that diverse populations have timely access to critical knowledge.

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KEYWORDS

health communication; COVID-19; trust in information sources; social distancing; behavior; coronavirus

Introduction

An unusual virus outbreak was documented in Wuhan, China in December 2019 [1]. By mid-March 2020, the World Health Organization (WHO) declared the COVID-19 outbreak to be a worldwide pandemic [1]. In early April, the number of COVID-19 cases in the United States exceeded 500,000 [2], and the death toll was approaching 30,000 [3]. In response, various states decided to implement serious measures to attempt to slow viral transmission. The US Centers for Disease Prevention and Control (CDC) asked individuals to wear masks,

sanitize surfaces, and, most importantly, limit their social lives, including reducing face-to-face contacts and staying at least 6 feet apart from others [4]. Official stay-at-home orders were issued in at least 42 states, 3 counties, and 10 cities in the United States [5]. Americans were instructed to work from home when possible and limit nonessential trips and social gatherings [6]. Public places, including bars, restaurants, and playgrounds, were closed, and public events such as concerts and sports tournaments were canceled. The purpose of these restrictions was to save lives and avoid overburdening the health care system [7]. Evidence from data and predictive modeling showed that timely restriction of movements within countries with developed economies prevented more than 500,000 deaths [8]. Public adherence to restrictions can influence the success of the implementation of restrictive rules. Adherence depends on how well-informed people are about both the consequences of infection [9,10] and the steps that should be taken to prevent virus spread [11].

Previous research has shown that trust in sources is an essential component associated with both individual understanding of information and willingness to act on it [12]. Additionally, research in China has shown that people vary in their risk perception of COVID-19 depending on whether they received information from mass media or social media [13]. Therefore, in our work, we aimed to provide an overview of the sources people trusted early in the pandemic to inform policy makers on how to best disseminate critical information to reach different populations. We also explored the association between trust in different sources and accurate knowledge about COVID-19 to determine which information sources potentially need to improve the quality of their information to ensure that the public is well-informed about pandemic policies. Finally, following previous research that showed the association between understanding of COVID-19 and adherence to recommended risk-reducing behavior [14], we explored whether knowledge and trust were associated with adherence to social distancing behavior.

Methods

Data Collection

Data were collected via a cross-sectional national survey. An independent company that specializes in national data collection, Qualtrics Panels, implemented the recruitment procedures [15,16]. Individuals received an email invitation to the study if they preregistered for Qualtrics Panels and completed a baseline survey. Participants were informed about confidentiality, risks, and benefits at the beginning of the survey. Participants were then directed to the questionnaire; upon completion of the questionnaire, they received compensation. Qualtrics rewards participants with company points that can be redeemed for game rewards, gift cards, charitable contributions, or airline miles. Duke University's institutional review board approved the study and deemed it exempt. The study design and analysis plan were preregistered at Open Science Framework [17].

To ensure representativeness of the sample, we stratified data collection by age, gender, and the following US regions: New England, Mid-Atlantic, East North Central, West North Central, South Atlantic, East South Central, West South Central, Mountain, and Pacific. The survey opened on April 10, 2020, and the data quality was evaluated after 200 responses. After this initial step, additional screening logic was implemented to exclude individuals aged <18 years. Likewise, participants who spent less than 6 minutes completing the survey were excluded from the survey. Between April 13 and April 14, 2020, 1000 participants completed the survey. Data collected on April 10 and April 13 to 14 were included in the analysis.

Survey

The survey was part of a larger study to explore how Americans were responding to CDC recommendations and guidelines during the pandemic. Participants reported their demographics, current work/income circumstances, location, and health status, including conditions that were associated with increased risks of dying from COVID-19. In the current work, we focused on exploring the association between trust in information sources, knowledge about COVID-19, and adherence to social distancing. A full copy of the survey can be found in Open Science Framework (OSF) Registries [17].

Trust in Information Sources About COVID-19

To evaluate trust in different information sources, we provided examples of government-affiliated sources, privately affiliated sources, and social networks. We asked participants to rank their trust on a 5-point Likert scale that ranged from 1 ("not trustworthy at all") to 5 ("extremely trustworthy"). Additionally, an "I don't know" option was available for participants who were unfamiliar with the provided examples. For government-affiliated sources, we chose the following examples: The White House, the CDC, the US Food and Drug Administration (FDA), the WHO, and local health departments. To evaluate participant trust in privately affiliated media, we used the MarketWatch summary [18], which sorts sources into two dimensions: political orientations and facts vs opinions. The examples represented liberal, conservative, and neutral sides. In each political domain, two sources were included: a source that was classified as providing facts and a source that was classified as providing opinions. The liberal sources were the *New York Times* (facts) and MSNBC (opinions); the conservative sources were a news website, The Hill (facts), and Fox News (opinions); and the neutral sources were Reuters (facts) and CNN (opinions). Examples of social networks include Facebook and Twitter.

To ensure the inclusiveness of the news sources, we allowed participants to indicate other sources that they trusted the most via open-response items. Participants were instructed to specify if a trusted source was not listed in a survey section (eg, social networks) and then provide the name of their trusted source (eg, "Reddit") and rate the source on the same scale as the other sources. For analysis, we considered a source as "trusted" when participants rated it as "trustworthy" or "extremely trustworthy."

Frequency of Accessing Information About COVID-19

To evaluate whether participants followed news about COVID-19, we asked them to rate their agreement with the following statement: "I follow updates about the coronavirus and the outbreak closely." This item was scored on a 5-point

scale that ranged from "strongly disagree" to "strongly agree." Participants also reported how frequently they checked the news on an 8-point scale ranging from "never" to "5 or more times a day." Furthermore, we provided examples of information sources (discussed above) and asked the participants to rate how frequently they checked each source of information in the past week. Participants reported the frequency on a 5-point scale ranging from "never" to "multiple times a day."

Knowledge About COVID-19

To evaluate the participants' knowledge about COVID-19, seven items were adopted from previous research on COVID-19 by RTI International [19,20]. Five additional items were designed based on current CDC guidelines and common myths about COVID-19 that circulated in the media at the end of March 2020. The response mode of the scale included binary endpoints of "true" and "false." The scale consisted of items related to facts and myths about the virus, such as "Antibiotics can be used to treat the coronavirus" and "Most people who are infected with the coronavirus die from it." The scale also included items related to risk-reducing behavior, such as "I cannot be infected if I wear a mask" and "By limiting the contact I have with people outside my household, I could prevent somebody's death." The knowledge score was calculated using the percent of correct responses to all 12 items (listed in Multimedia Appendix 1).

Social Distancing

We asked participants about the frequency of seven specific social distancing behaviors recommended by the CDC at the beginning of April to prevent the spread of COVID-19 [4]. Participants reported how often they engaged in specific behaviors over the past seven days on a 5-point scale ranging from "not at all" to "several times a day." Individual negative behaviors included "Hugging or touching people who do not live with me," "Standing or walking close (within arm's length) to someone who does not live with me," "Meeting face-to-face with people who do not live with me," "Going to gatherings with five or more people," "Going inside someone else's house," and "Having friends or family over to visit" (see Multimedia Appendix 1). If participants reported leaving their house at least once in the past week, they were also asked how often they stayed six feet away from people who did not live in their household. For analysis, participants were considered to be adherent to all social distancing behaviors if they responded "not at all" to all negative behavior questions and "always" stayed six feet away from people outside their household (or did not leave their house in the past week).

Data Analysis

Demographics, location, work, and health status were reported as both frequencies and percentages.

Trust in Information Sources About COVID-19

For each example of an information source, we summarized the percentage of people who trusted the source. Further, the percentages of participants who trusted (versus those who did not trust) each source were determined for age, race, and region groups. For age groups, we were specifically interested in older Americans (>65 years of age), as the CDC considers them to be a vulnerable population.

Frequency of Accessing Information About COVID-19

We reported the percentage of participants who reported "closely" following the news about COVID-19 and the percentage of participants who checked the news about COVID-19 at least "once a day." We also summarized how often individuals reported checking specific information sources.

Knowledge About COVID-19

We presented the total percentages of correct responses to all knowledge items and correct answers by item. The Spearman correlation was used to estimate the association between correct responses ("accurate knowledge") and trust in different information sources.

Social Distancing

The percentage of people who adhered to social distancing behavior (as defined by the CDC) was reported, along with the frequencies of adherence to each specific behavior. Chi-square statistics and significance levels were used to evaluate whether there were more adherent participants among those who trusted a particular information source than among those who did not trust a particular source.

Elastic Net Regression

We used *trust* in information sources to model *accurate* knowledge about COVID-19. The primary goal was not prediction per se; rather, we aimed to identify the information sources that contributed the most to the accuracy of participant knowledge about COVID-19 when all the sources were simultaneously included in the prediction model. Participant trust in each information source were the independent variables, while the percentage of correct responses to COVID-19 knowledge items was the dependent variable. We chose elastic net regression because it allowed us to determine the model that fits our multiparameter data and highlighted the most influential information sources that predicted participant knowledge about COVID-19 [21,22]. This approach uses regularization parameters for shrinking the influence of "weak" information sources to "0," leaving only information sources that had a "strong" association with knowledge in the model. Additionally, this approach controls for potential multi-collinearity by considering correlations amongst the independent variables.

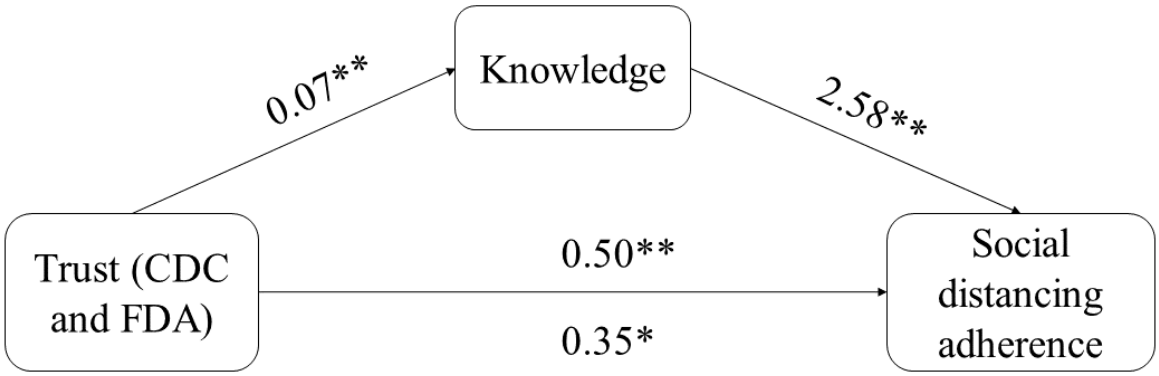
Data were randomly split into training and test data sets (80% and 20%, respectively). In the model, we used ordinary least squares regression. To evaluate the model fit, we used R^2 and root mean square error (RMSE) to tune these parameters for a better fit between the model and the data.

The same approach was utilized to establish the information sources that contributed most strongly to adherence to social distancing behaviors. In this case, the elastic net regression used logistic regression with regularization parameters. To evaluate the model fit, we used the area under the curve (AUC), which illustrates how well a model can predict the dependent variable (here, adherence to social distancing). We tuned the regularization parameters to maximize the AUC. For both models, elastic net regression was implemented in the glmnet package in R [23].

Exploratory Analysis

Although not preregistered, we also explored whether knowledge mediated the relationship between trust in an information source and adherence to social distancing. The source that contributed to the accuracy of knowledge the most, as defined by elastic net regression coefficients, was used as a predictor in our mediation analysis. We fit three models to the data with adherence to social distancing as an outcome and knowledge as a mediator (see Figure 1). Model 1 included a binary logistic regression of trust (X) on participant adherence to social distancing (Y), Model 2 was a linear regression of trust (X) on participant knowledge about COVID-19 (M), and Model 3 was a binary logistic regression predicting adherence (Y) by trust (X) and knowledge (M). An indirect effect and bootstrap procedure were conducted using the "process" macro [24].

Figure 1. Indirect effects of trust in CDC and FDA information sources and adherence to social distancing. CDC: US Centers for Disease Control and Prevention; FDA: US Food and Drug Administration. *Significant at .05, **significant at .001.



Results

The total sample included 1243 participants. Main parameters such as age, gender, race, location, and income were closely aligned with the general US population as per the 2018 Census [25] and are reported in Table 1.

Table 1. Demographic and descriptive statistics of the study participants (N=1243).

Characteristic	Value
Age (years)	
20-40, n (%)	579 (48.3)
40-60, n (%)	353 (29.4)
60-80, n (%)	267 (22.3)
Mean (SD)	44 (16)
Gender, n (%)	
Female	648 (52.1)
Male	580 (46.7)
Other	15 (1.2)
Race/ethnicity[a], n (%)	
White	888 (72.0)
Black or African American	162 (13.1)
Asian	85 (6.9)
Hispanic or Latino	92 (7.5)
American Indian and Alaska Native	35 (2.8)
Native Hawaiian and Other Pacific Islander	7 (<1.0)
Income (US $), n (%)	
Less than 14,999	192 (15.4)
15,000-74,999	715 (57.6)
75,000 to 99,999	143 (11.5)
100,000 to 149,999	110 (8.9)
More than 150,000	81 (6.6)
Did not answer	2 (0.1)
Location, n (%)	
New England	57 (4.6)
Mid-Atlantic	171 (13.8)
East North Central	168 (13.5)
West North Central	79 (6.4)
South Atlantic	256 (17.1)
East South Central	75 (6.0)
West South Central	150 (12.1)
Mountain	90 (7.3)
Pacific	193 (15.6)
Did not answer	4 (0.3)
Under stay-at-home order, n (%)	
Yes	979 (78.8)
No	192 (15.4)
Not sure	72 (5.8)
Employment status, n (%)	
Employed full-time	484 (38.9)
Employed part-time	135 (10.9)
Retired	190 (15.3)

Characteristic	Value
On disability	71 (5.7)
Self-employed	95 (7.6)
Unemployed	268 (21.6)
Work status, n (%)	
Working from home	422 (33.9)
Not working from home	292 (23.5)
Essential worker	343 (27.6)
Nonessential worker	346 (27.8)
Chronic health condition or care provider, n (%)	
Has chronic health condition	497 (40.0)
Lives with person with chronic health condition	455 (36.6)
Taking care of person outside household	158 (12.7)
Infected/suspected infected with COVID-19, n (%)	
Yes	53 (4.3)
No	1106 (89.0)
Maybe	84 (6.8)

[a]Data do not sum to 1243 because more than one option could be selected.

Trust in Information Sources About COVID-19

We found that the majority of participants trusted government sources (Table 2). Less than one-third of the participants trusted social media with regard to information about COVID-19. Older adults were more likely to trust government sources compared to younger adults. Conversely, middle-aged and younger populations trusted private sources and social networks more than older populations. On average, individuals who identified as White reported more trust in government sources than non-White participants, who trusted more private sources and social networks.

The trends of trust in the information sources were similar between regions. Notably, the highest prevalence rate of COVID-19 at the time of data collection was in the Mid-Atlantic region. However, this region had the lowest percentage of people (n = 102 out of 171; 60.0%) who trusted CDC and FDA sources compared to the average population (n=873, 70.3%); see Figure 2.

Table 2. Numbers of participants who trust each information source (N=1243), n (%). Trust was defined as binary (trust vs no trust) regarding providing accurate information about COVID-19.

Domain and information sources	Trust by total sample[a]	Trust by age group[b] (years)					Trust by race	
		<25	25-40	41-50	51-64	≥65	White	Non-White
Government sources								
CDC[c] and FDA[d]	874 (70.3)	99 (64.7)	298 (64.8)	*142 (75.1)*	*222 (79.0)*	*111 (75.5)*	*645 (72.2)*	229 (65.6)
Local health department	792 (63.7)	81 (52.9)	280 (60.0)	*129 (68.3)*	*195 (69.4)*	*105 (71.4)*	*574 (64.2)*	218 (62.5)
WHO[f]	736 (59.2)	*93 (60.8)*	269 (57.6)	*113 (59.8)*	*177 (63.0)*	*82 (55.8)*	529 (59.2)	207 (59.3)
White House	569 (45.8)	65 (42.5)	205 (43.9)	*94 (49.7)*	*134 (47.7)*	*69 (46.9)*	*426 (47.7)*	143 (41.0)
Other	196(15.8)	18 (11.8)	*91 (19.5)*	*32 (16.9)*	36 (12.8)	18 (12.2)	131 (14.7)	*65 (18.6)*
Private sources								
CNN	577 (46.4)	64 (42.8)	*229 (49.0)*	*88 (46.6)*	*133 (47.3)*	60 (40.8)	389 (43.5)	*188 (53.9)*
FOX	534 (42.9)	63 (41.1)	*201 (43.0)*	*90 (47.6)*	*122 (43.4)*	57 (38.8)	*392 (43.9)*	142 (40.7)
New York Times	523 (42.0)	*70 (45.8)*	*208 (44.5)*	*81 (42.9)*	105 (37.4)	55 (37.4)	352 (39.4)	*171 (49.0)*
MSNBC	515 (41.4)	56 (36.7)	*204 (43.7)*	*89 (47.1)*	108 (38.4)	55 (37.4)	346 (38.7)	*169 (48.4)*
Reuters	391 (31.5)	37 (24.2)	*151 (32.3)*	*64 (33.9)*	*89 (31.7)*	49 (33.3)	272 (30.4)	*119 (34.1)*
The Hill	273 (22.0)	*37 (24.2)*	*129 (27.6)*	*44 (23.3)*	43 (15.3)	19 (12.9)	179 (20.0)	*94 (26.9)*
Other	221 (17.8)	20 (13.0)	*96 (20.6)*	*35 (18.5)*	49 (17.4)	20 (13.6)	158 (17.7)	*63 (18.1)*
Social networks								
Facebook	335 (27.0)	335 (27.0)	38 (24.8)	161 (34.5)	62 (32.8)	60 (21.4)	226 (25.3)	*109 (31.2)*
Twitter	290 (23.3)	290 (23.3)	44 (28.8)	140 (30.0)	51 (27.0)	39 (13.9)	189 (21.1)	*101 (28.9)*
Other	115 (9.3)	115 (9.3)	14 (9.2)	58 (12.7)	24 (12.7)	14 (5.0)	73 (8.2)	*42 (12.0)*

[a]Percentages were calculated as the ratio of people who rated the source as trusted to the total sample size.

[b]Percentages for age and race were calculated as the ratio of people who rated the source as trusted to the sample size of each subgroup.

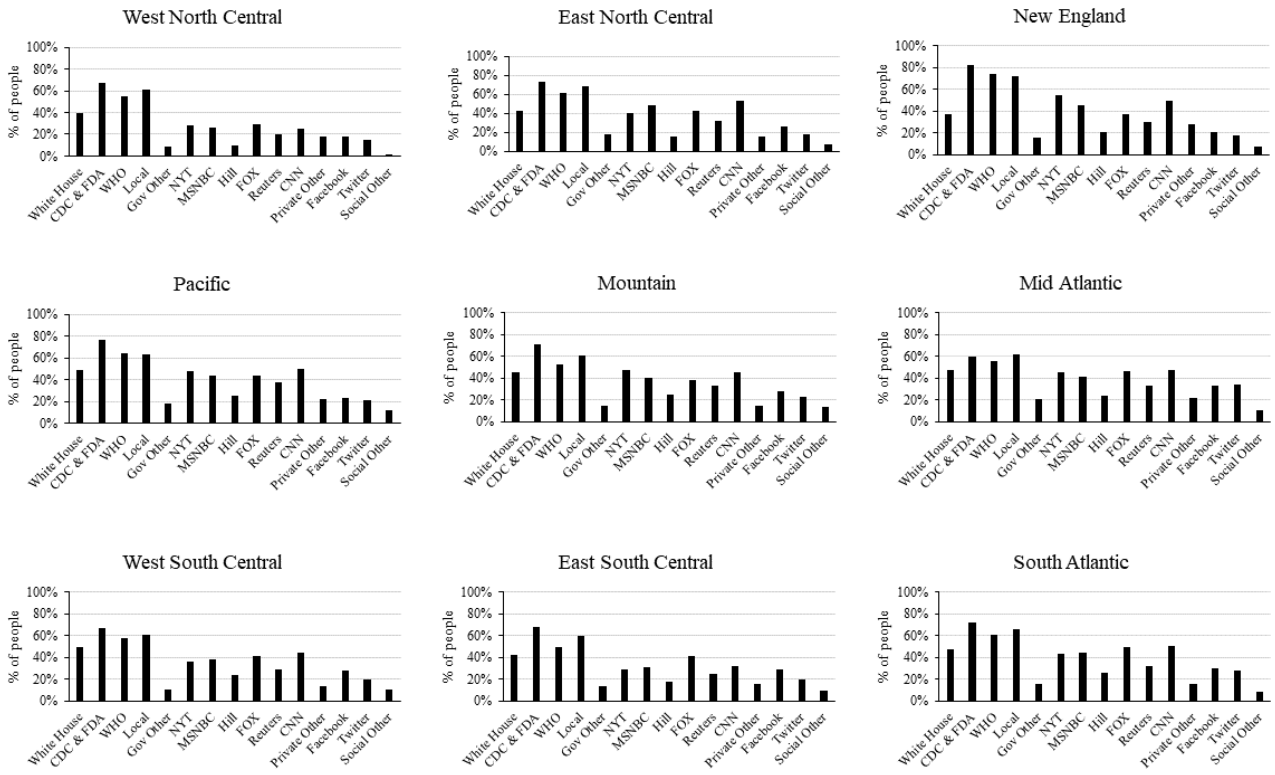
[c]CDC: US Centers for Disease Control and Prevention.

[d]FDA: US Food and Drug Administration.

[e]Italics highlight the subgroups in which the percentages of people who trusted the source were equal to or greater than that of the total sample.

[f]WHO: World Health Organization.

Figure 2. Percentages of participants who trusted in information sources (out of all people in a given region) presented by region and by information source. CDC: US Centers for Disease Control and Prevention; FDA: US Food and Drug Administration; Gov: government; NYT: New York Times; WHO: World Health Organization.



Frequency of Accessing Information About COVID-19

The majority of participants reported following the news about the COVID-19 outbreak "closely" (n=998, 80.3 % strongly agree/agree) and checking updates about the COVID-19 outbreak at least once a day (n = 1054, 84.6%). Table 3 presents the frequencies of access to different sources.

Table 3. Frequency at which participants reported checking information sources to obtain information about COVID-19 by source of information (N=1243), n (%).

Domain and name of the source	Never	Once a week	Several times a week	Daily	Multiple times a day
Government sources					
White House press briefings	342 (27.5)	226 (18.2)	268 (21.6)	321 (25.8)	86 (6.9)
Federal health agencies (CDC[a] and FDA[b])	226 (18.2)	252 (20.3)	341 (27.4)	315 (25.3)	109 (8.8)
International organization (WHO[c])	389 (31.3)	259 (20.8)	257 (20.7)	236 (19.0)	102 (8.2)
State/local health agencies	307 (24.7)	215 (17.3)	285 (22.9)	330 (26.6)	106 (8.5)
Private sources					
FOX News or The Hill	406 (32.7)	173 (13.9)	240 (19.3)	265 (21.3)	159 (12.8)
MSNBC or the *New York Times*	491 (39.5)	168 (13.5)	230 (18.5)	236 (19.0)	118 (9.5)
Reuters or CBS News	418 (33.6)	168 (13.5)	241 (19.4)	302 (24.3)	114 (9.2)
Community/local news	162 (13.0)	180 (14.5)	268 (21.6)	466 (37.5)	167 (13.4)
Social networks					
Facebook	465 (37.4)	133 (10.7)	167 (13.4)	307 (24.7)	171 (13.8)
Twitter	750 (60.3)	92 (7.4)	135 (10.9)	163 (13.1)	103 (8.3)
Podcasts	845 (68.0)	95 (7.6)	128 (10.3)	117 (9.4)	58 (4.7)
Blogs	855 (68.8)	91 (7.3)	112 (9.0)	118 (9.5)	67 (5.4)
Family	284 (22.8)	223 (17.9)	337 (27.1)	275 (22.1)	124 (10.0)

[a]CDC: US Centers for Disease Control and Prevention.

[b]FDA: US Food and Drug Administration.

[c]WHO: World Health Organization.

Knowledge About COVID-19

The mean COVID-19 knowledge score was 85% (SD 17%); this indicates that on average, people responded to 10 out of 12 questions correctly. However, only 306/1243 participants (30.6%) answered all the knowledge questions correctly. Some items were more difficult than others, as represented by the lower percentages of people who answered them correctly (Table 4).

Table 4. Numbers of participants who correctly answered individual items on the scale measuring knowledge about COVID-19 (N=1243), n (%). F: correct answer is false; T: correct answer is true.

Item	Correct responses
The United States is weeks away from having an FDA approved vaccine for coronavirus (F)	753 (60.6)
Antibiotics can be used to treat the coronavirus (F)	878 (70.6)
Most people who are infected with the coronavirus die from it (F)	991 (79.7)
I cannot be infected if I wear a mask (F)	1048 (84.3)
People do not transmit the virus if they don’t have symptoms (F)	1053 (84.7)
Eating garlic can lower your chances of getting infected with the coronavirus (F)	1054 (84.8)
Most people who are infected with the coronavirus recover from it (T)	1070 (86.1)
By limiting the contact I have with people outside my household, I could prevent somebody's death (T)	1128 (90.8)
The main symptoms of the coronavirus are fever and cough (T)	1142 (91.9)
People of all ages can be infected with the coronavirus (T)	1155 (92.9)
People of all racial and ethnic groups can become infected with the coronavirus (T)	1163 (93.6)
To protect myself I need to wash hands frequently (T)	1173 (94.4)

Using correlations, we found a positive association between knowledge and trust in government sources such as the CDC, the FDA, local health departments, and the WHO (Table 5). There was a negative association between accurate knowledge about COVID-19 and participants’ trust in private information sources and social media.

Table 5. Associations of trust in individual information sources with knowledge about COVID-19 and with adherence to social distancing (N=1243).

Domain and name of the source	Total participants who trusted the source, n (%)	Knowledge about COVID-19				Social distancing			
		Trusted source and answered all 12 knowledge questions correctly, n (%)	Did not trust source and answered all 12 knowledge questions correctly, n (%)	Spearman correlation of knowledge and trust, ρ	*P* value	Adhered to social distancing and trusted source, n (%)	Adhered to social distancing but did not trust source, n (%)	Adherence and trust, chi-square (1242)	*P* value
Government sources									
CDC [a] and FDA [b]	*874 (70.3) [c]*	*298 (34.1)*	*82 (22.2)*	*0.18 [d]*	*0.000*	*306 (35.0)*	*91 (24.7)*	*12.77 [d]*	*0.000*
Local health department	792 (63.7)	260 (32.8)	120 (26.6.)	0.10[e]	0.000	275 (34.7)	122 (27.1)	7.78[d]	0.005
WHO[f]	736 (59.2)	242 (32.9)	138 (27.2)	0.08[d]	0.007	255 (34.6)	142 (28.0)	6.09[e]	0.014
White House	569 (45.8)	143 (25.1)	237 (35.1)	–0.12[d]	0.000	178 (31.3)	219 (32.5)	0.21	0.649
Other	196(15.8)	33 (16.8)	347 (33.1)	–0.19[d]	0.000	46 (23.5)	351 (33.5)	7.68[d]	0.006
None	180 (15)	37 (20.6)	343 (32.3)	–0.14[c]	0.000	46 (25.6)	351 (33.0)	3.95[e]	0.047
Private sources									
CNN	577 (46.4)	178 (30.8)	202 (30.3)	–0.04	0.124	182 (31.5)	215 (32.3)	0.08	0.780
FOX	534 (42.9)	124 (23.2)	256 (36.1)	–0.17[d]	0.000	163 (30.5)	234 (33.0)	0.86	0.353
New York Times	523 (42.0)	171 (32.7)	209 (29.0)	–0.04	0.198	171 (32.7)	226 (31.4)	0.24	0.626
MSNBC	515 (41.4)	164 (31.8)	216 (29.7)	–0.05	0.067	171 (33.2)	226 (31.0)	0.65	0.421
Reuters	391 (31.5)	115 (29.4)	265 (31.1)	–0.12[d]	0.000	109 (27.9)	288 (33.8)	4.33[e]	0.037
The Hill	273 (22.0)	51 (18.7)	329 (33.9)	–0.27[d]	0.000	68 (24.9)	329 (33.9)	7.95[d]	0.005
Other	221 (17.8)	51 (23.1)	329 (32.2)	–0.13[d]	0.000	64 (29.0)	333 (32.6)	1.10	0.295
None	293 (24)	76 (25.9)	304 (32.0)	–0.01	0.705	97 (33.1)	300 (31.6)	0.24	0.624
Social networks									
Facebook	335 (27.0)	60 (17.9)	320 (35.2)	–0.29[d]	0.000	87 (26.0)	310 (34.1)	7.52[d]	0.006
Twitter	290 (23.3)	46 (15.9)	334 (35.0)	–0.31[d]	0.000	69 (23.8)	328 (34.4)	11.55[d]	*0.001*
Other	115 (9.3)	15 (13.0)	365 (32.4)	–0.21[d]	0.000	20 (17.4)	337 (33.4)	12.34[d]	*0.000*
None	796 (64)	291 (36.6)	89 (19.9)	0.29[d]	0.000	280 (35.2)	117 (26.2)	10.53[d]	0.001

[a]CDC: US Centers for Disease Control and Prevention.

[b]FDA: US Food and Drug Administration.

[c]Italics illustrate sources that were suggested by elastic net regression to be associated with knowledge and adherence while controlling for trust in all other sources.

[d]Significant at .001.

[e]Significant at .05.

[f]WHO: World Health Organization.

Elastic net regression suggested that seven information sources had the strongest associations with participant knowledge. The standardized regression coefficients illustrated a positive association between knowledge and the CDC/FDA (β=.06), local health department (β=.01), and a negative association with "other" government sources (β=–.01), The Hill (β=–.07), Facebook (β=–.03), Twitter (β=–.06) and other social networks (β=–.02). The model included the following parameters ($RMSE_{training}$=0.14, $RMSE_{test}$ = 0.16, $R^2_{training}$=0.27, R^2_{test}=0.22).

Social Distancing

In total, only 32% of participants reported adhering to all seven recommended social distancing behaviors. The most compliant behavior was avoiding gatherings with 5 or more people. The least compliant behaviors were meeting people face-to-face and

walking close to others. Table 6 shows the participants' reported frequency of engaging in the six negative social distancing behaviors. For the positive social distancing behavior, staying 6 feet from other people, the 1243 participants reported frequencies of always (n=801, 64.4%), usually (n=287, 23.1%), sometimes (n=104, 8.4%), rarely (n=24, 1.9%), and never (n=27, 2.2%). The statistics includes these who did not leave the house in past seven days. Participants were considered adherent if they did not engage in risk-increasing behaviors or always stayed 6 feet apart from other people.

Table 6. Self-reported frequency of social distancing behavior not recommended by the US Centers for Disease Control and Prevention (N=1243), n (%). Note that the statistics include people who did not leave the house for seven days.

Behavior	Social distancing adherence scale				
	Not at all	Once a week	Several times a week	Daily	Several times a day
Went to a gathering with 5 or more people	919 (73.9)	110 (8.8)	83 (6.7)	71 (5.7)	60 (4.8)
Hugged or touched someone who does not live with you	909 (73.1)	103 (8.3)	88 (7.1)	97 (7.8)	46 (3.7)
Went inside someone else's house	854 (68.7)	152 (12.2)	104 (8.4)	84 (6.8)	49 (3.9)
Had friends or family over to visit	841 (67.7)	159 (12.8)	101 (8.1)	88 (7.1)	54 (4.3)
Stood or walked close to someone who does not live with you	678 (54.5)	230 (18.5)	167 (13.4)	97 (7.8)	71 (5.7)
Met face-to-face with people who don't live with you	673 (54.1)	227 (18.3)	171 (13.8)	114 (9.2)	58 (4.7)

The percentage of people who adhered to social distancing behaviors was *higher* among participants who trusted government sources such as the CDC and FDA, local health departments, and the WHO than among those who did not trust these sources (Table 5). In contrast, the percentage of people who adhered to social distancing behaviors was *lower* among participants who trusted some private sources and social networks than among those who did not trust these sources.

Elastic net regression suggested that four variables had the strongest association with participant adherence. Final standardized regression coefficients included positive associations with trust in the CDC and FDA (β=.02) and the local health department (β=.01), and negative associations with trust were observed for Twitter (β=–.02), and "other" social networks (β=–.05). However, the model had low explanatory power when predicting adherence ($AUC_{training}$=63, AUC_{test}=59). We suggested testing a mediation effect to evaluate whether trust in information sources is associated with adherence via increasing knowledge about COVID-19, as reported below.

Exploratory Analysis

We observed that trust in the CDC and FDA was associated with more accurate knowledge about COVID-19 and adherence to all social distancing behaviors (see Table 7 and Figure 1, Model 1). We found that as knowledge increased, so did the participants' likelihood of reporting that they tended to distance from those who did not live in their household. When knowledge was included in the regression model, the predicted relationship between trust and adherence decreased in size, indicating partial mediation (Model 3). The odds ratio (OR) for knowledge in our final model equaled 1.24, meaning that for every additional question answered correctly, we would expect a 24% increase in the odds of adhering to all recommended social distancing behaviors.

Subsequent exploratory analysis showed that health status, income, being under a stay-at-home order, and working from home were not associated with adherence, while age had a significant association with adherence to social distancing guidelines (β=.02; SE .004; P<.001). Including age in the mediation model did not change significance levels reported in the baseline model; the indirect effect remained significant (b=0.13*). The OR for the knowledge variable was 1.21.

Table 7. Results of the mediation analysis of trust in the CDC and FDA (X), knowledge about COVID-19 (M), and adherence to social distancing behaviors (Y). Null prediction for adherence to all social distancing behavior was 32%; reported coefficients are unstandardized.

Model	B	*P* value	SE	Bootstrap 95% CI	R^2 [a]	Odds ratio
Model 1: Adherence (yes/no; binary logistic regression)					0.02	
Constant	–1.12[b]	<.001	0.12	N/A[c]		0.33
Trust in CDC[d] and FDA[e]	0.50[b]	<.001	0.14	N/A		1.65
Model 2: Knowledge (linear regression)					0.03	
Constant	0.80[b]	<.001	0.01	N/A		
Trust in CDC and FDA	0.07[b]	<.001	0.01	N/A		
Model 3: Adherence (yes/no: binary logistic regression)					0.06	
Constant	–3.23[b]	<.001	0.38	N/A		0.04
Trust in CDC and FDA	0.35[f]	.02	0.14	N/A		1.42
Knowledge	2.58[b]	<.001	0.43	N/A		1.24
Indirect effect	0.18[b]	<.001	0.04	0.11-0.27		1.20

[a]For logistic regression models, R^2 is the version proposed by Nagelkerke.

[b]Significant at .001.

[c]N/A: not applicable.

[d]CDC: US Centers for Disease Control and Prevention.

[e]FDA: US Food and Drug Administration.

[f]Significant at .05.

Discussion

Principal Findings

In a cross-sectional survey, we explored which information sources the public trusted with regard to health information and how the trust in specific sources was associated with accurate knowledge about COVID-19 and adherence to recommended social distancing behaviors. We found that the majority of participants trusted government information sources, such as the CDC, FDA, local health departments, and the WHO. Although concerns are increasing about the public's use of social networks to learn about the risks of COVID-19 [26,27], we found that only 36% of people trusted information in social networks. Although not explicitly tested, general trends in our data suggested that trust in information sources varied by age and race. White and older respondents were more likely to trust government sources than non-White and younger respondents, who were more likely to trust private sources and social media. These findings highlight the importance of using different channels to distribute timely health information that reaches diverse populations.

Further, we investigated whether trust in specific information sources was associated with participant knowledge about COVID-19. Trust in government sources (the CDC, the FDA, and local health departments) had a positive association with accurate knowledge about COVID-19, whereas trust in private sources and social networks had a negative association. Consistent with our findings, other studies have shown that private media sources distribute messages that can reduce public trust in scientific knowledge and health policies [28,29]. Several studies have shown that social networks can become a platform for the distribution of misinformation. Kouzy and colleagues [30] manually evaluated tweets at the beginning of the pandemic and identified that 25% of tweets contained misinformation. In addition, another study showed an association between beliefs in conspiracy theories and social media use [31].

We also identified that adherence to social distancing guidelines was positively associated with trust in government information sources and further explored the mechanism behind this association via mediation analysis. We found that knowledge about COVID-19 partially mediated this relationship. Similar relationships between trust, knowledge, and adherence were found in a cross-sectional survey conducted in China [14]. The researchers conducted a path analysis using a structural model approach and found that trust in formal and informal sources increased participants' awareness about SARS-CoV-2; then, in turn, the awareness was associated with social distancing measures. Noteworthily, trust and accurate knowledge explained only a fraction of the variability in adherence to social distancing. For instance, if participants answered 50% of the knowledge questions correctly, the model suggested only a 17% probability of adherence to social distancing behavior if the participants trusted the CDC and FDA. In the same vein, if the participants answered all the knowledge questions correctly, there was still only an approximately 44% probability of adherence to social distancing behaviors. It was surprising that our elastic net regression model, which included trust in all sources, had low predictive power, specifically in regard to predicting adherence to social distancing. However, the model

served well for the main goal of the analysis by distilling the predictive value of the specific sources that contributed the most to knowledge and adherence. Further research should investigate other factors that influence adherence to social distancing, including social, logistic, economic, and political issues.

Our results support several practical recommendations that could help increase knowledge about COVID-19 and improve the adoption of risk-reducing behavior. First, our work showed that trust in information sources was associated with participants' knowledge about COVID-19. Thus, maintaining and increasing trust in information sources is an important task for policy makers. During unprecedented events such as pandemics, health messages might change and, at times, contradict previously reported information and recommendations. For instance, early on in the pandemic, the US Surgeon General communicated that face masks were "NOT effective" [32]. However, the CDC later recommended wearing masks as a mandatory requirement for people who visited public places [33]. To maintain trust in information sources, policy makers should communicate information only when there is a strong scientific consensus. Building relationships with well-established, trusted scientific experts could help in achieving this goal [34]. Furthermore, it is important to acknowledge the uncertainty of delivered information. For instance, at the beginning of April 2020, Dr Anthony Fauci, head of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, said about asymptomatic cases: "It's somewhere between 25 and 50 percent, and trust me, that is an estimate. I don't have any scientific data yet" [35]. It is expected but not yet tested that communicating uncertainty will help individuals be more open about updating their beliefs when more information becomes available.

Second, we noticed that trust in specific sources of information varied among people by age and by ethnic and racial characteristics. Therefore, policy makers should consider communicating information through multiple sources. Establishing and maintaining relationships with journalists and private sources and maintaining organized and updated social media accounts could help ensure that individuals with diverse backgrounds receive critical health messages in a timely fashion. Policy makers could also consider novel approaches toward information distribution, such as crowdsourcing. For instance, YouTube encouraged its viewers to create video clips about activities they were engaging in while staying at home (eg, singing, meditating) and played them as a social advertisement to promote adherence to stay-at-home orders [36]. Although these campaigns are interesting, their effectiveness must be evaluated in future research.

Third, we found negative associations between participants' knowledge and trust in private and social media sources. We believe that this finding supports and echoes other voices calling for improvement of the quality of the information disseminated through these sources. For instance, media platforms can flag unverified information and disrupt automated accounts (bots) that distribute false information [37]. Recently, Twitter added fact-checking links to individual tweets that provide unverified or suspicious information [38]. Additionally, individual users of social networks can receive "accuracy reminders" that encourage them to verify the trustworthiness of their sources. This approach has been shown to be effective in reducing participants' intention to repost COVID-19–related misinformation [39].

The data collection occurred shortly after stay-at-home orders were implemented in the majority of US states, and Americans were constantly receiving updates on the changing policies related to COVID-19. Previous research has shown that the beginning stages of pandemics attract the most attention [40]. This is consistent with our study, as the majority of participants reported checking COVID-19–related updates daily and were motivated to follow the news closely. However, as the pandemic persists, motivation to continue to learn about COVID-19 and risk-reducing actions may decrease [40], posing an additional challenge for policy makers who are trying to inform the public about updated safety measures. Further research should investigate the longitudinal patterns of public interest in health information to better tailor messages and choose information sources to control virus spread.

Limitations

A limitation of the study was that for each individual participant, we treated trust in different sources independently; however, we acknowledge that participants tend to trust several sources rather than a single source exclusively. While elastic net regression accounted for relationships between sources, it would be interesting to explore if trust in different combinations of sources yields better knowledge and adherence. It is also important to note that we did not explore relationships between the frequency of news consumption, trust, and their joined association with knowledge. Focusing our questions on trust in specific sources allowed us to better understand whether participants take the information from a targeted source seriously. However, future research should explore in detail how the frequency of news consumption and trust of sources jointly influence participants' knowledge and adherence. Finally, while we found significant results in the mediation analysis, the casual relationship should be interpreted in light of the fact that the data were collected in a cross-sectional survey [41,42] and that ultimately, the mediation model may have alternative causal explanations. For instance, compliance might be overreported by nonadherent participants who have accurate knowledge about what actions need to be taken (social desirability bias). Further longitudinal or experimental studies should replicate the mediation analysis reported in our work.

Lastly, while our sample demographics closely matched the White, African American, and Asian populations in the US, Hispanic respondents were underrepresented among our participants (18.3% as per US Census vs 7.5% in our data set) [25]. Future research should focus on a more detailed exploration of the associations between trust and knowledge in Hispanic populations.

Conclusions

Distribution of accurate information through trusted sources is essential for facilitating public compliance with necessary health policies. Our work has identified a trend suggesting that trust in information sources varies among people of different ages

and races. We recommend that policy makers use multiple sources to disseminate health information to ensure that different populations receive timely and accurate health information. Public trust in government-affiliated sources was positively associated with knowledge about COVID-19 and adherence to social distancing, whereas public trust in privately affiliated sources and social networks was negatively associated with knowledge and adherence. Private sources and social media must establish policies to control information quality to prevent the spread of misinformation, especially during a state of emergency, when inaccurate knowledge might contribute to public mortality.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Survey questions measuring knowledge about COVID-19 and social distancing behavior.
[DOCX File , 15 KB - publichealth_v6i3e22060_app1.docx]

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Abbreviations

AUC: area under the curve
CDC: US Centers for Disease Control and Prevention
FDA: US Food and Drug Administration
OR: odds ratio
OSF: Open Science Framework
RMSE: root mean square error
WHO: World Health Organization

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Original Paper

Using Open-Source Intelligence to Detect Early Signals of COVID-19 in China: Descriptive Study

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Abstract

Background: The coronavirus disease (COVID-19) outbreak in China was first reported to the World Health Organization (WHO) on December 31, 2019, and the first cases were officially identified around December 8, 2019. Although the origin of COVID-19 has not been confirmed, approximately half of the early cases were linked to a seafood market in Wuhan. However, the first two documented patients did not visit the seafood market. News reports, social media, and informal sources may provide information about outbreaks prior to formal notification.

Objective: The aim of this study was to identify early signals of pneumonia or severe acute respiratory illness (SARI) in China prior to official recognition of the COVID-19 outbreak in December 2019 using open-source data.

Methods: To capture early reports, we searched an open source epidemic observatory, EpiWatch, for SARI or pneumonia-related illnesses in China from October 1, 2019. The searches were conducted using Google and the Chinese search engine Baidu.

Results: There was an increase in reports following the official notification of COVID-19 to the WHO on December 31, 2019, and a report that appeared on December 26, 2019 was retracted. A report of severe pneumonia on November 22, 2019, in Xiangyang was identified, and a potential index patient was retrospectively identified on November 17.

Conclusions: The lack of reports of SARI outbreaks prior to December 31, 2019, with a retracted report on December 26, suggests media censorship, given that formal reports indicate that cases began appearing on December 8. However, the findings also support a relatively recent origin of COVID-19 in November 2019. The case reported on November 22 was transferred to Wuhan approximately one incubation period before the first identified cases on December 8; this case should be further investigated, as only half of the early cases were exposed to the seafood market in Wuhan. Another case of COVID-19 has since been retrospectively identified in Hubei on November 17, 2019, suggesting that the infection was present prior to December.

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KEYWORDS

COVID-19; infectious disease; surveillance; epidemiology; biosecurity

Introduction

Background

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) is a new betacoronavirus that was first reported in Wuhan, China, in December 2019; this virus has caused the worst pandemic of the past 100 years [1-3]. On December 31, 2019, Chinese authorities notified the World Health Organization (WHO) of an outbreak of pneumonia in Wuhan [2]. The WHO declared the coronavirus disease (COVID-19) outbreak to be a public health emergency of international concern on January 30, 2020, and it was declared a pandemic on March 12 [2,4]. It is commonly believed that the outbreak began in early December 2019.

Coronaviruses are a large family of viruses that are found in many different species of animals, including camels, cattle, cats, and bats. Zoonotic coronaviruses that have emerged in humans are Middle Eastern respiratory syndrome coronavirus (MERS-CoV), sudden acute respiratory syndrome coronavirus (SARS-CoV), and now SARS-CoV-2. This is the third time in two decades that a zoonotic coronavirus has emerged from animals to infect humans [4]. Of the betacoronaviruses, SARS-CoV-2 is more closely related to SARS-CoV than to MERS-CoV [5].

