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Original Paper

Rapid Creation of an Online Discussion Space (r/nipah) During a Serious Disease Outbreak: Observational Study

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Abstract

Background: During health emergencies, the people within affected communities ask many questions at a time when professional medics and health agencies are overstretched and struggling to cope. Our previous research has shown that, during the 2014-2015 West Africa Ebola crisis, volunteer-moderated online discussion forums were able to provide peer-to-peer reliable, trustworthy, and well-managed information. We speculated that with the right mix of epistemic and experiential knowledge, such a discussion forum could be set up rapidly during a future serious disease outbreak.

Objective: The aim of this study was to set up a peer-to-peer health information exchange forum within the shortest time possible after the emergence of a real outbreak of a serious infectious disease. An outbreak of Nipah virus in Kerala, India, in May 2018 provided the opportunity to test our theories.

Methods: We initiated a Nipah virus discussion forum on the platform Reddit, recruiting volunteer moderators from within the existing Reddit community. This facilitated posts and comments to the forum from genuine Reddit users. We gathered and analyzed data on the number of posts, comments, page views, and subscribers during the period of May 24 to June 23, 2018, by using the data analysis tools embedded in the Reddit platform.

Results: We were able to set up a functioning health information exchange platform by May 24, 2018, within two weeks of the index case and one week of the official World Health Organization verification of a Nipah virus outbreak. Over the following five weeks, the forum received a steady flow of traffic including posts (36) and comments (21) submitted, page views (840), and subscribers (33). On the busiest day, 368 page views were recorded. The forum provided information in the languages spoken in the outbreak region as well as in English on how the virus spreads, symptoms of the disease, and how to take measures to avoid contracting it. Information on government helpline numbers and frequently asked questions was also provided to the community at risk.

Conclusions: The delivery of a fully functional discussion forum within a short space of time during an actual health emergency demonstrates that our suggestion is fully practical. Our theory that Reddit could provide a suitable platform to host such a forum was upheld. This offers great potential for public health communication during future serious disease outbreaks.

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KEYWORDS

information science; internet; disease outbreaks; public health; behavior; communication

Introduction

Background

In a public health emergency when health care systems may be overwhelmed, the ability of affected communities to crowdsource reliable information could have a significant impact on the extent to which a disease outbreak might be contained or its spread slowed [1-3]. Funk et al [4] have theorized that behavioral changes might influence the spread of disease, and Funk and Jansen [5] have modeled the impact of peer influence on disease spread. Cole [6] has investigated how reliable, trustworthy, and timely public health information can be exchanged over peer-to-peer platforms, including in the event of a public health emergency, and how this might be best achieved by using platforms that are already widely used by the affected population—in particular, the already existing and highly popular information sharing platform Reddit. Her case study on the use of Reddit during the 2014-2016 Ebola virus outbreak in the West African countries of Sierra Leone, Liberia, and Guinea [7] suggests that such forums can provide a useful resource during disease outbreaks.

Near at Risk, Far at Risk, Real at Risk

Cole and Watkins [8] have identified three different stages through which people experience disease outbreaks: Real at Risk, Near at Risk, and Far at Risk. In each stage, how people seek out information and the type of information they require differs. Real at Risk information seekers are defined as being in close physical proximity to a person displaying symptoms or known to be infected. Near at Risk information seekers live in a region where cases have been recorded in locations they are likely to visit, requiring behavior modifications that will reduce their likelihood of becoming infected. Far at Risk information seekers are geographically distanced from outbreaks and in no real danger of contracting the virus. Closeness can be defined not only by geographical proximity to cases of the disease but also by intimacy and socioeconomic similarity to those affected [7-9]. Participation in online forums can lead participants to perceive themselves as being in a higher risk category than is actually the case [7-9], opening up interesting possibilities for spreading public health information and encouraging risk avoidance behavior to be adopted ahead of the actual arrival of a disease outbreak.

From Passive Absorption of Facts to Active Questioning

During the Far at Risk phase of the 2014-2016 Ebola outbreak, health information seekers were content to passively collect facts, statistics, and scientific information relating to disease characteristics and spread. During the Near at Risk and Real at Risk phases, however, interaction, discussion, and advice tailored to personal circumstances became increasingly important. The community came together in online forums to answer each other’s questions and provide advice, particularly during the latter phases of the outbreak when an increasing number of people had the experience of living with the disease [7].

When information on how to protect oneself from infection, how to recognize symptoms, and how to treat loved ones at home is provided through peer-to-peer online communities rather than through professional authorities, credibility of the information provided becomes vital [10,11]. Advice must be accurate if it is to be not only distributed but also acted on [6]. In online forums, the community can collaborate by upvoting material as well as posting it, making particular posts not only more visible but also adding to their credibility: users are more likely to trust information that other users have shown they also trust and value [7,12].

Credibility of Information

On the subreddit r/ebola, community collaboration allowed for credible and accurate information to be shared among those experiencing the crisis firsthand, while also providing factual information for those Far at Risk [8]. The quality of information presented on subreddits depended, however, not only on contributors who had expertise in the subject matter, but also on expert moderators who managed the forums and regulated the posts. These expert moderators use technical skills to code the subreddit and set automoderation tools that reduce the time burden on the human moderators by, for example, automatically removing posts that contain racist or sexist terms or profanity or those from media sources known to be sensationalist or biased. Equally important is experiential knowledge of the platform that enables a forum to scale up quickly in times of high traffic and recruit quickly new moderators who have specific skills, experience, and knowledge. For example, moderators of other forums on the same platform may have knowledge of local languages spoken in the affected region or of local conditions and facilities. Experiential knowledge of the platform is vital for knowing how to seek out individuals with these skills.

Lessons From Ebola

The Ebola virus public health emergency of international concern (PHEIC) of 2014-2016 led to high rates of morbidity and mortality that imposed a severe economic burden on West Africa but also provided a key insight into the information requirements of those in the midst of an epidemic and how a peer-to-peer information platform could address this. It showed that there are three linked requirements needed to set up and manage a forum: subject matter expertise, experience with the platform chosen for use, and technical ability, all of which are essential to enable a discussion forum capable of hosting thousands of users to be set up quickly in the wake of an unexpected and rapid-onset outbreak of infectious disease [7].

Existing sites such as Reddit that are widely used and already familiar to many users have the potential to become highly trusted platforms for sharing vital medical information during a pandemic, epidemic, or outbreak. They can provide information that is accurate and well regulated [6,7]. Prior to 2018, this hypothesis had not been tested during a real-life outbreak of a serious infectious disease. We had considered creating a subreddit dedicated to a disease outbreak in the hope of validating our theory but needed an actual disease outbreak to occur in order to test it in vivo.

Kerala Nipah Virus Outbreak

The opportunity to create such a subreddit arose in May 2018 [13], when an outbreak of Nipah virus (NiV), a viral infection causing severe flu-like symptoms with a case fatality rate of 50% to 75%, occurred in the Indian state of Kerala.

On May 19, 2018, the World Health Organization (WHO) confirmed that three people had died in Kozhikode District, Kerala State, India, due to NiV [14]. NiV is a zoonotic disease that can be transmitted to humans from animals such as pigs and bats (fruit bats of the Pteropodidae family are widely accepted to be the natural host), through direct human-to-human contact, or through consumption of contaminated foods, in particular fruits and palm sap contaminated with bat saliva or urine [15,16]. At the time of the Kerala outbreak, there was no vaccine for the disease, which could only be treated by supportive care [17].

To validate our hypothesis that sites such as Reddit can be a stable platform through which to share useful information (including medical advice, likely sources of infection, routes of primary and secondary transmission, and effective treatment options) with affected communities in the midst of a public health emergency, we aimed to build a subreddit dedicated to discussing the outbreak, from scratch, in as short a time as possible that could serve a genuinely at-risk community.

Reddit Use in Kerala

For our experiment to work, the population affected by the outbreak needed to be using Reddit prior to the outbreak. Kerala has a population of 34 million [16] and an above average level of affluence for India [18]; at the time, average income in the region was Rs 59,000 (US $850) per annum compared with Rs 38,900 (US $550) for India as a whole. Educational attainment is also higher than in surrounding regions; the literacy rate for Kerala was 94% compared with a national average of 74%. A subreddit dedicated to the region, r/Kerala, has been active since March 2008 [19]. At the time of the NiV outbreak, this forum had just over 4000 subscribers. Observation of the discussions taking place on the site suggested that most users were based in Kerala, and the forum serves the community rather than being an information site for visitors or tourists.

The NiV outbreak, therefore, offered an ideal opportunity to create an online health information forum on an existing and widely used platform that could potentially be taken up and used by a population Near at Risk to a serious disease outbreak.

Methods

Building a Forum

Our previous research [6-8] has indicated that forums for high-quality peer-to-peer information exchange during disease outbreaks work well when existing popular platforms are used and the forum moderators have experience in both the subject under discussion and the platform on which the discussion is hosted. We therefore aimed to build a suitable forum on an appropriate platform and recruit a moderator team to run it.

We chose to build the forum on Reddit, a news aggregator site that also hosts discussion forums. It is one of the world’s 20 most popular websites [20], allowing users to post content, comment on content, and vote on both posts and comments made by other users. Content is socially curated and promoted by site members through voting [21]. Reddit is composed of hundreds of thousands of individual subreddits—forums on specific topics—all of which share information and host discussions to which any reddit user is free to contribute. Our previous research has shown that Reddit can host huge discussions and is capable of rapid growth [7].

Each subreddit is monitored and managed by volunteer moderators who are able to set rules and remove posts and comments that are deemed inappropriate, offensive, or inaccurate (for example, those that contain information that is factually incorrect, use racist or sexist language or profanities, or are aggressive), resulting in an online space where useful and interesting information can be shared among users. Further research has shown that while the quality of the information on such forums is variable, on well-managed forums it can be scientifically accurate and in line with accepted medical practice [6]. When doctors were asked to rate the usefulness and accuracy of comments and posts, the ratings they gave the information validated the Reddit community’s perception of which contained the better information [7]. As such, we believe that Reddit has many characteristics conducive to ensuring the promotion of reliable, trustworthy, and high-quality information, including its voting structure, volunteer moderators, and complex system of trust markers [6,7].

The suggestion to set up r/nipah was initially made by an experienced reddit moderator, known by the username u/IIWIIM8, who had been interviewed during our previous r/ebola study [7] and remained in contact with the research team. This moderator suggested that a forum dedicated to sharing valuable content about events and the infection itself (such as symptoms and treatments) and responding to common queries through frequently asked questions (FAQs) would be beneficial to the affected community. The subreddit r/nipah was set up through the Reddit platform on May 24, 2018, by u/JenniferColeRHUK (one of the authors of this paper). The user u/IIWIIM8 was invited to become a moderator and provide technical and experiential expertise, with u/JenniferColeRHUK proving subject matter expertise if and when appropriate.

Recruiting a Moderator Team

Once the subreddit had been initiated, we next needed to recruit an effective group of moderators to help keep the forum running. Our previous study [7] had identified three distinct moderation tasks that needed to be covered by a moderation team (or a single moderator): subject matter expertise, technical expertise, and experience in Reddit’s norms and structure. We were able to access and draw on all of these through the Reddit community and construct an effective and efficient moderator team within a reasonably short time frame.

We set out to recruit a team of moderators that conformed to the skillset identified above and the group dynamic identified as most beneficial to enabling the emergence of collective intelligence [22], a form of crowd wisdom greater than the sum of its parts. Through a post made to r/CSShelp [23] we recruited u/nortonism, a CSS programmer willing to help with formatting the forum, in particular to help with setting up the AutoModerator, an inbuilt function that can automatically remove information posted by users that is insensitive (eg, racist language suggesting that lack of personal hygiene is responsible for the outbreak) or inaccurate (eg, comments that might suggest the virus is airborne if this is not the case). We invited u/rodomontadeferrago, a Reddit user who was posting useful information on r/Kerala, including a well-received FAQ, to provide subject matter expertise and later become a moderator. The additional moderators listed on the forum are the authors of this paper (u/Snowflake1000, u/breezehair, and u/roses1997) and a bot (u/BotBust).

We also approached posters who were posting information on the NiV outbreak, including information on its transmission and government responses to the outbreak, in r/India [24] and r/Kerala [25], directing them to the r/nipah subreddit. We asked them to cross-post (enabling content they posted to appear on more than one subreddit) and conferred Approved Submitters status on those providing high-quality information.

Data Collection

Data from the subreddit were collected, added to an Excel spreadsheet (Microsoft Corp), and analyzed (Multimedia Appendix 1). Data collection included the number of posts and details of each post by username, time and date, number of comments received, points received (average of upvotes and downvotes), user karma (posting history and rating), and whether the post was cross-posted.

Results

Platform Construction and Management

Drawing on Cole's [6,7] previous experience with Reddit (gained during the Ebola PHEIC of 2014-2016), a functioning health information exchange platform, the subreddit r/nipah, was set up on May 24, 2018. The first post, titled "Welcome to r/nipah" [26], introduced the subreddit as a place to "share reputable news items on Nipah outbreaks, factually correct scientific information about Nipah, and advice on what to do if you are concerned about outbreaks." The forum encouraged discussions between those affected and medical professionals in the local area or more distant.

The forum was constructed on the existing Reddit platform within 2 weeks of the index case and just 5 days after the official WHO verification of a NiV outbreak on May 19, 2018, following three deaths in Kerala [13]. This was within the first 10 days after the outbreak was announced, the prime time frame required for containment [1].

During the first week of the forum's existence, 18 posts were contributed by moderators and 5 spontaneous users from the Reddit community who simply wanted to share information and were not part of the research team, following requests for contributions on r/Kerala and r/India. Early posts included links to NiV fact sheets produced by the WHO and the US Centers for Disease Control and Prevention (CDC), news items on crematorium staff shunning NiV victim's bodies, and advice on food safety and personal hygiene. After a Reddit user asked whether they should seek medical diagnosis for a mild fever [27], information was provided on government helpline numbers in India. Links were also posted to responsible professional media coverage from agencies such as the Times of India. The forum had already been running for 4 days when the spread of the virus appeared to worsen: 15 people in Kerala were infected by May 28, 2018 [13].

Over the following 4 weeks, until June 23, 2018, when the outbreak was considered to be over [28], the forum received 36 posts and 840 page views (including 368 on the forum's busiest day, May 26, 2018). Posts linked to news items from reputable international sources such as WHO, Stanford University, and the Times of India giving scientific information about how the virus spread and how the outbreak was being managed by the local authorities. The forum provided information in local languages as well as English. Permanent links to government helpline numbers were posted and disease-specific FAQs—lists of questions frequently asked by posters, with answers provided—were developed.

The users of the forum expressed views that located them in the affected regions of India (eg, by stating where they lived or worked) and thus indicated that participants did include some Near at Risk candidates, although it was not possible to determine the location of all forum users.

Moderator Team

We recruited a diverse set of moderators who were male and female, aged 21 to more than 50 years, based in America and the United Kingdom with support from approved posters in India. The moderators displayed a diverse skillset covering technical expertise, subject matter expertise, and experience using Reddit. Two of this paper's authors (JC and CW) are sufficiently experienced Reddit users and moderators to be considered a genuine part of the moderation team; SE was a nonparticipant observer. Reddit users u/nortonism and u/IIWIIM8 (neither had an academic affiliation) ensured that only relevant posts and comments appeared on the subreddit, coded the flair categorizations for the posts, and organized the layout of the subreddit. A further moderator recruited from the Reddit community, u/rodomontadeferrago, provided subject matter expertise. The moderation team were all Far at Risk [8], geographically distributed between the United Kingdom and the United States. With the moderators regulating site content, the site was left open for Reddit users who were either experiencing or interested in the crisis to post material.

Posts Made to the Subreddit r/nipah

Across the 31-day time period between May 24, when the forum was set up, and June 23, when the forum users and local Kerala newspapers considered the outbreak to be over [29] (although the official WHO declaration was not made until 6 weeks later [28]), 36 posts were made to r/nipah. These consisted of 29 link posts (links to content posted on external websites such as news media, WHO, or CDC) and 7 self-posts (generally questions or comments that do not link to content hosted elsewhere) of which 3 were FAQs. The site gained 33 subscribers during this period. Self-posts included FAQs to help those who were Real at Risk assess the crisis and a medical query from someone in fear of having caught the illness. An external user also shared their suggestions for how to improve the subreddit site, such as a crackdown on jokes that some users might find inappropriate. When information was posted in Hindi, which none of the moderators spoke and whose quality they were therefore unable to verify, moderators sent a personal message through the Reddit internal mail system to one of the posters known to be based in India, u/Valarauko, asking for translation. A full translation was provided and posted on the site for the benefit of other users.

The 36 posts received an average score of 3 points per post (range 1-6) from the community, indicating an average ratio of 3 upvotes to every downvote received with a range of 60% to 100% upvoting (specific numbers of upvotes-to-downvotes are not available). A total of 113 points were recorded across all posts.

The forum received a reasonable amount of community interaction during the outbreak, including 21 comments made against the posts and 12 cross-posts to or from other subreddits including r/India, r/generalsciences, and r/medicine. Discussions under the top-level posts addressed the validity of articles posted on r/nipah, r/sciences, r/infectiousdiseases, r/Kerala, and r/EcoInternet.

Once the NiV outbreak was announced to have been fully contained in Kerala, on June 9, 2018, posting activity slowed down on the site. The final active post made within the lifetime of the outbreak, titled "Kerala bids musical farewell to Nipah virus—r/Kerala" [29], was posted on June 23, 2018. This was followed by a disclaimer post [30] explaining that the subreddit had been set up as part of an academic research project and inviting any other researchers to contact us to share data and findings.

Discussion

Principal Findings

The r/nipah subreddit does seem to have achieved its ultimate goal of creating a safe space for information exchange where people could refer to information relating to the NiV outbreak, make queries, and receive reputable responses. As far as we can ascertain, the content on the subreddit contained high-quality information, with no conspiracy theory posts or scaremongering. Genuine concerns were expressed and answered with useful information and advice. Very quickly, we had created the basis of what could potentially become a very useful public information platform.

In comparison with many subreddits, r/nipah attracted only a modest number of subscribers (33), however. This is likely to be due to the small-scale nature of outbreak and the fact that authorities handled the situation well. With the outbreak under control, there was little need for an unofficial information forum. Had the outbreak spread and the situation become more serious, we believe we had put in place the necessary platform architecture, information, and expertise needed to run the forum; however, there was insufficient opportunity to test this fully or assess the extent to which the forum made a measurable contribution to the management, progression, or containment of the outbreak.

Nonetheless, we feel that the Kerala NiV outbreak of 2018 provided an opportunity to study the efficacy of health solutions offered via Reddit. It allowed us to study a real outbreak in real time that occurred in an area where many people already used the forum, evidenced by the existence of both r/Kerala, a local community forum used by people living in Kerala, and r/India. This was a major difference from the Ebola outbreak studied in our previous research [7] where internet penetration in the affected region was low, and people did not, by and large, post on Reddit. The r/ebola community was almost entirely Far at Risk, while Real at Risk nongovernmental organization workers interviewed during the same study were not widely using Reddit. The r/Kerala community was, by contrast, Near at Risk with a realistic likelihood of a transition to Real at Risk and did use Reddit.

The heavier ratio of link posts to self-posts (4:1) seen on r/nipah is consistent with the pattern that we would have expected from our previous research [7,8], which is that when cases and perceived risk are low, information seekers are more interested in facts and statistics and are happy to passively receive information from the media and official sources but do not necessarily want to interact or discuss that information through two-way dialogues.

Spread of Conspiracy Theories

Unlike on other disease outbreak subreddits including r/ebola and r/zika, no conspiracy or openly negative posts were made on r/nipah that could have hindered its ability to maintain a safe space in which to discuss the events. This was possibly because there were no existing antigovernment or antitechnology narratives on which conspiracy theorists felt the need to jump; conspiracy theories on other forums tend to rely on preexisting narratives (eg, that the Sierra Leone government was prone to kill off voters in regions held by the opposition party, seen during the Ebola outbreak, or the narrative that genetically modified crops were responsible for the Zika virus outbreaks in South America [7]). This may be because, in contrast to the 2014-2016 Ebola outbreak, the Kerala NiV virus outbreak was small in terms of the geographic area affected and number of cases recorded and thus did not attract disruptive attention. Another reason might be that as the outbreak appeared to be handled well by the national government and health care system, there was little room for credible criticism.

By distributing tasks across a moderator team, with some taking on dedicated roles such as programming the AutoModerator function, pressure was taken off the team during a period when the site was likely to experience rapidly increasing traffic.

Location of Posters

One final observation of interest is that the profiles of users who posted and their activity on other subreddits suggests that more of them were Far at Risk than Near at Risk or Real at Risk. Even those who posted from within India did not seem to be within close proximity to Kerala, although they did express genuine concerns. This is, however, an assumption based on user activity observed: we cannot confirm the actual location of each user. An interesting avenue of future research would be an analysis of the geographic location of users, which may enable us to better understand the audience the subreddit attracted: did it truly serve those who were Real at Risk/Near at Risk of contracting NiV or only those who were Far at Risk but interested in the outbreak? These data would be crucial in helping to develop a site that would fully prove our theory. However, we also suggest that providing information to people ahead of their actual exposure to the virus, enabling them to learn about it, prepare for it, and consider how they might need to modify their behavior in the event of a closer outbreak, is unlikely to have any disadvantages and may help communities to remain calm during an escalating epidemic.

The results we obtained indicate a measure of success: a fully functional discussion forum was constructed swiftly within a short space of time, an effective moderator team was recruited, and although the number of subscribers and posts was small, the information provided was high quality. The self-posts and FAQs in particular stand as a good example of how the community came together on this platform. This was all achieved during an actual health emergency, proving our theory that such a delivery is practical and fully achievable. We believe that these results validate our idea that Reddit can be a suitable platform where those experiencing or interested in serious disease outbreaks can come together to share valuable information and advice regarding the crisis.

This research offers great potential for public health communication during future serious disease outbreaks, particularly if such a discussion platform could be supported by or linked to an existing trusted health brand such as ProMED or WebMD and used in conjunction with notifications of disease outbreaks to provide information on how best to react to known and expected events. Public communication at scale is completely feasible; well-moderated subreddits manage discussions with contributions from tens of thousands of users and tens of millions of readers.

Limitations

The study is limited by the resources available to the researchers and the information available on the Reddit users. We were not able to confirm, for example, the geographic location of the posters or of the Reddit users responsible for the page views and so cannot determine whether the majority were Far at Risk, Near at Risk, or Real at Risk. Access to such information in future studies would be advantageous.

The study was also limited by the low number of cases of NiV infections, which did not overstretch local health care systems. Despite the mortality rate of the virus being significantly high, with a 74.5% average case fatality rate [31], the Indian government was able to contain the outbreak rapidly. It is therefore somewhat unrealistic to compare r/nipah and the NiV outbreak with r/ebola, as the 2014-2016 West African Ebola outbreak lasted for more than 2 years and affected a much larger global area. The situation also differed in that the NiV outbreak took place in a middle-income country where there was much higher access to and use of the internet.

Comparison With Prior Work

This work draws largely on our own previous research into the potential use of peer-to-peer, self-regulated discussion forums (particularly those hosted by Reddit) during a PHEIC featuring a serious infectious disease with limited treatment options [6-8]. We are not aware of any other research teams that are currently examining the potential use of such forums during similar events or other public health emergencies and consider our approach to be unique.

Conclusions

We had previously theorized that we could use an online social networking platform such as Reddit to be a valuable knowledge exchange space in the event of an epidemic. The NiV outbreak created an opportunity for us to test this theory in real time, allowing us to set up the r/nipah subreddit, a space where people could come together in the time of crisis, be updated regularly with information regarding the virus, and receive advice on their concerns. Our results suggest that Reddit and sites like it can perform as platforms where medical and health information can be distributed, enabling people in need to communicate and discuss any issues encountered during a public health emergency. This could be an extremely efficient use of time, money, and other limited resources during future outbreaks, allowing such forums to deal with minor cases and queries regarding epidemics while leaving valuable professional resources free to deal with more urgent cases.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Spreadsheet of data captured from r/nipah.
[XLSX File (Microsoft Excel File), 27 KB - publichealth_v5i4e13753_app1.xlsx]

References

1. Outbreak Communication Planning Guide. Geneva: World Health Organization; 2008. URL: https://www.who.int/ihr/elibrary/WHOOutbreakCommsPlanngGuide.pdf [accessed 2019-06-05]
2. Glik DC. Risk communication for public health emergencies. Annu Rev Public Health 2007;28:33-54. [doi: 10.1146/annurev.publhealth.28.021406.144123] [Medline: 17222081]

3. Kittler AF, Hobbs J, Volk LA, Kreps GL, Bates DW. The Internet as a vehicle to communicate health information during a public health emergency: a survey analysis involving the anthrax scare of 2001. J Med Internet Res 2004 Mar 03;6(1):e8 [FREE Full text] [doi: 10.2196/jmir.6.1.e8] [Medline: 15111274]
4. Funk S, Gilad E, Watkins C, Jansen VAA. The spread of awareness and its impact on epidemic outbreaks. Proc Natl Acad Sci U S A 2009 Apr 21;106(16):6872-6877 [FREE Full text] [doi: 10.1073/pnas.0810762106] [Medline: 19332788]
5. Funk S, Jansen V. The talk of the town: modeling the spread of information and changes in behaviour. In: Modeling the Interplay Between Human Behavior and the Spread of Infectious Diseases. New York: Springer; 2013:93-102.
6. Cole J, Watkins C, Kleine D. Health advice from internet discussion forums: how bad is dangerous? J Med Internet Res 2016 Jan 06;18(1):e4 [FREE Full text] [doi: 10.2196/jmir.5051] [Medline: 26740148]
7. Cole J. Royal Holloway, University of London. The role of online discussion forums during a public health emergency URL: https://pure.royalholloway.ac.uk/portal/files/28632161/2017ColeJAPhD.pdf [accessed 2019-09-16]
8. Cole J, Watkins C. International employees' concerns during serious disease outbreaks and the potential impact on business continuity: lessons identified from the 2014-15 West African Ebola outbreak. J Bus Contin Emer Plan 2015;9(2):149-162. [Medline: 26642172]
9. McInnes C. Old wine in new bottles? Use of twitter by established UK news media during the 2014-15 West African Ebola outbreak. In: Social Media Use In Crisis and Risk Communication. Bingley: Emerald Publishing; 2018:135-154.
10. Jarvenpaa S, Cantu C, Lim S. Trust in virtual online environments. In: Hertel G, Stone DL, Johnson RD, Passmore J, editors. The Wiley Blackwell Handbook of the Psychology of the Internet at Work. Chichester: Wiley-Blackwell; 2017:13-30.
11. Sillence E, Hardy C, Briggs P. Why don't we trust health websites that help us help each other? An analysis of online peer-to-peer healthcare. 2013 Presented at: Proceedings of the 5th Annual ACM Web Science Conference; 2013 May 2; Paris p. 396-404. [doi: 10.1145/2464464.2464488]
12. Wang Z, Walther JB, Pingree S, Hawkins RP. Health information, credibility, homophily, and influence via the Internet: web sites versus discussion groups. Health Commun 2008 Jul;23(4):358-368. [doi: 10.1080/10410230802229738] [Medline: 18702000]
13. Chatterjee P. Nipah virus outbreak in India. The Lancet 2018 Jun;391(10136):2200. [doi: 10.1016/s0140-6736(18)31252-2]
14. World Health Organization. 2018 May 31. Nipah virus—India URL: https://www.who.int/csr/don/31-may-2018-nipah-virus-india/en/ [accessed 2018-12-21]
15. Doke O, Kale S, Mujawar FB, More P, More T. A report on Nipah virus. J Drug Delivery Ther 2019 Mar 15;9(2):449-452. [doi: 10.22270/jddt.v9i2.2378]
16. Chattu VK, Kumar R, Kumary S, Kajal F, David JK. Nipah virus epidemic in southern India and emphasizing. J Family Med Prim Care 2018;7(2):275-283 [FREE Full text] [doi: 10.4103/jfmpc.jfmpc_137_18] [Medline: 30090764]
17. World Health Organization. 2018 May 30. Nipah virus URL: https://www.who.int/news-room/fact-sheets/detail/nipah-virus [accessed 2018-12-21]
18. Ariyari S, Vijayan N, Sadanandan R. The first ever Nipah virus outbreak and the best possible response by a tiny state of India. In: Int J Infect Dis. 2018 Presented at: Proceedings of the International Meeting on Emerging Diseases and Surveillance; 2018; Vienna URL: http://imed.isid.org/downloads/OralPresentations2018.pdf [doi: 10.1016/j.ijid.2018.11.057]
19. Reddit metrics: r/Kerala. 2019. URL: http://redditmetrics.com/r/Kerala [accessed 2019-09-16]
20. Alexa topsites. URL: https://www.alexa.com/topsites [accessed 2019-09-16]
21. Rouse M. SearchCIO.com. 2016 Dec. What is Reddit? URL: https://searchcio.techtarget.com/definition/Reddit [accessed 2018-10-06]
22. Woolley AW, Aggarwal I, Malone TW. Collective intelligence and group performance. Curr Dir Psychol Sci 2015 Dec 10;24(6):420-424. [doi: 10.1177/0963721415599543]
23. r/CSShelp. URL: https://www.reddit.com/r/csshelp/ [accessed 2019-09-16]
24. r/India. URL: https://www.reddit.com/r/India [accessed 2019-09-16]
25. r/Kerala. URL: https://www.reddit.com/r/Kerala [accessed 2019-09-16]
26. Cole J. Welcome to r/Nipah!. 2018 May 24. URL: https://www.reddit.com/r/nipah/comments/8lw6j6/welcome_to_rnipah/ [accessed 2019-09-16]
27. u/defenceofthedota. Should I get myself checked out for mild fever?. 2018 May 02. URL: https://www.reddit.com/r/nipah/comments/8o0wvv/should_i_get_myself_checked_out_for_mild_fever/ [accessed 2019-09-16]
28. WHO: India's Nipah outbreak over. 2018 Aug 08. URL: https://www.reddit.com/r/nipah/comments/95x0j6/who_indias_nipah_outbreak_over_07aug18/ [accessed 2019-09-16]
29. u/Snowflake1000. Kerala bids musical farewell to Nipah virus. 2018 Jun 23. URL: https://www.reddit.com/r/nipah/comments/8t8bcw/kerala_bids_musical_farewel_to_nipah_virus_rkerala/ [accessed 2019-09-16]
30. u/Snowflake1000. Disclaimer: research activity on r/nipah. 2019 Aug 15. URL: https://www.reddit.com/r/nipah/comments/97j1bl/disclaimer_research_activity_on_rnipah/ [accessed 2019-09-16]
31. World Health Organization. 2018. Nipah virus outbreaks in the WHO South-East Asia Region URL: http://www.searo.who.int/entity/emerging_diseases/links/nipah_virus_outbreaks_sear/en/ [accessed 2019-09-16]

Abbreviations

CDC: US Centers for Disease Control and Prevention
FAQ: frequently asked question
NiV: Nipah virus
PHEIC: public health emergency of international concern
WHO: World Health Organization

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Review

Combining Nonclinical Determinants of Health and Clinical Data for Research and Evaluation: Rapid Review

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Abstract

Background: Nonclinical determinants of health are of increasing importance to health care delivery and health policy. Concurrent with growing interest in better addressing patients’ nonmedical issues is the exponential growth in availability of data sources that provide insight into these nonclinical determinants of health.

Objective: This review aimed to characterize the state of the existing literature on the use of nonclinical health indicators in conjunction with clinical data sources.

Methods: We conducted a rapid review of articles and relevant agency publications published in English. Eligible studies described the effect of, the methods for, or the need for combining nonclinical data with clinical data and were published in the United States between January 2010 and April 2018. Additional reports were obtained by manual searching. Records were screened for inclusion in 2 rounds by 4 trained reviewers with interrater reliability checks. From each article, we abstracted the measures, data sources, and level of measurement (individual or aggregate) for each nonclinical determinant of health reported.

Results: A total of 178 articles were included in the review. The articles collectively reported on 744 different nonclinical determinants of health measures. Measures related to socioeconomic status and material conditions were most prevalent (included in 90% of articles), followed by the closely related domain of social circumstances (included in 25% of articles), reflecting the widespread availability and use of standard demographic measures such as household income, marital status, education, race, and ethnicity in public health surveillance. Measures related to health-related behaviors (eg, smoking, diet, tobacco, and substance abuse), the built environment (eg, transportation, sidewalks, and buildings), natural environment (eg, air quality and pollution), and health services and conditions (eg, provider of care supply, utilization, and disease prevalence) were less common, whereas measures related to public policies were rare. When combining nonclinical and clinical data, a majority of studies associated aggregate, area-level nonclinical measures with individual-level clinical data by matching geographical location.

Conclusions: A variety of nonclinical determinants of health measures have been widely but unevenly used in conjunction with clinical data to support population health research.

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KEYWORDS

social determinants of health; socioeconomic factors; inequalities; population characteristics; social conditions

Introduction

Nonclinical Determinants of Health

Nonclinical determinants of health, which refer collectively to the social, behavioral, and environmental factors and contexts that influence patient health outside of health care settings, are of growing importance to health care delivery and health policy. In terms of individual care, unmet needs related to nonclinical determinants of health can influence patient nonadherence to health care recommendations, limit patient-provider communication, exacerbate health conditions, and require significant time and organizational resources to address [1]. Moreover, nonclinical determinants of health needs are common. Estimates suggest that as many as half of primary care patients in the United States have unmet social needs [2,3]. For health care organizations, nonclinical determinants can inform risk stratification or patient segmentation efforts as health systems work to develop and target interventions and outreach appropriately [4,5]. From a health policy perspective, the nonclinical determinants of health illustrate disparities within the current US health system, many of which can only be addressed through policy interventions [6]. As such, health care organizations and policy makers are becoming more attentive to nonclinical determinants of health, as evidenced by initiatives from large, innovative health systems [7,8] and the specific screening and service linkage requirements in the Centers for Medicare and Medicaid Services Accountable Health Communities program [9].

The Potential Utility of Combining Nonclinical Determinants with Clinical Data

Concurrent with growing interest in better addressing patients' nonmedical issues is the exponential growth in availability of data sources that provide insight into the nonclinical determinants of health. Data potentially relevant to nonclinical determinants range from detailed individual-level observations (such as shopping behavior collected through a grocery store's rewards application) to social networks and area-level measures of climate, built environment, or policy environment [10]. Numerous researchers and commentators see vast potential for indicators derived from these data to improve both the health care system and individual patient care [11-13]. In particular, the greatest gains might be realized using nonclinical determinants of health data in conjunction with clinical data sources, such as electronic health records (EHRs) and clinical registries [10]. These novel combinations of data could provide new insights into patient risk behaviors, factors complicating care delivery, population-level health assessment, health system evaluation, provider decision making, and more [14,15].

However, within this context of increasing availability of nonclinical determinants data, it is not widely understood which nonclinical determinants of health constructs and indicators are supported by the literature as useful for health services and policy research. Therefore, the purpose of this review was to characterize the state of the existing literature on the use of nonclinical health indicators in conjunction with clinical data. Specifically, we sought guidance on the domains of determinants (eg, socioeconomic status [SES] or built environment), data sources (eg, population registries and US Census data), and specific measures (eg, area median household income) that are necessary to characterize the nonclinical determinants of health for use in combination with clinical patient-level data. Review findings will be used to guide the development of a population health data commons that will link to comprehensive, community-wide clinical information.

Methods

Overview

We undertook a rapid review [16] of the published literature and relevant policy reports to support our institution's broader project of developing the data architecture and governance policies necessary to create a data commons for clinical and nonclinical determinants of health information. Rapid reviews are literature reviews that are limited in scope and have a shorter time frame, typically up to 6 months [16]. Our institution's broader initiative to develop a data architecture was in direct response to high-priority funding focused on the opioid epidemic and needed feedback from the review team within a few months. The information obtained from this rapid review informed the overall architecture of the system and corresponding metadata dictionaries and prioritized data for inclusion.

Search Strategy

For the purpose of this review, we adopted a broad definition of nonclinical determinants of health that included individual-level behaviors, social contexts, physical environments, and health policies [6,17-19]. We operationalized *environment* to refer to different levels, such as a community, neighborhood, or family [20]. We took this approach to reflect the wide variation in potential use cases and research questions that could benefit from combined nonclinical determinants and clinical data.

Study Eligibility

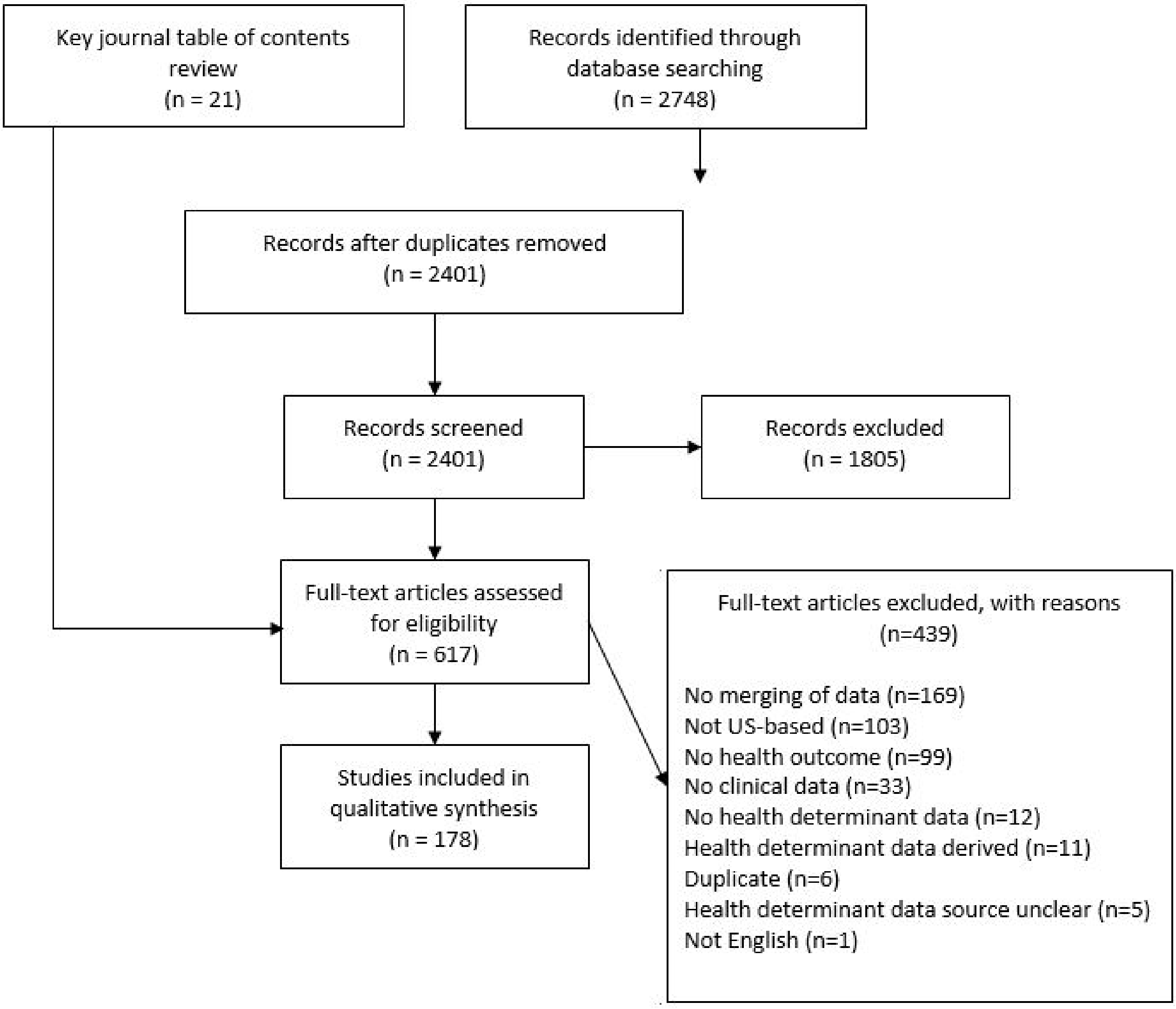
Articles and reports describing the effect of, the methods for, or the need for combining nonclinical determinants data with clinical data were eligible for inclusion. For this review, we defined clinical data as any patient-level data that were generated by health care encounters (eg, EHR data, claims, discharge records, immunization records, cancer or other disease registries, or genomic data). We did not consider public health surveys (eg, the National Health and Nutrition Examination Survey) to be clinical data. We did not limit study eligibility by study type and allowed for the inclusion of any study design and nonempirical expert commentaries. Only articles from peer-reviewed publications or reports from governmental agencies and grant-making organizations were eligible for inclusion. We limited the literature to English-language studies published in 2010 or after to reflect the widespread clinical information system adoption resulting from the introduction of the Health Information Technology for Economic and Clinical Health Act.

Information Sources and Search Terms

The primary search concepts were nonclinical determinants of health and clinical data. Although there are numerous specific nonclinical determinants of health to make the search and screening manageable in the short amount of time available for a rapid review, we used keywords and Medical Subject Headings terms such as social determinants or factors, socioeconomic factors, behavioral factors, health disparities, environmental exposure, and exposome, a specialized term referring to the measure of all lifetime exposures of an individual and how these exposures relate to health. For the clinical data concept, we used terms such as EHR, electronic or computerized patient and medical data, medical order entry systems, and decision support systems. We selected these concepts based on several key reviews and reports [17,21,22]. Multimedia Appendix 1 provides the full search strategy. We searched 2 databases, MEDLINE (via Ovid) and Web of Science, in April 2018.

All English-language articles from 2010 to April 2018 were exported to EndNote Version 8 citation management software (Clarivate Analytics). In addition, we manually reviewed the articles cited within selected articles, the table of contents from key journals (Multimedia Appendix 1), and the websites of the World Health Organization, Agency for Healthcare Research and Quality, National Institutes of Health, the National Academy of Medicine, and the Robert Wood Johnson Foundation for citations to relevant articles. We elected to search the websites of these governmental and nonprofit organizations in particular because of their focus on nonclinical determinants and population health. If the report summarized or presented previously published findings, we obtained those citations. The initial search yielded 2748 unduplicated records from the database search and 21 records from table of contents screening of key journals and website review (Figure 1).

Figure 1. Diagram of articles reviewed for inclusion and qualitative synthesis.



Study Selection

First, we screened the titles and abstracts of all records retrieved from the search. The primary goal of title and abstract screening was to exclude all non-US–based articles and articles with no indication of a focus on nonclinical determinants of health combined with clinical data. A total of 4 members of the research team first conducted a joint screening session on a random selection of citations to establish operational definitions and develop a cohesive screening approach. The team members then independently reviewed the title and abstract for each record to arrive at the included set. Our primary screening based on title and abstract resulted in 617 records for full-text review (Figure 1).

The research team members then independently read the full text of each article and determined its inclusion status on a randomly selected approximately 10% subsample from the 617 records identified from primary review. Agreement on inclusion status for the 10% subsample was kappa=0.70. The research team resolved differences by consensus in a joint reading session and independently reviewed the remainder of the articles. We retained articles for inclusion in the review if the article described the measurement or data source of at least one nonclinical determinant of health, which eliminated articles on technical architectures or database design issues that did not describe actual measurement. Owing to the study focus on nonclinical determinants and clinical data source linkages, we excluded articles in which the only nonclinical determinants of health measures were derived from clinical data (eg, insurance status or smoking history recorded within an EHR). Nonclinical determinants of health measures had to be derived from information systems, repositories, or collection methods apart from a clinical information system, including data from population surveys, epidemiologic registries, and US Census data. Furthermore, because our focus was on the use of these data for research, we limited inclusion to articles that used nonclinical determinants to describe, explore, or relate to a health outcome (eg, disease, condition, health status, and utilization). In addition, we reassessed each full-text article according to the exclusion criteria used for the initial title and abstract screening (ie, non-US–based articles or no focus on nonclinical determinants of health and clinical data). A total of 178 articles met the inclusion criteria after full-text review.

Data Abstraction

An initial codebook was established, and after joint coding and discussion on a subset of articles to ensure consistent and calibrated data collection, the reviewers independently abstracted and coded relevant data elements from the full text using a standardized data collection instrument. We developed and refined the data collection instrument in light of the articles read jointly in the previous steps. We abstracted the measures, data sources, and level of measurement (individual or aggregate) for each nonclinical determinant of health reported. To organize the diverse set of reported nonclinical determinants into meaningful groups, we created domains based on a combination of existing conceptual frameworks and definitions [22-24]. We did not rely on any single framework to ensure that we captured a breadth of nonclinical determinants of health concepts and not only those of greatest interest to US policy makers and researchers. The domains are summarized in Table 1.

Table 1. Nonclinical determinants of health measurements by domain.

Nonclinical determinants domain	Example measures
Socioeconomic status and material conditions	Income, poverty, access to food, employment, living conditions, race and ethnicity, gender, insurance status
Behaviors	Smoking and tobacco use, diet, illicit substance use, alcohol use, medication adherence, physical activity
Built environment	Transportation, sidewalks, walkability, buildings
Natural environment	Air quality, pollution, climate, greenspace
Public policies	Health policies, social policies, laws, regulations
Health services and conditions	Access to health care, utilization, health literacy, disease prevalence
Social circumstances	Family, social support, caregivers, marital status, civic participation, community stigma

Furthermore, we grouped the reported study populations according to the key defining characteristics for inclusion in the study: geographic location, population focus (eg, Medicare enrollees, females only, and members of a specific racial or ethnic group), health condition of interest, or organization (ie, the study was focused on individuals who were part of the same health system or insurance plan). We also abstracted the study outcome, which we grouped into the broad categories of utilization, disease or health condition status, mortality, behaviors, risk scores, multiple outcomes, and all others. Other data elements that we abstracted include study design, type of clinical data source, use of census measures, and geographic level of measurement (for aggregate measures).

Results

Primary Findings

A total of 178 articles reported combining nonclinical determinants of health with clinical data (Multimedia Appendix 2 [25-145]). The most common source of clinical data was EHRs (62.9%; 112/178), followed by claims or discharge data (20.2%; 36/178) and disease registries (19.1%; 34/178). Approximately one-third of the articles (34.3%; 61/178) focused on utilization outcomes, and more than one-fourth (27.0%; 48/178) treated disease or condition status as the outcome. Among studies in which disease or condition status was the outcome, health status indicators were commonly related to body mass index or obesity, asthma, and diabetes. A common health condition (eg, diabetes and cancer) defined the study population for the majority of articles (53.9%; 96/178). One-fifth of studies included children in the study sample.

Included articles contained a mix of determinants measured at the aggregate (50.0%; 89/178) and individual (29.2%; 52/178) levels, with many studies using measures at both the aggregate and individual levels (20.7%; 37/178). Among the articles that included any aggregated measures, the geographic level tended toward smaller areas, with 43.6% (55/126) using areas smaller than a ZIP code (eg, a census tract) and 2.3% (3/126) using ZIP code–level measures. Articles with aggregated measures relied heavily on US Census Bureau data (81.7%; 103/126). Individual-level measures typically relied on questionnaires or supplemental screening (eg, studies by Sheppard et al [146] and Hall et al [147]). The literature appeared to be growing over time, as the number of articles meeting our inclusion criteria generally increased annually from ten articles in 2010 to almost forty in 2018.

The articles collectively reported on 744 different nonclinical determinants of health measures (Multimedia Appendix 3). The majority of articles reported using multiple measures as independent variables (Multimedia Appendix 4; however, several articles used existing or created new indices or composite measures (Multimedia Appendix 5). Most indices intended to summarize the SES and material conditions domain using various measures of income, employment, housing conditions, or other material deprivation. Below, we describe specific findings for each domain of nonclinical determinants.

Socioeconomic Status and Material Conditions

Although the literature reflected all 7 of our identified nonclinical determinants of health domains, measures from the SES and material conditions domain dominated the literature, with 89.9% (160/178) of all articles including measures from this area. More than half of articles (57.9%; 103/178) used determinants from only a single domain, and if only 1 domain was reported, it was again largely from the SES and material conditions area. When articles reported on more than 1 domain, the additional domain was also most frequently an SES and material conditions measure.

Income, education, employment, and race and ethnicity-based measures were the most common approaches to representing this domain in the literature. Moreover, measures were highly variable and nuanced. For example, articles reported income as annual household income (eg, a study by Toledo et al [148]), mean household income (eg, a study by Seligman et al [149]), median household income (eg, a study by Grimberg et al [150]), or by various poverty measures (eg, studies by Ye et al [151], Kanzaria et al [152], and Patzer [153]). Similarly, multiple articles used the Gini coefficient to describe income inequality (eg, a study by Wallace [154]). Likewise, articles expressed employment status variously as employed (eg, a study by Shuman et al [155]), unemployment (eg, a study by Tanenbaum et al [156]), seasonal status (eg, a study by Castaneda et al [157]), job class (eg, a study by Eapen et al [158]), hours worked (eg, a study by DeMaria et al [159]), or employment rates by different age groups (eg, studies by Grimberg [150] and Wu [170]).

Behaviors

All identified studies combining behavioral data with clinical data sources involved individual-level measurement (Multimedia Appendix 2), and nearly all (90%) in combination with EHR data. Current or historical substance, alcohol, or tobacco use [147,155,161-168]; self-care behaviors [169-171]; and self-reported physical activity levels and nutrition were commonly reported measures in the behaviors domain [147,172,173].

Built Environment

The built environment domain included articles with measures ranging from a detailed description of neighborhood aesthetics [169] to traffic volume [174] and land use [175]. Measures were predominately at the aggregate level, and compared with articles with other domains, a higher proportion of articles considering built environment factors listed disease or condition status as outcomes.

Natural Environment

Articles with measures related to the natural environment domain measured air pollution and quality [176-179], climate and altitude [179,180], and various hazardous exposures [147,181,182]. This small set of articles linked these measures mostly to EHR and registry data sources.

Public Policies

The search strategy only identified 2 articles that linked public policy to clinical data sources. Achkar et al [183] combined state-level policy dates with prescription drug monitoring system usage data in an interrupted time series. Blosnich et al [184] used multiple measures to determine sociopolitical climate for hate crime protection in relationship to mental health status for transgender US veterans.

Health Services and Conditions

The health services and conditions domain exhibited substantial variation in measures. Aggregate measures of health services and conditions included both the extent of a particular condition within an area (eg, infectious disease incidence rates [185], percent of population reporting a disability [186], or obesity prevalence [151]) and measures of the supply of providers and facilities within an area (eg, studies by Xiao et al [162], Beck et al [187], Roth et al [188], and Newman et al [189]). Measures reported on an individual basis included travel time and distance to health care provider [190,191]. Unique to this domain, variables such as emergency department overcrowding [192] and hospital quality [193,194] were measured at a facility level.

Social Circumstances

Social circumstances was the second most common domain (25%) in the article set, and the most commonly employed measure was an indicator of a patient’s marital status, living arrangements, or family composition (eg, studies by Wu et al [170], Dupre et al [195], and Newgard et al [196]). Some measures moved toward deeper categorization of these arrangements by specifically looking at intimate partner violence or family conflict dynamics (eg, studies by Valentine et al [197] and Schuler et al [198]). Additional social circumstances reflected community stigma [190], social cohesion [169], self-reported social support [199], and structural racism [200].

Discussion

Summary of Findings

In this review, we sought to describe the extent to which existing research has combined numerous nonclinical determinants of health measures with different clinical datasets to explore a variety of health outcomes and conditions. Using domains derived from several established frameworks, we identified a comprehensive, but unevenly distributed, representation of nonclinical determinants domains across included studies. Measures related to SES and material conditions were most prevalent, followed by the closely related domain of social circumstances, reflecting the existing widespread availability and use of standard demographic measures such as marital status, education, race, ethnicity in public health surveillance. Although used less frequently in included studies, nonclinical determinants of health measures related to the domains of the built environment, the natural environment, and public policies may indicate a small but growing research base connecting these higher-level determinants with clinical data.

Comment on Findings

We do not contend that any domain of nonclinical determinants is the most important; although different determinants arguably have varying importance or relative value, we could not assess the *value* of every reported measure within the scope of this study. Using the existing literature as a guide, measures reflective of SES and material conditions may be an appropriate initial focus for any work seeking to combine nonclinical determinants of health data with clinical data sources. The frequency with which this domain appears in the literature suggests it is a reasonable starting point for future work in this area that may be applicable to numerous different outcomes. Within this domain, income or lack of income was the most common measure, which is appropriate, given that multiple studies support income as an important determinant of health [201]. In addition, employment and education were common measures in the literature, conceptually distinct from income [202,203], and are supported by expert panels as key nonclinical determinants of health measures [204]. Conversely, a future area of focus may be where the literature is not well-developed (eg, housing and housing stability metrics). In addition, measures derived from race and ethnicity also appeared frequently in the literature. However, patient race and ethnicity are commonly recorded as data elements in routine clinical practice, and many sources of clinical data may already contain these data. Future work might explore the use and role of measures related to race and ethnicity that are less commonly recorded in clinical contexts, such as racism or cultural assimilation, but are significant nonclinical determinants of patient health.

Of potential further value, the SES and material conditions domain also had the largest number of indices and composite measures. Indices may be particularly useful for classification studies [203]. However, indices and composite measures have limitations as well. Indices developed in other countries may not be applicable to US populations, indices that were developed to measure specific constructs may not be applicable to all research studies, and indices and composite measures by design obscure the relationships between individual component measures [202,203].

Nonetheless, the literature in this area may be largely colored by the availability of nonclinical determinants of health data. As noted, most articles used data collected by the US Census Bureau. On the one hand, Census data have the dual advantages of longitudinal data and small area measurement. On the other hand, limitations exist with regard to the accuracy of some Census measures [205], and many measures are probability-based samples with errors around point estimates [206]. Problematically, the extent to which researchers consider the imprecision of measures in their analyses is not always immediately obvious. In addition, although clearly valuable, Census data do not readily, or thoroughly, extend to all nonclinical determinants of health domains. With Census data, nonclinical determinants of health related to SES and material conditions are well described, as are those related to the built environment and social circumstances, albeit to a lesser extent. However, other nonclinical determinants of health are largely unmeasurable using Census data (eg, person-level SES data and housing stability) and require either unique data collection or consideration of sources typically not used by health services and policy researchers. As more data sources become publicly and freely available, the distribution of studies using Census and non-Census sources may become more balanced and, in turn, highlight the growing potential to combine additional nonclinical determinants of health domains with clinical data. Similarly, the use of publicly available nonclinical determinants of health data sources is a reflection on the lack of relevant social determinant and social risk factors data currently captured in clinical information systems. Reliance on Census measures may further decrease as more individual-level measures of social risk are included in clinical datasets through wider implementation of social determinants of health (SDoH) screening tools [207,208] and collection of select social measurers in EHRs [209].

Articles included in this review reported both combining individually measured nonclinical determinants of health with clinical data sources (eg, measures of social support obtained by survey merged with EHR data) as well as combining aggregate, area-level measures with individual-level data sources through common geographical location (eg, applying area-level measures such as median household income to individual patients in an EHR, matched by patient address). In our study, the latter approach was more common. The various individual-level nonclinical determinants of health measures, such as transportation needs or social support, are consistent with the medical concept of a social history and express individual needs or resources [210]. The appropriateness of aggregate, area-level measures applied to individuals in the case of public policy is straightforward, as policy within a geographical jurisdiction is (at least theoretically) universally applied. However, the intention and reasoning for the differing levels of measurement linked to clinical data requires clear articulation for the other nonclinical determinants of health domains because characteristics of the aggregate cannot be attributed to the individual. For example, individuals residing within a high-poverty geographic area may not be themselves living in poverty; in fact, it is possible they are living well above the poverty line. When combined with individual-level data, aggregate or area-level measures are reflective of individuals' situations and contexts but may not accurately capture individual circumstances [211-213]. As opportunities increase to link both aggregate-level and more comprehensive individual-level nonclinical determinants indicators (eg, derived from social media data, financial records, and surveys), the literature would benefit from a stronger articulation of the theoretical and methodological choices for levels of linkage with clinical data that to best explains the relationships between social determinants and health outcomes. Moreover, this growing data availability increases opportunities to empirically explore the value of combining individual and area-level SDoH data in explaining outcomes relevant at different levels of intervention, such as provider decision making, population health management, and research.

Previous reviews have commented on the frequent lack of theoretical justification for measurement choices and strategies [214,215]. The level of theoretical justification among the articles included in this review was highly variable. At one end of the spectrum, numerous articles provided extensive justification for selected constructs and measurement strategies (eg, studies by Valentine et al [197] and Schuch et al [216]). These articles tended to be those specifically interested in understanding the role of nonclinical determinants in influencing health outcomes. Other articles used nonclinical determinants of health measures as known confounding factors to be controlled and as such provided less explication and interpretation. Although many nonclinical determinants measures are, indeed, important and widely used confounders in analyses of health-related outcomes, it may be fruitful for future research in this area to provide more thoughtfully considered rationale for the selection of the nonclinical determinants used and how they may relate to the health outcome of interest. For example, income is reflective of the money received over a period of time by an individual or family. However, using income as a catch-all control measure may fail to capture the nuances and significant theoretical implications. For example, individuals and families have differing sources of income, such as salary versus investment, overall income fails to account for expenditures, and how income varies from others in society (ie, inequalities) may have stronger relationships with the health outcome of interest [217-219].

This review has several limitations. Although we grounded our categorization of the multiple nonclinical determinants of health in existing frameworks, other authors have grouped determinants in markedly different ways, thereby inhibiting direct comparisons with previous work. Differences may be most pronounced in our domain of SES and material conditions, which tended to be more expansive than in other frameworks. In addition, our search strategy undoubtedly undercounted articles describing the linkage of public policy and clinical data sources. Linking policy data to clinical records is very common in health policy, health services, and health economics research. However, our search strategy did not locate such articles because these disciplines tend to focus on the role of policy change, instead of framing public policy as a social determinant. Similarly, health services and conditions may also be undercounted because these measures may not be presented as measures of nonclinical determinants of health. Regardless, as our objective was focused on identifying measures, our smaller set of articles was still representative of the whole within these 2 domains. Also, our strategy excluded articles that did not merge nonclinical determinants of health data with clinical data. This requirement eliminated both articles that leveraged single information systems (such as EHRs) that already included nonclinical determinants of health measures, as well as articles focused solely on the measurement and impact of the nonclinical determinants of health. Similarly, our approach was focused on data that were linked to clinical information systems; as such, we do not discuss social factors or risks that may be inferred from clinical data (eg, homeless or transportation barriers) or that could be extracted from narrative texts in clinical documents. In addition, we do not comment on the appropriateness of measure choice, level of measurement, or linkage strategy. Finally, our review cannot be generalized to settings outside the United States.

Conclusions

In conclusion, this review represents a comprehensive synthesis of existing attempts to link nonclinical determinants of health indicators with clinical data. Characterizing the work done so far in this area is an important first step in guiding future attempts to harness nonclinical determinants of health data for population health management initiatives. A better understanding of the types of determinants, data sources, and measures used successfully to integrate nonclinical determinants of health indicators with clinical and administrative health services data can help to shed light on feasibility, best practices, and future need in this important, emerging arena of research.

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Authors' Contributions

JV conceived the study. RH and JV designed the search strategy. RH conducted the literature search. EG, KA, AB, and JV extracted data. EG, KA, AB, RH, and JV drafted the manuscript and revised for critical content. All authors had final approval of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Search strategy.
[PDF File (Adobe PDF File)131 KB - publichealth_v5i4e12846_app1.pdf]

Multimedia Appendix 2
Characteristics of literature on nonclinical determinants of health used in combination with clinical patient-level data.
[PDF File (Adobe PDF File)104 KB - publichealth_v5i4e12846_app2.pdf]

Multimedia Appendix 3
Social determinant of health measures reported in the literature.
[PDF File (Adobe PDF File)130 KB - publichealth_v5i4e12846_app3.pdf]

Multimedia Appendix 4
Combinations of social determinant domains reported by article.
[PDF File (Adobe PDF File)253 KB - publichealth_v5i4e12846_app4.pdf]

Multimedia Appendix 5
Composite and index measures by social determinant of health domain.
[PDF File (Adobe PDF File)165 KB - publichealth_v5i4e12846_app5.pdf]

References

1. Fiscella K, Epstein RM. So much to do, so little time: care for the socially disadvantaged and the 15-minute visit. Arch Intern Med 2008 Sep 22;168(17):1843-1852 [FREE Full text] [doi: 10.1001/archinte.168.17.1843] [Medline: 18809810]
2. Page-Reeves J, Kaufman W, Bleecker M, Norris J, McCalmont K, Ianakieva V, et al. Addressing social determinants of health in a clinic setting: the WellRx pilot in Albuquerque, New Mexico. J Am Board Fam Med 2016;29(3):414-418 [FREE Full text] [doi: 10.3122/jabfm.2016.03.150272] [Medline: 27170801]
3. Vest JR, Grannis SJ, Haut DP, Halverson PK, Menachemi N. Using structured and unstructured data to identify patients' need for services that address the social determinants of health. Int J Med Inform 2017 Nov;107:101-106. [doi: 10.1016/j.ijmedinf.2017.09.008] [Medline: 29029685]
4. Kangovi S, Barg FK, Carter T, Long JA, Shannon R, Grande D. Understanding why patients of low socioeconomic status prefer hospitals over ambulatory care. Health Aff (Millwood) 2013 Jul;32(7):1196-1203. [doi: 10.1377/hlthaff.2012.0825] [Medline: 23836734]
5. Kasthurirathne SN, Vest JR, Menachemi N, Halverson PK, Grannis SJ. Assessing the capacity of social determinants of health data to augment predictive models identifying patients in need of wraparound social services. J Am Med Inform Assoc 2018 Jan 1;25(1):47-53. [doi: 10.1093/jamia/ocx130] [Medline: 29177457]
6. Solar A, Irwin A. World Health Organization. 2010. A Conceptual Framework for Action on the Social Determinants of Health URL: https://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf [accessed 2019-08-13]
7. Deloitte US. 2017. Social Determinants of Health: How Are Hospitals and Health Systems Investing in and Addressing Social Needs? URL: https://www2.deloitte.com/content/dam/Deloitte/us/Documents/life-sciences-health-care/us-lshc-addressing-social-determinants-of-health.pdf [accessed 2019-08-13]
8. Chaiyachati KH, Grande DT, Aysola J. Health systems tackling social determinants of health: promises, pitfalls, and opportunities of current policies. Am J Manag Care 2016 Nov 1;22(11):e393-e394 [FREE Full text] [Medline: 27849349]
9. Alley DE, Asomugha CN, Conway PH, Sanghavi DM. Accountable health communities--addressing social needs through medicare and medicaid. N Engl J Med 2016 Jan 7;374(1):8-11. [doi: 10.1056/NEJMp1512532] [Medline: 26731305]
10. Weber GM, Mandl KD, Kohane IS. Finding the missing link for big biomedical data. J Am Med Assoc 2014 Jun 25;311(24):2479-2480. [doi: 10.1001/jama.2014.4228] [Medline: 24854141]
11. Sadana R, Harper S. Data systems linking social determinants of health with health outcomes: advancing public goods to support research and evidence-based policy and programs. Public Health Rep 2011;126(Suppl 3):6-13 [FREE Full text] [doi: 10.1177/00333549111260S302] [Medline: 21836730]
12. Gottlieb L, Tobey R, Cantor J, Hessler D, Adler NE. Integrating social and medical data to improve population health: opportunities and barriers. Health Aff (Millwood) 2016 Nov 1;35(11):2116-2123. [doi: 10.1377/hlthaff.2016.0723] [Medline: 27834254]
13. Murdoch TB, Detsky AS. The inevitable application of big data to health care. J Am Med Assoc 2013 Apr 3;309(13):1351-1352. [doi: 10.1001/jama.2013.393] [Medline: 23549579]
14. Hemingway H, Asselbergs FW, Danesh J, Dobson R, Maniadakis N, Maggioni A, Innovative Medicines Initiative 2nd programme, Big Data for Better Outcomes, BigData@Heart Consortium of 20 academic and industry partners including ESC. Big data from electronic health records for early and late translational cardiovascular research: challenges and potential. Eur Heart J 2018 Apr 21;39(16):1481-1495 [FREE Full text] [doi: 10.1093/eurheartj/ehx487] [Medline: 29370377]

15. Beam AL, Kohane IS. Big data and machine learning in health care. J Am Med Assoc 2018 Apr 3;319(13):1317-1318. [doi: 10.1001/jama.2017.18391] [Medline: 29532063]
16. Haby MM, Chapman E, Clark R, Barreto J, Reveiz L, Lavis JN. What are the best methodologies for rapid reviews of the research evidence for evidence-informed decision making in health policy and practice: a rapid review. Health Res Policy Syst 2016 Nov 25;14(1):83 [FREE Full text] [doi: 10.1186/s12961-016-0155-7] [Medline: 27884208]
17. Vrijheid M. The exposome: a new paradigm to study the impact of environment on health. Thorax 2014 Sep;69(9):876-878. [doi: 10.1136/thoraxjnl-2013-204949] [Medline: 24906490]
18. US Interagency Program Office. 2013. #1 Background & Introduction to Non-Traditional Determinants of Health URL: https://www.healthit.gov/sites/default/files/2019-01/DoDVAIPOUpdate.pdf [accessed 2019-08-13]
19. Williams DR, Costa MV, Odunlami AO, Mohammed SA. Moving upstream: how interventions that address the social determinants of health can improve health and reduce disparities. J Public Health Manag Pract 2008 Nov(14 Suppl):S8-17 [FREE Full text] [doi: 10.1097/01.PHH.0000338382.36695.42] [Medline: 18843244]
20. World Health Organization. In: Currie C, Zanotti C, Morgan A, Currie D, Looze MD, Roberts C, editors. Social Determinants of Health and Well-Being Among Young People: Health Behaviour in School-Aged Children: International Report from the 2009/2010 Survey. Geneva, Switzerland: World Health Organization; 2010.
21. Braveman P, Egerter S, Williams DR. The social determinants of health: coming of age. Annu Rev Public Health 2011;32:381-398. [doi: 10.1146/annurev-publhealth-031210-101218] [Medline: 21091195]
22. Gnadinger T. Health Affairs. 2014. Health Policy Brief: The Relative Contribution Of Multiple Determinants To Health Outcomes URL: https://www.healthaffairs.org/do/10.1377/hblog20140822.040952/full/ [accessed 2019-08-13]
23. Healthy People 2020. 2018. Social Determinants of Health URL: https://www.healthypeople.gov/2020/topics-objectives/topic/social-determinants-of-health?topicid=39 [accessed 2018-05-01]
24. World Health Organization. 2008. Closing The Gap In a Generation: Health Equity Through Action on The Social Determinants of Health URL: https://www.who.int/social_determinants/final_report/csdh_finalreport_2008.pdf [accessed 2019-08-13]
25. Tomayko EJ, Flood TL, Tandias A, Hanrahan LP. Linking electronic health records with community-level data to understand childhood obesity risk. Pediatr Obes 2015 Dec;10(6):436-441 [FREE Full text] [doi: 10.1111/ijpo.12003] [Medline: 25559099]
26. Tannenbaum SL, Hernandez M, Zheng DD, Sussman DA, Lee DJ. Individual- and neighborhood-level predictors of mortality in Florida colorectal cancer patients. PLoS One 2014;9(8):e106322 [FREE Full text] [doi: 10.1371/journal.pone.0106322] [Medline: 25170910]
27. Small AC, Tsao CK, Moshier EL, Gartrell BA, Wisnivesky JP, Godbold J, et al. Trends and variations in utilization of nephron-sparing procedures for stage I kidney cancer in the United States. World J Urol 2013 Oct;31(5):1211-1217 [FREE Full text] [doi: 10.1007/s00345-012-0873-6] [Medline: 22622394]
28. Sleder A, Tackett S, Cerasale M, Mittal C, Isseh I, Radjef R, et al. Socioeconomic and racial disparities: a case-control study of patients receiving transcatheter aortic valve replacement for severe aortic stenosis. J Racial Ethn Health Disparities 2017 Dec;4(6):1189-1194. [doi: 10.1007/s40615-016-0325-x] [Medline: 28039604]
29. Siminoff L, Thomson M, Dumenci L. Factors associated with delayed patient appraisal of colorectal cancer symptoms. Psychooncology 2014 Sep;23(9):981-988 [FREE Full text] [doi: 10.1002/pon.3506] [Medline: 24615789]
30. Sheppard VB, O'Neill SC, Dilawari A, Horton S, Hirpa FA, Isaacs C. Patterns of 21-gene assay testing and chemotherapy use in black and white breast cancer patients. Clin Breast Cancer 2015 Apr;15(2):e83-e92 [FREE Full text] [doi: 10.1016/j.clbc.2014.11.011] [Medline: 25555816]
31. Sheppard VB, Hurtado-de-Mendoza A, Talley CH, Zhang YH, Cabling ML, Makambi KH. Reducing racial disparities in breast cancer survivors' ratings of quality cancer care: the enduring impact of trust. J Healthc Qual 2016;38(3):143-163. [doi: 10.1097/JHQ.0000000000000046] [Medline: 27152910]
32. Sehgal NK, Scallan C, Sullivan C, Cedeño M, Pencak J, Kirkland J, et al. The relationship between verified organ donor designation and patient demographic and medical characteristics. Am J Transplant 2016 Apr;16(4):1294-1297 [FREE Full text] [doi: 10.1111/ajt.13608] [Medline: 26603147]
33. Sankaranarayanan J, Collier D, Furasek A, Reardon T, Smith LM, McCartan M, et al. Rurality and other factors associated with adherence to immunosuppressant medications in community-dwelling solid-organ transplant recipients. Res Social Adm Pharm 2012;8(3):228-239. [doi: 10.1016/j.sapharm.2011.04.001] [Medline: 21856247]
34. Patzer RE, Perryman JP, Pastan S, Amaral S, Gazmararian JA, Klein M, et al. Impact of a patient education program on disparities in kidney transplant evaluation. Clin J Am Soc Nephrol 2012 Apr;7(4):648-655 [FREE Full text] [doi: 10.2215/CJN.10071011] [Medline: 22344515]
35. Strauchler D, Freeman K, Miller TS. The impact of socioeconomic status and comorbid medical conditions on ionizing radiation exposure from diagnostic medical imaging in adults. J Am Coll Radiol 2012 Jan;9(1):58-63. [doi: 10.1016/j.jacr.2011.07.009] [Medline: 22221637]
36. Oyana TJ, Podila P, Wesley JM, Lomnicki S, Cormier S. Spatiotemporal patterns of childhood asthma hospitalization and utilization in Memphis metropolitan area from 2005 to 2015. J Asthma 2017 Oct;54(8):842-855 [FREE Full text] [doi: 10.1080/02770903.2016.1277537] [Medline: 28055280]

