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Original Paper

Near-Real-Time Surveillance of Illnesses Related to Shellfish Consumption in British Columbia: Analysis of Poison Center Data

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Abstract

Background: Data from poison centers have the potential to be valuable for public health surveillance of long-term trends, short-term aberrations from those trends, and poisonings occurring in near-real-time. This information can enable long-term prevention via programs and policies and short-term control via immediate public health response. Over the past decade, there has been an increasing use of poison control data for surveillance in the United States, Europe, and New Zealand, but this resource still remains widely underused.

Objective: The British Columbia (BC) Drug and Poison Information Centre (DPIC) is one of five such services in Canada, and it is the only one nested within a public health agency. This study aimed to demonstrate how DPIC data are used for routine public health surveillance in near-real-time using the case study of its alerting system for illness related to consumption of shellfish (ASIRCS).

Methods: Every hour, a connection is opened between the WBM software Visual Dotlab Enterprise, which holds the DPIC database, and the R statistical computing environment. This platform is used to extract, clean, and merge all necessary raw data tables into a single data file. ASIRCS automatically and retrospectively scans a 24-hour window within the data file for new cases related to illnesses from shellfish consumption. Detected cases are queried using a list of attributes: the caller location, exposure type, reasons for the exposure, and a list of keywords searched in the clinical notes. The alert generates a report that is tailored to the needs of food safety specialists, who then assess and respond to detected cases.

Results: The ASIRCS system alerted on 79 cases between January 2015 and December 2016, and retrospective analysis found 11 cases that were missed. All cases were reviewed by food safety specialists, and 58% (46/79) were referred to designated regional health authority contacts for follow-up. Of the 42% (33/79) cases that were not referred to health authorities, some were missing follow-up information, some were triggered by allergies to shellfish, and some were triggered by shellfish-related keywords appearing in the case notes for nonshellfish-related cases. Improvements were made between 2015 and 2016 to reduce the number of cases with missing follow-up information.

Conclusions: The surveillance capacity is evident within poison control data as shown from the novel use of DPIC data for identifying illnesses related to shellfish consumption in BC. The further development of surveillance programs could improve and enhance response to public health emergencies related to acute illnesses, chronic diseases, and environmental exposures.

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KEYWORDS

poison control centers; public health surveillance; shellfish poisoning; norovirus; *Vibrio parahaemolyticus*

Introduction

Background

Poison centers across the United States, Canada, Europe, Australia, and New Zealand have been long recognized for the direct patient care and educational programs that fulfill their core mandate [1-5]. The services provided by specialized pharmacists, nurses, and physicians at these centers typically include telephone consultations available 24 hours per day, every day of the year. Calls come from homes, workplaces, hospitals, and other health care facilities in urban, rural, and remote settings. Beyond their primary mandate to support the general public and health care professionals, poison centers also provide essential expertise in the field of toxicology through published articles and community outreach. Several studies in the United States have explored the direct impact of poison centers on avoided emergency room visits, physician visits, ambulance services, and other medical treatments [6-11]. A recent review found that every US \$1 spent on poison centers translated to US \$8 saved on unnecessary health care costs [12]. These studies also demonstrated that consultation with poison centers was associated with decreased hospital admissions for poisonings treated in emergency departments [7-11,13].

Public health concern over poison exposures is increasing because there are more potentially toxic products entering the consumer market [14-17], more pharmaceuticals being prescribed [18,19], new illicit drugs becoming available [19,20], and more toxins in the ambient environment [14,16,17]. Intentional and unintentional poison exposures are caused by hazardous mixtures of chemical, physical, and biological agents that affect humans and animals. Poisonings are the third leading cause of mortality from unintentional injury in Canada, behind motor vehicle crashes and falls [21]. One key tool in poison prevention is routine surveillance to identify long-term trends, short-term aberrations from those trends, and near-real-time changes in the occurrence of high risk cases. However, such surveillance is typically within the mandate of public health agencies and not within the mandate of poison centers. As such, strong partnerships are needed to fully harness the surveillance potential of data from poison centers.

Development of these partnerships has been prioritized in the United States, Europe, and New Zealand, where poison data have increased the capacity of public health surveillance to address morbidity and mortality from poisonings. Specifically, these systems have informed the response to food-borne illness [22,23], substance abuse [24], pharmaceutical misuse [25], and aquatic toxins [26]. They have also improved monitoring of covert threats [3] and mass public gatherings [27]. In the United States, much of this work is accomplished through the National Poison Data System (NPDS) [28], which provides nation-wide surveillance of exposures in near-real-time using a centralized database maintained by the American Association of Poison Control Centers. There is no equivalent infrastructure in Canada, and there is no routine review of the national data at predefined intervals [2]. Indeed, several recent reports comment on the reactive rather than proactive use of Canadian poison data to address specific issues, such as the meltdown of the nuclear

reactors in Fukushima, Japan [29], deaths from contaminated ecstasy [30], and food-borne illnesses [31,32]. All of these examples highlight the potential for more systematic use of Canadian poison data for surveillance at the provincial and national scales.

Canadian Poison Centers

There are 5 poison centers in Canada, all but one of which services more than one province or territory. In addition, 4 of these centers are associated with acute care facilities, but the British Columbia (BC) Drug and Poison Information Centre (DPIC) is located at the BC Centre for Disease Control (BCCDC) [2]. As a provincial public health agency, the BCCDC has the mandate and the resources necessary to conduct routine surveillance for a wide range of acute illnesses, chronic diseases, and environmental exposures. This mandate and these resources were extended to DPIC when it joined the BCCDC in 2011, making it possible to use the poison data for regular and systematic reporting to internal and external stakeholders. Since then, DPIC and the BCCDC have developed multiple surveillance systems related to different toxic exposures that operate on various time scales.

In late 2014, the research team launched the near-real-time alerting system for illness related to the consumption of shellfish (ASIRCS), which detects new cases within 1 hour of DPIC receiving the call. This was our first near-real-time system, and we highlight it here because (1) all cases of paralytic shellfish poisoning (PSP) are reportable under the Public Health Act of BC, (2) the automated system replaced a manual system with the same objectives, (3) shellfish-related illnesses are not limited to a particular demographic group or a particular time of year, and (4) it can easily be adapted to other applications or data from other poison centers.

Shellfish contaminated with bacteria, viruses, toxins, or some combination of the three can cause severe illness in those who consume them, and the incidence of such cases has been rising in BC over the past decade [33-35]. Examples of harmful contaminants include norovirus, *Vibrio parahaemolyticus* (VP), and different toxins that can accumulate in bivalve shellfish during harmful algal blooms.

Outbreaks related to all types have been reported in BC. In 2010, a norovirus outbreak caused 36 laboratory-confirmed illnesses among raw oyster consumers [33]. In 2015, an outbreak of VP caused acute gastroenteritis in 73 documented cases, which led to a ban on the sale of raw oysters in grocery stores and restaurants across the greater Vancouver area [34]. Estimates suggest there are approximately 350 unreported cases of infectious enteric illness for every reported case in BC [36]. In comparison with infectious agents, cases of toxic shellfish poisoning are rarer [37]. In 2011, an outbreak of diarrhetic shellfish poisoning (DSP) caused 60 illnesses in people who ate cooked mussels [35]. There have been 4 documented cases of PSP [38], which can cause paralysis, respiratory failure, and death [39]. Finally, concentrations of domoic acid, the toxin responsible for amnesic shellfish poisoning (ASP), have been increasing along the BC coast in recent years [40]. Although BC has not reported an outbreak related to ASP, the Canadian Food Inspection Agency notified the BCCDC of one case in

2016, and DPIC received a call from another suspected exposure involving three individuals in the same year.

The concept of reportable or notifiable diseases is fundamental to the practice of public health. Such diseases are considered to be of sufficient risk to the entire population that any cases diagnosed by doctors or laboratories must be reported to some central authority, often by law. These centralized data can then be used to identify and track outbreaks, and to inform public health decisions. Bacterial enteric illnesses are typically reported by a laboratory to a health authority following clinically relevant results, such as a positive test in stool or blood.

However, there are no clinical tests for shellfish biotoxins, and illnesses can only be confirmed if the toxin is detected in leftover products. This limitation means that most illnesses are reported as probable based on the symptoms collected by doctors. As there are no laboratory results, there is no systematic mechanism by which to report these illnesses to the responsible health authorities.

Sometimes there may be direct communication by doctors or individuals who are ill, but this is rare. Thus, it is challenging for health authorities to meet their duty to report cases of PSP or other shellfish toxins. Given that (1) DPIC receives calls about shellfish-related illnesses and is located within the BCCDC, and (2) the BCCDC has a responsibility to support mandatory reporting of PSP and other shellfish-related illnesses, the BCCDC decided to develop a system that would identify, isolate, and alert on all relevant cases. Here, we describe how ASIRCS works, the cases it identified in 2015 and 2016, and the public health actions related to those cases.

Methods

Study Area

The province of BC is located on the west coast of Canada, and it has more than 25,000 km of coastline between its mainland and island areas [41]. These coastal waters have always been an important source of fish and shellfish for the First Nations of Canada [42]. In more recent history, they have played an important role in broader subsistence, recreational, and commercial fisheries. For example, BC oysters account for approximately 60% of all Canadian oyster production, which had a market value of CAN \$27.3 million in 2013 [43]. The wholesale value of the entire BC shellfish industry was estimated at CAN \$279 million in 2015 [44]. The 2015 population of BC was approximately 4.7 million residents, the majority of whom live in close proximity to the coast in greater Vancouver (2.3 million), on Vancouver Island (767,000), or elsewhere (186,000) [45].

How the Drug and Poison Information Centre Operates

The DPIC service has a dedicated 24×7 phone line that provides poison information to the general public and health care professionals, including doctors, nurses, and emergency medical personnel in the province of BC and the Yukon Territory. Poison information services are provided by pharmacists and nurses certified as poison information specialists. When someone calls

the poison line, the responding DPIC specialist gathers the information necessary to assess the urgency of the concern, and then begins to obtain a complete history by following set guidelines. In some cases, the exposed individual makes the call, but in the other cases, the caller has not been exposed. Furthermore, a single caller may be calling about an incident in which multiple people were exposed.

In some situations, the single call will automatically generate a separate record for each exposed individual, meaning that the number of calls DPIC receives is smaller than the number of cases DPIC manages. Once there is a full understanding of the exposure, the DPIC poison specialists triage the exposed individual or individuals to a health care facility if needed or provide home or on-site management recommendations where appropriate.

Depending on the nature of the exposure, the poison specialists routinely use their clinical experience and judgment along with other sources of toxicological information such as the Poison Management Manual [46] and Micromedex Solutions [47] to manage cases. Severe or unusual exposures may require follow-up calls to the treating health care facility until symptoms have subsided or life-threatening conditions have been resolved. All follow-up information is included in the single record for each case.

Since October 2011, DPIC has maintained records of all cases using the WBM software Visual Dotlab Enterprise (VDLE) [48], an electronic system specifically designed for use by poison centers. Like many other poison centers, DPIC staff use SAP Crystal Report XI Developer [49] to generate in-house summaries of data in VDLE, but this system lacks the analytic capacity to support routine surveillance. All of the DPIC surveillance systems, including ASIRCS, have been built in the R statistical computing environment [50], using the *R*ODBC package [51] to interface with the VDLE database. Working with the data in R allows easy and flexible processing, manipulation, analysis, tabulation, plotting, and reporting on data collected by DPIC.

How the Alerting System for Illness Related to the Consumption of Shellfish Works

Every hour on the hour, ASIRCS connects to the VDLE database and extracts all cases from the past 24 hours. The system uses a 24-hour period rather than a 1-hour period because it sometimes takes several hours for a case to be closed within VDLE. Case information is then extracted and merged from the relevant raw data tables before data cleaning.

The multistep procedure of data cleaning is challenging because it requires the transcription of information captured by the DPIC poison specialist into a standardized tabular format. For example, it is particularly challenging to extract relevant information from free-text fields in VDLE, where poison specialists document history, assessment, and recommendations as in a medical chart. Once all the data have been extracted and merged, ASIRCS scans the data for cases related to the consumption of shellfish based on criteria established by BCCDC food safety specialists.

An alert is generated when the following criteria are met:

- The case originated from within BC. At the time of the consultation, the DPIC poison specialists enter a city or postal code for the caller location, and this is georeferenced in the data cleaning stage.
- The case was about a human subject. This information is collected upon initial contact between the caller and the DPIC poison specialists and is entered into VDLE via a drop-down menu.
- The case was about a specific exposure rather than as a general inquiry. This information is entered into VDLE via a dropdown menu.
- The case was classified as “unintentional/food poisoning,” “adverse reaction/food,” or “unintentional/general.” This information is recorded by the DPIC poison specialists and is entered into VDLE via a dropdown menu following the NPDS Coding User Manual [52].
- Clinical free-text notes about the case contained one or more of the following words in a singular or plural form: clam, mussel, oyster, shellfish, paralytic, or neurolytic.
- The case has not been previously alerted. This is evaluated within ASIRCS by comparing the cases within the past 24 hours with the complete list of calls that have already alerted using their VDLE unique case identifiers.

Public Health Follow-Up

When new cases are detected, ASIRCS generates an automated report tailored to the needs of the BCCDC food safety specialists (Multimedia Appendix 1). The file is saved in a secure location to protect personal privacy, and ASIRCS sends an automatic email to system users to let them know that an alert has been generated. The BCCDC food safety specialists review the alerted case or cases and use the information along with their expertise to assess whether the case or cases should be referred to the most responsible of the 5 regional health authorities for potential reporting. Once referred, the environmental health officers contact the patient or patients to collect further information about the case or cases, provided that consent and contact information for such follow-up was given at the time of the call to DPIC.

Summary of Alerted and Missed Calls

Beta testing of ASIRCS started in late 2014, and we now have complete data for both 2015 and 2016. Here, we have reviewed all cases identified by the system over these 2 years and summarized them with respect to the nature of the exposure and public health follow-up. Specifically, we have identified those that were referred to the regional health authorities, and we have identified potential exposures to each group of shellfish toxins: PSP, ASP, or DSP. The cases were categorized into these 3 groups based on the reported symptoms matching each of the shellfish toxin exposure: numbness and tingling are indicative of PSP; headache, confusion, and disorientation are indicative of ASP; and diarrhea and abdominal cramps are indicative of DSP when symptom onset is <10 hours. Norovirus, VP, and other enteric illnesses may be considered when symptom onset is >10 hours.

Finally, we retrospectively checked all VDLE records from the same 2 years to evaluate whether we missed any cases that should have generated alerts. First, we applied the same criteria described above to all cases in the VDLE database and compared the results with the list of alerted cases. Second, we added the keyword “seafood” to the criteria above to evaluate whether extension of the keyword list would provide improved results.

Results

The ASIRCS system identified 79 cases from January 2015 to December 2016, 50% (40/79) of the cases were in 2015 and 49% (39/79) were in 2016. Approximately one-half of the cases occurred during the summer months of May to August in both years (Figure 1).

Consent for follow-up and the appropriate contact information were received by the DPIC poison specialists in all but 8% (6/79) of the cases. Of the 79 ASIRCS-alerted cases, 58% (46/79) were referred to the most responsible regional health authority for follow-up, but there was a difference between years. Of the 40 cases in 2015, 45% (18/40) were referred and 13% (5/40) were missing the necessary follow-up information. Of the 39 cases in 2016, 72% (28/39) were referred and none were missing follow-up information (Figure 1).

Of the 46 cases referred to local health authorities, 57% (26/46) were classified as potential toxic shellfish poisonings because of PSP, ASP, or DSP (Figure 2), and Norovirus or VP was indicated in the remaining 44% (20/46) of the cases. Several of these cases coincided with a VP outbreak that occurred in the summer of 2015 [54] and a norovirus outbreak that began in November 2016 [53]. Of the 79 cases identified by ASIRCS, 42% (33/79) were not referred to regional health authorities following review by BCCDC food safety specialists.

Of these, 15% (5/33) would have been referred, but consent for follow-up was not provided. Among the remaining 85% (28/33) cases, some were because of allergic reactions and some were because of identification of nonshellfish-related cases from the keywords in the search algorithm. For example, at least one call related to oyster *mushrooms* (rather than bivalve mollusks) was flagged.

Retrospective validation found that ASIRCS missed 2 cases in 2015 and 9 cases in 2016, mostly because of system errors after updates to the R code. Delayed review of these cases by BCCDC food safety specialists found 1 (50%) of the 2 cases would have been referred to regional health authorities in 2015, and 5 (56%) of the 9 cases would have been referred in 2016. Of those cases that would have been referred, 33% (2/6) would have been classified as PSP, 17% (1/6) would have been classified as DSP, and 50% (3/6) would have been classified as bacterial or viral foodborne illnesses. When we included the additional keyword for “seafood,” an additional 11 cases were identified. Upon review by BCCDC food safety specialists, 55% (6/11) were related to foodborne illness associated with seafood, and 9% (1/11) may have been classified as a suspect bivalve biotoxin shellfish poisoning based on the details recorded during the call.

Figure 1. Time series of the total number of cases identified by the alerting system for illnesses related to consumption of shellfish, and the number of cases referred to regional health authorities from January 2015 to December 2016. The white areas indicate summer months, ** indicates a *Vibrio parahaemolyticus* outbreak, and * indicates a norovirus outbreak.

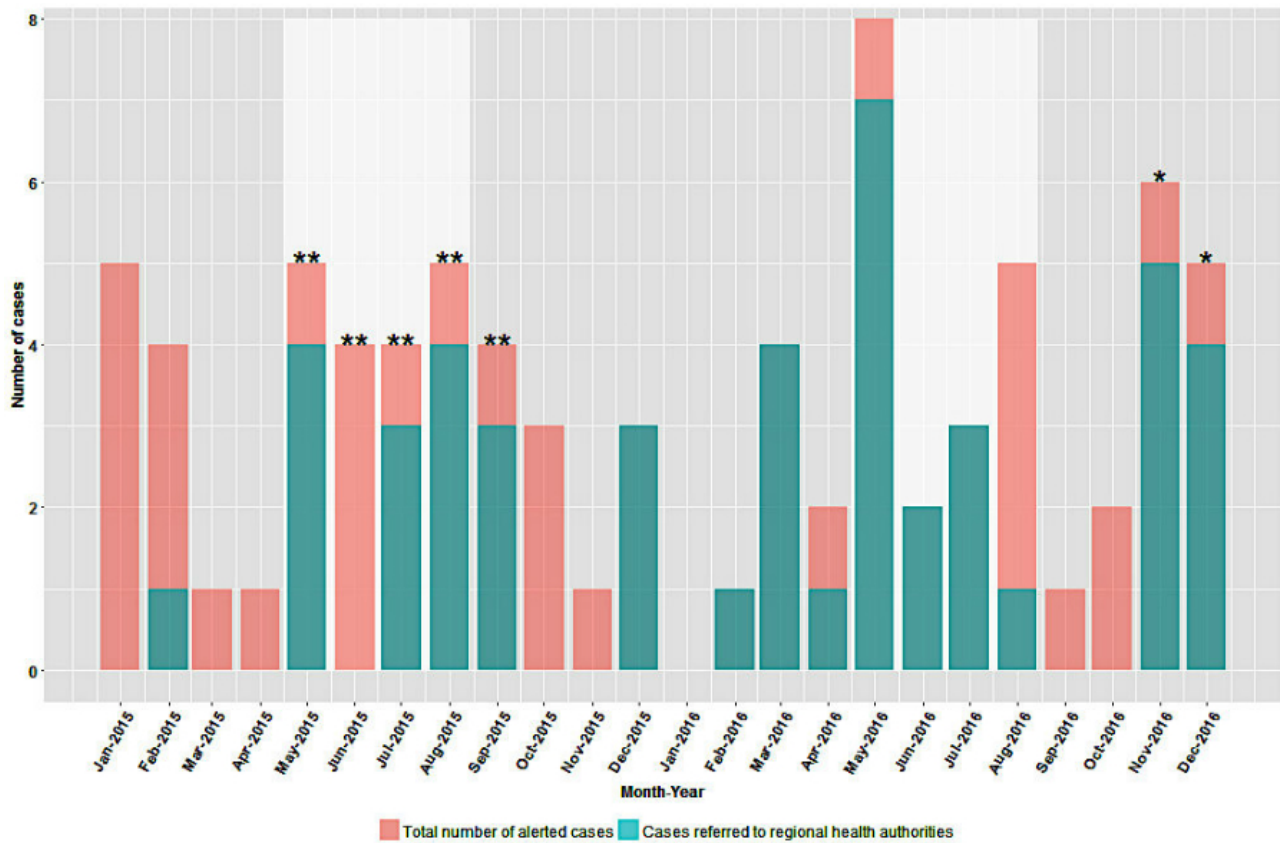
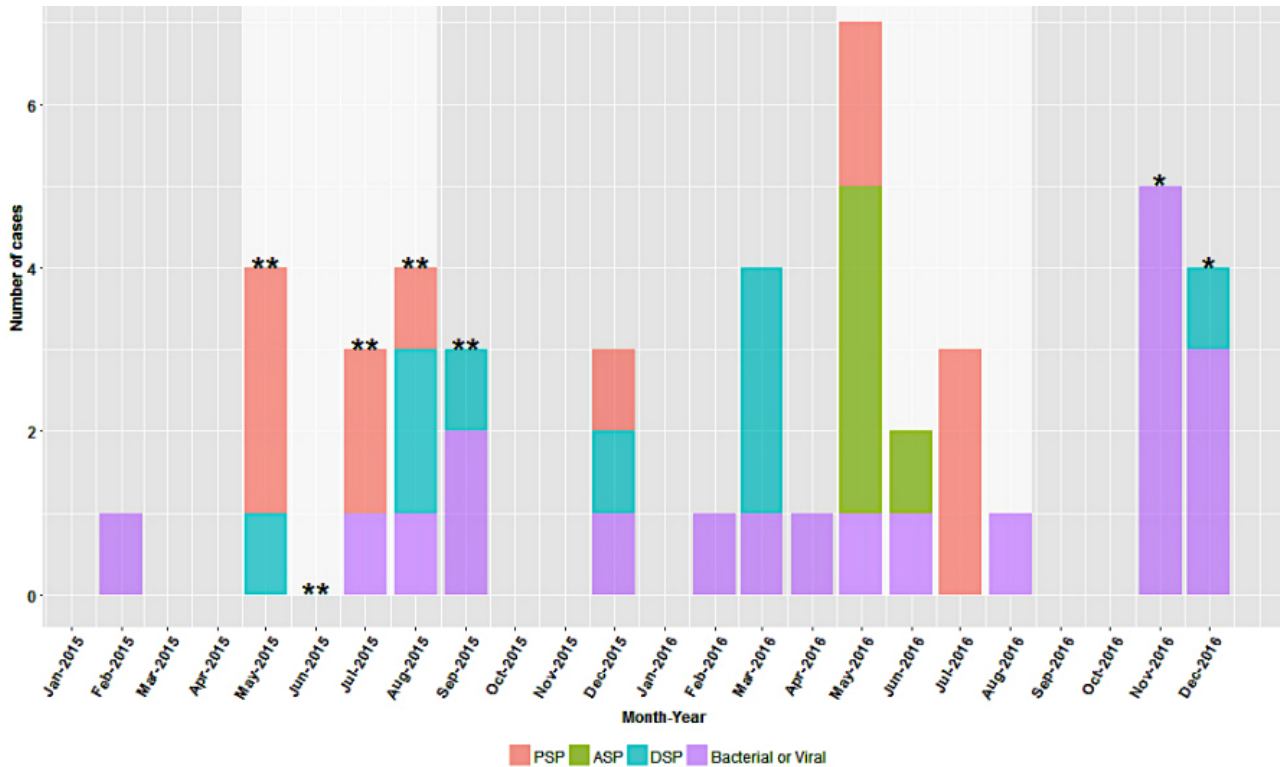


Figure 2. Time series of number of cases classified as paralytic shellfish poisoning (PSP), amnesic shellfish poisoning (ASP), diarrhetic shellfish poisoning (DSP), or bacterial or viral from January 2015 to December 2016. The white areas indicate summer months, ** indicates a *Vibrio parahaemolyticus* outbreak, and * indicates a norovirus outbreak.



Discussion

During its first 2 years of operation, ASIRCS identified 79 cases, with an equal number in each year. Of these cases, 58% (46/79) were referred to the most responsible regional health authority for follow-up. A total of 11 cases that should have been referred were not referred either because of missing contact information (5 cases, 45%) or failure of ASIRCS to alert (6 cases, 55%). More calls were referred in 2016 than in 2015, possibly reflecting greater presence of shellfish-related illness and ascertainment of more complete contact information collected by DPIC poison specialists at the time of call. On the basis of symptoms recorded in clinical notes, 20% (9/46) referred cases were classified as DSP, 26% (12/46) were classified as PSP, 11% (5/46) were classified as ASP, and 44% (20/46) were classified as bacterial or viral.

The automated, systematic elements of ASIRCS allow BCCDC food safety specialists to refer cases of shellfish-related illnesses to the appropriate reporting authorities within hours of DPIC receiving the call. The response time allows for rapid public health action, particularly during outbreaks of infectious or toxic agents. We chose to highlight ASIRCS in this report because it replaced an older, multistep system that was prone to human error and oversight (Figure 2). The old method required DPIC poison specialists to personally inform BCCDC food safety specialist about cases of shellfish illness when they responded to a relevant call. However, this step could easily be forgotten if such calls were received by DPIC during a period of heavy volume or in the midst of managing more critical cases. Indeed, ASIRCS was developed after an informal audit of the old system found that half of relevant cases had not been flagged for review by BCCDC food safety specialists.

Once a computer is correctly programmed to do a task, it is incapable of making human errors. Using computers to reliably detect and report aberrations in large data is fundamental to modern public health surveillance. Even so, our analyses demonstrate that automated systems are not infallible, and that ongoing evaluation is required to ensure optimal performance. Furthermore, ongoing training of poison specialists is required to ensure that the quality of poison control data meets the needs of public health surveillance. Specifically, poison specialists must understand how any given surveillance system uses the data they collect so they have it in mind when recording details about a relevant case. This requires clear and ongoing communication between the poison specialists, developers, and end users to optimize and improve the accuracy and performance of operational systems. Retrospective application of the ASIRCS algorithm to complete data identified 11 cases that failed to generate alerts, of which 6 would have been referred to regional health authorities. These findings highlight the need for code developed using the principles of computer science rather those of data analysis, such that errors are caught and reported as they occur. The code for ASIRCS now performs a self-check every

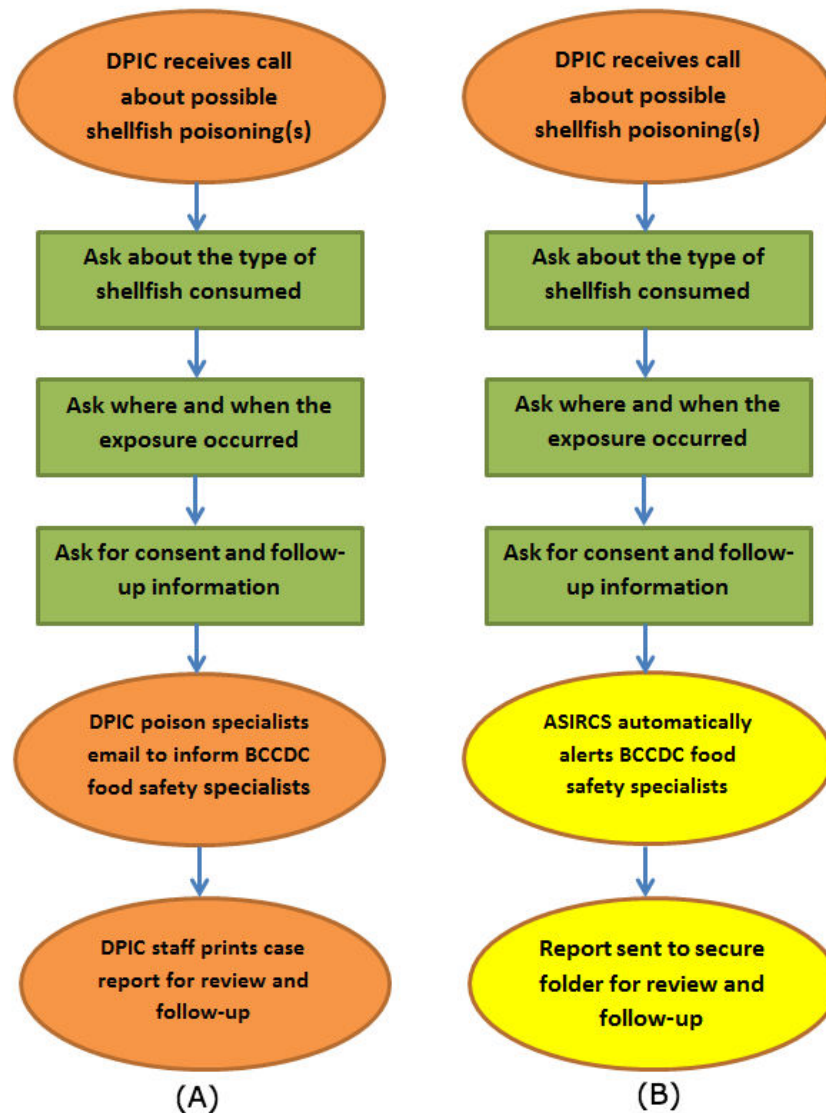
hour confirming its status, and automatically sends an email to technicians.

Furthermore, the addition of “seafood” to the keyword list identified 11 new cases, 1 of which would have been referred to the responsible health authority. This keyword has been permanently added to the list, and work is ongoing to improve the free text search. For example, ASIRCS does not currently account for common misspellings of the keywords because the BCCDC does not have adequate in-house experience or capacity in this area of data science [55].

As public concern over poison exposures grows, developing and upgrading methods for real-time automated alerting on poison center data can improve responses to public health threats. The model we describe for surveillance systems developed in R provides a flexible and adaptable framework with the potential to identify new threats as they emerge. Examples include the following: newly introduced household products, such as laundry pods [56]; drugs, such as paramethoxymethamphetamine [30]; commercially available toxicants, such as pesticides [57,58]; and illnesses resulting from intentional or unintentional exposures at a single site or across a large area, such as oil spills [59]. At present, the BCCDC is using a similar system to detect potential overdoses from exposure to fentanyl, which is part of a larger provincial effort to address the ongoing public health emergency in BC [60]. The BCCDC is also supporting a work-in-progress collaboration between all Canadian poison centers to establish a national database similar to that of the NPDS, which would vastly improve national surveillance of poisonings.

The surveillance utility and value of DPIC data are evident here. During this study, there were two large shellfish outbreaks in BC because of (1) *VP* in May to September 2015 and (2) norovirus in November 2016, both of which were evident in ASIRCS alerts (Figures 2 and 3). However, the use of poison control data is limited by a number of factors. First, DPIC case data can be incomplete depending on the nature of the call. As seen with ASIRCS, there were 6 cases where public health action could not be taken because of the absence of follow-up contact information. Second, exposures are often self-reported and may not represent true shellfish poisoning incidents; so, the system relies on the precision of DPIC poison specialists when gathering information about each case. This is especially challenging because BC shellfish can be contaminated with viruses, bacteria, and toxins that may have overlapping symptoms. Fortunately, other surveillance mechanisms allow us to contextualize information from DPIC using other environmental and laboratory data [61]. Unfortunately, complementary data from the national shellfish biotoxin monitoring program are not readily available for public health surveillance at this time. Finally, surveillance systems such as ASIRCS require considerable technical expertise to develop and maintain, and some poison centers may not have the necessary human resources.

Figure 3. An illustration of the old (A) and new (B) procedures alerting British Columbia Centre for Disease Control (BCCDC) food safety specialists about calls made to the Drug and Poison Information Centre (DPIC) related to shellfish consumption. The new procedure (B) uses the automatic alerting system for illness related to consumption of shellfish (ASIRCS) running in the R statistical computing environment.



The core function of DPIC and other poison centers is to serve and educate the public and health care providers. Although this foundation remains unchanged, there is increasing pressure on poison centers to integrate their data with public health surveillance mandates. Here, we have described the development and application of a novel system of data collected by DPIC

poison specialists made readily and quickly accessible to the BCCDC food safety specialist for improved public health. By combining rich poison data with the analytic power of the R computing environment, the possibilities for future work are almost limitless.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

A sample of the report (based on falsified data) generated by the alerting system for illnesses related to consumption of shellfish for review by food safety specialists. BC: British Columbia; DPIC: Drug and Poison Information Centre.

[[PNG File, 565KB - publichealth_v4i1e17_app1.png](#)]

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Abbreviations

- ASIRCS:** alerting system for illness related to consumption of shellfish
- ASP:** amnesic shellfish poisoning
- BC:** British Columbia
- BCCDC:** British Columbia Centre for Disease Control
- DPIC:** Drug and Poison Information Centre
- DSP:** diarrhetic shellfish poisoning
- NPDS:** National Poison Data System
- PSP:** paralytic shellfish poisoning
- VP:** *Vibrio parahaemolyticus*
- VDLE:** Visual Dotlab Enterprise

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Original Paper

Online Health Monitoring using Facebook Advertisement Audience Estimates in the United States: Evaluation Study

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Abstract

Background: Facebook, the most popular social network with over one billion daily users, provides rich opportunities for its use in the health domain. Though much of Facebook's data are not available to outsiders, the company provides a tool for estimating the audience of Facebook advertisements, which includes aggregated information on the demographics and interests, such as weight loss or dieting, of Facebook users. This paper explores the potential uses of Facebook ad audience estimates for eHealth by studying the following: (1) for what type of health conditions prevalence estimates can be obtained via social media and (2) what type of *marker interests* are useful in obtaining such estimates, which can then be used for recruitment within online health interventions.

Objective: The objective of this study was to understand the limitations and capabilities of using Facebook ad audience estimates for public health monitoring and as a recruitment tool for eHealth interventions.

Methods: We use the Facebook Marketing application programming interface to correlate estimated sizes of audiences having health-related interests with public health data. Using several study cases, we identify both potential benefits and challenges in using this tool.

Results: We find several limitations in using Facebook ad audience estimates, for example, using *placebo* interest estimates to control for background level of user activity on the platform. Some Facebook interests such as *plus-size clothing* show encouraging levels of correlation ($r=.74$) across the 50 US states; however, we also sometimes find substantial correlations with the placebo interests such as $r=.68$ between interest in *Technology* and Obesity prevalence. Furthermore, we find demographic-specific peculiarities in the interests on health-related topics.

Conclusions: Facebook's advertising platform provides aggregate data for more than 190 million US adults. We show how disease-specific *marker interests* can be used to model prevalence rates in a simple and intuitive manner. However, we also illustrate that building effective marker interests involves some trial-and-error, as many details about Facebook's *black box* remain opaque.

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KEYWORDS

social media; public health; Internet; infodemiology

Introduction

Facebook Use in Health Domain

Nearly one third of the world population is using social media and the Internet for entertainment, study, work, and socializing. Currently, Facebook is the most popular social network, with over 1.7 billion monthly active users (as of the end of 2016). Due to this popularity, many health organizations, including hospitals, governments, and patients associations, use Facebook as a channel for health communication [1]. For example, a study by Griffi et al found that over 90% of the US Medicaid/Medicare hospitals had Facebook accounts [2].

Since as early as 2008, there has been interest in the health domain concerning the use of Facebook. For example, at the time Parslow highlighted that among the 60 million users, there were many medical students using the social network as a channel for medical education [3]. On the other hand, Ybarra et al found that teenagers shared unhealthy risk behaviors such as unwanted sexual solicitation on Facebook [4].

Since these early studies, the interest in Facebook within the health domain has continued to grow, not only due to the increase in Facebook's reach but also due to new features of the platform, which include the development of social games [5,6] and apps [7,8]. Over the last decade, Facebook has been used for medical education [9], patient education [10], peer-to-peer support, organ donation promotion [7], hospital quality estimation [11], and health policy making [12]. Overall, the 2 most popular use cases of Facebook in the health domain, as explained below, are for recruitment and health communication, and public health monitoring. Increasingly, both of these practices rely on the use of Facebook Advertising platform, as we also explain below.

Facebook for Recruitment and Health Communication

One of the main advantages of Facebook's popularity is the possibility of using it for the recruitment of people affected by not-so-common conditions such as auditory hallucinations [13]. It can also be used for targeted recruitment of people with particular demographic profiles [14-16] or health behavior (eg, long-term smoking [17]). This can be done by interacting with different Facebook groups [15] or via targeted advertisement. Furthermore, many health care organizations are using Facebook for communication with health consumers. For example, hospitals use Facebook to increase awareness about health-related topics and also to communicate with their patients [2]. Public health administrations also use Facebook to raise awareness about important topics, such as smoking cessation [18], organ donation [7], newborn screening [19], and health education [20]. Furthermore, this communication from public health authorities can be used as mechanisms for health policy making [12] and notifying people at risk of infectious diseases [21].

Social Media as a Health Tracking Tool

The study of new social media data sources to understand health interests and behaviors is a crucial part of infodemiology [22]. Indeed, social media has been widely used by researchers to study health trends, such as those in health care facility usage

[23], abortion information seeking [24], outbreak detection [25], vaccine hesitancy [26], and others. Studies have also found that using social media for seasonal flu tracking outperforms the use of Google search logs for this purpose [27,28] as social media provides more context about why a term is used (or searched for), thus reducing false-positive rates. Moreover, mobile advertisement tools provide fine-grained demographics of mobile app users. One of the most popular is Flurry Analytics, which is owned by Yahoo Inc., which has been used to study the demographics of health apps [29,30]. However, the boundary between mobile analytics and Web analytics is becoming increasingly blurry as the usage of online websites is becoming increasingly mobile and social media companies such as Facebook acquire mobile apps such as Instagram or WhatsApp.

Facebook Advertisements

As an advertising platform, Facebook allows advertisers to selectively show their ads to Facebook users matching certain criteria, specified by the advertiser. Even before launching—and paying for—the ad, Facebook provides estimates of the expected audience size. As an example, one can ask Facebook for the number of users residing in Alabama who are male, aged 25 to 34 years, and who have shown an interest in *Diabetes mellitus awareness* to receive an estimate of 11,000 users. These tools are available for free in the Facebook Adverts Manager [31]. Facebook documentation explains that the interests are determined from “things people share on their Timelines, apps they use, ads they click, Pages they like and other activities on and off of Facebook and Instagram. Interests may also factor in demographics such as age, gender, and location” [32].

A few recent studies have attempted to link what people like on Facebook to behavioral aspects related to health conditions [33,34]. Gittelman et al converted over 30 Facebook *likes* categories to 9 factors to use in the modeling of mortality [35]. Although they show an improvement in the statistical models, their approach avoided determining relationships between each individual category with the real-world data, limiting the insight into the usefulness of each Facebook interest. On the other hand, Chunara et al explored the relationship between 2 factors, namely, interest in television and outdoor activities, and the obesity rates in metros across the United States and neighborhoods within New York City [36]. Although showing promising correlations, the latter study failed to account for baseline user activity, potentially reporting relationships indistinguishable from general Facebook. In this paper, we address the shortcomings of both these studies.

Study Goals

Previous studies have attempted to demonstrate the value of using Facebook ad audience estimates for modeling regional variations of the prevalence of certain health conditions [35,36]. However, these studies fail to compare the strength of the relationships between Facebook interests and real-world health statistics to *baseline* relationships, potentially reporting spurious results due to the *black box* nature of the tool. In this study, we propose 2 methods for gauging the strength of such relationships: first by introducing *placebo* interests which to a varying extent represent baseline Facebook user behavior, and second by examining alternative normalization populations.

Thus, we contribute to the methodological literature addressing the different variables that can affect the use of Facebook interest data for public health monitoring, in an attempt to lessen the barriers for comparison and reproducibility of studies employing such data.

Methods

Facebook Advertisement Audience Data Collection

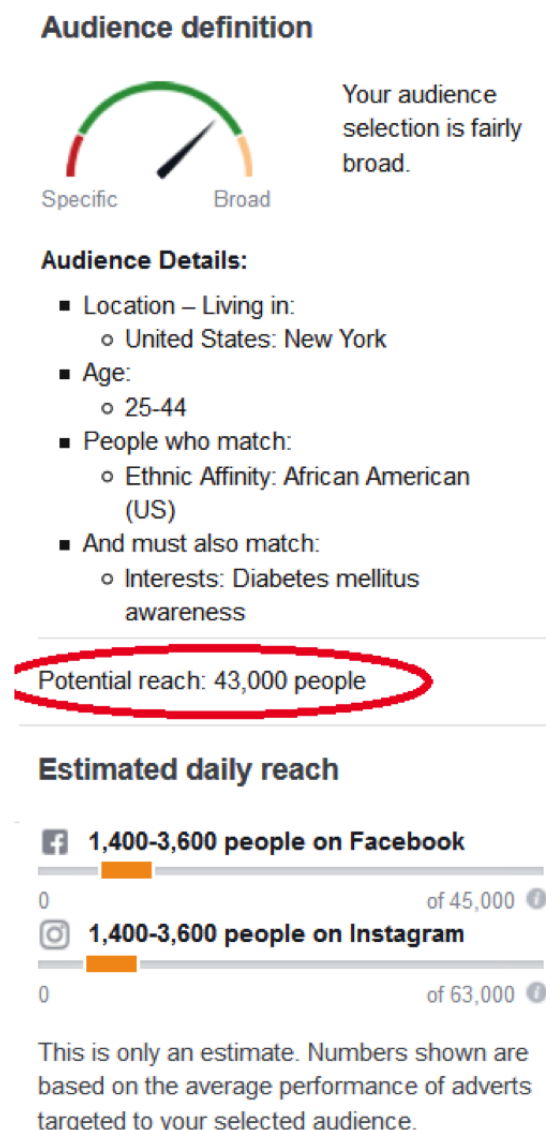
All data used for the following analysis are provided by the Facebook's Marketing application programming interface (API) [37]. Equivalent data could have been obtained through the Web interface of the Adverts Manager, but using the API makes programmatic access easier and gives more precise audience estimates, down to +/-20 users as opposed to +/-1000 users. The numbers we used are the so-called *Reach Estimates*: "Potential reach is the number of monthly active people on Facebook that match the audience you defined through your audience targeting selections" [38]. Figure 1 shows a screenshot of Facebook's

Adverts Manager [31], illustrating the capabilities. As previously defined, Facebook provides an aggregate mapping between users and interests, hiding the source of the data (whether it comes from likes, posts, or other Facebook properties which include Instagram), providing a simplified interface, while also hiding potentially useful information.

For our study, we obtained Facebook data that are potentially related to the prevalence of 4 diverse health conditions: (1) diabetes (type II), (2) obesity, (3) food sensitivities, and (4) alcoholism. As largely behavior-related conditions, these are prominent causes of serious illness and death across the United States. Moreover, they range in the extent of potential social stigma, and their impact on the personal and social life of an individual.

For each of these 4 conditions, we defined a number of *marker interests*. A *marker interest* is an interest of a Facebook user that could plausibly be used to measure the prevalence of a certain condition due to a potential causal link between the condition and the interest.

Figure 1. Part of a screenshot of Facebook's Adverts Manager, illustrating some of the targeting capabilities (under "Audience Details") as well as the reach estimate.



We used an iterative process to obtain these marker interests—employing domain knowledge, we used the Facebook Adverts Manager interface to exhaustively enumerate interests related to the selected illnesses, selecting all those passing the threshold of US-wide audience in hundreds of thousands. For example, both of the interests *Alcohol* and *Alcoholics Anonymous* are marker interests for alcoholism.

Similarly, we defined a set of *placebo interests*. A *placebo interest* is an interest of a Facebook user that should not have an obvious causal link with a given condition, but that might still turn out to be correlated due to latent factors such as common user demographics.

Placebo interests are helpful to understand how much of any predictive power of marker interests is due to spurious correlations or due to unknown latent factors. Intuitively, these interests are meant as a *placebo* wherein no topic-specific *treatment* is performed, and any effect observed is due to the random or causal factors outside the topic. For this, we used the popular generic interests (ie, *Facebook*, *Reading*, *Entertainment*, *Music*, and *Technology*) that, a priori, should not have any strong link to the 4 conditions studied. Each of these interests is shared by hundreds of millions of Facebook users worldwide, and serves as approximations of the level of involvement of users with the platform in general.

Finally, we also defined a health-related *baseline interest*. A *baseline interest* is a broad health-related interest on Facebook that could plausibly be used to measure general health awareness.

In this study, we used the interest *Fitness and wellness* as a baseline interest. This baseline interest helps to clarify if any predictive power of a marker interest is really due to a condition-specific link to the interest, or if we are only picking up the general health awareness level.

Using these interests, we then queried the Facebook Graph API [39] for the estimation of audience size for each combination of interest and US state, as well as gender (including *both*), age group (18-24, 25-44, 45-64, 65+ years, and all combined), and ethnic affinity (African American, Asian American, Hispanic, none of the above, and all combined). This allows us to look at both correlations across the 50 US states, as well as at correlations across different demographic groups.

On its own, a single audience estimate is of little value. It is only when seen in context that one can judge if a number is high or low. Thus, to normalize the raw audience estimate counts, we defined 3 *reference populations*: (1) number of Facebook users (widest selection), (2) number of users interested in *Facebook* (thus who are more likely to be active on the site), and (3) number of users interested in *Fitness and Wellness* (thus who are more likely to be interested in health-related topics). We then divided the marker and placebo interests by the reference populations, producing 3 variants of proportionate interest measurement. Finally, the Facebook API was queried for the audience estimates in September 2016.

Public Health Data Collection

The US state-level public health data were obtained via the America's Health Rankings Annual Report [40], which combines data from well-recognized sources including Centers for Disease Control and Prevention, American Medical Association, Federal Bureau of Investigation, Dartmouth Atlas Project, US Department of Education, and Census Bureau. For our study, we used the most recent available data for 2015 [41]. Data for the District of Columbia were not used, as they had several missing values.

Comparing Public Health Data and Facebook Advertisements Data

As described above, for each of the 50 states, we have (1) a set of indices derived from Facebook's ads audience estimates, for example, the fraction of monthly active Facebook users with an interest in the topic *Diabetic Diet*, and (2) a set of public health indices, such as the fraction of the adult population that has diabetes. Each Facebook index f consists of a marker, placebo or baseline interest (see definitions above), and a choice of reference population (the set of all Facebook users by default). To see if an index f could be used to approximate a particular public health index h , we computed the Pearson correlation coefficient r_{fh} across the 50 states. Thus, we hypothesized that Facebook indices (independent variables) are related to public health indices (dependent variable). We deliberately chose Pearson r for its simplicity and did not experiment with any model fitting, such as multi-variate linear regression, or with non-linear measures of correlation, such as Spearman rank correlation coefficient to clearly show the relationship of each interest, as well as to compare marker interests to the placebos and baselines.

To avoid reporting spurious correlations, we applied a significance threshold of $P=.05/k$. Here k , the number of experiments performed, is a Bonferroni correction factor to avoid false positives when testing multiple hypotheses. In our setting, each pair of indices f and h constitutes one hypothesis that is being tested.

Analyzing Potential Comorbidity

To explore the feasibility of using Facebook data to discover comorbidity, where suffering from one condition increases the probability of suffering from another, we choose *Fatigue* as a target condition. Concretely, we explored these relationships by computing the *lift* statistic between fatigue-related marker interests and others which may be associated with them. Lift is often used in association rule mining as a measure for strength of the association between 2 occurrences, normalized by the likelihood of them occurring by random chance, and has the following formula:

$$\text{lift}(A,B)=P(A\cap B)/\{P(A)\times P(B)\}$$

It can intuitively be understood as $P(A/B)/P(A)=P(B/A)/P(B)$, that is, the *lift* in probability of event A (or B) occurring over its baseline probability, given that event B (or A) has occurred. A value greater than 1.0 indicates an increase in conditional probability, whereas a value smaller than 1.0 indicates a decrease.

Results

Interest Selection

Table 1 shows the US-wide audience estimates for the selected marker, placebo, and baseline interests. At the bottom, we also show the Facebook audience of US residents who are aged 18 years or older. Recall that to constrain the number of considered interests, we selected only those having at least hundreds of thousands US-wide audience. Indeed, some interests, such as *Alcoholic beverages* (at 74 million), span a great deal of US Facebook users (totaling at 194 million users, as listed at the bottom of the table). A bootstrapping approach was taken to these, whereby we began with a keyword relevant to the topic (such as *alcohol* for *alcoholism*), and added other related interests, which the Facebook Advertisement Marketing interface provides. Thus, the selection of the interests was seeded by domain expertise, and expanded via internal Facebook usage statistics.

Relation to Public Health Data

We began with a question—how much do the populations having particular *interests* in health-related topics, as determined by Facebook, correlate with ground truth statistics gathered by Centers for Disease Control and Prevention (CDC)? For visual examination, we plotted the intensities of diabetes prevalence and the percent of interest *Diabetes mellitus awareness* (normalized by the number of Facebook users, FB_{pop}) in Figure 2. The intense colors in both plots are concentrated in the south, as well as West Virginia, and less so in mountain states as well as Vermont and New Hampshire.

Next, we quantified the relationship between Facebook advertisement audience figures and the ground truth statistics. First, we examined the placebo interests (normalized by FB_{pop}), as shown in Table 2, along with the accompanying 2-tail significance levels. The health statistics are proportions of the population, including engaging in excessive drinking (results for binge and chronic drinking were similar; hence, we omitted them here), as well as obesity and diabetes rates. Note the strength of the association between some variables, especially obesity and diabetes, with Pearson correlation $r=.68$ between the placebo interest *Technology* and both diabetes and obesity prevalence. Regardless of the forces at play, these figures caution us against considering high r values as indicative of causal relationships in the following experiments.

Table 3 shows the correlations of each health-related interest with the appropriate health statistic (eg, between Alcoholism interests and statistics on excessive drinking). The 2-tailed significance tests for these correlations have been adjusted using Bonferroni correction to address the problem of multiple comparisons and guard against false positives. We observe a

complex relationship between alcohol-related variables. Although *Alcohol* and *Bars* have little correlation with excessive drinking, *Alcohol abuse* and *Alcoholism awareness* are positively related to it. Interventions, on the other hand, including *Alcoholics Anonymous* and *12-step program*, are negatively associated with drinking. Note, however, that most values of r achieved for Alcoholism are barely larger than the values for the placebo interests *Reading* and *Technology* of around $r=-.35$.

Considering obesity and diabetes, most marker interests are positively correlated with their real-world corresponding statistics, although some correlations vary drastically with the choice of reference population. The strongest and most consistent correlations are between *Plus-size clothing* ($r=.74$) and obesity, as well as *Diabetes mellitus awareness* ($r=.78$) and *Diabetic diet* ($r=.75$) and diabetes.

The variation between correlations across the 3 different reference populations shows that the reference point used for the raw audience counts has strong effects on the results. Facebook interest (FB_{int}) normalization, for instance, removes the effect of users who are in general likely to be active and have interests, some of which by chance may include health-related topics. Similarly, the *Fitness and Wellness* interest (FW_{int}) removes the effect of general interest in health. As we can see in Table 3, these normalizations affect each interest in a different manner.

Furthermore, we assessed the combined power of these interests in modeling the real-life phenomena by building linear regression models to predict the real-world statistics. As there were only 50 data points in the dataset, we used feature selection using backward feature elimination optimizing Akaike Information Criterion scores, in which least-contributing features were removed until an optimal performance was achieved. The resulting linear models achieve the adjusted R^2 of .533 for modeling Alcoholism, .712 for Obesity, and .790 for Diabetes. Next, we included the following additional control variables: (1) demographics, including age, gender, and race distributions; (2) financial statistics, including median annual household income and unemployment rate; (3) health care-related statistics, including health spending per capita and rate of uninsured persons; (4) internet access rate; and (5) health-related variables, including life expectancy and poor mental health days reported. When applied to this much larger set of variables, the Facebook marker variables were still selected, and the resulting models had an improved performance of .698 (Alcoholism), .827 (Obesity), and .894 (Diabetes). Interestingly, only in the case of Obesity were placebo interests selected for the final models, which were Entertainment and Technology. We discuss the interpretation of these further in the Discussion section.

Table 1. List of marker interests: Facebook marker interests for tracking diabetes, obesity, food sensitivities, and alcoholism, along with placebo interests, and a generic health baseline. This table also shows the estimated Facebook audience for US residents aged 18+ years.

Health condition interest	Estimated Facebook audience
Alcoholism	
Alcohol	13,000,000
Alcohol abuse	610,000
Alcoholic beverages	74,000,000
Alcoholics anonymous	670,000
Alcoholism awareness	4,600,000
Bars	33,000,000
Sobriety	3,100,000
Twelve-step program	640,000
Obesity	
Bariatrics	710,000
Obesity awareness	7,400,000
Plus size	430,000
Plus-size clothing	9,100,000
Weight loss (fitness and wellness)	15,000,000
Dieting	27,000,000
Diabetes	
Gestational diabetes	650,000
Insulin index	250,000
Insulin resistance awareness	500,000
Diabetes mellitus awareness	12,000,000
Diabetes mellitus type 1 awareness	1,200,000
Diabetes mellitus type 2 awareness	2,100,000
Diabetic diet	2,100,000
Diabetic hypoglycemia	230,000
Food sensitivities	
Gluten sensitivity awareness	250,000
Gluten-free diet	10,000,000
Lactose intolerance	240,000
Food allergy	690,000
Food intolerance	200,000
Peanut allergy	140,000
Placebos and baselines	
Facebook	83,000,000
Reading	141,000,000
Entertainment	171,000,000
Music	152,000,000
Technology	157,000,000
Fitness and wellness	110,000,000
No interest constraint	194,000,000

Figure 2. Geographic distribution of (left) diabetes prevalence and (right) percentages for the marker interest "Diabetes mellitus awareness" normalized by FB_{pop} , where color saturation represents strength of the variable.

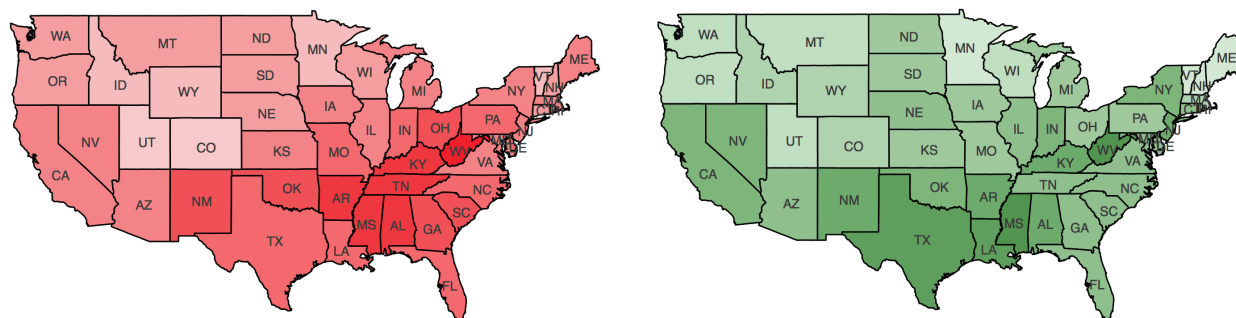


Table 2. Pearson correlation coefficient r between placebo Facebook interest estimates and the US health statistics (normalized by FB_{pop} and state population, respectively).

Facebook interest	Health condition					
	Alcoholism		Obesity		Diabetes	
	r	P value	r	P value	r	P value
Reading	-.34 ^c	.01	.67 ^a	<.001	.58 ^a	<.001
Music	-.23	.19	.54 ^a	<.001	.59 ^a	<.001
Entertainment	-.06	.67	.47 ^a	<.001	.24 ^b	.09
Technology	-.39 ^b	.005	.68 ^a	<.001	.68 ^a	<.001

^a $P < .001$.

^b $P < .01$.

^c $P < .05$.

Comorbidities and Related Behaviors

In the previous analysis, we have only considered audience estimates for 1 Facebook interest at a time. However, Facebook's advertising platform supports the definition of more complex target groups, which express not only those interests that are directly related to the illnesses but also those that indicate behaviors or conditions which may be linked to it. Alcoholism, for example, is associated with depression and anxiety [41], whereas obesity has been linked to poor dietary choices and sedentary lifestyle. As described in the Methods section, we use the notion of *lift* to measure the relationship between 2 interests. It can intuitively be understood as the *lift* in probability of event A (or B) occurring over its baseline probability, given that event B (or A) has occurred. A value greater than 1.0 indicates an increase in conditional probability, whereas a value smaller than 1.0 indicates a decrease.

We selected a variety of interests that may be related to obesity, diabetes, alcoholism, and food sensitivities. Specifically, for the first 2, the interests include physical activities (like *hiking* and *yoga*), nutrition interests (*healthy diet*, *desserts*), specific restaurants (*McDonald's*, *Subway*), and spectator sports (*NASCAR*). For alcoholism, we included places associated with drinking (*nightclubs*), as well as mental health interests (*mental health*). As the task is exploratory, we did not include all

possible related interests, but instead used a selection of 45 having the best Facebook ads audience coverage.

Table 4 shows the 20 marker interests and related interests with greatest lift (that is, which appear more often together than would be predicted by chance), and with smallest lift (which appear less often together than one would observe by chance). Some relationships make sense, such as that between *Alcoholics Anonymous* and *Anxiety Awareness*, as alcoholism is associated with mental health issues. Another example may be *Bariatrics* and *Panera Bread* (a restaurant chain promoted as healthy). However, we caution the reader to impose meaning on these relationships, as these may be caused by other means. For example, the interest *Nightlife* may be highly expressed in urbanized states. Thus, a positive lift might be due to a latent factor, such as urbanization, giving rise to both interests. In future studies it might be worth exploring such alternative explanations by limiting the analysis to urban centers.

Demographic Exploration

Another potentially powerful feature of Facebook Advertising Manager is the demographic information of its users, including age, gender, and ethnic affinity [42]. We related these to the illness interests in Table 5, similarly listing relationships that are more likely (above) and less likely (below) than one would expect by chance.

Table 3. Pearson correlation coefficient r between Facebook marker interests and US health statistics, normalized by Facebook users (FB_{pop}), Facebook interest (FB_{int}), and Fitness and Wellness interest (FW_{int}).

Health condition and corresponding interest	FB_{pop}, r	FB_{int}, r	FW_{int}, r
Alcoholism			
Alcohol	-.17	.08	-.07
Alcohol abuse	.38	.49 ^a	.44
Alcoholic beverages	-.06	.50 ^a	.32
Alcoholics anonymous	-.36	-.30	-.33
Alcoholism awareness	.30	.42	.36
Bars	-.08	.09	.00
Sobriety	-.38	-.26	-.35
Twelve-step program	-.25	-.07	-.15
Obesity			
Bariatrics	.49 ^a	.37	.45 ^a
Obesity awareness	.60 ^b	.37	.55 ^b
Plus size	.70 ^b	.65 ^b	.70 ^b
Plus-size clothing	.74 ^b	.72 ^b	.75 ^b
Weight loss (fitness and wellness)	.76 ^b	-.09	.33
Dieting	.08	-.34	-.12
Diabetes			
Gestational diabetes	.32	.25	.28
Insulin index	.58 ^b	.43	.53 ^b
Insulin resistance awareness	.52 ^b	.39	.46 ^a
Diabetes mellitus awareness	.78 ^b	.72 ^b	.79 ^b
Diabetes mellitus type 1 awareness	.29	.02	.14
Diabetes mellitus type 2 awareness	.43	.33	.39
Diabetic diet	.75 ^b	.62 ^b	.68 ^b
Diabetic hypoglycemia	.62 ^b	.49 ^a	.57 ^b

^a $P < .01$.^b $P < .001$.

The most powerful relationship is between *Plus size* and *African American* demographic. This relationship is corroborated by the literature on obesity. For instance, according to the US Department of Health and Human Services, “In 2014, African Americans were 1.5 times as likely to be obese as Non-Hispanic Whites” [43]. The association between diabetes and elderly is also supported by CDC, with an estimated 25.9% of the US population aged ≥ 65 years having diabetes in 2012 [44]. Similarly, the association between diabetes and *Hispanic* demographic is justified by research, with Hispanic adults being 1.7 times more likely than non-Hispanic white adults to have been diagnosed with diabetes by a physician [45].

Some inverse relationships in the right-hand side columns of Table 5 can also be justified by prior literature. Food sensitivities

(such as *Lactose intolerance*) are less likely in adult men than women [46]. Similarly, we find a lift of 1.61 between women and *Gluten-free diet*, and women are diagnosed with Celiac disease (hypersensitivity to gluten) 2 to 3 times more often than men [47]. However, these numbers may also show the interests of certain demographics. For instance, it may be that Facebook users over 65 years of age are not interested in *Obesity awareness* or *Diabetes mellitus type 1 awareness* (as the latter is often discovered in children), each having lifts of 0.02. However, not all interpretations are straightforward. Although men are more likely to have diabetes (13.6% males vs 11.2% females have diabetes), they are very unlikely to have an interest in *Insulin index*.

Table 4. Most directly related and inversely related illness interests and related interests, as measured using lift.

Illness interest	Related interest	Lift
Directly related illness interests		
Insulin resistance awareness	Nightlife	25.32
Insulin index	Nightlife	23.12
Insulin index	Panera Bread	22.40
Insulin resistance awareness	Panera Bread	22.34
Bariatrics	Nightlife	21.54
Bariatrics	Panera Bread	19.93
Gestational diabetes	Healthy diet	18.90
Alcoholics anonymous	Anxiety awareness	17.67
Food intolerance	Healthy diet	17.23
Insulin index	Mental health	17.19
Diabetic hypoglycemia	Healthy diet	17.12
Alcoholism awareness	Anxiety awareness	16.99
Insulin resistance awareness	Mental health	16.94
Diabetes mellitus type 2 awareness	Panera Bread	16.22
Twelve-step program	Anxiety Awareness	16.21
Major depressive disorder awareness	Nightlife	16.19
Sobriety	Mental health	16.15
Food allergy	Anxiety awareness	15.81
Diabetes mellitus type 1 awareness	Mental health	15.81
Gluten sensitivity awareness	Mental health	15.81
Inversely related illness interests		
Hepatitis awareness	Nightlife	0.31
Lactose intolerance	National Football League	0.32
Hypertension awareness	Fast food restaurants	0.38
Lactose intolerance	Nightlife	0.42
Gestational diabetes	Muscle and fitness	0.47
Food allergy	Fast food restaurants	0.48
Hepatitis awareness	Dunkin' Donuts	0.49
Lactose intolerance	Muscle and Fitness	0.51
Alcoholism awareness	Fast food restaurants	0.54
Diabetic hypoglycemia	National Football League	0.57
Diabetic hypoglycemia	Muscle and Fitness	0.57
Lactose intolerance	Dunkin' Donuts	0.57
Gestational diabetes	National Football League	0.58
Alcoholics anonymous	CrossFit	0.58
Lactose intolerance	Nightclubs	0.60
Lactose intolerance	Basketball	0.61
Hypertension awareness	National Football League	0.62
Diabetic hypoglycemia	Nightlife	0.63
Lactose intolerance	Fast food restaurants	0.64
Lactose intolerance	McDonald's	0.69

Table 5. Most directly related and inversely related illness interests and demographics, as measured using lift.

Marker interest	Demographic	Lift
Directly related illness interests		
Plus size	African American	5.38
Diabetic hypoglycemia	65+ years	3.93
Diabetic diet	65+ years	3.59
Insulin resistance awareness	Hispanic	3.48
Diabetes mellitus awareness	Hispanic	3.01
Dieting	Hispanic	2.89
Diabetic hypoglycemia	Asian American	2.86
Bariatrics	Hispanic	2.71
Plus-size clothing	African American	2.67
Diabetes mellitus type 2 awareness	Hispanic	2.60
Insulin index	Hispanic	2.57
Obesity awareness	Hispanic	2.57
Alcohol	Hispanic	2.55
Diabetic hypoglycemia	Hispanic	2.22
Bars	Hispanic	2.17
Lactose intolerance	45-64 years	2.14
Lactose intolerance	65+ years	2.12
Alcoholics anonymous	65+ years	2.10
Insulin index	25-44 years	2.10
Insulin index	African American	2.06
Inversely related illness interests		
Diabetic hypoglycemia	18-24 years	0.01
Insulin index	Male	0.01
Diabetes mellitus type 1 awareness	65+ years	0.02
Obesity awareness	65+ years	0.02
Plus size	Male	0.06
Food allergy	Male	0.07
Diabetic diet	18-24 years	0.07
Bariatrics	65+ years	0.08
Lactose intolerance	Male	0.09
Alcoholics anonymous	Asian American	0.09
Gestational diabetes	Male	0.10
Diabetes mellitus type 1 awareness	45-64 years	0.10
Alcohol	65+ years	0.11
Plus size	65+ years	0.11
Plus-size clothing	65+ years	0.11
Plus-size clothing	Male	0.11
Food allergy	18-24 years	0.11
Gluten sensitivity awareness	65+ years	0.12
Diabetic hypoglycemia	25-44 years	0.13
Sobriety	65+ years	0.13

Discussion

Methodological Contributions to Using Facebook Advertisement Audience Estimates

To use Facebook advertisement audience estimates for public health is not trivial, as there are many aspects that can affect the interpretability of the data from Facebook. At first, our results seem to confirm previous findings that variations in interests on Facebook across different geographic locations can be used for modeling lifestyle disease prevalence. We were able to find clear correlations of Facebook advertisement audience estimates with available public health data. This is consistent with some of the previous studies published in the literature [14,15,17,35,36]. However, unlike Gittelman et al [35], we examined the contribution of each *marker* interest, and consequently found a variety of behaviors. For example, the performance for *Weight loss* ($r=.76$ for FB_{pop}) and *Dieting* ($r=.08$ for FB_{pop}) for modeling obesity rates were vastly different. This means that, as of now, there is a certain amount of trial-and-error involved in finding marker interests that are informative.

Crucially, this work introduces the use of the *placebo interests*, which provides a baseline performance estimate with which the above *marker* interests may be compared. In this study, we show that common topics such as *Reading* and *Technology* can display a nontrivial correlation with ground-truth statistics, making them an important step in verifying the significance of health-specific results. The fact that the interests we have not expected to have a strong relationship with the illnesses have shown substantial correlation may be due to the following: (1) Facebook usage, which may predispose users to certain conditions, (2) a direct relationship between the variables (interest in reading may be associated with a sedentary lifestyle, which is in turn related to diabetes [48]), or (3) some causal relationship via latent factors influencing both variables. Regardless, the strength of the correlations found with these *placebos* stands as a cautionary observation for future social media researchers that *marker* variables need to be interpreted in the light of possible confounding factors.

As a causal explanation may still be at play in an indirect way, the choice of interests that have no relationship with health-related statistics becomes an interesting challenge, as any behavior may have a tangential connection with the lifestyles involved. For instance, during the feature selection process we find *Technology* and *Entertainment* being selected to model *Obesity* (although not *Alcoholism* or *Diabetes*). However, if such interests which have no theoretical grounding to be correlated with the disease are found, the extent of their observed relationship with it—as discovered in the data—may provide a glimpse into a *placebo effect* inherent in the data. It is precisely this effect that should determine whether *marker* correlations are strong enough to be considered interesting.

Similar conclusions can be drawn about the exploration of normalization factors. The employment of generic population estimates of Facebook users (FB_{pop}), compared with general interest in *Facebook* (FB_{int}), or domain-specific interest in *Fitness and Wellness* (FW_{int}) all provide a different interpretation

of the raw audience estimates, and must be selected according to the aims of the study. Even interests which we found to have lift of 1 could be used as topic-specific placebos. In future work, we plan to design and validate methods to normalize interests across different cohorts. For example, if we know the most common interest among teenagers, we will have a better baseline for gauging interest among teenager for certain interests, such as ultra-caffeinated drinks.

Challenges of Using Facebook Advertisements as a Black Box

Going forward, the biggest question that one has to address when using Facebook's advertisement audience estimates for certain interests is the following: what does it *mean* when a certain user has a certain interest as detected by Facebook?

Finding the answer involves understanding 2 different aspects: (1) Facebook's algorithmic black box and (2) Facebook users. On the algorithmic side, Facebook employs a number of classifiers to detect if, for instance, a given user is interested in the topic *Obesity awareness*. The features that go into this classification are largely derived from Facebook pages the user has liked, but also from general Web browsing history (through tracking cookies on pages with Facebook like or share buttons), as well as other information [49]. Understanding this can have important implications for the applicability of this data source for observing stigmatized health conditions where it is less likely that a Facebook user publicly *likes* a page on, for example, genital herpes. However, apart from understanding the importance of various features, there is also the issue of understanding the class labels. What exactly does *Obesity awareness* refer to? And what is the difference between an interest in *Dieting* versus *Weight loss*? Unfortunately, Facebook does not provide the option to show pages labeled with a given interest, or any other way to obtain a better understanding.

But even if one was to perfectly understand the inner workings of Facebook's classification setup, there still is the fundamental challenge of understanding the user's inner workings. What does it mean if a user *likes* a page about lung cancer? Has the user been diagnosed with lung cancer? Or someone in their family? Are they just generally concerned about the topic? Having a better understanding of the user's motivations can lead to a better selection of marker interests. As an example, we observe that an interest in *plus-size clothing* has good predictive power in modeling regional variation in obesity rates. Arguably, this is because having and expressing this interest is closely related to being overweight. However, the same cannot be said for an interest in *Alcohol* and its use to model prevalence of alcoholism. A potential solution to these questions would be to employ the advertisement platform to recruit participants for a survey designed to assess the above questions, and thus evaluate the efficacy of Facebook's interest inference algorithm. Although research on even smaller regions such as ZIP codes have been performed [50,51], Facebook Advertisement Manager allows for queries focused on even smaller geographical regions—the interface allows for areas as small as 2 km across.

Finally, interests in Facebook can vary longitudinally, both as Facebook's user base expands and contracts, and as yearly seasonal variations occur. The first change in estimates would

explain the general upward trend in the figures reported by this study, as compared with the previous ones [35,36]. The second will require longitudinal tracking and normalization if Facebook advertisement audience estimates are used for monitoring interests over long periods of time. Similarly, such dated information can then be synched with ground truth such as CDC reports for a more precise overlap of the time frame.

Consequences for Public Health

As explained above, there are limitations in the use of Facebook advertising for public health. We also need to be aware of potential negative consequences of using it. The focus on online sources can exacerbate health disparities due to the heterogeneous levels of digital health literacy [52,53]. If public health stakeholders are relying exclusively on social media data, they might unintentionally leave behind large segments of the population. For example, people with visual impairment might less frequently use social media due to accessibility problems [54].

Furthermore, advanced advertising allows tailoring by interests that are not necessarily health related and can be controversial. For example, it is possible to target people with interest in both cars and alcohol for a campaign to reduce driving under the influence of alcohol. This can be seen by many as a potential violation of privacy. Although users have agreed to the terms of use of social media and mobile apps, often they are not aware of the privacy implications [55]. We strongly advise the development of ethical guidelines and training for conducting health-related studies and interventions in social media. Some of those guidelines already exist, but they require continued updates as the technology evolves [56,57].

This paper, as any health-social media paper, can be also used intentionally as a source of information to do harm [58]. We need to be aware that our research can be used by communities that engage in Facebook to do harm (intentionally or unintentionally), such as promoting anorexia as a lifestyle [59], hampering vaccination efforts [60], or even promoting smoking [61]. This potential challenge should not pose a barrier for research in this area; on the contrary, more research can help identify ways to tackle the misleading use of social media in the health domain.

Privacy

As this research did not involve human subjects, it did not require approval by an institutional review board. All the information we used was collected via an open API provided by Facebook in the public domain. The data provided are always aggregated and cannot be linked to the individual. The provider of data (Facebook) is not a collaborator in the study here described. Furthermore, the Terms of Use of the platform allows the collection of data so that Facebook can provide services to third party organizations with those data, given that it is deidentified. Finally, as discussed in the Methods section, Facebook API rounds up the aggregate numbers to nearest 20, thus allowing for k-anonymity [62] for individuals within an audience for a query of any specificity. We note here that, indirectly, these data may reveal to what extent users feel comfortable revealing personal information to social media

providers (ostensibly to enrich their interaction with the platform), without researchers having direct access to the said information.

Limitations

One of the most important problems we faced with our study was the temporal mismatch between validated public health data and Facebook advertising data. We compared the current Facebook advertising data with public health data collected nearly a year before. This is an important shortcoming as interests can change rapidly due to many external factors that are nearly impossible to control. As we mentioned earlier, waiting to obtain the *ground truth* data may be a solution. Furthermore, we do not have data on interests within Facebook from years ago. This is, however, something available in other tools such as Google Trends or Insights.

Beside the black-box limitations discussed above, more domain knowledge is required to select more *marker* interests potentially important in tracking illnesses, and our preliminary study by no means exhausts the potential interests that could be used for this purpose. In fact, we purposefully limited the selection of interests to avoid the multiple hypotheses problem, and to focus just on the major ones. However, a fuller list of interests may be provided by the experts when studying a particular phenomenon. We found the Facebook Advertising Manager to be a useful tool in this, as it provides suggestions of interests related to ones already selected. We also must notice that taxonomies and categories of online health data, including Facebook, do not always correspond with the taxonomies of health authorities. This is a strong limitation for the integration of social media and public health data.

One more potential limitation of this study is that some users do avoid using Facebook due to privacy concerns [63]. A danger of relying on social media platforms such as Facebook for public health monitoring is that we might be excluding parts of the population that avoid such platforms due to ethical and privacy concerns. On the other hand, the high adoption of those platforms also calls for the utilization of such platforms in public health, but always considering the overall context of the health care system. Furthermore, there might be some topics of high importance in public health that are not present in Facebook due to privacy issues and socio-cultural factors (eg, family planning, sexual health, mental health). For these, studies using hybrid methodologies, which encompass resources other than social media, are necessary.

Conclusions

In this study, we explored whether Facebook advertising audience estimates can be used to track real-world health statistics. We proposed methodological baselines, aka *placebos*, for the evaluation of these estimates, and illustrate their performance on selection of use cases. The health-related interests can be useful for the design of health-risk surveillance, health interventions recruitment, among many other applications. This study describes experimentally driven approaches to tackle the closed (aka black-box) nature of Facebook advertising, as in any social media tool, for the use in public health monitoring.

Conflicts of Interest

None declared.

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Abbreviations

- API:** Application Programming Interface
CDC: Center for Disease Control and Prevention
FB: Facebook

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Original Paper

Accurate Influenza Monitoring and Forecasting Using Novel Internet Data Streams: A Case Study in the Boston Metropolis

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Abstract

Background: Influenza outbreaks pose major challenges to public health around the world, leading to thousands of deaths a year in the United States alone. Accurate systems that track influenza activity at the city level are necessary to provide actionable information that can be used for clinical, hospital, and community outbreak preparation.

Objective: Although Internet-based real-time data sources such as Google searches and tweets have been successfully used to produce influenza activity estimates ahead of traditional health care-based systems at national and state levels, influenza tracking and forecasting at finer spatial resolutions, such as the city level, remain an open question. Our study aimed to present a precise, near real-time methodology capable of producing influenza estimates ahead of those collected and published by the Boston Public Health Commission (BPHC) for the Boston metropolitan area. This approach has great potential to be extended to other cities with access to similar data sources.

Methods: We first tested the ability of Google searches, Twitter posts, electronic health records, and a crowd-sourced influenza reporting system to detect influenza activity in the Boston metropolis separately. We then adapted a multivariate dynamic regression method named ARGO (autoregression with general online information), designed for tracking influenza at the national level, and showed that it effectively uses the above data sources to monitor and forecast influenza at the city level 1 week ahead of the current date. Finally, we presented an ensemble-based approach capable of combining information from models based on multiple data sources to more robustly nowcast as well as forecast influenza activity in the Boston metropolitan area. The performances of our models were evaluated in an out-of-sample fashion over 4 influenza seasons within 2012-2016, as well as a holdout validation period from 2016 to 2017.

Results: Our ensemble-based methods incorporating information from diverse models based on multiple data sources, including ARGO, produced the most robust and accurate results. The observed Pearson correlations between our out-of-sample flu activity estimates and those historically reported by the BPHC were 0.98 in nowcasting influenza and 0.94 in forecasting influenza 1 week ahead of the current date.

Conclusions: We show that information from Internet-based data sources, when combined using an informed, robust methodology, can be effectively used as early indicators of influenza activity at fine geographic resolutions.

KEYWORDS

epidemiology; public health; machine learning; regression analysis; influenza, human; communicable diseases; statistics; patient generated data

Introduction

Traditional Influenza Surveillance

Seasonal influenza is a major public health concern across the United States. Each year, over 200,000 hospitalizations from complications related to influenza infection occur nationwide, resulting in 3000 to 50,000 deaths [1]. Worldwide, up to 500,000 deaths occur annually due to influenza [2]. Vaccination is the primary prevention method [3], but other prevention and mitigation strategies are also important for reducing transmission and morbidity, including infection control procedures, early treatment, allocation of emergency department (ED) resources, and media alerts. Accurate and timely surveillance of influenza incidence is important for situation awareness and response management.

Governmental public health agencies traditionally collect information on laboratory confirmed influenza cases and reports of visits to clinics or EDs showing symptoms of influenza-like illness (ILI). ILI is symptomatically defined by the Centers for Disease Control and Prevention (CDC) as a fever greater than 100 F and cough or sore throat [4]. The CDC publishes weekly reports for national and multistate regional incidence, whereas state and city data are sometimes published by local agencies such as the Boston Public Health Commission (BPHC). These systems provide consistent historical information to track ILI levels in the US population [5,6]. However, they often involve a 1- to 2-week lag, reflecting the time needed for information to flow from laboratories and clinical databases to a centralized information system, and tend to undergo subsequent revisions. The time lag delays knowledge of current influenza activity, thus limiting the ability for timely response management. Additionally, this time lag makes it harder to predict future activity.

Real-Time Surveillance Models

To address this issue, research teams have demonstrated the ability to monitor national and regional (collections of 5 states within the United States defined by the Department of Health and Human Services) influenza incidence in near real-time by combining various disparate sources of information. Historical flu activity shows both seasonal and short-term predictability, and models that use such autoregressive information can capture and estimate the salient features of epidemic outbreaks [7]. Rapidly updating data streams have also been found to show strong value in influenza monitoring at the national and regional levels. As early as 2006, analysis of Internet search activity has shown the potential to predict official influenza syndromic data [8]. In 2008, Google Flu Trends (GFT) launched one of the first projects to utilize Internet searches as predictors of influenza activity, eventually providing predictions from 2003 to 2015 using search volumes around the globe [9]. Although flaws have been identified in Google's original methods and results [10],

methodological improvements have shown that Internet searches are a viable way to monitor influenza [7,11-13].

Cloud-based electronic health records (EHRs) are another data source that can be obtained in near real-time [14]. Participating health care providers can report influenza cases as they occur, giving early approximations of the true infection rate. In Santillana et al [15], an ensemble approach combining these data sources outperformed any other methods in national flu predictions. In addition, traditional susceptible-infected-recovered (SIR) epidemiological models coupled with data assimilation techniques have shown strong potential in predicting influenza activity in multiple spatial resolutions [16,17]. Finally, participatory disease surveillance efforts where a collection of participants report whether they experienced ILI symptoms on a weekly basis, such as Flu Near You (FNY) in the United States, Influenzanet in Europe, and Flutracking in Australia, show promise in monitoring influenza activity in populations not frequently surveilled by health care-based surveillance systems [18-21].

Finer Spatial Resolutions

Although significant progress in tracking and predicting influenza activity using novel data sources has been made at larger geographical scales, detection at finer spatial resolutions, such as the city level, is less well understood [7,12,14-15,22-26]. Models aiming at tracking the number of influenza-positive case rates at the city level have been developed with moderate success, including a network mechanistic model for the neighborhoods and boroughs of New York City based on the traditional SIR methodology [27]. Models combining Twitter and Google Trends data have also been tested in the same city [28], as well as in a Baltimore hospital [29].

In this paper, we demonstrate the feasibility of combining various Internet-based data sources using machine learning techniques to monitor and forecast influenza activity in the Boston metropolitan area, by extending proven methods from the national- and regional-level influenza surveillance literature to the city-level resolution. We then develop ensemble meta-predictors on these methods and show that they produce the most robust results at this geographical scale. Our methods were used to produce out-of-sample influenza estimates from 2012 to 2016 as well as out-of-sample validation on previously unseen official influenza activity data from the 2016-2017 seasons. Our contribution shows that the lessons learned from tracking influenza at broader geographical scales, such as the national and regional levels in the United States, can be adapted with success at finer spatial resolutions.

Methods

Data Collection

We used syndromic data collected by the BPHC as our reference for influenza activity in the metropolis. Other data sources included Google searches, Twitter posts, FNY mobile app reports, and EHRs, as described below. Data were collected from the weeks starting September 6, 2009, to May 15, 2016, and separately from the weeks starting May 22, 2016, to May 7, 2017, for the holdout set.

Epidemiological Data

The Greater Boston area is defined using zip codes within Suffolk, Norfolk, Middlesex, Essex, and Plymouth counties. These zip codes are associated with over 90% of Boston ED visits. Limited data for ED visits from all 9 Boston acute care hospitals are sent electronically every 24 hours to the BPHC, which operates a syndromic surveillance system. Data sent include visit date, chief complaint, zip code of residence, age, gender, and ethnicity.

Our prediction target for Greater Boston was %ILI (percentage of ILI), which is calculated as the number of ED visits for ILI divided by the total number of ED visits each week. These data are updated between Tuesday and Friday with the %ILI of the previous week along with retrospective revisions of previous weeks. We used this dataset as the ground truth against which we benchmarked our predictive models. Inspection of the past 5 years of ILI activity in the Boston area, compared with US national ILI activity, shows that the peak weeks and length of outbreaks are not synchronous, and the scales (%ILI) are not necessarily comparable ([Multimedia Appendix 1](#)).

The exogenous near real-time data sources mentioned below were used as inputs to our predictive models.

Google Trends Data

Weekly search volumes within the Boston Designated Market Area (which has a similar size and coverage to Greater Boston) of 133 flu-related queries were obtained from the Google Trends application programming interface (API). These include query terms taken from the national influenza surveillance literature [7] as well as Boston-specific terms (all terms displayed in [Multimedia Appendix 2](#)). Each query is reported as a time series, where each weekly value represents a sample frequency out of total Google searches made during the week, scaled by an undisclosed constant. Data from the previous week are available by the following Monday. The data are left-censored, meaning that the API replaces search frequencies under some unspecified threshold with 0. To filter out the sparse data, search terms whose frequencies were over 25.1% (88/350) composed of 0s were removed, leaving 50 predictors.

Electronic Health Record Data

Weekly aggregated EHR data were provided by athenahealth. Although athenahealth data aggregated at the city level for Boston were not available for this study, we used state-level data as an indicator of influenza flu activity in Boston. We believe this is a suitable proxy because most of the population of Massachusetts lives in Greater Boston, which suggests that

Greater Boston's %ILI is a large subset of and likely highly correlated with the state's %ILI. Three time series at the Massachusetts' level were used as our input variables: "influenza visit counts," "ILI visit counts," and "unspecified viral or ILI visit counts." A fourth time series, "total patient visit counts," was used to convert the case counts into rates. Reports from the previous week are available on the following Monday. Detailed information on EHR data from athenahealth is provided in Santillana et al [14].

To convert the 3 influenza-related case counts into frequencies, they were each divided with a 2-year moving average of the weekly total patient visits to construct smoothed rate variables. The justification for this approach is provided in [Multimedia Appendix 2](#).

Flu Near You Data

FNY is an Internet-based participatory disease surveillance system that allows volunteers in the United States and Canada to report their health information during the previous week and in real-time, using a brief survey. The system collects and publishes symptom data on its website on a weekly basis and offers an interface to compare its data with data from the CDC sentinel influenza network [18]. Data for the previous week are available the following Monday. FNY participants located in the Greater Boston area were identified using the zip code provided at registration. Raw FNY %ILI for Boston was calculated by dividing the number of participants reporting ILI in a given week by the total number of FNY participant reports in that same week.

Twitter Data

We used the GNIP Historical Powertrack service to collect all tweets from April 15, 2015, to March 24, 2017, that were geocoded (using the GNIP location field) within a 25-mile radius from Boston (defined as 42.358056, -71.063611), the maximum radius supported by GNIP. The definition of Greater Boston used in this study is approximately the same radius. A subset of tweets was extracted from the Twitter dataset according to criteria specified by a generated list of key influenza-related terms and phrases. Initialized with a set of common hashtags related to disease (including #sick and #flu), the list was expanded based on linguistic term associations identified in disease-related tweets to include terms such as #stomachache and #nyquil.

Models

We adapted a variety of models from the influenza surveillance literature to answer the following 2 questions: (1) What are the data sources that best track influenza activity as reported by the BPHC? and (2) What are the methodologies that best estimate the influenza activity by combining the data sources identified in (1)?

The models fall into 2 categories: single source variable analyses to investigate the value of a specific dataset in tracking %ILI and multisource analyses to inspect the value of combining disparate information sources for tracking %ILI. Motivated by the analyses presented in Yang et al for national influenza tracking [30], most of our models combine 52-week

autoregressive components with terms from real-time Internet-based data in a multivariate linear regression with L1 regularization (LASSO). The initial regression model was trained using the first 2 years of data (104 weeks), and subsequent models were retrained each week using the 2-year sliding window (ie, most recent 104 weeks of data). Following the convention in [30], these models are indicated as ARGO (autoregression with general online information).

Because exogenous data for each week are available by the following Monday, whereas the official BPHC %ILI is published by the following Friday, we have 2 useful estimation targets: (1) a nowcast of %ILI for the week that just ended (concurrent with the exogenous data) and (2) a forecast of %ILI over the coming week (1 week ahead of the exogenous data). Predictions on the forecast horizon were produced by retraining the models from the nowcast horizon with the %ILI targets shifted 1 week forward.

Models on Single Data Sources

Endogenous Model

AR52

An autoregressive baseline model was constructed to evaluate the benefit of using only past values of the BPHC %ILI time series to estimate the current %ILI. To predict the %ILI in a given week, the %ILI of the previous 52 weeks was used as the independent variables in a LASSO regression.

Exogenous Models

ARGO(FNY)

The raw FNY rate at time t was combined with 52 autoregressive terms in a LASSO regression.

ARGO(Google)

We constructed the model presented in [7], using the Google Trends search frequencies and 52 autoregressive terms in a LASSO regression.

ARGO(athena)

As in [14], athenahealth rates from the 3 most recently available weeks were combined for each week's prediction, resulting in a stack of 9 variables. These weeks are denoted as " $t-1$," " $t-2$," and " $t-3$ " in our analysis. The model combines the 9 variables at time t with 52 autoregressive terms in a LASSO regression.

Twitter

The modeling approach involved developing a multistage pipeline framework described in detail in [31]. Initially, a list of flu-related tweets was extracted as described in the Data section. We subsequently clustered each relevant tweet within its hashtag corpus according to the calculated term frequency-inverse document frequency vectors [32], and we classified a random subset of tweets within each cluster into 3 categories—self reporting, non-self-reporting, and spam—according to a second set of engineered linguistic attributes. Clusters with large proportions of non-self-reporting and spam tweets were subsequently eliminated, with the remaining tweets and associated timestamps forming a daily frequency distribution corresponding to %ILI over time. The

results were finally aggregated at the weekly level and scaled to the BPHC %ILI. Because Twitter data were available for a period of less than 2 years, we did not include Twitter in our ARGO models.

ARGO(athena+Google+FNY)

The athenahealth rates, Google Trends search frequencies, and raw FNY rate were combined with 52 autoregressive terms in a modified LASSO regression with grouped regularization as in [30]. The model includes additional processing and hyper-parameter settings, details of which are presented in [Multimedia Appendix 3](#).

Ensemble

Finally, we developed a meta-predictor on a layer of 7 input models, including most of those previously defined. The flu estimates of these input models were combined based on the historical performances of the models. In the nowcast horizon, a performance-adjusted median on the outputs of the individual models was selected as the ensemble meta-predictor. In the forecast horizon, a performance-adjusted LASSO regression was selected as the ensemble meta-predictor.

A detailed description and comparison of all models, including ensembles, are presented in [Multimedia Appendix 4](#).

All experiments were conducted in Python 2.7 (Python Software Foundation) using scikit-learn version 0.18.1 [33].

Models Combining Multiple Datasets

Comparative Analyses

Model performance was evaluated using 5 metrics: root mean square error (RMSE), mean absolute error (MAE), mean absolute percentage error (MAPE), Pearson correlation coefficient (CORR), and correlation of increment (COI). For an estimation \hat{y} of the official %ILI y , the definitions are as follows:

$$\text{RMSE} = [(1 / n) \sum_{t=1, \dots, n} (\hat{y}_t - y_t) ^ 2] ^ { 1 / 2 }$$

$$\text{MAE} = (1 / n) \sum_{t=1, \dots, n} | \hat{y}_t - y_t |$$

$$\text{MAPE} = (1 / n) \sum_{t=1, \dots, n} | \hat{y}_t - y_t | / y_t$$

$$\text{COI} = \text{CORR} (\hat{y}_t - \hat{y}_{t-1} , y_t - y_{t-1})$$

For guidance, a method is more accurate when the prediction errors (RMSE, MAE, and MAPE) are smaller and closer to 0. The LASSO objective minimizes RMSE, so this metric will be our primary way to assess model accuracy. A method tracks the movement of the flu activity better when the correlation values (CORR and COI) are closer to 1.

Metrics were computed between each model's predictions and the official BPHC %ILI over the entire test period (September 2, 2012, to May 15, 2016), as well as for each influenza season (week 40 to week 20 of the next year) including the holdout set.

The following 2 additional benchmarks were constructed to establish a baseline for comparison between all models:

1. A naive model that uses the %ILI from the previous week as the prediction for the current week

2. GFT influenza activity estimates from September 5, 2010, to August 9, 2015, accessed on December 2016, from [9].

Because Google reported values as intensities between 0 and 1 without a clear scaling constant, the data were linearly rescaled to fit BPHC %ILI using the same initial training set as the above models (September 5, 2010, to August 26, 2012).

Results

Out-of-sample weekly estimates of Greater Boston ILI activity from all models were produced retrospectively for the period starting from September 2, 2012, to May 15, 2016. After the 2016-2017 flu season, previously unseen BPHC %ILI data from May 22, 2016, to May 7, 2017, were used to validate model performances.

Single Data Source Evaluation

Table 1 shows the metrics calculated by comparing retrospective estimates from all models built with a single exogenous dataset against BPHC %ILI, over 5 flu seasons. ARGO(athena) is the best performing model in this category, both overall and across the majority of flu seasons. For example, ARGO(athena) yields a 5% (0.011/0.206) lower RMSE than the nearest competitor ARGO(Google), 36% (0.108/0.303) lower error than AR52, and 27% (0.071/0.266) lower error than the naive approach. As shown in Figure 1, ARGO(athena) tends to capture peaks of ILI activity more accurately than the other models.

Because each ARGO model in Table 1 combines an exogenous dataset with AR52, comparing each model with AR52 indicates how much predictive value the dataset adds to the historical ILI time series. Both athenahealth and Google Trends datasets show a marked improvement over a simple AR52 model, indicating that they contain valuable information for influenza monitoring. Both models also demonstrate reduced error (RMSE, MAE, and MAPE) compared with the GFT benchmark in seasons where GFT was available. ARGO(FNY) performs about the same as AR52 overall, indicating that FNY may not necessarily track the BPHC %ILI. It is important to highlight that although the Twitter %ILI estimates perform worse than all other models, this approach was not dynamically trained with AR52 information, due to the short period when these values were produced. Twitter %ILI estimates nevertheless show a similar pattern of peaks and dips compared with the BPHC %ILI (Figure 1).

Multiple Data Sources Evaluation

In Table 2, the performance of the best single-dataset model, ARGO(athena), is compared with the performance of the multi-dataset models for the nowcast horizon. Over the entire period and for all flu seasons besides 2015-16, ARGO(athena+Google+FNY) shows a decrease in error and increase in correlation compared with ARGO(athena). In particular, it achieves a 15% (0.03/0.195) decrease in RMSE and a 20% (0.109/0.547) increase in COI compared with ARGO(athena), significantly improving on the performance of the single-dataset approach. A similar pattern is present in the one week ahead forecast horizon, with significantly better performance over the entire period except for the 2014-15 and 2015-16 seasons (Table 3). With a 25% (0.08/0.325) decrease

in RMSE and a 23% (0.101/0.432) increase in COI compared with ARGO(athena), the multi-dataset model again provides a distinct improvement.

The comparison between ARGO(athena+Google+FNY) and ARGO(athena) shows that models combining multiple data sources generally perform better than the best dataset alone, consistent with previous findings on influenza prediction at the US national level [15,30]. However, the superiority of ARGO(athena+Google+FNY) is not consistent over all seasons. As shown in Multimedia Appendix 4, when compared with the full array of models we tested, ARGO(athena+Google+FNY) underperforms in not only the seasons previously mentioned where it loses to ARGO(athena) but also in the 2013-14 influenza season. In other words, even though ARGO(athena+Google+FNY) is overall stronger than the other models discussed, its results in any given season could be significantly worse than the best-performing model of that season. Similarly, the other models (non-ensembles) exhibit variations in performance over time, with none consistently performing at the top.

Ensemble Modeling Approach Evaluation

To develop a more robust and consistent set of influenza estimates, we trained an ensemble meta-predictor that takes predictions from all the above models and combines them into a single prediction. As shown in Tables 2 and 3, our ensembles achieve the best overall performance in every metric, in both nowcast and forecast horizons. In the nowcast, the ensemble is consistently the strongest model, with the lowest RMSE and highest correlation in 4 out of 5 seasons. In the forecast, the meta-predictor is less dominant over ARGO(athena+Google+FNY), but still has the advantage of consistency: even when it is not the strongest model over a season, it is never far from the best performance. This is illustrated in Multimedia Appendix 4, where the ensembles achieve top 2 performances over all influenza seasons more consistently than any other model in the input layer. Figure 2 confirms this consistency by showing that the ensemble curve accurately predicts the magnitude of peaks in each influenza season, with less prediction error than the other models.

We found that different ensemble methods performed better at each time horizon. The results of 4 different meta-predictors are shown in Multimedia Appendix 4. The performance-adjusted median showed the best performance for the nowcast, and LASSO showed the best performance for the forecast.

In multiple seasons including 2016-17, the predicted nowcast peak occurs slightly later than the observed %ILI peak (Figure 1), which likely occurs because of the autoregressive contribution in the input variables for each model. This delay becomes more significant when predicting the 1-week forecast, as shown in the bottom panel of Figure 2. As noted in Yang et al [7], a trade-off occurs between robustness and responsiveness when using ARGO, where robustness refers to avoiding large errors in any given week and responsiveness refers to predicting the gold standard without delay. The top panel of Figure 2 shows that the presence of this lag in the nowcast is mitigated when using our ensemble approach, improving responsiveness while preserving robustness.

Table 1. Comparison of single data source models for nowcasting Boston Public Health Commission's percentage of influenza-like illness over the assessment period (September 2, 2012, to May 7, 2017). Each flu season starts on week 40 and ends on week 20 of the next year.

Model ^a	Whole period	Flu seasons				Holdout
	2012-16	2012-13	2013-14	2014-15	2015-16	2016-17
Root mean square error						
AR52	0.303	0.577	0.199	0.305	0.217	0.229
ARGO(athena) ^b	0.195	0.306	0.229	0.192	0.133	0.182
ARGO(Google)	0.206	0.312	0.194	0.247	0.161	0.188
ARGO(FNY) ^c	0.299	0.552	0.204	0.343	0.172	0.280
Twitter	—	—	—	0.162	0.427	0.351
GFT ^d	—	0.352	0.271	0.284	—	—
Naive	0.266	0.481	0.208	0.280	0.202	0.219
Mean absolute error						
AR52	0.180	0.345	0.146	0.218	0.176	0.176
ARGO(athena)	0.137	0.205	0.189	0.136	0.102	0.154
ARGO(Google)	0.150	0.206	0.155	0.213	0.131	0.153
ARGO(FNY)	0.182	0.362	0.153	0.221	0.140	0.213
Twitter	—	—	—	0.136	0.338	0.251
GFT	—	0.294	0.225	0.227	—	—
Naive	0.167	0.290	0.165	0.213	0.158	0.168
Mean absolute percentage error						
AR52	0.184	0.188	0.137	0.185	0.188	0.130
ARGO(athena)	0.163	0.128	0.193	0.124	0.110	0.129
ARGO(Google)	0.179	0.134	0.152	0.209	0.146	0.125
ARGO(FNY)	0.192	0.210	0.139	0.186	0.143	0.157
Twitter	—	—	—	0.212	0.308	0.189
GFT	—	0.308	0.221	0.228	—	—
Naive	0.172	0.169	0.152	0.188	0.162	0.130
Pearson correlation coefficient						
AR52	0.898	0.882	0.846	0.834	0.806	0.898
ARGO(athena)	0.959	0.964	0.843	0.950	0.943	0.949
ARGO(Google)	0.956	0.968	0.856	0.910	0.896	0.930
ARGO(FNY)	0.901	0.909	0.845	0.824	0.886	0.879
Twitter	—	—	—	0.888	0.416	0.759
GFT	—	0.974	0.785	0.921	—	—
Naive	0.922	0.912	0.846	0.868	0.848	0.906
Correlation of increment						
AR52	0.222	0.359	-0.105	0.115	-0.048	0.222
ARGO(athena)	0.547	0.657	0.220	0.483	0.486	0.515
ARGO(Google)	0.546	0.730	0.399	0.284	0.267	0.417
ARGO(FNY)	0.252	0.387	-0.056	-0.025	0.122	0.253
Twitter	—	—	—	-0.481	-0.291	0.095
GFT	—	0.892	0.281	0.575	—	—

Model ^a	Whole period	Flu seasons				Holdout
	2012-16	2012-13	2013-14	2014-15	2015-16	2016-17
Naive	0.291	0.480	-0.100	0.280	-0.070	0.193

^aThe best performance within each season and metric is italicized. Results for each model are shown where available.

^bARGO: autoregression with general online information.

^cFNY: Flu Near You.

^dGFT: Google Flu Trends.

Figure 1. Retrospective nowcasts from single data source models are shown, compared with Boston Public Health Commission’s official percentage of influenza-like illness (BPHC official %ILI) (black), over the entire study period (September 2, 2012, to May 7, 2017). The gold section indicates the holdout period from May 22, 2016, to May 7, 2017. The bottom panel shows the corresponding errors of each model compared with the official %ILI (ARGO: autoregression with general online information; FNY: Flu Near You).

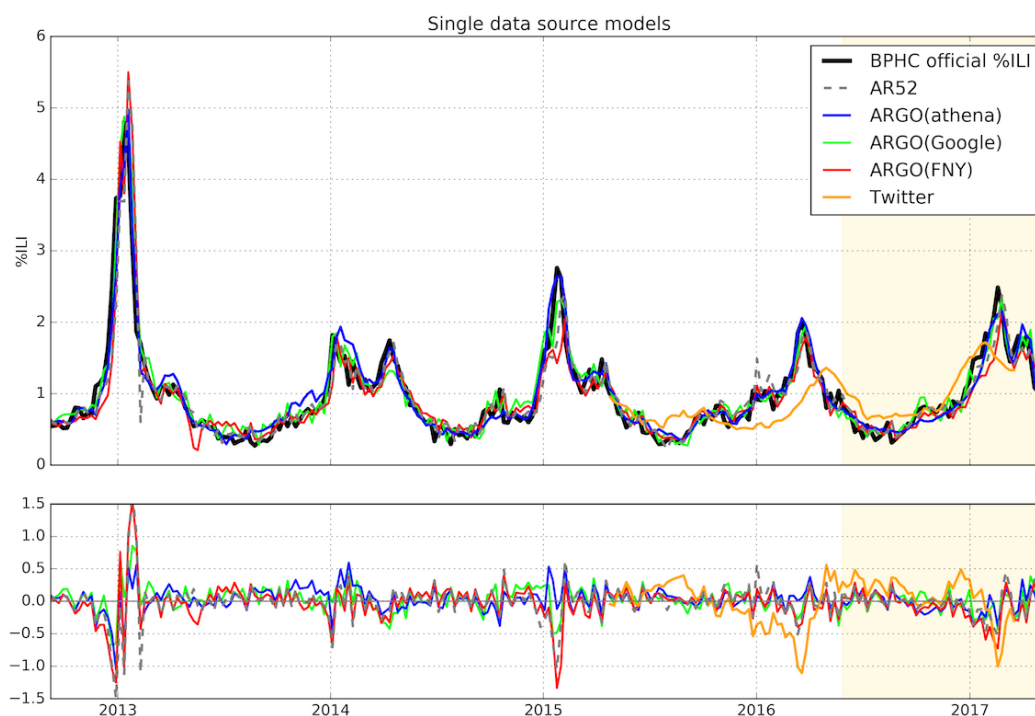


Table 2. Comparison of models using multiple data sources for nowcasting Boston Public Health Commission's percentage of influenza-like illness over the study period (September 2, 2012, to May 7, 2017). ARGO(athena) and the naive model are included as benchmarks for comparison.

Model ^a	Whole period	Flu seasons				Holdout
	2012-16	2012-13	2013-14	2014-15	2015-16	2016-17
Root mean square error						
ARGO(athena) ^b	0.195	0.306	0.229	0.192	<i>0.133</i>	0.182
ARGO(athena+Google+FNY) ^c	0.165	0.199	0.192	0.189	0.168	0.156
Ensemble	<i>0.151</i>	<i>0.193</i>	<i>0.170</i>	<i>0.176</i>	0.139	<i>0.150</i>
Naive	0.266	0.481	0.208	0.280	0.202	0.219
Mean absolute error						
ARGO(athena)	0.137	0.205	0.189	0.136	<i>0.102</i>	0.154
ARGO(athena+Google+FNY)	0.124	0.146	0.144	0.154	0.128	0.131
Ensemble	<i>0.112</i>	<i>0.140</i>	<i>0.131</i>	<i>0.135</i>	0.106	<i>0.118</i>
Naive	0.167	0.290	0.165	0.213	0.158	0.168
Mean absolute percentage error						
ARGO(athena)	0.163	0.128	0.193	<i>0.124</i>	<i>0.110</i>	0.129
ARGO(athena+Google+FNY)	0.154	0.112	0.136	0.153	0.142	0.104
Ensemble	<i>0.140</i>	<i>0.100</i>	<i>0.123</i>	0.132	0.118	<i>0.093</i>
Naive	0.172	0.169	0.152	0.188	0.162	0.130
Pearson correlation coefficient						
ARGO(athena)	0.959	0.964	0.843	0.950	<i>0.943</i>	0.949
ARGO(athena+Google+FNY)	0.972	0.985	0.861	<i>0.964</i>	0.916	0.957
Ensemble	<i>0.976</i>	<i>0.986</i>	<i>0.890</i>	<i>0.964</i>	0.928	<i>0.958</i>
Naive	0.922	0.912	0.846	0.868	0.848	0.906
Correlation of increment						
ARGO(athena)	0.547	0.657	0.220	0.483	<i>0.486</i>	0.515
ARGO(athena+Google+FNY)	0.656	0.807	0.419	<i>0.660</i>	0.312	<i>0.620</i>
Ensemble	<i>0.689</i>	<i>0.827</i>	<i>0.447</i>	0.633	0.357	0.565
Naive	0.291	0.480	-0.100	0.280	-0.070	0.193

^aThe best performance within each season and metric is italicized.

^bARGO: autoregression with general online information.

^cFNY: Flu Near You.

Table 3. Comparison of models using multiple data sources for forecasting Boston Public Health Commission's percentage of influenza-like illness, over the study period (September 2, 2012, to May 7, 2017). ARGO(athena) and the naive model are included as benchmarks for comparison.

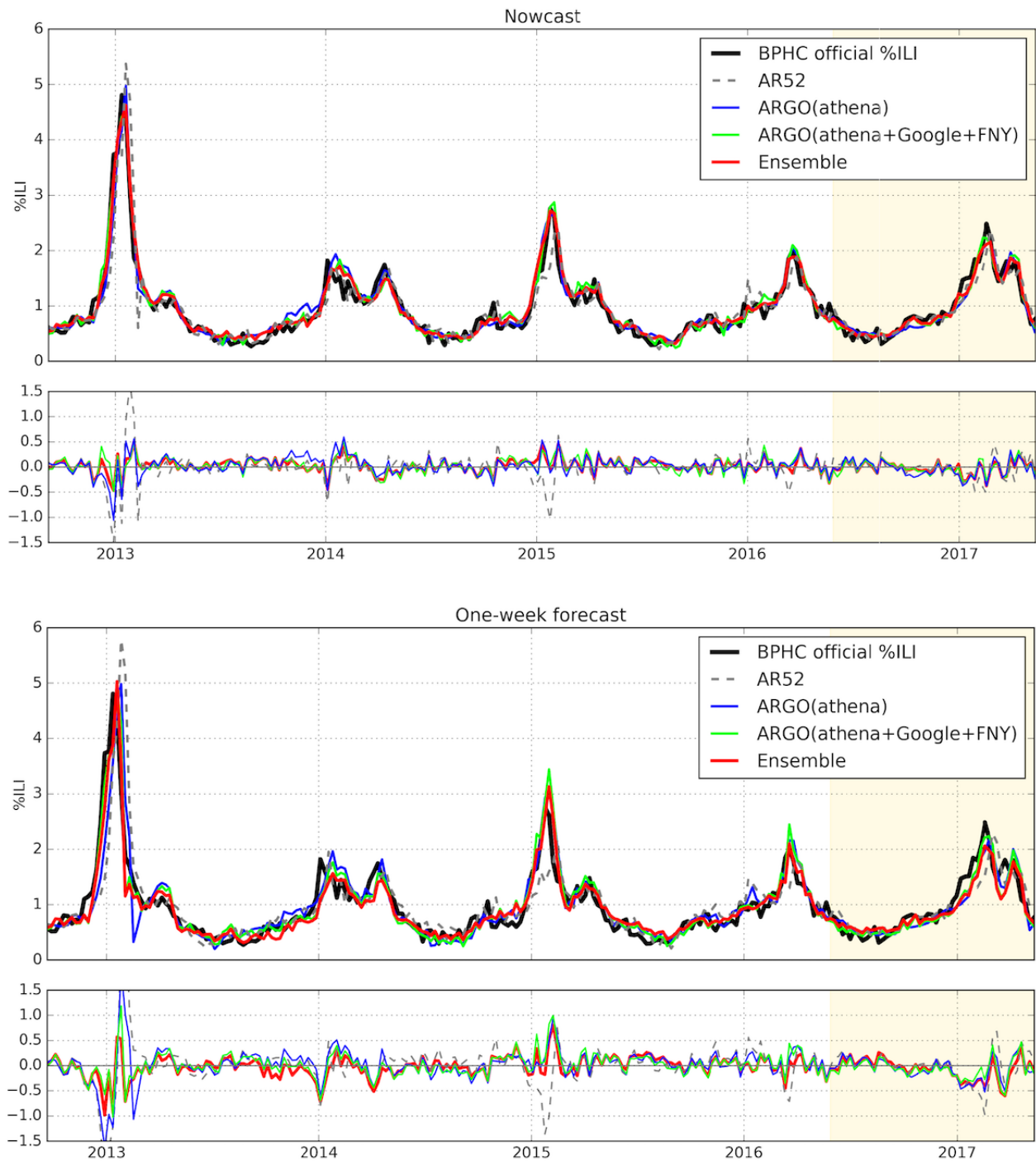
Model ^a	Whole period	Flu seasons				Holdout
	2012-16	2012-13	2013-14	2014-15	2015-16	2016-17
Root mean square error						
ARGO(athena) ^b	0.325	0.647	0.249	0.260	0.188	0.261
ARGO(athena+Google+FNY) ^c	0.245	0.367	<i>0.221</i>	0.314	0.190	<i>0.240</i>
Ensemble	<i>0.222</i>	<i>0.348</i>	<i>0.237</i>	<i>0.251</i>	<i>0.155</i>	0.251
Naive	0.428	0.827	0.276	0.447	0.271	0.340
Mean absolute error						
ARGO(athena)	0.203	0.432	0.200	<i>0.184</i>	0.156	0.221
ARGO(athena+Google+FNY)	0.169	0.247	<i>0.161</i>	0.225	0.151	<i>0.189</i>
Ensemble	<i>0.157</i>	<i>0.245</i>	0.171	0.202	<i>0.123</i>	0.198
Naive	0.252	0.528	0.203	0.329	0.201	0.251
Mean absolute percentage error						
ARGO(athena)	0.217	0.254	0.186	<i>0.168</i>	0.163	0.175
ARGO(athena+Google+FNY)	0.192	0.167	<i>0.142</i>	0.214	0.147	0.149
Ensemble	<i>0.180</i>	<i>0.160</i>	0.155	0.198	<i>0.130</i>	<i>0.144</i>
Naive	0.238	0.308	0.169	0.272	0.195	0.204
Pearson correlation coefficient						
ARGO(athena)	0.887	0.842	0.785	<i>0.933</i>	0.898	0.891
ARGO(athena+Google+FNY)	0.938	0.949	0.826	0.922	0.903	0.910
Ensemble	<i>0.944</i>	<i>0.956</i>	<i>0.847</i>	0.916	<i>0.906</i>	<i>0.913</i>
Naive	0.799	0.739	0.744	0.663	0.728	0.775
Correlation of increment						
ARGO(athena)	0.432	0.452	0.259	<i>0.624</i>	<i>0.312</i>	0.472
ARGO(athena+Google+FNY)	0.533	0.621	<i>0.451</i>	0.508	0.285	0.477
Ensemble	<i>0.573</i>	<i>0.682</i>	0.441	0.515	0.286	<i>0.510</i>
naive	0.102	0.212	0.174	-0.181	0.043	-0.065

^aThe best performance within each season and metric is italicized.

^bARGO: autoregression with general online information.

^cFNY: Flu Near You.

Figure 2. Estimations with multiple data source models over the entire study period (September 2, 2012, to May 7, 2017), with corresponding errors for each model compared with Boston Public Health Commission percentage of influenza-like illness (BPHC official %ILI). The gold section indicates the holdout period from May 22, 2016, to May 7, 2017. Predictions are shown separately for the nowcast horizon (top) and the forecast horizon (bottom) (ARGO: autoregression with general online information; FNY: Flu Near You).



Relevance of Different Data Sources

To understand the predictive power of each data source when used together as input, we displayed the weekly coefficient values associated with each (normalized) input variable in the ARGO(athena+Google+FNY) model, over time, in heatmaps (Figures 3 and 4). It can be seen that the state-level athenahealth variables have the strongest signal in both nowcast and forecast horizons, suggesting that information from EHRs is a strong

predictor of metropolitan level influenza. Although most of the long-term autoregressive terms show little to no signal, the most recent ILI value is predictive for the nowcast horizon. Finally, the selection of Google Trends variables and FNY by LASSO appears to be fairly scattered, with a few terms such as “chest cold,” “flu contagious,” and “sinus” appearing more consistently. Interestingly, FNY reports show a stronger signal in the forecast time horizon, suggesting that perhaps early self-reporting of symptoms correlates with later ED visits.

Figure 3. Heatmap of input variable coefficients for ARGO(athena+Google+FNY) from September 2, 2012, to May 15, 2016, for the nowcast horizon (ARGO: autoregression with general online information).

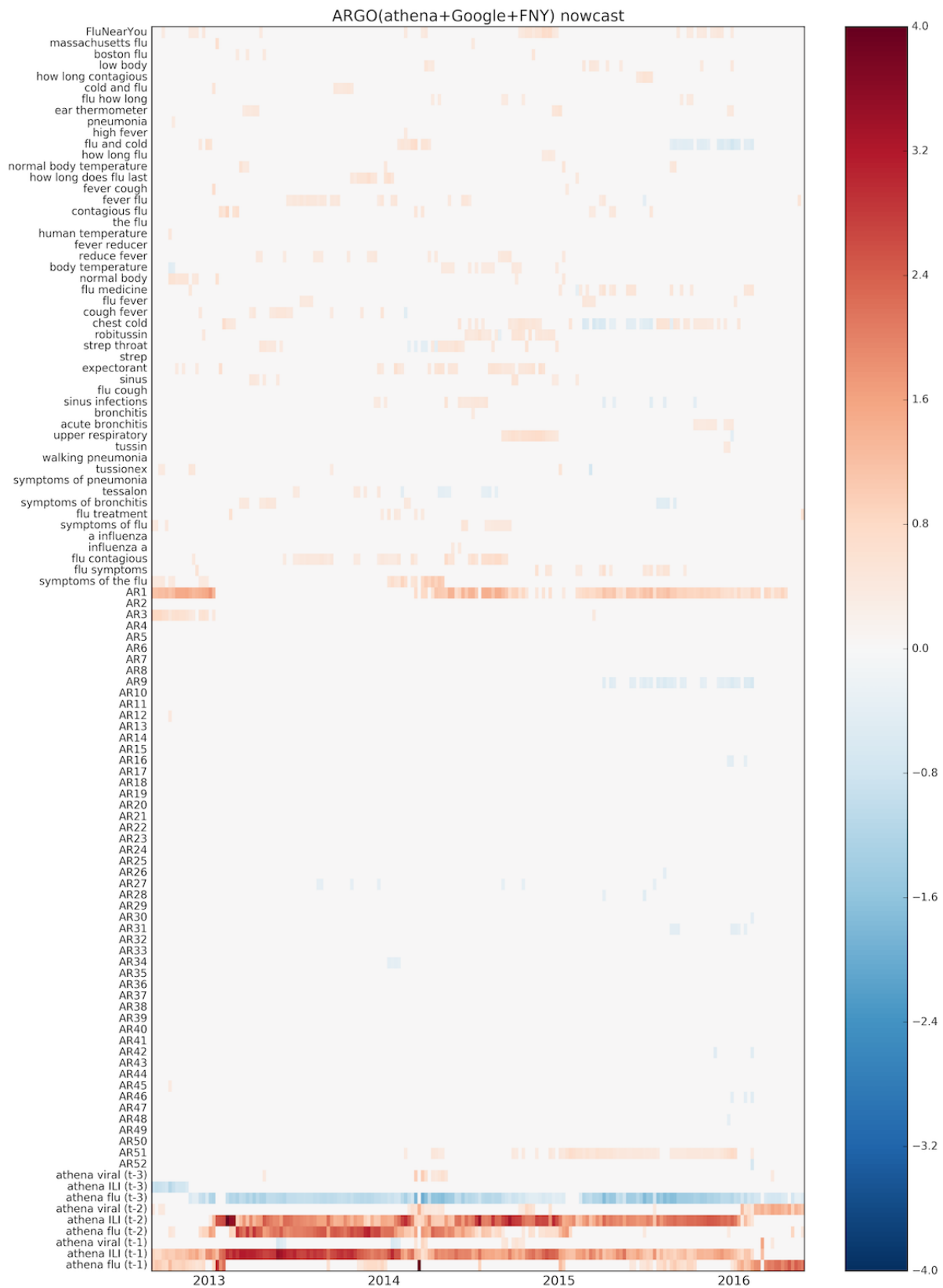


Figure 4. Heatmap of input variable coefficients for ARGO(athena+Google+FNY) from September 2, 2012, to May 15, 2016, for the 1-week forecast horizon (ARGO: autoregression with general online information).

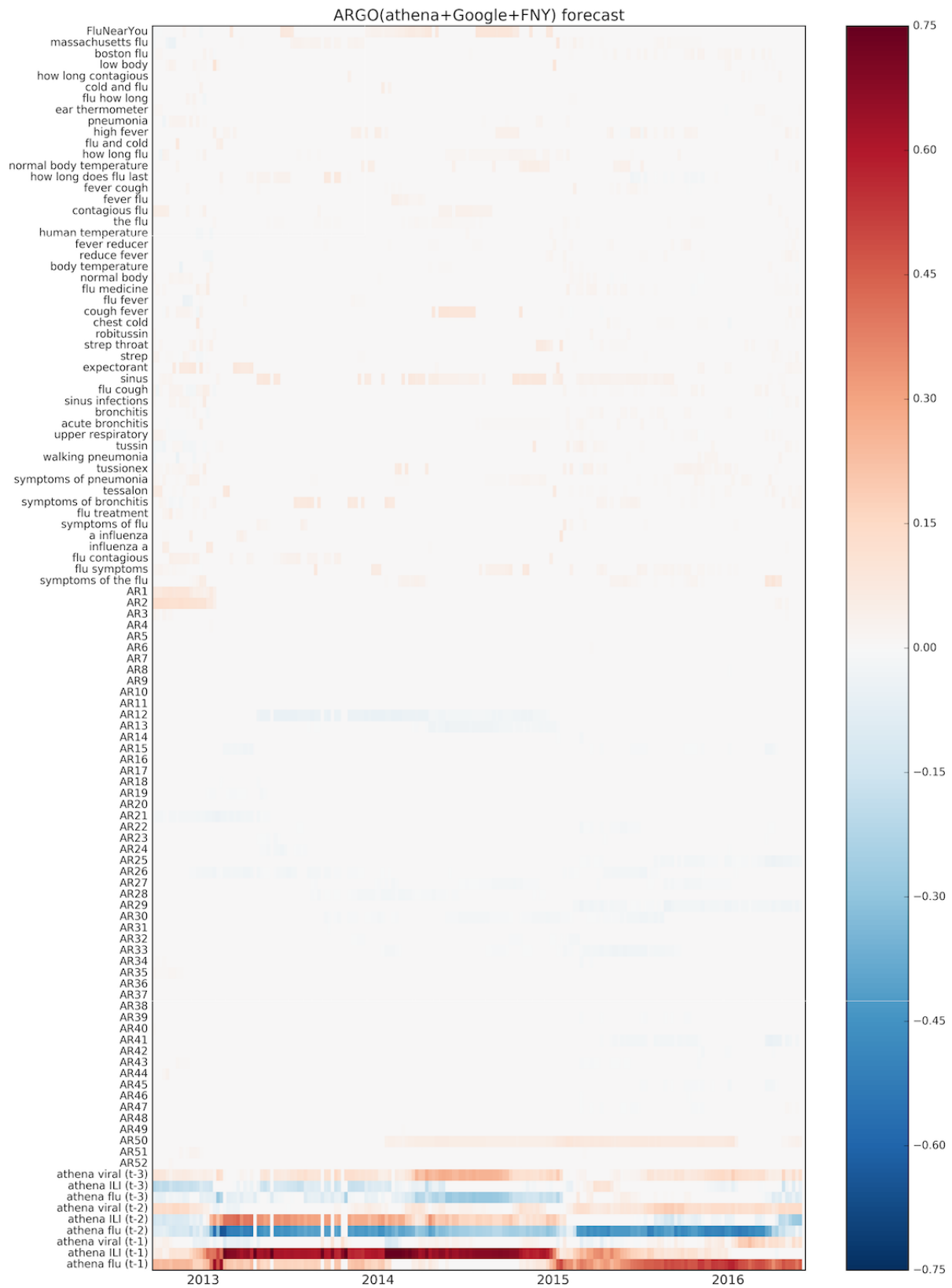


Table 4. Efficiency improvement of ensemble method with 95% confidence intervals over the period of September 2, 2012, to May 15, 2016, using the stationary block bootstrap with mean length 52 weeks.

Model	Mean ^a	95% CI
Nowcast		
AR52	4.03	2.11-6.83
athena	1.91	1.14-3.01
Google	2.16	1.46-2.78
athena+Google	1.51	1.25-1.77
ARGO(athena) ^b	1.67	1.31-2.18
ARGO(Google)	1.87	1.57-2.30
ARGO(athena+Google+FNY) ^c	1.20	1.10-1.29
Forecast		
AR52	4.55	1.98-7.16
athena	2.37	1.54-3.14
Google	2.78	1.98-3.63
athena+Google	2.21	1.20-3.24
ARGO(athena)	2.14	1.20-3.08
ARGO(Google)	6.09	2.12-10.27
ARGO(athena+Google+FNY)	1.21	1.03-1.35

^aMean values of the error for each methodology are displayed as multiples of the error associated to the best ensemble approach (for which the efficiency is assigned to be 1).

^bARGO: autoregression with general online information.

^cFNY: Flu Near You.

Statistical Significance Test

Using the stationary block bootstrap for time series [34], we calculated the mean square error reduction of the ensemble method compared with all other models. The efficiency metrics and corresponding 95% confidence intervals are provided in Table 4. In the nowcast time horizon, our ensemble method shows a four-fold error reduction when compared with an autoregressive model, and a 17% (0.2/1.2) error reduction over the best multi-dataset model ARGO(athena+Google+FNY). The confidence intervals confirm the statistical significance of these results. Our ensemble method shows similar improvements in the forecast horizon as well.

Discussion

Indicators of Influenza Activity

Robust estimates of influenza activity in a population are desirable to monitor and prepare for unusual events. However, different sectors of the population in a local area behave differently, and thus, the incidence and dynamics of the spread of flu cannot be captured by a single system. Multiple influenza surveillance systems may provide valuable complementary information representing activity in multiple interacting populations within an area. For example, syndromic surveillance systems, such as the one set up by BPHC, provide the number of people seeking emergency care with ILI symptoms. We used BPHC %ILI as our reference for syndromic ILI in this paper,

because it has been well established and consistently reporting for several years. Previous analysis of the coordination between the BPHC ILI syndrome coding and official lab results has shown a correlation of 0.84, $P < 0.001$, with Boston viral isolate data [35]. On the other hand, crowd-sourced systems such as FNY, where only 35% of self-reported sick users visit a doctor [19], may help us understand influenza activity in populations that may not seek medical treatment or at times when weather activity, such as snowstorms, limits access to health care systems. The network of outpatient providers served by athenahealth characterizes yet another sector of the population. As such, there is no gold standard of influenza activity, and surveillance systems should be compared to identify if upward or downward trends are observed across them.

Analysis of Our Findings

Our study shows that novel influenza surveillance approaches that leverage information from Internet search engines, Twitter posts, self-reporting crowd-sourced influenza reports, and EHRs can monitor and forecast influenza activity as reported by a well-established metropolitan surveillance system, in near real-time. In terms of tracking the BPHC %ILI, our findings show that Google search frequency data and EHR information have strong predictive power. This confirms that these 2 data sources are valuable indicators of ILI activity, not only at the national and regional scales but also at spatial resolutions as small as the metropolitan level. Machine learning models based on these data sources outperform autoregressive models based

solely on past values of the BPHC %ILI time series, achieving lower error and higher correlations. Combining the above information and other data sources, such as FNY, using methods that dynamically learn from the past, results in strong performances in both monitoring and forecasting influenza activity.

Compared with previous studies at the national level, combining all data sources in a single model, specifically ARGO(athena+Google+FNY), does not show the same degree of precision or consistency at the metropolitan level. We believe that the finer spatial resolution of Boston compared with national and regional levels may be a limiting factor for the quality of some of the exogenous datasets used in this study, namely, Google Trends, Twitter, and FNY. As noted in previous studies, as we zoom in on finer spatial resolutions, we found that (1) Google search frequencies are more susceptible to noise from people who may search for flu-related terms but are not infected by the flu [30,36], (2) the accuracy of Twitter-based disease surveillance decreases as it becomes difficult to capture enough related Twitter posts to extrapolate an %ILI curve [37,38], and (3) FNY may have too few participants to infer meaningful population-wide flu incidence estimates, as Boston receives only around 300 reports per week. This can result in variables having inconsistent predictive strength over time and different seasons. Because ARGO selects variables for a week's regression based on predictive strength over the past 104 weeks, it may give worse estimations when, for example, a variable that performed strongly over the training set starts to perform poorly in the current season.