The origin of SARS-CoV-2, its intermediary animal host, and the mechanism of its species jump to humans are not known [6,7]. Initially, it was believed that the COVID-19 pandemic originated at the Huanan Seafood Wholesale Market located in Wuhan, China, where farm animals, bats, and snakes were also sold [8]; this is still believed by many people. Approximately half of the initial cases were exposed to the seafood market; however, the first two identified cases did not visit the seafood market [9]. Viral RNA was found in environmental samples from the wet market, such as surfaces [10]. Phylogenetic analysis revealed that the viral RNA found in the environmental samples was very closely related to viruses sampled from the earliest Wuhan patients, suggesting that the market played a role in the early spread of the virus [10]. The source of positive environmental samples from the market is unknown, and animal samples from the market are not available. Therefore, it has not been possible to identify an animal source at the market [10].

On March 2020, however, the timeline of the pandemic was questioned when it was determined that the first person infected with the new disease may have been a Hubei resident who was infected on November 17, 2019 [11]. However, official information states that the first patient presented on December 8, 2019, and that the first exposure may have been around December 1 in the Huanan Seafood Wholesale Market [2]. Local health authorities initially failed to report the coronavirus epidemic, resulting in a delay in reporting it to the WHO until December 31, 2019.

Emerging infectious diseases are becoming increasingly common [12,13]. The world is increasingly interconnected; therefore, it is essential to identify epidemics early [14]. A disease with true epidemic potential can grow exponentially within weeks or months; thus, each day of delay is a lost opportunity for prevention [15]. Rapid prediction, detection, and surveillance of outbreaks are critical in fighting emerging infectious diseases with epidemic potential [12]. The media may have reported a surge of unknown or undiagnosed cases of severe pneumonia, severe acute respiratory illness (SARI), or other related diseases prior to the official reporting of confirmed COVID-19 confirmed cases in China. Epidemic intelligence from open-source, informal data can provide early warnings of public health emergencies [12-14,16,17].

EpiWatch is a curated epidemic observatory that searches media reports, press releases, official reports, and social media for early detection of outbreaks of infectious diseases; it can be tailored for different languages [18]. EpiWatch provides early outbreak alerts and can be used to detect and monitor early reports of potential COVID-19 outbreaks through publicly available sources in settings with poor disease surveillance or censorship of information [19]. Early reports of unknown pneumonia in Hubei Province in China that appeared prior to official reports can be identified using open-source data, providing insight into whether COVID-19 was present in China before December 2019.

Aim

The aim of our study was to use open-source data to identify early signals of pneumonia and SARI in China prior to official recognition of the COVID-19 outbreak in December 2019.

Methods

EpiWatch is an open-source epidemic observatory that was developed at the University of New South Wales as a management web application enhanced by machine learning; it has been used to collect outbreak data since 2016. The principle of EpiWatch is that cases of infectious diseases or outbreaks may be reported in the news or discussed on social media before official notification by health authorities. EpiWatch mines open-source data to detect early signals, which can be customized for common clinical infectious disease syndromes. Many countries have weak or delayed surveillance systems and poor reporting. In other countries, censorship may prevent notification of serious epidemics. Open-source data can be used to help identify epidemic signals in such circumstances.

The system includes three major features. First, reports are gathered from international organizations and news outlets by an intelligent and modular system. An administrator can easily add new sources without requiring further development of the application. The data collected include news reports and social media posts as well as grey literature, such as government reports. If the format in which data is delivered changes for a given source, an administrator can promptly modify the system to adapt to this change. This includes adding or changing the languages used for searching. The system is set up to support a variety of intelligent data gathering elements, such as natural language processing algorithms, regular expression matching, and supervised machine learning algorithms, to process reports and attempt to identify important data points such as outcomes, locations, and diseases mentioned within the gathered data.

Second, EpiWatch reports are reviewed by a team of epidemiologists, ensuring a good level of quality control as well as increased accuracy and relevance. The EpiWatch management system is a web application that enables the internal team to log on and review reports and key data points identified by the automated data gathering system. The team can check the data collected by the automated system and correct any mistakes that are present. A machine learning system learns from this human input and corrections and uses that feedback to improve its ability to group reports and identify key information over time.

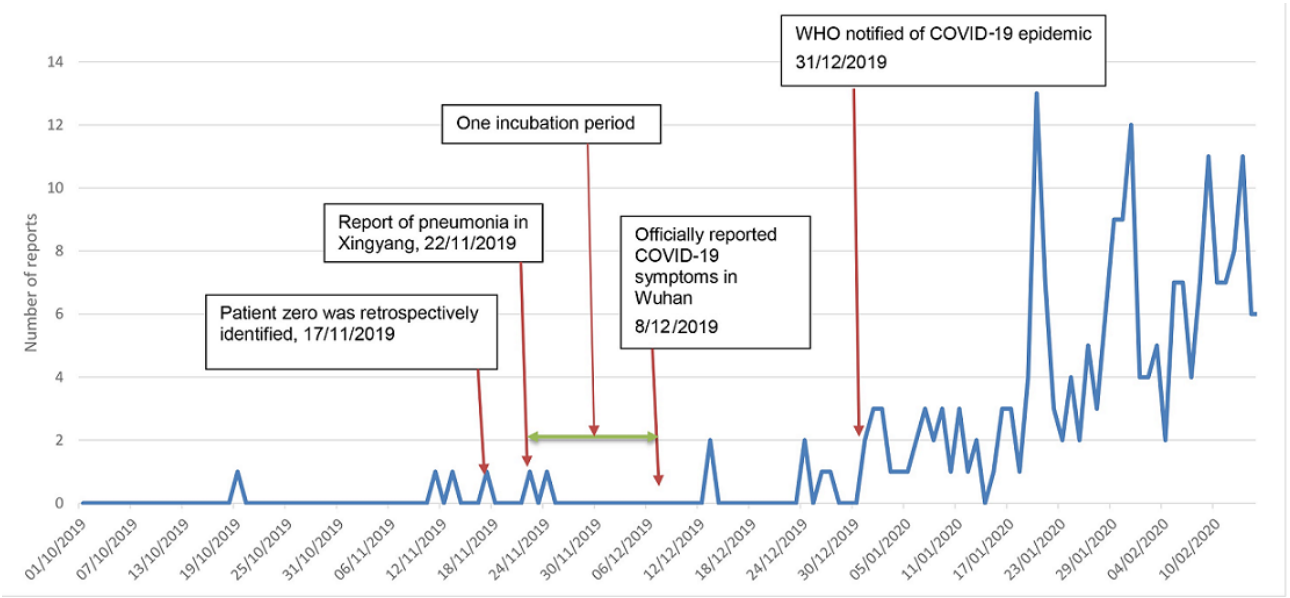
Finally, the EpiWatch management web application consists of two software programs. One is a web application that is built on the Vue framework, and the other is a server-side application built on the NodeJS framework. Both applications are written in JavaScript. The third software program is the data-gathering program, which is also a NodeJS application written in JavaScript. This program is scheduled to run on a regular basis to re-scan sources at intervals chosen by the system administrator. Searches can be tailored for specific languages or regions as well as for specific infectious disease syndromes. The data are stored in a PostgreSQL database. Most of the data is textual in nature and is easily compressed; therefore, the storage requirements are currently very modest (<100 MB). The EpiWatch observatory is managed and funded by the Australian National Health and Medical Research Council (NHMRC) Centre of Research Excellence, Integrated Systems for Epidemic Response (ISER) and is managed by staff at the Biosecurity Program, The Kirby Institute, University of New South Wales Sydney.

To capture early reports of SARI or pneumonia-related illnesses in China, searches were performed in the Chinese language using keywords reflecting severe acute respiratory syndrome or pneumonia as well as Wuhan and China as geolocations. We performed searches from October 1, 2019, to February 14, 2020. Any relevant news reports with the keywords *pneumonia*, *SARI* and related terms, and *coronavirus* were extracted. The information before December 31, 2019 (the date on which the WHO was notified of the COVID-19 outbreak) was reviewed for potential early signals of COVID-19. Google and the Chinese search engine Baidu were used [20,21]. Reports in Chinese were retrieved and reviewed by EK, XC, and MZ and translated to English.

Results

Between October 2019 and February 2020, a total of 218 reports were found and included in the study. There were no duplicates. We identified two potentially relevant news reports prior to December 31, 2019. Figure 1 shows the number of pneumonia and/or SARI reports from October 1, 2019, to February 14, 2020. It shows an increase in reports after the official notification to the WHO on December 31, 2019. A report appeared on December 26, 2019, with the heading “One sample is suspected as novel coronavirus”; this report appears to have been retracted, as the link to the news item has become invalid [22]. We found 11 reports of cases of pneumonia between October 1 and December 31, 2019, including a case identified retrospectively in March 2020, which is believed to be an index case. The number of reports in the same period one year prior was determined for comparison; there were 12 reports in 2018. Of the 11 reports in 2019, 3 (27%) were cases of pneumonia of unknown cause, and 7 (64%) had known causes; 2 reports (18%) were related to pulmonary nodules, 3 (27%) were caused by lung cancer, cerebral infarction, or asthma, and 2 cases (18%) were caused by bacterial infection. The information of interest was the single report of unknown serious pneumonia in November 2019 in Hubei, the province in China where the COVID-19 pandemic arose.

Figure 1. Reports of pneumonia, severe acute respiratory illness, or coronavirus from October 1, 2019, to February 14, 2020. COVID-19: coronavirus disease; WHO: World Health Organization.



On November 22, 2019, a local newspaper, the *Wuhan Evening News*, reported that a patient with severe pneumonia of unknown cause was taken to Wuhan as an emergency transfer by helicopter from Xiangyang in Hubei Province, 325 kilometers

from Wuhan [23]. Figure 2 shows the location of Xiangyang in relation to Wuhan. After November 22, there were no reports of pneumonia in the local media, although it was later confirmed that by December 30, 2019, there were 27 cases of pneumonia of unknown cause in Wuhan.

Figure 2. Location of Xiangyang relative to Wuhan within Hubei Province.

Discussion

The origin of the COVID-19 epidemic is unknown. Only half the initial patients were exposed to the Huanan Seafood Wholesale Market [9], and the first two cases in Wuhan did not visit the market. No pneumonia or SARI signals in Wuhan were identified prior to December 31, which supports the relatively recent emergence of COVID-19. However, open-source intelligence identified a case of severe pneumonia in Xiangyang, Hubei Province, 325 km from Wuhan, who was transferred to Wuhan for treatment on November 21, 2019. This case may be part of an early outbreak cluster. In early March, it was reported that the first case of COVID-19, a different case identified retrospectively, may have been observed on November 17 [24-26]. Approximately one COVID-19 incubation period (2 weeks) [9] after November 17 to November 21, the first formally reported cases in Wuhan became symptomatic (around December 1-8). If no definitive diagnosis was made, further diagnostic investigation of the case from Xiangyang and epidemiological investigation is warranted to determine if this case did have COVID-19. There may be a connection between the Xiangyang patient and an unidentified early cluster of COVID-19.

From December 31, 2019, through January 3, 2020, a total of 44 case patients with pneumonia of unknown etiology were detected by syndromic surveillance by the China Center for Disease Control and Prevention. Exposure to the Huanan Seafood Wholesale Market was initially suspected to be the origin of the virus, and the market was closed on January 1, 2020. At least 35 environmental samples from the seafood section of the Huanan Seafood Market in Wuhan tested positive for the virus [27,28]. However, the first two cases did not report visiting the seafood market, and there is no epidemiological link between the first patient and later cases [5,28]. This, together with the identification of at least two severe pneumonia cases in November (the one identified in this study and the case on November 17, 2019), suggests that the epidemic originated earlier than December 2019.

The absence of news reports in December is curious given that the outbreak appears to have been recognized in early December. It is possible that media reporting was censored; this is supported by what appears to be a retracted news item on December 26. The findings also support the relatively recent origin of COVID-19 in November 2019. The case reported on November 22 was transferred to Wuhan approximately one incubation period before the first cases were reported on December 8. This case should be further investigated, as only half of the early cases were exposed to the Huanan Seafood Market. The Chinese government has been questioned about its failure to identify and report the epidemic early, which resulted in worldwide spread of the disease and led to a pandemic [29]. Surveillance of waste water may also shed light on the origin. A sample of stored waste water in Spain tested positive for SARS-CoV-2 in March 2019, raising questions about whether the infection was present much earlier than December that year [30].

Epidemic diseases grow exponentially and rapidly [31], as seen in China, Europe, and the United States [32]. Early detection and epidemic control can reduce epidemic growth and prevent further spread. Open-source intelligence is a potential tool to aid early detection, especially where formal surveillance data are lacking. Although these data are not validated, once a signal is detected, it can and should be formally investigated, tested, and validated. The use of open-source epidemic intelligence can supplement conventional surveillance to provide early detection of serious emerging epidemics, especially where official disease surveillance reporting is lacking.

Acknowledgments

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Conflicts of Interest

EK works as a research associate at ISER. She receives a salary from ISER (grant number APP1107393).

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Abbreviations

COVID-19: coronavirus disease
ISER: Integrated Systems for Epidemic Response
MERS-CoV: Middle Eastern respiratory syndrome coronavirus
NHMRC: National Health and Medical Research Council
SARI: severe acute respiratory illness
SARS-CoV: severe acute respiratory syndrome coronavirus
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2
WHO: World Health Organization

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Original Paper

Flexible, Freely Available Stochastic Individual Contact Model for Exploring COVID-19 Intervention and Control Strategies: Development and Simulation

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Abstract

Background: Throughout March 2020, leaders in countries across the world were making crucial decisions about how and when to implement public health interventions to combat the coronavirus disease (COVID-19). They urgently needed tools to help them to explore what will work best in their specific circumstances of epidemic size and spread, and feasible intervention scenarios.

Objective: We sought to rapidly develop a flexible, freely available simulation model for use by modelers and researchers to allow investigation of how various public health interventions implemented at various time points might change the shape of the COVID-19 epidemic curve.

Methods: "COVOID" (COVID-19 Open-Source Infection Dynamics) is a stochastic individual contact model (ICM), which extends the ICMs provided by the open-source EpiModel package for the R statistical computing environment. To demonstrate its use and inform urgent decisions on March 30, 2020, we modeled similar intervention scenarios to those reported by other investigators using various model types, as well as novel scenarios. The scenarios involved isolation of cases, moderate social distancing, and stricter population "lockdowns" enacted over varying time periods in a hypothetical population of 100,000 people. On April 30, 2020, we simulated the epidemic curve for the three contiguous local areas (population 287,344) in eastern Sydney, Australia that recorded 5.3% of Australian cases of COVID-19 through to April 30, 2020, under five different intervention scenarios and compared the modeled predictions with the observed epidemic curve for these areas.

Results: COVOID allocates each member of a population to one of seven compartments. The number of times individuals in the various compartments interact with each other and their probability of transmitting infection at each interaction can be varied to simulate the effects of interventions. Using COVOID on March 30, 2020, we were able to replicate the epidemic response patterns to specific social distancing intervention scenarios reported by others. The simulated curve for three local areas of Sydney from March 1 to April 30, 2020, was similar to the observed epidemic curve in terms of peak numbers of cases, total numbers of cases, and duration under a scenario representing the public health measures that were actually enacted, including case isolation and ramp-up of testing and social distancing measures.

Conclusions: COVOID allows rapid modeling of many potential intervention scenarios, can be tailored to diverse settings, and requires only standard computing infrastructure. It replicates the epidemic curves produced by other models that require highly detailed population-level data, and its predicted epidemic curve, using parameters simulating the public health measures that were enacted, was similar in form to that actually observed in Sydney, Australia. Our team and collaborators are currently developing an extended open-source COVOID package comprising of a suite of tools to explore intervention scenarios using several categories of models.

(JMIR Public Health Surveill 2020;6(3):e18965) doi:10.2196/18965

KEYWORDS

COVID-19; epidemic curve; infection dynamics; public health interventions

Introduction

March 2020 was a critical time in the global coronavirus disease (COVID-19) pandemic, when political leaders and policy makers were making crucial decisions that would shape the lives and futures of people and communities. “Flattening the curve” had become a rallying cry in the fight against COVID-19, popularized by media outlets and leaders worldwide. However, the ubiquitous COVID-19 “flattening the curve” infographic [1] can be traced back to a purely conceptual diagram in a 2007 US Centers for Disease Control and Prevention report recommending strategies for pandemic influenza mitigation [2]. It was essential that political leaders and their advisers had ready access to more sophisticated mathematical and computational tools to allow them to explore quickly and iteratively how implementing various public health interventions would potentially change the shape of the COVID-19 epidemic curve in their settings.

Stochastic individual contact models (ICMs), also known as individual-based or agent-based models, are increasingly used for epidemic simulation modeling. These models represent individual units in the population and the contacts between them as discrete events and capture the stochasticity seen in real-world disease outbreaks. Compared with more traditional deterministic compartmental models (DCMs), which are based on systems of differential equations for the movement of the population through discrete states at specified rates, they may produce more realistic results, especially in situations where microepidemics emerge at city and community levels [3].

On March 30, 2020, ICMs for COVID-19 had recently been reported for the United Kingdom, the United States [4], and Australia [5], adapted from existing models for pandemic influenza. These use whole-of-population census data and model contacts between individuals in the population within households, schools, workplaces, and in the wider community. The UK model appears to have been influential in driving a turnaround in the COVID-19 response strategy in that nation [6]. The Australian model highlighted the potential for the virus to spread virtually unchecked unless there were high levels of compliance with social distancing measures [7].

Given the enormous consequences of decisions about public health interventions that were being made at that time, it was highly desirable to independently assess the robustness of these (not yet peer reviewed) ICMs. However, the software code for these models has not been made publicly available, limiting scrutiny of their underlying structure and making it impossible to exactly replicate their findings or test sensitivity to alternative assumptions.

Furthermore, the ICMs reported on March 30, 2020, reflected the circumstances of high-income western nations. Their findings may not be applicable in countries and communities that have substantially different demography, social network structures, education and health systems, workplaces, and community resources. Replicating them rapidly in other settings is challenging because they require the ready availability of detailed population-level data. Furthermore, running them requires access to high-performance computing, which is not feasible in many settings.

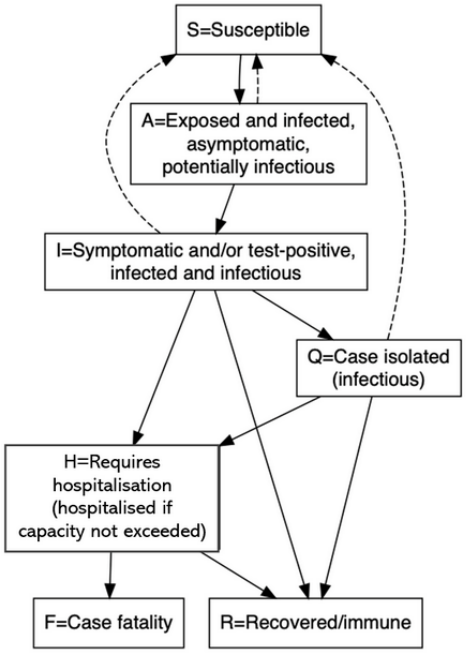
Our objective is to develop a flexible, freely available COVID-19 ICM simulation model for use by modelers and researchers that can be tailored to diverse settings and run using standard desktop or laptop computing hardware. Importantly, given the quickly evolving situation worldwide, we sought to build a model that permitted highly flexible definitions of intervention strategies that more closely reflect the real world, in which epidemic control measures tend to take time to implement, often less completely than hoped, and that cannot be and are not sustained indefinitely.

Methods

Model Building

“COVOID” (COVID-19 Open-Source Infection Dynamics) is a stochastic ICM that we constructed by extending the peer-reviewed [8] open-source EpiModel package [9] for the widely-used, open-source R statistical computing environment (R Foundation for Statistical Computing) [10]. Our model extensions allocate each member of a hypothetical population to one of seven compartments (Figure 1). We have replaced the traditional E (exposed) compartment as used in susceptible-exposed-infectious-recovered (SEIR) models, with an A (infected and asymptomatic) compartment, representing infected, asymptomatic individuals who are nonetheless potentially infectious. Additional compartments, representing symptomatic or individuals who have tested positive in self-isolation (isolated [Q]) and an infected individual that requires hospitalization (H) were also added, as well as a compartment for deaths due to COVID-19 (F) as distinct from deaths due to other causes, which together with emigration are handled by a separate demographic removal process.

Figure 1. Structure of the COVID-19 Open-source Infection Dynamics stochastic individual contact model. The dashed arrows represent interpersonal interactions through which transmission of infection may occur. The solid arrows indicate possible transitions between compartments. COVID-19: coronavirus disease.



At each 1-day time step of the simulation, individuals randomly encounter and are exposed to other individuals in the population. The intensity of this population mixing is controlled by an act rate parameter specific to each of the infectious compartments (A, infected and infectious [I], and Q), with each "act" representing an opportunity for disease transmission or at least those "acts" between susceptible individuals and infectious individuals. Recovered individuals are no longer infectious and are assumed to be immune from further reinfection; thus, their interactions do not result in infections, nor do interactions between pairs of susceptible individuals nor pairs of infectious individuals; only the interactions between susceptible and infectious individuals may give rise to new infections. However, not every such opportunity for disease transmission will result in actual disease transmission. The probability of transmission at each interaction is controlled by an infection probability parameter, also specific to each of the infectious compartments (A, I, and Q).

Thus, the interventions are simulated by varying the act rate parameter (equivalent to social distancing in the population) and the infection probability parameter (equivalent to increased practice of hygiene measures such as hand washing, use of hand sanitizers, not touching one's face, and mask wearing by the infectious). The act rate and infection probability for the isolated compartment (Q) are set to lower levels than for the asymptomatic infected and infectious (A) and symptomatic or test-positive infected and infectious (I) compartments. Other parameters can also be changed, as a function of time (so they can be ramped up and ramped down or pulsed, as required) to simulate public health interventions, such as changes to the rate at which individuals in the symptomatic or test-positive I compartment enter the isolation Q compartment.

Intervention Scenarios Modeled for March 30, 2020

We used COVOID to model intervention scenarios in a hypothetical population of 100,000 people. A baseline case assuming no interventions were established using parameters based on values in the literature. Interventions were then simulated by varying the number of times individuals in the various compartments interact with each other (the act rate for each of the infectious compartments A, I, and Q).

The baseline case assumes 3 symptomatic infected individuals (compartment I) at day 1, plus 4 asymptomatic but infected individuals (compartment A). The initial value for the I compartment was chosen heuristically, and we assumed that 60% of infected individuals were asymptomatic based on the findings in Japanese citizens repatriated from Wuhan, as reported by Mizumoto et al [11], which were the best estimates available at the time. Other parameters were based on those used by Constantino, Heslop, and Macintyre [12], which were in turn based on the best estimates available in the preprint literature at the time. We specified an average of 8.5 interpersonal interactions per day, 5% probability of infection following interactions with symptomatic infectious individuals (I compartment), 2% probability of infection following interactions with asymptomatic infectious individuals (A compartment), and just 3% of symptomatic individuals (I compartment) self-isolate on each day of illness, with subsequently 2.5 personal interactions per day while in self-isolation. Hospital capacity is set at 1148 beds, approximating the Australian average of 3.8 beds per 1000 population [13], and the rate of fatalities in those requiring hospitalization (H compartment) is doubled for the prevalent cases above this capacity limit who require hospitalization.

The parameters for both the initial and subsequent baseline models are shown in Table 1.

Table 1. Parameters used for baseline models.

Parameter	Value	Description	Rationale
Start date	March 1, 2020	Day 1 of simulation	Beginning of sustained community transmission in NSW[a], Australia
Initial S[b] compartment (March 30 models), n	100,000	Susceptible population at day 1	Hypothetical population used for initial March 30, 2020 models
Initial S compartment (April 30 models), n	287,337	Susceptible population at day 1	Population of Waverley, Woolahra, and Randwick local government areas in eastern Sydney [14]
Initial A[c] compartment, n	4	Infected but asymptomatic persons at day 1	Assuming 60% of infected persons are asymptomatic based on Mizumoto et al [11]
Initial I[d] compartment, n	3	Infected but symptomatic or persons who are test-positive at day 1	Number of detected cases in modeled population in 3 weeks prior to start date
Q[e], R[f], H[g], and F[h] compartments, n	0	Other compartments at day 1	Assumed empty at start
Act rate (social contact rate) per day for A and I compartments, n	8.5	Number of social contacts with potential for infection per day per individual	Based on average daily contact rates given in Table 1 of Eames et al
Act rate (social contact rate) per day for Q compartment, n	1.5	As above	Adapted from reduction in transmission for those in isolation or quarantine used by Constantino et al [12]
Infection probability, n	0.05 for I compartment, 0.02 for A and Q compartments	Probability of transmitting infection at each encounter as defined by *act rate*	No published values for COVID-19[i] found in literature, heuristic values based on discussions with subject matter experts
Isolation rate per day, n	0.033	Proportion of symptomatic people putting themselves into self-isolation per day of symptoms, in absence of public health information encouraging then to do so	No values found in literature, heuristic value based on discussions with subject matter experts
Progression rate	Discrete Weibull distribution, mean 5, shape 1.5	Distribution of time in A compartment, equivalent to the incubation time	Adapted from values used by Constantino et al [12]
Hospitalization rate per day, n	0.01	Crude (non–age-specific) proportion of people in I compartment that require hospitalization per day in compartment	Adapted from values used by Constantino et al [12]
Discharge rate per day, n	0.05	Proportion of persons in H compartment who are discharged from needing hospital care each day	Reciprocal of mean length of stay, based on values used by Constantino et al [12]
Recovery rate per day, n	0.05	Proportion recovering each day, based on reciprocal of mean duration of illness of 20 days	Based on value used by Constantino et al [12]
Fatality base rate per day, n	0.02	Proportion of persons in H compartment if number is less than or equal to hospital capacity who die each day	Based on mean death rates used by Constantino et al [12]
Fatality above capacity rate per day, n	0.04	Proportion of persons in H compartment in excess of hospital capacity who die each day	Heuristic value, no relevant COVID-19 data relating to this found in literature

[a]NSW: New South Wales.

[b]S: susceptible.

[c]A: infected and asymptomatic.

[d]I: infected and infectious.

[e]Q: isolated.

[f]R: recovered.

[g]H: requires hospitalization.

[h]F: deaths due to COVID-19.

[i]COVID-19: coronavirus disease.

Chang et al [5] used a highly detailed agent-based model for the entire Australian population, originally developed to investigate influenza transmission, to investigate the effect of 90-day periods of reduced social mixing (social distancing) in which 90%, 80%, and 70% of the population were assumed to be instantaneously compliant, compared to their baseline model.

Using the baseline parameters shown in Table 1, we investigated the same intervention scenarios, as well as 60% and 50% compliance levels, by using weighted means of compliant and noncompliant act rate parameters. The scenarios are listed in Table 2. Because we were simulating in a hypothetical population of only 100,000, resulting in faster spread than would occur in the full Australian population of 25 million, we initiated the social distancing interventions at 15 days, rather than at 45 days as done by Chang et al [5].

Table 2. Scenarios modeled for March 30, 2020.

Scenario	Description
Scenario 01	Starting at day 15 (March 15, 2020), instantaneous imposition of 90% social distancing for 90 days, then instantaneous reversion to baseline social contact rate
Scenario 02	Starting at day 15 (March 15, 2020), instantaneous imposition of 80% social distancing for 90 days, then instantaneous reversion to baseline social contact rate
Scenario 03	Starting at day 15 (March 15, 2020), instantaneous imposition of 70% social distancing for 90 days, then instantaneous reversion to baseline social contact rate
Scenario 04	Starting at day 15 (March 15, 2020), instantaneous imposition of 60% social distancing for 90 days, then instantaneous reversion to baseline social contact rate
Scenario 05	Starting at day 15 (March 15, 2020), instantaneous imposition of 50% social distancing for 90 days, then instantaneous reversion to baseline social contact rate

Comparison of Modeled vs Observed Epidemic Curves in Sydney, Australia for April 30, 2020

The first cases of COVID-19 were reported in Australia on January 24, 2020. The island of Australia has a vast geography and sparse population, and has limited border entry points. The city of Sydney, capital of the state of New South Wales (NSW), is the major entry point for international travelers. As of April 30, 2020, 358 out of 6746 (5.3%) of Australia's recorded locally acquired cases of COVID-19 were among residents of three contiguous local government areas of Sydney: Randwick, Waverley, and Woollahra, with a combined population of 287,344 [14]. As of April 30, 55% of cases in Woollahra, Waverley, and Randwick were locally acquired [14], and they were among 13 "high risk" local government areas in NSW where immediate testing of all symptomatic people was encouraged from April 6, 2020. To compare scenarios modeled using COVOID with observed Australian data from the COVID-19 epidemic, we ran simulations for incident cases in the combined population of these three local areas, where it could be assumed that the population had ample opportunities for mixing and exposure to the virus.

A staged series of public health measures were enacted in Australia from February 1, 2020, summarized as they applied in the state of NSW in Table 3.

Table 3. Coronavirus disease public health measures enacted in the state of New South Wales, Australia, February 1 to April 30, 2020.

Date (2020)	Public health measures enacted
February 1	Borders closed to all nonresidents and non-Australian citizens who had left or transited through Mainland China
March 16	Outdoor events with more than 500 attendees banned
March 17	Self-isolation (14 days) for overseas travelers
March 20	Borders closed to all nonresidents and non-Australian citizens
March 21	Social distancing rule of 4 square meters per person in any enclosed space
March 23	Pubs, clubs, gyms, indoor sporting venues, entertainment venues closed, and food outlets restricted to takeaway or delivery
March 26	Closures extended to include places such as personal services, arcades, brothels, galleries, museums, swimming pools, community facilities, libraries, gambling venues, and markets
March 29	Public gatherings limited to two people; people only to leave their houses for: shopping for essentials, medical or compassionate needs, exercise in compliance with the public gathering restriction, or work or education purposes.
March 30	Mandatory isolation in hotels for travelers
April 28	Gradual easing of restrictions commences

To compare our simulations with observed incidence data, we chose a starting date for our simulations of March 1, 2020, 15 days prior to the gradual ramp-up of social distancing measures in NSW. At that date, 3 cases had been recorded in the three eastern Sydney local government areas used for our model; thus, we initialized the model with 3 persons in the I

compartment. As previously noted, we assumed approximately 60% of infections were asymptomatic and thus also initialized the model with 4 persons in the A compartment. Other parameters were also as per the baseline model previously described.

Using this baseline model for eastern Sydney, we then modeled several scenarios to explore the effect of various intervention strategies on the fit of our baseline model to the observed data. The scenarios are described in Table 4. In particular, scenarios 08 and 10 were intended to mimic the actual interventions that had occurred in Sydney on April 30, 2020.

Table 4. Scenarios modeled for April 30, 2020.

Scenario	Description
Scenario 06	Starting at day 1 (March 1, 2020), linear ramp up of self-isolation rate (per day) from 3.3% to 33% over a 15-day period, then hold at 33% indefinitely
Scenario 07	Isolation rates per scenario 06, plus a moderate increase in social distancing to 50% starting at day 15 (March 15, 2020) by linearly ramping the *act rate* per day down from 8.5 to 4.75 over a 15-day period (through to March 30, 2020), then maintaining social distancing at 50% (*act rate*=4.65) for a further 45 days, then reverting immediately to no social distancing (*act rate*=8.5 per day)
Scenario 08	Isolation rates as per scenario 06, plus a substantial increase in social distancing to 80% starting at day 15 (March 15, 2020) by linearly ramping the *act rate* per day down from 8.5 to 2.5 over a 15-day period (through to March 30, 2020), then maintaining social distancing at 80% (*act rate*=2.5) for a further 30 days, then reverting immediately to 50% social distancing (*act rate*=4.75 per day) on an ongoing basis
Scenario 09	Isolation rates as per scenario 06 plus a substantial increase in social distancing to 80% starting at day 15 (March 15, 2020) by linearly ramping the *act rate* per day down from 8.5 to 2.5 over a 15-day period (through to March 30, 2020), then maintaining social distancing at 80% (*act rate*=2.5) for a further 30 days, then slowly reverting to no social distancing (*act rate*=8.5 per day) over the subsequent 90-day period
Scenario 10	As per scenario 09 but, immediately following the full "lockdown" period between March 30 and April 30, 2020, there is a linear increase of the isolation rate (per day) from 33% to 66% over a 30-day period through to May 28, 2020, with subsequent maintenance of self-isolation with high compliance (66% per day) on an ongoing basis.

We compared the epidemic curves simulated by COVOID with reported data for locally acquired new cases for Randwick, Waverley, and Woollahra for the period March 1, 2020, to April 30, 2020 [15], by examining modeled and observed daily peak and total numbers of incident cases.

Software and Code

COVOID is implemented on top of EpiModel v1.8 [9] running on R version 3.6.1 [10]. The COVOID model is described in more detail in the technical blog of the first author [16], and all the code used for the simulations reported in this paper is available at [17] and [18].

Results

Computing Resources

The twelve simulations reported in this paper were each run eight times and the results averaged, taking approximately 60 minutes to complete when running in parallel on an eight-core Intel central processing unit (CPU). The same set of simulations for a population of 1,000,000 were also run successfully on the same hardware, taking approximately 3 hours and using less than 16GB of RAM, suggesting that run times scale as a low-order power of the population size. Running on 1, 2, 4, or 8 CPU cores resulted in near-linear reductions in total run times, which was expected given that each simulation run is independent. Scaling to use more CPU cores is automatic, and near real time response would be possible on suitably sized cloud computing infrastructure, if required.

Baseline Model

The results of the baseline model simulated for a hypothetical population of 100,000 people, without any public health interventions, is shown in Figure 2. Unsurprisingly, nearly 90% of the population are infected within 2 months, with several thousand projected deaths due to COVID-19 infection. These projections are unrealistic because a complete lack of public health intervention (or equivalent spontaneous behavior modification in the population) has not occurred anywhere, but they serve to show that the baseline model produces the expected results.

An important but rarely reported aspect of simulation models is the distribution of (simulated) persons in each compartment of the model. This provides additional assurance that flows between compartments reflect known or expected distributions of real-life times in various disease states corresponding to the compartments. The distribution of durations in key model compartments for the baseline model are shown in Figure 3.

Figure 2. Baseline simulation with hypothetical 100,000 population. COVID-19: coronavirus disease.

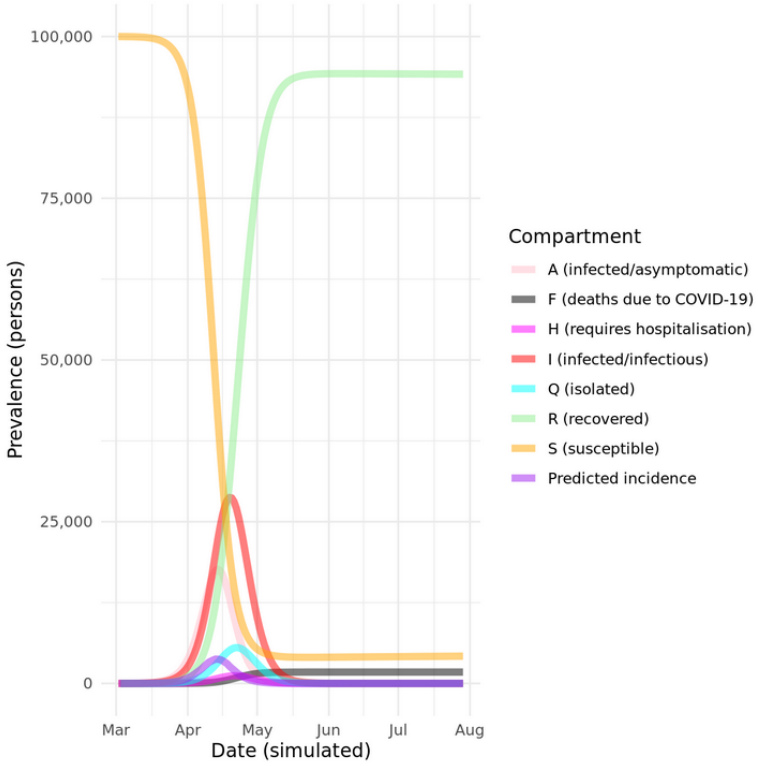
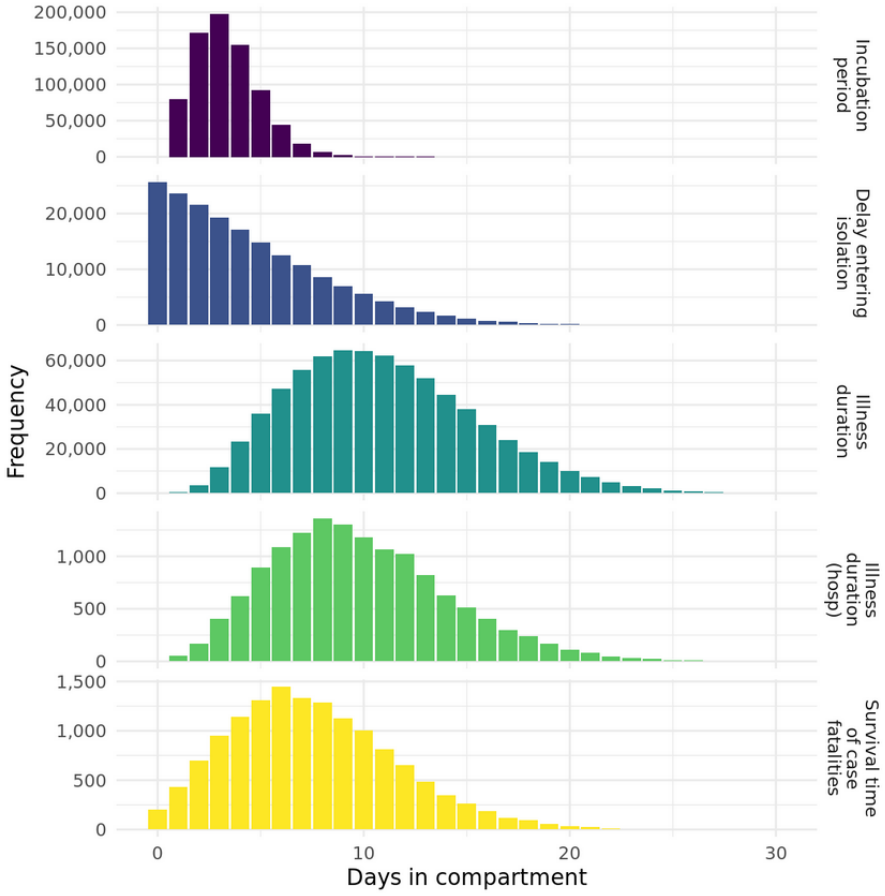


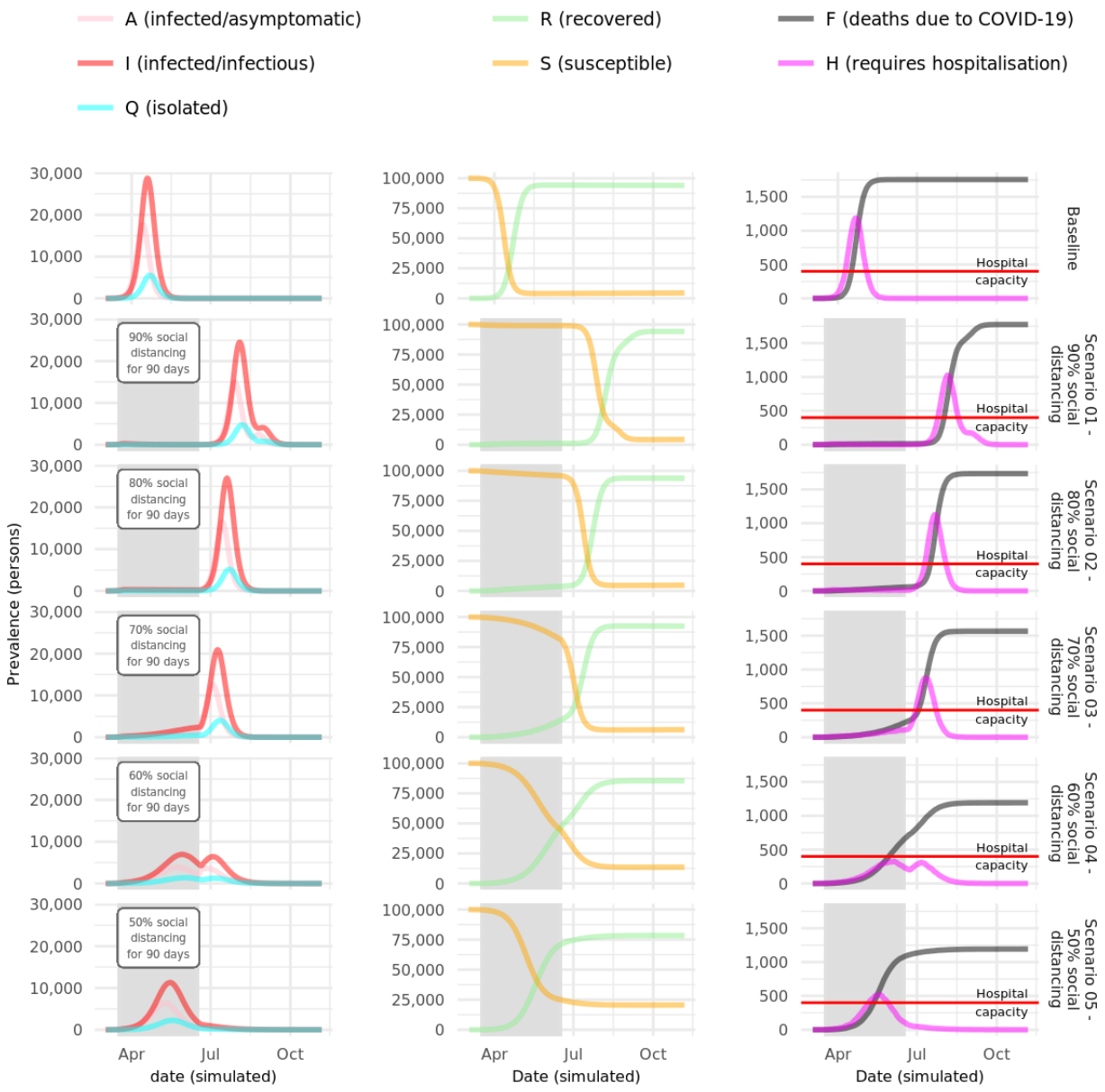
Figure 3. Distributions of time in each compartment in the baseline model. hosp: hospital.



Social Distancing Scenarios With Varying Compliance Modeled for March 30, 2020

The results of COVOID modeling of 90-day periods of social distancing with instantaneous effect and varying levels of compliance, based on interventions modelled by Chang et al [5], are shown in Figure 4. Social distancing with at least 80% compliance completely suppresses the epidemic for the duration of the intervention, while compliance of 70% still substantially reduces cases and deaths. In each of these scenarios, cases rebound dramatically once social distancing is relaxed, demonstrating that ongoing control measures will be required. These findings are similar overall to those reported by Chang et al [5], noting the differences in time frames due to the different population sizes being modeled.

Figure 4. Social distancing scenarios with varying compliance modeled on March 30, 2020. COVID-19: coronavirus disease.



We modeled two additional scenarios of 60% and 50% compliance with social distancing and found that, although these flatten the epidemic curve compared to the baseline scenario, transmission is not halted, and substantial numbers of cases and deaths occur during the intervention period. In the 50% compliance scenario, hospital capacity is overwhelmed during the intervention period. However, sufficient herd immunity is attained in the 50% social distancing scenario to prevent any second wave of infection after social distancing is relaxed at the expense of considerable morbidity and mortality, and an overwhelmed hospital system while social distancing is in place.

Comparison of Modeled Interventions vs Observed Epidemic Curves in Sydney, Australia for April 30, 2020

The results of COVOID modeling of the eastern Sydney population, using the same parameters as the baseline model previously shown, are displayed in Figure 5. Unsurprisingly,

hospital capacity is quickly exceeded, resulting in a large number of deaths as people die without receiving adequate medical care. However, as can be seen in the left panel of Figure 5, in retrospect, this scenario is also completely unrealistic. The results using various scenarios that approximate public health interventions as they occurred in NSW, Australia during March and April 2020 are shown in Figures 6 and 7. The actual, observed incidence of confirmed COVID-19 infections in the same eastern Sydney population is similarly shown in the left two columns in those figures. Under all scenarios, compared to the baseline simulation, the COVID-19 epidemic curve is substantially flattened and "shrunk" due to case-based interventions, specifically isolation and self-isolation of all symptomatic or test-positive cases with moderate alacrity (33% of cases entering isolation each day post–symptom onset or test result). Under none of the modeled intervention scenarios does the number of cases requiring hospitalization overwhelm assumed hospital capacity, but a significant number of deaths nevertheless occur in several of the scenarios.