37. Ng DK, Brotman DJ, Lau B, Young JH. Insurance status, not race, is associated with mortality after an acute cardiovascular event in Maryland. J Gen Intern Med 2012 Oct;27(10):1368-1376 [FREE Full text] [doi: 10.1007/s11606-012-2147-9] [Medline: 22821570]
38. Neuman HB, Weiss JM, Leverson G, O'Connor ES, Greenblatt DY, Loconte NK, et al. Predictors of short-term postoperative survival after elective colectomy in colon cancer patients ≥ 80 years of age. Ann Surg Oncol 2013 May;20(5):1427-1435 [FREE Full text] [doi: 10.1245/s10434-012-2721-8] [Medline: 23292483]
39. Ndao-Brumblay SK, Green CR. Predictors of complementary and alternative medicine use in chronic pain patients. Pain Med 2010 Jan;11(1):16-24. [doi: 10.1111/j.1526-4637.2009.00767.x] [Medline: 20447293]
40. Movsas A, Ibrahim R, Elshaikh MA, Lamerato L, Lu M, Sitarik A, et al. Do sociodemographic factors influence outcome in prostate cancer patients treated with external beam radiation therapy? Am J Clin Oncol 2016 Dec;39(6):563-567. [doi: 10.1097/COC.0000000000000093] [Medline: 24879473]
41. Mosen DM, Schatz M, Gold R, Mularski RA, Wong WF, Bellows J. Medication use, emergency hospital care utilization, and quality-of-life outcome disparities by race/ethnicity among adults with asthma. Am J Manag Care 2010 Nov;16(11):821-828 [FREE Full text] [Medline: 21348553]
42. Moffet HH, Parker MM, Sarkar U, Schillinger D, Fernandez A, Adler NE, et al. Adherence to laboratory test requests by patients with diabetes: the diabetes study of northern California (DISTANCE). Am J Manag Care 2011 May;17(5):339-344 [FREE Full text] [Medline: 21718081]
43. Ratanawongsa N, Karter AJ, Quan J, Parker MM, Handley M, Sarkar U, et al. Reach and validity of an objective medication adherence measure among safety net health plan members with diabetes: a cross-sectional study. J Manag Care Spec Pharm 2015 Aug;21(8):688-698 [FREE Full text] [doi: 10.18553/jmcp.2015.21.8.688] [Medline: 26233541]
44. Mayer V, McDonough K, Seligman H, Mitra N, Long JA. Food insecurity, coping strategies and glucose control in low-income patients with diabetes. Public Health Nutr 2016 Apr;19(6):1103-1111. [doi: 10.1017/S1368980015002323] [Medline: 26328922]
45. Maxson P, Miranda ML. Pregnancy intention, demographic differences, and psychosocial health. J Womens Health (Larchmt) 2011 Aug;20(8):1215-1223. [doi: 10.1089/jwh.2010.2379] [Medline: 21671765]
46. Li D, Collins B, Velayos FS, Liu L, Lewis JD, Allison JE, et al. Racial and ethnic differences in health care utilization and outcomes among ulcerative colitis patients in an integrated health-care organization. Dig Dis Sci 2014 Feb;59(2):287-294. [doi: 10.1007/s10620-013-2908-2] [Medline: 24173809]
47. Keegan TH, Kurian AW, Gali K, Tao L, Lichtensztajn DY, Hershman DL, et al. Racial/ethnic and socioeconomic differences in short-term breast cancer survival among women in an integrated health system. Am J Public Health 2015 May;105(5):938-946. [doi: 10.2105/AJPH.2014.302406] [Medline: 25790426]
48. Mack JW, Chen K, Boscoe FP, Gesten FC, Roohan PJ, Weeks JC, et al. Underuse of hospice care by medicaid-insured patients with stage IV lung cancer in New York and California. J Clin Oncol 2013 Jul 10;31(20):2569-2579 [FREE Full text] [doi: 10.1200/JCO.2012.45.9271] [Medline: 23733768]
49. Mack CD, Carpenter W, Meyer AM, Sanoff H, Stürmer T. Racial disparities in receipt and comparative effectiveness of oxaliplatin for stage III colon cancer in older adults. Cancer 2012 Jun 1;118(11):2925-2934 [FREE Full text] [doi: 10.1002/cncr.26622] [Medline: 22072441]
50. Goodman SM, Mandl LA, Parks ML, Zhang M, McHugh KR, Lee YY, et al. Disparities in TKA outcomes: census tract data show interactions between race and poverty. Clin Orthop Relat Res 2016 Sep;474(9):1986-1995 [FREE Full text] [doi: 10.1007/s11999-016-4919-8] [Medline: 27278675]
51. Miranda ML, Ferranti J, Strauss B, Neelon B, Califf RM. Geographic health information systems: a platform to support the 'triple aim'. Health Aff (Millwood) 2013 Sep;32(9):1608-1615 [FREE Full text] [doi: 10.1377/hlthaff.2012.1199] [Medline: 24019366]
52. Comer KF, Grannis S, Dixon BE, Bodenhamer DJ, Wiehe SE. Incorporating geospatial capacity within clinical data systems to address social determinants of health. Public Health Rep 2011;126(Suppl 3):54-61 [FREE Full text] [doi: 10.1177/00333549111260S310] [Medline: 21836738]
53. Tumin D, Horan J, Shrider E, Smith SA, Tobias JD, Hayes Jr DJ, et al. County socioeconomic characteristics and heart transplant outcomes in the United States. Am Heart J 2017 Aug;190:104-112 [FREE Full text] [doi: 10.1016/j.ahj.2017.05.013] [Medline: 28760203]
54. Tomayko EJ, Weinert BA, Godfrey L, Adams AK, Hanrahan LP. Using electronic health records to examine disease risk in small populations: obesity among American Indian children, Wisconsin, 2007-2012. Prev Chronic Dis 2016 Feb 25;13:E29 [FREE Full text] [doi: 10.5888/pcd13.150479] [Medline: 26916900]
55. Takahashi PY, Ryu E, Hathcock MA, Olson JE, Bielinski SJ, Cerhan JR, et al. A novel housing-based socioeconomic measure predicts hospitalisation and multiple chronic conditions in a community population. J Epidemiol Community Health 2016 Mar;70(3):286-291 [FREE Full text] [doi: 10.1136/jech-2015-205925] [Medline: 26458399]
56. Sánchez E, Rasmussen A, Riba L, Acevedo-Vasquez E, Kelly JA, Langefeld CD, et al. Impact of genetic ancestry and sociodemographic status on the clinical expression of systemic lupus erythematosus in American Indian-European populations. Arthritis Rheum 2012 Nov;64(11):3687-3694 [FREE Full text] [doi: 10.1002/art.34650] [Medline: 22886787]

57. Nijhawan AE, Clark C, Kaplan R, Moore B, Halm EA, Amarasingham R. An electronic medical record-based model to predict 30-day risk of readmission and death among HIV-infected inpatients. J Acquir Immune Defic Syndr 2012 Nov 1;61(3):349-358. [doi: 10.1097/QAI.0b013e31826ebc83] [Medline: 23095935]
58. Nau C, Schwartz BS, Bandeen-Roche K, Liu A, Pollak J, Hirsch A, et al. Community socioeconomic deprivation and obesity trajectories in children using electronic health records. Obesity (Silver Spring) 2015 Jan;23(1):207-212 [FREE Full text] [doi: 10.1002/oby.20903] [Medline: 25324223]
59. Martínez ME, Anderson K, Murphy JD, Hurley S, Canchola AJ, Keegan TH, et al. Differences in marital status and mortality by race/ethnicity and nativity among California cancer patients. Cancer 2016 May 15;122(10):1570-1578 [FREE Full text] [doi: 10.1002/cncr.29886] [Medline: 27065455]
60. Geraghty EM, Balsbaugh T, Nuovo J, Tandon S. Using geographic information systems (GIS) to assess outcome disparities in patients with type 2 diabetes and hyperlipidemia. J Am Board Fam Med 2010;23(1):88-96 [FREE Full text] [doi: 10.3122/jabfm.2010.01.090149] [Medline: 20051547]
61. Flood TL, Zhao YQ, Tomayko EJ, Tandias A, Carrel AL, Hanrahan LP. Electronic health records and community health surveillance of childhood obesity. Am J Prev Med 2015 Feb;48(2):234-240 [FREE Full text] [doi: 10.1016/j.amepre.2014.10.020] [Medline: 25599907]
62. Rutten LJ, Wilson PM, Jacobson DJ, Agunwamba AA, Breitkopf CR, Jacobson RM, et al. A population-based study of sociodemographic and geographic variation in HPV vaccination. Cancer Epidemiol Biomarkers Prev 2017 Apr;26(4):533-540 [FREE Full text] [doi: 10.1158/1055-9965.EPI-16-0877] [Medline: 28196849]
63. Dalton JE, Perzynski AT, Zidar DA, Rothberg MB, Coulton CJ, Milinovich AT, et al. Accuracy of cardiovascular risk prediction varies by neighborhood socioeconomic position: a retrospective cohort study. Ann Intern Med 2017 Oct 3;167(7):456-464 [FREE Full text] [doi: 10.7326/M16-2543] [Medline: 28847012]
64. Collins JE, Katz JN, Donnell-Fink LA, Martin SD, Losina E. Cumulative incidence of ACL reconstruction after ACL injury in adults: role of age, sex, and race. Am J Sports Med 2013 Mar;41(3):544-549 [FREE Full text] [doi: 10.1177/0363546512472042] [Medline: 23302260]
65. Casey JA, Cosgrove SE, Stewart WF, Pollak J, Schwartz BS. A population-based study of the epidemiology and clinical features of methicillin-resistant Staphylococcus aureus infection in Pennsylvania, 2001-2010. Epidemiol Infect 2013 Jun;141(6):1166-1179 [FREE Full text] [doi: 10.1017/S0950268812001872] [Medline: 22929058]
66. Finks J, Osborne N, Birkmeyer J. Trends in hospital volume and operative mortality for high-risk surgery. N Engl J Med 2011 Jun 2;364(22):2128-2137 [FREE Full text] [doi: 10.1056/NEJMsa1010705] [Medline: 21631325]
67. Zuckerman SL, Zalneraitis BH, Totten DJ, Rubel KE, Kuhn AQ, Yengo-Kahn AM, et al. Socioeconomic status and outcomes after sport-related concussion: a preliminary investigation. J Neurosurg Pediatr 2017 Jun;19(6):652-661. [doi: 10.3171/2017.1.PEDS16611] [Medline: 28338445]
68. Leonard T, Hughes AE, Pruitt SL. Understanding how low-socioeconomic status households cope with health shocks: an analysis of multi-sector linked data. Ann Am Acad Pol Soc Sci 2017 Jan;669(1):125-145 [FREE Full text] [doi: 10.1177/0002716216680989] [Medline: 28413218]
69. Solem CT, Sun SX, Sudharshan L, Macahilig C, Katyal M, Gao X. Exacerbation-related impairment of quality of life and work productivity in severe and very severe chronic obstructive pulmonary disease. Int J Chron Obstruct Pulmon Dis 2013;8:641-652 [FREE Full text] [doi: 10.2147/COPD.S51245] [Medline: 24376348]
70. Grinspan ZM, Patel AD, Hafeez B, Abramson EL, Kern LM. Predicting frequent emergency department use among children with epilepsy: a retrospective cohort study using electronic health data from 2 centers. Epilepsia 2018 Jan;59(1):155-169 [FREE Full text] [doi: 10.1111/epi.13948] [Medline: 29143960]
71. Bristow RE, Powell MA, Al-Hammadi N, Chen L, Miller JP, Roland PY, et al. Disparities in ovarian cancer care quality and survival according to race and socioeconomic status. J Natl Cancer Inst 2013 Jun 5;105(11):823-832 [FREE Full text] [doi: 10.1093/jnci/djt065] [Medline: 23539755]
72. Baldwin MR, Sell JL, Heyden N, Javaid A, Berlin DA, Gonzalez WC, et al. Race, ethnicity, health insurance, and mortality in older survivors of critical illness. Crit Care Med 2017 Jun;45(6):e583-e591 [FREE Full text] [doi: 10.1097/CCM.0000000000002313] [Medline: 28333761]
73. Drewnowski A, Rehm CD, Moudon AV, Arterburn D. The geography of diabetes by census tract in a large sample of insured adults in King County, Washington, 2005-2006. Prev Chronic Dis 2014 Jul 24;11:E125 [FREE Full text] [doi: 10.5888/pcd11.140135] [Medline: 25058671]
74. Fessele KL, Hayat MJ, Mayer DK, Atkins RL. Factors associated with unplanned hospitalizations among patients with nonmetastatic colorectal cancers intended for treatment in the ambulatory setting. Nurs Res 2016;65(1):24-34 [FREE Full text] [doi: 10.1097/NNR.0000000000000134] [Medline: 26657478]
75. Chu DI, Moreira DM, Gerber L, Presti Jr JC, Aronson WJ, Terris MK, et al. Effect of race and socioeconomic status on surgical margins and biochemical outcomes in an equal-access health care setting: results from the shared equal access regional cancer hospital (SEARCH) database. Cancer 2012 Oct 15;118(20):4999-5007 [FREE Full text] [doi: 10.1002/cncr.27456] [Medline: 22415377]

76. Sills MR, Hall M, Cutler GJ, Colvin JD, Gottlieb LM, Macy ML, et al. Adding social determinant data changes children's hospitals' readmissions performance. J Pediatr 2017 Jul;186:150-7.e1. [doi: 10.1016/j.jpeds.2017.03.056] [Medline: 28476461]
77. Hu J, Gonsahn MD, Nerenz DR. Socioeconomic status and readmissions: evidence from an urban teaching hospital. Health Aff (Millwood) 2014 May;33(5):778-785. [doi: 10.1377/hlthaff.2013.0816] [Medline: 24799574]
78. Nagasako EM, Reidhead M, Waterman B, Dunagan WC. Adding socioeconomic data to hospital readmissions calculations may produce more useful results. Health Aff (Millwood) 2014 May;33(5):786-791 [FREE Full text] [doi: 10.1377/hlthaff.2013.1148] [Medline: 24799575]
79. Lord JH, Young MT, Gruhn MA, Grey M, Delamater AM, Jaser SS. Effect of race and marital status on mothers' observed parenting and adolescent adjustment in youth with type 1 diabetes. J Pediatr Psychol 2015;40(1):132-143 [FREE Full text] [doi: 10.1093/jpepsy/jsu078] [Medline: 25248850]
80. Salvaggio C, Han SW, Martires K, Robinson E, Madankumar R, Gumaste P, et al. Impact of socioeconomic status and ethnicity on melanoma presentation and recurrence in Caucasian patients. Oncology 2016;90(2):79-87. [doi: 10.1159/000441524] [Medline: 26840790]
81. Novotny R, Oshiro CE, Wilkens LR. Prevalence of childhood obesity among young multiethnic children from a health maintenance organization in Hawaii. Child Obes 2013 Feb;9(1):35-42 [FREE Full text] [doi: 10.1089/chi.2012.0103] [Medline: 23373877]
82. Nguyen OK, Makam AN, Clark C, Zhang S, Xie B, Velasco F, et al. Predicting all-cause readmissions using electronic health record data from the entire hospitalization: model development and comparison. J Hosp Med 2016 Jul;11(7):473-480 [FREE Full text] [doi: 10.1002/jhm.2568] [Medline: 26929062]
83. Miller AL, Simon D, Roe MT, Kontos MC, Diercks D, Amsterdam E, et al. Comparison of delay times from symptom onset to medical contact in blacks versus whites with acute myocardial infarction. Am J Cardiol 2017 Apr 15;119(8):1127-1134. [doi: 10.1016/j.amjcard.2016.12.021] [Medline: 28237284]
84. Robbins AS, Cox DD, Johnson LB, Ward EM. Persistent disparities in liver transplantation for patients with hepatocellular carcinoma in the United States, 1998 through 2007. Cancer 2011 Oct 1;117(19):4531-4539 [FREE Full text] [doi: 10.1002/cncr.26063] [Medline: 21448933]
85. McGee SA, Durham DD, Tse CK, Millikan RC. Determinants of breast cancer treatment delay differ for African American and white women. Cancer Epidemiol Biomarkers Prev 2013 Jul;22(7):1227-1238 [FREE Full text] [doi: 10.1158/1055-9965.EPI-12-1432] [Medline: 23825306]
86. Lu JC, Lowery R, Yu S, Mahani G, Agarwal PP, Dorfman AL. Predictors of missed appointments in patients referred for congenital or pediatric cardiac magnetic resonance. Pediatr Radiol 2017 Jul;47(8):911-916. [doi: 10.1007/s00247-017-3851-8] [Medline: 28432402]
87. Lipner EM, Knox D, French J, Rudman J, Strong M, Crooks JL. A geospatial epidemiologic analysis of nontuberculous mycobacterial infection: an ecological study in Colorado. Ann Am Thorac Soc 2017 Oct;14(10):1523-1532 [FREE Full text] [doi: 10.1513/AnnalsATS.201701-081OC] [Medline: 28594574]
88. Lee SL, Yaghoubian A, Stark R, Shekherdimian S. Equal access to healthcare does not eliminate disparities in the management of adults with appendicitis. J Surg Res 2011 Oct;170(2):209-213. [doi: 10.1016/j.jss.2011.02.009] [Medline: 21470638]
89. Le H, Wong S, Iftikar T, Keenan H, King GL, Hsu WC. Characterization of factors affecting attainment of glycemic control in Asian Americans with diabetes in a culturally specific program. Diabetes Educ 2013;39(4):468-477 [FREE Full text] [doi: 10.1177/0145721713492217] [Medline: 23771841]
90. Lafata JE, Karter AJ, O'Connor PJ, Morris H, Schmittdiel JA, Ratliff S, et al. Medication adherence does not explain black-white differences in cardiometabolic risk factor control among insured patients with diabetes. J Gen Intern Med 2016 Feb;31(2):188-195 [FREE Full text] [doi: 10.1007/s11606-015-3486-0] [Medline: 26282954]
91. Black MH, Zhou H, Takayanagi M, Jacobsen SJ, Koebnick C. Increased asthma risk and asthma-related health care complications associated with childhood obesity. Am J Epidemiol 2013 Oct 1;178(7):1120-1128 [FREE Full text] [doi: 10.1093/aje/kwt093] [Medline: 23924576]
92. Nguyen BC, Alawadi ZM, Roife D, Kao LS, Ko TC, Wray CJ. Do socioeconomic factors and race determine the likelihood of breast-conserving surgery? Clin Breast Cancer 2016 Aug;16(4):e93-e97. [doi: 10.1016/j.clbc.2016.05.008] [Medline: 27297238]
93. Rubens SL, Patrick KE, Williamson AA, Moore M, Mindell JA. Individual and socio-demographic factors related to presenting problem and diagnostic impressions at a pediatric sleep clinic. Sleep Med 2016 Sep;25:67-72. [doi: 10.1016/j.sleep.2016.06.017] [Medline: 27823719]
94. Wu JR, Moser DK, DeWalt DA, Rayens MK, Dracup K. Health literacy mediates the relationship between age and health outcomes in patients with heart failure. Circ Heart Fail 2016 Jan;9(1):e002250 [FREE Full text] [doi: 10.1161/CIRCHEARTFAILURE.115.002250] [Medline: 26721913]
95. Doll KM, Barber EL, Bensen JT, Revilla MC, Snavely AC, Bennett AV, et al. The impact of surgical complications on health-related quality of life in women undergoing gynecologic and gynecologic oncology procedures: a prospective longitudinal cohort study. Am J Obstet Gynecol 2016 Oct;215(4):457.e1-457.13 [FREE Full text] [doi: 10.1016/j.ajog.2016.04.025] [Medline: 27131589]

96. Roth C, Payne PR, Weier RC, Shoben AB, Fletcher EN, Lai AM, et al. The geographic distribution of cardiovascular health in the stroke prevention in healthcare delivery environments (SPHERE) study. J Biomed Inform 2016 Apr;60:95-103 [FREE Full text] [doi: 10.1016/j.jbi.2016.01.013] [Medline: 26828957]
97. Berger RR, Fromkin JB, Stutz H, Makoroff K, Scribano PV, Feldman K, et al. Abusive head trauma during a time of increased unemployment: a multicenter analysis. Pediatrics 2011 Oct;128(4):637-643. [doi: 10.1542/peds.2010-2185] [Medline: 21930535]
98. Downing J, Karter A, Rodriguez H, Dow WH, Adler N, Schillinger D, et al. No spillover effect of the foreclosure crisis on weight change: the diabetes study of northern California (DISTANCE). PLoS One 2016;11(3):e0151334 [FREE Full text] [doi: 10.1371/journal.pone.0151334] [Medline: 26985671]
99. Sharifi M, Sequist TD, Rifas-Shiman SL, Melly SJ, Duncan DT, Horan CM, et al. The role of neighborhood characteristics and the built environment in understanding racial/ethnic disparities in childhood obesity. Prev Med 2016 Oct;91:103-109 [FREE Full text] [doi: 10.1016/j.ypmed.2016.07.009] [Medline: 27404577]
100. Laraia BA, Downing JM, Zhang YT, Dow WH, Kelly M, Blanchard SD, et al. Food environment and weight change: does residential mobility matter?: the diabetes study of northern California (DISTANCE). Am J Epidemiol 2017 May 1;185(9):743-750 [FREE Full text] [doi: 10.1093/aje/kww167] [Medline: 28387785]
101. Fiechtner L, Sharifi M, Sequist T, Block J, Duncan DT, Melly SJ, et al. Food environments and childhood weight status: effects of neighborhood median income. Child Obes 2015 Jun;11(3):260-268 [FREE Full text] [doi: 10.1089/chi.2014.0139] [Medline: 25923838]
102. Zenk SN, Tarlov E, Wing C, Matthews SA, Jones K, Tong H, et al. Geographic accessibility of food outlets not associated with body mass index change among veterans, 2009-14. Health Aff (Millwood) 2017 Aug 1;36(8):1433-1442 [FREE Full text] [doi: 10.1377/hlthaff.2017.0122] [Medline: 28784736]
103. Moshkovich O, Lebrun-Harris L, Makaroff L, Chidambaran P, Chung M, Sripipatana A, et al. Challenges and opportunities to improve cervical cancer screening rates in US health centers through patient-centered medical home transformation. Adv Prev Med 2015;2015:182073 [FREE Full text] [doi: 10.1155/2015/182073] [Medline: 25685561]
104. Ponce NA, Ko M, Liang SY, Armstrong J, Toscano M, Chanfreau-Coffinier C, et al. Early diffusion of gene expression profiling in breast cancer patients associated with areas of high income inequality. Health Aff (Millwood) 2015 Apr;34(4):609-615. [doi: 10.1377/hlthaff.2014.1013] [Medline: 25847643]
105. Pimentel L, Anderson D, Golden B, Wasil E, Barrueto F, Hirshon JM. Impact of health policy changes on emergency medicine in Maryland stratified by socioeconomic status. West J Emerg Med 2017 Apr;18(3):356-365 [FREE Full text] [doi: 10.5811/westjem.2017.1.31778] [Medline: 28435485]
106. Noel L, Connors SK, Goodman MS, Gehlert S. Improving breast cancer services for African-American women living in St Louis. Breast Cancer Res Treat 2015 Nov;154(1):5-12 [FREE Full text] [doi: 10.1007/s10549-015-3584-z] [Medline: 26409834]
107. Bernheim SM, Parzynski CS, Horwitz L, Lin Z, Araas MJ, Ross JS, et al. Accounting for patients' socioeconomic status does not change hospital readmission rates. Health Aff (Millwood) 2016 Aug 1;35(8):1461-1470. [doi: 10.1377/hlthaff.2015.0394] [Medline: 27503972]
108. Bailey SR, Marino M, Hoopes M, Heintzman J, Gold R, Angier H, et al. Healthcare utilization after a children's health insurance program expansion in Oregon. Matern Child Health J 2016 May;20(5):946-954 [FREE Full text] [doi: 10.1007/s10995-016-1971-7] [Medline: 26987861]
109. Angier H, Marino M, Sumic A, O'Malley J, Likumahuwa-Ackman S, Hoopes M, et al. Innovative methods for parents and clinics to create tools for kids' care (IMPACCT Kids' Care) study protocol. Contemp Clin Trials 2015 Sep;44:159-163 [FREE Full text] [doi: 10.1016/j.cct.2015.08.010] [Medline: 26291916]
110. Beck AF, Huang B, Chundur R, Kahn RS. Housing code violation density associated with emergency department and hospital use by children with asthma. Health Aff (Millwood) 2014 Nov;33(11):1993-2002 [FREE Full text] [doi: 10.1377/hlthaff.2014.0496] [Medline: 25367995]
111. Ahluwalia SK, Peng RD, Breysse PN, Diette GB, Curtin-Brosnan J, Aloe C, et al. Mouse allergen is the major allergen of public health relevance in Baltimore city. J Allergy Clin Immunol 2013 Oct;132(4):830-5.e1 [FREE Full text] [doi: 10.1016/j.jaci.2013.05.005] [Medline: 23810154]
112. Pollack CE, Kurd SK, Livshits A, Weiner M, Lynch J. A case-control study of home foreclosure, health conditions, and health care utilization. J Urban Health 2011 Jun;88(3):469-478 [FREE Full text] [doi: 10.1007/s11524-011-9564-7] [Medline: 21491152]
113. Bruden DJ, Singleton R, Hawk CS, Bulkow LR, Bentley S, Anderson LJ, et al. Eighteen years of respiratory Syncytial virus surveillance: changes in seasonality and hospitalization rates in southwestern Alaska native children. Pediatr Infect Dis J 2015 Sep;34(9):945-950. [doi: 10.1097/INF.0000000000000772] [Medline: 26065863]
114. Omachi TA, Gregorich SE, Eisner MD, Penaloza RA, Tolstykh IV, Yelin EH, et al. Risk adjustment for health care financing in chronic disease: what are we missing by failing to account for disease severity? Med Care 2013 Aug;51(8):740-747 [FREE Full text] [doi: 10.1097/MLR.0b013e318298082f] [Medline: 23703646]

115. Dhingra L, Dieckmann NF, Knotkova H, Chen J, Riggs A, Breuer B, et al. A high-touch model of community-based specialist palliative care: latent class analysis identifies distinct patient subgroups. J Pain Symptom Manage 2016 Aug;52(2):178-186. [doi: 10.1016/j.jpainsymman.2016.04.001] [Medline: 27208864]
116. Derakhshan A, Miller J, Lubelski D, Nowacki AS, Wells BJ, Milinovich A, et al. The impact of socioeconomic status on the utilization of spinal imaging. Neurosurgery 2015 Nov;77(5):746-53; discussion 753. [doi: 10.1227/NEU.0000000000000914] [Medline: 26214318]
117. Chan DC, Shrank WH, Cutler D, Jan S, Fischer MA, Liu J, et al. Patient, physician, and payment predictors of statin adherence. Med Care 2010 Mar;48(3):196-202. [doi: 10.1097/MLR.0b013e3181c132ad] [Medline: 19890219]
118. Epstein D, Reibel M, Unger JB, Cockburn M, Escobedo LA, Kale DC, et al. The effect of neighborhood and individual characteristics on pediatric critical illness. J Community Health 2014 Aug;39(4):753-759 [FREE Full text] [doi: 10.1007/s10900-014-9823-0] [Medline: 24488647]
119. Roy A, Mehra S, Kelly CP, Tariq S, Pallav K, Dennis M, et al. The association between socioeconomic status and the symptoms at diagnosis of celiac disease: a retrospective cohort study. Therap Adv Gastroenterol 2016 Jul;9(4):495-502 [FREE Full text] [doi: 10.1177/1756283X16637532] [Medline: 27366218]
120. Stahl JE, Drew MA, Kimball AB. Patient-clinician concordance, face-time and access. Int J Health Care Qual Assur 2014;27(8):664-671. [doi: 10.1108/IJHCQA-04-2013-0048] [Medline: 25417372]
121. Richardson M, van den Eeden SK, Roberts E, Ferrara A, Paulukonis S, English P. Evaluating the use of electronic health records for type 2 diabetes surveillance in 2 California counties, 2010-2014. Public Health Rep 2017;132(4):463-470 [FREE Full text] [doi: 10.1177/0033354917708988] [Medline: 28586621]
122. Krivchenia K, Hayes Jr D, Tobias JD, Tumin D. Long-term work participation among cystic fibrosis patients undergoing lung transplantation. J Cyst Fibros 2016 Nov;15(6):846-849 [FREE Full text] [doi: 10.1016/j.jcf.2016.07.007] [Medline: 27497927]
123. Klobusicky JJ, Aryasomayajula A, Marko N. Evolving patient compliance trends: integrating clinical, insurance, and extrapolated socioeconomic data. AMIA Annu Symp Proc 2015;2015:766-774 [FREE Full text] [Medline: 26958212]
124. Johns TS, Estrella MM, Crews DC, Appel LJ, Anderson CA, Ephraim PL, et al. Neighborhood socioeconomic status, race, and mortality in young adult dialysis patients. J Am Soc Nephrol 2014 Nov;25(11):2649-2657 [FREE Full text] [doi: 10.1681/ASN.2013111207] [Medline: 24925723]
125. Jhamb M, Cavanaugh KL, Bian A, Chen G, Ikizler TA, Unruh ML, et al. Disparities in electronic health record patient portal use in nephrology clinics. Clin J Am Soc Nephrol 2015 Nov 6;10(11):2013-2022 [FREE Full text] [doi: 10.2215/CJN.01640215] [Medline: 26493242]
126. Holmes L, Vandenberg J, McClarin L, Dabney K. Epidemiologic, racial and healthographic mapping of Delaware pediatric cancer: 2004-2014. Int J Environ Res Public Health 2015 Dec 22;13(1):ijerph13010049 [FREE Full text] [doi: 10.3390/ijerph13010049] [Medline: 26703649]
127. Franco I, Franco J, Harding S, Rosconi D, Cupelli E, Collett-Gardere T. Are seasonal and income variations accountable for bowel and bladder dysfunction symptoms in children? Neurourol Urodyn 2017 Jan;36(1):148-154. [doi: 10.1002/nau.22896] [Medline: 26474444]
128. Buu MC, Sanders LM, Mayo JA, Milla CE, Wise PH. Assessing differences in mortality rates and risk factors between Hispanic and non-Hispanic patients with cystic fibrosis in California. Chest 2016 Feb;149(2):380-389 [FREE Full text] [doi: 10.1378/chest.14-2189] [Medline: 26086984]
129. Butler J, Binney Z, Kalogeropoulos A, Owen M, Clevenger C, Gunter D, et al. Advance directives among hospitalized patients with heart failure. JACC Heart Fail 2015 Feb;3(2):112-121 [FREE Full text] [doi: 10.1016/j.jchf.2014.07.016] [Medline: 25543976]
130. Bourgi K, Brar I, Baker-Genaw K. Health disparities in hepatitis C screening and linkage to care at an integrated health system in southeast Michigan. PLoS One 2016;11(8):e0161241 [FREE Full text] [doi: 10.1371/journal.pone.0161241] [Medline: 27525983]
131. Aseltine Jr RH, Yan J, Gruss CB, Wagner C, Katz M. Connecticut hospital readmissions related to chest pain and heart failure: differences by race, ethnicity, and payer. Conn Med 2015 Feb;79(2):69-76. [Medline: 26244203]
132. Aneja S, Khullar D, Yu JB. The influence of regional health system characteristics on the surgical management and receipt of post operative radiation therapy for glioblastoma multiforme. J Neurooncol 2013 May;112(3):393-401 [FREE Full text] [doi: 10.1007/s11060-013-1068-8] [Medline: 23412775]
133. Feng J, Iser JP, Yang W. Medical encounters for opioid-related intoxications in southern Nevada: sociodemographic and clinical correlates. BMC Health Serv Res 2016 Aug 24;16:438 [FREE Full text] [doi: 10.1186/s12913-016-1692-z] [Medline: 27557947]
134. Eneriz-Wiemer M, Saynina O, Sundaram V, Lee HC, Bhattacharya J, Sanders LM. Parent language: a predictor for neurodevelopmental follow-up care among infants with very low birth weight. Acad Pediatr 2016;16(7):645-652. [doi: 10.1016/j.acap.2016.04.004] [Medline: 27130810]
135. Cheng ER, Hawkins SS, Rifas-Shiman SL, Gillman MW, Taveras EM. Association of missing paternal demographics on infant birth certificates with perinatal risk factors for childhood obesity. BMC Public Health 2016 Jul 14;16:453 [FREE Full text] [doi: 10.1186/s12889-016-3110-1] [Medline: 27411308]

136. Freeman K, Strauchler D, Miller TS. Impact of socioeconomic status on ionizing radiation exposure from medical imaging in children. J Am Coll Radiol 2012 Nov;9(11):799-807 [FREE Full text] [doi: 10.1016/j.jacr.2012.06.005] [Medline: 23122347]
137. Berkowitz SA, Terranova J, Hill C, Ajayi T, Linsky T, Tishler LW, et al. Meal delivery programs reduce the use of costly health care in dually eligible medicare and medicaid beneficiaries. Health Aff (Millwood) 2018 Apr;37(4):535-542 [FREE Full text] [doi: 10.1377/hlthaff.2017.0999] [Medline: 29608345]
138. van Vilsteren M, Boot CR, Knol DL, van Schaardenburg D, Voskuyl AE, Steenbeek R, et al. Productivity at work and quality of life in patients with rheumatoid arthritis. BMC Musculoskelet Disord 2015 May 6;16:107 [FREE Full text] [doi: 10.1186/s12891-015-0562-x] [Medline: 25940578]
139. Guerrero WR, Gonzales NR, Sekar P, Kawano-Castillo J, Moomaw CJ, Worrall BB, et al. Variability in the use of platelet transfusion in patients with intracerebral hemorrhage: observations from the ethnic/racial variations of intracerebral hemorrhage study. J Stroke Cerebrovasc Dis 2017 Sep;26(9):1974-1980. [doi: 10.1016/j.jstrokecerebrovasdis.2017.06.014] [Medline: 28669659]
140. Salow AD, Pool LR, Grobman WA, Kershaw KN. Associations of neighborhood-level racial residential segregation with adverse pregnancy outcomes. Am J Obstet Gynecol 2018 Mar;218(3):351.e1-351.e7. [doi: 10.1016/j.ajog.2018.01.022] [Medline: 29421603]
141. Bukowski LA, Blosnich J, Shipherd JC, Kauth MR, Brown GR, Gordon AJ. Exploring rural disparities in medical diagnoses among veterans with transgender-related diagnoses utilizing veterans health administration care. Med Care 2017 Sep;55(Suppl 9 Suppl 2):S97-103. [doi: 10.1097/MLR.0000000000000745] [Medline: 28806372]
142. Brown GR, Jones KT. Mental health and medical health disparities in 5135 transgender veterans receiving healthcare in the veterans health administration: a case-control study. LGBT Health 2016 Apr;3(2):122-131. [doi: 10.1089/lgbt.2015.0058] [Medline: 26674598]
143. Cary MP, Baernholdt M, Anderson RA, Merwin EI. Performance-based outcomes of inpatient rehabilitation facilities treating hip fracture patients in the United States. Arch Phys Med Rehabil 2015 May;96(5):790-798 [FREE Full text] [doi: 10.1016/j.apmr.2015.01.003] [Medline: 25596000]
144. Chien LC, Schootman M, Pruitt SL. The modifying effect of patient location on stage-specific survival following colorectal cancer using geosurvival models. Cancer Causes Control 2013 Mar;24(3):473-484 [FREE Full text] [doi: 10.1007/s10552-012-0134-4] [Medline: 23306551]
145. Blount RJ, Pascopella L, Catanzaro DG, Barry PM, English PB, Segal MR, et al. Traffic-related air pollution and all-cause mortality during tuberculosis treatment in California. Environ Health Perspect 2017 Sep 29;125(9):097026 [FREE Full text] [doi: 10.1289/EHP1699] [Medline: 28963088]
146. Sheppard VB, Oppong BA, Hampton R, Snead F, Horton S, Hirpa F, et al. Disparities in breast cancer surgery delay: the lingering effect of race. Ann Surg Oncol 2015 Sep;22(9):2902-2911. [doi: 10.1245/s10434-015-4397-3] [Medline: 25652051]
147. Hall MA, Dudek SM, Goodloe R, Crawford DS, Pendergrass SA, Peissig P, et al. Environment-wide association study (EWAS) for type 2 diabetes in the Marshfield personalized medicine research project biobank. Pac Symp Biocomput 2014:200-211 [FREE Full text] [doi: 10.1142/9789814583220_0020] [Medline: 24297547]
148. Toledo P, Eosakul ST, Grobman WA, Feinglass J, Hasnain-Wynia R. Primary spoken language and neuraxial labor analgesia use among Hispanic medicaid recipients. Anesth Analg 2016 Jan;122(1):204-209. [doi: 10.1213/ANE.0000000000001079] [Medline: 26646349]
149. Seligman HK, Bolger AF, Guzman D, López A, Bibbins-Domingo K. Exhaustion of food budgets at month's end and hospital admissions for hypoglycemia. Health Aff (Millwood) 2014 Jan;33(1):116-123 [FREE Full text] [doi: 10.1377/hlthaff.2013.0096] [Medline: 24395943]
150. Grimberg A, Feemster KA, Pati S, Ramos M, Grundmeier R, Cucchiara AJ, et al. Medically underserved girls receive less evaluation for short stature. Pediatrics 2011 Apr;127(4):696-702 [FREE Full text] [doi: 10.1542/peds.2010-1563] [Medline: 21422085]
151. Ye C, Fu T, Hao S, Zhang Y, Wang O, Jin B, et al. Prediction of incident hypertension within the next year: prospective study using statewide electronic health records and machine learning. J Med Internet Res 2018 Jan 30;20(1):e22 [FREE Full text] [doi: 10.2196/jmir.9268] [Medline: 29382633]
152. Kanzaria HK, Niedzwiecki MJ, Montoy JC, Raven MC, Hsia RY. Persistent frequent emergency department use: core group exhibits extreme levels of use for more than a decade. Health Aff (Millwood) 2017 Oct 1;36(10):1720-1728. [doi: 10.1377/hlthaff.2017.0658] [Medline: 28971916]
153. Patzer RE, Perryman JP, Schrager JD, Pastan S, Amaral S, Gazmararian JA, et al. The role of race and poverty on steps to kidney transplantation in the southeastern United States. Am J Transplant 2012 Feb;12(2):358-368 [FREE Full text] [doi: 10.1111/j.1600-6143.2011.03927.x] [Medline: 22233181]
154. Wallace ME, Mendola P, Chen Z, Hwang BS, Grantz KL. Preterm birth in the context of increasing income inequality. Matern Child Health J 2016 Jan;20(1):164-171 [FREE Full text] [doi: 10.1007/s10995-015-1816-9] [Medline: 26450504]
155. Shuman AG, Entezami P, Chernin AS, Wallace NE, Taylor JM, Hogikyan ND. Demographics and efficacy of head and neck cancer screening. Otolaryngol Head Neck Surg 2010 Sep;143(3):353-360 [FREE Full text] [doi: 10.1016/j.otohns.2010.05.029] [Medline: 20723771]

156. Tanenbaum J, Cebul RD, Votruba M, Einstadter D. Association of a regional health improvement collaborative with ambulatory care-sensitive hospitalizations. Health Aff (Millwood) 2018 Feb;37(2):266-274. [doi: 10.1377/hlthaff.2017.1209] [Medline: 29401005]
157. Castañeda SF, Rosenbaum RP, Holscher JT, Madanat H, Talavera GA. Cardiovascular disease risk factors among Latino migrant and seasonal farmworkers. J Agromedicine 2015;20(2):95-104 [FREE Full text] [doi: 10.1080/1059924X.2015.1010060] [Medline: 25906268]
158. Eapen ZJ, McCoy LA, Fonarow GC, Yancy CW, Miranda ML, Peterson ED, et al. Utility of socioeconomic status in predicting 30-day outcomes after heart failure hospitalization. Circ Heart Fail 2015 May;8(3):473-480 [FREE Full text] [doi: 10.1161/CIRCHEARTFAILURE.114.001879] [Medline: 25747700]
159. DeMaria AL, Lugo JM, Rahman M, Pyles RB, Berenson A. Association between body mass index, sexually transmitted infections, and contraceptive compliance. J Womens Health (Larchmt) 2013 Dec;22(12):1062-1068 [FREE Full text] [doi: 10.1089/jwh.2012.4116] [Medline: 24093760]
160. Gebauer S, Salas J, Scherrer JF. Neighborhood socioeconomic status and receipt of opioid medication for new back pain diagnosis. J Am Board Fam Med 2017;30(6):775-783 [FREE Full text] [doi: 10.3122/jabfm.2017.06.170061] [Medline: 29180552]
161. Zellner BS, Dawson JR, Reichel LM, Schaefer K, Britt J, Hillin C, et al. Prospective nutritional analysis of a diverse trauma population demonstrates substantial hypovitaminosis D. J Orthop Trauma 2014 Sep;28(9):e210-e215. [doi: 10.1097/BOT.0000000000000053] [Medline: 24464095]
162. Xiao H, Tan F, Goovaerts P, Ali A, Adunlin G, Gwede CK, et al. Multilevel factors associated with overall mortality for men diagnosed with prostate cancer in Florida. Am J Mens Health 2014 Jul;8(4):316-326 [FREE Full text] [doi: 10.1177/1557988313512862] [Medline: 24297455]
163. Morris EJ, Jordan C, Thomas JD, Cooper M, Brown JM, Thorpe H, CLASICC Trialists. Comparison of treatment and outcome information between a clinical trial and the national cancer data repository. Br J Surg 2011 Feb;98(2):299-307. [doi: 10.1002/bjs.7295] [Medline: 20981742]
164. Kinsky S, Stall R, Hawk M, Markovic N. Risk of the metabolic syndrome in sexual minority women: results from the ESTHER study. J Womens Health (Larchmt) 2016 Aug;25(8):784-790 [FREE Full text] [doi: 10.1089/jwh.2015.5496] [Medline: 26885574]
165. Fletcher FE, Vidrine DJ, Tami-Maury I, Danysh HE, King RM, Buchberg M, et al. Cervical cancer screening adherence among HIV-positive female smokers from a comprehensive HIV clinic. AIDS Behav 2014 Mar;18(3):544-554 [FREE Full text] [doi: 10.1007/s10461-013-0480-6] [Medline: 23605155]
166. Cantonwine DE, Ferguson KK, Mukherjee B, Chen Y, Smith NA, Robinson JN, et al. Utilizing longitudinal measures of fetal growth to create a standard method to assess the impacts of maternal disease and environmental exposure. PLoS One 2016;11(1):e0146532 [FREE Full text] [doi: 10.1371/journal.pone.0146532] [Medline: 26731406]
167. Blashill AJ, O'Cleirigh C, Mayer KH, Goshe BM, Safren SA. Body mass index, depression and sexual transmission risk behaviors among HIV-positive MSM. AIDS Behav 2012 Nov;16(8):2251-2256 [FREE Full text] [doi: 10.1007/s10461-011-0056-2] [Medline: 21983696]
168. Henninger ML, Irving SA, Kauffman TL, Kurosky SK, Rompala K, Thompson MG, Pregnancy and Influenza Project Workgroup. Predictors of breastfeeding initiation and maintenance in an integrated healthcare setting. J Hum Lact 2017 May;33(2):256-266. [doi: 10.1177/0890334417695202] [Medline: 28418800]
169. Smalls BL, Gregory CM, Zoller JS, Egede LE. Assessing the relationship between neighborhood factors and diabetes related health outcomes and self-care behaviors. BMC Health Serv Res 2015 Oct 1;15:445 [FREE Full text] [doi: 10.1186/s12913-015-1086-7] [Medline: 26428459]
170. Wu JR, Lennie TA, Moser DK. A prospective, observational study to explore health disparities in patients with heart failure-ethnicity and financial status. Eur J Cardiovasc Nurs 2017 Jan;16(1):70-78. [doi: 10.1177/1474515116641296] [Medline: 27013334]
171. Bellin MH, Dicianno BE, Levey E, Dosa N, Roux G, Marben K, et al. Interrelationships of sex, level of lesion, and transition outcomes among young adults with myelomeningocele. Dev Med Child Neurol 2011 Jul;53(7):647-652 [FREE Full text] [doi: 10.1111/j.1469-8749.2011.03938.x] [Medline: 21410695]
172. Kwan ML, Ergas IJ, Somkin CP, Quesenberry Jr CJ, Neugut AI, Hershman DL, et al. Quality of life among women recently diagnosed with invasive breast cancer: the pathways study. Breast Cancer Res Treat 2010 Sep;123(2):507-524 [FREE Full text] [doi: 10.1007/s10549-010-0764-8] [Medline: 20140494]
173. Chambers EC, Wong BC, Riley RW, Hollingsworth N, Blank AE, Myers C, et al. Combining clinical and population-level data to understand the health of neighborhoods. Am J Public Health 2015 Mar;105(3):510-512 [FREE Full text] [doi: 10.2105/AJPH.2014.302326] [Medline: 25602860]
174. Galler A, Lindau M, Ernert A, Thalemann R, Raile K. Associations between media consumption habits, physical activity, socioeconomic status, and glycemic control in children, adolescents, and young adults with type 1 diabetes. Diabetes Care 2011 Nov;34(11):2356-2359 [FREE Full text] [doi: 10.2337/dc11-0838] [Medline: 21926289]

175. Schwartz BS, Stewart WF, Godby S, Pollak J, Dewalle J, Larson S, et al. Body mass index and the built and social environments in children and adolescents using electronic health records. Am J Prev Med 2011 Oct;41(4):e17-e28. [doi: 10.1016/j.amepre.2011.06.038] [Medline: 21961475]
176. Di Q, Wang Y, Zanobetti A, Wang Y, Koutrakis P, Choirat C, et al. Air pollution and mortality in the medicare population. N Engl J Med 2017 Jun 29;376(26):2513-2522 [FREE Full text] [doi: 10.1056/NEJMoa1702747] [Medline: 28657878]
177. Sheffield P, Roy A, Wong K, Trasande L. Fine particulate matter pollution linked to respiratory illness in infants and increased hospital costs. Health Aff (Millwood) 2011 May;30(5):871-878 [FREE Full text] [doi: 10.1377/hlthaff.2010.1279] [Medline: 21543422]
178. Kranjac AW, Kimbro RT, Denney JT, Osiecki KM, Moffett BS, Lopez KN. Comprehensive neighborhood portraits and child asthma disparities. Matern Child Health J 2017 Jul;21(7):1552-1562. [doi: 10.1007/s10995-017-2286-z] [Medline: 28181157]
179. Boland MR, Parhi P, Li L, Miotto R, Carroll R, Iqbal U, et al. Uncovering exposures responsible for birth season - disease effects: a global study. J Am Med Inform Assoc 2017 Sep 28 (epub ahead of print). [doi: 10.1093/jamia/ocx105] [Medline: 29036387]
180. Wang VJ, Cavagnaro CS, Clark S, Camargo Jr CA, Mansbach JM. Altitude and environmental climate effects on bronchiolitis severity among children presenting to the emergency department. J Environ Health 2012 Oct;75(3):8-15; quiz 54. [Medline: 23091965]
181. Saligan LN, Levy-Clarke G, Wu T, Faia LJ, Wroblewski K, Yeh S, et al. Quality of life in sarcoidosis: comparing the impact of ocular and non-ocular involvement of the disease. Ophthalmic Epidemiol 2010 Aug;17(4):217-224 [FREE Full text] [doi: 10.3109/09286586.2010.483754] [Medline: 20642344]
182. Davis MA, Higgins J, Li Z, Gilbert-Diamond D, Baker ER, Das A, et al. Preliminary analysis of in utero low-level arsenic exposure and fetal growth using biometric measurements extracted from fetal ultrasound reports. Environ Health 2015 Mar 30;14:12 [FREE Full text] [doi: 10.1186/1476-069X-14-12] [Medline: 25971349]
183. Al Achkar M, Grannis S, Revere D, MacKie P, Howard M, Gupta S. The effects of state rules on opioid prescribing in Indiana. BMC Health Serv Res 2018 Jan 18;18(1):29 [FREE Full text] [doi: 10.1186/s12913-018-2830-6] [Medline: 29347984]
184. Blosnich JR, Marsiglio MC, Gao S, Gordon AJ, Shipherd JC, Kauth M, et al. Mental health of transgender veterans in US states with and without discrimination and hate crime legal protection. Am J Public Health 2016 Mar;106(3):534-540. [doi: 10.2105/AJPH.2015.302981] [Medline: 26794162]
185. Fine AM, Reis BY, Nigrovic LE, Goldmann DA, Laporte TN, Olson KL, et al. Use of population health data to refine diagnostic decision-making for pertussis. J Am Med Inform Assoc 2010;17(1):85-90 [FREE Full text] [doi: 10.1197/jamia.M3061] [Medline: 20064807]
186. Leukhardt WH, Golob JF, McCoy AM, Fadlalla AM, Malangoni MA, Claridge JA. Follow-up disparities after trauma: a real problem for outcomes research. Am J Surg 2010 Mar;199(3):348-52; discussion 353. [doi: 10.1016/j.amjsurg.2009.09.021] [Medline: 20226908]
187. Beck AF, Sandel MT, Ryan PH, Kahn RS. Mapping neighborhood health geomarkers to clinical care decisions to promote equity in child health. Health Aff (Millwood) 2017 Jun 1;36(6):999-1005 [FREE Full text] [doi: 10.1377/hlthaff.2016.1425] [Medline: 28583957]
188. Roth C, Foraker RE, Payne PR, Embi PJ. Community-level determinants of obesity: harnessing the power of electronic health records for retrospective data analysis. BMC Med Inform Decis Mak 2014 May 8;14:36 [FREE Full text] [doi: 10.1186/1472-6947-14-36] [Medline: 24886134]
189. Newman KL, Lynch RJ, Adams AB, Zhang R, Pastan SO, Patzer RE. Hospitalization among individuals waitlisted for kidney transplant. Transplantation 2017 Dec;101(12):2913-2923 [FREE Full text] [doi: 10.1097/TP.0000000000001839] [Medline: 28590946]
190. Evon DM, Simpson KM, Esserman D, Verma A, Smith S, Fried MW. Barriers to accessing care in patients with chronic hepatitis C: the impact of depression. Aliment Pharmacol Ther 2010 Nov;32(9):1163-1173 [FREE Full text] [doi: 10.1111/j.1365-2036.2010.04460.x] [Medline: 21039678]
191. Pendleton C, Cristofalo EA, Biondo GN, Jallo GI, Quiñones-Hinojosa A, Ahn ES. Posthemorrhagic hydrocephalus in preterm neonates: socioeconomic characteristics in a single-institution experience. Pediatr Neurosurg 2012;48(2):80-85. [doi: 10.1159/000342539] [Medline: 23038417]
192. Zook HG, Kharbanda AB, Flood A, Harmon B, Puumala SE, Payne NR. Racial differences in pediatric emergency department triage scores. J Emerg Med 2016 May;50(5):720-727 [FREE Full text] [doi: 10.1016/j.jemermed.2015.02.056] [Medline: 26899520]
193. SooHoo NF, Farng E, Zingmond DS. Disparities in the utilization of high-volume hospitals for total hip replacement. J Natl Med Assoc 2011 Jan;103(1):31-35. [doi: 10.1016/s0027-9684(15)30240-6] [Medline: 21329244]
194. Huntington SF, Weiss BM, Vogl DT, Cohen AD, Garfall AL, Mangan PA, et al. Financial toxicity in insured patients with multiple myeloma: a cross-sectional pilot study. Lancet Haematol 2015 Oct;2(10):e408-e416. [doi: 10.1016/S2352-3026(15)00151-9] [Medline: 26686042]

195. Dupre ME, Nelson A, Lynch SM, Granger BB, Xu H, Churchill E, et al. Socioeconomic, psychosocial and behavioral characteristics of patients hospitalized with cardiovascular disease. Am J Med Sci 2017 Dec;354(6):565-572 [FREE Full text] [doi: 10.1016/j.amjms.2017.07.011] [Medline: 29208253]
196. Newgard CD, Schmicker RH, Sopko G, Andrusiek D, Bialkowski W, Minei JP, Resuscitation Outcomes Consortium Investigators. Trauma in the neighborhood: a geospatial analysis and assessment of social determinants of major injury in North America. Am J Public Health 2011 Apr;101(4):669-677. [doi: 10.2105/AJPH.2010.300063] [Medline: 21389292]
197. Valentine SE, Elsesser S, Grasso C, Safren SA, Bradford JB, Mereish E, et al. The predictive syndemic effect of multiple psychosocial problems on health care costs and utilization among sexual minority women. J Urban Health 2015 Dec;92(6):1092-1104 [FREE Full text] [doi: 10.1007/s11524-015-9989-5] [Medline: 26438415]
198. Schuler TA, Zaider TI, Li Y, Hichenberg S, Masterson M, Kissane DW. Typology of perceived family functioning in an American sample of patients with advanced cancer. J Pain Symptom Manage 2014 Aug;48(2):281-288 [FREE Full text] [doi: 10.1016/j.jpainsymman.2013.09.013] [Medline: 24766739]
199. Parker MM, Moffet HH, Schillinger D, Adler N, Fernandez A, Ciechanowski P, et al. Ethnic differences in appointment-keeping and implications for the patient-centered medical home--findings from the Diabetes Study of Northern California (DISTANCE). Health Serv Res 2012 Apr;47(2):572-593 [FREE Full text] [doi: 10.1111/j.1475-6773.2011.01337.x] [Medline: 22091785]
200. Wallace ME, Mendola P, Liu D, Grantz KL. Joint effects of structural racism and income inequality on small-for-gestational-age birth. Am J Public Health 2015 Aug;105(8):1681-1688. [doi: 10.2105/AJPH.2015.302613] [Medline: 26066964]
201. Chetty R, Stepner M, Abraham S, Lin S, Scuderi B, Turner N, et al. The association between income and life expectancy in the United States, 2001-2014. J Am Med Assoc 2016 Apr 26;315(16):1750-1766 [FREE Full text] [doi: 10.1001/jama.2016.4226] [Medline: 27063997]
202. Shavers VL. Measurement of socioeconomic status in health disparities research. J Natl Med Assoc 2007 Sep;99(9):1013-1023. [Medline: 17913111]
203. Braveman PA, Cubbin C, Egerter S, Chideya S, Marchi KS, Metzler M, et al. Socioeconomic status in health research: one size does not fit all. J Am Med Assoc 2005 Dec 14;294(22):2879-2888. [doi: 10.1001/jama.294.22.2879] [Medline: 16352796]
204. Committee on the Recommended Social and Behavioral Domains and Measures for Electronic Health Records, Board on Population Health and Public Health Practice, Institute of Medicine. Capturing Social and Behavioral Domains in Electronic Health Records: Phase 1. Washington, DC: National Academies Press; 2014.
205. Boudreaux MH, Call KT, Turner J, Fried B, O'Hara B. Measurement error in public health insurance reporting in the American community survey: evidence from record linkage. Health Serv Res 2015 Dec;50(6):1973-1995 [FREE Full text] [doi: 10.1111/1475-6773.12308] [Medline: 25865628]
206. Macdonald H. The American community survey: warmer (more current), but fuzzier (less precise) than the decennial census. J Am Plan Assoc 2008 Mar 5;72(4):491-503. [doi: 10.1080/01944360608976768]
207. Center for Medicare & Medicaid Innovation - CMS. 2019. The Accountable Health Communities Health-Related Social Needs Screening Tool URL: https://innovation.cms.gov/Files/worksheets/ahcm-screeningtool.pdf [accessed 2019-08-13]
208. National Association of Community Health Centers. 2019. About the PRAPARE Assessment Tool URL: http://www.nachc.org/research-and-data/prapare/about-the-prapare-assessment-tool/ [accessed 2019-08-13]
209. HealthIT. 2019. Vocabulary/Code Set/Terminology Standards and Implementation Specifications URL: https://www.healthit.gov/isa/section-i-vocabularycode-setterminology-standards-and-implementation-specifications [accessed 2018-05-01]
210. Behforouz HL, Drain PK, Rhatigan JJ. Rethinking the social history. N Engl J Med 2014 Oct 2;371(14):1277-1279. [doi: 10.1056/NEJMp1404846] [Medline: 25271600]
211. Marra CA, Lynd LD, Harvard SS, Grubisic M. Agreement between aggregate and individual-level measures of income and education: a comparison across three patient groups. BMC Health Serv Res 2011 Mar 31;11:69 [FREE Full text] [doi: 10.1186/1472-6963-11-69] [Medline: 21453534]
212. Soobader MJ, LeClere FB, Hadden W, Maury B. Using aggregate geographic data to proxy individual socioeconomic status: does size matter? Am J Public Health 2001 Apr;91(4):632-636. [doi: 10.2105/ajph.91.4.632] [Medline: 11291379]
213. Geronimus AT, Bound J. Use of census-based aggregate variables to proxy for socioeconomic group: evidence from national samples. Am J Epidemiol 1998 Sep 1;148(5):475-486. [doi: 10.1093/oxfordjournals.aje.a009673] [Medline: 9737560]
214. Rajaratnam JK, Burke JG, O'Campo P. Maternal and child health and neighborhood context: the selection and construction of area-level variables. Health Place 2006 Dec;12(4):547-556. [doi: 10.1016/j.healthplace.2005.08.008] [Medline: 16188483]
215. O'Campo P, O'Brien CM. Measures of residential community contexts. In: Oakes JM, Kaufman JS, editors. Methods in Social Epidemiology. San Francisco, CA: Jossey-Bass; 2017.
216. Schuch L, Curtis A, Davidson J. Reducing lead exposure risk to vulnerable populations: a proactive geographic solution. Ann Am Assoc Geogr 2017 Feb 13;107(3):606-624. [doi: 10.1080/24694452.2016.1261689]
217. Marmot M. The influence of income on health: views of an epidemiologist. Health Aff (Millwood) 2002;21(2):31-46. [doi: 10.1377/hlthaff.21.2] [Medline: 11900185]

218. Cauthen NF, Fass S. National Center for Clinical in Poverty. 2008. Measuring Poverty in the United States URL: http://www.nccp.org/publications/pub_825.html [accessed 2019-08-13]
219. Betson DW, Warlick JL. Measuring poverty. In: Oakes JM, Kaufman JS, editors. Methods in Social Epidemiology. Second Edition. San Francisco: Jossey-Bass; 2017.

Abbreviations

EHR: electronic health record
SDoH: social determinants of health
SES: socioeconomic status

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Original Paper

Social Media Recruitment of Marginalized, Hard-to-Reach Populations: Development of Recruitment and Monitoring Guidelines

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Abstract

Background: Social media can be a useful strategy for recruiting hard-to-reach, stigmatized populations into research studies; however, it may also introduce risks for participant and research team exposure to negative comments. Currently, there is no published formal social media recruitment and monitoring guidelines that specifically address harm reduction for social media recruitment of marginalized populations.

Objective: The purpose of this research study was to investigate the utility, successes, challenges, and positive and negative consequences of using targeted Facebook advertisements as a strategy to recruit transgender and gender nonconforming (TGNC) people into a research study.

Methods: TGNC adults living in the Southeast Unites States were recruited via targeted Facebook advertisements over two cycles in April and June 2017. During cycle 1, researchers only used inclusion terms to recruit the target population. During cycle 2, the social media recruitment and monitoring protocol and inclusion and exclusion terms were used.

Results: The cycle 1 advertisement reached 8518 people and had 188 reactions, comments, and shares but produced cyberbullying, including discriminatory comments from Facebook members. Cycle 2 reached fewer people (6976) and received 166 reactions, comments, and shares but produced mostly positive comments.

Conclusions: Researchers must consider potential harms of using targeted Facebook advertisements to recruit hard-to-reach and stigmatized populations. To minimize harm to participants and research staff, researchers must preemptively implement detailed social media recruitment and monitoring guidelines for monitoring and responding to negative feedback on targeted Facebook advertisements.

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KEYWORDS

transgender; LGBTQ; TGNC; marginalized populations; cyberbullying; engagement; compassion fatigue; human subjects; research protections; adverse events

Introduction

Between the years of 2008 and 2018, social media use among adults in the United States tripled from 21% to 69% [1]. Today, nearly 7 in 10 Americans use social media to connect with peers, engage with news content, and share information [1]. Across the available social media platforms, Facebook is the leading social network with 1.49 billion active members [2]. In the United States, 78% of adults aged 30 to 49 years and 64% of adults aged 50 to 64 years report using Facebook daily [3].

Given the increased popularity of social media platforms, social science researchers are using social media to recruit participants into health, medical, and psychosocial research studies [4-8]. Reliance on social media recruitment has grown as traditional recruitment methods (eg, flyers, newspaper advertisements, mailings, randomized digit dialing) continue to experience barriers to successful study recruitment, especially for hard-to-reach and stigmatized groups [8-10]. Researchers have successfully used Facebook to recruit a vast array of populations who experience stigma or discrimination due to their country of origin [11,12], race or ethnicity [13,14], sexual orientation [15,16], health behaviors [17,18] or mental health status [19,20]. Examples include Spanish-speaking Latino gay men [21], black women in HIV-prevalent urban areas [22], partnered gay men [23], long-term smokers [10], immigrants with limited English proficiency [24], and adults suffering from depressive symptoms [25].

Facebook may be a more effective recruitment tool than traditional methods for capturing marginalized groups. For example, Carter-Harris and colleagues [10] determined that Facebook advertising was a more effective strategy than newspaper advertisements for recruiting stigmatized lung cancer patients who were long-term smokers. Facebook advertising produced more participants than newspaper advertisements (311 vs 30) for substantially lower cost per participant ($1.51 vs $40.80). Researchers' success in using Facebook as a recruitment tool for marginalized populations may be due to the varied levels of anonymity that social media affords users. Recruitment ads distributed via social media allow users to respond to online survey requests immediately and without requirement for in-person contact with the research team. Facebook users from stigmatized populations who view online recruitment ads may be more likely to participate in survey research that does not require direct contact with the research team, as is often required by traditional recruitment methods (ie, print advertisement providing an email or phone number for more information). For example, in Carter-Harris and colleagues' study [10], lung cancer patients who feared smoking-related stigma were more successfully recruited in a completely online setting that allowed for greater privacy and anonymity during recruitment and participation.

Facebook users also control the visibility and authenticity of their online identities by including personally identifying details in profiles or restricting access to their profiles by other users via privacy settings. Consequently, when engaging with study recruitment ads distributed via Facebook, potential study participants can choose to remain anonymous or share their online identity by engaging with the recruitment advertisement (eg, by liking, commenting, or reposting). Accordingly, members of marginalized populations may feel more comfortable engaging with social media recruitment advertisements (eg, to ask questions or share study information) because they can choose profile and privacy settings to assert control over how much of their personal information is available to both study team members and other users.

Historically, transgender and gender nonconforming people (TGNC; individuals whose gender identity does not match their sex assigned at birth) [26] are underrepresented in peer-reviewed health-related literature [27,28]. One explanation is that most publicly available, population-based health surveillance surveys do not include gender identity measures [28,29]. Therefore, researchers wishing to document and describe the health of this population must recruit TGNC people into research studies via convenience samples in community-based spaces [30-32]. These spaces may be in-person via TGNC-inclusive organizations or groups or via online platforms, including social media [33].

While several studies have successfully used Facebook to recruit a wide range of hard-to-locate and/or stigmatized populations [4,5,10,22,23,34,35], there is little evidence describing the possible benefits and risks of using Facebook to recruit TGNC people. This is especially important because TGNC are at high risk of experiencing digital harassment, abuse, and cyberbullying online. In their study assessing cyberbullying among young adults worldwide, Myers and colleagues [36] concluded that transgender participants experienced digital harassment at a substantially higher frequency than cisgender (individuals whose gender identity matches their sex assigned at birth) males and females. Similarly, in a study assessing digital harassment and abuse among adults in England and Australia, almost two-thirds of transgender participants reported being threatened with physical harm by another person online and 60% reported experiencing digital harassment in the forms of offensive and degrading posts and direct messages about their gender identity and sexuality [37]. It is possible that TGNC participants who engage with research study advertisements distributed via Facebook may experience digital harassment, abuse, or cyberbullying in these forums; however, no evidence documents this phenomenon in the scholarly, peer-reviewed literature.

Using targeted Facebook advertisements is a relatively new recruitment method for engaging participants from highly stigmatized groups in research studies [38]. While several white papers and articles outline best practices and ethical considerations for researchers considering social media recruitment in general [6,39,40], no published guidelines exist in the peer-reviewed literature detailing safety and monitoring strategies for recruiting marginalized populations via social media. In the absence of evidence-based and best practice guidance, researchers cannot anticipate potential challenges or harms in social media recruitment of stigmatized populations or proactively build adequate safety and monitoring strategies into study protocols. Developing social media recruitment safety and monitoring guidelines require researchers who are using social media for study recruitment to be prepared to address risks of using social media including protecting participants and research staff and share methodological lessons learned to guide the development of safety and monitoring guidelines that can be applied to future recruitment-related processes.

The purpose of this research was to investigate the utility, successes, challenges, and positive and negative consequences of using targeted Facebook advertisements as a strategy to recruit TGNC people into a research study. We also sought to translate lessons learned from this study into recommendations for formal, duplicable guidelines (Social Media Recruitment Safety and Monitoring Guidelines) for researchers who are considering Facebook advertisements as a recruitment method for marginalized populations.

Methods

Ethics

The University of Tennessee institutional review board (IRB) approved all study procedures (UTK IRB-16-03275-XP).

Recruitment

Participants for this study were recruited via targeted Facebook advertisements for an original study investigating experiences of food insecurity among TGNC people living in the Southeast United States [41]. Using a public Facebook page designed to represent a public health research lab at a state university, two successive recruitment cycles were conducted in April (Textbox 1) and June (Textbox 2) 2017. The same image and text (Figure 1) were used in both recruitment cycles, containing a brief introduction to the study and contact information for the study's principal investigator (PI).

Textbox 1. Cycle 1 selection criteria.

Inclusion criteria:

- Aged 18 to 50 years, male and female
- Interests: lesbian, gay, bisexual, transgender (LGBT)
- Locations: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, and West Virginia
- Additional interests: Gay, Lesbian, Bisexual, Transgender, Straight Alliance; genderqueer; Lesbian, Gay, Bisexual, Transgender Community Center; National Center for Transgender Equality; trans women; transgender; transgender activism; Transgender Day of Remembrance; Transgender Law Center; transgenderism; Coming Out; Gay Pride; Gay Times; gender identity; homosexuality; Human Rights Campaign; LGBT community; LGBT network; LGBT social movements; Out Magazine; Pink (LGBT magazine); same-sex marriage; transgender youth

Exclusion criteria:

- None

Textbox 2. Cycle 2 selection criteria.

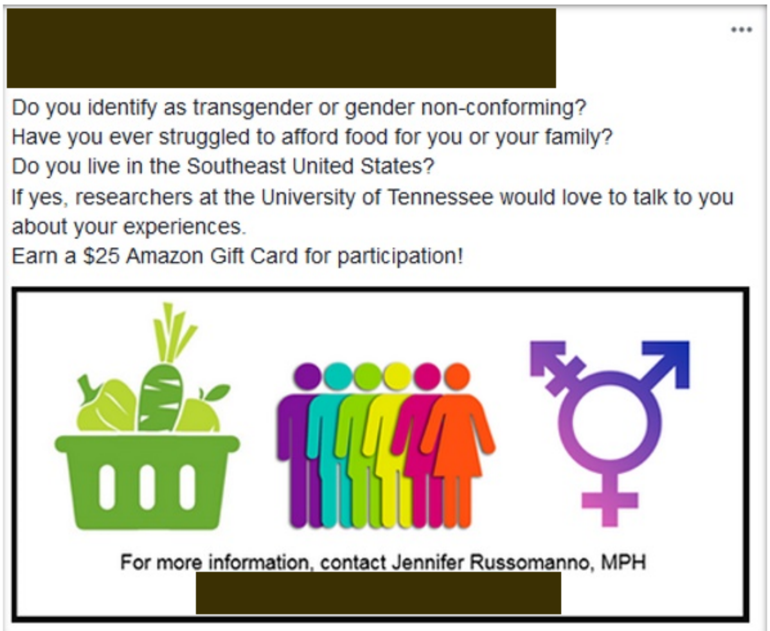
Inclusion criteria:

- Aged 18 to 50 years, male and female
- Interests: lesbian, gay, bisexual, transgender (LGBT)
- Locations: Alabama, Arkansas, Florida, Georgia, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee, Virginia, and West Virginia
- Additional interests: Gay, Lesbian, Bisexual, Transgender, Straight Alliance; genderqueer; Lesbian, Gay, Bisexual, Transgender Community Center; National Center for Transgender Equality; trans women; transgender; transgender activism; Transgender Day of Remembrance; Transgender Law Center; transgenderism

Exclusion criteria:

- Demographics > politics: US politics (conservative)
- Demographics > work > employers: Republican National Committee, Republican Party
- Interests > additional interests: Donald Trump, Guns & Ammo, Mike Pence, Paul Ryan, The Conservative

Figure 1. Targeted Facebook advertisement.



[redacted]

Do you identify as transgender or gender non-conforming?
Have you ever struggled to afford food for you or your family?
Do you live in the Southeast United States?
If yes, researchers at the University of Tennessee would love to talk to you about your experiences.
Earn a $25 Amazon Gift Card for participation!

For more information, contact Jennifer Russomanno, MPH

[redacted]

Measures

Facebook monitors all forms of engagement in real time for the duration of any recruitment cycle and provides counts and summaries of each form of engagement at the cycle's conclusion. We measured Facebook member engagement with each recruitment advertisement cycle by counting number and type of reactions, number of shares, and number and quality of comments. Likes, loves, and shares were counted as positive engagements. Angry, laughing, or sad reactions were counted as negative engagements. Laughter was considered a negative engagement because we interpreted laughing at the advertisement to be laughing at the recruitment content (food insecurity among those who identify as TGNC), which is not a positive affective response to a troubling public health issue.

We considered comments positive or negative based on their written content. A comment was considered negative if it included any derogatory language aimed at the target population (TGNC people) or study topic (food security), used profanity, or if the comment contained language that could be perceived as actual or potential threats of violence toward TGNC people. Comments were considered positive if they contained language that was supportive of TGNC people or the study topic.

Facebook business notifications are updates that Facebook sends to users reflecting any activity on Facebook advertisements or posts with which the user is associated [42]. Research team members were notified on their mobile phones each time there was engagement with the recruitment advertisement. Once the advertisement's designated duration concluded, Facebook produced a summary of the advertisement's overall results including the total number of Facebook members reached by the advertisement and the number of specific engagements on the advertisement. After each cycle was completed, the PI downloaded measures of engagement from Facebook for analysis.

Analysis

We calculated summary and descriptive statistics using Facebook's autogenerated engagement activity for both recruitment cycles. Counts of specific reactions, shares, and comments were tallied and summarized for each advertisement cycle. Individual advertisement cycle counts were then entered into an Excel spreadsheet (Microsoft Corp) and compared between cycles. The research team consistently and continuously monitored open-ended comments posted by Facebook members in reaction to each advertisement throughout each advertisement's duration.

Results

Summary Statistics

Table 1 summarizes engagement activity for both recruitment cycles. Figures 2 and 3 provide an overview of the cycle 1 and cycle 2 summary statistics autogenerated by Facebook at the conclusion of each cycle duration. We successfully recruited TGNC participants from both cycles. Seven participants were recruited from cycle 1. Seven participants were also recruited from cycle 2, with 3 additional people contacting the PI to participate after the study was closed to recruitment.

The cycle 1 advertisement reached 8518 Facebook members with 188 unique engagements (reactions, comments, and shares). Cycle 1 drew 85 positive engagements (65 likes, 2 loves, and 18 shares) and 12 negative engagements (3 angry reactions and 9 laughing reactions). Cycle 1 also drew several negative comments, which included derogatory, threatening, and discriminatory remarks about TGNC people. The cycle 2 advertisement reached 6976 Facebook members with 166 unique engagements. Cycle 2 drew 134 positive engagements (87 likes, 7 loves, and 40 shares) and only 2 negative engagements (laughing reactions). The cycle 2 advertisement received more positive feedback from Facebook members than cycle 1. The cycle 2 advertisement had a 40% increase in positive reactions (likes and loves: 67 in cycle 1 vs 94 in cycle 2) and a 122%

increase in post shares by Facebook members compared with cycle 1 (18 in cycle 1 vs 40 in cycle 2). Compared with cycle 1, cycle 2 reached 178 more Facebook members on a daily basis due to the increase in advertisement post shares.

Table 1. Facebook engagements for recruitment cycles 1 and 2.

Interactions	Cycle 1 – 7 days (n=8518)	Cycle 2 – 5 days (n=6976)	Difference
Total engagement (reactions, comments, and shares)	188	166	–22
Positive interactions			
Total likes	65	87	22
Total loves	2	7	5
Total shares	18	40	22
Negative interactions			
Total haha	9	2	–7
Total sad	1	0	–1
Total angry	3	0	–3
Other interactions			
Total comments	91	30	–61
Total person reach per day	1217	1395	178

Figure 2. Cycle 1 advertisement Facebook summary report.

Post Details

Reported stats may be delayed from what appears on posts

[redacted]

Do you identify as transgender or gender non-conforming?
Have you ever struggled to afford food for you or your family?
Do you live in the Southeast United States?
If yes, researchers at the University of Tennessee would love to talk to you about your experiences.
Earn a $25 Amazon Gift Card for participation!

For more information, contact Jennifer Russomanno, MPH

[redacted]

8,518 people reached

55 19 Comments 17 Shares

8,518 People Reached

188 Reactions, Comments & Shares

65 Like	**41** On Post	**24** On Shares
2 Love	**1** On Post	**1** On Shares
9 Haha	**9** On Post	**0** On Shares
1 Sad	**1** On Post	**0** On Shares
3 Angry	**3** On Post	**0** On Shares
91 Comments	**40** On Post	**51** On Shares
18 Shares	**17** On Post	**1** On Shares

691 Post Clicks

536 Photo Views	**0** Link Clicks	**155** Other Clicks

NEGATIVE FEEDBACK

1 Hide Post	**0** Hide All Posts
0 Report as Spam	**0** Unlike Page

Figure 3. Cycle 2 advertisement Facebook summary report.

Post Details

Reported stats may be delayed from what appears on posts

[redacted]

Do you identify as transgender or gender non-conforming?
Have you ever struggled to afford food for you or your family?
Do you live in the Southeast United States?
If yes, researchers at the University of Tennessee would love to talk to you about your experiences.
Earn a $25 Amazon Gift Card for participation!