Ensemble approaches show promise for achieving robust results in situations where the performance of a single method over time is not robust. By allowing contributions from a group of different models, individual fluctuations of accuracy tend to be smoothed out. In an ideal situation where each model is valid but biased differently, the median is a robust way to lend equal weight to all models. In our case, where there are clear differences in overall predictive strength between models, we needed to apply a performance-based adjustment. Our proposed ensemble for the nowcast dynamically rewards the most accurate model and penalizes the least accurate model in an out-of-sample fashion each week. In the forecast horizon, however, the median approach was unsuccessful, suggesting that there are systematic biases (eg, all of the models overpredict in some weeks) that the median fails to correct for. However, a regression-based methodology, which was the best method for the forecast horizon, allows systematic error to be modeled and incorporated into the model, at the cost of being more susceptible to the original issue of overfitting on inconsistencies over the training set. (In this case, rather than a data source being inconsistent over time, it is the model produced on that data source that is inconsistent.) These trade-offs may explain why different methods were successful at each estimation horizon.

Models utilizing Google Trends information performed especially well compared with the naive method in the 2012-13 season but poorly in the subsequent season. The 2012-13 season notably featured a large outbreak of influenza, which led the naive and AR52 methods to perform especially poorly as their predictions tend to be lagged. In such a situation, Google Trends

data can improve the model by adding responsiveness. This situation is reflected in the nowcast heatmap (Figure 3), where the signal from AR1 disappears at the beginning of 2013, as the big influenza peak was occurring. At around the same time, athenahealth signal increased and remained consistent until 2016, suggesting that athenahealth increased its strength as a predictor of BHCP %ILI. This is supported by Table 1, where ARGO(athena) shows a steady decrease in RMSE from the 2012-2013 season until the 2015-2016 season. The overall improvement suggests that as athenahealth becomes further established, its predictive accuracy may continue to rise.

Using Influenza-Like Illness Incidence as the Target Variable

We chose to estimate %ILI visit rates as our target rather than attempt to infer diagnosed influenza incidence. On one hand, confirmed influenza case counts are useful for specifying transmission dynamic models and virology analysis. On the other hand, %ILI incidence serves a practical and actionable role by directly predicting the quantity of ILI visits that health care facilities may need to be prepared for. Preparedness is an increasingly significant task for public health and requires an epidemiology framework beyond outbreak detection, because influenza activity is not uniform across geographic areas and downward trends are equally important as upward trends for decision making. ILI nowcasting and forecasting at the local level can improve the timeliness, efficiency, and effectiveness of response and control measures. Examples include planning (long-term care management, changes in sick note requirements), recommendations regarding engineering controls (masking, cohorting), and enhanced information needs (antivirals, bed counts).

Limitations

As with any predictive method, the quality of past performance does not guarantee the quality of future performance. Additionally, the future performance of real-time flu estimates produced with our methodology depends directly on the timely availability and quality of the external data sources used as input. Our findings in the Boston metropolitan area are dependent on Google search volumes, Twitter posts, EHR information, crowd-sourced infection reports, and epidemiological data from the BPHC. Our team's previous experience nowcasting and forecasting flu activity at the national and regional levels during the past 3 flu seasons has shown us that data availability and acquisition challenges may lead to delays in our flu predictions and may affect the performance of our methods.

Conclusions

Because transmission happens on a local scale, city-level detection and monitoring can provide useful measures of influenza incidence and risk. Consistent detection on a smaller scale is subject to challenges, such as limitations in data availability; erratic incidence patterns influenced by local factors such as geography, weather, and population movement; and lower signal-to-noise ratio for data sources such as Internet search patterns and crowd-sourced influenza reporting systems. Nevertheless, we show that information from Internet-based

data sources, when combined using an informed, robust methodology, can be effectively used as early indicators of flu activity at fine geographic resolution. Successful real-time implementation of an ensemble-based approach to produce robust estimates in the Boston metropolitan area could inform future influenza modeling efforts in other cities.

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Conflicts of Interest

JG and AZ were employed by athenahealth when this study was conducted. The rest of the authors declare no conflicts of interest.

Multimedia Appendix 1

Comparison between Boston %ILI curve as reported by the Boston Public Health Commission (BPHC) and the US national %ILI as reported by the Centers for Disease Control and Prevention, over the past 5 years. Our best nowcast model for BPHC %ILI is displayed to show strength of fit.

[[PDF File \(Adobe PDF File\), 20KB - publichealth_v4i1e4_app1.pdf](#)]

Multimedia Appendix 2

Data processing details for athenahealth and Google Trends.

[[PDF File \(Adobe PDF File\), 78KB - publichealth_v4i1e4_app2.pdf](#)]

Multimedia Appendix 3

ARGO model formulation and implementation details.

[[PDF File \(Adobe PDF File\), 85KB - publichealth_v4i1e4_app3.pdf](#)]

Multimedia Appendix 4

Details of ensemble methods, including input model layer and comparison of various ensemble predictors.

[[PDF File \(Adobe PDF File\), 76KB - publichealth_v4i1e4_app4.pdf](#)]

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Abbreviations

API: application programming interface
ARGO: autoregression with general online information
BPHC: Boston Public Health Commission
CDC: Centers for Disease Control and Prevention
COI: correlation of increment
CORR: Pearson correlation coefficient
ED: emergency department
EHRs: electronic health records
FNY: Flu Near You
GFT: Google Flu Trends
ILI: influenza-like illness
MAE: mean absolute error
MAPE: mean absolute percentage error
RMSE: root mean square error
SIR: susceptible-infected-recovered

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Original Paper

Monitoring Freshman College Experience Through Content Analysis of Tweets: Observational Study

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Abstract

Background: Freshman experiences can greatly influence students' success. Traditional methods of monitoring the freshman experience, such as conducting surveys, can be resource intensive and time consuming. Social media, such as Twitter, enable users to share their daily experiences. Thus, it may be possible to use Twitter to monitor students' postsecondary experience.

Objective: Our objectives were to (1) describe the proportion of content posted on Twitter by college students relating to academic studies, personal health, and social life throughout the semester; and (2) examine whether the proportion of content differed by demographics and during nonexam versus exam periods.

Methods: Between October 5 and December 11, 2015, we collected tweets from 170 freshmen attending the University of California Los Angeles, California, USA, aged 18 to 20 years. We categorized the tweets into topics related to academic, personal health, and social life using keyword searches. Mann-Whitney *U* and Kruskal-Wallis *H* tests examined whether the content posted differed by sex, ethnicity, and major. The Friedman test determined whether the total number of tweets and percentage of tweets related to academic studies, personal health, and social life differed between nonexam (weeks 1-8) and final exam (weeks 9 and 10) periods.

Results: Participants posted 24,421 tweets during the fall semester. Academic-related tweets (n=3433, 14.06%) were the most prevalent during the entire semester, compared with tweets related to personal health (n=2483, 10.17%) and social life (n=1646, 6.74%). The proportion of academic-related tweets increased during final-exam compared with nonexam periods (mean rank 68.9, mean 18%, standard error (SE) 0.1% vs mean rank 80.7, mean 21%, SE 0.2%; $Z=-2.1$, $P=.04$). Meanwhile, the proportion of tweets related to social life decreased during final exams compared with nonexam periods (mean rank 70.2, mean 5.4%, SE 0.01% vs mean rank 81.8, mean 7.4%, SE 0.01%; $Z=-4.8$, $P<.001$). Women tweeted more often than men during both nonexam (mean rank 95.8 vs 76.8; $U=2876$, $P=.02$) and final-exam periods (mean rank 96.2 vs 76.2; $U=2832$, $P=.01$). The percentages of academic-related tweets were similar between ethnic groups during nonexam periods ($P>.05$). However, during the final-exam periods, the percentage of academic tweets was significantly lower among African Americans than whites ($\chi^2_4=15.1$, $P=.004$). The percentages of tweets related to academic studies, personal health, and social life were not significantly different between areas of study during nonexam and exam periods ($P>.05$).

Conclusions: The results suggest that the number of tweets related to academic studies and social life fluctuates to reflect real-time events. Student's ethnicity influenced the proportion of academic-related tweets posted. The findings from this study provide valuable information on the types of information that could be extracted from social media data. This information can be valuable for school administrators and researchers to improve students' university experience.

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KEYWORDS

social networking; big data; population surveillance; education; students; social media; Twitter

Introduction

The first year of university is a critical period for students to get acclimated to the postsecondary environment [1]. Studies have shown that students' success is largely influenced by their freshman experiences (eg, academic studies, personal health, and social life) during their first year [1,2]. However, traditional methods of monitoring the freshman experience, such as conducting surveys, can be resource intensive and time consuming. Reports of students' experiences may not be available until the following semester [3]. Consequently, this can significantly limit the ability of schools to understand students' experiences in real time and rapidly offer assistance to help improve the students' experiences.

Social media technology may be well suited to address this challenge. Use of social media, such as Twitter, has been rapidly growing among postsecondary students [4]. In the past 3 years, Twitter use among college students in the United States has increased by 20% [4]. Users often share their daily lives on these social media platforms and, as a result, social media data may be used to provide useful information about student experiences. However, to our knowledge, no studies have examined how frequently postsecondary students talk about topics related to academic studies, personal health, and social life on Twitter. Furthermore, little is known about whether these topic discussions differ by demographics (eg, sex, ethnicity, and major area of study) or whether the topic discussion changes throughout the semester (eg, nonexam vs exam periods). Understanding the types of content and frequency of content discussion is an important first step to determining whether it is feasible to use Twitter data to monitor students' college experience in real time. Therefore, the primary objective of this study was to describe the proportion of content posted on Twitter by college students relating to academic studies, personal health, and social life throughout the semester. The secondary objective was to examine whether the proportion of content differed by demographics and during nonexam versus exam periods.

Methods

Overview

This was an observational study that took place from September 21, 2015 to December 11, 2015. We recruited 197 first-year undergraduate freshman students at the University of California Los Angeles (UCLA), California, USA, aged 18 to 20 years. A total of 170 participants were active Twitter users who posted at least 3 tweets per week, and they were included in the analysis. We obtained ethics approval from the UCLA Research Ethics Board.

Recruitment and Study Protocol

We recruited participants from September 21 to October 4, 2015. Participants were informed about the study through flyers on social media websites and on the UCLA campus. Eligible participants who provided consent were asked to complete an

online questionnaire that assessed their demographic characteristics, which included age, sex, ethnicity, and area of study. Participants were asked to share their Twitter handle. We extracted all participants' tweets from October 5 to December 11, 2015, for analysis using the Twitter streaming application program interface.

Content Analysis

We converted data to lowercase and removed punctuation. We then stemmed all words to remove suffixes; for example, "studied" and "studying" simply became "study." All English stop words were also removed from the data. Any retweeted tweets using the notation "RT" were excluded to prevent popular posts or spam from saturating the sample. Only English tweets were included in our analyses. We then created an algorithm that counted the most frequently used words. Using an iterative process, we manually categorized the words into topic contents related to academic, personal health, and social life. Each tweet was then classified, using a search algorithm, into the topics if it contained at least one keyword. The topics were nonmutually exclusive. A sample of randomly selected (20%) tweets was manually checked to ensure they were accurately related to the categories.

Statistical Analysis

We used descriptive statistics to tabulate types of tweets. Our data were not normally distributed; thus, we used nonparametric statistics that compare mean ranks rather than medians to compare differences between groups. Specifically, we used the Mann-Whitney *U* and Kruskal-Wallis *H* tests to examine whether the posted content differed by sex, ethnicity, and major. The Friedman test was used to determine whether the total number of tweets and percentage of tweets related to academic studies, personal health, and social life differed between nonexam (weeks 1-8) and final-exam (weeks 9 and 10) periods. To protect against type I error, we used the Bonferroni adjustment for post hoc comparison. Statistical significance was defined by a 2-tailed test with a *P* value <.05. All analyses were performed using IBM SPSS 20.0 (IBM Corporation).

Results

Participants

A total of 170 participants (women: 104, 61.2%) were included in our analysis. The mean age was 18.1, standard deviation (SD) 0.34 years. There was a wide range of distribution for ethnicity (white: *n*=33, 19.4%; African American: *n*=22, 12.9%; Latino: *n*=50, 29.4%; Asian: *n*=43, 25.3%; other minorities: *n*=27, 15.9%). The areas of study were health science (*n*=78, 45.9%), business (*n*=16, 9.4%), mathematics and engineering (*n*=21, 12.4%), social science and arts (*n*=30, 17.6%), and undeclared (*n*=30, 17.6%).

Tweet Content During the Semester

There were 24,421 tweets posted during the fall semester (October 5 to December 13; Figure 1). The mean number of

tweets posted per participant throughout the fall semester was 138 (SD 210, range 3-1310). **Table 1** displays the 10 most frequently used keywords related to academic study, personal health, and social life. Most of the participants tweeted about personal health, academic study, and social life. Specifically, we extracted tweets related to academic study, personal health, and social life-related tweets from 94.7% (n=161), 87.6% (n=149), and 94.1% (n=160) of the participants, respectively. **Figure 2** shows the total percentage of weekly tweets related to academic study, personal health, and social life throughout the semester. Overall, academic-related tweets (n=3433, 14.06%) were the most prevalent during the entire semester, compared with tweets related to personal health (n=2483, 10.17%) and social life (n=1646, 6.74%). Since categories were not mutually exclusive, some tweets contained keywords from multiple categories. The overall overlap between all the categories was low: academic and social life overlap: 4.43% (n=223 tweets); academic and personal health overlap: 3.72% (n=446 tweets);

social life and personal health overlap: 7.41% (n=308 tweets); and academic, social, and personal health overlap: 0.64% (n=49 tweets). We found that significantly fewer weekly tweets were posted during the final-exam period than the rest of the semester (final-exam weeks: mean rank 78.6, mean 13.3, standard error (SE) 1.5; nonfinal-exam weeks: mean rank 96.4, mean 14.0, SE 1.7; $Z=-2.0$, $P=.04$). The proportion of academic-related tweets increased during final-exam period compared with nonexam periods (final-exam weeks: mean rank 68.9, mean 18%, SE 0.1%; nonexam weeks: mean rank 80.7, mean 21%, SE 0.2%; $Z=-2.1$, $P=.04$). Meanwhile, the proportion of tweets related to social life decreased during final exams compared with nonexam periods (final-exam weeks: mean rank 70.2, mean 5.4%, SE 0.01%; nonfinal weeks: mean rank 81.8, mean 7.4%, SE 0.01%; $Z=-4.8$, $P<.001$). We found no significant difference for the proportion of personal health-related tweets between the final-exam and nonfinal-exam periods.

Figure 1. Total number of tweets throughout the semester (October 5 to December 13, 2015).

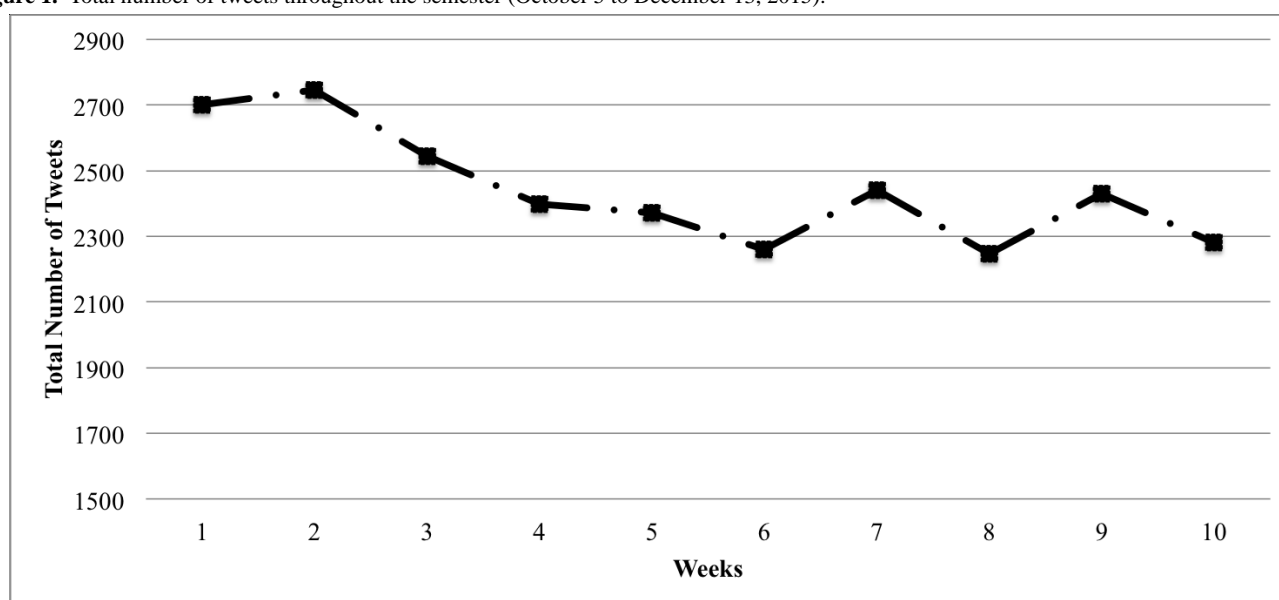
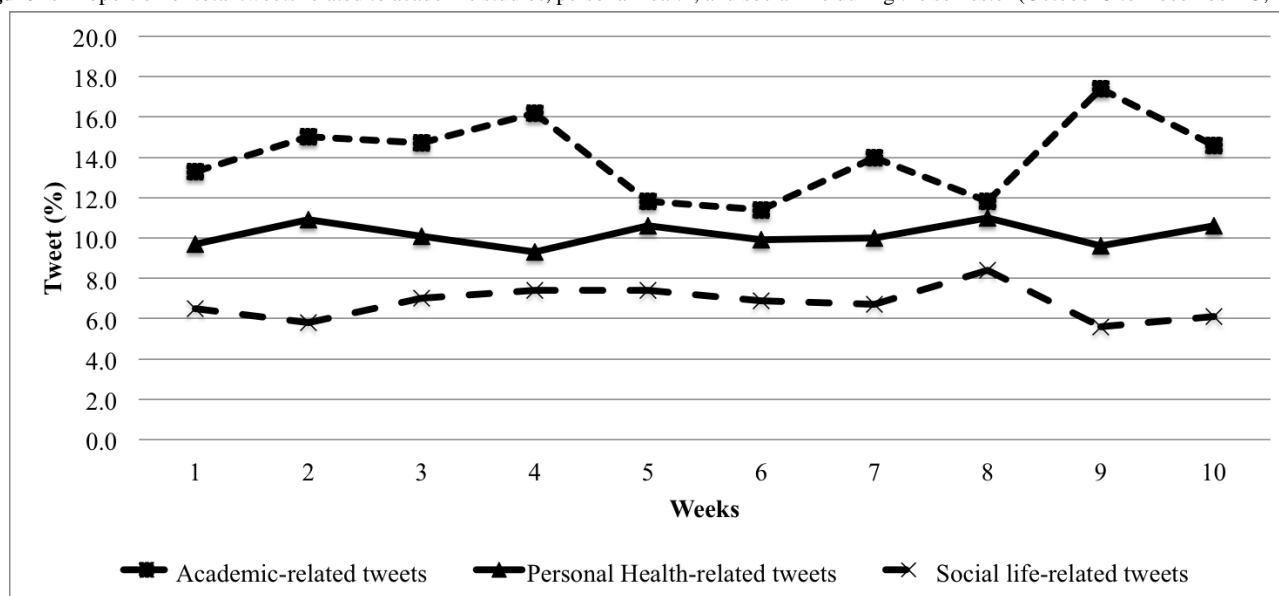


Table 1. The 10 most popular words in tweets associated with each category.

Rank	Academic study		Personal health and lifestyle		Social life	
	Word	Frequency	Word	Frequency	Word	Frequency
1	Class	634	Sleep	375	Friends	373
2	College	403	Running	163	Birthday	290
3	School	368	Stress	100	Music	156
4	Final	350	Sick	90	Weekend	153
5	Midterm	322	Hurt	70	Chill	132
6	Study	260	Walking	62	Party	113
7	Work	227	Gym	61	Friday	104
8	Quarter	225	Healthy	48	Concert	58
9	Essay	210	Workout	25	Drunk	54
10	Paper	182	Weights	14	Sex	24

Figure 2. Proportion of total tweets related to academic studies, personal health, and social life during the semester (October 5 to December 13, 2015).**Table 2.** Weekly number of tweets posted during nonexam and exam periods by participants, by sex, ethnicity, and area of study.

Characteristics	Nonexam period (weeks 1-8)			Exam period (weeks 9 and 10)		
	Mean	SE ^a	Range	Mean	SE	Range
Sex						
Female	14.7	11.9	0-90	14.9	2.1	0-98
Male	12.8	13.0	0-148	10.8	2.2	0-96
Ethnicity						
White	7.0	2.3	0-77	7.6	2.7	0-83
African American	23.4	5.9	0-93	17.5	3.3	0-95
Latino	19.0	14.0	0-148	17.3	4.2	0-84
Asian	10.5	12.8	0-114	9.8	2.6	0-94
Other minorities	12.3	12.8	0-48	15.8	5.3	0-98
Area of study						
Health science	14.3	12.4	0-113	14.6	2.3	0-94
Business	16.1	7.4	0-93	14.4	7.2	0-92
Mathematics and engineering	9.1	2.1	1-33	8.3	1.9	0-31
Social science and arts	19.0	5.3	0-148	16.8	4.0	0-98
Undeclared	11.1	3.4	0-88	9.4	3.6	0-95

^aSE: standard error.

Sex and Tweet content

Women tweeted more often than men during both nonexam (women: mean rank 95.8; men: mean rank 76.8; $U=2876$, $P=.02$) and final-exam periods (women: mean rank 96.2; men mean rank 76.2; $U=2832$, $P=.01$; [Table 2](#)). However, during both nonexam and exam periods, the proportion of the tweets related to academic studies (nonexam: women's mean rank 83.7, men's

mean rank 96.1, $U=3157$, $P=.12$; exam: women's mean rank 77.4, men's mean rank 84.7, $U=2618$, $P=.34$), personal health (nonexam: women's mean rank 83.7, men's mean rank 96.1, $U=3157$, $P=.12$; exam: women's mean rank 75.8; men's mean rank 87.7, $U=2451$, $P=.11$), and social life (nonexam: women's mean rank 89.6, men's mean rank 96.7, $U=3549$, $P=.78$; exam: women's mean rank 80.1, men's mean rank 80.0, $U=2878$, $P=.98$) were similar between the sexes ([Table 3](#)).

Table 3. Weekly percentage of tweets posted during nonexam and exam periods by participants, by sex, ethnicity, and area of study.

Characteristics	Academic tweets, mean % (SE) ^a		Personal health tweets, mean % (SE)		Social life tweets, mean % (SE)	
	Nonexam period	Exam period	Nonexam period	Exam period	Nonexam period	Exam period
Sex						
Female	16.1 (1)	19 (1.9)	10.2 (1)	8.2 (0.9)	7.6 (0.6)	5.0 (1)
Male	20 (2)	24 (3.3)	11 (0.9)	12.3 (2.2)	7.0 (0.7)	6.2 (2)
Ethnicity						
White	19 (2.4)	32 (0.5)	10.4 (1.1)	6.7 (1.6)	8.9 (1.1)	7.4 (2.9)
African American	16.5 (0.2)	12 (3)	10.1 (1.1)	6.9 (1.4)	8.2 (1.6)	5.9 (1.5)
Latino	20 (2.4)	18.7 (2.1)	11.5 (1)	11.2 (2.0)	7.5 (1.0)	6.5 (1.8)
Asian	18 (1.6)	23 (3.9)	9.2 (0.8)	11.4 (2.8)	5.3 (0.5)	2.5 (0.6)
Other minorities	12 (2.0)	15.1 (4.5)	10.0 (2.6)	10.1 (2.7)	7.8 (1.1)	4.9 (1.9)
Areas of study						
Health science	11.5 (1.0)	18.8 (1.7)	11.5 (1.0)	11.5 (1.9)	6.8 (1.1)	6.6 (1.4)
Business	10.0 (2.1)	20.2 (0.4)	10.0 (2.1)	2.7 (1.2)	7.9 (1.1)	2.2 (1.2)
Mathematics and engineering	9.3 (0.8)	21 (2.5)	9.3 (0.8)	7.4 (1.7)	7.9 (1.2)	4.9 (2.0)
Social science and arts	8.1 (0.7)	13 (1.6)	8.0 (0.7)	5.7 (1.1)	6.9 (1.2)	6.5 (2.6)
Undeclared	10 (1.4)	15.5 (2.3)	10.4 (1.4)	14.5 (2.6)	7.2 (1.0)	4.9 (2.0)

^aSE: standard error.

Ethnicity and Tweet Content

African Americans tweeted most frequently compared with other ethnic groups during both nonexam ($\chi^2_4=13.3$, $P=.01$) and exam periods ($\chi^2_4=11.1$, $P=.03$; [Table 2](#)). Interestingly, the percentages of academic-related tweets were similar between the ethnic groups during nonexam periods ($\chi^2_4=7.3$, $P=.12$). However, during the final-exam periods, the percentage of academic tweets was significantly lower among African Americans than among whites ($\chi^2_4=15.1$, $P=.004$). The proportion of academic-related tweets decreased only among African Americans and Latinos during the exam period compared with the nonexam period. During nonexam and exam periods, the percentages of tweets related to personal health (nonexam: $\chi^2_4=8.9$, $P=.08$; exam: $\chi^2_4=3.8$, $P=.43$) and social life (nonexam: $\chi^2_4=7.3$, $P=.11$; exam: $\chi^2_4=6.9$, $P>.13$) were not significantly different between ethnic groups ([Table 2](#)).

Area of Study and Tweet Content

Students in social science and arts had the highest number of weekly tweets throughout the semester compared with participants in other majors. However, the mean difference was not significant ($\chi^2_4=3.5$, $P=.48$). During nonexam and exam periods, the percentages of tweets related to academic studies (nonexam: $\chi^2_4=7.5$, $P=.11$; exam: $\chi^2_4=9.1$, $P=.06$), personal health (nonexam: $\chi^2_4=4.4$, $P=.35$; exam: $\chi^2_4=4.6$, $P=.30$), and social life (nonexam: $\chi^2_4=3.0$, $P=.55$; exam: $\chi^2_4=5.2$, $P=.27$)

were not significantly different between areas of study ([Table 3](#)).

Discussion

Principal Findings

This study examined the content of the tweets of college freshman throughout a single semester. To our knowledge, this is the first study that examined the types of social media content posted and the frequency of content discussed among college freshmen. These results could have several important implications for academic researchers and school administrators.

First, our results suggest that the number of tweets related to academic studies and social life fluctuates to reflect real-time events. The proportion of academic tweets increased while the proportion of tweets related to social life decreased during the exam period compared with the nonexam period. This change in the proportion of tweets reflects the types of activities that students are experiencing at these different points in time and thus suggests that it may be possible to monitor students' college experience through the study of their tweets. Previous studies have shown that the analysis of tweet sentiment (positive, negative, or neutral) can be used to monitor user experience [5-7]. A possible future application to monitoring student experience in real time is to combine the Twitter analytic methods used in this study with sentiment analysis. For example, tweets related to academic studies, personal health, or social life could be extracted. Sentiment analysis could then be applied to the categories to determine whether an individual's attitude toward or perception of that category (eg, academic study or

personal health) is positive, negative, or neutral. This study provides preliminary evidence to suggest that Twitter data can be used to monitor students' experience related to academic study, personal health, social life. Future studies in this area are warranted.

Second, our results suggest that students' ethnicity influenced the proportion of academic-related tweets they posted. During exam periods, African American students tweeted significantly less about academic studies than did white students, even though African American students tweeted more often in total than other ethnic groups. The difference in academic-related content may suggest academic disengagement [8]. Previous studies have shown that African Americans and Latinos have underperformed compared with white students due to factors such as differences in cultural patterns or socioeconomic status [9-11]. Social media data can offer an alternative method to study the influence of ethnicity and academic disengagement by providing another tool for understanding organic, real-time data on racial and ethnic differences. Furthermore, talking about academic studies on social media may be a way for students to share their academic experience and cope with academic-related stress. Previous studies have found that Latinos are more likely than whites to turn to family and friends for coping with academic-related stress [1,12]. Therefore, the difference in coping strategy (eg, family, friends, and online) between ethnic groups could be a contributing factor to differences in the academic-related tweets we observed. A potential future application for academic researchers and school administrators is to use social media to understand student behavior and engage with the students to promote academic studies.

Third, the overall number of weekly tweets of individual students related to academic studies, personal health, and social life remained relatively low, and the data were sparse. This means that a longer period of data collection would be required to reach a sufficient sample size to monitor students' college experience on an individual level. The optimal amount of time required for data collection remains unclear. De Choudhury et al [13] conducted one of the first studies that used an individual's tweets to predict risk of depression. The authors collected Twitter data over a 1-year period to build a model that was able to monitor and predict risk of depression in adults. Despite the small sample size and sparse data on an individual level observed in our study, Twitter data could be well suited to monitor students' college experience on a population level. Study participants (n=170) posted between 100 and 300 weekly tweets related to academic study, personal health, and social life. A previous study found that the number of tweets related to risky sexual behavior and drug use was associated with HIV prevalence on a countywide level in the United States [14]. Similarly, tweets related to physical activity were negatively

associated with obesity rates on a countywide level [15]. Academic researchers and school administrators could use similar methods to monitor students' college experience by combining other data sources (eg, grade point average or stress level) with Twitter data. Future studies need to examine whether this method could offer real-time information on students' college experience that school administrators and researchers could use to help improve this experience.

Limitations

The study was not without limitations. We collected data during freshmen's first semester at one university, and this was because this study was part of a larger study in which only freshman students were recruited. It is possible that the types and frequency of content expressed by students in other universities or upper years would be different. The students were aware that their tweets were being collected for research, which may have led to a bias in the form of self-censoring during the study period. Furthermore, 25% of Internet users are registered on Twitter [16]. It may be possible that these users differ from non-Twitter users in demographic characteristics, cultural background, or socioeconomic status. Nevertheless, the sample that we collected in this study included a wide range of ethnic groups and study majors. These factors need to be taken into consideration to ensure that Twitter content analyses are generalizable. Additionally, we were able to categorize up to 34% of all tweets into categories of academic studies, personal health, and social life by using keyword searches. It is possible that we missed certain tweets by excluding other keywords from our analyses. Future studies should also examine other topic modeling methods such as latent Dirichlet allocation.

Conclusion

The ability to use social media data to provide real-time information on students' postsecondary experience has significant implications for universities and school administrators. In this study, we found that it is feasible to extract tweets related to academic studies, personal health, and social life posted by college freshmen. The proportion of academic-related tweets increased, while tweets related to social life decreased during the exam period versus nonexam period. Finally, ethnicity influenced the types of tweet content. Specifically, during the exam period, African Americans tweeted less content related to academic studies than did whites. The findings from this study provide valuable information on the types of information that could be extracted from social media data posted by postsecondary students. Future studies need to examine whether school administrators and researchers may use this method combined with other Twitter analysis techniques (eg, sentiment analysis) to monitor students' university experience in real time.

Conflicts of Interest

None declared.

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Abbreviations

SD: standard deviation

SE: standard error

UCLA: University of California Los Angeles

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Original Paper

Associations of Topics of Discussion on Twitter With Survey Measures of Attitudes, Knowledge, and Behaviors Related to Zika: Probabilistic Study in the United States

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Abstract

Background: Recent outbreaks of Zika virus around the world led to increased discussions about this issue on social media platforms such as Twitter. These discussions may provide useful information about attitudes, knowledge, and behaviors of the population regarding issues that are important for public policy.

Objective: We sought to identify the associations of the topics of discussions on Twitter and survey measures of Zika-related attitudes, knowledge, and behaviors, not solely based upon the volume of such discussions but by analyzing the content of conversations using probabilistic techniques.

Methods: Using probabilistic topic modeling with US county and week as the unit of analysis, we analyzed the content of Twitter online communications to identify topics related to the reported attitudes, knowledge, and behaviors captured in a national representative survey (N=33,193) of the US adult population over 33 weeks.

Results: Our analyses revealed topics related to “congress funding for Zika,” “microcephaly,” “Zika-related travel discussions,” “insect repellent,” “blood transfusion technology,” and “Zika in Miami” were associated with our survey measures of attitudes, knowledge, and behaviors observed over the period of the study.

Conclusions: Our results demonstrated that it is possible to uncover topics of discussions from Twitter communications that are associated with the Zika-related attitudes, knowledge, and behaviors of populations over time. Social media data can be used as a complementary source of information alongside traditional data sources to gauge the patterns of attitudes, knowledge, and behaviors in a population.

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KEYWORDS

Zika; Twitter; topic modeling; public policy; public health

Introduction

Outbreaks of Zika virus in 2016 in various areas of the world [1] led to increased communications about this issue on Twitter and other social media platforms. These communications may provide digital markers of attitudes, behaviors, and knowledge in a population, thus supplying an easily accessible thermometer of variations in psychological responses that are important for

public policy. In this paper, our objective was to identify these markers by correlating Twitter data with survey measures of attitudes, behaviors, and knowledge in a representative sample of the US adult population.

Studying attitudes, knowledge, and behaviors has a longstanding theoretical interest. People’s attitudes and knowledge about the world allow them to make behavioral decisions and avoid public health threats throughout the course of their lives. An attitude

is regarded as an evaluation of an object as positive or negative [2-3]. For example, an attitude relevant to Zika may entail favoring policies that can reduce infection, such as spraying. These attitudes may be linked to knowledge—factual information about the life cycle of the *Aedes* mosquitos and types of transmission of the Zika virus, for example. Attitudes may be assessed with semantic differential, Likert, or other items tapping evaluations, whereas knowledge measures involve true/false determinations about factual statements about Zika. Attitudes and knowledge as well as behaviors such as repellent use or calls for action on Congress are classic psychological responses to public health information [3]. In decision making and behavior studying, theories of reasoned action [4] and planned behavior [5] specify a limited number of psychological variables that influence a behavior: (1) intention, (2) attitude toward behavior, (3) subjective norms, and (4) perceived behavioral control. Also, there are studies that have investigated the relationships among knowledge, belief, and behavior [6-7] and studies that involve social media along with other psychological variables [8].

Designing a health communication strategy often requires an understanding of how messages may be linked to the attitudes, knowledge, and behaviors of an audience. With the advent of online communication technologies, this understanding can be derived from the analysis of social media data. Twitter, for example, has been used to predict the age, gender, and political orientation [9-13], level of depression [12], and emotions and attitudes [9] of social media users. The work of De Choudhury et al [12] has discovered that those with major depressive disorder have less Twitter activity and higher self-attentional focus and express greater negative emotion, relational and medical concerns, and a greater number of religious thoughts. Also, an analysis of Facebook postings in relation to personality found variations in language with respect to personality, age, and gender [14]. This research suggests that Twitter may be useful in identifying discussion topics in the Zika domain as well.

In this study, we investigated the possibility of discovering topics of discussion on Twitter that are related to the ongoing public health challenge of Zika virus and whether their variations reveal important information regarding changes of Zika-related attitudes, knowledge, and behaviors of populations over time. To discover the topics of discussion, we used probabilistic topic modeling techniques and examined different weighting schemes (binary, term occurrence, and term frequency-inverse document frequency [tfidf]) on the learned models.

Methods

Overview

We examined Twitter data to identify topics in the content of the online communications that were about Zika. Employing latent Dirichlet allocation (LDA), we analyzed tweets aggregated based on location information and used the learned models to infer the probability of occurrence of each topic over time using weekly aggregated test tweets. To train the topic models, different weighting schemes (binary, term occurrence, and tfidf) were compared to find the model with the best weighting

scheme. We then explored the associations of topics that showed variability over time with weekly aggregated measures of Zika attitudes, knowledge, and behaviors obtained from a survey representing the US adult population. The resulting correlations were used to describe the topics of discussion associated with the psychological measures of our samples.

Twitter Data

Our Zika corpus was collected from the Twitter network by searching for a set of Zika-related keywords (“Zika,” “dengue,” “yellow fever,” “Zika virus,” “Zika fever,” “flaviviridae,” “brain shrink,” “fetal brain disruption sequence,” “mosquitoes,” “birth defects,” “insect bites,” “mosquito bites,” “insect-borne virus,” “mosquito-borne virus,” “microcephaly,” and “Guillain-Barre syndrome”) using Twitter streaming application programming interface. The resulting dataset contains 3.8 million tweets from February 1, 2016, to August 30, 2016. Using location information, we were able to map about 10% of all the tweets in our corpus into 2695 different US counties. The rest of the tweets (the other 90%) were aggregated using the timestamp information of each tweet, assigning each to weekly documents. We aggregated tweets for the weeks of February 16, 2016, to August 18, 2016, to match the survey data described next.

Survey Data

The Annenberg Public Policy Center of the University of Pennsylvania designed and carried out a survey of attitudes, knowledge, and behaviors relevant to Zika virus over 33 weeks (N=33,193). Table 1 summarizes the attitude, knowledge, and behavior questions that were asked of the participants each week. Each week, a dual-frame sample was designed to represent the adult US population (including Hawaii and Alaska). A fully replicated, single-stage, random-digit-dialing sample of landline telephone households, along with randomly generated cell phone numbers, was employed. Each weekly wave consisted of 1000 interviews of which at least 600 were obtained from cell phone respondents. Within each landline household, a single respondent (the youngest adult) was selected. Because the interview could take place outside the respondent’s home, cell phone respondents were considered separately from landlines. Surveys were conducted in 5-day intervals, in English and Spanish, typically from Wednesday through Sunday to include both weekdays and weekends.

Each weekly wave was weighted to provide nationally representative and projectable estimates of the adult population 18 years of age and older. The weighting process took into account the disproportionate probability of household and respondent selection due to the number of separate telephone landlines and cell phones answered by respondents and their households, as well as the probability associated with the random selection of an individual household member. Following application of the weights, the sample was post-stratified and balanced by the key demographics of age, race, sex, region, and education. The sample was also weighted to reflect the distribution of phone usage in the general population, meaning the proportion of those who are cell phone only, landline only, and mixed users (see Multimedia Appendix 1 for more details regarding the survey design and data collection method). Our data included 51.61% females, 39.58% college-educated

participants (14.88% with some college and 45.54% with high school education or less), 37.21% living in regions at risk for Zika virus, 45.99% aged 18 to 44 years (17.68% ages 45 to 54 years and 36.33% aged 55 years or older), and 5.57% with current/intended pregnancy. The average response rate over the weeks was 7.50%, a figure comparable to that of other national surveys conducted in the United States [15-16].

Data Analysis

We analyzed the content of a sample of communications from Twitter (within a 10-month time span) following the process depicted in Figure 1.

We analyzed the sampled tweets using the topic modeling of LDA [17] to uncover topics that users addressed in their communications. This method is a probabilistic way to discover salient patterns (topics) in a collection of text documents; along with its multiple variations, this approach has been used to analyze long news articles, blogs, and scientific papers in various domains [18]. However, optimal applications of LDA to Twitter data deserve further attention because a single tweet is short (140 characters), uses informal language, and contains misspellings, emoticons, acronyms, and nonstandard abbreviations, as well as Twitter names, hashtags, and URLs.

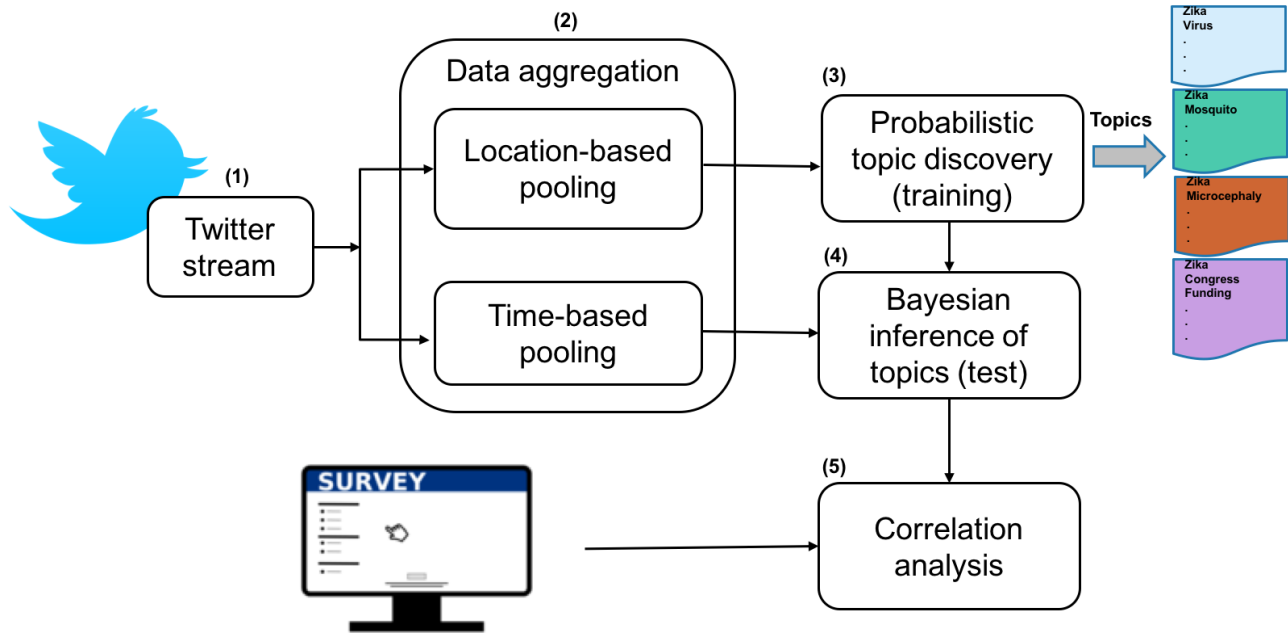
When LDA-based methods are applied directly to posts from microblogging platforms (considering each single tweet as a document), which are usually short and often noisy, these methods result in topics that are uninformative and hard to interpret [19]. To improve the performance of topic modeling of tweets, we incorporated 2 aggregation techniques (Figure 1, phase 2). In order to amass a sufficient number of documents in our training set and generate longer documents, before learning the topic models we created a document for each county

in the United States by aggregating all tweets of a county. Not all tweets and Twitter accounts are associated with location information. Typically, 1% of Twitter users have enabled the geocoordinate mobile device service, which tags each tweet with their current geocoordinates [20]. Additionally, some Twitter users have completed the free response location field in their Twitter account profile. For the tweets that contain geolocation coordinates, we found the county corresponding to the coordinates. In addition to using the precise coordinates to locate counties, we geotagged tweets based on the location field when information about a city/state pair or a city name was included. These methods have been described elsewhere [20-21] and were used to generate the training set of tweets. The testing set used in analyses (Figure 1, phase 2) included the tweets that did not have any location information, which comprised 90% of our corpus. Using the timestamp information of each tweet, all tweets created in a week were merged into a single document.

We first applied LDA to the tweets pooled by location that constituted our training data to discover topics from the online communications (Figure 1, phase 3). Within each topic, some terms have high probabilities, whereas others have low ones. After discovering the topics, the proportion of each topic for a particular week document was calculated using Bayesian inferences from the learned models (Figure 1, phase 4). To accomplish this, we used the documents in our test set that were pooled weekly based on their timestamp information. This modeling resulted in a signal indicating the variation of each topic over time. We then correlated the extracted topics with our survey items (Figure 1, phase 5). Each item measuring attitudes, knowledge, and behaviors was averaged for a particular week, and these averages were then correlated with the variation of topics over weeks.

Table 1. Attitudes, knowledge, and behavior questions.

Category and survey item	Survey question
Attitude	
ZI-22	If there were cases of people getting infected with Zika virus in your city or town, would you approve or disapprove of special spraying at the ground level against mosquitoes to prevent the spread of the Zika virus (on a scale 1=strongly disapprove to 5=strongly approve)?
ZI-23	If there were cases of people getting infected with the Zika virus in your city or town, would you approve or disapprove of special spraying from the air against mosquitoes to prevent the spread of the Zika virus (on a scale 1=strongly disapprove to 5=strongly approve)?
Knowledge	
ZG-03b	How do scientists think someone can get the Zika virus? By sitting next to someone who has the Zika virus (on a scale 1=not likely at all to 4=very likely).
ZG-03c	How do scientists think someone can get the Zika virus? By being bitten by a mosquito that has already bitten someone who has the Zika virus (on a scale 1=not likely at all to 4=very likely).
ZG-05	How accurate is it to say that a pregnant woman who is infected with the Zika virus is more likely to have a baby with an unusually small head and brain (on a scale 1=not accurate at all to 4=very accurate)?
Behavior	
ZG-47	If there were a vaccine that protected you from getting Zika how likely, if at all, is it that you would get the vaccine (on a scale 1=not likely at all to 4=very likely)?
ZG-54	In the past 3 months, have you done anything to protect yourself from getting Zika (on a scale 0 to 1)?
GM-20	In the past week, how many days, if any, did you discuss the effects of the Zika virus with family or friends (on a scale 0 to 7)?

Figure 1. Flow of data processing and analyses.**Figure 2.** The perplexity formula used to compare the probability models. The log-likelihood of a set of held-out documents can be calculated and used for comparing the models.

$$L(W_{test}) = \log p(W_{test} | \alpha, \Psi) = \sum_{d \in W_{test}} \log p(d | \alpha, \Psi)$$

$$\text{Perplexity}(W_{test}) = \exp \left\{ - \frac{L(W_{test})}{\text{Size of the vocabulary}} \right\}$$

LDA uses the bag-of-words approach and represents each document using a vector with the dimension of the considered vocabulary size. To examine the impact of various weighting schemes on the topic models, we compared 3 popular weighting schemes: binary, term occurrence, and tfidf representations. Topic models are probability models for a collection of documents. One approach to evaluate probability models involves comparing how well they model a held-out test set. A trained topic model is described by topic matrix Ψ and hyper parameter α for topic distribution of documents. Given those parameters, the log-likelihood of a set of held-out documents can be calculated and used for comparing the models. Traditionally, the perplexity of a model can be calculated as illustrated (see [Figure 2](#)), which shows a decreasing function of the log-likelihood of the held-out test set—the lower the perplexity, the better the model.

Results

Identification of Optimal Modeling Parameters

For different numbers of topics ($k=5, 10, 15, 20, 30, 40, 50, 100, 150,$ and 200) and the 3 different weighting schemes

(binary, term occurrence, and tfidf), we trained topic models and calculated the perplexity of the held-out test set using Bayesian inference. As mentioned before, perplexity is a common measure used to compare different probability models. The lower the perplexity on the test set, the better the model. As [Figure 3](#) shows, the perplexity of the trained models with term occurrence weighting scheme is lower than the binary and tfidf weighting schemes. Thus, we decided to use term occurrence representation as the weighting scheme for the rest of the study.

Probabilistic Topic Discovery

To qualitatively demonstrate the discovered topics using different topic models with $k=100, 150,$ and 200 , [Table 2](#) represents each topic with its top 10 most probable terms. The topics in [Table 2](#) reveal that many of the Zika-related issues such as “mosquito,” “pregnancy,” “microcephaly,” “dengue,” “Congress act for Zika funding,” “insect repellent,” “Florida,” “Miami,” “Brazil,” and “Puerto Rico” are discoverable through analysis of the content of the communications using topic modeling.

Figure 3. Comparison of weighting schemes (binary, term occurrence, and term frequency–inverse document frequency [tfidf]) for a vocabulary size of 8200. Perplexity of the held-out test set is the lowest for the term occurrence weighting scheme.

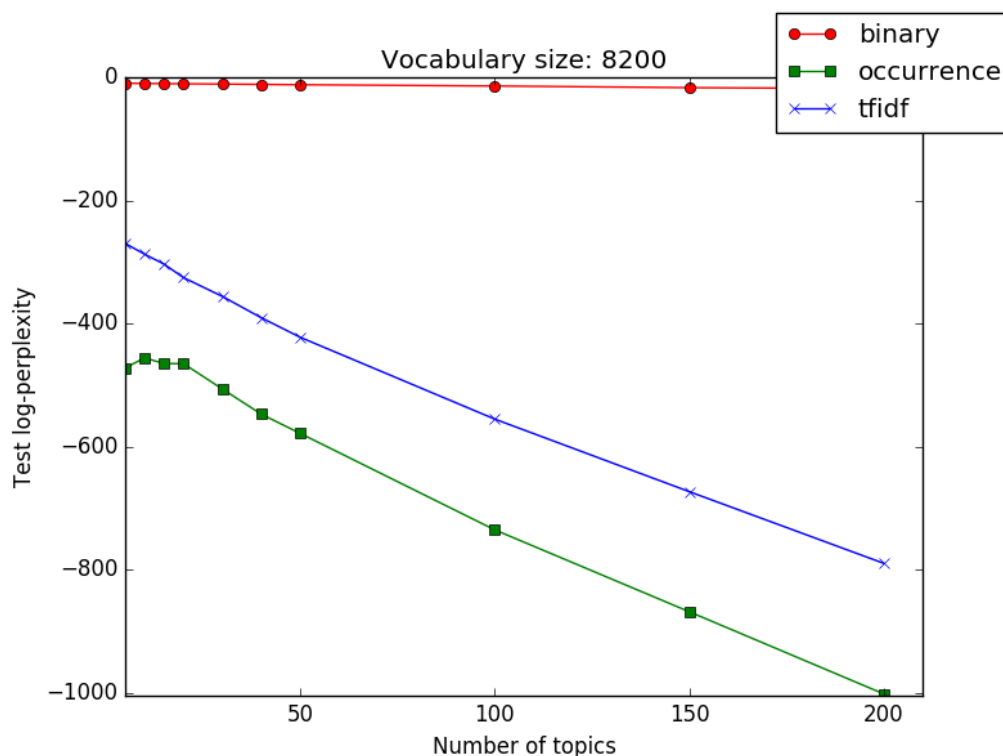


Table 2. Top 10 words of some of the topics of the trained latent Dirichlet allocation (LDA) models used to examine the association with the survey items. Terms that could be used to label a topic are italicized.

Topic number	Top 10 terms
4-LDA100	<i>zika</i> , <i>virus</i> , <i>mosquito</i> , health, amp, <i>zika</i> , <i>pregnant</i> , new, zikavirus, first
57-LDA100	<i>mosquito</i> , many, <i>zika</i> , amp, <i>virus</i> , wish, <i>summer</i> , full, look, leg
63-LDA100	<i>congress</i> , <i>funding</i> , <i>act</i> , <i>emergency</i> , tell, via2026, <i>approve</i> , add, lirikoph, <i>zika2014fast</i>
96-LDA100	<i>mosquito</i> , <i>virus</i> , <i>zika</i> , <i>microcephaly</i> , bill, <i>repellent</i> , <i>mosquito</i> , <i>summer</i> , amp, natural
2-LDA150	<i>virus</i> , <i>zika</i> , <i>mosquito</i> , <i>birth</i> , like, first, <i>health</i> , buy, <i>bill</i> , <i>dengue</i>
12-LDA150	<i>virus</i> , <i>cdcgov</i> , <i>zika</i> , via, test, <i>pregnant</i> , <i>mosquito</i> , <i>cdc</i> , <i>prevention</i> , amp, primarily, <i>contraception</i>
15-LDA150	<i>virus</i> , <i>zika</i> , <i>mosquito</i> , thing, hot, <i>congress</i> , <i>pregnant</i> , amp, <i>funding</i> , <i>emergency</i>
73-LDA150	<i>zika</i> , <i>virus</i> , <i>tech</i> , <i>blood</i> , <i>mosquito</i> , outbreak, <i>threat</i> , <i>pregnancy</i> , <i>government</i> , <i>brazil</i>
120-LDA150	<i>zika</i> , <i>virus</i> , <i>mosquito</i> , <i>zika</i> , health, amp, <i>funding</i> , <i>congress</i> , via, <i>pregnant</i>
149-LDA150	<i>virus</i> , <i>zika</i> , <i>mosquito</i> , around, like, <i>protect</i> , money, suspected, <i>health</i> , <i>travel</i>
10-LDA200	<i>zika</i> , <i>virus</i> , amp, <i>zika</i> , <i>funding</i> , <i>mosquito</i> , <i>congress</i> , new, like, house
37-LDA200	<i>zika</i> , <i>virus</i> , <i>insect</i> , <i>abortion</i> , <i>virus</i> , <i>repellent</i> , <i>prevent</i> , rubio, <i>mosquito</i> , <i>pregnant</i>
39-LDA200	<i>mcilroy</i> , <i>ror</i> , <i>zika</i> , <i>virus</i> , <i>pesticide</i> , crisis, <i>rio</i> , <i>florida</i> , <i>zika</i> , <i>vaccine</i>
87-LDA200	<i>mosquito</i> , <i>virus</i> , <i>zika</i> , <i>miami</i> , state, <i>dengue</i> , national, need, <i>fever</i> , month
104-LDA200	<i>zika</i> , <i>virus</i> , <i>medical</i> , <i>rio</i> , <i>brazil</i> , new, everything, <i>mosquito</i> , <i>baby</i> , amp
135-LDA200	<i>virus</i> , <i>zika</i> , <i>mosquito</i> , <i>central</i> , light, <i>zika</i> , <i>health</i> , clean, video, amp
165-LDA200	<i>virus</i> , <i>zika</i> , <i>mosquito</i> , <i>cdc</i> , breaking, <i>zika</i> , <i>pregnant</i> , amp, u.s., rather
197-LDA200	<i>virus</i> , <i>zika</i> , <i>rico</i> , <i>puerto</i> , <i>congress</i> , <i>funding</i> , <i>obamacare</i> , <i>zika</i> , emergency, scott

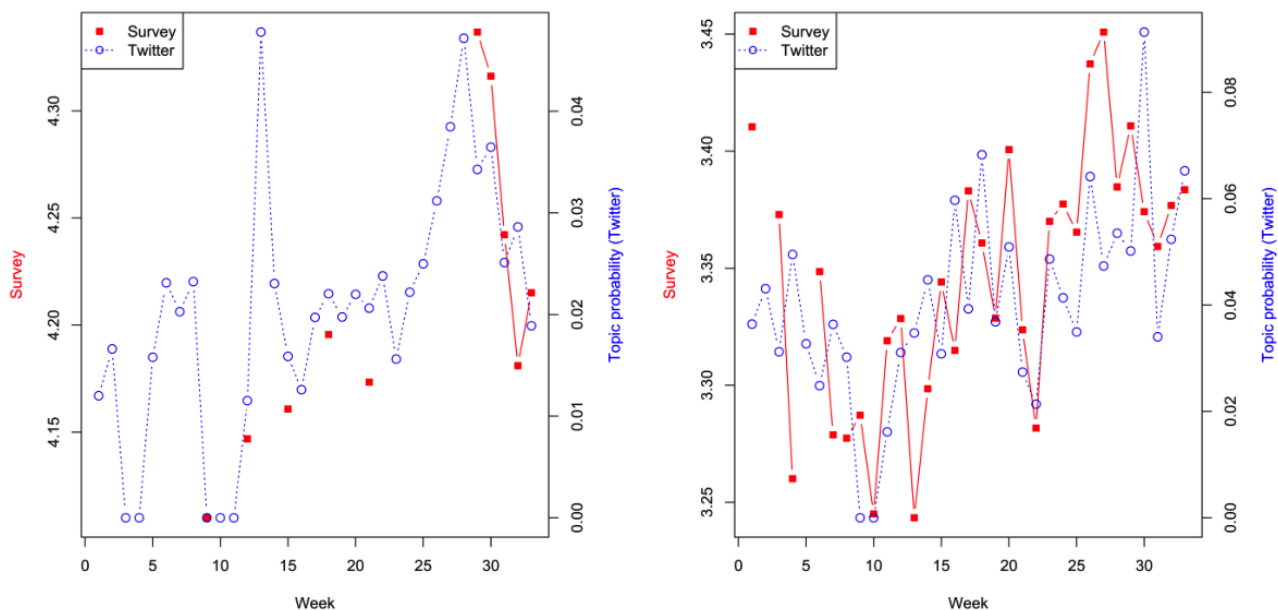
Associations of Topics With Weekly Measures of Attitudes, Knowledge, and Behaviors

The associations of topics with the weekly averages of attitudes, knowledge, and behavior items appear in Table 1. As one can surmise, the content of the online communications of each week focuses on a handful of the discovered topics. In other words, there are topics that only appear in some weeks and there are a limited number of topics that appear in many. For the correlation analysis presented here, the topics that appeared in just a few (2 to 3) weeks were discarded; we only considered those topics that appeared in almost all weeks. We calculated correlations using our trained topic models with a vocabulary size of 8200, term occurrence weighting scheme, and with $k=100, 150,$ and 200 topics. We were interested in discovering topics whose variations over time mimic the variations of the Zika survey items. Therefore, we calculated the posterior probability of all topics in each week and looked into the variation of the topics over time (weeks).

Figure 4 shows the variations of topics and survey items over time. Because some of the survey items were not asked of the respondents in all of the weeks, there are missing data in the survey. Since the variation of topics over time generated from our analyses can be used to monitor/predict the variation of survey measures, Twitter data can be used as a good measure to gauge attitudes, knowledge, and behaviors.

Table 3 shows topics with significant correlation with attitude, knowledge, or behavior questions, and Figure 5 depicts these topics with their word clouds. We have reported the P values for the t tests of the Pearson correlations to determine statistically significant correlations in Table 3.

Figure 4. Probability of topics (circle markers) and survey items (square markers) over time. Using the trained model, the probability of each topic can be calculated in each week. The survey items at each week are the average of the participants' responses. Survey items missing in some weeks were not asked of the respondents in those weeks. Left: Attitude toward ground spraying (survey) compared with congress funding (Twitter) (197/LDA200). Right: Knowledge about microcephaly (survey) compared with Zika protection and travel (Twitter) (149/LDA150). LDA: latent Dirichlet allocation.



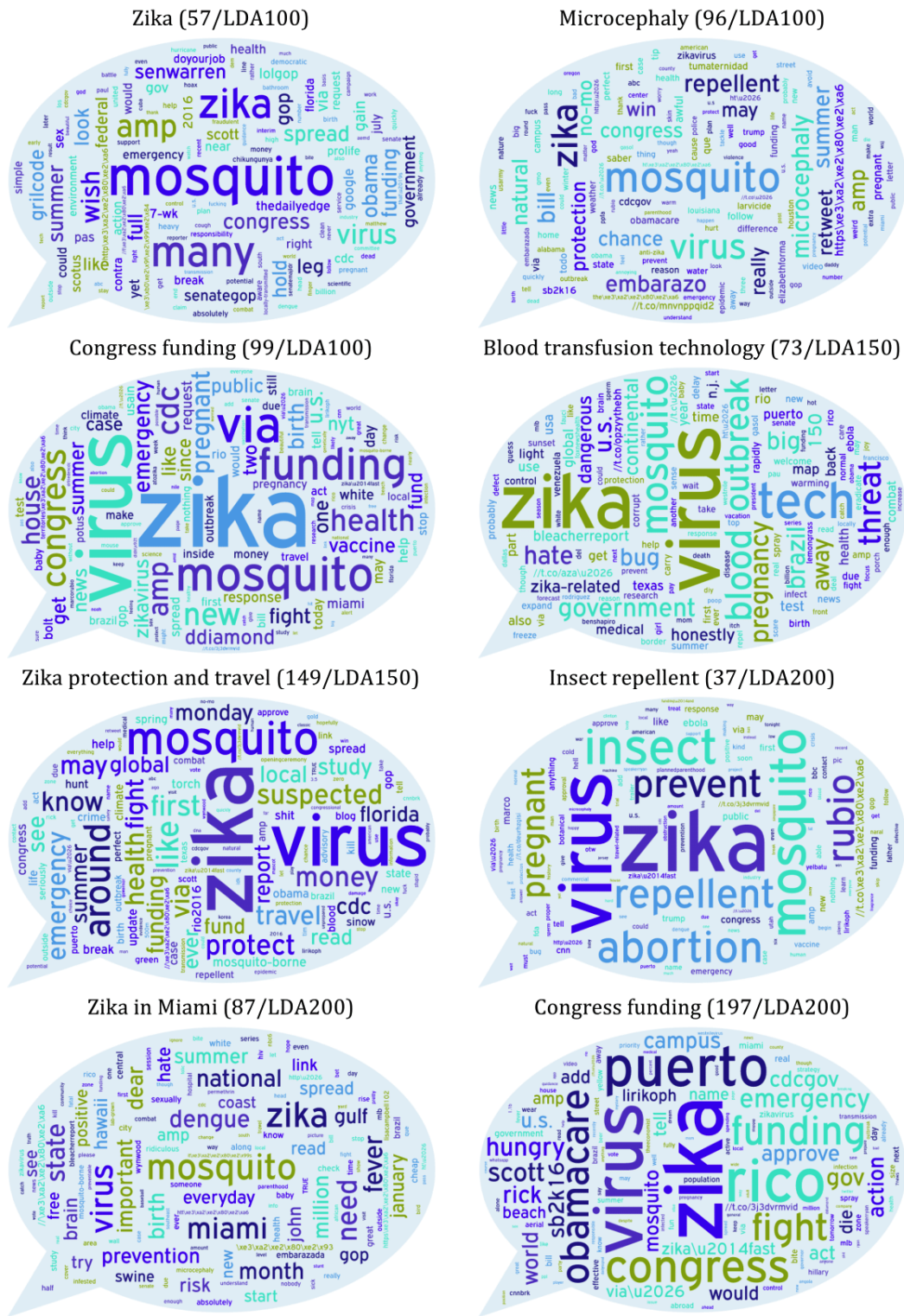
Items ZI-22 and ZI-23 of the Zika survey measured attitudes toward ground and air spraying against mosquitoes; these correlated positively with topics about “Congress funding,” “Zika protection and travel,” and “Zika in Miami” (Table 3). “Congress funding” and “Zika protection and travel” also correlated with the microcephaly knowledge item, and this item also positively correlated with a topic that specifically captures discussions about “microcephaly” online.

According to the results (Table 3), the behavioral item GM-20 that is measuring the amount of Zika-related discussion with family/friends of the respondents correlates with “Zika,” “Zika protection and travel,” “Congress funding,” and “insect repellent” topics. Thus, our content analyses of the online communications not only discovered topics that can serve as a gauge of the amount of Zika-related discussion but also revealed the most probable topics that construct the body of their communications (in this case, “travel plan/change” and “insect repellent”). The other behavioral item of the survey that is asking about recent preventive action to avoid Zika infection correlates with the topic “insect repellent.” Some of the discovered topics do not correlate significantly with any of the Zika items. For instance, topic 104/LDA200 can be interpreted as capturing those communications regarding the “rio2016 olympics.” Because none of the analyzed survey items were directly related to this topic, there is not a significant correlation between this topic and any of the survey items. This observation indicates the possibility of discovering topics by analyzing the content of the communications that may not be measured by conducted surveys but were captured by our model.

Table 3. Summary of topic correlates for survey items. LDA: latent Dirichlet allocation.

Category, survey item, and topic	Correlation (<i>P</i> value)
Attitude	
Ground spraying (ZI-22)	
“Congress funding” (197/LDA200)	.88 (<.001)
“Zika protection and travel” (149/LDA150)	.68 (<.001)
Aerial spraying (ZI-23)	
“Congress funding” (197/LDA200)	.92 (<.001)
“Zika in Miami” (87/LDA200)	.67 (<.001)
Knowledge	
Microcephaly (ZG-05)	
“Zika protection and travel” (149/LDA150)	.52 (<.001)
“Congress funding” (99/LDA100)	.51 (<.001)
“Microcephaly” (96/LDA100)	.43 (<.001)
Behavior	
Getting Zika vaccine (ZG-47)	
“Blood transfusion tech” (73/LDA150)	-.68 (<.001)
Practicing any preventive behavior to avoid Zika (ZG-54)	
“Zika” (57/LDA100)	.65 (<.001)
“Insect repellent” (37/LDA200)	.59 (<.001)
Discussing Zika with family/friends (GM-20)	
“Zika” (57/LDA100)	.47 (<.001)
“Insect repellent” (37/LDA200)	.45 (<.001)
“Congress funding” (197/LDA200)	.44 (<.001)
“Zika protection and travel” (149/LDA150)	.30 (<.001)

Figure 5. Word cloud of topics that showed significant correlation with survey items. LDA: latent Dirichlet allocation.



Discussion

Principal Findings

In this paper, we used topic modeling to analyze the content of online communications on the Twitter microblogging service. Instead of relying simply on the volume of the online communications, we analyzed their content to identify topics whose variations over time could be associated with the

variations in attitudes, knowledge, and behaviors measured with survey methods. After collecting a corpus of tweets related to Zika virus, we aggregated them into longer documents by either using location or timestamp information. To parse out topics of discussion, we used LDA probabilistic topic modeling and calculated the variation of topics over time using Bayesian inference. Our results demonstrated the possibility of discovering evidence from social media that enables us to identify community attitudes, knowledge, and behaviors in a

timely manner at low cost. Our methodology can be applied to collections of tweets from other domains of interest, from business to politics to other public health areas.

We went beyond the frequency-based measures by analyzing the content of online discussions of Twitter. Tweets are in-the-moment updates and contain useful observations about the larger world. Analyzing the actual content of Twitter messages provides a finer granularity and enables us to identify topics of the discussions and associate particular topics to particular measures of interest. For instance, our analysis revealed that community members not only have discussed Zika with their family and friends but also that their discussions were primarily about insect repellent, Congress funding, and Zika-related travel.

Topic modeling techniques can discover patterns from a collection of text documents and automatically extract topics in the form of multinomial distributions over words. A challenge in applying topic models to any text mining problem is labeling and interpreting a multinomial topic model accurately. Interpreting the topics or labeling them is a step that is usually done manually after topic discovery. In our analyses, the correlations with attitude, knowledge, and behavior items helped to avoid the challenge of topic interpretation.

Limitations

One of the limitations of our approach is that we are unable to discover on Twitter all of the constructs that are being measured

in a survey because not all of the items of interest may appear in online communications content. However, this approach allows researchers to identify topics that have not been measured in a survey but have appeared in online discussions. These topics can then directly be measured using the proposed methodology or can be included in future surveys.

Conclusions

In this paper, we investigated the associations between the online communications on Twitter and attitudes, knowledge, and behaviors regarding the public health challenge of the Zika virus. Our results demonstrated that it is possible to uncover topics of discussions from Twitter communications that are associated with Zika-related attitudes, knowledge, and behaviors of populations over time. Our analyses showed that the discovered topics of US congressional funding for Zika, microcephaly, Zika-related travel discussions, insect repellent, blood transfusion technology, and Zika in Miami can be used to monitor and predict the population's attitudes toward ground and aerial special spraying, knowledge about microcephaly, and various preventive behaviors such as travel change or getting a Zika vaccine. Our work demonstrated that social media data can be used as a complementary source of information alongside traditional data sources to gauge patterns of attitudes, knowledge, and behaviors of a population and further developing and improving text mining tools have practical applications in public health domain.

Acknowledgments

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Authors' Contributions

MF prepared the first draft of the paper and did the data analysis and contributed to data interpretation and study design. MSC helped with Twitter data collection. KW provided the survey data. DA and KHJ were the principal investigators of the study. All authors contributed to editing and revising the paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Nationally representative telephone samples: SSRS omnibus and custom studies.

[[PDF File \(Adobe PDF File\), 100KB - publichealth_v4i1e16_app1.pdf](#)]

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Abbreviations

LDA: latent Dirichlet allocation

tfidf: term frequency–inverse document frequency

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Original Paper

Integrating Smart Health in the US Health Care System: Infodemiology Study of Asthma Monitoring in the Google Era

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Abstract

Background: With the internet's penetration and use constantly expanding, this vast amount of information can be employed in order to better assess issues in the US health care system. Google Trends, a popular tool in big data analytics, has been widely used in the past to examine interest in various medical and health-related topics and has shown great potential in forecastings, predictions, and nowcastings. As empirical relationships between online queries and human behavior have been shown to exist, a new opportunity to explore the behavior toward asthma—a common respiratory disease—is present.

Objective: This study aimed at forecasting the online behavior toward asthma and examined the correlations between queries and reported cases in order to explore the possibility of nowcasting asthma prevalence in the United States using online search traffic data.

Methods: Applying Holt-Winters exponential smoothing to Google Trends time series from 2004 to 2015 for the term “asthma,” forecasts for online queries at state and national levels are estimated from 2016 to 2020 and validated against available Google query data from January 2016 to June 2017. Correlations among yearly Google queries and between Google queries and reported asthma cases are examined.

Results: Our analysis shows that search queries exhibit seasonality within each year and the relationships between each 2 years' queries are statistically significant ($P < .05$). Estimated forecasting models for a 5-year period (2016 through 2020) for Google queries are robust and validated against available data from January 2016 to June 2017. Significant correlations were found between (1) online queries and National Health Interview Survey lifetime asthma ($r = -.82$, $P = .001$) and current asthma ($r = -.77$, $P = .004$) rates from 2004 to 2015 and (2) between online queries and Behavioral Risk Factor Surveillance System lifetime ($r = -.78$, $P = .003$) and current asthma ($r = -.79$, $P = .002$) rates from 2004 to 2014. The correlations are negative, but lag analysis to identify the period of response cannot be employed until short-interval data on asthma prevalence are made available.

Conclusions: Online behavior toward asthma can be accurately predicted, and significant correlations between online queries and reported cases exist. This method of forecasting Google queries can be used by health care officials to nowcast asthma prevalence by city, state, or nationally, subject to future availability of daily, weekly, or monthly data on reported cases. This method could therefore be used for improved monitoring and assessment of the needs surrounding the current population of patients with asthma.

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KEYWORDS

asthma; big data; forecasting; Google trends; health care; health informatics; internet behavior; nowcasting; online behavior; smart health

Introduction

Health informatics is the field where information technology, computer science, social sciences, and health care meet [1]. Recently, with the use of big data (ie, large data volumes characterized by high speed and wide dataset variety [2-4]) being all the more applied in research in general, health informatics provides fertile ground for big data applications.

According to Gu et al [5], big data health care research consists of 3 research stages: disease, life and health, and nursing. Focus is being given to various aspects of diseases, technology, and health care services in areas such as epidemics, data mining, machine learning, and customized service [5]. Big data is being increasingly integrated in health care informatics [5-6] and has been used in the past in smart city management.

Over the last few years during the integration of the health pillar in smart cities, where big data is being continuously gathered and analyzed [7], the concept of smart health has been rising [8-10]. Smart health as a concept is derived from the intersection of medical informatics, public health, and business, where large volumes of social media data, payer-provider big data, genomic-driven big data, and biomedical data are being used for the monitoring and evaluation of patients' conditions [10]. As life expectancy increases, so does the cost of health care, and thus innovative methods are required to achieve improved cost-effective quality services. The use of big data in smart health can assist in P4 medicine (preventive, participatory, predictive, and personalized) [8], in the detection, prediction, and prevention of diseases [5], and in the health industry in general [10] while also taking into account the cost, data sources and quality, and population [4].

What has been of notable popularity in big data analytics is the analysis of online search queries [11-12], mainly using Google Trends [13], a popular open tool that has been widely integrated in scientific research over the course of the past decade, mainly focused on health-related topics [6]. Examples include analysis of online interest in multiple sclerosis [14], epilepsy [15-16], silicosis [17], dementia [18], urinary tract infection [19], Ebola [20], the flu [21-23], tobacco and lung cancer [24], epidemics [25-26], and even in illegal drugs such as dabbing [27], krokodil [28], and methamphetamine [29]. This use of big data has formed the cornerstone of a new concept, the science of infodemiology, which uses the vast variety of data available on the internet such as online queries, publications, or posts on blogs and websites for real-time data analysis with the aim of informing public health and public policy, thus providing a viable alternative to the time-consuming traditional methods of gathering health care data such as population surveys and registries. The use of infodemiology data for surveillance purposes is called infoveillance and could potentially allow for more timely and targeted health care interventions [30].

In this study, online queries for the term "asthma" in the United States were analyzed in order to explore the possibility of

nowcasting (ie, forecasting the present) asthma prevalence using Google Trends. Asthma was selected because it is a common chronic respiratory disease characterized by exacerbations, also known as asthma attacks; therefore, the reported cases are bound to show seasonality as well as constant interest.

Asthma is a chronic condition characterized by airway inflammation and hyper-responsiveness that causes airways to constrict in response to exercise, infection, exposure to allergens, and occupational exposures [31]. In 2014, it was estimated that approximately 7.4% of the adult US population and 8.6% of US children lived with asthma [32]. During childhood, asthma is more prevalent in males, whereas in adulthood prevalence shifts toward females. Black and multirace people also have a higher prevalence than white people [33-34].

Asthma presents with coughing, wheezing, and chest tightness that seem to be worse during the night and early mornings. These symptoms, along with a family history of asthma or atopic dermatitis, can prompt investigations to confirm an asthma diagnosis. Exacerbation of normal asthma symptoms is more common in patients with uncontrolled asthma or in high-risk patients [35]. Certain types of asthma exacerbations are linked to particular seasons of the year with those caused by pollen and mold being truly seasonal [36]. It has been shown that pediatric patients experience a peak of asthma exacerbations during the fall and spring months [37], whereas adult patients experience a peak of asthma exacerbations at year end [38].

The management of asthma usually involves the use of several inhalers, leading to a rather complicated treatment regime that presents difficulties in terms of patient compliance because it interferes with their daily living activities. Poor compliance can lead to increased morbidity as well as increased cost of treatment [39]. Apart from treatment compliance, another important factor that weighs in the success of the treatment is inhaler technique, as improper inhaler use is linked to poor asthma control. Studies have shown that 33% to 94% of patients do not receive any training regarding proper inhaler technique, which leads to a great number of patients using inhalers incorrectly [40]. Asthma self-management education and personalized advice can improve a patient's asthma control and quality of life, along with reducing asthma exacerbations and hospital admissions [41].

Asthma has several social complications such as limiting patients' activity levels [42], which has an economic impact on the country's health care system. It was estimated that in 2007, medical expenses, missed work and school days, and early deaths due to asthma cost the United States \$56 billion [43].

Google Trends data have been previously shown to be valid by many studies [44], and work on the subject has shown the tool's contribution to forecasting [45-46] and analysis of online behavior, provided careful selection of the examined terms [47]. The aim of this paper is to examine if nowcasting asthma prevalence in the United States is possible using online search traffic data.

Methods

Monthly time series from Google Trends for the keyword “asthma” from 2004 to 2015 in the United States and by individual state were used. The data were normalized by Google and downloaded in .csv format on July 7, 2017, between 12:47 and 13:02 for the United States and on July 18 between 14:03 and 14:33 for each of the 50 states and the District of Columbia. The data adjustment procedure is reported by Google as follows [48]: “Search results are proportionate to the time and location of a query: Each data point is divided by the total searches of the geography and time range it represents, to compare relative popularity. Otherwise places with the most search volume would always be ranked highest. The resulting numbers are then scaled on a range of 0 to 100 based on a topic’s proportion to all searches on all topics. Different regions that show the same number of searches for a term will not always have the same total search volumes.”

The seasonality of asthma queries was explored followed by the estimation of the forecasts for the online interest in the term from 2016 through 2020 for the country as well as for each state. The additive method for the Holt-Winters exponential smoothing (using the statistical programming language R) is employed. The Holt-Winters equations [49] can be seen in Figure 1.

In order to further elaborate on the seasonality, the Pearson correlations for Google Trends data for the term “asthma” between each 2 years from 2004 to 2015 in the United States were calculated. Finally, the Pearson correlations between Google queries and the National Health Interview Survey (NHIS) prevalence data [50] from 2004 to 2015 and Behavioral Risk Factor Surveillance System (BRFSS) prevalence data [51] from 2004 to 2014 were examined.

Figure 1. Equations for Holt-Winters exponential smoothing, where y_x and \hat{y}_x denote the initial series and the forecasts, respectively. The l_x , b_x , and s_x denote the level, the trend, and seasonal estimates for month x , respectively, with m denoting the period of the seasonality (ie, 12 in this case), and $h_m^+ = (h-1) \bmod m + 1$. The level, trend, and seasonal change smoothing factors are denoted by constants α , β^* , and γ , respectively. The estimated values for the coefficients for the level and trend are denoted by a and b , respectively, while the seasonal coefficients are denoted by s_1, \dots, s_{12} , for month 1, ..., 12, respectively.

$$\begin{aligned} (1) \quad \hat{y}_{x+h|x} &= l_x + hb_x + s_{x-m+h_m^+} \\ (2) \quad l_x &= \alpha(y_x - s_{x-m}) + (1 - \alpha)(l_{x-1} + b_{x-1}) \\ (3) \quad b_x &= \beta^*(l_x - l_{x-1}) + (1 - \beta^*)b_{x-1} \\ (4) \quad s_x &= \gamma(y_x - l_{x-1} - b_{x-1}) + (1 - \gamma)s_{x-m} \end{aligned}$$

Results

Online Interest in the United States

Figure 2 shows a heat map of the United States classified into 5 groups of interest in the term “asthma” from 2004 to 2015

Asthma is not included in the list of diseases with a Centers for Disease Control and Prevention (CDC) surveillance case definition, defined as “a set of uniform criteria used to define a disease for public health surveillance. Surveillance case definitions enable public health officials to classify and count cases consistently across reporting jurisdictions. They provide uniform criteria of national notifiable infectious and non-infectious conditions for reporting purposes” [52]. Thus, nationwide surveys are used to gather information regarding asthma prevalence, including additional information on asthma control, medications, and hospitalizations [53]. The BRFSS is a “state-based, random-digit-dialed telephone survey designed to monitor the prevalence of the major behavioral risks among adults associated with premature morbidity and mortality,” and the NHIS is a “multistage probability sample survey designed to solicit health and demographic information about the population, conducted annually with face-to-face interviews in a nationally representative sample of households” [54].

In 2011, the BRFSS changed its weighting methodology in addition to also including mobile phone respondents. Therefore, any comparisons between years before and after 2011 should be carefully interpreted. In this study, no such comparisons are made, as each year’s online queries are compared with the respective year’s asthma reported cases, thus including no cross-year comparisons. For this study, we used the CDC definition of asthma prevalence, based on affirmative responses to the following NHIS questions: (adults) “Have you ever been told by a doctor or other health professional that you had asthma?” and “Do you still have asthma?” and (children) “Has a doctor or other professional ever told you that [sample child] had asthma?” and “Does [sample child] still have asthma?” [55].

(ie, 0 to 20, 21 to 40, 41 to 60, 61 to 80, and 81 to 100; light blue to darker blue).

Out of the 50 states and District of Columbia, 29 fall into the 81 to 100 group, 21 in the 61 to 80 group, only 1 (Oregon) in the 41 to 60 group, and none in the 21 to 40 and 0 to 20 groups. This classification indicates that the examined term is of high

interest to the population of the United States. The detailed data for Figure 2 are available in Multimedia Appendix 1, Table A1.

Figures 3 and 4 depict the changes in online interest in the term “asthma” for the period 2004 to 2015 and the seasonal changes for each year from 2004 to 2015, respectively. As is evident, the data follow a seasonal trend. All years’ data, as presented in Figure 4, follow a similar pattern during a full year, supporting our hypothesis that the seasonality of asthma prevalence in the United States is depicted in online searches.

Figure 5 consists of the changes by state in online interest in the term “asthma” by year from 2004 to 2015. All data are available in Multimedia Appendix 1, Table A2.

There has been a significant increase in searches for the term “asthma” in the states from 2004 to 2015, with the lowest count of states in the 81 to 100 group being in 2007 and the highest in 2012. The top asthma-related queries in the United States from January 2004 to December 2015 include “allergy asthma” (100), “asthma symptoms” (45), “asthma attack” (35), “what is asthma” (25), “asthma inhaler” (20), “asthma children” (15), “exercise asthma” (15), “asthma medications” (10), and “allergy and asthma center” (10).

As is evident, online behavioral changes toward the term “asthma” depict behavior toward said disease. The next steps are to examine if forecasting online interest in the United States is possible and identify existing relationships between online search traffic data and reported asthma cases.

Figure 2. Online interest by state in the term "asthma" from 2004 to 2015.

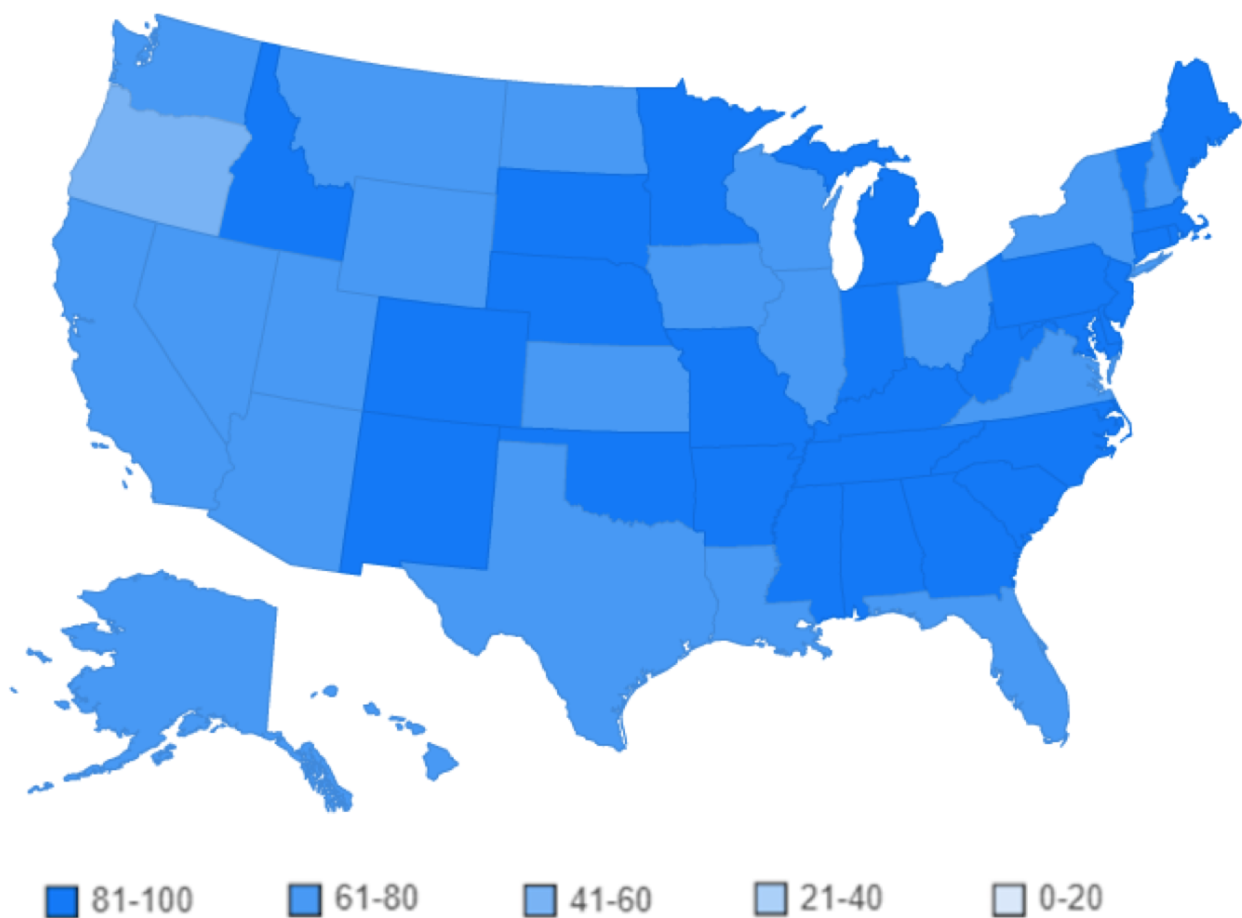


Figure 3. Monthly changes in online interest in the term "asthma" from 2004 to 2015.

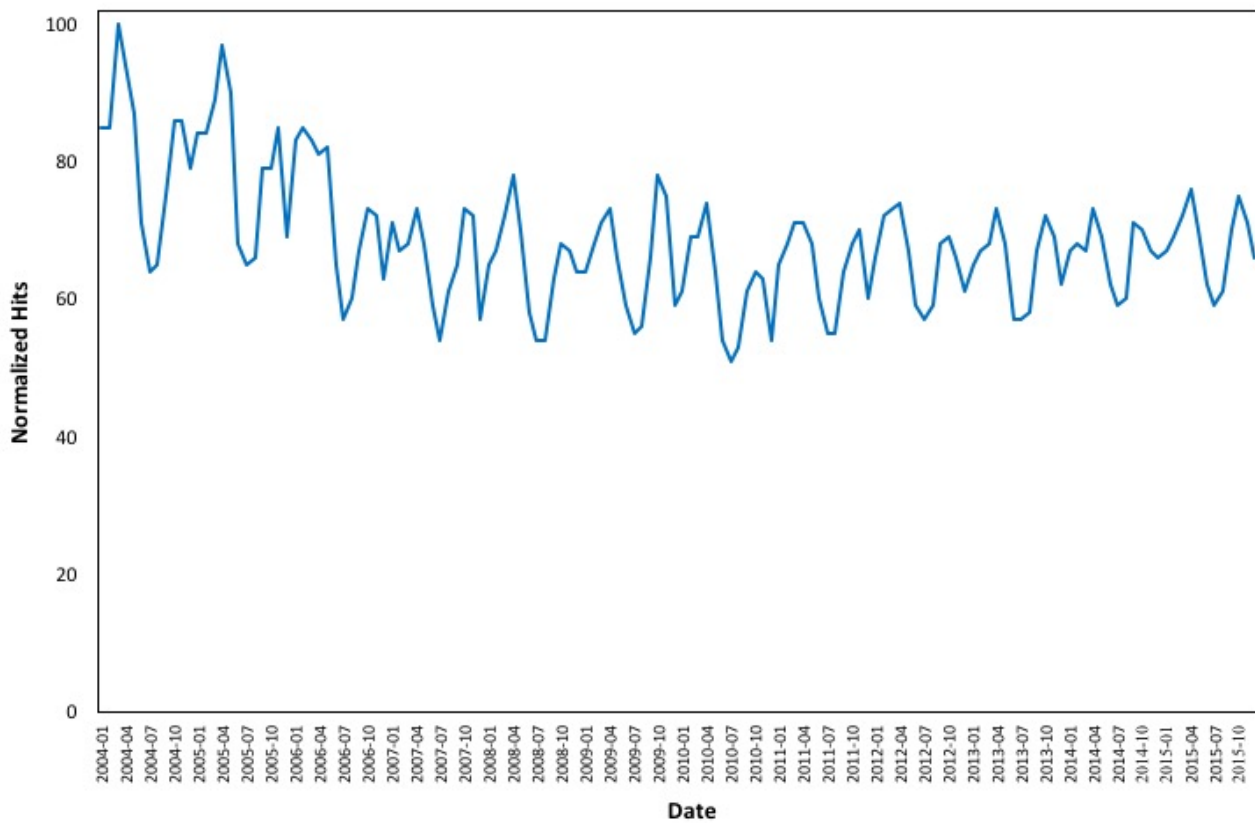


Figure 4. Weekly changes in online interest in the term "asthma" for each year from 2004 to 2015.

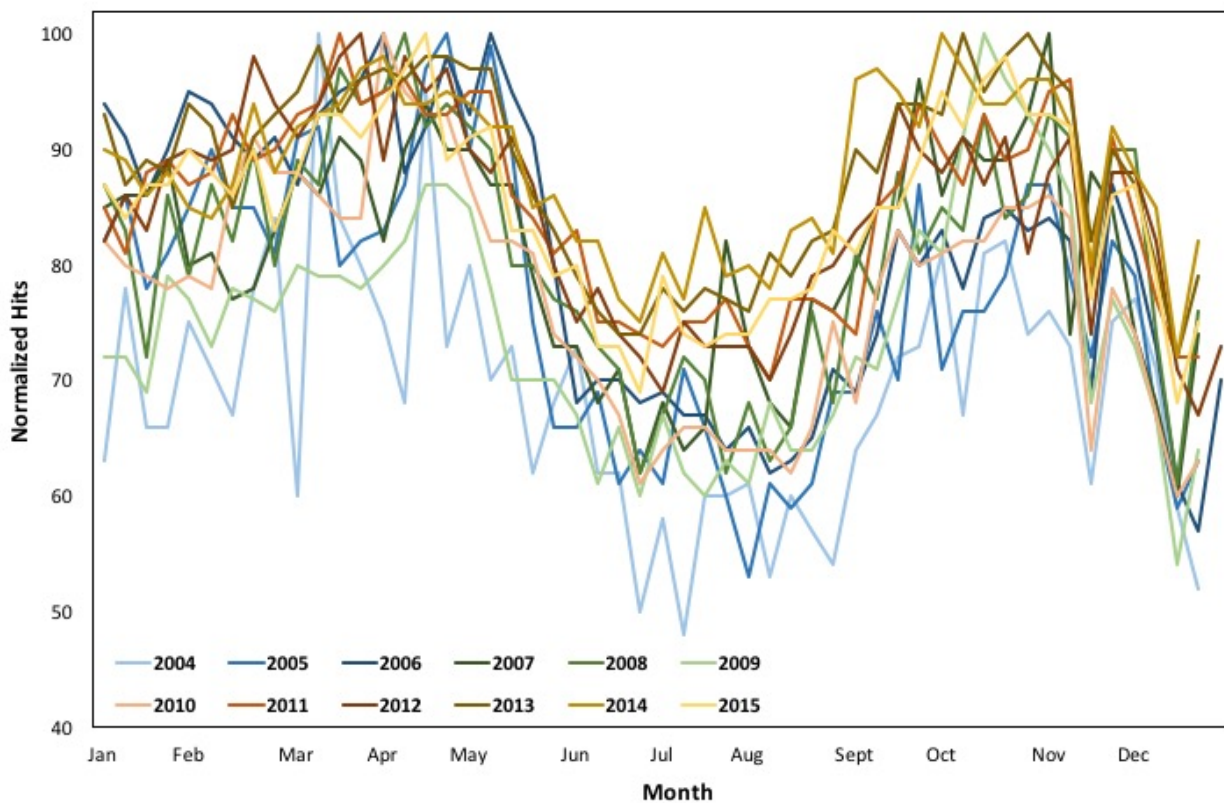
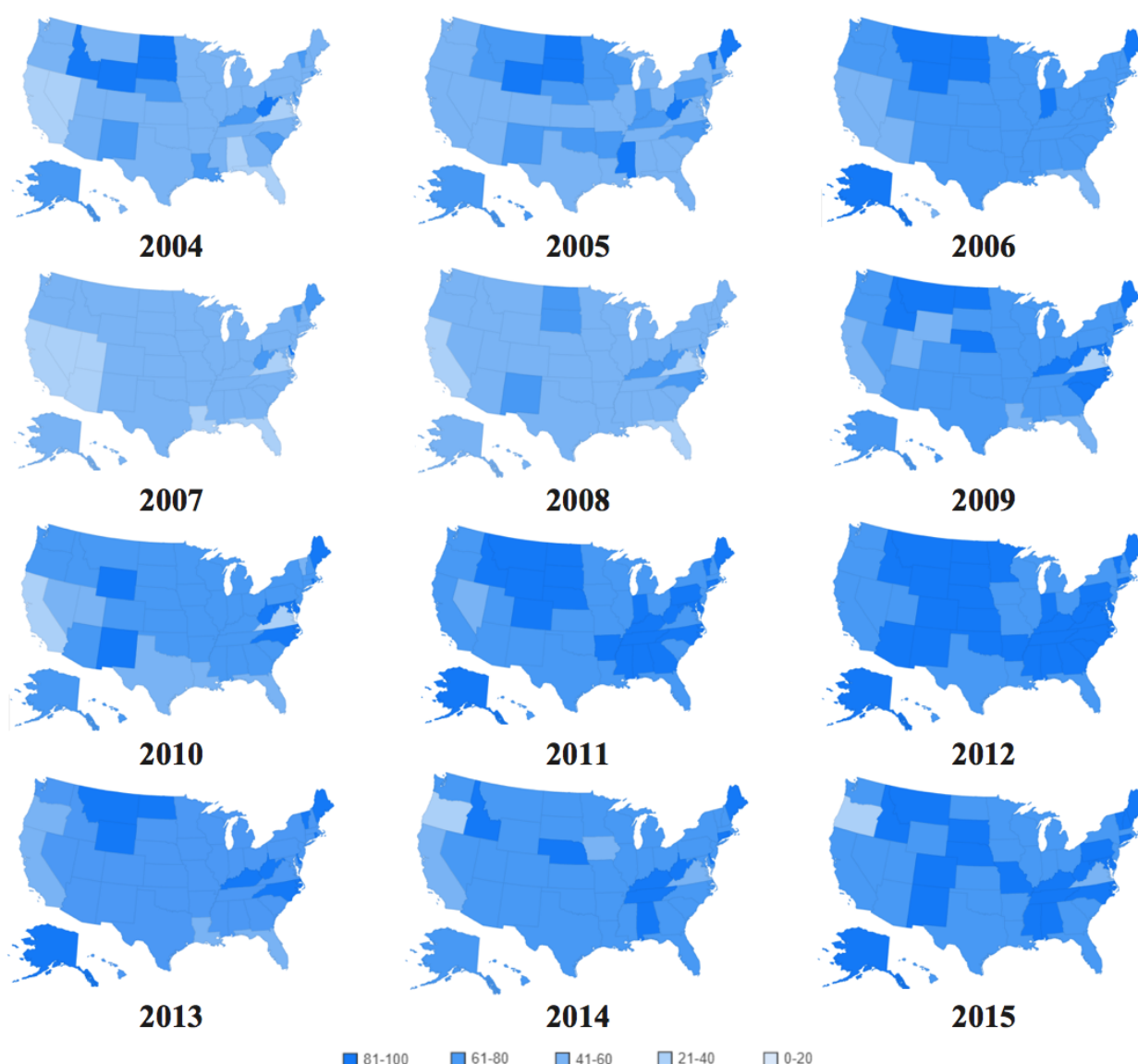


Figure 5. Online interest by state in the term "asthma" per year from 2004 to 2015.

Forecasting Online Interest in the United States

Figure 6 depicts changes in online interest over the period 2004 to 2015 and estimated forecasts from 2005 to 2020. The estimated model closely approximates the actual Google queries for the term "asthma" in the United States over the examined period.

The smoothing parameters for the additive Holt-Winters exponential smoothing with trend and additive seasonal component are $\alpha=.33$, $\beta^*=0$, and $\gamma=.65$. The estimated values for the coefficients for the level, trend and season are as follows: $a=69.54$, $b=-.07$, $s_1=-.94$, $s_2=1.44$, $s_3=3.37$, $s_4=7.84$, $s_5=2.51$, $s_6=-5.68$, $s_7=-8.51$, $s_8=-7.20$, $s_9=1.89$, $s_{10}=4.67$, $s_{11}=1.11$, and $s_{12}=-3.53$.

In order to elaborate on the robustness of the forecasting model, the estimated values are validated against the available Google queries for the term "asthma" from January 2016 to June 2017,

as is shown in Figure 7. It is evident that the forecasts follow the same curve and well approximate the actual Google Trends data for the aforementioned period.

It is therefore suggested that the online behavior exhibits seasonality and can be predicted. The last step in exploring if nowcasting of asthma prevalence in the United States is possible using Google Trends is to examine the correlations between Google Trends data and reported lifetime and current asthma.

Google Trends Versus Reported Asthma

As shown in Figure 4, each examined year's online interest seems to follow a similar seasonal trend from January to December. To elaborate on the seasonal trend, the Pearson correlations between each 2 years' queries are calculated (Table 1). The monthly Google Trends data between each 2 years from 2004 to 2015 exhibit high correlations, while all comparisons are statistically significant, with $P<.05$.

Figure 6. Google Trends (2004 to 2015) versus forecasts (2005 to 2020) in the United States.

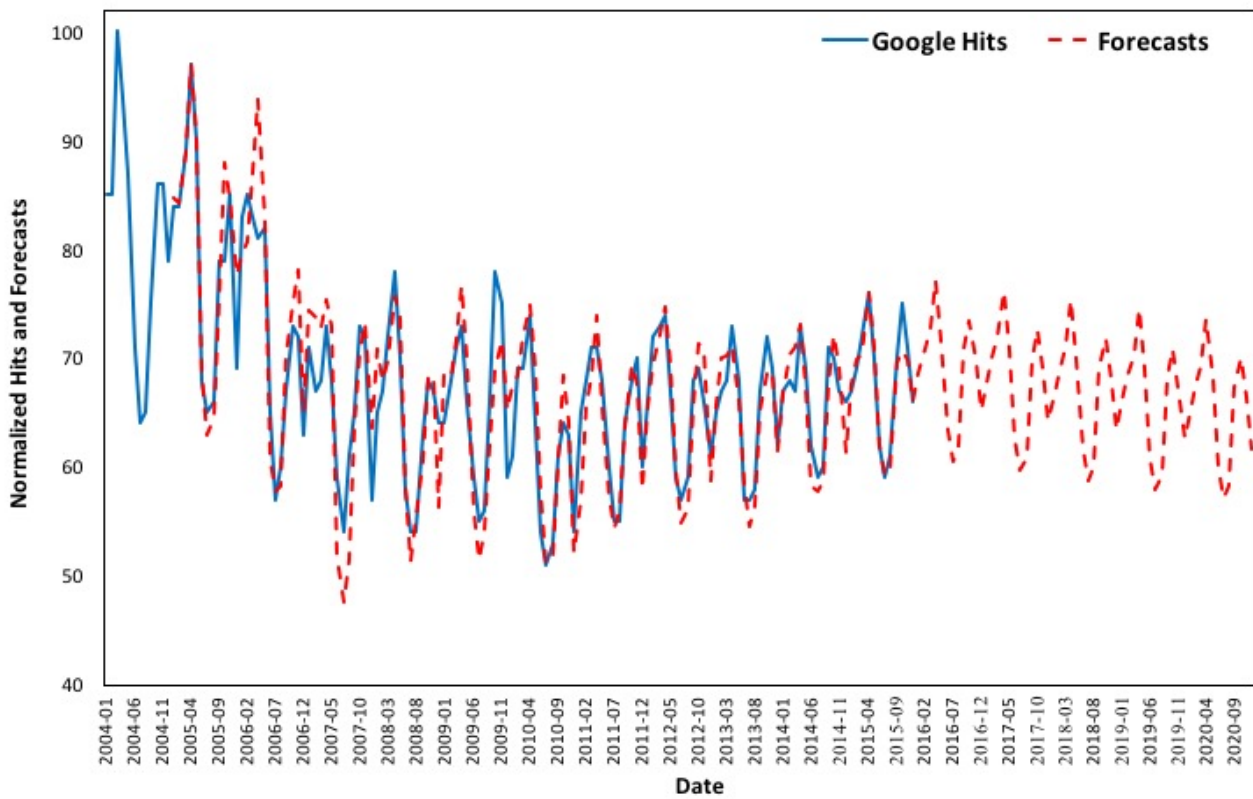


Figure 7. Google Trends (2004 to 2015) versus forecasts (January 2016 to June 2017) in the United States.

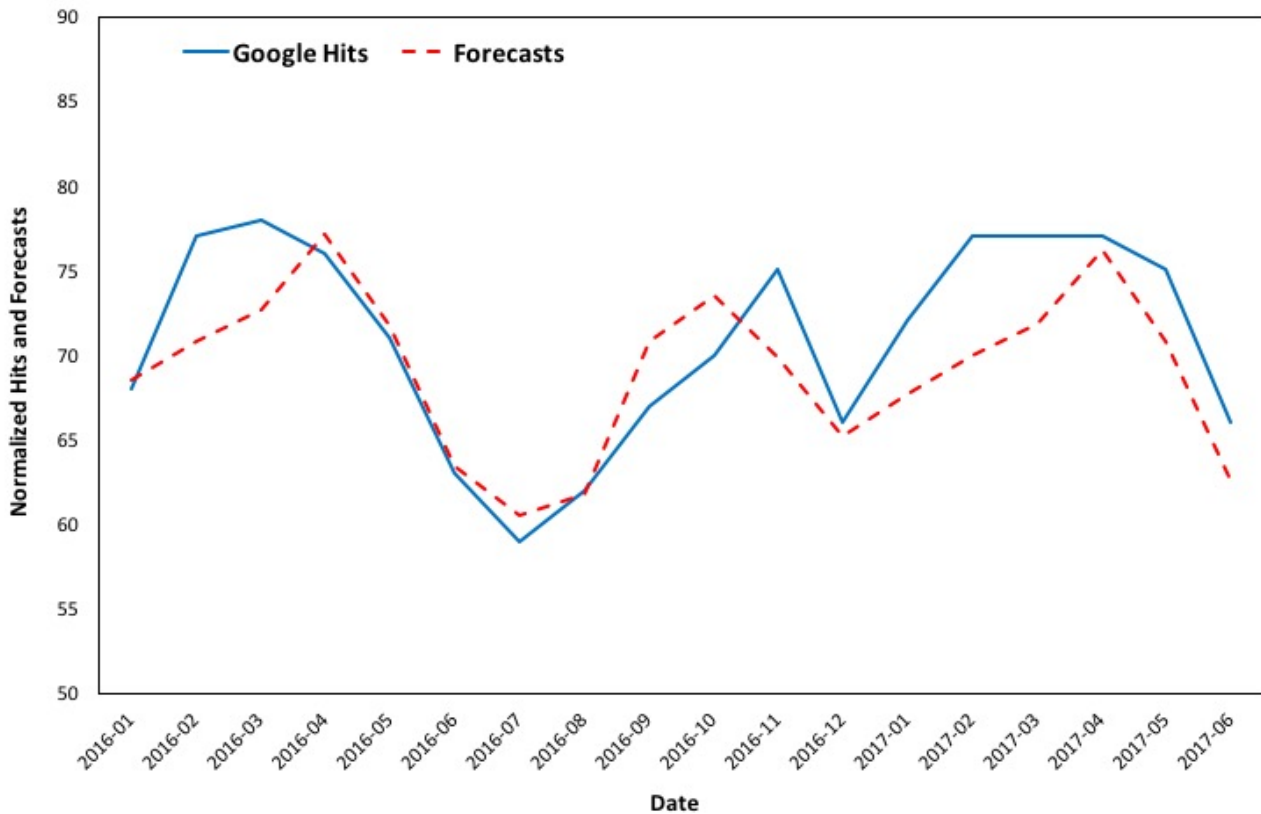


Table 1. Pearson correlations between each 2 years' normalized Google asthma queries in the United States from 2004 to 2015.

	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013	2014
2005	.89	—	—	—	—	—	—	—	—	—	—
2006	.86	.89	—	—	—	—	—	—	—	—	—
2007	.77	.85	.77	—	—	—	—	—	—	—	—
2008	.94	.93	.81	.78	—	—	—	—	—	—	—
2009	.79	.76	.64	.89	.80	—	—	—	—	—	—
2010	.88	.94	.87	.82	.92	.81	—	—	—	—	—
2011	.94	.93	.85	.87	.93	.91	.93	—	—	—	—
2012	.88	.90	.85	.81	.90	.82	.98	.91	—	—	—
2013	.84	.87	.72	.89	.90	.93	.89	.92	.90	—	—
2014	.75	.82	.68	.77	.87	.78	.82	.83	.86	.92	—
2015	.86	.85	.69	.86	.92	.93	.88	.92	.90	.98	.93

Table 2. Total lifetime and current asthma National Health Interview Survey (2004 to 2015) and Behavioral Risk Factor Surveillance System (2004 to 2014) prevalence data.

Year	NHIS ^a			BRFSS ^b		
	Lifetime asthma	Current asthma	Asthma hits ^c	Lifetime asthma	Current asthma	Asthma hits ^c
2004	30,189	20,545	81.41	33,084,183	20,422,385	83.17
2005	32,621	22,227	79.58	30,661,476	19,453,974	80.33
2006	34,132	22,876	72.58	35,107,599	22,853,570	73.92
2007	34,008	22,879	65.66	36,832,798	23,556,048	68.17
2008	38,450	23,333	65.00	38,050,505	24,521,005	66.92
2009	39,930	24,567	65.83	38,033,371	24,051,245	67.92
2010	39,191	25,710	61.41	39,005,338	25,069,373	62.83
2011	39,504	25,943	64.58	34,759,106	22,605,961	66.42
2012	39,982	25,553	65.91	39,085,744	25,954,771	67.67
2013	37,328	22,648	65.25	41,030,777	26,227,484	67.00
2014	40,461	24,009	66.58	40,706,401	26,957,918	68.75
2015	40,153	24,633	68.16	—	—	—

^aNHIS: National Health Interview Survey.

^bBRFSS: Behavioral Risk Factor Surveillance System.

^cValues slightly vary due to the different time frame: 2004 to 2015 for NHIS and 2004 to 2014 for BRFSS.

To further explore the relationships between online searches and asthma prevalence in the United States, data on the yearly cases of lifetime and current asthma for all ages from the NHIS prevalence data from 2004 to 2015 [50] and the BRFSS prevalence data [51] from 2004 to 2014 (Table 2) are used.

The Pearson correlations of the annual NHIS prevalence data with the annual averages of the normalized Google Trends data from 2004 to 2015 show high correlations between lifetime asthma ($r=-.82$, $P=.001$) and current asthma ($r=-.77$, $P=.004$). BRFSS prevalence data also exhibit high correlations with Google Trends data for lifetime ($r=-.78$, $P=.003$) and current asthma ($r=-.79$, $P=.002$). The Spearman correlations for the aforementioned pairs of variables all exhibit the same negative relationship, although not all are statistically significant.

Although statistically significant, all Pearson correlations are negative, and lag analysis should be employed to identify the time interval of response between asthma online interest and case reporting or vice versa. Although Google Trends data for the term “asthma” in the United States over the examined period are monthly, the data on lifetime and current asthma are yearly; until weekly or monthly data are available, further analysis cannot be done.

Forecasting Online Interest by State

In order to show that the method of nowcasting asthma prevalence in the United States using Google queries is possible, this methodology is applied in each of the 50 states and the District of Columbia and exhibits good forecasting results. Figures 8 to 11 depict the changes in online interest in the term

“asthma” from 2004 to 2015 and forecasts from 2016 to 2020 for the 4 most populated states (ie, California, Texas, Florida, and New York), and the graphs for all states can be found in [Multimedia Appendix 2](#), Figures B1-B51. The values of the smoothing parameters α , β^* , and γ and the coefficients for each state’s forecasts can be found in [Multimedia Appendix 1](#), Tables A3 and A4, respectively. As online behavioral changes can be predicted and data on asthma cases are correlated with online queries, nowcasting of asthma could be possible provided short-interval data (eg, monthly, weekly, or even daily) are available.

According to the results, online interest in Alaska, Nebraska, New Hampshire, Oklahoma, and Tennessee exhibits increasing forecast trends from 2016 to 2020. On the contrary, online interest in Delaware, Kansas, Oregon, and Virginia exhibits

decreasing forecast trends from 2016 to 2020. Overall, the states of Arizona, California, Connecticut, Florida, Georgia, Illinois, Indiana, Maryland, Michigan, Missouri, New Jersey, New York, North Carolina, Pennsylvania, Texas, and Washington show high interest in the term “asthma” throughout the examined period, while in Hawaii and Wyoming, interest is low. Virginia is the only state where online interest exhibits very significant variations from 2004 to 2016.

Our study indicates that analysis of online behavior toward asthma by state can assist with nowcasting asthma prevalence. Since search queries and reporting of asthma are shown to correlate in the United States, if short-interval data (eg, weekly or monthly) were made available, a robust nowcasting model could be developed.

Figure 8. Google Trends (2004 to 2015) versus forecasts (2005 to 2020) in California.

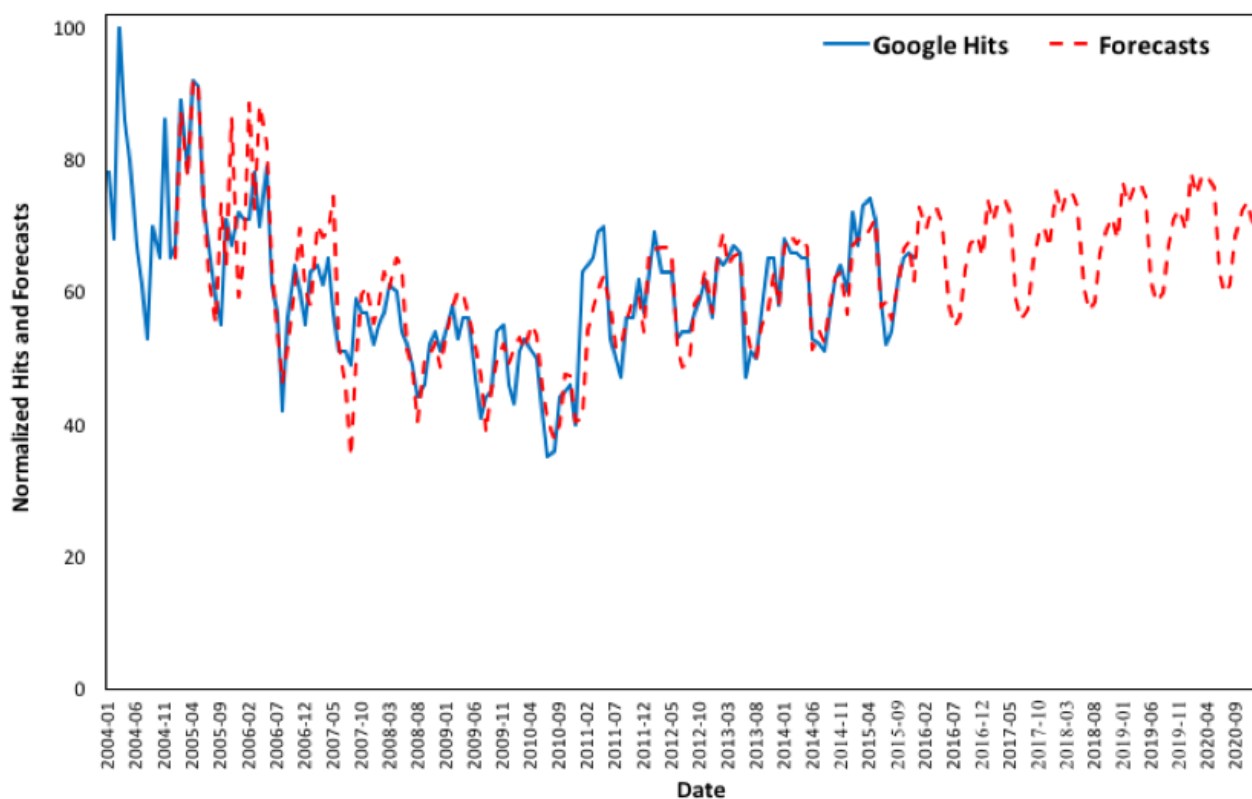


Figure 9. Google Trends (2004 to 2015) versus forecasts (2005 to 2020) in Texas.

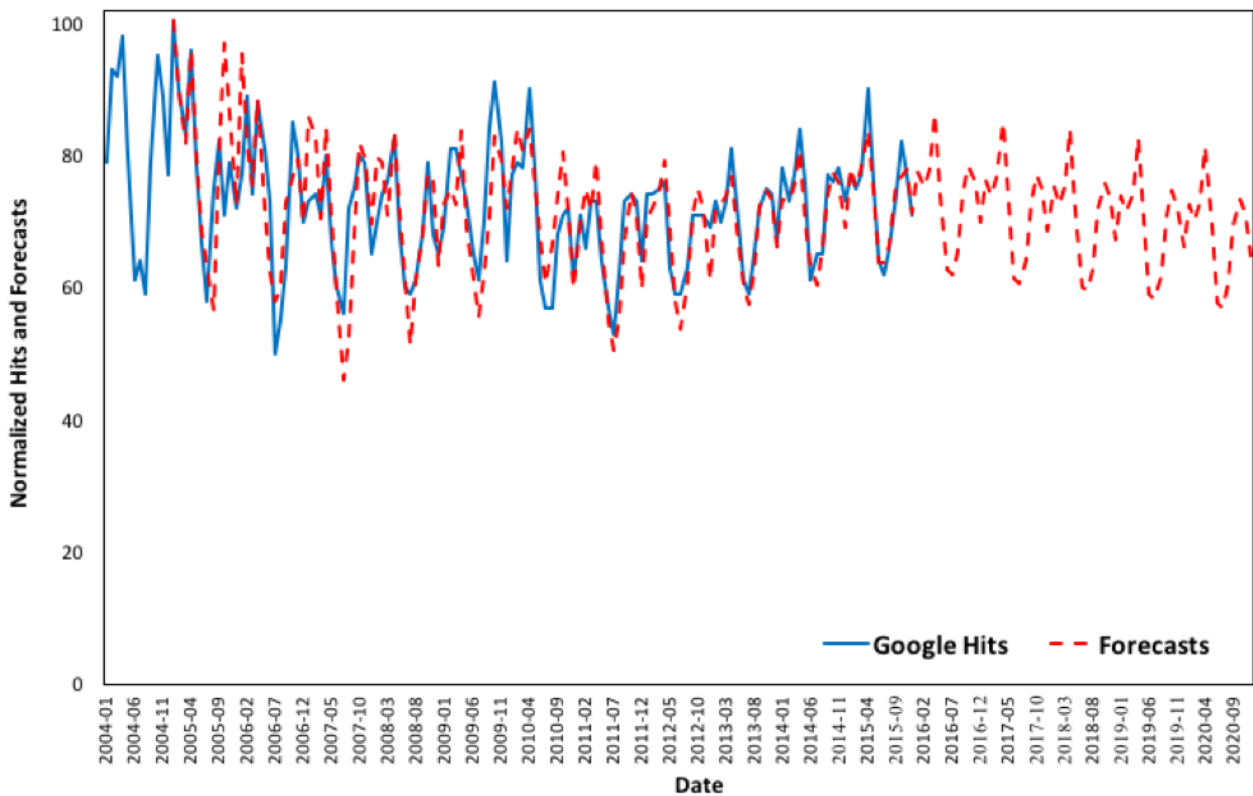


Figure 10. Google Trends (2004 to 2015) versus forecasts (2005 to 2020) in Florida.

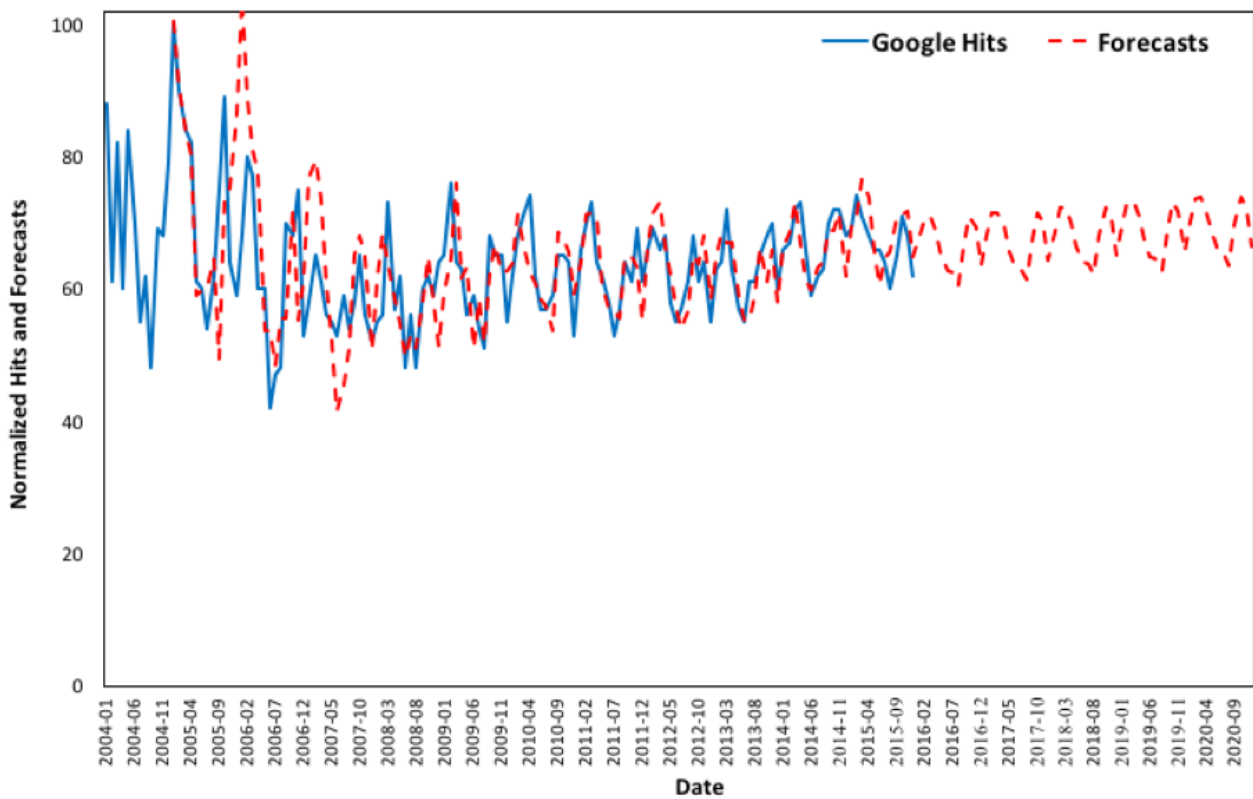
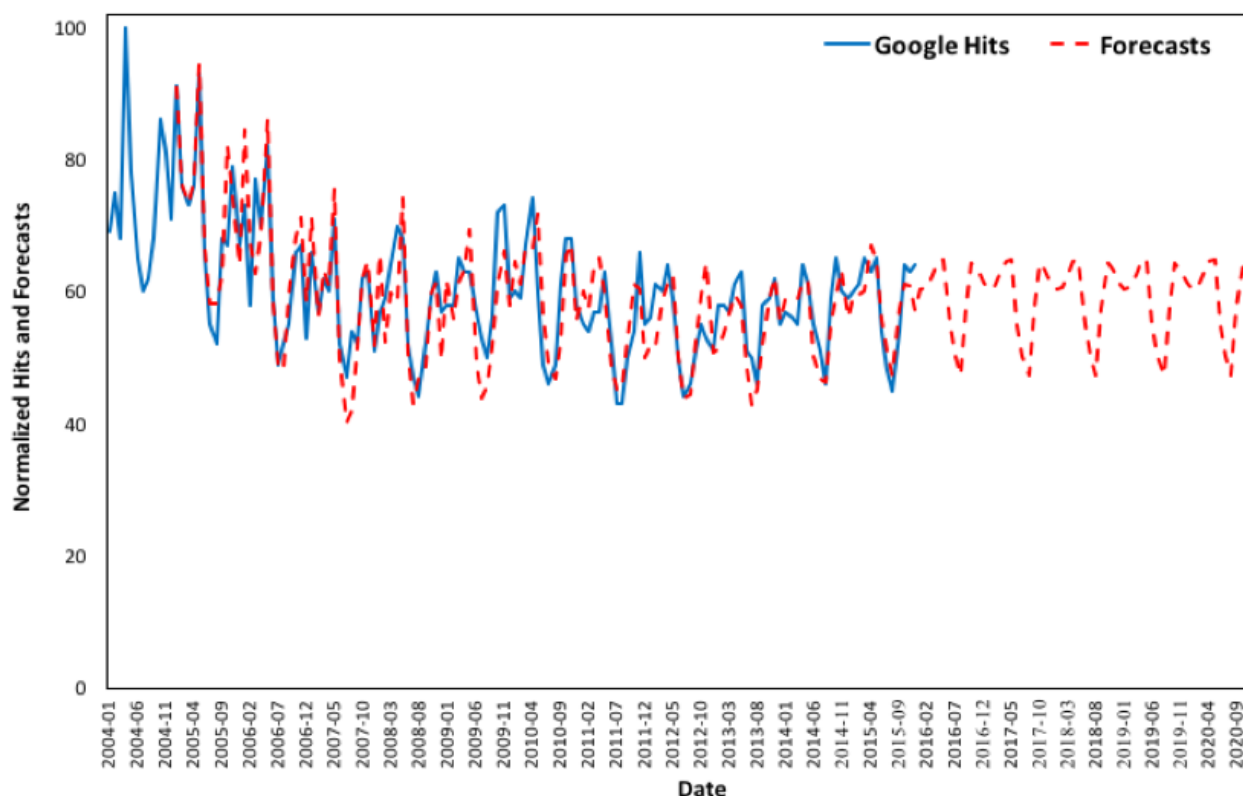


Figure 11. Google Trends (2004 to 2015) versus forecasts (2005 to 2020) in New York.

Discussion

Principal Findings

In addressing integration of smart health into smart city management, monitoring of search traffic data could be useful in predictions and nowcastings, as has also been suggested by previous work on the subject. This study shows that online interest can be predicted nationally and by state. Therefore, governments, policy makers, and health care officials have the ability to use these data to better address the responsiveness of the US health care system at national, regional, state, or even city level in order to nowcast asthma prevalence. Google Trends also provides detailed regional US data, and this method can be applied in other countries as well.

Empirical relationships between Google Trends and human behavior have been suggested, therefore nowcasting asthma prevalence in the United States is possible using online search traffic data, subject to availability of daily, weekly, or monthly data. In this study, it was shown that online search traffic data are highly correlated between each 2 years during the examined period and that Google Trends data are correlated with reported cases of lifetime and current asthma in the United States from 2004 to 2015.

After analyzing changes in online interest in the United States over the examined period, the next step was to identify any seasonal similarities between each 2 years' (monthly) search queries. As the hits between each 2 years from 2004 to 2015 on the term "asthma" were highly correlated, the seasonal effect was evident; using Holt-Winters exponential smoothing, 5-year

forecasts for online interest in the term from 2016 to 2020 nationally and in each state were estimated. Validated against available data from January 2016 to June 2017, the forecasts were well fitted and accurately approximated the actual Google Trends data for the same period, suggesting seasonal behavioral changes over the course of a year can be accurately predicted using the proposed method. Google Trends data are correlated with reported cases of lifetime and current asthma, and thus nowcasting asthma prevalence in the United States is suggested to be possible using online search traffic data. As the calculated correlations are negative at this point and there is a lag between internet queries and asthma reporting and vice versa, short-interval data (eg, monthly, weekly, and daily—not available at this point) are required in order to identify said lag.

Limitations

This study has limitations. It cannot be assumed that each hit corresponds to an asthma case and vice versa because hits could be also attributed to academic or research reasons or general interest on the subject, and they could be influenced by news reports or social media. Queries related to asthma could be also influenced by factors such as changes of health insurance and weather or environmental conditions that trigger similar symptoms. This is a general limitation when examining online queries, despite the empirical relationships that have been shown to exist between Google Trends and health data.

The sample is not representative, although as internet penetration increases, so does the possibility of higher volumes of online queries being related to asthma cases. Additionally, nowcasting asthma prevalence using online search queries is not possible at this point because the available data on reported lifetime and

current asthma are yearly. If monthly, weekly, or daily data on past asthma prevalence were available and the correlations between search traffic data and reported asthma are validated, the possibility of nowcasting asthma could be further explored.

This study has not accounted for state-by-state confounders that could influence search patterns, such as the socioeconomic status and demographics of different states that might be relevant to asthma prevalence, as this exceeds the scope of this paper. The latter, along with the impact of socioeconomic and cultural differences on asthma reporting and online search patterns, are of interest for further investigation. In addition, more search terms related to asthma symptoms such as “breathlessness” and “wheezing” could be included in future research on asthma monitoring in the United States.

Conclusion

The findings of this study support previous work on the subject and highlight the value of online data in health and medical informatics. Google Trends data have been shown to be useful and valuable in the monitoring, surveillance, or prediction of epidemics and outbreaks [20,25-26,56], as have been various other internet sources such as Twitter [57], medical portals [58], and Baidu [59]. Google queries provide us with the revealed and not the stated user interest contrary to traditional survey methods [60], and the use of Web data will benefit the

exploration of behavior in medical issues [61]. Data from traditional sources and big data should be combined in order to take full advantage of all available information [62]. When daily, weekly, or monthly data on reported asthma cases are made available, data from online sources like Google Trends could be used centrally and then applied by state or used by each city or state individually, assisting with the integration of the smart health concept in smart city management.