Scenario 06 demonstrates that moderate compliance with self-isolation, with no increase in social distancing, substantially dampens the epidemic and reduces deaths by 50%. Scenario 07, which adds 1 month of moderate social distancing (at considerable social and economic cost), shows that the epidemic is merely delayed by the social distancing, and the final result is almost identical to the case where no social distancing was attempted.

Scenario 08, in which substantial social distancing, effectively "lockdown" (80% reduction in average contacts), is implemented for 1 month, followed by a relaxation of social distancing to approximately 50% of baseline levels results in only a small initial epidemic, which closely resembles the observed data in both magnitude and duration, with ongoing suppression, but not complete elimination, of cases following the relaxation of the lockdown period.

Scenario 09, which is the same as scenario 08 except that social distancing slowly relaxes all the way back to baseline levels, results in a "second wave," which is much better than the first, but still only one-tenth the size of the no-intervention model epidemic.

Scenario 10 is the same as scenario 09 except that the isolation rate is increased postlockdown to double the level in the other scenarios. This simulates very high testing rates and very efficient case-based interventions. The result is almost complete suppression of any second or subsequent waves, despite social distancing slowly being relaxed to baseline levels.

Figure 5. Eastern Sydney baseline simulation, no interventions. COVID-19: coronavirus disease.

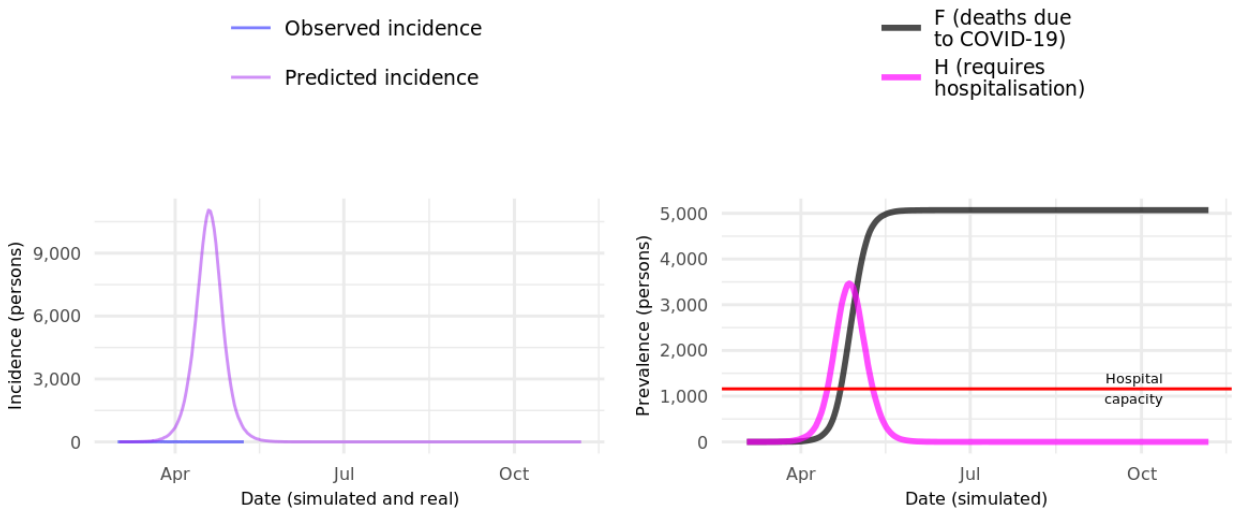


Figure 6. Comparison of modeled vs observed epidemic curves in Sydney, Australia on April 30, 2020. COVID-19: coronavirus disease.

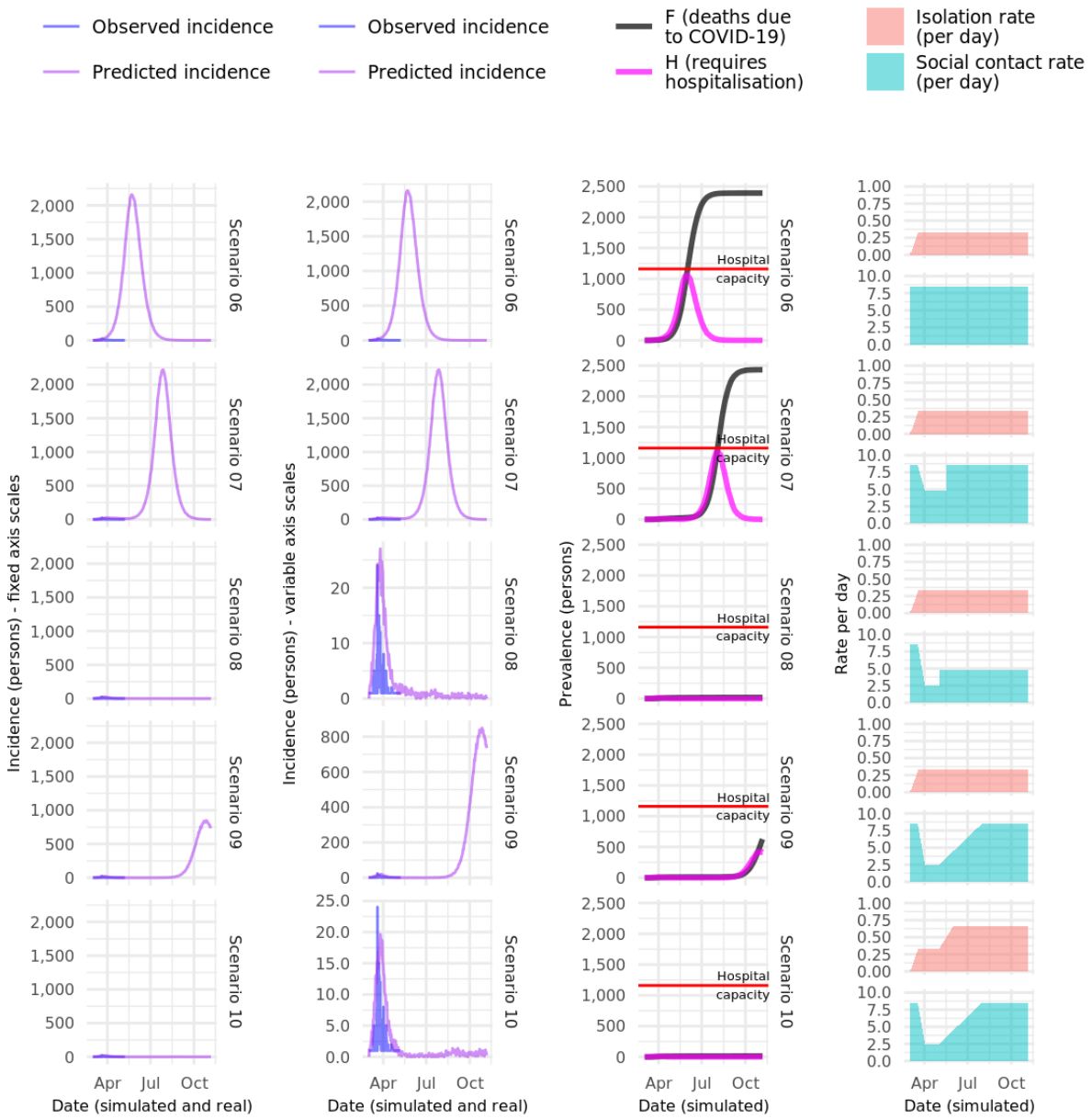
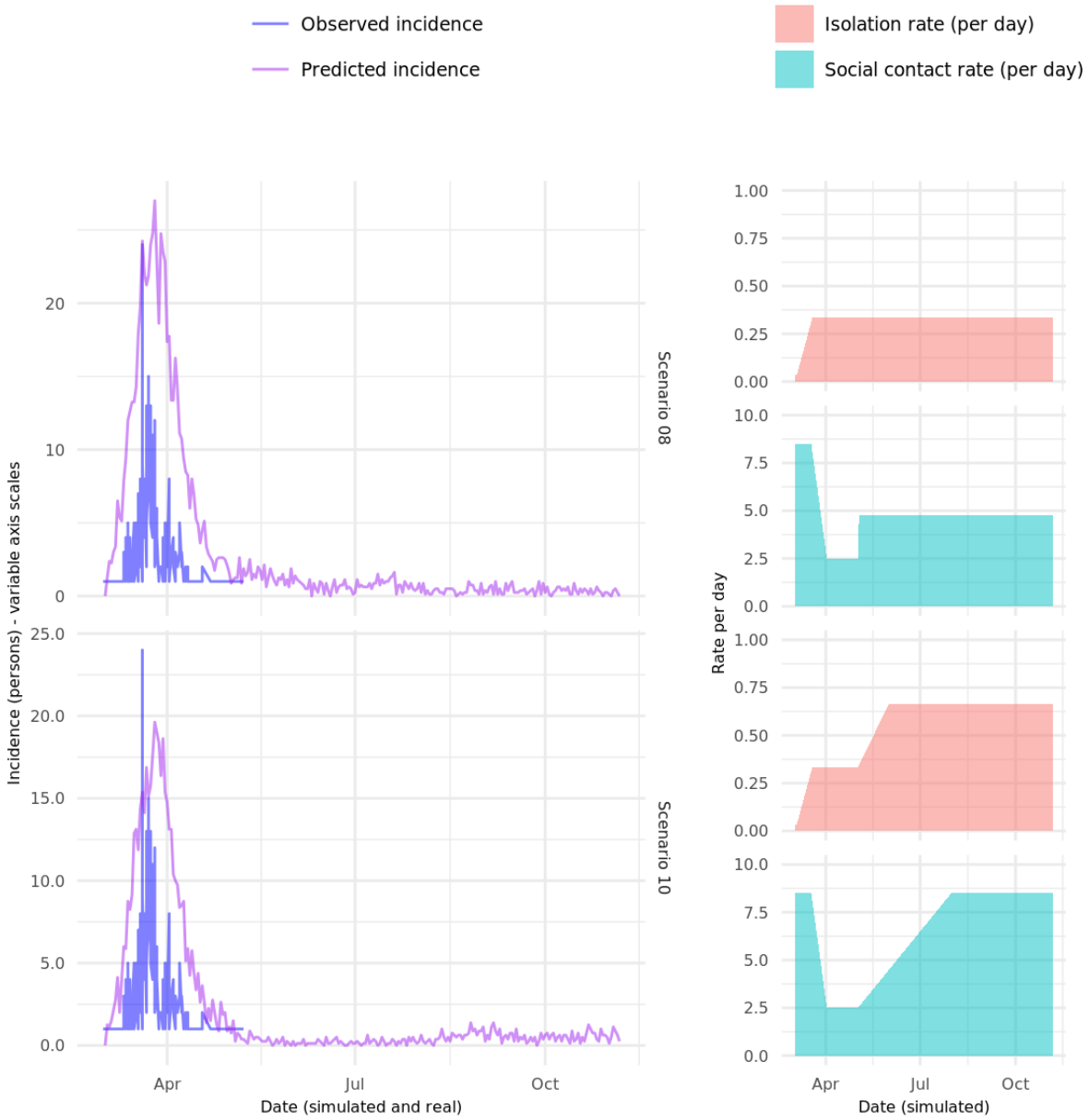


Figure 7. Details for scenarios 08 and 10.



Supplementary Files

The outputs of all the simulations reported here are provided in Multimedia Appendix 1 and 2 in CSV (comma-separated values) format.

Discussion

Principal Results

COVOID allocates each member of its hypothetical population to one of seven compartments. The number of times individuals in the various compartments interact with each other and their probability of transmitting infection at each interaction can be varied to simulate the effects of interventions.

Using COVOID for March 30, 2020, we were able to replicate the epidemic response patterns to specific social distancing intervention scenarios reported by other investigators at that time and to further investigate emergence of herd immunity effects with even lower levels of social distancing. Importantly, we confirmed "second wave" rebound behaviors of the epidemic after the higher levels of social distancing were relaxed, a phenomenon that was not remarked upon in the study that motivated the COVOID model [5].

Using COVOID on April 30, 2020, the simulated incidence for three local areas of Sydney from March 1 to April 30, 2020, was similar to the actual, observed epidemic curve in two of the intervention scenarios that were modeled. These two scenarios (08 and 10) are also arguably closest to the interventions that took place in Sydney during the months of March and April 2020. At the time of writing (early May 2020), these two scenarios also point to possible postlockdown "exit strategy" futures in which social distancing is gradually relaxed over several months, either to intermediate levels compared to pre–COVID-19, or completely but, in the latter case, allied with

greater expanded testing to detect cases as early as possible, and extremely efficient and swift isolation of cases and associated contact tracing and quarantining. At this stage, both Australian and NSW governments appear to be contemplating a path similar to scenario 10 and have invested heavily in both testing capacity and case-based intervention capacity, including deployment of a smartphone contact tracing "app" nationwide [19].

Limitations

COVOID was developed quickly in a rapidly evolving environment in terms of our understanding of the infection dynamics of COVID-19, and thus, several key parameters had to be informed by expert opinion from colleagues and other heuristics. In addition, we could not test the effects of closures of schools or universities because COVOID is a global mixing model that does not reflect mixing in specific settings such as schools or workplaces.

The absence of age-specific parameters is another key limitation of the current model; although, in the absence of detailed data on age differences in COVID-19 disease progression, with the exception of death rates, the added complication of age-specificity may not add much. Future versions of COVOID, which will leverage the POLYMOD age-specific contact matrices [20], will use age as an attribute of each person in the simulation.

Agent-based models are notoriously computationally intensive, and the COVOID model is no exception, although it does take advantage of parallel computation available on almost all computers these days. However, computational burden means that it is impractical to simulate very large populations; although, the model was successfully trialed with populations of 1 million. Further work is underway to improve the processing efficiency by rewriting critical sections of the R code as C++.

It is beyond the scope of this paper to undertake a comprehensive comparison of agent-based computational models with the more commonly used continuous- or discrete-time mathematical models implemented as systems of ordinary differential equations (ODE). However, it is well recognized that the systems of equations needed by mathematical models that seek to simulate different, potentially conditional or contingent, behaviors in subgroups can quickly become unwieldy and difficult to define. Adding stochastic behavior, which may be particularly important for modeling "exit strategies" where small numbers of incident cases may (or may not) establish new transmission chains, is an additional task with ODE models, whereas it is intrinsic in most computational models.

Due to time constraints in the rapidly evolving situation in March 2020, the initial COVOID model was released as a set of R scripts rather than as a software package with detailed documentation or simple user interface, and hence, its potential user base was limited to modelers and researchers with relevant technical expertise. Our team and collaborators are currently developing an extended open-source COVOID package for R comprising of a suite of tools to explore intervention scenarios using several categories of models.

Comparison With Prior Work

In our initial simulations for March 30, 2020, we explicitly sought to test the simulations produced by COVOID with those reported by Chang et al [5] based on a highly detailed agent-based models for the entire Australian population. Our findings regarding social distancing interventions with varying degrees of compliance are very similar to theirs [5] and broadly consistent with those for social distancing interventions produced by the UK Imperial College agent-based model [4]. Importantly, COVOID and the other agent-based models all highlight the potential for resurgence of cases once social distancing measures are relaxed. This indicates that these measures may "buy time" in which to put in place comprehensive measures for testing, case finding, isolation, and quarantine, rather than being sufficient in themselves to halt the epidemic.

It is encouraging that results produced by COVOID are similar to those so far reported from the more complex agent-based models that require highly detailed population data and high-performance computing.

As of April 30, 2020, we could locate only one other study that compared modeled predictions with observed data for COVID-19 incidence for a specific population. Turk et al [21] compared the DCM susceptible-infected-removed model predictions to observed prevalence data for North Carolina and the United States, and used EpiModel to simulate interventions by altering the probability of infection. They reported that a model incorporating parameters that simulated a stay-at-home intervention increasingly produced a better fit to the observed data as the epidemic progressed and emphasized the value of flexible, continuously iterated models for informing local responses.

Conclusions

COVOID allows rapid modeling of many potential intervention scenarios, can be tailored to diverse settings, and requires only standard computing infrastructure. It replicates the epidemic response patterns produced by other models that require highly detailed population-level data, and its predicted epidemic curve was similar in form to that observed in Sydney, Australia. In answer to the call for transparency and reproducibility in COVID-19 models [22], it is freely available as a tool to support public health decision makers in the current COVID-19 crisis. Our team and collaborators are currently developing an extended open-source COVOID package comprising of a suite of tools to explore intervention scenarios using several categories of models.

Acknowledgments

TC conceived the idea of COVOID and wrote all the code. Both authors participated in the design and implementation of the intervention scenarios and visualizations, and drafted the article. Both authors approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Model outputs for baseline and scenarios 01-05.
[ZIP File (Zip Archive), 73 KB - publichealth_v6i3e18965_app1.zip]

Multimedia Appendix 2
Model outputs for baseline and scenarios 06-10.
[ZIP File (Zip Archive), 65 KB - publichealth_v6i3e18965_app2.zip]

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Abbreviations

A: infected and asymptomatic
COVID-19: coronavirus disease
COVOID: COVID-19 Open-Source Infection Dynamics
CPU: central processing unit
CSV: comma-separated values
DCM: deterministic compartmental model
E: exposed
F: deaths due to COVID-19
H: requires hospitalization
I: infected and infectious
ICM: individual contact model
ODE: ordinary differential equations
NSW: New South Wales
Q: isolated
SEIR: susceptible-exposed-infectious-recovered

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Original Paper

Global Changes and Factors of Increase in Caloric/Salty Food Intake, Screen Use, and Substance Use During the Early COVID-19 Containment Phase in the General Population in France: Survey Study

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Related Article:

This is a corrected version. See correction statement: https://publichealth.jmir.org/2021/7/e31906

Abstract

Background: The international outbreak of coronavirus disease (COVID-19) has led many countries to enforce drastic containment measures. It has been suggested that this abrupt lockdown of populations will foster addiction-related habits such as caloric/salty food intake, screen use, and substance use.

Objective: Our aim was to assess the global changes and factors of increase in addiction-related habits during the early COVID-19 containment phase in France.

Methods: A web-based survey was provided from day 8 to day 13 of the containment and was completed by 11,391 participants. The questions explored sociodemographic features, psychiatric/addiction history, material conditions of lockdown, general stress, mental well-being, and reported changes in several addiction-related behaviors. Global changes were described and factors of increase were explored using population-weighted and adjusted logistic regression models, providing adjusted odds ratios (aORs) and their 95% confidence intervals.

Results: Overall, the respondents reported more increases in addiction-related habits than decreases, specifically 28.4% (caloric/salty food intake), 64.6% (screen use), 35.6% (tobacco use), 24.8% (alcohol use), and 31.2% (cannabis use). Reduced well-being scores and increased stress scores were general factors of increase in addiction-related habits (P<.001 for all habits). Factors of increase in caloric/salty food intake (n=10,771) were female gender (aOR 1.62, 95% CI 1.48-1.77), age less than 29 years (P<.001), having a partner (aOR 1.19, 95% CI 1.06-1.35), being locked down in a more confined space (per 1 square meter/person decrease: aOR 1.02, 95% CI 1.01-1.03), being locked down alone (aOR 1.29, 95% CI 1.11-1.49), and reporting current (aOR 1.94, 95% CI 1.62-2.31) or past (aOR 1.27, 95% CI 1.09-1.47) psychiatric treatment. Factors of increase in screen use (n=11,267) were female gender (aOR 1.31, 95% CI 1.21-1.43), age less than 29 years (P<.001), having no partner (aOR 1.18,

95% CI 1.06-1.32), being employed (*P*<.001), intermediate/high education level (*P*<.001), being locked down with no access to an outdoor space (aOR 1.16, 95% CI 1.05-1.29), being locked down alone (aOR 1.15, 95% CI 1.01-1.32), living in an urban environment (*P*<.01), and not working (*P*<.001). Factors of increase in tobacco use (n=2787) were female gender (aOR 1.31, 95% CI 1.11-1.55), having no partner (aOR 1.30, 95% CI 1.06-1.59), intermediate/low education level (*P*<.01), and still working in the workplace (aOR 1.47, 95% CI 1.17-1.86). Factors of increase in alcohol use (n=7108) were age 30-49 years (*P*<.05), a high level of education (*P*<.001), and current psychiatric treatment (aOR 1.44, 95% CI 1.10-1.88). The only significant factor of increase in cannabis use (n=620) was intermediate/low level of education (*P*<.001).

Conclusions: The early phase of COVID-19 containment in France led to widespread increases in addiction-related habits in the general population. Reduced well-being and increased stress were universal factors of increase. More specific factors were associated with increases in each of the explored habits.

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KEYWORDS

COVID-19; containment; eating behaviors; screen use; internet use; substance use; public health; mental health; pandemic; lifestyle; online survey; addiction

Introduction

In March 2020, the outbreak of coronavirus disease (COVID-19) led the national authorities of most countries worldwide to implement extraordinary measures that dramatically restricted the mobility and social interactions of their populations with the aim of limiting transmission of the virus [1]. In this respect, many countries, including Italy, France, and Spain, decided to establish total or at least very strict lockdown. In France, this containment was announced by the President on March 16, and it went into effect at noon ECT on March 17, 2020 [2]. Only activities deemed “essential” were maintained; these included some medical activities but also activities related to the food supply, including access to alcohol as well as to tobacco and electronic cigarette shops. In France, as in other countries, due to this unprecedented situation, a large majority of the population became locked down at home overnight.

These containment measures, as well as the abrupt international health and economic crises caused by COVID-19, may have caused substantial stress in the population and thus may have significantly impacted people’s general health and, more specifically, their mental well-being. Previous situations of reduced well-being and impaired social environment have been found to be associated with overeating and being overweight as well as increased substance and screen use [3-5]. In this context, it has been suggested that at-risk behaviors that are in the spectrum of addiction are likely to be exacerbated by the COVID-19 outbreak and the related containment but that this should be confirmed by studies [6].

The LockUwell study is a nationwide web-based survey aiming to assess the overall effects of the official containment on the French general population with respect to mental well-being and general health conditions, including eating habits as well as screen and substance use. In this study, we describe the containment-related changes in the respondents’ daily habits of eating, screen use, and substance use, and we explore the main characteristics of the participants who reported the most substantial changes.

Methods

Type of Study

An open web-based survey was launched on March 25, 2020, that is, 8 days after the official implementation of the containment in France.

The reporting of the survey follows the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) [7]. The completed checklist can be found in Multimedia Appendix 1.

Recruitment

Any French-speaking person older than 16 years was invited to participate in the survey without restriction criteria provided they could complete the questionnaire autonomously. The link leading to the online survey was disseminated on the internet using social media (ie, Twitter, LinkedIn, and Facebook) and national media. The recruitment strategy thus followed a convenience sampling method. To prevent individuals from completing the questionnaire multiple times, only one questionnaire could be submitted from a particular IP address.

Questionnaire

The English version of the full questionnaire is available in Multimedia Appendix 2. There was no preliminary assessment of the test-retest reliability or the internal consistency of the questionnaire; however, several tools included in it were previously validated in international studies.

The survey questions aimed to comprise a large range of items related to mental well-being and psychological distress and to collect sociodemographic and environmental data related to the situation of containment, such as total living space or number of persons sharing the house during the containment. The questionnaire was divided in six consecutive sections: 1) sociodemographic features; 2) the French version [8] of the Warwick-Edinburgh Mental Well-Being Scale (WEMWBS), which is a validated scale of 14 items that are rated from 1 to 5, leading to a single total score ranging from 14 (ie, minimum possible well-being) to 70 (ie, maximum possible well-being) to measure mental well-being in the general population [9]; 3) overall and specific (eg, professional, health-related, family) levels of stress, using a visual analog scale ranging from 0 (no

stress) to 10 (maximum possible stress) [10]; 4) medical history, in particular the history of psychiatric and addiction treatment; 5) perceptions and apprehensions about COVID-19 and the related official measures; and 6) personal and environmental conditions under which participants were facing the lockdown and their consequences.

In particular, question F-25 explored whether respondents had changed their intake of caloric/salty food, their use of screens, and their use of substances (tobacco, alcohol, cannabis, and other drugs). The response modalities were 1) no usual use; 2) no change in use; 3) decrease with craving/withdrawal; 4) decrease without craving/withdrawal; 5) increase (moderate); and 6) increase (difficult to control).

Data Extraction and Preprocessing

The data were extracted on March 30, 2020, that is, 5 days after the start of the survey. For the present analysis, we included only respondents aged 16 years and older who completed the questionnaire and were living in France at the time when containment was declared. Among the 20,235 participants who started the questionnaire, 11,742 (58.0%) completed it. After excluding inoperable questionnaires and respondents from countries other than France, 11,391/20,235 questionnaires (56.3%) were included in the analyses. A complete flowchart is displayed in Multimedia Appendix 3. Only the responses to questions A-1 to A-7, A-12 to A-14, A-16, B-1, C-1c, D-4b and D-4c, F-6 to F-9, F-17, and F-25 were used in this preliminary investigation.

Statistical Analysis

Statistical analyses were performed using SAS software version 9.4 (SAS Institute). To ensure respondents were representative of French residents aged 16 years and older, the data were weighted to French census targets for age and gender based on distributions reported in 2020 [11]. All descriptive and statistical tests were conducted using weighting variables. The descriptive statistics display categorical variables as the number and percentage of respondents (n, %), while quantitative variables are presented as mean (SD) or median (IQR). We explored caloric/salty food intake, screen use, and tobacco, alcohol, and cannabis use because insufficient data were collected regarding other substances. For each behavior and substance used, the different levels of subjective change (ie, no change, decrease with craving/withdrawal, decrease without craving/withdrawal, moderate increase, or difficult-to-control increase) are displayed.

Increase was expected to be a much more frequent pattern of change than decrease for all behaviors; therefore, we more deeply explored the parameters specifically associated with increase (both types of increase combined) in each type of behavior compared to other modalities of change using weighted logistic regression models. Respondents declaring no usual use were not included in the analyses. For each model, raw odds ratios (ORs) and adjusted odds ratios (aORs) are provided with their 95% confidence intervals. We entered the following variables in the model (each was adjusted with the others in the adjusted analyses): sociodemographic factors (age, gender, family, occupation, and educational level), psychiatric and addiction history, well-being (WEMWBS total score), stress (general stress VAS), housing conditions (surface, outdoor, geographical area) and working conditions during containment as explanatory variables. Multicollinearity was screened using the variance inflation factor and the COLLIN option in SAS.

Results

The raw and weighted descriptive data of the 11,391 participants are shown in Table 1. The weighted sample consisted of 52.1% female respondents with a mean age of 47.47 years (SD 17.28).

The overall changes reported in the daily habits that were explored in the survey are displayed in Figure 1.

Table 1. Descriptive characteristics of the survey population (N=11,391).

Characteristic	Values	
	Unweighted	Weighted
Age (years), mean (SD)		
16-29	3404 (29.88)	2421 (21.26)
30-49	5316 (46.67)	3488 (30.61)
50-64	2043 (17.94)	2651(23.27)
65-74	547 (4.80)	2469 (21.67)
≥75	81 (0.71)	364 (3.20)
Gender, n (%)		
Male	2557 (22.45)	5415 (47.5)
Female	8782 (77.10)	5932 (52.1)
Other	52 (0.46)	52 (0.4)
Marital status, n (%)		
Single, divorced, or widowed	4033 (35.41)	4215 (37)
In a couple	7358 (64.59)	7178 (63)
Employment status, n (%)		
Worker	8032 (70.51)	6486 (56.92)
Job seeker	568 (4.99)	475 (4.17)
Student	1407 (12.35)	987 (8.66)
No employment or retired	1384 (12.15)	3447 (30.25)
Educational level (ISCED[a] 2011), n (%)		
≤3	727 (6.38)	1074 (9.42)
4	1326 (11.64)	1485 (13.03)
5-6	3985 (34.98)	3727 (32.71)
≥6	5353 (46.99)	5108 (44.83)
Psychiatric history, n (%)		
Current	1244 (10.92)	1031 (9.05)
Past	1632 (14.33)	1622 (14.24)
Never	8515 (74.75)	8740 (76.71)
Addiction treatment, n (%)		
Current	78 (0.68)	80 (0.71)
Past	223 (1.96)	286 (2.51)
Never	11090 (97.36)	11026 (96.78)
Access to outdoor space, n (%)		
Yes	6911 (60.67)	7103 (62.34)
No	4480 (39.33)	4291(37.66)
Housing space (square meters/person), median (IQR)	34.67 (25-50)	40.00 (28-60)
Well-being (WEMWBS[b] score), mean (SD)	49.37 (8.12)	50.51 (8.17)
General stress (0-10 VAS[c]), mean (SD)	5.23 (2.35)	4.84 (2.43)
Housing location, n (%)		
Urban	6303 (55.33)	6375 (55.95)
Periurban	2419 (21.24)	2409 (55.95)

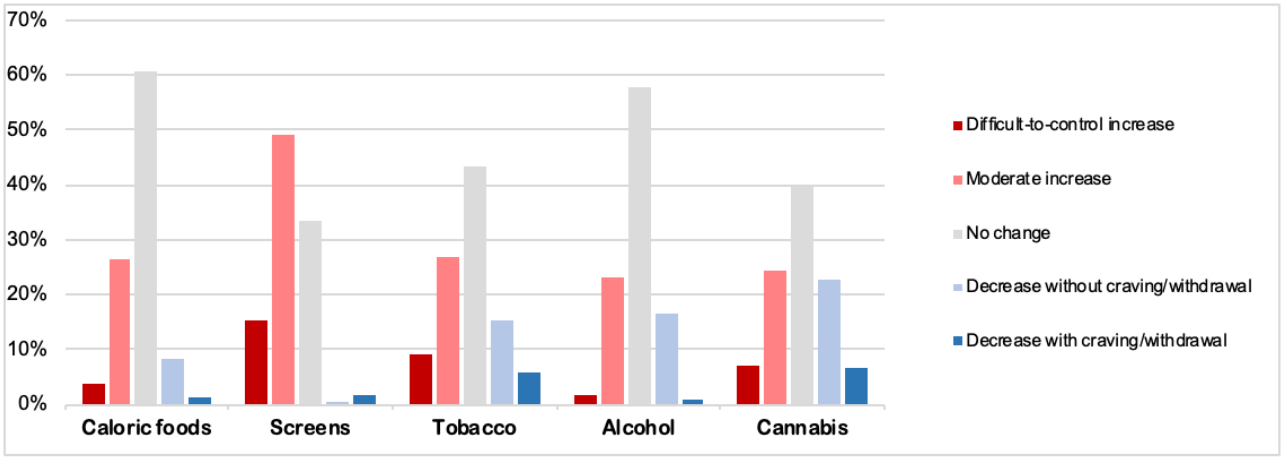
Characteristic	Values	
	Unweighted	Weighted
Rural	2669 (23.43)	2610 (55.95)
People locked down in the household (including the respondent), n (%)		
1	2528 (22.20)	3159 (27.73)
≥2 but <10	8845 (77.66)	8214 (72.10)
Work location during lockdown, n (%)		
In the workplace	2266 (19.89)	1755 (15.41)
Telecommuting	4708 (41.33)	3871 (33.97)
Not working	4417 (41.33)	5768 (50.62)
Change in caloric/salty food intake, n (%)		
No intake	511 (4.49%)	622 (5.50)
No change	5655 (49.64%)	6510 (57.14)
Increase	4125 (36.21%)	3233 (28.38)
Decrease	1100 (9.65%)	1028 (9.02)
Change in screen use, n (%)		
No use	99 (0.87)	127 (1.11%)
No change	3241 (28.45)	3785 (33.22)
Increase	7843 (68.85)	7274 (63.84)
Decrease	208 (1.82)	208 (1.82)
Change in tobacco use, n (%)		
No use	8241 (72.35)	8607 (75.55)
No change	1218 (10.69)	1208 (10.55)
Increase	1279 (11.23)	995 (8.74)
Decrease	653 (5.74)	589 (5.17)
Change in alcohol use, n (%)		
No use	4292 (37.68)	4285 (37.62)
No change	3708 (32.55)	4109 (36.07)
Increase	2023 (17.76)	1761 (15.46)
Decrease	1368 (12.0)	1237 (10.86)
Change in cannabis use, n (%)		
No use	10697 (93.91)	10724 (94.12)
No change	264 (2.32)	263 (2.31)
Increase	233 (2.05)	210 (1.84)
Decrease	197 (1.73)	195 (1.73)

[a]ISCED: International Standard Classification of Education.

[b]WEMWBS: Warwick-Edinburgh Mental Well-Being Scale.

[c]VAS: visual analog scale.

Figure 1. Changes in addiction-related habits in the early phase of COVID-19 containment in France from March 17 to 31, 2020.



Regarding eating patterns, 6510/11,391 (57.14%) participants reported that they did not increase or decrease their average daily intake of caloric/salty food, whereas 2836 (24.89%) moderately increased their intake, 397 (3.49%) increased their intake in a difficult-to-control manner, 874 (7.67%) reduced their intake without craving, and 154 (1.35%) reduced their intake with craving.

With respect to screen use, 124/11,391 (1.09%) respondents declared that they did not usually use screens. Among the 11,267 remaining participants, 3784 (33.59%) reported that they did not change their average daily screen use, whereas 5545 (49.22%) declared having moderately increased their screen use, 1729 (15.35%) increased their screen use in a difficult-to-control manner, 179 (1.59%) reduced or stopped their screen use without craving/withdrawal, and 29 (0.26%) reduced their screen use with craving/withdrawal.

Concerning tobacco use, 2787/11,391 (24.47%) respondents reported that they were current smokers. Among the 2787 smokers, 1208 (43.27%) reported that they did not change their average daily use of tobacco, whereas 746 (26.72%) declared having moderately increased their tobacco use, 249 (8.92%) increased their tobacco use in a difficult-to-control manner, 432 (15.47%) declared that they reduced or stopped their tobacco use without craving/withdrawal, and 157 (5.62%) reduced their tobacco use with craving/withdrawal. Regarding alcohol use, 7108/11,391 (62.40%) respondents were found to use alcohol more or less regularly. Among them, 4109/7108 (57.82%) reported that they had not changed their average daily use of alcohol, whereas 1654 (23.27%) moderately increased their alcohol use, 107 (1.50%) increased their alcohol use in a difficult-to-control manner, 1167 (16.4%) declared having reduced or stopped without craving/withdrawal, and 70 (0.98%) having reduced with craving/withdrawal.

Finally, regarding cannabis use, 620/11,391 (5.44%) participants reported using cannabis. Among the, 263/620 (39.49%) reported that they had not changed their average daily use of cannabis, whereas 162 (24.32%) declared having moderately increased their cannabis use, 46 (6.91%) increased their cannabis use in a difficult-to-control manner, 150 (22.52%) reduced or stopped their cannabis use without craving/withdrawal, and 45 (6.76%) reduced their cannabis use with craving/withdrawal.

Raw and adjusted analyses of the factors associated with the increase in each of the explored habits can be found in Table 2 and Table 3, respectively.

Table 2. Results of the unadjusted analyses exploring the increases in caloric/salty food, screen use, and substance use in the early phase of COVID-19 containment in France among the general population.

Characteristic	Caloric/salty food intake (n=10,771; 3233 increase vs 7538 no increase)		Screen use (n=11,267; 7274 increase vs 3993 no increase)		Tobacco use (n=2787; 996 increase vs 1791 no increase)		Alcohol use (n=7108; 1761 increase vs 5347 no increase)		Cannabis use (n=666; 208 increase vs 458 no increase)	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Gender										
Male	Reference	N/A[b]	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Female	1.59 (1.46-1.73)	<.001	1.33 (1.23-1.44)	<.001	1.36 (1.16-1.59)	<.001	1.13 (1.12-1.26)	.02	1.01 (0.71-1.44)	.96
Other	2.08 (1.17-3.68)	.01	1.57 (0.86-2.87)	.14	1.26 (0.46-3.50)	.67	0.53 (0.19-1.54)	.25	0.63 (0.13-3.05)	.57
Age (years)										
16-29	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
30-49	0.85 (0.77-0.95)	<.001	0.61 (0.54-0.69)	<.001	0.89 (0.73-1.08)	.25	1.33 (1.16-1.53)	<.001	0.90 (0.63-1.28)	.53
50-64	0.50 (0.44-0.56)	<.001	0.50 (0.45-0.57)	<.001	0.71 (0.57-0.89)	.003	0.79 (0.67-0.93)	.005	0.36 (0.21-0.62)[c]	<.001
≥65	0.28 (0.23-0.31)	<.001	0.40 (0.35-0.45)	<.001	0.22 (0.16-0.31)	<.001	0.49 (0.41-0.59)	<.001	N/A	
In a couple										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No	1.00 (0.92-1.09)	.98	1.44 (1.32-1.56)	<.001	1.27 (1.09-1.49)	.003	0.87 (0.77-0.97)	.01	1.33 (0.96-1.85)	.09
Professional situation										
Worker	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Student	1.25 (1.09-1.44)	.002	1.74 (1.49-2.04)	<.001	0.83 (0.64-1.09)	.174	0.73 (0.59-0.89)	<.001	0.80 (0.51-1.26)	<.001
Job seeker	0.94 (0.76-1.15)	.53	1.14 (0.93-1.39)	.21	0.81 (0.60-1.11)	.193	1.06 (0.82-1.36)	.69	1.02 (0.57-1.81)	.95
Not employed or retired	0.41 (0.37-0.45)	<.001	0.65 (0.60-0.71)	<.001	0.38 (0.30-0.48)	<.001	0.47 (0.41-0.54)	<.001	0.25 (0.12-0.52)	<.001
Educational level (ISCED[d] 2011)										
3	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
≥6	0.96 (0.84-1.09)	.55	0.91 (0.80-1.02)	.11	0.70 (0.55-0.89)	.004	1.58 (1.30-1.91)	<.001	0.46 (0.29-0.73)	<.001
4-5	1.05 (0.92-1.20)	.45	0.96 (0.84-1.09)	.51	0.68 (0.54-0.87)	.002	1.34 (1.10-1.64)	.004	0.47 (0.29-0.74)	<.001
1-2	0.64 (0.53-0.78)	<.001	0.55 (0.47-0.65)	<.001	0.67 (0.48-0.70)	.01	1.64 (0.80-1.42)	.69	0.48 (0.25-0.92)	.03
Access to outdoor space										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No	1.17 (1.07-1.27)	<.001	1.50 (1.38-1.63)	<.001	1.17 (1.01-1.37)	.043	1.04 (0.93-1.16)	.56	1.64 (1.17-2.29)	.004
Well-being (WEMWBS[e] score)										
Per 1-point increase	0.96 (0.95-0.96)	<.001	0.96 (0.96-0.96)	<.001	0.96 (0.95-0.97)	<.001	0.96 (0.96-0.97)	<.001	0.96 (0.94-0.98)	<.001
General stress (0-10 VAS[f])										

Characteristic	Caloric/salty food intake (n=10,771; 3233 increase vs 7538 no increase)		Screen use (n=11,267; 7274 increase vs 3993 no increase)		Tobacco use (n=2787; 996 increase vs 1791 no increase)		Alcohol use (n=7108; 1761 increase vs 5347 no increase)		Cannabis use (n=666; 208 increase vs 458 no increase)	
	OR[a] (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value	OR (95% CI)	*P* value
Per 1-point increase	1.15 (1.13-1.17)	<.001	1.12 (1.10-1.14)	<.001	1.14 (1.11-1.18)	<.001	1.12 (1.10-1.15)	<.001	1.09 (1.02-1.16)	.01
Living space										
Per 5 square meters/person increase	0.95 (0.94-0.96)	<.001	0.98 (0.97-0.99)	<.001	0.97 (0.96-0.99)	<.001	0.96 (0.95-0.97)	<.001	0.96 (0.93-1.00)	.64
Confined with other people										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No (alone)	0.92 (0.84-1.01)	.09	0.78 (0.72-0.86)	<.001	1.04 (0.88-1.23)	.69	0.77 (0.68-0.88)	<.001	0.95 (0.66-1.37)	.78
Housing location										
Urban	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Periurban	1.00 (0.90-1.11)	.95	0.75 (0.68-0.83)	<.001	0.85 (0.69-1.05)	.14	1.01 (0.88-1.16)	.86	0.81 (0.50-1.32)	.41
Rural	0.91 (0.82-1.01)	.07	0.71 (0.64-0.78)	<.001	0.88 (0.72-1.06)	.18	0.96 (0.85-1.15)	.57	0.81 (0.51-1.28)	.37
Working conditions										
Telecommuting	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Not working	0.58 (0.51-0.65)	<.001	1.11 (0.99-1.24)		0.48 (0.39-0.59)	<.001	0.68 (0.58-0.79)	<.001	0.69 (0.43-1.11)	.13
Working in the workplace	0.90 (0.80-1.02)	.10	1.23 (1.09-1.38)	<.001	0.66 (0.54-0.83)	<.001	0.99 (0.85-1.15)	.86	0.89 (0.56-1.44)	.66
Psychiatric treatment										
Never	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Past	1.27 (1.09-1.47)	<.001	1.28 (1.11-1.49)	<.001	1.04 (0.79-1.35)	.81	1.10 (0.90-1.34)	.35	1.13 (0.67-1.90)	.66
Current	1.94 (1.62-2.31)	.002	1.32 (1.10-1.59)	.003	1.64 (1.22-2.22)	.001	1.77 (1.39-2.26)	<.001	0.99 (0.52-1.85)	.97
Addiction treatment										
Never	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Past	1.01 (0.77-1.33)	.95	1.00 (0.78-1.28)	.98	1.48 (1.01-2.15)	.04	1.06 (0.73-1.54)	.77	0.82 (0.38-1.80)	.64
Current	1.11 (0.68-1.80)	.69	1.04 (0.66-1.66)	.87	1.15 (0.65-2.03)	.65	1.20 (0.63-2.29)	.58	0.62 (0.17-2.19)	.46

[a]OR: odds ratio.

[b]N/A: not applicable.

[c]Due to power requirements, the age categories of 50-64 years and ≥65 years were pooled in the model exploring cannabis use increase.

[d]ISCED: International Standard Classification of Education.

[e]WEMWBS: Warwick-Edinburgh Mental Well-Being Scale.

[f]VAS: visual analog scale.

Table 3. Results of the adjusted analyses exploring the increase in caloric/salty food, screen use, and substance use in the early phase of COVID-19 containment in France among the general population.