For more information, contact Jennifer Russomanno, MPH
[redacted]

6,976 people reached

6,976 People Reached

166 Reactions, Comments & Shares

87 Like	**70** On Post	**17** On Shares
7 Love	**7** On Post	**0** On Shares
2 Haha	**1** On Post	**1** On Shares
30 Comments	**18** On Post	**12** On Shares
40 Shares	**38** On Post	**2** On Shares

337 Post Clicks

178 Photo Views	**0** Link Clicks	**159** Other Clicks

NEGATIVE FEEDBACK

0 Hide Post	**0** Hide All Posts
0 Report as Spam	**0** Unlike Page

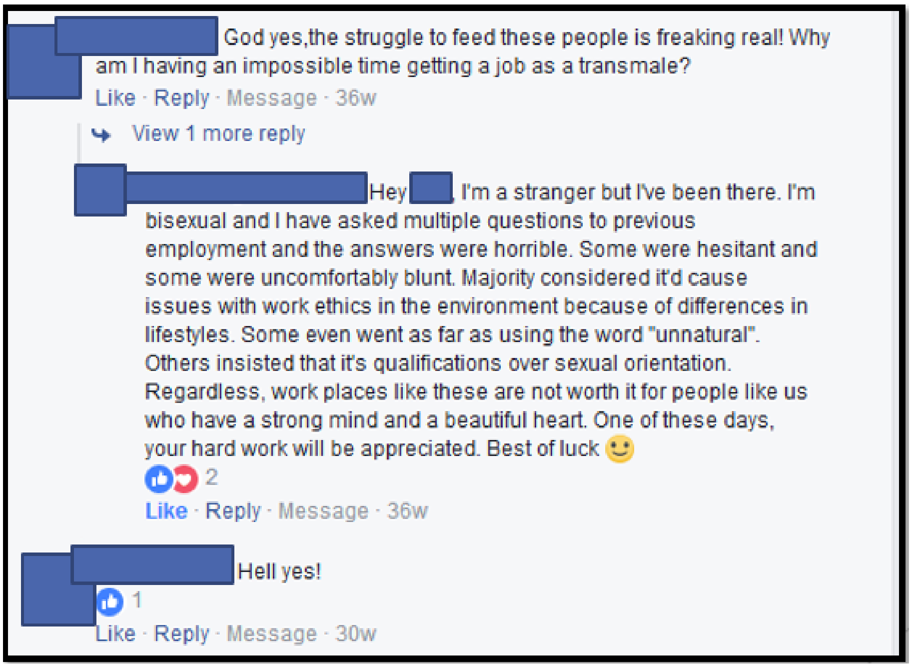
Negative Consequences of Targeted Facebook Advertisements

During recruitment cycle 1, Facebook members negatively engaged with the advertisement by posting haha (n=9), angry (n=3), and sad (n=1) reactions. There were also several negative, cyberbullying comments made by Facebook members that were derogatory in nature, inflammatory, and potentially emotionally and mentally damaging to TGNC people. As soon as negative comments and cyberbullying began during cycle 1, research team members began continuously monitoring the advertisement for any potential negative comments, reactions, or private messages. Specifically, we assigned team members to respond to Facebook notifications during specific time periods, so that we could monitor posts 24 hours per day for the remaining duration of the recruitment cycle. Research team members immediately deleted negative comments made in response to advertisements.

When using targeted Facebook advertisements to recruit gay men into a 2015 research study, Mitchell and colleagues [23] received negative feedback to their advertisement in three forms: public comments posted on the Facebook advertisement and on the study's public Facebook page, private messages sent to the Facebook study's page, and voicemail. When addressing their experiences of cyberbullying during recruitment with Facebook representatives, Mitchell and colleagues [23] learned that any interests used as inclusion terms for targeted Facebook advertisements reach Facebook members who indicate either positive or negative views about a given interest. This means that Facebook members with negative views or opinions about a given interest could be inadvertently exposed to an advertisement. This unintended exposure creates a context in which Facebook members with negative views can engage with an advertisement, potentially creating a scenario in which these members make negative comments and engage in cyberbullying toward the intended study population [23].

During study recruitment cycle 1, the inadvertent exposure of the advertisement to Facebook members with negative views resulted in transphobic and discriminatory comments on the advertisement. After the cycle 1 experiences, we applied exclusion criteria similar to those set forth by Mitchell and colleagues [23] to the cycle 2 recruitment advertisement, and the second advertisement received more favorable and positive interactions from Facebook members. During cycle 2 recruitment, negative engagements were minimal, and there were only 2 haha reactions. Comments made by Facebook members during cycle 2 were positive and supportive of the TGNC community. Figure 4 shows an example of a positive comment thread received during cycle 2.

Figure 4. Sample supportive comment thread received during cycle 2.



[redacted] God yes,the struggle to feed these people is freaking real! Why am I having an impossible time getting a job as a transmale?

Like · Reply · Message · 36w

View 1 more reply

[redacted] Hey [redacted] I'm a stranger but I've been there. I'm bisexual and I have asked multiple questions to previous employment and the answers were horrible. Some were hesitant and some were uncomfortably blunt. Majority considered it'd cause issues with work ethics in the environment because of differences in lifestyles. Some even went as far as using the word "unnatural". Others insisted that it's qualifications over sexual orientation. Regardless, work places like these are not worth it for people like us who have a strong mind and a beautiful heart. One of these days, your hard work will be appreciated. Best of luck 🙂

2

Like · Reply · Message · 36w

[redacted] Hell yes!

1

Like · Reply · Message · 30w

Discussion

Principal Findings

The purpose of this research study was to investigate the utility, successes, challenges, and positive and negative consequences of using targeted Facebook advertisements as a strategy to recruit TGNC people into a research study. TGNC people were quickly and effectively recruited into the study using Facebook; therefore, Facebook was determined to be a successful recruitment tool for the TGNC population. However, using Facebook to recruit TGNC people also produced unanticipated negative consequences for potential study participants, social media users viewing the advertisement in general (eg, TGNC people who were not potential participants), and research staff. During recruitment cycle 1, negative engagements in the form of degrading and derogatory comments were made by Facebook members on the advertisement's post. The comments were discriminatory, which could have resulted in mental and emotional distress for potential study participants or other in-group (ie, TGNC people) or allied (eg, lesbian, gay, and bisexual people and other non-TGNC allies) social media users who viewed the advertisement. The receipt of negative and discriminatory comments is consistent with previous studies by Myers et al [36] and Powell et al [37] where study participants who identified as transgender reported high rates of digital harassment and abuse in online settings.

In addition to the potential damaging consequences for social media users, negative Facebook comments can also adversely affect research team members who manage and monitor the advertisement. For research team members who identify as members of or allies to the TGNC and lesbian, gay, bisexual, transgender, and queer (LGBTQ) communities, witnessing digital harassment and abuse can be especially damaging. In our study, the research team comprised three cisgender females who all identify as members of the LGBTQ community, and exposure to negative and stigmatizing comments toward other members of the LGBTQ/TGNC community resulted in secondary trauma for team members.

Secondary traumatic stress (STS), also known as compassion fatigue, experienced by research staff is not widely addressed in published literature. Qualitative scholars [43,44], those engaged in feminist social work [45], and those who conduct research with trauma counselors or therapists [46] discuss STS as a common emotional response to engaging with challenging or emotionally laden subjects or experiences. Researchers involved in the recruitment of stigmatized populations who witness and manage adverse events, including harassment and abuse, may experience similar instances of STS. For researchers engaged in difficult and challenging subject matter, STS can occur when team members are given the ability to see the world through their participants' eyes [44]. In our study, team members were exposed daily to digital harassment and abuse faced by TGNC community members. Researchers who have a personal connection to the subject matter or who have experienced their own personal trauma are also at a high risk of experiencing STS [47]. To mitigate the potential effects of STS, we held weekly debrief sessions for all research team members to reflect and discuss emotional and psychological reactions arising from witnessing and responding to negative, degrading, and damaging Facebook advertisement comments.

Social Media Recruitment and Monitoring Guidelines for Targeted Facebook Advertisements

With careful consideration and strategic planning, targeted Facebook advertisements can be a useful method for recruiting marginalized people into research studies. To the best of our knowledge, this is the first formal, published safety and monitoring guidelines for researchers using social media for this purpose. As our team experienced positive and negative repercussions while using Facebook advertisements for recruitment, we dynamically adjusted our monitoring strategies across recruitment periods to minimize harm for participants and research staff. Given our experience, we offer a specific guidelines for monitoring and responding to Facebook advertisements aimed at marginalized or stigmatized populations. We have also included recommendations for preparing and responding to participant and staff/research team exposure to negative comments or interactions on a Facebook advertisement.

Monitoring

Defining Facebook Page Administration

Targeted Facebook advertisements are posted through publicly accessible Facebook pages associated with the study PI or research lab. To ensure adequate monitoring of the advertisement, at least two research team members should be assigned as administrators of the public page hosting the advertisement. Page administrators are able to define page and advertisement settings and receive automatic updates of posts to the public page or advertisement. We recommend that a research team use a shared decision-making process to assign page administrator roles, as page administrators work collaboratively to monitor and respond to comments made on the public page and study advertisements.

Notifications

To assure continuous monitoring, all page administrators should download the Facebook app to their mobile phones prior to beginning study recruitment. The administrators should monitor all notifications and interactions with the recruitment advertisement based on a predetermined schedule defined by the research team. Prior to launching the recruitment advertisement, the research team must determine how frequently (eg, hourly or daily) administrators should monitor the advertisement during active recruitment. A daily monitoring log should be established by research team members to ensure the advertisement has continuous monitoring throughout a cycle's duration.

Recruitment Cycle Duration

Advertisements should be posted for, at maximum, 7 days per cycle to minimize burnout to research staff during recruitment while maximizing reach to the population of interest. Multiple recruitment cycles may be used until the desired sample size is achieved.

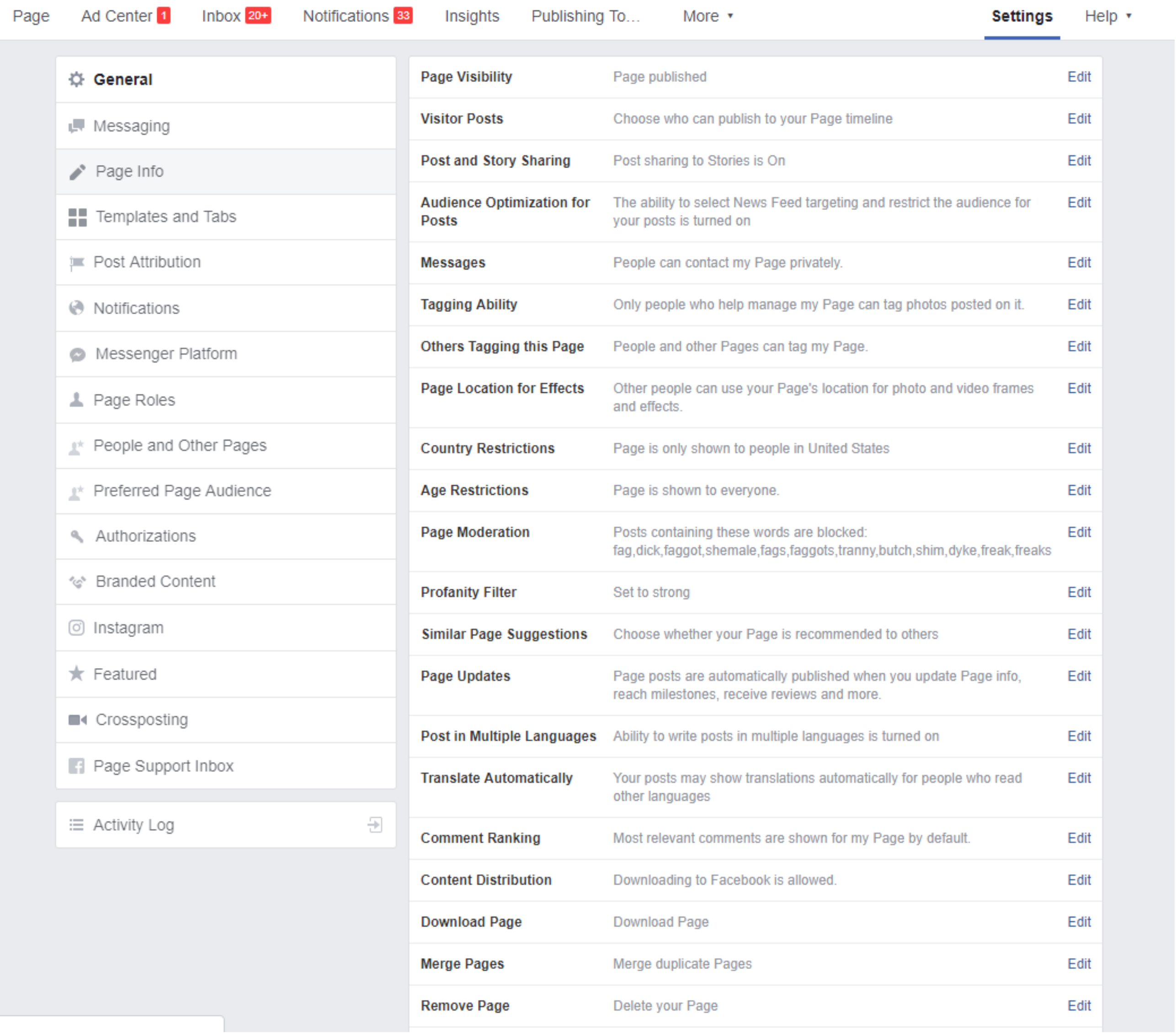
Inclusion and Exclusion Terms

To target advertisements to the study population of interest, researchers should use inclusion and exclusion terms based on study criteria. Inclusion terms include words, phrases, interests, or social/identity groups to which the advertisement applies. Exclusion terms include words, phrases, interests, or social/identity groups that may hold negative opinions of the target audience or research subject. Exclusion terms are included to guard against the inclusion of social media users who may engage in digital harassment and cyberbullying directed at the intended study population.

Public Page Settings and Moderation

Figure 5 outlines options that are available under the Settings tab on public Facebook pages or profiles. Researchers may restrict who can post directly to a public page by turning off the Visitor Posts feature. This ensures that only page administrators can post directly to the public site. If the study population of interest is US-based, researchers may restrict the country option to "US only" to ensure that only Facebook members residing in the United States can respond to the advertisement. This setting may be changed to direct advertisements to the researcher's country of interest. While researchers cannot restrict social media users from commenting on the recruitment advertisement [48], the Facebook profanity filter can be set to high. This feature automatically restricts any comment that includes profanity from being posted to the recruitment advertisement. Additionally, under page moderation, the research team may block words or phrases deemed as derogatory toward the target population.

Figure 5. Public Facebook page settings.



Page Visibility	Page published	Edit
Visitor Posts	Choose who can publish to your Page timeline	Edit
Post and Story Sharing	Post sharing to Stories is On	Edit
Audience Optimization for Posts	The ability to select News Feed targeting and restrict the audience for your posts is turned on	Edit
Messages	People can contact my Page privately.	Edit
Tagging Ability	Only people who help manage my Page can tag photos posted on it.	Edit
Others Tagging this Page	People and other Pages can tag my Page.	Edit
Page Location for Effects	Other people can use your Page's location for photo and video frames and effects.	Edit
Country Restrictions	Page is only shown to people in United States	Edit
Age Restrictions	Page is shown to everyone.	Edit
Page Moderation	Posts containing these words are blocked: fag,dick,faggot,shemale,fags,faggots,tranny,butch,shim,dyke,freak,freaks	Edit
Profanity Filter	Set to strong	Edit
Similar Page Suggestions	Choose whether your Page is recommended to others	Edit
Page Updates	Page posts are automatically published when you update Page info, reach milestones, receive reviews and more.	Edit
Post in Multiple Languages	Ability to write posts in multiple languages is turned on	Edit
Translate Automatically	Your posts may show translations automatically for people who read other languages	Edit
Comment Ranking	Most relevant comments are shown for my Page by default.	Edit
Content Distribution	Downloading to Facebook is allowed.	Edit
Download Page	Download Page	Edit
Merge Pages	Merge duplicate Pages	Edit
Remove Page	Delete your Page	Edit

Responding

While restricted and blocked comments are hidden to social media users, they can be seen by page administrators. As such, research team members have ample time to review and respond to profane or derogatory comments. For example, the research team may decide to unhide a comment if the content does not contain harassing or bullying behavior. However, in the case of threatening, negative, discriminatory, and/or bullying comments on recruitment advertisements, precautions must be taken. First, if not automatically blocked by Facebook via profanity or other filters, negative comments should be hidden by an authorized administrator. Researchers should continue to hide/block comments if the content constitutes digital harassment or cyberbullying. Research staff may also review blocked comments for patterns of repeated posts from troll users; these users may be blocked entirely from interacting with the public Facebook page (and associated advertisements) by page administrators. Facebook members responsible for negative or bullying comments may also be reported to Facebook for violating Facebook's community standards policy [49].

Given that social media development is a dynamic process, we strongly encourage research teams to review Facebook's updated privacy, page moderation, profanity, and reporting features prior to recruitment, while in the study planning phase. Reviewing these features and including them in a social media recruitment and monitoring guidelines proactively will help ensure that research teams are taking advantage of all automated protections offered by Facebook specific to page and advertisement moderation. Ultimately, the goal is to reduce burden on research staff in social media recruitment and monitoring while decreasing social media users' exposure to negative comments and cyberbullying.

Reporting

During the active recruitment and monitoring phase, all negative comments and interactions with social media and screenshots should be reported to the research PI by email within 24 hours. Screen shots should be saved by the PI in a secure, password-protected electronic location. The research team should reflect on their institution's policies to determine if negative comments and interactions made on Facebook recruitment advertisements or the public page should be reported to their IRB. Human subjects research protections require that unanticipated problems that are unexpected, related, or possibly related to the research study and may place participants or others at greater risk of harm than was initially known or recognized be reported promptly to the IRB [50]. Specifically, US Department of Health and Human Services guidance notes that "Unanticipated problems that are serious adverse events should be reported to the IRB within 1 week of the investigator becoming aware of the event" [50]. However, due to the fast-paced nature of online recruitment, we recommend that any negative comments or interactions reported by study participants to the research team as harmful (eg, emotional or psychological harm, threatened physical harm) be reported by the PI to the IRB within 48 hours of the event.

All interactions with the advertisement are quantitatively captured by Facebook analytics, and summary reports should be downloaded by page administrators and recorded after each recruitment cycle. Each summary report should be saved and reviewed as necessary for tracking interactions with recruitment advertisements. The number of negative comments and their content (ie, specific statements) should be documented by the research PI.

Dealing With Exposure to Negative Comments and Interactions

Research and Study Staff

We recommend that negative comments and interactions be processed and debriefed during frequent (ie, weekly) research team meetings to mitigate ST and compassion fatigue. This is especially important if study team members identify with the population of interest, as they may be at higher risk for experiencing STS. We also recommend that contact information for affordable and/or free and sliding scale psychological services be provided to research team members. For student research staff, this may include a mix of campus-based student psychological and mental health services and community-based resources. For employees, resources may include contact information for the employee assistance program and affordable community-based resources. It is important to consider the cultural background of research team members when providing community-specific resource lists. For example, for a study on LGBTQ or TGNC health wherein study team members also identify as LGBTQ, including LGBTQ-friendly resources is imperative.

General Public

It is possible that the general public may be exposed to negative comments and interactions on an advertisement for study recruitment before the comment can be identified and removed by study staff. We recommend that in the About section of the originating public social media page, page administrators list available support resources for individuals to access for support and coping with cyberbullying. These should be listed with appropriate contact information that is culturally specific to the region, topic, and/or target population and provides best possible accessibility (eg, a mix of national or regional hotlines, websites, and community-based resources as appropriate, including low or no-cost resources).

Areas for Future Research on Recruitment-Related Processes

No formal guidelines existed for social media recruitment of marginalized populations. Guideline recommendations provided in this paper address this gap. However, these guidelines should continue to be tested and adapted as needed by researchers using Facebook to recruit marginalized or stigmatized populations. Additionally, researchers should consider adding qualitative interviews or focus groups to studies using social media recruitment methods to assess the experiences of recruited study participants.

Conclusion

Facebook can be a useful tool when recruiting hard-to-reach, stigmatized populations. Targeted Facebook advertisements have the ability to reach large numbers of participants who otherwise may be hidden to research staff. However, for all the benefits that Facebook recruitment provides, there can be negative consequences of using this method. Creating detailed social media recruitment safety and monitoring guidelines in advance of using targeted Facebook advertisements may minimize and mitigate the risk to potential research participants and research team members.

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Conflicts of Interest

None declared.

References

1. Social media fact sheet. Washington: Pew Internet and American Life Project; 2019 Jun 12. URL: http://www.pewinternet.org/fact-sheet/social-media/ [accessed 2019-02-26]
2. Facebook reports third quarter 2018 results. Menlo Park: Facebook Investor Relations; 2018 Oct 30. URL: https://investor.fb.com/investor-news/press-release-details/2018/Facebook-Reports-Third-Quarter-2018-Results/default.aspx [accessed 2019-01-23]
3. Social media use in 2018. Washington: Pew Internet and American Life Project; 2018 Mar 01. URL: https://www.pewinternet.org/wp-content/uploads/sites/9/2018/02/PI_2018.03.01_Social-Media_FINAL.pdf [accessed 2019-10-14]

4. Whitaker C, Stevelink S, Fear N. The use of Facebook in recruiting participants for health research purposes: a systematic review. J Med Internet Res 2017 Aug 28;19(8):e290 [FREE Full text] [doi: 10.2196/jmir.7071] [Medline: 28851679]
5. Thornton L, Batterham PJ, Fassnacht DB, Kay-Lambkin F, Calear AL, Hunt S. Recruiting for health, medical or psychosocial research using Facebook: systematic review. Internet Interv 2016 May;4:72-81 [FREE Full text] [doi: 10.1016/j.invent.2016.02.001] [Medline: 30135792]
6. Topolovec-Vranic J, Natarajan K. The use of social media in recruitment for medical research studies: a scoping review. J Med Internet Res 2016 Nov 7;18(11):e286 [FREE Full text] [doi: 10.2196/jmir.5698] [Medline: 27821383]
7. Capurro D, Cole K, Echavarría MI, Joe J, Neogi T, Turner AM. The use of social networking sites for public health practice and research: a systematic review. J Med Internet Res 2014;16(3):e79 [FREE Full text] [doi: 10.2196/jmir.2679] [Medline: 24642014]
8. Allison M. Can web 2.0 reboot clinical trials? Nat Biotechnol 2009 Oct;27(10):895-902. [doi: 10.1038/nbt1009-895] [Medline: 19816442]
9. Yancey AK, Ortega AN, Kumanyika SK. Effective recruitment and retention of minority research participants. Annu Rev Public Health 2006;27:1-28. [doi: 10.1146/annurev.publhealth.27.021405.102113] [Medline: 16533107]
10. Carter-Harris L, Bartlett ER, Warrick A, Rawl S. Beyond traditional newspaper advertisement: leveraging Facebook-targeted advertisement to recruit long-term smokers for research. J Med Internet Res 2016;18(6):e117 [FREE Full text] [doi: 10.2196/jmir.5502] [Medline: 27306780]
11. Morey BN. Mechanisms by which anti-immigrant stigma exacerbates racial/ethnic health disparities. Am J Public Health 2018 Apr;108(4):460-463. [doi: 10.2105/AJPH.2017.304266] [Medline: 29470116]
12. Ramirez-Valles J, Fergus S, Reisen CA, Poppen PJ, Zea MC. Confronting stigma: community involvement and psychological well-being among HIV-positive Latino gay men. Hisp J Behav Sci 2016 Jul 25;27(1):101-119. [doi: 10.1177/0739986304270232]
13. Earnshaw VA, Bogart LM, Dovidio JF, Williams DR. Stigma and racial/ethnic HIV disparities: moving toward resilience. Am Psychol 2013;68(4):225-236 [FREE Full text] [doi: 10.1037/a0032705] [Medline: 23688090]
14. Wailoo K. Stigma, race, and disease in 20th century America. Lancet 2006 Feb 11;367(9509):531-533. [doi: 10.1016/S0140-6736(06)68186-5] [Medline: 16473131]
15. Saewyc EM. Research on adolescent sexual orientation: development, health disparities, stigma and resilience. J Res Adolesc 2011 Feb 15;21(1):256-272 [FREE Full text] [doi: 10.1111/j.1532-7795.2010.00727.x] [Medline: 27099454]
16. Ragins BR, Singh R, Cornwell JM. Making the invisible visible: fear and disclosure of sexual orientation at work. J Appl Psychol 2007 Jul;92(4):1103-1118. [doi: 10.1037/0021-9010.92.4.1103] [Medline: 17638468]
17. Evans-Polce RJ, Castaldelli-Maia JM, Schomerus G, Evans-Lacko SE. The downside of tobacco control? Smoking and self-stigma: a systematic review. Soc Sci Med 2015 Nov;145:26-34 [FREE Full text] [doi: 10.1016/j.socscimed.2015.09.026] [Medline: 26439764]
18. Graham H. Smoking, stigma and social class. J Soc Pol 2011 Jun 15;41(1):83-99. [doi: 10.1017/s004727941100033x]
19. Conner KO, Copeland VC, Grote NK, Koeske G, Rosen D, Reynolds CF, et al. Mental health treatment seeking among older adults with depression: the impact of stigma and race. Am J Geriatr Psychiatry 2010 Jun;18(6):531-543 [FREE Full text] [doi: 10.1097/JGP.0b013e3181cc0366] [Medline: 20220602]
20. Vega WA, Rodriguez MA, Ang A. Addressing stigma of depression in Latino primary care patients. Gen Hosp Psychiatry 2010;32(2):182-191. [doi: 10.1016/j.genhosppsych.2009.10.008] [Medline: 20302993]
21. Martinez O, Wu E, Shultz AZ, Capote J, López RJ, Sandfort T, et al. Still a hard-to-reach population? Using social media to recruit Latino gay couples for an HIV intervention adaptation study. J Med Internet Res 2014;16(4):e113 [FREE Full text] [doi: 10.2196/jmir.3311] [Medline: 24763130]
22. Jones R, Lacroix LJ, Nolte K. "Is Your Man Stepping Out" An online pilot study to evaluate acceptability of a guide-enhanced HIV prevention soap opera video series and feasibility of recruitment by Facebook advertising. J Assoc Nurses AIDS Care 2015;26(4):368-386 [FREE Full text] [doi: 10.1016/j.jana.2015.01.004] [Medline: 26066692]
23. Mitchell J, Lee J, Stephenson R. How best to obtain valid, verifiable data online from male couples? Lessons learned from an eHealth HIV prevention intervention for HIV-negative male couples. JMIR Public Health Surveill 2016 Sep 20;2(2):e152 [FREE Full text] [doi: 10.2196/publichealth.6392] [Medline: 27649587]
24. Carlini BH, Safioti L, Rue TC, Miles L. Using Internet to recruit immigrants with language and culture barriers for tobacco and alcohol use screening: a study among Brazilians. J Immigr Minor Health 2015 Apr;17(2):553-560. [doi: 10.1007/s10903-013-9934-1] [Medline: 24563138]
25. Morgan AJ, Jorm AF, Mackinnon AJ. Internet-based recruitment to a depression prevention intervention: lessons from the Mood Memos study. J Med Internet Res 2013;15(2):e31 [FREE Full text] [doi: 10.2196/jmir.2262] [Medline: 23403043]
26. Stryker S. Transgender History. Berkeley: Seal Press; 2008.
27. Boehmer U. Twenty years of public health research: inclusion of lesbian, gay, bisexual, and transgender populations. Am J Public Health 2002 Jul;92(7):1125-1130. [doi: 10.2105/ajph.92.7.1125] [Medline: 12084696]
28. Reisner SL, Conron K, Scout N, Mimiaga MJ, Haneuse S, Austin SB. Comparing in-person and online survey respondents in the US National Transgender Discrimination Survey: implications for transgender health research. LGBT Health 2014 Jun;1(2):98-106. [doi: 10.1089/lgbt.2013.0018] [Medline: 26789619]

29. Patterson JG, Jabson JM, Bowen DJ. Measuring sexual and gender minority populations in health surveillance. LGBT Health 2017 Apr;4(2):82-105 [FREE Full text] [doi: 10.1089/lgbt.2016.0026] [Medline: 28287877]
30. Marshall SA, Allison MK, Stewart MK, Thompson ND, Archie DS. Highest priority health and health care concerns of transgender and nonbinary individuals in a southern state. Transgend Health 2018;3(1):190-200 [FREE Full text] [doi: 10.1089/trgh.2018.0003] [Medline: 30581992]
31. Rosentel K, Hill BJ, Lu C, Barnett JT. Transgender veterans and the Veterans Health Administration: exploring the experiences of transgender veterans in the Veterans Affairs healthcare system. Transgend Health 2016;1(1):108-116 [FREE Full text] [doi: 10.1089/trgh.2016.0006] [Medline: 29159302]
32. Hill BJ, Rosentel K, Bak T, Silverman M, Crosby R, Salazar L, et al. Exploring individual and structural factors associated with employment among young transgender women of color using a no-cost transgender legal resource center. Transgend Health 2017;2(1):29-34 [FREE Full text] [doi: 10.1089/trgh.2016.0034] [Medline: 28795154]
33. Vincent BW. Studying trans: recommendations for ethical recruitment and collaboration with transgender participants in academic research. Psychol Sex 2018 Jan 30;9(2):102-116. [doi: 10.1080/19419899.2018.1434558]
34. Carter-Harris L. Facebook targeted advertisement for research recruitment: a primer for nurse researchers. Appl Nurs Res 2016 Nov;32:144-147. [doi: 10.1016/j.apnr.2016.07.006] [Medline: 27969019]
35. Lohse B. Facebook is an effective strategy to recruit low-income women to online nutrition education. J Nutr Educ Behav 2013;45(1):69-76. [doi: 10.1016/j.jneb.2012.06.006] [Medline: 23305805]
36. Myers ZR. Cyberbullying and traditional bullying: the experiences of poly-victimization among diverse youth. Int J Technoethics 2017;8(2):42-60. [doi: 10.4018/ijt.2017070104]
37. Powell A, Scott AJ, Henry N. Digital harassment and abuse: experiences of sexuality and gender minority adults. Eur J Criminol 2018 Jul 30:147737081878800. [doi: 10.1177/1477370818788006]
38. Miller-Perusse M, Horvath KJ, Chavanduka T, Stephenson R. Recruitment and enrollment of a national sample of transgender youth via social media: experiences from Project Moxie. Transgend Health 2019;4(1):157-161 [FREE Full text] [doi: 10.1089/trgh.2018.0062] [Medline: 31346546]
39. Gelinas L, Pierce R, Winkler S, Cohen IG, Lynch HF, Bierer BE. Using social media as a research recruitment tool: ethical issues and recommendations. Am J Bioeth 2017 Mar;17(3):3-14 [FREE Full text] [doi: 10.1080/15265161.2016.1276644] [Medline: 28207365]
40. Hunter RF, Gough A, O'Kane N, McKeown G, Fitzpatrick A, Walker T, et al. Ethical issues in social media research for public health. Am J Public Health 2018 Mar;108(3):343-348. [doi: 10.2105/AJPH.2017.304249] [Medline: 29346005]
41. Russomanno J, Patterson JG, Jabson JM. Food insecurity among transgender and gender nonconforming individuals in the southeast United States: a qualitative study. Transgend Health 2019;4(1):89-99 [FREE Full text] [doi: 10.1089/trgh.2018.0024] [Medline: 31032424]
42. Create an ad. Menlo Park: Facebook URL: https://www.facebook.com/business/ads/ad-targeting [accessed 2019-01-23]
43. Rager KB. Compassion stress and the qualitative researcher. Qual Health Res 2005 Mar;15(3):423-430. [doi: 10.1177/1049732304272038] [Medline: 15761109]
44. Rager KB. Self-care and the qualitative researcher: when collecting data can break your heart. Educ Res 2016 Jul;34(4):23-27. [doi: 10.3102/0013189x034004023]
45. Wahab S, Anderson-Nathe B, Gringeri C. Feminisms in Social Work Research: Promise and Possibilities for Justice-Based Knowledge. London: Routledge; 2014.
46. Jenkins SR, Baird S. Secondary traumatic stress and vicarious trauma: a validational study. J Trauma Stress 2002 Oct;15(5):423-432. [doi: 10.1023/A:1020193526843] [Medline: 12392231]
47. Baird K, Kracen AC. Vicarious traumatization and secondary traumatic stress: a research synthesis. Couns Psychol Q 2006 Nov 21;19(2):181-188. [doi: 10.1080/09515070600811899]
48. Admin's guide to moderating your page. Menlo Park: Facebook Business URL: https://www.facebook.com/business/a/page-moderation-tips [accessed 2019-08-22]
49. Community standards. Menlo Park: Facebook URL: https://www.facebook.com/communitystandards/ [accessed 2019-08-21]
50. Protections for Human Research Protections. Unanticipated problems involving risks and adverse events guidance (2007). Rockville: Dept of Health and Human Services URL: https://www.hhs.gov/ohrp/regulations-and-policy/guidance/reviewing-unanticipated-problems/index.html [accessed 2019-08-21]

Abbreviations

IRB: institutional review board
LGBTQ: lesbian, gay, bisexual, transgender, and queer
PI: principal investigator
STS: secondary traumatic stress
TGNC: transgender and gender nonconforming

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Original Paper

Differences in Regional Patterns of Influenza Activity Across Surveillance Systems in the United States: Comparative Evaluation

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Abstract

Background: The Centers for Disease Control and Prevention (CDC) tracks influenza-like illness (ILI) using information on patient visits to health care providers through the Outpatient Influenza-like Illness Surveillance Network (ILINet). As participation in this system is voluntary, the composition, coverage, and consistency of health care reports vary from state to state, leading to different measures of ILI activity between regions. The degree to which these measures reflect actual differences in influenza activity or systematic differences in the methods used to collect and aggregate the data is unclear.

Objective: The objective of our study was to qualitatively and quantitatively compare national and region-specific ILI activity in the United States across 4 surveillance data sources—CDC ILINet, Flu Near You (FNY), athenahealth, and HealthTweets.org—to determine whether these data sources, commonly used as input in influenza modeling efforts, show geographical patterns that are similar to those observed in CDC ILINet’s data. We also compared the yearly percentage of FNY participants who sought health care for ILI symptoms across geographical areas.

Methods: We compared the national and regional 2018-2019 ILI activity baselines, calculated using noninfluenza weeks from previous years, for each surveillance data source. We also compared measures of ILI activity across geographical areas during 3 influenza seasons, 2015-2016, 2016-2017, and 2017-2018. Geographical differences in weekly ILI activity within each data source were also assessed using relative mean differences and time series heatmaps. National and regional age-adjusted health care–seeking percentages were calculated for each influenza season by dividing the number of FNY participants who sought medical care for ILI symptoms by the total number of ILI reports within an influenza season. Pearson correlations were used to assess the association between the health care–seeking percentages and baselines for each surveillance data source.

Results: We observed consistent differences in ILI activity across geographical areas for CDC ILINet and athenahealth data. ILI activity for FNY displayed little variation across geographical areas, whereas differences in ILI activity for HealthTweets.org were associated with the total number of tweets within a geographical area. The percentage of FNY participants who sought health care for ILI symptoms differed slightly across geographical areas, and these percentages were positively correlated with CDC ILINet and athenahealth baselines.

Conclusions: Our findings suggest that differences in ILI activity across geographical areas as reported by a given surveillance system may not accurately reflect true differences in the prevalence of ILI. Instead, these differences may reflect systematic collection and aggregation biases that are particular to each system and consistent across influenza seasons. These findings are potentially relevant in the real-time analysis of the influenza season and in the definition of unbiased forecast models.

(JMIR Public Health Surveill 2019;5(4):e13403) doi:10.2196/13403

KEYWORDS

digital disease surveillance; influenza; surveillance; participatory syndromic surveillance; disease modeling

Introduction

Background

Influenza epidemics are responsible for a significant public health burden that includes an estimated 12,000 to 56,000 deaths each year in the United States [1]. Consequently, timely and reliable surveillance of influenza activity is essential for local, state, and national public health officials to monitor and respond to outbreaks. In the United States, the Centers for Disease Control and Prevention (CDC) collects and analyzes information on influenza activity throughout the year. As part of this national surveillance system, patients seeking medical attention for influenza-like illness (ILI) are tracked through the Outpatient Influenza-like Illness Surveillance Network (ILINet). This system contains thousands of volunteer health care specialists, including individual providers, group practices, and hospital-based clinics located throughout all 50 states, Puerto Rico, the District of Columbia, and the US Virgin Islands. As participation in ILINet is voluntary and each state is responsible for their own recruitment of health care providers, the composition of provider types, coverage of geographical regions, and consistency of provider reporting vary from state to state. This convenience sample–driven model of surveillance results in certain parts of the population being over- or underrepresented in the reported influenza activity [2-4].

At both national and Health and Human Services–defined regional levels (conglomerates of 2-8 states), the CDC routinely reports the weekly percentage of patients presenting with ILI to health care providers. In addition, the CDC calculates and reports region-specific baselines , using influenza activity data from previous seasons, to identify the beginning and end of the influenza season and contextualize the severity of a given region-specific outbreak. These baselines vary widely across regions, and the degree to which the differences in baselines, as well as the percentage of ILI visits during an influenza season, reflect actual differences in influenza activity or systematic differences in the methods used to collect the data is unclear. Recent models suggest that the spatial patterns in US sentinel ILI surveillance may be the result of socioenvironmental factors, state-specific health policies, and sampling [3]. Identifying and characterizing the presence of potential methodological measurement biases in ILINet is important, as it is frequently used as an indicator of influenza activity for decision-making purposes and as the ground truth in mechanistic and statistical predictive modeling efforts aimed at understanding disease transmission dynamics and monitoring and forecasting influenza activity [5-15]. Furthermore, because these models typically leverage data from outside of the public health systems, such as Google internet searches [15,16], participatory syndromic surveillance systems [17,18], Twitter [19], and electronic health record (EHR) [14,20], it is important to understand if input sources show similar structural aggregation patterns.

Objectives

In this study, we qualitatively and quantitatively compared national and region-specific baselines and ILI activity during 3 influenza seasons across 4 surveillance data sources—CDC ILINet; Flu Near You (FNY), a crowd-sourced participatory syndromic surveillance system; athenahealth, a provider of cloud-based EHR services; and HealthTweets.org, a research platform that shares health trends data from Twitter—to determine whether these surveillance data sources, commonly used as input in influenza modeling efforts, show regional structural patterns that are similar to those observed in CDC ILINet's data. We also compared yearly self-reported health care–seeking rates of FNY participants to determine if this factor can better characterize the differences in ILI activity across geographic areas.

Methods

Data

Centers for Disease Control and Prevention Outpatient Influenza-Like Illness Surveillance Network

The CDC reports the weighted percentage of patient visits to health care providers presenting ILI symptoms on a weekly basis at the national and regional levels. These values are weighted on the basis of state population and represent the percentage of patient visits to health care providers that present as ILI, defined as fever (temperature of 100°F [37.8°C] or greater) plus a cough and/or a sore throat without a known cause other than influenza.

Flu Near You

FNY is a participatory syndromic surveillance system that allows volunteers in the United States to report health information of the user and their family using brief weekly surveys [21]. Through these surveys, FNY users report any symptoms that they or any registered household members experienced during the previous week (Monday through Sunday). For all reported symptoms, FNY users are asked to provide the date of symptom(s) onset and whether or not they received medical care for the symptom(s). The national and regional percentage of ILI symptoms reported is calculated by dividing the number of participants reporting ILI, as defined by reporting fever plus cough and/or sore throat, in a given week by the total number of FNY participant reports in that same week. FNY participants are assigned to a region based on the zip code provided at registration. Unweighted FNY percentage of ILI symptoms is used to maintain consistency across previous studies and the FNY website.

athenahealth is a provider of cloud-based services and mobile apps for medical groups and health systems. National and regional percentage of visits for ILI is calculated by dividing the unspecified viral or ILI visit count, which is equal to the number of visits where the patient had an unspecified viral diagnosis, an influenza diagnosis, or a fever diagnosis with an accompanying sore throat or cough diagnosis, by the total number of visits for each week.

HealthTweets.org

This dataset is generated by a Web-based research platform (HealthTweets.org) that shares the output of Twitter data mining algorithms with researchers and public officials [19]. We use weekly aggregated trends data from each state to calculate the influenza prevalence measure for each region. Weekly national and regional influenza prevalence measures are calculated by normalizing the number of influenza infection tweets in the health stream by the total number of tweets in the general stream during the same week [22].

Statistics of Datasets

Baseline Comparison

Baselines are used as a single quantitative measure that compares ILI activity during noninfluenza weeks across geographical areas within each surveillance data source. The CDC ILINet national and regional baselines for the 2018-2019 influenza season are available on the CDC website [23]. National and regional baselines for FNY, athenahealth, and HealthTweets.org are estimated following the CDC's baseline definition. A baseline is defined as the mean percentage of ILI activity during *noninfluenza weeks*, for the previous 3 seasons, plus 2 SDs. *Noninfluenza weeks* during these seasons are the same for all 3 systems and are delineated, by the CDC, as periods of 2 or more consecutive weeks in which each week accounted for less than 2% of the season's total number of specimens that tested positive for influenza in public health laboratories. We used region-specific noninfluenza weeks. Descriptive statistics of baselines are presented as median (interquartile range, IQR).

Influenza-Like Illness Activity Comparison

Differences in ILI activity during noninfluenza as well as influenza weeks across geographical areas within each surveillance data source are assessed using data from the start of the 2015-2016 influenza season (week of October 5, 2015) to the end of the 2017-2018 influenza season (week of October 1, 2018). Weekly ILI activity across geographical areas within each data source is quantitatively compared by dividing the difference in ILI activity between 2 areas by the maximum within each week, defined by Figure 1.

Figure 1. Equation for the mean relative difference.

$$Mean\ Relative\ Difference = \frac{1}{K}\sum_{week_k}\frac{ILI_{ik} - ILI_{jk}}{max(ILI_{ik}, ILI_{jk})}\ for\ i,j \in \{Region\ 1{:}\ 10, National\}$$

Mean relative differences within each surveillance data source are summarized using heatmaps, where the geographical areas along the rows are represented by *i* in the equation and the geographical areas along the columns are represented by *j*. Geographical areas that have consistently higher weekly ILI activity compared with other geographical areas have positive mean relative differences, indicated by red shades across the row in the heatmap, whereas geographical areas that have consistently lower weekly ILI activity have negative mean relative differences, indicated by blue shades across the row. Time series heatmaps are also presented to qualitatively compare weekly ILI activity across geographical areas for each surveillance data source.

Health Care–Seeking Behavior

National and regional health care–seeking percentages are calculated for each influenza season by dividing the number of FNY participants who sought medical care for ILI symptoms, as defined above, by the total number of ILI reports within an influenza season. As health care–seeking behavior varies by age [24], health care–seeking percentages are adjusted by age group (<18 years, 18-49 years, 50-64 years, and ≥65 years) using population data from the 2010 US census [25]. We use Pearson correlation to assess the association between the adjusted health care–seeking percentages and baselines for each surveillance data source. All analyses are performed using R version 3.3.2. [26].

Results

Centers for Disease Control and Prevention Outpatient Influenza-Like Illness Surveillance Network

Table 1 and Figure 2 provide the ILI activity baselines for each surveillance data source across geographical areas. The national baseline for CDC ILINet during the 2018-2019 influenza season is 2.2, and the median CDC ILINet regional baseline is 2.1 (IQR 1.8-2.3). Region 10 has the smallest baseline, 1.1, whereas region 6 has the largest baseline, 4.0. As shown in Figure 3 regions 2 and 6 have consistently higher weekly percentage of ILI visits compared with other regions, indicated by the red shades across the row, whereas regions 1, 8, and 10 have consistently lower weekly percentage of ILI visits, indicated by the blue shades across the row. This pattern is also shown qualitatively in both Figure 4 and Multimedia Appendix 1, where darker shades of red, as seen for regions 2, 6, and 9, correspond to higher percentage of ILI visits.

Table 1. Regional and national influenza-like illness activity baselines for the 2018-2019 influenza season for Centers for Disease Control and Prevention Outpatient Influenza-like Illness Surveillance Network, Flu Near You, athenahealth, and HealthTweets.org.

Geographical area	Centers for Disease Control and Prevention Outpatient Influenza-like Illness Surveillance Network	Flu Near You	athenahealth	HealthTweets.org
Region 1[a]	1.8	2.1	1.3	0.8
Region 2[b]	3.1	2.4	1.7	0.4
Region 3[c]	2.0	2.4	1.5	0.5
Region 4[d]	2.2	2.7	1.4	0.6
Region 5[e]	1.8	2.6	1.1	0.5
Region 6[f]	4.0	2.6	1.9	0.7
Region 7[g]	1.6	2.5	1.0	0.7
Region 8[h]	2.2	2.9	1.0	0.8
Region 9[i]	2.3	2.5	1.7	0.6
Region 10[j]	1.1	2.5	0.6	0.7
National	2.2	2.3	1.4	0.5

[a] Region 1 includes Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

[b] Region 2 includes New Jersey, New York, Puerto Rico, and US Virgin Islands.

[c] Region 3 includes Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia.

[d] Region 4 includes Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

[e] Region 5 includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

[f] Region 6 includes Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

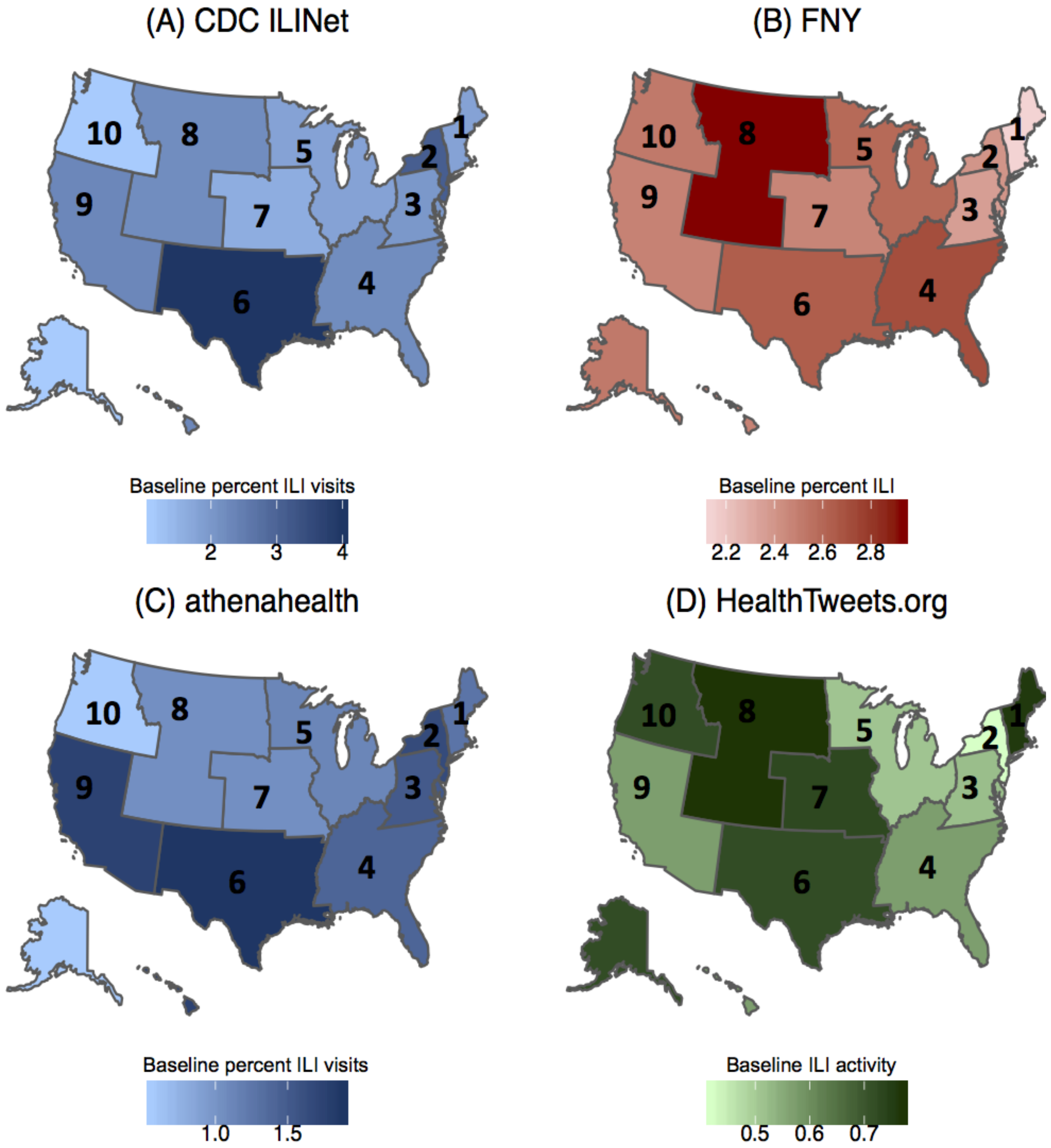
[g] Region 7 includes Iowa, Kansas, Missouri, and Nebraska.

[h] Region 8 includes Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming.

[i] Region 9 includes Arizona, California, Guam, Hawaii, and Nevada.

[j] Region 10 includes Alaska, Idaho, Oregon, and Washington.

Figure 2. Spatial heatmaps of US regional baseline influenza-like illness activity for the 2018-2019 influenza season for (A) Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network, (B) Flu Near You, (C) athenahealth, and (D) HealthTweets.org. CDC: Centers for Disease Control and Prevention; FNY: Flu Near You; ILINet: Influenza-like Illness Surveillance Network.



Flu Near You

For FNY, the national baseline is 2.3, and the median regional baseline is 2.5 (IQR 2.4-2.6). The minimum baseline is 2.1, region 1, and the maximum baseline is 2.9, region 8. Compared with other data sources, the mean relative differences for FNY in Figure 3 show less heterogeneity and no consistent patterns in the percentage of ILI across geographical areas. Although the timing of peaks in the percentage of ILI varies between regions, the relative percentage of ILI is consistent across geographical areas and seasons (Figure 4 and Multimedia Appendix 2).

The national baseline for athenahealth is 1.4, and the median regional baseline is 1.3 (IQR 1.0-1.6). Region 10 has the minimum baseline of 0.6, and region 6 has the maximum baseline of 1.9. Similar to CDC ILINet, regions 2, 6, and 9 have consistently higher weekly percentage of ILI visits compared with other regions, and regions 7, 8, and 10 have consistently lower weekly percentage of ILI visits. This pattern is reflected in Figure 4 and Multimedia Appendix 3, as regions 2, 6, and 9 have consistently higher percentage of ILI visits across all seasons.

HealthTweets.org

The national baseline is 0.5, the median baseline is 0.6 (IQR 0.5-0.7), the minimum baseline is 0.4 (region 2), and the maximum baseline is 0.8 (region 8). Unlike CDC ILINet and athenahealth, HealthTweets.org shows higher ILI activity in regions 1, 7, 8, and 10 (Figure 3). These regions have mean normalizing constants that are less than half the mean normalizing constants of other regions (Table 2). As shown in Figure 4 and Multimedia Appendix 4, this pattern is consistent across seasons.

Figure 3. Heatmaps of the mean relative difference of influenza-like illness activity across geographical areas for (A) Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network, (B) Flu Near You, (C) athenahealth, and (D) HealthTweets.org. CDC: Centers for Disease Control and Prevention; FNY: Flu Near You; ILINet: Influenza-like Illness Surveillance Network.

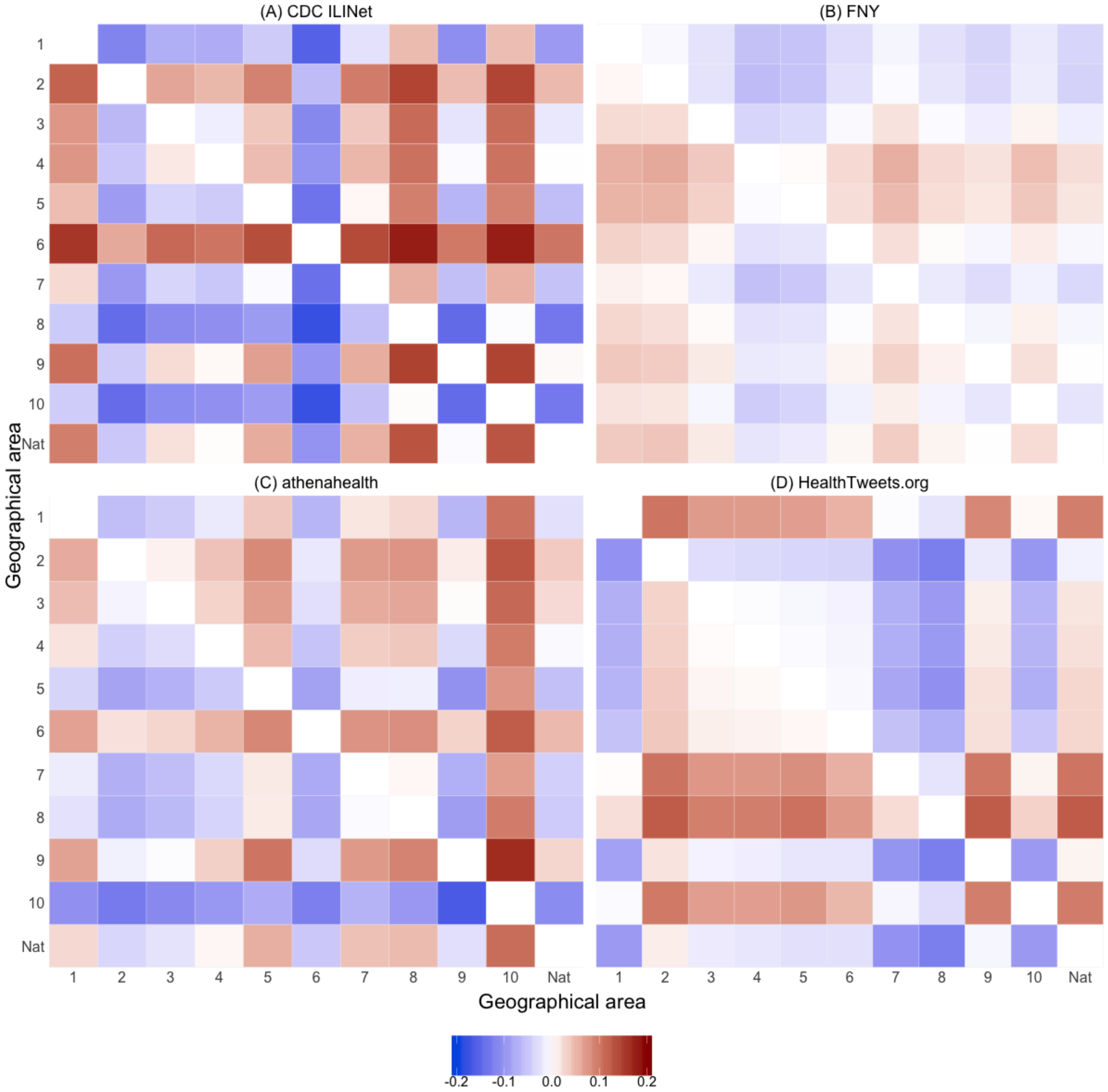


Figure 4. Time series heatmaps of influenza-like illness activity across geographical areas for (A) Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network, (B) Flu Near You, (C) athenahealth, and (D) HealthTweets.org. CDC: Centers for Disease Control and Prevention; FNY: Flu Near You; ILI: influenza-like illness ILINet: Influenza-like Illness Surveillance Network.

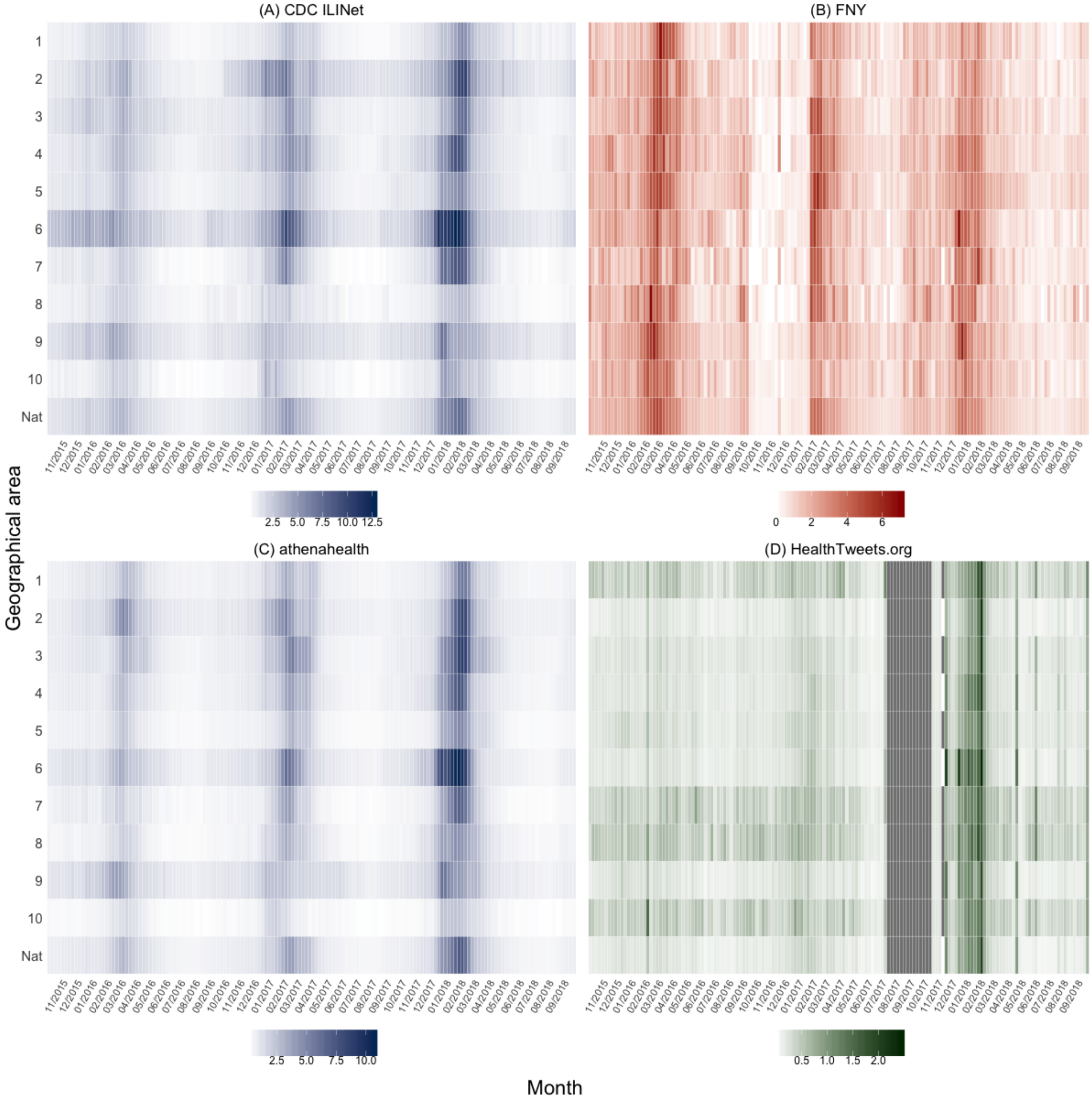


Table 2. Descriptive statistics of the HealthTweets.org normalizing constant at the national and regional levels.

Geographical area	Normalizing constant, mean (SD)
Region 1[a]	210.82 (114.917)
Region 2[b]	627.69 (330.270)
Region 3[c]	599.53 (293.320)
Region 4[d]	1103.78 (553.374)
Region 5[e]	798.25 (387.266)
Region 6[f]	845.30 (414.785)
Region 7[g]	171.05 (82.077)
Region 8[h]	121.96 (63.936)
Region 9[i]	5848.54 (3775.923)
Region 10[j]	181.33 (97.756)
National	6352.25 (3351.390)

[a] Region 1 includes Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

[b] Region 2 includes New Jersey, New York, Puerto Rico, and US Virgin Islands.

[c] Region 3 includes Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia.

[d] Region 4 includes Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

[e] Region 5 includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

[f] Region 6 includes Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

[g] Region 7 includes Iowa, Kansas, Missouri, and Nebraska.

[h] Region 8 includes Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming.

[i] Region 9 includes Arizona, California, Guam, Hawaii, and Nevada.

[j] Region 10 includes Alaska, Idaho, Oregon, and Washington.

Health Care–Seeking Behavior

The age-adjusted estimates of the percentage of FNY participants who sought health care for ILI symptoms are shown by season and across all seasons in Table 3 and Figure 5. At the national level, a higher age-adjusted percentage of participants sought health care for ILI symptoms during the 2016-2017 season, 35.1%, compared with the 2015-2016 and 2017-2018 seasons, 21.7% and 29.2%, respectively. Within each season, regions 2, 4, and 6 have the highest age-adjusted percentages of participants who sought health care, whereas regions 1, 5, 9, and 10 have the smallest age-adjusted percentages of participants who sought health care.

As shown in Figure 6, the age-adjusted estimates of the percentage of individuals who sought health care for ILI symptoms is significantly correlated with the baselines for CDC ILINet (*P*=.03) and is borderline significant for athenahealth (*P*=.08). There is no evidence of an association between the age-adjusted estimates of the percentage of individuals who sought health care and the baselines for FNY (*P*=.68) and HealthTweets.org (*P*=.76).

Table 3. Age-adjusted regional and national estimates of the percentage of Flu Near You participants who sought health care for influenza-like illness symptoms.

Geographical area	All seasons	2015-2016	2016-2017	2017-2018
Region 1[a]	25.98	20.82	33.29	27.77
Region 2[b]	29.97	26.05	36.03	31.79
Region 3[c]	28.66	22.07	37.03	31.73
Region 4[d]	32.61	25.47	43.23	34.77
Region 5[e]	26.43	21.53	34.59	26.73
Region 6[f]	35.17	28.58	44.83	37.47
Region 7[g]	30.93	23.79	41.95	32.09
Region 8[h]	25.50	22.74	30.86	26.16
Region 9[i]	22.49	19.06	27.77	24.69
Region 10[j]	20.03	17.03	23.39	22.33
National	27.12	21.73	35.06	29.23

[a] Region 1 includes Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

[b] Region 2 includes New Jersey, New York, Puerto Rico, and US Virgin Islands.

[c] Region 3 includes Delaware, District of Columbia, Maryland, Pennsylvania, Virginia, and West Virginia.

[d] Region 4 includes Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, and Tennessee.

[e] Region 5 includes Illinois, Indiana, Michigan, Minnesota, Ohio, and Wisconsin.

[f] Region 6 includes Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

[g] Region 7 includes Iowa, Kansas, Missouri, and Nebraska.

[h] Region 8 includes Colorado, Montana, North Dakota, South Dakota, Utah, and Wyoming.

[i] Region 9 includes Arizona, California, Guam, Hawaii, and Nevada.

[j] Region 10 includes Alaska, Idaho, Oregon, and Washington.

Figure 5. Spatial heatmap of age-adjusted regional percentage of Flu Near You participants who sought health care for ILI symptoms across all seasons.

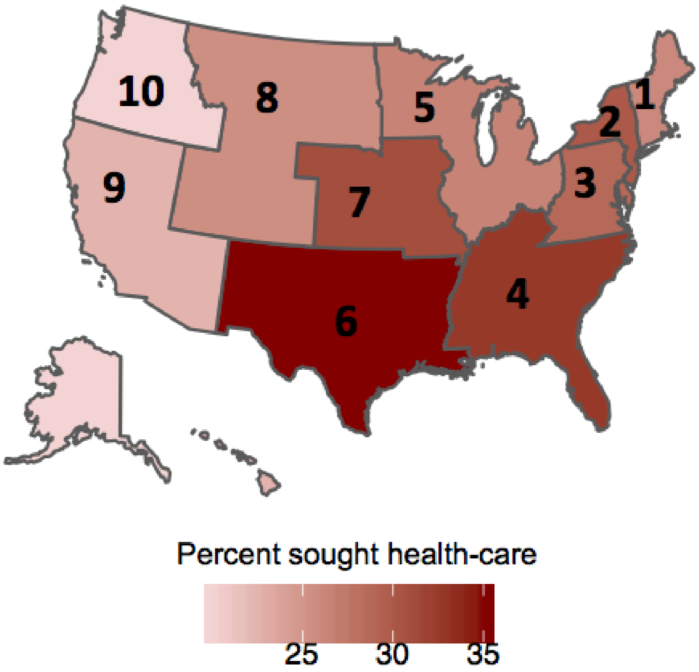
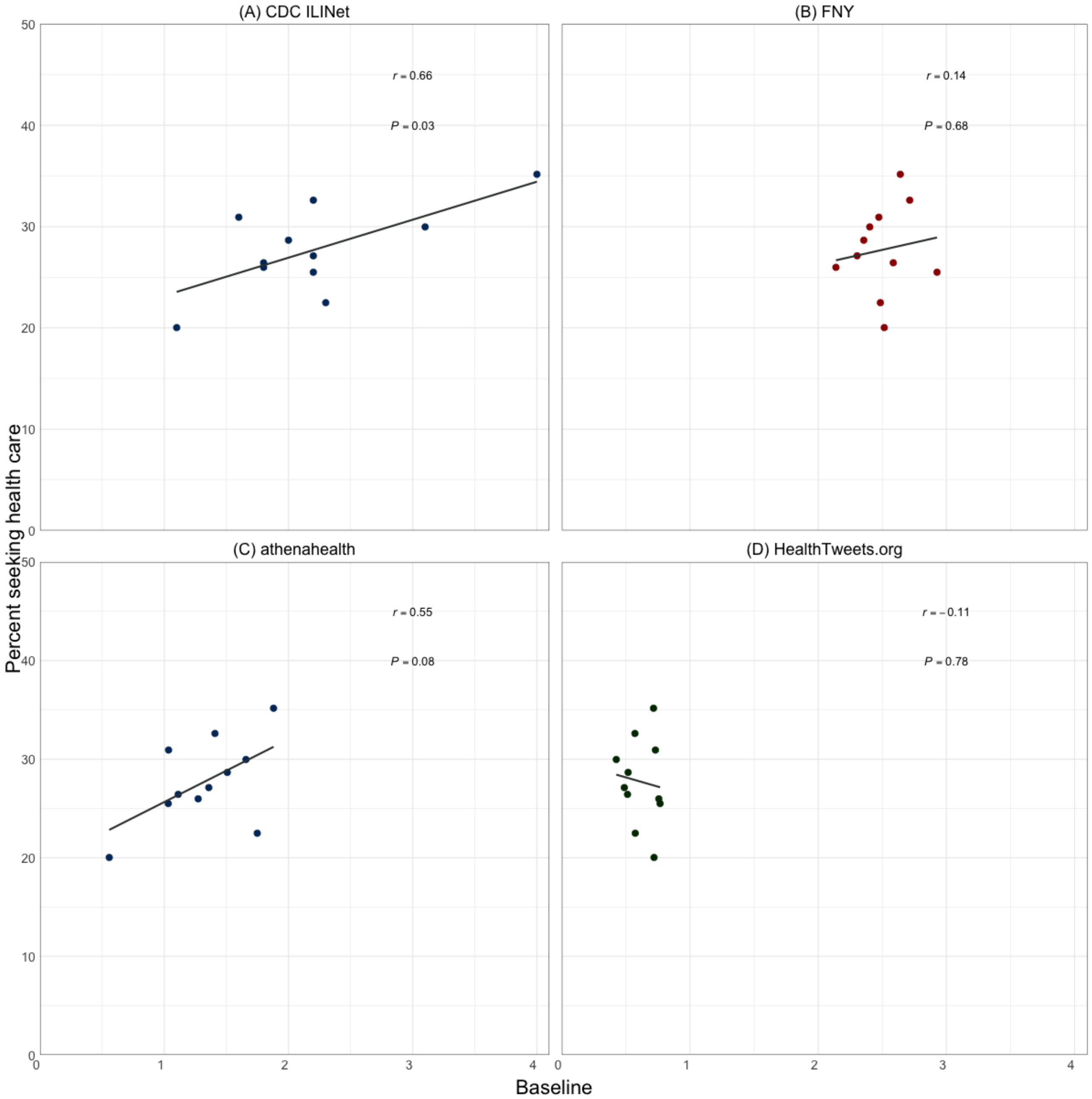


Figure 6. Scatterplot of the age-adjusted percentage of individuals who sought health care for influenza-like illness symptoms versus baseline influenza-like illness activity for (A) Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network, (B) Flu Near You, (C) athenahealth, and (D) HealthTweets.org. CDC: Centers for Disease Control and Prevention; FNY: Flu Near You; ILINet: Influenza-like Illness Surveillance Network.



Discussion

Principal Findings

Our findings show that differences in ILI activity across regions, as reported by a given surveillance system, are not consistent across surveillance platforms. In other words, regions that show larger baselines (and thus higher overall historical ILI activity) in one surveillance system appear to be different from their counterparts in other surveillance systems. The heterogeneity of recruitment practices of health care providers for each system, the composition of provider types, and the variability and consistency of coverage of geographical regions have the potential to contribute substantially to these systematic differences in baselines [3]. As such, our findings suggest that these structural differences reflect methodological collection practices rather than actual differences in influenza activity across regions. The observed structural patterns within each surveillance system are consistent across individual influenza seasons (Multimedia Appendix 5), which implies that the differences are not reflecting a specific time-period heterogeneity.

Specifically, baselines from CDC ILINet vary across different geographical areas, and the geographical areas with the largest baselines also have a consistently larger percentage of ILI visits during the influenza season. Conversely, FNY's baselines and the percentage of ILI were similar across geographical areas. This similarity is captured by the homogeneity in the mean relative differences. One potential contributing factor to the observed differences in patterns between these surveillance systems is the activity being measured. CDC ILINet measures the number of visits with ILI out of the total number of patient visits, whereas FNY measures the number of ILI reports out of enrolled persons who submitted a report. Furthermore, the population under surveillance also differs as FNY includes individuals who may not seek medical attention and FNY has a different demographic profile compared with CDC ILINet. For example, females and middle-aged participants are overrepresented in FNY [27].

Although not identical, athenahealth shows similar patterns in both baseline measures as well as the percentage of ILI visits to CDC ILINet across geographical areas. Both CDC ILINet and athenahealth use data from individuals seeking medical care. However, athenahealth has only a partially overlapping coverage of health care providers, and the proportion of visit settings differs slightly between the 2 systems. Most of athenahealth's providers see patients in office-based settings. Other settings, such as emergency room and nursing facilities, are underrepresented compared with CDC ILINet [28].

Unlike FNY, patterns across geographical areas within HealthTweets.org ILI activity appear to be the opposite of the patterns shown by CDC ILINet and athenahealth, as areas with consistently lower HealthTweets.org ILI activity have a consistently higher percentage of ILI visits for CDC ILINet and athenahealth, and vice versa. One potential reason for the differences in patterns in ILI activity across data sources is the difference in the activity being measured. As mentioned above, both CDC ILINet and athenahealth measure the number of ILI visits out of total visits, whereas HealthTweets.org normalizes the number of influenza infection tweets by the total number of tweets in the general stream. In addition, the groups most susceptible to influenza illness, young children and the elderly, may be underrepresented on Twitter. Furthermore, we found that smaller normalizing constants correspond to higher values of ILI activity.

Comparison With Previous Work

Despite the differences in patterns of ILI activity within systems, current research shows that these alternative data sources track CDC ILINet at both the national and regional levels. At the national level, the correlation between CDC ILINet and athenahealth is 0.97, and regional correlations range from 0.90 to 0.97 [29]. The correlation between CDC ILINet and FNY at the national level is 0.81, and regional correlations range from 0.64 to 0.81 [29]. Twitter-based influenza prevalence measures show a correlation of 0.93 with CDC ILINet at the national level and a correlation of 0.88 with New York City's weekly emergency department visits for ILI [22].

Compared with other recent publications, the percentage of FNY participants who sought medical care for ILI is less than reported estimates. A recent meta-analysis that used estimates from multiple countries across different influenza seasons estimated an overall pooled health care–seeking rate of 0.52 (95% CI 0.46-0.59) [30]. In the United States, national reported health care–seeking percentages for children were 56% and 57% during the 2009-2010 and 2010-2011 influenza seasons, respectively. Among adults, 40% reported that they sought health care during the 2009-2010 influenza season and 45% reported that they sought health care during the 2009-2010 influenza season [24,31]. Interestingly, the percentage of FNY participants who sought health care for ILI symptoms differs slightly across geographical areas. These differences may contribute to the differences in CDC ILINet and athenahealth baseline activity, as health care–seeking percentages are positively correlated with both CDC ILINet and athenahealth baselines.

From a predictive modeling perspective, our findings may explain why certain approaches designed to predict CDC ILINet values for the *Predict the Influenza season challenge*, weeks ahead of the publication of official CDC reports, may work better than others. As discussed in the 2 existing reports that document the performance of different methodologies to predict influenza activity, models that rely on local statistical approaches that exploit region-specific autoregressive information and historically observed ILI activity from previous seasons, as well as external predictors (such as humidity data, Google searches, and Wikipedia) [9,11], outperform mechanistic agent-based stochastic susceptible-infected-recovered (SIR) models that aim at modeling individual humans' behavior to infer epidemic activity across spatial resolutions [7,8,10]. The former modeling approaches are *trained* to track ILI levels in a region-specific fashion (frequently ignoring inconsistency across spatial resolutions), whereas the latter agent-based stochastic SIR models aim to predict the whole national epidemic outbreak across geographic areas. In other words, if the ILI activity report varies depending on how data are aggregated, then even a very accurate agent-based model may not be able to capture influenza activity correctly for every geographic area.

Limitations

Our study has several limitations. During the beginning of the 2015-2016 season, there were errors in FNY data collection, resulting in an underestimation in the weekly percentage of ILI reports. We did not adjust the estimates of these weeks. There was also an issue in data collection during the week of August 28, 2017. We adjusted the estimates for this week by taking the average percentage of ILI reports of the previous and subsequent weeks. In addition, there were a few weeks during the summer of 2017 during which there were no reports of ILI activity for HealthTweets.org. We did not input or estimate these missing weeks. As the overall patterns of ILI activity were similar across seasons (Multimedia Appendix 5), we do not suspect that these data issues affected our overall conclusions.

In addition, FNY relies on self-reported data that are subject to recall and social desirability bias. FNY participant reporting is also not consistent throughout the influenza season. Although previous students have used various methods, including restricting analyses to cohorts of users that report regularly [32-34], dropping the first report of all users, and applying a spike detector [21], we did not adjust for these potential reporting biases because reporting habits are consistent across regions [27]. Finally, because each system has a different measure of ILI activity, we cannot directly compare measures across systems.