Internet behavior can be measured by infodemiology metrics as information patterns and population health are related [30]. Surveillance of asthma is mainly assessed through nationwide surveys and interviews, and data on asthma prevalence are only available long after the cases of asthma are reported. Nowcasting Google queries on selected terms related to asthma could assist health officials at both national and state levels to detect any behavioral variations toward the disease, providing time-effective allocation of resources and a more cost-effective approach to asthma assessment. This study suggests a relationship between asthma prevalence and Google Trends data. In the future, analysis of online queries could be valuable in the monitoring and evaluation of the responsiveness of the US health care system to asthma patient admissions and prescription drug needs, as well as assisting with the implementation of targeted health interventions and campaigns during periods when increased asthma admissions are predicted.

Conflicts of Interest

None declared.

Multimedia Appendix 1

State data tables.

[PDF File (Adobe PDF File), 52KB - [publichealth_v4i1e24_app1.pdf](#)]

Multimedia Appendix 2

Google Trends (2004 to 2015) versus forecasts (2005 to 2020) by state.

[PDF File (Adobe PDF File), 3MB - [publichealth_v4i1e24_app2.pdf](#)]

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Abbreviations

BRFSS: Behavioral Risk Factor Surveillance System

CDC: Centers for Disease Control and Prevention

NHIS: National Health Interview Survey

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Original Paper

Relationships Among Tweets Related to Radiation: Visualization Using Co-Occurring Networks

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Abstract

Background: After the Fukushima Daiichi nuclear accident on March 11, 2011, interest in, and fear of, radiation increased among citizens. When such accidents occur, appropriate risk communication must be provided by the government. It is therefore necessary to understand the fears of citizens in the days after such accidents.

Objective: This study aimed to identify the progression of people's concerns, specifically fear, from a study of radiation-related tweets in the days after the Fukushima Daiichi nuclear accident.

Methods: From approximately 1.5 million tweets in Japanese including any of the phrases "radiation" (放射線), "radioactivity" (放射能), and "radioactive substance" (放射性物質) sent March 11-17, 2011, we extracted tweets that expressed fear. We then performed a morphological analysis on the extracted tweets. Citizens' fears were visualized by creating co-occurrence networks using co-occurrence degrees showing relationship strength. Moreover, we calculated the Jaccard coefficient, which is one of the co-occurrence indices for expressing the strength of the relationship between morphemes when creating networks.

Results: From the visualization of the co-occurrence networks, we found high citizen interest in "nuclear power plant" on March 11 and 12, "health" on March 12 and 13, "medium" on March 13 and 14, and "economy" on March 15. On March 16 and 17, citizens' interest changed to "lack of goods in the afflicted area." In each co-occurrence network, trending topics, citizens' fears, and opinions to the government were extracted.

Conclusions: This study used Twitter to understand changes in the concerns of Japanese citizens during the week after the Fukushima Daiichi nuclear accident, with a focus specifically on citizens' fears. We found that immediately after the accident, the interest in the accident itself was high, and then interest shifted to concerns affecting life, such as health and economy, as the week progressed. Clarifying citizens' fears and the dissemination of information through mass media and social media can add to improved risk communication in the future.

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KEYWORDS

Twitter; social media; public concern; nuclear power plants; morphological analysis; network analysis; radiation

Introduction

On Friday, March 11, 2011, a magnitude 9.0 earthquake occurred 24 km off shore in the Tohoku region in eastern Japan. The tsunami generated by that Great East Japan Earthquake also caused enormous damage. In addition to the loss of human life, serious damage was done to the Fukushima Daiichi Nuclear Power Station. Reactors 1-3, in operation at the time, were automatically shut down, with loss of all electrical power, including emergency power, due to the tsunami. Without power to control the station, there was a reactor core meltdown and hydrogen explosion, releasing the radioactive substances iodine-131 and cesium-137. The Fukushima Daiichi nuclear accident had worldwide repercussions and was classed as a level 7 disaster (severe incident) on the International Nuclear and Radiological Event Scale, similar to that for Chernobyl [1].

Soon after such accidents, public opinions are formed and expressed through various platforms including social networking sites. Twitter is one such platform that allows users to communicate information in tweets up to 140 characters in Japanese language on an individual, specified group, or global basis [2]. Twitter is easy to use because it is available on multiple devices, including mobile phones. People provide and share initial information and real-time situation updates during various crises [3]. The temporal, spatial, and social dynamics of Twitter activity have intrigued many researchers in developing applications to facilitate early event detection and increase situational awareness [2].

In March 2011, there was a large number of Twitter users in Japan. At the time of the earthquake, communications were cut or limited because telephone networks were seriously damaged by the earthquake itself and the subsequent tsunami waters and power loss. Telephone services were also severely affected by heavy use. Twitter was used as a means of communicating information [4]; however, uncertain information, misinformation, and rumors may have contributed to social anxiety and confusion.

Twitter research on the Fukushima Daiichi nuclear accident has focused on the formation of an online community [2], tracking the public mood of the population [5], and sustained interest in accidents [6]. As far we know, however, few studies have revealed specifically what kind of information was spread and what may have incited fear among people dealing with the accident. If an event similar to Fukushima Daiichi nuclear accident were to occur in the future, then understanding changes in people's concerns and fears early on would be beneficial in providing appropriate governmental responses. To ensure appropriate risk communication [7,8] in such a situation, identifying how people's interests (especially fears) change over time would be beneficial. Providing appropriate risk management processes in advance may reduce the potential for larger issues emerging.

To assist in appropriate risk communications during future events similar to the Fukushima Daiichi nuclear accident, this study aimed to identify and understand changes over time in

people's concerns, specifically fear, from an examination of radiation-related tweets.

Methods

Research Data

The data used in this research consisted of 1,457,230 tweets that included any of the terms "radiation," "radioactivity," and "radioactive substance(s)" that were communicated from March 11-17, 2011. Tweets were divided by day.

Extraction of Relevant Tweets

We used the AWK programming language [9] in this research. AWK is designed to handle text files and is characterized by its powerful capabilities of matching standard expressions. Using AWK, data from each day were processed using the following steps: (1) extraction of only those tweets containing an expression suggesting fear, (2) deletion of user and URL information, and deletion of the spaces before and after tweets, and (3) deletion of identical text.

In focusing on fear-related tweets, 89 expressions were found, including those using Japanese language postpositional particles and parts of speech, as well as expressions using hiragana and katakana Japanese text characters. Table 1 shows examples of the expressions, and the English translation is described with reference to WordNet [10].

Deleting user details, URLs, and extra spaces ensured that only the tweets themselves were extracted. Moreover, since many of the identical texts had spaces before and after said text, these texts would have been considered not exactly identical. These spaces were eliminated.

When deleting duplicate text, identical text was classified as BOTs (ie, abbreviation of "robot"; automatically tweeted items), official retweets (ie, without changes, of another person's tweet), and unofficial retweets (ie, transmission of another person's tweet with additional comments by sender). As unofficial retweets are considered useful for reading the thoughts of senders, BOT and official retweets were deleted, and only unofficial retweets were used for this study. We classified BOT as a tweet that is linked to "BOT" in the username or profile.

Morphological Analysis

Morphological analysis is a basic technique used in the field of natural language processing to break down a given text to its morphological elements (ie, morphemes), or the smallest elements in a language that still have meaning. Morphological analysis not only divides given text into morphemes, but it also provides information on the parts of speech and usage, etc, of these morphemes. Morphological analysis is used when one wants to confirm how many times a certain term was used and is indispensable for Japanese text analysis, such as the extraction of keywords.

In this study, we used the morphological analyzer, MeCab (version 0.996) [11], to perform morphological analysis of each tweet that included fear. Figure 1 shows an example of morphological analysis.

Table 1. Category of expressions that suggest fear in Japanese (examples).

Japanese	English
恐怖, 怖れる, 恐れる, 畏怖	fear, dread
心配, 不安, 危惧	fear
悪寒	shiver, shake, tremble
絶望	despair, desperation
悲鳴	scream, shriek, screaming, shrieking, screech, screeching
おぞましい, 怖い, 恐い	terrible, dreadful, frightening, awful, fearful, dire, “direful”, dread, dreaded, fearsome, horrendous, horrific
蒼白	pale
案じる	consider, debate, deliberate, moot, turn over
悪夢	nightmare, incubus
やばい, ヤバい	serious, grave, dangerous, grievous, severe, life-threatening
戦慄, 震える	shiver, shudder, thrill, throb
恐ろしい	frightful, awful, terrible, tremendous

Figure 1. Example of morphological analysis in Japanese.



Table 2. Visualization conditions of co-occurrence networks.

	Conditions
Jaccard index	≥0.1
Number of appearance terms	From 100-150 words
Part of speech	Noun, verb, adjective, adverb, personal name, geographical, unknown part of speech (words not included in the morphological analysis dictionary)
Drawing conditions of network diagram	Strong co-occurrence relationships are thicker lines A word with a larger number of occurrences has a larger circle Arrangement that labels do not overlap Detect subgraph

Co-Occurrence Rate and Network

Co-occurrence indicates that morphemes A and B were used at the same time. Co-occurrence rate is an index for expressing the strength of the relationship between morphemes. Although other calculation methods exist for ascertaining co-occurrence rates, computations were made in our study using the Jaccard coefficient expressed by the following mathematical formula:

$$\text{Jaccard coefficient} = F_i / (F_1 + F_2 - F_i)$$

where F_1 is the frequency of morpheme A’s appearance within all tweets, F_2 is frequency of morpheme B’s appearance, and F_i is the frequency of the simultaneous appearance of morphemes A and B.

A co-occurrence network uses the appearance frequencies and co-occurrence frequencies of each morpheme and is a quantitative depiction of the relationship among morphemes frequently expressed within a text, and morphemes frequently co-occurring with these morphemes. This study provides a graphic depiction of the co-occurrence networks of the relationships between various morphemes appearing in citizens’ tweets. These networks help us ascertain the concerns of the public. This study is limited to only those tweets that include expressions suggesting fear. We used the software, KH Coder [12], for visualizations. Table 2 shows the visualization conditions within KH Coder.

Results

Research Data

There were 82,905 tweets (5.7%) excluding BOTs and official retweets. The number of tweets per day and examples of new words that had not appeared before, on each day, are shown in [Table 3](#).

Co-Occurrence Networks

[Figures 2-8](#) show co-occurrence networks for March 11-17, 2011. In the co-occurrence network for March 11, the Fukushima Daiichi Nuclear Power Station group that is highlighted in red shows many Fukushima Daiichi Nuclear Power Station related terms and is a characteristically large group formation. [Figure 2](#) shows the existence of tweets that fanned people's worries.

In the co-occurrence network for March 12, just as for March 11, Fukushima Daiichi Nuclear Power Station again forms a large group. A new group related to health has appeared, centered on the terms "health," "damage," "human body," and "x-rays" ([Figure 3](#)).

On March 13, Fukushima Daiichi Nuclear Power Station, which was an extremely large group on March 12, now shows fewer related terms. This suggests the appearance and spread of new areas of concern other than Fukushima Daiichi Nuclear Power Station. The new topic of concern is health, which first appeared on March 12, and mass media ([Figure 4](#)).

The co-occurrence network for March 14 again shows citizen concern focused on health and mass media. Also appearing on this day are apprehensions about the impact of radiation spread by winds, as well as radiation contamination of foodstuffs. Other new terms appearing are "Tokyo" and "abroad" ([Figure 5](#)).

On March 15, a group of terms appears for material shortages, namely, "gasoline" and "food" ([Figure 6](#)).

On March 16, the small group formed the day before on material shortages in Iwaki City (Fukushima Prefecture) has grown to

a larger group, with the appearance of new terms, including "Iwaki," "request" (eg, for assistance)," "material goods," "support," "reach" (as in an item arriving at its destination), "government," "relief assistance," etc. Also trending this day on Twitter were terms not seen on March 15 or earlier, including "rumor," "cancer," "gag" (as in "joke," but can be negative), and "radium" ([Figure 7](#)).

In the co-occurrence network for March 17, the group concerning material shortages in the disaster-hit city, Iwaki, grew in size, while new terms such as "water" and "freeze to death" (literal sense) also appeared. Also, as on the previous day, trending terms were "acid," "bath," etc ([Figure 8](#)).

Comparing the network diagrams ([Figures 2-8](#)) with the new terms of each day ([Table 3](#)), the newly appearing groups tended to include newly emerged terms on that day.

Friday, March 11

Analysis of the group of tweets concerning "Fukushima Daiichi Nuclear Power Station" appearing in the co-occurrence network March 11 showed that many citizens used Twitter to disseminate reports from the mass media directly after the accident. Thus, media reports had a large impact on citizens, with expansion of the group regarding "Fukushima Daiichi Nuclear Power Station."

Saturday, March 12

Analysis of the group of tweets concerning health in the co-occurrence network for March 12 showed that this was instigated by a statement made by a radiologist on television: "It is difficult to think of any health damage occurring in regions not affected by the evacuation advisory." Another characteristic of the co-occurrence network were expressions used in the mass media referring to Fukushima Daiichi Nuclear Accident as a "second Chernobyl." Thus, just as on the previous day, expressions from media reports appeared in the co-occurrence network, meaning that such reports had a major impact on citizens.

Table 3. Number of tweets each day and examples of new words appearing each day.

	March 11	March 12	March 13	March 14	March 15	March 16	March 17
Tweets, n	6262	16,430	4879	4922	23,945	16,735	9732
Examples of words	<ul style="list-style-type: none"> • nuclear • Fukushima • fear • refuge • residents • water level • earthquake 	<ul style="list-style-type: none"> • explosion • operation • informa-tion • damage • human body • Roentgen • health 	<ul style="list-style-type: none"> • radiation • exposure • rain • technology • despair • dose • media • Kombu 	<ul style="list-style-type: none"> • pollution • Tokyo • Japan • hydrogen • scattering • Tokai • foreign country 	<ul style="list-style-type: none"> • economy • observa-tion • self-con-trol • one's home • gasoline • saving • food 	<ul style="list-style-type: none"> • goods • country • cancer • reach • help • Iwaki • relief 	<ul style="list-style-type: none"> • water • numerical number • shortage • self-de-fense forces • acid • cold death • bath

Figure 2. Co-occurrence networks on March 11.

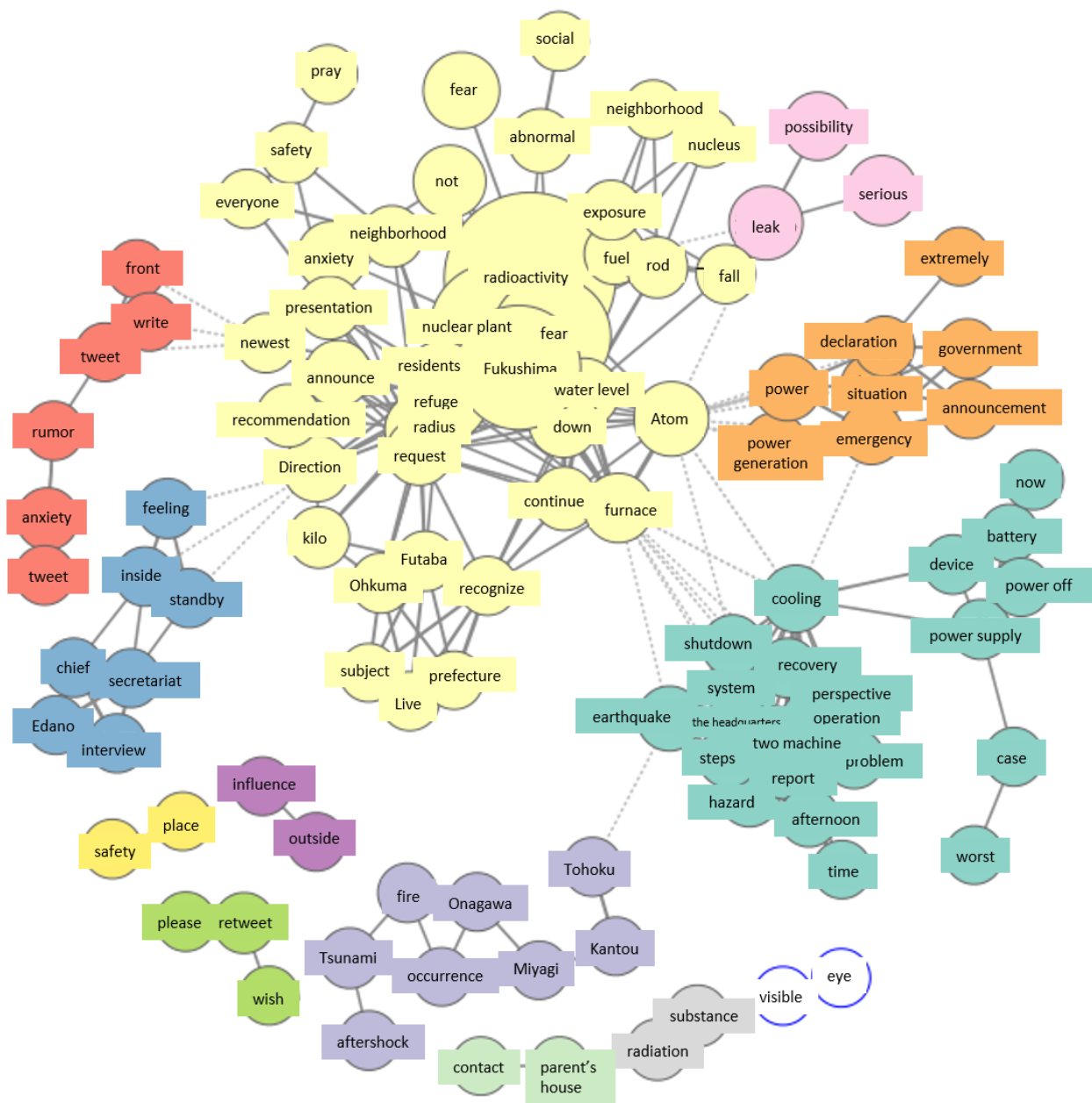


Figure 3. Co-occurrence networks on March 12.

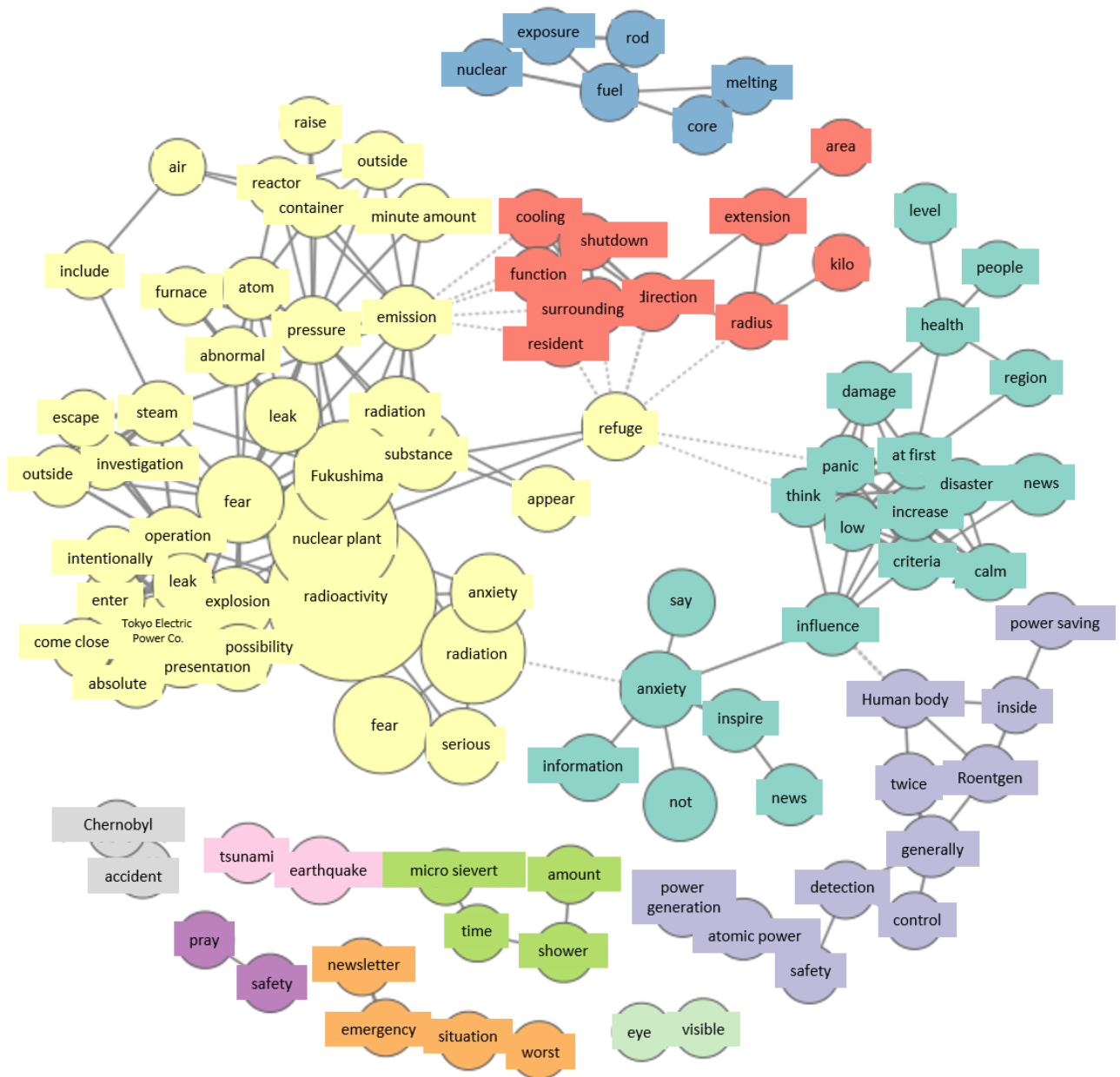


Figure 4. Co-occurrence networks on March 13.

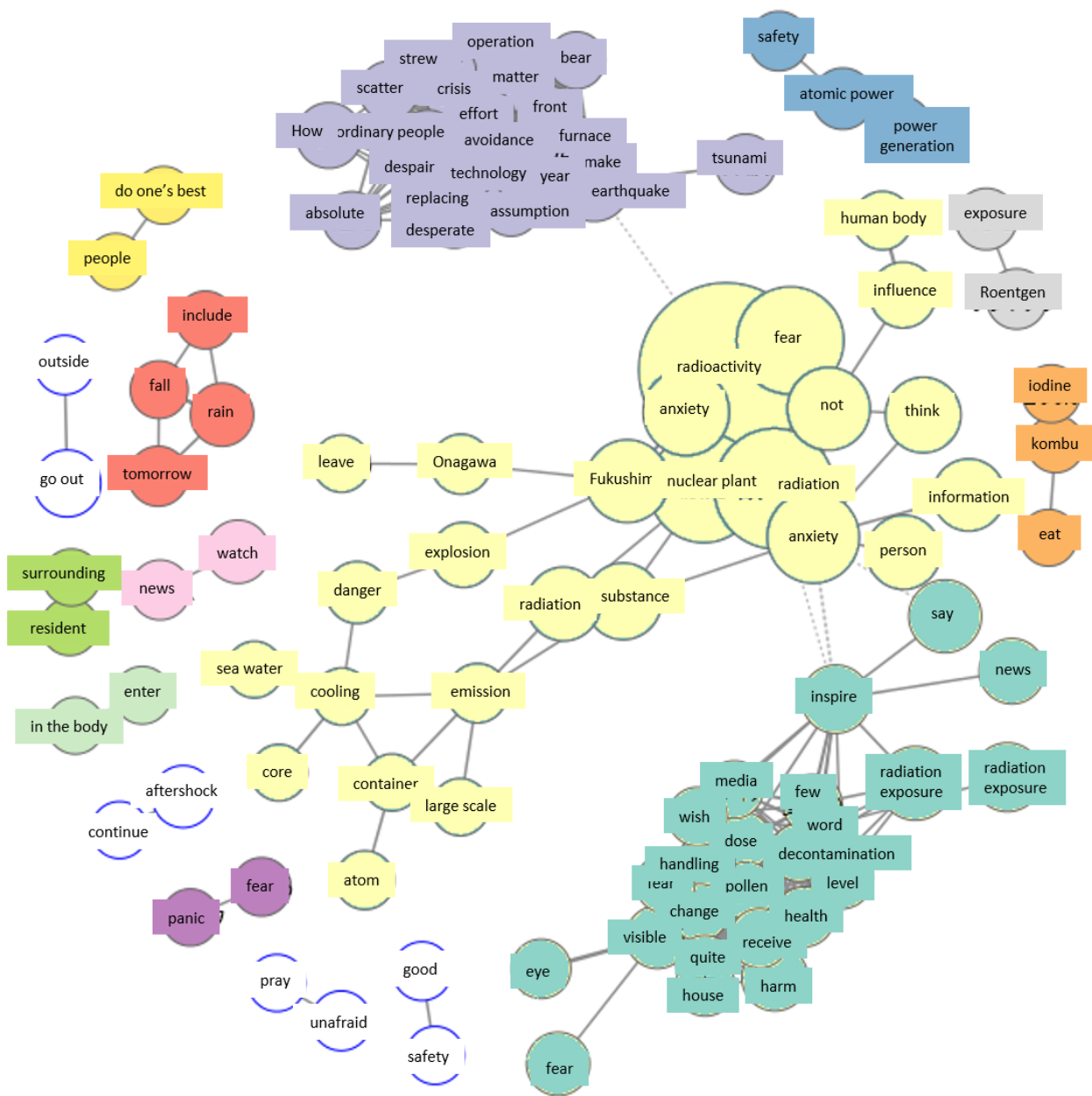


Figure 5. Co-occurrence networks on March 14.



Figure 6. Co-occurrence networks on March 15.

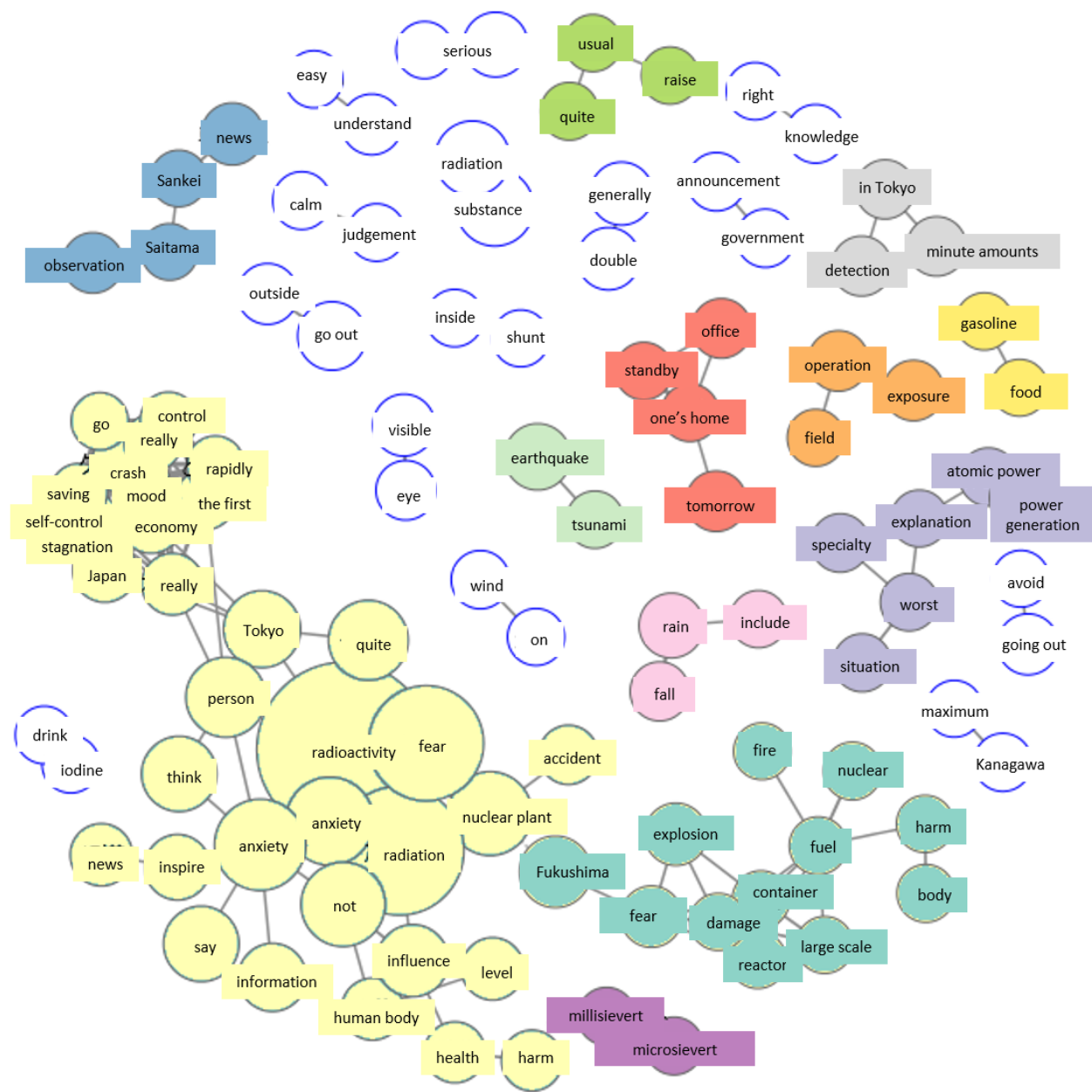


Figure 7. Co-occurrence networks on March 16.

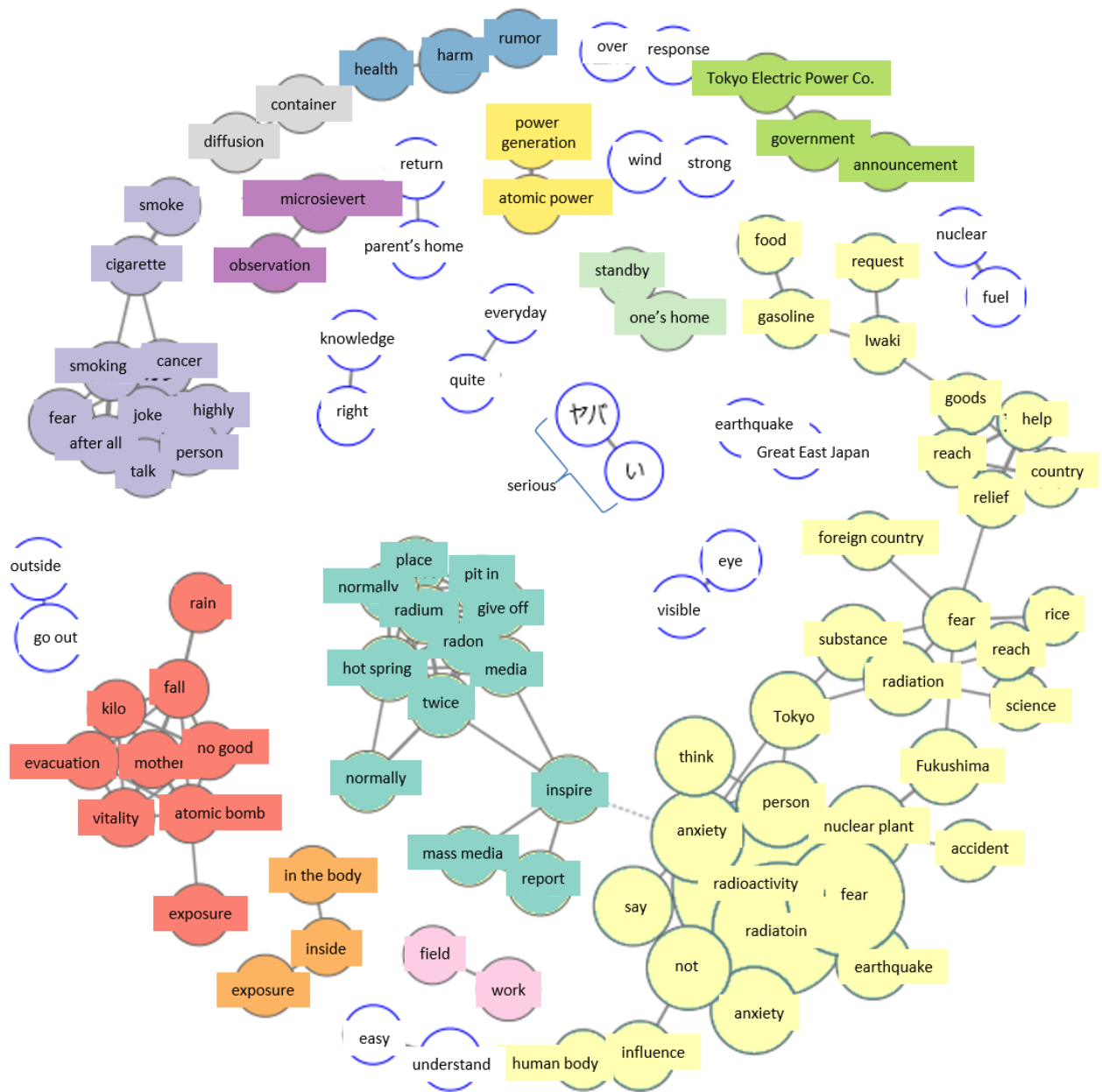
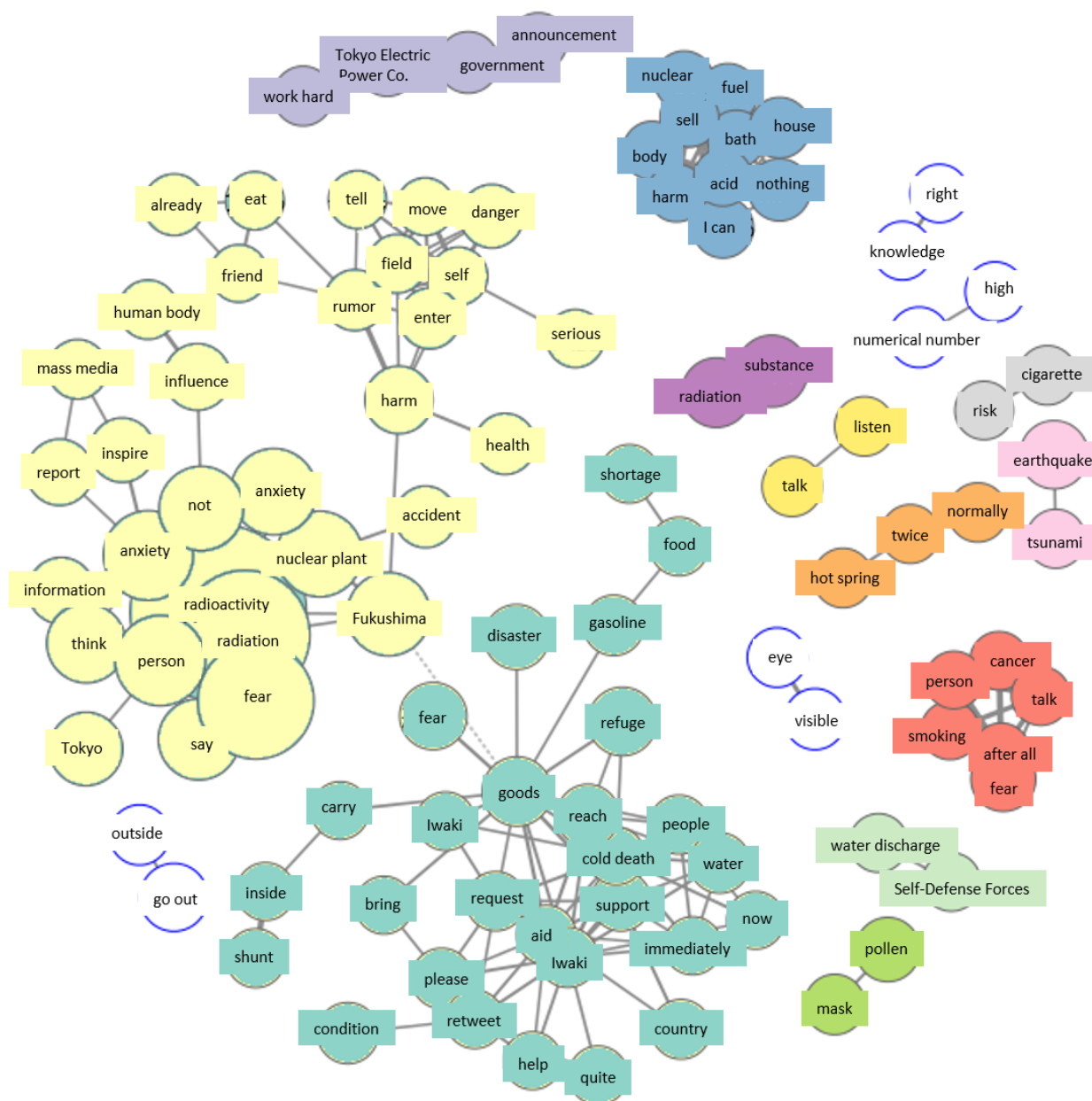


Figure 8. Co-occurrence networks on March 17.



Sunday, March 13

Analysis of the group of tweets concerning health and the media outlined in blue were centered on health-related reports in the media, including discontent with the way mass media presented information, summed up as, “They should not be reporting on whether we have been exposed to radiation, but instead to what extent we have been exposed, and what effects such exposure might have on health.” Also included were statements referring to measures for preventing internal radiation from iodine-131, such as eating seaweeds with trace amounts of iodine. Others worried about the effects of radioactive rainfall. Considering that media report contents had appeared in the co-occurrence networks for March 11 and 12, the group for “Fukushima Daiichi Nuclear Power Station” was smaller on March 13 than on the previous day, with expansion of the group related to

health. We believe this reflects the increased media reports about the effects of radiation on the body.

Monday, March 14

Analysis of tweets with the words “Tokyo” and “abroad” suggests that foreigners living in Tokyo were evacuating the city for points in Japan west of the capital. One factor is thought to be that reports in foreign media about the nuclear accident were causing people living outside Japan to tell their family members living in Tokyo to evacuate the city. It is thus assumed that the Fukushima Daiichi nuclear accident had become a huge concern in the foreign media and for people outside the country.

Tuesday, March 15

Analysis of the new group of tweets concerning “the economy” led to consideration of several factors, including reports in the Sankei Shimbun newspaper of “radiation reaching 20 times

normal levels in Saitama and 40 times normal levels in Tokyo,” and the fact that a famous entrepreneur, Takafumi Horie, had tweeted his opinions regarding the effects of radioactive substances on the Japanese economy. Tweet analysis also showed that citizens were agreeing with the thoughts expressed by famous people on Twitter. This suggests that even after such an accident, celebrities had a major impact on ordinary Japanese citizens. Analysis of the group of tweets concerning material shortages showed that, due to gasoline and food shortages, many of the citizens of Iwaki City were unable to evacuate and were forced to stay in that city.

Wednesday, March 16

Analysis of the material shortages group of tweets, which had expanded from the previous day, showed that accident areas were impacted by rumors that the news media and materials transport companies were hesitating to enter accident areas. Reports in the media about material shortages first appeared March 16. In addition, the fact that the material shortages group was already appearing in the March 15 co-occurrence network suggests that trending issues on Twitter can appear in a co-occurrence network without the influence of media reports. Newly appearing terms on this day, such as “cancer,” “gag,” and “radium,” were the result of numerous people in the surrounding areas sending unofficial retweets.

Thursday, March 17

The increased size of the material shortages group in accident areas on this day compared to the previous day was due to the increase of terms related to such material shortages. It seems to have occurred as the result of media reports of Fukushima Prefecture’s official request to the national government for relief. People surmised, therefore, that this request reflected the lack of goods in accident areas. This group was the result of unofficial retweets, just as with the terms “cancer” and “gag” on March 16.

Sources of Citizen Concern

We analyzed changes in citizens’ concerns in the visualization of the co-occurrence networks, finding the following changes in areas of concern: March 11 and 12, “nuclear power plants”; March 13 and 14, “health,” “media”; March 15, “economy”; March 16 and 17: “material shortages in accident-stricken areas.” Next, we tried to understand how such concerns grew in importance by identifying the mechanisms behind the occurrence of these concerns.

Concerns about “power plant,” “health,” and “mass media” are thought to be due to the fact that citizens took information from mass media sources and then transmitted them on Twitter with their own opinion added. Table 3 shows a timeline of power plant accident related words.

Groups concerned with “power plant” appearing on co-occurrence networks were the result of daily, detailed reports in the media following the accident. Health-related groups appeared from March 12 on. Although an evacuation advisory was issued on March 11 for a 3 km area surrounding the plant, this is deemed to have been too small for people to have become concerned about their health. On March 12, however, the media

reported that the evacuation zone had been extended considerably to 20 km, and this is thought to have stirred up citizens’ concerns for their health. Further, starting March 13, the media fanned people’s fears by repeatedly stressing that the accident was “at the same level as Three Mile Island,” or that radiation levels had increased “by several 10s or even 100s of times above normal,” resulting in the increase in health-related groups in the co-occurrence networks. People are assumed to have turned their attention to the mass media because it was producing reports that incited people’s anxieties.

The term “economy” appeared in the March 15 co-occurrence network. Among the days studied, March 15 was the only day when special concern for the economy became a trending topic. Analysis of related tweets showed that Takafumi Horie had used Twitter to communicate his opinions. His tweets reverberated among citizens:

The worst thing that could happen would be for people to leave Tokyo and slow down the economy, or cause the economy to stagnate due to a mood of self-restraint. Frugality and self-restraint will certainly cause the Japanese economy to crash. And that is more fearful than radioactivity.

People began to worry about the economy, which was manifested in such tweets as:

I’ll keep working on what I can do tomorrow.

Tokyo and Saitama are far from Fukushima. Rather than worrying about radiation, pour your whole heart and soul into the rebuilding of the economy! Support the nation’s infrastructure, keep lots of money in circulation, and send lots of assistance money to accident-stricken areas. That is what we can do now. That is our mission.

It is thus clear that citizens’ concerns about the economy did not result from mass media reports, but instead from information communicated on social media sites like Twitter.

As for the co-occurrence network groups concerning material shortages in the accident zone city, Iwaki, there was an increase over the days in number of related terms used, even though they were all related to material shortages. This was a major characteristic of the co-occurrence networks. On March 15, the concern was about “gasoline” and “food”; on March 16, the terms were “Iwaki,” “gasoline,” “food,” “materials”; on March 17, these were “Iwaki,” “gasoline,” “food,” “materials,” “water,” and “shortage.” Analysis of material shortages related tweet groups showed that people in accident-stricken areas made requests for assistance:

Please, somehow understand that, even if we are instructed to evacuate, almost none of the citizens here have the means to evacuate! There is no gasoline left in this city. We do not have the water we need to wash away the radioactive substances [official retweet request; from Iwaki City]

We ask for help. The tsunami damage along the coast in Iwaki City, Fukushima Prefecture, as well as in Ibaraki Prefecture, which are parts that haven’t received much coverage, has left us hopeless. The

media won't report our situation because they are afraid of radiation. We don't have any food or gasoline.

After receiving these tweets from accident victims reporting on the accident situation, people in other areas began to send tweets requesting people to restrict their use of materials: "Harmful rumors are circulating about Iwaki City. It seems that excessive fears of radiation have caused a halt to transports into the city. Please conserve gasoline!" From the above, it is clear that the concern about "material shortages in accident-stricken areas" was not fostered by the mass media, but rather through the transmission of information on Twitter. On March 15, there were no reports in the media about material shortages being a serious problem. Only with the announcement on March 16 by Yukio Edano, then Chief Cabinet Secretary, did the media first report such shortages. This is thought to have stemmed from the harmful rumors circulating about Iwaki City, such that the news media and materials transport companies feared radiation exposure if they entered that city. However, that such shortages appeared on the co-occurrence network for March 15 suggests the possibility that people learned of the worries of Iwaki residents via Twitter more quickly than they did from media reports.

Discussion

Principal Findings

In this study, we analyzed trends in citizens' focus on Twitter after the Fukushima Daiichi nuclear accident. A better understanding of citizens' fears after such an accident can assist in improved risk communication and government response in

similar situations in the future. Based on the results of this study, we will attempt to estimate the number of tweets before the accident and analyze them in order to compare the data and clarify the changes in citizen interest before and after the accident.

Limitations

One point to be improved in this study is that of optimization of extraction conditions. One of Japanese expressions for fear, "恐れ," has two meanings: one is "fear" and the other is "dread." By using "恐れ" as the extraction term, it is possible that tweets with "fear" meaning "possibility" were mixed with those about "fear" meaning "dread." For example, many Fukushima Daiichi nuclear accident related media reports included the use of "fear" with its meaning of "possibility," as in, for example, "there is fear of radiation leakage." People who encountered such reports may have therefore been influenced in the tweets they then sent. Thus, unnecessary terms that did not express people's fears (anxieties, dread) might have appeared in this study's co-occurrence networks. For future research, it will be necessary to optimize term extraction conditions.

Conclusions

This study used Twitter to understand changes in Japanese citizens' concerns in the week following the Fukushima Daiichi nuclear accident, with a focus specifically on citizens' fears. Immediately after the accident, the interest in the accident itself was high and then interest shifted to concerns about life, such as health and the economy throughout the following week. Understanding citizens' fears and the dissemination of information through mass media and social media can add to improved risk communication in the future.

Conflicts of Interest

None declared.

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Original Paper

Representations of Codeine Misuse on Instagram: Content Analysis

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Abstract

Background: Prescription opioid misuse has doubled over the past 10 years and is now a public health epidemic. Analysis of social media data may provide additional insights into opioid misuse to supplement the traditional approaches of data collection (eg, self-report on surveys).

Objective: The aim of this study was to characterize representations of codeine misuse through analysis of public posts on Instagram to understand text phrases related to misuse.

Methods: We identified hashtags and searchable text phrases associated with codeine misuse by analyzing 1156 sequential Instagram posts over the course of 2 weeks from May 2016 to July 2016. Content analysis of posts associated with these hashtags identified the most common themes arising in images, as well as culture around misuse, including how misuse is happening and being perpetuated through social media.

Results: A majority of images (50/100; 50.0%) depicted codeine in its commonly misused form, combined with soda (*lean*). Codeine misuse was commonly represented with the ingestion of alcohol, cannabis, and benzodiazepines. Some images highlighted the previously noted affinity between codeine misuse and hip-hop culture or mainstream popular culture images.

Conclusions: The prevalence of codeine misuse images, glamorizing of ingestion with soda and alcohol, and their integration with mainstream, popular culture imagery holds the potential to normalize and increase codeine misuse and overdose. To reduce harm and prevent misuse, immediate public health efforts are needed to better understand the relationship between the potential normalization, ritualization, and commercialization of codeine misuse.

(*JMIR Public Health Surveill* 2018;4(1):e22) doi:[10.2196/publichealth.8144](https://doi.org/10.2196/publichealth.8144)

KEYWORDS

prescription opioid misuse; social media; poly-substance use; Instagram

Introduction

Prescription Opioid Misuse

Prescription opioid misuse, defined by the National Institute on Drug Abuse as “the use of medication without prescription, in a way other than as prescribed, or for the experience or feelings

elicited” [1], has doubled over the past 10 years [2]. The rapid rise of prescription opioid misuse has been identified as a key public health problem by the 2016 US Surgeon General [3] and is the subject of the bipartisan Comprehensive Addiction and Recovery Act signed by President Obama in 2016 [4]. To inform opioid misuse prevention and treatment efforts, public health

leaders need a better understanding of the context, attitudes, and beliefs around these medications and their misuse.

Substance Misuse and Social Media Research

Researchers and public health advocates can use social media data to provide insight into real-time attitudes, beliefs, and misuse of prescription opioids because diverse individuals share opinions, information, and images via social media [5-8]. Individuals' posts on social media represent a lens through which researchers can examine risky behavior such as opioid misuse, while remaining unobserved themselves and thereby, mitigating the effects of observation bias [9-11]. Analysis of social media data may provide additional insights into opioid misuse to supplement the traditional approach of asking individuals to self-report behavior through surveys or interviews, similarly mitigating the effects of response bias [9].

Most studies characterizing prescription opioid misuse using social media have used text-based analysis of platforms such as Twitter [8,12]. For example, an analysis of Twitter conversations about nonmedical use of prescription opioids identified polysubstance use as a common theme, including combinations of classes of prescription drugs and illicit substances and the use of social media for trafficking prescription opioids [13,14]. Instagram, a primarily image-based tool, is the second most popular social media platform among teens, after Snapchat [15]. Given its prominence as a social media platform used to represent everyday life, Instagram-based research can help public health researchers discern attitudes and behaviors that may not be disclosed in more formal settings or through traditional research methodologies [16]. Instagram offers enhanced understanding of the functional context of and attitudes toward substance use through analysis of imagery, and it has been implicated as a more influential tool on substance use behavior than other forms of social media [17]. For example, one recent study categorized Instagram images of electronic cigarettes, highlighting the platform as a tool for supporting a vaping identity and for advertisers to reach a target audience of users [18]. Similarly, Cavazos-Regh et al describe how Instagram can offer insight into the patterns of marijuana use [19]. Furthermore, the sampling process is facilitated by the use of hashtags, words, or phrases preceded by the # symbol [20] that users incorporate in social media posts to contribute to, or create, an impromptu forum to discuss a specific topic or event by aggregating posts with the same hashtag.

In this paper, we sought to describe opioid misuse as depicted through images, videos, and captions publicly available on Instagram. We chose to focus on codeine because it has been hypothesized to be a gateway into opioid misuse and addiction [21]. Moreover, codeine misuse continues to increase despite rising costs for the drug and stricter regulations [22]. We chose to analyze images and videos on Instagram because it is the most popular social networking platform after Snapchat among US teens [15] who are the demographic group most at risk for initiating codeine misuse [21]. The purpose of this paper was to gain a better understanding of content related to codeine misuse as represented on social media to inform countermessaging and other public health efforts.

Methods

Study Design

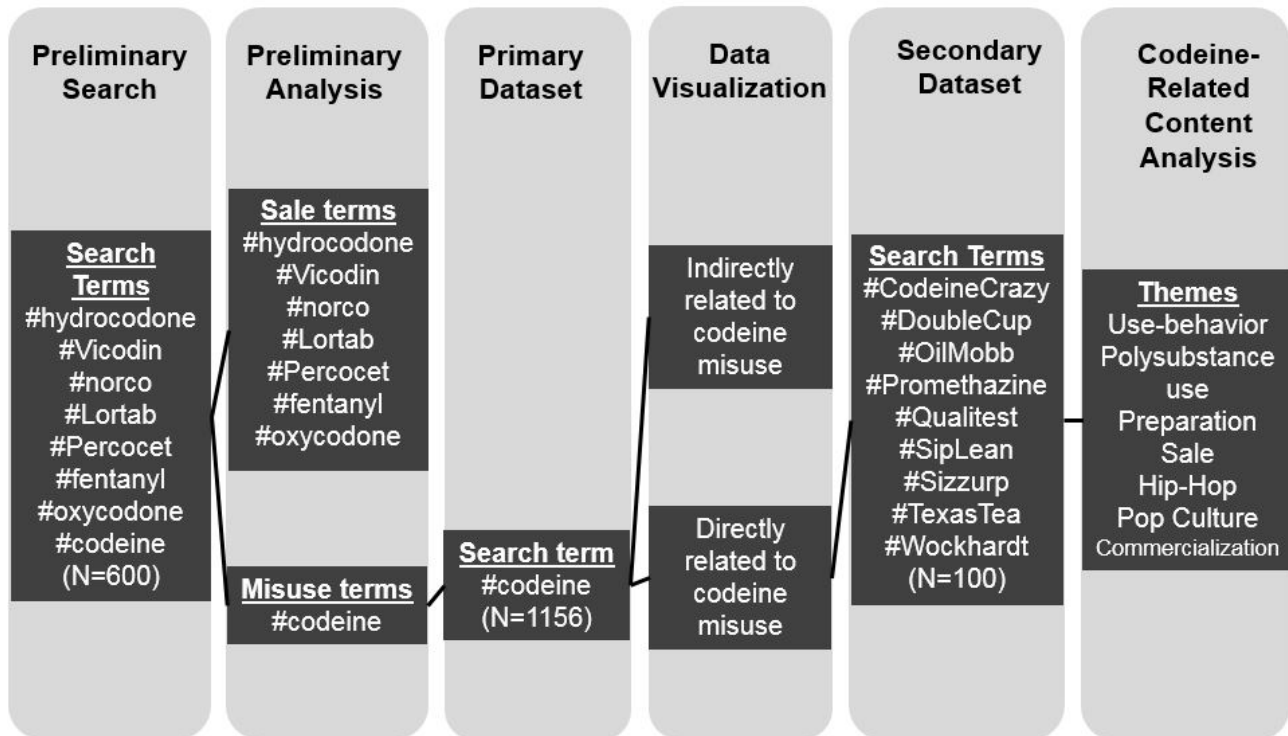
We collected and content analyzed publically available, user-generated content about prescription opioid misuse posted to Instagram to understand the motivations and narratives related to uptake and misuse. As we used publically available data and did not collect or store identifying information, the *University of California, San Francisco* Institutional Review Board determined that this study did not require review. For preliminary analysis, we explored posts tagged with hashtags derived from generic and brand names of opioids (eg, #*vicodin*). Except for posts under #*codeine*, other generic and brand names were predominantly associated with sale. For primary analysis, we downloaded and analyzed all posts under #*codeine* for 1 week, listing all of the other hashtags associated with these posts. Among these, we downloaded the first 10 posts under the 10 most salient codeine-related hashtags for secondary analysis. [Figure 1](#) visually represents our study design, which is described in detail below.

Preliminary Search

A preliminary analysis of Instagram posts related to opioids revealed that virtually all used multiple hashtags. We manually collected screenshots and video captures of posts with opioid-related hashtags, starting first with generic and brand names (eg, *hydrocodone* and *vicodin*) for opioid medications and then iteratively expanding the search terms as we uncovered the hidden lexicon of opioid misusers. Researchers conducted analysis of videos and images by noting the most prominent features in images and using a narrative summary for the videos. To uncover the hidden lexicon, we noted all of the hashtags that were associated with the posts we collected under #*codeine*. From there, we used simple counts to determine which of these associated hashtags were most prominently associated with codeine misuse ([Multimedia Appendix 1](#)).

We downloaded screenshots and video captures of the 75 most recent Instagram posts for the eight most common opioid hashtags for this preliminary search (#*hydrocodone*, #*vicodin*, #*norco*, #*lortab*, #*percocet*, #*fentanyl*, #*oxycodone*, and #*codeine*) on May 27, 2016. We selected these eight hashtags as they are all well-known generic or brand names for opioids [6]. Preliminary analysis demonstrated that, respectively, 56% (42/75), 59% (44/75), 87% (65/75), 72% (54/75), 39% (29/75), 78% (59/75), and 84% (63/75) of posts related to the hashtags #*hydrocodone*, #*vicodin*, #*norco*, #*lortab*, #*percocet*, #*fentanyl*, and #*oxycodone* depicted photographs of loose pills or pill bottles and appeared to offer to sell opioids or were ambiguous. Posts with the hashtag #*codeine*, however, depicted varied images and text related to codeine misuse, including but not limited to codeine misuse being associated with cartoon characters, hip-hop artists, and larger lifestyle choices. Given the high level of variability of imagery and its hypothesized role as a gateway to opioid misuse and addiction [21], posts with the hashtag #*codeine* demonstrated a clear public health significance and were thus chosen for further content analysis.

Figure 1. Study design.



Using the iterative sampling methods of grounded theory, we identified other opioid-related hashtags within #codeine posts to capture representations of codeine misuse that are not well known (eg, #sizzurp and #oilmobb) and identify slang terms for codeine, and thereby, understand how users represent misuse on Instagram [23]. The advantage of this approach is that it allows us to capture how users discuss codeine misuse on Instagram inductively and minimize the impact of our preconceived theories of misuse [23]. As the behaviors, as well as their associated meanings and representations tied to codeine misuse can change over time, it is important to have an agile, analytic approach capable of capturing not only preexisting patterns and narratives of misuse but new representations and subcultures as well.

Primary Data Acquisition and Sampling

We manually downloaded posts with the hashtag #codeine each day of the week to account for daily variation, beginning on July 10, 2016, and ending on July 16, 2016. Weekends had more posts with the hashtag #codeine, resulting in a range of 150 to 200 posts downloaded each day of the week. We set thematic saturation at the point where we began to see duplicate posts. We downloaded a total of 1156 posts for our primary dataset.

Primary Dataset: Data Visualization

The primary dataset comprised posts with the hashtag #codeine. For each post, we documented all listed hashtags and deductively designated them into lists of those that directly represented codeine misuse (eg, #CodeineCrazy) and those that did not (eg, #Trap) [24]. After sorting and counting terms directly and indirectly related to codeine misuse, we used

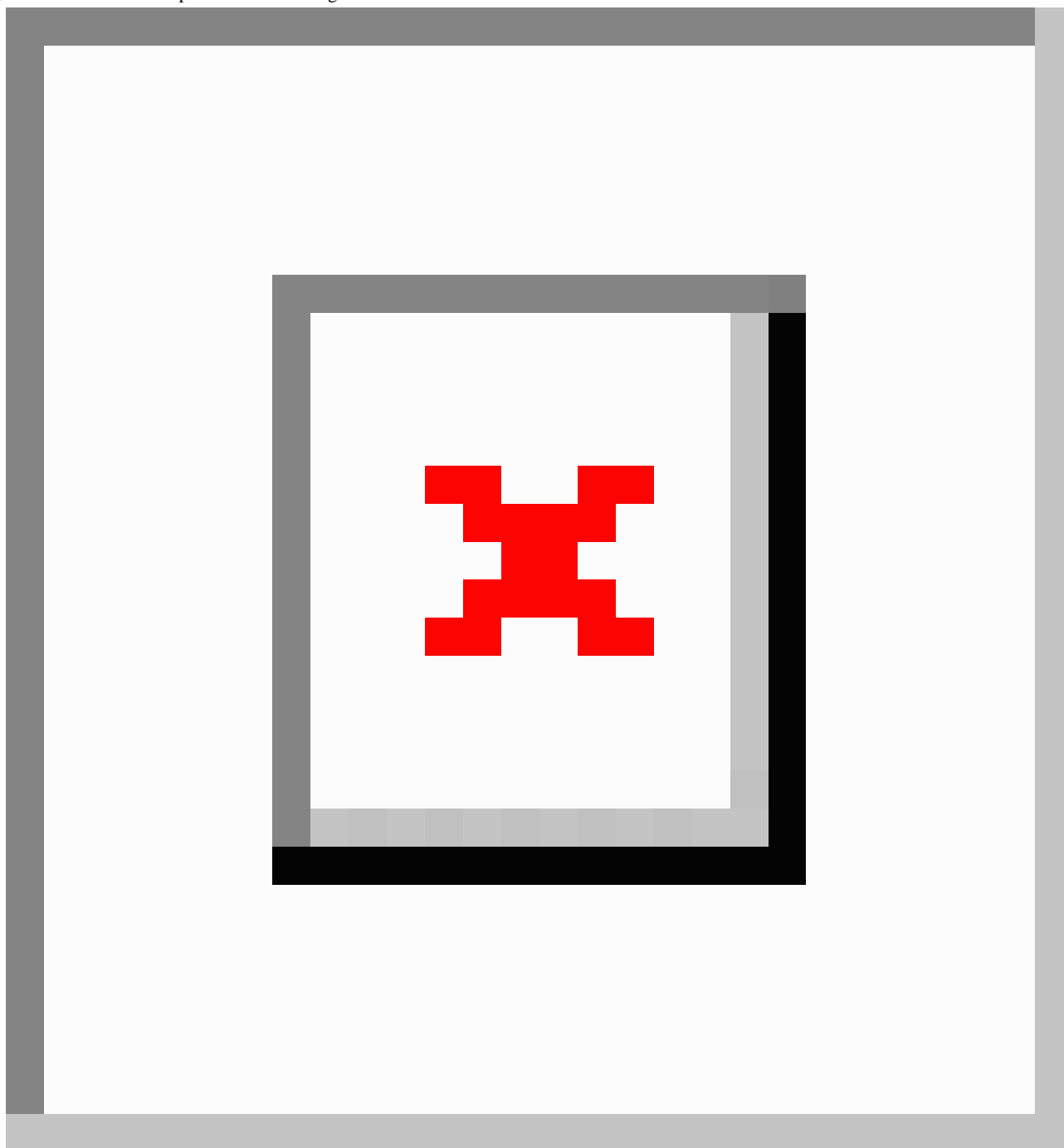
Tableau (Tableau Software), a data visualization software, to demonstrate the relative salience of slang terms for codeine misuse, as well as other terms associated with codeine misuse (Figure 2). In these visualizations, the size of each term corresponds to its frequency in the dataset and helps represent the hidden lexicon and social milieu of codeine misuse, respectively. From the list of hashtags that directly relate to codeine-misuse, we derived search terms for our secondary dataset.

Secondary Data Acquisition and Sampling

We used the 10 most common hashtags from the codeine-related list to identify a more focused sample of posts for our secondary dataset. A hashtag that was chosen had to have at least 1000 posts associated with it on Instagram and demonstrate codeine misuse in the top results shown by Instagram. Therefore, hashtags for secondary analysis not only had to be common in the initial sample, but also had to be commonly associated with codeine misuse on Instagram more broadly. Hashtags and their definitions are listed in Multimedia Appendix 1.

Secondary Dataset: Codeine-Related Content Analysis

For analysis, we focused on a total of 100 posts, derived from the first 10 unique posts under each of the 10 hashtags in Multimedia Appendix 1. These posts reflect 73 distinct individuals, of whom 13 posted more than one image in our sample. On average, Instagram users in our sample had 338 posts on their profile (range: 1-3018) and 1270 followers (range: 0-13,000+). Repeat posters were excluded from content analysis as their content was distinct and not relevant to the study question.

Figure 2. Most common opioid-related hashtags associated with #codeine.

We applied grounded theory's inductive approach for visual content analysis to code our secondary dataset [25]. As with the textual analysis for the primary dataset, this inductive approach to analyzing visual content allowed us to minimize the effect of personal bias surrounding codeine misuse. Through memo writing, we extracted the most salient features of each image or video. For example, a memo for a post demonstrating users preparing codeine for misuse: "user pouring codeine into a Styrofoam cup and mixing it with ice, soda and or hard candy." Recurrence of certain features or behaviors across multiple posts led us to distill these into themes, such as preparation of codeine. In this way, we produced an emergent coding scheme for our dataset. We discussed a sample of 25 posts (25%, 25/100) to reach consensus on this framework.

After the team developed a final coding scheme, RC and MW completed coding for the remaining posts. After all 100 images or videos were coded, RC then grouped codes under concepts and subsequently categorized these to come up with seven mutually exclusive themes: use-behavior, polysubstance use, preparation of lean, sale, hip-hop, pop culture, and commercialization. Although there is some conceptual overlap between themes (eg, use-behavior and polysubstance use), coders placed posts that were initially double-coded into the theme that most comprehensively captured its content after coming to consensus. Any discrepancies were discussed among team members, and a single theme was agreed upon.

Results

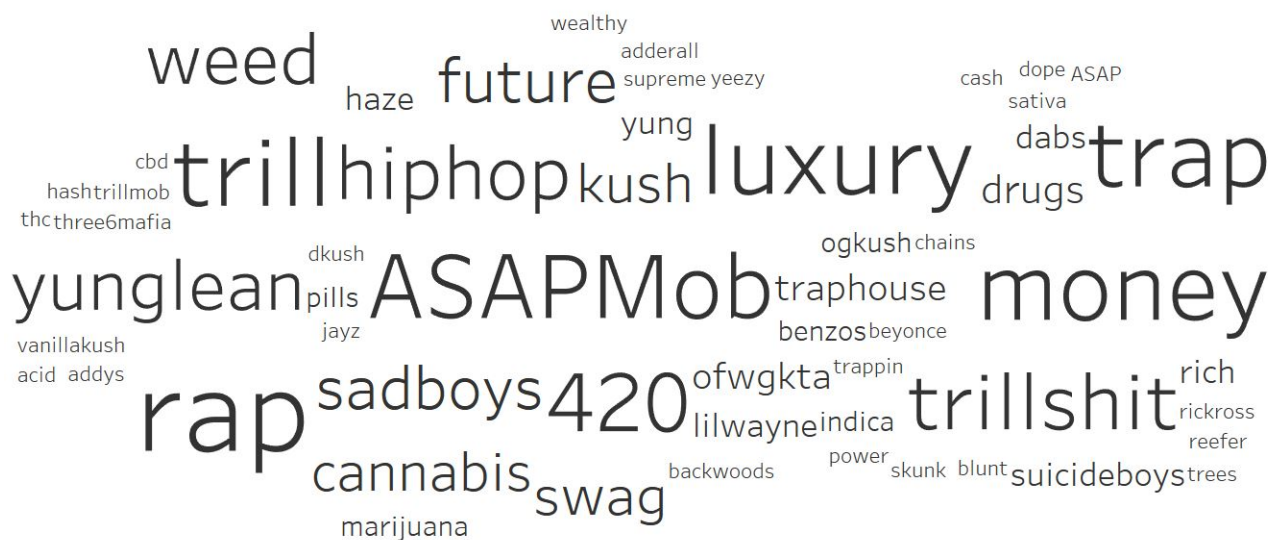
Primary Dataset: Data Visualization

Data visualization with prescription opioid hashtags demonstrated terms related to codeinemisuse (Figure 2) and to other activities that co-occurred with these hashtags (Figure 3). Among the terms related to codeine misuse, we came across a number of terms related to processing codeine into the form commonly used in nonmedical consumption, such as lean. Lean, also known as *sizzurp* or *purple drank*, is a concoction consisting of promethazine or codeine cough syrup, ice cubes, and soda, with the optional addition of hard candy [22,26]. Nonopioid hashtags that frequently occurred with codeine-related hashtags revealed a robust relationship between codeine misuse and polysubstance use, especially cannabis use (eg, *weed*, *cannabis*, and *kush*). Additionally, there was a less common association with hip-hop culture (eg, *hip hop* and *rap*; Figure 3).

Secondary Dataset: Codeine-Related Content Analysis

Definitions and examples of emergent themes are in Multimedia Appendix 2. The greatest proportion of posts were limited to images of codeine or lean in everyday places (*use-behavior*). Posts grouped under *use-behavior* contained images or videos of consuming in their homes, cars, or public places such as the beach. The preparation of codeine from a liquid, cough-syrup formulation into its misused form (ie, lean) was its own theme

Figure 3. Most common nonopioid-related hashtags associated with #codeine.



Finally, we also observed posts representing an affinity between codeine misuse in the form of lean and the chopped and screwed genre of hip hop described in previous work [27], as well as a novel association with the trap genre of hip-hop (*hip-hop*). Posts grouped under *hip-hop* featured recognizable recording artists (ie, Future) from this genre in either the imagery or the accompanying text of posts we grouped into this theme. Multimedia Appendix 2 represents definitions, counts, and frequency, as well as examples of each theme. As the sample is 100 posts, counts are equivalent to proportion for each category.

(preparation). Similar to use-behavior, posts grouped under *preparation* depicted the preparation, but not consumption, of lean in an array of common venues. The next most common type of post represented co-occurrence of codeine misuse with recreational alcohol, cannabis, and benzodiazepine consumption (*polysubstance use*). Posts grouped under *polysubstance use* depicted codeine alongside other intoxicants, concurrent consumption, and hashtagged (eg, #cannabis) in the caption. In our thematic framework, *use-behavior* is distinct from *polysubstance use*, in that we only applied the former to posts that showed codeine misuse exclusively, whereas we applied the latter to posts where users represented codeine misuse alongside alcohol or other drugs.

Next were posts those that sought to sell codeine illicitly (*sale*). We grouped posts under *sale* if they included a phone number or a prompt to direct message the user to make an inquiry or purchase. Images or videos with references to popular culture icons (*pop culture*) or those that evoked codeine misuse as a commodity (*commercialization*) were also featured in our sample. The posts grouped under *pop culture* often featured popular culture icons often associated with youth, such as Bart Simpson, Mickey Mouse, and Pokemon. Posts characterized as *commercialization* utilized narratives related to recreational codeine misuse to sell commodities such as a wine cozy with the word *Sizzurp*.

Terms directly referencing codeine misuse in the form of lean were the most prominent across this focused sample. Even after accounting for posts that were drawn into the sample because of a lean-specific hashtag (eg, #siplean, #sizzurp, and #texastea), 47 posts still had references to *lean*. Mentions of the brand names of codeine manufacturers were similarly prominent. Again, after accounting for posts that were drawn into the sample because of a brand-specific hashtag (eg, #actavis, #qualitest, and #wockhardt), 28 posts still had references to manufacturers of codeine.

Discussion

Principal Findings

Although further large-scale exploration is needed, our preliminary analyses of Instagram posts suggests that codeine misuse may be becoming normalized, commercialized, and ritualized. The most common theme uncovered was a simple visual depiction of lean, which is codeine cough syrup mixed with ice, soda, and occasionally hard candies (ie, Jolly Ranchers). Other prominent themes included depictions of codeine with other substances such as alcohol and cannabis and the preparation of *lean*.

With the majority of posts being limited to displays of preparation or consumption of lean in everyday settings, we can observe that codeine misuse has been integrated into the life of users as normalized, everyday—albeit ritualized—behavior. Moreover, these posts teach and normalize misuse while brazenly transgressing social and legal sanctions. Similarly transgressive, misusers' appropriation of household pop-culture icons (eg, Bart Simpson or Mickey Mouse or Pokémon) and their integration with lean subculture could make codeine use seem harmless and innocuous, coincident with its hypothesized spread beyond urban ghettos and toward younger, more affluent youth [26,28].

Another common theme in Instagram images was polysubstance use, reflecting findings in the literature that codeine is often combined with marijuana, alcohol, and benzodiazepines, which significantly increases the risk of harm, including overdose mortality, especially among teens [12,13,27,28]. The concurrent misuse of codeine and benzodiazepines is well-documented [29] and is associated with the overdose deaths of notable artists, including DJ Screw himself [22]. There is an urgent need for harm-reduction approaches that emphasize the heightened risks associated these forms of concurrent misuse alongside efforts for primary prevention.

Comparison With Prior Work

Our findings confirm prior work on opioid misuse using social media data [5-8]. In addition, as previous studies into codeine misuse have described [26,30], some posts in our sample referenced the *chopped and screwed* and *trap* subgenres of hip-hop. Although codeine misuse has existed in Houston since the 1960s and 1970s, its misuse in the form of lean only emerged in the 1980s and 1990s [22]. At this time, local hip-hop artists began incorporating references to its consumption in their music, which came to be known as *chopped and screwed* [22,31]. Chopped and screwed is a technique for remixing songs that was pioneered by DJ Screw in Houston, Texas, during the early 1990s [31]. *Chopped* alludes to the copy-cut-paste sampling technique and stutter effect used to chop up the original song to produce delays and repetition [31]. Although *screwed* was originally a namesake, it is now synonymous with the decreased tempo and thus pitched-down nature that characterizes the style, which the physiological effects of *lean* compliments [31]. Trap music is a subgenre of hip-hop also originating in the Southern United States marked by fast paced beats, synthesizers, and ominous, often nihilistic, lyrical content [32,33]. The term trap originated in Atlanta, Georgia and refers to drug corners and

the often inescapable lifestyle (ie, trap) associated with them [33]. Currently, trap music is aggressively marketed and features prominently among Billboard's top rap songs [34]. Knowing the history and context of codeine misuse is integral for researchers to understand its emergence and spread and ultimately develop appropriate interventions.

Furthermore, our findings demonstrate codeine misuse associated with American popular culture images. This suggests lean is becoming a more mainstream part of popular culture, potentially facilitated by the growing commercialization of trap music over the past decade [34]. Popular culture influences aside, the consumption of codeine in the form of a mixed drink (ie, lean) is inconspicuous and mimetic of a familiar and socially acceptable route of substance (alcohol) ingestion. The affinity between the consumption of codeine in the form of lean and mainstream social alcohol consumption may normalize misuse and promote uptake.

Although lean consumption remains linked to social marginalization [26] since the emergence of lean consumption in the 1980s, the illicit market for codeine has changed dramatically. Once cheaply available over the counter, codeine now requires a prescription or costs upwards of US \$1000 a pint on the street [22,35]. Its scarcity has imbued misuse with connotations of wealth, social capital, and exceptionalism. Given the new legal and financial constraints surrounding the procurement of codeine for misuse, it is unlikely that incidence of codeine misuse is occurring among previously studied populations [26]. Rather, we hypothesize that it is now more likely that incidence of misuse is occurring among novel populations who are socially and financially capable of appropriating the identity and lifestyles of mainstream celebrity trap artists (eg, Future) whose images remain prominent in this visual discourse.

The specificity of the narratives (eg, chopped and screwed or trap music) and paraphernalia (eg, double Styrofoam cups) associated with codeine misuse could speak to ritualized or performative activity [36]. Though apparently contradictory, ritualization does not necessarily proscribe normalization. Rather, ritualization is better understood as a process representing initiation into a particular social group that has its own unique sets of norms, practices, and aesthetics [37]. Correctly performing ritualized preparation of codeine cough syrup into the form of lean seems to signify participation or membership in a particular subculture. Similarly, references to trap and chopped and screwed in these representations of misuse speak to these as dominant narratives for codeine misuse. Novel populations of misusers may adopt these images to identify with this particular subculture, perpetuating its use over time [37].

Limitations

Given the known nonrepresentativeness of social media, our findings should be interpreted as capturing the behavior and narratives of only those misusers who can be identified through the content of their Instagram posts. Furthermore, preliminary analysis was derived from only 2 weeks' worth of publicly available data from Instagram. Consequently, our sample may not be representative of the full scope of codeine-related posts on Instagram. Relatedly, given the short sample period, there

is the possibility that our results are impacted by stationarity. Indeed references to Prince's death in the spring of 2016 saturated initial attempts at sampling when the study began. When we resumed data collection in summer 2016, no one theme seemed to dominate. However, further larger studies are necessary to confirm any such impact.

However, it was not our intention to undertake a comprehensive study of codeine misuse on Instagram. Rather, we sought to develop a general understanding of Instagram content related to misuse, to fill in current gaps in the literature, and inform future studies of this kind. At a stage where large-scale image analysis is still evolving, we feel that even this initial content analysis is informative for the public health community. Our study is in line with the multiphase approach used in other similar Internet-based research wherein preliminary qualitative analysis on small samples [38,39] are used to inform large-scale automated methodologies [40,41] such as machine learning. However, despite the prevalence of misuse, the paucity of data on this topic requires that any intermediate findings be tested further before deemed useful for the development of much-needed interventions to prevent uptake and curb misuse.

Due to an inability to assess demographics of Instagram users with any sense of reliability or validity, we could not explore whether our findings confirmed previous studies that described the makeup of codeine misusers. To optimize the representativeness of our sample, we extracted posts each day of the week for primary analysis and systematically explored an array of search terms for secondary analysis. Although our sample is not large enough for formal statistical inference, it reveals important trends to explore further and confirms others

already known. Future work should make an effort to distinguish the difference, if any, in demographic characteristics of misusers identified through social media content and the general population of misusers derived from survey data.

Although we see an association between a previously defined musical and culture genre and codeine misuse, our findings do not imply any causal relationship between black cultural expression and codeine misuse. Our findings only demonstrate that they co-occur. Though hip-hop may reproduce the phenomena that inform its lyrical content, psychosocial and economic conditions are fundamental causes for both risk behaviors and their aesthetic representation [42].

Conclusions

The normalization of codeine misuse and emerging associations with popular culture and celebrities suggest that codeine misuse has extended beyond a particular, well-circumscribed subculture. It is paramount to understand how codeine misuse is represented over time to better orient strategies that seek to prevent uptake and curb misuse in both well-known and novel populations.

From this study, it is evident that social media platforms provide forums for crafting and sharing narratives of opioid misuse. As such, platforms such as Instagram provide a lens to gauge perceptions and behaviors surrounding opioid misuse. Given the ubiquity of social media in the lives of adolescents and public nature of this exchange of information, the development of prevention efforts is essential. These data can inform development and testing of countermessaging for these rapidly emerging groups of misusers. We advocate consideration of social media data to inform public health strategies to combat opioid misuse and other shared health behaviors.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Opioid-related hashtags, definitions and examples.

[PDF File (Adobe PDF File), 303KB - [publichealth_v4i1e22_app1.pdf](#)]

Multimedia Appendix 2

Themes, definitions, and examples.

[PDF File (Adobe PDF File), 206KB - [publichealth_v4i1e22_app2.pdf](#)]

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Original Paper

Does Eating Chicken Feet With Pickled Peppers Cause Avian Influenza? Observational Case Study on Chinese Social Media During the Avian Influenza A (H7N9) Outbreak

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Abstract

Background: A hot topic on the relationship between a popular avian-origin food and avian influenza occurred on social media during the outbreak of the emerging avian influenza A (H7N9). The misinformation generated from this topic had caused great confusion and public concern.

Objective: Our goals were to analyze the trend and contents of the relevant posts during the outbreak. We also aimed to understand the characteristics of the misinformation and to provide suggestions to reduce public misconception on social media during the emerging disease outbreak.

Methods: The original microblog posts were collected from China's Sina Weibo and Tencent Weibo using a combination of keywords between April 1, 2013 and June 2, 2013. We analyzed the weekly and daily trend of the relevant posts. Content analyses were applied to categorize the posts into 4 types with unified sorting criteria. The posts' characteristics and geographic locations were also analyzed in each category. We conducted further analysis on the top 5 most popular misleading posts.

Results: A total of 1680 original microblog posts on the topic were retrieved and 341 (20.30%) of these posts were categorized as misleading messages. The number of relevant posts had not increased much during the first 2 weeks but rose to a high level in the next 2 weeks after the sudden increase in number of reported cases at the beginning of week 3. The posts under "misleading messages" occurred and increased from the beginning of week 3, but their daily posting number decreased when the daily number of posts under "refuting messages" outnumbered them. The microbloggers of the misleading posts had the lowest mean rank of followers and previous posts, but their posts had a highest mean rank of posts. The proportion of "misleading messages" in places with no reported cases was significantly higher than that in the epidemic areas (23.6% vs 13.8%). The popular misleading posts appeared to be short and consisted of personal narratives, which were easily disseminated on social media.

Conclusions: Our findings suggested the importance of responding to common questions and misconceptions on social media platforms from the beginning of disease outbreaks. Authorities need to release clear and reliable information related to the popular topics early on. The microbloggers posting correct information should be empowered and their posts could be promoted to clarify false information. Equal importance should be attached to clarify misinformation in both the outbreak and nonoutbreak areas.

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KEYWORDS

social media; misinformation; infodemiology; avian influenza A; disease outbreak

Introduction

A novel avian influenza A (H7N9) case was first reported in China on March 31, 2013 [1]. A total of 131 confirmed cases and 39 deaths were documented in China as of May 31, 2013 [2]. From May, the first outbreak subsided, with only 1 case reported each month in June and July [3,4]. Due to its severity, this outbreak drew great public attention from all over the world [5].

Emerging infectious disease outbreaks usually drive people to search for more relevant information because of the uncertainty about the source of infection and fear of the deadly consequences [6,7]. In China, Sina Weibo and Tencent Weibo were the two largest social media platforms with more than 300 million users when the outbreak occurred [8]. Weibo is the Chinese word for microblog and allows a 140-character limit. The Internet users who post on “Weibo” are known as microbloggers. Driven by the popularity of such platforms, the outbreak triggered great public concern, with over 850,000 posts related to the term of “H7N9” generated in Sina Weibo [5]. With the function of self-expression and networking, social media provides a fertile ground for unreliable information generation and circulation [6,9,10]. One study showed that 57% of the rumors about the tragedy of Malaysia Airlines MH370 were generated from social media platforms in China [11]. Such misinformation or rumors could lead to great confusion and pose challenges to the disease control [7,12]. The outbreak of severe acute respiratory syndrome in 2003 serves as a typical example where rumors stirred great panic in Chinese society and made it hard for disease prevention and control [7,13].

From the beginning of the outbreak, social media users started to query the safety of the avian-origin food. Due to the poultry origin, a kind of Chinese traditional food—Chicken feet with pickled pepper—sparked microbloggers’ discussion about its causal relationship with the avian influenza. Chicken feet with pickled pepper (known as Pao-jiao-feng-zhua in Chinese) is a popular food item widely loved by Chinese people. The chicken feet are boiled for about 20 min and pickled with peppers for 2 days or longer. Although the avian-origin influenza A (H7N9) virus exists in the live poultry, the virus is sensitive to heat and cannot survive in the boiling water for 2 min [14,15]. Therefore, the virus has no chance of survival during the production process of the chicken feet with pepper. However, the topic on the relationship between the 2 items was widely discussed. Many microbloggers released messages that misunderstood the causal relationship between the 2 counterparts, and their posts became very prevalent [16-18]. The false messages claiming that chicken feet with pepper would cause H7N9 influenza were identified as rumors and caused great confusion and panic during the outbreak [17].

Little research has been done to examine the information and misinformation generated on social media during emerging

disease outbreaks in China. The purpose of this observational case study is to understand the trend and characteristics of the relevant Weibo posts on the hot topic and to give the recommendations for effective health communication practice on social media in the context of emerging disease outbreaks.

Methods

Data Collection

We used a combination of *H7N9* or *Qinliugan* (the Chinese equivalent for avian influenza) and “Pao-jiao-feng-zhua” (the Chinese equivalent for chicken feet with pickled peppers) as keywords to search for the relevant original microblog posts from Sina Weibo and Tencent Weibo in September 2013. An original microblog post is defined as a short post where the content was not copied or forwarded from the news media or somewhere else [16,19]. The selected study period spanned 63 days or 9 weeks between April 1, 2013 (1 day after the official report of the first cases) and June 2, 2013 (when the government began to report the cases monthly instead of daily and weekly, indicating the outbreak was basically under control). We recorded the content of the posts, along with the posting date, geographic location, replies, number of retweets, number of microbloggers’ followers, and number of microbloggers’ existing posts. We examined the posting trend by weeks based on the posting date. The weekly reported case numbers were collected from the mainstream media.

Content Analysis

About 11.90% (200/1680) were randomly selected from the collected posts and reviewed by a panel of 3 researchers. Each researcher independently read the contents of each post and synthesized different themes. After that, the panel discussed all generated themes and made an agreement to code all the posts (1680) into 4 major categories: queries, misleading messages, refuting messages, and other messages. We set the sorting criteria before the coding process. Queries referred to the posts querying whether eating chicken feet with pickled peppers caused avian influenza A (H7N9). If the microbloggers asked rhetorical questions or the question was answered by themselves in the same posts, such posts were not included in this category. Misleading messages referred to posts claiming that influenza A (H7N9) was caused by chicken feet with pickled peppers or to the posts persuading other people to believe the incorrect statement. Refuting messages included posts that stated that there was no causal relationship between the 2 counterparts and posts that corrected the false information or reminded the readers not to believe the wrong messages. Other messages represented posts that could not be classified into the categories above. The posts in this category have not mentioned the relationship between eating chicken feet with pickled pepper and H7N9 avian influenza, or the information is too limited to be judged.

Table 1. The coding criteria and the sample posts.

Categories	Definition	Sample posts
Queries	Posts querying whether eating chicken feet with pickled peppers caused avian influenza A (H7N9). Posts with rhetorical questions by microbloggers or answering of the question by themselves in the same posts were not included.	<ul style="list-style-type: none"> • With so many H7N9 cases, is it dangerous or safe to eat chicken feet with pickled peppers? • I ate chicken feet with pickled peppers last night. Am I going to have avian influenza? • Is it the truth that the new H7N9 cases were caused by chicken feet with pickled peppers in our city?
Misleading messages	Posts claiming that influenza A (H7N9) was caused by chicken feet with pickled peppers or posts persuading other people to believe the incorrect statement.	<ul style="list-style-type: none"> • Our city had the first case of avian influenza caused by chicken feet with pickled peppers last night! • Don't eat chicken feet with pickled peppers because it causes H7N9. Tell the people around you. • A staff of my company was infected by H7N9 virus just because he had chicken feet with pickled peppers last night.
Refuting messages	Posts which stated that there was no causal relationship between the 2 counterparts and posts which corrected the false information or reminded the readers not to believe the wrong messages.	<ul style="list-style-type: none"> • Chicken feet with pickled peppers have no chance to carry H7N9 virus and cause illnesses. • It's really silly to believe that chicken feet with pickled peppers would cause H7N9 flu. • Don't spread the false message (Chicken feet with pickled peppers cause H7N9 avian influenza) among the public.
Other messages	Posts that could not be classified into the categories above. The posts in this category have not mentioned the relationship between eating chicken feet with pickled pepper and H7N9 infection, or the information is too limited.	<ul style="list-style-type: none"> • Chicken feet with pickled peppers is hot but H7N9 avian influenza is cold. • Avian influenza and my loved chicken feet with pickled peppers...

Two researchers of the same panel independently reviewed all the 1680 posts and categorized them based on the sorting criteria. The coefficient of agreement (Cohen kappa) of the coding results between the 2 reviewers was .82. The third reviewer discussed with the 2 reviewers about the posts with different coding results and finalized the categorization. Some sample posts are listed in [Table 1](#).

Statistical Analysis

We used WPS Office Excel (Kingsoft Office Software, Beijing, China) to plot the weekly trend of posting. The weekly and daily posts were presented in bar charts by the categories we defined earlier. Kruskal Wallis tests were performed to analyze the characteristics and potential impact of the posts in each category. We also used Pearson chi-square test to compare geographic locations of the posts by category. We further examined the popular "Misleading messages" with regard to their features. A *P* value < .05 was considered statistically significant.

The study has been reviewed and approved by the Institutional Ethics Committee in the Zhejiang Provincial Centers for Disease Control and Prevention. The identity of the microbloggers was kept confidential.

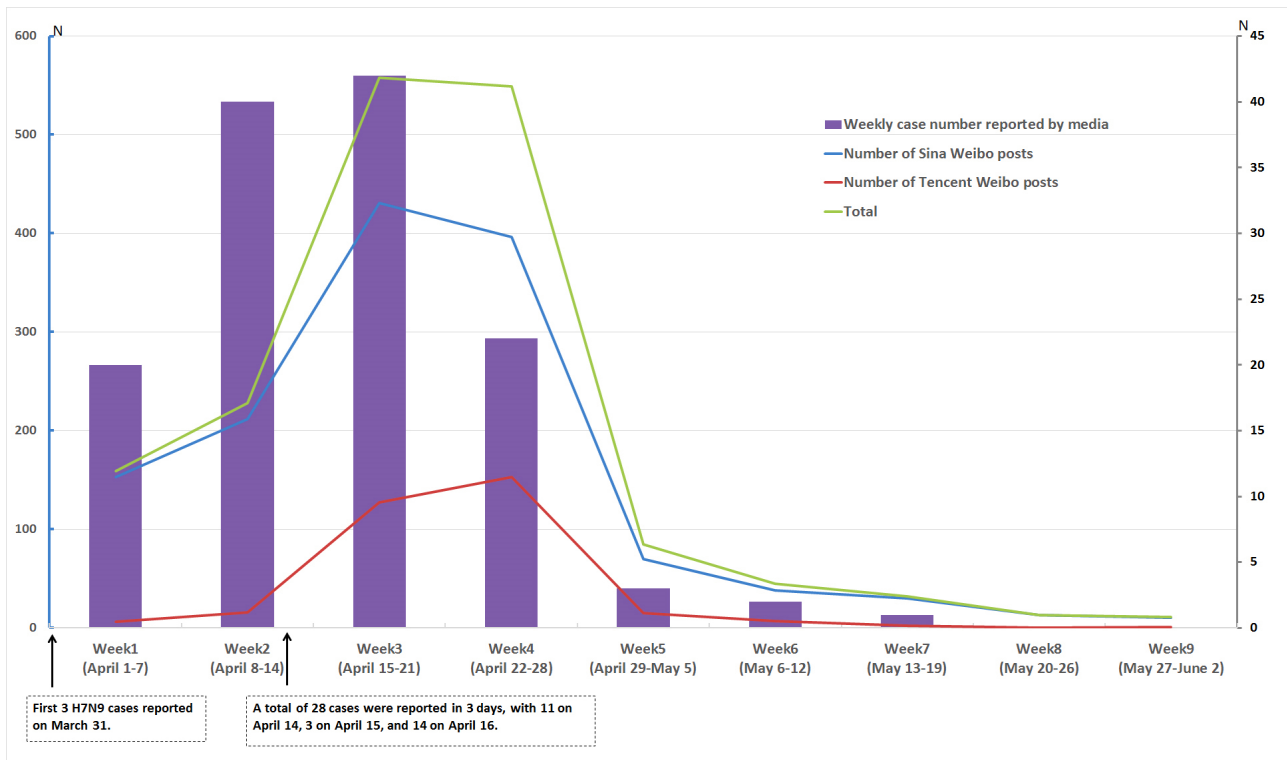
Results

A total of 1680 original microblog posts containing "chicken feet with pickled peppers" and "H7N9" or "avian influenza" were retrieved from the 2 largest microblog platforms, with 1353 posts (80.54%) from Sina Weibo and 327 posts (19.46%) from Tencent Weibo.

Posting Trend of Posts Related to the Topic

The weekly posting trends were similar between Sina Weibo and Tencent Weibo for our topic, except in week 4. The posting trend was consistent with the weekly reporting trend of H7N9 avian influenza case number. The posts increased gradually in the first 2 weeks (April 1-14) after the official announcement of the first 3 H7N9 cases in the Shanghai municipality and Anhui Province of China on March 31. From March 31 to April 13, the number of daily reported cases was ≤6. However, 28 new cases were reported in just 3 days, spanning from April 14 to April 16, with 11 new cases on April 14 and 14 cases on April 16. Subsequently, the weekly posts rose sharply from the start of week 3 (April 15-21) and peaked at 558 and remained high (549) in week 4 (April 22-28), which corresponded to more than 1100 posts in 2 weeks (April 15-28). In week 5, the posts dropped substantially and then gradually declined to a small number during weeks 6 to 9 ([Figure 1](#)).

Figure 1. Weekly posting trend of the observed microblog posts related to the topic and the number of weekly reported cases from April 1 to June 2, 2013.



Contents of the Posts and the Posting Trend of Posts Under Different Categories

Among the 1680 posts, 466 (27.74%) posts were classified as queries, 341 (20.30%) as misleading messages, 508 (30.24%) as refuting messages, and 365 (21.73%) as other messages.

Most of the posts dated in the first 2 weeks were under queries, with 66.7% (106/159) and 69.3% (158/228) in the first and second weeks, respectively. There were 33.3% (53/159) and 30.7% (70/228) posts recognized as other messages in the first 2 weeks. No posts under misleading messages and refuting messages were identified in the same period. In the third week, the posts under misleading messages increased to 32.3% (180/558) per week, yet the posts under refuting messages also appeared and rose to 35.7% (199/558) per week. The number of posts under “queries” decreased to 16.7% (93/558) and other messages kept steady at 15.4% (86/558). “Misleading messages” reduced to 24.7% (136/549) in the fourth week, whereas the number of posts under refuting messages peaked at 51.2% (281/549). The posts under the other 2 categories showed a steady trend in week 4. From week 5 to week 9, the posts of all 4 categories showed a downward trend, and the weekly posts dropped below 100 (Figure 2).

We took a closer look into the daily posting trend between week 3 and week 4 when most of the posts occurred. The first misleading message was identified on April 15. Three days later (April 18), the number of daily posts became 17 per day and

increased to 32 on April 19. From April 20 to April 22, the number of “misleading messages” was kept at high levels of 65, 63, and 63 per day, respectively. Along with the rising “misleading” posts, the number of refuting messages started to increase from April 18 and peaked at 179 on April 22. The posts under “misleading messages” outnumbered those under refuting messages before April 20, but a reverse was observed in the next 2 days because of a sharp growth of the posts under refuting messages. The other 2 kinds of posts showed a relatively steady trend during the above-mentioned period. In the weeks from April 22, the posts of all 4 categories gradually dropped to a low level on April 28 (Figure 2).

Characteristics of the Posts Under Different Categories

The characteristics of the posts under the 4 categories were different. The group of posts under misleading messages had the highest mean ranks of the number of retweets among the 4 groups ($P < .001$). However, the microbloggers of the posts under misleading messages had the lowest mean rank in terms of the numbers of followers and existing posts ($P < .001$). Their misleading posts had modest number of replies (mean rank=793.8). The posts under refuting messages were different in that their microbloggers had more followers and previous posts, but they had the lowest mean rank of the number of retweets ($P < .001$). The refuting messages received most comments among the 4 groups ($P < .001$). The posts under “queries” and “other messages” had moderate mean ranks of the number of microbloggers’ followers and previous post numbers (Table 2).

Figure 2. Weekly and daily microblog posts, by categoriescategory, during the periods from April 1 to June 2 and April 15 to April 28, 2013.



Table 2. Characteristics of the posts and their microbloggers under different categories.

Categories	Queries (N=466)	Misleading messages (N=341)	Refuting messages (N=508)	Other messages (N=365)	Chi-square (degrees of freedom)	P value
Mean rank of retweets	762.8	1050.1	852.3	727.4	137.1 (3)	<.001
Mean rank of comments	907.1	793.8	696.6	999.5	124.2 (3)	<.001
Mean rank of microbloggers' follower number	875.3	637.7	971.7	971.7	101.3 (3)	<.001
Mean rank of microbloggers' previous post number	843.7	651.0	968.1	835.9	87.3 (3)	<.001

Table 3. Geographic locations of the posts by category. Pearson $\chi^2_3=36.7$, $P<.001$.

Geographic location of microbloggers' ID	Queries, n (%)	Misleading messages, n (%)	Refuting messages, n (%)	Other messages, n (%)
Provinces with avian influenza A (H7N9) cases reported	151 (26.4)	79 (13.8)	191 (33.3)	152 (26.5)
Provinces or places with no cases reported (including countries abroad)	249 (28.8)	204 (23.6)	264 (30.5)	149 (17.2)
Total	400 (27.8)	283 (19.7)	455 (31.6)	301 (20.9)

Textbox 1. Top 5 most popular misleading posts.

<p>Top 5 posts in terms of the number of replies and forwards</p> <ul style="list-style-type: none"> Shenzhen municipality confirmed the first H7N9 cases at 2:25 am. The chicken feet with pickled peppers the patient ate had a lot of virus. Please boil them before eating. I have heard people got H7N9 avian influenza because of chicken feet with pickled pepper. Anyway, ban chicken feet with pickled pepper for our life! Xiamen municipality reported an H7N9 case. The virus infected people through chicken feet with pickled pepper... I heard eating chicken feet with pickled pepper would cause H7N9. I have just ate one pack. Be careful, my friend should. The first H7N9 case was reported in our city. The patient ate a lot of chicken feet with pickled pepper. Don't eat this food! <p>Top 5 posts released by microbloggers with most followers</p> <ul style="list-style-type: none"> Shenzhen municipality has reported an H7N9 case, and the cause of disease was that the patient ate chicken feet with pickled pepper which carried a lot of H7N9 viruses. I request all my friends not to eat chicken feet with pickled pepper! One of my classmates ate chicken feet with pickled pepper and is dying with avian influenza A (H7N9). Don't eat chicken feet with pickled pepper because H7N9 virus has been confirmed in that food. Luoyang municipality had the first H7N9 case and the transmission route was eating chicken feet with pickled pepper. Taiyuan municipality reported an avian influenza case. Examination of the patient's food discovered that the chicken feet with pickled pepper had a lot of viruses!
--

Geographic Distribution of the Misleading Messages and the Contents of the Top 5 Most Popular Misleading Posts

Geographic locations (IDs) of 1439 microblog posts were obtained, among which 573 posts were located in the provinces where avian influenza A (H7N9) cases were reported, and 866 posts were from the provinces or regions where no cases were reported. The proportion of rumor posts in the places with no reported cases was significantly higher than that in the epidemic areas (23.6%>13.8%; [Table 3](#)).

The top 5 posts under misleading messages in terms of the number of retweets and replies are listed in [Textbox 1](#). Three of them claimed that H7N9 avian influenza cases were reported

in the local areas, and the cause was eating chicken feet with pickled peppers. The other 2 posts expressed the microbloggers' concern, stating that the microbloggers had heard of people getting avian influenza after eating chicken feet with pickled peppers and reminded the readers not to eat such food. Of the top 5 misleading posts with most followers, 3 claimed that their local area had H7N9 cases due to eating chicken feet with pickled peppers, one claimed that his/her classmate was dying because he/she had eaten chicken feet with pickled peppers, and the other suggested not eating chicken feet with pickled peppers to prevent infection with avian influenza A (H7N9) virus ([Textbox 1](#)).

Discussion

Principal Findings

Using the keyword search, we collected all the original posts relevant to the hot topic on *chicken feet with pickled peppers* and *H7N9* or *avian influenza* in the study period. Employing methods provided by digital epidemiology, we mined and investigated posting trends, content, and characteristics of the posts [5,16,20,21]. More than 1600 original posts were collected, and 20.30% of the posts were recognized as misleading messages during the outbreak.

Posting Trend of the Topic

The weekly posting trend of the topic was consistent with the change of weekly reported cases in our study. From the beginning of the outbreak, microbloggers tend to rush to social media to seek information about the disease [18,20,22]. Relevant posts had occurred accompanying microbloggers' queries on the safety of the avian-origin food. However, the number of posts about this topic did not increase much in the first 2 weeks. With the increment of reported cases, people are likely to perceive more risk and severity [23-25]. In addition, limited information sources and unanswered questions could also raise people's anxiety and help generate misconceptions about the disease [23,26]. Accompanying the sharply rising number of reported cases at the beginning of week 3, misleading messages occurred on April 15, and the posting trend was greatly boosted from then on. This result indicated that early intervention with clear and sense-making messages was necessary for people's appropriate response to the outbreak during this period [16,27].

The situation reversed on April 21, 2013 when the posts under "refuting messages" started to prevail over those under misleading messages. From then on, the daily number of misleading posts decreased and was virtually controlled after April 24. Social media has the ability to purify itself and should be used as an effective information communication platform [11,28,29]. In our study, the microbloggers' timely and effective engagement in correcting the misinformation played an important role in the self-purification of social media [18,30].

Characteristics of the Relevant Posts Under Different Categories

In our study, the posts under misleading messages tended to receive most retweets among the 4 types of posts, suggesting their high virality on social media. The virality of the posts could be measured by the times they are forwarded, replied, and/or endorsed [22,31]. In contrast, the microbloggers of "misleading messages" had fewer followers and previous posts than other microbloggers. In other words, the microbloggers who posted misinformation seemed to be inactive on social media but their misleading messages were more likely to be disseminated. The microbloggers who posted "refuting messages" were recognized as active on social media because they had most followers and previous posts among the 4 groups. However, their correcting posts received fewer reposts as well as the least reposts. This fact suggests the need to empower these kinds of messages to strengthen the self-purification function of social media [11,28,29]. The queries and other

messages received more comments than the other 2 groups. These 2 groups of posts contained more content of questions and jokes, which we think were more interactive [31]. Thus, they received more replies than the other 2 groups of posts.

In terms of the geographic distribution of the misleading posts, we found misleading posts occurred more frequently in the provinces with no H7N9 cases reported than in the provinces with cases reported. Currently, people who were physically located far from disease outbreaks could obtain information rapidly from the Internet and contribute to the circulation of misinformation [11,32]. This was different from the traditional rumor dissemination. For the nonoutbreak areas, information monitoring and communication on social media are also very important.

Features of the Most Popular Misleading Messages

Previous studies showed that the individuals who created and/or disseminated misinformation might have the motives to draw more public attention [7,33]. Social media could be a good tool to generate such misleading but attractive information [6,9,10]. Most of the top 5 misleading posts disseminated false information that H7N9 cases had occurred in the local area because of eating "chicken feet with pickled pepper." They told a story containing information of where, when and who. Such posts were narrative and seemed to be real. This feature was similar to the traditional rumors. However, they were short and visible on the Internet, leading to the quick dissemination because of the high interactivity of social media. These kinds of misleading posts should be clarified as a priority.

Limitations

There are several limitations in our study. Instead of retrieving data at the beginning of the outbreak, we did it after the outbreak occurred, when some microbloggers might have deleted their posts. This might have led to information loss. The real-time data retrieval would have been preferable in future studies. Although the misinformation of the specific topic we studied was prevailing during the outbreak, it could not represent all misinformation that occurred in the same period and it may not be applied to other public health emergency. Due to the limited research resources and insufficient data, we could not conduct more secondary content analysis and observe the networking of the posts, which could have further revealed the model of the misinformation dissemination on social media.

Conclusions

This study has some implications for public health practice and health communication on social media during disease outbreaks. We think it is important to detect the microbloggers' common concern from the very beginning of the outbreak. It was also found necessary to release correct information in response to a misunderstood topic. The microbloggers on social media can and should be empowered to clarify wrong information by themselves. The microbloggers of posts under "misleading messages" in our study seemed to be less active, but their posts drew greater attention on social media. In the times of Web 2.0, it is of equal importance to monitor outbreak and nonoutbreak areas and prevent misinformation from spreading on social media.

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Authors' Contributions

BC, HG, and JJ conceived the idea and planned the study. ZJ and KL collected and sorted the data. BC, JS, KL, and GC analyzed the data. BC, YH, JS, and JJ contributed to the manuscript preparation.

Conflicts of Interest

None declared.

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Original Paper

Social Media Impact of the Food and Drug Administration's Drug Safety Communication Messaging About Zolpidem: Mixed-Methods Analysis

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Abstract

Background: The Food and Drug Administration (FDA) issues drug safety communications (DSCs) to health care professionals, patients, and the public when safety issues emerge related to FDA-approved drug products. These safety messages are disseminated through social media to ensure broad uptake.

Objective: The objective of this study was to assess the social media dissemination of 2 DSCs released in 2013 for the sleep aid zolpidem.

Methods: We used the MedWatcher Social program and the DataSift historic query tool to aggregate Twitter and Facebook posts from October 1, 2012 through August 31, 2013, a period beginning approximately 3 months before the first DSC and ending 3 months after the second. Posts were categorized as (1) junk, (2) mention, and (3) adverse event (AE) based on a score between -0.2 (completely unrelated) to 1 (perfectly related). We also looked at Google Trends data and Wikipedia edits for the same time period. Google Trends search volume is scaled on a range of 0 to 100 and includes "Related queries" during the relevant time periods. An interrupted time series (ITS) analysis assessed the impact of DSCs on the counts of posts with specific mention of zolpidem-containing products. Chow tests for known structural breaks were conducted on data from Twitter, Facebook, and Google Trends. Finally, Wikipedia edits were pulled from the website's editorial history, which lists all revisions to a given page and the editor's identity.

Results: In total, 174,286 Twitter posts and 59,641 Facebook posts met entry criteria. Of those, 16.63% (28,989/174,286) of Twitter posts and 25.91% (15,453/59,641) of Facebook posts were labeled as junk and excluded. AEs and mentions represented 9.21% (16,051/174,286) and 74.16% (129,246/174,286) of Twitter posts and 5.11% (3,050/59,641) and 68.98% (41,138/59,641) of Facebook posts, respectively. Total daily counts of posts about zolpidem-containing products increased on Twitter and Facebook on the day of the first DSC; Google searches increased on the week of the first DSC. ITS analyses demonstrated variability but pointed to an increase in interest around the first DSC. Chow tests were significant ($P < .0001$) for both DSCs on Facebook and

Twitter, but only the first DSC on Google Trends. Wikipedia edits occurred soon after each DSC release, citing news articles rather than the DSC itself and presenting content that needed subsequent revisions for accuracy.

Conclusions: Social media offers challenges and opportunities for dissemination of the DSC messages. The FDA could consider strategies for more actively disseminating DSC safety information through social media platforms, particularly when announcements require updating. The FDA may also benefit from directly contributing content to websites like Wikipedia that are frequently accessed for drug-related information.

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KEYWORDS

Food and Drug Administration; drug safety communications; surveillance; epidemiology; social media; Twitter; Facebook; Google Trends

Introduction

When the Food and Drug Administration (FDA) learns about new or emerging adverse drug reactions potentially caused by an FDA-regulated product, the agency may issue a Drug Safety Communication (DSC) to health care professionals, patients, and the public to help them make more informed medication-related decisions [1,2]. These safety issues can include new side effect profiles [3], dosing adjustments [4], previously unknown adverse events (AEs) [5], including increased risk of death [6], drug-drug interactions [7], and differential responses between patient subgroups [8].

The FDA disseminates safety messages about prescription and over-the-counter (OTC) drugs through online media outlets, as well as through numerous other platforms, to make information available where people will see it. The Internet is a primary source of medical information for a growing number of people, particularly through searches on Google and from resources such as Wikipedia [9]. Health care providers also frequently use online resources [10]. As news and information have become portable through mobile phones and other devices, social media platforms such as Twitter and Facebook have grown as a means of sharing personal experiences and opinions [11]. Given that 70% of Facebook users and 38% of Twitter users access the platforms daily, and that in 2012 approximately 28% of Facebook profiles [12] and 88% of Twitter feeds [13] were public, these platforms enable users to routinely and broadly share personal experiences with medical products. Social media can potentially have promising applications for public health and drug safety surveillance [14-17], though the potential for inaccurate information, length constraints, and other drawbacks may limit this utility.

The FDA issued a total of 233 DSCs between 2010 and 2016 [18]. In 2013, 2 DSCs were issued related to the sedative/hypnotic zolpidem (Ambien), which was first approved in 1992 to treat insomnia. On January 10, 2013, the FDA released a DSC that warned, in part, about the risk of next-morning impairment and recommended lower starting doses for zolpidem, particularly in women [19]. A follow-up DSC was released on May 14, 2013 providing updated information on the specific FDA-approved label changes for the affected zolpidem products, along with a recommendation to avoid driving the day after using extended-release versions of the product [20]. As part of its dissemination strategy for all

DSCs, FDA actively communicated the key message from each zolpidem DSC via some FDA social media accounts.

To assess online activity following the release of DSC messaging for zolpidem, we assessed trends in daily mentions on Twitter and Facebook, searches in Google, and edits to the zolpidem Wikipedia page. Our goal was to determine the extent to which safety messages were shared through social media and the content and wording of user posts about zolpidem, including how they may have changed following the release of the information in the DSCs.

Methods

Facebook and Twitter Posts

To collect Facebook and Twitter posts, we used MedWatcher Social, a media monitoring program developed by Epidemico and the Computational Epidemiology Group at Boston Children's Hospital and Harvard Medical School, based on technology from HealthMap [21]. Using the DataSift historic query tool, we collected historical Twitter and Facebook posts ranging from October 1, 2012 through August 31, 2013, a time period that allowed us to follow activity from approximately 3 months before the first DSC (DSC1) through 3 months after the second DSC (DSC2). We executed searches for English-language posts using the following queries: *ambien*, *ambian*, *zolpidem*.

The DataSift tool delivered the results in files in a standardized JavaScript Object Notation (JSON) format; the post content and date were then extracted and stored in a database system for ease of automated processing and manual review. Each post was then placed into 1 of the following 3 categories using an automated content classification algorithm: (1) junk, (2) mention, and (3) adverse event (AE). The classification algorithm is a machine learning system based on a Fisher-Robinson classifier and has previously been described in detail [17,22]. For a given post, it outputs a score signifying its likelihood of being relevant to discussion of an AE, ranging from -0.2 (completely unrelated) to 1 (perfectly related). The training set for the algorithm consists of over 411,000 manually-labeled historical dataset posts categorized as either AE or non-AE.

Posts with scores below 0.02 are tagged as junk, those with scores greater than or equal to 0.02 and less than 0.7 are labeled as mention, and those scoring greater than or equal to 0.7 are

marked as AE. AE posts were intended to capture negative outcomes attributed to the product. Mention posts represented legitimate mentions of the product, but not attributing any adverse outcome to it. The junk category was intended to collect and filter advertising, promotional, automated, spam, or otherwise irrelevant content. Repeated discussions of a single event were de-duplicated if they were posted twice within a 1-hour period with no or minimal changes to the text. Unexpected spikes in the Facebook and Twitter data were further examined for fidelity. Through this process, we found that spikes in counts of Facebook or Twitter postings on all other days besides the day of either DSC were largely due to misclassification of “spam storms” (large volumes of posts relating to advertisement, promotional, automated, or otherwise irrelevant content) as relevant postings. For example, we manually verified a spam storm resulting in 8243 Facebook posts on June 28, 2013, and an additional 505 posts the following day. To normalize the findings, June 28 data were replaced by the mean number of posts from June 21 to 27, and June 29 data were replaced by the mean number of posts from June 30 to July 6.

Separately, we collected posts from FDA Twitter and Facebook accounts relating to the 2 DSCs. Four accounts were identified as possible sources of data: 1 on Facebook (@FDA, the main FDA page) and 3 on Twitter (@US_FDA, @FDA_Drug_Info, and @FDAMedWatch). Relevant posts can be found in [Multimedia Appendix 1](#). Though FDA posts could not be specifically identified in the dataset, manual verification of posts containing language similar to the FDA’s were often identified and counted as junk in the MedWatcher Social analysis.

Google and Wikipedia Data

Google Trends data are comprised of an unbiased sample of Google search data, with each value representing a random sample of searches for a given time period [23]. Data are scaled on a range of 0 to 100, with 100 representing the maximum number of searches during the relevant time period. For shorter periods, daily results are available, but for longer time windows, data are reported weekly. For a given search, a score of 100 represented the day or week with the greatest number of individual queries for the drug over the selected time frame. The “Related queries” section of the Google trends output page provided information as to similar searches that were “Rising” in the relevant time period [24]. Any search with a greater than 5000% increase in search frequency is defined by Google Trends as a Breakout search. We searched for the term “ambien” in the same time interval as our Twitter and Facebook data (October 1, 2012 to August 31, 2013), obtaining weekly data points, with additional Google Trends searches reporting daily results during the months of January 2013 and May 2013 to focus in on the relevant DSC time periods. Given the likelihood that the average person would not remember or search for the trade name zolpidem, we elected to query the most popularized brand name.

Wikipedia edits were pulled from the editorial history of the page for “Zolpidem” (searches for Ambien are redirected to this page) [25]. The editorial history shows when revisions were made to the page and the content of those revisions side-by-side

with the original text. We queried the history for revisions made in the timeframe surrounding the 2 DSCs and manually examined the relevant content changes for completeness and accuracy. Relevant editorial changes are shown in [Multimedia Appendix 1](#).

Data Analysis

Data posted on Facebook and Twitter from October 2012 to August 2013 were collected and analyzed for their timing and content. We plotted the time series of historical daily Twitter and Facebook post counts. Google Trends data were also charted as a time series during the same time frame. All data analyses were conducted retrospectively using historical posts without identifiable data.

The intervals between the 3 segments, defined by DSC dates (Period 1 representing time from first data collection to DSC1, Period 2 representing time between DSC1 and DSC2, and Period 3 defined the time from DSC2 to end of data collection), varied in duration according to the outcome of interest, with the baseline trend arising from Period 1. We fitted segmented linear regression models to the ITS data to estimate the impact of each DSC. Since the structural breaks of interest were known a priori, we conducted Chow tests to assess for the presence of a structural break at the DSC times.

Analyses were conducted using Microsoft Excel and SAS (version 9.4). The study protocol was approved by the Institutional Review Board at Brigham & Women’s Hospital and FDA’s Research Involving Human Subjects Committee.

Results

Facebook and Twitter Posts

A total of 174,286 Twitter posts (tweets) and 59,641 Facebook posts met entry criteria, dating between October 1, 2012 and August 31, 2013. Among the tweets, 9.21% (16,051/174,286) were classified as AEs, 74.16% (129,246/174,286) as mentions, and 16.63% (28,989/174,286) as junk. Among Facebook posts, 5.11% (3050/59,641) were flagged as AEs, 68.98% (41,138/59,641) as mentions, and 25.91% (15,453/59,641) as junk. Because data were collected anonymously, it was not possible to ascertain the total number of unique individuals who generated these posts.

Time series plots of daily counts of posts for each category of posts are presented together with their predicted regression lines ([Figures 1-4](#)). For data outputs corresponding to each segmented linear regression model, see [Multimedia Appendix 2](#). Overall, we observed substantial variability in the daily counts of posts for both social media sources. Chow tests demonstrated statistical significance ($P<.0001$) for Twitter and Facebook posts at both DSC1 and DSC2. Overall counts of daily AE posts on Twitter varied from less than 10 to more than 80. ITS effect estimates were significant for all 3 periods. For the baseline Period 1, we observed a steady increase in numbers of posts. Periods 2 and 3 were marked by a decreasing trend over time after DSC1 and DSC2 ([Figure 1](#) and [Multimedia Appendix 2](#)).

Figure 1. Daily Twitter adverse event posts about zolpidem (Ambien) from October 2012 to August 2013.

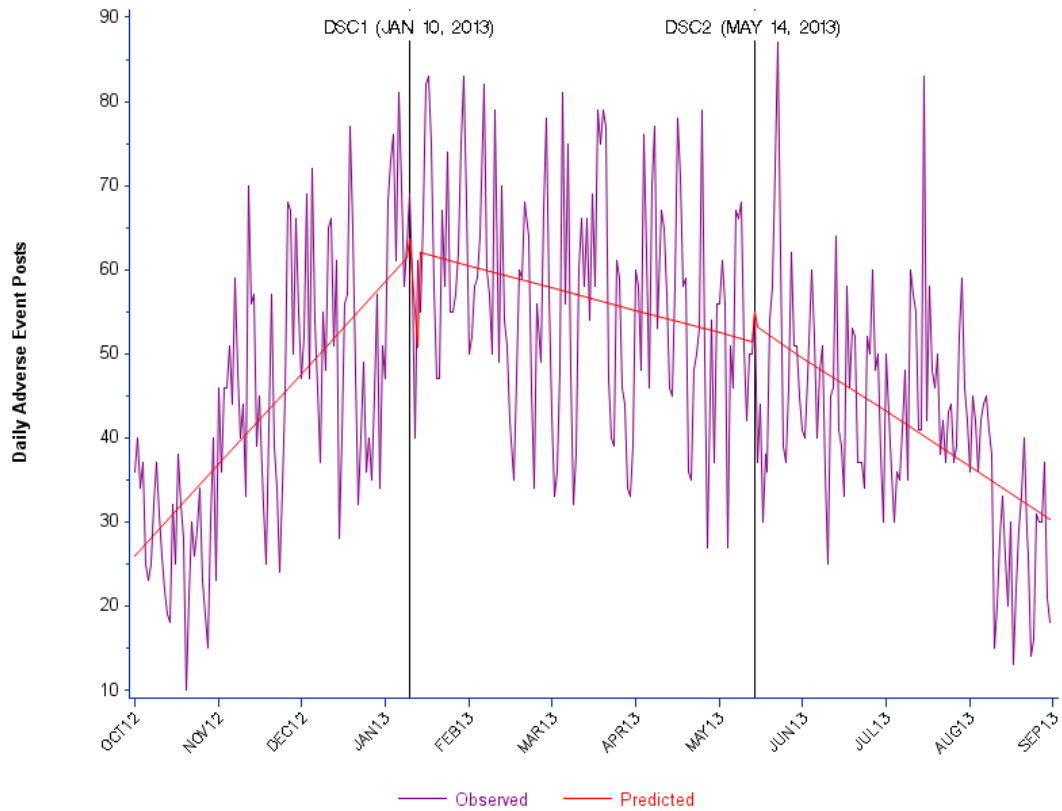


Figure 2. Daily Twitter mention posts about zolpidem (Ambien) from October 2012 to August 2013.

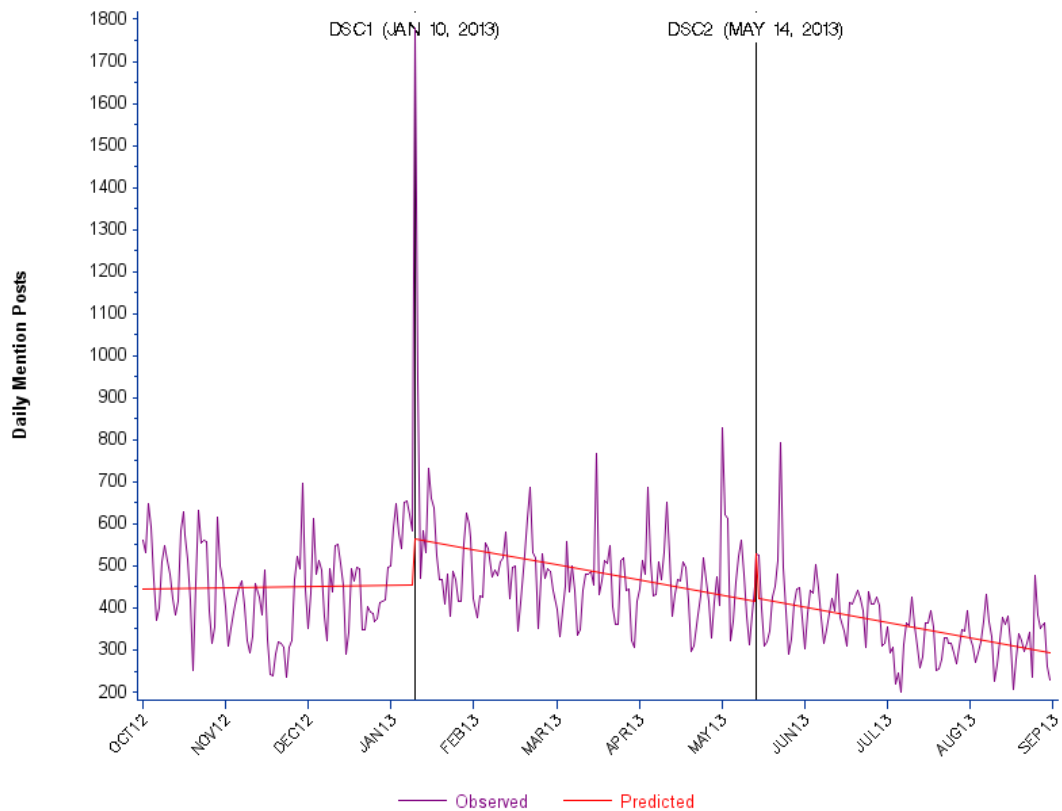
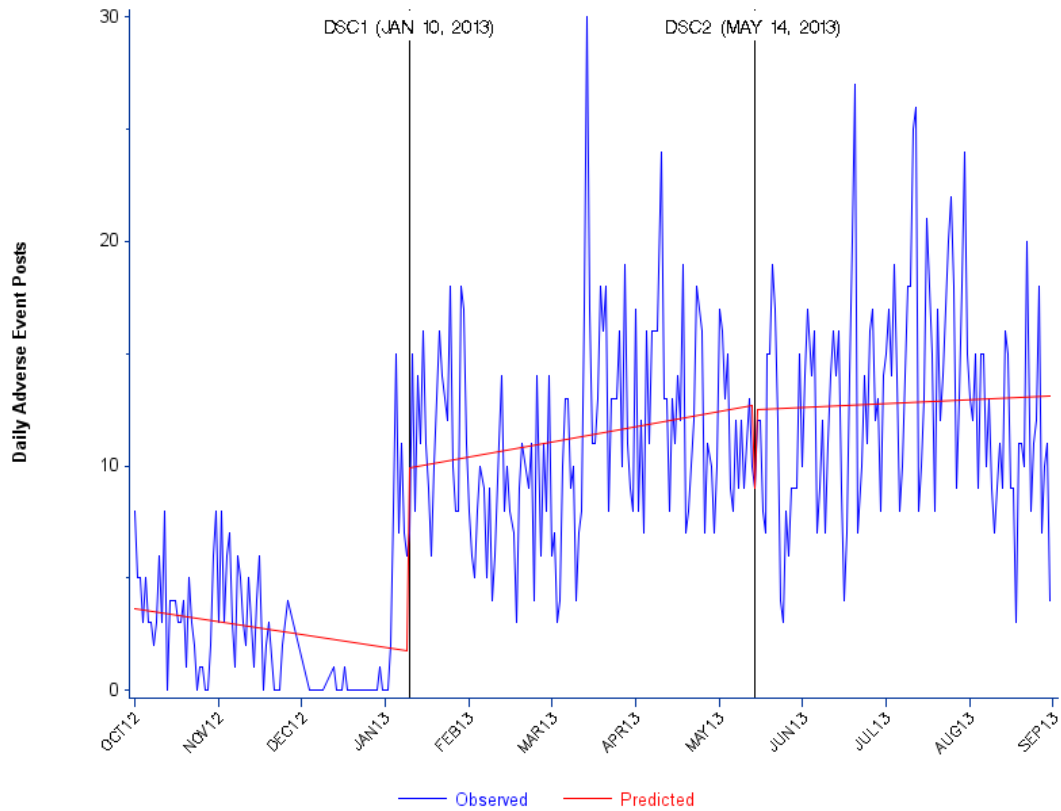
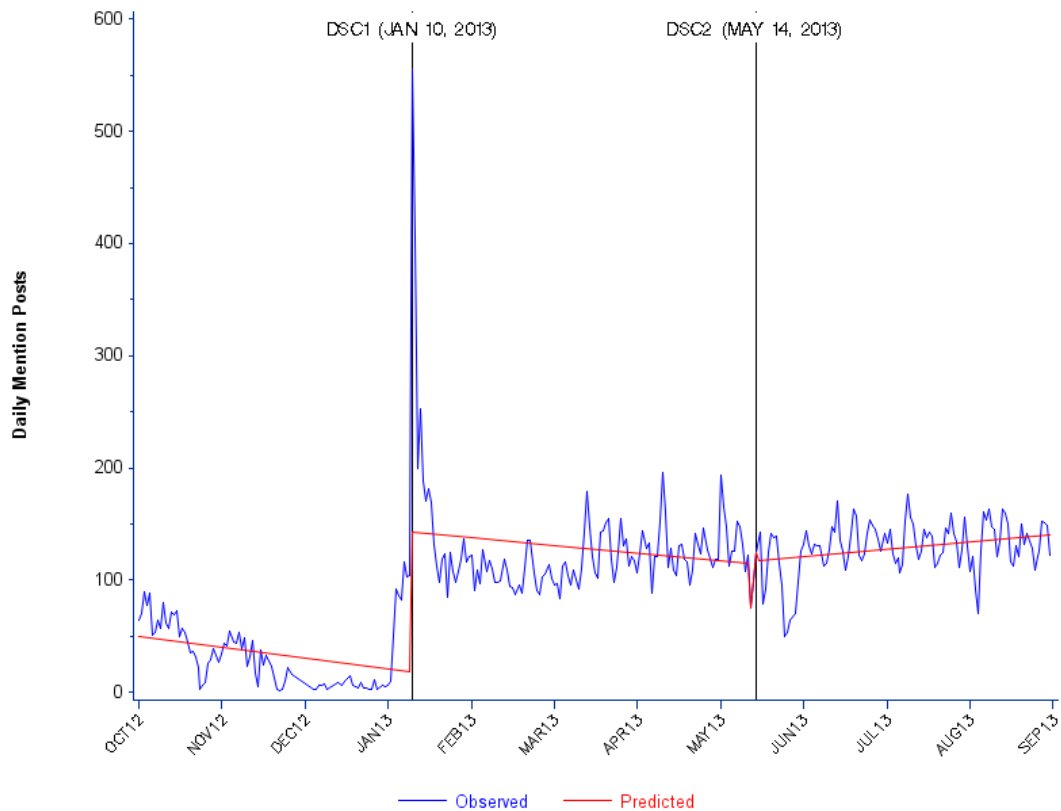


Figure 3. Daily Facebook adverse event posts about zolpidem (Ambien) from October 2012 to August 2013. DSC: drug safety communication.**Figure 4.** Daily Facebook mention posts about zolpidem (Ambien) from October 2012 to August 2013. DSC: drug safety communication.

For Twitter daily mention posts, we observed a spike at DSC1 but not at DSC2. This large and statistically significant ($P=.01$) increase in posts at DSC1 was followed by a significant

declining trend ($P=.01$) during Period 2. We did not observe additional changes in Period 3 compared with Period 2 (Figure 2 and Multimedia Appendix 2).