Characteristic	Caloric/salty food intake (n=10,771; 3233 increase vs 7538 no increase)		Screen use (n=11,267; 7274 increase vs 3993 no increase)		Tobacco use (n=2787; 996 increase vs 1791 no increase)		Alcohol use (n=7108; 1761 increase vs 5347 no increase)		Cannabis use (n=666; 208 increase vs 458 no increase)	
	aOR[a] (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value
Gender										
Male	Reference	N/A[b]	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Female	1.62 (1.48-1.77)	<.001	1.31 (1.21-1.43)	<.001	1.31 (1.11-1.55)	.002	1.02 (0.91-1.14)	.76	0.99 (0.67-1.46)	.95
Other	1.17 (0.64-2.14)	.63	0.66 (0.35-1.25)		0.95 (0.32-2.78)	.93	0.26 (0.08-0.89)	.03	0.45 (0.07-2.74)	.39
Age (years)										
16-29	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
30-49	0.81 (0.71-0.92)	<.001	0.70 (0.61-0.81)	<.001	0.81 (0.64-1.01)	.07	1.18 (1.01-1.39)	<.001	0.90 (0.58-1.39)	.65
50-64	0.54 (0.47-0.63)	<.001	0.68 (0.58-0.79)	<.001	0.71 (0.55-0.93)	.01	0.84 (0.69-1.01)	.07	0.48 (0.25-0.89)[c]	.02
≥65	0.42 (0.34-0.53)	<.001	0.65 (0.53-0.80)	<.001	0.32 (0.20-0.50)	<.001	0.76 (0.56-1.07)	.10		
In a couple										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No	0.84 (0.74-0.94)	.003	1.18 (1.06-1.32)	<.001	1.30 (1.06-1.59)	.01	0.92 (0.79-1.07)	.27	1.18 (0.77-1.79)	.46
Professional situation										
Worker	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Student	0.89 (0.75-1.05)	.17	1.17 (0.97-1.42)	.10	0.61 (0.44-0.84)	.003	0.71 (0.56-0.90)	.004	0.55 (0.31-0.95)	.03
Job seeker	0.86 (0.69-1.08)	.20	0.69 (0.55-0.86)	.001	0.84 (0.59-1.20)	.35	1.02 (0.77-1.36)	.87	0.94 (0.48-1.82)	.86
No employment/retired	0.72 (0.59-0.87)	<.001	0.51 (0.43-0.61)	<.001	0.68 (0.48-0.97)	.03	0.72 (0.55-0.94)	.02	0.22 (0.09-0.52)	<.001
Educational level (ISCED[d] 2011)										
3	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
≥6	0.87 (0.75-1.00)	.06	0.95 (0.83-1.09)	.46	0.69 (0.53-0.90)	.006	1.52 (1.24-1.86)	<.001	0.38 (0.22-0.65)	<.001
I4-5	0.94 (0.82-1.09)	.44	0.97 (0.85-1.11)	.65	0.68 (0.53-0.88)	.003	1.25 (1.02-1.54)	.03	0.41 (0.24-0.69)	<.001
1-2	0.74 (0.60-0.90)	.003	0.60 (0.50-0.71)	<.001	0.72 (0.51-1.02)	.06	1.14 (0.85-1.54)	.39	0.48 (0.23-1.01)	.05
Access to outdoor space										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No	0.95 (0.85-1.05)	.32	1.16 (1.05-1.29)	0.005	1.00 (0.82-1.23)	.98	0.92 (0.80-1.06)	.27	1.54 (1.01-2.38)	.048
Well-being (WEMWBS[e] score)										
Per 1-point increase	0.98 (0.97-0.98)	<.001	0.98 (0.97-0.98)	<.001	0.97 (0.96-0.98)[c]	<.001	0.97 (0.96-0.98)	<.001	0.96 (0.93-0.98)	<.001
General stress (0-10 VAS[f])										

Characteristic	Caloric/salty food intake (n=10,771; 3233 increase vs 7538 no increase)		Screen use (n=11,267; 7274 increase vs 3993 no increase)		Tobacco use (n=2787; 996 increase vs 1791 no increase)		Alcohol use (n=7108; 1761 increase vs 5347 no increase)		Cannabis use (n=666; 208 increase vs 458 no increase)	
	aOR[a] (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value	aOR (95% CI)	*P* value
Per 1-point increase	1.07 (1.05-1.10)	<.001	1.08 (1.05-1.10)	<.001	1.07 (1.03-1.11)	<.001	1.06 (1.03-1.09)	<.001	1.03 (0.95-1.12)	.46
Living space										
Per 5 square meters/person increase	0.98 (0.97-0.99)	.003	0.99 (0.98-1.01)	>0.99	1.01 (0.98-1.03)	.68	0.99 (0.98-1.00)	.19	1.01 (0.96-1.05)	.86
Confined with other people										
Yes	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
No (alone)	1.29 (1.11-1.49)	<.001	1.15 (1.01-1.32)	.049	0.91 (0.70-1.17)	.46	0.87 (0.72-1.05)	.16	0.90 (0.53-1.54)	.72
Housing location										
Urban	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Periurban	1.08 (0.96-1.22)	.21	0.88 (0.79-0.98)	.03	0.87 (0.68-1.11)	.26	1.04 (0.89-1.22)	.62	1.21 (0.69-2.14)	.50
Rural	0.98 (0.86-1.11)	.73	0.82 (0.73-0.92)	<.001	0.95 (0.75-1.21)	.71	1.06 (0.90-1.24)	.53	1.12 (0.63-1.98)	.72
Working conditions										
Telecommuting	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Not working	0.98 (0.87-1.11)	.72	1.69 (1.48-1.93)	<.001	0.87 (0.70-1.09)	.24	1.00 (0.85-1.18)	.98	0.87 (0.56-1.36)	.56
Working in the workplace	1.08 (0.95-1.23)	.21	0.83 (0.73-0.94)	.003	1.47 (1.17-1.86)	.001	1.06 (0.90-1.24)	.49	0.98 (0.58-1.65)	.93
Psychiatric treatment										
Never	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Past	1.27 (1.09-1.47)	<.001	1.07 (0.91-1.25)	.44	0.80 (0.60-1.08)	.15	1.00 (0.81-1.23)	.99	1.01 (0.55-1.86)	.99
Current	1.94 (1.62-2.31)	.31	0.92 (0.75-1.13)	.45	1.33 (0.94-1.88)	.10	1.44 (1.10-1.88)[d]	.008	1.12 (0.54-2.35)	.78
Addiction treatment										
Never	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A	Reference	N/A
Past	1.01 (0.77-1.33)	.45	0.95 (0.72-1.24)	.70	1.51 (0.99-2.29)	.06	1.01 (0.68-1.49)	.97	0.70 (0.29-1.73)	.45
Current	1.11 (0.68-1.80)	.89	0.88 (0.53-1.45)	.63	0.98 (0.53-1.82)	.96	0.78 (0.39-1.58)	.49	0.65 (0.15-2.78)	.57

[a]aOR: adjusted odds ratio.

[b]N/A: not applicable.

[c]Due to power requirements, the age categories of 50-64 years and ≥65 years were pooled in the model exploring cannabis use increase.

[d]ISCED: International Standard Classification of Education.

[e]WEMWBS: Warwick-Edinburgh Mental Well-Being Scale.

[f]VAS: visual analog scale.

After adjustment, the respondents who reported increasing their caloric/salty food intake were more likely to be female, to be aged ≤30 years (see Table 3), to have a partner, to be professionally active, a student, or a job seeker, to report a lower score of well-being and a higher score of general stress, to be locked down alone in a reduced space, and to report current or past treatment for psychiatric disorder (for ORs and 95% CIs, see Table 3).

Based on the results of the multivariable logistic regression models, the respondents who reported increasing their screen use were more likely to be female, to be aged <30 years, to have no partner, to be professionally active, to have a relatively high level of education (ie, ISCED 4 or more), to report a lower score of well-being and a higher score of general stress, to be locked down alone, in a city, and with no access to an outdoor space, and to have stopped their professional activity because of the lockdown (for ORs and 95% CIs, see Table 3).

After adjustment, the interviewees who reported increasing their use of tobacco were more likely to be female, to be aged <50 years, to have no partner, to be professionally active or a job seeker, to have a relatively low level of education (ie, ISCED 3 or less), to report a lower score of well-being and a higher score of general stress, and to continue working in the workplace (for ORs and 95% CIs, see Table 3).

After adjustment, the individuals who reported increasing their alcohol use were more likely to be aged 30 to 49 years, to be professionally active or job seekers, to have a high level of education (ie, ISCED 5 or more), to report a lower score of well-being and a higher score of general stress, and to report current treatment for a psychiatric disorder (for ORs and 95% CIs, see Table 3).

After adjustment, the participants who reported increasing their cannabis use were more likely to be aged <50 years, to have a relatively low level of education (ie, ISCED 4 or less), and to live in a dwelling with no access to an outdoor space (for ORs and 95% CIs, see Table 3).

Discussion

Principal Results

Overall, we found that increases were much more frequent than decreases for all the habits explored. Moreover, it appears that the use of screens increased greatly; 4125/11,391 (36.21%) of the survey population reported increased screen use, and 1729 (15.18%) noted difficulties in controlling their screen use.

The early impact of the COVID-19 outbreak and the related lockdown thus appear to be associated with substantial increases in the intake of caloric/salty food as well as in screen and substance use among the French population. In animal models, it is well-demonstrated that reducing social connections enhances stress; as a result, increases are observed in both eating and weight [12] as well as in substance use [13,14]. In humans, epidemiological studies on this topic are more limited, as situations of abrupt reduction in social interaction at the population level are relatively uncommon. However, analogies can be made to studies that investigated individuals enrolled in armed forces during conflicts, which revealed that the social interactions of the individuals were dramatically reduced and that their substance use increased in parallel. For example, studies by Lee Robins [15] among US soldiers who were sent to Vietnam in the 1970s found an important reduction in social interactions accompanied by an important increase in the use of opioids by soldiers during their presence in the field; meanwhile, these patterns of use rapidly and almost completely disappeared after the soldiers returned home. A comparison with our findings should be made with caution, as a situation of war is in no way comparable with that of the COVID-19 lockdown. However, the results of our survey are in line with the fact that a substantial reduction of social habits can be associated with enhanced stress and boredom and thus with increases in addiction-related habits.

Furthermore, our findings enlighten both common aspects and singularities between habits in the profiles of respondents who reported increases. Overall, reduced mental well-being and greater overall stress were shared risk factors of increase for all habits. A current or past history of addiction treatment did not appear to impact the observed changes; this is noteworthy because the respondents were supposed to be more vulnerable to stress and were thus expected to increase or relapse in addictive behaviors [6]. More specifically, the typology of respondents who increased their habits substantially differed depending on the habit. Respondents who increased their intake in caloric/salty foods were primarily young women who were living in smaller dwellings and were locked down alone. Previous studies have demonstrated that emotional eating in stressful environments is more common in women [16,17]. It can thus be hypothesized that women who faced the stress induced by the COVID-19 crisis and the related containment coped more by consuming caloric/salty food relative to men. In this context, living alone in a smaller space or reporting past or current treatment for psychiatric disorder can be seen as additional sources of stress.

Survey respondents who reported increasing their screen use were more likely to be female, less than 30 years of age, single, locked down alone, living in an urban area, without access to an outdoor space, and not working. Stress is also a well-demonstrated risk factor of increasing screen use; it is more expressed in younger people, although usually more commonly in men [18,19]. Living alone is another known risk factor for increased screen use [20,21], and this factor was certainly accentuated during the lockdown. Similarly, not working was previously found to be associated with increased internet use [22]. Interestingly, a previous study found that increased use of the internet in a stressful environment was more frequent in young people living in urban areas [23]. This is in line with our findings, which can be explained by a more confined environment in this case. However, fewer respondents who were currently working in the workplace reported increased screen use compared to telecommuting respondents; this also suggests that enhanced screen use is related to telecommuting in some cases.

Among tobacco smokers, the main risk factors for increased smoking were also being female, age less than 50 years, being single, and low level of education. In line with these findings, female gender, younger age, lower socioeconomic status, and psychological distress are the main factors associated with tobacco use [24]. It thus appears that the same risk factors that are associated with tobacco use in general were associated with increasing tobacco use in the case of the COVID-19 lockdown.

The profile of respondents who increased their alcohol use was different, as this increase preferentially affected people aged 30 to 49 years with high levels of education. A possible explanation

is that increased use of alcohol may be less stigmatized than that of tobacco or cannabis, as people who use cannabis and tobacco in France are globally younger, have lower income, and are less educated [25,26]. For this reason, alcohol use may have increased more than tobacco or cannabis use among more educated and middle-aged respondents. In line with this hypothesis, respondents who reported increased cannabis use more specifically consisted of very young workers with low levels of education. This reflects the population of regular users of cannabis in France, which is mainly aged less than 30 years [27]. Moreover, while no study has specifically explored this issue in France, international epidemiological studies have revealed that cannabis use is inversely correlated with level of education [28]. In sum, our findings suggest that increased stress and impaired well-being were common risk factors for increases in all types of addiction-related habits during the early phase of the COVID-19 lockdown in France. However, other sociodemographic characteristics and individual features related to lockdown conditions were associated with increases in more specific habits, thus reflecting a specific vulnerability of some parts of the French population with regard to the different habits explored, namely caloric/salty food intake, screen use, or tobacco, alcohol, or cannabis use.

Limitations

Our study was a web-based survey performed on a convenience sample with no a priori representativeness of the French population. Although our analyses were weighted based on several basic sociodemographic parameters, we cannot exclude the possibility that important parts of the French population were overrepresented or underrepresented, which may have had an impact on our findings. For example, although illiterate people represent a limited part of the French population, we acknowledge that participating in the survey would be difficult for them without external help. Given the context, however, it would be difficult to rapidly set up a study with more thorough methodological features. Despite this, the rate of tobacco smokers in our study (24.47%) was close to that observed in the French population (25.2% in 2018 [29]). Similarly, 62.40% of our sample declared that they used alcohol; meanwhile, the rate of French adults who used alcohol at least once per year in 2018 was 87%, while the rate of adults who used alcohol at least once a week was 49% [30]. However, a gap was found for cannabis use; 5.4% of our sample reported using this substance, whereas the rate of current users in the adult French population is estimated to reach 11% [27]. This gap may result from social desirability bias, which is the tendency to underreport socially undesirable attitudes and behaviors and to overreport more desirable attributes; this bias is more pronounced with illicit substances [31].

Another limitation pertains to what is conveyed under the notion of “screen use,” which can actually involve many habits, such as video gaming, social networking, or teleworking. The interview may thus have lacked precision on this point, and interpreting the participants’ answers may thus have been more difficult. An additional limitation is that the data we analyzed only pertained to the early phase of the lockdown, and it is perfectly possible that several findings reflected short-term adjustment behaviors that may not be durably sustained over the remaining phase of the lockdown. Another limitation is that we did not explore the interrelations in the changes between habits; thus, we did not explore overlaps in terms of affected populations. Finally, the assessment of how individual habits had changed was entirely subjective with no precise quantification in either terms of amounts or time, which limits the accuracy of the data.

Comparison With Prior Work

To our knowledge, no previous study has assessed the impact of a national COVID-19 containment measure on eating habits, screen use, or substance use. The increases found in our survey were hypothesized in a recent literature report [6]; however, our contribution provides the first data supporting these assumptions.

Conclusions

The early phase of COVID-19 containment in France was associated with a substantial proportion of survey respondents reporting increased caloric/salty food intake, screen use, and tobacco, alcohol, and cannabis use. The increase was particularly large for screen use, which affected two-thirds of the sample. Furthermore, the profiles of individuals who increased their habits displayed shared features, particularly poorer well-being and increased stress; however, specificities between each type of increase also revealed some populational singularities, particularly related to gender, age category, and level of education. Thus, targeted prevention messages should be developed to address the types of habits to which subcategories of the population are more vulnerable during and after the containment period.

Conflicts of Interest

None declared.

Multimedia Appendix 1
CHERRIES checklist.
[DOCX File , 20 KB - publichealth_v6i3e19630_app1.docx]

Multimedia Appendix 2
The questionnaire used for the survey (in English).
[PDF File (Adobe PDF File), 5169 KB - publichealth_v6i3e19630_app2.pdf]

Multimedia Appendix 3
Flowchart demonstrating how questionnaires were selected for the analyses.
[DOCX File , 27 KB - publichealth_v6i3e19630_app3.docx]

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Abbreviations

CHERRIES: Checklist for Reporting Results of Internet E-Surveys
COVID-19: coronavirus disease
ISCED: International Standard Classification of Education
VAS: visual analog scale
WEMWBS: Warwick–Edinburgh Mental Well-Being Scale

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Original Paper

Prediction of the Transition From Subexponential to the Exponential Transmission of SARS-CoV-2 in Chennai, India: Epidemic Nowcasting

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Abstract

Background: Several countries adopted lockdown to slowdown the exponential transmission of the coronavirus disease (COVID-19) epidemic. Disease transmission models and the epidemic forecasts at the national level steer the policy to implement appropriate intervention strategies and budgeting. However, it is critical to design a data-driven reliable model for nowcasting for smaller populations, in particular metro cities.

Objective: The aim of this study is to analyze the transition of the epidemic from subexponential to exponential transmission in the Chennai metro zone and to analyze the probability of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) secondary infections while availing the public transport systems in the city.

Methods: A single geographical zone "Chennai-Metro-Merge" was constructed by combining Chennai District with three bordering districts. Subexponential and exponential models were developed to analyze and predict the progression of the COVID-19 epidemic. Probabilistic models were applied to assess the probability of secondary infections while availing public transport after the release of the lockdown.

Results: The model predicted that transition from subexponential to exponential transmission occurs around the eighth week after the reporting of a cluster of cases. The probability of secondary infections with a single index case in an enclosure of the city bus, the suburban train general coach, and the ladies coach was found to be 0.192, 0.074, and 0.114, respectively.

Conclusions: Nowcasting at the early stage of the epidemic predicts the probable time point of the exponential transmission and alerts the public health system. After the lockdown release, public transportation will be the major source of SARS-CoV-2 transmission in metro cities, and appropriate strategies based on nowcasting are needed.

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KEYWORDS

COVID-19; epidemic; mathematical modeling; probabilistic models; public transport; exponential transmission

Introduction

Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), or the coronavirus disease (COVID-19) emerged in Wuhan, China and has quickly spread to most of the countries around the world. As of May 10, 2020, 3,917,366 COVID-19 cases and 274,361 related deaths were reported worldwide. At the same time, the Ministry of Health and Family Welfare, India reported 62,939 confirmed cases and 2109 deaths in India. India has 28 states and 8 union territories, out of which

26 states and 7 union territories have reported COVID-19 cases. However, a large proportion of the cases were reported from the 4 states Maharashtra, Tamil Nadu, Gujarat, and Delhi. The case-fatality rate in India remains low as compared to the global rate (7.0% vs 3.35%) [1].

The estimated population of the Tamil Nadu State for the year 2020 is 82.2 million and is the seventh most populated state in India. It has 37 districts and Chennai is the largest and most populated city in Tamil Nadu, and, based on the nationwide census in 2011, the projected total population of Chennai District is around 4,935,550 [2]. The whole geographical zone of Chennai District is well connected through two major public transport systems: Metropolitan Transport Corporation (MTC) and Chennai Suburban Railways. These transports are also extended to the three bordering districts, namely, Kanchipuram, Chengalpattu, and Thiruvallur. The Department of Health and Family Welfare of Tamil Nadu reported a total of 3839 COVID-19 cases in Chennai, 267 cases in Chengalpattu, 122 cases in Kanchipuram, and 337 cases in Thiruvallur, as of May 10, 2020. The maximum number of infected cases were registered in Chennai [3], and the first SARS-CoV-2 infection was reported in Kanchepurram District on March 7, 2020.

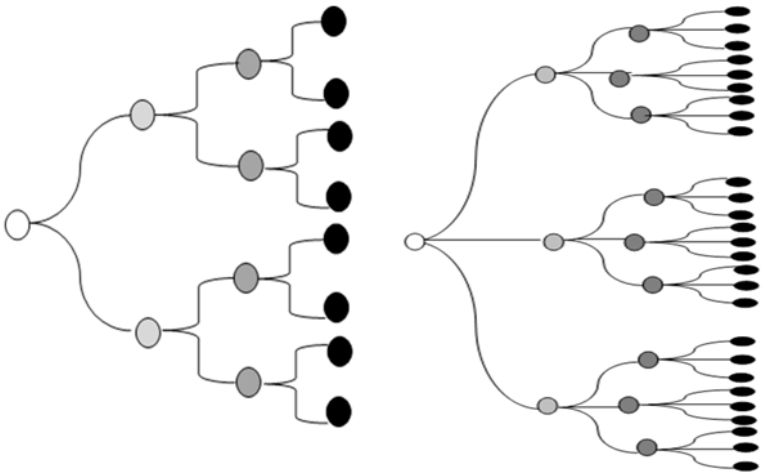
Public transportation such as trains and buses is an essential service with specific route systems. The Chennai suburban railway consists of two major networks: Chennai Suburban Railway Network and Mass Rapid Transport System; as of 2015-2016, it carried about 1.17 million passengers every day [4]. The MTC operates 3233 services and carries about 3.3 million passengers per day [5]. In the current COVID-19 pandemic situation, commuting in public transport is associated with two major risks: asymptomatic passengers play a major role in SARS-CoV-2 transmission through aerosol particles and indirect transmission from symptomatic passengers may occur through fomites. Furthermore, public transport employees are at a higher risk of infection for long hours with multiple sources of exposure [6]. Even an increase in the reproductive number (R_0) from a value of 2 to 3 leads to a significant amplification in the number of infected cases over subsequent generations, as shown in Figure 1.

Mathematical modeling plays an important role for predicting, assessing, and controlling potential outbreaks for infectious diseases such as H1N1 [7], severe acute respiratory syndrome (SARS) [8], Middle East respiratory syndrome (MERS) [9], and Ebola [10]. At present, several researchers have used mathematical modeling to predict the SARS-CoV-2 pandemic using model structures such as the susceptible-infected-recovered model, the exponential model, and the susceptible-exposed-infected-removed model [11-13]. The early epidemic growth can be well-drawn using subexponential and exponential models. Such models are highly appropriate when there is a major uncertainty regarding the epidemiology of a novel infectious disease, for which the transmission pathways are not completely known. In such cases, subexponential and exponential models serve as reasonable tools for analyzing the progression of the early epidemic and for short-time prediction of the infected cases in the near future [14].

Recently, modeling approaches have been used for analysis of the transmission of COVID-19 infection with travel interventions [15]. Anzai et al [16] have investigated the impact of travel interventions inside and outside of China during the COVID-19 pandemic and concluded that travel intervention during the COVID-19 pandemic resulted in less cases. However, a significant number of infected individuals with mild or no symptoms are likely to pass through border control if travel interventions are not imposed properly.

When India had gone through 5 weeks of continuous lockdown during the last week of April 2020, there were 33,050 confirmed cases and 1074 deaths [17]. An overview of the case distribution indicated that there were more from urban clustering, in particular, with the three major metro cities Mumbai, Delhi, and Chennai. Therefore, nowcasting was proposed for the COVID-19 epidemic in the Chennai metro zone using different predictive mathematical models to generate an evidence for focused public health interventions in metro zones. In support of this, the probability of infection and the related secondary infections due to the COVID-19 infected population in public transport systems such as buses and train coaches is analyzed using probabilistic models.

Figure 1. Increase in the number of cases over subsequent generations of the infection for (a) a reproductive number of 2 and (b) a reproductive number of 3.



Methods

Study Site

India reported more than 100,000 cases of COVID-19 as of May 18, 2020, even after consecutive lockdown for a period of 55 days. Though the epidemic was slowed down as expected, 3 states contributed more than 58% of the total cases in the country and in each State more than 60% of the cases were reported from the respective capital cities Mumbai, Chennai, and Ahmadabad. Therefore, containment of the SARS-CoV-2 transmission in these three cities is critical in favorably modifying the transmission in India. These 3 cities share the same characteristics in terms of population structure, density, and movement of the people toward these cities for employment.

Chennai is a metropolitan city surrounded by three other districts Kancheepuram, Thiruvallur, and Chengalpattu. Based on the connectivity of the three transport systems, widespread locations of the educational institutes, and the movement of the population from these three districts into every part of Chennai, we felt it appropriate to predict the SARS-CoV-2 transmission considering all four districts as a single unit. In this study, we construct a single geographical zone "*Chennai-Metro-Merge*" by combining Chennai District with the bordering three districts for the development of a predictive model (Figure 2).

Figure 2. Constructed study site "Chennai-Metro-Merge," combining Chennai District with the three bordering districts Chengalpattu, Kanchepuram, and Thiruvallur. The estimated total population of the constructed single geographical zone by 2020 is 15,208,505.

Modeling of the COVID-19 Epidemic in Four Districts of Tamil Nadu Using Subexponential and Exponential Models

In this study, the total reported COVID-19 cases in the constructed geographical zone *Chennai-Metro-Merge* (Figure 2) were considered for the development of a predictive model. The number of infected cases from March 7, 2020, to April 30, 2020, was adopted from the open-source data provided by the Department of Health and Family Welfare, Government of Tamil Nadu [18] and was used for modeling the short-term progression (nowcasting) of the epidemic in these four districts, considered in a single geographical boundary since these four districts are well connected by roadways and suburban train services for public movement and the movement of materials. The nowcasting was further extended up to June 30, 2020, by adopting the reported cases from May 16 to June 10, 2020.

Two different models were considered for the study. First, an exponential model of the form:

The solution of equation 1 is given as:

$$x(t) = x(0)e^{rt} \quad \textbf{(2)}$$

Second, a subexponential model of the form:

with solution:

where, $x(t)$ is the number of infected cases at time t,  , and  [17].

This study uses the subexponential and the exponential models to estimate the date of transition of the epidemic, and in the field of epidemiology, these models are well suited for the study of the early epidemic growth [19]. Using the reported cases, the parameters of both the considered models were estimated using the minimization of the objective function given by:

where, $x(t)$ is the model output, and $h(t)$ is the reported infections at t^{th} day. The optimization problem was solved using the MATLAB (MathWorks) programming software. The subexponential and exponential models were analyzed, and a technique for the prediction of the onset date of exponential transmission was identified. Furthermore, the developed model was simulated to approximately predict and analyze the future COVID-19 infections in these four districts.

Analysis of COVID-19 Transmission due to Public Transport in the Considered Districts of Tamil Nadu

In an enclosed environment, the number of secondary infections (R_A) arising due to the introduction of infectious cases into the susceptible population in an enclosed environment is given by:

$$R_A = (N - I)P \quad \textbf{(6)}$$

where, N is the total population inside the enclosed environment such as buses or train compartments, I is the number of infected individuals inside the same enclosed environment, and P is the probability of infection. Equation 6 was used to analyze the transmission of COVID-19 in buses and train compartments when the lockdown is released and the public transportation is resumed in Tamil Nadu. The buses in Tamil Nadu are to be operated with 50% capacity on the immediate release of the lockdown.

The probability of infection P is given by:

where, N is the number of individuals in the bus or train compartment, V is the volume of shared air space in m^3, t is the total exposure time in hours, p is the breathing rate in m^3/hour, f is the fraction of indoor air exhaled by the infected people, q is the quantum generation rate, and I is the initial number of infected people. The values of q, f, and p were adopted from [20]. The volume of the single train coach was considered from the literature [21]. Further, the maximum initially infected in the bus, train coach, and the ladies' compartment in the train was assumed as 3, 4, and 3, respectively. This assumption is based on the volume of the bus and the train, the number of passengers, and the commuter density in the bus stops and railway stations.

Results

Figure 3 shows the exponential and the subexponential models fitted to the reported number of infections in the four considered districts as a function of time in days. The data available from March 7, 2020, to April 29, 2020, was used to generate the models, and the predictions are further presented up to May 15, 2020. It was observed that, during the early stage of the epidemic, the subexponential model best describes the progression of the infected cases. However, after a particular point of time, infected cases are closely tracking the curve described by the exponential model. The week in which the transition from the subexponential to the exponential progression begins is an important marker of the change in the course of the epidemic, as described in Figure 3. Both the developed models were simulated to predict the future number of COVID-19 cases, and the resulting curves were compared with the actual reported cases. It is seen that there was no uniform pattern in the day-to-day reporting of the cases. Therefore, initially, the progression trend of the reported number of infections is close to the predictions made by the exponential phase and in short period to the subexponential phase. However, the merging and the transition from the subexponential to exponential phase was clearly visible at a particular time point.

The exponential model was further updated using the data available from May 16 to June 10, 2020, and the model was used to further predict the future number of cases up to June 30, 2020, in the considered geographical boundary. The updated exponential model output and the reported cases are shown in Figure 4.

Figures 5-7 show the probability of infection as a function of both the travelling time (exposure time) and the number of infected individuals travelling in the bus, a single train coach, and a single train coach (ladies compartment) with a total of 20 passengers, 54 passengers, and 36 passengers, respectively. It is seen that the increase in the initial number of infected individuals and the increase in the exposure time leads to an increased probability of infection of the susceptible. In the bus, for an exposure time of 2 hours and with 3 initial infected individuals, the probability of infection is around 0.4741 (47.41%). Furthermore, the number of secondary infections arising due to the infected individuals travelling in the bus, single train compartment, and a single train coach (ladies compartment) is shown in Figures 8-10, respectively, as a function of the probability of infection and for various numbers of initially infected individuals. The results demonstrated that the operation of the train coaches at a reduced capacity of 50%, provides a maximum probability of infection of 0.2674. Furthermore, the maximum probability of infection in a single train coach (ladies compartment) was found to be 0.3061.

Figure 3. The reported number of coronavirus disease cases (includes effect of intervention), and the output of the subexponential and the exponential models, shown as a function of time.

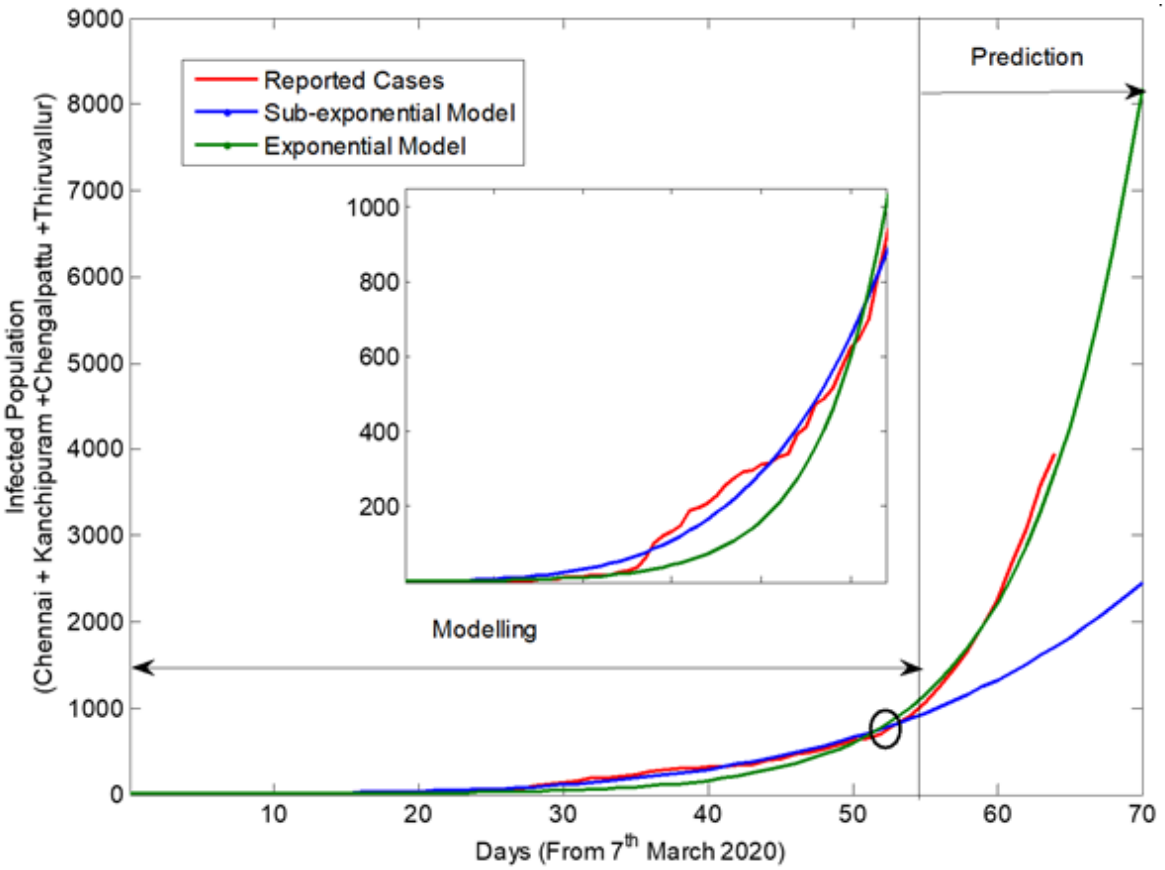


Figure 4. The total coronavirus disease cases in the four considered districts of Tamil Nadu predicted using the updated exponential model and the actual reported cases.

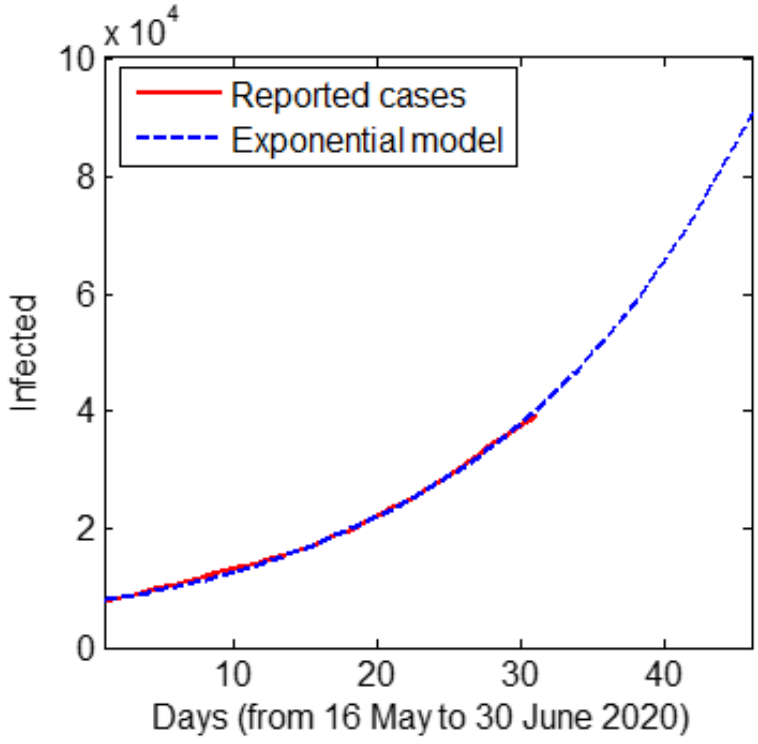


Figure 5. The probability of infection in a public bus with 20 passengers shown as a function of the total exposure time and the initial number of infected.

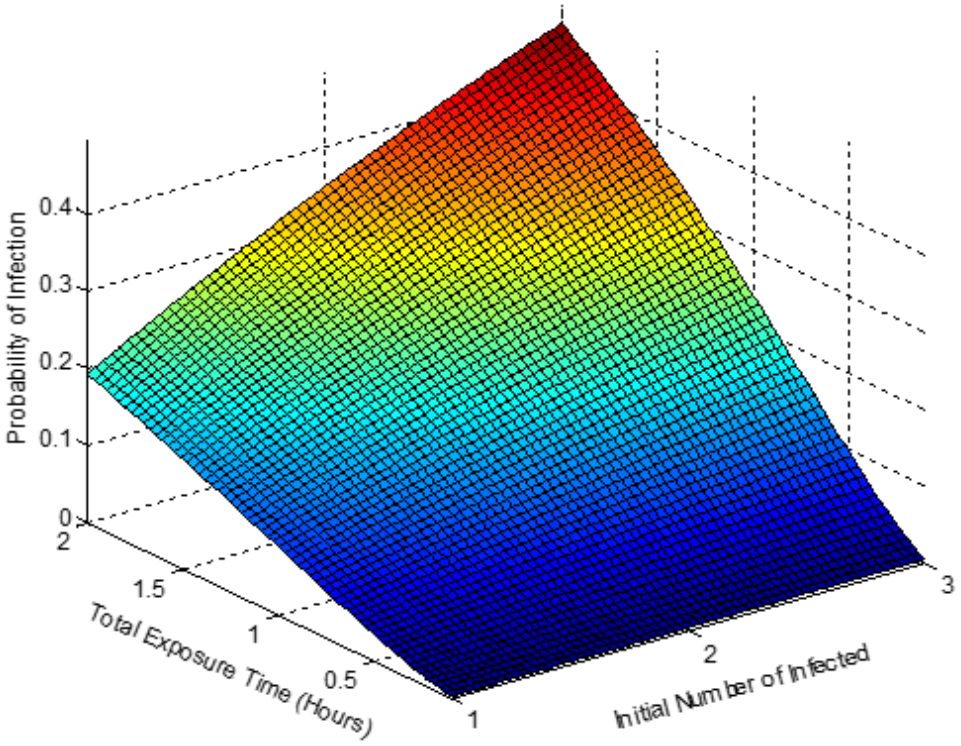


Figure 6. The probability of infection in a single train coach with 54 passengers shown as a function of the total exposure time and the initial number of infected.

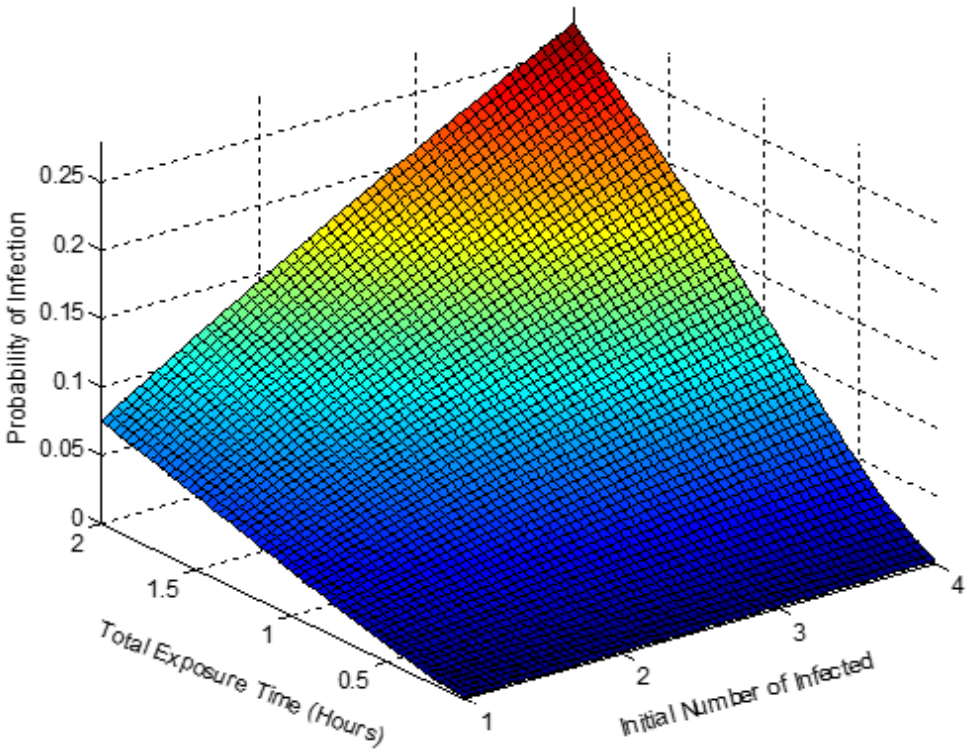


Figure 7. The probability of infection in a single train coach (ladies compartment) with 36 passengers shown as a function of the total exposure time and the initial number of infected.

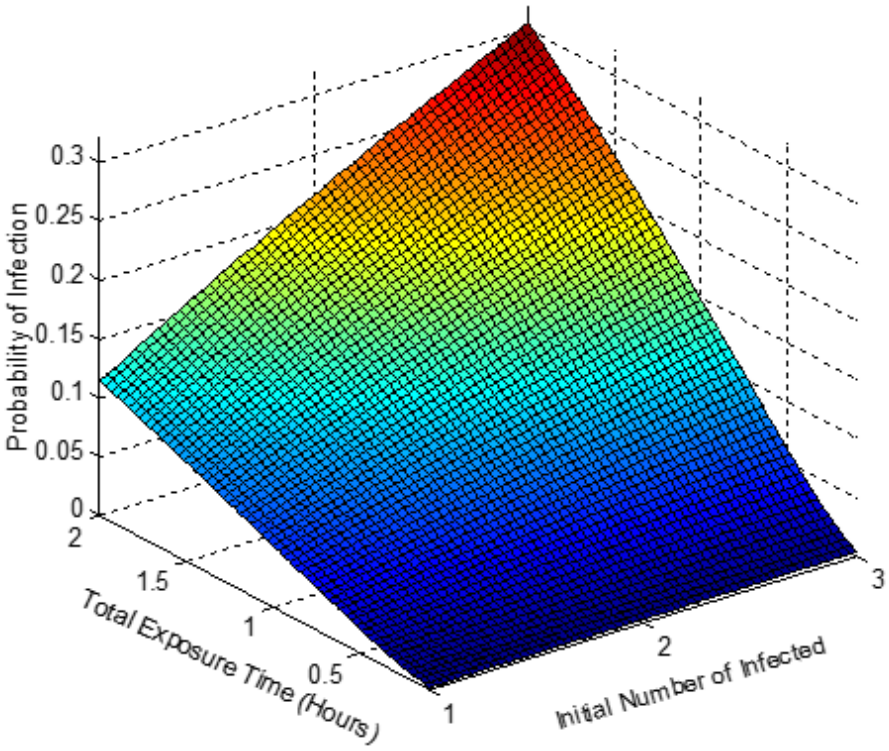


Figure 8. The number of secondary infections in the bus due to the introduction of infected individuals into the susceptible population (total population of N = S + I = 20), shown as a function of the estimated probability of infection.

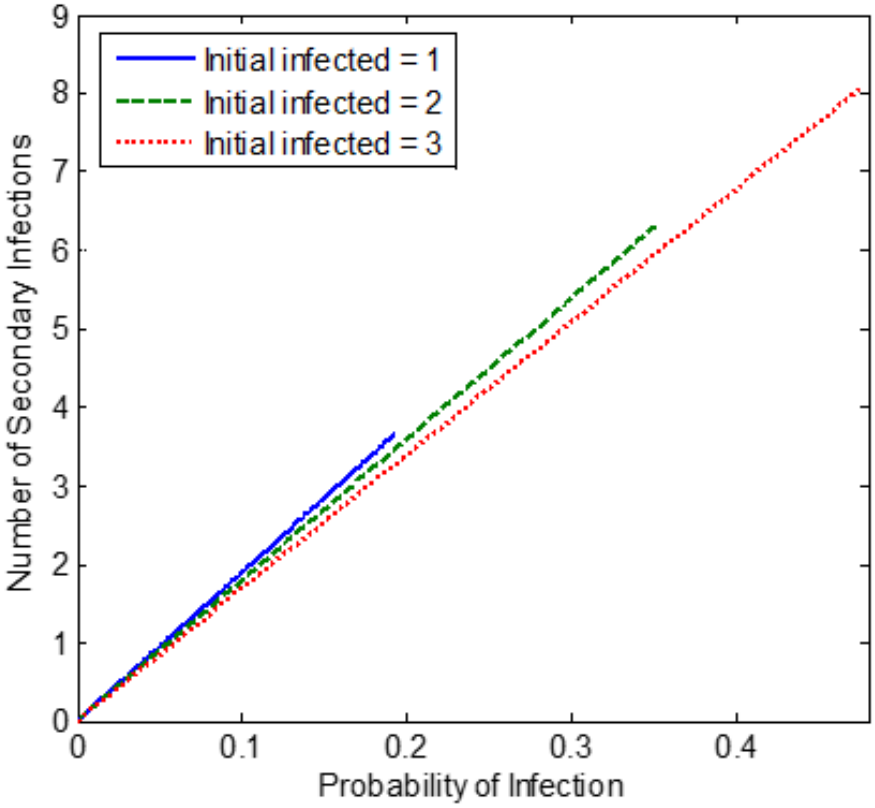


Figure 9. The number of secondary infections in the train compartment due to the introduction of infected individuals into the susceptible population (total population of N = S + I = 54), shown as a function of the estimated probability of infection.

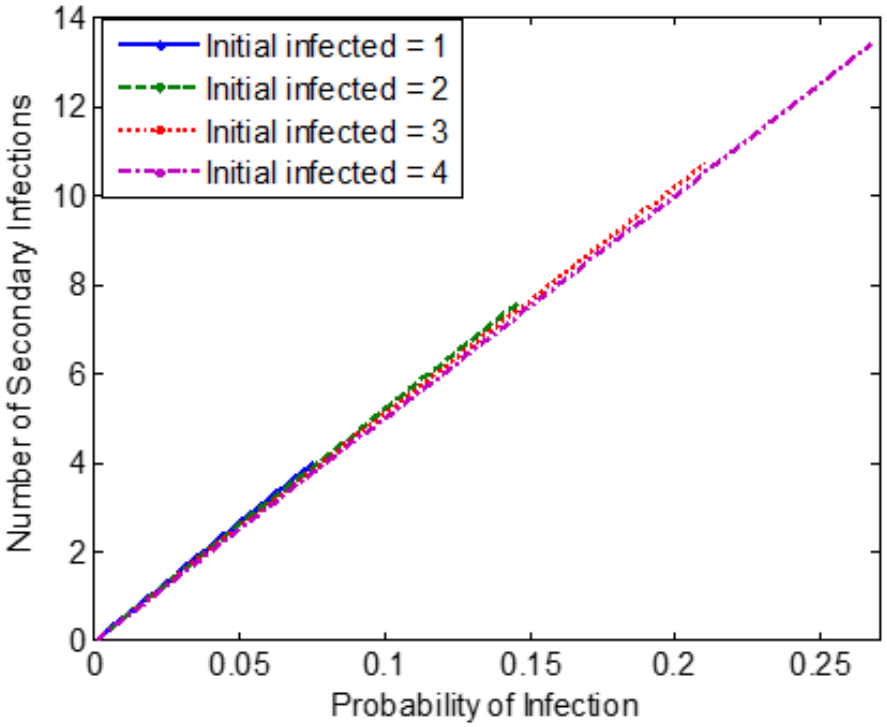
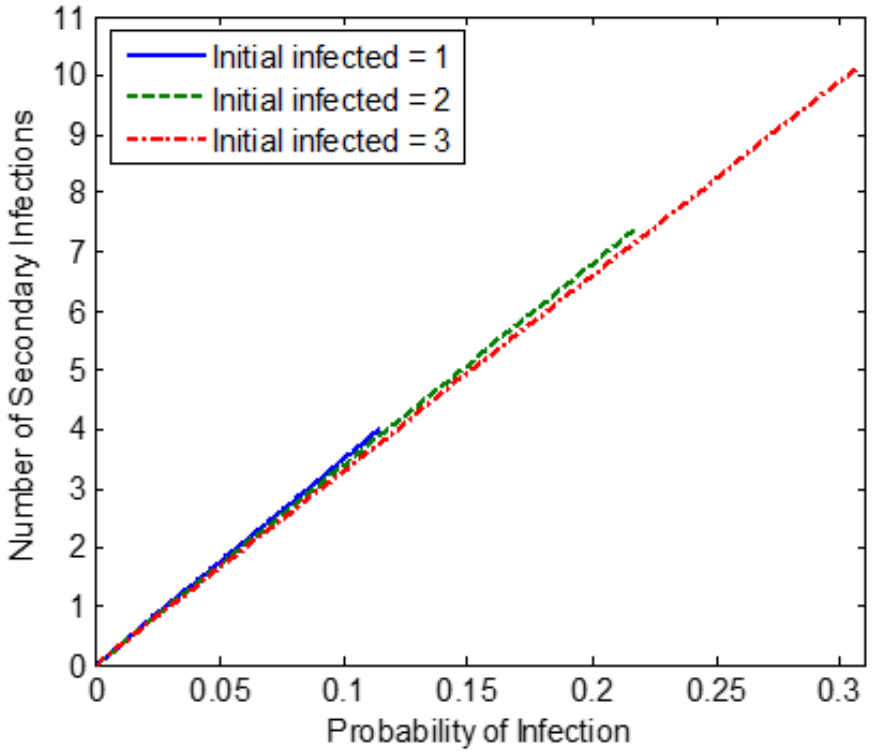


Figure 10. The number of secondary infections in the train coach (ladies compartment) due to the introduction of infected individuals into the susceptible population (total population of N = S + I = 36), shown as a function of the estimated probability of infection.



