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Original Paper

Twitter and Public Health (Part 2): Qualitative Analysis of How Individual Health Professionals Outside Organizations Use Microblogging to Promote and Disseminate Health-Related Information

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Abstract

Background: Twitter is the most popular form of microblogging that is being utilized in public health to engage audiences and to communicate health-related information. Although there is some research showing the various forms of Twitter use in public health, little is known about how individual public health professionals are using their personal Twitter accounts to disseminate health information.

Objective: The purpose of this research was to categorize public health professionals' tweets to evaluate how individual public health professionals are furthering the mission of public health.

Methods: Twitter accounts held by public health professionals were identified, and researchers proceeded to record 6 months' worth of each individual's Twitter feed. During the 6-month period, a total of 15,236 tweets were collected and analyzed using the constant comparison method.

Results: A total of 23 tweet categories among the 15,236 tweets were initially identified. Some of the most common topics among the 23 categories included the following: health nutrition (n=2008), conferences (n=815), Ebola (n=789), Affordable Care Act (ACA)/health care (n=627), and social justice (n=626). Each of these categories were then stratified into one of four themes: (1) informing and educating, (2) monitoring health statuses and trends, (3) social justice, and (4) professional development.

Conclusions: Using Twitter, public health professionals are helping dispel misinformation through education and by translating technical research into lay terms, advocating for health inequalities, and using it as a means to promote professional development.

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KEYWORDS

Twitter; social media; public health; technology transfer; diffusion of innovation

Introduction

In a recent paper published in JPHS we described how public health professionals use Twitter for professional development [1]. In the current paper, we describe how public health professionals disseminate health related information using Twitter. Facebook, Twitter, Instagram, Yik Yak, Snapchat, and YouTube are just a few of the social networking sites (SNSs) that 65% of adults use daily in the United States [2,3]. Each platform offers a unique way to disseminate information, share opinions, and connect with others around the world in a matter of seconds [2]. Microblogging, a subsection of SNSs, is defined as “short, frequent posts” or electronic word of mouth [4-6]. Through microblogging, individuals not only share personal mementos, opinions, political information, and news but also promote products and information, thereby raising awareness for causes or charities [4-6]. Research shows that microblogging is powerful in convincing/rallying other individuals because of immediacy, its far reach to individuals around the world, and is seen as credible because it appears in a print format [6]. As a result of its strong influence, many companies and organizations have adopted microblogging to disseminate information about their company or organization and to promote events and products [4-6]. With such a strong influence and reach, it is important to look at how public health organizations and professionals are using this influence to potentially spread credible knowledge and information to the public as well as a means of professional development.

The most popular form of microblogging, with 313 million active users, occurs through Twitter [7,8]. Twitter allows users to post tweets up to 140 characters or less, as well as links, pictures, and videos after the tweet [7]. The majority of Twitter accounts are public, so any individual can access information on another account simply by following that account [7]. Twitter users are mostly individuals in the age group of 18 to 29 years, who are statistically African American or Hispanic, live in urban areas, and have a higher participation rate than most other SNSs [7]. These users are a challenging population to reach in public health, making Twitter an ideal resource for public health organizations and individuals to focus their efforts [7]. Public health organizations currently use Twitter for (1) informing and education, (2) monitoring health status and trends, (3) surveillance and information in disasters, and (4) professional development [7,9].

Public health organizations disseminate information and education by tweeting about various health-related topics [7,10]. Local health departments often tweet information about tobacco cessation resources, events, frequently asked questions about immunizations, and other popular health-related topics. Twitter has also been used as a means to provide sex education and to promote the use of condoms by tweeting facts on sexual health and information about local clinics that provide free condoms [10]. When monitoring health statuses and health trends, also called syndromic surveillance, health departments can search for tweets using keywords or hashtags such as “sick,” “flu,” “dental pain,” and “food poisoning.” This allows health departments to identify the geographical area from where these tweets are being posted and to map instances of a potential flu outbreak, food contamination, or an area in need of dental services in real time [7,11,12]. Furthermore, health organizations use surveillance and information during disasters by tweeting updates about current local crises such as flooding, fires, hurricanes, and tornadoes [7]. Besides sending information, health organizations can also collect information by searching for geotagged tweets that indicate where emergency relief should focus their attention [7].

Health organizations are also beginning to use Twitter as a source of professional development by tweeting updates while at a conference or an important meeting, thereby allowing other organizations and health professionals to receive updates on the current work and research being conducted [7]. Professional development is also being facilitated via the creation of journal clubs by certain organizations, a Web-based format on Twitter that allows health professionals to tweet questions and responses to the paper as well as the author of the paper to respond to other health professionals in real time [13]. Although public health organizations are adapting to the current social media trends, the current research being conducted focuses primarily on organizations and excludes how individual public health professionals are disseminating health information. This study aims to target these public health professionals’ tweets over a 6-month period to evaluate how individuals are furthering the mission of public health.

Methods

When examining the implementation of new technology, Roger’s diffusion of innovation model is commonly used. Although Twitter was founded in 2006 and has gone through the full diffusion of innovation cycle (innovators, early adopters, early majority, late majority, and laggards), the diffusion of innovation model can be used to examine how new ideas and uses of Twitter spread throughout the population or a subpopulation/group. For example, public health organizations did not start using Twitter until more recently because of network filter blocks, but they created new uses for Twitter such as syndromic surveillance [7,11,12]. Public health organizations (eg, Centers for Disease Control and Prevention [CDC], local health departments, and National Institutes of Health [NIH]) are farther along the diffusion of innovation cycle, whereas individual public health professionals are just beginning to use Twitter for more than personal usage. These public health professionals can be considered early adopters, as they are expanding beyond the scope of personal usage and using their credentials to identify themselves as an authority and the field and to disseminate public health–related information outside a specific organization. Examining these tweets allows for the identification of information that public health professionals hope to disseminate to colleagues and eventually, to the general population.

Data Collection

Participants were chosen through Twitter’s search function using the terms “public health practitioner,” “MPH” (master’s in public health), “public health,” and “APHA” (American Public Health Association). After individuals were identified as public health professionals, participants were chosen based on a set of inclusion and exclusion criteria. Inclusion criteria were as follows: the individual was a public health professional and had to have a minimum of 300 followers. Exclusion criteria were as follows: the individual could not be a part of an academic institution, and it could not be an organization’s Twitter page (eg, CDC, local health departments, and NIH). Overall, 220 public health professionals were chosen to examine their tweets during a 6-month period from October 1, 2014 to March 31, 2015. A total of 15,236 tweets were collected and then analyzed using the constant comparison method.

Data Analysis

The constant comparison method was used to analyze the tweets to reduce the data into manageable units and coded information [14-16]. The process began with open coding, which can be defined as "the process of breaking down, examining, comparing, conceptualizing, and categorizing data," where 2 trained researchers (NS and MH) open-coded all the tweets and discovered major themes [14-16]. The tweets were then selectively coded into those major themes by the same 2 trained researchers (MH and NS; [14-16]). Open coding was done by hand versus using keyword searches through data mining software to take on the full context of the tweets/posts.

Results

The constant comparison method initially revealed 23 different tweet categories among the 15,236 tweets analyzed, as displayed in Table 1. Each of these categories were then analyzed and coded into four separate themes: informing and education, monitoring health status and trends, social justice, and professional development (Textbox 1).

Table 1. Tweet categories of public health professionals.

Tweet category	Tweets, n
Non-public health–related	4032
Health nutrition	2008
Other	1885
Conference/Forum/APHA[a]	815
Ebola	789
Noninfectious diseases	728
ACA[b]/Health care	627
Violence/Safety/Social justice	626
Health law and policy	567
Technology/Innovation	553
Environmental health/Factors	380
Charity/Organizations/NPO[c]	346
Vaccines	250
Education and literacy	233
Global famine/Water	196
Emergency/Emergency preparedness	176
Global poverty/Homelessness	170
Infectious diseases	158
Mental health	156
HIV[d]/AIDS[e]	143
Smoking/Tobacco/Marijuana	143
Medications/Drugs and alcohol	143
Influenza	112
Total	15,236

[a] APHA: American Public Health Association.

[b] ACA: Affordable Care Act.

[c] NPO: nonprofit organization.

[d] HIV: human immunodeficiency virus.

[e] AIDS: acquired immunodeficiency syndrome.

Textbox 1. Tweet themes of public health professionals and underlying categories.

Tweet theme: Informing/Education

Categories

- Ebola
- Human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS)
- Affordable Care Act (ACA)/Health care
- Health law and policy
- Emergency/Emergency preparedness
- Environmental health factors
- Health and nutrition

Tweet theme: Monitoring health status/Trends

Categories

- HIV/AIDS
- Health and nutrition
- Influenza
- Smoking/Tobacco/Marijuana
- Technology/Innovation
- Infectious diseases
- Noninfectious diseases

Tweet theme: Social justice

Categories

- Global poverty/Homelessness
- Global famine/Water
- Charity/Organizations/American Public Health Association (APHA)
- Education and literacy
- Mental health
- Violence/Safety/Social
- Non-public health–related

Tweet theme: Professional development

Categories

Conference/Forum/APHA

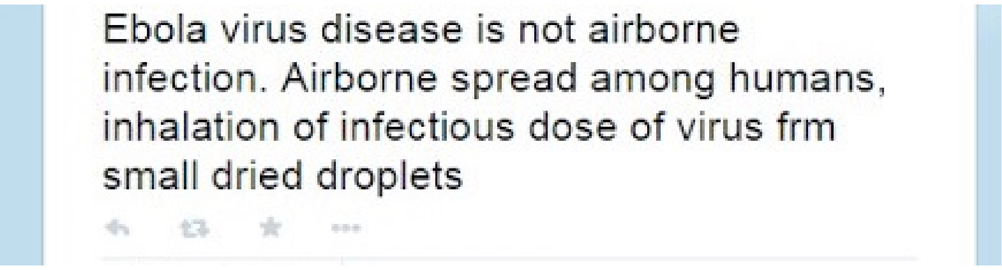
Informing and Education

Informing and education tweets centered around informing and educating the public on various aspects and updates in public health. Within the theme, there were seven major topic areas covered: Ebola; human immunodeficiency virus (HIV)/acquired immunodeficiency syndrome (AIDS); Affordable Care Act (ACA)/health care; health law and policy; emergency/emergency preparedness; environmental health factors; and health and nutrition (Textbox 1). During the 6-month period of tweets collected, panic about Ebola was prevalent, and many public health professionals tweeted information to dispel panic and myths (see Figure 1).

Another area where public health professionals tweeted information to dispel misinformation was about the ACA (see Figure 2).

Although social media has drastically changed the way of communication, it has also created a way to spread misinformation quickly. As public health professionals have the credentials/authority tied with their Twitter accounts, they can dispel misinformation as well as spread other important health information to the public at a rapid rate.

Figure 1. Public health professional dispels panic and myths during Ebola panic.



Ebola virus disease is not airborne infection. Airborne spread among humans, inhalation of infectious dose of virus frm small dried droplets

Figure 2. Public health professional dispels misinformation about the Affordable Care Act.

CBO #ACA will cost the government $142 billion less in next 10 years than last year's report. nytimes.com/2015/03/10/ups…

The New York Times

More Good News on the Deficit, This Time Because of Private Insurance...

Federal budget forecasters lowered estimates of what the government will spend on health insurance premiums, months after doing the same for Medicare.

View on web

Figure 3. Public health professional disseminates information about flu epidemic.

With 15 Children Dead, CDC Declares Flu Epidemic - ABC News abcn.ws/1ztM4NI via @ABC #H3N2 #Flu

ABC News

With 15 Children Dead, CDC Declares Flu Epidemic

By **#Liz Neporent** @Lizzyfit

The CDC has officially declared this year's flu an epidemic.

Figure 4. Public health professional shares a study about cigarettes with followers.

This Study Destroys The Myth That #Cigarettes 'Relieve Stress' huffingtonpost.com/2015/02/25/smo... #tobacco #healthyliving

HuffPost Living

This Study Destroys The Myth That Cigarettes 'Relieve Stress'

If you're looking for another reason to quit, here it is: Cigarettes may be a sign of mental health problems. Contrary to the perception of cigarettes as a stress reliever, smokers are 70 percent...

Monitoring Health Status and Trends

Tweets identified as monitoring health status and trends were not using surveillance techniques, instead they were informing the public of updates on specific health statuses and trends (see Figures 3 and 4). Within the theme, there were seven major topic areas covered: HIV/AIDS; health and nutrition; influenza; smoking/tobacco/marijuana; technology/innovation; infectious diseases; and noninfectious diseases (Textbox 1).

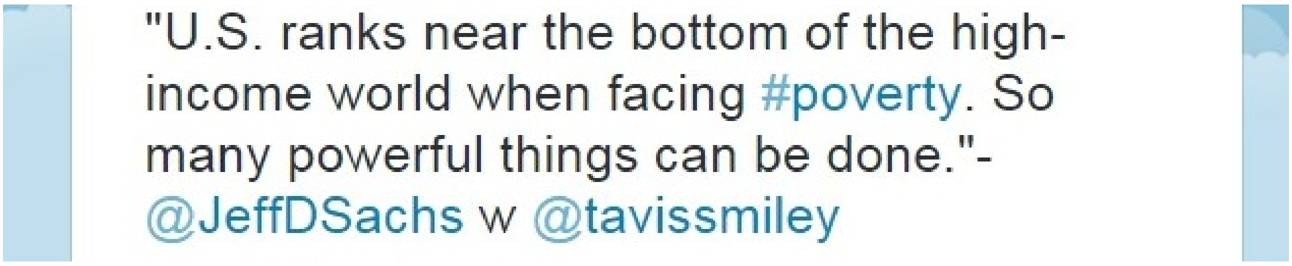
Through the word limit function in Twitter, public health professionals are forced to condense important information into 140 characters, making these important updates on specific health statuses and trends more relatable to the lay population.

Social Justice

Social justice tweets focused on raising awareness and support for various public health issues (see Figures 5 and 6). Within the theme, there were seven major topic areas covered: global poverty/homelessness; global famine/water; charity/organizations/APHA; education and literacy; mental health; violence/safety/social justice; and non-public health–related (Textbox 1).

Twitter provides a space for public health professionals to share items they are passionate about, within or outside, their field. This platform also allows them to connect and collaborate with other professionals who are interested in the same social justice issues.

Figure 5. Public health professional speaks about US poverty.



"U.S. ranks near the bottom of the high-income world when facing #poverty. So many powerful things can be done."- @JeffDSachs w @tavissmiley

Figure 6. Public health professional shows support for an organization.

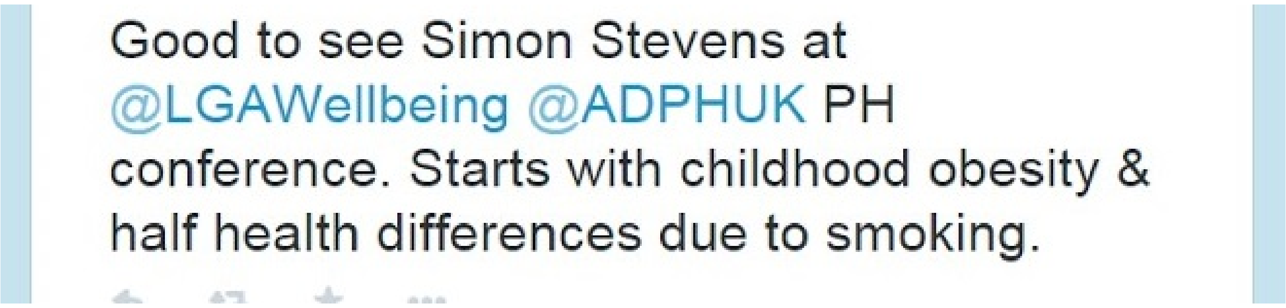
I support @MalalaFund fighting for 12 yrs of free quality education for all children bit.ly/1BWpbJA

Professional Development

Professional development occurred when health professionals tweeted new public health information obtained at conferences and forums, as well as with the exchange of sources of scientific literature back and forth between other public health professionals and the general public (see Figures 7 and 8). This particular theme contained only one tweet category: conference/forum/APHA (Textbox 1).

Twitter provides a unique platform for professional development as budget cuts decrease the opportunity to connect and collaborate with other public health professionals.

Figure 7. Public health professional shares his/herconference experience.



Good to see Simon Stevens at @LGAWellbeing @ADPHUK PH conference. Starts with childhood obesity & half health differences due to smoking.

Figure 8. Public health professional shares a photo of a conference.

Rain Henderson opens up the @ClintonFdn #HealthMatters2015 asking "What else can we do together" to improve health?

Indian Wells, CA

Discussion

Principal Findings

Similar to public health organizations, public health professionals are also using Twitter to inform and educate the public. These results are not surprising, as one of the main tenets of public health is to “educate and inform” [7]. This information and education on social media is crucial, as Twitter’s main users (aged 18 to 29 years), do not obtain “news” from regular media (newspapers, magazines, and television) but from social media [17]. As social media has become a main resource of knowledge for many, so has misinformation. With the credibility seen in microblogging, it is important for public health professionals with credentials/authority to dispel this misinformation among the public [6]. The results show public health professionals attempting to combat misinformation on Ebola.

Public health organizations use Twitter to monitor health status and trends through syndromic surveillance [7,11,12]. However, public health professionals were not using surveillance techniques, they were informing the public about updates on specific health statuses and trends. This also allows public health professionals to take technical research and translate it into 140 characters, or lay terms, for the public to understand and disseminate among their social groups. These tweets may also contain embedded links, which then lead individuals to health department websites or other credible websites where they might not have gone to in the first place [7]. The nature of Twitter also provides the public with a way to ask questions directly, allowing public health professionals to provide information they may not have otherwise [7].

The most visible tenet of public health is the concept of social justice [18]. The concept of social justice stems directly from public health’s mission to “protect and promote health of the population as a whole” [18]. Results mirror this founding ethical principle and show that public health professionals are passionate about many health inequalities. Twitter also allows these same professionals a way to connect with other professionals, within and outside public health, who are also advocating for the same issues.

Finally, akin to public health organizations, public health professionals are also using Twitter as a means of professional development. Over the years, many states have seen significant decreases in funding for public health, severely limiting resources available to the public as well as to the public health professionals (eg, continuing education and conferences). Twitter provides public health professionals with a unique platform, to still engage with local conferences, as individuals attending tweet about sessions while they are occurring. Twitter also provides a way for public health professionals to connect and collaborate with other public health professionals in real time, despite being limited in funding for travel.

Limitations

The scope of the tweets examined was during a 6-month window and was limited to that specific time frame. Although limited throughout the 6 months, the tweets reached saturation before 6 months, ensuring that tweets collected were representative of public health professionals' Twitter activity. A second limitation was that the individuals analyzed only had to have a minimum of 300 followers. Although this is a small number of followers, because public health professionals are early adopters, they will not have a large following yet. The final limitation was that the category "non-public health–related" was the most common tweet category. Looking at the categories as a whole makes it appear that public health professionals are not talking about public health the majority of the time, but when one looks at the tweets (see Table 1) as two categories—non-public health and public health—11,204 tweets were on various public health topics, and only 4032 were non-public health–related.

Conclusions

For more adoption to occur among public health professionals, public health organizations should consider removing social media filters, specifically from Twitter. The removal of social media filters would eliminate the barrier of public health professionals only being able to tweet during after work hours, thereby encouraging increased adoption of the social media platform among public health professionals as well as enabling them to rapidly spread critical health information to the public as it occurs "in real time." Unlike the majority of health organizations, public health professionals' individual Twitter accounts outside organizations are not monitored by the government, and they are able to disseminate important information to colleagues and the lay population, such as how climate change affects public health, that organizations may not be able to disseminate, despite how critical that information is to the overall public health in the United States.

Conflicts of Interest

None declared.

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Abbreviations

ACA: Affordable Care Act
AIDS: acquired immunodeficiency syndrome
APHA: American Public Health Association
CDC: Centers for Disease Control and Prevention
HIV: human immunodeficiency virus
MPH: master’s in public health
NIH: National Institutes of Health
SNS: social networking site

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Original Paper

A Smart Card-Based Electronic School Absenteeism System for Influenza-Like Illness Surveillance in Hong Kong: Design, Implementation, and Feasibility Assessment

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Abstract

Background: School-aged children have the highest incidence of respiratory virus infections each year, and transmission of respiratory viruses such as influenza virus can be a major concern in school settings. School absenteeism data have been employed as a component of influenza surveillance systems in some locations. Data timeliness and system acceptance remain as key determinants affecting the usefulness of a prospective surveillance system.

Objective: The aim of this study was to assess the feasibility of implementing an electronic school absenteeism surveillance system using smart card–based technology for influenza-like illness (ILI) surveillance among a representative network of local primary and secondary schools in Hong Kong.

Methods: We designed and implemented a surveillance system according to the Protocol for a Standardized information infrastructure for Pandemic and Emerging infectious disease Response (PROSPER). We employed an existing smart card–based education and school administration platform for data capture, customized the user interface, and used additional back end systems built for other downstream surveillance steps. We invited local schools to participate and collected absenteeism data by the implemented system. We compared temporal trend of the absenteeism data with data from existing community sentinel and laboratory surveillance data.

Results: We designed and implemented an ILI surveillance system utilizing smart card–based attendance tracking approach for data capture. We implemented the surveillance system in a total of 107 schools (including 66 primary schools and 41 secondary schools), covering a total of 75,052 children. The system successfully captured information on absences for 2 consecutive academic years (2012-2013 and 2013-2014). The absenteeism data we collected from the system reflected ILI activity in the community, with an upsurge in disease activity detected up to 1 to 2 weeks preceding other existing surveillance systems.

Conclusions: We designed and implemented a novel smart card technology–based school absenteeism surveillance system. Our study demonstrated the feasibility of building a large-scale surveillance system riding on a routinely adopted data collection approach and the use of simple system enhancement to minimize workload implication and enhance system acceptability. Data from this system have potential value in supplementing existing sentinel influenza surveillance for situational awareness of influenza activity in the community.

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KEYWORDS

influenza; public health surveillance; school health; absenteeism; smart cards

Introduction

School as a High-Risk Setting for Disease Transmission

Transmission of respiratory virus infections, including influenza virus infections, has always been a major concern in schools because of poorer personal hygiene practices, more frequent person-to-person close contacts, and relatively lower preexisting immunity among young children [1,2]. Besides associated morbidity and mortality, respiratory virus infections can also result in disruption to learning because of sickness absence [3] or school closure [4]. Outbreaks of influenza-like illnesses (ILIs) in schools often precede and may lead to further community epidemics, with transmission through family members [5].

Surveillance of School Absenteeism

School absenteeism is now increasingly being employed as a source of syndromic data for influenza surveillance to inform epidemic and pandemic preparedness in different locations [6-8]. Whereas previous studies generally suggested that school absenteeism data is useful for reflecting community influenza activity [9-11] and detecting outbreaks [12,13], data timeliness and system acceptance remain as key determinants affecting their usefulness for prospectively informing relevant public health actions and reducing disease transmission [14,15].

Use of Smart Card Technology for Disease Surveillance

Although verbal roll call with paper-based records still represents the predominant approach for attendance taking in most schools all over the world, a number of newer electronic means of attendance tracking, including the use of smart card technology, have also emerged in the market. A smart card (also called chip card or integrated circuit card) is a pocket-sized plastic card embedded with integrated circuits, allowing for individual identification, security authentication, data storage, and application processing in a wide variety of settings, including banking, retail business, bill payment, transportation, custom control, and educational settings [16]. In recent years, smart card technology–based systems are increasingly being adopted for various administration purposes in all levels of local educational institutions. In this respect, the situation in Hong Kong offers an unprecedented opportunity for assessing whether these automated data collection approaches in a school setting may offer the potential to contribute to more timely and efficient disease surveillance. In a previous pilot study, we demonstrated the feasibility of employing smart card–based technology to capture school absenteeism data for surveillance purposes [17]. Here, we report further details on the implementation and feasibility of building a comprehensive system for prospective ILI surveillance among a representative network of local primary and secondary schools in Hong Kong. On the basis of smart card technology, the system was being utilized to track absence from school, supplemented with additional back end systems for the automation of all subsequent steps required in the surveillance process, including a process to capture the reasons for absence.

Methods

Scientific Methodological Approach

We designed and implemented our surveillance system according to the standardized information infrastructure as laid out in the Protocol for a Standardized information infrastructure for Pandemic and Emerging infectious disease Response (PROSPER), with a view to better inform the three specific functions in relation to supporting influenza pandemic responses, namely capacity and needs analysis (CNA), response design modeling (RDM), and outcome and impact assessment (OIA) functions [18].

Study Setting

Currently, ILI surveillance in Hong Kong is administered under the Centre for Health Protection (CHP) of the Department of Health. The CHP prospectively monitors a number of data streams from different networks of surveillance partners covering different population subsectors. Sentinel doctors' networks included some 50 general practitioners (GPs) in private practice, 65 general outpatient clinics, and sentinel Chinese medicine practitioners in selected clinics, each reporting the proportions of patient consultations having ILI (a body temperature of 38.0°C plus cough or sore throat) on a weekly basis. Other additional systems included child care centers and kindergartens reporting children suffering from fever or cough and residential care homes for the elderly reporting inmates having fever [19]. For primary and secondary schools in Hong Kong, however, a mechanism does not exist for the prospective monitoring of ILIs besides the passive reporting of any confirmed or suspected outbreaks. After the severe acute respiratory syndrome epidemic, most schools in Hong Kong have required parents to monitor body temperature of their children every day and to abstain from sending them to school when having a fever, making absenteeism a suitable proxy for disease surveillance [20]. Many schools in Hong Kong now use smart cards rather than verbal roll call to track attendance at school because of convenience and efficiency.

Design and Implementation of the Surveillance System

In this study, we collaborated with BroadLearning Education (Asia) Limited, the commercial developer of a Web-based education and school administration platform *(eClass)* and employed its smart card–based attendance tracking functionality *(eAttendance)* for frontline data capturing. The *eClass* is an integrated platform for learning, administration, and communication, and *eAttendance* is a module that allows automatic generation of attendance report for internal use, as well as in a format ready for submission to the Education Bureau in Hong Kong. In a pilot study run from 2008 to 2011, captured data were sent to us from 20 schools by email on a daily basis. In this study, we used the same approach for frontend automatic data capture, with additional back end components developed, using scripts in the Linux Web server, to automate all subsequent steps in the surveillance process, including data transfer, cleaning, aggregation, analysis, and feedback intelligence report generation. The original user interface of the school administration system was customized with additional specific features aiming to improve data specificity and completeness and to minimize the time and workload involved in data submission. This study was approved by the institutional review board of the University of Hong Kong (HKU)/Hospital Authority Hong Kong West Cluster.

Recruitment of Schools

We extended our initial invitation to all local schools using the *eAttendance* system, targeting to recruit around 10.00% of local schools to participate in the surveillance system. Interested schools were visited by our research team to provide further explanation on study details and logistical arrangement. In consenting schools, we updated their *eClass* system as described in the following sections.

Data Collection

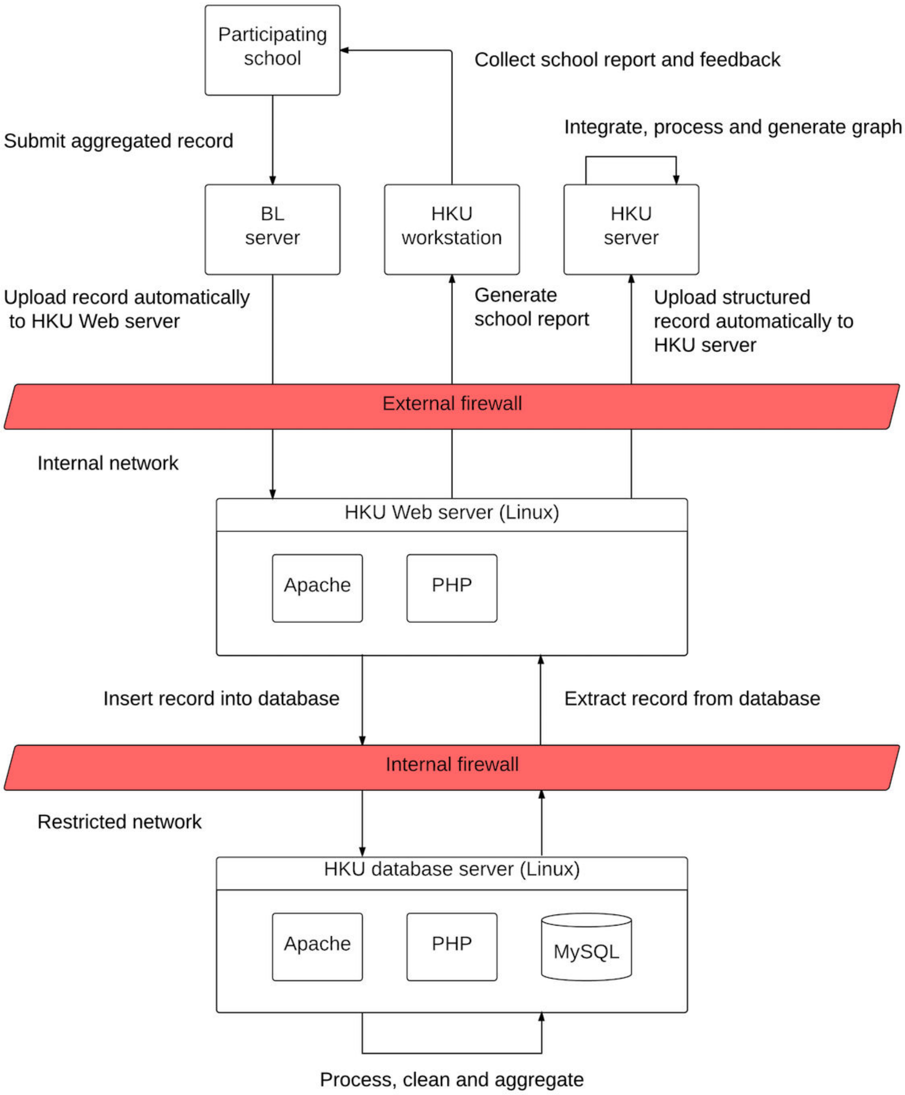
After implementing the system, absenteeism data were prospectively collected daily from all participating schools for 2 academic years using the system. We obtained data on community sentinel ILI surveillance from the CHP website and laboratory surveillance data from a regional tertiary hospital in Hong Kong (Queen Mary Hospital) as reference data and compared their temporal pattern with that of the absenteeism data. We also obtained feedback from participating schools regarding their experience of using the system by a short questionnaire at the end of the study.

Results

Technical Details of the Implemented Surveillance System

All system design and information technology implementation works were completed by May 2012. Figure 1 shows the overall system and data flow architecture of the school absenteeism surveillance system.

Figure 1. System architecture of the smart card-based school absenteeism surveillance system. BL: BroadLearning, HKU: The University of Hong Kong, PHP: Hypertext Preprocessor, MySQL: structured query language.

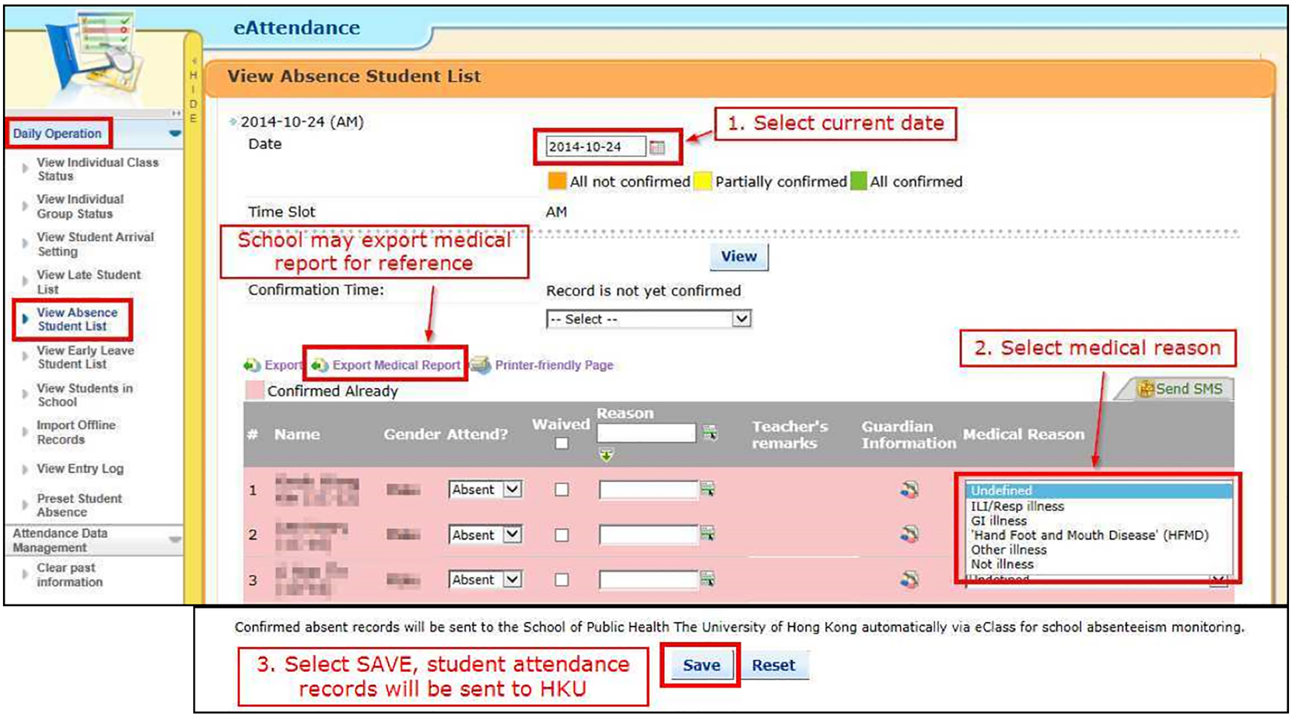


Data Capture

Attendance data in participating schools were automatically registered when students swiped their smart student identity card on the card reader on entering their school (Figure 2). Absenteeism was defined as a full day absence where the swiping of a smart card was never registered during the whole school day. Partial days of absenteeism, such as lateness to school with late card swiping or early departure, were not counted. On a daily basis, a list of absent students would be displayed automatically on the user interface of the system in each school for easy checking. In some participating schools, the specific causes of absence were then individually ascertained by telephone call and manually recorded into the system in free text format by designated school staff. In our updated surveillance system, a simple drop-down menu was added to the user interface (Figure 3) to allow for easy and standardized reporting of common causes of absence, such as ILI; gastroenteritis; hand, foot and mouth disease; acute conjunctivitis; other illnesses with specification; or non-sickness-related absence, to facilitate the capturing of these more specific data.

Figure 2. Example student identity card (anonymized) and smart card reader.

Figure 3. Screenshots of the user interface on the eClass eAttendance module, showing the steps for easy and standardised reporting of specific cause of absence using the drop-down menu (step 2) and for automatic submission of aggregated surveillance data in a standardised format by the Save button (step 3).



View Absence Student List

2014-10-24 (AM)

Date: 2014-10-24

1. Select current date

🟧 All not confirmed 🟨 Partially confirmed 🟩 All confirmed

Time Slot: AM

School may export medical report for reference

Confirmation Time: Record is not yet confirmed

-- Select --

2. Select medical reason

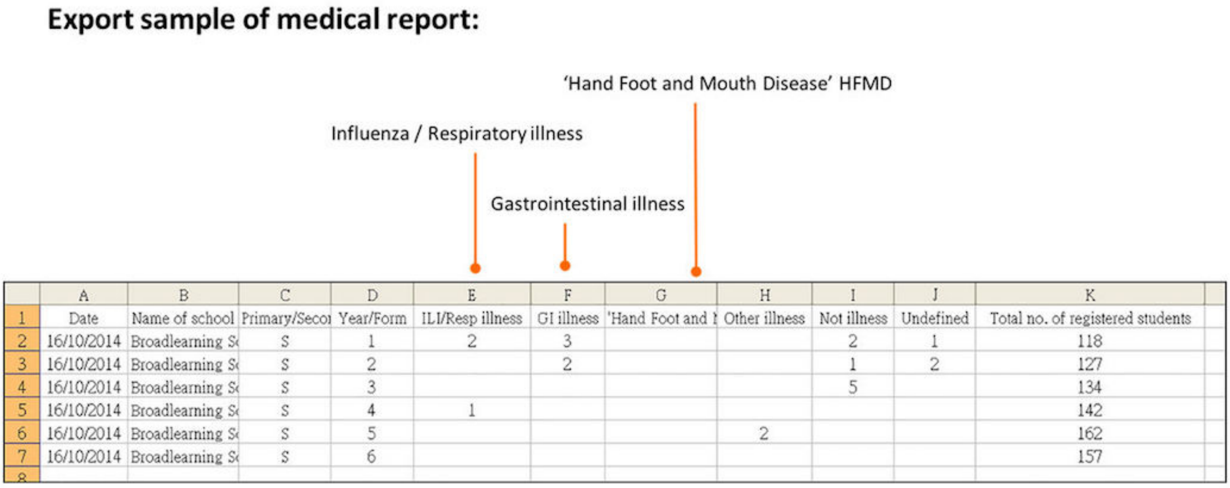
Confirmed Already

#	Name	Gender	Attend?	Waived ☐	Reason	Teacher's remarks	Guardian Information	Medical Reason
1	[redacted]	[redacted]	Absent	☐				Undefined ILI/Resp illness GI illness 'Hand Foot and Mouth Disease' (HFMD) Other illness Not illness
2	[redacted]	[redacted]	Absent	☐				
3	[redacted]	[redacted]	Absent	☐				Undefined

Confirmed absent records will be sent to the School of Public Health The University of Hong Kong automatically via eClass for school absenteeism monitoring.

3. Select SAVE, student attendance records will be sent to HKU

Figure 4. A sample of the daily data submission files in a standard comma separated values (CSV) data file format, containing the number of absentees (all-cause and cause-specific) and total number of enrolled students in each form of the school.



	A	B	C	D	E	F	G	H	I	J	K
1	Date	Name of school	Primary/Secoı	Year/Form	ILI/Resp illness	GI illness	'Hand Foot and ł	Other illness	Not illness	Undefined	Total no. of registered students
2	16/10/2014	Broadlearning S‹	S	1	2	3			2	1	118
3	16/10/2014	Broadlearning S‹	S	2		2			1	2	127
4	16/10/2014	Broadlearning S‹	S	3					5		134
5	16/10/2014	Broadlearning S‹	S	4	1						142
6	16/10/2014	Broadlearning S‹	S	5				2			162
7	16/10/2014	Broadlearning S‹	S	6							157
8											

Data Submission

During the initial pilot study (2008-2010), anonymized and aggregated data from participating schools were sent to an email account of our team, which was then manually downloaded from the email account and uploaded to the HKU Web server via Secure Shell. In this surveillance system, a simple *Save* icon was added to the user interface of the school system to facilitate automatic and efficient data submission on a daily basis with minimal workload implication to school (Figure 3). On clicking this icon by the school staff in each participating school, anonymized and aggregated daily absenteeism data would be automatically extracted from the school's system and sent directly to our central surveillance server via hypertext transfer protocol secure performed via the secure socket layer (SSL) connections with 2048-bit key. Daily data submission files were in a standard comma separated values data file format, containing the number of absentees (all-cause and ILI-specific) and total number of enrolled students in the school (Figure 4).

Data Flow Architecture and Privacy

For the back end electronic system we constructed for automatic data handling, there are three layers in the data flow architecture, namely (1) Internet, (2) internal network, and (3) restricted network (Figure 1). Internal network and restricted network are protected behind both the external firewall and internal firewall, where both are hosted by HKU. On the Internet, BroadLearning (BL) eClass server collects submitted aggregated school absenteeism records from the participating schools, which were immediately transferred to our server. The BL server and the HKU workstation are the only 2 computers with access allowed by the external firewall and the HKU Web server, with access from any other sources being denied for maximal data security. All transactions on the database server are logged in a separate table in the same database. All access activities on both the HKU Web server and the database server are logged in two sets of files in different folders with World Wide Web Consortium, or W3C, common log format.

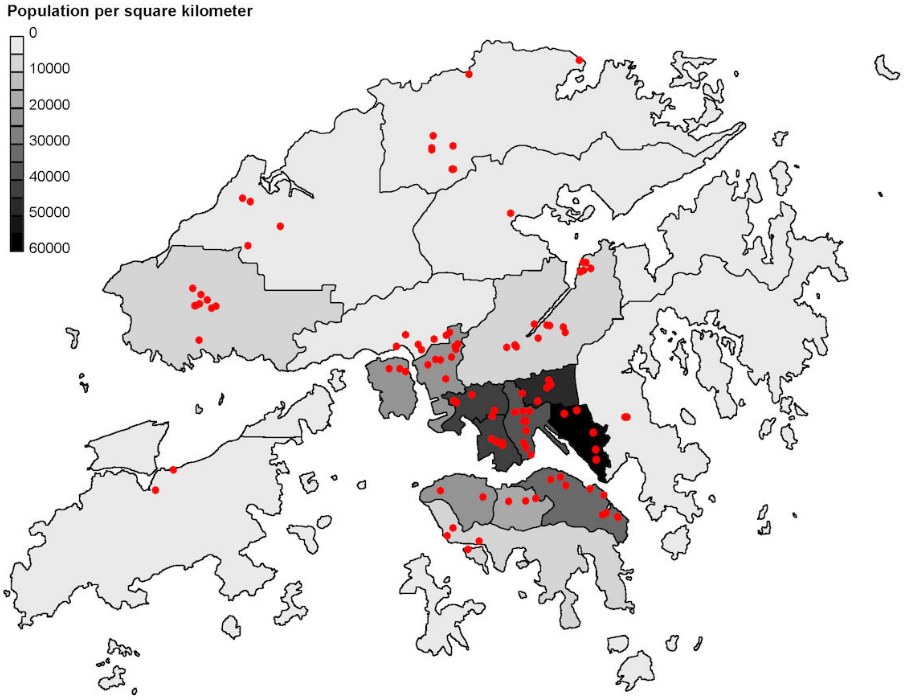
Data Cleaning and Aggregation

After receiving the updated records, we set up automatic processes on our HKU database server for prespecified data processing, cleaning, and aggregation steps to generate the data for further analysis. Automatic data validation steps include checking the school identity, school name, the date of cases, the number of cases, and the number of students on that date. Valid records are transferred in another SSL and inserted into the database on the HKU database server. Invalid records are stored in the HKU Web server folder for further manual checks by the HKU staff.

Data Analysis

"All-cause absenteeism" was defined as any episode of absence from school for any reasons. "ILI-specific absenteeism" was defined as any episode of absence from school that was labeled as due to either ILI, influenza or upper respiratory tract infection by a doctor or a parent, or when any symptom, including fever or cough or sputum, was mentioned as a cause of the absence if no such diagnostic label was available. Daily numbers of all-cause and ILI-specific absentees were correspondingly aggregated into a weekly count for the whole territory. The weekly absenteeism rate was then calculated by dividing the aggregated weekly absence counts by the total number of enrolled students in all participating schools. This was done for both all-cause and ILI-specific absenteeism. Two streams of reference data, including the proportion of ILI consultations among general outpatient attendance in the existing sentinel GP surveillance network [19], and positive influenza detection rate from hospital laboratory samples were used for comparison. Timeliness of influenza peak comparison was performed by comparing the weeks when the test data and reference data streams showed the highest activities. Cross-correlation coefficient (CCC) analyses using Pearson product-moment correlation were also done to assess the maximal correlation between different time lags of the corresponding test and reference data. All data received were anonymized for analysis.

Figure 5. Distribution of participating schools and population density (population/ km2) of the 18 districts in Hong Kong.



Feedback of Surveillance Intelligence

Two automated processes were developed for the feedback of intelligence from this surveillance system to participating schools and the wider community. A regular surveillance report was disseminated to all participating schools in an electronic format, which consisted of an updated absenteeism trend in the community and for each participating school, together with an interpretation of the overall influenza disease activity in the community and additional value-added health advice based on the current disease activity. We also included the data stream in a surveillance dashboard that we previously developed for dissemination of surveillance intelligence to the community [21].

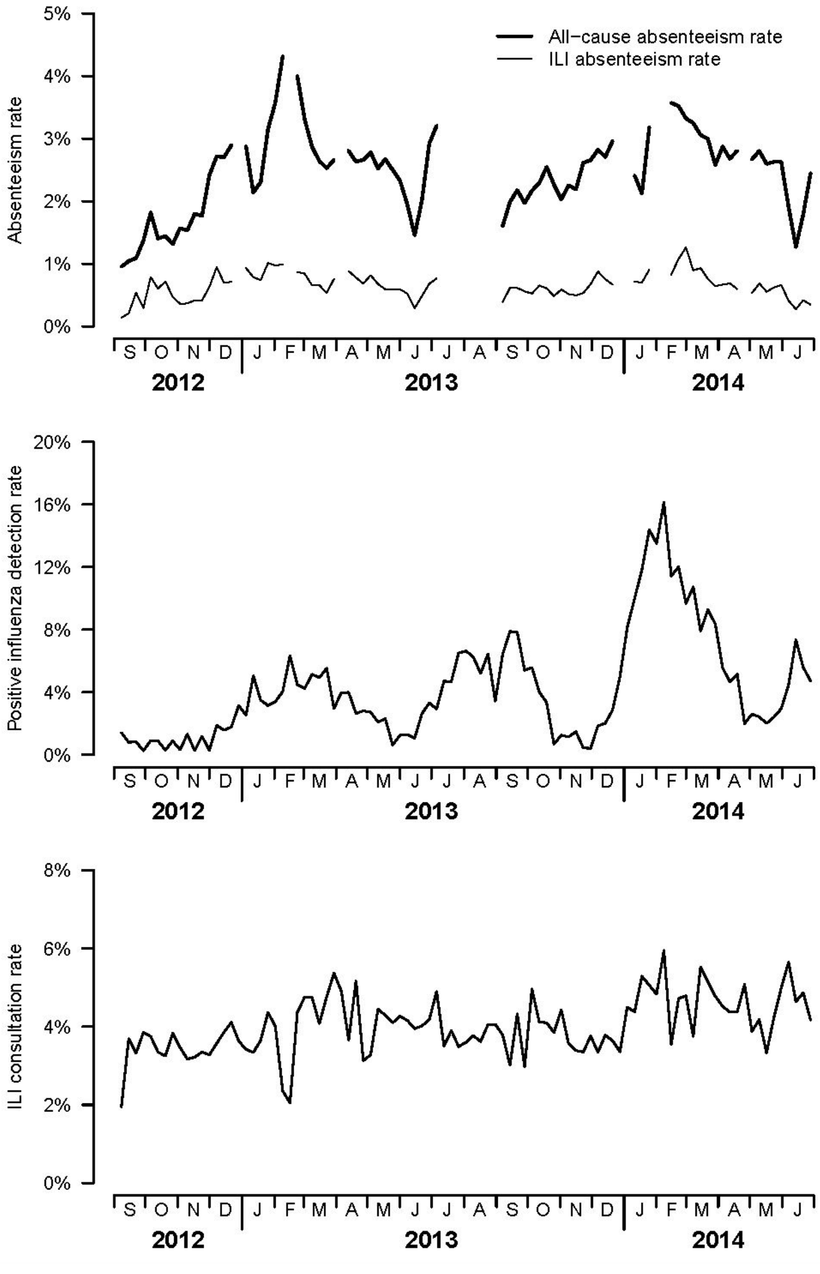
Feasibility of Routine Surveillance

We successfully recruited a total of 107 schools (including 66 primary schools and 41 secondary schools) from all 18 districts in Hong Kong to participate in the project (Figure 5), with a total of 75,052 enrolled students, covering 9.83% (107/1088) of schools, 11.6% (66/569) of primary schools and 7.9% (41/519) of secondary schools, and 10.19% (75,052/736,229) of the student population in Hong Kong. All participating schools received a system update of their *eClass* system, with a training session offered to responsible staffs for operating the updated system interface. Besides data submission using the updated system interface as detailed above, no additional workload was imposed on school staffs. A telephone hotline was also maintained by our staff to answer any queries and offer technical assistance that may be needed. With the newly developed system, daily absenteeism data from all participating schools were collected for 2 academic years from September 2012 to June 2014; each academic year starts in September and finishes in June of the subsequent year in Hong Kong, covering a total of four seasonal influenza epidemics locally (two winter and two summer epidemics). In general, the system took around 3 to 4 working days from data capturing to information dissemination. The longest time lag was the lag of 2 to 3 days between data submission and completion of data analysis, mainly to wait for data from all schools to be submitted. Reporting of all-cause absenteeism data was complete (100%) by all 107 participating schools reported. The number of schools reporting ILI-specific absenteeism data using the drop-down menu was initially only 13 (12.1%, 13/107) when they were first recruited, which increased to 38 (35.5%, 38/107) by the end of the project.

Among all 75,052 students in 107 schools, there were a mean all-cause weekly absence rate of 2.5% (ranging from 0%-6.4%) and mean ILI-related daily absence rate of 0.7% (ranging from 0%-1.6%) over the study period. Figure 6 shows the temporal patterns of all-cause and ILI-specific school absenteeism rates in relation to two other sources of surveillance data, including the proportion of ILI patients among general outpatient consultations in the existing sentinel GP surveillance network [19] and positive influenza detection rate from hospital samples. Generally, the rate of school absenteeism varied over the course of 2 years, with four periods of elevated absence over the study period that corresponded well with seasonal influenza activity as reflected by the laboratory detection data. Compared with data from the sentinel GP network, the rise, peak, and fall of influenza epidemic activities were much better delineated by the temporal trends reflected by either the all-cause or ILI-specific absenteeism rate. Two of the four epidemic peaks matched exactly temporally with the GP data. The remaining two peaks (early 2013 and early 2014), shown by the school-based surveillance, occurred 1 to 2 weeks before the peaks shown by the GP data. Result of cross-correlation analysis revealed that the maximum correlation occurred with a 3-week lag with the test data preceding the reference data, both between the ILI-specific absenteeism and laboratory data (Max CCC=.434 at lag=3) and between the ILI specific absenteeism and the GP data (Max CCC=.311 at lag=3). These observations agreed with our previous finding from the pilot study that epidemic peaks demonstrated by the school-based surveillance system can precede those shown by the sentinel GP network by 1 to 3 weeks [17].

Feedback from participating schools suggested that the surveillance system was generally well accepted, with 47/72 schools responding to our survey performed when the system had been running for 2 years. We found that 81% of schools agreed that the upgraded system was simple and easy to operate, and 64% of schools responded that data from the system were useful in enhancing their understanding of ILI activity in their schools.

Figure 6. All-cause (thick line) and influenza-like illness (ILI)-specific absenteeism rate (thin line) of students from participating local schools (top), positive influenza isolation rate from Queen Mary Hospital, Hong Kong (middle), and ILI consultation rate of the sentinel general practitioner (GP) network (bottom), 2012-2014.



Discussion

Principal Findings

We have reported the implementation of a comprehensive ILI surveillance system in schools to fill an existing surveillance gap in Hong Kong. Our study demonstrated the feasibility of using smart card–based technology for tracking attendance data, with the automation of subsequent steps by additional back end systems, for infectious disease surveillance in primary and secondary schools settings. As far as we are aware, this is the first prospective ILI surveillance system among schools in Hong Kong and the first disease surveillance system utilizing smart card technology in the world. Our system is designed to support the various functions of an information infrastructure needed to support pandemic response as detailed in the PROSPER protocol. The continuous baseline surveillance data collected in a stable and standardized manner in interpandemic times can help to inform the CNA and RDM functions. The customizability of the system helps to calibrate detection algorithms in the CNA function with regard to the new pathogen and epidemic. Data from the system also allows OIA for school closure and other relevant public health interventions targeted to reduce disease transmission in the school setting [18].

Although absenteeism surveillance in schools is a component of influenza surveillance and pandemic preparedness plan of many countries, this is generally neither the primary responsibility nor of a high priority for frontline teachers facing many competing educational and administrative duties in the school setting. For any surveillance system to be sustainable, additional workload for system operation needs to be minimized to enhance its acceptability and stability. Different Web-based approaches to facilitate data reporting were tried in previous disease surveillance studies, including a short-term system built for special events [22] and an adjunct system during the 2009 evolving pandemic [11]. Workload minimization, however, was not always achievable in practice, especially when an unfamiliar approach was being introduced in a new system. A recent school absenteeism surveillance system employing mobile devices and Web-based platforms for data reporting had poor acceptability and sustainability as a result of the extra workload required outside the normal daily routine of teachers [15]. Later attempts to use fingerprint scanning for automatic attendance data capture were also not successful as a result of the technical difficulty for a significant number of students to be accurately scanned by the system [15].

Comparing with other electronic approaches, smart card–based technology represents a simple and more reliable approach for automatic data capture. Its capabilities for automatic data capture and immediate compilation for downstream uses offer an advantage of improved data timeliness, making it an ideal approach to inform real-time disease surveillance with minimal additional workload implication for its ongoing collection. By riding on an existing electronic school administration system routinely in use at schools and already familiar to the frontline user, our system avoided potential problems with acceptability and helped to minimize additional workload required for data collection and system operation.

Our design approach may serve as an example to demonstrate how starting from an existing platform with some very simple system customization may help to facilitate the implementation and improve the functioning of a surveillance system. The addition of a drop-down menu is aimed to reduce the workload for the reporting of disease-specific information. This may have contributed to improve acceptability of the procedure as demonstrated by the increasing number of schools willing to collect and report such data over the course of the study. The standardized reporting of disease-specific absenteeism data is aimed to improve specificity of the system and offered a theoretical potential for the system to adapt for surveillance of other infectious diseases of outbreak potential in the school setting. Although we currently analyzed our data in weekly aggregation as all other existing local ILI surveillance systems to facilitate comparison, data from our system may allow for daily analysis when a more frequent surveillance is deemed necessary during an emerging epidemic.

Limitations

Our system has a number of limitations. First, validity of school absenteeism data in reflecting influenza activity is contingent on the compliance of students refraining from going to schools when being sick. However, we cannot ascertain the degree of nonadherence of schools and students to this policy, which may undermine the performance of this system. This may also affect the generalizability of the results to places where illness absenteeism practice are different because of local cultural or socioeconomic factors. Second, the ascertainment of the cause of absence still has to be done though a manual process. As a result of the additional workload implication, cause-specific absence data were only captured by a portion of schools in our system. This could be mitigated in future by enhancing the system to collect information from parents, for example, by sending an email or SMS text messaging (short service message, SMS) to parents to notify them of their child's absence and requesting them to provide a reason, with options such as ILI given. Third, data collection is only feasible on normal school days, and data gaps are present during school breaks and holidays (Figure 6), which limited the possibility for continuous surveillance during those periods.

Conclusions

In conclusion, we have demonstrated the feasibility of building and implementing a large-scale surveillance system by employing a routinely adopted smart card–based approach for automatic data capture in schools, supplemented by simple automation of later steps required for prospective surveillance. The absenteeism data we collected from the system reflected ILI activity in the community and we were able to detect an upsurge in its disease activity in a more timely manner than other existing surveillance data. As we previously demonstrated that the alerting of the onset of an epidemic can be greatly enhanced in terms of sensitivity and timeliness by the monitoring of multistream surveillance data [23], our absenteeism data is potentially useful for supplementing existing systems in Hong Kong for monitoring the trend of influenza disease activity in the community. With the increasing popularity of smart card–based electronic health record systems in different health care utilization settings [24,25], it offers an unprecedented potential for novel surveillance and risk monitoring systems to be developed based on this technology [26]. Our experience would be referential for other countries and cities facing a similar problem and in need of improving their existing surveillance systems, particularly in showing how this can be achieved by suitably and creatively adapting to an existing system.

Acknowledgments

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Conflicts of Interest

DKMI has received research funding from Hoffmann-La Roche Inc. BJC has received research funding from Sanofi Pasteur.

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Abbreviations

BL: BroadLearning
CCC: cross-correlation coefficient
CNA: capacity and needs analysis
CHP: Centre for Health Protection
GP: general practitioner
HKU: The University of Hong Kong
ILI: influenza-like illness
OIA: outcome and impact assessment
PROSPER: Protocol for a Standardized information infrastructure for Pandemic and Emerging infectious disease Response
RDM: response design modeling
SSL: secure socket layer

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Original Paper

Identifying Sentiment of Hookah-Related Posts on Twitter

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Abstract

Background: The increasing popularity of hookah (or waterpipe) use in the United States and elsewhere has consequences for public health because it has similar health risks to that of combustible cigarettes. While hookah use rapidly increases in popularity, social media data (Twitter, Instagram) can be used to capture and describe the social and environmental contexts in which individuals use, perceive, discuss, and are marketed this tobacco product. These data may allow people to organically report on their sentiment toward tobacco products like hookah unprimed by a researcher, without instrument bias, and at low costs.

Objective: This study describes the sentiment of hookah-related posts on Twitter and describes the importance of debiasing Twitter data when attempting to understand attitudes.

Methods: Hookah-related posts on Twitter (N=986,320) were collected from March 24, 2015, to December 2, 2016. Machine learning models were used to describe sentiment on 20 different emotions and to debias the data so that Twitter posts reflected sentiment of legitimate human users and not of social bots or marketing-oriented accounts that would possibly provide overly positive or overly negative sentiment of hookah.

Results: From the analytical sample, 352,116 tweets (59.50%) were classified as positive while 177,537 (30.00%) were classified as negative, and 62,139 (10.50%) neutral. Among all positive tweets, 218,312 (62.00%) were classified as highly positive emotions (eg, active, alert, excited, elated, happy, and pleasant), while 133,804 (38.00%) positive tweets were classified as passive positive emotions (eg, contented, serene, calm, relaxed, and subdued). Among all negative tweets, 95,870 (54.00%) were classified as subdued negative emotions (eg, sad, unhappy, depressed, and bored) while the remaining 81,667 (46.00%) negative tweets were classified as highly negative emotions (eg, tense, nervous, stressed, upset, and unpleasant). Sentiment changed drastically when comparing a corpus of tweets with social bots to one without. For example, the probability of any one tweet reflecting joy was 61.30% from the debiased (or bot free) corpus of tweets. In contrast, the probability of any one tweet reflecting joy was 16.40% from the biased corpus.

Conclusions: Social media data provide researchers the ability to understand public sentiment and attitudes by listening to what people are saying in their own words. Tobacco control programmers in charge of risk communication may consider targeting individuals posting positive messages about hookah on Twitter or designing messages that amplify the negative sentiments. Posts on Twitter communicating positive sentiment toward hookah could add to the normalization of hookah use and is an area of future research. Findings from this study demonstrated the importance of debiasing data when attempting to understand attitudes from Twitter data.

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KEYWORDS

hookah; waterpipe; Twitter; social media; bots; big data; sentiment

Introduction

The popularity of hookah (or waterpipe) use is increasing among youth and young adults in the United States and elsewhere [1]. This increase will have consequences for public health because hookah use has similar health risks to that of combustible cigarette use [2,3]. Hookah is often perceived as safer than cigarettes [4] and is subject to less regulation [5]. For example, hookah is offered in a variety of flavors and often receives exemptions on smoking bans in bars and nightclubs. As hookah use increases in popularity, social media data (Twitter, Instagram) can be used to capture and describe the social and environmental context in which individuals use, perceive, discuss, and are marketed this tobacco product [6]. These data may allow people to organically report on their sentiment toward tobacco products like hookah unprimed by a researcher, without instrument bias, and at low cost [7].

In a recent study analyzing hookah-related posts on Instagram, researchers reported that hookah was often cross-promoted with alcohol by nightclubs, bars, restaurants, and hookah lounges [8]. Instagram posts often showed hookah use in social settings as well as stylized and elaborate waterpipes [8]. Twitter posts have previously been used to study hookah. Krauss et al coded a sample of 5000 hookah-related tweets and reported that 87% of the tweets in their sample normalized or made hookah smoking appear common or portrayed positive experiences with smoking hookah [9]. The authors also noted that only 7% of tweets were against hookah or discouraged its use [9]. Grant and O’Mahoney coded a sample of 4439 tweets and reported that 59% of tweets were positive about hookah use, with 3% negative, 21% lacking sentiment, and 17% unclassifiable [10]. Myslín et al analyzed a sample of 7362 tobacco-related tweets, some referencing hookah, and found that sentiment toward tobacco was overall more positive (46% of tweets) than negative (32%) [11].

In this study, we demonstrate the feasibility of a Twitter-based “infoveillance” [6] methodology to document sentiment of hookah-related posts. This study also relied on machine learning to debias the data so that Twitter posts were reflective of sentiment of legitimate human users and not of social bots or marketing-oriented accounts that would possibly provide overly positive or overly negative sentiment [12-14]. As Allem and Ferrara described, “Studies using tweets and that aimed at gaining insights to individual-level attitudes and behaviors are now faced with data with substantial bias and noise. Any results drawn upon this data and not preprocessed with de-noising techniques lose validity and significance” [14]. To demonstrate the importance of debiasing Twitter data, comparisons were made between corpuses of tweets that included and excluded social bots. Findings from this study can inform tobacco control, demonstrate the utility in using social media data in understanding attitudes, and demonstrate the importance of debiasing Twitter data when attempting to understand attitudes.

Methods

Data were obtained from Twitter’s Streaming Application Program Interface (API) based on Twitter4J libraries, an open source database of java language used to analyze data from the API. Software was written to automate this process. Tweets posted between March 24, 2015, and December 2, 2016, were collected. The root terms used to collect the sample of tweets were hookah(s) or hooka(s) or sheesha(s) or shisha(s) or sesh(s). The root terms could have appeared in the post or in an accompanying hashtag, for example, hookah or #hookah. While the word waterpipe is commonly used in academic papers and presentations to refer to hookah, it is uncommon for individuals to use this term on social media and it was thus not included in this study [15].

The root terms used to collect tweets during the study period resulted in an initial corpus of tweets (N=986,320). However, Twitter has quickly become subject to third party manipulation where social bots, or computer algorithms designed to automatically produce content and engage with legitimate human accounts on Twitter, are created to influence discussions and promote specific ideas or products [12-14]. Social bots are meant to appear to be everyday individuals operating Twitter accounts that are complete with metadata (name, location, pithy quote) and a photo/image. Social bots make indiscriminate references to an array of content while at the same time perpetuating select conversations giving the appearance that a specific topic is more prominent than it actually is offline. In order to debias the data, select features—(1) the timing of tweets (periodic and regular), (2) spam or not (if the post contains known spam), and (3) ratio of tweets from mobile versus desktop (as compared to the average human Twitter user)—were used to differentiate between legitimate human accounts and social bots following the methods described by Chu et al [16].

Additionally, certain criteria such as information diffusion patterns (based on Twitter’s message forwarding function known as “retweets” or mentions), friend features (ratio of followers to followees), content (frequency of nouns/verbs/adverbs in a tweet in comparison to a legitimate human account), and sentiment features (derived from emotion scores) following Ferrara et al’s methods were combined to arrive at a single score that indicated if a Twitter account was a social bot or not [13]. Exactly 296,338 (30.04%) of the initial posts were determined to be from social bots and were removed from the corpus. Since marketing-specific tweets would not reflect public sentiment, they were manually removed based on occurrence of certain keywords. For example, “1100mah” (strength of hookah) was one such term commonly found in marketing posts. The number of marketing-specific tweets removed was 98,190, resulting in the final analytical sample of 591,792 tweets (Figure 1).

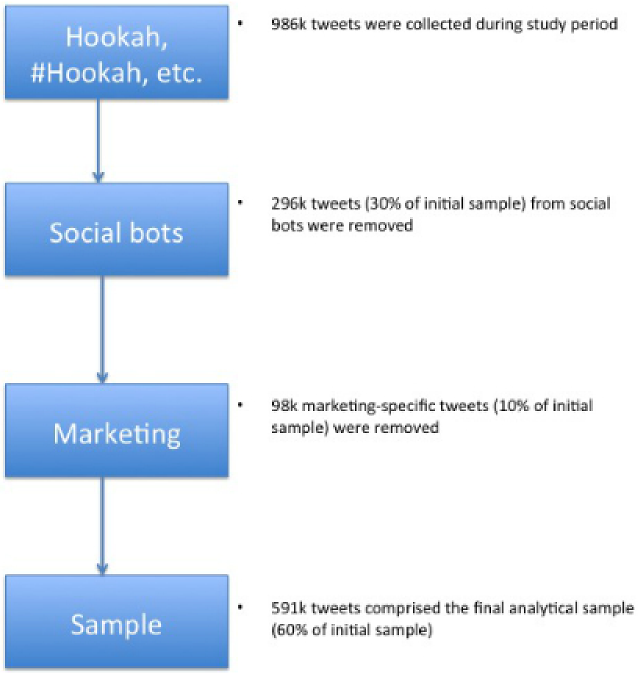
After debiasing the data, machine learning methods for natural language processing (NLP) were used to identify sentiment of tweets. NLP primarily involves either rule-based reasoning or automated inference logic, and in this study we used both approaches. Rule-based reasoning involves explicit rules to identify a sentence as “positive” or “negative.” Specific words or phrases were labeled and put on a spectrum ranging from -4 to 4, following the method of Hutto and Gilbert [17]. For example, a negative word such as “horrible” has a value of -2.5 and a positive word such as “wonderful” has a value of 2.7. Words and phrases were added to a list, and based on their occurrence in a tweet, an overall sentiment score was calculated for each tweet.

In addition to these explicit values, certain grammatical structures in English were exploited to add to or subtract from the overall sentiment scores. Capital letters, punctuation like an exclamation point, or degree modifiers such as "extremely" or "very" followed by a positive or negative word were considered twice. For example, "very happy smoking hookah" considered the word "happy" occurring twice because of the degree modifier "very" preceding it. Additionally, grammatical features such as the use of the word "but" show a shift in polarity of the words following it. By considering the shift in polarity in a statement, we could capture n-gram features (an n-gram is a phrase with n words). For example, we could identify the sentiment from the sentence "the hookah here isn't really all that great" as negative.

To determine the performance of the rule-based reasoning model, the sentiment output of the tweets was analyzed. The rule-based reasoning sentiment analysis provided an *F* score of 0.96. The *F* score is a measure of a test's accuracy that reflects the balance achieved between identifying cases correctly and recalling a high number of correct cases. In NLP, it considers both "Precision" or "P", which answers the question, "What portion of what you found was ground truth (eg, what percent of true cases were categorized accurately)?" and "Recall" or "R", which answers the question, "What portion of the ground truth did you recover (eg, what percentage of true cases did you recall?" The *F* score is the harmonic mean of P and R=[(2*P*R)/(P+R)].

The rule-based reasoning model was considered as a reference point, or baseline model, to inform a model based on a support vector machine (SVM) algorithm. Combining a manual rule based method with an automated one like SVM provided us with a more generalized solution for sentiment analysis. In the implementation of this algorithm, the model was trained on the SemEval [18] and the ISEAR [19] emotion datasets, and on an emotion-tagged tweet corpus that has been established in past studies to identify sentiments [20] with cross-validation. This comparison served to validate our results. Based on the frequency of occurrence of n-gram phrases from the SemEval [18] and ISEAR [19] datasets, the tweet corpus (test data) was tagged with the appropriate sentiments and scored. The aggregate emotion score of all tweets was calculated as a linear combination of the given emotion scores for individual tweets.

Figure 1. Flowchart of how the analytic sample was derived.



In order to utilize an SVM model, the data have to be prepared as follows. (1) First the tweets are cleaned to permit uniform analysis using a process called tokenization that involves removing uniform resource locators (URLs) and unrecognizable UTF-8 encoding forms from the text of tweets along with stop words such as "the" and "an," which frequently occur in spoken and written language but do not convey sentiment. Hypertext markup language (HTML) tags were replaced by whitespace, and then a pattern-matching algorithm was used to recognize any trailing URL patterns that remained in the text. (2) This preprocessing step also included allowing the model to recognize emoticons (eg, ☺), slang, and aggravated language usage (eg, "this is grrrrrreat!"). Emoticons were unified so that all types of smiley faces were considered one, while all types of sad faces were considered one. Slang was corrected and punctuation was fixed, for example, "don't" and "dont" were treated as one. Gerunds or stemming in NLP were handled by the program Porter's Stemmer [21], and elongations were removed to correct for aggravated language usage. (3) Part of Speech (POS) tagging was done using CoreNLP's POS tagger [22], in order to identify verbs, nouns, adjectives, and prepositions. Russell's range of 20 different emotions was used to tag tweets from unpleasant to pleasant on a negative to positive scale [23]. The SVM algorithm was used to generate feature vectors and arrive at a sentiment score for each tweet (*F*=0.90).

In order to quantify and compare the impact of bias from social bots, we reduced the 20 levels of emotions down to 5 primary emotions (anger, fear, joy, sadness, disgust) as described by Bradley et al [24]. We then report the specific probabilities that a tweet will have a specific sentiment from each corpus of tweets directly comparing the corpus of tweets from legitimate human accounts to that of tweets from the corpus with human accounts and social bots.

Results

A majority of tweets 352,116 (59.50%) were classified as positive while 177,537 (30.00%) were classified as negative (Figure 2), and 62,139 (10.50%) neutral. Among all positive tweets, 218,312 (62.00%) were classified as highly positive emotions (top right quadrant of Figure 2), for example, active, alert, excited, elated, happy, and pleasant. The remaining 133,804 (38.00%) positive tweets were classified as passive positive emotions (bottom right quadrant of Figure 2), for example, contented, serene, calm, relaxed, and subdued. Among all negative tweets, 95,870 (54.00%) negative tweets were classified as subdued negative emotions (bottom left quadrant of Figure 2), for example, sad, unhappy, depressed, and bored. The remaining 81,667 (46.00%) were classified as highly negative emotions (top left quadrant of Figure 2), for example, tense, nervous, stressed, upset, and unpleasant. The results change drastically once tweets from social bots are in the corpus. Among the 888,130 tweets (tweets from individual accounts and social bots but excluding marketing), 324,331 (36.52%) were classified as negative, while 300,660 (33.85%) were classified as positive and 263,139 (29.63%) neutral. When reducing the 20 levels of emotion down to 5 primary emotions, the probability of any one tweet reflecting joy was 61.30% from the debiased (or bot free) corpus of tweets (Figure 3). In contrast, the probability of any one tweet reflecting joy was 16.40% from the biased corpus (Figure 4).

Figure 2. Tagged tweets showing range of emotions from unpleasant to pleasant.

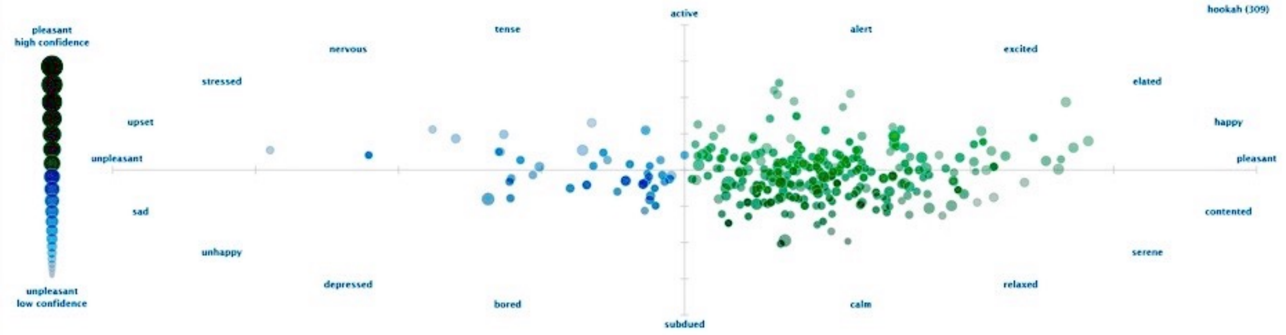


Figure 3. Probability of one tweet’s specific sentiment from the debiased (or social bot free) corpus of tweets.

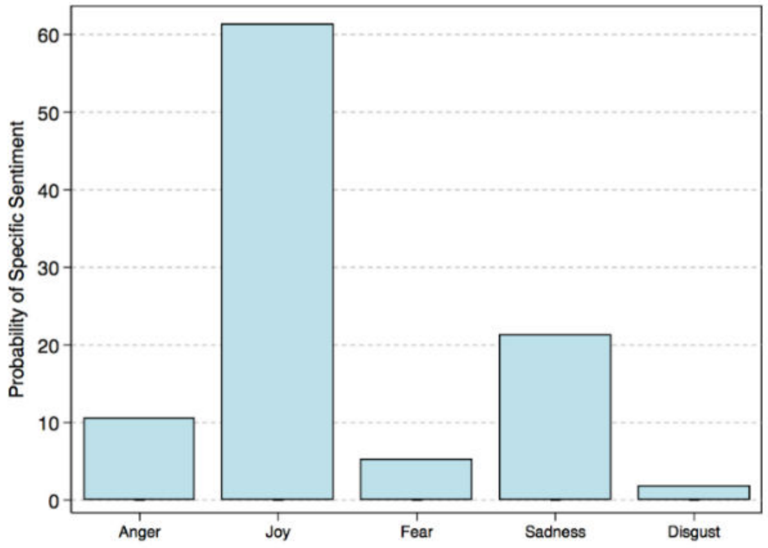
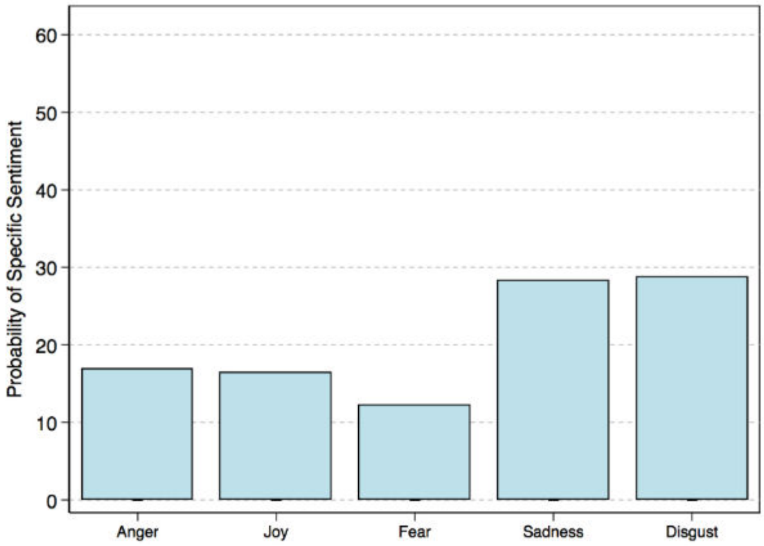


Figure 4. Probability of one tweet's specific sentiment from the biased corpus.



Discussion

Principal Findings

Social media data provide researchers the ability to understand public sentiment and attitudes by listening to what people are saying in their own words. By using Twitter data, we had the ability to document and describe individuals' sentiment toward a tobacco product without being primed by a researcher, allowing for spontaneous comments to emerge. We found that the majority of hookah-related posts on Twitter conveyed positive sentiment. Positive posts on Twitter may serve as a screener indicating that an individual is in need of tobacco-related education to reduce misconceptions about a product or to reduce positive social norms about that product. Tobacco control programmers in charge of risk communication may consider targeting individuals posting positive messages about hookah on Twitter or designing messages that amplify the negative sentiments. Twitter may be used to bolster the reach and delivery of health information that communicates the risk of tobacco use [25-27], and social media interventions hold promise for getting people to consider stopping smoking [28].

In comparison to earlier studies that relied on sample sizes small enough to reasonably code by hand [9,10] during brief study periods [9-11], we collected hundreds of thousands of Twitter posts continuously over 20 months that pertained to hookah. We also trained machine learning algorithms to automatically determine sentiment of these posts following Russell's [23] range of emotions to predict a sentiment score on 20 different emotions on a two-dimensional scale demonstrating greater depth in sentiment classifications. This range of emotion reflects a greater systematic assessment of sentiment than prior work that relied on dichotomous classification based on subjective individual judgment [9-11]. While Twitter posts referenced hookah use in a happy, excited, and alert fashion, posts also referenced hookah use in more passive ways. These nuances may reflect the social and environmental contexts in which hookah use often takes place. Posts on Twitter conveying positive sentiment toward hookah could add to the normalization of hookah use and is an area of future research.

While in this study, 30% of hookah-related posts contained negative sentiment, earlier studies found that negative posts were relatively rare. For example, Grant et al reported 3% of Twitter posts in their data conveyed negative sentiment [10]. This discrepancy could be a result of the sample size (n=4439) or short study period (1 week) in prior work [10]. Alternatively, findings from previous work may have been biased due to social bots in the Twitter data [14].

In this study, 296,338 Twitter posts were removed because they were found to be from social bots and would not accurately reflect individual sentiment toward hookah use. This number reflects 30% of the initial data that comprised the corpus of tweets. Removing social bots from the analytical corpus had marked effects on the results. The bot free corpus reflected that the overall sentiment was positive (eg, 59.5% of tweets were positive). The corpus that included bots and human accounts together reflected that only 33.9% of tweets were positive. While sentiment in tweets is only one of many possible ways bias from social bots can distort Twitter data, the findings from this study highlight the importance of debiasing data collected from Twitter in order to uncover the rich and nuanced information available to health researchers relying on social media data and aimed at understanding public attitudes [14].

Limitations

Data relied on Twitter's Streaming API, which prevented us from collecting tweets from private Twitter accounts. As a result, findings may not represent the sentiment toward hookah from individuals with private accounts. The result that more tweets were found to convey a positive sentiment than a negative one should be considered circumstantial and not absolute. While we identified the overall sentiment of posts, we did not track individual users to see whether their posts about hookah change over time. Additionally, a post classified as negative does not necessarily mean the person dislikes hookah. Rather, it means the post had more words conveying negative sentiment than positive. The method used in this study for bot detection is not a perfect system but scores a detection accuracy above 95% suggesting biases from inappropriate removal of legitimate accounts is minimal [13].

Conclusion

Despite these limitations, this study demonstrated the utility in using social media data to understand public attitudes that may influence acceptance of tobacco products such as hookah and defined types of positive and negative attitudes that could be incorporated into public health media campaigns to reduce acceptance of hookah. It also illustrated the importance of debiasing Twitter data so that posts reflect sentiment of legitimate human users and not of social bots or marketing-oriented accounts that could possibly provide overly positive or overly negative sentiment of hookah. Findings should spur efforts to better understand the consequences of hookah-related discussions on Twitter as an informative tool in planning tobacco control efforts.

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Authors' Contributions

JPA and JR conceived of the study and analyzed the data. JPA drafted the initial manuscript. JPA, JR, KL, KHC, TBC, and JBU revised the manuscript for important intellectual content and approved the final manuscript.

Conflicts of Interest

None declared.

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Abbreviations

API: application program interface
HTML: hypertext markup language
NLP: natural language processing
POS: part of speech
SVM: support vector machine
URL: uniform resource locator

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Original Paper

Syndromic Surveillance Models Using Web Data: The Case of Influenza in Greece and Italy Using Google Trends

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Abstract

Background: An extended discussion and research has been performed in recent years using data collected through search queries submitted via the Internet. It has been shown that the overall activity on the Internet is related to the number of cases of an infectious disease outbreak.

Objective: The aim of the study was to define a similar correlation between data from Google Trends and data collected by the official authorities of Greece and Europe by examining the development and the spread of seasonal influenza in Greece and Italy.

Methods: We used multiple regressions of the terms submitted in the Google search engine related to influenza for the period from 2011 to 2012 in Greece and Italy (sample data for 104 weeks for each country). We then used the autoregressive integrated moving average statistical model to determine the correlation between the Google search data and the real influenza cases confirmed by the aforementioned authorities. Two methods were used: (1) a flu score was created for the case of Greece and (2) comparison of data from a neighboring country of Greece, which is Italy.

Results: The results showed that there is a significant correlation that can help the prediction of the spread and the peak of the seasonal influenza using data from Google searches. The correlation for Greece for 2011 and 2012 was .909 and .831, respectively, and correlation for Italy for 2011 and 2012 was .979 and .933, respectively. The prediction of the peak was quite precise, providing a forecast before it arrives to population.

Conclusions: We can create an Internet surveillance system based on Google searches to track influenza in Greece and Italy.

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KEYWORDS

Google Trends; influenza; Web, syndromic surveillance; statistical correlation; forecast; ARIMA

Introduction

Syndromic Surveillance on Influenza

Syndromic surveillance systems refer to monitoring of infectious diseases through data collection from various sources. This is accomplished by setting indicators and methods and publishing reports for early detection of an infectious disease. The desired result is to minimize the extensive spread in the population and take precautionary measures.

These systems operate both at national and international levels and provide useful data and guidelines to deal with various outbreaks of different pathogens and infections. Influenza is considered as an important example for syndromic surveillance and response.

At the international level, the World Health Organization (WHO) has launched the Global Influenza Program [1]. It provides support to member states for a more efficient coordination of national health systems and for the proper preparation against seasonal influenza outbreaks.

Special monitoring and laboratories projects are used, such as the Global Influenza Surveillance and Response System [2]. This surveillance system works under the Pandemic Influenza Preparedness Framework. It became effective after the May 24, 2011 adoption by the 64th World Health Assembly [3].

In Europe, the competent public health authorities use the European Influenza Surveillance Network (EISN) [4] that combines epidemiological and virological surveillance of influenza. The purpose of this network is to assist in public health decision making. It provides experts in European Union (EU) or European Economic Area member states with the information required for better assessment of influenza activity in Europe, resulting in the appropriate action. Finally, EISN's goal is to contribute in reducing the costs associated with influenza in Europe. Epidemiological and virological influenza surveillance data are collected through the European Surveillance System [5].

As described in the Fact Sheet no. 211 (revised March 2003) of WHO [6], influenza is caused by a virus that mainly attacks specific parts of the human body, for example, nose, throat, bronchi, and rarely the lungs. The main symptoms are high fever, myalgia, headache and severe malaise, nonproductive cough, sore throat, and rhinitis. Severe health complications of influenza virus infection in susceptible individuals include pneumonia and eventually death. The influenza virus is easily transferred from person to person through air. It enters the body through the upper respiratory tract (nose or throat) when a person coughs or sneezes. A few days may pass before a patient's symptoms are clearly recognized. The development of symptoms may not be clear on the first day; however, it can be recognized after 7 days. Upper respiratory tract infections affect 5% to 15% of the population. The estimated annual impact of severe illness cases on the population is 3 to 5 million; 250,000-500,000 of which die. The spread of the disease among the population is very quick, especially in crowded cases. The survival period of the virus outside the body can be further enhanced in cold and dry weather. Consequently, the seasonal epidemics in temperate areas occur in winter. Influenza mostly appears in the weakest portion of population; people older than 65 years or those with serious health problems such as lung diseases, diabetes, cancer, and kidney or heart problems.

The corresponding health costs are high. Only in the United States, large sums of money are directed to influenza treatment and hospitalization. The annual cost for the United States [7] is US $71 to 167 billion. In Russia [8], the government allocated 4 billion rubles (US $140 million) to buy the initial 43 million doses of vaccines to perform mass swine flu vaccinations in the year 2009. Russia planned to have 35.5 million doses before the end of this year.

Related Research

Web data is now frequently being used in research conducted by scientists, and they show that the Internet may be an alternative source for collection of data that indicate the development of a syndromic disease using search engine queries. Eysenbach [9] and later also Ginsberg et al [10] examined the potential of Google search queries to *track influenza-like illness in a population*. The latter work uses data from the US Centers for Disease Control and Prevention (CDC) for influenza and linear regression methods to reveal statistical correlations and using the most significant keywords most searched into Web queries, constructs a kind of *flu score* and examines its statistical correlation to the data from the national disease center. The results of both studies showed that Web queries indicate the public interest and follow the actual spread of influenza in Canada or the United States, respectively.

Syndromic surveillance relies on the real-time use of information about the population to identify health issues of concern, and it is the current tool used by public health authorities to address them before they become epidemics. Consequently, a syndromic surveillance system implements a variety of outbreak detection algorithms, requiring a good understanding of the strengths and limitations of various detection techniques and their applicability. For example, Ping et al used data which were available via the Web and from physicians' databases [11].

Our group has conducted similar research for another infectious disease (scarlet fever) in the United Kingdom. We used Web data [12] from Google Insights for Search [13], which is now merged with Google Trends [14]. We correlated data using linear regression techniques and exploiting the benefits and properties of the gamma distribution.

Hopkins University researchers in Baltimore, United States, find *Google Flu Trends* a powerful early warning system for emergency departments (EDs) [15]. This study [16] was a retrospective observational study of patients with symptoms of influenza. These patients presented to urban academic EDs in Baltimore, Maryland. The annual visits were 60,000 for adults and 24,000 for pediatric cases. The period of the visits was 21 months, from January 25, 2009 to October 3, 2010.

According to the CDC's definition of fever and cough or sore throat, the researchers used the CDC's traditional surveillance methods reporting system from January 25, 2009 to October 18, 2009 and an ED electronic reporting system (from October 18, 2009 to October 3, 2010).

Google Flu Trends weekly data were collected for Baltimore, Maryland. They also collected data from ED, CDC-reported standardized influenza-like illness (ILI) data, and influenza data confirmed by laboratories.

The data were analyzed separately for adult and pediatric cases and correlated to the Google data using cross-correlation functions. The conclusions of this study were that city-level Google Flu Trends shows strong correlation with influenza cases and EDs' ILI visits, validating its use as an ED surveillance tool. Google Flu Trends correlated with several pediatric ED crowding measures and those for low-acuity adult patients.

Two other research studies were conducted using the autoregressive integrated moving average (ARIMA) model, by Dugas et al (*Influenza forecasting with Google Flu Trends*) [17] and by Preis and Moat (*Adaptive now casting of influenza outbreaks using Google searches*) [18]. This model combines autoregression and moving average model into one, as will be described further in the Methods section of this paper.

Recent research [19,20] has also shown the potential use of the Google Search engine to track influenza. The research on the use of Google reveals the strong statistical correlation between Google searches and influenza, even though there are variations over geographic location and time limits of this kind of estimation.

In 2017, several studies [21] investigated the use of the Internet to reveal the connections between the social activity on the Internet and the development of various diseases and mental disorders or problems such as norovirus epidemics, breast cancer, depression, cannabis dispensaries, Zika virus, Ebola virus, other drugs, Lyme borreliosis, whiplash syndrome, etc, using Google, Twitter, or other Internet sources.

In this study, we examine the development and the spread of seasonal influenza in Greece and Italy. Our goal is to define the correlation (and finally accomplish prediction patterns) between data from Google Trends and data collected by the Hellenic Center for Disease Control and Prevention (KEELPNO) [22] for Greece and data from the European Center for Disease and Control (ECDC) for Italy. The case as it pertains to Greece is quite different from those on previous studies. This is because, using the data from Google Trends for the term *influenza*, the correlation coefficient (Pearson *r*) is very low at .554 . This means that we cannot create estimation and prediction patterns using this keyword. For the Greek word of influenza (Γρίπη in Greek language), there are some data for years 2011 and 2012, but they are not very reliable. The following Methods and Results sections address the aforementioned problem.

Methods

Data Used

For the purposes of this study, we used datasets as follows:

- Weekly data for ILI from the sentinel system of KEELPNO for the years 2011 to 2012 (105 weeks), for which we could find data. In Greece, through the sentinel system, the influenza activity is monitored on a weekly basis. This system consists of three basic networks: (1) from selected health units of the largest social security organization (IKA) [23], which covers over 5,530,000 people and provides over 830,000 pensions; (2) from a network of selected private physicians; and (3) from a network of selected health centers and regional doctors’ offices. From these three networks, data are collected on a weekly basis regarding the number of patients’ visits for any cause, as well as the number of patients’ visits because of ILI based on the current EU case definition [24]. Data analysis includes weighting based on the resident population of classification of territorial units for statistics (NUTS I) geographical regions and rural and urban areas and produces the number of ILI cases per 1000 visits for every week of the year, for the total of the country. The collection and analysis of the data follow the ISO 8601 standard [25] (Greece ELOT EN 28601 standard [26]).
- We also used data from Italy for the same period and compared the results between the two countries. To get the ILI rates for Italy, we used the weekly reports from ECDC [27]. The ECDC calculates ILI rates per 100,000 people based on sentinel systems of the European member states.
- We used weekly data from the Google Trends for Greece and Italy, using C# programming code (see Multimedia Appendix 1).

Google Trends analyzes [28] a portion of Google Web searches to compute how many searches have been done for the terms entered in the search engine, relative to the total number of searches done on Google over time. This analysis indicates the likelihood of a random user to search for a search term from a certain location at a certain time. This system designates a certain threshold of traffic for search terms, so that these with low volume do not appear. Google Trends also eliminates repeated queries from a single user over a short period of time, so that the level of interest is not artificially impacted by these types of queries.

To calculate the popularity of a searched term among users in a certain geographical location (eg, country) and in a certain period, Trends examines a percentage of all searches for the specified term within the same time and location parameters. The results are then shown on a graph plotted on a scale from 0 to 100. The same information is also displayed graphically by the geographic heat map.

In our case, we must deal with the problem that for the term *influenza*, there is not appropriate search volume for Greece, as mentioned in the Introduction. For the Greek equivalent keyword (Γρίπη), a search volume exists but with low correlation or correlation below .90, as this is shown in Table 1.

The solution to this problem is to perform searches for separate keywords related to the term *influenza*. So, we downloaded data from Google Trends for the following keywords: γριπη, πυρετος, βηχας, πονοκεφαλος, πονολαιμος, φαρυγγιτιδα, and αντιβιωση. These keywords correspond to the following English terms: *influenza*, *fever*, cough, *headache*, *sore throat*, *pharyngitis*, and *antibiotics*, respectively. All these keywords refer to the symptoms and treatment of influenza.

Our next task was to determine whether we can use one of these or all together, creating a *flu score*. Using Statistical Package for the Social Sciences (SPSS) version 20 (IBM Corp), we wrote a command syntax code (see Multimedia Appendix 1) to perform multiple regressions by taking each Google dataset as the independent variable and data from the sentinel system of the KEELPNO as the dependent variable.

The results of the multiple regressions are shown in Table 1. In the table, x1, x2, x3, x4, x5, x6, and x7 represent the seven keywords or datasets of the independent variable (Google searches), whereas Y is the dependent variable (predicted variable, influenza ILI rates).

Table 1. Regressions of separate keywords (year 2011).

Keyword	English term	Variable	*r*	R^2	Standard error	Constant	Coefficient
γριπη	Influenza	x1	.888765	.789903	0.00996	.008855	.539551
πυρετος	Fever	x2	.655427	.429584	0.01641	−.03361	2.747708
βηχας	Cough	x3	.658775	.433984	.01634	−.01984	2.03161
πονοκεφαλος	Headache	x4	.007578	.000057	0.02172	.019887	.034104
πονολαιμος	Sore throat	x5	.242802	.058953	0.02107	.01486	.22728
φαρυγγιτιδα	Pharyngitis	x6	.340787	.116136	0.02042	.005607	.708454
αντιβιωση	Antibiotics	x7	.327644	.107351	0.02052	−.01148	1.596785

As shown in Table 1, no regression yields a correlation factor (*r*) >.90.

In our case, we decided to combine all the keywords and create a flu score.

To obtain the data from Google Trends, we used Visual Studio 2012 Ultimate and Visual C# as the programming language.

Methods Employed

Our goal was to construct prediction models based on the ARIMA model, previously used by other researchers, in specific data from Greece and Italy for influenza, describing two cases: using a flu score for Greece and without it for Italy.

We examined two different cases, both based on ARIMA models. The assumptions are based on that we can create a flu score from different keywords searched by people on the Internet. This score consists of the separate keywords, and it is the aggregation of them. In terms of statistics, this score is the average of all the values of each separate keyword, as shown in the following Figure 1 where x_i=the values of each independent variable (x1, x2, x3, x4, x5, x6, and x7).

The first case assumes that this score can be created and used (the case of Greece), whereas the other assumes that there is enough and reliable data from the Internet that can be safely used. In that case, we used data from a neighboring country using the keyword *influenza* from Google Trends (the case of Italy). Finally, we compared the two cases, having as criteria the statistical correlation coefficient *r* and the results of the ARIMA models. We conducted experiments with the ARIMA model with small parameters (parameters from 0-3), as the data sample is relatively small, and the ARIMA (1, 0, 0) model was found the only one to be statistically significant at level of $P<.05$ (two-tailed).

The Case of Greece Using a “Flu Score” and the ARIMA Model

Model Estimation for Year 2011

After creating the flu score, we used the model ARIMA (1, 0, 0) [29], a model also known as the Box-Jenkins model [30]. We used lags for the independent variable (Google data). This is a model that combines an autoregression and a moving average model.

Lags of the differenced series appearing in the forecasting equation are called autoregressive terms, lags of the forecast errors are called moving average terms, and a time series, which needs to be differenced to be made stationary, is said to be an integrated version of a stationary series. The ARIMA models are, in theory, the most general class of models for forecasting a time series, which can be stationarized by transformations such as differencing and logging.

A nonseasonal ARIMA model is classified as an ARIMA (p, d, q) model, where p is the number of autoregressive terms, d is the number of nonseasonal differences, and q is the number of lagged forecast errors in the prediction equation.

In more detail, the above parameters can be analyzed as follows:

p stands for the number of autoregressive orders in the model. Autoregressive orders specify which previous values from the series are used to predict current values. For example, an autoregressive order of 2 specifies that the value of the series two-time periods in the past be used to predict the current value.

d specifies the order of differencing applied to the series before estimating models. Differencing is necessary when trends are present (series with trends are typically nonstationary and ARIMA modeling assumes stationarity) and is used to remove their effect. The order of differencing corresponds to the degree of series trend—first-order differencing accounts for linear trends, second-order differencing accounts for quadratic trends, and so on.

Finally, q means the number of moving average orders in the model. Moving average orders specify how deviations from the series mean for previous values are used to predict current values. For example, moving average orders of 1 and 2 specify that deviations from the mean value of the series from each of the last two-time periods be considered when predicting current values of the series.

Figure 1. Flu-score equation.

$$flu - score = \frac{1}{7}\sum_{i=1}^{7} x_i$$

In our model, we do not use nonseasonal differences, as we examine a single period of a year, which means there is no seasonality inside the same year, and the peak occurs only once. This model is a special case of an ARIMA model (autoregressive moving average [ARMA] model).

As this model combines autoregression (AR) and moving averages (MA), mathematically, it can be expressed as seen in Figures 2 and 3. The combination of these models can be expressed as shown in Figure 4 where Y_t, is the predicted value; c, is the constant; μ, is the expectation of X_t; $\phi_i.....\phi_p$, and $\theta_i.....\theta_p$ are the parameters of each model; t, is the time; e_t, is the white noise error terms. Generally, the easiest way to think of ARIMA models is as fine-tuned versions of random-walk and random-trend models.

Model Prediction for Year 2012

First, we create an estimation (base) model for the year 2011. If we assume that the parameters, the constant, and the errors of the estimate for the year 2011 are the same as for the year 2012, by downloading the values from the Google Trends, we build a model for the year 2012. This means that we tried to forecast the influenza ILI rates of 2012 having the knowledge of only the Google Trends data.

The Case of Italy

The second method addresses the situation, when a flu score is not needed, as there is sufficient data volume of searches by Google Trends for the term *influenza*, and the correlation coefficient is above .90 (.906 for 2011 and .917 for 2012). In this case, we examined the possibility of using data from a neighboring country. We choose Italy for comparison because it is the nearest country for which we can find data from Google Trends and ECDC, and it is a close country next to Greece in the European Union.

The test case was the data for the year 2011, building a base model, as in the previous method.

The next task was to use the same parameters of the ARIMA (1, 0, 0) model (constant, ϕ, θ, and ε of year 2011) for the year 2012 (from the first to the last week of 2012) to develop a forecast.

As shown in the Results Section, the case of Italy is different from the Greek one because the official data from ECDC do not exist from a specific week until the end of the year 2012. Nevertheless, using the ARIMA model, we can predict the entire time series—that means the peak and the spread of influenza based on data from Google Trends.

Generally, the methodology could be summarized as shown in Figure 5.

Figure 2. Autoregression equation.

$$\text{AR:} \qquad Y_t = \sum_{i=1}^{p} \varphi_i X_t - {}_i + \varepsilon_t$$

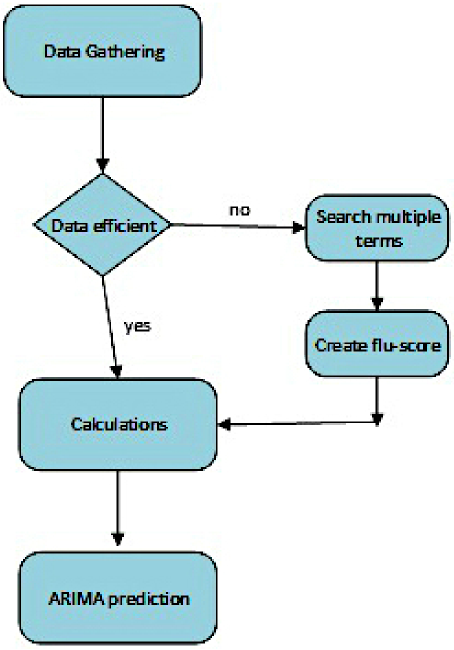
Figure 3. Moving averages equation.

$$\text{MA:} \qquad Y_t = \mu + \varepsilon_t \sum_{i=1}^{q} \theta_i \varepsilon_{t-i}$$

Figure 4. Autoregressive integrated moving average (ARIMA) equation.

$$\text{ARMA:} \quad Y_t = c + \varepsilon_t \sum_{i=1}^{p} \varphi_i X_{t-i} + \mu + \sum_{i=1}^{q} \theta_i \varepsilon_{t-i}$$

Figure 5. Flow diagram of methodology.



Results

Autoregression and moving averages models may be used to correlate data and build prediction models. The methods described above were developed to address the problem of insufficient or complete missing data of Google or even the statistical correlation is below .90. This correlation is denoted by the Pearson *r* correlation coefficient.

The Case of Greece

In the first method, combining the most relevant keywords in Greek language to the term *influenza*, we had the results for 2 years as follows:

For the year 2011, the *r* coefficient is above .90 at significance level *P*=.01 (two-tailed), and this means that the estimation is quite precise. This means that the distribution of the data gathered by Google follows the same distribution of the influenza cases notified by the public authority in Greece. Consequently, an early prediction is very accurate.

The results for the year 2011 are shown in Figure 6.

The horizontal axis in Figure 6 represents time, whereas the vertical axis represents the ILI cases of influenza. The ILI 2011 data line shows the values of the ILI data (ILI rates) from KEELPNO, which is the dependent variable. The prediction (red) line shows the estimated values calculated by the ARIMA model. As it is clear, using this model, we can obtain a very good estimation of the development of influenza in Greece for this year. The correlation (*r* coefficient) is greater than .90, and it is .909 at significance level *P*=.01.

Some interesting remarks can be mentioned about the above estimation:

- The predicted development of the disease is almost the same as the real one.
- The predicted peak appears with a delay of 1 week after the actual one in early February in the 6th week instead of the 5th week of the real cases.
- The predicted peak is 73.35, very close to the real peak, which is 76.98. The difference is below 5% (4.71%).
- It takes 4 weeks to reach the maximum value from the baseline, which are the 20 ILI cases (from the first week to the 5th week for the real values and from the second week to the 6th week for predicted values).
- The above estimation is very good, and we tested the same model with the same parameters to establish a prediction model for the next year.
- For the year 2012, the *r* coefficient is over .80 but below .90 at significance level *P*=.01. Nevertheless, we cannot reject the usability of the model, as we still predict the exact time of the peak of seasonal influenza (early March) and the size of the peak, as shown in Figure 7.
- The correlation coefficient (*r*) is greater than .80, and it is .831. Although it is below .90, we can still use the model.

Some interesting aspects of the forecast for the year 2012 are the following:

- The forecast of the peak of the seasonal flu is almost accurate, considering that during the year 2011 (from the first to the last week of 2011), the peak arrived very early in February (5th week), whereas in 2012 (from the first to the last week of 2012), there is a significant difference, as the peak arrived later in the 9th week.
- It takes the same time (as for the year 2011) for the peak to appear (4 weeks above the baseline of 20).
- The forecast model predicts almost accurately the year 2012. The predicted value is 76.61, and the real value is 73.26, which means that the difference is below 5% (4.58%).
- The predicted peak is shown 1 week earlier.
- The development of the curve after the peak also follows closely the observed data.

- The prediction in this case is based on that for both years the maximum activity of the disease appears exactly 4 weeks after the value comes to a point of more than 20 ILI cases, which is the baseline of influenza activity, as previously mentioned.
- The final point of the forecast will be the assumption of an early detection.

Table 2 shows the rising of influenza.

From Table 2, it is shown that the disease rises above the value of 20 in different weeks, but it takes the same time to reach the peak (9−5=4 weeks and 5−1=4 weeks). In conclusion, by using our forecast model for the year 2012, we predicted almost accurately the peak of seasonal influenza in Greece 4 weeks before it arrived, from the start of the year, based exclusively on the knowledge of the Google search queries, before the ILI rates are officially calculated by the competent authorities **.**

Finally, the comparison of real and predicted (ILI per 1000 people) cases is shown in Table 3.

The Case of Italy

In the case of Italy, we can see that for the year 2011, the coefficient *r* is greater than .90, which means that seasonal influenza estimated value is almost the same comparing to the real value. Using the ARIMA model, the coefficient *r* remains over .90, and this indicates a statistical correlation at significance level *P*=.01 (two-tailed). That means we can use this model as a good estimation for the development of the disease.

The result of the ARIMA model is shown in Figure 8.

Figure 6. Estimation for Greece using the autoregressive integrated moving average (ARIMA) model (year 2011).

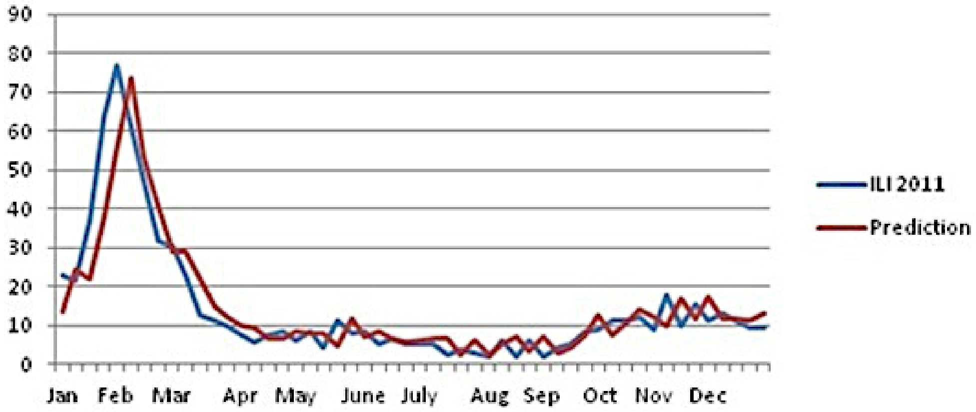


Figure 7. The prediction for Greece (year 2012).

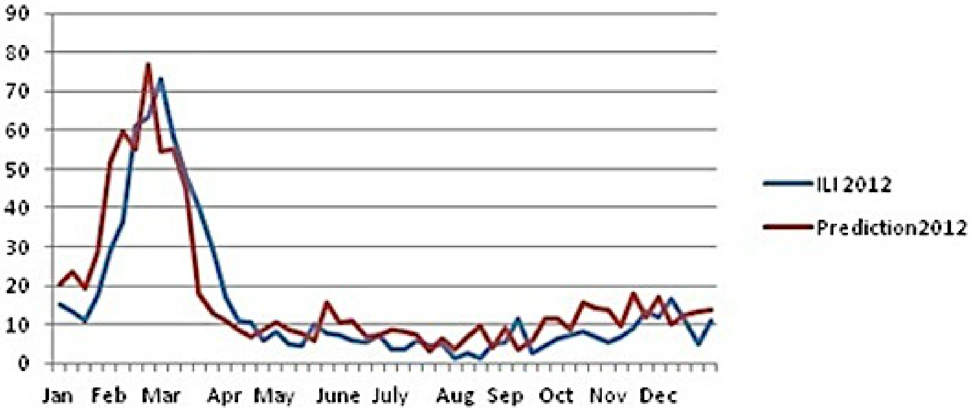


Table 2. Rising from 20 to maximum.

Value	Year	Week above 20	Week of the peak
>20	2012	5th	9th
>20	2011	1st	5th

Table 3. Prediction of the real cases for year 2012 (peak).

Predicted value	Real value	Difference	Difference (%)
76.61	73,260	3.35	4.58

The prediction of ILI rates for Italy, using the ARIMA model, is very good, and the correlation coefficient *r* is .979 at significance level *P*=.01.

The outcome of the model indicates that there is a strong and significant statistical correlation between the Google searches made by Italians for the word *influenza* and the ILI rates given by the European competent authority.

The main results of this estimation can be summarized as follows:

- The development of the disease is almost the same after the peak.
- The estimation model predicts the highest value 1 week later.
- The baseline is 500 ILI cases (per 100,000 people).
- It takes 4 weeks to reach the maximum value (1st to 5th week).
- The real maximum value is 1102.1, whereas the estimated value is 1013.05. The difference is −89.1 (−8.08%).

The prediction results for the year 2012 are as follows:

For the year 2012, the coefficient *r* is over .90 (.923), and this means that we can make a precise prediction. Using the ARIMA (1, 0, 0) model, the time of the peak of influenza is indicated in mid-February (6th week), even though with a higher value than the actual one. During the year 2011, Italian influenza peaked to the value of 1102.1. The predicted point for this year is 1037.461. The (predicted) difference is 35.361, whereas the actual difference is lower (947−1102.1=−155.1)

The prediction of this model for the year 2012 is shown in Figure 9.

As shown in Figure 9, the prediction for the year 2012, based on the ARIMA model parameters of the year 2011, is almost the same but with a little bit of higher values.

The statistical correlation is above .90. The correlation coefficient *r* is .923, and this means this correlation is statistically significant at a significance level of *P*=.01.

Let’s see the main results of this prediction model:

There is a lot of missing official data for ILI cases after the 16th week (mid-April).

Despite the missing values, the prediction of the peak and the size of the peak are very good. The predicted value is 1037.461, and the real peak is 947. The difference is 90.46 (9.55%). The predicted peak occurs 1 week later than the real peak (6th week instead of 5th week).

There is another peak to the end of the year, such as that of the 6th week. The value of the baseline before this peak arrives is 500 ILI cases and occurs at the end of the year starting 5 weeks earlier (46th week).

The predicted baseline is 400 ILI cases, above which it takes 4 weeks for the peak to arrive.

The summary of the results of ARIMA (1, 0, 0) model for both Greece and Italy cases is shown in Table 4.

Figure 8. Autoregressive integrated moving average (ARIMA) model for Italy (year 2011).

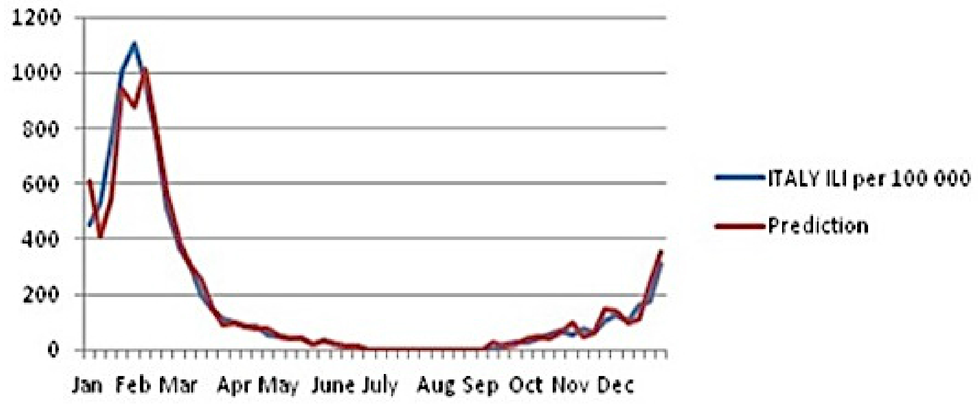


Figure 9. Autoregressive integrated moving average (ARIMA) model. Prediction for Italy (year 2012).

Table 4. Summary of the results.

Country	Year	Predicted peak	Real peak	Difference	Difference (%)	Weeks to reach the peak
Greece	2011	73.35	76.98	−3.63	−4.71	4
Greece	2012	76.61	73.26	3.35	4.58	4
Italy	2011	1013.05	1102.1	−89.05	−8.08	4
Italy	2012	1037.461	947	90.461	9.55	4
Italy	2012	1037.461				5

Discussion

Prediction

Autoregression and moving averages models may be used to correlate data and build prediction models. The methods described above were developed to use the data from Google searches found in the Google Trends system with the help of ARIMA models. The first method is used when searches for the term *influenza* do not give sufficient volume data, or the correlation coefficient is below .90. In such a case, the alternative is to seek other keywords related to influenza. These refer to the main symptoms.

The early detection of a future influenza pandemic activity is a key issue for all public health authorities [31]. The rationale for direct actions is based on the prediction of a likely spread across Europe and triggering of national operational plans. Therefore, an early prediction is necessary to design and implement public health preparedness plans. In our study, we concluded that an early detection of influenza activity can be made with the help of the Internet. In the case of influenza in Greece and Italy, by setting an Internet surveillance system, we can predict the peak, the time of the peak, and the spread of influenza at least 4 weeks earlier, before influenza reaches its maximum point.

Similar researches, mentioned in the Introduction, were conducted by scientists who used Internet data to make predictions and estimations for infectious diseases. Different models were used to detect and predict the outbreak of seasonal diseases. The results of other researches were focused to various countries such as the United States, Sweden, the United Kingdom, or to the countries of Asia. Our research is the first that examines a serious infectious disease such as influenza in small countries such as Greece and Italy. We consider the ARIMA model, already used by other scientists, very effective, and we made use of it to make estimations and predictions for the spread and the peak of seasonal influenza in Greece and Italy.

Restrictions

The main restrictions should be as follows:

- To perform analysis based on Google searches requires Google data to exist. This can be done when people can do searches on the Internet and, of course, it also requires a general extend of Internet penetration and use in the specific country. Although nowadays, Internet use has continuously risen; it is of great importance that the Internet speeds should be fast enough, and people are familiarized to the Google services.
- Another aspect is the language used. The keyword *influenza* may give enough data to perform analysis, but this can be a general rule for English-speaking countries, or even more for countries with the use of Latin language. As we mentioned in the first method, this cannot be done in countries with other languages, such as Greece. This is the main reason why we constructed a set of keywords and found their average values in the Greek language.
- The popularity and publicity regarding infectious diseases. The influenza disease can be safely used, as it is a very common disease among many countries of the world. Nevertheless, if there is a need for examination and study for another disease with less popularity, the first method will be possibly the only solution, when a researcher wishes to analyze data from Google Trends, specifically in smaller countries.
- Despite the above restrictions, it is certain, as other similar studies have shown that the Google Trends system can be safely used. In general, an Internet surveillance system can be an alternative system to the official sentinel systems for monitoring and evaluating the development of infectious diseases.
- There is a lot of discussion about the usability of Google Flu Trends, a service which was provided by Google. It has been found [32] that Google Flu Trends missed the emergence of the 2009 pandemic and overestimated the 2012 and 2013 influenza season epidemic. Google has shut down Google Flu Trends predictions, acknowledging the problem. Klembczyk et al suggests Google Flu Trends as a stand-alone surveillance system because it is most useful as an early signal system used in conjunction with other more comprehensive surveillance techniques.

Usability to National and International Systems

The outlook of testing different systems and generally the use of Internet surveillance systems is very important. This does not mean that monitoring systems based on Internet surveillance should totally substitute the traditional systems, but they can be certainly used on a supplementary basis.

Besides the above remark, a monitoring system based on Internet data may take advantage of the same definitions, methods, and indicators created and proposed by international and national organizations. Consequently, this means that this kind of system can have a great contribution to coordinate the different national monitoring systems.

The official definitions of diseases and the proposed specific indicators are made to coordinate the national systems. In Europe, ECDC monitors the levels of influenza activity in European countries reported by EISN members during the influenza season. The levels are based on the following three assessments or indicators [33] of influenza activity:

- An indicator of the overall intensity of influenza activity in the country
- An indicator of the geographical spread of influenza in the country
- An indicator of trend in ILI or acute respiratory infection (ARI) sentinel consultations in the country compared with the previous week

The main three indicators concern the overall intensity of influenza activity, the geographical spread of influenza, and the trend of the disease. These indicators can be described as follows:

Indicator of the Overall Intensity of Influenza Activity

The intensity of influenza activity is based on the overall level of clinical influenza activity in the country (or region). Each country assesses the intensity of clinical activity based on the historical data at its disposal. Some countries have historical data that date back over 30 years (eg, the United Kingdom [England] and the Netherlands), whereas others have data that date back over shorter periods of time (eg, Ireland). Some networks can establish numeric thresholds that define the different intensity levels of clinical influenza activity.

The EISN intensity definitions are denoted as low, medium, high, very high, and unknown.

The baseline influenza activity is the level that clinical influenza activity remains in throughout the summer and most of the winter. Usually, there will be a 6- to 12-week period in winter when the level of clinical influenza activity rises above the baseline threshold, but in the very occasional winter, activity never gets above the baseline level.

Indicator of the Geographical Spread of Influenza in the Country

Each country defines the geographical spread of influenza according to the definitions outlined below. The definitions are based on those used by the WHO global influenza surveillance system—FluNet [34].

- ILI: influenza-like illness
- ARI: acute respiratory infection
- Country: countries may be made up of one or more regions
- Region: the population under surveillance in a defined geographical subdivision of a country. A region should not (generally) have a population of less than 5 million unless the country is large with geographically distinct regions

The geographical spread is indicated through as no-activity, sporadic, local outbreak, regional activity, and widespread activity.

Indicator of Trend in ILI or ARI Sentinel Consultations in the Country Compared With the Previous Week

Trend is reported by the countries as increasing, stable, or decreasing. Trend is a comparison of the level of ILI or ARI sentinel consultations during 1 week with the previous week.

Outside the influenza season, when ILI and ARI rates are at baseline level, increasing or decreasing trends are not informative.

Increasing: evidence that the level of respiratory disease activity is increasing compared with the previous week.

Stable: evidence that the level of respiratory disease activity is unchanged compared with the previous week.

Decreasing: evidence that the level of respiratory disease activity is decreasing compared with the previous week.

The usability of the aforementioned definitions and indicators indicate that an Internet surveillance system may be a useful tool to manage a coordination of the different national systems that are currently used.

In terms of government spending, we mentioned in the introduction the huge costs connected to influenza through absenteeism, influenza complications, and hospital stays and deaths. We believe that early detection could provide useful means and tools for preventing purposes to reduce the overall spending but mostly to address public health issues concerning influenza tracking, monitoring, and treatment. Many studies in various universities and research centers have been conducted to indicate and propose the extensive use of the Internet to meet the requirements for a successful monitoring of epidemics and for creating an Internet surveillance system in an inexpensive way.

Conclusions

Finally, the main conclusions of this study can be summarized as follows:

- There is a significant statistical correlation with influenza ILI rates of Greece and Italy and the searches made in Google search engine.
- We can use the ARIMA statistical model for estimations and to create prediction rules and patterns for influenza in Greece and Italy based on searches made in Google search.
- By using Google Trends, we can predict the maximum point of influenza 4 weeks before it arrives.
- Google Trends can be a useful source of data. In cases of insufficient data or with low correlation of Google searches to the real cases for a single word (influenza) for a specific location (country) and for a certain period (year), a combined flu score can be created based on Google searches made by people with keywords related to the symptoms of the disease. When sufficient and reliable data volume of a keyword exists, we can still use ARIMA models for forecasts.
- An Internet surveillance system can be an alternative, as it can operate as a supplementary system, and it can use the same official definitions and indicators of the traditional

systems to help coordinating national monitoring systems across Europe.

- On the basis of Google search data, an Internet system can contribute to lowering costs by helping governments to prevent severe influenza outbreaks and manage their operational public health plans.

The term *Infodemiology* refers to information epidemiology and was first used by Gunther Eysenbach [9, 35] to propose a *new research discipline and methodology* on the study of the determinants and distribution of health information on the Internet, with the ultimate purpose to improve public health. The concept of *Infodemiology* (or *infoveillance*) is now widely used to describe the study and connection of serious disease development with the help of the Internet [21]. We believe that Google Trends could be a useful data source, which, with the help of statistics, can contribute to the abovementioned purpose by establishing an Internet surveillance system.

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Authors' Contributions

LS made the experiments and the programming code, MA examined and edited the codes, and EG edited the text. The conception and plan of the research conducted is part of LS’ ongoing PhD work and was done under the supervision of MA and EG.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Programming codes.

[PDF File (Adobe PDF File), 32KB - publichealth_v3i4e90_app1.pdf]

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Abbreviations

AR: autoregression
ARI: acute respiratory infection
ARIMA: autoregressive integrated moving average
ARMA: autoregressive moving average
CDC: Centers for Disease Control and Prevention
ED: emergency department
EISN: European Influenza Surveillance Network
EU: European Union

ILI: influenza-like illness
KEELPNO: Hellenic Center for Disease Control and Prevention
MA: moving averages
NUTS: classification of territorial units for statistics
WHO: World Health Organization

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Original Paper

Adverse Reactions Associated With Cannabis Consumption as Evident From Search Engine Queries

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Abstract

Background: Cannabis is one of the most widely used psychoactive substances worldwide, but adverse drug reactions (ADRs) associated with its use are difficult to study because of its prohibited status in many countries.

Objective: Internet search engine queries have been used to investigate ADRs in pharmaceutical drugs. In this proof-of-concept study, we tested whether these queries can be used to detect the adverse reactions of cannabis use.

Methods: We analyzed anonymized queries from US-based users of Bing, a widely used search engine, made over a period of 6 months and compared the results with the prevalence of cannabis use as reported in the US National Survey on Drug Use in the Household (NSDUH) and with ADRs reported in the Food and Drug Administration’s Adverse Drug Reporting System. Predicted prevalence of cannabis use was estimated from the fraction of people making queries about cannabis, marijuana, and 121 additional synonyms. Predicted ADRs were estimated from queries containing layperson descriptions to 195 ICD-10 symptoms list.

Results: Our results indicated that the predicted prevalence of cannabis use at the US census regional level reaches an R^2 of .71 NSDUH data. Queries for ADRs made by people who also searched for cannabis reveal many of the known adverse effects of cannabis (eg, cough and psychotic symptoms), as well as plausible unknown reactions (eg, pyrexia).

Conclusions: These results indicate that search engine queries can serve as an important tool for the study of adverse reactions of illicit drugs, which are difficult to study in other settings.

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KEYWORDS
cannabis; search engines; pharmacovigilance

Introduction

Cannabis is the most widely used illicit substance worldwide [1]. The United Nations Office on Drugs and Crime 2017 report indicates that over 180 million people use cannabis annually, accounting for roughly 3.8% of the global population [2], and lifetime prevalence of cannabis use among young adults in the United States has been reported to be around 50% [3].

In recent years, there is an increasing interest from a global health perspective into potential adverse effects of cannabis. This is particularly because of the rapidly shifting landscape regarding the legalization of cannabis in several US states, as well as the rising popularity of medicinal cannabis in several countries worldwide. Several additional factors, such as increased use among adolescents and young adults and the increasing potency of cannabis (as measured by concentration of the principal psychoactive constituent of cannabis, tetrahydrocannabinol [THC]), further contribute to concerns surrounding potential adverse effects of cannabis [4].

Traditionally, the safety of therapeutic agents and adverse effects are studied by a variety of methodologic approaches, including randomized controlled trials, observational studies, and pharmacovigilance studies [5]. Specifically, adverse effects are reported through a variety of regulatory agencies (such as MedWatch by the US Food and Drug Administration [FDA] in the United States and the International Drug Monitoring Programme by the World Health Organization). Several current projects (such as the FDA's Sentinel Initiative [6], the EU-ADR initiative [7], and the Observational Medical Outcomes Partnership [8]) are beginning to use observational data, including administrative claims and electronic health records, to identify adverse drug reactions (ADRs).

Aside from few cannabinoid-based pharmaceutical drugs, cannabis is largely overlooked by all these methods. The reasons for this oversight are that cannabis is still considered an illicit substance in most countries worldwide, and despite legislative changes in several US states, it is still a Schedule I drug according to federal law in the United States. As use of illicit substances is commonly underreported [9], its use may be associated with social disapproval and stigma, reducing reliable self-report of its use and of associated adverse reactions [10]. Furthermore, as opposed to pharmaceutical drugs, which are tracked by well-established programs described above, illicit drugs are not currently tracked by any such program. It should be noted that though there is no formal definition of *adverse effects* when dealing with illicit drugs, the common FDA definition of "any untoward medical occurrence associated with the use of a drug in humans" [11], with a particular emphasis on undesirable effects of the specific psychoactive substance, remains relevant.

Here we propose to identify the use of cannabis and associated adverse effects through novel observational data, namely, Web search query logs. Search queries contain a cornucopia of world knowledge [12], and prior studies have used query logs to track certain life events [13], the spread of disease [14], and most importantly in this context—adverse effects of medications [15,16]. As such, these data allow analyzing the data from hundreds of millions of people, and in some cases, a significant percentage of the patients using a given drug or an illicit substance.

Accordingly, the aims of this proof-of-concept study are: (1) to provide a *proof of concept* of estimating prevalence of cannabis use and identifying cannabis users through Web search query logs and (2) to explore adverse effects (both prevalence as well as temporality) of cannabis use using Web search query logs. We focus on data from the United States, for both the size of the country and the fact that population-level information on cannabis use exists in this country.

Methods

Data

We extracted all queries submitted to the Bing search engine by users located in the United States between November 2016 and April 2017 (inclusive). For each query, we extracted the text entered by the user, time and date, and the state from where the query was issued. Additionally, queries could be grouped to the same user through an anonymized user identifier [17]. We note that Bing users are known to be a representative sample of Internet users in the United States [17].

As baseline data, we extracted the three datasets shown below:

1. Cannabis usage rate (1-year prevalence) per state was extracted from the 2015 National Survey on Drug Use in the Household (NSDUH) survey [18]. This was the most recent available NSDUH state-level data at the time of the study.
2. Usage rate per census region was extracted from the 2012-2014 substate NSDUH estimates [19]. Each region consists of one or more counties. Both the first and second datasets are sponsored by the US Department of Health and Human Services. This was the most recent available NSDUH state-level data at the time of the study.
3. Reports on ADRs to the FDA's Adverse Drug Reporting System (FAERS) for the years 2013-2016, which mentioned marijuana or cannabis. A total of 11,382 reports from 9218 people were collected.

A list of words possibly related to marijuana consumption, comprising 123 terms, was constructed by browsing Web forums and the Urban Dictionary (see Multimedia Appendix 1).

Queries describing ADRs were identified by testing if they contained one or more of the terms used in previous studies (for a full background, see Yom-Tov and Gabrilovich [5]). This list is of layperson descriptions to 195 ICD-10 symptoms. This list was augmented with the following adverse reactions, listed in FAERS in conjunction with cannabis ("marijuana") but missing from the list above: emesis, abdominal pain, nausea, drowsiness, red eyes, red conjunctiva, appetite, aggression, agitation, cognitive disorder, delirium, withdrawal, fatigue, gastroschisis, hyperhidrosis, overdose, restlessness, sedation, seizure, and syncope.

Queries that were likely related to news events were removed by excluding queries that had the same text and appeared at a frequency of at least 10,000 times over the data period but with spikes of over 1000 queries during no more than between 1 and 10 days during the data period.

We note that the datasets (ground truth and Bing) do not overlap in dates, which may lead to mismatches in our estimates and hence, lower correlations between estimated and actual use. Therefore, the performance of our models should be considered an underestimate of the possible performance of these models.

Measures for Analysis of Bing Data

As will be described below, we first found terms (of the list of 123 terms) that are likely associated with cannabis consumption by correlating the fraction of people querying for these terms in each US census region and the cannabis consumption in that census region. We refer to these as the target terms. We then examined the use of terms to describe ADRs in the population using the target terms, compared with the rest of the population of Bing users. Following previous studies [5,15], we employed several ways to measure the association of ADRs with target terms. Here we briefly describe these measures, which give a score to each ADR (for formulas refer to Tables 1 and 2), as follows:

- Query ratio (QR): The fraction of people querying for the ADR who used the target terms, divided by the fraction of people who queried for the ADR (regardless of the target term) ((f+h)/(e+g)).
- Query log reaction score (QLRS): This is the original measure developed in Yom-Tov and Gabrilovich [5], which measures the change in queries for the ADR after queries for the target terms. It is computed as the chi-squared score from Table 2.
- Query proportional rate ratio (QPRR): A measure that accounts for the use of a term in the population making target queries, compared with the rest of the population (d/(d+b) / (c / (a+c)).
- Proportionality query ratio (PQR): A modification of QLRS found [15] to be more accurate than QLRS in identifying ADRs (h / (f+h) / (g / (e+g)).

Table 1. A 2×2 table for estimating query proportional rate ratio (QPRR) from Web-based query log data. Letters in the table indicate the number of people in the data who match the relevant conditions.