There were few daily posts in Facebook tagged as AEs, with a strikingly low number (approaching zero) in the 3 months leading up to DSC1. We observed a significant ($P < .0001$) positive change at DSC1, but no significant change at DSC2 (Figure 3 and Multimedia Appendix 2).

There were also few Facebook posts tagged as mentions in the 3 months leading up to DSC1, although they then spiked significantly ($P < .0001$) at DSC1, similar to the Twitter findings. No significant change was observed at DSC2 (Figure 4 and Multimedia Appendix 2). Daily posts in Facebook tagged as AEs (increased about 6 per day) and mentions (increased about 100 per day) then plateaued and were sustained at a higher level after DSC1.

FDA Accounts

Communications arising from FDA on the day of DSC1 release included 4 tweets sent from the @FDA_Drug_Info account (retweeted a collective 71 times), 1 tweet from the @FDAMedWatch account (retweeted 24 times), and 1 tweet from the @US_FDA account (retweeted 16 times). There was a single Facebook post published that day that had 61 shares.

For DSC2, no Facebook posts were made by FDA and no tweets were sent from the main @US_FDA Twitter account. Three tweets were sent from the @FDA_Drug_Info account with a collective 37 retweets. The @FDAMedWatch account tweeted a generic message related to all the recent prescribing changes FDA had made recently to 48 products, which did not mention zolpidem by name. It was retweeted 3 times, but only a single

reply to the original post referenced the drug: “check out revisions... esp Ambien”. That post was not retweeted.

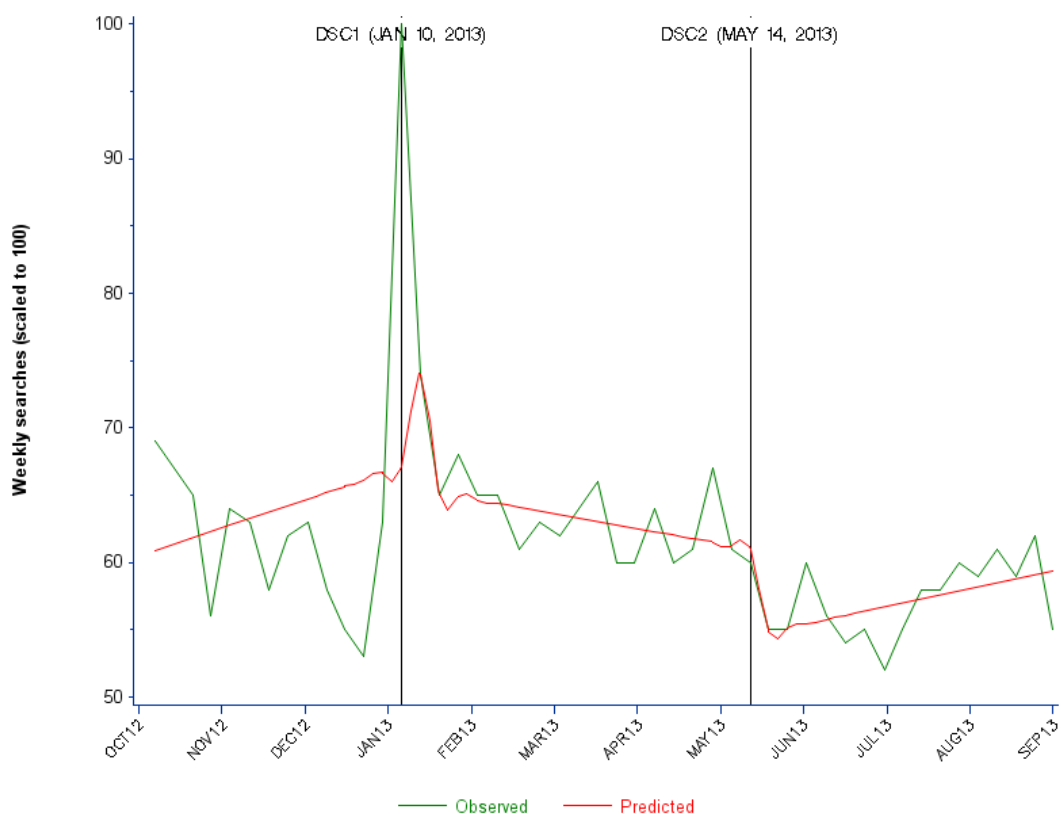
Each FDA tweet linked to a different internal Web page posted on the FDA website. For example, the @FDA_Drug_Info DSC1 tweets linked to the original DSC, a Spanish version of the DSC, and a related consumer article and press release. The DSC2 tweets linked to the DSC, its Spanish version, and an MP3 podcast addressing the DSC (see Multimedia Appendix 1).

Google Searches

The Google Trends graph for US-based Web searches for “Ambien” between October 1, 2012 and August 31, 2013 [26] reached a peak of 100 during the week of January 6 to January 12, 2013, which includes the release of DSC1 (Figure 5 and Multimedia Appendix 2). ITS was not significant for searches at DSC1 and DSC2 or within Periods 1 to 3, but Chow tests demonstrated statistical significance for Google at DSC1 but not DSC2.

The Google Trends plot mirrors the Facebook and Twitter Mentions data in 2 important ways: each has a visible peak at DSC1, but lacks any visible change at DSC2. Related queries rising in frequency over this 11-month time period include “ambien fda warning” (+1, 100%), “fda ambien” (+500%), “ambien dosage women” (+450%), “ambien warning” (+450%), “ambien and women” (+130%), and “ambien news” (+50%). In the graphs for each of these related queries, the peak centers around DSC1 but low search volume for these terms precludes further analysis. Search frequency for these multiple-word searches was lower than searches for “ambien”.

Figure 5. Weekly searches for zolpidem/Ambien on Google (scaled to 100) from October 2012 to August 2013.



When focusing more closely on the dates around the 2 zolpidem DSCs, the January 2013 graph of Google Trends Web searches [26] identified a peak around January 10 to January 11, 2013, returning to baseline within a few days. The volume of news searches showed a similar trend. Related queries for “ambien fda”, “ambien warning”, and “ambien fda warning” were classified as Breakout ($+>5000\%$), and “ambien news” ($+850\%$) also increased significantly during the month of January. In May 2013 [26], the peak search for “ambien” occurred on May 1, steadily declining through the month. There was a brief uptick of searches on May 14 to May 15, the day after the DSC was issued, but it did not exceed search frequency from May 1. Related queries in May did not pertain to the FDA or drug warnings and instead focused on Ambien more generally: “ambien side effects”, “ambien dosage,” and “ambien generic”. None were rising or breakout, meaning that search frequency of these terms did not change to an appreciable extent during May 2013.

Wikipedia Changes

An addition was made to the last paragraph of the opening section of the zolpidem Wikipedia page on January 10, 2013 to reflect some information included in DSC1. Citing a CBS News article, the page notes:

On January 10, 2013, the FDA announced it is requiring the manufacturer of Ambien and Zolpimist to cut the recommended dosage in half for women after laboratory studies showed that the medications can leave patients drowsy in the morning and at risk for car accidents.

It was edited again on April 30, 2013 to add the following information, the first sentence of which was included in DSC1:

The FDA recommended that manufacturers extend the new dosage cuts to men as well, who process the drug at a faster rate. However, the reasons why men and women catabolize the drugs at different rates is still unknown.

No additional citation was provided for this addendum.

Wikipedia page edits for zolpidem on May 15, 2013 included information from DSC2:

In May 2013, the FDA approved label changes specifying new dosage recommendations for Zolpidem products because of concerns regarding next-morning impairment.

The reference cited for this addition was an article on the Lawyers and Settlements website. The DSC language has since been moved up to the second paragraph of the article, but still does not contain a reference to the FDA DSC. As of January 3, 2018, the citations for these 2013 edits remain unchanged.

Discussion

Principal Findings

In this analysis, we examined uptake by various social media outlets of 2 FDA DSCs related to the sedative/hypnotic zolpidem, as well as associated changes in Google searches and

updates to Wikipedia. These communication pathways can lead to more widespread dissemination of the messaging in DSCs [9]. We observed a similar spike of Facebook and Twitter daily mentions, as well as weekly Google searches at DSC1; but the sharp increase in engagement was not sustained. We also found a significant increase in the number of daily AEs posted on Facebook after DSC1. Daily posts on Facebook tagged as AEs and as mentions both plateaued and were then sustained at a higher level after DSC1. By contrast, DSC2 largely failed to gain additional traction, reflected by no visible increase in Facebook and Twitter posts or Google searches at the time of DSC2.

This study builds on previous work looking at social media and pharmacovigilance in the United States [27-34] and Europe [35,36], in addition to a growing body of work on FDA DSC messaging [37] by systematically evaluating the social media impact of DSCs. There are a number of possible explanations for the differential effects of the 2 DSCs in social media. For example, DSC1 was accompanied by a press release and had more FDA-originated messaging on Facebook and Twitter as compared to DSC2. In addition, users of Twitter and Facebook may have perceived DSC2 as clarifying DSC1 rather than providing new information. Indeed, the FDA's web page for DSC2 notes: “This update is in follow-up to the FDA Drug Safety Communication issued on 1/10/2013”. Finally, zolpidem was not mentioned by name in FDA social messaging at the time of DSC2, which may have muted the immediacy of the public health information.

Facebook and Twitter reflect public conversations with peers, while Google Trends data reflect anonymous user searches for information, but the results were generally consistent. Google Trends “Related queries” for Ambien in January 2013 included the words “FDA” and “warning”, suggesting that users were searching Google for information pertaining to DSC1; however, searches for Ambien steadily declined through the month of May 2013. DSC2, therefore, stimulated less investigatory online activity and interpersonal communication.

Although Wikipedia was updated close to the original release of the DSCs, the editors did not cite the original DSCs from the FDA webpage and the January 2013 edit of zolpidem's Wikipedia page was incomplete. It took until April 30, 2013 for the Wikipedia page to be updated with an additional detail from DSC1. The information included on DSC2 was added to the Wikipedia page quickly as well. Given that informational sites like Wikipedia are commonly accessed by the lay public for information on drugs and that anyone can edit the content, the FDA could consider a plan to formally update the pages for appropriate content at the time a DSC is released and to ensure the continued accuracy of the information over time.

The FDA has a wide following on Facebook (528,000 likes as of September 2017) and Twitter (@US_FDA has 175,000 followers as of September 2017, @FDA_Drug_Info has 231,000 followers, and @FDAMedWatch has 38,700 followers). Social media communications should continue to be part of future public drug safety communications and consideration should be given to expanding their use in the context of DSC-related messaging. But what is the optimal amount and duration of

social media necessary to maximize public health benefits? Social media may provide a timely, singular update about changes to important prescribing information, but social media discussions are generally short-lived, while information on the proper use of a medicine needs to be available consistently. For example, if users of zolpidem are engaging on social media to learn about recent updates about their medicine, the transient social media interest in the zolpidem DSC is not likely to benefit future users of the medicine, who may find other sources (such as a Google search, Wikipedia, or the FDA website) more valuable. Future strategies for using social media should be based on a more detailed understanding of user profiles and preferences. FDA may develop multiple approaches to disseminating DSC messages, including posting the same information multiple times, because a single post may often be overlooked by followers.

Limitations

Some observed data could not be explained, such as the drop in Facebook posts to near-zero in December 2012. Coupled with lower daily post counts compared to Twitter, significant findings from Facebook data must be interpreted in this light. We could only observe public Facebook accounts and public posts from non-public accounts, and daily counts of Facebook posts were considerably lower than that of Twitter, so we may be underestimating the Facebook impact of the DSCs.

There is also the possibility of misclassification by the MedWatcher Social program, which may not be the optimal tool for the FDA to utilize when tracking DSC dissemination over time. The tool is designed to identify posts from individual users related to AEs, which may differ from the FDA's needs with regard to DSC content dissemination, including through news outlets. For instance, several posts excluded as junk by MedWatcher Social were from news sources reporting on the

2 DSCs. As a result, public interest in each DSC may have been underestimated.

As compared to Facebook and Twitter, Google Trends search data are aggregated, anonymous, and lack the privacy restrictions that may have precluded access to certain relevant Facebook and Twitter posts. However, the granularity of available Google Trends data (with weekly, rather than daily, data points) may have limited statistical power, though the general trend resembled that of mention posts on the other platforms. We did not cover all major search engines or other Web-based and mobile technologies to allow for a fuller view across major social channels. This particular social media study was conducted as a subset of a multimodal analysis of FDA DSC messages using zolpidem as an example [37]; therefore, we only evaluated social media content related to zolpidem DSCs. DSCs for other medical products are likely to have differential impacts and outcomes. In addition, the zolpidem DSCs were posted in 2013. The social media environment has changed significantly since then. Future studies including DSCs from multiple medications and issued more recently will provide comprehensive insight.

Conclusion

Our study of drug safety information dissemination through Twitter, Facebook, Google searches, and Wikipedia following the release of 2 DSCs providing key changes in prescribing recommendations related to zolpidem found substantial but short-lived social media uptake of only 1 of the 2 information releases. Outcomes from this case should be compared with uptake observed around other DSC messages and other drug safety-related content to help the FDA expand dissemination of these important messages and provide the greatest public health impact.

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Conflicts of Interest

The FDA-affiliated authors contributed to the design of the study, interpretation of the data, and review of the manuscript. They did not participate in the conduct of the study, collection, management, and analysis of the data, or initial drafting of the manuscript. CCF has a consulting/advisory position with Booz Allen Hamilton Epidemico, which maintains the MedWatcher Social system for monitoring AE reports in social media. The authors report no other conflict of interests.

Multimedia Appendix 1

Food and Drug Administration (FDA) social media posts about Ambien.

[PDF File (Adobe PDF File), 1MB - [publichealth_v4i1e1_app1.pdf](#)]

Multimedia Appendix 2

Interrupted time series (ITS) and Chow tests.

[PDF File (Adobe PDF File), 727KB - [publichealth_v4i1e1_app2.pdf](#)]

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Abbreviations

- AE:** adverse event
DSC: drug safety communication
FDA: Food and Drug Administration
ITS: interrupted time series
OTC: over-the-counter

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Original Paper

Trust in Health Information Sources: Survey Analysis of Variation by Sociodemographic and Tobacco Use Status in Oklahoma

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Abstract

Background: Modern technology (ie, websites and social media) has significantly changed social mores in health information access and delivery. Although mass media campaigns for health intervention have proven effective and cost-effective in changing health behavior at a population scale, this is best studied in traditional media sources (ie, radio and television). Digital health interventions are options that use short message service/text messaging, social media, and internet technology. Although exposure to these products is becoming ubiquitous, electronic health information is novel, incompletely disseminated, and frequently inaccurate, which decreases public trust. Previous research has shown that audience trust in health care providers significantly moderates health outcomes, demographics significantly influence audience trust in electronic media, and preexisting health behaviors such as smoking status significantly moderate audience receptivity to traditional mass media. Therefore, modern health educators must assess audience trust in all sources, both media (traditional and digital) and interpersonal, to balance pros and cons before structuring multicomponent community health interventions.

Objective: We aimed to explore current trust and moderators of trust in health information sources given recent changes in digital health information access and delivery to inform design of future health interventions in Oklahoma.

Methods: We conducted phone surveys of a cross-sectional sample of 1001 Oklahoma adults (age 18-65 years) in spring 2015 to assess trust in seven media sources: traditional (television and radio), electronic (online and social media), and interpersonal (providers, insurers, and family/friends). We also gathered information on known moderators of trust (sociodemographics and tobacco use status). We modeled log odds of a participant rating a source as “trustworthy” (SAS PROC SURVEYLOGISTIC), with subanalysis for confounders (sociodemographics and tobacco use).

Results: Oklahomans showed the highest trust in interpersonal sources: 81% (808/994) reported providers were trustworthy, 55% (550/999) for friends and family, and 48% (485/998) for health insurers. For media sources, 24% of participants (232/989) rated the internet as trustworthy, followed by 21% of participants for television (225/998), 18% for radio (199/988), and only 11% for social media (110/991). Despite this low self-reported trust in social media, 40% (406/991) of participants reported using social media for tobacco-related health information. Trust in health providers did not vary by subpopulation, but sociodemographic variables (gender, income, and education) and tobacco use status significantly moderated trust in other sources. Women were on the whole more trusting than men, trust in media decreased with income, and trust in friends and family decreased with education.

Conclusions: Health education interventions should incorporate digital media, particularly when targeting low-income populations. Utilizing health care providers in social media settings could leverage high-trust and low-cost features of providers and social media, respectively.

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KEYWORDS

tobacco use cessation; health communication; trust; social media; health care providers; electronic cigarettes; mass media; radio; television; Oklahoma

Introduction

Analysis of US patient health-seeking behavior online in the 2003 Health Information National Trends Survey (HINTS) noted a “tectonic shift in the ways in which patients consume health and medical information” [1]. This shift has significantly changed the landscape for interventions seeking to change health behavior, which can now utilize a growing number of sources to disseminate information, each with their own associated risks and benefits [2]. Digital health interventions (DHIs) are options that use short message service/text messaging, social media, and internet technology, and they have proven effective in mitigating both negative health habits (ie, smoking [3]) and outcomes (ie, cardiovascular disease [4]). In some cases, DHIs can be less expensive to create [5] and DHI programs may leverage patients’ increasing proactivity in obtaining health information online, but may not be trusted or reach all affected demographic groups [6,7]. Conversely, traditional mass media communication sources (eg, television, radio, newspapers, and billboards) are historically high impact, but they can be expensive and do not necessarily target specific populations [8]. Interpersonal communication standbys (eg, health care providers, family and friends, and health insurers) remain consistently ranked as reliable sources for health information, but they have a more limited reach compared to social and mass media, and may be difficult to quantify and standardize [9,10].

Tailoring health communication to an audience is an accepted best practice for interventions. Message source selection is part of this tailoring; considering the source strategy (online, mass media, and/or interpersonal) is complicated by audience receptivity to these sources. Trust is a key element of message receptivity and, in medical settings, trust has been associated with increased health self-efficacy, treatment adherence, and ultimately more positive overall health outcomes [7,11]. However, trust in a specific source may vary based on factors such as prior experience with the source, sociodemographic background, or health behaviors (eg, tobacco use status) [7].

Despite largely ubiquitous access, the trend toward health information-seeking online and in social media is fraught with barriers, misinformation, and mistrust. The internet may exacerbate health disparities: populations with health disparities face barriers to internet access, including disability, lower socioeconomic status, rural locations, and illiteracy [12,13]. Studies done in 2003 and 2012 found that respondents who were female, younger, had higher income, and were better educated were more inclined to seek health information online, leading to a “digital divide” that correlates with preexisting health disparities [13,14].

In addition to access barriers, online health information is of widely varying quality. It is only peer reviewed in certain settings, for instance when health authorities make available clear and well-sourced information [6]. Online health information can be intentionally or unintentionally inaccurate, contain incomplete information, be outdated, originate from lay sources such as chat rooms, or may even encourage pathological behaviors [6]. An example of the emerging issues online health information has created can be summarized in a 2010 case study of randomly selected Twitter status updates about antibiotics [15]. Although only 1.3% of tweets contained information suggesting antibiotic misuse, these few posts reached more than one million followers [15], the equivalent of the population of Oklahoma City, Oklahoma’s largest metropolis.

As data on effective preventive medicine strategies accumulates, public health agencies are devoting increased attention to well-designed, targeted, and longitudinal multicomponent interventions. The Oklahoma Tobacco Settlement Endowment Trust (TSET) was founded in 2000 with a mandate to prevent cancer and cardiovascular disease in Oklahoma. In 2008, TSET partnered with the Oklahoma State Department of Health to create a multiphase communications campaign to raise awareness on the health hazards of tobacco use and secondhand smoke. During campaign evaluations, TSET included questionnaires on trust by source, with the hope that the data would inform future preventive campaigns.

Oklahoma is of particular interest because it may represent a mix of early- and late-adopter mindsets with respect to emerging technologies. These opposite traits could have conflicting impacts on DHI and mHealth trust and acceptance, as indicated in one study showing an association between “personal innovativeness toward mobile services” and mHealth usage [16]. On the late-adoption side, internet penetration in Oklahoma is still the sixth lowest in the United States, at 67.9% [17]. Social media use, measured in Facebook users, is half that (35%) [17]. Oklahoma also remains a state defined by tobacco use, with comparatively high rates of smoking and smokeless tobacco use (21.1% and 6.9%, respectively) [18,19]. However, with respect to the particular technology of electronic cigarettes (“e-cigarettes”) Oklahoma leads in adoption, and has been identified as the only state planning to avoid taxing and sales licensing for these products [20].

Our aim for this study was to continue exploration of these “tectonic shifts” in health information consumption by focusing on trust in a variety of sources in the context of our state of interest (Oklahoma). Furthermore, analysis by tobacco use status and sociodemographic subpopulation would give us insights into positive strategies for targeted DHI and health behavior

change messaging, while helping us avoid the potential pitfall of relying on sources that would not be trusted by populations of interest for tobacco use control or other health behaviors.

Methods

Sampling Methods

We gathered cross-sectional survey data as part of the evaluation and monitoring of the Tobacco Stops with Me media campaign conducted by the TSET in the spring of 2015 [21]. This cross-sectional survey (N=1001 Oklahomans) took place between May and June 2015 and was a dual-frame sample with both landline telephone and cellular telephone numbers. Eligibility criteria included Oklahoma residency, English speaking, age 18 to 65 years, and verbal consent. Institutional review board approval was obtained from the University of Oklahoma Health Sciences Center.

Assessing Trust in Health Information by Source

We surveyed trust in seven common sources of health information: television, radio, internet, social media, health care provider, health insurer, and family/friends using this prompt: "Rate how much you trust each of these sources of information." Trustworthiness for each source was collected on a five-point scale with 1 being "least trustworthy" and 5 being "most trustworthy."

Initial data analysis revealed that participants tended to rate media sources (television, radio, internet, social media) as less trusted, and rate interpersonal sources (health care provider, health insurer, family/friends) as highly trusted. This skew left us underpowered to compare all seven sources with full scales. Even reduced and dichotomized scale options did not produce meaningful results across all sources. When we re-examined the literature for context, we were reminded of the fundamental differences between, and theoretically independent nature of, mass media and interpersonal sources [9,22]. Thus, for both practical and theoretical reasons, we chose to dichotomize and analyze mass media and interpersonal sources independently. The mass media cluster was dichotomized as trustworthy/neutral (responses 3-5) or not trustworthy (responses 1-2). The interpersonal cluster was dichotomized as trustworthy (responses 4-5) versus not trustworthy/neutral (responses 1-3).

Assessing Moderators of Trust in Health Information by Source

We assessed tobacco use status using this prompt: "Do you currently smoke cigarettes/use smokeless tobacco/use electronic cigarettes or vapor devices?" Behavior was collected on a three-point scale as "no," "some days," and "every day." For smokers, readiness to change was assessed using the prompt: "What best describes your intentions regarding smoking cigarettes." Three stages of readiness were collected with a four-point scale; those who selected "never expect to quit" or "may quit in the future, but not in the next 6 months" were categorized as "precontemplation," those who selected "will quit in the next 6 months" were categorized as "contemplation," and those who selected "will quit in the next month" were categorized as "preparation."

We used SAS PROC SURVEYLOGISTIC on both clusters to model the log odds of a participant responding that a source of information was trustworthy or not trustworthy. We addressed potential confounders with multivariate models that controlled for all participant characteristics related to sociodemographics (ie, gender, race/ethnicity, education, income, children in household) and health behavior (ie, smoking status, e-cigarette use status, smokeless tobacco use status). Because the population of Oklahoma is majority white, race/ethnicity was dichotomized into "white" and "other" to reduce degrees of freedom. All reported results are based on weighted data.

Additionally, for context, we assessed how likely respondents were to "look for information on social media about the dangers of secondhand smoke" and to "look for information on social media for free help to quit using tobacco to share with your friends" on four-point Likert scales (ie, "not at all likely," "not too likely," "somewhat likely," and "very likely").

Results

Our sample demographics were largely representative of Oklahoma as a whole based on the 2015 US census (Tables 1 and 2) [23]. When the total sample (N=1001) was weighted, 78.55% (725/991) of respondents self-identified as white, 9.48% (97/991) as American Indian, 7.77% (79/991) as African American, 1.66% (65/991) as Hispanic, and 2.54% (25/991) as another race. Half of respondents were female (50.1%, 540/997). Just over half of respondents had at least some college: 29.2% (369/988) had a college degree, 26.5% (312/988) had some college, and 44.3% (307/988) had a high school or equivalent degree or less. Approximately one-fifth of respondents were defined as low income (\leq US \$30,000/year: 16.9%, 199/891); 31.5% (249/891) were middle income (US \$30,000<US \$60,000/year), and 51.6% (443/891) were high income (\geq US \$60,000/year). The sample was relatively evenly distributed between those with children in the household (46.8%, 420/991) and those without children (53.2%, 571/991). In tobacco status, the sample also generally reflected Oklahoma overall: 22.36% (181/1001) were smokers. Smoker readiness to quit skewed toward not being ready (stage of change precontemplation: 62.2%, 96/167; contemplation: 27.8%, 50/167; and preparation: 10.0%, 21/167). Smokeless tobacco and e-cigarette users were slightly overrepresented at 9% each (8.97%, 66/1000 and 8.68%, 79/998, respectively). Close to half of respondents reported use of social media for tobacco-related health information: mean 40.01% (95% CI 36.19-43.99; 406/991) reported being likely to look for information about the dangers of secondhand smoke, and mean 46.13% (95% CI 42.16-50.10; 443/987) reported being likely to look on social media for free help to help friends quit using tobacco.

Trust in sources was split between media and interpersonal sources. For media sources, 24.0% (232/989) of respondents rated the internet as trustworthy, followed by television (20.9%, 225/998), radio (18.2%, 199/988), and social media (11.3%, 110/991) (Table 1). For interpersonal sources, 80.9% (808/994) of respondents rated "health care provider" as trustworthy, followed by friends and family (54.6%, 550/999), and health insurer (48.3%, 485/998) (Table 2).

Table 1. Oklahomans' trust in health information from mass media sources by demographic and tobacco use variables (survey conducted in spring 2015; N=1001).

Demographics	n (weighted %)	Mass media sources, n (weighted %)			
		Trust in social media	Trust in internet	Trust in radio	Trust in television
Overall	1001 (100.00)	110 (11.3)	232 (24.0)	199 (18.2)	225 (20.9)
Gender^a					
Male	457 (49.94)	43 (10.6)	84 (19.1)	84 (15.8)	84 (16.4)
Female	540 (50.06)	66 (11.9)	146 (28.7)	114 (20.5)	140 (25.3)
Race/ethnicity					
White	725 (78.55)	66 (10.1)	148 (21.7)	134 (16.9)	148 (19.8)
Native American	97 (9.48)	14 (18.1)	26 (31.5)	26 (25.1)	30 (29.9)
African American	79 (7.77)	13 (13.5)	30 (37.7)	19 (23.5)	22 (21.4)
Hispanic	65 (1.66)	11 (12.1)	18 (25.1)	13 (19.9)	18 (26.0)
Other	25 (2.54)	4 (15.6)	7 (24.3)	5 (18.1)	5 (16.0)
Education					
High school/GED ^b	307 (44.26)	58 (16.3)	80 (26.6)	63 (17.9)	80 (22.1)
Some college	312 (26.51)	27 (9.2)	74 (26.7)	61 (19.3)	60 (19.5)
College degree	369 (29.23)	22 (5.7)	73 (17.5)	73 (18.0)	83 (20.5)
Annual income (US\$)^c					
<30,000	199 (16.91)	36 (20.9)	48 (25.9)	42 (23.9)	58 (27.1)
30,000<60,000	249 (31.52)	30 (14.4)	75 (31.5)	66 (20.6)	61 (24.7)
≥60,000	443 (51.56)	29 (6.2)	86 (19.8)	71 (15.1)	86 (17.7)
Children in household					
Yes	420 (46.78)	47 (11.1)	105 (25.3)	91 (19.6)	92 (20.1)
No	571 (53.22)	61 (11.4)	123 (22.8)	106 (17.1)	131 (21.6)
Smoking status					
Smoker	181 (22.36)	26 (16.4)	33 (23.7)	37 (19.9)	42 (23.6)
Nonsmoker	820 (77.64)	84 (9.8)	199 (24.1)	162 (17.7)	183 (20.1)
E-cigarette status^d					
E-cigarette user	79 (8.68)	7 (16.1)	11 (27.0)	10 (16.6)	11 (14.9)
Nonuser	881 (91.32)	102 (10.8)	219 (23.6)	187 (18.2)	214 (21.5)
Smokeless status^e					
Smokeless user	66 (8.97)	8 (18.0)	13 (27.2)	12 (15.5)	12 (15.8)
Nonuser	934 (91.03)	102 (10.6)	219 (23.7)	186 (18.4)	213 (21.4)

^aMultivariable logistic regression showed differences in gender for social media ($P=.02$), internet ($P<.001$), and television ($P<.001$).

^bGED: General Education Diploma.

^cMultivariable logistic regression showed differences in annual income for social media ($P=.04$), internet ($P=.02$), and television ($P=.02$).

^dMultivariable logistic regression showed differences for radio by e-cigarette use status ($P=.001$).

^eMultivariable logistic regression showed differences for radio by smokeless tobacco use status ($P=.045$).

Table 2. Oklahomans' trust in health information from interpersonal sources by demographic and tobacco use variables (survey conducted in spring 2015; N=1001).

Demographics	n (weighted %)	Interpersonal sources, n (weighted %)		
		Trust in health insurers	Trust in friends & family	Trust in health care provider
Overall	1001 (100.00)	485 (48.3)	550 (54.6)	808 (80.9)
Gender^a				
Male	457 (49.94)	195 (40.6)	238 (51.0)	350 (77.0)
Female	540 (50.06)	288 (56.0)	310 (58.1)	454 (84.6)
Race/ethnicity				
White	725 (78.55)	347 (48.1)	385 (52.5)	590 (80.9)
Native American	97 (9.48)	47 (48.9)	51 (58.5)	76 (81.9)
African American	79 (7.77)	45 (51.8)	51 (65.1)	57 (76.2)
Hispanic	65 (1.66)	30 (48.6)	38 (59.1)	57 (86.6)
Other	25 (2.54)	12 (44.7)	18 (64.1)	23 (93.2)
Education^b				
High school/GED ^c	307 (44.26)	141 (45.0)	185 (59.7)	231 (76.7)
Some college	312 (26.51)	149 (51.0)	169 (52.4)	250 (82.3)
College degree	369 (29.23)	191 (51.3)	189 (48.5)	319 (86.3)
Annual income (US\$)				
<30,000	199 (16.91)	98 (46.5)	126 (64.7)	140 (70.4)
30,000<60,000	249 (31.52)	121 (50.2)	138 (54.9)	202 (81.1)
>60,000	443 (51.56)	221 (48.2)	225 (51.5)	379 (84.1)
Children in household				
Yes	420 (46.78)	202 (46.4)	229 (52.6)	350 (80.6)
No	571 (53.22)	279 (50.1)	315 (56.2)	452 (81.3)
Smoking status				
Smoker	181 (22.36)	66 (40.0)	94 (53.6)	126 (70.7)
Nonsmoker	820 (77.64)	419 (50.7)	456 (54.8)	682 (83.8)
E-cigarette status				
E-cigarette user	79 (8.68)	33 (43.3)	38 (53.0)	59 (72.8)
Nonuser	881 (91.32)	451 (48.8)	510 (54.7)	747 (81.7)
Smokeless status				
Smokeless user	66 (8.97)	29 (40.9)	34 (42.9)	50 (78.0)
Nonuser	934 (91.03)	456 (49.1)	515 (55.6)	757 (81.1)

^aMultivariable logistic regression showed differences in gender for health insurer ($P=.001$).

^bMultivariable logistic regression showed differences in education for friends and family ($P=.04$).

^cGED: General Education Diploma.

Demographic and tobacco use status moderators of trust in sources were determined by multivariate logistic regression, and included all participant characteristics (Tables 3 and 4). Within multivariate analyses, trust differences between men and women were significant for television, internet, and social media. Women were up to two times more likely to rate these sources as trustworthy (eg, internet: OR 2.0, 95% CI 1.4-2.9, $P<.001$), and expressed higher levels of trust for all sources.

Income also persisted as a factor significantly differentiating trust for social media ($P=.04$), internet ($P=.02$), and television ($P=.02$). As compared to low-income individuals, middle-income individuals were equally likely to trust social media (OR 1.0, 95% CI 0.6-1.8, $P=.04$), but high-income individuals much less so (OR 0.6, 95% CI 0.4-1.1, $P=.04$). As compared to low-income individuals, middle-income individuals were nearly twice as likely to trust internet (OR 2.0, 95% CI

1.2-3.5, $P=.02$), although high-income individuals were slightly less so (OR 1.3, 95% CI 0.8-2.2, $P=.02$). As compared to low-income individuals, middle-income individuals were slightly more likely to trust television (OR 1.2, 95% CI 0.7-2.0, $P=.17$), but high-income individuals were much less so (OR 0.6, 95% CI 0.4-1.1, $P=.02$).

Although tobacco use was not significantly associated with trust in media sources, trust in radio differed for e-cigarette and

smokeless users. E-cigarette users were less trusting of radio than nonusers (OR 0.3, 95% CI 0.1-0.6, $P<.001$). Conversely, smokeless users were more trusting of radio than non-smokeless users (OR 2.1, 95% CI 1.0-4.3, $P=.045$). The trustworthiness of providers did not differ by demographic or health indicators. Perceptions of trustworthiness of family and friends varied significantly by education; trust in these close social ties decreased with higher education.

Table 3. Summary of multivariable logistic regression analysis for sociodemographic and tobacco use status variables associated with trust in mass media sources (survey conducted in Oklahoma, spring 2015; N=1001).

Variable	Mass media sources							
	Trust in social media		Trust in internet		Trust in radio		Trust in television	
	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
Gender								
Male	ref ^a							
Female	1.5 (1.1-2.2)	.03	2.0 (1.4-2.9)	<.001	1.2 (0.9-1.8)	.25	1.9 (1.3-2.7)	.001
Race/ethnicity								
White	ref							
Other	1.1 (0.7-1.7)	.58	1.4 (0.9-2.1)	.15	0.9 (0.6-1.3)	.45	1.0 (0.7-1.5)	.94
Education								
High school/GED ^b	ref							
Some college	1.0 (0.6-1.5)	.86	1.4 (0.9-2.2)	.28	1.1 (0.7-1.6)	.42	1.1 (0.7-1.7)	.36
College degree	0.9 (0.6-1.4)	.86	1.4 (0.9-2.1)	.28	1.3 (0.8-2.1)	.42	1.4 (0.9-2.2)	.36
Annual income (US\$)								
<30,000	ref							
30,000<60,000	1.0 (0.6-1.8)	.04	2.0 (1.2-3.5)	.02	1.3 (0.7-2.1)	.30	1.2 (0.7-2.0)	.02
≥60,000	0.6 (0.4-1.1)	.04	1.3 (0.8-2.2)	.02	0.9 (0.5-1.5)	.30	0.6 (0.4-1.1)	.02
Children in household								
No	ref							
Yes	1.1 (0.7-1.5)	.78	1.4 (1.0-2.0)	.08	1.2 (0.9-1.8)	.24	0.9 (0.6-1.3)	.52
Smoking status								
Nonsmoker	ref							
Smoker	0.7 (0.4-1.1)	.11	0.9 (0.6-1.5)	.70	1.1 (0.7-1.8)	.75	0.7 (0.4-1.1)	.12
E-cigarette status								
Nonuser	ref							
E-cigarette user	1.6 (0.8-3.1)	.21	0.8 (0.4-1.6)	.56	0.3 (0.1-0.6)	.001	0.7 (0.3-1.4)	.27
Smokeless status								
Nonuser	ref							
Smokeless user	1.1 (0.5-2.2)	.86	1.0 (0.5-2.0)	.95	2.1 (1.0-4.3)	.046	1.1 (0.6-2.2)	.76

^aRef: reference group.

^bGED: General Education Diploma.

Table 4. Summary of multiple regression analysis for sociodemographic and tobacco use status variables associated with trust in interpersonal sources (survey conducted in Oklahoma, spring 2015; N=1001).

Variable	Interpersonal sources					
	Trust in health insurer		Trust in friends and family		Trust in health care provider	
	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
Gender						
Male	ref ^a					
Female	1.8 (1.3-2.5)	.001	1.3 (0.9-1.9)	.11	1.6 (1.0-2.5)	.06
Race/ethnicity						
White	ref					
Other	1.1 (0.7-1.7)	.60	1.4 (1.0-2.1)	.08	1.1 (0.7-1.9)	.65
Education						
High school/GED ^b	ref					
Some college	1.3 (0.8-2.0)	.49	0.7 (0.4-1.0)	.04	1.3 (0.8-2.30)	.40
College degree	1.3 (0.8-1.9)	.49	0.6 (0.4-0.9)	.04	1.5 (0.8-2.8)	.40
Annual income (US\$)						
<30,000	ref					
30,000<60,000	1.2 (0.7-2.0)	.64	0.8 (0.5-1.3)	.51	1.7 (0.9-3.2)	.16
≥60,000	1.0 (0.6-1.6)	.64	0.8 (0.5-1.3)	.51	1.8 (0.9-3.4)	.16
Children in household						
No	ref					
Yes	0.8 (0.6-1.1)	.21	0.9 (0.6-1.2)	.39	0.8 (0.5-1.3)	.44
Smoking status						
Nonsmoker	ref					
Smoker	0.8 (0.5-1.2)	.27	0.8 (0.5-1.2)	.29	0.6 (0.3-1.1)	.12
E-cigarette status						
Nonuser	ref					
E-cigarette user	1.0 (0.5-1.9)	.98	1.1 (0.6-2.0)	.85	0.8 (0.3-2.0)	.67
Smokeless status						
Nonuser	ref					
Smokeless user	1.0 (0.5-2.0)	.90	0.7 (0.4-1.3)	.25	1.3 (0.5-3.0)	.61

^aRef: reference group.

^bGED: General Education Diploma.

Discussion

In a largely representative survey sample of Oklahomans, we found self-reported trust in interpersonal health information sources was higher than in media sources. But this trust was significantly moderated by sociodemographic factors related to gender, income, and education. Women were on the whole more trusting than men, trust in media decreased with income, and trust in friends and family decreased with education. Additionally, and perhaps unexpectedly considering recent documented associations between smoking status and trust in information source [24], we found no association between smoking and trust in any individual source. Alternative tobacco use status, however, was associated with trust in radio:

e-cigarette users were less likely to trust radio and smokeless users were more likely to trust radio.

Although less trusted overall, media sources are inexpensive, standardizable, and scalable, so social media may still be effective in targeted DHIs for lower-income populations. A recent systematic review demonstrated the positive impact of mobile phone-based DHIs on cardiovascular disease in general [4], and on smoking specifically [3]. Health information often needs to be tailored to low-income population; the majority of smokers are lower income in Oklahoma [25], a trend repeated in the rest of the United States and globally. Previous studies have posited that low-income communities may be better positioned to receive social media DHIs because individuals may have mobile phone access to social media even if they do

not have access to the internet and social media through personal computers [26]. Our study supported these findings. We found that although overall trust in social media was low (11%), individuals in households making less than US \$30,000 yearly were significantly more likely than wealthier individuals to trust social media (21% rated social media as trustworthy). Previous reports on the rates of social media utilization in Oklahoma were modest at 36% [27], but rates are likely to increase in tandem with US trends. Our study found that self-reported rates for tobacco-related health information acquisition on social media were high (40%-46%), perhaps because our sample included representative numbers of low-income individuals.

Another argument for the use of social media in DHIs is its potential for social interaction, a desired attribute of successful interventions [28]. Our study found that interpersonal sources were more trusted than media sources, providers were trusted globally, and low-income respondents were more likely to trust friends and family. Social media for health messaging has been identified as a lower-cost communication tool existing in a framework that facilitates community engagement, personal empowerment, and collaboration [29]. An example of this would be TSET's tobacco prevention Tobacco Stops with Me campaign, where individuals have been invited to share their own stories through social media.

A next step in creating low-cost, high-trust communication could include utilizing health care providers on social media. Previous research has identified the need for tobacco experts to interact in social media to dispel myths about tobacco [22]. This study supports the potential for qualified individuals to make positive impacts in public health by combining high public trust in their opinions and recommendations with easily disseminated and personalized DHI venues. National Health Institutes could further support expert engagement in social media by specifically funding public education through social media as a low-cost way to reach target audiences.

Finally, a word of warning. Our results document that less-educated and lower-income individuals may be more trusting of, and thus more receptive to, health messages from social media and the internet. Although this finding is encouraging for health educators and interventionists, it also puts these health-disparate groups at risk to accept pseudo-health

messages from untrustworthy sources. Indeed, there are already indications that at-risk race-ethnicity groups are more trusting of e-cigarette and tobacco companies, that this trust is associated with greater risk of e-cigarette use, and that social media contains tobacco-promotion marketing accessible to youth [24,30,31].

This study has three limitations. Due to the skew of trust results, particularly for social media and providers, we treated mass media (internet, radio, television, and social media) and interpersonal (providers, insurers, and friends and family) sources differently, limiting our ability to compare across groups. Additionally, specific messages, websites, etc, were not tested, so we do not know exactly what participants had in mind when they rated the trustworthiness of each source. Finally, although we speculate about the potential impact on behavior of delivering health information through different sources, this analysis does not offer data to support connections between source trustworthiness and behavior change.

Overall, this study supports the growing body of evidence documenting the potential for DHIs to impact health outcomes, in this case specifically for lower-income and less-educated individuals who may be more receptive and trusting of social media and internet health messages. On a more basic level, in addition to validating previous studies showing the trustworthiness of health care providers regardless of participant smoking status [32], we have extended analysis of trust by smoking status to other sources, and find no significant differences between smokers and nonsmokers. Instead, differences in trust cluster around socioeconomic factors of income, education, and alternative tobacco use (radio), suggesting that successful DHI strategies should be adapted to novel health promotion areas. By contrast, even if content remains consistent, ideal successful programs should be fully reassessed as they are applied to new communities or socioeconomic groups. As DHI programs are reassessed or developed de novo, a primary recommendation based on our findings is to combine ubiquitous high trust in providers with the reach and potential of social media. As attempted in some smoking cessation social media interventions, such as the Tobacco Status Project [33], incorporating expert provider voices into social media interventions may bolster trust and potential efficacy.

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Authors' Contributions

CGBJ, AHW, and LAB conceptualized the topic and approach. Data collection was overseen and implemented by SP, AHW, and LAB. LMB performed statistical analyses, with direction from CGBJ, AHW, and LAB. All authors reviewed the statistical analyses. CGBJ led the writing of the article, assisted by ADB. All authors reviewed, revised, and approved the final article.

Conflicts of Interest

CGBJ has consulted with TSET. SP is currently TSET's Director of Health Communication. AHW and LAB are funded by TSET to evaluate their marketing campaigns through a contract with the University of Oklahoma Health Sciences Center, and ADB is professional medical writer and independent researcher who has consulted with CGBJ. The authors have no other conflicts of interest to declare.

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Abbreviations

DHI: digital health intervention

HINTS: Health Information National Trends Survey

GED: General Education Diploma

Ref: reference group

TSET: Oklahoma Tobacco Settlement Endowment Trust

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Original Paper

Influence of Flavors on the Propagation of E-Cigarette–Related Information: Social Media Study

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Abstract

Background: Modeling the influence of e-cigarette flavors on information propagation could provide quantitative policy decision support concerning smoking initiation and contagion, as well as e-cigarette regulations.

Objective: The objective of this study was to characterize the influence of flavors on e-cigarette–related information propagation on social media.

Methods: We collected a comprehensive dataset of e-cigarette–related discussions from public Pages on Facebook. We identified 11 categories of flavors based on commonly used categorizations. Each post’s frequency of being shared served as a proxy measure of information propagation. We evaluated a set of regression models and chose the hurdle negative binomial model to characterize the influence of different flavors and nonflavor control variables on e-cigarette–related information propagation.

Results: We found that 5 flavors (sweet, dessert & bakery, fruits, herbs & spices, and tobacco) had significantly negative influences on e-cigarette–related information propagation, indicating the users’ tendency not to share posts related to these flavors. We did not find a positive significance of any flavors, which is contradictory to previous research. In addition, we found that a set of nonflavor–related factors were associated with information propagation.

Conclusions: Mentions of flavors in posts did not enhance the popularity of e-cigarette–related information. Certain flavors could even have reduced the popularity of information, indicating users’ lack of interest in flavors. Promoting e-cigarette–related information with mention of flavors is not an effective marketing approach. This study implies the potential concern of users about flavorings and suggests a need to regulate the use of flavorings in e-cigarettes.

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KEYWORDS

e-cigarettes; flavors; social media; information propagation; social networks; electronic nicotine delivery systems; flavoring agents; information dissemination; social networking

Introduction

The electronic cigarette, commonly known as an e-cigarette or electronic nicotine delivery system, is a method of delivering vaporized nicotine instead of combusting tobaccos. The advent of e-cigarettes provided smokers with an alternative way to give

them a feeling similar to smoking but with less smoke ingestion, which is the major danger from using conventional cigarettes. A series of studies revealed the increasing popularity and ever-use of e-cigarettes in developed countries (eg, United Kingdom, United States), particularly among adolescents and young adults [1-4]. During 2011 to 2015, the use of e-cigarettes

among high school students increased from 1.5% to 16.0% in the United States [4]. Today, more than 2.7 million people have used e-cigarettes worldwide. Sales reached more than US \$2.8 billion in 2015 alone [5].

E-cigarettes are known to be effective in smoking cessation and less harmful in terms of the level of toxicants ingested [6-11]. Flavors of e-cigarettes play a critical role in enhancing the experience for e-cigarette users and helping smoking abstinence [12]. Thus, promoting flavors has become a major marketing strategy for e-cigarette manufacturers and retailers [13]. However, e-cigarettes may be harmful, as they could attract nonsmokers or former smokers to use conventional cigarettes [14]. The addition of flavors introduces new health risks to the use of e-cigarettes. Biochemical research identified positive correlations between cytotoxicity and the use of chemicals in flavor fluids [15-17]. In addition, similar to conventional tobacco products, the use of flavors in e-cigarettes is appealing to youth, young adults, and even children [3,18,19].

Despite the wide adoption and potential risks associated with e-cigarettes, regulation and legislation pertaining to e-cigarettes are still at their nascent stage. Researchers found an association between the popularity of e-cigarettes and stronger tobacco control, indicating that e-cigarettes are used to bypass smoking restrictions [1]. The US Food and Drug Administration has raised the concern that certain flavors' appeal to young adults could lead to their initiating smoking [20]. Due to the lack of appropriate restrictions, the excessive level of flavor chemicals in e-cigarettes might irritate the respiratory system [18,21]. Regulatory authorities and policy makers are urged to learn more about e-cigarettes and their flavors, particularly from e-cigarette users [3,12,13,16,20,22].

Social media provides valuable resources for studying e-cigarettes. Social media users have formed online communities to discuss various topics relating to e-cigarettes, such as their flavors, use of e-cigarettes in smoking cessation, and the safety of using e-cigarettes [23]. Meanwhile, most e-cigarette manufacturers and retailers have been actively using social media as a platform to promote products and collect feedback from consumers. The role of social media in marketing is strengthened by limitations on advertising and marketing of tobacco products [23].

Research has demonstrated that such social media and Internet data could be used to evaluate the diffusion of health products and health behaviors related to e-cigarettes [22-25]. A cross-sectional study revealed that e-cigarette-related Twitter posts were overwhelmingly commercial, with frequent mentions of smoking cessation [23]. Another study on the retweet network of e-cigarette-related posts validated the use of social media as a proxy filter for marketing messages [26]. Another study using YouTube data categorized e-cigarette-related videos by attitudes and types, and showed that most videos held positive views of e-cigarettes [25]. A content analysis of Reddit posts demonstrated that flavor-related social media information could reflect smokers' interest in e-cigarette products containing these flavors [22]. Several empirical studies examining flavor-related e-cigarette marketing on social media found that posts that mentioned flavor received more positive comments and had a

higher chance to be reposted than those without flavors [13,26,27]. However, previous studies did not recognize the possibility that the influence on information propagation may vary across different flavors. An in-depth understanding of the information propagation of posts mentioning specific flavors could inform practical marketing strategies for retailers and provide policy suggestions for regulatory authorities. Our research aimed to address this challenge to characterize the influence of flavors on the information propagation of e-cigarette-related posts on social media.

Methods

Data Description

In this study, we collected a comprehensive dataset from Facebook (Facebook, Inc), the biggest social media platform. In addition to social networking functions, Facebook allows individuals or organizations to create (public) Pages for users to form communities for various purposes. Facebook Pages have been widely used by companies (including all major e-cigarette manufacturers and retailers) as a platform for marketing and maintaining customer relations [28]. Those Pages also represent active communities for e-cigarette users to discuss topics related to e-cigarettes, including flavors, promotional campaigns, the pros and cons of consuming e-cigarettes, and safety issues. The rich discussions about e-cigarettes in public Pages provide an ideal data source to identify consumers' perceptions and preferences, and the diffusion of multiple flavors.

Based on keywords generated by domain experts (as [Textbox 1](#) shows), we retrieved a set of e-cigarette-related Facebook Pages through Facebook's application programming interface (API). We derived the keywords in [Textbox 1](#) from the combination of domain expertise and the published literature [29-31]. For consistency, we manually extracted the Pages related to smoking promotion run by e-cigarette manufacturers and retailers. Finally, we collected the full information of all posts with comments. In total, we collected 7132 e-cigarette-related Facebook Pages with 765,321 posts up to April 24, 2015. Of these posts, 86.68% (663,357/765,321) were generated during 2013 to 2015. A post may receive comments and likes from Facebook users and can be shared by users (to their own Facebook timelines). We collected 2,737,840 comment records and 17,671,614 like records. For each post, we collected the Page identifier (ID), post ID, user ID (who posted the post), time when the post was created, textual content, and the records of comments, likes, and shares. For each comment record, we collected user ID (who posted the comment), time when it was created, and textual content. For each like record, we collected user ID (who clicked the Like button of the original post) and time of clicking the Like button. In total, we identified 1,414,240 unique user IDs. Then, we collected the full public profiles of these users, including their screenname, language, location, and sex. To be consistent, we chose 384,792 posts generated by users with the label "en_US," indicating they were English-speaking Facebook users located in the United States.

Textbox 1. E-cigarette-related keywords for data collection.

electronic cigarette, disposable cigarette, e-cig, e-cigarette, rechargeable cigarette, rechargeable kits, flavor cartridge, vaporizer, vaporized, vapor, vaping, mod, apv, refill cartridges, vaping pen, refills, cigalikes, mechs, vape pen, electronic pipe, cartomizer, clearomizer, atomizer, hookah, electronic hookah, shisha, electronic shisha, e-hookah, e-shisha, electronic cigar, e-cigar, electronic juice, electronic liquid, e-juice, e-liquid, electronic joint, e-joint, electronic spliff, e-spliff, vape, vaping, istick, coil tank, coil, rda

Variables Description

We characterized the influence of different flavors on the information propagation patterns using regression models. In this section, we explain the variables for candidate regression models.

When users browse posts, photos, and other information on Facebook, they can click the Like button for that information, post comments, and share the information to their own timelines. The frequency of a post being shared and liked, and the number of comments received, are explicit proxy measures of information propagation. [Figure 1](#) shows the distributions of these 3 variables (note that we added 1 to each value on the x-axis to avoid the logarithm of zeros on the horizontal axis). In general, we observed a power law-shaped curve in these distributions. This “rich-get-richer” effect indicated that the popularity of a post and the information propagation were unevenly distributed, with most of the posts being seldom shared, commented on, or liked, while a small number of popular posts received a huge number of shares, comments, and likes.

When Facebook user *A* shares a post published on a Facebook Page, this post then appears in *A*'s timeline, as well as on the newsfeed (home page) of *A*'s friends. Therefore, the sharing behavior presents the information propagation from the Page to the user and the user's friends. If one of *A*'s friends, *B*, also shared the same post after reading it from the newsfeed (because *A* shared it), our data collection also captured this new sharing behavior. It is impossible to differentiate the original shares and subsequent shares caused by specific propagation paths through the newsfeed, because Facebook's API prohibits the collection of friendship information. On the other hand, 2 additional proxies of information propagation, comments and likes generated by user *A*, will not be explicitly presented to *A*'s friends. Therefore, data on post-sharing behaviors is the most effective and reliable proxy to identify, track, and model information propagation on Facebook [26,32]. In this study, we calculated the frequency of being shared by Facebook users for each post (denoted as Shares) as the dependent variable (representing information propagation) in regression models.

Because of the lack of regulations, manufacturers and retailers do not have a universal flavor classification system. Researchers have used questionnaires and data mining methods to identify a set of the main categories of e-cigarette flavors [12,22,27]. Borrowing and evaluating these categorizations, we identified 11 categories of flavors of e-cigarettes in our dataset: beverage, coffee, sweet, dessert & bakery, fruits, herbs & spices, menthol & mint, nutty, cream, tobacco, and chocolate. We also identified a set of keywords for each category (eg, coke and peps are keywords for beverage). It is worth mentioning that the content of a post could contain more than one flavor. [Figure 2](#) shows

the distribution of posts that mentioned flavors. Among all of the flavors, fruits was the most popular, followed by sweet and cream.

To characterize the influence of these 11 categories of flavors on information propagation (measured by the frequency of being shared), we introduced 11 binary variables for flavor categories. Each binary variable represented the existence of keywords belonging to the corresponding flavor category.

To avoid bias, we introduced a set of nonflavor-related variables that could have influenced information propagation and correlated with flavor-related variables. In Facebook Pages, manufacturers and retailers often promote their products by offering consumers rewards and gifts by lottery among those users who liked, shared, or commented on the posts. Obviously, such promotional activities would largely increase the appeal of posts to the users. We first identified promotion-related posts based on a set of keywords related to promotions (eg, reward, share, gifts, and free). Then, we added the binary dummy variable promotion to represent the existence of promotion in the corresponding post.

The activeness of a Facebook Page is often associated with its popularity. In general, the more active a Facebook Page is, the more frequently its posts can be viewed by users. To capture this effect, we used the count of posts in a Facebook Page as an independent variable, Posts, to measure the activeness of the Page. In addition, the level of user engagement is diverse because of many unknown factors (eg, the popularity of the brand). To differentiate the influence of flavors and the Page-specific user engagement level, we calculated the average number of shares per post of each Page as a control variable, average share.

The topics conveyed by posts could have a significant influence on information propagation. To capture the potential effect of topics, we employed the commonly used latent Dirichlet allocation, an unsupervised learning model for topic modeling, to extract 3 topics hidden in the text of posts: details about products (product), methods of consuming e-cigarettes (method), and other related discussions (other). [Table 1](#) lists the top 10 most frequent words for each topic. For more details about topic modeling, please refer to [Multimedia Appendix 1](#).

The content of posts often contained URLs and hashtags. URLs provide external information related to the posts. Hashtags are used to help Facebook users label and identify posts with specific topics. Both URLs and hashtags have been found to be associated with the likelihood of information propagation [33]. We introduced 2 control variables, URL mention and Hashtag, to represent the existence of URLs and hashtag labels, respectively. [Table 2](#) summarizes all variables, and [Multimedia Appendix 1](#) summarizes Pearson correlation coefficients.

Figure 1. Distributions of (a) shares, (b) comments, and (c) likes. We added 1 to each value on the x-axis to avoid the logarithm of zeros on the horizontal axis.

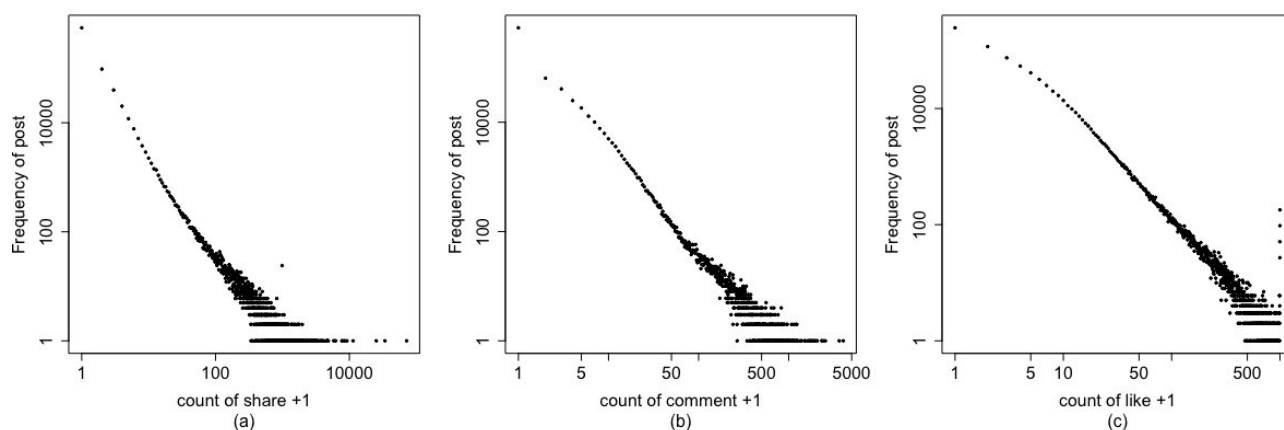


Figure 2. Occurrences of the 11 flavor categories in e-cigarette-related Facebook posts.

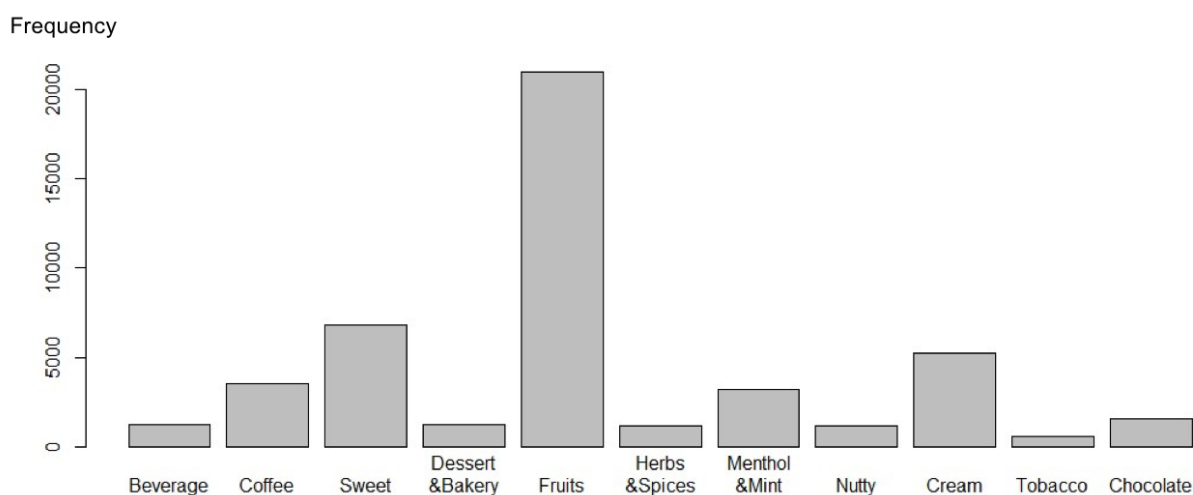


Table 1. Top 10 most frequent words for each topic.

Rank	Topic 1: product (details about e-cigarettes)		Topic 2: method (methods of e-cigarette consumption)		Topic 3: others (related discussions)	
	Words	Frequency (x 10 ⁻²)	Words	Frequency (x 10 ⁻²)	Words	Frequency
1	new	1.76	vape	1.80	tobacco	.77
2	now	1.26	get	1.69	Smoking	.73
3	flavor	.88	vapor	1.22	know	.06
4	stock	.84	free	1.17	smoke	.53
5	mod	.83	hookah	.89	thank	.52
6	available	.77	juice	.85	like	.52
7	flavors	.66	like	.79	want	.50
8	2 (oz.)	.61	vaping	.79	time	.50
9	1 (oz.)	.58	everyone	.78	help	.40
10	battery	.48	happy	.75	vaping	.40

Table 2. Summary statistics of dependent and independent variables and control variables.

Variables	Mean (SD)	Minimum	Maximum
Dependent variable			
Shares	7.10 (154.85)	0	71,668
Independent variables, mean (SD) x 10⁻²			
Beverage	0.33 (5.72)	0	1
Coffee	0.91 (9.59)	0	1
Sweet	1.77 (13.20)	0	1
Dessert & bakery	0.33 (5.73)	0	1
Fruits	5.44 (22.68)	0	1
Herbs & spices	0.30 (5.51)	0	1
Menthol & mint	0.84 (9.12)	0	1
Nutty	0.31 (5.58)	0	1
Cream	1.37 (11.64)	0	1
Tobacco	0.16 (4.04)	0	1
Chocolate	0.41 (6.39)	0	1
Control variables			
Promotion	0.04 (0.19)	0	1
Posts	618.11 (780.06)	1	5,980
Average share	7.10 (18.51)	0	2,258
Topic 1	0.33 (0.08)	0.03	0.97
Topic 2	0.34 (0.07)	0.01	0.91
Topic 3	0.33 (0.07)	0.01	0.94
URL mention	0.14 (0.35)	0	1
Hashtag	0.12 (0.33)	0	1

Model Selection

We evaluated a set of regression models for count data to characterize the influence of flavors on e-cigarette-related information propagation. We used Stata software version 12.0 (StataCorp LLC) to estimate parameters.

The Poisson regression model is the most common method to model count data. It assumes that the mean and variance of the dependent variable are equal; thus, we needed to test the overdispersion effect of the data to confirm the assumption. We used the following z score test to evaluate whether the overdispersion effect in the Poisson regression model was significant enough to violate the fundamental assumption [34]: $z = [(y - \mu)^2 - y] / \mu \sqrt{2}$, where y is the dependent variable and μ is the expectation. We obtained a z score of 1228.886 with a t probability of .04. This indicated that there was a significant overdispersion effect and the Poisson regression model was not ideal for these data. This was also reflected by the poor goodness-of-fit, as indicated by the large value of the Akaike information criterion (AIC).

The negative binomial regression model is widely used to resolve the overdispersion problem by relaxing the Poisson assumption through adding constant dispersion parameter α .

However, the negative binomial assumption is difficult to meet when excessive zeros exist in dependent variables.

In our study, we found that 61.1% of observations of the dependent variables were zero. To handle excessive zeros, we used the zero-inflated regression model and the hurdle regression model. In the zero-inflated model, the dependent variable is modeled as a mixture of the count data model (eg, Poisson regression model, negative binomial regression model) and a separate Bernoulli distribution. In the hurdle model, there are 2 components to model the dependent variable: positives are generated by a truncated-at-zero count data model, and zeros are generated by a Bernoulli distribution. Both models can overcome the limit of standard count data models, which assume that zeros and positives are both generated by the same process.

Results

We evaluated the performance of the proposed models using our data (as Table 3 shows with coefficients and P values). We observed that the negative binomial regression, the hurdle negative binomial regression model, and the zero-inflated negative binomial regression model performed significantly better than the Poisson model. The hurdle negative binomial regression model had the best performance as indicated by the

lowest AIC/n. Therefore, we selected the hurdle negative binomial regression model as the base model to characterize the relationship between the independent and dependent variables. Then, we examined the influence of nonflavor-related variables on the fit of flavor-related variables; Table 4 presents the final model, with coefficients and *P* values.

Regarding the results of the base and final regression models presented in Table 4, the first set of columns show our estimates of a specification of the initial model with only flavors as the independent variables. The negative and significant coefficients for coffee, fruits, and tobacco suggested that the existence of these flavors tended to reduce the chance of propagation of the corresponding e-cigarette-related information.

The additional control variables in the second and third sets of columns modified the estimates of flavors' influence on information propagation. Specifically, the estimates of tobacco became nonsignificant, indicating that its effect was weakened after adding control variables. The significance of herbs & spices, dessert & bakery and cream became visible with the addition of promotion. Most control variables were significant. Particularly, the large *z* score and coefficient of promotion suggested that promotion was the dominating variable among all the independent variables. This is reasonable because the promotions in a post would greatly increase its chance of being shared by users.

Table 3. Results of regression models.

Variables	Model		Negative binomial		Zero-inflated negative binomial		Hurdle negative binomial	
	Poisson							
	Coefficient ^a	<i>P</i> value	Coefficient ^a	<i>P</i> value	Coefficient ^a	<i>P</i> value	Coefficient ^a	<i>P</i> value
Independent variables								
Beverage	-0.65	.01	-0.11	.29	0.66	.02	-0.23	.12
Coffee	-0.85	<.001	-0.02	.73	0.14	.34	-0.15	.21
Sweet	-0.11	.34	-0.19	.006	-0.60	<.001	-0.34	.001
Dessert & bakery	-0.49	.003	-0.28	<.001	-0.70	<.001	-0.52	<.001
Fruits	-0.29	<.001	-0.16	<.001	-0.13	.008	-0.24	<.001
Herbs & spices	-0.07	.87	-0.57	<.001	-0.64	<.001	-0.60	<.001
Menthol & mint	-0.35		-0.20	.003	-0.12	.21	-0.08	.46
Nutty	0.11	.71	0.15	.17	-0.27	.11	0.002	.99
Cream	0.09	.49	-0.13	.13	-0.79	<.001	-0.15	.27
Tobacco	-1.22	<.001	-0.44	<.001	0.33	.14	-0.55	.001
Chocolate	-0.09	.59	0.03	.82	-0.36	.11	0.09	.65
Control variables								
Promotion	3.12	<.001	3.06	<.001	2.01	<.001	3.16	<.001
Posts (Coefficient x 10 ⁻⁴)	3.46	<.001	2.78	<.001	1.18	<.001	3.58	<.001
Average share (Coefficient x 10 ⁻²)	.48	<.001	6.67	<.001	4.18	<.001	10.17	<.001
Topic 1	6.15	<.001	1.61	<.001	0.79	<.001	1.39	<.001
Topic 2	7.75	<.001	1.11	<.001	1.42	<.001	1.17	<.001
URL mention	0.09	.12	0.25	<.001	0.27	<.001	0.19	<.001
Hashtag	-0.39	<.001	-0.05	.25	0.01	.75	-0.02	.72
Intercept	-3.73	<.001	-0.97	<.001	-0.53	<.001	-18.79	<.001
Model zero	No		No		Yes		Yes	
Model dispersion	No		Yes		Yes		Yes	
AIC/n ^b	33.74		3.20		3.24		3.14	

^aEstimate of coefficient for each variable in the model.

^bAIC: Akaike information criterion. The hurdle negative binomial regression model had the best performance as indicated by the lowest AIC/n (AIC value divided by number of observation).

Table 4. Results of the hurdle negative binomial regression models.

Variables	Model 1 ^a (n=384,792 ^b)		Model 2 ^c (n=384,792 ^b)		Model 3 ^d (n=384,792 ^b)		Without promotion (n=370,670 ^b)		With promotion (n=14,122 ^b)	
	Coefficient	P value	Coefficient	P value	Coefficient	P value	Coefficient	P value	Coefficient	P value
Independent variables										
Beverage	0.05	.94	0.64	.36	-0.23	.12	-0.20	.18	-1.38	<.001
Coffee	-1.69	<.001	-0.69	.003	-0.15	.21	-0.10	.40	-1.53	<.001
Sweet	0.11	.496	-0.31	.06	-0.34	.001	-0.35	.002	-0.04	.81
Dessert & bakery	-0.46	.09	-0.64	.04	-0.52	<.001	-0.57	<.001	-0.08	.78
Fruits	-0.31	.004	-0.67	<.001	-0.24	<.001	-0.25	<.001	-0.07	.48
Herbs & spices	0.20	.70	-1.19	<.001	-0.60	<.001	-0.61	<.001	0.14	.69
Menthol & mint	-0.24	.34	-0.01	.97	-0.08	.46	-0.06	.58	-0.24	.55
Nutty	-0.06	.86	0.01	.97	0.002	.99	-0.04	.79	0.65	.08
Cream	0.16	.38	-0.39	.02	-0.15	.27	-0.19	.18	0.52	.007
Tobacco	-1.65	<.001	-0.94	.06	-0.55	.001	-0.54	.001	-0.66	.10
Chocolate	-0.14	.63	0.28	.57	0.09	.65	0.10	.62	0.13	.59
Control variables										
Promotion			3.42	<.001	3.16	<.001				
Posts (Coefficient x 10 ⁻⁴)			— ^e	—	3.58	<.001	3.59	<.001	2.10	<.001
Average share (Coefficient x 10 ⁻²)			—	—	10.17	<.001	.11	<.001	3.20	<.001
Topic 1			—	—	1.39	<.001	1.19	<.001	3.54	<.001
Topic 2			—	—	1.17	<.001	0.73	.008	10.26	<.001
URL mention			—	—	0.19	<.001	0.20	<.001	0.01	.89
Hashtag			—	—	-0.02	.72	0.005	.94	-0.12	.24
Intercept	-18.18	<.001	-16.96	<.001	-18.79	<.001	-15.38	<.001	-2.42	<.001

^aEstimates of a specification of the initial model with only flavors as the independent variables.

^bNumber of observations is defined by n.

^cEstimates of flavors' influence on information propagation modified by adding promotion only.

^dEstimates of flavors' influence on information propagation modified by additional control variables.

^eVariable not used in the second "All data" model.

Although promotion had the major predictive power to explain e-cigarette-related information propagation, it caused an adverse effect on other, less-powerful independent variables. The effect of promotion was too overwhelming, making the observed influence of flavors unreliable. Therefore, we split the observations into 2 parts, 370,670 posts without promotions and 14,122 posts with promotions, and fit the model separately to eliminate the dominant effect. The fourth and fifth sets of columns of Table 4 show the results. We found that the results in the fourth column (without promotion effects) were similar to those in the third column (base model), but not the fifth column. The difference between the fourth and fifth columns suggested that these two types of posts (with and without promotions) had different sharing patterns, making the base model inappropriate. Eventually, we chose the fourth column (without promotion) to be the final model.

In the final model, sweet, dessert & bakery, fruits, herbs & spices, and tobacco had a significant negative influence on the

propagation of e-cigarette-related posts. The chance of a post being shared was lower when the post contained keywords belonging to these 5 flavor categories, indicating the lack of users' interests in these flavors. This is contradictory to previous research. Although previous studies were different from our research in that they did not categorize flavors, our finding still implies the general lack of interest in all flavors of e-cigarettes on Facebook, because we did not find a positive significance of any flavor category.

A closer look at these posts helped us identify a possible cause of the low interest in flavors: users may have had concerns about the safety issues of the flavoring additives in e-cigarettes. In the United States, flavoring additives approved by the US Food and Drug Administration were only tested for consumption in food and beverages. The safety of consuming these flavoring additives through inhalation (as with e-cigarettes) is not well tested or regulated [21]. In addition, certain flavors may contain untested elements that harm human health. For example, studies

showed that many e-cigarette flavorings contained an excessive amount of aldehyde, which is the primary irritant of the mucosal tissue in the respiratory tract [21]. The negative significance of the herbs & spices flavor in our regression model echoes recent studies showing the cytotoxicity of chemicals used in this type of flavor [15,16]. Similarly, the negative significance of sweet-related flavors (eg, sweet, dessert & bakery, and fruits) also echoes another study indicating the association between the use of certain chemicals in sweet-flavored e-cigarettes and respiratory diseases [17]. These potential risks associated with flavors could be a possible reason for the lower popularity of e-cigarette flavors among Facebook users.

Discussion

Principal Findings

This study was, to our knowledge, the first data-driven research to characterize the influence of categorized flavors in e-cigarette-related information propagation on social media. Surprisingly, we found that flavors did not enhance the popularity of e-cigarette-related information. Certain flavors even reduced the popularity, indicating users' lack of interest in flavors and potential concern about the safety issues of flavoring additives. For manufacturers and retailers, this study suggests that promoting e-cigarettes with flavors is not an effective marketing approach. For regulatory authorities and policy makers, this study suggests that new policies with updated regulations and restrictions on flavors are needed, for the sake of the health of e-cigarette users.

Limitations

Our study had several limitations. First, data derived from social media are obviously biased. We only studied English-language content posted by US users. Higher-resolution data with detailed demographic information could improve the practical value of this research significantly. In addition, for consistency, Facebook Pages in our dataset were mainly from parties making or selling e-cigarettes, with a commercial focus. The information propagation patterns on Facebook Pages of nongovernmental

organizations and health authorities could be different, thus needing further studies.

Second, information propagation is only one aspect of examining the diffusion of health products. Analyzing the content of information could help us extract users' opinions and emotions while discussing e-cigarette-related topics. Content analysis could also help us understand the root cause of the lack of interest in flavors revealed in this study.

Third, we evaluated the propagation of information by counting the number of shares of each post. This method measures the scale of propagations well, but could not measure the depth of propagations accurately. The Facebook API prohibited us from retrieving more detailed information about the accurate propagation path because of privacy concerns. There is a need for future research on the depth of information propagation using other data sources (eg, Twitter and Reddit).

Fourth, more data-driven medical research is critically needed to identify the root cause of the lower popularity of certain flavors of e-cigarettes.

Conclusions

This study found that mentions of flavors in posts did not enhance the popularity of e-cigarette-related information. There are several future works that we will pursue. First, we plan to validate the findings of this study using the data of other social media platforms under different cultural and language settings. In addition, we will develop state-of-the-art text mining methodologies to identify social media users' opinions of flavors and the use of e-cigarettes with different flavors. We will also develop probabilistic topic models to identify various topics related to e-cigarettes for smoking surveillance. This line of social media research has great potential to help e-cigarette manufacturers, retailers, regulatory authorities, and policy makers understand the behaviors and opinions of e-cigarette users. This study demonstrated the potential of using social media data to understand the behaviors of e-cigarette users through an empirical study of flavors, and it calls for more research from other perspectives to fulfill the potential of this valuable big data source.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary tables.

[PDF File (Adobe PDF File), 62KB - [publichealth_v4i1e27_app1.pdf](#)]

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Abbreviations

AIC: Akaike information criterion

API: application programming interface

ID: identifier

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Original Paper

Awareness of Prevention Strategies and Willingness to Use Preexposure Prophylaxis in Brazilian Men Who Have Sex With Men Using Apps for Sexual Encounters: Online Cross-Sectional Study

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Abstract

Background: Geosocial networking (GSN) smartphone apps are becoming the main venue for sexual encounters among Brazilian men who have sex with men (MSM). To address the increased HIV incidence in this population, preexposure prophylaxis (PrEP) was recently implemented in the Brazilian public health system in the context of combined HIV prevention.

Objective: This study aimed to describe the characteristics of MSM using GSN apps for sexual encounters, their awareness of prevention strategies, and willingness to use PrEP.

Methods: This study was an online cross-sectional study conducted in 10 Brazilian state capitals from July 1 to July 31, 2016. The questionnaire was programmed on SurveyGizmo and advertised in two GSN apps used by MSM to find sexual partners (Hornet and Grindr). Inclusion criteria were >18 years of age, cisgender men, with an HIV-negative status. Eligible individuals answered questions on: demographics; behavior; and knowledge, preferences, and willingness to use PrEP, nonoccupational postexposure prophylaxis (nPEP), HIV self-testing (HIVST), and condoms. Logistic regression modeling was performed to assess the factors associated with daily oral PrEP willingness.

Results: During the study period, 8885 individuals provided consent and started the questionnaire. Of these, 23.05% (2048/8885) were ineligible, 6837 (6837/8885, 76.94%) initiated, and 5065 (5065/8885, 57.00%) completed the entire questionnaire and were included in the present analysis. Median age was 30 years (interquartile range: 25-36), most self-declared as MSM (4991/5065, 98.54%), white (3194/5065, 63.06%), middle income (2148/5065, 42.41%), and had 12 or more years of schooling (3106/5062, 61.36%). The majority of MSM (3363/5064, 66.41%) scored >10 points (high risk) on The HIV Incidence Risk for MSM Scale, but only 21.39% (1083/5064) had a low perceived likelihood of getting HIV in the next year. Daily use of apps for sex was reported by 35.58% (1798/5054). Most MSM (4327/5065, 85.43%) reported testing for HIV at least once in their lifetime and 9.16% (464/5065) used nPEP in the previous year. PrEP, nPEP, and HIVST awareness was reported by 57.89% (2932/5065), 57.39% (2907/5065), and 26.57% (1346/5065) of participants, respectively. Half of all respondents (2653/5065, 52.38%) were willing to use daily oral PrEP, and this finding was associated with higher numbers of male sexual partners (adjusted odds ratio [AOR] 1.26, 95% CI 1.09-1.47), condomless receptive anal intercourse (AOR 1.27, 95% CI 1.12-1.44), sex with HIV-positive partner versus no HIV-positive partner (one HIV-positive partner: AOR 1.36, 95% CI 1.11-1.67), daily use of apps for sexual encounters (AOR 1.48, 95% CI 1.17-1.87), high and unknown perceived likelihood of getting HIV in the next year (AOR 1.72, 95% CI 1.47-2.02 and AOR 1.39, 95% CI 1.13-1.70), sexually transmitted infection diagnosis (AOR 1.25, 95% CI 1.03-1.51),

stimulant use (AOR 1.24, 95% CI 1.07-1.43), PrEP awareness (AOR 1.48, 95% CI 1.30-1.70), and unwillingness to use condoms (AOR 1.16, 95% CI 1.00-1.33).

Conclusions: Our results evidenced high-risk scores in the studied population, suggesting the importance of PrEP use. Those individuals presenting risky sexual behaviors were more willing to use PrEP. Nonetheless, only 58% (2932/5065) of individuals had heard about this prevention strategy. Efforts to increase awareness of new prevention strategies are needed, and mobile health tools are a promising strategy to reach MSM.

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KEYWORDS

HIV; prevention; MSM; app; internet; PrEP; Brazil; Latin America

Introduction

Brazil has the largest population of individuals living with HIV and acquired immune deficiency syndrome (AIDS) in Latin America [1], representing a concentrated epidemic with an estimated HIV prevalence of 0.6% in the general population (0.4% among women and 0.8% among men), and a 14.2% prevalence among men who have sex with men (MSM) [2]. Geographic differences have been reported in HIV prevalence among MSM (ranging from 5.2% [Recife] to 23.7% [Brasília]) in a respondent-driven sample survey conducted in 10 cities [2]. In 2016, approximately 60% of reported HIV infections were attributed to male-to-male sexual contact, although MSM represent only 3.5% of the Brazilian population [3,4]. New infections in this population continue to rise, especially among young people (24 years-old or less) [3].

Preexposure prophylaxis (PrEP) with tenofovir/emtricitabine is now a key component of prevention packages for MSM. The efficacy of treatment for this population has been shown with both once daily and on-demand use in clinical trials and open-label studies [5-9], and demonstration studies have been successfully implemented in different settings [10-13]. Results show that willingness to use PrEP among MSM may vary across different geographic locations, ranging from 32% to 92% [14-28].

With expanded access to the Internet via mobile phones, geosocial networking (GSN) smartphone apps are becoming the main venue for casual sexual encounters [29-32]. MSM report logging into GSN apps at least three times per day, with an average of 12 minutes spent per log-in [33,34]. These new technologies have generated quicker and easier ways for MSM to meet potential partners, and may facilitate the users' ability to have multiple concurrent partners, thereby increasing their risk for acquiring HIV [32,35-37]. Men who use the Internet to meet other men may present a different behavioral profile than men who meet men in physical venues. For instance, MSM who do not identify as such would be excluded from venue-sampling [38]. Therefore, a better understanding of the profile of MSM who use apps for sexual encounters is needed in order to design tailored, combined prevention interventions. This study aimed to describe the characteristics of Brazilian MSM using two GSN apps for sexual encounters, including risk behavior for HIV infection and their awareness of prevention strategies. In addition, factors associated with daily oral PrEP willingness were assessed.

Methods

Study Design

This was a cross-sectional online study targeting MSM from 10 Brazilian capitals (two from each Brazilian geographical region): Belém and Manaus (North); Salvador and Recife (Northeast); Brasília and Goiânia (Central-West); Florianópolis and Porto Alegre (South); and Rio de Janeiro and São Paulo (Southeast). According to the 2010 Brazilian Population Census, these are the cities with the greatest number of MSM couples from each region [39]. Individuals who met eligibility criteria (age >18 years, cisgender men, and HIV-uninfected) and who acknowledged reading the informed consent were directed to the online questionnaire.

The questionnaire was programmed on SurveyGizmo [40] and the project was advertised on two GSN apps: Hornet [41] and Grindr [42]. Hornet users received an inbox message with a link to the survey on July 1, 2016 and July 22, 2016. Grindr users received a pop-up advertisement in July 2016 (days 9, 13, 17, 23, 27). In addition, a total of 5,050,000 banners were advertised on the Grindr interface. The questionnaire remained open from July 1, 2016 to July 31, 2016. No incentives were provided for answering the survey.

Variables

Sociodemographics

Age was categorized into three brackets: (1) 18-to-24 years; (2) 25-to-34 years; and (3) >35 years. Skin color/race was dichotomized into "white" or "non-white" (Black, Asian, Native American, mixed-race, or don't know). Schooling was dichotomized into "<12 years" and ">12 years" (12 years is equivalent to completing high school education in Brazil). Family monthly income was grouped into "<3" (low income), "4-to-10" (middle income), and ">10" minimum (high income) wages (Brazilian minimum wage was 880 BRL or US \$267 dollars in July 2016). Sexual orientation was dichotomized into "MSM" (homosexual/gay/bisexual) or "other", and the options for a question regarding their friends with the same sexual orientation were "none", "a few", and "majority". Individuals were asked if they had a steady partner and the options were "yes/no", "male" and "female".

Substance Use

Binge drinking [43] was evaluated with the question, "In the last 6 months, did you drink 5 or more drinks in a couple of

hours?" Any substance use in the prior six months considered the use of any of the following: tobacco (cigarettes), stimulants (cocaine, crack, amphetamines), 4-hydroxybutanoic acid (GHB), marijuana or hash, and hallucinogens (solvents, lysergic acid diethylamide, ketamine), which were displayed in a predefined list of all substances.

Use of Apps

The variable "Apps" was created based on the question, "Where did you hear about this questionnaire?" (with response format as open text) and was categorized into *Hornet*, *Grindr*, and *other*. Although the project was advertised only on Hornet and Grindr, the link to the survey could be copied and exchanged through other media (ie, email, Facebook, Whatsapp). The use of apps for sexual encounters was categorized into "never", "sometimes" (once a month, once a week, only on weekends), "daily", and "only when traveling or vacations".

Sexual Behavior, Sexually Transmitted Diseases, and Nonoccupational Postexposure Prophylaxis

Sexual behavior in the last six months was assessed through the following questions: number of partners (0-5, >6-10, and more than 10); condomless receptive anal sex (yes or no); sex with HIV-positive partner (no, one, more than one, or unknown); number of insertive anal intercourses with HIV-positive partner (no, 1-4 intercourses, 5 or more intercourses, or unknown). These questions belong to *The HIV Incidence Risk for MSM Scale*, which is a 7-item questionnaire developed by Smith et al [44] to predict HIV seroconversion among MSM. It is recommended by the Centers for Disease Control and Prevention (CDC) to screen individuals who should be evaluated to receive PrEP [45]. Scores >10 were considered "high risk" [44,45]. Sex for money and sexually transmitted infections (STIs; syphilis, gonorrhea or rectal chlamydia) were dichotomized into "yes" or "no". Participants were asked if they used nonoccupational postexposure prophylaxis (nPEP) in the past 12 months.

Perceived Likelihood of Getting HIV in Next Year and HIV Testing

Perceived likelihood of getting HIV in the next year was assessed through the question, "What is your chance of getting HIV in the next year?" with possible options grouped into "Low" (None/Low), "High" (Some/High/Certainly) and "unknown" [21]. Additionally, individuals were asked about previous HIV testing (never, once in lifetime, once a year, more than once a year, every time I am exposed, or sporadically) and preferences (reasons for not testing, best place for testing, best way to obtain HIV self-testing (HIVST) if available at the Brazilian public health system; SUS), as well as if they know someone living with HIV (Yes/No).

Awareness and Willingness to Use HIV Prevention Measures

Awareness of HIV prevention measures including daily PrEP, postexposure prophylaxis (PEP), and HIVST were assessed through the question, "Have you ever heard of...to prevent HIV infection?" Willingness to use HIV prevention measures

including condoms, daily oral PrEP, and PEP was defined as the "High interest" option on a four-point Likert scale through the question, "In case it was available at SUS, what level of interest would you have in using...for preventing HIV?" A brief explanation on the preventive measures was provided before these questions were asked. These questions have previously been used by our research team to describe PrEP awareness and willingness [21]. Finally, we assessed individuals' willingness to use PrEP and HIV self-testing even if they had to pay for it.

Willingness to use different PrEP regimens was assessed with the following question, "Which of the following PrEP regimens would you take if available?" Participants could select one or more of the following options: "PrEP on demand" (two pills 24 hours before intercourse and one pill 24 hours and 48 hours after), "injection PrEP" (injection drug every 2 months), or "would never use PrEP".

Ethical Issues

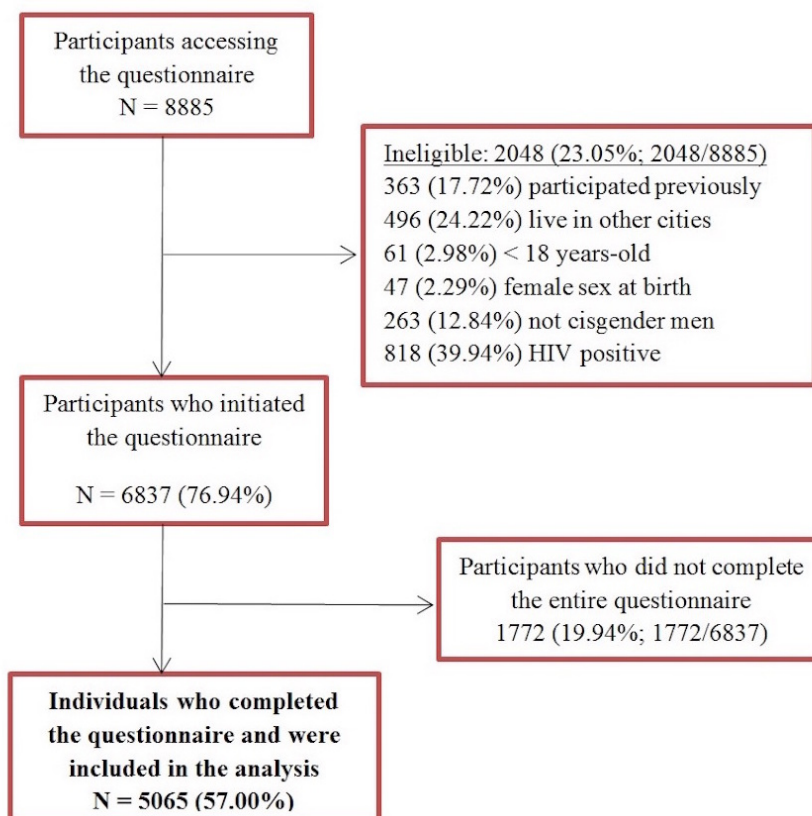
Instituto Nacional de Infectologia Evandro Chagas INI-FIOCRUZ institutional review board approved this study (#51595815.7.0000.5262 at "Plataforma Brasil") in accordance with all applicable regulations, and all study participants digitally signed an informed consent form. No identification of participants was collected.

Statistical Analysis

Characteristics, attitudes, and behaviors of the participants were described by their absolute and relative frequencies. Chi-square tests were used to compare characteristics of the individuals who completed and did not complete the questionnaire. A bivariate logistic regression analysis was performed to explore factors associated with willingness to use oral daily PrEP (odds ratios [OR]). Afterwards, a backwards stepwise logistic regression modeling approach was used to identify the factors independently associated with daily oral PrEP willingness [46]. Variables with $P < .25$ in bivariate analysis models were included in the initial multivariate model, and subsequently excluded if their P-value was $> .05$. The final multivariate model included both variables that remained significant (at a 5% significance threshold) and those found to be confounders (ie, those that changed the OR estimate of any of the remaining variables by more than 10%). Age, color/race, and schooling were defined a priori as confounders and were kept in the final multivariate model irrespectively of significance level (adjusted odds ratios [AOR]). Analyses were performed using PROC GENMOD available in the Software SAS [47].

Results

During the 30 days of the online survey, 8885 individuals provided informed consent. Of these, 23.05% (2048/8885) were ineligible, 6837 (6837/8885, 76.94%) initiated the questionnaire, and 5065 (5065/8885, 57.00%) completed the questionnaire and were included in the present analysis (Figure 1). Differences among those who did not complete the questionnaire (n=1772) and those who completed the questionnaire (n=5065) are presented in Table 1.

Figure 1. Study flow-chart.

Among all individuals who accessed the questionnaire and completed questions regarding HIV serostatus ($n=6664$), HIV prevalence was 12.27% (818/6664). Considering ineligible respondents ($n=2048$), 2.29% (47/2048) self-declared as cisgender women, 1.56% (32/2048) as transgender women or transvestites, 1.95% (40/2048) as transgender men, and 9.33% (191/2048) as other genders.

Among those included in this analysis ($n=5065$), most participants were from southeast Brazil (3532/5065, 69.73%) and accessed the survey through the Hornet app (2800/5065, 55.28%), and a total of 4618 (4618/5054, 91.37%) respondents used apps for sexual encounters. The median age of the cohort was 30 years old (interquartile range: 25-36), 63.06% (3194/5065) were white, 68.13% (3541/5065) reported middle-to-high income, and 61.36% (3106/5062) reported more than 12 years of schooling. Most respondents identified themselves as MSM (4991/5065, 98.54%) and reported having friends with the same sexual orientation (3368/5065, 66.50%). Only 20.48% (1029/5024) of respondents reported a male steady partner and 3.97% (198/4986) reported a female steady partner (Table 1).

Binge drinking and tobacco use in the last six months were reported by 71.79% (3636/5050) and 32.60% (1651/5065) of individuals, respectively (Table 2). Marijuana (or hash) was the most frequent illicit substance reported (1679/5065, 33.15%), followed by stimulants (1177/5065, 23.24%), hallucinogens

(519/5065, 10.25%) and GHB (222/5065, 4.38%). A total of 2305 (2305/5065, 45.51%) participants reported no substance use in the last six months.

In the previous 6 months, only 236 (236/5065, 4.66%) respondents reported having no sexual partners. Condomless receptive anal sex prevalence was high (2121/5065, 41.88%). Approximately 10% (480/5065, 9.48%) of respondents reported having had sex with one HIV-positive partner, 2.19% (111/5064) with more than one partner, and 18.62% (943/5064) reported that they did not know how many HIV-positive partners they had sex in the prior six months. Regarding the number of times they were the insertive partner without a condom with an HIV-positive partner, 18.90% (957/5064) of participants reported one to four times and 8.87% (449/5064) reported five times or more. Reported prevalence of STIs (syphilis, gonorrhea, or rectal chlamydia) in the previous 6 months was 12.06% (604/5010; Table 2). Most of the participants (3363/5064, 66.41%) scored >10 points in *The HIV Incidence Risk for MSM Scale* (high HIV risk) and fall into the category of individuals who should undergo evaluation for PrEP use. Conversely, only 21.39% (1083/5064) of participants had high HIV risk perception and 9.16% (464/5065) reported nPEP use in the last 12 months. Among those that used PEP, 81.68% (379/464), 12.72% (59/464), 2.59% (12/464), and 3.02% (14/464) reported nPEP use once, twice, three times, and more than three times in the past 12 months (respectively).

Table 1. Characteristics of the individuals who completed and did not complete the questionnaire.

Parameter	Incomplete ^a , n (%)	Complete, n (%)	Total, n (%)	P value ^b
Region				.01
North (Manaus and Belém)	72 (6.30)	185 (3.65)	257 (4.14)	
Northeast (Salvador and Recife)	112 (9.81)	442 (8.73)	354 (8.93)	
Central-West (Brasília and Goiânia)	102 (8.93)	500 (9.87)	602 (9.70)	
South (Florianópolis and Porto Alegre)	90 (7.88)	406 (8.01)	496 (7.99)	
Rio de Janeiro ^c	281 (24.61)	1225 (24.19)	1506 (24.26)	
São Paulo ^c	485 (42.57)	2307 (45.55)	2792 (44.98)	
Total	1142(18.40)	5065 (81.60)	6207 (100.00)	
Apps				<.001
Hornet	493 (42.28)	2800 (55.28)	3293 (58.85)	
Grindr	430 (36.88)	1867 (36.86)	2297 (36.86)	
Other ^d	243 (20.84)	398 (7.86)	641 (10.29)	
Total	1166 (18.71)	5065 (81.29)	6231 (100.00)	
Age (years)				.12
18-24	262 (26.60)	1212 (23.93)	1474 (24.36)	
25-35	458 (46.50)	2515 (49.65)	2973 (49.14)	
>36	265 (26.90)	1338 (26.42)	1603 (26.50)	
Total	985 (16.28)	5065 (83.72)	6050 (100.00)	
Color/Race				—
White	—	3194 (63.06)	3194 (63.06)	
Non-white ^e	—	1871 (36.94)	1871 (36.94)	
Total	—	5065 (100.00)	5065 (100.00)	
Family monthly income^f				—
<3 (low income)	—	1614 (31.87)	1614 (31.87)	
4-10 (middle income)	—	2148 (42.41)	2148 (42.41)	
>10 (high income)	—	1303 (25.73)	1303 (25.73)	
Total	—	5065 (100.00)	5065 (100.00)	
Schooling (years)				.01
<12	391 (45.41)	1956 (38.64)	2347 (39.63)	
>12	470 (54.59)	3106 (61.36)	3576 (60.37)	
Total	861 (14.54)	5062 (85.46)	5923 (100.00)	
Sexual orientation				<.001
MSM ^g	839 (96.11)	4991 (98.54)	5042 (84.97)	
Other	34 (3.89)	74 (1.46)	892 (15.03)	
Total	869 (14.64)	5065 (85.30)	5934 (100.00)	
Friends with same sexual orientation				.01
Majority	433 (56.72)	3368 (66.50)	3801 (65.65)	
A few	292 (40.28)	1697 (33.51)	1989 (34.35)	
Total	725 (12.52)	5065 (87.48)	5790 (100.00)	

Parameter	Incomplete ^a , n (%)	Complete, n (%)	Total, n (%)	P value ^b
Steady partner (male)				.02
Yes	205 (24.09)	1029 (20.48)	1234 (21.00)	
No	646 (75.91)	3995 (79.52)	4641 (79.00)	
Total	851 (14.49)	5024 (85.51)	5875 (100.00)	
Steady partner (female)				.08
Yes	44 (5.28)	198 (3.97)	242 (4.16)	
No	789 (94.72)	4788 (96.02)	5577 (95.84)	
Total	833 (14.32)	4986 (85.68)	5819 (100.00)	
Know someone living with HIV				.01
Yes	263 (31.0)	3491 (68.94)	1856 (31.72)	
No	462 (68.94)	1573 (31.06)	3953 (68.28)	
Total	725 (12.54)	5064 (87.48)	5789 (100.00)	
Use of apps for sexual encounters				.02
Never	85 (11.74)	436 (8.63)	521 (9.02)	
Sometimes	338 (46.69)	2564 (50.72)	2902 (50.22)	
Daily	259 (35.77)	1798 (35.58)	2057 (35.60)	
Only when travelling or vacations	42 (5.80)	256 (5.07)	298 (5.16)	
Total	724 (12.53)	5054 (87.47)	5778 (100.00)	

^aNo answer for variables color and race (last questions of the questionnaire).

^bChi-square test.

^cSoutheast Brazil.

^dOther social media (eg, Facebook, WhatsApp), email.

^eBlack, Asian, Native American, mixed-race, or don't know.

^fBrazilian monthly minimum wage in 2016 was 880 BRL (US \$267, currency from July 2016).

^gHomosexual, gay, or bisexual.

A total of 738 (738/5065, 14.57%) respondents had never performed an HIV test and one of the main reasons was the fear of having an HIV-positive result (263/738, 35.64%). Compared to those who had been tested before, these respondents were younger (24 years old, interquartile range: 21-30), had less years of schooling (<12 years: 495/736, 67.26%), had lower income (less than 4 minimum wage: 359/738, 48.64%), and almost half self-reported as white (370/738, 50.14%). Almost half of the respondents believed that the best testing venue is at home (2400/5065, 47.38%) and most would be comfortable with picking up the HIVST somewhere else (2867/5065, 56.60%; [Table 3](#)).

PrEP, nPEP and HIVST awareness was reported by 57.89% (2932/5065), 57.39% (2907/5065), and 26.57% (1346/5065) of respondents, respectively. Willingness to use different HIV prevention methods is depicted in [Figure 2](#). Willingness to use daily oral PrEP and injected PrEP was similar (2653/5065, 52.38% vs 2408/5065, 47.48%), while PrEP on demand was

lower (1751/5065, 35.57%) and PrEP during short periods or vacations was much higher (4652/5065, 91.85%). In addition, 51.08% (2587/5065) of respondents would use PrEP if available commercially and 4.72% (239/5065) would never use PrEP.

In the final multivariate model ([Multimedia Appendix 1](#)), variables independently associated with daily oral PrEP willingness were: high number of male sexual partners (>10) versus 0-5 partners (AOR 1.26, 95% CI 1.09-1.47), condomless receptive anal intercourse (AOR 1.27, 95% CI 1.12-1.44), sex with HIV-positive partner versus no HIV-positive partner (one HIV-positive partner: AOR 1.36, 95% CI 1.11-1.67), daily use of apps for sexual encounters versus never use (AOR 1.48, 95% CI 1.17-1.87), high and unknown perceived likelihood of getting HIV in the next year (AOR 1.72, 95% CI 1.47-2.02 and AOR 1.39, 95% CI 1.13-1.70), STI diagnosis (AOR 1.25, 95% CI 1.03-1.51), stimulant use (AOR 1.24, 95% CI 1.07-1.43), PrEP awareness (AOR 1.48, 95% CI 1.30-1.70), and unwillingness to use condoms (AOR 1.16, 95% CI 1.00-1.33).

Table 2. Binge drinking, substance use, and risk behaviors among the study population (n=5065). MSM: men who have sex with men.

Parameter	Total, n (%)
Binge drinking ^a (yes; n=5050)	3636 (71.79)
Substance use^a	
Tobacco	1651 (32.60)
Stimulants ^b	1177 (23.24)
GHB ^c	222 (4.38)
Marijuana or hash	1679 (33.15)
Hallucinogens ^d	519 (10.25)
Number of male sexual partners^a	
0-5	2609 (51.51)
6-10	1001 (19.76)
>10	1455 (28.73)
Condomless receptive anal sex ^a (yes)	2121 (41.88)
Number of male HIV-positive sexual partner(s)^a (n=5064)	
None	3530 (69.71)
1	480 (9.48)
>1	111 (2.19)
Unknown	943 (18.62)
Number of insertive condomless anal intercourse with HIV-positive partner^a (n=5064)	
None	3391 (66.96)
1-4 intercourses	957 (18.90)
5 or more intercourses	449 (8.87)
Unknown	267 (5.27)
The HIV Incidence Risk for MSM Scale ^{e,f} (>10 points; high risk)	3363 (66.41)
Money for sex ^a (n=5045)	202 (3.99)
Perceived likelihood of getting HIV^g	
Low	3516 (69.41)
High	1083 (21.39)
Unknown	466 (9.20)
STI diagnosis ^{a,h} (n=5010)	604 (12.06)

^aDuring the previous 6 months.

^bCocaine, poppers, crack, or ecstasy.

^c4-hydroxybutanoic acid.

^dSolvents, lysergic acid diethylamide, ketamine.

^eThe HIV Incidence Risk for MSM Scale was calculated based on sexual behavior in the previous 6 months (number of partners, condomless receptive anal intercourse, sex with HIV-positive partner, and use of stimulants; if >10 points, PrEP is recommended).

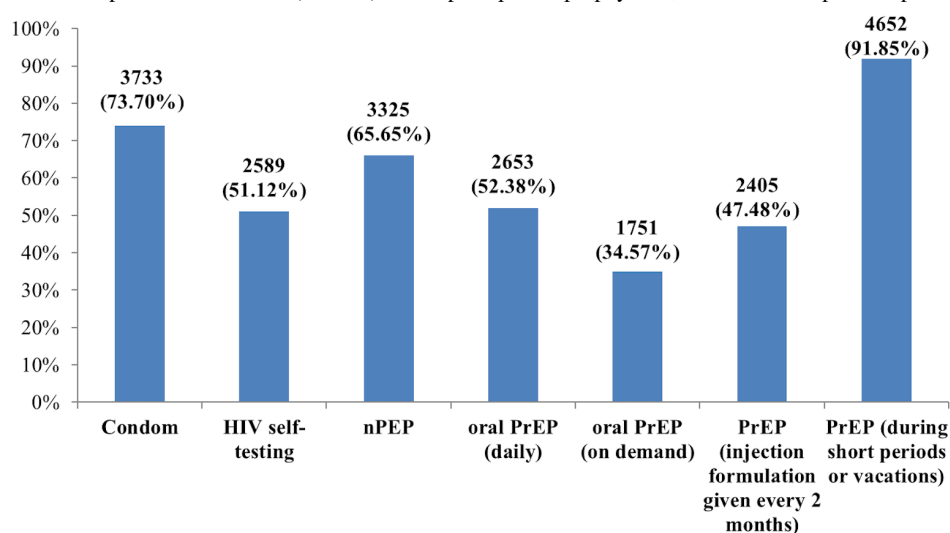
^f“Unknown” answers scored 0 points on *The HIV Incidence Risk for MSM Scale*.

^gIn the next 12 months.

^hSyphilis, gonorrhea, or rectal chlamydia.

Table 3. Previous HIV testing and preferences (N=5065). HIVST: human immunodeficiency virus self-testing; SUS: Brazilian public health system.

Parameter	Total, n (%)
HIV testing	
Never	738 (14.57)
Once (lifetime)	762 (15.04)
Once a year	1073 (21.18)
More than once a year	1171 (23.12)
Every time I am exposed	311 (6.14)
Sporadically	1010 (19.94)
Reasons for never testing (n=738)	
No risk of be infected	100 (13.55)
Not easy to reach health care provider	50 (6.78)
Shame	128 (17.34)
Afraid of being positive	263 (35.64)
Lazy	74 (10.03)
Other	123 (16.66)
Best place for testing	
At home	2400 (47.38)
Health care provider	1987 (39.23)
Pharmacy	468 (9.24)
Community center	61 (1.20)
Other	149 (2.94)
Best way to obtain HIVST (if available at SUS)	
Internet (home delivery)	2094 (41.34)
Internet (pick somewhere)	578 (11.41)
Pick up at a pharmacy	1059 (20.91)
Pick up at a health care provider	1126 (22.23)
Pick up at a nongovernmental organization	104 (2.05)
Other	104 (2.05)

Figure 2. Willingness to use HIV prevention methods (n=5065). PrEP: preexposure prophylaxis; nPEP: nonoccupational postexposure prophylaxis.

Discussion

Our findings provide important insights about the characteristics of Brazilian MSM based on two popular GSN apps for sexual encounters, and their preferences amidst the HIV prevention strategies. This information can potentially guide and support national prevention programs. Over half of the respondents would be willing to use daily oral PrEP if available through SUS, which is lower than previously reported in Brazil [21]. This finding is probably related to the fact that the previous studies also included individuals who were actively seeking PrEP, and thus possibly overestimated PrEP willingness. Nevertheless, our finding is consistent with reports from other settings [14,20-28,34] and represents a reassuring result, given that daily PrEP will soon be provided by SUS at no cost for MSM at higher risk of contracting HIV [48].

Our study showed that, in addition to daily oral PrEP, a high proportion of respondents were also interested in other PrEP formulations, such as injectable PrEP (2408/5065, 47.48%). Long-acting injectable PrEP can be very beneficial among individuals for whom adherence to a daily oral regimen is challenging [22,49,50]. Cabotegravir, an integrase inhibitor that can be administered through intramuscular injection, is one of the products currently under clinical development for PrEP formulation [51]. Individuals' personal preferences and priorities may have a significant impact on acceptability, uptake, and retention of different PrEP modalities and the ability to choose among multiple contraceptive methods, which was shown to be associated with increased population coverage [52].

Although nPEP has been available at no cost through SUS since 2009, awareness, willingness, and use were lower than expected. This problem is highly concerning given that almost half of our sample reported unprotected anal sex. Similar results have been described from other settings with MSM-concentrated epidemics [53,54].

Few of the respondents had heard about HIVST; however, half of them would be willing to use it and this strategy, which could increase serostatus awareness and facilitate integration into HIV care [55]. The acceptability of HIVST ranged from 21-98% in studies among MSM [56], including a pilot study using blood-based HIVST in Brazil and Peru [57], and an Internet-based feasibility study using oral fluid, which was conducted in Brazil [58]. As social networking advertisements on HIVST were shown to be effective at increasing HIVST awareness and uptake [59,60], feasibility of HIVST distribution through apps for sexual encounters should also be further evaluated.

Although smartphones became the main devices used for Internet access, especially in lower income families [61], it is hard to estimate the proportion and possible selection bias of online studies. Most of the MSM included in this study were white and aged 25-36 years, and reported middle to higher income with more schooling years, which may not reflect the Brazilian MSM population. Some of these characteristics are in accordance with a systematic review, which showed that those using apps were younger, presented higher educational levels, reported higher incomes, had higher proportions of risky

sexual behaviors, and were more likely to have tested for HIV in their lifetime compared to nonapp-using MSM [62]. In addition, our sample was similar to the one recruited on Grindr for a study in Los Angeles [63] and another from a social networking site for MSM in Latin America, Spain, and Portugal [38]. Indeed, studies have shown that online samples tend to be biased toward a lower median age, as younger MSM are over-represented on GSN apps [64]. Conversely, younger MSM aged 24 years or less was not the majority of this sample, perhaps because the content of the survey or the advertisement strategy was not attractive to this population.

Considering *The HIV Incidence Risk for MSM Scale*, most of the sample should be further evaluated for PrEP use, but perceived likelihood of getting HIV in next year was low. Moreover, rates of unprotected anal intercourse reported by study participants was high, which has also been found to be high among MSM who use Grindr in studies conducted in the United States [35,65] and among MSM from a website for sexual encounters in Latin America [38]. The CDC recommends that sexually active MSM should be tested annually, and clinicians should consider the potential benefits of more frequent HIV screening (eg, every three or six months) for some asymptomatic sexually active MSM, based on their individual risk factors, local HIV epidemiology, and local policies [66,67]. Almost 15% of the sample (738/5065) had never performed an HIV test and 15% (762/5065) were only tested once in their lifetime, which is almost two-fold higher than that observed in a US study using a GSN app [68], but much lower than that found in other Brazilian studies [2,69]. Knowledge of HIV status enables individuals to make decisions about behavioral strategies to reduce HIV transmission risks, such as serosorting [70-72], using condoms with partners who do not share the same HIV status, or restricting behaviors to partners who are HIV-positive and have undetectable viral loads (UVLs) or HIV-negative partners that take PrEP [73]. Disclosure of PrEP use and UVL is not uncommon among MSM using apps in the United States, and the majority of the respondents have engaged in condomless sex at least once based on this status [73]. This behavior is unknown in Brazil, as PrEP is still not available and information and knowledge about the relationship of UVL and HIV transmission is not widely spread. Hopefully this reality will change in the foreseeable future, and studies to evaluate this behavior shift are needed.

Binge drinking and tobacco and substance use were high in the study population, compared with the general population [74], which is consistent with previous reports [75,76]. In an online survey among MSM through Facebook in seven countries, including Brazil, it was observed that social networks and minority stressors can have significant effects on drug use and sex while drunk or high [77]. Binge drinking and drug use (eg, marijuana, amphetamines, poppers) in general have been associated with condomless intercourse [78-80]. A recent study in young lesbian, gay, and bisexual individuals showed that the use of marijuana is associated with sex with multiple partners [81]. Conversely, a lower prevalence of binge drinking and substance use was observed during the PrEP Brasil Study [10]. Nevertheless, public policies on HIV prevention still need to

acknowledge and address the relationship between substance use and risk behaviors.

Moreover, our results provide evidence that MSM reporting higher risk behaviors were more willing to use daily PrEP, as observed in other studies [21,82-87]. Accordingly, our results show that those reporting higher or unknown perceived HIV risk and STI diagnoses in the last six months were also more willing to use daily PrEP. This is an important finding since PrEP is recommended to high-risk MSM. In addition, those not willing to use condoms were more willing to use PrEP. In a study comparing preferences for PrEP, condoms, and both PrEP and condoms, MSM reporting recent risk behaviors were more likely to prefer PrEP compared with condoms only, and less likely to prefer both methods compared with condoms only [88].

Unequivocally, this study has limitations. First, online studies are not probabilistic sampling strategies, thus precluding the generalizability of the findings. Given the cross-sectional nature of the data, causality and the direction of association may not be inferred. All collected data were self-reported by participants

and may be subjected to bias, including social desirability bias. Our data were also subjected to recall bias due to 6-month or 12-month recall periods. There is also a concern about participants taking the survey multiple times. To avoid this issue, the first question of the survey was, “Are you answering this survey for the first time?” (4% of participants answered “no” and were excluded from the study). Finally, we have measured intention to use PrEP, nPEP, condoms, and HIVST as a proxy of willingness. There are different methods for accessing PrEP willingness, as reviewed by Young and McDaid [89], and as such our results should be interpreted with care.

In summary, our observed high HIV risk scores suggest that most MSM would be eligible for PrEP, and that those who present risky sexual behaviors were more willing to use it. Notwithstanding, only 58% (2932/5065) of individuals were aware of this prevention strategy. Additionally, awareness, willingness, and use of nPEP—which has been available in Brazil since 2009—were low. Efforts to increase awareness of new prevention strategies are urgently needed to create demand among those at the highest risk for HIV infection. Mobile health tools are a promising strategy to reach high risk MSM in Brazil.

Conflicts of Interest

Gilead Sciences covered the costs related to advertisement of the survey on Grindr and Hornet, but had no role in the study design, collection, analysis, or interpretation of data, the writing of the manuscript, or the decision to submit this manuscript for publication.

Multimedia Appendix 1

Factors associated with daily PrEP willingness.

[PDF File (Adobe PDF File), 35KB - [publichealth_v4i1e11_app1.pdf](#)]

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Abbreviations

AIDS: acquired immune deficiency syndrome
AOR: adjusted odds ratio
CDC: Centers for Disease Control and Prevention
GHB: 4-hydroxybutanoic acid
GSN: geosocial networking
HIVST: human immunodeficiency virus self-testing
MSM: men who have sex with men
nPEP: nonoccupational postexposure prophylaxis
OR: odds ratio
PEP: postexposure prophylaxis
PrEP: preexposure prophylaxis
STI: sexually transmitted infection
SUS: Brazilian public health system
UVL: undetectable viral loads

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Original Paper

Functional Knowledge of Pre-Exposure Prophylaxis for HIV Prevention Among Participants in a Web-Based Survey of Sexually Active Gay, Bisexual, and Other Men Who Have Sex With Men: Cross-Sectional Study

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Abstract

Background: Awareness of pre-exposure prophylaxis (PrEP) for HIV prevention is increasing, but little is known about the functional knowledge of PrEP and its impact on willingness to use PrEP.

Objective: The objective of this study was to assess the functional knowledge of PrEP among a sample of gay, bisexual, and other men who have sex with men (MSM) participating in a Web-based survey of sexually active MSM.

Methods: Men at least 18 years old, residing in the United States, and reporting sex with a man in the previous 6 months were recruited through social networking websites. PrEP functional knowledge included the following 4 questions (1) efficacy of consistent PrEP use, (2) inconsistent PrEP use and effectiveness, (3) PrEP and condom use, and (4) effectiveness at reducing sexually transmitted infections (STIs). Ordinal logistic regression was used to identify respondent characteristics associated with PrEP functional knowledge. In a subsample of participants responding to HIV prevention questions, we compared willingness to use PrEP by response to PrEP functional knowledge using logistic regression analysis adjusted for age, race and ethnicity, and education level.

Results: Among 573 respondents, PrEP knowledge was high regarding adherence (488/573, 85.2%), condom use (532/573, 92.8%), and STIs (480/573, 83.8%), but only 252/573 (44.0%) identified the correct efficacy. Lower functional PrEP knowledge was associated with minority race/ethnicity ($P=.005$), lower education ($P=.01$), and not having an HIV test in the past year ($P=.02$). Higher PrEP knowledge was associated with willingness to use PrEP ($P=.009$). Younger age was not associated with higher PrEP functional knowledge or willingness to use PrEP.

Conclusions: PrEP knowledge was generally high in our study, including condom use and consistent use but may be lacking in higher risk MSM. The majority of respondents did not correctly identify PrEP efficacy with consistent use, which could impact motivation to seek out PrEP for HIV prevention. Targeted messaging to increase PrEP knowledge may increase PrEP use.

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KEYWORDS

human immunodeficiency virus; pre-exposure prophylaxis (PrEP); men who have sex with men

Introduction

Since the release of clinical trials showing high efficacy of pre-exposure prophylaxis (PrEP) for preventing HIV acquisition [1-3] and the Food and Drug Administration (FDA) approval of Truvada for PrEP [4], increased evidence from PrEP demonstration projects show PrEP to be a robust addition to existing HIV prevention tools for reducing HIV acquisition in high-risk populations, such as sexually active men who have sex with men (MSM) [5-7]. Studies have found that consistent PrEP use is associated with high reduction in HIV acquisition, including reductions in HIV risk up to 92% among those with high adherence to daily pill regimen [2,8,9]. In addition, modeling data indicate increased PrEP coverage among MSM would result in a significant and sustained reduction in HIV prevalence in the United States [10]. The Centers for Disease Control and Prevention (CDC) have released guidelines for PrEP use, with specific recommendations for high-risk MSM [11].

Despite the proven efficacy of PrEP and recommendations for PrEP use among MSM, use of PrEP has remained low among priority populations at highest risk for HIV infection, including sexually active MSM [12-16]. In the past 5 years, awareness of PrEP for HIV prevention has been steadily increasing among MSM, and recent data indicate that the majority of MSM have heard of PrEP [13,15,17,18]. However, increased awareness of PrEP has not translated into high uptake of PrEP among MSM. Recent studies have found PrEP use at less than 10% among all MSM with lower rates among youth and racial/ethnic minority MSM [15,19-23]. Multiple individual barriers to scaling up PrEP have been identified, including concerns about adverse effects, cost, and stigma [12,19,24].

Considerable efforts are in progress to identify and reduce challenges in increasing PrEP coverage through targeted prevention messaging. However, although awareness of PrEP has been slowly but steadily increasing since the iPrEX study, a clinical trial finding significant PrEP efficacy among MSM [2], little is known about whether appropriate educational messaging about PrEP is reaching highest risk MSM. Low and inconsistent knowledge beyond general awareness of PrEP has been suggested as a potential barrier to PrEP uptake, but it has not been thoroughly assessed in relation to willingness to use PrEP [14,23,25,26]. Although there is increasing attention paid to the awareness of PrEP among MSM, there is relatively little attention paid to the presence of functional knowledge that is needed to use PrEP effectively. Functional knowledge includes knowledge around the efficacy of PrEP, the need to take PrEP consistently, the recommendation to use condoms while taking PrEP, and that PrEP does not reduce the transmission of sexually transmitted infections (STIs). Studies from other HIV prevention strategies, including male circumcision, condom use, and HIV testing, have found that level of knowledge is associated with increased willingness and uptake of these interventions [27-29], suggesting that knowledge beyond basic awareness of PrEP could impact willingness to use PrEP. Although understanding the proportion of MSM who have heard of PrEP will likely inform an understanding of awareness, an assessment of the

levels of functional knowledge may have more utility for understanding whether PrEP messaging is being absorbed by MSM. Thus, we sought to assess functional knowledge of PrEP, including efficacy, consistency, impact on STIs, and condom use, among a Web-based sample of predominantly white, college educated, sexually active MSM participating in a Web-based survey of HIV knowledge and priorities.

Methods

Study Population

The Prioritizing U survey was conducted in August and September 2015 to collect cross-sectional, self-reported data on HIV knowledge, prevention, and priorities among gay, bisexual, and other MSM. The survey and data collection methods have been previously described [30]. Briefly, study participants were recruited through convenience sampling methods using Web-based banner advertisements posted on social media targeting user profiles matching the study eligibility criteria. Men who clicked on the Webpage link were directed to an introductory page and given a brief screening questionnaire. Men were eligible for the survey if they reported being 18 years of age or older, identified as male, resided in the United States, and reported sex with a man in the past 6 months. Participants who completed the consent page and were eligible to participate completed a self-administered, confidential Web-based survey. In total, 2241 men were screened eligible and completed the survey. The study was approved by the University of Michigan Institutional Review Board. No monetary incentives were provided to the participants.

The survey included questions on demographics (eg, age, race and ethnicity, education, income, and employment), sexual behavior with male and female partners in the past 3 months, and HIV testing history. Participants were also asked a series of multiple-choice knowledge questions about HIV infection and prevention developed by the research team and adapted from previous surveys conducted in multiple populations [31,32], including questions from the stable and internally consistent HIV Knowledge Scale [33]. The HIV knowledge questions also included the following 4 questions about PrEP: (1) percent reduction in acquiring HIV through consistent use of PrEP, (2) decreased effectiveness of PrEP with inconsistent use, (3) continued use of condoms recommended for people using PrEP, and (4) PrEP does not help prevent other STIs (Figure 1). Additionally, participants were given a list of HIV prevention methods, including PrEP, and asked if they knew about, have used, or would use each method. However, substantially fewer participants responded to the HIV prevention questions. The prevention questions were presented at the end of the survey, and although we do not have information to explain the low response for these questions, survey fatigue or survey formatting could be possible reasons that participants did not complete the full survey. We wanted to assess the relationship between functional PrEP knowledge and willingness to use PrEP; thus, all analyses of willingness to use PrEP included only those respondents that responded to the HIV prevention questions.

Figure 1. Pre-exposure prophylaxis (PrEP) functional knowledge questions, Prioritizing U, 2015.

- Q5.10 Truvada as pre-exposure prophylaxis (PrEP) (i.e. the use of antiretroviral medications among HIV-negative individuals to help prevent HIV from establishing infection once inside the body) has been shown to reduce the risk of acquiring HIV among those who consistently took the drug as prescribed by what percent?
- 23 (1)
 - 47 (2)
 - 64 (3)
 - 92 (4)
- Q5.11 Inconsistent use of Truvada as PrEP does what to its effectiveness?
- Decreases effectiveness (1)
 - Nothing (2)
 - Increases effectiveness (3)
- Q5.12 Which of the following is true about using Truvada as PrEP and condom use?
- People using PrEP are not recommended to continue using condoms (1)
 - People using PrEP have to use condoms in order for the drug to be effective (2)
 - People using PrEP are recommended to continue using condoms (3)
- Q5.13 Which of the following is true about using Truvada as PrEP and other sexually transmitted infections (i.e. chlamydia, gonorrhea, syphilis)?
- Using PrEP helps prevent other sexually transmitted infections (1)
 - Using PrEP does not help prevent other sexually transmitted infections (2)
 - Using PrEP increases the risk for acquiring other sexually transmitted infections (3)

Statistical Analysis

For this analysis, we included only participants who self-reported HIV status as negative or unknown, had anal sex with a male partner in the past 3 months, and responded to PrEP knowledge questions. We excluded participants that did not provide their actual age (the screened questionnaire only confirmed age ≥ 18 years old). The smaller subset that completed the HIV prevention questions was compared with the larger cohort using chi-square test statistics. PrEP knowledge was defined as the proportion of each PrEP question correctly answered and an ordinal PrEP score calculated by the total number of correct responses.

We assessed PrEP knowledge by demographic characteristics (eg, age, race and ethnicity, education, and geographic region), sexual risk behavior in the past 3 months (eg, condomless sex, multiple male sex partners, and HIV status of primary male sex partner), HIV testing history (eg, ever tested and tested in the past 12 months), and interest in using PrEP (eg, have used and would use). Associations with PrEP knowledge were measured for the full sample and separately for younger respondents, aged 18-29 years, as this population is at particularly high risk for HIV acquisition with lower PrEP uptake. We assessed individual respondent characteristics to determine individual associations with PrEP knowledge. Predictors found to be significantly associated with PrEP knowledge at the $P < .05$ level in univariate analyses were assessed in 2 multiple ordinal regression models with tests for proportional odds. The models were not found to violate the proportional odds assumption. The regression coefficients in the multiple ordinal regression models were used to examine the log-odds of higher PrEP knowledge score with results expressed in terms of cumulative adjusted odds ratios (adjOR) with 95% CIs. To assess willingness to use PrEP by PrEP knowledge score, we included only participants that

responded to the HIV prevention questions, including willingness to use PrEP. We used a logistic regression model adjusted for statistically significant predictors from univariate analyses. We assessed the relationship between perceived efficacy and willingness to use PrEP using a Cochran-Armitage test for trend comparing responses to the efficacy knowledge question by PrEP willingness. All analyses were conducted in Statistical Analysis Software (SAS) version 9.4 (Cary, NC).

Results

Among 2241 eligible participants with complete surveys, 80 (3.60%) were excluded for not providing their age. Of the remaining, 2012 (93.10%) reported negative or unknown/never tested HIV status, of which 970 (48.21%) reported at least 1 anal sex partner in the previous 3 months. Moreover, 573 out of 970 (59.1%) completed all PrEP knowledge questions and were included in this analysis. The median age of the study participants was 43 years (range 18-86), with the majority (375/573, 65.4%) 35 years or older (Table 1). Most participants were white (80.5%), college educated (58.6%), and employed full-time (77.5%). Study participants reported an average of 3 (range 1-200) anal sex partners in the past 3 months, and most (71.9%) had anal sex without a condom at least once. Current PrEP use was reported among 11 (2.1%) participants.