Discussion

Principal Findings

In this study, we constructed a mathematical model based on the reported cases from March 7, 2020, to April 29, 2020, to analyze the transition of the COVID-19 epidemic from the subexponential to the exponential stage in the combined Chennai metro-merge. Furthermore, the reported cases from May 16 to June 10, 2020, were used to update the exponential model to nowcast the progression of the epidemic up to June 30, 2020. Currently, five metro cities in India and several cities in South East Asian Region are facing a similar SARS-CoV-2 epidemic. The results of the modeling indicated that the transmission in

all the four districts exhibited exponential transmission from the third or fourth week of the first reported case in each district. However, the number of predicted cases for this period was considerably less, and there was an opportunity until the eighth week (ie, the first week of May 2020) to favorably contain the epidemic and reverse to the subexponential transmission. On the other hand, the Government of Tamil Nadu proposed resuming both the bus and train services initially for the officials followed by the public in a phased manner. In public health, as well as the individual perspective, it is desirable to assess the risk of acquiring the SARS-CoV-2 infection while travelling for a considerable period of time in an enclosed environment. We used a probabilistic model and observed that the probability of acquiring the infection in the event of a single index case in the closed environment is lower in suburban train travel with a restricted occupancy of 50% as compared to the bus travel with the same proportion of occupancy (0.19 vs 0.07). The results also indicate that during the suburban train travel the probability of infection is higher in the ladies' compartment as compared to the open compartment for an exposure time of 2 hours and when a single infected case is introduced (0.11 vs 0.07).

For the predictions to be reliable, the model parameters were estimated with the reported values using the optimization technique of the minimization of the sum square error between the model outputs and the reported values. In addition, standard probabilistic models were used to analyze the probability of infection in buses and trains, which are to be operated at reduced passenger loads after the release of the lockdown. Using the probability of infection due to the total exposure or travel time of the passengers and the initial number of infected individuals travelling in the bus or train coach, the numbers of possible secondary infections were estimated. The modes of SARS-CoV-2 transmission in an enclosed environment are droplet nuclei from the asymptomatic persons as well as the aerosol droplet, especially when the infected person sneezes or coughs during travel. It had been reported earlier in SARS-CoV-1 transmission that all the passengers infected during the flight travel were seated in close proximity to index cases [22]. Another investigator showed that the persistence of SARS viruses is longer compared to the influenza virus [23]. Therefore, there are likely to be a higher number of SARS-CoV-2 secondary infections during the bus and train travel compared to those reported for SARS-CoV-1 transmission [24]. Data-driven estimates in China during the early phase of the SARS-CoV-2 epidemic showed a highly significant association with train travel [25]. A comprehensive review by Perri et al [26] revealed that the massive rail connectivity to Wuhan in China favored the widespread transmission.

The SARS-CoV-2 pandemic has gone through several continents in a short span of 12 weeks, and the length of the epidemics in various countries indicate that there is likely to be a prolonged pandemic for a period of 18-24 months as observed in the Spanish flu pandemic in the early twentieth century. Based on the R_0 during the initial phase of the epidemic in China, it is estimated that about 60% of the population will be infected if the epidemic is not mitigated [27]. Modeling studies suggest that to contain the epidemic before the exponential phase, about 70% of the contacts must be traced and quarantined [28]. Data from the earlier phase of the epidemics outside China indicate that nearly 80% of the infected remain asymptomatic or mildly symptomatic and resolve by self-healing [29].

Disease transmission models and the epidemic forecasts at national levels provide valuable information for the policy makers to implement appropriate intervention strategies in an appropriate time. However, it is critical to design data-driven reliable models for nowcasting and for smaller populations where clustering of transmission occurs. It is a routine practice among the public health specialists to rely on mechanistic epidemic models, and the major disadvantage with these models is that there is an underlying assumption of exponential transmission during the early phase of the epidemic itself [30,31] and, therefore, the predicted number of cases after 12 weeks or the final size of the epidemic is unusually high. Forecasts on the final size of the HIV and Ebola epidemics proved this phenomenon [32,33]. In our model, we considered both the subexponential and exponential transmission, and attempted to identify the time point at which there is a transition from subexponential to the exponential phase. The model predicted that the transition for the constructed geographical zone on Chennai-Metro-Merge falls at the eighth week of the epidemic. To avoid the unrealistic size of the epidemic for a small geographical area, we restricted the nowcasting approach to predict the number of cases for the next 6 weeks. In a nation-wide epidemic of SARS in large countries like India, there must be two levels of transmission control, one at the national level and the other at the state level. At both the levels, it is necessary to plan for the early forecast instead of identifying the magnitude of the epidemic as short-term; timely projections provide an opportunity for the type and intensity of interventions for the particular population [34] so that the epidemic is contained without causing any strain on public health infrastructure. It is important to know the size of the epidemic for the budget allocation and the mobilization of the public health infrastructure.

The major limitations of the study with reference to the predictions are that the data inputs for the study were based on the limited numbers of testing in the study districts and the limited period of predictions for only 6 weeks. In addition, when calculating the probability, we assumed the maximum possible number of initial infections in a single enclosure in a bus or train from the initial part of the journey as 3 and 4, respectively. Chennai metro services are always five times overcrowded during peak hours, and most of the enclosures are expected to be full if the restrictions on the occupancy are imposed during the initial phase of the release. With the current exponential trends, even with random contact, the passengers are likely to be exposed repeatedly during the point to point travel for a period of 2 hours.

At present, several countries are going through the early phase or the subexponential phase of the epidemic and have not yet reached the exponential phase; the methods, results, and experiences reported in this work are of high value in undertaking midcourse corrections in the implementation of the intervening strategies to contain the SARS-CoV-2 epidemic. The developed model in this study is simple and can be constructed easily in any software package using the reported

infections over a period of time. Hence, this methodology can be adopted by public health specialists and epidemiologists to trace the current trend of the epidemic and to nowcast the progression of the epidemic at a small population level like in metro cities and districts.

Conclusions

Though all the countries are well aware of the rapid response to the epidemics, each epidemic exhibits certain challenges. There are several challenges during the current COVID-19 epidemic globally and locally. India imposed lockdown as an intervention reasonably in advance as compared to other countries. However, this epidemic has shown categorically that lockdown alone is insufficient to contain the epidemic. Lockdown provides an opportunity for the symptomatic to surface out so that the contacts are traced, quarantined, and the severe forms of the diseases or complications are identified and treated. As shown by Keeling et al [28], it is essential to trace about 70% of the contacts to contain the epidemic spread. China succeeded in the COVID-19 epidemic control by strictly imposing lockdown, but a similar strategy may not be feasible in democratic countries. However, experiences during the MERS-related coronavirus epidemic in Taiwan proved that it was also possible to contain the epidemic by early intervention and community participation. The results of our study proved that there was 3-5 weeks for the SARS-CoV-2 epidemic to transit through the subexponential phase. If there had been an effective public health response in time, the exponential transmission could have been averted. We showed earlier that unplanned lockdown would enhance the exposure to the infection due to panic shopping and overcrowding in bus and train stations [35].

In India, the opportunity to favorably contain the exponential transmission was missed due to inadequate testing and contact tracing, especially in the overcrowded metro cities and urban settings. Exposures in religious meetings and marketplaces resulted in several epidemic clusters in Chennai City. Now, the three major cities Mumbai, Chennai, and Ahmadabad contribute about 58% of the total cases in India, and there are claims that there are only clusters of transmission in India. The results of our study show that the country needs an exclusive containment strategy in urban areas, in particular in metropolitan cities.

The modeling outcome also forecasts the probability of the infection in the metro zone when public transports are opened up after the lockdown. The long hours of travelling in a congested metro zone enhances the exposure, even if there is a single infected person in the closed environment. Train travel appears to be safer, although the travelling time is the same for the longest travel in the constructed study area due to the architecture of the train compartment that provides more air volume for the travelers. Our model did not include random contact with the infected person to estimate the probability of the infections and the resultant secondary infection. It is desirable to apply network modeling for precise estimation of the secondary infections.

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Conflicts of Interest

None declared.

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Abbreviations

COVID-19: coronavirus disease
MERS: Middle East respiratory syndrome
MTC: Metropolitan Transport Corporation
R_A: secondary infections
R_0: reproductive number
SARS: severe acute respiratory syndrome
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Self-Reported Symptoms of SARS-CoV-2 Infection in a Nonhospitalized Population in Italy: Cross-Sectional Study of the EPICOVID19 Web-Based Survey

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Abstract

Background: Understanding the occurrence of symptoms resembling those of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) in a large nonhospitalized population at the peak of the epidemic in Italy is of paramount importance; however, data are currently scarce.

Objective: The aims of this study were to evaluate the association of self-reported symptoms with SARS-CoV-2 nasopharyngeal swab (NPS) test results in nonhospitalized individuals and to estimate the occurrence of symptoms associated with coronavirus disease (COVID-19) in a larger nontested population.

Methods: EPICOVID19 is a self-administered cross-sectional voluntary web-based survey of adults throughout Italy who completed an anonymous questionnaire in the period of April 13 to 21, 2020. The associations between symptoms potentially related to SARS-CoV-2 infection and NPS results were calculated as adjusted odds ratios (aORs) with 95% CIs by multiple logistic regression analysis controlling for age, sex, education, smoking habits, and number of comorbidities. Thereafter, for each symptom and for combinations of the symptoms, we calculated the sensitivity, specificity, accuracy, and areas under the curve (AUCs) in a receiver operating characteristic (ROC) analysis to estimate the occurrence of COVID-19–like infection in the nontested population.

Results: A total of 171,310 people responded to the survey, of whom 102,543 (59.9%) were women; mean age 47.4 years. Out of the 4785 respondents with known NPS test results, 4392 were not hospitalized. Among the 4392 nonhospitalized respondents, those with positive NPS tests (856, 19.5%) most frequently reported myalgia (527, 61.6%), olfactory and taste disorders (507, 59.2%), cough (466, 54.4%), and fever (444, 51.9%), whereas 7.7% were asymptomatic. Multiple regression analysis showed that olfactory and taste disorders (aOR 10.3, 95% CI 8.4-12.7), fever (aOR 2.5, 95% CI 2.0-3.1), myalgia (aOR 1.5, 95% CI 1.2-1.8), and cough (aOR 1.3, 95% CI 1.0-1.6) were associated with NPS positivity. Having two to four of these symptoms increased the aOR from 7.4 (95% CI 5.6-9.7) to 35.5 (95% CI 24.6-52.2). The combination of the four symptoms showed an AUC of 0.810 (95% CI 0.795-0.825) in classifying positive NPS test results and then was applied to the nonhospitalized and nontested sample (n=165,782). We found that 7739 to 20,103 of these 165,782 respondents (4.4% to 12.1%) had experienced symptoms suggestive of COVID-19 infection.

Conclusions: Our results suggest that self-reported symptoms are reliable indicators of SARS-CoV-2 infection in a pandemic context. A nonnegligible number of symptomatic respondents (up to 12.1%) were undiagnosed and potentially contributed to the spread of the infection.

Trial Registration: ClinicalTrials.gov NCT04471701; https://clinicaltrials.gov/ct2/show/NCT04471701

(JMIR Public Health Surveill 2020;6(3):e21866) doi:10.2196/21866

KEYWORDS

SARS-CoV-2; COVID-19; voluntary respondents; web-based survey; self-reported symptom; nasopharyngeal swab testing; cross-sectional

Introduction

The outbreak of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), which started in late December 2019 in Hubei Province in China, caused millions of cases of coronavirus disease (COVID-19) worldwide in just a few months and evolved into a pandemic [1,2]. As of June 25, 2020, there were 239,706 confirmed cases of COVID-19 in Italy and 34,678 reported deaths [3].

It is worth noting that only approximately 20% of patients infected with SARS-CoV-2 require hospital care [4]. The vast majority of patients experience mild or subclinical forms of the disease that do not require hospital admission [5], and a relatively high percentage of patients (40% to 45%) remain asymptomatic [6].

Patients with SARS-CoV-2 frequently report fever, upper respiratory symptoms, myalgia, headache, and gastrointestinal disturbances [4,7] as well as olfactory and taste disorders [8]. However, the prevalence of COVID-19–related symptoms in the population of nonhospitalized patients has not been well investigated [9,10]. Early recognition of the conditions attributable to the infection is of paramount importance. This is particularly relevant for promptly identifying not only cases with severe clinical courses but also cases with milder symptomatology who can spread the infection and who must be immediately quarantined while testing and contact tracing is conducted.

This study is based on EPICOVID19, an anonymized self-administered web-based survey aimed at estimating the number of suspected cases of COVID-19 and investigating the role of potential determinants of SARS-CoV-2 infection in a large sample of respondents living in Italy during the lockdown, which started in Italy on March 9, 2020. The aims of this paper are to evaluate the association of self-reported symptoms with SARS-CoV-2 nasopharyngeal swab (NPS) test results in nonhospitalized individuals and to estimate the occurrence of COVID-19–like symptoms in the nontested population.

Methods

Study Design and Setting

EPICOVID19 is a national Italian internet-based survey that was conducted using a cross-sectional research design by a working group dedicated to collaborative public health research related to SARS-CoV-2. The survey was launched on April 13, 2020, and it targeted adult volunteers living in Italy during the lockdown. The study was registered (ClinicalTrials.gov NCT04471701).

Recruitment

To enroll as many participants as possible, the survey was promoted using social media (Facebook, Twitter, Instagram, and WhatsApp), press releases, web pages, local radio and television stations, and institutional websites that called upon volunteers to contact the study website [11]. The inclusion criteria were age >18 years; access to a mobile phone, computer, or tablet with internet connectivity; and provision of web-based consent to participate in the study.

Development of the Web-Based Questionnaire

EPICOVID19 was developed by the working group after a literature review of existing research into COVID-19, starting with the World Health Organization protocols [12], and of the standard and validated instruments previously used to investigate severe acute respiratory syndrome (SARS) and Middle Eastern respiratory syndrome (MERS) [13,14].

The questionnaire was adapted to the national context and implemented using the European Commission's open-source official EUSurvey management tool [15]. The participants were asked to complete the self-administered 38-item questionnaire, which mainly contained mandatory and closed questions divided into 6 sections: 1) sociodemographic data; 2) clinical evaluation;

3) personal characteristics and health status; 4) housing conditions; 5) lifestyle; and 6) behaviors following the lockdown (see Multimedia Appendix 1).

Data Collection and Variables

For the purposes of this study, we analyzed a subset of data collected between April 13 and 21, 2020. The sociodemographic information included sex (male and female), age (18 to 30, 30 to 39, 40 to 49, 50 to 59, 60 to 69, 70 to 79, and ≥80 years), educational level (primary school or less, middle or high school, and university degree or postgraduate degree), and occupational status (unemployed, employed, retired, student, and other). Smoking habits were classified as never smoked, former smoker, and current smoker. A new variable was created by summing the chronic conditions reported by participants, including lung diseases, heart diseases, hypertension, kidney diseases, immune system diseases, tumors, metabolic diseases, liver diseases, and depression and anxiety (categorized as no, 1, 2, or >3 comorbidities). The SARS-CoV-2–related symptoms included fever >37.5 degrees Celsius for at least three consecutive days; headache, chest pain, myalgia, olfactory and taste disorders, shortness of breath, and heart palpitations; gastrointestinal disturbances, including nausea, vomiting and diarrhea; conjunctivitis; and sore throat, rhinorrhea, and cough (all dichotomized as present/absent). The month of onset of the first symptoms (February/March/April 2020), NPS test results (categorized as not performed, performed with a negative result, performed with a positive result, and performed with an unknown result), and hospitalization for confirmed or suspected SARS-CoV-2 infection (dichotomized as yes/no) were also collected.

Study Group Definitions

To achieve the aims of this study, we defined three study samples:

1. Sample A, including the total population of respondents (N=171,310).
2. Subsample B, including nonhospitalized individuals and individuals who reported NPS tests with known results (n=4392).
3. Subsample C, including the nonhospitalized and nontested individuals (n=165,782).

Statistical Analysis

The continuous variables were expressed as mean (SD), and the categorical variables were expressed as counts and percentages. The chi-square test and one-way analysis of variance were used to compare the characteristics of respondents by NPS test results (sample A). The geographical coverage of the sample was evaluated by calculating the response rates by Italian region standardized by the number of residents aged >18 years on January 1, 2019 [16]. When analyzing subsample B, we calculated the matrix of pairwise tetrachoric correlations of self-reported symptoms, given the dichotomous nature of these variables. Crude and adjusted logistic regression models, controlling for age, sex, education, smoking habit, and number of comorbidities, were applied to assess the association between self-reported symptoms and SARS-CoV-2 positive NPS test versus negative NPS test by estimating the adjusted odds ratios (aORs) and 95% CIs. Subsequently, a numerical variable including all the symptoms significantly associated with NPS positivity was created and included in the logistic regression model instead of the single symptoms. Age- and sex-stratified analyses were also performed. In a sensitivity analysis, we excluded the respondents who reported February as the month of symptom onset to avoid possible confounding by influenza-like illness (the peak of the Italian influenza season in 2019-2020 occurred from January 27 to February 2) [17]. Finally, after assessing the sensitivity, specificity, and area under the curve (AUC) in a receiver operating characteristic (ROC) analysis, the symptoms significantly associated with positive NPS test results were combined as a proxy of COVID-19–like infection in subsample C. All the statistical analyses were carried out using SPSS version 25 (IBM Corp) and STATA version 15.0 (StataCorp LP). Two-tailed *P* values <.05 were considered statistically significant.

Ethics and Consent Form

The Ethics Committee of the Istituto Nazionale per le Malattie Infettive I.R.C.C.S. Lazzaro Spallanzani (Protocol No. 70, 12/4/2020) approved the EPICOVID19 study protocol. When participants first accessed the web-based platform, they were informed of the purpose of the study, the data to be collected, and the methods of storage, and they filled in the informed consent form. The planning, conduction, and reporting of the studies was in line with the Declaration of Helsinki as revised in 2013. Data were handled and stored in accordance with the European Union General Data Protection Regulation (EU GDPR) 2016/679, and data transfer was safeguarded by encrypting/decrypting and password protection.

Results

Characteristics of the Respondents

Table 1 summarizes the characteristics of the 171,310 respondents who completed the survey between April 13 and 21, 2020 (sample A). The respondents were prevalently female (102,543/171,310, 59.9%); the mean age of the female respondents was 46.8 years (SD 14.2) and that of the male respondents was 48.2 years (SD 15.0). Of the 171,310 respondents, 104,583 (61.0%) had a university degree or post-graduate qualification, and most were regularly employed (119,585, 69.8%). Smokers and ex-smokers accounted for 72,929/171,310 (42.6%) of the respondents, including 40,949/102,543 (39.9%) of the female respondents and 31,980/68,767 (46.5%) of the male respondents. About two-thirds of the 171,310 respondents (111,181, 64.9%) had no chronic conditions, and the vast majority (165,993, 96.9%) did not undergo NPS testing for SARS-CoV-2. Of the 5317/171,310 respondents (3.1%) who did undergo NPS testing, 1135 (21.3%) tested positive, 3650 (68.6%) tested negative, and 532 (10.0%) had not received the results at the time of completing the questionnaire. A total of 170,700 respondents were nonhospitalized.

Table 1. Characteristics of the survey respondents by sex (sample A).

Characteristic	Sex at birth		Total (N=171,310)
	Female (n=102,543, 59.9%)	Male (n=68,767, 40.1%)	
Age (years), mean (SD)	46.8 (14.2)	48.2 (15.0)	47.4 (14.5)
Age (years), n (%)			
18-30	13,538 (13.2)	8611 (12.5)	22,149 (12.9)
30-39	21,002 (20.5)	13,351 (19.4)	34,353 (20.1)
40-49	22,907 (22.3)	14,412 (21.0)	37,319 (21.8)
50-59	23,815 (23.2)	14,941 (21.7)	38,756 (22.6)
60-69	16,088 (15.7)	11,710 (17.0)	27,798 (16.2)
70-79	4386 (4.3)	4938 (7.2)	9324 (5.4)
≥80	807 (0.8)	804 (1.2)	1611 (0.9)
Education, n (%)			
Primary school or less	5036 (4.9)	4005 (5.8)	9041 (5.3)
Middle or high school	33,049 (32.2)	24,637 (35.8)	57,686 (33.7)
University degree or post-graduate degree	64,458 (62.9)	40,125 (58.3)	104,583 (61.0)
Occupational status, n (%)			
Unemployed	5632 (5.5)	2136 (3.1)	7768 (4.5)
Employed	70,577 (68.8)	49,008 (71.3)	119,585 (69.8)
Retired	12,281 (12.0)	10,594 (15.4)	22,875 (13.4)
Student	7196 (7.0)	4757 (6.9)	11,953 (7.0)
Other	6857 (6.7)	2272 (3.3)	9129 (5.3)
Smoking habit, n (%)			
Never smoked	61,594 (60.1)	36,787 (53.5)	98,381 (57.4)
Former smoker	22,017 (21.5)	18,986 (27.6)	41,003 (23.9)
Current smoker	18,932 (18.5)	12,994 (18.9)	31,926 (18.6)
Number of comorbidities, n (%)			
None	66,294 (64.6)	44,887 (65.3)	111,181 (64.9)
One	27,016 (26.3)	17,562 (25.5)	44,578 (26.0)
Two	7099 (6.9)	4841 (7.0)	11,940 (7.0)
Three or more	2134 (2.1)	1477 (2.1)	3611 (2.1)
Molecular test for SARS-CoV-2[a], n (%)			
Not performed	99,084 (96.6)	66,909 (97.3)	165,993 (96.9)
Performed, with a negative result	2440 (2.4)	1210 (1.8)	3650 (2.1)
Performed, with a positive result	668 (0.7)	467 (0.7)	1135 (0.7)
Performed, with an unknown result	351 (0.3)	181 (0.3)	532 (0.3)
Hospitalized for suspected/confirmed SARS-CoV-2 infection, n (%)	328 (0.3)	282 (0.4)	610 (0.4)
Not hospitalized with known molecular test results, n (%)	2931 (2.9)	1461 (2.1)	4392 (2.6)

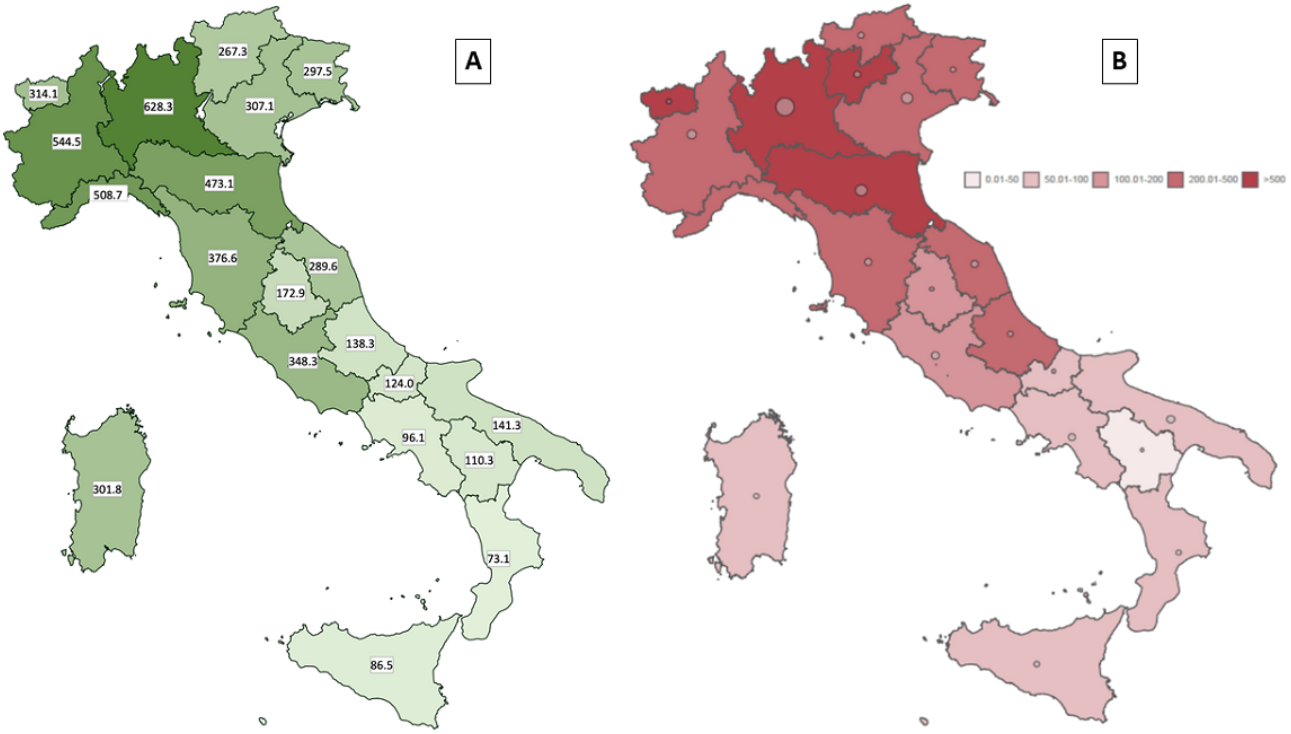
[a]SARS-CoV-2: severe acute respiratory syndrome coronavirus 2.

Of the 171,310 respondents, 610 (0.35%) said that they had been hospitalized between February 1 and April 21, 2020, including 399 of the 5317 respondents (7.5%) who were tested for SARS-CoV-2 infection (Supplementary Table S1 in Multimedia Appendix 2). Female and younger respondents were less likely to report positive NPS tests, whereas respondents who had a lower level of education or were retired more frequently reported positive NPS tests. Current smokers were less prevalent among the respondents with positive NPS tests (108/1135, 9.5%).

Geographical Coverage

Although the survey lacked a formal sampling strategy, a large number of participants were reached throughout Italy. Figure 1 shows the standardized response rates and the incidence of SARS-CoV-2 infection per 100,000 inhabitants by Italian region as of April 23, 2020 [16,18]. As expected, response rates were higher in the northern regions (Lombardy and Piedmont) and reflected the incidence of confirmed cases at that time.

Figure 1. Comparison of the survey response rates and the incidence of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) infection per 100,000 inhabitants by Italian region. A: Response rates × 100,000. B: Incidence rates of SARS-CoV-2 × 100,000.



Self-Reported Symptoms

Figure 2 shows that 68,337 of the 171,310 respondents (39.9%) indicated no symptoms. The most frequently reported symptoms were sore throat/rhinorrhea (56,324/171,310, 32.9%), headache (47,521/171,310, 27.7%), myalgia (32,856/171,310, 19.2%), gastrointestinal disturbances (28,212/171,310, 16.5%), conjunctivitis (15,872/171,310, 9.3%), and fever (13,752/171,310, 8.0%) (sample A). The absence of symptoms was less frequent among respondents with positive NPS tests than among those with negative tests (70/1135, 6.2%, vs 1100/3650, 30.1%), and there were also notable between-group differences in the frequency of fever (692/1135, 61.0%, vs 600/3650, 16.4%), olfactory and taste disorders (664/1135, 58.5%, vs 319/3650, 8.7%), myalgia (690/1135, 60.8%, vs 1015/3650, 27.8%), cough (653/1135, 57.5%, vs 1048/3650, 28.7%), headache (611/1135, 53.8%, vs 1265/3650, 34.7%), and gastrointestinal symptoms (508/1135, 44.8%, vs 863/3650, 23.6%). Table 2 shows that among 102,973 symptomatic respondents, the mean number of symptoms was 5.05 among respondents with positive NPS tests, 3.55 among respondents with unknown results, 3.16 among respondents with negative results, and 2.57 among respondents who did not undergo the molecular test (P<.001).

Figure 2. Self-reported symptoms by 171,310 survey respondents. Error bars are ±2*standard error (normal approximation).

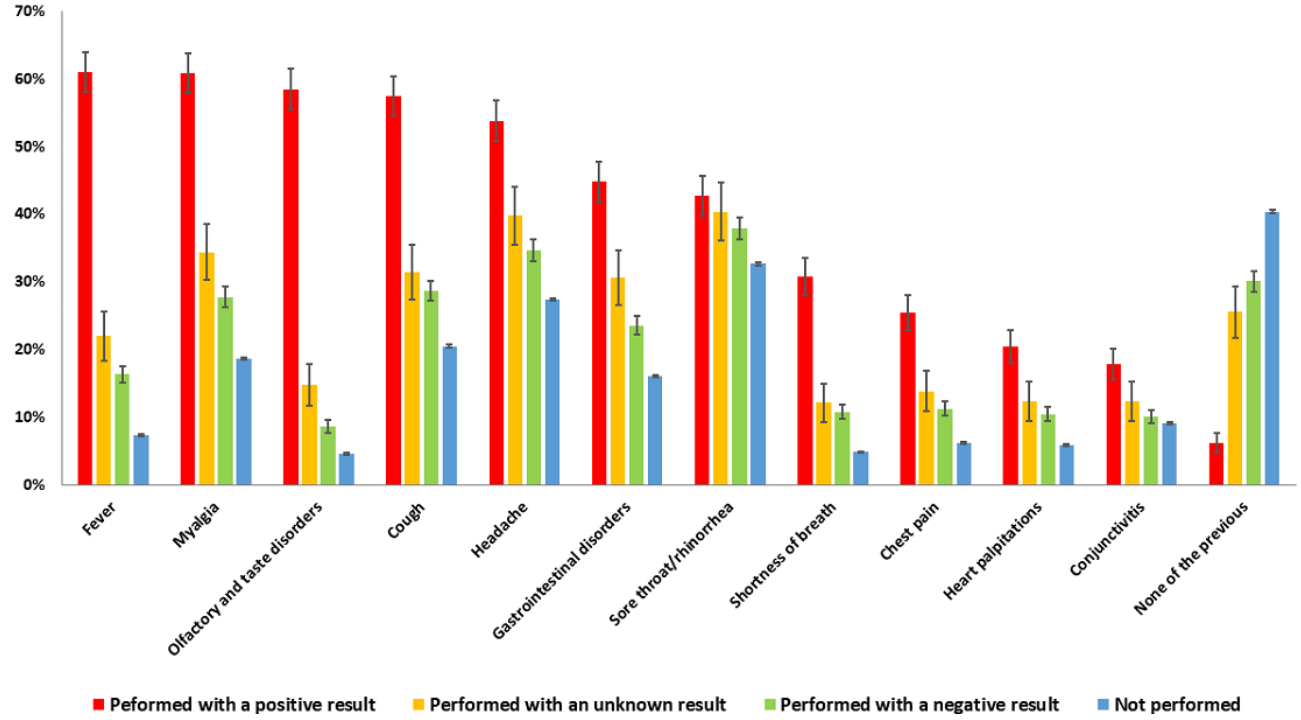


Table 2. Symptoms reported by survey respondents (n=102,973) and mean numbers of symptoms per symptomatic respondent based on molecular testing status.

Number of self-reported symptoms	Test performed with a positive result	Test performed with an unknown result	Test performed with a negative result	Test not performed	Total
Total (n)	5379	1407	8053	254,714	269,553
Per symptomatic respondent (mean)	5.05	3.55	3.16	2.57	2.62

In the tetrachoric correlation analysis between symptoms (Supplementary Table S2, Multimedia Appendix 2) performed in subsample B, values of the correlation coefficient >.6 were observed in the subgroup of symptoms including fever, olfactory and taste disorders, cough, and myalgia, while values <.3 were mainly observed for sore throat/rhinorrhea and conjunctivitis. In the same subsample B, from univariate and multiple logistic regression analysis controlling for sex, age, education, smoking habit, and number of comorbidities, all the considered symptoms were found to be positively associated with a positive NPS test (Table 3). In the final multiple regression model, with all symptoms included, olfactory and taste disorders (aOR 10.32, 95% CI 8.39-12.70), fever (aOR 2.46, 95% CI 1.98-3.05), myalgia (aOR 1.45, 95% CI 1.17-1.80), and cough (aOR 1.28, 95% CI 1.03-1.58) were found to be significantly associated with a positive NPS test. The odds of a positive test also increased with each additional year of age (aOR 1.02, 95% CI 1.01-1.03) and with male sex (aOR 1.34, 95% CI 1.11-1.63), whereas current smoking (aOR 0.66, 95% CI 0.50-0.87) was associated with decreased odds (data not shown). After adding the composite variables of fever, myalgia, cough, and olfactory and taste disorders to the model and simultaneously adjusting for the other symptoms, we found a strong positive and statistically significant association. The corresponding aORs for the presence of one, two, three, and four of these symptoms were 2.66 (95% CI 2.03-3.49), 7.35 (95% CI 5.57-9.70), 18.55 (95% CI 13.77-24.97), and 35.50 (95% CI 24.60-51.24), respectively.

Table 3. Odds ratios of positive molecular tests in nonhospitalized respondents with known molecular test results (n=4392, subsample B).

Symptom	Negative (n=3536, 80.5%), n (%)	Positive (n=856, 19.5%), n (%)	Model 1, OR[a] (95% CI)[b]	Model 2, aOR[c] (95% CI)[d]	Model 3, aOR (95% CI)[e]	*P* value[f]
Fever	518 (14.6)	444 (51.9)	6.28 (5.33-7.39)	6.08 (5.15-7.17)	2.46 (1.98-3.05)	<.001
Myalgia	961 (27.2)	527 (61.6)	4.29 (3.67-5.02)	4.33 (3.69-5.07)	1.45 (1.17-1.80)	.001
Olfactory and taste disorders	291 (8.2)	507 (59.2)	16.20 (13.51-19.42)	16.98 (14.07-20.48)	10.32 (8.39-12.70)	<.001
Cough	984 (27.8)	466 (54.4)	3.10 (2.66-3.61)	3.09 (2.65-3.61)	1.28 (1.03-1.58)	.02
Shortness of breath	335 (9.5)	182 (21.3)	2.58 (2.12-3.15)	2.63 (2.15-3.23)	0.89 (0.67-1.18)	.40
Chest pain	386 (10.9)	206 (24.1)	2.59 (2.14-3.12)	2.61 (2.15-3.16)	0.92 (0.70-1.20)	.54
Heart palpitations	354 (10.0)	165 (19.3)	2.15 (1.75-2.63)	2.21 (1.80-2.72)	0.93 (0.70-1.23)	.61
Gastrointestinal disturbances	817 (23.1)	382 (44.6)	2.68 (2.30-3.13)	2.82 (2.40-3.30)	1.20 (0.98-1.48)	.08
Conjunctivitis	351 (9.9)	156 (18.2)	2.02 (1.65-2.48)	2.07 (1.68-2.55)	1.11 (0.85-1.45)	.45
Sore throat/rhinorrhea	1332 (37.7)	415 (48.5)	1.56 (1.34-1.81)	1.64 (1.40-1.91)	0.87 (0.71-1.07)	.18
Headache	1213 (34.3)	485 (56.7)	2.50 (2.15-2.91)	2.64 (2.26-3.09)	1.18 (0.95-1.45)	.13
Number of symptoms[g]						
None	1931 (54.6)	118 (13.8)	1	1	1	N/A[h]
One	854 (24.1)	133 (15.5)	2.55 (1.96-3.31)	2.61 (2.01-3.39)	2.66 (2.03-3.49)	<.001
Two	441 (12.5)	185 (21.6)	6.86 (5.33-8.84)	7.06 (5.47-9.12)	7.35 (5.57-9.70)	<.001
Three	222 (6.3)	239 (27.9)	17.62 (13.58-22.86)	17.86 (13.71-23.27)	18.55 (13.77-24.97)	<.001
All	88 (2.5)	181 (21.1)	33.66 (24.56-46.14)	34.02 (24.71-46.85)	35.50 (24.60-51.24)	<.001

[a]OR: odds ratio.

[b]Crude ORs.

[c]aOR: adjusted odds ratio.

[d]Controlling for sex, age, education, smoking habit, and number of comorbidities.

[e]Controlling for sex, age, education, smoking habit, and number of comorbidities, including all symptoms.

[f]*P* values refer to model 3.

[g]Ordinal variable summing the presence of fever, myalgia, cough, and olfactory and taste disorders.

[h]N/A: not applicable.

Excluding the respondents who indicated that their first symptom appeared in February from the sensitivity analysis did not substantially change the results (Supplementary Table S3 in Multimedia Appendix 2).

Tables 4 and 5 show the results of the sex- and age-stratified multiple regression analyses. Olfactory and taste disorders were more closely associated with the odds of a positive test in female respondents (aOR 12.10, 95% CI 9.35-15.67) and respondents aged <50 years (aOR 15.88, 95% CI 12.10-20.84), whereas fever was more closely associated with a positive NPS test in male respondents (aOR 3.90, 95% CI 2.72-5.59) and respondents aged >50 years (aOR 3.46, 95% CI, 2.50-4.78).

Table 4. Sex-specific adjusted odds ratios of positive molecular tests in nonhospitalized survey respondents with known molecular test results (n=4392, subsample B).

Symptom	Female respondents (n=2931, 66.7%)				Male respondents (n=1461, 33.3%)			
	Negative test (n=2376, 81.1%), n (%)	Positive test (n=555, 18.9%), n (%)	aOR[a,b] (95% CI)	*P* value	Negative test (n=1160, 79.4%), n (%)	Positive test (n=301, 20.6%), n (%)	aOR (95% CI)	*P* value
Fever	341 (14.4)	272 (49.0)	1.87 (1.42-2.46)	<.001	177 (15.3)	172 (57.1)	3.90 (2.72-5.59)	<.001
Myalgia	674 (28.4)	352 (63.4)	1.42 (1.08-1.87)	.01	287 (24.7)	175 (58.1)	1.42 (0.99-2.06)	.06
Olfactory and taste disorders	210 (8.8)	357 (64.3)	12.10 (9.35-15.67)	<.001	81 (7.0)	150 (49.8)	8.58 (5.92-12.43)	<.001
Cough	667 (28.1)	306 (55.1)	1.34 (1.03-1.74)	.03	317 (27.3)	160 (53.2)	1.13 (0.79-1.62)	.50
Shortness of breath	239 (10.1)	131 (23.6)	0.88 (0.63-1.23)	.45	96 (8.3)	51 (16.9)	0.91 (0.54-1.55)	.74
Chest pain	276 (11.6)	154 (27.7)	1.04 (0.76-1.44)	.79	110 (9.5)	52 (17.3)	0.72 (0.43-1.18)	.19
Heart palpitations	279 (11.7)	129 (23.2)	0.91 (0.66-1.27)	.60	75 (6.5)	36 (12.0)	1.10 (0.62-1.94)	.75
Gastrointestinal disturbances	587 (24.7)	266 (47.9)	1.14 (0.88-1.48)	.34	230 (19.8)	116 (38.5)	1.34 (0.94-1.92)	.11
Conjunctivitis	244 (10.3)	112 (20.2)	1.19 (0.86-1.64)	.29	107 (9.2)	44 (14.6)	1.00 (0.61-1.63)	.99
Sore throat/rhinorrhea	950 (40.0)	279 (50.3)	0.77 (0.60-0.99)	.04	382 (32.9)	136 (45.2)	1.06 (0.75-1.49)	.76
Headache	900 (37.9)	338 (60.9)	1.09 (0.84-1.42)	.50	313 (27.0)	147 (48.8)	1.33 (0.93-1.90)	.11
Number of symptoms[c]								
None	1288 (54.2)	73 (13.2)	1	N/A[d]	643 (55.4)	45 (15.0)	1	N/A[d]
One	566 (23.8)	85 (15.3)	2.81 (2.00-3.96)	<.001	288 (24.8)	48 (15.9)	2.39 (1.53-3.72)	<.001
Two	306 (12.9)	112 (20.2)	7.13 (5.00-10.16)	<.001	135 (11.6)	73 (24.3)	7.95 (5.06-12.47)	<.001
Three	150 (6.3)	162 (29.2)	20.35 (14.00-29.57)	<.001	72 (6.2)	77 (25.6)	15.30 (9.29-25.22)	<.001
All	66 (2.8)	123 (22.2)	35.28 (22.44-55.47)	<.001	22 (1.9)	58 (19.3)	39.65 (20.69-76.00)	<.001

[a]aOR: adjusted odds ratio.

[b]After controlling for sex, age, education, smoking habit, and number of comorbidities.

[c]Ordinal variable summing up the presence of fever, myalgia, cough, and olfactory and taste disorders.

[d]N/A: not applicable.

Table 5. Age-specific adjusted odds ratios of positive molecular tests in nonhospitalized respondents with known molecular test results (n=4392, subsample B).

Symptom	Age <50 years (n=2659, 60.5%)				Age ≥50 years (n=1733, 39.5%)			
	Negative test (n=2176, 81.8%), n (%)	Positive test (n=483, 19.2%), n (%)	aOR[a,b] (95% CI)	*P* value	Negative (n=1360, 78.5%), n (%)	Positive (n=373, 21.5%), n (%)	aOR (95% CI)	*P* value
Fever	341 (15.7)	239 (49.5)	1.98 (1.47-2.65)	<.001	177 (13.0)	205 (55.0)	3.46 (2.50-4.78)	<.001
Myalgia	599 (27.5)	308 (63.8)	1.61 (1.20-2.18)	.002	362 (26.6)	219 (58.7)	1.35 (0.98-1.86)	.07
Olfactory and taste disorders	177 (8.1)	323 (66.9)	15.88 (12.10-20.84)	<.001	114 (8.4)	184 (49.3)	5.25 (3.75-7.34)	<.001
Cough	639 (29.4)	266 (55.1)	1.14 (0.85-1.53)	.37	345 (25.4)	200 (53.6)	1.39 (1.02-1.91)	.04
Shortness of breath	223 (10.2)	117 (24.2)	0.90 (0.62-1.31)	.58	112 (8.2)	65 (17.4)	0.79 (0.51-1.23)	.29
Chest pain	267 (12.3)	133 (27.5)	0.95 (0.67-1.35)	.76	119 (8.8)	73 (19.6)	0.90 (0.59-1.38)	.63
Heart palpitations	243 (11.2)	101 (20.9)	0.80 (0.55-1.17)	.25	111 (8.2)	64 (17.2)	1.12 (0.73-1.73)	.60
Gastrointestinal disturbances	543 (25.0)	231 (47.8)	1.33 (1.00-1.76)	.048	274 (20.1)	151 (40.5)	1.14 (0.83-1.57)	.42
Conjunctivitis	198 (9.1)	80 (16.6)	0.93 (0.64-1.36)	.71	153 (11.3)	76 (20.4)	1.34 (0.92-1.97)	.13
Sore throat/rhinorrhea	918 (42.2)	272 (56.3)	0.89 (0.68-1.17)	.41	414 (30.4)	143 (38.3)	0.85 (0.63-1.16)	.31
Headache	837 (38.5)	300 (62.1)	1.23 (0.92-1.63)	.16	376 (27.6)	185 (49.6)	1.21 (0.88-1.65)	.24
Number of symptoms[c]								
None	1167 (53.6)	52 (10.8)	1	N/A[d]	764 (56.2)	66 (17.7)	1	N/A[d]
One	521 (23.9)	80 (16.6)	3.70 (2.54-5.41)	<.001	333 (24.5)	53 (14.2)	1.83 (1.23-2.73)	.003
Two	285 (13.1)	101 (20.9)	8.91 (6.03-13.15)	<.001	156 (11.5)	84 (22.5)	6.20 (4.14-9.30)	<.001
Three	147 (6.8)	146 (30.2)	24.39 (16.19-36.75)	<.001	75 (5.5)	93 (24.9)	13.98 (8.92-21.90)	<.001
All	56 (2.6)	104 (21.5)	45.86 (27.94-75.29)	<.001	32 (2.4)	77 (20.6)	26.27 (14.95-46.17)	<.001

[a]aOR: adjusted odds ratio.

[b]After controlling for sex, age, education, smoking habit, and number of comorbidities.

[c]Ordinal variable summing up the presence of fever, myalgia, cough, and olfactory and taste disorders.

[d]N/A: not applicable.

After dichotomizing for the presence of two or more and of three or more symptoms, the resulting aORs were 12.17 (95% CI 9.50-15.59) and 22.44 (95% CI 16.93-29.75). When the four symptoms were singularly analyzed, a larger AUC (0.749, 95% CI 0.730-0.767) was found for olfactory and taste disorders, which were also characterized by a better specificity of 91.8%; however, myalgia showed higher sensitivity (61.6%) in classifying positive NPS tests. The combination of the four symptoms increased the AUC to 0.810 (95% CI 0.795-0.825), with higher sensitivity at the cutoff of two or more symptoms (70.7%) and higher specificity at the cutoff of three or more symptoms (91.2%) (data not shown).