Conditions	User did not query for target term	User queried for target term
User did not query for ADR[a]	a	b
User queried for ADR	c	d

[a] ADR: adverse drug reaction.

Table 2. A 2×2 table for estimating query ratio (QR), proportionality query ratio (PQR), and query log reaction score (QLRS) from Web-based query log data. Letters in the table indicate the number of people in the data who match the relevant conditions.

Conditions	User did not query for target term	User queried for target term
User queried for ADR[a] after day 0	e	f
User queried for ADR before day 0	g	h

[a] ADR: adverse drug reaction.

We measured the correlation between FAERS reports and Bing data in two ways. First, we selected the 22 ADRs whose prevalence was in the top 95% of FAERS reports for cannabis and assumed these were likely ADRs and that all other ADRs were not associated with cannabis use. We measured the Area Under Curve (AUC) of the Receiver Operating Characteristic Curve for each of the measures derived from the Bing data (see Methods section).

Second, we measured the correlation between the measures computed for Bing data and the number of reports in FAERS for the 85 ADRs that appeared at least once in conjunction with marijuana in FAERS. Following Yom-Tov and Gabrilovich [5], we also used the greedy method used therein for excluding five outliers and showed the improvement in correlation when these are excluded. Outliers (according to Yom-Tov and Gabrilovich [5]) are ADRs that appear with high frequencies in FAERS, but have a low query score, or vice versa. The former happens when ADRs are acute or appear shortly after the substance is used, whereas the latter are ADRs that appear long after people begin using the substance.

Results

Correlation With State and Region Prevalence

We filtered the queries to include only those queries that contained one or more words possibly related to cannabis consumption, as detailed in the Methods section. We then calculated the fraction of queries from each state and region using each term.

Region prevalence was modeled using a stepwise linear model [20], where the independent terms are the number of people making queries that mentioned each of the terms in a region, divided by the number of people who queried on Bing from that region. The model reached an R^2 of .71 (n=305 regions), using the terms shown in Table 3, implying that 71% of the variance in the regional prevalence is predictable from the fraction of people making queries shown in Table 3. In this table, a positive slope means that there is a positive correlation between the number of people who use this phrase and the number of people who are known to have used cannabis in the geographic region. Interestingly, the single term “cannabis” reached an R^2 of .24, and the highly collinear term (r=.81, P<.001) “marijuana” reached an R^2 of .26. The other positive terms in the list reached a lower R^2 (the highest is “caffeine” with R^2 of .18). Therefore, in the next stages of our analysis, where it is important to identify (anonymous) individual people who may have used cannabis, we focus on those people who queried for the terms “cannabis” and “marijuana.”

Collecting usage data at fine-grained resolution is frequently costly and time-consuming. Therefore, it is important to ascertain whether data that were collected at one (usually course) resolution can be used to build a model that can be applied at other (finer) resolutions. Therefore, we next applied the state-level model to the regional level, so as to estimate the feasibility of using low-resolution ground truth data to estimate higher resolution usage rates. The state-level model reached an R^2 of .93 (n=50). Applying the state-level model to region-level data resulted in a correlation of r=.90 (P<.001). Applying the region-level model to state-level data resulted in *r*=.57 (*P*<.001). Thus, it is possible to apply a model created from one level of aggregation to another level of aggregation, with a reasonably small degradation in performance. Therefore, we applied the region-level model to county-level data. The predicted prevalence of cannabis use at a county level is shown in Figure 1.

Correlation With FAERS Reports

The AUCs and correlations for the four measures (QR, QLRS, PQRR, and PQR) are shown in Table 4. Since the QR and QLRS measures achieved similar correlations and AUCs, we focused on the QLRS measure, which has also been validated for pharmaceutical drugs [5,15].

The AUC for QLRS is shown in Figure 2. As the figure shows, QLRS is especially useful at detecting ADRs with a high likelihood to be of relevance. The ADRs rated highest in QLRS were in descending order:

1. anxiety
2. pain
3. overdose
4. paranoia
5. depression
6. withdrawal
7. seizure
8. hallucination
9. headache
10. cough

Table 3. Statistically significant terms in a stepwise linear model to predict US region incidence of cannabis use.

Term	Slope direction[a]
Antisocial behavior	−
Attention deficit	+
Blue	+
Bozo	+
Caffeine	+
Cannabis	−
Color	−
Domes	−
Hombre	−
Mikes	+
Peyote	−
Psychiatry	+
Speedball	+
Spoon	−
Stuff	−
Tickets	−
Valium	+
Draw	+
Jay	+
Marijuana	+

[a] Positive slope means that there is a positive correlation between the number of people who use this phrase and the number of people who are known to have used cannabis in the geographic region.

Figure 1. Predicted county-level prevalence of cannabis use based on Web-search queries using terms synonymous with "cannabis" and "marijuana".

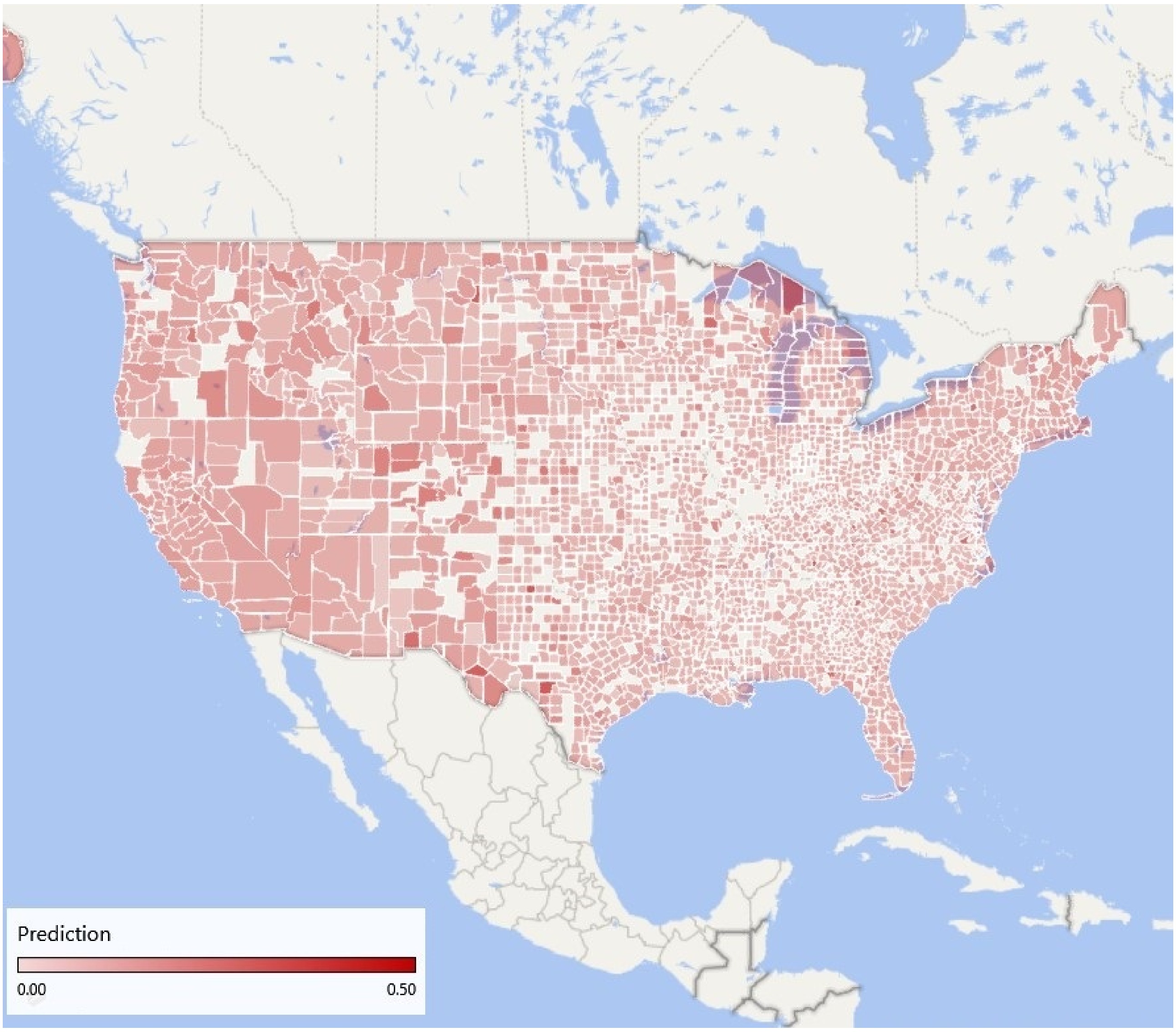


Table 4. Area Under the Receiving Operating Curve and Spearman correlation between Food and Drug Administration's Adverse Drug Reporting System reports and query measures for terms synonymous with "cannabis" and "marijuana."

Measure	AUC[a]	Correlation
QR[b]	0.77	.39
QLRS[c]	0.74	.31
QPRR[d]	0.68	.35
PQR[e]	0.61	.27

[a] AUC: area under curve.

[b] QR: query ratio.

[c] QLRS: query log reaction score.

[d] QPRR: query proportional rate ratio.

[e] PQR: proportionality query ratio.

Figure 2. Receiving Operating Curve (ROC) analysis for detecting Adverse Drug Reactions appearing in Food and Drug Administration's Adverse Drug Reporting System (FAERS) using Query Log Reaction Score (QLRS).

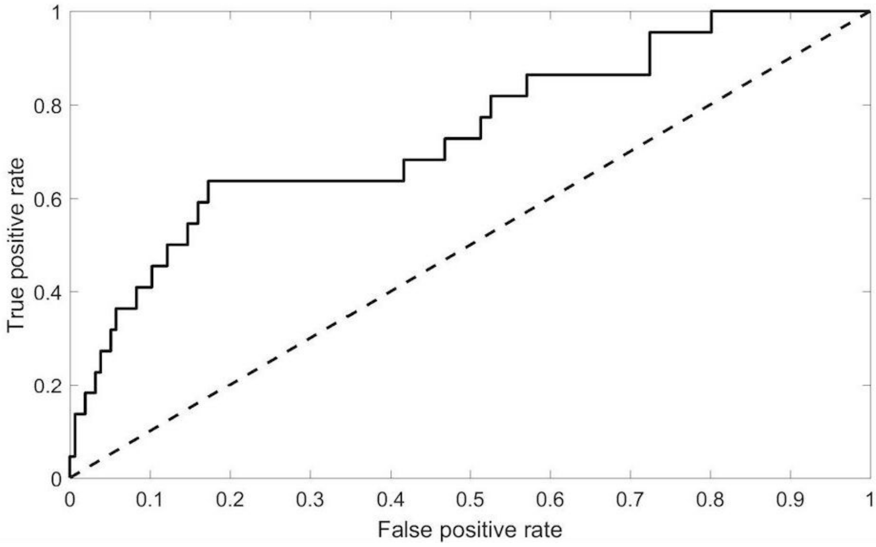
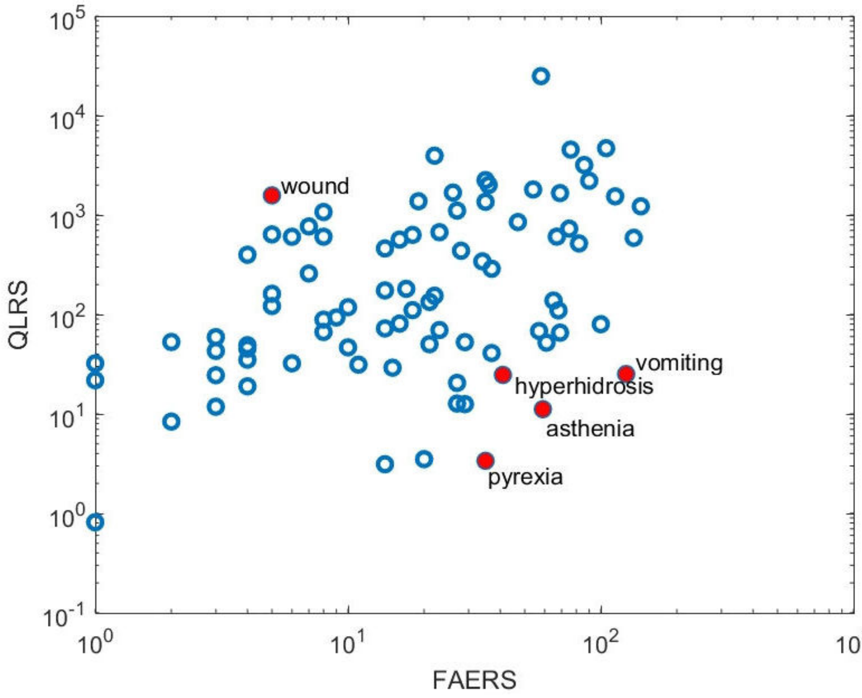


Figure 3. Plotted Query Log Reaction Scores (QLRS) versus the number of reports in Food and Drug Administration's Adverse Drug Reporting System (FAERS). Each dot represents an adverse drug reaction. Axes are log-scaled. Full red dots denote outliers, as identified by the analysis. Correlation between FAERS counts and QLRS scores for the blue unfilled dots is .42 (*P*<.001).



Outliers

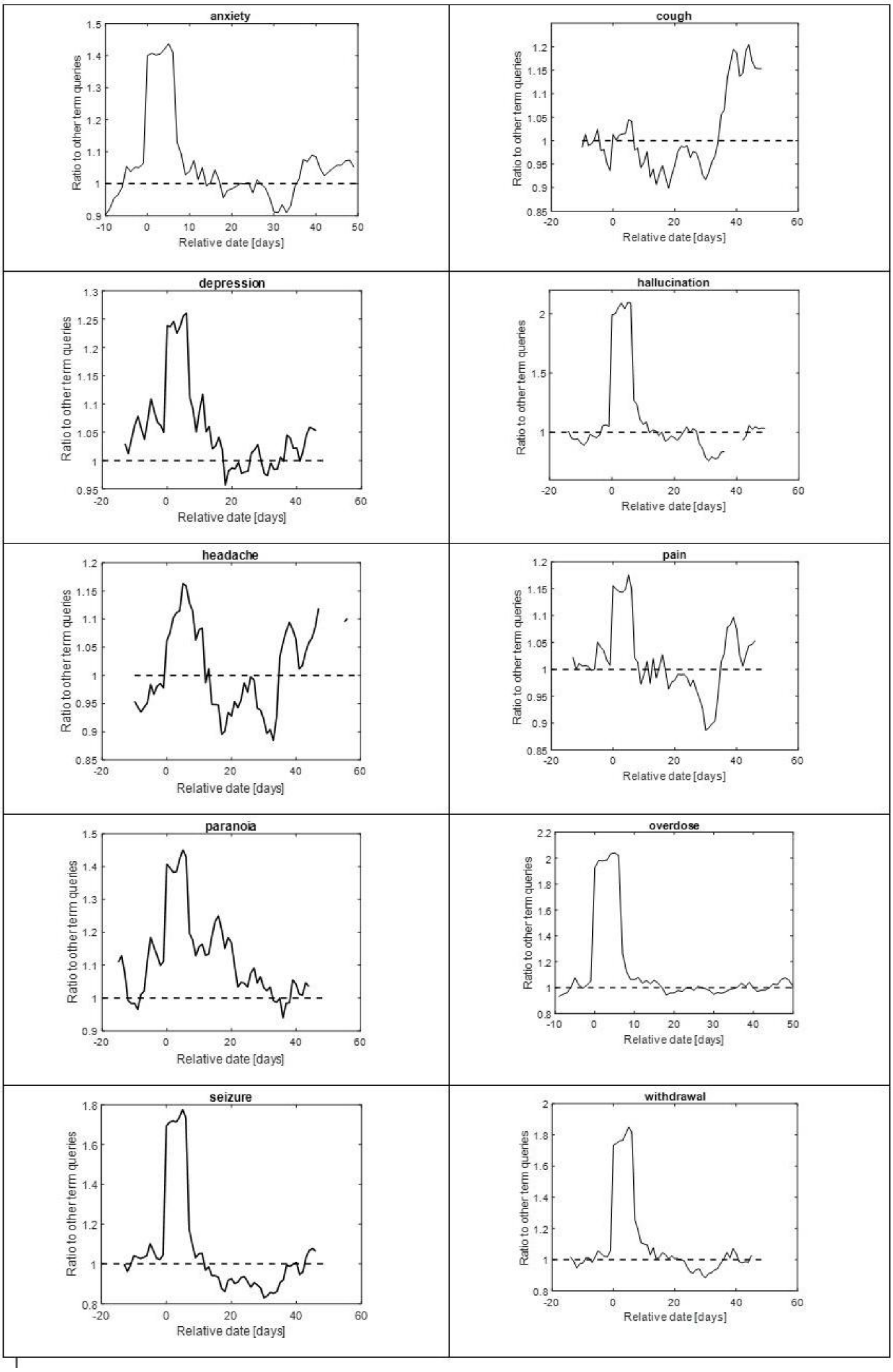
Figure 3 shows a scatter plot of the QLRS score versus the number of reports in FAERS, for the 85 ADRs analyzed. Marked separately are the ADRs identified as outliers using an iterative removal process, as described in Yom-Tov and Gabrilovich [5]. Correlation between FAERS counts and QLRS scores for the blue unfilled dots is .42 (*P*<.001), compared with .31 when these are not removed.

Temporal Profiles of Symptom Queries

We assessed the temporal patterns of the ADRs rated highest in QLRS (see above) by calculating the fraction of queries that mentioned an ADR, compared with the fraction of all ADR queries per day [13], as a function of the number of days since the first query for “cannabis” or “marijuana” by each person.

The resulting patterns are shown in Figure 4. As the figure shows, most ADRs (anxiety, depression, hallucination, pain, overdose, seizure, and withdrawal) begin on day 0 (the day on which the first query for “cannabis” or “marijuana” was made) and drop to baseline level within the following 10 days. However, “headache” begins only 3 to 5 days after day 0, and “cough” rises after approximately 40 days.

Figure 4. Temporal profiles of symptom queries (Day 0=first query for terms synonymous with "cannabis" and "marijuana"). Time series are smoothed with a 7-day moving average window. Shown are days with the 25% highest activity.



Discussion

Principal Findings

In this study, we sought to explore the applicability of Web search data for studying the prevalence of cannabis use as well as potential adverse effects thereof. Using a well-established model that has been repeatedly shown to be effective in exploring ADRs of pharmaceutical agents, we show that this novel low-cost method: (1) provides estimate data which is in line with epidemiological-derived studies on the spatial distribution of cannabis use and (2) reveals less common adverse effects of cannabis that are largely unreported. Together, this serves as a proof-of-concept for using this type of research design for studying the adverse effects of illicit drugs.

Our results from state and region-based data when compared with survey-based data indicate that it is possible to apply a model created from one level of aggregation to another, with small degradation in performance. Accordingly, we can estimate cannabis usage at the county level. The high accuracy of the model fit (which is similar in value to models for pharmaceutical drug use [5]) may indicate that: (1) people who use cannabis (particularly those concerned about adverse effects) ask about it online, perhaps because it is an anonymous channel of communication, which is thus more accessible and less stigmatizing than "official" channels such as family physicians and (2) that it is possible to estimate ADRs from these data. This may have significant implications for public health, as county-level data concerning drug use and other highly stigmatized behaviors are scarce and usually nonexistent. Estimates of county-level use may allow tailoring interventions in local educational and community-based facilities, focusing on specific counties within a region with highest rates of use.

Comparing the appearance of frequent ADRs in FAERS and QLRS, our results show high rates of correlation. Furthermore, several of the common side effects found in Web searches have been repeatedly reported in clinical and epidemiological studies. Our findings on common reports of anxiety and depression-related symptoms are in line with previous reports based on conventional data collection [21]. We found high rates of searches associated with cough among cannabis users; the findings echo research indicating higher rates of symptoms of chronic bronchitis compared with nonusers [22]. Common searches for psychotic symptoms such as paranoia and hallucinations are in line with previous reports of cannabis intoxication [23] as well as long-term effects of cannabis [24]. Other ADRs related to intensity of use (overdose) and cessation of cannabis use (withdrawal) echo previous reports as well [25]. Alongside these commonly reported adverse effects, specific pain-related ADRs (eg, pain and headache) and "seizures" found in our Web-based results are largely underreported and possibly understudied. We note that, since QLRS accounts for the time of ADR query vis-à-vis the query for cannabis, queries for pain occur after those for cannabis, and therefore, it is not the case that pain is the cause for queries regarding cannabis but more likely the obverse.

Alhough the correlation of ADRs as per FAERS and QLRS is high, there are several outliers: hyperhidrosis, asthenia, pyrexia, and vomiting appeared more commonly in FAERS compared with QLRS. This may indicate more acute side effects. For example, hyperhidrosis and asthenia may indicate panic-related symptoms, which may appear acutely following cannabis use [26]. Although cannabis has been shown to reduce (not increase) body temperature in preclinical models [27], there are reports of individuals reporting a subjective feeling of warmth when intoxicated [28], which may have increased searches of "pyrexia" and synonymous terms.

Our results regarding the temporal appearance of ADRs reveal interesting findings. For several potential ADRs, individuals searched for them on the same day on which the first query for "cannabis" or "marijuana" was made ("day 0"). Of these, some represent potentially acute ADRs (eg, hallucinations and overdose), whereas some may represent an inverse relationship. For example, in the case of seizure and pain, it is possible that individuals seeking relief from these problems conducted searches for cannabis as a potential treatment. However, as stated above, QLRS takes the time of query for ADR relative to that of cannabis into account. Therefore, we hypothesize that these queries were possibly caused by the ineffectiveness of cannabis for these symptoms, which caused people to continue asking about them (and even increasing the number of queries for them) after querying for cannabis. This could not be directly explored in this study. Interestingly, though anxiety and depression have been reported (in some cohorts) as long-term ADRs associated with cannabis, these appeared on "day 0" of the cannabis search as per QLRS.

Limitations

The main drawback of relying on Web search data is that it is inherently noisy. It is often impossible to ascertain whether a person searching for drugs and ADRs is doing so out of curiosity or conducting research for himself, a relative, or even for a patient. Admittedly, Internet users comprise a biased sample of the population, and thus the ADRs discovered may not be fully representative of the entire population. Nonetheless, our results suggest that the sheer size of the data alleviates these concerns, and the proposed method is able to identify adverse effects of drugs that are not captured by existing surveillance mechanisms. Another limitation of this study is using a restricted set of symptoms expanded through the use of synonyms. Although a larger dictionary would have allowed identification of additional (and possibly rarer) ADRs, our focus on more common symptoms is likely to lead to better identification of the more common concerns to patients. Future work will focus on professionally used term dictionaries which will allow focusing on knowledgeable patients and health providers. Another way to strengthen our results is the use of non-English search data, which will increase the volume of data (and the size of the observed population), thus enabling the analysis of less frequent drugs and ADRs. In any case, a particular challenge when exploring ADRs of illicit drugs is the plethora of street-names that may evolve rapidly and differ substantially across regions and countries. In addition, this approach raises specific challenges when exploring long-term effects of misuse of prescription drugs (such as opioids, stimulants, and sedatives), as this requires differentiating cases of prescription medication use (ie, according to physicians' recommendations) and misuse (eg, abuse or dependence). Finally, although this work is based on data from a large Internet search engine, it does not cover the entire population. However, privacy concerns preclude conducting our analysis across search engines, as the latter never share information about their users. Nevertheless, given the sheer number of users whose data were analyzed in the study (33% of the US population, which is especially notable compared with most epidemiological studies), we believe our findings are novel and significant. It should also be emphasized that QLRS discovers ADRs via aggregating queries across multiple users and query sessions. Consequently, the output of our method does not include any private, personal, or user-specific data whatsoever.

Conclusions

With rising prevalence rates in recent years and a growing controversy on its health-related effects and legal status, cannabis use is widely debated in academic, legislative, and popular platforms. In light of this debate, long-term effects of cannabis use must be carefully explored. Current epidemiological research, in the form of face-to-face interviews or telephone screening, suffers from several methodological drawbacks, including, for example, limited sample size and report bias. The latter may be particularly important when exploring effects of illicit substances, as false reporting is common because of social desirability bias [29]. Our proposed method provides a novel, low-cost, and rapid method for exploring prevalence of use, characteristics of users, and underreported adverse effects of illicit drug use. To the best of our knowledge, these methods have not been reported before and may provide a particularly valuable method for studying use and effects of illicit drugs.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Terms used to identify marijuana use.

[PDF File (Adobe PDF File), 14KB - publichealth_v3i4e77_app1.pdf]

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Abbreviations

ADR: adverse drug reactions
AUC: Area Under Curve
FAERS: Food and Drug Administration’s Adverse Drug Reporting System
FDA: Food and Drug Administration
NSDUH: National Survey on Drug Use in the Household
PQR: proportionality query ratio
QLRS: query log reaction score
QPRR: query proportional rate ratio
QR: query ratio

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Original Paper

Online Influence and Sentiment of Fitness Tweets: Analysis of Two Million Fitness Tweets

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Abstract

Background: Publicly available fitness tweets may provide useful and in-depth insights into the real-time sentiment of a person's physical activity and provide motivation to others through online influence.

Objective: The goal of this experimental approach using the fitness Twitter dataset is two-fold: (1) to determine if there is a correlation between the type of activity tweet (either workout or workout+, which contains the same information as a workout tweet but has additional user-generated information), gender, and one's online influence as measured by Klout Score and (2) to examine the sentiment of the activity-coded fitness tweets by looking at real-time shared thoughts via Twitter regarding their experiences with physical activity and the associated mobile fitness app.

Methods: The fitness tweet dataset includes demographic and activity data points, including minutes of activity, Klout Score, classification of each fitness tweet, the first name of each fitness tweet user, and the tweet itself. Gender for each fitness tweet user was determined by a first name comparison with the US Social Security Administration database of first names and gender.

Results: Over 184 days, 2,856,534 tweets were collected in 23 different languages. However, for the purposes of this study, only the English-language tweets were analyzed from the activity tweets, resulting in a total of 583,252 tweets. After assigning gender to Twitter usernames based on the Social Security Administration database of first names, analysis of minutes of activity by both gender and Klout influence was determined. The mean Klout Score for those who shared their workout data from within four mobile apps was 20.50 (13.78 SD), less than the general Klout Score mean of 40, as was the Klout Score at the 95th percentile (40 vs 63). As Klout Score increased, there was a decrease in the number of overall workout+ tweets. With regards to sentiment, fitness-related tweets identified as workout+ reflected a positive sentiment toward physical activity by a ratio of 4 to 1.

Conclusions: The results of this research suggest that the users of mobile fitness apps who share their workouts via Twitter have a lower Klout Score than the general Twitter user and that users who chose to share additional insights into their workouts are more positive in sentiment than negative. We present a novel perspective into the physical activity messaging from within mobile fitness apps that are then shared over Twitter. By moving beyond the numbers and evaluating both the Twitter user and the emotions tied to physical activity, future research could analyze additional relationships between the user's online influence, the enjoyment of the physical activity, and with additional analysis a long-term retention strategy for the use of a fitness app.

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KEYWORDS

Twitter; physical activity; mobile fitness apps; fitness tweet classification; sentiment

Introduction

Physical activity can reduce the risk for many different types of chronic diseases and can help people maintain a healthy weight. Although this knowledge is widely known, adults and children in many countries do not get recommended amounts of physical activity [1]. Recent advances in physical activity monitoring now provide researchers with unparalleled opportunities to increase and improve our understanding of the health benefits of physical activity by assessing daily quantities of activity, patterns, and trends [2], as well as the real-time sentiment of physical activity. Research suggests that technology is one factor that has contributed to the increase in sedentary behavior and decrease in physical activity, but it has also led to a number of innovative physical activity interventions [1].

One such innovation is through the use of mobile fitness apps and the sharing of one's workout through a social network. This paper will focus on the collection of self-reported fitness data through a mobile fitness app that is then shared with one's social network via Twitter. The dataset of these tweets along with other connected datasets of demographic information allows for a number of analyses, including but not limited to the potential influence of such tweets and the sentiment of these tweets. By combining the digital traces as people interact through mobile phones and emerging technology may now provide novel methods to assess a range of factors objectively and with minimal expense and burden to participants [3]. This paper will review both the potential online influence and the sentiment of the shared fitness tweets.

Social media has changed the way society is exposed to information [4]. Social networking sites such as Twitter have developed into increasingly useful platforms for the general public to share thoughts, ideas, and opinions. Twitter is a free social networking platform that is widely used around the world by businesses and individuals and is considered one of the most widely used microblogging platforms with 328 million monthly active users with more than 1 billion unique monthly visits to sites with embedded tweets with a mission to "to give everyone the power to create and share ideas and information instantly, without barriers" [5]. Twitter users can rapidly and directly share with and respond to a massive audience, using messages of 140 characters or less. With the creation and introduction of newly developing technologies such as Twitter, new opportunities to obtain global health data that may circumvent the limitations of traditional data sources used in population health and physical activity research are now available [3].

At the same time, these publicly shared data are resulting in vast and growing user-contributed repositories of data [6]. Twitter provides user-generated data that can be collected and analyzed to examine opinions around health-related foci, including discussions about physical activity, alcohol and marijuana use, depression, and suicide [3]. From a health-promotion standpoint, these data can be useful to measure participants' dependence on social support, given that exercisers today are just as, if not more, likely to seek motivation and validation from social media—in particular, Twitter—than their in-person friends and family members [7]. Because it is possible to glean precise information from tweets, including the time of the tweet and location of the user, this suggests that the 140-character messages could be predictive in other areas, such as the types of physical activity that users engage in and where and when they engage in these activities.

Using Twitter integration with mobile fitness apps can be a helpful tool for obtaining descriptive and predictive real-time shared health information in a noninvasive way. New and innovative cloud-based data collection and analysis tools may aid research efforts because they can yield a large collection of tweets in a short period of time. They may also be useful for longitudinal data collection [8]. The link between publicly available health and fitness data sources is made possible as more users publicly share their self-collected data from devices and apps through social media services such as Twitter [9]. An enhanced understanding of mobile fitness apps and the sharing of physical activity through one's social network, the different types of measurement properties, and the subsequent generated data are critical to furthering our understanding of daily physical activity.

Sentiment analysis is a classification process, the primary focus of which is to predict the polarity of words and to then classify these words as positive, negative, or neutral with the aim of identifying attitude and opinions [10]. Specific to Twitter, sentiment analysis is the task of automatically identifying and extracting subjective information from tweets. This method of data analysis has received increasing attention from the Web-mining community [11]. Although Twitter provides extremely valuable insight into publicly shared opinions, it also provides new big data challenges, including the processing of massive volumes of data and the identification of human expressiveness within short text messages [11]. Much of the existing research on textual information processing has been focused on the mining and retrieval of factual information, with little research on the processing of opinions [12].

The mining of Twitter for data provides a rich database of information on people's thoughts and sentiments about a myriad of health topics, including physical activity. Analysis of social networks data using Twitter has become a powerful tool that is currently being used to answer research questions across the health spectrum, including local and national flu surveillance [13], the sharing of information between cancer patients [14], marijuana usage among teens [15], and drug safety surveillance [16]. This paper represents, to the best of our knowledge, the first analysis of shared tweets from mobile fitness apps specific to physical activity. A significant proportion of tweets contained nonneutral sentiments regarding the shared physical activity of the four mobile apps featured in this research.

The ability to evaluate the sentiment of an individual immediately after a bout of physical activity has been completed can be powerful. A typical tweet might include the type of exercise performed, the duration and intensity of that exercise, and how the person felt during and after the activity. If the sentiment is negative (eg, "Just hiked to the top of Mt Pisgah. Took me 2 hours and I'm completely exhausted. Don't think I'll do that again! #myfitnesspal"), a coach or trainer can intervene and modify the activity accordingly. Finding exercise that is enjoyable and of the appropriate intensity is an important precursor to long-term adherence. Behavioral researchers suggest that one's emotions can profoundly affect individual behavior and decision making [17]. Simply stated, a tweet can be a window into real emotion provided in real time.

Other research reported that when fitness promoters initiated a #PlankADay challenge on Twitter—which was designed to encourage core-strengthening exercise—72% of users participated for at least 30 days straight and at the end of the challenge reported an increased enjoyment of the activity and expressed interest in continuing to do abdominal exercise [18]. This indicates that Twitter and other social networks can be useful in spreading exercise awareness and encouraging positive exercise behaviors. Together, this information can facilitate research on how technology can be used to monitor and motivate physical activity and how online social networks may play a role in physical activity promotion and adherence. Identifying the types of people who use mobile fitness apps and finding ways to track what they do and motivate them to continue to engage in physical activity is a form of data mining for this "customer base."

Methods

Collection of Tweets

After a review of online tools that could collect and manage tweets, an open-source program called TwapperKeeper was deemed appropriate as the Twitter data-collection tool. TwapperKeeper is a Web app designed to collect social media data via Twitter for long-term archival and analysis. The app uses a Twitter-enabled application program interface (API) that acts as an interface between the Twitter search function and a cloud database for tweet storage [19].

For this research, we chose four mobile fitness apps based on their availability on iPhone, the ability of the mobile fitness app to share workout information through Twitter, and the fact that they targeted beginner versus experienced exercisers. The research team used these criteria to narrow possible choices and reviewed additional academic research for previously used apps, researched publicly available reviews on different mobile fitness apps, interviewed both developers and users of mobile fitness apps to obtain their input, and met as a group to finalize the selected mobile fitness apps to study [20].

The four apps chosen were Endomondo, Nike+, RunKeeper, and DailyMile. Tweets were then collected from the mobile fitness apps using the following hashtags: #endomondo, #nikeplus, #runkeeper, and #dailymile. These were used because these apps automatically attach these hashtags to a tweet to indicate it has come from that particular mobile fitness app. It is through these hashtags that common themes or information can be grouped within Twitter.

Data collection using TwapperKeeper continued for 184 days. During this period, 2,856,534 user-generated mobile fitness app tweets were collected in 23 different languages. The Twitter data in this study was public, and the research was deemed exempt from human subjects review. This research was approved by the institutional review board of the National University of Ireland Galway in Galway, Ireland.

Two analyses were completed on a dataset of collected tweets from four mobile fitness apps. The first was to measure the online influence of Twitter users through their Klout Score. The second was to measure the sentiment of physical activity-related tweets.

Analysis 1: Measuring Online Influence

One important factor to consider when analyzing tweets to report physical activity is the credibility and authority of the person sending the tweets. Previous data collectors have looked at a Twitter user's number of followers, although researchers discovered that monitoring retweets and the messages themselves are a better predictive tool [21].

Websites such as Klout have developed the means to determine a user's reach or influence on social media. The Klout Score is the measurement of a person's overall online influence, with scores ranging from 1 to 100; higher scores represent a wider and stronger sphere of influence. Scores greater than 50 are rare [22]. A Klout Score places less emphasis on a user's number of followers and number of tweets, but rather measures the extent to which the user's content is retweeted [23]. One's influence on Twitter can be difficult to measure accurately. Klout uses more than 3600 features that capture the online social network activity of the user to conduct the influence analysis and calculate the Klout Score [24]. The Klout Score allows for tailored statistical analysis of social media usage and is tangible proof of the effect of the Internet on a person's lifestyle [25]. With regards to influence, Internet users perceived a mock Twitter page with a high Klout Score as more credible than the same page with a moderate or low Klout Score [26].

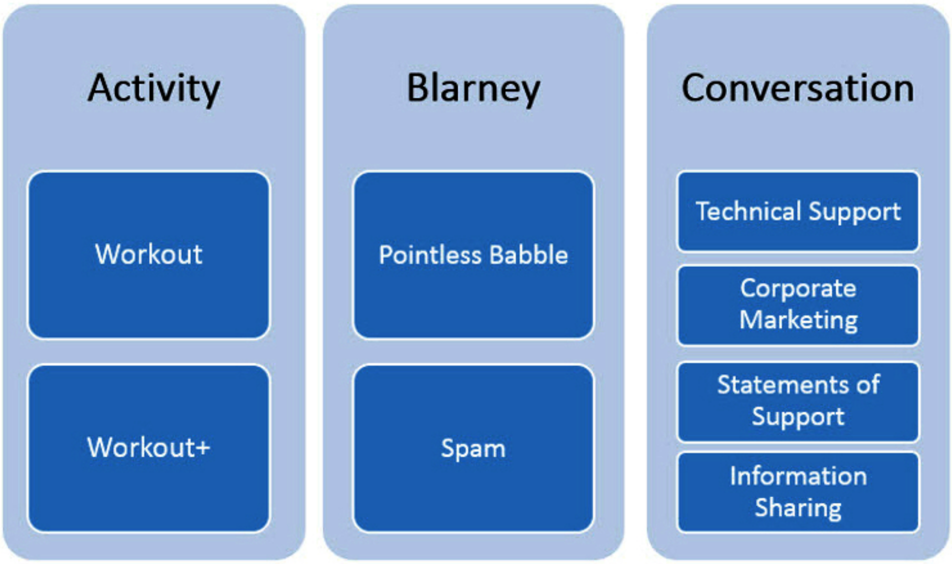
Online influence services such as Klout are in the process of scoring millions, eventually billions, of people on their level of influence. To proponents, the measurement of online influence is an inspiring tool that encourages the democratization of influence, where one no longer must be a celebrity, politician, or media personality to be considered influential.

Recruitment

For this experimental approach, the user's Klout Score—a measure of their online influence—was used to compare shared physical activity levels from mobile fitness apps.

In this experiment, we examined the sharing of fitness tweets from within mobile fitness apps (Nike+, RunKeeper, DailyMile, and Endomondo) and analyzed the data based on the participant's gender and online influence, as measured by their Klout Score. We identified two types of activity tweets from dataset: workout tweets, which included what was generated by the mobile fitness app, and workout+ tweets, which included the same information as a workout tweet but also contained user-created communication. We hypothesized that those with a higher Klout Score would share fewer minutes of activity and more overall workout+ tweets. We also hypothesized that across both genders, the higher the Klout Score, the lower the minutes of shared physical activity.

Figure 1. The fitness tweet classification model.



The data for this research were drawn from an existing dataset of fitness tweets from mobile fitness app users who shared their physical activity and, in some cases, additional conversation over Twitter. Over 184 days, 2,856,534 tweets were collected in 23 different languages. However, for the purposes of this study, only the English-language tweets were analyzed from the activity tweets, resulting in a total of 583,252 tweets.

The Fitness Tweet Classification Model [20] was used to classify each tweet into main categories of activity, blarney, and conversation and then into subcategories as shown in Figure 1.

The different types of collected information from the mobile fitness apps and each corresponding Twitter account provided a number of different and unique data points to review. For this experiment, those data points included the activity tweets, the user's gender, the minutes of physical activity, and the user's Klout Score. The statistical analysis of physical activity on Twitter from the four selected mobile fitness apps was performed in SAS 9.3, a software suite developed by the SAS Institute for advanced analytics, business intelligence, and predictive analytics, using two key datasets: (1) the first dataset included all user information about Twitter users who sent tweets relating to workout and workout+ and (2) the second dataset contained all the actual tweets sent by each user.

Analysis 2: Sentiment Analysis

Recruitment

Of the activity tweets, there were a total of 408,574 workout+ tweets. From this total, a random sample of 23,391 was created. These tweets were user-generated, where the end user provided additional text to a workout tweet (ie, the user provided supplementary information beyond that which was created by the app itself). Tweets were then grouped by mobile fitness app using the corresponding hashtags. There were no significant numbers of emojis available in the fitness tweets for use in the sentiment analysis.

Sentiment Analysis of Tweets

The AYLIEN Text Analysis for Google Sheet add-on was utilized for the analysis of the sentiment for each collected information-sharing conversation tweet as filtered by the Fitness Tweet Classification Model.

The AYLIEN Tweet Sentiment Analysis function is a three-step process:

1. Preprocessing: tweets are normalized and reformatted, and the parts that are considered irrelevant to the sentiment are stripped.
2. Parsing: tweets are parsed and their structure, tags, and negations are extracted.
3. Classification: tweets are classified as positive, negative, or neutral by a pretrained classifier, assisted by a lexicon-based approach as a second judge.

For this experiment, the sentiment analysis tool that analyzed each tweet and returned the value of positive, neutral, or negative was used for classification. These data were saved into an Excel spreadsheet for additional data processing by converting the text value to a numerical value (positive=1, neutral=0, and negative=–1).

Results

Analysis 1: Measuring Online Influence

Gender Assignment of Twitter Users Within the Dataset

Twitter does not collect the gender of users. To be able to compare across genders, a means of identifying the possible gender of the Twitter users was needed. To accomplish this, we used the US Social Security Administration's name database to match English names with gender. The name database from the Social Security Administration website included popular names ranked by gender since 1880.

The first gender-match calculation between the first names in the collected Twitter demographic database (the Twitter user's full name was one of the many demographic characteristics collected from Twitter) and the Social Security Administration database eliminated names that were used fewer than 200 times because many such names were much more popular among one gender than another (eg, girls were named Aaron <0.5% of the time). The assumption was that this adjustment eliminated a vast majority of gender confusion among names. Once this was completed, names were matched to genders using the VLOOKUP function in Excel.

A second gender-match calculation was performed for those Twitter users with names that appeared less than 200 times, in which we attempted to assign gender to the remaining names that did not match in the first round. Usernames that did not match either gender (<2%) were not included in the analysis.

After gender assignment, a descriptive statistical analysis was performed to compute the frequency of the following: (1) total minutes by gender, (2) total minutes by Klout Score, (3) total minutes by gender and Klout Score, (4) total number of tweets, (5) minutes exercised per tweet, and (6) total number of workout and workout+ tweets (separately).

Determination of Klout Quartiles

To examine the distribution of tweets, minutes of exercise described by said tweets and the categories mentioned in each tweet (workout or workout+), it was necessary to separate the users' Klout Scores into quartiles. We used the quartile method of data classification to create categories with a rank-ordered dataset split into four equal parts.

This was done through a two-step process in SAS. First, the distribution of Klout Scores was examined using the univariate procedure in SAS (PROC UNIVARIATE) and assigned quartiles based on that distribution. Second, using a data step, values of 1, 2, 3, and 4 were assigned to observations within the first, second, third, and fourth quartiles, respectively (Table 1). The maximum of any Klout Score is 100 and the minimum is 1. It was determined that the median Klout Score from the collected dataset was 20.50. As reported by Klout, the mean Klout Score is 40, with users with a score of 63 ranked in the 95th percentile [27].

Table 1. Klout Score quartiles.

Quartile	Klout Score
100% Maximum	100.00
99%	56.59
95%	49.03
90%	44.09
75% Q3	35.65
50% Median	20.50
25% Q1	11.92
10%	10.10
5%	10.00
1%	10.00
0% Minimum	1.00

Number of Activity Tweets (Male Versus Female)

The descriptive statistical analysis found that males produced 57.9% (336,109/583,252) of the total of activity tweets, whereas females produced 42.1% (247,143/583,252). This difference was consistent across Klout quartiles (Table 2).

Number of Tweets (Male/Female Among Workout Groups)

The descriptive analysis was expanded to compare males and females in the activity category. It was found that both genders tweeted far more among the workout group than the workout+ group (72.01%, 420,010/583,252 vs 27.99%, 163,242/583,252) in the lowest Klout quartile. This trend decreased slightly through the second and third Klout quartiles and then dramatically among the highest quartile of Klout Scores. In that quartile, the number of tweets varied much less (56.79%, 70,229/123,656 vs 43.21%, 53,427/123,656).

Mean Minutes Per Tweet (Males Versus Females)

The ANOVA procedure (PROC ANOVA) within SAS was used to compare the mean number of minutes tweeted by each gender using gender in the class statement and setting the model as minutes=gender. It was found that, overall, the mean number of minutes tweeted did not vary significantly between males and females. However, the mean number of minutes tweeted was almost double among females of the lowest Klout Score quartile (Klout ≤11.92).

Determination of Activity Tweets by Klout Quartile

After assigning quartiles, we examined the frequency of observations within each stratum of Klout Scores using PROC FREQ in SAS for the following (Table 3): (1) minutes by Klout Score quartile and (2) exercise types by Klout Score quartile.

Tests of Significance Between Groups: Minutes Tweeted Between Workout Categories

Also using the ANOVA procedure within SAS, analysis compared the total number of minutes tweeted among workout groups (workout vs workout+) and found a statistically significant difference (*P*=.01; Table 4).

Analysis 2: Sentiment Analysis

Sentiment Analysis of Workout+ Tweets

In total, there were 23,391 unique tweets within the original dataset that fit the filtering criteria from this random sample. Four of the mobile fitness apps were used in this analysis: DailyMile, Endomondo, Nike+, and RunKeeper. The overall sentiment of all mobile fitness apps suggests that half of these workout+ activity tweets were neutral in nature (Table 5). In addition, there were four times as many positive tweets than negative. The breakdown of sentiment analysis for negative, neutral, and positive sentiment by mobile fitness apps is also presented in Table 5.

Table 2. Klout Score by activity tweet (N=583,252) and gender.

Quartile and Klout Score	Activity tweets, n (%)	
	Male (n=336,109)	Female (n=247,143)
1: ≤11.92 (n=179,831)	102,007 (56.7)	77,824 (43.3)
2: >11.93 and ≤20.50 (n=154,669)	89,822 (58.1)	64,847 (41.9)
3: >20.51 and ≤35.65 (n=125,096)	73,394 (58.7)	51,702 (41.3)
4: >35.65 (n=123,656)	70,886 (57.3)	52,770 (42.7)

Table 3. Workout and workout+ tweets by Klout quartile.

Quartile and Klout Score	Workout tweets (n=420,010)			Workout+ tweets (n=163,242)		
	Tweets, n	Minutes (total)	Minutes per tweet, mean (SD)	Tweets, n	Minutes (total)	Minutes per tweet, mean (SD)
1: ≤11.92	143,552	6,320,924	44.05 (97.26)	36,279	1,745,722	48.12 (128.83)
2: >11.93 and ≤20.50	118,047	5,125,345	43.42 (65.54)	36,622	1,666,997	45.53 (91.67)
3: >20.51 and ≤35.65	88,182	4,348,112	49.32 (324.43)	36,914	1,694,811	45.91, (104.47)
4: >35.65	70,229	2,897,436	41.26 (54.97)	53,427	2,550,963	47.75 (285.42)

Table 4. Minutes exercised by gender and Klout Score among workout group.

Quartile and Klout Score	Male			Female		
	Tweets (% total males)	Minutes (total)	Minutes per tweet, mean (SD)	Tweets (% total females)	Minutes (total)	Minutes per tweet, mean (SD)
Workout[a]	241,254	10,935,339	45.33 (48.10)	178,756	7,756,479	43.40 (96.69)
1: ≤11.92	81,503 (33.78)	3,528,992	43.33 (48.10)	62,049 (34.71)	2,791,932	45.00 (137.26)
2: >11.93 and ≤20.50	67,666 (28.05)	2,942,049	43.48 (56.45)	50,381 (28.18)	2,183,296	43.34 (76.06)
3: >20.51 and ≤35.65	51,863 (21.50)	2,811,512	54.21 (420.74)	36,319 (20.32)	1,536,600	42.33 (51.54)
4: >35.65	40,222 (16.67)	1,652,786	41.09 (49.08)	30,007 (16.79)	1,224,650	41.50 (61.62)
Workout+[b]	94,855	4,437,573	46.79 (234.49)	68,387	3,220,919	47.10 (117.44)
1: ≤11.92	20,504 (21.62)	952,567	46.46 (114.94)	15,775 (23.07)	793,154	50.28 (144.89)
2: >11.93 and ≤20.50	22,156 (23.36)	1,002,024	45.24 (85.01)	14,466 (21.15)	664,973	45.97 (101.02)
3: >20.51 and ≤35.65	21,531 (22.70)	983,395	45.67 (112.10)	15,383 (22.49)	711,416	46.25 (98.06)
4: >35.65	30,664 (32.33)	1,499,587	48.90 (362.80)	22,763 (33.29)	1,051,375	46.19 (117.88)

[a] There was no significant difference between males and females in the number of tweets for workouts (*P*=.64).

[b] There was no significant difference between males and females in the number of tweets for workout+ (*P*=.55).

Table 5. Total number of tweets by sentiment and app.

Tweets and sentiment	Total	DailyMile	Endomondo	Nike+	RunKeeper
Total number of tweets, n	23,391	9298	820	3999	9284
Positive sentiment, n (%)	9389 (40.14)	7097 (76.41)	211 (25.73)	418 (10.45)	1663 (17.91)
Negative sentiment, n (%)	2342 (10.01)	1392 (14.99)	51 (6.22)	350 (8.75)	549 (5.91)
Neutral sentiment, n (%)	11,660 (49.85)	799 (8.60)	558 (68.05)	3231 (80.80)	7072 (76.17)

Figure 2. Word clouds by mobile fitness app.

Discussion

Analysis 1: Measuring Online Influence

This study further explored a novel approach to classify fitness tweets through Klout influence score. The study further stratified by gender through the use of a validated government database, which was probability matched to our data using exact matching procedures. This gender validation allowed for additional analysis of the gender breakdown of the existing dataset. The data were filtered through the matching criteria twice to improve precision, resulting in a 97% gender match. Although we gender matched twice, the process used to gender match could still be missing a few names that appear more often today than they did even a few years ago. Because popular names can change with high frequency, some gender matching in this study may not be valid within several years.

Based on the current database of collected fitness tweets from five mobile fitness apps, the highest Klout quartile included those individuals with a Klout Score of 35.65 or greater. Klout Scores can reach 100; therefore, our highest score tier may not capture an accurate representation of the most influential people on the Twitter platform. Additional insights from this research are described subsequently.

Men Share Their Physical Activity From Mobile Fitness Apps Via Twitter More Often Than Women

Based on this research, men share their workouts using Twitter and mobile fitness apps more often than women (54.35%, 336,109/618/458 vs 45.65%, 282,349/618,458). Although we believe this to be the first gender analysis of the sharing of physical activity from mobile fitness apps using Twitter, previous research on the overall gender use of Twitter suggests that more women than men use Twitter [28], with some nonacademic research suggesting that 40 million more women use Twitter on a monthly basis, that 62% of Twitter users are women [29], and those with a higher Klout Score tend to be women. Additional research regarding gender suggests that women are likely to be more active on Twitter as opposed to men, with women tweeting once every 20 hours versus men tweeting once every 26 hours [30].

However, additional research into our dataset using third-party software called Demographics Pro suggests that the average mobile fitness app user in the fitness tweet dataset is a male in his early thirties, typically married with children and having a high income. Additional insights into the users of mobile fitness apps who also tweet their physical activity includes that this group's most common professions are programmers, photographers, church leaders, designers, and teachers. The group has a notably high concentration of Web developers (within the top 10% of overall Twitter distribution in this respect). In their spare time, they particularly enjoy beer, political news, wine, comedy/humor, and cooking. People in this group are charitably generous and particularly health conscious. Sports that rise most notably above the Twitter norm include cycling, skiing, and golf. As a consumer, this group is relatively affluent, with spending focused most strongly on technology, wining/dining, and health/fitness. Their strongest brand affiliations include Apple Store, Trader Joe's, CrossFit, Trek Bicycle, and MyFitnessPal.

The Design of the Mobile Fitness App and the Sharing of Physical Activity Data to Social Networking Sites Matters

The sharing of workout+ tweets is dramatically enhanced by the user interface of the mobile fitness app. When comparing the four mobile fitness apps for the total number of activity tweets (workout tweets plus workout+ tweets), the most popular mobile fitness app was Endomondo (211,240 tweets), followed by NikePlus (203,991 tweets), DailyMile (183,732 tweets), and MyFitnessPal (70,723 tweets). The same usage ranking order was seen with men and women (men: 123,482 for Endomondo, 116,388 for NikePlus, 106,846 for DailyMile, and 70,723 for MyFitnessPal; women: 87,758 for Endomondo, 87,603 for NikePlus, 76,886 for DailyMile, and 30,233 for MyFitnessPal). However, there was a large difference when reviewing the workout+ tweets with 97.67% (173,790/177,943) of all workout+ tweets from DailyMile, 1.89% (3358/177,943) from NikePlus, 0.44% (776/177,943) from Endomondo, and no workout+ tweets from MyFitnessPal. In reviewing the user interface for all four mobile fitness apps, it is evident that the design of DailyMile made it much easier to share not only the workout, but also additional information about the workout when compared to the other three mobile fitness apps. Also during the evaluation time period for the activity tweets, Endomondo used a third-party service called @addthis to share workout+ tweets. With no workout+ tweets from MyFitnessPal, we determined that the app made a design decision to not allow users to share additional information regarding their physical activity workouts.

There is Brand Loyalty Regarding Mobile Fitness App Usage and the Sharing of Physical Activity Data Using Twitter

Of the 113,340 overall users in the dataset, 97.21% (110,186 users) tweeted their physical activity from just one mobile fitness app, 3105 (2.74%) used two mobile fitness apps, with 101 (0.09%) users sharing from three mobile fitness apps and just one user (0.0009%) sharing from four mobile fitness apps. We base this on the analysis of tweets per users and cannot determine the actual usage of the app, only the sharing of physical activity data from the apps. We surmise one reason that more than 97% used just one app could be loyalty, but other reasons such as poor user interface and difficulty in connecting one's Twitter account to the mobile fitness app may account for other reasons.

Analysis 2: Sentiment Analysis

A better understanding of the online influence of those who are sharing their fitness tweets may lead to new and innovative ways to encourage their followers to be more physically active through peer-to-peer influence, similar to programs created by marketing agencies to influence consumer behavior. Analogous to the other health-related research, physical activity researchers can monitor and attempt to influence physical activity Twitter chatter sent by influential Twitter users who are physically active and popular among various demographic groups and age ranges [15]. The findings can be used to inform online and offline efforts that work to target individuals who are most at risk for the harms associated with a lack of physical activity.

The relatively high number of neutral tweets was expected because each of the mobile fitness apps had a predetermined structure that limited additional information that could be included by the user. There also is the fact that a majority of the tweets simply did not contain words or phrases that could be classified as either positive or negative. Additional insights from this research are described subsequently.

The Real-Time Shared Sentiment of the Physical Activity Can Provide Additional Insights to Physical Activity

We believe that the sharing of one's physical activity with additional commentary (for the purposes of this research called workout+ tweets) from mobile fitness apps can provide researchers with new insights that in the past may have been difficult to measure. The design of many of the mobile fitness apps allows for the user to share characteristics such as who they were with, the type of weather, the location of the physical activity, and their immediate thoughts regarding the physical activity. These and other insights will allow physical activity researchers to have a greater understanding into the real-time reasons, thoughts, and sentiment of how and perhaps why a person partakes in physical activity. These data will enable a greater understanding surrounding the complexities of physical activity, which can then be used for an enhanced design of mobile fitness apps as a potential tool in the decrease of physical inactivity.

Most Shared Mobile Fitness App Physical Activity Is of a Structured Exercise Type

It is through the analysis and interpretation that the context of fitness tweeting from within mobile fitness apps provides insights into what is being shared, by whom, and for what reasons. Based on the type of information collected, it can be expected that a majority of the activities shared using mobile fitness apps through Twitter were of a more structured exercise type, as opposed to continuous monitoring of daily physical activity. This is possibly due to the additional battery drain on the mobile phone of the user, which would preclude daylong usage of the app. In addition, the structure of the tweets would also suggest that these activities were measured in terms of duration, suggesting activities such as a run, walk, bike, or traditional workout. Because of the nature of some of the activity tweets, it was possible to extract additional information, including the actual type, distance, and the amount of time spent on an activity. It was possible for outliers to be present within the database. For example, the first use of a mobile fitness app could be the user testing the mobile fitness app that may have prompted an activity tweet with a very short-duration activity (seconds rather than minutes), whereas very long-duration activities were sometimes recorded for activities when the person did not properly end his or her mobile fitness app activity session. It was possible that some of the longer-duration activities were, in fact, long exercise sessions. For example, a person training for a marathon would track long runs.

A Significant Majority of Users From Each App Used the App More Than Once

Based on the research data, the number of one-time users of a mobile fitness app that shared their workout using Twitter (activity tweets) was calculated. Although the research cannot determine if a person continued to use a mobile fitness app and decided not to share via Twitter, it was determined that of all users, between 17% and 27% used the sharing to Twitter feature only once depending on the app. A number of reasons could exist for one-time use, including user error, experimentation of sharing functionality, or testing by a user choosing a mobile fitness app. From the 165,768 users that posted activity using a mobile fitness app that was then shared via Twitter, the database included 76,192,059 minutes of activity over the 6-month time period. These minutes are equivalent to 52,911 days, 1738 months, or more than 145 years of combined activity minutes. We cannot determine if this physical activity was the only performed physical activity by each user during the time period because it is understood that users may have completed physical activity without using their mobile fitness app.

These findings and interpretations should be regarded as exploratory and speculative because they represent what can be potentially done in a short development time and with ease of use for non-computer programming health-promotion researchers.

Limitations

There are a number of limitations to this research study. Utilizing outside data, in this case the US government, to determine each user's gender leaves room for error. This research was conducted using the Twitter firehose, which allows for the collection of all publicly available tweets. Although we are confident in this data-collection process, there is no way to verify it without a financial expense to purchase all tweets. There also remains a challenge in the extraction of useful data from these repositories through data mining and knowledge discovery [6] due to a rapidly evolving explosion of data services and tools that can be used for analysis. This is due in large part to commercial pressures and the potential for using social networking data for computational research [31]. To minimize this limitation, we were able to link different datasets using the user's Twitter name as the unique identifier through free publicly available data. Future work could enhance our model by purchasing commercially available datasets for analysis.

There has been a steady growth of social media usage, from 5% of the US population in 2005 to close to 70% in 2015. As more Americans have adopted social media, the user base has also grown more representative of the broader population; however, it is still most used by younger age groups [32].

Comparison With Prior Work

The use of social media and emerging technologies to study physical activity and the possible lack thereof continues to increase with the development of such technologies. Previous research has shown an interest in specific characteristics of the social environments adversely affecting health outcomes [3]. Other research has studied the use of wearables and other smart devices to quantify various different health conditions with the self-reported data being shared on social networks, such as Facebook and Twitter [9], and have suggested that the adoption of such emerging technology to monitor physical activity has created new research opportunities to observe, quantify, and define physical activity in the real-world setting [2]. Our research continues to build on these previous studies by providing researchers with other options for data collection and different objectives to consider.

Previous work regarding the role of technology on physical activity through social media includes a dearth of studies that have studied various aspects of the impact of social media on physical activity. Some research has focused on the behavior change challenges that include self-monitoring, goal setting, and problem-solving strategies [33]. Other research has suggested a change in how we think about physical activity and sedentary behavior measurement, a research topic that includes the use of mobile fitness apps and social networks that can collect large amounts of real-time data that previously would have been difficult to collect [34]. Research by Tsoh [35] explores contextual and psychological factors that may underlie the observed low physical activity levels among mobile fitness app users. Our research is more closely related to that of Grundy et al [36] on the network analysis of prominent health and fitness apps and work by Haddadi et al [37] on the integration of shared health and fitness data from mobile fitness apps that are shared over social networks. Although these works are highly relevant to the research presented in this paper, we expand the research by carrying out data analysis including gender and online influence.

Similar approaches to inferring gender include works using a gender-based dictionary [38], through profile picture and background inference [39], and a third-party Web service that can often reveal gender through proprietary algorithms [40]. Specific research on using social media networks and physical activity include work by Althoff et al [41] on the influence of Pokemon Go, the tweeting of physical activity as a possible method to increase physical activity by Tsoh [35], and work by Liu and Young [42] on using social media data analysis for physical activity surveillance.

Future Work

We created a very powerful tool for conducting large-scale research by collecting physical activity data from Twitter, but the demographics used in this research could suggest a bias regarding the breakdown of mobile fitness app users and thus underrepresent certain groups. If researchers wish to use Twitter and mobile fitness apps for physical activity research, additional steps would need to be taken to ensure that all groups are represented in the data samples collected. Apart from technical limitations, there could be ethical challenges that are equally as challenging. Although tweets are considered public, they may contain information that many would consider “private” due to the possible misconception of the perceived audience (a user’s Twitter followers) versus the actual audience (data researchers) [9]. To expand on this work, additional investigation could address possible trends specific to forms of physical activity per gender that could constitute a higher Klout Score.

The popularity of consumer-facing health wearables (eg, Fitbit, Garmin) that also share physical activity data with online social networks would be a topic worthy of future research. By using these tracking devices, which monitor physical activity on an ongoing basis, a more inclusive picture of daylong physical activity can be achieved. This is in contrast to mobile fitness app data, which is typically collected and shared following a traditional “workout” (eg, a walk, run, bike). The same data collection and classification model presented in this paper can be used with minimal changes. With regards to online influence, other work could use an alternate measure of online influence rather than Klout.

Conclusion

This research analyzed publicly shared physical activity data collected via Twitter from five different mobile fitness apps. From this dataset, two analyses on the data were conducted to highlight the unique ability to use this type of data within the study of physical activity. The first analysis categorized the users into four quartiles that represented their online influence as calculated by Klout as well as a method to assign gender to each Twitter user. The analysis suggests that men share their workout tweets more than women, that there is more basic sharing of physical activity data (workout tweets) when compared to tweets that also contain commentary by the user (wourkout+ tweets), and that there is no significant difference in the tweeting of men and women. The second analysis was conducted with workout+ tweets and showed, across all apps, most of the shared tweets were neutral, but for those with a sentiment there were four times as many positive tweets as negative.

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Conflicts of Interest

None declared.

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Original Paper

Health Information–Seeking Patterns of the General Public and Indications for Disease Surveillance: Register-Based Study Using Lyme Disease

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Abstract

Background: People using the Internet to find information on health issues, such as specific diseases, usually start their search from a general search engine, for example, Google. Internet searches such as these may yield results and data of questionable quality and reliability. Health Library is a free-of-charge medical portal on the Internet providing medical information for the general public. Physician's Databases, an Internet evidence-based medicine source, provides medical information for health care professionals (HCPs) to support their clinical practice. Both databases are available throughout Finland, but the latter is used only by health professionals and pharmacies. Little is known about how the general public seeks medical information from medical sources on the Internet, how this behavior differs from HCPs' queries, and what causes possible differences in behavior.

Objective: The aim of our study was to evaluate how the general public's and HCPs' information-seeking trends from Internet medical databases differ seasonally and temporally. In addition, we aimed to evaluate whether the general public's information-seeking trends could be utilized for disease surveillance and whether media coverage could affect these seeking trends.

Methods: Lyme disease, serving as a well-defined disease model with distinct seasonal variation, was chosen as a case study. Two Internet medical databases, Health Library and Physician's Databases, were used. We compared the general public's article openings on Lyme disease from Health Library to HCPs' article openings on Lyme disease from Physician's Databases seasonally across Finland from 2011 to 2015. Additionally, media publications related to Lyme disease were searched from the largest and most popular media websites in Finland.

Results: Both databases, Health Library and Physician's Databases, show visually similar patterns in temporal variations of article openings on Lyme disease in Finland from 2011 to 2015. However, Health Library openings show not only an increasing trend over time but also greater fluctuations, especially during peak opening seasons. Outside these seasons, publications in the media coincide with Health Library article openings only occasionally.

Conclusions: Lyme disease–related information-seeking behaviors between the general public and HCPs from Internet medical portals share similar temporal variations, which is consistent with the trend seen in epidemiological data. Therefore, the general public's article openings could be used as a supplementary source of information for disease surveillance. The fluctuations in article openings appeared stronger among the general public, thus, suggesting that different factors such as media coverage, affect the information-seeking behaviors of the public versus professionals. However, media coverage may also have an influence on

HCPs. Not every publication was associated with an increase in openings, but the higher the media coverage by some publications, the higher the general public's access to Health Library.

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KEYWORDS

search engine; evidence-based medicine; medical informatics; information systems; communications media; Lyme disease; infodemiology; infoveillance; surveillance

Introduction

Background

Internet users seeking health information on the Web begin their search using general search engines such as Google, Bing, or Yahoo [1-5]. Some may start searching on a social networking site such as Facebook [1]. Adults looking for health information from the Internet and social media, sometimes called *online diagnosers*, are more likely to be women, younger adults, and people who have higher education and better household earnings [1,3,6]. Users explore only the first few links from the general search engine results [7], and when assessing the reliability of the website, they primarily look for the source, professional design, and signs of scientific or official touch [7]. General search engines, however, cannot profile their users [8], although the characteristics and behavior of those seeking health information have been assessed [1]. Those seeking health information from the Internet consist of both the general public and health care professionals (HCPs) [4,9]. Health-related information-seeking behavior may be affected by several factors such as personal health disorders, thirst for knowledge, or even media coverage [1,10]. Information is transmitted to large audiences using both conventional media (eg, television, newspapers, and radio) and digital media (ie, Internet and mobile). The Internet has allowed information to spread fast and far. In 2013, a random-sampled survey (4750 people in the age group of 16 to 89 years) from population information system in Finland was carried out via telephone interview. It showed that 86% (4085/4750) of Internet users read media websites, 76% (3610/4750) searched information from Wikipedia or similar wikis, and 56% (2660/4750) participated in social networks such as Facebook or Twitter [11]. In 2013, 80% (3800/4750) of all households in Finland had broadband Internet [11]. Of health information topics sought after on the Web, specific diseases are the most common [1], including disease with a seasonal incidence.

Lyme disease is a tick-borne bacterial infectious disease caused by a spirochete (*Borrelia burgdorferi sensu lato*) [12], which usually occurs in northern temperate climate zones worldwide [13], including Northern Europe (Nordic countries), Central and Eastern Europe, and North America (the United States and Canada). Incidences of Lyme disease differ depending on the month of the year (seasonal variation) and its specific ecological conditions, thus, making the risk of Lyme disease infection greatest between late spring and autumn [12]. In Finland, located in Northern Europe, the incidence of Lyme disease has increased, and seasonal and regional variation is apparent [13-16]. A bite from an infected tick and the resulting human infection typically occur when people spend time outdoors. Due to seasonal tick activity, the clinical manifestations of Lyme disease [12,13,17] mostly appear during summer [13,17]. In the early stage of the disease, local reddish ring-form skin rash, so called erythema migrans, occurs 3 to 30 days after exposure. Systematic symptoms such as fever, headache, muscular pain, and tiredness are common. Patients diagnosed early with localized Lyme disease can be treated with an oral antibiotic therapy [13,17]. If left untreated, the infection may disseminate throughout the body via bloodstream which results in, for example, joint inflammation and neurological and cardiac manifestations. The most common Internet queries on health information focus on specific diseases and medical treatments [1], including Lyme disease.

When searching current health issues, the searches used to access databases where this information is located may be utilized for disease surveillance. However, early warning systems may not monitor information only on a true epidemic but also on an epidemic of fear (*fear epidemiology*) [10,18]. The use of population health technologies during the severe acute respiratory syndrome (SARS) epidemic demonstrated that an epidemic of fear may trigger changes in collective searching behavior gathered by early warning systems. Thus, false positive warnings may lead to media reports and then affect the public's search behavior on the Internet [18]. Notably, the general population's awareness of currently common infectious diseases may have an effect on health information searches on Google, which could be escalated by the media [8,10]. Along with current common infectious diseases, Lyme disease has also stirred interest among Internet users who have searched information related to Lyme disease via Google [5]. These search data from Google Trends have approximated the trends in seasonality and spatial distribution previously identified in Lyme disease [5]. As in the SARS epidemic [18], Lyme disease could also trigger an epidemic of fear, especially at the time of extensive media coverage on Lyme disease. This may lead to a positive feedback loop between Lyme disease searches and media coverage [18]. Two terms are defined when framing methods on health-related Internet information and epidemiological data [19]: infodemiology (information epidemiology) and infoveillance (information surveillance). Infodemiology is defined as a discipline within public health informatics that studies information in an electronic medium or in a population, with the aim of informing public health and public policy. When infodemiology data are used for surveillance purposes, the term used is infoveillance [19]. Lyme disease, serving as a well-defined disease entity, was used in our previous study [14] where we showed that HCPs' searches of Internet evidence-based medicine sources coincided with national register-based data on the geographical findings of Lyme disease diagnoses. Lyme disease searches of Internet medical databases presented seasonal and regional variation, and a suggestion was made to consider searches as an additional information source for disease surveillance. Although Internet users' health information–seeking behavior has been studied previously [1-3,7,8], little data exist on the general public's health information searches of a dedicated medical database on the Internet. Therefore, Lyme disease was chosen as the indicator for our study to be evaluated from Internet medical portals.

Duodecim Medical Publications Ltd (owned by the Finnish Medical Society Duodecim) publishes a wide selection of medical information targeted at HCPs [20]. It also produces and maintains an Internet medical portal called Health Library (Terveyskirjasto in Finnish) aimed at the general public (population of Finland: 5.5 million people, 2016 [21]). This publicly available portal consists of more than 10,000 medical articles that were opened over 50 million times in the year 2016. Each opened article is tracked in a log file. The articles in Health Library follow the guidelines published on the Internet-based commercial portal service (Terveysportti), where the principal service is the Physician's Databases, produced and maintained by Duodecim Medical Publications Ltd. Quality criteria of Health on The Net [22] are met in the production process of the articles in Health Library. Physician's Databases includes point-of-care Evidence-Based Medicine Guidelines designed for clinical practice comprising 1300 primary care practice guidelines. In the guidelines, more than 4000 treatment, medication, or diagnostic recommendations are linked to quality-graded evidence summaries and further to Cochrane full-text reviews when available [23]. When producing the guidelines, Duodecim Medical Publications Ltd follows the process accredited by the National Institute for Health and Care Excellence (NICE). The databases also include, for example, 120 National Current Care Guidelines published by Duodecim Medical Society, access to the Cochrane library, *Duodecim Medical Journal*, *Finnish Medical Journal*, acute care database, drug databases, search engine for ICD-10, and procedure codes. Every year, approximately 15 million health-related articles are opened from Physician's Databases. Over 500 medical professionals within their own field of expertise participate in updating and developing the articles. Physician's Databases is available to HCPs throughout the Finnish health care system by employers; thus, the health care centers and hospitals purchase the right to use the service. The users of databases can be tracked in primary and specialized health care and also in pharmacies by an Internet protocol address included in a log file. Approximately two-thirds of Physician's Databases' users consist of physicians working in Finland (personal communication with P Mustonen, August 21, 2017), where there were over 20,000 working-age physicians in 2016 comprising 60% (12,507/20,970) females and 40% (8463/20,970) males [24]. Other users include nurses and pharmacists. The contents of both Health Library and Physician's Databases are in Finnish.

Hypotheses

The primary aim of our study was to compare the general public's openings of Health Library articles on Lyme disease to HCPs' openings of Physician's Databases articles on Lyme disease seasonally throughout Finland from 2011 to 2015 and to evaluate how information-seeking trends from Internet medical databases differ seasonally over a 5-year period (January 2011-December 2015). We hypothesized that the timing of the general public's and HCPs' article opening on Lyme disease is mainly similar, thus, making it possible to use the general public's article openings as an additional source of information for disease surveillance. However, we also assumed a priori that patterns would contain some differences in start and end points between openings in the Health Library and Physician's Databases. The secondary aim of our study was to evaluate whether media publications on Lyme disease are associated with the general public's Health Library openings outside epidemic seasons. The hypothesis was that media coverage has an influence on the general public's article opening related to Lyme disease.

Methods

Study Design and Data Collection From Internet Medical Portals

We carried out a descriptive register-based study on the general public's and HCPs' article openings related to Lyme disease from Internet medical portals to compare logs to evaluate seasonal variations of Lyme disease across Finland from 2011 to 2015. We retrieved retrospectively logs of both articles in the Health Library and Physician's Databases by assessing the number of openings of Lyme disease articles weekly by the general public and HCPs, respectively. The Health Library logs include only data on the article openings of Lyme disease across the entire country with no geographically distributional data, whereas the Physician's Databases logs include both openings and searches on Lyme disease for all 21 health care districts in Finland. Therefore, the article openings of Lyme disease for the whole country were chosen to allow comparable data from Health Library and Physician's Databases. Users may access the Health Library database through different paths. Less than a fifth of users are not directed to Health Library via Google (personal communication with P Mustonen, May 4, 2017). This seems to be the case in Lyme disease, as most search Lyme disease from a general search engine such as Google by using words *borrelioosi* (borreliosis in Finnish) or *borrelia*. Health Library's article on Lyme disease is one of the first links to come up directing the information seeker to the Health Library database, whereas others use the Health Library's home page link from the Web browser's address bar to link directly to the Health Library database. Along with accessing Internet medical databases, users may also browse media websites, including information on Lyme disease.

Table 1. The top five Finnish media websites, their types, and the number of weekly browsers.

Media website	Type of media	Number of weekly browsers on media website in December 2013 (week 50)
Helsingin Sanomat	The largest daily subscription newspaper	1.6 million
Ilta-Sanomat	Tabloid	2.6 million
Iltalehti	Tabloid	2.8 million
MTV	The commercial television station	1.6 million
Yle	The national public broadcasting company	1.8 million[a]

[a] In 2015 (week 50).

Collection of Publications From Media Websites

The three largest and most influential nationwide media companies in Finland are Sanoma, Yleisradio (Yle), and Alma Media [11]. Sanoma consists of the largest national subscription daily newspaper (Helsingin Sanomat) and a tabloid (Ilta-Sanomat). Alma Media consists of a commercial television station (MTV) and a tabloid (Iltalehti). Yle is the national public broadcasting company in Finland. In addition to printed (the daily newspaper, Helsingin Sanomat, and tabloids Ilta-Sanomat and Iltalehti) or broadcasted (television stations, MTV and Yle) information, these media also provide information to consumers via digital platforms, for example, on their websites. We chose these five media for further study because of the large number of weekly browsers on their websites in 2013 [11,25]. In December 2013, the number of website browsers ranged from 1.6 to 2.8 million per week. The data on Yle website browsers was 1.8 million per week in January 2015, whereas the data were not available for 2013. In 2013, a random-sampled survey via telephone interview (4750 people included) showed that Internet daily reached 84% (3990/4750) of Finnish people aged 15 to 69 years, 83% (3943/4750) of females and 85% (4038/4750) of males [11]. A total of 88% (4180/4750) and 77% (3658/4750) daily reached the Internet mass media in the younger age group of 15 to 44 years and older age group of 60 to 69 years, respectively [11]. The top five Finnish media websites with their characteristics are shown in Table 1. Each media website has a search functionality on their home page allowing consumers to search for the information they desire. We collected publications on Lyme disease by searching the words *borrelioosi* and *punkki* (borreliosis and tick in Finnish) using the websites' search functionality. Articles on Lyme disease were categorized by publication date for every week to be comparable to weekly openings in the Health Library and Physician's Databases.

Results

Visually Similar Patterns

Our study showed visually similar seasonal patterns in the general public's and HCPs' article openings on Lyme disease. The seasonal variation across Finland from 2011 to 2015 is shown in Figure 1. The general public's article openings related to Lyme disease start at the beginning of May, peak from May to September, and then decline to the lowest point from December to April. HCPs' article openings on Lyme disease start rapidly at the end of April, peak from June to August, and then decline to the lowest point from December to January. The openings of Health Library and Physician's Databases peaked at 14,956 in May 2015 and at 2144 in July 2012, respectively. The openings of Health Library were lowest at 169 in February 2011 and Physician's Databases at 79 in December 2012. From 2011 to 2015, the general public's article openings on Lyme disease considerably increased in both the maximum (from 3329 to 14,956, 4.5-fold increase) and minimum values (from 169 to 1197, 7.0-fold increase), whereas HCPs' maximum article openings per week mostly remained constant (from 1868 to 2132, 1.1-fold increase). The number of maximum and minimum article openings by year in the Health Library and Physician's Databases are shown in Table 2.

Three Off-Season Peaks

The number of media publications on Lyme disease published outside epidemic seasons from 2011 to 2015 are shown in Figure 2. From 2013 to 2014, there were three off-season peaks in openings occurring simultaneously with media publications. In January 2013, three media publications occurred simultaneously as a peak in the general public's article openings, whereas a peak in the HCPs' article openings appeared before the publications. In December 2013, peaks in HCPs and nonprofessionals' article openings were seen simultaneously with two media publications. In November 2014, two publications were simultaneously present with article openings in the Health Library.

Publications From Media Websites

Table 3 shows the number of Lyme disease media publications released on the top five Finnish media websites during off-season months from 2011 to 2015. A total of 25 media publications were retrieved from media website platforms comprising 21 text articles, two text articles with a notice of TV documentary, one notice of TV documentary, and one radio program. Publications were divided into three categories: institutional articles, personal stories, and other publications on Lyme disease. The 15 institutional articles included university or research institution publications or a specialist's view. The 7 personal stories included a person's experience on Lyme disease. One publication included both the institutional view and personal story. Two other articles included journalists' reports on ticks or Lyme disease excluding institutional or personal views. The data are shown in Table 3 and in Multimedia Appendices 1-3.

Figure 1. The general public’s article openings on Lyme disease in the Health Library (solid line) and health care professionals’ (HCPs’) article openings on Lyme disease in the Physician’s Databases (dashed line) across Finland from 2011 to 2015.

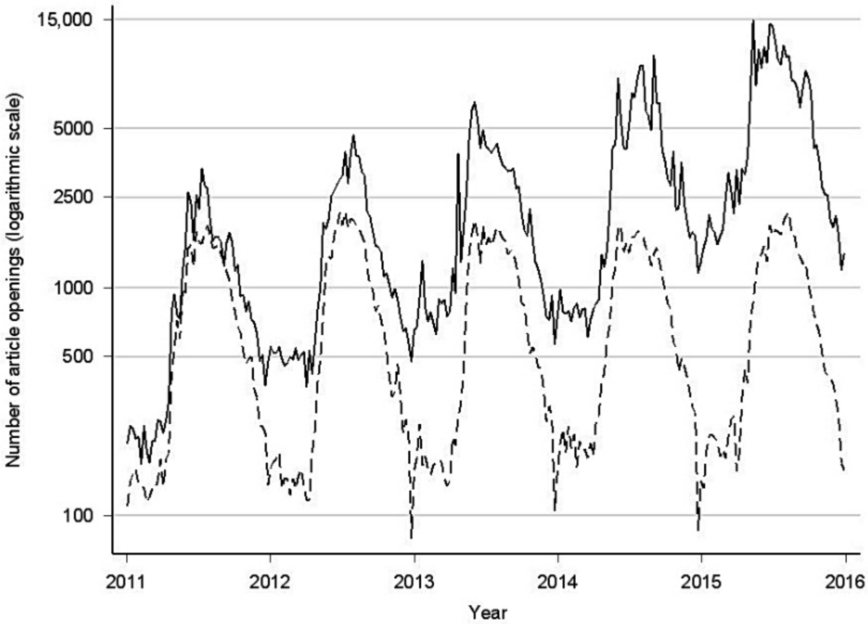

Table 2. The general public’s article openings on Lyme disease in the Health Library and health care professionals’ (HCPs’) article openings on Lyme disease in the Physician’s Databases across Finland from 2011 to 2015. The annual number of the maximum or minimum article opening shows when the opening took place (month, week) during each year.

Article openings on Lyme disease	Year				
	2011	2012	2013	2014	2015
Health Library					
Maximum number of article openings per year	3329	4660	6505	10430	14956
Maximum opening month per year	July	July	June	September	May
Maximum opening week per year	28	31	23	36	20
Minimum number of article openings per year	169	368	566	608	1197
Minimum opening month per year	February	April	December	March	December
Minimum opening week per year	6	14	52	12	52
Physician’s Databases					
Maximum number of article openings per year	1868	2144	1977	1874	2132
Maximum opening month per year	July	July	June	June	August
Maximum opening week per year	30	29	23	23	33
Minimum number of article openings per year	110	79	105	86	132
Minimum opening month per year	January	December	December	December	January
Minimum opening week per year	1	52	52	52	2

Figure 2. The general public’s article openings on Lyme disease in the Health Library (solid line) and health care professionals’ (HCPs’) article openings on Lyme disease in the Physician’s Databases (dashed line) across Finland during Lyme disease off-season months from 2011 to 2015. Vertical bars stand for media publications.

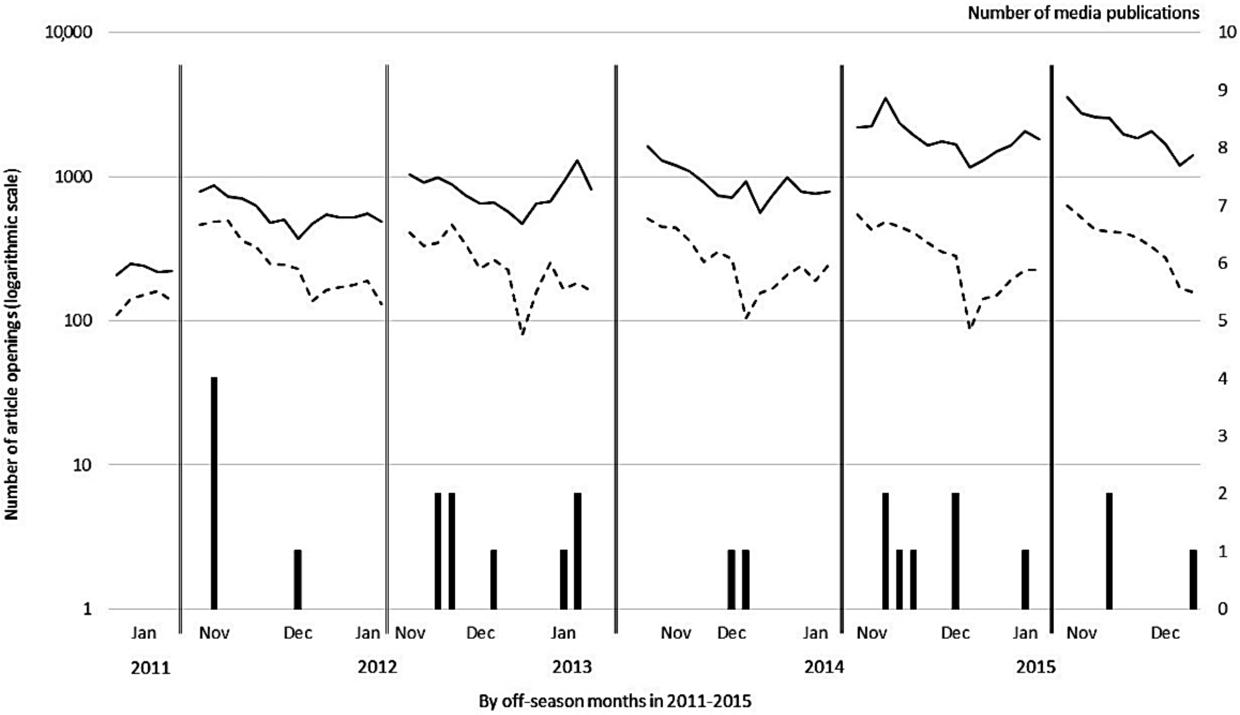

Table 3. The number of Lyme disease media publications released on the top five Finnish media websites during off-season months (January, November, and December) from 2011 to 2015. Publications are divided into institutional articles (university or research institution or specialist's view), personal stories, or other articles. The type of data retrieved from website's platform is placed in the parentheses.

Year	Month	Week	Number of media publications per month	Media (website)				
				Helsingin Sanomat	Ilta-Sanomat	Iltalehti	MTV	Yle
2011	January		-					
2011	November	45	4	Institutional (text)		Institutional (text)		Institutional (radio program), other[a] (text)
2011	December	51	1					Institutional (text)
2012	January		-					
2012	November	46-47	4	Institutional (2 texts)	Personal story (text)			Institutional (text)
2012	December	50	1		Personal story (text)			
2013	January	3-4	3		Institutional (text)		Institutional (text)	Personal story and institutional (text)
2013	November		-					
2013	December	50-51	2		Personal story (text)	Institutional (text)		
2014	January		-					
2014	November	46-48	4	Personal story (text including notice of TV documentary on Yle), other[b] (text)	Personal story (notice of TV documentary on Yle)			Institutional (text including notice of TV documentary on Yle)
2014	December	51	2					Institutional (2 texts)
2015	January	4	1		Personal story (text)			
2015	November	47	2	Institutional (text)				Institutional (text)
2015	December	53	1	Personal story (text)				

[a] A journalist reports ticks and Lyme disease.

[b] A journalist reports the different kind of ticks.

[c] A hyphen (-) and blank cell indicate that no publications are available.

Discussion

Principal Findings

To our knowledge, this is the first study on the general public's information-seeking behavior on Lyme disease from a dedicated Internet medical database. We found the information-seeking behavior of the general public and HCPs on Lyme disease to share a visually similar temporal pattern (Figure 1), which resembles the trend demonstrated by epidemiological data [13,14,16]. In addition, the general public's opening patterns from Health Library appeared more seasonally fluctuating, and they increased over time in comparison with the rather stable HCP-opening patterns of Physician's Databases. In addition, we found occasional associations between Health Library article openings and media publications on Lyme disease during off-season months.

Visually similar temporal patterns in information-searching behaviors between the general public and HCPs mirror the trend seen in epidemiological data on Lyme disease. Due to known seasonal and regional variation of Lyme disease and the conclusions in our previous study [14] using HCPs' Internet searches on medical databases as a supplementary source of information for disease surveillance, we suggest that the general public's article openings from Internet medical databases should be considered as an additional information source for disease surveillance. Such a conclusion should be drawn very carefully, however, and further studies are needed.

From 2011 to 2015, the general public's article openings from Health Library appeared to fluctuate more and showed a net increase compared with the seasonal steadiness and absence in weekly fluctuation in openings from Physician's Databases performed by HCPs. In Finland, the incidence of Lyme disease has increased and also geographically expanded [16]. Therefore, we speculate that across the country, the general public is more aware and is seeking more information on the disease. In addition, the significant increase in the article openings of Lyme disease in the Health Library may be the result of an increase in net openings in the Health Library. In addition, it is possible that whereas HCPs have easier access to English-language websites, a language barrier with the general public could direct more traffic to Health Library, which consists of articles in Finnish. The increasing minimums in openings from Health Library (7.0-fold increase) compared with steady openings from Physician's Databases are clearly present, which indicates the general public's interest in Lyme disease also in the wintertime. It is also likely that HCPs are better informed on Lyme disease than the general public, thus, showing less fluctuation in opening patterns. The general public has shown a seasonally different interest on Lyme disease compared with HCPs. Publications on Lyme disease released in the media may be one of the factors affecting the public's different information-seeking behavior.

Most media publications were text articles (21/25) and institutional texts (15/25). Considering the total of published articles, no clear relation between published institutional texts or personal stories and the general public's information-searching was found (Multimedia Appendices 1 and 2). However, if merging all types of publications (personal stories, institutional, and other publications), three opening peaks were associated with publications. The following peaks in searches by the general public coincided with released media publications. In January 2013, there were two institutional texts and one personal story with institutional view. In December 2013, there was one institutional text and one personal story. In November 2014, there were two personal stories with a notice of TV documentary on Lyme disease. It is possible that not only a certain type of publication changes searching behavior among the general public but actually a variety of them do, especially when published in a short period of time, ranging from a day to 2 weeks. In fact, a peak occurred with the public's openings in November 2014, perhaps caused by two personal stories with notices of TV documentaries on Lyme disease, thus, suggesting that personal stories trigger the public to watch the Lyme disease documentary on TV and then start searching for further information from Health Library. We hypothesized that the multiple-peaked patterns caused by vigorously fluctuating openings in the Health Library during both maximum and minimum seasons could have been affected by media publications. However, the general public's article openings outside epidemic seasons are not consistently caused by publications, although three peaks could be associated with media coverage.

Comparison With Prior Work

Google search engine log data on current diseases among the general population, for example, people's queries on influenza or acute respiratory or flu-like symptoms, have been used for disease surveillance [8,10,19]. Infodemiology studies health information on the Internet, such as log data on influenza, to improve public health [19]. Monitoring influenza, infoveillance has been used for assessing the epidemiology of influenza but with conflicting results. It included substantial flaws in geographic scales and timing, such as overestimating the intensity of the epidemic and missing the first wave of the influenza pandemic [8]. In addition, general search engines could not characterize their users, which consisted of both HCPs and the general public. We have previously demonstrated that Lyme disease searches by HCPs in evidence-based medicine databases on the Internet aimed at HCPs coincided with diagnoses, suggesting these searches could be used as an additional information source for disease surveillance [14]. However, it should be noted that not only do the diseases among the general public affect their information-seeking on the Internet but also health-related publications in the media and a fear of disease epidemic may have an influence on Internet searching behavior [8,10,19], also in the case of Lyme disease [12,26].

Limitations

The study includes certain limitations. Those searching information on Lyme disease using Google are presented with a large number of potential informational websites. Those choosing to proceed to the Health Library website may be more health conscious or more capable of filtering medical data than people not familiar with this. Although the regional variation of Lyme disease incidence in Finland is known [15,16], the geographical diversity data on Health Library openings are not available, and therefore, geographical comparisons could not be made. In addition, possibly because of the small number of off-season publications, the association between every media publication and Health Library opening during Lyme disease off-season months could not be defined, even if some publications did occur at a peak in Health Library or Physician's Databases article openings. It is, however, worth noting that not only the general public but also HCPs may have been influenced by media publications. Although we collected publications from media websites with the largest number of page browsers, Lyme disease publications on less frequented websites may also exist. We cannot rule out that some visitors in Health Library could have been HCPs. Furthermore, visitors other than HCPs could have accessed the Physician's Databases as well. However, we consider the strengths of our study to be its timeliness (real-time Internet databases) and representativeness (HCPs in the case of Physician's Databases).

Conclusions

We found that the general public's searching behavior on Lyme disease from medical Internet databases has considerably increased during summertime and wintertime from 2011 to 2015. This indicates that as interest in Lyme disease coincides with increasing numbers of Lyme cases, the Internet openings could be used as a supplementary source of information for disease surveillance. Vigorously fluctuating seeking behaviors outside epidemic seasons was associated with media coverage on Lyme disease only occasionally. Not every publication was associated with an increase in openings but the higher the media coverage by some publications, the higher the general public's access to Health Library. Further research will be needed to validate our method and apply it to other current diseases published in the media.

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Authors' Contributions

SP, MJV, JS, PM, MK, and OH were involved in planning the study concept. SP performed the literature search. PM and SP gathered and supplied the study data. SP carried out the data analysis. SP, MJV, and JS carried out the data interpretation. JS and OH were involved in the final approval and critical revision. MJV, JS, PM, and MK were involved in the critical revision. SP drafted the manuscript. SP and OH are the guarantors.

Conflicts of Interest

MK reports various trustee positions in the Medical Society Duodecim since the late 1990's. OH reports various trustee positions in the Medical Society Duodecim and Kustannus Oy Duodecim since 2009. Other authors have no competing interests.

Multimedia Appendix 1

The general public's article openings on Lyme disease in the Health Library (solid line) and HCPs' article openings on Lyme disease in the Physician's Databases (dashed line) across Finland during Lyme disease off-season months from 2011 to 2015. Vertical bars stand for Lyme disease media articles published by universities or research institutions or a specialist's view (institutional texts).

[JPG File, 76KB - publichealth_v3i4e86_app1.jpg]

Multimedia Appendix 2

The general public's article openings on Lyme disease in the Health Library (solid line) and HCPs' article openings on Lyme disease in the Physician's Databases (dashed line) across Finland during Lyme disease off-season months from 2011 to 2015. Vertical bars stand for media publications on a person with Lyme disease (personal stories).

[JPG File, 73KB - publichealth_v3i4e86_app2.jpg]

Multimedia Appendix 3

The general public's article openings on Lyme disease in the Health Library (solid line) and HCPs' article openings on Lyme disease in the Physician's Databases (dashed line) across Finland during Lyme disease off-season months from 2011 to 2015. Vertical bars stand for media publications other than personal stories or institutional publications in the media.

[JPG File, 72KB - publichealth_v3i4e86_app3.jpg]

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Abbreviations

HCPs: health care professionals
NICE: National Institute for Health and Care Excellence
SARS: severe acute respiratory syndrome

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Original Paper

Discrepancies Between Classic and Digital Epidemiology in Searching for the Mayaro Virus: Preliminary Qualitative and Quantitative Analysis of Google Trends

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Abstract

Background: Mayaro virus (MAYV), first discovered in Trinidad in 1954, is spread by the Haemagogus mosquito. Small outbreaks have been described in the past in the Amazon jungles of Brazil and other parts of South America. Recently, a case was reported in rural Haiti.

Objective: Given the emerging importance of MAYV, we aimed to explore the feasibility of exploiting a Web-based tool for monitoring and tracking MAYV cases.

Methods: Google Trends is an online tracking system. A Google-based approach is particularly useful to monitor especially infectious diseases epidemics. We searched Google Trends from its inception (from January 2004 through to May 2017) for MAYV-related Web searches worldwide.

Results: We noted a burst in search volumes in the period from July 2016 (relative search volume [RSV]=13%) to December 2016 (RSV=18%), with a peak in September 2016 (RSV=100%). Before this burst, the average search activity related to MAYV was very low (median 1%). MAYV-related queries were concentrated in the Caribbean. Scientific interest from the research community and media coverage affected digital seeking behavior.

Conclusions: MAYV has always circulated in South America. Its recent appearance in the Caribbean has been a source of concern, which resulted in a burst of Internet queries. While Google Trends cannot be used to perform real-time epidemiological surveillance of MAYV, it can be exploited to capture the public's reaction to outbreaks. Public health workers should be aware of this, in that information and communication technologies could be used to communicate with users, reassure them about their concerns, and to empower them in making decisions affecting their health.

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KEYWORDS

digital health; digital epidemiology; emerging viruses; Mayaro virus; arboviruses; epidemiology; epidemiological monitoring

Introduction

Mayaro virus (MAYV) was first discovered in Trinidad in 1954 and isolated by Charles Anderson and collaborators from the blood of 5 febrile forest workers [1-3]. MAYV is similar to the chikungunya and Semliki Forest viruses, being a linear, positive-sense, single-stranded, enveloped RNA virus, more specifically an arbovirus of the family Togaviridae and of the genus *Alphavirus*) [4]. MAYV is generally spread by the *Haemagogus* mosquito [5], but it can also be spread by *Aedes aegypti* and *Aedes albopticus* mosquitoes, which appear to be competent vectors as well [6,7]. Rubber workers are particularly at risk of developing MAYV infection.

In the past, small and occasional outbreaks have been described mainly in the Amazon basin of Brazil and a few other parts of South America [8-11]. The first epidemics were reported in 1955 in Brazil and Bolivia [12]. The reemergence of MAYV is cause for great concern for both public health organizations and communities. Anthropogenic changes in ecosystems and environments, due to a variety of phenomena, including urbanization, globalization and migration, agricultural intensification, and deforestation, together with displacement of populations and invasion of wildlife habitats by humans and domestic animals, are playing a major role in MAYV reemergence. Climate changes, economic downturns, and poverty are further drivers of the reemergence of neglected tropical diseases [13]. Therefore, eliminating mosquito breeding sites constitutes an important preventive measure. Efforts to strengthen and improve pathogen surveillance technologies are also fundamental in programs to control disease.

MAYV infection is a nonfatal and generally self-limiting disease causing arthritis in the knee, ankle, and small joints of the extremities, generalized myalgia, frontal headaches and photophobia, vertigo, nausea and epigastric pain, and chills, followed in two-thirds of patients by a fine maculopapular rash affecting the trunk and the extremities. In some cases, MAYV infection can persist up to 2 months.

In May 2007, an outbreak occurred in Chuquisaca Department, Bolivia, and involved 12 persons [14]. In January 2010, a French tourist, after a 15-day trip in the Amazon forest, Brazil, reported MAYV infection [15]. In 2011, MAYV was diagnosed in a 27-year-old male Swiss tourist returning from Peru [16]. MAYV disease was also imported into the United States by 2 infected people who had visited eastern Peru [17] and, more recently, into the Netherlands by a couple infected during their holidays in Suriname [18].

In June 2010, an outbreak occurred in Venezuela, with 69 cases in Ospino, Portuguesa state, and 2 additional cases in San Fernando de Apure, Apure state, on June 7, for a total of 71 confirmed cases as of June 8 (out of the initially reported 77 cumulative cases) [19]. A single case of MAYV infection in an 8-year-old child with fever and abdominal pain was described in rural Haiti (in the Gressier-Léogâne area, 20 miles west of Port-au-Prince) in 2015 [20].

In conclusion, MAYV has been so far isolated in humans, wild animals, and mosquitoes in Bolivia, Brazil [21,22], Colombia, Costa Rica, French Guiana [23], Guatemala, Guyana, Panama, Peru [24], Suriname, Trinidad, and Venezuela [25].

Given the emerging importance of MAYV [26-28], we here aimed to explore the feasibility of exploiting a Web-based tool for monitoring and tracking cases of MAYV infection.

Methods

Google Trends (Google Inc) is a freely available, online tracking system that, properly using keyword(s), enables a visualization of hit-search volumes in terms of relative search volumes (RSVs). In more detail, for each keyword or string of keywords, searches can be performed using search term or search topic strategies. With the first option, Google Trends tracks and monitors the exact text typed by the user. The second strategy, instead, consists of an exhaustive and systematic collection of all searches semantically related to the given query. Generally, the second search option results in broader findings.

A Google-based approach seems to be particularly useful to monitor infectious diseases epidemics [29]. Pelat and collaborators [30], as well as Valdivia and Monge-Corella [31], documented the usefulness of using Google Trends in capturing influenza and chickenpox outbreaks. The nowcasting or forecasting approach has been used also for other tropical diseases, such as malaria [32], Ebola [33], West Nile virus [34], and dengue [35].

In this study, we systematically searched Google Trends from its inception (January 2004 through to May 2017), using as keywords “virus Mayaro,” “Mayaro virus,” “virus de Mayaro,” and “virus del Mayaro.” We carried out this investigation according to the guidelines and recommendations put forth by Nuti and coworkers [36].

We built an ad hoc database of cases of MAYV by extensively mining Google, Google Scholar, the scholarly literature (PubMed or MEDLINE, Scopus, Scientific Electronic Library Online, and Latin American and Caribbean Health Sciences Literature), epidemiological alerts (from the US Centers for Disease Control and Prevention, European Centre for Disease Prevention and Control, World Health Organization, and Pan American Health Organization), HealthMap, and ProMED-mail reports.

Since Web searches can be prompted by different external or environmental cues (media coverage, education system, etc), we carried out a multivariate regression analysis according to the following predictive model:

$$\text{RSV}(\%) = \alpha \times \text{scientific interest} + \beta \times \text{epidemiology} + \gamma \times \text{media impact} + \varepsilon.$$

We measured “scientific interest” by counting the number of MAYV-related articles indexed in PubMed or MEDLINE in the study period, using scientific production as a proxy of the interest of the scientific community toward MAYV; “epidemiology” was the number of confirmed MAYV cases; we assessed “media impact” as the number of MAYV-related news items released in the openly available news aggregator Google News as a proxy of the media coverage and influence over public opinion; and ε is the intercept of the model.

This model was theoretically inspired by the extant scholarly literature on infodemiology and infoveillance [37-40] and, in particular, on Google Trends, as well as by a study by Segev and Baram-Tsabari [41], which systematically investigated different search patterns in terms of the roles of the media and the education system.

We chose the best model according to the goodness-of-fit statistical model.

All statistical analyses were performed with IBM SPSS (version 24.0; IBM Corporation). Figures with a *P* value less than .05 were considered statistically significant.

Results

Figure 1 shows the MAYV-related RSV trend. A burst in search volumes can be noticed in the period from July 2016 (RSV=13%) to December 2016 (RSV=18%), with a peak in September 2016 (RSV=100%). Before this burst, the average search activity related to MAYV was very low (median 1%).

Figure 2 and Table 1 show the countries with major search volumes. MAYV-related queries were concentrated in the Caribbean.

According to the best multivariate regression model, both scientific interest and media coverage had an impact on seeking behavior, with negative and positive effects, respectively (Table 2,Figure 3,Figure 4).

Textbox 1 lists the top MAYV-related and rising queries. These mainly related to MAYV infection symptoms (eg, fever, influenza-like symptoms), its carriers and vectors of transmission (eg, mosquitoes of the *Aedes* genus), and other similar tropical diseases (eg, yellow fever, malaria, dengue, chikungunya).

Table 3 reports the different models and their goodness-of-fit statistics.

Figure 1. Time trend of Mayaro virus-related Web searches as captured by Google Trends worldwide in the study period (from January 2004 to May 2017). RSV: relative search volume.

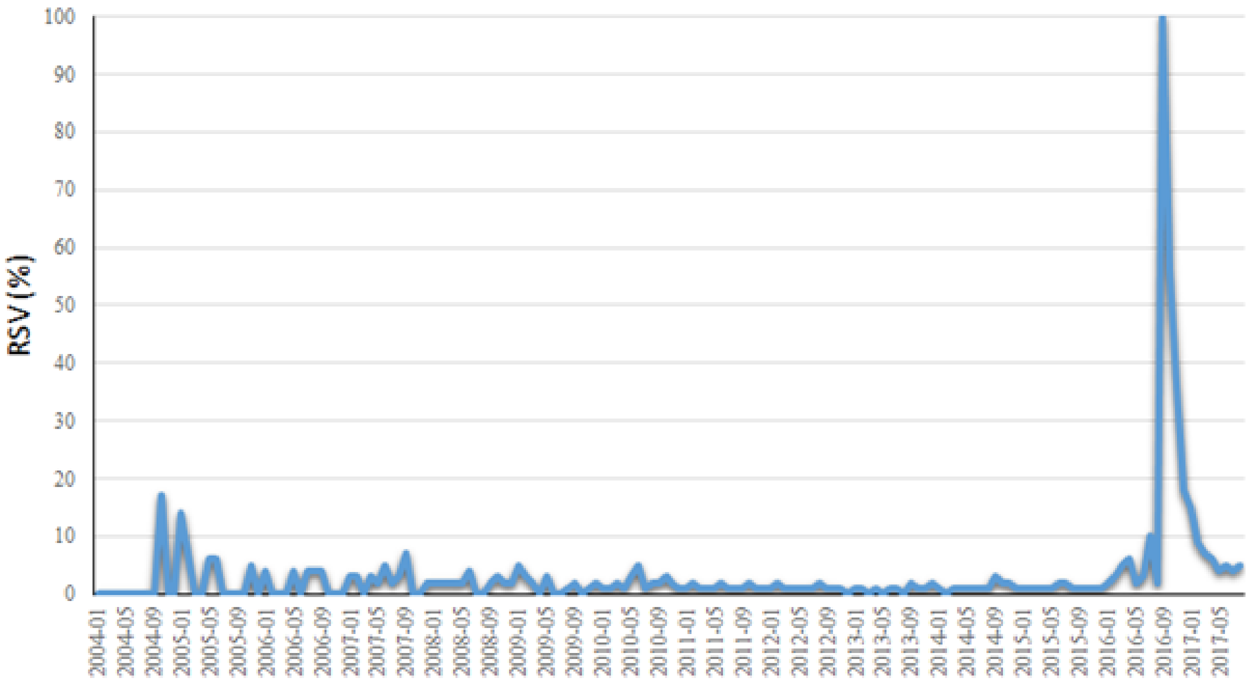


Figure 2. Spatial trend of Mayaro virus-related Web searches as captured by Google Trends worldwide in the study period (from January 2004 to May 2017).

Table 1. Countries in which Mayaro virus-related Web queries were concentrated in the study period.

Region	RSV[a] (%)
Curaçao	100
Dominican Republic	48
Trinidad and Tobago	24
Puerto Rico	22
Nicaragua	20
Honduras	17
El Salvador	15
Martinique	12
Guadalupe	11
Colombia	10
Guatemala	9
Venezuela	8
Jamaica	7
Panama	4
Mexico	3
Ecuador	2
Brazil	2
Costa Rica	2
Argentina	1

[a] RSV: relative search volume.

Table 2. Multivariate regression models estimating the impact of different predictors[a].

Source	Value	SE	T	*P* value	95% CI
Epidemiology					
Intercept	27.313	22.046	1.239	.24	–20.720 to 75.347
Cases	0.352	0.434	0.811	.43	–0.593 to 1.297
Epidemiology + media impact					
Intercept	14.684	4.313	3.405	.006	5.192 to 24.176
Cases	0.028	0.086	0.328	.75	–0.160 to 0.217
Google News	0.718	0.041	17.648	<.001	0.628 to 0.807
Epidemiology + scientific interest					
Intercept	–12.942	31.445	–0.412	.69	–82.152 to 56.267
PubMed	5.628	3.331	1.689	.12	–1.704 to 12.960
Cases	0.341	0.404	0.846	.42	–0.547 to 1.230
Epidemiology + media impact + scientific interest					
Intercept	27.358	5.288	5.173	<.001	15.575 to 39.141
Confirmed cases	0.002	0.065	0.038	.970	–0.143 to 0.148
Google News	0.783	0.037	20.936	<.001	0.699 to 0.866
PubMed	–1.931	0.635	–3.043	.01	–3.345 to –0.517

[a] The epidemiological predictor is given by the number of confirmed Mayaro virus cases; the bibliometric predictor is given by the number of articles published in PubMed or MEDLINE; the media predictor is given by the number of news items concerning the Mayaro virus.

Figure 3. Temporal trends of the different data streams used in the investigation, during the study period (January 2004 to May 2017). GN: Google News; GT: Google Trends; MAYV: Mayaro virus; RSV: relative search volume.

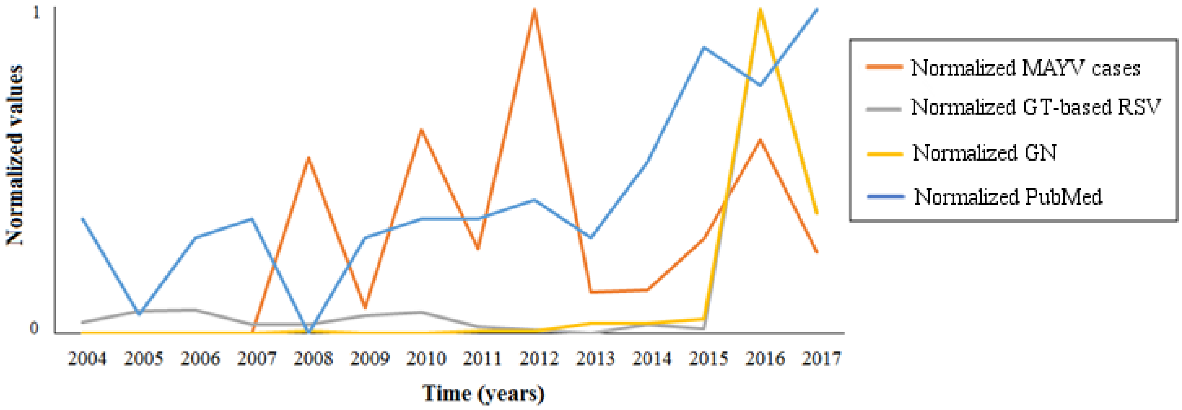
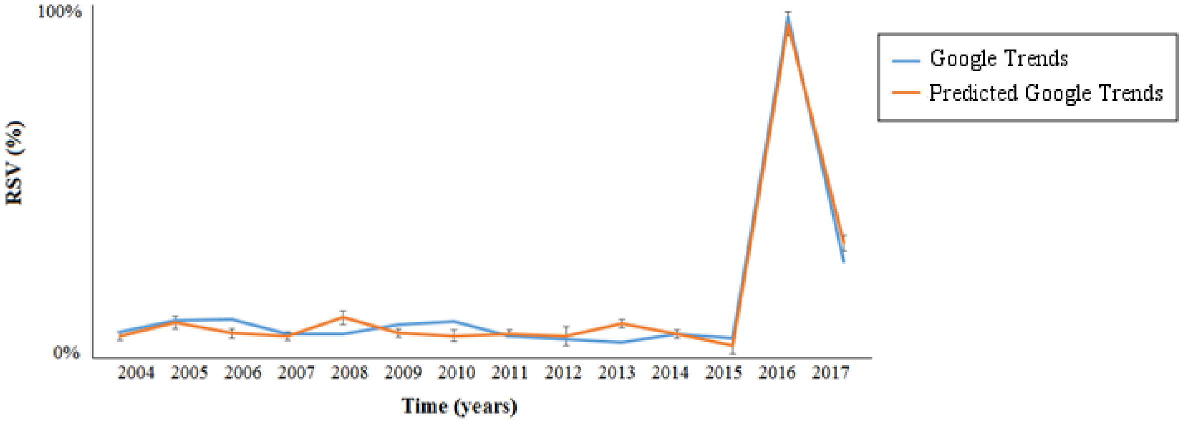


Figure 4. Fit between Google Trends and its prediction according to the best multivariate regression model. RSV: relative search volume.



Textbox 1. The top Mayaro virus-related and rising queries as captured by Google Trends in the study period.

Top related queries

- Virus
- Symptoms
- Disorder
- Fever
- Mayaro, Trinidad
- Chikungunya
- Virus Zika
- Dengue
- Aedes
- Mosquito
- Yellow fever mosquito
- Virus Usutu
- Colombia
- Venezuela
- Haiti
- Yellow fever
- World Health Organization
- Midge
- Vaccine
- Alphavirus
- Encephalitis
- Influenza
- Centers for Disease control and prevention
- Malaria

Rising queries

- Symptoms
- Disorder
- Fever
- Mayaro, Trinidad
- Chikungunya
- Virus Zika
- Dengue
- Aedes
- Mosquito
- Yellow fever mosquito
- Virus Usutu
- Colombia
- Venezuela
- Haiti
- Yellow fever
- World Health Organization

- Midge
- Vaccine
- Alphavirus
- Encephalitis
- Influenza
- Centers for Disease control and prevention
- Epidemic outbreak

Table 3. Goodness-of-fit statistics for the different multivariate regression models.

Fitting parameter	Epidemiology	Epidemiology + media impact	Epidemiology + scientific interest	Epidemiology + scientific interest + media impact
R^2	.052	.968	.247	.983
Adjusted R^2	–.027	.962	.110	.978
Mean square of errors	3898.689	145.088	3376.945	82.855
Root mean square of errors	62.439	12.045	58.111	9.102
Mean absolute percentage error	119.495	36.418	122.541	29.780
Durbin-Watson statistic	1.615	1.447	2.489	1.796
Mallows C_p coefficient	2.000	3.000	3.000	4.000
Akaike information criterion	117.599	72.306	116.370	65.129
Schwarz Bayesian criterion	118.878	74.224	118.287	67.685
Amemiya prediction criterion	1.264	0.050	1.163	0.030

Discussion

Principal Findings

The geospatial and temporal epidemiology of MAYV as captured by Google Trends did not reflect the real-world epidemiology of MAYV. For example, Google Trends did not capture several epidemic outbreaks (briefly overviewed in the introduction), including one of the largest MAYV outbreaks, which occurred in northwestern Venezuela in 2010, in a rural village, with 77 cases and 19 individuals confirmed seropositive [19].

Moreover, areas in which MAYV is known to circulate and spread were scarcely represented in terms of search volumes, while areas in which MAYV has been isolated only recently and has never been seen before, such as in the Caribbean, were overrepresented. In the case of MAYV, Google Trends seemed to capture more of the public reaction to MAYV reemergence in terms of worries and concerns, rather than the real-world epidemiological figures. In the last years, there have been concerns about the ability of MAYV to mutate and adapt to new environments, spreading from South America to North America and other countries, and emerging as a “new Ebola,” a “new Zika,” or the “next chikungunya,” thus giving rise to a new public health emergency [26]. The last decades have been characterized by the reemergence of several arboviruses and, above all, by unexpected changes in their clinical history, such as that Zika virus infection can result in neurological disorders and fetal microcephaly [42]. This has led to public concerns and worries, amplified, in their turn, by imbalanced and distorted media coverage. In the case of MAYV, as can be seen using Google News, a freely available aggregator of media news, the report of a single case of an infected child attracted more media attention than all other MAYV cases in South America, as well as receiving more tweets and videos. On the other hand, this single case report suggested that MAYV-related scenarios are changing or could be further changing in the near future, making the possibility of finding MAYV in urban locations carried by anthropophilic insect vectors more concrete [43].

MAYV-related queries concerned above all the symptoms of the infectious disease. No query was related to preventive measures (either environmental or personal hygiene) that could be taken to reduce and mitigate its spreading. This undoubtedly constitutes a major gap in knowledge that public health workers and officials should fill, by providing and disseminating adequate information.

Specifically concerning Google Trends, its validity in complementing classic epidemiological and surveillance techniques and approaches has recently been questioned by some scholars. While there is a relatively huge body of literature reporting the feasibility of exploiting Google Trends in the field of digital epidemiology [44,45], some scholars have criticized Google Trends, showing that it may be inaccurate in some cases, such as that of influenza surveillance [46,47]. Google Flu Trends, based on Google Trends for the epidemiological monitoring of influenza, has been publicly withdrawn, following different criticisms (Google Dengue Trends met a similar fate).

On the other hand, Santillana and collaborators [48] demonstrated that some techniques, inspired by data assimilation techniques, supervised machine learning, and artificial intelligence, could be applied to improve the reliability of Google Flu Trends.

Cervellin and colleagues [49], on the contrary, found that Google Trends was a scarcely reliable epidemiological tool in a variety of clinical settings, ranging from renal colic or epistaxis to mushroom poisoning, meningitis, *Legionella pneumophila* pneumonia, and Ebola fever.

Similarly, Tran and coworkers [50], searching Google Trends for "suicide" from 2004 to 2010 in the United States and Switzerland, and from 2004 to 2012 in Germany and Austria, found that Google Trends was not able to forecast national suicide rates.

Our study showed that media coverage resulted in seeking behavior and that this impact can be quantified using a multivariate regression model. This is in line with the findings of Segev and Baram-Tsabari [41], who found that ad hoc events or current concerns correlated better with media coverage than did general or well-established scientific terms. Indeed, MAYV, being an emerging virus, represents a relatively overlooked research field and only recently has caused severe public health problems and concerns, which have resulted both in increased media attention and coverage (as shown by Google News) and increased interest from the scientific community (as shown by the bibliometric data), as well as in higher search volumes from the public (as shown by Google Trends).

Strengths and Limitations

This study has some strengths, including the systematic search of MAYV-related queries and the novelty of the investigation, being the first, to the best of our knowledge, to address the topic of the relationship between MAYV and information and communication technologies (ICTs).

However, our investigation is not without limitations. The major drawback is that Google Trends returns relative, normalized values instead of providing scholars with absolute, raw figures that can be further handled, refined, and statistically processed. A second shortcoming is the digital divide, in that Google Trends captures only that segment of the population that actively uses the new ICTs and devices. However, this segment is constantly growing and increasing. A third drawback is that, when using Google Trends, only Google-based searches and queries can be tracked and monitored. On the other hand, Google is the most commonly used search engine worldwide.

Conclusions

MAYV, an arthropod-borne virus, has always circulated in South America. Its recent appearance in the Caribbean has been a source of concern, which has resulted in a burst of Internet queries. While Google Trends cannot be used to perform real-time epidemiological surveillance of MAYV, it can be exploited to capture the public reaction to outbreaks, in terms of worries, and knowledge needs and gaps [51]. Public health workers and officials should be aware that they can use Google Trends to easily track and monitor public reaction and popular perceptions, and use ICTs to communicate with users, reassure them about their concerns, and empower them in making decisions affecting their health [51-54].

Further studies in the field are needed, especially using other ICTs and social media or networks, such as Twitter, Facebook, or Instagram, as well as carrying out a content analysis of MAYV-related digital material. Moreover, techniques for correcting and revising Google Trends should be systematically explored, for example, correlating Web searches with environmental parameters (such as rainfall, temperature, or weather), which are well known to have an impact on the epidemiology of neglected tropical infectious diseases.

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Conflicts of Interest

None declared.

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Abbreviations

ICTs: information and communication technologies
MAYV: Mayaro virus
RSV: relative search volume

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Original Paper

The Seasonal Periodicity of Healthy Contemplations About Exercise and Weight Loss: Ecological Correlational Study

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Abstract

Background: Lack of physical activity and weight gain are two of the biggest drivers of health care costs in the United States. Healthy contemplations are required before any changes in behavior, and a recent study has shown that they have underlying periodicities.

Objective: The aim of this study was to examine seasonal variations in state-by-state interest in both weight loss and increasing physical activity, and how these variations were associated with geographic latitude using Google Trends search data for the United States.

Methods: Internet search query data were obtained from Google Trends (2004-2016). Time series analysis (every 2 weeks) was performed to determine search volume (normalized to overall search intensity). Seasonality was determined both by the difference in search volumes between winter (December, January, and February) and summer (June, July, and August) months and by the amplitude of cosinor analysis.

Results: Exercise-related searches were highest during the winter months, whereas weight loss contemplations showed a biphasic pattern (peaking in the summer and winter months). The magnitude of the seasonal difference increased with increasing latitude for both exercise (R^2=.45, $F_{1,49}$=40.09, beta=−.671, standard deviation [SD]=0.106, P<.001) and weight loss (R^2=.24, $F_{1,49}$=15.79, beta=−.494, SD=0.124, P<.001) searches.

Conclusions: Healthy contemplations follow specific seasonal patterns, with the highest contemplations surrounding exercise during the winter months, and weight loss contemplations peaking during both winter and summer seasons. Knowledge of seasonal variations in passive contemplations may potentially allow for more efficient use of public health campaign resources.

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KEYWORDS

healthy lifestyle; weight loss; exercise; Internet; motivation

Introduction

One of the biggest drivers of health care costs in the United States is poor health behavior [1], and the two most associated factors with cardiovascular disease are obesity [2] and a sedentary lifestyle [3]. Attempts to promote diet and exercise are expensive; in fact, the US Government spends approximately 75 billion dollars per year in public health campaigns [4] with mixed results [5].

Traditionally, surveys have been used to examine health behaviors, but they have well-known limitations such as the tendency of respondents to answer in a socially desirable manner

[6] and a long time lag between data collection and analysis [7]. A new technique, referred to as “Infodemiology,” allows researchers to look into the motivations of patients through the use of open access records of Internet search activity [8,9]. As Google has made their search data accessible to the public, analysis of these data allows a glimpse into a population’s hidden healthy contemplations, an area that is difficult to measure with standard surveys [7]. This open access search data allow researchers to undertake a new type of ecological correlational study [6]. Ecological studies that examine the association between variables at a population level have a long history in the generation of hypotheses for future research [10]. This study looks for population-wide associations between Google search data and latitude to look for potential seasonal and geographic patterns in healthy contemplations.

The real-time nature of Internet search data [7] allows new investigations into the periodicity of healthy contemplations. A recent study has examined the day of the week that is the “healthiest day” [11] and the day on which more people are contemplating smoking cessation [12]. The seasons also have an effect on healthy contemplations; interest (as measured by Internet search activity) on mental health conditions peaks during the winter months [13], whereas searches for information on restless leg syndrome [14] and urinary tract infections [15] peak during the summer months. Healthy behaviors such as healthy eating [16] and increased physical activity [17] show strong variations with the seasons. Low levels of vitamin D also show strong seasonal variability [18], and this variability increases with increasing northerly latitude [19]. Given the well-established associations between both obesity [19] and low levels of outdoor activity [20] with vitamin D levels, it suggests that contemplations around weight loss and exercise may also show both seasonal (winter vs summer) and geographic (increasing northern latitude) patterns. Discovering the periodicity of healthy contemplations allows us insight into the otherwise hidden thoughts of populations and is one potential method of more accurately timing public health education initiatives.

This study seeks to examine the seasonality of passive healthy contemplations on a state-by-state basis with respect to weight loss and exercise by examining the relationship between the seasonal variations in Google searches for these terms and geographic latitude. As a previous study has suggested that physical activity [17] and healthy eating [16] increase in the summer months, we hypothesized that healthy contemplations surrounding increasing physical activity would show much more seasonality than those surrounding weight loss.

Methods

Internet Search Data

Google Trends is a Web-based tool that can compute how many searches have been performed for any given keyword or combination of keywords. This system automatically normalizes search activity for overall search activity to a score between 0 and 100 [21]. Search activity can be narrowed to any given country and state within a country. In keeping with the current standards for reporting Google Trends data [22], search data were obtained in weekly intervals from 2004 to 2016, the database was accessed on August 17, 2016, and the complete text is reported below. As this study only uses publicly available aggregate data, approval from human subjects ethics board was deemed unnecessary.

As in previously published studies, all search terms using search data in the public health field [11-13] were chosen systematically before starting any data analysis and are shown below. We initially started with two initial search terms: “exercise” and “weight loss.” Each of these terms was entered into the keyword search tool [21], a Web-based application (Alphabet Inc.) that suggests keywords commonly related to any entered keyword and the normalized search activity associated with it. All related keywords with a higher search volume were added to our list, and each new keyword was in turn entered into the keyword search tool until no new search terms were located. Our eventual keyword lists for interest in weight loss and exercise were entered together into Google Trends using logical “or” operators. Our total keywords consisted of the following:

- *Exercise keywords*: “exercise,” “how to exercise,” “exercise more,” “exercises,” or “do more exercise.”
- *Weight loss keywords*: “weight loss,” “how to lose weight,” “lose weight,” “losing weight,” “weight loss diet,” “weight loss plan,” “diet plan,” or “diet meal plan.”

Analysis of Seasonality

The magnitude of the seasonal shifts in Internet searches for both weight loss (DeltaWeight) and exercise (DeltaExercise) was initially determined by the difference between the average volume of searches in winter months (December, January, and February) and summer months (June, July, and August) as done in previous studies [13,15].

Seasonal variation in search activity was also obtained using cosinor analysis [23]. Cosinor analysis uses the entire year’s dataset, has been used previously with Google Trends data [14], and uses a parametric seasonal model in which a sinusoid is fit to an observed time series as part of a generalized linear model [23]. Specifically, cosinor analysis provides an assessment of the amplitude, which is a measure of the magnitude of the seasonal variation in the data [23]. Amplitude was determined for search terms related to weight loss (weight loss amplitude) and exercise (exercise amplitude). Cosinor analyses were performed using the season package in R version 3.1.0 (R Project) [24] and were determined using weekly running normalized search data for our total keywords from 2004 to 2016. Latitudes for the center of each state were obtained from the US Department of Commerce [25].

As opposed to seasonality, the average weekly search activity was determined by averaging the number of exercise (MeanExercise)- and weight loss-related (MeanWeight) searches over the entire 2004 to 2016 period.

Statistical Analysis

Our primary response variables were DeltaWeight, DeltaExercise, exercise amplitude, weight loss amplitude, MeanExercise, and MeanWeight on a state-by-state basis. Our predictor variable was the latitude of the center of each state.

Scatterplots were visually inspected for outlier data, and density plots were examined to identify data skewing. Any predictor that demonstrated skewing was logarithmically transformed (base ten) before both univariate and multivariate analyses [26]. Plots of residuals and a quantile-quantile plot were examined for each model. For each simple linear regression, the *F* statistic, the coefficient of determination (R^2), degrees of freedom, and standardized beta coefficients are reported [26]. The R core software package version 3.0.1 (The R Project for Statistical Computing) was used for statistical analysis with a significance level of $P<.05$ [25].

Results

Overall Seasonal Search Patterns

Weekly exercise-related searches in the United States had a mean of 79.6 (SD 0.3), and weight loss-related searches had a mean of 59.2 (SD 0.7). As shown in Figure 1, interest in exercise was highest during winter months, dropping off steadily afterwards. For the entire United States, exercise-related search activity was 91.4 (SD 1.3) during winter months, falling to 80.8 (SD 1.5) during summer months. Weight loss searches demonstrated a biphasic response, with peak search observed during winter (72.7 [SD 5.3]) and summer (70.3 [SD 5.2]) months.

Latitude and Seasonality of Exercise Searches

Seasonal peaks and troughs were more pronounced in states geographically situated at southern latitudes versus those located further to the south (Figure 2). The average number of normalized weekly searches related to exercise (R^2=.07, $F_{1,49}$=3.45, beta=−.256, SD=0.014, *P*=.07) did not demonstrate a statistically significant correlation with state latitude. However, the seasonal difference (DeltaExercise) in exercise-related searches increased at higher latitudes (Figure 3). The correlation between seasonal differences and latitude was demonstrated by both DeltaExercise (R^2=.45, $F_{1,49}$=40.09, beta=−.671, SD=0.106, *P*<.001) and with the cosinor analysis (R^2=.16, $F_{1,49}$=9.37, beta=.401, SD=0.131, *P*=.004).

Latitude and Seasonality of Weight Loss Searches

Similar to the exercise search results, the average number of searches related to weight loss (R^2=.07, $F_{1,49}$=3.78, beta=−.268, SD=0.138, *P*=.06) did not show a significant correlation with latitude. With respect to weight loss-related search activity, DeltaWeight showed a significant correlation with state latitude (R^2=.24, $F_{1,49}$=15.79, beta=−.494, SD=0.124, *P*<.001). However, the cosinor analysis did not show any statistically significant relationship between state latitude and amplitude (R^2=.015, $F_{1,49}$=0.73, beta=−.122, SD=0.142, *P*=.40).

Figure 1. The seasonal changes in healthy contemplations with respect to exercise and weight loss using Google Trends. Google Trends normalizes search activity for overall search activity to a score between 0 and 100.