Conclusions

Although ILI activity differs across geographical areas and data sources, the general region-specific seasonal trends are similar and provide valuable information about changes in influenza activity. Together, these platforms offer a more comprehensive view of influenza surveillance that helps public health offices monitor and respond to seasonal influenza epidemics.

Acknowledgments

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Authors' Contributions

KB, MS, AV, and RR conceived the research. KB conducted the statistical analysis. KB, MS, AV, RR, and JG drafted the manuscript. JG and DR made substantial contributions to the acquisition and collection of data. All authors critically revised the intellectual content of the manuscript and approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Time series plots of weekly percentage of influenza-like illness visits from Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network across 3 influenza seasons (2015-2016, 2016-2017, and 2017-2018) with baselines. Geographical areas on the columns are presented in black, and geographical areas on the rows are presented in blue.
[PNG File 426 KB - publichealth_v5i4e13403_app1.png]

Multimedia Appendix 2
Time series plots of weekly percentage of influenza-like illness from Flu Near You across 3 influenza seasons (2015-2016, 2016-2017, and 2017-2018) with baselines. Geographical areas on the columns are presented in black, and geographical areas on the rows are presented in red.
[PNG File 462 KB - publichealth_v5i4e13403_app2.png]

Multimedia Appendix 3
Time series plots of weekly percentage of influenza-like illness visits from athenahealth across 3 influenza seasons (2015-2016, 2016-2017, and 2017-2018) with baselines. Geographical areas on the columns are presented in black, and geographical areas on the rows are presented in blue.
[PNG File 396 KB - publichealth_v5i4e13403_app3.png]

Multimedia Appendix 4
Time series plots of weekly influenza-like illness activity from HealthTweets.org across 3 influenza seasons (2015-2016, 2016-2017, and 2017-2018) with baselines. Geographical areas on the columns are presented in black, and geographical areas on the rows are presented in green.
[PNG File 386 KB - publichealth_v5i4e13403_app4.png]

Multimedia Appendix 5
Heatmaps of the mean relative difference of ILI activity across geographical areas for (A) Centers for Disease Control and Prevention Influenza-like Illness Surveillance Network, (B) Flu Near You, (C) athenahealth, and (D) HealthTweets.org for each influenza season.
[PNG File 113 KB - publichealth_v5i4e13403_app5.png]

References

1. Molinari NM, Ortega-Sanchez IR, Messonnier ML, Thompson WW, Wortley PM, Weintraub E, et al. The annual impact of seasonal influenza in the US: measuring disease burden and costs. Vaccine 2007 Jun 28;25(27):5086-5096. [doi: 10.1016/j.vaccine.2007.03.046] [Medline: 17544181]

2. Polgreen PM, Chen Z, Segre AM, Harris ML, Pentella MA, Rushton G. Optimizing influenza sentinel surveillance at the state level. Am J Epidemiol 2009 Nov 15;170(10):1300-1306 [FREE Full text] [doi: 10.1093/aje/kwp270] [Medline: 19822570]
3. Lee EC, Arab A, Goldlust SM, Viboud C, Grenfell BT, Bansal S. Deploying digital health data to optimize influenza surveillance at national and local scales. PLoS Comput Biol 2018 Mar;14(3):e1006020 [FREE Full text] [doi: 10.1371/journal.pcbi.1006020] [Medline: 29513661]
4. Scarpino SV, Dimitrov NB, Meyers LA. Optimizing provider recruitment for influenza surveillance networks. PLoS Comput Biol 2012;8(4):e1002472 [FREE Full text] [doi: 10.1371/journal.pcbi.1002472] [Medline: 22511860]
5. Zhang Q, Gioannini C, Paolotti D, Perra N, Perrotta D, Quaggiotto M, et al. Social Data Mining and Seasonal Influenza Forecasts: The FluOutlook Platform. In: Proceedings of the Joint European Conference on Machine Learning and Knowledge Discovery in Databases. 2015 Presented at: ECML PKDD'15; September 7-11, 2015; Porto, Portugal p. 237-240 URL: https://doi.org/10.1007/978-3-319-23461-8_21 [doi: 10.1007/978-3-319-23461-8_21]
6. Zhang Q, Perra N, Perrotta D, Tizzoni M, Paolotti D, Vespignani A. Forecasting Seasonal Influenza Fusing Digital Indicators and a Mechanistic Disease Model. In: Proceedings of the 26th International Conference on World Wide Web. 2017 Presented at: WWW'17; April 3-7, 2017; Perth, Australia p. 311-319 URL: https://doi.org/10.1145/3038912.3052678 [doi: 10.1145/3038912.3052678]
7. Biggerstaff M, Alper D, Dredze M, Fox S, Fung IC, Hickmann KS, Influenza Forecasting Contest Working Group. Results from the centers for disease control and prevention's predict the 2013-2014 influenza season challenge. BMC Infect Dis 2016 Jul 22;16:357 [FREE Full text] [doi: 10.1186/s12879-016-1669-x] [Medline: 27449080]
8. Biggerstaff M, Johansson M, Alper D, Brooks LC, Chakraborty P, Farrow DC, et al. Results from the second year of a collaborative effort to forecast influenza seasons in the United States. Epidemics 2018 Sep;24:26-33 [FREE Full text] [doi: 10.1016/j.epidem.2018.02.003] [Medline: 29506911]
9. Brooks LC, Farrow DC, Hyun S, Tibshirani RJ, Rosenfeld R. Flexible modeling of epidemics with an empirical Bayes framework. PLoS Comput Biol 2015 Aug;11(8):e1004382 [FREE Full text] [doi: 10.1371/journal.pcbi.1004382] [Medline: 26317693]
10. Tizzoni M, Bajardi P, Poletto C, Ramasco JJ, Balcan D, Gonçalves B, et al. Real-time numerical forecast of global epidemic spreading: case study of 2009 A/H1N1pdm. BMC Med 2012 Dec 13;10:165 [FREE Full text] [doi: 10.1186/1741-7015-10-165] [Medline: 23237460]
11. Shaman J, Pitzer VE, Viboud C, Grenfell BT, Lipsitch M. Absolute humidity and the seasonal onset of influenza in the continental United States. PLoS Biol 2010 Feb 23;8(2):e1000316 [FREE Full text] [doi: 10.1371/journal.pbio.1000316] [Medline: 20186267]
12. Yang S, Santillana M, Brownstein JS, Gray J, Richardson S, Kou SC. Using electronic health records and internet search information for accurate influenza forecasting. BMC Infect Dis 2017 May 8;17(1):332 [FREE Full text] [doi: 10.1186/s12879-017-2424-7] [Medline: 28482810]
13. Yang S, Santillana M, Kou SC. Accurate estimation of influenza epidemics using Google search data via ARGO. Proc Natl Acad Sci U S A 2015 Nov 24;112(47):14473-14478 [FREE Full text] [doi: 10.1073/pnas.1515373112] [Medline: 26553980]
14. Santillana M, Nguyen AT, Dredze M, Paul MJ, Nsoesie EO, Brownstein JS. Combining search, social media, and traditional data sources to improve influenza surveillance. PLoS Comput Biol 2015 Oct;11(10):e1004513 [FREE Full text] [doi: 10.1371/journal.pcbi.1004513] [Medline: 26513245]
15. Santillana M, Zhang DW, Althouse BM, Ayers JW. What can digital disease detection learn from (an external revision to) Google flu trends? Am J Prev Med 2014 Sep;47(3):341-347. [doi: 10.1016/j.amepre.2014.05.020] [Medline: 24997572]
16. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. Nature 2009 Feb 19;457(7232):1012-1014. [doi: 10.1038/nature07634] [Medline: 19020500]
17. Wójcik OP, Brownstein JS, Chunara R, Johansson MA. Public health for the people: participatory infectious disease surveillance in the digital age. Emerg Themes Epidemiol 2014;11:7 [FREE Full text] [doi: 10.1186/1742-7622-11-7] [Medline: 24991229]
18. Leal-Neto OB, Dimech GS, Libel M, Oliveira W, Ferreira JP. Digital disease detection and participatory surveillance: overview and perspectives for Brazil. Rev Saude Publica 2016;50:17 [FREE Full text] [doi: 10.1590/S1518-8787.2016050006201] [Medline: 27191153]
19. Paul MJ, Dredze M, Broniatowski D. Twitter improves influenza forecasting. PLoS Curr 2014 Oct 28;6:ecurrents.outbreaks.90b9ed0f59bae4ccaa683a39865d9117 [FREE Full text] [doi: 10.1371/currents.outbreaks.90b9ed0f59bae4ccaa683a39865d9117] [Medline: 25642377]
20. Lu FS, Hou S, Baltrusaitis K, Shah M, Leskovec J, Sosic R, et al. Accurate influenza monitoring and forecasting using novel internet data streams: a case study in the Boston metropolis. JMIR Public Health Surveill 2018 Jan 9;4(1):e4 [FREE Full text] [doi: 10.2196/publichealth.8950] [Medline: 29317382]
21. Smolinski MS, Crawley AW, Baltrusaitis K, Chunara R, Olsen JM, Wójcik O, et al. Flu near you: crowdsourced symptom reporting spanning 2 influenza seasons. Am J Public Health 2015 Oct;105(10):2124-2130. [doi: 10.2105/AJPH.2015.302696] [Medline: 26270299]

22. Broniatowski DA, Paul MJ, Dredze M. National and local influenza surveillance through Twitter: an analysis of the 2012-2013 influenza epidemic. PLoS One 2013;8(12):e83672 [FREE Full text] [doi: 10.1371/journal.pone.0083672] [Medline: 24349542]
23. Centers for Disease Control and Prevention. Overview of Influenza Surveillance in the United States URL: https://www.cdc.gov/flu/weekly/overview.htm [accessed 2018-11-01] [WebCite Cache ID 75R8li3IP]
24. Biggerstaff M, Jhung MA, Reed C, Fry AM, Balluz L, Finelli L. Influenza-like illness, the time to seek healthcare, and influenza antiviral receipt during the 2010-2011 influenza season-United States. J Infect Dis 2014 Aug 15;210(4):535-544 [FREE Full text] [doi: 10.1093/infdis/jiu224] [Medline: 24731959]
25. American FactFinder - Census Bureau. Annual Estimates of the Resident Population for Selected Age Groups by Sex for the United States, States, Counties, and Puerto Rico Commonwealth and Municipios: April 1, 2010 to July 1, 2018 URL: http://factfinder.census.gov/ [accessed 2018-11-01] [WebCite Cache ID 75R9KGNMr]
26. R: The R Project for Statistical Computing. 2019. URL: https://www.R-project.org/ [accessed 2018-11-01] [WebCite Cache ID 75R9dPErN]
27. Baltrusaitis K, Santillana M, Crawley AW, Chunara R, Smolinski M, Brownstein JS. Determinants of participants' follow-up and characterization of representativeness in flu near you, a participatory disease surveillance system. JMIR Public Health Surveill 2017 Apr 7;3(2):e18 [FREE Full text] [doi: 10.2196/publichealth.7304] [Medline: 28389417]
28. Santillana M, Nguyen AT, Louie T, Zink A, Gray J, Sung I, et al. Cloud-based electronic health records for real-time, region-specific influenza surveillance. Sci Rep 2016 May 11;6:25732 [FREE Full text] [doi: 10.1038/srep25732] [Medline: 27165494]
29. Baltrusaitis K, Brownstein JS, Scarpino SV, Bakota E, Crawley AW, Conidi G, et al. Comparison of crowd-sourced, electronic health records based, and traditional health-care based influenza-tracking systems at multiple spatial resolutions in the United States of America. BMC Infect Dis 2018 Aug 15;18(1):403. [doi: 10.1186/s12879-018-3322-3] [Medline: 30111305]
30. Ma W, Huo X, Zhou M. The healthcare seeking rate of individuals with influenza like illness: a meta-analysis. Infect Dis (Lond) 2018 Oct;50(10):728-735. [doi: 10.1080/23744235.2018.1472805] [Medline: 30009680]
31. Biggerstaff M, Jhung M, Kamimoto L, Balluz L, Finelli L. Self-reported influenza-like illness and receipt of influenza antiviral drugs during the 2009 pandemic, United States, 2009-2010. Am J Public Health 2012 Oct;102(10):e21-e26. [doi: 10.2105/AJPH.2012.300651] [Medline: 22897525]
32. Chunara R, Goldstein E, Patterson-Lomba O, Brownstein JS. Estimating influenza attack rates in the United States using a participatory cohort. Sci Rep 2015 Apr 2;5:9540 [FREE Full text] [doi: 10.1038/srep09540] [Medline: 25835538]
33. Cantarelli P, Debin M, Turbelin C, Poletto C, Blanchon T, Falchi A, et al. The representativeness of a European multi-center network for influenza-like-illness participatory surveillance. BMC Public Health 2014 Sep 20;14:984 [FREE Full text] [doi: 10.1186/1471-2458-14-984] [Medline: 25240865]
34. Patterson-Lomba O, van Noort S, Cowling BJ, Wallinga J, Gomes MG, Lipsitch M, et al. Utilizing syndromic surveillance data for estimating levels of influenza circulation. Am J Epidemiol 2014 Jun 1;179(11):1394-1401 [FREE Full text] [doi: 10.1093/aje/kwu061] [Medline: 24748609]

Abbreviations

CDC: Centers for Disease Control and Prevention
EHR: electronic health record
FNY: Flu Near You
ILI: influenza-like illness
ILINet: Influenza-like Illness Surveillance Network
IQR: interquartile range
SIR: susceptible-infected-recovered

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Original Paper

Enhanced Safety Surveillance of Influenza Vaccines in General Practice, Winter 2015-16: Feasibility Study

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Abstract

Background: The European Medicines Agency (EMA) requires vaccine manufacturers to conduct enhanced real-time surveillance of seasonal influenza vaccination. The EMA has specified a list of adverse events of interest to be monitored. The EMA sets out 3 different ways to conduct such surveillance: (1) active surveillance, (2) enhanced passive surveillance, or (3) electronic health record data mining (EHR-DM). English general practice (GP) is a suitable setting to implement enhanced passive surveillance and EHR-DM.

Objective: This study aimed to test the feasibility of conducting enhanced passive surveillance in GP using the yellow card scheme (adverse events of interest reporting cards) to determine if it has any advantages over EHR-DM alone.

Methods: A total of 9 GPs in England participated, of which 3 tested the feasibility of enhanced passive surveillance and the other 6 EHR-DM alone. The 3 that tested EPS provided patients with yellow (adverse events) cards for patients to report any adverse events. Data were extracted from all 9 GPs' EHRs between weeks 35 and 49 (08/24/2015 to 12/06/2015), the main period of influenza vaccination. We conducted weekly analysis and end-of-study analyses.

Results: Our GPs were largely distributed across England with a registered population of 81,040. In the week 49 report, 15,863/81,040 people (19.57% of the registered practice population) were vaccinated. In the EPS practices, staff managed to hand out the cards to 61.25% (4150/6776) of the vaccinees, and of these cards, 1.98% (82/4150) were returned to the GP offices. Adverse events of interests were reported by 113 /7223 people (1.56%) in the enhanced passive surveillance practices, compared with 322/8640 people (3.73%) in the EHR-DM practices.

Conclusions: Overall, we demonstrated that GPs EHR-DM was an appropriate method of enhanced surveillance. However, the use of yellow cards, in enhanced passive surveillance practices, did not enhance the collection of adverse events of interests as demonstrated in this study. Their return rate was poor, data entry from them was not straightforward, and there were issues with data reconciliation. We concluded that customized cards prespecifying the EMA's adverse events of interests, combined with EHR-DM, were needed to maximize data collection.

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KEYWORDS

vaccines; safety management; medical records systems, computerized; drug-related side effects and adverse reactions; influenza, human; influenza vaccines; general practice; England

Introduction

Background

The European Medicines Agency (EMA) released interim guidance on enhanced safety surveillance for seasonal influenza vaccines in August 2014 [1]. All Marketing Authorization Holders (MAHs) commercializing influenza vaccines in Europe must follow this guidance which sets out new standards for safety surveillance. Its goal is to rapidly detect, in near real-time early in the season, any significant increase in the frequency or severity of a defined list of adverse events of interest (AEIs). These AEIs can be local, systemic, or allergic reactions, indicating a potential or more serious risk.

For this request, the EMA defines 3 types of surveillance: (1) active surveillance, using existing methods of postauthorization surveillance; (2) enhanced passive surveillance (EPS), estimating vaccine usage rapidly and taking additional steps to facilitate passive adverse drug reactions (ADR) reporting of incidence of AEIs; and (3) electronic health record data mining (EHR-DM).

English general practice (GP) is a suitable setting to implement EPS and EHR-DM, as it has a registration-based list system with linked medical records, it has been highly computerized since 2004, and data extracted from these systems are widely used in research [2,3]. Furthermore, GPs are largely independent professional partnerships and make their own decision about which brand of influenza vaccine to purchase before the start of each influenza season [4]. Practices administer influenza vaccines to recommended groups, starting in September of each year [5].

Objectives

In 2015-16, one of the major suppliers of influenza vaccines to UK health care was GSK (GlaxoSmithKline). Collaborating with the University of Surrey, GSK took the opportunity of the UK computerized infrastructure to implement EPS and EHR-DM with the aim to test the feasibility of using EPS and EHR-DM within GP to identify AEIs in subjects vaccinated with GSK's and other influenza vaccine brands. An additional aim was to ascertain if using EPS in GP has any advantages over EHR-DM alone. The key components of this surveillance were as follows: (1) to provide a weekly estimation of vaccine coverage, by age, risk group, and vaccine brand; and (2) to estimate weekly AEI reporting rates among subjects vaccinated against seasonal influenza, by age, comorbidity, and brand from the GPs using the EHR-DM method, and those using the EPS system.

Methods

Setting

Following the request of EMA stating that MAHs must conduct enhanced seasonal influenza vaccines safety surveillance, GSK, together with the University of Surrey, launched a pilot safety surveillance study for GSK's seasonal influenza vaccines. The University of Surrey has developed methods to extract timely surveillance data from GP. This system was developed to support the Royal College of General Practitioners (RCGP) Research and Surveillance Centre (RSC) weekly surveillance reports [6] and is capable of being adapted to support the EMA-specified surveillance (ClinicalTrials.gov number: NCT02567721).

We recruited 9 GPs spread across England, from varying types of locality (North and South, and urban and rural) and using different EHR systems (Egton Medical Information Systems) and The Phoenix Partnership). We compared the demographic characteristics—age, gender, ethnicity, and deprivation scores—using the Index of Multiple Deprivation, on the basis of each patient's Lower Super Output Area (a small local geographical location [7,8]) of the registered population, with the national average data obtained from the Office for National Statistics [9].

Design

This feasibility study period ran from International Organization for Standardization (ISO) week 35 to week 49 of 2015 (08/24/2015 to 12/06/2015).

As this was a feasibility study, there was no attempt to determine a priori the size of the study on the basis of power calculation. However, considering the average GP size of 7034 in England and Wales, it was expected that 9 GPs would provide a study population of 63,300. Ultimately, the population registered in the recruited practices was larger (N=81,040).

GPs were recruited in summer 2015; some months after they had selected their brand of vaccine for the coming influenza season. Out of the 9 practices recruited, 3 joined the EPS group and 6 joined the EHR-DM group. As this was a feasibility study, there was no attempt to randomize the practices into groups according to the type and brand of seasonal influenza vaccine used by the practices. Each group (EPS vs EHR-DM) was based on practices' willingness to participate in the study.

The EPS group involved every patient who was vaccinated and received a *yellow card*; on the basis of the standard ADR cards used by the Medicines & Healthcare Products Regulatory Agency (MHRA) [10]. The patients were asked to complete a *yellow card* if they experienced an AEI in the 14-day postvaccination window; they were invited to return the card to their registered practice. The reported information was coded into the patient's EHR by their GP and extracted weekly:

- EHR data mining: The EHR-DM group (n=6) had routine clinical data extracted from their EHR, pseudonymized and automatically sent to a secure sever on a weekly basis. In case of data extraction failure, a local data extraction was conducted using a Department of Health data extraction tool (MIQUEST—Morbidity Information Query and Export

Syntax [11,12]). All practices in the EHR-DM group used a non-GSK influenza vaccine.

- Enhanced passive surveillance: The EPS group of practices (n=3) had their routine clinical data extracted from their EHR in the same way as the EHR-DM group. In addition, these practices also distributed a yellow card to patients receiving the seasonal influenza vaccine. Patients were asked to return the card to their own practice within 14 days. The information in the returned cards was then coded by practice staff into each patient's EHR and then extracted in the same manner as the EHR-DM group. In this group, 2 practices used GSK influenza vaccine and 1 practice non-GSK vaccines.

All practices were given induction training and a preferred code list for the specific AEIs identified by EMA to facilitate standardized data coding. We created this list using an ontological approach [13,14]. We grouped these conditions into body system categories: respiratory, gastrointestinal, fever, sensitivity and anaphylaxis, rash, general symptoms, neurological, musculoskeletal, and local reactions (Multimedia Appendix 1). We provided GPs a full code list and a screen-side prompt list.

We requested that, when a patient presented with one of these conditions, they should use the recommended code (as per the instruction sheet). We advised GPs that GPs should code the conditions they felt a patient was reporting accurately. We stressed that the overarching purpose was not to purposively make any causal link between vaccination and a given condition, particularly for common conditions, such as cold and headache. However, they were reminded that they should report, in parallel to this study, any serious or important events on the basis of their professional judgment through the standard MHRA reporting system as per local regulation.

Study Measures

The primary outcome measure was to report AEI frequencies among influenza-vaccinated subjects and observe any discrepancies in these frequencies in the EPS versus EHR-DM group and GSK versus non-GSK vaccines. To identify event date, we used the event date for the actual episode, not the recorded date.

- Estimation of vaccine uptake rates by age-band, risk group, and vaccine brand: We classified patients as vaccinated when a prescription or administration code for an influenza vaccine was recorded in the patient's EHR. Whichever had the earliest date was taken as the vaccine administration date; prescription issue dates often lag behind the administration dates.
- Estimation of AEI rates by age, risk group, vaccination status, and vaccine brand: We included presentations up to 14 days, notwithstanding the EMA recommendations being for 7 days, to allow for any lag between experiencing an AEI and obtaining an appointment to see a GP or to return the yellow card. Both EHR and yellow card data were used to estimate AEIs in the EPS practices. We predicted that the yellow cards would increase AEI reporting; therefore, EPS practices should have a larger percentage of AEIs recorded.
- To observe the reporting trend from a broader pool of GPs, we also extracted the AEIs from the RCGP RSC Network: We focused on records of vaccinated subjects only, using data for the same weeks (35-49) in 2015. We did not include any events before vaccination for the 9 study practices or the RCGP RSC network. Analysis was concentrated on AEIs at any time after vaccination (not just in the 14-day window after vaccination).

Throughout the study, we produced weekly reports of AEIs. At the end of the study, we produced an end-of-season report. The end-of-season report enabled us to identify whether the approach was appropriate to adequately capture the vaccination uptake, to enhance the collection of AEs, easily transcribe the events reported from the yellow cards to the electronic system, more comprehensively capture the AEIs experienced, and extract them on an ongoing basis in a near real-time manner.

- Weekly reports: We produced weekly reports of the incidence of AEIs in influenza-vaccinated patients. We also reported cumulative vaccination rates. These weekly reports were intended to be produced the week following data recording. These reports provided practices feedback about the rate of AEIs recorded in their practice to encourage data recording. We reported the cumulative data adding the information as the data collection was progressing with patients registered until week 49 with the objective to assess the data in a near real-time manner. We included all patients with a valid registration (defined as fully registered with a valid registration) on the Friday of the week, before data extraction took place.
- End of study period analysis: We conducted an analysis at the end of the study period between weeks 35 and 49. We included patients registered with the pilot practices throughout the whole observation period with medical records valid 12 months before the start of the study; this objective being to ensure further that we had sufficient medical history about any long-term condition that might affect their priority for influenza vaccination.

Our established data extraction method means that only coded data (Read code version 2 and CTV3) [15] were used to collect the relevant information. Free text was not extracted as it might include patient identifiable information. We excluded people with a code that indicated that they opted out of sharing data; estimated at around 1.25% of the registered population [16]. Data were pseudonymized as close to source as possible and encrypted.

Analyses

For all AEIs, we report the rate and the 95% CI, using the critical binomial function in Microsoft Excel [17].

Results

Setting

Our practices were largely distributed across England, with most in the Midlands and East National Health Service (NHS) Region (NHS Regions: North, n=3; Midlands and East, n=5; and South, n=1). Practices were mainly from urban areas (rural, n=3; and urban, n=6). In the week 49 weekly report (data extracted in a near real-time manner), the overall population registered in the 9 GP practices was 81,040. The end-of-study cohort population was 71,407 (owing to restriction of longer registration as described earlier).

In the week 49 data extraction, the practice populations had a female to male ratio of 49.76% (40, 323/81,040) to 50.24% (40,717/81,040. The proportion of people aged 20 to 24 years and over 50 years was above the national average (Figure 1). The study population had a higher proportion of people of white ethnicity recorded 92.57% (38,154/41,218 compared with 85.42% nationally; (45,281,142/53,012,456). The study population was less deprived than the national average, with almost three-fourths 72.20% (56,545/78,322) of the population in the least deprived half (Multimedia Appendix 2).

When comparing the EHR-DM practices and the EPS practices using the end-of-season dataset, the EPS practices were slightly older, the proportion of 65 years and over was 21.64% (n=9842/45,519) in EHR-DM compared with 25.44% (6586/25,888) in EPS (Table 1). The EHR-DM practices also had a smaller proportion of at-risk patients at 40.43% (18,403/45,519) compared with 45.21% (11,703/25,888) in the EPS practices.

Figure 1. Age and sex distribution of pilot practices compared against the census.

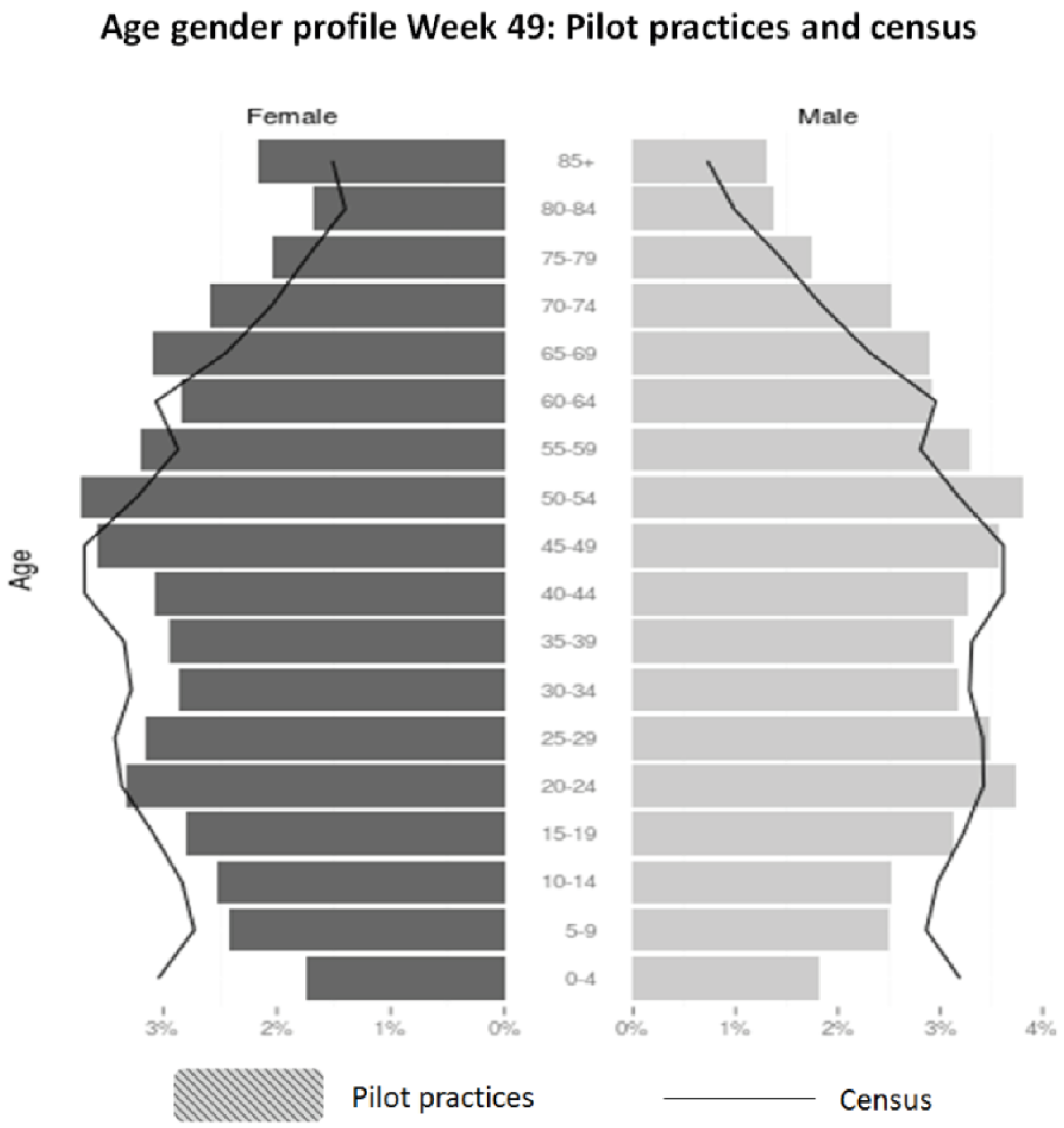

Table 1. Summary of practice population from end of season cohort.

Variables	Vaccination status (cohort)	
	EHR-DM[a]	EPS[b]
Number of practices	6	3
Age group (years)		
<5		
n (%)	1097 (2.41)	535 (2.07)
LCI[c], %	2.27	1.90
UCI[d], %	2.55	2.24
5-14		
n (%)	4725 (10.38)	2638 (10.19)
LCI, %	10.10	9.82
UCI, %	10.66	10.56
15-64		
n (%)	29,855 (65.59)	16,129 (62.30)
LCI, %	65.15	61.71
UCI, %	66.03	62.89
65+		
n (%)	9842 (21.62)	6586 (25.44)
LCI, %	21.64	24.91
UCI, %	22.00	25.97
Gender		
Male		
n (%)	23,035 (50.64)	12,853 (49.65)
LCI, %	50.19	49.04
UCI, %	51.10	50.26
Female		
n (%)	22,466 (49.36)	13,035 (50.35)
LCI, %	48.90	49.74
UCI, %	49.81	50.96
Risk group		
Specific risk group		
n (%)	18,403 (40.43)	11,703 (45.21)
LCI, %	39.98	44.60
UCI, %	40.88	45.81

[a] EHR-DM: electronic health record data mining.

[b] EPS: enhanced passive surveillance.

[c] LCI: lower confidence interval.

[d] UCI: upper confidence interval.

Measures

Most vaccinations took place between weeks 39 and 45 (Figure 2). From the weekly cumulative data extractions (weeks 35-49), 19.57% (15,863/81,040) of the registered practice population overall and 57.48% (9969/17,344) of people aged 65 years or older were vaccinated (Table 2).

Figure 2. Cumulative vaccines.

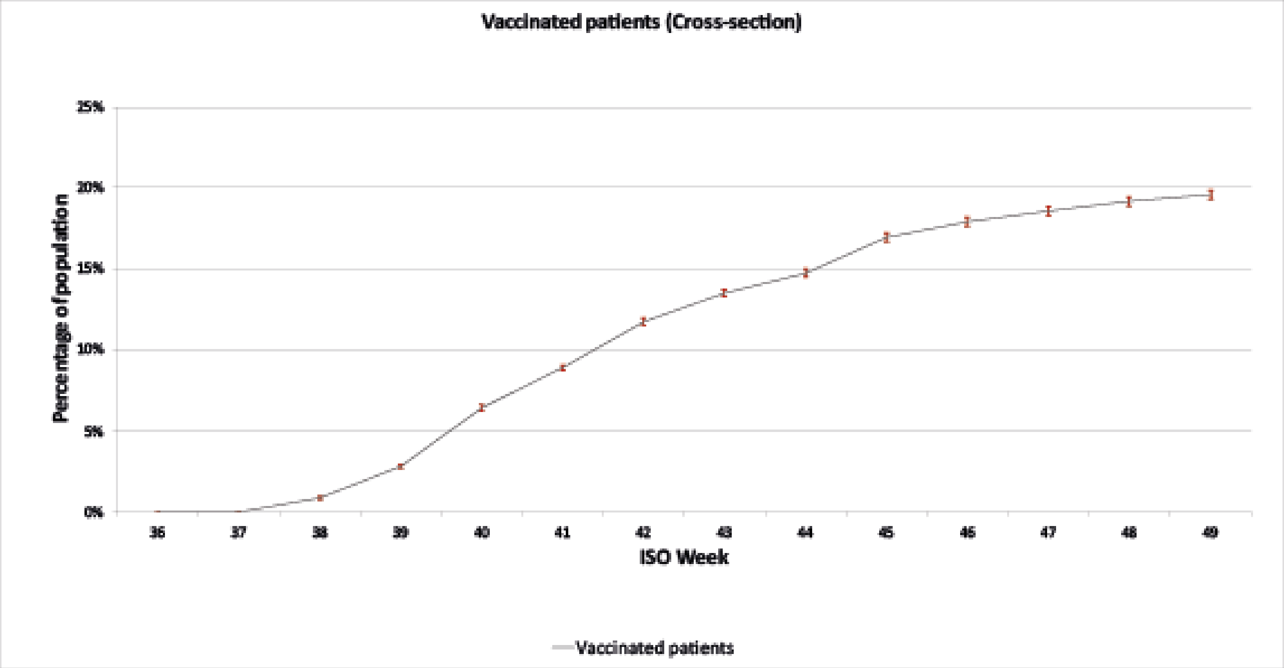

Table 2. Summary of vaccinations from weekly data extractions by risk group.

Variables	Vaccination status (weekly cumulated data)			
	EHR-DM[a] vaccinated (Non-GSK)	EPS[b]		
		Vaccinated (Non-GSK)	Vaccinated (GSK)	Vaccinated (All)
Number of practices	**6**	**1**	**2**	**3**
n (%)	8640 (16.62)	3607 (12.41)	3616 (12.44)	7223 (24.85)
LCI[c], %	16.30	12.03	12.06	24.35
UCI[d], %	16.95	12.79	12.82	25.35
Risk group				
Specific risk group				
n (%)	7422 (36.26)	2967 (22.66)	3301 (25.21)	6268 (47.88)
LCI, %	35.60	21.94	24.47	47.02
UCI, %	36.92	23.38	25.96	48.73
Under 4 years old				
n (%)	277 (14.70)	113 (10.89)	53 (5.11)	166 (15.99)
LCI, %	13.11	9.06	3.85	13.78
UCI, %	16.30	12.81	6.45	18.21
65 years or older				
n (%)	5198 (49.98)	2130 (30.67)	2641 (38.03)	4771 (68.71)
LCI, %	49.02	29.59	36.90	67.61
UCI, %	50.94	31.75	39.17	69.80

[a] EHR-DM: electronic health record data mining.

[b] EPS: enhanced passive surveillance.

[c] LCI: lower confidence interval.

[d] UCI: upper confidence interval.

Enhanced Passive Surveillance Practices

In the 3 practices that conducted *yellow card*–based surveillance, the staff managed to hand out the cards to 61. 24% (4150/6776) of the vaccinees, and of these cards, 1.97% (82/4150) were returned to the GP offices, which represented 1.21% (82/6776) of the vaccinated population covered by this surveillance system.

Some practices found it challenging to interpret and link the free-text comments on the cards to the specified AEI codes. With this respect, 1 practice faced some challenges to record all the information on the returned cards into the practice EHR system, the main reason being the difficulty to transcribe the events reported in the yellow cards to the electronic system.

Of those vaccinated (19.57% (15,863/81,040) of the population); 77.20% (12,247/15,863) were vaccinated using a non-GSK vaccine. The non-GSK vaccines that patients were administered were manufactured by Astra Zeneca, Sanofi Pasteur Europe, Seqirus Vaccines Limited, and Abbot Biologicals.

Adverse Events of Interest

From the weekly cumulative data extractions (weeks 35-49), the rates of AEIs in the 14-days postvaccination between GSK and non-GSK vaccines were similar: non-GSK=3.02% (370/12,247; 95% CI 2.72-3.33) and GSK=2.63% (95/3616; 95% CI 2.13-3.15) (Table 3). The most common AEIs presenting were respiratory, fever, and musculoskeletal symptoms (Multimedia Appendix 3).

The GSK vaccine had fewer AEI presentations of respiratory symptoms and fever but more musculoskeletal symptoms. The rates of these AEIs were as follows:

- Respiratory—0.96% (95% CI 0.79%-1.14%, 118/12,247) for non-GSK and 0.88% (95% CI 0.58%-1.19% 32/3616) for GSK vaccine.
- Fever—0.79% (95% CI 0.64%-0.96%, 97/12,247) for non-GSK and 0.66% (95% CI 0.41%-0.94%, 24/3616) for GSK vaccine.
- Musculoskeletal conditions—0.51% (95% CI 0.39%-0.65%, 63/12,247) for non-GSK and 0.91% (95% CI 0.61%-1.24%,33/3616) for GSK vaccine (Multimedia Appendix 3).

The highest rate of AEIs was identified in adults aged 15 to 64 years for GSK vaccines (3.2%; 25/781) (Table 3).

Table 3. Summary of adverse events of interest from weekly data extractions.

Any AEI[a]	Vaccination status (weekly cumulated data)			
	EHR-DM[b] vaccinated (Non-GSK)	EPS[c]		
		Vaccinated (Non-GSK)	Vaccinated (GSK)	Vaccinated (All)
Number of practices	**6**	**1**	**2**	**3**
Total				
n (%)	339 (3.92)	31 (0.43)	95 (1.32)	126 (1.74)
LCI[d], %	3.52	0.29	1.07	1.45
UCI[e], %	4.34	0.58	1.58	2.05
Age groups (years)				
<5				
n (%)	15 (5.42)	1 (0.60)	1 (0.60)	2 (1.20)
LCI, %	2.12	0.00	2.31	0.00
UCI, %	6.06	7.50	6.15	5.66
5-14				
n (%)	24 (3.37)	1 (0.18)	1 (0.18)	2 (0.36)
LCI, %	0.98	0.00	1.32	0.00
UCI, %	2.50	5.88	2.89	5.26
15-64				
n (%)	111 (4.53)	12 (0.69)	25 (3.20)	38 (2.20)
LCI, %	3.11	2.05	2.95	1.73
UCI, %	4.46	4.48	4.19	3.93
65+				
n (%)	189 (3.64)	17 (0.36)	67 (1.40)	84 (1.76)
LCI, %	2.34%	1.95%	2.27%	1.67%
UCI, %	3.11%	3.16%	2.99%	2.76%
Risk group				
Any risk group				
n (%)	293 (3.95)	29 (0.46)	87 (1.39)	116 (1.85)
LCI, %	3.52	0.30	1.10	1.53
UCI, %	4.39	0.64	1.69	2.19

[a] AEI: adverse events of interest.

[b] EHR-DM: electronic health record data mining.

[c] EPS: enhanced passive surveillance.

[d] LCI: lower confidence interval.

[e] UCI: upper confidence interval.

Hospital Admissions

We explored hospital admission data recorded in the practice EHR. The rate of admissions of vaccinees with an AEI was 2.50% (44/1,761; 95% CI 1.8-3.2).

Those receiving GSK vaccine had a numerically lower rate of hospital admission, although small numbers were reported. For example, 2% (2/92; 95% CI 2.2%-3.3%) of people vaccinated with GSK influenza vaccine were admitted to hospital with an AEI in the 14 days following vaccination, while in the non-GSK vaccines group, the rate was 3.9% (13/333; 95% CI 1.8%-2.1%).

There were timeliness, completeness, and accuracy issues with the retrieved hospital data. The hospital admission data and diagnoses took up to 10 to 20 days to be recorded in the practices' EHR and, in some cases, up to 42 days.

Analyses

End-of-Season and Weekly Comparison

The AEIs reported in the end of season and weekly extractions were comparable. For example, focusing on GSK vaccines, for any adverse event, the end-of-study cohort had an AEI recording of 92/3434 (2.68%) and weekly report of 95/3616 (2.63%). For GSK vaccines, the largest difference in AEIs was for any sensitivity or anaphylaxis (end of season: n=0, 0%; cohort: n=1, 0.03%).

Data Extraction From the Royal College of General Practitioners' Research and Surveillance Centre

Overall, the study data were comparable with that of the rest of the RCGP RSC (see Multimedia Appendix 3). This suggests that the AEIs reporting patterns from the 9 GPs recruited and the RCGP RSC were similar and that the data extraction approach was valid.

Timeliness was comparable with RCGP RSC. Data were extracted each week using the same automated system. However, 2 practices required local extracts (carried out where the remote systems installation failed); these 2 practices had delays of up to 2 weeks, particularly early in the observation period.

The RCGP RSC rate of overall influenza vaccine uptake (excluding the study practices) is 21.80% (238,519/1,094,352); the overall rate of these 9 practices, using the end-of-study cohort data, was 20.73% (14,801/71,407) suggesting a good completeness of the study data for vaccine uptake.

Discussion

Principal Findings

This study showed that using GP data for EHR-DM was a feasible method of near real-time surveillance. This was demonstrated by the timeliness of data extraction and the validity of the data.

The use of *yellow cards* (EPS) to enhance surveillance was not successful as there was only a 1.97% (82/4150) return rate; and this small additional return rate did not yield useful additional information. However, there were only 3 practices in this group.

Rates of AEI (within 14 days postvaccination) in the vaccinated group were around 3% (3.02% 333/11,367 for non-GSK and 2.63% 92/3434 for GSK) with around 1% (150/15,863) of AEIs were respiratory conditions. The differences in rates were not statistically significant, and no safety concerns were raised during the weekly assessment or at the end of the study period.

Implications of Findings

The study demonstrated the feasibility of setting up a network that could, with further refinement, rapidly detect potential safety concerns, allowing prompt investigation if deemed appropriate [18], originating from a significant change in AEIs associated with influenza vaccination using EHR-DM observing, for example, trends from week to week.

This network still needs additional adaptations to be worked out in the next phase of its implementation. For example, further thought needs to be given regarding improving the return rate of *yellow cards*. To improve the return rate, any future ADR card should ideally have predefined categories that patients can tick if present (or record if no AEI is experienced following vaccination), to standardize coding into the EHR.

To harmonize and standardize the Enhanced Safety Surveillance in Europe, one recommendation could be to establish a network of organizations involved in EHR data mining in real time, supplemented with vaccination-customized ADR cards (ie, *yellow cards* in this study) reporting scheme, with criteria defining the prerequisites of data quality. However, a *yellow card* is not a good long-term choice of color or label. In the United Kingdom, *yellow cards* are developed by the MHRA and are generally completed when a GP suspects an ADR related to the vaccination. In this study, the approach was to collect as comprehensively as possible AEIs, prespecified by the EMA, regardless of the possible causal association with immunization.

Another potential way to collect AEI following vaccination could be to develop a mobile phone application to collect events in a more comprehensive manner. This approach could be an interesting approach to overcome the suboptimal return. Future research could investigate the feasibility of designing such an app to collect this information in a more reliable manner.

Generalizability

A near real-time enhanced brand-specific surveillance network could produce weekly reports of AEIs to meet the EMA requirements. The data extraction element of the project could readily be extended; the *yellow card* scheme could be refined and expanded. Introducing an ADR card as part of the process may be an optimal and sustainable way to stimulate reporting of AEIs from those with a lower propensity to consult (ie, for mild events).

Data collection over several seasons may be required to achieve a better understanding of background rates of AEIs. A particular challenge is that people immunized in the first weeks of immunization may differ from those immunized in subsequent weeks due to annual recommendations to promptly vaccinate the more vulnerable patients early in the season.

It is feasible to set up a weekly reporting, using an enhanced passive and EHR-DM surveillance system, to detect EMA-specified AEIs across specific brands; though further refinements are needed before such a system can be fully operationalized.

Limitations

Data were inevitably passive surveillance data, largely derived from medically attended events for those who consult. Considering that some groups have a lower propensity to consult (eg, men [19]), this is a likely confounding factor. Future EPS may need to be designed to be more inclusive of less represented groups; for instance, using customized ADR cards to continuously enhance the reporting.

A further limitation of our design was the potential bias in the practice selection for EPS, which was conditional on the willingness of practice to participate in the study and hand out, collect, and code any data on the *yellow cards*. We drew conclusions about the unsuitability of the yellow card on basis of data from 3 practices, not selected at random. Return rates were low and what was written on the cards was challenging to transcribe and thus to code consistently.

In addition, in the United Kingdom, vaccines are preferentially recommended for different age and risk groups which preclude any possibility to systematically compare the findings from different vaccine brands. In addition, the sample for future studies could have improved representativeness by recruiting more inner-city practices. Our study practice populations were less ethnically mixed and less deprived than the English national average, likely due to a lack of inner-city practices.

Our remote data extraction system was reasonably reliable, although it had gaps. It is challenging to use a local extract system in a timely way, although it did fill gaps in our data. One other challenge was to properly analyze all the collected data to allow near real-time assessment. In the longer term, comparing rates with historic data may be an additional option to have more insights on baseline rates as a basis for comparison with findings in the current season. For this study, we had a lack of historical background rates of AEI in the same population or availability of an appropriate comparison group.

In future studies, we should either compare rates with AEIs derived from the RCGP or from previous years of these studies, assuming that the study design and the approach remain overall unchanged.

A limitation of our design was training GPs in coding. While this should help with data within the season, it has the potential to produce biased results when comparing with historical data when no training was given. Furthermore, the preferred code list given to practices (Multimedia Appendix 1) notes that these codes should be used for adverse events postvaccination. In this respect, it does not appear to use as baseline for comparison historical data where no specific training was provided.

Conclusions

Overall, this study showed that using GP data was a feasible method for enhanced near-real time surveillance in terms of EHR-DM. However, the use of *yellow cards* (EPS) in GP did not capture a significant amount of additional data. There are many lessons learnt from this initial study, and these are reflected in the limitations of the design and study approach. Future enhanced surveillance should focus on ways to improve and standardize AEIs reporting, data collection, and extraction.

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Conflicts of Interest

GDS reports that he was employed by Business & Decision Life Sciences on behalf of GSK at the time of the study and is now employed by the GSK group of companies. NM and FH are employees of the GSK group of companies. GDS and NM hold shares in the GSK group of companies as a part of their employee remuneration.

Multimedia Appendix 1
Age and sex distribution of pilot practices compared against the census.
[PDF File (Adobe PDF File), 224 KB - publichealth_v5i4e12016_app1.pdf]

Multimedia Appendix 2
Distribution of deprivation within pilot practices in comparison to the census.
[PNG File , 79 KB - publichealth_v5i4e12016_app2.png]

Multimedia Appendix 3
Tabular summary of AEIs.
[PDF File (Adobe PDF File), 138 KB - publichealth_v5i4e12016_app3.pdf]

References

1. European Medicines Agency. 2014. Interim Guidance on Enhanced Safety Surveillance for Seasonal Influenza Vaccines in the EU. URL: https://www.ema.europa.eu/documents/scientific-guideline/interim-guidance-enhanced-safety-surveillance-seasonal-influenza-vaccines-eu_en.pdf [accessed 2018-10-17] [WebCite Cache ID 73EXVc7DJ]
2. de Lusignan S, Hague N, van Vlymen J, Kumarapeli P. Routinely-collected general practice data are complex, but with systematic processing can be used for quality improvement and research. Inform Prim Care 2006;14(1):59-66 [FREE Full text] [doi: 10.14236/jhi.v14i1.615] [Medline: 16848968]
3. de Lusignan S, van Weel C. The use of routinely collected computer data for research in primary care: opportunities and challenges. Fam Pract 2006 Apr;23(2):253-263. [doi: 10.1093/fampra/cmi106] [Medline: 16368704]

4. UK Government Web Archive. 2013 Jan. Determining Arrangements for Supporting Research in Primary and Community Care. URL: http://webarchive.nationalarchives.gov.uk/20130124004303/http://www.dh.gov.uk/health/files/2012/12/Determining-arrangements-for-supporting-research-in-primary-and-community-care-updated-January-2013.pdf [accessed 2018-10-17] [WebCite Cache ID 73EXaFIBe]
5. National Health Services England. 2015. Enhanced Service Specification Seasonal Influenza and Pneumococcal Polysaccharide Vaccination Programme 2015/16. URL: https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/09/seasnl-flu-pneumococcal-upd.pdf [accessed 2018-10-17] [WebCite Cache ID 73EXeLPyT]
6. Correa A, Hinton W, McGovern A, van Vlymen J, Yonova I, Jones S, et al. Royal College of General Practitioners Research and Surveillance Centre (RCGP RSC) sentinel network: a cohort profile. BMJ Open 2016 Apr 20;6(4):e011092 [FREE Full text] [doi: 10.1136/bmjopen-2016-011092] [Medline: 27098827]
7. Find Open Data. 2011. Postcode to Output Area to Lower Layer Super Output Area to Middle Layer Super Output Area to Local Authority District (December 2011) Lookup in England and Wales. URL: https://data.gov.uk/dataset/e428c474-2e09-4ec0-aa37-a58364c8ccce/postcode-to-output-area-to-lower-layer-super-output-area-to-middle-layer-super-output-area-to-local-authority-district-december-2011-lookup-in-england-and-wales [accessed 2018-08-20] [WebCite Cache ID 71oN4CgzR]
8. Assets: How They Work. 2016. The English Indices of Deprivation 2015 – Frequently Asked Questions (FAQs). URL: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/579151/English_Indices_of_Deprivation_2015_-_Frequently_Asked_Questions_Dec_2016.pdf [accessed 2018-08-05] [WebCite Cache ID 71rjGpeLI]
9. Office for National Statistics. 2013. 2011 Census: Population Estimates by Five-Year Age Bands, and Household Estimates, for Local Authorities in the United Kingdom. URL: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/2011censuspopulationestimatesbyfiveyearagebandsandhouseholdestimatesforlocalauthoritiesintheunitedkingdom [accessed 2018-08-22] [WebCite Cache ID 71rjiZCd4]
10. Medicines and Healthcare products Regulatory Agency. Yellow Card URL: https://yellowcard.mhra.gov.uk/ [accessed 2019-10-09]
11. Sadek NH, Sadek A, Tahir A, Khunti K, Desombre T, de Lusignan S. Evaluating tools to support a new practical classification of diabetes: excellent control may represent misdiagnosis and omission from disease registers is associated with worse control. Int J Clin Pract 2012 Sep;66(9):874-882 [FREE Full text] [doi: 10.1111/j.1742-1241.2012.02979.x] [Medline: 22784308]
12. de Lusignan S, Navarro R, Chan T, Parry G, Dent-Brown K, Kendrick T. Detecting referral and selection bias by the anonymous linkage of practice, hospital and clinic data using Secure and Private Record Linkage (SAPREL): case study from the evaluation of the Improved Access to Psychological Therapy (IAPT) service. BMC Med Inform Decis Mak 2011 Oct 13;11:61 [FREE Full text] [doi: 10.1186/1472-6947-11-61] [Medline: 21995837]
13. de Lusignan S. In this issue: ontologies a key concept in informatics and key for open definitions of cases, exposures, and outcome measures. J Innov Health Inform 2015 Jul 10;22(2):170 [FREE Full text] [doi: 10.14236/jhi.v22i2.170] [Medline: 26245238]
14. Liyanage H, Krause P, de Lusignan S. Using ontologies to improve semantic interoperability in health data. J Innov Health Inform 2015 Jul 10;22(2):309-315 [FREE Full text] [doi: 10.14236/jhi.v22i2.159] [Medline: 26245245]
15. de Lusignan S. Codes, classifications, terminologies and nomenclatures: definition, development and application in practice. Inform Prim Care 2005;13(1):65-70 [FREE Full text] [doi: 10.14236/jhi.v13i1.580] [Medline: 15949178]
16. Pulse. 2015. NHS Overriding 700,000 Patient Opt-Outs to GP Data Being Shared. URL: http://www.pulsetoday.co.uk/news/gp-topics/it/nhs-overriding-700000-patient-opt-outs-to-gp-data-being-shared/20009761.article [accessed 2018-08-10] [WebCite Cache ID 73EXxRGJO]
17. UW Faculty Web Server. 2005. Confidence Bounds and Intervals for Parameters of the Poisson and (Negative) Binomial Distributions. URL: http://faculty.washington.edu/fscholz/Reports/poissonconfbd6.pdf [accessed 2018-10-17] [WebCite Cache ID 73EY6g6p3]
18. Hauben M, Aronson JK. Defining 'signal' and its subtypes in pharmacovigilance based on a systematic review of previous definitions. Drug Saf 2009;32(2):99-110. [doi: 10.2165/00002018-200932020-00003] [Medline: 19236117]
19. Wang Y, Hunt K, Nazareth I, Freemantle N, Petersen I. Do men consult less than women? An analysis of routinely collected UK general practice data. BMJ Open 2013 Aug 19;3(8):e003320 [FREE Full text] [doi: 10.1136/bmjopen-2013-003320] [Medline: 23959757]

Abbreviations

ADR: adverse drug reactions
AEIs: adverse events of interest
EHR-DM: electronic health record data mining
EMA: European Medicines Agency

EPS: enhanced passive surveillance
GP: general practice
MAHs: Marketing Authorization Holders
MHRA: Medicines & Healthcare Products Regulatory Agency
NHS: National Health Service
RCGP: Royal College of General Practitioners
RSC: Research and Surveillance Centre

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Original Paper

Perceptions and Experiences of Women Participating in a Digital Technology–Based Physical Activity Intervention (the mPED Trial): Qualitative Study

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Abstract

Background: Despite the benefits of regular physical activity, women in every age group have lower activity levels than men, and few women meet the recommended levels of physical activity. Digital technologies have been useful in increasing physical activity during the course of an interventional study. However, sustaining that activity once the clinical trial was complete was a major challenge.

Objective: This study aimed to describe the experiences and perspectives of physically inactive women who completed the mobile phone–based physical activity education (mPED), a randomized controlled trial, at 12 months.

Methods: Of 210 women who were enrolled in the mPED trial, 203 completed a 12-month open-ended exit interview and survey through phone. The participants were asked about their physical activity levels; their digital technology use; what they learned from, liked, and would change about the trial; their motivations to keep active post-trial; and their advice for other women. Interviews were transcribed verbatim and thematically analyzed using the brief survey qualitative description. Descriptive statistics were used to describe the survey data with the significance level set at $P<.05$.

Results: In the 12-month survey, a greater proportion of the participants in the intervention group, compared with the control group, reported that they regularly wore a pedometer or physical activity tracker (49.3%, 66/143 vs 26.1%, 18/69; $P=.002$) and engaged in brisk walking (54.5%, 73/134 vs 30.4%, 21/69; $P=.001$). The experiences and perceptions of physical activity of physically inactive women over time were embedded in a complex interplay of internal and external factors. A total of 6 interactive themes emerged as critical in supporting continued engagement in physical activity postintervention: tracking, technology versus personal touch, accountability, resources and environment, motivation, and habit formation. Technology allowed for self-tracking, which supported internal accountability. However, tracking by another person (personal touch) was needed for external accountability. Resources and environment underpinned the relationship among the themes of tracking, technology versus personal touch, accountability, motivation, and habit formation.

Conclusions: Future research is needed to identify the best ways to harness this dynamic process in promoting and sustaining physical activity among inactive women. Digital technology is evolving at an exponential rate and provides new opportunities to transform research into new approaches to promote physical activity.

Trial Registration: ClinicalTrials.gov NCT01280812; https://clinicaltrials.gov/ct2/show/NCT01280812

International Registered Report Identifier (IRRID): RR2-10.1186/1471-2485-11-933

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KEYWORDS

mHealth; randomized controlled trial; behavior; interview; physical activity; maintenance; women; motivation; accountability

Introduction

Despite the numerous benefits of physical activity for women, few women meet the recommended levels of physical activity [1,2]. In fact, women in every age group self-report lower activity levels than men [3]. Research has demonstrated that regular physical activity is associated with a reduced risk for chronic illnesses, such as type 2 diabetes, hypertension, and some cancers [3-8]. The Physical Activity Guidelines for Americans—2nd edition recommends that adults should engage in at least 150 to 300 min a week of moderate-intensity activity or 75 to 150 min a week of vigorous-intensity aerobic activity [9]. Yet, self-reported surveys administered nationally show that only 49% of adults in the United States met these recommended minimum activity levels [10]. Given that comparisons between self-report and accelerometer data demonstrate that people tend to overestimate their physical activity, the actual percentage of adults meeting minimum levels of activity is likely to be lower [11].

Use of digital technologies such as mobile phone, apps, and activity trackers to encourage physical activity has gained popularity. The prevalence of mobile phone ownership has significantly increased, reaching 77% in the United States in 2015 [12]. Similarly, the availability of activity trackers or accelerometers that connect with mobile phone health apps has also grown. According to a 2015 Pew Research Center survey, more than half of mobile phone users had downloaded a health app, with fitness and nutrition apps being the most common categories of health apps downloaded [13].

Research has shown that mobile phone apps or activity trackers or accelerometers seem to improve physical activity and reduce sedentary behaviors, at least in the short term [14-17]; however, few clinical trials using digital technology–based interventions to increase physical activity have examined the sustainability of these interventions [18-21]. To help address this knowledge gap, we recently completed the mobile phone–based physical activity education program (mPED) study, a randomized controlled trial (RCT) designed to examine the efficacy of a 3-month mobile app and accelerometer-based physical activity intervention and a 6-month maintenance intervention for physically inactive women (see the study design in Multimedia Appendix 1). The main outcomes of the trial have been previously published [22]. In sum, subjects in the intervention (regular and plus) groups, compared with the control group, substantially increased their accelerometer-measured daily steps by an average net difference of 2060 steps per day at 3 months (95% CI 1296-2825) and 1360 steps per day at 9 months (95% CI 694-2026) and a net difference of moderate-to-vigorous physical activity of 18.2 min per day at 3 months (95% CI 10.9-25.4) and 8.4 min per day at 9 months (95% CI 2.0-14.9). In the plus group, who kept the trial app and accelerometer for an additional 6 months, there were no additional improvements in physical activity compared with the regular group who kept only the accelerometer [22]. Within the control group, the participants significantly increased their physical activity levels (approximately 1000 steps per day) from baseline through 9 months. To explore the experience of continuing physical activity once the study digital technologies were removed from participants, we conducted a telephone interview at 12 months with women who completed the mPED trial to see if their activity level changed after the final 9-month research office visit and the reasons why participants did or did not continue to engage in physical activity. Therefore, the aim of this paper was to explore physically inactive women’s experiences and perspectives on participating in and continuing to engage in physical activity after the 9-month visit.

Methods

Study Design and Sample

We used qualitative description to elicit participants’ experiences and perspectives of their engagement during the mPED trial and after the 9-month final office visit [23,24]. Participants were interviewed through phone using a quantitative survey and qualitative interview (open-ended questions) at 12 months. The study protocol was approved by the University of California, San Francisco, Committee on Human Research and the mPED Data and Safety Monitoring Board. Detailed descriptions of the study design and outcomes have been previously published [15,22,25,26]. In short, physically inactive women aged 25 to 69 years were recruited from the San Francisco Bay Area between May 2011 and April 2014. The Social Cognitive Theory [27] and the Stages of Change Model (SCM) [28] were used to guide the design of the trial, and the SCM was also used to identify participants who were in the *contemplation* or *preparation* stages of behavior change (ie, an appropriate target study population for the intervention). During the telephone screening, research staff assessed participants’ behavior change readiness (*contemplation or preparation*).

In brief, the mPED trial was an unblinded, parallel RCT conducted with 3 groups (control, regular, and plus groups; see Multimedia Appendix 1). The trial consisted of a 3-week run-in period, a 3-month intervention period, and a 6-month maintenance period. The control group was asked to use an Omron Active Style Pro HJA-350IT (Omron Healthcare) accelerometer to record and store physical activity every day for the entire 9-month study period but did not receive any physical activity intervention. In contrast, the regular and plus groups received the identical physical activity intervention, consisting of an accelerometer, brief in-person counseling sessions, and the mPED trial app for the first 3 months. The mPED trial app developed by the research team has 2 main functions: (1) a daily message or video clip and (2) a daily diary. The trial app provided each participant’s weekly daily step goals, which were set to increase at a 20% rate from each study participant’s average baseline daily steps. Once daily step goals reached 10,000 steps, the study participant was asked to maintain at least 10,000 steps per day, 7 days a week during the remaining study period. Personalized automated feedback was provided daily via the mPED trial app. In addition, in the 6-month maintenance period, the plus group kept using both the mPED trial app and accelerometer, whereas the regular group kept using only the accelerometer. In this trial, the research team used the term *pedometer*, instead of accelerometer, to the study participants.

Procedures for the 12-Month Data Collection

At the 9-month visit, all participants returned all research equipment, including accelerometers and study mobile phones (if any) to the research office. If the study app was installed on their mobile phones, the research staff removed the study app. Participants were encouraged to purchase an activity tracker, if they reported that they did not have one, using the US $40 compensation for their time. At the end of the 9-month visit, all participants scheduled a 12-month follow-up telephone interview and then received a text, an email, or a telephone call to confirm their 12-month telephone interview appointment. The 12-month interview consists of 2 parts: (1) a survey and (2) a semistructured interview using open-ended questions (see Multimedia Appendix 2). Owing to the need to have a sufficient sample for the survey, all 203 participants were interviewed quantitatively and qualitatively. The interviews were conducted over the telephone by research assistants trained in both interviewing techniques [29]. Interviews were digitally recorded and transcribed verbatim by a professional transcriptionist. The average length of the semistructured interviews was 18 (SD 6) min, ranging from 7 to 41 min.

Analytic Strategy

Transcribed interview data were imported into ATLAS.ti 8.0 to assist in qualitative data analysis. Alphanumeric identifiers were used to ensure participant confidentiality, and audio files were kept on a secure device in a locked drawer in the research office. A total of 3 researchers reviewed 10 transcripts to inductively develop the initial codebook based on the answers provided to the research questions. Overall, 10 interviews were chosen because some of the interviews were relatively short, and the normally recommended number of 3 interviews was too small to sufficiently capture emerging codes [30]. After reviewing and comparing codes for how well the codes were capturing the perspectives of the participants, agreement on the coding scheme was achieved. Overall, 15% (30/203) of the transcripts were doubled coded, with 90% intercoder agreement. One researcher then coded the rest of the interviews for consistency. The 3 investigators reviewed the coding weekly within and across all interviews and discussed emerging commonalities. As the trial was effective in improving physical activity outcomes [22], we presented the qualitative interview data between the control versus intervention (regular and plus) groups. Constant and collaborative reviewing of data led to collapsing and grouping of codes into broader categories reflective of emerging themes that were evident across all 3 research groups [30]. Although theory development was not a goal, we sought more conceptual parsimony in the themes than in the descriptions [31]. Further examination, merging, connecting, and refining of codes within themes allowed for clarification of meaning and identification of patterns and relationships among the themes. Quotes associated with collapsed categories were then examined collectively by the research team to clarify broader themes across all groups (see Multimedia Appendix 2) and determine which best described the final themes. For the survey data, descriptive statistics were used with the significance level set at $P<.05$. As there was no statistical difference in the physical activity outcomes between the 2 intervention (regular and plus) groups [22], the 2 intervention groups were combined in this paper.

Results

Quantitative Findings

Overall, 96.7% (203/210) of the mPED trial participants completed the 12-month phone interview. The baseline characteristics in the sample of 203 participants did not differ from the 7 nonparticipants ($P>.05$). Baseline demographics are presented in Table 1. Mean participant age was 52.6 (SD 11.0) years, 56.7% (115/203) self-identified as non-Hispanic white, 74.4% (151/203) had a full- or part-time job, and 74.9% (152/203) completed 4 years of college. There was no difference in baseline characteristics between the control and intervention groups ($P>.05$).

At 12 months, 67.2 % (90/134) of participants in the intervention group and 51.5% (35/69) of participants in the control group reported that they owned a pedometer or activity tracker ($P=.03$), whereas 49.3% (66/134) of participants in the intervention group and 26% (18/69) of participants in the control group reported that they regularly wore the pedometer or activity tracker ($P=.002$; Table 2). In response to the question “Has your physical activity been more, less, or about the same compared with the first 9 months of the study?,” a significantly higher proportion of participants in the control group, compared with the intervention group, reported engaging in more physical activity from 9 to 12 months ($P=.001$). However, a greater proportion of participants in the intervention group engaged in more brisk walking compared with the control group ($P=.001$).

Table 1. Baseline demographics of mobile phone–based physical activity education participants who completed the 12-month interview.

Characteristics	Total (N=203)	Control (n=69)	Intervention (regular and plus groups; n=134)	*P* value
Age (years), mean (SD)	52.6 (11.0)	52.0 (9.9)	52.8 (11.5)	.66
Race and ethnicity, n (%)				.46
African American	16 (7.9)	3 (4)	8 (6.0)	
Hispanic or Latino	11 (5.4)	3 (4)	8 (6.0)	
Asian	41 (20.2)	13 (18)	28 (20.9)	
White (non-Hispanic)	115 (56.7)	36 (52)	79 (59.0)	
More than 1 race	20 (9.9)	9 (13)	11 (8.2)	
Education, n (%)				.14
Completed high school or some college coursework	51 (25.1)	23 (33)	28 (20.9)	
Completed college (4 years)	83 (40.9)	24 (34)	59 (44.0)	
Completed graduate school	69 (34.0)	22 (31)	47 (35.1)	
Annual household income (US $; before tax), n (%)				.66
<40,000	31 (15.3)	13 (18)	18 (13.4)	
40,001-75,000	49 (24.1)	14 (20)	35 (26.1)	
>75,000	107 (52.7)	36 (52)	71 (53.0)	
Decline to state or do not know	16 (7.9)	6 (8)	10 (7.5)	
Marital status, n (%)				.24
Never married, divorced, or widowed	97 (47.8)	29 (42)	68 (50.7)	
Currently married or cohabitating	106 (52.2)	40 (58)	66 (49.3)	
Employment, n (%)				.14
Employed for pay (full or part time)	151 (74.4)	47 (68)	104 (77.6)	
Retried or unemployed or homemaker	52 (25.6)	22 (31)	30 (22.4)	
Living with a child (children), n (%)				.17
Yes	50 (24.6)	21 (30)	29 (21.6)	
Body mass index (kg/m^2), mean (SD)	29.9 (6.2)	30.4 (5)	29.6 (6.2)	.46

Table 2. Comparison of app and pedometer use and self-reported physical activity between control and intervention groups.

Survey questions	Overall (N=203), n (%)	Control (n=69), n (%)	Intervention (regular and plus; n=134), n (%)	Overall *P* value
Do you currently have a health-related mobile application? (yes)	84 (42.0)	29 (42)	55 (41.7)	.89
Do you currently wear a pedometer? (yes)	84 (41.4)	18 (26)	66 (49.3)	.002
Do you have your own pedometer? (yes)[a]	125 (61.9)	35 (51)	90 (67.2)	.03
Reasons for not purchasing a pedometer after the study visit[b]	n=77	n=33	n=44	N/A[c]
Still planning to purchase or keep looking	31 (40)	13 (39)	18 (53)	N/A
Too expensive or financial difficulty	17 (22)	2 (6)	15 (44)	N/A
Use app or phone or be able to estimate steps	9 (12)	4 (12)	5 (15)	N/A
Do not help or do not like	8 (10)	6 (18)	2 (6)	N/A
Technology challenging or not accurate	6 (8)	4 (12)	2 (6)	N/A
Has one somewhere or has not set up	6 (8)	5 (15)	1 (3)	N/A
Other	6 (8)	2 (6)	4 (12)	N/A
Since your 9-month visit, what types of exercise have you engaged in to be physically active? (multiple choice question)[d]	n=203	n=69	n=134	N/A
Walking	126 (62.1)	49 (71)	77 (57.5)	.06
Brisk walking	94 (46.3)	21 (30)	73 (54.5)	.001
Yoga	20 (9.9)	3 (4)	17 (12.7)	.06
Hiking	15 (7.4)	5 (7)	10 (7.5)	.96
Gardening or yard work	16 (7.9)	7 (10)	9 (6.7)	.39
Cycling	19 (9.4)	7 (10)	12 (9.0)	.78
Other	110 (54.2)	39 (56)	71 (53.0)	.77
Since your 9-month study visit, has your physical activity been more, less, or about the same (compared with the first 9 months of the study)?[e]	n=203	n=69	n=134	N/A
About the same	66 (32.5)	27 (39)	39 (29.1)	.001
More	64 (31.5)	29 (42)	35 (26.1)	.001
Less	73 (36.0)	13 (18)	60 (44.8)	.001
Top 3 reasons for being less active after the 9-month visit (multiple choice question)[f]	n=73	n=13	n=60	N/A
Study ended	20 (28)	0 (0)	20 (33)	N/A
Lack of time	20 (28)	4 (31)	16 (27)	N/A
Did not have a pedometer	12 (16)	2 (15)	10 (17)	N/A

[a] Missing 1 participant.

[b] Total N=77, control n=33, intervention n=34.

[c] N/A: not applicable.

[d] N=203 but some subjects answered more than once.

[e] N=203.

[f] Total N=73, control n=13, intervention n=60.

Qualitative Findings

Overall, participants, regardless of group, appeared to like participating in the trial itself and enjoyed interacting with the research team. Although not all aspects of the study program were addressed in the 12-month interview, participants talked about their experiences with these digital technologies (pedometers and the mobile phone app), increasing their physical activity and challenges in maintaining physical activity. A total of 6 conceptual themes, such as tracking, technology versus personal touch, accountability, environment and resources, motivation, and habit formation, emerged from the data. Multimedia Appendix 2 shows commonalities and small differences between the 2 groups in their experiences of participating in the study and perspectives on maintaining physical activity and motivation poststudy. These themes connect with the survey data reported above.

Tracking

Participants in all groups talked a lot about the importance of tracking or keeping track of one’s activity to remain motivated:

> *There is something about keeping track because it is very difficult to discipline yourself, the whole thing is to get to a new habit.* [ID 1060, control, age 50 years]

Wearing a pedometer was seen as the primary method for tracking by both control and intervention groups as it allowed for one to “check how many steps I walked in one day” [ID 1003, plus, age 33 years].

Two subthemes emerged from participants discussion of tracking: self-awareness (internal tracking) and tracking by others (external tracking).

Self-Awareness

Knowing how many steps the participant had taken was also seen as a mechanism of self-awareness as 1 woman in the control group clearly articulated:

> *I learned how physically inactive I was prior to the study (And how did you learn that?) Just by tracking those steps and seeing...I work remotely so when you’re at home and you are doing 1000 steps a day, that sounds like a lot, you know. You don’t know. And then as time progresses you realize that you didn’t even go to the driveway and back for a thousand steps, that it’s just barely nothing. I just think I was more conscious of being physical active, more physically active...because I had the pedometer on, and it kept me conscious of what I was doing.* [ID 1238, control, age 57 years]

For some, having a pedometer provided the needed tracking information as it alerted them to the number of steps they had taken that day so that if they had missed the mark (or the expected goal) they could work to increase their steps before bedtime:

> *In the evening when I text that I haven’t been doing much activity or anything, I will walk until I hit a certain goal or until I am tired and then I will stop and go to bed.* [ID 1063, control, age 65 years]

Others looked at the pedometer’s tracking ability to get a sense of how well they have done over the course of a week rather than a daily reminder:

> *I would like the pedometer to keep track of my activity. The daily tracking was boring. What I like about the pedometer is that I could see my previous activity. That I like. So, I know if it is a good week or a bad week and then I will make up the difference in the following week.* [ID 1083, plus, age 44 years]

However, for some participants, self-awareness and pedometer tracking were not enough to maintain their increased level of physical activity, and they desired external tracking.

Tracking by Others

Additional tracking was needed by some participants to encourage them to keep up their physical activity. Although the intervention group discussed this theme more than the control group, participants from both groups talked about the importance of tracking by someone else. This tracking came through having to *report in* to the research team the number of steps per day through either the download of pedometer data (control group) or the research designed app (intervention group). A woman in the control group stated the following:

> *I like reporting into you. I like reporting my success. It was validation. I like getting validated...I felt value. And I also got validated that each time I was measured and weighed that I was a success.* [ID 1291, control, age 59 years]

An intervention participant remarked that she “actually liked having to report my steps every day on the phone. I would have liked doing that every day” (ID 1078, regular, age 68 years).

Intervention participants received feedback after reporting in their steps via the phone app. Feedback included praise for meeting their step goals or encouragement to do better in the coming days. One participant noted:

> *[I realized] how much I needed someone monitoring what I am doing. How, honestly, I could see the difference when I went from being in the group where you reported every night to being in the group that was set free and you only recorded when you went to the soft tablet. That really did make a difference, the daily check-ins, as intrusive as it seems, they were really a factor [in keeping me active].* [ID 1113, regular, age 55 years]

Tracking was closely linked to participants’ discussion about technology versus personal touch. Pedometers were mechanisms of tracking, and reporting one’s steps required engaging with a human researcher, both of which were important components of tracking.