As a final step, we quantified the number of probable SARS-CoV-2 infections in the nonhospitalized and nontested populations (subsample C) by calculating the frequencies for the combination of the four symptoms resulting from the analysis of subsample B. We found that 20,103 of the 165,782 respondents in subsample C (12.1%, 95% CI 12.0%-12.3%) had two or more symptoms suggestive of novel coronavirus disease and 7739 respondents (4.4%, 95% CI 4.3%-4.6%) had three or more symptoms, with accuracies of 77.2% and 83.0%, respectively.

Discussion

Principal Findings

This study, based on the responses of >170,000 persons to a web-based survey, outlined the COVID-19 symptom profiles of cases that did not require hospitalization during the outbreak of the epidemic in Italy. Olfactory and taste disorders, myalgia, fever, and cough are symptoms associated with laboratory-proven SARS-CoV-2 infection. Among 165,782 nonhospitalized and nontested respondents, 7739 to 20,103 (4.4% to 12.1%) experienced symptoms suggestive of COVID-19.

Although 102,973 of the 171,310 respondents (60.1%) reported at least one symptom compatible with viral infection, only 3.4% of these respondents had access to NPS testing for

SARS-CoV-2. Respondents with at least one symptom accounted for 1065/1135 (93.8%) of patients with positive NPS tests, 2550/3650 (69.9%) of patients with negative NPS tests, and 396/532 (74.4%) of patients with unknown NPS test results. We here report that subgroups with symptomatology similar to that of people with positive NPS tests were not tested; this is a worrying finding that suggests that a large number of cases remained undiagnosed or were not correctly quarantined [19]. Active case finding with prompt isolation and contact tracing is a highly important means of ending the spread of SARS-CoV-2 infection [20], which otherwise is likely to continue through households [21]. The very limited number of respondents who were diagnosed based on NPS testing is a consequence of the decision by health authorities to reserve the use of diagnostics for clinically severe cases, thus creating suboptimal conditions for effective contact tracing.

A number of papers have described the clinical characteristics, symptoms, and disease course of inpatients [22,23] and outpatients [24] with SARS-CoV-2; however, little is still known about the natural history of the infection and its clinical spectrum or rate of symptoms in nonhospitalized cases with COVID-19. In our analyses, we showed a strong association between olfactory and taste disorders and positive NPS tests; respondents with positive NPS tests had a more than 10-fold increased risk of having olfactory and taste disorders. In line with our findings, olfactory and taste disorders have been reported to be symptoms specific of SARS-CoV-2 infection in clinical [8,25] and nonclinical [9,26,27] settings. Among 18,401 users of a COVID symptom tracker mobile app in the United Kingdom and United States who underwent molecular testing, loss of smell in addition to fever and persistent cough were found to be potential predictors of COVID-19 [9]. Similar results were recently reported from two other web-based surveys of Italian [26] and French [27] populations. Consistent with the aforementioned population studies, we also found that other COVID-19–related symptoms as fever, myalgia, or cough were significantly associated with positive NPS test results, although the association was less specific than that of olfactory and taste disorders. Overall, the four above-mentioned symptoms demonstrated an additive effect that increases the probability of a positive NPS test.

Interestingly, our subset analyses revealed some associations between the respondents' symptoms and their demographic characteristics. The association between olfactory and taste disorders and positive NPS test results was stronger in younger patients, possibly because the known deterioration in the sense of smell during aging [28] means that younger respondents are more likely to notice its loss. We also found that positive NPS test results were more closely associated with olfactory and taste disorders in women and with fever in men, although both symptoms were significantly associated with positive NPS tests in both sexes. An association between female sex and olfactory and taste disorders has also been reported in hospitalized COVID-19 patients [8].

Notably, in the subpopulation of 165,782 participants who had not undergone NPS testing and were nonhospitalized, we calculated with an accuracy close to 80% that 12.1% of these participants had two or more of these symptoms and 4.4% had three or more, indicating a substantial number of adults with COVID-19–like illness. Applying the most conservative criterion (presence of three or more symptoms at the same time), characterized by a specificity of 91.2%, we estimated that about 2.2 million Italian adults had high probability of being symptomatic for COVID-19 up to April 21, 2020.

The estimation of the real proportion of the infected population is a fundamental indicator for public health policy makers in the ongoing COVID-19 pandemic. During the epidemic peak, model-based estimates [29] suggested that the ratio of notified to actual cases ranged from 1:5 to 1:20. However, to date in Italy, real-world data have been limited to restricted local settings or have only been available in the case of NPS testing of symptomatic patients with serious illness who require intensive or subintensive medical care. This lack has led to a wide underestimation of the spread of COVID-19 in mildly symptomatic individuals or in those with limited access to testing. Our results appear to be quite consistent with those of other surveys performed in large populations. A model that combined symptoms to predict probable infection was applied to the data derived from the COVID symptom tracker mobile app in the United Kingdom and United States [9], and the results indicated that 17.4% of users were likely to have COVID-19–like infection. Data from a nationally representative survey in Canada indicated that approximately 8% of adults reported that they or someone in their household had symptoms suggestive of COVID-19 in March 2020 [10].

These findings suggest that during a pandemic, when testing and contact tracing should be prioritized, the presence of such symptoms, also detected through a simple anamnestic investigation, may be an early indicator of SARS-CoV-2 infection in individuals who should be quarantined and molecularly tested.

It is also interesting to note that 66/856 (7.7%) of nonhospitalized patients with a positive NPS test reported no symptoms. A number of studies have suggested that asymptomatic patients can spread the virus [30,31]. According to the results of 16 SARS-CoV-2 testing studies pooled by Oran and colleagues, asymptomatic persons accounted for approximately 40% to 45% of COVID-19 infections [6]. In an Italian population study carried out on about 2500 residents in the municipality of Vò, the authors showed that the age-adjusted prevalence of COVID-19 asymptomatic cases was 43.2% (95% CI 32.2%-54.7%) [5]. Due to the characteristics of our study, it is unsuitable for precisely estimating the percentage of completely asymptomatic individuals, and our lower-than-expected findings can be explained by the limited access to molecular testing for asymptomatic individuals and by the possible overreporting of symptoms.

Our data concerning an apparently protective role of smoking in relation to positive NPS test results add new evidence to a panorama in which it has been suggested that this habit may have divergent clinical, prognostic, and epidemiological effects in patients with COVID-19 [32]. This issue will be investigated in more detail in a separate paper to contribute further to the current debate [33].

Study Limitations and Strengths

Given the voluntary nature of the survey, it was not intended to assess a representative sample of the general population. However, extensive participation allowed us to collect a sample that is quite balanced although it is more shifted toward women and younger respondents with a higher level of education, as can be expected from a web-based questionnaire. The characteristics of a web-based survey may have also introduced a bias that led people with symptoms to respond more often than those without symptoms, and people who are health-conscious may have exaggerated (overreported) their symptoms. In addition, some symptoms (eg, olfactory and taste disorders) are more likely to be subject to recall bias due to media emphasis on their association with the disease.

At the date of the survey collection, the NPS testing rate among Italian adults (age ≥18 years) was estimated to be 1.92% [3], versus 3.10% among responders to the EPICOVID19 survey; this is suggestive of a greater propensity to participate for individuals who felt at higher risk, for symptomatology or closeness to COVID-19 cases. On April 21, the total number of SARS-CoV-2 cases in Italy was 183,957 [3] of the 971,246 individuals who underwent the NPS test, with an NPS-positive cumulative prevalence rate of 18.9%, similar to the rate of 23.7% observed in our study. By that time, the cumulative number of hospitalized patients with COVID-19 in Italy was 78,205, and the number of deceased due to COVID-19 (unknown if hospitalized) was 24,648. The cumulative prevalence rate of hospitalized COVID-19 cases therefore ranged from 0.15% to 0.20% among Italian adults. The total number of EPICOVID19 respondents who were hospitalized for suspected or confirmed COVID-19 illness was 610/171,310 (0.36%); among these patients, 279 (0.16%) had positive NPS tests, in line with the hospitalization rates in the general population.

As the sample was self-selected, our results should be generalized with caution. Finally, a single self-reported negative test cannot exclude a possible SARS-CoV-2 infection.

Web-based surveys have become an accepted, low-cost, and scalable means of efficiently and rapidly involving a large number of people in a study regardless of geographical distance [34,35]; therefore, they are preferable to more traditional, time-consuming, and expensive methods, especially in an ongoing emergency situation. Further, in the context of this outbreak, the EPICOVID19 survey may have included people who have had no other opportunity to report their symptoms. It is noteworthy that our survey achieved satisfactory geographical coverage; as expected, the coverage was proportional to the distribution of COVID-19 infection and to the reasonable likelihood that communities living in more affected areas would be more willing to respond.

To the best of our knowledge, this is the largest Italian web-based survey of SARS-CoV-2 symptoms; notably, it was carried out during the peak of the epidemic in Italy, when data at the population level were unavailable. National authorities, health care workers, and the public have received little information about the real spread of the infection since it started. Our preliminary findings shed some light on paucisymptomatic or mild infections with COVID-19 in Italy.

Conclusions

The adoption of effective strategies and ready-to-use digital tools such as the real-time reporting internet-based survey EPICOVID19 to ascertain the positivity of paucisymptomatic carriers is still urgently needed in Italy and worldwide. The implementation of these strategies is also fundamental in countries, like those in Europe, where the spread of the infection is currently declining but where programs of active surveillance are necessary to reduce the risk of a new SARS-CoV-2 outbreak in the future. Many individuals with COVID-like infection are destined to remain beyond the control of health authorities, thus representing an important source of further spread of the infection. The determination of a symptomatic profile capable of easily identifying a suspected case may greatly contribute to containing the pandemic. Although they are also associated with other respiratory tract infections, the simultaneous presence of symptoms such as fever, cough, myalgia, and olfactory and taste disorders revealed by this study appears to be associated with a high probability of carrying active SARS-CoV-2 infection in a pandemic context.

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Authors' Contributions

FA and FP contributed equally to this paper. FA and FP had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. MG, FA, FP, FB, AG, GP, SR, RAI, and MT conceptualized and designed the study. MG, FP, FA, FB, AG, and GP drafted the manuscript. FA and FP analyzed the data. SR, SMa, CT, MN, SMo, LB, AS, NJ, CP, DB, MT, MA, CM, and RAI critically revised the manuscript for important intellectual content. NJ and LF provided technical and material support. RAI, SMa, and MG supervised the study. All authors participated in the data interpretation

and read and approved the final version of the manuscript. The corresponding author, MG, attests that all listed authors meet authorship criteria and that no others meeting the criteria have been omitted.

Conflicts of Interest

None declared.

Multimedia Appendix 1
EPICOVID19 web-based survey questionnaire.
[DOCX File , 36 KB - publichealth_v6i3e21866_app1.docx]

Multimedia Appendix 2
Supplementary tables.
[DOCX File , 22 KB - publichealth_v6i3e21866_app2.docx]

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Abbreviations

aOR: adjusted odds ratio
AUC: area under the curve
COVID-19: coronavirus disease
EU GDPR: European Union General Data Protection Regulation
MERS: Middle Eastern respiratory syndrome
NPS: nasopharyngeal swab
ROC: receiver operating characteristic
SARS: severe acute respiratory syndrome
SARS-CoV-2: severe acute respiratory syndrome coronavirus 2

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Original Paper

Hospital Epidemics Tracker (HEpiTracker): Description and Pilot Study of a Mobile App to Track COVID-19 in Hospital Workers

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Abstract

Background: Hospital workers have been the most frequently and severely affected professional group during the COVID-19 pandemic, and have a big impact on transmission. In this context, innovative tools are required to measure the symptoms compatible with COVID-19, the spread of infection, and testing capabilities within hospitals in real time.

Objective: We aimed to develop and test an effective and user-friendly tool to identify and track symptoms compatible with COVID-19 in hospital workers.

Methods: We developed and pilot tested Hospital Epidemics Tracker (HEpiTracker), a newly designed app to track the spread of COVID-19 among hospital workers. Hospital staff in 9 hospital centers across 5 Spanish regions (Andalusia, Balearics,

Catalonia, Galicia, and Madrid) were invited to download the app on their phones and to register their daily body temperature, COVID-19–compatible symptoms, and general health score, as well as any polymerase chain reaction and serological test results.

Results: A total of 477 hospital staff participated in the study between April 8 and June 2, 2020. Of note, both health-related (n=329) and non–health-related (n=148) professionals participated in the study; over two-thirds of participants (68.8%) were health workers (43.4% physicians and 25.4% nurses), while the proportion of non–health-related workers by center ranged from 40% to 85%. Most participants were female (n=323, 67.5%), with a mean age of 45.4 years (SD 10.6). Regarding smoking habits, 13.0% and 34.2% of participants were current or former smokers, respectively. The daily reporting of symptoms was highly variable across participating hospitals; although we observed a decline in adherence after an initial participation peak in some hospitals, other sites were characterized by low participation rates throughout the study period.

Conclusions: HEpiTracker is an already available tool to monitor COVID-19 and other infectious diseases in hospital workers. This tool has already been tested in real conditions. HEpiTracker is available in Spanish, Portuguese, and English. It has the potential to become a customized asset to be used in future COVID-19 pandemic waves and other environments.

Trial Registration: ClinicalTrials.gov NCT04326400; https://clinicaltrials.gov/ct2/show/NCT04326400

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KEYWORDS

app; COVID-19; coronavirus; e-medicine; monitoring; symptoms; surveillance

Introduction

The rapid spread of severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), the virus responsible for COVID-19, requires an urgent, collaborative, and multidisciplinary response supported by innovative methods [1]. Hospital staff (including both health-related and non–health-related professionals) form the backbone of the response to the ongoing pandemic. However, these professionals are among the most frequently and severely affected by COVID-19 [2,3]. Indeed, the disease has had a tremendous impact on the hospital workforce of affected areas due to the high risk of infection and heavy workloads. The dissemination of SARS-CoV-2 within hospitals may result in large nosocomial outbreaks and other devastating consequences. In the current scenario, timely information on how these risks evolve and are managed is almost anecdotal and reliable scientific data are urgently needed. In addition, understanding the determinants of SARS-CoV-2 infection and transmission by individuals with asymptomatic or very mild symptomatic cases of COVID-19 is crucial for the design of containment strategies.

In August 2020, the World Health Organization (WHO) declared that the COVID-19 pandemic is far from controlled. The cumulative number of confirmed COVID-19 cases across 216 countries, areas, or territories worldwide amounts to over 21,989,366, and 775,893 confirmed deaths have been reported to date [4]. Record daily numbers of both infections and deaths are seen in many countries, with many of them already experiencing “second waves” after lockdowns were lifted [5]. Spain is among the countries hardest hit by the pandemic, with over 376,000 total cases and over 28,000 deaths as of August 2020 [6].

COVID-19–related symptoms are nonspecific, resembling common cold symptoms in immunocompetent individuals. According to the Centers for Disease Control and Prevention (CDC) [7], the list of common COVID-19 symptoms includes fever, cough, and shortness of breath that may appear 2 to 14 days after exposure to SARS-CoV-2; other nonrespiratory symptoms are also frequent [8]. Whenever these symptoms appear with epidemiological evidence (ie, after close contact with an infected subject or after visiting an area with ongoing community spread), further clinical assessment is needed.

The real-time assessment of COVID-19–related symptoms, their spread, and testing capabilities in hospital settings requires the use of innovative tools. In this context, digital health technologies have great potential to improve surveillance and epidemic control, primarily through increased information coverage, faster acquisition and distribution of information, rapid case tracking, and improved proximity tracing [9-11]. Consequently, smartphone- and web-based health apps aimed at tracking COVID-19 are on the rise. Although digital tools can promote public health, they can be intrusive, erode individual freedoms, or leave vulnerable populations behind [12].

Here, we summarize the development of Hospital Epidemics Tracker (HEpiTracker) [13], a newly designed app to track COVID-19 and other epidemics in hospitals. We also describe the pilot study performed across different areas and phases of the outbreak. The goal of the app is to help already overwhelmed hospital staff to actively monitor and assess COVID-19 infections and compatible symptoms in a population of hospital workers. We provide the basic data of the app and descriptive statistics of the pilot study, which illustrate the applicability of HEpiTracker in practical settings.

Methods

Overview

On March 14, 2020, a multidisciplinary group of individuals with varied backgrounds held the first of many daily meetings to discuss, by means of a “think tank” approach, research avenues aimed at mitigating the impact of the COVID-19 crisis. As part of the Active Monitoring And Determinants of Incident Infection of COVID-19 in a Hospital population (AMADIICH) initiative, this multidisciplinary group created a framework designed to collect large amounts of heterogeneous data

regarding COVID-19 in hospital staff, from shoe-leather epidemiology to big data and biosensors [14-16]. One of the main priorities of the group was speed, and the tools were designed with the aim of being applied during the first wave of COVID-19, and any subsequent outbreaks. Ethics approval of the AMADIICH research protocol was granted by the University Hospital of la Princesa's ethics board on March 19, 2020 (Proceedings of the Standing Commission CEIm 02/20, registry number 4061). The study was registered on ClinicalTrials.gov with the identifier NCT04326400. Individual informed consent was a requirement of participation and was obtained on the first screen of the HEpiTracker app, with tick boxes to give or deny consent.

The standard process of reporting COVID-19–related symptoms differs by area and center, but typically starts with a phone call from the employee to the occupational health unit (OHU) of the center. The employee is then advised to self-isolate at home, where he/she receives a polymerase chain reaction (PCR) test. If the test is positive, he/she remains in home isolation. If the test is negative but there are symptoms, the employee remains in isolation and the test is repeated during the following days. Therefore, workers can only return to work once they do not have symptoms and have returned two consecutive negative PCR tests. The OHU should always have access to the status of all employees and is typically responsible for escalating the data. The purpose of the HEpiTracker app is to provide an easier, homogenous, and transparent way of tracking positive PCR results and symptoms. The tracking happens automatically and relieves the health manager from manually updating the aggregated information and calculating statistics. It can also provide the updated information to the workers themselves in a transparent manner.

We provide descriptive data obtained in the pilot study that illustrate the applicability of the app in practical settings. We would like to clarify that we do not intend to study the factors behind app adoption or the effect these types of tools have on infection rates. These, and other related issues, are beyond the scope of this article. What we do present is a working app that can help already overwhelmed hospital staff to actively monitor and assess COVID-19 infections and compatible symptoms in the hospital worker population.

App Development Process

As mentioned above, a mobile app to help monitor the spread of COVID-19 within hospitals was conceived after a state of emergency and full lockdown were declared in Spain on March 14, 2020. Following initial discussions and ethical approval, a stepwise approach was carried out by ASELCIS software developers [17] to create the first version of the new app within a week and then to enhance its functionalities regularly. After several iterations, a minimum set of variables to include in the HEpiTracker App were identified, including demographic and occupational data, symptoms, previous comorbidities, and lab testing variables (Table 1).

There was a feedback process from users within our scientific committee, which includes doctors, nurses, computer science specialists, mathematicians, physicists, and statisticians, but not patients themselves, although during the development of the app several authors became infected or were quarantined due to COVID-19. The app also included a self-assessment of overall health status based on an ordinal Likert scale from 0 to 10. HEpiTracker was made available for both Android and iOS operating systems at Google and Apple stores, respectively.

Once HEpiTracker was up and running, we designed a pilot study in real-world conditions to test the feasibility of the app. Specifically, we tested the app in several hospitals across regions with different incidence rates and undergoing different phases of the COVID-19 pandemic: Hospital Can Misses (Eivissa) from April 9, 2020; Hospital Lucus Augusti (Lugo) from April 10, 2020; Hospital Álvaro Cunqueiro (Vigo) from April 10, 2020; Hospital Institut Català d'Oncologia (ICO; l'Hospitalet, Badalona, Girona, Tarragona-Terres de l'Ebre) from April 8, 2020; Hospital de Alta Resolución Loja (Granada) from April 13, 2020; and Hospital Universitario de La Princesa (Madrid) from April 9, 2020.

Hospital staff in 5 Spanish autonomous communities (Andalusia, Balearics, Catalonia, Galicia, and Madrid) were invited to download the app on their smartphones [13], and to register their daily body temperature, COVID-19–compatible symptoms, and general health score, as well as any PCR or serological test results. All staff in the participating hospitals, namely doctors, nurses, technicians, administrative workers, wardens, cleaners, managers, cafeteria staff, security, and other occupations were invited to participate, with no exclusion criteria.

In addition to answering Yes/No for the presence of daily symptoms, participants self-assessed their overall health by means of a visual analog scale (VAS), and they disclosed whether they had a history (either of diagnosis or treatment) of rhinitis, allergy, or chronic obstructive pulmonary disease (COPD)/chronic bronchitis, as well as their smoking status. Further, participants manually entered their body temperature in degrees Celsius to one decimal. They were also invited to register the outcome and the date of any COVID-19 laboratory test (PCR, IgG, or IgM); these could have been performed routinely at their center, throughout the study by risk exposure, or as a result of the presence of symptoms or suspicion of having the disease (Figure 1).

Table 1. Variables included in the HEpiTracker App.

Type and variable	Values
Demographic data	
Personal ID	DNI/NIE[a] and email
Age (years)	18-122
Sex	Male/Female
Occupational data	
Current job category	Physician, nurse, technician, administrative, warden, cleaner, manager, cafeteria, security, other[b]
Department	Service[c]
Symptoms	
Body temperature	Degrees Celsius, reported to one decimal
Cough	Yes/No
Shortness of breath	Yes/No
Odynophagia or pain when swallowing	Yes/No
Malaise	Yes/No
Alterations of sense of smell	Yes/No
"My health today is…"	Visual analog scale from 0 to 10
Previous comorbidities	
Rhinitis	Yes/No
Asthma	Yes/No
Chronic bronchitis or chronic obstructive pulmonary disease	Yes/No
Smoker	Never/former/current
Lab testing	
COVID-19 test[d]	Positive or negative

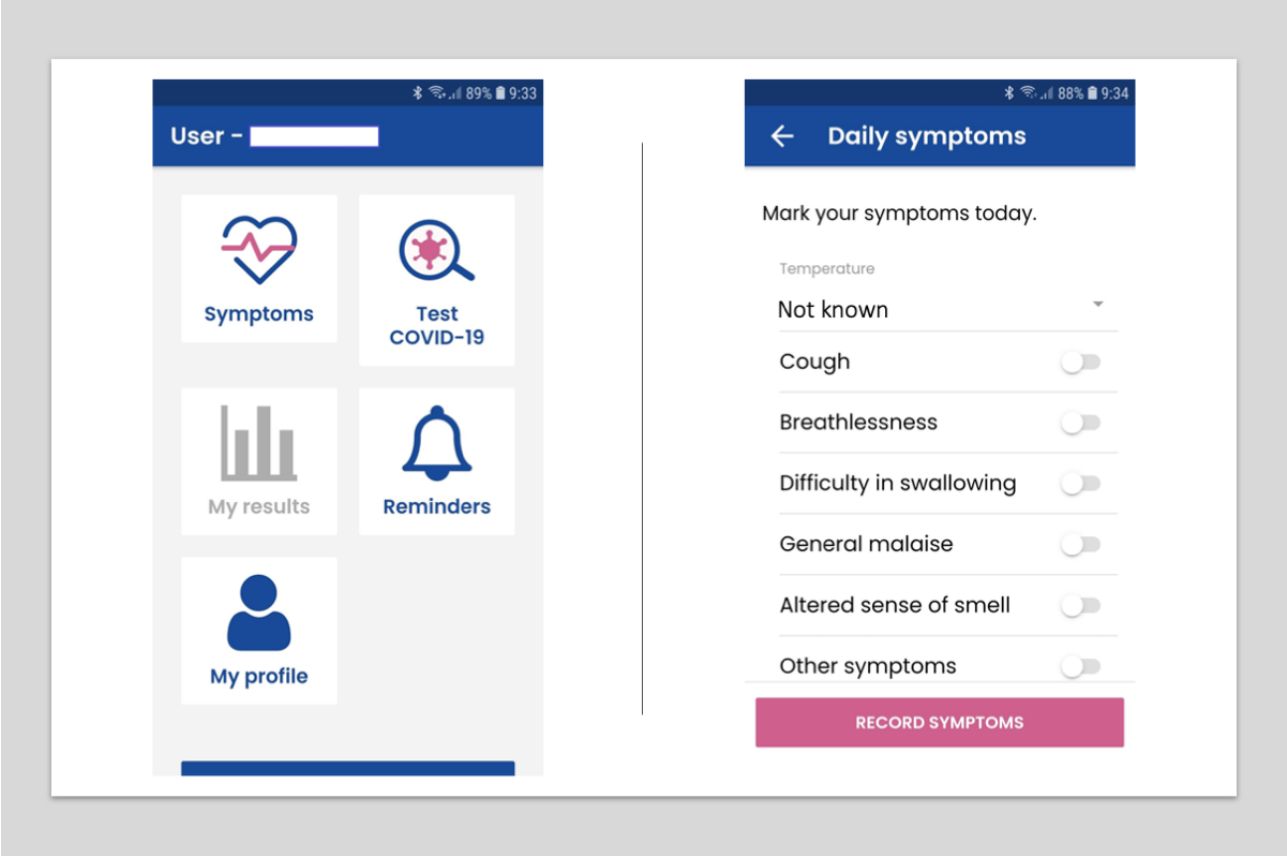
[a]DNI: Documento nacional de identidad; NIE: Número de identificación de extranjero.

[b]"Other" category without text/alphanumericals.

[c]Departments/services include the following: Pathology, Cardiology, General and Digestive System Surgery, Oral and Maxillofacial Surgery, Plastic and Reconstructive Surgery, Medical-Surgical Dermatology and Venereology, Gastroenterology - Digestive System, Gynecology and Obstetrics, General Medicine, Nuclear Medicine, Preventive Medicine, Neurophysiology, Neurology, Ophthalmology, Medical Oncology, Radiation Oncology, Otorhinolaryngology, Pediatrics and Specific Areas Children's Health, Radiodiagnosis - Diagnostic Imaging, Traumatology and Orthopedic Surgery, Urology, Emergencies, restricted-COVID-19 area, quarantine area, isolation area.

[d]Information recorded includes the date and type of test: polymerase chain reaction, IgG, or IgM.

Figure 1. HEpiTracker graphical display and screens.



Participant Withdrawal Criteria

A participant could withdraw from the study at any time (by simply not filling in their own information or by removing the app from their smartphone). However, given the ongoing public health emergency during this COVID-19 outbreak, it was agreed that any data already obtained would be kept for analysis and grouped tabulation. In addition, participants would be withdrawn at the discretion of the investigators if they failed to comply with the protocol procedures (eg, dummy data, relative of hospital staff, and other).

Data Life Cycle

The first data entry was made by a user of the mobile app. The coding language is based on Ionic, which allows developers to create native apps with web coding such as HTML, CSS, and JavaScript. Users' initial data and subsequent symptom records are automatically transferred to an Odoo V11 Enterprise Edition server application [18]. The coding language is Python 3 on the back-end and JavaScript on the front-end. This first data transfer is carried out in encrypted form with an SSL certificate and a HTTPS protocol. In this server application, the data is processed and sent to the PostgreSQL database via an SSL certificate.

Final Data Storage

The storage of data is done in a PostgreSQL database in an encrypted way. In addition, user data is stored anonymously with an internal code assigned to each participant. In this way, the user's identification number is related to the internal code, and all data entered is linked to it, preventing the end user (principal investigator) from having access to the user's personal data.

Backups

To guarantee the storage of data and avoid its loss or modification, a backup is made daily that is kept in three data centers (DCs) on three different continents, thus ensuring the integrity of the data in the event of any serious problem or inconvenience in any of the three DCs.

All individual participants' collected data were stored on secure ASELCIS servers. Data were anonymized with a unique identifier by user and hospital. Statistics were performed by ISGlobal and IdIsBa with databases already anonymized over a PostgreSQL connection under a user and password requirement.

Statistical Analysis

Study reports were sent to the participating hospitals. These reports included descriptive information regarding changes in the symptoms and incidence of COVID-19 infection by age group, sex, job category, and department/section. We followed the STROBE (Strengthening the Reporting of Observational Studies in Epidemiology) guidelines for reporting observational studies [19]. Continuous variables were expressed as mean and standard deviation, and categorical variables were expressed as number and percentage.

Results

A total of 477 hospital staff participated in the study between April 8 and June 2, 2020 (Table 2).

Of note, both health-related (n=329) and non–health-related (n=148) professionals participated in the study. Overall participation by center was low; the highest participation rate of potential participants was 5.06% at Hospital Álvaro Cunqueiro (128 of 2529 potential participants), followed by a participation rate of 2.97% at ICO L'Hospitalet (20 of 674 potential participants). Most participants were female (67.7%), with a mean age of 45.4 years (SD 10.6). Regarding smoking habits, 13.0% and 34.2% of participants were current or former smokers, respectively (Table 2). Over two-thirds of participants (68.8%) were health workers (43.4% physicians and 25.4% nurses); however, the proportion of non–health workers by center ranged from 40% to 85%, and the distribution of job category by center was also highly variable. Participation was therefore lower for non–health workers, although we did obtain valuable data about them. Regarding comorbidities, participants reported being previously diagnosed with or currently in treatment for the following respiratory conditions: allergic rhinitis (25.4%), asthma (13.8%), and chronic bronchitis/COPD (1.0%).

The daily report of symptoms was highly variable across participants; overall, 2% to 6% of the source population in each hospital engaged with the app. Although we observed a decline in adherence after an initial participation peak in some hospitals, other sites were characterized by poor participation rates since inception and throughout the study period (Figure 2).

There were no major differences across hospitals in the distribution of respiratory comorbidities (asthma, rhinitis, and chronic bronchitis/COPD), smoking status, or symptoms, namely cough, shortness of breath, malaise, or anosmia (Table 3).

However, for temperature and overall health status scored from 0 to 10, there were subtle but not clinically significant differences. Finally, the percentage of positive PCR tests was highly variable, from 39% of participants at La Princesa (16/41 participants), to 20% at ICO Girona (2/10), 9.5% (16/169) at Álvaro Cunqueiro, 8.8% (6/68) at ICO L’Hospitalet, and 3.6% (4/116) at Lucus Augusti.

A daily summary display of these results was made available for circulation at all participating sites each morning during the study period (Figure 3).

Table 2. Demographic and clinical characteristics of 477 HEpiTracker users.

Characteristics	Value
Female, n (%)	323 (67.7)
Age (years), mean (SD)	45.4 (10.6)
Hospital, n (%)	
Hospital Can Misses (Eivissa)	11 (2.3)
Hospital Lucus Augusti (Lugo)	112 (23.5)
Hospital Álvaro Cunqueiro (Vigo)	169 (35.4)
Hospital Institut Català d'Oncologia	100 (21.0)
l'Hospitalet	68 (14.3)
Badalona	20 (4.2)
Girona	10 (2.1)
Tarragona-Terres de l'Ebre	2 (0.4)
Hospital de Alta Resolución de Loja (Granada)	20 (4.2)
Hospital Universitario de La Princesa (Madrid)	48 (8.6)
Other	24 (5.0)
Job description, n (%)	
Physician	207 (43.4)
Nurse	121 (25.4)
Technician	40 (8.4)
Administrative	38 (8.0)
Warden	12 (2.5)
Cleaner	7 (1.5)
Manager	6 (1.2)
Cafeteria	3 (0.8)
Security	1 (0.2)
Other	41 (8.6)
Respiratory conditions, n (%)	
Allergic rhinitis	121 (25.4)
Asthma	66 (13.8)
Chronic bronchitis or chronic obstructive pulmonary disease	5 (1.0)
Smoking status, n (%)	
Never smoker	252 (52.8)
Former smoker	163 (34.2)
Current smoker	62 (13.0)

Figure 2. Distribution of HEpiTracker coverage in each hospital by calendar day (April 8 to May 30, 2020) as of June 2, 2020. ICO: Institut Català d'Oncologia.

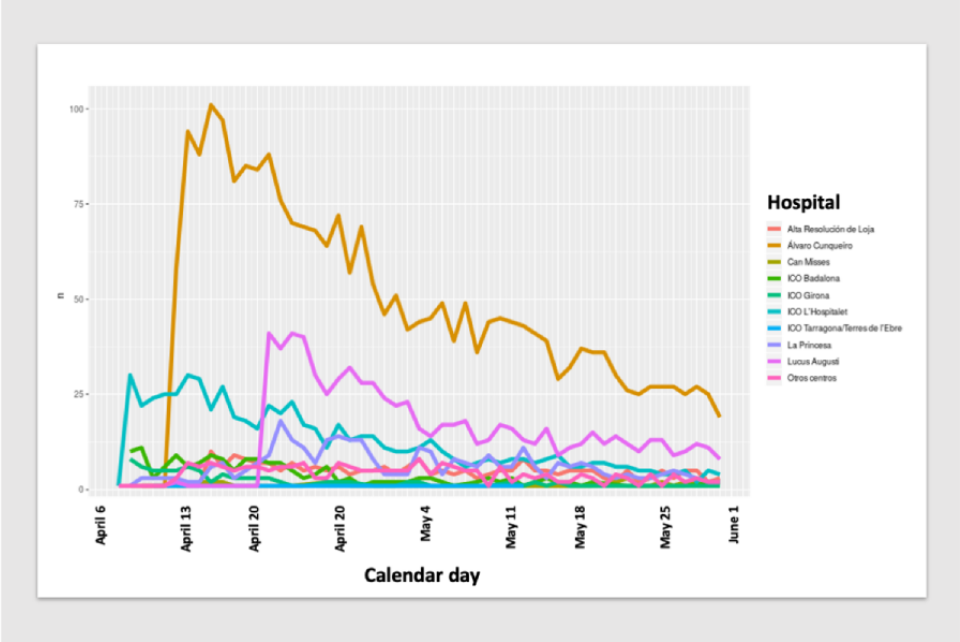


Figure 3. HEpiTracker results by hospital and by calendar day.

Table 3. Distribution of HEpiTracker variables by hospital.

Variables	Alta Resol de Loja (N=20)	Álvaro Cunqueiro (N=169)	Can Misses (N=11)	ICO[a] Badalona (N=20)	ICO Girona (N=10)	ICO L'Hospitalet (N=68)	ICO Tarragona (N=2)	La Princesa (N=41)	Lucus Augusti (N=112)	Other centers (N=24)
Comorbidities, n (%)										
Asthma	3 (15.0)	29 (17.2)	3 (27.3)	2 (10.0)	2 (20.0)	7 (10.3)	0 (0.00)	4 (9.76)	10 (8.93)	6 (25.0)
Rhinitis	4 (20.0)	52 (30.8)	6 (54.5)	3 (15.0)	1 (10.0)	12 (17.6)	1 (50.0)	11 (26.8)	23 (20.5)	8 (33.3)
Chronic bronchitis or COPD[b]	0 (0.00)	3 (1.78)	0 (0.00)	0 (0.00)	1 (10.0)	0 (0.00)	0 (0.00)	0 (0.00)	1 (0.89)	0 (0.00)
Smoking, n (%)										
Former	6 (30.0)	61 (36.1)	2 (18.2)	7 (35.0)	4 (40.0)	25 (36.8)	0 (0.0)	11 (26.8)	38 (33.9)	9 (37.5)
Never	7 (35.0)	87 (51.5)	9 (81.8)	12 (60.0)	6 (60.0)	36 (52.9)	2 (100)	28 (68.3)	56 (50.0)	9 (37.)
Current	7 (35.0)	21 (12.4)	0 (0.00)	1 (5.00)	0 (0.0)	7 (10.3)	0 (0.00)	2 (4.88)	18 (16.1)	6 (25.0)
Symptoms, n (%)										
Cough	0 (0.00)	14 (8.28)	0 (0.00)	2 (10.0)	1 (10.0)	6 (8.82)	0 (0.00)	4 (9.76)	3 (2.68)	4 (16.7)
Shortness of breath	0 (0.00)	2 (1.18)	0 (0.00)	1 (5.00)	0 (0.0)	3 (4.41)	0 (0.00)	2 (4.88)	0 (0.00)	2 (8.33)
Malaise	0 (0.00)	2 (1.18)	1 (9.09)	0 (0.00)	0 (0.0)	3 (4.41)	0 (0.00)	3 (7.32)	0 (0.00)	1 (4.17)
Anosmia	0 (0.00)	2 (1.18)	0 (0.00)	0 (0.00)	0 (0.0)	5 (7.35)	0 (0.00)	2 (4.88)	1 (0.89)	1 (4.17)
Temperature, mean (SD)	35.7 (0.58)	35.8 (0.58)	29.4 (14.5)	35.7 (0.67)	35.6 (0.53)	35.6 (0.67)	35.0 (0.00)	35.9 (0.78)	35.7 (0.65)	34.3 (7.33)
Overall health, mean (SD)	0.80 (2.28)	1.11 (2.31)	0.64 (1.80)	1.05 (2.31)	0.40 (0.84)	0.99 (1.59)	0.00 (0.00)	1.17 (2.23)	0.62 (1.47)	2.71 (3.01)

[a]ICO: Institut Català d'Oncologia.

[b]COPD: chronic obstructive pulmonary disease.

Discussion

Summary of Results

HEpiTracker is a newly designed mobile app aimed at monitoring the spread of COVID-19 symptoms and testing among professionals in hospital settings. Although the first wave of the pandemic in Spain and other countries is thought to be over, many experts warn that lockdown lifts might be premature [20]. In the current situation, the use of novel tools to measure and track the effects of the pandemic in real time may help tackle the forthcoming waves of the pandemic [4,6].

We tested the HEpiTracker app in a sample of 477 hospital staff including both health-related and non–health-related professionals from 9 centers in 5 regions of Spain experiencing different stages of the COVID-19 pandemic. The daily report of COVID-19–related symptoms was highly variable across participating hospitals, as well as the reported infection testing rates. We observed a decline in adherence after an initial participation peak in some hospitals, while other sites were characterized by low participation rates throughout the study period. It is worth noting that our pilot study aimed to test the technical aspects of the app in different real-world hospital settings, all in different stages of the COVID-19 pandemic, but not its deployment or coverage. In general, an acceptable response rate for any epidemiological study is 80% or higher for usability [21,22]. Having said that, the total workforce in our 9 participating hospitals ranges from around 150 to over 3000 workers, which fluctuate seasonally and yearly. As reported, the overall response rate varied from 2% to 6% of the source population in each hospital in this study.

In future analyses, techniques and tools used in artificial intelligence and machine learning will be explored. For instance, machine learning can be used to forecast new cases or to identify relevant phenotypes [20].

Discussion of Results and Work in the Field

Mobile apps are effective, valid tools for monitoring very diverse patterns in real-life conditions [23]. However, a key issue in mobile app–based monitoring involves increasing adherence and reinforcement for changing established behaviors. Our participation data show that adherence to the app should be improved, perhaps by providing some real-time feedback, composed of aggregated data from a given user's hospital and overall estimates, to the users. In response to the ongoing COVID-19 pandemic, several apps and digital health solutions have already been developed [24-26], as digital technology has the potential to improve surveillance and epidemic control. This is achieved primarily through increased information coverage, faster acquisition and distribution of information, rapid case tracking, and improved proximity tracing. In this context, some have already identified new opportunities to reshape current health care systems, including the widespread adoption of

electronic health records and the development of better mobile health apps and other disruptive technologies [10]. Indeed, digital health solutions are a promising asset to improve the quality of health care at a more sustainable cost. In a recent review, the uptake of and engagement with health and well-being smartphone apps was associated with capability, opportunity, and motivation [27].

It should be stressed that the present study did not intend to study the factors that determine app adoption or the impact of the app on infection rates. These, along with other relevant issues, are outside the scope of this paper and would only be addressed by a larger-scale study that would be complex in its design and execution. However, this pilot study allowed us to identify some strengths and limitations of the app that will be addressed in the following sections.

Strengths and Potential of the Platform

Some strengths of HEpiTracker include novelty, flexibility, and the ability to quickly modify it and include new updates and information. Notably, the app is now available in several languages (Spanish, English, and Portuguese) and is accepted by both health care professionals and non–health care professionals in hospital settings. In the near future, we plan to design customized versions to be used in primary care, by security forces, and even in universities once in-class teaching is resumed.

Limitations

However, our results must be interpreted in light of the following limitations. Despite fulfilling all European Union regulations and disclaimers on data protection, concerns with data privacy were raised by legal departments or individual managers in several nonparticipating hospitals, so clarity among leadership should be ensured. When evaluating usability and user experience of mobile health (mHealth) solutions, there are standardized questionnaires such as The Standardized User Experience Percentile Rank Questionnaire (SUPR-Qm) [28] for user experience and the mHealth App Usability Questionnaire (MAUQ) [29], which can aid the evaluation of apps; these can be used to prospectively assess HEpiTracker. However, the main limitation of the study was adherence to the app. In particular, we found it difficult to maintain participant engagement for weeks, especially when the local COVID-19 situation deescalated by the end of April/May 2020.

Unfortunately, the inclusion of alarm reminders for the daily recording of symptoms and temperature was not effective. Indeed, a proper communication and marketing strategy for wider implementation will be critical for its future use. We have already developed QR codes and templates of posters to pin in hospital entrances, elevators, and notice boards, which serve as a way to download HEpiTracker directly on any platform.

This lack of adherence, however inspired the next evolution of the app, consisting of an activity wristband that will incorporate HEpiTracker plus a number of other utilities. This evolution of HEpiTracker, named Epiwrist (an “epidemiologist on your wrist”), could passively monitor all HEpiTracker variables, as well as others. Epiwrist would include a gyroscope to assess hand-washing behavior (duration and frequency), synchronized with a cough sensor to identify if the cough is directed to your sleeve (good) or your hand (bad), and a continuous heart rate monitor, oxygen saturation meter, and built-in thermometer. It is envisaged that Epiwrist will also measure physical activity, sleep duration and patterns, blood pressure, and respiratory rate. The development of this software and hardware started in May 2020; it was designed by engineers at Softlution [30]. Although the development of Epiwrist is envisaged and a first prototype has been manufactured in China, it will require time and effort to perform real-life testing and obtain approvals.

During the COVID-19 epidemic, OHUs in hospitals were in charge of diagnosing health care workers with symptoms of the disease, and applying and changing protocols from their respective public health institutions, which included the study of contacts within the hospital, affecting both hospitalized patients and staff. OHUs also reported the cases to the local epidemiological surveillance systems. Moreover, OHUs participated in the constant updating and implementation of internal protocols for COVID-19 prevention in collaboration with the preventive medicine units. In our study, some hospitals showed an unwillingness to participate because they believed that HEpiTracker would interfere with established tracking of health care providers and surveillance. Moreover, they claimed that it could affect the privacy rights of participants. In general, public health interventions during infectious outbreaks can be divided into those consisting of personal actions (eg, physical distancing, personal hygiene, and use of protective equipment), case and contact identification (eg, test-trace-track-isolate, reactive school or workplace closure), regulatory actions (eg, governmental limits on sizes of gatherings or business capacity; stay-at-home orders; proactive school, workplace, and public transport closure or restriction; cordon sanitaire or internal border closures), and international border measures (eg, border closure or enforced quarantine).

Conclusions

A key priority during the ongoing COVID-19 pandemic is to identify the combination of measures that minimizes societal and economic disruption while adequately controlling infection [31]. Our aim with HEpiTracker was therefore focused on case and contact identification, namely test-trace-track-isolate within hospital staff, as they were becoming infected with COVID-19 disproportionately more frequently and severely than the general population. The significance and impact of mobile apps, including HEpiTracker, in helping to tackle COVID-19 should be assessed further with more research conducted by other groups in real conditions. As we are facing a new virus and disease [32], future directions and scenarios should be further assessed [33].

HEpiTracker is an already available tool to monitor COVID-19 and other epidemics in hospital workers. It has been tested in real conditions and might represent a stepping stone toward effective health policies in response to future waves of the pandemic. HEpiTracker is available in Spanish, Portuguese, and English and holds the potential to become a customized asset to be used in future COVID-19 pandemic waves and other environments.

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Authors' Contributions

All authors declare that they participated in the conception and design of the work, the collection of data, or the analysis and interpretation of the data; participated in the writing or critical revision of the article; and gave approval of the final version for publication. JBS guarantees that all aspects that make up the manuscript have been reviewed and discussed with precision and integrity. Finally, JBS guarantees the accuracy, transparency, and integrity of the data and information contained in the study; that no relevant information has been omitted; and that all discrepancies between authors have been adequately resolved and described.

Conflicts of Interest

None declared.

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Abbreviations

AMADIICH: Active Monitoring And Determinants of Incident Infection of COVID-19 in a Hospital population
CDC: Centers for Disease Control and Prevention
COPD: chronic obstructive pulmonary disease
HEpiTracker: Hospital Epidemics Tracker
ICO: Institut Català d'Oncologia
mHealth: mobile health
OHU: occupational health unit
PCR: polymerase chain reaction
VAS: visual analog scale
WHO: World Health Organization

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Original Paper

Adoption of a Contact Tracing App for Containing COVID-19: A Health Belief Model Approach

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Abstract

Background: To track and reduce the spread of COVID-19, apps have been developed to identify contact with individuals infected with SARS-CoV-2 and warn those who are at risk of having contracted the virus. However, the effectiveness of these apps depends highly on their uptake by the general population.