Figure 2. The seasonal difference in healthy contemplations surrounding exercise are shown by state. Seasonal difference was defined as the normalized number of searches in winter months (December, January, and February) minus the number in summer months (June, July, and August). The lighter blue color corresponds with an increase in seasonal variation.

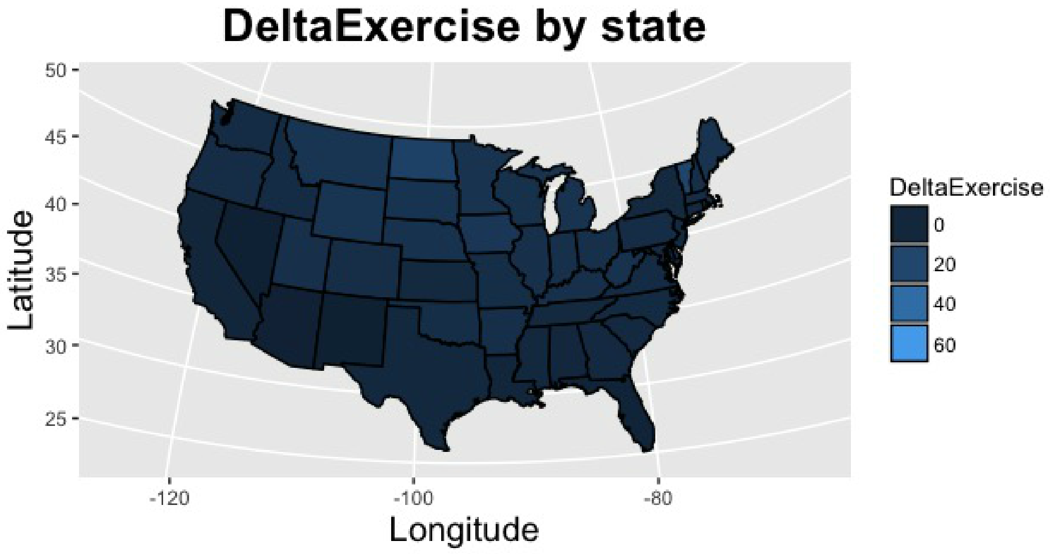
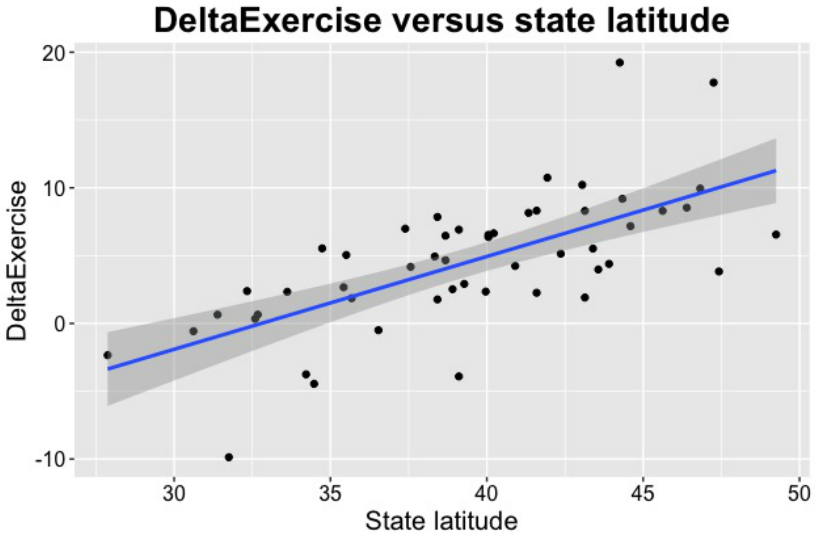


Figure 3. The increasing seasonal difference in healthy contemplations surrounding exercise with increasingly northern latitudes is demonstrated. Seasonal difference was defined as the normalized number of searches in winter months (December, January, and February) minus the number in summer months (June, July, and August).



Discussion

Principal Findings

Healthy contemplations surrounding exercise (as measured by Internet search activity) showed a peak during the winter months as compared with the summer months. Exercise-related searches also showed a strong state-by-state seasonality, showing more seasonal differences with increasing northern latitude. Unlike healthy contemplations around exercise, weight loss search activity demonstrated a biphasic pattern, peaking in both winter and summer months.

Previous Work

It has been well established that physical activity shows strong seasonal variations. Both African American and white children show higher levels of vitamin D in the summer, likely because of increased outdoor physical activity [27]. Objective accelerometer measures have demonstrated higher levels of physical activity in adult women [17], patients with chronic obstructive lung disease [28], and older adults [29,30] during the summer months. Physical activity as measured by a 7-day patient recall of adults aged 20 to 70 years has also shown similar peaks in physical activity during the summer months [31]. Although health behaviors were not measured in this study, our findings demonstrate that contemplations about physical activity do not necessarily parallel health behavior patterns; Internet searches surrounding exercise were shown to peak in the winter as opposed to summer months, and this seasonality increased with increasing latitude.

Previous examination of the seasonality of healthy eating behaviors has shown conflicting results. Dietary log data have suggested that dietary intake patterns have remained stable across all seasons [32,33]. However, a longitudinal examination of the Healthy Eating Index in women aged 40 to 60 years demonstrated less healthy diets during the winter [34]. Markers of healthy eating, such as salad [35] and vegetables [16], are more frequently eaten during the spring and summer months. A more detailed examination of dietary components has shown that both fat and caloric intake are highest during autumn months, but carbohydrate intake is highest in the spring [31]. The seasonality of caloric intake has also been supported by a worldwide correlation between satellite measures of artificial light and obesity [36]. Although this study did not examine dietary behaviors, we were able to demonstrate a biphasic (summer and winter) peak in weight loss contemplations, which diverge from previously established patterns of health behaviors.

Other investigations have examined the periodicity of healthy considerations over various different time scales. A previous analysis of Google Trends data has shown that many healthy contemplations seem to peak earlier in the week (Mondays) as shown for both smoking cessation [12] and searches for the word “healthy” [11]. This weekly pattern suggests that individuals may be more susceptible to public health messaging earlier in the week [11,12]. Our results suggest that the periodicity of healthy contemplations follow a seasonal cycle, as well as a circaseptan cycle, with increased contemplations about exercise occurring in winter months and increased contemplations surrounding weight loss occurring in both winter and summer months.

Clinical Implications and Potential Mechanisms

Our Google Trends measures of healthy contemplations have demonstrated that searches for both exercise and weight loss follow specific seasonal patterns. This suggests that at certain times of the year, populations might be more susceptible to public awareness campaigns, both for exercise (winter months) and weight loss (winter and summer months), and that this greater susceptibility is even larger in more northerly states. Knowledge of seasonal variations in passive contemplations may allow for more effective use of public health campaign resources, although this requires further study. Our study also demonstrated that seasonal patterns in *healthy contemplations* do not necessarily parallel previously demonstrated seasonal patterns in *healthy behaviors*.

The peak in interest in both exercise and weight loss in the winter months may be explained by the tradition of forming New Year’s resolutions; 50% of all Americans participate in this tradition and the most common resolutions involve healthy behaviors [37]. In addition, the fact that interest in both exercise and weight loss showed a larger seasonal shift with increasing latitude indicates that there may be underlying physiological mechanisms behind this pattern. The winter months are characterized by more exposure to artificial light sources [38], resulting in decrease in melatonin production in humans [39]. There is a well-documented relationship between decreased melatonin levels and increasing weight [40]; in fact, melatonin administration in both human [41] and animal studies [42] results in weight loss. This increased weight gain in the winter months may explain both the observed increase in healthy contemplations and the exacerbation of this seasonality in northern states. The peak in weight loss searches during the summer months may be because of the differences in summer as opposed to winter clothing; previous motivational surveys have demonstrated that appearance is the second most common motivating factor for losing weight [43].

Limitations and Future Research

Although this study is suggestive with respect to the seasonal timing of healthy contemplations, Internet searches do not necessarily indicate an intent to pursue healthy behaviors, given that the context underlying each search is not known. Even without this underlying context, a previous study examining tobacco products has suggested that online search behavior can predict offline behavior [44]. It remains to be investigated whether timing public health awareness campaigns to coincide with the seasonal patterns noted in this study will increase their efficacy. In addition, Google Trends only provides normalized results of search data as opposed to absolute number of searches. Offsetting this, however, is the fact that the number of keyword searches for diet and exercise number in the billions [45]; thus, any seasonal increase in normalized results likely represents millions of additional searches.

Conclusions

Healthy contemplations follow specific seasonal patterns, with highest contemplations surrounding exercise during the winter months, and weight loss contemplations peaking during both winter and summer seasons.

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Conflicts of Interest

None declared.

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Abbreviations

SD: standard deviation

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Original Paper

E-Cigarette Surveillance With Social Media Data: Social Bots, Emerging Topics, and Trends

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Abstract

Background: As e-cigarette use rapidly increases in popularity, data from online social systems (Twitter, Instagram, Google Web Search) can be used to capture and describe the social and environmental context in which individuals use, perceive, and are marketed this tobacco product. Social media data may serve as a massive focus group where people organically discuss e-cigarettes unprimed by a researcher, without instrument bias, captured in near real time and at low costs.

Objective: This study documents e-cigarette–related discussions on Twitter, describing themes of conversations and locations where Twitter users often discuss e-cigarettes, to identify priority areas for e-cigarette education campaigns. Additionally, this study demonstrates the importance of distinguishing between social bots and human users when attempting to understand public health–related behaviors and attitudes.

Methods: E-cigarette–related posts on Twitter (N=6,185,153) were collected from December 24, 2016, to April 21, 2017. Techniques drawn from network science were used to determine discussions of e-cigarettes by describing which hashtags co-occur (concept clusters) in a Twitter network. Posts and metadata were used to describe where geographically e-cigarette–related discussions in the United States occurred. Machine learning models were used to distinguish between Twitter posts reflecting attitudes and behaviors of genuine human users from those of social bots. Odds ratios were computed from 2x2 contingency tables to detect if hashtags varied by source (social bot vs human user) using the Fisher exact test to determine statistical significance.

Results: Clusters found in the corpus of hashtags from human users included behaviors (eg, #vaping), vaping identity (eg, #vapelife), and vaping community (eg, #vapenation). Additional clusters included products (eg, #eliquids), dual tobacco use (eg, #hookah), and polysubstance use (eg, #marijuana). Clusters found in the corpus of hashtags from social bots included health (eg, #health), smoking cessation (eg, #quitsmoking), and new products (eg, #ismog). Social bots were significantly more likely to post hashtags that referenced smoking cessation and new products compared to human users. The volume of tweets was highest in the Mid-Atlantic (eg, Pennsylvania, New Jersey, Maryland, and New York), followed by the West Coast and Southwest (eg, California, Arizona and Nevada).

Conclusions: Social media data may be used to complement and extend the surveillance of health behaviors including tobacco product use. Public health researchers could harness these data and methods to identify new products or devices. Furthermore, findings from this study demonstrate the importance of distinguishing between Twitter posts from social bots and humans when attempting to understand attitudes and behaviors. Social bots may be used to perpetuate the idea that e-cigarettes are helpful in cessation and to promote new products as they enter the marketplace.

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KEYWORDS

electronic cigarettes; vaping; Twitter; social media; social bots; electronic nicotine delivery system; infoveillance

Introduction

Electronic cigarettes (e-cigarettes) have climbed in popularity in the United States and elsewhere [1-6]. As e-cigarette use (vaping) rapidly becomes more prevalent, data from online social systems (eg, Google Web Search, Instagram, Twitter, YouTube) can be used to capture and describe the social and environmental context in which individuals use, perceive, and are marketed this tobacco product [7]. These data may serve as a massive focus group allowing for people to organically discuss e-cigarettes unprimed by a researcher, without instrument bias, captured in near real time and at low costs [8].

Internet searches (Google Web Search) for e-cigarette–related terms increased by 450% from 2010 to 2014 in the United States with search volume for e-cigarettes greater in coastal areas (California and New York) in 2010 before becoming more uniformly searched across the contiguous United States in 2014 [9]. Searches for terms indicative of purchasing e-cigarettes have outpaced searches indicative of interest in health concerns or smoking cessation [9]. In a study analyzing e-cigarette–related posts on Instagram, Chu and colleagues [10] reported that images often showed “cloud chasing” (ie, large clouds of aerosol being blown) and “hand checks” (ie, e-cigarette device paired with specific e-juice bottle all held in one hand), suggesting these are appealing characteristics of this emerging tobacco product.

Twitter has been used in tobacco control research with studies showing how tobacco education campaigns can be informed by monitoring tweets [11,12] and which e-cigarette–related messages are likely to spread on Twitter [13], among other studies [14-21]. Ayers and colleagues [22] recently analyzed a sample of e-cigarette–related tweets and reported that social image was the most identified reason for e-cigarette use in 2015. Other identified reasons for e-cigarette use included quitting combustible cigarettes and use indoors [22].

In this study, we demonstrate the feasibility of a Twitter-based infoveillance [7] methodology to document and describe e-cigarette–related conversations on Twitter. We used social network analyses to identify discussions of e-cigarettes by describing which hashtags co-occur in a massive Twitter network. Twitter users use hashtags (ie, terms prepended by the hash mark #) to indicate the context, emotions, or subject matter related to a post. Hashtags serve as a marker for the content of posts that allows users to search for and see posts of other Twitter users even if they do not follow them. Multiple hashtags can be adopted in a single post. When 2 hashtags co-occur in the same post, one can infer that they are related. Building the network of co-occurrence of hashtags (ie, hashtag network) will illustrate concept clusters giving us insights to e-cigarette–related discussions by individuals in their own words. This clustering allows us to see underlying dimensions of meaning that might not otherwise be possible in complex data.

We also used posts and metadata from Twitter to describe where geographically e-cigarette–related discussions in the United States occur to identify priority areas for e-cigarette education campaigns. Additionally, this study builds on earlier work [23,24] and demonstrates the importance of removing social bots (ie, computer algorithms designed to automatically produce content and engage with legitimate human accounts on Twitter) from Twitter data when attempting to understand public health–related behaviors and attitudes. Taken together, findings from this study should inform tobacco control and demonstrate the utility in using Twitter data in enhancing surveillance of health behaviors in general and e-cigarette use.

Methods

Data were obtained by means of Python scripts that continuously polled Twitter’s streaming application programming interface. This service provides a sample stream of data based on key terms and hashtag searches. Tweets were collected between December 24, 2016, and April 21, 2017. The key terms used to collect the tweets included e-cigarette, vaping, etc (see Multimedia Appendix 1 for complete list). The key terms could have appeared in the post or in an accompanying hashtag (ie, vaping or #vaping). The university’s institutional review board approved all procedures.

The terms used to collect tweets during the study period resulted in an initial corpus of 6,185,153 tweets. However, Twitter has quickly become subject to third-party manipulation where computer algorithms designed to automatically produce content and engage with legitimate human accounts on Twitter (social bots) are created to influence discussions and promote specific ideas or products [25]. Social bots are meant to appear as genuine human users operating Twitter accounts; their profiles are often complete with metadata (name, location, pithy quote) and a photo/image. Social bots on average generate more tweets than the average human user. Therefore, social bots are producing more content on a topic. Social bots make indiscriminate references to an array of content while at the same time perpetuating select conversations, giving the appearance that a specific topic is more prominent than it is offline. Their adoption has been documented in a variety of domains, including political astroturfing [26], stock market manipulation [27], spread of misinformation [28], promotional content [29], and in sentiment classification [24].

In order to distinguish between human users and social bots, certain criteria such as information diffusion patterns (based on retweets or mentions), friend features (for example, ratio of followers to followees), content (frequency of nouns/verbs/adverbs in a tweet), and sentiment features (emotion scores) are used. The BotOrNot algorithm combines these features to obtain a single score between 0 and 1 that indicates if a Twitter account is a social bot or not [28,30]. Evaluations of the BotOrNot program have shown that an account is most likely to be a bot if the account score is ≥0.6 [24,27,29]. The method used for bot detection has a detection accuracy above

95%, suggesting that error from inappropriate removal of legitimate accounts is minimal [25]. Spam-specific, unrelated to e-cigarettes, tweets were manually removed based on occurrence of certain keywords (see Multimedia Appendix 1 for complete list). Among the 6,185,153 tweets, 3,994,481 (64.58%) were identified as spam and were removed leaving 2,190,672 tweets remaining in the clean dataset. About a quarter of these tweets, 412,816, contained at least 1 hashtag, yielding 119,964 unique hashtags. Hashtags provide useful information to identify topics of conversation.

To identify topics of e-cigarette–related conversations, we created a Twitter hashtag co-occurrence network and identified co-occurring clusters of hashtags. The concept clusters are built as follows: the network nodes represent all the different hashtags extracted from the tweets, and for each tweet that contains more than 1 hashtag, an edge (link) is placed between the nodes corresponding to the co-occurring hashtags. A weight is associated to each edge to convey the number of co-occurrences. The weighted network that emerges from this procedure is then plotted using the network visualization tool Gephi [31] and inspected to learn which topics are often discussed together.

Given the volume of data, we used specific network conditions to filter the visualized clusters. Among Gephi’s visualization algorithms, we choose the Fruchterman Reingold force-directed layout [32]. The algorithm works in analogy to gravity forces in natural systems: 2 nodes attract each other based on the strength of their interaction (ie, the weight of their link). This type of layout maximizes readability of network visualizations by minimizing node overlap. Given the scale of the Twitter hashtag co-occurrence network, to limit the number of nodes to display, we imposed a filter to hide nodes with low degrees. This filtering process allows us to focus on the most important clusters and nodes, namely those that co-occur more frequently. From Gephi’s algorithms we finally used the Louvain community detection algorithm which is used to reveal the most significant clusters, groups of nodes tightly interconnected [33]. In order to illustrate how results can change due to social bots, we created and inspected the concept clusters from the 2 corpora of tweets, respectively including and excluding social bots and their tweets. We then computed odds ratios from 2×2 contingency tables ([occurrence of specific hashtag among social bots/occurrence of specific hashtag among humans]/[occurrence of all other hashtags among bots except the specific hashtag/occurrence of all other hashtags among humans except the specific hashtag]) to detect if hashtags varied by source using a Fisher exact test to determine statistical significance.

To identify where in the United States e-cigarette–related discussions were taking place, we extracted the user location from the geographic coordinates field of each tweet, which Twitter collects automatically. However, we observed that many tweets did not have the coordinates defined because each individual Twitter account can elect to turn off this function on their mobile phone, device, or computer, preventing Twitter from collecting this information. To overcome this limitation, we translated the location entered by the user in their metadata (eg, Los Angeles) to latitude and longitude coordinates. Given these 2 strategies, we could identify user location for approximately 1% of all users in the analytical sample, representing 36,549 users in the United States. We used a heat map plot to determine where individuals discuss e-cigarettes. In a heat map, stronger color intensity (similarly to heat) suggests higher intensity of use in a specific area and vice versa. By looking at frequency of tweets by location we can see where priority areas exist for e-cigarette education campaigns.

Results

The cluster analysis from the corpus of hashtags from human users contained 238 specific hashtags or nodes and 5203 edges (Multimedia Appendix 2). Cluster 1 (pink) contained hashtags indicative of behaviors (eg, #vaping), vaping identity (eg, #vapelife), and vaping community (eg, #vapenation) (Table 1). Cluster 2 (green) contained hashtags indicative of vaping products (eg, #eliquids), vaping identity, and vaping community. Cluster 3 (orange) contained hashtags indicative of dual tobacco use (eg, #hookah) and polysubstance use (eg, #marijuana).

Table 1. Most common hashtags in each respective cluster from the bot-free corpus.

Cluster[a]	Hashtags
1 (pink)	vaping, ecigs, vapelife, vapeporn, weed, buzz, vaporizer, vapenation, eliquid, cannabis, vape, vapes, bigtobacco, ejuice, smokeshop
2 (green)	eliquids, vaper, vapelife, smoke, instavape, vapecommunity, ecig, vapors, atomizer, vapeclub, vapestagram, vapesociety
3 (orange)	smokers, nowsmoking, cigaretters, tobacco, week, marijuana, cigars, whisky, scotch, smoker, cigarettes, hookah, addiction, blu

[a] Colors correspond to the figure found in Multimedia Appendix 2.

Table 2. Most common hashtags in each respective cluster from the bot corpus.

Cluster[a]	Hashtags
1 (orange)	Cigars, cigar, blu, tobacco, cigarette, smoke, smoking, photography, galanecigars, lifelove
2 (gray)	vapes, vape, vaping, vapor, ecig, ecigs, vapefam, vapelife, vapor, smok, vaporstorm, eliquids, vapepen, vapefamily, vapeshop, vapecommunity, vapeporn, vapers, vaporizer, ecigaretters
3 (blue)	esmoke, esmoking, online, beast, mod, cheap, cigpet, starterskit, esmoker, mobile, ismog, modbox
4 (green)	marijuana, smoking, health, weed, tobacco, cannabis, cbd, thc, cool, bongs, tobacco, quality, cheap, vapes, ejuice, quitsmoking

[a] Colors correspond to the figure found in Multimedia Appendix 3.

Table 3. Associations between hashtags and data source (bots vs humans coded) with an odds ratio > 1 indicating greater likelihood from a bot.

Hashtags	Odds ratio	*P* value
addiction	0.62	.006
atomizer	0.53	<.001
beast	2.72	<.001
bigtobacco	0.08	<.001
blu	1.33	<.001
bongs	1.79	<.001
tobacco	1.05	.002
buzz	0.66	<.001
cannabis	1.81	<.001
cheap	1.81	<.001
cigar	0.66	<.001
cigarette	1.65	<.001
cigarettes	0.55	<.001
cigars	0.54	<.001
cigpet	2.73	<.001
cool	1.58	.03
ecig	0.54	<.001
ecigs	1.52	<.001
ejuice	0.97	.23
eliquid	0.73	<.001
eliquids	1.06	.40
esmoke	2.88	<.001
esmoking	2.87	<.001
esmoker	2.89	<.001
health	1.00	.92
hookah	0.29	<.001
instavape	0.80	.03
ismog	2.89	<.001
marijuana	1.25	<.001
mobile	1.68	<.001
mod	2.47	<.001
modbox	2.41	<.001
nowsmoking	0.70	.003
online	2.78	<.001
photography	0.96	.87
quality	1.80	<.001
quitsmoking	2.27	<.001
scotch	0.02	<.001
smoke	1.00	.85
smoker	2.61	<.001
smokers	1.66	<.001
smokeshop	1.33	.07

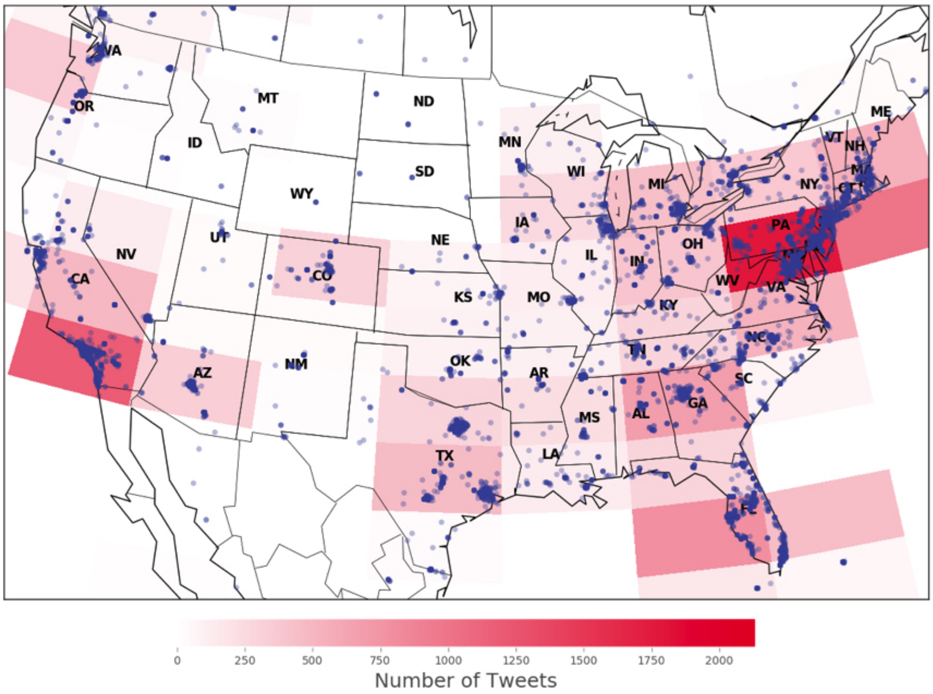
Hashtags	Odds ratio	*P* value
smoking	1.04	.31
starterskit	2.88	<.001
thc	2.43	<.001
tobacco	1.05	.002
vape	0.82	<.001
vapecommunity	0.19	<.001
vapefam	0.34	<.001
vapefamily	1.42	<.001
vapelife	0.63	<.001
vapenation	0.78	<.001
vapepen	0.89	.03
vapeporn	0.90	<.001
vaper	1.86	<.001
vapers	1.67	<.001
vapeshop	1.13	.03
vapesociety	0.34	<.001
vapestagram	0.69	<.001
vaping	1.15	<.001
vapor	0.68	<.001
vaporizer	0.29	<.001
vapors	0.52	.0002
vaporstorm	2.94	<.001
weed	1.03	.5694
whiskey	0.02	<.001

The cluster analysis from the corpus of hashtags from social bots contained 4 clusters with 137 hashtags or nodes and 1600 edges (Multimedia Appendix 3). Cluster 1 (orange) contained hashtags indicative of behaviors and dual tobacco use (Table 2). Cluster 2 (gray) contained hashtags indicative of behaviors and vaping identity and vaping community. Cluster 3 (blue) contained hashtags indicative of products (eg, #starterskit, #modbox), including brand new products (eg, #ismog, a new smart device with touch technology on a vaping box, #cigpet, a new high wattage tank or “super tank”). Cluster 4 (green) contained hashtags indicative of smoking cessation (eg, #quitsmoking), interest in health (eg, #health), and polysubstance use.

Social bots were more likely to post hashtags that referenced smoking cessation and new e-cigarette devices compared to human users (Table 3). For example, social bots were significantly more likely to post #quitsmoking, #ismog, and #cigpet compared to human users.

The heat map representing 26,565 tweets collected from December 24, 2016, to April 21, 2017, shows that the volume of tweets is highest in the Mid-Atlantic (eg, Pennsylvania, New Jersey, Maryland, and New York) and high on the West Coast and Southwest (eg, California, Arizona and Nevada) (Figure 1).

Figure 1. Heat map from December 25, 2016, to April 21,2017, for 26,565 tweets.



Discussion

Principal Findings

Data from online social systems may be used to complement and extend the surveillance of health behaviors including tobacco product use. The hashtags we studied here provide several direct insights into e-cigarette–related attitudes and behaviors with the identification of 3 clusters that represent the most cohesive posts. The cluster analysis from the corpus of hashtags from human users demonstrated the existence of a vaping identity and vaping community. Use of these hashtags may serve further internalization of, and social bonding around, vaping-related identities. These hashtags also suggest discussions of vaping may occur in an echo chamber on Twitter in which ideas and beliefs are amplified by those in the network [34], normalizing vaping.

In the cluster analysis from the corpus of hashtags from human users, we found many references to vaping-related products. These hashtags represent a way for commercial users to make their posts searchable and integrate themselves into online communities of vapers. Noncommercial users may also use these hashtags to communicate to their followers which products they recently purchased or which products they like to use together (eg, their favorite modifiable device paired with their favorite e-liquid) [10].

The third hashtag cluster found in the corpus from human users indicated dual tobacco use and polysubstance use. These co-occurring hashtags may reflect a syndrome of risky behavior among select vapers. While research is accumulating about dual e-cigarette and cigarette use [35,36], there is a dearth of research on the associations between vaping and hookah, marijuana, alcohol, and other substance use. The findings from this study should spur efforts to investigate these associations further. When the population-level impact of e-cigarettes is being debated, the co-occurrence of vaping with alcohol and other substances should also be considered.

In the corpus of hashtags from social bots, several results stood out in contrast to the results from the human user corpus. For one, a cluster of hashtags was detected that referenced smoking cessation. This suggests social bots may be used to perpetuate discussions on e-cigarettes as a cessation device. While earlier research has suggested Twitter posts about vaping referenced the use of e-cigarettes in cessation [22], it is important to distinguish between individual users and social bots when analyzing posts on Twitter [23,24,37]. Social bots may perpetuate misinformation about the efficacy of e-cigarettes in cessation, thus requiring education campaigns to serve as a vehicle to correct this misinformation.

Hashtags from social bots also represented newly introduced products to the marketplace (eg, #ismog and #cigpet) which were significantly less prevalent in the human user corpus of hashtags. This finding highlights a clear benefit of using social media data in public health surveillance. In addition to searching for known keywords and observing trends in the number of social media posts that contain those keywords, the concept cluster analysis can identify new keywords or hashtags posted on Twitter. This process can serve as an early warning system informing public health researchers about new products or new ways in which products are appealing to the public. By using social media data and keyword co-occurrence analyses we can identify new products (like ismog or cigpet), brands, marketing themes, activities, and events associated with tobacco product use as they emerge in near real time. The findings from this study complement recent research that relied on search navigation data to detect growing interest in heat-not-burn tobacco products [38]. Taken together, public health researchers could use data from online social systems to fill knowledge gaps quickly and respond more readily to the populations they serve.

Most posts were from the Mid-Atlantic and Southwest, which is compatible with earlier research relying on search navigation data [9]. The findings mark priority areas for e-cigarette education campaigns. Social media may be one way to engage with nonusers of tobacco products to inform them of the addictive properties of nicotine as well as the harms of e-cigarette use [39]. Using social media as a complementary surveillance system could allow public health researchers to identify geographic disparities in emerging tobacco product use earlier than traditional methods. While Twitter data should not be used to supersede traditional health behavior surveillance systems, social media could be used to fill information gaps quickly and can provide an important starting off point to address an issue of great import to public health or policy.

Limitations

Data collection relied on Twitter's streaming application programming interface, which prevents collecting tweets from private Twitter accounts. As a result, findings may not represent the attitudes and behaviors from individuals with private accounts. This study used hashtags to identify themes in posts on Twitter but did not specifically read and interpret each post that the hashtags accompanied. Additional valuable information could have been learned from the content of the posts that was not described herein. Approximately 1% of all users in the analytical sample provided data that allowed us to describe the geographic areas in which e-cigarette–related discussions took place in the United States. While this is a small percentage, it is compatible with earlier work [25,40] and represents 36,549 users in the United States. Additionally, we did not have the necessary demographic information (eg, age) of Twitter users to consider population density and age distributions of geographic areas.

Conclusion

The findings from this study can inform the design of public health surveillance in the future. This study demonstrated the utility in using social media data in understanding attitudes and behaviors and the importance of distinguishing between Twitter posts from social bots and humans during this process if the intent is to assess views held by real users. Findings should spur efforts to better understand the consequences of e-cigarette–related discussions on Twitter.

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Authors' Contributions

JPA and EF conceived of the study. EF collected the data. EF, SPU, and JPA analyzed the data. JPA drafted the initial manuscript. JPA, EF, TBC, and JBU revised the manuscript for important intellectual content and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Key search terms.

[PDF File (Adobe PDF File), 12KB - publichealth_v3i4e98_app1.pdf]

Multimedia Appendix 2

Concept cluster built from hashtags collected from a bot-free corpus.

[PNG File, 1MB - publichealth_v3i4e98_app2.png]

Multimedia Appendix 3

Concept cluster built from hashtags collected from a bot corpus.

[JPG File, 592KB - publichealth_v3i4e98_app3.jpg]

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Original Paper

Characteristics of Articles About Human Papillomavirus Vaccination in Japanese Newspapers: Time-Series Analysis Study

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This is a corrected version. See correction statement: http://www.jmir.org/2018/3/e27/

Abstract

Background: Media coverage and reports have a major influence on individual vaccination and other health-related activities. People use the media to seek information and knowledge on health-related behaviors. They obtain health-related information from media such as television and newspapers, and they trust such information. While several studies have examined the relation between media coverage and individual health, there is a lack of studies that have analyzed media reports of health information. In particular, we have found no analyses related to cervical cancer (human papillomavirus [HPV]) vaccine.

Objective: This study aimed to identify mentions of cervical cancer vaccine in Japan's printed news media and to determine their characteristics.

Methods: We used the archival databases of 2 Japanese newspapers, *Yomiuri Shimbun* (Yomidasu Rekishikan) and *Asahi Shimbun* (Kikuzo II Visual), for text mining. First, we created a database by extracting articles published between January 1, 2007, and December 31, 2014, that matched the terms "cervical cancer" AND "vaccination" in a keyword search. Then, we tallied the extracted articles based on the month of publication and number of characters in order to conduct a time-series analysis.

Results: We extracted a total of 219 articles. Of these, 154 (70.3%) were positive and 51 (23.3%) were negative toward HPV vaccination. Of the 51 negative articles, 4 (7.8%) were published before June 2013, when routine vaccination was temporarily discontinued due to concerns regarding side effects, and 47 (92.2%) were published since then. The negative reports commonly cited side effects, although prior to June 2013, these issues were hardly mentioned. Although foreign media reports mentioned side effects before routine vaccination was temporarily discontinued, fewer articles mentioned side effects than recommendations for vaccination. Furthermore, on June 13, 2013, the World Health Organization's advisory body Global Advisory Committee on Vaccine Safety issued a statement regarding the safety of HPV vaccines, but hardly any articles reported this statement. Rather, several articles were published about the side effects after June 2013.

Conclusions: Since we consider media coverage to be a factor affecting human health behavior, the media should extensively report on the cost of not receiving cervical cancer vaccination, global trends concerning cervical cancer vaccination, and statements released by various agencies on the subject.

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KEYWORDS

papillomavirus vaccines; immunization programs; uterine cervical neoplasms; newspapers as topic; mass media; data mining; Japan

Introduction

Vaccinations play a significant role in preventing epidemics and the spread of infectious diseases, and a vaccination rate as high as possible is required to maintain the health of an entire society [1]. Japan's vaccination program is regulated by the Vaccination Act [2]. Although it changed from a legal obligation to an obligation requiring an effort in 1994, the current recommended vaccinations include influenza, mumps, and hepatitis B [3]. When it comes to the cervical cancer (human papillomavirus [HPV]) vaccine, public funds are being used in more than 50 countries to provide vaccinations to adolescent girls [4]. In Australia, vaccination is recommended for girls aged 12 to 13 years, and the cost of providing cervical cancer vaccination is entirely covered by public funds. Japan started providing vaccination for cervical cancer in 2010 for girls in the first grade of elementary school to the final year in high school using a grant from public funds. In Japan, Gardasil and Cervarix are the cervical cancer vaccines used. They are effective in preventing infection with HPV types 16 and 18, which are the main causes of cervical cancer. In addition, Gardasil prevents types 6 and 11 HPV, which account for 90% of the cause of condyloma acuminata [5]. By April 2013, considering the reduction in the number of cervical cancer cases, the Vaccination Act stipulated that this vaccination should be mandatory rather than optional. However, the cervical cancer vaccine has become a social issue, with lawsuits being filed due to alleged side effects [6].

From the perspective of herd immunity, one of the key factors of a vaccine's effectiveness is the rate of vaccination. Therefore, the main concern is how to increase it. In general, the factors relating to rate increase have to do with availability of public funds to support programs and the ease of access to medical facilities. Tauil et al reported that the mother's level of education and her socioeconomic condition had an impact on the vaccination rate [7]. Tsuchiya et al found that the mother's age and the primary care physician's recommendation influenced the vaccination rate [8].

Media coverage and reports are also major factors in influencing individual vaccination and other health-related activities. People use the media to seek information and knowledge on health-related behaviors [9]. A study by Hagihara et al found that coverage of suicides in newspapers is significantly correlated to the number of suicides committed the following month [10]. Ishii reported that the number of suicides increased after articles were published on a celebrity's suicide [11]. According to Uesugi, people obtain health-related information from media such as television and newspapers, and they trust such information [12]. On the other hand, Fujioka stated that people may also be skeptical or even critical of health-related activities reported in the media [13].

While several studies have examined the relation between media coverage and individual health, studies analyzing media reports of health information are lacking. In particular, there are few analyses related to cervical cancer vaccine [14,15]. Further studies are needed to examine the relation between media coverage and cervical cancer vaccine.

Therefore, this study aimed to identify reports of the cervical cancer vaccine in Japan's printed news media and to determine their characteristics.

Methods

With the increasing cross-ownership of print media and television networks in recent years, newspapers now report the same type of news as television. On this basis, for this research, we used Yomidasu-Rekishikan, the archival database of *Yomiuri Shimbun* (hereafter, *Yomiuri*), the newspaper with the largest circulation in Japan [16], and Kikuzo II Visual, the archival databases of *Asahi Shimbun* (hereafter, *Asahi*), the newspaper with the second largest circulation. First, we created a database on the subject by extracting articles published between January 1, 2007, and December 31, 2014, and matching the terms "cervical cancer" AND "vaccination" in a keyword search. Then, we tallied the extracted articles based on the number of articles published per month, the number of characters used per month, and the average character count, as well as parsing the articles into the number with a positive or supportive viewpoint, and the number with a negative or oppositional viewpoint. We defined supportive articles as those that included positive comments such as "public funding method of acquisition for programs" or words such as "prevention" and "recommendation." We defined oppositional articles as those that featured content such as side effects and used terms that shed a negative light on cervical cancer vaccination, such as "refrain from" or "pain." Additionally, for each positive and negative article, we counted the numbers of articles that included commentary from experts, that gave an explanation about the cervical cancer vaccine, that included information related to consultation, that included photographs or diagrams, and that dealt with compensation. We then conducted a time-series analysis based on this information.

Results

Tallied Articles and Basic Characteristics

Figure 1 charts the 219 extracted articles to indicate the change in the number of articles published during the years 2007 to 2014. The first article related to the cervical cancer vaccine was published in *Asahi* on February 4, 2007. The number of articles concerning the cervical cancer vaccine increased during 2010. Overall, there were 154 (70.3%) positive articles and 51 (23.3%) negative articles. Figure 1 further shows the change in the number of positive and negative articles published each month since the start of 2010, when the number of articles being published on the subject increased rapidly, until 2013, when both the regulation of the vaccination program and the articles that specifically covered this issue changed. From September 2010, when a grant was established using public funds for the cervical cancer vaccine, until a temporary interruption in the vaccination program in June 2013, a total of 110 positive articles, which made up 96.5% of all articles up to that point, had been published. However, starting in June 2013, all articles on the subject were negative.

Figure 1. Trends in number of articles related to cervical cancer vaccine (January 2010-December 2013) and their viewpoint (positive or negative). GACVS: Global Advisory Committee on Vaccine Safety.

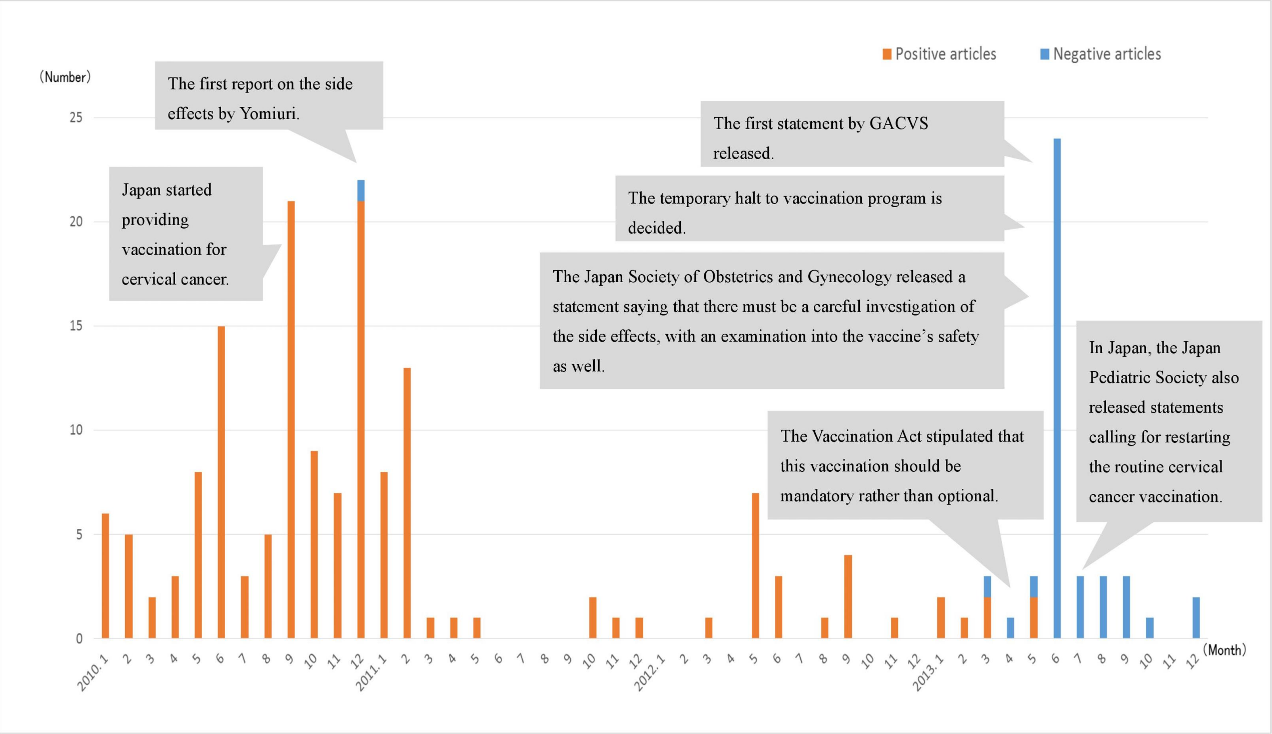

Table 1. Tally of articles with positive and negative viewpoints on cervical cancer vaccination and their characteristics (2007-2014).

Characteristics	Year of publication								Total
	2007	2008	2009	2010	2011	2012	2013	2014	
No of articles retrieved	3	0	1	105	31	17	48	14	219
Total no. of characters	3338	0	829	75,354	21,389	21,810	42,198	42,198	207,166
No. of characters per article	1129	0	829	718	690	1283	879	3014	8542
Positive articles	2	0	1	97	28	17	7	2	154
Expert commentary	2	0	1	60	10	6	0	1	80
Detailed explanation of cervical cancer vaccine	1	0	1	31	8	6	3	1	51
Places where people could consult experts and obtain advice	1	0	1	10	5	0	0	0	17
Photographs or charts	0	0	0	13	2	2	0	0	17
Government compensation	0	0	0	0	1	1	0	0	2
Negative articles	0	0	0	1	0	0	39	11	51
Expert commentary	0	0	0	1	0	0	19	5	25
Explanation of side effects	0	0	0	1	0	0	29	8	38
Places where people could consult experts and obtain advice	0	0	0	0	0	0	1	1	2
Photographs or charts	0	0	0	0	0	0	0	1	1
Government compensation	0	0	0	0	0	0	3	1	4

Analysis of the Coverage of and Article Contents on Cervical Cancer Vaccine

A total of 219 articles regarding cervical cancer were published from 2007 through 2014 (Table 1). No articles on the subject were published during 2008, while most (n=105) were published during 2010. During 2014, the highest number of characters per article (n=3014 characters) was allocated to this subject. Of the 154 positive articles, most (n=97) were published in 2010. The content of the positive articles included commentary by knowledge experts (80 articles), which was the most common characteristic of the positive articles, and 60 of the positive articles with expert commentary were published in 2010. Of the positive articles, 51 included a detailed explanation of the cervical cancer vaccine, and most such articles (n=31) were published in 2010. A total of 17 positive articles listed places where people could consult experts and obtain advice, and 10 of these were published in 2010. Also, 17 positive articles included photographs or charts, and most of these (n=13) were published in 2010. Only 2 articles, 1 published in 2011 and 1 in 2012, focused on government compensation.

Of the 51 negative articles, the majority (n=39) were published in 2013. The content of the negative articles had the following characteristics. Of the 25 articles with expert commentary, 19 were published in 2013. A total of 38 articles gave a detailed explanation of side effects, which was the top characteristic of the negative articles, and 29 of these were published in 2013. In total, 2 articles, 1 published in 2013 and 1 in 2014, focused on where people could obtain consultation and advice. Only 1 article, published in 2014, used photographs or charts. Of the 4 articles that mentioned government compensation, 3 were published in 2013.

Discussion

In this study, we used *Yomiuri* ’s and *Asahi* ’s archival databases to analyze the characteristics of media coverage regarding cervical cancer vaccination in Japan. The first article on cervical cancer vaccination was published by *Asahi* in 2007. There was a marked increase in the number of articles in 2010, and most of them were positive. In 2013, there was an increase in the number of negative articles published.

In 2010, a decision to publicly assist the funding of cervical cancer vaccination led to an increase in the number of articles published that year. On the other hand, the first report on side effects was by *Yomiuri* in a 2010 article titled “Cervical cancer vaccine: many faint, shots on shoulder muscle, severe pain.” This article reported that the research conducted by the Japan Ministry of Health, Labour and Welfare found that one of the side effects of the cervical cancer vaccine was a disruption in balance controlled by the autonomic nervous system, which in many cases causes people to faint [16]. Additionally, the number of articles published on the subject increased in 2013, due to repeated coverage of reported cases about side effects, along with articles about the Ministry of Health, Labour and Welfare recommending discontinuation of the cervical cancer vaccine.

After June 2013, an advisory body of the World Health Organization, the Global Advisory Committee on Vaccine Safety (GACVS), issued 3 statements to encourage restarting routine cervical cancer vaccination [17,18]. The first statement was made on June 13, 2013. After considering the reports on the side effects of the cervical cancer vaccine in Japan, GACVS reassured readers of the vaccine’s safety. The second statement, made on March 12, 2014, emphasized the effectiveness of the vaccine after giving due consideration to the causal relationship between the cervical cancer vaccine and its side effects. In the third statement, released on December 17, 2015, while referring to the policy decision to temporarily discontinue routine cervical cancer vaccination, the GACVS recommended restarting the vaccination program. In Japan, the Japan Pediatric Society and the Japan Society of Obstetrics and Gynecology also released statements calling for restarting routine cervical cancer vaccination [19,20]. Just 8 days after the government paused routine cervical cancer vaccination, the Japan Society of Obstetrics and Gynecology released a statement calling for a careful investigation of side effects, with an examination into the vaccine’s safety as well. However, our study clarified that the newspaper companies barely covered this. In addition, when we overviewed worldwide trends regarding cervical cancer vaccination (Figure 2), it was clear that there was already information available on side effects, yet no articles mentioned this [6]. Additionally, even though the Japan Medical and Scientific Communications Association was established in 2006, no writers or reporters had knowledge about or covered the subject. This suggests that the Japanese printed news media are out of touch when it comes to medical news reports from outside of Japan.

Figure 2. Worldwide trends in cervical cancer vaccination. HPV: human papillomavirus. (Modified by the authors based on Wilson et al [6]).

The research findings indicated that there were very few balanced articles covering the effect and effectiveness of the cervical cancer vaccine, along with its side effects, and most articles were biased and one-sided. Witteman et al reported that biased commentary affects the individual's health-related activities [21]. With public funds came positive reports, and with the temporary halt in the vaccination program, negative articles appeared. It became obvious that reports by each newspaper relied on official statements by the Ministry of Health, Labour and Welfare and victim organizations. Since the causal relationship between the cervical cancer vaccine and its side effects is yet to be proven scientifically, we suggest that, after reading reports relying on official statements, readers would find it even more difficult to make an accurate decision on this issue. At the same time, Chung noted that parents are far more afraid of losing their children to vaccination than to the disease itself [22]. Some parents have a tendency to not vaccinate their children, and media coverage may be encouraging and influencing such tendencies.

In Japan, every year, approximately 15,000 people are given a diagnosis of cervical cancer, and approximately 3500 die of it [23]. This is the second-highest morbidity rate among female-specific cancers after breast cancer and the highest morbidity rate for cancer among those in their 20s and 30s [24]. As we consider media coverage as a factor affecting human health behavior, the media should extensively report on the cost of not receiving cervical cancer vaccination, global trends concerning cervical cancer vaccination, and statements released by various agencies on the subject.

Since we examined only newspaper articles in this study, to develop this research theme further, television, Internet, and other media coverage beyond printed newspaper articles must be researched as well.

Conflicts of Interest

None declared.

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Abbreviations

GACVS: Global Advisory Committee on Vaccine Safety
HPV: human papillomavirus

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Original Paper

Preliminary Findings of a Technology-Delivered Sexual Health Promotion Program for Black Men Who Have Sex With Men: Quasi-Experimental Outcome Study

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Abstract

Background: Human immunodeficiency virus (HIV) disproportionately affects black men who have sex with men (MSM), yet there are few evidence-based interventions specifically designed for black MSM communities. In response, the authors created Real Talk, a technology-delivered, sexual health program for black MSM.

Objective: The objective of our study was to determine whether Real Talk positively affected risk reduction intentions, disclosure practices, condom use, and overall risk reduction sexual practices.

Methods: The study used a quasi-experimental, 2-arm methodology. During the first session, participants completed a baseline assessment, used Real Talk (intervention condition) or reviewed 4 sexual health brochures (the standard of care control condition), and completed a 10-minute user-satisfaction survey. Six months later, participants from both conditions returned to complete the follow-up assessment.

Results: A total of 226 participants were enrolled in the study, and 144 completed the 6-month follow-up. Real Talk participants were more likely to disagree that they had intended in the last 6 months to bottom without a condom with a partner of unknown status (mean difference=−0.608, *P*=.02), have anal sex without a condom with a positive man who was on HIV medications (mean difference=−0.471, *P*=.055), have their partner pull out when bottoming with a partner of unknown HIV status (mean difference=−0.651, *P*=.03), and pull out when topping a partner of unknown status (mean difference=−0.644, *P*=.03). Real Talk participants were also significantly more likely to disagree with the statement “I will sometimes lie about my HIV status with people I am going to have sex with” (mean difference=−0.411, *P*=.04). In terms of attitudes toward HIV prevention, men in the control group were significantly more likely to agree that they had less concern about becoming HIV positive because of the availability of antiretroviral medications (mean difference=0.778, *P*=.03) and pre-exposure prophylaxis (PReP) (mean difference=0.658, *P*=.05). There were, however, no significant differences between Real Talk and control participants regarding actual condom use or other risk reduction strategies.

Conclusions: Our findings suggest that Real Talk supports engagement on HIV prevention issues. The lack of behavior findings may relate to insufficient study power or the fact that a 2-hour, standalone intervention may be insufficient to motivate behavioral change. In conclusion, we argue that Real Talk's modular format facilitates its utilization within a broader array of prevention activities and may contribute to higher PReP utilization in black MSM communities.

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KEYWORDS

HIV; health promotion; sexuality; harm reduction; African Americans; sexual minorities; telemedicine

Introduction

Background

Human immunodeficiency virus (HIV) has disproportionately affected black men who have sex with men (MSM) since the beginning of the epidemic. Today, nearly 40% of individuals living with HIV in the United States are African American, even though African Americans represent only 12% of the US population [1]. Among the more than 350,000 black men living with HIV, approximately half (53%) are MSM [2]. Since 2014, black MSM have been the subpopulation with the highest number of new HIV diagnoses [3], and a recent meta-analysis estimated black MSM incidence rates at 4.16% [4]. If these trends continue, 50% to 60% of black gay and bisexual men will receive an HIV diagnosis in their lifetime, nearly 3 times the percentage of gay and bisexual men overall [3,4].

Despite the devastating impact of HIV on black MSM, there are relatively few evidence-based HIV prevention interventions designed specifically for black MSM [5]. Nor are there any demonstrated efficacious technology-delivered interventions targeting black MSM, despite the growth of effective eHealth and mHealth sexual health programs in recent years [6]. Because funders such as Centers for Disease Control and Prevention (CDC) often require practitioners to use programs with demonstrated efficacy, the lack of evidence-based programs designed specifically for black MSM may limit our ability to respond to black MSM's diverse sexual health needs, identities, and intervention format preferences.

The Real Talk Program

Seeking to offer additional evidence-based HIV prevention options for black MSM and the providers who serve them, the investigators developed Real Talk in both face-to-face and computer or tablet-delivered formats, the latter of which is the focus of this study (see [7] for a detailed presentation of Real Talk's product development and intervention content). Real Talk is loosely based on a popular suite of Afrocentric, group-level HIV prevention interventions developed for adult, teenage, and HIV-positive African-American women—SISTA, SiHLE, and WiLLOW [8]. The trilogy focuses on risk reduction strategies, skills building and peer support using a social cognitive theoretical framework within the context of the intersectionalities experienced by black women. These interventions are part of CDC's Diffusion of Effective Behavioral Interventions (DEBI) library [9] and are also available in 2-hour long computer-delivered versions, all of which demonstrated preliminary efficacy in reducing HIV-related risks [10-12]. Given that black MSM face many of the intersectionalities addressed in the trilogy, including gender/sexuality power dynamics and racism in interactions with the mainstream (white) gay community, the developers believed that the trilogy's Afro-centric empowerment approach might resonate with black MSM and similarly generate improved sexual health outcomes.

In adapting the SISTA/SiHLE/WiLLOW trilogy for black MSM, Real Talk positions HIV prevention within a growing gay health movement that defines sexual health as more than safer sex practices or the absence of disease [13-15]. Real Talk does this through affirming black MSM's resilience in the face of intersecting forms of discrimination and oppression while acknowledging the reality of high levels of HIV prevalence among black MSM [16]. And because individuals vary in their ability—and indeed, desire—to engage in consistent condom use, Real Talk uses a sexual harm reduction framework that recognizes the many HIV prevention strategies that MSM use today. These include serosorting, negotiated safety agreements, and for HIV-negative men, pre-exposure prophylaxis (PReP) [17-19]. Our starting point is to meet people where they are [20] and not judge men because of their (unsafe) sexual behaviors. In addition, unlike many DEBI programs, Real Talk does not attempt to persuade participants to adopt a particular HIV risk reduction strategy or set of strategies (eg, 100% condom use with all partners, monogamous relationships, and decreasing the number of sexual partners). The program instead offers men a 6-step harm reduction tool to help them make sexual health decisions that are in line with their values, life objectives, and the current HIV prevention landscape outlined above. In this framework, condom use is an important, but not the only, sexual health promotion strategy. By being upfront about these realities, we believe Real Talk can more credibly engage men who might otherwise be less responsive to condom-focused interventions while nonetheless not discounting the importance of condoms as an HIV prevention strategy.

We created both the computer and face-to-face versions of Real Talk using an iterative agile product development process that included the following: (1) a Web-based needs assessment of national practitioners recruited through the National Minority AIDS Council in 2012, focus groups with black MSM in Atlanta and San Francisco in 2012-2013, and interviews with HIV prevention providers in these same cities in 2012-2013, (2) prototype testing of 2 activity components of the computer/tablet-delivered program with black MSM in 2013, (3) a run-through of the complete 12-hour face-to-face program in early 2014, and (4) input on design, activity format, and storyboards from a community panel of 6 black MSM throughout programming of the computer/tablet-delivered version in the second half of 2014. The final technology-delivered version of Real Talk plays on PC and Mac computers and Android mobile tablets, with WiFi necessary for optimal user experience. The program's 6 modules take users approximately 2 hours to complete, in comparison to 12 hours for the face-to-face format (Multimedia Appendix 1). Users may stop at any point, resume where they left off, and if they desire, repeat the already completed activities. All modules combine audio narration, visual presentations, interactive components (eg, drop and drag, list creation, and scroll over pop-ups), games, and video clips of black MSM talking about their lives (Multimedia Appendices 2 and). We have also consciously inserted humor within each module to maintain viewer interest (eg, the “mad scientist” presenter for Module 4’s Condom Laboratory) and to defuse potentially emotionally challenging topics (eg, Module 5’s communication style videos, which mirror the over-the-top role-plays that participants created in the 2014 face-to-face curriculum pilot tests).

Real Talk’s content builds on the three central themes identified in our formative research: (1) stigma, discrimination, and intersectionalities in the lives of black MSM, (2) the need for safe spaces and community, and (3) the need for sexual harm reduction approaches in HIV prevention programming [7]. For example, the opening “My Community” module situates sexual health within the broader context of men’s lives and includes self-reflections on user’s relationships with black, gay, and black gay communities and video content addressing racism in gay communities and homophobia within the family. These activities enable men to examine the tensions that can arise from balancing racial, sexual, and other identities and how these processes may affect sexual health decision-making. These themes are revisited in Module 3, where men reflect on stress and coping strategies; in Module 4, where men explore different harm reduction strategies in the unique contexts of their own lives; and in Module 7, where men examine what kind of relationships they would like to have and where they might turn to for sexual health and relationship support.

Study Aims

This study aimed to determine whether a culturally tailored, computer/tablet-delivered, sexual health program can engage black MSM on sexual health issues, promote HIV risk reduction practices, and produce improvements in psychosocial factors linked to sexual risk behaviors. We hypothesized that, relative to the control condition, men in the Real Talk condition at follow-up would report the following: (1) higher levels of intention to reduce HIV risk, (2) increased HIV disclosure with partners, (3) higher levels of condom use for insertive and receptive anal sex, and (4) less risky sexual practices overall. These findings would provide preliminary support for the efficacy of Real Talk and offer organizations a technologically contemporary and easily scalable evidence-based HIV program for black gay men/MSM.

Methods

Recruitment

From June 2015 to May 2016, we conducted a quasi-experimental, 2-arm outcome study at 4 sites to test the preliminary efficacy of the computer/tablet-delivered version of Real Talk in reducing sexual health risks and improving psychosocial factors associated with sexual health (Portland State University IRB Protocol #153352). Two study sites were located in Florida, and one each in Georgia and New Jersey, and all sites have long histories of providing prevention and care services to black MSM. Due to the endogamous structures of black MSM communities [21] and the possibility of intervention effect contamination, we assigned sites to either the Real Talk condition (the 2 Florida sites) or the control condition (the Georgia and New Jersey sites). Our target enrollment was 276 men. Accounting for 15% study attrition, we projected a sample size of 240 men who would complete the baseline, condition, and 6-month follow-up. Based on our formative research and the epidemiological literature on black MSM sexual practices, we estimated that the control condition would report an average of 70% condom protected sex at the 6-month follow-up. Using alpha=.05 and a 2-sided test, this sample size would support the detection of a 10% difference in condom-protected sex between the control and intervention conditions with 80% power.

Sites recruited men through their existing client base, venue-based outreach, social media spaces, and snowball sampling. To be eligible, men were required to self-identity as black/African-American, be between the ages of 18 and 49 years, and report having had sex with a man in the past 3 months. We decided on a cutoff age of 49 years because of the following reasons: (1) the intervention does not include any specific content on aging and sexual health issues, (2) program aesthetics and role-play scenarios were directed toward the 20s to 40s age range, and (3) individuals in the 18 to 49 age range are on average more likely to be sexually active than their older counterparts. During the first session, participants completed a baseline assessment using a computer or tablet administered SurveyMonkey instrument, used Real Talk (intervention condition) or reviewed 4 sexual health brochures (the standard of care control condition), and completed a 10-minute user-satisfaction survey on their impressions of their respective study condition. Six months later, participants from both conditions returned to complete the follow-up assessment. The baseline and follow-up assessments were identical and assessed demographic characteristics; mental health and social support; HIV/STI (sexually transmitted infection) knowledge and prevention atitiudes; partner communication; HIV/STI history; race, identities, and sexuality (intersectionalities); alcohol and drug use; and sexual behavior/risk reduction strategies.

Over the period of June to October 2015, 226 participants were enrolled in the study and completed the baseline assessment and their particular condition, with 106 men in the Real Talk arm and 120 men in the control (Multimedia Appendix 4). Participants received US $50 for completing the first session and US $75 for completing the follow-up assessment. A total of 140 participants returned for the 6-month follow-up assessment, 72 in the intervention condition (67.9% retention rate) and 68 in the control condition (56.7% retention rate). There were no significant sociodemographic differences between the 140 participants retained in the study at follow-up compared with the 86 men unavailable for the follow-up assessment. Men who completed the 6-month post assessment were significantly less likely, however, to report being connected to their families (94/140, 67.1% vs 186/226, 82.3%, *P*=.03) and having healthy relationships with their partners (90/140, 64.3% vs 199/226, 88.1%, *P*=.01) than the baseline sample. One hypothesis to explain this difference may be that socially isolated men may interact more frequently with community-based organizations to meet their psychosocial needs than their more social integrated peers and, as a result, be less likely to be lost to follow-up.

Measures

Risk Reduction Intentions and Disclosure Practices

Risk reduction intentions over the past 6 months were assessed using 22, 1-5 scale, Likert items addressing risk reduction strategies (eg, condom use, serosorting, strategic positioning, pulling out, and not using condoms when positive partner is on ART or has an undetectable viral low) [22]. A 5-item index (alpha=.928) assessed men's confidence in negotiating safe sexual practices with their partners, with higher scores indicating greater partner communication efficacy [23]. Twelve Likert-type items addressed disclosure-related issues (eg, "I will wait for my partner to tell me his status before I tell him mine," "I will tell my partners my HIV status before I have sex with them," and "I will sometimes lie about my HIV status to people I am going to have sex with"). Fifteen questions addressed intentions on sexual practices and risk reduction strategies for the next 6 months [22].

Condom Use and Other Risk Reduction Practices

Condom use and other risk reduction practices were assessed through questions addressing the following: (1) the number of times participants had engaged in particular risk reduction strategies for insertive and receptive anal sex, with separate sections for positive, negative, and unknown status male partners (8 questions per partner HIV status type) and (2) a 24-question examination on each of the participants' last 3 sexual partners, including partner characteristics, discussion of HIV status, risk reduction practices for insertive and receptive anal sex, and reasons for not using condoms for topping and bottoming if applicable [22].

Sexually Transmitted Infections and HIV Status

Men's HIV/STI history was assessed using self-reports of gonorrhea, chlamydia, syphilis, and human papillomavirus diagnoses in the past 6 months, date of last HIV test, result of last HIV test, PrEP use in self-reported HIV-negative men, and ART and viral load testing among self-reported HIV-positive men.

Psychosocial Mediators

We derived psychosocial mediators from the intervention's underlying social cognitive and gender and power theoretical framework and the literature discussed in the introduction section of this study, with the goal of capturing potential changes in mental health, social support, and other factors that may mediate an individual's HIV risk and risk reduction practices. All constructs were assessed using scales with satisfactory psychometric properties developed in evaluations of the face-to-face and computer-delivered versions of the SiSTA/SiHLE/WiLLOW trilogy [11,12,23,24] and behavioral studies with black MSM [18,22,25].

Mental Health and Social Support

Self-esteem was assessed using the 10-item Rosenberg Self-Esteem Scale (alpha=.885) [26] and the 18-item Ways of Coping Questionnaire [27]. We also created 14 yes/no questions addressing men's social support from family, friends, work, and black and gay communities (5 questions on practical support, 5 on connectedness, and 4 on relationship quality).

Prevention Knowledge and Attitudes

Six true/false questions addressed HIV transmission risk knowledge (eg, "HIV is only transmitted through anal sex," "STIs put people at a greater risk of HIV infection," and "sheepskin condoms are better than latex condoms for preventing HIV transmission"). A 5-item index assessed negative attitudes to condom use (alpha=.585) [22], and several sections from the ASSORT! study instrument addressed attitudes toward HIV prevention [22]: importance of HIV risk reduction given the realities of effective HIV treatment (4 questions), relative responsibility of HIV-negative and HIV-positive men for HIV prevention (8 questions), and perceived HIV risk based on the race/ethnicity and age of partners (9 questions).

Identities and Intersectionalities

Fourteen yes/no questions compared the experiences of black men to gay men, women, and heterosexual men of different race/ethnicities. Two open-ended questions and 3 ranking questions examined experiences of discrimination. Nine questions asked where respondents socialize and meet partners, 4 questions measured the number of people who know they have sex with men (ie, friends, family, work, and overall), and the 45-item Aspects of Identity Questionnaire IV (alpha=.971) [28] assessed personal, relational, social, and collective identity orientations.

Alcohol and Substance Use

Two questions addressed alcohol consumption frequency (days used) and intensity (number of drinks per day) in the past 30 days. Four questions addressed substance use just before or during sex in the past 30 days (alcohol, poppers, downers, and painkillers), and 10 questions covered non-prescription substance use in the past 30 days for marijuana, hallucinogens, ecstasy, ketamine, GHB, methamphetamine, crack, powder cocaine, heroin, and erectile dysfunction medications.

User Satisfaction

Participants completed a 22-item user satisfaction survey immediately after viewing Real Talk (intervention) or reviewing the sexual health brochures (control). The user satisfaction included Likert-like scale questions on experience with the program or brochures (ie, enjoyment, presentation, held attention, and clarity) and intervention/material quality (ie, overall design, ease of use, usefulness of information, and potential to help people lower their sexual health risks). Open-ended questions addressed overall impressions, likes and dislikes, new information learned, and suggestions for improving Real Talk or the sexual health brochures.

Data Analysis

Statistical analyses occurred in 3 phases. We first calculated descriptive statistics for sociodemographic variables, hypothesized mediators, and sexual behaviors. We then conducted bivariate analyses to assess differences between conditions, using *t* tests for continuous variables and chi-square test for dichotomous variables. In our third analytic stage, we constructed linear, negative binomial, and linear regressions to assess Real Talk intervention effects at the 6-month follow-up. Variables for which differences at baseline between study conditions were statistically significant ($P<.05$) and which were hypothesized to be linked to outcomes were included as covariates in the models. For continuous outcomes (eg, all scales and the Likert-scale risk reduction practice questions), we constructed separate linear multiple regression models and calculated mean differences, percent relative change, and the corresponding 95% CI and *P* values. For count variables (eg, # of times the participant used particular risk reduction strategies for HIV-positive, HIV-negative and unknown status partners), we constructed separate negative binomial regression models and calculated adjusted means, likelihood ratios, and the corresponding 95% CI and *P* values. For dichotomous outcomes (eg, used condoms during the last anal sex, all yes/no disclosure, social support, connectedness, and knowledge questions), we constructed multiple logistic regression models and calculated adjusted odds ratios, 95% CIs, and corresponding *P* values. Analyses were conducted using SPSS statistics version 23 (IBM Analytics, Armonk, New York).

Results

Participants

A total of 140 participants completed the baseline assessment, study condition, and 6-month post assessment. At baseline, participants had a mean age of 33 years. A total of 66 men (47%) reported being HIV-positive and 57 (41%) being HIV-negative, with the remainder not reporting their HIV status. Sixty-two men (44%) described their sexual identity as gay, 40 (29%) homosexual, 9 (6%) same-gender loving, 15 (11%) bisexual, and 4 (3%) heterosexual. For the sample as a whole, 65% of people in the men's lives knew that they have sex with other men. In terms of the highest level of education, 12 men (9%) reported having less than a high school degree, 46 (33%) a high school diploma, 42 (30%) some college degree, 18 (13%) a 2-year or technical degree, 17 (12%) a 4-year degree, and 4 (3%) having completed graduate work beyond a 4-year degree. Participants' incomes were below national averages, with 34 men (24%) reporting less than $6000/year, 24 (17%) between $6000 and $12,000/year, 33 (24%) between $12,000 and 24,000/year, 33 (24%) between $24,000 and 48,000/year, and 12 (9)% earning over $48,000/year.

Participants reported relatively low levels of stress (mean=2.4 on a 1 to 5 scale, with 5=a great deal of stress, SD=0.84251), high levels of self-esteem (mean=4.2 on a 1 to 5 scale, with 5=highest self-esteem, SD=0.80244), moderately high levels of self-efficacy (mean=3.9 on a 1 to 5 scale, with 5=highest self-efficacy, SD=0.76667), and moderate levels of coping skills (mean=3.26 on a 1 to 5 scale, with 5=the highest level of coping, SD=0.55940). A total of 94 men (67%) also said they had a healthy relationship with their families. Only 51 (36%) men felt that the black community accepts black gay men, whereas 85 men (61%) thought that the white gay community accepts black gay men. In terms of where men socialize, 105 (75%) men reported hanging out and meeting men online, 94 (67%) at gay bars, 92 (66%) at dance clubs, 78 (58%) at community organizations, 77 (55%) at coffee shops and restaurants, 71 (51%) at professional networks, 64 (46%) at the gym, 49 (35%) at church, and 30 (21%) at bathhouses.

Regarding sexual behaviors and risk reduction strategies, 100 of 140 men (71%) reported being single at baseline. The median number of male sex partners in the past 6 months was 2, with a mean of 6 and a mode of 1 (SD=14.064). Of 59 men who reported having insertive anal sex with their last male partner, 25 (42%) said they used a condom the whole time, whereas 35 (58%) of the 60 men who reported having receptive anal sex with their last male partner said they used a condom the whole time. Moreover, 89 of the 125 (71%) men reporting a male sex partner in the past 6 months said that they discussed HIV status with their last male sexual partner. Respondents reported an average of 4.1 on a 1-5 Likert scale (4=agree and 5=strongly agree) for both condom use with different status partners and condom use with unknown status partners. Regarding intentions to use risk reduction strategies other than condoms in the past 6 months, on a 1-5 Likert scale, baseline respondents reported a 3.5 average on serosorting (3=neutral and 4=agree), 2.6 on negotiated safety agreements (2=somewhat disagree and 3=neutral), and 2.5 pulling out when topping. Only 3 men stated they were on PrEP at baseline.

We found statistically significant differences ($P<.05$) between the intervention and control conditions at baseline for 3 variables theorized to be linked to sexual behavior outcomes—age, HIV status, and having someone to talk about dating and relationships. These 3 variables were included as covariates in the linear regression and logistic regression analyses.

Intervention Effects

Intentions and Disclosure

In comparision with the control group condition, Real Talk participants were more likely to disagree that they had intended in the last 6 months to bottom without a condom with a partner of unknown status (mean difference=−0.608, 95% CI=−1.23 to −0.09, $F_{1,94}=5.4$, $P=.02$), have their partner pull out when bottoming with a partner of unknown HIV status (mean difference=−0.651, 95% CI=−1.25 to −0.05, $F_{1,86}=4.64$, $P=.03$), and pull out when topping a partner of unknown status (mean difference=−0.644, 95% CI=1.2 to −0.08, $F_{1,88}=5.23$, $P=.03$), and have anal sex without a condom with a positive man who was on HIV medications approached significance (mean difference=−0.471, 95% CI=−0.95 to 0.01, $F_{1,99}=3.77$, $P=.055$; see Multimedia Appendix 5). Real Talk participants were also significantly more likely to disagree with the following statement: "I will sometimes lie about my HIV status with people I am going to have sex with" (mean difference=−0.411, 95% CI=−0.79 to −0.03, 4, $F_{1,100}=1.54$, $P=.04$). There were no other significant differences on the remaining 11 disclosure Likert scale questions, disclosure of HIV status with the last male sex partner, or the partner communication self-efficacy scale.

Condom Use and Other Risk Reduction Practice

There were no significant differences between Real Talk and control participants regarding condom use for insertive or receptive anal sex at last sexual encounter and the number of partners in the past 6 months with whom they always used condoms for insertive and receptive anal sex. Nor were there any signficant differences regarding use of non-condom-based risk reduction practices, although there were insufficient data to support detailed analyses of the number of times respondents used risk reduction strategies by partner HIV status and type.

Mediators

Men in the control condition were significantly more likely to agree that they had less concern about becoming HIV positive because of the availability of antiretroviral medications (mean difference=0.778, 95% CI=−1.47 to −0.08, $F_{1,110}$=4.84) P=.03), post-exposure prophylaxis (mean difference=0.826, 95% CI=−1.33 to −.33, $F_{1,108}$=10.76, P=.001), and PrEP (mean difference=0.658, 95% CI=−1.31 to −.01, $F_{1,106}$=4.06, P=.05). Control condition participants were also significantly more likely to agree with the statement “sheepskin condoms are better than latex condoms in preventing HIV transmission” (17.6% vs 4.8%, exp (b)=7.10, P=.03). There were no significant differences between the intervention and control conditions on stress, self-esteem, negative and positive coping, self-efficacy, or social support variables.

User Satisfaction

Real Talk participants provided higher satisfaction ratings on a 1 to 5 scale than control condition participants in the 4 principal user experience categories: enjoyment (4.25 vs 3.31, t_{200}=7.02, P<.001), presentation (4.30 vs 3.58, t_{190}=5.53, P<.001), held attention (4.07 vs 3.40, t_{190}=4.43, P<.001), and clarity (4.39 vs 3.68, t_{200}=5.68, P<.001). Real Talk participants also gave significant higher ratings on a 1 to 7 scale on design (6.10 vs 4.68, t_{166}=6.23, P<.001), ease of use (6.07 vs 5.44, t_{196}=2.09, P=.003), usefulness (6.36 vs 5.37, t_{177}=4.65, P<.001), potential to help people lower their sexual health risks (6.39 vs 5.30, t_{170}=5.28, P<.001), and learning something new (83.4% vs 64.2%, χ^2_4=22.8, P<.001).

Discussion

Main Findings

Our study demonstrates that a technology-delivered sexual health promotion program (Real Talk) resonates with black gay men/MSM and supports self-reflection on sexual health and relationship issues. The data further support our first 2 study hypotheses, with Real Talk participants demonstrating, in comparison with the control condition, less intention to have risky forms of anal sex with unknown status partners and to lie about their status to their partners. These results suggest that despite a well-documented trend toward decreased concern about HIV infection and increased sexual risk behaviors in MSM communities [17,29-32], it is possible to reengage MSM on HIV prevention issues. This finding is of particular importance given the results of 2 recent studies that describe how black MSM have higher levels of treatment optimism than men of other race/ethnicities and link these beliefs to increased sexual risks [33,34].

Nonetheless, we found no significant differences between Real Talk and control participants regarding actual risk reduction practices in the past 6 months. There are several possible explanations as to why Real Talk did not generate lower sexual risks. It may be that a one-time, 2-hour intervention is insufficient to support behavioral change on its own, and that Real Talk might contribute more effectively to improved sexual behavioral outcomes if combined with other strategies, including treatment as prevention modalities [35-37]. A second interpretation of the lack of sexual behavioral change may relate to self-presentation and social desirability [38]. Our outcome study data suggest that Real Talk’s extended discussion of the benefits and risks of different sexual harm reduction strategies (eg, serosorting, strategic positioning, and pulling out before ejaculation), including the relative risk ranking of these activities, results in heightened awareness of the risks associated with these acts. This realization may make men less willing to admit that they intend to engage in these practices, a possibility exacerbated when reporting such findings in a survey conducted at an HIV prevention organization. It is also interesting to note that despite its normatively neutral presentation of risk reduction strategies other than condoms, Real Talk did not cause participants to increase their utilization of these strategies, much as participating in needle exchange programs does not lead to increased risk or harm, despite public perceptions to the contrary [39].

Limitations

This study has several limitations. One concern is the sample size. Despite monetary compensation and extensive recruitment and follow-up activities, we did not achieve our target sample size of 240, and our retention rate of 62% was substantially less than the 80% to 90% retention rates we have achieved in similar outcome studies of eHealth interventions in communities of color over the past 5 years. In addition, 20% of men reported having had no male sex partner partners in the past 6 months, and not all men had sex with positive, negative, and unknown status partner or practiced both receptive and insertive anal sex. As a result, our sample does not support detailed analyses of the number of times respondents utilized different risk reduction strategies according to partner HIV status, differences in risk reduction strategies based on relationship status and particular sexual acts (eg, insertive vs receptive anal sex), and the reasons men did not use condoms with their most recent sexual partners. It is possible that with greater power, we would have been able to detect more nuanced differences in sexual risk behaviors between the Real Talk and control groups.

A second concern is the study’s reliance on self-reported data for its outcomes measures—even with computer-administered instruments, such data may not always accurately capture respondents’ actual sexual behavior and may include inconsistent responses [40]. For example, in our study’s post survey, 88 men reported having more than one male sexual partner in the past 6 months in the opening question of the sexual history section. Yet, in the concluding sections on the details of their last 3 sexual partners, only 50 men reported having had a second male partner. This difference could be a result of recollection, but perhaps is more likely a reflection of survey burnout—after 30-45 minutes, men may have preferred to respond that they had not had a second or third partner in the past 6 months to get to the end of the survey more quickly.

A third limitation is our focus on sexual behavior outcomes. We designed our study in this manner to obtain evidence to support Real Talk's inclusion in CDC's DEBI library. However, a growing literature demonstrates that black MSM, in comparison with MSM of other race/ethnicities, have higher rates of HIV infection due to structural factors (eg, health care access, culturally component care, and HIV/STI testing rates) rather than higher levels of sexual risk [41,42]. It is possible that Real Talk may support men's ability to negotiate such structural barriers to sexual health, but we were unable to address these dimensions in our study.

A fourth limitation relates to Real Talk's technological specifications. Our decision to develop a relatively long and unidirectional program (ie, each module's content directly builds on that of preceding modules), rather than a shorter and more flexible app for mobile phones, was based on the promising preliminary efficacy findings of the development team's similar, 2-hour computer-delivered versions of the SiSTA/SiHLE/WiLLOW trilogy [10-12]. At the same time, our development team believed that user experience optimization for a 2-hour long program with extensive video content and interactive components required desktop or tablet platforms rather than a mobile phone app. The lack of a mobile phone app version of Real Talk may have limited men's willingness to participate in the study and may also limit the ability of practitioners and black MSM to access the program in the future.

Conclusions

In recent years, researchers and policy makers have called for the expansion of culturally appropriate HIV-related programs, social marketing campaigns, and health care services to address the elevated HIV rates in black MSM communities [5,43]. This study demonstrates that holistic, harm-reduction-based, eHealth interventions can reengage men on HIV prevention issues in the current age of treatment optimism, safer sex burnout, and multiple risk reduction strategies. This possibility of reaching black MSM through a technologically contemporary intervention is critical given that many men meet their sexual partners using the Internet and mobile phone apps [44-46] and increasingly rely on technology for their health information seeking [47,48].

Seeking to promote program utilization and longevity, we designed Real Talk to be a flexible tool focused on skills acquisition, self-reflection, and participant-generated content that enables men to address emerging sexual health issues without requiring a major reworking of the intervention. Real Talk's modular format also facilitates its utilization in conjunction with a broader array of prevention activities, including HIV testing and counseling, online outreach, and community-level programs, and may help address the currently low levels of PrEP utilization in black MSM communities [17]. In our future research, we are particularly interested in examining the processes through which interventions produce changes, including, in the case of Real Talk, the possible connection between sexual health and experiences with stigma and intersectionalities.

Our interest in identifying mediating variables and key intervention components [49,50] stems from the realities of real-world program implementation, where providers often combine pieces of evidence-based programming to complement their existing programs and services rather than implementing a complete evidence-based intervention. We observed this dynamic during our outcome study site trainings, where all 4 organizations expressed a desire to integrate parts of both the face-to-face curriculum and the computer/tablet-delivered programs into their everyday activities upon the completion of the study. By examining the connections between outcomes and real-world utilization patterns, including hybrid formats that combine face-to-face and technology-delivered activities, researchers may be able to identify what might be called health promotion chunks (on cognitive chunking more generally, see [51]) that support healthy practices and outcomes in diverse utilization contexts and populations. The identification of efficacious health promotion chunks would help inform the development of an emerging wave of multidirectional, mobile sexual health apps for MSM [52-54]. Such products would not only help support the scaling up of cost-effective HIV prevention/sexual health promotion in resource-tight environments, but could provide a model for health promotion programs more generally in the Internet age.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Real Talk content.

[PDF File (Adobe PDF File), 20KB - publichealth_v3i4e78_app1.pdf]

Multimedia Appendix 2

Real Talk screenshot 1.

[PNG File, 388KB - publichealth_v3i4e78_app2.PNG]

Multimedia Appendix 3

Real Talk screenshot 2.

[PNG File, 329KB - publichealth_v3i4e78_app3.PNG]

Multimedia Appendix 4

Real Talk outcome study flowchart.

[JPG File, 64KB - publichealth_v3i4e78_app4.JPG]

Multimedia Appendix 5

Real Talk outcome study findings.

[PDF File (Adobe PDF File), 42KB - publichealth_v3i4e78_app5.pdf]

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Abbreviations

ART: antiretroviral therapy
CDC: Centers for Disease Control and Prevention
DEBI: Diffusion of Effective Behavioral Interventions
GHB: gamma-hydroxybutyric acid

MSM: men who have sex with men
PrEP: pre-exposure prophylaxis
SiHLE: Sisters Informing Healing Living and Empowering
SISTA: Sisters Informing Sisters about Topics on AIDS
STI: sexually transmitted infections
WiLLOW: Women Involved in Life Learning from Other Women

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Original Paper

Examining E-Loyalty in a Sexual Health Website: Cross-Sectional Study

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Abstract

Background: Web-based sexual health resources are typically evaluated in terms of their efficacy. Information is lacking about how sexual health promotion websites are perceived and used. It is essential to understand website use to address challenges with adherence and attrition to Web-based health interventions. An existing theoretical framework for examining loyalty to electronic health (eHealth) interventions has been not yet been applied in the context of sexual health promotion nor has the association between e-loyalty and intended intervention efficacy outcomes been investigated.

Objective: The objectives of this study were to investigate users' loyalty toward a sexual health website (ie, e-loyalty), measure user perceptions of the website, and measure the association between e-loyalty and perceived knowledge increase and intent to change behavior.

Methods: Over 4 months, website users (clients and health care providers) participated in an open, online, cross-sectional survey about their user experiences that measured e-loyalty, user perceptions, and intended website efficacy outcomes. Relationships between user perceptions and e-loyalty were investigated using structural equation modeling (SEM). Associations between e-loyalty and website efficacy outcomes were tested using Spearman rank correlation.

Results: A total of 173 participants completed user perception questions and were included in the analysis. E-loyalty was high for both clients and providers and was significantly correlated with clients' perceived knowledge increase ($\rho(171)=.30$, $P<.001$), their intent to have safer sex ($\rho(171)=.24$, $P=.01$), and their intent to get tested for sexually transmitted infections ($\rho(171)=.37$, $P<.001$). The SEM showed that trustworthiness, overall experience, active trust, and effectiveness were directly related to e-loyalty. Finding the website "easy to understand" was significantly related to active trust (ie, participants' willingness to act upon information presented on the website).

Conclusions: E-loyalty may be related to the efficacy of the selected website in improving one's sexual health and was significantly associated with all three intended knowledge and behavioral outcomes. To increase e-loyalty, trustworthiness and active trust are important user perceptions to deliberately engender. Our findings indicate that understanding a website contributes to active trust, thereby highlighting the importance of considering eHealth literacy in designing health promotion websites. Our study confirms the relevance of e-loyalty as an outcome for evaluating the antecedents of the use and efficacy of online public health interventions across disciplines by adapting and validating an existing e-loyalty framework to the field of sexual health promotion. Our findings suggest that e-loyalty is positively associated with measures of website efficacy, including increased knowledge and intent to change behavior. Longitudinal research with larger samples could further investigate the relationships between e-loyalty, website understandability, and outcomes of online health interventions to determine how the manipulation of website characteristics may impact user perceptions and e-loyalty.

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KEYWORDS

e-loyalty; sexual health; Internet; patient satisfaction; cross-sectional studies

Introduction

Background

Web-based resources for sexual health promotion, including the resources on prevention of sexually transmitted infections (STIs) and human immunodeficiency virus (HIV), have been accessible for over 15 years, by virtue of the advantage of the Internet to deliver personal or tailored sexual health information to large audiences [1]. Web-based sexual health resources are easily accessible, can be accessed anonymously, and can be visited repeatedly and at convenient times [2,3]. Although barriers to accessing Web-based sexual health interventions (eg, low income, low education or geographic remoteness) persist in Canada, the digital divide is continuously closing [4]. Increasingly, focus is turning to Web-based sexual resources to reach groups at high risk for STIs and HIV, such as youth and men who have sex with men (MSM) [5] as Web-based resources can uniquely provide sexual health information that is relevant and free of prejudice to users regardless of their gender, age, sexual orientation, and location [6,7].

Web-based sexual health resources are typically evaluated in terms of their efficacy, for example, using randomized controlled trials to assess self-reported outcomes before and after exposure to the intervention [8,9]. However, a new pragmatic field of research has been emerging to focus on the *use* of health interventions, which seeks to understand why individuals in the general public choose to engage with and remain loyal to a particular website [10]. Studying website use is particularly important because attrition and low usage are fundamental challenges to Web-based interventions and the low threshold to participate makes it easy for users to leave [11]. E-loyalty, or loyalty to a website, is a well-described concept in e-commerce that pertains to users' behavioral intent, such as the intention to buy a product online from one website rather than another or the intention to return to a website in the future [12]. Models of the cognitive elements related to e-loyalty from the e-commerce field have recently been applied and validated in the field of eHealth [13,14]. Understanding how users' perceptions of a website contribute to e-loyalty is important for the design of websites and for establishing trust and eliciting repeat visits with the objective of delivering impactful public health interventions that ultimately will lead to better health outcomes for users [13,14].

A theoretical framework to conceptually define e-loyalty and its antecedents for public health interventions was developed by Crutzen et al (2011) and has been applied to websites in health domains, including cancer patient education, mental health and addictions, and injury prevention [13]. This study applies the e-loyalty framework to sexual health, based on a Canadian provincial sexual health website that is developed and managed by the British Columbia Centre for Disease Control (BCCDC). SmartSexResource (SSR) is an open website (ie, no username or password required) with both interactive and static features, comprising content for both individuals seeking sexual health information (clients) and health care professionals (providers) [15]. Users can access pages for specific topics, input their postal code or city and search for clinics based on their services and opening hours, and interact with a health care provider by chatting with a nurse during specified hours or by submitting an anonymous question to which a nurse responds in a private email or via a public posting. One of the main objectives of SSR is to increase visitors' satisfaction with sexual health services in British Columbia and improve the visitor experience by engendering perceptions of confidentiality and trustworthiness—concepts well aligned with the e-loyalty framework.

Theoretical Framework

The study employed an e-loyalty framework for health interventions, put forth by Crutzen et al, which involves measuring user perceptions of a website that contribute to the outcome measures of e-loyalty (ie, intention to visit the site again and recommending a website to others). The e-loyalty concept maintains that a positive user experience leads to increased website use [13]. See Table 1 for the constructs that comprise the e-loyalty framework.

Given the sensitive and personal nature of sexual health topics, and the fact that visitors to SSR often submit questions that are motivated by uncertainty or fear and related to personal sexual experiences, we modified the e-loyalty framework by removing a previously validated component called "enjoyment" and substituting a question to reflect the overall experience of the website.

Furthermore, our study included a measure of visitors' understanding of the website, acknowledging the importance of considering eHealth literacy in the online presentation of health information. The term "eHealth literacy" is defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem" [16]. Existing components of the e-loyalty framework can be considered to reflect eHealth literacy (eg, the questions about efficiency and effectiveness measure "information literacy," one of the six components of eHealth literacy, which involves the ability to navigate resources, search strategically, and filter results to find relevant information). Therefore, we decided to include "understanding" as an additional user perception in our analysis of e-loyalty. Understanding was measured on a 7-point Likert scale, in which respondents rated their agreement with the statement, "I found the information easy to understand."

In summary, we sought to measure the e-loyalty of visitors to SSR and determine how the e-loyalty framework applies to sexual health promotion. We also explored how understanding fits within the e-loyalty framework and whether e-loyalty was associated with self-reported knowledge and behavior changes following the use of SSR.

Methods

Study Design and Recruitment

We administered a cross-sectional online survey to SSR visitors between April and August 2014. The aim of the survey was to learn about the experiences and perceptions of visitors who use SSR as a resource for Web-based sexual health information. Participants were recruited either from a banner ad on the SSR homepage or through an email invitation to health care providers who subscribed to an SSR email distribution list. The survey was an open survey, available to all visitors of the SSR website regardless of their location [17]; however, given the focus of SSR on providing information relevant to Canadians and the residents of British Columbia in particular, we provided an incentive to oversample Canadian participants (entered into a draw for one of two mini tablet computers if they had a Canadian postal code).

Survey Description

The user perception questions were located midway through the 31-item survey, with demographic questions at the end. At the start, participants were classified by visitor type (either “client” or “provider”) based on their response to initial questions assessing whether they were visiting SSR for work or for personal reasons. Adaptive questioning was used to tailor questions to each group. Although prior e-loyalty research has employed 2 to 3 items per user perception, we used a single item per user perception, given the internal structure in prior research and the conceptual robustness of the user perceptions that have now been validated in multiple eHealth fields, as well as a desire to minimize survey length [13,14].

The user perception questions were followed by 3 questions pertaining to behavioral and knowledge outcomes of visiting the website. Clients and providers both reported whether their knowledge about STIs or sexual health had increased as a result of visiting SSR, and only clients reported whether they were more likely to have safer sex and get tested for HIV and STIs. All of the aforementioned outcomes were measured by presenting participants with a statement to which they reported their level of agreement on a 7-point Likert scale (strongly disagree to strongly agree). The survey questions included in this study are described in Table 1.

Table 1. E-loyalty user perceptions.

Model	Explanation	Survey item[a]
User perceptions derived from Crutzen et al [10]		
Intention to visit again (return)		I would use this website again.
Recommend to others		I would recommend this website to others.
Effectiveness	Quality and relevance of the information	The website provided me with relevant information about sexual health.
Efficiency	Easy search of and access to information	I was able to access the information quickly on this website.
Trustworthiness	Believability of the provided information	I trusted the information presented on this website.
Active trust	Confidence in acting on the provided information	I would act upon the information presented on this website.
User perceptions added in this study		
Overall experience	Positive perception of the website	Based on today’s visit, how would you rate your SSR experience overall? (7-point Likert scale from very poor to very good)
Understanding		I found the information easy to understand.
Behavioral and knowledge outcomes		
Knowledge increase		As a result of visiting SmartSexResource, my knowledge about STIs or sexual health has increased.
Behavioral intent #1		As a result of visiting SmartSexResource, I am more likely to have safer sex.
Behavioral intent #2		As a result of visiting SmartSexResource, I am more likely to get tested for HIV[b] or STIs[c].

[a] Unless otherwise specified, the question was answered on a 7-point Likert scale from strongly disagree (1) to strongly agree (7).

[b] HIV: human immunodeficiency virus.

[c] STIs: sexually transmitted infections.

Table 2. Sample characteristics for SmartSexResource visitor survey 2014, n=173.

Characteristic	Clients (N=131) n (%)[b]	Providers (N=42) n (%)[b]	Total n (%)[b]
Age, in years			
<20	16 (15)	1 (3)	17 (12)
20-29	41 (38)	8 (21)	49 (34)
30-39	22 (21)	10 (26)	32 (22)
40-49	11(10)	10 (26)	21 (14)
>50	17 (16)	9 (24)	26 (18)
Total[a]	107	38	145
Gender identity			
Female (woman)	55 (58)	31 (82)	86 (65)
Male (man)	38 (40)	5 (13)	43 (32)
Transgender	2 (2)	0 (0)	2 (2)
Genderqueer	0 (0)	2 (5)	2 (2)
Total[a]	95	38	133
Education			
Primary	5 (5)	0 (0)	5 (3)
Secondary	28 (26)	1 (3)	29 (20)
College or university	59 (55)	21 (54)	80 (54)
Graduate level	16 (15)	17 (43)	33 (22)
Total[a]	108	39	147
Location			
Canada	97 (74)	39 (95)	136 (79)
International	34 (26)	2 (5)	36 (21)
Total[a]	131	41	172

[a] Total represents the data available (ie, excluding missing values) or number of respondents to the survey question.

[b] Percentage is the proportion of respondents who answered the survey question (ie, excluding missing values).

The survey was pilot-tested and revised to make the majority of questions optional. Mandatory questions were limited to 2 questions that oriented clients and health care providers to slightly different survey streams (eg, providers were not asked about their intentions to change sexual health behaviors) [17].

Additional survey domains included frequency and purpose of visiting SSR, use of other sexual health information sources, use of or preference for particular features of SSR, and sexual identity.

Analysis

We used chi-squared tests (Fisher exact tests where cell counts were less than 5) to determine significant differences between respondents who completed the e-loyalty section and those who did not (and thus were excluded from further analysis). Respondents' location was determined by triangulating data from the Fluidsurveys software, Piwik Open Analytics Platform website metrics software, and respondents' self-reported location.

Summary measures of user perceptions were reported using the mean to describe the average rating on a 7-point Likert scale. Differences in e-loyalty and user perceptions by respondent characteristics were determined by the Wilcoxon rank-sum test as the data were non-normal. Accordingly, associations between e-loyalty and knowledge and behavioral intent outcomes were measured using a nonparametric measure of association, Spearman ρ (rho; two-tailed).

The relationships between user perceptions and e-loyalty were investigated through structural equation modeling (SEM), using MPlus V7.2 software (Muthén & Muthén) . Covariates in model building included education, gender, and visitor type (ie, client or provider). The model was built to optimize fit indices, including the comparative fit index (CFI), Tucker-Lewis Index (TLI), and root mean squared error of approximation (RMSEA). Because the two e-loyalty outcomes “recommend to others” and "intention to visit again" were highly correlated ($\rho(171)=.77$, $P<.001$), we used the mean of the two outcome measures to represent overall e-loyalty.

Results

Respondents

During the 4-month study period, the mean number of unique visitors per day was 879 (range: 571-1209), of which the mean number of returning visitors was 146 per day (range: 80-227). In total, 501 unique survey responses were received. Of those, 37 responses (7.4%; 37/501) were from Internet Protocol (IP) addresses associated with two or more survey responses. The majority of respondents (96.4%; 483/501) accessed the survey through a banner ad on SSR; the rest (3.6%; 18/501) followed an email link. In total, 173 respondents (34.5%; 173/501) completed all e-loyalty questions and were included in the analysis. Participants completing the e-loyalty questions were more likely to be health care providers (67% [42/63] vs 30.0% [131/438] of clients, n=501, $\chi^2_1=31.3$, $P<.001$), self-reported returning visitors to the site (73% [52/71] vs 45.6% [121/265] of first-time visitors, n=336, $\chi^2_1=17.1$, $P<.001$), female or woman (99% [86/87] vs 78% [47/60] of other gender identities, n=147, $\chi^2_1=17.4$, $P<.001$), and Canadians (47.4% [136/287] vs 17.1% [36/210] of non-Canadians, n=497, $\chi^2_1=49.0$, $P<.001$). Completion of the e-loyalty section was not significantly associated with age or level of education. The final sample for the analysis comprised 131 clients (75.7%; 131/173) and 42 health care providers (24.3%; 42/173), of which 30.1% (52/173) in total were returning visitors to the site. The sample of clients represented youth younger than 20 years (15.0%; 16/107) and MSM (10.8%; 12/111, data not shown)—high-risk groups that are key target audiences for the website. For a description of participants, see Table 2.

E-Loyalty Outcome

The average e-loyalty score was high for both clients (mean 5.62) and providers (mean 6.52). Visitors returning to the site had higher mean e-loyalty scores than first-time visitors (6.48 vs 5.61, n=170, W=1390.5, $P<.01$). For clients and providers combined, the highest rated user perception was "understanding," with a mean rating of 6.01, followed by "trustworthiness" (mean: 5.99) and "active trust" (mean: 5.97). Providers consistently gave higher ratings for all user perceptions and both e-loyalty measures (Table 3). Among clients and providers combined, e-loyalty was most highly correlated with active trust ($\rho=.79$) and trustworthiness ($\rho=.79$), followed by understanding ($\rho=.69$). See Table 4.

Knowledge and Behavior Outcomes

After visiting the site, 71% of respondents reported that their knowledge increased. The majority of clients reported that after visiting SSR, they were more likely to have safer sex (58%) and get tested for HIV and STIs (61%); health care providers were not asked these 2 behavioral questions. All three outcome measures were significantly associated with higher e-loyalty scores. For all respondents, e-loyalty was positively correlated with perceived knowledge increase ($\rho(171)=.30$, $P<.001$). For clients, e-loyalty was positively correlated with both intent to have safer sex ($\rho(171)=.24$, $P=.01$) and intent to get tested for STIs ($\rho(171)=.37$, $P<.001$).

User Perceptions and E-Loyalty

Our SEM tested the relationships between user perceptions and e-loyalty, the effect of understanding and trustworthiness on active trust, and the effect of gender, visitor type, and education on e-loyalty. The final model had adequate acceptable fit according to fit indices, with a CFI of 0.95, TLI of 0.92, and RMSEA of 0.06 (90% CI 0.03-0.09) [18]. The SEM developed to identify relationships between user perceptions and e-loyalty is shown in Figure 1 (output is shared in Multimedia Appendix 1). The variance in e-loyalty was well explained by the model ($R^2=.76$).

Table 3. Summary of outcome and user perception ratings for SmartSexResource visitor survey 2014.

Measure	Mean rating by visitor type (scale: 1-7[a])		
	Client (n=131)	Provider (n=42)	*P* value
Outcomes			
E-loyalty	5.62	6.52	<.001
Return	5.78	6.51	<.001
Recommend	5.50	6.54	<.001
User perceptions			
Overall	5.59	6.14	.004
Effectiveness	5.78	6.17	.008
Efficiency	5.73	5.98	.15
Understanding	5.85	6.50	<.001
Trustworthiness	5.78	6.64	<.001
Active trust	5.79	6.52	<.001

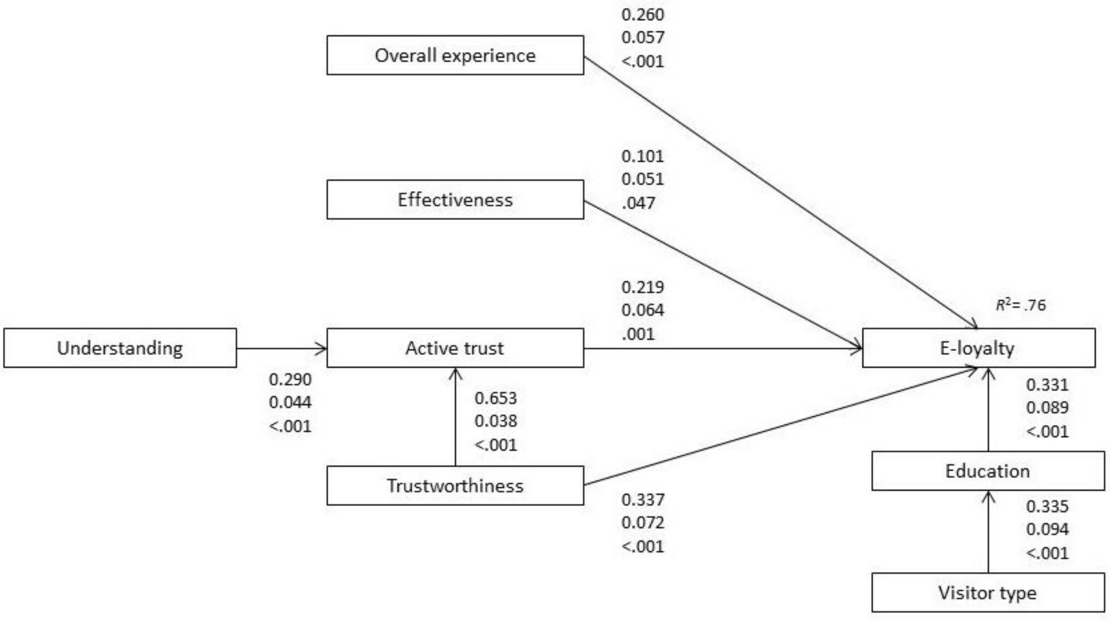
[a] Scale: 1=strongly disagree, 2=disagree, 3=somewhat disagree, 4=neutral, 5=somewhat agree, 6=agree, 7=strongly agree.

Table 4. Correlation matrix and mean user perception ratings, clients and providers (n=173).

Measure	Mean (range: 1-7)	SD[a]	1	1a	1b	2	3	4	5	6	7
1. E-loyalty	5.84	1.28	-	.90	.96	.61	.56	.56	.72	.79	.79
a. Return	5.96	1.25		-	.77	.63	.56	.57	.67	.71	.73
b. Recommend	5.74	1.39			-	.56	.54	.52	.70	.81	.77
2. Overall experience	5.72	1.11				-	.67	.59	.57	.56	.55
3. Effectiveness	5.87	0.96					-	.61	.57	.50	.55
4. Efficiency	5.79	1.16						-	.64	.50	.53
5. Understanding	6.01	0.95							-	.68	.72
6. Trustworthiness	5.99	1.08								-	.86
7. Active trust	5.97	1.08									-

[a] SD: standard deviation.

Figure 1. Structural equation model for the relationships between five user perceptions and e-loyalty. (Note: Numbers next to paths indicate standardized estimates, standard errors, and P values).



Note: the user perception ‘efficiency’ and the covariate ‘gender identity’ were considered in model-building but were not retained in the final model as they were not significant.

Four user perceptions were positively related with e-loyalty. The effect size was highest for trustworthiness on e-loyalty directly (ß=.34), and trustworthiness was also partially mediated by active trust. Finding the website that is “easy to understand” was positively related to active trust.

Females had higher mean scores than males and other genders for e-loyalty (6.19 vs 5.80, n=133, W=2482.5, *P*=.02), trustworthiness (6.23 vs 6.02, n=133, W=2454.5, *P*=.03), and understanding (6.24 vs 5.98, n=133, W=2468, *P*=.02). However, gender identity was not found to be significantly associated with e-loyalty in the SEM and was not retained. In the SEM, increasing levels of education were associated with higher mean e-loyalty scores. Education level fully mediated the effect of visitor type (ie, client vs health care provider) on e-loyalty because health care providers generally had higher education than clients (97% [38/39] of providers had college-level education or higher vs 69.4% [75/108] of clients).

Discussion

Overall, our study demonstrated high e-loyalty and positive user perceptions among SSR users. A new user perception, understanding, was significant in the SEM describing e-loyalty. Also, as one of the first eHealth studies to link e-loyalty with knowledge and behavioral intent outcomes, we found significant associations between e-loyalty and perceived knowledge increase for clients and providers, as well as intent to change sexual health behavior among clients.

This study contributes to the literature by presenting a parsimonious model that illustrates associations between e-loyalty to a sexual health website and user characteristics that are potentially modifiable. Understanding the nature of the inter-relationships among factors that influence e-loyalty helps to both inform the development of theory and provide insights into the processes by which we might intervene to enhance the occurrence and strength of e-loyalty. The analysis identified a set of key factors that are most amenable to intervention and ongoing monitoring. Targeting efforts toward these factors may be particularly useful considering that the way visitors currently interact with sexual health resources has limited capacity for nuance and complexity. Future research should further explore the effect of manipulating website characteristics to change such user perceptions, e-loyalty, knowledge gained, and intent to change behavior.

E-Loyalty and Website Efficacy

The associations between e-loyalty and the survey's other key outcomes, perceived knowledge increase, and intent to change behavior (among clients) lead us to hypothesize that e-loyalty contributes to the efficacy of this website in improving sexual health. A meta-analysis of Web-based health interventions found conflicting results regarding the relationship between intervention adherence (a reflection of e-loyalty) and behavioral outcomes but concluded they are likely to be related [19]. More longitudinal research could be done to further elucidate the relationship between e-loyalty and outcomes resulting from loyal engagement with Web-based health resources.

Our SEM provides further insights into associations between user perceptions and e-loyalty for health promotion websites, confirming previous findings and revealing new relationships.

Trustworthiness

Trustworthiness had the strongest direct effect on e-loyalty in this model, and its effect was also partially mediated by active trust. This finding is in line with prior social marketing research that showed active trust partially mediating the effect of website credibility on behavioral intent [20]. In our study, trustworthiness and active trust were highly correlated (ρ=.86), yet both independently captured variance in e-loyalty that the other could not. This finding differs from previous health-related applications of the e-loyalty framework, in which trustworthiness was not found to be significantly related to e-loyalty for health information websites about sports injury prevention, alcohol consumption, and depression [13]. Crutzen et al hypothesized that active trust could capture all the variance in e-loyalty that could be explained by trustworthiness. We hypothesize that this differs in our study because of the inclusion of both clients and providers. On average, clients gave similar scores for trustworthiness and active trust (5.78 and 5.79, respectively), perhaps because clients' trust in the website is directly applicable to their confidence in acting upon the information, whereas providers gave a higher score for trustworthiness than active trust (6.64 vs 5.78), which may be because their confidence in acting upon the information is not applicable as they are using the website for work. Therefore, trustworthiness may be a relevant user perception independent of active trust in the context of a website that provides information for other purposes in addition to behavior change.

There is a large body of literature recognizing the importance of trust in the use of Web-based health information [21-23]. Trust in health websites in general is known to be predicated on the reputation and respect of the organization that operates the website, the demonstration of in-depth knowledge of a variety of relevant topics, and *the delivery of clear information* [23]. For sexual health resources specifically, American studies have shown that youth are distrustful of online information about sexual health and preferred traditional forms of sexual health education, such as from parents, school, medical professionals, and friends [24,25]. However, being able to access personal expertise (ie, a traditional form of education) through a novel delivery system (an online one-on-one chat with a nurse) was considered to be a trustworthy source of information among youth in British Columbia [26]. The online presence of nurses on SSR through the "Ask a Nurse" or "Chat" functions may contribute to increased trust of both the interactive services and the static information.

SSR also has other features known to be associated with trustworthiness among specific populations. When searching for sexual health information online, youth have been shown to assess credibility largely upon a website's domain name—dot com, dot gov, or dot org—or its association with government [24,27,28]. A study of gay and bisexual men indicated that their trust in Web-based sexual health information was based on hospital or university affiliations and also the convergence of information across multiple websites [29]. We expect that the SSR website's clear affiliation with the BCCDC, a provincial, government-funded service provider, contributes to its trustworthiness along the path to e-loyalty.

In our model, the effect of trustworthiness on e-loyalty was also partially mediated by active trust. Active trust is characterized by a user's confidence in acting upon information presented on a website, the only user perception in the e-loyalty model that speaks to action. As the ultimate client-oriented objective of an interactive Web-based resource such as SSR is to provide information that contributes to behavior change (eg, engaging in safer sex or getting tested for STIs), active trust is arguably the most important user perception to engender along the pathway to e-loyalty.

Increasingly, people are seeking health information on the Internet before going to health care providers, and youth are more likely than older adults both to go online first and to trust online health content [30]. As the Internet contributes to filling the sexual health information gap for youth [24] and other groups at higher risk for STIs and HIV such as MSM [31], future research could examine trust as it relates to e-loyalty toward Web-based sexual health resources across age and population subgroups.

Understanding as an Antecedent to Active Trust

Our hypothesis that "understanding" may be related to e-loyalty was supported by the data. The SEM indicates that respondents who reported better understanding of content were more likely to have active trust; in other words, understanding was an antecedent to active trust along the pathway to e-loyalty.

These findings suggest an overlap between the theoretical frameworks of e-loyalty and eHealth literacy. As much as understanding is a component of eHealth literacy, we acknowledge that understanding content is only one small piece; eHealth literacy comprises much more than having the reading skills to understand information at an appropriate reading level [16,32]. Understanding also plays only a partial role in a new conception of “sexual health literacy,” which is envisioned as a combination of the level of sexual health knowledge one has and the capacity to employ this knowledge within sexual and social contexts [33].

Links between understanding, active trust, and e-loyalty are not yet well developed in the literature, but our findings are congruent with prior research, including a study showing strong support that understanding impacts trust beliefs and intention to use health information websites [23]. A study among adolescents suggested a connection between understanding and trust, in that a lack of capacity to analyze medical information (ie, low understanding or information-seeking skills) may hinder one’s ability to assess trustworthiness and credibility of an online source of health information [2], an essential step on the pathway to developing active trust and e-loyalty. Furthermore, a study among adults found that individuals with higher e-literacy were more likely to scrutinize and evaluate the reliability of the source and accuracy of the information to form an opinion of the site, compared with those with lower eHealth literacy [34], as measured by a validated eHealth literacy scale [35].

Limitations

The main limitation of this study was the small sample size. Our challenges with attrition, despite offering an incentive, are reflective of the fundamental challenges of open online surveys. The use of a lottery-style incentive was selected based on cost and feasibility, informed by a literature search in 2013 [36-38], and intended to determine the most successful and economically feasible incentive style for open, Web-based surveys. The incentive was successful in oversampling Canadian respondents as intended (79% of survey respondents vs 28% of overall visitors to the website). The education level of respondents was driven up by the inclusion of health care providers and indicates that in terms of education level, the sample is neither representative of the Canadian population nor representative of youth who are a key target group for the site (70% of respondents had postsecondary education compared with 64% of the adult Canadian population) [39]. Given these limitations, further research is needed to determine how generalizable our findings are to user populations of other Web-based sexual health websites.

We also recognize the potential for bias in an open, online survey in which participants could respond more than once. In 37 (7%) instances, responses originated from the same IP address as other responses. We retained these responses in our sample, as we were unable to differentiate between duplicate responses from the same individual and different individuals accessing the survey from a shared computer or an institutional network, which may be likely among survey respondents (ie, students at a school or health care providers in a clinic).

Another limitation is evident in the selection process and the differences between respondents who completed and did not complete the e-loyalty section. As our participant recruitment method was related to e-loyalty (ie, those with e-loyalty to the site were more likely to be exposed to the banner ad or invitation email and enter the survey than the general public), and as completers of the e-loyalty section were more likely to be returning SSR users and health care providers, our findings may be biased toward visitors with higher e-loyalty. This is also evident in that returning visitors reported significantly higher e-loyalty scores, leading us to consider whether self-reported, cross-sectional surveys are an appropriate way to capture e-loyalty. Nevertheless, user perceptions from 173 unique respondents supported an SEM with adequate fit and statistically significant relationships between variables that provides useful insight into relationships between user perceptions, including the novel user perception, “understanding,” as well as knowledge and behavioral outcomes.

Finally, as a cross-sectional survey, we are not able to draw any conclusions regarding causation or determine whether the intended behavioral outcomes (seek STI and HIV testing, change sexual behavior) did, in fact, occur. Future research that includes a longitudinal component (eg, pre- and postassessment of behavior change) to validate our findings is needed.

Conclusions

This exploratory study contributes to a growing field of literature on the applications of an e-loyalty framework to Web-based public health interventions. With the addition of a novel user perception to a theoretical framework of e-loyalty, we have shown that users’ understanding of the content affects their confidence in acting upon information presented, which in turn affects their e-loyalty to the site. Furthermore, we found positive associations between e-loyalty and measures of intervention efficacy (ie, knowledge and behavioral outcomes). We propose that e-loyalty and related user perceptions, including trustworthiness and understanding, are constructs relevant to consider in addition to efficacy measures in studies that evaluate Web-based sexual health interventions.

There is a need to further investigate how sexual health websites can deliberately engender understanding, trust, and active trust to develop e-loyalty among their users, for example, by manipulating website characteristics to change user perceptions. We echo the call to action to bring sexual health interventions to their full potential on the Internet by continuing to explore ways to increase their use and impact [40]. As the first study to adapt the e-loyalty framework specifically for a sexual health intervention, we confirm the relevance of e-loyalty as an outcome for evaluating the antecedents of the use and efficacy of Web-based public health interventions across health disciplines.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Structural equation modeling output (Mplus v7.2) for examining e-loyalty in an online sexual health promotion intervention.

[PDF File (Adobe PDF File), 30KB - publichealth_v3i4e75_app1.pdf]

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Abbreviations

BCCDC: BC Centre for Disease Control
CFI: comparative fit index
eHealth: electronic health
HIV: human immunodeficiency virus
IP: Internet Protocol
MSM: men who have sex with men
RMSEA: root mean squared error of approximation

SEM: structural equation modeling
SSR: SmartSexResource
STI: sexually transmitted infection
TLI: Tucker-Lewis index

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Original Paper

Factors Associated With Access to HIV Testing and Primary Care Among Migrants Living in Europe: Cross-Sectional Survey

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Abstract

Background: There is a heavy and disproportionate burden of human immunodeficiency virus (HIV) infection among migrant communities living in Europe. Despite this, the published evidence related to HIV testing, prevention, and treatment needs for migrants is sparse.

Objective: The aim of this study was to identify the factors associated with access to primary care and HIV testing among migrant groups living in Europe.

Methods: A Web-based survey (available in 14 languages) was open to all people aged 18 years and older, living outside their country of birth in the World Health Organization (WHO) European area. Community organizations in 9 countries promoted the survey to migrant groups, focusing on those at a higher risk of HIV (sub-Saharan Africans, Latin Americans, gay or bisexual men, and people who inject drugs). Multivariable analysis examined factors associated with access to primary care and previous history of an HIV test.

Results: In total, 559 women, 395 heterosexual men, and 674 gay or bisexual men were included in the analysis, and 68.1% (359/527) of women, 59.5% (220/371) of heterosexual men, and 89.6% (596/664) of gay or bisexual men had tested for HIV. Low perceived risk was the reason given for not testing by 62.3% (43/69) of gay or bisexual men and 83.3% (140/168) of women and heterosexual men who reported never having tested for HIV. Access to primary care was >60% in all groups. Access to primary care was strongly positively associated with living in Northern Europe compared with Southern Europe (women: adjusted odds ratio, aOR 34.56 [95% CI 11.58-101]; heterosexual men: aOR 6.93 [95% CI 2.49-19.35], and gay or bisexual men: aOR

2.53 [95% CI 1.23-5.19]), whereas those with temporary residency permits were less likely to have access to primary care (women: aOR 0.41 [95% CI 0.21-0.80] and heterosexual men: aOR 0.24 [95% CI 0.10-0.54] only). Women who had experience of forced sex (aOR 3.53 [95% CI 1.39-9.00]) or postmigration antenatal care (aOR 3.07 [95% CI 1.55-6.07]) were more likely to have tested for HIV as were heterosexual men who had access to primary care (aOR 3.13 [95% CI 1.58-6.13]) or reported “Good” health status (aOR 2.94 [95% CI 1.41-5.88]).

Conclusions: Access to primary care is limited by structural determinants such as immigration and health care policy, which varies across Europe. For those migrants who can access primary care and other health services, missed opportunities for HIV testing remain a barrier to earlier testing and diagnosis for migrants in Europe. Clinicians should be aware of these potential structural barriers to HIV testing as well as low perception of HIV risk in migrant groups.

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KEYWORDS

HIV; migrants; HIV serodiagnosis; primary health care; health services accessibility

Introduction

Within Europe, migrant populations form a substantial proportion of the number of people living with human immunodeficiency virus (HIV). From 2007 to 2012, migrants represented two-fifths of HIV cases reported and had higher odds of late presentation compared with nonmigrants [1]. In 2014, the European Centre for Disease Control and Prevention reported that 31% of new diagnoses were among people living outside their country of birth [2]. Whereas trends show that new HIV diagnoses among migrants born outside Europe are decreasing, in the 9 years to 2014, the rates of new diagnosis among European-born migrants have increased by 48% [2]. Despite the disproportionate representation of migrants in the European HIV epidemic, the published evidence base related to the HIV testing, prevention, and treatment needs is sparse and mainly focuses on sub-Saharan migrants living in the European Union [3,4].

Migrants are at an increased risk of ill health in general and sexual ill health in particular [5,6]. Studies have highlighted that cultural, financial, and structural barriers may prevent migrants from accessing HIV health care services [4,7-11]. Yet these studies focus on migrants originating from 1 region [7,9-14] or residing in 1 country [8,10-15], and few studies focus on the role of access to primary care as a gateway to providing HIV testing and earlier diagnosis [16-18]. Additionally, recent literature reviews have found that the evidence base for understanding HIV risk behaviors among migrant men who have sex with men is similarly poor [19].

This paper presents findings from the Advancing Migrant Access to Health Services in Europe (aMASE) study. This collaborative European study aimed to provide the evidence to prevent HIV infection and improve diagnosis and prognosis of migrant populations living with HIV in Europe to support policy development at the European level. Our study objectives were to identify the structural, cultural, and financial barriers to HIV prevention, diagnosis, and treatment among migrants living in Europe. We present the findings of a community participatory cross-sectional survey that identifies the factors associated with access to health care and HIV testing among multiple migrant groups.

Methods

Study Design

Full details of the methods used in the aMASE study have been described elsewhere [20]. In summary, all people aged 18 years and older living outside their country of birth in the World Health Organization (WHO) European area, irrespective of their HIV status or current country of residence, were eligible to participate in the aMASE community survey. The survey, hosted by FluidSurveys version 5.0 (Fluidware, now SurveyMonkey), was available online between April 2014 and July 2015.

No sampling frame for migrants in Europe exists; therefore, a convenience sampling strategy was used. In calculating the sample size, the primary outcome measures were access to primary care and the proportion of participants previously tested for HIV—both assumed to have an overall outcome prevalence of 50%. The target sample size was 1000 migrants, which allowed for estimates of the primary outcomes by gender within 5%. The survey was actively promoted from June 2014 to May 2015 using social marketing and community participatory methods in Belgium, France, Germany, Greece, Italy, The Netherlands, Portugal, Spain, and the United Kingdom. These countries were selected because they complemented data available from a companion study, the aMASE clinic survey [20]. A Community Advisory Group (CAG) comprising representatives from local community-based organizations providing services to migrant communities was contracted to promote the survey as previously described [20]. The CAG was given promotional materials, and the survey was advertised on websites, social media, and dating sites (eg, Grindr and Gay Romeo). Four population groups with unmet HIV prevention needs [21] were targeted for recruitment: sub-Saharan Africans, Latin Americans, men who have sex with men, and people who inject drugs.

The survey instrument was available in 14 languages: Amharic, Arabic, Dutch, English, French, German, Greek, Italian, Polish, Portuguese, Russian, Turkish, Spanish, and Somali. All participants provided within-survey tick-box consent.

Ethics

Ethical approval was obtained from the London Bentham Research Ethics Committee (11/LO/1600). Additional approvals were obtained in countries that actively promoted the survey [20].

Outcomes and Variables of Interest

The main outcome measures were access to primary care and ever having tested for HIV. Access to primary care was defined as reported possession of a health card (Italy and Spain), access to a permanent medical doctor (Greece), or registration with a family doctor or general practitioner (GP) for all other countries. Respondents who reported living with diagnosed HIV were excluded from analysis identifying factors associated with ever having tested for HIV.

Data were analyzed separately for 3 gender-related groups as it was assumed that women, men who reported their sexual orientation as straight, and men who identified as gay or bisexual were all likely to be different with regard to HIV testing history, sexual behavior, and HIV prevention needs.

Geographical variables (region of birth, region of current country of residence) were created using geographic regions and subregions classifications by the United Nations Statistics Division [22].

Statistical Analysis

We undertook statistical analysis using Stata version 14.1 (StataCorp LLC). Individuals who reported their gender as other or who had not been—or did not intend to be—living in their current country of residence for 6 months or more were excluded from the analysis. Binary logistic regression was used to examine associations between demographic and behavior variables and the main outcome measures; we present crude odds ratios (OR) and adjusted OR (aOR) for each gender. Behavior and demographic factors that showed significant associations (alpha=.05) in a univariate analysis were included in a backwards stepwise model selection process conducted separately for each gender. We specified *a priori* that age, region of birth, sexual orientation, immigration status, and age at migration or diagnosis would be factors of interest in a multivariable analysis [20]. After models were selected, we examined whether associations between the primary outcomes and the included factors differed significantly by region of current residence or by region of birth by testing interaction terms.

Results

The exact number of individuals invited to complete the survey or who saw advertising online or via a dating app is unknown; therefore, an overall participation rate is unavailable. It is known that 3420 individuals completed the within-survey consent form (102 or 2.98% declined to take part at that stage). Of the 3321 people who agreed to participate, 1727 went on to complete the survey, of whom 1637 (49.29% of those who consented) were included in the analysis (90 tourists were excluded from further analysis). Attrition rate analysis showed that 85.93% (2217/2580) of those who dropped out did so by question 7 (data not shown).

The 1637 respondents, of which 34.15% (559/1637) were women, reported 140 different countries of birth and 31 different countries as their current residence (9 transgender individuals were excluded from further analysis; see Multimedia Appendix 1 for full list of countries). The survey's targeted populations were well represented, with 62.96% (673/1069) of men identifying as gay or bisexual (209/673 born in Latin America and the Caribbean), 3.96% (64/1618) of participants reporting a history of injecting drugs, and around half of women (272/559) and heterosexual men (214/396) born in Africa or Latin America and the Caribbean (Table 1).

Participants differed across gender for almost all sociodemographic characteristics, with the notable exception of age at migration (Table 1), and the average age of gay or bisexual men was lower than in the other 2 groups. Just over a fifth (148/673, 22.0%) of gay or bisexual men reported living with diagnosed HIV compared with 8.8% (49/559) of women and 6.6% (26/396) of heterosexual men (P<.001) (Table 1; see also Multimedia Appendices 1-3 for full demographic details).

Table 1. Sociodemographic characteristics of respondents, by gender (men separated by self-reported sexual orientation).

Sociodemographics	Women	Heterosexual men	Gay or bisexual men	*P* value[a]
Current country of residence (by European region), n (%) [b,c]				<.001
Northern Europe	124 (22.1)	46 (11.6)	123 (18.3)	
Southern Europe	279 (49.9)	261 (65.9)	139 (20.7)	
Rest of Europe	156 (27.9)	89 (22.5)	411 (61.1)	
Age, years, median (IQR)[b,d]	35 (28-43)	36 (28-43)	33 (28-43)	<.001
In current country, years, median (IQR)[b,d]	8 (3-13)	8 (3-15)	5 (2-12)	<.001
Age at migration, years, mean (SD)[b,e]	26.8 (10.3)	27.2 (10.1)	26.8 (9.3)	.78
Region of birth, n (%) [b,f]				<.001
Africa	155 (27.7)	167 (42.2)	36 (5.4)	
Latin America and the Caribbean	117 (20.9)	47 (11.9)	209 (31.1)	
Rest of the world	24 (4.3)	4 (1.0)	38 (5.7)	
Asia	43 (7.7)	71 (17.9)	57 (8.5)	
Europe	220 (39.4)	107 (27.2)	333 (49.5)	
Ethnicity (n=1618), n (%)				<.001
Arab or Magrhebian	13 (2.4)	30 (7.7)	9 (1.3)	
Asian	28 (5.1)	42 (10.7)	49 (7.3)	
Black African or Caribbean	125 (22.6)	125 (31.9)	17 (2.5)	
Latin American or Hispanic	64 (11.6)	31 (7.9)	124 (18.5)	
Mixed ethnicity	40 (7.2)	21 (5.4)	88 (13.1)	
Other	44 (7.9)	55 (14.0)	39 (5.8)	
White European	201 (36.3)	83 (21.2)	302 (44.9)	
White other	39 (7.0)	5 (1.3)	44 (6.6)	
Education: upper secondary or more, n (%)[b]	398 (71.2)	248 (62.6)	600 (89.2)	<.001
Employment: working full- or part-time, n (%)[b]	297 (53.1)	177 (44.7)	501 (74.4)	<.001
Relationship status, n (%) [b]				<.001
Married or cohabitating	283 (50.6)	165 (41.7)	205 (30.5)	
Single	206 (36.8)	182 (46.0)	397 (59.0)	
Living apart relationship or marriage	70 (12.5)	49 (12.3)	71 (10.6)	
Religion of those who attend services (n=627), n (%)				<.001
Christian (all denominations)	196 (83.4)	119 (59.5)	167 (87.0)	
Muslim or Islam	23 (9.8)	66 (33.0)	9 (4.7)	
Other	16 (6.8)	15 (7.5)	16 (8.3)	
Monthly income compared with national minimum wage (n=1575), n (%)				<.001
More or a lot more	169 (32.1)	113 (29.4)	372 (56.0)	
About the same	65 (12.3)	40 (10.4)	88 (13.3)	
Less than minimum wage	122 (23.2)	89 (23.2)	120 (18.1)	
No earnings	171 (32.5)	142 (37.0)	84 (12.7)	
Not known	169 (32.1)	113 (29.4)	372 (56.0)	
Moderate or severe household hunger in the past 4 weeks (n=1520), n (%)	130 (25.8)	121 (34.5)	89 (13.4)	<.001
Immigration status, n (%) (n=1625)				<.001

Sociodemographics	Women	Heterosexual men	Gay or bisexual men	*P* value[a]
Permanent residency	343 (61.6)	183 (46.3)	482 (71.6)	
Temporary residency	86 (15.4)	84 (21.3)	157 (23.3)	
Asylum seeker or refugee status	35 (6.3)	63 (16.0)	9 (1.3)	
Undocumented[f]	78 (14.0)	55 (13.9)	23 (3.4)	
Unknown	15 (2.7)	10 (2.5)	2 (0.3)	
Living with diagnosed HIV, n (%)[b,g]	49 (8.8)	26 (6.6)	148 (22.0)	<.001
Previously injected drugs (n=1618), n (%)	19 (3.4)	20 (5.1)	25 (3.7)	.38

[a] Chi-square comparing gender-related groups.

[b] n=1628.

[c] Respondents living in Cyprus (classified as Western Asia by the United Nations but included in the World Health Organization European area) were classified as living in Southern Europe.

[d] IQR: interquartile range.

[e] SD: standard deviation.

[f] Those who checked “None of the above” in the multichoice list of all possible immigration statuses.