Technology Versus Personal Touch

Both control and intervention groups spoke about the importance of technology and personal touch in engaging in physical activity. What was evident in the data was that some embraced the technology. As 1 control participant advised others:

> *Get a pedometer and, you know, get one with an application attached to it. That you know, it does encourage you to get the steps, and get some physical activity.* [ID 1166, control, age 60 years]

Others are more technology adverse, as 1 intervention participant stated:

> *The cell phone was especially bad for me because I turned into one of those people that’s always looking*

> *at their phones...The phone made me somewhat antisocial and dehumanized me.* [ID 1013, plus, age 66 years]

Regardless of their attitude toward technology, 41% (28/69) of the control group stated in their interviews that they liked the pedometer, and 39% (52/134) of the intervention group mentioned that they liked the pedometer and the app, finding them useful in helping them to keep walking. Women in the control group spoke exclusively about the pedometer as that was the only technology they received. Furthermore, 1 control participant statement reflected many others:

> *I liked having the pedometer. Being able to see even the little bit of activity, like oh walking to the printer or walking across the street to grab lunch, it all adds up.* [ID 1182, control, age 39 years]

Some women from both groups complained about the size or bulkiness of the pedometer, whereas others found having to wear it daily irritating:

> *I don't like wearing a pedometer...it was just like, kind of a pain in the butt, kind of thing. It was just annoying, like, putting it on every day and that kind of thing.* [ID 1191, control, age 39]

Although the intervention group demonstrated similar perspectives about the pedometer, they also discussed the app provided by the study. As 1 participant noted, the app had both positive and negative aspects:

> *The app—there were some days that it felt like a really harsh ... supervisor, you know, like, it'd be 8:00pm and I'd think "Oh, I gotta enter that information! And I haven't done my exercises yet." I'd feel guilty. But I don't see that as a bad thing. You know, somebody's gotta be the task master, ya know, and that helped me be my own.* [ID 1245, regular, age 49 years]

The app provided external tracking (having to check-in via the app), feedback, and encouragement, which work well for the majority of study participants. Although the control group spoke about monitoring their steps in general, only the intervention group discussed reaching their step goals. Yet, the pedometer (especially for the control group) and the app were not perceived as only technology. There was also a person (a research team member) on the other end monitoring their steps. Women from both groups explicitly stated that they liked or needed to be able to talk to someone, to reach out to someone who was tracking their steps and to whom they would be accountable, which is why this study design worked for them. Although the control group only met with research team members periodically to download their pedometer readings, be measured, and complete survey tools, they also talked about the importance of the personal interactions in keeping them active. As 1 person noted:

> *I actually liked the check in, coming in and interacting with you. That was encouraging.* [ID 1039, control, age 61 years]

Discussions about tracking via technology or personal touch reflect the importance of accountability in both initiating physical activity within the study and maintaining it poststudy.

Accountability

Participants from both groups used the word *accountability* or *being accountable* frequently. *Accountability* involved *having responsibility for* setting a goal and then being held accountable for reaching it. The study itself had built-in accountability, but it varied by group. The control group talked about being held accountable to the research team when they had to come in every study visit and download pedometer data, be measured, and complete questionnaires:

> *I liked that I could discuss with you and others that worked there and discussed these issues, for the support, measurement itself, and ask questions that I had about this issue. It created some motivation for me.* [ID 1077, control, age 59 years]

On the contrary, the intervention group talked about the accountability established through reporting daily steps via the app and getting immediate feedback as well as being measured every study visit. Most participants felt that they needed to be held accountable to increase their daily steps. As 1 person noted:

> *As time goes on you tend to get on to other things, so having something that I am kind of accountable for, makes a difference to me. I work better under accountability, just kind of keeping on track. If I was doing this myself, I could easily get lazy.* [ID 1115, plus, age 57 years]

Several participants from both groups indicated that the reason they signed up for the study was the *accountability factor*, which they felt they needed to *get motivated* and *get moving*:

> *I loved being in the study. I really did. You motivated me to walk more. But also, I really loved knowing that somebody had my back. You know. That I was accountable to somebody for my walking. And that makes a big difference for me. It was hard for me letting go of that pedometer. I almost cried. But I really miss it.* [ID 1165, control, age 59 years]

Engaging in the study also generated a sense of responsibility to do their best to achieve good results:

> *The study provided a way for checks and balances. You had to be true to yourself because you were trying to do well for the study. I wanted the study to be successful and I wanted to fulfill my agreement to do it to the best of my ability. So sometimes I could be out there walking from 8-9 pm because I haven't finished my steps. So, I felt a responsibility about it. I liked it. I could be in the study forever and I'd be happy.* [ID 1091, plus, age 68 years]

Accountability could be internal, being accountable to one's self, or external, being accountable to others, such as the research team, friends, or family. For some, having an accurate pedometer was sufficient to *take accountability of your own life*. As 1 person stated:

> *The accountability. You know, you wear the pedometer every day and it's going to tell the truth regardless and so it makes you want to do better, you*

> *know, walk more and perform better, even if it's just a number.* [ID 1162, regular, age 51 years]

Others, however, seemed to need more external accountability, knowing that they had to report their steps to someone else held them accountable:

> *The external reinforcement—I liked having the pedometer and having external motivation. I liked being embarrassed if I had to tell you I hadn't done anything that day.* [ID 1053, plus, age 66 years]

Having to *check-in* with someone was a critical aspect of external accountability.

Resources and Environment

In talking about what supports or inhibits their continued physical activity, the environment and resources emerged as an underlying issue. In this theme, we saw a clear difference between the control and intervention groups. Control group participants discussed the fact that they did not receive the same resources as the intervention group, and they were not happy about it:

> *I felt that I was in the control group and I sort of wished that I had more assistance with exercise information, you know. Information not just support, umm, emotional or psychological support, but yeah support in terms of information.* [ID 1224, control, age 59 years]

Intervention participants discussed the resources provided by the study in the form of opportunities for walking or exercise groups and information about other forms of exercise. Indeed, some participants bemoaned the loss of this information although it was available if one searched various websites. Participants liked the convenience of a 1-stop resource repository. This resource was important for participants' ability to find or create walking groups or buddies to enhance their accountability and sustain physical activity.

Embedded in their discussion of resources were barriers to maintain physical activity poststudy. Consistent with the quantitative data, the 2 main barriers addressed were money and time. Although most agreed that having a pedometer helps in tracking and accountability, not everyone bought one after returning the study pedometer at the end of 9 months.

Money also played a significant role in acquiring a pedometer poststudy, as 1 control participant noted:

> *I really wanted to buy a new pedometer, but I didn't have money to do it.* [ID 1165, control, age 59 years]

Although some participants had sufficient income to join a gym or find a personal trainer, most did not, opting to continue walking on their own.

The biggest resource that was lacking was time, and this perspective is consistent with the 12-month survey where lack of time was one of the top 3 reasons for not engaging in physical activity. Although committing time to actively engage in the study was a responsibility participants embraced, once the study was complete, finding time to be active became an issue. The interaction between time and money was addressed as a major problem:

> *I think that time is still my number one enemy in this regard. Time and money—because we have a great gym nearby, but I can't really afford a membership. But being able to go somewhere for ½ an hour, in a safe space, as opposed to walking outside at night, would definitely improve my activity levels.* [ID 1253, regular, age 34 years]

The environment was positively addressed by both groups when talking about the beauty of the physical environment and how it enhanced their walking experience:

> *I often used my walk to look around, and enjoy looking at people's gardens, or enjoy the architecture, or the scenery, or whatever is out there, looking for things.* [ID 1165, control, age 59 years]

Although a few spoke of issues of safety within the environment, especially walking at night, the physical environment was not as critical to their continued engagement in physical activity. Although resources and environment underpin the themes of tracking, technology versus personal touch, and accountability, they also frame discussions about what motivates engagement in physical activity.

Motivation

Motivation or being motivated was mentioned frequently across both control and intervention groups. Finding motivation was seen as critical to initiate physically active and important to keep one engaged once the study was complete, even if the motivation process was elusive:

> *So, just find whatever can motivate you, [use] tools or programs that kind of keep track of that. Because it so easy to just fall back and say "Oh, I'm just going to watch TV."* [ID 1115, plus, age 57 years]

Tracking, technology, and accountability play important roles in motivation. Control participants highlighted the importance of wearing a pedometer in and of itself in their motivation to be active as it allowed self-tracking and self-accountability. For the intervention group, using pedometers and apps to track, encourage, and assess progress increased their motivation. Participants in both groups commented that the tracking provided by the pedometer and accountability to the study team was important to maintaining their activity.

Conversely, others talked about what either did not motivate them or what reduced motivation once the study tools were returned at 9 months. Unexpectedly, 1 person noted that the technology used in the study was not a motivator:

> *I was not motivated by the pedometer. You know because that's the primary reason why I wanted to participate [in the study]. I felt that wearing the pedometer and looking at the number every day, it would be [a] motivating factor for me to make the number increase and it was not.* [ID 1127, control, age 41 years]

However, others remarked that the loss of the pedometer and the external accountability had a negative impact on their motivation poststudy:

> *I think giving up the pedometer and knowing that I never had to come back and be measured and everything. I think that just sort of took away my motivation.* [ID 1078, regular, age 68 years]

Tracking, via technology and personal touch, and accountability were more critical to sustaining physical activity than motivation.

For some, getting a pedometer and tracking themselves seemed to be enough to keep them active. However, others really spoke about the need to create some form of external accountability and encouragement, a *force of accountability*. One of the most common advice for sustaining a walking regime was finding an *activity buddy*, such as a friend, a neighbor, a coworker, a family member, or an activity-focused group. For some, this meant having someone to walk with:

> *Get a group of people together that are of the same mindset that are going to actually show up and participate, not by yourself. I think the hardest part of being active is doing it alone.* [ID 1182, control, age 39 years]

Although others preferred to walk alone, they liked the idea of being accountable to someone else:

> *If you can't have the mPED study then I think the idea of having a friend or someone that you are accountable to is good. You don't necessarily have to do it together.* [ID 1091, plus, age 68 years]

In general, the ultimate goal of physical activity programs is to establish a routine or habit of physical activity. Although habit formation was not necessarily achieved by participants, it was discussed by some participants.

Habit Formation

Participants from both control and intervention groups discussed the goal of establishing a routine or habit, but more participants from the intervention group brought up this idea than control participants. One control participant talked about wanting to establish a habit but found it difficult:

> *I learned that I guess that it's pretty easy to make the habit, but I still have problems of actually making the habit. So, I don't know, I don't know, you know you learn.* [ID 1268, control, age 62 years]

Conversely another participant discussed how the tracking, technology, and accountability of the study helped her establish a habit or routine:

> *I want to be a little more active, so that's what motivated me to join the study and I wanted [it] to help me establish a habit of moving. So, since I had to report daily or they are tracking me daily, so it helps me to establish a routine.* [ID 1129, control, age 52 years]

Intervention participants situated their discussion about habit formation differently, demonstrating their synthesis of what they learned from the study about making changes and creating habits. One woman stated that she learned that developing a habit is difficult:

> *Umm, that it takes a lot to change a habit. ...it took being conscious many times each day to actually become eventually conscious enough to just do it to have it become part of my routine instead of a big ordeal.* [ID 1072, plus, age 58 years]

One woman talked about how making *small habitual changes* in activity can add up to more steps per day, whereas another woman addressed the importance of having a measuring tool in habit formation:

> *The importance of forming a habit and for me the necessity of having a measuring device to motivate me to do it.* [ID 1187, regular, age 62 years]

However, another woman who stated she had developed a habit of physical activity and no longer felt the need for a measuring tool:

> *I already formed that habit and I know, uhh, now I use, I don't use steps. I use time. How much time I walked, so I know how many steps I might have walked, and I use time to increase my uhh, my physical activity.* [ID 1289, plus, age 56 years]

Another lesson learned was that developing a habit of physical activity does not necessarily mean having to do it every day:

> *What the study [showed me is] that, umm exercise habits can be developed. Part of my biggest thing before was that I don't think I'm able to do it, maintain some type of program or routine every day; and the study has totally changed that idea for me and at least I am going to maintain my walking. Probably not as rigorous as it should be but at least it's a big improvement for myself.* [ID 1151, regular, age 42 years]

Finally, several women discussed the importance of having social support, through family and friends, to motivate them to develop a physical activity habit:

> *Anything that can kind of motivate you. I got my sister on that walking telephone thing. She went out and bought a pedometer. And she way passed me. She is all over it now. Prior to that she didn't know what she was doing. And then she got the pedometer and it was like Okay. ... So umm, so just find whatever can motivated you, tools or programs that kind of keep track of that.* [ID 1115, plus, age 57 years]

Discussion

Principal Findings

Feedback from women's experiences and perspectives of physical activity after completing the mPED trial reflect complex interactions among internal and external factors. Although we previously reported on the efficacy of the 3-month and additional 6-month effects of a mobile phone app in conjunction with brief in-person counseling on physical activity [22], participants at the 12-month interview spoke about the challenges of maintaining physical activity after the intervention technologies were removed [14,21]. In the 12-month survey, one of the interesting findings was that a significantly higher proportion of participants in the intervention group, compared with the control group, reported engaging in less physical activity from 9 to 12 months. For the intervention group only, the major reason for being less active was that the study had ended. Yet, approximately half of the participants in the intervention group reported that they still regularly wore a pedometer or activity tracker and engaged in brisk walking after the trial ended, and this proportion was higher than in the control group.

These quantitative differences between the intervention and control groups from the 12-month survey results were supported by the findings of the qualitative interviews. The themes identified in this study as influencing women’s continued engagement in physical activity were tracking, technology versus personal touch, accountability, resources and environment, motivation, and habit formation. Although motivation, resources, and accountability have been mentioned in other studies [14,18,20], it is the interaction among all the themes that emerged as particularly important. Researchers have suggested that the factors leading to the adoption of physical activity in the short term are different from those needed to sustain physical activity over time [32,33]. Study participants in this trial seemed to agree that what motivated them to start a physical activity program did not necessarily keep them active after completion of the study. The Physical Activity Maintenance Model [33] suggests that goal setting, motivation, and self-efficacy, mediated by life stress and environment, influence physical activity maintenance. The qualitative data support motivation as an important element in physical activity maintenance and life stress in the form of lack of time and money and environmental resources as mediators of maintaining physical activity. However, self-efficacy did not emerge as a key aspect of maintaining physical activity postintervention. Although participants mentioned the importance of meeting goals, goal setting did not emerge from the interviews. As goal setting was a part of the intervention, participants may not have seen the need to specifically address it. Instead, tracking, both digital and human, and internal and external accountability are what kept participants engaged in physical activity over time.

The trial used the SCM as a framework for the study [28] and posited that the intervention would take people in the contemplation or preparation stages and move them into the action and maintenance stages. Given the fact that all participants in the intervention and control groups increased their physical activity during the trial [22], it is clear that the participants did move into the action stage. Although there was a slight reduction in steps at the end of the maintenance intervention, all the participants continued to engage in higher levels of physical activity compared with their baseline levels. However, reaching the termination stage where physical activity becomes a habit was more elusive, reflecting issues with resources and environment, motivation, and accountability. Both the 12-month survey and qualitative interview findings highlighted the difficulties of habit formation, which is the process by which regular physical activity becomes automatic and routine. However, some participants in the intervention group clearly applied some of the things they had learned during the first 3 months of the trial to successfully develop a physical activity habit or routine.

The findings of this study are also somewhat inconsistent with self-determination theory (SDT) [34] often used by studies investigating exercise motivation. A systematic review of exercise, physical activity, and SDT demonstrated that intrinsic motivation, defined as doing an activity because of the satisfaction it brings, is more predictive of long-term exercise adherence than extrinsic motivation, which is predicated upon a desire for social reward to avoid disapproval [34]. Consistent with the literature, being motivated or finding your motivation was seen as an important aspect of long-term sustainability of physical activity [14,20]. Motivation was seen as an individual resource or need and that each person had to find what motivated them to continue engaging in physical activity. However, motivation was not central to their discussion of what kept them active poststudy. The interaction between tracking, technology versus personal touch, resources and environment, and accountability emerged as more critical to forming their physical activity habits over time.

In both groups, pedometers or activity trackers clearly provided a mechanism for keeping track of one’s steps, providing for self-monitoring of ones’ own physical activity [35]. Being able to see how well they did over the course of the day or week and knowing whether they had reached their goal was helpful to those who bought and wore activity trackers. As such, tracking and technology interact to both encourage and measure physical activity. Indeed, this is what these technologies are designed for, namely promoting self-monitoring of physical activity. However, what was also evident in the data was the importance of the personal touch in tracking. Participants remarked on the importance of knowing that someone on the research team was keeping track of their steps, a form of external monitoring, reflecting a desire to meet research team members’ expectations. Participants noted that they really missed having to report their steps to a study personnel and knowing that they could reach out and talk to a person as needed. This perceived value of both internal (supported by technology) and external tracking (supported through personal touch) is related to participants’ feedback on the importance of accountability.

Being held accountable or the need for accountability was mentioned frequently by participants and therefore emerged as critical to both motivation and physical activity habit formation. Those who remarked on the value of physical activity trackers and the importance of internal motivation also indicated that one had to be self-accountable. Use of tracking technology provided the means to determine if one had met one’s goals, thereby keeping oneself accountable. However, many of the participants struggled with lack of accountability at the end of the 9-month maintenance intervention, regardless of whether they owned a pedometer or not. The removal of the intervention technology, while problematic for some, was less of an issue than the absence of external tracking by research staff. Many participants remarked that not having the external monitoring made them less accountable and took away motivation. Participants also sought out external trackers in the form of activity buddies or walking groups or even family and friends to remain accountable. This need to be accountable to others is consistent with other research exploring exercise adherence in older adults [19,21,36]. Although internal and external accountability are not synonymous with intrinsic or extrinsic motivation, participants in this study revealed that contrary to SDT studies [34], external accountability was necessary for continued engagement in physical activity.

Underpinning the participants' discussions about sustaining physical activity was the importance of access to and use of resources within their social, economic, and physical environment. Limited economic resources impacted some participants who seemed to struggle a bit more with sustaining their physical activity. Although the participants were encouraged to purchase a pedometer (if they did not have one), budgetary constraints impacted some participants' ability to purchase a pedometer, whereas others did not perceive the need to buy one. Research has shown that walkability, often measured using built-in environment features such as sidewalks and street connectivity, predicts walking patterns and physical activity [37-39]. Although we did not ask about the physical environment, we expected this to emerge as a reason for not walking. However, participants remarked that the wealth of environmental walking resources available encouraged them to walk and gave them a chance to see the beauty of their neighborhoods.

The resource that was most important and seemed in shortest supply was time. This finding emerged from both the 12-month survey and the qualitative interview and is consistent with research that shows that time scarcity reduces physical activity [40]. Some participants noted that you had to make time or find time to walk or exercise, and most indicated that they committed the time for the sake of the study; but once the study ended, their busy lives took over, and walking or activity time was no longer a priority. The intersection of lack of time and money was also addressed by some of the participants. The need to make money superseded finding time to walk, and both time and money have been addressed in previous research on adherence to exercise among middle-aged women [14,21,40]. Participants generally found the time to engage in physical activity to fulfill their commitment to the study, but this was not enough to keep them fully engaged poststudy.

Strengths and Limitations

One of the strengths of the study was an excellent retention rate at 12 months. Overall, 97% (203/210) of the randomized participants in the mPED trial were interviewed and analyzed in this qualitative study, enhancing the credibility of the findings. Although interviews lasted, on average, only 18 min, sufficient data were generated to saturate the themes. All interview transcripts were quality checked for accuracy, and the dual coding of 15% (30/203) of the transcripts to achieve 90% agreement enhanced dependability. The qualitative analysis was supported by the quantitative findings from the survey, enhancing confirmability [41,42].

Despite these strengths, there are limitations to this study. As the digital technologies used by the trial to measure physical activity in the form of steps per day had been removed from the participants at 9-months, we relied on participants' self-perception of their physical activity postintervention, which is subject to bias. Transferability of the findings of this study may be limited because of the unique social and environmental factors present in the San Francisco Bay Area. In addition, the study participants were women; therefore, these findings may be applicable to men and children.

Conclusions and Implications

Both the 12-month survey and qualitative interview findings highlight the experiences and perspectives of physically inactive women who participated in the mPED trial. As the 12-month survey did not objectively measure participants steps for the last 3 months of the study, we cannot determine the maintenance of physical activity at 12 months. However, a higher proportion of the participants in the intervention group reported regular wearing of the pedometer and more brisk walking than the control group, indicating continued engagement in physical activity. Tracking via technology and personal touch and accountability emerged as central factors in initiating and maintaining activity over time. Resources, in the form of time and money, supported or impeded continued engagement in physical activity and habit formation. Digital technology, especially in the form of activity trackers, is moving faster than research, providing more opportunities to harness this dynamic interactive process in promoting and forming physical activity habits among inactive women.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Overall study design and interview questions.
[PDF File (Adobe PDF File), 443 KB - publichealth_v5i4e13570_app1.pdf]

Multimedia Appendix 2
Comparison of thematic quotes between control and intervention groups.
[DOCX File , 20 KB - publichealth_v5i4e13570_app2.docx]

References

1. Troiano RP, Berrigan D, Dodd KW, Mâsse LC, Tilert T, McDowell M. Physical activity in the United States measured by accelerometer. Med Sci Sports Exerc 2008 Jan;40(1):181-188. [doi: 10.1249/mss.0b013e31815a51b3] [Medline: 18091006]
2. Tucker J, Welk G, Beyler NP. Physical activity in US: adults compliance with the Physical Activity Guidelines for Americans. Am J Prev Med 2011 Apr;40(4):454-461. [doi: 10.1016/j.amepre.2010.12.016] [Medline: 21406280]
3. Rossi A, Dikareva A, Bacon SL, Daskalopoulou SS. The impact of physical activity on mortality in patients with high blood pressure: a systematic review. J Hypertens 2012 Jul;30(7):1277-1288. [doi: 10.1097/HJH.0b013e3283544669] [Medline: 22573122]
4. Ford E, Li C, Zhao G, Pearson W, Tsai J, Churilla JR. Sedentary behavior, physical activity, and concentrations of insulin among US adults. Metabolism 2010 Sep;59(9):1268-1275. [doi: 10.1016/j.metabol.2009.11.020] [Medline: 20060142]
5. Gallaway P, Miyake H, Buchowski M, Shimada M, Yoshitake Y, Kim A, et al. Physical activity: a viable way to reduce the risks of mild cognitive impairment, alzheimer's disease, and vascular dementia in older adults. Brain Sci 2017 Feb 20;7(2):pii: E22 [FREE Full text] [doi: 10.3390/brainsci7020022] [Medline: 28230730]
6. Gonçalves AK, Florencio GL, Silva MJ, Cobucci RN, Giraldo PC, Cote NM. Effects of physical activity on breast cancer prevention: a systematic review. J Phys Act Health 2014 Feb;11(2):445-454. [doi: 10.1123/jpah.2011-0316] [Medline: 23416687]
7. Mammen G, Faulkner G. Physical activity and the prevention of depression: a systematic review of prospective studies. Am J Prev Med 2013 Nov;45(5):649-657. [doi: 10.1016/j.amepre.2013.08.001] [Medline: 24139780]
8. Olver IN. Prevention of breast cancer. Med J Aust 2016 Nov 21;205(10):475-479. [doi: 10.5694/mja16.01007] [Medline: 27852187]
9. Health. 2018. The 2018 Physical Activity Guidelines Advisory Committee: Scientific Report URL: https://health.gov/paguidelines/second-edition/report/ [accessed 2018-10-10]
10. Winston G, Phillips E, Wethington E, Devine C, Wells M, Peterson J, et al. Social network characteristics associated with weight loss among black and hispanic adults. Obesity (Silver Spring) 2015 Aug;23(8):1570-1576 [FREE Full text] [doi: 10.1002/oby.21155] [Medline: 26179578]
11. Ward BW, Nugent CN, Schiller JS. Centers for Disease Control and Prevention. Early Release of Selected Estimates Based on Data From the 2015 National Health Interview Survey URL: https://www.cdc.gov/nchs/data/nhis/earlyrelease/earlyrelease201605.pdf [accessed 2019-10-01]
12. Pew Research Center. Mobile Fact Sheet URL: https://www.pewinternet.org/fact-sheet/mobile/ [accessed 2019-06-18]
13. Krebs P, Duncan DT. Health app use among US mobile phone owners: a national survey. JMIR Mhealth Uhealth 2015 Nov 4;3(4):e101 [FREE Full text] [doi: 10.2196/mhealth.4924] [Medline: 26537656]
14. Crain AL, Martinson BC, Sherwood NE, O'Connor PJ. The long and winding road to physical activity maintenance. Am J Health Behav 2010;34(6):764-775 [FREE Full text] [doi: 10.5993/AJHB.34.6.11] [Medline: 20604700]
15. Fukuoka Y, Gay C, Haskell W, Arai S, Vittinghoff E. Identifying factors associated with dropout during prerandomization run-in period from an mHealth physical activity education study: the mPED trial. JMIR Mhealth Uhealth 2015 Apr 13;3(2):e34 [FREE Full text] [doi: 10.2196/mhealth.3928] [Medline: 25872754]
16. Fukuoka Y, Vittinghoff E, Hooper J. A weight loss intervention using a commercial mobile application in Latino Americans-Adelgaza trial. Transl Behav Med 2018 Sep 8;8(5):714-723 [FREE Full text] [doi: 10.1093/tbm/ibx039] [Medline: 29474702]
17. Fukuoka Y, Vittinghoff E, Jong S, Haskell W. Innovation to motivation--pilot study of a mobile phone intervention to increase physical activity among sedentary women. Prev Med 2010;51(3-4):287-289 [FREE Full text] [doi: 10.1016/j.ypmed.2010.06.006] [Medline: 20600263]
18. Fjeldsoe B, Neuhaus M, Winkler E, Eakin E. Systematic review of maintenance of behavior change following physical activity and dietary interventions. Health Psychol 2011 Jan;30(1):99-109. [doi: 10.1037/a0021974] [Medline: 21299298]
19. Floegel T, Giacobbi PR, Dzierzewski J, Aiken-Morgan A, Roberts B, McCrae C, et al. Intervention markers of physical activity maintenance in older adults. Am J Health Behav 2015 Jul;39(4):487-499 [FREE Full text] [doi: 10.5993/AJHB.39.4.5] [Medline: 26018097]
20. Lefler L, Jones S, Harris B. Key strategies for physical activity interventions among older women: process evaluation of a clinical trial. Am J Health Promot 2018 Mar;32(3):561-570. [doi: 10.1177/0890117117711340] [Medline: 28587472]
21. McArthur D, Dumas A, Woodend K, Beach S, Stacey D. Factors influencing adherence to regular exercise in middle-aged women: a qualitative study to inform clinical practice. BMC Womens Health 2014 Mar 26;14:49 [FREE Full text] [doi: 10.1186/1472-6874-14-49] [Medline: 24666887]
22. Fukuoka Y, Haskell W, Lin F, Vittinghoff E. Short- and long-term effects of a mobile phone app in conjunction with brief in-person counseling on physical activity among physically inactive women: the mPED randomized clinical trial. JAMA Netw Open 2019 May 3;2(5):e194281 [FREE Full text] [doi: 10.1001/jamanetworkopen.2019.4281] [Medline: 31125101]

23. Sandelowski M. Whatever happened to qualitative description? Res Nurs Health 2000 Aug;23(4):334-340 [FREE Full text] [doi: 10.1002/1098-240x(200008)23:4<334::aid-nur9>3.0.co;2-g]
24. Sandelowski M. What's in a name? Qualitative description revisited. Res Nurs Health 2010 Feb;33(1):77-84. [doi: 10.1002/nur.20362] [Medline: 20014004]
25. Fukuoka Y, Haskell W, Vittinghoff E. New insights into discrepancies between self-reported and accelerometer-measured moderate to vigorous physical activity among women - the mPED trial. BMC Public Health 2016 Aug 11;16(1):761 [FREE Full text] [doi: 10.1186/s12889-016-3348-7] [Medline: 27514368]
26. Fukuoka Y, Komatsu J, Suarez L, Vittinghoff E, Haskell W, Noorishad T, et al. The mPED randomized controlled clinical trial: applying mobile persuasive technologies to increase physical activity in sedentary women protocol. BMC Public Health 2011 Dec 14;11:933 [FREE Full text] [doi: 10.1186/1471-2458-11-933] [Medline: 22168267]
27. Bandura A, Adams N, Hardy A, Howells G. Tests of the generality of self-efficacy theory. Cogn Ther Res 1980 Mar;4(1):39-66 [FREE Full text] [doi: 10.1007/bf01173354]
28. Prochaska J, DiClemente CC. Stages and processes of self-change of smoking: toward an integrative model of change. J Consult Clin Psychol 1983 Jun;51(3):390-395. [doi: 10.1037//0022-006x.51.3.390] [Medline: 6863699]
29. Rubin H, Rubin I. Qualitative Interviewing: The Art of Hearing Data. Thousand Oaks, CA: Sage; 2012.
30. Creswell JW, Poth CN. Qualitative Inquiry And Research Design: Choosing Among Five Approaches. Fourth Edition. Los Angeles, CA: Sage Publications Inc; 2018.
31. Cutcliffe J, Harder HG. The perpetual search for parsimony: enhancing the epistemological and practical utility of qualitative research findings. Int J Nurs Stud 2009 Oct;46(10):1401-1410. [doi: 10.1016/j.ijnurstu.2009.05.005] [Medline: 19523627]
32. Blue S. Maintaining physical exercise as a matter of synchronising practices: experiences and observations from training in Mixed Martial Arts. Health Place 2017 Jul;46:344-350. [doi: 10.1016/j.healthplace.2016.11.002] [Medline: 27894846]
33. Nigg C, Borrelli B, Maddock J, Dishman RK. A theory of physical activity maintenance. Appl Psychol-Int Rev 2008;57(4):544-560 [FREE Full text] [doi: 10.1111/j.1464-0597.2008.00343.x]
34. Teixeira P, Carraça EV, Markland D, Silva M, Ryan RM. Exercise, physical activity, and self-determination theory: a systematic review. Int J Behav Nutr Phys Act 2012 Jun 22;9:78 [FREE Full text] [doi: 10.1186/1479-5868-9-78] [Medline: 22726453]
35. Finkelstein E, Haaland B, Bilger M, Sahasranaman A, Sloan R, Nang E, et al. Effectiveness of activity trackers with and without incentives to increase physical activity (TRIPPA): a randomised controlled trial. Lancet Diabetes Endo 2016;4(12):983-995 [FREE Full text] [doi: 10.1016/s2213-8587(16)30284-4]
36. Osuka Y, Jung S, Kim T, Okubo Y, Kim E, Tanaka K. Does attending an exercise class with a spouse improve long-term exercise adherence among people aged 65 years and older: a 6-month prospective follow-up study. BMC Geriatr 2017 Jul 31;17(1):170 [FREE Full text] [doi: 10.1186/s12877-017-0554-9] [Medline: 28760148]
37. Koohsari MJ, Owen N, Cerin E, Giles-Corti B, Sugiyama T. Walkability and walking for transport: characterizing the built environment using space syntax. Int J Behav Nutr Phys Act 2016 Nov 24;13(1):121 [FREE Full text] [doi: 10.1186/s12966-016-0448-9] [Medline: 27881173]
38. National Academies. 2013. US Health in International Perspective Shorter Lives, Poorer Health URL: http://www.nationalacademies.org/hmd/~/media/Files/Report%20Files/2013/US-Health-International-Perspective/USHealth_Intl_PerspectiveRB.pdf [accessed 2019-10-01]
39. Owen N, Cerin E, Leslie E, duToit L, Coffee N, Frank L, et al. Neighborhood walkability and the walking behavior of Australian adults. Am J Prev Med 2007 Nov;33(5):387-395. [doi: 10.1016/j.amepre.2007.07.025] [Medline: 17950404]
40. Venn D, Strazdins L. Your money or your time? How both types of scarcity matter to physical activity and healthy eating. Soc Sci Med 2017 Jan;172:98-106. [doi: 10.1016/j.socscimed.2016.10.023] [Medline: 27839899]
41. Fukuoka Y, Lindgren TG, Mintz YD, Hooper J, Aswani A. Applying natural language processing to understand motivational profiles for maintaining physical activity after a mobile app and accelerometer-based intervention: the mPED randomized controlled trial. JMIR Mhealth Uhealth 2018 Jun 20;6(6):e10042 [FREE Full text] [doi: 10.2196/10042] [Medline: 29925491]
42. Holloway I, Wheeler S. Qualitative Research in Nursing and Healthcare. Third Edition. Chichester, UK: Wiley-Blackwell; 2010.

Abbreviations

mPED: mobile phone–based physical activity education
RCT: randomized controlled trial
SCM: Stages of Change Model
SDT: self-determination theory

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Original Paper

The Association Between Internet Searches and Moisturizer Prescription in Japan: Retrospective Observational Study

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Abstract

Background: Heparinoid is a medication prescribed in Japan for skin diseases, such as atopic dermatitis and dry skin. Heparinoid prescription has increased with instances of internet blogs recommending its use as a cosmetic.

Objective: This study aimed to examine the prescription trends in moisturizer use and analyze their association with internet searches.

Methods: We used a claims database to identify pharmacy claims of heparinoid-only prescriptions in Japan. Additionally, we used Google Trends to obtain internet search data for the period between October 1, 2007, and September 31, 2017. To analyze the association between heparinoid prescriptions and internet searches, we performed an autoregressive integrated moving average approach for each time series.

Results: We identified 155,733 patients who had been prescribed heparinoid. The number of prescriptions increased from 2011 onward, and related internet searches increased from 2012 onward. Internet searches were significantly correlated with total heparinoid prescription (correlation coefficient=.25, *P*=.005). In addition, internet searches were significantly correlated with heparinoid prescription in those aged 20-59 years at –1-month lag in Google Trends (correlation coefficient=.30, *P*=.001).

Conclusions: Google searches related to heparinoid prescriptions showed a seasonal pattern and increased gradually over the preceding several years. Google searches were positively correlated with prescription trends. In addition, in a particular age group (20-59 years), prescriptions increased with the increase in internet searches. These results suggest that people obtained health-related information on the internet and that this affected their behavior and prescription requests.

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KEYWORDS

internet; moisturizer; heparinoid; Google Trends; time series analysis; infodemiology

Introduction

Heparinoid is a transdermal medicine (ie, cream, ointment, lotion, spray, or gel) used as an anti-inflammatory aid, blood circulation promoter, and moisturizer in Japan [1]. It is generally prescribed to patients with thrombophlebitis, pain, and inflammatory disease caused by vascular insufficiency, chilblains, hypertrophic and keloid scars, keratodermia tylodes palmaris progressive, asteatosis, and posttraumatic swelling and pain [2]. Japanese guidelines for atopic dermatitis state that hydrophilic and water-absorptive ointment, including urea, heparinoid, and water-soluble collagen, should be used for dry skin [3]. Consequently, approximately 70% of patients younger than 15 years of age are prescribed moisturizers or protective agents [4], but the long-term trends in moisturizer prescription in Japan remain unknown.

In October 2017, the increase in heparinoid prescriptions became news in Japan. This was because the National Federation of Health Insurance Societies proposed that heparinoid should be eliminated from insurance if it was prescribed only for patients with dry skin [5]. The increase in prescriptions is considered to have occurred because blogs or social media recommended using moisturizer as a cosmetic. However, whether this is attributed to the dissemination of information via the internet remains unclear.

The internet is an important tool in searching for information. In Japan, 83.5% of people had used the internet during 2016 [6]. In particular, the proportion of usage in people aged 20-59 years has been more than 90% during the past several years. In addition, many people worldwide use the internet to seek health-related information on diseases and medicines [7-11]. They seek such information to understand their current health status, their disease, someone else’s disease, or prescription drugs, and so they are able to communicate with their physician [11-13]. This leads to an increase in their knowledge, satisfaction, and confidence as well as a reduction in their anxiety and stress. According to a previous study from 2007, although television (60.1%) and newspapers (50.3%) were major sources of health-related information, personal computers (23.8%) and mobile phones (6.0%) were also important tools for seeking such information via the internet [14]. We can easily guess that even more people are using the internet now given the further development of the internet since 2007.

Searching for health-related information on the internet has been shown to have positive effects on the frequency of visits to health professionals for those who seek such information compared to those who did not [15]. Health-related information seeking affects individuals’ demands for health care services and increases health care utilization. However, many people can obtain and disseminate information via the internet, regardless of whether health-related information is correct [16,17]. This field of study, called infodemiology, identifies the distribution and pattern of information and assesses subsequent changes in knowledge and health behavior. Sometimes, health-seeking behavior on the internet happens before changes occur in the actual health behavior [17,18]; we can obtain data about such health-seeking behavior from various sources, such as internet search engines, blogs, or social media [19]. Google facilitates the analysis of search queries using Google Trends [20], one of the most frequently used tools to analyze such data; it has been used to analyze the association between search queries and various topics. For instance, research examining the following topics has been conducted using internet search results: the prediction of influenza and infection [21,22], the seasonal change in depression [23], the influence of certain topics on suicide rate [24,25], the relationship between the search volume of certain topics and cancer incidence [26], the impact of celebrities’ diseases on public opinions [27], and the monitoring of drug utilization [28].

Although many studies have used Google Trends, none have examined the relationship between internet searches and prescriptions in Japan. Therefore, the purpose of this study was to examine the trend in prescription moisturizer use and to analyze its association with internet searches.

Methods

Claims Database

We used the administrative claims database provided by JMDC Inc [29], which is one of the largest commercial databases in Japan [30]. Since 2005, it has held anonymized data for a population of 5,600,000, including individuals 65 years of age and younger as well as employees of large corporations and their dependents. The database consists of inpatient data, outpatient data, pharmacy data, diagnosis procedure combination data, and insured-population data. In addition, it contains anonymous data regarding patient characteristics; diagnostic codes according to the International Statistical Classification of Diseases and Related Health Problems, Tenth Revision (ICD-10); surgery; procedures; drug prescriptions; medical institutions; costs; and prescription dates. Regarding drug data, it contains the World Health Organization Anatomical Therapeutic Chemical codes, generic drug names, product names, prescription dates, and dispensing dates. The database also includes data regarding insured people; therefore, we were able to not only obtain information about populations, but also determine if patients had changed medical institutions from hospitals to clinics.

We used pharmacy data for the period from October 2007 to September 2017, because television and newspaper coverage of moisturizer prescription increased in October 2017. Therefore, to assess the association between prescription moisturizer and internet searches, we decided to use the data from October 2007 until September 2017. Additionally, we identified heparinoid prescription—the World Health Organization Anatomical Therapeutic Chemical code: C05B01. We focused on heparinoid prescriptions only, as prescriptions of heparinoid with other drugs, such as antihistamines, might not have been affected by internet searches. We defined prescriptions from insurance identification numbers, prescription dates, and medical facilities. The study protocol was approved the ethics committee at Meiji Pharmaceutical University (approval number: 2959).

Internet Search Data

The internet search data was obtained from Google Trends, which is a product provided by Google. We included geography and time range in the Google Trends search terms. Search trend data were available for the period from 2004 to 36 hours before our search on April 23, 2018. Search results were shown on a scale ranging from 0 to 100, based on the ratio of searches on a given topic to searches on all topics. For example, imagine we were obtaining search results of the word “A” for every month for a year. If “A” was searched most frequently in April, the search results have a score of 100 for April, and the search frequency of other months are scored relative to the frequency in April. When we compare two words, “A” and “B,” the most frequently searched month is identified for both “A” and “B” [26].

We chose three search terms that we considered most closely related to heparinoid. We used the Japanese “” (Hirudoid) and “” (Besoften), which are the names of major products containing heparinoid in Japan. In addition, we entered “” (heparinoid), which is the generic drug name. We performed the search on April 23, 2018, and compared the three terms in Google Trends from October 1, 2007, to September 31, 2017, in Japan.

Statistical Analysis

We performed a descriptive analysis to examine patient characteristics, monthly internet search data, and prescription trends. Patient age was stratified into three groups: 0-19 years, 20-59 years, and ≥60 years. This is because previous reports showed that moisturizer prescription increased in the 20-59-year-old age group; also, these individuals comprised a high proportion (>90%) of internet users during the past several years [6,31]. If patients’ ages crossed two age groups (ie, they moved into another age group during the course of the study), we included them in the younger group. We showed data regarding diagnoses related only to prescription heparinoid when more than 5% of patients were diagnosed with a disease of skin and subcutaneous tissue based on the ICD-10.

We adjusted the prescription time series according to the insured population’s data and showed prescriptions per 100,000 members of the population. We then selected two time series for cross-correlation. In correlating the time series, we accounted for trend and seasonality in time series data to avoid mistaken correlations. To examine the association between internet searches and moisturizer prescription, we used the Box-Jenkins approach to fit an autoregressive integrated moving average (ARIMA) model [32]. We used a seasonal ARIMA model, as all-time series data showed seasonality that increased from fall to winter and decreased from spring to summer annually. We performed the Kwiatkowski-Phillips-Schmidt-Shin test to render the series stationary and estimated the model parameters and diagnosed acceptability using the Akaike Information Criterion. We then checked the adequacy of the model, regardless of autocorrelation between residuals, using the Ljung-Box test. We performed cross-correlation analysis for each residual to assess the relationship between the two time series.

Cross-correlation analysis was performed for the following: (1) internet search trends for ”” (Hirudoid) and prescription trends (total) and (2) internet search trends for ”” (Hirudoid) and trends in heparinoid prescription in those aged 20-59 years. All trend data were calculated monthly. We used R, version 3.5.0 (The R Foundation), for statistical analysis.

Results

The pharmacy data showed that 704,585 patients (population A) were prescribed heparinoid along with other medicines between October 1, 2007, and September 31, 2017. In total, 155,733 patients (population B) were prescribed only heparinoid; of these, 70,819 (45.47%) were men and 84,914 (54.53%) were women (see Figure 1 and Table 1). The total number of prescriptions was 289,361 for all patients; 132,850 for men; and 156,511 for women. The most common diagnosis was xerosis cutis (ICD-10 code L853), followed by dermatitis, unspecified (ICD-10 code L309); atopic dermatitis, unspecified (ICD-10 code L209); and other atopic dermatitis (ICD-10 code L208). Compared to the characteristics of population A, the proportion of patients from population B with dermatitis, unspecified, and atopic dermatitis, unspecified, decreased by 50%.

Figure 1. Study flowchart.

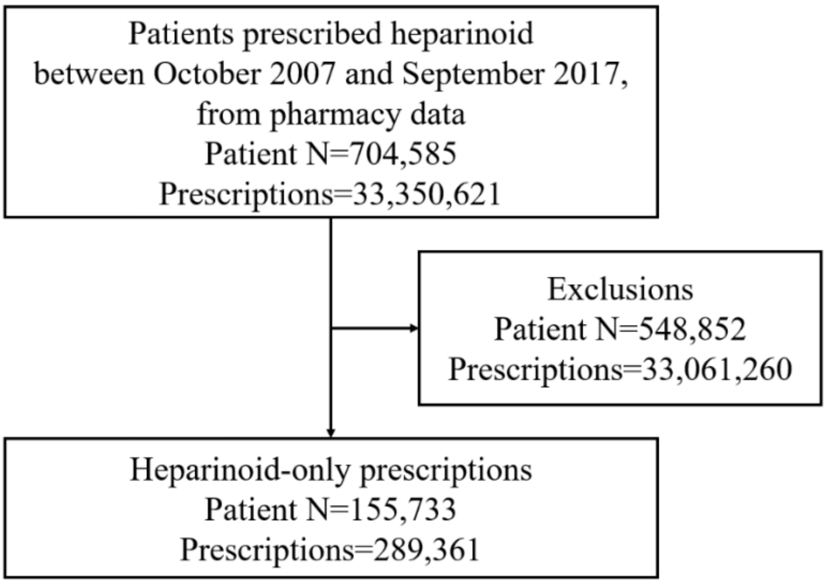

Table 1. Patients’ baseline characteristics.

Characteristics	Population A: patients prescribed heparinoid along with other medicines			Population B: patients prescribed only heparinoid		
	Total (N=704,585)	Men (n=327,694)	Women (n=376,891)	Total (N=155,733)	Men (n=70,819)	Women (n=84,914)
Age group (years), n (%)						
0-19	396,761 (56.31)	200,973 (61.33)	195,788 (51.95)	114,503 (73.53)	57,572 (81.29)	56,931 (67.05)
20-59	278,625 (39.54)	111,891 (34.14)	166,734 (44.24)	36,421 (23.39)	11,194 (15.81)	25,227 (29.71)
≥60	29,199 (4.14)	14,830 (4.53)	14,369 (3.81)	4809 (3.09)	2053 (2.90)	2756 (3.25)
Diagnosis, n (%)						
Xerosis cutis	571,167 (81.06)	264,301 (80.65)	306,866 (81.42)	117,450 (75.42)	53,117 (75.00)	64,333 (75.76)
Dermatitis, unspecified	301,528 (42.80)	138,321 (42.21)	163,207 (43.30)	34,234 (21.98)	15,539 (21.94)	18,695 (22.02)
Atopic dermatitis, unspecified	196,975 (27.96)	101,037 (30.91)	95,938 (25.45)	22,656 (14.55)	11,191 (15.80)	11,465 (13.50)
Other atopic dermatitis	60,584 (8.60)	31,581 (9.64)	29,003 (7.70)	11,769 (7.58)	6073 (8.58)	5696 (6.71)
Prescriptions						
Total, N	3,350,692	1,680,423	1,670,269	289,361	132,850	156,511
Age group (years), n (%)						
0-19	2,182,796 (65.14)	1,150,733 (68.48)	1,032,063 (61.79)	226,044 (78.12)	113,415 (85.37)	112,629 (71.96)
20-59	1,069,036 (31.90)	477,357 (28.41)	591,679 (35.42)	55,547 (19.20)	16,219 (12.21)	39,337 (25.13)
≥60	98,860 (2.95)	52,333 (3.11)	46,527 (2.79)	7770 (2.69)	3225 (2.43)	4545 (2.90)

Heparinoid prescription increased from 2011 and peaked in the winter of 2017 (see Figure 2, b and c). Heparinoid prescription showed seasonality, in that it increased in the winter. Between October 1, 2007, and September 31, 2017, “” (Hirudoid) was the most frequently searched term of the three terms entered into Google Trends (see Figure 2, a). In addition, “” (Besoften) and “” (heparinoid) showed similar search volumes. The search volume for “” (Hirudoid) increased from 2012 and peaked in the winter of 2017.

The trend data allowed us to define a seasonal ARIMA model for each time series. Google Trends data, trends in total prescriptions, and prescription trends in patients aged 20-59 years fit the seasonal ARIMA model (5,1,4 and 0,1,1; 2,1,5 and 2,1,0; and 4,1,5 and 0,1,1 (12), respectively) (see Table 2). Cross-correlation analysis of ARIMA residuals for two time series showed a positive correlation (see Table 3). Trends in total prescription peaked at the 0-month lag, with a correlation coefficient of .25 (*P*=.005). Prescription trends for patients aged 20-59 years peaked at the −1-month lag, with a correlation coefficient of .30 (*P*=.001).

Figure 2. Time series data of Google Trends and prescriptions. (a) Google Trends search volume with three search terms from October 2007 to September 2017; search volume is the ratio of searches on each topic to searches on all topics, from 0 to 100. (b) Number of heparinoid-only prescriptions per 100,000 members of the population from October 2007 to September 2017. (c) Number of heparinoid-only prescriptions for patients aged 20-59 years per 100,000 members of the population from October 2007 to September 2017.

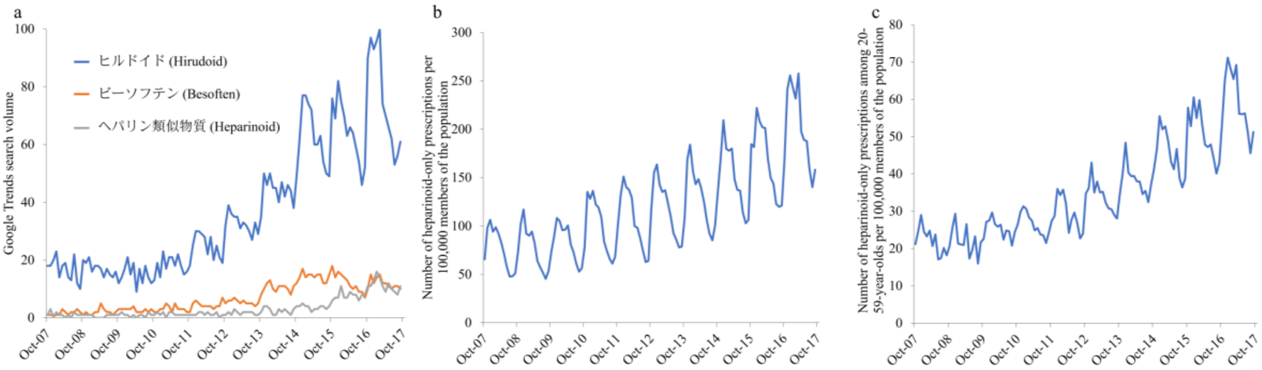

Table 2. ARIMA[a] model parameter and Q statistics[b].

Time series	Model	AIC[c]	Q statistic	*P* value
Google Trends “” (Hirudoid)	Seasonal ARIMA (5,1,4 and 0,1,1) (12)	704	17.7	.22
Prescriptions (total)	Seasonal ARIMA (2,1,5 and 2,1,0) (12)	823	19.4	.19
Prescriptions (patients aged 20-59 years)	Seasonal ARIMA (4,1,5 and 0,1,1) (12)	567	23.3	.055

[a] ARIMA: autoregressive integrated moving average.

[b] Q statistics test for residual autocorrelation. The null hypothesis is that autocorrelation with 24 lags would be equal to zero.

[c] AIC: Akaike Information Criterion.

Table 3. Cross-correlation between prescriptions and Google Trends for “” (Hirudoid).

Prescriptions	Lag (months)	Correlation coefficient	*P* value
Total	0	.25	.005
Patients aged 20-59 years	–1	.30	.001

Discussion

Principal Findings

The results showed that heparinoid prescriptions increased from 2012 onward and that “” (Hirudoid) was the most frequently searched of the three terms entered into Google Trends. In addition, prescription of heparinoid only had a weak positive correlation with internet search data obtained from Google Trends.

A previous study showed that drug utilization time series for antibiotics—amoxicillin, azithromycin, and cefdinir—and Google Trends were correlated [28]. This study showed similar results for heparinoid prescription. In particular, the results for the population aged 20-59 years correlated to a −1-month lag in Google Trends. This implies that there was a possibility that this population was affected by the internet and/or that they tend to seek out medical information before going a doctor. We cannot assess this relationship directly; however, we showed that there is a relationship between medical prescriptions and internet searches.

There are many reasons why people search for health-related information using the internet [33]. For instance, they may perform searches for a newly diagnosed health problem, ongoing medical condition, newly prescribed medication or treatment, or health-related knowledge. Therefore, people could search before or after undergoing medical treatment [34]. In this study, Google Trends showed that “” (Hirudoid) was the most commonly searched term related to heparinoid in patients aged 20-59 years. This result suggested that people visited a physician after obtaining information regarding heparinoid; it also suggested that internet searching affected their behavior and physicians’ decision making.

Many people were prescribed heparinoid in a clinic or hospital in this study, even though heparinoid is sold in pharmacies as an over-the-counter (OTC) medicine. There could be several reasons for this. First, people have to obtain a prescription from a physician to get Hirudoid, specifically. While people can get OTC medicines containing heparinoid, they cannot buy Hirudoid without a prescription. Results of Google Trends showed that *Hirudoid* was the most frequently searched of the three terms; this could be the main reason that people sought prescriptions. Second, because of the way the Japanese health care system works, some Japanese people might choose to visit clinics or hospitals for prescribed medicine in order to obtain it at a cheaper rate relative to the OTC price. In Japan, everyone has some type of insurance because of the national health insurance system. Therefore, they pay up to 30% of the total medical expenditure in hospitals, clinics, and pharmacies [35]. In a past questionnaire survey, 36.1% of patients did not consider the use of OTC drugs before visiting medical institutions. In addition, 40.5% of participants answered that visiting medical institutions was cheaper [36]. When people choose whether to visit a medical institution or buy OTC drugs, there are many reasons that affect their decision [37]. However, this could explain why people visit clinics or hospitals rather than buying OTC medicines.

Patients’ medical decision making is changed though health information, regardless of credibility [7,18]. A previous study showed no difference in the effects of high- and no-credibility sources [38]; judgment of credible information could be difficult for many consumers. Health literacy has been considered an important factor affecting health behavior and health information access [39-41]. However, levels of health literacy among the Japanese population are lower relative to those observed among the European population. They concluded that there are few reliable, understandable Japanese websites such as MedlinePlus, as well as a lack of health communication specialists and an inefficient primary health care system in Japan [42]. Moreover, some patients have explained that they do not use OTC drugs because they do not know which OTC drugs are the highest quality or most suitable for their symptoms and they cannot be trusted [36]. This may imply that people do not have the opportunity to learn how to obtain the correct information. Thus, education to enable people to achieve high internet health literacy levels and the ability to search and judge credible information is more important than ever.

On October 31, 2018, the Japanese Dermatological Association reported on medical heparinoid prescriptions for cosmetic purposes and stated that members should prescribe it appropriately; if it is prescribed for cosmetic application, patients should pay for the medication themselves [43]. In addition, the Central Social Insurance Medical Council developed two policies on February 7, 2018. The first policy states that heparinoid prescriptions shall not be covered for the purpose of cosmetic use to promote circulation and skin moisturization (ie, heparin sodium and heparinoid) [44]. The second policy states that examination and payment agencies should deal with prescriptions appropriately. However, prescriptions were not limited because of a lack of evidence regarding heparinoid prescription. Therefore, these findings provide important evidence for trends in heparinoid prescription.

Limitations

This study was subject to several limitations. For example, the JMDC database contains data for employees of large corporations and their family members. However, because of a lack of data for employees of small and medium-sized businesses, public officials, and self-employed people, the results cannot be generalized to the wider population in Japan. In addition, Google and Yahoo are the main internet search engines used in Japan [45], and Google Trends does not include the entire Japanese population. However, the use of Google is increasing and it may, therefore, represent most Japanese people. Moreover, Google Trends shows data only for search queries; we did not have access to details about how research words were recognized and aggregated on Google or the information obtained using specific search terms. This study examined only the association between internet searches and prescriptions. Therefore, it did not clarify the cause of the increase in prescriptions or the number of people prescribed the moisturizer for cosmetic purposes due to a lack of detailed information about attitudes and prescription behaviors. To elucidate this relationship, another approach is needed; for example, a questionnaire survey administered to physicians or patients could assess moisturizer prescriptions for cosmetic purposes.

Conclusions

This was the first study to report on the association between internet searches and prescriptions in Japan. The results of the analysis suggested that internet searching for health-related information affected heparinoid prescription, although the positive correlation between these variables was weak. In particular, prescriptions for people aged 20-59 years correlated with the –1-month lag in Google Trends. Seeking internet-based information changed peoples' behavior and physicians' prescription habits. Also, Google Trends quantitatively demonstrated peoples' interest and could be effective in detecting changes in drug utilization. The internet provides beneficial information to patients, medical personnel, and healthy people for decision making. However, it is not easy to distinguish between correct and incorrect information because of the volume included.

Authors' Contributions

MA supervised the study, interpreted the results, and corrected the manuscript. WM designed the study and analyzed the data.

Conflicts of Interest

None declared.

References

1. Electric Medicines Compendium. Hirudoid cream URL: https://www.medicines.org.uk/emc/product/1341/smpc [accessed 2018-10-08] [WebCite Cache ID 730RDrTQH]
2. RAD-AR. Drug information sheet URL: http://www.rad-ar.or.jp/siori/english/kekka.cgi?n=36153 [accessed 2018-12-11] [WebCite Cache ID 74ZiIJx8p]
3. Katayama I, Aihara M, Ohya Y, Saeki H, Shimojo N, Shoji S, Japanese Society of Allergology. Japanese guidelines for atopic dermatitis 2017. Allergol Int 2017 Apr;66(2):230-247 [FREE Full text] [doi: 10.1016/j.alit.2016.12.003] [Medline: 28209325]
4. Komura Y, Kogure T, Kawahara K, Yokozeki H. Economic assessment of actual prescription of drugs for treatment of atopic dermatitis: Differences between dermatology and pediatrics in large-scale receipt data. J Dermatol 2018 Feb;45(2):165-174. [doi: 10.1111/1346-8138.14133] [Medline: 29168213]
5. National Federation of Health Insurance Societies. URL: https://www.kenporen.com/include/outline/pdf/chosa29_01.pdf [accessed 2019-05-10] [WebCite Cache ID 78Fr4iCsy]
6. Communications Usage Trend Survey in 2016 Compiled. Tokyo, Japan: Ministry of Internal Affairs and Communications; 2017 Jun 08. URL: http://www.soumu.go.jp/johotsusintokei/tsusin_riyou/data/eng_tsusin_riyou02_2016.pdf [accessed 2018-09-24] [WebCite Cache ID 72fKRWJM8]
7. Moreland J, French TL, Cumming GP. The prevalence of online health information seeking among patients in Scotland: A cross-sectional exploratory study. JMIR Res Protoc 2015 Jul 15;4(3):e85 [FREE Full text] [doi: 10.2196/resprot.4010] [Medline: 26177562]
8. Eysenbach G, Kohler C. What is the prevalence of health-related searches on the World Wide Web? Qualitative and quantitative analysis of search engine queries on the Internet. AMIA Annu Symp Proc 2003:225-229 [FREE Full text] [Medline: 14728167]

9. Lombardo S, Cosentino M. Internet use for searching information on medicines and disease: A community pharmacy-based survey among adult pharmacy customers. Interact J Med Res 2016 Jul 13;5(3):e22 [FREE Full text] [doi: 10.2196/ijmr.5231] [Medline: 27417304]
10. Weaver JB, Mays D, Weaver SS, Hopkins GL, Eroglu D, Bernhardt JM. Health information-seeking behaviors, health indicators, and health risks. Am J Public Health 2010 Aug;100(8):1520-1525. [doi: 10.2105/AJPH.2009.180521] [Medline: 20558794]
11. Chen Y, Li C, Liang J, Tsai C. Health information obtained from the Internet and changes in medical decision making: Questionnaire development and cross-sectional survey. J Med Internet Res 2018 Feb 12;20(2):e47 [FREE Full text] [doi: 10.2196/jmir.9370] [Medline: 29434017]
12. Tan SS, Goonawardene N. Internet health information seeking and the patient-physician relationship: A systematic review. J Med Internet Res 2017 Jan 19;19(1):e9 [FREE Full text] [doi: 10.2196/jmir.5729] [Medline: 28104579]
13. Longo DR. Understanding health information, communication, and information seeking of patients and consumers: A comprehensive and integrated model. Health Expect 2005 Sep;8(3):189-194 [FREE Full text] [doi: 10.1111/j.1369-7625.2005.00339.x] [Medline: 16098149]
14. Takahashi Y, Ohura T, Ishizaki T, Okamoto S, Miki K, Naito M, et al. Internet use for health-related information via personal computers and cell phones in Japan: A cross-sectional population-based survey. J Med Internet Res 2011 Dec 14;13(4):e110 [FREE Full text] [doi: 10.2196/jmir.1796] [Medline: 22169526]
15. Suziedelyte A. How does searching for health information on the Internet affect individuals' demand for health care services? Soc Sci Med 2012 Nov;75(10):1828-1835. [doi: 10.1016/j.socscimed.2012.07.022] [Medline: 22884947]
16. Eysenbach G. Infodemiology: The epidemiology of (mis)information. Am J Med 2002 Dec 15;113(9):763-765. [doi: 10.1016/s0002-9343(02)01473-0] [Medline: 12517369]
17. Eysenbach G. Infodemiology and infoveillance: Framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. J Med Internet Res 2009 Mar 27;11(1):e11 [FREE Full text] [doi: 10.2196/jmir.1157] [Medline: 19329408]
18. Hesse BW, Nelson DE, Kreps GL, Croyle RT, Arora NK, Rimer BK, et al. Trust and sources of health information: The impact of the Internet and its implications for health care providers: Findings from the first Health Information National Trends Survey. Arch Intern Med 2005;165(22):2618-2624. [doi: 10.1001/archinte.165.22.2618] [Medline: 16344419]
19. Grajales FJ, Sheps S, Ho K, Novak-Lauscher H, Eysenbach G. Social media: A review and tutorial of applications in medicine and health care. J Med Internet Res 2014 Feb 11;16(2):e13 [FREE Full text] [doi: 10.2196/jmir.2912] [Medline: 24518354]
20. Google Trends. URL: https://trends.google.com/trends/?geo=US [accessed 2018-10-08] [WebCite Cache ID 730ShAY2e]
21. Ginsberg J, Mohebbi MH, Patel RS, Brammer L, Smolinski MS, Brilliant L. Detecting influenza epidemics using search engine query data. Nature 2009 Feb 19;457(7232):1012-1014. [doi: 10.1038/nature07634] [Medline: 19020500]
22. Milinovich GJ, Avril SM, Clements AC, Brownstein JS, Tong S, Hu W. Using Internet search queries for infectious disease surveillance: Screening diseases for suitability. BMC Infect Dis 2014 Dec 31;14:690 [FREE Full text] [doi: 10.1186/s12879-014-0690-1] [Medline: 25551277]
23. Yang AC, Huang NE, Peng C, Tsai S. Do seasons have an influence on the incidence of depression? The use of an Internet search engine query data as a proxy of human affect. PLoS One 2010 Oct 28;5(10):e13728 [FREE Full text] [doi: 10.1371/journal.pone.0013728] [Medline: 21060851]
24. Yang AC, Tsai S, Huang NE, Peng C. Association of Internet search trends with suicide death in Taipei City, Taiwan, 2004-2009. J Affect Disord 2011 Jul;132(1-2):179-184. [doi: 10.1016/j.jad.2011.01.019] [Medline: 21371755]
25. Sueki H. Does the volume of Internet searches using suicide-related search terms influence the suicide death rate: Data from 2004 to 2009 in Japan. Psychiatry Clin Neurosci 2011 Jun;65(4):392-394 [FREE Full text] [doi: 10.1111/j.1440-1819.2011.02216.x] [Medline: 21569178]
26. Phillips CA, Barz Leahy A, Li Y, Schapira MM, Bailey LC, Merchant RM. Relationship between state-level Google online search volume and cancer incidence in the United States: Retrospective study. J Med Internet Res 2018 Jan 08;20(1):e6 [FREE Full text] [doi: 10.2196/jmir.8870] [Medline: 29311051]
27. Mahroum N, Bragazzi NL, Sharif K, Gianfredi V, Nucci D, Rosselli R, et al. Leveraging Google Trends, Twitter, and Wikipedia to investigate the impact of a celebrity's death from rheumatoid arthritis. J Clin Rheumatol 2018 Jun;24(4):188-192. [doi: 10.1097/RHU.0000000000000692] [Medline: 29461342]
28. Simmering JE, Polgreen LA, Polgreen PM. Web search query volume as a measure of pharmaceutical utilization and changes in prescribing patterns. Res Social Adm Pharm 2014;10(6):896-903. [doi: 10.1016/j.sapharm.2014.01.003] [Medline: 24603135]
29. JMDC. Corporate information URL: https://www.jmdc.co.jp/en/company/ [accessed 2019-05-10] [WebCite Cache ID 78FrODWxS]
30. Kimura S, Sato T, Ikeda S, Noda M, Nakayama T. Development of a database of health insurance claims: Standardization of disease classifications and anonymous record linkage. J Epidemiol 2010;20(5):413-419 [FREE Full text] [doi: 10.2188/jea.je20090066] [Medline: 20699602]

31. Kyodo News. 2017 Oct 30. Survey finds 9.3 bil. yen in insurance claims for "beauty cream" URL: https://english.kyodonews.net/news/2017/10/b28423bc26fe-survey-finds-93-bil-yen-in-insurance-claims-for-beauty-cream.html [accessed 2019-05-05] [WebCite Cache ID 788as2DiE]
32. Helfenstein U. Box-Jenkins modelling in medical research. Stat Methods Med Res 1996 Mar;5(1):3-22. [doi: 10.1177/096228029600500102] [Medline: 8743076]
33. Rice RE. Influences, usage, and outcomes of Internet health information searching: Multivariate results from the Pew surveys. Int J Med Inform 2006 Jan;75(1):8-28. [doi: 10.1016/j.ijmedinf.2005.07.032] [Medline: 16125453]
34. Flynn KE, Smith MA, Freese J. When do older adults turn to the Internet for health information? Findings from the Wisconsin Longitudinal Study. J Gen Intern Med 2006 Dec;21(12):1295-1301 [FREE Full text] [doi: 10.1111/j.1525-1497.2006.00622.x] [Medline: 16995892]
35. Ishii M. DRG/PPS and DPC/PDPS as prospective payment systems. Japan Med Assoc J 2012 Jul;55(4):279-291. [Medline: 25237234]
36. Tsutsumi M, Shaku F, Ozone S, Sakamoto N, Maeno T. Reasons for the preference of clinic visits to self-medication by common cold patients in Japan. J Gen Fam Med 2017 Dec;18(6):336-340 [FREE Full text] [doi: 10.1002/jgf2.81] [Medline: 29264062]
37. Aoyama I, Koyama S, Hibino H. Self-medication behaviors among Japanese consumers: Sex, age, and SES differences and caregivers' attitudes toward their children's health management. Asia Pac Fam Med 2012 Sep 11;11(1):7 [FREE Full text] [doi: 10.1186/1447-056X-11-7] [Medline: 22962853]
38. Bates BR, Romina S, Ahmed R, Hopson D. The effect of source credibility on consumers' perceptions of the quality of health information on the Internet. Med Inform Internet Med 2006 Mar;31(1):45-52. [doi: 10.1080/14639230600552601] [Medline: 16754366]
39. Ishikawa H, Kato M, Kiuchi T. Associations of health literacy and information sources with health-risk anxiety and protective behaviors. J Commun Healthc 2016 Feb 24;9(1):33-39. [doi: 10.1080/17538068.2015.1133004]
40. Suka M, Odajima T, Okamoto M, Sumitani M, Igarashi A, Ishikawa H, et al. Relationship between health literacy, health information access, health behavior, and health status in Japanese people. Patient Educ Couns 2015 May;98(5):660-668. [doi: 10.1016/j.pec.2015.02.013] [Medline: 25739344]
41. Mitsutake S, Shibata A, Ishii K, Oka K. Associations of eHealth literacy with health behavior among adult Internet users. J Med Internet Res 2016 Jul 18;18(7):e192 [FREE Full text] [doi: 10.2196/jmir.5413] [Medline: 27432783]
42. Nakayama K, Osaka W, Togari T, Ishikawa H, Yonekura Y, Sekido A, et al. Comprehensive health literacy in Japan is lower than in Europe: A validated Japanese-language assessment of health literacy. BMC Public Health 2015 May 23;15:505 [FREE Full text] [doi: 10.1186/s12889-015-1835-x] [Medline: 26001385]
43. Japanese Dermatological Association. 2017 Oct 31. Problems related to cosmetic prescriptions of medical heparin analogs (2nd report) URL: https://www.dermatol.or.jp/modules/news/index.php?content_id=462 [accessed 2018-10-08] [WebCite Cache ID 730PVtPYu]
44. Japanese Dermatological Association. 2018 May 19. Problems related to cosmetic prescriptions of medical heparin analogues (Part 3) URL: https://www.dermatol.or.jp/modules/news/index.php?content_id=490 [accessed 2018-10-08] [WebCite Cache ID 730Qfyg32]
45. StatCounter. URL: http://gs.statcounter.com/ [accessed 2018-10-08] [WebCite Cache ID 730anl0FA]

Abbreviations

AIC: Akaike Information Criterion
ARIMA: autoregressive integrated moving average
ICD-10: International Statistical Classification of Diseases and Related Health Problems, Tenth Revision
OTC: over-the-counter

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Original Paper

Access to Primary Care and Internet Searches for Walk-In Clinics and Emergency Departments in Canada: Observational Study Using Google Trends and Population Health Survey Data

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Abstract

Background: Access to primary care is a challenge for many Canadians. Models of primary care vary widely among provinces, including arrangements for same-day and after-hours access. Use of walk-in clinics and emergency departments (EDs) may also vary, but data sources that allow comparison are limited.

Objective: We used Google Trends to examine the relative frequency of searches for walk-in clinics and EDs across provinces and over time in Canada. We correlated provincial relative search frequencies from Google Trends with survey responses about primary care access from the Commonwealth Fund's 2016 International Health Policy Survey of Adults in 11 Countries and the 2016 Canadian Community Health Survey.

Methods: We developed search strategies to capture the range of terms used for walk-in clinics (eg, urgent care clinic and after-hours clinic) and EDs (eg, emergency room) across Canadian provinces. We used Google Trends to determine the frequencies of these terms relative to total search volume within each province from January 2011 to December 2018. We calculated correlation coefficients and 95% CIs between provincial Google Trends relative search frequencies and survey responses.

Results: Relative search frequency of walk-in clinic searches increased steadily, doubling in most provinces between 2011 and 2018. Relative frequency of walk-in clinic searches was highest in the western provinces of British Columbia, Alberta, Saskatchewan, and Manitoba. At the provincial level, higher walk-in clinic relative search frequency was strongly positively correlated with the percentage of survey respondents who reported being able to get same- or next-day appointments to see a doctor or a nurse and inversely correlated with the percentage of respondents who reported going to ED for a condition that they thought could have been treated by providers at usual place of care. Relative search frequency for walk-in clinics was also inversely correlated with the percentage of respondents who reported having a regular medical provider. ED relative search frequencies were more stable over time, and we did not observe statistically significant correlation with survey data.

Conclusions: Higher relative search frequency for walk-in clinics was positively correlated with the ability to get a same- or next-day appointment and inversely correlated with ED use for conditions treatable in the patient's regular place of care and also with having a regular medical provider. Findings suggest that patient use of Web-based tools to search for more convenient or accessible care through walk-in clinics is increasing over time. Further research is needed to validate Google Trends data with administrative information on service use.

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KEYWORDS

internet; ambulatory care facilities; emergency departments; primary health care; health services accessibility

Introduction

Primary Care, Emergency Department, and Walk-In Clinic Use in Canada

This paper used Google Trends to explore search patterns for walk-in clinics and emergency departments (EDs) in Canada. High-quality, accessible primary care is central to the effectiveness and efficiency of health care systems [1,2]. In Canada, primary care is intended to be the first point of contact with the health care system and provides access to referred health care services and coordination of care [3]. However, access to primary care continues to be a challenge for many Canadians, with Canada ranking below average in cross-national surveys of primary care access. For example, according to the Commonwealth International Health Policy Survey for adults in 11 countries, Canada ranks below average on timely access to care with only 43% of Canadians reporting to have gotten a same- or next-day appointment at their regular place of care and only 34% reporting to have access to after-hours care without going to the emergency room [4]. In the absence of access to care with a regular provider, patients may turn to EDs or walk-in clinics as alternatives.

EDs provide crucial lifesaving health care and are designed to provide episodic care to patients with injuries or acute illnesses, though patients may also turn to them for primary care services that are otherwise inaccessible or inconvenient [5-7]. The ED setting is also a costly setting to deliver chronic and continuing care and may lead to mishandling or poor attention to upstream social and chronic health issues of frequent ED users within the episodic ED setting [8]. Walk-in clinics also provide primary care services to patients without an appointment [6]. They may be a more convenient alternative for patients with another regular source of primary care [9] or the only source of care for patients without a regular primary care provider. As with EDs, there are concerns that walk-in clinics may disrupt continuity of care or neglect preventive health care [6] and lead to duplication of services, failure to manage complex care needs, and higher costs [9]. Understanding patterns of walk-in clinic use is therefore important in planning primary care policy more broadly.

In Canada, primary care is financed and organized provincially, and provinces have undertaken quite varied approaches to primary health care reform, including changing models of care, physician remuneration, and after-hours access programs [10-12]. The province of Ontario has adopted the use of various models of interprofessional care, including family health networks and family health teams [13]. Western provinces and Quebec have implemented different organizational reforms, including family medicine groups, local services networks, medical homes, and primary care networks [14-17]. The proportion of clinical payments through capitated and salaried payment models is higher in Ontario, eastern provinces, and the territories, whereas the western provinces and Quebec have a higher proportion of fee-for-service payments [14,15,18]. Walk-in clinic practice may be more common under a fee-for-service model as physicians are paid per service without ongoing responsibility for specific patients. Provinces also have varying mechanisms for after-hours coverage. Most have a toll-free number that connects patients to a registered nurse who can provide advice and direct patients to after-hours care [10,14]. Under capitated models, physicians may receive negation if their patients access services from another primary care provider, including walk-in clinics. This variability in the organization and delivery of primary care may shape availability and use of walk-in clinic services, and also use of EDs for conditions that could be treated in primary care.

Despite the importance of monitoring the use of walk-in clinics and EDs, there are no comparable nationwide data sources to track their use. Although each province collects data on use of primary care services, there are no standard approaches to identify walk-in practices [19,20]. The Canadian Institute of Health Information collects some standardized data on ED use through the National Ambulatory Care Reporting System. Though coverage is increasing, this is currently available for only a subset of facilities in Canada [21].