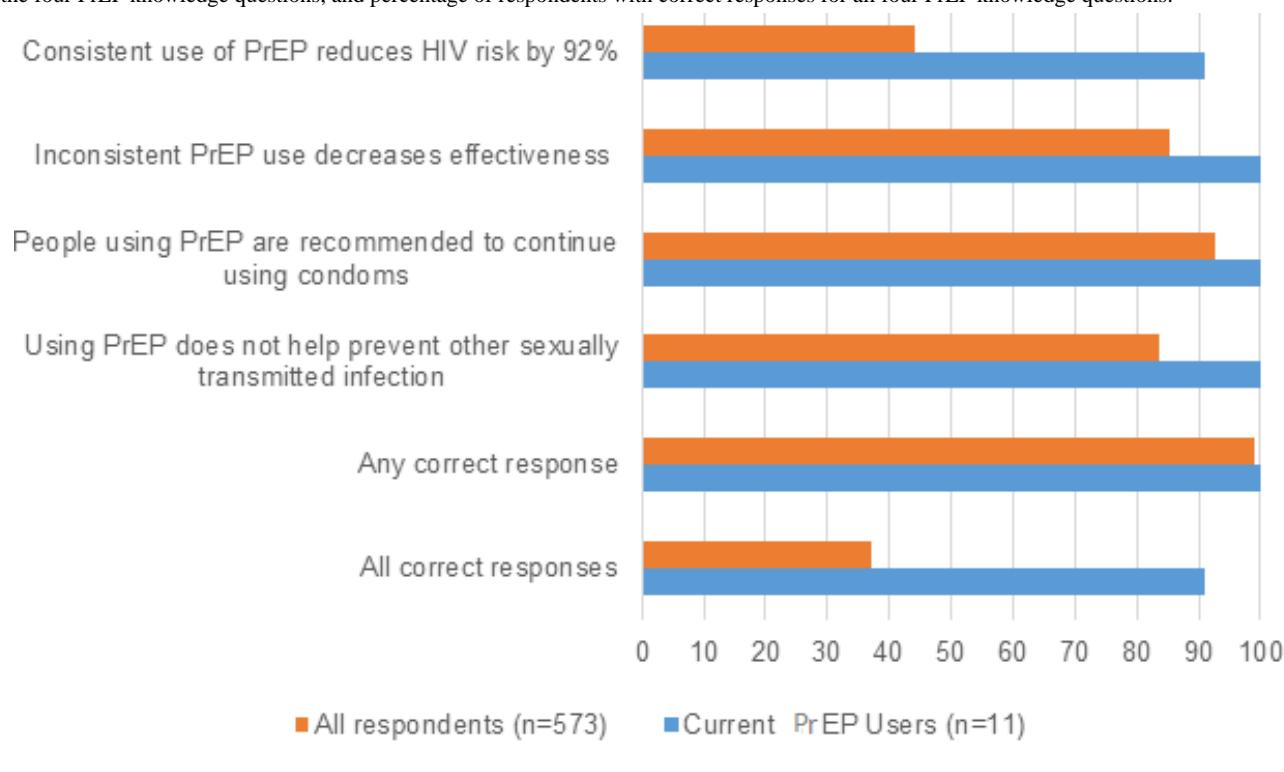
Nearly half of the participants (280/573, 48.9%) responded to HIV prevention questions (Table 1). Compared with participants that did not respond to the HIV prevention questions, those that responded to the HIV prevention questions were more likely to be younger (< 35 years, 41.4% vs 28.0%, $P < .001$), from the South (42.1% vs 30.0%, $P = .003$), had multiple anal sex partners in the past year (48.9% vs 35.8%, $P = .02$), and have been HIV tested in the previous year (54.3% vs 49.2%, $P = .004$).

Table 1. Characteristics of respondents, Prioritizing U survey, 2015.

Characteristics	PrEP ^a knowledge question respondents (N=573) n (%)	Prevention questions respondents (N=280) n (%)
Age (years)		
18-24	101 (17.6)	62 (22.1)
25-34	97 (16.9)	54 (19.3)
35-44	71 (12.4)	32 (11.4)
45+	304 (53.1)	132 (47.1)
Race		
Black/African American	12 (2.1)	7 (2.5)
Hispanic/Latino	68 (11.9)	34 (12.1)
White	461 (80.5)	224 (80.0)
Other/multiple	31 (5.4)	15 (5.4)
Geographic region		
Midwest	139 (24.3)	64 (22.9)
Northeast	105 (18.3)	40 (14.3)
South	206 (36.0)	118 (42.1)
West	112 (19.6)	53 (18.9)
Education		
<High school or diploma/equivalent	40 (7.0)	15 (5.4)
Some college or technical degree	197 (34.4)	97 (34.6)
College degree or postgraduate	336 (58.6)	168 (60.0)
Employment		
Full-time work	444 (77.5)	208 (74.3)
Part-time work	62 (10.8)	35 (12.5)
Unemployed/other	66 (11.5)	37 (13.2)
Number of anal sex partners in the past 3 months		
1	331 (57.8)	143 (51.1)
2-4	157 (27.4)	83 (29.6)
5+	85 (14.8)	54 (19.3)
Any condomless anal sex in the past 3 months		
Yes	412 (71.9)	210 (75.0)
No	126 (22.0)	55 (19.6)
Condomless anal sex with nonprimary partner in the past 3 months		
Yes	158 (27.6)	102 (36.4)
No	415 (72.4)	178 (63.6)
More recent HIV test		
Within the past year	315 (55.0)	171 (61.1)
>1 year ago	198 (34.6)	85 (30.4)
Never/not sure when last tested	60 (10.5)	24 (8.6)

^aPrEP: pre-exposure prophylaxis.

Figure 2. The percentage distribution of correct responses to pre-exposure prophylaxis (PrEP) functional knowledge questions by all respondents and respondents reporting current PrEP use, Prioritizing U, 2015. The percentage distribution of correct responses by full sample of respondents (orange) and by respondents reporting current PrEP use (blue), and percentage of correct responses for the four PrEP knowledge questions, percentage with any of the four PrEP knowledge questions, and percentage of respondents with correct responses for all four PrEP knowledge questions.



The majority of respondents identified the correct response to 3 of the 4 PrEP knowledge questions: (1) inconsistent PrEP use decreases effectiveness (85.2%), (2) people using PrEP are recommended to continue using condoms (92.8%), and (3) PrEP does not prevent other STIs (83.8%). Less than half of the respondents correctly identified the percent reduction in HIV risk with consistent PrEP use (252/573, 44.0%). Overall, 213 out of 573 (37.2%) correctly answered all 4 PrEP knowledge questions, 224 out of 573 (39.1%) answered only 3 questions correctly, 98 out of 573 (17.1%) answered only 2 correctly, 32 out of 573 (5.6%) answered only 1 correctly, and 6 out of 573 (1.1%) answered none of the questions correctly. Nearly all current PrEP users (90.9%) answered all questions correctly (Figure 2).

All responses for PrEP knowledge questions are shown in Table 2. Higher PrEP knowledge scores were found to be significantly associated with having at least some college education (adjOR 3.11, 95% CI 1.71-5.65, $P < .001$), having an HIV test in the past year (adjOR 2.14, 95% CI 1.54-2.98, $P \leq .001$), and reporting condomless sex with a nonprimary partner in the past 3 months (adjOR 2.83, 95% CI 1.71-4.68, $P < .001$). Respondents reporting nonwhite race/ethnicity were significantly more likely to have lower PrEP knowledge scores (adjOR 0.56, 95% CI 0.34-0.84, $P = .005$). Age, geographic region of residence, and number of

male sex partners were not significantly associated with correctly responding to PrEP knowledge questions. Among only younger respondents, lower PrEP knowledge was only found to be associated with nonwhite race/ethnicity (adjOR 0.26, 95% CI 0.10-0.71, $P = .01$).

Participants that responded to HIV prevention questions had a significantly higher odds of correctly responding to PrEP knowledge questions (adjOR 3.38, 95% CI 2.44-4.69, $P < .001$). Willingness to use PrEP was significantly associated with correct responses to PrEP knowledge questions (adjOR 1.62, 95% CI 1.13-2.33, $P = .009$). Specifically, correctly identifying PrEP efficacy was significantly associated with those that would use PrEP (adjOR 2.65, 95% CI 1.55-4.54 $P < .001$; Table 3). Furthermore, we found a significant trend in willingness to use PrEP by the level of efficacy selected by respondents, with those that perceived the lowest efficacy reporting lower willingness to use PrEP (chi-square $P < .001$). Younger respondents were not significantly more likely to report greater willingness to use PrEP. Among younger respondents, willingness to use PrEP was associated with correct response to the PrEP efficacy question (adjOR 4.95, 95% CI 1.63-15.08, $P = .003$) and correctly responding to all PrEP knowledge questions (adjOR 3.48, 95% CI 1.14-10.64, $P = .02$).

Table 2. Distribution of responses for pre-exposure prophylaxis functional knowledge questions for all respondents and younger respondents (age 18-29 years), Prioritizing U survey, 2015.

Questions	All respondents (N=573) n (%)	Younger ^a respondents only (N=153) n (%)
Consistent use of PrEP^b reduces HIV risk by what percent?		
23	113 (19.7)	23 (15.0)
47	116 (20.2)	42 (27.5)
64	92 (16.1)	30 (19.6)
92 ^d	252 (44.0)	58 (37.9)
Inconsistent use of PrEP does what to its effectiveness?		
Decreases effectiveness ^c	488 (85.2)	130 (85.0)
Nothing	44 (7.7)	11 (7.2)
Increases effectiveness	41 (7.2)	12 (7.8)
Which of the following is true about using PrEP and condom use?		
Not recommended to continue using condoms	13 (2.3)	5 (3.3)
Condoms are required for PrEP to be effective	28 (5.0)	10 (6.5)
Recommended to continue using condoms ^c	532 (92.8)	138 (90.2)
Which of the following is true about using PrEP and other STIs^d?		
PrEP helps prevent other STIs	74 (12.91)	23 (15.03)
Does not help prevent other STIs ^c	480 (83.8)	125 (81.7)
Increases risk of STIs	19 (3.3)	5 (3.3)

^aAge 18-29 years.

^bPrEP: pre-exposure prophylaxis.

^cCorrect response.

^dSTIs: sexually transmitted infections.

Table 3. Association between correct pre-exposure prophylaxis (PrEP) functional knowledge responses and willingness to use PrEP by each PrEP functional knowledge question and correct responses to all PrEP knowledge questions, Prioritizing U survey, 2015.

Questions	Would use PrEP ^a , n (%)		adjOR ^b (95% CI) ^c
	Yes (N=204)	No (N=80)	
Consistent use of PrEP reduces HIV risk by 92%			
Correct	126 (61.8)	31 (38.8)	2.65 (1.55-4.54)
Incorrect	78 (38.2)	49 (61.3)	
Inconsistent PrEP use decreases effectiveness			
Correct	183 (90.2)	70 (87.5)	0.52 (0.07-3.91)
Incorrect	20 (9.9)	10 (12.5)	
People using PrEP are recommended to continue using condoms			
Correct	200 (98.5)	78 (97.5)	1.50 (0.07-31.06)
Incorrect	3 (1.5)	2 (2.5)	
Using PrEP does not help prevent other STIs^d			
Correct	184 (92.0)	73 (91.3)	1.55 (0.37-6.45)
Incorrect	16 (8.0)	7 (8.8)	
Responded correctly to all PrEP knowledge questions			
Correct	106 (52.0)	27 (33.8)	3.48 (1.14-10.64)
Incorrect	98 (48.0)	53 (66.3)	

^aPrEP: pre-exposure prophylaxis.

^badjOR: adjusted odds ratio.

^cadjusted for age, race/ethnicity, and education

^dSTIs: sexually transmitted infections

Discussion

Principal Findings

Understanding the role of PrEP in HIV prevention beyond simple awareness may be critical in making informed decisions to use PrEP. In our analysis, we found that higher functional knowledge was associated with willingness to use PrEP among a sample of MSM participating in a Web-based survey of HIV knowledge and priorities. We found respondents to be generally knowledgeable about PrEP, although knowledge was higher among white, college-educated MSM. Lower awareness of PrEP has been found, in previous studies, to be associated with younger age, lower education, and racial/ethnic minorities [21,34] and is consistent with our findings of lower knowledge of PrEP among racial/ethnic minority and lower-educated MSM. Additionally, we found PrEP knowledge to be lower among those who had not had an HIV test in the past year, suggesting a lack of opportunity to learn more about PrEP through routine testing and counseling. Studies have found lower PrEP knowledge among primary care physicians compared with HIV specialists that may limit opportunities for MSM to learn about and receive PrEP, particularly among MSM not already engaged in HIV prevention [35-39].

Perceptions of PrEP effectiveness and understanding of how PrEP fits into sexual risk behavior is necessary to increase interest in using PrEP. In general, the majority of respondents successfully answered 3 of the 4 PrEP knowledge questions:

inconsistent PrEP use decreases effectiveness in preventing HIV, continued condom use is recommended when using PrEP, and PrEP does not prevent other STIs. However, less than half of the respondents correctly selected the correct percent reduction in HIV risk with consistent PrEP use. Communicating information about PrEP is challenging due to the ongoing studies exploring alternative regimens and drug options. The effectiveness of PrEP among MSM may be the most difficult to articulate in HIV prevention messaging due to the seemingly discrepant results from PrEP clinical trials and demonstration projects. Efficacy results from PrEP clinical trials ranged from futility to 75%, with additional results as high as 92% in iPrEX among adherent participants [40]. Furthermore, the misinformation and misinterpretation of efficacy may lead to lower understanding of individual PrEP effectiveness [26,41]. The low proportion of correct responses to efficacy with consistent PrEP use may be the result of the varying data and interpretations of findings from multiple PrEP studies. We found that perceptions of PrEP efficacy were associated with willingness to use PrEP, suggesting a critical importance of effectively messaging PrEP efficacy to increase uptake.

We found that most respondents knew the importance of using PrEP consistently and continued condom use with PrEP based on CDC recommendations [11]. However, it is not clear if these recommendations are translated into practice among MSM using PrEP. Adherence to daily PrEP regimens is a primary concern of health care providers [42-44], and low retention in PrEP programs is associated with HIV acquisition [45]. Results from

iPrEX and other clinical trials showed a dramatic decrease in PrEP efficacy with adherence of less than 80% across all populations, leading to guidelines for PrEP for HIV prevention in addition to other prevention methods [2,11]. Furthermore, data from recent studies show an increase in condomless sex among MSM since PrEP implementation was initiated, particularly among MSM using PrEP, although it is unclear if this trend is the direct result of the introduction of PrEP [13,46]. We found higher sexual risk, measured by condomless sex with a nonprimary male partner, to be associated with higher PrEP knowledge. If higher knowledge is consistent with increased PrEP use, then our findings are consistent with other studies showing higher PrEP use among MSM engaged in higher risk sexual activity and higher perception of HIV risk [13,47,48]. In our subgroup analysis, willingness to use PrEP was significantly associated with higher PrEP knowledge, although the sample was too small to make adequate comparisons by sexual risk behavior. This finding is important in illustrating the need of adequate and appropriate communication of PrEP information to high-risk MSM.

Participants in our study were generally aware of the need for continued condom use and that PrEP does not decrease risk of STIs. Increases in STIs have recently been noted among MSM PrEP users in clinical trials and PrEP demonstration projects, indicating potential risk compensation associated with PrEP use through reduction in condom usage [49,50]. However, in a recent systematic review, Freeborn and Portillo did not find conclusive data that PrEP users engage in increased sexual risk behavior and rates of STIs did not significantly increase [51]. Furthermore, the benefit of PrEP in HIV risk reduction seems to outweigh moderate increases in risk compensation among MSM [52]. PrEP should continue to be seen as a complementary risk reduction tool along with condoms and routine HIV testing.

Willingness to use PrEP was significantly associated with higher PrEP functional knowledge among MSM participating in our study. This is consistent with previous studies finding an association between PrEP awareness and willingness to use PrEP [53]. However, PrEP awareness and knowledge is a single factor in a host of indicators for PrEP use, and increasing functional knowledge about PrEP is not a sufficient strategy for increasing PrEP uptake among MSM [54]. Unwillingness to use PrEP has been found to be associated with concerns about side effects, access to health care, and HIV-related stigma across multiple populations of MSM [19,20,55-57]. Addressing concerns about PrEP and reducing barriers to PrEP access may be more critical to motivating PrEP, particularly in populations where general PrEP awareness is already high.

Limitations

We acknowledge several limitations to our study. First, we used a convenience sampling method with recruitment through online

social media; thus, our sample is not representative of MSM or specifically high-risk MSM. Our sample was older, primarily white and college educated and does not reflect the highest risk MSM, specifically young and race/ethnic minority MSM. PrEP awareness and use have been shown to be higher among older white MSM [21,23,58], and our study shows lower PrEP knowledge among nonwhite and lower educated MSM, suggesting a need for targeted messaging to highest risk MSM. However, we found no significant difference in PrEP functional knowledge by age, and younger respondents reported a higher proportion of willingness to use PrEP. Further research is needed to understand perceptions and interpretations of PrEP information among young and racial/ethnic minority MSM. Second, our analysis of willingness to use PrEP was limited to a subgroup of respondents that answered questions about HIV prevention. We do not have information to explain the substantial drop in responses to the HIV prevention questions, although the survey was long and participants may have felt survey fatigue by the time they were presented with these questions. Thus, due to smaller sample sizes, we were not able to make more detailed comparisons among MSM willing and not willing to use PrEP. Third, we did not collect information on where respondents heard/learned information about PrEP that would be useful in exploring opportunities for increasing messaging about PrEP and HIV prevention to MSM. Finally, although we tested the survey with a panel of volunteers, we do not have data to determine if the PrEP knowledge questions were fully understood by the study participants, particularly the PrEP efficacy question. We recognize that the questions may have been more challenging to participants with little or no prior knowledge about PrEP and recommend additional testing of these questions before use in future assessments of PrEP knowledge.

Conclusions

Despite these limitations, our findings provide additional information to increasing data on PrEP perceptions and intentions among MSM. Prioritization of PrEP to highest risk populations optimizes the impact of PrEP in reducing HIV infections [6,47,59]. However, to increase PrEP coverage, it is imperative to increase knowledge and acceptance of PrEP among targeted populations through increased education and messaging at the individual, provider, and community level [60,61]. Furthermore, additional research is needed to create more effective messaging tools for increasing PrEP knowledge and acceptability among MSM through community outreach, public health campaigns, and provider participation [54,61]. Our findings show that PrEP functional knowledge is generally high, although not consistent across all demographics of MSM. More data are needed to determine if PrEP knowledge translates to motivation to use and retention in PrEP.

Conflicts of Interest

None declared.

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Abbreviations

adjOR: adjusted odds ratios
CDC: Centers for Disease Control and Prevention
FDA: Food and Drug Administration
MSM: men who have sex with men
PrEP: pre-exposure prophylaxis
STIs: sexually transmitted infections

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Original Paper

Pre-Exposure Prophylaxis YouTube Videos: Content Evaluation

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Abstract

Background: Antiretroviral (ARV) medicines reduce the risk of transmitting the HIV virus and are recommended as daily pre-exposure prophylaxis (PrEP) in combination with safer sex practices for HIV-negative individuals at a high risk for infection, but are underused in HIV prevention. Previous literature suggests that YouTube is extensively used to share health information. While pre-exposure prophylaxis (PrEP) is a novel and promising approach to HIV prevention, there is limited understanding of YouTube videos as a source of information on PrEP.

Objective: The objective of this study was to describe the sources, characteristics, and content of the most widely viewed PrEP YouTube videos published up to October 1, 2016.

Methods: The keywords “pre-exposure prophylaxis” and “Truvada” were used to find 217 videos with a view count >100. Videos were coded for source, view count, length, number of comments, and selected aspects of content. Videos were also assessed for the most likely target audience.

Results: The total cumulative number of views was >2.3 million, however, a single Centers for Disease Control and Prevention video accounted for >1.2 million of the total cumulative views. A great majority (181/217, 83.4%) of the videos promoted the use of PrEP, whereas 60.8% (132/217) identified the specific target audience. In contrast, only 35.9% (78/217) of the videos mentioned how to obtain PrEP, whereas less than one third addressed the costs, side effects, and safety aspects relating to PrEP. Medical and academic institutions were the sources of the largest number of videos (66/217, 30.4%), followed by consumers (63/217, 29.0%), community-based organizations (CBO; 48/217, 22.1%), and media (40/217, 18.4%). Videos uploaded by the media sources were more likely to discuss the cost of PrEP ($P<.001$), whereas the use of PrEP was less likely to be promoted in videos uploaded by individual consumers ($P=.002$) and more likely to be promoted in videos originated by CBOs ($P=.009$). The most common target audience for the videos was gay and bisexual men.

Conclusions: YouTube videos can be used to share reliable PrEP information with individuals. Further research is needed to identify the best practices for using this medium to promote and increase PrEP uptake.

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KEYWORDS

YouTube; pre-exposure prophylaxis (PrEP); Truvada; video content.

Introduction

Between 2005 and 2015, the number of people diagnosed with HIV in the United States has declined substantially (19%) [1]. Prevention efforts have reduced HIV infection rates in several key populations, including people who inject drugs (PWID),

heterosexuals, and African Americans. However, HIV remains a persistent problem among some population subgroups, particularly among men who have sex with other men (MSM), where the number of new infections has increased by 9% between 2010 and 2014 [2]. Worldwide, an estimated 35 million

people live with HIV, the majority of whom live in Sub-Saharan Africa [3].

Recent scientific advancements have provided additional prevention options with the potential to reduce rates of new infections. Early treatment with antiretroviral (ARV) medicines improves the health of people living with HIV and reduces the risk of transmitting the virus by 96% [4]. Furthermore, findings from several clinical trials [5-7] led the Food and Drug Administration (FDA) to approve use of once daily ARV (Truvada) as the pre-exposure prophylaxis (PrEP) to be used in combination with safer sex practices for HIV-negative individuals at a high risk for infection [8]. The World Health Organization (WHO) recommended PrEP as an additional prevention strategy for any person at a substantial risk of contracting HIV [9]. While PrEP can be a viable approach to controlling the spread of HIV, it is not being used to its full potential. Certain estimates suggest that too few people in the United States are taking PrEP, whereas many others at a risk of contracting HIV are not even aware of PrEP [10]. Although, awareness of PrEP has increased among highly sexually active MSM [11,12], uptake has been slow, particularly among younger MSM and MSM of color [13,14]. Researchers have hypothesized that the slow uptake of PrEP may be due to cost [15], lack of awareness coupled with the belief that PrEP is for only for those who engage in high-risk behaviors [16], stigma [17], psychological and social barriers [18], or even provider-initiated barriers [19]. Worldwide, most countries have not taken any steps yet, due to concerns about local relevance, costs and sustainable funding, and other health system issues [20,21]. Some researchers state that communicating reliable information about PrEP to the public is not straightforward, as people may not be willing to seek information about PrEP through their close interpersonal networks [22] or even through their health care providers [23]. Researchers have argued that the effectiveness of PrEP will depend largely on the informed involvement of various stakeholders, including government officials, primary care providers, recipients, and community educators [22,24].

Previous communication research has shown that mediated interaction can reflect and shape popular understanding of important health issues [25,26]. The internet, including social media, is now used extensively not only to communicate but also to search for health information [27,28]. Video-sharing sites such as YouTube are among the most popular websites with over a billion users and hundreds of millions of hours of content [29]. YouTube also contains a vast amount of videos pertaining to health information, including information about HIV and HIV prevention. For many, particularly the younger audiences and sexual and racial minorities, YouTube can serve as a platform where users seek PrEP information, generate content, share information within their networks, and disseminate content to reach a wider audience [30,31]. An additional feature of the video-sharing format is its capacity for timely updates. A nationwide survey focusing on how adults in the United States use Web-based resources for health information found that 26% watched someone else's experience about a health issue [32]. In other parts of the globe, internet

users are also seeking health information using social media [33].

Health professionals are becoming increasingly aware of the fact that health consumers use social media to gather health information. Consequently, examining social media to understand the content of health information has become a growing area of public health research. For example, video content on YouTube has been analyzed on a variety of topics, including the viral pandemics [34,35], contraception [36], electronic cigarettes [37], cancer [38,39], rheumatoid arthritis [40], or immunizations [41-44]. While social media could represent critical communication channels for increasing awareness and interest about health issues, previous research shows that health information posted on such media can be incorrect or misleading [45,46]. Videos uploaded by the lay public not only contained information that contradicts public health guidelines but in some cases received high view counts and user ratings [47,48]. Hence, studying health content on social media is important to understand these novel forms of health information dissemination [49].

To our knowledge, no published study investigated PrEP-related information that is disseminated through YouTube videos. The primary purpose of this study was to describe the sources, characteristics, and content of the most widely viewed YouTube videos associated with PrEP. Understanding what information on PrEP is currently available on social media such as YouTube, whether users are seeking information on PrEP through this source, and who is generating this information may help HIV prevention efforts to tailor messages, promote more effective knowledge translation, and increase the rates of PrEP uptake.

Methods

Search Strategy

A search of YouTube was conducted using two terms: "pre-exposure prophylaxis" and "Truvada." The YouTube interface provides an approximation of the number of videos retrieved for a keyword search (eg, typing "pre-exposure prophylaxis" into the YouTube search bar yielded approximately 5200 results on September 23, 2016). We were interested in the most viewed videos (as determined by filtering and sorting by the number of views on YouTube), hence search results were limited to videos that were viewed 100 times or more. A single YouTube account's viewing history was used to document the videos examined. Videos were excluded if they were not in English. Country of origin was determined by the source information provided in the YouTube video description. Duplicate videos were excluded, as were those with no accompanying audio. The final tally included 217 unique videos retrieved by one or both keywords (ie, "pre-exposure prophylaxis" and "Truvada"). Unique videos were then reviewed to assess their relevance to PrEP. This study was not classified as being a human subject's research by the institutional review boards at William Paterson University and Teachers College because it involved use of public access data.

Data Review and Analysis

Video data were coded into an Excel (Microsoft Corporation, Redmond, Washington) spreadsheet and analyzed by a trained research assistant (RA). We recorded the objective characteristics of each video, including video title, URL, date of upload, length of the video, number of views, number of likes and dislikes, number of comments posted by YouTube users, and descriptive text included by the user who uploaded the video. Sources of information were defined as the following: (1) individual consumer (information provided by an individual with no professional credentials or established organizational affiliation), (2) institutional (information provided by individuals with professional credentials, eg, medical doctor [MD], registered nurse [RN], established organizational affiliations such as academic organization, or any government organization, eg, Centers for Disease Control and Prevention [CDC]), (3) news or media (information provided by network or internet-based news organization, eg, American Broadcasting Company [ABC]), and (4) community-based organizations (CBO; information provided by CBO or their representatives).

Seven content categories were identified a priori using the CDC fact sheet on PrEP [10], literature related to PrEP and social media [22], and previous studies exploring the content of YouTube videos [50-52]. These categories included (see Table 1): (1) defining PrEP (ie, prevention tool used to reduce the risk of HIV infection); (2) explaining how PrEP works; (3) describing who can use PrEP; (4) mentioning PrEP as a safe treatment; (5) describing PrEP side effects; (6) describing how to obtain PrEP, and (7) mentioning PrEP costs. Finally, we assessed whether the video promoted use of PrEP as a prevention tool. All content categories were coded dichotomously (0=no, 1=yes).

Additionally, the study team was interested in the visual representation of the content. On the basis of who the presenter of the PrEP-related information was, all videos were coded into

5 categories: (1) a single individual, (2) multiple individuals, (3) animations/videos/advertisements, (4) newsreels, and (5) other (ie, scientific slides presentation). On the basis of the overall narrative, visuals, description, and the source of each video, the most likely target audience for each video was documented (ie, MSM, racial minority MSM, transgender population, women and heterosexual couples regardless of race/ethnicity, scientific/professional audience, nonspecific/anyone who may benefit/anyone at risk of contracting HIV). For example, if gay African American men narrated their PrEP experience, these videos were classified as more likely to target racial minority MSM. Similarly, if the source of the video was the Ball community, it was labeled as more likely to appeal to racial minority MSM. The study team was particularly interested in videos aimed at racial minority MSM due to the known slower uptake of PrEP by men of color. If the video discussed more than one of the above groups as a beneficiary of PrEP (ie, gay men, sex workers, transgender population, PWID, heterosexual couples in serodiscordant relationship), the video was labeled as targeting anyone who may benefit from PrEP or anyone at risk of contracting HIV."

To ensure consistency in coding, the first 10 videos were coded collaboratively by the first author and the RA until a consensus was reached. All analyses of the video and content characteristics were performed using SPSS 23.0 (IBM Corporation). Given that the video lengths, the number of views and comments were not normally distributed, analyses used the Kruskal-Wallis test, followed by post hoc tests, to examine the differences in video characteristics between different sources. To examine differences in content categories among different sources, we calculated frequencies and percentages, medians and ranges, and chi-square tests of independence followed by post hoc tests using adjusted standardized residuals with Bonferroni corrections of the *P* values [53]. An alpha level of .05 was used to determine the significance for all tests.

Table 1. Pre-exposure prophylaxis (PrEP)-related content categories, definitions, and examples.

Category	Definition	Example
Defines/explains PrEP	The taking of a prescription drug as a means of preventing HIV infection in an HIV-negative person.	“An option for someone who is HIV negative, but who is at a substantial risk of contracting it, to prevent HIV infection.”
Describes how PrEP works	By taking Truvada (a combination of 2 drugs, tenofovir and emtricitabine) daily, the presence of the medicine in the bloodstream can stop HIV from taking hold and spreading in the body.	“HIV-negative individuals use Truvada daily to reduce their risk of becoming infected. It works to prevent HIV from establishing infection inside the body.”
Describes who can use PrEP	Claiming or mentioning who should receive PrEP	“Truvada prevents infection in sexually active adults.”
Promoted PrEP as a safe, effective option	Discussing the effectiveness of using PrEP to prevent HIV	“You take one pill a day, and you stay HIV-negative.”
Discusses side effects	Mentioning side effects from taking PrEP/Truvada	“There are concerns about increased kidney function and decreased bone mineral density.”
Describes how to obtain PrEP	Mentioning where and/or how to obtain PrEP	“PrEP can be prescribed only by a doctor, so talk to yours to find out if PrEP is the right thing for you”
Discusses the cost of PrEP	Mentioning cost of PrEP and if insurance covers it	“My insurance covers Truvada, I paid copay only.”
Promotes use of PrEP	Encouraging PrEP use among those at risk	“People at a risk should take a pill every day.”

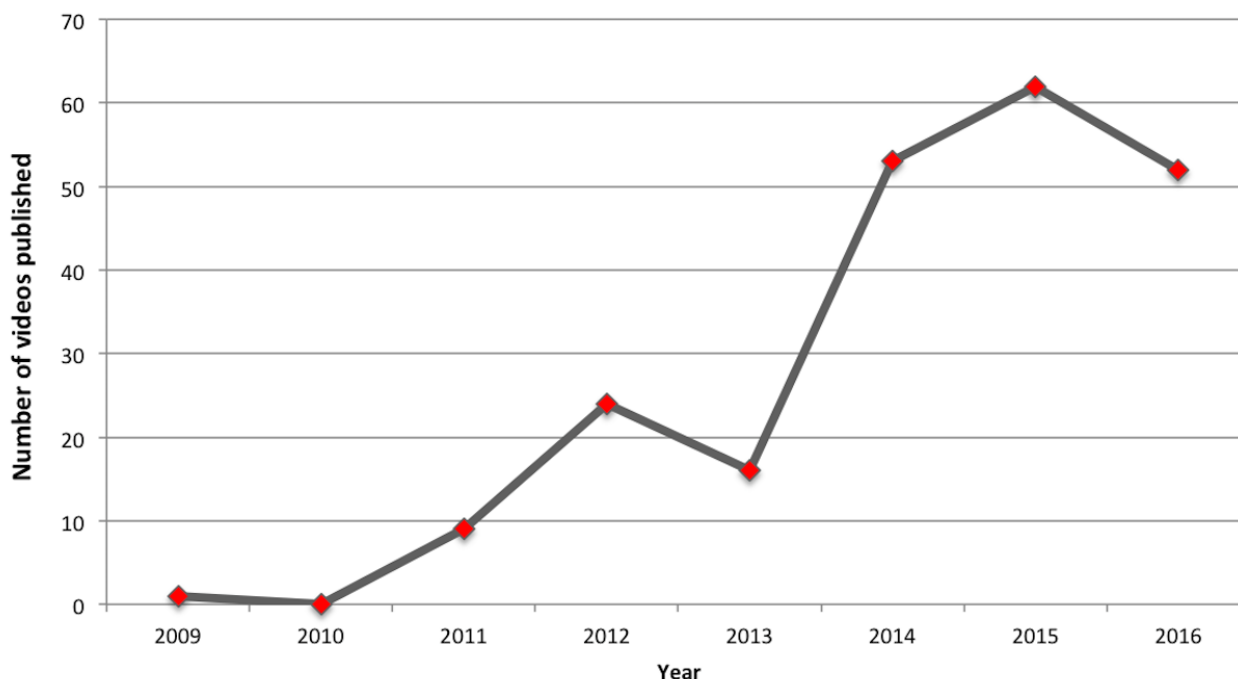
Results

Figure 1 presents the number of PrEP YouTube videos published per year. We observed a significant increase in the number of published videos from 2013 to 2014. The 217 PrEP videos identified in this study were posted from 189 unique YouTube accounts. The overwhelming majority of videos originated in the United States (171/217, 78.8%), followed by Canada (18/217, 8.2%), the United Kingdom, and Australia (each 8/217, 3.7%). The remainder of the videos (12/217, 5.4%) originated in the rest of the world, including a few international organizations.

Collectively, these videos were viewed 2,369,003 times, however, a single CDC video accounted for over 1.2 million views. This video was animation accompanied by voiceover, published on January 7, 2016 and was 2 minutes and 51 seconds in length. The second most viewed video was viewed over 193,000 times and originated by the online media source, VICE.

This video was published on June 26, 2015 and was 27 minutes and 10 seconds in length.

Characteristics of videos classified according to their source are described in Table 2. Institutions (66/217, 30.4%) and consumers (63/217, 29.0%) presented the largest number of videos followed by CBOs (48/217, 22.1%) and media (40/217, 18.4%). While no significant differences in the length of videos between different sources were observed, the Kruskal-Wallis test indicated significant differences in both number of views ($P=.003$) and number of comments ($P<.001$) between different sources. With regard to the number of views, the institution videos had a mean rank significantly lower than the consumer ($P=.05$) and media ($P=.02$) videos, adjusted for multiple comparisons. With regard to the number of comments, the consumer videos had a mean rank significantly higher than the institution ($P<.001$) and the CBO ($P<.001$) videos, while media videos had a mean rank significantly higher than the institution ($P=.002$) videos, all adjusted for multiple comparisons.

Figure 1. Number of pre-exposure prophylaxis (PrEP) YouTube videos published per year (until October 1, 2016).**Table 2.** Characteristics (length, number of views, and number of comments) of the most viewed pre-exposure prophylaxis (PrEP) YouTube videos by their sources.

Video characteristics	Consumer (N=63)	Institutions ^a (N=66)	Media (N=40)	Community-based organization (N=48)	Total (N=217)	Kruskal-Wallis test—H (degrees of freedom); <i>P</i> value
Length in mm:ss, median (IQR ^b)	05:35, (02:13-09:57)	05:21, (01:55-16:55)	04:01 (02:30-06:14)	04:06, (01:38-09:57)	04:40, (02:15-09:57)	2.2 (3); .53
Number of views, median (IQR)	728 ^c , (371-4097)	412 ^d , (210-774)	881 ^c , (281-9449)	353 ^{c,d} , (158-1419)	520, (253-2416)	13.9 (3); .003
Number of comments, median (IQR)	4 ^e (1-23)	0 ^f (0-1)	1 ^{e,g} (0-12)	0 ^{f,g} (0-1)	1 (0-4)	43.6 (3); <.001

^aGovernment, health or academic professional.

^bIQR: interquartile range.

^{c,d}Superscript letters indicate classes of information providers whose mean ranks for views do not differ significantly from each other at alpha=.05, following post hoc tests.

^{e,f,g}Superscript letters indicate classes of information providers whose mean ranks for comments do not differ significantly from each other at alpha=.05, following post hoc tests.

Table 3. Content characteristics of the most viewed YouTube pre-exposure prophylaxis (PrEP) videos by their sources.

Content categories	Consumer (N=63), n (%)	Institutions ^a (N=66), n (%)	Media (N=40), n (%)	Community-based organization (N=48), n (%)	Total (N=217), n (%)	Chi-square test (degrees of freedom); <i>P</i> value
Defines PrEP	47 (74)	55 (83)	38 (95)	40 (83)	180 (82.9)	7.2 (3); .07
Describes how PrEP works	27 (42)	37 (56)	18 (45)	25 (52)	107 (49.3)	2.7 (3); .44
Describes who can use PrEP	34 (54)	41 (62)	31 (77)	26 (54)	132 (60.8)	6.9 (3); .08
Promotes PrEP as safe option	11 (17)	16 (24)	11 (27)	12 (25)	50 (23.0)	1.7 (3); .63
Discusses side effects	18 (28)	26 (39)	13 (32)	13 (27)	70 (32.3)	2.5 (3); .48
Describes how to obtain PrEP	22 (34)	22 (33)	13 (32)	21 (43)	78 (35.9)	1.7 (3); .63
Discusses the cost of PrEP	18 (28) ^b	13 (19) ^b	21 (52)	8 (16) ^b	60 (27.6)	17.4 (3); .001
Promotes use of PrEP	45 (71)	58 (87) ^c	32 (80) ^c	46 (95) ^c	181 (83.4)	13.2 (3); .004

^aGovernment, health or academic professional.

^bIndicates information providers whose proportion of videos discussing cost of PrEP do not differ significantly from each other at the $\alpha=.05$, following post hoc tests.

^cIndicates information providers whose proportion of videos promoting use of PrEP do not differ significantly from each other at the $\alpha=.05$, following post hoc tests.

Overall, more than 80% of the videos defined and promoted the use of PrEP, and more than 60% described who can use PrEP (ie, people who are HIV-negative and want to protect themselves from contracting HIV) (Table 3). In contrast, less than one-third of the videos addressed the cost, side effects, or safety aspects of PrEP. Over one-third of the videos (78/217, 35.9%) discussed how to obtain PrEP, and over one-quarter (60/217, 27.6%) discussed the costs of PrEP. Chi-square analyses were conducted to explore differences among the 4 sources of information in each of the content categories. Statistically significant differences were observed for costs of PrEP ($\chi^2_3=17.4$, $P=.001$) and whether use of PrEP was promoted by the video ($\chi^2_3=13.2$, $P=.004$). While videos uploaded by media sources comprised less than 20% of the sample, they were approximately twice as likely to present content related to the cost of PrEP ($P<.001$). Some consumer videos voiced concerns that PrEP would not be affordable for everyone. While the majority of videos reported that the cost is covered by health

insurance plans, including Medicare, only a few more recent videos reported the availability of a commercial assistance program that provides free PrEP to people with limited income and no insurance. Compared with videos uploaded by institutions and media, those posted by consumers were less likely to promote the use of PrEP ($P=.002$), whereas those posted by CBOs were more likely to promote the use of PrEP ($P=.009$).

Positive views were emphasized by messages that PrEP is an appropriate prevention strategy for our time. For example, a number of videos oriented toward gay men emphasized that we need to “meet boys where they are.” CBO’s videos, in particular, highlighted a commitment to condom promotion, but acknowledged that many people are not successful in using condoms every time. Hence, these sources emphasized the need for additional prevention strategies. Some videos highlighted that PrEP is a niche opportunity that can be offered safely to people who are at a high risk for HIV infection.

Table 4. The most likely target audience of pre-exposure prophylaxis (PrEP) videos (N=217).

Most likely target audience of pre-exposure prophylaxis (PrEP) videos	n (%)	Median # of views	Median # of comments
General population of men who have sex with men (MSM)	83 (38.2)	556 ^b	1.7 ^d
Others at risk for HIV categories^a	44 (20.3)	706 ^{b,c}	1.3 ^{d,e}
Racial minority MSM	31 (14.3)	827	1.9
Transgender population	5 (2.3)	722	1
Women/heterosexual couples	8 (3.7)	254	0.5
Scientific/professional audience	17 (7.8)	351 ^c	0.4 ^e
Nonspecific/anyone who may benefit from PrEP/anyone at risk for HIV	73 (33.6)	429 ^{b,c}	0.5 ^e
Kruskal-Wallis Test—H (degrees of freedom); <i>P</i> value		8.0 (3); .05	19.1 (3); <.001

^aFor Kruskal-Wallis test racial minority MSM, transgender population and Women/heterosexual couples were grouped into one *Others at risk for HIV* category.

^{b,c}Superscript letters indicate target audience groups whose mean ranks for views do not differ significantly from each other at the alpha=.05, following post hoc tests.

^{d,e}Superscript letters indicate target audience groups whose mean ranks for comments do not differ significantly from each other at the alpha=.05, following post hoc tests.

Less supportive voices expressed the fear of stigmatization such as that those using PrEP will be viewed as “Truvada whores,” or that PrEP is about selfishness and not taking responsibility for practicing safe sex. Additional concerns were raised that individuals with lower levels of income and education will still have hard time accessing the medication or proper health care. Many videos supported a once-a-day pill regimen (ie, “taking one pill a day to stay HIV-negative doesn't seem like asking too much”), and some emphasized that the issue of adherence is secondary (ie, “focusing on adherence is focusing on the wrong side of the problem, as we are meeting people where they are”).

The largest number of videos (98/217, 45.2%) featured a single individual discussing PrEP. These videos were almost universally shot with a single camera, usually with an individual talking directly to the camera. Slightly over a quarter of the videos (60/217, 27.6%) featured multiple individuals, often in the form of interviews, panel discussion or Q&A sessions. Smaller number of videos was either in the form of animation or music videos (25/217, 11.5%) or newsreel and news interviews (20/217, 9.2%). The remainder of the videos (14/217, 6.4%) was in the form of academic presentations accompanied by slides.

Table 4 summarizes the most likely target audience of PrEP videos. To a large extent, videos were directed toward gay and bisexual men (83/217, 38.2%). Racial minority gay and bisexual men were the target of 14.3% (31/217) of the videos. While only 5 videos discussed how PrEP relates to the transgender population specifically, a number of other videos included this population as beneficiaries of PrEP. A PrEP appeal to women was addressed exclusively with 6 videos, and additional 2 videos discussed PrEP in relation to heterosexual serodiscordant couples. The scientific audience was the target of 7.8% (17/217) of reviewed videos. The Kruskal-Wallis test indicated significant differences in both, the number of views ($P=.05$) and the number of comments ($P<.001$) among videos targeting a specific audience. With regard to the number of views, videos appealing to the general population of MSM had a mean rank significantly

higher than the videos appealing to a scientific audience ($P=.04$), adjusted for multiple comparisons. With regard to the number of comments posted, videos appealing to the general population of MSM had a mean rank significantly higher than the videos appealing to a scientific audience ($P=.01$), and videos appealing to a general audience ($P=.002$), adjusted for multiple comparisons.

Discussion

PrEP is the powerful tool for HIV prevention, yet it remains a complex subject with a number of uncertainties concerning implementation. Discussions in literature reinforce the difficulties in communicating reliable and direct information about PrEP to the public [22]. YouTube videos represent a potentially effective approach for communicating reliable information about PrEP to individuals and communities. YouTube can also be a useful instrument for communities to share or retrieve timely health information and advice. However, the health information that is available on YouTube, and social media in general, can also provide contradictory or even misleading information [22,50]. Besides addressing the efficacy and quality of health information content of the YouTube videos [45], researchers can use YouTube videos to investigate public perception of certain diseases, medications, and health care services [54]. To our knowledge, this study represents the first to assess the sources and content of PrEP YouTube videos.

While the first video on PrEP was published in 2009, we observed the surge in the number of published videos in 2014. It is possible that this increase in the number of published PrEP YouTube videos corresponds to pervasive media coverage and to the CDC and WHO clinical practice guidelines issued in 2014. This study indicates that sources of information on PrEP in YouTube videos are diverse. These sources included individuals describing and discussing their experiences while on PrEP, medical professionals providing information about the PrEP regimen, academic institutions offering updates surrounding HIV prophylaxis, CDC providing information on

PrEP guidelines, media discussing PrEP as part of a news report, and various CBOs focusing on community dialogue, awareness, and promotion of PrEP.

The most viewed video was published by the CDC, which received the majority of the cumulative total number of views. Interestingly, this video was available online for approximately 9 months only. It is likely that the CDC included this video on their Facebook page and Twitter feed, allowing rapid and expansive reach of the content. While some prior studies of health information in YouTube videos have found that videos uploaded by agencies of the United States Public Health Service are among the most widely viewed [34,44], other studies have shown that videos uploaded by such agencies were not among the most widely viewed [55]. Our results may suggest that viewers are interested in getting reliable and accurate information about PrEP from an authoritative and trusted source. A recent study [56] found that those who learned about PrEP from HIV service agencies and health care professionals were more likely to know a lot about the PrEP medication. Given this finding and the wide reach of YouTube videos, this media channel represents an important way for health care professionals to communicate with the public in ways that will help them make informed decisions about reducing their risk of HIV infection by using PrEP. Considering the ease of access to YouTube, it may be particularly prudent for international organizations and health authorities to consider social media as tools for influencing social and behavioral change in ways that support PrEP uptake and use.

The findings of this study show that YouTube videos cover a wide range of issues associated with PrEP, including intended beneficiaries, how to obtain it, side effects, costs and insurance coverage. The findings highlight that the personal experiences one might have in taking Truvada are covered in YouTube videos. Studies have found that such anecdotal information presented in video format may have an expansive impact on individuals' health care decisions, extending its benefits from being a diagnostic aid or an educational tool for health care conditions to being a source for information sharing among patients coping with various health issues [57,58]. Hence, it is important for the medical professionals to integrate consumers' narratives into their messages. The majority of videos have applauded the advent of this new prevention possibility and encouraged those at a risk for HIV to consider this option. However, some videos expressed the views that this intervention is fraught with the unknown. Some voiced concerns about whether Truvada provides a false sense of security, thereby leading to increased rates of sexually transmitted diseases (STDs), and whether users will be exposed to moral judgments, that is, become labeled as "Truvada whores." Additionally, concerns have been raised regarding the toxicity of the medications and the cost of the treatment. Some, while acknowledging that PrEP is not an intervention for everyone, emphasized that it should be combined with other protective efforts such as using condoms, choosing partners carefully, and monogamy. Yet, by and large, in our sample of most viewed videos, PrEP was promoted and encouraged as a means of HIV prophylaxis, particularly for those at a high risk for HIV infection.

While we are unable to ascertain the demographics of the viewers, majority of the videos seem oriented toward gay men. Furthermore, these videos had more views and comments than other categories, suggesting that this population has high interest in acquiring information about PrEP. As a group of individuals who face multiple barriers to contact with health professionals, sexual minorities are also more likely than heterosexual people to access the internet at higher rates than heterosexual people to seek health information. For example, one study found that sexual minority participants were 58% more likely to watch a health-related video on YouTube than heterosexual participants [59]. Yet, only a limited number of videos focused on other sexual minority populations at a high risk of contracting HIV, namely the transgender community. A smaller number of videos were directed specifically toward racial minority MSM. None of the videos were directed specifically toward PWID. While previous research has shown that populations that face barriers to contact a health care professional (eg, adolescents, ethnic and racial minorities) are more likely to use the internet to seek health information and to inform their health care decision making [60-63], our findings suggest lack of PrEP information content directed at various other populations at risk. It is, therefore, important to broaden the appeal of PrEP through videos directed at these vulnerable populations.

Limitations

The findings from this study must be considered in light of the limitations, including the cross-sectional design (popularity based on number of views changes constantly), and the inclusion of videos that had 100 or more views (an arbitrary cut point). By placing this arbitrary cut point we may have created bias toward higher quality and more user-friendly content. While this study represents an important first step in exploring the types of PrEP content available to target audiences, the findings and the insights generated from using predefined categories are somewhat limited. Qualitative exploration of the meaning and scope of these categorizations may provide additional nuances to the issues around PrEP. This data is from a single video-broadcasting website on the internet, as we did not include other video-sharing websites. Although we recorded a number of views for each video in the sample, we have no information on how many unique individuals viewed these videos. YouTube viewers may be more likely to choose videos by default rather than relevance sorting. View counts are an imperfect proxy for measuring the videos' reach. Furthermore, the study team was also not able to draw conclusions about the possible effects of watching these videos (eg, whether someone decided to seek PrEP upon watching). In addition, the study was based solely on videos in English, the majority of which originated in the United States. The specific comments of viewers were not coded for content. Finally, we did not focus on the additional visual aspects (ie, number of cuts, visual effects, slow motion, bold or unusual colors, and/or intense imagery). Nonetheless, this study contributes to the literature about an emerging topic, namely how social media is providing information related to PrEP use.

Conclusions

Our study explored PrEP content available on YouTube. The findings demonstrate that content is being uploaded to the site by variety of sources; however, one video from a government source was the most viewed, which may indicate that the public is seeking reliable information about PrEP. Public health

professionals should be aware of the extent to which PrEP-related content appears on social media and, more importantly, be attuned to the content, which can be inaccurate or misleading. Future research is needed to identify aspects of YouTube videos that attract viewer attention and best practices for using this medium for increasing public awareness and understanding of PrEP.

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Conflicts of Interest

None declared.

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Abbreviations

- ARV:** antiretroviral
- CDC:** Centers for Disease Control and Prevention
- FDA:** Food and Drug Administration
- MSM:** men who have sex with other men
- PrEP:** pre-exposure prophylaxis
- PWID:** people who inject drugs
- RA:** research assistant
- WHO:** World Health Organization

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Review

Examining Influences of Parenting Styles and Practices on Physical Activity and Sedentary Behaviors in Latino Children in the United States: Integrative Review

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Abstract

Background: Research indicates that parents influence their children's physical activity (PA) and sedentary behaviors (SB) through their parenting styles and practices.

Objective: The objectives of this paper were to evaluate existing research examining the associations between parenting styles, parenting practices, and PA and SB among Latino children aged between 2 and 12 years, highlight limitations of the existing research, and generate suggestions for future research.

Methods: The method of this integrative review was informed by methods developed by Whittemore and Knafl, which allow for the inclusion of qualitative, quantitative, and mixed-methods studies. Using the Preferred Reporting Items for Systematic Reviews Meta-Analyses guidelines, five electronic academic databases (PubMed, SPORTDiscus, PsycINFO, PsycARTICLES, and CINAHL) were searched for peer-reviewed, full-text papers published in English. Of the 641 unique citations identified, 67 full-text papers were retrieved, and 16 were selected for review.

Results: The majority of the 16 reviewed studies were conducted with predominantly Mexican American or Mexican immigrant samples, and only 1 study examined the association between parenting styles and Latino children's PA and SB. Most (n=15) reviewed studies assessed the influence of parenting practices on children's PA and SB, and they provide good evidence that parenting practices such as offering verbal encouragement, prompting the child to be physically active, providing logistic support, engaging and being involved in PA, monitoring, and offering reinforcement and rewards encourage, facilitate, or increase children's PA. The examined studies also provide evidence that parenting practices, such as setting rules and implementing PA restrictions due to safety concerns, weather, and using psychological control discourage, hinder, or decrease children's PA.

Conclusions: Because this review found a very small number of studies examining the relationship between parenting styles and Latino children's PA and SB, additional research is needed. Given that the majority of reviewed studies were conducted with predominantly Mexican American or Mexican immigrant samples, additional research examining parenting styles, parenting practices, and PA and SB among multiethnic Latino groups is needed to design interventions tailored to the needs of this ethnically diverse population group.

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KEYWORDS

parenting; styles; practices; physical activity; children; Hispanic; Latino

Introduction

Background

Latinos or Hispanics (hereafter referred to as Latinos) are the largest and most rapidly growing population group in the United States [1]. Despite recent declines in the prevalence of childhood obesity in the United States [2,3], evidence indicates that racial/ethnic minority children, including Latinos, remain at increased risk of childhood obesity [2,3]. Therefore, childhood obesity among Latinos is a pressing public health concern because child weight status tracks into adulthood [2,3]. In addition, racial/ethnic minority children are at high risk of physical inactivity and increased levels of sedentary behaviors (SB) (eg, watching TV/videos, playing video games, and being on the computer) [3-5].

Physical activity (PA) is a key component of energy balance, and promoting PA is essential to prevent childhood obesity and to promote children's health [6,7]. Physically active children have healthier cardiovascular profiles, leaner body frames, and higher peak bone mass compared to physically inactive children [4,6,8,9]. In addition to regulating body weight and improving body composition, PA improves psychological and social well-being [4,6,9,10].

Despite the well-documented benefits of PA, children's PA levels have declined over the past decades, with most children in the United States not getting the recommended 60 min of PA daily [11,12]. Physical inactivity is even a greater problem among racial/ethnic minority children in the United States, with a greater prevalence of physical inactivity among Hispanic children than non-Hispanic white children [13-15]. Therefore, it is essential to understand the factors that influence Latino children's PA and sedentary levels to address disparities in PA and obesity rates among this population group.

Parents influence their children's PA and SB, and existing scientific evidence suggests that one way parents do this is through their parenting style [16,17]. *Parenting style* encompasses the overarching attitudes and behaviors that characterize how a parent interacts with a child across domains of parenting [18-20]. Parenting style includes 2 main dimensions: *demandingness* (also defined as control) and *responsiveness* (also defined as warmth). In total, 4 parenting-style typologies have been described: (1) authoritarian (high demandingness/low responsiveness), (2) authoritative (high demandingness/high responsiveness), (3) permissive (low demandingness/high responsiveness), and (4) uninvolved (low demandingness/low responsiveness) [21,22]. Available evidence examining the association between parenting styles and children's PA and SB is mixed [22-29]. A recent study conducted in the United Kingdom documented that permissive parenting was associated with higher levels of PA among 10- to 11-year-old children [23]. In contrast, a systematic review of general parenting and overweight- and obesity-related behaviors revealed mixed results for an association between parenting styles and children's PA [17]. Overall, however,

results suggest that children raised in authoritative homes are more physically active and have lower body mass index (BMI) levels than children raised to other parenting styles (authoritarian, permissive/indulgent, uninvolved/neglectful) [17].

In terms of PA and SB, parenting practices are context-specific behaviors that parents use to encourage or facilitate their children's PA and/or reduce SB, such as providing logistic support for PA, encouraging their children to be physically active (eg, verbal encouragement), restricting or setting limits for SB (eg, limiting screen time), monitoring children's PA and sedentary time, and modeling PA behaviors [22-24,29,30-32]. Moreover, although parenting styles are independent of parenting practices, evidence suggests that parenting styles may facilitate or hinder positive PA parenting practices [23-27,31,33]. For example, parents who exhibit a more controlling parenting style (authoritarian) are more likely to engage in parenting practices such as setting overzealous or strict boundaries on children's free outdoor play that hinder their children's PA [23,24,29].

Prior research indicates that cultural norms and values and social context influence parental attitudes toward child-rearing; therefore, the effects of different parenting styles and parenting practices often vary across ethnic groups [34-42]. Available research on general parenting practices suggests that Latino parents' parenting styles are usually characterized as showing high levels of parental control [40-43] and sometimes (especially maternal) indulgency [37,43,44]. Moreover, available research on PA parenting styles and practices suggests that Latino parents often employ authoritarian and indulgent/permissive styles, and parenting practices that often reflect high control (eg, strict boundaries on children's free outdoor play) and permissiveness (eg, lack of setting limits on screen time) [35-40,44,45].

Objectives

Given the low prevalence rates of PA and high rates of SB among Latino children [46] and the increasing evidence linking parenting styles and practices to children's PA and SB [17,23,27,31,32], the objectives of this integrative review were to: (1) evaluate existing research examining the associations between parenting styles, parenting practices, and PA and SB in Latino children aged between 2 and 12 years; (2) highlight limitations of existing studies; and (3) generate suggestions for future research.

Methods

Design

The method of this integrative review was informed by methods developed by Whitemore and Knafel [47], which allow for the inclusion of qualitative, quantitative, and mixed-methods studies. This review had 3 key steps: (1) conducting a systematic literature search; (2) evaluating retrieved studies using a thematic analysis process—data reduction, data display, and drawing and verifying conclusions; and (3) presenting

conclusions. In addition, we used the reporting guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) statement [48] to guide the inclusion and exclusion of research papers.

Search Strategy

We searched 5 databases—PubMed, SPORTDiscus, PsycINFO, PsycARTICLES, and Cumulative Index to Nursing and Allied Health Literature (CINAHL). The search, conducted between August 2016 and September 2017, was limited to full-text, peer-reviewed papers published in English before September 2017. Search terms included: (parent* AND (styles OR practice OR strategy* OR behavior) AND (“physical activity” OR exercise OR sedentary behavior*) AND (children OR pediatric) AND (Hispanic OR Latin* OR Mexican* OR Spanish OR immigrant OR ethnic*).

A team of 2 authors (MW, ACL) independently examined the titles and abstracts of all citations identified and excluded citations when both authors determined that the study did not meet the inclusion criteria. Next, the same 2 authors independently reviewed the full-text papers and the reference lists of the studies that were not excluded based on title and abstracts. In addition, the same 2 authors also searched the reference lists of papers that cited the 16 included papers. A final set of agreed-upon papers was examined to extract the relevant information pertaining to the objectives of this integrative review. The search strategy is illustrated in [Multimedia Appendix 1](#).

Study Selection

Qualitative and quantitative studies examining the influence of parenting styles and parenting practices on PA and SB of Latino children were eligible for inclusion if they met the following criteria: (1) peer-reviewed, full-text papers published in English before September 2017; (2) parents (18+ years old) of children between 2 and 12 years of age; and (3) at least 50% of the total sample self-identified as Latino. Review and validation studies were excluded.

The PRISMA statement guidelines [48] were used to report the review process (see [Multimedia Appendix 1](#)). The initial search identified 730 papers. After removing duplicate studies, 641 papers were assessed based on title and abstract by 2 authors independently. Studies were excluded when both authors determined that the study did not meet the inclusion criteria: 574 citations were excluded, and 67 full-text papers were selected for further assessment. Of the 67 full-text papers, 52 did not meet the inclusion criteria upon full-text review and were excluded for various reasons (sample was not at least 50% Latino or studies included special population groups), yielding 15 eligible papers. In addition, to identify additional potentially eligible studies, 2 authors searched the reference lists of full-text papers (n=15) that satisfied the inclusion criteria. This manual search yielded 1 additional eligible study. In total, 16 papers were selected for final inclusion in this integrative review.

Data Extraction and Synthesis

The 16 identified eligible studies were analyzed and synthesized using the Matrix Method [49], and 2 authors (ACL, MW)

independently read all papers and completed a data extraction form created to gather the following information: (1) authors, (2) study setting, (3) study aim(s), (4) study population, (5) study design, (6) measure(s) of parenting styles or PA parenting practices, (7) measure(s) of child’s PA, and (8) study results. The completed data extraction forms were compared, and discrepancies were discussed and resolved with feedback from a third author (MAM). This review synthesizes the extracted data, examining associations between parenting styles or PA parenting practices (exposures) and children’s PA level or SB (outcomes). Due to the range of study designs, assessment of exposure, and outcomes, conducting a meta-analysis was not appropriate, and results of this review are presented as a narrative summary.

Quality Assessment of Included Studies

Included studies were evaluated using one of two quality frameworks. Quantitative studies were assessed using the appraisal framework [50] to rate study quality, with the maximum score being 5 ([Multimedia Appendix 2](#)). Qualitative studies were assessed using the Critical Appraisal Skills Program [51], a 9-question appraisal tool ([Multimedia Appendix 3](#)). Two researchers (ACL, MW) independently assessed the study quality using these checklists and discussed and resolved any uncertainty.

Quantitative Studies

A total of 11 quantitative studies [52-62] were identified, out of which only one fulfilled all of Glasziou’s methodological criteria [50]. This review found that selection and measurement bias could have possibly affected the results of the other 10 studies; in 5 studies, it was not clear whether participants were randomly selected, and there was limited or no information on comparison between respondents and non-respondents or information on participation rates ([Multimedia Appendix 2](#)).

Qualitative Studies

Our review indicated that all of the 5 qualitative papers [63-67] were of good quality. Nevertheless, none of the examined qualitative studies considered the relationship between the researcher and participants or other possible power imbalances that might have influenced the studies’ findings ([Multimedia Appendix 3](#)).

Results

Search Results

After studies were assessed for eligibility using the inclusion and exclusion criteria previously discussed, 16 original research papers were deemed eligible to be included in this integrative review [52-67]. Qualitative and quantitative studies included in this review explored or assessed associations between the following: (1) parenting styles and children’s PA and/or SB, and (2) PA parenting practices and children’s PA and/or SB.

Study Characteristics

[Multimedia Appendix 4](#) presents a description of included studies, whereas additional study characteristics are presented in [Multimedia Appendix 5](#). Eligible studies examined parenting

styles [48] and a range of PA parenting practices [52-65,67] and children's PA levels and behaviors using a wide variety of research methods. Of the 16 included studies, 1 focused on parenting styles [48] and 15 on PA parenting practices [52-60,63-65,67]. Of the 16 reviewed studies, 11 employed quantitative methods [52-62] and 5 qualitative research methods [63-67]. Of the 11 quantitative studies, 5 were observational cross-sectional studies [58-62], and 6 used quasi-experimental designs to determine intervention efficacy [52-57].

In total, 4 validated questionnaires—the Parenting Strategies for Eating and Activity Scale (PEAS) [68], the Preschooler Physical Activity Parenting Practices (PPAPP) [49], the Activity-Related Parenting Practices Scale [69], and an adapted version of the Girls Health Enrichment Multi-Site Studies (GEMS) [70]—were used in 9 studies [52-60] to assess PA parenting practices. In addition, 2 studies [61,62] used an observational system called Behaviors of Eating and Activity for Child Health: Evaluation System (BEACHES) [71] to assess, among other factors, parenting practices that correlated with children's PA.

All 16 studies were conducted in the United States, but in only 5 states (California, Massachusetts, North Carolina, Texas, and Wisconsin). Sample sizes ranged from 33 to 812 participants, and the majority of samples were predominantly Mexican American or Mexican immigrant [52-63,65-67], except for 1 study conducted in Massachusetts, which included a multiethnic sample of Latina mothers [64]. Children included in study samples were aged between 3 and 12 years.

This review is organized into 2 sections: (1) studies that explored or assessed associations between parenting styles and children's PA levels or behaviors and (2) studies that explored or assessed associations between parenting practices and children's PA levels and/or behaviors or SB. Findings from the 16 reviewed studies are presented and discussed in multiple sections of the synthesis of findings of this review where applicable.

Synthesis of Findings

[Multimedia Appendix 6](#) presents a synthesis of the 14 themes identified in the examined studies relating to parenting styles and PA parenting practices of Latino parents. Most themes, except for three related to parenting styles, focused on PA parenting practices and fell into either of 2 categories: (1) factors that either encourage, facilitate, or increase PA (ie, parental engagement and/or involvement, verbal encouragement or motivational support, prompting the child to be physically active, providing logistic or instrumental support, limiting SB, using reinforcement and rewards, monitoring) and (2) factors that discourage, hinder, or decrease PA (ie, rules and restrictions, discipline [eg, making children stay inside as punishment], and psychological control [eg, parental criticism, intimidation and insults, manipulation of child's behavior to satisfy parents' needs]) in Latino children.

Parenting Styles

Only 1 study explored the influence of parenting styles on children's PA. This qualitative study [66] included 4 focus groups conducted with Mexican American or Mexican immigrant mothers and fathers, and its analysis determined that

permissive, authoritative, and authoritarian parenting styles were perceived as being related to children's PA. Findings suggested that Latina mothers' statements were more reflective of a permissive approach to their children's PA, whereas the fathers' approach used authoritative (ie, setting expectations, but willing to negotiate) or authoritarian (ie, dictating what the children do) parenting styles to promote children's PA.

Parenting Practices

Of the 16 included studies, 15 examined the association between PA parenting practices and children's PA and/or SB. Overall, studies showed that parenting practices such as providing verbal encouragement or offering motivational support for the child's PA, prompting the child to be physically active, engaging and being involved in PA with the child, providing logistic or instrumental support (eg, transportation, enrolling child in sports class), offering positive reinforcement, monitoring the child's PA and screen time, and setting limits on screen time, encourage, facilitate, or increase children's PA, whereas parenting practices such as using psychological control, setting rules and restrictions for PA due to the weather (eg, cold weather) and/or safety concerns (eg, traffic, neighborhood violence), using disciplinary action limiting child's PA (eg, not allowing the child to play outside because of poor behavior) discourage, hinder, or decrease children's PA (see [Multimedia Appendix 4](#)).

Logistic or Instrumental Support

Of the included studies, 5 explored the influence of parental logistic or instrumental support on children's PA [54-57,63]. A qualitative study [63] using focus groups with parents (mothers and fathers) and children (boys and girls aged 10-12 years) revealed that both parents and children viewed parental logistic support for PA as being an important factor for increasing children's PA [63].

An intervention study conducted in Texas with parents with low incomes and their 5- to 9-year-old children examined the effect of parental support for children's active living, including parental support for PA and reducing SB. Parental support was assessed using a scale adapted from the GEMS [55] that assessed parent's verbal support (eg, "I encourage my child to play outside when the weather is nice"), logistic support (eg, "I take my child to his/her sport practice, dance class, or other PA program"), and instrumental encouragement of PA (eg, "I assign active chores for my child such as vacuuming or doing lawn work"). Analysis determined that parental verbal and logistic support for PA reduced children's SB. In addition, although girls were less sedentary than boys, girls were less affected by parental support [55].

A randomized controlled trial (RCT) testing the feasibility of Helping Healthy Activity and Nutrition Directions (Helping HAND), a 6-month obesity intervention study in primary care settings with 40 parent-child dyads of 5- to 8-year-old children with BMI in the 85th to 99th percentile (82.5% Hispanic), targeted behavior-specific parenting practices, including PA [57]. PA parenting practices were assessed using the Activity-Related Parenting Practices Scale [69]. The intervention changed parenting practices, including logistic support for PA, but did not increase PA. Nevertheless, the intervention group

watched less TV than the control group post intervention (14.9 [standard error 2.3] hour/week vs 23.3 [standard error 2.4] hour/week [$P < .05$]).

A study using baseline data from *Aventuras Para Niños* (“Adventures for Kids”), an RCT of an intervention designed to prevent childhood obesity conducted in 13 elementary schools in southern California with children enrolled in kindergarten to second grade (5-9 years of age), showed that parents of children who were overweight provided less instrumental support for their children to engage in PA than parents of children who were not overweight [54] and that provision of instrumental support was associated with children’s PA [54]. A second longitudinal study using data from *Aventuras Para Niños* examined the efficacy of an intervention aimed at improving several dimensions of parenting related to childhood obesity, including selected PA parenting practices (limit setting, monitoring, discipline, control, reinforcement, and support for PA), showed a positive effect of the intervention on parent logistic support for PA [53]. Finally, a third longitudinal study analyzing data from *Aventuras Para Niños*, determined that an increase of PA as reported by the parent was mediated by increases in parental support of a child’s PA (eg, parents providing transportation, encouragement, or actively participating in PA with child) [56].

Monitoring

In total, 3 studies explored the influence of the parental practice of monitoring on children’s PA. Arredondo et al examined survey data from parent-child dyads enrolled in *Aventuras Para Niños* study (see above) and determined that parental monitoring of children’s PA and SB was positively associated with children’s PA [52]. Children’s PA was measured using parental reports of their children’s PA level compared with other children, whereas PA parenting practices were assessed using PEAS [68], a self-administered parental questionnaire consisting of a 26-item scale that includes 5 subscales (limit setting, monitoring, discipline, control, and reinforcement). Similarly, a second study also using data from *Aventuras Para Niños* showed that increased PA and reduced SB was mediated by increases in parental monitoring of children’s PA and SB [56]. Finally, a third study designed to examine the efficacy of *Aventuras Para Niños* showed a positive effect of the intervention on the parenting practice of monitoring a child’s PA [53]. The intervention included monthly home visits by a native Spanish-speaking health worker (aka *promotora*) over a 7-month period, plus monthly mailed newsletters [53]. Parents who received the home visits reported more frequent monitoring of their children’s PA, with parents reporting that the children increased their PA and reduced SB.

Parental Engagement and Involvement

In total, 5 studies reported on the influence of parental engagement and involvement on children’s PA [58,59,63,65,66]. A qualitative study [66] conducted in Texas with 66 Mexican American and Mexican immigrant mothers and fathers revealed that mothers viewed themselves as being less likely to engage in PA with their children and to have limited involvement in their children’s PA. Fathers viewed themselves as being more physically active, much more engaged in PA with their children,

and much more involved in their children’s PA [66]. Similarly, a qualitative study conducted in Wisconsin with primarily Mexican American mothers and fathers and their 10- to 12-year-old children revealed that parental involvement, as perceived by the children, was an important influence on their PA levels [63]. Likewise, a qualitative study using a nominal group technique (a structured multistep group procedure) with 74 parents or legal guardians of 3- to 5-year-old children revealed that parents believed that parental engagement (eg, participating in PA with child, playing sports with child) was a positive PA parenting practice that influenced children’s PA [65]. This finding was further examined in a cross-sectional study with 240 parents in Texas using the validated PPAPP [58], an instrument that assesses parenting practices that encourage and discourage child PA. Results showed that parental perception of a neighborhood’s physical (eg, traffic hazard, safety including stranger danger) and social (disorder) environment was positively associated with parental engagement for promoting the child’s PA [59].

Setting Limits

A total of 2 studies explored the influence of parental limit setting on children’s PA. A qualitative study with parents or legal guardians of 3- to 5-year-old children described earlier [65] revealed that parents perceived that not setting limits (eg, allowing child to “watch a lot of TV and use videogames”) discouraged children from being physically active [65]. A study described earlier used baseline data from *Aventuras Para Niños* [54] and found that parents of overweight children set fewer limits on their child’s activities (eg, TV watching) and that their children watch more TV than children who are not overweight.

Reinforcement and Reward

Of the selected studies, 2 explored the influence of parents’ use of reinforcement and rewards on children’s PA [52,63]. A qualitative study with parents and children (boys and girls aged 10-12 years) revealed that the use of positive reward for a child being physically active was identified by mothers, fathers, and children as being an important factor in increasing children’s PA [63].

A quantitative study by Arredondo et al [52] determined that parental reinforcement of their children’s PA, as measured by a parent’s praising of a child being physically active, was positively associated with children’s PA [52]. On the other hand, parental use of screen time (eg, offering TV, video, or video games to children as rewards) as a reward for good behavior was not significantly associated with children’s PA.

Verbal Encouragement

A qualitative study [63] with parents (mothers and fathers) and children aged between 10 and 12 years revealed that parents’ offering verbal encouragement (eg, telling the child he/she did a good job) of a child’s PA was identified by both parents and children as an important factor in increasing PA in children.

Prompting

Of the quantitative studies, 2 [61,62] used the BEACHES [71] observational system (described earlier) and determined that parental prompting of children to be physically active was

associated with increased children's PA levels at home. Moreover, 1 study [62] showed that most activity prompts came from parents interacting with children when the child was sedentary. Furthermore, findings from this study [62] showed that with increasing age, children seem to rely less on the interpersonal interaction with adults for cues to be active.

Rules and Restrictions

Of the identified studies, 5 explored the association between setting rules and restricting PA and children's PA. A qualitative study conducted in Massachusetts using focus groups and in-depth interviews [64] with multiethnic Latina mothers of preschool-age children (2-5 years) revealed that mothers limit their young children's PA because of safety concerns (eg, perceived neighborhood violence) and weather-related (eg, the cold weather) reasons negatively impacted their children's PA. Similarly, a more recent qualitative study [67] found that Latina mothers of preschool-aged children who were farm workers living in North Carolina perceived that their concerns about neighborhood safety constrained their children's PA.

A quantitative study conducted in California with Mexican American preschool-age children (4-year-olds) and parents using the BEACHES observational system (described earlier) determined that parental attempts to control children's PA through the enforcement of rules (eg, "staying close to the house"; "don't play rough games"; "no balls in the house"; "don't run") were associated with low levels of observed activity [61].

A quantitative study conducted in Texas with 84 children aged between 3 and 5 years and one of their parents who completed the PPAPP (described earlier) showed that the parenting practice of restricting children's PA because of safety concerns was negatively associated with preschool children's PA levels [60].

Discipline

A quantitative study by Arredondo et al [52] using data from parent-child (kindergarten to second-grade) dyads enrolled in *Aventuras Para Niños* explored the influence of the parenting practice of using discipline, as measured by a parent's disciplining of the child for watching TV or videos or playing video/computer games on kindergarten to second-grade children's PA. Findings revealed that parental use of discipline was not significantly associated with children's PA [52].

Psychological Control

In total, 2 studies explored the influence of parental use of psychological control (eg, parental criticism, intimidation, and insults) on children's PA. A qualitative study with parents and legal guardians of 3- to 5-year-old children (described earlier) revealed that parents perceived psychological control as a negative parenting practice that discourages children from being physically active [65]. An observational study conducted in Houston, Texas, found that parental use of psychological control (manipulation of the child's behavior to satisfy parents' needs) was negatively associated with preschool children's PA levels [60].

Discussion

Summary of Findings

A growing body of research indicates that parenting styles and PA parenting practices influence children's PA levels and behaviors and SB [72-81]. This integrative review identified and synthesized existing research examining associations between parenting styles and practices and PA and SB in Latino children aged between 2 and 12 years. A total of 16 studies met the inclusion criteria of this integrative review, and this small number of studies indicates the need for additional research in this area.

Across the reviewed studies, one qualitative study conducted with Mexican American and Mexican immigrant parents explored the influence of parenting styles on children's PA, with results showing that maternal permissive parenting styles were viewed as facilitating children's increased SB (eg, screen time), and paternal authoritative parenting styles encouraged children's PA [66]. These findings concur with results of a study [23] conducted with white parents, which found that when compared with authoritative maternal parenting, permissive maternal parenting was associated with a higher risk of children exceeding the American Academy of Pediatrics' guideline recommending that children's TV viewing should be limited to 1 to 2 hours of quality programming per day [5]. In contrast, some studies suggest that a permissive parenting style facilitates children's PA [27] and is associated with higher levels of children's PA [24,27,32].

Researchers suggest that the differential influence of permissive parenting style on PA and SB are consistent with the idea that these two behaviors are separate and distinct [22-24]. Therefore, key predictors of SB and PA such as parenting styles may differ. Nevertheless, available evidence examining the influence of parenting style on children's objectively measured PA is conflicting, with some studies showing that parenting style does not predict children's PA [27,30] and others showing a positive association [23]. Given that only one qualitative study included in this review explored the influence of parenting styles on children's PA, additional qualitative and quantitative studies are needed in this area. As suggested in a recent review by Patrick et al [22], a better understanding of how parenting styles influence parenting practices related to PA and screen-viewing behaviors may generate important insights to the existing evidence base. In addition, most examined studies focused on PA and less on sedentary time, indicating a need for further studies in this area as well.

Studies included in this review provide good evidence for the influence of several PA parenting practices on Latino children's PA and SB. Provision of logistic or instrumental support, monitoring, use of reinforcement and reward, and limit setting were the most consistent PA parenting practices positively associated with encouraging, facilitating, or increasing Latino children's PA and decreasing SB (eg, screen time). It is important to note that all of the 6 intervention studies included in this review showed positive effects of the intervention on these PA parenting practices (ie, logistic or instrumental support, monitoring, use of reinforcement and reward, and limit setting).

On the other hand, use of rules and restrictions for safety concerns and use of psychological control were associated with discouraging, hindering, or decreasing Latino children's PA.

Studies included in this review provide consistent evidence for a positive association between the provision of logistic or instrumental support and children's PA [54-57,63]. Previous studies indicate that logistic or instrumental support can have an important influence on children's PA [32,82,83].

Consistent with prior research, 3 studies included in this review documented that parental monitoring of children's PA was positively associated with children's PA [52,53,56]. Similarly, previous research suggests that parental monitoring, especially maternal monitoring, of a child's screen time is associated with lower levels of screen time in children [84,85].

Although setting limits may reduce children's screen time, results from a growing literature show mixed evidence that media-related parenting practices are associated with youth screen viewing. It is possible that the lack of association may be partially due to the variety of measures used [23,25,69,84,86-91]. The two studies included in this review that examined the association between limit setting and children's PA found that allowing a higher limit for sedentary activities (eg, TV viewing and use of video game) was associated with higher screen time [54,65]. The findings of these studies concur with results of a study by Carlson et al [25], which documented that children whose parents report consistent limits about screen time have a lower prevalence of exceeding recommendations for sedentary time than children whose parents do not or are inconsistent in setting screen-time limits [25]. Similarly, in a recent systematic review of screen-time viewing, Hoyos et al [72] found that young children living with less parental screen rules and limit setting were more likely to have higher levels of screen viewing. Likewise, a recent multicenter, cluster RCT conducted in 5 countries (Belgium, Germany, Greece, Hungary, and Norway) with school-age children (10-12 years) found that the presence of rules limiting screen time was significantly associated with less time watching TV/DVD and use of computer/game console time [88]. In contrast, a recent cross-sectional study conducted in the United Kingdom with parents of 6- to 8-year-old children documented that limit setting is associated with greater screen viewing [89]. Given the mixed evidence from existing literature and the paucity of studies among Latino children, further research is needed to examine the associations between limit setting and PA and screen time among Latino children.

Evidence from the extant literature underscores the importance of parental engagement and involvement in promoting children's PA [6,8,15,17,22,24,29,30,32,33,74,82-84]. Previous studies suggest that parental engagement and involvement, such as playing sports or engaging in PA with children, are positively associated with children's PA [23,74,85,92]. Studies included in this review concur with these findings [58,59,63,65,66].

Parent's positive reinforcement of children's PA has been found to be associated with children's PA [17,29]. Two studies included in this review showed that use of positive reinforcement (as measured by a parent's praising of the child being physically active) was positively associated with children's PA [52,63].

However, parental use of screen time as a reward (eg, offering TV, video, or video games to a child as a reward for good behavior) was not associated with children's PA [52].

Parental use of verbal encouragement of PA was explored in one qualitative study [63] included in this review. Study findings were consistent with prior studies showing that parent-reported parental verbal encouragement of PA positively influences child-reported PA and discourages time spent watching TV or playing video games [88], and encourages children's PA behaviors [93,94].

Consistent with research conducted with white children [95] and African American adolescents [84,96], there was good evidence (2/2 studies) [61,62] that parental prompting for children to be physically active encouraged children's PA. One of these 3 studies [62], which assessed associations at 4 years of age and then again at the 6.5 years follow-up, found that the association of parental prompting for children to be active was particularly influential when children were younger, suggesting that, as children aged, they seemed to rely less on the interpersonal interaction with adults for cues to be active.

There was good evidence (4/4) that parental use of rules about and restrictions of PA because of safety concerns, traffic, or weather discouraged children's PA [59,60,64,67]. Prior research shows that parents report that their concerns about safety, including concerns related to neighborhood and community safety (eg, crime, traffic), inhibit their children's PA [29,96-100].

Of the studies included in this review, 2 [60,65] showed negative influence of parental use of psychological control (parental criticism, intimidation, and insults or manipulation of child behavior to satisfy parents' needs) on children's PA. There is limited research examining the influence of psychological control on children's PA [100,101]. Additional research is needed to further explore the influence of psychological control on children's PA.

Limitations and Strengths

Our evaluation of the methodologies of studies included in this integrative review suggests some limitations and, therefore, caution in the interpretation of study findings. More than half (69%; 11/16) of the studies included only or predominantly Mexican American and Mexican immigrant parents and children [52-54,59-63,65,66]. Additional longitudinal and intervention studies including multiethnic Latino parents and children are necessary to understand the influence of both parenting styles and PA parenting practices on Latino children's PA. There was limited or no assessment of the different parenting styles and parenting practices on different parent-child dyad genders (ie, father-son, father-daughter, mother-son, and mother-daughter) in the studies reviewed. Future studies should explore any potential differences and implications for design of interventions.

Furthermore, the majority of included quantitative studies (9/11) used an array of self-reported questionnaires alone or in combination with objective assessments (accelerometers) (2/11) or direct observation (BEACHES) of children's PA levels (2/11), and self-reported PA data are potentially problematic because

of possible parents' misreporting of children's PA levels. Variability in the assessment of PA parenting practices (eg, PEAS, PPAPP, GEMS, BEACHES) makes it difficult to compare findings across studies, and caution must be taken in drawing conclusive assertions. Another possible limitation of this review is limited generalizability due the fact that the included studies were conducted in only 5 states (California, Massachusetts, North Carolina, Texas, and Wisconsin).

None of the qualitative studies included in this review considered the relationship between the researcher and participants or other possible power imbalances, which might have influenced the studies' findings [63-67]. Therefore, future qualitative studies should reflect on how these interactions may impact the study's results. Finally, publication bias also should be considered, as should the fact that this review is limited to full-text studies published in English and may have excluded studies published in other formats and/or languages.

Strengths of this review include the use of systematic criteria (ie, PRISMA) to identify and select studies and quality assessment tools for the critical appraisals of studies.

Future Directions

Given the increasing evidence of the importance of parenting styles as a mediator of children's PA, the paucity of research examining the influence of parenting styles of Latino parents on the PA of Latino children is noteworthy, and further research on this topic is warranted. Moreover, studies including multiethnic Latino parents and children are needed, especially because the majority of studies identified and included in this review were conducted with predominantly Mexican American or Mexican immigrant parents and children [52-54,59-63,65,66]. Given that Latinos represent heterogeneous ethnic groups with a great amount of diversity among Latino individuals, it is important to understand the impact that this diversity has on Latino parenting styles and practices. Additional studies with multiethnic Latino parents and children would help elucidate differentials in parenting styles and PA parenting practices that

may exist among various Latino groups. Finally, future research may benefit from further examining differentials of parenting styles and PA parenting practices of multiethnic Latino parents and Latino children's PA according to the gender of parents and children.

Conclusions

In summary, this review identified very limited research examining the relationship between parenting styles and PA and SB in Latino children. Given evidence suggesting that parenting styles may facilitate or hinder positive PA parenting practices, future research examining factors associated with PA in Latino children may benefit from greater exploration of the influence of parenting styles on Latino children's PA and SB.

Studies synthesized in this review provide good evidence for the influence of several PA parenting practices, including offering logistic or instrumental support, monitoring, limit setting, and providing reinforcement and rewards, in encouraging, facilitating, or increasing Latino children's PA, whereas the influences of parenting practices such as rules, restriction, and psychological control discourage, hinder, or decrease children's PA. Nevertheless, given that the majority of studies reviewed were conducted with predominantly Mexican American or Mexican immigrant parents and children [52-54,59-63,65,66], further understanding of parenting styles and PA parenting practices among other ethnic Latino groups is likely to provide important insights into the development of interventions tailored to the needs of multiethnic Latino groups and aimed at promoting the PA of Latino children.

Given the increased availability and use of the Internet by Latino parents of various socioeconomic and educational levels [102,103], online interventions (eHealth) [104-106] may offer a viable way to provide health information and professional support to Latino parents regarding PA parenting practices that encourage, facilitate, and increase Latino children's PA and decrease their SB.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

PRISMA Flow Diagram.

[[JPG File, 108KB - publichealth_v4i1e14_app1.jpg](#)]

Multimedia Appendix 2

Quality assessment: quantitative studies.

[[PDF File \(Adobe PDF File\), 17KB - publichealth_v4i1e14_app2.pdf](#)]

Multimedia Appendix 3

Quality assessment: qualitative studies.

[PDF File (Adobe PDF File), 15KB - [publichealth_v4i1e14_app3.pdf](#)]

Multimedia Appendix 4

Description of studies included in integrative review.

[PDF File (Adobe PDF File), 17KB - [publichealth_v4i1e14_app4.pdf](#)]

Multimedia Appendix 5

Characteristics of studies included in integrative review.

[PDF File (Adobe PDF File), 18KB - [publichealth_v4i1e14_app5.pdf](#)]

Multimedia Appendix 6

Synthesis of results of studies included in integrative review.

[PDF File (Adobe PDF File), 24KB - [publichealth_v4i1e14_app6.pdf](#)]

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Abbreviations

BEACHES: Behaviors of Eating and Activity for Child Health: Evaluation System

BMI: body mass index

GEMS: Girls Health Enrichment Multi-Site Studies

PA: physical activity

PEAS: Parenting Strategies for Eating and Activity Scale

PPAPP: Preschooler Physical Activity Parenting Practices

PRISMA: Preferred Reporting Items for Systematic Reviews and Meta-Analysis

RCT: randomized controlled trial

SB: sedentary behavior

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Original Paper

Detecting Novel and Emerging Drug Terms Using Natural Language Processing: A Social Media Corpus Study

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Abstract

Background: With the rapid development of new psychoactive substances (NPS) and changes in the use of more traditional drugs, it is increasingly difficult for researchers and public health practitioners to keep up with emerging drugs and drug terms. Substance use surveys and diagnostic tools need to be able to ask about substances using the terms that drug users themselves are likely to be using. Analyses of social media may offer new ways for researchers to uncover and track changes in drug terms in near real time. This study describes the initial results from an innovative collaboration between substance use epidemiologists and linguistic scientists employing techniques from the field of natural language processing to examine drug-related terms in a sample of tweets from the United States.

Objective: The objective of this study was to assess the feasibility of using distributed word-vector embeddings trained on social media data to uncover previously unknown (to researchers) drug terms.

Methods: In this pilot study, we trained a continuous bag of words (CBOW) model of distributed word-vector embeddings on a Twitter dataset collected during July 2016 (roughly 884.2 million tokens). We queried the trained word embeddings for terms with high cosine similarity (a proxy for semantic relatedness) to well-known slang terms for marijuana to produce a list of candidate terms likely to function as slang terms for this substance. This candidate list was then compared with an expert-generated list of marijuana terms to assess the accuracy and efficacy of using word-vector embeddings to search for novel drug terminology.

Results: The method described here produced a list of 200 candidate terms for the target substance (marijuana). Of these 200 candidates, 115 were determined to in fact relate to marijuana (65 terms for the substance itself, 50 terms related to paraphernalia). This included 30 terms which were used to refer to the target substance in the corpus yet did not appear on the expert-generated list and were therefore considered to be successful cases of uncovering novel drug terminology. Several of these novel terms appear to have been introduced as recently as 1 or 2 months before the corpus time slice used to train the word embeddings.

Conclusions: Though the precision of the method described here is low enough as to still necessitate human review of any candidate term lists generated in such a manner, the fact that this process was able to detect 30 novel terms for the target substance based only on one month's worth of Twitter data is highly promising. We see this pilot study as an important proof of concept and a first step toward producing a fully automated drug term discovery system capable of tracking emerging NPS terms in real time.

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KEYWORDS

natural language processing; street drugs; social media; vocabulary

Introduction

With the rapid development of new psychoactive substances (NPS) and changes in the use of more traditional drugs, it is increasingly difficult for researchers and public health practitioners to keep up with emerging trends in how these substances are referred to by their users. Further complicating the matter, linguistic innovation is often magnified with the discussion of taboo substances and behaviors, which may cause drug-related vocabulary to emerge and recede more quickly than vocabulary in other domains [1]. Developing a method for detecting and tracking emerging drug terms in near real time is essential for researchers and professionals working in drug-related fields, yet most Web-based compendia of drug terms put out by official agencies such as the Centers for Disease Control and Prevention (CDC) and the Drug Enforcement Agency (DEA) are infrequently updated and rarely contain the most recent terms.

Social media use offers an opportunity to address this problem, since these communications can be one of the earliest records of innovative use of vocabulary [2]. Furthermore, streaming social media corpora can be continuously updated as new posts are uploaded, ensuring that such corpora always reflect language use on the platform in near real time.

This article details a pilot study designed to explore the feasibility of applying methods for synonym detection drawn from the field of natural language processing to a streaming social media corpus comprising posts (tweets) to the microblogging platform Twitter in order to uncover novel terms referring to marijuana. Though marijuana was used as the target substance here, the goal of this pilot study was to develop a method for drug-term discovery that may be extended to other illicit substances and other social media platforms. It is our hope that this line of research will eventually lead to a system that is easily deployable, capable of providing public health practitioners with lists of slang and street terms currently in use for most illicit drugs of interest, and updated continuously in near real time.

Social Media and Health

Though it has not to our knowledge been used for the purpose of uncovering new drug terms, the use of social media corpora in the discovery and analysis of drug-related health information more generally is not a novel concept. For example, Paul and Drezde [3] showed that it is possible to use a social media corpus to automatically learn relationships between drugs, their routes of administration, and other aspects of use. Recent years have also seen a rush of new work in the area of pharmacovigilance, where social media has been used to monitor adverse drug reactions (see [4] for a recent overview of research on the utility of social media monitoring for pharmacovigilance). Sinnenberg et al [5] provide an overview of the use of Twitter specifically for health care research, including drug-related applications. However, the majority of previous studies employing social media to investigate drug-related health trends (eg, [6-9]) have typically either used relatively small-scale datasets or have specifically precluded attention to unknown terms for the drug and therefore ruled out new term discovery [10].

Synonym Detection

The task of uncovering novel terms that refer to known drug substances may in many respects be boiled down to an exercise in emergent synonym detection. In other words, in order to find new terms that refer to known drugs, an obvious way to go about doing so is to search for new terms that are synonymous or nearly synonymous with *known* terms for said drugs.

Synonym detection has been a richly explored area in information retrieval, and over the last decade, it has become a subject of increasing interest in various fields of health science and medicine. Most modern approaches employ some species of vector space model (VSM; sometimes referred to as a vector space model), in which words within a corpus are represented as continuous vectors (also called word embeddings) in high-dimensional vector space. These word vectors are constructed with respect to the linguistic contexts in which they occur within a given corpus, meaning that words appearing in similar contexts (ie, with similar surrounding words) will have similar vector representations. This feature of VSMs allows them to take advantage of the distributional hypothesis of semantics—the idea that words occurring in similar linguistic contexts tend to have similar meanings, and conversely that words with similar meanings tend to occur in similar contexts [11,12]. Insofar as the vector representation of a word accurately captures the probabilistic linguistic contexts in which it is likely to appear, the spatial similarity (measured as cosine similarity between vector angles within the n -dimensional vector space) between any 2 word vectors within the model can be taken as a proxy measure for the degree of semantic similarity between the 2 target words.

VSMs have been used within health science and medical research for a number of tasks related to synonym detection. Kuffner et al [13], for example, describe a vector space approach termed ConceptMaker to detect associational relations between gene and protein names in the NCBI PubMed corpus. Similarly, Henriksson et al [14] use a combination of vector space methods known as random indexing (RI) [15] and random permutation (RP) [16] to uncover and map the relation between different medical terms that are used synonymously across different clinical contexts. Henriksson et al [17] use a similar ensemble of RI and RP to uncover synonymic relations between various idiosyncratic abbreviations and their expansions within a medical context.


Despite the interest in semantic-relatedness detection and the increasing use of VSMs to achieve this goal in areas related to public health, we are unaware of any attempts so far to apply this type of approach to the problem of emergent drug terms. It is the hope of the researchers that by applying such an approach to a continually updating social media corpus, it will be possible to create a system capable of uncovering and tracking novel and emerging drug terms in near real time.

Methods

Broadly, the method employed here can be summarized into four steps: (1) a VSM was trained over a large Twitter corpus to map all the terms within the corpus with respect to semantic

similarity, (2) in consultation with drug-research experts, 2 well-known and prevalent street terms were selected to serve as the target query terms for the target substance—that is, the prototypical street terms for the target substance to which other such street terms within the corpus should hold a high degree of semantic similarity, (3) the word vectors within the trained VSM were sorted according to semantic similarity to the target query terms and filtered to exclude any terms below an optimized threshold for semantic similarity, creating a candidate list of those terms within the corpus which could be considered as most likely to refer to the target substance, and (4) this candidate term list was then evaluated by hand to determine which of the candidate terms in fact referred to the target substance and which terms were false positives. These steps are presented in more detail in the following subsections.

Data Collection and Preprocessing

This study was conducted using a corpus of Twitter messages collected by the National Drug Early Warning System (NDEWS) Coordinating Center at the Center for Substance Abuse Research (CESAR). The corpus comprises tweets continuously collected from a *spritzer* level (ie, a random 1% sampling of all tweets) connection to Twitter's streaming application programming interface (API) from October 1, 2015 until the present. The incoming tweet stream was filtered to exclude tweets written in languages other than English and those originating from outside the continental United States of America. Due to these requirements, tweets with no associated geographic or language metadata were excluded. For this pilot study, we used a subset of this larger Twitter corpus, comprising tweets from July 1 to July 31, 2016. Before analysis, the subset was preprocessed to remove Twitter handles (eg, @MyCoolName) and URL links. Hashtags (eg, #NLProc), and emoticons or emojis (eg, :) or ) were retained. All tweets were then tokenized using the tweet tokenizer from the Natural Language Tool Kit (NLTK) Python package [18]. The resulting dataset contained 82.6 million tweets and 884.2 million tokens.

It is worth noting here that focusing only on geotagged tweets when analyzing Twitter data inherently introduces a sampling bias, in that doing so samples only from those users who choose to turn on geolocation services—a subpopulation that may not be representative of Twitter users as a whole [19]. However, because we are specifically interested in drug terms as used in the United States, ensuring that all tweets come from the target population was deemed more important for this study than avoiding such a sampling bias.

Selection of Target Substances and Terms

For this pilot study, marijuana was chosen as the substance of primary focus because of its relatively high level of use within the American population [20] and comparatively low social stigmatization [21,22]. Frequent, casual discussion of this substance over Twitter was hypothesized to accord us enough linguistic data to assess the efficacy of the current method under circumstances of high volume and high noise. In consultation with our drug-research expert collaborators, 2 slang terms were selected for subsequent model querying based on the frequency in the corpus and geographic ubiquity of use: *weed* and *ganja*.

These terms served as the prototypical street terms for marijuana to which other such street terms in the corpus were hypothesized to have a high degree of semantic similarity during candidate term retrieval.

Modeling

Before training the VSM, the corpus was analyzed in order to identify 2-word sequences (bigrams) that had an unusually high probability of appearing together as a unit and were therefore likely better treated as one multiword token rather than 2 separate tokens (eg, sequences of *los angeles* were treated as one token *los_angeles* rather than 2 separate tokens *los* and *angeles*). Multiword token identification was accomplished using the method described by Mikolov et al [23], implemented in the open-source software package *gensim* [24]. The resulting corpus was then used to train a continuous bag of words (CBOW) VSM of the type introduced by Mikolov et al [25], again implemented in *gensim*. After hyperparameter tuning, our final model was trained with a context window of 5 and a dimensionality of 200, excluding from the vocabulary tree any terms that did not appear at least 10 times within the training corpus. The resulting VSM included 662,742 unique token-type word vectors.

Candidate Term Retrieval

Recall that the spatial similarity between 2 word vectors (measured in cosine similarity—that is, the cosine of the angle between 2 word vectors) can be taken as a proxy for semantic similarity in trained VSMs. Therefore, to extract from the trained model a list of terms that were most likely to refer to the target substance, we first calculated the cosine similarity between each of the 662,742 word vectors within the trained model and our target query terms, with the assumption that those token-types with the highest cosine similarity to our query terms would in turn have the highest degree of semantic similarity and thus have the highest likelihood of referring to the target substance. Having done so, we were then able to sort the corpus in descending order of semantic similarity to our 2 target query terms. To pare down the list of terms and reduce the number of false positives, it was necessary to select a cosine similarity threshold below which terms were considered too dissimilar from our target query terms to be likely to refer to our target substance. An optimum threshold would result in a list that includes as few false positives as possible, yet includes most or all terms used in the corpus to refer to the target substance. In other words, an optimal threshold for this particular task is one which results in a relatively high recall rate (ie, percentage of all possible terms for the target-substance that were included in the resulting candidate list) and an acceptable level of precision (ie, percentage of terms on the resulting candidate list which in fact refer to the target substance) such that a human reviewer with expert knowledge could vet all the terms on the list in a matter of hours. An obvious problem in calculating recall and precision in this context, however, is that the true status of any of the terms in the corpus with respect to whether or not they refer to the target substance is unknown. Therefore, we reached out to community researchers at three of the 12 regional drug research sites of the NDEWS. These three sites (Denver, Chicago, and Philadelphia) exist in communities

experiencing significant substance abuse or misuse problems [26]. The field experts were asked to provide a list of terms for marijuana that they considered to be currently in use in their own communities. Collating the lists obtained from each of these three groups of field experts resulted in a list of 32 unique terms, including our 2 target terms. These 32 terms and common spelling variants thereof were then considered as the only terms that referred to the target substance for the purpose of cosine similarity threshold optimization.

With the expert generated list in hand, we calculated recall and precision for each possible cosine similarity threshold from 0.01 to 1.00 in steps of 0.01, optimizing for an F-measure with a beta value of 2 (F_2 rather than F_1 was chosen as our optimization function because we place more importance on recall than precision for this task). To determine which query term or combination of query terms resulted in the highest recall, precision, and F_2 score, optimization runs were performed under four conditions: once for each of the 2 target query terms using only the cosine similarity results for that query term, once using

the set union of cosine similarity results for both query terms (ie, all terms in the corpus with a level of cosine similarity above the given threshold for *either* term), and once using the cosine similarity results calculated against the simple mean of the 2 target query vectors. Recall, precision, and F_2 values for the cosine similarity threshold at which maximum F_2 was achieved for each of the four runs is presented in Table 1. F_2 , recall, and precision for all thresholds during the optimization run with the highest resulting F_2 score are presented in Figure 1.

As the candidate term list created using only *ganja* as the prototypical query vector with a cosine similarity threshold of 0.46 achieved the highest F_2 scores of all four runs, this was the candidate term list used moving forward. Considering all terms with a cosine similarity of 0.46 or greater to our target query term *ganja* resulted in 200 terms in total (This number is somewhat inflated because spelling variants are treated as unique items. For example, *weed* and *weeed* are counted as distinct terms in this list.).

Table 1. Cosine similarity threshold optimization.

Term or unit	Cosine similarity threshold	F_2	Recall	Precision
ganja	0.46	0.351	0.547	0.144
weed	0.49	0.280	0.453	0.111
union	0.53	0.295	0.396	0.146
simple mean	0.50	0.306	0.490	0.122

Figure 1. Recall, precision and F_2 scores for the ganja optimization run.

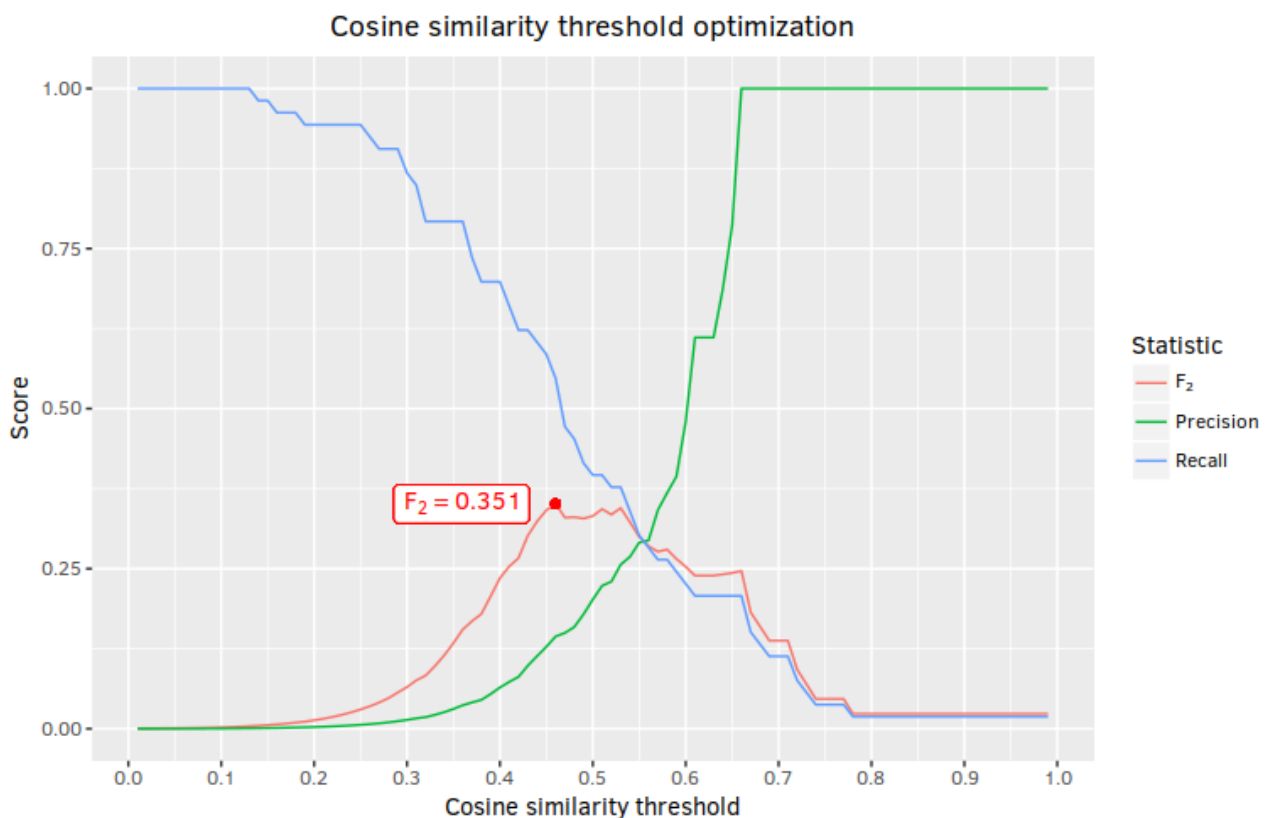


Table 2. Candidate term categories.

Category	Description	Examples
Marijuana	Terms for the substance itself, including specific strain names	kush dro sour diesel
Paraphernalia or process	Marijuana related, but not terms for the substance itself	doobie blunts bong rips
Other-drug	Drug related but not marijuana-related	opium shrooms mdma
Nondrug	Unrelated to drugs specifically	rasta catnip herbal

Candidate Term Categorization

Though only terms in the expert-generated list were treated as marijuana-related for the purpose of cosine similarity threshold and query term optimization, the major goal of this study was to determine whether the current method captures terms for the target substance that are unknown to such experts. To do so, all terms on the resulting candidate term list were then classified by 2 researchers into the following four categories: marijuana, process or paraphernalia, other-drug, and nondrug. A description of these categories along with examples is given in [Table 2](#).

First-pass categorization was performed using lists of possible slang terms for marijuana and associated processes and paraphernalia published by the DEA [27] and the Center for Substance Abuse Research (CESAR) [28]. All candidate terms included on these lists were categorized as either (i) *marijuana* or (ii) *process* or *paraphernalia*. Second-pass categorization consisted of searching websites such as Urban Dictionary [29] and Marijuana Dictionary [30] as well as marijuana-focused online drug forums for definitions and/or exemplar usage of the remaining terms. Candidate terms for which the researchers could determine that the term referred to marijuana were classified as *marijuana*. Terms determined to refer to ingesting marijuana or to tools used in ingesting marijuana were categorized as *process* or *paraphernalia*. Terms that we were able to confirm as relating to the drug realm but to a substance other than marijuana were categorized as *other-drug*. Terms for which we were unable to find any sort of drug-related meaning or usage or terms for which the exact meaning was unclear were categorized as *nondrug*. Both researchers categorized the candidate terms independently, agreeing in 78.0% (156/200) of cases (Cohen kappa=.703). A third researcher evaluated cases in which the primary categorizers disagreed. These cases were categorized according to the judgment of the third categorizer (there were no cases in which the third categorizer did not agree with either of the primary categorizers).

Evaluation Metrics

The overarching goal of this study was to develop a method capable of mining social media to produce a list of candidate terms that are highly likely to refer to a target substance (in the

case of this pilot study, marijuana). Success in this task is characterized by producing a candidate term list with the following three characteristics:

1. Includes all terms for the target substance known to experts in the field
2. Includes terms for the target substance *not* known to experts in the field
3. Includes a minimal number of false positives

To determine success with respect to the first criterion, we determine the recall for our candidate term list with respect to marijuana terms on the term list obtained from the field experts at NDEWS. To determine success with respect to the second criterion, we removed those terms which appeared on the expert-derived list from the set of terms which during categorization were determined to be terms for the substance itself. Those terms which were determined to be used to refer to the substance itself yet which were not included on the expert-generated lists were deemed to be novel for our purposes and possibly unknown to researchers. To determine success with respect to the third criterion, we evaluated the precision of the resulting candidate list treating terms categorized as *marijuana* as true positives and all other terms as false positives.

Results

[Table 3](#) summarizes the category frequency for terms in the candidate term list as determined by the categorization procedure described above.

Of the 200 terms returned as potential terms for marijuana, 86.0% (172/200) were drug-related. Of the drug-related terms, 115 (57.5% of all terms) were marijuana-related and 65 (32.5% of all terms) referred to the substance itself. A list of the candidate terms classified as *marijuana* is provided in [Table 4](#). The third column provides the cosine similarity within our VSM between the listed term and the query term *ganja*.

Some terms in [Table 4](#) are well known (eg, *reefer* and *weed*), and some are orthographic variants of one another (eg, *weed* and *weeed*). Several, such as *gorilla glue* or *hawaiian punch*, refer to specific strains of marijuana. Researching these terms on the various drug forum websites [29,30] suggests that some

may be relatively new or are gaining popularity within marijuana-focused communities. The terms *moonrock* and *moonrocks*, for example, refer to a particular preparation of marijuana, apparently introduced sometime in 2012. The term *jazz cabbage* appears to have entered into marijuana parlance as recently as early to mid-2016 [29]. Some even appear to be specific to certain communities of practice, such as *pacc*: an orthographic variant of *pack*, referring to *loud pack* or good-quality marijuana. *Pacc* avoids the *ck* letter combination that is taboo among members of the Crip gang (as it can represent *Crip killer*) [31]. Interestingly, one of the candidate terms used to refer to marijuana is not traditionally thought of as a *term* at all, but rather a sequence of 2 *leaffluttering in wind* emoji characters. The use of leaf-based emojis is mentioned as an obfuscatory tactic to covertly reference marijuana in a number of online drug-focused blogs, such as [32], but so far as we are aware is not acknowledged in any of the lists of marijuana-signifying terms put out by the CDC or other official organizations.

Evaluation Outcomes

As mentioned, we consider 3 criteria in evaluating the candidate term list produced via the above method: 1) recall with respect to terms on the expert-generated list, 2) number of terms determined to refer to marijuana but not appearing on any of the expert-generated lists, and 3) precision with respect to terms relating to the substance of marijuana.

Comparison of Candidate List to Expert-Generated Lists

Of the 35 terms for marijuana provided by NDEWS experts, 91%, or all but 3 terms—*sour d*, *blue cheese*, and *love boat*—occurred within the corpus. These 3 terms were excluded from further analysis.

The remaining 32 terms from the expert-provided list are given in Table 5. As with Table 4, for each row, column 3 provides the cosine similarities between the listed term and the target

query term *ganja*. For each term we wanted to know not only whether it was included at all within the corpus but also whether it was used in the expected, drug-related sense—and if so, how often. To capture this, column 6 of Table 5 presents a measure of drug-relevancy for each term—that is, the percentage of instances in which that term was used to refer to the target substance.

Drug-relevancy was calculated as follows. For each term in the list of 32, a random sample of 200 tweets containing that term was extracted from the corpus (for cases in which the term appeared fewer than 200 times in the corpus, all instances were extracted.). Each tweet was then coded independently by 2 researchers to determine whether the term referred to the target substance or not. These annotators were highly consistent with one another in terms of the percentage of tweets determined to refer to the target substance for each term ($r=.978$). The average between the 2 annotators for the percentage of tweets in which the term was judged to be used to refer to the target substance was then taken as a proxy for the overall *drug-relevancy* of that term within the corpus. If the term was not used to refer to the target substance in any of the randomly sampled tweets that contained it, it received a drug-relevancy of 0%. If the term was used to refer to the target substance in all of the sampled tweets, it received a drug relevancy of 100%.


The terms in Table 5 are sorted by descending drug-relevancy. Those items marked with a superscript a represent terms provided by NDEWS experts which were included in the model-derived list of 200 candidate terms. Those terms marked with a superscript b represent expert-provided terms that were not included in the candidate term list returned by our model queries. Columns 4 and 5 reflect the number of tweets judged to refer to the target substance out of the total number of tweets sampled for each annotator. Column 6 represents the average of drug-relevancy ratings between the 2 annotators.

Table 3. Category frequency of candidate terms.

Category	Number	Percentage
Marijuana	65	32.5
Process or paraphernalia	50	25.0
Other-drug	57	28.5
Nondrug	28	14.0
Total	200	100

Table 4. Marijuana terms from candidate list.

Rank	Term	Cosine similarity to query term ganja
1	kush	0.772
2	reefer	0.738
3	dro	0.722
4	reefa	0.717
5	weed	0.712
6	sativa	0.682
7	sour diesel	0.676
8	purp	0.670
9	devils lettuce	0.670
10	og kush	0.667
11	doja	0.654
12	kief	0.649
13	gorilla glue	0.640
14	thrax	0.633
15	piff	0.632
16	weeed	0.605
17	moonrocks	0.603
18	pacc	0.603
19	tookah	0.601
20	devil's lettuce	0.600
21	moonrock	0.598
22	tooka	0.587
23	edibles	0.584
24	mids	0.581
25	bubba kush	0.563
26	gasss	0.562
27	gass	0.562
28	marijuana	0.556
29	ganj	0.550
30	dodi	0.546
31	indica	0.544
32	jazz cabbage	0.543
33	faygo	0.540
34	dank	0.539
35	dabs	0.538
36	oregano	0.533
37	wata	0.527
38	bammer	0.527
39	tincture	0.517
40	marijuanas	0.514
41	k2	0.513
42	thc	0.497

Rank	Term	Cosine similarity to query term ganja
43	gas	0.495
44	rosin	0.493
45	smarties	0.492
46	pot	0.490
47		0.489
48	gassss	0.488
49	danky	0.487
50	hemp	0.483
51	weeeeed	0.480
52	herb	0.477
53	kool aid	0.473
54	hawaiian punch	0.472
55	cannabis	0.469
56	reggie	0.469
57	jolly ranchers	0.468
58	kushy	0.465
59	grape juice	0.464
60	cheech	0.461
61	goop	0.461
62	khalifa kush	0.461
63	tropical fusion	0.461
64	broccoli	0.460
65	medicinal	0.460

In total, 15 out of the 32 terms present in the expert-derived term lists appeared on our candidate term list. This translates to a recall rate of 46.9%. Although at first blush, this appears to be relatively low, this is quite similar to recall rates that others have obtained in related tasks. Henriksson et al [17], for example, report a recall rate of between 33% and 47% using a similar method in performing synonym and abbreviation detection in medical texts. Similarly, Henriksson et al [14] report a recall rate of 44% in matching synonymous medical terms across different genres of clinical text.

Sorting Table 5 by descending drug relevancy appears to provide some insight as to why our method resulted in the inclusion of some of the expert terms on our candidate term list but not others. Every term on the expert-derived list with a drug relevancy of 21.8% or higher was included in our candidate list (items marked with superscript a in Table 5), whereas every expert-derived term with a drug relevancy of less than 21.8% was not (items marked with superscript b in Table 5). This suggests that while recall over the whole expert-derived list was somewhat low, our method actually performed quite well above a certain relevancy threshold—namely when the term was used to refer to the target substance in at least roughly one out of every five cases within the corpus. That is to say, though recall was 46.9% overall, examining the drug relevancy of each term

reveals that recall for terms with at least 21.8% relevancy was actually 100%, whereas recall for terms with below this relevancy threshold was 0%.

Discovery of Novel Terms

In addition to uncovering all marijuana-related terms on the expert-generated list with a drug relevancy of at least 21.8%, our model also returned a number of marijuana-related terms that were not included on the lists provided by experts. In all, 65 of the 200 terms on the candidate term list were determined to refer to the target substance itself. Of these, 29 could be considered known terms for our purposes—that is, either technical terms of which we can assume experts to be aware (eg, *the* and *cannabis*) but which were not included on the expert-generated list (as experts were explicitly instructed to include slang and street terms, not technical terms), or terms specifically included on the expert-generated lists (eg, *kush*) and spelling variants thereof (eg, *kushy*). Excluding spelling variants, the remaining 36 terms accounted for 23 unique terms for the general substance marijuana (eg, *thrax* and *piff*) and 7 unique terms for specific strains of marijuana (eg, *gorilla glue* and *hawaiian punch*). These 30 terms, which we consider for our purposes to be novel (ie, not included on the expert-generated list), are provided below in Table 6.


Table 5. Expert-generated marijuana terms.

Rank	Term	Cosine similarity	Drug relevancy		
			Annotator 1	Annotator 2	Average relevancy, %
1	edibles ^a	0.58	180/200	185/200	91.3
2	weed ^a	0.71	186/200	177/200	90.8
3	ganja ^a	1.00	190/200	169/200	89.8
4	kush ^a	0.77	192/200	165/200	89.3
5	sativa ^a	0.68	176/200	177/200	88.3
6	sour diesel ^a	0.68	91/112	98/112	84.4
7	indica ^a	0.54	132/200	170/200	75.5
8	devil's lettuce ^a	0.67	145/200	150/200	73.8
9	dro ^a	0.72	136/200	134/200	67.5
10	dabs ^a	0.54	123/200	142/200	66.3
11	purp ^a	0.67	75/200	59/200	33.5
12	pot ^a	0.49	64/200	69/200	33.3
13	dank ^a	0.54	56/200	43/200	24.8
14	herb ^a	0.48	37/200	54/200	22.8
15	reggie ^a	0.47	41/200	46/200	21.8
16	wax ^b	0.45	42/200	43/200	21.3
17	nug ^b	0.36	16/200	55/200	17.8
18	mary jane ^b	0.31	24/200	36/200	15.0
19	pineapple express ^b	0.38	29/200	27/200	14.0
20	chronic ^b	0.26	35/200	18/200	13.3
21	shatter ^b	0.16	18/200	32/200	12.5
22	bud ^b	0.36	20/200	21/200	10.3
23	skunk ^b	0.31	24/200	14/200	9.5
24	haze ^b	0.36	13/200	17/200	7.5
25	exotics ^b	0.19	9/143	12/143	7.3
26	hydro ^b	0.32	15/200	12/200	6.8
27	shard ^b	0.14	5/138	4/138	3.3
28	flower ^b	0.29	1/200	9/200	2.5
29	fire ^b	0.30	0/200	10/200	2.5
30	mud ^b	0.31	1/200	4/200	1.3
31	flame ^b	0.40	0/200	5/200	1.3
32	green ^b	0.25	1/200	3/200	1.0

^aTerms provided by author-affiliated experts included in the model-derived list of 200 candidate terms.

^bExpert-provided terms that were not included in the candidate term list returned by our model queries.

Table 6. Marijuana terms on candidate list but not on expert lists.

Number	Term	Note
1	bammer	
2	broccoli	
3	cheech	
4	dodi	
5	doja	
6	gas or gass or gasss or gassss	
7	goop	
8	jazz cabbage	
9	kief	
10	mids	
11	oregano	
12	pacc	
13	piff	
14	reefer or reefa	
15	thrax	
16	tookah or tooka	
17	moonrock or moonrocks	particular preparation
18	rosin	particular preparation
19	tincture	particular preparation
20	wata	particular preparation
21		<i>leaf in wind</i> emoji sequence
22	k2	synthetic marijuana
23	faygo	strain
24	gorilla_glue	strain
25	grape_juice	strain
26	hawaiian_punch	strain
27	jolly_ranchers	strain
28	kool_aid	strain
29	smarties	strain
30	tropical_fusion	strain

Some of those terms included in [Table 6](#) such as *reefer* are well known in general and surely known to experts, despite the fact that they were left off of the expert-generated lists used here. However, several of the general terms listed in [Table 5](#) as well as strain names appear to be relatively new and thus perhaps truly unknown to many experts in the field. Regardless, the large number of terms uncovered by the current method which were not part of the expert-generated lists suggests that this may be a fruitful method for detecting drug terms of which drug-research experts may not yet be aware.

Precision of the Current Method

In total, 65 of the 200 terms included on the candidate term list were determined to refer to the substance marijuana, resulting in a precision of 32.5%. This means that as it currently stands,

a human is still needed to review candidate lists produced by the method evaluated here before distributing any such lists to public health practitioners—a less than desirable outcome. However, at this stage no attempts have yet been made to post process the candidate list in an attempt to weed out the false positives. There are several relatively simple methods of doing so, which would raise the precision rate, such as eliminating from the candidate list all terms that are not generally used as nouns (thereby eliminating from the list false positives such as *smoking*), using a stop-list to exclude common terms for known drugs that are not the target drug (thereby eliminating false positives such as *cocaine* and *mdma*) and so on. This is an area for future work and refinement.

Discussion

Principal Findings

On the whole, we consider this pilot study to be an important proof of concept. Though the candidate term list had a relatively low recall rate with respect to the expert-generated terms overall, annotating the expert terms for drug relevancy revealed that the terms that were not in the candidate list were wholly predictable. All expert-derived terms that were used in the corpus to refer to the target substance in 21.8% or more of instances were included on the candidate list, whereas all expert-derived terms with relevancy rates lower than 21.8% were not. This suggests that whereas future work should focus on methods of improving identification of low drug-relevancy terms, our method performs quite well in capturing terms with a drug relevancy over this (relatively low) threshold.

In addition, our method enabled us to identify 30 novel terms for the target substance which were not included on any expert-derived list, nearly equaling the number of terms provided on the expert list in the first place. On the basis of the recall rate with respect to the expert terms, it seems likely that our candidate list includes all or most terms used in the corpus to refer to the target substance in at least 21.8% of instances, though of course this is impossible to know for certain. These are encouraging results and suggest that the method described above and subsequent refinements thereof can be a viable framework for the detection of novel drug terms using social media.

Strengths and Limitations

An obvious shortcoming of this method is that it performs poorly in identifying terms that have drug-relevant meanings, but which are only used in drug-relevant senses in fewer than 22% of cases. This is a significant shortfall, as taboo terms are often reappropriations of existing words into new meanings [1]. It is unclear at the moment as to how to go about addressing this issue. One possible solution is to require a step that takes advantage of other grammatical and semantic information to disambiguate homographs either before or concurrent with training the VSM. One such word sense disambiguation method introduced in late 2015 is *sense2vec* [33]. The recently introduced Word to Gaussian Mixture (w2gm) model framework [34], which models each word as a mixture of Gaussians, may also prove useful for the purpose of sense disambiguation. Both of these approaches will be explored in future work.

A further limitation of this method is the relatively low precision rate (32.5%) of the model-generated candidate term list with respect to terms referring to the target substance. Whereas, at present, this precludes the possibility of eliminating human review of the candidate term list before distributing it to health professionals, there are various methods for postprocessing, which may substantially raise the precision rate, and that have yet to be explored. It is also possible that training word embeddings on a longer time slice of the corpus (ie, more data) would result in higher quality word embeddings, potentially raising rates of both precision and recall. These are areas of ongoing work.

Finally, although this pilot study has been reasonably successful and has demonstrated proof of concept, the extensibility of the method used here for detecting drug terms referring to substances other than marijuana is unclear. Trial runs targeting terms for methamphetamine and heroin suggest that these drugs are not discussed as frequently on Twitter and therefore appear potentially unsuitable for this sort of analysis. Initial inquiry into the application of this method to prescription drugs such as *oxycontin* and *party* drugs such as MDMA, however, appears encouraging.

Future Work

This pilot study made use of a 1-month portion of the Twitter corpus, thereby giving us a static snapshot of language use on Twitter at that time. An area of future research is to perform a trend study, looking at the way language use surrounding a particular target substance changes over time. Such a trend study could provide insight on the rate of rise and fall of drug vocabulary, as well as how terms spread geographically throughout the country.

Relatedly, taking advantage of the geotag metadata associated with the tweets collected could provide important dialectal data. The model employed for this study is a national model, however, the same method could be applied to tweets binned by geotag. In theory, this could reveal the use of different terms in different regions, though success may be mitigated by the necessarily smaller volume of data circumscribed in that way.

Extensions of this method to different areas of social media are also warranted. It may be that discovery of novel terms for more socially stigmatized substances may require the use of corpora from platforms that lend themselves more to user anonymity. Applications of the method developed above using corpora drawn from the discussion forum website Reddit, as well as from several online forums specifically geared toward drug use are currently being planned.

As our focus here has been on uncovering terms specifically referring to the target substance, we should note that we have not explored in detail why terms for certain nontarget drugs appear in the candidate list in addition to terms for the target substance. It may be that we are collecting terms related to drugs of a certain category or drugs that have similar effects and are therefore talked about similarly in the corpus. Thus, our candidate list may reflect a broader conceptual category on the part of users, such as *party drug*. If this is the case, attention in this area may lead to the development of a model representing users' knowledge of drug behaviors, which may in turn reveal novel practices such as new combinations of drugs.

These topics are currently being explored by the research team in collaboration with the NDEWS Coordinating Center.

Conclusions

Twitter represents a fruitful venue in which to identify and track emerging drug term trends, particularly with reference to terms for marijuana. Furthermore, the VSM model and approach documented here successfully identified new terms heretofore unknown to many experts in the field.

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Conflicts of Interest

None declared.

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Abbreviations

- API:** application programming interface
- CESAR:** Center for Substance Abuse Research
- CBOW:** continuous bag of words
- CDC:** Centers for Disease Control and Prevention
- DEA:** Drug Enforcement Agency
- NPS:** new psychoactive substances
- NLTK:** natural language tool kit
- RI:** random indexing
- RP:** random permutation
- VSM:** vector space model

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Original Paper

Why Clinicians Don't Report Adverse Drug Events: Qualitative Study

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Abstract

Background: Adverse drug events are unintended and harmful events related to medications. Adverse drug events are important for patient care, quality improvement, drug safety research, and postmarketing surveillance, but they are vastly underreported.

Objective: Our objectives were to identify barriers to adverse drug event documentation and factors contributing to underreporting.

Methods: This qualitative study was conducted in 1 ambulatory center, and the emergency departments and inpatient wards of 3 acute care hospitals in British Columbia between March 2014 and December 2016. We completed workplace observations and focus groups with general practitioners, hospitalists, emergency physicians, and hospital and community pharmacists. We analyzed field notes by coding and iteratively analyzing our data to identify emerging concepts, generate thematic and event summaries, and create workflow diagrams. Clinicians validated emerging concepts by applying them to cases from their clinical practice.

Results: We completed 238 hours of observations during which clinicians investigated 65 suspect adverse drug events. The observed events were often complex and diagnosed over time, requiring the input of multiple providers. Providers documented adverse drug events in charts to support continuity of care but never reported them to external agencies. Providers faced time constraints, and reporting would have required duplication of documentation.

Conclusions: Existing reporting systems are not suited to capture the complex nature of adverse drug events or adapted to workflow and are simply not used by frontline clinicians. Systems that are integrated into electronic medical records, make use of existing data to avoid duplication of documentation, and generate alerts to improve safety may address the shortcomings of existing systems and generate robust adverse drug event data as a by-product of safer care.

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KEYWORDS

adverse events; pharmacovigilance; drug safety; adverse drug reaction; adverse drug event; electronic health records; information and technology; medication reconciliation; qualitative research

Introduction

Adverse drug events are harmful and unintended consequences of medication use [1]. They include adverse drug reactions and harmful events related to drug dosing, noncompliance, treatment failures, ineffective drugs, drug interactions, the inappropriate use of drugs, and events due to errors [1]. Up to 70% are deemed preventable [2-4], yet they remain a leading cause of emergency department visits and hospitalizations [2,5,6], indicating a need to strengthen postmarket surveillance and drug safety research to develop more effective prevention strategies [7,8].

Patient safety and quality improvement initiatives have focused on reducing medication errors, which can be investigated using root cause analysis. However, most clinically significant adverse drug events are *not* error-related [2,9] and require the identification of patient-, medication-, provider-, and system-level factors that can be used to develop and implement prevention strategies. These activities are limited by lack of robust representative population-level data on adverse drug events [8].

Drug regulators and researchers rely on few data sources and methods to ascertain adverse drug event outcomes including administrative data, disease- or drug-specific registries, and paper-based or electronic records mined using triggers consisting of diagnostic codes, words, phrases, or laboratory values suggesting an adverse drug event occurred. These data sources and methods generate incomplete data lacking important details. For example, a validation study comparing trigger methods to prospectively collected data found that only 2% to 15% of events were identifiable using trigger methods compared to prospectively collected data and these lacked important details [10-12]. Spontaneous reporting systems put in place by drug regulators to stimulate reporting by clinicians suffer from reporting rates of less than 5%, even in jurisdictions where reporting is mandatory [8,13,14]. Underreporting contributes to delays until sufficient data accumulate for drug safety signals to be detected and undermines comparative risk assessments that would be useful when several treatment options exist [7]. Finally, underreporting in spontaneous reporting systems is more likely to affect older, commonly prescribed drugs, shifting the focus away from them even though older drugs cause a high burden of disease and should continue to be the focus of drug safety research [2,5,15,16]. Active surveillance systems in which trained staff follow up with patients to investigate previously identified safety signals are currently used to gather high-quality information on suspect events [14]. Such systems require dedicated staff and funding, have thus far focused on high-risk drugs and specialized patient populations, and may be less practical for widespread surveillance.