[g] Self-reported HIV status.

Overall, 60.8% (236/388) of heterosexual men, 73.3% (399/544) of women, and 72.6% (484/667) of gay or bisexual men reported access to a primary care physician (Table 2). The majority of participants had attended health care services in their current country of residence in the past 12 months, although 13.6% (76/559) of women, 8.8% (35/396) of heterosexual men, and 19.5% (131/673) of gay or bisexual men had returned to their country of birth and attended health care services in the previous 12 months. In each gender-related group, over 97% of the people who reported living with diagnosed HIV described visiting their HIV doctor in the last 12 months. More than a third (9/25, 36%) of heterosexual men, 25% (12/48) of women, and 4.9% (7/143) of gay or bisexual men reported missing appointments at their HIV clinic because of travel costs. Paying prescription costs was a difficulty for 53% (9/17) of heterosexual men, 41% (15/37) of women, and 19.1% (20/105) of gay or bisexual men living with diagnosed HIV.

Table 2. Access to health care services and human immunodeficiency virus testing among participants by gender (men separated by self-reported sexual orientation).

Services and testing variables	Women n (%)	Heterosexual men n (%)	Gay or bisexual men n (%)
Living with 1 or more chronic illnesses, not HIV[a] (n=1628)	183 (32.7)	126 (31.8)	243 (36.1)
Has access to primary care physician (n=1599)	399 (73.3)	236 (60.8)	484 (72.6)
Visited COB[b] for health care in the last 12 months (n=1628)	76 (13.6)	35 (8.8)	131 (19.5.)
Doctor or nurse visited in CCOR[c] in the last 12 months (n=1625)	484 (86.6)	311 (78.9)	539 (80.2)
Health care service attended in CCOR ever (n=1628)			
Any health service	519 (92.8)	361 (91.2)	587 (87.2)
GP[d] or family doctor	374 (66.9)	197 (49.7)	433 (64.3)
STI[e] clinic	75 (13.4)	48 (12.1)	346 (51.4)
Emergency	251 (44.9)	149 (37.6)	261 (38.8)
Outpatient	187 (33.5)	103 (26.0)	193 (28.7)
Inpatient	148 (26.5)	99 (25.0)	153 (22.7)
Outreach	24 (4.3)	41 (10.4)	9 (1.3)
Antenatal	138 (24.7)	4 (1.0)	—
HIV testing mentioned during attendance (n=1467)			
Any health service	196 (37.8)	129 (35.7)	374 (63.7)
Inpatient (n=400)	31 (20.9)	26 (26.3)	28 (18.3)
Emergency (n=661)	9 (3.6)	11 (7.4)	23 (8.8)
Antenatal (n=142)	67 (48.6)	0 (0)	—
STI clinic (n=469)	40 (53.3)	25 (52.1)	274 (79.2)
Outpatient (n=483)	13 (7.0)	15 (14.6)	30 (15.5)
Outreach (n=74)	21 (87.5)	32 (78.0)	7 (77.8)
GP or family doctor (n=1004)	53 (14.2)	36 (18.3)	159 (36.7)
Previously tested for HIV (n=1562)	359 (68.1)	220 (59.6)	596 (89.6)
Place diagnosed or of last test (n=1086)			
Antenatal service	51 (14.7)	2 (0.9)	1 (0.2)
Hospital service (emergency, inpatient, or outpatient)	68 (19.6)	57 (26.4)	56 (10.7)
GP or family doctor	46 (13.3)	21 (9.7)	108 (20.7)
Sexual health clinic or HIV testing clinic	58 (16.7)	36 (16.7)	250 (47.8)
Community or outreach setting	41 (11.8)	50 (23.1)	43 (8.2)
Private clinic	36 (10.4)	11 (5.1)	42 (8.0)
Other	47 (13.5)	39 (18.1)	23 (4.4)
Reasons for never testing (n=387)			
Perceived low risk	140 (83.3)	125 (83.3)	43 (62.3)
Fear of positive result and consequences	8 (4.8)	10 (6.7)	17 (24.6)
Structural barriers to accessing health care	15 (8.9)	11 (7.3)	17 (24.6)
Fear of test procedure	3 (1.8)	6 (4.0)	3 (4.3)
Other	20 (11.9)	10 (6.7)	6 (8.7)
Reasons for last test (n=1175)			
Perceived risk	57 (15.9)	46 (20.8)	227 (38.2)

Services and testing variables	Women n (%)	Heterosexual men n (%)	Gay or bisexual men n (%)
Feeling unwell or health problems	38 (10.6)	30 (13.6)	58 (9.7)
Routine health checkup	148 (41.2)	96 (43.4)	337 (56.6)
Pregnancy, blood donation, or other hospital appointment	80 (22.3)	10 (4.5)	8 (1.3)
Job application, visa, or insurance	23 (6.4)	20 (9.0)	17 (2.9)
Other	47 (13.1)	44 (19.9)	36 (6.1)
People living with HIV only (n=223)			
Previous negative HIV test (n=208)	20 (45.5)	8 (38.1)	111 (77.6)
Visited an HIV doctor in the past 12 months (n=221)	48 (98.0)	25 (100)	143 (97.3)
Missed appointments because of travel costs (n=216)	12 (25.0)	9 (36.0)	7 (4.9)
Delayed or forwent medication because of prescription costs (n=159)	15 (40.5)	9 (52.9)	20 (19.1)

[a] HIV: human immunodeficiency virus.

[b] COB: country of birth.

[c] CCOR: current country of residence.

[d] GP: general practitioner.

[e] STI: sexually transmitted infection.

The most frequently attended health service postmigration was general practice. Access to primary care (regardless of actual attendance) varied according to current region of residence (Table 3). Among women, this ranged from nearly ubiquitous access in Northern Europe (120/124, 96.8%) to less widespread access in Southern Europe at 56.4% (149/264, Table 3). This pattern was similar among heterosexual men; however, for gay or bisexual men, the lowest access to primary care was observed in the Western and rest of Europe regions (284/411, 69.1%). Multivariable analysis showed that differences in access to primary care among the regions in Europe remained significant for all 3 gender-related groups (Table 3). For women, additional factors that influenced access to care were world region of birth and immigration status. Among heterosexual men, region of birth and immigration status remain significant after adjusting for other factors, including religious practice and number of children cared for in the home (Table 3). Gay or bisexual men living with HIV were more than twice as likely to have access to primary care (aOR 2.74, 95% CI 1.53-4.86; *P*=.001), but individuals who had been resident in their current country for less than 1 year were less likely to be in receipt of primary care than those who had been in the country for 2 to 5 years (aOR 0.32, 95% CI 0.19-0.53).

Table 3. Factors associated with access to primary care, by gender (men separated by self-reported sexual orientation).

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
Women (n=541)					
Current region of residence					<.001
Northern Europe	120 (96.8)	23.15	34.56	11.58-101	
Southern Europe	149 (56.4)	1.00	1.00	—	
Western and rest of Europe	130 (85.0)	4.01	5.30	3.00-9.39	
Age, years					.79
18-24	29 (67.4)	0.88	1.26	0.55-2.86	
25-34	152 (69.4)	1.00	1.00	—	
35-44	117 (77.0)	1.52	1.09	0.61-1.92	
45-54	65 (75.6)	1.41	0.88	0.43-1.78	
55+	36 (87.8)	3.27	1.78	0.59-5.32	
World region of birth					<.001
Africa	106 (72.1)	1.02	1.70	0.91-3.17	
Latin America and the Caribbean	94 (80.3)	1.62	5.71	2.85-11.43	
Rest of the world	45 (69.2)	0.89	0.95	0.42-2.15	
Europe	154 (71.6)	1.00	1.00	—	
Years resident in CCOR [d]					.18
1 or less	38 (66.6)	0.49	0.65	0.29-1.46	
2-5	91 (64.1)	0.45	0.52	0.28-0.98	
6-9	96 (78.0)	0.89	0.97	0.51-1.82	
10 or more	174 (79.5)	1.00	1.00	—	
Immigration status					<.001
Permanent residency	274 (80.8)	1.00	1.00	—	
Temporary residency	51 (60.7)	0.37	0.41	0.21-0.80	
Refugee status, unknown, or undocumented	74 (62.7)	0.39	0.64	0.33-1.23	
Heterosexual men (n=301)					
Current region of residence					<.001
Northern Europe	36 (83.7)	5.19	6.93	2.49-19.35	
Southern Europe	92 (48.7)	1.00	1.00	—	
Western and rest of Europe	53 (76.8)	2.67	2.74	1.28-5.86	
Age, years					.16
18-24	14 (48.3)	1.18	1.24	0.46-3.32	
25-34	48 (49.0)	1.00	1.00	—	
35-44	49 (58.3)	1.76	1.10	0.51-2.34	
45-54	42 (73.7)	2.71	1.89	0.76-4.70	
55+	28 (84.8)	3.72	3.94	1.14-13.57	
World region of birth					<.001
Africa	71 (61.7)	0.96	2.14	0.92-4.95	
Latin America and the Caribbean	33 (89.2)	3.29	21.52	5.63-82.17	
Rest of the world	24 (38.1)	0.35	1.43	0.54-3.89	
Europe	53 (61.6)	1.00	1.00	—	

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
Years resident in CCOR					.55
1 or less	14 (48.3)	0.37	1.20	0.40-3.59	
2-5	40 (46.5)	0.31	0.65	0.30-1.41	
6-9	31 (62.0)	0.71	0.93	0.40-2.16	
10 or more	96 (70.6)	1.00	1.00	—	
Immigration status					.003
Permanent residency	117 (77.0)	1.00	1.00	—	
Temporary residency	28 (45.2)	0.26	0.24	0.10-0.54	
Refugee status, unknown, or undocumented	36 (41.4)	0.29	0.42	0.18-0.97	
Religious practice					.14
Christian	84 (73.7)	1.00	1.00	—	
Other	33 (44.6)	0.33	0.66	0.29-1.46	
Does not attend religious services	64 (56.6)	0.50	0.51	0.25-1.05	
One or more child cared for in the home					.13
No	97 (52.4)	1.00	1.00	—	
Yes	84 (72.4)	2.18	1.66	0.87-3.19	
Gay or bisexual men (n=667)					
Current region of residence					.03
Northern Europe	98 (79.7)	1.19	2.53	1.23-5.19	
Southern Europe	102 (76.7)	1.00	1.00	—	
Western and rest of Europe	284 (69.1)	0.68	1.28	0.74-2.20	
Age, years					.38
18-24	50 (53.8)	0.54	0.74	0.43-1.26	
25-34	186 (68.1)	1.00	1.00	—	
35-44	141 (78.3)	1.69	0.91	0.55-1.51	
45-54	79 (88.8)	3.70	1.47	0.66-3.28	
55+	28 (87.5)	3.27	2.12	0.60-7.49	
World region of birth					.66
Africa	28 (82.4)	1.75	1.83	0.63-5.28	
Latin America and the Caribbean	152 (73.1)	1.02	1.16	0.71-1.89	
Rest of the world	62 (67.4)	0.78	0.97	0.51-1.83	
Europe	242 (72.7)	1.00	1.00	—	
Years resident in CCOR					<.001
1 or less	40 (38.5)	0.09	0.10	0.05-0.19	
2-5	152 (65.5)	0.26	0.32	0.18-0.56	
6-9	102 (88.7)	1.07	1.19	0.57-2.48	
10 or more	190 (88.0)	1.00	1.00	—	
Immigration status					.40
Permanent residency	370 (76.9)	1.00	1.00	—	
Temporary residency	97 (62.2)	0.49	0.86	0.51-1.45	
Refugee status, unknown, or undocumented	17 (56.7)	0.39	0.54	0.22-1.32	
Living with diagnosed HIV [e]					.001

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
No	355 (68.3)	1.00	1.00	—	
Yes	129 (87.8)	3.33	2.72	1.53-4.86	

[a] After the final model selection, each gender-related group adjusted for the factors listed under the corresponding heading in the table.

[b] OR: odds ratio.

[c] aOR: adjusted odds ratio.

[d] CCOR: current country of residence.

[e] HIV: human immunodeficiency virus.

More than two-thirds (359/527, 68.1%) of women, 59.5% (220/371) of men, and 89.6% (596/664) of gay or bisexual men had previously tested for HIV (Table 2). Respondents were asked about the place of their last test (or where they were diagnosed in the case of those living with HIV); whereas a fifth (108/523) of gay or bisexual men had tested at the GP, only 13.3% (46/347) of women and 9.7% (21/216) of heterosexual men had done so. Just over half of women and heterosexual men (40/75, 53.3%, and 25/48, 52.1%, respectively) and 79.2% (274/346) of gay men recalled being offered an HIV test in sexually transmitted infection (STI) clinics; 47.8% (250/523) of gay or bisexual men and 16.7% (58/347) of women and heterosexual men (36/216) cited an STI clinic as the place of their last test. Less than half (67/138, 48.6%) of the women who had attended antenatal care recalled being offered a test, with 14.7% (51/347) of women reporting an antenatal service as the place of their last test. Among those who had attended a GP, over a third (159/433, 36.7%) of gay or bisexual men, 14.2% (53/374) of women, and 18.3% (36/197) of heterosexual men recalled being offered an HIV test. Routine and quasi-routine health checks (such as pregnancy or other hospital appointments) were the impetus for testing for 63.5% (228/359) of women. Among all men, routine health checks and a perceived risk of HIV were the main reasons for testing.

Respondents who had never tested were asked to select their reasons for not having done so. Among women and heterosexual men, most (140/168, 83.3%, and 125/150, 83.3%, respectively) who had not tested reported that they were at no or low risk, and a few (8/168, 4.8%, and 10/150, 6.7%, respectively) reported fear of a positive test result. Although low risk of infection was a reason for not testing for 62.3% (43/69) of gay or bisexual men, around a quarter (17/16, 24.6%) also reported fears of a positive test result or structural barriers to accessing health care (Table 2).

Table 4 shows HIV risk factors among participants not living with HIV. Respondents' basic knowledge of HIV and acquired immune deficiency syndrome (AIDS) was assessed by asking whether they "knew that AIDS was caused by a virus called HIV." Whereas 97.1% (509/524) of gay or bisexual men responded they "knew this before today," around 1 in 10 women (55/506, 10.9%) and 14.5% (53/366) of heterosexual men did not. A large proportion (233/500, 46.6%) of gay or bisexual men reported more than 100 lifetime sexual partners, and a similar proportion (220/520, 42.3%) reported more than 11 partners in the past year. In comparison, 2.7% (13/483) of women and 5.0% (17/338) of heterosexual men reported 100 or more sexual partners in their lifetime and the majority reported 1 or no sexual partners in the past year. A small proportion of women (20/467, 4.3%) reported no condom use in their last sexual act with a nonregular partner, and 17.2% (88/511) of gay or bisexual men reported not using a condom in their last sexual encounter with a nonregular partner.

Table 4. Human immunodeficiency virus (HIV) risk factors among participants not living with diagnosed HIV by gender (men separated by sexual orientation).

Risk factors	Women n (%)	Heterosexual men n (%)	Gay or bisexual men n (%)
Unaware that AIDS[a] is caused by a virus called HIV[b] (n=1396)	55 (10.9)	53 (14.5)	15 (2.9)
Total number of lifetime sexual partners (n=1321)			
0-1	100 (20.7)	70 (20.7)	4 (0.8)
2-5	188 (38.9)	70 (20.7)	26 (5.2)
6-10	70 (14.5)	66 (19.5)	40 (8.0)
11-20	64 (13.3)	56 (16.6)	44 (8.8)
21-50	37 (7.7)	42 (12.4)	68 (13.6)
51-100	11 (2.3)	17 (5.0)	85 (17.0)
More than 100	13 (2.7)	17 (5.0)	233 (46.6)
Total number of sexual partners in the past year (n=1384)			
None	84 (16.6)	68 (19.0)	20 (3.8)
1	314 (61.9)	153 (42.9)	43 (8.3)
2-10	98 (19.3)	114 (31.9)	237 (45.6)
≥11	11 (2.2)	22 (6.2)	220 (42.3)
At last sex: no condom use (n=1308)	337 (72.2)	203 (61.5)	182 (35.6)
At last sex: no condom and nonregular partner (n=1308)	20 (4.3)	43 (13.0)	88 (17.2)
Previously diagnosed with an STI (n=952)[c,d]	74 (23.9)	44 (22.6)	227 (50.8)
Does not know where to access free condoms (n=1349)	236 (48.8)	186 (53.6)	242 (46.7)
Cannot afford condoms (n=661)[e]	167 (71.7)	112 (60.2)	201 (83.1)
Previously exchanged sex for money, food, or drugs (n=1346)			
Ever	36 (7.4)	22 (6.4)	78 (15.1)
n the last 12 months (n=126)	16 (53.3)	11 (55.0)	37 (48.7)
Previously paid for sex (n=1561)			
Ever	3 (0.6)	122 (36.2)	96 (18.5)
In the last 12 months (n=209)	0 (0)	51 (44.3)	35 (37.6)
Experienced forced sex (n=1331)	55 (11.6)	13 (3.8)	51 (10.0)
Previously used a needle to inject drugs (n=1396)	13 (2.6)	12 (3.3)	16 (3.0)
Previously shared a needle when injecting drugs (n=41)	9 (69.2)	6 (50.0)	5 (31.3)
Used drugs in the last 5 years—excluding cannabis (n=1388)	64 (12.8)	54 (14.8)	234 (44.7)
Used methamphetamine or GHB[f] or GBL[g] in last 5 years (n=1388)	5 (1.0)	6 (1.6)	66 (12.6)

[a] AIDS: acquired immune deficiency syndrome.

[b] HIV: human immunodeficiency virus.

[c] STI: sexually transmitted infection.

[d] Does not include those who have never tested for HIV.

[e] Only those who cannot access free condoms.

[f] GHB: gammahydroxybutyric acid.

[g] GBL: gammabutyrolactone.

In the multivariable analysis, the only HIV risk factor significantly associated with previous HIV testing in all groups was the number of lifetime partners (Table 5). For women and heterosexual men, additional associations were found for region of birth. Further factors for women were experience of forced sex (aOR 3.55, 95% CI 1.40-9.01) and receiving antenatal care postmigration (3.09, 95% CI 1.56-6.13). For heterosexual men, additional factors included access to primary care (aOR 2.67, 95% CI 1.43-4.97), and those with poorer health were less likely to have tested (aOR 0.22, 95% CI 0.22-0.84).

Table 5. Factors associated with ever having human immunodeficiency virus (HIV) tested among participants not living with diagnosed HIV, by gender (men separated by self-reported sexual orientation).

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
Women (n=426)					
Current region of residence					.13
Northern Europe	53 (55.2)	0.62	0.51	0.26-0.99	
Southern Europe	147 (66.5)	1.00	1.00	—	
Western and rest of Europe	76 (69.7)	1.17	0.85	0.45-1.60	
Age, years					.37
18-24	22 (57.9)	0.61	0.55	0.23-1.30	
25-34	119 (65.4)	1.00	1.00	—	
35-44	81 (70.4)	1.25	1.23	0.66-2.31	
45-54	34 (55.7)	0.62	0.74	0.32-1.67	
55+	20 (66.7)	1.18	1.32	0.46-3.85	
Region of birth					<.001
Africa	75 (84.3)	4.00	5.42	2.48-11.83	
Latin America and the Caribbean	66 (68.8)	1.79	2.46	1.22-4.95	
Rest of the world	29 (55.8)	0.86	0.97	0.46-2.05	
Europe	106 (56.1)	1.00	1.00	—	
Years resident in the country					.06
1 or less	34 (77.3)	1.31	3.09	1.13-8.44	
2-5	60 (55.6)	0.61	0.85	0.43-1.68	
6-9	64 (64.6)	0.86	1.01	0.52-1.95	
10 or more	118 (67.4)	1.00	1.00	—	
Immigration status					.13
Permanent residency	187 (66.8)	1.00	1.00	—	
Temporary residency	41 (68.3)	0.96	0.59	0.26-1.33	
Refugee status, unknown, or undocumented	48 (55.8)	0.71	0.44	0.20-0.95	
Total number of lifetime sexual partners					<.001
0-1	37 (47.4)	0.52	0.53	0.28-1.01	
2-5	103 (59.5)	1.00	1.00	—	
6-10	42 (66.7)	1.28	1.54	0.76-3.11	
More than 10	94 (83.9)	3.43	4.25	2.16-8.36	
Experience of forced sex					.008
No	235 (62.2)	1.00	1.00	—	
Yes	41 (85.4)	3.79	3.55	1.40-9.01	
Children or antenatal care in CCOR [d]					.001
No children	127 (61.7)	1.00	1.00	—	
Has children, no antenatal care in CCOR	69 (58.0)	0.82	0.77	0.41-1.41	
Has children, antenatal care in CCOR	80 (79.2)	2.36	3.09	1.56-6.13	
Self-reported health status					.07
Very good	86 (78.2)	2.31	2.08	1.12-3.88	
Good	100 (57.1)	1.00	1.00	—	
Other response	90 (63.8)	1.30	1.39	0.78-2.46	

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
Heterosexual men (n=301)					
Current region of residence					.08
Northern Europe	20 (52.6)	1.06	0.93	0.38-2.26	
Southern Europe	102 (51.8)	1.00	1.00	—	
Western and rest of Europe	46 (69.7)	2.13	2.13	1.04-4.35	
Age, years					.14
18-24	22 (61.1)	1.46	1.79	0.74-4.36	
25-34	53 (51.5)	1.00	1.00	—	
35-44	52 (66.7)	1.65	1.86	0.90-3.81	
45-54	26 (50.0)	0.78	0.93	0.40-2.18	
55+	15 (46.9)	0.71	0.57	0.20-1.65	
Region of birth					.01
Africa	79 (66.4)	1.00	1.00	—	
Latin and the Caribbean	22 (59.5)	0.54	0.38	0.16-0.93	
Rest of the world	29 (47.5)	0.36	0.57	0.27-1.18	
Europe	38 (45.2)	0.32	0.32	0.16-0.67	
Years resident in the country					.71
1 or less	20 (55.6)	0.85	1.45	0.54-3.95	
2-5	51 (55.4)	1.02	1.19	0.57-2.47	
6-9	26 (55.3)	1.08	0.80	0.35-1.85	
10 or more	71 (56.3)	1.00	1.00	—	
Immigration status					.57
Permanent residency	81 (55.9)	1.00	1.00	—	
Temporary residency	42 (64.6)	1.40	1.46	0.65-3.27	
Refugee status, unknown, or undocumented	45 (49.5)	0.77	1.03	0.45-2.35	
Total number of lifetime sexual partners					<.001
0-1	23 (35.9)	0.29	0.20	0.09-0.44	
2-5	29 (47.5)	0.47	0.39	0.19-0.80	
6-10	35 (64.8)	0.93	1.00	0.46-2.15	
More than 10	81 (66.4)	1.00	1.00	—	
Access to primary care					<.001
No	61 (47.3)	1.00	1.00	0.20-0.70	
Yes	107 (62.2)	1.82	2.67	1.43-4.97	
Self-reported health status					.04
Very good	49 (55.1)	0.65	0.68	0.36-1.30	
Good	81 (65.3)	1.00	1.00	—	
Other response	38 (43.2)	0.40	0.43	0.22-0.84	
Gay or bisexual men (n=492)					
Current region of residence					.64
Northern Europe	76 (87.4)	0.97	1.18	0.53-2.61	
Southern Europe	69 (83.1)	0.70	0.72	0.32-1.66	
Western and rest of Europe	282 (87.6)	1.00	1.00	—	

Factors[a]	n (%)	OR[b]	aOR[c]	95% CI	*P* value
Age, years					.35
18-24	61 (72.6)	0.34	0.53	0.26-1.09	
25-34	188 (89.1)	1.00	1.00	—	
35-44	115 (89.1)	1.10	0.75	0.32-1.73	
45-54	48 (96.0)	3.27	1.86	0.36-9.62	
55+	15 (83.3)	0.54	0.56	0.11-2.82	
Region of birth					.87
Africa	22 (81.5)	0.71	1.18	0.31-4.48	
Latin America and the Caribbean	119 (88.1)	1.21	1.34	0.62-2.87	
Rest of the world	69 (87.3)	1.11	1.37	0.53-3.52	
Europe	217 (86.5)	1.00	1.00	—	
Years resident in the country					.46
1 or less	70 (76.9)	0.50	0.57	0.27-1.23	
2-5	153 (87.9)	1.00	1.00	—	
6-9	77 (90.6)	1.41	1.10	0.41-2.93	
10 or more	127 (89.4)	1.17	0.81	0.34-1.94	
Immigration status					.86
Permanent residency	321 (87.5)	1.00	1.00	—	
Temporary residency	89 (87.3)	0.94	0.99	0.44-2.21	
Refugee status, unknown, or undocumented	17 (73.9)	0.43	0.71	0.20-2.54	
Total number of lifetime sexual partners					<.001
0-10	56 (62.9)	0.06	0.07	0.02-0.23	
11-20	36 (78.3)	0.13	0.15	0.04-0.54	
21-50	79 (92.9)	0.47	0.53	0.14-2.01	
51-100	73 (91.3)	0.37	0.36	0.10-1.33	
101-500	112 (96.6)	1.00	1.00	—	
501 or more	71 (93.4)	0.51	0.49	0.12-1.93	

[a] After model selection, each gender-related group adjusted for the factors listed under the corresponding heading in the table.

[b] OR: odds ratio.

[c] aOR: adjusted odds ratio.

[d] CCOR: current country of residence.

Discussion

Principal Findings

This paper presents findings on access to primary care and HIV testing from the first European study focused on multiple migrant populations. It captures a diverse sample of migrant communities at risk of HIV infection, including migrant gay or bisexual men who form a substantial, relatively underresearched, proportion of the HIV epidemic in Europe. We have shown that determinants of access to primary care are dependent on immigration status and where an individual resides within Europe. A high proportion of participants had previously tested for HIV, but there is evidence that missed opportunities for increasing the uptake of HIV testing remain. A previous history of testing for HIV was strongly associated with sexual behavior. Accordingly, low perception of risk was identified as one of the main barriers to HIV testing among all 3 gender-related groups.

Previous studies have suggested that cultural factors act as barriers to health-seeking behavior among black African heterosexuals [10,11,17,23,24]. Whereas we found that region of origin influences access to primary care for women and heterosexual men, perhaps providing additional evidence, this association was not present for gay or bisexual men and suggests that other factors influence health-seeking behaviors in this population. Additionally, previous studies have suggested that African migrants have high rates of late diagnosis because this population has different health-seeking norms or competing priorities in comparison with Europeans [7,24]. However, this study found no significant difference in access to primary care between migrants from Africa and other regions, with the exception of Latin America and the Caribbean. This suggests that rather than sociodemographic characteristics, cultural practices, or individual health status, it is perhaps the structural factors that present the largest barriers to primary care for migrants, regardless of country of origin.

The importance of such structural or macro-level barriers may indicate changing policies and practices regarding rights to health care of both documented and undocumented migrants (including those whose visas have expired or asylum applications have been rejected). For example, in Spain, the government rescinded access to primary health care for migrants without residency papers in September 2012 only to reinstate it again in March 2015 [25,26]. In the United Kingdom, proposals to charge short-term, temporary, and undocumented migrants for primary medical care were debated in 2013 and partially implemented through a new Immigration Act in 2014 [27]. The impact of these policies regarding health care is perhaps reflected in the findings of our study. However, additional evidence is needed regarding the impact of immigration policies on access to HIV testing for migrants.

Findings are consistent with other studies showing that low perception of risk is a barrier to HIV testing for various migrant or black and minority ethnic communities [11,24,28-30]. Many of those studies focus on the needs of heterosexual migrant men and women. Our study also highlights risk perception as a barrier to testing for migrant gay or bisexual men, which may reflect a difference with nonmigrant gay men. Indeed, the European Men-Who-Have-Sex-With-Men Internet Survey Network found that HIV testing in the last 12 months was negatively associated with migrant status [31]. Given that gay or bisexual men reported fears surrounding the consequences of a positive test result and experienced structural barriers to testing (eg, having to pay for the test, not knowing where to go for a test, and being unable to test anonymously), these findings provide evidence for HIV testing initiatives aimed at migrant gay or bisexual men. Additionally, women and heterosexual men born in Africa were more likely to test than those born in other regions, but given that late presentation remains a feature for these communities [2], structural barriers may be preventing early diagnosis.

There was evidence of missed opportunities for HIV testing. Studies have shown that offering HIV tests in general practice is feasible and acceptable [17,18]. Data from this study show that general practice might be a key gateway to improving the uptake and awareness of HIV among migrant populations, particularly among heterosexual men. Given that over 80% of the participants had visited a doctor or nurse in their current country of residence in the last year and 9 out of 10 had visited some type of health service since migrating, the proportion who recalled HIV being mentioned while at a health service (47%) is comparatively low. This disparity is particularly problematic in services where there should be a policy of a routine offer or opt-out for HIV testing. Less than half of women recalled anyone mentioning HIV in antenatal care. Given that opt-out or universal HIV testing at antenatal services is available in almost all the countries featured in this survey [32], it is possible that the women tested but did not recall being offered the test. As routine testing is also available at sexual health clinics in these countries [33], the same explanation could account for our finding that nearly half of women and heterosexual men were not offered an HIV test at that service.

In addition to the structural barriers to accessing health care and HIV testing, this study provides evidence of individual-level obstacles to HIV prevention and testing. Over 1 in 10 women and heterosexual men did not have basic HIV knowledge; in all groups, around half of the respondents did not know where to access free condoms and 17% to 40% of those who did not know where to access condoms could not afford them. Whereas the finding about basic HIV knowledge might be consistent with other studies [34], we nevertheless highlight the importance of continued HIV knowledge and awareness initiatives aimed at migrant communities.

Limitations

Our study has a number of limitations [20]. Our sample is a convenience sample; therefore, it is not representative of the European migrant population. Over half of those who consented to the survey did not complete it. Given that attrition was largely confined to the first part of the survey (the curiosity plateau), it is possible that those who dropped out at that stage had consented out of curiosity and withdrew when the survey did not meet their expectations [35]. The very large percentage of men who have sex with men in the survey reflects our targeting and advertising strategy. Individuals who fall into more than 1 population group (eg, Latin American men who have sex with men) may have been exposed to advertising and marketing on multiple occasions and different media. Nevertheless, by conducting analyses separately within gender-related subgroups, we have limited bias in our findings.

In this sample, the proportion of respondents who reported living with HIV was similar to another study that used community mobilization and engagement recruitment methods [36]. It is also possible that the high proportion of respondents who had visited an HIV doctor in the past 12 months also reflects the recruitment strategy used in this survey, particularly as around half of the respondents living with HIV reported contact with a nongovernmental organization providing HIV support (data not shown). Regardless of the recruitment methods, our findings show people living with HIV are missing appointments and forgoing or delaying medication for financial reasons. This suggests that there are possible implications for treatment adherence and service attendance.

Conclusion

Improving access to primary care and HIV testing represents an important strategy to reduce the risk of postmigration acquisition of HIV and reduce ill health among migrants in Europe. Our data suggest that improving access to GPs, particularly for migrants without permanent residency permits, could increase the uptake of HIV testing. Clinicians and others should consider the impact of structural policies that inhibit access to HIV testing as well as interventions that increase individual knowledge, raise awareness of risk, or induce behavior change.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Sociodemographic characteristics of respondents.

[XLSX File (Microsoft Excel File), 18KB - publichealth_v3i4e84_app1.xlsx]

Multimedia Appendix 2

Current country of residence of all participants in the Advancing Migrant Access to Health Services in Europe Community Survey. Color gradient indicates number of participants, with color increasing in saturation with increasing number of people. N=1637.

[JPG File, 249KB - publichealth_v3i4e84_app2.jpg]

Multimedia Appendix 3

Country of birth of all eligible participants in the Advancing Migrant Access to Health Services in Europe Community Survey. Color gradient indicates number of participants, with color increasing in saturation with increasing number of people. N=1637.

[JPG File, 325KB - publichealth_v3i4e84_app3.jpg]

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Abbreviations

AIDS: acquired immune deficiency syndrome
aMASE: Advancing Migrant Access to Health Services in Europe
aOR: adjusted odds ratio
CAG: Community Advisory Group
CCOR: current country of residence
COB: country of birth
FISPSE: Foundation for AIDS Research and Prevention in Spain (Spanish)
GBL: gammabutyrolactone
GHB: gammahydroxybutyric acid
GP: general practitioner
HIV: human immunodeficiency virus
IQR: interquartile range
NIHR: National Institute for Health Research
NHS: National Health Service
OR: odds ratios
STI: sexually transmitted infection
WHO: World Health Organization

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Original Paper

A Human-Centered Platform for HIV Infection Reduction in New York: Development and Usage Analysis of the Ending the Epidemic (ETE) Dashboard

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Abstract

Background: Dashboards have been increasingly used in clinic-based interventions, such as clinical performance improvement and monitoring risk of hospital readmissions, and are now gaining traction in population-based interventions, especially in disease assessment.

Objective: We describe the design, development, and usage analysis of a geovisualization dashboard, the Ending the Epidemic (ETE) Dashboard. The ETE dashboard is a tool developed to track New York's progress towards achieving the goal of its ETE Initiative, to reduce new HIV infections from 3000 per year to 750 per year by the end of 2020.

Methods: The ETE dashboard was adapted from an existing human-centered geovisualization platform, SanaViz, an Internet-enabled, interactive app incorporating principles of human-centered design and cognitive fit theory to enhance visual exploration of population health data. Usage evaluation of the ETE geovisualization dashboard was conducted using Google Analytics over a 4-week period from March 19 to April 18, 2016. The aim was to monitor user activity and analyze traffic on the ETE dashboard using evidence-based metrics that can provide adequate feedback to enhance its utilization. Usage was characterized based on three metrics: (1) number of unique visits to each page, (2) average time on each page in seconds, and (3) page bounce rate (ie, percentage of visits where user left the site immediately after viewing just a single page). Further analysis was also conducted by cross-tabulating specific usage metrics.

Results: Of 860 sessions, 324 sessions were initiated by unique users (37.7%). The most common acquisition channels included direct source (353/860, 41.0%); followed by referral traffic (340/860, 39.5%) and organic search (134/860, 15.5%). Usage statistics indicate that for the 860 sessions initiated by both new and returning users, the average viewing time was 8 minutes, 51 seconds, and the bounce rate was 46%. These statistics reflect positive results given that prior literature estimates an average session duration of 10-20 seconds and a bounce rate of 40-60% for most websites. Key findings from our study showed that the highest bounce rates were seen for the "About" page of the ETE website (65%), which describes the ETE initiative. The lowest bounce rates were seen for the ETE blog page (17%), consistent with prior research on website usage metrics that indicate that blog pages are often the most frequently viewed pages on Web portals.

Conclusions: Our findings reveal the potential of Google Analytics as a tool to enhance user traffic and performance of the ETE geovisualization platform by using feedback from regular monitoring of key parameters including page bounce rates and average time on page. It also identifies the need for a follow-up usability assessment of the system.

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KEYWORDS

geo-visualization; ETE dashboard; HIV/AIDS; human centered design

Introduction

Global population growth has been accompanied by a corresponding expansion of health datasets. The aggregation of these health datasets from diverse sources including the pharmaceutical, medical, and health insurance sectors is commonly referred to as big data. The relevance of big data in health care has been exemplified by its use in assessing hospital readmission patterns, mining of medical data to identify most effective treatments for health conditions, and identifying innovative methods to reduce patient costs [1]. Generating such aggregate data is facilitated by advances in technology, as recent trends indicate a rise in innovative tools to foster improved dissemination and use of health data in decision making [1]. Integration of health data has been defined by the Association for Behavioral Health and Wellness as “whole person care that focuses on overall health; creates partnerships across all aspects of health; and is facilitated by a variety of clinical, structural, financial arrangements and community supports that remove barriers between physical and behavioral health care” [2]. Health data integration offers immense potential to foster efficiency, improve quality of care, increase patient satisfaction, and ultimately promote population health outcomes [3]. Integrated technology platforms both benefit from and foster clinical integration, which leads to increased collaboration of health care providers, reduced waste of health care resources, improved care coordination, patient-centered communication, enhanced pharmaceutical management, and improved health data systems development [3].

Dimensions of public health data include spatial (ie, geographic), temporal (ie, time), and attribute (ie, context), which provide valuable insight into tackling population-level health issues and support effective decision making. Spatial components refer to location-related features such as region or country [4]. The temporal component refers to timing of the occurrence or conditions and is useful in describing trends over time [5], while attributes refer to the specific characteristic of interest. These factors combined inform stakeholders in monitoring, disseminating, and improving population-level outcomes. Visualization tools provide an immense capacity to examine the various dimensions of public health data including spatial, temporal, and other attributes, as well as intuitive exploration of the relationships between the various elements beyond the capacity of traditional statistical analysis [6]. Dashboards are visualization tools that present aggregated data graphically, thereby streamlining cognitive effort in assessing decision alternatives while providing the users with the ability to self-select the desired information for display and to explore [7,8]. Empirical studies have identified numerous uses and features of dashboards including dissemination of integrated data to a broad audience, presentation of coding systems to alert users of essential events or changes in metrics [7], efficient analytical mechanisms to provide rapid feedback on key metrics and outcome measures [7], comprehensive summaries of multiple information sources in a single view [9], systems for early detection of adverse events, facilitation of informed decision making in clinical and community settings [7-9], and user-centered and interactive features that allow manipulation of data displays based on desired outcomes [9].

Dashboards have been increasingly used in clinic-based interventions, such as clinical performance improvement and monitoring risk of hospital readmissions, and are gaining traction in population-based interventions, especially in disease assessment [10]. The efficiency of dashboards are exemplified in their description as a single platform incorporating multiple functions including data collection tools, data aggregation, data analysis, mapping/geographic information system technology, and data visualization [7]; or as a combination of one or more of these platforms [11]. Dashboards have been described as conceptual design frameworks in the existing literature based on their applications in health improvement, design features, evaluation reports, and implementation challenges [9]. A commonality in the features of dashboards across these empirical studies is the flexible architecture of dashboards to incorporate various functionalities [8]. Data visualization has also been identified as a key component of dashboards, largely attributable to cognitive theories that underscore the importance of using graphs in examining relationships and recognizing patterns to facilitate real-time data dissemination and decision making, which is preferable to tables and static reports [12].

Prior research has utilized a variety of Google Analytics metrics in website performance and informing their design and development. They include metrics for (1) evaluating and improving content (ie, search engine, key words, top entry and exit pages, page viewing time, and referrers), (2) enhancing navigation (ie, search key words, error pages, path analysis), (3) evaluating accessibility (ie, search key words, search engines, entry pages, referrer), and (4) informing site design (ie, browser usage and platform statistics) [13], a framework consisting of 20 log-based metrics for enhancing user experience [14]. Our study used a combination of these Google Analytics metrics in evaluating usage of the Ending the Epidemic (ETE) website. The objective of this study is to describe the design, development, and a usage analysis of the ETE geovisualization platform, which was adapted from an existing human-centered framework, SanaViz.

Challenges in Geovisualization

Geovisualization is a technique that uses mapping tools to represent data insights and visual interactions [15]. Through its capacity to generate geospatial displays of aggregated data, geovisualization provides an ideal and efficient way to generate hypotheses and foster evidence-driven solutions [16]. The use of maps provides a user-friendly approach to view complex data in a simplified way [16]. Maps have the potential to elicit visual thinking and readily understood patterns and relationships between data elements that are key for data exploration, hypothesis generation, and decision making [17]. Despite the immense potential of geovisualization and spatial analysis, their use in population health has been limited [16]. This has been attributed to a lack of sufficient research that provides detailed guidance on design and development of user-friendly geovisualization tools for use in population health [18,19].

Prior research has shown that the design framework of major geovisualization tools and technologies solely utilizes information technology and software engineering principles. These frameworks do not incorporate adequate user input into the initial design phases, but rather they are included after the main functionality and interface requirements have been decided [20,21]. The resulting geovisualization apps are often generic, lack user-friendliness, and fail to meet the range of user-specific needs [18]. The need for human-centered theoretical frameworks is pertinent in the design and implementation of geovisualization tools and technologies to enhance their usage and benefits.

Role of Human-Centered Approach in the Design of the ETE Dashboard

Understanding user characteristics, needs, and preferences are critical for developing human-centered geovisualization tools and technologies such as the ETE dashboard. Analysis of user demographics such as age and education, as well as prior exposure to and familiarity of spatial visualization and computers play a key role in ensuring optimal utilization of geovisualization apps. The primary feature of user interactivity in geovisualization platforms facilitates control over the display of the data, enables comparisons and layering of different mapping environments, and presents complex data in a format that can be easily appreciated by the user. The format in which visual displays are used to present information will largely influence information processing and knowledge generation. Creating the most effective display format to improve information processing and knowledge generation remains a crucial challenge in most geovisualization platforms. In addition, user tasks and operations need to be clearly defined and collectively evaluated to meet the goals of data exploration, analysis, and knowledge development [21,22].

Description of the ETE Dashboard

The ETE dashboard is a geovisualization dashboard designed to measure, track, and disseminate actionable information on progress towards achieving the goals of New York State’s ETE Initiative to all stakeholders. The information contained in the dashboard system needs to be accessible and useful to a very wide array of stakeholders ranging from policy makers who often want high-level information to practitioners, community-based organizations, and advocacy organizations that often request more granular and technical information. The ETE geovisualization dashboard was adapted using the SanaViz platform (meaning “health view”) [23]. The dashboard included 2 phases: (1) a static component and (2) an interactive component. The primary subject matter experts who informed the content and interface of the ETE dashboard included the New York State Department of Health AIDS Institute, the New York City Department of Health and Mental Hygiene, the data subcommittee of the New York State Ending the Epidemic Task Force, and the Institute for Implementation Science in Population Health at the City University of New York (CUNY), and the CUNY Graduate School of Public Health and Health Policy.

The ETE geovisualization dashboard provides information about different data sources that have been used to present HIV epidemic-related information in static as well as interactive formats. The information is presented using a combination of maps, charts, and graphs. The dashboard has a series of interactive features including highlights and multiple linkages to facilitate visual exploration of the data across different perspectives. Individuals using the interactive version of the dashboard can filter the variables of interest to present the data in a meaningful format using a combination of maps, graphs, and charts. The dashboard also has a blog that is regularly updated to communicate HIV and acquired immune deficiency syndrome (AIDS) epidemic-related information. The dashboard facilitates data entry, import, export, and integration across different data sources. The Measures tab represents seven broad data realms of HIV/AIDS information including prevention of HIV infections, incidence, testing, new diagnoses and linkage, prevalence and care of HIV/AIDS, AIDS diagnoses, and deaths among people living with HIV/AIDS. Additional features of the dashboard include information on events and news as well as HIV/AIDS-related resources (Multimedia Appendices 1 and 2).

Technical Architecture and Technologies Used

The ETE geovisualization dashboard is built on open source technologies including hypertext preprocessor (PHP), hypertext markup language (HTML), cascading style sheets (CSS), JavaScript, jQuery, and recent versions of JavaScript libraries as main components for the frontend and MySQL as the database engine. The technologies that have been used for ETE dashboard Web app development include PHP 5.2.4 (minimum), MySQL 5.0.15 or later (MySQL 5.1.x recommended), WordPress, HTML 4 and 5, CSS and CSS3, Google Chart application programming interface (API), scalable vector graphic (SVG) vector (converted from Shapefiles Provided), JavaScript, jQuery, asynchronous JavaScript (Ajax), cURL, and Google Web fonts API. The Web app is compatible with several versions of Google Chrome, Mozilla, Internet Explorer, Safari, Microsoft Edge, and Opera. The minimum Web server requirements include 2 GB disk space/Web space or more, PHP version 5.2.4 or greater, MySQL version 5.0.15 or greater, Apache Server, Apache mod_rewrite module (for clean URIs known as Permalinks), PHP data objects (PDO) database driver for MySQL (pdo_mysql or pdo_mysqli) or Postgres (pdo_pgsql) or MSSQL (pdo_sqlsrv), and PHP Mail Function enabled or simple mail transfer protocol (SMTP) support. The Web app has two main interfaces: frontend interface and admin panel. The frontend is publically accessible, and the admin panel can be accessed by defined username and password assigned to the administrators. The Web app has static and dynamic pages, blog posts, categories, events, charts, graphs, and visualizations, which are manageable from the admin panel. User management includes signup, login, and profile management. The admin panel also manages and filters datasets and creates visualizations.

Data Sources for the Dashboard

There are several sources of aggregated data that are utilized and integrated in the dashboard to allow visual exploration of various measures to track and monitor the HIV epidemic.

All data are aggregated from the individual or line level by ETE dashboard staff and then imported into the dashboard. Data sources are shown in Table 1.

Data Measures Represented on the Dashboard

The system requires the inclusion and integration of aggregate data from different realms and data sources. Key realms of data include HIV prevention, incidence, testing, new diagnoses, prevalence and care, AIDS diagnoses, and deaths (see Table 2). Key data sources include routine HIV surveillance, vital statistics, eHIVQUAL, Community Health Survey/Behavioral Risk Factor Surveillance System, sexually transmitted infection (STI) surveillance, NYLinks, and Medicaid. A realm can contain information from many data sources (eg, the continuum of care outcome measure, retention in care, is captured both by a facility-reported source, NYLinks, as well as via lab results from HIV surveillance). A data source can likewise contain information that fits into multiple realms.

Table 1. Data sources for the Ending the Epidemic (ETE) geovisualization dashboard.

Source	Description (level of data aggregation)	Format	Timeframe	Distribution	Measures
Surveillance data	Population-based registry: electronic reporting of lab tests; physician reports; active field surveillance; case investigations (as low as ZIP code, but may be a larger geographic area when numbers all small to protect privacy)	Prepared in SAS, converted to Excel	Annual	New York State, New York City	Number of new HIV/AIDS[a] diagnoses, prevalent cases, linkage to care, retention in care, viral load suppression, late and concurrent diagnoses, CD4 count, AIDS diagnoses, deaths among people living with HIV/AIDS
NYC Community Health Survey	Telephone survey (United Hospital Fund neighborhood)	Prepared in SAS, converted to Excel	Annual	New York City (all 5 boroughs)	HIV testing and condom use
Behavioral Risk Factor Surveillance System	Telephone survey (County)	Static reports	Annual	New York State	HIV testing
NY State Department of Health Quality of Care program (eHIVQUAL)	Facility-reported performance measurement review (Facility)	Static reports	Biennial	New York State	Visit frequency, new patient retention, viral load suppression, antiretroviral therapy usage
NYLinks	Facility-reported performance measurement web application (Facility)	Static reports	Bi-monthly, quarterly	Regions: Upper Manhattan, Western New York, Hudson Region, Queens, Long Island	Linkage to care among newly diagnosed, short-term retention, 2-year retention in care
Vital statistics	Registry of all deaths and live births, collected administratively (County)	Excel	Annual	New York State, New York City	Deaths with underlying cause of HIV/AIDS
Medicaid	Administrative billing data (County)	Excel	Annual	New York State	PreP prescriptions filled

[a] AIDS: acquired immune deficiency syndrome.

Table 2. Key data measures represented using the Ending the Epidemic (ETE) geovisualization dashboard.

Data realm	Key measures
HIV prevention	Condom use, STI[a] prevalence, perinatal infections
New infections	Estimated new infections in New York State (NYS) and New York City (NYC), incidence rates
HIV testing	Ever tested for HIV (NYS); tested for HIV in last 12 months (NYC); never tested (NYC)
New diagnoses and linkage	New diagnoses (NYS), HIV diagnosis rates (NYC), median CD4 count at diagnosis, concurrent HIV/AIDS[b] diagnosis, linkage to care among newly diagnosed within 90 days/30 days
Prevalence and care	HIV/AIDS prevalence, engagement in care, retention in care, antiretroviral therapy use, viral load suppression
AIDS diagnoses	New AIDS diagnoses
Deaths among people with HIV/AIDS	Number of deaths and age-adjusted death rates among people with HIV/AIDS, HIV-related deaths (underlying cause of death HIV/AIDS)

[a] STI: sexually transmitted infection.

[b] AIDS: acquired immune deficiency syndrome.

To meet the ongoing need for routinely updated data, each data source is set up as a stream of aggregate county or ZIP code level data that feed into the various data realms to generate high-level metrics, such as state or city wide trend data on new infections or HIV-related deaths, and additionally allows the user to drill down into specific geographic areas and population groups (eg, by gender, age, or race/ethnicity). Because data in the dashboard are linkable by geography and calendar time, the capability to develop and deploy visualizations that integrate data across multiple realms using data from the dashboard is now possible.

Data Integration and Visualization Processes

Data are imported into the ETE in an MS Excel sheet with an .xls or .xlsx extension. They are then converted into Comma Separated Values (CSV) format. Data cleaning is then carried out to remove white spaces and special characters. Lowercase letters and numbers are preferred as variable names in this process. The CSV file is then uploaded to the server and imported into the database by reading it with a PHP script added in a WordPress plugin. After successful import of the datafile, routine checks are carried out to ensure that records were successful saved. The saved records are then converted into JavaScript Object Notation (JSON) content with keys as column titles in first rows. JSON is an open-standard file format that uses human-readable text in transmitting data objects consisting of attribute–value pairs and array data types.

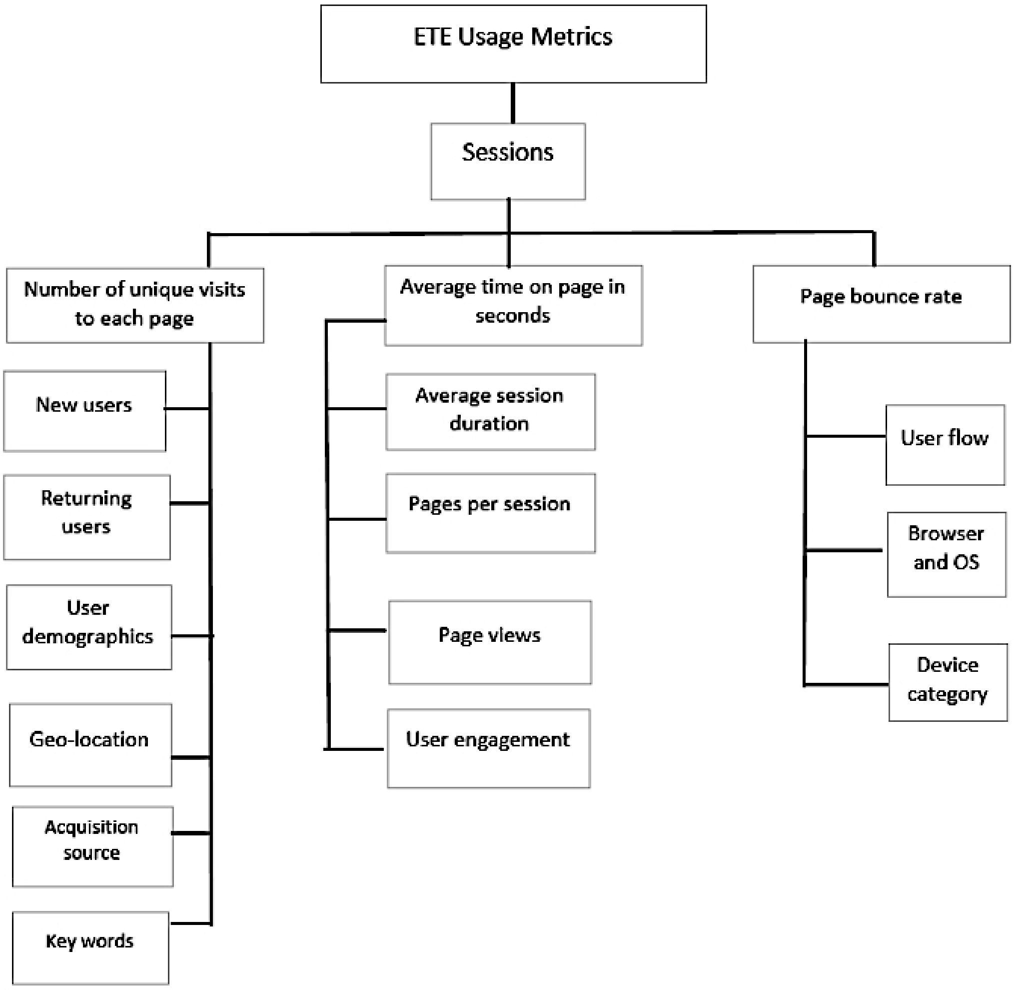
For the visualization process, a custom plugin is created that includes the function, shortcodes, CSS, scripts, images, and SVG files for the visualization functionality. It calls the Google API and loads the scripts. In a separate plugin, a unique shortcode is created for each visualization to be drawn on the frontend. The records of the dataset in question are retrieved in JSON and decoded in the form of PHP arrays. The logic on the PHP array is then applied as per the requirements of visualization (including PHP, JavaScript, jQuery). Data are filtered with JS on the frontend on changing the filter columns. For much larger datasets, the Asynchronous JavaScript and XML (AJAX call) is employed to load the data dynamically on each filter change.

Methods

Usage Evaluation of the Dashboard

Usage evaluation of the ETE geovisualization dashboard was conducted using Google Analytics during a 4-week period from March 19 to April 18, 2016, for which initial analytics data on the static version of the ETE were available (see Figure 1).

Figure 1. Usage metrics assessed on the ETE dashboard.



Google Analytics reflect real-time views informing the stakeholders of the pages that are most popular and the number of users visiting the website [24]. Prior research has characterized usage based on the following three indicators: (1) number of unique visits to each page, (2) average time on page in seconds, and (3) page bounce rate (ie, percentage of visits where users left the site immediately after viewing only one page). Institutional review board approval was not required for this study since the data used were aggregate data collected for non-research purposes.

Variables Assessed

The authors assessed the following variables: (1) session, which refers to the period of time in which a user was actively engaged with the website; all usage data are associated with a session, (2) the percentage of new sessions represents the fraction of new sessions initiated by unique users, (3) new and returning users are assessed; new visitors are identified by a unique session, while returning users have previously initiated sessions on the geovisualization dashboard, (4) demographics, which included the age groups and gender of visiting users, (5) bounce rate, which refers to the percentage of single-page visits (ie, visits in which the person left the site from the entrance page without interacting with the page), usually estimated based on a time period, (6) pages per session, which refers to average number of pages viewed during a session (average page depth), (7) average session duration (mins/secs), which refers to the average time spent during a session, (8) unique page views, which refers to the number of sessions during which the specified page was viewed at least once; a unique page view is counted for each page URL + page Title combination, (9) average time on page, which refers to average amount of time users spent viewing a specified page or screen, or set of pages or screens, and (10) average percentage exits, which is estimated as (number of exits) / (number of page views) for the page or set of pages. It indicates how often users exit from that page or set of pages when they view the page(s).

Results

Usage Evaluation of the ETE Dashboard

Descriptive analysis of ETE usage was obtained using Google Analytics. Further analysis was also conducted by cross-tabulating specific metrics. The usage metrics generated were classified by acquisition (ie, metrics that define the way users were able to access a given Web portal), behavior (ie, metrics that display user activity on the Web portal), and page visits (ie, characterizing page transitions) (Figure 1).

Description of Usage Metrics

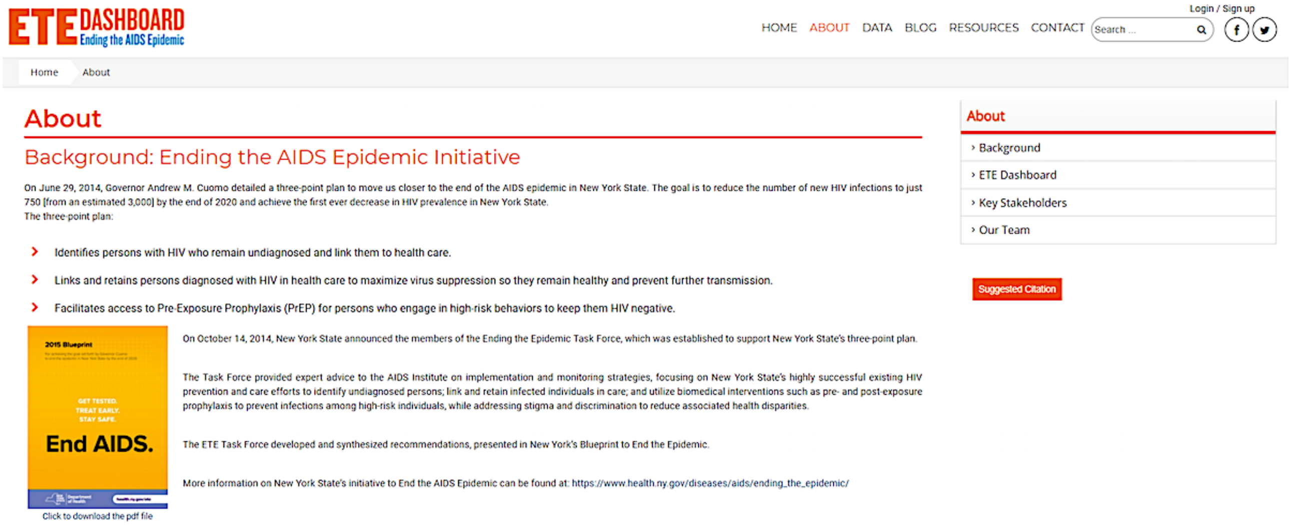
Acquisition

In total, 37.7% of the sessions (324/860) were initiated by unique users (Table 3). The majority of the sessions were initiated across North America (616/860, 71.6%), followed by Asia (191/860, 22.2%) and Europe (51/860, 6%) (Multimedia Appendix 3). The most common acquisition channels included direct source (353/860, 41.0%), followed by referral traffic (340/860, 39.5%), and organic search (134/860, 15.5%). The usage distribution implies the need for improved search engine optimization that facilitates easy location of the ETE site in other parts of the world, since the majority of traffic to the site was via direct sources. Direct traffic represents those users that arrive directly to the site by typing the uniform resource locator (URL) into the browser's address bar; clicking on a bookmark; or clicking on a link in an email, text message, or chat message. Referral site traffic represents those users who click a link on another site and land on the analyzed site [25]. Organic search refers to users referred by an unpaid search engine listing such as Google.com search [26].

Table 3. Usage metrics by acquisition, behavior, and page visits from March 19-April 18, 2016.

Descriptive analysis	Usage metrics
Acquisition	
Sessions, n	860
New sessions, %	38
Behavior	
New users, n	324
Returning users, n	536
Bounce rate, %	46
Pages per session, n	4.45
Average session duration, min:sec	8 min:51 sec
Page visits	
Page views, n	3828
Unique page views, n	1994
Average time on page, min:sec	2 min:34 sec
Average % exit for view	22

Figure 2. The "About" page of the ETE dashboard.



About

Background: Ending the AIDS Epidemic Initiative

On June 29, 2014, Governor Andrew M. Cuomo detailed a three-point plan to move us closer to the end of the AIDS epidemic in New York State. The goal is to reduce the number of new HIV infections to just 750 [from an estimated 3,000] by the end of 2020 and achieve the first ever decrease in HIV prevalence in New York State.
The three-point plan:

- Identifies persons with HIV who remain undiagnosed and link them to health care.
- Links and retains persons diagnosed with HIV in health care to maximize virus suppression so they remain healthy and prevent further transmission.
- Facilitates access to Pre-Exposure Prophylaxis (PrEP) for persons who engage in high-risk behaviors to keep them HIV negative.

On October 14, 2014, New York State announced the members of the Ending the Epidemic Task Force, which was established to support New York State's three-point plan.

The Task Force provided expert advice to the AIDS Institute on implementation and monitoring strategies, focusing on New York State's highly successful existing HIV prevention and care efforts to identify undiagnosed persons; link and retain infected individuals in care; and utilize biomedical interventions such as pre- and post-exposure prophylaxis to prevent infections among high-risk individuals, while addressing stigma and discrimination to reduce associated health disparities.

The ETE Task Force developed and synthesized recommendations, presented in New York's Blueprint to End the Epidemic.

More information on New York State's initiative to End the AIDS Epidemic can be found at: https://www.health.ny.gov/diseases/aids/ending_the_epidemic/

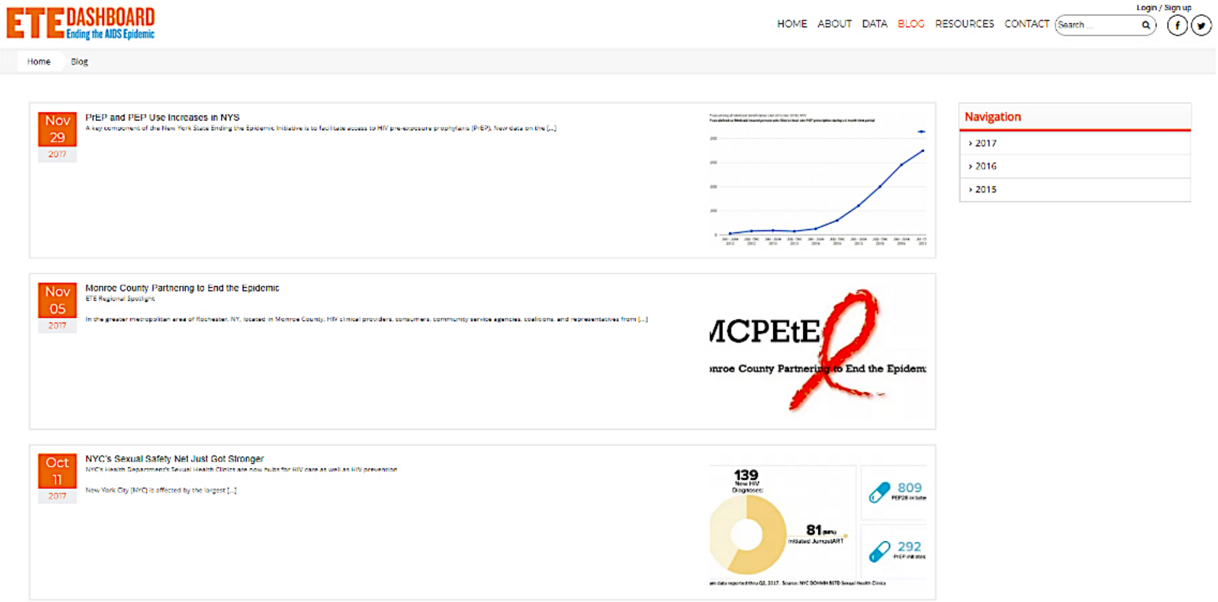
Of the 528 sessions (N=860 during the time period) where age of users was estimated, more than half were initiated by users within the age group of 25-34 years (320/528, 60.6%) followed by 35-44 years (101/528, 19.1%). Of the 539 sessions in which gender was recorded, the majority were initiated by males (365/539, 67.7%). Of the 136 new users, the proportion of new users being females (78/136, 57.4%) was higher than the males (58/136, 42.6%). Fifteen percent (134/860) of the sessions initiated had records of key words utilized in direct searches. The most common keywords used in accessing the ETE dashboard were not made visible by the Google Analytics platform (115/134, 85.8%). Other common key words included “ete dashboard” (5/134, 4%) and “etedashboardny.org” (4/134, 3%).

Behavior

The average session duration for both new and returning users was 8 minutes, 51 seconds. Average session duration was higher among returning users (12 min:41 sec), compared to the new users (2 min:31 sec). The total page views for the entire period of observation was 3828, of which 1994 were unique. The average time spent on page viewing was 2 minutes, 34 seconds, and overall page views were highest for the HIV testing page (4 min:1 sec) and lowest for the measures page (1 min:4 sec). Unique page views were highest (413/1194, 34.6%) for the landing page of the ETE dashboard, and users spent an average of 2 minutes, 25 seconds on this page. This page also had one of the highest percentage exits (49.1%, compared to the average bounce rate of 46.3%).

New users (324/860) had a higher average bounce rate of 59.9% compared to returning users (536/860) who had an average bounce rate of 38.1%. The average number of pages viewed per session among the returning users (5.35 pages/session) was also higher compared to the new users (2.35 pages/session). Overall, the average session duration was higher among males (13 min:38 sec) than females (8 min:58 sec). The highest bounce rates were seen for the “about” page, which describes the ETE initiative (bounce rate=65%). The lowest bounce rates were seen for the ETE blog page (bounce rate=17%). See Figures 2 and 3.

Figure 3. Blog page of the ETE dashboard.



PrEP and PEP Use Increases in NYS

A key component of the New York State Ending the Epidemic Initiative is to facilitate access to HIV pre-exposure prophylaxis (PrEP). New data on the [...]

Monroe County Partnering to End the Epidemic

ETE Regional Spotlight

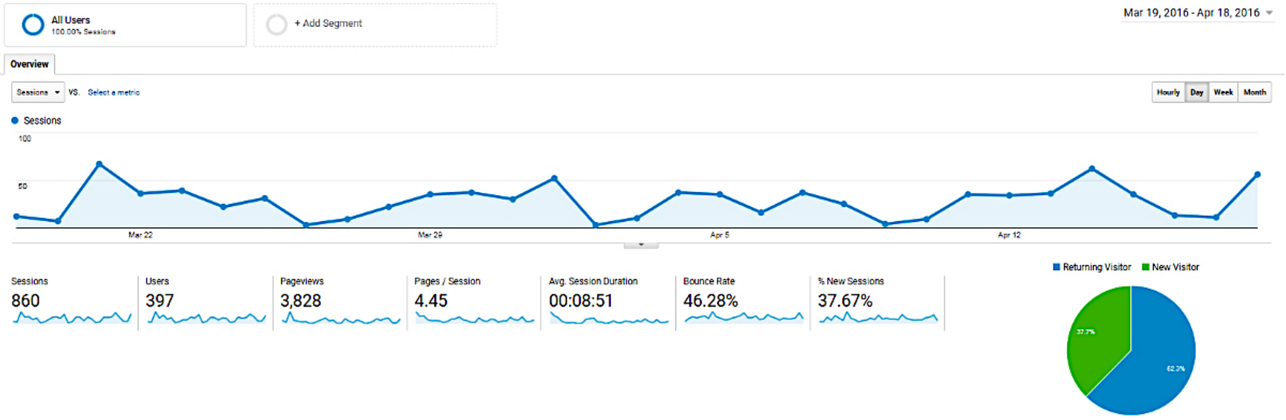
In the greater metropolitan area of Rochester, NY, located in Monroe County, HIV clinical providers, consumers, community service agencies, coalitions, and representatives from [...]

NYC's Sexual Safety Net Just Got Stronger

NYC's Health Department's Sexual Health Clinics are now hubs for HIV care as well as HIV prevention

New York City (NYC) is affected by the largest [...]

Figure 4. Usage patterns from March 19-April 18, 2016 (Google Analytics screenshot).



Sessions	Users	Pageviews	Pages / Session	Avg. Session Duration	Bounce Rate	% New Sessions
860	397	3,828	4.45	00:08:51	46.28%	37.67%

Browser Operating System and Device Category

Google Chrome was the most common Web browser chosen by users in accessing the ETE geovisualization dashboard (459/860, 53.4%). This was followed by Internet Explorer (194/860, 22.6%), Mozilla Firefox (108/860, 12.6%), and Safari (87/860, 10.1%). The average bounce rate across the browsers was 46.3%, and this was highest among those using Mozilla Firefox (59.3%) and least for Google Chrome users (37.0%).

Bounce rate was similar for Safari (54.0%) and Internet Explorer users (55.2%). Desktops were the most common devices used in accessing the ETE dashboard (820/860, 95.3%). Other devices included mobile phones (37/860, 4%) and tablets (3/860, 0.4%). Bounce rates were highest among tablet users (66.7%) with an average session duration of 1 minute, 19 seconds. However, the number of pages viewed per session was similar between tablet users (4.00) and desktop users (4.56). Mobile device users had the lowest page per session views (2.14).

Page Visits

The user flow describes the overall page path level including the landing pages, transition pages, and exit pages accessed by the user. The landing page with the maximum page views was the ETE home page, which is a static page that provides a snapshot of estimated metrics for tracking progress towards ending the HIV epidemic in New York. The home page also outlines the initiative’s objectives and key stakeholders. Following the home page, user traffic on the ETE dashboard was maximum on the HIV Care Cascades page, which is a dynamic page that allows users to self-select different cascades of HIV care by various data measures. The top exit page through which users left the ETE dashboard was the home page. Bounce rates were slightly higher for the static home page (49.4%) compared to the dynamic cascade page (47.1%). Users also spent more time on the HIV Care Cascades page (15 min:16 sec) (Multimedia Appendix 4).

Usage Patterns

Figure 4 shows the variation in usage patterns during the 4-week period from March 19 to April 18, 2016, for which initial analytics data on the static version of the ETE were available. Site usage was lowest on April 2, with a total of 3 sessions initiated, and highest on March 21 with a total of 67 sessions initiated. In particular, the least site usage (exemplified by lowest points on the chart below) was observed during weekends (Saturdays and Sundays). New data were ported into ETE during the time period of assessment, but only for display on the test site and not the public URL.

Discussion

Principal Findings

This study describes the design and usage analysis of the ETE geovisualization dashboard, with the aim of integrating epidemiologic and other data and disseminating knowledge on the HIV epidemic in New York State in the context of the Ending the Epidemic Initiative. Empirical reports indicate that regardless of the timeliness and accuracy of disease surveillance data collection, translation of data into accessible and useful knowledge will ultimately determine its utility in decision making [27]. Hence, the modality for disseminating aggregate data is crucial. The relevance of visualization tools and technologies is underscored by their ability to explore the relationships between data elements beyond the capacity of traditional statistical analysis in a timely manner, thereby providing an effective tool for informing decision making by health system planners, policy makers, and other key stakeholders. The unique benefits of visualization tools in reducing cognitive effort in data analysis allows users with limited expertise in data visualization or statistical analysis to effectively and rapidly gain key insights. In addition, geovisualization technologies provide a user-friendly interface that enhances user experience and enables seamless visualization of complex data. A distinguishing feature of the ETE dashboard is its flexible architecture adapted from SanaViz, which allows the incorporation of additional features and functionalities that enhance user experience in disease monitoring and assessment. Presently, the ETE dashboard is undergoing further development to enhance user interactivity and maximize data translation across all of its key data sources and realms.

Commercial use of Google Analytics has been promising [28]. Google Analytics has been widely used in examining usage metrics and predicting progress and challenges of a variety of surveillance-based and Internet-delivered eHealth interventions including HIV monitoring, mental health, neurosurgery, depression, stress, and anxiety [29-32]. Our findings reveal the potential of Google Analytics as a tool to enhance user traffic and performance of the ETE geovisualization dashboard by identifying key user metrics for potential modification. Usage statistics of the ETE geovisualization dashboard indicate that for the 860 sessions initiated by both new and returning users, the average session duration was 8 minutes, 51 seconds, and the bounce rate was 46%. These statistics reflect positive results given that prior literature estimates a bounce rate of 40-60% for most websites. Prior studies examining Internet-delivered interventions report an average range of site visit durations between 7-13 minutes [29,33]. However, the average viewing time for the ETE was 2 minutes, 31 seconds, reflecting lower usability, since prior studies assessing website performance have reported an average page viewing time exceeding 3 minutes as an indicator of good usability [13]. Similarly, our results showed a range of page visits between 1 and 12 pages per session, possibly indicative of content issues since previous studies report page visits between 3 and 17 pages as markers of interest in page content [13].

Key findings from our study showed that the highest bounce rates were seen for the “about” page, which describes the ETE initiatives (65%). The lowest bounce rates were seen for the ETE blog page (17%), which is consistent with prior research on website usage metrics using Google Analytics, which indicates that blog pages are often the most frequently viewed pages on Web portals [33]. The ETE blog page in particular is the most frequently updated page on the ETE system, providing research, news, and updates on a routine basis. Blogs pages are of increasing interest to users and have recorded lower bounce rates compared to the majority of website pages [33]. This has been attributed to various factors including their ability to serve as a medium for conveying advice to policy makers and the idea that such policy blogs were written by credible stakeholders [33]. However, more recent studies focused on engaging policy makers with research findings report that the number of articles, and not blogs, may be a more significant predictor of webpage visits and sustained usage and may be attributed to topic relevance [34]. In addition, page views for blogs were significantly higher for those targeted at one’s agency compared to external agencies, with a stronger association for internally authored blogs [34]. This indicates a variety of considerations that need to be accounted for in trying to drive usage for specific pages. Further analysis will be required over a longer time period to better capture the user demographics for the ETE site.

More than two-thirds of the sessions were initiated in North America (72%) indicating the need for improved search engine optimization that facilitates easy location of the ETE site in other parts of the world. Search engine optimization is relevant especially since most of the traffic arriving at the ETE site was via direct traffic (41%), which is consistent with prior studies indicating direct traffic as one of the highest acquisition channels [35].

Desktop computers were the most common devices used in accessing the ETE geovisualization dashboard (95%), compared to mobile phones (4%) and tablets (0.4%). This may suggest the need for better optimization of the ETE dashboard on mobile and tablet platforms. Prior research has shown that websites designed for desktop usage and not optimized for mobile usage may hamper incoming traffic [36]. In addition, mobile analytics is yet to be fully explored, as data collection using mobile devices has not been fully optimized [36]. Google Chrome was the predominant browser chosen by users in accessing the dashboard (53%) among others, including Internet Explorer (23%), Mozilla Firefox (13%), and Safari (10%).

Strengths and Limitations

A strength of this study is its description of the utilization and significance of interactive dashboards in disseminating information related to public health programs and policies to diverse stakeholders for better informed decision making. However, a limitation is that the usage evaluation of the ETE dashboard was conducted for short period and it may require evaluation for a longer period.

Future Work

Future studies will employ a user survey among stakeholders of the ETE program to adequately characterize usage patterns and further evaluate user-friendliness and interactivity of the ETE geovisualization dashboard from the perspectives of potential users, in line with the human-centered design approach [37].

Conclusion

Enhancing user-friendliness of a system provides added benefits of user satisfaction, acceptability, alongside financial benefits such as improved product quality and reduced production and support costs [37]. The data gathered from the usability assessment of the ETE will be used to further modify the ETE dashboard for optimal performance and utility.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Static version of the ETE dashboard.

[PDF File (Adobe PDF File), 105KB - publichealth_v3i4e95_app1.pdf]

Multimedia Appendix 2

Interactive version of the ETE dashboard.

[PDF File (Adobe PDF File), 136KB - publichealth_v3i4e95_app2.pdf]

Multimedia Appendix 3

Usage distribution of the ETE dashboard by geolocation from March 19-April 18, 2016.

[PDF File (Adobe PDF File), 36KB - publichealth_v3i4e95_app3.pdf]

Multimedia Appendix 4

User transitions across the ETE dashboard.

[PDF File (Adobe PDF File), 71KB - publichealth_v3i4e95_app4.pdf]

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Abbreviations

AIDS: acquired immune deficiency syndrome
AJAX: asynchronous JavaScript
API: application programming interface
CSS: cascading style sheets
CSV: Comma Separated Values
eHIVQUAL: New York State Department of Health Quality of Care program
ETE: Ending the Epidemic
HTML: hypertext markup language
JSON: JavaScript Object Notation
NYC: New York City
NYS: New York State
PHP: Hypertext Preprocessor
SQL: structured query language
SVG: scalable vector graphic

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Review

Randomized Controlled Trials of Technology-Based HIV/STI and Drug Abuse Preventive Interventions for African American and Hispanic Youth: Systematic Review

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Abstract

Background: HIV/sexually transmitted infections (STIs) and drug abuse remain significant public health concerns in the United States, and African American and Hispanic youth are disproportionately affected. Although technology-based interventions are efficacious in preventing and reducing HIV/STI and licit/illicit drug use behaviors, relatively little is known regarding the state of the science of these interventions among African American and Hispanic youth.

Objective: The aim of this review is to identify and examine randomized controlled trials (RCTs) of technology-based HIV/STI and/or drug abuse preventive interventions for African American and Hispanic youth.

Methods: We searched electronic databases (ie, PubMed, Proquest, PsycINFO, Ebscohost, Google Scholar) to identify studies between January 2006 and October 2016. RCTs of technology-based interventions targeting African American and Hispanic youth HIV/STI risk behaviors, including sexual risk, licit and illicit drug use, and HIV/STI testing were included.

Results: Our search revealed a total of three studies that used an RCT design and included samples comprised of >50% African American and/or Hispanic youth. The follow-up assessments ranged from two weeks to six months and the number of participants in each trial ranged from 72 to 141. The three interventions were theory-driven, interactive, and tailored. The long-term effects of the interventions were mixed, and outcomes included reductions in sex partners, licit drug use, and condomless anal sex acts.

Conclusions: Although technology-based interventions seem promising in the prevention of HIV/STI and drug abuse among African American and Hispanic youth, more research is needed.

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KEYWORDS

technology; HIV; prevention; drug use; adolescents

Introduction

HIV/sexually transmitted infections (STIs) and drug abuse remain major public health concerns in the United States. Although youth in general (defined here as adolescents 13-25 years of age) are at increased risk of HIV/STI, African American and Hispanic youth are disproportionately affected [1,2]. African American and Hispanic youth disproportionately engage in sexual risk and licit/illicit drug use behaviors [3,4], which increase their risk for STI and HIV infection [5,6]. However, HIV testing—a National Institutes of Health HIV/acquired immune deficiency syndrome (AIDS) research priority

[7]—among African American and Hispanic youth remains underutilized [8]. Furthermore, many youths are not routinely screened for asymptomatic STIs, as recommended by the Centers for Disease Control and Prevention [2]. Youth experience multiple barriers to access HIV/STI preventive services, and exploring the use of technology as a platform to improve the delivery and uptake of such services is warranted.

Given the ubiquity of technology among youth, technology-based interventions provide an ideal platform for the dissemination of HIV/STI and drug abuse preventive interventions to populations disproportionately affected by HIV/STIs, including African American and Hispanic youth [6,9,10]. However, a gap in knowledge persists in the literature with respect to the state of the science of technology-based HIV/STI and drug abuse preventive interventions. The purpose of this review is to identify randomized controlled trials (RCTs) of technology-based HIV/STI and/or drug abuse preventive interventions for African American and Hispanic youth.

The Prevalence of HIV/STI Risk Behaviors and HIV/STIs Among African American and Hispanic Youth

African American and Hispanic youth are disproportionately at risk of engaging in HIV/STI risk behaviors, including licit and illicit drug use and sexual risk behaviors [4,11-13]. Alcohol remains the most widely used licit drug among youth [4]. National surveillance data from the *Monitoring the Future* survey indicate that 9.5% of Hispanic 8th grade youth report past 30-day alcohol use, relative to 8.2% of non-Hispanic white and 6.9% of African American 8th grade youth, respectively [4]. By 10th grade, however, these trends change such that 23.0% of non-Hispanic white youth report past 30-day alcohol use, compared to 21.4% of Hispanic and 13.9% of African American youth, respectively [4]. Furthermore, 39% of non-Hispanic white youth report past 30-day alcohol use, compared to 34.9% of Hispanic and 21.8% of African American 12th grade youth, respectively [4]. Marijuana remains the most widely used illicit drug among youth [4]. Approximately 17.5% of Hispanic and 17.2% of African American 8th grade youth report lifetime marijuana use, compared to 10.0% of non-Hispanic white 8th grade youth, respectively [3]. Furthermore, 35.2% of Hispanic and 33.0% of African American 10th grade youth report lifetime marijuana use, relative to 28.9% of non-Hispanic white 10th grade youth, respectively [4]. Moreover, 50.3% of Hispanic 12th grade youth report lifetime marijuana use, relative to 43.6% of non-Hispanic white and 41.8% of African American 12th grade youth, respectively [4]. Licit and illicit drug use behaviors increase the risk of sexual risk behaviors, which in turn increase the vulnerability to STI and HIV infections [14]. National data from the *Youth Risk Behavior Surveillance* survey indicate that 44.4% Hispanic 9th-12th grade youth report condomless sex during last sexual intercourse, compared to 43.2% of non-Hispanic white youth [5]. Furthermore, 22.8% of Hispanic and 21.8% of African American 9th-12th grade youth report alcohol or drug use before last sexual intercourse, relative to 19.3% of non-Hispanic whites [5].

Due (in part) to the aforementioned risk behaviors, youth are at disproportionate risk of STI and HIV infections. Youth between the ages of 15 and 24 represent 25% of the sexually experienced population, and comprise nearly 26% and 50% of new HIV infections and new STIs, respectively [1,2]. African American and Hispanic youth are disproportionately affected by HIV/STIs. In 2014, an estimated 9731 youth were diagnosed with HIV in the United States; 78% of those diagnoses occurred in African American and Hispanic youth [3,5]. Indeed, the majority of these infections are among young men who have sex with men (YMSM). Importantly, 86% of young females acquire HIV through heterosexual sex [3,15,16]. Furthermore, African American and Hispanic female youth are disproportionately affected by STIs, which increase the risk of HIV infection [5].

HIV and STI Testing Among African American and Hispanic Youth

Despite the disproportionate prevalence of HIV/STI risk behaviors and infections among African American and Hispanic youth, HIV testing remains low. Approximately 16.6% and 11.2% of African American and Hispanic 9th-12th grade youth report having ever been tested for HIV (not including tests when donating blood), respectively [3,5]. Although the low prevalence of HIV testing is alarming, even more disconcerting is the fact that between 2013 and 2015, HIV testing among youth has significantly decreased [5]. Concern for the downward trend in HIV testing among youth is underscored by recent shifts in the HIV/AIDS research priorities issued by the National Institutes of Health, in conjunction with practice recommendations issued by the US Preventive Services Task Force, which call for the urgent need for sound science and practice efforts aimed at improving HIV testing in youth [7,17,18].

Beyond the need to improve youth HIV testing in general, and in African American and Hispanic youth in particular, increasing STI testing remains a federal priority [7]. Screening for STIs is particularly important in preventing and reducing the transmission and acquisition of HIV, because the presence of an STI increases the risk of HIV infection [2]. Unfortunately, 60% of youth do not know they are infected with an STI, and many youths are only being tested based on their perceived risk and are not routinely screened for asymptomatic STIs [2,16]. However, this perceived risk is based, in part, on youth disclosing their HIV/STI risk behaviors to their clinician, and clinicians initiating patient-client risk communication. Researchers have shown that youth in clinical settings are not always forthcoming with respect to their HIV/STI risk behaviors, and some clinicians do not engage in youth-clinician HIV/STI risk communication [19]. Indeed, clinician-youth HIV/STI risk communication is brief or nonexistent, and some clinicians report discomfort or lack of HIV/STI risk communication training, which may partially explain the low rates of HIV and STI testing among African American and Hispanic youth [20,21].

Harnessing the Power of Technology in the Prevention of HIV/STIs and Drug Abuse Among African American and Hispanic Youth

Technology is ubiquitous in the lives of many youths in the United States. For example, among youth aged 13-17 years, 73% and 58% have access to a smartphone or tablet, respectively [22]. Relative to non-Hispanic whites, African American youth are more likely to report smartphone ownership [22]. Thanks to the prevalence of these mobile devices, many youths utilize mobile technology to access the Internet and download apps. In fact, 74% of youth 12-17 years of age report accessing the Internet via mobile devices, and 58% report downloading apps to their smartphone or tablet [22].

Given the widespread use of mobile technology, it should not be surprising that mobile health (mHealth) interventions—the science and practice of health promotion through technology—are burgeoning [23]. In fact, data indicate that between 2010 and 2015 the overall app growth was 38.1% compounded annually over the past five years, compared to 41.9% for health-related apps [24]. In 2015, the number of health-related apps surpassed 165,000 [25]. Among adult populations, national data indicate that 36% of smartphone or tablet owners report having health-related apps on their devices [26]. Of those adults with apps, 60% report the usefulness of mHealth apps in achieving health behavior goals, 35% report helpfulness for medical care decision-making, and 38% report usefulness in asking their clinician new questions or seeking a second opinion [26]. However, limited data are available among youth populations. Extending the findings from adult populations, technology-based interventions may reduce some of the challenges that youth face that keep them from participating in face-to-face interventions (eg, transportation), offer a more cost-effective option, improve and extend the quality of care, and customize and prioritize the needs and preferences of youth [26,27]. In fact, HIV and drug abuse prevention scientists suggest that technology-based interventions show promise in preventing and reducing HIV and drug abuse among youth populations, but much work remains [28,29]. However, the literature on technology-based HIV/STI and drug abuse preventive interventions among youth remains limited, and even less is known about racial and ethnic minority populations.

A systematic review that focuses on African American and Hispanic youth populations is important for several reasons. First, African American and Hispanic youth are at disproportionate risk of engaging in HIV/STI risk behaviors (including licit and illicit drug use and sexual risk behaviors), acquiring STI and HIV infections, and HIV/STI testing is underutilized in these populations. Therefore, the identification of rigorously tested, culturally congruent, preventive interventions is warranted. Second, African American and Hispanic populations encompass important biological, psychological, social, historical, political, and cultural heterogeneity that underscores the need to develop and test culturally congruent preventive interventions [30-32]. In fact, researchers have shown how culturally specific preventive interventions may lead to optimal behavioral outcomes among African American and Hispanic youth [33,34]. Third, researchers conducting intervention research with African American and Hispanic youth populations have employed inclusion criteria with predominately African American or Hispanic samples in the identification of culturally congruent, efficacious preventive interventions [35,36]. Despite decades of prevention and intervention research, a review of RCTs comprised of primarily African American or Hispanic youth samples (ie, >70%) identified only 10 face-to-face interventions [37]. Unfortunately, the literature on technology-based interventions that are focused on African American and Hispanic youth is relatively limited. Therefore, the purpose of this review is to identify and examine RCTs of technology-based HIV/STI and/or drug abuse preventive interventions among African American and Hispanic youth.

Methods

Data Sources and Search Criteria

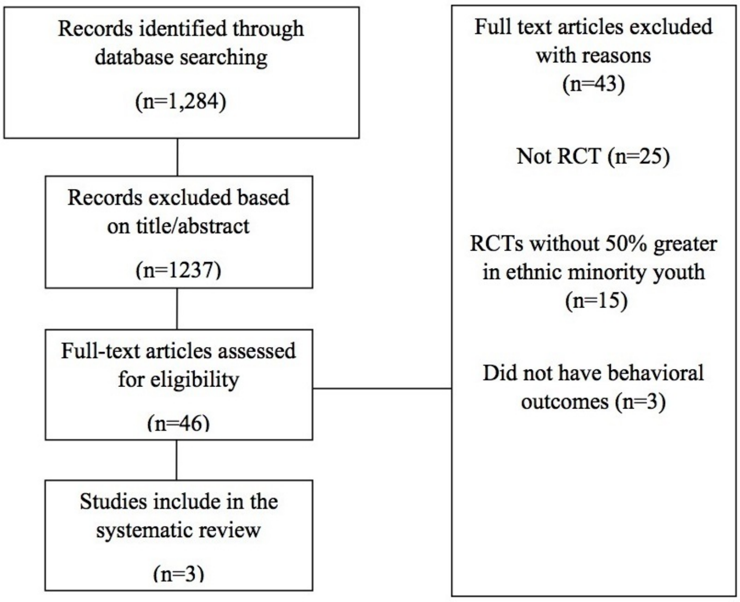
In the present review, we employed the methodological guidelines established for conducing systematic reviews [38-40], including the search, retrieval, selection, and coding of published articles. We searched electronic databases for relevant citations between January 2006 and October 2016, including PubMed, Proquest, PsycINFO, Ebscohost, and Google Scholar. Search terms included: “Intervention,” “Prevention,” “mHealth,” “eHealth,” “Telemedicine,” “HIV,” “STD (Sexually Transmitted Disease),” “STI,” “Risk Behavior,” “Substance Use,” “Substance Abuse,” “Adolescent,” “Web,” “Internet,” “Online,” “Mobile,” and “Phone.”

Study Selection

For the purposes of this review, we included articles if they reported on preventive interventions delivered through mobile technologies or Web-based platforms that targeted HIV/STI risk behaviors (ie, sexual risk, and licit and illicit drug use), and HIV or STI testing. Additionally, studies had to employ an RCT design and focus on youth 13-25 years of age. Following the methodological approach employed by Szapocznik et al [37], we initiated the present review of RCTs with samples comprised of primarily African American or Hispanic youth (ie, >70%). This approach resulted in only one study that met the criteria. Therefore, the inclusion criteria in the present review was revised to a>50% threshold. We excluded articles that were nonrandomized trials, narrative reviews, observational studies, qualitative studies, treatment approaches (eg, medication adherence), face-to-face only interventions, did not include behavioral outcomes (eg, intentions, beliefs, knowledge), or adult populations. Additionally, we reviewed the references of the potential articles identified to ensure that any studies that may meet inclusion criteria of the present review were included.

Following the methodological approach for conducting systematic reviews [38-40], we screened and excluded articles that did not meet inclusion criteria (eg, nonrandomized trials, intervention was not technology-based, study did not include behavioral outcomes). Once studies were excluded that did not meet inclusion criteria, the full text of the remaining studies was reviewed and three were included for the purposes of this review (Figure 1).

Figure 1. Primsa flow diagram.



Data Extraction and Interrater Reliability

We conducted an interrater reliability check. Three of the authors (DC, LO, FML) independently screened and coded the articles that were identified as having fit the search criteria. Results were compared and any discrepancies regarding which articles met inclusion criteria were discussed until consensus was reached. We extracted the following information into a spreadsheet database: method of delivery (eg, mobile application, Web-based); author; publication year; study title; targeted sample; sample size; study site; study phase (eg, efficacy, effectiveness); and study findings.

Results

As shown in Table 1, our search revealed three RCTs, all of which were published in 2013 or later. The studies examined the preliminary efficacy [41], efficacy [42], and comparative effectiveness [43] of a preventive intervention. Two studies used an intention-to-treat approach [41,43], one study used an attention control condition [42], and type of randomization was documented in two of the studies [41,42]. Sample sizes ranged from 72 [42] to 141 participants [43]. The longitudinal designs ranged from two weeks [43] to six months [42] follow-up, and two trials were registered with ClinicalTrials.gov [41,43]. The primary outcomes across the three studies included reductions in past 30-day sex partners [43], number of cigarettes smoked in the past 30 days [42], and rate of condomless anal sex acts [41].

Marsch et al [43] examined the comparative effectiveness of an interactive, customizable, Web-based intervention on sexual risk behaviors and the potential theoretical underpinnings by which change occurs (eg, skills acquisition), relative to a traditional educator-delivered intervention, among youth in an outpatient community-based substance abuse treatment clinic. Employing an intention-to-treat approach, 141 youth were randomized to either the experimental or control condition, and assessed at baseline and two-weeks postintervention.

Table 1. Randomized controlled trials of HIV/STI and/or drug abuse preventive interventions with African American and Hispanic youth.

Author	Platform	Sample	n	Study Stage	Study Design	Results
Marsch et al, 2015	Internet (Web)	Youth aged 12-18 years; 51% Hispanic, 43% Black	141	Effectiveness	RCT; face-to-face intervention or Web-delivered therapeutic education system. Follow-up conducted two weeks postbaseline.	Participants in both conditions reported reductions in past 30-day sex partners at two-week follow-up
Mason et al, 2015	Mobile (texting)	Youth aged 14-18 years; 90.8% African American	72	Efficacy	RCT; personalized motivational text messages or general health text control condition. Follow-up conducted at one, three, and six months postbaseline.	Participants in the experimental group had decreased past 30-day cigarette smoking, compared to control at six-month follow-up
Mustanski et al, 2013	Internet (Web)	Youth aged 18-24 years; 47% Hispanic, 12.7% African American	102	Preliminary efficacy	RCT; experimental condition or an online didactic HIV knowledge control condition. Follow-up conducted at six and twelve weeks.	Participants in the experimental condition reported a 44 % lower rate of unprotected anal sex acts at the 12-week follow-up

Marsch et al [43] provide descriptive statistics whereby participants could indicate both their race and ethnicity, with 44.6% identifying as Black and 51.0% Hispanic, respectively. Participants in the experimental condition received a self-directed, interactive, Web-based intervention. Guided by a community reinforcement approach to behavior therapy [44], the Web-based intervention aims to prevent and reduce HIV risk behaviors by improving skills, including decision-making and negotiation skills. The Web-based intervention is comprised of a computerized risk behavior assessment, followed by a total of 26 tailored modules. Using a computer at the clinic, the intervention was delivered in 60-minute sessions and the time for completing each module ranged between 10 and 30 minutes. On average, participants completed the sessions in approximately three sessions. Participants assigned to the control condition received two group or individual sessions, each of which lasted approximately one hour. Based on the National Institute on Drug Abuse HIV prevention principles in drug-using populations, the sessions focused on the epidemiology of HIV, promotive strategies to prevent and reduce HIV risk behaviors (including sexual risk and drug use), and HIV testing information [45]. Additionally, participants received a 20-minute youth-centered HIV prevention video. Findings indicated that participants in both conditions reported reductions in past 30-day sex partners (P=.05), however no significant differences in condition x time were observed. Furthermore, findings suggested that participants in both conditions reported improvements in condom use skills (P<.001), and this difference did not significantly differ across conditions two-weeks postintervention [43].

Mason et al [42] examined the efficacy of a text-based motivational interviewing intervention, relative to an attention control condition, on reducing smoking among a sample of predominately African American (90.8%) youth. Using a respondent-driven sampling design, 72 youth were randomized to either the experimental or attention control condition via block randomization, and were assessed at baseline, 1, 3, and 6-months postbaseline. Participants in the experimental condition received a text-based intervention that delivered 30 interactive text messages and three booster text messages over a five-day period that focused on rapport building, tobacco use feedback, social network information and feedback, and summary and plans with respect to the prevention of tobacco use [42]. By integrating motivational interviewing and social network counseling, the intervention aims to prevent and reduce tobacco use by increasing psychological precursors of behavior change, and reducing risk in close peer social networks. The attention control condition consisted of 30 health-based texts, including diet, exercise, and study habits. Findings indicated that participants in the experimental condition reduced the number of cigarettes smoked in the past 30 days, relative to the attention control condition. The results yielded a large and significant effect size, F (1,55)=4.39, P<.01, η^2=0.17 [42]. Furthermore, youth in both conditions increased their readiness to change and willingness to refuse cigarettes from their friends, and decreased the number of close friends who were daily smokers, however no significant differences across conditions were found [42].

Mustanski et al [41] examined the preliminary efficacy of the *Keep It Up!* intervention, compared to an online didactic HIV knowledge condition. Using an intention-to-treat approach, 102 predominately African American (12.7%) and Hispanic (47%) YMSM were randomized via a computerized algorithm stratified by race, and assessed at baseline, immediate postintervention, prior to a 6-week booster session, and 12 weeks postintervention [41]. Participants in the experimental condition received the *Keep It Up!* intervention. Informed by the information motivation behavioral skills model of HIV risk behavior change, *Keep It Up!* consists of 7 tailored, interactive modules delivered across three sessions and completed at least 24 hours apart. *Keep It Up!* aims to prevent and reduce condomless sex via improvements in HIV knowledge, safer-sex self-efficacy, beliefs and intentions to use condoms, and condom use errors.

Table 2. Cochrane summary of findings for randomized controlled trials of HIV/STI and/or drug abuse preventive interventions with African American and Hispanic youth.

Author	Outcomes	Sample	Number of participants followed-up (studies)	Quality of the evidence (grade)	Anticipated absolute effects	
					Risk with control	Risk difference with technology intervention
Marsch et al, 2015	Reduction of 30-day sex partners	Youth aged 12-18 years; 51% Hispanic 43% African American	74 (1 RCT)	High	The mean reduction of 30-day sex partners was 0	Mean difference 5.67 higher (5.2 higher to 6.14 higher)
Mason et al, 2015	Number of cigarettes smoked in the past 30 days	Youth aged 14-18 years; 90.8% African American	72 (1 RCT)	High	The mean number of cigarettes smoked in the past 30 days was 0	Mean difference 0.6 lower (1.45 lower to 0.25 higher)
Mustanski et al, 2013	Condomless anal sex acts	Youth aged 18-24 years; 47% Hispanic, 12.7% African American	102 (1 RCT)	High	The mean condomless anal sex acts was 0	Mean difference 2.5 lower (6.19 lower to 1.19 higher)

Participants in the control condition received an HIV knowledge intervention consisting of 7 nontailored, noninteractive modules delivered across three sessions. The didactic intervention included HIV information and facts, including condom use, and the epidemiology of HIV and STIs in YMSM. Findings indicate that, relative to the control condition, participants in the experimental condition reported a 44% lower rate of unprotected anal sex acts at the 12-week follow-up (Risk Ratio=.056, *P*<0.05). Participants in both conditions showed a large increase in HIV knowledge at postintervention (Cohen's d for *Keep It Up!*=0.75; control=0.87), however no significant differences were found across conditions [41]. As shown in Table 2, we computed Cochrane summary of findings to designate the score for each criterion in each article reviewed. All three articles that were reviewed received a high grade with respect to the quality of the evidence.

Discussion

The present systematic review indicates that although advances in technology-based HIV/STI and drug abuse preventive interventions for African American and Hispanic youth have been made, only three studies that utilized an RCT design and included licit and illicit drug use or sexual risk behavior outcomes were identified. To the best of our knowledge, this is among the first systematic reviews focused on the state of the science on technology-based HIV/STI and drug abuse preventive interventions for African American and Hispanic youth. From this review, we identified four important gaps in the literature. First, there remains the need to employ methodological and statistical rigor, including the use or RCTs, to develop a fuller understanding of the effects of technology-based interventions on HIV/STI risk behaviors. Second, studies examining the long-term effects of technology-based HIV/STI and drug abuse preventive interventions are limited. Third, the identification of how, and for whom, technology-based prevention interventions do and do not work are needed. Finally, a dearth of rigorously tested technology-based HIV/STI and drug abuse preventive interventions for African American and Hispanic youth exist. Addressing these important gaps in the literature may be helpful in moving the field forward.

There remains a need to employ rigorous methodological and statistical analytic approaches to test the effects of technology-based HIV/STI and drug abuse preventive interventions. The RCT remains the standard when examining the impact of interventions [46], yet we identified only three studies that employed an RCT design. Therefore, future research should use RCT designs when examining the effects of technology-based interventions on HIV/STI and drug use among African American and Hispanic youth. Although studies examining the effects of technology-based HIV/STI and drug abuse preventive interventions using RCT designs in the United States are limited, perhaps we can draw from international studies aimed at moving the field forward. In fact, during the review process, we identified five studies conducted internationally that have employed an RCT design when examining HIV/STI risk behavioral outcomes [47-51]. For example, Ybarra et al [47] examined the effects of CyberSenga, a five-hour online healthy sexuality program on past 90-day condom use and abstinence over a six-month period. A total of 366 youth aged 12 years and older from Mbarara, Uganda, were randomized via parallel group with adaptive randomization to CyberSenga, CyberSenga with booster sessions, or a control group [47]. Although no statistically significant results were found among the main outcomes, study findings may help inform the development and testing of future technology-based interventions. For example, it seems that abstinent youth in the CyberSenga group benefited most in the short-term, whereas sexually active participants in the CyberSenga with booster group benefited long-term [47]. Future research to examine whether (and extent to which) these findings hold true in other youth populations is needed.

The long-term effects of technology-based HIV/STI and drug abuse preventive interventions are not well understood. Of the three studies included in this review, a relatively short-term follow-up assessment (ie, range from 2 weeks to 6 months) was used. Therefore, developing a more complete understanding of the long-term effects of technology-based HIV/STI and drug abuse preventive interventions on behavioral outcomes is essential to moving the field forward. Importantly, variations in the types of drug use behaviors and vulnerability to HIV infection exist. For example, alcohol use behaviors alone are not a risk factor for HIV infection. However, alcohol use behaviors increase the risk of engaging in sexual risk behaviors, which in turn enhances vulnerability to HIV infection [52]. Injection drug use (IDU), conversely, is a direct and efficient mechanism for the transmission and acquisition of HIV [53]. Despite this knowledge, we did not identify one single study with IDU as a behavioral outcome. Given the recent rise in opioid use in the United States and links to HIV infections [54], the development and testing of technology-based interventions focused on opioid use behaviors may be warranted.

Beyond the need to establish the long-term efficacy of technology-based interventions, there also remains the need to understand the pathways through which such interventions work. Indeed, scientists have underscored the necessity of developing and testing theory-driven interventions, which can aid in identifying the mechanisms through which preventive interventions have an impact on HIV/STI testing and risk behaviors among youth. Although our review suggests that investigators have developed theory-driven technology-based preventive interventions, the testing of the theoretical underpinnings that guide these interventions is limited. In fact, our review did not reveal a single study that tested for mediation. Therefore, future research should examine the pathways through which technology-based interventions may have an effect on HIV/STI risk behaviors and testing.

There also remains a need to develop a more complete understanding of the populations for which preventive interventions do and do not work [55,56]. That is, investigators examining both malleable and nonmalleable sample and contextual study characteristics may have great utility in working toward optimally efficacious technology-based interventions. For example, some studies indicate that the effects of technology-based interventions varied as a function of gender, suggesting a potential need for gender-specific interventions [48,51,57,58].

Although stark racial and ethnic disparities exist in the incidence of new STI and HIV infections among youth [1,2], our review revealed that the majority of studies did not include samples comprised of >50% racial and ethnic minority populations. Given the facts that African American and Hispanic youth disproportionately engage in HIV/STI risk behaviors [4,5], are disproportionately affected by STI and HIV infections [1,2], and underutilize HIV and STI testing [5], more research on the development and testing of technology-based HIV/STI interventions focusing on African American and Hispanic youth is warranted. Moreover, because African Americans (12%) and Hispanics (13%) are more likely to report being smartphone-dependent compared to non-Hispanic whites (4%) [22], mobile-technology interventions utilizing smartphones may be an effective approach to engaging and retaining African American and Hispanic youth in prevention services.

Findings from the present review may have implications for practice in at least two ways. First, improving clinician-delivered HIV/STI preventive services, including screening for HIV/STI risk behaviors and status, remains a federal priority [18]; however, clinicians face numerous challenges, including interpersonal and structural-level factors. Technology-based interventions have the potential to overcome many of the challenges associated with providing HIV/STI preventive services, including improving youth-clinician HIV/STI risk communication [27], providing access to HIV/STI prevention programs [28], and supporting and enhancing traditional prevention models by supplementing face-to-face intervention efforts [59]. Second, technology-based interventions have the potential to improve clinicians' delivery of targeted, tailored, and cost-effective HIV/STI preventive services. For example, some technology-based interventions include a youth risk assessment [43,60], which can be used to deliver targeted and tailored HIV/STI prevention services based on the youth's specific risk behaviors.

Findings from the present review should be interpreted in light of an important limitation. Specifically, we did not include quasi-experimental studies in our review. RCTs may not always be a feasible intervention design, and well-designed quasi-experimental studies may have added to the evidence-base of the present review. We did not include quasi-experimental studies in our review for several reasons. First, the key distinction between quasi-experimental studies and RCTs is the random assignment of participants to either the treatment or control group. This distinction is particularly important during analyses given the increased potential of nonequivalence between groups, yielding challenges in comparisons. Second, the aim of the present review is to establish the efficacy of technology-based HIV/STI and drug abuse preventive interventions for African American and/or Hispanic youth. As such, it was pertinent that our review focus on RCTs, which has been established as the primary method that allows for better causation implications. Finally, in our systematic review, we followed the methodological approach of including only RCTs, as employed in other studies in medical Internet research [61,62].

Conclusions

In summary, although important advances have been made in the development and testing of technology-based HIV/STI and drug abuse preventive interventions, few interventions that target *both* sexual risk and licit/illicit drug use behaviors—behaviors that often co-occur [5]—and even fewer interventions aimed at improving HIV and STI testing among youth exist [27]. Importantly, efficacious interventions for African American and Hispanic youth are limited. The results from this review demonstrate the promise of technology-based interventions to prevent and reduce new STI and HIV infections among African American and Hispanic youth. Although there is some empirical support for technology-based HIV/STI preventive interventions, much work remains. The present review identified four critical gaps, including the need to develop a more complete understanding of: (1) the effects of technology-based interventions on HIV/STI risk behaviors and testing through cutting-edge methodological and statistical approaches, including the use or RCTs; (2) the long-term effects of technology-based interventions; (3) the pathways through which such interventions work; and (4) for whom these interventions do and do not work. For example, there have been a relatively large number of studies focused on establishing the feasibility and acceptability of technology-based interventions, compared to studies focused on demonstrating the short-term and long-term behavioral outcomes [63]. Indeed, findings from this review suggest that there remains a need for the development and testing of technology-based interventions for populations most affected by HIV/STIs, including African American and Hispanic youth. This review will help advance the state of the science on technology-based youth HIV/STI and drug abuse preventive interventions.

Conflicts of Interest

None declared.

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Abbreviations

IDU: injection drug use
mHealth: mobile health
RCT: randomized controlled trial

STI: sexually transmitted infection
YMSM: young men who have sex with men

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Original Paper

Knowledge, Attitudes, and Practices Regarding Zika: Paper- and Internet-Based Survey in Zhejiang, China

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Abstract

Background: As public access to the Internet increases, many health workers prefer to carry out health education online, reducing the use of traditional community-based health education methods. Since March 2016, four Zika cases have been confirmed in Zhejiang, China. Rapid assessment of people's knowledge, attitudes, and practices (KAP) regarding Zika is crucial to its prevention and control. Web-based surveys to assess public KAP may be a growing trend; however, we had little experience with this method.

Objectives: The aim of this study was to explore KAP regarding Zika in residents of Zhejiang using both traditional paper- and innovative Internet-based investigations.

Methods: A questionnaire was designed by Zhejiang Provincial Center for Disease Control and Prevention. A paper-based version of the survey was used in a cross-sectional community study following multistage cluster random sampling, and an Internet-based survey was promoted through a local health education site. Data were interpreted via univariate and multivariate analyses.

Results: A total of 447 community residents participated in the paper-based survey, with a response rate of 89.4% (447/500), and 621 eligible Internet users participated in the Internet-based survey, with a response rate of 36.92% (621/1682). Age, education level, and occupation differed significantly between participants in the paper- and Internet-based surveys. Participants completing the Internet-based survey were much younger (χ^2_2=144.7, P<.001) and had a higher level of education (χ^2_2=423.5, P<.001) than those completing the paper-based survey. Among participants completing the paper-based survey, there were more farmers, housewives, and unemployed people (χ^2_3=413.7, P<.001). Overall, 83.52% of participants (892/1068) knew the transmission route for Zika, 76.12% (813/1068) knew that pregnant women were at high risk of severe complications, 66.39% (709/1068) knew that contracting Zika during pregnancy could lead to newborn babies with microcephaly, and 98.88% (1056/1068) knew places where mosquitos could usually be found. After controlling for sociodemographic variables, participants completing the Internet-based survey were more likely to know the transmission route of Zika (odds ratio [OR]=5.0, 95% CI 3.0-8.0), the association between pregnant women with Zika and newborn babies with microcephaly (OR 2.1, 95% CI 1.4-3.0), and that pregnant women were at high risk for Zika (OR 5.5, 95% CI 3.5-8.4) than those completing the paper-based survey. They were less likely to worry about contracting Zika (OR 0.6, 95% CI 0.4-0.9) and more likely to actively seek information about Zika than participants completing the paper-based survey (OR 3.3, 95% CI 2.0-5.6).

Conclusions: Participants completing the Internet-based survey had a higher level of basic knowledge and more positive attitudes and behaviors than participants completing the paper-based survey. In addition to providing Web-based health information, the government should ensure sufficient access to health information for the elderly and less educated people in the community to improve health equity.

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KEYWORDS

Zika virus disease; knowledge, attitudes, and practice; Internet-based survey; paper-based survey

Introduction

Zika is a mosquito-borne flavivirus that was first identified in a rhesus monkey in the Zika Forest of Uganda in 1947 [1]. Such as the dengue virus, the symptoms of the Zika virus tend to be mild. Symptoms of Zika include fever, rash, pain in the joints, and pink eye [2]. Zika is transmitted by the common mosquito vector, *Aedes* species. In 2015, the international spread of Zika infection attracted global attention, when a marked increase in microcephaly cases in Brazil was linked to an epidemic of Zika infection [3].

In 2016, there were 24 imported Zika cases in China. Zhejiang province, located in southeast China and famous worldwide for its small commodity trade and vibrant market, had four of these Zika cases imported from South America [4]. Zhejiang exports 65% of its products to over 215 countries and regions, especially Southeast Asia and South America where Zika is endemic [5]. Moreover, Zhejiang has a hot, humid climate in summer, making it a suitable habitat for the *Aedes* species [6].

With the emergence of a new disease, inaccurate information and negative attitudes may lead to unnecessary concerns, rumors, and even panic [7,8]. Therefore, it is important for governments and health workers to assess the public's knowledge, attitudes, and practices (KAP) toward Zika. Traditionally, paper-based questionnaires have been used for research such as this. However, these take time, energy, and resources to administer. As public access increases, the Internet offers an unprecedented opportunity to conduct rapid assessments of community KAP related to emerging new diseases. Internet-based investigations are cost-effective, have rapid data collection, and the data can easily be transferred to statistical software for analysis. Some traditional paper-based investigations have already been superseded by Internet-based ones [9,10]. A disadvantage of Internet-based investigations is that data collected online may not be representative of the general population. However, data collected in the paper-based investigation may not be representative either. Web-based surveys are considered more feasible for large population-based cross-sectional studies [11].

The speed of data collection with Web-based surveys far exceeds that of paper-based investigations, which is what is needed for emergency health education and risk communication. Some research on infectious diseases is already based on Web-based data [12,13]. However, we found no study that compared Internet- and paper-based surveys in Zhejiang regarding emerging infectious diseases such as Zika.

The purpose of this study was to explore KAP regarding Zika in Zhejiang by using both paper- and Internet-based investigations. We also wanted to compare a traditional paper-based investigation with an innovative Internet-based investigation, providing scientific evidence for future assessments of emergency health education needs.

Methods

Questionnaire

The questionnaire was designed by the Zhejiang Provincial Center for Disease Control and Prevention (Zhejiang CDC). It collected sociodemographic data (sex, age, occupation, education level, and residential area); KAP regarding Zika; and sources of information on Zika. The questions about knowledge of Zika were (1) How is Zika transmitted to humans? (2) Which population group is at a high risk of severe complications from Zika? (3) If pregnant women contract Zika, what is the adverse outcome? and (4) Where are mosquitoes extremely common? Questions about attitudes to Zika were (1) Do you worry about contracting Zika? and (2) How do you think your body will be harmed if you contract Zika? Questions about practices related to Zika were (1) Do you use strategies to prevent mosquito bites at home? and (2) Do you actively seek information regarding Zika? Questions about Zika were based on the latest official report of World Health Organization and literature. The original questionnaire was developed in Chinese by research group members and refined over two rounds of Delphi method collaboration.

Recruitment

Participants of the Internet-based survey were recruited via Zhejiang Health Education, a public WeChat site with 100,000 users in the Zhejiang Province of China that is used to popularize health knowledge. A message stating "A 10-minute investigation on Zika will get you 20 RMB cell phone recharge" was created on the Zhejiang Health Education site, with a link to the questionnaire. Users who viewed the message could share it through the Internet, which allows news and information to be spread quickly to a large number of people. The questionnaire was hosted on *wenjuan* a large free questionnaire platform that has an innovative editing interface and a result analysis interface.

Participants who completed the paper-based survey were recruited from among community residents at Yiwu and Hangzhou, the two cities in Zhejiang Province where the first four Zika cases were found. Hangzhou is the capital of Zhejiang Province, and Yiwu is a prefecture city. Multistage cluster random sampling was undertaken. First, one district was selected randomly from each city. Then, one community was randomly selected from each of these districts. Families in the chosen communities were numbered and again chosen randomly. Finally, the randomly selected family members were informed about the study by a leaflet that contained the same information provided online and were invited to complete the questionnaire. Contact with potential participants was made by local health center professionals conducting a home visit. For each questionnaire, an investigator received 25 RMB and a respondent received a gift worth 20 RMB. We assumed that, overall, the level of those in the community with good knowledge about Zika would be about 50%, with 95%

confidence in the estimate, precision of 5%, and 20% of nonresponse rate. Hence, the minimum required sample size was 500 participants.

The study was approved by the ethics committee at Zhejiang CDC. Informed consent was obtained from all participants before their information was collected.

Statistical Analysis

Data from paper-based surveys were entered onto EpiData 3.03 (EpiData Association). Internet-based data were exported from the wenjuan to Excel (Microsoft). Data were analyzed using Statistical Package for the Social Sciences (SPSS) version 19.0 (IBM Corp). Standard descriptive statistics were used to summarize the data. Demographic characteristics of participants taking the Internet- and paper-based surveys were compared using chi-square tests. Chi-square tests were also used to explore differences in KAP regarding Zika between the two groups. Univariate and multivariate analyses were conducted to explore the association between sociodemographic variables and KAP variables. Items of KAP were analyzed separately. We dummy-coded categorical variables. Participants who were able to correctly answer the knowledge-based questions about transmission of Zika, main at-risk population, adverse outcomes of Zika during pregnancy, and where mosquitoes were extremely common were coded into the high-KAP category; all others were coded into the low-KAP category. Participants who were not at all worried about contracting Zika were coded into one category; the remainder were coded into another category. Those who replied that contracting Zika could cause serious harm were coded into one category; all others were coded into another category. For practices related to Zika, participants who carried out strategies to prevent mosquitoes and those who actively sought information about Zika were coded into one category; all others were coded into another category. *P* values of <.05 were considered statistically significant (two-sided).

Results

Differences in Sociodemographic Characteristics Between Participants of Paper- and Internet-Based Surveys

A total of 1682 WeChat users from Zhejiang Province visited the page hosting the Web-based survey, and 36.92% (621/1682) of them completed the questionnaire and were included in the study. Of the 500 community residents in Zhejiang Province who were invited to participate in the paper-based survey, 53 refused and 447 agreed. The response rate was 89.4% (447/500).

The proportion of participants aged <30, 30-49, and ≥50 years was 17.0% (76/447), 50.6% (226/447), and 32.4% (145/447), respectively, among those completing the paper-based survey and 25.1% (156/621), 70.1% (435/621), and 4.8% (30/621), respectively, among those completing the Internet-based survey. There was a significant difference between the two groups (χ^2_2=144.7, *P*<.001). Across all participants, 69.57% (743/1068) were female, and 30.43% (325/1068) were male, with no difference detected between those completing the Internet- and paper-based surveys. Among participants completing the Internet-based survey, 91.1% (566/621) had a postsecondary education level, which was a much higher level than participants completing the paper-based survey (χ^2_2=423.5, *P*<.001).

Table 1. Sociodemographic characteristic of participants completing Internet- and paper-based surveys.

Characteristic	Investigation approach		Total (n=1068), n (%)	χ^2 (degrees of freedom)	*P* value
	Paper-based (N=447), n (%)	Internet-based (N=621), n (%)			
Sex					
Female	305 (68.2)	438 (70.5)	743 (69.57)	0.6 (1)	.42
Male	142 (31.8)	183 (29.5)	325 (30.43)		
Age (years)					
<30	76 (17.0)	156 (25.1)	232 (21.72)	144.7 (2)	<.001
30-49	226 (50.6)	435 (70.1)	661 (61.89)		
≥50	145 (32.4)	30 (4.8)	175 (16.39)		
Education					
Primary or less (<9 years)	194 (43.4)	15 (2.4)	209 (19.57)	423.5 (2)	<.001
Secondary (9-12 years)	111 (24.8)	40 (6.5)	151 (14.14)		
Postsecondary (>12 years)	142 (31.8)	566 (91.1)	708 (66.29)		
Occupation					
Staff of government institution	51 (11.4)	451 (72.6)	502 (47.00)	413.7 (3)	<.001
Staff of business or service industry	139 (31.1)	71 (11.4)	210 (19.66)		
Farmer	69 (15.4)	3 (0.5)	72 (6.74)		
Other (eg, retired, housewife or househusband, and unemployed)	188 (42.1)	96 (15.5)	284 (26.59)		

The proportion of participants who worked in government institutions, in businesses or service industries, as farmers, and other occupation groups (eg, retired, housewife, househusband, and unemployed) were 11.4% (51/447), 31.1% (139/447), 15.4% (69/447), and 42.1% (188/447), respectively, among those completing paper-based surveys and 72.6% (451/621), 11.4% (71/621), 0.5% (3/621), and 15.5% (96/621), respectively, among those completing Internet-based surveys. The chi-square test found a significant difference in occupation distribution between the two groups (χ^2_3=413.7, *P*<.001; Table 1).

KAP Regarding Zika by Investigation Approach

Knowledge Regarding Zika

Among the total participants, 83.52% (892/1068) had some knowledge of the transmission route of Zika. The knowledge that the Zika virus was primarily transmitted to humans through mosquito bites was demonstrated by 95.2% (591/621) and 67.3% (301/447) of participants completing the Internet-based and paper-based surveys, respectively; a statistically significant difference (χ^2_2=152.1, *P*<.001). A total of 76.12% of all participants (813/1068) knew that pregnant women were at high risk of severe complications. This group was made up of 90.0% (559/621) and 56.8% (254/447) of participants completing the Internet-based and paper-based surveys, respectively; another statistically significant difference (χ^2_2=1173.7, *P*<.001). The association between Zika infection during pregnancy and newborn babies with microcephaly was known by 66.39% (709/1068) of all participants. This knowledge was demonstrated by 80.0% (497/621) and 47.4% (212/447) of participants completing the Internet-based and paper-based surveys, respectively; a statistically significant difference (χ^2_2=190.5, *P*<.001). Of the 1068 total participants, 1056 (98.88%) knew that mosquitos were extremely common in dark, wet places such as river banks and parks. This group was made up of 98.4% (611/621) and 99.5% (445/447) of participants completing the Internet-based and paper-based surveys, respectively, which was a statistically significant difference (χ^2_2=684.9, *P*<.001; Table 2).

Attitudes Regarding Zika

Of the 1068 of total participants, 502 (47.00%) were worried about contracting Zika. This group was made up of 55.6% (345/621) and 35.1% (157/447) of participants completing the Internet-based and paper-based surveys, respectively. The difference between the two groups was found to be significant (χ^2_1=43.6, *P*<.001). Potential harm due to contracting Zika was thought to be serious, mild, and nil by 31.39% (335/1068), 62.83% (671/1068), and 5.81% (62/1068), respectively. There was no difference between the two participant groups (χ^2_2=90.7, *P*=.60; Table 2).

Practices Regarding Zika

Among the total participants, 98.50% (1052/1068) carried out preventive strategies such as using a mosquito net or mosquito repellent. There was no significant difference in practices between participants completing the Internet-based survey and the paper-based survey (χ^2_1=2.8, *P*=.09). There was a significant difference between the two participant groups regarding seeking out information about Zika (χ^2_1=90.7, *P*<.001). Among all participants, 84.64% (904/1068) actively sought out information, made up of 93.6% (581/624) and 72.3% (323/447) of participants completing the Internet- and the paper-based surveys, respectively. (Table 2).

Table 2. Knowledge, attitudes, and practices regarding Zika of participants completing Internet- and paper-based surveys.

Variables	Investigation approach		Total (N=1068), n (%)	χ^2 (degrees of freedom)	*P* value
	Paper-based (N=447), n (%)	Internet-based (N=621), n (%)			
Knowledge					
Zika virus is primarily transmitted to humans through mosquito bites					
Yes	301 (67.3)	591 (95.2)	892 (83.52)	152.1 (2)	<.001
No	108 (24.2)	30 (4.8)	138 (12.92)		
Unclear	38 (8.5)	0 (0.0)	38 (3.56)		
Pregnant women are at a high risk of severe complications from Zika					
Yes	254 (56.8)	559 (90.0)	813 (76.12)	173.7 (2)	<.001
No	105 (23.5)	54 (8.7)	159 (14.89)		
Unclear	88 (19.7)	8 (1.3)	96 (8.99)		
Pregnant women infected with might have newborn babies with microcephaly					
Yes	212 (47.4)	497 (80.0)	709 (66.39)	190.5 (2)	<.001
No	93 (20.8)	107 (17.2)	200 (18.73)		
Unclear	142 (31.8)	17 (2.7)	159 (14.89)		
Where are mosquitoes extremely common					
Dark wet places	445 (99.5)	611 (98.4)	1056 (98.88)	3.3 (2)	.19
Other	2 (0.5)	9 (1.4)	11 (1.02)		
Unclear	0 (0.0)	1 (0.2)	1 (0.10)		
Attitudes					
Do you worry about contracting Zika					
Yes	157 (35.1)	345 (55.6)	502 (47.00)	43.6 (1)	<.001
No	290 (64.9)	276 (44.4)	566 (53.00)		
How much harm do you think would occur to your body if you contracted Zika					
Serious	147 (32.9)	188 (30.3)	335 (31.39)	1.0 (2)	.60
Mild	273 (61.1)	398 (64.1)	671 (62.83)		
No harm	27 (6.0)	35 (5.6)	62 (5.81)		
Practices					
Carry out strategies to prevent mosquito bites at home					
Yes	437 (97.8)	615 (99.0)	1052 (98.50)	2.8 (1)	.09
No	10 (2.2)	6 (1.0)	16 (1.50)		
Actively seeks information about Zika					
Yes	323 (72.3)	581 (93.6)	904 (84.64)	90.7 (1)	<.001
No	124 (27.7)	40 (6.4)	164 (15.36)		

Table 3. Unadjusted and adjusted (multivariate logistic regression, adjusted for the other factors shown in the table) odds ratios (OR) and 95% CI for knowledge about Zika by sociodemographic variables.

Predictors	Zika virus is primarily transmitted to humans through mosquito bites				Pregnant women are the main at-risk population for Zika			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Sex								
Female	1		1		1		1	
Male	0.8 (0.6-1.2)	.26	0.8 (0.6-1.3)	.40	1.1 (0.8-1.4)	.71	1.0 (0.7-1.5)	.81
Age (years)								
<30	1		1		1		1	
30-49	1.2 (0.8-1.9)	.33	1.5 (0.9-2.4)	.12	1.4 (1.0-2.0)	<.001	1.6 (1.0-2.3)	.03
≥50	0.6 (0.4-0.9)	.04	2.1 (1.1-3.8)	.02	0.5 (0.4-0.8)	<.001	1.4 (0.8-2.3)	.25
Education								
Primary or less (<9 years)	1		1		1		1	
Secondary (9-12 years)	2.5 (1.5-4.1)	<.001	2.3 (1.3-4.0)	<.001	1.7 (1.1-2.6)	.02	1.5 (0.9-2.5)	.09
Postsecondary (>12 years)	6.4 (4.3-9.3)	<.001	2.0 (1.2-3.5)	.01	4.0 (2.8-5.6)	<.001	1.4 (0.8-2.3)	.19
Occupation								
Staff of government institution	1		1		1		1	
Staff of business or service industry	0.1 (0.1-0.2)	<.001	0.3 (0.2-0.7)	<.001	0.3 (0.2-0.4)	<.001	0.8 (0.5-1.3)	.30
Farmer	0.1 (0-0.1)	<.001	0.4 (0.2-0.9)	.02	0.3 (0.1-0.4)	<.001	1.3 (0.6-2.6)	.51
Other (eg, retired, housewife or househusband, and unemployed)	0.2 (0.1-0.2)	.04	0.4 (0.2-0.8)	.01	0.3 (0.2-0.4)	<.001	0.7 (0.5-1.2)	.22
Source of participants								
Community	1		1		1		1	
Internet	9.6 (6.3-14.5)	<.001	5.0 (3.0-8.0)	<.001	6.9 (5.0-9.5)	<.001	5.5 (3.5-8.4)	<.001

[a] OR: odds ratio.

[b] AOR: adjusted odds ratio.

Association Between Sociodemographic Variables and KAP Regarding Zika

Univariate and multivariate logistic regression analyses were conducted to explore the association between sociodemographic variables and KAP variables. As shown in Tables 3 and 4, after controlling for other sociodemographic variables, age, education, occupation, and source of participants were associated with knowledge about Zika transmission routes and the association between pregnant women with Zika and newborn babies with microcephaly. Age and source of participants were associated with knowledge that pregnant women are a high-risk group for severe complications. Education and source of participants were associated with knowing that mosquitoes are extremely common in dark, wet places.

Participants aged ≥50 years were more likely to know the transmission route for Zika (OR 2.1, 95% CI 1.1-3.8) and to know of the association between pregnant women with Zika and newborn babies with microcephaly (OR 1.9, 95% CI 1.2-3.1) than participants <30 years old.

The likelihood of knowing the transmission route for Zika (OR 2.0, 95% CI 1.2-3.5) and the association between pregnant women with Zika and newborn babies with microcephaly (OR 2.0, 95% CI 1.3-3.2) were significantly higher among participants with postsecondary education than those with primary or less education.

Participants from nongovernment institutions (staff of businesses or service industries) (OR 0.3, 95% CI 0.2–0.7) and farmers (OR 0.4, 95% CI 0.2-0.9) were less likely to know the transmission route for Zika than participants working in government institutions. Participants recruited on the Internet were more likely to know the transmission route for Zika (OR 5.0, 95% CI 3.0-8.0) and know of the association between pregnant women with Zika and newborn babies with microcephaly (OR 2.1, 95% CI 1.4-3.0) than community-recruited participants.