Use of Google Trends in Health Services and Policy Research

Access to health care starts before the clinic door, and patients may use search engines like Google to navigate access to needed care, including walk-in clinics and EDs. They may use Google searches to identify sources of care, confirm location, check hours, or obtain other information such as wait times. Though not a direct measure of health care use, relative search frequency may provide insight into patterns of care seeking across provinces and over time.

The application of internet data provided by tools like Google Trends in health services research has potential to complement and extend the data that presently exist, collected primarily through survey and administrative sources. For example, internet data have been used quite extensively in epidemiology and public health research for the surveillance of infectious disease outbreaks, determining patterns and seasonality of disease incidence, and examining information seeking about health conditions [22,23]. Application of Google Trends in health care and health services research has been more limited but has included information seeking on addiction treatment programs and correlation between Google searches for dementia and Alzheimer diseases, and outpatient visits [21,24-29]. A systematic review of studies using Google Trends in health care research found a 7-fold increase in publications from 2009 to 2013, with 27% of the studies on infectious diseases, 24% on mental health and substance use, 16% on other noncommunicable diseases, and 33% on general population behavior [22]. However, to our knowledge, no studies have used Google Trends to examine searches for walk-in clinic or ED services.

In this paper, we used Google Trends to compare search frequencies for walk-in clinics and EDs across provinces in Canada and over time (2011-2018). We compared observed search patterns with survey data capturing access to primary care.

Methods

Data

Google Trends

Google Trends provides an index of the volume of searches by geographic location. The search index reflects search volume for each search term in a given geographic region divided by the total search volume in that region, over a defined time period [30,31].

We developed search strategies to capture the range of terms used for walk-in clinics and EDs across Canadian provinces. These were based on both researcher knowledge and additional suggested terms supplied by the Google Trends interface. Multiple search terms can be combined with a plus sign (+) that denotes OR [32], and results include searches containing either term. The resulting searches were as follows:

- Search 1: walk-in clinics: "walk-in clinic + walk-in clinic + urgent care clinic + medical clinic + after-hours clinic"
- Search 2: EDs: "emergency department + emergency room + ER"

Though *emergency department* is commonly abbreviated as *ED*, it was not possible to separate relevant searches from those seeking information on *erectile dysfunction*, also commonly abbreviated as *ED*. It was therefore excluded from the final search.

We downloaded province-level search indices over the period from January 1, 2011, to December 31, 2018. We began our study period in 2011 as a change in geographic assignment was implemented by Google effective January 1, 2011. As only 5 comparisons could be made per batch within the Google Trends interface, the Canada-wide search was included in all batches and used to standardize search frequency for each province by dividing each monthly provincial search frequency by the Canadian average over the entire study period. The reported *relative search frequency* values in this manuscript, therefore, reflect search frequency for each province and month relative to the Canadian average over the entire study period.

We developed French-language search terms, but the Google Trends interface limits the number of terms that can be included. It was not possible to combine both French and English terms within 1 batch, and so we excluded Quebec from analysis, as search frequencies would not be comparable. As the populations of Yukon, Northwest, and Nunavut Territories are small, Google Trends does not return a search index, and we could not include them in analysis.

National Survey Data

No data exist tracking ED and walk-in clinic visits consistently over time or across provinces, so it was not possible to compare information from Google sources to other administrative data sources directly capturing service use. To explore the plausibility of search results, we compared information from Google Trends with province-level, cross-sectional survey data capturing patient-reported primary care access. We used data from 2 national surveys to capture primary care access. The Commonwealth Fund's International Health Policy Survey of Adults is conducted annually over the phone among nationally representative samples of noninstitutionalized adults ages 18 years and older in 11 high-income countries. [4]. The following variables were analyzed:

- Same- or next-day access: percentage of respondents who were able to get an appointment to see a doctor or a nurse the same or next day the last time they were sick;
- After-hours access: percentage of respondents who thought it was very easy or somewhat easy to get medical care in the evenings, weekends, or holidays without going to the hospital ED;
- Use of ED for condition treatable at a regular place of medical care: percentage of respondents who reported that the last time they went to the hospital ED, it was for a condition that they thought could have been treated by providers at usual place of care if they had been available.

The Canadian Community Health Survey (CCHS) is conducted annually among noninstitutionalized people 12 years of age and above across all 10 provinces and 3 territories. An area frame is used to select the CCHS target population aged 18 years and over, and the Canadian Child Tax Benefit frame used to select participants aged 12 to 17 years [33]. We analyzed the following variable from the CCHS Survey:

- Access to a regular health care provider: percentage of respondents with a regular health care provider (a health professional that one sees or talks to regularly when they need care or advice on health) [33].

Analysis

All search frequencies are expressed as a ratio of each monthly provincial value to the Canadian average over the study period (2011-2018). Plots of these data are included in Multimedia Appendices 1 and 2. To identify provinces with higher and lower search volumes, and those that experienced more dramatic changes over the study period, we used linear regression to calculate the intercept (model-predicted relative search frequency in January 2011), slope, average over the study period, and relative increase from January 2011 to December 2018 (based on model-predicted values at these time points). We report the Pearson correlation coefficients (r) and associated 95% CIs for the relationship between each province's relative search frequencies for walk-in clinics and EDs over the 8-year study period, and provincial survey results (expressed as a percentage within each province). We interpret correlation coefficients between 0.7 and 1.0 as indicating variables that are highly correlated, between 0.5 and 0.7 as moderately correlated, and between 0.3 and 0.5 as being weakly correlated.

Results

On average, over the study period from 2011 to 2018, walk-in clinic searches were most frequent in the western provinces of British Columbia, Alberta, Saskatchewan, and Manitoba. Relative search frequencies for walk-in clinics increased steadily, doubling in most provinces between 2011 and 2018 (Table 1). ED searches were most frequent in Prince Edward

Island and Manitoba. There was no consistent pattern of change over time in ED searches among provinces.

Provincial variation was also evident in survey data covering topics related to primary care access (Table 2). The percentage of respondents reporting that they were able to get a same- or next-day appointment tended to be higher in the western provinces (Table 2). After-hours access was highest in Alberta and Ontario. Eastern provinces of Newfoundland and Labrador, Prince Edward Island, Nova Scotia, and New Brunswick reported highest use of ED for conditions treatable at a regular place of medical care. Western provinces of British Columbia, Alberta, Saskatchewan, and Manitoba had lower percentages of adults reporting having a regular medical doctor.

We observed a strong positive correlation between walk-in clinic relative search frequencies and being able to get a same- or next-day appointment (*r*=0.77, 95% CI 0.23 to 0.95; Table 3). We observed a strong negative correlation between walk-in clinic relative search frequency and use of ED for conditions treatable at the patient's regular place of care (*r*=−0.71, 95% CI −0.93 to −0.09), and having a regular health care provider (*r*=−0.89, 95% CI −0.98 to −0.56; Table 3). We observed no significant correlations between ED relative search frequencies and survey data (Table 3).

Table 1. Intercepts and trends for Google Trend relative search frequencies by province.

Province	Google Trends walk-in clinic searches[a]				Google Trends emergency department searches[a]			
	Intercept (January 2011)	Slope (monthly change)	Average over study period	Change over study period	Intercept (January 2011)	Slope (monthly change)	Average over study period	Change over study period
British Columbia	0.99	0.013	1.59	2.25	0.98	0.004	1.18	1.39
Alberta	1.01	0.012	1.55	2.13	0.69	0.007	1.01	1.97
Saskatchewan	0.92	0.014	1.59	245	0.79	0.002	0.85	1.24
Manitoba	0.87	0.011	1.38	2.20	0.79	0.013	1.39	2.56
Ontario	0.64	0.007	1.00	2.03	0.82	0.004	1.00	1.46
New Brunswick	0.50	0.002	0.53	1.38	1.40	0.005	1.00	1.34
Nova Scotia	0.73	0.009	1.13	2.18	0.92	0.004	1.10	1.41
Prince Edward Island	1.48	−0.004	1.06	0.74	0.10	0.028	1.58	27.60
Newfoundland and Labrador	0.51	0.007	0.82	2.30	0.71	–0.003	1.01	0.60

[a] Search frequencies are expressed relative to the Canadian average search frequency over the study period from January 2011 to December 2018 (ie, a value of 1.00 is equal to the Canadian average, values less than 1 are lower than the Canadian average, and values greater than 1 are higher than the Canadian average).

Table 2. Provincial percentage responses from the 2016 Commonwealth Fund International Health Policy Survey of Adult and the 2016 Canadian Community Health Survey.

Province	Same- or next-day access, %[a]	After-hours access, %[b]	Use of ED[c] for condition treatable at a regular place of medical care, %[d]	Has a regular health care provider, %[e]
British Columbia	44	27	36	83
Alberta	48	42	30	82
Saskatchewan	49	32	43	81
Manitoba	47	34	40	85
Ontario	44	40	44	90
New Brunswick	33	35	52	90
Nova Scotia	34	26	48	90
Prince Edward Island	30	25	60	89
Newfoundland and Labrador	34	16	49	90

[a] Same- or next-day access: percentage of respondents who were able to get an appointment to see a doctor or a nurse the same or next day the last time they were sick.

[b] After-hours access: percentage of respondents who thought it was very easy or somewhat easy to get medical care in the evenings, weekends, or holidays without going to the hospital ED.

[c] ED: emergency department.

[d] Use of ED for condition treatable at a regular place of medical care: percentage of respondents who reported that the last time they went to the hospital ED, it was for a condition that they thought could have been treated by the doctors or staff at the place where they usually get medical care if they had been available.

[e] Has a regular health care provider: percentage of respondents who have a regular health care provider (a health professional that one sees or talks to regularly when they need care or advice on health).

Table 3. Correlation between Google Trends relative search frequency (average 2011-2018) and provincial percentage responses from the 2016 Commonwealth Fund International Health Policy Survey of Adult and the 2016 Canadian Community Health Survey.

Correlations	Walk-in clinic		Emergency department	
	r	95% CI	*r*	95% CI
Same- or next-day access	0.77	0.23 to 0.95	−0.34	−0.82 to 0.42
After-hours access	0.23	−0.51 to 0.78	−0.24	−0.78 to 0.51
Use of ED[a] for condition treatable at a regular place of medical care	−0.71	−0.93 to −0.09	0.37	−0.39 to 0.83
Has a regular health care provider	−0.89	−0.98 to −0.56	0.17	−0.56 to 0.75

[a] ED: emergency department.

Discussion

Principal Findings

Walk-in clinic relative search frequency was highest in western provinces and is increasing over time across Canada. Provinces that had high walk-in clinic relative search frequencies reported greater same- or next-day access to care and lower use of ED for conditions treatable at the patient’s regular place of medical care. The percentage of patients with a regular medical doctor is also lower in provinces with high relative search frequency for walk-in clinics.

Findings may suggest that challenges accessing primary care have contributed to increasing patient use of Web-based tools to search for more convenient and easily accessible care through walk-in clinics [34]. The degree to which the rapid increase in searches for walk-in clinics reflects increased availability of this option relative to other sources of primary care [3], a preference for the convenience of walk-in style practice [9], or another explanation cannot be determined from our data.

The strong positive correlation between walk-in clinic searches and same- or next-day access and strong negative correlations with ED use for treatable condition and having a regular medical provider lend credibility to the Google Trend results. Walk-in clinics may make it easier to get timely services without going to ED [35]. However, this could raise concerns about discontinuity and poor coordination of care [6] as more patients also lack regular medical providers. It may be that people lack regular medical providers because physicians are not taking more regular patients but are instead choosing walk-in style practice [19].

ED search frequency varies by province, but there is no clear pattern east to west nor consistent pattern of increase or decrease over the study period. In the province of Manitoba, ED closures were a prominent topic in the media over the study period, which may explain high relative search frequencies in this province and would in no way correspond to service use. We did not observe correlations between ED search frequency and survey data, including ED use for condition treatable by provider at a regular place of care. It is likely that Google Trends less directly reflects ED service use than walk-in clinic use. Most people already know the location of major hospitals and attached EDs, which are open 24/7. As such, people may not need to search through Google to find their location or operating hours. Walk-in clinics are more numerous, may open and close in different locations, and may have fluctuating hours of operation and so service use may be better reflected in search data for walk-in clinics.

Limitations

This study is subject to a number of limitations. First, Google searches can only partially reflect patterns of care seeking. Not all searches correspond to actual use, and not all use would be preceded by a search. It is plausible that the use of Google as a tool in accessing health care also differs across patients and provinces, independent of realized service use. We have no ability to validate Google Trends data against administrative data sources collected over time. Comparison with survey data adds credibility to search frequency for walk-in clinics, but this analysis is limited by the sample size for cross-provincial comparisons. This study builds on an existing body of literature that has confirmed the plausibility of Google Trends search results as public health indicators by correlating Google Trends data with other sources [36].

The correlations made are at the ecological level and require caution in interpretation. People who answered the surveys are not the same as those doing the searches. Survey data include only those who choose to respond, and search data only reflects Canadians who use the internet [37]. We were unable to disaggregate search data by demographic characteristics or other characteristics related to both search behavior and primary care access. It may be that internet users more commonly use walk-in clinics, but this would be true across provinces and over time and would not explain the province-level relationships observed.

Conclusions

Findings from Google Trends are consistent with survey information about the province-level access to primary care, and may offer some insight into how the organization of primary care differs across provinces. Findings suggest that patient use of Web-based tools to search for more convenient or accessible care through walk-in clinics is increasing. Further research is needed to validate Google Trends data with administrative information on service use.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Relative search frequency for walk-in clinics from 2011-2018 across nine Canadian provinces.

[PNG File, 359 KB - publichealth_v5i4e13130_app1.png]

Multimedia Appendix 2

Relative search frequency for emergency departments from 2011 to 2018 across nine Canadian provinces.

[PNG File, 330 KB - publichealth_v5i4e13130_app2.png]

References

1. Starfield B, Shi L, Macinko J. Contribution of primary care to health systems and health. Milbank Q 2005;83(3):457-502 [FREE Full text] [doi: 10.1111/j.1468-0009.2005.00409.x] [Medline: 16202000]
2. Starfield B, Birn AE. Income redistribution is not enough: income inequality, social welfare programs, and achieving equity in health. J Epidemiol Community Health 2007 Dec;61(12):1038-1041 [FREE Full text] [doi: 10.1136/jech.2006.054627] [Medline: 18000124]
3. Canadian Institute for Health Information. Experiences With Primary Health Care in Canada URL: https://secure.cihi.ca/free_products/cse_phc_aib_en.pdf [accessed 2019-10-24]
4. Canadian Institute for Health Information. How Canada Compares: Results From The Commonwealth Fund's 2016 International Health Policy Survey of Adults in 11 Countries URL: https://www.cihi.ca/sites/default/files/document/text-alternative-version-2016-cmwf-en-web.pdf [accessed 2019-10-24]
5. Chan BT, Schull MJ, Schultz SE. Institute for Clinical Evaluative Sciences. 2001 Nov. Emergency Department Services in Ontario URL: https://www.ices.on.ca/Publications/Atlases-and-Reports/2001/ED-services-in-Ontario [accessed 2019-10-24]
6. Howard M, Goertzen J, Kaczorowski J, Hutchison B, Morris K, Thabane L, et al. Emergency department and walk-in clinic use in models of primary care practice with different after-hours accessibility in Ontario. Healthc Policy 2008 Aug;4(1):73-88 [FREE Full text] [doi: 10.12927/hcpol.2008.20009] [Medline: 19377344]
7. MacKichan F, Brangan E, Wye L, Checkland K, Lasserson D, Huntley A, et al. Why do patients seek primary medical care in emergency departments? An ethnographic exploration of access to general practice. BMJ Open 2017 May 4;7(4):e013816 [FREE Full text] [doi: 10.1136/bmjopen-2016-013816] [Medline: 28473509]

8. Howard M, Goertzen J, Kaczorowski J, Hutchison B, Morris K, Thabane L, et al. Emergency Department and Walk-in Clinic Use in Models of Primary Care Practice with Different After-Hours Accessibility in Ontario. Healthc Policy 2008 Aug;4(1):73-88 [FREE Full text] [Medline: 19377344]
9. Szafran O, Bell NR. Use of walk-in clinics by rural and urban patients. Can Fam Physician 2000 Jan;46:114-119 [FREE Full text] [Medline: 10660793]
10. Peckham A, Ho J, Marchildon G. Institute of Health Policy, Management and Evaluation. 2018. Policy Innovations in Primary Care Across Canada URL: https://ihpme.utoronto.ca/wp-content/uploads/2018/04/NAO-Rapid-Review-1_EN.pdf [accessed 2019-10-24] [WebCite Cache ID 75HumFY4m]
11. Aggarwal M, Hutchison B. Toward a Primary Care Strategy for Canada. Ottawa, Ontario, Canada: Canadian Foundation for Healthcare Improvement; Dec 2012.
12. Morris ME, Aguilera A. Mobile, social, and wearable computing and the evolution of psychological practice. Prof Psychol Res Pr 2012 Dec;43(6):622-626 [FREE Full text] [doi: 10.1037/a0029041] [Medline: 25587207]
13. Glazier RH, Zagorski BM, Rayner J. Institute for Clinical Evaluative Sciences. 2012 Mar. Comparison of Primary Care Models in Ontario by Demographics, Case Mix and Emergency Department Use, 2008/09 to 2009/10 URL: https://www.ices.on.ca/Publications/Atlases-and-Reports/2012/Comparison-of-Primary-Care-Models [accessed 2019-10-24]
14. Suter E, Mallinson S, Misfeldt R, Boakye O, Nasmith L, Wong S. Advancing team-based primary health care: a comparative analysis of policies in western Canada. BMC Health Serv Res 2017 Jul 17;17(1):493 [FREE Full text] [doi: 10.1186/s12913-017-2439-1] [Medline: 28716120]
15. Wranik D, Hanrahan K, Tarrant F. Interdisciplinary Primary Health Care Teams. 2012. Contractual Arrangements and Remuneration Methods for Interdisciplinary Teams in Primary Health Care in Public Payer Systems URL: http://primaryhealthcareteams.ca/wp-content/uploads/2016/07/Report-1-Inventory-of-PHC-Team-Compensation-Models-copy.pdf [accessed 2019-10-24] [WebCite Cache ID 75HtRCb5H]
16. Government of Alberta. Alberta's Primary Health Care Strategy URL: https://open.alberta.ca/dataset/9781460108635 [accessed 2019-10-24]
17. Pineault R, Levesque JF, Roberge D, Hamel M, Couture A. National Institute of Public Health of Quebec. Primary Care Services Organizational Models and the Population's Care Experience URL: https://www.inspq.qc.ca/sites/default/files/publications/843_modeles_organisation_ang_mir.pdf [accessed 2019-10-24]
18. Katz A, Valdivia J, Chateau C, Taylor C, Walld R, McCulloch S, et al. A Comparison of Models of Primary Care Delivery in Winnipeg. Winnipeg, MB: Manitoba Centre for Health Policy; 2016.
19. Government of New Brunswick. A Primary Health Care Framework for New Brunswick. New Brunswick, Canada: New Nouveau Brunswick; 2012.
20. McGrail K, Lavergne R, Lewis SJ, Peterson SL, Barer M, Garrison SR. Classifying physician practice style: a new approach using administrative data in British Columbia. Med Care 2015 Mar;53(3):276-282. [doi: 10.1097/MLR.0000000000000310] [Medline: 25634088]
21. Canadian Institute for Health Information. 2014. Data Quality Documentation, National Ambulatory Care Reporting System— Current-Year Information, 2013–2014 URL: https://www.cihi.ca/sites/default/files/nacrs_dataquality_2013_2014_en_0.pdf [accessed 2019-10-24]
22. Nuti SV, Wayda B, Ranasinghe I, Wang S, Dreyer RP, Chen SI, et al. The use of google trends in health care research: a systematic review. PLoS One 2014;9(10):e109583 [FREE Full text] [doi: 10.1371/journal.pone.0109583] [Medline: 25337815]
23. Solano P, Ustulin M, Pizzorno E, Vichi M, Pompili M, Serafini G, et al. A Google-based approach for monitoring suicide risk. Psychiatry Res 2016 Dec 30;246:581-586. [doi: 10.1016/j.psychres.2016.10.030] [Medline: 27837725]
24. Zhang Z, Zheng X, Zeng DD, Leischow SJ. Information seeking regarding tobacco and lung cancer: effects of seasonality. PLoS One 2015;10(3):e0117938 [FREE Full text] [doi: 10.1371/journal.pone.0117938] [Medline: 25781020]
25. Wang H, Chen D, Yu H, Chen Y. Forecasting the incidence of dementia and dementia-related outpatient visits with google trends: evidence from Taiwan. J Med Internet Res 2015 Nov 19;17(11):e264 [FREE Full text] [doi: 10.2196/jmir.4516] [Medline: 26586281]
26. Mavragani A, Ochoa G, Tsagarakis KP. Assessing the methods, tools, and statistical approaches in Google trends research: systematic review. J Med Internet Res 2018 Nov 6;20(11):e270 [FREE Full text] [doi: 10.2196/jmir.9366] [Medline: 30401664]
27. Vasconcellos-Silva PR, Carvalho DB, Trajano V, de la Rocque LR, Sawada AC, Juvanhol LL. Using Google trends data to study public interest in breast cancer screening in Brazil: why not a pink February? JMIR Public Health Surveill 2017 Apr 6;3(2):e17 [FREE Full text] [doi: 10.2196/publichealth.7015] [Medline: 28385679]
28. Parker J, Cuthbertson C, Loveridge S, Skidmore M, Dyar W. Forecasting state-level premature deaths from alcohol, drugs, and suicides using Google Trends data. J Affect Disord 2017 Apr 15;213:9-15. [doi: 10.1016/j.jad.2016.10.038] [Medline: 28171770]
29. Tkachenko N, Chotvijit S, Gupta N, Bradley E, Gilks C, Guo W, et al. Google Trends can improve surveillance of type 2 diabetes. Sci Rep 2017 Jul 10;7(1):4993 [FREE Full text] [doi: 10.1038/s41598-017-05091-9] [Medline: 28694479]

30. Ling R, Lee J. Disease monitoring and health campaign evaluation using Google Search activities for HIV and AIDS, stroke, colorectal cancer, and marijuana use in Canada: a retrospective observational study. JMIR Public Health Surveill 2016 Oct 12;2(2):e156 [FREE Full text] [doi: 10.2196/publichealth.6504] [Medline: 27733330]
31. Varian HR, Choi H. Predicting the Present with Google Trends. Economic Record 2012;88(1). [doi: 10.2139/ssrn.1659302]
32. Kardes S, Kardes E. Seasonality of bruxism: evidence from Google Trends. Sleep Breath 2019 Jun;23(2):695-701. [doi: 10.1007/s11325-019-01787-6] [Medline: 30790220]
33. Statistics Canada. Health Characteristics, Annual Estimates URL: https://www150.statcan.gc.ca/t1/tbl1/en/cv.action?pid=1310009601 [accessed 2019-10-24]
34. Betts D, Korenda L. Deloitte US. Inside the Patients' Journey: Three Key Touch Points for Consumer Engagement Strategies URL: https://www2.deloitte.com/content/dam/insights/us/articles/4632_CHS-Consumer-survey/DI_CHS-consumer-survey.pdf [accessed 2019-10-24]
35. Tetanish R. Truro News. Walk-in Clinic to Start Booking Same-day Appointments URL: https://www.trurodaily.com/news/local/walk-in-clinic-to-start-booking-same-day-appointments-146707/ [accessed 2018-11-27]
36. Kang M, Song W, Choi S, Kim H, Ha H, Kim S, et al. Google unveils a glimpse of allergic rhinitis in the real world. Allergy 2015 Jan;70(1):124-128. [doi: 10.1111/all.12528] [Medline: 25280183]
37. Jun SP, Yoo HS, Choi S. Ten years of research change using Google Trends: From the perspective of big data utilizations and applications. Technological Forecasting and Social Change 2018 May;130:69-87 [FREE Full text] [doi: 10.1016/j.techfore.2017.11.009]

Abbreviations

CCHS: Canadian Community Health Survey
ED: emergency department

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Original Paper

Prevalence and Characteristics of Twitter Posts About Court-Ordered, Tobacco-Related Corrective Statements: Descriptive Content Analysis

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Abstract

Background: Three major US tobacco companies were recently ordered to publish corrective statements intended to prevent and restrain further fraud about the health effects of smoking. The court-ordered statements began appearing in newspapers and on television (TV) in late 2017.

Objective: The objective of this study was to examine the social media dissemination of the tobacco corrective statements during the first 6 months of the implementation of the statements.

Methods: We conducted a descriptive content analysis of Twitter posts using an iterative search strategy through Crimson Hexagon and randomly selected 19.74% (456/2309) of original posts occurring between November 1, 2017, and March 27, 2018, for coding and analysis. We assessed post volume over time, source or author, valence, linked content, and reference to the industry (eg, big tobacco, tobacco industry, and Philip Morris) and media outlet (TV or newspaper). Retweeted content was coded for source/author and prevalence.

Results: Most posts were published in November 2017, surrounding the initial release of the corrective statements. Content was generally neutral (58.7%, 268/456) or positive (33.3%, 152/456) in valence, included links to additional information about the statements (94.9%, 433/456), referred to the industry (87.7%, 400/456), and did not mention a specific media channel on which the statements were aired or published (15%). The majority of original posts were created by individual users (55.2%, 252/456), whereas the majority of retweeted posts were posted by public health organizations (51%). Differences by source are reported, for example, organization posts are more likely to include a link to additional information compared with individual users (P=.03).

Conclusions: Conversations about the court-ordered corrective statements are taking place on Twitter and are generally neutral or positive in nature. Public health organizations may be increasing the prevalence of these conversations through social media engagement.

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KEYWORDS

social media; Twitter; tobacco corrective statements; tobacco industry/legislation and jurisprudence

Introduction

After an 18-year legal battle, 3 major US tobacco companies (Altria, its subsidiary Philip Morris USA; RJ Reynolds Tobacco; and ITG Brands) were recently ordered by the US District Court for the District of Columbia to publish tobacco corrective statements as 1 of 4 legal remedies originally included in a 2006 judgment to *prevent and restrain* the tobacco companies from continuing to engage in fraud about the harms of cigarettes. These statements were ordered in a federal racketeering lawsuit brought against the tobacco companies in 1999 by the US Department of Justice under the Racketeering Influenced and Corrupt Organizations Act [1-2]. The companies were mandated to publish corrective statements as full-page advertisements in at least 50 newspapers across the country, in 5 issues appearing from late November 2017 to early March 2018, and broadcast statements as 30- and 45-second prime-time spots on major television (TV) networks 5 times a week for 1 year. The statements address 5 areas: (1) adverse health effects of cigarette smoking; (2) adverse health effects of exposure to secondhand smoke; (3) manipulation of cigarette design and composition to enhance nicotine delivery; (4) addictiveness of cigarette smoking and nicotine; and (5) no health benefit from smoking *light*, *low tar*, *ultra light*, *mild*, and *natural* cigarettes.

Since the initial court judgement in 2006, the media landscape has changed substantially. Newspaper readership has declined about 36% [3] and is the least common platform for news consumption [4]. Although TV viewership is still high among older adults, 61% of adults aged 18 to 29 years use streaming services over traditional TV services [5]. In 2006, 16% of US adults reported ever using social media [6], compared with 90% today [7]. Previous studies have found Twitter to be a useful platform for assessing public response to public health topics around tobacco regulation [8], health behaviors [9], and product use [10,11] as 90% of Twitter posts are publicly available from a diverse user base [12]. We examined the prevalence, characteristics, and sources of public Twitter posts about tobacco corrective statements to describe how corrective statements have extended beyond the media outlets in which they were ordered to appear.

Methods

We used descriptive content analysis to focus on describing the prevalence and characteristics of Twitter posts, without inference to subsequent behavior or message processing [13]. Describing post prevalence and characteristics is an essential step to generating hypotheses and designing future studies to further understand the dissemination and reach of the tobacco corrective statements [14].

Sample

Crimson Hexagon, a social media analytics tool, was used to collect publicly available Twitter posts related to tobacco corrective statements posted from November 1, 2017, to March 27, 2018. Posts before the release of corrective statements on November 26, 2017, are included as a baseline assessment of changes in post volume. Keywords and search terms were informed by a preliminary review of tobacco corrective statement mentions on social media and in mainstream Web-based news outlets. An iterative refinement process yielded 2309 original posts (as opposed to retweets); 387 (387/ 5167, 7.48%) of the original posts were retweeted a total of 2858 times for a total of 5167 posts during the data interval. Per guidelines set forth by the Department of Health and Human Services Office of Human Research Protections, the data retrieved from Twitter posts set to *public* do not meet the *private and identifiable* standards for personally identifiable information and, therefore, do not meet the definition of human subjects research [15]. See Multimedia Appendix 1 for search process details.

Overall, 19.74% (456/2309) of the original posts were randomly selected for coding and analysis. Furthermore, 90 posts were double coded for interrater reliability by proportion of agreement and Krippendorff alpha. The codebook was refined as necessary. Reliability across constructs ranged from 94% to 100% (Krippendorff alpha .8-1.0), representing moderate-to-perfect agreement.

Measures

Crimson Hexagon provides descriptive data regarding the volume of posts over time; however, understanding who posted what content is important for contextualizing the communication environment [16]. Posts were coded for source, defined as organization, individual, or undeterminable. To understand post characteristics, the overall tone was coded as positive, positive-unsatisfied (posts in favor of the statements that expressed desire for more corrective action), neutral, and negative. As corrective statements were ordered to appear in newspapers and TV during the data interval of this study, posts were coded for mention of statements in newspapers or on TV. The presence of a link to additional content, and the link's relevance (relevant/irrelevant) to tobacco corrective statements was coded to understand if users were being referred to additional content [17]. To understand how posts connected the tobacco industry to corrective statements, tobacco industry mentions were coded as no mention, plural (eg, *tobacco industry*), or specific (eg, *Altria*) mention.

To understand post amplification, each of the 387 original posts that were retweeted were further reviewed and categorized by 2 researchers according to the source of the original post: public health organization, news organization, individual, and celebrity.

Analyses

Frequencies and proportions are reported for the sample of original posts. Chi-square tests were used to understand the differences across sources. Numerical data on retweet prevalence were provided by Crimson Hexagon and analyzed for prevalence by source.

Results

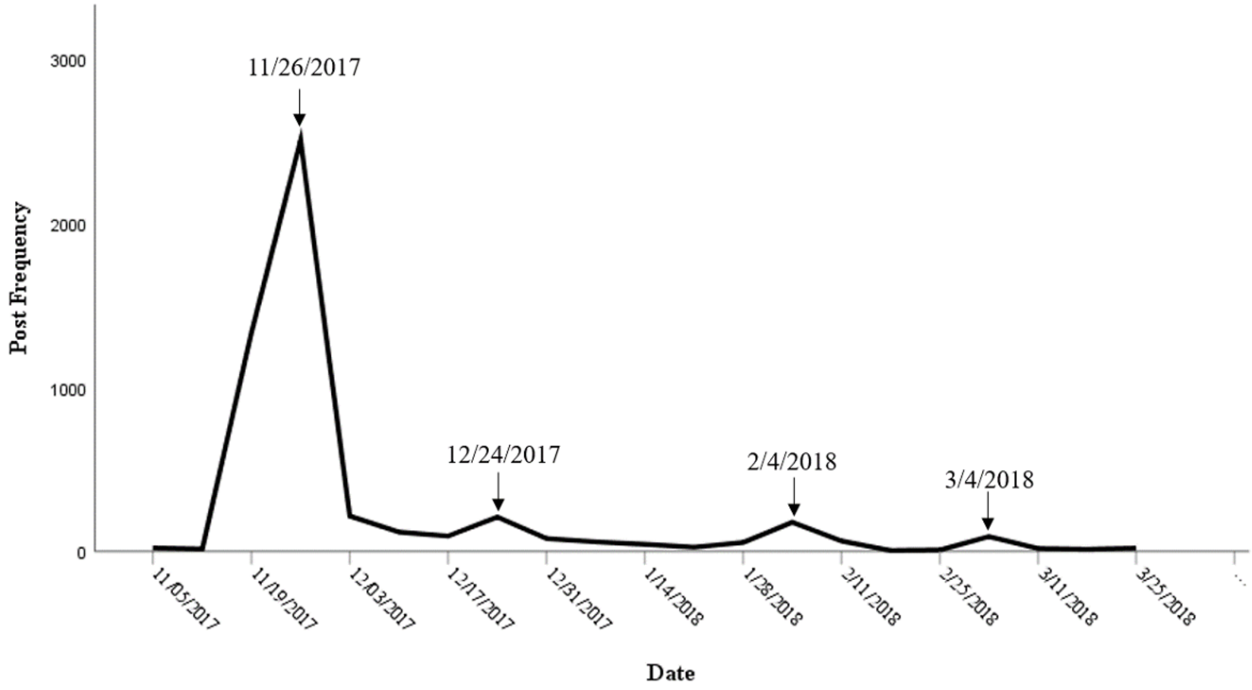
Of the 5167 posts that appeared between November 1, 2017, and March 27, 2018, 1343 (25.99%) appeared during the week leading up to the release of the corrective statements; 2532 (49.00%) were posted on the day the statements were released. A substantial decrease was observed in the first week of December, and the post volume remained low even after the release of the second and third statements. Modest spikes were observed on the days of the release of the fourth (February 4, 2018) and fifth (March 4, 2018) statements (Figure 1).

Over half (58.7%, 268/456) of the posts were neutral in valence, and 152 of 456 posts (33.3%) were positive or supportive. Most posts (84.8%, 387/456) did not mention a specific media outlet on which the corrective statements were aired or seen. Almost all posts (94.9%, 433/456) contained a link to additional information about the statements, 97.9% (424/433) of which were active and relevant. Furthermore, 87.7% (400/456) of posts referred to the industry generally, whereas less than 1.3% (6/456) mentioned a specific tobacco company. Individual-owned Twitter accounts represented the majority (55.2%, 252/456) of original posts, followed by organization (38.8%, 177/456), and undeterminable accounts (5.9%, 27/456).

Differences across sources were found for media outlet mentioned, presence of link, and industry mentioned. Organizations were more likely to mention that statements appeared in TV and newspapers compared with individual and undeterminable ($\chi^2_2=32.6$; $P=.001$). Compared with individuals, organizations more often included a link ($\chi^2_2=12.7$; $P=.03$) and used plural terms to refer to the tobacco industry ($\chi^2_2=25.8$; $P=.001$), whereas individuals often did not mention the tobacco industry compared with organizations and undeterminable ($\chi^2_2=19.7$; $P=.001$). The table in Multimedia Appendix 1 describes the post characteristics and differences by source.

Most retweeted posts were from public health organizations (169 posts retweeted 2251 times), followed by individuals (131 posts retweeted 1457 times), news organizations (86 posts retweeted 607 times), and a celebrity (1 post retweeted 126 times).

Figure 1. Post prevalence over time.



Discussion

These results provide a snapshot of the social media conversation around tobacco corrective statements. The presence of posts about these statements demonstrates the public health utility of such platforms for adapting to changes in the communication and regulatory landscape. Considering the drastic changes in the use of the media outlets decided by the court over a decade ago, findings from this study are promising in that most posts were informative or supportive and included links to additional information; thus, the reach of corrective statements may be extended to a broader audience through social media. Consistent with other research that has documented the utility and reach of Twitter for other public health topics [18-22], this study adds evidence to a growing body of literature on Twitter as an important tool for adapting to a dynamic tobacco communication and regulatory environment and for understanding a variety of tobacco-related questions around social conversations about tobacco [23], industry messaging and branding [24-25], tobacco use [10], interventions [9], advocacy [26], and public reactions to tobacco regulation [8]. Findings suggest that public health organizations have been proactive in disseminating tobacco corrective statements and engage with the population in real time. Compared with individual users, organizations maximized information provision by specifying where corrective statements were published, explicitly connecting the tobacco industry to corrective statements, and providing relevant links to additional information.

These findings raise important questions warranting further exploration. First, this study identified the presence of posts about corrective statements and organizations' potential to expand the reach of these statements beyond the court-ordered media platforms. However, exactly who is exposed to these posts remains unknown. Social network analysis could explore this question and reveal key characteristics such as tobacco-related attitudes and audience affinities to enhance messaging efforts. Second, it is unclear how exposure to corrective statements on social media compares with the court-ordered platforms. Future research could use market research and nationally representative surveys to explore exposure rates across platforms. It is unclear if exposure is associated with tobacco-related attitudes and behaviors and if mode of exposure (ie, social media, TV, and newspaper) modifies such outcomes. Longitudinal studies of exposure and subsequent outcomes are needed.

This study is not without limitations. Data for this study were limited to public Twitter posts, precluding analysis of potential conversations on private accounts. However, over 90% of Twitter accounts are public and accessible through Crimson Hexagon [12] and users tend to be younger and have greater minority representation [7], representing the populations most vulnerable to tobacco use. By analyzing a random subset of posts, the results may not reflect the collective body of corrective statement posts. Smoking behavior was not determinable for most posts, hindering the extrapolation findings to tobacco use behaviors. An inherent limitation to any keyword search strategy is that it is unlikely that all related posts were retrieved. Finally, despite high interrater reliability, our valence code required interpretation, possibly introducing subjective bias.

This snapshot of Twitter conversations about tobacco court-ordered corrective statements indicates that these statements are represented in a larger public information environment that extends beyond traditional media. Continued surveillance of social media responses to corrective statements is warranted to inform public health efforts.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Search process and terms, Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram, and table for characteristics of Twitter posts about the corrective statements by post source.

[PDF File (Adobe PDF File)212 KB - publichealth_v5i4e12878_app1.pdf]

References

1. *US v Philip Morris USA, Inc, et al*. 1:99-CV-02496-PLF (Order #72-Remand) Document 6227, 1-17 (US District Court DC 2017).
2. *US v Philip Morris USA, Inc, et al*. 449 F Supp 2d 1, 1-987 (US District Court DC 2006).
3. Pew Research Center. 2019. Newspapers Fact Sheet URL: http://www.journalism.org/fact-sheet/newspapers/ [accessed 2018-11-21] [WebCite Cache ID 746GkqePb]
4. Shearer E. Pew Research Center. 2018. Social Media Outpaces Print Newspapers in the US As a News Source URL: http://www.pewresearch.org/fact-tank/2018/12/10/social-media-outpaces-print-newspapers-in-the-u-s-as-a-news-source/ [accessed 2019-03-15] [WebCite Cache ID 76taCEfdi]
5. Pew Research Center. 2017. About 6 in 10 Young Adults in US Primarily Use Online Streaming to Watch TV URL: http://www.pewresearch.org/fact-tank/2017/09/13/about-6-in-10-young-adults-in-u-s-primarily-use-online-streaming-to-watch-tv/ [accessed 2019-03-15] [WebCite Cache ID 76taElIAR]
6. Lenhart A. Pew Research Center. 2009. Adults and Social Network Websites: Main Findings URL: http://www.pewinternet.org/2009/01/14/main-findings-13/ [accessed 2019-03-15] [WebCite Cache ID 76taHk62r]
7. Pew Research Center. 2019. Social Media Fact Sheet URL: http://www.pewinternet.org/fact-sheet/social-media/ [accessed 2019-05-01] [WebCite Cache ID 746HD3ESn]
8. Lazard AJ, Wilcox GB, Tuttle HM, Glowacki EM, Pikowski J. Public reactions to e-cigarette regulations on Twitter: a text mining analysis. Tob Control 2017 Dec;26(e2):e112-e116. [doi: 10.1136/tobaccocontrol-2016-053295] [Medline: 28341768]
9. Chung JE. A smoking cessation campaign on Twitter: understanding the use of Twitter and identifying major players in a health campaign. J Health Commun 2016 May;21(5):517-526. [doi: 10.1080/10810730.2015.1103332] [Medline: 27115179]

10. Unger JB, Urman R, Cruz TB, Majmundar A, Barrington-Trimis J, Pentz MA, et al. Talking about tobacco on Twitter is associated with tobacco product use. Prev Med 2018 Sep;114:54-56 [FREE Full text] [doi: 10.1016/j.ypmed.2018.06.006] [Medline: 29898418]
11. Myslín M, Zhu SH, Chapman W, Conway M. Using Twitter to examine smoking behavior and perceptions of emerging tobacco products. J Med Internet Res 2013 Aug 29;15(8):e174 [FREE Full text] [doi: 10.2196/jmir.2534] [Medline: 23989137]
12. Meeder B, Tam J, Kelley PG, Cranor LF. Carnegie Mellon School of Computer Science. 2010. RT @IWantPrivacy: Widespread Violation of Privacy Settings in the Twitter Social Network URL: http://www.cs.cmu.edu/~jdtam/Documents/Meeder-SNSP2010.pdf [accessed 2019-08-23]
13. Neuendorf KA. The Content Analysis Guidebook. Thousand Oaks, CA: Sage Publications; 2002.
14. Riff D, Lacy S, Fico F. Analyzing Media Messages: Using Quantitative Content Analysis in Research. Third Edition. New York: Routledge; 2013.
15. The US Department of Health and Human Services. 2013. Attachment B: Considerations and Recommendations Concerning Internet Research and Human Subjects Research Regulations, With Revisions URL: https://www.hhs.gov/ohrp/sachrp-committee/recommendations/2013-may-20-letter-attachment-b/index.html [accessed 2019-05-30] [WebCite Cache ID 78lIJ83QB]
16. Lienemann BA, Unger JB, Cruz TB, Chu KH. Methods for coding tobacco-related twitter data: a systematic review. J Med Internet Res 2017 Mar 31;19(3):e91 [FREE Full text] [doi: 10.2196/jmir.7022] [Medline: 28363883]
17. Zhang N, Campo S, Janz KF, Eckler P, Yang J, Snetselaar LG, et al. Electronic word of mouth on twitter about physical activity in the United States: exploratory infodemiology study. J Med Internet Res 2013 Nov 20;15(11):e261 [FREE Full text] [doi: 10.2196/jmir.2870] [Medline: 24257325]
18. Sinnenberg L, Buttenheim AM, Padrez K, Mancheno C, Ungar L, Merchant RM. Twitter as a tool for health research: a systematic review. Am J Public Health 2017 Jan;107(1):e1-e8. [doi: 10.2105/AJPH.2016.303512] [Medline: 27854532]
19. Veale HJ, Sacks-Davis R, Weaver ER, Pedrana AE, Stoové MA, Hellard ME. The use of social networking platforms for sexual health promotion: identifying key strategies for successful user engagement. BMC Public Health 2015 Feb 6;15:85 [FREE Full text] [doi: 10.1186/s12889-015-1396-z] [Medline: 25884461]
20. Ramanadhan S, Mendez SR, Rao M, Viswanath K. Social media use by community-based organizations conducting health promotion: a content analysis. BMC Public Health 2013 Dec 5;13:1129 [FREE Full text] [doi: 10.1186/1471-2458-13-1129] [Medline: 24313999]
21. Hanson CL, Cannon B, Burton S, Giraud-Carrier C. An exploration of social circles and prescription drug abuse through Twitter. J Med Internet Res 2013 Sep 6;15(9):e189 [FREE Full text] [doi: 10.2196/jmir.2741] [Medline: 24014109]
22. Himelboim I, Han JY. Cancer talk on Twitter: community structure and information sources in breast and prostate cancer social networks. J Health Commun 2014;19(2):210-225. [doi: 10.1080/10810730.2013.811321] [Medline: 24111482]
23. Cole-Lewis H, Pugatch J, Sanders A, Varghese A, Posada S, Yun C, et al. Social listening: a content analysis of e-cigarette discussions on Twitter. J Med Internet Res 2015 Oct 27;17(10):e243 [FREE Full text] [doi: 10.2196/jmir.4969] [Medline: 26508089]
24. Lazard AJ, Saffer AJ, Wilcox GB, Chung AD, Mackert MS, Bernhardt JM. E-cigarette social media messages: a text mining analysis of marketing and consumer conversations on Twitter. JMIR Public Health Surveill 2016 Dec 12;2(2):e171 [FREE Full text] [doi: 10.2196/publichealth.6551] [Medline: 27956376]
25. Watts C, Hefler M, Freeman B. 'We have a rich heritage and, we believe, a bright future': how transnational tobacco companies are using Twitter to oppose policy and shape their public identity. Tob Control 2019 Mar;28(2):227-232. [doi: 10.1136/tobaccocontrol-2017-054188] [Medline: 29666168]
26. Hefler M, Freeman B, Chapman S. Tobacco control advocacy in the age of social media: using Facebook, Twitter and change. Tob Control 2013 May;22(3):210-214. [doi: 10.1136/tobaccocontrol-2012-050721] [Medline: 23047890]

Abbreviations

NIH: National Institutes of Health
TV: television

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Original Paper

Youth Study Recruitment Using Paid Advertising on Instagram, Snapchat, and Facebook: Cross-Sectional Survey Study

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Abstract

Background: The use of paid social media advertising for targeted study recruitment is an effective strategy in health research and evaluation, specifically to reach diverse youth participants. Although the literature adequately describes the utility of Facebook in recruitment, limited information exists for social media platforms that are more popular with youth, specifically Instagram and Snapchat.

Objective: This paper outlines a paid advertising approach using Instagram, Snapchat, and Facebook to evaluate a statewide youth marijuana prevention campaign. The objective of this study was to compare recruitment metrics across Instagram, Snapchat, and Facebook for two surveys documenting youth knowledge, attitudes, and behaviors related to retail marijuana in Colorado post legalization. In addition, the study assessed the feasibility of using Instagram and Snapchat as effective additions to Facebook for youth study recruitment.

Methods: A social media recruitment strategy was used to conduct two cross-sectional surveys of youth, aged 13 to 20 years, in Colorado. Geographically targeted ads across 3 social media platforms encouraged the completion of a Web-based self-administered survey. Ad Words and Snap Ads were used to deploy and manage advertising campaigns, including ad design, placement, and analysis. Ad costs and recruitment metrics (ie, impressions, link clicks, and conversion rates) were calculated across the three social media platforms.

Results: Over two 1-month periods, 763,613 youth were reached (ie, impressions), 6089 of them clicked survey links (ie, clicks), and 828 eligible youth completed surveys about knowledge, attitudes, and behaviors related to retail marijuana. Instagram converted 36.13% (803/2222) of impressions to clicks (ie, conversion rate) in the first survey and 0.87% (864/98982) in the second survey. Snapchat generated the most impressions and link clicks, but it did so with the lowest conversion rate for both surveys, with a 1.40% (1600/114,200) conversion rate in the first survey and a 0.36% (1818/504700) conversion rate in the second survey. Facebook maintained a consistent conversion rate of roughly 2% across both surveys, despite reductions in budget for the second survey. The cost-per-click ranged between US $0.25 and $0.37 across the three platforms, with Snapchat as both the most cost-effective platform in the first survey and the most expensive platform in the second survey.

Conclusions: Recruitment and enrollment outcomes indicate the use of Instagram and Snapchat, in addition to Facebook, may be a modern, useful, and cost-effective approach to reach youth with surveys on sensitive health topics. As the use of Facebook declines among youth, the use of more popular social media platforms can augment study recruitment for health research and evaluation efforts.

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KEYWORDS

social media; youth; surveys and questionnaires

Introduction

In the United States, social media is becoming increasingly valuable to recruit youth participants in health research and program evaluation. Evidence supports that social media is an advantageous approach to recruit hard-to-reach populations and individuals with specific disease states [1-6]. Some studies find social media recruitment strategies more cost effective, compared with traditional enrollment methods [2]. Many reviews suggest that using these platforms for study recruitment is effective in reaching adolescents and young adults [3,7,8]. These reviews demonstrate that youth are more forthcoming with self-administered surveys, using technology platforms, particularly when it comes to disclosing information on sensitive topics [9].

The universal use of social media among younger populations motivates researchers to utilize Web-based strategies. According to the US Department of Health and Human Services and the PEW Research Center, 71% of teens use more than one social media platform; finding Facebook is no longer the social media platform of choice for young people [6,10]. In 2018, the social media landscape shifted, reporting YouTube (85%), Instagram (72%), and Snapchat (69%) as the most utilized social media platforms by young people [6,11]. As social media preferences evolve, a continued understanding of how to reach youth is critical to eliciting information on health behavior.

Targeted paid advertising on social media platforms is a useful way to increase the reach and diversity of young study participants. Existing literature describes the utility of Facebook in youth recruitment [1,2,10,12-16], but there is limited understanding about the role of other (more popular) social media platforms, including Instagram and Snapchat. This paper outlines a paid advertising approach using Instagram, Snapchat, and Facebook to reach and enroll 2 cross-sectional samples of youth potentially exposed to a statewide marijuana prevention campaign. The objective of this study was to compare recruitment metrics (ie, impressions, link clicks, conversions, and recruitment cost per survey) across Instagram, Snapchat, and Facebook for surveys documenting youth knowledge, attitudes, and behaviors related to retail marijuana in Colorado. In addition, this study assessed the feasibility of using Instagram and Snapchat, in addition to Facebook, for youth study recruitment.

Methods

Overview

From December 9 to December 29, 2017, and from May 4 to June 1, 2018, the evaluation team used a social media recruitment strategy to obtain 2 cross-sectional samples of youth in Colorado. The strategy utilized paid, geographically targeted ads on Instagram, Snapchat, and Facebook to encourage the completion of a self-administered, Web-based survey. Ad images contained virtual links that prompted youth to complete an anonymous survey using Qualtrics software (Qualtrics, Provo, UT), hosted by The University of Colorado [17]. A total of 8 US $50 gift cards (ie, Target, Amazon, Spotify, and VISA) were raffled weekly to incentivize survey completion. The study was classified as program evaluation and was considered exempt from institutional review board approval; all methods adhered to ethical human subjects' research protections.

Eligibility Criteria

Eligibility criteria included youth (1) aged 13 to 20 years, (2) currently living in Colorado, and (3) who completed a Web-based survey.

Ad Design

Ads for Instagram and Facebook were maintained using Ads Manager, a Web-based ad campaign creation and management tool [18]. Snapchat ads were developed and monitored using Snap Ads [19]. Each social media platform required specifications on ad delivery, ad content, design language, targeted audience, and dates of deployment (Table 1). Social media advertisement designs delineated by modality are available in Multimedia Appendix 1.

Instagram and Facebook ads utilized carousel images, headings, caption text, and hyperlinks to promote link clicks to enroll in the Web-based survey. Youth advisors from stakeholder groups provided feedback to the images, headings, and hashtags to ensure relevant and engaging content for the target population. Similarly, using a Snap Ads design template, the ad comprised a headline, animated images, and a call to action (ie, swipe) to promote participation.

Each social media platform reviewed ads before deployment. Ads underwent 3 to 5 days' worth of appeals and iterations to meet each social media platform's policies [18,19]. Snap Ads rejected any ads that included *Marijuana* or *Weed*. In addition, Ads Manager required multiple appeals to ensure the ads were not promoting illegal substances. The evaluation team addressed the concerns by describing the intent of the ads and removing sensitive language (ie, "weed" or "marijuana").

Table 1. Social media recruitment ad summary for cross-sectional Web-based surveys.

Platform	Dates	Image	Headline	Subheading	Text	Target audience	Target location
Snapchat	12/14-12/23; 05/09-05/18; 05/29-06/01	Animated image	Be Blunt	Colorado School of Public Health	"Share your thoughts on substance use for a chance to win $50."; "Participate anonymously"	Youth, 13-20 years old; Gender: All	Colorado, United States
Instagram	12/09-12/28; 05/04-05/29	Images (2)	Winner gets $50; Jump into the Discussion	None	"Be blunt: give us your thoughts on marijuana for a chance to #win a $50 gift card. Click here to participate anonymously. #colorado #teen #poll #survey."	Youth, 13-20 years old; Gender: All	Colorado, United States
Facebook	12/09-12/28; 05/04-05/29	Image carousel (2)	Marijuana and Teens	Click to take an anonymous survey	"Give us your word on weed for the chance to #win a $50 gift card. Click here to take an anonymous survey now. #colorado"	Youth, 13-20 years old, from select counties; Gender: All	Alamosa (+30 miles), Colorado Springs (+30 miles), Denver (+30 miles), Fort Morgan (+30 miles), Grand Junction (+30 miles), Greeley (+30 miles), Pueblo (+30 miles), South Fork (+30 miles), Sterling (+30 miles), Vail Rd, Vail (+30 miles); Colorado, United States

Ad Placement

Ads Manager and Snap Ads defined ad placement using ad sets. Ad sets determine the reach of the ads, specifically the location, age group, genders, and budget of the recruitment ad campaign. Ads ran during specified date ranges, targeting youth (aged 13-20 years) in Colorado (Table 1). To narrow the scope of the Facebook campaign, specific counties were targeted using a 30-mile radius for harder-to-reach rural communities.

On Facebook, ads were displayed as News Feed ads (ie, ads embedded in the dynamic news field central column) and right column ads (ie, displayed in the static column on the right side of the screen). Youth accessing Facebook on their desktop computers viewed both ads, whereas mobile users saw News Feed ads only. On Instagram, images were displayed in a linear format, labeled as a sponsored ad within the user's personal Instagram feed. On Snapchat, images were displayed using the Stories feature; links were introduced to end users, when browsing local stories, and the survey was accessed by *swiping up*.

Social Media Ad Costs

Advertising costs differed among social media platforms on the basis of predetermined budgets and payment methods. The evaluation team allocated lifetime and daily budgets per ad to set maximum dollar amounts spent, also referred to as bids. Purchased through an auction basis, bids charge was based on link clicks (ie, pay per click), impressions, or actions during the advertising window. Advertisers compete for ad placements using a bidding process. Higher bid amounts improve the campaigns' chances of securing more impressions. Snap Ads and Ads Manager monitored these transactions with their respective Web-based dashboards to improve ad delivery efficiency and optimize campaign delivery [20].

Each cross-sectional survey maintained a total budget of US $1000. The evaluation team delineated daily and lifetime budgets throughout the campaign: Snapchat (US $50/day; US $300/lifetime), Instagram (US $13/day; US $350/lifetime), and Facebook (US $13/day; US $350/lifetime). During cross-sectional survey #2, a lack of impressions in Facebook ads allowed the team to reallocate dollars to Snapchat's lifetime budget, a higher impression-generating platform, to maximize response rate. This adjustment increased Snapchat's lifetime budget to US $670 and decreased Facebook's lifetime budget to US $25. Excluding incentive budgets, the cost per completed survey (across all social media platforms) was US $1.62 for initial recruitment periods, and for the subsequent recruitment periods the cost per respondent was US $4.76.

Analysis

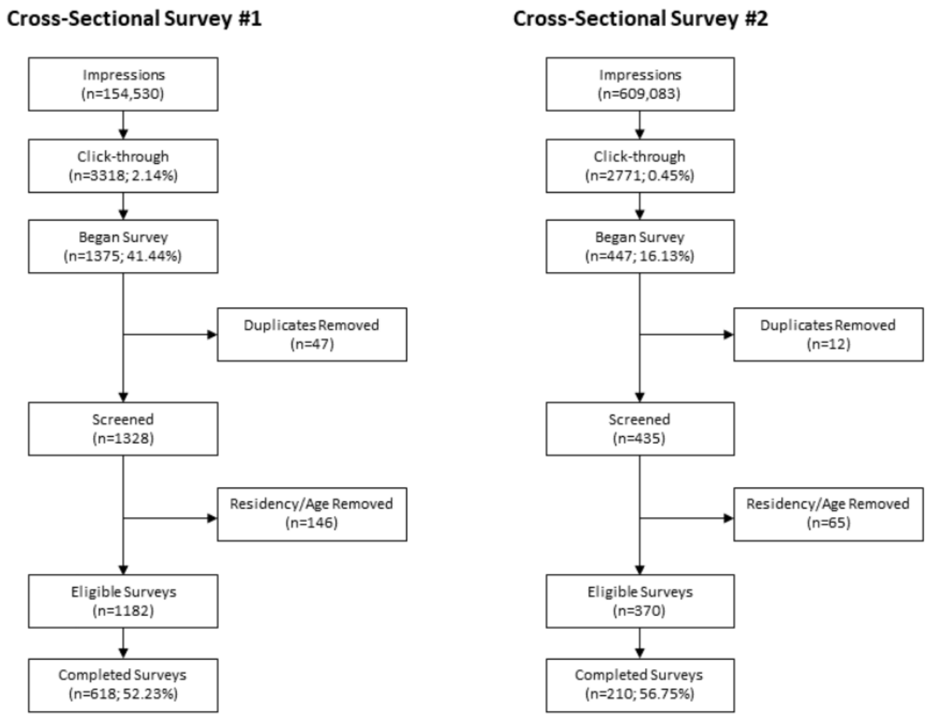
The dashboards for Ads Manager and Snap Ads presented recruitment outcomes for analysis. Measures included the following: (1) *impressions*, which describe the number of which ads were displayed, as indicated by the ad set target population, and this included whether the ad was clicked or not; (2) *link clicks*, the number of participant clicks to the ads' desired destination (ie, Qualtrics survey); (3) *conversion rates*, which indicate the proportion of people exposed to the image (ie, impressions) who clicked on it (ie, link clicks); (4) standard *response rate* formulas, which calculate the screening, refusal, and completion rates for the survey based on eligible participants; (5) *recruitment cost-per-survey*, which is calculated by dividing ad costs by the total number of completed surveys.

The analytic sample excluded youth who indicated their age was younger than 13 or older than 20, and the sample excluded those who did not provide a valid Colorado zip code. To ensure participant veracity and uniqueness, the team conducted consistency checks (ie, asking age at a point in the survey and month and year of birth at another) and reviewed the internet protocol (IP) address for all participants. When the team found inconsistencies in reported age and duplicate IP addresses, the analysts removed participants from the sample. In addition, the final analytic sample removed all partially completed surveys. The team compiled and cleaned the exported data from Ads Manager, Snap Ads, and Qualtrics. Recruitment measures were calculated by ad delivery dates. Completion rates were determined on the basis of the number of eligible surveys completed via Qualtrics.

Results

For cross-sectional survey #1, 618 participants were retained as eligible on the basis of age, residency, and survey completion (Figure 1). This represents a 52.28% (618/1182) response rate. For cross-sectional survey #2, the screening process retained 210 participants, representing a 57.8% (210/370) survey response rate.

Figure 1. Recruitment eligibility and screening process results.



In both surveys, older youth aged 17 to 20 years represented over half of the sample and illustrated similar racial and ethnic demographics within the region [21]. For cross-sectional survey #1, among eligible respondents (n=618), 274 (44.3%, 274/618) identified as being 13 to 16 years in age, and 344 (55.7%, 344/618) as being 17 to 20 years in age. Respondents identified as male (53.5%) or female (43.5%). Respondents identified as Hispanic/Latino (16.2%), American Indian/Native American (4.5%), Native Hawaiian/Other Pacific Islander (0.8%), Asian (2.3%), white (86.6%), and black/African American (1.9%). The majority of the sample identified as heterosexual (75.4%). Among eligible respondents in the second cross-sectional survey (n=210), 91 (43.3%, 91/210) identified as being 13 to 16 years in age, and 119 (56.7%, 119/210) as being 17 to 20 years in age. Primarily, respondents identified as male (52.9%) or female (42.4%). Respondents identified as Hispanic/Latino 39 (18.6%), American Indian/Native American 3.8%), Native Hawaiian/Other Pacific Islander (4.3%), Asian (4.3%), white (87.1%), and black/African American (3.8%). The majority of the sample identified as heterosexual (69.5%).

Recruitment metrics for both cross-sectional surveys included impressions, link clicks, conversion rates, advertising costs, and costs per link click (Tables 2 and 3). For both data collection periods, Snapchat generated the most impressions and link clicks among the social media platforms.

Table 2. Summary of social media recruitment metrics (cross-sectional survey #1).

Modality	Dates	Impressions	Link clicks	Conversion rate (%)	Ad costs (US $)	Cost per link click (US $)
Instagram	12/09-12/28	2222	803	36.13	267.26	0.33
Snapchat	12/14-12/23	114,200	1600	1.40	400.00	0.25
Facebook	12/09-12/29	38,108	915	2.40	274.56	0.30
Total	—[a]	154,530	3318	—	941.82	0.28

[a] Data not applicable.

Table 3. Summary of social media recruitment metrics (cross-sectional survey #2).

Modality	Dates	Impressions	Link clicks	Conversion rate (%)	Ad costs (US $)	Cost per link click (US $)
Instagram	05/04-05/29	98,982	864	0.87	300.00	0.34
Snapchat	05/09-05/18; 05/29-06/01	504,700	1818	0.36	674.00	0.37
Facebook	05/04-05/29	5401	89	1.64	25.44	0.28
Total	—[a]	609,083	2771	—	999.44	0.36

[a]Data not applicable.

In cross-sectional survey #1, Snapchat and Facebook had a higher number of impressions and link clicks than Instagram; however, Instagram outperformed Snapchat and Facebook in conversion rates. Instagram's high conversion rate (ie, 36%) remained an outlier. In cross-sectional survey #2, Instagram and Snapchat had a higher number of impressions and link clicks than Facebook. Although Instagram and Snapchat conversion rates were lower in the second survey, Facebook conversion rate was consistent in both the first and second survey. It is important to note that for the second survey, the team decreased the budget spending for Facebook ads and increased the budget for Instagram and Snapchat ads. Response rates were lower in subsequent recruitment periods. Instagram and Snapchat had a marked increase in the number of impressions and a moderate increase in number of link clicks in the second survey. Although Snapchat impressions were the highest among the social media platforms, costs per link click were the most expensive for cross-sectional survey #2.

Discussion

Principal Findings

This paper outlined a paid advertising recruitment strategy, comparing recruitment across Instagram, Snapchat, and Facebook for surveys documenting youth knowledge, attitudes, and behaviors related to retail marijuana in Colorado. Although retail marijuana is legalized in Colorado, it remains illegal for those under 21. Obtaining a mechanism to engage with youth and document marijuana knowledge, attitudes, and behavior is critical, particularly where retail marijuana use is legal for older populations [22]. Social media platforms are useful mechanisms to reach youth and understand their illicit behaviors, given broad reach and the opportunity to share information anonymously [23]. As youth move away from older social media platforms and adopt the use of newer versions on the Web, additional research is needed to determine if Web-based recruitment strategies are equally effective across diverse social media platforms. In health-related studies that have incorporated social media platforms (ie, MySpace, Facebook, Instagram, and Twitter) for recruitment, Facebook proves the most successful platform, compared with MySpace, Instagram, and Twitter, across age groups [5,14]. Both Instagram and Snapchat are the more recent social media platforms that should also be further examined for recruitment capabilities.

Thus, this study expanded on current evidence-based social media recruitment practices and included social media platforms that are currently more popular and relevant to youth (ie, Instagram and Snapchat) [5,24-26]. Differences were observed across platforms in youth recruitment in the 2 Web-based cross-sectional surveys; demonstrating that higher than typical numbers of youth who were exposed to our Web-based ads clicked on them [27]. The second survey had a high response rate for Web-based survey research, which typically ranges between 10% and 15% [28], but it ultimately yielded a lower response rate compared with the first survey [28].

The Ads Manager dashboard displayed few impressions on Facebook, which the evaluation team inferred was a reflection of declining interest in Facebook ads; however, Facebook still presented a feasible way to reach some younger adults (ie, 18-20 years old) for each survey. Such feasibility has been shown with a similar age groups (ie, 18-24 years old) [5]. It is possible that the reduced budget for Facebook ads for the second survey may have contributed to a lower number of impressions and link clicks. Subpopulations or hard-to-reach populations may require a larger Facebook ad budget and more time for ads to run to get a higher frequency yield [5]. In addition, it could be inferred that ads in regional counties, with high participation in the first survey, deterred participation in the second. Youth may have ignored an ad after having seen it for a previous survey. It is also possible that Facebook ads were ignored for the second survey if youth had already seen the ads in their Instagram and Snapchat feeds before they saw it on Facebook.

Instagram and Snapchat had a marked increase in the number of impressions and a moderate increase in number of link clicks in the second survey. This could have resulted from the increased ads budget, which increased ad visibility across the 2 platforms. Although a specific cost-effectiveness assessment is beyond the scope of this paper, the cost-per-survey comparison was generally consistent with what is observed in other studies [2].

Other Web-based health-related campaigns [5,23,24,29,30] demonstrated similar success in recruiting youth and young adults through Instagram and Facebook [13,22,31], although most cross-sectional studies used Facebook for recruitment [32]. In the first cross-sectional survey, the social media ads ran for 20 days and showed a total of 154,530 impressions and 3318 link clicks, across Instagram, Snapchat, and Facebook, and 618 completed surveys. In the second cross-sectional survey, social media ads ran for 28 days and showed a total of 609,083 impressions and 2771 link clicks, across the same 3 platforms, and 210 completed surveys. A study using Facebook ads only for 48 days produced a total of 144,635 impressions, 2129 link clicks, and 26 completed surveys among an adult multiethnic population [29]. A study using Facebook and Instagram ads for 1 week to recruit and reach young adults at high risk for smoking reached 324,959 individual users and resulted in 7249 link clicks, 6661 screener completions, and 1709/3357 (50.90%, eligible) completed surveys [5]. These findings suggest that recruitment and reach through a single social media platform might not yield targeted enrollment and ads using multiple platforms may be more advantageous. Other studies using social media platforms for recruitment of younger populations have instituted the use of multiple platforms (ie, Facebook, Instagram, and Twitter) [5,25] to reach target enrollment. Some studies have combined different recruitment methods to include social media, interceptive (face to face), and postal recruitment [5,31]. Though similar studies have also paid cost per click, this type of recruitment is shown to be cost effective than traditional methods [5,13,31].

This study showed the feasibility of incorporating Instagram and Snapchat to a traditional Facebook paid advertising recruitment strategy. Both Instagram and Snapchat required similar elements of ad content, design, placement, and budget considerations. Instagram utilized the same Web-based platform as Facebook (ie, Ads Manager) and streamlined logistics associated with setting up and monitoring the 2 campaigns. Not only is Instagram feasible for recruitment but it also has been associated with youth retention in a Web-based mental health and substance use interventions [26]. Thus, the initial draw to a study through social media may maintain interest in completing Web-based interventions and surveys. Although Snapchat ads required artistic animation, Snap Ads' design templates offered user-friendly ways to create ads even for researchers lacking graphic design skills. Both Instagram and Snapchat followed similar advertising policies, which aligned with Facebook. This allowed researchers to prepare for the approval and appeal process accordingly. Finally, the differences in advertising costs across platforms were negligible. Although more robust comparisons of recruitment strategies should be investigated, findings suggest incorporating Instagram and Snapchat as an accessible and practical addition to recruiting youth on the Web for health studies.

Limitations

Study limitations exist despite successful recruitment using social media ads. The recruitment evaluation design lacked a comparison recruitment process using in-person recruitment methods. In addition, the cross-sectional surveys gathered convenience samples; therefore, findings are not generalizable to the population of 13- to 20-year-old Coloradans. Understanding knowledge, attitudes, and behaviors of youth younger than 13 years old is critical for preventing retail marijuana intentions and use. However, because of social media advertising policies, sampling youth younger than 13 years old was not permitted. The findings only illustrate descriptive results related to social media recruitment methods for youth aged 13 to 20 years. Altering the budget in the second cross-sectional survey created a potential bias for Snapchat and Instagram success.

Although it is an unsupported hypothesis, the research team considered how external factors (eg, school holidays, final exams, and weather) may have contributed to responses across the data collection period. Such contextual factors should be considered in future social media recruitment approaches. In addition, all ads used the same images and content. Individuals who completed the survey before might have thought they could not complete it a second time. In addition, because of the anonymous survey link used in ads, there is limited understanding of which social media platform yielded the most completed surveys and which were most cost-effective. However, it would seem that the approach is more economically viable than hiring staff to recruit youth, travelling to specific recruitment locations, and spending time administering in-person surveys.

There are few methods in the scientific literature using popular social media platforms for youth recruitment, such as Instagram and Snapchat [25,33]. Although this study explored the use of modern social media platforms to reach young people, additional research is needed as technology and internet use trends continue to change.

Strengths

This study highlighted several strengths to the health sciences literature. First, limited scholarship describes the use of Instagram and Snapchat paid advertising for youth study recruitment. This offered a significant contribution to understanding how to utilize diverse social media platforms for health-related research and evaluation. The study demonstrates the usefulness of social media recruitment in health-related research, particularly in its ability to reduce data collection time and provide rapid results about emerging public health problems, such as illegal marijuana use in states where retail marijuana sell is legal. Traditional recruitment methods may take months, thereby adding to the time it takes to collect data and disseminate results. Innovative use of Snapchat as an avenue for recruitment showed high impressions, suggesting a noteworthy method to reach young people. Second, this evaluation offered unique contributions on how social media campaigns can use multiple platforms to maximize recruitment, reach, and engagement. Third, the study contributed to the literature by describing low-cost approaches for reaching young people using paid social media advertising [5,29,31].

Conclusions

Social media platforms can play a significant role in reaching young people for research and evaluation of youth-focused programs. These platforms are appealing to younger populations, allowing for easier design and tailoring to recruit specific populations [5,34]. The findings represent a feasible and modern approach to recruit cross-sectional samples using social media platforms beyond Facebook. A social media recruitment strategy that includes platforms most used by youth (eg, Instagram and Snapchat) can enhance Facebook recruitment approaches. Although no social media platform is a solution to study recruitment, diversifying recruitment across multiple platforms may increase response rates and improve researchers' ability to reach youth in an efficient manner. The use of multiple platforms may also broaden the reach for subpopulations and hard-to-reach youth populations [31] and increase sample representativeness [25]. As the use of Facebook declines among youth, alternative, more popular social media platforms, such as Instagram and Snapchat, provide promise for health research and evaluation recruitment practices.