Objective: The present study investigated factors influencing app use intention, based on the health belief model. In addition, associations with respondents' level of news consumption and their health condition were investigated.

Methods: A survey was administered in Flanders, Belgium, to 1500 respondents, aged 18 to 64 years. Structural equation modeling was used to investigate relationships across the model's constructs.

Results: In total, 48.70% (n=730) of respondents indicated that they intend to use a COVID-19 tracing app. The most important predictor was the perceived benefits of the app, followed by self-efficacy and perceived barriers. Perceived severity and perceived susceptibility were not related to app uptake intention. Moreover, cues to action (ie, individuals' exposure to [digital] media content) were positively associated with app use intention. As the respondents' age increased, their perceived benefits and self-efficacy for app usage decreased.

Conclusions: Initiatives to stimulate the uptake of contact tracing apps should enhance perceived benefits and self-efficacy. A perceived barrier for some potential users is privacy concerns. Therefore, when developing and launching an app, clarification on how individuals' privacy will be protected is needed. To sustain perceived benefits in the long run, supplementary options could be integrated to inform and assist users.

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KEYWORDS

COVID-19; SARS-CoV-2; health belief model; contact tracing; proximity tracing; privacy

Introduction

The rapid spread of COVID-19 has led to numerous efforts to contain the pandemic as scientists endeavor to develop potential vaccinations. While policy makers have implemented several measures, it has been proposed that technologies be integrated into countries' deconfinement strategies. To reduce the risk of spreading SARS-CoV-2 when exiting lockdown measures, several apps have been developed. At the core of these apps is contact tracing. Through contact tracing, the potential transmission routes of a virus in the population can be assessed to isolate and assist individuals who may have been in contact with someone with COVID-19 [1]. By using an app that traces contact with COVID-19–infected individuals and offers advice on how to prevent infection, citizens can help limit the spread of the virus.

However, the effectiveness of this app depends on uptake by the population [1]. Therefore, this study investigated factors

that can influence citizens' willingness to use an app that traces contact with COVID-19–diagnosed individuals and notifies app users of this contact, without revealing the identity of the diagnosed app user(s) or where this contact occurred. This proximity tracing is made possible by the exchange of random identification codes between smartphones that are running the app and are in each other's proximity. The smartphones save this list of codes for a period of time (eg, the incubation period of the virus). When a smartphone user is diagnosed with the virus, they can upload anonymized data to the app's server, with the explicit permission of the user and approval of a health professional. App users who have been in the proximity of the infected app user during the incubation period of the virus will be informed that they have been in contact with an individual who has been infected with COVID-19 and therefore might be at risk of having contracted the virus. This notification to at-risk individuals can further advise users on what steps to undertake (eg, getting tested, self-isolation).

A number of countries have integrated this kind of tracing app into their deconfinement plans or are presently discussing this option [2,3]. Research has concentrated on contact tracing and symptom tracking systems [1,4-6] as well as the association between app usage and the epidemiological spread of the virus [7]. Some studies have focused on the differences between apps implemented in several countries [3], while others have analyzed the legal or ethical aspects (eg, data protection) [2,8,9]. Questions still remain about the factors that influence citizens' uptake of COVID-19 contact tracing apps. Insight into these factors provides developers and policy makers information on aspects that need to be taken into account when launching an app and stimulating app uptake.

The aim of this study is to investigate which factors influence individuals' intention to use a COVID-19 app by adopting the health belief model (HBM) [10,11] perspective. The HBM states that, in response to a threat, an individual's health behavior is determined by two cognitive processes: how severe one assesses the consequences of a threat to be (ie, threat appraisal) and how efficient and feasible a protection behavior is (ie, coping appraisal) [12].

Applied to the current COVID-19 pandemic, threat appraisal consists first of one's *perceived susceptibility* or perceived risk for contracting SARS-CoV-2. We expect that if someone perceives themselves to be at risk of COVID-19 infection and related health complications, the individual will be inclined to use the app to assess potential COVID-19 infection risks. *Perceived severity* refers to individuals' perceptions of the impact of infection for them. Therefore, individuals who assess this risk to their personal health as high will be more inclined to adopt the app.

Behavioral intention is further determined by the *perceived benefits*—in this case, the expected positive consequences of using the COVID-19 app. Individuals who are more convinced of the app's social (eg, using the app to contribute to knowledge about the viral spread) and individual (eg, being informed of potential infection) benefits would be more willing to use the app. However, in the current debate on tracing apps, some have voiced concerns about the protection of app users' personal data [3]. These concerns can form *perceived barriers* to adopt the app. Additionally, tensions may occur between infected and healthy individuals [13], which could also present barriers to using the app. By contrast, *cues to action* can stimulate individuals to engage in protective behaviors. Since media coverage of the COVID-19 pandemic is high, we assessed respondents' perceived exposure to (digital) media content. We expect that the more individuals consult news platforms during the pandemic, the more inclined they will be to use the app.

Users may have various expectations concerning their potential mastery of the app. Individuals' *self-efficacy* was added to the original HBM [14], which is, in short, one's belief of having mastered performance of a requisite protective behavior [15]. We therefore expect that individuals' adoption of the app will be influenced by their belief in their competence to use the app. The HBM is often complemented by factors that relate to the particular behaviors being investigated [16]. We included health conditions that increase respondents' risk when infected with the virus as an additional factor that may influence behavioral intentions. Finally, we investigate potential differences in gender, age, and education.

Methods

Procedure and Sample

Our study was conducted in Belgium, one of the top 15 countries with the greatest number of cumulative confirmed COVID-19 cases (from January to April 2020) [17]. At the time of this study, no contact tracing technology had been implemented in Belgium.

An online survey was administered to respondents, aged 18 to 64 years. The study was approved by the University of Ghent Ethics Committee. The data were collected from April 17 to 19, 2020. The recruitment of respondents was organized by a professional research agency.

Using the statistical program G*Power, the calculation of an *a priori* sample size, with an effect size of 0.1, a desired power value of at least .80, and an alpha score of no greater than .05, returned a recommended minimum sample size of 614 respondents.

A sample of 1500 respondents was recruited with the following eligibility criteria: (a) a resident of Belgium, (b) aged 18-64 years, and (c) speak Dutch. To achieve a heterogeneous sample, we followed a stratified sampling procedure. Based on Belgian federal statistics, we stratified *a priori* the data regarding gender (50.42% male and 49.58% female), age (33.28% between 18-34 years, 32.15% between 35-49 years, and 34.57% between 50-64 years), and educational degree (22.50% with lower secondary education, 40.65% with upper secondary education, and 36.85% with higher education) so that the proportion of the sample's strata would reflect the Flemish population. In total, 8000 panel members were emailed an invitation to participate, which included a short description of the study. When 1500 respondents were recruited, in accordance with the strata, data collection was truncated. Respondents were not remunerated for their participation but were entered into a contest organized by the agency to win vouchers worth a maximum of 50 euros.

The respondents were informed of study objectives and asked for informed consent. They were then provided with a brief description of the key features of a potential COVID-19 app—the use of Bluetooth or GPS signals to detect proximity, the anonymous disclosure of users' COVID-19–positive status to other users who have been in their proximity, access to supplementary information, and advice on dealing with COVID-19. This information was based on available explanations from apps that have been developed [18,19] since a COVID-19 app was not available in Belgium at the time of the study. This introduction and the questionnaire were assessed by 3 respondents to check for clarity.

Measures

We measured HBM constructs following Champion's recommendations [20]. All answers were on 5-point Likert scales ranging from *disagree* to *agree*. *Perceived susceptibility* was measured with 3 items assessing respondents' views on how likely a COVID-19 infection would affect them. *Perceived severity* was assessed with 3 items investigating how serious respondents assess the consequences for their health of a COVID-19 infection to be. In total, 6 items measured the *perceived benefits* respondents find in using the COVID-19 app (individual as well as social benefits). Based on current debates about COVID-19 apps, 2 items measured *perceived barriers*. This construct focused on privacy issues raised by the app and how it could contribute to tensions among citizens with a different COVID-19 status. *Cues to action* that would stimulate individuals to use the app concentrated on (online) news consumption during the COVID-19 crisis. This news consumption was measured by asking respondents: "When you think of the news you consult during the corona period (this is the period since the Belgian government announced strict measures on Friday, March 13, 2020), how often do you consult the news through the sources below?". In line with previous research [21,22], respondents rated the online sources. Answers were recorded using a 5-point scale ranging from *never* to *multiple times a day*. Finally, 3 items were designed to capture *self-efficacy*, which is the respondents' own assessment of how easy it would be for them to use the app. In addition, the respondents' gender, age, and education level were asked. Finally, individuals' COVID-19 personal health risk was assessed by asking if they suffered from one or several health conditions that can be a risk factor when infected with SARS-CoV-2 (ie, heart or lung condition, renal disease, diabetes, cancer, weakened immune system, high blood pressure).

Data Analysis

We applied structural equation modeling to the collected data using Mplus 8.4 (Muthén & Muthén) to examine the relationships among the HBM constructs [23]. First, we built a measurement model to test whether the observed variables reliably reflect the hypothesized latent variables (ie, intention, perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy). Thereafter, we examined the relationship between the study variables and our covariates (ie, gender, age, education, COVID-19 personal health risk). Finally, we estimated a structural model with intention to use the COVID-19 app as the outcome.

We evaluated the model fits of the measurement and path models according to several fit indices. Given that the χ^2 is almost always significant and not an adequate test of the model fit [24,25], we also report the comparative fit index (CFI), root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR). The CFI ranges from 0 to 1.00, with a cut-off of .95 or higher indicating that the model provides a good fit [24,26]. RMSEA values below .05 indicate a good model fit [27]. The SRMR is a standardized summary of the average covariance residuals [25]. A relatively good model fit is indicated when the SRMR is less than .08 [26].

Results

Descriptive Results

Descriptive statistics of the variables, together with Cronbach alpha values of the constructs, are presented in Table 1. A correlation matrix of the latent variables is presented in Table 2. All items were included in the survey in Dutch and were translated for this paper. Table 3 provides descriptive statistics of the sample, including age, gender, and highest level of education.

Table 1. Description of study variables.

Question	Score, mean (SD)	Cronbach alpha
Behavioral intention		.98
BI1. I would be willing to use the COVID-19 app.	3.18 (1.41)	
BI2. I plan to use the COVID-19 app.	3.08 (1.40)	
BI3. I want to use the COVID-19 app in the future.	3.18 (1.41)	
Perceived susceptibility		.74
PSU1. I am at risk of being infected by the COVID-19 virus.	2.86 (0.95)	
PSU2. It is likely that I would suffer from the COVID-19 virus.	3.4 (0.99)	
PSU3. It is possible that I could be infected by the COVID-19 virus.	3.18 (1.07)	
Perceived severity		.85
PSE1. If I were infected by the COVID-19 virus, it would have important health consequences for me.	3.74 (1.02)	
PSE2. If I were infected by the COVID-19 virus, my health would be severely affected.	3.7 (1.04)	
PSE3. If I were infected by the COVID-19 virus, my health would be significantly reduced.	3.79 (1.01)	
Perceived benefits		.90
PBE1. The COVID-19 app will offer me the opportunity to contribute to better knowledge about the spread of the virus.	3.49 (1.17)	
PBE2. With the COVID-19 app, I will collaborate to reduce the spread of the COVID-19 virus.	3.38 (1.23)	
PBE3. Thanks to the COVID-19 app, I will be more on my guard when I have face-to-face contact.	3.36 (1.23)	
PBE4. Thanks to the COVID-19 app, I will take more precautions not to spread the COVID-19 virus myself (eg, wash my hands, maintain distance from others [social distancing], limit my outside movements).	3.18 (1.26)	
PBE5. By using the COVID-19 app, I will help public authorities to combat the COVID-19 virus.	3.45 (1.20)	
PBE6. The COVID-19 app will allow me to protect myself from the COVID-19 virus.	3.37 (1.17)	
Perceived barriers		.60
PBA1. The COVID-19 app will reduce its users' privacy.	3.69 (1.11)	
PBA2. The COVID-19 app will create tensions between individuals who are infected by the COVID-19 virus and those who are not.	3.61 (1.09)	
Cues to action		.66
CTA1. Website of a newspaper, TV or radio station, or magazine.	4.14 (1.82)	
CTA2. App of a newspaper, TV or radio station, or magazine.	2.89 (2.03)	
CTA3. News shared on social media (Facebook, YouTube, Twitter, Instagram, etc).	3.68 (1.87)	
CTA4. News shared through messaging apps (personal messages through WhatsApp, Messenger, etc).	2.99 (1.95)	
CTA5. Alerts through email and newsletters.	2.94 (1.81)	
Self-efficacy		.79
SE1. I have the knowledge needed to use the COVID-19 app.	3.62 (1.23)	
SE2. I have the necessary resources to use the COVID-19 app.	3.78 (1.21)	
SE3. I can get help from others if I experience difficulties using the COVID-19 app.	3.71 (1.14)	

Table 2. Correlation matrix of latent variables.

Variable	1	2	3	4	5	6	7
1. Behavioral intention							
2. Perceived susceptibility	.009						
3. Perceived severity	.080[a]	.078[a]					
4. Perceived benefits	.468[a]	.007	.170[a]				
5. Perceived barriers	–.052[b]	.138[a]	.057[b]	.103[a]			
6. Cues to action	.228[a]	.046	.071[a]	.198[a]	.085[a]		
7. Self-efficacy	.285[a]	.068[a]	.023	.205[a]	.196[a]	.211[a]	

[a]*P*<.01.
[b]*P*<.05.

Table 3. Characteristics of the study sample.

Characteristic	Study sample (N=1500)
Gender, n (%)	
Male	756 (50.4)
Female	744 (49.6)
Age (years), mean (SD)	41.58 (13.94)
18-34, n (%)	499 (33.3)
35-49, n (%)	483 (32.2)
50-65, n (%)	518 (34.5)
Educational level, n (%)	
No diploma or primary or lower secondary education diploma	338 (22.5)
Secondary education diploma	611 (40.7)
Higher education diploma	551 (36.7)

In total, 48.70% (n=730) of respondents agreed with the statement that, when launched, they intend to use the app; 20.40% (n=306) disagreed, 10.40% (n=156) somewhat disagreed, 20.50% (n=308) neither disagreed nor agreed, 27.90% (n=418) somewhat agreed, and 20.80% (n=312) agreed that they intended to use the COVID-19 app. No significant differences were found between women (n=356, 47.80%) and men (n=374, 49.50%) in their intention to use the app (χ^2_1=0.395, *P*=.53). Comparing the three age categories of respondents resulted in no significant differences in app adoption intentions between 18-34-year-olds (n=234, 46.90%), 35-49-year-olds (n=247, 51.10%), or 50-65-year-olds (n=249, 48.10%) (χ^2_2=1.883, *P*=.39). Regarding respondents' education, individuals with higher education did not significantly differ in their intention to use the app (n=261, 47.4%) from respondents with, at most, secondary education (n=469, 49.4%) (χ^2_1=0.588, *P*=.44). Individuals suffering from health conditions that make them more vulnerable to COVID-19 complications did not differ in their intention to use the app (n=243, 50.10%) compared to respondents without health problems (n=487, 48.00%) (χ^2_1=0.592, *P*=.44).

Measurement Model

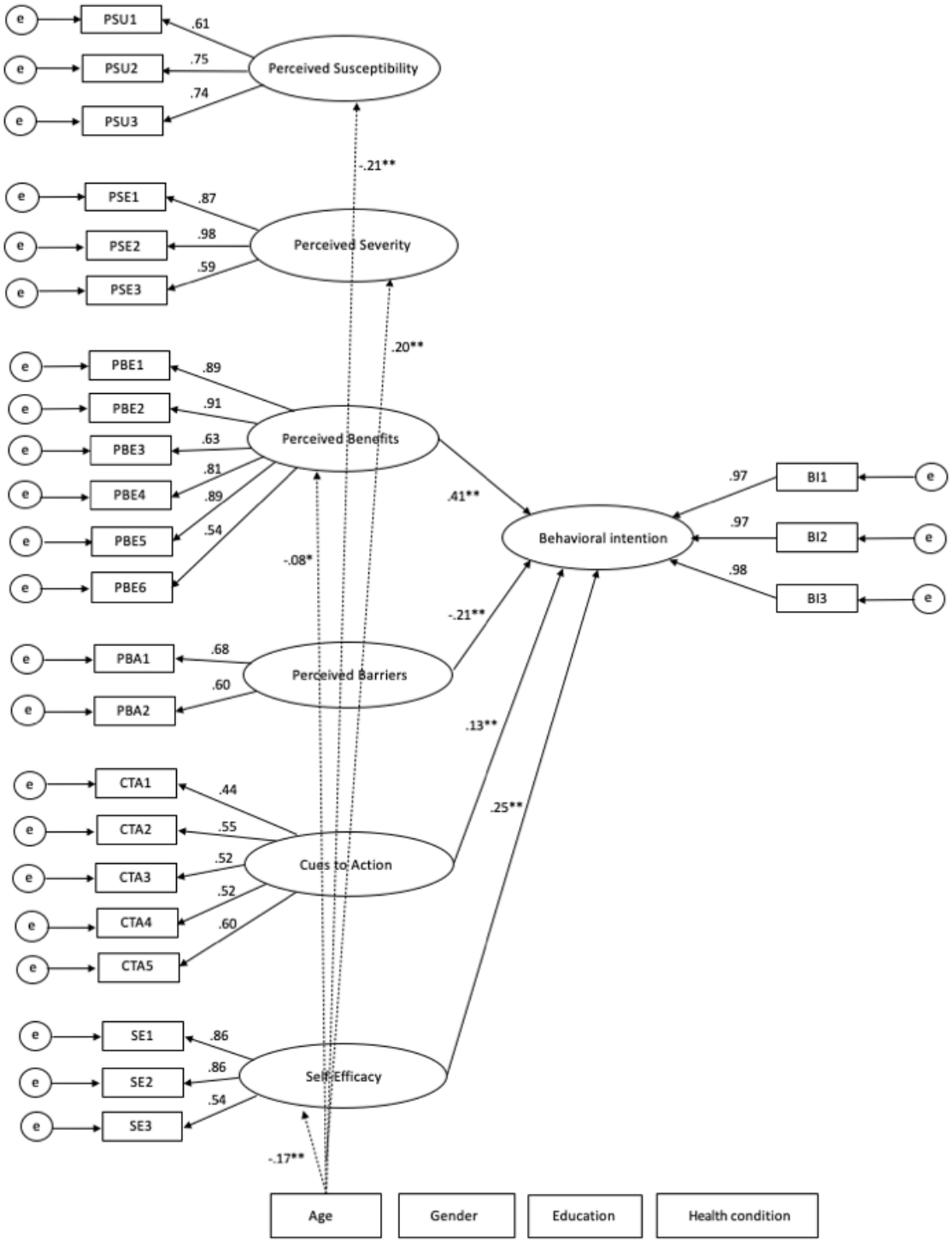
The measurement model provided a good fit for the data (χ^2_{254}=750.87, *P*<.001; CFI=.976, RMSEA=.036, 90% CI .033-.039, SRMR=.034). All factor loadings were significant and above .44. We subsequently included age, gender, education, and COVID-19 personal health risk as covariates in the analyses and examined the relationships between the covariates and the study variables.

Gender and education were not significantly associated with any of the study variables. Age was significantly related to perceived severity (β=.20, *P*<.001), susceptibility (β=–.21, *P*<.001), benefits (β=–.08, *P*=.003), and self-efficacy (β=–.17, *P*<.001). Having a health condition that can be a risk factor when infected with COVID-19 was not significantly related to the model's constructs. Our structural model has been adjusted for these variables' influence.

Structural Model

The results of the structural model are presented in Figure 1. The results of the fit statistics indicate a good model fit (χ^2_{350}=1070.46, *P*<.001; CFI=.966, RMSEA=.037, 90% CI .035-.040, SRMR=.042).

Figure 1. Structural model. Nonsignificant paths are not included. Dashed lines refer to covariates. *P<.01 **P<.001.



Our analyses revealed that perceived severity, perceived susceptibility, perceived benefits, perceived barriers, cues to action, and self-efficacy, together with the covariates, explained 32.30% of the variance in intention. The most important predictor of intention was perceived benefits (β=.41, P<.001), followed by self-efficacy (β=.25, P<.001) and perceived barriers (β=–.21, P<.001). Cues to action were significantly related to intention (β=.13, P<.001). However, perceived severity (β=.01, P=.95) and perceived susceptibility (β=.03, P=.38) were not significantly associated with intention.

Discussion

Principal Results

In recent months, several countries have implemented or are discussing the integration of a COVID-19 app in their deconfinement plans [28]. Still, questions remain regarding

citizens' motivation to use the app. Epidemiologists state that more than half of the population should use a contact tracing app for it to become effective [29]; in our study sample, almost half intend to use it.

As far as the HBM constructs are concerned, we found that perceived benefits, self-efficacy, perceived barriers, and cues to action were associated with respondents' intention to adopt the app. However, perceived severity and perceived susceptibility were not. This last finding is consistent with meta-analyses of studies that used the HBM or the related protection motivation theory. These studies showed that, in general, threat appraisal (vulnerability and severity) was least often significantly associated with intention, whereas coping appraisal (perceived benefits and self-efficacy) proved to be more consistently associated with health-related intentions and behaviors [30-32]. This suggests that future research and initiatives to stimulate COVID-19 app uptake should investigate the best ways to enhance perceived benefits and self-efficacy. An optimal strategy proposed by Bandura [33] is to provide individuals with concrete experiences with a target behavior, for instance, through role-play. Offering potential users a clear go-through where they experience the use of the app, the limits of its data processing, and the clarity of the app's feedback could make the advantages more concrete. Especially because the present study showed a negative relationship between age and self-efficacy, it is important to develop information on the app's usability that is suitable for all age groups. Moreover, older potential users need to be more convinced of the app's benefits, as a negative relationship was found between age and perceived benefits.

Based on our findings, individuals' belief of the gravity of the COVID-19 crisis and their personal vulnerability did not predict app uptake intention. When the threat is assessed as severe and the prevention behavior is complex or not well known, the role of perceived vulnerability may be diluted [32]. This could be the case for a novel COVID-19 app, which could be seen by some respondents as too complex a digital tool to use. Other variables related to app use might be involved. Further research could therefore assess how respondents perceive the ease of use of the app and how app usage can be swiftly integrated in their daily routines.

Another possible reason for the nonsignificance of threat appraisal in terms of adoption intention could be that the government's stay-at-home order could lead people to think that they are less susceptible to the virus. However, at the time of the survey, the Belgian government's confinement measures still allowed citizens to go outside for a walk and participate in individual sports and shopping (in grocery stores, supermarkets, and pharmacies). Working from home was mandatory (except for specific sectors and positions). Interpersonal contact was limited to people living under the same roof. Although physical distancing and wearing a mask were advised (but not compulsory), people could be in close proximity to each other and thereby contract the virus; hence, at that stage of the crisis, the app could have been useful. Occasions to be in close proximity with other people were possible but limited. This limited contact with others could have influenced individuals' threat appraisal and its relation to app uptake intention.

Furthermore, perceived barriers and cues were significantly related to app uptake intention. A perceived barrier for some potential users is their concern about privacy. Especially in a health care context, concerns on the security and confidentiality of data can rise. Privacy advocates have raised concerns about data protection issues related to the implementation of contact tracing apps [34,35]. That is why some contact tracing methods that do not use location data have been proposed [1]. By using data-minimizing solutions, not only are the privacy rights of users being protected but the impact of the app will increase as more people trust and thus install it [2]. Therefore, when developing and launching an app, how individuals' privacy is protected should be further clarified to potential users. In this respect, citizens' privacy and other concerns should be further investigated to gain insight into factors that could slow down app uptake.

Cues to action were found to positively correlate with app use intention. In recent months, the media have extensively reported on the pandemic and response measures that have been taken [36]. Additionally, contact tracing apps have been frequently discussed. Although the country where this study was conducted did not implement a COVID-19 app, several strategies such as using traditional contact tracing (through a call center) or a contact tracing app were discussed in mass media and on social media. Our study found a positive relationship between exposure to (online) information and intention to adopt the app. As its effectiveness depends on the app's uptake, further insight is needed into media coverage on the app's functionalities and effectiveness. At the same time, it is important to analyze press coverage and online conversations to gain insight into questions that are raised concerning the app's ethical and legal challenges and how they are addressed. Next to research on how the media report the COVID-19 crisis [37], specific *framing analyses* could be conducted to examine news items and online comments concerning contact tracing apps. Results could inspire governments' and companies' app development and communication strategies. In addition, how citizens' media consumption (specifically, potential changes in media consumption during a crisis period) influences citizens' attitudes and behavioral intentions toward the app could be investigated.

Because perceived benefits formed the most important factor in relation to app uptake intention, the functionalities and efficacy of the app in controlling COVID-19 should be made clear. Therefore, when launching a COVID-19 tracking app, the importance of tracing contacts and reporting possible exposure to the virus needs to be explained and visualized. Several presentations have been created to concretize the aerosolization of the virus through breathing and could inform on how using a COVID-19 app could map close individual contact that presents a high propensity for infection. To sustain perceived benefits in the long run, supplementary options could be integrated to inform and assist users (eg, including advice on preventing COVID-19–related infection, supplementary resources, and professional assistance). In sum, the app could be further developed as a central hub including detection, advice, and assistance to avoid infection as well as provide users advice during self-isolation [38].

Notwithstanding the value of a contact tracing app, this technology is only one potential instrument. Even with great uptake, some transmissions of the virus (eg, through objects) may not be captured [1]. Therefore, contact tracing needs to be integrated into broader public health interventions, including raising awareness of preventive behaviors and testing [38]. Moreover, the effectiveness of contact tracing apps depends on the general public's uptake. Uptake by a substantial portion of the population is needed to collect enough data. Therefore, further insight into the predictors of contact tracing app adoption is needed to influence uptake and continued use.

Limitations

Notwithstanding its results, this study has some limitations. First, although our sample was heterogeneous with regard to age, gender, and educational level in Flanders (ie, the Dutch speaking part of Belgium), the use of convenience samples limits the generalizability of our findings. Furthermore, due to our sampling procedure we may have specifically missed out those who are already disadvantaged and less visible in society due to a lower income level, health status, social status, or migration background. Corroboration of our findings produced by representative data as well as data derived from disadvantaged groups would lend credibility to the findings.

Second, because COVID-19–related apps have not yet been deployed in Belgium (at the time this study was conducted), future research could investigate individuals' uptake when an app is launched. Additionally, in countries in which a similar app has already been released, determinants of use and, even more importantly, continued use should be investigated. Future research could investigate app uptake (intention) longitudinally to assess citizens' willingness to use the app and whether changes in threat and coping appraisal occur at different levels of the COVID-19 outbreak and influence intention and behavior.

Third, since we measured intention to use the app based on a general app description, future researchers could use vignettes to describe several concrete options and their combinations to assess how respondents would be willing to adopt the app, depending on specific characteristics.

Conclusion

Contact tracing apps are being considered by many governments as a crucial part of their lockdown exit strategies during the COVID-19 pandemic. High uptake is crucial for these apps to be efficient in the mitigation of the virus. However, it remains unclear how we can motivate citizens to use these apps. Our results indicate that it is necessary to act on citizens' perceived self-efficacy and increase the perceived benefits of COVID-19 apps. At the same time, perceived barriers such as privacy concerns have to be overcome. Finally, the media can play an important role in stimulating app uptake by informing citizens about the functions, benefits, and use cases of the app, thereby increasing self-efficacy and perceived benefits.

Conflicts of Interest

None declared.

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Abbreviations

CFI: comparative fit index
HBM: health belief model
RMSEA: root mean square error of approximation
SRMR: standardized root mean square residual

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Original Paper

The Association Between State-Level Racial Attitudes Assessed From Twitter Data and Adverse Birth Outcomes: Observational Study

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Abstract

Background: In the United States, racial disparities in birth outcomes persist and have been widening. Interpersonal and structural racism are leading explanations for the continuing racial disparities in birth outcomes, but research to confirm the role of racism and evaluate trends in the impact of racism on health outcomes has been hampered by the challenge of measuring racism. Most research on discrimination relies on self-reported experiences of discrimination, and few studies have examined racial attitudes and bias at the US national level.

Objective: This study aimed to investigate the associations between state-level Twitter-derived sentiments related to racial or ethnic minorities and birth outcomes.

Methods: We utilized Twitter's Streaming application programming interface to collect 26,027,740 tweets from June 2015 to December 2017, containing at least one race-related term. Sentiment analysis was performed using support vector machine, a supervised machine learning model. We constructed overall indicators of sentiment toward minorities and sentiment toward race-specific groups. For each year, state-level Twitter-derived sentiment data were merged with birth data for that year. The study participants were women who had singleton births with no congenital abnormalities from 2015 to 2017 and for whom data were available on gestational age (n=9,988,030) or birth weight (n=9,985,402). The main outcomes were low birth weight (birth weight ≤2499 g) and preterm birth (gestational age <37 weeks). We estimated the incidence ratios controlling for individual-level maternal characteristics (sociodemographics, prenatal care, and health behaviors) and state-level demographics, using log binomial regression models.

Results: The accuracy for identifying negative sentiments on comparing the machine learning model to manually labeled tweets was 91%. Mothers living in states in the highest tertile for negative sentiment tweets referencing racial or ethnic minorities had greater incidences of low birth weight (8% greater, 95% CI 4%-13%) and preterm birth (8% greater, 95% CI 0%-14%) compared with mothers living in states in the lowest tertile. More negative tweets referencing minorities were associated with adverse birth outcomes in the total population, including non-Hispanic white people and racial or ethnic minorities. In stratified subgroup analyses, more negative tweets referencing specific racial or ethnic minority groups (black people, Middle Eastern people, and Muslims) were associated with poor birth outcomes for black people and minorities.

Conclusions: A negative social context related to race was associated with poor birth outcomes for racial or ethnic minorities, as well as non-Hispanic white people.

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KEYWORDS

social media; racial bias; birth outcomes; racial or ethnic minorities

Introduction

Preterm birth and low birth weight (LBW) are the leading causes of infant mortality and childhood disability [1,2]. In the United States, racial disparities in birth outcomes persist [3,4] and have been widening [5]. In 2017, the preterm birth rate was 9.05% for non-Hispanic white mothers but 13.93% for black mothers. The LBW rate among black infants has consistently been more than twice that among non-Hispanic white infants from 2006 to 2016 [6]. Maternal health behaviors, adequacy of prenatal care, and sociodemographic characteristics do not fully explain the observed disparities [3]. There is increasing evidence that racial bias may partially contribute to these persistent disparities [3,7,8].

Traditionally, experiences with discrimination are assessed at the individual level by self-reports [9,10]. Self-reported racial attitudes and beliefs are subject to a number of limitations including social desirability bias and self-censorship [11,12], risking invalid exposure assessment [13,14]. Self-reports of racial discrimination can be influenced by a variety of factors including coping (eg, denial), trait- or state-based aspects of personality (eg, stigma consciousness and race-based rejection sensitivity), and aspects of racial identity (eg, internalized racism) [13]. While individual self-reported experiences of discrimination can provide important information, the social climate of a place represents a complimentary aspect of racial bias and discrimination that may have its own influence on health, independent of individual-level experiences. Thus, relying only on individual self-reported data can underestimate the effect of racism on health.

There are several mechanisms by which discrimination may impact poor birth outcomes. For example, the experience of discrimination may activate a stress response that may contribute to poor birth outcomes if experienced chronically. Maternal stress may impact birth outcomes through the following three major pathways: (1) altered neuroendocrine function, which leads to activation of the maternal-placental-fetal endocrine system that promotes childbirth [15,16]; (2) altered immune function that results in increased susceptibility to infections and inflammatory responses [17]; and (3) maladaptive coping behaviors, such as smoking and alcohol consumption [18]. Discrimination is also hypothesized to influence birth outcomes through access to resources, such as education, employment, health care, and housing [3], but these are long-term processes.

An innovative study highlighted the potential impact of a race- or ethnicity-related event that creates a change in the contextual-level social climate. The authors investigated birth outcomes after a federal immigration raid in Postville, Iowa in 2008, which at the time, was the largest single-site raid in US history [19]. Comparing the birth weight of infants born in the 37 weeks after the raid in Iowa with the same 37-week period 1 year prior, Latina mothers, including US-born Latina mothers, experienced a 24% increase in the risk of having an LBW infant after the raid. Changes in LBW were not observed for non-Latina white mothers. The investigators conducted a state-level analysis and found estimated effects in not only Postville but also the state of Iowa. Another study found that Arab-named women experienced a relevant increase in the risk of having an LBW or preterm infant following the September 11, 2001, attacks on comparing the 6 months after the attacks to the same 6-month period 1 year prior [20]. These studies provide evidence for the potential influence of the social context on the health of affected communities.

Social media represents an under-used source of data for public health research. Millions of tweets are sent daily, and 90% of Twitter users have made their profile public [21]. In the web-based space, people express a variety of views and beliefs, including those that are related to race. In addition, research suggests that the sense of anonymity provided by web-based spaces emboldens people to express views they may not state during in-person interactions [22]. These aspects make social media an attractive source for capturing sensitive topics such as race-related discussions.

Previous studies have used Twitter data to examine topics, such as vaccination [23] and national patterns in nutrition, exercise, and happiness [24], and to conduct health surveillance [25]. However, little research has been performed to investigate sensitive topics, such as race and racism on social media, and previous studies examining racism using social media data have focused on hate speech [26] and racial slurs [27].

To provide a race- or ethnicity-related measure of the social climate and address prior limitations of self-reported individual-level measures, we developed a novel area-level measure of racial sentiment and examined its association with LBW and preterm birth. We took a broad approach and collected tweets referencing racial or ethnic groups, not just hate speech tweets or tweets using racial slurs. However, terms conventionally perceived as racial slurs can be used in nonderogatory ways, and such reappropriation is common on Twitter. For instance, in popular culture, the term “nigga” is often used as an in-group term without valuation [27]. Furthermore, discussions conveying racial sentiment can occur without the use of racial slurs. A more comprehensive examination of tweets using race-related terms may include a sentiment analysis of tweets using racial slurs, as well as neutral racial terms such as “black,” “African American,” or “Asian.” In a previous paper, we examined the association between racial sentiment derived from Twitter data and adverse birth outcomes in 2015 [28]. In this paper, we improve upon the accuracy of

the machine learning model to label the sentiment of tweets, increase the sample size of tweets by 20 fold, and examine the relationships using Twitter and birth outcome data for multiple years rather than a single year.

Methods

Twitter Data

A random 1% sample of publicly available tweets was collected from June 2015 to December 2017, using Twitter's Streaming application programming interface. The analysis included English language tweets from the United States with latitude and longitude coordinates or other "place" attributes that permitted the identification of the state where the tweet was associated. All tweets included in the sample also used one or more of the 518 identified race-related keywords (Multimedia Appendix 1). The terms were compiled from racial and ethnic categories used by the US census, prior studies examining race-related online conversations [27,29], and an online database of racial slurs [30]. Tweets were classified into the following five main racial or ethnic categories according to the keywords used: black, Hispanic, Asian, white, and Middle Eastern. The Middle Eastern category included tweets that were anti-Islamic or related to Muslims.

The Twitter data were cleaned and processed for the analysis. We removed duplicate tweets according to the "tweet_id." We identified exclusion terms that tended to retrieve irrelevant tweets such as "black smoke" and "Indian Rd." To prevent undue influence from a small number of very frequent users, we excluded tweets from users who tweeted more than 1000 times a year in the data set, which represented 3% to 4% of all tweets. In total, we collected 26,027,740 tweets from 2,498,717 Twitter users. This study was determined to be exempt by the Institutional Review Board of the University of California, San Francisco.

Sentiment Analysis

We utilized support vector machine (SVM), a supervised machine learning model, to label the tweets. We obtained training data from manually labeled Sentiment140 (n=498) [31], Kaggle (n=7086) [32], and Sanders (n=5113) [33] and 6481 tweets labeled by our research group. Sentiment140, Kaggle, and Sanders datasets are publicly available training datasets specifically labelled for sentiment analysis. For our primary analysis, we compared negative tweets (assigned a value of 1) to all other tweets, which were positive or neutral tweets (assigned a value of 0). We used five-fold cross validation to assess the model performance and reached a high level of accuracy for the negative classification (91%) and a high F1 score (84%). Tweets were also labeled as positive or not positive. We similarly used five-fold cross validation and achieved an accuracy of 89% and a F1 score of 81%. State-level sentiment variables were created by averaging the dichotomous sentiment of tweets referencing various racial or ethnic groups.

Individual-Level Health Data

We used data from the 2015-2017 restricted US natality files with geographic identifiers as individual-level birth outcome data. The files were obtained after submitting a research proposal to and obtaining approval for data access from the National Center for Health Statistics [34]. The analysis was restricted to singleton births with no congenital abnormalities. Congenital abnormalities [35] and twins, triplets, and other higher order multiple births increase the risk for LBW and preterm birth [36]. The primary outcomes were LBW (defined as birth weight ≤2499 g) and preterm birth (defined as gestational age <37 weeks). Models for preterm birth included data from 9,988,030 births and models for LBW included 9,985,402 births.

Covariates

We adjusted for potential confounders of the association between racial sentiment and birth outcomes. Individual-level maternal characteristics included birth year, maternal age (linear spline with knots at 19, 25, 29, 33, and 38 years), race (white, non-Hispanic; black, non-Hispanic; American Indian/Alaskan Native, non-Hispanic; Asian, non-Hispanic; Native Hawaiian/Pacific Islander, non-Hispanic; multiracial, non-Hispanic), Hispanic ethnicity, marital status (married/unmarried), education (less than high school, high school or General Education Development [GED], some college, bachelor's degree, master's degree, or doctorate), body mass index (kg/m^2), smoking during pregnancy (first, second, or third trimester), first birth (yes/no), and prenatal care initiation during the first trimester (yes/no). We also adjusted for state-level characteristics including proportions of non-Hispanic black and Hispanic individuals, population density (per square mile), southern state indicator (yes/no), and economic disadvantage (standardized factor score [37,38] summarizing the following variables [%]: unemployed; some college education, high school diploma, children in poverty, single parent household, and median household income) to account for state-level compositional differences in demographic and economic characteristics. Use of the factor score has been previously published [24]. State-level covariates were derived from 2013 to 2017 through 5-year estimates from the American Community Survey [39].

Statistical Analysis

For each year, state-level sentiment toward racial or ethnic minorities was merged with data on births during that year. We estimated incidence ratios (IRs) using log binomial regression models, controlling for individual-level maternal characteristics and state-level demographic characteristics. In our main analyses, we modeled negative sentiment of tweets using race-related terms, but in the sensitivity analysis, we modeled the ratio of negative to positive sentiments to examine whether the results were robust for modeling different polarities of sentiment. We evaluated statistical significance at $P<.05$. Stata MP 15 (StataCorp LP, College Station, Texas, USA) was used for statistical analyses, and R software (R Foundation for Statistical Computing, Vienna, Austria) was used for mapping [40].

Results

From 2015 to 2017, we collected 26,027,740 tweets containing at least one of the relevant keywords pertaining to a racial or

ethnic group. Among the 518 terms assessed, 20 terms were present in 75% of all tweets with reference to a racial or ethnic minority group. The top Twitter terms were “nigga/niggas” (13,561,626/ 26,027,740, 52.10%), “racist” (1,070,770/ 26,027,740, 4.11%), “Mexican” (620,957/ 26,027,740, 2.39%), “white people” (514,111/ 26,027,740, 1.98%), and “Chinese” (498,775/ 26,027,740, 1.92%) (Table 1). Additionally, there were 15,683,909 tweets about black people, 1,801,780 about Asian people, 1,577,568 about white people, 1,512,566 about Hispanic people, and 1,274,827 about Middle Eastern people (Table 2). We have previously examined the emerging themes of tweets using race-related keywords [41]. Briefly, for negative sentiment tweets, tweets ranged from complaints about hassles in daily life (eg, “I hate when ppl Try to Join a Sport all late like niggah you didn't put in the work I did”) to race-related insults using derogatory language (eg, “Middle Eastern/Arabic accents piss me off more than most things”) and rare tweets expressing hostility or mentioning violence (eg, “if they are carrying a Mexican flag in Az. they need to be arrested.”) The use of “nigga” was common in negative sentiment tweets. However, Twitter users frequently use this term casually as slang.

Table 1. Top Twitter terms.

Term	Tweets (N=26,027,740), n (%)
Nigga	8,300,511 (31.89)
Niggas	5,261,115 (20.21)
Racist	1,070,770 (4.11)
Mexican	620,957 (2.39)
White people	514,111 (1.98)
Chinese	498,775 (1.92)
Racism	422,279 (1.62)
Muslim	381,601 (1.47)
Asian	312,520 (1.20)
Muslims	259,998 (1.00)
Japanese	238,588 (0.92)
Immigration	214,416 (0.82)
Indian	193,782 (0.74)
Islam	189,739 (0.73)
Syria	181,771 (0.70)
White girl	180,426 (0.69)
Jewish	170,040 (0.65)
Ghetto	167,128 (0.64)
Refugees	165,674 (0.64)
Black people	163,062 (0.63)

The geographic distributions of negative and positive sentiment tweets are displayed in Multimedia Appendix 2 and Multimedia Appendix 3, respectively. There was clustering of a higher proportion of negative tweets in the southeastern region of the United States (Multimedia Appendix 2) and clustering of a higher proportion of positive tweets in the western region of the United States (Multimedia Appendix 3). Twitter-derived measures of racial sentiment are presented in Table 2. Approximately 40.33% (9,657,039/23,945,052) of the tweets using race-related terms were categorized as negative. Tweets related to Middle Eastern people had the highest proportion of negative sentiment (638,688/1,274,827, 50.10%), whereas tweets related to Asian people had the lowest proportion of negative sentiment (113,172/1,801,780, 6.28%). Demographic characteristics of mothers giving birth from 2015 to 2017 are presented in Table 3. The mean age of mothers was 29 years, 59.74% (6,466,521/10,824,077) were married, and 85.99% (9,578,803/11,139,992) completed at least high school. Additionally, 6.37% (717,541/11,272,819) of singleton babies with no congenital abnormalities were born LBW and 7.91% (891,628/11,273,872) were born preterm.

Table 2. Negative sentiment for race-related terms used in tweets.

Race-related term	Number of tweets	Number of tweets with negative sentiment (%)
Racial or ethnic minorities	23,945,052	9,657,039 (40.33)
Black people	15,683,909	7,073,443 (45.10)
Middle Eastern people	1,274,827	638,688 (50.10)
Hispanic people	1,512,566	172,433 (11.40)
Asian people	1,801,780	113,172 (6.28)
White people	1,577,568	700,440 (44.40)

Table 3. Characteristics of mothers giving birth from 2015 to 2017.

Characteristic	Mean (SD) or n/N (%)
Age, years	28.6 (5.82)
Married	6,466,521/10,824,077 (59.74)
White, non-Hispanic	5,852,869/11,187,000 (52.32)
Black, non-Hispanic	1,600,020/11,187,000 (14.30)
Asian, non-Hispanic	717,706/11,187,000 (6.42)
Hispanic ethnicity	2,666,823/11,187,000 (23.84)
US born	8,645,413/11,257,974 (76.79)
Education	
Less than high school	1,561,190/11,139,992 (14.01)
High school	2,829,005/11,139,992 (25.40)
Some college	3,238,463/11,139,992 (29.07)
College	2,221,480/11,139,992 (19.94)
Master's or doctorate	1,289,855/11,139,992 (11.58)
Birth outcomes	
Low birth weight	717,541/11,272,819 (6.37)
Preterm birth	891,628/11,273,872 (7.91)

State-level racial sentiment was associated with LBW and preterm birth. In the entire population, mothers living in states with the highest level (third tertile) of negative tweets referencing racial or ethnic minorities had a 8% greater incidence of LBW (95% CI 1.04-1.13) and 8% greater incidence of preterm birth (95% CI 1.00-1.14) compared with mothers living in states with the lowest level (first tertile) of negative sentiment (Table 4). On investigating birth outcomes for racial or ethnic minorities, the direction and magnitude of effects were similar, with more negative tweets referencing racial or ethnic minorities being associated with a 13% increase in LBW (95% CI 1.06-1.21) and 10% increase in preterm birth (95% CI 1.05-1.16) among racial or ethnic minority mothers.

Examining sentiment toward specific groups, we found that states in the highest level (third tertile) of negative tweets referencing Middle Eastern people were associated with a greater incidence of LBW among racial or ethnic minorities (IR 1.07, 95% CI 1.02-1.12). More negative tweets referencing black people (IR 1.08, 95% CI 1.03-1.14) were associated with a greater incidence of LBW among black mothers (Table 5). A similar magnitude of effects was observed for preterm birth. While the sentiment of tweets referencing white people was not associated with birth outcomes among white mothers, the sentiment of tweets referencing racial or ethnic minority groups was associated with a greater incidence of LBW (IR 1.08, 95% CI 1.03-1.14) and preterm birth (IR 1.08, 95% CI 1.00-1.17) among non-Hispanic white mothers (Table 5).