Knowledge that pregnant women are the main at-risk population for Zika, was more common among participants aged 30-49 years than participants aged under <30 years (OR 1.6, 95% CI 1.0-2.3) and also among Internet-recruited participants compared with community-recruited participants (OR 5.5, 95% CI 3.5-8.4).

Table 4. Unadjusted and adjusted (multivariate logistic regression, adjusted for the other factors shown in the table) odds ratios (OR) and 95% CI for knowledge about Zika by sociodemographic variables.

Predictors	Pregnant women infected with Zika might have newborn babies with microcephaly				Mosquitoes are extremely common in dark, wet places			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Sex								
Female	1		1		1		1	
Male	1.1 (0.9-1.5)	.34	1.2 (0.9-1.7)	.20	1.2 (0.3-3.9)	.81	1.0 (0.3-3.5)	.99
Age (years)								
<30	1		1		1		1	
30-49	1.0 (0.8-1.5)	.71	1.1 (0.8-1.6)	.47	0.8 (0.2-3.8)	.84	0.9 (0.2-4.4)	.90
≥50	0.7 (0.5-1.1)	.10	1.9 (1.2-3.1)	.01	0.5 (0.1-3.0)	.41	0.2 (0.0-1.8)	.16
Education								
Primary or less (<9 years)	1		1		1		1	
Secondary (9-12 years)	1.7 (1.1-2.6)	.01	1.8 (1.1-2.9)	.02	2.3 (0.2-22.0)	.52	7.8 (0.6-9.5)	.11
Postsecondary (>12 years)	4.4 (3.2-6.2)	<.001	2.0 (1.3-3.2)	<.001	1.3 (0.3-5.0)	.85	9.8 (1.2-83.5)	.04
Occupation								
Staff of government institution	1		1		1		1	
Staff of business or service industry	0.1 (0.1-0.2)	<.001	0.3 (0.2-0.4)	<.001	0.9 (0.2-3.8)	.96	0.7 (0.1-3.6)	.65
Farmer	0.1 (0.1-0.2)	<.001	0.4 (0.2-0.7)	<.001	>999 (<0.01->999)	.98	>999 (<0.01->999)	.96
Others (eg, retired, housewife or househusband, and unemployed)	0.2 (0.2-0.3)	<.001	0.4 (0.3-0.6)	<.001	2.0 (0.4-9.7)	.39	2.5 (0.3-18.9)	.37
Source of participants								
Community	1		1		1		1	
Internet	4.3 (3.3-5.6)	<.001	2.1 (1.4-3.0)	0. 001	0.3 (0.1-1.3)	.10	0.1 (0.0-0.5)	.01

[a] OR: odds ratio.

[b] AOR: adjusted odds ratio.

Table 5. Unadjusted and adjusted (multivariate logistic regression, adjusted for the other factors shown in the table) odds ratios (OR) and 95% CI for attitudes regarding Zika by sociodemographic variables.

Predictors	I am worried about contracting Zika				I think contracting Zika will cause serious damage to my body			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Sex								
Female	1		1		1		1	
Male	1.0 (0.8-1.3)	.97	1.0 (0.8-1.3)	.90	2.0 (1.5-2.7)	<.001	2.1 (1.5-2.8)	<.001
Age (years)								
<30	1		1		1		1	
30-49	1.0 (0.8-1.4)	.82	1.0 (0.7-1.3)	.86	0.8 (0.6-1.1)	.42	0.9 (0.6-1.2)	.38
≥50	2.3 (1.5-3.4)	<.001	1.4 (0.9-2.1)	.20	0. 8 (0.5-1.2)	.60	0.9 (0.6-1.5)	.71
Education								
Primary or less (<9 years)	1		1		1		1	
Secondary (9-12 years)	0.6 (0.4-0.9)	.02	0.7 (0.4-1.1)	.12	1.3 (0.9-2.1)	.19	1.5 (0.9-2.4)	.14
Postsecondary (>12 years)	0.4 (0.3-0.5)	<.001	0.6 (0.3-0.9)	.01	1.1 (0.8-1.5)	.69	1.5 (0.9-2.4)	.12
Occupation								
Staff of government institution	1		1		1		1	
Staff of business or service industry	1.7 (1.2-2.4)	<.001	1.1 (0.7-1.6)	.61	1.4 (1.0-1.9)	.049	1.4 (0.9-2.2)	.08
Farmer	2.9 (1.7-5.1)	.01	1.0 (0.5-2.1)	.90	1.3 (0.8-2.2)	.36	1.6 (0.8-3.2)	.16
Others (eg, retired, housewife or househusband, and unemployed)	1.5 (1.1-2.1)	<.001	0.9 (0.6-1.3)	.55	1.1 (0.8-1.5)	.53	1.1 (0.7-1.6)	.73
Source of participants								
Community	1		1		1		1	
Internet	0.4 (0.3-0.6)	<.001	0.6 (0.4-0.9)	.01	0.9 (0.7-1.1)	.30	0.9 (0.6-1.3)	.44

[a] OR: odds ratio.

[b] AOR: adjusted odds ratio.

Participants with postsecondary education were more likely than those with less education to know that mosquitoes were common in dark, wet places (OR 9.8, 95% CI 1.2-83.5); Internet-recruited participants were less likely to know this than community-recruited participants (OR 0.1, 95% CI 0.0-0.5).

Table 5 shows the association between sociodemographic variables and attitude variables. After controlling for other factors, education and sources of participants were associated with worrying about contracting Zika. Participants with postsecondary education were less likely to worry about contracting Zika than participants with primary or less education (OR 0.6, 95% CI 0.3-0.9). Internet-recruited participants were also less likely to worry than community-recruited participants (OR 0.6, 95% CI 0.4-0.9). Male participants were much more likely to think that contracting Zika would cause serious damage (OR 2.1, 95% CI 1.5-2.8).

Table 6 shows the association between sociodemographic variables and practice variables. After controlling for other factors, only the source of participants was found to be associated with the practice of actively seeking information regarding Zika. Internet-recruited participants were more likely to seek information regarding Zika than community-recruited participants (OR 3.3, 95% CI 2.0-5.6).

Time and Cost

For the paper-based surveys, we spent almost 2 weeks on data collection. For each questionnaire, the investigator got paid 25 RMB, and the respondent received a gift worth 20 RMB. Thus, for 447 questionnaires, the total expenditure for paper-based investigation was 20,115 RMB. Most respondents to the Internet-based survey (83.4%, 518/621) completed the questionnaire in the first week. From days 1 to 7, the number of responses were 327 (52.7%), 107 (17.2%), 26 (4.2%), 58 (9.3%), 30 (4.8%), 7 (1.1%), and 36 (5.8%), respectively. Each online participant got 20 RMB cell phone recharge worth 20 RMB. For the 621 online respondents, the total cost was 12,420 RMB.

Table 6. Unadjusted and adjusted (multivariate logistic regression, adjusted for the other factors shown in the table) odds ratios (OR) and 95% CI of practices about Zika by sociodemographic variables.

Predictors	Carry out strategies to prevent mosquito bites at home				Actively seek information about Zika			
	OR[a] (95% CI)	*P* value	AOR[b] (95% CI)	*P* value	OR (95% CI)	*P* value	AOR (95% CI)	*P* value
Sex								
Female	1		1		1		1	
Male	1.1 (0.4-3.1)	.92	1.0 (0.4-3.1)	.94	0.9 (0.6-1.3)	.48	0.9 (0.6-1.3)	.56
Age (years)								
<30	1		1		1		1	
30-49	1.4 (0.4-4.6)	.34	1.4 (0.4-5.0)	.57	1.3 (0.9-2.1)	.18	1.5 (0.9-2.3)	.11
≥50	0.8 (0.2-3.0)	.44	1.1 (0.2-5.8)	.89	0.5 (0.3-0.8)	<.001	1.1 (0.6-2.0)	.72
Education								
Primary or less (<9 years)	1		1		1		1	
Secondary (9-12 years)	1.9 (0.4-9.9)	.69	1.6 (0.3-9.6)	.60	1.3 (0.8-2.1)	.27	1.1 (0.7-1.9)	.67
Postsecondary (>12 years)	2.0 (0.7-6.0)	.50	1.0 (0.2-4.8)	.97	4.2 (2.8-6.2)	<.001	1.6 (0.9-2.7)	.10
Occupation								
Staff of government institutions	1		1		1		1	
Staff of business or service industry	0.5 (0.1-1.9)	.86	0.7 (0.1-3.5)	.84	0.2 (0.1-0.4)	<.001	0.6 (0.3-1.1)	.08
Farmer	0.3 (0.1-1.7)	.35	0.6 (0.1-5.4)	.67	0.2 (0.1-0.4)	<.001	0.8 (0.3-1.8)	.55
Other (eg, retired, housewife or househusband, and unemployed)	0.6 (0.2-1.9)	.96	0.9 (0.2-4.1)	.65	0.2 (0.2-0.4)	<.001	0.7 (0.4-1.2)	.15
Source of participants								
Community	1		1		1		1	
Internet	2.4 (0.9-6.6)	.09	2.1 (0.5-8.6)	.30	5.6 (3.8-8.2)	<.001	3.3 (2.0-5.6)	<.001

[a] OR: odds ratio.

[b] AOR: adjusted odds ratio.

Discussion

Principal Findings

Rapid assessment of health education needs is necessary for emergent infectious diseases. Usually, paper-based investigations were used. Our study used both paper- and Internet-based approaches to carry out a rapid assessment of health education needs when Zika virus cases were detected in China. This is the first study in the Zhejiang Province that has used both the methods to investigate a public health issue and provides a detailed comparison between the two. The main finding of our study was that participants in the Internet-based survey had a higher level of basic knowledge and more positive attitudes and behaviors toward Zika than participants in the paper-based survey, even after controlling for factors such as age, sex, and education level. The Internet-based survey required fewer resources and was much faster than the paper-based survey. However, if Internet-based surveys are used to carry out emergency assessments of health education needs, we should be cautious about the results because self-selected participants of Internet-based surveys do not represent the general population.

Our study found that participants in the Web-based study had characteristics different from those in the paper-based study. First, the Internet-recruited sample was younger, with 95.2% (591/621) of participants <50 years of age, whereas in the community-recruited sample only 67.6% (302/447) were <50 years of age. Second, participants in the Web-based study had higher levels of education than those in the paper-based study. Over 90% (566/621, 91.1%) of the Internet-recruited participants had postsecondary education compared with 31.8% (142/447) of community-recruited participants. Third, occupational distribution comparisons also found a significant difference between the two groups. More participants in the Web-based study were employed in government agencies or businesses, whereas in the paper-based study there were more farmers and people who stayed at home (eg, retired, housewife or househusband, and unemployed). This correlates with education levels of the two groups. Other studies have also shown that participants in Web-based studies have characteristics different from those participating in paper-based studies [14-17]. Due to the different characteristics of Internet users and other community residents, different health education methods should be applied. For example, for the elderly and people with low levels of education, materials such as posters, bulletin boards, banners, and booklets would be more helpful. For younger and well-educated people who are used to obtaining information via the Internet, Web-based health education using new media such as WeChat, blogs, and Web pages may be more appropriate.

This study found no difference in sex distribution between the two groups. However, both groups had more female than male participants (about 7:3). This might be because women are more concerned about their health than men [18-20], so they are more willing to participate in investigations on health-related issues.

By comparing the cost and time of the paper- and Internet-based surveys, we found that our Internet-based study was faster and more cost-effective. In this study, over 500 questionnaires were collected online within 1 week, whereas it took 2 weeks to collect 447 questionnaires through face-to-face interviews. Additionally, the Web-based study only cost half as much as the paper-based investigation.

Under conditions of new infectious diseases, the ability to rapidly assess health education needs is necessary for health workers to understand the public’s KAP about the new disease to carry out targeted health education and risk communication. Our study confirmed that, compared with a paper-based survey, collecting data with a Web-based survey involves considerably fewer resources including money, time, and human resources [21-23], which is what health education assessment needs for an emerging infectious disease. However, participants in the Internet-based survey might not represent the whole population; thus, if a Web-based survey was used to carry out an emergency assessment of health education needs, we should be quite cautious about the results.

The study also found that participants in the Internet-based survey had a higher level of knowledge about Zika than participants in the paper-based survey. This might be because of having more young and well-educated participants in the Web-based survey. However, after controlling for sociodemographic variables such as age, education, and sex, Internet participants in the Internet-based survey still had a higher level of knowledge about Zika than participants in the paper-based survey. As new media such as WeChat and microblogs become a primary source of information, health workers move from community-based to Internet-based health education, there is a risk of health inequity. Our study suggests that in the event of an outbreak of a new infectious disease, while providing health information online, the government, health workers, and the media should also ensure sufficient access to health information for older and less well-educated people in the community to ensure equity.

Fewer participants in the paper-based survey worried about contracting Zika than participants in the Web-based survey. This might be because they knew less about Zika, and ignorance gave them less anxiety. Our study found that 98.50% (1052/1068) of participants carried out strategies to prevent mosquito bites at home. This suggests that the public of Zhejiang have positive behaviors toward preventing mosquito-borne diseases. Participants in the Internet-based survey tended to seek information on Zika more actively than participants in the paper-based survey. This suggests that, in an outbreak of a new infectious disease, to achieve better health education, health workers should provide information in a range of ways, which will be attractive to the community, to ensure positive messages are heard by the public. Web-based health information should be communicated through official channels as much as possible, to minimize the flow of inaccurate information and rumors.

Limitations

This study has some limitations. First, selection bias might exist. Data for the paper-based study were collected in the community during the daytime, so participation may have been biased toward the elderly and unemployed. Online participants were usually younger and better educated and also had more interest in the study. Thus, KAP results about Zika from both our paper- and Internet-based surveys may not be generalizable to the whole population. Second, to get a quick understanding of the levels of KAP about Zika, we kept the questionnaire short, which limited the depth of the study.

Conclusions

Our study provides valuable insights into KAP related to Zika among people in the southern part of China. The Internet-based survey had a larger proportion of participants with a basic knowledge regarding Zika, and they tended to seek information on Zika more actively and be less worried about contracting Zika than participants in the paper-based survey. Although, the Internet-based survey involved fewer resources and was much faster than the paper-based survey in the community, if only an Internet-based survey were used to carry out an emergency assessment of health education needs, you would need to be cautious about the generalizability of the results. Finally, our study suggests that in the outbreak of a new infectious disease, as well as providing health information on the Internet, the government and health workers should also ensure adequate access to health information for older and less educated people in the community to achieve greater equity in health.

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Conflicts of Interest

None declared.

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Abbreviations

AOR: adjusted odds ratio
OR: odds ratio
KAP: knowledge, attitudes, and practices

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Original Paper

Online Perceptions of Mothers About Breastfeeding and Introducing Formula: Qualitative Study

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Abstract

Background: Although the benefits of breastfeeding are well established for babies and their mothers, many women give formula to their infants. Whether to breastfeed or to give infant formula is a complex decision to make. Many parents use the Internet to find information and support that relate to infant feeding decisions.

Objective: The aim of this study was to analyze the perceptions of mothers, who are discussing the topic on Web forums, about introducing infant formula.

Methods: This is a qualitative, descriptive, and cross-sectional study on online data from parenting Web forums. The text was analyzed using qualitative content analysis.

Results: The analysis resulted in 1 main theme, “balancing between social expectations and confidence in your parental ability,” which is further divided into 3 themes: “striving to be a good mother,” “striving for your own well-being,” and “striving to discover your own path.”

Conclusions: Breastfeeding is complex, and health care personnel can, with a more open approach toward formula, create better support for mothers by helping them to be more confident in their parental ability.

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KEYWORDS

breast feeding; bottle feeding; mothers; decision making; Internet; patient web portals

Introduction

The benefits of breastfeeding for babies and their mothers are well established [1-3]. The World Health Organization and the United Nations Children’s Fund recommend exclusively breastfeeding for 6 months and partial breastfeeding for 2 years or beyond [4,5]. Many countries, such as Sweden, have followed these recommendations [6].

Breastfeeding rates differ globally, where low- and middle-income countries have the highest breastfeeding rates. In high-income countries, the prevalence varies a great deal between countries [2]. Formula feeding is most common in Western Europe, Australia, and North America, and its frequency is affected by the marketing and the availability of formula [7]. In Sweden, marketing of infant formula is regulated by the international code [4,8].

Breastfeeding is the most common way to feed the child in Sweden, with 96% of the women breastfeeding (exclusively or partly) at 1 week of age and 63% at 6 months [9]. The Swedish child health services promote breastfeeding and inform the parents about breastfeeding advantages and the negative impact on breastfeeding that formula may present [6].

A woman's decision to breastfeed is a complex one [10], influenced by a convergence of factors that include sociodemographic and psychosocial aspects as well as historical and cultural factors [7]. Breastfeeding can be experienced as difficult, and although many mothers have expressed a need for support, they feel that they do not always get the support they need from health care professionals [11,12]. A support system may have a positive effect on the initiation and duration of breastfeeding [13]. Different interventions regarding breastfeeding support have shown to increase breastfeeding duration [7,14-16], including using the Internet [17,18]. Many parents use the Internet as support in their parenthood, and for many, it is the firsthand choice to find information about pregnancy and parenthood, including infant feeding [19-21]. Despite this, studies have shown that among health care personnel there exists a negative attitude toward social media and a concern about patients seeking information online [22,23]. With the knowledge of what is actually discussed about introducing formula feeding on parenting Web forums, health care personnel can have a better understanding of the situation, and thus will be able to better adjust the breastfeeding support with the family's needs.

The aim of this study was to analyze the perceptions of mothers, who are discussing the topic on Web forums, about introducing infant formula.

Methods

Design and Setting

This is a qualitative, descriptive, cross-sectional study conducted in 2015 using online data from 2 Swedish parenting Web forums. Much social interaction has been relocated to the Internet, and online data have thus become a good data source to capture experiences and views of people in the social and cultural contexts in which they appear [24,25]. The design was inspired by LiLEDDA, a 6-step forum-based ethnographic method for nursing research [26], which involves literature review and identification of research questions, locating the field online, ethical considerations, data gathering, analysis and abstractions, and trustworthiness.

Sample

The participants in this study were the people posting their views on the 2 chosen online forums.

Most posters on these forums were anonymous, and therefore, we have little knowledge of the characteristics of the people who posted them. However, statistics provided by the websites show that most participants are women (88%), around 30 years of age, and who are either already a parent (61%), pregnant (14%), or planning pregnancy (5%). On the basis of how they expressed themselves in the posts, we were able to conclude that most were women with personal experience of breastfeeding.

Data Collection

The forums were chosen because they were public forums that required no registration, they were easily accessible by large search engines, and they had a high frequency of postings, which make a meaningful analysis possible [26]. Following criteria were used for selecting the posts for the study: posts matching the aim, arguments for or against formula feeding and opinions about formula feeding, and opinions posted from August 2014 to August 2015. The posts could be shorter or longer and may consist of only 1 sentence or many sentences building a story. Posts concerning practical details about formula feeding were excluded. The data collection took place during September 2015, and the study was conducted by the second and third authors who searched through subject categories in the forums concerning infant feeding by using the search functions of the websites.

Data Analysis

The data collection resulted in 107 pages of text that were analyzed by using Graneheim and Lundman's [27] qualitative content analysis. Meaning units matching the aim were identified, condensed when necessary, and coded. A meaning unit could consist of a few words, 1 or several sentences, or even longer parts of the text, but should express the same content [27]. The meaning units were then interpreted and coded with shorter labels. These codes were then sorted and grouped into subthemes by comparing similarities and contrasts. This should not be seen as a linear process, rather a moving back and forth between the original text, meaning units, and codes. Finally, 3 themes that were identified formed a main theme, which described the latent content of the text. The analysis was made by the first, second and third authors, but to increase trustworthiness, all steps of the analysis and any uncertainties in coding and thematic sorting were discussed with the whole research team.

Ethical Considerations

This study was exempt from ethical approval as the forums were public forums that did not require passwords or registration for access [26,28], and there were no policies on the websites forbidding the use of the information for studies. Informed consent from the posters was not obtained because the study was considered archival [26] and because posts were published publicly [24,28]. To protect the anonymity of the participants, the posts have not been identified and exemplifying quotes used are not traceable to the person who wrote those [26].

Results

Study Findings

Findings from the analysis is presented in Table 1 below as well as in text. In total, 370 posts resulting in 107 pages of text were analyzed. The analysis resulted in a main theme, "balancing between social expectations and confidence in your parental ability," which has been derived from the following 3 themes: "striving to be a good mother," "striving for your own well-being," and "striving to discover your own path." These 3 themes in turn have 3 subthemes each. The themes are presented in the text as headings, and subthemes are presented in italics directly in the text with exemplifying quotations.

Table 1. Main theme, themes, and subthemes.

Main theme	Themes	Subthemes
Balancing between the expectations of others and confidence in your parental ability	Striving to be a good mother	Breast is best
		Breastfeeding at any cost
		Bonding of importance
	Striving for your own well-being	Giving up due to pain and problems
		Feeling tied up—losing freedom
		Getting into control to feel secure
	Striving to discover your own path	Negotiating pros and cons
		Dealing with pressure and impact of others
		Standing up for your decision

Striving to Be a Good Mother

In the forums, the assumptions that *breast is best* and that breastfeeding was the firsthand choice were often stated. Mother's milk was frequently described as the best start for the child and being the most important during the first months. Breastfeeding recommendations were, according to some posts, considered as arguments not to introduce formula, whereas some participants questioned these recommendations and their validity for their child.

> *I try to stimulate my milk production, it feels like hard work but I trust that my milk is better for my children than formula.*

The assumption that *breastfeeding should occur at any cost* and statements such as everyone who could breastfeed should breastfeed were expressed on the forums. Many had difficulty understanding why anyone would choose not to. Breastfeeding was sometimes described as a sacrifice that the mother should make for her child. On the other hand, some thought it could be acceptable not to breastfeed if the mother had strong enough reasons not to, but she should at least try before deciding not to.

> *I know that not everybody can breastfeed, but to choose not to without even trying that I cannot understand.*

Women whose breastfeeding was not successful expressed that striving to breastfeed at any cost sometimes led to feelings of failure and inadequacy, and they felt that they were not good mothers. Giving formula could be associated with feelings of shame and guilt. Other women commented that one could be a good enough mother, even if the child received formula.

> *Talking about breastfeeding, it seems to be more important than anything else you do, I get the impression that breastfeeding is connected to being the "good mother" and in some way a measurement on how good a mother you are.*

Online discussions about how bonding with the child would be affected by giving formula frequently took place. Although some discussions indicated that breastfeeding led to better bonding, others indicated that it did not influence *the bonding*. The natural aspects of breastfeeding and the resulting closeness to the child were stressed. However, other ideas were also expressed about whether the child would bond better with the father or partner when giving formula and that bonding with the mother would be negatively affected by breastfeeding when she was reluctant.

Striving for Your Own Well-Being

The well-being of the mother was considered an important part of the decision to introduce formula. Many bloggers described problems with breastfeeding; sore nipples, mastitis, infections, and *giving up due to pain and problems* were common examples. Women struggled to give their child the best but many worried about how long they would have the energy.

> *I'm starting to wonder if it's worth all the effort and bother I go through with it. It drains me of all my energy; I simply can't even enjoy her like I want.*

The participants often tried to normalize the breastfeeding problems of others by describing their own experiences and encouraging them to keep trying and not to give up. They also thought that previous difficult breastfeeding experiences would not necessarily mean that future experiences would be the same. In the forums, emotional and psychological aspects of breastfeeding and related stress were frequently discussed. Some felt uncomfortable when breastfeeding; women could also *feel tied up—losing freedom*. The opportunity for both parents to share the responsibility of feeding was sometimes seen as an advantage for giving formula. The woman could get relief and the partner could participate more in the care of the child.

> *I support bottle feeding if you find it mentally straining. It is easier to get assistance if bottle feeding is an option.*

In the end, the main concern of many participants was that their child should be healthy and satisfied. Many posts pointed out that formula helped their children to sleep better, be more satisfied after the feeding, and gain weight better. Giving their child formula could be one way of *getting into control to feel secure*, for example, gaining control over their child's intake.

> *Then I can see exactly how much [formula] my baby swallows and if it is always enough.*

Striving to Discover Your Own Path

In many discussions, *negotiations of pros and cons* were evident. Posts on the forums expressed concerns regarding the negative effect of formula on breastfeeding and concerns about how an early introduction of formula could interact with breastfeeding. Despite this, many comments encouraged partly breastfeeding when experiencing breastfeeding problems. Breastfeeding and formula were not always seen as conflicting. Some commented that children can grow and become healthy regardless of whether they had been raised on mother's milk or on formula.

> *You never know how it will go or what you yourself will feel, or how things will work out for the baby. It will be okay no matter what, so take it easy and whatever will be, will be.*

While making the decision to introduce formula, women had to *deal with the pressure and impact of others.* Health care personnel were sometimes seen as intrusive when they promote breastfeeding, and this could cause women to feel pressured and coerced into breastfeeding. Some described the personnel as being almost hysterical and sometimes almost violating the woman's integrity.

> *I was exactly in the same situation as you! Everyone was getting at me, grabbing my breasts to get my breastfeeding going! Totally insane!*

Some participants described that, after deciding to introduce formula, they no longer received support from the health care personnel. Concerns about the reactions from health care personnel were present both before and after birth. Pressure could also come from others in the woman's surroundings. The experiences of others sometimes became arguments for whether the woman herself could breastfeed and influenced the choice of introducing formula. In the forums, contradictory advice was often given, which also created confusion and feelings of doing something wrong, no matter what you chose. Lack of understanding from family and friends could add to the feeling of guilt that the women had not lived up to expectations. However, examples of positive meetings with health care personnel could ease these feelings and justify their decision.

In the forums, women were often encouraged to *stand up for their decision* to introduce formula. Most posters considered feeding choices to be a personal decision of the mother. The woman should not have to justify herself or have a reason; it was enough to base it on her feelings and instincts. Some posts pointed out that the decision was up to the woman to make because it involved her body. However, it was still important that the decision should be based on facts and not arbitrary advice from others.

> *It doesn't make any difference to me why a woman chooses not breastfeed. It is her own business. On the other hand, it would be interesting to know why so many women deliberately belittle each other's choice with something as personal as breastfeeding.*

Discussion

Principal Findings

The main theme in this study expresses how mothers are balancing between the expectations of others and their own confidence in their parental ability in relation to infant feeding. The 3 themes highlighted that the participants strived to be good mothers, but they also strived for their own well-being. To manage that, they strived to find their own path.

Result Discussion

Breastfeeding was sometimes described as natural, whereas infant formula was characterized as a synthetic secondary alternative where women felt they had to justify the fact that the child was fed formula. There has been a link between infant feeding and the identity of a mother, and some felt that to be *a good mother*, one was supposed to breastfeed. This has been described in previous studies as failing to live up to womanhood and motherhood [29,30], perceptions of inadequate mothering [31], and feelings of having to defend the decision to feed formula to support their identity as a good mother [30,32].

The participants in our study expressed insecurity about doing right and being good enough mothers. They had to state valid reasons to give formula. Those who were unable or chose not to breastfeed had feelings of guilt and shame, something that has been confirmed by previous studies [29,31,33,34]. Taylor and Wallace [29] described how feelings of guilt were connected to giving formula for selfish reasons, such as putting your own needs before those of the child and thereby denying your child what is considered best. This notion of selfishness has been described as conflicting with the concept of being a good mother [32]. Giving formula for selfish reasons, such as not wanting to breastfeed, collides with the image of the self-sacrificing mother who gives endlessly of herself [33]. In addition to the feeling of guilt of doing something wrong when giving formula, women reported experiencing shame connected to failure, inadequacy, and not being a good mother [29,31]. Shame has been connected to social and cultural norms and "the right way" to feed your child [31].

In the Internet forums, many posts described how health care personnel reinforced the image of breastfeeding as a means of being a good mother, and thus inflicted guilt when women experienced breastfeeding problems and introduced formula. In breastfeeding promotion, focus often lies on the mechanism of transferring milk from mother to child and the nutritional benefits of human milk. Little is said about other aspects of the woman's life that are affected. Women in our study sometimes expressed how they felt objectified in situations when health care personnel tried to support breastfeeding. If women's desires and needs are belittled due to, for them, misguided focus, feelings of guilt and shame might arise. Today's parenting culture is often expert-guided, primarily by the medical-scientific view that makes medical professionals authorities on defining risks and what constitutes a good choice [30]. According to Benoit et al [33], focusing on the biological aspects of breastfeeding exemplifies how health care personnel use their power to reinforce "the correct" maternal behavior. Primary focus on the biological aspects of breastfeeding diminishes the breastfeeding experience of the woman, making it physical instead of being a part of all aspects of her life. For instance, this can make women experience their breasts as a possession of their child instead of their own [33].

Women giving formula also need support and information as they have concerns about their child's well-being. However, they also have their *own well-being* in focus to be *good mothers*. In our study, worries about the reactions from health care personnel were expressed and occurred when women had decided not to breastfeed. Sometimes, women even had difficulties bringing up the subject of formula feeding, something that has been described in previous studies [34,35].

Our results indicate that when health care personnel informed and supported women regarding formula feeding, their feelings of shame and guilt decreased. By opening the door to other options than merely breastfeeding, partial breastfeeding can also be promoted, which refers to our result about mothers' need to *discover their own path*. Results from a previous study indicate that women who experience positive interactions with health care personnel breastfeed more than those who experience negative interactions [36]. Perhaps the conflict lies in the impossible equation of being the self-sacrificing, good mother and the informed, independent woman, which makes the issue of supporting breastfeeding more complex and stressful than just feeding a child. From literature, we know that stress is associated with the shorter duration of any and exclusive breastfeeding [37]. To promote breastfeeding without inflicting guilt and shame, health care personnel need to focus more on perceived stress and on the relationship between the mother and the child instead of the biological aspects of breastfeeding. They also need to be more open and listen to the woman's desires and needs, take into account the amount of stress and her well-being in her particular situation, and support her in finding her own path, instead of assuming that all women should breastfeed.

Study Limitations

This study was conducted in a Swedish context, where the social security system allows paid leave for parents for more than a year after birth. This environment is conducive to high breastfeeding rates and a maternity and child health care that can easily promote breastfeeding. The frequency of breastfeeding and norms surrounding breastfeeding might be typical of Sweden, and these circumstances can vary internationally and need to be taken in consideration when reading and reflecting about the transferability of our results.

The data collection was also conducted from online Web forums. On these forums, there are both active writers and passive readers. Our results mirror the perceptions of the active writers, and it is of course possible that the experiences of others would have been expressed if the silent readers had been studied, for example, in interviews. On the other hand, we view it as a strength that the participants could speak freely, without responding to a researcher's questions. Therefore, we interpreted that the quotes were honest and based on inner perceptions and feelings.

Conclusions

For women in early parenthood, it is important to feel that they are good mothers, to feel well, and also to find an individual path regarding breastfeeding. Feelings of guilt and shame may occur when women choose to formula-feed their children. To balance between the expectations of others and confidence in their own parental ability, women use Web forums for advice on whether to formula-feed or not. It could therefore be questioned whether health care personnel are fairly open about women's different choices and often stressful situations. Therefore, Web forums are an important complement to health care. Parental Web forums could further be used by health care professionals to become familiar with women's ambiguities.

Authors' Contributions

All authors designed the study together. SJ and JZJ collected data and analyzed data together with ALW and with constructive input from AH. SJ and JZJ drafted the primary manuscript in Swedish. The manuscript was rewritten and translated into English by ALW and AH.

Conflicts of Interest

None declared.

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Original Paper

The Association Between Commonly Investigated User Factors and Various Types of eHealth Use for Self-Care of Type 2 Diabetes: Case of First-Generation Immigrants From Pakistan in the Oslo Area, Norway

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Abstract

Background: Sociodemographic and health-related factors are often investigated for their association with the active use of electronic health (eHealth). The importance of such factors has been found to vary, depending on the purpose or means of eHealth and the target user groups. Pakistanis are one of the biggest immigrant groups in the Oslo area, Norway. Due to an especially high risk of developing type 2 diabetes (T2D) among this population, knowledge about their use of eHealth for T2D self-management and prevention (self-care) will be valuable for both understanding this vulnerable group and for developing effective eHealth services.

Objective: The aim of this study was to examine how commonly were the nine types of eHealth for T2D self-care being used among our target group, the first-generation Pakistani immigrants living in the Oslo area. The nine types of eHealth use are divided into three broad categories based on their purpose: information seeking, communication, and active self-care. We also aimed to investigate how sociodemographic factors, as well as self-assessment of health status and digital skills are associated with the use of eHealth in this group.

Methods: A survey was carried out in the form of individual structured interviews from September 2015 to January 2016 (N=176). For this study, dichotomous data about whether or not an informant had used each of the nine types of eHealth in the last 12 months and the total number of positive answers were used as dependent variables in a regression analysis. The independent variables were age, gender, total years of education, digital skills (represented by frequency of asking for help when using information and communication technology [ICT]), and self-assessment of health status. Principal component analyses were applied to make categories of independent variables to avoid multicollinearity.

Results: Principal component analysis yielded three components: *knowledge*, comprising total years of education and digital skills; *health*, comprising age and self-assessment of health status; and *gender*, as being a female. With the exception of closed conversation with a few specific acquaintances about self-care of T2D (negatively associated, P=.02) and the use of ICT for relevant information-seeking by using search engines (not associated, P=.18), the *knowledge* component was positively associated with all the other dependent variables. The *health* component was negatively associated with the use of ICT for closed conversation with a few specific acquaintances about self-care of T2D (P=.01) but not associated with the other dependent variables. *Gender* component showed no association with any of the dependent variables.

Conclusions: In our sample, knowledge, as a composite measure of education and digital skills, was found to be the main factor associated with eHealth use regarding T2D self-care. Enhancing digital skills would encourage and support more active use of eHealth for T2D self-care.

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KEYWORDS

immigrants; type 2 diabetes; self-care; information seeking behavior

Introduction

Factors Associated With Electronic Health (eHealth) Use

In the last decade, we have seen a rapid development of accessible information and communication technology (ICT). The cost of accessing the Internet has decreased, especially mobile broadband, and there has been an increase in the variety of services and products for personal self-care. Commensurate with this trend, the use of electronic health (eHealth) has become a general practice in many developed countries. Purposes for using eHealth for self-care include, for example, seeking related information [1-10], Web-based communication with health care experts or peers [9,11-13], and keeping track of user's health information or self-assessment for reflection on self-care [5,9,14,15]. These purposes are common for both prevention and self-management of various types of diseases, especially lifestyle-related chronic diseases. The World Health Organization [16] defines self-care as keeping health, prevention of, and dealing with illness. In this paper, we use the term "self-care" as an all-embracing definition that includes both self-management and prevention of illness.

A large number of studies have explored how different factors are associated with target users' eHealth use for self-care, both in general and with focus on chronic diseases [5,7,9,10,14,15,17-46]. Factors such as demographic information (including age, gender, and education level) are often investigated as independent variables of eHealth use. Health-related factors are also often used as independent variables, but such factors vary considerably depending on the purpose of the study. Knowledge about the association between user factors and eHealth use is vital when designing and developing new eHealth services for similar target users.

We reviewed relevant literature that were published within the last 5 years and that analyzed data obtained in 2010 or later. We limited ourselves to this time frame for two reasons: one is the rapid evolution of mobile phone technology in the years preceding 2010, and the other is the time it would have taken until published literature reflected such changes. Moreover, some studies have found that the factors influencing the use of eHealth changed over time. By comparing data from 2005, 2007, and 2012, Bjunowska-Fedak [21] showed that, in Poland, the association between gender and Internet use for health-related information has switched over the years. McCully et al [47] also found that in the United States, those using the Internet to help with diet, weight, and physical activity had become "younger, less educated, and more likely to be female and single in 2011 than in 2007."

Tables 1-3 show summaries of studies exploring the use of eHealth for different purposes. Although a number of studies do not distinguish types of Internet use and include a very broad purpose related to health care and illness, we sorted studies and findings depending on their purpose and means where possible. The tables show how education level, age, and being a female are associated with the use of eHealth in each study. Multimedia Appendix 1 shows a complete summary of each study shown in Tables 1-3.

Table 1. Studies investigating Web-based health information–seeking and associating factors.

Author (year)	Description of eHealth[a] use	Education level	Age (years)	Female
Kalantzi et al, 2015 [29]	Using the Internet as an important source for information about diabetes	(+)[b]	(−)[c]	NS[d]
Lee et al, 2012 [31]	Using the Internet to seek health or medical information	(+)	(−)	None[e]
Mesch et al, 2012 [36]	Frequency of searching for health information on the Internet	(−) College, graduate school	(−)	(+)
Gonzalez et al, 2016 [24]	Health information–seeking behavior in the last 12 months	(+)	(−) >65	(+)
Wangberg et al, 2015 [9]	Experience in reading about diet and exercise on the Web	(+)	None	(+)
Manierre et al, 2015 [34]	(Among Internet users) Experience in looking for health information on the Internet for self or someone else in the past 12 months	None	None	(+)
Lee et al, 2014 [48]	Experience in either of the following in the last 12 months: 1. Participating in an online support group for people with similar health or medical issues 2. Using email or the Internet to communicate with a doctor or doctor's office 3. Using the Internet to look up health or medical information	(+)	NS	NS
Kontos et al, 2014 [5]	Using the Internet to download health-related information to a mobile device in the last 12 months	(+) College degree or more versus some college	NS	NS
	Using the Internet to look for health or medical information for self in the last 12 months	NS	(−)	NS
AlGhamdi et al, 2015 [17]	Using the Internet to search for health-related information	(+)	Inconsistent (see Multimedia Appendix 1 for details)	(+)
Bjunowska-Fedak et al, 2015 [20]	Using the Internet to obtain information about health or illness	(+)	(−) Sample age above 60	NS
Bjunowska-Fedak, 2015 [21]	Using the Internet to get information about health or illness at least once a year (including using interactive Internet health services)	NS	(−)	(+)
Duplaga et al, 2013 [23]	Declaration of the Internet as one of main sources of health-related information	(+)	(−)	NS
Beck et al, 2014 [18]	Having used the Internet to look for information or advice about health during the past 12 months	None	(+) Sample age 15-30	Conditionally (+) those with psychological distress, being pregnant, or having a child or more
Nölke et al, 2015 [38]	Using the Internet to search for information on medical or health issues	(+) On the basis of social class index comprising of “educational qualification,” “occupational status,” and “household net income”	NS	(+)

[a] eHealth: electronic health.

[b] (+) indicates positive association with eHealth use ($P<.05$).

[c] (−) indicates negative association with eHealth use ($P<.05$).

[d] NS: not significant; no significant association with eHealth use.

[e] None: the factor was not investigated in a study.

Table 2. Studies investigating Web-based communication with experts or peers about health and associating factors.

Author (year)	Description of eHealth[a] use	Education level	Age (years)	Female
Mesch et al, 2012 [36]	Frequency of participating in Internet forums about health issues or sent an email to a physician or a nurse	NS[b]	NS	NS
Wangberg et al, 2015 [9]	Experience in asking questions about exercise or diet to experts	(−)[c]	None[d]	NS
	Experience in posting a status about exercise or diet on a social networking site	(+)[e]	None	(−)
	Experience in sharing exercise or diet data with others online	NS	None	(+)
	Experience in discussing exercise or diet with peers	NS	None	NS
Kontos et al, 2014 [5]	Experience of using email or the Internet to communicate with a doctor or doctor's office in the last 12 months	(+) College degree or more versus high school degree or less	(−) Age between 18-34 versus >65	(+)
	Experience of participating in an online support group for people with a similar health or medical issue in the last 12 months	NS	NS	(+)
	Experience of visiting a social networking site to read and share about medical topics in the last 12 months	Inconsistent	(−) Age between 18-34 versus >65; and age between 35-49 versus >65	NS
Tennant et al, 2015 [42]	Having used the Internet for any of the following reasons to locate or share health information in last 12 months: (1) participated in a Web-based support group, (2) used a social networking site such as Facebook, Twitter, or LinkedIn, or (3) wrote in a Web-based diary or blog	(+) 4 years of college or more versus less than high school	NS (sample: age >50)	(+)
Thackeray et al, 2013 [43]	Using a social networking site (SNS) for health-related activities	NS	(−)	(+)

[a] eHealth: electronic health.

[b] NS: not significant; no significant association with eHealth use.

[c] (−) indicates negative association with eHealth use (*P*<.05).

[d] the factor was not investigated in a study.

[e] (+) indicates positive association with eHealth use (*P*<.05).

Most of the studies concentrate on experiences of Web-based health information search. The number of studies investigating Web-based communication or use of Web applications is still limited. In general, having a high education, being young, and being female are positively associated with eHealth use in many of the studies listed. However, a few studies ([36] in Table 1, [9] regarding “Experience in asking questions about exercise or diet to experts” in Table 2, and [9] regarding “Experience in posting a status about exercise or diet on a social networking site” in Table 2) found associations opposite to this. Moreover, some studies found inconsistent or no significant association between these factors and eHealth use, especially regarding Web-based communication with experts or peers (see Tables 1-3).

In addition to the three factors above, health-related factors and socioeconomic status are also commonly examined for their association with eHealth use. Examples of health-related factors include subjective measure of being in good health [9,15,20,21,29-31,38,42,43] and diagnosis of a chronic disease, either a nonspecific disease [14,17,18,20,21,24,38] or a specific disease type [5,23,29,30,36]. Socioeconomic status is most typically expressed by income and income-based variables [14,17,22,24,29,32,34,36,42,43,49]. Associations between these factors and use of eHealth do not seem as consistent as education, age, and gender (see Multimedia Appendix 1).

Table 3. Studies investigating the use of mobile apps or Web applications for active self-care and associating factors.

Author (year)	Description of eHealth[a] use	Education level	Age (years)	Female
Krebs et al, 2015 [14]	Experience of having ever downloaded an "app" to track anything related to a user's own health	(+)[b] (Ref less than high school)	(−)[c]	NS[d]
Bender et al, 2014 [15]	Experience of downloading health apps	(+) Ref high school	(−)	NS
Wangberg et al, 2015 [9]	Using Internet- or mobile-based programs to support health behavior	NS	None[e]	(+)
	Keeping a Web-based exercise or diet journal	(+)	None	(+)
Kontos et al, 2014 [5]	Experience of using the Internet to keep track of personal health information in the last 12 months	(+) College degree or more versus high school degree or less	NS	(+)
	Experience of using a website to help with diet, weight, or physical activity in the last 12 months	(+)	(−)	NS

[a] eHealth: electronic health.

[b] (+) indicates positive association with eHealth use (*P*<.05).

[c] (−) indicates negative association with eHealth use (*P*<.05).

[d] NS: not significant; no significant association with eHealth use.

[e] None: the factor was not investigated in a study.

Interestingly, few studies have investigated the relationship between factors relevant to digital skills and eHealth use. Lee et al [30] found that the use of social network services (SNS) is positively associated with eHealth use among Hispanic adults in Northern Manhattan. Here, eHealth use was seen as having an experience of either (1) participating in an online support group for people with similar health or medical issues, (2) using email or the Internet to communicate with a doctor or doctor's office, or (3) using the Internet to look up health or medical information. It is therefore unclear which of these three types had a significant association with SNS use. Bender et al [15] carried out a survey by letting informants choose either a Web-based form or paper form. They found that taking the paper survey was negatively associated with experience of downloading health apps compared with having taken a Web-based survey.

A Case: First-Generation Immigrants From Pakistan in Norway and eHealth Use

Norway is one of the most highly digitalized countries in Europe. As of 2016, 96% of the population has access to the Internet, and 75% have basic digital skills [50]. The government promotes digitalization of public services, including a health and care service portal with self-service solutions [51]. The national health and care service portal is growing in use [51,52]. In 2015, 62% of the population in the age range of 16 and 79 years had searched the Internet for health-related information in the last 3 months [4]. However, it is not yet clear whether the same applies to specific populations of different demographic makeups. For example, several recent studies show that being an immigrant is a negatively associated factor of eHealth use for certain purposes within self-care [24,36,38,45]. On the other hand, ethnicity is not consistently associated with eHealth use [14,41,47,53-56]. Two studies in the United States observed changes in association between ethnical background and eHealth use over time. McCully et al [47] found that compared with non-Hispanic whites, the proportion of users of the Internet for diet, weight, and physical activity decreased among non-Hispanic blacks, whereas it increased among Hispanics from 2007 to 2011. Wilson et al [57] found that more Hispanics used online support groups in 2012 than in 2007.

Pakistani immigrants are one of the large immigrant groups in the Oslo area [58]. Previous studies have shown that they have an alarmingly high prevalence rates of diabetes (women: 26.4%, men: 20.0%) compared with ethnic Norwegian population (women: 2.7%, men: 6.4%) [59], in addition to having relatively low ICT skills [60]. These two factors make this group of particular interest with regard to the use of eHealth for self-care of type 2 diabetes (T2D). We should note that the referred study [59] reports the prevalence rate of diabetes without dividing diabetes into type 1 diabetes (T1D) and T2D. However, the prevalence rate of T1D of the Pakistani population is considered to be much lower than that of ethnic Norwegian population [61]. Regarding the ICT skills, the only source of information on ICT skills of the first-generation immigrants from Pakistan in Norway is a survey [60] published in 2010. Since then, Smartphones have become much more popular, and more and more people have access to ICT. Moreover, there is a distinct lack of contemporary literature on eHealth use for self-care among the immigrant population in European countries that is from outside Europe [45]. Investigating the use of eHealth in relation to ICT skills and other relevant factors will give a new and updated insight of the potential for and barriers to benefit from eHealth in this population.

Objectives

From a larger survey among first-generation Pakistani immigrants in Oslo, this paper focuses on results regarding the use of eHealth for self-care of T2D depending on its purpose and means, which are categorized as follows: (A) For seeking T2D-relevant information: (a) by using search engines that require input of search terms, (b) on specific websites or by email subscriptions that can be navigated by only scrolling and clicking, or (c) by searching for software programs on personal computers, or apps on a mobile phone or a tablet (mobile apps) that could be used as a look-up tool; (B) For communicating or consulting about T2D self-care: (d) by using ICT in general for closed conversation with a few specific acquaintances such as voice or video or text communication, (e) via SNS, (f) on portals for peer communication, or (g) by online consulting with experts in diabetes; (C) For active decision making on T2D self-care (h) by using Web applications for or mobile apps tracking health information such as diet, physical activities, weight, blood glucose level, and so on, or (i) by using Web applications or mobile apps to assess one's own health status with regard to T2D.

The objective of this paper is to answer the following research questions: (1) How common is eHealth use for T2D self-care among first-generation immigrants from Pakistan in the Oslo area? and (2) To what extent are education, age, gender, digital skill, and self-assessed health associated with the use of eHealth for self-care of T2D in this population?

Methods

Description of Survey

We carried out the survey from September 2015 to January 2016. Ethical approval was given to the project protocol by Norwegian Social Science Data Services in June 2015 (project number: 43549). We employed purposive sampling for the recruitment of informants. Reflecting the results from our pilot, the following inclusion criteria were set, as shown in the survey protocol paper [62]: (1) immigrated from Pakistan after the age of 18 years; (2) live in the Oslo area; (3) speak Urdu (the official language of Pakistan) as the primary language in their private life; (4) aged between 25 and 59 years; (5) have access to or interest in ICT tools (personal computer, tablet, or smartphone), connected to the Internet in daily life; and (6) motivated for and capable of performing activities for self-care of T2D.

On the basis of the recommendations on recruitment in immigrant populations [63] and experience from previous studies that included Pakistani immigrants in Norway [64-67], we used a multirecruitment strategy. This included recruiting informants first via an already established network of 2 research assistants in the target group, approaching new potential informants in the local community, and snowball sampling [68]. In total, 176 informants participated in the survey.

The survey employed individual structured interviews. The research assistants, who are fluent in speaking Urdu, interviewed the informants and recorded their verbal responses. The protocol of the whole survey, as well as the entire set of questions used in the survey, can be found elsewhere [62].

Variables

We chose to analyze the following variables to be able to compare eHealth use in our survey sample with relevant studies shown in Tables 1-3.

Independent Variables

Demographic variables include being a female, age group by a range of birth year, and the total years of education from Pakistan and Norway. The decision to use age group by a range of birth year rather than exact age was made to avoid a potential risk that, because of the relatively small sample size, an informant could be identified by a combination of the answers provided to some questions in the survey [68]. To enable dealing with age group as one variable, we used the middle year of each range as the representative year of birth of each group.

In Pakistan, primary education lasts for 5 years, starting from the age of 5. This is followed by a 3-year junior secondary education after which there is 2-year secondary school and then 2-year higher secondary school before undergraduate level [69]. In case an informant had education in Norway, we added the number of completed years of education to the years of education taken in Pakistan.

Self-assessment of health status was obtained by a multiple-choice question with answer alternatives being "Excellent (5)," "Very good (4)," "Good (3)," "Fair (2)," "Going up and down (1)," and "Poor (0)" based on a question used in [70]. The question was associated with health status in general. Nevertheless, we considered this variable to be potentially highly relevant with self-care of T2D, given their interest in this disease as one of the inclusion criteria.

Lack of digital skills were captured by a question related to the frequency of asking for assistance when using ICT devices, with answer alternatives being "Always (4)," "Often (3)," "Sometimes (2)," "Seldom (1)," and "Never (0)." In the analysis, these two variables were treated as continuous data as they present ordinal categorical data with more than five categories [71].

Dependent Variables

As dependent variables, we used dichotomous answers to the nine questions asking about whether or not informants had used eHealth for self-care of T2D in the last 12 months, depending on the purpose and means described in the Objective subsection. We also used a total number of positive answers to these nine questions as a variable showing how a wide variety of eHealth activities an informant was engaged with for self-care of T2D.

Statistical Analysis

Logistic regressions were used to assess associations between experience with each purpose of eHealth use (dependent variable) and the independent variables. The variety of eHealth use can be interpreted as a count variable, therefore, we resorted to Poisson regression.

Although we were interested in digital skills as a separate factor from education level, it is probable that they are correlated to each other. Given the result of a report about digital skills of immigrants with a Pakistani background in Norway, it is also probable that the age and gender would be also highly correlated to digital skills [60]. To avoid multicollinearity, we used the principal components of the independent variables. Three principal components were selected, based on the scree plot [72], and we used Varimax rotation [73]. Variables with a high score in absolute value were used to characterize each principal component. Principal component scores were computed, and the scores were used as the independent variables in regression analyses.

Results

Characteristics of the Sample and eHealth Use

Table 4 shows the distribution of the informants by each variable. Male informants (n=42) were considerably fewer than female informants (n=134). However, the informants were similarly distributed by age group for both genders. In total, 80 informants (45.5%, 80/176) had up to 10 years of education; 28 informants (15.9%, 28/176) had only up to 5 years of primary education—they were all women. On the other hand, 42 female informants, which is nearly one-third of the female sample, had completed college education or higher. In total, 12 informants had been to a Norwegian school, among which 7 informants had been to college level or higher.

The majority of the informants answered that their health status, in general, was good or better. One who answered “going up and down” mentioned explicitly that the condition was due to pregnancy.

Forty-four informants (25.0%, 44/176) reported that they need assistance in the use of ICT tools always or often. On the other hand, 68 informants (38.6%, 68/176) expressed they did not need any assistance in the use of ICT tools.

Regarding eHealth use for information seeking, 63 informants (35.8%, 63/176) reported use of portals and similar sources that required only simple operations such as scrolling and clicking (b). On the other hand, no more than 35 informants (19.9%, 35/176) reported the use of a search engine that requires text input (a). Only 8 informants (4.5%, 8/176) had searched the Internet for mobile apps or software programs on personal computers for look-up of relevant information to T2D self-care (c).

Eighty-four informants (47.7%, 84/176) had used ICT for closed communication with acquaintances regarding self-care of T2D (d), and 58 informants (33.0%, 58/176) had used SNS for communication with others about self-care of T2D (e). However, only 9 informants reported using portals for peer communication in the context of T2D self-care (f). There was only 1 informant who had asked about issues relevant to T2D self-care to an expert on the Web (g). Mobile apps and Web applications for active decision making on T2D self-care were not very popular. Twenty-five informants (14.2%, 25/176) reported the use of mobile apps or Web applications for keeping track of health information (h), 38 informants (21.6%, 38/176) used mobile apps or Web applications for self-assessment of health status (i), and 41 informants (23.2%, 41/176) had never used ICT for T2D self-care. Among the 46 informants (26.1%, 46/176) who had used only one type of eHealth in the context of T2D self-care, 31 informants (17.6%, 31/176) answered that they were using ICT for closed communication with acquaintances (d). No informant had experience of eight or more types of eHealth for T2D self-care.

Association Between User Factors and eHealth Use

Table 5 shows the computed principal components. We see that the total years of education (positive value) and the frequency of asking for help (negative value) dominate the first principal component (PC1). Education means acquiring knowledge, whereas asking for help indicates lack of knowledge. We therefore refer to this principal component as *knowledge* below.

The second principal component (PC2) is strongly related to health status (positive value) and to some extent to age (negative value). The self-assessment of health status and age were negatively correlated according to Pearson correlation test that was separately applied to these variables (correlation=−.32, $P<.001$). This result is reasonable, given that health status in general declines with age. Therefore, we refer to this principal component as *health*.

The third principal component (PC3) is related to *gender*.

Table 4. Descriptive characteristics of the survey informants (N=176).

Variables	Informants, n (%)
Gender	
Male	42 (23.9)
Female	134 (76.1)
Age group by birth year range	
1981–1990	54 (30.7)
1971-1980	61 (34.7)
1956-1970	61 (34.7)
Total years of education from Pakistan and Norway	
0 years	14 (8.0)
5 years	13 (7.4)
<10 years	17 (9.7)
<12 years	33 (18.8)
<14 years	39 (22.2)
14 years or more	55 (31.3)
Self-assessment of health status (score)	
Excellent (5)	11 (6.3)
Very good (4)	27 (15.3)
Good (3)	70 (39.8)
Fair (2)	37 (21.0)
Going up and down (1)	19 (10.8)
Poor (0)	12 (6.8)
Frequency of asking for help when using ICT[a]	
Always (4)	18 (10.2)
Often (3)	26 (14.8)
Sometimes (2)	51 (29.0)
Seldom (1)	12 (6.8)
Never (0)	68 (38.6)
Experience of eHealth[b] use for T2D[c] self-care in the last 12 months	
(A) For seeking relevant information	
(a) By using search engines that require input of search terms	35 (19.9)
(b) On specific websites or by mail subscriptions that can be navigated by only scrolling and clicking	63 (35.8)
(c) By searching for software programs on personal computers or applications on mobile phone or tablet (mobile apps) that could be used as a look-up tool	8 (4.5)
(B) For communication and consulting	
(d) By using ICT in general for closed conversation with a few specific acquaintances	84 (47.7)
(e) By social networking sites	58 (33.0)
(f) On portals for peer communication	9 (5.1)
(g) By online consulting with experts in diabetes	1 (0.6)
(C) For active decision making on self-care by using Web applications or mobile apps for	
(h) Keeping track of health information	25 (14.2)
(i) Self-assessment of health status	38 (21.6)

Variables	Informants, n (%)
Total number (variety) of eHealth types experienced	
8 or more	0 (0.0)
7	2 (1.1)
6	5 (2.8)
5	7 (4.0)
4	9 (5.1)
3	28 (15.9)
2	38 (21.6)
1	46 (26.1)
0	41 (23.3)

[a] ICT: information and communication technology.

[b] eHealth: electronic health.

[c] T2D: type 2 diabetes.

Table 5. Computed principal components (PCs).

Variables	PC1[a]	PC2	PC3
Being a female	−.24	−.15	.87
Age	−.41	−.58	−.49
Total years of education	.85	.13	−.08
Self-assessment of health status	.17	.90	−.21
Frequency for asking help when using ICT[b]	−.82	−.23	.15

[a] PC: principal component.

[b] ICT: information and communication technology.

Table 6 refers to the results of the regression analyses. The analysis included all the dependent variables presented in the Methods section excluding (g), that is, online consulting with experts in diabetes because only one informant had such an experience.

The *knowledge* component is strongly and positively related to the total number (variety) of eHealth experience types and all the dichotomous dependent variables, with the exception of two variables: (1) closed online communication about T2D with a few acquaintances (d), which is negatively related and (2) seeking relevant information by using search engines that require input of search terms (a), which is unrelated. The *health* component is negatively related to closed online communication about T2D with a few acquaintances (d), and there is an indication of a positive relation between the *health* component and the use of Web applications and mobile apps for active decision making on T2D self-care by tracking of health information (*P*=.05). The *gender* component has no significant association with any of the dependent variables.

Table 6. Result of regression analyses.

Variables	Estimate	Standard error	z value	*P* value
(A) For seeking relevant information				
(a) By using search engines that require input of search terms				
Intercept	−1.415	0.194	−7.299	<.001
Knowledge	0.282	0.207	1.358	.18
Health	0.002	0.192	0.011	>.99
Gender	−0.137	0.181	−0.754	.45
(b) On specific websites or by email subscriptions that can be navigated by only scrolling and clicking				
Intercept	−0.615	0.164	−3.750	<.001
Knowledge	0.489	0.179	2.734	.006
Health	0.093	0.163	0.571	.57
Gender	−0.082	0.157	−0.522	.60
(c) By searching for software programs on personal computers or applications on mobile phone or tablet (mobile apps) that could be used as a look-up tool				
Intercept	−3.955	0.706	−5.602	<.001
Knowledge	1.298	0.650	1.996	.046
Health	0.518	0.440	1.177	.24
Gender	0.745	0.517	1.441	.15
(B) For communication and consulting				
(d) By using ICT[a] in general for closed conversation with a few specific acquaintances				
Intercept	−0.084	0.158	−0.531	.60
Knowledge	−0.375	0.160	−2.341	.02
Health	−0.400	0.163	−2.454	.01
Gender	0.231	0.159	1.450	.15
(e) By social networking sites				
Intercept	−0.766	0.171	−4.487	<.001
Knowledge	0.597	0.191	3.120	.002
Health	0.068	0.168	0.406	.69
Gender	−0.015	0.161	−0.092	.93
(f) On portals for peer communication				
Intercept	−3.329	0.481	−6.928	<.001
Knowledge	0.988	0.500	1.976	.048
Health	−0.132	0.361	−0.364	.72
Gender	0.298	0.378	0.788	.43
(C) For active decision making on T2D[b] self-care by using Web applications or mobile apps for				
(i) Self-assessment of health				
Intercept	−1.640	0.249	−6.597	<.001
Knowledge	1.165	0.289	4.036	<.001
Health	0.312	0.206	1.515	.13
Gender	0.096	0.189	0.509	.61
(h) Keeping track of health information				

Variables	Estimate	Standard error	z value	*P* value
Intercept	−2.309	0.334	−6.922	<.001
Knowledge	1.257	0.365	3.447	<.001
Health	0.487	0.251	1.942	.05
Gender	0.039	0.218	0.181	.86
Total number (variety) of eHealth types experienced				
Intercept	0.566	0.582	9.725	<.001
Knowledge	0.290	0.063	4.644	<.001
Health	0.024	0.057	0.420	.68
Gender	0.046	0.055	0.823	.41

[a] ICT: information and communication technology.

[b] T2D: type 2 diabetes.

Discussion

Principal Findings and Implications For Future Studies

This study targeted first-generation immigrants from Pakistan living in the Oslo area and examined their use of various types of eHealth in the context of T2D self-care. As there has not been any data showing eHealth use by this target population, this study increased our understanding of one of the biggest minority groups in Norway. Wilson et al [57] argue that “it can be misleading to study use of aggregated eHealth services within portals, as results are likely to mask true usage patterns of the distinct services.” By asking about the use of eHealth depending on its purpose and means, this study could highlight how and for what the target group use eHealth for T2D self-care, as well as the difference in how user factors are associated with use of eHealth.

The finding that nearly half of the survey sample has used ICT for closed communication with acquaintances about T2D self-care implies that T2D self-care is not a rarity among the target population. This is reasonable, considering the high prevalence of diabetes among the target population [59]. This is also supported by the findings that more than one-third of the sample has used SNS for communicating or consulting about T2D self-care. A low proportion of the informants had an experience in peer communication or online consulting with experts regarding T2D self-care, which is in line with findings in similar studies [5,9,31]. Despite the common awareness and high attention to T2D self-care, our findings indicated that individuals in this population sample have not yet taken much advantage of ICT for active self-care for keeping track of health or self-assessment of health status.

To the authors’ best knowledge, there is no other similar study investigating eHealth use concerning T2D self-care among the ethnic Norwegian population. The closest is the study by Wangberg et al [9], based on a Web-based survey to a sample of 1028 informants (aged above 15 years) registered as Web panel, shown in Tables 1-3. The study was about diverse types of eHealth use, with a focus on diet and physical activity. Due to the difference in questions and inclusion criteria of the informants, the studies cannot be directly compared. However, the proportion of users of each type of eHealth in our sample seems less than that of their sample (Multimedia Appendix 1). More research investigating samples from ethnic Norwegian populations who are interested in and capable of T2D self-care is required to investigate whether there are any gaps between the two target user groups.

As shown in Table 1, many relevant studies do not specify the means for Web-based health information seeking. Nevertheless, based on the literature review, which showed that most studies have found a positive association between education level and Web-based health information seeking and the nature of search engines, we expected that the principal component *knowledge* would have a positive association with use of search engines for relevant information about T2D self-care. However, the *knowledge* component was not associated with use of search engines in our study. Rather, it was positively associated with use of ICT-based T2D self-care information resources that can be used by simple operations. In our study, a larger proportion of participants had used Web portals and similar resources that require only simple operations compared with search engines, for seeking relevant information about T2D self-care. Search engines are normally used for exploring a specific topic or question. The fact that T2D is a common topic among the target population may partly explain the low percentage of the informants having attempted to use search engines to seek and explore in depth relevant information to T2D self-care. We need a further analysis of the whole survey data, including language proficiency and preference as to ICT use and for the purpose of T2D self-care, to understand the finding.

The principal component *knowledge* was differently associated with use of ICT for communicating or consulting about T2D self-care depending on its means and who they communicate with (Table 6). Studies listed in Table 2 also show that education level is not a consistently associated factor of such use. The *knowledge* component was strongly associated with the search of software and the use of Web applications or mobile apps. As *knowledge* component is strongly related to education level, this result is in line with the studies listed in Table 3. At the same time, the *knowledge* component includes the independent variable related to digital skills. Implication here is positive because enhanced digital skills may have a potential to engage the target population with use of eHealth for active T2D self-care. Cultivating digital skills by providing courses, for example, would be a more reasonable solution than increasing the total years of formal education.

In this study, the principal component *health* was found to have a negative association with use of ICT for closed communication with a few acquaintances about T2D self-care. Other than this, the *health* component did not have any associations with purpose or mean of eHealth use. The principal component *health* had strong positive loadings for self-assessment of health status and negative loadings for age. The implication here could be that the older and less healthy people are more likely to use Web-based conversations with their acquaintances regarding T2D self-care compared with younger and healthy people, but otherwise, users of eHealth for T2D self-care in this sample are varied in age and health status. However, all the three principal components had quite similar level of loadings for age. Given that age was very often negatively associated with eHealth use in relevant studies, whereas self-assessment of health status was not as often correlated to eHealth use as age, it might be worth looking at age as an independent factor in a future study with a larger sample.

Limitations

Due to the existing privacy and security regulation, use of the middle year of each range of age group as the representative year of birth was the best possible solution within the choices we could make. However, the results might have changed slightly if we instead could have used the actual age of each informant in the analyses.

The study sample had uneven gender balance, which may not reflect the gender balance of the population that fulfills our inclusion criteria. The 2 research assistants reported several cases where they failed to recruit male informants because of them falling outside one of the inclusion criteria or their unwillingness to participate. The cases included immigration to Norway at the age of 16 or 17 years, which caused exclusion because of one of the inclusion criteria. We set an inclusion criterion that informants had immigrated to Norway after age of 18 years because of the age authorized as a legal adult in Norway. In Pakistan, age at completion of higher secondary education can be 17 years. If our inclusion criterion regarding the age at immigration had been 16 years, we might have been able to include more male informants. The other cases are negative attitudes toward being asked about personal health, engagement in night-shift work and sleeping during the daytime, and a negative reaction to interaction with the female research assistants. For future similar studies, using male research assistants may also help to ensure recruiting male informants. Due to the limited budget of the project and cost ineffectiveness of purposeful sampling, we needed to focus on recruiting as many informants as possible, instead of focusing on including more males. Gender was controlled for in the regression analysis to account for the imbalance.

In a survey about digital skills of immigrant groups in Norway [60], 40 concrete questions were used to measure informant's digital skills. We considered that the number is too large and many topics covered in the 40 questions were irrelevant to the survey. Therefore, we decided to use frequency of asking for help as a subjective measure of digital skills. This is one possible limitation because the question may not be able to reflect objectively measured digital skills.

Conclusions

This study adds to the knowledge about the use of eHealth for T2D self-care among first-generation Pakistani immigrants living in the Oslo area, especially those who are interested in and capable of T2D self-care. *Knowledge* as a composite measure of education and digital skills was related to the use of eHealth for self-care of T2D, except for seeking relevant information by using search engines. *Health*, as a composite measure of self-assessment of general health status and younger age, was negatively related to use of closed online communication services with acquaintances about T2D self-care. Otherwise, neither *health* nor *gender* was considered to be an important factor associated with eHealth use for T2D self-care. Pakistani immigrants in the Oslo area are using eHealth for active self-care of T2D to a limited extent. Providing courses with focus on digital skills would have a good potential to increase engagement with active T2D self-care by using eHealth in this high-risk group.

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Authors' Contributions

NT conceived this study and drafted the study design and the first version of the manuscript. HLH designed and conducted the statistical analyses and wrote the relevant part of the draft. All the other 3 authors contributed to further development of the study design and in finalizing the manuscript by giving comments to all versions of the manuscript draft. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Complete summary of studies shown in Tables 1-3.

[PDF File (Adobe PDF File), 524KB - publichealth_v3i4e68_app1.pdf]

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Abbreviations

eHealth: electronic health
ICT: information and communication technology
NS: not significant
PC: principal component
SNS: social network service
T1D: type 1 diabetes
T2D: type 2 diabetes

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Original Paper

Implications of Attrition in a Longitudinal Web-Based Survey: An Examination of College Students Participating in a Tobacco Use Study

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Abstract

Background: Web-based survey research has several benefits, including low cost and burden, as well as high use of the Internet, particularly among young adults. In the context of longitudinal studies, attrition raises concerns regarding the validity of data, given the potential associations with individual and institutional characteristics, or the focal area of study (eg, cigarette use).

Objectives: The objective of this study was to compare baseline characteristics of nonresponders versus responders in a sample of young adult college students in a Web-based longitudinal study regarding tobacco use.

Methods: We conducted a secondary data analysis of 3189 college students from seven Georgia colleges and universities in a 2-year longitudinal study. We examined baseline tobacco use, as well as individual- and institutional-level factors, as predictors of attrition between wave 1 (October and November 2014) and wave 2 (February and March 2015) using multilevel modeling.
Results: A total 13.14% (419/3189) participants were lost to follow-up at wave 2. Predictors of nonresponse were similar in the models examining individual-level factors and institutional-level factors only and included being black versus white (odds ratio [OR] 1.74, CI 1.23-2.46); being male versus female (OR 1.41, CI 1.10-1.79); seeking a bachelor’s degree versus advanced degree (OR 1.41, CI 1.09-1.83); not residing on campus (OR 0.62, CI 0.46-0.84); past 30-day tobacco use (OR 1.41, CI 1.10-1.78); attending a nonprivate college (OR 0.48, CI 0.33-0.71); and attending a college with ≤10,000 students (OR 0.56, CI 0.43-0.73).

Conclusions: Future longitudinal studies should assess predictors of attrition to examine how survey topic and other individual and institutional factors might influence the response to allow for correction of selection bias.

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KEYWORDS

young adults; risk factors; tobacco use; methods; surveys and questionnaires

Introduction

Rapid development of new information technology tools has revolutionized survey implementation. In parallel with this innovation, however, researchers have noticed a universal and consistent decline in survey participation. The rate of nonresponse in survey research has increased within the past decade when compared with the latter half of the 20th century [1,2]. The inability to recruit and retain study participants within longitudinal studies poses potential threats to the validity of population-based studies when the participation itself is related to survey or other unobserved variables [3-5]. Further, investigations of the potential threats to validity (ie, biases) due to nonparticipation are often insufficiently explored, particularly, in studies of substance use by young adults [6-9].

Although avoiding bias is desirable in public health research, researchers conducting longitudinal studies are often forced to contend with unit nonresponse. Unit nonresponse, in the context of this analysis, refers to a failure to retain participants in subsequent waves of a study after some initial participation and is often viewed as difficult to interpret and account for during analysis. Although loss to follow-up does not always result in biased estimates, problems arise when the nature of the nonresponse becomes systematic with regard to individual or institutional factors. Additionally, having a high-retention rate between waves does not guarantee unbiased estimation if this systematic attrition exists [2,4,9].

Previous longitudinal studies of tobacco and other substance use in student and young adult populations have encountered varying levels of attention to missing data. Methods for managing attrition have included comparing characteristics of participants and nonparticipants [10-13], comparing early versus late respondents in terms of recruitment period [14], reporting conservative baseline estimates [15], or descriptive analysis of those retained [16]. Mixed results have been reported from studies where correlates were explored.

Topic of survey and substance use may be two factors contributing to attrition. For example, one study of hookah use by young adults transitioning from high school to college found that those who completed a 1-month follow-up survey were more likely to be lifetime hookah nonusers and lifetime smokeless tobacco nonusers; however, current alcohol use and current cigarette use were unrelated to attrition [17]. Similarly, prior research found that those who participated at the final wave of data collection were less likely to have smoked the month before the wave 1 [18]. Other tobacco studies in this population, however, found no associations with substance use [13]. Given the mixed findings regarding the presence or absence of previous tobacco or other substance use and attrition, examining correlates of attrition and attempting to understand reasons for attrition is a vital step in the research process. For example, if a study is primarily concerned with tobacco use [19], the literature suggests that those dropping out might do so because of a lack of topic salience or relevancy. Conversely, it is also possible that those who use tobacco might be dropping out at a higher rate because of perceived stigma related to smoking or other tobacco use [20].

Very few studies have examined predictors of study retention at the higher education and institutional level (eg, school level for individual student attrition). In terms of sociodemographics, prior research in adolescents and young adults has found greater attrition and recruitment nonresponse among men [21-25], non-whites [17,22], and those whose parents reported lower education levels [9,22]. Few studies have investigated the association between school status (eg, public vs private) and attrition rates. Although, one study found that students recruited from public schools or those located in urban areas showed higher odds of nonresponse [26]. Additionally, institutions with larger student population size have exhibited lower levels of survey participation [26]. Another factor worth exploring is the place of residence (on campus vs elsewhere); smoking status may be different because of smoke-free policies and because of the potential of greater exposure to other students participating in the study both of which may influence response. Cross-sectional research has suggested that those who live on campus are more likely to participate [24]. Although attention has been given to the relationship between survey recruitment and institutional factors, further efforts need to be taken to understand area-level predictors of longitudinal survey retention.

In this study, we conducted a secondary data analysis to estimate the association between baseline (wave 1) 30-day substance use, specifically tobacco use, and wave 2 attrition using a sample of young adult college students participating in a longitudinal Web-based survey study of tobacco use. In addition, we explored individual (eg, sociodemographics, academic variables, and place of residence) and institutional factors (eg, urban or rural location, type of college or university, and school size) associated with wave 2 attrition, using a multilevel mixed effects modeling approach.

Drawing from the literature, we hypothesized that attrition will be higher for non-whites, men, those whose parents reported lower education levels, those seeking lower academic degrees, and those residing off campus. Second, we hypothesized that attrition will be higher for those at urban schools versus rural schools and those at schools with larger student populations compared with those with smaller student populations. Of note, given the contradictory findings in the literature regarding substance use and attrition, we do not have a specific hypothesis but will explore this potential predictor.

Methods

Study Design and Participants

Project DECOY—Documenting Experiences with Cigarettes and Other Tobacco in Young Adults—is a quantitative longitudinal assessment of tobacco use predictors in Georgia college students [19]. Our overall study and reporting approaches were guided by the Checklist for Reporting Results of Internet E-Surveys (CHERRIES) guidelines [27]. This study was approved by the institutional review boards of the Emory University and ICF, International, as well as those of the participating colleges.

The study was initiated in 2014. Data were collected from seven Georgia colleges, including two public schools, two private schools, two community colleges and technical colleges, and one historically black university. Surveys were administered every 4 months across six waves of data collection during spring, summer, and fall.

Eligible participants were aged between 18 and 25 years and were able to read English. A list of students was obtained from each institution’s office of the registrar. Using these lists as the sampling frame, 3000 randomly selected students from each one of the private school and two public schools were invited to participate. The remaining institutions contained fewer than 3000 students, and the invitations were emailed to all eligible participants. The invitation emails described the study (longitudinal study with six assessments over 2 years) and the incentives for participating. If potential participants were interested, they clicked on a link embedded in the email, which launched them to the consent form. After reading the consent form, they had the option to consent by clicking a link, which then launched the baseline (wave 1) survey. Recruitment at each school was closed after recruitment goals at each school were reached. Response rates ranged from 11.99% (1872/15,607) to

59.40% (9270/15,607), with an overall response rate of 22.90% (3574/15,607). A week after completion of the baseline survey, participants were asked to confirm their participation in the study via an emailed link and were provided their first gift card (US $30). The response rate after confirmation was 95.64% (3418/3574).

Several techniques were used to increase the retention of the participants during follow-up [19]. In brief, social media contacts (ie, Facebook and Twitter), in addition to primary and alternate email addresses, were obtained to increase probability of reaching participants. An option to provide contact information of relatives and others likely to know the whereabouts of the participant was given. Additionally, small gifts (eg, key chains) were provided, as well as access to Project DECOY social media was employed to enhance engagement with the participants. Before launching each wave of assessment, updates and reminders regarding survey procedures were provided through the DECOY Twitter account and Facebook page, and text messages were sent to the participants 1 month before the survey's administration via Trumpia (DoCircle, Inc, Anaheim, California) to remind participants of the survey and to allow them to update their email address. Once each wave of assessment was launched, up to 5 email reminders within a 4-week period were sent before the opportunity to participate in that wave was closed. To further encourage participation, survey incentives were provided on a gradual schedule (US $30 for the first 2 waves, US $40 for the second 2 waves, and US $50 for the final 2 waves). If participants completed all 6 surveys, they received an additional US $100 (for a total of US $340). If participants did not complete 1 wave of assessment, they were eligible for the subsequent waves of assessment, regardless.

The secondary analysis examined predictors of baseline (wave 1) participants completing the wave 2 (ie, 4-month follow-up) assessment. After assessing refusal or missing data for variables included in the final model, our analytic sample comprised 93.30% (3189/3418) of the confirmed participants. A total of 13.14% (419/3189) of the participants were lost to follow-up at wave 2.

Measures

The baseline DECOY survey was developed by Emory University, programmed by ICF, International and pilot-tested by both Emory University and ICF, International to ensure functionality of the programming and survey content. The baseline assessment was administered via the Web using a closed survey (ie, only invited participants could access the survey), which involved each user being assigned a unique link to monitor that individual's response (ie, only one response allowed). The survey took between 30 and 45 mins to complete. Measures included a range of variables, such as sociodemographics, general health information, psychosocial characteristics, and substance use, all of which were presented in the same order for all participants. Certain skip patterns were applied (ie, those not reporting past 30-day tobacco use skipped the section regarding types of products used, use frequency, readiness to quit, etc). Participants were required to respond to each question, with particularly sensitive questions (eg, illegal substance use) having a response option of *efuse*. Participants were not allowed to return to prior screens of the survey once they had moved on in order to prevent participants from retroactively changing answers to move past sections involved in skip patterns. However, each page included study staff contact information to correct errors. All data were automatically recorded via ICF, International's software and were stored in secure servers at ICF, International transferred to Emory University using a secure portal, and then stored in secured servers at Emory University.

Substance Use

To assess tobacco use, we first asked participants whether they had used a range of tobacco products (cigarettes; e-cigarettes; hookah; flavored little cigars or cigarillos; and chewing tobacco, snuff, or dip, snus–collectively called smokeless tobacco) in their lifetime at wave 1 using standard items from the Centers for Disease Control and Prevention National Adult Tobacco Survey. Those indicating lifetime use were then asked to report the number of days they used the respective tobacco products in the past 30 days. A similar approach was taken for assessing alcohol use.

Individual-Level Factors

Several individual-level characteristics were assessed, including age; race and ethnicity (non-Hispanic white, non-Hispanic black, other); sex; highest level of parental education; highest level of degree sought; and place of residence (on campus vs other).

Institutional-Level Factors

The following three types of institutional factors were examined: (1) rural versus urban status of the area in which the institution resided (based on census classification); (2) type of school (private, public, community or technical, historically black); and (3) student population (< vs >10,000 based on distribution of population sizes). On the basis of our preliminary analyses, the type of school was operationalized as private school versus other given differential nonresponse rates.

Data Analysis

First, bivariate associations between each predictor and nonresponse at wave 2 were assessed. *t* tests and chi-square (or Fisher exact test) tests were used for continuous and categorical variables, respectively, comparing baseline data for responders and nonresponders. The Wilcoxon rank-sum test was used for variables with distributions, which were non-normal.

A generalized linear mixed model containing all relevant individual- and institutional-level variables was used to determine predictors of nonresponse at wave 2. Results were expressed as adjusted OR with the corresponding 95% CI. An unconditional model with no variables entered was first used to estimate the intracluster correlation coefficient (ICC), which describes the variability in nonresponse at wave 2 because of the nesting of students within the institution. Students attending the same institution are assumed to be more similar because of the characteristics of that institution, and this variability due to institution may also be explored in addition to the effect of individual characteristics. Models containing only individual-level variables, only institutional-level variables, and both individual and institutional variables were then constructed. Individual characteristics were entered into the model based on a priori considerations. Model fit statistics were calculated and likelihood ratio tests were used to compare the change in deviance of nested models. Lastly, the reduction in level-2 (school level) variance compared with the unconditional model was calculated for each subsequent model. All analyses were conducted in SAS Institute's SAS version 9.4 (Cary, North Carolina, USA), and alpha was set at .05.

Results

Table 1 provides descriptive characteristics and bivariate analyses comparing those who responded to the wave 2 assessments versus the nonresponders to the wave 2 assessment. Note that, at baseline (wave 1), over a quarter (949/3189, 29.76%) of the participants indicated that they had used at least one tobacco product within the last 30 days, and over half reported past 30-day alcohol use (2019/3189, 63.31%).

Total 13.14% (419/3189) of the participants were lost to follow-up at wave 2. Baseline (wave 1) predictors of being lost to follow-up at wave 2 included being black (*P*<.001); having parents' with an advanced degree (*P*<.001); seeking an associate's or bachelor's degree (*P*<.001); not residing on campus (*P*<.001); past 30-day tobacco use (*P*<.001), specifically cigarette (*P*<.001), hookah (*P*=.024), and little cigar and cigarillo (*P*<.001) use; and attending an urban college, a nonprivate college, and college with smaller student populations (ie, ≤10,000 students; *P*<.001).

Results from the model building process are found in Tables 2 and 3. First, the unconditional model containing no predictors was fit. Covariance parameter estimates indicated an ICC of 10.1%, indicating that 10.1% of the variability in nonresponse was due to between-school-level characteristics. Model selection criteria and likelihood ratio tests using deviance statistics indicated that model fit increased significantly when comparing the model containing individual predictors only (*P*<.001) and institutional predictors only (*P*<.001) to the unconditional model. The full model containing all predictors was tested against the individual level model and had significantly better fit (*P*<.001). The Akaike information criterion (AIC) and the Bayesian information criterion (BIC) fit statistics were consistent with these findings. Given the optimal fit of the full model, the parameter estimates of the full model are interpreted. Predictors of nonresponse were similar in the models examining individual-level factors and institutional-level factors only, respectively, and included being black (vs white; OR 1.74, CI 1.23-2.46); being male (vs female; OR 1.41, CI 1.10-1.79); seeking a bachelor's degree (vs advanced degree; OR 1.41, CI 1.09-1.83); not residing on campus (vs residing on campus; OR 0.62, CI 0.46-0.84); past 30-day tobacco use (vs nonuse; OR 1.41, CI 1.10-1.78); attending a nonprivate college (vs a private college; OR 0.48, CI 0.33-0.71); and attending a college with <10,000 students (vs a college with >10,000 students; OR 0.56, CI 0.43-0.73).

Table 1. Descriptive characteristics and bivariate associations of institutional and individual factors associated with nonresponse at wave 2 among young adults in a longitudinal cohort study.

Variables	Overall sample (N=3189)	Responders (n=2770)	Nonresponders (n=419)	*P* value[a]
	n (%)	n (%)	n (%)	
Individual level				
Age (mean, SD)	20.54 (1.96)	20.53 (1.93)	20.60 (2.13)	.35
Race				<.001
White	2010 (63.03)	1795 (64.80)	215 (51.31)	
Black	793 (24.87)	634 (22.89)	159 (37.95)	
Other	386 (12.10)	341 (12.31)	45 (10.74)	
Sex				.94
Female	2053 (64.38)	1784 (64.40)	269 (64.20)	
Male	1136 (35.62)	986 (35.60)	150 (35.80)	
Parental education				<.001
No college degree	864 (27.09)	781 (28.19)	83 (19.81)	
Bachelor's degree	1098 (34.43)	962 (34.73)	136 (32.46)	
Advanced degree	1227 (38.48)	1027 (37.08)	200 (47.73)	
Degree sought				<.001
≤Associate’s degree	226 (7.09)	182 (6.57)	44 (10.50)	
Bachelor’s degree	652 (20.45)	537 (19.39)	115 (27.45)	
Advanced degree	2311 (72.47)	2051 (74.04)	260 (62.05)	
Reside on campus	1397 (43.81)	1266 (45.70)	131 (31.26)	<.001
Past 30-day tobacco use	949 (29.76)	828 (29.89)	184 (43.91)	<.001
Past 30-day use by product				
Cigarettes	421 (13.20)	344 (12.42)	77 (18.38)	<.001
E-cigarettes	345 (10.82)	290 (10.47)	55 (13.13)	.10
Hookah	419 (13.14)	329 (11.88)	74 (17.66)	.02
Little cigars/cigarillos	363 (11.38)	289 (9.35)	74 (17.66)	<.001
Smokeless tobacco	114 (3.57)	97 (3.50)	17 (4.06)	.57
Past 30-day alcohol use	2019 (63.31)	1743 (62.92)	276 (65.87)	.24
Institutional level				
Urban school (vs rural)	1218 (38.19)	1003 (36.21)	215 (51.31)	<.001
Private school (vs other)	1236 (38.76)	1155 (41.70)	81 (19.33)	<.001
Student population >10,000	1412 (44.28)	1271 (45.88)	141 (33.65)	<.001

[a] *P* value comparing responders and nonresponders using Student *t* test for continuous variables and chi-squared for categorical variables.

[b] Those who answered “don’t know,” “refuse,” or were in a respondent group with very small cell size for one or multiple covariates (N=229) were coded missing for the analytic sample. Missing values occurred for Parental education (N=48), Race (N=45), Degree sought (N=158), Sex (N=4 reporting “other”), and School (N=74).

Table 2. Results from a multilevel model assessing institutional and individual factors associated with nonresponse at wave 2 among young adults in a longitudinal cohort study (n=3189).

Variables	Unconditional model	Individual level	Institutional level	Full model
	OR[a] (95% CI)	OR[a] (95% CI)	OR[a] (95% CI)	OR[a] (95% CI)
Individual level				
Age		0.94 (0.89-1.00)		0.95 (0.89-1.01)
Race				
White		ref		ref
Black		1.57[b] (1.14-2.16)		1.74[b] (1.23-2.46)
Other		1.30 (0.90-1.87)		1.43 (0.99-2.05)
Sex				
Female		ref		ref
Male		1.36[b] (1.07-1.74)		1.41[b] (1.10-1.79)
Parental education				
No college degree		1.02 (0.75-1.39)		0.97 (0.72-1.32)
Bachelor’s degree		1.01 (0.74-1.38)		0.97 (0.71-1.31)
Advanced degree		ref		ref
Degree sought				
<Associate’s degree		1.05 (0.69-1.60)		1.01 (0.68-1.52)
Bachelor’s degree		1.46[b] (1.22-1.90)		1.41[b] (1.09-1.83)
Advanced degree		ref		ref
Reside on campus		0.62[b] (0.46-0.85)		0.62[b] (0.46-0.84)
Past 30-day tobacco use		1.42[b] (1.12-1.80)		1.41[b] (1.10-1.78)
Past 30-day alcohol use		1.14 (0.89-1.47)		1.14 (0.89-1.45)
Institutional level				
Urban school (vs rural)			1.14 (0.74-1.79)	1.05 (0.75-1.47)
Private school (vs other)			0.37[b] (0.22-0.60)	0.48[b] (0.33-0.71)
Student population >10,000			0.59[b] (0.41-0.86)	0.56[b] (0.43-0.73)

[a] OR: odds ratio.

[b] $P<.05$.

Table 3. Model fit from a multilevel model assessing institutional and individual factors associated with nonresponse at wave 2 among young adults in a longitudinal cohort study (n=3189).

Model fit criteria	Unconditional model	Individual level	Institutional level	Full model
τ_{00}	0.3694	0.2112	0.0417	0.0014
Reduction in τ_{00}	ref	51.0%	89.6%	99.4%
Deviance	2547.55	2336.54	2534.65	2321.32
Akaike information criterion	2551.55	2362.54	2544.65	2353.32
Bayesian information criterion	2551.44	2361.84	2544.38	2352.46
χ^2 (degrees of freedom = 14)	ref	211.0[a]	12.90[a]	15.2

[a] $P<.05$.

Discussion

Principal Findings

This study investigated individual- and institutional-level predictors of dropouts from a longitudinal survey in a diverse sample of students enrolled in universities of various types. Previous literature showed that dropping out was related to a few key factors relevant to this study, including survey topic salience [13,17-20], behaviors related to the survey topic [13,17-20], participant sociodemographics [9,17,21-25], and institutional factors [24-26].

The results of the multilevel model indicated that 30-day tobacco use predicted nonresponse at wave 2. This finding is consistent with survey attrition research conducted with young adults in the general population [18] although the subject matter of these studies was not primarily concerned with tobacco use, or they studied unique populations such as young adult military personnel. It is unique in its relevancy to college students participating in a study primarily concerned with tobacco use, and it rejects the idea that student's dropping out is largely because of a lack of interest or relevance with regard to the survey topic. Instead, attrition could be related to feelings of stigmatization as a tobacco user in a less socially acceptable setting or some other unmeasured factor; that is, young adults may attempt to avoid cognitive dissonance related to either not reporting their behaviors because of stigmatization or related to reporting behaviors that are stigmatized. It is also unique in its consideration of contextual- and institutional-level factors such as school size, school type, and urban rural status.

At the individual level, many of our findings were consistent with previous literature. For instance, higher odds of nonresponse were seen in blacks and in men; similar results that have been replicated in many different samples of college students [17,23-25]. We also found that, compared with those seeking an advanced degree, those seeking a bachelor's degree–but not those seeking an associate's degrees–were more likely to be lost at follow-up, indicating a curvilinear relationship. This finding warrants further examination but may be related to parental education and reflects financial motivation because of potentially being from a lower socioeconomic background (which was significant in the bivariate but not multivariate analyses); this is particularly compelling, given that the degree sought and parental education are correlated in this sample. Additionally, those living off campus were more likely to be nonresponders at wave 2, which aligned with our hypotheses.

Institutional variables also accounted for varying levels of nonresponse. For example, private schools exhibited lower odds of nonresponse compared with public schools. In our sample, private schools had smaller student populations, which were predictive of responding at wave 2, which is consistent with prior findings. School's urban or rural status was not associated with nonresponse. This, however, could be because of the relatively small number of schools and should be investigated with a more representative sample.

Study Strengths and Limitations

In terms of strengths, selecting from a diverse group of schools and participants provided a heterogeneous sample relative to many other studies of student populations, including students of different races and ethnicities, urban and rural status, and socioeconomic status. Furthermore, the use of individual- and institutional-level variables has been rare in studies of cross-sectional and longitudinal nonresponse, particularly, in studies of students' tobacco and substance use, and our analysis of both levels is important for building a greater understanding regarding the factors that are most impactful when college students are deciding to continue participating in a tobacco use study.

However, a small number of schools were used to predict school characteristics associated with nonresponse, given that this was a secondary analysis of data. Although simulation studies have shown that inferences can still be drawn with a low number of area-level units [28], caution should be exercised in drawing conclusions from these results. Second, certain covariates utilized measurement scales available for a secondary data analysis, such as parental education as a proxy for socioeconomic status; alternative methods should be used to explore these associations further. Additionally, although institutional variables were included, the nature of community or technical colleges may account for unexplained variance (eg, socioeconomic status and residential differences); this could be explored in future studies. Additionally, other factors such as college major, jobs, and extracurricular activities may have been relevant; however, these factors are difficult variables to operationalize given their variety (and instability). Lastly, this study analyzed dropout between two subsequent waves of a longitudinal study, and future studies should attempt to assess dropouts across multiple waves to determine whether predictors attrition remain the same or differ across different intervals of time (eg, 4-months vs 1-year). Given the desire to understand participant's dropping out early on in the data collection phase, this analysis focused on the first two waves. Although the analysis of dropout between all waves is recommended, the authors felt this initial approach would be very informative, given the current limitations in the literature.

Conclusions and Future Directions

This study indicated that, in addition to individual and institutional factors previously explored in the literature, tobacco use at baseline predicted subsequent attrition at the follow-up assessment. Future studies should replicate these results in a broader sample of students and colleges not confined to one state. Although we obtained sufficient samples from each of our seven schools, replication of these findings in large samples and across other areas of the United States could potentially add to the knowledge of what predicts nonresponse in tobacco use studies in contextual settings. Additionally, this analysis highlights the need to understand both individual and contextual factors (including research topic and incentives for participation) that may have strong effects on decisions to continue participation in a survey study. Understanding these factors will allow for superior methods of tailoring recruiting efforts to those at highest risk of nonresponse and preventing bias due to systematic dropout in longitudinal studies. Moreover, these findings have implications for how such data are interpreted and also highlight the need to examine the impact of nonresponse over the course of such longitudinal studies. These efforts will assist researchers in decreasing study bias and developing best practices to decrease smoking and other substance use behaviors in college students, a vulnerable population to these behaviors.

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Abbreviations

DECOY: Documenting Experiences with Cigarettes and Other Tobacco in Young Adults
ICC: intraclass correlation coefficient
OR: odds ratio

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Original Paper

Effects of the Ambient Fine Particulate Matter on Public Awareness of Lung Cancer Risk in China: Evidence from the Internet-Based Big Data Platform

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Abstract

Background: In October 2013, the International Agency for Research on Cancer classified the particulate matter from outdoor air pollution as a group 1 carcinogen and declared that particulate matter can cause lung cancer. Fine particular matter ($PM_{2.5}$) pollution is becoming a serious public health concern in urban areas of China. It is essential to emphasize the importance of the public's awareness and knowledge of modifiable risk factors of lung cancer for prevention.

Objective: The objective of our study was to explore the public's awareness of the association of $PM_{2.5}$ with lung cancer risk in China by analyzing the relationship between the daily $PM_{2.5}$ concentration and searches for the term "lung cancer" on an Internet big data platform, Baidu.

Methods: We collected daily $PM_{2.5}$ concentration data and daily Baidu Index data in 31 Chinese capital cities from January 1, 2014 to December 31, 2016. We used Spearman correlation analysis to explore correlations between the daily Baidu Index for lung cancer searches and the daily average $PM_{2.5}$ concentration. Granger causality test was used to analyze the causal relationship between the 2 time-series variables.

Results: In 23 of the 31 cities, the pairwise correlation coefficients (Spearman rho) between the daily Baidu Index for lung cancer searches and the daily average $PM_{2.5}$ concentration were positive and statistically significant ($P<.05$). However, the correlation between the daily Baidu Index for lung cancer searches and the daily average $PM_{2.5}$ concentration was poor (all $r^2_s<.1$). Results of Granger causality testing illustrated that there was no unidirectional causality from the daily $PM_{2.5}$ concentration to the daily Baidu Index for lung cancer searches, which was statistically significant at the 5% level for each city.

Conclusions: The daily average $PM_{2.5}$ concentration had a weak positive impact on the daily search interest for lung cancer on the Baidu search engine. Well-designed awareness campaigns are needed to enhance the general public's awareness of the association of $PM_{2.5}$ with lung cancer risk, to lead the public to seek more information about $PM_{2.5}$ and its hazards, and to cope with their environment and its risks appropriately.

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KEYWORDS

lung cancer; risk factors; particulate matter; PM2.5; Baidu Index; information seeking behavior; public awareness; China

Introduction

Air pollution has become the most severe and worrisome environmental problem and a major threat to public health in China [1-4]. The daily concentration of ambient fine particulate matter <5 μm in diameter ($PM_{2.5}$) and its negative consequences are major public health concerns in China [5-7]. According to the Global Burden of Diseases Study, $PM_{2.5}$ concentration has been the fifth-ranking mortality risk factor, an estimated 4.2 million deaths were attributed to $PM_{2.5}$ around the globe in 2015, and $PM_{2.5}$ contributed to 1.1 million deaths in China in 2015 [8]. In 194 Chinese cities, the total estimated premature deaths and lung cancer deaths attributed to $PM_{2.5}$ pollution were 722,370 and 67,452, respectively, in 2014 and 2015 [5]. The estimated per capita mortality attributable to air pollution by 2050 was projected to be even higher in Chinese megacities [9].

Lung cancer is the most common incident cancer and the leading cause of cancer death in China. New cancer cases and cancer deaths were estimated to be 733,000 and 591,000, respectively, every year [10]. The International Agency for Research on Cancer has classified particulate matter from outdoor air pollution as a group 1 carcinogen that can cause lung cancer [11]. Many studies found that exposure to $PM_{2.5}$ was an important risk factor for lung cancer [12-17]. Increasing the public's awareness of lung cancer is important for early detection, diagnosis, and intervention of lung cancer.

With the development of a well-established network, the Internet has become a vital channel for the public to access health information. About 63% of cancer patients use the Internet to search for information regarding cancer specifically, and use of the Internet as a source for oncological information is increasing rapidly [5,18,19]. Previous studies have demonstrated that network tools such as Twitter or Google can be used to examine public interest in disease epidemics and to perform disease surveillance, by tracking health-seeking behaviors [20-24].

Baidu is one of the most important Internet big data platforms in China. According to the Chinese Internet Users Search Behavior Study, the Baidu search engine is the most popular among Chinese Internet users, with a priority selection incidence of 93.1% [25]. The Baidu Index stems from search frequencies on the Baidu search engine, and is calculated and displayed on the basis of special keywords by search volume used by netizens on the Baidu search engine. The Baidu Index can serve as a data source for determining the awareness of Internet users on specific topics.

Using the Baidu Index, we examined Chinese public search interest in lung cancer. The goal of this study was to explore public awareness of the association of $PM_{2.5}$ with lung cancer risk by analyzing the relationship between daily $PM_{2.5}$ concentration and daily Baidu Index searches for the term "lung cancer" in China.

Methods

Air Pollution Data

We collected air pollution data from the Chinese Air Quality Online Monitoring and Analysis Platform [26], which began air quality monitoring in 2013 for all major Chinese cities. We extracted daily average $PM_{2.5}$ concentration data of 31 Chinese capital cities from January 1, 2014 to December 31, 2016.

Search Data

The Baidu Index is a useful tool to process and analyze search query data. Its database contains logs of online and mobile phone search query volume submitted from January 2011. The daily Baidu Index is the weighted sum of the search frequency for a keyword based on its daily search volume on the Baidu search engine. The Baidu Index has been proved to be a useful indicator of public interest in and awareness of health-related topics. In this study, we hypothesized that the Baidu Index would offer potential insight into the general population's awareness of lung cancer. The conceptualized awareness of lung cancer in this study could be considered to be based on the general population's ability to seek knowledge and information for the disease or pay attention to the disease. We used the Baidu Index to determine the relevance of the search term "lung cancer" as an indicator of the public's awareness of lung cancer. We collected daily Baidu Index data from the Baidu Index websites [27] for the search term "肺癌" (lung cancer) in Chinese for each of 31 Chinese capital cities from January 1, 2014 to December 31, 2016.

Baidu Media Data

The Baidu media index is the number of news items containing a specified keyword in their headlines collected by the Baidu news database, sourced from Chinese major websites, including national and local news websites and networks. We collected daily Baidu media index data for the keyword "lung cancer" from the Baidu Index websites [27] from January 1, 2014 to December 31, 2016.

Statistical Analyses

We calculated descriptive statistics for the 2 variables. These included the mean, standard deviation, median and interquartile range, and the minimum and maximum values of both variables.

We used the Kruskal-Wallis *H* test to examine differences in the daily Baidu Index for lung cancer searches across all cities by month, season, year, and city, separately. We examined the differences in daily $PM_{2.5}$ concentration using the same method.

We used Spearman and Pearson correlation analyses to explore the correlation between the daily Baidu Index for lung cancer searches, daily Baidu media index for lung cancer, and daily average $PM_{2.5}$ concentration, with the statistical significance level set at .01. We calculated Pearson partial correlation coefficients to assess the intercorrelations between the Baidu Index, Baidu media index, and daily $PM_{2.5}$ concentration.

Multiple linear regression analysis explored the potential influence of the daily Baidu media index for lung cancer and daily average $PM_{2.5}$ concentration on the daily Baidu Index for lung cancer searches.

Granger causality is a concept of causality derived from the idea that causes cannot occur after effects and that, if one variable is the cause of another, knowing the status of the cause at an earlier point in time can enhance prediction of the effect at a later point in time [28]. We used the Granger causality test to analyze whether there was a causal relationship between the 2 time-series variables. We conducted the Engle-Granger test to examine whether there was co-integration or a long-term association between the 2 time series [29]. In the first step, we used unit root tests to examine whether the time series of the Baidu Index for lung cancer searches and the time series of daily $PM_{2.5}$ concentration were stationary. If the 2 time series were both stationary at the same level, then we estimated the co-integrating regression model using ordinary least squares. We used the daily Baidu Index for lung cancer searches as the dependent variable and the daily average $PM_{2.5}$ concentration as the independent variable. We estimated regression coefficients to assess the effect of daily average $PM_{2.5}$ concentration on the daily Baidu Index for lung cancer searches. In the second step, we used unit root tests to examine whether the residual series of the co-integrating regression model was stationary, which would indicate that the 2 time-series variables were co-integrated, which satisfies the precondition of the Granger causality test. Then, we performed the Granger causality test.

We conducted the descriptive statistics, Kruskal-Wallis H test, and Spearman correlation analysis in IBM SPSS version 19.0 (IBM Corporation), and the Granger causality test using EViews 9 student version (IHS Global Inc).

Results

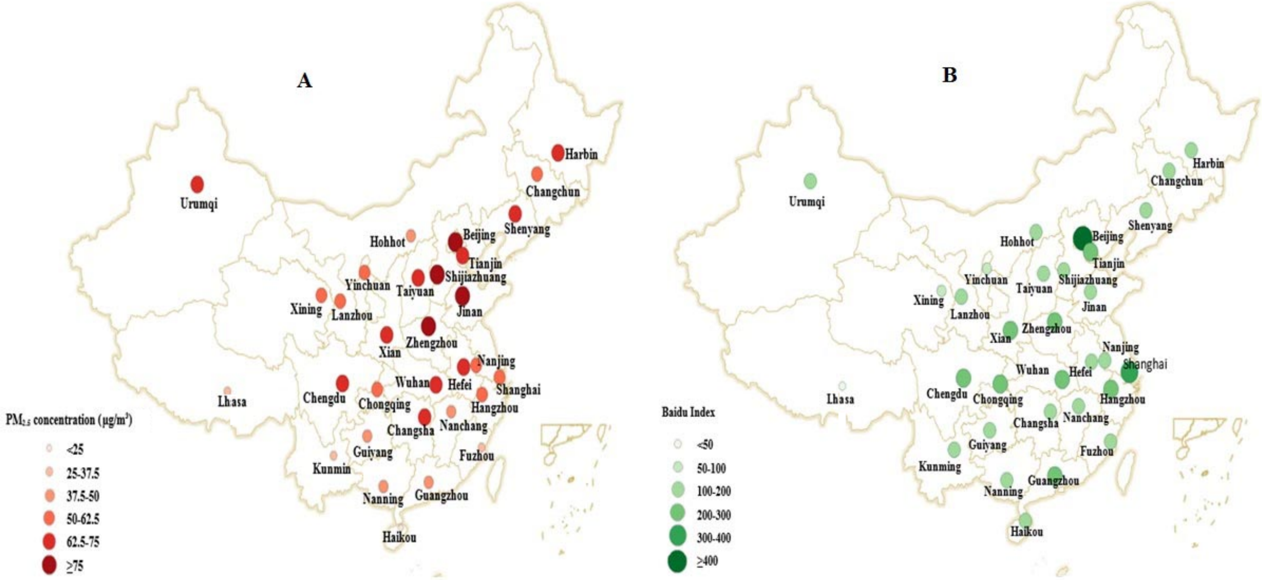
Descriptive Analysis

Table 1 shows the mean and median of the daily Baidu Index for lung cancer searches and daily average $PM_{2.5}$ concentration for each of 31 Chinese cities over the period from January 1, 2014 to December 1, 2016. The mean daily average $PM_{2.5}$ concentration across all cities was 57.37 (SD 47.54) μg/m^3. For air pollution, Shijiazhuang city in Hebei Province ranked first among the 31 cities, with a mean daily average $PM_{2.5}$ concentration of 104.01 (SD 88.55) μg/m^3, and Haikou city in Hainan Province ranked last, with a mean daily average $PM_{2.5}$ concentration of 21.64 (SD 15.2) μg/m^3. In our data, the highest daily average $PM_{2.5}$ concentration was 897.5 μg/m^{3}in Shenyang on November 8, 2015, whereas the lowest was 2.5 μg/m^{3}in Nanjing on September 16, 2016. The mean daily Baidu Index for lung cancer searches was 180 (SD 83.21) across all cities; that is, there were on average 180 searches daily for the term “lung cancer” from January 1, 2014 to December 31, 2016. The mean of daily Baidu Index for lung cancer searches in Beijing was 408 (SD 69.53) and ranked first among the 31 cities. On May 16, 2016, the daily Baidu Index for lung cancer searches for Beijing peaked at 1185, which was the highest of all Baidu Index data points. The Baidu Index data scale ranged from 0 to 1185, with a median of 73 during the study period. Across all cities, there were significant differences in the daily Baidu Index for lung cancer searches and daily average $PM_{2.5}$ concentration by month, season, year, and city, separately (all *P*<.05).

Table 1. Summary statistics of daily average fine particulate matter ($PM_{2.5}$) concentration and daily Baidu Index for the search term “lung cancer” in 31 Chinese capital cities from January 1, 2014 to December 31, 2016.

City	Daily Baidu Index for lung cancer searches		Daily average $PM_{2.5}$ concentration (μg/m^3)	
	Mean (SD)	Median (25th, 75th percentile)	Mean (SD)	Median (25th, 75th percentile)
Beijing	408 (69.53)	91 (366, 441)	79.23 (68.25)	60.85 (29.9, 106.43)
Changchun	146 (28.52)	74 (139, 162)	58.68 (50.44)	43.25 (28.43, 72.38)
Changsha	195 (31.42)	75.5 (178, 216)	62.8 (39.91)	52.15 (36, 79.2)
Chengdu	277 (58.8)	80 (236,308)	65.9 (44.22)	53.35 (35.53, 82.98)
Chongqing	208 (24.63)	71 (194, 222)	57.24 (34.19)	47.3 (33.9, 68.98)
Fuzhou	165 (28.19)	52 (151, 180)	29.17 (16.14)	26 (18.5, 36.1)
Guangzhou	285 (40.96)	55.5 (258.25, 306.75)	40.78 (21.95)	35.8 (24.4, 51.78)
Guiyang	122 (29.93)	56.5 (87, 143)	40.13 (21.75)	35.9 (24.73, 49.28)
Harbin	168 (24.36)	67 (159, 182)	64.39 (65.96)	40.95 (24.13, 83.48)
Haikou	111 (30.37)	35 (76, 135)	21.64 (15.2)	16.3 (12.3, 26.5)
Hangzhou	250 (42.41)	72 (219.25, 278.75)	55.23 (30.74)	48.9 (33, 70.28)
Hefei	188 (31.58)	85 (171, 209)	67.45 (41.39)	58.2 (41.03, 83.35)
Hohhot	124 (30.98)	74 (91, 146)	42.24 (33.96)	32.05 (19.2, 55.3)
Jinan	196 (29.76)	111 (177, 214)	85.06 (51.35)	73.3 (51.83, 103.28)
Kunming	157 (27.95)	51 (148, 173)	29.79 (13.25)	27.25 (19.9, 37.15)
Lanzhou	117 (32.65)	83 (83, 146)	54.06 (28.25)	46.2 (35.73, 65)
Lhasa	26 (31.4)	57 (0, 57)	25.17 (12.11)	22 (16.5, 30.3)
Nanchang	149 (32.31)	63 (137, 167)	45.21 (30.93)	37.1 (23.5, 57.68)
Nanjing	189 (25.97)	78 (173, 205)	58.49 (38.18)	49.65 (31.03, 76.25)
Nanning	143 (29.23)	57 (133, 161)	41.91 (28.42)	34.15 (22, 53.5)
Shanghai	335 (52.13)	64 (303, 358)	50.17 (32.09)	42.15 (27.2, 65)
Shenyang	171 (25.25)	82 (156, 188)	65.68 (54.92)	49.6 (33.6, 82.43)
Shijiazhuang	176 (32.92)	115 (158, 200)	104.01 (88.55)	80.25 (43.53, 131.1)
Taiyuan	150 (32.5)	88 (137, 171)	64.81 (45.83)	53.15 (32.8, 83.33)
Tianjin	204 (24.9)	90 (186, 220)	74.63 (53.61)	60.6 (37.33, 95.08)
Urumqi	116 (29.92)	87 (82, 139)	66.97 (61.11)	41.65 (27.6, 82.28)
Wuhan	227 (26.54)	87 (212.25, 240)	69.48 (46.95)	58.9 (38.13, 86.28)
Xian	207 (29.64)	87 (192, 223)	68.3 (54.44)	51.35 (35.2, 79.1)
Xining	73 (29.5)	80 (59, 74)	52.63 (24.34)	47.35 (35.73, 65.05)
Yinchuan	82 (30.54)	76 (61, 118)	50.04 (31.12)	40.9 (30.13, 58.38)
Zhengzhou	223 (29.74)	107 (203, 242)	87.02 (61.2)	71.4 (46.8, 108.78)
All cities	180 (83.21)	73 (136, 218)	57.37 (47.54)	44 (27.6, 71.3)

Figure 1. Distribution of (A) mean daily average fine particulate matter ($PM_{2.5}$) concentration and (B) mean daily Baidu Index for the search term "lung cancer" in 31 Chinese capital cities, January 1, 2014 to December 31, 2016.



Compared with 2014, the Baidu Index for lung cancer searches across all cities for 2015 and 2016 decreased by 2% and 5%, respectively. The annual mean daily average $PM_{2.5}$ concentration had decreased slightly from 2014 to 2016. The Baidu media index for lung cancer ranged from 0 to 6523, with a median of 9 (25th, 75th percentile 4, 14) in 2016. The Baidu media index for lung cancer peaked on September 17, 2015. Figure 1 shows the distributions of mean daily average $PM_{2.5}$ concentration and mean daily Baidu Index for lung cancer searches in the 31 Chinese capital cities during the study period.

Correlation Analysis

Except for Chengdu and Hohhot, the pairwise correlation coefficients (Spearman rho) between the daily Baidu Index for lung cancer searches and daily average $PM_{2.5}$ concentration were positive. Most of the Spearman rank correlation coefficients were statistically significant ($P<.05$). However, the correlations between the daily Baidu Index for lung cancer searches and daily average $PM_{2.5}$ concentration was poor (all $r^2_s<.1$) (Table 2). The top 3 correlations were .240 for Hangzhou, .238 for Zhengzhou, and .231 for Hefei (All $P<.001$). For all cities, there was a positive correlation between the daily Baidu Index for lung cancer searches and daily $PM_{2.5}$ concentration ($\rho=.247$, $P<.001$). Multimedia Appendix 1 shows the results of Pearson correlation analysis and Multimedia Appendix 2 shows the results of multiple linear regression analysis. The correlation between daily $PM_{2.5}$ concentration and the daily Baidu Index for lung cancer searches was more than that between daily $PM_{2.5}$ and daily Baidu media index. When the daily Baidu media index for lung cancer was the control variable, the partial correlation coefficient for each city, between the daily Baidu Index for lung cancer searches and the daily average $PM_{2.5}$ concentration, was almost equal to the Pearson correlation coefficient. The daily Baidu media index for lung cancer had little influence on the relationship between the daily Baidu Index for lung cancer searches and daily average $PM_{2.5}$ concentration according to the partial correlation coefficients. Overall, both the correlation and intercorrelation between the daily Baidu Index for lung cancer searches, daily Baidu media index, and daily $PM_{2.5}$ concentration were poor.

Granger Causality

We used the augmented Dickey-Fuller unit root test to test the stationarity of the 2 time series. The lag length was determined automatically using the Schwarz information criterion. The series for all cities except Chengdu were stationary at the statistical significance level set at .01, and the series for Chengdu were also stationary at the first difference (Table 3). Since the series for each city were found to be stationary at the same level, therefore, the 2 variables satisfied the precondition of co-integration and were checked for a long-term co-integration relationship.

Table 2. Spearman correlation between daily Baidu Index for the search term “lung cancer,” daily Baidu media index, and daily fine particulate matter ($PM_{2.5}$) concentration.

City	Correlation					
	Baidu Index & $PM_{2.5}$		Baidu Index & Baidu media index		Baidu media index & $PM_{2.5}$	
	r_s	*P* value	r_s	*P* value	r_s	*P* value
Beijing	.093[a]	.002	.359[a]	<.001	–.013	.68
Changchun	.060[b]	.048	.167[a]	<.001	.122[a]	<.001
Changsha	.184[a]	<.001	.196[a]	<.001	.047	.12
Chengdu	–.041	.17	.006	.84	.026	.40
Chongqing	.139[a]	<.001	.189[a]	<.001	–.015	.62
Fuzhou	.125[a]	<.001	.191[a]	<.001	.099[a]	.001
Guangzhou	.167[a]	<.001	.303[a]	<.001	.003	.93
Guiyang	.062[b]	.04	.096[a]	.001	.029	.34
Harbin	.219[a]	<.001	.269[a]	<.001	.145[a]	<.001
Haikou	.091[a]	.002	.164[a]	<.001	–.018	.55
Hangzhou	.240[a]	<.001	.253[a]	<.001	.133[a]	<.001
Hefei	.231[a]	<.001	.225[a]	<.001	.098[a]	.001
Hohhot	.036	.23	.188[a]	<.001	.028	.36
Jinan	.149[a]	<.001	.164[a]	<.001	.052	.09
Kunming	.024	.42	.081[a]	.007	.031	.30
Lanzhou	.057	.06	.149[a]	<.001	.046	.13
Lhasa	.001	.98	.039	.19	.123[a]	<.001
Nanchang	.118[a]	<.001	.228[a]	<.001	.047	.12
Nanjing	.220[a]	<.001	.232[a]	<.001	.125[a]	<.001
Nanning	.039	.19	.165[a]	<.001	–.005	.87
Shanghai	.050	.10	.269[a]	<.001	.115[a]	<.001
Shenyang	.100[a]	.001	.276[a]	<.001	.103[a]	.001
Shijiazhuang	.204[a]	<.001	.179[a]	<.001	.030	.33
Taiyuan	.088[a]	.003	.218[a]	<.001	.027	.38
Tianjin	.085[a]	.005	.290[a]	<.001	.037	.22
Urumqi	.153[a]	<.001	.115[a]	<.001	.058	.06
Wuhan	.154[a]	<.001	.201[a]	<.001	.055	.07
Xian	.111[a]	<.001	.253[a]	<.001	.035	.25
Xining	.081[a]	.007	.105[a]	.001	.109[a]	<.001
Yinchuan	–.012	.68	.102[a]	.001	.012	.69
Zhengzhou	.238[a]	<.001	.277[a]	<.001	.085[a]	.005

[a] Correlation is significant at the .01 level (2-tailed).

[b] Correlation is significant at the .05 level (2-tailed).

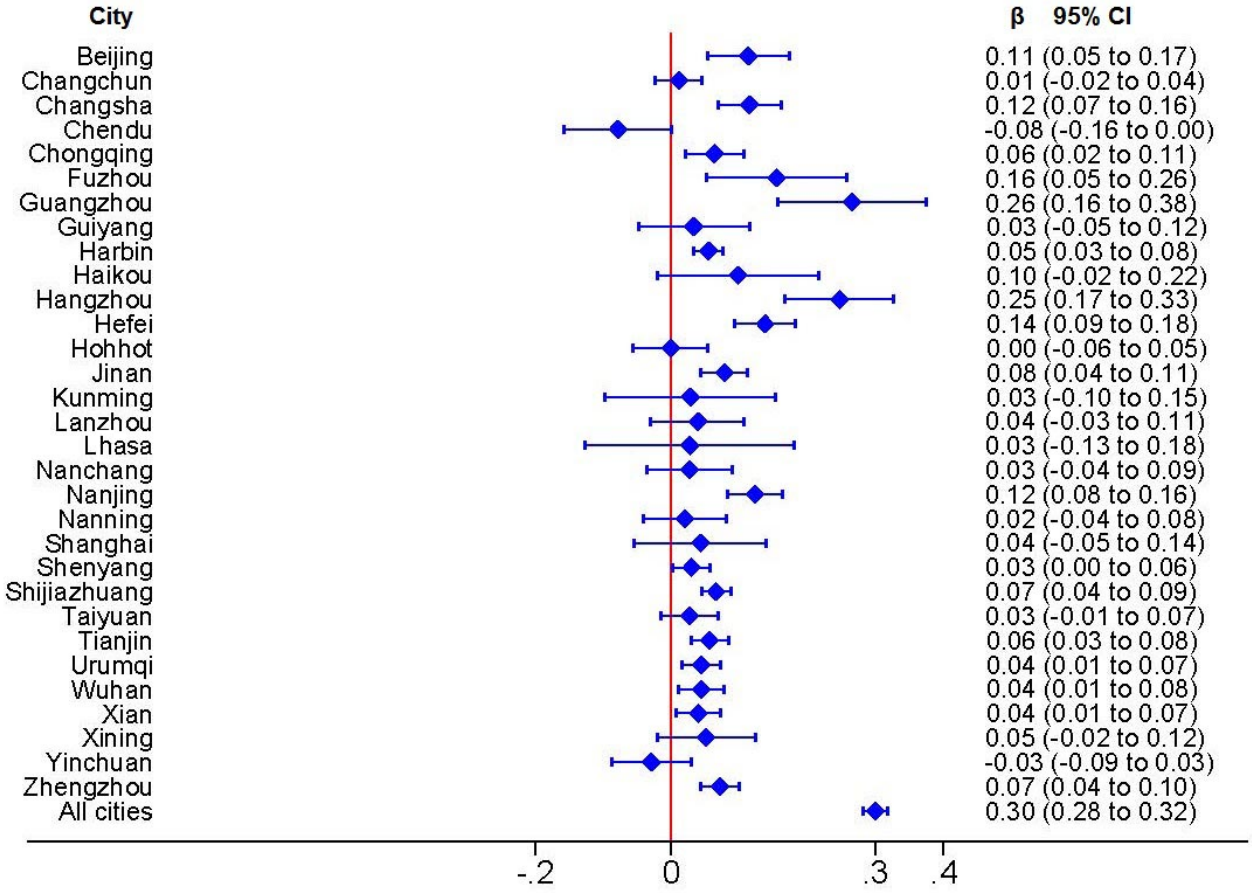
Table 3. Results of unit root tests for the time series of daily average fine particulate matter ($PM_{2.5}$) concentration and daily Baidu Index for the search term “lung cancer.”

City	Unit root test for time series of daily Baidu Index for lung cancer searches			Unit root test for time series of daily $PM_{2.5}$ concentration			Result[a]
	ADF[b]	1% Level	*P* value	ADF	1% Level	*P* value	
Beijing	–5.23	–3.44	<.001	–18.44	–3.44	<.001	Stationarity
Changchun	–7.83	–3.44	<.001	–7.32	–3.44	<.001	Stationarity
Chengdu	–23.41	–3.44	<.001	–17.18	–3.44	<.001	Stationarity
Chongqing	–5.70	–3.44	<.001	–10.18	–3.44	<.001	Stationarity
Changsha	–5.25	–3.44	<.001	–9.76	–3.44	<.001	Stationarity
Fuzhou	–5.00	–3.44	<.001	–8.88	–3.44	<.001	Stationarity
Guiyang	–29.62	–3.44	<.001	–8.78	–3.44	<.001	Stationarity
Guizhou	–6.01	–3.44	<.001	–13.39	–3.44	<.001	Stationarity
Harbin	–7.21	–3.44	<.001	–6.49	–3.44	<.001	Stationarity
Hefei	–4.50	–3.44	<.001	–7.13	–3.44	<.001	Stationarity
Hohhot	–27.24	–3.44	<.001	–4.58	–3.44	<.001	Stationarity
Haikou	–30.13	–3.44	<.001	–10.92	–3.44	<.001	Stationarity
Hangzhou	–3.79	–3.44	<.001	–4.53	–3.44	<.001	Stationarity
Jinan	–5.10	–3.44	<.001	–15.65	–3.44	<.001	Stationarity
Kunming	–7.64	–3.44	<.001	–9.28	–3.44	<.001	Stationarity
Lhasa	–4.33	–2.57	<.001	–4.24	–3.44	<.001	Stationarity
Lanzhou	–28.38	–3.44	<.001	–5.47	–3.44	<.001	Stationarity
Nanchang	–7.17	–3.44	<.001	–10.42	–3.44	<.001	Stationarity
Nanjing	–5.60	–3.44	<.001	–6.29	–3.44	<.001	Stationarity
Nanning	–7.48	–3.44	<.001	–7.62	–3.44	<.001	Stationarity
Shanghai	–5.68	–3.44	<.001	–18.64	–3.44	<.001	Stationarity
Shijiazhuang	–4.58	–3.44	<.001	–4.71	–3.44	<.001	Stationarity
Shenyang	–5.23	–3.44	<.001	–12.08	–3.44	<.001	Stationarity
Tianjin	–5.84	–3.44	<.001	–6.99	–3.44	<.001	Stationarity
Taiyuan	–5.80	–3.44	<.001	–4.69	–3.44	<.001	Stationarity
Wuhan	–5.47	–3.44	<.001	–4.38	–3.44	<.001	Stationarity
Xian	–5.20	–3.44	<.001	–4.31	–3.44	<.001	Stationarity
Xining	–30.74	–3.44	<.001	–5.49	–3.44	<.001	Stationarity
Yinchuan	–19.20	–3.44	<.001	–10.21	–3.44	<.001	Stationarity
Zhengzhou	–5.16	–3.44	<.001	–5.44	–3.44	<.001	Stationarity

[a] Time series of daily average $PM_{2.5}$ concentration and of daily Baidu Index for lung cancer were stationary at the same level.

[b] ADF: augmented Dickey-Fuller unit root test.

Figure 2. Estimate of regression coefficient (β) with 95% CI.



For 17 of the 31 Chinese capital cities, regression analysis revealed that the positive effects of daily average $PM_{2.5}$ concentration on the daily Baidu Index for lung cancer searches were statistically significant (Figure 2). We observed the strongest relationship in Guangzhou as indicated by a regression coefficient of 0.26 (95% CI 0.16-0.38). The effect of daily average $PM_{2.5}$ concentration was negative in Chengdu and Yinchuan, but was not statistically significant, with a regression coefficient of –0.08 (95% CI –0.16 to 0) for Chengdu and –0.03 (95% CI –0.09 to 0.03) for Yinchuan. For all cities, the regression coefficient was 0.30 (95% CI 0.28-0.32). Overall, the relationship between daily average $PM_{2.5}$ concentration and the daily Baidu Index for lung cancer searches was modest.

The result of the panel co-integration (Engle-Granger) test indicated the existence of co-integration between variables for each city at the 1% significance level (Table 4). The co-integration test revealed the existence of a long-term relationship between variables but did not indicate the direction of the causal relationship. The results of the Granger causality test suggested the absence of a unidirectional causality from $PM_{2.5}$ to the Baidu Index, which was statistically significant at the 5% level for all cities (Table 5).

Table 4. Results of co-integration test of the 2 time series of daily average fine particulate matter ($PM_{2.5}$) concentration and daily Baidu Index for the search term “lung cancer.”

City	Unit root test for the residual series					Result[a]
	ADF[b]	1% Level	5% Level	10% Level	*P* value	
Beijing	–5.26	–2.57	–1.94	–1.62	<.001	Co-integration
Changchun	–7.84	–3.44	–2.86	–2.57	<.001	Co-integration
Chengdu	–23.32	–3.44	–2.86	–2.57	<.001	Co-integration
Chongqing	–5.89	–3.44	–2.86	–2.57	<.001	Co-integration
Changsha	–5.52	–3.44	–2.86	–2.57	<.001	Co-integration
Fuzhou	–5.08	–3.44	–2.86	–2.57	<.001	Co-integration
Guiyang	–29.63	–3.44	–2.86	–2.57	<.001	Co-integration
Guizhou	–6.18	–3.44	–2.86	–2.57	<.001	Co-integration
Harbin	–7.53	–3.44	–2.86	–2.57	<.001	Co-integration
Hefei	–4.74	–3.44	–2.86	–2.57	<.001	Co-integration
Hohhot	–27.24	–3.44	–2.86	–2.57	<.001	Co-integration
Haikou	–30.22	–3.44	–2.86	–2.57	<.001	Co-integration
Hangzhou	–4.06	–3.44	–2.86	–2.57	<.001	Co-integration
Jinan	–5.24	–3.44	–2.86	–2.57	<.001	Co-integration
Kunming	–7.65	–3.44	–2.86	–2.57	<.001	Co-integration
Lhasa	–20.05	–3.44	–2.86	–2.57	<.001	Co-integration
Lanzhou	–28.46	–3.44	–2.86	–2.57	<.001	Co-integration
Nanchang	–7.22	–3.44	–2.86	–2.57	<.001	Co-integration
Nanjing	–5.78	–3.44	–2.86	–2.57	<.001	Co-integration
Nanning	–7.48	–3.44	–2.86	–2.57	<.001	Co-integration
Shanghai	–5.71	–3.44	–2.86	–2.57	<.001	Co-integration
Shijiazhuang	–4.85	–3.44	–2.86	–2.57	<.001	Co-integration
Shenyang	–5.35	–3.44	–2.86	–2.57	<.001	Co-integration
Tianjin	–5.95	–3.44	–2.86	–2.57	<.001	Co-integration
Taiyuan	–5.83	–3.44	–2.86	–2.57	<.001	Co-integration
Wuhan	–5.51	–3.44	–2.86	–2.57	<.001	Co-integration
Xian	–5.21	–3.44	–2.86	–2.57	<.001	Co-integration
Xining	–30.80	–3.44	–2.86	–2.57	<.001	Co-integration
Yinchuan	–19.20	–3.44	–2.86	–2.57	<.001	Co-integration
Zhengzhou	–5.44	–3.44	–2.86	–2.57	<.001	Co-integration

[a] Time series of daily average $PM_{2.5}$ concentration and of daily Baidu Index for lung cancer were co-integrated.

[b] ADF: augmented Dickey-Fuller unit root test.

Table 5. Results of Granger causality test of the causal relationship between daily average fine particulate matter ($PM_{2.5}$) concentration and daily Baidu Index for the search term "lung cancer."