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Authors' Contributions

SB conceptualized and designed the study, supervised data collection, and critically reviewed the manuscript for important intellectual content. KF carried out the initial analyses, drafted the initial manuscript, reviewed, and revised the manuscript. TA cowrote discussion section. TA, TD, KC, and JN reviewed and revised the manuscript. All authors approved the final manuscript as submitted and agree to be accountable for all aspects of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Social media advertisement designs delineated by modality.
[PDF File (Adobe PDF File)276 KB - publichealth_v5i4e14080_app1.pdf]

References

1. Amon KL, Campbell AJ, Hawke C, Steinbeck K. Facebook as a recruitment tool for adolescent health research: a systematic review. Acad Pediatr 2014;14(5):439-47.e4. [doi: 10.1016/j.acap.2014.05.049] [Medline: 25169155]
2. Topolovec-Vranic J, Natarajan K. The use of social media in recruitment for medical research studies: a scoping review. J Med Internet Res 2016 Nov 7;18(11):e286 [FREE Full text] [doi: 10.2196/jmir.5698] [Medline: 27821383]
3. Park BK, Calamaro C. A systematic review of social networking sites: innovative platforms for health research targeting adolescents and young adults. J Nurs Scholarsh 2013 Sep;45(3):256-264. [doi: 10.1111/jnu.12032] [Medline: 23676115]
4. Ryan GS. Online social networks for patient involvement and recruitment in clinical research. Nurse Res 2013;21(1):35-39. [doi: 10.7748/nr2013.09.21.1.35.e302] [Medline: 24004430]
5. Guillory J, Wiant KF, Farrelly M, Fiacco L, Alam I, Hoffman L, et al. Recruiting hard-to-reach populations for survey research: using Facebook and Instagram advertisements and in-person intercept in LGBT bars and nightclubs to recruit LGBT young adults. J Med Internet Res 2018 Jun 18;20(6):e197 [FREE Full text] [doi: 10.2196/jmir.9461] [Medline: 29914861]
6. Pew Research Center. 2019. Social Media Fact Sheet URL: http://www.pewinternet.org/fact-sheet/social-media/ [accessed 2019-06-01] [WebCite Cache ID 76yDNKNyG]
7. Rait MA, Prochaska JJ, Rubinstein ML. Recruitment of adolescents for a smoking study: use of traditional strategies and social media. Transl Behav Med 2015 Sep;5(3):254-259 [FREE Full text] [doi: 10.1007/s13142-015-0312-5] [Medline: 26327930]
8. Fazzino TL, Rose GL, Pollack SM, Helzer JE. Recruiting US and Canadian college students via social media for participation in a web-based brief intervention study. J Stud Alcohol Drugs 2015 Jan;76(1):127-132 [FREE Full text] [doi: 10.15288/jsad.76.1.127] [Medline: 25486401]
9. Prescott T, Phillips II G, Bull S, Parsons J, Mustanski B, Ybarra M. F1000 Research. 2015. Reaching Adolescent Gay, Bisexual, and Queer Men Online: Development and Refinement of a National Recruitment Strategy URL: https://f1000research.com/slides/4-1170 [accessed 2018-08-26]
10. Akers L, Gordon JS. Using Facebook for large-scale online randomized clinical trial recruitment: effective advertising strategies. J Med Internet Res 2018 Nov 8;20(11):e290 [FREE Full text] [doi: 10.2196/jmir.9372] [Medline: 30409765]
11. The US Department of Health and Human Services. 2016. Teens' Social Media Use: How They Connect & What It Means for Health URL: https://www.hhs.gov/ash/oah/news/e-updates/february-2016-teens-social-media-use/index.html [accessed 2019-06-01] [WebCite Cache ID 76yDAZXiK]
12. Ramo DE, Prochaska JJ. Broad reach and targeted recruitment using Facebook for an online survey of young adult substance use. J Med Internet Res 2012 Feb 23;14(1):e28 [FREE Full text] [doi: 10.2196/jmir.1878] [Medline: 22360969]
13. Chu JL, Snider CE. Use of a social networking web site for recruiting Canadian youth for medical research. J Adolesc Health 2013 Jun;52(6):792-794. [doi: 10.1016/j.jadohealth.2012.12.002] [Medline: 23352727]
14. Whitaker C, Stevelink S, Fear N. The use of Facebook in recruiting participants for health research purposes: a systematic review. J Med Internet Res 2017 Aug 28;19(8):e290 [FREE Full text] [doi: 10.2196/jmir.7071] [Medline: 28851679]

15. Valdez RS, Guterbock TM, Thompson MJ, Reilly JD, Menefee HK, Bennici MS, et al. Beyond traditional advertisements: leveraging Facebook's social structures for research recruitment. J Med Internet Res 2014 Oct 27;16(10):e243 [FREE Full text] [doi: 10.2196/jmir.3786] [Medline: 25348050]
16. Reiter PL, Katz ML, Bauermeister JA, Shoben AB, Paskett ED, McRee A. Recruiting young gay and bisexual men for a human papillomavirus vaccination intervention through social media: the effects of advertisement content. JMIR Public Health Surveill 2017 Jun 2;3(2):e33 [FREE Full text] [doi: 10.2196/publichealth.7545] [Medline: 28576758]
17. Qualtrics. 2005. URL: http://www.qualtrics.com [accessed 2019-06-01] [WebCite Cache ID 76yCgF8sV]
18. Facebook. 2018. Facebook Advertising Guidelines URL: https://www.facebook.com/policies/ads/ [accessed 2019-06-01]
19. Snap. 2018. Snap Advertising Policies URL: https://www.snap.com/en-US/ad-policies/ [accessed 2019-03-18] [WebCite Cache ID 76yDZSyCk]
20. Facebook. 2018. Facebook Ads: Reach Out to Future Customers and Fans URL: https://www.facebook.com/business/ads#basics [accessed 2019-06-01]
21. United States Census Bureau. 2018. QuickFacts: Colorado URL: https://www.census.gov/quickfacts/CO [accessed 2019-06-01]
22. Berg CJ, Buller DB, Schauer GL, Windle M, Stratton E, Kegler MC. Rules regarding marijuana and its use in personal residences: findings from marijuana users and nonusers recruited through social media. J Environ Public Health 2015;2015:476017 [FREE Full text] [doi: 10.1155/2015/476017] [Medline: 26576162]
23. Dalessandro C. Recruitment tools for reaching millennials: the digital difference. Int J Qual Methods 2018 May 14;17(1):160940691877444. [doi: 10.1177/1609406918774446]
24. Pepper JK, Farrelly MC, Watson KA. Adolescents' understanding and use of nicotine in e-cigarettes. Addict Behav 2018 Jul;82:109-113. [doi: 10.1016/j.addbeh.2018.02.015] [Medline: 29518664]
25. Gu LL, Skierkowski D, Florin P, Friend K, Ye Y. Facebook, Twitter, & QR codes: an exploratory trial examining the feasibility of social media mechanisms for sample recruitment. Comput Human Behav 2016 Jul;60:86-96. [doi: 10.1016/j.chb.2016.02.006]
26. Lattie EG, Ho J, Sargent E, Tomasino KN, Smith JD, Brown CH, et al. Teens engaged in collaborative health: the feasibility and acceptability of an online skill-building intervention for adolescents at risk for depression. Internet Interv 2017 Jun;8:15-26 [FREE Full text] [doi: 10.1016/j.invent.2017.02.003] [Medline: 28584734]
27. Kim L. Search Engine Land. 2014. 7 Conversion Rate Truths That Will Change Your Landing Page Strategy URL: https://searchengineland.com/7-conversion-rate-truths-will-change-landing-page-optimization-strategy-191083 [accessed 2019-06-01]
28. Wright KB. Researching internet - based populations: advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. J Comput-Mediat Commun 2005;10(3):-. [doi: 10.1111/j.1083-6101.2005.tb00259.x]
29. Tsai W, Zavala D, Gomez S. Using the Facebook advertisement platform to recruit Chinese, Korean, and Latinx cancer survivors for psychosocial research: web-based survey study. J Med Internet Res 2019 Jan 10;21(1):e11571 [FREE Full text] [doi: 10.2196/11571] [Medline: 30632966]
30. Lattie EG, Kaiser SM, Alam N, Tomasino KN, Sargent E, Rubanovich CK, et al. A practical do-it-yourself recruitment framework for concurrent ehealth clinical trials: identification of efficient and cost-effective methods for decision making (part 2). J Med Internet Res 2018 Nov 29;20(11):e11050 [FREE Full text] [doi: 10.2196/11050] [Medline: 30497997]
31. Batterham PJ. Recruitment of mental health survey participants using internet advertising: content, characteristics and cost effectiveness. Int J Methods Psychiatr Res 2014 Jun;23(2):184-191. [doi: 10.1002/mpr.1421] [Medline: 24615785]
32. Thornton L, Batterham PJ, Fassnacht DB, Kay-Lambkin F, Calear AL, Hunt S. Recruiting for health, medical or psychosocial research using Facebook: systematic review. Internet Interv 2016 May;4:72-81 [FREE Full text] [doi: 10.1016/j.invent.2016.02.001] [Medline: 30135792]
33. Gelinas L, Pierce R, Winkler S, Cohen IG, Lynch HF, Bierer BE. Using social media as a research recruitment tool: ethical issues and recommendations. Am J Bioeth 2017 Mar;17(3):3-14 [FREE Full text] [doi: 10.1080/15265161.2016.1276644] [Medline: 28207365]
34. Parkinson S, Bromfield L. Recruiting young adults to child maltreatment research through Facebook: a feasibility study. Child Abuse Negl 2013 Sep;37(9):716-720. [doi: 10.1016/j.chiabu.2013.04.009] [Medline: 23768931]

Abbreviations

IP: internet protocol

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Original Paper

Social Media Use and HIV Screening Uptake Among Deaf Adults in the United States: Cross-Sectional Survey Study

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Abstract

Background: About 46% of US adults obtain recommended HIV screening at least once during their lifetime. There is little knowledge of screening rates among deaf and hard-of-hearing adults who primarily use American Sign Language (ASL), or of social media as a potentially efficacious route for HIV prevention outreach, despite lower HIV/AIDS-specific health literacy and potentially higher HIV seropositivity rates than hearing peers.

Objective: We investigated both the likelihood of HIV screening uptake among deaf adults in the past year and over one year ago, and the relationship between social media use and HIV screening uptake among deaf adult ASL users.

Methods: The Health Information National Trends Survey in ASL was administered to 1340 deaf US adults between 2015-2018. Modified Poisson with robust standard errors was used to assess the relationship between social media usage as a predictor and HIV screening as an outcome (screened more than one year ago, screened within the past year, and never been screened), after adjusting for sociodemographics and sexually transmitted disease (STD) covariates.

Results: The estimated lifetime prevalence of HIV screening uptake among our sample was 54% (719/1340), with 32% (429/1340) in the past year. Being of younger age, male gender, black, lesbian, gay, bisexual, or queer, or having some college education or a prior STD were associated with HIV screening uptake. Adjusting for correlates, social media use was significantly associated with HIV screening in the past year, compared to either lifetime or never.

Conclusions: Screening falls well short of universal screening targets, with gaps among heterosexual, female, Caucasian, or older deaf adults. HIV screening outreach may not be effective because of technological or linguistic inaccessibility, rendering ASL users an underrecognized minority group. However, social media is still a powerful tool, particularly among younger deaf adults at risk for HIV.

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KEYWORDS
HIV; sexually transmitted disease; sexually transmitted infection; deaf; sign language; social media; internet

Introduction

The United States Department of Health and Human Services and the Centers for Disease Control and Prevention (CDC) prioritize HIV screening tests as a cornerstone of the national HIV prevention strategy [1,2]. The United States Preventive Services Task Force (USPSTF) recommends all adults 15-65 be screened for HIV at least once, with increased frequency of screening among men who have sex with men (MSM), injection drug users, and high-prevalence settings, including sexually transmitted disease (STD) clinics, homeless shelters, tuberculosis clinics, and correctional settings [3]. However, data from the Behavioral Risk Factor Surveillance System (BRFSS) shows that only 36.1% of all adults, and 46% of adults ages 18-64, have reported ever being tested for HIV [4,5]. Despite the USPSTF recommendation, many physicians screen based on risk stratification or by patient request [6-8]. Factors found to increase the likelihood that a person receives an HIV test include: being MSM [9,10], a young adult [11], black [10,12], having recent STD testing or an STD diagnosis [13], and having access to HIV screening [13]. Gender has been found to indicate both higher and lower likelihood of receiving HIV screening [9-11,13].

Scant data exists on HIV screening uptake among deaf American Sign Language (ASL) users, who represent a medically underrepresented linguistic and cultural group [14]. One ASL adaptation of the BRFSS survey given to 282 (mean age 44.6 years) deaf adults in Rochester, New York, reported a lifetime screening rate of 47.5% in 2008, though this sample reflected primarily Caucasian, higher-educated, deaf adults and did not include diverse members from other regions in the United States [15].

One strategy for increasing HIV screening uptake may be implemented through social networking sites. People increasingly use social networking sites (eg, Facebook, Twitter) and mobile networking sites (eg, Grindr, Tinder) as avenues for sexual health information [16,17]. Several studies reported that adolescents and young adults were most likely to use social media or the internet in general [17], including using them to seek health information [16,18]. One systematic review of studies on communication about HIV prevention and treatment via internet platforms identified online outreach benefits, which included: increased access to information, increased communication among users, and between consumers and professionals, anonymity, community, and geographical reach [19].

Perhaps because of these benefits, online health information seeking is particularly prevalent among gay and bisexual men compared to lesbian or bisexual women and heterosexual peers [20]. Higher rates of internet use were associated with increased screening among MSM in a 2014 cross-sectional study of 9613 MSM across 20 US cities [17]. Social media use was also linked to increased HIV screening, although to our knowledge all currently published studies target adolescents or MSM and transgender women adults. Among 42 black MSM aged 18-30 in Los Angeles, a Facebook-mediated video intervention resulted in seven times higher odds of subsequent HIV screening over six weeks postintervention [21]. Another study found that MSM individuals who discussed HIV prevention and treatment in a closed Facebook group requested an HIV test kit more often compared to MSM individuals who did not take part in online discussion [22]. Conversely, at least one study in Australia found that never-tested MSM were more likely to spend time on social networking websites [23].

Recent studies support that deaf adults use the Internet as readily as their peers. In a study of 515 deaf adults, those who engaged in social media networking were more likely to discuss health issues with their healthcare providers via electronic platforms compared to nonusers of social media sites, potentially reducing communication barriers that contribute to health disparities [24]. Similarly, deaf gay, bisexual, and queer (GBQ) men who connected with lesbian, gay, bisexual, transgender, and queer (LGBTQ) peers online were more likely to be aware of preexposure prophylaxis (PrEP) compared to deaf GBQ men who did not have online connections [25,26]. Belief in PrEP's effectiveness was also associated with discussing LGBTQ issues online or through social media (odds ratio [OR] 3.12; 95% CI 1.12-8.75) [26].

To better understand the need for tailored and accessible HIV prevention and treatment services in the deaf community, this study utilized data from a US sample of deaf ASL users to investigate: (1) the sample rate of HIV screening uptake; and (2) the association of HIV screening uptake with social media use after adjusting for correlates.

Methods

Data Source

Data for this study was drawn from a large Health Information National Trends Survey in American Sign Language (HINTS-ASL) dataset [27]. This included HIV or STD items which were administered to US deaf adults from October 2015 to March 2016, and October 2016 to May 2018. Prior to survey administration, all items were translated into ASL, tested through cognitive interviews with deaf adults, and the final translations were captured on film [27]. All participants were either born or became deaf before the age of 13.

Survey Items

For the purposes of the current study, sexual orientation was assessed with the question, "What is your sexual orientation?" with response options of gay, lesbian, heterosexual, bisexual, asexual, queer, and other, please specify. Gender was assessed with the question, "What gender do you identify as now?" with response options of male, female, and nonbinary or genderqueer.

STD history was assessed with the question, "Have you ever had a sexually transmitted disease? IF YES, once or more than once?" Response options were once, more than once, and never. A question about HIV screening was asked as follows: "When was the last time that you were tested for HIV?" Response options were less than 3 months ago, in the past year, more than 1 year ago, and I have never been tested for HIV. A binary response was used for the social media question: "In the last 12 months, have you used the Internet to visit a social networking site, such as Facebook or Twitter?" Finally, regular healthcare provider was measured using the binary question: "Not including psychiatrists and other mental health professionals, is there a particular doctor, nurse, or other health professional that you see most often?"

Procedure

Following Institutional Review Board approval by Gallaudet University, research staff recruited deaf ASL users throughout the United States. Recruitment methods included snowball sampling through personal networks [28], distribution of flyers, and advertisements on deaf-centered organizations' websites and electronic newsletters. Communication between the research staff and participants occurred through accessible channels, including mail, email, social media, and video chat programs. Only those who self-reported using ASL as their primary language were included because this group was identified as a medically underserved group [29-31], while exclusion criteria included being under the age of 18 years old or having unilateral hearing loss. Deaf lesbian, gay, bisexual, and queer (LGBQ) individuals were oversampled to create a high-powered sample.

After the participant viewed the information in ASL and English online, the participant was directed to a page where they could choose to provide consent to participate or decline. Following consent, the fully accessible ASL-English online survey took approximately one hour to complete. Each participant received a $25 gift card for participating in the study. If the participant met with the research staff remotely, ASL instructions were given through a videoconferencing method and a URL survey link was emailed to the participant. The research staff remained visible to the participant through video conferencing and were readily available to answer questions or troubleshoot as the participant progressed through the consent document and survey. For on-site survey administration, the research staff stayed in the interview room with the participant. If the participant did not feel comfortable watching the ASL question as signed on the pre-recorded video, a research staff repeated and signed the question for the participant. For some participants, such as those with low vision or who did not feel comfortable with self-administration on a computer, the research staff signed all the questions and response options and recorded the participants' responses on the computer. No names or identifying information were included in the online survey and a unique identifier was used to avoid storing personal information in the same online survey dataset. The identifying information was stored in a separate database that was accessible only to the principal investigator.

Statistical Analyses

Descriptive statistics, including chi-square and two-tailed *t* tests, were used to summarize the sample characteristics. The level of significance was set at *P*<.05. Unweighted descriptive statistics, such as cross-tabulation and percentage procedures, were used to describe the sample. Responses to the HIV screening uptake question were recoded into three groups: (1) had HIV screening within 1 year; (2) had HIV screening more than 1 year ago; and (3) had never been screened. Social networking site usage was entered as the main predictor, along with other sociodemographic variables, for HIV screening uptake. To evaluate the association of social media both in the short-term (within the past one year) and long-term (lifetime) with never being tested for HIV, we ran two separate modified Poisson analyses with robust standard errors using binary outcomes: (1) never been screened (referent group) versus screened within the past year; and (2) never been screened (referent) versus screened more than one year ago. Modified Poisson regression with robust standard errors was used to calculate prevalence ratio estimates and 95% confidence intervals for HIV screening uptake with social media usage as the main predictor, adjusting for sociodemographic and sexual health indicators. The modified Poisson approach was recommended for models with binomial outcomes, and the application of robust standard errors helps rectify the overestimation for the prevalence ratio of HIV screening uptake [32].

The adjusted prevalence ratios (aPR) were used to estimate the likelihood of being screened for HIV within the past year, or more than a year ago, compared to never been screened (reference category). Covariates included age, gender, race, education, sexual orientation, and STD history. Age groups were chosen as the commonly used 18-24, 25-34, 35-49, and 50 and older, with 50 and older being the referent group. Sexual orientation was dichotomized as heterosexual and LGBQ. STD history was dichotomized as any STD history or none. Due to the low-powered sample size for the nonbinary or genderqueer group, this gender identity subgroup was not entered in the modified Poisson model. SPSS version 25.0 (IBM Corp, Armonk) was used for all analyses.

Results

A total of 1340 deaf adult ASL users (66%, 883/1340 Caucasian; 65%, 874/1340 heterosexual) who responded to the question about HIV screening met the criteria for inclusion in this analysis. Geographically, approximately 40% (536/1340) of the respondents were from the South, 30% (402/1340) were from the West, 17% (228/1340) were Midwestern, and 13% (174/1340) were from the Northeast. In our sample, the estimated lifetime prevalence of HIV screening was 54% (719/1340). Table 1 describes and compares the characteristics of 338 (25%) deaf participants who were screened for HIV within one year, 381/1340 (28%**)** deaf participants who received screening more than one year ago, and 621/1340 (46%) deaf participants who have never been screened. Table 1 includes the distribution of age, sex at birth, present gender identity, sexual orientation, and race of our diverse sample. Because STD history implied an opportunity for concurrent HIV screening, further analysis revealed 151/1322 (11%) people with a history of one STD and 65/1322 (5%) people with more than one STD.

Chi-square analyses showed significant group differences in HIV screening uptake rates for gender, age, race, education, sexual orientation, history of having an STD, and having visited a social networking site in the last 12 months. Table 2 shows the adjusted prevalence ratios of demographic and sexual health factors associated with HIV screening uptake, relative to the never screened category, from a modified Poisson with robust standard errors model.

Table 1. General sociodemographic characteristics by time of HIV screening uptake.

Variable	Overall (N=1340), n (%)	HIV screening uptake within one year (n=338), n (%)	HIV screening uptake more than one year (n=381), n (%)	Never had HIV screening (n=621), n (%)	χ^2_{df}	*P* value
Age groups					**135.57$_6$**	**.001**
18-24 years old	235 (18)	78 (33)	35 (15)	122 (52)		
25-34 years old	335 (25)	118 (34)	107 (32)	110 (33)		
35-49 years old	370 (27)	90 (24)	149 (40)	131 (35)		
>50 years old	400 (30)	52 (13)	90 (23)	258 (64)		
Birth sex					**22.60$_2$**	**.001**
Male	545 (41)	174 (32)	135 (25)	236 (43)		
Female	792 (59)	163 (21)	244 (31)	385 (49)		
Gender identity					**28.48$_4$**	**.001**
Male	544 (41)	167 (31)	134 (24)	243 (45)		
Female	763 (57)	158 (21)	232 (30)	373 (49)		
Nonbinary or genderqueer	30 (2)	12 (40)	13 (43)	5 (17)		
Missing data[a]	3 (0)	1 (33)	2 (67)	0 (0)		
Race					**24.95$_6$**	**.001**
Causcasian	883 (66)	187 (21)	261 (30)	435 (49)		
Black	130 (10)	43 (33)	42 (32)	45 (35)		
Latinx	181 (14)	60 (33)	43 (24)	78 (43)		
Other	139 (10)	44 (32)	35 (25)	60 (43)		
Missing data	7 (0)	4 (57)	0 (0)	3 (43)		
Education					**68.13$_4$**	**.001**
High school	263 (20)	54 (21)	40 (15)	169 (64)		
Some college	300 (22)	98 (33)	65 (22)	137 (46)		
College graduate	776 (58)	185 (34)	276 (36)	315 (41)		
Missing data	1 (0)	1 (100)	0 (0)	0 (0)		
Sexual Orientation					**91.56$_4$**	**.001**
Gay or lesbian	263 (20)	109 (41)	86 (33)	68 (26)		
Heterosexual	874 (65)	170 (20)	227 (26)	477 (55)		
Bisexual	181 (14)	58 (32)	63 (35)	60 (33)		
Missing data	22 (1)	1 (5)	5 (23)	16 (73)		
Have STD[b]					**103.64$_4$**	**.001**
Once	151 (11)	58 (38)	66 (44)	27 (18)		
More than once	65 (5)	32 (49)	27 (42)	6 (9)		
Never	1106 (83)	242 (22)	285 (26)	579 (52)		
Missing data	18 (1)	6 (33)	3 (17)	9 (50)		
Regular provider					**1.03$_2$**	**.60**
No	524 (39)	139 (27)	142 (27)	243 (46)		
Yes	804 (60)	198 (25)	236 (29)	370 (46)		
Missing data	12 (1)	1 (8)	3 (25)	8 (67)		

Variable	Overall (N=1340), n (%)	HIV screening uptake within one year (n=338), n (%)	HIV screening uptake more than one year (n=381), n (%)	Never had HIV screening (n=621), n (%)	χ^2_{df}	*P* value
Visited a social networking site in the last 12 months					**18.36_2**	**.001**
No	75 (6)	7 (9)	20 (27)	48 (64)		
Yes	797 (60)	231 (29)	239 (30)	327 (41)		
Missing data	468 (34)	100 (21)	122 (26)	246 (53)		

[a] Participants were permitted to skip questions that they did not wish to answer.

[b] STD: sexually transmitted disease.

Table 2. Modified Poisson with robust standard errors estimation of adjusted prevalence ratios for HIV screening status.

Demographics	Screened within one year versus never screened, aPR[a] (95% CI)	*P* value	Screened more than one year ago versus never screened, aPR (95% CI)	*P* value
Age				
18-24	1.99 (1.32-3.01)	.001	0.90 (0.61-1.33)	.60
25-34	2.25 (1.55-3.28)	<.001	1.48 (1.15-1.91)	.003
35-49	2.07 (1.40-3.05)	<.001	1.64 (1.28-2.09)	<.001
>50	Reference	—[b]	Reference	—
Gender				
Female	Reference	—	Reference	—
Male	1.25 (1.03-1.50)	.02	0.94 (0.78-1.12)	.47
Race				
Caucasian	Reference	—	Reference	—
Black	1.56 (1.18-2.05)	.002	1.33 (1.04-1.70)	.02
Latinx	1.33 (1.05-1.68)	.02	0.99 (0.76-1.29)	.92
Others	1.06 (0.83-1.35)	.67	0.91 (0.63-1.31)	.60
Education				
High School	0.85 (0.59-1.21)	.36	0.53 (0.36-0.80)	.002
Some College	1.12 (0.91-1.04)	.29	0.86 (0.68-1.10)	.23
College	Reference	—	Reference	—
Sexual orientation				
Heterosexual	Reference	—	Reference	—
LGBQ[c]	1.73 (1.41-2.12)	<.001	1.54 (1.30-1.83)	<.001
STD[d]				
Never tested	Reference	—	Reference	—
Tested	1.76 (1.49-2.08)	<.001	1.77 (1.49-2.10)	<.001
Social media use				
Never used	Reference	—	Reference	—
Used	2.01 (1.09-3.70)	.03	0.97 (0.68-1.39)	.87

[a] aPR: adjusted prevalence ratios.

[b] Not applicable.

[c] LGBQ: lesbian, gay, bisexual, and queer.

[d] STD: sexually transmitted disease.

As shown in Table 2 for adjusted prevalence ratios, respondents who were younger were incrementally more likely to have had HIV screening within one year. With female gender as a reference group, those who reported male gender had higher relative prevalence of HIV screening uptake within the past year only. Compared with those with a college degree, people who had only high school education had lower prevalence of having had been tested for HIV more than one year ago. Similarly, those who self-identified as black or Latinx were significantly more likely to have been screened in the past year than those who self-identified as Caucasian. Self-identification as LGBQ and having a positive STD history were associated with prevalent HIV screening uptake. Social media use was positively associated with HIV screening uptake within the past year, but not more than one year ago.

Discussion

Key Results

Prior research has explored demographic characteristics associated with HIV screening uptake [9-13], as well as the potential of using the internet and social networking sites as outreach avenues to increase HIV screening, particularly among high risk groups [16,19,22,33,34]. Our study expands such research to US-based deaf adults who use ASL, estimates the prevalence of HIV screening uptake in this medically underserved group, and investigates the role of social media as a predictor of HIV screening uptake among deaf adults.

Overall, our sample showed a higher lifetime prevalence of HIV screening (54%) compared to other studies drawn from the US population [4,5]. This is consistent with the 2016 BRFSS survey data that showed people with disabilities had similar or higher rates of lifetime HIV screening [15,35,36], possibly reflecting that people with disabilities, including deaf adults, often have increased frequency of healthcare visits and higher likelihood of Medicaid-sponsored health insurance coverage. However, the lifetime screening rate of 54% in our sample is modest, far from recommended universal screening targets [37], and may be influenced by our oversampling of LGBQ individuals who typically get tested more often than nonLGBQ individuals.

Screening rates within the past twelve months or one year were low in our sample (25%) yet higher than a national sample (10.1%), likely for the same reason as lifetime screening rates [38]. Such low rates are concerning, because 75% of a nationally representative probability sample of adults (n=3174) reported sexual activity in the past year in the 2015 National Survey of Sexual Health and Behavior (NSSHB) [39]. Rates of sexual activity among deaf adults appears to be like hearing peers: only 18.4% of 282 deaf adult residents in Rochester, NY, reported abstinence in the past 12 months in the 2008 Deaf Health Survey, which is like 19.3% of 1890 hearing adults (ages 18 to 64) in the 2006 Adult Health Survey [15]. More recently, only 24.8% of a nationally representative probability sample of adults in the 2015 NSSHB survey reported not being sexually active in the past year [39]. Since most adults are sexually active, they may need an annual HIV screening if they have new partners or multiple partners, or if they deal with other risk factors, so lifetime screening is not enough. In particular, if deaf adolescents and adults have low HIV literacy, as Goldstein and others have reported [40-42], they may not request frequent screening based on their risk factors, leaving the responsibility to providers and outreach workers to educate and inquire about HIV screening frequency.

Specific demographic groups had disparate HIV screening rates in the past year in our deaf sample, with increased rates of recent HIV screening found among younger adults (18-34), nonCaucasian adults, and persons who identified as LGBQ. These results from our study were like other studies that identified MSM, Black, and younger adults as more likely to have received screening [9-12]. This suggests that hearing status or language use did not change the pattern of other sociodemographic factors contributing to HIV screening uptake likelihood. Male gender, as predictive in our sample, may reflect the overrepresentation of LGBQ and represent nonGBQ-identified MSM. It is less likely, yet possible, that our sample shows a recent upswing in HIV screening in heterosexual men after the 2015 CDC HIV screening recommendations, as seen following the 2006 recommendations [10]. The finding that deaf respondents with only high school education were less likely to ever have been screened is consistent with prior research that reported positive correlation between deaf ASL users' health literacy and educational attainment [31]. If deaf adults are more aware of HIV risk factors, they may advocate for screening more often.

People screened were more likely to have had an STD in the past, which mirrors clinician recommendations for concurrent HIV counseling if presenting with an STD [2]. However, the HIV screening rates for both the past year and more than one year ago among respondents with an STD history were not different. The lack of an increased number of HIV screenings in the past year among respondents with a history of an STD may be a missed opportunity for increased frequency of screening and early HIV diagnosis, particularly among those who have a history of a bacterial STD [43,44].

Our modified Poisson prediction model showed a significant association of social media use with recent HIV screening, adjusting for sociodemographic correlates and STD history. Given that the adjusted prevalence ratio for HIV screening within the past year was more robust than the adjusted prevalence ratio for HIV screening over one year ago, social media may be particularly useful in enhancing frequent risk-based or exposure-driven screening rather than sustained routine screening habits. While this study did not interrogate causation, nor ask about respondents' experiences with online or social media driven HIV screening campaigns, it is possible that the exchange of information through social media channels, including about HIV screening, sexual health, and PrEP, informs deaf individuals to seek HIV screening. We find it particularly interesting that social media use, as a main predictor, remained robust for recent screening considering the high prevalence of social media users in the past 12 months (91%). Such high utility provokes serious consideration as an avenue of outreach and shows its extensive reach across diverse deaf adults. Social media may be an avenue to mitigate cultural and linguistic barriers, particularly for deaf adolescents and young adults.

Evidence for social media and its role in promoting HIV-related awareness comes from a recent US study of 121 deaf GBQ men who used ASL, which found that a majority (85%) knew about

PrEP for HIV prevention. Moreover, the perceived effectiveness of PrEP in preventing HIV was strongly associated with engaging in LGBTQ-related discussions online or on social networking sites [26]. While this study was restricted to GBQ men, and HIV screening knowledge and practice are not always equivocal, this offers further evidence that social media may play a powerful role in mitigating HIV screening disparities among deaf ASL users.

Strengths of this study include its diverse representation as a large population-based sample, including demographic and geographic variation across the United States, and its consistency with prior studies about HIV screening patterns in nonexclusively deaf populations. Conversely, our sample is not nationally representative, and some comparisons to other population-based estimates may be limited. Our study did not explore patient centered pretest counseling in which HIV screening was obtained, limiting our understanding of whether increased HIV screening uptake in our large deaf sample is synonymous with self-initiated requests for screening or self-assessments of HIV risk. Our interpretation of the survey data is limited in several key ways. The query about STD history was not defined and open to interpretation by each participant, which could extend to including HIV or excluding other lesser recognized STDs, potentially underestimating the number of participants with a history of STDs and its impact on HIV screening patterns. HIV status was not obtained, potentially affecting our prevalence of screening. Though given its overall low prevalence, we do not think obtaining HIV status would significantly impact our findings. The data is self-reported and subject to recall biases, which is typical for any survey in English or other languages.

Conclusion

Given low to moderate screening rates, deaf patients should be evaluated whenever possible for the need for HIV screening and associated risk factors. As funding and resources for HIV or STD outreach programs continue to be tightened, program managers and healthcare providers should consider promoting culturally and linguistically accessible social media campaigns informing deaf ASL users of the need for routine HIV screening. Further research to better understand the implementation steps between education and screening uptake among deaf ASL users would inform potential interventions to reduce HIV-related disparities. Given potential gaps in health literacy, a logical next step might be mixed-methods interventional studies, using social media to enhance frequency of screening and self-assessment of risk factors. Expanded sexual behavior items among deaf ASL users would highlight groups that should be targeted by such social media outreach, regardless of screening prevalence. However, integration of social networking sites should take care to not overlook older adults or heterosexual adults who may not utilize social media as readily, requiring public health interventions to be multiplatform. A cohesive strategy, combined with increasing the evidence base, will mitigate existing gaps between subgroups and bring deaf adults closer to universal screening, diminishing the collective risk of HIV in this diverse and tightknit community.

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Conflicts of Interest

None declared.

References

1. United SDOHAHS. HIV.gov. 2018 Jun 20. HIV Testing Activities URL: https://www.hiv.gov/federal-response/federal-activities-agencies/hiv-testing-activities [accessed 2019-08-25]
2. Workowski KA, Bolan GA, Centers for Disease Control and Prevention. Sexually transmitted diseases treatment guidelines, 2015. MMWR Recomm Rep 2015 Jun 05;64(RR-03):1-137 [FREE Full text] [Medline: 26042815]
3. US Preventive Services Task Force, Owens DK, Davidson KW, Krist AH, Barry MJ, Cabana M, et al. Screening for HIV Infection: US Preventive Services Task Force Recommendation Statement. JAMA 2019 Jun 18;321(23):2326-2336. [doi: 10.1001/jama.2019.6587] [Medline: 31184701]
4. Centers for Disease Control and Prevention. BRFSS: Graph of Current HIV-AIDS testing among adults | Chronic Disease and Health Promotion Data & Indicators URL: https://chronicdata.cdc.gov/Behavioral-Risk-Factors/BRFSS-Graph-of-Current-HIV-AIDS-testing-among-adul/gbdh-6xcr [accessed 2019-08-25]
5. Kaiser FF. Kaiser Foundation Family. 2017. Percentage of Persons Aged 18-64 Who Reported Ever Receiving an HIV Test, 2017 URL: https://www.kff.org/other/state-indicator/hiv-testing-rate-ever-tested/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D [accessed 2019-08-25]

6. Dandachi D, Dang BN, Wilson Dib R, Friedman H, Giordano T. Knowledge of HIV Testing Guidelines Among US Internal Medicine Residents: A Decade After the Centers for Disease Control and Prevention's Routine HIV Testing Recommendations. AIDS Patient Care STDS 2018 May;32(5):175-180. [doi: 10.1089/apc.2018.0035] [Medline: 29750550]
7. Arya M, Patel S, Kumar D, Zheng MY, Kallen MA, Street RL, et al. Why Physicians Don't Ask: Interpersonal and Intrapersonal Barriers to HIV Testing-Making a Case for a Patient-Initiated Campaign. J Int Assoc Provid AIDS Care 2016 Jul 23;15(4):306-312 [FREE Full text] [doi: 10.1177/2325957414557268] [Medline: 25421929]
8. Wong EY, Jordan WC, Malebranche DJ, DeLaitsch LL, Abravanel R, Bermudez A, et al. HIV testing practices among black primary care physicians in the United States. BMC Public Health 2013 Feb 02;13(1):96 [FREE Full text] [doi: 10.1186/1471-2458-13-96] [Medline: 23375193]
9. John Leung S, Sinclair AH, Battles HB, Swain CE, French PT, Anderson BJ, et al. HIV test offers and acceptance: New York State findings from the behavioral risk factor surveillance system and the National HIV behavioral surveillance, 2011-2012. J Acquir Immune Defic Syndr 2015 Jan 01;68 Suppl 1:S37-S44. [doi: 10.1097/QAI.0000000000000421] [Medline: 25545492]
10. Woodring JV, Kruszon-Moran D, Oster AM, McQuillan GM. Did CDC's 2006 revised HIV testing recommendations make a difference? Evaluation of HIV testing in the US household population, 2003-2010. J Acquir Immune Defic Syndr 2014 Nov 01;67(3):331-340. [doi: 10.1097/QAI.0000000000000303] [Medline: 25153918]
11. Kapadia SN, Singh HK, Jones S, Merrick S, Vaamonde CM. Missed Opportunities for HIV Testing of Patients Tested for Sexually Transmitted Infections at a Large Urban Health Care System From 2010 to 2015. Open Forum Infect Dis 2018 Jul;5(7):ofy165 [FREE Full text] [doi: 10.1093/ofid/ofy165] [Medline: 30087904]
12. Seth P, Walker T, Hollis N, Figueroa A, Belcher L, Centers for Disease Control and Prevention (CDC). HIV testing and service delivery among Blacks or African Americans--61 health department jurisdictions, United States, 2013. MMWR Morb Mortal Wkly Rep 2015 Feb 06;64(4):87-90 [FREE Full text] [Medline: 25654608]
13. Gwadz M, Cleland CM, Kutnick A, Leonard NR, Ritchie AS, Lynch L, et al. Factors Associated with Recent HIV Testing among Heterosexuals at High Risk for HIV Infection in New York City. Front Public Health 2016;4:76 [FREE Full text] [doi: 10.3389/fpubh.2016.00076] [Medline: 27200330]
14. Padden C, Humphries T. Inside Deaf Culture. Cambridge: Harvard University Press; 2006:1-224.
15. Heiman E, Haynes S, McKee M. Sexual health behaviors of Deaf American Sign Language (ASL) users. Disabil Health J 2015 Oct;8(4):579-585 [FREE Full text] [doi: 10.1016/j.dhjo.2015.06.005] [Medline: 26242551]
16. Aicken CR, Estcourt CS, Johnson AM, Sonnenberg P, Wellings K, Mercer CH. Use of the Internet for Sexual Health Among Sexually Experienced Persons Aged 16 to 44 Years: Evidence from a Nationally Representative Survey of the British Population. J Med Internet Res 2016 Jan 20;18(1):e14 [FREE Full text] [doi: 10.2196/jmir.4373] [Medline: 26792090]
17. Paz-Bailey G, Hoots BE, Xia M, Finlayson T, Prejean J, Purcell DW, NHBS Study Group. Trends in Internet Use Among Men Who Have Sex With Men in the United States. J Acquir Immune Defic Syndr 2017 Jul 01;75 Suppl 3:S288-S295 [FREE Full text] [doi: 10.1097/QAI.0000000000001404] [Medline: 28604430]
18. Li Y, Polk J, Plankey M. Online health-searching behavior among HIV-seropositive and HIV-seronegative men who have sex with men in the Baltimore and Washington, DC area. J Med Internet Res 2013 May 03;15(5):e78 [FREE Full text] [doi: 10.2196/jmir.2479] [Medline: 23644412]
19. Taggart T, Grewe ME, Conserve DF, Gliwa C, Roman Isler M. Social Media and HIV: A Systematic Review of Uses of Social Media in HIV Communication. J Med Internet Res 2015 Nov 02;17(11):e248 [FREE Full text] [doi: 10.2196/jmir.4387] [Medline: 26525289]
20. Dahlhamer JM, Galinsky AM, Joestl SS, Ward BW. Sexual Orientation and Health Information Technology Use: A Nationally Representative Study of U.S. Adults. LGBT Health 2017 Apr;4(2):121-129 [FREE Full text] [doi: 10.1089/lgbt.2016.0199] [Medline: 28287875]
21. Washington TA, Applewhite S, Glenn W. Using Facebook as a Platform to Direct Young Black Men Who Have Sex With Men to a Video-Based HIV Testing Intervention: A Feasibility Study. Urban Soc Work 2017;1(1):36-52 [FREE Full text] [doi: 10.1891/2474-8684.1.1.36] [Medline: 29276800]
22. Young SD, Jaganath D. Online Social Networking for HIV Education and Prevention. Sexually Transmitted Diseases 2013;40(2):162-167. [doi: 10.1097/olq.0b013e318278bd12]
23. Holt M, Rawstorne P, Wilkinson J, Worth H, Bittman M, Kippax S. HIV testing, gay community involvement and internet use: social and behavioural correlates of HIV testing among Australian men who have sex with men. AIDS Behav 2012 Jan 7;16(1):13-22. [doi: 10.1007/s10461-010-9872-z] [Medline: 21213035]
24. Ryan C, Kushalnagar P. Towards Health Equity: Deaf Adults' Engagement in Social e-Health Activities and e-Communication with Health Care Providers. J Health Commun 2018;23(9):836-841. [doi: 10.1080/10810730.2018.1527875] [Medline: 30281000]
25. HIV.gov. 2018 May 07. State-level PrEP Utilization Data Now Available from AIDSVu URL: https://www.hiv.gov/blog/state-level-prep-utilization-data-now-available-aidsvu [accessed 2019-08-25]
26. Biskupiak A, Smith S, Kushalnagar P. Pre-Exposure Prophylaxis Knowledge and Perceived Effectiveness to Prevent HIV Among Deaf Gay, Bisexual, and Queer Men. LGBT Health 2018 Nov 01 [FREE Full text] [doi: 10.1089/lgbt.2018.0102] [Medline: 30383466]

27. Kushalnagar P, Harris R, Paludneviciene R, Hoglind T. Health Information National Trends Survey in American Sign Language (HINTS-ASL): Protocol for the Cultural Adaptation and Linguistic Validation of a National Survey. JMIR Res Protoc 2017 Sep 13;6(9):e172 [FREE Full text] [doi: 10.2196/resprot.8067] [Medline: 28903891]
28. Sadler GR, Lee H, Lim RS, Fullerton J. Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. Nurs Health Sci 2010 Sep 01;12(3):369-374 [FREE Full text] [doi: 10.1111/j.1442-2018.2010.00541.x] [Medline: 20727089]
29. Smith S, Chin N. Social Determinants of Health in Deaf Communities. In: Maddock J, editor. Social and Behavioral Health. London: InTechOpen; May 16, 2012:449-460.
30. Barnett S, McKee M, Smith S, Pearson T. Deaf sign language users, health inequities, and public health: opportunity for social justice. Prev Chronic Dis 2011 Mar;8(2):A45 [FREE Full text] [Medline: 21324259]
31. McKee MM, Paasche-Orlow MK, Winters PC, Fiscella K, Zazove P, Sen A, et al. Assessing Health Literacy in Deaf American Sign Language Users. J Health Commun 2015;20 Suppl 2:92-100 [FREE Full text] [doi: 10.1080/10810730.2015.1066468] [Medline: 26513036]
32. Zou G. A modified poisson regression approach to prospective studies with binary data. Am J Epidemiol 2004 Apr 01;159(7):702-706. [doi: 10.1093/aje/kwh090] [Medline: 15033648]
33. Dowshen N, Lee S, Matty Lehman B, Castillo M, Mollen C. IknowUshould2: Feasibility of a Youth-Driven Social Media Campaign to Promote STI and HIV Testing Among Adolescents in Philadelphia. AIDS Behav 2015 Jun;19 Suppl 2:106-111 [FREE Full text] [doi: 10.1007/s10461-014-0991-9] [Medline: 25563502]
34. Aliabadi N, Santelli J. Internet use associated with HIV testing in adults in a national sample: Findings from the National Health Interview Survey, 2009. Prev Med Rep 2014;1:27-31 [FREE Full text] [doi: 10.1016/j.pmedr.2014.09.004] [Medline: 26844036]
35. Pharr JR, Bungum T. Health disparities experienced by people with disabilities in the United States: a Behavioral Risk Factor Surveillance System study. Glob J Health Sci 2012 Sep 09;4(6):99-108 [FREE Full text] [doi: 10.5539/gjhs.v4n6p99] [Medline: 23121746]
36. Neri SV, Bradley EH, Groce NE. Frequency of HIV testing among persons with disabilities: results from the National Health Interview Survey, 2002. AIDS Educ Prev 2007 Dec;19(6):545-554. [doi: 10.1521/aeap.2007.19.6.545] [Medline: 18190278]
37. Moyer VA, U.S. Preventive Services Task Force*. Screening for HIV: U.S. Preventive Services Task Force Recommendation Statement. Ann Intern Med 2013 Jul 02;159(1):51-60. [doi: 10.7326/0003-4819-159-1-201307020-00645] [Medline: 23698354]
38. Pitasi MA, Delaney KP, Brooks JT, DiNenno EA, Johnson SD, Prejean J. HIV Testing in 50 Local Jurisdictions Accounting for the Majority of New HIV Diagnoses and Seven States with Disproportionate Occurrence of HIV in Rural Areas, 2016-2017. MMWR Morb Mortal Wkly Rep 2019 Jun 28;68(25):561-567 [FREE Full text] [doi: 10.15585/mmwr.mm6825a2] [Medline: 31246940]
39. Fu T, Herbenick D, Dodge B, Owens C, Sanders S, Reece M, et al. Relationships Among Sexual Identity, Sexual Attraction, and Sexual Behavior: Results from a Nationally Representative Probability Sample of Adults in the United States. Arch Sex Behav 2019 Jul;48(5):1483-1493. [doi: 10.1007/s10508-018-1319-z] [Medline: 30523472]
40. Heuttel KL, Rothstein WG. HIV/AIDS Knowledge and Information Sources Among Deaf and Hearing College Students. American Annals of the Deaf 2001;146(3):280-286. [doi: 10.1353/aad.2012.0067]
41. Bat-Chava Y, Martin D, Kosciw JG. Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people. AIDS Care 2005 Jul;17(5):623-634. [doi: 10.1080/09540120412331291751] [Medline: 16036248]
42. Goldstein MF, Eckhardt EA, Joyner-Creamer P, Berry R, Paradise H, Cleland CM. What do deaf high school students know about HIV? AIDS Educ Prev 2010 Dec;22(6):523-537. [doi: 10.1521/aeap.2010.22.6.523] [Medline: 21204628]
43. Bernstein KT, Marcus JL, Nieri G, Philip SS, Klausner JD. Rectal gonorrhea and chlamydia reinfection is associated with increased risk of HIV seroconversion. J Acquir Immune Defic Syndr 2010 Apr 01;53(4):537-543. [doi: 10.1097/QAI.0b013e3181c3ef29] [Medline: 19935075]
44. Pathela P, Braunstein SL, Blank S, Shepard C, Schillinger JA. The high risk of an HIV diagnosis following a diagnosis of syphilis: a population-level analysis of New York City men. Clin Infect Dis 2015 Jul 15;61(2):281-287. [doi: 10.1093/cid/civ289] [Medline: 25870333]

Abbreviations

aPR: adjusted prevalence ratios
ASL: American Sign Language
BRFSS: Behavioral Risk Factor Surveillance System
CDC: Centers for Disease Control and Prevention
GBQ: gay, bisexual, and queer
HINTS-ASL: Health Information National Trends Survey in American Sign Language
LGBQ: lesbian, gay, bisexual, and queer

LGBTQ: lesbian, gay, bisexual, transgender, and queer
MSM: men who have sex with men
NSSHB: National Survey of Sexual Health and Behavior
OR: odds ratio
PrEP: preexposure prophylaxis
STD: sexually transmitted disease
USPSTF: United States Preventive Services Task Force

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Original Paper

Paper-Based Versus Web-Based Versions of Self-Administered Questionnaires, Including Food-Frequency Questionnaires: Prospective Cohort Study

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Abstract

Background: Web-based questionnaires allow collecting data quickly, with minimal costs from large sample groups and through Web-based self-administered forms. Until recently, there has been a lack of evidence from large-scale epidemiological studies and nutrition surveys that have evaluated the comparison between traditional and new technologies to measure dietary intake.

Objective: This study aimed to compare results from the general baseline questionnaire (Q_0) and the 10-year follow-up questionnaire (Q_10) in the Seguimiento Universidad de Navarra (SUN) prospective cohort, obtained from different subjects, some of whom used a paper-based version, and others used a Web-based version. Both baseline and 10-year assessments included a validated 136-item semiquantitative food-frequency questionnaire (FFQ), used to collect dietary intake.

Methods: The SUN project is a prospective cohort study (with continuous open recruitment and many participants who were recently recruited). All participants were university graduates. Participants who completed the validated FFQ at baseline (FFQ_0, n=22,564) were selected. The variables analyzed were classified into 6 groups of questions: (1) FFQ (136 items), (2) healthy eating attitudes (10 items), (3) alcohol consumption (3 items), (4) physical activity during leisure time (17 items), (5) other activities (24 items), and (6) personality traits (3 items). Multiple linear and logistic regression models were used to assess the adjusted differences between the mean number of missing values and the risk of having apparently incorrect values for FFQ items or mismatches and inconsistencies in dietary variables.

Results: Only 1.5% (339/22564) and 60.71% (6765/11144) participants reported their information using the Web-based version for Q_0 and Q_10, respectively, and 51.40 % (11598/22564) and 100.00% (11144/11144) of participants who completed the Q_0 and Q_10, respectively, had the option of choosing the Web-based version. Sociodemographic, lifestyle, health characteristics, food consumption, and energy and nutrient intakes were similar among participants, according to the type of questionnaire used in Q_10. Less than 0.5% of values were missing for items related to healthy eating attitudes, alcohol consumption, and personality traits in the Web-based questionnaires. The proportion of missing data in FFQ, leisure time physical activity, and other activities was higher in paper-based questionnaires than Web-based questionnaires. In Web-based questionnaires, a high degree of internal consistency was found when comparing answers that should not be contradictory, such as the frequency of fruit as dessert versus total fruit consumption and the frequency of fried food consumptions versus oil consumption.

Conclusions: Incorporating a Web-based version for a baseline and 10-year questionnaire has not implicated a loss of data quality in this cohort of highly educated adults. Younger participants showed greater preference for Web-based questionnaires. Web-based questionnaires were filled out to a greater extent and with less missing items than paper-based questionnaires. Further research is needed to optimize data collection and response rate in Web-based questionnaires.

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KEYWORDS

epidemiologic studies; cohort studies; surveys and questionnaires

Introduction

Background

A key aspect in epidemiology is the adequate classification of exposure [1]. For this reason, the valid estimation of usual dietary intake in nutritional epidemiology studies is a topic of emerging interest, posing a complex and challenging task [2,3]. In general, the selection of the most appropriate instrument for assessing usual food intake in large-scale epidemiological studies depends on the research purpose. In this context, several dietary assessment methods are available, all of which have their own advantages and limitations [4]. There are 2 methods that prevail: the food-frequency questionnaire (FFQ), most frequently used in studies assessing the association between diet and health-related outcomes, and the 24-hour dietary recalls, primarily used in nutrition surveillance research [2]. Traditional approaches for gathering information from study participants include face-to-face or telephone interviews administered by trained dieticians, as well as paper or printed questionnaires, usually self-reported data [5,6]. These methods require a great deal of resources in terms of personnel, logistics, and materials [5,7]. However, in the past years, advances in technology and the wide use of the internet have allowed researchers to collect data quickly, with minimal costs from large sample groups, through the use of Web-based self-administered questionnaires [8-10]. It has been suggested that a Web-based FFQ can increase the response rate, which may result in greater validity of the data collected, compared with paper-based response rates [10]. However, most of the major limitations of conventional FFQs are similar to Web-based FFQs; therefore, the measurement errors in both approaches may remain essentially equivalent [11]. In fact, the cognitively complex completion process, inherent to the FFQ method (eg, averaging the usual frequency and portion size for each food group or specific food item), seems to be similar for paper-based and interactive computer-based or Web-based formats. The effectiveness of these types of data collection has previously been tested in different fields of health, several populations, and a variety of settings [12-18]. On the other hand, the integration of new technologies, including computer software and Web-based apps, has created novel and unique opportunities to conduct research focused on data collection in nutritional epidemiology [19]. In fact, there are several Web-based cohort studies in which the participants enroll via internet and all data are collected by Web-based questionnaires [5,7,17,20-23]. However, until now, there has been a scarcity of evidence from large-scale epidemiological studies and nutrition surveys that evaluate the comparison between traditional and new technologies to measure dietary intake. In the past 5 years, research in this area has attracted a growing interest [6,24]. The Seguimiento Universidad de Navarra (SUN) project offers an excellent opportunity to study this purpose, given that it is a large and well-known European cohort that uses both paper-based and Web-based FFQs, at baseline and/or during the follow-up, among participants with a high education level.

Objectives

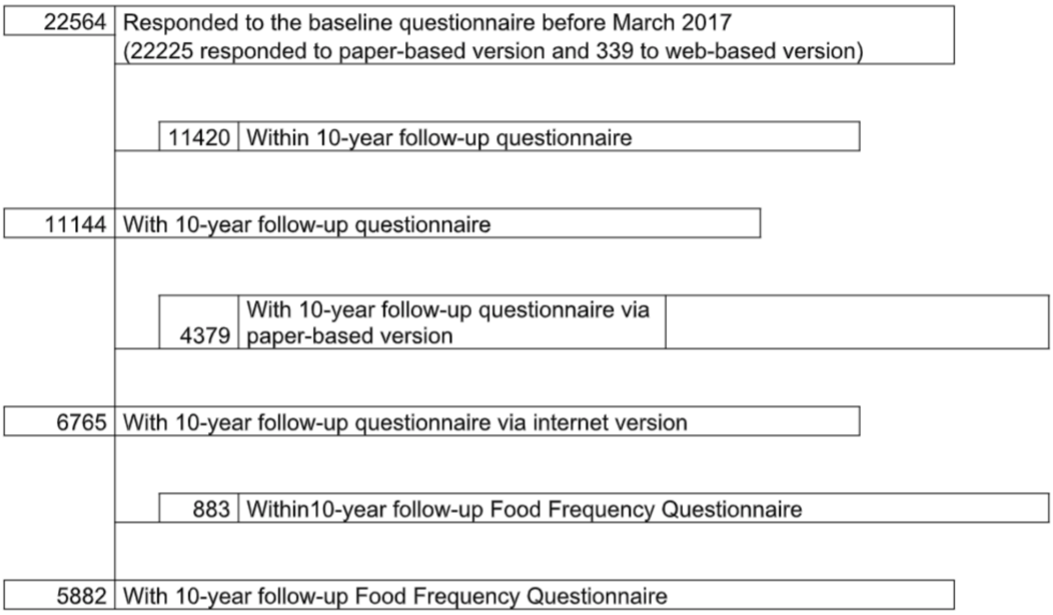
Therefore, we aimed to compare results from the general baseline questionnaire (Q_0) and the 10-year follow-up questionnaire (Q_10) of the SUN prospective cohort obtained in different subjects, some of whom used a paper-based version, and others used a Web-based version.

Methods

Study Population

The SUN project is a multipurpose and prospective Spanish cohort of university graduates, designed to study the impact of several sociodemographic, nutrition, and lifestyle characteristics on the prevention of noncommunicable diseases. Open enrollment began in 1999. The design and methods used in the SUN project have been formerly described in detail elsewhere [25]. The study protocol was supported by the Institutional Review Board of the University of Navarra. We considered a response to the initial questionnaire as informed consent to participate. Participation in this cohort is only by invitation or registration. Currently, all questionnaires of the SUN cohort can be filled by paper or Web-based questionnaires. Web-based questionnaires were available since 2004, using a password-protected area of the SUN website. Starting at the beginning of 2004, participants were offered the possibility of answering their questionnaires either on the paper-based version or on the Web-based version. Thus, in each baseline or follow-up questionnaire since 2004, they can choose how to complete this questionnaire. For example, if a participant received the paper-based questionnaire, he or she can request his or her password to complete the Web-based version of the questionnaire on the SUN website. The participants who have access to the questionnaires do not necessarily have to complete all the questions. Diet in this cohort is evaluated through a repeatedly validated baseline semiquantitative FFQ [26,27]. At this time, the full-length FFQ has been administered only twice throughout the study, at baseline (FFQ_0) and after 10 years of follow-up (FFQ_10). Only those participants who have completed the Q_10 after 10 years on the internet can also fill the FFQ_10, although its filling is absolutely voluntary. For the present analysis, we used the latest available database from March 1, 2017, which included those participants who had responded to the Q_0. Of the 22,564 participants who completed the Q_0, 22,225 (98.5%) of them reported their data using the paper-based version; meanwhile, only 339 (1.5%) participants completed the Web-based version (see Figure 1). After a 10-year follow-up period, we collected questionnaires from 4379 (39.3%) participants by using the paper version and from 6765 (60.7%) participants by using the Web-based questionnaire. Among these 6765 participants who answered the 10-year questionnaire using the Web-based version, 5882 participants also completed a full-length FFQ via the internet (52.8% of the completed Q_10).

Figure 1. Flow chart of the study.



Exposure Assessment

In the SUN cohort, the Q_0, and follow-up questionnaires are self-administered. The Q_0 includes information about sociodemographic variables (eg, sex, age, marital status, and employment status), lifestyle-related variables (eg, smoking status, physical activity, and special diets), anthropometric variables (weight, height), and clinical variables (medical history, family health history, blood pressure levels, medication use, and not gaining more than 5 kg of weight in previous years). On the other hand, the Q_10 collected information on a wide array of characteristics, including weight, height, marital status, and diagnosis of several diseases. Both of these general questionnaires can be filled out in paper form or on the Web, and they are exactly equivalent. The paper-based FFQ comprises 136 food and beverage items, categorized into 9 frequency categories of consumption. These items capture the usual consumption of listed foods during the previous year. There are 9 options for the average frequency of consumption (never or almost never: at least 6 times per day). The Web-based FFQ is a Web-based questionnaire, with a format very similar to that of the paper-based version including the same items.

Measures of Data Quality

Nutrient intakes were calculated as the frequency multiplied by the nutrient composition of specified portion sizes for each food item by using an ad hoc computer program that was specifically developed for this aim. A trained dietitian updated the nutrient database using the latest available information from food composition tables for Spain [28,29]. We considered total energy intakes lower than 800 or 500 kcal/d for men and women, respectively, and greater than 4000 or 3200 kcal/d for men and women, as proposed by Willett as implausible energy intake [30]. In addition, we calculated the outliers of energy intake, defined as either percentiles 1 and 99 or 5 and 95. For each food group, the consumption was considered implausible if it fell outside the 25th percentile minus 3 times this interquartile range or the 75th percentile plus 3 times this interquartile range. For the sake of comparing the proportion of missing responses to the paper-based versus the Web-based questionnaires, we calculated the mean number of missing values in 6 sections of the baseline assessment of the cohort: (1) FFQ (136 items), (2) healthy eating attitudes questions (10 items), (3) alcohol consumption questions (3 items), (4) physical activity during leisure time questions (17 items), (5) other activities questions (24 items), and (6) personality traits questions (3 items). Finally, we evaluated differences in the following potential internal inconsistencies in reporting between paper-based and Web-based questionnaires: (1) eating fruit for dessert but reporting a total fruit consumption equal to 0, (2) eating fried foods at home but reporting olive oil consumption or other vegetable oil consumption equal to 0, (3) drinking alcohol sometimes but reporting total alcohol consumption equal to 0, and (4) drinking wine sometimes at lunch or dinner but reporting a total alcohol consumption equal to 0.

Assessment of Other Variables

Physical activity information is obtained at baseline through a questionnaire validated in Spain [31], which collects information on 17 sports participated in, in the past year (with 10 answer options from never to more than 11 hours a week). The physical activity level during leisure time was quantified by assigning metabolic equivalents (METs) to each activity. Total METs-hours/week for each participant was calculated as the sum of the number of hours spent in each activity multiplied by the specific METs of that activity. Healthy eating attitudes are evaluated through 10 questions, asking the participants if they tried to eat more fruit, more vegetables, more fish, less meat, less sweets and pastries, more fiber and less fat, and if they tried to avoid the consumption of butter, removed fat from meat, and did not add sugar to drinks. We developed a score to capture the gathered information from these 10 questions, which was used in previous publications of the SUN cohort [32,33].

Data Analysis

The aim of our study was not to compare repeated measurements of the same variables within the same subjects using 2 different methods; the aim of this study was to compare the reliability and comprehensiveness of the information gathered with each of both methods (paper-based or Web-based) from different subjects. Descriptive statistics were used to describe the differences at baseline and follow-up between participants who completed the questionnaire in paper-based version and among those who filled out the Web-based version. We used means and SDs for continuous variables or percentages for categorical variables. Multiple linear regression models were used to assess the association between the type of questionnaire (paper or Web-based version) and the differences in the mean number of missing values at baseline. Logistic regression models were run to assess the relationship between the type of questionnaire at baseline and the risk of having implausible data of food items and mismatches or inconsistencies in dietary variables. Both analyses were adjusted for sex, age, level of education (bachelor, graduate, postgraduate, and doctorate), and year entering the cohort (1999-2000, 2001, 2002-2003, 2004, 2005-2007, and 2008-2017). The Q_0 paper-based version was always considered as the reference category. Analyses were performed with STATA version 12 (STATA Corp). All *P* values are 2 tailed, and statistical significance was set at the conventional cut-off of *P*<.05.

Results

Baseline Characteristics

We have compared several potential measures of data quality between Web-based and paper-based data collection at baseline and at 10-year follow-up. Overall, the sociodemographic, lifestyle, and health characteristics were well balanced between the 2 approaches for administering the questionnaires, particularly Q_10, which had a higher number of participants and similar year of completion (Table 1).

Subjects who fulfilled the paper-based Q_0 were more likely to be older, married, workers, current smokers and ex-smokers, and they were more likely to have a lower level of university education. Moreover, they were less active and showed a higher prevalence of hypertension, cancer, diabetes, and weight gain in the past 5 years. On the other hand, participants who completed the Web-based Q_10 were more likely to be men, younger, physically active during leisure time, not married, workers, never smokers, had a higher adherence to the Mediterranean diet, and generally had less prevalence of chronic disease related to diet. Beneficial changes in the consumption of most food and macronutrients and a positive response to dietary attitudes were observed after 10 years of follow-up, mainly when comparing the paper FFQ_0 and FFQ_10 (Table 2).

Table 1. Baseline characteristics, mean (SDs), or percentages, of participants who filled out the paper- or Web-based questionnaires at baseline and at 10-year follow-up.

Variable	Baseline questionnaires (Q_0)		10-year of follow-up questionnaires (Q_10)	
	Paper-based (n=22,225)	Web-based (n=339)	Paper-based (n=4379)	Web-based (n=6765)
Age (years), mean (SD)	37.5 (12.4)	34.0 (11.7)	40.1 (12.8)	36.2 (10.9)
Men, n (%)	8592 (38.66)	129 (38.1)	1714 (39.14)	2786 (41.18)
Year of completing the questionnaire, mean (SD)	2004 (4)	2012 (4)	2002 (2)	2002 (2)
Body Mass Index (kg/m^2), mean (SD)	23.5 (3.6)	23.6 (3.7)	23.6 (3.5)	23.4 (3.4)
Marital status, n (%)				
Married	10973 (49.37)	108 (31.9)	2457 (56.11)	3336 (49.31)
Single, widowed, divorced, and others	11252 (50.63)	231 (68.1)	1922 (43.89)	3429 (50.69)
Occupation, n (%)				
Worker	17463 (78.57)	238 (70.2)	3419 (78.08)	5475 (80.93)
Retired, housewife, and unemployed	4762 (21.43)	101 (29.8)	960 (21.92)	1290 (19.07)
Educational level (years of education), mean (SD)	5.0 (1.5)	5.5 (1.6)	5.0 (1.5)	5.0 (1.5)
Physical activity during leisure time (metabolic equivalents-h/week), mean (SD)	27.3 (24.3)	30.4 (25.5)	27.0 (24.2)	27.1 (23.1)
Mediterranean diet score (0 to 9 score), mean (SD)	4.3 (1.8)	4.5 (1.7)	4.2 (1.8)	4.1 (1.8)
TV (hours/week), mean (SD)	5.2 (2.1)	5.8 (2.0)	5.1 (2.0)	5.5 (2.0)
Smoking status, n (%)				
Current smokers	4796 (21.57)	38 (11.2)	983 (22.45)	1500 (22.17)
Ex-smokers	6202 (27.91)	74 (21.8)	1299 (29.66)	1872 (27.67)
Never smokers	10597 (47.68)	224 (66.1)	2097 (47.89)	3303 (50.16)
Hypertension at baseline, n (%)	1933 (8.70)	21 (6.2)	437 (9.98)	483 (7.14)
Cancer at baseline, n (%)	843 (3.79)	12 (3.5)	175 (4.00)	232 (3.43)
Diabetes at baseline, n (%)	419 (1.89)	3 (0.9)	79 (1.8)	86 (1.27)
Dyslipemia at baseline, n (%)	1495 (6.73)	29 (8.6)	312 (7.1)	406 (6.00)
Cardiovascular disease at baseline, n (%)	335 (1.51)	7 (2.1)	70 (1.6)	80 (1.18)
Weight gain in past 5 years, n (%)	6692 (30.11)	93 (27.4)	1388 (31.70)	2086 (30.84)
Special diets, n (%)	1797 (8.09)	42 (12.4)	340 (7.76)	493 (7.29)
Between-meals snacking, n (%)	7723 (34.75)	135 (39.8)	1499 (34.23)	2331 (34.5)
Dietary supplement use, n (%)	4306 (19.37)	77 (22.7)	779 (17.79)	1152 (17.0)

Table 2. Baseline food consumption, energy and nutrient intakes, and dietary attitudes of the participants, of the Seguimiento Universidad de Navarra cohort, who filled out the paper-based and Web-based questionnaire at baseline and at 10-year follow-up.

Variable	Baseline questionnaires (Q_0)		10-year of follow-up questionnaires (Q_10)	
	Paper-based (n=22,225)	Web-based (n=339)	Paper-based (n=4379)	Web-based (n=6765)
Energy intake (kcal/d), mean (SD)	2532 (957)	2342 (882)	2566 (985)	2537 (904)
Protein intake (% total energy), mean (SD)	18.1 (3.5)	18.1 (4.7)	18.0 (3.7)	17.7 (3.3)
Carbohydrate intake (% total energy), mean (SD)	43.3 (7.7)	41.9 (10.6)	43.4 (8.0)	43.6 (7.3)
Fat intake (% total energy), mean (SD)	36.6 (6.8)	35.8 (8.9)	36.6 (7.1)	36.7 (6.5)
Polyunsaturated fatty acid intake (% total energy), mean (SD)	5.2 (1.6)	4.9 (1.7)	5.3 (1.7)	5.3 (1.6)
Monounsaturated fatty acid intake (% total energy), mean (SD)	15.7 (3.8)	15.3 (4.6)	15.8 (4.0)	15.7 (3.7)
Saturated fatty acid intake (% total energy), mean (SD)	12.5 (3.4)	11.6 (3.9)	12.5 (3.6)	12.6 (3.1)
Fiber intake (g/d), mean (SD)	30.0 (16.5)	30.6 (17.7)	30.7 (17.5)	28.8 (14.7)
Cholesterol intake (mg/d), mean (SD)	440.5 (208.7)	401.2 (183.2)	447.8 (218.5)	440.0 (185.1)
Alcohol intake (g/d), mean (SD)	6.8 (10.8)	5.1 (7.6)	6.9 (11.4)	7.0 (10.7)
Fruits (g/d), mean (SD)	370.9 (354.4)	353.9 (341.3)	380.6 (360.3)	349.1 (345.6)
Vegetables (g/d), mean (SD)	555.8 (409.8)	611.7 (533.0)	554.4 (446.0)	519.6 (336.1)
Nuts (g/d), mean (SD)	8.4 (16.6)	13.6 (27.3)	8.5 (16.5)	7.8 (16.1)
Legumes (g/d), mean (SD)	24.2 (25.2)	23.3 (17.9)	24.6 (25.7)	23.3 (20.8)
Dairy products (g/d), mean (SD)	209.4 (226.0)	136.1 (150.9)	222.3 (237.0)	231.1 (227.6)
Meats (g/d), mean (SD)	185.9 (105.4)	175.4 (94.2)	185.7 (110.0)	181.7 (92.9)
Fish (g/d), mean (SD)	103.0 (81.9)	100.3 (75.1)	104.8 (87.6)	98.2 (69.8)
Olive oil (g/d), mean (SD)	16.0 (14.5)	16.7 (16.1)	16.1 (15.1)	15.6 (14.3)
Fast food (g/d), mean (SD)	23.4 (27.5)	27.8 (23.6)	19.7 (25.9)	22.7 (29.0)
Do you try to eat more fiber? (% yes), n (%)	13153 (59.18)	223 (65.8)	2644 (60.38)	3820 (56.47)
Do you try to eat more fruit? (% yes), n (%)	15209 (68.43)	246 (72.6)	3059 (69.86)	4410 (65.19)
Do you try to eat more vegetables? (% yes), n (%)	17768 (79.95)	271 (80.0)	3551 (81.09)	5303 (78.39)
Do you try to eat more fish? (% yes), n (%)	13170 (59.26)	201 (59.3)	2644 (60.38)	3820 (56.47)
Do you avoid the consumption of butter? (% yes), n (%)	15649 (70.41)	247 (72.9)	3148 (71.89)	4574 (67.61)
Do you try to eat less fat? (% yes), n (%)	17312 (77.89)	270 (79.7)	3473 (79.31)	5079 (75.08)
Do you try to eat less meat? (% yes), n (%)	7747 (34.86)	145 (42.8)	1589 (36.29)	2205 (32.59)
Do you try to remove fat from meat? (% yes), n (%)	16549 (74.46)	187 (55.2)	3321 (75.84)	5064 (74.86)
Do you add sugar to some beverages? (% yes), n (%)	6712 (30.20)	99 (29.2)	1308 (29.87)	2125 (31.41)
Do you try to eat less sweets and pastries? (% yes), n (%)	14098 (63.43)	244 (72.0)	2720 (62.11)	3989 (58.87)

Principal Results

We have found similar results to those previously published [32,33]. In Table 3, we provide the adjusted differences in the mean number of missing values in several items of the general questionnaire at baseline.

Generally, the adjusted differences in the 6 sections evaluated at Q_0 were low. In all cases, they were lower than 3.5%, even for questions on healthy eating attitudes, alcohol consumption, and personality traits; they were very low, lower than 0.5%. However, when we compared participants who completed Q_0 at baseline using the Web-based versus paper-based version, we found some contradictory data. Thus, the mean amount of missing data in the FFQ_0 and physical activity during leisure time questions was significantly higher among subjects who had completed the Web-based version (ß=3.3, 95% CI 2.03-4.64 and ß=2.01, 95% CI 1.45-2.57, respectively) but significantly lower in the other activity questions (ß=–2.01, 95% CI –3.04

to –1.35). Overall, the percentage of participants with implausible data on food consumption in the FFQ was always lower than 3% in participants who used the paper-based version at baseline or at 10-year follow-up (Table 4).

However, we found the following exception: the implausible reporting of nuts consumption, accounting for more than 16% of participants. On the other hand, when we considered all participants, generally, no significant differences among food group consumption were found, except for the implausible reporting of nuts consumption, more probable in these same subjects—odds ratio (OR) 1.54 (95% CI 1.20-1.99). When we classified participants according to the type of questionnaire chosen at 10-year follow-up, the implausible reporting of legume and meat consumption was less frequent in those who collected the Web-based version. The number of participants with implausible olive oil consumption was 1 among those who used the Web-based version and 0 among those who used the paper-based version. For this reason, we could not present the OR for Web-based versus paper-based version. Finally, overall, in both the paper-based and Web-based FFQ_0, the items with higher frequency of mismatches and inconsistencies were total energy intake (near 10%) and self-reported alcohol consumption (approximately 2%; Table 5).

On the contrary, mismatches and inconsistencies were lower in reported consumption of fruit dessert versus total fruit consumption and fried food versus oil consumption. In addition, subjects who filled the Q_0 via internet exhibited a significantly higher risk of presenting inconsistencies in reporting alcohol consumption and wine consumption versus total alcohol intake, compared with those who chose the paper-based version: adjusted OR 3.58 (95% CI 2.01-6.22) and OR 3.01 (95% CI 1.21-7.48), respectively, although the mismatches in relation to total energy intake outside of the reference subset had a lower risk: OR 0.31 (95% CI 0.17-0.56).

Table 3. Adjusted differences for the mean number of missing values in paper-based or Web-based questionnaire at baseline (Beta regression coefficients and 95% CIs). The Q_0 paper-based version was always considered as the reference category.

Missing values	All participants		Participants with successful 10-year follow-up	
	Missing values in baseline questionnaire[a], mean (n=22,225)	Beta (95% CI)[b,c] (n=339)	Missing values in 10-year of follow-up questionnaire[d], mean (n=4379)	Beta (95% CI)[b,e] (n=6765)
Missing values in the food-frequency questionnaire (136 items)	12.93	3.33 (2.03 to 4.64)[f]	14.54	–1.16 (–1.63 to –0.69)[f]
Missing values in the healthy eating attitudes (10 items)	0.29	0.13 (0.001 to 0.25)[g]	0.28	0.002 (–0.04 to 0.04)
Missing values in the alcohol consumption questions (5 items)	0.05	0.09 (0.05 to 0.12)[f]	0.07	–0.01 (–0.03 to 0.0002)
Missing values in the physical activity during leisure time questions (17 items)	2.99	2.01 (1.45 to 2.57)[f]	4.20	–0.21 (–0.43 to 0.01)
Missing values in the other activities questions (24 items)	4.60	–2.20 (–3.05 to –1.35)[f]	4.86	–0.45 (–0.74 to –0.16)[h]
Missing values in the personality traits questions (3 items)	0.04	0.07 (0.04 to 0.10)[f]	0.04	0.007 (–0.004 to 0.02)

[a] Q_0, paper-based.

[b] Adjusted for sex, age, level of education (bachelor, graduate, postgraduate, and doctorate) and year entering the cohort (1999-2000, 2001, 2002-2003, 2004, 2005-2007, and 2008-2017).

[c] In the mean number of missing values in baseline questionnaire (Q_0, Web-based -paper-based).

[d] Q_10, paper-based.

[e] In the mean number of missing values in 10-year of follow-up questionnaire (Q_10, Web-based -paper-based).

[f] *P*<.001.

[g] *P*<.05.

[h] *P*<.01.

Table 4. Percentage of participants with implausible report of food items in the paper-based or Web-based questionnaire at baseline. Odds ratios and 95% CIs to have implausible data in these dietary variables. The Q_0 paper-based version was always considered as the reference category.

Implausible report[a]	All participants		Participants with successful 10-year follow-up	
	Q_0[b] Paper-based (n=22,225)	ORs[c] (95% CI)[d] for Web-based versus paper-based in Q_0 (n=339)	Q_10[e] Paper-based (n=4379)	ORs (95% CI)[d] for Web-based versus paper-based in Q_10 (n=6765)
Fruit consumption	1.77	0.49 (0.15-1.59)	1.99	0.77 (0.57-1.04)
Vegetable consumption	1.25	1.03 (0.44-2.43)	1.21	0.71 (0.48-1.06)
Legume consumption	2.84	1.07 (0.60-1.92)	2.88	*0.78 (0.61-0.99)* [f]
Fish consumption	0.75	0.76 (0.18-3.22)	0.73	0.81 (0.49-1.32)
Meat consumption	0.62	0.33 (0.00-1.79)[g]	0.8	*0.32 (0.18-0.57)* [h]
Dairy products consumption	1.09	0.19 (0.00-1.002)[g]	1.42	0.77 (0.54-1.09)
Cereal consumption	0.85	0.79 (0.19-3.37)	1.14	0.85 (0.57-1.27)
Nuts consumption	16.67	1.54 (1.20-1.99)[i]	16.4	0.94 (0.85-1.05)

[a] For each food group, the consumption was considered implausible if it fell outside the 25th percentile minus 3 times this interquartile range or 75th percentile plus 3 times this interquartile range.

[b] Q_0: Baseline questionnaire.

[c] OR: odds ratio.

[d] Adjusted for sex, age, level of education (bachelor, graduate, postgraduate, and doctorate), and year entering the cohort (1999-2000, 2001, 2002-2003, 2004, 2005-2007, and 2008-2017).

[e] Q_10: 10-year of follow-up questionnaire.

[f] *P*<.05.

[g] Exact logistic regression, as there was 0% of missing values in the Web-based questionnaire (unadjusted).

[h] *P*<.001.

[i] *P*<.01.