The uptake of electronic medical records provides opportunities for adverse drug event reporting to be integrated into point-of-care documentation. Repeat exposures to medications that previously caused harm are common in elderly populations and cause repeat adverse drug events [17,18]. If functional adverse drug event reporting software could be integrated into electronic medical records, adverse drug event reports could be used to generate patient-level alerts to prevent reexposures to

medications that previously caused harm [19-21]. If successful, this could stimulate reporting by improving patient safety while generating new data on adverse drug events.

Without an understanding of adverse drug event reporting barriers, newly designed reporting software risks being ineffective [22]. To date, studies investigating underreporting have focused on provider knowledge and attitudes and advocated for interventions targeting provider behaviors [23,24]. They have framed underreporting as a failure of individuals without investigating work practice or system-level issues and have seen limited success [8,13]. Therefore, our objectives were to understand how adverse drug events are diagnosed and documented in clinical practice and examine barriers to reporting within existing systems to inform the design of software for adverse drug event reporting.

Methods

Design and Setting

We conducted a qualitative study using ethnographic workplace observations and focus groups between March 2014 and December 2016 in 1 rural ambulatory care center and in the emergency departments and wards of 2 urban tertiary and 1 urban community hospital in British Columbia, Canada [25,26]. The University of British Columbia Research Ethics Board approved the study protocol. We obtained verbal consent from participating health care providers and implied consent from focus group participants.

Observational Fieldwork

Trained research assistants shadowed clinical pharmacists and physicians in emergency departments and on hospital wards during 4- to 8-hour data collection shifts. We scheduled shifts at varying times of the day and days of the week to account for variations in activity over time. We focused observations on pharmacists because identifying, documenting, and reporting adverse drug events are central to their role. We focused on emergency department settings because our prior work showed that patients with clinically significant events commonly present to emergency departments, where the diagnosis is often first suspected [2,15]. We recruited a convenience sample of participants through the contacts of clinicians on our team, email invitations, and word of mouth. We paid attention to the health care settings, presentations in which adverse drug events were suspected and managed, artifacts that mediated work (such as forms, computer applications, faxes, or phones), information flow, and interactions between clinicians. In this study, we use the terms “documentation” and “communication” of adverse drug events to refer to their recording for the purposes of providing clinical care, whereas we use the term “reporting” to refer to the activity of preparing and submitting a formal report to a pharmacosurveillance agency (eg, the MedEffect program in Canada or British Columbia’s Patient Safety Learning System).

Focus Groups

We recruited a purposive sample of focus group participants from study hospitals, primary care offices, and community pharmacies in the Lower Mainland of British Columbia through

team contacts, posters, and email invitations, targeting provider groups that encounter adverse drug events on a regular basis. We held 1-hour sessions at lunchtime rounds for participants practicing in-hospital and evening sessions for those practicing in other settings. We informed participants that our goal was to design a new electronic adverse drug event reporting system to reduce repeat events and improve reporting. The primary aim of the focus groups was to iteratively refine a set of data fields that would be relevant to clinical work and discuss the practicalities of diagnosing, documenting, and reporting adverse drug events. A practicing physician (CMH) and/or clinical pharmacist (KB) on our team led or co-led sessions while research assistants took field notes.

Data Analysis

Two members of the project team (SSS and DP) independently coded observational field notes and notes from focus groups using NVivo 11 qualitative data analysis software (QSR International). After an initial review, we met regularly to discuss emerging findings and developed a formal coding structure ([Multimedia Appendix 1](#)). After coding all data, we performed an in-depth analysis by creating thematic summaries, workflow diagrams, and event summaries. We followed a qualitative descriptive approach to produce a description of the perceptions and experiences of our provider informants [27,28]. We iteratively presented interim findings from earlier focus groups and observations to later groups and to care providers to validate and contextualize our findings and refine data collection. We generated a set of generalizations based on the data collected, reflected on the practical application of our findings, and concluded observations and focus groups when they no longer yielded novel insights. Clinicians subsequently

critiqued and validated our findings and provided examples of cases from their clinical work to illustrate the concepts we had identified.

Results

Data Collection

We completed 238 hours of observations with clinical pharmacists, including 197 hours in emergency departments and 14 hours on hospital wards, and 27 hours of observation with physicians in emergency departments. During our observations, providers investigated 65 cases of suspect adverse drug events. We held 7 focus groups with 85 care providers: 4 with hospital pharmacists, 1 with emergency department physicians, 1 with general practitioners, and 1 with hospitalists.

Clinically Significant Versus Reportable Events

We observed care providers diagnosing a wide range of events ([Textbox 1](#)). Many were not categorized as adverse drug reactions but were categorized as dosing problems, noncompliance, treatment failures, ineffective drugs, drug interactions, untreated indications, and drug use without an indication. None of the observed events was due to errors in drug ordering, transcribing, dispensing, or administration. Events could often be categorized in various ways. For example, a seizure related to the coprescription of 2 drugs could have been categorized as an adverse drug reaction, a drug-drug interaction, or a prescribing error ([Textbox 1](#), example 3).

Providers generally made their own judgments about what events should be documented, with some rejecting the use of the term adverse drug event for events related to nonadherence or suboptimal dosing ([Textbox 1](#), examples 2 and 6).

Textbox 1. Examples of adverse drug event categorizations deemed clinically significant.

<p>Low-dose adverse drug events:</p> <ul style="list-style-type: none"> • Example 1: When a patient presented with swelling in her legs, the pharmacist observed the patient had been newly prescribed a diuretic. The pharmacist noted that the choice of diuretic and the dose were reasonable but the dose was likely ineffective. The patient had been prescribed too low of a dose and, as a result, developed symptoms that brought her to the emergency department . • Example 2: A patient diagnosed with high blood pressure and atrial fibrillation had been taking the oral anticoagulant warfarin at prescribed doses but presented to the emergency department with a low international normalized ratio (INR; a measure of the effect of warfarin) and an ischemic stroke. This was thought to be due to the low dose of warfarin the patient had been taking, leading to a subtherapeutic INR. <p>Drug interactions:</p> <ul style="list-style-type: none"> • Example 3: A patient presented to the emergency department with a seizure after having taken bupropion, citalopram, and clonazepam. The pharmacist noted that bupropion alone could have caused seizures at high doses; however, the patient was taking a low dose. The pharmacist then discovered the reported seizure risk was highest when bupropion was taken together with other antidepressants such as citalopram. After a negative workup for other causes, the pharmacist and physician concluded that an adverse drug event from the coingestion of multiple medications was possible. • Example 4: A patient with a history of atrial fibrillation, stroke, and seizures presented to the emergency department with new neurological deficits. Imaging revealed a new stroke. During the patient's hospitalization, the pharmacist discovered the patient had recently been started on phenytoin to treat his seizures. This drug interacted with the patient's anticoagulant, dabigatran, which had been prescribed to prevent further strokes, and reduced dabigatran's anticoagulant effect. This drug interaction was likely the cause of the patient's recurrent stroke. <p>Nonadherence:</p> <ul style="list-style-type: none"> • Example 5: A patient presented to the emergency department with a seizure after having missed some doses of the anticonvulsant carbamazepine. The patient was unsure of how many doses they had taken during the week and was evasive in responding to the pharmacist's questions. Alternative diagnoses were ruled out. • Example 6: A patient with a history of atrial fibrillation who had been prescribed dabigatran for stroke prevention presented to the emergency department with left-sided face, arm, and leg paralysis and was diagnosed as having suffered a large ischemic stroke. The patient reported that he had missed 1 dose of dabigatran the night before.
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Regardless of the variability in terminology used, all types of events were important to patients, their caregivers, and clinicians, as adverse drug event symptoms were often uncomfortable, could be associated with permanent disability, required changes to the patient's management, and often resulted in hospital admission or additional health care visits. Despite the clinical relevance of a broad range of adverse drug events, pharmacists were often uncertain about which ones to report to external agencies.

Finally, some care providers were concerned about using the term adverse drug event for events that were an expected part of clinical care or had previously been described in the literature. Others used the term adverse drug event to refer to preventable events, rejecting the term when a patient experienced a nonpreventable predictable side effect. Severity also affected how providers characterized events. In one case, the pharmacist was reluctant to classify hyponatremia due to a thiazide diuretic as an adverse drug event even though the medication had to be withdrawn to prevent deterioration (Table 1, example 7).

Challenges in Diagnosing Adverse Drug Events

We identified several sources of complexity when care providers diagnosed adverse drug events (Table 1). We witnessed care providers making difficult, context-specific decisions while managing high-acuity patients in high volumes with frequent patient turnover, limited time, and many interruptions.

The medication and medical histories were often limited or uncertain at the time care providers made prescribing recommendations or decisions (Table 1, examples 1 and 2). As

a result, care providers often managed patients based on a working rather than definitive diagnosis (Table 1, example 5).

Care providers diagnosed adverse drug events over time and often across different settings. While one care provider may have suspected the adverse drug event and held the medication, a different care provider may have confirmed the event (Table 1, examples 3 and 4). In 45 of 65 suspect adverse drug events (69%), the diagnosis could not be confirmed before the end of the initial provider's shift, and the patient required follow-up to confirm the event and guide further management (Table 1, examples 3 to 5). Often, more than one type of complexity compounded the difficulty in confirming adverse drug events.

Providers took ad hoc and informal approaches to coordinate and ensure follow-up of suspect events, making phone calls or sending faxes to outpatient providers or instructing patients and caregivers to follow up with their physician or outpatient pharmacist. Clinicians identified that inadequate monitoring and follow-up and informational discontinuity of care posed a risk to patients. These problems could arise at handovers at the end of their shift, between provider groups, or across health settings if the patient was discharged. Establishing continuity of care was identified as challenging. As one pharmacist expressed, "This is one of the challenges with adverse drug events in the emergency department. Once the patients leave, it's not entirely clear what happens in their care."

Documentation

We observed providers document 41 adverse drug events in clinical charts. They documented to record their clinical assessments, justify a therapeutic action, or ensure informational

continuity of care. Events were documented in site-specific electronic or paper-based medical records (Table 2). In general, pharmacists faxed care providers in the community when they felt the patient was at risk of reexposure or when it was important to notify the patient's physician. British Columbia's provincial electronic medication dispensing database, PharmaNet, allows for free-text information on adverse reactions to be recorded within a patient's profile. However, few providers have access to enter this information, and we observed only 3 instances in which a pharmacist documented in PharmaNet. Care providers criticized the inflexible design of reporting options as being restrictive and incompatible with the complex nature of many adverse drug events, noting limited dropdown menus, dosing options, and character counts. One pharmacist noted, "sometimes the complex real story just doesn't fit; there's nowhere to specify the ifs, ands, or buts." In addition, reporting systems did not allow for reports to be changed, updated, or removed when new information became available over time or in different health care settings (Table 1, examples 3 to 5), making pharmacists reluctant to use electronic reporting forms even when they were certain about the diagnosis. Providers

found documenting complex adverse drug events to be less problematic when writing in clinical notes, where they could structure their own notes and make reference to contingencies, follow-up requirements, and uncertainty.

Time pressures influenced the extent to which care providers documented as they commonly managed multiple patients simultaneously. They were regularly interrupted and were often busy or off shift when information required to confirm an adverse drug event became available (Figure 1). Emergency physicians reported suffering from near-constant interruptions. One emergency physician commented: "I want to give [the patient] to someone who has more time than me," and "I'm still waiting on phone calls so I'll be interrupted again—it's killing me." Adding to this, the documentation process was itself time-consuming. In order to diagnose and document adverse drug events, care providers needed to search multiple sources for relevant information (eg, medication dispensing information, laboratory tests). The consequence of time pressures was that demands related to providing immediate patient care took precedence over documentation, which in busy times was often delayed, incomplete, or not completed at all.

Table 1. Complexities in diagnosing or refuting adverse drug event diagnoses.

Complexity description	Examples (from observation field notes)
Medication history uncertain	
Obtaining an accurate medication history and establishing the timeline between medication exposure (or lack thereof) and symptom onset is challenging and makes it difficult to recommend changes to the medication regimen.	Example 1: A patient presented to the emergency department with rectal bleeding. The pharmacist discovered that the patient's INR ^a was too high, indicating an adverse drug reaction or a high-dose adverse drug event. The patient showed the pharmacist 2 bottles of warfarin (one in 3-mg dose from August 2014 and another in 4-mg dose from January 2013) and said he could not remember which dose he had been taking and that he might have been alternating between 3 mg and 4 mg doses every other day. The patient's other drugs were blister packed, and upon inspection the pharmacist found that the patient was also nonadherent with the other drugs. This made it difficult to ascertain the dose of warfarin that led to the patient's high INR, making dosing adjustment challenging. In addition, the patient's INR could have been elevated for some time and just hadn't been measured. This made recommending a new warfarin dose challenging.
Lack of adequate definitive information	
Time constraints, incomplete documentation within a medical record, and inability to recall information may make an adverse drug event assessment impossible.	Example 2: A patient with chest pain was seen by a pharmacist in the emergency department. The patient was confused and could not describe their medications or the timeline of symptom onset. The confusion had not previously been documented in the hospital record. The patient was from a long-term care facility where care providers administer medications, but the medication administration record was not available so the pharmacist could not verify the medications. Assumptions about this patient's medication use had to be made while managing him according to a working diagnosis. While an adverse drug event was possible, the pharmacist could not obtain sufficient information to refute or confirm an adverse drug event diagnosis.
Diagnostic evolution over time	
The signs and symptoms of adverse drug events develop and are diagnosed over time, often involving multiple care providers and care settings. Definitive diagnostic test results may not be available, and care providers may have to manage patients according to a working diagnosis.	Example 3: A patient recently finished a course of antibiotics to treat pneumonia, but the cough persisted. The pharmacist suspected that the patient's relatively new prescription of ramipril may have been contributing to the cough but was uncertain given that the cough developed before the patient began taking ramipril. Causality was uncertain, but after consultation with the physician, ramipril was changed to an alternative agent. The pharmacist faxed the patient's general practitioner to request follow-up for this patient to determine whether the cough persisted after the change in medication. Only the general practitioner would be able to confirm the adverse drug event diagnosis if the cough persisted despite resolution of the infection. Example 4: A patient presented to the emergency department with diarrhea, having recently been on amoxicillin-clavulanic acid to treat a dental infection. The patient was well enough to go home, but the diagnostic test to confirm <i>Clostridium difficile</i> colitis was still pending. The patient's family physician would make the definitive diagnosis. Example 5: A patient presented to the emergency department vomiting blood. The patient had been on naproxen, a drug that can cause gastrointestinal inflammation and ulcers. On endoscopy, the patient was diagnosed with a gastric ulcer that was attributed to naproxen and managed accordingly. However, biopsy results that became available several weeks later revealed a gastric adenocarcinoma, thus refuting the previous diagnosis of an adverse drug reaction.
Causality assessment	
Complex presentations make assessment of causality uncertain. It can be difficult to distinguish whether symptoms are due to an adverse drug event or an exacerbation of a preexisting medical condition.	Example 6: A patient presented to the emergency department with suicidal ideation. About 1 week prior, the patient decided to stop the antidepressant and antipsychotic medications trazodone, methotrimeprazine, and quetiapine hoping to increase their energy level. The patient expressed being under high stress related to a cockroach infestation in the home and concerns over their father's health. It was unclear whether stopping the medications or the patient's extenuating circumstances caused the patient's deterioration.
Expectedness of event impacts propensity to document and report	
Providers may not consider documenting and reporting adverse drug events for mild, frequently encountered, or expected adverse effects.	Example 7: A patient was hyponatremic due to the prescribed diuretic indapamide. Prior to the patient's discharge, the clinical pharmacist advised the patient and family member about discontinuing the drug and suggested that the patient follow up with his general practitioner. After the patient consult, the pharmacist noted that other providers may interpret the term adverse drug event differently and may assume that a documented adverse drug event means that the drug is contraindicated. She noted that, given the particulars of this case, she thought that the patient's low sodium was something to be expected and was not critical to communicate directly with the general practitioner. She documented the event in her clinical note.

Complexity description	Examples (from observation field notes)
Providers may suspect an adverse drug event but not consider it worthy of documentation or reporting if the presenting signs and symptoms have not previously been described as being related to medication use.	Example 8: A patient presented to the emergency department with a subarachnoid hemorrhage, a life-threatening neurosurgical emergency. The patient did not report a preceding head injury or history of migraines but had taken ergotamine. The pharmacist speculated that the subarachnoid bleed may be related to the patient's use of ergotamine. Ergotamine causes vasoconstriction and raises blood pressure, which the pharmacist hypothesized could have contributed to the subarachnoid hemorrhage. The pharmacist could not find conclusive evidence linking ergotamine to subarachnoid hemorrhage, so she decided not to document or report the event as a suspect adverse drug event.

^aINR: international normalized ratio; a measure of the effect of the oral anticoagulant warfarin.

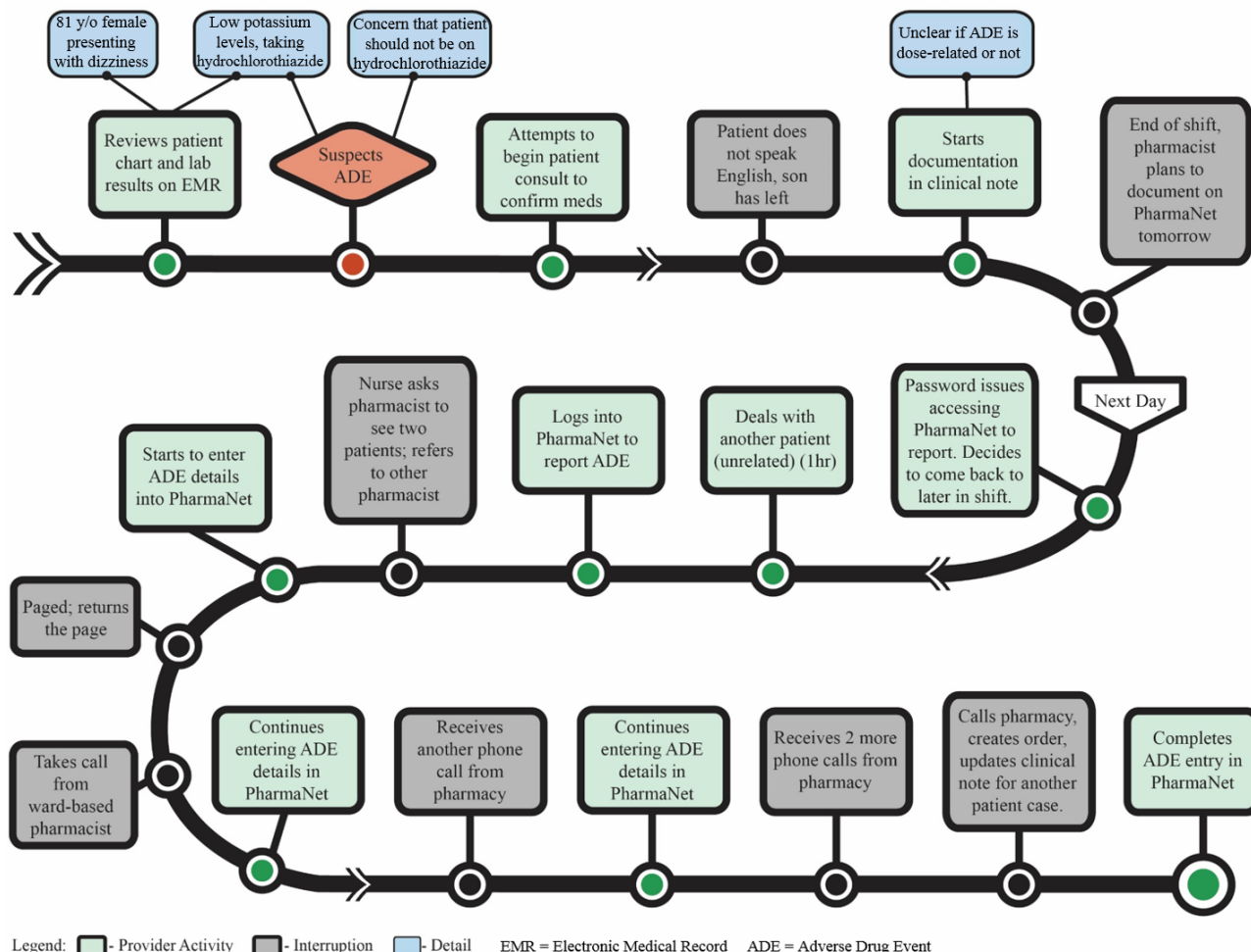
Table 2. Modes of adverse drug event documentation and communication observed.

Type of documentation and communication	Total instances ^a
Paper chart	35
Electronic chart	14
Fax to general practitioner	6
PharmaNet	3
Community pharmacy system ^b	2
MedEffect Canada	0
Not documented	24

^aMore than one instance may have occurred per event; therefore, total instances of documentation exceeds total number of observed events.

^bProvider called community pharmacy to have a note added to the patient's profile within the pharmacy system.

Figure 1. Clinical pharmacist's workflow documenting an adverse drug event.



Textbox 2. Sample comments from providers related to documentation burden.

- “A huge barrier [for electronic reporting] is the time it takes for the process of getting from opening my [office] door to getting this screen open in front of me.” [hospitalist]
- “Motivators to report are the simplicity of [a new reporting] tool, the fit into clinical workflow or processes, and the time taken to complete a report.” [emergency department physician]
- “I don’t have time to take ownership [of routine reporting], but I would happily collaborate with the pharmacists and do my part in it.” [hospitalist]
- “The more fields, the less likely I am to enter it.” [clinical pharmacist]
- “[Reporting] is duplicative and potentially quite onerous, especially for older patients who are on a number of medications.” [hospitalist]
- “There won’t be any buy-in if there’s too much stuff to fill out.” [general practitioner]

Reporting

Our team never observed a pharmacist or physician report to an external agency such as Canada’s MedEffect program. Care providers viewed reporting to regulatory agencies as a burden and told us that convenience, speed, and simplicity should be central design considerations for new reporting tools (Textbox 2). In order to report adverse drug events, they noted that they would have needed to search for paper or online forms external to their facility’s electronic medical record which demanded time they did not have. Furthermore, these forms typically contained around 35 data fields and collected information that they had already documented in the patient’s record, representing duplication of work.

Discussion

Principal Findings

Our objective was to understand how adverse drug events were diagnosed and documented in hospitals and examine barriers to reporting. We found a high degree of complexity and uncertainty in diagnosing adverse drug events in clinical practice. Despite these challenges, care providers regularly documented events as part of their work to provide informational continuity of care. However, they never used existing electronic reporting systems, which would have required data entry at one point in time by a single individual and did not reflect the complexity of the clinical diagnosis or the providers’ workflow. Clinicians faced time constraints and perceived existing reporting systems as an additional documentation burden, requiring time to access and representing a duplication of tasks without providing additional benefit to the patient.

Our results confirm that clinicians are interested in documenting and reporting adverse drug events and would welcome reporting mechanisms that meet clinical needs while allowing them to observe the direct impact of reporting on clinical care. For example, clinicians on our study spent an inordinate amount of time attempting to contact other care providers (eg, by phoning or faxing) to ensure that adverse drug events were communicated to other care providers. Electronic reporting systems could facilitate communication by automating the electronic communication of standardized adverse drug event reports between clinicians or creating patient-level alerts to ensure that other care providers do not inadvertently reexpose patients to culprit drugs. This form of feedback was perceived as highly relevant and would motivate the use of a reporting system.

Previous studies drew on a theoretical model that outlined a set of provider attitudes, including complacency, indifference, and ignorance, to which underreporting was ascribed [29-31]. Studies that used this model have been questionnaire- or interview-based and implied that providers neglect their responsibility to research, safety, and regulatory agencies and the public by not reporting [23,24,32-34]. As a result, attempts to improve reporting have focused on using incentives, education, legislation, or guidelines to correct provider behaviors [35]. While some of these initiatives have led to short-term local improvements, adverse drug event underreporting remains problematic [8,13]. Initiatives aimed at improving reporting would likely benefit from a similar paradigm shift as the patient safety movement, which has moved away from a culture of individual blame toward system-level analysis to examine and improve organizational structures and technology design [36,37].

In contrast to prior studies, our approach offers a qualitative analysis of the real-world management and documentation of adverse drug events. Our findings suggest that failure to document and report is a system-level problem that might more successfully be solved by redesigning reporting systems to address the practical concerns of care providers, assist them in their clinical work, and reflect the complex nature of adverse drug events. We suggest an approach that builds on new capacities offered by electronic medical records, which are now widely used. In contrast to existing reporting systems that are oriented to data collection for research and regulatory purposes, systems might be repurposed to facilitate documentation and information flow between care providers and across health sectors (eg, between ambulatory care settings, hospitals, and community pharmacies), addressing major concerns for care providers [21]. Such systems may reduce the risk of reexposures to harmful medications while generating high-quality adverse drug event data for surveillance and research.

Our team developed 5 core recommendations in order to mitigate system-level issues in adverse drug event reporting. First, in order to ensure uptake and utility for clinical care, reporting systems must act as a mechanism to document work and share information between care providers. This approach minimizes duplication of work. By linking patient-level adverse drug event reporting to clinical documentation and enabling communication to prevent harmful reexposures, new approaches may motivate care providers to report events. Second, by integrating adverse drug event reporting into existing electronic interfaces, the time and barriers (eg, multiple passwords) required to access reporting forms can be minimized, and fields can be

autopopulated with readily available information to minimize data entry. Third, systems that clinical care providers are expected to report in should only include data fields relevant to clinical practice. Fourth, systems should enable standardized and categorized data entry to speed up reporting and enable standardized data to be generated while allowing free-text entry in other locations so care providers can document nuanced information for complex events. Fifth, adverse drug event reports should be living documents that enable multiple providers to edit, update, and remove data as information becomes available or a patient's condition changes.

Limitations

Our findings reflect the activities and opinions of pharmacists and physicians working in the settings where we were able to conduct the study. While many care providers had worked outside of these institutions and in other provinces prior to our project, the generalizability of our findings to other clinical areas and jurisdictions may be limited, as environmental conditions, work organization, information infrastructures,

culture, and job tasks vary across facilities and jurisdictions. Finally, we sought to explore and describe barriers to underreporting but found reporting to external agencies to be so rare that we were unable to observe any reports being created for external agencies. Our focus was on adverse drug events and not on patient safety incidents or errors, as these types of events cause a minority of adverse drug events in our clinical setting.

Conclusion

While providers routinely document adverse drug events in clinical records to inform patient care, barriers exist to report to external agencies. We recommend that future reporting systems are designed to enable providers in documenting and communicating adverse drug events as ambiguous, unfolding, and uncertain events and help clinicians meet patient safety goals. Integrating such reporting systems into electronic medical records could alleviate time pressures for clinicians and may produce more robust and complete adverse drug event data as a by-product of safer clinical care.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Coding structure.

[[PDF File \(Adobe PDF File\), 71KB - publichealth_v4i1e21_app1.pdf](#)]

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Abbreviations

INR: international normalized ratio

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Original Paper

Comparative Analysis of Women With Notable Subjective Health Indicators Compared With Participants in the Australian Longitudinal Study on Women's Health: Cross-Sectional Survey

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Abstract

Background: At least six communities with unusually good health and longevity have been identified, but their lifestyles aren't adopted widely. Informal evidence suggests that women associated with Universal Medicine (UM), a complementary medicine health care organization in Eastern Australia and the United Kingdom with normal lifestyles, also have several unusual health indicators.

Objective: Our objective was to determine how UM participants compared with women in the Australian population at large on a variety of health indicators.

Methods: In an Internet survey conducted July to September 2015, a total of 449 female UM participants from 15 countries responded to 43 health indicator questions taken from the Australian Longitudinal Study on Women's Health (ALSWH).

Results: Survey responses revealed large positive differences in mental and physical health when compared with the ALSWH respondents, except for abnormal Pap test and low iron history. Differences and corresponding effect size estimates (Cohen *d*; ≥ 0.8 is a high difference, ≥ 0.5 a medium and ≥ 0.2 a small one with $P < .001$ except where indicated) included body mass index (BMI; 1.11), stress level (0.20, $P = .006$), depression (0.44), summary physical (0.31) and mental health (0.37), general mental health (0.39), emotional (0.15, $P = .009$) and social functioning (0.22), vitality (0.58), and general health (0.49), as well as lower incidences of diabetes, hypertension, and thrombosis ($P < .001$ each). Neither education levels nor country of residence had predictive value. Age did not predict BMI.

Conclusions: The women's responses notably claim substantially lower levels of illness and disease than in the general Australian population.

Trial Registration: Australian New Zealand Clinical Trials Registry (ANZCTR): ACTRN12617000972325; <https://www.anzctr.org.au/Trial/Registration/TrialReview.aspx?id=373120&isReview=true> (Archived by WebCite at <http://www.webcitation.org/6wEDDn45O>)

International Registered Report Identifier (IRRID): DERR2-10.2196/7993

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KEYWORDS

women's health; health surveys; public health; Australian Longitudinal Study on Women's Health; ALSWH; Universal Medicine; preventive medicine; health care costs; complementary therapies; cross-sectional studies

Introduction

The population in the developed world is getting both older and, even after accounting for age, less healthy. Increasing morbidity and the associated rise in health care costs [1-4], especially for diabetes and obesity [5-8], present serious and ever-growing societal challenges.

There have always been individuals who live exceptionally healthy lives, but entire communities that demonstrate superior health are rare; 4 such groups are the residents of the small US Pennsylvanian town of Roseto [9], Seventh Day Adventists [10], traditional Japanese [11], and senior Whitehall (UK) civil servants [12]. However, their lifestyles have not been adopted widely.

We report a survey of a group of people, primarily women, who form a community that is scattered throughout the world. The unifying characteristic is participation in an organization called Universal Medicine (UM), as described below. Informal evidence that can be gathered by visiting any UM-run event shows a low number of overweight or obese participants present, even though most events do not involve physical activity and few members profess to be on weight loss diets at any time. In addition, older participants seem not to have a higher body mass index (BMI) than younger participants.

Methods

Participants

Of all UM participants, 76% are female; therefore, for this initial investigation, we chose to focus on comparing the health of women in UM with that of a larger female population. For comparison, we adopted a substantial portion of questions from the Australian Longitudinal Study on Women's Health (ALSWH). The ALSWH survey was inaugurated in 1996 and includes data from approximately 75,000 women [13-16].

We designed this study to answer the following questions. (1) Do women who participate in UM appear to have overall health substantially different from that of the general female population, as represented by ALSWH respondents? (2) In which specific aspects of health do UM participants differ, and in which aspects are there no differences? (3) Is UM participants' health correlated with age, education, or their country of residence?

Universal Medicine

UM is a complementary medicine health care organization founded in 1999 near Lismore, in Eastern Australia. UM has approximately 200 male and 500 female regular attendees at its workshops and conferences. We drew the study sample from these regular participants.

Information on the UM website [17] describes the organization as follows:

Universal Medicine is committed to providing Complementary Health & Healing Services that are Universal [sic] in their approach towards medicine and healing.

Through practical philosophies that inspire more self-caring and self-loving choices in daily life, Universal Medicine supports people to explore their overall well-being, the development of energetic awareness, and the depth they can bring to their quality of life and relationships.

Teachings are delivered in the form of lectures, talks, audios and treatments from Universal Medicine clinics. [It] regularly holds courses, workshops and retreats throughout Australia and internationally.

This survey is the first scientific investigation to look at the health of the UM participants.

UM has developed several treatment modalities. One such modality, called Esoteric Connective Tissue Therapy, is being studied in a randomized controlled trial on chronic low back pain [18]. These treatment modalities were used by 99.7% (367/368) of UM respondents in the 12 months prior to taking the survey.

Like other institutions that support self-empowerment of women, such as the family court, women's shelters, and social services, UM has been the target of criticism in the form of "a vigorous, determined campaign" [19] by a small number of detractors. In contrast, at least 34 registered medical professionals are among the regular visitors to UM events. The curious coexistence of harsh critics, medical professional advocates, and anecdotal evidence of substantial benefit could make UM an interesting object of study.

General Characteristics of the UM Survey and its Relationship to the ALSWH

The full UM survey comprised 43 questions from the ALSWH, as well as a newly developed menstrual attitudes questionnaire; the latter is not discussed in this paper. We chose the ALSWH

items to maximize comparability of the 2 groups. For comparisons, we used the electronic ALSWH data books [20], which give frequencies, mean scores, and, in some cases, standard deviations.

The ALSWH website [21] states that the ALSWH is

...a longitudinal survey of over 58,000 women in three cohorts who were aged 18-23 (the 1973-1978 cohort), 45-50 (the 1946-1951 cohort), and 70-75 when surveys began in 1996....ALSWH assesses women's physical and mental health, as well as psychosocial aspects of health (such as socio-demographic and lifestyle factors) and their use of health services.

An additional 17,000 participants were added after the definition was written.

Study Population

Our study population of interest comprised 500 UM-participating women who, although they were consumers of complementary medical services, had profiles that differed in important ways from those of typical complementary medicine adherents [22]: UM participants, as recorded in this survey, did not have poorer health or a higher use of registered medical professionals (nor was their use substantially lower) than the ALSWH respondents. One difference is that UM women were more likely to be middle-aged.

Design, Privacy of Data, and Recruitment

The portion of the data collection that was relevant to this study was a quantitative, cross-sectional online survey of women's health. We did not collect any directly identifying data; however, we did collect indirectly identifying data such as partial medical history and age in years. Due to privacy considerations, portions of the data will not be available for inclusion in a public repository. We present age as a range, and we exclude the medical history data.

We recruited participants via 2 overlapping mailing lists of 650 and 350 UM members, and by distributing flyers at several UM-sponsored events in 2015.

Ethical approval was given by the University of Queensland School of Public Health Research Ethics Committee on June 23, 2015 (CS23062015). The first item on the survey explained the purpose of the survey and asked participants to either grant their consent or decline to do so. The study is registered with the Australian New Zealand Clinical Trials Registry (ACTRN12617000972325). [Multimedia Appendix 1](#) shows a Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist.

Deidentified data will be made available from the corresponding author on reasonable request. Data will not include potential identifiers, as outlined by Hrynaskiewicz et al [23]. Specifically, this means that age will be categorized into intervals, and a list of medical procedures undergone and major illnesses will be excluded. Regrettably, the data cannot be shared in a public repository, as with such a small group, it would be relatively easy to identify individuals even with the above measures taken.

Implementation

The survey was completed online in July to September 2015, using the Survs survey platform (Enough Pepper Lda). In the case of duplicates, we removed 1 of them.

Data Analysis

We conducted informal focus groups with UM-participating women to help us identify the ALSWH items that seemed most relevant for comparison in this preliminary study, and not to exceed an average of 75 minutes in response time. Demographic items related to age, BMI, menstrual status, education, and lifestyle questions about smoking, alcohol use, number of general practitioner visits, and number of UM event visits were included. In addition to the 36-Item Short Form Survey (SF-36) [24], other standardized scales we incorporated were the Center for Epidemiologic Studies Depression Scale (CES-D) [25,26], Perceived Control Scale [27,28], and an ALSWH-developed multi-item summed score for perceived stress [14,29]. A further 6 items solicited information about sleep quality, 47 past diagnoses of medical issues, and frequency of 24 physical symptoms in the previous 12 months, with response options being "often," "sometimes," "rarely," and "never."

Of the ALSWH questions, 27 were asked twice, once with reference to the present, and once with reference to the time of the respondent's first attendance at a UM event.

Adjusting for Age and Cohort

The ALSWH age data from the data books [20] consisted of frequencies, means, and standard deviations. Individual data were not available. The ALSWH longitudinal study consists of surveys that are typically administered every 3 years, with numerous changes made to the items from one administration to the next. The results for 15 surveys of 3 age cohorts, born in 1921-1926, 1946-1951, and 1973-1978 have been published.

Because the ALSWH questions can change from one administration to the next, for each particular UM survey question, not all 15 ALSWH surveys included a comparable question.

We calculated the adjusted UM group responses for each variable by first excluding all UM respondents with an age that was not covered by an ALSWH survey. For example, in the question asking about past skin cancer diagnoses, we calculated the UM rate from only the 69 respondents aged 45 to 50 years and the 6 respondents aged 70 to 75 years.

The weighted ALSWH data are weighted by the frequency of UM respondents for that age group. For example, a question about any skin cancer diagnosis in the past was used in 2 ALSWH surveys: the first ALSWH survey of the 1946-1951 cohort with respondents aged 45 to 50 years, and the first ALSWH survey with respondents born between 1921 and 1926 and aged 70 to 75 years. There were 69 UM respondents aged 45 to 50 years and 6 UM group respondents aged 70 to 75 years who gave valid responses; hence, the frequency weights used to calculate the weighted ALSWH skin cancer percentage (11.9%) were 69 and 6. This makes the UM results comparable with the ALSWH weighted results in terms of age.

Adjusting for Education

Age was a major predictor of the responses to many questions, but education turned out to have no predictive value. Hence, we did not adjust the data for education.

Effect Size Calculations

We calculated Cohen d using the Stata command `esize1` (version 14.2; StataCorp LLC). The ALSWH standard deviations are reported to only 1 significant digit, so we assumed the maximum possible standard deviation (eg, 0.1 became 0.149 and 0.0 became 0.049, reducing Cohen d), from which we used the pooled standard deviation [30] with Welch's approximation.

A superior approach for calculating P values and effect sizes would be to compare the UM respondents with their closest ALSWH counterparts, taking account of age, education, and BMI. When the full ALSWH data are available, we will take this approach.

Results

Survey Responses

This survey produced 449 responses, of which 373 (83.1%) were complete. The respondents answered from 17 countries (Australia, $n=273$; United Kingdom, $n=97$; Germany, $n=26$; the Netherlands, $n=11$; other European countries, $n=18$; United States, $n=11$; rest of the world, $n=13$). Of the respondents, 13 did not consent, 3 were male, 20 did not give their menses status, 5 were less than 18 years of age, and 1 completed the survey twice, leaving 407 valid and 338 completed responses (Figure 1).

Table 1 and Table 2 show demographic and survey administration data. The UM group was more highly educated than the ALSWH cohort. The average UM group survey respondent's age was 48 (range 18-86) years; age was normally distributed (Shapiro-Wilk $P=.42$). The proportion of smokers among UM women was 1.6% (4/240), compared with 13.9% among ALSWH women. The rate of alcohol use among UM women was 1.8% (6/338) versus 86.3% for ALSWH women.

Figure 1. Recruitment flowchart for participants in the Universal Medicine survey.

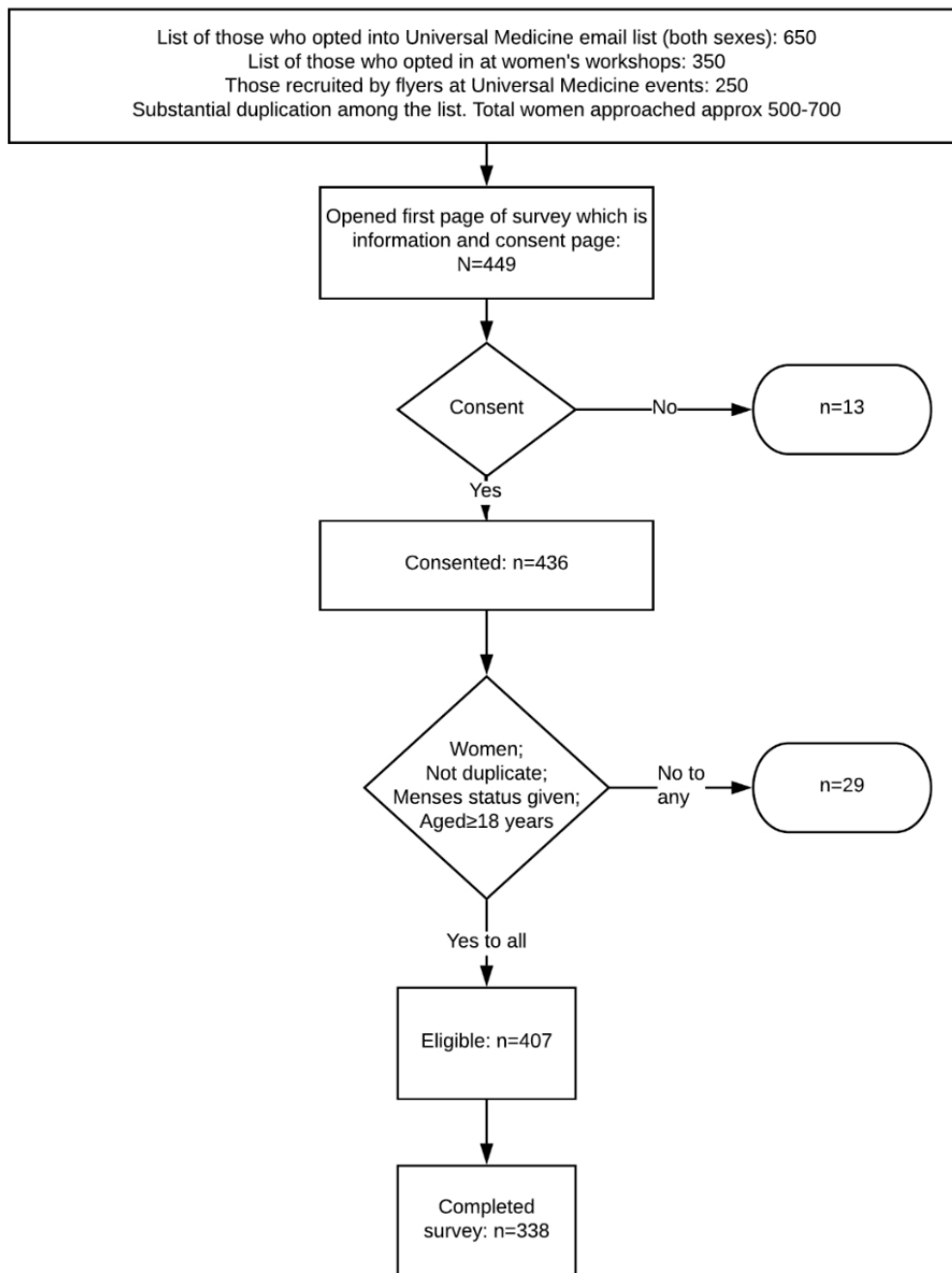


Table 1. Demographic and survey administration data for Universal Medicine (UM) participants compared with data from the Australian Longitudinal Study on Women's Health (ALSWH).

Characteristics	UM cohort n (%)	ALSWH frequency weighted ^a	P value
Menstrual status			
Total ^b	407		
Menses	173 (42.5)		
Perimenopausal	75 (18.4)		
Menopausal	159 (39.1)		
Educational attainment			<.001
Total ^b	193		
No formal education	12 (6.2)	11.4	
School certificate	3 (1.6)	21.2	
High school	21 (10.9)	19.4	
Trade, certificate, or diploma	71 (36.8)	20.9	
Degree	66 (34.2)	17.3	
Higher degree	20 (10.4)	9.8	
Number of UM events attended per year by survey participants			
0-1	1 (0.25)		
2-5	54 (13.3)		
6-10	81 (19.9)		
≥11	271 (66.6)		
General practitioner visits			<.001
Total ^b	275		
None	27 (9.8)	6.6	
1-2	134 (48.7)	33.6	
3-4	63 (22.9)	28.6	
5-6	31 (11.3)	15.9	
≥7	20 (7.3)	15.3	
Smoking			<.001
Total ^b	240		
Not at all	236 (98.3)	86.2	
Less than weekly	2 (0.8)	1.7	
Weekly	0 (0.0)	1.2	
Daily	2 (0.8)	11.0	
Alcohol consumption (drinks)			<.001
Total ^b	338		
Daily	1 (0.3)	6.5	
1-6/week	0 (0.0)	36.8	
<1/week	5 (1.5)	42.8	
Not for a year	38 (11.2)		
Not for 5 years	294 (87.0)		
Never		13.7	

^aALSWH percentages with UM group frequency weights.

^bNumber of UM respondents with ages that were surveyed in ALSWH for this particular question. Example: skin cancer was covered in ALSWH Mid 1 (45-50 years old) and Old 1 (73-78 years old) surveys; UM group had 69 respondents aged 45-50 years and 6 aged 73-78 years who gave valid responses; 4 of the 69+6=75 had skin cancer.

Table 2. Continuous demographic variables for Universal Medicine (UM) participants.

Continuous variables	n	Mean	SD ^a	Median	Range		Interquartile range	
					Minimum	Maximum	25%	75%
Age (years)	407	47.7	11.8	47	18	86	40	56
Years with UM	392	7.9	3.3	8.0	0.5	15.6	5.2	10.1
Body mass index (kg/m ²)	323	21.0	3.0	20.6	15.2	39.0	19.1	22.4
Age at menopause (years)	137	49.9	5.1	50	27	58	47	52
Age at menstruation (years)	338	13.1	1.6	13	9	19	12	14

^aSD: standard deviation.

The UM respondents' average BMI of 21.0 kg/m² was substantially lower than the ALSWH weighted BMI of 26.1 kg/m² (see [Table 3](#)). A regression analysis showed that the BMI for the UM respondents was related to neither education ($P=.63$) nor age ($P=.56$), in contrast to data from the ALSWH and the Australian Bureau of Statistics showing obesity rates increasing to ages 55-64 (men) and 65-74 (women) [31]. A fractional polynomial graph (a visual means for determining whether a relationship is linear or, for example, U-shaped) of age and BMI shows an almost straight horizontal line; that is, there is no apparent relationship ([Figure 2](#)).

[Table 3](#) shows the lower BMI scores for UM respondents. UM responses scored higher (better) on the 4 common psychological health scales that measure stress, the level of perceived control, depression, and the mental and physical health scales of the SF-36.

[Table 4](#) compares the proportion of UM respondents who reported ever having had a particular health issue (including the time before they became associated with UM) with weighted ALSWH responses. The UM respondents had substantially higher rates than the ALSWH group of abnormal Pap tests and diagnoses of low iron, and substantially lower rates of diabetes, hypertension, and thrombosis.

P values use Pearson chi-square for the hypothesis that the rows and columns in the 2-way listing of UM respondents and ALSWH respondents in [Table 4](#) are independent.

UM respondents had fewer sleep issues than did ALSWH respondents, with 68.9% (228/331) of the former and 27.9% of the latter reporting no issues at all. For lying awake most of the night, the percentages were 2.4% (UM, 8/331) versus 14.2% (ALSWH); taking a long time to get to sleep (38/331, 11.5% vs 28.8%), being kept awake by worrying (28/331, 8.5% vs 18.9%), and sleeping badly at night (44/331, 13.3% vs 35.2%) ([Multimedia Appendix 2](#)).

[Multimedia Appendix 3](#) shows the symptoms for which the UM respondents were noticeably different (in all cases noticeably fewer incidences) from their ALSWH counterparts. The lower rates of back pain, allergies, breathing difficulties, depression,

panic attacks, headaches, migraines, hot flashes, and night sweats could be of interest ([Figure 3](#)).

We detected no difference of any substance for an effect of education, including BMI, Stress Scale, Perceived Control Scale, CES-D, and SF-36. [Multimedia Appendix 4](#) shows this in graphical form.

UM survey responses scored more highly than ALSWH responses on composite physical and mental health (see [Figure 4](#)). For ALSWH respondents, physical scores peaked at age 18 to 23 years and mental scores peaked at age 73 to 78 years. UM survey respondents' scores were similar to peak ALSWH scores; that is, UM respondents had the higher physical scores of the very young and the higher mental scores of the very old.

Effect Sizes

Observed effect sizes (Cohen *d*) ranged from 0.6 to 11.9 ([Table 3](#)). These values are with one exception higher than the 0.8 considered to denote a large effect [33,34].

Linking UM Participation to Outcomes: Preliminary Exploration

A cross-sectional survey is not able to establish causality, so it is possible that participants for whom UM events held appeal were already healthier. However, there are indications in the data that this was not the case. The UM survey asked respondents to answer 27 of the 43 ALSWH questions as per their memory of how they were feeling at the time of their first UM event and to answer the same questions in relation to the present. [Multimedia Appendix 2](#) shows BMI changes. Retrospective reports are always subject to the vagaries of memory and have low reliability, but until a prospective longitudinal study is undertaken, these data are the best available. The data indicate the UM respondents were of average or below-average physical health and below-average mental health at the time of their first UM event. Examples are the proportion who often had back pain in the previous 12 months: 25.8% (UM past, 87/337) versus 3.3% (UM present, 11/336) versus 17.8% (ALSWH); those who had depression: 18.3% (61/333) versus 0.6% (2/332) versus 6.6%; and those who had allergies: 26.0% (86/331) versus 0.9% (3/332) versus 14.9%.

Table 3. Results from standard survey scales in the Australian Longitudinal Study on Women's Health (ALSWH) and Universal Medicine (UM) groups, with *r* values and standard deviation.

	Survey respondents with ages covered by ALSWH surveys				ALSWH respondents with UM frequency weights			Effect size			
	n ^a	Mean	95% CI	SD ^b	Mean	95% CI	SD ^b	Cohen	95% CI	<i>r</i> ^c	<i>p</i> ^c
Body mass index (kg/m ²)	253	21.0	20.7-21.4	2.97	26.1	25.9-26.2	4.6	1.11	0.98-1.23	.48	4*10 ⁻⁶⁶
Stress ^d (lower is better)	200	0.63	0.55-0.70	0.52	0.73	0.72-0.75	0.53	0.20	0.057-0.38	.10	0.0059
Perceived Control Scale ^d	135	4.9	4.8-5.0	0.63	4.3	4.3-4.3	0.79	0.74	0.57-0.91	.35	2*10 ⁻¹⁷
CES-D ^d (lower is better)	233	3.6	3.1-4.2	5.60	6.1	6.1-6.2	5.6	0.44	0.31-0.57	.21	6*10 ⁻¹¹
SF-36^d											
Summary Physical Health	272	52.8	51.9-53.6	10.0	49.7	49.4-49.9	10.0	0.31	0.19-0.43	.15	6*10 ⁻⁷
Summary Mental Health	272	51.4	50.4-52.5	10.0	47.7	47.5-47.9	10.0	0.37	0.25-0.50	.18	10 ⁻⁹
General Mental Health	295	80.1	78.5-81.7	13.6	73.2	72.9-73.4	17.9	0.39	0.27-0.51	.19	5*10 ⁻¹¹
Role Emotional	294	85.3	82.2-88.3	26.5	79.6	79.2-79.9	36.9	0.15	0.038-0.27	.08	0.0091
Social Functioning	295	87.1	84.9-89.3	19.1	81.9	81.7-82.1	24.0	0.22	0.10-0.33	.11	0.0002
Vitality	295	69.5	67.6-71.5	17.2	57.5	57.2-57.8	20.7	0.58	0.47-0.70	.28	9*10 ⁻²³
General Health	275	81.9	80.0-83.8	15.9	71.8	71.6-71.9	20.9	0.49	0.36-0.61	.24	3*10 ⁻¹⁵
Bodily Pain	294	82.8	80.6-85.0	19.5	70.7	70.4-70.9	24.0	0.51	0.39-0.62	.25	2*10 ⁻¹⁷
Role Physical	294	84.8	81.6-88.0	27.9	78.2	77.9-78.6	36.2	0.18	0.10-0.34	.09	0.0019
Physical Function	294	89.5	87.9-91.0	13.3	84.6	84.1-85.1	19.7	0.25	0.16-0.40	.12	0.00003

^aNumber of UM respondents with ages that were surveyed in ALSWH for this particular question.

^bSD: standard deviation.

^cThe *r* value was calculated as $r=d/(\sqrt{4+d^2})$, where *d* is Cohen *d* as derived from the formula given by Nakagawa and Cuthill [32]. *P* value calculated with Satterthwaite's *t* test.

^dMulti-item summed scores for perceived stress, Perceived Control Scale, Center for Epidemiologic Studies Depression Scale (CES-D), and 36-Item Short Form Survey (SF-36) using Australian coefficients.

Figure 2. Distribution of body mass index (BMI) by age of participants using fractional polynomial line of best fit including 95% CI. Note that the line is almost straight; that is, there is almost no association between BMI and age. In the general population, BMI rises with age up to 69 years (source: Australian Bureau of Statistics).

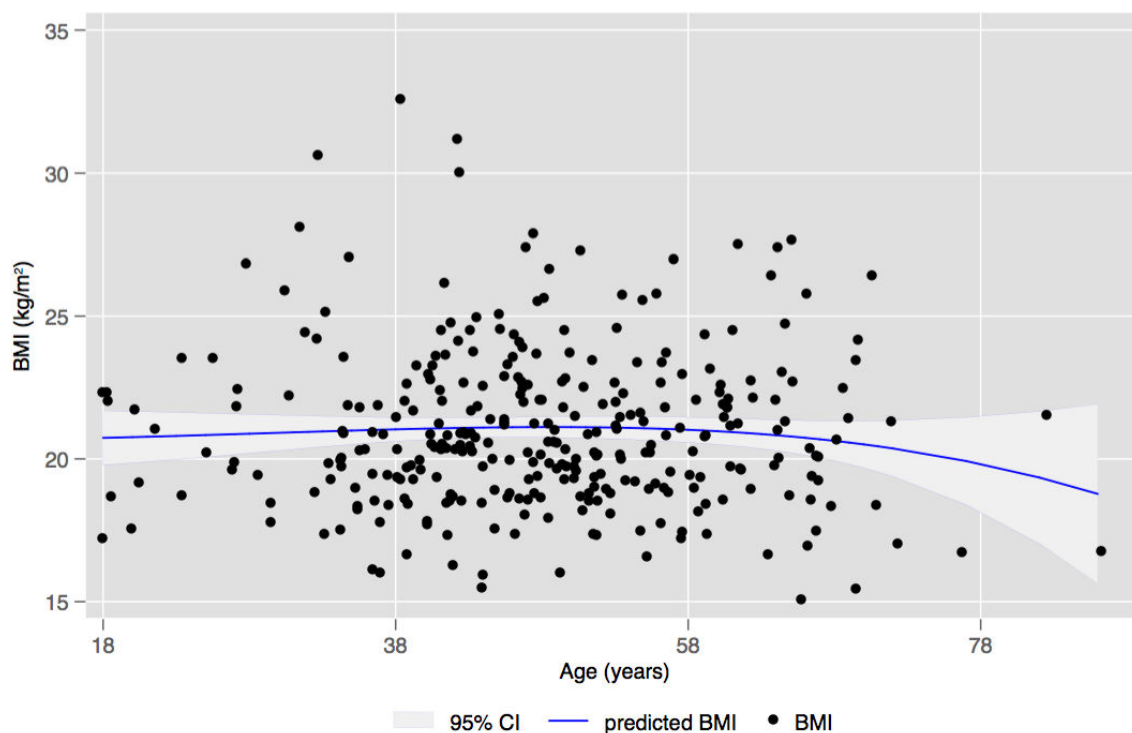


Table 4. Reported diagnoses among Universal Medicine (UM) and Australian Longitudinal Study on Women's Health (ALSWH) respondents.

Have you ever been diagnosed with:	UM response "yes" (ALSWH ages ^a)		ALSWH ^b weighted (%)	P value
	n	%		
UM worse than ALSWH				
Abnormal Pap test	73	35.3	22.2	<.001
Low iron	38	41.3	29.8	.02
No significant difference				
Abnormal mammogram	38	22.0	17.8	.16
Asthma	13	15.1	16.6	.71
Bronchitis or emphysema	14	18.7	18.9	.96
Breast cancer	2	2.7	2.4	.88
Cervical cancer	3	4.0	3.1	.66
Heart disease	2	2.2	2.8	.72
Osteoporosis	6	8.0	5.6	.37
Skin cancer	4	5.3	11.9	.08
Stroke	0	0.0	1.2	.34
UM better than ALSWH				
Diabetes	0	0.0	3.1	<.001
Hypertension	0	0.0	19.2	<.001
Thrombosis	2	0.7	4.5	<.001

^aPercentage of UM respondents with ages that were surveyed in ALSWH for this particular question. Example: skin cancer was covered in ALSWH Mid 1 (45-50 years old) and Old 1 (73-78 years old) surveys; UM group had 69 respondents aged 45-50 years and 6 aged 73-78 years who gave valid responses; 4 of the 69+6=75 had skin cancer.

^bALSWH percentages with UM group frequency weights.

Figure 3. Differences in symptoms between women participating in Universal Medicine (UM) and respondents to the Australian Longitudinal Study on Women’s Health (ALSWH). All *P* values <.001.

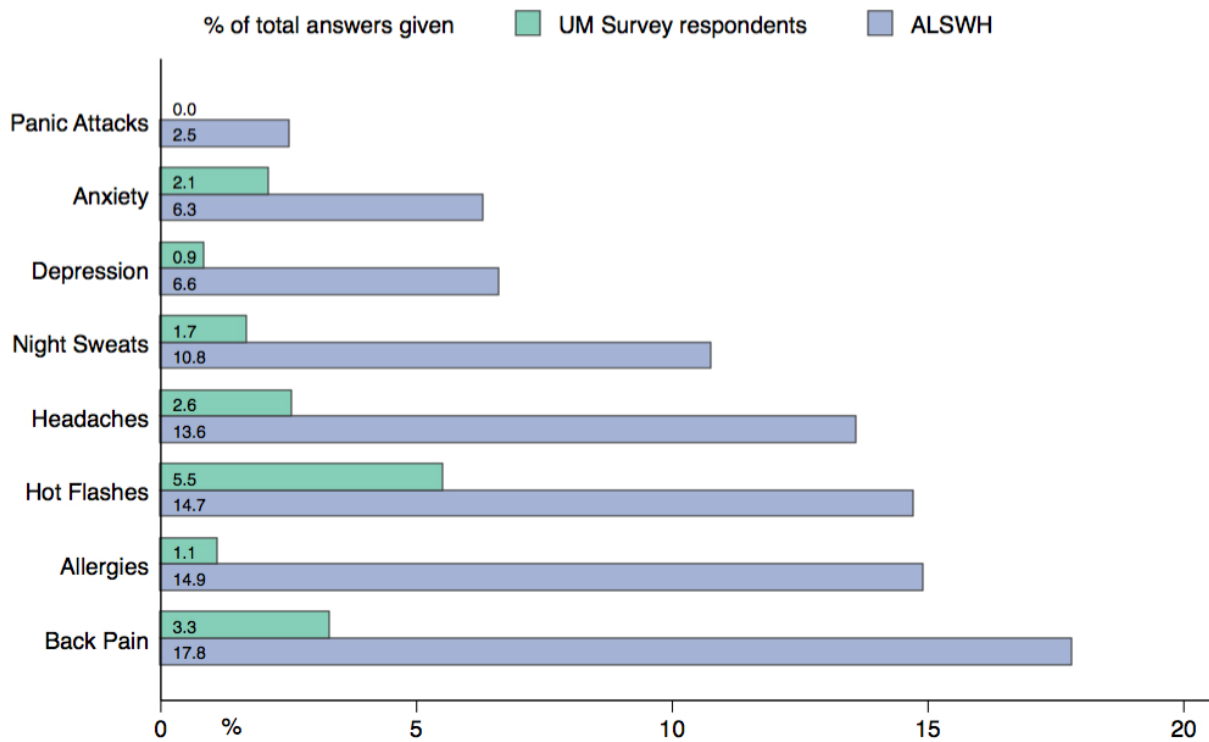
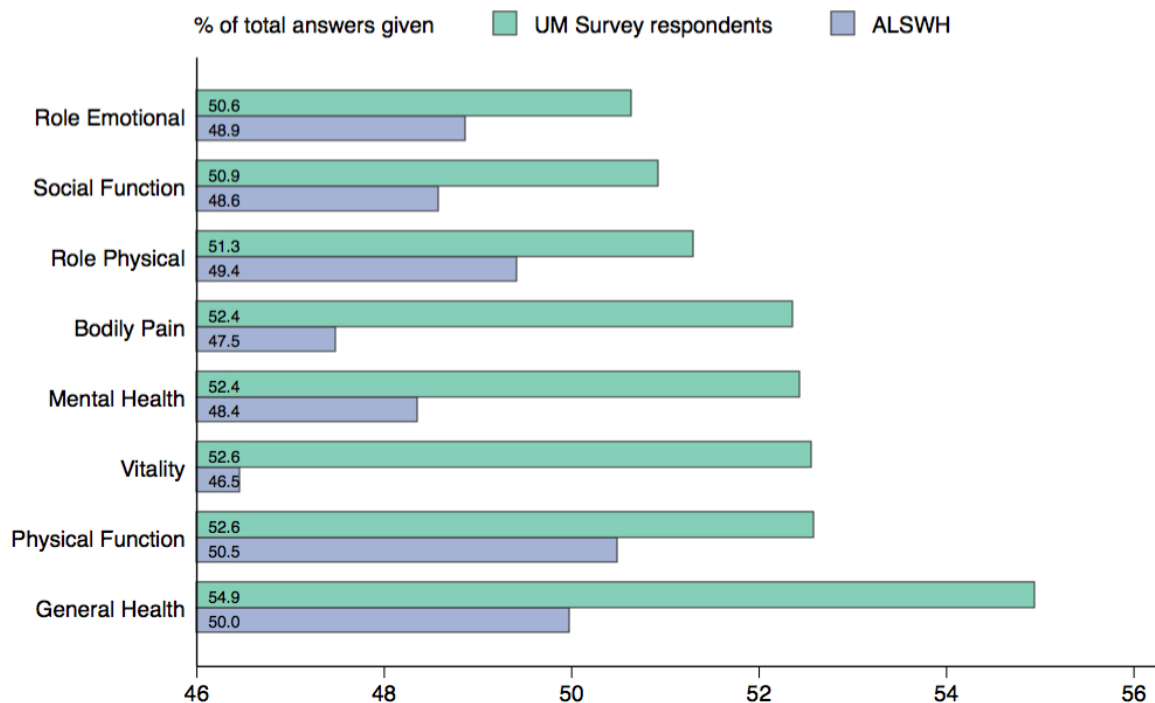


Figure 4. Differences in composite health indicators (36-Item Short Form Survey, SF-36) between women participating in Universal Medicine (UM) and respondents to the Australian Longitudinal Study on Women’s Health (ALSWH). Weighted responses; all scores are normalized to mean 50, standard deviation 10.



Discussion

The results from this survey suggest that on several health indicators this group of women was faring notably differently from, and from looking at the data, better than, the general

population, as represented by the ALSWH respondents. UM respondents differed in a variety of aspects of physical and mental health, except for lifetime diagnoses of positive Pap smears and low iron. However, these results should be

interpreted with caution, as a cross-sectional survey is not able to establish causality.

Principal Findings

The results show that the UM participants, who on average were 48 years old and had been associated with UM for 8 years, had a lower BMI than the general population; experienced substantially less frequent back pain, lower stress, and depression scores; and scored higher on general mental and physical health, vitality, and perceived level of control. UM participants also had noticeably lower lifetime diagnoses of hypertension, used less hormone replacement therapy, had fewer sleep issues, and had notably fewer instances of allergies, sinusitis, anxiety, breathing difficulties, panic attacks, headaches, migraines, hot flashes, and night sweats. Major differences in lifestyle choices were apparent between the UM participants and the ALSWH population, with very low rates of both alcohol use and smoking in the UM group.

There are other groups that demonstrate aspects of above-average health. What may make it worthwhile to investigate the UM group further is the breadth of health indicators for which their scores are better than those of the general population.

About Universal Medicine

If it is the case that UM participants are healthier than their population cohorts, and that they were not already healthier when they began participating in UM, this raises the question of whether UM practices or interventions could be responsible for this difference and whether there is any plausible mechanism that could explain UM's effects, if any.

The organization's founder, Serge Benhayon, has described UM as encompassing the concept:

...that [there] is medicine in responsibility, that there's medicine in caring, that there's medicine in nurturing. There is great medicine in love, there is great medicine in stillness, great medicine in harmony, great medicine in surrender, tenderness, preciousness, that there is medicine in everything. Everything is, in fact, eventually medicine, or bad medicine, if we abuse it.

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Authors' Contributions

CS and VM convened and ran the informal focus groups. CS wrote most of the paper. EJM and JK contributed substantively to writing the paper. JK was also a member of the focus groups. All authors read and approved the final manuscript.

Conflicts of Interest

All four authors have varying degrees of association with Universal Medicine and are currently members of the Esoteric Practitioners' Association (EPA) which is the body regulating practitioners who are qualified to practice Universal Medicine modalities.

Universal Medicine has a focus on complementary-to-medicine practices, that aim to support and augment medical treatments.

Study Limitations

One limitation of the study is that only summary ALSWH data were available for comparison. This precluded a case-control analysis, wherein UM respondents would be individually matched to ALSWH respondents. A second limitation is that the UM sample was self-selected and much smaller than the ALSWH group, although 449 respondents constitutes a large majority of the estimated 500 to 600 eligible UM event visitors (women in 2015 who had participated in at least one UM event). While this study is not able to make causal inferences about UM, it might have served to inform identification of promising variables to include in future studies. A third limitation is the possibility of response bias or memory bias among UM respondents. A fourth limitation is that 17% of UM respondents dropped out during the survey; however, the dropout population did not differ significantly in their health outcomes from the rest of the respondents.

Future Research

A future study using regression analysis to uncover the association of lifestyle choices and demographics with physical and mental health may be of value. As mentioned previously, a true longitudinal, controlled study of UM participants would be worthwhile, as it would give a more accurate picture of participants' initial health levels, the type and level of specific UM services they access, and the trajectory of their health changes. Such investigation of dose-response relationships and causal factors could inform development of lifestyle modification programs that individuals could use in concert with medicine.

Conclusions

UM-participating women appear to be notable in that they exhibit better than average health and are not members as a result of any competitive selection, unlike senior Whitehall public servants, who are selected on a competitive basis; nor are UM-participating women part of a population with a limiting cultural or religious tradition. UM women also come from a wide range of backgrounds, ages, and countries. Identifying a group of women who are not part of the obesity epidemic and measuring their other health indicators may be of use for further research. Therefore, further research on this group of women could be worthwhile.

Jane Keep has attended Universal Medicine workshops since October 2003. Jane Keep was a director of Universal Medicine UK until 2013. She is a member of the EPA, and a committee member of the EPA, and has been accredited by the EPA to offer Esoteric Healing Modalities since 2010. From 2009-2012 Jane ran a small clinic in England which offered Universal Medicine healing modalities. Since 2012 Jane has been working in corporates/universities/hospitals and occasionally offered paid private Esoteric Healing sessions, though since 2014 she has offered no paid private Esoteric Healing sessions. She was a contributor to Unimed Living 2013 – 2016. Jane has a PhD which referenced the work of over 300 people including Serge Benhayon.

Eunice Minford is a Consultant General Surgeon, and has trained as an Interfaith Minister and Spiritual Counsellor. She also attended the National University of Ireland and obtained a degree of “Master of Applied Christian Spirituality” studying Sacred Esoteric Healing in her thesis. Eunice is also editor of the website “Medicine and Serge Benhayon” and a contributor to that website and to the “Unimed Living” website. She has her own blog “The Soulful Doctor” where she discusses, et al, Universal Medicine. She is also on the EPA professional committee as well as a medical advisor to, and the International Patron of, the EPA. She is a trained esoteric healing practitioner and provides occasional private sessions.

Christoph Schnelle is a financial adviser and has some Universal Medicine associated persons among his client base. Christoph is currently working towards his PhD with The University of Queensland, the subject of which is two randomised controlled trials of Esoteric Connective Tissue Therapy (a Universal Medicine modality) on chronic low back pain and has accumulated case studies as part of this project. Christoph Schnelle’s wife, Nicola Lessing, is involved in voluntary activities around producing content for “Unimed Living” and other websites. Nicola is company secretary of Unimed Living and does this in an honorary capacity. She is not a director or shareholder of Unimed Living. She is not employed by Universal Medicine or Unimed Living and does not receive any financial incentives from Universal Medicine or Unimed Living.

Vanessa McHardy is involved in voluntary activities around producing content for “Unimed Living”, presenting at a conference on Psychological Well Being in 2013 on the Gold Coast of Australia. She has no other involvement other than what is set out below.

All four authors have experienced substantial health benefits since they started visiting Universal Medicine events. They all have published blogs on Universal Medicine associated websites and all four have commented on other blogs published on those websites.

All four have no financial ties and have received no money from Universal Medicine or its related entities including no reimbursements of expenses. Each one attends more than 10 Universal Medicine events a year and regularly receive treatments from Universal Medicine accredited practitioners.

Multimedia Appendix 1

Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist.

[PDF File (Adobe PDF File), 53KB - [publichealth_v4i1e6_app1.pdf](#)]

Multimedia Appendix 2

Sleep issues, BMI changes, and BMI changes by age.

[PDF File (Adobe PDF File), 252KB - [publichealth_v4i1e6_app2.pdf](#)]

Multimedia Appendix 3

Symptoms for which Universal Medicine (UM) respondents fared better than Australian Longitudinal Study on Women’s Health (ALSWH) respondents.

[PDF File (Adobe PDF File), 49KB - [publichealth_v4i1e6_app3.pdf](#)]

Multimedia Appendix 4

Lack of association between education and other scales.

[PDF File (Adobe PDF File), 444KB - [publichealth_v4i1e6_app4.pdf](#)]

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Abbreviations

ALSWH: Australian Longitudinal Study on Women's Health

BMI: body mass index

CES-D: Center for Epidemiologic Studies Depression Scale

SD: standard deviation

SF-36: 36-Item Short Form Survey

STROBE: Strengthening the Reporting of Observational Studies in Epidemiology

UM: Universal Medicine

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Original Paper

Internet Exposure Associated With Canadian Parents' Perception of Risk on Childhood Immunization: Cross-Sectional Study

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Abstract

Background: There is a large presence of provaccination and antivaccination content on the Internet. The Internet has been identified as an important source for parents to seek and share vaccine information. There are concerns that parental fears or hesitancy on childhood immunizations are increasing due to the popularity of social media and exposure to online antivaccination sentiment. No other studies have investigated the association between seeking vaccine information online and Canadian parents' perception of risk on childhood immunization.

Objective: We aimed to investigate the potential association between seeking vaccine information on the Internet and Canadian parents' perception of risk on childhood immunization in order to quantify the perceived association and increase our understanding on the impact of the Internet to help guide public health interventions.

Methods: We analyzed this association in two population samples: a self-selecting Web-based sample of Canadian parents recruited through Facebook (n=966) and a population-based sample of parents recruited by random digit dialing (RDD; n=951). The outcome was parental perception of vaccine safety on a seven-point ordinal scale from "not safe" to "extremely safe." An ordinal regression model was used to investigate if Internet information seeking on childhood vaccination predicted parental perception of vaccine safety.

Results: After adjusting for income level, Internet reliability, age of parent, and region, the odds of perceiving vaccines as less safe rather than more safe were 1.6 times higher (95% CI 1.3-2.1) for parents who used the Internet to search for vaccination information compared to parents who did not search the Internet in the Web-based sample, and 2.0 times higher (95% CI 1.6-2.5) in the population-based RDD sample.

Conclusions: The results suggest the Internet is significantly associated with Canadian parents' negative perception of vaccine risk. Governmental and scientific sectors should consider the development and implementation of Web-based vaccine interventions to promote confidence in immunization.

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KEYWORDS

Canadian parents; vaccination; immunization; Internet; vaccine safety

Introduction

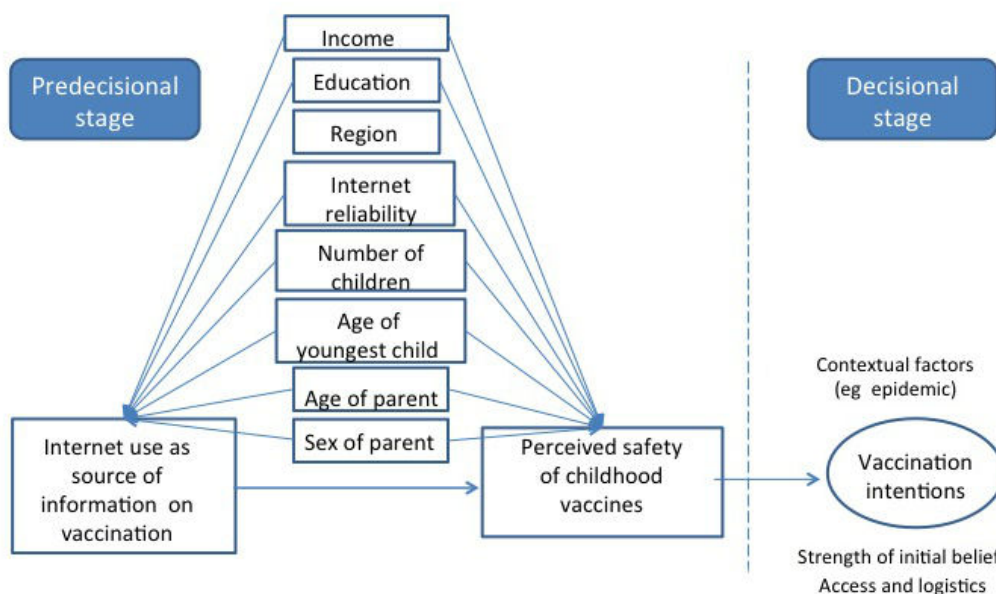
A decrease in public confidence in the safety of vaccines and subsequent lower vaccine uptake has been described as an “impending crisis” in the developed world [1,2]. In Canada, the public’s confusion and doubt over the measles-mumps-rubella (MMR) vaccine was highlighted by a 2010 study reporting that 65% of women and 72% of men believe the vaccine is unsafe or are unsure whether or not the vaccine could cause autism [3]. In addition, a 2015 survey revealed that two in five Canadians believe “the science on vaccinations isn’t quite clear” [4]. In 2011, a national survey of Canadians revealed suboptimal coverage rates for childhood immunizations [5], and several measles outbreaks have been reported across Canada since 2011 [6,7]. In 2014 and 2015, the Public Health Agency of Canada (PHAC) released a public health notice warning Canadians of the unusually high number of measles cases in Canadian provinces [8-10]. The most recent report on measles trends in Canada found that areas of low immunization coverage and case importations are presenting a challenge to Canada’s measles elimination status [11]. In 2017, several outbreaks of mumps were reported across Canada, prompting the Chief Public Health Officer to issue a statement reminding Canadians on the importance of vaccination [12].

The popularity of social media has been identified by the public health community as one of the reasons for the increase in parental fears about childhood vaccines because the Internet is an important vehicle for individuals seeking health information and support, and sharing health knowledge, opinions, and experiences [13]. For example, Statistics Canada reports that 80% of Canadians 16 years of age or older use the Internet [14]; 64% of these Internet users search for medical- or health-related information, with the majority of these Internet users between the ages of 16 to 44 years [15]. At the time of this study, Facebook is reported as the most popular social media platform

in Canada. More than half of the population logs into Facebook at least once per month and Canadian usage rates are higher than global and US averages [16,17]. With the increasing popularity of social media, the public appears to be bypassing conventional sources of health information and looking for the “wisdom of the crowd,” where health decisions depend on other Internet users’ experiences [18]. The Internet allows for rapid sharing of opinions and information, self-organization, the creation of social networks, and empowerment of online groups or people such as antivaccine communities or activists [2]. The large presence of online antivaccination sentiment together with the current pattern of mistrust in the medical community has led to an environment of parents seeking and sharing immunization information [19]. A recent study investigating parents’ confidence in childhood vaccines in the United States found that both vaccine-declining and vaccine-accepting parents have questions, concerns, or misperceptions about vaccines [20]. The majority of parents reported seeking information about vaccine safety prior to vaccinating their children, and identified the Internet as an important source of information. The authors reported a need for the public health community to have a more informed understanding of parents’ Internet use, and of how and to what extent social media interactions with recognized public health organizations can address parents’ vaccine questions. Given the increasing popularity of social media platforms in Canada among Generation X and millennial parents, as well as the suggested influence of social media on parental beliefs and behaviors toward childhood immunization, it is important to investigate and understand this influence in order to inform Web-based interventions that could influence hesitant or undecided parents.

The Health Belief Model is widely applied to determine what factors influence individuals when making vaccination decisions. In terms of immunization, the decision to vaccinate is balanced by the perceived risk of contracting a vaccine-preventable disease and the perceived risk of vaccine adverse events.

Figure 1. Conceptual model on the association between using the Internet to search for information on vaccinations and parental perception on safety of vaccinations.



Due to the abundance and availability of antivaccination sentiment online and the relatively low prevalence of vaccine-preventable disease in the population, it is suggested that individuals may perceive a greater risk of suffering from vaccination side effects than from contracting a vaccine-preventable disease [13]. Therefore, information obtained online that clarifies one's understanding of vaccination risks should also affect the intent to vaccinate (Figure 1). This study investigates the impact of reported online vaccine information-seeking behaviors on perceived immunization risk in two different samples of Canadian parents. We hypothesized that parents who report seeking vaccination information online will perceive vaccines as less safe compared to parents who do not seek information online. Examining this association will increase our understanding and provide evidence on the impact of the Internet on parental perception of risk in the context of childhood immunization to help guide public health interventions.

Methods

Data Sources and Collection

We examined the potential association between seeking vaccine information on the Internet and Canadian parents' perception of risk on childhood immunization data on two different data sources: primary data collected via Web-based survey and secondary data collected via population-based random digit dialing (RDD). We used two independent data sources with the same variables to test the association in two Canadian parent populations recruited at different times and via different methods. Both the Web-based and RDD survey contained questions on respondent demographics and knowledge, awareness, attitudes, and behaviors related to immunization. Identical questions to the RDD survey were used to measure the exposure, main outcome, and confounders in the primary data collection via Web-based survey, with the question format slightly altered for Web-based delivery.

We collected the Web-based survey data via targeted advertisement recruitment on Canada's most popular social media platform, Facebook. French and English advertisements invited Canadian parents to click on the advertisement and participate in a Web-based survey on childhood immunization with a chance to win an iPad mini. Based on sample size calculations to detect an odds ratio of 1.5 and available budget, we aimed to recruit 800 participants. An odds ratio of 1.5 was used for two reasons: (1) to ensure sufficient sample size should the exposure be mildly but statistically associated with the outcome [21], and (2) the value of 1.5 was determined to be a meaningful increase from a public health standpoint and reasonable from an operational research standpoint. We piloted the survey with a convenience sample of 20 Facebook users and their "friends" before advertising to the larger Facebook population. For 4 weeks in December 2013 and January 2014, we displayed the advertisements on the newsfeed of users who were (1) located in Canada, (2) 18 years or older, and (3) parents of a child aged 0 to 15 years. Users who clicked on the advertisement were redirected to a secure Web-based survey, which contained details on the study, eligibility criteria, and

informed consent. The survey automatically terminated if the respondent did not provide informed consent or did not meet eligibility criteria. We were successful in recruiting our targeted population via this method, as also reported by several recent studies that were successful using Facebook as a viable and cost-effective recruitment tool for health research and/or to reach targeted populations [22-27]. The survey response rate was 22.89% (1097 respondents/4792 unique Facebook users who clicked on the Facebook advertisements) and the survey completion rate was 64.68% (1097 respondents/1696 unique Facebook users who started the Web-based survey) with little missing data, resulting in a sample size of 1097 Canadian parents [28]. Further details on the methods and results of the recruitment strategy are available [28].

The population-based RDD data are secondary data deidentified and extracted from a survey collected by a reputable research company, EKOS Research Associates, contracted by PHAC. Experts in immunization and epidemiology at PHAC worked with the research company in the development and testing of the questionnaire. The objective was to collect descriptive data on Canadian parents' knowledge, awareness, attitudes, and behaviors related to immunization to inform policy makers. The secondary data were collected via telephone survey on a population-based RDD sample of Canadian parents during a period of 3 weeks in March 2011. Respondent inclusion criteria were (1) 18 years of age or older, (2) parents of at least one child younger than 18 years, (3) resident of Canada, and (4) able to respond to questions in English or French. The research company compiled a summary report available online [29] and PHAC provided the raw data for the purposes of this study.

Researchers calculated the response rate based on the empirical method (completed + ineligible) / (unresolved + ineligible + nonresponding eligible + completed + nonresponding unknown) and reported a rate of 23.43% (7898/33,698) resulting in a sample size of 1745 Canadian parents [29]. Power calculations estimated 90% power to detect an odds ratio of 1.5 with 95% two-sided significance level.

Ethical approval was obtained from the University of Toronto's Office of Research Ethics (REF#29309).

Primary Exposure

We classified respondents who sought out information on childhood vaccines and reported the Internet as one of their top three sources used for information on vaccines as "used the Internet" and those who do not seek out information on childhood vaccines or do not report the Internet as one of their top three sources as "did not use the Internet."

Outcome

We measured respondent perception on vaccine safety as an ordinal variable from 1 to 7: 1=not at all safe, 4=moderately safe, and 7=extremely safe.

Potential Confounders

We hypothesized parental education level and income, parental age and sex, age of youngest child, number of children, place or residence, and the relative importance of the Internet as a source of information relative to the importance of family,

friends, and/or a health care professional as potential confounders. We measured education level according to four levels: high school or less, trade or vocational school, some university, and bachelors/graduate degree/professional certification. We measured household income level in Can \$10,000 increments ranging from less than Can \$30,000 to Can \$120,000 and we categorized the variable into four levels (less than Can \$30,000, Can \$30,000-\$59,999, Can \$60,000-\$99,000, and more than Can \$100,000) in order for sufficient sample size in each category and to make comparisons among intermediary groups from lowest to highest income. We measured parental age as continuous (years) in the Web-based survey and it was measured as a categorical variable in the RDD survey (younger than 30 years, 30-34 years, 35-39 years, 40-44 years, and 45 years and older). The age of youngest child was measured as continuous (years) in both surveys, and the number of children was measured as categorical (1, 2, 3, 4, 5, and 6 or more) in the Web-based survey and as continuous in the RDD survey. We classified the perceived reliability of the Internet relative to family, friends, or health care professionals as (1) "reported as most reliable and trustworthy source on vaccines" to (4) "not reported in respondent's top three choices as a reliable source of information on vaccines." We categorized place of residence into six regions due to low numbers and to reflect the regions reported in the RDD data: British Columbia, Alberta, Saskatchewan or Manitoba, Ontario, Québec, and Atlantic provinces or Territories.

Statistical Analysis

We excluded participants with missing data from the analyses as sufficient power remained and differences were not detected on the primary independent and dependent variables [21]. We conducted descriptive statistics to describe the characteristics of both samples. We then conducted bivariate ordinal logistic regression to assess associations between each variable and the outcome, respondent perception of vaccine safety. We chose the largest category size as the reference category for categorical variables [21]. We used multivariate ordinal logistic regression modeling to assess the association between Internet use and respondent perception of vaccine safety. The ordinal regression modeled the cumulative odds of perceiving vaccines as "not safe" using the seven-point ordinal outcome variable. As proposed by Hosmer and Lemeshow [30], we used the purposeful selection algorithm to select covariates to retain in the final predictive models. The method uses purposeful variable entry and retention parameters that retain significant covariates but also important confounding variables [30,31]. We included all variables significant at $P \leq .25$ in the multivariable analyses because more traditional levels (eg, .05) can miss important confounding variables [32]. We tested interaction terms of all possible two-way interaction terms against a reduced model using the likelihood ratio test and, in the first analysis, we considered all interaction terms for removal from the model as a block and contrasted against the model with all the main effects but without interaction terms [33]. We removed covariates from the multivariable model if they were not statistically significant at the .1 alpha level and not a confounder. We measured confounding as a 15% or greater change in the parameter estimate of our main association in the reduced model

compared to the full model [30]. We utilized purposeful entry and retention parameters, including the choice of the 15% change-in-parameter-estimate criterion, due to the lack of prior information on known confounders for the investigated association [34]. At the end of this iterative process, we added any variable not entered into the original full model back in one at a time to further assess confounding [30]. This step can help to identify confounders that may not have been significant independently, yet make an important contribution in the presence of other variables [31]. We performed model diagnostics to rule out multicollinearity among covariates, to test for departure from linearity, and to examine the effect of influential observations and variables on our final models. The score test for the proportional odds assumption can be over conservative with large sample sizes or in multivariable analyses, thus we tested the proportional odds assumption by comparing the cumulative odds ratios in a series of six binary logistic models [35]. The assumption held as the odds ratios were all in the same direction and of approximately similar magnitude [35]. We decided to further validate the models from ordinal regression by also conducting binary logistic regression by categorizing the seven-point ordinal variable into a dichotomized outcome variable (levels 1-4: not safe to moderately safe; levels 5-7: safe to extremely safe) We utilized those cut-offs because levels 1 to 4 could be indicative of vaccine hesitancy and concerns with vaccination, whereas levels 5 to 7 indicated confidence in vaccines. We assessed model fit with Pearson and deviance goodness-of-fit statistics (and the Hosmer-Lemeshow test for the binary models) [21]. Although multivariable analyses using non-weighted data produced similar results, we utilized complex sampling procedures available in SAS version 9.3 for descriptive and multivariable analyses of the RDD data to reflect the complex survey design and population weights. We conducted all data analyses using SAS version 9.3 (SAS Institute Inc, Cary, NC, USA).

Results

Descriptive Statistics

Both samples had similar education and income level distributions with almost half of the respondents following the education distribution of Canadian adults by completing some level of higher education [36], and the majority being close to or above the 2012 median total household income of Can \$74,540 for Canadian families [37]. In the Web-based sample, approximately half of respondents reported higher education with a university degree or professional certification, and 38.5% (379/985) reported an income greater than Can \$100,000, followed by 35.6% (351/985) reporting an income of Can \$60,000 to Can \$99,999. In the population-based RDD sample, 42.19% (722/1738) of respondents reported a bachelor's degree or higher, and 33.50% (519/1559) reported an income greater than Can \$100,000, followed by 32.09% (498/1559) reporting an income of Can \$60,000 to Can \$99,999. The distribution on place of residency was similar in both samples; however, the Web-based sample had a lower proportion of Québec residents (10.96%, 120/1097 vs 24.26%, 427/1745) and a higher proportion of Alberta residents (23.65%, 259/1097 vs 10.17%, 200/1745). In both samples, approximately one-third of the

respondents were Ontario residents, which corresponds to the Canadian geographic distribution as it is estimated that 38.5% of Canadians reside in Ontario [38]. There were noted differences in the distributions of parental age and sex, and age of youngest child in the two samples. In the Web-based sample, the mean age of respondents was 32 (SE 3.78) years and the median age of their youngest child was 2 (IQR 1.0) years.

The majority of Web-based respondents (68.77%, 751/1092) were younger than 35 years, female (92.61%, 1003/1083), and reported two or fewer children (81.49%, 894/1097). In the population-based RDD survey, the majority of respondents (62.29%, 674/1082) were 40 years or older and the mean age of their youngest child was 8.3 (SE 0.1) years. In addition, 41.02% (711/1745) were male and the median number of children per respondent was 2 (IQR 1.0).

For both data sources, approximately one-quarter of the respondents reported the Internet to be a reliable source for information on vaccines or vaccination, and approximately 40% (39.10%, 427/1092 vs 41.57%, 716/1729) reported using the Internet to search for information on vaccines. In terms of perception on safety of childhood immunizations, 26.77% (292/1091) of the Web-based survey respondents and 18.74% (324/1729) of the RDD survey respondents reported childhood immunizations as not at all safe to moderately safe (Table 1). A significant linear trend (Cochrane-Armitage tests for trend $P < .001$) was found between looking for information on the Internet and perception of risk of childhood immunizations for both data sources. Note that 11 respondents in the Web-based survey data and 32 respondents in the RDD data were excluded due to missing data (Figure 2).

Multivariable Analysis

Web-Based Survey Data

Complete data were available for 966 respondents. The variables sex of parent and age of youngest child were removed from the multivariable analysis due to nonsignificance in bivariate analyses. Multicollinearity was not present and no interaction terms were retained due to nonsignificance of the likelihood ratio test between the model with all possible covariates and two-way interaction terms and the reduced model without interaction terms. Thus, ordinal logistic regression was performed with the following full model: Internet use, education level, income level, age of parent, age of youngest child, region, and reliability of the Internet. Nonsignificant variables (education level, number of children, and income level) were tested for potential confounding with only income level being retained in the model due to a significant change (26%) in the

predictor's estimate compared to the full model excluding education level and number of children. Originally excluded variables (sex of parent and age of youngest child) were individually re-entered into the model and were not found to be significant confounders. The covariates income level, Internet reliability, age of parent, and regions of residence remained in the final model (Table 2). After adjusting for income level, Internet reliability, age of parent, and region, the odds of perceiving vaccines as less safe rather than safe are 1.6 times higher (95% CI 1.3-2.1) for parents who use the Internet to search for vaccination information compared to parents who do not search the Internet. Chi-square statistics (deviance $P > .99$, Pearson $P = .10$) indicated model fit. Furthermore, the binary logistic regression produced similar estimates and precision (OR 1.6, 95% CI 1.1-2.3), and good model fit (Hosmer and Lemeshow $P = .09$).

Population-Based Random Digit Dialing Data

Complete data were available for 951 RDD respondents. The variables sex of parent and income level were removed from the multivariable analysis due to nonsignificance in bivariate analyses. Multicollinearity was not present and all interaction terms were removed from the model. No interaction terms were retained due to nonsignificance of the likelihood ratio test between the model with all possible covariates and two-way interaction terms and the reduced model without interaction terms. Thus, ordinal logistic regression was performed with the following full model: education level, age group of parent, age of youngest child, number of kids, region, and reliability of the Internet. Nonsignificant variables in the full model (education level, number of children, age of youngest child, and age group of parent) were tested for potential confounding with only age group of parent being retained in the model due to a significant change (21.7%) in the predictor's estimate compared to the full model excluding education level, number of children, and age of youngest child. All originally excluded variables (sex of parent and income level) were individually re-entered into the reduced model to check for confounding, and income level was then retained in the final model due to a significant change (16%) of the predictor's estimate (Table 2). After adjusting for income level, Internet reliability, age of parent, and region, the odds of perceiving vaccines as less safe rather than safe are 2.0 times higher (95% CI 1.6-2.5) for parents who use the Internet to search for vaccination information compared to parents who do not search the Internet. Chi-square statistics (deviance $P > .99$, Pearson $P > 1.0$) indicated model fit. Binary logistic regression produced similar estimates and precision (OR 2.2, 95% CI 1.5-3.1), and good model fit (Hosmer and Lemeshow $P = .63$).

Table 1. Characteristics of both study samples for continuous and categorical variables.

Characteristic	Web-based survey (n=1097)	Population-based RDD survey (n=1745) ^a
Age of parent (years), mean (SE)	32.24 (6.69)	—
Age of youngest child (years), mean (SE)	2.50 (3.78)	8.31 (0.14)
Number of children, mean (SE)	—	1.84 (0.02)
Age group of parent (years), n (%)		
<30	395 (36.17)	57 (5.07)
30-34	356 (32.60)	129 (11.97)
35-39	189 (17.31)	222 (19.66)
40-44	96 (8.79)	244 (22.61)
≥45	56 (5.13)	430 (40.69)
Missing, n	5	663
Number of children, n (%)		
1	492 (44.85)	—
2	402 (36.65)	—
3	147 (13.40)	—
4	44 (4.01)	—
5	5 (0.46)	—
≥6	7 (0.64)	—
Sex of parent, n (%)		
Male	80 (7.39)	711 (41.02)
Female	1003 (92.61)	1034 (58.98)
Missing, n	14	—
Education level, n (%)		
High school or less	172 (16.09)	358 (20.41)
Trade or vocational	286 (26.75)	514 (29.63)
Some university	110 (10.29)	144 (7.75)
Bachelor's or graduate degree or professional certification	501 (46.87)	722 (42.19)
Missing, n	28	7
Household income level (Can\$), n (%)		
<\$30,000	85 (8.6)	157 (9.89)
\$30,000-\$59,999	170 (17.3)	385 (24.52)
\$60,000-\$99,999	351 (35.6)	498 (32.09)
≥\$100,000	379 (38.5)	519 (33.50)
Missing, n	112	186
Region of residence, n (%)		
British Columbia	160 (14.61)	175 (10.41)
Alberta	259 (23.65)	200 (10.17)
Saskatchewan and Manitoba	137 (12.51)	197 (6.50)
Ontario	336 (30.68)	486 (38.19)
Québec	120 (10.96)	427 (24.26)
Atlantic/Territories	83 (7.58)	260 (10.47)
Use of Internet to search for information on vaccines (exposure), n (%)		
Used the Internet	427 (39.10)	716 (41.57)

Characteristic	Web-based survey (n=1097)	Population-based RDD survey (n=1745) ^a
Did not use the Internet	665 (60.90)	1013 (58.43)
Missing, n	5	16
Perception on safety of childhood immunizations (outcome), n (%)		
1 (Not at all safe)	49 (4.49)	43 (2.49)
2	48 (4.40)	24 (1.39)
3	64 (5.87)	50 (2.89)
4 (Moderately safe)	131 (12.01)	207 (11.97)
5	134 (12.28)	275 (15.90)
6	338 (30.98)	500 (28.92)
7 (Extremely safe)	327 (29.97)	630 (36.44)
Missing, n	6	16
Perceived reliability of Internet relative to family/ friends/health care/other, n (%)		
Most reliable	64 (5.88)	149 (8.80)
Second most reliable	97 (8.91)	282 (16.82)
Third most reliable	123 (11.29)	30 (1.78)
Not in top three choices	805 (73.92)	1247 (72.60)
Missing, n	8	37

^aRDD: random digit dialing. Percentages for the population-based RDD survey are weighted.

Figure 2. Perception of risk of childhood immunizations in parents who used the Internet to search for information on immunizations (Web-based survey data: n=1086; RDD data: n=1713).

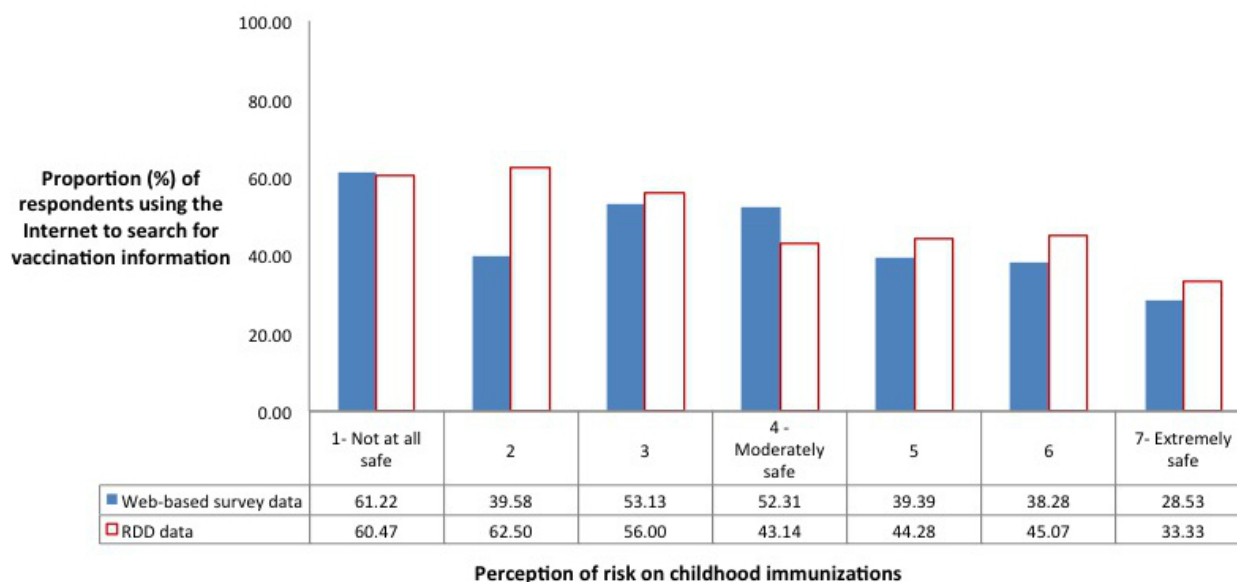


Table 2. Adjusted cumulative odds ratios of proportional odds logistic regression analysis for the association between parental Internet use to search for information on immunizations and parental perception on safety of childhood immunizations.

Variables	Online survey (n=966) OR (95% CI)	Population-based RDD ^a survey (n=951) OR (95% CI)
Predictor of interest		
Use of the Internet	1.61 (1.25-2.09)	1.99 (1.55-2.54)
Did not use the Internet	1.00 Reference	1.00 Reference
Confounders		
Income level (Can\$)		
<\$30,000	1.42 (0.91-2.21)	1.60 (1.03-2.48)
\$30,000 to \$59,999	1.67 (1.20-2.33)	1.19 (0.86-1.63)
\$60,000 to \$99,999	1.23 (0.94-1.62)	1.10 (0.82-1.47)
≥\$100,000	1.00 Reference	1.00 Reference
Perceived Internet reliability		
Most reliable	4.77 (2.88-7.91)	2.18 (1.41-3.36)
Second most reliable	3.96 (2.58-6.07)	1.12 (0.81-1.57)
Third most reliable	1.12 (0.78-1.62)	1.66 (0.61-4.50)
Not in top three choices	1.00 Reference	1.00 Reference
Age of parent (continuous)	0.98 (0.96-0.99)	—
Age of parent (categorical)		
<30	—	1.71 (0.98-2.98)
30-34	—	0.99 (0.68-1.45)
35-39	—	1.20 (0.87-1.67)
40-44	—	1.16 (0.86-1.57)
≥45	—	1.0 Reference
Region of residence		
British Columbia	0.93 (0.65-1.33)	1.63 (1.04-2.57)
Alberta	0.77 (0.56-1.06)	1.38 (0.89-2.15)
Saskatchewan and Manitoba	0.64 (0.43-0.95)	1.71 (1.13-2.59)
Ontario	1.00 Reference	1.00 Reference
Québec	1.89 (1.27-2.83)	1.26 (0.89-1.78)
Atlantic/Territories	1.00 (0.63-1.60)	1.08 (0.75-1.56)

^aRDD: random digit dialing.

Discussion

Although the Internet has been reported as an important influence on parental perception of risk on childhood immunizations, to our knowledge no study has quantified the association between seeking vaccine information on the Internet and perception on safety of childhood immunizations among Canadian parents. The analyses on both datasets resulted in the same conclusion with similar effect sizes not significantly different from one another. The findings from both data sources confirm the assumed relationship between looking for vaccine information on the Internet and perception of risk on vaccine safety, with both samples revealing higher odds of perceiving vaccines as “not safe” in parents who used the Internet to search

for information on vaccines compared to parents who did not use the Internet for vaccine information. These results are consistent with a before-and-after Internet experiment study conducted in Germany where participants exposed to short searches on vaccine critical websites reported an increase perceived risk of vaccinating [39].

This study utilized two different data sources on Canadian parents, sampled at different times. The RDD data were collected in March 2011 and the Web-based data were collected between December 2013 and January 2014, thus the results represent a specific period in time. To our knowledge, there have been no significant policy changes from 2011 to 2014 and although several measles outbreaks have occurred since early 2011, both populations would have been exposed to the media

coverage. Respondents were also asked about factors influencing vaccination decisions and there was no significant difference in time-related contextual influences reported. Furthermore, we received similar results in both samples, thus the bias introduced by time-varying contextual influences is likely nondifferential.

Due to incomplete and unreliable data, our study could not account for the reliability of the websites parents searched or in the type of communications they were exposed to on the Internet. For example, many Web-based respondents reported using search engines and clicking on the websites from their search results, as opposed to identifying specific websites or types of websites. According to the summary report by the research company who conducted the RDD survey, “Google search engine” was the primary website reported to be used by almost half of the respondents who searched for vaccination information online, followed by various government websites and other websites such as medical sites (eg, WebMD), online chat rooms, wikis, etc [29]. Thus our respondents were likely exposed to a variety of messages, but several studies have shown an abundance of antivaccination messaging via Internet searching (or “Googling”) for information on vaccines [40-43]. In addition, this study did not take into account the respondents’ perceptions of risk on vaccine safety prior to the Internet search, and if the Internet altered prior perceptions of risk or acted to support previously held beliefs. Thus, we can establish a significant association between parents seeking vaccine information online and negative perception of risk on childhood immunizations; however, we cannot establish causality or direction of causality.

As more people abandon landline telephones, the validity of traditional population telephone surveys is compromised with low response rates and potentially nonrepresentative samples. Representativeness and validity concerns are also relevant for Web-based surveys as research relies on the collection of self-reported data by self-selected online participants [44]. Both sampling techniques produced low response rates of 23%, which could produce biased samples; however, analysis of the two different samples via two different regression methods produced similar models and conclusions indicating the results were likely not due to chance. In addition, the Web-based sample achieved a similar or better response rate to other studies using Web-based recruitment [27], and the increase in cell phone utilization and call display presents a challenge in preventing noncoverage bias in the RDD sample [45]. Furthermore, the intent of the study was not to generalize the results to Canadian parents but to have

sufficient power to examine the relationship between the predictor and the outcome. Thus, the results from our primary data collection can only be applied to our sampled Web-based population and not generalizable to the Canadian population. Nonetheless, we had similar results in the Web-based sample as the RDD sample, which was intended to be representative of Canadian parents.

Current initiatives aiming to reach and influence parents’ decision to vaccinate have not adequately abated the influence of the online antivaccination movement. Health agencies currently have an online presence; however, they have been slow to fully adopt the true nature of social media platforms and communication remains mostly by top-down dissemination of information [18,46]. However, studies have shown that health communications in the form of stories or testimonials are important influences on risk perception [39,47] and that there is a need for more dialogue-based approaches targeted to specific subpopulations [48]. As evidenced in this study, using the Internet for vaccination information and the relative importance of the Internet as a trustworthy and reliable source are important factors in individual perception of vaccine safety. The evidence provided here suggests the need for increased efforts in Web-based interventions that promote confidence in immunization. In Canada, search terms of “vaccine,” “vaccination,” and “immunization” via Google will produce more provaccination than antivaccination websites [19] and lead to highly placed sites with significant authority. However, these sites do not meet user expectation of more complex interaction tools and engagement. In addition, mistrust in health care professionals and the government has been reported as an important factor in vaccine hesitancy or refusal [49-51], thus trusted authorities could consider working with other popular websites and influential platforms (such as “Mommy blogs”) to provide information supportive of immunization. Health authorities need to tackle the negative influence of online vaccine information or communications, and better utilize social media for positive communication to reach and influence vaccine-hesitant Canadian parents searching for information on the Internet. The Internet has become an important risk factor for vaccine hesitancy, with exposure nearly doubling the risk that parents will question the value of immunization. This study provides evidence that searching the Internet for vaccination information is significantly associated with Canadian parents’ negative perception of risk on childhood immunizations, thus there is a need for improved Web-based interventions by public health professionals to better understand and mitigate this risk.

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Conflicts of Interest

None declared.

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Abbreviations

MMR: measles-mumps-rubella

PHAC: Public Health Agency of Canada

RDD: random digit dialing

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Original Paper

Objectively Measured Baseline Physical Activity Patterns in Women in the mPED Trial: Cluster Analysis

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Abstract

Background: Determining patterns of physical activity throughout the day could assist in developing more personalized interventions or physical activity guidelines in general and, in particular, for women who are less likely to be physically active than men.

Objective: The aims of this report are to identify clusters of women based on accelerometer-measured baseline raw metabolic equivalent of task (MET) values and a normalized version of the METs ≥ 3 data, and to compare sociodemographic and cardiometabolic risks among these identified clusters.

Methods: A total of 215 women who were enrolled in the Mobile Phone Based Physical Activity Education (mPED) trial and wore an accelerometer for at least 8 hours per day for the 7 days prior to the randomization visit were analyzed. The k-means clustering method and the Lloyd algorithm were used on the data. We used the elbow method to choose the number of clusters, looking at the percentage of variance explained as a function of the number of clusters.

Results: The results of the k-means cluster analyses of raw METs revealed three different clusters. The unengaged group (n=102) had the highest depressive symptoms score compared with the afternoon engaged (n=65) and morning engaged (n=48) groups (overall $P < .001$). Based on a normalized version of the METs ≥ 3 data, the moderate-to-vigorous physical activity (MVPA) evening peak group (n=108) had a higher body mass index ($P = .03$), waist circumference ($P = .02$), and hip circumference ($P = .03$) than the MVPA noon peak group (n=61).

Conclusions: Categorizing physically inactive individuals into more specific activity patterns could aid in creating timing, frequency, duration, and intensity of physical activity interventions for women. Further research is needed to confirm these cluster groups using a large national dataset.

Trial Registration: ClinicalTrials.gov NCT01280812; <https://clinicaltrials.gov/ct2/show/NCT01280812> (Archived by WebCite at <http://www.webcitation.org/6vVyLzwft>)

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KEYWORDS

accelerometer; physical activity; cluster analysis; women; randomized controlled trial; machine learning; body mass index; metabolism; primary prevention; mHealth

Introduction

Background

Increasing physical activity is associated with a reduction in chronic illnesses and an increase in psychological well-being [1-3]. The 2008 Physical Activity Guidelines for Americans recommends US adults engage in a total 150 minutes of moderate-intensity aerobic activity (ie, brisk walking) each week or 75 minutes of vigorous-intensity aerobic activity each week, to be done in at least 10-minute bouts of activity [4]. The guidelines were developed mainly based on self-reported physical activity data in relation to health outcomes [5]. Since the current guidelines were issued, more objectively measured physical activity data in relation to health outcomes have become available. Recently, the US Department of Health and Human Services announced that they intend to publish new physical activity guidelines in 2018 [6].

Recent investigations have shown that there is a large discrepancy between self-reported and objectively measured moderate-to-vigorous physical activity (MVPA) [7]. Although half of adults meet the current physical activity guidelines by self-report, only 3.5% of American adults meet these guidelines by accelerometer [8]. In particular, women and older adults are less likely to be physically active than men and younger adults regardless of measurement methods [9,10]. Dichotomization of meeting or not meeting the physical activity guidelines provides only one-dimensional information. However, identifying patterns of physical activity throughout the day may help develop more personalized interventions or physical activity guidelines in general, and in particular for women and older adults.

Cluster analysis is a useful statistical technique that can allocate observations/individuals into groups based on similar characteristics [11]. In the past, a cluster analysis technique was used to cluster individuals based on self-reported physical activity and sedentary behavior. Few studies utilized objectively measured (ie, accelerometer) physical activity data. In a large cohort study in Hong Kong, two clusters were identified: (1) the active group characterized by a routine activity pattern on weekdays and a varied pattern on weekends and (2) the less active group characterized by a low activity pattern on weekdays and weekends [12]. A total of 72% of adults in this Hong Kong sample were classified as the less active group, and the daily average duration of MVPA in the active groups was two times greater than in the less active group. One of the limitations of this cohort study was that only four consecutive days of accelerometer data were used.

Goals of This Study

Our research team had a unique opportunity to analyze seven consecutive days of accelerometer data in women who were screened and completed the run-in period of the Mobile Phone Based Physical Activity Education (mPED) randomized controlled trial (RCT). To our knowledge, no study has used cluster analyses to explore daily patterns of physical activity using seven consecutive days of accelerometer data in female adults. The aims of this paper are (1) to identify clusters of women who enrolled in the mPED study based on overall

accelerometer-measured baseline physical activity and MVPA and (2) to compare sociodemographic and cardiometabolic risks among these identified clusters.

Methods

Study Design and Sample

The mPED study is a RCT of the app-based physical activity intervention in physically inactive women (trial registration: ClinicalTrials.gov NCT01280812). Detailed descriptions of the study design and study protocol have been published previously [7,13,14]. The study protocol was approved by the University of California, San Francisco Committee on Human Research and the Data and Safety Monitoring Board. All participants provided written consent prior to study enrollment. In this paper, we analyzed only the sociodemographic, clinical, and self-reported questionnaires data collected at the screening/baseline study visit and accelerometry data collected during the last 7 days of the run-in period prior to a randomization visit.

Initial inclusion criteria for the mPED trial were (1) physically inactive at work and/or during leisure time based on the Stanford Brief Activity Survey [15], (2) intent to be physically active, (3) female aged 25 to 69 years, (4) access to a home telephone or mobile phone, (5) speak and read English, (6) body mass index (BMI) of 18.5 to 43.0 kg/m², and (7) no mild cognitive impairment screened by the Mini-Cog test [16,17]. Initial exclusion criteria were (1) known medical conditions or physical problems that require special attention in an exercise program, (2) planning an international trip during the next 4 months (which could interfere with daily server uploads of mobile phone data), (3) pregnant/gave birth during the past 6 months, (4) severe hearing or speech problem, (5) history of eating disorder, (6) current substance abuse, (7) current participation in lifestyle modification programs or research studies that may confound study results, and (8) history of bariatric surgery or plans for bariatric surgery in the next 12 months.

In total, 318 women came in for a screening/baseline visit. Of those, 57 did not start or complete the run-in period and 46 did not have sufficient accelerometer wear time of at least 8 hours per day for the last 7 days prior to the randomization visit. The remaining 215 participants were analyzed in this report.

Measures

A triaxial accelerometer (HJA-350IT, Active Style Pro, Omron Healthcare Co, Ltd) was used to assess objectively measured physical activity [18,19]. Its dimensions are 74×46×34 mm (width/height/depth) including the clip, and it weighs 60 grams (2.1 oz). Throughout the run-in period, participants were asked to wear the accelerometer all day on their waist, except when showering, bathing, swimming, or sleeping, from the time they got up in the morning until they went to bed at night. All participants were also instructed to engage in their regular daily activity and not increase this activity during the run-in period. The accelerometer displayed only date and time. To avoid providing any feedback and to collect the clean baseline activity data, neither the step counts nor metabolic equivalent of task (MET) values were displayed. Activity data were stored minute

by minute for the entire duration of the run-in period, and the accelerometer's data was automatically reset at midnight. A trained research staff downloaded the data to a personal computer with the software program provided by the manufacturer in the research office prior to randomization visit. In this paper, only recorded accelerometer data during the seven consecutive days prior to the randomization visit were used to identify patterns of physical activity. In order for accelerometer data to be valid, all 7 days of accelerometer activity needed to indicate at least 8 hours per day of recorded wear time for the device. The METs determined by this accelerometer are closely correlated with METs calculated using energy expenditure measured by indirect calorimetry [20,21]. This accelerometer was programmed to collect physical activity intensity every 10 seconds per minute and the mean intensity value of a 1-minute epoch was calculated as the mean of six 10-second epochs. Moderate- or vigorous-intensity activity was defined as ≥ 3 to < 6 or ≥ 6 METs, respectively, using the Compendium of Physical Activities [20,21].

The Center for Epidemiological Studies Depression Scale (CES-D) is a 20-item questionnaire widely used for assessing symptoms of depression [22]. Scores can range from 0 to 60, with higher scores indicating more depressive symptoms. The 12-item Short-Form Health Survey (SF-12) is an instrument derived from the longer 36-item Short-Form Survey, which was designed to measure general health functioning [23]. The SF-12 provides two summary scores, the Physical Component Summary and the Mental Component Summary. Scores are standardized; the mean score in the population is 50 with a standard deviation of 10 points. Higher scores indicate better functioning in physical function or mental status. The Television/Computer Usage Scale is a semistructured interview that estimates an individual's time spent (1) using a computer, Internet, or mobile phone and (2) watching television or movies for the 7 days prior to the interview. This measure was developed by the investigator prior to the trial. A trained research staff used the 7-day worksheet to assess the duration of these activities for the 7 days. The Social Support for Exercise Survey consists of 13 items assessing the level of perceived support from family and friends for behavior changes related to exercise [24]. Each item is scored separately for family and friends, and scores can range from 13 to 65 with higher scores indicating greater support. The Barriers to Being Active Quiz consists of 21 items assessing seven subscales: lack of time, lack of social influence, lack of energy, lack of willpower, fear of injury, lack of skill, and lack of resources. Each subscale can range from 0 to 9 and total scores can range from 0 to 63, with higher scores indicating more barriers to physical activity [25]. The Modified Self-Efficacy for Physical Activity Scale, consisting of six items (five original questions plus one extra question), was used to assess confidence in one's ability to exercise, an important determinant of the stages of change for exercise behavior. Total scores can range from 6 to 30, with higher scores indicating greater self-efficacy for physical

activity. Anthropometric measures included height, weight in kilograms, and waist and hip circumferences; BMI was calculated based on height and weight in kilograms at the screening/baseline visit. Participants were asked to change to a hospital gown and remove their shoes prior to the measurement.

Statistical Analysis

The k-means clustering method (hereafter referred to as k-means) [26] was applied to the accelerometer dataset. This method takes as input: (1) a set of data points with each data point corresponding to a single individual, (2) a subset of characteristics summarizing each data point, and (3) a number of desired clusters. In the terminology of machine learning, the subset of summarizing characteristics is known as the features of the data [27]. As output, this method separates the data points into distinct groups (ie, clusters) such that the data points within each group have similar characteristics and the data points between different groups have different characteristics.

To apply k-means, we used the Lloyd algorithm [28] to perform the computations. To ensure accurate modeling, we repeated the Lloyd algorithm a total of 25 times with random initialization to find the most accurate clustering (as measured by the percentage of variance of the data explained by the identified cluster medians). To determine an appropriate number of desired clusters, we applied the elbow method [29]. The elbow method selects the number of clusters to be such that adding an additional cluster does not significantly reduce the within-group sum of squares. We applied k-means two times, and each time we used a different subset of summarizing characteristics. The two different subsets we used in our analysis are described subsequently. After applying k-means, chi-square or ANOVA tests were used to compare sociodemographic and clinical characteristics among these clustered groups. To visualize the clusters, we first computed the mean for each group selected by k-means of the corresponding data points. Then we applied Loess smoothing [30] in time to better visualize average temporal trends. Statistical analyses were performed in R 3.1.1 [31].

Raw METs Data

The k-means clustering was applied to raw METs data from each enrolled participant to evaluate if raw minute-level METs were able to classify participants by physical activity and time to do physical activity. All observations including day and night were included because participants engaged in activity at various time points. Thus, naively removing night data would lead to a loss of information. Specifically, the features for each individual consisted of a 10,080-dimensional vector comprised of consecutive (at the minute interval) METs observations for 7 days. Missing data occurred mainly during nighttime and hence were simply replaced by 1, which is the METs reading for a stationary individual.

Figure 1. Equations 1-3.

$$(1) b_{i,t} = \begin{cases} 1, & \text{if } d_{i,t} \geq 3 \\ 0, & \text{otherwise} \end{cases}$$

(2) For $i=1,2,\dots,215$ and for $t=1,2,\dots,1440$:

$$m_{i,t} = \frac{1}{7} (\sum_{k=0}^6 b_{i,t+1440k})$$

$$(3) x_{i,t} = \frac{m_{i,t}}{SD(m_{i,t})}$$

Normalized METs ≥ 3 Data

We also explored how MVPA (METs ≥ 3) were associated with sociodemographic data and clinical outcomes. Thus, k-means clustering was applied to a normalized version of the METs data from each enrolled participant, and the data were normalized as follows: suppose for each participant i ($i=1,2,\dots,215$) and time t ($t=1,2,\dots,10,080$), the raw METs record was $d_{i,t}$. We first converted the raw METs records into binary values (see Equation 1 in Figure 1). This binary conversion corresponds to whether the participant was having MVPA or not, which is an important indicator to characterize a person's physical activity level. Next, we averaged the binary values for the 7 days to compute the MVPA frequency for a typical day for each individual. We ended up with 1440 features for each individual, which indicates the minute-level normalized METs for the day averaged over all days (see Equation 2 in Figure 1).

Finally, we normalized this vector for each individual by time to have unit Euclidean norm (see Equation 3 in Figure 1). This normalization ensured that the overall physical activity level of each participant was similar and that the clustering results then categorized participants using the time in day (ie, morning, noon, evening) information.

Results

Overall Participants' Characteristics

Overall, the mean age of participants was 52.4 (SD 11.2) years, 54.4% (117/215) were white, 48.8% (105/215) were single or divorced, and 73.0% (157/215) were well educated, reporting college- or graduate-level educations. In addition, 49.3% (106/215) had used a pedometer and 57.2% (123/215) had participated in a diet/weight loss plan prior to study enrollment. The majority of the sample (80.5%, 173/215) drove a car at least once per week.

Clustering on Raw METs Data

The k-mean clustering separated the participants into three groups (Figure 2). The elbow method indicated that separating the data into four groups did not reduce within-group sum of squares significantly. Therefore, we chose three clusters for this analysis (Multimedia Appendix 1). There were 65, 48, and 102 participants in groups 1, 2, and 3, respectively. We refer to these clusters as the "morning engaged," "afternoon engaged," and "unengaged" groups. Figure 1 shows the mean METs for each minute in a day by the three groups after Loess smoothing with span 0.1. The plot in Figure 2 indicates that the morning engaged group engaged in activity earlier than the afternoon engaged group and both groups had similar overall activity level, whereas the unengaged group did not engage in activity as much as the other two groups.

Figure 2. A k-means cluster analysis of raw METs (metabolic equivalent of tasks) data with the Lloyd algorithm (N=215) for physical activity frequency during the day for each cluster.

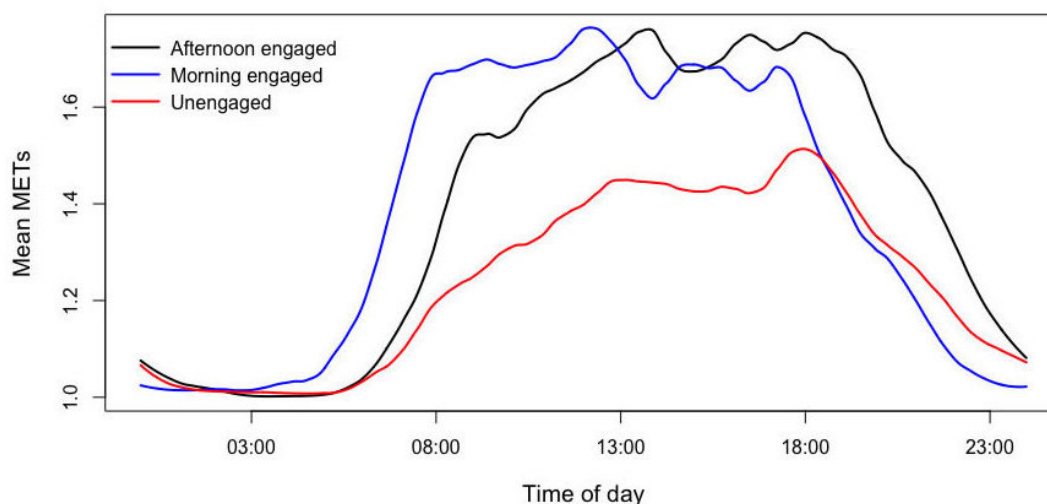


Table 1. Comparison of sociodemographic and clinical characteristics among the three clustered groups based on raw metabolic equivalent of tasks (METs) data (N=215).

Sociodemographics and clinical characteristics	Afternoon engaged group (n=65)	Morning engaged group (n=48)	Unengaged group (n=102)	Overall <i>P</i> value ^a
Sociodemographics				
Age (years), mean (SD)	52.2 (11.3)	53.7 (9.8)	51.8 (11.8)	.64
Education, n (%)				.009 ^b
High school/some college	21 (32.3)	19 (39.6)	18 (17.6)	
College/Graduate school	44 (67.7)	29 (60.4)	84 (82.4)	
Race, n (%)				.15
White	32 (49.2)	22 (45.8)	63 (61.8)	
Asian and Pacific Islander	19 (29.2)	15 (31.3)	16 (15.7)	
Nonwhite and Multiracial	14 (21.5)	11 (22.9)	23 (22.5)	
Marital status (married/cohabitating), n (%)	39 (60.0)	25 (52.1)	46 (45.1)	.17
Occupation, n (%)				.19
Paid full time/part time	42 (64.6)	38 (79.2)	76 (74.5)	
Homemaker/retried/disabled	23 (35.4)	10 (20.8)	26 (25.5)	
Previous pedometer usage, n (%)	34 (52.3)	24 (50.0)	48 (47.1)	.80
Drives a car at least once a week, n (%)	57 (87.7)	37 (77.1)	79 (77.5)	.21
Has a dog, n (%)	12 (18.5)	12 (25.0)	16 (15.7)	.39
Participated in diet plan prior to the study, n (%)	38 (58.5)	25 (52.1)	60 (58.8)	.72
Has a gym membership, n (%)	14 (21.5)	11 (22.9)	38 (37.3)	.05
Accelerometer (objective measure), mean (SD)				
Weekly total minutes of MVPA ^c by accelerometer with 1 minute criteria	372.1 (137.5)	401.5 (132.8)	205.7 (92.6)	<.001 ^d
Weekly total minutes of MVPA by accelerometer with 5 minutes criteria	93.2 (90.8)	119.8 (113.1)	63.3(62.1)	.001 ^e
Weekly total minutes of MVPA by accelerometer with 10 minutes criteria (a 1 or 2 minutes interruption allows)	57.3 (73.3)	78.1 (105.1)	37.8 (47.8)	.006 ^f
Average daily steps	6436.1 (2216.9)	6722.9 (1718.9)	4796.9 (1723.9)	<.001 ^g
Other self-reported measures, mean (SD)				
Weekly total hours of TV watching and computer usage time	25.5 (17.6)	23.3 (16.8)	30.3 (18.3)	.048
SF-12^h				
Physical Component score	52.0 (6.0)	51.7 (6.1)	50.9 (6.6)	.53
Mental Component score	49.2 (8.6)	50.5 (9.6)	46.6 (10.3)	.04
Total CESD ⁱ score	7.5 (7.1)	8.1 (6.5)	11.9 (8.9)	<.001 ^j
Total self-efficacy for physical activity score	18.3 (4.4)	19.6 (4.2)	19.1 (5.0)	.30
Social support for physical activity				
Total family score	31.1 (9.2)	32 (7.7)	30.9 (10.2)	.82
Total friends score	30.8 (7.5)	30.9 (8.1)	32.3 (9.1)	.46
Total barriers to being active score	24.0 (9.5)	22.2 (10.0)	23.6 (10.2)	.91
Clinical data, mean (SD)				
Body mass index (kg/m ²)	29.3 (6.5)	28.1 (5.3)	29.9 (6.1)	.23
Waist circumference (cm)	96.4 (14.4)	94.4 (13.0)	99.0 (14.8)	.17

Sociodemographics and clinical characteristics	Afternoon engaged group (n=65)	Morning engaged group (n=48)	Unengaged group (n=102)	Overall <i>P</i> value ^a
Hip circumference (cm)	109.7 (13.5)	107.2 (12.6)	112.3 (13.9)	.09
Resting systolic blood pressure (mm Hg)	121.1 (14.0)	118.8 (13.4)	121.5 (14.7)	.56
Resting diastolic blood pressure (mm Hg)	76.1 (10.1)	74.7 (8.9)	78.5 (9.9)	.07
Cholesterol, total (mg/dL)	205.5 (35.2)	199.9 (41.4)	203.4 (40.9)	.76
Triglycerides (mg/dL)	117.6 (54.3)	103.9 (46.9)	117.0 (53.4)	.31
LDL ^k (mg/dL)	119.5 (33.0)	115.4 (35.7)	118.8 (33.8)	.80
HDL ^l (mg/dL)	62.6 (15.8)	63.7(18.8)	61.2 (16.5)	.68
HbA _{1c} (%)	5.8 (0.56)	5.7 (0.4)	5.7 (0.5)	.34
Fasting plasma glucose (mg/dL)	95.1 (17.1)	95.5 (12.2)	97.0 (16.0)	.71

^aIf overall *P* values were significant, pairwise comparisons were made. Only significant pairwise comparison *P* values are reported.

^bPairwise comparison between Morning engaged and Unengaged in those with High school/some college: *P*=.008.

^cMVPA: moderate-to-vigorous physical activity.

^dPairwise comparison between Afternoon engaged and Unengaged: *P*<.001; between Morning engaged and Unengaged: *P*<.001.