City	Null hypothesis[a]					
	Daily average $PM_{2.5}$ concentration does not Granger cause daily Baidu Index for lung cancer searches			Daily Baidu Index for lung cancer searches does not Granger cause daily average $PM_{2.5}$ concentration		
	F statistic	*df*	*P* value	*F* statistic	*df*	*P* value
Beijing	1.25	15, 1066	.23	0.66	15, 1066	.81
Changchun	1.62	5, 1086	.15	0.30	5, 1086	.91
Chengdu	0.17	5, 1086	.97	1.39	5, 1086	.22
Chongqing	1.32	6, 1084	.24	1.41	6, 1084	.20
Changsha	1.30	6, 1084	.25	1.14	6, 1084	.33
Fuzhou	0.93	6, 1079	.47	1.21	6, 1079	.29
Guiyang	0.19	1, 1090	.66	0.36	1, 1090	.54
Guizhou	1.54	5, 1086	.17	1.84	5, 1086	.10
Harbin	1.14	6, 1084	.33	2.78	6, 1084	.01
Hefei	1.94	6, 1084	.07	2.62	6, 1084	.01
Hohhot	1.72	1, 1090	.19	0.15	1, 1090	.69
Haikou	1.69	1,1090	.19	1.44	1,1090	.22
Hangzhou	0.86	6, 1084	.52	1.86	6, 1084	.08
Jinan	1.57	6, 1084	.15	1.42	6, 1084	.20
Kunming	1.13	6, 1084	.34	0.88	6, 1084	.50
Lhasa	0.81	1, 1090	.37	0.14	1, 1090	.70
Lanzhou	1.97	1, 1090	.16	2.91	1, 1090	.08
Nanchang	1.28	6, 1084	.26	1.45	6, 1084	.19
Nanjing	1.49	6, 1084	.18	2.05	6, 1084	.05
Nanning	0.62	5, 1086	.68	1.82	5, 1086	.10
Shanghai	0.59	8, 1080	.79	0.65	8, 1080	.73
Shijiazhuang	0.52	6, 1084	.79	1.62	6, 1084	.13
Shenyang	0.39	6, 1078	.88	0.88	6, 1078	.50
Tianjin	0.89	5, 1086	.48	0.90	5, 1086	.47
Taiyuan	2.42	7, 1082	.02	0.66	7, 1082	.7
Wuhan	0.95	6, 1084	.45	1.09	6, 1084	.36
Xian	1.35	7, 1082	.22	0.72	7, 1082	.64
Xining	3.40	1, 1090	.06	0.17	1, 1090	.67
Yinchuan	0.24	1, 1090	.61	0.00	1, 1090	.99
Zhengzhou	1.71	6, 1084	.11	1.28	6, 1084	.26

[a] Null hypothesis is rejected when $P<.01$.

Discussion

Principal Results

Our analysis showed a slightly positive correlation between daily average $PM_{2.5}$ concentration and the daily Baidu Index for the search term "lung cancer" in most of the 31 cities. The result of the regression analysis also showed that daily average $PM_{2.5}$ concentration had a weak impact on the daily Baidu Index for lung cancer searches. The Granger causality test indicated that there was no causal relationship between daily average $PM_{2.5}$ concentration and the daily Baidu Index for lung cancer searches.

Some studies have assessed the association between $PM_{2.5}$ and subsequent risks of lung cancer incidence and mortality, suggesting that $PM_{2.5}$ could be a risk factor for lung cancer. Therefore, the mass media in China often remind people to use the necessary protection at a high concentration of $PM_{2.5}$. The public's search interest in lung cancer reflects their concern about this disease. In China, the general population can easily get daily information about the $PM_{2.5}$ concentration through the government's official website, the news media, and many weather forecast mobile phone apps. However, little is known about whether the reported daily information about $PM_{2.5}$ concentration significantly stimulates the public's interest in lung cancer in China. Google Trends and the Baidu Index have proved to be useful indicators of public interest in and attention to health-related topics [30-32]. In our study, we hypothesized that the Baidu Index would offer potential insight into the general population's interest in lung cancer as a reflection of the daily $PM_{2.5}$ concentration.

Wang et al [30] investigated the value of Chinese social media for monitoring air quality trends and related public perceptions and response; they found that media data contain rich details, including perceptions, behaviors, and self-reported health effects, which provides a theoretical basis for our research. In our study, we extracted real search data from the Baidu search engine and we examined the relationship between the reported daily $PM_{2.5}$ concentration data and the search data for the specific search term "lung cancer" to test our hypothesis.

In 2013, the European Study of Cohorts for Air Pollution Effects reported that each 5 μg/m^3increase of $PM_{2.5}$ was statistically significantly associated with a hazard ratio for lung cancer of 1.18 (95% CI 0.96-1.46) [12]. Many studies had indicated the $PM_{2.5}$ could cause lung cancer, and there are still many ongoing studies on the relationship between $PM_{2.5}$ and lung cancer. However, it's still unknown whether the association between $PM_{2.5}$ and lung cancer risk has been recognized by the general public. In addition to traditional methods such as surveys and interviews, we can use Internet-based data to investigate the existing perception and augment health-related data. We therefore used Baidu Index data to measure the public's awareness of the association of $PM_{2.5}$ with an increased risk of lung cancer.

Our result showed that the daily average $PM_{2.5}$ concentration had a modest impact on the daily Baidu Index for lung cancer searches, but there was still substantial uncertainty about the association. First, the effect of daily average $PM_{2.5}$ concentration on the public's awareness of its health hazards might be marginal. People may not be concerned much about lung cancer risks until serious health hazards of $PM_{2.5}$ emerge. However, online searches for lung cancer may decline when the significance of $PM_{2.5}$ has become widely recognized. Similarly, the initial panic over lung cancer caused by some events might increase searches for the term "lung cancer" during the first few days, which may drop after the initial panic; such possibilities may have biased our results. Second, lung cancer is a chronic disease with a slow onset, and exposure to $PM_{2.5}$ is more detrimental to lung cancer risk in the long term. The daily average $PM_{2.5}$ concentration had a relatively long, slow impact on the search rate for lung cancer, indicating a possible long time lag in the relationship. Third, lack of awareness that $PM_{2.5}$ can increase the risk of lung cancer might have an important effect on the association between $PM_{2.5}$ and the Baidu Index for lung cancer searches.

China is a vast and diverse country, with a population of more than 1.3 billion people. The effect of $PM_{2.5}$ on the Baidu Index for lung cancer searches might also depend on demographic and socioeconomic conditions, and differences in health literacy among residents in different cities. For the city Shijiazhuang, the daily average $PM_{2.5}$ concentration was highest, but the Baidu Index for lung cancer searches was significantly lower than for some developed cities, such as Beijing, Fuzhou, and Guangzhou. People in the densely populated and economically developed cities in east China have higher health awareness, have better access to the Internet, and more frequently search for health information than do people in sparsely populated and developing cities. The daily average $PM_{2.5}$ concentration in Lhasa was similar to that in Haikou, but the Baidu Index for lung cancer searches in these 2 cities was notably different. In our data, the mean daily average $PM_{2.5}$ concentration across all cities was 53.47 (SD 47.54) μg/m^3, which is more than the World Health Organization standard of 25 μg/m^3[33]. Although air quality has been improving in recent years, $PM_{2.5}$ pollution in wintertime is worsening, especially in northern China. $PM_{2.5}$ pollution is an emerging problem that threatens public health, especially in Chinese megacity clusters [34]. People in most of the 31 cities in China that we studied had serious health problems attributed to $PM_{2.5}$. Therefore, the health effects of $PM_{2.5}$ on a local scale for each city need be taken seriously. Local authorities should make a greater effort to improve the air quality and the eHealth literacy in their cities. Online health information should be made more accessible to the public, especially in economically underdeveloped areas.

November is Lung Cancer Awareness Month internationally, and November 18 is Lung Cancer Day, which aim to raise lung cancer awareness among the public. In this study, we found a significant difference in the Baidu media index of lung cancer among different months by Kruskal-Wallis *H* test. The mean rank of the Baidu media index was highest in November (Multimedia Appendix 3); however, it was not highest for any of the 31 cities individually in November. The influence of the Lung Cancer Awareness Month campaign on public interest in lung cancer searches in China was below our expectations. According to the analyses of correlation between the daily Baidu Index, the daily Baidu media index, and the daily $PM_{2.5}$ concentration, both the correlation and intercorrelation between these variables were poor, and the daily Baidu media index had little impact on the correlation between the daily Baidu Index and the daily $PM_{2.5}$ concentration. This suggests that the reported daily $PM_{2.5}$ concentration might have little impact on increasing either the public's or the media's attention to lung cancer in China.

Contrary to our expectations, the daily average $PM_{2.5}$ concentration did not notably enhance the public's awareness of lung cancer. Lung cancer is one of the most prevalent and deadliest cancers. An increase of 10 μg/$m^3$of $PM_{2.5}$ could result in up to a 22% increase in lung cancer prevalence [12,35]. It is vital to emphasize the importance of the public's awareness and knowledge of modifiable risk factors of lung cancer for prevention. Lack of awareness of the risk for lung cancer due to $PM_{2.5}$ might have deleterious consequences for the public, in consideration of lifestyle modification and risk factor avoidance, and might limit the public's participation in lung cancer prevention or the avoidance of $PM_{2.5}$. Enhancing this awareness might raise self-protective avoidance of lung cancer risk factors. Ngo et al indicated that awareness of the connection between air pollution and its negative health effects can help the public improve their understanding of air pollution and develop responses to it. This awareness could also lead the public to seek more information about air pollution and its hazards, and to cope with their environment and its risks [36]. According to the 39th China statistical report on Internet development, 195 million people used the Internet for health care, with an annual growth rate of 28%, and the number of queries for health information was up 10.8% in 2016 [37]. The Internet can be treated as a sensor of perceptions, behaviors, and self-reported health effects [30]. This advantage of the Internet and social media should be used fully to increase public awareness of the association of $PM_{2.5}$ with lung cancer risk. At the same time, monitoring the public response to the health hazards of $PM_{2.5}$ is necessary to avoid causing social panics. Limited awareness about cancer can hamper primary prevention and the early detection of cancer, as can lack of awareness about the association of $PM_{2.5}$ with lung cancer risk. Cancer awareness campaigns can effectively stimulate the response and online activities of the general public, and can improve knowledge and awareness of cancer [31,32]. Awareness campaigns are needed to increase public knowledge of the lung cancer risk of $PM_{2.5}$ and should be designed to improve knowledge of lung cancer and promote actively taking effective measures to reduce exposure to $PM_{2.5}$ on hazy days.

Strengths and Limitations

The strength of this study is that it is the first, to our knowledge, to explore the relationship between daily average $PM_{2.5}$ concentration and the daily Baidu Index for the search term "lung cancer" across 31 cities in China.

There are some limitations to this study. We collected the Internet search data from a single search engine, Baidu. Baidu is the most commonly used search engine in China. The Baidu Index provides absolute search data by cities and can be used to perform a direct comparative analysis among cities. We used only the term "lung cancer," which might have limited the search data. It was also not possible to identify the type of Internet user or which stakeholders were responsible for the search activity. Search engine search term trends might be affected by factors such as public panic [38]. Some people might have searched the term "lung cancer" for other purposes. That the search data are affected by such random factors is an unavoidable limitation in studies using search engine data. We, and many other scholars, are committed to solving this problem and are seeking ways to identify and reduce biases that are embedded in search engine data. This study was also limited by the study areas. We only focused on 31 cities, so the results cannot be extrapolated to other cities and rural areas. It was beyond the scope of our work to explore the relation between $PM_{2.5}$ and online searches for information on other diseases or the relation between online searches for lung cancer and other risk factors.

Conclusion

Daily average $PM_{2.5}$ concentration has a weak positive impact on Internet searches on the term "lung cancer." Well-designed awareness campaigns are needed to improve general public awareness of the association of $PM_{2.5}$ with lung cancer risk, to lead the public to seek more information about $PM_{2.5}$ and its hazards, and to cope with their environment and its risks appropriately.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Results of Pearson correlation analysis.

[PDF File (Adobe PDF File), 43KB - publichealth_v3i4e64_app1.pdf]

Multimedia Appendix 2

Results of multiple linear regression analysis.

[PDF File (Adobe PDF File), 30KB - publichealth_v3i4e64_app2.pdf]

Multimedia Appendix 3

Mean rank of the daily Baidu Index for the term “lung cancer," daily Baidu media index, and daily $PM_{2.5}$ concentration for different months from 2014 to 2016.

[PDF File (Adobe PDF File), 40KB - publichealth_v3i4e64_app3.pdf]

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Abbreviations

PM $_{2.5}$: ambient fine particulate matter <5 µm in diameter

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Original Paper

College Freshmen Students' Perspectives on Weight Gain Prevention in the Digital Age: Web-Based Survey

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Abstract

Background: College freshmen are highly vulnerable to experiencing weight gain, and this phenomenon is associated with an increased risk of chronic diseases and mortality in older adulthood. Technology offers an attractive and scalable way to deliver behavioral weight gain prevention interventions for this population. Weight gain prevention programs that harness the appeal and widespread reach of Web-based technologies (electronic health or eHealth) are increasingly being evaluated in college students. Yet, few of these interventions are informed by college students' perspectives on weight gain prevention and related lifestyle behaviors.

Objective: The objective of this study was to assess college freshmen students' concern about weight gain and associated topics, as well as their interest in and delivery medium preferences for eHealth programs focused on these topics.

Methods: Web-based surveys that addressed college freshmen students' (convenience sample of N=50) perspectives on weight gain prevention were administered at the beginning and end of the fall 2015 semester as part of a longitudinal investigation of health-related issues and experiences in first semester college freshmen. Data on weight gain prevention-related concerns and corresponding interest in eHealth programs targeting topics of potential concern, as well as preferred program delivery medium and current technology use were gathered and analyzed using descriptive statistics.

Results: A considerable proportion of the freshmen sample expressed concern about weight gain (74%, 37/50) and both traditional (healthy diet: 86%, 43/50; physical activity: 64%, 32/50) and less frequently addressed (stress: 82%, 41/50; sleep: 74%, 37/50; anxiety and depression: 60%, 30/50) associated topics within the context of behavioral weight gain prevention. The proportion of students who reported interest in eHealth promotion programs targeting these topics was also generally high (ranging from 52% [26/50] for stress management to 70% [35/50] for eating a healthy diet and staying physically active). Email was the most frequently used electronic platform, with 96% (48/50) of students reporting current use of it. Email was also the most frequently cited preferred eHealth delivery platform, with 86% (43/50) of students selecting it. Facebook was preferred by the second greatest proportion of students (40%, 20/50).

Conclusions: Most college freshmen have concerns about an array of weight gain prevention topics and are generally open to the possibility of receiving eHealth interventions designed to address their concerns, preferably via email compared with popular social media platforms. These preliminary findings offer a foundation to build upon when it comes to future descriptive investigations focused on behavioral weight gain prevention among college freshmen in the digital age.

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KEYWORDS

weight gain prevention; college freshmen; social media

Introduction

Background

It is well established that weight gain and the onset of obesity are common in college students [1]. Over one-third of college students were overweight or obese in 2016 [2]. Although both men and women are vulnerable to weight gain across each year of college [3-6], freshmen are at the highest risk for the greatest weight increases [4]. Weight gain during young adulthood is associated with an increased risk of chronic disease and mortality in older adulthood [7-9]. Lifestyle behaviors such as physical inactivity, unhealthy diet, poor sleep habits, and inadequate stress management have been linked to weight gain [10-15]. Behavioral interventions can address these topics and thus potentially attenuate adverse weight gain [16].

Technology represents a particularly attractive and scalable platform for behavioral weight gain prevention interventions in college students. Nearly all (99%) college students regularly use the Internet [17] to access information and socialize with others via nonmobile and mobile devices, especially through Web-based social media platforms. Most college students (80%) report using Web-based social networks (eg, Facebook, Instagram, and Twitter) [17]. Increasingly, weight gain prevention programs that capitalize on the appeal and widespread reach of Web-based technologies (ie, programs that represent one area of the Internet or electronic health [eHealth] interventions) [18] are being evaluated in college students [19-23], and these studies [19-23] have shown mixed findings for effectively promoting maintenance of current weight. Moreover, few of these weight gain prevention interventions [21] are informed by college students' perspectives on this topic (ie, concerns about weight gain and associated lifestyle behaviors, interest in the specific components that might be included in a comprehensive eHealth weight gain prevention program, and preferred delivery medium). Indeed, findings from a recent systematic review of literature, focused in part on weight gain prevention in young adults, prompted a call to better understand young adults' attitudes toward engaging in healthy lifestyle behaviors, as well as their weight gain prevention intervention preferences [16]. Such formative information is critical for designing effective technology-based, weight gain prevention interventions for college students, including the subgroup most susceptible to experiencing this phenomenon—freshmen.

Concerns regarding physical inactivity and poor dietary habits among college freshmen have been described previously [24-26], but these studies do not provide a detailed assessment of the range of topics relevant to effective weight gain prevention. Furthermore, a national survey by the American College Health Association [27] reported that two-thirds of college students are interested in receiving information about physical activity and diet, but only a few previous studies have measured interest in [28] and preferred delivery medium [28,29] for receiving an eHealth intervention focused on the promotion of healthy weight [28] or physical activity and diet [29]. One of these studies focused solely on young adult women and weight loss [28], and both studies do not differentiate among popular social media platforms [28,29]. There is a clear need to continue to build upon this small research base and address these topics within the context of weight gain prevention. Doing so will further help guide investigators and practitioners interested in efficiently and effectively addressing college freshmen weight gain via refined, technology-oriented approaches.

Objective

Thus, the primary purpose of this study was to collectively gauge college freshmen students' level of concern about weight gain prevention topics, level of interest in and preferred delivery platforms for eHealth programs focused on these topics, and technology use in general and for the purposes of maintaining current weight.

Methods

Study Design

Survey data concerning college freshmen students' perspectives on weight gain prevention were collected as part of a longitudinal investigation focused on health issues and first semester experiences of college freshmen. Specifically, two separate Web-based surveys were administered to a sample of male and female college freshmen at the beginning (baseline) and end (follow-up) of the fall semester.

Participant Recruitment and Eligibility

A convenience sample of incoming college freshmen was recruited from a large public university in the Southeastern United States during the first 2 weeks of the fall semester via fliers distributed around campus, as well as the direct distribution of fliers in conjunction with verbal invitations in large freshmen classes and at the student union. Individuals had to be self-identified first-year college freshmen with Internet access to participate in the study.

Procedures

The recruitment fliers provided the directions and link (URL) needed to access the baseline Web-based survey. Before the completion of this survey, participants gave informed consent via a secure website. The survey was available to complete beginning the first day of class (August 20, 2015) and ending on September 2, 2015. Participants received an email 11 weeks later, at the end of the fall semester, asking them to complete the follow-up Web-based survey. The opportunity to complete this follow-up assessment occurred over a 1-month time period (November 4, 2015-November 30, 2015). Participants who completed the Web-based surveys were eligible for a gift card drawing (US $50 drawing at baseline and US $100 drawing at follow-up). The study was approved by the University of South Carolina's institutional review board.

Survey Measures

The baseline and follow-up surveys were developed and administered via a secure website (Qualtrics, Provo, Utah). Variables of present interest measured as part of either the baseline survey or follow-up survey are described below.

Concern About Weight Gain Prevention and Associated Topics

As part of the follow-up survey, students reported their level of concern about six specific health topics (ie, weight gain, stress management, getting enough sleep, anxiety and depression, eating a healthy diet, and maintaining physical activity during the freshmen year) on a 4-point Likert scale (not concerned, neutral, somewhat concerned, and very concerned).

Interest in eHealth Promotion Programs and Preferred Delivery Platform

As part of the follow-up survey, students were asked to respond to the following item: “Please rate how interested you might be in an eHealth promotion program (such as through Facebook, Twitter, Instagram, etc) tailored to college freshmen on these different topics.” Students specifically rated their level of interest on different health topics relevant to weight gain prevention (ie, maintaining a healthy weight, staying physically active, eating healthy on campus, handling stress, depression and anxiety, and adequate sleep) on a 4-point Likert scale (not interested, neutral, somewhat interested, and very interested). Students also responded to the following item on the baseline survey: “If you were to receive health information delivered by social media, which would be your preferred platforms from which to get the health promotion information? Please select up to 3 to indicate your top 3 choices.” Response options to this item included the following: email, Twitter, Facebook, Instagram, Vine, private discussion board or bulletin board or forum, Snapchat, other (specify), and would prefer not to receive health information via social media.

Technology Use

Students indicated which popular electronic platforms they used regularly via the baseline survey (ie, email, Twitter, Facebook, Instagram, Vine, private discussion board or bulletin board or forum, Snapchat, other [specify], and do not use any social media or electronic platforms) [30,31].

Weight Gain Prevention Practices

Self-Weighing

Students reported their frequency of self-weighing on the baseline survey (ie, 1 time/day, 1 time/week, a few times/month, or less often or never).

Self-Monitoring of Diet and Physical Activity

Students also responded to items about whether or not they used a smartphone app to track diet, used a smartphone app to track physical activity, and used a wearable physical activity monitoring device on the follow-up survey.

Demographics

Demographic data, specifically age, sex, race, and ethnicity, were obtained as part of the baseline survey.

Height, Body Weight, and Body Mass Index

Students reported their height and body weight via the baseline Web-based survey. Body mass index was calculated as weight (kg)/height (m^2).

Statistical Analyses

Statistical analyses were conducted using the statistical package for the social sciences (SPSS) version 22.0 for Windows (IBM Corp). Descriptive statistics were calculated for all variables. Means and standard deviations (SDs) are presented for continuous variables. Frequencies and percentages are presented for categorical variables. For the items addressing level of concern about specific health topics, very concerned and somewhat concerned response categories were aggregated to highlight the collective proportion for which there was at least some level of concern. Similarly, for the items indicating degree of interest in eHealth promotion programs focused on different topics, very interested and somewhat interested responses were coalesced to highlight the collective proportion who expressed at least some interest. Independent *t* tests and chi-square analyses were used to measure differences in baseline characteristics between study completers and noncompleters. A *P* value of less than .05 was used to determine statistical significance.

Results

Sample Characteristics

Fifty-five college freshmen enrolled in the study and completed the baseline survey. Fifty (91%, 50/55) also completed the follow-up survey. Those who completed both surveys averaged 18.3 years of age (SD 0.6) and were predominantly white and normal weight. Two-thirds were women (Table 1). There were no significant differences in any baseline variables between the study completers and noncompleters. Analyses focused on those who completed both surveys and thus provided responses for all variables of present interest.

Survey Findings

Table 1 summarizes demographic and physical characteristics, reported health concerns, interest in eHealth programs, and weight gain prevention practices among the sample. Three-fourths of students reported being concerned about weight gain during their first college semester, and an even greater proportion reported being concerned about eating a healthy diet (86%, 43/50) and managing stress (82%, 41/50). A low proportion of students reported engaging in empirically validated weight gain prevention strategies [26,32,33] such as weighing oneself at least once a week (22%, 11/50), self-monitoring dietary intake via a smartphone app (12%, 6/50), and self-monitoring physical activity using a smartphone app (24%, 12/50) or wearable device (12%, 6/50). The proportion of students who were at least somewhat interested in receiving an eHealth promotion program focused on different weight gain prevention topics ranged from 52% (26/50) for a program focused on stress management to 70% (35/50) for programs focused on physical activity and healthy eating.

Table 1. Demographic and physical characteristics, reported health concerns, interest in electronic health (eHealth) programs, and weight gain prevention practices among college freshmen, fall 2015 semester.

Measure	All (N=50)
Age (years), mean (SD[a])	18.3 (0.6)
Sex, n (%)	
Female	33 (66)
Male	17 (34)
Race, n (%)	
White	43 (86)
African-American	1 (2)
Asian	3 (6)
Multiracial	3 (6)
Hispanic or Latino	2 (4)
Self-reported height, cm, mean (SD)	171.3 (9.1)
Self-reported weight, kg, mean (SD)	63.3 (1.7)
Self-reported BMI[b], kg/m^2, mean (SD)	21.5 (2.9)
Weight status based on self-reported BMI, n (%)	
Underweight	7 (14)
Normal weight	38 (76)
Overweight	5 (10)
Self-reported self-weighing, n (%)	
1 time/day	1 (2)
1 time/week	10 (20)
A few times/month	15 (30)
Less often or never	24 (48)
Use a smartphone app to track diet, n (%)	6 (12)
Use a smartphone app to track physical activity, n (%)	12 (24)
Use a wearable device to track physical activity, n (%)	6 (12)
Very or somewhat concerned about, n (%)	
Weight gain	37 (74)
Stress	41 (82)
Maintaining physical activity	32 (64)
Healthy diet	43 (86)
Sleep	37 (74)
Anxiety and depression	30 (60)
Very or somewhat interested in eHealth program on, n (%)	
Maintaining a healthy weight	34 (68)
Handling stress	26 (52)
Staying physically active	35 (70)
Healthy eating	35 (70)
Sleep	30 (60)
Anxiety and depression	27 (54)

[a] SD: standard deviation.

[b] BMI: body mass index.

Table 2. College freshmen students' (N=50) reported current technology use and preferred methods for receiving an eHealth promotion program in their first college semester (fall 2015).

Program delivery method	Currently use platform[a] n (%)	Prefer eHealth delivery medium[b] n (%)
Email	48 (96)	43 (86)
Facebook	33 (66)	20 (40)
Twitter	23 (46)	12 (24)
Instagram	34 (68)	10 (20)
Snapchat	38 (76)	8 (16)
Discussion board or bulletin board or forum	1 (2)	3 (6)
Vine	8 (16)	0 (0)
Other		
Tumblr	1 (2)	0 (0)
Pinterest	1 (2)	0 (0)
Groupie	1 (2)	0 (0)

[a] Forty-seven (94%, 47/50) students reported using at least one platform in addition to or other than email.

[b] Six (12%, 6/50) students indicated they would not prefer to receive health information via social media.

Table 2 presents results for electronic platforms utilized and preferred electronic methods for receiving a health promotion program. Of note, email was most frequently selected as a preferred platform for receiving health promotion information, with 86% (43/50) of the students identifying it as a preferred platform. Facebook represented the next most frequently selected preferred eHealth platform as it was chosen by 40% (20/50) of the students. Although Snapchat was the second most widely used platform (76%, 38/50) after email (96%, 48/50), it was one of the least preferred mediums for receiving an eHealth promotion program (16%, 8/50).

Discussion

Summary of Principal Findings and Comparison With Existing Literature

This formative study preliminarily suggests that a considerable proportion of college freshmen have concerns about weight gain and associated lifestyle behaviors during their first semester and are interested in receiving eHealth programs focused on different weight gain prevention topics. The findings also indicate that the technology platforms most frequently preferred for receiving eHealth programs are email and Facebook.

To our knowledge, this study is the first to provide an assessment of freshmen college students' level of concern about a range of weight gain prevention topics. The first semester of freshman year has been identified as the period of highest risk for weight gain during the college experience [4], and the level of concern about weight gain during this period is therefore quite relevant to considerations about how to address this issue [16]. It is also the first study to integrate this assessment of concern with a measure of interest in and preferred delivery medium for receiving an eHealth promotion program focused on different weight gain prevention topics.

Our findings are congruent with previous studies that have gauged freshmen college students' level of concern about weight gain prevention topics [24-26]. For example, de Vos et al found that 50% of the normal weight students and 56% of the overweight students in their sample of 1095 college freshmen reported being concerned about their eating habits during the fall semester [25]. Furthermore, all first-year college students (N=45) in another previous study indicated their concern for eating healthy and being physically active by reporting that the consequences of not doing so were significant enough to try to avoid [24]. In this study, eating a healthy diet concerned the greatest proportion of freshmen relative to other weight gain prevention topics, and the overall concern for weight gain was evident among three-fourths of the students. Despite these concerns, most freshmen reported not practicing regular self-weighing or using technology to track their diet and physical activity, which reflect key behaviors for weight gain prevention [26,32,33]. These findings are consistent with results from a qualitative assessment of first- and second-year college students' (N=43) weight gain prevention behaviors, which revealed that most students reported weighing themselves infrequently (<1-2 times/month) and not monitoring their physical activity and diet [26].

Nevertheless, in this study, the students' level of concern for weight gain prevention and associated topics generally paralleled their level of interest in eHealth promotion programs centered on these topics, pointing to their openness to receive guidance and support about maintaining their current weight through popular technology mediums [17,30,31]. However, the gap between the proportion of students who were concerned about stress (82%, 41/50) and those who were interested in an eHealth program targeting stress management (52%, 26/50) was somewhat large. Unlike more traditional weight gain prevention foci (ie, diet and physical activity), perhaps students cannot conceive how stress management can be effectively facilitated via electronic mediums [29], or they may simply prefer to receive stress management guidance through other means (eg, in person). Future research designs should employ more in-depth quantitative and qualitative assessment methods to help elucidate students' reasoning for their concerns and interests. The majority of the students' concern about stress is a particularly notable finding as the role of stress in the etiology of obesity is becoming increasingly recognized [34,35]. Yet, few studies in adults, let alone college freshmen, have applied a considerable focus on stress management to help facilitate a healthy weight [36-38]. The present findings suggest that it may be important to consider offering eHealth weight gain prevention programs targeting relevant traditional and less frequently addressed topics, particularly during students' first college semester when their concern and interest in eHealth support for most weight gain prevention topics are generally aligned.

Given that email was used and preferred as an eHealth delivery method by the highest proportion of students relative to other platforms, researchers and practitioners may want to consider employing this medium when designing electronic-based weight gain prevention programs for first-year college students [29]. These findings are similar to previous studies in other populations [29,39,40]. For instance, Quintilliani et al [29] electronically surveyed 397 college students about their usage patterns of and preferences for potential eHealth delivery channels. They found that 98% of respondents used email, and it was the most frequently cited preferred eHealth channel (86%). Although a distant second, Facebook was the second most frequently preferred eHealth program delivery platform in this study. Initial studies using email and Facebook among college students seeking to maintain a healthy weight or lose weight have shown promise [23,41,42].

A high proportion of students in this study reported using Snapchat (76%, 38/50), which is consistent with a recent market study of 9381 college students [43]. This market study found that most students (58%) open Snapchat first before checking other social media platforms [43]. However, few students in this study selected Snapchat as one of their top preferred eHealth delivery methods. These findings underscore the need to ask specific questions about preference for program delivery rather than assume social usage patterns reflect health promotion preferences. There is a chance that students could not envision how health promotion program components could be delivered by Snapchat [29] and thus selected other platforms by default. To avoid this, perhaps researchers and practitioners seeking to extend applications of these widely used platforms from social networks to health promotion efforts targeted at college freshmen should consider providing concrete examples of how the platforms might be utilized and then asking about preference. Indeed, one of the primary advantages of technology is that it provides the opportunity to tailor the delivery of messages in such a way that the same messages can be distributed via a variety of platforms.

Study Limitations and Strengths

This study was characterized by several limitations that must be considered when interpreting the findings. The sample size was small and homogeneous (primarily comprising white college students who were of normal weight). Thus, it is unknown whether different response patterns may have emerged for different subgroups of college freshmen. Similarly, it is unknown how a different target outcome (eg, weight loss) may have affected responses in certain subgroups. The sample also comprised self-selected students who may have had more interest in weight gain prevention, other health issues, and technology than those who did not volunteer. Given these factors, it may be premature to generalize the findings broadly. However, these results point to the need for further exploration into these important research questions in a larger, more diverse sample in the different contexts of weight gain prevention, weight loss, and prevention of weight regain after weight loss. Additionally, this study did not inquire about all potential preferred eHealth delivery platforms, which represents another study limitation. Assessing students' preferences for an even broader array of widely accessible technology delivery mediums (eg, mobile health tools and features) [44], as it relates to weight gain prevention, should be considered in future research. Similarly, this study did not inquire about preferred eHealth delivery platforms for the facilitation of different behavior change strategies (eg, social support, goal-setting, self-monitoring, and feedback) targeting different types of weight gain prevention-related behaviors. Future investigations should address this aspect and consider employing a mixed methods design to better understand the underlying reasoning behind students' responses.

Despite these limitations, this study was the first to simultaneously assess concern about and interest in receiving eHealth programs via different delivery platforms focused on a range of lifestyle topics relevant to weight gain prevention among college freshmen, expanding the focus from diet and physical activity to other areas associated with weight gain prevention, which might be pertinent to the target population. Unlike previous studies [28,29], this study also differentiated among various social media platforms when assessing students' preferred eHealth delivery method.

Conclusions

Overall, this descriptive, formative study preliminary demonstrated that college freshmen have concerns about a range of weight gain prevention-related topics and are generally interested in receiving eHealth promotion programs focused on these topics. The greatest majority of students selected a traditional medium (ie, email) as their preferred method for receiving an eHealth program, although a substantial proportion also preferred Facebook. This study fully opens the conversation on an impactful and under-researched area, yielding findings that provide a foundation to build upon when it comes to future descriptive investigations focused on behavioral weight gain prevention among college freshmen in the digital age. Ultimately, such studies may help inform the design of future, far-reaching technology-based weight gain prevention interventions that have the potential to enhance program receptiveness, exposure, engagement, and effectiveness for college freshmen.

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Authors' Contributions

DSW conceived the study and was the principal investigator. CMM took the lead in drafting the manuscript. DSW, CMM, and GT-M took the lead in study design. DSW, CMM, KM, and CAL were responsible for data collection. SW, HMB, BS, and CAL provided study design contributions. DSW, GT-M, SW, HMB, BS, and CAL edited the manuscript.

Conflicts of Interest

None declared.

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Abbreviations

BMI: body mass index
eHealth: electronic health
SD: standard deviation
SPSS: statistical package for the social sciences

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Original Paper

Will Participatory Syndromic Surveillance Work in Latin America? Piloting a Mobile Approach to Crowdsource Influenza-Like Illness Data in Guatemala

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Abstract

Background: In many Latin American countries, official influenza reports are neither timely nor complete, and surveillance of influenza-like illness (ILI) remains thin in consistency and precision. Public participation with mobile technology may offer new ways of identifying nonmedically attended cases and reduce reporting delays, but no published studies to date have assessed the viability of ILI surveillance with mobile tools in Latin America. We implemented and assessed an ILI-tailored mobile health (mHealth) participatory reporting system.

Objective: The objectives of this study were to evaluate the quality and characteristics of electronically collected data, the user acceptability of the symptom reporting platform, and the costs of running the system and of identifying ILI cases, and to use the collected data to characterize cases of reported ILI.

Methods: We recruited the heads of 189 households comprising 584 persons during randomly selected home visits in Guatemala. From August 2016 to March 2017, participants used text messages or an app to report symptoms of ILI at home, the ages of the ILI cases, if medical attention was sought, and if medicines were bought in pharmacies. We sent weekly reminders to participants and compensated those who sent reports with phone credit. We assessed the simplicity, flexibility, acceptability, stability, timeliness, and data quality of the system.

Results: Nearly half of the participants (47.1%, 89/189) sent one or more reports. We received 468 reports, 83.5% (391/468) via text message and 16.4% (77/468) via app. Nine-tenths of the reports (93.6%, 438/468) were received within 48 hours of the transmission of reminders. Over a quarter of the reports (26.5%, 124/468) indicated that at least someone at home had ILI symptoms. We identified 202 ILI cases and collected age information from almost three-fifths (58.4%, 118/202): 20 were aged between 0 and 5 years, 95 were aged between 6 and 64 years, and three were aged 65 years or older. Medications were purchased from pharmacies, without medical consultation, in 33.1% (41/124) of reported cases. Medical attention was sought in 27.4% (34/124) of reported cases. The cost of identifying an ILI case was US $6.00. We found a positive correlation (Pearson correlation coefficient=.8) between reported ILI and official surveillance data for noninfluenza viruses from weeks 41 (2016) to 13 (2017).

Conclusions: Our system has the potential to serve as a practical complement to respiratory virus surveillance in Guatemala. Its strongest attributes are simplicity, flexibility, and timeliness. The biggest challenge was low enrollment caused by people’s fear of victimization and lack of phone credit. Authorities in Central America could test similar methods to improve the timeliness, and extend the breadth, of disease surveillance. It may allow them to rapidly detect localized or unusual circulation of acute respiratory illness and trigger appropriate public health actions.

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KEYWORDS

crowdsourcing; human flu; influenza; grippe; mHealth; texting; mobile apps; short message service; text message; developing countries

Introduction

Influenza Surveillance in Latin America

The routine collection, analysis, and reporting of disease and injury data is the foundation of public health: it provides health officials with current information to ground public health decisions and action [1,2]. Despite efforts to improve disease surveillance and response, developing countries still have difficulty in accurately identifying, diagnosing, and reporting infectious diseases [3]. In Latin America, influenza and other respiratory virus surveillance lacks timeliness and is nonspecific, particularly in remote areas [4-7]. The recommendations that were proposed more than a decade ago to advance surveillance [7]—improving the quality of available data, enhancing communication of the information obtained by surveillance activities to stakeholders, and increasing awareness of health authorities of influenza impact in public health—have yet to be fully implemented in the region [5].

Guatemala is illustrative of this challenge. Disease surveillance activities are constrained by scarcity of resources, personnel, and infrastructure [8,9]. Seasonal influenza information is incomplete and delayed because reports are publicly available 2 to 3 weeks after the emergence of medically attended cases from which samples are collected. Low usage of government health facilities conducting sentinel surveillance of influenza makes it difficult to accurately estimate the geographic distribution of influenza in the country [8]. The effect of the data shortcomings is that authorities and providers are forced to make decisions, such as defining the timing of effective vaccination campaigns, using inadequate information on a seasonal disease. Countries in the region facing the same challenges are in need of effective tools to improve the quality and timeliness of surveillance data.

The Promise of Culturally Relevant Participatory Surveillance

Participatory surveillance strategies, by which individuals report symptoms voluntarily, have the potential to serve as a viable complement to existing outpatient, hospital-based, and laboratory surveillance systems because they can be flexible, sensitive, and accurate [10,11]. Studies suggest that electronic participatory surveillance may mitigate delays in reporting, improve timeliness of surveillance, extend surveillance to unmonitored locations, reduce costs, increase the population size under surveillance, and characterize cases of nonmedically attended illnesses [10,12-19]. Although attention has mainly been focused on using data from Internet posts and search queries for influenza surveillance [18], other approaches to participatory surveillance of influenza, such as Flu Near You [10] (and its extension Salud Boricua [20] in Puerto Rico), InfluenzaNet [21,22], or the Web-based Reporta [23] in Mexico, have generated relevant information by collecting data from users who periodically report symptoms; the data have been used to signal the beginning of yearly influenza epidemics, allowing an appropriate mobilization of communities to seek vaccines and a targeted promotion of nonpharmaceutical interventions such as avoiding close contact or covering the mouth and nose when coughing or sneezing [21].

An electronic bottom-up surveillance system may offer new ways of strengthening situational awareness by engaging citizens in countries such as Guatemala. Implementing functional participatory surveillance systems, however, requires designing systems that are appropriate and scalable, and developing local strategies for encouraging participation [11,24]. In Latin America, the unsuitability of Google Flu Trends to accurately predict influenza outbreaks across countries has been attributed to low Internet penetration rates and to heterogeneous usage of search engines among non-English speaking populations [24]. Alternatively, the ubiquity of feature phones—a midway point between smartphones and basic mobile phones [25], which are only capable of voice calling and text messaging—coupled with the increasing penetration of smartphones provides culturally relevant infrastructure opportunities to capture health information with the use of apps and short message service (SMS) (or text messages) [26,27]; it is almost four times more likely to be a mobile phone user than an Internet user in Central America (34 Internet users per 100 people [28] vs 130 mobile subscriptions [29] per 100 people). No published studies to date have assessed the viability of ILI surveillance with mobile-based tools in the region.

The Study in Guatemala

We implemented and assessed a participatory, bimodal, mobile phone–based surveillance system for ILI symptoms, the first in the Latin American region. The mobile health (mHealth) system was purposely developed to make use of popular mobile communication tools—SMS and Android apps—in Guatemala. SMS provides a cross-platform mobile communication channel that is widely used in the country, where mobile penetration rates exceed 100% [29]. Android smartphones dominate Central and South American markets with approximately 80% of the market share [30]; in Guatemala, the leading telecom—with 54.5% of active mobile lines—reported that the four most used smartphones in 2016 ran on the Android operating system [28]. We conducted a study between August 2016 and March 2017 in San Marcos, Guatemala, to assess the relevance, performance, and potential of the ILI-tailored reporting system. Specific aims were to evaluate the quality and characteristics of the collected data, the user acceptability of the platform, and the costs of running the system and of identifying ILI cases and to use the collected data to characterize cases of reported ILI in the study population.

Methods

The Bimodal Data Capturing System

We created a system capable of capturing ILI reports from two sources, SMS and the smartphone app “Mi Gripe” (“My Flu” in Spanish) (see Figure 1 for screenshots). Our ILI case definition was as follows: measured fever and cough or sore throat, with onset within the last 7 days.

We used a Dell Laptop running on Microsoft Windows 7 Professional with an Intel Core Duo processor and 4-GB RAM, a Huawei E173 GSM Modem connected to the laptop, and a subscriber identity module (SIM) card compatible with the GSM Modem. We used the open-source program FrontlineSMS [31] to import contact datasets and to schedule the delivery of weekly reminders. We configured the software to send automatic follow-up questions to participants based on keywords contained in incoming SMSs. The logic for the SMS exchange was as follows: at the beginning of each week, the platform sent the question: “How many people at home had fever with cough or sore throat in the last 7 days? Send 0 if none. Respond with the number if there were any.” If the answer was 0, the system sent a “Thank you” message. If the answer was a number between 1 and 15, the system sent the next question: “Did the people who had fever with cough or sore throat in the last 7 days seek medical attention (excluding traditional medicine and pharmacies)? Send 111 if yes, 222 if no.” If the answer contained either 111 or 222, the system sent the question: “Did the people who had fever and cough or sore throat in the last 7 days buy medicines at a pharmacy? Send 333 if yes, 444 if no.” If the answer contained 333 or 444, the following question was sent automatically: “What are the ages of the people who had fever with cough or sore throat? Send AGE followed by their ages.” If the system identified the keyword AGE in the text, a “Thank you” message was sent, marking the end of a weekly SMS report (see Multimedia Appendices 1 and 2).

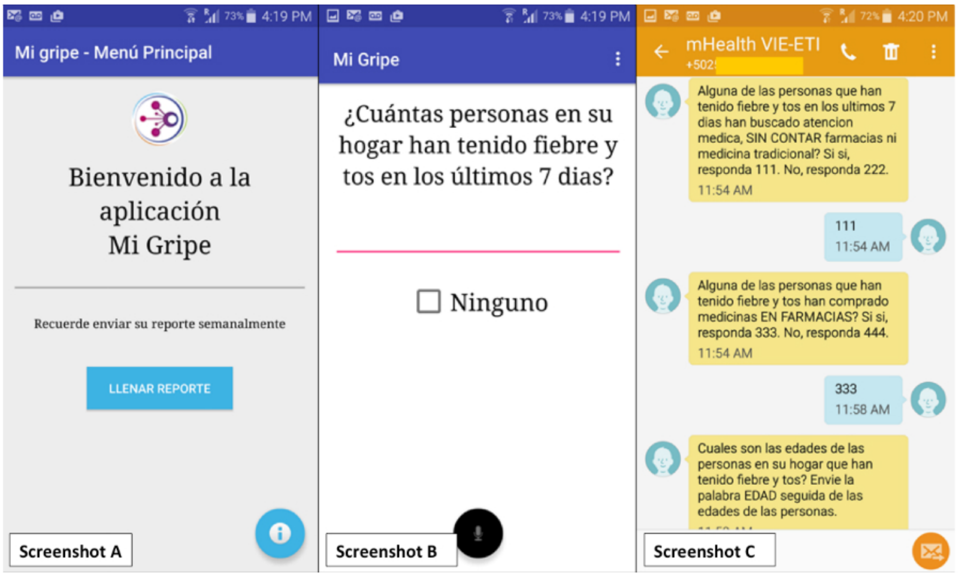
We also created the app “Mi Gripe” for Android smartphones. The app “Mi Gripe” allowed participants to complete a weekly report by answering a set of questions (the same ones we used in the SMS modality). A reminder popped up every week to remind users to complete the weekly report. Participants could not skip questions in the app because data entry validation required them to answer questions before moving to the next one. A message was displayed if the report for the week had been sent. Reports were sent if and when the mobile device found connectivity to the Internet.

Location and Participants

The study was conducted between August 2016 and March 2017 in southwestern Guatemala, close to the Mexican border and the Pacific Ocean coast, in the municipalities of San Marcos and San Pedro (Department of San Marcos).

As part of a health utilization survey conducted in the coverage area of the San Marcos and San Pedro public health centers, we selected 1671 households using a cluster random sample strategy (paper forthcoming). We invited heads of Spanish-speaking households to participate in the study. The inclusion criteria for the study were as follows: households with at least one mobile phone and households where at least one person knew how to read and write in Spanish. Visits were organized as follows: clusters of houses in the coverage area of the health centers were first selected using a probabilistic cluster stratified sampling.

Figure 1. Two screenshots of the app “Mi Gripe” (left and middle) and screenshot of exchanges for short message service (SMS) users (right). Screenshot A: Translation: "Welcome to the Mi Gripe App. Please remember to send your weekly report." Screenshot B: Translation: “How many people at home had fever with cough or sore throat in the last 7 days? None." Screenshot C: Translation: “Did the people who had fever with cough or sore throat in the last 7 days seek medical attention, excluding traditional medicine and pharmacies? Send 111 if yes, 222 if no,” “Did the people who had fever and cough or sore throat in the last 7 days buy medicines at a pharmacy? Send 333 if yes, 444 if no,” “What are the ages of the people who had fever with cough or sore throat? Send AGE followed by their ages.”.



Bienvenido a la aplicación Mi Gripe

Recuerde enviar su reporte semanalmente

¿Cuántas personas en su hogar han tenido fiebre y tos en los últimos 7 dias?

☐ Ninguno

+502[redacted]

Alguna de las personas que han tenido fiebre y tos en los ultimos 7 dias han buscado atencion medica, SIN CONTAR farmacias ni medicina tradicional? Si si, responda 111. No, responda 222.
11:54 AM

111
11:54 AM

Alguna de las personas que han tenido fiebre y tos han comprado medicinas EN FARMACIAS? Si si, responda 333. No, responda 444.
11:54 AM

333
11:58 AM

Cuales son las edades de las personas en su hogar que han tenido fiebre y tos? Envie la palabra EDAD seguida de las edades de las personas.

The stratification was based on the location (urban or rural) of houses. Within each cluster, a random sample of households was selected to conduct a health utilization survey, which would help estimate the burden of influenza and other respiratory viruses in sentinel surveillance clinics, with each head of the household. At the end of the 1- to 2-hour survey, the field personnel invited the heads of households to participate in the study.

Interested participants who signed an informed consent form were instructed to send reports once per week via SMS if they had a feature phone or via app if they had a smartphone, using their phone credit. The study's field personnel installed "Mi Gripe" on smartphones of app participants and saved the reporting number under the contact name "Report symptoms" for SMS participants. Participants were credited with ~US $0.40 for each report sent at the end of each month (to cover the cost of sending 4 SMSs). Maximum compensation was set at ~US $1.60 per month, thus compensating no more than four reports per month.

Coding of SMS Reports

SMS participants were instructed to follow response rules described at the end of every text message, for example, "Send AGE followed by the ages" (details are provided in Multimedia Appendices 1 and 2). At the design stage, we anticipated that participant reports would not systematically comply with the response rules. We therefore prospectively included variants of possible responses in the automatic response system created in FrontlineSMS to optimize interactions with participants. At the end of the project, investigators manually reviewed all answers and recoded them when necessary to have standardized answers for each question, to calculate response times, and to simplify data aggregation and analysis.

Analysis

We used descriptive statistics to characterize households and electronic reports and the t test to compare means. A significance level of .05 was prespecified for all comparisons. The Pan American Health Organization (PAHO) publishes in the Health Intelligence Platform [32] the weekly number of laboratory-confirmed cases of respiratory viruses. In Guatemala, information is based on samples collected by sentinel surveillance sites: we calculated the Pearson correlation test to investigate the correlation between the number of electronically identified ILI cases in participants' reports and the official number of reported, laboratory-confirmed cases of influenza and other respiratory viruses (respiratory syncytial virus [RSV], metapneumovirus, adenoviruses, and parainfluenza viruses) published by PAHO, for Guatemala. We hypothesized that there would be a weak to moderate positive correlation ($.20 \leq r \leq .59$) between the number of electronically identified ILI cases and the number of reported, laboratory-confirmed cases of respiratory virus during the study period. Costs incurred for text messages, participant compensation, electricity, rental space, and personnel are presented in US dollars. We summarized age information of electronically identified ILI cases by age group of people at high risk for developing flu-related complications (children younger than 5 years and adults 65 years of age and older). Statistical analysis was conducted using STATA, version 13.0 for Macintosh, and Microsoft Excel for Mac 2011. On the basis of the Centers of Disease Control and Prevention (CDC) Updated Guidelines for Evaluating Public Health Surveillance Systems [33], we assessed, in Discussion, the simplicity, flexibility, acceptability, stability, timeliness, representativeness, and data quality of the system. All data generated or analyzed during this study are included in this published paper and its Multimedia Appendices. Further information from the study can be requested from the corresponding author on reasonable request.

Ethics Approval

This study was conducted in accordance with all applicable local regulatory requirements and the principles of the Declaration of Helsinki. The study was approved by the Ethics Committee of Universidad del Valle de Guatemala on July 5, 2016, and by the Guatemalan National Ethics Committee on August 5, 2016 (resolution 17-2016). Both committees provided ethical oversight during the study.

Results

Demographic Information

Approximately one-fifth (20.41%, 341/1671) of visited households were not eligible because the head of household reported not having a mobile phone at home. The majority of eligible households (85.79%, 1141/1330) refused to participate because of security concerns or lack of credit at the time of enrollment. We recruited the heads of 189 eligible households (14.21%, 189/1330), comprising 584 people.

Among participants, 84.1% (159/189) used feature phones, and 15.9% (30/189) used smartphones. During the home visits, 177 households provided demographic information. The mean age of people at participating homes was 28 years and ranged between 0 and 89 years. The mean age of head of households was 40 years (Table 1).

Only 22.0% (39/177) of participants had access to a fixed telephone line at home. Households in the SMS and app modalities were similar: the t test revealed no significant differences between SMS and app households in terms of the number of people per home, the ages of people living at home, or the ages of the heads of households.

SMS and App Reports

From August 2016 to March 2017, we received 468 reports, a mean of 2.5 reports per participant household (Table 2).

Table 1. Demographic information of participant households.

Indicator	Modality		Total
	SMS[a]	App	
Number of recruited households	160	29	189
Number of people per home	**N=149**	**N=28**	**N=177**
Mean (IQR[b])	3 (2-4)	4 (3-5)	3 (2-4)
Range	1-7	1-6	1-7
Age of people in household	**N=149**	**N=28**	**N=177**
Mean	29	27	28
Median (IQR)	26 (15-42)	23 (15-40)	25 (25-42)
Minimum-maximum	0-89	0-73	0-89
Age of head of household	**N=151**	**N=26**	**N=177**
Mean	40	40	40.3
Median (IQR)	39 (28-51)	39 (25-50)	39 (28-50)
Minimum-maximum	18-83	20-68	18-83
Percentage of homes with	**N=151**	**N=26**	**N=177**
Electricity, n (%)	148 (98.0)	26 (100)	98.3 (17.4)
Running water, n (%)	150 (99.3)	25 (96)	175 (98.9)
Fixed telephone line, n (%)	33 (21.8)	6 (23)	39 (22.0)
Education of head of household	**N=141**	**N=25**	**N=166**
No studies, n (%)	4 (2.8)	1 (4)	5 (3.0)
Some primary school, n (%)	42 (30.0)	5 (20)	47 (28.3)
Some secondary school, n (%)	26 (18.4)	4 (16)	30 (18.1)
Some university, n (%)	69 (48.9)	15 (60)	84 (50.6)

[a] SMS: short message service.

[b] IQR: interquartile range.

Table 2. Reporting from August 2016 to March 2017.

Indicator	SMS[a]	App	Total
Reports per user			
Mean	2.4	2.6	2.5
Minimum-maximum	0-25	0-25	0-25
Participants who			
Sent no reports, n (%)	85 (53.1)	15 (51.7)	100 (52.9)
Sent between 1 and 5 reports, n (%)	56 (35.0)	11 (37.9)	67 (35.5)
Sent between 6 and 15 reports, n (%)	9 (5.6)	1 (3.5)	10 (5.3)
Sent 16 or more reports, n (%)	10 (6.3)	2 (6.9)	12 (6.3)
Age group of ILI[b] cases			
0-5 years	13	7	20
6-64 years	73	22	95
>64 years	0	3	3

[a] SMS: short service message.

[b] ILI: influenza-like illness.

More than four-fifths (83.5%, 391/468) of reports were received via SMS and the remainder (16.4%, 77/468) via the app “Mi Gripe.” Almost nine-tenths (88.0%, 412/468) of reports were received within 24 hours and 93.6% (438/468) within 48 hours of transmission of weekly reminders. Nearly half (47.1%, 89/189) of participants sent one or more reports. Moreover, 12 participants (6.3%, 12/189) sent 16 or more reports during the study.

Nearly three quarters of reports (73.5%, 344/468) indicated that no one at home developed ILI symptoms during the project period. Over a quarter of reports indicated that someone at home developed ILI symptoms (26.5%, 124/468). The 124 reports indicated that 202 individuals presented ILI symptoms during the study (see Figure 2 for weekly details about the number of reported ILI episodes to the electronic platform and the number of official laboratory-confirmed cases of respiratory viruses in Guatemala).

We received age data for 118 of those 202 cases: the majority (80.5%, 95/118) were aged between 6 and 64 years, 16.9% (20/118) were aged between 0 and 5 years, and three (2.6%, 3/118) were 75 years old. Most ILI cases for which we had age data (89.0%, 105/118) occurred among family members rather than the respondent: in 105 cases, the ages of the ILI cases did not correspond to the ages of the heads of households.

According to PAHO data [32], the number of reported, laboratory-confirmed cases of influenza in Guatemala started to increase in epidemiological weeks 6 and 7 of 2016 and started to decrease in week 12, with the end of the influenza season around week 17 of 2016. The number of reported, laboratory-confirmed cases of RSV, metapneumovirus, adenovirus, and parainfluenza started to increase between epidemiological weeks 20 and 23 of 2016 and started to decrease between weeks 40 to 41 of 2016, with the end of the season around week 1 of 2017.

We found a positive correlation (Pearson correlation coefficient=.8) between the number of ILI cases reported to our system and the number of reported, laboratory-confirmed cases of noninfluenza respiratory viruses (RSV, metapneumovirus, adenovirus, and parainfluenza virus) in Guatemala, published by PAHO from epidemiological week 41 in 2016 to 13 in 2017. The correlation was weaker (Pearson correlation coefficient=.6) when we combined the number of reported, laboratory-confirmed cases of influenza and other respiratory virus cases (Table 3).

We found a negative correlation (*r*=−.3) between the number of ILI cases reported to our system and the number of reported, laboratory-confirmed cases of influenza published by PAHO. No correlation was found between positivity for electronically identified ILI (defined as the number of electronically identified cases of ILI divided by the total number of household members involved in weekly reports) and positivity for laboratory-confirmed respiratory viruses in Guatemala in 2016 and 2017 (Multimedia Appendix 3).

Figure 2. Electronically-identified influenza-like illness (ILI) in San Marcos and official respiratory virus surveillance data in Guatemala, 2016 and 2017. *Weekly reminders were not sent to participants from weeks 38 to 40, when the project was interrupted. In week 10 of 2017, the GSM modem was accidentally disconnected from the short message service (SMS) platform and the scheduled reminders were not sent. **Official respiratory virus surveillance activities are normally stopped the last 2 weeks of every year. ***Noninfluenza respiratory viruses for the considered period include the following: respiratory syncytial virus, metapneumovirus, adenovirus, and parainfluenza virus.

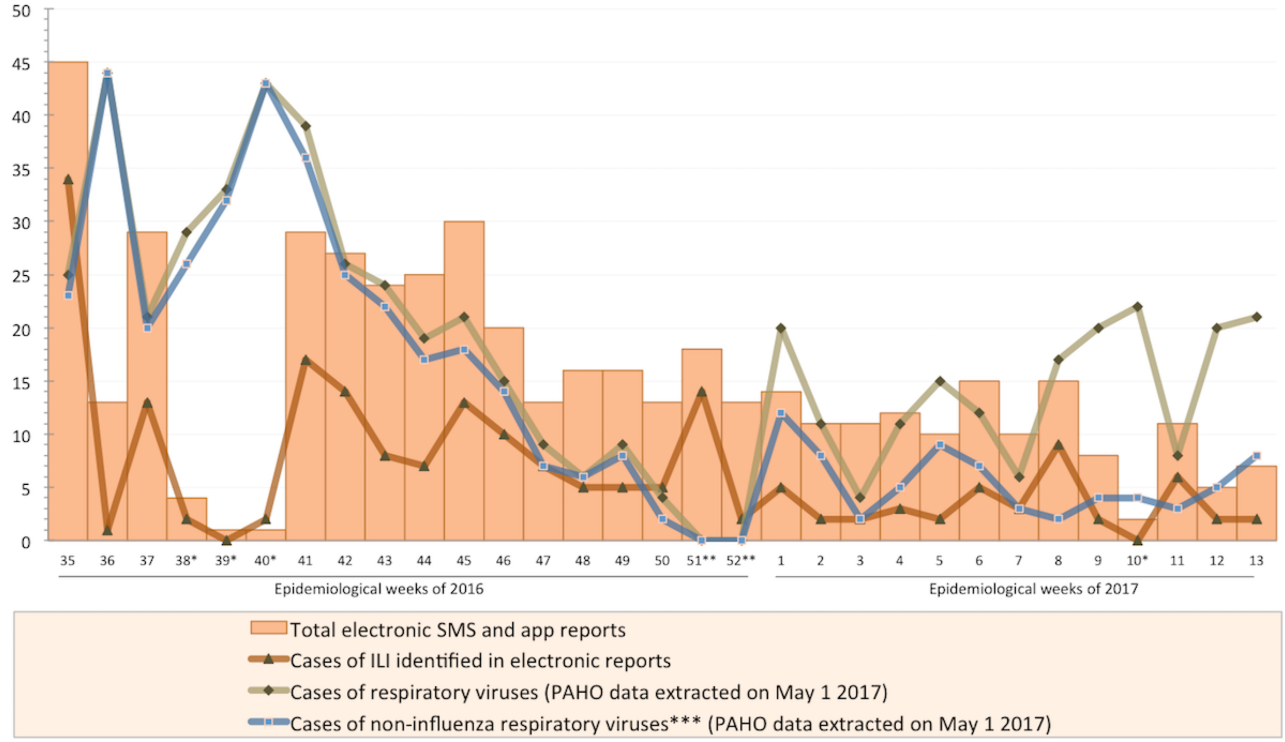


Table 3. Pearson correlation between electronically identified influenza-like illness (ILI) in San Marcos and San Pedro and respiratory virus laboratory data published by the Pan American Health Organization for Guatemala.

Variables	Pearson correlation, *r*	
	From epidemiological week 41 in 2016 to 13 in 2017[a]	From epidemiological week 41 in 2016 to 13 in 2017 (excluding 10, 51, and 52)[b]
Influenza and electronically identified ILI[c]	−.412	−.342
Noninfluenza respiratory viruses and electronically identified ILI	.656	.802
Influenza and other respiratory viruses and electronically identified ILI	.373	.623

[a] The project started in epidemiological week 35 of 2016 and was temporarily interrupted from epidemiological weeks 38 to 40. We considered data from week 41 in 2016 to 13 in 2017 to conduct the correlation analysis.

[b] We excluded weeks 51 and 52 of 2016 because official respiratory virus surveillance activities are stopped during the last 2 weeks of the year, and no official surveillance data are published. We excluded week 10 of 2017 because the GSM modem was accidentally disconnected from the SMS platform and the scheduled reminders were not sent.

[c] ILI: influenza-like illness.

Costs

Running the ILI surveillance system for 7 months cost approximately US $1212.58: one mHealth operator monitored the electronic platforms 3 hours per week during the study, amounting to US $738.21 in personnel; the system sent 5147 text messages, amounting to US $275.24; we reimbursed participants who sent a complete report either via SMS or the app, amounting to US $158.02; and the laptop and the server receiving reports were turned on 24 hours a day for 212 days, amounting to US $5.77 in electricity and US $35.33 in rental space. The cost of identifying one new ILI case in electronic reports was US $6 (details are provided in Multimedia Appendix 4).

Discussion

Summary

The results show the ability of the developed system to capture ILI data that could be used to improve the timeliness and expand the breadth of syndromic surveillance activities. The data collected could be used to rapidly detect localized or unusual circulation of acute respiratory illness. The strategy could be further explored to determine the start of epidemic activity of respiratory viruses each year. This would allow authorities to trigger appropriate public health action such as collecting samples outside of normal surveillance, increasing communication to the public about the need to vaccinate target groups, and promoting nonpharmaceutical interventions to prevent transmission of viruses. The pilot allowed us to monitor the performance of the participatory surveillance system and assess some of its attributes, particularly its simplicity, flexibility, acceptability, stability, timeliness, representativeness, and data quality.

Simplicity, Flexibility, and Timeliness

The system was designed to maximize ease of operation. By using autonomous processes (SMS and app-driven), we minimized time spent on maintaining and monitoring the system. The reporting platform was sufficiently stable: it remained fully functional for 7 months, except for 1 week in March 2017, when the GSM modem was accidentally disconnected from the SMS platform. The reporting platform was accessible through the most popular mobile communication methods in the region. From the user’s perspective, it was designed to be intuitive to maximize acceptability. Nearly half of the participants (47.1%, 89/189) sent at least one report. In total, we received 468 reports through SMS and the app. The rate of long-term, consistently reporting participants in our project (those who sent 16 reports or more) was lower than in a similar project in the United States [10] (6.3% vs 10.4%).

An important characteristic of the system was its timeliness: it generated data more rapidly than official surveillance methods. Almost all (93.6%, 438/468) ILI reports were received within 48 hours of transmission of weekly reminders, whereas the average time between symptoms onset and laboratory tests in sentinel surveillance sites in Guatemala was 161 hours (almost 7 days) in 2014 (data provided by the Department of Epidemiology of the Guatemalan Ministry of Health). The PAHO surveillance data that we used to calculate correlations took 2 to 3 weeks to become public during the study period. In a scaled-up implementation, this approach would allow the enactment of immediate actions while waiting for laboratory results.

Results were derived from reports sent by the heads of participant households. The coding of SMS reports revealed that, even when instructed to do so, the reporters did not consistently comply with the predefined response rules. During the study, we prospectively adjusted keyword-based responses to gradually improve interactions with participants and increase the flexibility of the system. At the end of the project, we recoded the remaining uncategorized reports. Due to the informational benefits of each SMS—rule-compliant or not—associated efforts in developing tools that assist in the interpretation of their meaning are justified. A useful participatory electronic system must be able to capture structured and unstructured data, as well as expected and unexpected data, and transform them into relevant high-quality information in a timely manner [34]. A future version of the system could use this knowledge to train machine-learning algorithms that would automatically code incoming reports and self-increase flexibility.

This would enable the generation of real-time data graphs and statistics for epidemiologists and public health experts. With modest development and configuration efforts, the approach may also make it possible to monitor other syndromes and contribute to the identification of febrile disease outbreaks in the region, such as dengue, chikungunya, or zika. It may also contribute to improved response to disease outbreaks by providing near real-time syndromic data and rapidly detecting localized and unusual incidence of specific symptoms [35-37]. Such information could prompt public health authorities to focus resources on actively sampling cases to determine the etiology of an ILI cluster.

Representativeness, Data Quality, and New Information

The pilot surveillance system was not designed to be representative; it was a proof-of-concept for participatory surveillance in Guatemala. Reports submitted during the study may in fact not be representative of all Guatemalan households either in terms of the incidence of ILI or of willingness to participate in the participatory system. One-seventh (14.21%, 189/1330) of eligible households accepted to participate in the study. The low uptake is consistent with that of similar projects [10] but might be explained by three different factors. First, participants were invited to the project after answering a 1- to 2-hour-long survey. Individuals were fatigued by the lengthy questionnaire and only occasionally wanted to hear about the project. Second, the area of San Marcos in Guatemala is particularly affected by gang violence. The heads of households often communicated their concerns about security to the field personnel when deciding to participate. Third, participants were told that they would be compensated for every report they would send during the study; however, many of them did not have phone credit at enrollment and were not interested in being reimbursed at the end of the month. A more effective strategy could have been to invite participants to the study before conducting the survey, give credit to interested participants before sending reminders, and let participants handle the installation of the app or the saving of the reporting number.

Reports suggest that on 41 occasions (33.1% of reported ILI cases; 41/124), people at home self-medicated and only 27.4% (34/124) of participants who reported ILI symptoms sought medical attention (vs 35% for Flu Near You users [38]). On 50 occasions (40.3% of reported ILI cases; 50/124), medical attention was not sought, thus impeding the collection of samples and a laboratory confirmation of their diagnosis. The project generated information during epidemiological weeks 51 and 52 of 2016, when no official data were published for any respiratory virus in Guatemala [32]. This new information about health-seeking behavior during ILI episodes may be used to estimate the burden of the syndrome in the San Marcos department using recent modeling methods [39,40]; with additional representative data coming from more locations, it might also be used to estimate the burden of ILI in the country, which is likely substantial [41,42]. The approach presented here could contribute to strengthen disease surveillance activities in neighboring countries (Honduras, El Salvador, Nicaragua, and Belize) that have similar challenges in conducting influenza and other respiratory virus surveillance. As highlighted in a recent scientific commentary [43], crowdsourcing could make governments more agile in responding to public health problems. The strategy echoes the European Influenzanet in its ability to monitor ILI in the population, including individuals who do not seek medical attention [22].

Retrospective credit compensation and weekly reminders were used to secure the periodic contributions of participants. The importance of weekly reminders was serendipitously demonstrated; from weeks 39 to 41 in 2016 and in week 10 in 2017, reminders were not sent to participants and the number of reports decreased dramatically (Figure 2). But even when weekly reminders were sent, results reveal that more than half (52.9%, 100/189) of participants did not send reports and almost one quarter (23.3%, 44/189) sent one or two reports only during the study. The finding suggests that new sustainable arrangements and incentives should be tested to motivate a continued participation. The feeding of weekly professional health information in exchange for reports and gamification methods, for example, could be effective ways of engaging citizens in the participatory system [44-46], especially in Latin American countries where access to public health centers is challenging and the demand for health information is expected to intensify [47]. Future systems should exploit lessons learned from related systems, such as Flutracking in Australia [48], to engage and motivate sustained participation. Some of these lessons seem relevant for the Latin-American context (eg, collect minimum answers and invite participants to report on household members [48]), but others (eg, use social media and website analytics or leverage organizational email invitations [48]) should be further explored to create a culturally appropriate and sustainable system in the region.

Electronic Participatory ILI Surveillance Opportunities in the Region

The collected data allowed us to identify 202 cases of ILI at home at a cost of less than US $6.00 per identified case. We did not find a strong correlation between the number of electronically identified ILI and the number of reported, laboratory-confirmed cases of influenza, probably because the 2016 flu season ended around May in Guatemala [32]; however, we found a strong positive correlation (r=.8) between the number of electronically identified ILI and the number of reported, laboratory-confirmed cases of noninfluenza respiratory viruses cases from epidemiological week 41 in 2016 to 13 in 2017 (Table 3; Figure 2), precisely during a period of increased circulation of noninfluenza respiratory viruses. The study shows the viability of capturing valuable citizen-sourced health data and seems more culturally appropriate than other recently studied alternatives [24,30] in the Latin-American realm. Our choice of reporting platforms, SMS and an Android app, maximizes the chances of having a culturally appropriate solution and minimizes additional software development efforts in a scale-up scenario for Central America. We plan to apply lessons learned and measure associations between self-reported ILI and laboratory-confirmed respiratory virus surveillance in a forthcoming, larger-scale crowdsourcing project.

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Authors' Contributions

JTP devised the study, was the principal investigator, and wrote the first draft of this paper. SCK, JJ, and JPA contributed to the study design, interpretation of results, and revised the paper. PJB, LF, CM, and JG contributed to interpretation of results and revised the paper. JTP had full access to all data. All authors read and approved the final manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Processes for the app reporting platform.

[PNG File, 53KB - publichealth_v3i4e87_app1.png]

Multimedia Appendix 2

Processes for the SMS reporting platform.

[PNG File, 67KB - publichealth_v3i4e87_app2.png]

Multimedia Appendix 3

Positivity for electronically identified ILI (defined as the number of electronically identified cases of ILI divided by the total number of household members involved in weekly reports) and positivity for laboratory-confirmed respiratory viruses in Guatemala 2016 and 2017.

[PNG File, 171KB - publichealth_v3i4e87_app3.png]

Multimedia Appendix 4

Dataset and main calculations.

[XLSX File (Microsoft Excel File), 660KB - publichealth_v3i4e87_app4.xlsx]

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Abbreviations

CDC: Centers of Disease Control and Prevention
ILI: influenza-like illness
IQR: interquartile range
mHealth: mobile health
PAHO: Pan American Health Organization
RSV: respiratory syncytial virus
SIM: subscriber identity module
SMS: short message service

UVG: Universidad del Valle de Guatemala

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Corrigenda and Addenda

Reference Correction to: Making Air Pollution Visible: A Tool for Promoting Environmental Health Literacy

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Related Article:

Correction of: http://publichealth.jmir.org/2017/2/e16/

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The authors of “Making Air Pollution Visible: A Tool for Promoting Environmental Health Literacy” (JMIR Public Health Surveill 2017;3(2):e16) would like to make a correction to the text in Reference 26. It should read:

26. An interactive map of traffic pollution for Boston Chinatown. URL: http://chinatown.oicweave.com [accessed 2017-08-14] [WebCite Cache ID 6siTaGLNk]

The corrected article will appear in the online version of the paper on the JMIR website on December 20, 2017, together with the publication of this correction notice. Because this was made after submission to PubMed Central, the corrected article also has been re-submitted to PubMed Central.

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Original Paper

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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Abstract

Background: In using regularly collected or existing surveillance data to characterize engagement in human immunodeficiency virus (HIV) services among marginalized populations, differences in sampling methods may produce different pictures of the target population and may therefore result in different priorities for response.

Objective: The objective of this study was to use existing data to evaluate the sample distribution of eight studies of female sex workers (FSW) and men who have sex with men (MSM), who were recruited using different sampling approaches in two locations within Sub-Saharan Africa: Manzini, Swaziland and Yaoundé, Cameroon.

Methods: MSM and FSW participants were recruited using either respondent-driven sampling (RDS) or venue-based snowball sampling. Recruitment took place between 2011 and 2016. Participants at each study site were administered a face-to-face survey to assess sociodemographics, along with the prevalence of self-reported HIV status, frequency of HIV testing, stigma, and other HIV-related characteristics. Crude and RDS-adjusted prevalence estimates were calculated. Crude prevalence estimates from the venue-based snowball samples were compared with the overlap of the RDS-adjusted prevalence estimates, between both FSW and MSM in Cameroon and Swaziland.

Results: RDS samples tended to be younger (MSM aged 18-21 years in Swaziland: 47.6% [139/310] in RDS vs 24.3% [42/173] in Snowball, in Cameroon: 47.9% [99/306] in RDS vs 20.1% [52/259] in Snowball; FSW aged 18-21 years in Swaziland 42.5% [82/325] in RDS vs 8.0% [20/249] in Snowball; in Cameroon 15.6% [75/576] in RDS vs 8.1% [25/306] in Snowball). They were less educated (MSM: primary school completed or less in Swaziland 42.6% [109/310] in RDS vs 4.0% [7/173] in Snowball, in Cameroon 46.2% [138/306] in RDS vs 14.3% [37/259] in Snowball; FSW: primary school completed or less in Swaziland 86.6% [281/325] in RDS vs 23.9% [59/247] in Snowball, in Cameroon 87.4% [520/576] in RDS vs 77.5% [238/307] in Snowball) than the snowball samples. In addition, RDS samples indicated lower exposure to HIV prevention information, less knowledge about HIV prevention, limited access to HIV prevention tools such as condoms, and less-reported frequency of sexually transmitted infections (STI) and HIV testing as compared with the venue-based samples. Findings pertaining to the level of disclosure of sexual practices and sexual practice–related stigma were mixed.

Conclusions: Samples generated by RDS and venue-based snowball sampling produced significantly different prevalence estimates of several important characteristics. These findings are tempered by limitations to the application of both approaches in practice. Ultimately, these findings provide further context for understanding existing surveillance data and how differences in methods of sampling can influence both the type of individuals captured and whether or not these individuals are representative of the larger target population. These data highlight the need to consider how program coverage estimates of marginalized populations are determined when characterizing the level of unmet need.

(JMIR Public Health Surveill 2017;3(4):e72) doi:10.2196/publichealth.8116

KEYWORDS

HIV; public health surveillance; health surveys; sex work; sexual minorities; homosexuality, male; Cameroon; Swaziland

Introduction

Background

Although probability sampling is often preferred over nonprobability sampling for ensuring representativeness, there is no gold standard method for measuring the coverage of health services for marginalized populations and, consequently, the magnitude of the gaps in service coverage. This gap in characterization of health service needs is true for a number of different health conditions, including, especially, in the realm of human immunodeficiency virus (HIV). HIV key populations include gay men and other men who have sex with men (MSM), female sex workers (FSW), people who inject drugs, and transgender people. Despite much recent progress that has been made toward reducing the incidence of HIV globally, these key populations continue to bear a significant proportion of the HIV burden across high-, middle-, and low-income countries [1-9]. In a wide range of settings, these same populations have been shown to have suboptimal engagement in the HIV care cascade far below the 90-90-90 goals established by the Joint United Nations Program on HIV/AIDS for 2020 [10]. The stigma affecting these key populations, including stigma from health care workers, friends and family, and community members, makes relying on traditional passive biological and behavioral surveillance methods, such as population-based surveys and sexually transmitted disease (STD) or health clinic surveillance, challenging. Stigma may cause the members of key populations to hide their membership and not want to disclose to others their key population defining behavior. This is especially the case in Sub-Saharan African regions where sex work and sex between men is, generally, criminalized, and the HIV epidemic is often widespread. In addition to the issue of stigma, the lack of a traditional sampling frame for key population groups also makes relying on traditional passive surveillance methods difficult [4].

To get a sense of the disproportionate burden of HIV faced by these key populations, the adult prevalence (aged 15-49 years) of HIV, in Cameroon, for example, is 4.5%, with an estimated prevalence of 37% among MSM according to a respondent-driven sampling (RDS) study, and 24% among FSW in a meta-analysis [11-13]. In Swaziland, a nation experiencing a broadly generalized HIV epidemic with around 26% of people aged 15 to 49 years living with HIV, prevalence is about 13% in MSM and approximately 61% among FSW according to RDS studies [14,15]. In Swaziland and Cameroon, both sex work and sex between men are criminalized, with punishment ranging from fines to imprisonment [16-18].

Whereas key populations remain hard to sample in many settings, multiple recruitment strategies have been developed to improve sampling as a means of characterizing current gaps in service coverage [19]. These approaches can be broadly characterized as those that either leverage networks of key populations or those that focus on geographic hotspots—where groups of key populations congregate, such as brothels, gay clubs, or venues where HIV prevention, treatment, and care services are available [20,21]. Specifically, these approaches have often been used to assess the burden of HIV and other sexually transmitted infections (STI), as well as the current coverage of evidence-based services. Although there remains no universal standard for sampling key populations, the implications of using a particular sampling approach appear to be significant [22]. The results often are used to define the current coverage of services and, in turn, the necessary investment for HIV prevention, care, and treatment services for key populations [23-25]. Many studies seek to enroll generalizable samples of MSM and FSW to measure important indicators related to the HIV epidemic and to inform public health programs. However, concerns about insufficient data quality may delay or impede resource allocation decisions [26].

Two of the most commonly used strategies for sampling hard-to-reach populations are snowball sampling and respondent-driven sampling (RDS) [21,27]. Snowball sampling is a process in which seeds are utilized to recruit peers, although the relationship between recruiters and recruits and personal network size are not documented. In snowball sampling, the number of waves reached and the number of coupons issued per recruit is not considered, and the number of seeds can be as high as needed. In addition, sampling biases cannot be adjusted for. The final sample composition is often largely influenced by the initial nonrandom choice of seeds, which also tend to bias participation toward those who are a part of larger social networks [28,29]. Similarly, RDS uses initial recruits or *seeds* to recruit peers through waves of recruitment and allows for calculation of selection probabilities [28-30]. In RDS, the relationship between recruiters and recruits is documented so that recruitment biases can be adjusted and assessed in the analysis [28,29,31,32]. In addition, RDS captures the social network sizes of individuals, so that these can also be taken into account and adjusted for in the analyses [28,29,31,32]. Given the time, resources, and other practical constraints, RDS and snowball sampling can also be used in conjunction with geographical approaches as an alternative to traditional probability and nonprobability sampling strategies by targeting the sampling of key populations at hotspot venues [20,21]. In this study, two of our samples utilized venue-based snowball sampling in which key informants, who worked at community organizations, establishments, clinics, and programs serving MSM or FSW, identified the venues. Study staff visited MSM and FSW venues, and participants were approached at each of the venues to provide an informed written consent and complete the interviewer-administered survey. In many locations, venue managers or key community leaders acted as key informants and assisted the staff in identifying MSM and FSW and facilitating introductions.

Objective

In this study, we aimed to analyze and compare existing data collected from FSW and MSM using RDS and venue-based snowball sampling approaches in two locations within Sub-Saharan Africa: Manzini, Swaziland and Yaoundé, Cameroon. We compared these samples by a number of characteristics to determine the impact of sampling methodology on inference about these populations. In particular, we examined the prevalence of sociodemographics, self-reported HIV status, frequency of HIV testing, level of experienced stigma, and other HIV-related characteristics. In comparing these characteristics across different samples, we hoped to gain a greater understanding of how sampling methodology influences the type of individuals captured and whether differences in sampling methodology result in differences in underlying target population being measured. Due to the ability of RDS to generate large numbers of recruitment waves [33], we hypothesized that the RDS studies would generate samples with a larger range of HIV prevention and treatment needs than those samples recruited through venue-based snowball samples.

Methods

Data Collection and Key Measures

These analyses represent post hoc analyses of data collected by the study investigators. Data were initially collected for HIV bio-behavioral surveillance and population size estimation of MSM and FSW populations in multiple cities in Swaziland [33-39] and Cameroon [40,41]. Manzini and Yaoundé were selected for analyses because these were the only cities in which data were collected for both MSM and FSW using both RDS and venue-based snowball sampling. A summary of the data collection process and key measures is provided below, with more detailed descriptions of study methods provided in Table 1.

Swaziland

In Manzini, Swaziland, we recruited 326 MSM and 325 FSW participants using RDS between July and December 2011. A total of 173 MSM and 249 FSW were recruited through snowball sampling through outreach at *hotspot* venues in and near Manzini between October and November 2014. The venues were determined by key informant interviews and then verified by study staff. Outreach at those venues, including referrals, served as the basis for snowball sampling. During all study visits, participants were administered a structured survey instrument that included measures of sociodemographics, self-identified sexual orientation (for MSM), sexual behavior–related stigma, disclosure of sexual practices to family members and health care providers, access to relevant HIV prevention information, HIV-related knowledge, ease in accessing condoms, sexual risk behaviors, and HIV/STI testing and diagnoses [42].

We assessed participants' level of sexual behavior–related stigma by asking them whether they had ever felt excluded from family gatherings or were afraid to seek health care because of same-sex practices or selling sex, for MSM and FSW, respectively. Disclosure of sexual practices was measured by asking participants whether they had ever told any member of their family or any health care worker that they have sex with other men or that they sell sex. Access to HIV prevention information was measured by asking MSM participants whether they had received any HIV prevention information on sex between men in the past 12 months. Among FSW, this was measured by asking whether participants received any HIV prevention information in the past 12 months. HIV-related knowledge was measured by asking all participants what type of sex carries the most sexual risk for HIV, and what type of lubricant is safest to use for vaginal or anal sex. In addition, participants were asked how difficult or easy it was to access condoms when they need them. Response options were dichotomized to "some access" or "easy access" and "difficult" or "little access." Network size was captured through self-report. Question-and-answer responses were phrased in the same way across recruitment strategies and for both populations.

For MSM sexual risk behaviors, we assessed the participant's reported number of male anal sex partners within the past 12 months and whether they had any condomless anal sex in the past 12 months. For FSW, we asked the participants to report their average number of clients per week. There were no comparable condom-use questions for FSW across the RDS and snowball studies. All participants were asked to report whether they had been tested for HIV or STI in the past 12 months. In addition, all participants were asked if they had ever been told by a doctor or health care provider that they have HIV.

Cameroon

In Yaoundé, Cameroon, 306 MSM were recruited through RDS from November 2015 to January 2016 and 576 FSW from December 2015 to February 2016. The snowball sampling studies accrued 259 MSM and 308 FSW at venues frequented by these groups between April and May 2013. Similar to Swaziland, venues were determined through key informant interviews and then leveraged as a basis for snowball sampling of key populations.

Similar to the Swaziland studies, all participants in Cameroon were administered a questionnaire that included questions about sociodemographics, self-identified sexual orientation (for MSM), sexual behavior–related stigma, disclosure of sex work to health care providers (FSW), whether any family members knew that they had sex with men (for MSM), and HIV/STI testing and diagnoses. Network size was captured through self-report. Question-and-answer responses, again, were phrased in the same way across recruitment strategy and for both populations. However, information regarding access to relevant HIV prevention information, HIV-related knowledge, ease in accessing condoms, and sexual risk behaviors were either not available or not comparable across recruitment studies and were not included in these analyses.

Table 1. Detailed description of study methods.

Study population (recruitment dates)	Detailed sampling methods[a]	Eligibility criteria[b]
Respondent-driven sampling[c]	Seeds were recruited from local MSM- or FSW-affiliated communicated-based organizations (although not all seeds were members. Each participant was given three coupons to distribute. Sample size calculations for the initial data collection were powered based on the ability to estimate local HIV prevalence of MSM and FSW, and the required sample sizes were achieved.	Possess valid recruitment coupon
Swaziland[d] (July - December 2011)		
MSM	4 of 5 seeds successfully accrued 326 men through up to 14 waves. A few participants (n=16) could not be traded back to valid sees and were excluded post-hoc.	Report receptive or insertive anal sex with another man for the last 12 months
FSW	10 of 14 seeds successfully recruited 325 FSW through up to 7 waves	Report exchanging sex for money, favors, or goods in last 12 months
Cameroon[e]		
MSM (November 2015 - January 2016)	2 of 4 MSM seeds successfully accrued 306 men through up to 12 waves	Report receptive or insertive anal sex with another man for the last 12 months
FSW (December 2015 - February 2016)	2 of 3 seeds successfully recruited 576 FSW through up to 22 waves	Report more than half income in the past 12 months from sex work
Snowball sampling	Participants were recruited through snowball sampling at “hotspot” venues. MSM and FSW venues were visited by study staff, and participants were approached at each of the venues to provide informed written consent and completed the interviewer-administered survey. In many locations, venue managers or key community leaders acted as key informants and assisted staff in identifying MSM and FSW and facilitating introductions.	
Swaziland[d] (October - November 2014)	A modified version of the PLACE method [43] was used to characterized venues where MSM and FSW meet new potential sexual partners.	
MSM	173 MSM were recruited. 7 unique venues in Manzini/Matsapha were mapped and 2 were sampled from.	Report receptive or insertive anal sex with another man for the last 12 months
FSW	249 FSW were recruited. 12 venues were mapped and 2 were sampled from.	Report exchanging sex for money, favors, or goods in last 12 months
Cameroon[e] (April - May 2013)		
MSM	259 MSM were recruited. 4 unique venues were mapped and 3 were sampled from.	Report receptive or insertive anal sex with another man for the last 12 months
FSW	308 FSW were recruited. 15 venues were both mapped and sampled from.	Report more than half income in the past 12 months from sex work

[a] All surveys were conducted using face-to-face interviews in private locations.

[b] All participants had to be at least 18 years of age.

[c] Recruiters were additionally compensated the equivalent of up to US $2 for each participant they recruited into the study.

[d] Participants were reimbursed for their time and travel to the study site dependent on distance traveled to and from the study site.

[e] Participants were reimbursed for the average cost of a meal and transportation (~US $5).

Ethics

Data collection was approved by the Swaziland Ministry of Health and Scientific Ethics and the Cameroon National Ethics Committee. All studies were also approved by the institutional review board of the Johns Hopkins School of Public Health.

Statistical Analysis

Crude prevalence estimates were generated for each sample; additionally, 95% CIs were generated for RDS samples. For the RDS samples, RDS-adjusted prevalence estimates (RDS-I estimator) and 95% CIs were created using Respondent-Driven Sampling Analysis Tool (RDSAT Version 7.0, Cornell University, Ithaca, New York). To assess whether or not it was likely that RDS samples had become independent from seed selection, we reported the wave number at which equilibrium was reached. Equilibrium was measured by calculating the cumulative sample proportions of a variable at each wave. When the proportions came within 2% of the final sample proportions at a particular wave, and did not fluctuate more than 2% during the sampling of additional waves, then that wave was considered the *point* of equilibrium [28]. Samples that accrued several waves beyond equilibrium were more likely to be independent from the nonrandom choice of seeds [28]. Crude prevalence estimates from the venue-based snowball samples were compared with the overlap of the RDS-adjusted prevalence estimates between both FSW and MSM in Cameroon and Swaziland.

Results

Swaziland

In Manzini, Swaziland, MSM who were recruited using venue-based snowball sampling in 2014, as compared with those recruited through RDS in 2011, tended to be older than 26 years, less likely to belong to the youngest age group (18-21 years), more highly educated, more likely to be employed, less likely to be a student, and less likely to be single/never married (Table 2). In addition, MSM recruited using venue-based snowball sampling were more likely to have received MSM-specific HIV prevention information within the past 12 months, were more likely to report having access or easy access to condoms when they needed them, were less likely to report condomless anal sex in the past 12 months, more likely to report 5 or more sexual partners in the past 12 months, and more likely to have had an STI test in the past 12 months. Venue-based snowball-recruited MSM were also more likely to know what type of sex was riskiest for HIV transmission. Among those self-reporting not living with HIV, MSM recruited using snowball sampling were also more likely to have taken an HIV test in the past 12 months. Finally, MSM recruited using snowball sampling in 2014 were less likely to have disclosed their sexual practices to a health care provider and were less likely to report being afraid to seek health care services.

FSW in Manzini, Swaziland, who were recruited using venue-based snowball sampling in 2014 as compared with RDS in 2011 were older and more highly educated (Table 3). They also had greater levels of HIV prevention knowledge, were more likely to know that anal sex carries the most sexual risk for HIV and that water-based lubricant is the safest type of lubricant to use for vaginal sex. FSW who were recruited using venue-based snowball sampling in 2014 reported greater ease in accessing condoms when they needed them, were more likely to report 10 or more clients per week, were more likely to report having an STI test in the past 12 months, were less likely to self-report being living with HIV, were less likely to have disclosed selling sex to family members, were less likely to feel excluded by family members because of selling sex, were less likely to have disclosed to a health care worker that she sells sex, and were less likely to be afraid of seeking health care services because she sells sex. Among those who self-reported not living with HIV, FSW who were recruited using snowball sampling in 2014 were more likely to report having an HIV test in the past 12 months.

Cameroon

Among MSM in Yaoundé, Cameroon, compared with those recruited by RDS in 2015-2016, those recruited using venue-based snowball sampling in 2013 tended to be less likely to belong to the youngest (18-21 year) age group, were less likely to have completed only up to a primary school education, were more likely to have completed secondary school/high school, were more likely to be employed, and were less likely to be a student (Table 4). Those recruited using snowball sampling in 2013 were more likely to have received an HIV test in the past 12 months, among those who were not aware of living with HIV. They were also more likely to self-report as not living with HIV and were less likely to self-report being not tested. Finally, those recruited using snowball sampling in 2013 were less likely to report that family members know they have sex with men, were less likely to be treated poorly in a health care center, were more likely to feel like police refuse to protect them, and were more likely to be blackmailed because of having sex with men.

For FSW in Yaoundé, Cameroon, those who were recruited using snowball sampling in 2013 as compared with RDS in 2015-2016 were less likely to belong to the youngest age group (18-21 years), were more likely to be married, were less likely to have completed only a primary school education, and were more likely to have completed secondary school or high school (Table 5). FSW recruited using snowball sampling were more likely to self-report as HIV-negative, were less likely to self-report as HIV-positive, but similarly likely to report having never tested for HIV. Finally, FSW recruited using snowball sampling were more likely to have told a health care worker that she sells sex and were more likely to report feeling like police refused to protect her because she sells sex.

Table 2. Crude and respondent-driven sampling (RDS)-adjusted prevalence estimates from men who have sex with men (MSM) recruited using snowball sampling and RDS methods in Manzini, Swaziland.

Characteristics	Snowball	RDS (N=310)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[a]
Age (years)				
18-21	42 (24.3)	139 (44.8)	47.6 (39.2-57.0)	5
22-25	54 (31.2)	94 (30.3)	29.6 (22.4-36.9)	5
26+	77 (44.5)	77 (24.8)	22.8 (16.2-30.0)	7
Education completed				
Primary school or lower	7 (4.0)	109 (35.2)	42.6 (33.3-51.4)	4
Secondary school/high school	88 (50.9)	133 (42.9)	42.4 (34.5-50.5)	9
More than high school	84 (45.1)	68 (21.9)	15.0 (10.0-21.0)	4
Employment status				
Unemployed	61 (35.3)	96 (32.3)	29.2 (22.3-36.1)	7
Student	28 (16.2)	101 (34.0)	40.0 (30.1-47.7)	7
Employed	84 (48.6)	100 (33.7)	30.8 (23.8-41.0)	7
Single/never married				2
Yes	147 (90.7)	295 (96.1)	96.6 (93.0-99.4)	
No	15 (9.3)	12 (3.9)	3.4 (0.6-7.0)	
Sexual orientation				
Heterosexual	2 (1.2)	5 (1.6)	3.0 (0.1-7.5)	4
Bisexual	59 (35.1)	112 (36.4)	41.4 (33.6-49.5)	7
Gay/homosexual	107 (63.7)	191 (62.0)	55.6 (47.3-63.1)	7
Received HIV prevention info on sex between men, past 12 months				5
Yes	122 (73.5)	83 (26.9)	79.3 (74.2-84.8)	
No	44 (26.5)	226 (73.1)	20.7 (15.2-25.8)	
Knowledge of what type of sex is riskiest for HIV transmission				7
Yes	69 (40.1)	74 (24.0)	20.4 (14.5-27.0)	
No	103 (59.9)	235 (76.1)	79.6 (73.0-85.5)	
Knowledge of what type of anal sex is riskiest for HIV transmission				7
Yes	51 (29.7)	93 (30.0)	29.2 (23.2-36.4)	
No	121 (70.4)	217 (70.0)	70.8 (63.6-76.8)	
Ease in accessing condoms				5
Access or easy access	155 (90.1)	249 (80.8)	82.3 (76.2-87.6)	
Difficult or little access	17 (9.9)	59 (19.2)	17.7 (12.4-23.8)	
Condomless anal sex, past 12 months				6
Yes	56 (34.8)	132 (49.3)	49.3 (39.8-58.4)	
No	105 (65.2)	136 (50.7)	50.7 (41.6-60.2)	
Number of male anal sex partners, past 12 months				
1	54 (32.5)	143 (46.7)	52.5 (43.8-59.8)	8
2-4	73 (44.0)	133 (43.5)	41.1 (34.1-49.0)	6
5 or more	39 (23.5)	30 (9.8)	6.5 (3.3-10.1)	3
STI test in past 12 months				3

Characteristics	Snowball	RDS (N=310)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[a]
Yes	78 (45.3)	40 (13.2)	15.1 (9.8-21.2)	
No	94 (54.7)	263 (86.8)	84.9 (78.8-90.2)	
HIV test in past 12 months, among those not living with HIV				9
Yes	121 (89.0)	152 (52.9)	52.1 (44.0-60.7)	
No	15 (11.0)	138 (47.1)	47.9 (39.3-56.0)	
Self-reported HIV status				7
Negative/don’t know/not tested	135 (92.5)	285 (94.4)	94.4 (88.6-97.5)	
Positive	11 (7.5)	17 (5.6)	5.6 (2.5-11.4)	
Told family he has sex with men				4
Yes	77 (44.5)	166 (53.5)	41.7 (36.1-50.3)	
No	96 (55.5)	144 (46.5)	58.3 (49.7-63.9)	
Felt excluded from family because he has sex with men				4
Yes	37 (21.4)	80 (25.8)	28.5 (22.0-36.2)	
No	136 (78.6)	230 (74.2)	71.5 (63.8-78.0)	
Told health care worker he has sex with men				5
Yes	36 (21.3)	94 (30.3)	25.7 (20.4-32.4)	
No	133 (78.7)	216 (69.7)	74.3 (67.6-79.6)	
Afraid to seek health care because he has sex with men				9
Yes	42 (24.3)	173 (56.4)	60.4 (52.1-67.9)	
No	131 (75.7)	134 (43.6)	39.6 (32.1-47.9)	

[a] Respondent-driven sampling (RDS) recruitment wave number at which equilibrium was reached for given variable.

Table 3. Crude and respondent-driven sampling (RDS)-adjusted prevalence estimates from female sex workers (FSW) recruited using snowball sampling and RDS methods in Manzini, Swaziland.

Characteristics	Snowball	RDS (N=325)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[a]
Age (years)				
18-21	20 (8.0)	82 (25.2)	42.5 (31.6-49.6)	6
22-25	63 (25.3)	85 (26.2)	22.9 (20.5-32.1)	4
26+	166 (6.7)	158 (48.6)	34.6 (25.4-42.1)	5
Education completed				
Primary school or lower	59 (23.9)	281 (86.5)	86.6 (78.7-92.3)	3
Secondary school/high school	166 (67.2)	40 (12.3)	11.2 (6.9-17.8)	3
More than high school	22 (8.9)	4 (1.2)	2.2 (0-5.7)	1
Single/never married				4
Yes	210 (85.4)	285 (88.8)	89.6 (86.4-95.4)	
No	36 (14.6)	36 (11.2)	10.4 (4.6-13.6)	
Received HIV prevention info, past 12 months				3
Yes	211 (85.1)	276 (86.0)	84.0 (77.8-91.7)	
No	37 (14.9)	45 (14.0)	16.0 (8.3-22.2)	
Knowledge of what type of sex is riskiest for HIV transmission				2
Yes	62 (25.1)	34 (10.5)	7.0 (4.4-11.5)	
No	185 (74.9)	290 (89.5)	93.0 (88.5-95.6)	
Knowledge that water-based lubricant is safest for vaginal sex				5
Yes	73 (29.7)	39 (12.1)	10.4 (4.9-15.9)	
No	173 (70.3)	284 (87.9)	89.6 (84.1-95.1)	
Knowledge that water-based lubricant is safest for anal sex				4
Yes	26 (10.6)	23 (7.3)	3.3 (1.8-6.2)	
No	219 (89.4)	293 (92.7)	96.7 (93.8-98.2)	
Ease in accessing condoms				4
Access or easy access	242 (98.0)	266 (83.1)	87.3 (82.3-90.9)	
Difficult or little access	5 (2.0)	54 (16.9)	12.7 (9.1-17.7)	
Number of clients per week				
0-3	55 (22.5)	95 (29.9)	36.3 (25.9-42.9)	3
4-9	104 (42.6)	143 (45.0)	46.4 (39.3-54.9)	5
10 or more	85 (34.8)	80 (25.2)	17.3 (12.8-25.6)	4
STI test in past 12 months				4
Yes	145 (58.7)	89 (27.5)	24.9 (19.4-31.6)	
No	102 (41.3)	235 (72.5)	75.1 (68.4-80.6)	
HIV test in past 12 months, among those not living with HIV				4
Yes	121 (83.4)	92 (62.6)	55.5 (45.9-80.1)	
No	24 (16.6)	55 (37.4)	44.5 (19.9-54.1)	
Self-reported HIV status				5
Negative/don’t know/not tested	142 (61.7)	146 (45.3)	44.5 (38.5-53.2)	
Positive	88 (38.3)	176 (54.7)	55.5 (46.8-61.5)	

Characteristics	Snowball	RDS (N=325)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[a]
Told family she sells sex				3
Yes	45 (18.9)	98 (30.2)	24.8 (19.2-32.0)	
No	203 (81.9)	226 (69.8)	75.2 (68.0-80.8)	
Felt excluded from family because she sells sex				4
Yes	32 (13.0)	124 (38.3)	37.5 (28.9-43.2)	
No	215 (87.0)	200 (61.7)	62.5 (56.8-71.1)	
Told health care worker she sells sex				5
Yes	20 (8.1)	84 (25.9)	14.6 (10.4-20.5)	
No	226 (91.9)	240 (74.1)	85.4 (79.5-89.6)	
Afraid to seek health care because she sells sex				4
Yes	38 (15.3)	143 (44.0)	41.2 (32.9-47.9)	
No	211 (84.7)	182 (56.0)	58.8 (52.1-67.1)	

[a] Respondent-driven sampling (RDS) recruitment wave number at which equilibrium was reached for given variable.

Table 4. Crude and respondent-driven sampling (RDS)-adjusted prevalence estimates from men who have sex with men (MSM) recruited using snowball sampling and RDS methods in Yaoundé, Cameroon.

Characteristics	Snowball	RDS (N=306)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[a]
Age (years)				
18-21	52 (20.1)	99 (32.4)	47.9 (35.7-57.5)	9
22-25	101 (39.0)	106 (34.6)	32.6 (23.6-43.6)	6
26+	106 (40.9)	101 (33.0)	19.5 (13.6-27.6)	9
Education completed				
Primary school or lower	37 (14.3)	138 (45.1)	46.2 (35.9-57.4)	9
Secondary school/high school	112 (43.2)	29 (9.5)	15.3 (6.9-24.8)	8
More than high school	110 (42.5)	139 (45.4)	38.5 (29.2-48.4)	9
Employment status				
Unemployed	31 (12.5)	51 (16.8)	12.9 (7.4-20.6)	7
Student	103 (41.5)	159 (52.3)	63.8 (53.3-73.3)	8
Employed	114 (46.0)	94 (30.9)	23.4 (15.0-32.5)	7
Married				4
Yes	7 (2.7)	9 (2.9)	1.0 (0.3-2.2)	
No	251 (97.3)	297 (97.1)	99.0 (97.8-99.7)	
Sexual orientation				
Heterosexual	3 (1.2)	1 (0.3)	1.5 (0.0-4.1)	4
Bisexual	158 (62.0)	187 (61.9)	59.4 (50.1-70.5)	11
Gay/homosexual	94 (36.9)	114 (37.8)	39.2 (28.2-49.0)	11
HIV test in past 12 months, among those not living with HIV				11
Yes	188 (88.7)	152 (67.6)	55.9 (42.3-73.3)	
No	24 (11.3)	73 (32.4)	44.1 (26.7-57.7)	
Self-reported HIV status				
Negative	212 (88.3)	174 (59.8)	60.6 (48.8-71.4)	7
Positive	14 (5.8)	65 (22.3)	15.1 (8.6-24.5)	10
Not tested	14 (5.8)	52 (17.9)	24.3 (14.2-34.7)	11
Family knows he has sex with men				7
Yes	117 (45.5)	182 (59.5)	57.9 (48.1-67.7)	
No	140 (54.5)	124 (40.5)	42.1 (32.3-51.9)	
Treated poorly in health care center because he has sex with men				6
Yes	10 (3.9)	27 (8.8)	7.4 (3.6-12.0)	
No	248 (96.1)	279 (91.2)	92.6 (88.0-96.4)	
Felt like police refused to protect him because he has sex with men				9
Yes	39 (15.1)	26 (8.5)	7.1 (3.6-11.9)	
No	219 (84.9)	280 (91.5)	92.9 (88.1-96.4)	
Blackmailed because he has sex with men				7
Yes	116 (45.3)	113 (36.9)	32.6 (24.0-42.3)	
No	140 (54.7)	193 (63.1)	67.4 (57.7-76.0)	

[a] Respondent-driven sampling (RDS) recruitment wave number at which equilibrium was reached for given variable.

Table 5. Crude and respondent-driven sampling (RDS)-adjusted prevalence estimates from female sex workers (FSW) recruited using snowball sampling and RDS methods in Yaoundé, Cameroon.

Characteristics	Snowball	RDS (N=576)		
	n (%)	n (%)	Adjusted % (95% CI)	Equilibrium wave[b]
Age (years)				
18-21	25 (8.1)	75 (13.0)	15.6 (10.3-19.0)	12
22-25	68 (22.1)	129 (22.4)	26.7 (21.8-33.1)	15
26+	215 (69.8)	372 (64.6)	57.7 (51.2-65.0)	15
Education completed				
Primary school or lower	238 (77.5)	520 (90.3)	87.4 (81.8-92.2)	12
Secondary school/high school	60 (19.5)	22 (3.8)	4.3 (2.4-7.1)	8
More than high school	9 (2.9)	34 (5.9)	8.3 (4.0-13.1)	13
Married				3
Yes	19 (6.3)	17 (3.0)	4.5 (1.9-7.6)	
No	285 (93.8)	559 (97.0)	95.5 (92.4-98.1)	
HIV test in past 12 months, among those not living with HIV				14
Yes	182 (70.3)	291 (70.0)	65.2 (55.7-72.1)	
No	77 (29.7)	125 (30.1)	34.8 (27.9-44.3)	
Self-reported HIV status				
Negative	254 (83.3)	434 (76.3)	76.8 (71.7-81.9)	8
Positive	21 (6.9)	75 (13.2)	10.5 (6.5-14.7)	9
Not tested	30 (9.8)	60 (10.5)	12.7 (8.9-16.7)	10
Told a health care worker that she sells sex				14
Yes	107 (34.7)	85 (14.8)	15.9 (12.1-21.7)	
No	201 (65.3)	491 (85.2)	84.1 (78.3-87.9)	
Treated poorly in health care center because she sells sex				6
Yes	5 (1.6)	3 (0.5)	0.1 (0.0-0.3)	
No	300 (98.4)	573 (99.5)	99.9 (99.7-1.0)	
Felt like police refused to protect her because she sells sex				13
Yes	139 (45.3)	87 (15.1)	13.2 (10.2-17.7)	
No	168 (54.7)	489 (84.9)	86.8 (82.3-89.8)	
Blackmailed because she sells sex				9
Yes	176 (57.9)	305 (53.0)	56.4 (50.7-62.5)	
No	128 (42.1)	270 (47.0)	43.6 (37.5-49.3)	

[a] Respondent-driven sampling (RDS) recruitment wave number at which equilibrium was reached for given variable.

Discussion

Principal Findings

In these secondary analyses, the Swaziland and Cameroon studies that recruited MSM and FSW using RDS and venue-based snowball sampling methods produced samples that had different compositions for key sociodemographic, stigma, and HIV-related characteristics. In particular, the RDS as compared with the venue-based snowball samples were younger, less educated, had reduced exposure to HIV prevention interventions, had limited access to HIV prevention tools such as condoms, and showed less-reported frequency of STI and HIV testing. MSM and FSW in Swaziland recruited using venue-based snowball sampling as compared with RDS reported larger numbers of sexual partners and sex work clients, respectively, suggesting larger sexual and personal network sizes for individuals in these samples.

In the context of health and HIV surveillance, our snowball sampling studies in Cameroon and Swaziland leveraging *hotspot* venues estimated much higher coverage of services, such as

HIV and STI testing and access to condoms, compared with the studies conducted using RDS. Despite the fact that the intent of all of the studies was to capture the same underlying target population, the results presented here suggest that the two sampling methodologies might reach different subgroups of this population.

These analyses are based on studies that were previously conducted for the objective of conducting HIV bio-behavioral surveillance of key populations, and the studies similarly had limited time and resources. As a result, there were some limitations to the application of both approaches in practice. For example, with the exception of FSW in Cameroon, only a small number of venues were mapped and sampled from. Of the sampled venues, the majority of participants were recruited from only a single venue (99.4% of MSM in Manzini, 99.2% of FSW in Manzini, 95.8% of MSM in Yaoundé). If a probability sample of individuals had been taken from either a random selection of venues or a set of venues with special attention to diversity of characteristics of venues (eg, large vs small and high-end vs low-end), coverage estimates may have been closer to the true underlying target population. Even then, those sampled at venues, regardless of the number or diversity of characteristics of venues, may not ever provide a representative estimate of all members of the larger target population. In addition, RDS equilibrium was reached late for some variables, suggesting that in some cases RDS may not have achieved the goal of reaching deeper into population networks, and some traits may still have been dependent on seed selection. Thus, our findings may have been different had these studies reached a greater number of venues or penetrated more deeply into social networks. In particular, the results from the venue-based snowball studies are likely very sensitive to whether program services reached the venue from which the vast majority of participants were recruited. Taking into account this caveat, the limited amount of time and resources available, and the similar objectives of each of the studies to conduct HIV bio-behavioral surveillance of MSM and FSW, RDS in this particular context appears to provide a very different estimate of program coverage when compared with venue-based snowball sampling.

As expected, RDS and venue-based snowball sampling differed in the characteristics of key populations recruited, and as expected, the group recruited by convenience sampling was more likely to be linked to a program, as indicated by the fact that the largest differences among samples were seen for services that participants may have received together (HIV prevention materials, improved HIV knowledge, recent HIV and STI testing). It may be especially important when using venue-based sampling to consider the types of venues used for recruitment and whether or not HIV-related services are also offered either at or through these venues. In sampling key populations, it is important to clarify early and often the intended purpose and use of the generated estimates—that is, who really is the target population and who are we really trying to capture with our surveys and surveillance strategies. For example, in the case of MSM, is the purpose of the study or surveillance system to capture all MSM regardless of degree of prevention or treatment need, the most at-risk MSM who are likely hidden and hard-to-reach, or well-connected MSM who already frequent hotspots and facilities that provide HIV services? Without a clear definition of the target population, it will be difficult to even begin to think about a method for sampling that population. Future studies should work to clearly define their target population and to evaluate, given time and cost constraints, which sampling methodology may be the best fit for different definitions of the target population.

As prioritization of resources and targeted interventions requires a representative estimation of service coverage [24], RDS may be a more useful surveillance tool for capturing key populations with varying HIV prevention needs, particularly in settings with limited existing programs and known venues. However, from a program science perspective [44], it may also be useful to conduct studies using alternative sampling methodology every few years to assess the validity of current programs. Discrepant results between samples recruited using different methodology provides some insight into key components that may be missed or exaggerated for program delivery purposes. Other factors to consider for surveillance program implementation include cost efficiency, long-term sustainability, and potential for scale up [45]. Critical analysis of empirical data will be key to integrating evidence-based approaches for surveillance and translating results into effective programs for key populations across different settings.

In a previous analysis, the prevalence of HIV-related characteristics and other sample characteristics were examined across recruitment waves among MSM in Swaziland, Malawi, and Lesotho [33]. Those findings indicated that men who were recruited in later waves of RDS were more likely to have not tested for HIV and to be unaware of living with HIV [33]. It was hypothesized that by reaching higher number of recruitment waves, the composition of the RDS-generated sample shifted toward individuals who were less engaged in existing HIV prevention services. The results presented in the current analyses are supportive of these prior findings, suggesting that RDS can reach MSM with varying HIV prevention needs if sufficient sample sizes and recruitment waves are achieved. However, results from the current analyses were not as consistent across settings among FSW as they were for MSM. For example, FSW recruited using snowball sampling in Swaziland were not more or less likely than FSW recruited using RDS to have received HIV prevention information, and they were less likely to have HIV transmission prevention knowledge. Further, FSW in Cameroon had similar HIV testing histories regardless of how they were recruited. Perhaps this could be partially attributed to more extensive and uniform uptake of and exposure to targeted HIV-related prevention initiatives for sex workers as compared with MSM in the region in recent years [46,47].

In addition, findings pertaining to the relationship of sampling method with level of sexual practice disclosure and sexual practice–related stigma were mixed. This could be because we were limited to using only a limited number of items to assess stigma and disclosure; namely, those items that were used consistently across the different studies. It could be because of structural- or community-level differences in stigma between the two countries and key population groups [16-18]. Both MSM and FSW who were snowball-sampled at venues as compared with RDS-sampled were less likely to have disclosed their sexual practices to family members and health care workers, with the only exception being that snowball-sampled FSW in Cameroon were more likely than RDS-sampled FSW to have disclosed selling sex to health care workers. Although we might expect those with greater levels of disclosure of sexual practices to be more visible at venues and more *visible*, it should be noted that the converse, that those who have not disclosed are therefore less visible, is not necessarily true. With respect to sexual practice–related stigma among the MSM and FSW, snowball-sampled MSM and FSW in Swaziland reported being less afraid to seek health care services than RDS-sampled MSM and FSW. Given the often geographical targeting of programs, the exposure to programs by these populations may have mitigated the fear of seeking services in health care settings. However, MSM and FSW from venues in Cameroon were more likely than their RDS-sampled counterparts to report feeling like police refused to protect them.

Limitations

There are several limitations of this study to consider. First, comparisons across studies should be done with caution because our comparisons were limited to the subset of variables that were most similar across existing datasets. Our results may not be generalizable outside Swaziland and Cameroon, although findings may be comparable to other settings where stigma affecting key populations is prevalent. The venue-based snowball samples were smaller in terms of sample size, and recruitment was for a shorter period of time compared with RDS. In addition, RDS and venue-based snowball studies were conducted between 2 and 3 years apart, making these interpretations potentially subject to a period effect. If the source populations changed over time, then the differences in the sample compositions could be because of differing source populations as opposed to different sampling methodologies. However, there were no changes in HIV prevention policies or laws about sex work or same-sex practices during this time, making it unlikely that the composition of key populations in these two cities changed dramatically over this time frame. Further, RDS was conducted before snowball sampling in Swaziland but was conducted after snowball sampling in Cameroon. However, we cannot rule out the possibility of uncontrolled time-varying confounders or changes to the population-level prevalence of characteristics of MSM or FSW over time.

Conclusions

There remains a sustained and often growing burden of HIV between these two key populations [1-9], reinforcing the need for evidence-based public health and HIV surveillance to inform resource allocation. The findings presented here indicate that samples with varying composition of HIV prevention needs and program exposure are generated by different sampling methodologies. Ultimately, these findings provide further context for understanding existing surveillance data and how differences in methods of sampling can influence both the type of individuals captured and whether or not these individuals are representative of the larger target population. These data highlight the need to consider who we really intend to capture when developing program estimates and how these program coverage estimates of marginalized populations are determined when characterizing the level of unmet need.

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Conflicts of Interest

None declared.

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Abbreviations

FSW: female sex workers
HIV: human immunodeficiency virus
MSM: men who have sex with men
NIH: National Institutes of Health
STI: sexually transmitted infections
RDS: respondent-driven sampling

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Viewpoint

HIV Surveillance Among Pregnant Women Attending Antenatal Clinics: Evolution and Current Direction

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Abstract

Since the late 1980s, human immunodeficiency virus (HIV) sentinel serosurveillance among pregnant women attending select antenatal clinics (ANCs) based on unlinked anonymous testing (UAT) has provided invaluable information for tracking HIV prevalence and trends and informing global and national HIV models in most countries with generalized HIV epidemics. However, increased coverage of HIV testing, prevention of mother-to-child transmission (PMTCT), and antiretroviral therapy has heightened ethical concerns about UAT. PMTCT programs now routinely collect demographic and HIV testing information from the same pregnant women as serosurveillance and therefore present an alternative to UAT-based ANC serosurveillance. This paper reports on the evolution and current direction of the global approach to HIV surveillance among pregnant women attending ANCs, including the transition away from traditional UAT-based serosurveillance and toward new guidance from the World Health Organization and the Joint United Nations Programme on HIV/AIDS on the implementation of surveillance among pregnant women attending ANCs based on routine PMTCT program data.

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KEYWORDS

HIV; surveillance; prenatal; pregnant women; ethics

Introduction

Countries affected by the human immunodeficiency virus (HIV) epidemic require information on trends in HIV prevalence to monitor the course of their HIV epidemics, allocate HIV control resources, and plan programs for HIV prevention and control [1]. Over the last 20 years, HIV serosurveillance has provided valuable information about trends in HIV prevalence among pregnant women attending regular antenatal clinics (ANCs), provided key inputs to HIV epidemic modeling, and—combined with household surveys, key population surveys, and surveillance of sexually transmitted infections (STIs)—allowed programs to address key aspects of the "know your epidemic" approach of second-generation surveillance of HIV [2].

As HIV control programs expanded in coverage and quality, routine HIV testing with return of results was increasingly available to pregnant women attending ANCs. This evolution raised questions about the appropriateness of the serosurveillance approach. From an ethical perspective, testing pregnant women for HIV without their consent or the return of results became increasingly untenable. From a sustainability perspective, the cost and effort of serosurveillance were called into question, given that the provision of HIV testing and the registering of test results were being accomplished routinely.

This paper attempts to summarize the evolution of the global approach to HIV surveillance among pregnant women attending ANCs, including origins of ANC serosurveillance, program expansion and questioning of the serosurveillance approach, and movement to consensus, culminating in the 2015 World Health Organization (WHO) guidelines recommending the use of routine program data for HIV surveillance among pregnant women.

The Evolution of HIV Sentinel Surveillance Among Pregnant Women Attending Antenatal Clinics

In 1988, 2 years after the global program on acquired immunodeficiency syndrome (AIDS) was founded by the WHO, epidemiologists recommended the establishment of HIV sentinel surveillance systems among different health services to monitor the HIV epidemic in select populations, including pregnant women [3]. This strategy identified the availability of remnant blood from routine syphilis testing among pregnant women attending ANCs as an opportunity to conduct HIV surveillance. ANC attendees were thought to represent an accessible cross section of healthy, sexually active women in the general population, and results from ANC HIV sentinel serosurveillance were considered a general proxy for HIV prevalence in the underlying community [4,5]. The names and personally identifying information of the pregnant women were removed in such a way that it would not be possible to link a specimen to a specific person, thus assuring the confidentiality of the pregnant women. This strategy came to be known as unlinked anonymous testing (UAT) [6].

International guidelines for HIV sentinel serosurveillance describing UAT were disseminated by WHO in 1989 and updated in 2003 [2,7]. These guidelines presented UAT as an important and effective method of public health surveillance that, if approved by national ethics committees and implemented in accordance with rigorous standards, did not compromise core bioethical principles. Foremost among these standards was the permanent delinking of personally identifying information from surveillance data and the safeguarding of the confidentiality and privacy of pregnant women sampled by surveillance. UAT-based ANC serosurveillance was a key element of HIV surveillance for at least 20 years, particularly in countries with generalized epidemics where serosurveillance was conducted on an annual or biannual basis.

UAT-based ANC serosurveillance has provided valuable information about trends in HIV prevalence among pregnant women attending ANCs and served as a proxy for trends in prevalence among the general population, enabling countries to monitor the course of their HIV epidemics; advocate for support for HIV programming and resources; allocate resources for design; and measure the effectiveness of HIV control and prevention interventions [6,8]. Between 1993 and 2012, at least 84 ANC serosurveillance activities were conducted in sub-Saharan Africa [9]. Indeed, before the scale-up and destigmatization of routine HIV screening at ANC in sub-Saharan Africa, the UAT approach was important in limiting participation biases in serosurveillance HIV estimates. ANC serosurveillance has also been used as a key data source for the Joint United Nations Programme on HIV/AIDS (UNAIDS) and individual countries to model national, regional, and global HIV incidence and trends, using the UNAIDS-supported Spectrum modeling software (Avenir Health, Glastonbury, CT) [10-13].

Concerns About UAT-Based ANC Serosurveillance

Despite the historical contributions of UAT-based ANC serosurveillance to monitor the HIV epidemic, its use as a surveillance strategy has been questioned on ethical grounds since the early 1990s [14]. Critics viewed this strategy as inconsistent with the core bioethical principle of respect for persons (as outlined in the 1979 US Department of Health, Education, and Welfare’s *Belmont Report*, the 1991 Council for International Organizations of Medical Sciences and WHO *International Guidelines for Ethical Review of Epidemiological Studies*, and the 2009 *International Ethical Guidelines on Epidemiological Studies*), as it failed to respect the autonomy of pregnant women to make informed choices about participation in surveillance and surveillance-related testing [14-18]. The advent of effective drug therapy to prevent mother-to-child transmission of HIV in the mid-1990s increased ethical concerns about UAT as it did not provide notification of HIV test results or the opportunity for intervention [19]. Consequently, UAT-based serosurveillance among pregnant women in the United States was discontinued in 1995 [20]. However, many other countries, including high-income countries such as the United Kingdom, retained UAT and have continued to use this strategy to monitor HIV epidemics [21,22].

Over the last 15 years (spurred substantially by the creation of the Global Fund to Fight AIDS, Tuberculosis and Malaria in 2002, and the President’s Emergency Plan for AIDS Relief [PEPFAR] in 2003), coverage of HIV services has increased significantly in low- and middle-income countries, including HIV testing among women attending ANCs, prevention of mother-to-child transmission (PMTCT), and antiretroviral therapy (ART). The introduction of provider-initiated HIV testing and counseling within ANC services also contributed to substantial increases in coverage of HIV testing among pregnant women attending ANCs. In 2015, an estimated 16,738,964 pregnant women in sub-Saharan Africa had an HIV test and received their results at their first ANC visit [23].

In 2013, WHO published Consolidated Guidelines on General HIV Care and the Use of Antiretroviral Drugs for Treating and Preventing HIV Infection, recommending immediate initiation of life-long ART (option B+) for all pregnant women diagnosed with HIV [24]. As of April 2017, all priority countries have adopted such policies [25]. More recently, in 2015, WHO recommended initiation of treatment for all people living with HIV (PLHIV) [26]. In the following year, an estimated 1,024,480 pregnant women living with HIV in sub-Saharan Africa received ARTs to prevent mother-to-child transmission of HIV [23].

The move to offer treatment for all sharpened ethical questions surrounding UAT, namely, (1) UAT did not obtain informed consent from pregnant women tested for HIV for surveillance purposes, provide them with their surveillance HIV test results, or refer women with HIV-positive surveillance test results to available HIV care, treatment, and prevention interventions and (2) information needed for surveillance (such as sociodemographic, syphilis, and HIV testing data) was largely present in routine PMTCT program records, rendering UAT-based serosurveillance redundant [18,22]. In addition, a published manuscript conducting statistical testing of differences between UAT- and PMTCT-based HIV prevalence estimates at the site level found few statistical differences [27].

In February 2009, UNAIDS and WHO held a partner consultation in Geneva, Switzerland, to review ethical issues associated with HIV testing in the context of national population surveys and sentinel surveillance among pregnant women. This meeting recommended that WHO and UNAIDS commission formal guidance on ethical issues in HIV surveillance [28]. The resulting 2013 publication, *Guiding principles on ethical issues in HIV surveillance*, states that UAT should be used for surveillance only when data from clinical settings and other studies cannot provide the necessary information and that surveillance programs implementing UAT must demonstrate that program data are not adequate for the purpose of public health surveillance [29]. In addition, WHO’s 2015 *Consolidated guidelines on HIV testing services* recommended that “HIV surveillance systems should work toward assuring that all participants in biological surveillance receive their HIV status” and specifically recommended that countries move from traditional ANC surveillance to using routine program data for surveillance among pregnant women attending ANCs [30]. Finally, in 2016, PEPFAR released a policy statement, *HIV testing in PEPFAR-supported survey and surveillance activities*, specifying that “All PEPFAR-supported survey and surveillance activities will provide participants the opportunity to receive final HIV status information generated by the activity.”

Transition to Using Routine Program Data for Surveillance

Over the past several years, a shared vision has emerged in the global HIV surveillance community that recognizes the advantages and desirability of transitioning to using routine program data for ANC surveillance. The urgency of this transition has been underlined by the dramatic expansion in the coverage of HIV services in ANC settings.

ANC surveillance based on routine program data offers multiple potential advantages over UAT-based serosurveillance. First, this approach adheres to the WHO and UNAIDS guidelines by guaranteeing that all HIV serostatus data used for surveillance come from HIV testing that ensures—as per routine clinical practice—that pregnant women have the informed and free choice to accept or decline (ie, opt out of) testing, receive pre- and posttest counseling, receive their HIV test result, and are referred to HIV services if the test result is positive. Second, because ANC surveillance based on routine data would eliminate or substantially reduce the need for additional training, human resources, logistics, and HIV testing associated with traditional ANC serosurveillance, such a system can significantly reduce the workload and financial costs associated with monitoring the HIV epidemic. This can improve the sustainability of surveillance systems by integrating surveillance into routine activities and data systems. Third, increased use of program data for surveillance can contribute to the monitoring, use, and strengthening of routine data and routine HIV testing to benefit program implementation, program monitoring, and surveillance.

In the context of increasing global consensus on the benefits of using routine program data for surveillance, in 2013 the WHO and UNAIDS HIV Global Surveillance Working Group, in collaboration with the US Centers for Disease Control and Prevention (CDC), published guidelines for countries to assess how routine PMTCT program data can be used for surveillance. The guidelines stressed that collaboration between surveillance, monitoring and evaluation, and program (Maternal and child health [MCH], lab, PMTCT) is foundational to the use of routine data for surveillance. Cooperation among these entities is crucial to monitor and strengthen the quality and completeness of routine PMTCT program data, the accuracy of routine PMTCT HIV testing, and quality assurance (QA) for routine PMTCT HIV testing [31].

In the context of the new WHO guidance, a broad contingent of countries has conducted studies examining how to use routine program data for surveillance. Since 2013, at least 22 countries examined or are currently examining how to use PMTCT program data for surveillance, including Angola, Botswana, Burkina Faso, Cameroon, Cote D’Ivoire, Democratic Republic of the Congo, Ethiopia, Ghana, Haiti, India, Kenya, Lesotho, Mozambique, Namibia, Nigeria, Rwanda, Senegal, Sierra Leone, South Africa, Swaziland, Zambia, and Zimbabwe [27,32-39]. As of this writing, Rwanda, Botswana, and Zimbabwe have implemented, or are implementing, rounds of surveillance among pregnant women based on routine PMTCT program data.

New WHO Guidelines on ANC Surveillance Based on Routine Program Data

In September 2013, the WHO and CDC organized a consultation of African countries that had conducted assessments of how to use routine program data for ANC surveillance. The consensus was that countries are moving toward using routine data for surveillance in the coming years, and countries in attendance requested that the WHO provide technical guidance on how to operationalize the transition and to ensure the continued quality of HIV surveillance estimates and epidemic modeling estimates such as those produced by Spectrum. To this end, *Guidelines for conducting HIV surveillance among pregnant women attending antenatal clinics based on routine programme data* was developed by WHO and UNAIDS in collaboration with other international stakeholders and ministries of health and published in 2015 [40].

This WHO and UNAIDS guidance provides comprehensive direction for surveillance programs through each step of designing and implementing ANC surveillance based on routine program data, including ethical considerations, sample size calculations, data collection, data management, QA of surveillance activities, data analysis, surveillance monitoring, and results’ interpretation and dissemination.

Importantly, the WHO and UNAIDS guidance includes the use of routine syphilis testing data for the surveillance of syphilis among pregnant women attending ANCs. Routine syphilis testing in pregnancy is considered an essential antenatal care intervention by WHO; testing for reactive syphilis serology using rapid diagnostic tests and providing treatment of seropositive women are highly effective and cost-efficient. Historically, HIV serosurveillance of ANC attendees frequently included surveillance for maternal syphilis. This integrated approach to surveillance is both practical and epidemiologically appropriate and is reinforced in the new guidance. Furthermore, in the same way that reliance on routine testing and data for HIV surveillance can provide information to improve routine services, surveillance of maternal syphilis based on routine data can help identify gaps, and drive improvements, in the provision of routine syphilis testing and treatment services.

Important elements of the new WHO and UNAIDS guidance, which include principles of ANC surveillance, operational design approaches, monitoring and QA, and ethical issues, are discussed below:

Principles of ANC Surveillance

New WHO and UNAIDS guidance stresses three principles of ANC surveillance. First, epidemiologic information provided by ANC surveillance, combined with other sources of epidemiological data, allows surveillance programs to address key aspects of the “know your epidemic” approach of second-generation surveillance of HIV and provides a key input for modeling national and global HIV incidence and burden [41]. Second, ANC surveillance should (1) be methodologically sound to produce reliable data, (2) adhere to ethical standards, and (3) be resource-economical. Finally, ANC surveillance should be a collaborative endeavor that profoundly engages and involves program partners to strengthen routine HIV testing and routine data collection to benefit service delivery, program monitoring, and surveillance.

Operational Design Approaches to ANC Surveillance

New WHO and UNAIDS guidance describes two methodological approaches to ANC surveillance. The first approach involves a census of ANC—the gathering of individual-level or aggregate data from all pregnant women attending all (or nearly all) ANC sites providing PMTCT services by leveraging existing above-site (eg, regional and national) data repositories such as health management information systems (HMIS) or routine reporting systems. Census is the preferred design because it is highly resource-efficient and provides complete geographical coverage of surveillance of pregnant women attending ANCs. However, census requires the availability of routine PMTCT HIV testing and high-quality routine data at all (or nearly all) ANC sites. The guidelines encourage countries to strengthen and expand routine testing and data systems to progress, over time, toward a census approach.