On examining the association between negative sentiment and birth outcomes over time, there was evidence of an interaction between sentiment referencing black people and year. As a result, we present the absolute differences in the proportions and numbers of LBW and preterm births by year in Table 6 for the associations between negative tweets referencing black people and birth outcomes of black mothers, as well as the associations between tweets referencing racial or ethnic minorities and the birth outcomes of the entire population. For black mothers, the associations became stronger over time. For example, in 2015, black mothers living in states in the highest tertile for negative tweets referencing black people had a 0.65% difference in the proportion of LBW, translating to an excess of 3039 LBW babies as compared with that for mothers living

in states in the lowest tertile for negative sentiment. In 2017, this increased to a difference of 1.82% or 8711 LBW babies.

Table 4. State-level sentiment toward racial or ethnic minorities and individual-level birth outcomes.

State-level Twitter-derived variables (tertiles for race-related tweets that are negative)	Low birth weight[a,b], incidence ratio (95% CI) or n	Preterm birth[a,b], incidence ratio (95% CI) or n
Total sample		
Second tertile vs first tertile (lowest)	1.08 (1.03-1.13)	1.09 (1.04-1.13)
Third tertile	1.08 (1.04-1.13)	1.08 (1.00-1.14)
Number	9,985,402	9,988,030
Minorities		
Second tertile vs first tertile (lowest)	1.12 (1.04-1.19)	1.10 (1.05-1.15)
Third tertile	1.13 (1.06-1.21)	1.10 (1.05-1.16)
Number	4,920,300	4,921,577
White people		
Second tertile vs first tertile (lowest)	1.07 (1.02-1.12)	1.09 (1.03-1.15)
Third tertile	1.08 (1.03-1.14)	1.08 (1.00-1.17)
Number	5,407,779	5,409,230

[a]Data sources for health outcomes were 2015, 2016, and 2017 natality files. Tweets were collected from June 2015 to December 2017.

[b]Adjusted log binomial models were run for each outcome separately. Models were controlled for year and state-level factors including percent non-Hispanic black people, percent Hispanic people, southern state indicator, population density, and economic disadvantage (standardized factor score summarizing the following variables [%]: unemployed, some college education, high school diploma, children in poverty, single parent household, and median household income), as well as individual-level factors including maternal age, sex, race, ethnicity, foreign birth, education, marital status, smoking, body mass index, first birth status, and prenatal care. Twitter-derived characteristics were categorized into tertiles, with the lowest tertile serving as the reference group. Cluster-adjusted errors are reported.

Table 5. Stratified analyses of associations between state-level sentiment and birth outcomes among subgroups.

State level sentiment toward specific groups (tertiles for tweets that are negative)	Low birth weight[a,b], incidence ratio (95% CI) or n	Preterm birth[a,b], incidence ratio (95% CI) or n
Middle Eastern people and Muslims (minorities)		
Second tertile vs first tertile (lowest)	1.09 (1.04-1.14)	1.07 (1.03-1.12)
Third tertile	1.07 (1.02-1.12)	1.05 (1.02-1.09)
Number	4,920,300	4,921,577
Black people		
Second tertile vs first tertile (lowest)	1.10 (1.04-1.17)	1.10 (1.06-1.16)
Third tertile	1.08 (1.03-1.14)	1.09 (1.04-1.15)
Number	1,413,336	1,413,938
Hispanic people		
Second tertile vs first tertile (lowest)	0.96 (0.87-1.06)	0.96 (0.94-0.99)
Third tertile	0.96 (0.89-1.04)	0.90 (0.84-0.97)
Number	2,254,029	2,254,401
Asian people		
Second tertile vs first tertile (lowest)	0.98 (0.91-1.04)	1.02 (0.97-1.07)
Third tertile	1.03 (0.93-1.13)	1.10 (1.00-1.21)
Number	599,580	599,769
White people		
Second tertile vs first tertile (lowest)	1.01 (0.97-1.04)	1.00 (0.96-1.03)
Third tertile	1.02 (0.97-1.07)	0.98 (0.93-1.04)
Number	5,407,779	5,409,230

[a]Data sources for health outcomes were 2015, 2016, and 2017 natality files. Tweets were collected from June 2015 to December 2017.

[b]Adjusted log binomial models were run for each outcome separately. Models were controlled for year and state-level factors including percent non-Hispanic black people, percent Hispanic people, southern state indicator, population density, and economic disadvantage (standardized factor score summarizing the following variables [%]: unemployed, some college education, high school diploma, children in poverty, single parent household, and median household income), as well as individual-level factors including maternal age, sex, race, ethnicity, foreign birth, education, marital status, smoking, body mass index, first birth status, and prenatal care. Twitter-derived characteristics were categorized into tertiles, with the lowest tertile serving as the reference group. Cluster-adjusted errors are reported.

Table 6. Differences in the absolute numbers and proportions of low birth weight and preterm births between mothers living in states in the highest tertile for negative racial sentiment and mothers living in states in the lowest tertile.

Year	Low birth weight, n/N (%)		Preterm, n/N (%)	
	Total[a]	Black[b]	Total[a]	Black[b]
2015	11,712/3,444,706 (0.34)	3,039/469,659 (0.65)	14,261/3,444,783 (0.41)	3,466/470,019 (0.74)
2016	23,598/3,506,457 (0.67)	3,391/477,984 (0.71)	23,737/3,506,174 (0.68)	4,415/478,272 (0.92)
2017	10,490/3,040,622 (0.35)	8,711/479,384 (1.82)	16,827/3,037,346 (0.55)	7,060/465,674 (1.52)

[a]For the total sample, exposure is negative sentiment tweets referencing racial or ethnic minorities.

[b]For the sample of black mothers, exposure is negative sentiment tweets referencing black people.

Sensitivity analyses were conducted by modeling the ratio of negative to positive sentiments to investigate whether the findings were robust for modeling different polarities of sentiment. The findings showed a similar pattern (Multimedia Appendix 4) as compared to that for modeling negative sentiment alone, where states with a greater proportion of negative to positive tweets toward racial or ethnic minorities had a higher incidence of LBW and preterm birth.

Discussion

This study found that negative sentiment toward racial and ethnic minorities, expressed in tweets geolocated to states, was associated with LBW and preterm birth. These adverse associations were similar for the population of all births, births in non-Hispanic white mothers, and births in racial or ethnic minorities overall. Negative tweets referencing black people

were associated with adverse birth outcomes for black mothers. Similarly, negative tweets referencing Middle Eastern people were associated with poor birth outcomes among minorities. Associations were not consistently observed for negative tweets referencing non-Hispanic white or Hispanic mothers. While associations tended to be stable over the period from 2015 to 2017, for black mothers, the association between racial sentiment referencing black people and adverse birth outcomes became stronger over time.

This is among the few papers utilizing social media data to assess the racial climate in relation to health outcomes. Moreover, we did so on a national basis and accounted for individual characteristics. The results are consistent with prior work showing that the community-level racial climate is related to birth outcomes [19,20] and mortality [42] in the area. Stress has been identified as a pathway through which discrimination may impact health, and it is a known risk factor for adverse birth outcomes [43]. However, other pathways are possible, including access to resources such as education, employment, health care, and housing [3].

Previous research has provided evidence for the influence of the social context on the health of communities. Past studies have compared birth outcomes before and after a single-site immigration raid [19], the attacks on September 11, 2001 [20], and the 2016 presidential election [44] and found elevated adverse birth outcomes for minority populations following these events. One limitation of these studies is that the social context was not measured. Thus, we cannot directly evaluate whether area-level racial bias explained the association between the events and birth outcomes. Developing place-level measures of racial bias will advance the field and provide new opportunities to investigate the role of the social context in shaping health and health disparities.

Our results indicate that negative sentiment tweets referencing racial or ethnic minorities impacted the total population including non-Hispanic white people. Prior studies on racial bias and discrimination have tended to only examine the impact on racial and ethnic minorities. This study is unusual as it examined the health outcomes of the total population. A social climate that is hostile to racial and ethnic minorities might create an environment that is detrimental to all, including white people. This is consistent with prior work indicating that social cohesion promotes population health [45,46]. Animus toward racial and ethnic minorities may lead to withdrawal of support for shared resources and social policies and programs that might benefit white people and other racial and ethnic groups [47,48]. Prior work has found that living in black-segregated areas is associated with poor birth outcomes for black as well as white mothers [49,50]. There have been a few studies investigating the negative cognitive and affective impacts of racism on the perpetrators [51,52].

Although the rates of adverse birth outcomes have declined for all groups over the past century, a marked racial disparity has persisted. Similar disparities prevail for many other outcomes, including maternal mortality [53] and many adult morbidities and causes of death [54]. Interpersonal and structural racism are leading explanations for the continuing racial disparities in health, but research to confirm the causal role of racism and evaluate trends of the impact of racism on health outcomes has been hampered by the challenge of measuring racism. Our approach has important advantages in that it is easily measured and monitored, does not depend on self-reporting, is available nationally, and could likely be extended globally.

Nonetheless, the study has some limitations. The analyses did not take into account residential histories and the length of time individuals lived in their current communities. The data collected represent what people were willing to express on Twitter. Twitter users are not representative of the US population, with younger populations being over-represented on Twitter as compared with the US population [55]. However, the use of social media has been steadily increasing over time. Access to the internet and social media via cell phones has enabled people from all socioeconomic strata to engage on social media.

While the sentiment analysis represents a substantial contribution to the creation of an area-level measure of racial sentiment, there are important limitations to sentiment analysis. The sentiment analysis used the entire tweet to assess the sentiment or emotional tone of the tweet rather than focusing on just the racial terms mentioned in the tweet. Similarly, coders, who manually labeled tweets to provide training data for the machine learning algorithm, labeled the emotional tone of the tweet as a whole. Thus, it is possible that while the tone of the tweet may be negative, the race or ethnicity referenced in the tweet may not be the subject of that negativity, which was the case in many of the tweets. Additionally, the emotional tone of the tweet may display a negative sentiment, but it does not necessarily express a prejudiced statement, which was also common in our data. Our prior research indicated that prejudiced tweets can be distinct from the sentiment of the tweet [41]. For some tweets, negative sentiment also expressed negative racial attitudes or prejudiced beliefs (eg “Middle Eastern/Arabic accents piss me off more than most things.”) However, there were also negative sentiment tweets using race-related terms that did not express prejudiced beliefs. We commonly noted this with the term “nigga” (eg, “Can’t Watch The (professional basketball team) play. These Niggas Boring AF”). We also came across tweets where the sentiment was positive, but they expressed a prejudiced belief or racial or ethnic stereotype (eg, “Must have hired a Mexican cleaning crew. Bathroom got the fabuloso clean smell”). Regardless, the associations observed in our study seem to capture a signal related to the average level of racial attitudes and birth outcomes. Future work is needed to develop models to capture race-related topics as well as sentiment and to align the Twitter-based characterization of racial context to other measures of structural or interpersonal racism.

This study contributes to the nascent body of literature on place-level indicators of racial attitudes and bias. While not comprehensive, our measure of racial sentiment may represent a signal of the broader social and cultural context in which mothers reside. Data collected from Twitter may be unique as compared with what can be obtained from traditional surveys on racial attitudes or bias. Social media can represent a rich source of timely data regarding perspectives on a range of topics, including racial attitudes. This study revealed that the racial

climate toward minorities may have implications for racial or ethnic minorities, as well as the entire population. The promotion of a social climate of respect, positivity, and inclusion may have beneficial health impacts for birth outcomes in the population at large.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Terms used in Twitter data collection.
[DOCX File , 26 KB - publichealth_v6i3e17103_app1.docx]

Multimedia Appendix 2
Geographic distribution of negative sentiment tweets using race-related terms, 2015-2017.
[DOCX File , 245 KB - publichealth_v6i3e17103_app2.docx]

Multimedia Appendix 3
Geographic distribution of positive sentiment tweets using race-related terms, 2015-2017.
[DOCX File , 245 KB - publichealth_v6i3e17103_app3.docx]

Multimedia Appendix 4
Ratio of negative to positive sentiment toward race or ethnic minorities and individual level birth outcomes.
[DOCX File , 19 KB - publichealth_v6i3e17103_app4.docx]

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Abbreviations

IR: incidence ratio
LBW: low birth weight

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Original Paper

Profiling Clinical Research Activity at an Academic Medical Center by Using Institutional Databases: Content Analysis

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Abstract

Background: It is important to monitor the scope of clinical research of all types, to involve participants of all ages and subgroups in studies that are appropriate to their condition, and to ensure equal access and broad validity of the findings.

Objective: We conducted a review of clinical research performed at New York University with the following objectives: (1) to determine the utility of institutional administrative data to characterize clinical research activity; (2) to assess the inclusion of special populations; and (3) to determine if the type, initiation, and completion of the study differed by age.

Methods: Data for all studies that were institutional review board–approved between January 1, 2014, and November 2, 2016, were obtained from the research navigator system, which was launched in November 2013. One module provided details about the study protocol, and another module provided the characteristics of individual participants. Research studies were classified as observational or interventional. Descriptive statistics were used to assess the characteristics of clinical studies across the lifespan, by type, and over time.

Results: A total of 22%-24% of studies included children (minimum age <18 years) and 4%-5% focused exclusively on pediatrics. Similarly, 64%-72% of studies included older patients (maximum age >65 years) but only 5%-12% focused exclusively on geriatrics. Approximately 85% of the studies included both male and female participants. Of the remaining studies, those open only to girls or women were approximately 3 times as common as those confined to boys or men. A total of 56%-58% of projects focused on nonvulnerable patients. Among the special populations studied, children (12%-15%) were the most common. Noninterventional trial types included research on human data sets (24%), observational research (22%), survey research (16%), and biospecimen research (8%). The percentage of projects designed to test an intervention in a vulnerable population increased from 17% in 2014 to 21% in 2015.

Conclusions: Pediatric participants were the special population that was most often studied based on the number of registered projects that included children and adolescents. However, they were much less likely to be successfully enrolled in research studies compared with adults older than 65 years. Only 20% of the studies were interventional, and 20%-35% of participants in this category were from vulnerable populations. More studies are exclusively devoted to women's health issues compared with men's health issues.

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KEYWORDS

database; clinical studies as topic; vulnerable populations; pediatrics; geriatrics

Introduction

Background

Clinical research has spanned a wide range of activities. Projects include retrospective chart reviews, observational cohort studies, surveys and questionnaires, behavioral interventions, evaluation of educational and public service programs, investigations of normal physiology and mechanism of disease, and interventional trials of drugs and devices. The majority of these activities are conducted at academic medical centers in collaboration with other departments in the university and pharmaceutical or medical device companies.

For clinical research to truly achieve its mission of alleviating the burden of disease and improving health outcomes, it must address problems that arise throughout the population. For many years, clinical research has focused primarily on middle-aged adult men, which limited the ability to generalize to women, children, or older adults [1]. In recognition of this problem, the National Institutes of Health (NIH) required investigators to provide assurances that men and women would be eligible to participate in a planned clinical research project unless the condition being studied precluded inclusion of one gender [1,2]. Similarly, clinical research must address health problems that occur across the entire lifespan. This led to the inclusion of an additional requirement to include children in clinical research in the absence of significant risk in the pediatric age group. Finally, there are special populations that have historically been neglected and that even now are not fully included in the clinical research enterprise. Special populations are groups of individuals who may have limited access to clinical research because of physical, emotional, or socioeconomic factors that present barriers to full participation. Vulnerable groups are those that are susceptible to coercion or undue influence and have an inability to provide voluntary informed consent. Their exclusion from clinical research may be the result of barriers to participation caused by social discrimination, communication issues, language problems, lack of awareness of ongoing clinical research activity, community and cultural barriers, financial barriers (eg, inability to miss time at work and lack of back-up resources), or logistic difficulties involved in outreach to and the inclusion of these groups. Examples include older adults, immigrant groups, those with mental health disorders, and the lesbian-gay-bisexual-transgender-queer community. The relative importance is likely to vary from center to center depending upon location and the unique features of health care delivery at each site.

New York University (NYU) Langone Health serves a diverse population across the entire lifespan (Table 1).

Table 1. New York University Langone population statistics.

Site[a]	NYU[b] Langone	NYU Lutheran	NYU HJD[c]	Bellevue (HHC)[d,e]	Gouverneur (HHC)[e]	Woodhull (HHC)[e]	NYU Dental	NYU Fink/Hassenfeld
Number of inpatients per year	38,000	26,500	6588	30,000	N/A[f]	14,000	N/A	N/A
Number of outpatient visits per year	912,059	620,000	227,900	492,924	250,726	385,452	392,444	14,313
Number of unique patients per year	331,034	102,067	65,972	86,961	39,372	74,495	145,532	8504
White, %	65.7	17.8	52.3	12.3	5.7	9.5	7.5	51
Black, %	8.3	18	12.6	17.2	9.1	34.1	5.5	11
Asian, %	5.1	10.1	5.5	11.5	30.4	2.6	2.7	10
Hispanic[g], %	2.8	50	8.6	28.4	32.3	34.8	N/A	28
Native American/Pacific Islander, %	8.0	<1	0.3	N/A	N/A	N/A	<1	<1
Other or unknown, %	21.0	6	20.8	30.6	22.5	19	84.3	<1
More than 1, %	__[h]	47.4	—	—	—	—	N/A	N/A

[a]Administrative data for the period 2012-2014.

[b]NYU: New York University.

[c]HJD: Hospital for Joint Diseases.

[d]HHC: Heath+Hospitals Corporation.

[e]Includes children and adolescents.

[f]N/A: not applicable.

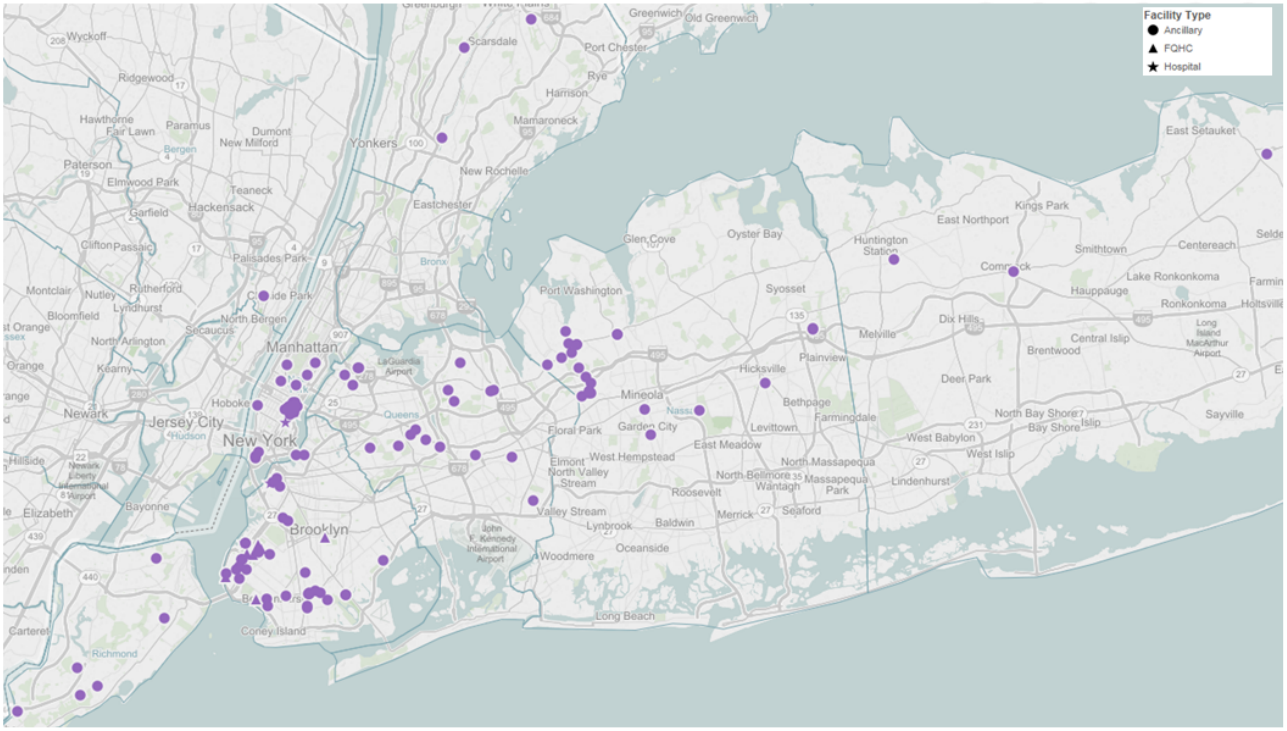
[g]Captured as ethnicity, not race.

[h]Data unavailable.

Moreover, the geographical distribution of sites within the NYU clinical network where care is provided and their catchment areas mirrors the diversity of the populations served (Figure 1). Although select populations such as African Americans and Asians have been studied, there has been little work at an

institutional level to identify barriers and promote the inclusion of vulnerable and special populations in clinical research.

Figure 1. Geographical distribution of clinical sites within the New York University Langone Health network.



Objectives

The New York University-Health+Hospitals (NYU-H+H) Clinical Translational Science Institute (CTSI) has been in operation for 10 years. One of the primary objectives has been to ensure that clinical research is being performed in *special or vulnerable populations* determined by the funder, which includes pediatrics and geriatrics. Therefore, we conducted the following review of clinical research performed at NYU, including the Bellevue Medical Center and Woodhull Medical Center, to provide a baseline assessment of participation by special populations. Our primary objective was to use NYU institutional administrative data to characterize the spectrum of clinical research activity and to determine whether special populations were being included in this enterprise and to enable monitoring of changes over time. A second objective was to determine if the type, initiation (enrollment of first participant), and completion (achievement of target enrollment) of studies differed by younger or older population (ie, those aged <18 years and >65 years) compared with the main population of adults aged 18 to 65 years who were not members of special populations. This profile will guide the design and implementation of programs that intend to improve participation by special populations who are underrepresented in the clinical research enterprise.

Methods

Data Sources

Data for this study were obtained via the NYU Langone Health's research navigator (RNav) system. RNav was launched on November 19, 2013, and is a study management system comprising multiple modules, including institutional review board (IRB) submissions, grant proposals, a clinical research management system (CRMS), and others. All human subjects research studies that occur at NYU Langone need to be registered within RNav. In total, 2 modules were used for the collection of data for this study: (1) MyStudies for details on the study protocol and (2) CRMS, which in its current form mostly captures industry-sponsored studies and does not capture much of the clinical research conducted at NYU, was reviewed for characteristics of individual participants. MyStudies is a registration module, in which researchers summarize the study protocol as a required part of the IRB submission. CRMS is used for the capture of individual research participant information for billing compliance purposes, and therefore, it tends to be used more for clinical trials rather than population-based health studies.

A report was obtained with selected information on all studies registered in RNav as of November 2, 2016 (Multimedia Appendix 1). Data were reviewed for all studies that were IRB approved between January 1, 2014, and November 2, 2016. Studies with earlier IRB approval dates were excluded due to inconsistencies in data resulting from the transfer of data between systems upon the launch of RNav in late 2013.

Data Collected

We collected the following demographic variables regarding participants in research: age, gender, race or ethnicity, and whether the participant was a member of a special population. The character of the research study was classified by the lead investigator of each study as observational or interventional. The latter category included studies of normal physiology, cohort studies, and population-based projects. The variables are summarized in Table 2.

As age at the time of enrollment is not a required field, an approximate age was calculated by subtracting a reference date (December 13, 2016) from the participant's date of birth. Using this method, it is possible that the age of participants was overestimated by at most 3 years.

Table 2. Characteristics of clinical research captured in institutional databases.

Participants	Studies
Age	Observational • Cohort • Population based • Data sets • Survey • Biospecimen • Mechanistic • Educational practices • Health outcomes • Benefit of service outcomes
Gender	Interventional • Medication • Device • Surgical • Behavioral
Race or ethnicity	N/A[a]
Member of special population	N/A

[a]N/A: not applicable.

This procedure was followed because the actual date of consent and/or enrollment was not always recorded in the system. The planned minimum and maximum age of participants, as reported by study teams, were consolidated into age groups (0-17 years, 18-39 years, 40-64 years, 65-74 years, and 75+ years). There were some pediatric studies that included participants aged under 21 years, and they were included in the first category. There were no adult studies that included patients aged under 18 years. In instances in which minimum and maximum age were obviously reversed (eg, studies with a minimum age of 90 years or maximum age of 18 years), the data were edited to correct the error. Studies with missing data were excluded from the analysis. In addition, we only reported the number of participants who enrolled into a study (ie, those who signed an informed consent) because of inconsistencies in completion of the accrual field (ie, those who were not screen failures).

To limit the analysis to those studies that had achieved the target enrollment and completed recruitment, only studies that were closed with the IRB in between 2014 and 2016 were included in the enrollment dataset.

This study was not classified as research, and the requirement for informed consent was waived by the IRB because only anonymous, aggregate data without personal health information were analyzed.

Results

Demographics of Patients

We examined the eligibility criteria in clinical studies that were IRB approved, whose current status was open, closed, or lapsed. Of those that were performed during the 3-year survey period of 2014-2016, 22%-24% defined the pediatric age range, 0-17 years, as the minimum age. The maximum age was 17 years in 4%- 5% of studies, which more clearly indicates the contribution of pediatric studies.

Most of the remaining studies presumably had a minimal age of 18 years because fewer than 5% specified an age above 39 years. Most of the studies included geriatric patients (age at enrollment >65 years) because the maximum projected age was ≥75 years in 64%-72% of the studies. Only 5%-12% of studies were focused exclusively on the elderly geriatric defined as minimum age above 65 years.

When examining the actual patient characteristics in studies that were closed in 2014-2016 that had individual subject data entered into CRMS, the approximate peak age at the time of enrollment was 50-59 years, with fewer participants at the pediatric and geriatric ends of the lifespan (Multimedia Appendix 2). In total, 60% of participants were aged 18-64 years at the time of enrollment, 3% were aged under 18 years, and 37% were aged 65 years or older. Initiation of recruitment (enrollment of the first participant) occurred in 31% of projects involving participants aged above 65 years versus 3% for projects involving participants aged 0-17 years. This difference occurred despite the larger number of pediatric versus geriatric studies included in the survey.

Approximately 85% of the studies were open to inclusion of both male and female participants. Of the remaining studies, those that were open only to girls or women were approximately 3 times as common as those that were confined to boys and men. Approximately 56%-58% of the projects focused on nonvulnerable patients. Among the special populations studied, children (12%-15%) were the most common. Employees, students, cognitively impaired, economically disadvantaged,

and pregnant women were equally represented, 4%-7% in each subgroup, with small variations between years. Approximately one-third of the clinical studies were directed at healthy subjects and the remainder targeted individuals with specific diseases or conditions.

Study Characteristics

Noninterventional trial types included research on human data sets (24%), observational research (22%), survey research (16%), and biospecimen research (8%). Mechanistic or physiological studies, studies involving educational practices, studies assessing expanded access or screening protocols, and those that evaluated the public benefit of service programs were infrequent.

The percentage of interventional studies among projects that did not have a vulnerable population as the primary focus was 24%-27% over the survey period. This category included drugs, devices, and surgical or behavioral interventions. This figure was higher than the percentage in projects that were designed to test an intervention in a vulnerable population. In this subgroup, the percentage of interventional trials increased from 17% in 2014 to 21% in 2015. The number ranged between 20% and 35% of all studies in most subgroups of vulnerable populations including children and cognitively impaired participants. The percentage of interventional studies was demonstrably lower (below 15%) in employees, students, and pregnant women. The number of studies performed in fetuses, neonates, and prisoners was too low to comment on the breakdown into study type.

There were no significant trends in the demographics of study participants or the type of research projects that were conducted over the 3-year study period.

This study was exempted from the requirement for ethics approval by the Institutional Review Board of NYU School of Medicine because it does not involve individual patient data.

Discussion

Principal Findings

This report represents a snapshot of the full gamut of clinical research activity at a large academic center. As a recipient of a Clinical Translational Science Award from the National Center for Advancing and Translational Science, NYU serves as a centralized hub capable of supporting the full spectrum of clinical investigation. Our main objectives were to characterize the spectrum of clinical research activity using institutional administrative data and to determine whether special populations were being included in this enterprise. Our main findings are as follows: (1) only 20% of the studies were interventional and 20%-35% of participants in this category of study were from special or vulnerable populations, (2) pediatric participants were the most studied special population based on the number of approved projects designed to include them, (3) fewer children than older patients were actually enrolled into approved research projects, (4) women are fully represented and more studies are exclusively devoted to women's health issues compared with men's health issues.

Whether administrative databases can be used to document clinical research at an institutional level may seem like a straightforward question with an obvious affirmative answer. Clinical studies are monitored from an ethical standpoint by the IRB and from a financial standpoint by grants administration offices. Registration and status reports are generally mandatory at all institutions. However, compliance is contingent upon investigator diligence and the intensity of administrative oversight. These are often less than optimal, and there can be substantial gaps in data accuracy regarding the type of study and target and actual enrollment. This is illustrated by the less than complete adherence to federal guidelines for listing clinical studies, detailing the objectives, updating enrollment, and providing final reports in a timely manner [3]. There are a number of proposals to improve the timeliness and quality of the data provided by investigators regarding their clinical research. Our findings provide an initial look at the completeness and accuracy of the data at a large academic center and provide a baseline to evaluate the efficacy of these suggestions.

The experience at NYU should have broad relevance. Historically, NYU included Bellevue Medical Center as a teaching hospital. With the recent incorporation of Lutheran Medical Center into NYU Langone Health, the patient population has become even more diverse, ethnically and economically. Thus, it is likely that issues related to clinical research identified in this report will be applicable to other institutions. Additional work is needed to determine whether the distribution of participants in clinical research matches the population served by the hospital. However, this will not detract from the availability of the full range of patient groups in the NYU-H+H CTSI.

Our inventory of clinical studies performed at NYU indicated that most of the clinical research is focused on adults and only 5% of projects are devoted to pediatric patients. Approximately 70% of studies include geriatric patients because the maximum age allowed was ≥75 years, but only 5%-12% focus exclusively on older patients (aged >65 years). This predominance of adult studies is reflected in the characteristics of the patients who were actually enrolled in the studies. Older adults were more likely to be included in the studies, but younger adults were more often the focus of studies. Thus, there was a 10-fold greater enrollment in geriatric *versus* pediatric clinical studies. Most studies included both genders, and of the remaining projects, there was a 3-fold greater number of studies that focused exclusively on women *versus* those that examined men's health issues. There were no data regarding gender nonconforming groups. Efforts are underway to capture this information accurately without compromising participant confidentiality. Interestingly, although pediatric studies were infrequent, they represented the largest special population that was studied. This review suggests that there is a pressing need to increase the involvement of children in clinical research. The standard bias of restricting access to clinical research for participants aged under 18 years until the completion of studies in adults may need to be reconsidered. This may be especially relevant in clinical conditions in which the impact on health is as serious in children as it is in adults, such as infectious diseases [4]. This may even apply when the impact of the health problem may not

be apparent in childhood, but in which the adverse consequences emerge later in life during adulthood, such as hypertension, diabetes, or obesity.

Only one-fifth of the studies performed during the survey period were interventional in nature. The representation of vulnerable populations including children and cognitively impaired individuals ranged from 20% to 35% in this category of study. This suggests that although it may be more difficult to enroll these subgroups into observational survey or biospecimens projects because of a lack of potential benefit, these individuals are being offered the opportunity and are enrolling in interventional trials. However, there are select groups such as neonates and pregnant women who may still be underrepresented in interventional clinical trials [5].

Our findings suggest that there may be a need to adopt regulatory strategies that will promote the involvement of pediatric patients in clinical research. Although our data suggest that the elderly are being included in clinical research, this claim requires ongoing reassessment as the number of patients older than 80 years continues to rise in the general population. The effect of strategies to promote the participation of underserved populations while ensuring safety and confidentiality requires real-time monitoring [6]. The advent of new integrated methods to approach patients and obtain consent for participation in clinical research, including novel uses of the electronic medical record for research (eg, direct invitations for research studies via patient portals such as Epic's MyChart, big data mining of these clinical records), social media, and mobile devices with specific study apps, and recruitment in nonmedical centers and via direct email communication will increase the need for close surveillance to ensure efficacy and safety of all clinical research projects [7,8]. It is beyond the scope of this report to evaluate these and other novel recruitment and retention strategies, especially those that target underrepresented populations.

Approximately 30% of the trials included vulnerable populations, including children. It is unclear if this figure reflects the percentage in the general population because these individuals may be difficult to track for a variety of reasons including poor access to their place of residence, compromised mobility, and concerns raised by the individual's legal status. The composition of this group is also likely to change over time based on the conditions that prevail generally and locally across the United States. As this group may disproportionately experience the adverse effects of common health problems, it is important to include them in clinical research activity. Potential strategies to achieve this goal include improved outreach in the less visible communities, clarification of the health problems that are key concerns, and providing legal protection to those who participate in clinical research. The efficacy of these policies needs to be evaluated systematically to ensure the selection of approaches that promote this goal.

It is important to note that the categories of vulnerable and special populations used in this report are in accordance with the objectives of the Clinical and Translational Research Unit funding opportunity guidelines, namely, the inclusion of pediatric, geriatric, and relatively inaccessible patients. This mandate provided the rationale for the formation of an Integrating Special Populations Unit in the NYU-H+H CTSI to promote recruitment of these groups. We recognize that other racial or ethnic subgroups such as African Americans and handicapped persons represent important patients who have been underrepresented in clinical research. Our study provides a benchmark for the evaluation of the participation by these other patient groups.

The gap between the initiation of clinical research studies by recruiting the first participant and completing a project by achieving the target enrollment is an important consideration. Studies that are open to enrollment for extended period of time but fail to achieve the required sample size consume valuable institutional resources. Studies like ours may provide a method to identify studies with poor recruitment, assist in designing remedial approaches to enrollment, and development of guidelines for termination of underperforming studies.

Strengths and Limitations

There are several limitations to this study. There is a lack of detailed information about most of the studies. Moreover, there is no *gold standard* to compare information supplied by investigators with the actual number and type of clinical research being performed. However, the categories of research and the patient subgroups are generalizable, and our deidentified findings should be helpful to other institutions that are attempting to track research activity at their institution. NYU has not developed a uniform system to accurately track clinical trials, including key information about the specific target population and sample size, number of patients screened, number of patients enrolled, and number of patients studied. The CRMS in its current form mostly captures industry-sponsored studies and does not capture much of the clinical research conducted at NYU. Efforts are underway to include NIH- and foundation-sponsored projects. There is no difference in how the institution tracks studies performed in children or adults. Nonetheless, if the number of industry-sponsored projects performed varies by site or the percentage of industry-sponsored studies that are open to pediatric patients is low, these factors may impact the profile of clinical research performed at NYU versus other academic institutions in the region or more broadly around the country. In addition, we have not accounted for the number of faculty members who are involved in pediatric research compared with research on adult participants in other departments. This is an important issue, and we plan to assess this aspect of clinical research at NYU versus other institutions in a future report. The classification of studies is carried out by the lead investigator, and there may be some error in this process. During the registration of studies in the ClinicalTrials.gov registry, studies that are misclassified as interventional may be correctly listed as observational or other. However, the accuracy of other studies has not been verified. There are numerous variables being tracked, including research expenditures, IRB documentation, and participant enrollment, which are currently monitored by nonoverlapping systems. It is hoped that these important indices can be consolidated into one instrument that will improve the efficiency and accuracy of monitoring and at the same time reduce the administrative burden on the clinical research team. We are also unable to compare the clinical research activity

done at NYU with the activities of other institutions in the region and across the United States. It is likely that local factors, such as the presence of competing institutions and the demographic nature of the population, influence the clinical research activity profile at any specific academic medical center. It will be important to compare the data on the scope of clinical research at single sites using institutional databases with those of mandatory clinical trial registries such as ClinicalTrials.gov [8]. We lack longitudinal data and are unable to assess the impact of the CTSI of NYU and Health+Hospitals on the volume and character of clinical research at this institution. Finally, it will be important to incorporate patients' attitudes, including parents and other care providers, toward clinical research to gain a full perspective on the work being performed at NYU Langone Health.

We are unaware of any recent studies comparable with ours that provide a description of clinical research in a large health care system based on institutional databases. There are examples of research profiles that focus on a single disease, a defined goal, or the use of a combination of resources [9-12]. As such, this report is unique and provides a basis for comparison within our site over time and with other institutions of similar size and capacity.

Conclusions

Using institutional databases, we documented that only 20% of the studies performed at a large, urban academic medical center were interventional and 20%-35% of participants in this category were from vulnerable populations. Although pediatric participants were the largest special population studied, they were much less likely to be included in research compared with older adults. Women are fully represented, and more studies are exclusively devoted to women's health issues compared with men's health issues. We anticipate that future refinements in the methodology of institutional databases will ensure that the information collected can be used to monitor research activity and guide decisions about the policies and direction of this important work. Finally, institutional databases may inform future strategies for marketing and communicating research opportunities to vulnerable populations, enhancing protocol design, and streamlining informed consent documents for clarity and understanding.

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Authors' Contributions

AL, SS, BC, JH, and HT conceived the study. AL, SS, RT, KN, NL, and HT retrieved and analyzed the data. ALK, SS, RT, KN, and HT wrote the manuscript. AL, SS, RT, KN, SK, DC-K, NL, BC, JH, and HT reviewed and contributed to the final version of the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Template report of studies registered in Research Navigator (RNav).
[DOCX File , 21 KB - publichealth_v6i3e12813_app1.docx]

Multimedia Appendix 2
Approximate age at the time of enrollment (closed studies).
[PNG File , 118 KB - publichealth_v6i3e12813_app2.png]

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Abbreviations

CRMS: clinical research management system
CTSI: Clinical Translational Science Institute
IRB: institutional review board
NIH: National Institutes of Health
NYU: New York University
NYU-H+H: New York University-Health+Hospitals
RNav: Research Navigator

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Viewpoint

COVID-19 and Slums: A Pandemic Highlights Gaps in Knowledge About Urban Poverty

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Abstract

According to the United Nations, about 1 billion persons live in so-called slums. Numerous studies have shown that this population is particularly vulnerable to infectious diseases. The current COVID-19 pandemic, caused by the novel coronavirus SARS-CoV-2, emphatically underlines this problem. The often high-density living quarters coupled with a large number of persons per dwelling and the lack of adequate sanitation are reasons why measures to contain the pandemic only work to a limited extent in slums. Furthermore, assignment to risk groups for severe courses of COVID-19 caused by noncommunicable diseases (eg, cardiovascular diseases) is not possible due to inadequate data availability. Information on people living in slums and their health status is either unavailable or only exists for specific regions (eg, Nairobi). We argue that one of the greatest problems with regard to the COVID-19 pandemic in the context of slums in the Global South is the lack of data on the number of people, their living conditions, and their health status.

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KEYWORDS

slums; informal settlements; COVID-19, pandemic; infectious disease; living conditions; lifestyle; risk; risk group; health information

Introduction

The spread of SARS-CoV-2 poses one of the greatest challenges to humankind in recent history. According to current estimates (as of July 23, 2020) from Johns Hopkins University [1], there are over 15 million known infections and about 624,000 deaths worldwide in connection with the COVID-19 pandemic.

In the beginning, most COVID-19 infections occurred in countries of the Global North (eg, the United States, Spain, Italy, etc); however, the focus of the pandemic is now shifting toward countries of the Global South (eg, Brazil, India, South Africa, Peru, Chile, and Pakistan). Although only 5% of all confirmed cases (approximately 769,000 as of July 23, 2020) come from African countries, it can be assumed that the number of cases in this region will continue to increase with potentially serious consequences due to limited medical resources [2]. Many African as well as some South Asian countries have the lowest income in the world, with a large proportion of the population living in precarious housing situations often referred to as "slums," "informal settlements," or "deprived areas." According to United Nations estimates, about 1 billion people worldwide currently live in slums [3].

The socioeconomic situation of a person or a group may influence the course of COVID-19. Previous analyses in the United States have shown that socioeconomically disadvantaged groups are at more risk, since they are more frequently affected by the comorbidities that lead to a severe course of COVID-19 compared to the rest of the population [4]. These risk factors are cardiovascular diseases, high blood pressure, diabetes, as well as previous diseases or damage to the lungs [5]. For example, relative to the total population, Black individuals are more likely to experience a severe course of COVID-19 than their White counterparts [6] (the terminology used here—"Black" and "White"—corresponds to that used by Garg et al [6]). Similar distributions of serious cases have been reported in other countries, such as the United Kingdom [7].

Since many studies have shown that slum dwellers are socioeconomically disadvantaged (eg, [8,9]), we need to assess what we know about this group of people in order to determine the risk posed by the virus. We must also examine what we do not know and what we should know.

What We Know

There is much to be said about the fact that the COVID-19 threat is particularly prevalent in low-income countries, particularly the poorer parts of the population; inhabitants of slums could be especially impacted by the pandemic [10]. There are several reasons for this.

Firstly, social distancing, which is currently being implemented on a large scale across the world, is a physical impossibility in slums due to the high density of buildings and persons per dwelling [11,12]. Furthermore, we know that residents of low- and middle-income countries have increased risks for respiratory infections due to elevated levels of air pollution [13].

As Dahab et al [10] pointed out, if the pandemic enters the slums, their occupants could be much more threatened by severe disease outcomes due to the higher transmissibility of the disease, higher infection-to-case ratios, and higher case fatality. They also demonstrate which measures should be taken, which are realistic (eg, shielding at different levels like households, streets, or blocks), and which are not (eg, tracking of patients) to protect underprivileged and underserved areas [10].

Corburn et al [14] discussed how slums and informal settlements are poorly prepared to manage the pandemic and offered suggestions to minimize the risk of the virus. This is not only a matter of treating the inhabitants of informal settlements on a level equal to the rest of the population but also involves providing them with special support in order to adequately counter the risks associated with their living conditions [15].

What We Do Not Know

In addition to the studies mentioned above, the pandemic highlights very clearly how limited our knowledge of the living conditions of slums is. We outline below three areas where information is lacking.

1. *Distribution of risk factors among slum dwellers.* Different studies show that the above-mentioned risk factors for severe diseases are not well researched. Data are especially limited on noncommunicable diseases that lead to severe courses of COVID-19 [16]. Although there are many studies on infectious diseases, findings on risk groups, such as people with cardiovascular diseases, are scarce and sometimes contradictory [17,18]. Therefore, we do not know how dangerous the virus is, particularly for these groups.
2. *Regional similarities and differences.* Recent, largescale reviews showed that our knowledge of the health of slum inhabitants is very limited [16,19]. What we know is mostly limited to individual regions, such as Nairobi and Kenya [20]. These findings are confirmed when researching current measures to determine the extent to which countries are taking measures to protect their vulnerable populations. In Nairobi, for example, special attention is given to inhabitants of informal settlements and attempts are made to respond to their needs in the best possible way [21]. Looking at the current data situation, however, Nairobi seems to be an exception. We do not know whether health authorities in other countries and cities have such data or whether they are inaccessible to outside researchers.
3. *Number of inhabitants.* Estimates of residents living in these settlements often differ substantially. Taubenböck et al [22] reported that population estimates for Mumbai vary by a factor of 5 (ie, between 200,000 and 1,000,000 people). Without information on inhabitants, no adequate measures can be taken, both in terms of patient follow-up and in terms of providing necessary care for patients with severe courses of disease. Unreliable population estimates means we are unable to assess the capacity required to deliver these services.

The pandemic unequivocally underlines that we know too little about this vulnerable part of the world's population, their living conditions, state of health, and thus their inclusion in COVID-19 risk groups. In order to initiate appropriate countermeasures to contain the pandemic, adequate information is necessary.

What We Should Know

As mentioned above, researchers have already developed proposals to prevent or contain the spread of COVID-19 in slums in a very concrete way [10,14]. Beyond this, however, we think that the following long-term measures are necessary:

1. *Analyses of slum populations and their surroundings.* Recent publications have repeatedly pointed out that it is necessary to identify and classify both individual households and larger low-resource urban areas using uniform frameworks [23]. For this purpose, in addition to the large number of studies that have been conducted in different locations, it is necessary to establish common databases to collect information on the population and spatial characteristics of these settlements.
2. *Detailed comparative research on slum dwellers' state of health.* It is necessary to investigate what commonalities and differences in the health status of slum dwellers exist [20]. This refers both to the differences within a city between groups living in formal and informal settlements [24], which was done for HIV in South Africa [25], and to the differences across slums in different global regions. The aim here is to become aware of cultural, economic, geographical, infrastructural, religious, or other circumstances, their influences on the health of occupants, and the associated allocation to risk groups. The local population should be involved in information gathering, which can be supported by modern mobile health concepts [26,27]. It is necessary that regionally appropriate countermeasures be taken in the event of challenges such as the current pandemic.

Although these measures are of a longer-term nature and cannot be achieved during the pandemic, they do indicate a way of

making visible again the part of the world population that is currently invisible.

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Authors' Contributions

Both authors conceptualize this paper, and read and approved the final version. JF wrote the initial draft. PFP was responsible for project administration.

Conflicts of Interest

None declared.

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