^ePairwise comparison between Morning engaged and Unengaged: *P*=.001.

^fPairwise comparison between Between Morning engaged and Unengaged: *P*=.005

^gPairwise comparison between Afternoon engaged and Unengaged: *P*=.001; between Morning engaged and Unengaged: *P*<.001.

^hSF-12: 12-item Short-Form Health Survey.

ⁱCES-D: Center for Epidemiological Studies Depression Scale.

^jPairwise comparison between Afternoon engaged and Morning engaged: *P*=.001; between Morning engaged and Unengaged: *P*=.02.

^kLDL: low-density lipoprotein.

^lHDL: high-density lipoprotein.

In [Table 1](#), sociodemographic self-reported questionnaires and physical activity measures were compared among the three groups. The unengaged group represented 47.4% of the sample (102/215). The unengaged group had significantly lower weekly total minutes of accelerometer-measured MVPA with 10 minutes criteria and mean daily steps than the other two groups (overall *P*=.006 and *P*<.001, respectively). Furthermore, the unengaged group had the highest depressive symptoms score compared with the afternoon engaged and the morning engaged groups (overall *P* value <.001).

Clustering on Normalized METs ≥3 Data

The k-mean clustering separated the participants into three groups ([Figure 3](#)). This number of clusters was also chosen by the elbow method, and it showed the within-group sum of squares corresponding to the different number of clusters, and using four clusters did not reduce the within-group sum of squares significantly ([Multimedia Appendix 2](#)). There were 46, 61, and 108 participants in groups 1, 2, and 3, respectively. We will refer to these groups as the MVPA morning and evening

active, MVPA noon peak active, and MVPA evening peak active groups. The clusters were named as such because the MVPA morning and evening active group engaged in MVPA either in the morning or in the evening, the MVPA noon peak active group engaged in MVPA around noon, and the MVPA evening peak active group engaged in MVPA in the evening and at night. The mean normalized METs for each group are shown in [Figure 3](#) after Loess smoothing with span 0.1. We can interpret the vertical axis as the frequency of participants in that group who engaged in MVPA at a particular time. The MVPA morning and evening active group had two peaks: one in the morning and one in the evening. The MVPA noon peak active group tended to engage in MVPA around noon and did slightly less in the evening. The evening peak active group tended to gradually increase MVPA toward evening and with a peak around 6 pm. As seen in [Table 2](#), the MVPA evening peak group (n=108) had higher BMI (*P*=.03), waist circumference (*P*=.02), and hip circumference (*P*=.03) than the MVPA noon peak group (n=61).

Figure 3. A k-means cluster analysis of normalized METs (metabolic equivalent of tasks) ≥ 3 data (N=215). MVPA: moderate-to-vigorous physical activity.

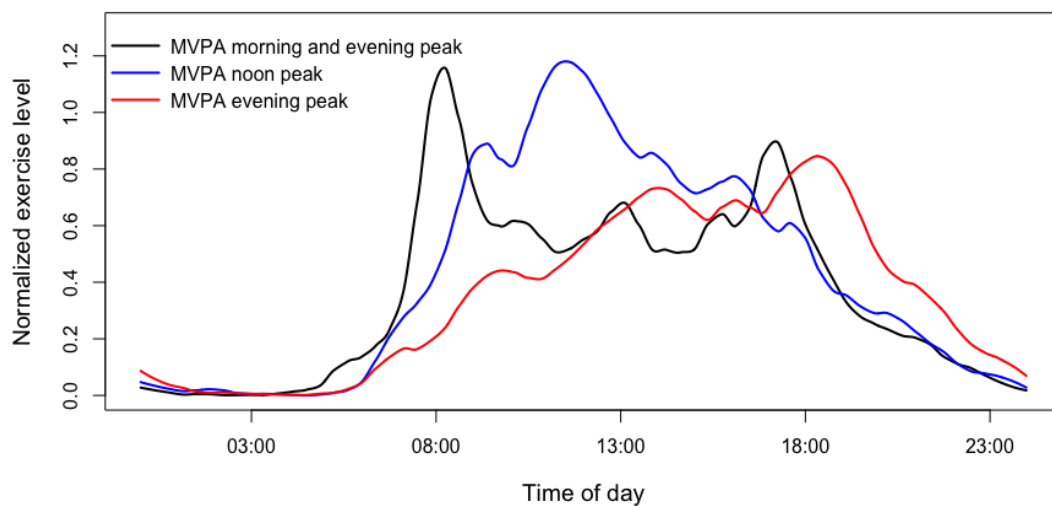


Table 2. Comparison of sociodemographic and clinical characteristics among three clustered groups based on normalized METs ≥ 3 data (N=215).

Sociodemographic and clinical characteristics	MVPA ^a Morning and evening peak group (n=46)	MVPA Noon peak group (n=61)	MVPA Evening peak group (n=108)	Overall <i>P</i> value ^b
Sociodemographics				
Age (years), mean (SD)	51.9 (11.7)	52.4 (10.5)	52.6 (11.5)	.94
Education, n (%)				.81
High school/some college	11 (23.9)	18 (29.5)	29 (26.9)	
College/Graduate school	35 (76.1)	43 (70.5)	79 (73.1)	
Race, n (%)				.20
White	20 (43.5)	31 (50.8)	66 (61.1)	
Asian and Pacific Islander	12 (26.1)	18 (29.5)	20 (18.5)	
Nonwhite and multiracial	14 (30.4)	12 (19.7)	22 (20.4)	
Marital status (Married/cohabitating), n (%)	23 (50.0)	36 (59.0)	51 (47.2)	.33
Occupation, n (%)				.11
Paid full time/part time	39 (84.8)	43 (70.5)	74 (68.5)	
Homemaker/retried/disabled	7 (15.2)	18 (29.5)	34 (31.5)	
Previous pedometer usage, n (%)	25 (54.3)	29 (47.5)	52 (48.1)	.74
Drives a car at least once a week, n (%)	38 (82.6)	48 (78.7)	87 (80.6)	.88
Has a dog, n (%)	9 (19.6)	13 (21.3)	18 (16.7)	.74
Participated in diet plan prior to the study, n (%)	26 (56.5)	31 (50.8)	66 (61.1)	.43
Has a gym membership, n (%)	18 (39.1)	13 (21.3)	32 (29.6)	.13
Accelerometer (objective measure), mean (SD)				
Weekly total minutes of MVPA by accelerometer with 1 minute criteria	287.7 (121.1)	388.4 (168.9)	254.7 (121.2)	<.001 ^c
Weekly total minutes of MVPA by accelerometer with 5 minutes criteria	70.7 (65.0)	120.1 (113.2)	71.1 (72.6)	.001 ^d
Weekly total minutes of MVPA by accelerometer with 10 minutes criteria (a 1-or 2 minutes interruption allows)	41.0 (48.8)	81.3 (101.8)	41.5 (57.2)	.001 ^e
Average daily steps	5754.0 (1560.4)	6663.7 (2359.9)	5211.7 (1936.8)	<.001 ^f
Other self-reported measures, mean (SD)				
Weekly total hours of TV watching and computer usage time	28.7 (19.5)	27.7 (19.5)	26.5 (16.4)	.76
SF-12^g				
Physical Component score	52.3 (5.9)	50.9 (7.1)	51.3 (6.0)	.51
Mental Component score	49.3 (7.6)	47.7 (11.4)	48.1 (9.5)	.69
Total CES-D ^h score	9.5 (8.6)	9.9 (8.3)	9.8 (7.9)	.97
Total self-efficacy for physical activity score	20.0 (4.5)	18.5 (4.3)	18.8 (4.8)	.23
Social support for physical activity				
Total family score	31.1 (8.2)	32.6 (8.8)	30.5 (10.1)	.36
Total friends score	29.8 (7.8)	31.3 (7.7)	32.5 (8.9)	.20
Total barriers to being active score	21.3 (10.0)	25.6 (9.1)	23.5 (10.2)	.08
Clinical data, mean (SD)				
Body mass index (kg/m ²)	29.6 (6.1)	27.6 (5.5)	30.2 (6.2)	.03 ⁱ
Waist circumference (cm)	95.9 (14.2)	93.6 (12.8)	99.7 (14.9)	.02 ^j

Sociodemographic and clinical characteristics	MVPA ^a Morning and evening peak group (n=46)	MVPA Noon peak group (n=61)	MVPA Evening peak group (n=108)	Overall <i>P</i> value ^b
Hip circumference (cm)	111.3 (13.3)	106.5 (12.6)	112.2 (13.9)	.03 ^k
Resting systolic blood pressure (mm Hg)	120.0 (14.1)	119.4 (13.7)	121.7 (14.6)	.57
Resting diastolic blood pressure (mm Hg)	75.3 (10.7)	75.2 (8.7)	78.6 (9.9)	.04
Cholesterol, total (mg/dL)	198.6 (41.0)	203.9 (32.8)	204.9 (41.8)	.66
Triglycerides (mg/dL)	110.4 (54.9)	117.8 (54.8)	113.9 (50.2)	.77
LDL ^l (mg/dL)	113.7 (36.1)	118.4 (28.6)	120.1 (35.7)	.57
HDL ^m (mg/dL)	62.9 (18.1)	62.0 (15.6)	62.0 (17.0)	.95
HbA _{1c} (%)	5.8 (0.5)	5.8 (0.6)	5.7 (0.5)	.68
Fasting plasma glucose (mg/dL)	95.3 (12.3)	98.2 (17.2)	95.2 (15.8)	.46

^aMVPA: moderate-to-vigorous physical activity.

^bIf overall *P* values were significant, pairwise comparisons were made. Only significant pairwise comparison *P* values are reported.

^cPairwise comparison between Morning and evening peak and Noon peak: *P*=.001; between Noon peak and Evening peak: *P*<.001.

^dPairwise comparison between Morning and evening peak and Noon peak: *P*=.009; between Noon peak and Evening peak: *P*<.001.

^ePairwise comparison between Morning and evening peak and Noon peak: *P*=.01; between Noon peak and Evening peak: *P*=.002.

^fPairwise comparison between Noon peak and Evening peak: *P*<.001.

^gSF-12: 12-item Short-Form Health Survey.

^hCES-D: Center for Epidemiological Studies Depression Scale.

ⁱPairwise comparison between Noon peak and Evening peak: *P*=.03.

^jPairwise comparison between Noon peak and Evening peak: *P*=.02.

^kPairwise comparison between Noon peak and Evening peak: *P*=.02.

^lLDL: low-density lipoprotein.

^mHDL: high-density lipoprotein.

Discussion

Principal Results

This study is the first to identify clusters of women aged between 25 and 69 years based on seven consecutive days of accelerometer-measured METs and MVPA (≥ 3 METs). This first cluster analysis successfully identified three groups based on accelerometer-measured METs. It appears that only the difference between the afternoon engaged and the morning engaged groups is timing of activity throughout the day. However, the unengaged group (representing 47.4% of the sample) had a much lower activity level than the other two groups.

We found that the unengaged group was more likely to have a college or graduate degree compared to the afternoon engaged and morning engaged groups. In the cluster analysis study of self-reported physical activity involving 3324 individuals in France, Omorou et al [32] also reported that individuals with high socioeconomic status were less likely to engage in occupational physical activity and active transportation compared to those with low socioeconomic status. In contrast, there is an inverse association between leisure physical activity and socioeconomic status [33]. In other words, individuals with high socioeconomic status had greater leisure physical activity time than those with low socioeconomic status.

Furthermore, consistent with previous study findings [34,35], the unengaged group had a significantly higher depressive

symptom score than the other two groups. It is estimated that approximately 20% to 25% of female adults have significantly elevated depressive symptoms (eg, CES-D score ≥ 16 points) [36]. This inverse association between depressive symptoms and physical activity levels has been well established. More than a dozen RCTs have examined the effect of physical activity on depressive symptoms, and some studies demonstrated physical activity could prevent or mitigate mild-to-moderate depressive symptoms [37]. The unengaged group may respond to a physical activity intervention differently compared with the afternoon active and morning active groups. However, this assumption needs to be confirmed in further studies.

The second cluster analysis based on MVPA (normalized ≥ 3 METs data) also showed three distinct groups (MVPA morning and evening peak, MVPA noon peak, and MVPA evening peak). A two-peak pattern of MVPA (7-8 am and 5-6 pm) in the MVPA morning and evening peak group might be explained by active commuting. The MVPA noon peak group appeared to have the greatest duration of MVPA compared with the other two groups. Moreover, this MVPA noon peak group had significantly lower metabolic risks (BMI, hip and waist circumferences) than the MVPA evening peak group. In a recent large epidemiologic study, the investigators also reported that bouts of 10 minutes or more of MVPA (as per current guidelines) and even bouts of less than 10 minutes were associated with lower levels of adiposity and a lower risk of metabolic syndrome in older adults [38]. The other studies found that bouts of at least 10 minutes of MVPA were a stronger predictor for metabolic risks than

bouts of less than 10 minutes of MVPA [39,40]. Given the benefit of MVPA regardless of its duration, less emphasis on bouts of at least 10 minutes of MVPA might help encourage physically inactive women to engage in MVPA throughout the day.

Strengths and Limitations of the Study

The strengths of this study were that we were able to use seven consecutive days of accelerometer-measured physical activity data instead of depending on participant recall to collect the vast majority of types of activities (active transportation, occupational and leisure activity), and to identify physical activity patterns that were specific to certain times of the day. In addition, the participants were not able to view their steps taken and intensity of physical activity during the data collection period; thus, this blinding function helped prevent participants from modifying their daily activity. Despite these strengths, some limitations need to be taken into account. First, the findings of this study might not be generalizable to men or children. Men tend to be more active than women are across their life spans. Second, in general, individuals with high levels of depressive symptoms are less likely to be enrolled in clinical

studies compared to those with low symptoms. The proportion of the unengaged group could be larger than this data. Lastly, the accelerometer used in the mPED trial was not able to capture activities such as swimming, bicycling, and weight lifting. However, women who engaged in these activities in the mPED trial were relatively low in this sample [7].

Despite the use of objectively measured physical activity, the sample size was relatively small in this study. Thus, these identified cluster groups need to be cross-validated using a large national dataset such as the National Health and Nutrition Examination Survey.

Conclusions

Classifying physically inactive individuals into more precise activity patterns could assist in tailoring the timing, frequency, duration, and intensity of physical activity interventions for women. For example, recommending bouts of physical activity before noon to the unengaged group or MVPA evening peak group may lead to an increase in their activity levels. Future research should consider examining how different types of baseline physical activity cluster groups will respond to different types of physical activity interventions.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Result of the Elbow Method for the raw METs data.

[[PNG File, 89KB - publichealth_v4i1e10_app1.png](#)]

Multimedia Appendix 2

Result of the Elbow Method for the normalized METs ≥ 3 data.

[[PNG File, 77KB - publichealth_v4i1e10_app2.png](#)]

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Abbreviations

- BMI:** body mass index
- CES-D:** Center for Epidemiological Studies Depression Scale
- HDL:** high-density lipoprotein
- LDL:** low-density lipoprotein
- MET:** metabolic equivalent of task
- mPED:** Mobile Phone Based Physical Activity Education
- MVPA:** moderate-to-vigorous physical activity
- RCT:** randomized controlled trial
- SF-12:** 12-item Short-Form Health Survey

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Original Paper

Defining Care Patterns and Outcomes Among Persons Living with HIV in Washington, DC: Linkage of Clinical Cohort and Surveillance Data

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Abstract

Background: Triangulation of data from multiple sources such as clinical cohort and surveillance data can help improve our ability to describe care patterns, service utilization, comorbidities, and ultimately measure and monitor clinical outcomes among persons living with HIV infection.

Objectives: The objective of this study was to determine whether linkage of clinical cohort data and routinely collected HIV surveillance data would enhance the completeness and accuracy of each database and improve the understanding of care patterns and clinical outcomes.

Methods: We linked data from the District of Columbia (DC) Cohort, a large HIV observational clinical cohort, with Washington, DC, Department of Health (DOH) surveillance data between January 2011 and June 2015. We determined percent concordance between select variables in the pre- and postlinked databases using kappa test statistics. We compared retention in care (RIC), viral suppression (VS), sexually transmitted diseases (STDs), and non-HIV comorbid conditions (eg, hypertension) and compared HIV clinic visit patterns determined using the prelinked database (DC Cohort) versus the postlinked database (DC Cohort + DOH) using chi-square testing. Additionally, we compared sociodemographic characteristics, RIC, and VS among participants receiving HIV care at ≥ 3 sites versus < 3 sites using chi-square testing.

Results: Of the 6054 DC Cohort participants, 5521 (91.19%) were included in the postlinked database and enrolled at a single DC Cohort site. The majority of the participants was male, black, and had men who have sex with men (MSM) as their HIV risk factor. In the postlinked database, 619 STD diagnoses previously unknown to the DC Cohort were identified. Additionally, the proportion of participants with RIC was higher compared with the prelinked database (59.83%, 2678/4476 vs 64.95%, 2907/4476; $P < .001$) and the proportion with VS was lower (87.85%, 2277/2592 vs 85.15%, 2391/2808; $P < .001$). Almost a quarter of participants (23.06%, 1279/5521) were identified as receiving HIV care at ≥ 2 sites (postlinked database). The participants using ≥ 3 care sites were more likely to achieve RIC (80.7%, 234/290 vs 62.61%, 2197/3509) but less likely to achieve VS (72.3%, 154/213 vs 89.51%, 1869/2088). The participants using ≥ 3 care sites were more likely to have unstable housing (15.1%, 64/424 vs 8.96%, 380/4242), public insurance (86.1%, 365/424 vs 57.57%, 2442/4242), comorbid conditions (eg, hypertension) (37.7%, 160/424 vs 22.98%, 975/4242), and have acquired immunodeficiency syndrome (77.8%, 330/424 vs 61.20%, 2596/4242) (all $P < .001$).

Conclusions: Linking surveillance and clinical data resulted in the improved completeness of each database and a larger volume of available data to evaluate HIV outcomes, allowing for refinement of HIV care continuum estimates. The postlinked database also highlighted important differences between participants who sought HIV care at multiple clinical sites. Our findings suggest that combined datasets can enhance evaluation of HIV-related outcomes across an entire metropolitan area. Future research will evaluate how to best utilize this information to improve outcomes in addition to monitoring them.

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KEYWORDS

HIV/AIDS; health information technology; surveillance; retention; viral suppression; antiretroviral therapy

Introduction

A central feature of the updated 2020 National HIV/AIDS (human immunodeficiency virus/acquired immunodeficiency syndrome) Strategy is to measure progress along the HIV care continuum to ensure that target goals are met for each stage. The ability to monitor progress in meeting these goals is often hampered by varying methodologies for data collection, analyses, and variation in measurement approaches, with estimates often relying on either clinic-level or population-based data [1,2]. Both approaches have their advantages and disadvantages. Clinic data provides more detailed and real-time data from the site where care is being delivered, and whether the patient kept or missed primary care visits. However, compared with surveillance-based data, clinic data is less informative for tracking patients who become incarcerated, move, or transfer care [3-5]. These silent transfers of care and the limitation that clinic-attending populations may not represent the general population, present a challenge when trying to make robust estimates of HIV care [6-8]. In contrast, surveillance data are useful for monitoring population-based outcomes but sometimes lack data accuracy and completeness for describing patient-level characteristics and often are subject to reporting time lags [9-16].

In the absence of a unified health record for HIV infected persons, triangulating data from multiple sources such as clinical cohort and surveillance data can help improve our ability to describe care patterns, service utilization, comorbidities and ultimately measure and monitor clinical outcomes. For example, collaborations between local HIV clinics and health departments seeking to identify out-of-care HIV infected patients have found that their combined efforts resulted in timelier, more accurate and complete data, and improved ascertainment of care status [4,8,17,18].

The District of Columbia (DC) Cohort study is a prospective observational clinical cohort study of persons living with HIV/AIDS and receiving care across 13 clinical care sites in Washington, DC [19]. Through an innovative data linkage process, DC Cohort participant data, including sociodemographics, HIV-related diagnosis and laboratory values, and sexually transmitted disease (STD) diagnosis data, are matched with the DC Department of Health (DOH) surveillance data every 6 months [19]. After recognizing the limitations of each database alone, the linkage process was designed to improve the completeness and accuracy of both databases. The primary objectives of this analysis were to perform an assessment of the utility of the linkage process in

its ability to improve the completeness of the DC Cohort database and the DOH data. We sought to do this by (1) quantifying the differences between the pre- and postlinked databases, (2) evaluating HIV care continuum outcomes, STD diagnoses, and HIV clinic visit patterns using the prelinked databases compared with the postlinked database, and (3) using the postlinked database to compare sociodemographic characteristics and HIV care continuum outcomes among participants receiving HIV care at multiple sites.

Methods

Data Sources

The DC Cohort Study

Washington, DC has one of the highest HIV rates among cities in the United States, with 2.0% of its population living with HIV—about 14,000 residents as of 2015 [20]. The design of the DC Cohort study, which began enrollment in 2011, has been described previously [19,21,22]. Its source population consists of adults and children diagnosed with HIV infection who received outpatient HIV care at one or more DC Cohort sites and consented to participate. Participants can consent to participate at multiple clinics in which they receive HIV care. DC Cohort sites include 8 hospital-based or affiliated sites and 5 community-based clinics that collectively serve over half of persons living with HIV/AIDS (PLWHA) in DC [19,20]. Clinical data recorded during HIV care visits were abstracted from each site's electronic medical record and merged into a centralized Web-based database (Discovere; Cerner Corporation, Kansas City, MO) that collects data on demographics, diagnoses, laboratory tests, pathology and clinical procedures, medications, and drug resistance information. Informed consent included participant acknowledgment of record linkage between patient data collected by DC Cohort study sites and data reported to DC DOH. The study protocol, consent forms, and research instruments were approved by the George Washington University Institutional Review Board (IRB), the DC DOH IRB, and individual study sites' IRBs [20].

DC Department of Health HIV/AIDS Hepatitis, STD, Tuberculosis Administration

The DC DOH has conducted confidential name-based HIV reporting since 2007 and HIV-related electronic laboratory data reporting of cluster of differentiation 4 (CD4) counts and viral load (VL) values since 2009 (22 District of Columbia Municipal Regulations § 206, 21, 23). STD reporting is also conducted in a confidential named-based manner, with over 45,000 syphilis,

gonorrhea, and chlamydia cases being reported annually [20]. The HIV/AIDS, Hepatitis, STD, Tuberculosis Administration (HAHSTA) receives over 140,000 HIV- and STD-related laboratory reports from 29 different laboratories annually (HAHSTA internal communication).

Linkage of DC Cohort and DC Department of Health HIV/AIDS Hepatitis, STD, Tuberculosis Administration Data

Linkage Methods

Linkage of the DC Cohort and DC DOH databases is performed semiannually and is ongoing. Data on DC Cohort patients enrolled between January 1, 2011 and June 15, 2015 were linked to this analysis. The linkage algorithm is shown in Figure 1. First, each DC Cohort site sends a limited dataset electronically via a secure file transfer protocol (FTP) site to the DC DOH. The limited dataset includes the study ID, patient name, date of birth, and social security number, if available. Simultaneously, the DC Cohort Data and Statistics Coordinating Center (DSCC) prepares a limited dataset for the DC DOH containing the study identification (ID) as well as HIV-related variables collected at the site. The DOH is authorized to receive both these files since it is already authorized to receive named data on all persons living with HIV/AIDS diagnosed with or receiving HIV care in DC. Additionally, DC Cohort participants provided consent for the linkage [9,23].

Data from the sites and the DSCC are then merged with data from the DC enhanced HIV/AIDS Reporting System (eHARS)

and the STD surveillance database (STD*MIS). The postlinkage database containing only the DC Cohort ID is sent back to the DSCC through the FTP site.

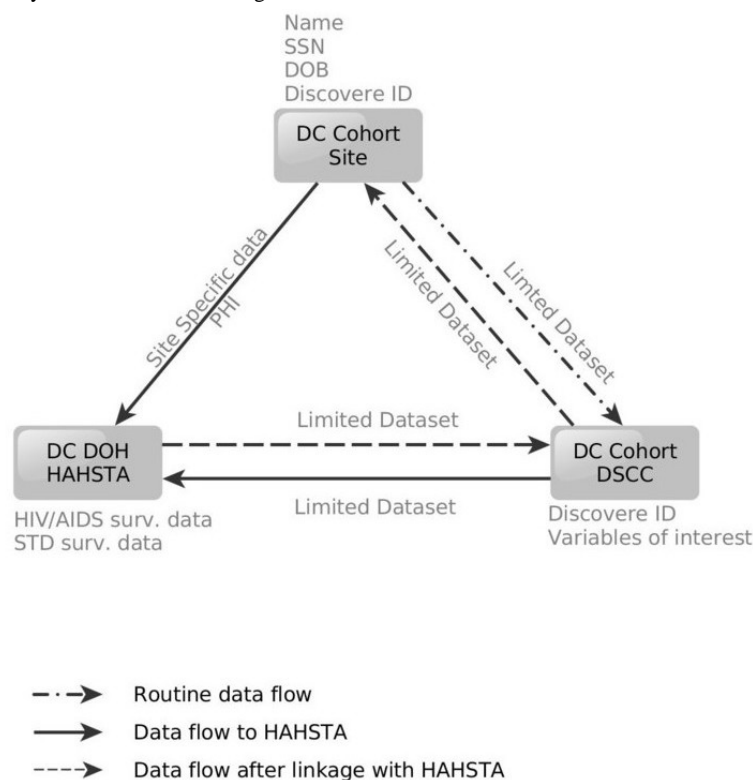
Linkage Algorithm

Electronic linkage of HIV-related datasets is conducted using an 11-key algorithm, using identifiers including patient first and last name, date of birth, sex at birth and social security number. For both the DC Cohort prelinked and DOH datasets, the algorithm creates identifier-based keys that generated variables to systematically match records in the datasets, while taking into account the misspellings of names and data entry errors. After these 11 variables are created in both datasets, each key is matched separately, producing 11 discrete datasets that were later merged and deduplicated by a patients' study and eHARS ID. Similarly, DC Cohort and STD surveillance data are matched using a 10-key algorithm, based on identifiers such as first name, last name, date of birth, and sex at birth. After linkage, the combined dataset is deduplicated by study ID, disease type, and disease date.

Postlinkage Database

Results from the match (the postlinked database) include data on HIV, AIDS, and STD diagnoses, AIDS-defining opportunistic infections (OIs), laboratory data such as CD4 counts and VL, and vital status. Differences in laboratory dates or laboratory values by the data source (DC Cohort vs DC DOH) are reconciled using fuzzy matching. For the date of HIV or AIDS diagnosis, the earlier date is used regardless of the data source.

Figure 1. Linkage algorithm for DC Cohort and DC Department of Health (DOH) data. DC DOH HAHSTA: DC Department of Health HIV/AIDS, Hepatitis, STD, TB Administration; SSN: social security number; DOB: date of birth; PHI: personal health information; Surv.: surveillance; DSCC: Data and Statistics Coordinating Center. Variables of interest include those variables that overlap between what is routinely collected in both the DC Cohort and the DC DOH HAHSTA, including but not limited to dates of HIV diagnoses, CD4 (cluster of differentiation 4) and viral laboratory data, opportunistic infections, and sexually transmitted disease diagnoses.



The United States Centers for Disease Control and Prevention surveillance guidelines regarding the hierarchical risk of HIV transmission are used to reconcile differences in documented transmission risk, independent of data source [24,25].

Eligibility Criteria

For this analysis, participants' data were matched if they were actively enrolled in the DC Cohort as of January 1, 2011, had not withdrawn from the study, or transferred care to another clinical site. To assess continuum of care measures such as retention in care, we reviewed viral load, CD4 tests, and encounters for those participants with at least 1 year of follow-up for the period of June 15, 2014 to June 15, 2015. Participants were considered lost-to-follow-up if, after manual review, no laboratory data from either the DOH or the DC Cohort, and no medical-chart based data from the DC Cohort data were available for 18 months or longer as of June 15, 2015, as per study protocol.

Receipt of Care by Number of Clinical Sites

To determine the number of clinical sites where a participant was receiving care, CD4 and VL test results, proxies for HIV care, were flagged as originating from either a DC Cohort site or a non-DC Cohort site [26,27]. Receipt of care was grouped into three categories: care at one, two, or three or more sites. Care at one site included participants who only had labs from their DC Cohort enrollment site. Care at two sites included participants enrolled at only one DC Cohort site but who had labs from another site (ie, either a non-DC Cohort site or a site that was not their enrollment site). Care at three or more sites included participants enrolled at only one DC Cohort who had 2 or more labs from two or more other sites (ie, either a non-DC Cohort site or another DC Cohort site that was not their enrollment site). Of note, additional labs obtained through the linkage may have been related to HIV primary care or the result of referrals to specialists who were also drawing HIV-related labs. Since we were unable to determine the reason for the CD4 and VL tests conducted outside of the DC Cohort sites, receipt of care at more than one site does not necessarily indicate receipt of HIV primary care at more than one site.

HIV Care Continuum Outcomes: Retention in Care on Antiretroviral Therapy and Viral Suppression

A participant was defined as meeting the definition of being retained in care (RIC) if there was evidence of at least two HIV-related encounters (eg, either HIV-related medical visit and/or laboratory test results) at least 90 days apart in a 12-month period from June 15, 2014 to June 15, 2015 [6,16,28-31]. For the purposes of this analysis, a participant was considered RIC even if the encounters occurred at multiple sites. Being on antiretroviral therapy (ART) was defined as being prescribed an ART regimen anytime during the study period, that is, from June 15, 2014 to June 15, 2015. ART status was based solely on prelinked data as ART data are not collected by the DC DOH. Viral suppression (VS) was defined as participants whose last VL on file was <200 copies/mL among those who were retained in care and on ART.

Statistical Analysis

Frequencies on demographic and clinical characteristics at study enrollment (baseline) were computed in the prelinked DC Cohort database, prelinked DC DOH database, and postlinked database. Chi-square test statistics and Wilcoxon rank-sum tests were used to determine differences among categorical and continuous variables, respectively. Percent concordance between select variables in the prelinked DC Cohort database and postlinked databases were computed using kappa test statistics to assess the comparative accuracy of the databases. Participant outcomes (ie, RIC and VS) in the prelinked DC Cohort database and postlinked database were compared. In the postlinked database, participant demographic and clinical data were also compared based on the number of sites where a participant had evidence of receiving care (1 site, 2 sites, ≥ 3 sites). These comparisons were made using chi-square test statistics. Statistical comparisons with P values <.05 were considered statistically significant. Analyses were conducted in SAS 9.3 (SAS Institute, Inc., Cary, NC) and R (version 3.2.4).

Results

Assessment of Differences in Demographic and Clinical Characteristics Between the Pre- and Postlinkage Databases

The DC Cohort DSCC submitted data on 6054 study IDs to the DC DOH of which 5633/6054 (93.05%) unique participants matched to the DC DOH database and 421/6054 (6.95%) did not (see Figure 2). Of those who did not match, 352/421 (83.6%) were non-DC residents. Among those that matched, 5521/5633 (98.01%) were enrolled at a single DC Cohort site; 112/5521 (2.03%) were enrolled at more than one DC Cohort site. Of the matched participants, 4476/5521 (81.07%) were actively enrolled in the study with at least 1 year of follow-up by the end of 2015.

The demographic and clinical characteristics are displayed by the database from which they were calculated: the prelinked DC Cohort database, the prelinked DC DOH database, and the postlinked database as shown in Table 1. In the prelinked DC Cohort database, among the 5521 participants enrolled at one DC Cohort site, 25.99% (1435/5521) of the study sample was female (data not shown), 4069/5521 (73.70%) non-Hispanic black, and 4093/5521 (74.14%) were DC residents. Nearly 50% (2220/4477) were identified as men who have sex with men (MSM) as their HIV transmission risk. Mean age was 44 years (data not shown) and mean time since HIV diagnosis was 14 years. Since enrollment, 4719/5333 (88.49%) participants had ever been virally suppressed, 521/2273 (22.92%) had an OI at AIDS diagnosis, and 2123/5521 (38.45%) had ever had an STD diagnosis.

When comparing the prelinked DC Cohort database with the postlinked database, a significantly higher percentage of participants were found to be black, deceased, infected through MSM sexual contact, to have had an OI at AIDS diagnosis, and to have ever been virally suppressed. ($P < .001$ for all). The mean duration of HIV diagnosis in the postlinked database increased from 14 to 14.8 years, indicative of earlier diagnosis dates.

Additionally, the number of STD diagnoses increased from 2123 to 2739. Furthermore, post linkage, a higher percentage of participants were Maryland and Virginia residents, more infections were attributed to MSM sexual contact and fewer to MSM/IDU, the mean duration of infection increased from 12.2 to 14.8 years, and the proportion of participants ever virally suppressed increased ($P < .001$ for all).

Interrater reliability of selected variables that overlapped between the prelinked DC Cohort database and the postlinked database varied in agreement. There was strong agreement for race/ethnicity ($\kappa = .75$) and state of residence ($.72$); moderate agreement for vital status ($\kappa = .55$) and OI at AIDS diagnosis ($\kappa = .40$), and poor to fair agreement for transmission risk ($\kappa = .36$) and whether a participant had ever been virally suppressed (ie, < 200 copies/mL; $\kappa = .20$).

The prelinked DC Cohort database included laboratory data collected at clinical sites, while the prelinked DC DOH database included laboratory data collected for surveillance purposes. While the number of CD4 results were fairly similar when comparing prelinked DC Cohort ($n = 33,505$) and prelinked DC DOH ($n = 35,990$) databases, the number of VL results was not. The prelinked DC Cohort database had 31,715 VL results, yet the prelinked DC DOH database had only 12,381 VL results.

Differences in Demographic and Clinical Characteristics by Number of HIV Care Sites

Differences in demographic and clinical characteristics of DC Cohort participants who were matched through June 15, 2015 were assessed based on the number of HIV care sites using the postlinked database. The number of sites where a participant received HIV care was determined using the source of HIV labs. Of the sample, 4242/5521 (76.83%) had evidence of receiving HIV care at only one DC Cohort site, 855/5521 (15.49%) at two sites, and 424/5521 (7.68%) at three or more sites (Table 2). Those who received care at three or more sites differed demographically and clinically from those who received care at fewer sites; they were more likely to be non-Hispanic black, have a history of AIDS, be homeless or report temporary housing, and to have been referred to substance use treatment. Those receiving care at three or more sites were also more likely to have public insurance, be enrolled in primary care at their DC Cohort site, and receive care at a community-based DC Cohort site. This group also fared worse clinically; they were more likely to have lower CD4 counts (≤ 350 cells/mm³), have a detectable VL (ie, > 200 copies/mL), and have uncontrolled viremia (ie, VL $\geq 100,000$ copies/mL) on their most recent VL test. They were also more likely to suffer from comorbid conditions, including hypertension, cardiovascular disease, and mental health issues ($P < .001$; Table 2) and more likely to have died by June 2015.

Figure 2. Results of linkage of DC Cohort and DC Department of Health (DOH) surveillance data as of June 2015 (N=5521). DOH: Department of Health; VL: viral load; CD4: cluster of differentiation 4.

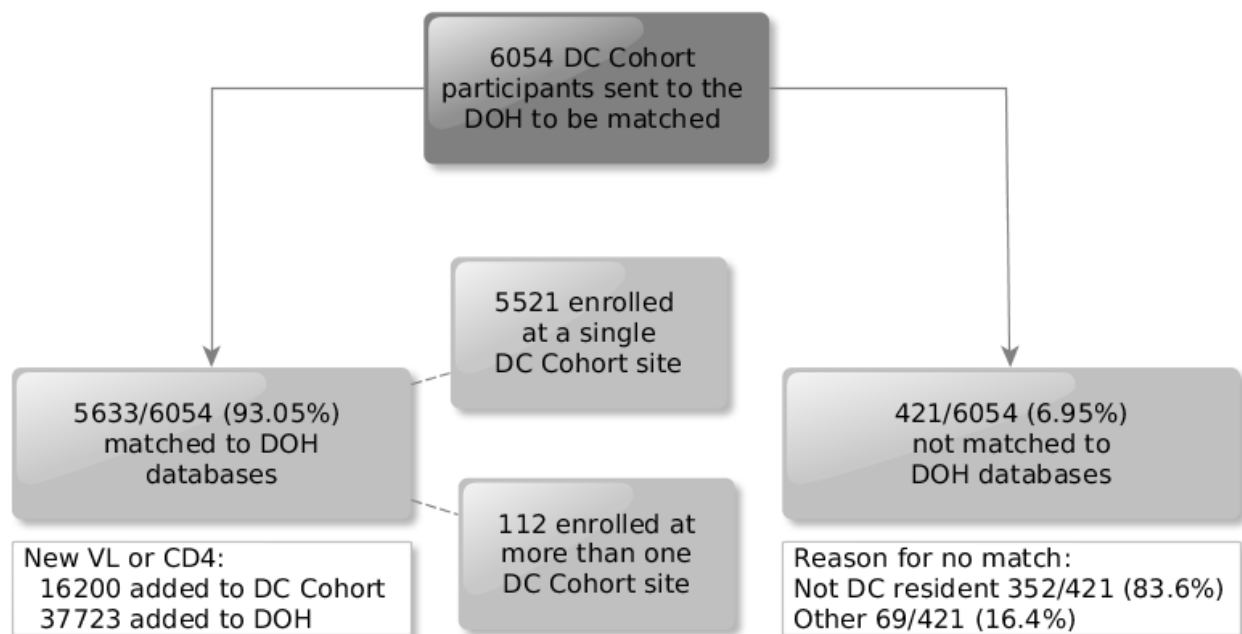


Table 1. Demographic and clinical characteristics of matched participants by data source (DC Cohort and DC Department of Health [DOH]) and linkage status as of June 2015 (N=5521).

Characteristic ^a	Prelinked DC cohort data, n (%)	Prelinked DOH ^b data, n (%)	Postlinked data, n (%)	Prelinked DC cohort versus postlinked (<i>P</i> value ^c)	Prelinked DOH versus postlinked (<i>P</i> value)	Agreement/concordance between prelinked DC cohort and postlinked data (Kappa)
Race/ethnicity						
Non-Hispanic black	4069 (73.70)	4142 (75.02)	4175 (75.62)	<i><.001</i>	.01	
Non-Hispanic white	865 (15.67)	860 (15.58)	912 (16.52)			.75
Other/unknown ^d	587 (10.63)	519 (9.40)	434 (7.86)			
State of residence						
District of Columbia	4093 (74.14)	4088 (74.04)	4091 (74.10)	<i>>.99</i>	<i><.001</i>	
Maryland	1040 (18.84)	882 (15.98)	1042 (18.87)			.72
Virginia	314 (5.69)	269 (4.87)	313 (5.65)			
Other	74 (1.43)	282 (5.11)	75 (1.36)			
Vital status	106 (1.92)	122 (2.21)	163 (2.95)	<i><.001</i>	.016	.55
Transmission risk^e						
MSM ^f /IDU ^g	75 (1.68)	206 (4.31)	93 (1.74)	<i><.001</i>	<i><.001</i>	
MSM	2220 (49.59)	2311 (48.36)	2850 (53.23)			
Heterosexual	1519 (33.93)	1374 (28.75)	1439 (26.88)			.36
Perinatal	223 (4.98)		215 (4.02)			
Other	440 (9.83)	888 (18.58)	757 (14.14)			
Mean HIV duration in years (IQR ^h)	14.0 (8.3)	12.2 (7.0)	14.8 (8.2)	<i><.001</i>	<i><.001</i>	-
OI ⁱ at AIDS diagnosis ^j	521 (22.92)	975 (30.20)	981 (28.58)	<i><.001</i>	.16	.40
Ever STD ^k	2123 (38.45)	694 (12.57)	2739 (49.61)	-	-	-
Number of Viral Load labs	31,715	12,381	37,663	-	-	-
Number of CD4 ^l labs	33,505	35,990	43,757	-	-	-
Ever virally suppressed ^m	4719 (88.47)	2532 (47.48)	4848 (90.91)	<i><.001</i>	<i><.001</i>	.20

^aDate of birth and sex at birth were treated as matching variables for the linkage.

^bDOH: Department of Health.

^c*P* values for categorical variables were calculated using chi-square tests; *P* values for continuous distributions were obtained from Wilcoxon rank-sum tests. *P* values in italics denote statistical significance at the .001 level.

^dOther race groups include those of multiple race group and unknown.

^eThe denominator for transmission risk was 4477, 4779, and 5354 for prelinked DC Cohort data, prelinked DOH data and the postlinked data, respectively.

^fMSM: men who have sex with men.

^gIDU: male or female injection drug user.

^hIQR: interquartile range.

ⁱOI: opportunistic infection.

^jOpportunistic infections at AIDS diagnosis is an AIDS-defining condition that does not include those with CD4 counts <200 cells/mm³ or CD4% <14. The denominator for OIs was 2273, 3229, and 3433 for prelinked DC Cohort data, prelinked DOH data, and postlinked data, respectively.

^kSTD: sexually transmitted disease.

^lCD4: cluster of differentiation 4.

^mThe denominator for ever virally suppressed was 5521, 5333, and 5333 for prelinked DC Cohort data, prelinked DOH data, and postlinked data, respectively. Any viral load <200 copies/mL since enrollment was considered suppressed among participants enrolled anytime between January 1, 2011 and June 15, 2015.

Table 2. Demographic and clinical characteristics of DC Cohort participants by number of sites where they were receiving HIV-related care (N=5521).

Characteristic	Total ^a	Care at 1 site	Care at 2 sites	Care at ≥3 sites	P value ^b
Participants, n (%)	5521 (100.00)	4242 (76.8)	855 (15.49)	424 (7.68)	Not applicable
Mean age at entry (SD)	44.3 (13.2)	44.4 (13.4)	44.1 (912.9)	44.6 (11.4)	.63
Gender at birth, n (%)					
Female	1435 (25.99)	1011 (23.83)	280 (32.7)	144 (34.0)	
Race/ethnicity, n (%)					<.001
Non-Hispanic black	4175 (75.62)	3060 (72.14)	726 (84.9)	389 (91.7)	
Non-Hispanic white	912 (16.52)	805 (18.98)	82 (9.6)	25 (5.9)	
Other/unknown ^c	434 (7.86)	377 (8.89)	47 (5.5)	10 (2.4)	
State of residence, n (%)					<.001
District of Columbia	4091 (74.09)	2915 (68.72)	770 (90.1)	406 (95.8)	
Maryland	1042 (18.87)	958 (22.58)	69 (8.1)	15 (3.5)	
Virginia	313 (5.67)	300 (7.07)	13 (1.5)	0 (0)	
Other	75 (1.36)	69 (1.63)	3 (0.4)	3 (0.7)	
Vital status (died), n (%)	163 (2.95)	110 (2.59)	31 (3.6)	22 (5.2)	.001
Transmission risk^d, n (%)					<.001
MSM ^e /IDU ^f	93 (1.74)	58 (1.42)	20 (2.4)	15 (3.6)	
MSM	2850 (53.23)	2293 (55.95)	386 (46.1)	171 (40.8)	
Heterosexual	1439 (26.88)	1089 (26.57)	243 (29.0)	107 (25.5)	
Perinatal	215 (4.02)	170 (4.15)	36 (4.3)	9 (2.1)	
Other/unknown ^g	757 (14.14)	488 (11.91)	152 (18.2)	117 (27.9)	
Housing status, n (%)					<.001
Permanent	4421 (80.07)	3445 (81.21)	663 (77.5)	313 (73.8)	
Temporary	484 (8.77)	333 (7.85)	96 (11.2)	55 (13.0)	
Homeless	66 (1.19)	47 (1.11)	10 (1.2)	9 (2.1)	
Other/unknown	550 (9.96)	417 (9.83)	86 (10.1)	47 (11.1)	
Employment status, n (%)					<.001
Working, full-time	1498 (27.13)	1320 (31.12)	150 (17.5)	28 (6.6)	
Working, part-time	185 (3.35)	145 (3.42)	28 (3.3)	12 (2.8)	
Unemployed	1373 (24.87)	940 (22.16)	270 (31.6)	163 (38.4)	
Other ^h	2465 (44.65)	1837 (43.31)	407 (47.6)	221 (52.1)	
Insurance status, n (%)					<.001
Private	1697 (30.74)	1487 (35.05)	178 (20.8)	32 (7.5)	
Public	422 (61.98)	2442 (57.57)	615 (71.9)	365 (86.1)	
Other	402 (7.28)	313 (7.38)	62 (7.3)	27 (6.4)	
Referral to drug treatment, n (%)	570 (10.32)	375 (8.84)	113 (13.2)	82 (19.3)	<.001
Ever AIDS, n (%)	3497 (63.34)	2596 (61.20)	571 (66.8)	330 (77.8)	<.001
Mean nadir CD4 ⁱ cells/mm ³ (SD)	330.7 (591.6)	329.2 (551.7)	335 (626.2)	336.9 (850.2)	.02
Most recent CD4 cells/mm, n (%)^j					<.001
<50	51 (1.21)	25 (0.79)	10 (1.4)	16 (4.5)	
50-200	282 (6.69)	170 (5.37)	65 (9.4)	47 (13.2)	

Characteristic	Total ^a	Care at 1 site	Care at 2 sites	Care at ≥3 sites	<i>P</i> value ^b
200-350	492 (11.67)	357 (11.27)	82 (11.8)	53 (14.9)	
350-500	791 (18.76)	602 (19.00)	114 (16.5)	75 (21.1)	
500+	2601 (61.68)	2014 (63.57)	422 (60.9)	165 (46.3)	
Most recent viral load copies/ml, n (%)^k					<i><.001</i>
<200	3458 (83.83)	2729 (86.72)	518 (78.5)	211 (66.4)	
200-1000	188 (4.56)	128 (4.07)	40 (6.1)	20 (6.3)	
1000-10,000	183 (4.44)	120 (3.81)	39 (5.9)	24 (7.5)	
10,000-50,000	182 (4.41)	104 (3.30)	40 (6.1)	38 (11.9)	
50,000-100,000	66 (1.60)	39 (1.24)	14 (2.1)	13 (4.1)	
100,000+	48 (1.16)	27 (0.86)	9 (1.4)	12 (3.8)	
Primary care at DC Cohort site, n (%)	3790 (68.6)	2774 (65.39)	646 (75.6)	370 (87.3)	<i><.001</i>
Comorbid conditions, n (%)					
Mental health	2345 (42.47)	1650 (38.90)	435 (50.9)	260 (61.3)	<i><.001</i>
Hypertension	1396 (25.29)	975 (22.98)	261 (30.5)	160 (37.7)	<i><.001</i>
Cardiovascular	939 (17.01)	662 (15.61)	168 (19.6)	109 (25.7)	<i><.001</i>
Hepatitis C	586 (10.61)	377 (8.89)	127 (14.9)	82 (19.3)	<i><.001</i>
Diabetes	554 (10.03)	376 (8.86)	115 (13.5)	63 (14.9)	<i><.001</i>
Respiratory	473 (8.57)	269 (6.34)	115 (13.5)	89 (21)	<i><.001</i>
Chronic renal failure	462 (8.37)	310 (7.31)	94 (11.0)	58 (13.7)	<i><.001</i>
Hepatitis B	136 (2.46)	107 (2.52)	7 (0.8)	22 (5.2)	.20
Chronic liver disease	139 (2.52)	106 (2.50)	20 (2.3)	13 (3.1)	.66
Type of clinic, n (%)					<i><.001</i>
Hospital-based	3024 (54.77)	2563 (60.42)	365 (42.7)	96 (22.6)	
Community-based	2497 (45.23)	1679 (39.58)	490 (57.3)	328 (77.4)	

^aData are for participants enrolled through June 15, 2015. Care at one site included singly-enrolled participants who had 0 or ≥1 lab from their DC Cohort enrollment site. Care at two sites included singly-enrolled participants who had 0 or ≥1 lab from their DC Cohort enrollment site and ≥1 lab from a second site (ie, a non-DC Cohort site or another DC Cohort site that was not their enrollment site). Care at three or more sites included singly-enrolled participants who had 0 or ≥1 lab from their DC Cohort site and ≥2 labs from ≥2 other sites (ie, a non-DC Cohort site or another DC Cohort site that was not their enrollment site).

^b*P* values for categorical variables were calculated using chi-square tests; *P* values for continuous distributions were obtained from Wilcoxon rank-sum tests. *P* values in italics denote statistical significance at the .001 level.

^cOther race groups include those with multiple races and missing; unknown is unknown race/ethnicity.

^dThe denominator for transmission risk was 5354, 4098, 837, and 419 for the total sample, care at 1 site, care at 2 sites, and care at ≥3 sites, respectively.

^eMSM: men who have sex with men.

^fIDU: male or female injection drug user.

^gOther transmission risk includes missing and risk not identified.

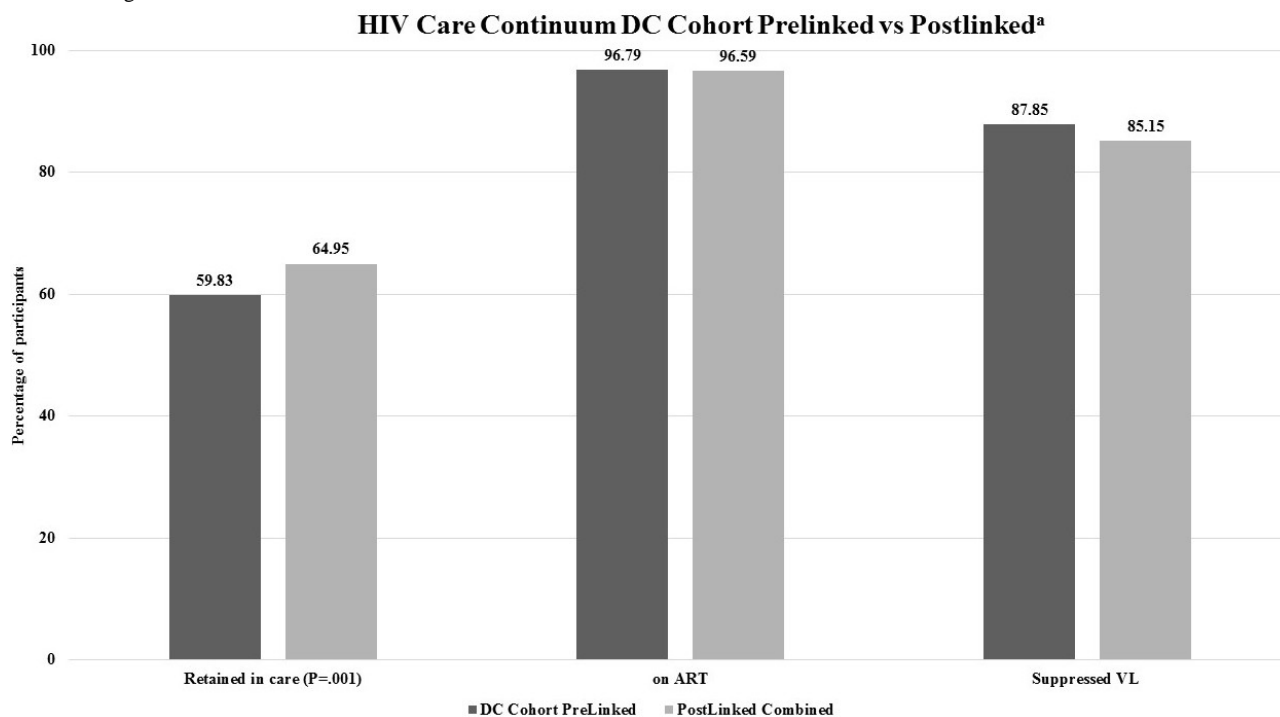
^hOther employment status includes student, disabled, retired and other/unknown.

ⁱCD4: cluster of differentiation 4.

^jThe denominators for CD4 count are 4217, 3168, 693, and 356 for the total sample, care at 1 site, care at 2 sites, and care at ≥3 sites, respectively.

^kThe denominators for viral load are 4125, 3147, 660, and 318 for the total sample, care at 1 site, care at 2 sites, and care at ≥3 sites, respectively.

Figure 3. Percentage of participants matched, retained in care, on antiretroviral therapy (ART) and having suppressed viral load (VL) in Washington, DC 2014-2015 stratified by linkage status (pre vs post) (N=4476). The symbol "a" signifies DC Cohort participants who matched with DC Department of Health records and were actively enrolled, not withdrawn, or transferred care from the Cohort, alive, and with at least 1 year of follow-up as of June 15, 2014. Retention in care was defined as matched participants with evidence of at least two HIV-related encounters (eg, either HIV-related medical visit and/or laboratory test results) at least 90 days apart in a 12-month period from June 2014 to June 2015. Being on ART was defined as the number of Cohort participants who were prescribed an antiretroviral therapy (ART) regimen that overlapped with the study period. ART status was based on prelinked data as ART data are not collected by the DC DOH. Suppressed viral load (VL) was defined as matched participants whose last VL was <200 copies/mL among those who were retained in care and on ART.

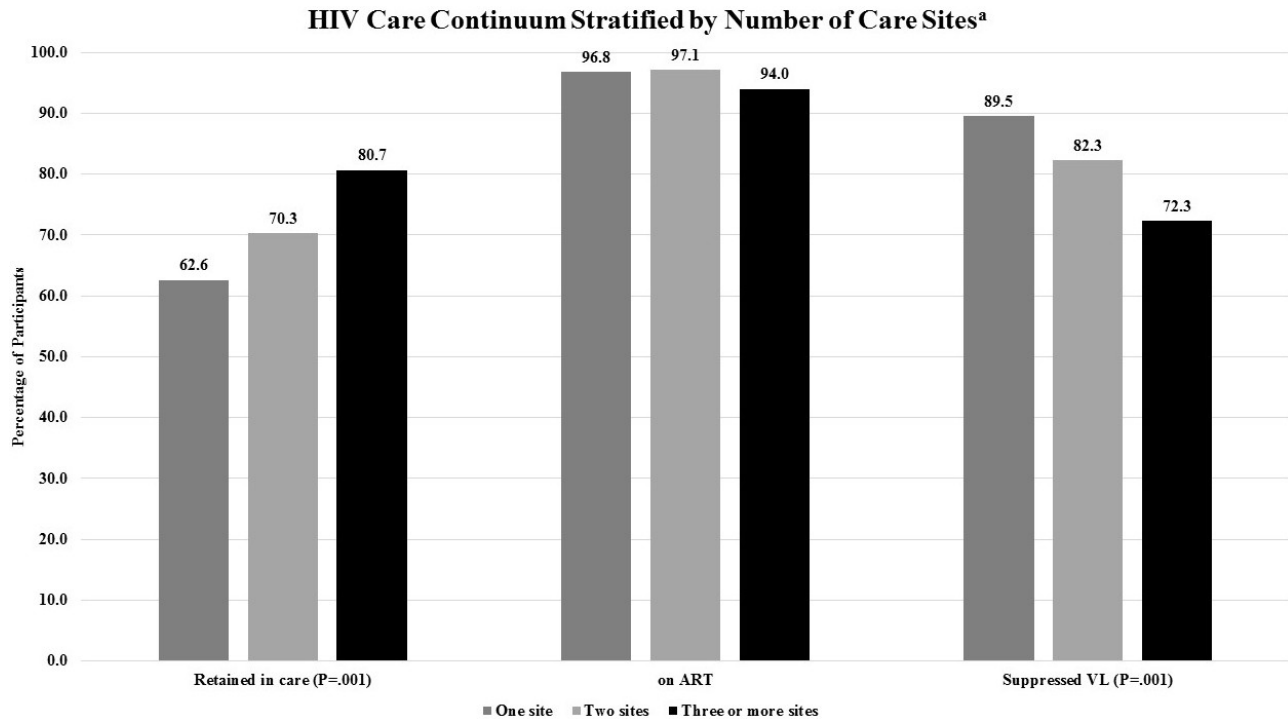


Differences in Care Continuum Outcomes

Among the 4476 participants who were actively enrolled in the study with at least 1 year of follow-up as of June 15, 2014, when measuring the care continuum using the prelinked DC Cohort database compared with the postlinked database, we found that retention in care was higher (59.83% (2678/4476) vs 64.95% (2907/4476)); however, the proportion with viral suppression was lower (87.85% (2277/2592) vs 85.15% (2391/2808) ($P<.001$ for both) (see Figure 3). The proportion of participants on ART

was high at 96.79% (2592/2678), and was only able to be assessed in the prelinked DC Cohort database. In the postlinked database, the proportion of participants classified as retained and as virally suppressed differed according to the number of sites where care was being received (see Figure 4). Those participants who received care at three or more sites were more likely to meet the definition of retention in care (80.7%, 234/290) compared with those receiving care at one site (62.61%, 2197/3509; $P<.001$) but were less likely to be virally suppressed (72.3% (154/213) vs 89.51% (1869/2088); $P<.001$).

Figure 4. Percentage of participants matched, retained in care, on antiretroviral therapy (ART) and having suppressed viral load (VL) in Washington, DC 2014-2015 stratified by receipt of care at 1, 2 or ≥ 3 sites (N=4476). The letter "a" signifies DC Cohort participants who matched with DC Department of Health records and were actively enrolled, not withdrawn or transferred care from the Cohort, alive, and with at least 1 year of follow-up as of June 15, 2014. Retention in care was defined as matched participants with evidence of at least two HIV-related encounters (eg, either HIV-related medical visit and/or laboratory test results) at least 90 days apart in a 12-month period from June 2014 to June 2015. Being on ART was defined as the number of Cohort participants who were prescribed an antiretroviral therapy (ART) regimen that overlapped with the study period. ART status was based on prelinked data as ART data are not collected by the DC DOH. Suppressed viral load (VL) was defined as matched participants who had a VL test in the time period and whose last VL was <200 copies/mL among those who were retained in care and on ART.



Discussion

Principal Findings

Linking clinical data collected in an observational HIV cohort with routinely collected public health surveillance data was mutually beneficial for both the clinical database as well as public health surveillance efforts. Specifically, for the DC Cohort, the linkage improved the accuracy of dates of diagnosis, vital status, and modes of transmission and resulted in the identification of more than 600 additional STD diagnoses, which may otherwise have not been captured in the Cohort database. From the DC DOH perspective, linkage of surveillance data to the DC Cohort database found that the majority of participants had been captured in the DC DOH surveillance data (93%) consistent with the relatively high completeness of surveillance reporting [32]. In addition, among those not matching, most were not DC residents, highlighting the large volume of care being delivered to non-DC residents by DC-based clinics. The linkage also improved measurement of dates of diagnoses, modes of transmission for HIV, and viral suppression for both databases.

With respect to the completeness of laboratory reporting, the linkage resulted in a substantial increase in the number of VLs post linkage. Further examination of the VLs included in the prelinked DC DOH surveillance data revealed that very few results were under 200 copies/mL. This is also reflected in the finding that only 47.5% of participants in the prelinked DC DOH database had ever achieved viral suppression. Given that

a relatively high proportion of individuals obtaining care in DC have achieved an undetectable VL [33], this likely reflects that although reportable, all VL values may not be as routinely reported to the DC DOH surveillance program, whereas CD4 results are included in surveillance data regardless of the numeric value [34]. Furthermore, because the prelinked DC Cohort data includes non-DC residents using DC health care facilities, VL labs for individuals who live outside of Washington, DC, are reported to their respective health departments and may not be captured in the DC DOH surveillance database. Given the relatively high proportion of non-DC residents participating in the Cohort who did not match to the DC DOH surveillance database, this may further explain the differences in VL reporting. The DC DOH surveillance program is constantly striving to improve the completeness of all laboratory reporting through routine checks with laboratory facilities and standard regional data exchanges. Nevertheless, despite the low initial number of VLs included in the DC DOH database, they were still of added value to the DC Cohort database.

Discriminating between DC Cohort and non-DC Cohort HIV laboratories was also key to ascertaining whether participants were coenrolled at more than one DC Cohort site or receiving care at multiple sites throughout the city, or receiving care at DC Cohort sites and non-DC Cohort sites. While most DC Cohort participants were receiving care at one site, almost one-quarter had evidence of receipt of HIV-related care at two or more sites. Furthermore, participants with evidence of care at three or more sites fared worse clinically and while they were

most likely to be retained in care, they were less likely to be virally suppressed. These findings were consistent with previous analyses on-site migration in DC which also found lower CD4 and higher VLs among persons seeking care at more than one site [35]. These trends may be reflective of other individual-level factors such as homelessness, substance abuse, and more fragmented care in general, among patients with multiple comorbid conditions. Furthermore, this more vulnerable group may have had seemingly higher retention in care as they may have returned to care more often for follow-up visits based on provider concerns about client health, fear of losing contact with the most transient clients, or based on receipt of more referrals to other clinics or specialists for their comorbid conditions [35,36]. However, while a higher proportion of these participants may have met the retention in care definition, their care patterns appear to reflect more disparate care, as meeting the definition did not translate into higher viral suppression. Thus, given the complexity in measuring retention in care with the shifting standards of clinical care and movement across clinics, emphasis should be placed on achieving viral suppression—a clear goal of treatment.

Additional laboratory data, used as supplemental and complementary information, allowed for re-estimation of retention and viral suppression and improved understanding of drop-offs along the HIV care continuum. Using a nested care continuum approach in which each step is dependent on the prior step, our initial clinic-based care continuum would have underestimated the percentage of participants meeting the retention in care definition and overestimated viral suppression; however, by combining additional laboratories from the health department, we were able to achieve a more accurate measure of these key indicators. Hence, routine data linkages such as these could assist in refining the accuracy of care continua and help prioritize clinical and public health interventions that seek to re-engage persons who are not optimally in care [37,38].

Overall, our care continuum estimates were similar to those of other HIV cohorts in the United States, including the HIV Outpatient Study (HOPS), a convenience sample of patients at selected HIV clinics in the United States, and the Medical Monitoring Project (MMP) study, a multisite supplemental surveillance system in the United States designed to provide nationally representative data on PLWHA [38]. DC Cohort estimates for proportion 'on ART' and viral suppression fell within the range of HOPS and MMP estimates in 2012 (97% and 92% on ART, respectively and 85% and 78% virally suppressed, respectively). DC Cohort estimates were also comparable to findings from the North American AIDS Cohort Collaboration on Research and Design (NA-ACCORD). Among more than 35,000 NA-ACCORD participants with at least one HIV care visit in the first 6 months of 2008, 82% were prescribed ART and 78% had suppressed VLs [39].

Limitations

This study has certain noteworthy limitations. Without knowing the full context in which CD4 and VL labs were drawn, deriving inference about the ability of DC Cohort participants to establish and maintain a primary medical home for HIV care is a challenge. We cannot exclude the possibility that additional labs may be the result of referrals to specialists who are also drawing HIV-related labs or acute encounters with the medical system such as emergency department visits and hospitalizations. Given the way laboratory results are reported, we are unable to fully describe the source of the laboratory (eg, inpatient, emergency department, outpatient, a specialty of reporting provider, etc), which would allow for better characterization of care pattern by type of encounter. However, additional analyses to determine whether participants were receiving care sequentially at these sites versus in an overlapping manner, may help further delineate these care patterns. Finally, DC Cohort participants may not be generalizable to all HIV-infected persons in DC, given that a certain proportion of PLWH in DC is not consistently engaged in care [30]. In future analyses, we intend to compare characteristics of DC Cohort participants to city-wide HIV population characteristics to assess whether Cohort-based care estimates approximate care trajectories for the city as a whole.

Conclusions

Despite these limitations, this analysis represents a successful triangulation of data from clinical cohort and public health surveillance data and demonstrated that the data linkages were mutually beneficial. The linkage not only helped to improve the accuracy and completeness of each database but also helped to describe care patterns among PLWHA, and enhanced measurement of clinical outcomes and the HIV care continuum at a population-level. The results derived through combining these databases will help inform HIV programmatic efforts and strengthen the DC DOH surveillance system as they will not only enhance the completeness of case data but contribute to the measurement of a more complete care continuum. The DC Cohort intends to use these data to inform the development of interventions focused on case management and improved care coordination across clinical sites and across jurisdictions. The DC DOH will be retooling its approaches to ensure continuity of care in DC and the surrounding metropolitan area in an enhanced data-to-care intervention strategy. With a more complete and relevant dataset, DC DOH will collaborate with community providers and deploy its public health team to address interruptions in care. DC DOH also has a data sharing agreement and protocol with Maryland and Virginia to ensure that the most complete data available can be used to inform jurisdictional partners in their data-to-care activities. Performance and findings from this type of linkage provide a reference point for design and interpretation of data from similar data linkages in North America and could potentially be used at the regional and national level as we strive to improve care outcomes [28,39,40].

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Conflicts of Interest

None declared.

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Abbreviations

ART: antiretroviral therapy

CD4: cluster of differentiation count

DC: District of Columbia

DOH: Department of Health

DSCC: Data and Statistics Coordinating Center

eHARS: enhanced HIV/AIDS Reporting System

FTP: file transfer protocol

HAHSTA: HIV/AIDS, Hepatitis, STD, Tuberculosis Administration

HOPS: HIV Outpatient Study

IDU: injection drug user

ID: identification

IRB: Institutional Review Board

IQR: interquartile range

MMP: Medical Monitoring Project

MSM: men who have sex with men

NA-ACCORD: North American AIDS Cohort Collaboration on Research and Design

OI: opportunistic infection

PLWHA: persons living with HIV or AIDS

RIC: retention in care

STD: sexually transmitted disease

STD*MIS: Sexually Transmitted Diseases Management Information System

VL: viral load

VS: viral suppression

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Original Paper

Web-Based Survey Application to Collect Contextually Relevant Geographic Data With Exposure Times: Application Development and Feasibility Testing

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Abstract

Background: Although studies that characterize the risk environment by linking contextual factors with individual-level data have advanced infectious disease and substance use research, there are opportunities to refine how we define relevant neighborhood exposures; this can in turn reduce the potential for exposure misclassification. For example, for those who do not inject at home, injection risk behaviors may be more influenced by the environment where they inject than where they live. Similarly, among those who spend more time away from home, a measure that accounts for different neighborhood exposures by weighting each unique location proportional to the percentage of time spent there may be more correlated with health behaviors than one's residential environment.

Objective: This study aimed to develop a Web-based application that interacts with Google Maps application program interfaces (APIs) to collect contextually relevant locations and the amount of time spent in each. Our analysis examined the extent of overlap across different location types and compared different approaches for classifying neighborhood exposure.

Methods: Between May 2014 and March 2017, 547 participants enrolled in a Baltimore HIV care and prevention study completed an interviewer-administered Web-based survey that collected information about where participants were recruited, worked, lived, socialized, injected drugs, and spent most of their time. For each location, participants gave an address or intersection which they confirmed using Google Map and Street views. Geographic coordinates (and hours spent in each location) were joined to neighborhood indicators by Community Statistical Area (CSA). We computed a weighted exposure based on the proportion of time spent in each unique location. We compared neighborhood exposures based on each of the different location types with one another and the weighted exposure using analysis of variance with Bonferroni corrections to account for multiple comparisons.

Results: Participants reported spending the most time at home, followed by the location where they injected drugs. Injection locations overlapped most frequently with locations where people reported socializing and living or sleeping. The least time was spent in the locations where participants reported earning money and being recruited for the study; these locations were also the least likely to overlap with other location types. We observed statistically significant differences in neighborhood exposures according to the approach used. Overall, people reported earning money in higher-income neighborhoods and being recruited for the study and injecting in neighborhoods with more violent crime, abandoned houses, and poverty.

Conclusions: This analysis revealed statistically significant differences in neighborhood exposures when defined by different locations or weighted based on exposure time. Future analyses are needed to determine which exposure measures are most strongly associated with health and risk behaviors and to explore whether associations between individual-level behaviors and neighborhood exposures are modified by exposure times.

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KEYWORDS

spatial analysis; geographic mapping; substance-related disorder

Introduction**Geographic Information Systems Approaches in Substance Use and Infectious Disease Research**

The risk environment and geography both play important roles in shaping overdose risk, risk behaviors associated with the transmission of sexually transmitted infections including HIV and hepatitis C virus (HCV), and the use of prevention and treatment services [1-6]. For example, geographic data are increasingly used in HIV and HCV prevention research and substance use research to identify hot spots for diseases, poor health outcomes, and risk behaviors [7-10] and health service deserts (ie, areas with decreased availability of or access to health services) [11,12]. Geographic information systems approaches are also used to evaluate the association between proximity to health services and their use (eg, clinics [10,13], drug treatment programs [11,12,14], and syringe exchange programs [15-18]) or travel distance as a barrier [19-22] to their use. Furthermore, studies that aim to characterize the risk environment link contextual factors with individual-level data to better understand how the built and social environment influence individual-level behaviors and health outcomes [23].

Limitations of Current Approaches

Although the approaches described above have led to important advancements in HIV, HCV and substance use research, there are opportunities to refine how relevant neighborhood exposures are defined to reduce the potential for exposure misclassification. For example, spatial analyses typically use residential addresses to identify hot spots and health service deserts and to calculate distances to services. Similarly, analyses that focus on characterizing the risk environment join neighborhood-level data to individual-level data using one's place of residence and treat exposure to neighborhood factors as static, rather than dynamic [9,24-27]. Using one's residential address for these analyses assumes that individuals are only (or are primarily) influenced by their residential environment and that individuals preferentially seek health care at facilities near their home. However, a study conducted among 400 persons receiving primary HIV medical care in Philadelphia reported that most participants traveled farther than the nearest available source of medical care and nearly half traveled more than 3 miles further [28]. As many people spend significant portions of their day away from home and certain behaviors might be more influenced by the social context in which they occur, there is rationale for exploring alternative approaches for classifying one's neighborhood exposure. For example, the social environment where people inject drugs may be more likely to influence their injection behaviors than their residential environment (if the two are not the same). Similarly, other health behaviors may be influenced more by one's weighted neighborhood exposure (ie, influenced by different neighborhood exposures according to the amount of time spent in each) than one's residential neighborhood exposure. Due to convenience (ie, the number of hours spent at work and the

overlap between working hours and the operating hours of most health service providers), the availability of health services in the neighborhood where they work versus live (ie, number of providers, type of health service, quality of care), or greater access to public transportation in the neighborhood where they work, some may preferentially seek care closer to where they work than where they live. Consequently, one's health service use may be more influenced by the neighborhood attributes associated with one's place of work than one's place of residence. As some people spend more time away from home (or at work) than others, it is also possible that the association between one's residential (or work) environment and health service use may be modified by the amount of time spent at that location. Similarly, the association between one's injection risk behaviors and the injection risk environment may be modified by the amount of time spent in that environment.

Although the vast majority of studies use residential addresses as a proxy, some researchers ask participants to provide addresses or intersections for additional locations, which are then geocoded with varying success [29-33]. For example, in one study, participants were asked to report the intersections nearest to the locations where participants most often hung out during the day, most often slept at night, and most often used drugs (one response per question) [32]. Although this change to the data collection protocol can result in more contextually relevant measures of one's risk environment, biases in memory and data entry errors can still influence the amount of missing data and the generalizability of study findings. For example, before data collected in this way can be used for analyses or linked with secondary data sources, addresses and intersections must be geocoded. Data entry errors such as spelling errors, missing or incorrectly specified street names (eg, Rd., Blvd., St.), missing street numbers, incorrectly specified directional values (eg, North, South), or nonexistent intersections prevent some locations from being geocoded successfully. Furthermore, software programs used to geocode locations (1) are often unable to find matches for some locations, (2) produce multiple matches for others, and (3) do not have error checking programs to ensure that the geocoded locations are valid. In the studies noted above, authors reported being able to successfully geocode approximately 90% of reported addresses and intersections [29,32]. Others noted that participant concerns related to providing exact addresses for one's residence and illegal activities may have resulted in more incomplete data for these responses; those with missing information on injection locations were significantly more likely to inject in public places and shooting galleries [31]. Missing data can reduce statistical power; missing data and the inclusion of invalidated geographic locations could induce sampling biases [34].

A few researchers have used Google Maps to eliminate the need for geocoding and to improve the accuracy of the location information collected. For example, in one study, interviewers used Google Maps to obtain and validate (via the Google Maps Street View image) each location provided by respondents and then copied and pasted the latitude and longitude coordinates

corresponding with each location entry into a database [35]. One limitation of this approach is that there is still a possibility for data entry errors due to errors in the transfer of coordinates from Google Maps to the database. In another study, respondents used Google Enterprise tools including Google Earth and Google Street View to virtually navigate to and pinpoint each location [36]. The interviewer then asked the participant to zoom in to identify the precise location based on visual anchors and landmarks. Following participant confirmation, the interviewer entered the geocoordinates into the corresponding data entry field in a separate Questionnaire Development System (QDS) interview database (QDS Systems, NOVA Research, Bethesda, USA). The authors acknowledged a significant limitation in this approach due to data entry errors that occurred in the transfer of coordinates from Google Street View to QDS. In a subsequent study, this research group developed a software plug-in to reduce this error by directly transmitting geocoordinate information to QDS [36]. Another research team used a Google Map tool embedded in an Internet survey instrument. This survey displayed a map view of Atlanta (initial zoom set to 1:127,000 or 1 inch representing approximately 2 miles). Although respondents could zoom in as much as needed, the zoom level was not recorded in the database and no street-view image was provided for validation [37]. Because users can more precisely locate places when they zoom in further, the error around each estimate will vary according to the zoom level, which is not recorded.

Although the real-time collection of such data in one's natural environment (ie, geographic momentary assessments [GMA]) has the potential to increase the ecological validity of the data collected and can be used to provide a more comprehensive understanding of the environmental context of risk and health-seeking behaviors among substance-using populations, sometimes the pace of technological innovation exceeds that of ethical standards and guidance [38]. Several researchers have evaluated the feasibility and acceptability of GMA among substance-using populations [39,40], and others have discussed potential privacy and confidentiality concerns, particularly when the behavioral data collected may be illegal or highly stigmatized [38,41,42]. In-depth interviews with persons who use drugs in Baltimore revealed a preference for collecting location-based information using a Web-based mapping survey approach versus GMA. Participants raised privacy and confidentiality concerns associated with GMA; as a result, many said that they would be unwilling to participate in a GMA study or to comply with study procedures. In fact, some said that they would take measures to prevent sensitive location information from being collected. Concerns raised in qualitative interviews with persons who used drugs in Baltimore suggest that, in this setting, GMA could result in differential study participation or study compliance and location data with questionable accuracy or validity for sensitive behaviors [38,41,42].

Study Objective: Addressing the Gap

To address the limitations of other data collection tools, we developed an interviewer-administered Web-based survey application that interacts with several Google Maps Application Program Interfaces (APIs) to collect and store geographic coordinates and the amount of time spent in each location in a

separate and secure database. Our goal was to develop a user-friendly Web-based survey application that could accurately collect data on participants' key geographic settings. This paper will (1) describe the Web-based survey application developed to collect contextually relevant location information and the amount of time spent in each location using an interviewer-administered survey, (2) examine the extent to which individuals in our sample engage in different activities in nonoverlapping spaces, and (3) compare different approaches for classifying neighborhood exposure (ie, based on where individuals who were recruited for this study live or sleep, work, inject, socialize, and spend the majority of their time, and based on a weighted average of the Baltimore neighborhoods where the individual reports spending time).

Methods

Recruitment

Between May 2015 and March 2017, 565 individuals were recruited for a study on HIV care and prevention in Baltimore, Maryland. Due to interviewer error, only 547 of these individuals completed the mapping survey. Participants were recruited using targeted street outreach (n=277 index participants) and peer referral (n=270 network participants). To be eligible to participate, index participants had to be at least 18 years of age, not currently participating in other intervention studies at the research site, and HIV positive (validated with documentation or OraQuick), and should have a history of drug use (heroin, cocaine, or crack) or use any drug to get high including marijuana (effective May 13, 2015). Eligible index participants also had to report one of the following: (1) no HIV medical care in the past 6 months or having gone more than 6 months without seeing a doctor for HIV care in the past 2 years, (2) missed taking prescribed HIV medications in past 90 days, (3) shared injection equipment in the past 90 days, (4) smoked crack in the past 90 days, or (5) unprotected anal or vaginal sex in the past 90 days, and all of the following: (1) currently lives in Baltimore metro area with no plans to move from the Baltimore metro area in the next year, (2) willing to attend group sessions, and (3) willing to talk to people about HIV. Network participants were eligible if they were at least 18 years of age and had received a peer referral coupon from someone verified as an index participant.

Ascertainment of Key Variables

Using interviewer-administered questionnaires, participants were asked to report the locations (if applicable) where he or she: (1) was when recruited to participate in this study (n=538), (2) most often lived or slept (n=540), (3) most often injected (n=120), (4) most often worked or earned money (n=163), (5) most often socialized (n=426), and (6) spent the most time (n=534) over the last 6 months. Of note, the location or area where participants spent the most time over the last 6 months was asked to (1) capture instances where participants did not spend a majority of their time in one of the other 5 locations and (2) ascertain whether the location where the participant perceived spending the most time overlapped with any of the other location types reported.

Figure 1. Screenshot of the Web-based map survey.

Inner Harbor, Baltimore, MD, United States

Map Satellite

Map data ©2017 Google Terms of Use Report a map error

Map data © Tyler Moore Terms of Use Report a problem

In the past 6 months, how many days per week did you typically spend at this location or in this area? select response

In the past 6 months, on a typical day that you were at this location or in this area, how many hours did you typically spend there? select response

Comments

As seen in the screenshot of this Web-based survey application (Figure 1), each question was presented as a unique map with 2 follow-up questions to ascertain the amount of time spent in the corresponding location. Interviewers first read the location prompt aloud. The participant then provided an address or intersection, which the interviewer entered. If an exact address or intersection was unknown, participants could enter a proxy location or a landmark (ie, church, corner store, park) and then refine their search using the Google Maps navigation features (ie, zoom in and out, rotate, left, right, drag the pointer) to reposition the pointer to the correct location. To prevent instances where participants would otherwise provide misinformation to avoid disclosing certain locations [41,42], interviewers were trained to inform the participant that they could provide a location within a few blocks of the exact location rather than the exact address or use the map to navigate to a location in the correct vicinity that they were comfortable disclosing. After the location was loaded, the participant was asked to confirm whether the location appeared to be correct based on the map-view and the street-view images. If the location was not confirmed by the participant, a new location could be entered without the old location being stored in the database. Only the final location (ie, the corresponding latitude and longitude coordinates; not the location queries) that was confirmed by the participant was stored in the database. Of note, we used the Place Autocomplete feature to provide a type-ahead search box to reduce search errors due to typographical errors in the initial query. After the respondent confirmed the location, the interviewer asked 2 follow-up questions: (1) How many days per week do you typically spend at this location or in this area? and (2) On a typical day that you are at this location or in this area, how many hours do you typically spend there?

Response options for the first question include 0-7 days, <1 day, not applicable, and decline to answer. Response options for the second question include 0-24 hours, <1 hour, not applicable, and decline to answer. After selecting responses for each of these questions, the interviewer pushes “submit” to record the coordinates and question responses (but not the location, question details, or address information) in a password-protected MySQL database.

Web Application Development and Security Features

The Web-based survey application was developed using a MySQL database and the PHP server-side programming language. The program was developed using a model-view-controller framework. The client-side of the application was developed with Hypertext Markup Language, Cascading Style Sheets, and Javascript; it utilizes the Bootstrap Library for user interface elements; the Google Maps API for mapping, street-view, and geocoding functions; and the autocomplete feature of the Places library in Google Maps.

All data (ie, questions, answers, and administrative login information) are stored in a password-protected MySQL database. Of note, although the questions are presented in the survey, the database collects and stores only the unique identifier corresponding with each question and not the question itself. Consequently, there is no label associated with any of the coordinates stored in the database, and the link between the question label and the unique identifier can only be retrieved with an administrative password that is encrypted with a one-way hash. Data can be exported from this administrative view as a .csv file, but only by those with administrative rights.

The resulting database contains only the interviewer identifier, participant identifier, question identifier, coordinates for each question identifier, and the amount of time spent in each location. The website was also protected with a security certificate.

Statistical Analysis

Of note, because 80.5% (430/534) of participants had not injected drugs in the past 6 months, only 120 participants provided an injection location. Similarly, because the primary source of income for many participants was government-issued assistance or support from network members, only 163 participants provided a location for where he or she worked or earned money. As 83.3% (445/534) of individuals in this sample were unemployed, participants were also permitted to provide the locations for informal sources of income (ie, panhandling, washing cars). Individual-level geographic coordinates (and the corresponding location type and amount of time spent at each set of coordinates) were mapped in ArcGIS 10.2 [43] and assigned to the corresponding Baltimore Community Statistical Area (CSA). In Baltimore City, there are 55 CSAs, 200 census tracts, and over 270 neighborhoods. The Baltimore Neighborhood Indicators Alliance [44] is a repository for Baltimore geographic data, which uses CSAs to present data from multiple sources in a consistent way over time. CSAs were initially designated by the Baltimore Data Collaborative with the Baltimore City Department of Planning according to the following guidelines: CSA boundaries must (1) align with census tracts, (2) consist of 1-8 tracts with 5000 to 20,000 residents, (3) define a demographically homogeneous area, and (4) reflect the city planners' understanding of residents' and institutions' perceptions of community boundaries [44]. This resulted in the loss of 13 individuals, who reported locations outside of this area (N=534 overall, with 118 injection locations and 160 locations reported for where individuals earned money).

To calculate a weighted neighborhood exposure for each participant, we first computed the fraction of time spent in each location by an individual (ie, the amount of time spent in each unique location [numerator] divided by the total amount of time spent in Baltimore [denominator] per person). We then multiplied the fraction of time spent in each CSA by the neighborhood-level data corresponding with that CSA and summed the results for each person. The result is a weighted assessment of one's neighborhood exposure. In SAS version 9.4 (Cary, NC) [45], we compared the neighborhood exposures by location type (and the weighted neighborhood exposure) using analysis of variance tests with a Bonferroni correction to account for multiple comparisons. For example, given that there are 42 pairwise comparisons for 7 different measures, the adjusted level of significance is 0.05/42, or 0.001.

Results

Study Sample

As seen in Table 1, the median age of sampled participants was 51 years (interquartile range [IQR] 43-56), 56.9% (304/534) were male, 62.6% (334/534) had obtained at least a high school degree or the equivalent, 83.3% (445/534) were unemployed, 89.0% (475/534) were black or African American, 85.6% (457/534) had health insurance, and the majority reported using public transportation (78.2% [415/531]), followed by walking (9.6% [51/531]), to get around the city. Of those reporting injection drug use in the past 6 months (19.5% [104/534]), the median time spent traveling to obtain injection drugs was 30 min (IQR 20-60 min).

Map Survey Descriptive Statistics

The median amount of time required to complete the 6-question map survey was 5 min and 35 s (IQR 4-7 min and 19 s). Participants responded to a median of 4 (IQR 4-5) different location questions (ie, injection and work locations were often not applicable); of these, participants reported a median of 2 (IQR 2-3) different unique locations. As seen in Table 2, locations were considered to be the same if the coordinates matched exactly or were within 0.4 miles (or less than 9 min walking distance from one another). As we permitted individuals to provide approximate addresses for sensitive locations, the distance threshold used to define exact matches in this analysis was informed by our data (ie, locations within several blocks of one another where participants reported spending the same amount of time). The median amount of time spent at home was 89.4%, and the median amount of time spent in the neighborhood where they socialized with friends was 50.0%. Participants spent the least amount of time in the location where they were recruited to participate in this study (median 17.8%). Among those who injected, the median amount of time spent in the location where they injected drugs was 76.1%. Among those who worked, the median amount of time spent in that area was 25.1%.

Overall, the locations where participants reported earning money and being recruited for this study were the least likely to overlap with the locations they reported for other location questions. With respect to overlap in locations, 89.1% (481/540) of the locations where individuals reported living and sleeping overlapped with at least one other location, 81.7% (98/120) of injection locations overlapped with at least one other location, 73.5% (313/426) of locations where individuals reported socializing overlapped with at least one other location, 44.8% (241/538) of locations where participants reported being recruited for the study overlapped with at least one other location, and 41.1% (67/163) of the locations where participants reported working or earning money overlapped with at least one other location (Table 3).

Table 1. Sample demographic characteristics, Baltimore, Maryland (N=534), 2014-2017.

Variable	Data
Age, median (IQR ^a)	51 (43-56)
Years in Baltimore (N=533), median (IQR)	47 (34-54)
Living situation, n (%)	
Own house or apartment	267 (50.0)
With a parent or family member	123 (23.0)
At someone else's house or apartment	68 (12.7)
Rooming, boarding, or halfway house	63 (11.8)
On the street	5 (0.9)
Other	8 (1.5)
Homeless in the past 6 months, n (%)	127 (23.8)
Gender identity, n (%)	
Male	304 (56.9)
Female	221 (41.4)
Transgender	9 (1.7)
At least a high school diploma or GED ^b , n (%)	334 (62.6)
Race, n (%)	
Black or African American	475 (89.0)
White	48 (9.0)
Other or mixed or multiracial	11 (2.1)
Unemployed, n (%)	445 (83.3)
Health insurance, n (%)	457 (85.6)
Get around city (N=531), n (%)	
Drive a car that you own	31 (5.8)
Drive a car that you borrow	13 (2.5)
A friend or relative drives you	10 (1.9)
Taxi or sedan	4 (0.8)
Public transportation	415 (78.2)
Walk	51 (9.6)
Other (bike, drive company cab, someone else drives me, motor wheel chair)	7 (1.3)
Phone usage, n (%)	
Own a cell phone (N=416)	381 (91.6)
Own a smartphone (N=380)	202 (53.2)
Own a government-issued phone (N=380)	199 (52.4)
Ever used the Internet (N=415), n (%)	246 (59.3)
Ever used Facebook (N=416) n (%)	181 (43.5)
Neighborhood clean (somewhat or very hopeful) (N=414), n (%)	347 (83.8)
Neighborhood crime (somewhat or very hopeful) (N=413), n (%)	311 (75.3)
Baltimore homicides (somewhat or very hopeful) (N=416), n (%)	278 (66.8)
Community association (yes) (N=383), n (%)	244 (63.7)
Neighborhood activities (yes) (N=415), n (%)	199 (48.0)
Vacant housing (more of a problem on your block) (N=414), n (%)	51 (12.3)

Variable	Data
Trash in streets (more of a problem on your block) (N=413), n (%)	64 (15.5)
Groups of teenagers (more of a problem on your block) (N=414), n (%)	97 (23.4)
Selling drugs (more of a problem on your block) (N=414), n (%)	118 (28.5)
Robbed or beaten (more of a problem on your block) (N=413), n (%)	54 (13.1)
History of injection drug use, n (%)	
Never	264 (49.4)
≥6 months ago	166 (31.1)
Within the past 6 months	104 (19.5)
Prior drug treatment enrollment, n (%)	
Any drug treatment	277 (51.9)
Detox (N=276)	67 (24.3)
Methadone maintenance (N=276)	138 (50.0)
Outpatient (N=275)	114 (41.5)
Residential (N=275)	64 (23.3)
Self-help meeting (N=276)	243 (88.0)
Minutes traveled to get injection drugs (N=127), median (IQR)	30 (20-60)

^aIQR: interquartile range.

^bGED: General Equivalency Diploma

Table 2. Hours and percentage of time spent in a variety of different types of locations (N=547), 2014-2017.

Location type ^a	Percentage of time spent in each location ^b Median (interquartile range)	Hours in an average week spent in each location Median (interquartile range)
Live or sleep (N=540)	89.4 (67.2-99.4)	112 (70-147)
Inject (N=120)	76.1 (16.1-99.5)	70 (14-132.25)
Spend most time (N=534)	89.6 (65.9-99.4)	112 (70-154)
Work or earn money (N=163)	25.1 (12.9-47.9)	40 (15.5-55.5)
Socialize (N=426)	50.0 (12.9-99.1)	58 (15-126)
Recruited for study (N=538)	17.8 (2.3-94.1)	19 (3-89.25)

^aLocations were considered to be the same if the latitude and longitude matched exactly or were within 0.4 miles (or less than a 9 min walking distance apart). In this table, 13 individuals are not included in the neighborhood analyses that joined individual data with neighborhood because they were outside of Baltimore City and no neighborhood indicators were available.

^bPercentages do not sum to 100% due to overlap.

As shown in Table 3, in total, there were 1224 different locations listed by 547 individuals. Of these 1224 locations, 624 (50.98%) were listed only once by individuals (ie, for one location type), 287 (23.45%) were listed for 2 different locations types, 175 (14.30%) were listed for 3 different location types, 100 (8.17%) were listed for 4 different location types, 30 (2.45%) were listed for 5 different location types, and 8 (0.65%) were listed for all 6 location types. The top row displays the number of locations listed in each category that were listed for that location category only. For example, there were 624 locations reported by individuals that did not overlap with any other location listed by that same individual. Of these, 59 were the locations where participants reported living or sleeping most often in the past 6 months. Of all the locations listed by participants as the places where they lived or slept most often in the past 6 months, this

represents 10.9% (59/540). Therefore, the majority of these locations (89.1%) overlapped with at least one other location type listed by a participant; 34.8% (188/540) were also listed for one other activity and 1.5% (8/534) overlapped with all 5 other activities listed. As seen in the top row, 297 of the unique locations listed were the locations where people reported being recruited to participate in this study. This corresponds with over half (55.2% [297/538]) of the recruitment locations listed by participants. The remaining locations overlapped with at least one other location reported by the participant. As seen in the bottom row, 8 individuals reported spending time at the same location for all 6 location types. Of note, 6.9% (37/534) of individuals reported spending most of their time in a location other than one of the locations they reported for the other 5 questions.

Table 3. Number of times a particular location is listed by a participant in the 6-question location survey for each location type.

Number of times a particular location is listed by a participant in the 6-question location survey ^a	Live or sleep (N=540), n (%)	Inject (N=120), n (%)	Spend most time (N=534), n (%)	Work or earn money (N=163), n (%)	Socialize (N=426), n (%)	Recruited for study (N=538), n (%)	Total (N=1224), n (%)
1	59 (10.9)	22 (18.3)	37 (6.9)	96 (58.9)	113 (26.5)	297 (55.2)	624 (50.98)
2	188 (34.8)	17 (14.2)	203 (38.0)	23 (14.1)	82 (19.2)	61 (11.3)	287 (23.45)
3	158 (29.3)	26 (21.7)	158 (29.6)	16 (9.8)	98 (23.0)	69 (12.8)	175 (14.30)
4	98 (18.1)	25 (20.8)	98 (18.4)	8 (4.9)	95 (22.3)	76 (14.1)	100 (8.17)
5	29 (5.4)	22 (18.3)	30 (5.6)	12 (7.4)	30 (7.0)	27 (5.0)	30 (2.45)
6	8 (1.5)	8 (6.7)	8 (1.5)	8 (4.9)	8 (1.9)	8 (1.5)	8 (0.65)

^aLocations were considered to be the same if the latitude and longitude matched exactly or were within 0.4 miles (or less than a 9 min walking distance apart). In this table, 13 individuals are not included in the neighborhood analyses that joined individual data with neighborhood because they were outside of Baltimore City and no neighborhood indicators were available.

Table 4. Overlap in location types (N=547).

Location types ^a	Live or sleep (N=540), n (%)	Inject (N=120), n (%)	Spend most time (N=534), n (%)	Work or earn money (N=163), n (%)	Socialize (N=426), n (%)	Recruited for study (N=538), n (%)
Live or sleep	—	71 (59.2)	458 (85.8)	35 (21.5)	218 (51.2)	172 (32.0) ^b
Inject	71 (13.1)	—	66 (12.4)	21 (12.9)	68 (16.0)	46 (8.6)
Spend most time	458 (84.8)	66 (55.0)	—	40 (24.5)	237 (55.6)	172 (32.0)
Work or earn money	35 (6.5)	21 (17.5)	40 (7.5)	—	43 (10.1)	28 (5.2)
Socialize	218 (40.4)	68 (56.7)	237 (44.4)	43 (26.4)	—	157 (29.2)
Recruited for study	172 (31.9)	46 (38.3)	172 (32.2)	28 (17.2)	157 (36.9)	—

^aLocations were considered to be the same if the latitude and longitude matched exactly or were within 0.4 miles (or less than a 9 min walking distance apart). In this table, 13 individuals are not included in the neighborhood analyses that joined individual data with neighborhood.

^bA few individuals who indicated recruitment locations that overlapped with the location where they lived or slept most often may have been homeless, been recruited for the study by a friend in their own home, or called the study staff to inquire about potential studies for which they may be eligible.

As seen in [Table 4](#), when the location listed as the area where the participant spent most of their time overlapped with another location, it was most likely to overlap with the location where they reported living or sleeping (85.8% [458/534]), followed by the location where they socialized (44.4% [237/534]). When people reported injecting drugs, the location was most likely to overlap with the locations where they reported living and socializing with friends.

[Multimedia Appendix 1](#) provides the definitions and data sources for the neighborhood indicators used in this analysis. It also provides a summary of the statistically significant differences observed between the neighborhood attributes corresponding with each location type ($P < .001$; $\alpha = .05/42$). [Multimedia Appendix 2](#) compares neighborhood-level exposures according to the location used to define the neighborhood. In general, the neighborhoods where people reported going to work or earn money tended to differ from other locations reported in the following ways: (1) a higher median household income and higher educational attainment; (2) lower rates of poverty, unemployment, and families receiving temporary assistance; (3) fewer vacant or abandoned properties and reports for dirty streets and alleys; (4) more nonviolent crimes but fewer shootings and homicides; and (5) a larger proportion of people walk to work, but a smaller proportion of people take public

transportation to work. People reported injecting in neighborhoods characterized by (1) a lower median household income; (2) higher rates of poverty, unemployment, and families receiving temporary assistance; (3) more vacant or abandoned properties; (4) the highest rate of dirty streets and alleys reports; and (5) more shootings and narcotics 911 calls. People lived in areas characterized by lower crime rates and incidents of shootings and with a smaller proportion of the population reporting that they walked to work.

Discussion

Feasibility of Administering a Web-Based Survey

The Web-based survey application developed for use in this study facilitated data entry in the following ways: (1) the interviewer and participant could search for each location using an interactive map even when exact addresses were not known, (2) using Google Map and Street Views, participants could confirm that each location entered was correct before it was stored in the database, (3) the Google Place Autocomplete feature was used to reduce typographical errors in the initial query, (4) invalid and missing data entries were further minimized because participants could search for nearby landmarks or cross-streets and use the navigation features to identify more precise locations or locations in the correct vicinity

that they were willing to disclose, and (5) each location was automatically geocoded, which reduced data entry errors and missing data.

Using this Web-based survey application permitted the collection of contextually relevant location information and the amount of time spent in each location, both of which can be used to better characterize the risk environment or to better identify health services in close proximity to where participants spend time. Our findings also demonstrate the feasibility of using this Web-based survey application among a sample of persons with a history of drug use and their peer-referrals, who were predominately unemployed (83.3% [445/534]), who reported some homelessness in the past 6 months (23.8% [127/534]), and who did not have much prior experience with the Internet or Google Maps (ie, 40.7% [169/415] reported never having used the Internet).

Different Neighborhood Exposures by Location Type

To date, most analyses that have examined the influence of neighborhood characteristics on health service use have assumed that individuals are only influenced by the environments in which they live. Our Web-based survey application was developed to address existing methodological limitations. Our analysis demonstrates that participants spent time in multiple nonoverlapping locations and revealed statistically significant differences in one's environmental exposure when exposure was defined using different areas where participants reported spending time. Our analysis also showed that among those who worked, participants worked and lived in very different types of neighborhoods. For example, the neighborhoods where participants worked were characterized by variables indicating less physical and social disorder compared with all other locations considered. Furthermore, the neighborhoods where participants reported injecting and being recruited for this study had scores indicating higher levels of physical and social disorder.

Limitations

In this analysis, neighborhood exposures were defined by Baltimore CSAs. Of note, there are 55 CSAs within Baltimore City and 54 are represented in our sample. As there are over 270 neighborhoods in Baltimore, several neighborhoods were combined to compute the indicators for this analysis. Although aggregating individuals to smaller area units could make neighborhood differences more apparent, some measures used in this analysis were not available at more granular levels. Given that our analysis showed significant differences in neighborhood

indicators at the CSA level, we would expect to see more differences when neighborhood indicators are incorporated for smaller area units. Future analyses could examine demographic differences between block groups or differences in the neighborhood indicators available for the 278 neighborhoods that comprise the neighborhood inventory for environmental typology (NifETy) [46]. Of note, 173 of the 278 NifETy neighborhoods are represented in our dataset. There are also countless other data sources (ie, pollution, crime data, overdose event data, arrest data from the sheriff's office) that could be merged with these data to examine a myriad of health outcomes. Although using the Google Maps API for mapping, street-view, and geocoding functions, and the autocomplete feature of the Places library in Google Maps facilitated data entry, participants' responses may still be influenced by recall bias. Additionally, this analysis collected only the location where individuals reported injecting most often, socializing most often, and working most often. Future analyses could collect more detailed information about each unique location within a specific type of location.

Conclusions

In this manuscript, we show that using an interviewer-administered Web-based geographic data collection approach is feasible among a sample of persons who use drugs in Baltimore, Maryland. In this sample, about half of the locations reported by participants were reported for more than one activity; recruitment locations and locations where people reported going to work or earn money were the least likely to overlap with other location types. Our analyses also show that there were statistically significant differences in the neighborhood environments associated with each of the location types examined (ie, live or sleep, work, socialize, inject, recruit, weighted exposure). Future analyses are needed to (1) determine which neighborhood exposure measures are most strongly correlated with risk and health-seeking behaviors, (2) examine whether the association between one's environment and health-related outcomes (or risk behaviors) is modified by the amount of time spent in that environment, and (3) compare the availability of health service providers in close proximity to work environments versus other locations (ie, one's residence). Future research in this and other disciplines could extend these methods to collect the locations where individuals drink alcohol or meet sex partners, and permit multiple locations (and the corresponding amount of time spent in each location) for each location type (ie, multiple injecting locations).

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Description of variables and significant findings.

[[PDF File \(Adobe PDF File\), 182KB - publichealth_v4i1e12_app1.pdf](#)]

Multimedia Appendix 2

Comparison of neighborhood-level variables by the location used to define the neighborhood.

[[PDF File \(Adobe PDF File\), 106KB - publichealth_v4i1e12_app2.pdf](#)]

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Abbreviations

API: application program interface
CSA: community statistical area
GED: General Equivalency Diploma
GMA: geographic momentary assessments
HCV: hepatitis C virus
IQR: interquartile range
NIFETY: Neighborhood Inventory for Environmental Typology
QDS: Questionnaire Development System

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Original Paper

Population Size Estimation of Gay and Bisexual Men and Other Men Who Have Sex With Men Using Social Media-Based Platforms

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Abstract

Background: Gay, bisexual, and other cisgender men who have sex with men (GBMSM) are disproportionately affected by the HIV pandemic. Traditionally, GBMSM have been deemed less relevant in HIV epidemics in low- and middle-income settings where HIV epidemics are more generalized. This is due (in part) to how important population size estimates regarding the number of individuals who identify as GBMSM are to informing the development and monitoring of HIV prevention, treatment, and care programs and coverage. However, pervasive stigma and criminalization of same-sex practices and relationships provide a challenging environment for population enumeration, and these factors have been associated with implausibly low or absent size estimates of GBMSM, thereby limiting knowledge about the dynamics of HIV transmission and the implementation of programs addressing GBMSM.

Objective: This study leverages estimates of the number of members of a social app geared towards gay men (Hornet) and members of Facebook using self-reported relationship interests in men, men and women, and those with at least one reported same-sex interest. Results were categorized by country of residence to validate official size estimates of GBMSM in 13 countries across five continents.

Methods: Data were collected through the Hornet Gay Social Network and by using an a priori determined framework to estimate the numbers of Facebook members with interests associated with GBMSM in South Africa, Ghana, Nigeria, Senegal, Côte d'Ivoire, Mauritania, The Gambia, Lebanon, Thailand, Malaysia, Brazil, Ukraine, and the United States. These estimates were compared with the most recent Joint United Nations Programme on HIV/AIDS (UNAIDS) and national estimates across 143 countries.

Results: The estimates that leveraged social media apps for the number of GBMSM across countries are consistently far higher than official UNAIDS estimates. Using Facebook, it is also feasible to assess the numbers of GBMSM aged 13-17 years, which demonstrate similar proportions to those of older men. There is greater consistency in Facebook estimates of GBMSM compared to UNAIDS-reported estimates across countries.

Conclusions: The ability to use social media for epidemiologic and HIV prevention, treatment, and care needs continues to improve. Here, a method leveraging different categories of same-sex interests on Facebook, combined with a specific gay-oriented app (Hornet), demonstrated significantly higher estimates than those officially reported. While there are biases in this approach, these data reinforce the need for multiple methods to be used to count the number of GBMSM (especially in more stigmatizing settings) to better inform mathematical models and the scale of HIV program coverage. Moreover, these estimates can inform programs for those aged 13-17 years; a group for which HIV incidence is the highest and HIV prevention program coverage, including the availability of pre-exposure prophylaxis (PrEP), is lowest. Taken together, these results highlight the potential for social media to provide comparable estimates of the number of GBMSM across a large range of countries, including some with no reported estimates.

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KEYWORDS

AIDS; estimates; HIV; key populations; men who have sex with men; social media

Introduction

Consensual sex between adult men remains stigmatized in much of the world. Same-sex practices and relationships are criminalized in over 70 countries, many of which are countries where the HIV epidemic is most generalized [1]. Given pervasive social stigma around the world and punitive laws specifically affecting gay, bisexual, and other cisgender men who have sex with men (GBMSM), it remains challenging to count the numbers of GBMSM to inform the content and scale of specific health programs, including HIV prevention, treatment, and care services [2,3]. The biological risks that predispose GBMSM to HIV infection are similar around the world; however, there has been an assumption that there are less GBMSM in countries with generalized epidemics. In turn, this view has supported a further assumption regarding the limited relevance of the HIV prevention needs of GBMSM in the broader HIV transmission dynamics in these countries [4].

There is no consensus on the optimal strategy of measuring the numbers of GBMSM. The limited consensus reflects challenges in enumerating a diverse group of men comprising different sexual orientations and sexual practices over time. Specifically, there are GBMSM who identify as gay, bisexual, straight, or do not identify with a particular sexuality at all. There are those that only have sex with men, or both men and women, and those that report sexual practices with people along the gender continuum [5]. Moreover, there are those that only have sexual attraction to other men; however, they have not had sex, or have had certain forms of sex, but not penetrative anal sex with men. Finally, there is often conflation of sexual and gender identities, which complicates the enumeration of cisgender GBMSM because transgender women who have sex with men are sometimes (inappropriately) included within these counts [6,7]. These challenges are compounded by a pervasive stigma of homosexuality, and by the lack of consensus about the optimal questions and measures to enumerate men who have health risks associated with their sexual behaviors [8].

Population counts of GBMSM have included both in-person assessments, digital assessments, or surveys. In the United Kingdom, the Annual Population Survey has been used to estimate the numbers of GBMSM in the population, and multiple nationally representative samples have been leveraged in the United States to generate estimates of population size [9].

However, in most settings, including the United States, there is a greater reliance on digital strategies given that sexual identity is not included on the United States national census. Small area estimation methods have also been used for estimating GBMSM population sizes at smaller geographic levels within the United States [10]. In the United Kingdom in 2016, approximately 2.3% of men identified as gay or bisexual, whereas a Gallup Poll in the United States noted that approximately 4.1% of all people identified as lesbian, gay, bisexual, or transgender (LGBT), representing approximately 10 million people [11]. Not all national estimates of population size of GBMSM are from higher income settings. For example, investigators from the Other Foundation in South Africa reported that an estimated 530,000 people identified as gay, bisexual, or gender nonconforming [12].

In settings without methodologically sound national surveys, which represents most countries of the world, there is a great reliance on population size estimation strategies to assess the numbers of GBMSM. However, these approaches are collectively more difficult to implement in countries with stigmatizing settings where homosexuality may be criminalized, and where political will or leadership is absent. This issue reinforces a data paradox: we know the least about the numbers and social experiences of the most vulnerable communities of GBMSM in settings deemed the most hostile [13,14]. Additionally, high HIV service coverage goals may disincentivize accurate size estimates for countries with implausibly low or absent population estimates [15].

The normative agency responsible for providing estimates of population size to inform mathematical models of HIV transmission is the Joint United Nations Programme on HIV/AIDS (UNAIDS). Given the lack of national estimates of GBMSM, UNAIDS relies on United Nations member states to submit data on population size estimates [16]. These estimates have significant variability in the quality of the underlying studies and representativeness. Ultimately, many countries do not include any estimates of the numbers of GBMSM. In the absence of population estimates, especially in more generalized HIV epidemic settings, dedicated HIV prevention, treatment, and care programs for GBMSM remain limited or missing altogether. This lack of adequate data and resulting resource allocation might account for the increased mortality and morbidity among men living with HIV in countries with

generalized HIV epidemics [17]. For example, in Tanzania in October of 2017, people working with organizations aimed at addressing the HIV prevention and treatment needs of GBMSM were arrested and then deported, highlighting the inherent challenges of understanding and ultimately addressing HIV risks among GBMSM [18].

Given the need to reliably estimate the proportion of the male population who do not identify as heterosexual, or who are not exclusively behaviorally heterosexual, this study compares UNAIDS estimates (where available) to estimates of members of Hornet (a social app geared towards gay men [19]) and Facebook members with specific interests associated with GBMSM in 13 countries across five continents.

Methods

The overarching goal of this study was to assess the utility of using data on users of mobile phone apps and social media communities to obtain estimates of GBMSM population sizes. These estimates of GBMSM obtained from a gay social network app and Facebook users were compared to the most recent officially reported UNAIDS [20] and national estimates [10,21] across 13 countries. A selection of countries with geographic representation, along with areas with significant investment from the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund for AIDS, Tuberculosis, and Malaria were included. These countries included seven from Sub-Saharan Africa (South Africa, Ghana, Nigeria, Senegal, Côte d'Ivoire, Mauritania, and The Gambia), one from the Middle East and North Africa (Lebanon), two from Asia (Thailand and Malaysia), one from South America (Brazil), one from Europe (Ukraine), and the United States. The number of unique active gay app users in 2015 who resided in each country were provided by the Hornet Gay Social Network (Hornet) [19].

Detailed targeting of unique users within Facebook's Advertising (Ads) Manager was utilized to estimate the number of men who are interested in men (MIM), men who are interested in men or men and women (MIMW), and those men with at least one reported same-sex interest (MSSI) by country of residence (Multimedia Appendix 1, Multimedia Appendix 2, Multimedia Appendix 3). Facebook's Ads Manager is structured around four domains that can be used to stratify users and produce size estimates: (1) location, (2) demographics, (3) interests, and (4) behaviors [22]. Facebook's intelligent analytics engine can track online behavior (on and off Facebook) and code the user's behavior into interest and behavior categories that appear in the Ads Manager; this is done based on: (1) what people share on their timelines; (2) apps they use; (3) ads they click on; (4) pages they engage with; (5) activities people engage in on and off Facebook related to things like their device usage, purchase behaviors or intents, and travel preferences; (6) demographics like age, gender, and location; and (7) the mobile device they use and the speed of their network connection [23]. Specifically, Facebook defines these variables as *interests* and *behaviors* [24]. Interests are used by marketers to reach specific audiences by looking at people's interests, activities, the pages and posts they like, posts and comments they make, and closely related topics. Behaviors are used to facilitate targeting based

on purchase behaviors, device usage, and other activities. While it is feasible to use both interests and behaviors to assess population size, this study used interests. Specifically, the following keywords were used to identify same-sex interests: "bisexual," "gay," "gender," "homosexual," "LGBT," "pride," "same-sex," and "trans." Related interests were also suggested by Facebook's Ads Manager based on the aforementioned search terms. Identified same-sex interests were subsequently assigned to one of eight thematic groups, representing men who have expressed an interest in (or liked pages related to) at least one included same-sex interest (Multimedia Appendix 4). Only same-sex interests endorsed by at least 100,000 Facebook users across all of Facebook were included in the analysis. No ads were created. During the process of planning advertisements, the Facebook Ads Manager interface displays an estimated number of users in the geographic area with those interests. This estimate was used to capture the potential size of each country-specific audience meeting specified criteria (ie, the number of adult MIM, MIMW, and MSSI Facebook users who may be exposed to the ad per country). UNAIDS GBMSM population size estimation methodology has been reported elsewhere [16].

Results

A comparison of GBMSM estimates from UNAIDS, Hornet, and Facebook is presented in Table 1 (see Multimedia Appendix 5 for more details). Recent UNAIDS and national estimates are less than those reported by active Hornet app users in Brazil, Thailand, and Ukraine, with differences in estimates of 1,018,520, 603,942, and 66,670, respectively. UNAIDS and national estimates of GBMSM are less than all three Facebook estimates categories (MSSI, MIMW, MIM) in Malaysia, Ghana, Nigeria, Lebanon, Senegal, Côte d'Ivoire, Mauritania, and The Gambia. UNAIDS and national estimates are less than the reported numbers of MSSI, MIMW, and MIM in 13, 9, and 8 selected countries, respectively.

The number of adult Facebook users identified in the eight same-sex interest categories, including *Entertainment/Media*, *Gay*, *Gender*, *LGBT*, *Pride*, *Relationships*, *Sexuality*, and *Trans*, is presented in Table 2 (see Multimedia Appendix 6 for more details), with all interest categories available in Multimedia Appendix 4. The proportions of men with Facebook that identified same-sex interest categories among the overall Facebook estimate of males >18 years of age is also presented. The proportion of men reporting a same-sex interest within the category of *Relationships* ranged from 1.6% in Ukraine to 25.5% in Nigeria, and those reporting interests categorized as being related to being *Gay* ranged from <0.5% in The Gambia to 9.4% in Ukraine.

The age distribution of Facebook users identified as MSSI, MIMW, and MIM is presented in Multimedia Appendix 7. The proportions of MSSI, MIMW, and MIM among the overall Facebook estimates of males by country is also presented.

The proportion of males aged 13-17 years reporting same-sex interests ranged from 4.7% in Côte d'Ivoire to 21.2% in the United States, and estimated MIM in the same age group ranged from <0.2% in Ukraine to 3.2% in Malaysia. In several

countries, Facebook estimates of one or two age cohorts alone exceeded the UNAIDS total population estimate of GBMSM for the respective country.

Table 1. Comparison of GBMSM^a estimates from UNAIDS^b, Hornet, and Facebook. MIM: men (>18 years of age) interested in men ; MIMW: men (>18 years of age) interested in men or men and women; MSSI: men (>18 years of age) with at least one reported same-sex interest.

Country	UNAIDS estimate ^b	Facebook estimates				Differences (UNAIDS minus indicated estimate)			
		MSSI	MIMW	MIM	Hornet Users	MSSI	MIMW	MIM	Hornet
United States ^c	4,503,080	17,000,000	1,500,000	740,000	2,482,802	(-12,496,920)	3,003,080	3,763,080	2,020,278
Brazil	2,037,741	9,900,000	510,000	240,000	3,056,261	(-7,862,259)	1,527,741	1,797,741	(-1,018,520)
South Africa ^d	654,979	870,000	430,000	61,000	38,013	(-215,021)	224,979	593,979	616,966
Thailand	571,000	3,600,000	760,000	290,000	1,174,942	(-3,029,000)	(-189,000)	281,000	(-603,942)
Ukraine	176,000	620,000	38,000	15,000	242,670	(-444,000)	138,000	161,000	(-66,670)
Malaysia	170,000	3,000,000	2,100,000	290,000	311,472	(-2,830,000)	(-1,930,000)	(-120,000)	(-141,472)
Ghana	30,579	700,000	550,000	42,000	31,165	(-669,421)	(-519,421)	(-11,421)	(-586)
Nigeria	29,470	3,300,000	2,800,000	180,000	14,793	(-3,270,530)	(-2,770,530)	(-150,530)	14,677
Lebanon	3114	260,000	68,000	29,000	25,916	(-256,886)	(-64,886)	(-25,886)	(-22,802)
Senegal	1840	260,000	190,000	31,000	2870	(-258,160)	(-188,160)	(-29,160)	(-1030)
Côte d'Ivoire	1343	340,000	220,000	23,000	3575	(-338,657)	(-218,657)	(-21,657)	(-2232)
Mauritania	160	47,000	31,000	7300	177	(-46,840)	(-30,840)	(-7140)	(-17)
The Gambia	150	34,000	20,000	1800	194	(-33,850)	(-19,850)	(-1650)	(-44)

^aGBMSM: Gay, bisexual, and other cisgender men who have sex with men.

^bUNAIDS: Joint United Nations Programme on HIV/AIDS. Reported GBMSM size estimate from the UNAIDS AIDS Info Online Database [20] unless otherwise specified.

^cUnited States GBMSM size estimate from Grey et al 2016 [10].

^dSouth Africa GBMSM size estimate from 2017 PEPFAR COP [21].

Table 2. Distribution of Facebook-identified same-sex interests by country. Reported in thousands, n (%).

Country	Entertainment/ Media	Gay	Gender	LGBT	Pride	Relationships	Sexuality	Trans
United States	7100 (6.8)	4500 (4.3)	2800 (2.7)	11,000 (10.6)	5600 (5.4)	3800 (3.7)	4900 (4.7)	23 (0.0)
Brazil	2900 (5.3)	2200 (4.0)	710 (1.3)	7400 (13.5)	3500 (6.4)	4700 (8.5)	2800 (5.1)	110 (0.2)
South Africa	150 (2.0)	100 (1.4)	51 (0.7)	330 (4.5)	140 (1.9)	480 (6.5)	130 (1.8)	<1 (0.0)
Thailand	530 (2.3)	400 (1.7)	110 (0.5)	2200 (9.6)	390 (1.7)	920 (4.0)	1200 (5.2)	6.6 (0.0)
Ukraine	470 (9.8)	450 (9.4)	14 (0.3)	170 (3.5)	71 (1.5)	79 (1.6)	77 (1.6)	<1 (0.0)
Malaysia	350 (2.7)	260 (2.0)	89 (0.7)	780 (6.0)	320 (2.5)	2200 (16.9)	400 (3.1)	6.2 (0.0)
Ghana	55 (1.7)	24 (0.8)	30 (0.9)	130 (4.1)	43 (1.3)	580 (18.1)	50 (1.6)	<1 (0.0)
Nigeria	220 (2.0)	110 (1.0)	81 (0.7)	470 (4.3)	140 (1.3)	2800 (25.5)	210 (1.9)	1.9 (0.0)
Lebanon	59 (3.0)	55 (2.8)	18 (0.9)	100 (5.0)	50 (2.5)	83 (4.2)	84 (4.2)	<1 (<0.1)
Senegal	16 (0.9)	6.6 (0.4)	18 (1.1)	59 (3.5)	13 (0.8)	190 (11.2)	13 (0.8)	<1 (<0.1)
Côte d'Ivoire	16 (0.6)	8.4 (0.3)	13 (0.5)	72 (2.9)	57 (2.3)	240 (9.6)	32 (1.3)	<1 (0.0)
Mauritania	3.5 (0.9)	2.3 (0.6)	6.9 (1.9)	8.6 (2.3)	2.5 (0.7)	32 (8.6)	3.9 (1.1)	n/a
The Gambia	1.3 (0.7)	<1 (<0.5)	1.3 (0.7)	13 (6.5)	1.3 (0.7)	21 (10.5)	12 (6.0)	n/a

Discussion

Principal Findings

Comparisons of UNAIDS GBMSM size estimates to numbers of users on a gay-oriented app and Facebook users with same-sex interests suggest that UNAIDS data may significantly underestimate GBMSM populations to varying extents across all countries. Although there are several limitations to our approach, there is a clear signal towards higher estimates of GBMSM when digital approaches are utilized. While several studies have focused on the role dating apps and websites play in risk-taking behaviors among GBMSM [25], only recently has there been interest in leveraging apps to serve the HIV prevention, treatment, and care needs among GBMSM. Our data suggest that same-sex dating apps and social media networks are promising data sources for designing population estimates and programmatic targets for GBMSM.

The usage of the Internet is becoming increasingly normalized throughout the world, and this trend will only continue. Empirical and market-research data, generally derived from higher income settings, demonstrate that GBMSM are high utilizers of the Internet, often using the Internet to find partners, given limited venues and significant social stigma [26-30]. Moreover, GBMSM who find partners online may be at higher risk of HIV acquisition and transmission [31]. This trend towards online spaces has largely been attributed to stigma that same-sex behaviors face and the confidentiality that is afforded in online spaces [32-34], which enable users to more accurately report their attraction (or in some instances, trace their behavior) and eliminate biases in self-reported data. Although these studies were predominantly completed in higher income settings, similar results have been observed among GBMSM in Southern Africa and Nigeria [35,36]. Given the significant usage of the Internet, online spaces likely represent an important approach for collecting same-sex attraction and behavioral data, especially in more stigmatizing settings. However, these same spaces also represent a currently underutilized approach to better address the HIV prevention and treatment needs of GBMSM [37].

Little is known about the needs of GBMSM under 18 years of age, because these young GBMSM are often not allowed to enroll in studies or seek services. However, most men have their first sexual encounters with other men before the age of 18, and HIV incidence has been shown to be high among young GBMSM across settings [38,39]. Moreover, men under the age of 18 are generally not included in surveys or HIV prevention, treatment, and care programs, given the challenges in achieving consent [40]. Given that younger GBMSM are more likely to leverage virtual spaces, as evidenced by these data, the use of digital data for size estimation represents a strategy to inform the numbers and HIV prevention, treatment, and care needs of young GBMSM [41]. While the legal challenges of consent remain, especially in settings where same-sex practices are criminalized, there is a clear need to scale up evidence-based and human rights-affirming HIV prevention strategies for younger GBMSM, including condoms, lubricants, and preexposure prophylaxis (PrEP).

Limitations

There are several limitations in the methods and results presented here. Detailed information about how Facebook's Ads Manager projects ad reach estimates—or population estimates for the intents and purposes of this article—is not public, and discrepancies have been identified between their projections and census data [42,43]. The definitions of men's same-sex interests used here were derived by the authors and may be nonspecific, potentially including people interested in LGBT equality (allies). Moreover, the extent of specificity is likely subject to specific cultural contexts, thereby leading to overestimating the numbers of GBMSM with this metric. The metric used for Hornet was unique users with only one account allowed per device. While it is feasible to create multiple accounts on Facebook with unique email addresses, this likely represents a very low proportion of users. Although Internet usage is increasing rapidly, there is less access in many lower- and middle-income countries, which may underestimate the numbers of GBMSM. However, Internet access around the world continues to increase, especially due to the rapid increase in affordable smartphones, suggesting that the utility of social media-based estimates of population size will increase over time. Moreover, some of the respondents captured online in low- and middle-income countries may be expatriates rather than GBMSM from that country. The contribution of expatriates to these estimates is considered to be low, given the limited number of expatriates, and only people who noted the country as their country of residence were included. Additional research studying appropriate search strategies according to each social media platform, including large platforms not studied in these analyses, are required. Building collaborations with social media platforms may also facilitate improved estimates of population size along with insights into appropriate strategies to deliver interventions that leverage these platforms. Taken together, these data clearly suggest a significant discrepancy between size estimates of GBMSM reported by normative agencies and estimates from digital sources.

Conclusions

Over four decades of the HIV pandemic, GBMSM have been well known to bear a disproportionate burden of HIV due to the biology of the virus, which is compounded by criminalization, intersectional stigma, discrimination, and violence. Deriving estimates of the numbers of people at risk of acquiring and living with HIV is complex, and other studies have highlighted these challenges for other populations. For GBMSM, deriving estimates is further complicated by hostile policy settings, where HIV epidemics are also characterized as *generalized*. Developing common methods of counting GBMSM, especially the use of central data collection with consistent approaches, provides an additional data source that is directly comparable across settings. Although these additional approaches have biases, they are complementary to the biases of existing methods. The approach presented here that leverages social media is imperfect, but is relatively low cost to implement and provides comparable estimates across a large range of countries, including some with no extant estimates. Triangulating multiple data sources (including social media) may facilitate optimal estimations of the numbers of GBMSM

for program planning, evaluation, and estimates of HIV epidemic dynamics. These methods also allow for the estimation of numbers of GBMSM in settings where stigma and risks of violence are too great to even report in this paper [44]. As violence targeting GBMSM continues to escalate, traditional estimation of the numbers of GBMSM are increasingly problematic. The practice of pointing to no data (in this instance nonexistent GBMSM size estimates) to justify not funding or

grossly underresourcing programs for GBMSM has long been identified by advocates, and should be challenged. Not doing so runs the risk of having evidence-based and human rights-affirming programs that address specific needs of GBMSM disappear. Ultimately, we cannot overstate the importance of understanding the characteristics and numbers of those most affected by HIV to truly achieve an AIDS-free generation.

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Conflicts of Interest

SH is the President of Hornet and AG serves as a Senior Health Innovation Strategist at Hornet. All other authors declare no conflicts of interest.

Multimedia Appendix 1

Screenshot of detailed targeting within Facebook's Ads Manager used to estimate the number of adult male residents of Malaysia who are interested in men (MIM).

[[PNG File, 232KB - publichealth_v4i1e15_app1.png](#)]

Multimedia Appendix 2

Screenshot of detailed targeting within Facebook's Ads Manager used to estimate the number of adult male residents of Malaysia who are interested in men or both men and women (MIMW).

[[PNG File, 234KB - publichealth_v4i1e15_app2.png](#)]

Multimedia Appendix 3

Screenshot of detailed targeting within Facebook's Ads Manager used to estimate the number of adult male residents of Malaysia who report at least one same-sex interest (MSSI).

[[PNG File, 229KB - publichealth_v4i1e15_app3.png](#)]

Multimedia Appendix 4

Facebook identified same-sex interest categories included for MSSI.

[[PNG File, 379KB - publichealth_v4i1e15_app4.png](#)]

Multimedia Appendix 5

Comparison of gay, bisexual, and other men who have sex with men (GBMSM) estimates from UNAIDS, Hornet, and Facebook — expanded [Table 1](#).

[[PNG File, 128KB - publichealth_v4i1e15_app5.png](#)]

Multimedia Appendix 6

Distribution of Facebook identified same-sex interests by country — expanded [Table 2](#).

[[PNG File, 93KB - publichealth_v4i1e15_app6.png](#)]

Multimedia Appendix 7

Age distribution of male Facebook users by country (proportion of males).

[[PDF File \(Adobe PDF File\), 265KB - publichealth_v4i1e15_app7.pdf](#)]

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Abbreviations

Ads: Advertisements
AIDS: acquired immunodeficiency syndrome
GBMSM: gay, bisexual, and other men who have sex with men
LGBT: lesbian, gay, bisexual, or transgender
MIM: men interested in men
MIMW: men interested in men or men and women
MSSI: men with at least one reported same-sex interest
NIH: National Institutes of Health
PEPFAR: President's Emergency Plan for AIDS Relief
PrEP: pre-exposure prophylaxis
UNAIDS: Joint United Nations Programme on HIV/AIDS

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Corrigenda and Addenda

Authorship Correction: Sampling Key Populations for HIV Surveillance: Results From Eight Cross-Sectional Studies Using Respondent-Driven Sampling and Venue-Based Snowball Sampling

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In the paper by Amrita Rao et al, "Sampling Key Populations for HIV Surveillance: Results from Eight Cross-Sectional Studies using Respondent-Driven Sampling and Venue-Based Snowball Sampling," a mistake was made in the metadata and Duncan Kochelani was included twice, while Brian Rice was not included. Brian Rice was always an intended author of this publication. The authors have records of previous versions that had been reviewed by the editorial team in which Brian is included as an author, as well as the final publishing agreement

signed by all authors, with both Duncan and Brian as coauthors of this work.

The corrected article will appear in the online version of the paper on the JMIR website on January 15, 2018, together with the publication of this correction notice. Because this was made after submission to PubMed or Pubmed Central and other full-text repositories, the corrected article also has been re-submitted to those repositories.