A census based on individual-level data is preferable because it allows subgroup analyses that take advantage of demographic parameters (eg, examining prevalence trends in young or primigravid women) and clinical variables (eg, examining the coincidence of HIV infection and syphilis antibody positivity). The complete geographic coverage of individual-level census data could be a valuable input into global efforts to create geospatial models that estimate trends in new HIV infections at the local level. Individual-level data, as compared with aggregate counts, also enable closer monitoring of surveillance data, facilitating the identification of gaps in routine data quality. However, a census based on individual-level data is only feasible in the presence of electronic medical records (EMR) systems (with a verified high degree of accuracy, completeness, and integrity) to capture individual-level ANC data and the capacity to safeguard the confidentiality of, and manage, large volumes of individual-level data. Furthermore, the coverage of EMR systems is currently limited in ANC settings. Therefore, a more feasible approach to census in the short term is to use aggregate service counts reported by an HMIS or routine reporting system that has a verified high degree of accuracy, completeness, and integrity. Aggregate data systems for program monitoring are already in place, and these data have the advantages of simplicity, economy, and the absence of personally identifying information. However, aggregate data may limit the ability of surveillance to conduct subanalyses (as aggregate data may not be structured in such a way as to permit analysis by finer age groups, parity or gravidity, or HIV and STI coinfection) or to monitor data quality.

The second design option for ANC surveillance is a sentinel surveillance design—a convenience sample of ANC sites that are chosen to represent geographical areas or populations of interest for HIV surveillance. Sentinel surveillance has the advantages of familiarity, collecting rich individual-level data, and the ability to prescreen sentinel sites (or provide additional support) to ensure readiness to participate in surveillance. In addition, sentinel surveillance can involve either retrospective or real-time data collection, which can allow surveillance programs to provide extra support to routine PMTCT activities to ensure the quality of routine PMTCT testing and data that are used for surveillance. However, sentinel surveillance requires the safeguarding of personally identifying information present in individual-level data, necessitates fieldwork to collect routine data from ANC sites, and does not provide representative estimates of HIV prevalence among ANC attendees at national or subnational levels. A sentinel surveillance design could be an appropriate option for countries initially transitioning to using routine program data for surveillance.

Monitoring and Quality Assurance

Just as UAT serosurveillance included robust surveillance monitoring and QA, ANC surveillance based on routine data requires similar mechanisms to ensure the reliability of surveillance methods and estimates. Because ANC surveillance based on routine program data relies on data and activities owned and managed by nonsurveillance programs (eg, maternal and child health and PMTCT programs and the national reference laboratory), monitoring HIV surveillance among pregnant women attending ANCs is best viewed as a collaborative activity that engages these partners. Results of surveillance monitoring provide valuable information to strengthen routine activities. Surveillance monitoring can augment, reinforce, and highlight the value of routine monitoring and QA of the following: (1) the completeness of routine site-level data and data in HMIS or routine reporting systems and the appropriateness of routine data collection and reporting tools and (2) HIV rapid testing, including accuracy of testing, adherence to appropriate testing algorithms and practices, staff training, record keeping, and stock management.

Ethical Issues

All HIV surveillance activities, regardless of the data source, adhere to ethical principles of biomedical research and surveillance, including respect for persons, beneficence, and justice [29]. In the context of ANC surveillance based on routine data, the WHO and UNAIDS guidelines emphasize that surveillance should adhere to ethical standards by ensuring that HIV serostatus data used for surveillance come from HIV testing that includes, as per routine clinical practice, the informed and free choice to accept or decline (ie, opt out of) testing; pre- and posttest counseling; return of test results to the client; and referral to PMTCT and HIV treatment services if test results are positive. In addition, it is essential that the confidentiality of pregnant women whose routine data are collected for surveillance is protected. These protections include human, physical, and electronic measures to ensure confidentiality and data security at every stage of surveillance, including data collection, transfer, storage, analysis, and dissemination. Finally, surveillance should collect as little personally identifying information as possible, and preferably none.

Estimating Burden of Disease

Data from ANC surveillance are a key input for modeling national, regional, and global HIV trends and burden using HIV modeling software. Continuing work is needed to evolve best methods to incorporate routine program data into HIV modeling software, calculate adjustment factors, and understand the implications of this new data source for modeled estimates [42].

Looking Forward

The transition to ANC surveillance based on routine data is an important milestone in HIV surveillance that enhances the efficiency, integration, sustainability, and ethical approach of surveillance. This shift represents a substantial achievement in building strong routine data systems to support HIV service delivery, program monitoring, and strategic information. Routine program data also enable surveillance estimates and UNAIDS Spectrum models to provide a more geographically granular description of subnational HIV epidemics, enabling highly targeted HIV control programs.

The use of routine data for surveillance and monitoring the response to the HIV epidemic is essential to inform planning, and measure country progress, towards achieving UNAIDS 90-90-90 goals (90% of PLHIV know their HIV status, 90% of PLHIV with known status are on treatment, and 90% of PLHIV on treatment are virally suppressed) at the national and subnational levels [43]. The WHO, UNAIDS, PEPFAR, and the CDC are committed to support this process through ongoing technical collaboration.

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Conflicts of Interest

None declared.

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Abbreviations

AIDS: acquired immunodeficiency syndrome
ANC: antenatal clinic
ART: antiretroviral therapy
CDC: Centers for Disease Control and Prevention
EMR: electronic medical record
HIV: human immunodeficiency virus
HMIS: health management information system
PEPFAR: President’s Emergency Plan for AIDS Relief
PLHIV: people living with HIV
PMTCT: prevention of mother-to-child transmission
QA: quality assurance
STI: sexually transmitted infection
UAT: unlinked anonymous testing
UNAIDS: United Nations Joint Programme on HIV/AIDS
WHO: World Health Organization

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Viewpoint

Viral Hepatitis Strategic Information to Achieve Elimination by 2030: Key Elements for HIV Program Managers

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Abstract

Evidence documenting the global burden of disease from viral hepatitis was essential for the World Health Assembly to endorse the first Global Health Sector Strategy (GHSS) on viral hepatitis in May 2016. The GHSS on viral hepatitis proposes to eliminate viral hepatitis as a public health threat by 2030. The GHSS on viral hepatitis is in line with targets for HIV infection and tuberculosis as part of the Sustainable Development Goals. As coordination between hepatitis and HIV programs aims to optimize the use of resources, guidance is also needed to align the strategic information components of the 2 programs. The World Health Organization monitoring and evaluation framework for viral hepatitis B and C follows an approach similar to the one of HIV, including components on the following: (1) context (prevalence of infection), (2) input, (3) output and outcome, including the cascade of prevention and treatment, and (4) impact (incidence and mortality). Data systems that are needed to inform this framework include (1) surveillance for acute hepatitis, chronic infections, and sequelae and (2) program data documenting prevention and treatment, which for the latter includes a database of patients. Overall, the commonalities between HIV and hepatitis at the strategic, policy, technical, and implementation levels justify coordination, strategic linkage, or integration, depending on the type of HIV and viral hepatitis epidemics. Strategic information is a critical area of this alignment under the principle of what gets measured gets done. It is facilitated because the monitoring and evaluation frameworks for HIV and viral hepatitis were constructed using a similar approach. However, for areas where elimination of viral hepatitis requires data that cannot be collected through the HIV program, collaborations are needed with immunization, communicable disease control, tuberculosis, and hepatology centers to ensure collection of information for the remaining indicators.

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KEYWORDS

hepatitis; HIV; surveillance; evaluation

Introduction

The Global Hepatitis Report [1] indicated that in 2015, 1.34 million persons died from the consequences of viral hepatitis. Hence, mortality from viral hepatitis is at par with tuberculosis, and higher than the HIV infection or malaria [2]. More than 90% of this burden is due to cirrhosis and hepatocellular carcinoma, the sequelae of infections with hepatitis B virus (HBV) and hepatitis C virus (HCV) [1]. In May 2016, the World Health Assembly endorsed the Global Health Sector Strategy (GHSS) for 2016-2021 on viral hepatitis that proposes to eliminate viral hepatitis as a public health threat by 2030 (elimination is defined as a 90% reduction in new chronic infections and a 65% reduction in mortality compared with the

2015 baseline.) [3]. The World Health Organization (WHO) conceived this strategy using the same universal health coverage and public health frameworks that were used for strategies for HIV [4] and sexually transmitted infections (STIs) [5]. These 3 strategies were developed and adopted together; their 5 strategic directions are as follows: (1) information for focused action, (2) interventions for impact, (3) delivering for equity, (4) financing for sustainability, and (5) innovation for acceleration.

To eliminate viral hepatitis as a public health threat, the GHSS proposes to scale up prevention interventions currently available, such as universal immunization of children against hepatitis B, including a timely birth dose to prevent mother-to-child transmission [6]. In addition, it also introduces newer programmatic components, such as testing and treatment (older policy responses did not address chronic infection). Testing and treatment services for HBV, HCV, and HIV infections can use similar programmatic and delivery approaches. Thus, implementation of hepatitis and HIV interventions at the global, regional, and country level is being progressively considered as a coordinated approach where it is possible and improves impact and efficiency.

Strategic information can be defined as data collected at all administrative levels to inform policy and program decisions. The WHO published consolidated strategic information guidelines for HIV, including a monitoring and evaluation framework that includes 10 core indicators [7]. In 2016, the WHO also published guidance for strategic information in the field of viral hepatitis, including surveillance [8], and monitoring and evaluation [9]. This paper summarizes the approach proposed by the WHO to collect, analyze, and use viral hepatitis strategic information so that HIV and hepatitis services have aligned approaches in terms of service delivery and data management.

HIV, HBV, and HCV: Similarities and Differences

Similarities

In infected persons, HIV, HBV, and HCV are present in blood and most body fluids. Hence, these viruses share a number of modes of transmission, including mother-to-child, blood-borne, and sexual. HIV, HBV, and HCV lead to infections that may be silent for a number of years before consequences of infections lead to fatal sequelae. HIV, HBV, and HCV infections can be prevented with safer sex, interventions to reduce mother-to-child transmission, blood safety, standard universal precautions in health care and other settings, and harm reduction interventions for people who inject drugs (PWID). Specific risk groups (eg, PWID and men who have sex with men) are often disproportionally affected by HIV, HBV, and HCV and can be reached through coordinated health sector and community-based services, using the people-centered approaches recommended by the Sustainable Development Goals (SDGs). Mortality from chronic HBV and HCV infections can be reduced by testing and treatment, similar to HIV.

Differences

Aside from the many similarities between HIV, HBV, and HCV, there are a number of differences that need to be understood for optimized program implementation, including surveillance, monitoring, and evaluation.

Burden

Globally, HBV and HCV infections are more prevalent than HIV infection (Table 1) and may be distributed differently by region. However, in the absence of treatment, the case fatality of HIV is higher, and deaths tend to occur earlier in the course of the infection (50% within 10 years of infection), and therefore at an earlier age [2]. Regional variations in the differences in prevalence and mortality between HIV, HBV, and HCV have implications in the way that these areas of work may relate, from coordination to strategic linkages or integration, according to the magnitude of the epidemics [10].

New Infections

New infections with HIV are asymptomatic in most cases or may result in a nonspecific illness. Among adults, new infections with HBV and HCV lead to acute hepatitis in less than 50% of instances. The burden of disease from acute hepatitis is small in comparison with the burden from chronic infections [1]. However, if identified and reported in the context of enhanced case reporting, these cases of acute hepatitis can provide critical information on incidence trends and risk factors [8]. For HBV, this is facilitated by the availability of a marker of recent infection (IgM antibodies against HBV core antigen [anti-HBc IgM]). For HCV, in the absence of a biomarker of recent infection, case definitions are available for the surveillance of acute hepatitis C. The case definition of acute hepatitis C is an acute hepatitis that is non-A, non-B, and non-E and positive for HCV biomarkers [8].

Chronic Infections

In the case of HIV infection, most untreated persons will develop acquired immunodeficiency syndrome (AIDS) (with the exception of about 5% who are “elite controllers”) [11]. In the case of hepatitis, some patients newly infected with HBV and HCV spontaneously clear infection (80%-95% for HBV and about 20% for HCV) [8]. Hence, for hepatitis, it is relevant to use biomarkers to differentiate evidence of past or present infection from evidence of present (current) infection. Markers of past or present infection include antibody to HBV core antigen (total anti-HBc) and antibody to HCV (anti-HCV). Markers of present infection include hepatitis B surface antigen (HBsAg) and HCV RNA. As for HIV, the age at which HBV and HCV infection occurs influences the natural history. For HBV, infections acquired in the first 5 years of life most often lead to chronic infections and sequelae [12]. They account for the largest proportion of the burden of disease affecting adults. In contrast, the incidence of HCV infection in children is generally low, and infections acquired in childhood are probably of a better prognosis [13].

Table 1. Key characteristics of hepatitis B virus (HBV), hepatitis C virus (HCV), and HIV infection, including epidemiology, clinical manifestations, biomarkers, routes of transmission, prevention, and treatment.

Characteristics	Hepatitis B virus (HBV)	Hepatitis C virus (HCV)	HIV
Estimates of epidemiology and burden			
Prevalence (millions of infections)	257	71	33
Annual mortality (millions of deaths)	0.887	0.399	1.341
Clinical manifestations			
Clinical manifestations of new infections	Acute hepatitis (uncommon in <5 years, 50% of new infections among persons aged ≥5 years)	Acute hepatitis (<20% of new infections)	Nonspecific clinical manifestations of acute HIV infection
Spontaneous clearance of infection	80%-95% of new infections	20% of new infections	None
Long-term complications	Cirrhosis and hepatocellular carcinoma	Cirrhosis and hepatocellular carcinoma	Chronic infection leading to immune suppression (AIDS[a])
Biomarkers			
New/recent infection	IgM anti-HBc[b]	None[c]	Some options available with nucleic acid testing or “recency” serological tests
Past or present infection	Total anti-HBc	Anti-HCV	Anti-HIV
Present infection	HBsAg[d]	HCV RNA[e] or HCV core antigen	Anti-HIV
Routes of transmission			
Perinatal	Delivery and uncommonly, before birth	Uncommon[f]	Before, during, and after birth
Sexual	++[g]	+/−[g] Common in HIV-infected men who have sex with men	+++
Blood-borne	++++	+++	++
Vaccine	Yes	No	No
Approach to prevention			
Mother-to-child transmission	Universal immunization of infants, starting at birth +/− HBIg[h] +/− antivirals during pregnancy	Cure mothers before pregnancy	Test and treat
Prevention of other new infections	Universal immunization, safe injection practices, infection control, blood safety, and safe sex	Safe injection practices, infection control, blood safety, and safe sex	Safe sex, voluntary surgical male circumcision, safe injection practices, infection control, blood safety, preexposure prophylaxis
Treatment	Lifelong treatment with nucleos(t)ides analogues	Treatment available leading to cure after short course	Lifelong treatment with a combination of medicines

[a] AIDS: acquired immunodeficiency syndrome.

[b] Anti-HBc: antibody to the hepatitis B core antigen.

[c] RNA or core antigen positive in the absence of anti-HCV suggests recent HCV infection.

[d] HBsAg: hepatitis B surface antigen.

[e] RNA: ribonucleic acid.

[f] Risk of mother-to-child transmission is higher among HIV-infected pregnant women.

[g] symbol +/- and + quantifies the importance of transmission.

[h] HBIg: Hepatitis B immune globulin.

Sequelae

Ten years after initial infection, without treatment, about 50% of persons with HIV infection will have developed AIDS [14]. AIDS may be recognized by infectious disease physicians or the diagnosis may be missed if the patient dies of other opportunistic infections. In contrast, HBV and HCV infections lead to cirrhosis and hepatocellular carcinoma, two conditions that may be primarily managed by internists or gastroenterologists rather than infectious disease physicians in settings where patients have access to specialized care. The duration between infection and death is longer in the case of HIV, in the range of 20 to 30 years [15-17]. Other cofactors (eg, alcohol use, metabolic syndrome, toxins, and substance abuse) can also affect the risk of developing cirrhosis or hepatocellular carcinoma. As a result, the hepatitis virus infection that led to these sequelae may not be recognized or reported as the cause of death. This complicates the measurement of the burden of disease associated with HBV and HCV infection [18]. Historically, the Global Burden of Disease took a number of years to attribute cirrhosis and hepatocellular carcinoma to HBV and HCV infections [18], and the current approach still does not take into account the extrahepatic manifestation of the HCV infection [19].

Transmission and Prevention

HIV, HBV, and HCV can be transmitted through the same routes (Table 1). However, the relative importance of these routes varies according to the viruses. HBV is often transmitted through percutaneous, sexual, and perinatal routes. HIV is most often transmitted through sexual contacts. Injection drug use is also a common route of HIV transmission, but health care injections are an uncommon source of infection, even though outbreaks have occurred [20,21]. HCV is more often transmitted through the percutaneous route and accounts for the largest number of health care injections–associated infections [20]. Despite these differences in the relative importance of the various routes of transmission, methods of primary prevention do not differ (Table 1). However, for HBV, a safe and effective vaccine is also available [6]. Three doses of hepatitis B vaccine, with the first one administered soon after birth, can prevent the majority of chronic HBV infections [6]. Recommendations for the prevention of mother-to-child transmission also vary for the 3 viruses: immunoprophylaxis to prevent mother-to-child transmission of HBV and antiretroviral treatment for mother and child against HIV. Mother-to-child transmission of HCV is rare, and there is no specific approach to prevent it [22].

Treatment

As of 2016, treatment for HBV infection was in most cases lifelong. A single antinucleos(t)ide with a high barrier to resistance is sufficient to achieve viral suppression for patients who are eligible for treatment [23]. Hence, from a data management point of view, the approach to monitoring treatment is similar to HIV. Since 2013, HCV can be cured through a short-course treatment of a few months [13]. This revolution in curative treatment led to a new momentum for elimination. Hence, the approach to monitoring HCV treatment is more similar to curable infections such as tuberculosis. All HCV-infected patients are potentially eligible for treatment. Coinfections with any combination of the 3 viruses require specific management considerations (see Table 1).

GHSS on Viral Hepatitis

The 2014 World Health Assembly requested the WHO to examine the feasibility of eliminating hepatitis B and C. In 2015, the SDGs committed to combating viral hepatitis (Target 3.3) [24]. As a result, the WHO coordinated a think tank to examine options. As part of this work, a mathematical model suggested that if the viral hepatitis response reached 5 synergistic prevention and treatment service coverage targets (Table 2), hepatitis B and C could be eliminated as a public health threat [25,26]. These 5 interventions now endorsed by a World Health Assembly resolution are as follows: (1) hepatitis B immunization, (2) prevention of mother-to-child transmission of HBV, (3) blood and injection safety, (4) prevention of transmission among persons who inject drugs through comprehensive harm reduction services, and (5) testing and treatment. Service coverage targets for 2030 with respect to testing and treatment are 90% of patients diagnosed and 80% of patients eligible treated (using a logic similar to 90% of people with HIV diagnosed, 90% of people diagnosed with HIV treated, and 90% of those on treatment virally suppressed by 2020 for HIV targets) [4].

Monitoring Framework for Viral Hepatitis B and C

Levels and Indicators

The WHO proposed a monitoring and evaluation framework for viral hepatitis B and C (Multimedia Appendix 1) that, similar to the 10 core indicators recommended for HIV, follows the result chain, from (1) context and needs to (2) input, (3) output and outcomes, and (4) impact [9].

Context

Given the focus on chronic HBV and HCV infections, prevalence of infection in the population is the best reflection of context and needs (C.1), similar to what is being used for HIV.

Input

Input refers to systems and resources available for hepatitis elimination. One of the most challenging service coverage targets of the GHSS is to increase the proportion diagnosed among those who are infected (30% by 2020 and 90% by 2030; Table 2). This will require a substantial increase in the capacity to test individuals for HBV or HCV infection. Hence, the WHO selected the number of health care facilities that are able to test for HBV and HCV infections per 100,000 people as a core input indicator (C.2).

Output and Outcomes

Prevention

Three core prevention indicators reflect modes of transmission that are key for hepatitis. These include coverage of the third dose of hepatitis B vaccine and of timely birth dose (hepatitis B vaccine birth dose or other methods to prevent mother-to-child transmission of HBV infection) (C.3), the number of syringe and needle sets distributed to persons who inject drugs (C.4) [27], and the proportion of safe injections at the health care facility level (C.5) [28]. Indicators reflecting sexual transmission are not included among these core indicators because sexual transmission accounts for a lower proportion of HBV and HCV infections than HIV [29].

Table 2. Global service coverage targets that would eliminate HBV[a] and HCV[b] as public health threats, 2015-2030.

Target areas	Baseline 2015	2020 target	2030 target
Service coverage			
Prevention			
Three-dose HBV for infants (coverage %)	84	90	90
Prevention of mother-to-child transmission of HBV: hepatitis B birth-dose vaccination or other approaches (coverage %)	39	50	90
Blood and injection safety			
Blood safety: donations screened with quality assurance (coverage %)	97	95	100
Injection safety: use of engineered devices[c] (coverage %)	5	50	90
Harm reduction (sterile syringe/needle set distributed per person per year for people who inject drugs [PWID])	20	200	300
Treatment			
Diagnosis of HBV and HCV (coverage %)	9-20	30	90
Treatment of HBV and HCV	7%-8%	5 million (HBV) and 3 million (HCV)	80% eligible treated
Impact leading to elimination			
Incidence of chronic HBV and HCV infections	6-10 million	30% reduction	90% reduction
Mortality from chronic HBV and HCV infections	1.34 million	10% reduction	65% reduction

[a] HBV: hepatitis B virus.

[b] HCV: hepatitis C virus.

[c] Although the service coverage target is about output (adoption of reuse prevention injection devices), the C.5 indicator focuses on outcome (provision of safe injections).

Cascade of Care

Using an approach very similar to HIV, the indicators of the cascade of care (for HBV) or cure (for HCV) include the proportion of people living with viral hepatitis diagnosed (C.6), treatment coverage (in the case of HBV infection, C.7.a) or initiation (in the case of HCV infection, C.7.b), and treatment outcome, which includes the proportion of people on treatment who are virally suppressed (C.8.a, for HBV infection) or the proportion of people cured among those who completed treatment (C.8.b, for HCV infection). In the case of HBV infection, a high proportion of people with chronic infection are not eligible for treatment [23]. Hence, the coverage of linkage to care among those diagnosed is also important as some diagnosed patients will require long-term follow-up to determine when they become eligible for treatment (Indicator A.8) [9].

Impact

Similar to HIV, the results chain is linked to impact (incidence and mortality). These are the parameters upon which elimination is defined (ie, 90% reduction in incidence and 65% reduction in mortality compared with the 2015 baseline). The WHO designated the cumulative incidence of HBV infection among children at 5 years of age (C.9.a) to evaluate progress in "combatting hepatitis" as per the SDG [30]. The restriction to this age group is because HBV infections among children below 5 years of age contribute most to the burden of chronic infections among adults [12]. The incidence of HCV infection is measured in the whole population (C.9.b). There is a mortality indicator designated for HBV (C.10.a) and HCV (C.10.b).

Practical Implementation of the Monitoring and Evaluation Framework

The data systems needed to report against the core indicators of the monitoring and evaluation framework for viral hepatitis (Table 2) include the following:

- C.1: regular biomarker surveys to estimate the prevalence of HBV and HCV infection (see the Surveillance for Chronic Infections section below). This could be coordinated with HIV surveys [31] and surveys to evaluate the impact of hepatitis B immunization [32].
- C.2: program data or health care facility surveys to estimate the ratio of facilities that can test for HBV and HCV infection per 100,000 population. This is compatible with the indicators for laboratory diagnosis capacity measured in the context of the SDGs and compatible with the WHO-recommended approach for survey of health care facilities (Service Availability and Readiness Assessment [SARA]) [33].
- C.3: routine data from the Expanded Program on Immunization to estimate vaccine coverage (estimates generated by WHO and UNICEF [United Nations International Children's Emergency Fund] are available on the Web) [34].

- C.4: program data on needle and syringe distribution that reflects broader harm reduction activities (using the same data sources as for HIV).
- C.5: population surveys or health care facility surveys to estimate the proportion of safe injections [28]. This can be coordinated with other population surveys or with SARA [33].
- C.6-7-8: data from a patient's database to monitor the cascade of diagnosis and treatment. In the absence of a separate database, unique identifiers allow patients to be tracked along the cascade and link patients across disease registries, clinics, and vital statistics. This can be coordinated with monitoring of patients with HIV infection where clinics routinely diagnose and treat hepatitis and HIV or in epidemics characterized by high prevalence of coinfection [7].
- C.9.a: biomarker survey in children who were vaccinated to estimate the impact of hepatitis B immunization on the cumulated incidence of chronic HBV infection [32]. This may be difficult to coordinate with household surveys that incorporate HIV testing (AIDS indicator surveys or public health impact assessments) because of sample size requirements and age group considerations [32].
- C.9.b: modeling estimates from biomarker surveys in the population (or specific groups) and trends on enhanced case reporting for acute hepatitis C8 to estimate the incidence of HCV infection (see the Surveillance for Acute Hepatitis section below). This could be coordinated with HIV modeling activities, where relevant, depending on the type of epidemic [31].
- C.10: combination of vital statistics data on the mortality from hepatocellular carcinoma and cirrhosis processed with data on the prevalence of HBV and HCV infection in patients with these sequelae (See the Surveillance for Sequelae section below).

Surveillance for Viral Hepatitis

Surveillance for viral hepatitis refers to the systematic, ongoing collection, transmission, analysis, and use of epidemiological data on viral hepatitis [8]. Surveillance focuses on epidemiological parameters such as incidence, prevalence, and mortality. The WHO monitoring and evaluation framework for viral hepatitis B and C addresses other components, such as behaviors. Surveillance for viral hepatitis has 3 components (see Table 3) that correspond to the natural history of HBV and HCV infections. These are as follows: (1) surveillance for acute hepatitis that reflects new infections, (2) surveillance for chronic, prevalent infections, and (3) surveillance for sequelae, including cirrhosis and hepatocellular carcinoma. These 3 components contribute to a comprehensive picture of the epidemiological situation of viral hepatitis. They feed the viral hepatitis monitoring and evaluation framework with key data (Multimedia Appendix 1). However, they may be implemented by different actors in a country's public health system. Thus, these different actors must coordinate to consolidate and triangulate pieces of information from different sources. As for all surveillance activities, standardized case definitions are essential to viral hepatitis surveillance, including surveillance for acute hepatitis and chronic infections (Table 4).

Surveillance for Acute Hepatitis

The majority of new infections with hepatitis viruses are asymptomatic or undiagnosed. However, surveillance for acute hepatitis can be informative through capturing a constant fraction of cases. Surveillance for acute hepatitis is usually implemented in the context of communicable disease surveillance systems. It differs from reporting of newly diagnosed cases of chronic infections that must be handled through patient registries (see the Patients Database section below). The WHO formulated standardized case definitions for surveillance for acute hepatitis (Table 4) [8]. In the field of surveillance for acute hepatitis, 2 different activities need to be distinguished: syndromic surveillance and enhanced case reporting.

Syndromic surveillance for undifferentiated acute viral hepatitis involves reporting by all health care facilities of clinical cases of acute hepatitis in the absence of in vitro diagnosis. This type of surveillance may detect large outbreaks, which are usually outbreaks of hepatitis A or E. However, surveillance for undifferentiated acute viral hepatitis is not essential to eliminate hepatitis B and C as public health threats.

Enhanced case reporting involves reporting by health care facilities of cases of acute hepatitis, by type (ie, A, B, C, D, or E), with in vitro diagnosis (ie, IgM tests) and collection of information of possible exposures. Cases of acute hepatitis are uniquely informative as they denote recent infections. Hence, collection of information on possible exposures during the referent exposure period (or the incubation period) informs on sources of infection. Enhanced case reporting may be difficult to implement countrywide. Hence, countrywide enhanced case reporting is mostly limited to high-income countries. However, in resource-limited settings, it can be done in sentinel sites where there is access to good in vitro diagnosis (eg, emergency departments). Enhanced case reporting allows description of trends in type-specific acute hepatitis and contributes to the generation of hypotheses regarding prevailing risk factors in a given setting. If enhanced case reporting is in place countrywide, it is probably implemented in the context of the communicable disease surveillance system. In the absence of a national system, a small number of sentinel sites may be needed, for example, in selected hospitals where IgM in vitro diagnosis is available for the diagnosis of recent infections. Monitoring the strength of the association between health care or injection drug use and new HBV or HCV infection can be beneficial to HIV prevention. HBV [35] and HCV [36] are more easily transmitted through percutaneous exposures than HIV [37]. New HBV and HCV infections are also easier to detect. Therefore, documentation of transmission of HBV or HCV through these routes using surveillance of acute hepatitis can provide early warning signals for the risk of HIV transmission, as recently illustrated with the outbreak of HBV and HCV associated with injection drug use in the United States [38,39].

Table 3. Surveillance activities needed to describe the epidemiology of viral hepatitis, including hepatitis B and hepatitis C.

Parameter	Activities that contribute to surveillance for viral hepatitis				
	Surveillance for acute hepatitis that reflect new infections		Surveillance for chronic, prevalent hepatitis		Surveillance for sequelae
Activities	Syndromic surveillance in the general population; Event-based surveillance[a]	Enhanced case reporting (with in vitro diagnosis and collection of information on risk factors) countrywide or in sentinel sites[b]	Case reporting from laboratories or health care facilities	Regular biomarker surveys	Combination of data from cancer registries, death certificates, and testing of cirrhosis and HCC[c] patients for HBV[d] and HCV[e] infection
Population under surveillance	Persons presenting with acute hepatitis in health care facilities (discrete onset of symptoms)	Persons presenting with acute hepatitis in health care facilities (discrete onset of symptoms)	Persons without acute symptoms tested in health care facilities/laboratories	Person without acute symptoms tested during population surveys	Persons diagnosed with cirrhosis and HCC
Usual implementer	Communicable disease surveillance	Communicable disease surveillance (if countrywide); hepatitis program (if sentinel sites)	Communicable disease surveillance and/or hepatitis program	Hepatitis program in coordination with the other actors implementing biomarker surveys	Hepatitis program collating data from various different sources, including vital registration
Case definitions to use (see Table 4)	Presumptive case of acute hepatitis	Confirmed case of acute hepatitis (by type)	Chronic HBV and HCV infection; serological evidence of past or present HCV infection	Chronic HBV and HCV infection; serological evidence of past or present HCV infection	Cases of HCC or cirrhosis with chronic HBV or HCV infection
Objective of the surveillance activity	Detect outbreaks	Describe trends in type-specific acute hepatitis[f] and identify risk factors	Estimate the proportion of chronically infected persons who have been identified	Estimate the burden of chronic infections; model incidence trends	Estimate the incidence of HCC and cirrhosis

[a] In vitro diagnosis needs to be organized on a sample of cases when an outbreak is reported.

[b] High-quality data (ie, reliable in vitro diagnosis and good information on risk factors) from a smaller number of tertiary centers is preferable and more efficient than poor-quality data from many sites.

[c] HCC: hepatocellular carcinoma.

[d] HBV: hepatitis B virus.

[e] HCV: hepatitis C virus.

[f] Surveillance for acute hepatitis cannot be used directly to quantify new infections. The reported number of cases of acute hepatitis needs to be adjusted for the large proportion of asymptomatic cases and underreporting.

Table 4. World Health Organization (WHO) surveillance case definitions for viral hepatitis. Case definitions are for the purpose of reporting and surveillance and may differ from criteria to be used for the management of patients.

Stage of infection	Criteria	Types of viral hepatitis			
		Hepatitis A	Hepatitis E	Hepatitis B	Hepatitis C
Acute hepatitis	Presumptive case: clinical criteria	Discrete onset of an acute illness with signs/symptoms of acute infectious illness (eg, fever, malaise, and fatigue) and liver damage (eg, anorexia, nausea, jaundice, dark urine, right upper quadrant tenderness, OR raised ALT[a] levels more than 10 times the upper limit of normal of the laboratory)[b]	Discrete onset of an acute illness with signs/symptoms of acute infectious illness (eg, fever, malaise, and fatigue) and liver damage (eg, anorexia, nausea, jaundice, dark urine, right upper quadrant tenderness, OR raised ALT levels more than 10 times the upper limit of normal of the laboratory)	Discrete onset of an acute illness with signs/symptoms of acute infectious illness (eg, fever, malaise, and fatigue) and liver damage (eg, anorexia, nausea, jaundice, dark urine, right upper quadrant tenderness, OR raised ALT levels more than 10 times the upper limit of normal of the laboratory)	Discrete onset of an acute illness with signs/symptoms of acute infectious illness (eg, fever, malaise, and fatigue) and liver damage (eg, anorexia, nausea, jaundice, dark urine, right upper quadrant tenderness, OR raised ALT levels more than 10 times the upper limit of normal of the laboratory)
	Confirmed case: clinical criteria AND biomarker or epidemiological criteria	IgM[c] anti-HAV[d] +ve OR Epidemiological link with a confirmed case	IgM anti-HEV[e] +ve OR Epidemiological link with a confirmed case	IgM anti-HBc[f] +ve[g]	HCV[h] RNA[i] +ve and anti-HCV[j] −ve OR Seroconversion to anti-HCV[k] OR Anti-HCV +ve AND IgM anti-HBc −ve AND Anti-HAV IgM −ve AND Anti-HEV IgM −ve
Chronic infections (Only confirmed cases that all require clinical and biomarker criteria)	Clinical criteria	Not applicable	Rare event, no WHO standard case definition	Person *not* meeting the case definition for acute hepatitis[l]	Person *not* meeting the case definition for acute hepatitis[l]
	Biomarker criteria	Not applicable	Rare event, no WHO standard case definition	HBsAg +ve[m,n]	HCV RNA +ve OR HCV Ag +ve

[a] ALT: alanine aminotransferase.

[b] Ten times the upper limit of normal (400 IU/L) is the threshold used by the United States' State and Territorial Epidemiologists (CSTE). Countries may also select lower (more sensitive) or higher (more specific) thresholds.

[c] Ig: immunoglobulin.

[d] anti-HAV: antibody against hepatitis A virus.

[e] anti-HEV: antibody against hepatitis E virus.

[f] anti-HBc: antibody against hepatitis B core antigen.

[g] Hepatitis test panels usually include HBsAg with anti-HBc IgM test (positive predictive value of anti-HBc IgM is higher if HBsAg is +ve). Specific test/threshold needed to exclude transient IgM during flares in chronic hepatitis B virus (HBV) infection.

[h] HCV: hepatitis C virus.

[i] RNA: ribonucleic acid.

[j] anti-HCV: antibody against hepatitis C virus.

[k] Among patients tested regularly at short time intervals, seroconversion to anti-HCV suggests a recent HCV infection. Seroconversions to anti-HCV should be followed by reflex RNA test (when available).

[l] Person tested in the context of the evaluation of a chronic liver disease, a check-up, or a survey.

[m] Most testing strategies would also test for total anti-HBc. The combination of total anti-HBc and HBsAg is more specific of chronic HBV infection than HBsAg alone.

[n] HBsAg: hepatitis B surface antigen.

Surveillance for Chronic Infections

The reference method for surveillance for chronic infections is regular biomarker surveys. When the opportunity to conduct population-based surveys is not available, *data mining* can also be undertaken to collate existing data on HBV or HCV infection [8]. Reporting cases of chronic infections present in health care facilities is not informative in terms of surveillance for chronic infections. This should be seen more as a way to monitor treatment in the context of a national database of patients with HBV or HCV infection (see the Patients Database section below) [8].

Regular biomarker surveys are the method of reference to estimate the prevalence of chronic infections in the general population. The viral hepatitis program can organize such biomarker surveys alone or in coordination with Demographic and Health Surveys, AIDS indicator surveys, or population HIV impact assessments that provide opportunities for coordination (depending on target populations, age groups, and sample sizes) [31]. Planning this integration ahead of time to include HIV, HBV, and HCV as part of the objectives of the survey may be better than testing stored specimens. Testing stored sera may raise methodological issues when specimens are not available from all study participants [40]. It can also raise ethical issues if participants identified with HBV or HCV cannot be linked to care [8]. The WHO prepared a template protocol to conduct biomarker surveys for viral hepatitis. This protocol will be available from the WHO upon request while in draft form and will be made available electronically on the Web when finalized. In addition to surveys conducted in the general population, surveys among specific groups (eg, PWID and men who have sex with men) can inform about risk behaviors and the prevalence of infection in these groups. This type of surveillance is often conducted in the context of HIV programs. Information from such surveys in specific populations may be used in combination with information from the general population to estimate the overall size of the infected population.

Reporting of cases of chronic HBV and HCV infections from health care facilities can be implemented in the context of a database of chronically infected patients (see the Patients Database section below) that documents the cascade of diagnosis, care, and treatment. Cases of chronic infection reported from health care facilities estimate the number of cases diagnosed. Reporting systems for these cases of chronic infections need to be completely separate from systems to report acute hepatitis. Reporting of cases of acute hepatitis is done for a different objective, which is to estimate incidence and identify risk factors for new infections. The practice of reporting cases of chronic infection together with cases of acute hepatitis may lead to a database that contains cases of acute hepatitis diluted in a larger number of chronic infections. This complicates interpretation of the data on acute hepatitis. Acute hepatitis data are particularly useful because they reflect recent infections. If they are merged with data on chronic infections for which the date of infection is unknown, they lose specificity and usefulness.

Surveillance for Sequelae (Including Mortality)

Viral hepatitis–associated mortality is spread across various causes of death in vital registration systems. These include acute hepatitis (that accounts for a small proportion of deaths), cirrhosis, and hepatocellular carcinoma (for which the link with HBV and HCV infection is not documented in the death certificates) [41]. To quantify deaths from the sequelae of HBV and HCV infections, the WHO proposes to start from the mortality envelope from sequelae (the deaths from cirrhosis and hepatocellular carcinoma from vital registration data) and to correct it on the basis of the fraction of these sequelae that are attributable to HBV and HCV infection. This may be done using national data on the prevalence of HBV and HCV infection among patients with cirrhosis and hepatocellular carcinoma. Such estimates may be obtained from published studies, unpublished data, or regional estimates [18,42].

Patient Database for Testing and Treatment

At an early stage of a program, estimates describing the cascade of testing and treatment may be obtained from ad hoc mechanisms (eg, surveys and data on sales of medicines). However, the best approach to monitor and evaluate a national program for testing and treatment of HBV and HCV infection is to establish a national database of persons with chronic infections.

If feasible, combining case reporting and patient monitoring systems can create a national database of patients with chronic HBV and HCV infection. Health care providers can use such databases to manage data on personal characteristics, diagnosis, treatment initiation or deferral, monitoring, and viral suppression/cure. When a person is diagnosed (ie, newly identified cases of chronic infection), his/her record is added to the database. The record is censored when the person is cured or dies. The system may be made of standardized patient cards, paper registers, or an electronic data entry system. If data collection is paper-based, information then needs to be entered on a computer. Unique identifiers are necessary to identify and remove duplicate reports (ie, deduplication) and to protect confidentiality of patients. They can also be used to follow individuals along the cascade of services over the medium term and as they move between facilities. Automated data analysis can then aggregate individual data and calculate core indicators on treatment coverage/initiation (C.7.a/C.7.b) and viral suppression/cure (C.8.a/C.8.b) using a cohort approach. From 2017, the WHO will be assisting countries through the preparation of a template patient card, database metadata, and analyses plans that will allow setting up electronic patient registries. However, ideally, such a database should be compatible with other existing health information systems, such as the one used for HIV.

Coinfections

About 2.3 million people living with HIV are coinfected with HCV [43] and 2.6 million with HBV [44,45]. HBV-HIV coinfection became easier to handle as the first-line recommended antiretroviral regimens now include tenofovir, which would also effectively treat HBV infection [46]. With respect to HCV-HIV coinfection, testing of HIV-infected patients for HCV infection is necessary as coinfection requires specific management and treatment [13]. HCV treatment may be administered before HIV treatment if the patient is not immunosuppressed. If the patient is immunosuppressed, HIV treatment needs to be started first, and the HCV treatment regimen will need to be adapted to avoid drug interactions [13].

The consolidated strategic information guidelines for HIV included two indicators for coinfection, LINK 27 for HBV and LINK 28 for HCV [7]. LINK 27 and LINK 28 reflect the proportion of patients in care for HIV that have been screened for HBV and HCV, respectively. In 2016, in view of the new “treat all” HIV treatment guidelines, the WHO proposed to amend the LINK 27/28 indicators so that the numerator would be the number of persons newly placed on anti-retroviral treatment screened for hepatitis B/C during the reporting period and the denominator would be the number of persons newly placed on ART. For HCV infection, testing for HCV infection would mean implementing the full testing strategy that includes HCV nucleic acid test testing if the patient is anti-HCV positive. This modification would best reflect the need to look for hepatitis before starting treatment. It will help ensure that HBV-infected patients are placed on tenofovir-based therapy and that HCV-infected people are being considered for specific treatment.

Conclusions

The many commonalities between HIV, HBV, and HCV in terms of the diseases that they cause and response required justify implementation of the programs with coordination, strategic linkages, or integration, according to the respective magnitudes of the HIV and viral hepatitis epidemics. These articulations should be considered at the strategic, policy, technical, and implementation levels. Alignment of the collection, analysis, and use of strategic information are critical areas of this coordinated implementation. The WHO monitoring and evaluation frameworks for HIV, HBV, and HCV have been constructed using a similar logic to facilitate alignment. However, the differences between HIV, HBV, and HCV call for collaborations with other areas of work to ensure a comprehensive approach. These include communicable disease surveillance for acute hepatitis surveillance, immunization, and hepatology centers for sequelae surveillance. The focus of the SDGs on a single health goal and the similarities in the targets for HIV, HBV, HCV, and tuberculosis mean that the overarching priority would be to integrate viral hepatitis strategic information and HIV strategic information within the broader existing health information systems and thus contribute toward strengthening the health system. With this approach, a coordinated incremental investment in the data system will provide the evidence base needed to guide elimination of viral hepatitis.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Monitoring and evaluation framework.

[PDF File (Adobe PDF File), 32KB - publichealth_v3i4e91_app1.pdf]

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Abbreviations

AIDS: acquired immune deficiency syndrome
ALT: alanine aminotransferase
anti-HAV: antibody against hepatitis A virus
anti-HBc: antibody against hepatitis B core antigen
anti-HCV: antibody against hepatitis C virus
anti-HEV: antibody against hepatitis E virus
GHSS: Global Health Sector Strategy
HBIg: Hepatitis B immune globulin
HBsAg: Hepatitis B surface antigen
HBV: hepatitis B virus
HCC: hepatocellular carcinoma
HCV: hepatitis C virus
Ig: immunoglobulin
PWID: people who inject drugs
RNA: ribonucleic acid
SARA: Service Availability and Readiness Assessment
SDGs: Sustainable Development Goals
STIs: sexually transmitted infections
UNICEF: United Nations International Children’s Emergency Fund

WHO: World Health Organization

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Original Paper

Monitoring Prevention Impact of Mother-to-Child Transmission of HIV in Concentrated Epidemics With Program and Survey Data

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Abstract

Background: The prevention of mother-to-child transmission (PMTCT) of HIV program was introduced in Vietnam in 2005. Despite the scaling up of PMTCT programs, the rate of mother-to-child HIV transmission in Vietnam was estimated as high as 20% in 2013.

Objective: The objective of this study was to assess the outcomes of PMTCT and identified factors associated with mother-to-child transmission and infant survival using survey and program data in a high HIV burden province in Vietnam.

Methods: This community-based retrospective cohort study observed pregnant women diagnosed with HIV infection in Thai Nguyen province from October 2008 to December 2012. Data were collected through interviews using a structured questionnaire and through reviews of log books and medical charts in antenatal care and HIV clinics. Logistic regression and survival analysis were used to analyze data using Stata (StataCorp).

Results: A total of 172 pregnant women living with HIV were identified between 2008 and 2012. Most of these women had acquired the HIV infection from their husband (77/119, 64.7%). Significant improvement in the PMTCT program was documented, including reduction in late diagnosis of HIV for pregnant women from 62.5% in 2008 to 30% in 2012. Access to antiretrovirals (ARVs) improved, increasing from a rate of 18.2% (2008) to 70.0% (2011) for mothers and from 36.4% (2008) to 93.3% (2012) for infants. For infants, early diagnosis within 2 months of birth reached 66.7% in 2012 compared with 16.7% in 2009. Transmission rate reduced from 27.3% in 2008 to 6.7% in 2012. Late diagnosis was associated with increased risk for HIV transmission (odds ratio [OR] 14.7, 95% CI 1.8-121.4, P=.01), whereas ARV therapy for mother and infant in combination with infant formula feeding were associated with reduced risk for HIV transmission (OR 0.01, 95% CI 0.001-0.1; P<.001). Overall survival rate for HIV-exposed infants at 12 months was 97.7%.

Conclusions: A combination of program and survey data measured the impact of prevention of HIV transmission from mother-to-child interventions. Significant improvement in access to the interventions was documented in Thai Nguyen province. However, factors that increased the risk of HIV transmission, such as late diagnosis, remain to be addressed.

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KEYWORDS

HIV; prevention; mother-to-child transmission; Vietnam

Introduction

There are nearly 5 million people living with HIV (PLHIV) in Asia and the Pacific region, and key populations at the greatest risk for contracting HIV are people who inject drugs (PWID), men who have sex with men (MSM), and female sex workers (FSW) [1]. Vietnam is one of the 12 countries with the highest HIV burden in the region [1]. As of 2014, it was estimated that

256,000 people were living with HIV in Vietnam. The HIV prevalence among PWID, FSW, and MSM in 2013 was 22%, 5.3%, and 2.4%, respectively, whereas HIV prevalence in general population and pregnant women was 0.26% and 0.2%, respectively [2]. The prevalence of HIV among pregnant women varies by provinces. For example, it was 0.25% in Thai Nguyen province in 2014 (unpublished data) and higher (0.42%) in Ho Chi Minh City in 2013 [3].

Vietnam introduced the prevention of mother-to-child transmission of HIV (PMTCT) program in 2005. Since then, the proportion of pregnant women who received an HIV test and their results, including those with previously known status as HIV positive, increased from 11% in 2008 to 50% in 2013 [2]. Access to antiretrovirals (ARVs) to reduce the risk of mother-to-child transmission improved concurrently. The proportion of HIV-positive pregnant women receiving ARVs increased from 33% in 2008 to 57% in 2013 [2]. Despite these improvements in access to HIV testing and ARVs for pregnant women, the mother-to-child HIV transmission rates were estimated as high as 20% in 2013 because of limited coverage of PMTCT, late diagnosis, and delayed antiviral intervention [2].

A universal HIV testing policy for pregnant women is not yet adopted by Vietnam. Resources for PMTCT are focused on provinces with high and medium HIV burden as determined by HIV case reporting and mainly supported by donors such as the US President's Emergency Plan for AIDS (acquired immunodeficiency syndrome) Relief as well as the Global Fund to Fight AIDS, Tuberculosis and Malaria. Currently, because of limited resources, a universal testing policy is only applied in high-burden districts. At the same time, the Ministry of Health is developing a standard package for antenatal care (ANC), which includes HIV, hepatitis B virus, and syphilis testing. Advocacy to cover these tests under health insurance is ongoing.

At the time of this study, ARV prophylaxis using azidothymidine (AZT) was recommended for all HIV-infected pregnant women to prevent transmission to their neonates (option A per WHO [World Health Organization] 2010 guidelines) [4]. A short course of ARV prophylaxis (single dose of nevirapine [NVP] and 4 weeks of AZT) was recommended for HIV-exposed infants. Infant formula was provided free of charge for up to 18 months. The current national guidelines that were updated in 2015 recommend ARV treatment for all pregnant women regardless of cluster of differentiation 4 (CD4) and clinical stage, as well as 6 to 12 weeks of NVP for all HIV-exposed infants [5].

In line with the guidance from WHO and the Joint United Nations Program on HIV and AIDS (UNAIDS), the Vietnam National Strategy on HIV/AIDS Prevention and Control has set a target of reducing HIV transmission from mother to child to less than 2% by 2020 [6], with an aim of eliminating HIV transmission from mother to child by 2015. To reach this target, identification of the barriers to the elimination of mother-to-child transmission is important.

The barriers may exist at any stage of the PMTCT cascade, which includes HIV testing of pregnant women, referral of HIV-positive women for ARV therapy (ART), uptake of ART by pregnant women living with HIV, treatment of neonate, infant feeding, and early infant diagnosis. Data from Vietnam and elsewhere show a range of barriers to access PMTCT services, including individual and health system issues such as lack of knowledge and information, fear of stigma and discrimination, late diagnosis, poor quality of care, and service accessibility [7,8]. Thus, understanding what factors were associated with mother-to-child transmission within the program context would help program managers to design appropriate service delivery models and allocation of resources for optimizing the effectiveness of recommended interventions. With this fact in mind, this study was conducted in Thai Nguyen, a province located in the north of Vietnam with a high HIV prevalence among PWID (34%) [2], which aimed to use a method relying primarily on routine data to assess the outcomes of the PMTCT program in Thai Nguyen and to identify factors associated with HIV transmission from mother to child and infant survival.

Guidelines of UNAIDS and WHO encourage a shift from using ANC survey data to using the program data for HIV. As countries confront the required quality improvement for program data to make this shift, implementers should consider the additional steps that could improve impact monitoring of PMTCT programs at the same time.

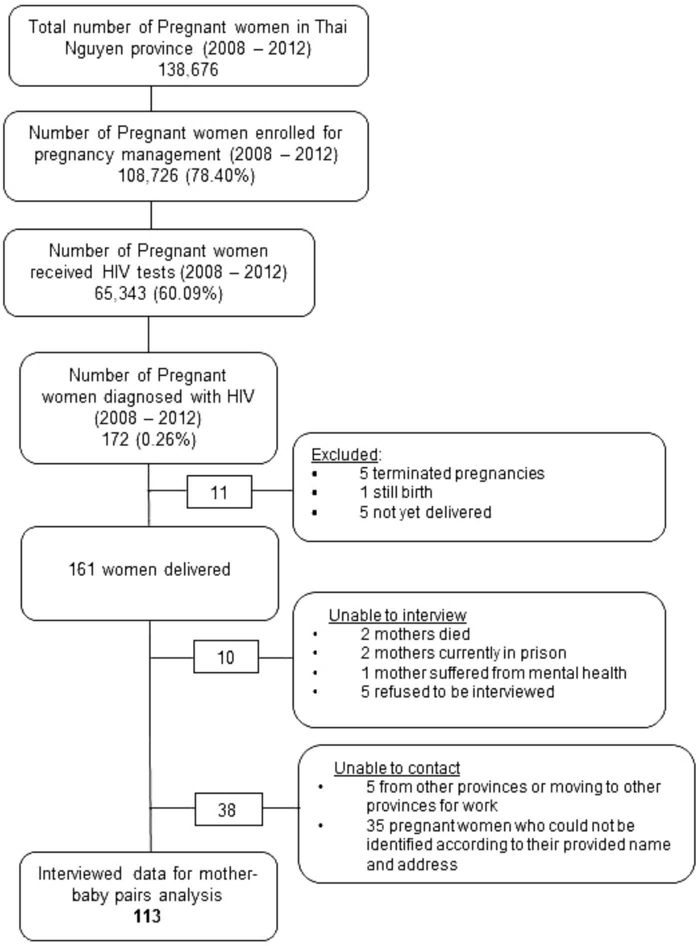
This study aims to assess the outcomes of PMTCT and identified factors associated with mother-to-child transmission and infant survival using survey and program data in a high HIV burden province in Vietnam.

Methods

Data Collection

This community-based retrospective cohort study was conducted between November 2011 and January 2013 to assess the outcomes of the PMTCT program, including uptake of ANC and PMTCT services among pregnant women living with HIV, infants' HIV and survival status, and associated factors. A list of pregnant women who were diagnosed with HIV infection in the entire province, including 9 districts and towns, from October 2008 to 2012 was developed. After removing duplicate cases, the list was finalized with 172 pregnant women living with HIV. The records of these women were traced back through registration in outpatient clinics (OPCs) and district PMTCT clinics. All 172 HIV-infected pregnant women were contacted by OPC doctors either through telephone numbers that they had given upon registration or through the peer educators who support the treatment program, and they were invited for a face-to-face interview at their district OPCs or at their preferred locations. For women who were not contactable by telephone, the health care workers at the district PMTCT focal point visited them in their house to invite them to participate in the study. The interviews were conducted with those who provided informed consent by the provincial AIDS center staff using a structured questionnaire. Information on demographics, mothers' access to HIV testing and ARVs, infant ARV prophylaxis, and infant feeding was collected through the interview.

Figure 1. Flow chart of recruiting participants. PW: pregnant women.



Data related to ART for the mothers during labor and pregnancy, access to HIV care, and treatment for mothers and infants were also collected through the review of medical records in provincial and district obstetrics departments, pediatric clinics, and OPCs. Wherever possible, data from interviews were triangulated with data from medical charts to validate interview data.

Data Analysis

Data collected from interviews and linked to medical records were analyzed to describe characteristics of the pregnant women living with HIV and their access to PMTCT interventions.

To determine the transmission rate and HIV-free survival, data related to this cohort of infants born to HIV-infected mothers were analyzed. The endpoint for the infant follow-up was HIV status as recorded either at the last visit to a pediatric clinic or at the time of the death. Children with unknown HIV status who did not return to a pediatric clinic within 90 days of the last visit were defined as lost to follow-up, and the date of last visit recorded in the medical chart was used as the censoring date. Survival rate was determined among infants with and without HIV infection by survival analysis.

For analysis of HIV transmission risk factors, only 113 mother-infant pairs were available for inclusion in logistic regression analysis. We excluded those who could not be interviewed for various reasons or whose pregnancies were terminated (see Figure 1). To understand the effect of combined interventions of ARVs for mother, ARV prophylaxis for infant, and infant formula feeding, a new variable was generated with three level categories: full access (received all three interventions), partial access (received one or two interventions), and no access (missed all interventions).

Data analysis was performed by using STATA 11.1. Logistic regression and survival analysis were conducted to identify factors associated with HIV transmission from mother to child and survival rate for HIV-exposed infants.

The study was reviewed and approved by Local Ethics Review Committee—Hanoi School of Public Health—and by Ethics Review Committee of WHO Regional Office for Western Pacific.

Results

From 2008 to 2012, there were 108,726 out of 138,676 (78.40%) pregnant women enrolled for pregnancy management in the province. Of those who enrolled, 65,343 (60.1%) received HIV tests (Figure 1). Prevalence of HIV among pregnant women who received HIV testing was 0.26% (172/65,343). Among 172 HIV-positive pregnant women, 161 women delivered and 113 were interviewed (Figure 1). Most of the interviewed pregnant women living with HIV were young (mean age: 28.2 years) and married (94.1%). More than half (55.5%) had an education level of high school or higher, and 58.0% reported having a stable job. Nearly one-third of the interviewed women were from ethnic minority groups. The most common route of infection reported was from an HIV-positive husband (64.7%). Although less common, nearly 3% of the women reported that they had more than one sexual partner, and 3.4% of the women reported ever sharing needles when injecting drugs (Table 1).

Uptake of Antenatal Care Among HIV-Positive Women

The proportion of pregnant women with a first ANC visit during the first trimester improved over the study period, whereas the number of late ANC visits (during trimester) or number of women with no ANC visit declined (Figure 2). A majority of women delivered at national/provincial hospital (76.3%) or district health facilities (19.3%), whereas a small number delivered at community health stations or at home (4.4%). Cesarean sections were 36.8% of all deliveries (Table 1).

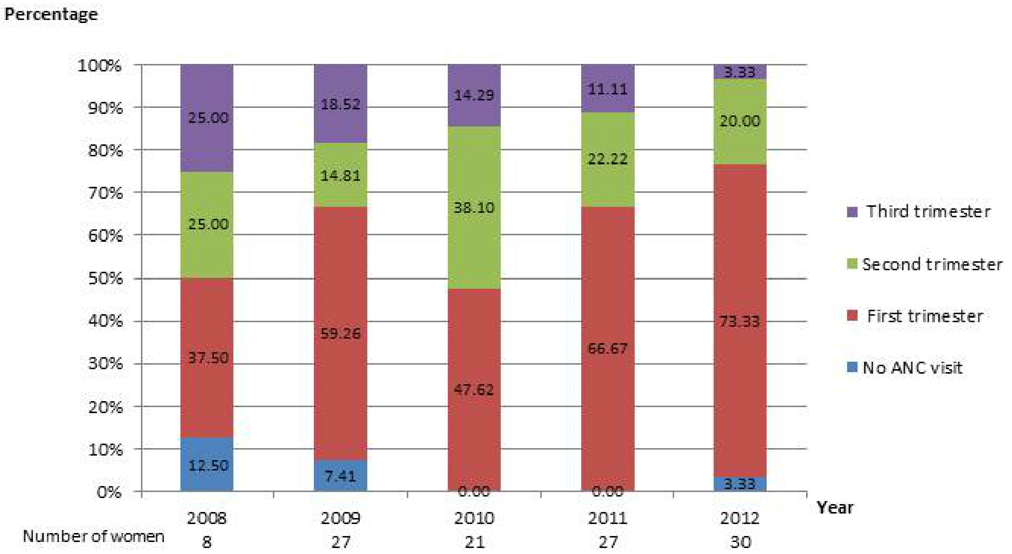
Table 1. Characteristics of pregnant women living with HIV infection (including 5 women who terminated their pregnancies and 1 woman who had still birth).

Variables	Values (N=119)
Age range in years (mean, standard deviation)	19-42 (28.2, 4.5)
Marital status, n (%)	
Married	112 (94.1)
Other (single, widow, and divorced)	7 (5.9)
Ethnicity, n (%)	
Kinh	87 (73.1)
Minority	32 (29.3)
Education, n (%)	
Primary or secondary school	53 (44.5)
High school or higher	66 (55.5)
Employment [a], n (%)	
Stable job	69 (58.0)
Unstable job	31 (26.1)
Unemployed	18 (15.1)
Reported transmission route, n (%)	
Having more than one sexual partners	3 (2.5)
Spouse infected with HIV	77 (64.7)
Spouse using drugs and unknown HIV status	21 (17.6)
Ever injecting drugs and sharing needles	4 (3.4)
Unknown/No answer	14 (11.8)
Location of delivery [b], n (%)	
District hospital	22 (19.3)
National/Provincial hospital	87 (76.3)
Community health station or at home	5 (4.4)
Mode of delivery [b], n (%)	
Natural delivery	72 (63.2)
Cesarean	42 (36.8)

[a] Value missing for one.

[b] Of the total, 5 women had their pregnancy terminated.

Figure 2. Time of first antenatal care visit among pregnant women living with HIV infection by year. ANC: antenatal care.



Access to PMTCT Services

In 2008, 5 out of 8 (62%) HIV-positive pregnant women were diagnosed at the time of labor. Following the introduction of the PMTCT program, late diagnosis declined to 30% (9/30) in 2012 (Figure 3). From 2010 onward, the proportion of pregnant women whose HIV status was known before or during pregnancy increased (Figure 3). Although in 2008 only 25% (2/8) of HIV-infected pregnant women received ARVs, this figure increased to 70% (21/30) in 2012. Infant ARV prophylaxis (single-dose NVP and 4 weeks of AZT) also increased from 36% (4/11) in 2008 to 93% (28/30) in 2012. During the study period, formula feeding was encouraged for HIV-positive mothers whenever possible. Since 2011, 100% of exposed infants were formula fed. Breastfeeding was reported for 10 infants born before 2011.

The proportion of HIV-exposed infants less than 18 months of age receiving polymerase chain reaction (PCR) tests increased over time from 71.4% (30/42) in 2009 to 100% (30/30) in 2012. Notably, the proportion of infants receiving PCR tests within 60 days of birth increased from 16% (5/30) in 2009 to 67% (20/30) in 2012 (Figure 4).

Figure 3. Time of HIV diagnosis among pregnant women living with HIV by year.

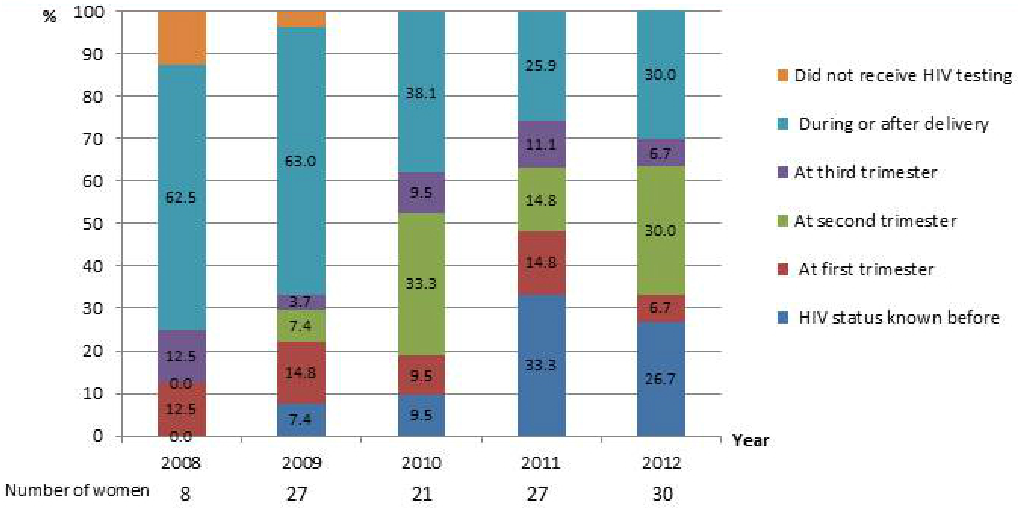
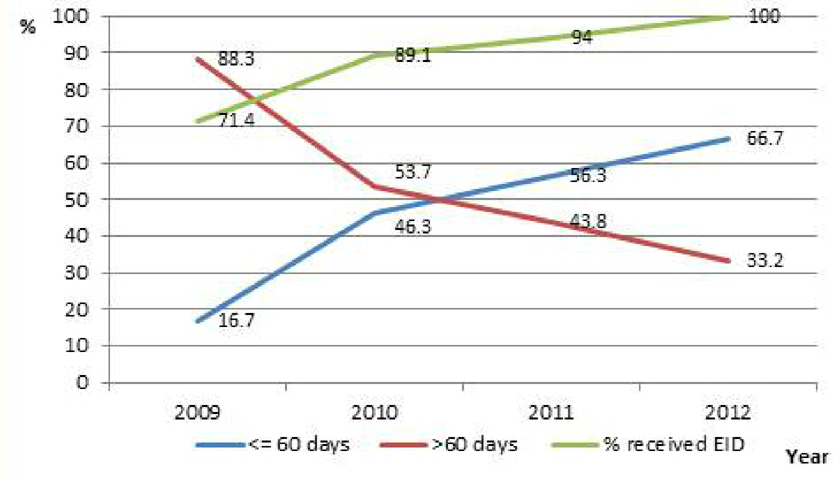


Figure 4. Access to early infant diagnosis (EID) by year.



Program Limitations

Despite these improvements, there are limitations to be addressed. Late diagnosis of HIV during labor/delivery still occurred in a significant proportion of pregnant women in 2012. By the time this study concluded, only 45.4% (54/119) HIV-positive pregnant women enrolled for care and received ART. Time from delivery to enrollment in care varies from 6 days to 3 months; for 79% (43 out 54) of the women on ART, enrollment took place after 30 days following the delivery. There were 7 HIV-exposed infants documented as lost to follow-up.

Outcomes for HIV-Exposed Infants

Data from 163 pediatric records of children born to 161 HIV-positive mothers from 2008 to 2012 showed that 84.7% infants were HIV free, 11.0% were HIV positive, and 4.3% had unknown HIV status. All 18 HIV-infected children were enrolled in care and treatment, of whom 11 received ART (1 of them died) and 7 received cotrimoxazole prophylaxis therapy for the prevention of opportunistic infections (1 of them died). Among 7 children with unknown HIV status, 2 died and 5 were lost to follow-up. The mean birth weight of infants in this cohort was 3039 g. Low birth weight (<2500 g) was observed in 3% of HIV-exposed infants.

Transmission Rate and Risk Factors for Transmission

HIV transmission from mother to child was documented in 18 infants. The transmission rate substantially decreased from 27.3% in 2008 to 6.7% in 2012. Univariate analysis found that late HIV diagnosis for mothers increased the risk for HIV transmission to their children (odds ratio [OR] 14.7, 95% CI 1.8-121.4; *P*=.01), whereas access to ARVs for mothers (OR 0.07, 95% CI 0.008-0.6; *P*=.01), access to ARV prophylaxis for infants (OR 0.1, 95% CI 0.03-0.4; *P*=.002), and formula feeding (OR 0.3, 95% CI 0.005-0.1; *P*<.001) reduced the risk for HIV transmission from mothers to infants (Table 2). Other factors such as age and education level of mothers, delivery mode, living area, ethnicity, and employment status were not associated with HIV transmission (Table 2). We were unable to conduct multivariate analysis because of the small sample size and high collinearity among variables. Instead, we generated new variables on combined interventions to analyze their synergistic effects in preventing mother-to-child transmission. The findings show that full access to effective interventions significantly reduced the risk for the transmission (OR 0.01, 95% CI 0.001-0.1; *P*<.001), and to a lesser extent, access to either ARV for mother or infant and/or formula feeding reduced the likelihood of HIV transmission when compared with no interventions (Table 3).

Infant Survival

Mean age of children born to HIV-infected mothers in this study was 17 months (0.9-49 months). At 12 months, overall survival rate was 97.7%. For HIV-negative children, 12-month survival was 100%; for infants with unknown or HIV-positive status, it was 87%. High 12-month survival rates were also found among formula-fed HIV-exposed infants (98.7%). The overall infant mortality rate was 9.7/1000 live infants. Kaplan Meier survival estimates show that infants with unknown HIV status or infants who missed all interventions had lower survival rates (Figures 5 and 6). Birth weight, infant gender, and feeding mode were not associated with infant survival. Owing to small sample size, it was not possible to conduct further analysis.

Table 2. Univariate analysis of factors associated with infant HIV status. This table included 113 mother-baby pairs.

Variables	Infant HIV status		OR[a] (95% CI)	*P* value
	Negative, n (%)	Positive, n (%)		
Time of mother's HIV diagnosis				
Before or during pregnancy	63 (98.4)	1 (1.6)	Referent	.01
During or after labor/delivery	36 (80)	9 (20)	14.7 (1.8-121.4)	
Mother received antiretroviral (ARV) during pregnancy				
No	41 (82)	9 (18)	Referent	.01
Yes	62 (98.4)	1 (1.6)	0.07 (0.008-0.6)	
Infant received ARV prophylaxis				
No	10 (66.7)	5 (3.3)	Referent	.002
Yes	93 (94.9)	5 (5.1)	0.1 (0.03-0.4)	
Infant feeding				
Breastfeeding	4 (40)	6 (60)	Referent	<.001
Formula feeding	99 (96.1)	4 (3.9)	0.3 (0.005-0.1)	
Mode of delivery				
Cesarean section	36 (94.7)	2 (5.3)	Referent	
Vagina delivery	49 (94.1)	3 (5.9)	0.9 (0.1-5.7)	.90
Unknown	18 (75.0)	5 (25)	4.5 (0.98-20.9)	.05
Education of mother				
Primary/Secondary school	39 (90.7)	4 (9.3)	Referent	.60
High school or higher	40 (87)	6 (13)	1.4 (0.4-5.3)	
Age of mother, in years				
<25	26 (96.3)	1 (3.7)	Referent	.30
≥25	9 (11.0)	3.0 (0.4-25.2)	73 (89.0)	
Living area				
Urban	24 (96)	1 (4)	Referent	.30
Rural	75 (89)	9 (11)	2.7 (0.3-22.7)	
Ethnic minority				
No	77 (91.7)	7 (8.3)	Referent	.70
Yes	26 (89.7)	3 (10.3)	1.3 (0.3-5.3)	
Employment				
Having stable job	59 (90.8)	6 (9.2)	Referent	.60
Having an unstable job or no job	44 (91.7)	4 (8.3)	0.9 (0.2-3.3)	

[a] OR: odds ratio.

Table 3. Multivariate analysis of combined interventions for pregnant women living with HIV infection. Interventions used were antiretrovirals (ARVs) for mothers and ARV and infant formula for infants. The table included 113 mother-baby pairs.

Variables	HIV status		OR[a] (95% CI)	*P* value
	Negative, n (%)	Positive, n (%)		
Missed all three interventions	4 (44.4)	5 (55.6)	referent	-
Missed one or two interventions	38 (90.5)	4 (9.5)	0.08 (0.02-0.4)	.004
Full access to interventions	61 (98.4)	1 (1.6)	0.01 (0.001-0.1)	<.001

[a] OR: odds ratio.

Figure 5. Kaplan-Meier curve for survival by accessing to intervention.

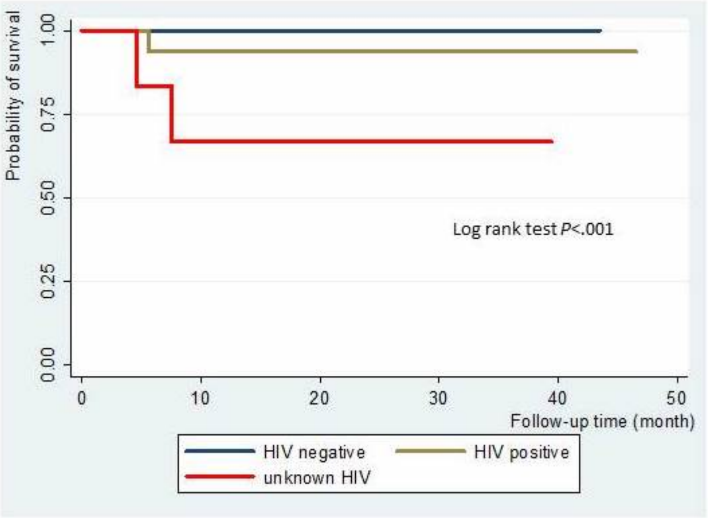
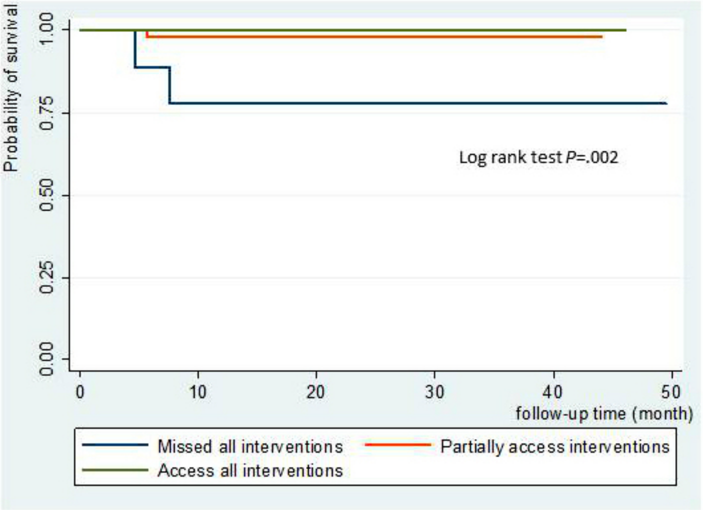


Figure 6. Kaplan-Meier curve for survival by accessing to intervention.



Discussion

Principal Findings

The Thai Nguyen PMTCT program achieved higher coverage of ARV prophylaxis (70% vs 47.4%) and early diagnosis (66.7% vs 24.4%) than the national average in 2012 [2]. The increasing trend in access to PMTCT services, including early HIV diagnosis for mothers and infants, and ARV prophylaxis has reduced HIV infection among newborn infants from 27.3% in 2008 to 6.7% in 2012. A study that reviewed data on early infant diagnosis in 29 selected provinces in Vietnam reported the HIV transmission rate in the same period (2010-2012) to be 8.5% higher than that in Thai Nguyen [9]. We also observed a shift toward more women with a known HIV status enrolling in PMTCT program over time.

The Vietnam national response to HIV has substantially scaled up since 2005. The number of PLHIV receiving ART increased to 82,687 in 2013 (67.6% of those eligible) [2]. Similarly, the proportion of pregnant women living with HIV receiving ARV prophylaxis also increased from 13.9% in 2007 to 57% in 2013 [2]. Program monitoring and impact evaluation are moving toward increased use of program data in the interest of sustainability and more rapid assessments. Stand-alone surveillance activities are being replaced with more sustainable systems. Those systems need to be built on routinely collected program data. This community-based retrospective cohort study relied on routinely collected data augmented by surveys to illustrate that PMTCT program in Thai Nguyen significantly improved outcomes in access to HIV testing, ARV, and early infant diagnosis, thereby resulting in a reduction in HIV transmission from mother to child. The study also identified some gaps including mothers' late enrollment to care and loss to follow-up of the infants. Factors associated with vertical HIV transmission and infant survival were examined. The risk for HIV transmission was significantly reduced if mothers accessed ARV during pregnancy and infants has access to both ARV and infant formula. Infant survival rate was significantly associated with HIV status.

WHO released *Guidelines for assessing the utility of prevention of mother-to-child transmission (PMTCT) programme data for HIV sentinel surveillance among pregnant women* in 2013 [10], followed by *Guidelines for conducting HIV surveillance based on routine programme data* in 2015 [11]. Taken together, the guidelines encourage national surveillance programs to improve PMTCT data to replace periodic ANC surveys. This study demonstrates the potential for program data to measure impact with some modifications. The lessons learned suggest additional modifications to PMTCT program data to extend the use of these data beyond standard HIV surveillance.

National data for PMTCT programs, especially capturing each step of the continuum of care cascade, is still limited because of weak or incomplete health information systems, low quality data, and challenges to link each step of the cascade. The current reporting system does not link testing and treatment/prophylaxis for pregnant women and HIV status of their infants. An important challenge encountered was the lack of a link between the different program data sources. With the absence of such a link, data validation and use to analyze PMTCT cascades is laborious and time consuming. This impedes the ability to inform national planning and policy development for prevention of new HIV infection among newborns. As recommended by WHO HIV testing guidelines [12], data from high-performing PMTCT sites that meet specified criteria can be used to replace ANC sentinel surveillance data, freeing those resources and potentially providing a more national picture than ANC-based surveys. In addition, methods used in this study can be used to measure the impact of national PMTCT programs, which is also recommended by WHO [13]. Although this study demonstrates that it is feasible to conduct retrospective cohort studies to measure impact of PMTCT programs, it would be more cost-effective and timely if a unique identifier system can link data from pregnant women living with HIV with their infants' health records to minimize time and cost for linking and validating mother-baby pairs and to facilitate tracking and follow-up of women and their HIV-exposed infants.

The issue of enrollment of HIV-infected pregnant women in OPCs at a late stage of infection remains. In this study, only 62% of pregnant women living with HIV attended an OPC for care and treatment (excluding 10 women who terminated their pregnancies or died). Some women enrolled for care and treatment several months after delivery. This suggests poor linkages between maternal and child health services and HIV services. A functioning linkage from testing to enrollment for PMTCT and treatment and care requires strong and effective collaboration between reproductive health and HIV programs. Currently, Vietnam has adopted WHO 2016 recommendations [14] on treating all HIV-infected pregnant women, which could facilitate the enrollment in care and minimize loss to follow-up. Linkages can improve overall care and retention; Cambodia uses linkages and a strong referral and follow-up system to increase uptake of HIV testing among pregnant women and link with PMTCT services [15].

Although HIV transmission in Thai Nguyen has been reduced remarkably, it is still above 5%. To achieve the goal of elimination of mother-to-child transmission, it is important to understand factors associated with HIV transmission. Late maternal HIV diagnosis, high maternal viral load and low CD4 count, breastfeeding, vaginal delivery, and invasive procedure are documented risk factors for mother-to-child HIV transmission [16-20]. In our univariate analysis, education level, ethnicity, living area, and employment status were not associated with infant HIV status, although a study in Vietnam found an association between young age of the mothers (<25) and HIV transmission [21]. It is important to note that key effective interventions, including time of early HIV diagnosis, access to ARVs for mothers and infants, and infant formula feeding, were associated with low risk for HIV transmission. The full access to combined interventions of ARV for mothers and infants and formula feeding for infants has significantly reduced the risk for HIV transmission from mother to child. This finding suggests that a universal HIV-testing strategy should be implemented to achieve the national target of elimination of HIV transmission from mother to child by 2030. Universal testing may require initial investments, but it has been shown to be cost-effective even in a low and concentrated HIV epidemic country such as Vietnam [22].

The ultimate goal of PMTCT is to save the lives of infants born to HIV-positive mothers. The impact of the PMTCT program could be measured in terms of lives saved/infections averted. The Thai Nguyen study showed higher survival rate among HIV-negative infants (100%) compared with HIV-positive or unknown HIV-status infants (87%) at 12 months of age. This is consistent with another study from Vietnam [21], which demonstrated that no HIV-negative infants died in the first 12 months of their lives. Factors that increased mortality risk among HIV-exposed infants reported in several studies [23-26] were maternal death, maternal high viral load and low CD4 count, and infant HIV infection.

Limitations

There are several limitations in this study. A small number of mother-child pairs could not be found according to the address given at clinics, which may introduce biases to our understanding of program effectiveness, although without knowing the status of the women who were lost, it is difficult to assess. In addition, the data were based on program data and therefore did not include those who were not diagnosed or not reported; thus, results might have been underestimated. Recall bias may also have occurred as mothers were asked to report on events that happened in the past such as time of first ANC visits and time of HIV diagnosis. The analysis of factors associated with mother-to-child transmission of HIV was limited because of small sample size and lack of data on psychological, social support, and biological variables such as mothers' CD4 count and viral load. Finally, improvement of the PMTCT outcomes might have been influenced by other factors, including expansion of the national ART program, which could not be determined in this study.

Conclusions

This study demonstrated that modifications to routine data collection systems can yield data to evaluate the impact of PMTCT programs. A routine data-based surveillance system derived from PMTCT program data can be established to provide rich information on programs' challenges and successes. Significant improvement in access to HIV services and prevention of HIV transmission from mother to child was documented in Thai Nguyen province. However, factors that increased the risk of HIV transmission, including late diagnosis and late enrollment for care, remain to be addressed. In addition to expanding current harm reduction programs to reduce the rate of new infection among PWID and their female partners, enhancements to facilitate better uptake of ANC, identification of HIV-infected pregnant women, and their linkage to care are still needed. Increased access to CD4 and viral load testing, as well as steps to reduce loss to follow-up will also improve outcomes.

To achieve the national goal of elimination of mother-to-child transmission by 2020, greater efforts are needed to ensure that pregnant women know their HIV status earlier, preferably in the first trimester. Considering this, integration of HIV testing as a part of ANC package is expected to improve coverage of HIV testing for pregnant women. Finally, a strong information management system linking HIV and maternal and child health programs is required to ensure sustainable ongoing measurement of the impact of PMTCT programs to better serve pregnant women living with HIV and their infants with appropriate treatment.

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Authors' Contributions

VTTN developed the proposal, conducted data analysis, developed the manuscript, and coordinated the review of the manuscript with other coauthors. KS worked with the lead author on proposal development, data collection, and data analysis and worked as a part of writing group. MK provided technical input in the development of the proposal, data collection, and data analysis and took part in the critical review of the manuscript. HC provided technical input in the development of the proposal and data collection and took part in reviewing the manuscript. LAKA provided technical input in the development of the proposal and participated in data collection and in reviewing the manuscript. HQT provided technical input in the development of the proposal and participated in data collection and in reviewing the manuscript.

Conflicts of Interest

The authors are staff members of the World Health Organization. The authors alone are responsible for the views expressed in this publication and they do not necessarily represent the views, decisions or policies of the World Health Organization.

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Abbreviations

AIDS: acquired immunodeficiency syndrome
ANC: antenatal care
ART: antiretroviral therapy
ARV: antiretroviral
AZT: zidovudine
CD4: cluster of differentiation 4
FSW: female sex workers
MSM: men who have sex with men
NVP: nevirapine
PLHIV: people living with HIV
PMTCT: prevention of mother-to-child transmission of HIV
PW: pregnant women
PWID: people who inject drugs
OPC: outpatient clinic
OR: odds ratio

UNAIDS: Joint United Nations Program on HIV and AIDS
WHO: World Health Organization

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Original Paper

Lessons From the Implementation of Mo-Buzz, a Mobile Pandemic Surveillance System for Dengue

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Abstract

Background: Approximately 128 countries and 3.9 billion people are at risk of dengue infection. Incidence of dengue has increased over the past decades, becoming a growing public health concern for countries with populations that are increasingly susceptible to this vector-borne disease, such as Sri Lanka. Almost 55,150 dengue cases were reported in Sri Lanka in 2016, with more than 30.40% of cases (n=16,767) originating from Colombo, which struggles with an outdated manual paper-based dengue outbreak management system. Community education and outreach about dengue are also executed using paper-based media channels such as pamphlets and brochures. Yet, Sri Lanka is one of the countries with the most affordable rates of mobile services in the world, with penetration rates higher than most developing countries.

Objectives: To combat the issues of an exhausted dengue management system and to make use of new technology, in 2015, a mobile participatory system for dengue surveillance called Mo-Buzz was developed and launched in Colombo, Sri Lanka. This paper describes the system's components and uptake, along with other similar disease surveillance systems.

Methods: We developed Mo-Buzz and tested its feasibility for dengue. Two versions of the app were developed. The first was for use by public health inspectors (PHIs) to digitize form filling and recording of site visit information, and track dengue outbreaks on a real-time dengue hotspot map using the global positioning system technology. The system also provides updated dengue infographics and educational materials for the PHIs to educate the general public. The second version of Mo-Buzz was created for use by the general public. This system uses dynamic mapping to help educate and inform the general public about potential outbreak regions and allow them to report dengue symptoms and post pictures of potential dengue mosquito–breeding sites, which are automatically sent to the health authorities. Targeted alerts can be sent to users depending on their geographical location.

Results: We assessed the usage and the usability of the app and its impact on overall dengue transmission in Colombo. Initial uptake of Mo-Buzz for PHIs was low; however, after more training and incentivizing of usage, the uptake of the app in PHIs increased from less than 10% (n=3) to 76% (n=38). The general public user evaluation feedback was fruitful in providing improvements to the app, and at present, a number of solutions are being reviewed as viable options to boost user uptake.

Conclusions: From our Mo-Buzz study, we have learned that initial acceptance of such systems can be slow but eventually positive. Mobile and social media interventions, such as Mo-Buzz, are poised to play a greater role in shaping risk perceptions and managing seasonal and sporadic outbreaks of infectious diseases in Asia and around the world.

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KEYWORDS

pandemics; dengue; health communication; telemedicine; epidemiology; participatory surveillance; participatory epidemiology

Introduction

Underreporting of *Aedes*-borne viruses is high. For instance, only 2 million cases of dengue fever are reported each year to the World Health Organization although an estimated 98 million symptomatic cases occur [1,2]. Engaging communities in the surveillance of dengue, Zika, and other *Aedes*-borne viral diseases has the potential to increase reporting and reduce the incidence and transmission of *Aedes aegypti* [3]. Dengue is a global disease, with around half the world's population estimated to be at risk of infection. Incidence of dengue has increased over the past decades, with outbreaks rising in frequency, magnitude, and the number of affected countries [4,5]. It is estimated that 128 countries and 3.9 billion people are at risk of dengue [6,7]. The impact of dengue has been measured in terms of both monetary value, as well as public health metrics such as disability-adjusted life-years [8,9].

Dengue has been a national public health concern for Sri Lanka in recent years, with nearly 55,150 dengue cases reported in 2016. More than 30.40% (n=16,767) of these cases have originated from the western province of Colombo, which grapples with an exhausted dengue outbreak management system [10]. The problem is characterized by manual mechanisms of conducting surveillance (including identifying breeding sites), paper-based reporting of dengue cases to the hospitals, and challenges to coordinating health authorities, such as the Colombo Municipal Council (CMC), with public health inspectors (PHIs) and hospital epidemiological staff who find cases of dengue so that breeding sites can be treated [11]. Additionally, mapping of dengue hotspots during dengue outbreaks has been done reactively as each outbreak unravels, as opposed to relying on models to develop proactive mapping that can help both authorities and the public undertake preventive actions in advance.

Sri Lanka is one of the countries with the most affordable rates of mobile services in the world and has witnessed an unprecedented growth in the penetration of mobile services; its mobile phone penetration rates are higher than those in most developing countries [12]. However, dengue programs have yet to benefit from this technological trend, even as vast swathes of the Sri Lankan population become increasingly susceptible to this vector-borne disease. Community education and outreach about dengue continue to be executed using outdated media channels such as pamphlets and brochures. As a result, the capacity of public health institutions to persuade the public to practice healthy behaviors that protect from dengue is limited.

This paper describes the lessons and learning experiences from the development and launch of Mo-Buzz, a mobile participatory system for dengue surveillance, which was launched in Colombo, Sri Lanka, in 2015. Two versions of Mo-Buzz for dengue were launched: the first for use by PHIs and the second for the general public. Both versions are described here. For comparison and to highlight interest and growth in this type of surveillance system, we also describe other vector disease surveillance systems. A major objective of the development of Mo-Buzz and similar systems was to improve dengue surveillance and to reduce the spread of dengue, with the hope of expanding the technology to other infectious diseases.

Methods

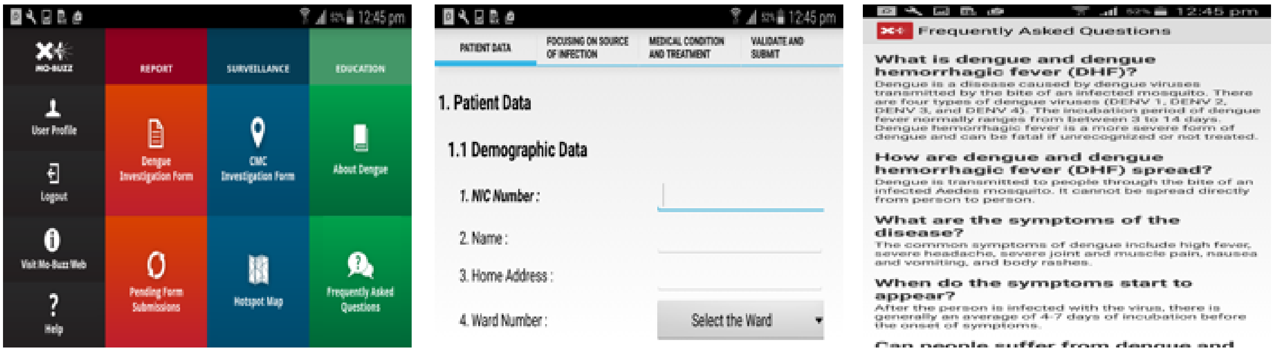
Development of the System

Two forms of the Mo-Buzz mobile participatory system for dengue surveillance were developed in Colombo, Sri Lanka, which are described below. The research was approved by the institutional review board of the Nanyang Technological University for the protection of human subjects.

Mo-Buzz for Public Health Inspectors

Before Mo-Buzz was developed for PHIs, the Mo-Buzz research team conducted a series of in-depth needs assessment interviews with Sri Lankan PHIs to ascertain informational and technological needs pertaining to dengue [13]. The interviews were recorded and transcribed by a professional, and a research assistant coded the data into NVIVO (QSR International), a statistical package used in qualitative analysis. The data were analyzed to derive themes relating to issues affecting the effectiveness of the work of the PHIs. The Mo-Buzz research team found several key challenges concerning the PHIs and then developed solutions for each key challenge.

First, PHIs reported that filling in lengthy forms was extremely tedious and time-consuming and often resulted in mistakes. The Mo-Buzz research team postulated that digitizing the process would decrease the time taken to fill in the forms and would reduce the number of errors made. Second, the PHIs were using a separate global positioning system (GPS) tag, which the researchers found to be woefully inaccurate. The Mo-Buzz research team proposed utilizing tablets that have in-built GPS technology with increased sensitivity. Third, the PHIs took photographs of dengue mosquito–breeding sites, which had to be transported manually, and they often reported that the photos were misplaced or damaged, making them inadmissible. The Mo-Buzz research team suggested using the in-built digital cameras in the smart devices to transmit the pictures onto a Web-based database automatically. Finally, the PHIs reported that many of the educational materials being used by them were outdated. The research team postulated that having updated infographics would serve as interesting and entertaining platforms for the PHIs to educate the general public on dengue [14].



1. Patient Data

1.1 Demographic Data

1. NIC Number:

2. Name:

3. Home Address:

4. Ward Number: Select the Ward

What is dengue and dengue hemorrhagic fever (DHF)?

Dengue is a disease caused by dengue viruses transmitted by the bite of an infected mosquito. There are four types of dengue viruses (DENV 1, DENV 2, DENV 3, and DENV 4). The incubation period of dengue fever normally ranges from between 3 to 14 days. Dengue hemorrhagic fever is a more severe form of dengue and can be fatal if unrecognized or not treated.

How are dengue and dengue hemorrhagic fever (DHF) spread?

Dengue is transmitted to people through the bite of an infected Aedes mosquito. It cannot be spread directly from person to person.

What are the symptoms of the disease?

The common symptoms of dengue include high fever, severe headache, severe joint and muscle pain, nausea and vomiting, and body rashes.

When do the symptoms start to appear?

After the person is infected with the virus, there is generally an average of 4-7 days of incubation before the onset of symptoms.

Can people suffer from dengue and

Figure 1. Screenshots of the Mo-Buzz for Public Health Inspectors application. Home page, Dengue Investigation Form (DIF), Frequently Asked Questions (FAQ) (left to right).

On the basis of the Mo-Buzz research team's formative needs assessment interviews and the proposed solutions, the Mo-Buzz system that was developed for PHI use digitizes the three main roles of the PHIs: (1) recording field and site visit information (digitized surveillance), (2) keeping track of outbreak clusters in their regions (digitized dengue monitoring and mapping), and (3) providing dengue-related information to members of the general public (digitized dengue education). Each of these is described in turn below. Figure 1 shows the iPad (Apple Inc) view of the Mo-Buzz app for use by PHIs.

Digitized surveillance enables PHIs to record details of the case on a digital dengue investigation form (DIF). The digitized version of the form is clear and concise and has in-built alerts in the event that the PHI leaves a mandatory section blank. Both the DIFs and any photos of potential breeding sites taken by PHIs are automatically geotagged and can be shared with relevant health authorities with the press of a button.

Digitized dengue monitoring and mapping offers a real-time dengue hotspot map that is automatically updated when PHIs submit a DIF. The automatic geotagged breeding site reports (described above) are also represented on this same map. These map blips allow PHIs and relevant authorities to plan preventative interventions according to outbreak patterns, increasing both the efficacy and efficiency of their work.

Digitized dengue education seeks to increase positive interactions between the PHIs and the general public. The Mo-Buzz system offers PHIs information related to dengue in the form of entertaining infographics. Information is translated into the three main languages of Sri Lanka: English, Sinhalese, and Tamil. The educational materials include existing pamphlets handed out by the CMC and new information gathered from the Centers for Disease Control and Prevention.

Mo-Buzz for the General Public

The general public version of Mo-Buzz was designed for the general local population. As with Mo-Buzz for PHIs, a formative research survey was conducted before deployment. A total of 513 members of the general public in Colombo were surveyed to assess the potential receptivity to the Mo-Buzz system for public use through baseline surveys [15].

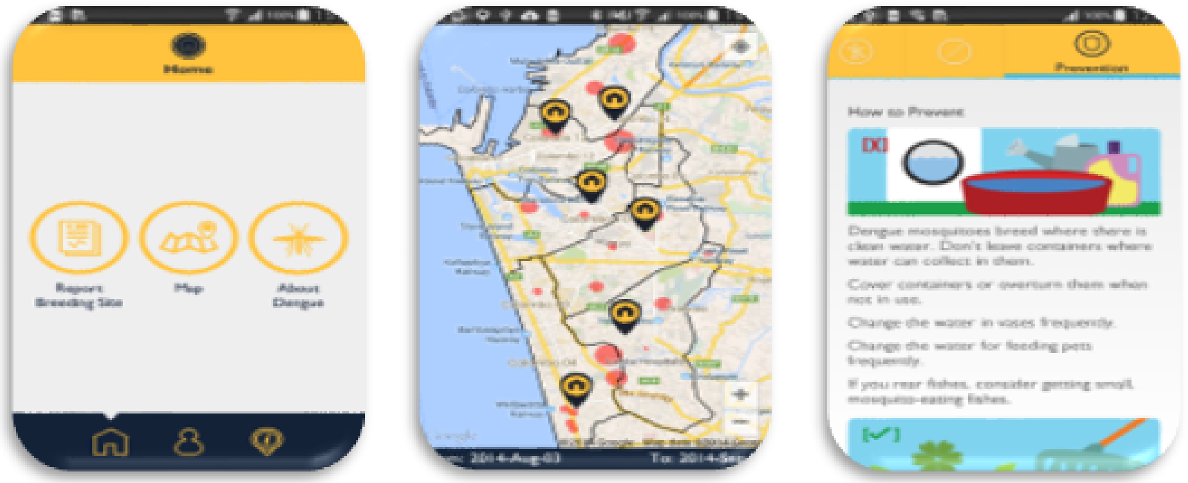
Protection motivation theory, which suggests that an individual's intention to perform behavior is intrinsically driven by the need to protect him or her from the health threat under consideration, was used as a framework in our research. Protection motivation theory regression models that are used to predict intention to use rely on variables such as perceived susceptibility and severity [16].

The survey found that the overall receptivity to the proposed Mo-Buzz system was high, with a score of greater than 4 on a 5-point scale. However, although the level of perceived severity of dengue was high with scores consistently greater than 4 when stratified by age, education, income, and ethnicity, the level of perceived susceptibility was low, with scores below 4 on a 5-point scale. In multivariate analyses, severity and susceptibility were found to be significant predictors of intention to use. We concluded that a social media–based system for dengue prevention would be positively received among Colombo residents, but that a targeted strategic health communication effort to raise dengue-related threat perceptions will be needed to encourage greater adoption and use of the system [17].

The public version of Mo-Buzz integrated three components: (1) dynamic disease mapping, (2) civic engagement, and (3) health communication. Each of these is briefly described below. More detailed descriptions are available elsewhere [18]. Screenshots of the Mo-Buzz public version app are shown in Figure 2.

Dynamic mapping helps to inform the general public about potential outbreak regions using an algorithm and computer simulation that utilizes both archival and current dengue-related data. The purpose of the component is to forewarn stakeholders (eg, health authorities) and members of public in the form of hotspot mapping, and it was designed to facilitate the planning of preventative measures and more efficient and effective management of resources.

Figure 2. Screenshots of Mo-Buzz for the general public. Home page, hotspot mapping, health education materials (left to right).



How to Prevent

Dengue mosquitoes breed where there is clean water. Don't leave containers where water can collect in them.

Cover containers or overturn them when not in use.

Change the water in vases frequently.

Change the water for feeding pets frequently.

If you rear fishes, consider getting small mosquito-eating fishes.

Homepage for general public to report breeding sites

Dengue hotspot maps made available to the general public

Citizens receive tailored health messages

The civic engagement component was developed because in the past, disease surveillance during an epidemic or pandemic has been the sole preserve of epidemiological divisions. The Mo-Buzz research team endeavored to develop a two-way platform built on the concept of crowdsourcing that allows public health officials to not only transmit information but also receive real-time intelligence on the spread of disease. Specifically, Mo-Buzz allows the general public to report dengue symptoms and/or post pictures of potential dengue mosquito–breeding sites. As with Mo-Buzz for PHIs, such reports and postings are automatically geotagged and sent to the health authorities with a click of a button, thereby stimulating the first stage of response by health authorities.

The health communication component consists of two modules. The first module is static and contains health education materials that discuss dengue transmission, symptoms, treatment, and prevention. The second module is dynamic and includes targeted alerts that are sent to users, depending on a user's geographical status and predictions developed by the hotspot maps.

Results

Mo-Buzz for Public Health Inspectors

When the Mo-Buzz for PHIs system was about 8 months into deployment by the CMC, the Mo-Buzz research team conducted follow-up in-depth interviews with 16 PHIs to ascertain the efficacy of Mo-Buzz.

The researchers found that Mo-Buzz reduced the amount of time taken to fill out and submit the dengue forms. Previously, this was a lengthy process that took 7 to 10 days and involved various stages of sending paperwork to all the relevant agencies; however, Mo-Buzz enabled PHIs to send information in real time at the click of a button, expediting the whole process to 2 to 3 days. However, minor tweaks still needed to be made, such as providing a place on the form to report specific ages of clients in years and months. GPS technology was found to be far more accurate than the previous mode of geotagging, and minor glitches occurred far more infrequently. The PHIs noted that the dynamic disease mapping component (ie, hotspot mapping), although useful for them, was not deemed necessary for the public. They were worried that it might trigger outbreaks of panic. However, the general public was receptive to this component. The PHIs also mentioned that the educational materials were useful but could be more interactive and that the in-built camera needed to be of better quality and include flash, as most breeding sites were in areas with poor lighting.

Communication with stakeholders (specifically, CMC, which employs PHIs, and Mobitel and the University of Colombo, which recruit general public users) was problematic, as the Mo-Buzz research team was based in Singapore. The Mo-Buzz research team overcame this issue by learning about Sri Lankan customs and culture from Sri Lankans living in Singapore and by undertaking field trips and interviews. These activities allowed researchers to understand the people of Sri Lanka better. Stakeholder communication was made more difficult by differences in opinions borne of views that were influenced by different specialties. For example, although the Mo-Buzz research team offered expertise in health communication, psychology, behavioral science, and computer science, collaborators from the CMC were medical physicians. However, the openness of both parties to new and different ideas vastly facilitated discussions on the implementation of Mo-Buzz.

The Mo-Buzz research team ran into several difficulties during baseline interviews with the PHIs. First, language posed a barrier. The main mode of communication in Sri Lanka is Sinhalese or Tamil, but none of the researchers were proficient in either language. As such, an external translator who was fluent in Sinhalese, Tamil, and English was employed to overcome this language barrier.

Regarding uptake of Mo-Buzz, the Mo-Buzz research team found that PHIs were initially resistant and that most were not mobile technology literate. Thus, initial uptake of Mo-Buzz was low, as roughly less than 10% (n=3) of PHIs were utilizing the technology. This was a cause for concern because Mo-Buzz was developed to simplify the duties of the PHIs and streamline the epidemiological process. Even some PHIs who were mobile literate were not inclined to take up a technological approach to submitting reports, as there was an innate fear and distrust of technology. As a solution, CMC decided to send one of the more technically proficient PHIs to Singapore to work with the researchers and learn the system well. The PHI who was sent was also tasked with troubleshooting issues faced by other PHIs. On learning the system, the PHI returned to Colombo as an ambassador to train his fellow PHIs and help promote the usage and troubleshoot. Following this training, uptake of the app increased.

Another method implemented by the CMC to increase uptake of Mo-Buzz was to incentivize reports submitted by the PHIs (ie, from October 2015 onward). The total number of reports submitted by a PHI was taken into account when considering the PHI’s yearly performance bonuses and pay increments. These methods caused a massive rise in users, with 38 of the 50 PHIs (76%) using Mo-Buzz to submit reports (see Figure 3). The remaining 12 PHIs were unable to use the app because either the tablets issued were unusable or the PHIs were not issued a tablet.

Conducting postintervention evaluation proved tricky but important, as a representative from the Mo-Buzz research team had to make a separate trip to Colombo to conduct the interviews together with the translator. The researcher was able to conduct only 16 interviews in total, across a period of 4 days. A faculty member of the University of Colombo School of Computing assisted in translating and transcribing the interview sessions. Feedback from the PHIs proved to be invaluable and led toward significant redevelopment and upgrading of the existing Mo-Buzz for PHI application.

In 2015, it was reported that the dengue cases in Colombo have reduced to less than 9881 [19]. These findings, as well as positive feedback from the CMC, indicate that the Mo-Buzz system has helped to bring down about one-third of dengue cases compared with the number of cases in 2014.

Mo-Buzz for the General Public

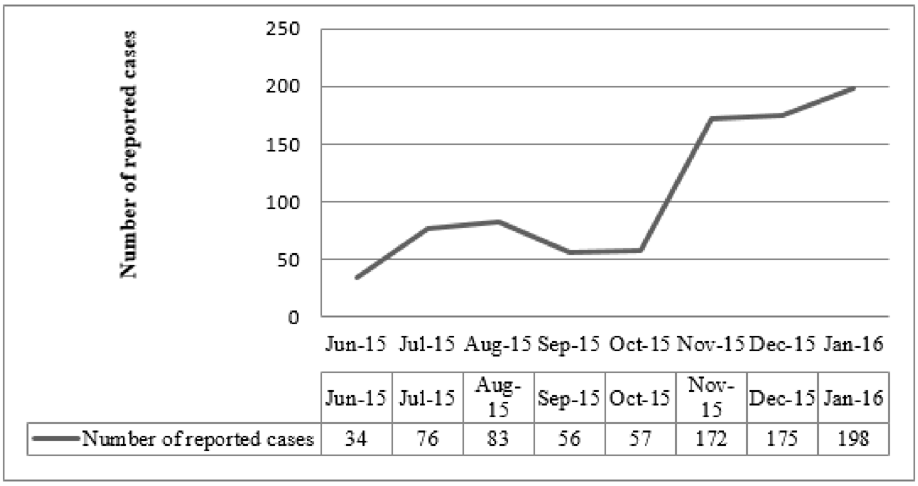
The Mo-Buzz research team had taken great stock in feedback given by members of the public who were surveyed during the conducting of the baseline surveys. However, there were several challenges faced by the Mo-Buzz research team during the various phases of the development of Mo-Buzz for the general public.

Baseline surveys proved difficult to conduct, as most of the general public was unwilling to participate in the survey. The researchers had to conduct baseline surveys on the public via word of mouth using the aid of students, staff, and faculty members of the University of Colombo, People’s Bank, Mobitel, and Rupavahini Corporation. Finally, the researchers were able to recruit 513 members of the general public to participate, which helped to provide vital information in the development of the public system.

After integrating knowledge provided from the baseline survey, a pilot test of the public version of Mo-Buzz system was launched among 80 working adults and local university students. After 1 week of use, they were given a feedback survey. Participants were found to be receptive to the app, with 93.8% (n=481) saying they would use the app when it was launched. On the basis of the feedback, the Mo-Buzz app included up-to-date dengue education materials for the perusal of the general public. Efforts were also made to make the app more interactive for the users, and graphic designers were utilized to create interesting infographics for users to peruse. The pilot study participants also provided ideas on how to boost participation, such as providing 1500 Sri Lankan rupees (about US $10) as tokens of appreciation.

Using the baseline survey and pilot test data to improve the system, initial efforts were made to avail the Mo-Buzz app for mass usage in Colombo; however, launching of the system was delayed as a political election was underway during the agreed-upon launch date, which could have had implications for government approvals.

Figure 3. Public Health Inspector usage of mobile Mo-Buzz app for reporting dengue cases over time.



	Jun-15	Jul-15	Aug-15	Sep-15	Oct-15	Nov-15	Dec-15	Jan-16
Number of reported cases	34	76	83	56	57	172	175	198

A soft launch of the app was then undertaken, where users within the general population were allowed to download the public version of Mo-Buzz. The number of users was low with approximately 50 participants downloading and using the app. So, the Mo-Buzz research team partnered with communication students from our university in Singapore to conduct additional research to develop marketing and advertising solutions to spread awareness of Mo-Buzz. Then a fieldwork assessment was conducted in late 2015. At present, the team is working with CMC and Mobitel by hosting a hackathon event with the hopes of connecting technologists, designers, and public health experts to reassess and ideate the public launch strategy and app content.

Discussion

Principal Findings

Mobile and social media interventions, such as Mo-Buzz, are poised to play a greater role in shaping risk perceptions and managing seasonal and sporadic outbreaks of infectious diseases in Asia and around the world. An example of a comparable participatory surveillance system for dengue and other mosquito-borne infectious diseases is Kidenga, a US-based system, described below.

Mo-Buzz is one of several community-based surveillance systems designed to engage the public in reporting mosquito activity and syndromes consistent with *Aedes*-borne diseases. Other systems include Kidenga, which targets the United States-Mexico border region, SaludBoricua in Puerto Rico, and Dengue Na Web in Brazil. These systems differ in their approach to engagement and data collection, but all share a common goal of detecting and informing the public about dengue transmission.

Kidenga is a mobile community-based syndromic surveillance app available exclusively on Android and iPhone mobile phones released in 2016. It was developed to detect individuals with symptoms suggestive of dengue, Zika, and Chikungunya virus infections and to track the activity of their vectors, *Ae aegypti* and *Ae albopictus*. Currently, Kidenga targets populations in three high-risk states: Arizona, Florida, and Texas [20]. The objectives of the app, similar to Mo-Buzz, were threefold: (1) to detect potential transmission, (2) to educate the public about existing disease trends and disease and mosquito prevention and control, and (3) to provide education to clinicians. Each week, a push notification is sent to users to notify them to report symptoms of illness, travel history, and mosquito activity. When an individual reports that she, he, or a family member has been ill, this triggers two educational messages to the user’s email address on file, which include: (1) prevention and control strategies directed to the user and (2) treatment and testing information directed to clinicians the user may see. Within the app, such as with Mo-Buzz, maps of user-generated data, confirmed case counts from public health partners, mosquito distribution maps, and information about prevention and control strategies are accessible for users to browse and to learn more. Additionally, current news on the diseases and vectors are provided on an active news feed. These components add value to the app for users. However, identifying standard sources of data for confirmed cases can prove challenging in countries with decentralized health systems, such as the United States. Data must be accessed for each state separately, as formats and accessibility differ widely. Additional functionality of Kidenga may include a similar interface to Mo-Buzz for community health workers, a linked mosquito-hunt game to sustain interest and targeted weather-based mosquito warnings to personalize messaging and to motivate action.

SaludBoricua and Dengue Na Web are both Web-based systems that are marketed through social marketing and traditional channels to enroll users to report symptoms on a weekly basis [21,22]. Dengue Na Web is distinguished as the first community-based syndromic system designed to track a non-influenza-like syndrome. This system is used in Salvador de Bahia, Brazil. Established in 2011, it has received over 2 million visitors at the time of writing this paper. Individuals are depicted as suspected dengue, other symptoms, no symptoms, or no report. General information on dengue, its symptoms, and its prevention are further included as Web content. Mosquito activity is not tracked by Dengue Na Web, and confirmed case information is not presented. Similarly, SaludBoricua uses a Web-based interface. SaludBoricua was developed as a partner system to the FluNearYou system for detecting influenza activity. In addition to influenza, SaludBoricua is being used to monitor symptoms reported by users for dengue and leptospirosis. Minimal information is presented within the Webpage, but links to public health information from organizations such as the Pan American Health Organization provide general information to users about the diseases under surveillance. One particularly valuable feature of SaludBoricua is news items tailored to the region and diseases prevalent in that region.

These complementary systems are all at different stages of development and have relative strengths and weaknesses. Lack of a community–health worker interface may minimize the reach of these other systems, which could be considered in next phases. In addition, a mobile phone–based platform, such as Kidenga, may bias users toward higher income groups and not fully represent the target population. All of these systems will require a rigorous evaluation process to determine whether they fulfill the criteria of a useful surveillance system, including positive predictive value, sensitivity, acceptability, flexibility, data quality, simplicity, representativeness, and timeliness [23].

Conclusion and Future Development

After general population baseline surveys and discussions with PHIs, the Mo-Buzz app was developed for and tested among two groups: PHIs and the general public. Overall, the PHIs were receptive of the system, and after facing several challenges, the uptake and reporting of dengue increased. However, although the general public was originally receptive of the idea of Mo-Buzz, the uptake and engagement with the app remain low; solutions for this are currently being discussed.

Mo-Buzz, Dengue Na Web, SaludBoricua, and Kidenga represent novel interventions for mosquito-borne diseases where social media is being used not only for disseminating persuasive health messages but also for bolstering the health services infrastructure and creating real-time or near real-time links between the general public and health authorities. These apps, as previously mentioned, follow the same overall targets: detection of potential transmission, educating the public about the disease and vector control measures, and providing education to clinicians. It is anticipated that these types of systems will increase when a history of effectiveness is established. Several potential future directions for these systems include the expansion of the app's usage to other diseases. Currently, SaludBoricua and Kidenga are being used to monitor additional syndromes indicative of influenza and leptospirosis (SaludBoricua) and Zika and Chikungunya (Kidenga). Although the value of these systems may increase with expansion to viruses in addition to dengue, this can lead to additional challenges. For example, using these systems to monitor Zika-like illness may be especially problematic given the challenges because of vague presentation of symptoms and in developing a syndrome definition with sufficient specificity to warrant public health action. Inclusion of other diseases also makes the creation of educational materials more challenging.

From our Mo-Buzz study, we have learned that initial acceptance of such systems can be slow but eventually positive. We predict that future adoption and sustained use will be driven by a complex set of variables at different levels of the social ecosystem, such as social trust and willingness to share information. On the basis of previous research, we foresee that passive (viewing hotspot maps) and active (reporting dengue hotspot) participation might be driven by different kinds of variables [24]. To boost participation in Mo-Buzz, we are now in the process of launching a communication campaign to create greater awareness and uptake of the app. Future work will focus on expanding the capabilities of Mo-Buzz to address other health problems in Sri Lanka and around the region and integrating its capabilities with the larger eHealth information architecture in the region, as well as building upon existing technologies to create surveillance systems catering to other diseases [25].

Acknowledgments

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Authors' Contributions

All authors except KCE contributed to the writing of all sections except the part describing Kidenga, for which KCE was the sole author.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Dengue Investigation Form (DIF) utilized by Public Health Inspectors (PHIs) in Colombo, Sri Lanka.

[PDF File (Adobe PDF File), 2MB - publichealth_v3i4e65_app1.pdf]

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Abbreviations

CMC: Colombo Municipal Council
DIF: dengue investigation form
GPS: global positioning system
PHIs: public health inspectors

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Original Paper

Participatory Disease Surveillance: Engaging Communities Directly in Reporting, Monitoring, and Responding to Health Threats

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Abstract

Background: Since 2012, the International Workshop on Participatory Surveillance (IWOPS) has served as an informal network to share best practices, consult on analytic methods, and catalyze innovation to advance the burgeoning method of direct engagement of populations in voluntary monitoring of disease.

Objective: This landscape provides an overview of participatory disease surveillance systems in the IWOPS network and orients readers to this growing field of practice.

Methods: Authors reviewed participatory approaches that include human and animal health surveillance, both syndromic (self-reported symptoms) and event-based, and how these tools have been leveraged for disease modeling and forecasting. The authors also discuss benefits, challenges, and future directions for participatory disease surveillance.

Results: There are at least 23 distinct participatory surveillance tools or programs represented in the IWOPS network across 18 countries. Organizations supporting these tools are diverse in nature.

Conclusions: Participatory disease surveillance is a promising method to complement both traditional, facility-based surveillance and newer digital epidemiology systems.

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KEYWORDS

public health surveillance; global health; communicable diseases; epidemiologic surveillance

Introduction

Finding outbreaks faster no matter where they first appear on the planet is a continuous challenge. New approaches to detect and monitor disease threats have emerged to supplement “traditional” disease surveillance approaches such as indicator- and facility-based surveillance (eg, notifiable diseases and laboratory tests). One of these novel approaches leverages digital connectivity to engage the public in “actively” providing public health practitioners with data that can be aggregated and analyzed for a variety of purposes including monitoring disease trends, identifying risk factors, and detection of outbreaks. This active approach of direct engagement is often referred to as participatory disease surveillance. While participatory epidemiology originated within the animal health community as a way to monitor health events in rural areas where surveillance resources are often limited, one of the first uses of crowdsourcing for public health surveillance was initiated in 2003 in the Netherlands by Science in Action [1-5].

Participatory disease surveillance collects data for public health action by directly involving the population at risk in submitting relevant data through a variety of survey tools. This can happen in many forms, from sophisticated mobile phone apps to simple hotlines. Participatory disease surveillance is “active” in the sense that it requires those who engage with the system to willingly and knowingly provide information necessary for public health action. Enlisting the help of individuals to provide data creates the potential to increase our collective understanding of disease risk and transmission patterns. Direct engagement is also an opportunity to provide information to participants about endemic disease risks and potentially enable a more rapid response to public health emergencies.

Participatory disease surveillance is considered by many to be a form of “citizen science,” though the connection to this specific term has rarely been made in the public health literature. Kullenberg et al (2016) note two general understandings of the term citizen science: one focuses on the use of public participation to collect and share data with scientists, whereas the other emphasizes a set of approaches that empower citizens to address needs or concerns in their communities [6]. These understandings are not mutually exclusive, and participatory disease surveillance as currently practiced often encompasses both.

Many participatory disease surveillance systems are structured around the reporting of syndromic information, that is, self-reported symptoms of illness rather than reports of suspected cases of a particular disease. This approach allows for expanded monitoring of the community at large, which can lead to the identification of signals of disease when coverage is sufficient. Thus, participatory disease surveillance provides a high degree of sensitivity while admittedly lacking the specificity of a laboratory test for pathogen confirmation. However, in low- and middle-income countries in particular, where traditional disease surveillance systems (including laboratory capacity) may be limited by financial and human resources, participatory disease surveillance approaches can serve as a low-cost method for routine monitoring with a sufficient level of specificity. Through this approach, unusual health events may be revealed as clusters of symptoms in both time and place. Early signals can be further investigated to verify potential health threats and compared with other surveillance systems as part of an ecosystem of public health surveillance tools.

Participatory disease surveillance can also be useful in monitoring events beyond human health symptoms. Using event-based surveillance approaches, systems have been developed, for example, that track disease vectors, report environmental hazards (or risk factors), and identify animal sickness and death in both livestock and wildlife populations [7-10].

While participatory disease surveillance methods leverage digital connectivity to directly engage the public, this is not the only approach made possible by the digital revolution. Using “big data” and computer algorithms, digital disease detection approaches seek to uncover signals of potential outbreaks and disease trends by scouring Web-based media reports, examining aggregated search queries, or analyzing social media posts [11-16]. Digital disease detection is often passive by design and may function without the direct knowledge of the user, a key difference from active, participatory disease surveillance. As such, digital disease detection has its own set of benefits and limitations. What they have in common is the “gradual” acceptance of these innovative approaches among public health authorities.

Methods

The International Workshop on Participatory Surveillance (IWOPS) Network

A loose collaboration of participatory disease surveillance system creators and stewards have convened periodically as the International Workshop on Participatory Surveillance (IWOPS), which met for the first time in 2012 in San Francisco, again in 2013 in Amsterdam and most recently in 2016 in Newcastle, Australia. While the IWOPS community is not an exhaustive list of relevant actors in community engagement for public health surveillance, these convenings have provided a mechanism to share best practices and insights into the evolving approach of participatory disease surveillance. This manuscript is intended to serve as an introduction to the systems and organizations that have engaged within the IWOPS community, with more detailed descriptions and results being shared throughout the accompanying articles in the theme issue of JMIR Public Health and Surveillance. The authors would like to emphasize that, even among the IWOPS community of systems, the tools and approaches described here are not exhaustive and may not fully capture the developments in this rapidly advancing practice.

Most of the IWOPS systems rely on users who volunteer to participate under the conditions of confidentiality; the systems then aggregate and map anonymous user data in an openly shared Web-based or mobile platform. Some IWOPS systems rely on trained volunteers to collect information about their communities. Table 1 outlines some of the major features of select participatory surveillance systems from the IWOPS network.

Participatory disease surveillance systems that monitor influenza-like illness (ILI) are prevalent in the IWOPS community, with Europe, Australia, and the United States having established such systems for many years. Several other systems have been designed with a broad list of symptoms intended to capture a range of emerging infectious diseases in humans [17-21]. Still others take an event-based approach to reporting health threats at the community level, such as the sale of counterfeit or fraudulent medications, food safety incidents, and environmental hazards like poor air and water quality [10,22]. For systems that monitor animal health events, reports may be structured to capture either illness or death of domestic or wild animals and human-animal interactions such as dog bites. Finally, some systems in the IWOPS network involve identification of potential mosquito breeding sites or other vector reporting tools to inform community control measures [7,8]. Figure 1 maps the participatory surveillance systems discussed here by country.

Table 1. Select participatory disease surveillance systems from the International Workshop on Participatory Surveillance (IWOPS) network.

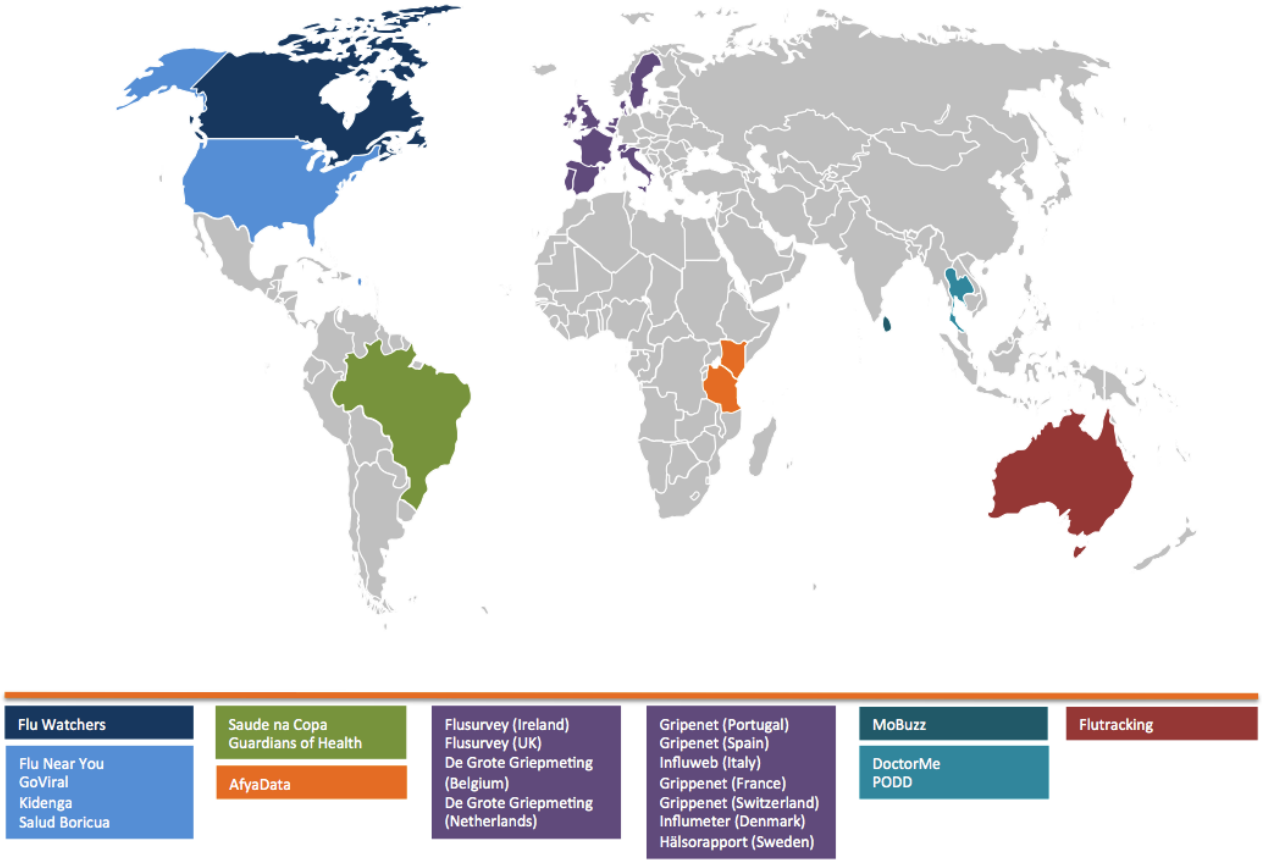
Participatory surveillance system	System launch date	Health sector	Disease focus	Registered users	Frequency of reporting	Modality
De Grote Griepmeting (Netherlands)	November 2003	Human	ILI[a], FBI[b]	15,000-50,000	Weekly	Website, mobile app, email
De Grote Griepmeting (Belgium)	November 2003	Human	ILI, FBI	15,000-50,000	Weekly	Website, mobile app, email
Gripenet (Portugal)	October 2005	Human	ILI	500-5000	Weekly	Website
Flutracking (Australia)	June 2006	Human	ILI	15,000-50,000	Weekly	Website, email
Influweb (Italy)	November 2008	Human	ILI, FBI	500-5000	Weekly	Website, mobile app, email
Flusurvey (England)	July 2009	Human	ILI	5000-15,000	Weekly	Website, email
Hälsorapport (Sweden)	November 2011	Human	ILI	500-5000	Monthly	Website
Flu Near You (United States)	November 2011	Human	ILI	>50,000	Weekly	Website, mobile app
Grippenet (France)	December 2011	Human	ILI	5000-15,000	Weekly	Website, email
Gripenet (Spain)	October 2012	Human	ILI	500-5000	Weekly	Website, mobile app
Salud Boricua (Puerto Rico)	October 2012	Human	ILI, VBD[c]	500-5000	Weekly	Website
Influmeter (Denmark)	October 2013	Human	ILI	500-5000	Weekly	Website, email
Flusurvey (Ireland)	November 2013	Human	ILI	500-5000	Weekly	Website, email
Saúde na Copa (Brazil)	May 2014	Human	ILI, VBD, FBI	500-5000	Daily	Website, mobile app
Doctorme (Thailand)	July 2014	Human	ILI	15,000-50,000	Daily	Mobile app
Participatory One Health Disease Detection (Thailand)	January 2015	Human or animal or environment	All syndromes; livestock outbreaks; natural disasters	500-5000	Event-based, periodic	Mobile app
FluWatchers (Canada)	November 2015	Human	ILI	<500	Weekly	Website, email
Guardiões da Saúde (Brazil)	March 2016	Human	ILI, VBD, FBI	500-5000	Daily	Website, mobile app
Mo-Buzz (Sri Lanka)	March 2016	Human or environment	VBD, breeding sites, environmental pollution	<500	Daily	Mobile app
AfyaData (Tanzania)	July 2016	Human or animal or environment	All syndromes; livestock outbreaks; wildlife outbreaks	<500	Event-based, periodic	Website, mobile app
Kidenga (United States)	August 2016	Human or environment	VBD, breeding sites	<500	Weekly	Mobile app
Grippenet (Swiss-German)	December 2016	Human	ILI	<500	Weekly	Website, email
Grippenet (Swiss-French)	December 2016	Human	ILI	<500	Weekly	Website, email

[a] ILI: influenza-like illness.

[b] FBI: foodborne illness.

[c] VBD: vector-borne disease.

Figure 1. Mapping the International Workshop on Participatory Surveillance (IWOPS) participatory surveillance systems.



Results

Syndromic Systems in IWOPS

Participatory disease surveillance systems began to proliferate in 2003 with the creation of “De Grote Griepmeting” in The Netherlands and Belgium by the organization Science in Action [5]. Over time this effort grew into the “Influenzanet” consortium that now includes 10 countries in Western Europe, coordinated by the ISI Foundation in Italy [18,23]. In 2006, the “FluTracking” program began in Australia and now operates as a joint initiative of Newcastle University, Hunter New England Population Health, and the Hunter Medical Research Institute [17,24]. Inspired by these systems, the Skoll Global Threats Fund (SGTF) and HealthMap of Boston Children’s Hospital partnered to launch “Flu Near You” in the United States in 2011 [19,25]. All three systems aim to track ILI through capturing symptom-based reports from volunteers on a weekly basis and have demonstrated a strong correlation with trends seen in traditional influenza surveillance systems in their respective countries [18,19,26,27]. Since Fall 2015, the Public Health Agency of Canada has been piloting a similar influenza-focused system, the “FluWatchers” platform [28]. Data being collected by these systems vary from basic demographics and symptoms of illness, such as with Flu Near You, to risk factors that may be relevant to understanding disease transmission (eg, health-seeking behavior and vaccine status), which “Influenzanet” collects through use of more robust questionnaires. “FluTracking” includes self-reported laboratory diagnosis among the data collected in their system.

In late 2012, “Salud Boricua” was developed specifically for Puerto Rico as an expansion to “Flu Near You” through a collaboration between SGTF, HealthMap, the Department of Health of Puerto Rico, and the US Centers for Disease Control and Prevention (CDC) . “Salud Boricua” maintained a similar design and interface to “Flu Near You,” with additional symptoms to track influenza and two other febrile illnesses: dengue and leptospirosis [29]. Another approach to broadening the scope of citizen-reported symptom data beyond an influenza focus was developed with the expansion of the “DoctorMe” mobile app in Thailand in 2014. As a preexisting health app available via Web and mobile devices, “DoctorMe” added a mechanism for volunteers to report on symptoms of disease, leveraging the popularity of the “DoctorMe” app and its utility for diagnosing potential maladies [20,30].

International mass gatherings have become a focal point for disease surveillance and pandemic prevention. The 2014 World Cup tournament that took place in Brazil provided an opportunity to test the use of participatory disease surveillance tools in the context of such gatherings. The Brazilian Ministry of Health partnered with SGTF and Epitrack to create and deploy “Saúde na Copa” (healthy cup), a smartphone app that encouraged users to report healthy status or symptoms of illness on a daily basis throughout the tournament; a first attempt at using this approach in a mass-gathering setting. Encouraged by the success of this technology, the same partners created “Guardiões da Saúde” (guardians of health) for use during the 2016 Olympic and Paralympic Games in Rio de Janeiro [21,31].

Today, “Guardiões da Saúde” continues as a complement to routine disease surveillance throughout Brazil.

Vector-borne diseases have also emerged as another use case for public reporting of health threats in the wake of the recent and rapid spread of chikungunya and Zika viruses in the Western Hemisphere, in addition to the ongoing burden of dengue worldwide. As a result, community-reporting applications such as “MoBuzz” and “Kidenga” have been deployed in Sri Lanka and the southern United States, respectively [7,8,32]. Both systems seek to not only leverage community participation in reporting and tracking of symptoms but also to provide education on prevention strategies such as personal protection and disruption of mosquito breeding environments.

Event-Based and One Health Surveillance Systems in IWOPS

Participatory surveillance approaches are not limited only to the symptom-based reporting model. The AfyaData system in Tanzania and the Participatory One Health Disease Detection (PODD) system in Thailand both apply event-based surveillance models with a One Health focus to community reporting for human, animal, and environmental health events [9,10,22]. These systems leverage the use of trained volunteers (rather than general public crowdsourcing) in local communities to report on health events that range from suspect cases of dengue fever, to disease outbreaks in livestock, to contamination of water sources. Both systems have developed strong partnerships with regional or national government authorities to ensure that threats reported through these novel systems can be acted upon in a timely manner by relevant health authorities.

Integration of Modeling and Forecasting in IWOPS

As the many surveillance systems in the IWOPS community continue to improve our understanding of disease transmission and spread, opportunities are increasing to leverage these datasets for the modeling and forecasting of disease trends and for anticipating health threats before they emerge. The MoBuzz system integrates predictive analytics to provide feedback on vector hotspots to users [32]. HealthMap’s “FluTrends” tool integrates data from “Flu Near You” alongside other datasets, and “Influenzanet” data feeds into the “FluOutlook” platform; both efforts seek to model the spread of influenza and provide forecasting of peak ILI activity [33-36].

Discussion

Benefits of Participatory Disease Surveillance

Foremost among the benefits of participatory surveillance is the ability to conduct large scale, population-based monitoring at low cost. As the number of users in a system increases, the sensitivity afforded by the expanded monitoring of participatory surveillance increases as well. Additionally, in some contexts, traditional health care-based surveillance methods may underestimate the true disease burden in the population due to a dependence on health care-seeking behavior on the part of the individual. In contrast, participatory surveillance systems can engage people who may not interact with a health care provider due to lack of access, resource constraints, or cultural norms. If participation is high enough and reflective of the larger population, participatory surveillance provides an opportunity to develop a more complete estimate of disease burden in a population in complement with sentinel provider networks [37]. Thus, capturing data on the general population, many of whom may not be represented in other surveillance systems, can bring significant benefit, especially when performed with the speed enable by digital reporting.

Participatory disease surveillance may also provide insights about user health behaviors. For example, systems such as “Influenzanet” are able to identify certain behavioral risk factors for ILI, assess attitudes toward influenza vaccination among pregnant women, estimate health care-seeking behavior during a pandemic, and examine social contact patterns [38-41]. Both “FluTracking” and “Influenzanet” researchers have also endeavored to leverage their platforms to provide measures of field vaccine effectiveness [27,42-45]. The advantage of this approach is found in rapidly capturing vaccine data on the general population, many of whom may not otherwise be evaluated, while the lack of laboratory or case confirmation limits the inferences that can be made from this information.

As participatory systems grow over time, the need to identify characteristics of participants that contribute consistently has become a priority. Fortunately, these characteristics can be continually assessed and approaches revised to ensure strong participation from across all segments of a population. In one study of “Influenzanet” participants, it was determined that lower participation was associated with characteristics such as lower educational status, smoking, younger age, not being vaccinated against seasonal influenza, and living in a household with children [40]. A study of “Flu Near You” participants found similar results for the effect of age but noted that users reporting on behalf of household members (who are often children) were more likely to be consistent reporters than other participants [46]. These findings might allow public health staff to increase promotion efforts to populations with low levels of participation in order to achieve a reporting population that reflects the general public. Understanding motivations for participation is also critical. Results from a survey targeting Dutch “Influenzanet” participants, for example, showed that the desire to contribute to a scientific goal is the most important motivator for all types of participants and that availability of scientific information and data are important for learning [47]. Although it is likely that factors affecting participation for different systems vary by nation and culture, these insights provide grounds for hypothesis testing and refining recruitment and retention practices.

The potential for rapid two-way communication between health authorities and participatory disease surveillance system users provides another important opportunity for public health messaging and education. As users are actively engaged in providing information to the system, opportunities exist to inform users about disease activity levels in their neighborhoods, provide automatic messaging back to volunteers and local authorities, and share appropriate prevention and control measures during disease outbreaks or other health emergencies. Having a way for health authorities to message a large population of volunteer users, which may include hard-to-reach populations, can be especially valuable for disease control and prevention activities. Many participatory disease surveillance systems have included useful information for the user, such as the location of vaccine distributors and mapping of disease activity [19,29]. Others have included health quizzes and other gamification approaches to increase user engagement and improve health promotion, while targeted alerts are used in some systems to trigger local government health interventions for the reporting population [9,10,20,31,32]. Though the degree to which IWOPS systems provide feedback to users varies greatly, it is likely that this mechanism will continue to be leveraged to provide greater value to users and increase participation in these systems.

Finally, participatory disease surveillance provides flexible data systems and user interfaces that enable health authorities to rapidly modify the data elements being collected and disseminate information in near-real time. For syndromic systems, new symptoms can be added if an emerging infectious disease is associated with additional symptoms not currently collected. “Flu Near You,” for example, tested the addition of new symptoms related to dengue and Zika viruses as these diseases became more prevalent in the United States. For event-based systems, the addition of new types of health threats that may emerge allows health agencies to be more responsive to community needs or concerns.

Challenges of Participatory Disease Surveillance

Perhaps the most consistent challenge for participatory disease surveillance systems is the recruitment and retention of participants of a demographic mix that reflects the population at risk. Marketing and recruitment efforts have had varying levels of success. “FluTracking,” which has been very successful in growing and maintaining a large volunteer network, has employed a number of tactics where they have found success; these include using friend-referral emails, inviting users to report for household members, and refraining from the use of barriers such as usernames and passwords [48]. “Mo-Buzz” incentivizes reports that were submitted by public health inspectors (PHIs), with the total number of reports submitted by an investigator contributing toward their yearly performance bonuses and pay increments [49]. “Flu Near You” has experimented with paid marketing efforts and social media campaigns with some success. The cost of some marketing tactics such as online ad buys, however, may adversely impact the low-cost nature of participatory disease surveillance. The efficient use of marketing efforts combined with smart design principles and a user-friendly approach may help sustain participation in these systems over time.

Symptom-based, self-reporting systems lack the ability to determine the causative agent of each reported syndrome, a limitation shared by many sentinel provider networks that may only test a limited number of patients. For systems focused on monitoring ILI, several pathogens may cause the nonspecific symptoms that comprise an ILI definition. With this in mind, the “GoViral” study was launched in late 2013 to compare acquired community generated diagnostic samples with participatory symptom reporting. Users are enrolled into a self-reporting system, sent a home testing kit, and instructed to perform specimen collection and a rapid diagnostic test within 48 hours of experiencing any flu symptoms. The study, which has expanded beyond its original target sites in Massachusetts and has collected hundreds of samples to date, may serve as a model for improving linkages between participatory systems and laboratory diagnostics [50,51]. Those linkages will allow participatory disease surveillance to increase in specificity as home test kits and rapid diagnostics increase in availability and accuracy and decrease in cost.

Not every system within the IWOPS network is established enough to draw firm conclusions on user characteristics, especially as the growth trajectory of users in many systems is on a steady increase. The behaviors and characteristics identified through “Flu Near You” and “Influenzanet,” for example, indicate that participants tend toward higher socioeconomic status and healthier behaviors than the general populations in their respective countries [40,46]. Whether these trends will continue to hold true as recruitment efforts increase and whether similar trends in other regions of the world are present, remain to be explored. Other questions include whether reporting rates increase when an outcome of interest is present for volunteers (eg, experiencing symptoms and finding a dead chicken) as opposed to when users would otherwise submit a “zero report” to confirm no event or the absence of any symptoms.

While participatory disease surveillance has been increasingly accepted by public health agencies, a continued effort to integrate these data sources into broader disease surveillance frameworks and public health decision-making processes remains a challenge. Identifying how these systems contribute to effective public health action in various contexts will be an ongoing effort. Certain event-based tools can provide concrete case studies—such as when PODD was used to detect and control a backyard chicken outbreak in Chiang Mai, Thailand—and health agencies’ use of syndromic tools like “Influenzanet” and “FluTracking” for monitoring and situational awareness can be documented as successful examples [22]. Health agencies should approach the adoption of participatory disease surveillance tools with the aim of integrating insights from multiple, complementary data sources, recognizing that each have their own underlying populations and data collection methods that contain specific biases. As noted by Leal-Neto et al (2017), collaborations in this space often need government engagement to be successful. It is vital that the role of government health agencies and partner organizations such as telecommunication companies, is clear from the outset [31].

Evaluative methods for judging the quality, timeliness, or representativeness of information returned by participatory systems must continue to aid the evolution, adoption, and integration of these systems as part of routine health monitoring in the community. This is made difficult by a range of variables such as population size, reporting consistency, and balancing the amount of data gathered on users while still respecting privacy. Practitioners and evaluators must continue to find ways to improve evaluative approaches and identify outcomes that are indicative of success. Potential measurable outcomes include the volume of reports submitted, the system’s role in initiating or accelerating responses, and the system’s influence on behaviors and population health outcomes [52]. The role or roles that participatory disease surveillance can play in overall community health monitoring need to be more clearly defined to properly evaluate performance against stated aims.

Future Opportunities

Innovative surveillance approaches are increasingly needed to provide public health officials, from the local to global, with scalable, affordable, and flexible tools that enable population-based disease monitoring for prevention and control of emerging health threats. Both the International Health Regulations (IHR) and the Global Health Security Agenda (GHSA) have mandated that countries develop the ability to rapidly report emerging events [53]. The GHSA "Real-Time Surveillance" Action Packages Detect 2 and 3 specifically focus on "real-time surveillance." These action packages call for interoperable, electronic systems with the capability to detect health threats through both syndromic and event-based surveillance [54]. These aims could be well served by the inclusion of participatory disease surveillance methods in countries seeking to meet these targets.

To realize their full potential, participatory tools must be extended to all communities, not simply those with reliable Internet connections and high rates of smartphone penetration. It is no secret that some of the most at-risk communities are those furthest removed from the reach of health authorities. Efforts must be made to connect rural and low-income populations to health systems and surveillance networks. In doing so, opportunities exist to improve populations' health literacy in terms of both understanding disease risk in their community and receiving feedback about preventive actions.

The promise of participatory disease surveillance may only be fully realized when it becomes an integrated component of a surveillance ecosystem that includes data from health facilities, sentinel surveillance systems, digital disease detection tools, and other sensors such as wearable technology and wireless thermometers. Additionally, as integration of disparate data sources becomes more viable, exploration into the value of linking self-reported data with electronic medical records may also yield significant returns. As participatory disease surveillance continues to emerge as a community of practice, continued knowledge sharing around best practices and lessons learned should be sustained. The authors hope that the IWOPS community described in this manuscript and throughout the theme issue of JMIR Public Health and Surveillance can serve as one such vehicle as we all endeavor to improve disease surveillance.

Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
GHSA: Global Health Security Agenda
IHR: International Health Regulations
ILI: influenza-like illness
IWOPS: International Workshop on Participatory Surveillance
PHI: public health inspector
PODD: Participatory One Health Disease Detection
SGTF: Skoll Global Threats Fund

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Original Paper

Combining Participatory Influenza Surveillance with Modeling and Forecasting: Three Alternative Approaches

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Abstract

Background: Influenza outbreaks affect millions of people every year and its surveillance is usually carried out in developed countries through a network of sentinel doctors who report the weekly number of Influenza-like Illness cases observed among the visited patients. Monitoring and forecasting the evolution of these outbreaks supports decision makers in designing effective interventions and allocating resources to mitigate their impact.

Objective: Describe the existing participatory surveillance approaches that have been used for modeling and forecasting of the seasonal influenza epidemic, and how they can help strengthen real-time epidemic science and provide a more rigorous understanding of epidemic conditions.

Methods: We describe three different participatory surveillance systems, WISDM (Widely Internet Sourced Distributed Monitoring), Influenzanet and Flu Near You (FNY), and show how modeling and simulation can be or has been combined with participatory disease surveillance to: i) measure the non-response bias in a participatory surveillance sample using WISDM; and ii) nowcast and forecast influenza activity in different parts of the world (using Influenzanet and Flu Near You).

Results: WISDM-based results measure the participatory and sample bias for three epidemic metrics i.e. attack rate, peak infection rate, and time-to-peak, and find the participatory bias to be the largest component of the total bias. The Influenzanet platform shows that digital participatory surveillance data combined with a realistic data-driven epidemiological model can provide both short-term and long-term forecasts of epidemic intensities, and the ground truth data lie within the 95 percent confidence intervals for most weeks. The statistical accuracy of the ensemble forecasts increase as the season progresses. The Flu Near You platform shows that participatory surveillance data provide accurate short-term flu activity forecasts and influenza activity predictions. The correlation of the HealthMap Flu Trends estimates with the observed CDC ILI rates is 0.99 for 2013-2015. Additional data sources lead to an error reduction of about 40% when compared to the estimates of the model that only incorporates CDC historical information.

Conclusions: While the advantages of participatory surveillance, compared to traditional surveillance, include its timeliness, lower costs, and broader reach, it is limited by a lack of control over the characteristics of the population sample. Modeling and simulation can help overcome this limitation as well as provide real-time and long-term forecasting of influenza activity in data-poor parts of the world.

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KEYWORDS

forecasting; disease surveillance; crowdsourcing; nonresponse bias

Introduction

Epidemiological surveillance is an important facet in the detection and prevention of the spread of an epidemic [1]. Knowing which diseases and variations of these diseases are present can help medical researchers identify appropriate interventions as well as strategies for treatment to reduce overall impact of the disease, including mortality. Because of the utility of such data, a number of agencies collect and distribute surveillance reports on prevailing epidemics or other diseases of interest. In the United States, the Centers for Disease Control and Prevention (CDC) produces surveillance counts for influenza and other diseases based on reports from state and local laboratories and medical health centers (www.cdc.gov/flu/weekly/summary.htm). Internationally, the World Health Organization and other agencies produce surveillance data for a number of emerging diseases such as Zika and Ebola (www.who.int/emergencies/zika-virus/situation-report/25-august-2016/en/).

While these clinically-based disease surveillance systems are necessary to keep track of disease prevalence and contain their spread, they have practical limitations [2]. Given the time required to collate surveillance numbers, the reports are usually several weeks old, resulting in a mismatch between the public health response and conditions on the ground [3]. Depending upon the transmissibility of the epidemic, there can be a big difference in prevalence from week to week. Additionally, even when collecting data from local medical centers, coverage is not always uniform. As a result, the CDC weights the public health response based on state population as well as a region’s past history of influenza-like illness (ILI) cases [1]. Finally, the level of detail afforded by the medical laboratories and centers reporting to these clinically-based systems may not be sufficient for examining the type of regional demographics that help to identify interventions that are likely to be effective [3].

A number of algorithms and technical approaches have been developed in recent years to attempt to mitigate the shortcomings in clinically collected surveillance data. To address the time delay between when surveillance data become available and the current date, approaches have been developed for ILI that use mechanistic modeling based on epidemiological knowledge of the pathways of flu transmission to estimate near real-time and future estimates of flu activity [4,5]. Other approaches have attempted to leverage information from constantly changing Internet-based data sources to identify patterns that may signal a change in the incidence of ILI cases in a population. These data sources include Internet search engines [6-12], Twitter and its microblogs [13-17], clinicians’ Internet search engines [18], and participatory disease surveillance systems where responders on the ground report on disease propagation [19]. Sharpe et al [20] conducted a comparative study to analyze whether Google-, Twitter-, or Wikipedia-based surveillance performs the best when compared to CDC ILI data.

In addition to helping address the time delay problem, participatory disease surveillance can also offer valuable insight into the characteristics of a disease and the demographics of the affected population [19,21-24]. It can help to augment coverage in areas where there are fewer medical centers or where infected people are less likely to go for clinical evaluation. Finally, participatory surveillance also offers a good opportunity to promote awareness of an epidemic [25].

Participatory surveillance has its limitations as well, especially participatory bias resulting from nonuniform coverage and from waning interest and participation over the duration of an epidemic [22]. Additionally, although not addressed with the examples in this paper, training and trust issues may lead to under- or incorrect reporting [23]. Combining participatory surveillance with modeling and simulation can not only help to reduce participatory bias but can also improve real-time forecasting and thus help identify which interventions are most likely to be effective over time in a given area.

In this article, we investigate how an understanding of the results from 3 participatory disease surveillance systems, WISDM (Widely Internet-Sourced Distributed Monitoring), Influenzanet, and Flu Near You (FNY), can be or have been extended through the use of modeling, simulation, and forecasting.

Methods

Widely Internet-Sourced Distributed Monitoring and Synthetic Information

Using Modeling to Measure Participatory Bias

WISDM is a Web-based tool developed at Virginia Tech that supports crowdsourced behavioral data collection, inspection, and forecasting of social dynamics in a population. When integrated with online crowdsourcing services such as Amazon’s Mechanical Turk (MTurk), WISDM provides a cost-effective approach to real-time surveillance of potentially evolving disease outbreaks [26]. So far, WISDM has been used primarily to collect demographic and health behavior data for epidemiological research. Here, we describe how modeling can be used in combination with WISDM to measure participatory (nonresponse) bias.

Crowdsourcing platforms like MTurk can be used to recruit responders for a low fee. MTurk allows requesters to recruit human intelligence to conduct tasks that computers cannot do; individuals who browse among existing jobs are called workers. However, there is some concern that users recruited on crowdsourcing platforms may not be representative of the population at large [27,28]. MTurk workers tend to be young, educated, and digitally savvy, so their responses may systematically differ from the responses of those who did not participate in the survey. Given this potential for nonresponse or participatory bias, understanding how to use data from such surveys for epidemic surveillance is a challenge.

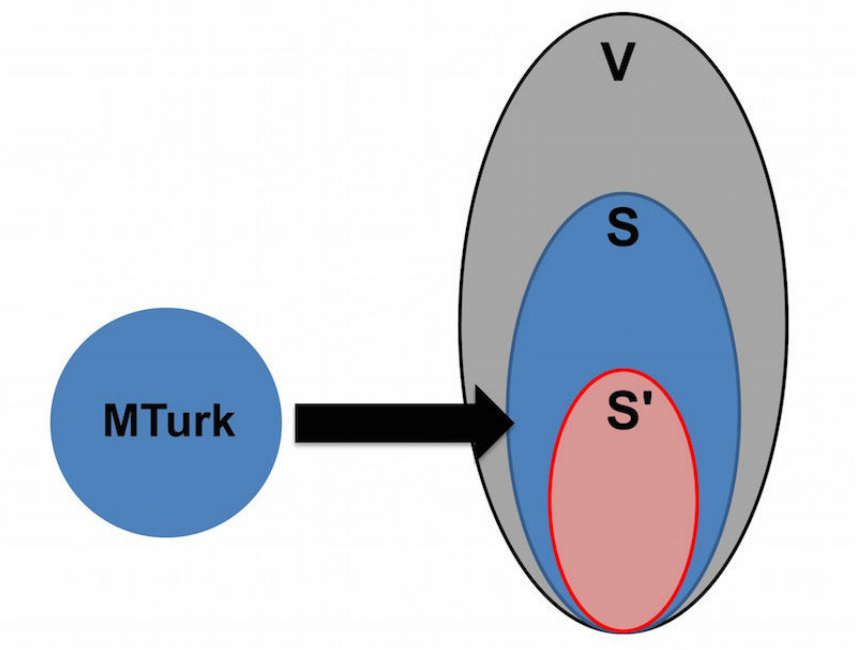
To address this issue, we developed a simulation-based approach. Specifically, we combined results of a survey of Delhi, India, residents conducted on WISDM through MTurk with agent-based simulations of the Delhi population to understand the MTurk sample bias. First, we constructed a synthetic population that was statistically indistinguishable from the Delhi census (V in Figure 1), thus providing the best extant at-scale representation of the population.

The synthetic population is generated by combining marginal distributions of age, household income, and household size for each Census block group with the corresponding Public Use Microdata Sample. This is done using the iterative proportional fitting procedure [29]. Validation is done by comparing distributions of variables not included in the iterative proportional fitting step with the corresponding distributions in the generated synthetic population. The procedure is guaranteed to converge [30] and the inferred joint distribution is the best in the maximum entropy sense [31].

The synthetic population is generated for each block group, which is the highest resolution at which US Census data are available publicly. We generate social contact networks (contact matrices) for the synthetic population through a detailed data-driven model where, after the agents matching the region's demographics are generated, they are assigned home locations using road network data (from Here, formerly known as Navteq), daily activity patterns are assigned using the National Household Travel Survey data, and activity locations are assigned using Dun and Bradstreet data. This allows social contact networks to be extracted based on agents being simultaneously present at locations for overlapping durations. We refer to the literature for a detailed description of the construction of synthetic populations and their applications [32-41].

From this synthetic population, we selected individuals whose demographics most closely matched the demographics of the MTurk respondents of the WISDM survey (the S in Figure 1). Then, epidemic characteristics of this selected subsample were studied and compared to the epidemic characteristics of the entire synthetic population.

Figure 1. Mapping of MTurk sample to synthetic individuals.



Process for Finding the Mechanical Turk–Matched Delhi Synthetic Population

First, we used WISDM to collect demographics and health behaviors of about 600 MTurk workers; the health behaviors included preventative and treatment behaviors related to influenza. Then we calculated the Euclidean distance between each of these approximately 600 responders and every person in the synthetic population of the same age, gender, and household size. Next, we selected the closest synthetic matches to each survey respondent. If more than 1 match was identified, all of the matches were retained. We repeated this procedure for each responder in the survey, which provided us with a subpopulation of the synthetic population that most closely matched the WISDM-based survey respondents. This subpopulation is denoted by S in Figure 1, and V denotes the total synthetic population of Delhi.

However, the synthetic subpopulation (S) was not statistically representative of the MTurk sample given that survey respondents could be matched with multiple individuals. Thus, we used stratified sampling to construct a finer sample of the synthetic population that was equivalent to those who took the MTurk survey.

Specifically, we divided both the survey and synthetic subpopulation (S) data into H mutually exclusive strata, where each stratum corresponded to a unique combination of 3 demographic variables, specifically age, gender, and household size. Only these 3 demographic factors were used for stratification since India Census did not have information on other common socioeconomic variables like income, education, employment, and access to Internet. Variables such as income and access to Internet could be especially important in matching MTurk with individuals in the synthetic population, but due to lack of data this could not be done. This is a significant limitation of the current analysis which we expect to improve upon as more data becomes available in the future.

We discretized age into A distinct intervals and household size into B intervals. Gender was split into 2 groups. This resulted in H=2AB strata. Because all matched synthetic people had been retained, the number of observations (N_1) in the synthetic subpopulation (ie, first stratum of subpopulation S) was much larger than the number of observations (n_1) in the first stratum in the MTurk survey (ie, first stratum of the actual survey sample). Thus, to obtain a representative sample of this first stratum, n_1 observations were randomly sampled from the synthetic subpopulation without replacement. The same procedure was performed for all the remaining strata. This provided us with the final MTurk-matched Delhi synthetic population sample set S' in Figure 1, which demographically matched the MTurk survey data.

Comparing Epidemic Outcomes Using Widely Internet-Sourced Distributed Monitoring

Our goal was to understand the differences in influenza epidemic outcomes across the 3 populations (V, S, and S’). We considered 3 different metrics for measuring epidemics: (1) the size of the epidemic (ie, the attack rate), (2) the peak number of infections, and (3) the time it takes for the epidemic to peak. A difference in these metrics between S and S' would be equivalent to the sample bias if we assume S captures the entire MTurk population. This may not be true unless the sample size is very large, which is not the case in this study. However, for very large samples, it would give the sample bias since S' is the sample and S is the entire synthetic subpopulation that matches the attributes of the sample. Differences between V and S metrics would be equivalent to the nonresponse bias because individuals outside S did not participate in the survey.

In order to compare the epidemic outcomes, we simulated an influenza outbreak using a susceptible, exposed, infected, and recovered (SEIR) disease model [34,35] in the synthetic Delhi population. Each node in the network represents an individual, and each edge represents a contact on which the disease can spread. Each node is in 1 of 4 states at any given time: S, E, I, or R. An infectious person spreads the disease to each susceptible neighbor independently with a probability referred to as the transmission probability, given by $p=\lambda(1-(1-\tau)^{\Delta t})$, where λ is a scaling factor to lower the probability (eg, in the case of vaccination), τ is the transmissibility, and Δt is the duration of interaction in minutes. Durations of contact are labels on the network edges. A susceptible person undergoes independent trials from all of its neighbors who are infectious. If an infectious person infects a susceptible person, the susceptible person transitions to the exposed (or incubating) state. The exposed person has contracted influenza but cannot yet spread it to others. The incubation period is assigned per person according to the following distribution: 1 day (30%), 2 days (50%), 3 days (20%). At the end of the exposed or incubation period, the person switches to an infected state. The duration of infectiousness is assigned per person according to the following distribution: 3 days (30%), 4 days (40%), 5 days (20%), 6 days (10%). After the infectious period, the person recovers and stays healthy for the simulation period. This sequence of state transitions is irreversible and is the only possible disease progression. We seed the epidemic in a susceptible population with 10 infections that are randomly chosen every day. A total of 25 replicates were run to account for the stochastic randomness arising from the selection of initial infectors.

Influenzanet

In 2008, a large research project funded by the European Commission and coordinated by the Institute for Scientific Interchange in Turin, Italy, led to the creation of Influenzanet, a network of Web-based platforms for participatory surveillance of ILI in 10 European countries [42]. The ambition was to collect real-time information on population health through the activity of volunteers who provide self-reports about their health status and, by combining this real-time data feed with a dynamical model for spatial epidemic spreading, build a computational platform for epidemic research and data sharing. The results of this multiannual activity have been used to create a novel, modular framework (the FluOutlook framework) capable of capturing the disease transmission dynamics across country boundaries, estimating key epidemiological parameters, and forecasting the long-term trend of seasonal influenza [43].

The framework consists of 3 main components: (1) input, (2) simulation and forecast, and (3) output (Figure 2).

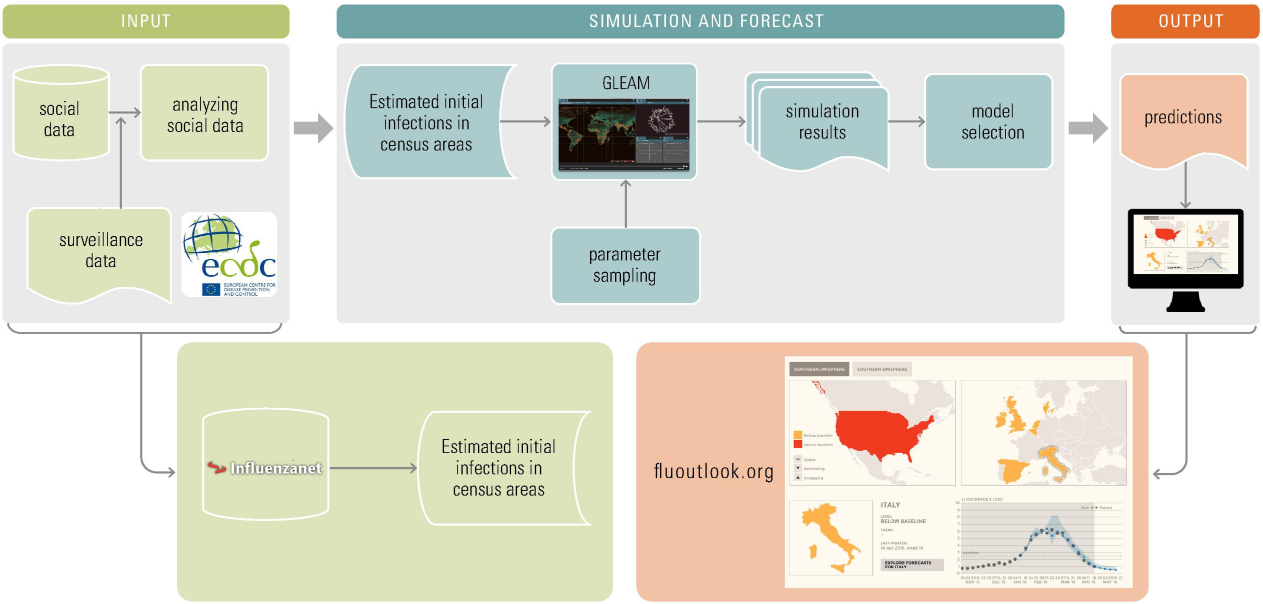
The input component estimates initial infections for a given week in any census area from collected self-reported information from volunteers on Influenzanet platforms or from other data proxies like Twitter. Influenzanet data collection has been described in several previous papers [44]. The number of users reporting a case of ILI each week is used to calculate the weekly incidence of ILI among active users. Active users are those who completed at least 1 Influenzanet symptoms questionnaire during the influenza season. Since users report their place of residence at the level of postal codes, the ILI weekly incidence can be calculated at the resolution level of postal codes.

The simulation and forecast component is a computational modeling and simulation engine named Global Epidemic And Mobility model (GLEAM) [45,46]. The GLEAM dynamical model is based on geographical census areas defined around transportation hubs and connected by long- and short-range mobility networks. The resulting meta-population network model can be used to simulate infectious disease spreading in a fully stochastic fashion. The simulations, given proper initial conditions and disease model, generate an ensemble of possible epidemic evolution for epidemic parameters such as newly generated cases. In the application to seasonal influenza, GLEAM is limited to the level of a single country with only the population and mobility of the country of interest taken into account. The number of ILI cases extracted from the Influenzanet platforms are mapped onto the corresponding GLEAM geographical census areas and used as seeds to initialize the simulations. The unique advantage provided by using the data collected by the Influenzanet platform as initial conditions consist in the high resolution, in time (daily) and space (postal code level), with which data are available. This geographical and temporal resolution for the initial conditions cannot be achieved with any other signal. Moreover, these are not proxy data for the ILI activity among the population but indeed represent a high-specificity ground truth for the initial conditions that cannot be obtained with any other source of information. Given these high quality and highly reliable initial conditions, the GLEAM simulations perform a Latin hypercube sampling of a parameter space covering possible ranges of transmissibility, infection periods, immunization rates, and a tuning parameter regulating the number of generated infected individuals. In the prediction component of the framework, the large-scale simulations generate a statistical ensemble of the epidemic profiles for each sampled point in the parameter space. From each statistical ensemble, the prediction component measures its likelihood function with respect to up-to-date ILI surveillance data and selects a set of models by considering a relative likelihood region [47].

The set of selected models represents the output component and provides both long-term (ie, 4 weeks in advance) and short-term predictions for epidemic peak time and intensity. Results are disseminated as interactive plots that can be explored on the public website fluoutlook.org [48].

To quantify the simulation’s forecast performance, the Pearson correlation between each predicted time series and sentinel doctors’ surveillance time series can be used. Moreover, the mean absolute percent error can be used to evaluate the magnitude estimation and the peak week accuracy defined as the percentage of the selected ensemble of simulations providing predictions within 1 week for peak time.

Figure 2. The FluOutlook framework.



Flu Near You

FNY is a participatory disease surveillance system launched in October 2011 by HealthMap of Boston Children’s Hospital, the American Public Health Association, and the Skoll Global Threats Fund [17]. FNY maintains a website and mobile app that allows volunteers in the United States and Canada to report their health information using a brief weekly survey. Every Monday, FNY sends users a weekly email asking them to report whether or not they experienced any of the following symptoms during the previous week: fever, cough, sore throat, shortness of breath, chills, fatigue, nausea, diarrhea, headache, or body aches. Users are also asked to provide the date of symptom onset for any reported symptoms. Users experiencing fever plus cough and/or sore throat are considered by FNY to be experiencing an ILI. FNY’s definition of ILI differs slightly from the US CDC outpatient Influenza-Like Illness Surveillance Network (ILINet) definition, which defines ILI as fever plus cough and/or sore throat without a known cause other than influenza.

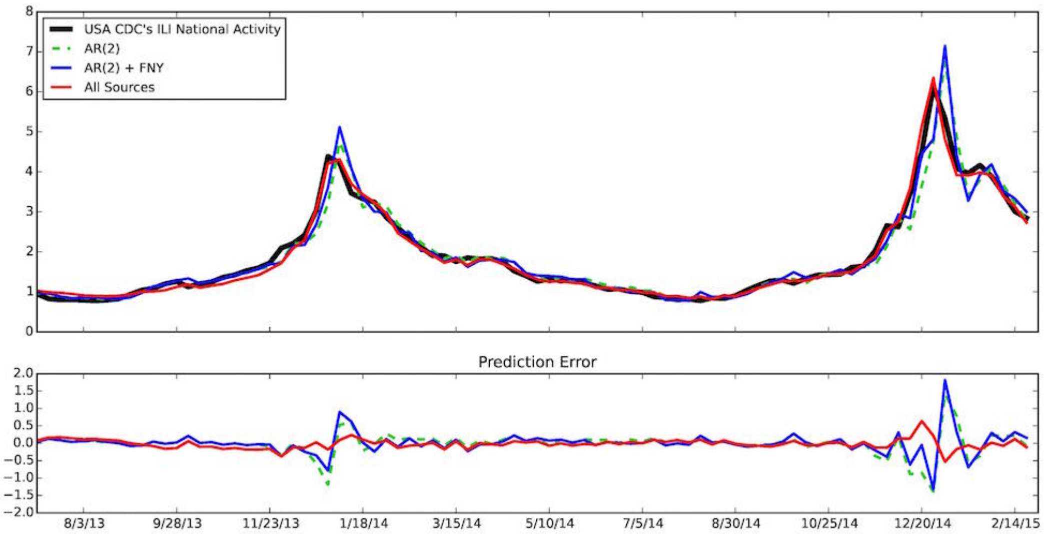
FNY was conceived to capture flu activity in a population group that may not necessarily seek medical attention, while CDC’s ILINet was designed to monitor the percentage of the population seeking medical attention with ILI symptoms. Recent estimates confirm that only approximately 35% of FNY participants who report experiencing ILI symptoms seek medical attention. Despite this design (and observed) difference and because these 2 distinct groups (those seeking medical attention versus those not doing so) interact, large changes in ILI in the CDC’s ILINet are also generally observed in the FNY signal, as shown in Figure 3 for the 2013-2014 and 2014-2015 flu seasons and as previously shown by Smolinski et al [19]. To produce Figure 3, spikes of unrealistic increased FNY ILI rates (calculated as the weekly number of users who experienced ILI divided by the total number of reports received during the same week) were first removed. These unrealistic spikes (defined as a weekly change in the FNY ILI rates larger than 10 standard deviations from the mean change of the last 4 weeks) are often associated with media attention on FNY that causes a temporary surge of interest in the system among people sick with the flu, as described Aslam et al [17]. Flu estimates were then produced 1 week ahead of the publication of CDC reports by combining historical CDC-reported flu activity (via a lag-2 autoregressive model) with the smoothed weekly FNY rates. These flu estimates are displayed in blue and labeled AR(2)+FNY on Figure 3.

The reason why we used CDC-reported ILI rates as our reference for traditional flu surveillance is because these ILI rates have been recorded for multiple years, and public health officials have used them as proxies of influenza levels in the population. This is consistent with multiple influenza activity prediction studies in the United States [7-9,49-50]. With the intent of providing more timely yet still familiar information to public health officials, we use the smoothed FNY ILI rates as one of multiple data inputs into the HealthMap Flu Trends influenza surveillance and forecasting system [51].

The HealthMap Flu Trends system relies on a machine-learning modeling approach to predict flu activity using disparate data sources [49] including Google searches [8-9], Twitter [15], near real-time electronic health records [50], and data from participatory surveillance systems such as FNY [19]. The HealthMap Flu Trends system provides accurate real-time and forecast estimates of ILI rates at the national as well as regional levels in the United States up to 2 weeks ahead of CDC's ILINet flu reports.

The multiple data sources entered into the HealthMap Flu Trends system are each individually processed using machine-learning algorithms to obtain a predictor of ILI activity. These individual predictions of ILI rates are then fed into an ensemble machine-learning algorithm that combines the individual predictions to produce robust and accurate ILI estimates, described by Santillana et al [49]. The estimates produced by this ensemble machine-learning approach outperform all of the predictions made using each of the data sources independently.

Figure 3. (Top panel) The US Centers for Disease Control and Prevention (CDC) influenza-like illness (ILI) percent value (y-axis) is displayed as a function of time (x-axis). Predictions produced 1 week ahead of the publication of CDC-ILI reports using (1) only historical CDC information via an autoregressive model, AR(2), (2) an autoregressive model that combines historical CDC information with Flu Near You (FNY) information, AR(2)+FNY, and (3) an ensemble method that combines multiple data sources including FNY, Google search frequencies, electronic health records, and historical CDC information (all sources) are shown. (Bottom panel) The errors between the predictions and the CDC-reported ILI for each prediction model are displayed.



Results

Widely Internet-Sourced Distributed Monitoring–Based Results

The results based on WISDM are illustrated as time series of daily infections (also called epidemic curves) in Figure 4. Figures 4 a and 4 b correspond to low transmission (0.00003 per minute of contact time and R_0=1.4) and high transmission (0.00006 per minute of contact time and R_0=2.7) rates, respectively. The red epidemic curve in each represents the entire Delhi synthetic population (V). The black and blue epidemic curves show results for the MTurk-matched Delhi synthetic population (S') and the entire MTurk-matched Delhi synthetic population (S), respectively. Under a high transmission rate, the attack rate and peak infection rate are higher but the time-to-peak is lower. This is expected since a higher transmission rate spreads the disease quickly and to more individuals in the population.

If surveillance is restricted to only the MTurk sample (S'), the level of bias would equal the difference between the red and black curves. This difference represents a combination of the nonresponse bias (difference between the red curve and blue curve) and the sample-size bias (difference between the blue curve and black curve).

In order to measure the significance of the total bias, the nonresponse bias, and the sample-size bias of the simulation illustrated in Figure 4, we tested the differences in attack rate, peak infection rate, and time-to-peak by using the 2-sample *t* test. The mean difference, 95% confidence intervals, and *P* values are summarized in Tables 1 and 2 for low and high transmission rates, respectively.

As shown in Table 1, with a low transmission rate (0.00003), the attack rate for S' is about 10% lower than that for V, while the peak infection rate for S' is 1.36% lower and the epidemic curve peaks 1 day later. Total biases for all 3 metrics are statistically significant. Also for all 3 metrics, the nonresponse bias is larger than the sample bias and dominates the total bias. This is consistent with the fact that MTurk survey responders tend to be younger, educated males among whom the incidence of disease is typically lower than much of the rest of the population.

Results for the higher transmission rate (0.00006) are similar (Table 2). Note, however, that the difference between the red and black curves (in Figure 4) shrinks as the transmission rate becomes higher.

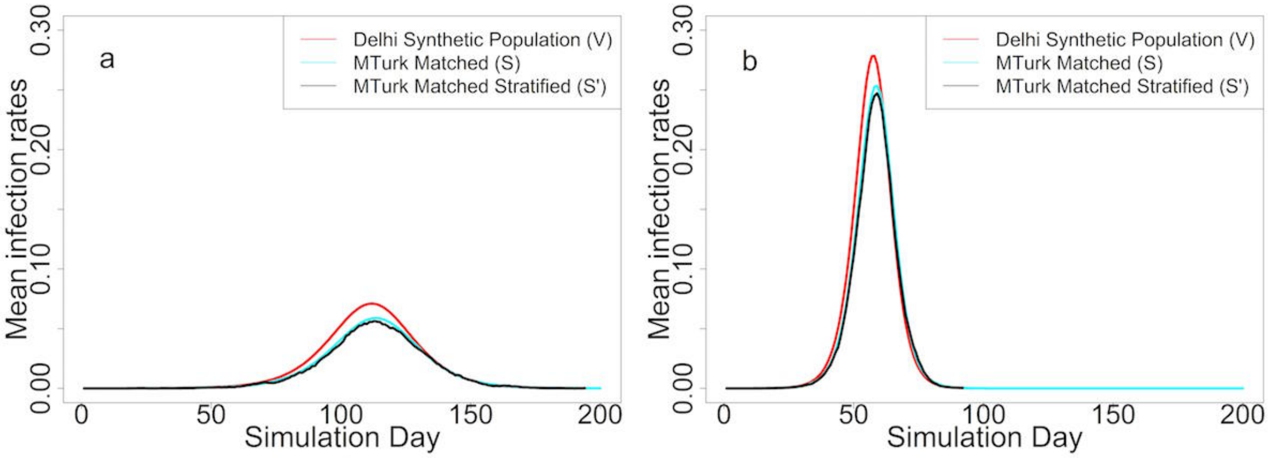
Table 1. Bias in epidemic metrics under low transmission rate.

Metric	Nonresponse bias (V-S)	Sample-size bias (S-S')	Total bias (V-S')
Attack rate			
Mean difference, %	7.90	2.13	10.03
95% CI	7.88 to 7.91	1.58 to 2.68	9.47 to 10.58
P value	<.001	<.001	<.001
Peak infection rate			
Mean difference, %	1.22	0.14	1.36
95% CI	1.22 to 1.22	0.05 to 0.23	1.27 to 1.45
P value	<.001	.003	<.001
Time to peak			
Mean difference, days	–1.76	0.76	–1
95% CI	–1.96 to –1.56	0.16 to 1.36	–1.58 to –0.42
P value	<.001	.02	.002

Table 2. Bias in epidemic metrics under high transmission rate.

Metric	Nonresponse bias (V-S)	Sample-size bias (S-S')	Total bias (V-S')
Attack rate			
Mean difference, %	6.31	3.58	9.90
95% CI	6.30 to 6.32	3.06 to 4.10	9.38 to 10.42
P value	<.001	<.001	<.001
Peak infection rate			
Mean difference, %	2.51	0.63	3.14
95% CI	2.50 to 2.53	0.49 to 0.77	3.01 to 3.28
P value	<.001	<.001	<.001
Time to peak			
Mean difference, days	–1.44	0.12	–1.32
95% CI	–1.69 to –1.20	–0.10 to 0.34	–1.59 to –1.05
P value	<.001	.28	<.001

Figure 4. (a) Epidemic curves under low transmission rate. (b) Epidemic curves under high transmission rate.



Influenzanet-Based Results

In this section, we show results for simulations and forecasts performed for the 2015-2016 influenza season. The input component of the framework has been initialized with ILI cases from a number of selected countries that are part of the Influenzanet network: Belgium, Denmark, Italy, the Netherlands, Spain, and the United Kingdom. In the simulation component, weekly surveillance data of sentinel doctors, also called traditional surveillance, in each of the selected countries have been used as ground truth to select the set of models with maximum likelihood.

Figure 5 illustrates the results of 1-week, 2-week, 3-week, and 4-week predictions. We include results for 1-week, also called now-casting, predictions for the following reason. The now-casting predictions (ie, inferring the incidence value that the traditional influenza surveillance will report in the following week) are usually used to evaluate the performance of the predictions based on the model described in this work with respect to predictions based on linear regression models applied to traditional surveillance data only. In a recent work by Perrotta et al [52], it has been shown how real-time forecasts of seasonal influenza activity in Italy can be improved by integrating traditional surveillance data with data from the participatory surveillance platform called Influweb, and the now-casting predictions have been used as a benchmark test to compare the 2 approaches.

Figure 5 shows that for all countries under study, the empirical observations (ie, the ground truth of the traditional surveillance reference data represented as black dots in the figure) lie within the 95% confidence intervals for most weeks. This gives a qualitative indication of the accuracy of the predictions.

In Figure 6, we show results for the Pearson correlation between each predicted time series and sentinel doctors' surveillance time series and also results for the mean absolute percent error (MAPE). As expected, the statistical accuracy of the ensemble forecasts increase as the season progresses. In the case of a 1-week lead prediction, the correlation is close to 1 for Italy and Belgium. The correlations are around 0.8 for 2-week predictions for the United Kingdom, around 0.7 for the Netherlands, and above 0.8 for 4-week lead predictions for United Kingdom and Italy. The peak magnitude is 1 of the free parameters we fit in the model. As the correlation increases as the season progresses, the MAPE (ie, the percentage error on the peak magnitude estimated by the model) decreases or remains quite stable for countries like the United Kingdom, in which the correlation is consistently high. For other countries, the performance is not as good and the peak magnitude is not so well estimated. Belgium and Spain are the 2 countries in which the performance is the worst. This might be due to the fact that the ILI incidence curve from Influenzanet in Spain is very noisy, mainly due to low participation, and this has affected the quality of the predictions in terms of amplitude and correlation. In Belgium, the ILI incidence data from traditional surveillance have been very noisy due to an unusually mild influenza season in this country. More information about the Influenzanet ILI incidence curves in the various countries can be found at the Influenzanet page (www.influenzanet.eu/en/flu-activity/). The peak week accuracy also increases as the season progresses and, notably, accuracy is already above 60% with up to 4 weeks lead time in the case of Italy, the Netherlands, and Spain.

Overall, even for a peculiar influenza season such as 2015-2016, with an unusually late peak, the results show that our framework is capable of providing accurate short-range (1-week, 2-week) forecasts and reasonably accurate longer range (3-week, 4-week) predictions of seasonal influenza intensities and temporal trends.

Figure 5. Epidemic profiles for Belgium, Denmark, Italy, the Netherlands, Spain, and the United Kingdom considering 4-week, 3-week, 2-week, and 1-week lead predictions. The best estimation (solid line) and the 95% confidence interval (colored area) are shown together with sentinel doctors' surveillance data (black dots) which represent the ground truth (ie, the target signals).

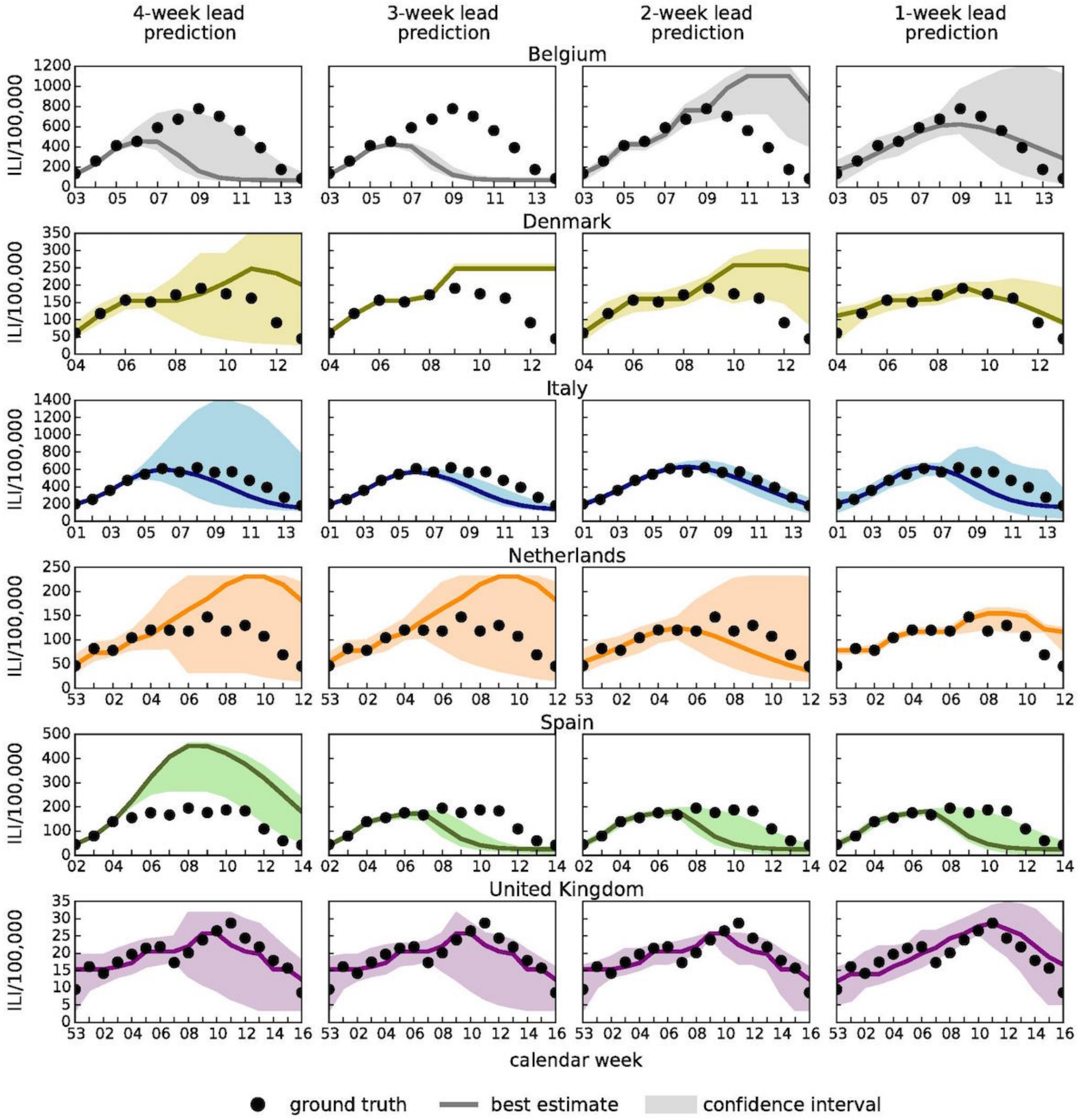
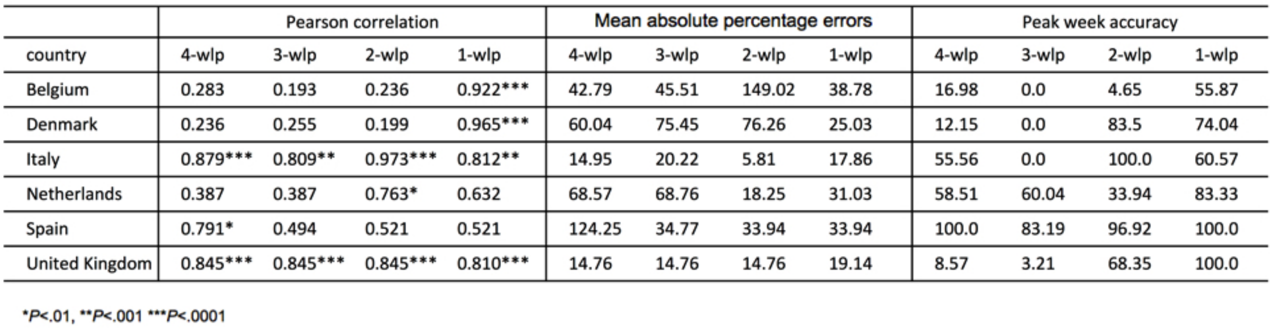


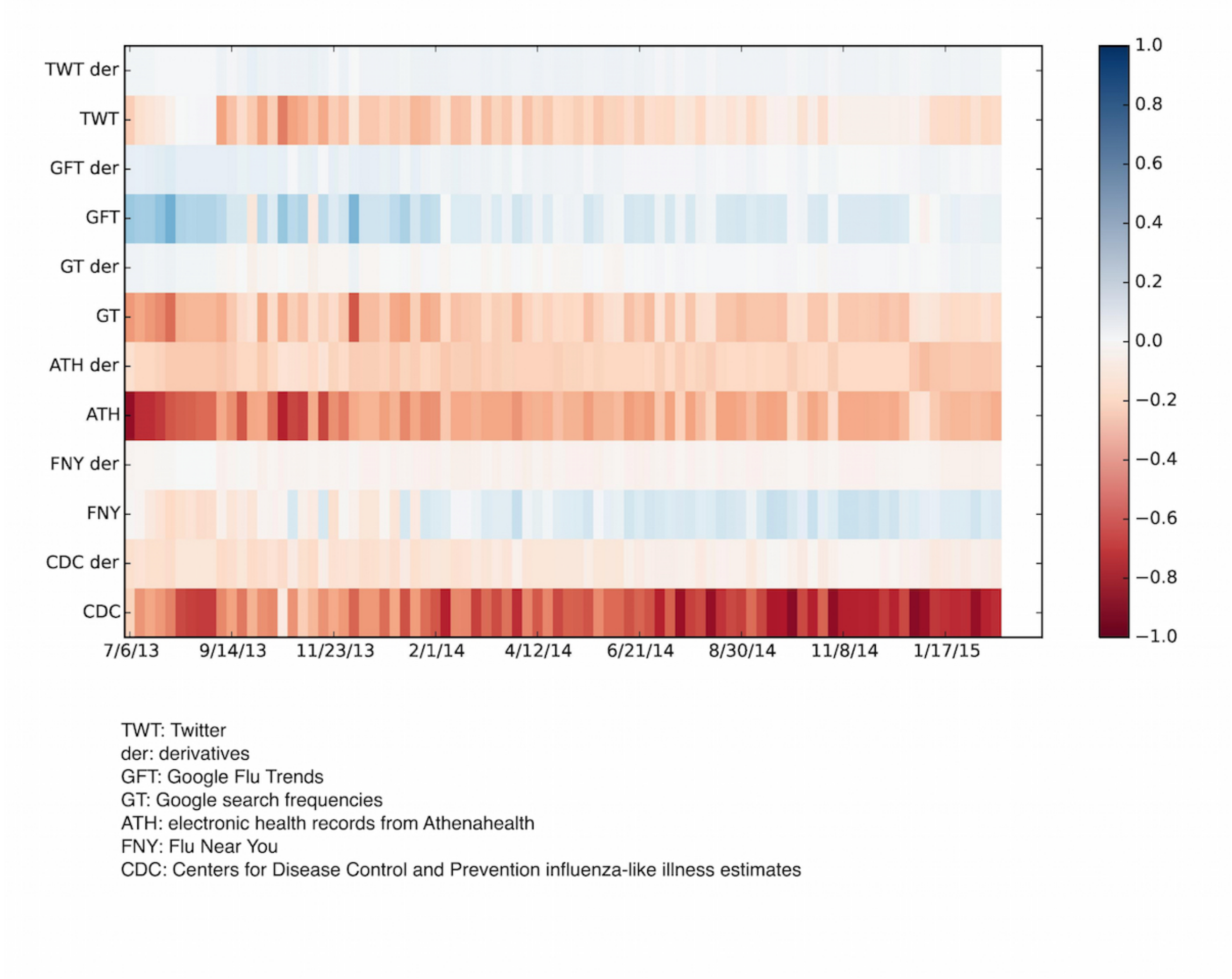
Figure 6. Pearson correlations, mean absolute percentage errors, and peak week accuracy obtained by comparing the forecast results and the sentinel doctors' influenza-like illness surveillance data along the entire season in each country.



	Pearson correlation				Mean absolute percentage errors				Peak week accuracy			
country	4-wlp	3-wlp	2-wlp	1-wlp	4-wlp	3-wlp	2-wlp	1-wlp	4-wlp	3-wlp	2-wlp	1-wlp
Belgium	0.283	0.193	0.236	0.922***	42.79	45.51	149.02	38.78	16.98	0.0	4.65	55.87
Denmark	0.236	0.255	0.199	0.965***	60.04	75.45	76.26	25.03	12.15	0.0	83.5	74.04
Italy	0.879***	0.809**	0.973***	0.812**	14.95	20.22	5.81	17.86	55.56	0.0	100.0	60.57
Netherlands	0.387	0.387	0.763*	0.632	68.57	68.76	18.25	31.03	58.51	60.04	33.94	83.33
Spain	0.791*	0.494	0.521	0.521	124.25	34.77	33.94	33.94	100.0	83.19	96.92	100.0
United Kingdom	0.845***	0.845***	0.845***	0.810***	14.76	14.76	14.76	19.14	8.57	3.21	68.35	100.0

*P<.01, **P<.001 ***P<.0001

Figure 7. Heatmap showing the relevance of each of the input data sources on the flu prediction during the 7/2013-4/2015 time window (x-axis). These values change from week to week due to a dynamic model recalibration process. The multiple data sources entered into the HealthMap Flu Trends system are on the y-axis with their tendencies, or derivatives. The bar on the right is a color code of the magnitude of the regression coefficients of the multiple data sources used as inputs.



Flu Near You–Based Results

We quantitatively confirmed that incorporating data from our participatory surveillance system improved real-time influenza predictions by comparing the aforementioned influenza estimates with estimates produced using a model based only on historical CDC-reported influenza activity (a lag-2 autoregressive model), labeled AR(2) in Figure 3. The correlation between the observed influenza activity and the estimates obtained using a model based only on historical ILI information for the 2013-2015 time window was 0.95, whereas the correlation with the model that incorporates FNY information was 0.96. While this represents a mild improvement in the correlation values, a more statistically robust test introduced by Yang et al [9] showed that the incorporation of FNY information led to a 10% mean error reduction (90% CI 0.04 to 0.24) when compared to the baseline autoregressive model. The bottom panel of Figure 3 shows visually the errors from each model.

HealthMap Flu Trends national-level real-time predictions that were available 1 week ahead of the publication of the weekly CDC reports for the 2013-2014 and 2014-2015 influenza seasons are shown in red on Figure 3. For comparison purposes, the correlation of the HealthMap Flu Trends estimates with the observed CDC ILI rates is 0.99 for the 2013-2015 time window, and the addition of multiple data sources leads to a mean error reduction of about 83% (90% CI 0.69 to 0.85) when compared to the estimates of the model that only uses CDC historical information (AR(2)). In Figure 7, the historical contributions of the different individual predictors (and their tendencies) in the HealthMap influenza estimates are displayed. As illustrated in Figure 7, FNY inputs do contribute to the ensemble-based influenza prediction estimates.

Discussion

We have described 3 different participatory surveillance systems, WISDM, Influenzanet, and FNY, and we have shown how modeling and simulation can be or has been combined with participatory disease surveillance to (1) measure the nonresponse bias present in a participatory surveillance sample using WISDM and (2) now-cast and forecast influenza activity in different parts of the world using Influenzanet and FNY.

While the advantages of participatory surveillance, compared to traditional surveillance, include its timeliness, lower costs, and broader reach, it is limited by a lack of control over the characteristics of the population sample. Modeling and simulation can help overcome this limitation.

Use of MTurk and WISDM combined with synthetic population modeling, as shown here, is one way to measure nonresponse and sample bias. The results measure the nonresponse and sample bias for three epidemic outcomes (ie, epidemic size, peak infection rate, and time-to-peak). As shown in Table 1, a lower transmission rate results in a higher nonresponse bias and higher total bias. Total biases for all 3 metrics are statistically significant. Also for all three metrics, the nonresponse bias is larger than the sample bias and dominates the total bias. This is consistent with the fact that MTurk survey responders tend to be younger, educated males among whom the incidence of disease is typically lower than much of the rest of the population. Results for the higher transmission rate are similar. In summary, WISDM-based results show that the bias that occurs in a skewed survey sample can be measured through modeling and simulation to infer more dependable observations than what can be derived from the survey data alone.

Our results confirmed that combining participatory surveillance information from FNY with modeling approaches improve short-term influenza activity predictions. In addition, we described how combining participatory surveillance information with other data sources, by means of a robust machine-learning modeling approach, has led to substantial improvements in short-term influenza activity predictions [49]. Information from participatory surveillance may also help improve influenza forecasting approaches such as those proposed in other studies [53-56].

Moreover, we have shown how by combining digital participatory surveillance data with a realistic data-driven epidemiological model we can provide both short-term now-casts (1 or 2 weeks in advance) of epidemic intensities and long-term (3 or 4 weeks in advance) forecasts of significant indicators of an influenza season. It is indeed the participatory surveillance data component that allows for real-time forecasts of seasonal influenza activity. ILI incidence estimates produced by traditional surveillance systems undergo weekly revisions, are usually released with at least a 1-week lag, and lack the geographical resolution needed to inform high-resolution dynamical models such as GLEAM. Participatory surveillance data are available as soon as participants report their health status. This real-time component allows for accurate now-casting (1 week) and forecasting (2, 3, and 4 weeks) as soon as the influenza activity among the population begins, even before the epidemic curve surpasses the threshold. Data from traditional surveillance up until a specific week are used to fit the selected ensembles which then provide predictions for the upcoming weeks, but these ensembles need to be generated by using the high-resolution real-time data from participatory surveillance.

For future work aimed at harmonizing these three approaches, results from the WISDM platform about nonresponse bias could be used to assess similar biases in groups of self-selected individuals participating in Influenzanet and FNY [24].

The projects described here not only strengthen the case for modeling and simulation becoming an integral component of the epidemic surveillance process, but they also open up several new directions for research. Important questions are yet to be answered. How do we optimally integrate other sources of data with data obtained through participatory surveillance? How do we incorporate participatory surveillance data that are reweighted at each point in time based on active learning techniques to maximize forecast accuracy? How can hypotheses be generated and tested in an abductive setting? An abductive setting is where the models and experiments can be run iteratively to test data-driven hypotheses that evolve as new data arrives in real time.

With the increasing reach of the Internet and cellular communication, participatory surveillance offers the possibility of early detection of and response to infectious disease epidemics. Continued integration of participatory surveillance with modeling and simulation techniques will help to strengthen real-time epidemic science and provide a more rigorous understanding of epidemic conditions.

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Conflicts of Interest

None declared.

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Abbreviations

CDC: Centers for Disease Control and Prevention
FNY: Flu Near You
GLEAM: Global Epidemic And Mobility model
ILI: influenza-like illness
ILINet: Influenza-Like Illness Surveillance Network
MAPE: mean absolute percentage error
MIDAS: Models of Infectious Disease Agent Study
MTurk: Mechanical Turk
NIH: National Institutes of Health
NSF: National Science Foundation
SEIR: Susceptible, Exposed, Infected, and Recovered
WISDM: Widely Internet-Sourced Distributed Monitoring

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Original Paper

A Smartphone App (AfyaData) for Innovative One Health Disease Surveillance from Community to National Levels in Africa: Intervention in Disease Surveillance

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Abstract

Background: We describe the development and initial achievements of a participatory disease surveillance system that relies on mobile technology to promote Community Level One Health Security (CLOHS) in Africa.

Objective: The objective of this system, Enhancing Community-Based Disease Outbreak Detection and Response in East and Southern Africa (DODRES), is to empower community-based human and animal health reporters with training and information and communication technology (ICT)–based solutions to contribute to disease detection and response, thereby complementing strategies to improve the efficiency of infectious disease surveillance at national, regional, and global levels. In this study, we refer to techno-health as the application of ICT-based solutions to enhance early detection, timely reporting, and prompt response to health events in human and animal populations.

Methods: An EpiHack, involving human and animal health experts as well as ICT programmers, was held in Tanzania in 2014 to identify major challenges facing early detection, timely reporting, and prompt response to disease events. This was followed by a project inception workshop in 2015, which brought together key stakeholders, including policy makers and community representatives, to refine the objectives and implementation plan of the DODRES project. The digital ICT tools were developed and packaged together as the *AfyaData* app to support One Health disease surveillance. Community health reporters (CHRs) and officials from animal and human health sectors in Morogoro and Ngorongoro districts in Tanzania were trained to use the *AfyaData* app. The *AfyaData* supports near- to real-time data collection and submission at both community and health facility levels as well as the provision of feedback to reporters. The functionality of the One Health Knowledge Repository (OHKR) app has been integrated into the *AfyaData* app to provide health information on case definitions of diseases of humans and animals and to synthesize advice that can be transmitted to CHRs with next step response activities or interventions. Additionally, a WhatsApp social group was made to serve as a platform to sustain interactions between community members, local government officials, and DODRES team members.

Results: Within the first 5 months (August-December 2016) of *AfyaData* tool deployment, a total of 1915 clinical cases in livestock (1816) and humans (99) were reported in Morogoro (83) and Ngorongoro (1832) districts.

Conclusions: These initial results suggest that the DODRES community-level model creates an opportunity for One Health engagement of people in their own communities in the detection of infectious human and animal disease threats. Participatory approaches supported by digital and mobile technologies should be promoted for early disease detection, timely reporting, and prompt response at the community, national, regional, and global levels.

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KEYWORDS

public health; surveillance systems; epidemics; outbreak; technology

Introduction

Background

A growing body of evidence shows that infectious diseases have significant negative socioeconomic consequences on vulnerable populations across the world [1-5]. The impact is enormous in most low- and middle-income countries (LMICs) in sub-Saharan Africa, where capacity for risk management of emerging and reemerging diseases is inadequate, thereby posing challenges to both human and livestock health systems. Infectious diseases account for approximately 40% to 50% of global morbidity and mortality in humans [1], with LMICs recording higher proportions of infectious disease contributions to morbidity and mortality compared with high-income countries [2,3]. It has been recognized that approximately 70% of emerging diseases of humans have an animal origin [4]. Furthermore, infectious diseases in animals constitute a major constraint to livestock-dependent livelihoods and are the single most important barrier to the export of African livestock commodities to lucrative markets [5,6]. These observations, together with increasing international movement of people and commodities, alarming increase in antimicrobial resistance, as well as climate variability or change, emphasize the need for a One Health approach to strengthen risk management of infectious diseases in LMICs in Africa.

Response to infectious disease epidemics largely depends on appropriate and effective surveillance programs that inform both human and animal health decision making and practice. The current disease surveillance systems and strategies in Tanzania are based on the International Health Regulations (IHR 2005) and the World Organization for Animal Health (OIE), which mandate the flow of information from the community to the global level [7]. However, existing systems have been performing suboptimally [8,9]. This raises the question of whether participatory engagement of local communities improves the performance of disease surveillance systems.

The fact that disease outbreaks typically erupt in communities, that is, at the local level, suggests that communities are a key driver influencing the persistence and transmission dynamic of infectious diseases. This is especially true among pastoralists and poor rural communities [10-13]. Moreover, the most vulnerable communities are typically located in remote areas that are hard to reach and that do not have reliable communication which calls for utilization of innovative approaches for early detection and reporting of disease events in near-real time. Some initiatives have been made to facilitate collection of health data in the locations without the Internet. For instance, WeFarm, which is a free peer-to-peer service that enables farmers to share information via short message service without the Internet, has been reported to be useful to support farmers to ask questions on farming and receive crowdsourced prompt responses from other farmers around the world [12]. Another example is Cojengo from a Scotland-based technology company that developed a disease surveillance tool, which is branded as *VetAfrica app*, to help farmers expedite diagnosis of livestock diseases and provide suitable drugs for farm animals [13].

Opportunities for Strengthening Disease Surveillance

Community-based disease surveillance strategies have the potential to benefit from improved data quality and access, given the current increased trend in the penetration of smartphones and ownership, as well as universal Internet access by rural communities. The use of paper-based system to record and submit health events data in resource-poor countries contributes enormously to delayed response. It is also common practice in African cultures that the health care pathway does not start off at official health facilities but rather at home or traditional healers. Thus, most health events within communities are not captured in the official health surveillance system. The quest for an early warning system calls for community members to be directly involved in the surveillance and detection of health events (ie, participatory epidemiology). Innovative solutions are therefore needed to bridge the gap of capturing health events at community level that should inform the relevant authorities to provide appropriate responses in a timely manner. A disease surveillance approach that not only is grounded in One Health principles but is also participatory, supporting sharing of health information among stakeholders is likely to enhance early detection of human and animal diseases at the community level by empowering communities to take ownership and control over local decisions and to have a stake in maintaining the surveillance structures and practices [12].

The widening use of mobile phones in sub-Saharan Africa, where the penetration rate has reached 67% [14], offers the opportunity to develop innovative participatory surveillance strategies that rely on the design and deployment of digital and mobile technology solutions. In this paper, we describe the Southern African Centre for Infectious Disease Surveillance's (SACIDS) experience in implementing a participatory surveillance system that relies on digital and mobile technology solutions through the Enhancing Community-Based Disease Outbreak Detection and Response in East and Southern Africa (DODRES) project. In this study, we refer to techno-health as the application of information and communication technology (ICT)–based solutions to enhance early detection, timely reporting, and prompt response to health events in human and animal populations. The DODRES project is supported by Skoll Global Threats Fund. Its overall goal is to promote Community Level One Health Security (CLOHS), thus complementing international disease surveillance strategies with participatory engagement of local communities and enhancing early disease detection and response at community, national, regional, and global levels.

Methods

Development and Implementation of Innovative Ideas to Strengthen Disease Surveillance

The DODRES project is a part of SACIDS’ continuing efforts to champion a CLOHS initiative to support participatory approaches in disease surveillance that complement the Global Health Security Agenda. The Global Health Security Agenda is a partnership of nearly 50 nations, international organizations, and nongovernmental stakeholders that was launched in February 2014 to help build countries’ capacities to create a world that is safe and secure from infectious disease threats and to elevate global health security as a national and global priority [15,16].

SACIDS held two events to promote CLOHS and lay the groundwork for the DODRES project. The first was EpiHack Tanzania, which was held in Arusha, Tanzania, in December 2014. EpiHack is a collaborative gathering of software developers and health professionals to create digital technological solutions that address specific public and animal health issues. The aim of EpiHack Tanzania was to bring together experts from the animal and human health sectors, as well as ICT developers to collaborate in providing solutions to challenges facing infectious disease surveillance and response in the Southern and Eastern African regions. The second event was a project inception workshop held in August 2015, also in Arusha, Tanzania. The workshop was organized to bring together key stakeholders considered to be important for successful implementation of the project. In the two events, it was agreed to promote CLOHS through (1) enhancing working across animal and human sectors to fight epidemics in human and animal populations; (2) developing ICT tools to support data capture, reporting, and feedback at health facilities and within communities that feed into the official Integrated Disease Surveillance and Response (IDSR) and veterinary national surveillance systems; and (3) strengthening local cross-border collaboration to fight epidemics.

In November 2015, the Techno-Health Innovative Laboratory was established at Morogoro Regional Hospital in Morogoro, Tanzania, to host the DODRES design and implementation team of epidemiologists and ICT programmers. While the SACIDS-National Institute for Medical Research (NIMR) Design and Implementation team led ICT tool development, the US-based Innovative Support to Emergencies, Diseases, and Disasters (InSTEDD) provided mentorship and quality assurance of the tools developed. Subsequently, project sites for piloting DODRES were selected. A theory of change (ToC) framework was used to guide the DODRES project implementation process. A ToC refers to a tool that is used to hypothesize on how and why an initiative works [17]. It is a systematic and cumulative study of the links between activities and inputs, outcomes, and contexts of the initiative. The ICT team developed four prototype ICT tools and then implemented three finalized ICT tools (packaged together as the *AfyaData* app) for near real-time participatory data collection, reporting, and feedback. SACIDS trained One Health community health reporters (CHRs) and facility and district officials to use the new tools. Each of these activities is described in detail below.

Description of the Project Sites

Two project sites were strategically selected for the piloting of DODRES project (Figure 1). One was the Ngorongoro district of Tanzania and Narok County in Kenya. The two districts share the same cross-border ecosystem. This inland ecosystem is not only contiguous with the major wildlife ecosystems of the Ngorongoro Conservation Area Authority, Serengeti National Park, and Maasai Mara Wildlife Reserve but is also characterized by maximum informal interactions of the local pastoral (Maasai) community in both Tanzania and Kenya. Thus, human-domestic-wildlife interactions are frequent, and the area is at high risk for both human and animal disease epidemics, including Rift Valley fever (RVF, 2006/2007), contagious bovine pleuropneumonia (CBPP, 2010-2012), contagious caprine pleuropneumonia (CCPP), peste des petits ruminants (PPR, 2008 to date) [18-20], and anthrax (Ngorongoro District Council, unpublished). The area is inhabited by an estimated 1,025,198 people and 3,458,027 livestock (ie, cattle, goats, and sheep). The total land area of this ecosystem is approximately 31,957 square kilometers. SACIDS has plans to also deploy *AfyaData* tools in Narok County in Kenya to strengthen local cross-border collaboration.

The second site was the Morogoro Urban district in central-eastern Tanzania. This district is inhabited by 602,114 people occupying approximately 260 square kilometers. It was strategically selected to participate in DODRES project implementation because the core project design and implementation team is hosted within the Morogoro Urban district. Thus, ICT tools can be more readily tested in proximity to where the ICT team is housed before being deployed for field data collection and reporting in other project sites.

Theory of Change for Guiding DODRES Implementation

A ToC (Figure 2) was developed to guide DODRES project implementation. The ToC is a tool normally developed to guide planning, participation, and monitoring and evaluation of a given project that aims at bringing social change.

Figure 1. Map showing DODRES project sites in the Morogoro Urban and Ngorongoro districts of Tanzania.

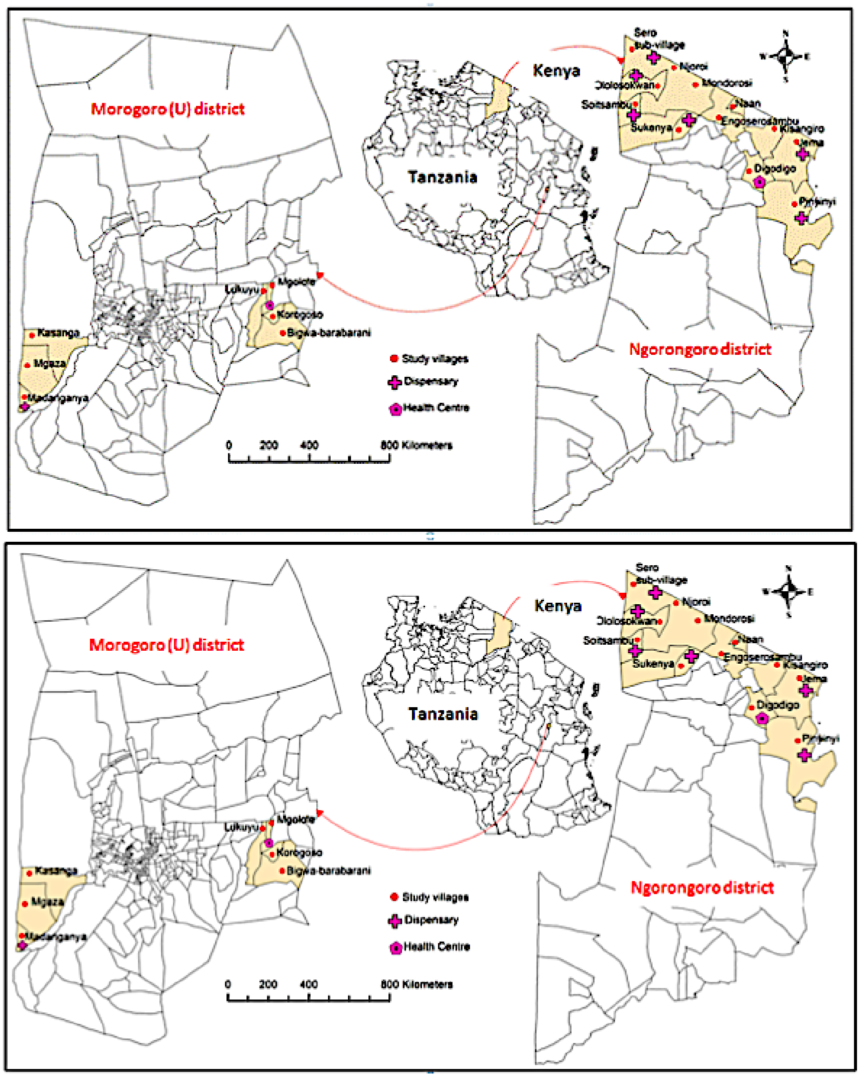
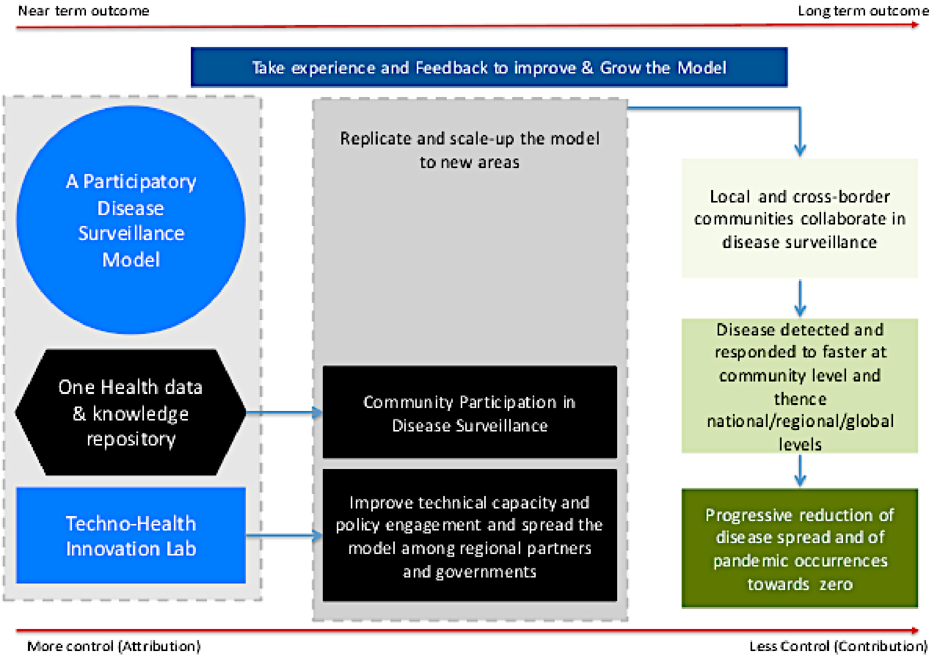


Figure 2. Community Level One Health Security theory of change.



Key components of the ToC are as follows: (1) a participatory disease surveillance model; (2) improvement and growth of the model; and (3) long-term contribution to progressive reduction of disease spread and of pandemic occurrences at the community, national, and global levels. It was perceived that, as a first step to achieving its ultimate goal, establishing the Techno-Health Innovation Laboratory to support the design of participatory disease surveillance tools and the One Health Knowledge Repository (OHKR) were processes that were within the ability of DODRES project to plan and implement. It was further considered that implementation of both processes would improve community participation in disease surveillance and produce evidence to influence policy change with respect to disease surveillance in both the human and animal health sectors. The ultimate goal of the DODRES project is to contribute to the reduction of infectious disease spread and pandemic occurrences toward zero prevalence—an achievement that requires joint efforts with other actors and less control by the DODRES project.

The ToC was therefore developed using participatory approach involving human and animal health experts in collaboration with the ICT experts. This ToC is centered on the theory of promoting use of participatory disease surveillance, ICT tools, and application of One Health collaborative approaches as key inputs/activities to support early disease outbreak detection and response (outputs) (Figure 2). The outcomes of such an initiative, which are contributed to by the DODRES project in partnership with other stakeholders, include faster detection of infectious diseases at different levels (community, national, regional, and global) that consequently add to progressive reduction of disease spread and pandemic occurrences globally. The ToC was used to guide development of potential One Health participatory disease surveillance technological solutions, taking into consideration the main challenges to effective infectious disease surveillance that were identified during EpiHack Tanzania and at the 2015 project inception workshop. These challenges and technical solutions are outlined in Figure 2.

Challenges to Disease Surveillance

Through a participatory problem identification process, the following list of key challenges was jointly developed by ICT programmers and human and animal health experts:

- Failure to capture major disease events occurring at the community level because of application of traditional nonparticipatory approaches in public and animal health disease surveillance
- Delayed submission and incompleteness of official disease surveillance data submitted by health facilities to the subnational and national levels
- Lack of feedback (two-way communication) to the disease surveillance data collectors
- Inability to trace individual humans and animals, as well as their locations, during disease outbreaks

Recommended Technical Solutions

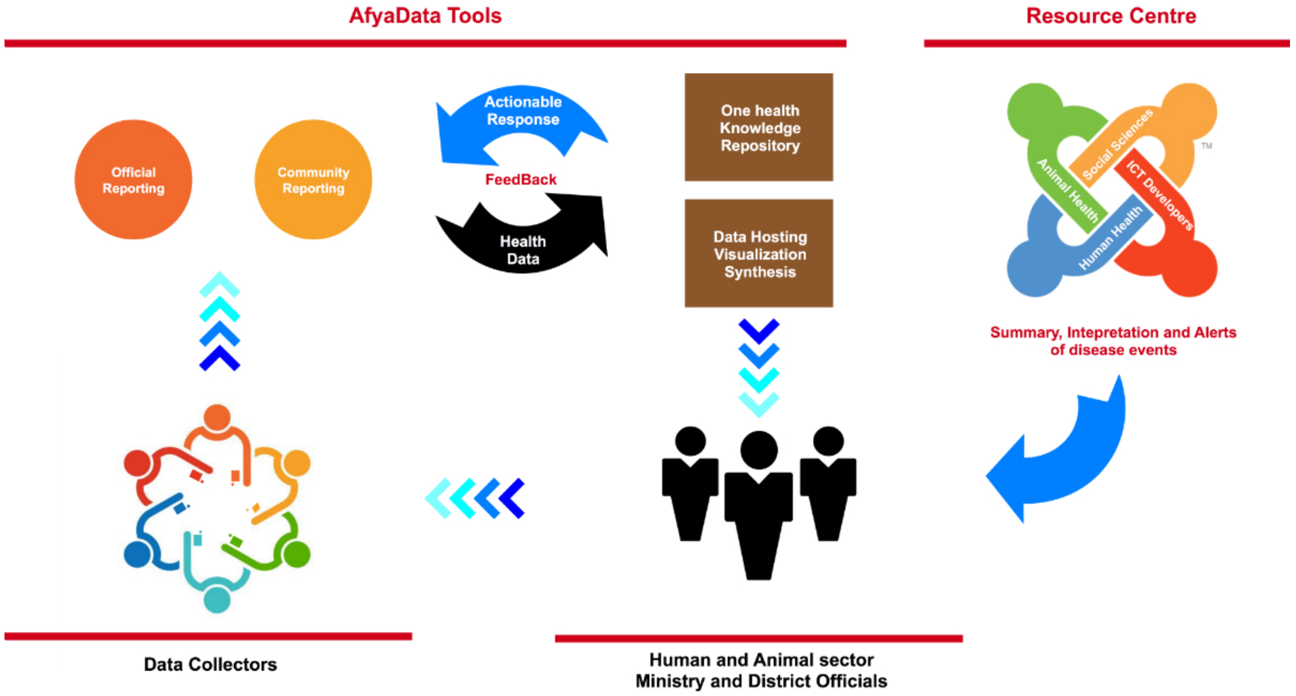
The ICT programmers, in collaboration with human and animal health experts, designed the following four prototype technological solutions to address these challenges:

1. Community-based participatory disease surveillance for timely detection and reporting of disease events at the community level
2. Official surveillance strategy for timely collection and submission of disease data at the health facility level
3. Two-way communication feedback loops to provide prompt feedback and hence value to individuals who report disease events at community and health facility levels
4. Contact tracing, including identification of affected households or livestock herds and their locations, to support official tracking of potential disease outbreaks and to aid outbreak investigation

Development of ICT Tools to Support Participatory Disease Surveillance

From the abovementioned prototypes, three (1, 2, and 3) were integrated into an *AfyaData* app (Figure 3) and developed into a stable beta version to support technical solutions for near real-time data collection at community and health facility levels and for the provision of feedback to reporters. *AfyaData* is a set of two apps; a native mobile Android-based client and a Web-based app acting as a server. The mobile client is inspired by Open Data Kit (ODK), used for collecting and submitting syndromic data and receiving and/or tracking feedback from health officials. The server component consists of a set of Web service that handles the entire lifecycle for initializing, collecting, registering, and managing forms ready for the *AfyaData* mobile client to utilize.

Figure 3. Integrated development of information and communication technology (ICT) tools (the AfyaData app) to support data collection and feedback on disease events occurring in human and animal populations.



The system is designed to collect data using a mobile phone with or without Internet connectivity, and data can be submitted at a location with the Internet. Source code is hosted on GitHub [21], manufactured by GitHub, Inc.One of the most common challenges in the traditional infectious disease surveillance systems in human and animal health is a lack of timely feedback. In particular, feedback to persons collecting and submitting surveillance data is critical to encourage them to continue reporting quality data, as well as initiate quick actions to prevent or mitigate the extent of possible epidemics. Having recognized the importance of prompt detection, reporting, and feedback, an OHKR module was developed as an integral component of the *AfyaData* app hosted on the server at the Sokoine University of Agriculture. To start with, SACIDS has engaged specialists in the fields of human and animal health to develop OHKR contents for priority endemic and epidemic-prone diseases in East Africa. The source code is open source, and data are accessible to ascribed stakeholders.

The OHKR is a decision-making system with expert-authored content that helps to support the prediction of likely disease conditions based on signs and symptoms reported by CHRs, thereby guiding confirmation of diseases. The contents of OHKR include specific disease standard case definition, percentage weight of clinical signs for each disease, and answers to frequently asked questions. The specialists from human and animal health sectors assigned percentage weight to each clinical manifestation associated with specific disease based on the extent to which such a clinical manifestation explains the disease. For instance, in cattle, the presence of blisters on snout, tongue, and space between hoofs (interdigital space) would explain about 80% chances of the disease being foot-and-mouth disease (FMD), whereas salivation, fever, and sudden onset of lameness would explain about 40% chances of the disease being FMD. The OHKR has been programmed to predict the most likely disease condition based on these percentage weights to inform subsequent strategic investigation/confirmation. We report herein the preliminary performance of the system, and plans are under way to validate it. The OHKR comprises three subsystems: (1) content subsystem—expert-authored content; (2) score map subsystem—symptom scores, weighted with respect to a particular disease, species, and location; and (3) turnkey mapper subsystem—a three-dimensional iterative matching algorithm. The OHKR system initiates its process as it receives clinical manifestations from a newly reported case/incident in AfyaData mobile app. These data are cleaned, combined, and compared with a preset clinical manifestation scores map. Weighted scores are cumulatively added for each combination of clinical manifestation received for the particular disease it matches with. Relevant content of the most likely diseases based on the cumulative score is then retrieved and fed into the feedback system. A list of recommended actions has been created per targeted user (community health workers/reporters, livestock extension officers, in-charge of health facilities, and district medical/veterinary officers). The OHKR automatically sends messages to relevant user on artificial intelligence and alerts of possible disease conditions occurring in human and animal populations.

Training and Support of Community Health Reporters and Officials

With funding from the Rockefeller Foundation (2010-2012) and the Canadian International Development Research Centre (IDRC) (2013-2017), between 2010 and 2016, SACIDS trained and empowered 82 frontline One Health CHRs, 41 facility-based health officials, 33 livestock field officers, and 14 data managers and analysts based at district medical and veterinary offices in Tanzania, Zambia, Burundi, and Kenya. During this period, the open source EpiCollect and ODK apps were used to sustain mobile-supported disease surveillance at health facility and community levels. The DODRES project built on this work, training an additional 29 CHRs and 17 officials in Morogoro Urban and Ngorongoro districts in early disease detection, reporting, and response. With DODRES, SACIDS changed its training policy by supporting more reporters (CHRs) at the community level, rather than at the health facility level (ie, official), to increase the likelihood of capturing events at the community level. Additionally, in remote areas where there is no alternative power source, the DODRES project provided the CHRs with solar chargers to ensure that their mobile phones remain powered.

The health data collected by CHRs and associated geographical coordinates are submitted to a centralized server system that supports near real-time access to all ascribed stakeholders. The spatial distribution of health events was created on ArcGIS 10.4.1. The latitude and longitude coordinates were projected onto the map using the World Geodetic System 1984 datum. In addition to the CHRs receiving feedback after submitting health events data, the *AfyaData* system provides a two-way interaction between the CHR and the health specialists to inform appropriate actions. The established WhatsApp social networking serves as a *crowdsourcing* platform that provides opportunity to share best practices, challenges, and solutions among CHR themselves and between CHRs and health specialists from animal and human health sectors.

Since March 2016, the DODRES project has also engaged ICT developers, health experts, and policy makers through monthly publication of the *TechnoHealth Surveillance* newsletter. The newsletter is used as a channel to disseminate disease surveillance information among project partners and the general public. The mailing list that receives the newsletter currently stands at 350. Additionally, all trained CHRs are networked with district health experts and DODRES project team members via the WhatsApp social platform. The WhatsApp networking not only contributes to sustained interactions between community members, government officials, and DODRES team members, but it also provides unstructured real-time information, thereby complementing the feedback mechanism tool of the *AfyaData* app. Using the same networking, health experts can provide instant technical support and advice on community-level outbreak management.

Ethics Statement

This study was approved by the Tanzania Medical Research Coordinating Committee of the National Institute for Medical Research (NIMR/HQ/R.8a/Vol.IX/2037).

Results

Disease Syndromes Reported

Of the 1915 clinical cases in livestock (1816) and humans (99) reported by CHRs using *AfyaData* app from August 2016 to December 2016, 95.98% (1838/1915) and 4.02% (77/1915) cases were from Ngorongoro and Morogoro Urban districts, respectively. Overall, a total of 1816 livestock cases were reported from a total population of 12,114 animals, of which 867 died, translating to a population morbidity rate and case fatality rate (CFR) of 14.99% (1816/12,114) and 47.74% (867/1816), respectively. The Ngorongoro animal population included 7613 goats from 45 flocks, 1948 cattle from 26 herds, 2250 sheep from 8 flocks, 144 chickens from 2 flocks, and 14 dogs from 2 kennels. The animal population in Morogoro included 5 goats from 1 flock, 6 cattle from 1 herd, 115 chickens from 4 flocks, and 13 dogs from 1 kennel. Out of 1816 livestock cases, 1750 were reported in Ngorongoro, whereas 66 out of 1816 livestock cases were reported in Morogoro. On the other hand, 82 out of 99 human cases were reported in Ngorongoro, whereas 17 out of 99 human cases were reported in Morogoro. Out of 1816 animal cases, 1762 were reported in domestic ruminants (goats, cattle, and sheep), whereas 54 out of 1816 cases were reported in chicken, pigs, and dogs. Out of 1826 animal cases, 1053 were reported in goats. Other livestock cases were reported in sheep (435), cattle (253), chicken (73), and dogs (2). Of 1816 livestock cases, 1736 were reported in domestic ruminants, of which 1042, 434, and 260 were goats, sheep, and cattle, respectively. Out of 1736 domestic ruminant cases, 1180 were aged ≥1 year. Generally, there was a tendency for the number of domestic ruminant cases and associated CFR to increase over subsequent months from 79 cases (CFR=6% [5/79]) reported in August 2016 to 793 cases (CFR=54% [431/793]) reported in December 2016.

The spatial distribution of syndromes reported in animals in the two districts is shown in Figure 4. Overall, the most frequently reported clinical manifestations were related to the respiratory system (ie, coughing, rapid breathing, sneezing, difficulty breathing, and nasal discharge; 159 reports), digestive system (ie, loss of appetite, diarrhea, frothy discharge from mouth, bloody diarrhea, and lesions in the mouth; 93 reports), reproductive system (ie, reduced milk production and abortion; 55 reports), and systemic disease (ie, fever and bleeding from natural body openings; 43 reports). Other reported manifestations were related to the nervous system (ie, twisted neck, circling, and abnormal behavior; 18 reports) and integumentary system (ie, swollen joints; 5 reports). Clinical manifestations such as reluctance to walk (36 reports) and discharge from eyes (19 reports) were also reported.

Using chi-square test, the overall population morbidity rate was significantly higher for domestic ruminants aged <1 year (30.21%, 564/1867) than those aged ≥1 year (11.77%, 1172/9955; *P*<.05). The CFR in the animals aged <1 year and ≥1 years were 46.6% (263/564) and 47.35% (555/1172), respectively. (*P*=.08). The population morbidity rate varied significantly by month for domestic ruminants aged ≥1 year, with higher values recorded in December (21%) and November (16%; *P*<.05). The CFR also varied significantly with calendar month in domestic ruminants aged ≥1 year, with similarly higher values been recorded in November (61.0%, 213/349) and December (50.7%, 262/517; *P*<.05). In addition, the population morbidity rate for domestic ruminants aged ≥1 year varied significantly among the study villages, with higher values been recorded in Bigwa-Barabarani (100%, 3/3), Naan (35.00%, 353/1463), Sukenya (29%, 17/58), and Kindibwa (25%, 1/4) villages (*P*<.05).

The spatial distribution of syndromes reported in humans in the two districts is shown in Figure 5. A total of 99 human cases were reported in 16 out of 18 study villages, with significantly larger number of cases (82) being from 10 of the 11 study villages in Ngorongoro compared with 17 cases being reported in 6 out of 7 study villages in Morogoro Urban district (*P*<.001). The majority of human cases reported in Ngorongoro (n=82) were from Kisangiro (36 cases), followed by Ololosokwan (18 cases), Jema (11 cases), Njoroi (5 cases), and Pinyinyi (5 cases) villages. Other human cases in the district were reported in Naan (4 cases), Engueserosambu, Mondorosi, Soitsambu, and Sukenya (1 case each) villages. In Morogoro Urban district, human cases (n=17) were reported from Kasanga (7 cases), Bigwa-Barabarani (3 cases), Mikoroshini (3 cases), Chamwino (2), and Lukuyu and Mgaza (1 case each). Overall, out of 99 human cases, 56 were reported among males, and 68 cases were reported among individuals aged ≥5 years. Out of 31 cases among individuals aged <5 years, 10 were reported in October, whereas 19 out of 68 cases among individuals aged ≥5 years were reported in August.

Overall, the most frequently clinical manifestations reported among humans in both districts were those related to the digestive system (104), including loss of appetite (27), diarrhea (24), vomiting (18), stomach ache (17), constipation (6), bloody vomiting (5), bloody diarrhea (4), and lesions in the mouth (3); the values in parenthesis represent the number of clinical manifestations. The next most frequently reported clinical manifestations were related to the respiratory system (56), including coughing (38), difficulty breathing (8), rapid breathing (6), and bloody coughing (4). The most frequently reported clinical manifestations among humans in Ngorongoro included coughing (34), headache (30), loss of appetite (22), diarrhea (18), body weakness (15), fever (14), vomiting (13), and stomach ache (13).

On the basis of the clinical manifestations reported, the most probable infectious conditions identified in goats by OHKR, with likelihood percentages in parentheses, were PPR (90%) and CCPP (80%). The most probable infectious diseases in cattle were CBPP (50%), brucellosis (50%), and anthrax (30%). The most probable disease in dogs was rabies (90%), whereas those in humans were malaria (65%), cholera (60%), and anthrax (30%).

Lessons Learned During Implementation

Since 2010, SACIDS-managed initiatives to utilize participatory approaches and mobile technologies have been contributing to improved disease surveillance in both human and animal populations in East and Southern African regions.

Figure 4. Spatial distribution of major clinical syndromes reported in livestock population in Morogoro Urban and Ngorongoro districts in Tanzania.

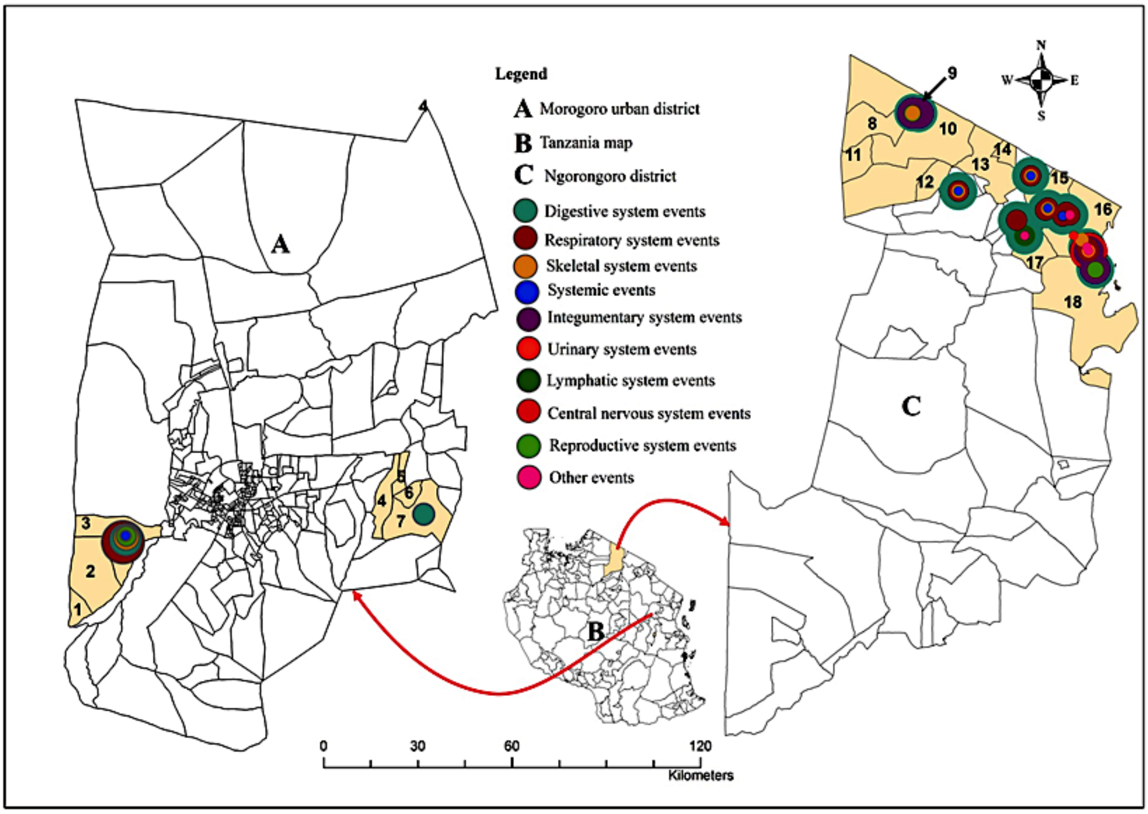
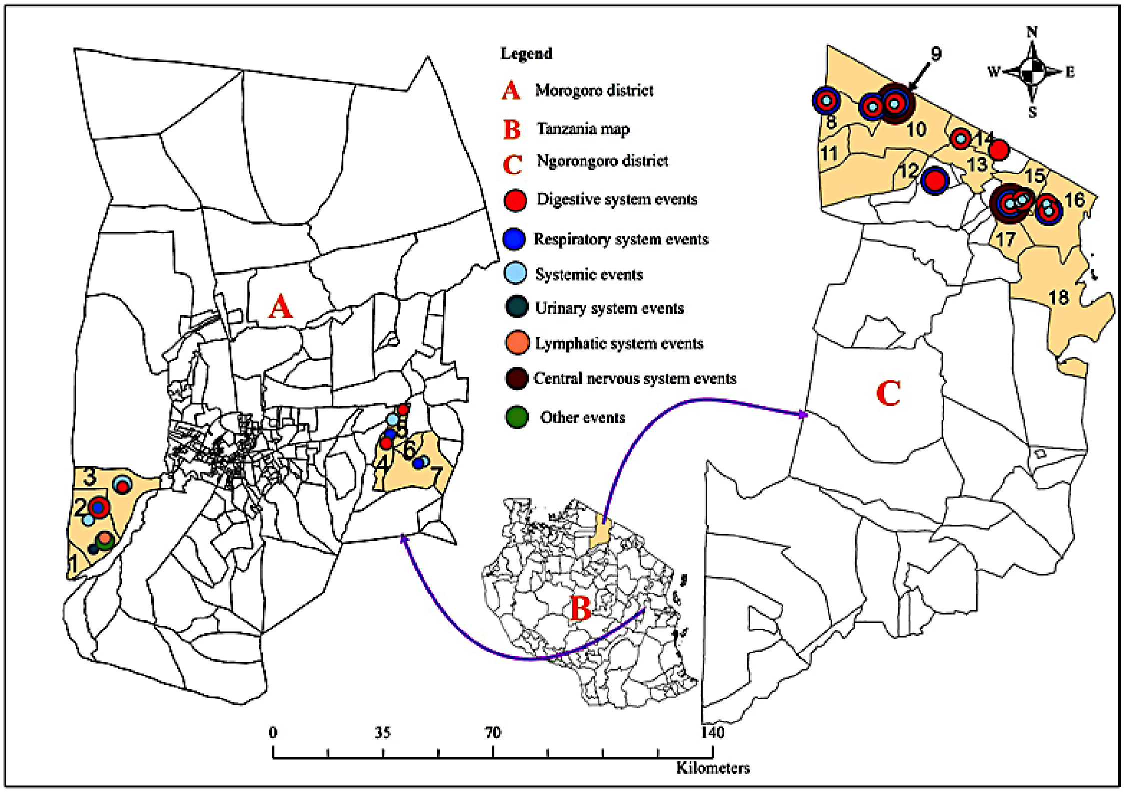


Figure 5. Spatial distribution of major clinical syndromes reported in human population in Morogoro Urban and Ngorongoro districts in Tanzania.



The DODRES ICT programming team has worked in close collaboration with the epidemiology team to design and deploy ICT tools that are relevant to disease surveillance in both the public and animal health sectors. An important lesson learned during the implementation of these various SACIDS projects, including DODRES, is the importance of making use of local expertise to design and maintain ICT-supported systems. The local team provided immediate technical support and was found to be reliable. In all of these projects, open-source apps have been used. Maintaining an open-source policy allows for contributions to app development by the open-source communities and provides a means of technical support for designing, testing, and refining newly developed ICT tools.

A baseline field assessment conducted by SACIDS in 11 villages in Ngorongoro and 7 villages in Morogoro Urban districts in April 2016 to establish benchmark values for performance indicators measured throughout DODRES project implementation indicated that CHRs and field-based health officials in the project sites considered mobile technologies to be more useful than paper-based systems for disease surveillance. Although field workers have run into some challenges, such as failing to synchronize data on their mobile phones with the server, recording geographical coordinates of more than one case at one location, and failing to locate clinical cases in mobile pastoral communities after receiving a call, the ICT developers have helped to correct some of these challenges.

Discussion

Principal Findings

Using participatory community-based digital disease surveillance approaches, we recorded a total number of 1915 clinical cases in livestock and humans within the first 5 months of *AfyaData* deployment in Morogoro and Ngorongoro districts.

Initial results of DODRES project show more clinical cases in both humans and livestock captured and reported by CHRs in Ngorongoro than in Morogoro Urban district. This difference may be attributed to lifestyle differences between the two sites. Morogoro is a densely populated urban district where the majority of population can easily access medical and veterinary services. In contrast, Ngorongoro is a rural-based district with sparsely populated villages located far from health facilities, thus making the work of CHRs even more valued than in urban areas. Similarly, the livestock production systems between the two areas differ, with Morogoro Urban district having a backyard zero grazing production system. In contrast, Ngorongoro is dominated by a pastoral production system. Using a participatory approach, CHRs were able to detect and report different clinical cases and identify symptoms related to a broad range of body systems (eg, digestive, respiratory, integumentary, and central nervous).

Utilization of mobile phones and ICT technologies to improve disease surveillance in public and animal health has been reported in other countries, including China [22], Sri Lanka [23], Zambia, Madagascar, Uganda, and Kenya [24]. The use of community health workers in public and animal heath sectors has been piloted in other countries as well [25-27]. A few of these studies or systems have combined the use of mobile technologies with participatory approaches as SACIDS has done. The combination of participatory community-based approaches with mobile technology has the potential to support not only early detections of disease events happening at the community level [28] but also near real-time responses.

By supporting detection of early disease epidemic signals, the DODRES approach has great potential to complement traditional public and animal health surveillance systems as recorded elsewhere [29]. The DODRES project did not support laboratory confirmation of reported disease events; its diagnostic capacity could be enhanced by doing so. Adoption of point-of-care diagnostics in particular, especially in remote areas, would likely hasten confirmation of events where they occur and thereby contribute to timely appropriate management and control of both known and unknown diseases [30]. More studies are needed to evaluate the contribution of community-level approaches to health outcomes, particularly in resource-restricted countries and ecosystems.

Conclusions

The DODRES model of CLOHS has the potential to contribute significantly to the Global Health Security Agenda by engaging *neglected* members of the community. Participatory approaches supported by mobile technologies should be promoted for enhanced early disease detection and response at the community, national, regional, and global levels.

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Authors' Contributions

All coauthors developed the manuscript together. EDK led manuscript development and data analysis. EBM, CS, LM, MM, NK, ST, JO, and MR critically appraised the manuscript and improved language.

Conflicts of Interest

None declared.

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Abbreviations

CBPP: contagious bovine pleuropneumonia
CCPP: contagious caprine pleuropneumonia
CHRs: community health reporters

CLOHS: Community Level One Health security
DODRES: Enhancing Community-Based Disease Outbreak Detection and Response in East and Southern Africa
FMD: foot-and-mouth disease
ICT: information and communication technology
IDRC: International Development Research Centre
IDSR: Integrated Disease Surveillance and Response
IHR: International Health Regulations
InSTEDD: Innovative Support to Emergencies, Diseases, and Disasters
LMICs: low- and middle-income countries
NIMR: National Institute for Medical Research
ODK: Open Data Kit
OHKR: One Health Knowledge Repository
OIE: World Organization for Animal Health
PPR: peste des petits ruminants
SACIDS: Southern African Centre for Infectious Disease Surveillance
ToC: theory of change

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Short Paper

Check and Report Ebola (CARE) Hotline: The User Perspective of an Innovative Tool for Postarrival Monitoring of Ebola in the United States

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Abstract

Background: The response to the 2014-2016 Ebola epidemic included an unprecedented effort from federal, state, and local public health authorities to monitor the health of travelers entering the United States from countries with Ebola outbreaks. The Check and Report Ebola (CARE) Hotline, a novel approach to monitoring, was designed to enable travelers to report their health status daily to an interactive voice recognition (IVR) system. The system was tested with 70 Centers for Disease Control and Prevention (CDC) federal employees returning from deployments in outbreak countries.

Objective: The objective of this study was to describe the development of the CARE Hotline as a tool for postarrival monitoring and examine the usage characteristics and user experience of the tool during a public health emergency.

Methods: Data were obtained from two sources. First, the CARE Hotline system produced a call log which summarized the usage characteristics of all 70 users' daily health reports. Second, we surveyed federal employees (n=70) who used the CARE Hotline to engage in monitoring. A total of 21 (21/70, 30%) respondents were included in the survey analytic sample.

Results: While the CARE Hotline was used for monitoring, 70 users completed a total of 1313 calls. We found that 94.06% (1235/1313) of calls were successful, and the average call time significantly decreased from the beginning of the monitoring period to the end by 32 seconds (Z score=−6.52, $P<.001$). CARE Hotline call log data were confirmed by user feedback; survey results indicated that users became more familiar with the system and found the system easier to use, from the beginning to the end of their monitoring period. The majority of the users were highly satisfied (90%, 19/21) with the system, indicating ease of use and convenience as primary reasons, and would recommend it for future monitoring efforts (90%, 19/21).

Conclusions: The CARE Hotline garnered high user satisfaction, required minimal reporting time from users, and was an easily learned tool for monitoring. This phone-based technology can be modified for future public health emergencies.

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KEYWORDS

Ebola; postarrival monitoring; interactive voice recognition

Introduction

The 2014-2016 Ebola epidemic in West Africa was an unprecedented public health emergency afflicting more than 28,000 people and claiming more than 11,000 lives [1]. The Centers for Disease Control and Prevention (CDC) extended international efforts to control and prevent disease spread in West Africa and implemented domestic measures to prevent the introduction and transmission of Ebola in the United States [2,3]. In late October 2014, CDC recommended postarrival monitoring of all travelers arriving to the United States from countries with Ebola outbreaks and called on state and local public health authorities to monitor travelers for signs and symptoms of Ebola at least once daily for 21 days following each traveler's last possible exposure [4]. The purpose of postarrival monitoring was to ensure that people with epidemiologic risk factors who became ill were identified as soon as possible after symptom onset to be quickly isolated, evaluated, and treated, if necessary [5].

In response to CDC's recommendation [6], state and local public health authorities quickly initiated programs to monitor all potentially exposed travelers arriving within their jurisdictions. To aid state and local public health authorities in postarrival monitoring and as part of a larger effort to engage with and educate travelers at a number of the US ports of entry, CDC provided all travelers arriving to the United States from countries with Ebola outbreaks with a prepaid cell phone with short message service (SMS) text capabilities [2,3]. The purpose of this was two-fold; first, to provide travelers with a means to connect with public health authorities in the event they did not have a cell phone and, second, to ensure that public health authorities had phone numbers for travelers in their jurisdictions.

State and local public health authorities utilized various reporting mechanisms, including in-person health checks, centralized call centers, SMS text reporting of symptoms, mobile apps, and Web-based reporting systems to collect the daily health reports [7-10]. Although the systems differed in approach, a common theme was the need for supplementary resources beyond routine funding, personnel, and technology for the rapid and effective establishment of monitoring systems [3,11,12].

This report focuses on an innovative monitoring system, the Check and Report Ebola (CARE) Hotline, which allowed travelers to report their daily health status to an interactive voice recognition (IVR) system. The CARE Hotline was developed through a collaboration between CDC and Innovative Support to Emergencies, Diseases, and Disasters (InSTEDD, a nonprofit technology organization based in Sunnyvale, California), with support from Skoll Global Threats Fund. The goal of the partnership was to provide state and local public health authorities with an efficient and effective tool that could be used to conduct monitoring. More specifically, the intended result was to build and deploy a system that allowed travelers to fulfill monitoring requirements and provided public health authorities with timely and accurate data that met the changing needs of the outbreak response. InSTEDD contributed their open-source technology, Verboice (IVR software) and mBuilder (SMS text software), to design the CARE Hotline interface.

The aim of this evaluation was to describe the usage characteristics and user experience of the CARE Hotline as a tool for postarrival monitoring. Similar telephonic monitoring systems have been used in other communicable and noncommunicable disease monitoring and surveillance activities [13-21]. High user satisfaction, usability, and adherence have been found in IVR, Web-based, and SMS text monitoring systems for chronic health conditions [18,21]. Low usability and adherence has been found in infectious disease medication monitoring in a resource-limited setting [14]. However, on the basis of our review of the literature, the usage characteristics and user experience of an IVR to conduct required monitoring in an emergency response are still unknown. To the best of our knowledge, this is the first report describing and evaluating a combined IVR and SMS system for postarrival monitoring for Ebola.

Methods

IVR Interface and SMS Feature

The CARE Hotline included a simple IVR interface with three prompts and an SMS feature that pushed text reminders to elicit travelers' participation. Users were provided with a phone number for the CARE Hotline and were instructed to call daily for monitoring. Users who failed to call into the system by 3:00 PM each day received an SMS reminder prompting report of health status. The CARE Hotline was developed with standard scripts, including an initial registration call script that was intended to provide users with information about the hotline, monitoring of symptoms, and to introduce them to the interface as well as the daily health report script. CDC and InSTEDD designed the health report script with the following three yes/no answer-format questions related to key monitoring requirements:

1. Have you taken your temperature today?
2. Is your temperature at or above 99.5º Fahrenheit?
3. Do you have other symptoms such as severe headache, muscle pain, weakness, diarrhea, vomiting, stomach pain, or unexplained bleeding or bruising?

Those who reported fever or symptoms were immediately transferred to a live person. Additionally, users could request to interact in real time with a person whether or not they exhibited symptoms. Lastly, scripts were created in English and French, the two most common languages of travelers arriving from outbreak countries.

CDC deployed a live version of the CARE Hotline on November 26, 2014, approximately 1 month after US public health authorities initiated their monitoring programs. This live version of the CARE Hotline was tested among CDC federal employees returning from deployments in outbreak countries. While the CARE Hotline project team managed the system, CDC's Occupational Health Clinic oversaw the monitoring of employees and and followed up with noncompliant users—users who failed to report their health status in a 24-hour period. Starting November 26, all returning CDC employees based in Atlanta were enrolled in the system and were instructed to call the CARE Hotline to submit their daily health reports. Health reports were collected through January 18, 2015. During that time, 70 employees used the system for monitoring. In addition to using the CARE Hotline to engage in monitoring, CDC employees were simultaneously required to report daily to their state or local public health authority.

Data Collection

While the CARE Hotline was being used as a monitoring tool by CDC employees, it generated a call log that summarized usage characteristics, including call length, frequency of calls, responses to the three prompting questions, and referrals to a live person. These data were used for the call log analyses.

CDC developed a Web-based survey using SurveyMonkey (SuveyMonkey Inc, San Mateo, California). The survey included

25 open- and closed-ended questions that assessed perceptions of the CARE Hotline, including ease of use, familiarity, confidence, and satisfaction. The closed-ended questions were categorical, dichotomous, or based on a 6-point Likert scale. The survey was pilot-tested using cognitive interviewing, and survey questions were revised based on feedback from matched CDC volunteers (CDC employees who returned from deployments in outbreak countries and fulfilled postarrival monitoring requirements using a different system than the CARE Hotline). The survey was distributed approximately 1 year after employees used the CARE Hotline. To reduce recall bias and encourage familiarity, survey respondents were prompted to call the CARE Hotline before completing the survey.

Participants were asked to provide their name when completing the survey to pair their survey responses to their call log data. The data collection was therefore confidential but not anonymous. The evaluation was reviewed and approved as a public health response program evaluation activity and not as research involving human subjects.

Sample

During CDC’s live test of the CARE Hotline from November 26, 2014, through January 18, 2015, a total of 70 employees were enrolled in the system for monitoring. Call log data from all users (n=70) were included in the analyses of the call metrics. All employees who used the system (n=70) were invited by email to complete the survey voluntarily. A total of 26 (37%) of the 70 eligible employees completed the survey, but 5 respondent surveys were excluded from the final analyses because of incomplete survey response, leaving an analytic sample of 21 (30%).

Analysis

Call Log Metrics

Call log data for all users (n=70) were analyzed in Microsoft Excel and SPSS version 21. Standard descriptive statistics were used to summarize all call log data (n=1313 calls). To compare average call lengths derived from the first three calls, after registration, and the last three calls, the nonparametric Wilcoxon signed-rank test was used since the data were not normally distributed. First, we used the Tukey method to identify extreme outliers in this set of call logs [22]. Extreme outliers are defined as those that are 3 times the interquartile range (IQR=59 seconds) for the upper (3rd quartile; 1 minute and 24 seconds) and lower (1st quartile; 25 seconds) quartiles. For all call log data (n=1313 calls), the upper bounds were determined to be 4 minutes and 21 seconds (3rd quartile + [3×IQR]). Therefore, for this mean comparison analysis, 12 calls lasting longer than 4 minutes and 21 seconds were removed from the call log data.

Survey Feedback

Quantitative survey data (n=21) were imported into Microsoft Excel for analysis. Standard descriptive statistics were used to summarize these data. Qualitative data were imported into Microsoft Excel, and an applied thematic approach was used; that is, raw data from open-ended fields were reviewed and common themes were coded by a single analyst and then enumerated and summarized.

Results

Call Log Metrics

Call data were pulled from the CARE Hotline call log. On average, the 70 users reported to the system for 16 days of monitoring and made 19 calls per user for a total of 1313 calls to the CARE Hotline. Of the total, 94.06% (1235/1313) of those calls were successful where users completed the IVR prompts and (1) reported that they were healthy (n=1208, 92.00% of all calls) or (2) reported they had fever and/or symptoms *and* were connected to a live representative (n=18, 1% of all calls) or (3) requested to be *and* were connected to a live representative (n=9, 1% of all calls). Of the total, 4.72% (62/1313) of calls were coded as unsuccessful in that users (1) did not complete the three IVR prompts (46/1313, 3.50% of all calls) or (2) were not connected to a live representative when reporting fever or symptoms (16/1313, 1.22% of all calls). By reviewing unsuccessful call logs, we noted two repeat behaviors related to the 62 unsuccessful calls: 74% (46/62) of users ended existing calls and called back within 2 hours to rereport healthy symptoms, and 26% (16/62) of users ended calls during the referral process to a live representative. Lastly, due to a technical error in late December 2014, time data for 1.22% (16/1313) of all calls were collected, but IVR prompt responses were not recorded and could not be retrieved. Therefore, we are unable to categorize those calls as successful or unsuccessful.

As expected, registration calls (n=92, users could register multiple phone numbers), which contained additional script, lasted longer than subsequent calls for an average of 2 minutes and 54 seconds. Therefore, the registration call was excluded from the Wilcoxon signed-rank test. A total of 67 users had at least 6 call records and were included in this analysis. This test required that users have a minimum of 6 calls to be included in the analysis; the average of the first three calls was compared with the average of the last three. For this Wilcoxon signed-rank test, we found that call time decreased for users (n=67, 402 calls included in this analysis) from the beginning to the end. The average call time for the first three calls was 1 minute and 14 seconds but was reduced to 42 seconds for the last three calls (Z score=−6.52, $P<.001$).

The majority of calls, excluding the initial registration call (747/1221, 61.18%), were made before 3:00 PM and, thus, there were only a total of 474 SMS reminders. Of the total, 24.1% (114/474) of SMS reminders were successful at nudging users to report to the system within 2 hours. The remaining 75.9% (360/474) did not increase user compliance within 2 hours. Administrators of the CARE Hotline in CDC’s Occupational Health Clinic were alerted to follow up 95 times during the live test. Alerts to follow-up occurred if users failed to submit their health report within a 24-hour period.

Survey Feedback

As users progressed in their monitoring period, they reported becoming more familiar with the system and their confidence in reporting accurately to the system increased. Overall, 19 of 21 respondents (90%) reported that the system was “very easy” (n=15) or “easy” (n=4) to use for monitoring.

Table 1. Key themes and illustrative responses.

Variable and theme	Response
Ease of use	
Simple instructions	The instructions were straightforward and answering the questions was easy
	Simple instructions, quick process, minimal fuss; automated and rapid
Easy system	Simple, easy task
	Easy due to use of technology in performing day-to-day tasks
	The process was easy to follow
Straightforward system	It was straightforward, and it worked
	Very straightforward and did not require much time investment to file accurate and timely reports
Overall satisfaction	
Easy, convenient, and unobtrusive	Easy to use and nonintrusive, so I could fit in my schedule without disruption
	Simple, easy to do, unobtrusive
	Given the required frequency of monitoring, the system could not have been easier or [more] convenient to use
	The overall process was not invasive and allowed me to monitor health while continuing with day-to-day activities
	Could get used to prompts and pattern, use it quickly and when it was convenient in my schedule
Effective solution	Very satisfied—I cannot think of changing anything to improve the process, technology, or system
	The hotline was easy to use and an effective way to monitor returning travelers
	I thought it was a great solution to the active monitoring requirement
Recommended improvements	
Recommendations (many respondents indicated no recommendations)	Develop a phone app
	Text option; ability to skip the introductory info[rmation] after, say, day 3
	I think something a bit simpler would be better, especially a text with instructions every day, to which someone could respond with one letter or word
	Texting may be even better than calling in and dealing with the prompts

More than three-quarters (17/21, 81%) noted they became more familiar with the CARE Hotline and the three prompts during their monitoring period; the remaining four could not remember. The majority (86%) of respondents reported feeling “very confident” (11/21) or “confident” (7/21) in submitting their first health report to the system; the remaining 3 (14%) felt “somewhat confident.” After using the system, confidence increased; all reported feeling “very confident” (17/21, 81%) or “confident” (4/21, 19%) in submitting their last report to the system.

Of the 21 respondents, 11 indicated receiving an SMS reminder. When asked about their experience with the SMS feature, all 11 participants indicated that this feature was “very helpful” or “helpful” in prompting them to submit a health report. Of the 11 respondents, 7 (64%) reported that without this feature, they would have missed a day of monitoring.

When asked to indicate their overall level of satisfaction with the CARE Hotline, all responded favorably; 90% (19/21) reported being either “very satisfied” (n=11) or “satisfied” (n=8), and 10% (2/21) reported being “somewhat satisfied.” Almost all (19/21, 90%) would recommend the system for monitoring. When asked to explain why they were satisfied, ease and simplicity were the most common themes. Users liked being able to call at their convenience, as well as the ability to move quickly through the prompts. The most commonly offered suggestion for improvement was to allow users to submit reports entirely via texting or a mobile app. Table 1 highlights qualitative responses that respondents provided for their ratings for the following variables: ease of use, overall satisfaction, and recommendations for improvement.

Discussion

Principal Findings

The CARE Hotline was quickly built, deployed, and tested by CDC employees as a monitoring system during the Ebola emergency response. Our evaluation of the live test demonstrated that the vast majority of CDC users were able to successfully engage in monitoring using the CARE Hotline. Additionally, they were adequately confident in their ability to use the system initially, becoming more confident over time. Users identified ease of use, convenience, and the unobtrusive nature of the system as main factors in their overall satisfaction. Users’ confidence with the technology and the ease of using the tool made the quick user adoption of the CARE Hotline feasible.

The tech components of the system required minimal funds; the hotline phone number, IVR, and SMS cost less than US $42 total to operate. Cost data are based on the establishment and use of the hotline number (2 lines for production and 2 lines for staging, costing US $1 per month for a total of US $12 for 3 months), IVR minutes (US $0.0085 per minute), and the number of SMS texts (US $0.0075 per SMS) sent. These ongoing costs appear less than other IVR systems that report US $0.23 per minute and US $0.05 per SMS [14].

Limitations

Although these findings are positive in terms of the user experience and the ability to quickly and successfully report to the CARE Hotline, we recognize the limitations in this sample. First, there was approximately a year lag time between engaging with the CARE Hotline and evaluating the user experience. However, attempts were made to reduce recall bias; users were provided with memory aids and guided through the CARE Hotline before completing the survey. Additionally, in the survey instructions, users were reminded that they were reporting their health status simultaneously to state or local public health authorities; they were prompted to only consider their experiences with the CARE Hotline when answering survey questions. Second, the final survey respondent analytic sample contained 30% of the CARE Hotline users. Although this is small, we believe that this is a fair response rate for survey data and that the responses obtained provide important insight into the user experience. Lastly, we recognize that CDC employees may differ from the general public and, therefore, recommend future testing among a more diverse audience to help confirm these preliminary findings of high acceptability and feasibility. Even though these results are preliminary and there are limitations, this system should be considered as a resource-saving alternative to human-driven monitoring systems such as call centers for future monitoring efforts that may have inadequate financial and human resources.

Considerations for Future Application

Beyond these results, several additional insights may be helpful when considering the use of a similar system in an emergency response. During the IVR development phase, CDC and InSTEDD followed an agile approach by managing the project iteratively and incrementally, with frequent conversations and short feedback loops. This encouraged stakeholder engagement, helped to confirm design decisions, and ensured high quality. CDC and InSTEDD developed and deployed early versions of the CARE Hotline within a condensed time frame. The CARE Hotline moved from an idea to a tested functional system within weeks.

The use of flexible, easy, and free open-source tools kept the development and launch costs low. The team relied on InSTEDD’s mBuilder and Verboice tools to integrate voice and SMS capabilities. These tools can be used off the shelf and allowed for customization to meet specific and evolving needs. Such free and open-source technologies can be used individually or as building blocks for larger solutions tailored to support future public health emergencies. Additionally, support from Skoll Global Threats Fund served as a catalyst for this effort and demonstrates the role philanthropy and established partner networks can play in helping even the largest institutions stay nimble and explore innovative techniques.

When designing an IVR system to support an emergency response, basic user requirements should be considered. IVRs require access to phone service. Landlines and mobile phones can be used to submit reports to the system, although mobile phones with text capabilities would be required of IVR systems that depend on SMS components for engaging or nudging users. IVRs require that users can easily access the system, input reports, and reply to text messages for systems that include SMS functionality.

When determining whether to deploy an IVR, audience demographics, including primary languages, should be considered. Nonetheless, IVRs can easily support various languages and dialects. When resources permit, call scripts can be translated and recorded by voice talent. Quality assurance measures ensure that the prompts are understood by native speakers and reflect differences between dialects.

Ultimately, the CARE Hotline was not adopted following the CDC live test for a number of reasons. State and local public health authorities had, by that time, implemented their own monitoring systems. In addition, monitoring strategies varied between states and even among local jurisdictions within a state as authorities tailored their systems to the local need. This complicated the deployment of a standardized and centralized monitoring system at the state or local level. There were also concerns about implementing a newly developed automated, technology-based system for Ebola postarrival monitoring before thoroughly evaluating its effectiveness and reliability.

Should states need to perform monitoring following communicable disease exposures in a future public health emergency, an IVR such as the CARE Hotline could be implemented on a state or federal level. Future administrators might consider additional mobile phone functionality such as graphic and audio file sharing. The system could be adapted for other public health response efforts, such as monitoring during contact investigations, for surveillance purposes, or for health education or promotion purposes [15,16]. Such a system could be programmed to share health information, including, but not limited to, emergency updates, instructions, reminders for medication, or prevention messaging for infectious disease outbreaks. As outlined by Patrick et al [16], evidence is emerging that supports the effectiveness of mobile phones for diagnosis, management, and treatment of disease, along with health promotion and prevention messaging. A high successful usage rate, positive user experience, and system adaptability are key for the potential deployment of similar systems in routine and future outbreak-related monitoring and surveillance efforts. The IVR described here might have applications far beyond postarrival monitoring for Ebola.

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Conflicts of Interest

None declared.

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Abbreviations

CARE: Check and Report Ebola
CDC: Centers for Disease Control and Prevention
InSTEDD: Innovative Support to Emergencies, Diseases, and Disasters
IVR: interactive voice recognition
IQR: interquartile range
SMS: short message service

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