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Editorial

Know Your Epidemic, Strengthen Your Response: Developing a New HIV Surveillance Architecture to Guide HIV Resource Allocation and Target Decisions

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Abstract

To guide HIV prevention and treatment activities up to 2020, we need to generate and make better use of high quality HIV surveillance data. To highlight our surveillance needs, a special collection of papers in *JMIR Public Health and Surveillance* has been released under the title “Improving Global and National Responses to the HIV Epidemic Through High Quality HIV Surveillance Data.” We provide a summary of these papers and highlight methods for developing a new HIV surveillance architecture.

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KEYWORDS

HIV; data; systems; surveillance; testing; treatment; prevention; monitoring; key populations

In 2014, targets were set to diagnose 90% of all people living with HIV, provide antiretroviral therapy for 90% of those diagnosed, and achieve viral suppression among 90% of those treated by 2020 [1]. In 2016, a United Nations Political Declaration called on countries to achieve 500,000 fewer people newly infected with HIV, 500,000 fewer people dying from AIDS-related causes, and the elimination of HIV-related discrimination by 2020 [2].

To guide HIV prevention and treatment activities up to 2020 and beyond will necessarily require developing a new surveillance architecture that better delivers and leverages high quality HIV surveillance data. We must plan for more sustainable, country-led, action-oriented HIV surveillance platforms that can serve both local decision making and global reporting and modelling needs. In May 2015 the World Health

Organization (WHO) and the Joint United Nations Programme on HIV/AIDS held their third global consultation meeting on HIV surveillance [3]. Over four days, discussions focused on recognizing priority gaps in current surveillance systems, identifying the surveillance data needed to monitor achievement of long-term goals such as the 90-90-90 indicators, and consolidating a global surveillance agenda to guide global and national programs. To reflect these discussions, we have released a special collection of papers in *JMIR Public Health and Surveillance* entitled, “Improving global and national responses to the HIV epidemic through high quality HIV surveillance data.” This special collection includes papers that present creative methods for developing, collecting, and using HIV surveillance data to guide HIV resource allocation and targeting decisions.

The galvanizing consensus around the 90-90-90 targets highlights our need to more accurately track the reach of testing and treatment programs. This will be best achieved by drawing on data generated through the delivery of these services rather than self-reports in surveys or the screening of non-HIV test blood specimens. A number of the papers in the special collection explore how existing information from HIV testing and treatment services can be valuable surveillance data, particularly for monitoring achievement of HIV care goals. Dee et al assessed how the move away from unlinked anonymous testing among pregnant women attending select antenatal clinics to surveillance based on routine HIV testing in these facilities may enhance our surveillance efforts [4]. The authors concluded that this shift represents a substantial achievement in building strong routine data systems to support HIV service delivery, program monitoring, and strategic information.

To ensure broader national surveillance and monitoring and evaluation (M&E) systems do not go the same way as antenatal sentinel surveillance, they must evolve. Rice et al and Bozicevic et al considered how best to strengthen existing systems [5,6]. Focusing on the use of routine HIV data collected in sub-Saharan Africa through service delivery platforms, Rice et al presented four priorities for action to drive more effective and efficient clinical management and prevention programming [5]. Bozicevic et al conducted a needs assessment of HIV strategic information systems in non-European Union countries in the WHO European region [6]. The authors identified a number of areas for capacity building to ensure these systems meet future needs, including improving their ability to disaggregate data by demographical and epidemiological factors.

A majority of national surveillance and M&E systems are limited in how information can be presented since they rely on the collection of aggregate data. To overcome the limitations of aggregate data, we need to develop comprehensive strategic HIV information systems that leverage individual-level data collected at HIV diagnosis and over time. Case-based surveillance (CBS) is such a system. Currently, no such system exists in sub-Saharan Africa, where the burden of disease is greatest. To identify systems that may be utilized in the development of CBS, Harklerode et al conducted situational assessments in Tanzania, South Africa, and Kenya [7]. To promote the collection and use of individual-level data through CBS, the authors made a number of recommendations based on their observations—recommendations that have informed recent global guidelines on person-centered HIV patient monitoring and case surveillance [7,8]. In their review of global surveillance priorities, Low-Beer et al outlined the fifteen steps required to develop a person-centered surveillance approach, five of these relate to CBS [9]. The remaining ten directions are categorized under improving patient monitoring and scaling up unique identifiers.

Commenting on the importance of surveillance data in program implementation, Low-Beer et al highlighted the need for integrating HIV activities with those related to sexually transmitted infections, hepatitis, and health [9]. In response to this, Hutin et al identified similarities and differences between the hepatitis and HIV response [10]. Concluding that integration or linkage is possible, the authors presented an approach to align

the two streams of strategic information. Linkage across health sectors is something Nguyen et al call for in their analyses of a community-based retrospective cohort study among pregnant women diagnosed with HIV infection in Vietnam [11]. To bridge serious gaps in efforts to eliminate mother-to-child transmission, the authors endorsed data linkage across HIV and maternal and child health programs.

Despite understandable skepticism with regard behavioral surveillance, which has been undermined by social desirability biases and poor data quality, it will be critical to improve our capacity to track risk if we are to accurately predict epidemic pathways and reinvigorate HIV prevention efforts. To substantially reduce levels of HIV transmission, it is essential we improve strategic information among key populations, including better leverage of data on the size and location of populations most at risk. A number of the papers in the special collection focus on methods to improve surveillance activities with key populations at risk of HIV infection.

Reviewing the adequacy and relevance of current surveillance methods in key populations, Weir et al proffer a number of strategies to improve strategic information and estimates [12]. Among these is a recommendation to assess selection bias and subgroup representation. Analyzing data collected among female sex workers in Zimbabwe, Fearon et al investigated sample size effects on population size estimates using multiplier methods and respondent driven sampling [13]. A high variance in estimates was reported. Complementary to this work, Rao et al presented an analysis of eight studies on female sex workers and men who have sex with men, where participants were recruited using respondent-driven or venue-based snowball sampling in Swaziland and Cameroon [14]. The authors demonstrated how different sampling methodologies generate samples with a varying composition of HIV prevention needs and program exposure. In both of these analytic research papers, recommendations for reducing bias and improving population size estimates were presented.

To promote comprehensive HIV and general health programming, it is essential to include adolescents who sell sex, engage in same-sex relationships, and/or inject drugs. It is also important to integrate validated stigma scales to characterize key populations. These were the principal recommendation of Johnston et al [15] and Stahlman et al [16]. Arguing that adolescent groups disproportionately affected by HIV are largely ignored, Johnston et al put forward a number of suggestions for including these groups in future surveillance activities in a manner that is both ethical and effective [15]. With the intention of improving HIV-related outcomes, Stahlman et al outlined a vision for integrating validated stigma scales in key population epidemiologic, surveillance, and intervention studies [16].

As testing and treatment have expanded, so has the amount of data on HIV infections generated through service delivery. These data now dwarf those collected through bespoke research or surveillance activities. The rapid expansion of networked infrastructures provides an opportunity to develop a new surveillance architecture to harness these data at scale. The collection and secure storage of routine individual level data, linked within and across systems, will deliver more accurate,

disaggregated and sustainable measurements of HIV incidence, HIV transmission risk, and HIV acquisition risk at a level and timeliness that can support resource allocation decisions and targeted action that will accelerate the reduction of HIV incidence.

Conflicts of Interest

None declared.

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Abbreviations

WHO: World Health Organization
M&E: monitoring and evaluation
CBS: case-based surveillance

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Original Paper

A Participatory System for Preventing Pandemics of Animal Origins: Pilot Study of the Participatory One Health Disease Detection (PODD) System

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Abstract

Background: Aiming for early disease detection and prompt outbreak control, digital technology with a participatory One Health approach was used to create a novel disease surveillance system called Participatory One Health Disease Detection (PODD). PODD is a community-owned surveillance system that collects data from volunteer reporters; identifies disease outbreak automatically; and notifies the local governments (LGs), surrounding villages, and relevant authorities. This system provides a direct and immediate benefit to the communities by empowering them to protect themselves.

Objective: The objective of this study was to determine the effectiveness of the PODD system for the rapid detection and control of disease outbreaks.

Methods: The system was piloted in 74 LGs in Chiang Mai, Thailand, with the participation of 296 volunteer reporters. The volunteers and LGs were key participants in the piloting of the PODD system. Volunteers monitored animal and human diseases, as well as environmental problems, in their communities and reported these events via the PODD mobile phone app. LGs were responsible for outbreak control and provided support to the volunteers. Outcome mapping was used to evaluate the performance of the LGs and volunteers.

Results: LGs were categorized into one of the 3 groups based on performance: A (good), B (fair), and C (poor), with the majority (46%, 34/74) categorized into group B. Volunteers were similarly categorized into 4 performance groups (A-D), again with group A showing the best performance, with the majority categorized into groups B and C. After 16 months of implementation, 1029 abnormal events had been reported and confirmed to be true reports. The majority of abnormal reports were sick or dead animals

(404/1029, 39.26%), followed by zoonoses and other human diseases (129/1029, 12.54%). Many potentially devastating animal disease outbreaks were detected and successfully controlled, including 26 chicken high mortality outbreaks, 4 cattle disease outbreaks, 3 pig disease outbreaks, and 3 fish disease outbreaks. In all cases, the communities and animal authorities cooperated to apply community contingency plans to control these outbreaks, and community volunteers continued to monitor the abnormal events for 3 weeks after each outbreak was controlled.

Conclusions: By design, PODD initially targeted only animal diseases that potentially could emerge into human pandemics (eg, avian influenza) and then, in response to community needs, expanded to cover human health and environmental health issues.

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KEYWORDS

community-owned disease surveillance system; PODD; mobile app; one health; participatory approach; backyard chicken; pandemic prevention

Introduction

Pandemics

As an estimated 61% of human pathogens are zoonoses [1], a key strategy to avert pandemics is the early detection of pathogen occurrence or disease outbreak in domestic animals and management of the outbreak, so that disease transmission from animal to human populations can be prevented. This is particularly true of influenza pandemics, which can be triggered by emerging avian influenza (AI) viruses. In 2004, an AI outbreak (subtype H5N1) resulted in more than 500 human infections worldwide. On January 23, 2004, in Thailand, an AI outbreak (subtype H5N1) was confirmed in a layer chicken farm by the National Library of Thailand [2]. An abnormal death in a backyard chicken, which is an early indicator of an AI outbreak, is especially worrisome in countries where animal health services need to be improved. The link between disease in backyard chickens and the potential for a global human influenza pandemic requires a holistic view of human, animal, and environmental health. Community participation and a One Health approach—enabling early reporting of suspected cases and implementing effective control measures—played a key role in controlling and eradicating the 2004 H5N1 outbreak in Thailand [3].

Early Detection

Recognizing the key roles that community participation and a One Health approach play in averting AI pandemics, coupled with the US Flu Near You system having previously demonstrated how participatory reporting using digital tools can help detect influenza outbreaks in human populations faster than traditional surveillance [4], we developed a new type of surveillance tool to enable early detection of potential zoonotic events using a participatory, digital approach grounded in One Health concepts. The system was developed in Chiang Mai, Thailand, and is called Participatory One Health Disease Detection (PODD). This paper describes the following: (1) the core functions of PODD; (2) PODD system's emphasis on participatory surveillance and community empowerment; (3) PODD system's initial focus on animal health; (4) results of a performance evaluation of local governments (LGs) and volunteer reporters participating in PODD; and (5) initial effectiveness of PODD in preventing potential AI outbreaks.

Methods

Participatory One Health Disease Detection Surveillance Core Functions: Data Reporting, Analysis, and Response

The PODD system is a digital disease surveillance tool with three parts: (1) data reporting to a data collection system via a mobile phone; (2) automated outbreak capturing (ie, automated matching of each reported case or event with case definitions); and (3) automated notification of suspected outbreaks to local governments (LGs), surrounding villages, and all relevant authorities so that they can closely monitor the situation and immediately implement the LG contingency plan to stop the spread of disease.

Volunteer reporters played an important role in reporting. Each LG selected 4 people, who live in the community, who have the willingness to be a volunteer, and who have experience about livestock raising, to be PODD volunteers in the community. A total of 300 volunteers from 75 LGs were recruited in the project. After being trained about how to use PODD and important clinical signs in animals and humans, volunteer reporters continue to meet their trainers every 3 months to be updated on new content and new features of the app and to have their reporting skills tested and improved.

Volunteers reported abnormal animal sicknesses and deaths, animal diseases, animal bites, food safety issues, human diseases, and environmental problems. For abnormal events in animal or animal diseases, the volunteers reported via a PODD mobile app in the animal section. As shown in [Figure 1](#), an automated system matched each report with potential case definitions immediately and assigned a “case” status. In case of a mismatch, the status of the reports was immediately changed to “insignificant report.” If there was a match, reported data were immediately sent to the PODD epicenter, where the epicenter staff, who were mostly veterinarians, verified the reported data by calling reporters and confirming the details within 24 hours. The status of any given report was changed to “suspected outbreak” only after the report had been verified. Upon verification, a short message service text message and an email alert was automatically sent to all stakeholders (ie, researchers, PODD staff, officers from provincial and district Department of Livestock Development [DLD], and LG staff). Additionally, the reporter was given a set of guidelines to

manage and to contain the outbreak promptly; LGs and local authorities were notified to activate the LG contingency plan; and district and provincial DLD and public health officers were sent warning messages about the suspected case. Meanwhile, epicenter staff and the district livestock officer, together with the volunteer reporter and other community volunteers, continued to investigate and collect field samples for laboratory confirmation. If the investigative team did not detect an epidemic disease and decided that the case was not a serious issue, the “suspected outbreak” status was changed to “finish.” Despite this, the volunteer reporter was asked to continue the monitoring of the case once a week. If the investigative team detected multiple cases of an infectious disease in either a household or a village, the “suspected outbreak” status was changed to “outbreak.” At this stage, all stakeholders were requested to follow their LG’s contingency plan to control the disease. The “outbreak” status was changed to “finish” only after the outbreak had been controlled.

For human health and environmental problems, volunteers could report via the human and environmental sections, separately. The information of an individual report was sent to PODD system’s data center. Staff at the Provincial Public Health office reviewed the information and allocated it to the specific section to verify and respond to the report. The epidemiology section was responsible for human diseases and zoonosis, the food safety section was responsible for food safety issues, and the environmental section was responsible for environmental problems and public nuisance. The verification process in human health and environmental problems involved calling the reporter, who reported the event, and examining the photograph that the reporter sent via the app.

All events—related to animal health, human health, or environmental problems—were sent to the PODD epicenter to detect whether any relationship exists among them with respect

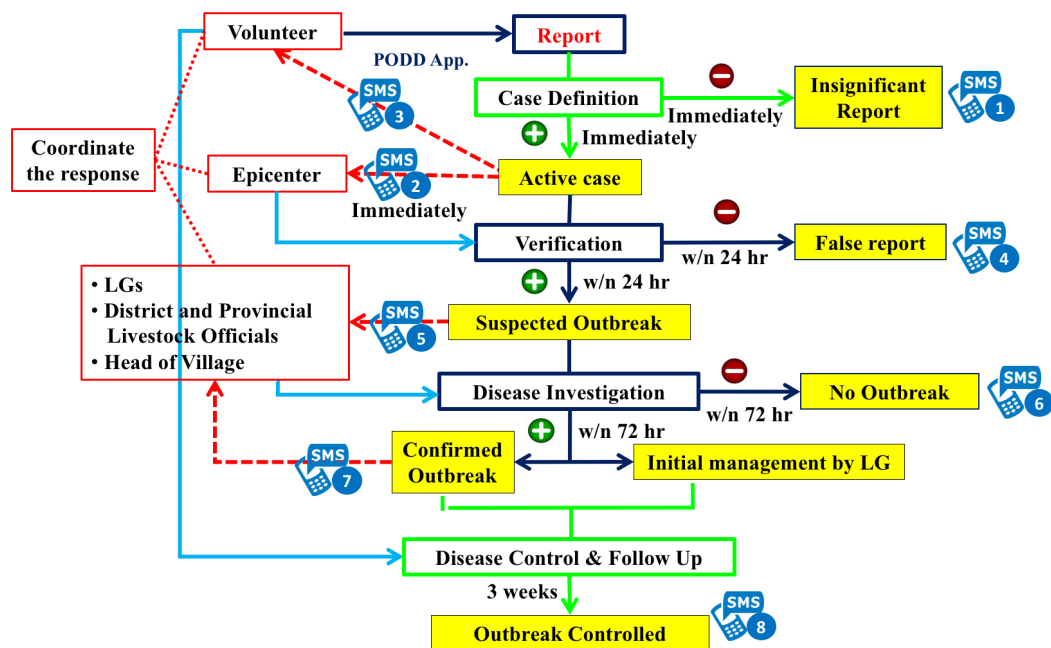
to place or time. The analysis was performed weekly by the staff and reported monthly to researchers. If the link between different events was detected, animal and public health authorities and communities would be notified. Then, disease investigation and response would be processed collaboratively by the animal health authority, the public health authority, and the LG.

In Chiang Mai, the pilot area, the Provincial One Health Committee had been set up, for more than 10 years, to prevent and control issues related to animal health, human health, and environmental problems. This organization had taken the responsibility of serious cases, which were notified from the epicenter and the LG staff in the affected community.

Participatory One Health Disease Detection System’s Participatory Approach and Community Empowerment

PODD was designed as a community-owned surveillance system that focuses on immediate community benefits, rather than the longer-term goals typically associated with traditional surveillance systems. As described previously and in [Figure 1](#), the PODD system was designed for villagers to serve as volunteer reporters and LGs to take responsibility for controlling outbreaks within their jurisdictions. For piloting the PODD system, 3 LGs in each of the 25 districts in Chiang Mai Province were involved in the project. Due to logistical difficulties, one LG was forced to exit the pilot program. Therefore, 74 LGs covering 296 villages in all regions of Chiang Mai Province participated in the pilot study. The pilot study area covered urban as well as rural areas, including mountainous area. The PODD research team convened the volunteers and LGs every 2 to 4 months to assess progress and discuss potential changes to the system. Critical activities were designed together before implementation.

Figure 1. Detailed Participatory One Health Disease Detection (PODD) system workflow indicating roles and responsibilities to control animal diseases. LG: local government; SMS: short message service.



As community empowerment was the primary goal of PODD, the PODD program had to make several concerted efforts to help participating communities in developing their ability to prevent and control animal epidemics sustainably. These efforts included developing contingency plans for LGs to address abnormal animal deaths; establishing a revolving fund for a chicken vaccination campaign; and providing knowledge via a “Training on Prevention and Control of Disease in Chickens” program to chicken raisers about prevention and control of chicken diseases, including the method of vaccinating their animals in a proper and timely manner.

The Training on Prevention and Control of Disease in Chickens program was an integrated effort among LGs, the PODD project team, and district DLD offices. Knowledge of important chicken diseases, including avian influenza, Newcastle disease, infectious bronchitis, and infectious bursal disease, was provided to chicken farmers in the program. It started with meetings being conducted with all relevant stakeholders to develop an operational plan. Once the plan was developed, it was forwarded to all LGs and the director of the PODD project to request financial support. The LGs and the PODD project team provided equal financial support. After financial approval, communities

conducted group meetings to specify the directions of operation for providing services such that the communities would play a role and then conducted activities according to the plan. At the end of the program, the program was evaluated with respect to the reduction of chicken deaths and sickness; the use of funds; and the participation of the community members, the PODD project team, and the LG. A total of 20 LGs have run this program in their community.

Initial Focus on Priority Animal Diseases

Because animal infectious diseases are the primary focus of PODD surveillance, a specific set of priority animal diseases was incorporated into the PODD app initially (Textbox 1). Volunteer reporters were trained to detect either symptoms of these diseases or the diseases themselves (ie, based on case definitions, as presented in Textbox 1) and enter their observations into the PODD system. After 1 year, human diseases and environmental problems were added to the tool (see Textboxes 2 and 3). The list of animal diseases, human diseases, and environmental problems is provided in the PODD mobile app for early detection of problems, which have potential subsequent effect on another component in One Health.

Textbox 1. Animal diseases and case definitions used in the Participatory One Health Disease Detection (PODD) mobile app.

- Poultry (chicken and duck)
 - Fowl cholera: sudden death and rapid spread
 - Fowl pox: pus or black pimple on the face; death possible
- Pig
 - Foot and mouth disease: blister or wound at hoof and mouth; salivation; pain
 - Brucellosis: abortion in many sows
 - Influenza: coughing; dyspnea; runny nose
 - Leptospirosis: jaundice, yellowish eyes; bloody urine (hematuria)
- Ruminants (cow, buffalo, goat, and sheep)
 - Anthrax: sudden death; bleeding from body opening
 - Foot and mouth disease: blister or wound at hoof and mouth; salivation; pain
 - Brucellosis: abortion in many animals
 - Leptospirosis: jaundice; yellowish eyes; bloody urine (hematuria)
 - Tuberculosis: emaciation; chronic coughing; pustules in carcass
- Dog and cat
 - Rabies: biting; aggression; inability to swallow; lack of coordination; seizure; death
 - Canine distemper: wet eyes; pustules in the belly; convulsion
 - Enteritis: vomiting; bloody diarrhea
- Horse
 - Influenza: coughing; dyspnea; runny nose
 - Surra: swollen legs; pale; cannot stand; bleeding in the eyes possible

Textbox 2. Human diseases, risks, and problems that volunteers can report via the Participatory One Health Disease Detection (PODD) mobile app.

The following diseases are zoonoses with high impacts on human health:

- Infection caused by *Streptococcus suis*
- Leptospirosis
- Suspected bovine tuberculosis
- Influenza
- Trichinosis

The following are human diseases with high impacts on human health; they need to be controlled early to limit disease spreading:

- Hand, foot, and mouth disease
- Suspected dengue virus

The following are risks to food safety that can harm the quality of people's lives. Reporters can take a photo, indicate location, and send the data to public health authority via the PODD app. The authorities must check and investigate all reports:

- Food poisoning
- Dirty restaurant/ butcher
- Toxic mushroom
- Suspected contaminated food (chemical/biological/physical)
- Low price meat
- Low quality food

The following problems, all of which still occur in several places across Thailand, were added to the PODD app for consumer protection and community monitoring:

- Unsafe/nonapproved cosmetics
- Fraudulent drugs
- Drugs containing steroids
- Unapproved drugs or herbs
- Reused cooking oil
- The sale of animal drugs without a sale certificate
- The sale of unapproved animal drugs

The following was added to the PODD app to monitor the risk of rabies in communities. Reporters report humans who have been bit by animals, particularly dogs and cats, and then follow the animals for 10 days after the biting. If the animal dies within 10 days, they immediately report the death to public health officers in their community:

- Animal bite

Textbox 3. Environmental problems that volunteers can report via the Participatory One Health Disease Detection (PODD) mobile app.

The following pollution types are very common in many communities across Thailand, especially in the urban areas. Reported data are sent to local government (LGs) to check and solve the problems:

- Loudness
- Bad smell
- Smog
- Water pollution
- Garbage
- Mosquito reproductive source

The following natural disasters generally occur in rural or suburban areas. Because reported data are sent directly to LGs, LGs can use this part of the POD app for the monitoring and early detection of disasters in their communities:

- Outdoor burning
- Forest fire
- Flooding
- Landslide

Results

Performance Evaluation of Local Governments and Reporting Volunteers

After 12 months of PODD system implementation, outcome mapping was used to evaluate the changing behaviors, relationships, activities, and actions of the LGs and volunteers involved with the PODD system [5]. The LG and volunteer performances were classified using the results of the outcome mapping process. Criteria used to evaluate the level of achievement of LGs included LG enthusiasm, endorsement and recognition of the PODD system, and resources donated. Evaluation criteria for volunteer reporters included regularity of reporting, participation in training, leadership, enthusiasm, and possibility of being a role model for other volunteers.

On the basis of these evaluations, 3 groups of LGs (A-C) and 4 groups of volunteers (A-D) were identified. Among LGs, those categorized into the A group were very active with the PODD project. The B group LGs had achieved PODD project

requirements or had met PODD project requests but were not as active. The group C LGs were least involved with the PODD project. The majority of LGs (34/74, 46%) were categorized into group B. Although they were willing to participate in the project and ran PODD activities in their community at the request of PODD, they were not proactive with respect to initiating the activities by themselves. The least number of LGs were in group C (15/74, 20%; [Table 1](#)).

Among volunteer reporters, group A reporters were those who showed excellent performance. Group D reporters showed the poorest performance. After 1 year of implementation, 20.0% (60/300) of volunteer reporters showed great performance with group A. Most reporters were categorized as either group B (104/300, 34.7%) or C (113/300, 37.7%; [Table 2](#)). These reporters were those who attended PODD training and activities and regularly reported abnormal events but were not as proactive as reporters in group A. Only about 7.7% (23/300) were categorized as group D. Group D performers could improve their performances if further training and learning sources were provided.

Table 1. The proportion of local governments in each group (A-C), with group A being the most engaged in Participatory One Health Disease Detection (PODD) and group C being the least engaged after 1 year of PODD implementation.

Group	Local government, n (%)
A	25 (34)
B	34 (46)
C	15 (20)

Table 2. The proportion of volunteer reporters in each group (A-D), with group A being the most engaged and group D being the least engaged after 1 year of Participatory One Health Disease Detection (PODD) implementation.

Group	Volunteer reporters, n (%)
A	60 (20.0)
B	104 (34.7)
C	113 (37.7)
D	23 (7.7)

System Effectiveness in Early Detection and Rapid Response to Abnormal Deaths in Backyard Chickens

The primary goal of the PODD system is to detect emerging diseases in animals before it spreads to humans; thus, PODD primarily focused on animal population rather than human population. During the first 16 months of PODD operation, a total of 113,911 reports were sent by PODD volunteers. Of these, 98.82% (112,571/113,911) indicated that conditions were normal in their communities, whereas 1.18% (1340/113,911) reported abnormal events. Among the abnormal event reports, 76.79% (1029/1340) were confirmed to be true reports, whereas the remainder were found to be false positives or human error reports. The majority of abnormal reports were of sick or dead animals (404/1029, 39.26%), followed by zoonoses and other human diseases (129/1029, 12.54%), environmental problems (112/1029, 10.88%), and animal bites (110/1029, 10.69%). Among sick and dead animal reports, chicken (140/404, 34.6%) and cattle (132/404, 32.7%) were the two most frequently reported species.

Upon further investigation of these abnormal event reports, a total of 36 disease outbreaks, all in backyard animals, were detected by the PODD system during its first 16 months. These included 26 chicken disease outbreaks, 4 cattle disease outbreaks, 3 pig disease outbreaks, and 3 fish disease outbreaks.

Case Study: Participatory One Health Disease Detection Controls a Backyard Chicken Disease Outbreak, March 2016

A chicken disease outbreak occurred in a 50-chicken household in Ping Kong, Chiang Dao District, in the northern part of Chiang Mai. In this household, 25 chickens were sickened and the other 25 died. The outbreak was reported through the PODD app by a volunteer in mid-March 2016. Clinical signs in the chickens included convulsion, paralysis, diarrhea, edema eyelids, depression, loss of appetite, and sudden death. The PODD volunteer reported similar clinical signs in 10 additional households near the index case household. The PODD epicenter verified the cases and classified them as a “suspected outbreak.” All local stakeholders, including provincial and district DLD officers, the LG mayor and staff, and PODD staff and researchers, were notified; a disease investigation team was sent into the field 3 days later. This response was faster than it would have been through a traditional (ie, nonparticipatory) surveillance process.

The disease investigation team determined that similar cases had occurred 2 weeks before in 20 additional households, all

located within the same small area, and that each of those households had lost 5 to 10 chickens.

After the LG received notification from the PODD epicenter, the LG staff went to the affected area and disinfected it. The Chiang Dao District DLD officer and epicenter staff collected lab samples and provided vitamins and medicines to the chicken owners. No additional sick or dead chickens were reported 7 days after the first report was sent to the epicenter. Thus, the outbreak was controlled. Even though this case was animal disease, public health authorities were informed for monitoring similar clinical signs in humans.

However, the cause of the outbreak was not confirmed. Several essential chicken vaccines, including vaccines for Newcastle disease, infectious bronchitis, and infectious bursal disease, were administered to chickens in the community. Additionally, the Ping Kong LG collaborated with the Chiang Dao District DLD office to train chicken owners in the community about disease prevention, especially the vaccination program. Villagers and chicken owners, who were affected by the outbreak, responded to the LG staff, DLD officer, and PODD staff in a positive way.

Discussion

Disease surveillance is important for the early detection of disease, particularly emerging diseases, in a population [6]. Both human and animal health authorities also use disease surveillance as a main tool for monitoring diseases. Since the outbreak of severe acute respiratory syndrome in 2003 and the emergence of highly pathogenic avian influenza (subtype H5N1) between 2003 and 2005, disease surveillance has played an important role in global health security.

Significant progress in communication technology has led to several new disease surveillance technologies that can complement the traditional reporting systems. The Program for Monitoring Emerging Diseases, a global list that serves in infectious disease reporting [7], and the Global Public Health Information Network, a news aggregation system that detects early signs of disease outbreaks [8], were two of the first efforts to leverage the Internet for global infectious disease surveillance. Other systems such as HealthMap, MedISys, and Biocaster have also been developed, using a variety of digital media and a blend of computer algorithms and human expertise to detect the first signs of disease transmission [9]. In addition to these more passive data collection approaches, active participatory disease surveillance has been evolving.

In this paper, we have described the initial achievements of PODD, a new disease surveillance tool that integrates One

Health, community participation, and digital technology (ie, a mobile app) for the early detection and management of emerging zoonotic pathogens, since their inception, in backyard animal populations. In PODD, community members play an important role in disease surveillance. Due to the involvement of the LGs and villagers (eg, volunteer reporters) in the PODD project, communities are empowered to seek solutions and solve challenges by themselves [10]. On the basis of its 12-month outcome mapping and evaluation, the PODD research team was able to better understand motivations of both the LGs and volunteers and choose appropriate strategies to strengthen the capacities of the LGs and volunteer reporters to conduct disease surveillance in their communities. In March 2016, the collaborative use of PODD by the community and DLD officers enabled early detection of a backyard chicken disease outbreak, which led to an immediate response that reduced the size and spread of the outbreak. The outbreak was controlled within 7 days, which was faster than the time taken by a traditional system to respond.

PODD has also applied the One Health approach to the new disease surveillance system by integrating the collaboration among transdisciplinary stakeholders and linking the cooperation between animal, human, and environmental sectors. In Tanzania, the Epicollect mobile app was implemented, with the One Health approach, participatory epidemiology, and technology, for infectious disease surveillance. The study indicated that this approach is suitable for countries with limited resources and reduces the time of disease detection in both animals and

humans [11]. Another study recommends that health policy decisions must be made in sync with community if One Health approach is applied for infectious disease surveillance [12]. PODD has begun in resource-limited areas, such as Thailand, and has engaged stakeholders from different levels, from community members to policy makers. These procedures could assist emerging disease control in communities where PODD is implemented.

The participatory surveillance with digital technology through community commitment showed several advantages, including timeliness, affordability, and scalability, particularly in resource-limited areas [13,14]. PODD system is another tool that provides these advantages to the community. PODD integrated the efforts of communities, authorities, and policy makers to prevent health problems through participation. It could be expanded to all area in Thailand to gain those advantages.

Although PODD has been researched and developed for 2 years, it needs to be further developed. In the future, the PODD project will work to reduce the time required to respond to the reports and to improve the specificity and sensitivity of disease detection, particularly for animal diseases. For example, as part of the effort to improve disease detection, reports from the PODD system could be compared with reports from official sources, such as animal disease reports from the Department of Livestock or human disease reports from the Ministry of Public Health. The existing system needs to be integrated with upcoming technology for sustainability.

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Authors' Contributions

LS conceptualized and led the study as the primary investigator and wrote the manuscript. TY conceptualized the study, implemented the method, and wrote the manuscript. WC and KK conceptualized the study and implemented the methods. PS and PP developed the digital technology component of the PODD system, including the PODD app itself. SW and SM implemented methods in the human and environmental health component of the project. KC led data analysis and coordinated with the Department of Livestock Development, Thailand. PT and BK analyzed outcome mapping and social impact data. CS analyzed economic impact data. SP and PR coordinated with and introduced the concept to the Chiang Mai Province One Health Committee and implemented methods in the animal health component of the PODD project. PH and AC developed the Geographic Information System (GIS) component of the PODD system. CSR and LR implemented the community approach component of the system. CS analyzed the reported and GIS data. EL, SP, and TT implemented methods in selected areas.

Conflicts of Interest

PODD was developed as a novel disease surveillance system with mutual benefits to the One Health community. These benefits were not financial. The mobile app and the digital technology component of the PODD system were developed as open sources.

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Abbreviations

- AI:** avian influenza
DLD: Department of Livestock Development
LG: local government
PODD: Participatory One Health Disease Detection
SMS: short message service

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Original Paper

The SMART Study, a Mobile Health and Citizen Science Methodological Platform for Active Living Surveillance, Integrated Knowledge Translation, and Policy Interventions: Longitudinal Study

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Abstract

Background: Physical inactivity is the fourth leading cause of death worldwide, costing approximately US \$67.5 billion per year to health care systems. To curb the physical inactivity pandemic, it is time to move beyond traditional approaches and engage citizens by repurposing sedentary behavior (SB)—enabling ubiquitous tools (eg, smartphones).

Objective: The primary objective of the *Saskatchewan, let's move and map our activity* (SMART) Study was to develop a mobile and citizen science methodological platform for active living surveillance, knowledge translation, and policy interventions. This methodology paper enumerates the SMART Study platform's conceptualization, design, implementation, data collection procedures, analytical strategies, and potential for informing policy interventions.

Methods: This longitudinal investigation was designed to engage participants (ie, citizen scientists) in Regina and Saskatoon, Saskatchewan, Canada, in four different seasons across 3 years. In spring 2017, pilot data collection was conducted, where 317 adult citizen scientists (≥18 years) were recruited in person and online. Citizen scientists used a custom-built smartphone app, Ethica (Ethica Data Services Inc), for 8 consecutive days to provide a complex series of objective and subjective data. Citizen scientists answered a succession of validated surveys that were assigned different smartphone triggering mechanisms (eg, user-triggered and schedule-triggered). The validated surveys captured physical activity (PA), SB, motivation, perception of outdoor and indoor environment, and eudaimonic well-being. Ecological momentary assessments were employed on each day to capture not only PA but also physical and social contexts along with barriers and facilitators of PA, as relayed by citizen scientists using geo-coded pictures and audio files. To obtain a comprehensive picture of participant location, motion, and compliance, 6 types of sensor-based (eg, global positioning system and accelerometer) data were surveilled for 8 days. Initial descriptive analyses were conducted using geo-coded photographs and audio files.

Results: Pictures and audio files (ie, community voices) showed that the barriers and facilitators of active living included intrinsic or extrinsic motivations, social contexts, and outdoor or indoor environment, with pets and favorable urban design featuring as the predominant facilitators, and work-related screen time proving to be the primary barrier.

Conclusions: The preliminary pilot results show the flexibility of the SMART Study surveillance platform in identifying and addressing limitations based on empirical evidence. The results also show the successful implementation of a platform that engages participants to catalyze policy interventions. Although SMART Study is currently geared toward surveillance, using the same platform, active living interventions could be remotely implemented. SMART Study is the first mobile, citizen science surveillance platform utilizing a rigorous, longitudinal, and mixed-methods investigation to temporally capture behavioral data for knowledge translation and policy interventions.

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KEYWORDS

exercise; sedentary lifestyle; smartphone; ecological momentary assessments; epidemiological monitoring; translational medical research; health policy

Introduction

Physical Inactivity and the Current Active Living Research Landscape

Physical inactivity is the fourth leading cause of death worldwide, costing approximately US \$67.5 billion per year to health care systems globally [1,2]. According to the World Health Organization, rising physical inactivity and sedentary behavior (SB) can be attributed to the combined effects of urbanization and screen time-based, desk-bound lifestyles [3]. Responding to this phenomenon and the need for policy interventions to facilitate more active lifestyles, the interdisciplinary field of active living research (ALR) has gained prominence [4]. ALR envisions physical activity (PA) beyond exercise to include any movement in *free living* conditions in any environment (ie, home, school, work, and neighborhood). ALR focuses on both PA and SB, as these two behaviors are separate entities [5]. Accumulating high PA does not preclude one from accumulating high SB as well, and it is important to capture these distinct behaviors together because of their interrelationship [6].

Most ALR has been cross-sectional, generating correlational evidence that needs to be corroborated with objective, longitudinal studies [7-11]. Although surveys and other self-report measures have been validated for PA and SB, objective measurement tools (eg, accelerometers) that address limitations such as recall bias often pose logistical difficulties because of high costs and challenges with deployment [12,13]. Additionally, in measuring PA and SB, contextual information, which is imperative to understanding barriers and facilitators to active living, is often missing from objective measures. For instance, accelerometers do not capture *how* (type of activity), *where* (location), *why* (motivation), and *with whom* (social networks) PA and SB are accumulated.

The predominant emphasis of ALR has been on the outdoor environment, including urban design and neighborhood built environment [11,14]. However, individuals in Western nations spend much of their day being sedentary indoors. Although some consensus has been emerging in studying the influence of the indoor environment on SB, especially in home, occupational, and educational settings [15], thus far, progress in this area has been limited. Apart from Western lifestyles, another reason individuals spend prolonged periods of time indoors is because of adverse weather, with seasonal variations

contributing to fluctuations in PA [16-23]. To date, ALR has focused on the influence of weather on PA patterns [19-23], ignoring the relationship between the outdoor or indoor physical environments, social environment, and weather [24,25].

In informing active living policies, it is imperative to understand pathways through which physical and social environments influence active living, and in turn, how active living influences downstream health outcomes (ie, weight status and cardiovascular disease risk) [26-29]. Moreover, given the role of individual motivation in engaging PA, it is also important to better understand how and if intrinsic motivation affects the direction of these pathways [30-33].

Employing Citizen Science in Active Living Research

Capturing complex active living pathways, which includes physical, social, and individual determinants among populations, requires longitudinal surveillance, with consistent compliance from research participants. Citizen science is a participatory approach where participants, termed citizen scientists, actively engage in the research process from data collection to knowledge translation, thus improving the probability of longitudinal participant compliance [34]. Citizens' involvement in cocreating knowledge enhances their role as constituents and advocates for the outputs of the research, which may provide impetus for decision makers to engage with researchers in implementing active living policies [35].

In recent years, the successful spread of virtual citizen science has been built upon the dispersal of Internet-connected computers around the globe [36]. The ubiquitous presence of smartphones allows researchers to leverage citizen-owned Internet-connected devices as mobile data collection tools. Currently, there are over 2.5 billion smartphone owners globally, and this number is projected to increase beyond 6 billion by the year 2020 [37]. These staggering numbers open up a pool of potential research participants never before available, each of them carrying their own technology capable of facilitating participation in research.

More importantly, the technology that powers these devices provides extraordinary research opportunities to overcome traditional constraints in terms of participant recruitment and retention, data collection and analysis, interventions, and knowledge translation. Smartphones have become a key part of day-to-day life and the primary one-stop communication device at home, at work, and on the go [38]. By utilizing sensors (eg, accelerometers and pedometers) embedded in smartphones

and engaging with participants in their daily environments in real time (eg, via ecological momentary assessments, EMAs) [39,40], the current technology environment provides an opportunity to develop novel models of population health surveillance to address gaps in the current ALR landscape.

Study Aims and Objectives

The objective of the *Saskatchewan, let's move and map our activity* (SMART) Study is to develop and test a mobile citizen science platform for active living surveillance, knowledge translation, and policy interventions [41]. An important component of the platform is collaboration with key stakeholder groups (decision makers at multiple levels and citizen scientists) to ensure integrated knowledge translation and create opportunities for policy interventions in different settings.

SMART Study is a rigorous, longitudinal, and mixed-methods investigation employing citizen science in engaging participants via their smartphones. Participants are citizen scientists who play an important role in shaping data collection and driving knowledge translation. The key factor distinguishing SMART Study citizen scientists from participants in other studies is real-time engagement with researchers, where citizen scientists provide not only objective and subjective data with and without researcher-triggered prompts (self-motivated), but also their perceptions about data collection approaches (eg, timing of survey deployment).

The aim of this study was to understand how physical (eg, built environment and weather) and social contexts, as well as participant motivation, interact with each other to influence both PA and SB, and in turn, how PA and SB influences eudaimonic well-being. Eudaimonic well-being is a positive and holistic indicator of mental health, which is characterized as fulfilling or realizing one's true potential [42-46]. The purpose of measuring eudaimonic well-being is to connect active living with a positive mental health outcome.

Through citizen engagement and collaborations with decision makers at multiple levels (provincial, local jurisdictional, community, and institutional levels), SMART Study's ultimate purpose is to facilitate integrated knowledge translation and influence active living policies. This is a methodology paper that enumerates the SMART Study platform's conceptualization, design, implementation, data collection procedures, analytical strategies, and potential for informing policy interventions. In doing so, preliminary and aggregated results and knowledge translation efforts from pilot data collection are discussed to depict the flexibility of the methodological platform to adapt longitudinally.

Methods

Study Overview

SMART Study is a prospective cohort study designed to obtain longitudinal data from a convenience sample of adults (≥ 18 years) from the two largest urban centers in Saskatchewan, Canada (Regina and Saskatoon). Out of Saskatchewan's

population of 1,033,381, Saskatoon and Regina census metropolitan areas account for 260,600 and 210,556 people, respectively [47]. The longitudinal data collection is scheduled in different seasons (winter, spring, summer, and autumn), with each seasonal cycle consisting of 8 consecutive days of data collection. After scrutinizing the historical weather data for seasonality in Regina and Saskatoon [48-51], January or February, April or May, July or August, and October or November have been selected as the months to include for seasonal data collection cycles to capture data in all seasons and account for the influence of seasonality on active living.

Pilot Recruitment and Data Collection Strategy

To track longitudinal behavior patterns and their influence on health outcomes within the context of seasonal variations, all types of data (PA, SB, perception of environment, individual motivation, and eudaimonic well-being) will be collected in different seasons. The pilot data collection cycle (1st cycle), which was scheduled between April 1 and May 31, 2017, resulted in the recruitment of 317 citizen scientists. Our goal is to recruit and retain 1000 citizen scientists throughout the 3-year study period. Ethics approval was obtained from the universities of Regina and Saskatchewan through a synchronized review protocol.

Aided by a social media campaign that raised awareness of the project in the two jurisdictions (Figure 1), citizen scientists were recruited in person from community centers located in different areas in each city and the universities of Regina and Saskatchewan to ensure recruitment of a representative sample. During in-person recruitment, potential citizen scientists were guided in downloading Ethica (Ethica Data Services Inc), an epidemiological mobile phone app specifically adapted for the SMART Study. Citizen scientists had the option to download the app using both Android phones and iPhones through the Google Play Store and Apple App Store. The social media campaign also directed interested participants to visit the study website to learn more about the study and to become citizen scientists by downloading the study app (Figure 2).

All potential citizen scientists, whether they were recruited in person or online through social media, were required to complete an informed consent process through the app (Figure 3) and confirm their age (≥ 18 years) before being recruited. Citizen scientists were informed that the initial data collection period would last 8 consecutive days from the day they downloaded the app, followed by similar data collection cycles in different seasons, where citizen scientists would have to provide informed consent each time they participated. With the exception of demographic and historical PA data, all data will be collected in 8-day cycles in different seasons over 3 years from the same citizen scientists. Citizen scientists were also informed that they were free to withdraw from the study without explanation or penalty anytime during the 8-day data collection period. Clear instructions were provided regarding study withdrawal within the app (Figure 4). Citizen scientists were informed not to change their usual mobile phone-carrying habits so as to capture objective mobile phone sensor data in free-living conditions.

Figure 1. Saskatchewan, let's move and map our activity (SMART) Study: Social media campaign.

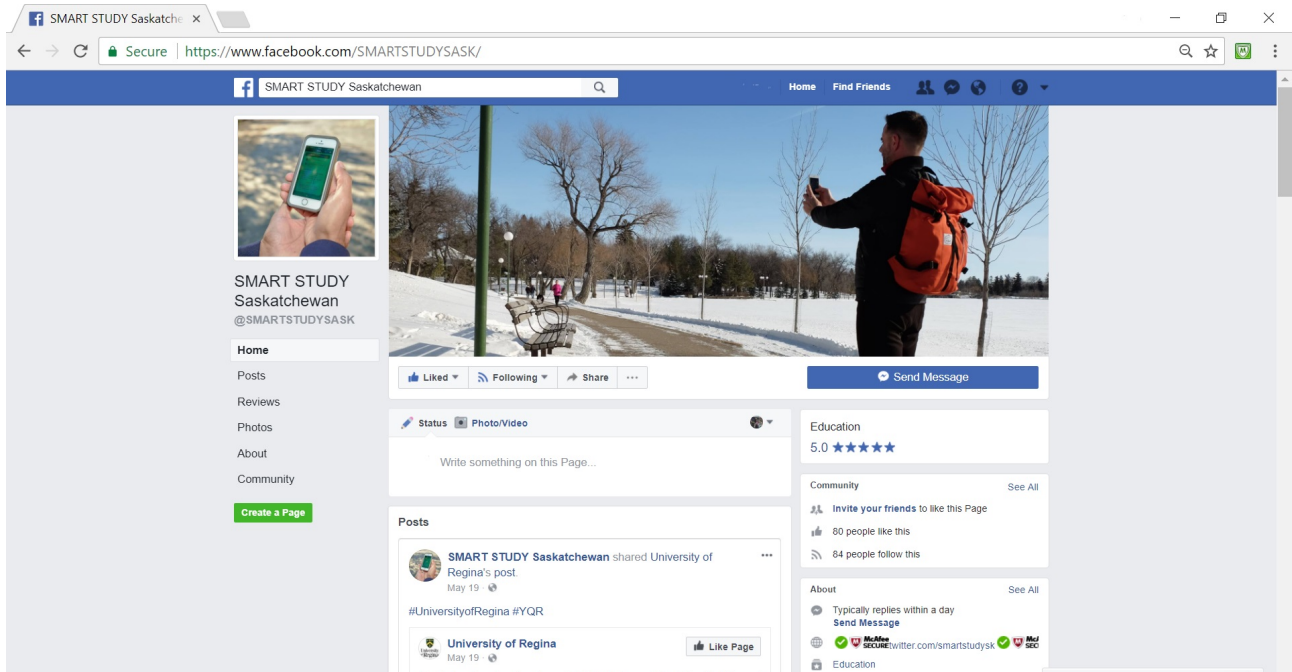


Figure 2. Online instructions to become a citizen scientist.

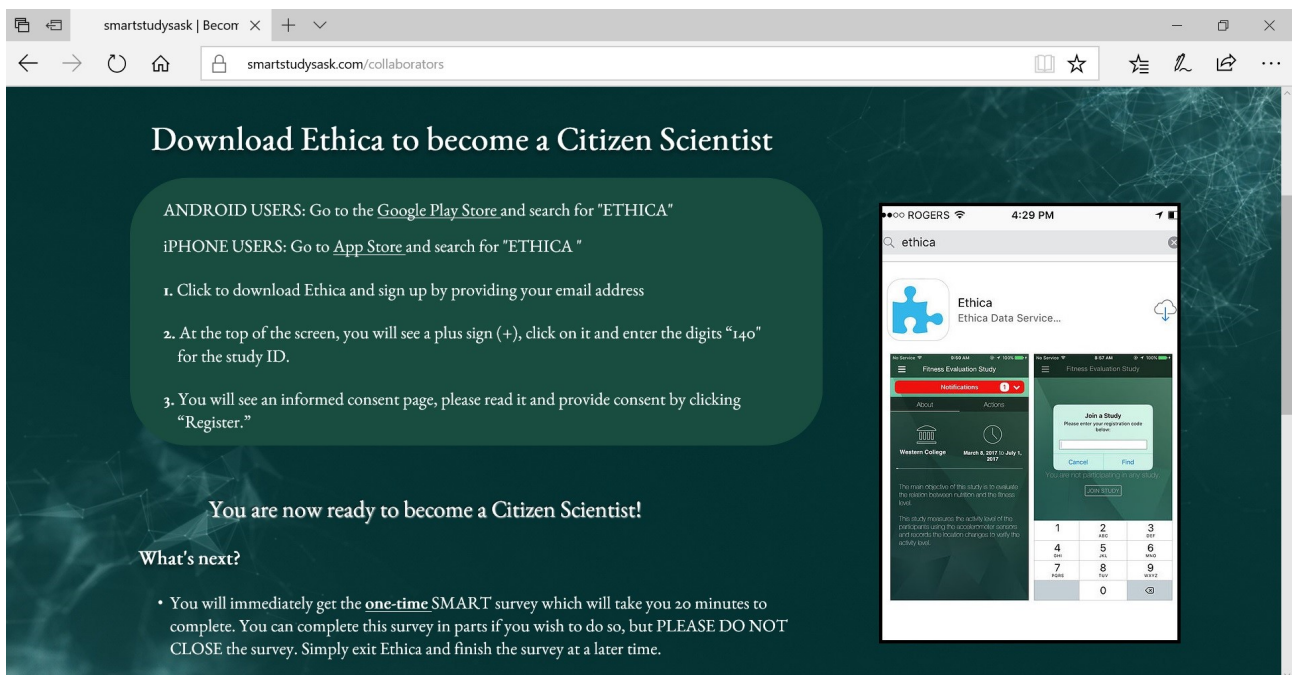


Figure 3. Informed consent provided via smartphone app.

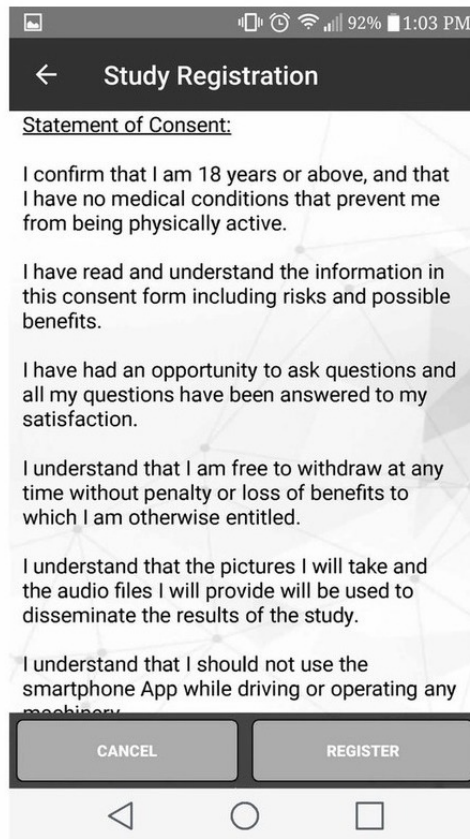
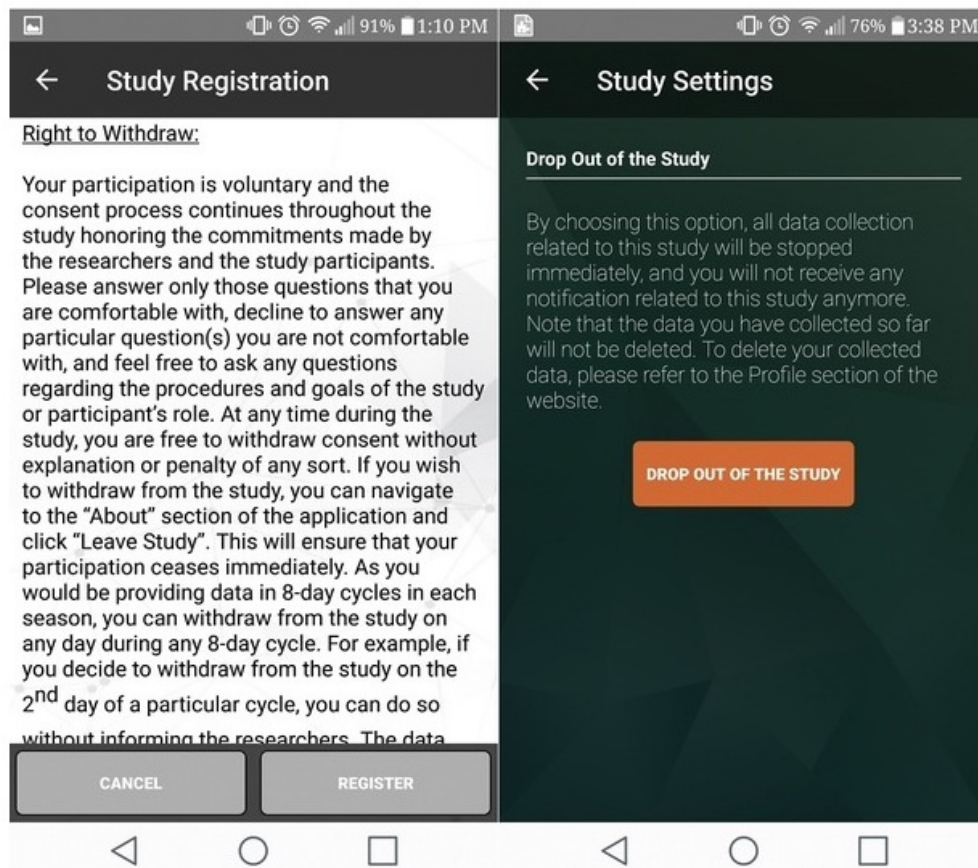


Figure 4. Study dropout option in the smartphone app.



Data Collection Tools

The SMART Study adapted the Ethica app by modifying features ranging from processes of informed consent and participant recruitment to survey development, deployment and triggering mechanisms, and selection of appropriate sensors that enable real-time data collection. Ethica is being used to collect a wide variety of valid and reliable health data in different geographic regions (high-density urban and rural regions) and in diverse populations such as university students and lower-income communities across North America [52-54], Australia, and Europe. It allows both subjective (via surveys) and objective (via smartphone sensors) data collection. Beyond typical objective and subjective data, Ethica can also enable capture of contextual perceptions via smartphone camera and audio function, as well as deployment of EMAs.

Sensor-Based Objective Data

Six smartphone sensors were used to obtain the following time-stamped objective data for 8 consecutive days: (1) accelerometer (activity intensity and frequency-25 second epochs), (2) pedometer (step counts-1 record/step), (3) screen state (smartphone screen time-1 record/event, ie, screen turned on or off), (4) global positioning systems (GPS; location-1 minute of GPS data/5 min), (5) Wi-Fi (proxy for indoor location or usage—proximity to all Wi-Fi access points once every 5 min), and (6) battery (smartphone usage or compliance-1 record/5 min; Figure 5).

SMART Survey

SMART survey (Figure 6) is the primary 209-item integrated questionnaire that combines validated self-report surveys to record PA, SB, motivation, eudaimonic well-being, and perception of outdoor and indoor environment. PA data were collected using the 27-item International PA Questionnaire (IPAQ), which measures PA domains [55,56]. The 9-item SB Questionnaire was adapted to measure different types of screen time and non-screen time-based SB on weekdays and weekends [57]. To capture the complexity of screen time accumulation, citizen scientists were given the option of recording common screen time behaviors (television, Internet surfing, and video games) over a range of digital devices (computer, laptop, tablet, smartphone, etc). Individual motivation and eudaimonic well-being were collected using the 16-item Motivation for PA Questionnaire [58] and the 21-item Questionnaire for Eudaimonic Well-being [59].

Perception of outdoor built environment was measured by using the 17-item PA Neighborhood Environment Survey [60]. Utilizing evidence from emerging studies [61], an indoor built environment survey was developed and used to capture participants' perception of the indoor environment at home, work, and any fitness center associated with the participant [59]. Apart from these surveys, citizen scientists were also asked to report demographic and historical PA data (age, gender, income, education, employment, activity levels in adolescence in different seasons, etc), height (in feet or inches or cm), and weight (in pounds or kg) to calculate body mass index and perception of their health (self-rated health).

Figure 5. Saskatchewan, let's move and map our activity (SMART) Study sensors.

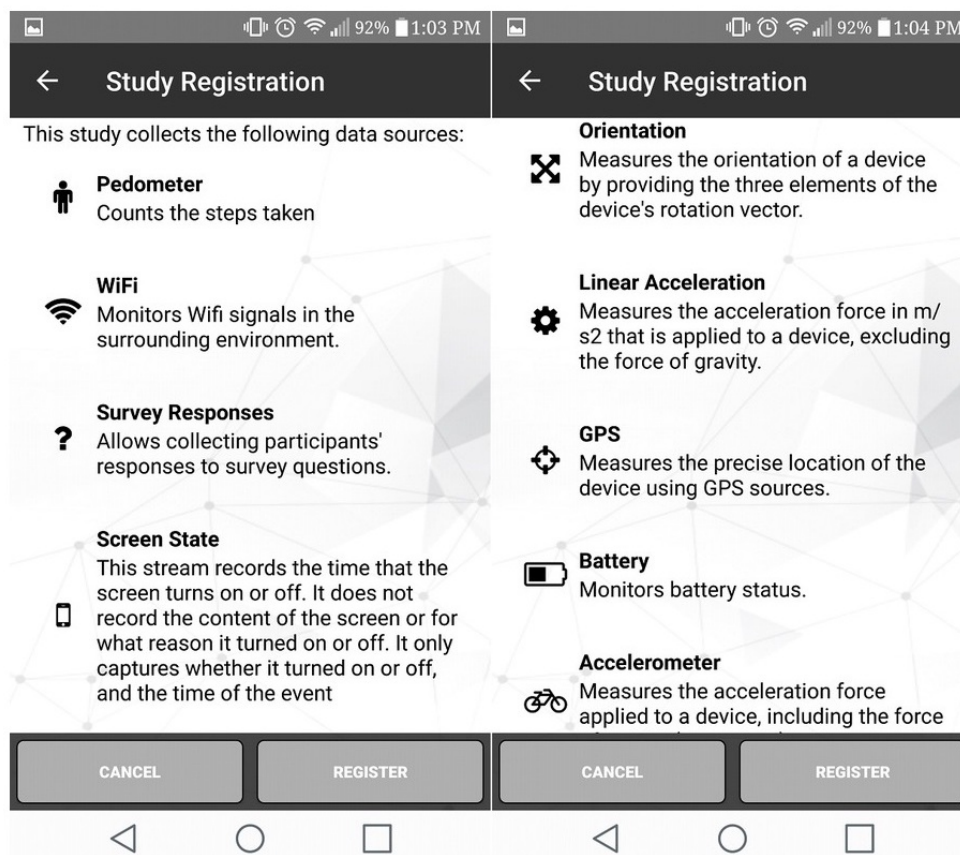
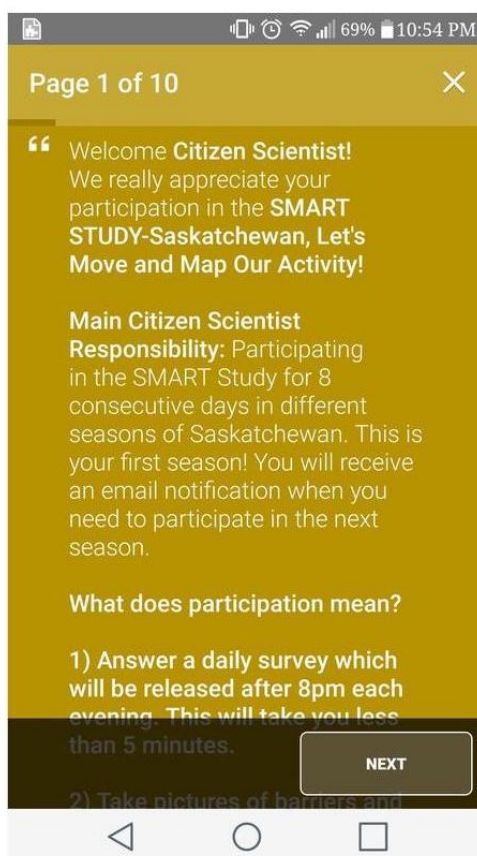


Figure 6. Saskatchewan, let's move and map our activity (SMART) survey.

Ecological Momentary Assessments

Two EMAs were deployed in the first cycle. The first EMA recorded daily PA types or intensities along with the physical and social contexts within which these activities were accumulated (Figure 7). The second EMA (Figure 8) captured barriers and facilitators of active living by asking citizen scientists to randomly take pictures of their outdoor or indoor environment. After citizen scientists took pictures, they were prompted to describe the pictures using an audio recording to explain how they perceived their immediate environment to be a barrier or facilitator of active living. These pictures and audio files were automatically geo-coded to the exact latitude-longitude location as measured via smartphone-based location services.

Paradata

Objective paradata, which are essentially the by-products of research, are automatically generated using Ethica [62,63]. Paradata can be classified as device-specific or participant-specific. Examples of device-specific paradata include battery level and proximity to Wi-Fi networks or Bluetooth devices. Examples of participant-specific paradata include number of nudges it takes for participants to respond to a survey and the time it takes for participants to complete surveys (as a whole or questions therein).

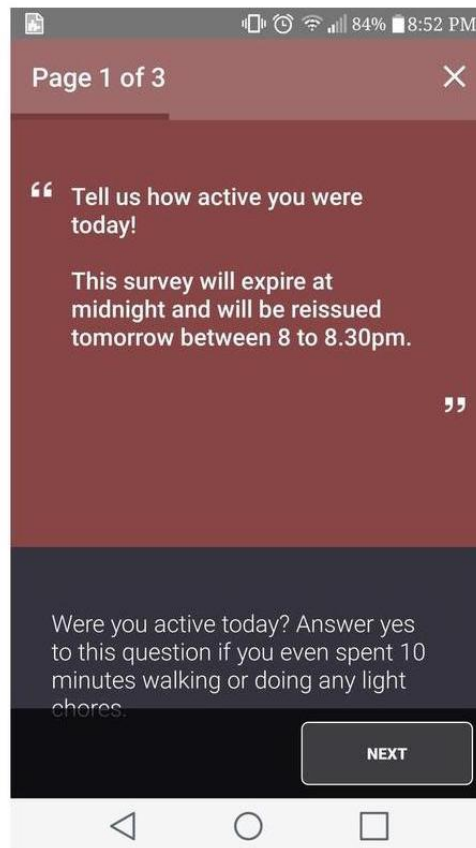
Apart from the objective sensor-based paradata, three separate feedback surveys were triggered to obtain important paradata regarding EMAs and the citizen scientists' response to SMART

Study itself (ie, if participating in SMART Study changed their activity behavior, and if yes, how and why?). These surveys could provide evidence to inform future methodological decisions such as survey triggering and expiry mechanisms.

Survey Triggering and Expiry Mechanisms

Over the 8-day data collection period, various triggering mechanisms (time vs user-triggered) were used to deploy different surveys. Time-triggers (ie, prompts) are controlled, preselected time points on specific days, and user-triggers are citizen scientist-controlled and can be randomly triggered by them any time during the 8 days of study participation.

On the basis of their scope, surveys were also assigned a predetermined expiry mechanism, and before expiration, a survey could be accessed from the smartphone's notification menu. The SMART survey was deployed on day 1 and was not set to expire until the citizen scientists completed or exited the survey. The first EMA (daily PA and contexts) was deployed every evening from day 1 to day 8 from 8 PM to 11:30 PM and was set to expire at midnight each day. The second EMA (barriers and facilitators of active living) was deployed using a combination of time (every day from 12 PM to 1 PM) and user-triggers and did not expire until completed or exited. The feedback surveys that collected paradata were time-triggered and were set not to expire until completed or exited. All daily time-triggered surveys were released as single-triggers without retriggering (ie, reprompting) the same surveys on the same day.

Figure 7. Ecological momentary assessment 1.**Figure 8.** Ecological momentary assessment 2.

Weather Data

To match the 8-day time period of each cycle of data collection, including the pilot data collection cycle, detailed hourly weather data (ie, daily maximum and minimum temperature, wind speed, precipitation, etc) will be obtained retrospectively from Environment Canada at the study locations [48-50].

Analytical Strategies

The SMART Study's comprehensive surveillance platform generates complex data that requires effective analytical strategies for linkage, validation, and modeling. Although the following strategy categories summarize some key approaches, the overall analyses are not limited to these examples.

Data Linkages

Given the diversity of data collected, linkages would be necessary before analyzing data. The following are examples of data linkages:

- Objective sensor data will be extracted in a cross-linked fashion (eg, GPS-accelerometer-screen state)
- Objective sensor data will be linked with subjective surveys and EMAs (eg, accelerometer-IPAQ)

Validation Analyses

Validation is a necessary step for cross-referencing the accuracy of subjective data with objectively collected measures. Validation analyses would include:

- Validation of smartphone deployed IPAQ with smartphone accelerometers
- Validation of IPAQ with EMAs

Cross-Sectional and Longitudinal Analyses

A variety of cross-sectional and longitudinal analyses would be conducted, including, but not limited to:

- Quantitative geo-coded mapping of barriers and facilitators of active living in different seasons
- Quantitative hierarchical influence of changing physical contexts on PA, and in turn, the influence of changing PA on eudaimonic well-being

Paradata Analyses

Objective (Wi-Fi) and subjective (feedback surveys) paradata will be used to adapt study implementation strategies temporally and survey triggering mechanisms within each 8-day data collection cycle. These paradata-informed strategies and mechanisms will play an important role in enhancing the rigor of study methods and address nonresponse, compliance, and attrition [62,63].

Hybrid Simulation Modeling

The sensor-based "big data" collected in SMART Study enables systems sciences approaches in developing hybrid simulation models using longitudinal data to inform decision makers at multiple levels [64-66]. For instance, simulation modeling can be conducted to test research questions that could inform policy makers of the impact of potential future active living interventions [67].

Pilot Data Analysis

The purpose of preliminary pilot data analysis is to depict evidence of successful implementation, as well as the flexibility of the SMART platform in which early identification of limitations could be addressed in subsequent data collection cycles. Initial pilot data analyses presented are examples of implementation and modifications and were conducted using SPSS version 14 (IBM Corp) software to understand the distribution of data and compliance for different surveys. Thematic analyses were also conducted using geo-coded photographs and audio files to understand major active living barriers and facilitators.

Data and Risk Management

To ensure confidentiality, data are encrypted before being stored on the smartphone and streamed to servers when a device establishes Wi-Fi connection. Any identifiable artefacts (eg, photos) are removed or deidentified before data analysis. Permissions built into the Ethica app are restricted so that the app cannot access personally identifiable information that is present on the smartphones (eg, contact list or network sites visited). MAC address anonymization is used to protect citizen scientists' data based on a simple hash algorithm that is infeasible to backtrack. Risks and privacy management options are made clear to citizen scientists while obtaining informed consent. For example, citizen scientists can use the "snooze" function in the app that allows them to disable monitoring for a set duration.

Results

Of the 317 citizen scientists (mean: 34.14 years; range: 18-69 years) registered for the spring 2017 pilot data collection cycle of SMART Study, only 5.0% (16/317) dropped out. Within the remaining 301 citizen scientists, 36.8% (112/301) were male, 60.1% (181/301) were female, 2.6% (8/301) were missing values; 54.1% (163/301) citizen scientists completed the 209-item SMART survey. Among those who completed the SMART survey, the proportion of females (65.6%, 107/163) was significantly higher ($P<.001$) than the proportion of males (34.3%, 56/163).

Overall, during the spring cycle, 57.4%, (173/301) citizen scientists responded (at least once) to the first EMA (Figure 6), and 21.5% (65/301) citizen scientists responded (at least once) to the second EMA (Figure 7), both of which were time-triggered. A total of 27.2% (82/301) citizen scientists initiated and completed the user-triggered second EMA at least once (Figure 7).

Figures 9 and 10 show examples of different resolutions of geo-coded pictures of barriers and facilitators of active living, as perceived by citizen scientists across Saskatoon and Regina. Further examination of these pictures revealed several patterns of perceptions of barriers and facilitators of active living, which were similar across both cities. These patterns have been summarized as "Community Voices" on the SMART Study website, as part of the integrated knowledge translation platform.

In the "What makes us move in spring?" page of the SMART Study website [68], citizen scientists' perceptions of active

living facilitators were analyzed by common themes and summarized through pictures and the explanations that accompanied them. A selection of images that are representative of the larger sample of pictures taken by the citizen scientists

show that neighborhood design enables active living, and access to fitness facilities, pleasant weather, and ownership of pets are perceived as facilitating active living (Figure 11).

Figure 9. Geo-coded barriers and facilitators of active living in Saskatoon, Saskatchewan, *let's move and map our activity* (SMART) Study.

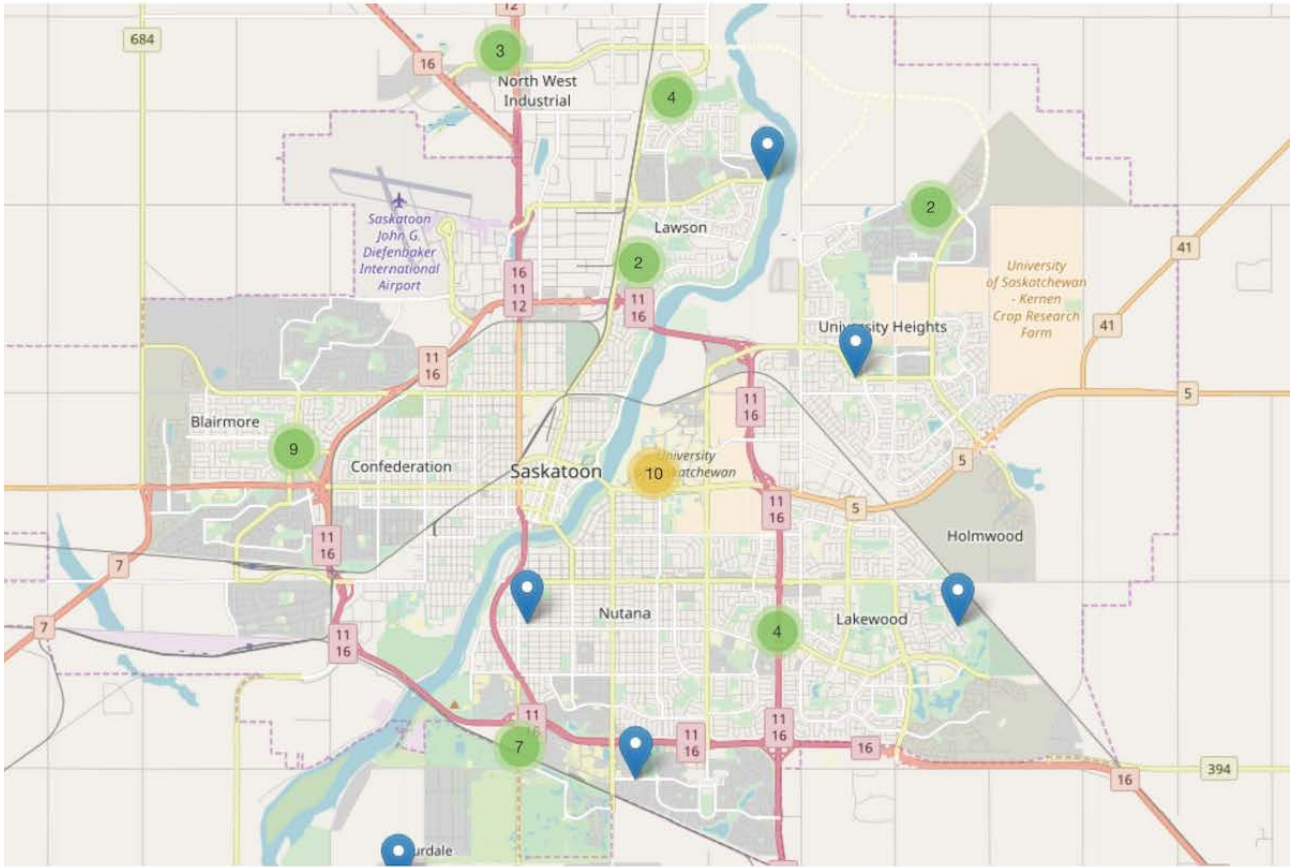


Figure 10. Geo-coded barriers and facilitators of active living in Regina, Saskatchewan, *let's move and map our activity* (SMART) Study.

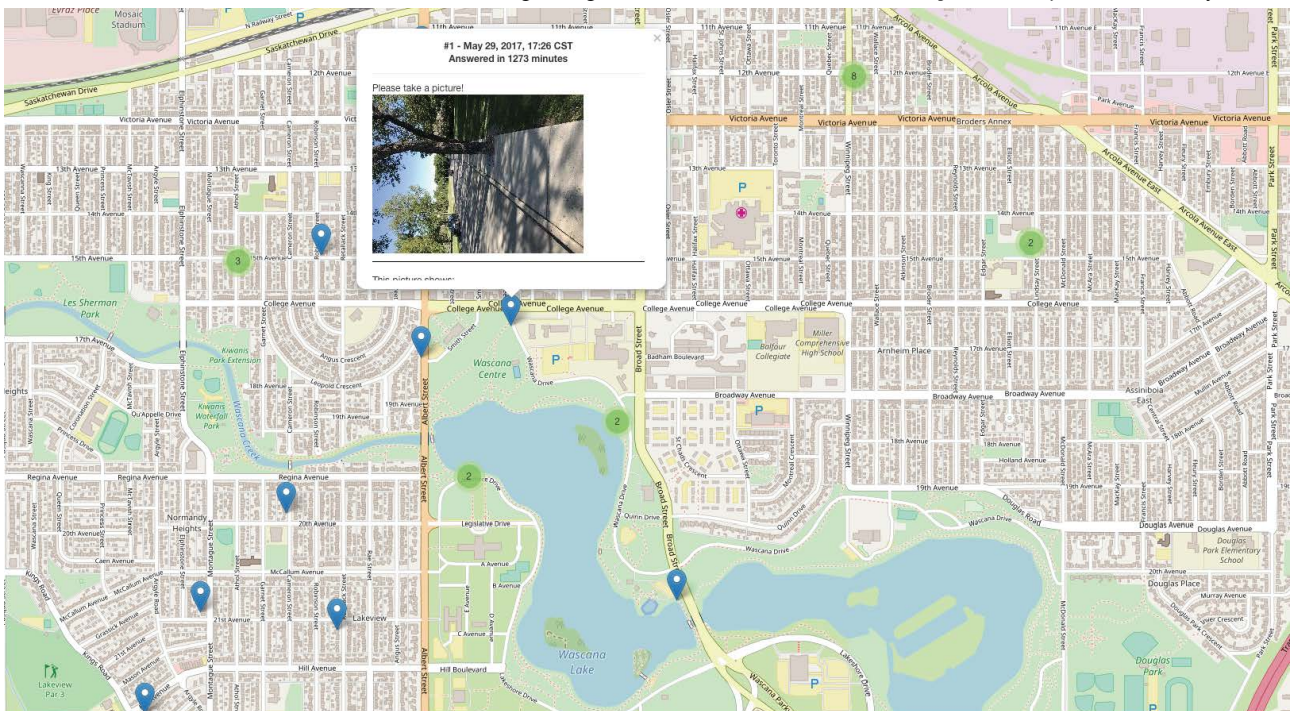


Figure 11. Community voices: pictures taken by the citizen scientists to illustrate their perception of active living facilitators.

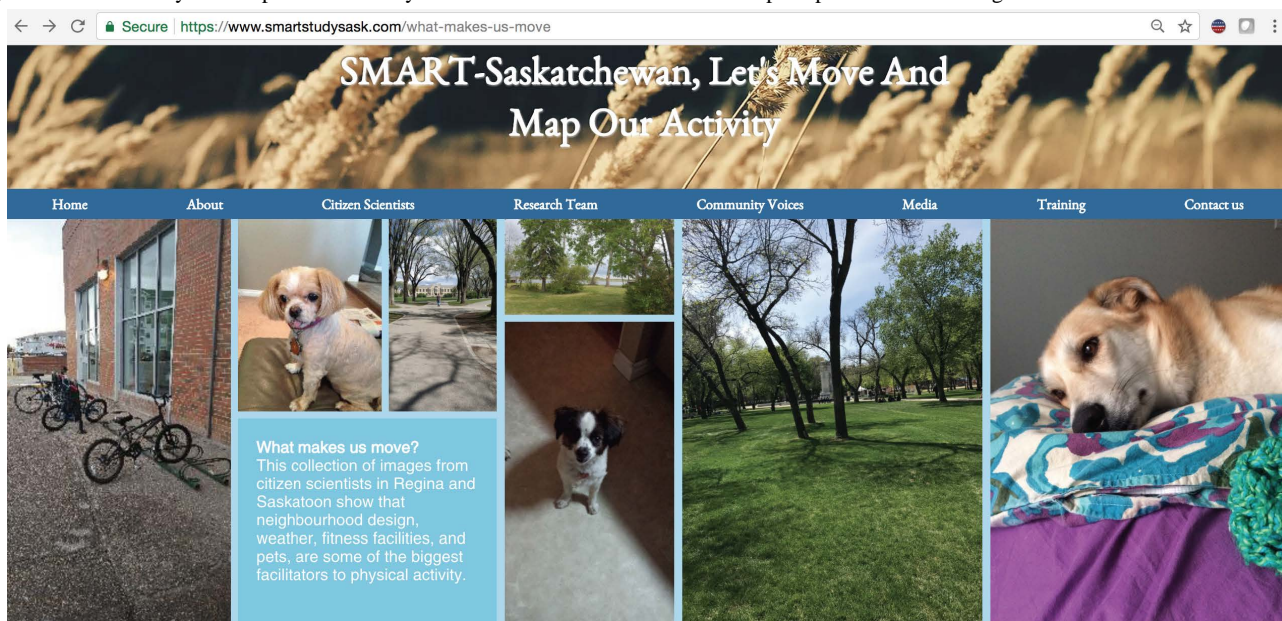
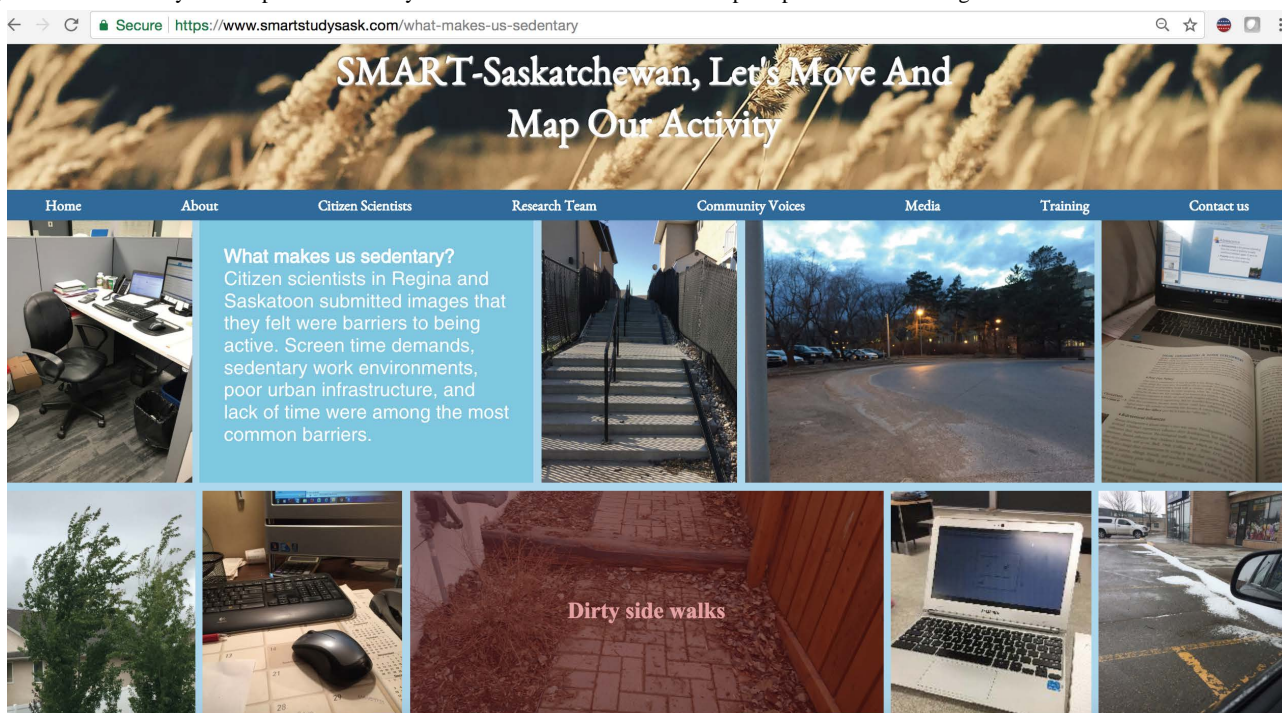


Figure 12. Community voices: pictures taken by citizen scientists to illustrate their perception of active living barriers.

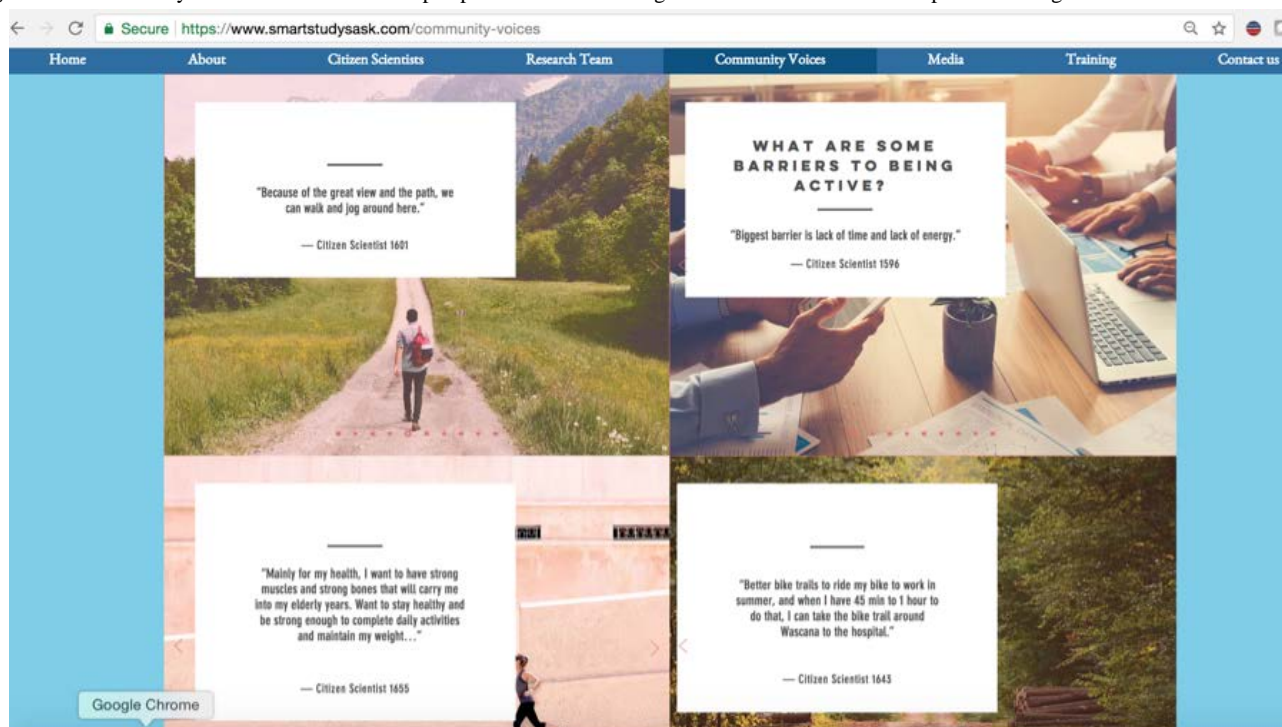


Similarly, in the “What makes us sedentary in spring?” page of the SMART Study website [69], citizen scientists’ perception of active living barriers are summarized. Screen time demands, sedentary work environments, and poor urban infrastructure were revealed as the primary perceived barriers to active living (Figure 12). Apart from the physical and social contexts of active living depicted through citizen scientists’ pictures, the audio files provided another layer of evidence.

In the “citizen scientist quotes” page of the SMART Study website, a representation of the larger sample of transcribed

audio files portrays both individual and environmental levels of active living facilitators and barriers. At the individual level, citizen scientists with intrinsic motivations predominantly stated that maintenance of health is the main motivation to stay active. Another dominant individual level factor was the lack of time in one’s daily routine. At the environmental level, citizen scientists reported that key facilitators of active living included access to better biking and walking infrastructure, as well as aesthetics of the urban infrastructure (Figure 13).

Figure 13. Community voices: citizen scientists' perspective of active living facilitators and barriers as explained through their transcribed audio files.



Discussion

Principal Findings

The objective of the SMART Study was to develop a mobile and citizen science methodological platform for active living surveillance, knowledge translation, and policy interventions. Longitudinal surveillance of disparate behavioral data to inform policy interventions would benefit from citizen science, as evidence that carries the weight of public perception may provide impetus for decision makers to engage more effectively with researchers [34,35]. In engaging citizens, especially with respect to ALR, leveraging citizen-owned smartphones would be critical because of the ubiquitous presence of these devices, as well as the potential to repurpose smartphone sensors to obtain objective data [37,53].

To illustrate the evidence of successful implementation and flexibility of the SMART platform, preliminary pilot data analyses were conducted. The results of these analyses provide examples of how limitations could be identified and addressed between data collection cycles and how knowledge could be continuously translated as shown by the “Community Voices” pages of the study website.

Strengths and Limitations: Lessons From Pilot Data Collection

The major strengths of the SMART Study platform include innovative approaches to capture complex data, ability to translate knowledge continuously, and flexibility to adapt the platform longitudinally from one seasonal data collection cycle to the next. For example, the limitations identified in the pilot data collection will be addressed in the next seasonal data collection, and this strategy will be repeated in the future.

The pilot data collection revealed that the main limitation is low compliance to both the 209-item SMART survey and the EMAs. Another apparent limitation was the higher proportion of females in the sample. Apart from these study-specific limitations that were identified at the pilot stage, key issues that need to be addressed are the differences between sensors across different smartphone models and validation of smartphone sensors with traditionally used active living measurement tools (eg, accelerometers and GPS loggers)

Compliance

During the pilot, citizen science compliance to stay in the study and provide continuous objective sensor data was very high (94.9, 301/317), with only 16 out of 317 registered citizen scientists opting to drop out. To our knowledge, the primary 209-item SMART survey is one of the most rigorous smartphone-based survey tools that integrates validated questionnaires capturing PA, SB, perception of indoor and outdoor environment, motivation, and eudaimonic well-being. Despite the considerable burden, 54.1% (163/301) citizen scientists completed the SMART survey in full. Nevertheless, 54.1% (163/301) completion rate would be construed as low compliance by traditional measures. The pilot was built to test the response rate with maximum burden. In the upcoming cycles of data collection, a combination of recruitment and deployment strategies will be employed (ie, administering the survey in segments over the 8 days) and compared within subsamples of the total sample to generate evidence for the most compliant approach for the SMART survey.

Compliance to EMAs varied widely, from 57.4% (173/301; EMA 1) to 27.2% (82/301; user triggered EMA 2) and 21.5% (65/301; time-triggered EMA 2). Similar variation was observed in a recent study by Bedard et al (2017) that examined the

feasibility of EMA among young adults (mean age: 18.3 years), where the EMA compliance ranged from 64% to 47% [70].

However, a few key differences exist between other PA studies that used EMAs and the SMART Study [70-73]. First, the SMART Study age range was wider (18-69 years), with the mean age being 34.14 years. Second, the EMAs were different in content, context, length, and triggering mechanisms (user-triggered or time-triggered). More importantly, all time-triggered EMAs were triggered only once, whereas other studies used multiple prompts [70-73]. In the future data collection cycles, subsamples within the total sample of citizen scientists will be exposed to different frequency and timing of triggers to identify the optimum type, timing, and frequency of EMA triggers.

Citizen Scientist Retention

Several tactics will be used to reduce participant attrition. First, new citizen scientists will be recruited during each data collection cycle to maintain the proposed participant pool. Second, citizen scientists will be engaged through integrated knowledge translation processes to shape the course of the study [36]. Third, paradata will be used to address attrition by making the necessary changes to minimize burden. Finally, a constant feedback mechanism will be employed through social media (Facebook and Twitter) and the study website (ie, Community Voices), which will serve as a motivator for participants to stay engaged in the study on a long-term basis.

Mobile Phone Surveillance via Citizen Science

The use of mobile phones is a relatively new phenomenon in ALR, and a recent systematic review conducted by Bort-Roig et al (2014) on the viability of smartphones to measure PA concluded that few studies have addressed the validity of smartphone measures [74]. Nevertheless, this review also points toward the potential of smartphones to increase participant engagement, with a call for future longitudinal studies to explore the measurement capabilities of smartphones [74].

Another recent review that appraised the technological features of smartphone apps promoting PA, highlights the versatility of smartphones for engaging participants through a combination of social networking-related extrinsic motivation and PA self-monitoring mechanism [75]. ALR using citizen science is now slowly emerging, albeit with smaller participant samples, as depicted by the deployment of a mobile app called the Stanford Healthy Neighborhood Discovery Tool [76]. In this study, 20 citizen scientists used an innovative app with minimal training to conduct a neighborhood environmental assessment through GPS-tracked walking routes, photographs, audio narratives, and surveys. They ultimately used this data to advocate for healthier neighborhoods [76].

The SMART Study combines the methodological capabilities and participant engagement opportunities provided by smartphones with a citizen science participatory approach to create a platform for longitudinal surveillance. SMART Study employs a mixed-methods design that repurposes smartphone sensor data critical to not only capturing PA and SB, but also the physical and social contexts within which these activities occur. For instance, the objective sensor data include GPS,

accelerometer, and pedometer data that enable the categorization of physical and social contexts of PA; GPS-equipped screen state and gyroscope or magnetometer data that objectively capture the location of screen time and SB accumulation; and Bluetooth-Wi-Fi-Battery data that help confirm indoor location, as well as usage and compliance levels.

Moreover, SMART Study uses a combination of validated surveys, camera and audio-enabled EMAs, and feedback surveys (paradata) to not only triangulate the objective data with subjective and qualitative perception of citizen scientists, but also to take into consideration citizen scientists' input in enhancing the surveillance platform on an ongoing basis. More importantly, this study provides citizen scientists an opportunity to proactively interact with the researchers in real time. Real-time data collection can be executed both via citizen scientist-triggered prompts and researcher-triggered prompts. For example, a citizen scientist can trigger a survey or upload a picture or audio file to provide important information about a certain barrier to active living. The platform could be adapted by automatically triggering a series of surveys in quick succession after receiving initial citizen scientist-triggered information to obtain more detailed data from the citizen scientists.

Another important aspect of SMART Study's surveillance would be capturing seasonality's influence on active living. On the basis of existing evidence, it is expected that warmer weather will be correlated with higher PA and lower SB [19-22]. Nevertheless, as PA and SB have been significantly influenced by wind speed and precipitation during a single seasonal transition in the participating cities [24,25], the influence of these weather factors on active living in different seasons would potentially provide new evidence for future behavioral and infrastructure-related interventions. Finally, in connecting the upstream determinants of active living with downstream outcomes of active living, SMART Study also obtains data on health outcomes, including eudaimonic well-being, self-rated health, and weight status.

Platform for Integrated Knowledge Translation and Policy Interventions

The key to the successful implementation of SMART Study was strong collaborations with decision makers at multiple levels during the conceptualization of the study. Decision makers at the provincial level (appropriate Ministries), local jurisdictional level (cities of Regina and Saskatoon), community level (Young Men's Christian Associations in Regina and Saskatoon), and institutional level (universities of Regina and Saskatchewan) were consulted and invited to become stakeholders in the SMART Study. With the support of these varied stakeholders, especially citizen scientists, SMART Study has been developed to translate knowledge using innovative means and to inform policy interventions at multiple levels. Integrated knowledge translation [77] will be conducted through citizen scientist-driven community voices webpage of the study website, social media accounts of the study, direct consultations with the stakeholders, traditional measures (eg, reports and publications), and strategic annual knowledge translation symposia involving all stakeholders and interested citizen

scientists, where the agenda will revolve around knowledge exchange, identification of active living challenges, and proposal of solutions [78].

Implications Beyond Active Living Research

As depicted by a recent study that leveraged smartphone data from 717,527 people residing in 111 countries across the globe [79], ubiquitous tools can be used effectively to identify inequities in active living within and between countries and influence decision makers to address them via healthy public policies across different sectors (eg, urban planning and education). Apart from the potential to influence policy, the ability to repurpose smartphone sensors (eg, accelerometers) minimizes cost, allows large-scale recruitment and retention, and provides avenues to test new approaches in ALR, such as a citizen science. This methodology of combining smartphone-based methods with citizen science can be replicated in other fields of study to address issues related to health policy and beyond.

Conclusions

SMART Study introduces a novel and replicable smartphone-based methodological platform for surveillance, knowledge translation, and policy intervention by using citizen science. The preliminary results show the flexibility of such a surveillance platform in identifying and addressing limitations based on empirical evidence. The results also show the successful implementation of a platform that engages participants to catalyze policy interventions. Although SMART Study is currently geared toward surveillance, using the same platform, active living interventions could be remotely implemented [74,80]. In conclusion, SMART Study is the first mobile, citizen science surveillance platform utilizing a rigorous, longitudinal, and mixed-methods investigation to temporally capture behavioral data for knowledge translation and policy interventions.

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Conflicts of Interest

None declared.

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Abbreviations

ALR: active living research

EMA: ecological momentary assessment
GPS: global positioning system
IPAQ: International Physical Activity Questionnaire
PA: physical activity
SB: sedentary behavior

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Original Paper

Effect of Mobile Phone Text Message Reminders on Routine Immunization Uptake in Pakistan: Randomized Controlled Trial

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Abstract

Background: Improved routine immunization (RI) coverage is recommended as the priority public health strategy to decrease vaccine-preventable diseases and eradicate polio in Pakistan and worldwide.

Objective: The objective of this study was to ascertain whether customized, automated, one-way text messaging (short message service, SMS) reminders delivered to caregivers via mobile phones when a child is due for an RI visit can improve vaccination uptake and timelines in Pakistan.

Methods: This was a randomized controlled trial, conducted in an urban squatter settlement area of Karachi, Pakistan. Infants less than 2 weeks of age with at least one family member who had a valid mobile phone connection and was comfortable receiving and reading SMS text messages were included. Participants were randomized to the intervention (standard care + one-way SMS reminder) or control (standard care) groups. The primary outcome was to compare the proportion of children immunized up to date at 18 weeks of age. Vaccine given at 6, 10, and 14 weeks schedule includes DPT-Hep-B-Hib vaccine (ie, diphtheria, pertussis, and tetanus; hepatitis B; and Haemophilus influenzae type b) and oral poliovirus vaccine (OPV). Data were analyzed using chi-square tests of independence and tested for both per protocol (PP) and intention-to-treat (ITT) analyses.

Results: Out of those approached, 84.3% (300/356) of the participants were eligible for enrollment and 94.1% (318/338) of the participants had a working mobile phone. Only children in the PP analyses, who received an SMS reminder for vaccine uptake at 6 weeks visit, showed a statistically significant difference (96.0%, 86/90 vs 86.4%, 102/118; $P=.03$). The immunization coverage was consistently higher in the intervention group according to ITT analyses at the 6 weeks scheduled visit (76.0% vs 71.3%, $P=.36$). The 10 weeks scheduled visit (58.7% vs 52.7%, $P=.30$) and the 14 weeks scheduled visit (31.3% vs 26.0%, $P=.31$), however, were not statistically significant.

Conclusions: Automated simple one-way SMS reminders in local languages might be feasible for improving routine vaccination coverage. Whether one-way SMS reminders alone can have a strong impact on parental attitudes and behavior for improvement of RI coverage and timeliness needs to be further evaluated by better-powered studies and by comparing different types and content of text messages in low- and middle-income countries (LMICs).

Trial Registration: ClinicalTrials.gov NCT01859546; <https://clinicaltrials.gov/ct2/show/NCT01859546> (Archived by WebCite at <http://www.webcitation.org/6xFr57AOc>)

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KEYWORDS

SMS; mobile phone; reminders; low- and middle-income countries; routine immunization; children

Introduction

Routine Immunization Globally

Routine immunization (RI) among children is one of the most successful and cost-effective public health interventions that have considerably reduced global child morbidity and mortality [1]. However, annually, an estimated 18.7 million children under 1 year do not receive basic vaccination worldwide, and as a consequence, millions of children die from vaccine-preventable diseases [2]. In addition, the emergence of polio cases, continuous measles outbreaks, and high vaccination dropout rates are major issues faced in low- and middle-income countries (LMICs) [3]. Global Vaccine Action Plan (GVAP), launched by World Health Organization (WHO) to increase global vaccination coverage, has set a target of 90% for national vaccination coverage and at least 80% at the district level by 2020 [4].

Routine Immunization Pakistan

Pakistan ranks fourth in child mortality worldwide, with over 60% of all deaths due to infectious diseases and many of which are vaccine-preventable [5]. Pakistan is also the major contributor of polio-confirmed cases since the past few years and the main country in focus for the eradication of polio cases [6]. Although strategies to strengthen the polio vaccination coverage in Pakistan depend not only on curtailing violence and advocacy, improved RI coverage is recommended as the priority public health strategy to eradicate polio [6]. With the reemergence of polio in Nigeria, improvement in polio vaccine uptake as part of RI seems to be the only way forward to eliminate polio and sustain eradication in Pakistan and worldwide [7]. Unfortunately, the immunization coverage in Pakistan is estimated to be 59%, with rates as low as 16% in the Baluchistan province [8].

Despite all the Expanded Program of Immunization (EPI) scheduled vaccines being free of cost, the coverage rate in Pakistan is well under 90%, as recommended for RI programs in LMICs. A major reason for poor coverage is the lack of awareness among parents and caregivers regarding the need for immunization and the importance of completing the entire series of vaccines [9]. There is an immense need for enhancement in the leverage between care seeker and the health care provider to improve vaccine uptake and complete all doses according to the schedule. New, innovative, and cost-effective techniques are required for improvement in vaccination uptake and coverage.

Mobile Health

There has been a rapid increase in mobile phone use with around 7 billion mobile phone subscribers globally, with the majority living in developing countries [10,11]. Short message service (SMS) messages have also shown a considerable impact on disease prevention efforts in LMICs and have particularly been quite effective for changing behavior in treatment adherence, smoke cessation, and health care appointment attendance [12-18]. Pakistan has also seen a drastic rise in the use of mobile phones in the last decade, with more than 133 million current

subscribers of the mobile phone in the country and with a mobile penetration density of 71% [10]. In addition, there has been a major increase in the use of SMS texting, with 237.58 billion person-to-person SMS generated in 2011 [11]. Given the mobile phone access and acceptability in Pakistan, there is great potential for SMS-based interventions to improve immunization coverage. Available data suggest mHealth as a great potential in connecting health care services to women and caregivers who can now be directly connected through this mode of communication, bypassing different hurdles encountered during physical visits or contact [19,20]. In this study, we evaluated the role of automated one-way SMS text reminders for improvement in uptake of childhood vaccines included in the RI at 6, 10, and 14 weeks of EPI schedule in Pakistan.

Methods

Study Design

A randomized control trial was conducted to determine the efficacy of automated SMS reminders to parents in improving the on-time vaccination rates in children. This study was conducted in an urban squatter settlement area, Ibrahim Haidry (IH) union council in Karachi where the Aga Khan University's Department of Paediatrics and Child Health is conducting a health demographic surveillance system (HDSS) on maternal and child health since 2008. It is a low-income community where most of the adult males are fishermen. The total population of the active surveillance catchment area is 120,725; approximately 5000 pregnant women and 4800 newborns are added to the surveillance system annually. The study was conducted from March to December 2013. An ethical review committee of Aga Khan University and WHO approved the study protocol and documents.

Participants

The study inclusion criteria were as follows: child less than 2 weeks of age, parent or guardian or at least one person in the household has a valid mobile phone connection, ability to use and read SMS text messages, and parent or guardian providing consent. Study exclusion criteria were a child from outside HDSS area or family plans to stay in the catchment area for less than 6 months.

Sample Size Calculation

Target enrollment was 300 infants per site, 150 in each arm [21]. Assumptions used for calculating sample size increased in coverage rate from 60% to 80% power at 0.8, an alpha error at .05, and allowing for 10% dropout.

Randomization

The study staff, after obtaining the information from the surveillance team, visited the homes of newborns in the surveillance catchment area and offered enrollment to the parents in the study area. The intervention and control group ratio was 1:1; the randomization list was generated through computer assignments with a block of 6 children, allocated in sealed opaque envelopes that were opened at the time of enrollment after informed consent.

Table 1. Schedule of EPI^a vaccines at weeks 6, 10, and 14 in Pakistan.

Treatment arm	6 week (41, 42, 43, and 44 days)	10 week (69, 70, 71, and 72 days)	14 week (97, 98, 99, and 100 days)
Arm 1 (Intervention)	Four standard EPI reminder SMS ^b	Four standard EPI reminder SMS	Four standard EPI reminder SMS
Arm 2 (Control)	One-time counseling at the baseline survey	One-time counseling at the baseline survey	One-time counseling at the baseline survey

^aEPI: Expanded Program of Immunization. Standard EPI in Pakistan is oral poliovirus vaccine (OPV) plus bacillus Calmette-Guerin at birth; DPT-Hep-B-Hib and OPV at 6, 10, and 14 weeks, and measles at 9 months and second year of life at the time of the study. The pneumococcal vaccine was included in the Pakistan EPI program after the study.

^bSMS: short message service.

The study staff administered the baseline questionnaire at the household level; however, the participants could not be blinded due to overt participation and nature of the intervention.

Intervention

In this study, due to time constraint and budget, we only included RI scheduled at 6, 10, and 14 weeks of life. The control group received one-time standard verbal counseling at the time of initial visit (enrollment) by the study staff regarding the timing for EPI vaccines at 6, 10, and 14 weeks. The intervention group, in addition to this standard counseling, received 4 SMS reminders in the week that the enrolled child was due for the EPI vaccines according to the RI schedule. Four one-way SMS text reminders according to the language preference as captured in the baseline survey were sent in the week that the child was due for EPI vaccine according to the EPI schedule. The content of the text message was “‘Child name’ is due for 6-week vaccination immediately take your child to the nearest EPI center.” Same message was sent when the child was 6, 10, and 14 weeks of age [22]. The details about the SMS schedule and vaccines covered in the Pakistan EPI at 6, 10, and 14 weeks are provided in Table 1 [23].

Data Collection

An initial baseline survey was conducted after individual randomization at the household; information on basic demographics, mobile phone, and SMS text use preference was collected. Automated SMS text messages were designed according to the feedback obtained through the baseline survey and language preferred. A second interview was conducted at 18 weeks of age of the enrolled child; the study team again visited each study subject at the household and documented information regarding EPI RI scheduled at 6, 10, and 14 weeks in both the intervention and control arms. Vaccination records were verified by physically looking at the EPI immunization cards of the child during home visits.

Statistical Analysis

The primary outcome was to compare the proportion of children immunized up to date at 18 weeks of age. The secondary outcome was to evaluate the timing of the vaccine received according to the schedule of the EPI. Data analysis was done using Statistical Package for Social Sciences for Windows version 19 (IBM SPSS Statistics, IBM Corporation, Somers, NY, USA). Characteristics regarding sociodemographics, mobile phone use, and immunization status were expressed in percentages across the intervention and control arms. For assessing comparability of the data on sociodemographics and

mobile phone use across the 2 arms and vaccination status on the defined time intervals (6, 10, and 14 weeks after birth), chi-square test of independence was employed. *P* value, if found less than .05, was considered significant. The study hypotheses were tested for both per protocol (PP) and intention to treat (ITT) analyses.

Results

Overview

We approached 364 parents or caregivers of newborns, and out of which 300 participants were eligible for the study (84.3%, 300/356; Figure 1). The reasons for not participating in the study included the following: declined to participate (32%, 18/56), not having a valid mobile phone number (36%, 20/56), not comfortable with using SMS text messages (4%, 2/56), did not provide mobile phone number (5%, 3/56), child greater than 14 days of life (18%, 10/56), and stay in HDSS less than 6 months (5%, 3/56). A total of 150 participants were randomly allocated to the intervention arm, and the same numbers of participants were enrolled in the control arm.

Baseline and Demographic Information

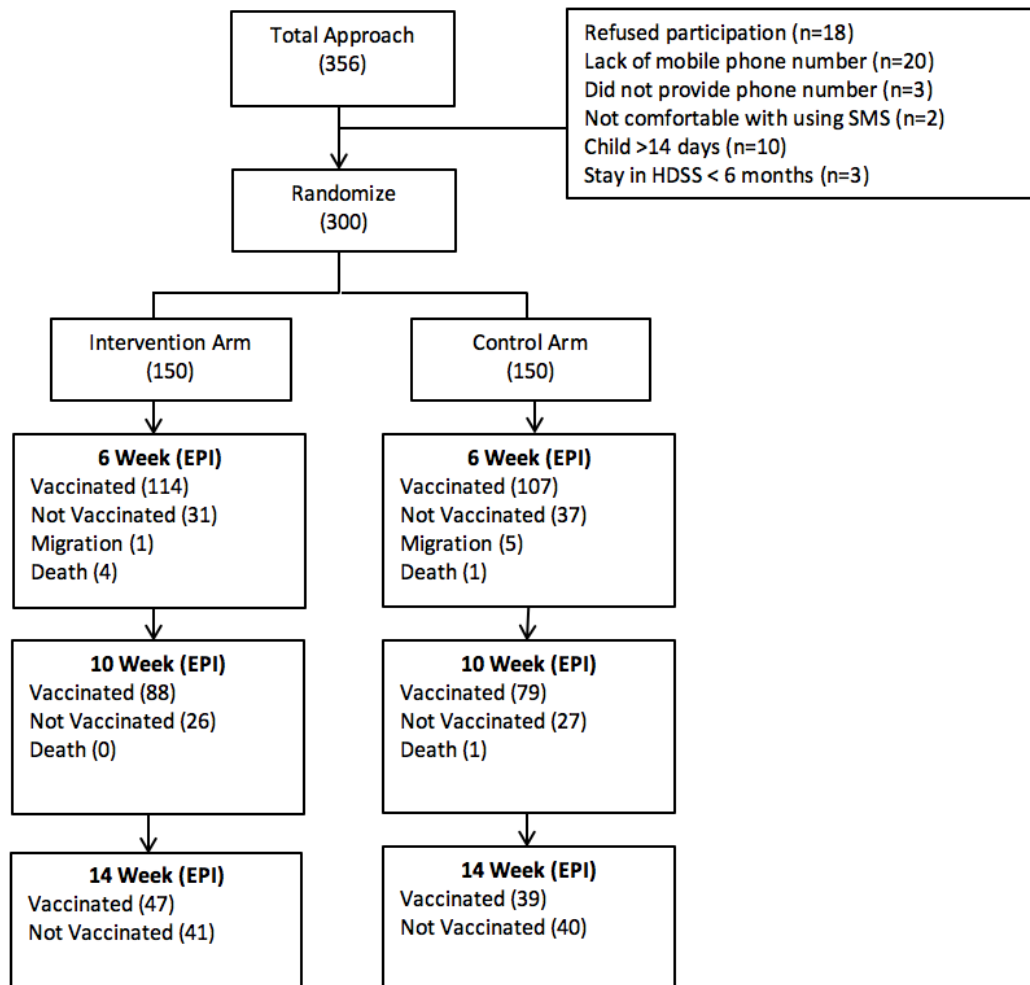
There was no important difference in the baseline and demographics information among intervention and control arms (Table 2). A total of 94.1% (318/338) of the participants approached had at least one working mobile phone in the house, out of which 99.4% (316/318) were comfortable in receiving and reading SMS text messages and 99.1% (313/316) shared their phone numbers with the study staff.

Trial Results

At 18 weeks of life follow-up, 96.0% (288/300) participants gave follow up interview.

Six participants shifted from their homes during the study period (1 in the intervention arm and 5 in the control arm), and 6 children died during the study period (4 in the intervention arm and 2 in the control arm). A total of 1776 messages were sent to the intervention group in the week the child was due for vaccination at 6, 10, and 14 weeks of life. When inquired regarding receiving the SMS text messages in the intervention arm (n=145), 75.9% (110/145), 73.8% (107/145), and 71.0% (103/145) responded “yes,” respectively, at 6, 10, and 14 weeks of life; 4.8% (7/145), 4.8% (7/145), and 7.6% (11/145) said “no,” respectively, at 6, 10, and 14 weeks of life; and 18.6% (27/145), 20.7% (30/145), and 22.1% (32/145) said “don’t know,” respectively, at 6, 10, and 14 weeks of life.

Figure 1. Consort diagram of the study, describing the trial profile at the time of enrollment. Baseline information was obtained when child was less than 14 days of age and vaccination information (exit interview) at 18 weeks of age. SMS: short message service; EPI: Expanded Program of Immunization; HDSS: health demographic surveillance system.



When asked at the baseline survey, 22.7% (68/300) of the participants reported that they were vaccinated for both birth bacillus Calmette-Guerin (BCG) and polio vaccine. When asked at follow-up interviews at 18 weeks of age, the child vaccination status of birth BCG and polio vaccination was reported as 87.2% (251/288) and 8.9% (256/288), respectively.

Both the intervention and control arms were analyzed for immunization at 6, 10, and 14 weeks of life, for ITT and PP. For all those who were enrolled for ITT analyses, the numbers were slightly higher in the intervention group, however not statistically significant (Table 3). At 6 weeks, the Pentavalent 1 (DPT-Hep-B-Hib) immunization coverage in the intervention arm was 76.0% (114/150) as compared with 71.3% (107/150) in the control group ($P<.36$). Immunization coverage at 10 weeks for Pentavalent 2 in the intervention group was 58.7% (88/150) and in the control group was 52.7% (79/150) ($P<.30$). Similarly, immunization coverage at 14 weeks for Pentavalent 3 was 31.3% (47/150) in the intervention arm and 26.0% (39/150) in the control group ($P<.31$).

For PP analysis, we excluded the following children: (1) 12 children who died or migrated between study enrollment and

study exit interview 96.0% (288/300), (2) 80 children whose immunization was not confirmed through the EPI card 69.3 (208/300), and (3) 4.7% (7/145), 4.7% (7/145), and 7.6% (11/145) participants at 6, 10, and 14 weeks, respectively, who stated that they did not receive the SMS text. The vaccination coverage was consistently higher in the intervention group; however, it was statistically significant only at the 6-week schedule (Table 3). At 6 weeks, the Pentavalent 1 immunization coverage in the intervention arm was 96% (86/90) as compared with 86.4% (102/118) in the control group ($P<.03$).

Immunization coverage at 10 weeks for Pentavalent 2 in the intervention group was 78% (67/86) and in the control group was 75.5% (77/102) ($P<.69$). Similarly, immunization coverage at 14 weeks for Pentavalent 3 was 58% (36/67) in the intervention arm and 51% (39/77) in the control group ($P<.36$).

Only 30% of the participants, both in the intervention and control arms, were vaccinated within the scheduled time when their appointment was due. However, there was no statistically significant difference in the timing of the vaccine received according to the EPI schedule in both the arms.

Table 2. Demographic details of the short message service (SMS) group participants versus the control group participants. Percentages may not total 100% due to nonrespondents and missing data.

Parameter	SMS group (n=150), n (%)	Control group (n=150), n (%)	P value
Male	84 (56.0)	76 (50.7)	.36
Ethnicity			
Urdu	61 (40.7)	62 (41.3)	.93
Sindhi	30 (20.0)	30 (20.0)	
Punjabi	7 (4.7)	11 (7.3)	
Others	52 (34.7)	47 (31.3)	
Monthly income (US\$)			
<US \$68	32 (21.3)	36 (24.0)	.60
US \$68-97	57 (38.0)	54 (36.0)	
US \$97-146	40 (26.7)	44 (29.3)	
>US \$194	9 (6.0)	3 (2.0)	
Don't know	12 (8.0)	13 (8.7)	
Relationship of child with cell phone provider			
Father	72 (48.0)	77 (51.3)	.90
Mother	38 (25.3)	39 (26.0)	
Grandparent	12 (8.0)	12 (8.0)	
Aunt	15 (10.0)	11 (7.3)	
Others	13 (8.7)	11 (7.3)	
Preferred language for SMS			
Roman Urdu	45 (30.0)	41 (27.3)	.32
Urdu	98 (65.3)	106 (70.7)	
Sindhi	2 (1.3)	0 (0.0)	
English	5 (3.3)	2 (1.3)	
Others	0 (0.0)	1 (1.3)	
Education of cell phone owner (n=77)			
No formal education	11 (14.2)	14 (18.2)	.18
Primary	7 (9.1)	8 (10.4)	
Secondary	18 (23.4)	6 (7.8)	
Tertiary	3 (3.8)	3 (3.8)	
Madrasah education only	2 (2.6)	5 (6.5)	
Education of child's mother			
No formal education	50 (33.3)	42 (28.0)	.34
Primary	31 (20.7)	22 (14.7)	
Secondary	37 (24.7)	47 (31.3)	
Intermediate	10 (6.7)	16 (10.7)	
Religious education	22 (14.7)	23 (15.33)	
Education of child's father			
No formal education	53 (35.3)	51 (34.0)	.68
Primary	13 (8.7)	21 (14.0)	
Secondary	55 (36.7)	58 (38.7)	
Intermediate	16 (10.7)	9 (6.0)	

Parameter	SMS group (n=150), n (%)	Control group (n=150), n (%)	P value
Religious education	13 (8.7)	11 (7.3)	

Table 3. Intention-to-treat and per protocol analyses of immunization rates at 6, 10, and 14 weeks.

Analysis and vaccination schedule	Intervention (n=150), n (%)	Control (n=150), n (%)	P value
Intention-to-treat			
Vaccination at 6 weeks	114 (76.0)	107 (71.3)	.36
Vaccination at 10 weeks	88 (58.7)	79 (52.7)	.30
Vaccination at 14 weeks	47 (31.3)	39 (26.0)	.31
Per protocol			
Vaccination at 6 weeks	86 (96)	102 (86.4)	.03
Vaccination at 10 weeks	67 (78)	77 (75.5)	.69
Vaccination at 14 weeks	36 (58)	39 (51)	.36

Discussion

Principal Findings

In this study, we evaluated the effectiveness of one-way SMS messages as a reminder on a mobile phone in improving RI coverage among children in Pakistan. The study results showed that the reminders text messages improved vaccination uptake according to the RI schedule at 6, 10, and 14 weeks. The coverage in the intervention arm as compared with the control arm was consistently higher at 6, 10, and 14 weeks visit according to the EPI schedule in both the ITT and PP analyses. However, only the RI coverage scheduled at 6 weeks, according to PP analysis, was statistically significant. This study is the first to evaluate the immunization coverage improvement through SMS reminders in an HDSS population in a real-world setting in Pakistan.

There was no significant difference between the intervention and control arm in the baseline and demographic characteristics of the study. A total of 96% of the enrolled participants gave the follow-up interview at the 18 weeks of child age and 6% and 20% stated not receiving an SMS text message or don't know, respectively. In our study, the enrollment and randomization process was done at the household level located within the HDSS population, and there was no contact of the study staff with the participants before 18 weeks of life of the child, apart from the SMS text reminders. This was different as compared with other studies in which telephonic calls or physical contact was made at the time of immunization and next SMS reminder was scheduled accordingly [24,25]. However, we were intrigued by the huge drop in vaccination rate from 6 weeks (76%) to 10 weeks (58.6%) and 14 weeks (31.3%) in the intervention arm, and similar trends were seen in the control arm in ITT analyses.

Mobile phone and text message use in Pakistan like other developing countries are quite high, with studies showing at least one working mobile phone connection in the household [11,12,26,27]. Our study also showed similar trends with 94% coverage of mobile phone ownership at home and 75.3% belonging to parents of the child to be vaccinated. This is on

the higher side, compared with mobile phone ownership and sharing in other LMICs settings [26-28]. Similarly, willingness to receive SMS reminders for immunization was also quite high as 99.3% of the participants were comfortable in receiving the SMS text messages and 98% shared their mobile number with the study staff.

Previously conducted SMS-based studies have shown improvement in the vaccination uptake primarily focusing on influenza vaccine among children and adolescents in the United States [29]. The majority of these studies evaluated one-way SMS reminders; however, interactive messages showed higher improvement in coverage, although the difference was minor [30]. In comparison, 3 randomized clinical trials focused on the role of one-way reminder text messages for RI coverage in the LMIC setup. Two studies conducted in Africa, namely, Zimbabwe and Kenya with a sample size of 304 and 1116 participants, respectively, have shown statistically significant improvement of 8% and 13%, respectively, at 14 weeks EPI schedule [24,31]. However, a randomized clinical trial conducted in Guatemala including 370 participants was not statistically significant [32]. Our finding was quite similar to this study with acceptability for SMS and mobile phone use and an increase of 5% coverage at 6, 10, and 14 weeks vaccination schedules. However, we were able to see the statistically significant difference in PP analyses.

Qualitative studies conducted in the United States have also shown parents' acceptability for text message immunization reminders, factors affecting mothers or caregivers' decision to vaccinate their child, and benefits of receiving text for immunizations [33,34]. Furthermore, the SMS text messages' content was explored with parents or caregivers to prompt them to schedule their child's immunization appointment [35]. However, there is limited data looking into different perceptions and barriers that may affect SMS-based interventions for improvement in childhood RI in resource-constrained settings [36].

Although the major focus up till now has been on reminder messages, the impact of educational or provoking messages for vaccination improvement might also improve vaccination

coverage and should be evaluated in future studies in LMIC settings [30,37]. In addition, the impact of two-way SMS-based models using text messages as better assignment compared with one-way SMS also needs to be assessed for RI program, given the cost difference due to the population size and technology constraints in low-income settings [14,38]. A meta-analysis of clinical trials showed that two-way SMS text messages improved adherence to medication as compared with one-way messages; the relative risk estimate was 1.04 for one-way text messaging and 1.23 for two-way text messaging ($P=.007$) [39]. Adding incentives to SMS text messages have also shown a positive association; however, there might be cost implications for scaling up this model at the program level in LMICs setups [24,40–42]. Furthermore, automated calls could be a good alternative for low-literate population, although the cost could be a major hindrance as well.

Previous studies have advocated that level of literacy might have a direct impact on the efficacy of SMS messages for improvement in immunization coverage [11,43]. We had a very high acceptance for receiving and reading SMS; this was with the understanding that someone in the household can read and reply to SMS. Only one-third of the parents and person having the mobile phone in the house had no formal education; however, this information cannot rule out the capacity of replying to simple text messages. Although SMS text messages have the limitation of 160 characters and even less if translated into other characters, these limitations might help in making the messages simple and brief, especially for low-literacy level population [44]. More than two-third of the participants opted for Pakistan's national language Urdu and the majority of the remaining chose Roman Urdu (Urdu written with English alphabets), despite participants belonging to different ethnic groups with Urdu not being their mother tongue. This signifies the importance of SMS content according to the language preference.

The huge drop in vaccination rate from 6 to 10 and 14 weeks in our study is of paramount interest. It shows that families are not opposed to the vaccine at 6 weeks (76% coverage) and that something happens after 6 weeks that makes the child's vaccine a second priority for the family. When discussing informally the reasons with few families, some of the reasons reported were as follows: (1) the change in mother's status at 6 weeks (need to resume normal work activities) while their life was protected before; (2) poor experience with the first vaccine, perceived as painful for the child, responsible for fever, and other adverse effects; (3) forgot child's due date for the next vaccination visit or child's EPI card is misplaced; (4) not permitted by family members to have her child immunized; (5) difficulties in reaching the EPI centers at a convenient time (distance, opening time, or fare of travel); and (6) low trust regarding vaccines provided through EPI and government health care providers. Incorporating these reasons to develop new SMS messages, including educational or proactive messages, might bring about the behavior change and strategies to decrease the drop in follow-up visits during the infancy period.

Notably, the vaccination coverage at 14 weeks in both the intervention and control arms was even lower than the national estimates, indicating the importance of additional interventions

or support for improvement in vaccination uptake. A study in Bangladesh showed that mobile phone-based registration incorporated with SMS text reminders improved childhood vaccination coverage [45]. To scale up the SMS-based interventions in the national EPI programs, the major challenge would be getting the mobile phone numbers of parents or caregivers due to privacy law, trust, and social norms in certain communities and below par immunization registries. A mobile phone numbers' registry containing phone numbers of young mothers and children less than 5 years needs to be established. This can be captured through health workers visiting the households, parents visiting the EPI centers, national government database, and mobile phone service providers. However, a policy to ensure that these numbers are not shared and misused needs to be implemented to have the confidence of the population to be part of these registries. The other major challenge is poor population-based immunization registries and electronic records in LMICs setup [46]. Incorporation of SMS messages in these registries as compared with developed nations is another hurdle that needs to be resolved.

Limitations

Our findings have several limitations. These include a small sample size; the sample size estimation was done with the assumption of 20% increase in coverage of the intervention arm. There were limited data on the effect of SMS-based studies, and we took the effect size on the higher side. This might have given us a small sample size and possibility of type II error. We had calculated the sample size assuming that the vaccination uptake due to the intervention would be 20%; however, the analysis yielded the difference to be around 5% and less across each points of vaccination; hence, we indicated the lower sample size as a major limitation, which might have underpowered the study results. We only evaluated the coverage for completion of all DPT or pentavalent doses rather than the entire EPI-recommended series at 0, 6, 10, 14 weeks and 9 months and 15 months for measles, as a lot of children fall behind their immunization coverage between these schedules. There was no confirmation through gateway service of the SMS being read even though sending through the gateway and "getting the SMS" was confirmed through study end interview. There is a possibility of recall bias related to receiving the SMS text message during the study enrollment period. We were able to verify that 69.3% of the participant's vaccination status by physically looking at their EPI card; however, rest of the participant's vaccination status was verbally captured as they were not able to retrieve and show the EPI cards to the study team staff. Since the study enrollment was conducted within households in the HDSS area, the SMS text messages were scheduled for 6, 10, and 14 weeks of life according to the date of birth. In case of a delay in getting vaccinated according to the schedule, participants might not have received the message in the week their child was eligible for immunization, which is 4 weeks after the last immunization scheduled for 6 or 10 weeks is received. Due to multiple immunization centers, it was not possible to confirm the immunization received and reschedule message accordingly for the next dose.

With increased shared phone access and acceptance of technological advances, there is a higher chance of improving

the reach to the majority of the population. This provides a great opportunity to improve engagement through text messages from early pregnancy and continue until completion of immunization of the child after birth. Pakistan being the major contributor to the polio epidemic, any strategy to support an improvement in the RI will have a direct impact on the polio endgame strategy.

Conclusions

In conclusion, automated simple one-way SMS reminders in local languages might be feasible for improving routine

vaccination coverage. Further studies are required to look into whether an automated simple one-way SMS reminder in local languages can have a strong impact in improving routine vaccination coverage in a resource-constrained setting. Whether SMS reminders alone alter parental attitudes and behavior needs to be evaluated by better-powered studies, comparing the different types and content of text messages in LMICs settings. In addition, information on perceptions, barriers, and text content according to the local settings that may affect SMS-based interventions should be assessed as well.

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Authors' Contributions

AMK and SAA conceived the topic and designed the experiments. AMK, MA, KZ, and HK executed the experiments. AMK, SPI, and MA analyzed the data. AMK, ANK, JPC, and SAA wrote the paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1

CONSORT - EHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 96KB - publichealth_v4i1e20_app1.pdf](#)]

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Abbreviations

DPT-Hep-B-Hib: diphtheria, pertussis, tetanus, hepatitis B, and Haemophilus influenza type b

EPI: Expanded Program of Immunization

GVAP: Global Vaccine Action Plan

HDSS: health demographic surveillance system

ITT: intention to treat

LMICs: low-and middle-income countries

OPV: oral poliovirus vaccine

PP: per protocol

RI: routine immunization

SMS: short message service

WHO: World Health Organization

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