Table 5. Percentage of participants with mismatches and inconsistencies in dietary variables the paper-based or the Web-based questionnaire at baseline. Odds ratios and 95% CIs for presenting mismatches and inconsistencies in dietary variables.

Mismatches and inconsistencies in dietary variables	All participants		Participants with successful 10-year follow-up	
	Q_0[a] (paper- based; n=22,225)	ORs[b] (95% CI)[c]for Web-based versus paper-based in Q_0 (n=339)	Q_10[d] (paper-based; n=4379)	ORs (95% CI)[c] for Web-based versus paper-based in Q_10 (n=6765)
Total energy intake outside the pre-defined limits (Willett; <800 or >4000 kcal/d for men, <500 or >3500 kcal/d for women)	9.49	0.77 (0.54-1.13)	10.16	1.14 (0.99-1.30)
Total energy intake outside of the reference subset (<P1 or >P99)	1.96	*0.31 (0.17-0.56* **)**[e]	2.19	1.23 (0.93-1.63)
Total energy intake outside of the reference subset (<P5 or >P95)	9.96	0.73 (0.52-1.02)	10.46	1.11 (0.98-1.27)
Inconsistencies in reporting fruit dessert versus total fruit consumption	0.14	3.06 (0.36-26.0)	0.21	0.41 (0.14-1.18)
Inconsistencies in reporting fried food consumption versus oil consumption	0.81	1.63 (0.37-7.07)	1.14	0.70 (0.45-1.07)
Inconsistencies in reporting alcohol consumption	2.25	*3.58 (2.06-6.22)* [e]	2.72	1.02 (0.79-1.30)
Inconsistencies in reporting wine consumption versus total alcohol intake	1.45	*3.01 (1.21-7.48)* [f]	2.01	1.20 (0.89-1.62)

[a] Q_0: Baseline questionnaire.

[b] OR: odds ratio.

[c] Adjusted for sex, age, level of education (bachelor, graduate, postgraduate and doctorate), and year entering the cohort (1999-2000, 2001, 2002-2003, 2004, 2005-2007, and 2008-2017).

[d] Q_10: 10-year of follow-up questionnaire.

[e] *P*<.001.

[f] *P*<.05.

Discussion

Principal Findings

To the best of our knowledge, our research is the first to compare the quality of the answers, at baseline and after a 10-year follow-up period, in different subjects in a large prospective cohort, where some of them used the traditional version (paper-based) and others used a new method (Web-based) for data collection in a large prospective cohort. Our most important objective was to compare the respective ability of each method (Web-based or paper-based) to gather the relevant information in a reliable and comprehensive manner. The overall response rates in Q_0 were higher for the paper-based version than the Web-based version, 98.5% and 1.5%, respectively, as the electronic version of the questionnaire has only been available since 2004. In addition, the paper-based version was always offered as the first choice. However, in Q_10, the proportion of participants choosing the Web-based version was 61%, because of the fact that if participants are given a choice, they prefer the electronic version. A previous publication suggested that it could be useful to offer all subjects both a paper-based and a Web-based version of a long-term instrument, such as the FFQ, to avoid selection bias [34]. We found that in both methods, baseline characteristics, including food consumption and energy and nutrient intake, were comparable across a range of parameters, with a few exceptions. Although our present assessment does not represent a proper validation study, these findings are in agreement with previous studies that have shown few differences in health questionnaire scores or measures among different methods of administration [13,14]. For example, the NutriNet-Santé study published that the Web-based sociodemographic and economic questionnaire provided information of similar-to-superior quality compared with the traditional paper-based version [17]. Overall, the percentage of missing values in FFQ_0, with 136 items, was higher than 9%, whereas the missing information on physical activity during leisure time and activity questions, with 17 items, was higher than 17%, despite these questionnaires being shorter and simpler than the FFQ. On the other hand, although several studies in different areas have suggested that the validity and reliability of data obtained on the Web are comparable with those obtained by classical methods [35], our findings reveal that the quality of the data has not worsened with the incorporation of the Web-based version in the SUN cohort of highly educated adults. In fact, for some measures of data quality, the results have been more favorable among subjects who filled in questionnaires using the Web-based version, but for other measures, the data quality was worse. An exception is in relation to the implausible values of nut consumption, greater than 24% in FFQ_10. This is probably because of the fact that the majority of these participants reported their FFQ_10 after 2013, when the evidence on the health effects of this food group in the cardiovascular prevention of Primary Prevention of Cardiovascular Disease with a Mediterranean Diet trial had been published [36]. Moreover, the prominence of nuts in the latest published dietary guidelines has also contributed to the remarkable increase in their consumption. In addition, it is possible that SUN participants with longer follow-up were more aware of their diet because of general study participation and the administration of dietary recall methods, which resulted in improvements in their dietary habits (Hawthorne effect).

Strengths and Limitations

The strengths of the SUN study are its high retention rate (91%) [25], a relatively long follow-up, its prospective design, the large sample, and its coordination in a single center, as well as the fact that many of the measurements have been validated. In addition, this study is a comparison and not a validation. Thus, we compared within the same study the self-reported Q_0 and Q_10 and the same FFQ_0 and the FFQ_10. Both FFQs had an identical format and did not incorporate photographs of serving sizes. For this reason, all answers to Q_O and Q_10 are most definitely comparable among themselves. We acknowledge that this study has several limitations. First, this study is not a validation of the same method of dietary assessment; rather, it has two different versions of assessment: paper-based or Web-based. In addition, the aim of this publication was not to compare repeated measurements of the same variables within the same subjects using 2 different methods. Consequently, our findings should be interpreted with caution, and they should never be analyzed as results of a validation study. Second, our sample of Web-based responders of FFQ_10 was small, with respect to the responders of the general Q_0. Thus, among participants with Q_10 (n=11,144), 6765 filled it out using internet, and among them, only 5882 completed the full-length FFQ_10, approximately 53% of participants with 10-year assessment. In addition, only 1.5% of Q_0 was filled out using the internet, and the results of the comparisons of this questionnaire, according to the form of administration, should be interpreted with caution. Third, Web-based cohorts were used to include motivated internet-skilled volunteers; this selection bias is not likely in our cohort, as there is wide access to the internet in all subgroups of the population [7]. On the other hand, despite a selection bias that could be the major factor limiting the generalizability of results, because of the nonrepresentative nature of the internet population, this bias is not very likely, as in Spain, 84.6% of the population between 16 and 74 years had easy access to the internet in the last 3 months [37]. However, it is possible that some older study participants who have greater difficulty using the computer did not fill out the Web-based questionnaires, as they needed a completion guide. Although in the SUN project all participants are university graduates with total access to internet and computers, without apparent difficulties of use, we could have hoped for higher response rates for the Web-based questionnaires [38]. Fourth, there was a difference in the way the Q_0 (paper) and the Q_10 (by internet) were filled out, which could have introduced a systematic error in our results. Although they contained exactly the same items and portions and only varied in format of presentation, it is possible that the previous knowledge of participants when they completed the follow-up questionnaire may have also interfered in their answers of follow-up questionnaires, but this bias affects both groups. Fifth, in the SUN cohort, if participants forget to click on an answer, an error message does not appear before they can go to the next page. For this reason, in some questions of Q_0 or Q_10 by internet, the average number of data missing is high. Sixth, this cohort was formed by graduates from University of Navarra, as well as from other different Spanish universities and professional associations, limiting the external validity of our results, which is required to extrapolate the present findings to the general population. However, epidemiology cohorts are usually nonrepresentative, and generalization should be based on biological plausibility. Seventh, participants could complete the Web-based questionnaires only since 2004, and this fact might result in underestimation of the effects of administration mode on the survey metrics. Finally, the SUN study is based on self-reported information; however, because of the high motivation of the participants (only 10% of the participants accepted to enter to the cohort) [39] and their high education level, we can assume high quality data. This paper provides an overview of the implementation of novel technologies in a large-sample cohort. The main lesson learned from methodological research in the context of the SUN cohort is the following: there is a need for the electronic version to be validated against the original paper-based format. On the other hand, the Web-based form should be designed to be completed in parts, should automatically reject incomplete questionnaires, and should also point out missing or contradictory items [35]. However, these messages may increase respondent frustration and thus decrease completion rates [40]. Minimal technical problems still need improvement before these new methods become common practice [41]. In conclusion, in the digital era, technological progress is having a significant impact on all aspects of our lives, and it is also accelerating scientific discoveries and changing research methods [2]. Several methods for the assessment of dietary intake are currently available in nutritional epidemiology, all have their own limitations and advantages. Thus, the dietary assessment methods should always be selected with caution, considering the research, objective, hypothesis, design, and available resources [10]. Finally, although the performance of innovative dietary assessment technologies has been investigated, more research is needed in regard to their validity and the most effective future strategies that could be incorporated into nutritional epidemiology [20,40,41].

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Authors' Contributions

MAMG was involved with the conception and design of the study. Analysis and interpretation of the data was conducted by IZ, SS, MBR, and MAMG. IZ and SS wrote the first draft. All the authors were involved in the critical revision of the article for important intellectual content and final approval of the article.

Conflicts of Interest

None declared.

References

1. Boeing H. Nutritional epidemiology: new perspectives for understanding the diet-disease relationship? Eur J Clin Nutr 2013 May;67(5):424-429. [doi: 10.1038/ejcn.2013.47] [Medline: 23443832]
2. Brennan L, McNulty B. New technology in nutrition research and practice. Proc Nutr Soc 2017 Dec;76(3):173-174. [doi: 10.1017/S0029665117001021] [Medline: 28514985]
3. van Gelder MM, Bretveld RW, Roeleveld N. Web-based questionnaires: the future in epidemiology? Am J Epidemiol 2010 Dec 01;172(11):1292-1298. [doi: 10.1093/aje/kwq291] [Medline: 20880962]
4. Illner A, Freisling H, Boeing H, Huybrechts I, Crispim SP, Slimani N. Review and evaluation of innovative technologies for measuring diet in nutritional epidemiology. Int J Epidemiol 2012 Aug;41(4):1187-1203. [doi: 10.1093/ije/dys105] [Medline: 22933652]
5. Hercberg S. Web-based studies: the future in nutritional epidemiology (and overarching epidemiology) for the benefit of public health? Prev Med 2012 Dec;55(6):544-545. [doi: 10.1016/j.ypmed.2012.09.016] [Medline: 23010436]
6. Amoutzopoulos B, Steer T, Roberts C, Cade JE, Boushey CJ, Collins CE, et al. Traditional methods new technologies-dilemmas for dietary assessment in large-scale nutrition surveys and studies: a report following an international panel discussion at the 9th International Conference on Diet and Activity Methods (ICDAM9), Brisbane, 3 September 2015. J Nutr Sci 2018;7:e11 [FREE Full text] [doi: 10.1017/jns.2018.4] [Medline: 29686860]
7. Kesse-Guyot E, Assmann K, Andreeva V, Castetbon K, Méjean C, Touvier M, et al. Lessons learned from methodological validation research in E-epidemiology. JMIR Public Health Surveill 2016 Oct 18;2(2):e160 [FREE Full text] [doi: 10.2196/publichealth.5880] [Medline: 27756715]
8. Touvier M, Kesse-Guyot E, Méjean C, Pollet C, Malon A, Castetbon K, et al. Comparison between an interactive web-based self-administered 24 h dietary record and an interview by a dietitian for large-scale epidemiological studies. Br J Nutr 2011 Apr;105(7):1055-1064. [doi: 10.1017/S0007114510004617] [Medline: 21080983]
9. Benedik E, Koroušić Seljak B, Simčič M, Rogelj I, Bratanič B, Ding EL, et al. Comparison of paper- and web-based dietary records: a pilot study. Ann Nutr Metab 2014;64(2):156-166. [doi: 10.1159/000363336] [Medline: 25116257]
10. Shim JS, Oh K, Kim HC. Dietary assessment methods in epidemiologic studies. Epidemiol Health 2014;36:e2014009 [FREE Full text] [doi: 10.4178/epih/e2014009] [Medline: 25078382]
11. González Carrascosa R, García Segovia P, Martínez Monzó J. Paper and pencil vs online self-administered food frequency questionnaire (FFQ) applied to university population: a pilot study. Nutr Hosp 2011;26(6):1378-1384. [doi: 10.1590/S0212-16112011000600027] [Medline: 22411386]
12. Ngo J, Engelen A, Molag M, Roesle J, García-Segovia P, Serra-Majem L. A review of the use of information and communication technologies for dietary assessment. Br J Nutr 2009 Jul;101(Suppl 2):S102-S112. [doi: 10.1017/S0007114509990638] [Medline: 19594959]
13. Gwaltney CJ, Shields AL, Shiffman S. Equivalence of electronic and paper-and-pencil administration of patient-reported outcome measures: a meta-analytic review. Value Health 2008;11(2):322-333 [FREE Full text] [doi: 10.1111/j.1524-4733.2007.00231.x] [Medline: 18380645]
14. Muehlhausen W, Doll H, Quadri N, Fordham B, O'Donohoe P, Dogar N, et al. Equivalence of electronic and paper administration of patient-reported outcome measures: a systematic review and meta-analysis of studies conducted between 2007 and 2013. Health Qual Life Outcomes 2015 Oct 07;13:167 [FREE Full text] [doi: 10.1186/s12955-015-0362-x] [Medline: 26446159]
15. Campbell N, Ali F, Finlay AY, Salek SS. Equivalence of electronic and paper-based patient-reported outcome measures. Qual Life Res 2015 Aug;24(8):1949-1961. [doi: 10.1007/s11136-015-0937-3] [Medline: 25702266]

16. Touvier M, Méjean C, Kesse-Guyot E, Pollet C, Malon A, Castetbon K, et al. Comparison between web-based and paper versions of a self-administered anthropometric questionnaire. Eur J Epidemiol 2010 May;25(5):287-296. [doi: 10.1007/s10654-010-9433-9] [Medline: 20191377]
17. Vergnaud AC, Touvier M, Méjean C, Kesse-Guyot E, Pollet C, Malon A, et al. Agreement between web-based and paper versions of a socio-demographic questionnaire in the NutriNet-Santé study. Int J Public Health 2011 Aug;56(4):407-417. [doi: 10.1007/s00038-011-0257-5] [Medline: 21538094]
18. Ebert JF, Huibers L, Christensen B, Christensen MB. Paper- or web-based questionnaire invitations as a method for data collection: cross-sectional comparative study of differences in response rate, completeness of data, and financial cost. J Med Internet Res 2018 Dec 23;20(1):e24 [FREE Full text] [doi: 10.2196/jmir.8353] [Medline: 29362206]
19. Smith B, Smith T, Gray G, Ryan MA, Millennium Cohort Study Team. When epidemiology meets the internet: web-based surveys in the millennium cohort study. Am J Epidemiol 2007 Dec 01;166(11):1345-1354. [doi: 10.1093/aje/kwm212] [Medline: 17728269]
20. Mikkelsen EM, Hatch E, Wise L, Rothman K, Riis A, Sørensen HT. Cohort profile: the Danish web-based pregnancy planning study--'Snart-Gravid'. Int J Epidemiol 2009 Aug;38(4):938-943 [FREE Full text] [doi: 10.1093/ije/dyn191] [Medline: 18782897]
21. Knudsen VK, Hatch EE, Cueto H, Tucker KL, Wise L, Christensen T, et al. Relative validity of a semi-quantitative, web-based FFQ used in the 'Snart Forældre' cohort - a Danish study of diet and fertility. Public Health Nutr 2016 Apr;19(6):1027-1034. [doi: 10.1017/S1368980015002189] [Medline: 26235206]
22. Wise LA, Rothman KJ, Mikkelsen EM, Stanford JB, Wesselink AK, McKinnon C, et al. Design and conduct of an internet-based preconception cohort study in North America: pregnancy study online. Paediatr Perinat Epidemiol 2015 Jul;29(4):360-371 [FREE Full text] [doi: 10.1111/ppe.12201] [Medline: 26111445]
23. Lind L, Elmståhl S, Bergman E, Englund M, Lindberg E, Michaelsson K, et al. EpiHealth: a large population-based cohort study for investigation of gene-lifestyle interactions in the pathogenesis of common diseases. Eur J Epidemiol 2013 Feb;28(2):189-197. [doi: 10.1007/s10654-013-9787-x] [Medline: 23435790]
24. Conrad J, Nöthlings U. Innovative approaches to estimate individual usual dietary intake in large-scale epidemiological studies. Proc Nutr Soc 2017 Dec;76(3):213-219. [doi: 10.1017/S0029665116003025] [Medline: 28162110]
25. Carlos S, De La Fuente-Arrillaga C, Bes-Rastrollo M, Razquin C, Rico-Campà A, Martínez-González MA, et al. Mediterranean diet and health outcomes in the SUN cohort. Nutrients 2018 Mar 31;10(4):- [FREE Full text] [doi: 10.3390/nu10040439] [Medline: 29614726]
26. Martin-Moreno J, Boyle P, Gorgojo L, Maisonneuve P, Fernandez-Rodriguez JC, Salvini S, et al. Development and validation of a food frequency questionnaire in Spain. Int J Epidemiol 1993 Jun;22(3):512-519. [doi: 10.1093/ije/22.3.512] [Medline: 8359969]
27. Fernández-Ballart JD, Piñol JL, Zazpe I, Corella D, Carrasco P, Toledo E, et al. Relative validity of a semi-quantitative food-frequency questionnaire in an elderly Mediterranean population of Spain. Br J Nutr 2010 Jun;103(12):1808-1816. [doi: 10.1017/S0007114509993837] [Medline: 20102675]
28. Mataix VJ. [Spanish Food Composition Table]. Granada: Universidad de Granada; 2003.
29. Moreiras O, Carbajal A, Cabrera L. Tablas de composición de alimentos (Food Composition Tables), 9th ed. Madrid: Ed. Pirámide; 2005.
30. Willett W. Issues in analysis and presentation of dietary data. In: Nutritional Epidemiology, 2nd edition. New York: Oxford University Press; 1998:322.
31. Martínez-González MA, López-Fontana C, Varo JJ, Sánchez-Villegas A, Martinez JA. Validation of the Spanish version of the physical activity questionnaire used in the Nurses' Health Study and the Health Professionals' Follow-up Study. Public Health Nutr 2005 Oct;8(7):920-927. [Medline: 16277809]
32. Andrade L, Zazpe I, Santiago S, Carlos S, Bes-Rastrollo M, Martínez-González MA. Ten-year changes in healthy eating attitudes in the SUN cohort. J Am Coll Nutr 2017 Jul;36(5):319-329. [doi: 10.1080/07315724.2016.1278566] [Medline: 28506187]
33. Santiago S, Zazpe I, Gea A, de la Rosa PA, Ruiz-Canela M, Martínez-González MA. Healthy-eating attitudes and the incidence of cardiovascular disease: the SUN cohort. Int J Food Sci Nutr 2017 Aug;68(5):595-604. [doi: 10.1080/09637486.2016.1265100] [Medline: 28029068]
34. Illner AK, Harttig U, Tognon G, Palli D, Salvini S, Bower E, et al. Feasibility of innovative dietary assessment in epidemiological studies using the approach of combining different assessment instruments. Public Health Nutr 2011 Jun;14(6):1055-1063. [doi: 10.1017/S1368980010003587] [Medline: 21385523]
35. Eysenbach G, Wyatt J. Using the internet for surveys and health research. J Med Internet Res 2002;4(2):E13 [FREE Full text] [doi: 10.2196/jmir.4.2.e13] [Medline: 12554560]
36. Estruch R, Ros E, Salas-Salvadó J, Covas M, Corella D, Arós F, PREDIMED Study Investigators. Primary prevention of cardiovascular disease with a Mediterranean diet supplemented with extra-virgin olive oil or nuts. N Engl J Med 2018 Jun 21;378(25):e34. [doi: 10.1056/NEJMoa1800389] [Medline: 29897866]

37. The National Statistics Institute. Survey on Equipment and Use of Information and Communication Technologies in Households URL: https://www.ine.es/dyngs/INEbase/en/operacion.htm?c=Estadistica_C&cid=1254736176741&menu=ultiDatos&idp=1254735976608
38. Greenlaw C, Brown-Welty S. A comparison of web-based and paper-based survey methods: testing assumptions of survey mode and response cost. Eval Rev 2009 Oct;33(5):464-480. [doi: 10.1177/0193841X09340214] [Medline: 19605623]
39. Naska A, Lagiou A, Lagiou P. Dietary assessment methods in epidemiological research: current state of the art and future prospects. F1000Res 2017;6:926 [FREE Full text] [doi: 10.12688/f1000research.10703.1] [Medline: 28690835]
40. Lo Siou G, Csizmadi I, Boucher BA, Akawung AK, Whelan HK, Sharma M, et al. The comparative reliability and feasibility of the past-year Canadian diet history questionnaire II: comparison of the paper and web versions. Nutrients 2017 Feb 13;9(2) [FREE Full text] [doi: 10.3390/nu9020133] [Medline: 28208819]
41. Christensen T, Riis AH, Hatch EE, Wise LA, Nielsen MG, Rothman KJ, et al. Costs and efficiency of online and offline recruitment methods: a web-based cohort study. J Med Internet Res 2017 Dec 01;19(3):e58 [FREE Full text] [doi: 10.2196/jmir.6716] [Medline: 28249833]

Abbreviations

FFQ: food-frequency questionnaire
FFQ_0: baseline semiquantitative food-frequency questionnaire
FFQ_10: 10 years of follow-up food-frequency questionnaire
MET: metabolic equivalent
OR: odds ratio
Q_0: baseline questionnaire
Q_10: 10-year of follow-up questionnaire
SUN: Seguimiento Universidad de Navarra

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Original Paper

A Crowdsourced Physician Finder Prototype Platform for Men Who Have Sex with Men in China: Qualitative Study of Acceptability and Feasibility

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Abstract

Background: Men who have sex with men (MSM), including both gay and bisexual men, have a high prevalence of HIV and sexually transmitted infections (STIs) in China. However, healthcare seeking behaviors and engagement in clinical services among MSM are often suboptimal. Global evidence shows that embedding online HIV or sexual health services into gay social networking applications holds promise for facilitating higher rates of healthcare utilization among MSM. We developed a prototype of a gay-friendly health services platform, designed for integration within a popular gay social networking app (Blued) in China.

Objective: The purpose of this study was to evaluate the acceptability of the platform and ask for user feedback through focus group interviews with young MSM in Guangzhou and Shenzhen, cities in Southern China.

Methods: The prototype was developed through an open, national crowdsourcing contest. Open crowdsourcing contests solicit community input on a topic in order to identify potential improvements and implement creative solutions. The prototype included a local, gay-friendly, STI physician finder tool and online psychological consulting services. Semistructured focus group discussions were conducted with MSM to ask for their feedback on the platform, and a short survey was administered following discussions. Thematic analysis was used to analyze the data in NVivo, and we developed a codebook based on the first interview. Double coding was conducted, and discrepancies were discussed with a third individual until consensus was reached. We then carried out descriptive analysis of the survey data.

Results: A total of 34 participants attended four focus group discussions. The mean age was 27.3 years old (SD 4.6). A total of 32 (94%) participants obtained at least university education, and 29 (85%) men had seen a doctor at least once before. Our survey results showed that 24 (71%) participants had interest in using the online health services platform and 25 (74%) thought that the system was easy to use. Qualitative data also revealed that there was a high demand for gay-friendly healthcare services which could help with care seeking. Men felt that the platform could bridge gaps in the existing HIV or STI service delivery system, specifically by identifying local gay-friendly physicians and counselors, providing access to online physician consultation and psychological counseling services, creating space for peer support, and distributing pre-exposure prophylaxis and sexual health education.

Conclusions: Crowdsourcing can help develop a community-centered online platform linking MSM to local gay-friendly HIV or STI services. Further research on developing social media–based platforms for MSM and evaluating the effectiveness of such platforms may be useful for improving sexual health outcomes.

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KEYWORDS

gay-friendly doctors; social media; crowdsourcing; prototype evaluation; men who have sex with men; China

Introduction

HIV prevalence has steadily increased among men who have sex with men (MSM) in China. According to a national estimate, the prevalence increased from 1.2% in 2003 to 7.8% in 2016 [1]. However, healthcare seeking behaviors and engagement in clinical services among MSM are often suboptimal. Many MSM living with HIV in China have poor retention along the HIV care continuum [2]. Limited knowledge of HIV and HIV care, stigma against people living with HIV and against nonheterosexual practices, and lack of navigation guidance in the health system are commonly identified factors that contribute to attrition along the HIV care cascade [3-6]. A Chinese study also revealed men’s concerns about inadvertent disclosure of their sexual orientation [7].

Electronic health technologies (ie, electronic Health [eHealth]) have become a common platform for behavioral interventions because of their wide coverage, convenience, and low cost [8]. eHealth programs use an electronic device or information technologies to provide their services [9]. Among MSM, eHealth interventions may be even more appealing because of the anonymity and the protection of their confidentiality.

Many MSM in China use the internet to find sexual partners, creating an opportunity for online sexual health promotion [10]. Several studies suggest that MSM are interested in using eHealth tools for HIV prevention or sexual health promotion and would be willing to share personal information on the use of such apps [11,12]. A cross-sectional survey of MSM in the United States in 2015 found that over 80% of the participants had an interest in embedding tools for finding lesbian, gay, bisexual, transgender, and queer (LGBTQ)-friendly doctors, and for directly consulting with physicians, into their social apps [13]. Lists of LGBTQ-friendly physicians are now available in the United States [14] and several other high-income countries [15,16]. However, there has not been as much research done on the development of eHealth interventions that help men find gay-friendly physicians in middle-income countries.

Given the need for improving MSM’s linkage to services, we developed a prototype of a platform designed to be embedded within a popular gay social app (Blued) in China. The goal of the platform was to facilitate higher rates of healthcare utilization among MSM by identifying local gay-friendly health services. The platform presents Blued users with a list of gay-friendly doctors endorsed by community members who have used their services. The platform allows users to seek online counseling or schedule in-person appointments. The purpose of this study was to evaluate the acceptability of the platform and ask for user feedback through focus group discussions with young MSM in two major cities in Southern China.

Methods

Participant Recruitment

Both convenience and purposive sampling strategies were used to recruit men who were willing to share their experiences and perspectives. By using a qualitative approach, we did not aim to generalize the study results to the wider community but instead to have a better understanding of some key issues. In focus group discussions, group interactions and dynamics facilitate rich information generation, which can help establish a range of perceptions on a topic of interest [17]. Thus, we conducted a total of four focus groups, each made up of 8-10 MSM, to evaluate the platform. Two focus groups were conducted in Shenzhen and two were conducted in Guangzhou, both cities in Southern China's Guangdong Province. Men were recruited through local community-based organizations (CBOs) that work with MSM in Shenzhen and Guangzhou. Recruitment was conducted both on-site and via an announcement on WeChat, an instant messaging mobile app which has a widespread posting function like Twitter. Participants were considered eligible for the study if they met the following criteria: (1) aged 18 years or older; (2) born biologically male; (3) have had sex with a man at least once; and (4) currently residing in Guangzhou or Shenzhen, China. Other purposive sampling criteria included whether they disclosed their sexual orientation to others (yes/no), whether they had ever been tested for HIV before (yes/no), and past experiences of seeing a physician (within 1 year, 1-2 years, 2-5 years, and never saw a physician before).

Platform Development

The prototype of the health-seeking mobile platform was developed based on submissions to an open crowdsourcing contest, which was held from March 1, 2018 to March 25, 2018. Open crowdsourcing contests ask for community input on a topic to identify potential improvements and implement creative solutions [18,19]. The contest was promoted through social media announcements on WeChat. We solicited submissions about the function, content, and design of the platform, but specifically, we collected ideas for the name, logo, slogan, and features of the platform. Figure 1 shows the start page of the prototype, which includes the name, logo, and slogan. Submissions were voted on by the public through social media and then evaluated by a panel consisting of public health researchers, a representative from a local LGBT CBO, and a Blued developer. Using the winning name, slogan, logo, and function content, we created a prototype for a health seeking platform tailored for MSM. Please see Multimedia Appendix 1 for details on the contest.

The mobile platform, as the most exceptional design product of the contest, had the following main functions: (1) it could identify local sexually transmitted infections (STI) physician services; (2) it provided online psychological consulting services; and (3) it created a network for peer communication and support. The local physician finder connected users to nearby gay-friendly physicians, and users could sort and view physician profiles by specialty (HIV and other STIs), user recommendations, and distance from their location. For the consulting feature, users could choose different forms of service delivery, including online, via phone call, and via an in-person appointment. The psychological consulting service feature aimed to provide support and mental health care for MSM navigating life as a sexual minority in China (eg, psychologists might provide advice on methods for disclosing sexual orientation to friends and family). Peer communication and support aimed to facilitate peer-led online communications within the platform, and users could anonymously ask and answer questions about sexual health, coming out, health services, and so on.

Figure 1. Start page of the prototype.

Focus Group Discussion

The focus group discussions were conducted in a private conference room and facilitated by two researchers experienced in qualitative research. Each interview lasted between one and two hours. Snacks and drinks were provided to ease participant burden and build rapport. We explained the purpose of the study and stressed confidentiality to participants, and written consent was obtained before the focus group discussion began. Then, we played a video showing the features of the online healthcare seeking platform and asked the men to share their reactions (see Multimedia Appendix 2). The focus group discussions focused on evaluating the acceptability and feasibility of the early product of the crowdsourcing contest rather than the contest method. A topic guide was used to guide the overall structure of the interview, but discussions were kept relatively open, and participants were invited to provide any feedback they thought might be relevant for improving the platform. A short survey on the acceptability and usability (perceived ease of use) of the platform was collected following the focus group discussions. Perceived ease-of-use is an important construct of usability and positively affects user acceptability of information technology [20]. The survey was used to triangulate the qualitive findings as an approach to enhance validity. Each participant received a small monetary award of ¥50 (7.50 United States Dollars) for their participation. We ceased focus group discussions once we reached thematic saturation.

Data Analysis

The focus group discussions were audio-recorded and transcribed, then a thematic analysis of the transcripts was conducted [21]. We developed an initial code framework based on the interview guide and applied this code to the first interview. In addition to predetermined codes, during the first coding process we also used an inductive coding approach to allow unexpected codes to emerge from the raw data. The revised codebook, consisting of predefined and inductive-derived codes, was then applied to the remaining transcripts. All transcripts were double coded by DW and PZ, and discrepancies were discussed with a third independent individual (WH). We then read and organized the coded text to find themes and subthemes, and selected relevant quotes were then translated into English. Nvivo 12 software (QSR International, Melbourne) was used to carry out all qualitative data analysis. Descriptive analysis was conducted to analyze survey data using SPSS version 25 (IBM, New York).

Ethical Statement

This study received approval from institutional review boards at the University of North Carolina at Chapel Hill and Southern Medical University Dermatology Hospital.

Results

Participant Characteristics

A total of 34 participants attended four focus group discussions. Table 1 shows the participants characteristics. The mean age was 27.3 years old (SD 4.6). At the time of the focus group discussions 18 (53%) men were living in Guangzhou and 16 (47%) men were living in Shenzhen. A total of 33 (97%) individuals self-identified as male and one self-identified as female. In addition, 32 (94%) had obtained at least a university education, 7 (21%) men were students, and 20 (59%) earned an annual salary of $14,052 or less. Overall, 27 (79%) men took at least one HIV test in the past 12 months, and 29 (85%) men had seen a doctor at least once before. Among them, 18/29 (62%) had never disclosed their sexual orientation to health professionals and 15/29 (52%) were satisfied with their last physician encounter.

Table 1. Demographic characteristics of focus group discussion participants in China, 2018 (N=34).

Characteristics	Value
Age in years (mean, SD)	27.3 (4.6)
City, n (%)	
Guangzhou	18 (53)
Shenzhen	16 (47)
Gender identity, n (%)	
Male	33 (97)
Female	1 (3)
Sexual orientation, n (%)	
Men who only have sex with men	32 (94)
Bisexual	1 (3)
Not sure	1 (3)
Highest education, n (%)	
High school	2 (6)
University	27 (79)
Postgraduate	5 (15)
Annual income (USD), n (%)	
<3516	6 (18)
3516-8784	7 (21)
8784-14052	7 (21)
>14052	14 (41)
Employment status, n (%)	
Student	7 (21)
Employed	26 (77)
Unemployed	1 (3)
Ethnicity, n (%)	
Han	32 (94)
Non-Han	2 (6)
Number of HIV tests done in past 12 months, n (%)	
0	7 (21)
1	10 (29)
2	11 (32)
4 or above	6 (18)
Last time saw a physician, n (%)	
Within 1 year	25 (74)
1-2 years	3 (9)
2-5 years	1 (3)
Never	5 (15)
Sexual orientation disclosure to your physician (N=29), n (%)	
Yes	11 (38)
No	18 (62)
Degree of satisfaction with last experience of seeing a doctor time (N=29), n (%)	
Very satisfied	5 (17)

Characteristics	Value
Satisfied	10 (35)
Neutral	14 (48)

Acceptability

Table 2 shows participants' responses to the survey questions. We found that 24/34 (71%) participants showed interest in using an online health services platform, and the prototype of the platform we presented was highly acceptable to our participants. Qualitative interviews revealed that there was a high demand for gay-friendly healthcare services, and men commented that a platform linking online and offline gay-friendly healthcare services would encourage healthcare seeking behaviors.

Further, privacy and confidentiality were considered to be well protected by the security measures of the platform. For example, participant 2 from group one in Shenzhen commented that the:

> *two most important features of this platform are privacy protection and gay-friendly services.*

Allowing a user to seek health information securely and anonymously with this online platform was particularly helpful to alleviate fears of being discriminated or judged (see Multimedia Appendix 3, Box 1, Quote 1).

Participants expected that such a platform would help expand men's access to in-person health services. One man said that:

> *This platform is meaningful because if I know that there are gay-friendly services in other hospitals, I don't have to confine my access in one specific hospital.*

Another participant from the same group mentioned that such a platform was a necessity for those who had already developed relevant STI symptoms and felt anxious about finding out the cause (see Multimedia Appendix 3, Box 1, Quote 2).

Table 2. Acceptability and perceived usability of the online health care seeking prototype platform by MSM[a] in China, 2018 (N=34). All values are given as n (%).

Acceptability and perceived usability items	Strongly agree	Agree	Neutral	Disagree	Strongly disagree
I am willing to use this platform frequently	7 (21)	17 (50)	7 (21)	3 (9)	0 (0)
I think this platform is unnecessarily complicated	3 (9)	5 (15)	10 (29)	15 (44)	1(3)
I think this platform is easy to use	6 (18)	19 (56)	8 (24)	0 (0)	0 (0)
I think that I would need the support of a technical person to be able to use this system	1 (3)	0 (0)	2 (6)	16 (47)	15 (44)
I find the various functions in this system are well integrated	6 (18)	11 (32)	16 (47)	1 (3)	0 (0)
I think there is too much inconsistency in the system	3 (9)	2 (6)	11 (32)	17 (50)	1 (3)
I would imagine that most people would learn to use this system very quickly	10 (29)	18 (53)	4 (12)	2 (6)	0 (0)
I find the system very cumbersome to use	0 (0)	0 (0)	2 (6)	22 (65)	10 (29)
I feel very confident using the system	12 (35)	16 (47)	4 (12)	1 (3)	0 (0.0)
I think I need to learn a lot of things before I can get going with this system	1 (3)	2 (6)	4 (12)	17 (50)	9 (27)

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

Perceived Usability

About three quarters (25/34, 74%) of men thought that the system was easy to use and only one (3%) commented that he would need technical support to be able to use it. Half of them regarded the various functions of the platform as well integrated. Most men (28/34, 82%) felt confident about using it.

Specific Functions of the Platform

We asked for participants' views towards the functions of the prototype, specifically about physician consultation services, psychological support and consulting services, and peer communication and support. Participants tended to view peer communication and support as a part of psychological counselling services. Additionally, we found that men were interested in pre-exposure prophylaxis (PrEP) services and sexual health education.

Physician Consultation Services

Participants discussed the various forms and timing of service delivery, quality of services, and desirable types of health services. Many men showed preferences for audio or video consultations compared to text-image consultations, as the former was thought to be more efficient (Multimedia Appendix 3, Box 2, Quotes 1 and 2). Others felt a combination of all forms would be most acceptable (Multimedia Appendix 3, Box 2, Quote 3). Participants expressed concerns about delayed service delivery via the platform due to the demands of a physicians' schedule (Multimedia Appendix 3, Box 2, Quote 4). Appointment services may mitigate such concerns and would be important for ensuring prompt service delivery (Multimedia

Appendix 3, Box 2, Quote 5). In terms of quality of services, the qualifications of physicians and recognition by a public medical authority were the most essential considerations for participants (Multimedia Appendix 3, Box 2, Quotes 6 and 7).

Men expressed a desire for services relevant to sexual health and homosexual practices from the platform. Several particular services were preferred, including HIV or STI testing and treatment, anorectal services, urology, and relevant dermatological services (Multimedia Appendix 3, Box 2, Quote 8). One group in Shenzhen described that long-term, follow-up services were especially necessary for elderly patients and those living with chronic conditions, such as people living with HIV (Multimedia Appendix 3, Box 2, Quote 9 and 10).

Psychological Support and Consultations

To facilitate a more comprehensive analysis, we divided this issue of psychological services into peer support and professional consultations. Participants acknowledged that there is a great need for mental health care, but that gay-friendly psychological services were lacking (Multimedia Appendix 3, Box 3, Quotes 1 and 2). Some attributed nondisclosure of sexual orientation to the health professions' lack of capacity to deal with mental health issues (Multimedia Appendix 3, Box 3, Quote 3). A man from group 1 in Guangzhou said that:

> *You can provide peer counselling first, then move to professionals.* [Participant 2]

According to the same participant, peer counselling was "free and easier to find", while "professional consultation services are more expensive". Another participant from group 1 responded:

> *They (professionals) are standing in a high position and looking down, and we would feel pressure or even be subject to discrimination, which makes it worse.* [Participant 1]

However, other men from group 2 in Guangzhou disagreed, saying that "peers are far from professional" (Participant 1). Professional psychological consultations were considered to be most useful as a resource for the coming out process and for treating mental disorders such as depression (Multimedia Appendix 3, Box 3, Quotes 4 and 5).

Pre-Exposure Prophylaxis

Additionally, although not an aspect of the prototype design, men mentioned the necessity of providing both educational information and accessibility for PrEP. Group 1 in Guangzhou mentioned that "both PrEP and PEP services should be strengthened" and this platform could be a good channel for promotion and education. However, risk compensation, like having more condomless sex, was also recognized by our participants (group 1 in Guangzhou).

Sexual Health Education

Health education about HIV and sexual health was thought to be an important platform function. This function is particularly important for those who have recently identified as gay and have limited knowledge about safe sex practices. Men suggested that such a feature include information about HIV, methods of HIV prevention, and other safe sex practices (Multimedia Appendix 3, Box 4, Quotes 1 and 2). Providing educational information about HIV might generate interest in using the platform because of its relevance to potential users' daily lives (Multimedia Appendix 3, Box 4, Quote 3). They also showed interest in information about coping with HIV infection and navigating life either as, or with, a partner living with HIV (Multimedia Appendix 3, Box 4, Quote 4).

Discussion

Principal Results

Many MSM delay seeking necessary healthcare and have difficulty finding gay-friendly physician services, and few interventions focus on linking MSM to local health services in low-and-middle income countries. We collected qualitative and survey data to evaluate men's acceptability and usability of a crowdsourced social media–based eHealth intervention tailored to MSM. This study extends the literature by evaluating men's acceptability of an online health service prototype that aims to link MSM to local health services in China.

We found that an online healthcare platform which links online to offline services was highly acceptable among our participants. This is consistent with previous research in China [12] and the United States [22]. We identified three main reasons for strong interest in the platform. First, as an online platform tailored to MSM, it provided a channel for anonymously seeking sexual health services, which may have mitigated some of the hesitation about using facility-based services [23], as men are fearful of health professional discrimination in traditional clinics [24]. Second, a platform where men can comfortably disclose their sexual history holds promise for reducing such fears and facilitating help seeking. Third, the crowdsourced platform provided a mechanism to compile all local, gay-friendly, sexual, and psychological health services into a single platform. This simplified the process of finding a gay-friendly doctor.

We also found that most men felt the platform was easy to use and were confident in their ability to use it, which is like findings from previous literature on eHealth platforms supporting HIV patient self-management [25]. Levels of ease-of-use in health information technology significantly affect a customer's intention to engage [26], and it is important for MSM to continue using a health app over time [27]. We developed the prototype platform based on our previous crowdsourcing contests. Crowdsourcing is an effective approach to improve community engagement in sexual health promotion and HIV prevention programs [28,29]. This community-centered platform design approach may contribute to a user-friendly health information product; however, another reason may be that our participants were young adults who were well educated and skilled at using complicated products. The usability of the prototype platform among elderly groups, those with poor health literacy, or those with little experience with using mobile phones is still unknown.

Men in our study desired help in finding physicians and services related to PrEP. This is consistent with earlier findings of high demand for PrEP among MSM in China [30]. PrEP services are not currently approved by the China Food and Drug

Administration and are largely unavailable in the country, but several pilot programs in developed cities suggest that there is growing demand [31]. Strong evidence has confirmed the efficacy of PrEP in preventing HIV acquisition in key populations [32], and the World Health Organization recommends PrEP for use in MSM [33]. Thus, incorporating information about PrEP into eHealth platforms may be useful.

Limitations

Our study has several limitations. First, we evaluated men's acceptability and perceived usability by describing the platform, showing a short video, and providing a PowerPoint presentation. Men were not able to download the platform within the Blued environment, however, acceptance of various platforms was found, in earlier research, to be correlated to actual eHealth use [34]. Second, a qualitative study design has limited generalizability. Quantitative evaluations are needed to further determine community acceptance. Additionally, our focus group discussions only recruited men from two Chinese cities. Our subjects were mainly young, had higher education, and had a higher income. Thus, the results may not reflect views of MSM with different sociodemographic backgrounds and in other social contexts. Finally, we assessed one major construct of usability and did not evaluate other aspects such as learnability, operability, and understandability. Usability should be more comprehensively evaluated when the platform becomes available for men to use.

Implications

More research is called for to help develop eHealth programs to meet MSM's needs for sexual health services. Linking local, gay-friendly health services to MSM via social media platforms may be a promising approach to encourage necessary healthcare seeking. Further developing the platform, monitoring actual use by MSM, and refining the platform are also worthy of exploration. In addition, PrEP services are an important strategy to prevent HIV spread and the men in our study showed a great interest in PrEP, which both indicates a need to introduce it into China's healthcare system and the establishment of supportive policies. Preparing men for PrEP by incorporating relevant information and services into the platform is also worthy of consideration. Meanwhile, integrating a gay-friendly physician finder with an MSM social networking app may introduce ethical concerns, as approval from the Chinese Food and Drug Administration is necessary for online health service provision. In summary, developing platforms that can be embedded into social media apps for MSM may be useful for improving the HIV care cascade and sexual health.

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Authors' Contributions

JDT led the project. BC, PZ and YW led the design and development of the prototype platform. DW, WH, PZ, SS, ZL and WT collected data. DW, WH, and PZ analyzed data. DW, CL and WH wrote and revised this manuscript. Other authors provided constructive comments and edited the manuscript, and all authors approved the final version.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Crowdsourcing Contest for the Prototype Development.
[PDF File (Adobe PDF File)224 KB - publichealth_v5i4e13027_app1.pdf]

Multimedia Appendix 2
Focus group discussion guide.
[PDF File (Adobe PDF File)296 KB - publichealth_v5i4e13027_app2.pdf]

Multimedia Appendix 3
Focus group discussion quotations.
[PDF File (Adobe PDF File)78 KB - publichealth_v5i4e13027_app3.pdf]

References

1. National Health and Family Planning Commission of the People's Republic of China. 2015. 2015 China AIDS Response Progress Report URL: http://www.unaids.org/sites/default/files/country/documents/CHN_narrative_report_2015.pdf [accessed 2019-08-28]
2. Wong NS, Mao J, Cheng W, Tang W, Cohen MS, Tucker JD, et al. HIV Linkage to Care and Retention in Care Rate Among MSM in Guangzhou, China. AIDS Behav 2017 Aug 28;22(3):701-710. [doi: 10.1007/s10461-017-1893-4] [Medline: 28849284]
3. Wei C, Yan H, Yang C, Raymond HF, Li J, Yang H, et al. Accessing HIV testing and treatment among men who have sex with men in China: A qualitative study. AIDS Care 2013 Aug 02;26(3):372-378. [doi: 10.1080/09540121.2013.824538] [Medline: 23909807]
4. Xu J, Ming Z, Zhang Y, Wang P, Jing J, Cheng F. Family support, discrimination, and quality of life among ART-treated HIV-infected patients: a two-year study in China. Infect Dis Poverty 2017 Nov 21;6(1). [doi: 10.1186/s40249-017-0364-5] [Medline: 29157301]
5. Zhang D, Li C, Meng S, Qi J, Fu X, Sun J. Attrition of MSM with HIV/AIDS along the continuum of care from screening to CD4 testing in China. AIDS Care 2014 Mar 31;26(9):1118-1121. [doi: 10.1080/09540121.2014.902420] [Medline: 24684294]
6. Zhang Y, Fan Y, Dai S, Li B, Xu W, Hu L, et al. HIV/AIDS stigma among older PLWHA in south rural China. Int J Nurs Pract 2015 Jun 12;21(3):221-228. [doi: 10.1111/ijn.12254] [Medline: 24621391]
7. Liu Y, Osborn CY, Qian H, Yin L, Xiao D, Ruan Y, et al. Barriers and Facilitators of Linkage to and Engagement in HIV Care Among HIV-Positive Men Who Have Sex with Men in China: A Qualitative Study. AIDS Patient Care STDS 2016 Feb;30(2):70-77 [FREE Full text] [doi: 10.1089/apc.2015.0296] [Medline: 26784360]
8. Noar SM, Harrington NG. Building an evidence base for eHealth applications: Research Questions and Practice Implications. In: eHealth Applications: Promising Strategies for Behavior Change. New York: Routledge Communication Series; 2012.
9. Blaya JA, Fraser HS, Holt B. E-health technologies show promise in developing countries. Health Aff (Millwood) 2010 Feb;29(2):244-251. [doi: 10.1377/hlthaff.2009.0894] [Medline: 20348068]
10. Zou H, Fan S. Characteristics of Men Who Have Sex With Men Who Use Smartphone Geosocial Networking Applications and Implications for HIV Interventions: A Systematic Review and Meta-Analysis. Arch Sex Behav 2017 May 4;46(4):885-894. [doi: 10.1007/s10508-016-0709-3] [Medline: 27043837]
11. Nehl EJ, He N, Wang X, Lin L, Wong FY, Yu F. Feasibility and willingness of using e-technologies for HIV prevention and research targeting Chinese MSM. AIDS Care 2013;25(7):926-930 [FREE Full text] [doi: 10.1080/09540121.2012.726344] [Medline: 23061806]
12. Muessig KE, Bien CH, Wei C, Lo EJ, Yang M, Tucker JD, et al. A mixed-methods study on the acceptability of using eHealth for HIV prevention and sexual health care among men who have sex with men in China. J Med Internet Res 2015 Apr 21;17(4):e100 [FREE Full text] [doi: 10.2196/jmir.3370] [Medline: 25900881]
13. Ventuneac A, John SA, Whitfield THF, Mustanski B, Parsons JT. Preferences for Sexual Health Smartphone App Features Among Gay and Bisexual Men. AIDS Behav 2018 Oct;22(10):3384-3394. [doi: 10.1007/s10461-018-2171-9] [Medline: 29948335]
14. GLMA. 2019. Health Professionals Advancing LGBTQ Equality URL: http://www.glma.org/index.cfm?fuseaction=Page.viewPage&pageId=532 [accessed 2019-08-28]
15. Rainbow Health Victoria. 2019. Supporting LGBTIQ health and well-being URL: https://www.glhv.org.au/ [accessed 2019-08-28]
16. Transfigurations. 2019. Trans Friendly Doctors and GP's Register URL: https://transfigurations.org.uk/trans-friendly-doctors/ [accessed 2019-08-28]
17. Kitzinger J. Qualitative research. Introducing focus groups. BMJ 1995 Jul 29;311(7000):299-302 [FREE Full text] [doi: 10.1136/bmj.311.7000.299] [Medline: 7633241]
18. Tucker JD, Fenton KA. Innovation challenge contests to enhance HIV responses. Lancet HIV 2018 Mar;5(3):e113-e115 [FREE Full text] [doi: 10.1016/S2352-3018(18)30027-4] [Medline: 29519613]
19. UNICEF. Crowdsourcing in health and health research: a practical guide. Geneva: World Health Organization; 2018.
20. Davis FD. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. MIS Quarterly 1989 Sep;13(3):319. [doi: 10.2307/249008]
21. Braun V, Clarke V. Using thematic analysis in psychology. Qualitative Research in Psychology 2006 Jan;3(2):77-101. [doi: 10.1191/1478088706qp063oa]
22. Rosengren AL, Huang E, Daniels J, Young SD, Marlin RW, Klausner JD. Feasibility of using GrindrTM to distribute HIV self-test kits to men who have sex with men in Los Angeles, California. Sex. Health 2016;13(4):389. [doi: 10.1071/sh15236] [Medline: 27209076]
23. Feng Y, Wu Z, Detels R. Evolution of Men Who Have Sex With Men Community and Experienced Stigma Among Men Who Have Sex With Men in Chengdu, China. JAIDS Journal of Acquired Immune Deficiency Syndromes 2010;53:S98-S103. [doi: 10.1097/qai.0b013e3181c7df71] [Medline: 20104118]

24. Watson J, Tang W, Pan S, Wu D, Zhao P, Cao B, et al. Out of the Closet, Into the Clinic: Opportunities for Expanding Men Who Have Sex With Men-Competent Services in China. Sex Transm Dis 2018 Aug;45(8):527-533 [FREE Full text] [doi: 10.1097/OLQ.0000000000000808] [Medline: 29465638]
25. Swendeman D, Farmer S, Mindry D, Lee SJ, Medich M. HIV Care Providers' Attitudes regarding Mobile Phone Applications and Web-Based Dashboards to support Patient Self-Management and Care Coordination: Results from a Qualitative Feasibility Study. J HIV AIDS 2016 Oct;2(4) [FREE Full text] [doi: 10.16966/2380-5536.127] [Medline: 28066820]
26. Kim J, Park H. Development of a health information technology acceptance model using consumers' health behavior intention. J Med Internet Res 2012 Oct 01;14(5):e133 [FREE Full text] [doi: 10.2196/jmir.2143] [Medline: 23026508]
27. Mitchell JW, Torres MB, Joe J, Danh T, Gass B, Horvath KJ. Formative Work to Develop a Tailored HIV Testing Smartphone App for Diverse, At-Risk, HIV-Negative Men Who Have Sex With Men: A Focus Group Study. JMIR Mhealth Uhealth 2016 Nov 16;4(4):e128 [FREE Full text] [doi: 10.2196/mhealth.6178] [Medline: 27852558]
28. Tang W, Han L, Best J, Zhang Y, Mollan K, Kim J, et al. Crowdsourcing HIV Test Promotion Videos: A Noninferiority Randomized Controlled Trial in China. Clin Infect Dis 2016 Jun 01;62(11):1436-1442 [FREE Full text] [doi: 10.1093/cid/ciw171] [Medline: 27129465]
29. Pan SW, Stein G, Bayus B, Tang W, Mathews A, Wang C, et al. Systematic review of innovation design contests for health: spurring innovation and mass engagement. BMJ Innov 2017 Sep 27;3(4):227-237 [FREE Full text] [doi: 10.1136/bmjinnov-2017-000203] [Medline: 29576873]
30. Holt M. HIV pre-exposure prophylaxis and treatment as prevention: a review of awareness and acceptability among men who have sex with men in the Asia-Pacific region and the Americas. Sex. Health 2014;11(2):166. [doi: 10.1071/sh13060]
31. Mou Y, Xu J, Ma Y. Cohort retention in HIV pre-exposure prophylaxis clinical trial among men who have sex with men. Modern Preventive Medicine 2017;44(16):2904-2889.
32. McCormack S, Dunn DT, Desai M, Dolling DI, Gafos M, Gilson R, et al. Pre-exposure prophylaxis to prevent the acquisition of HIV-1 infection (PROUD): effectiveness results from the pilot phase of a pragmatic open-label randomised trial. The Lancet 2016 Jan;387(10013):53-60. [doi: 10.1016/s0140-6736(15)00056-2] [Medline: 26364263]
33. World Health Organization. 2016. Consolidated guidelines on the use of antiretroviral drugs for treating and preventing HIV infection: Recommendations for a public health approach-Second edition URL: https://www.who.int/hiv/pub/arv/arv-2016/en/ [accessed 2019-08-28]
34. Mburu S. A predictive model for optimizing acceptance and use of mHealth interventions in low-resource settings: A case of Mamacare prototype. IEEE 2017:A. [doi: 10.1109/AFRCON.2017.8095535]

Abbreviations

CBO: community-based organization
eHealth: electronic health
LGBTQ: lesbian, gay, bisexual, transgender, and queer
MSM: men who have sex with men
PrEP: pre-exposure prophylaxis
STIs: sexually transmitted infections

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Review

Using Web-Based Pin-Drop Maps to Capture Activity Spaces Among Young Adults Who Use Drugs in Rural Areas: Cross-Sectional Survey

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Abstract

Background: Epicenters of harmful drug use are expanding to US rural areas, with rural young adults bearing a disproportionate burden. A large body of work suggests that place characteristics (eg, spatial access to health services) shape vulnerability to drug-related harms among urban residents. Research on the role of place characteristics in shaping these harms among rural residents is nascent, as are methods of gathering place-based data.

Objective: We (1) analyzed whether young rural adults who used drugs answered self-administered Web-based mapping items about locations where they engaged in risk behaviors and (2) determined the precision of mapped locations.

Methods: Eligible individuals had to report recently using opioids to get high; be aged between 18 and 35 years; and live in the 5-county rural Appalachian Kentucky study area. We used targeted outreach and peer-referral methods to recruit participants. The survey asked participants to drop a pin in interactive maps to mark where they completed the survey, and where they had slept most; used drugs most; and had sex most in the past 6 months. Precision was assessed by (1) determining whether mapped locations were within 100 m of a structure and (2) calculating the Euclidean distance between the pin-drop home location and the street address where participants reported sleeping most often. Measures of central tendency and dispersion were calculated for all variables; distributions of missingness for mapping items and for the Euclidean distance variable were explored across participant characteristics.

Results: Of the 151 participants, 88.7% (134/151) completed all mapping items, and ≥92.1% (>139/151) dropped a pin at each of the 4 locations queried. Missingness did not vary across most participant characteristics, except that lower percentages of full-time workers and peer-recruited participants mapped some locations. Two-thirds of the pin-drop sex and drug use locations were less than 100 m from a structure, as were 92.1% (139/151) of pin-drop home locations. The median distance between the pin-drop and street-address home locations was 2.0 miles (25th percentile=0.8 miles; 75th percentile=5.5 miles); distances were shorter for high-school graduates, staff-recruited participants, and participants reporting no technical difficulties completing the survey.

Conclusions: Missingness for mapping items was low and unlikely to introduce bias, given that it varied across few participant characteristics. Precision results were mixed. In a rural study area of 1378 square miles, most pin-drop home addresses were near a structure; it is unsurprising that fewer drug and sex locations were near structures because most participants reported engaging in these activities outside at times. The error in pin-drop home locations, however, might be too large for some purposes. We offer several recommendations to strengthen future research, including gathering metadata on the extent to which participants zoom in on each map and recruiting participants via trusted staff.

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KEYWORDS

rural; substance use disorder; Web-based data collection; geospatial methods; risk environment; activity spaces

Introduction

Epicenters of harmful drug use in the United States are shifting from cities to rural areas; rural young adults bear the brunt of these epidemiologic transitions [1]. Since the mid-1990s, rates of nonmedical prescription opioid use and heroin use have surged among young adults in rural areas. As a result, young adults in rural areas are now at the forefront of the national hepatitis C virus (HCV) epidemic, and their children bear a disproportionate burden of neonatal abstinence syndrome [2,3].

A large body of theoretical and empirical work suggests that characteristics of the *activity spaces* of people who use drugs shape their drug use patterns, drug-related harms, and health service use. Activity spaces are defined as “local areas within which people move or travel in the course of their daily activities” [4]. The Risk Environment Model, Social Ecological Model, Andersen’s Behavioral Model of Health Care Utilization, and other theoretical frameworks posit that characteristics of places (eg, census tract poverty rates and income inequality in states) powerfully affect health behavior and health service use [5-7]. Evidence supports these propositions among those living in cities. For example, urban people who use drugs are more likely to use health care services that are closer to where they live, and those living in areas with greater densities of dilapidated buildings are more likely to overdose [8,9]. Documenting the characteristics of the activity spaces of young adults who use drugs can elucidate why some people who use drugs are more likely to engage in risk behavior than others and can strengthen planning efforts to ensure spatial access drug-related [3] health services (eg, syringe service programs, drug treatment programs).

The methods to measure activity spaces were, however, developed in urban environments and are predicated on assumptions that may not hold for rural populations or populations engaging in illegal behavior, including rural young adults who use drugs. For example, studies of activity spaces often require that participants travel to the study storefront, either to take part in an interviewer-administered survey about activity spaces or to retrieve a global positioning system (GPS) unit (which later needs to be returned). Traveling to a storefront may, however, be difficult in rural areas, where travel distances are longer on average than they are in cities; public transportation is rare; and low-income residents (including young adults who use drugs) often lack cars [10-12]. Moreover, methods that require participants to travel with a GPS unit that records their movements may not be acceptable to people who use drugs who engage in illegal behavior. Survey-based methods of capturing activity spaces may also fail. These surveys tend to query specific addresses where an activity occurs, or the nearest intersection. In rural areas, however, activities may occur in places that have no street address (eg, in a forest, by a lake), and intersections are relatively rare.

Interactive digital maps embedded in a Web-based survey might, however, prove a valid alternative method of capturing activity spaces of rural young adults who use drugs. Young adults in rural areas report high rates of internet use [13]. Web-based interactive maps bypass the need to travel to a storefront or carry a GPS unit and would not require that participants report street addresses or intersections. This method has proved feasible for men who have sex with men and generates relatively precise geospatial data [14]. This method’s feasibility for young adults who use drugs is, however, unknown, as is the validity of the resulting geospatial data. Technical difficulties navigating digital interactive maps and hesitation to disclose the locations of illegal or stigmatizing behaviors could impact data quality.

Here, we test the *feasibility* of using self-administered interactive digital maps embedded in a Web-based survey to capture risk-related activity spaces of rural, young adults who use drugs, and the *precision* of the resulting geospatial data. We define *risk-related* activity spaces as the *local areas within which people move or travel in the course of their daily activities while engaging in drug-related and sexual risk behaviors*. Participants were invited to *drop pins* in these digital maps to mark particular locations (eg, where they have slept most and where they have misused prescription opioids most). Specifically, our analyses were designed to explore the following questions:

1. Do participants report technical difficulties while completing Web-based mapping items?
2. Do participants answer mapping questions about their risk-related activity spaces, and does item completion vary by participant characteristics, including sociodemographic characteristics and drug-related behaviors?
3. How precise are pin-drop mapping data about the locations where participants live and engage in risk-related behaviors?

Methods

Survey Overview

Questions about activity spaces, sociodemographic characteristics, and technical difficulties were queried as part of a self-administered Web-based survey about risk of HIV and HCV infection and overdose. This survey was administered between August 27, 2017 and July 31, 2018 to young adults who use drugs living in rural Appalachian Eastern Kentucky, a region with high rates of HCV and overdoses [2,15]. The Web-based survey was programmed in SurveyGizmo [16].

Eligibility and Recruitment

To be eligible to take part in the self-administered Web-based survey, individuals had to be aged between 18 and 35 years; currently live in 1 of the 5 rural Appalachian Kentucky counties studied here; and report recent (past 30 days) use of an opioid to get high; opioids included heroin, prescription pain pills (eg, Percocet), and medication-assisted therapies (eg, buprenorphine).

Participants were recruited using targeted outreach and Web-based peer-referral methods. Targeted outreach strategies included (1) holding neighborhood cookouts in areas with high rates of overdoses and other drug-related harms; (2) disseminating information about the study through community partners and through staff working in another local study of adults who use drugs (the "CARE2HOPE" study); and (3) posting flyers in places where young adults who use drugs might spend time (eg, gas stations, health departments, and social service offices). Regardless of recruitment method, participants completed a Web-based screener to determine eligibility; eligible and interested individuals provided consent online and completed the Web-based survey. Surveys were self-administered and could be completed at the place and on the device of the participant's choosing (eg, mobile in a car, tablet at home, or computer at the CARE2HOPE storefront). Toward the end of the survey, participants were asked if they were interested in referring people to be screened for the study. Participants who agreed to help recruit were emailed or texted electronic recruitment coupons with a unique identifier that they could forward to others. Participants received US $10 for each of the first 3 eligible people they referred. Referred individuals, in turn, completed the Web-based screener, and eligible and consenting individuals took part in the Web-based survey and were given the opportunity to recruit others. Participants received US $30 for completing the survey.

As eligibility was ascertained online, we created an intensive Web-based screener to reduce fraud. This screening process included a quiz on the county the individual reported living in, and a quiz on the dose, appearance, and cost of the opioid they reported using most frequently in the past 30 days.

Measures

Measures analyzed here included sociodemographic items (eg, age and gender); activity space pin-drop mapping items; and technical problems encountered during the survey.

Mapping Activity Space Locations

Before launching the survey, we conducted cognitive interviews with 4 young adults who met the survey's eligibility criteria. These individuals completed the pin-drop mapping items in the presence of study staff and shared insights into how to address future participants' concerns on disclosing the locations of highly sensitive and sometimes illegal behaviors and how to clarify mapping instructions. Suggestions (eg, highlight data confidentiality) were incorporated into the final survey's mapping items.

A secure digital map for each item was embedded in the Web-based survey, and participants were instructed to *drop a pin* on each map as close to the correct location as they felt comfortable (Figure 1). We created mapping items to capture 6 locations for each participant:

- Pin-drop home location: "Show us on the map where you have slept most in the past 6 months."
- Pin-drop injection location: "Show us on the map the place where you have injected heroin or prescription pain pills the most often in the past 6 months."
- Pin-drop noninjection opioid use location: "Show us on the map the place where you have taken heroin or prescription pain pills to get high WITHOUT INJECTING THEM the most often in the past 6 months."
- Pin-drop transactional sex location: "Show us on the map where you have had VAGINAL or ANAL sex with someone to get drugs, money, housing or other resources most often in the past 6 months."
- Pin-drop sex location (nontransactional): "Show us on the map where you have had vaginal or anal sex that was NOT in exchange for drugs, money, housing, or other resources most often in the past 6 months."
- Pin-drop survey completion location: "Show us on the map where you are now."

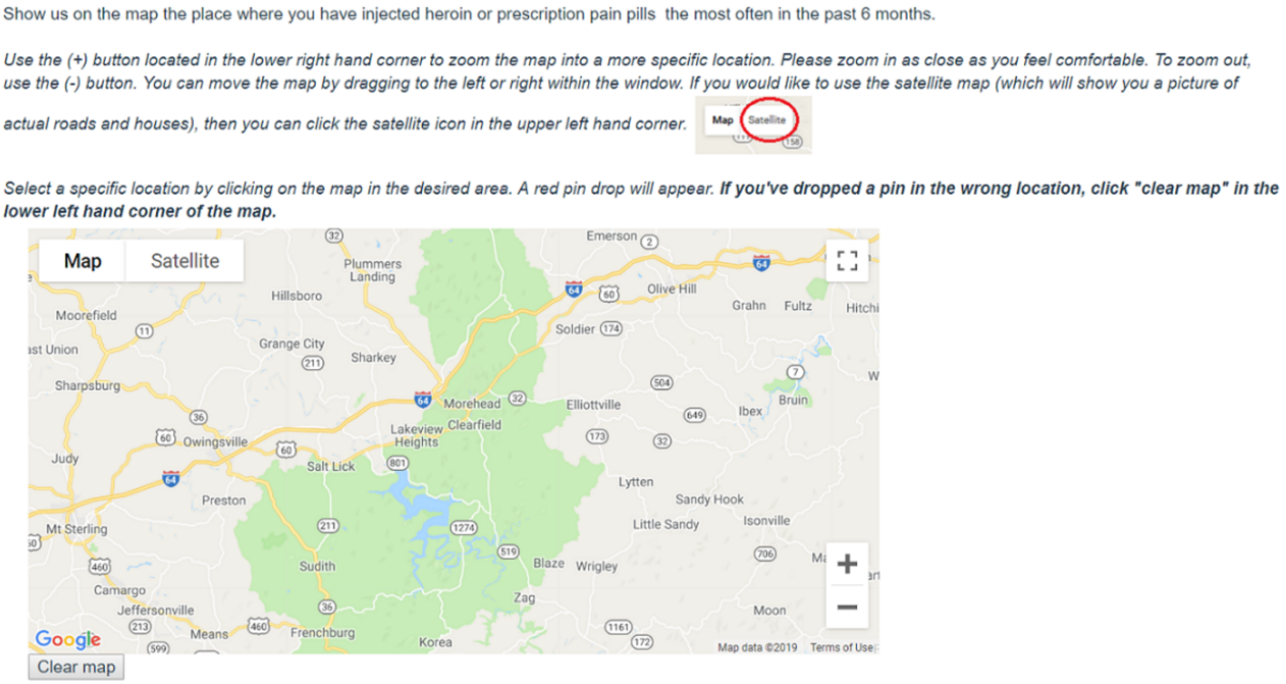
The consent form noted that individuals could skip items without jeopardizing their incentive.

During the analysis phase, we merged the items querying opioid injection location and smoking or snorting location into a single *drug use location* variable; participants who shared data on both were assigned to their injection location. Due to a coding error in the survey, individuals who reported only oral ingestion were not asked the noninjection drug use location item (N=45).

Each mapping item contained instructions about how to navigate the map, including how to zoom closer and remove an incorrectly dropped pin. All maps were centered in the county that contained the largest city in the study area.

The location where participants slept most was queried first (*pin-drop home location*). Every subsequent mapping item first asked whether the location was the same as the person's home. Participants responding affirmatively skipped that mapping item, and their home location was used as the response, assessed using either the *pin-drop home location* or, if that was missing, the street address they entered into the screener for the place where they had *slept most in the past 6 months*. The survey was programmed so that participants skipped mapping items for behaviors in which they had not engaged in the past 6 months (eg, participants who had not engaged in transactional sex in the past 6 months were not asked to map the location of this behavior). All pins were automatically geocoded to their latitude and longitude in SurveyGizmo.

Figure 1. Survey item to gather pin-drop data on drug use location.



Show us on the map the place where you have injected heroin or prescription pain pills the most often in the past 6 months.

Use the (+) button located in the lower right hand corner to zoom the map into a more specific location. Please zoom in as close as you feel comfortable. To zoom out, use the (-) button. You can move the map by dragging to the left or right within the window. If you would like to use the satellite map (which will show you a picture of actual roads and houses), then you can click the satellite icon in the upper left hand corner.

Select a specific location by clicking on the map in the desired area. A red pin drop will appear. ***If you've dropped a pin in the wrong location, click "clear map" in the lower left hand corner of the map.***

Measuring Precision

We assessed the precision of pin-dropped locations in 2 ways:

1. Using Google Maps, we manually assessed whether or not each pin-drop location was located within 100 m of a structure. Unpublished qualitative data from young adults who use opioids to get high and live in these counties suggested that, while they may use drugs or have sex outside at times, they greatly prefer to engage in these behaviors inside (eg, their home or their partner's home). In this rural area with county-level population densities ranging from 31 to 84 people per square mile, the vast majority of the surface area does not have structures; randomly dropped pins would thus not be near a structure.
2. We calculated the Euclidean distance (ie, as the crow flies) between the pin-drop home location and the street address (street-address home location) where participants reported sleeping most in the past 6 months, an item queried in the screener. Street addresses were geocoded to their latitude and longitude location (96% match).

Assessing Technical Challenges

Participants answered questions about technical problems experienced while completing the survey, including while dropping pins on the maps. Technical problems queried included yes or no items on frozen screens, internet connectivity, and problems saving answers. Questions specific to the mapping items included the following: maps were slow to load, maps would not zoom in or out, and trouble dropping a pin on the map in the correct place.

Analysis

We used several methods to detect and eliminate fraud [17]. First, the survey experienced an onslaught of entries during two 48-hour periods from individuals who reported living in the same house. A scan of the house suggested that it could not be home to so many people, and so we excluded all participants who completed the survey during those periods who listed that house as their address (N=49 entries excluded). Next, we applied components of a fraud-detection protocol created by Ballard and colleagues to identify fraud in Web-based surveys [17]. We investigated repeated names and dates of birth across entries and inconsistencies in names within entries. This excluded another 12 entries. Finally, we eliminated individuals who completed the survey implausibly rapidly (<10 min for people who injected; <8 min for others), excluding another 6 entries. The final sample included 151 participants.

Descriptive statistics were used to explore distributions of variables across this sample of 151 participants. Chi-square, independent t-tests for age and monthly income, and Fisher exact tests were used to detect group differences in the likelihood of responding to mapping items, and in the distance between the address-based home location and pin-drop home location (*precision analysis*). Variables of interest included a range of sociodemographic characteristics (age, educational attainment, homelessness status, car access, parenting status, and whether the participant lived in the county on which the maps were centered); injection drug use status; criminal justice involvement; and recruitment method (eg, peer referral, CARE2HOPE staff). The number of people who reported transactional sex (N=55) was too small to support analyses of the correlates of missingness and precision.

We limited the sample for the precision analyses in 2 ways:

1. Each participant's street-address home location was queried in the screener and at several points in the survey. To help ensure that the street-address home location could be considered the gold standard against which pin-drop home locations were compared, we restricted the sample to participants who reported the same street address on the

screener and on at least one survey item capturing home address (N=96).

2. In a corollary analysis, we further reduced the sample to participants who reported no technical difficulties completing the survey (N=80) to try to capture threats to precision above and beyond these technical difficulties.

We used ArcGIS 10.6 Network Analyst to calculate distances and activity spaces [18]. Statistical analyses were conducted in SAS version 14.2 [19].

Ethics

The Emory institutional review board (IRB) approved study protocols, and the University of Kentucky’s IRB deferred to this Board. A Certificate of Confidentiality was secured to protect data from subpoena.

Results

Sample Overview

A total of 151 valid surveys were completed. On average, survey participants were aged 28.9 years (standard deviation [SD] 4.1), and 61.6% (93/151) were men (Table 1). Consistent with the racial or ethnic composition of the area, 96.7% (146/151) of participants identified as white, and 98.7% (150/151) identified as non-Hispanic. The sample was deeply impoverished: the median monthly income was US $300 (interquartile range: US $664), and almost half (45.0% [68/151]) were currently homeless (ie, living on the street, or in a car, park, abandoned building, or shelter). Two-thirds of participants were recruited via CARE2HOPE staff contact; 27.8% (42/151) was recruited via peer referral. Over 70% (109/151) of the sample had used heroin in the past 6 months; 51.7% (78/151) reported using prescription pain pills to get high in the past 6 months. Two-thirds of the sample reported injecting drugs in the past 6 months.

Table 1. Participant characteristics and difficulties encountered while completing an online survey, for a sample of young adult residents of rural Appalachian Kentucky who used opioids to get high (N=151).

Participant characteristic	Values[a]
Age (years), mean (SD)	28.9 (4.1)
Gender, n (%)	
Man	93 (61.6)
Woman	58 (38.4)
Race, n (%)	
White	146 (96.7)
Black or African American	4 (2.7)
Other	1 (0.7)
Hispanic/Latino ethnicity, n (%)	1 (0.7)
Homeless, n (%)	68 (45.0)
Educational attainment, n (%)	
Less than high school	46 (30.5)
High-school graduate	59 (39.1)
Some college or associate’s degree	40 (26.5)
College graduate or higher	3 (2.0)
Employment status, n (%)	
Full-time	27 (17.1)
Part-time	28 (17.7)
Other	103 (65.2)
Monthly income (US $), mean (SD)	300 (664)
Usually drive myself where I need to go, n (%)	69 (45.7)
Caregiver to a child, n (%)	29 (19.2)
History of arrest, n (%)	60 (39.7)
Injected drugs to get high (past 6 months), n (%)	100 (66.2)
Primary drugs used (multiple responses possible), n (%)	
Heroin	109 (72.2)
Methamphetamines	89 (58.9)
Buprenorphine or methadone	92 (60.9)
Opioid prescription pain pills	78 (51.7)
Gabapentin or Neurontin	60 (39.7)
Prescription sedatives/tranquilizers	40 (26.5)
Crack or cocaine	34 (22.5)
Live in the most populous county (ie, where maps centered), n (%)	118 (78.2)
Recruitment method, n (%)	
Staff contact	100 (66.2)
Peer referral	42 (27.8)
Other	9 (6.0)
Device used to complete the survey, n (%)	
Mobile phone	72 (48.3)
Computer	43 (28.9)
Tablet	16 (10.7)

Participant characteristic	Values[a]
Other	18 (12.1)
Technical challenges experienced while completing the survey (participants could select >1 response), n (%)	
None	119 (78.8)
Maps were slow to load	10 (6.6)
Trouble dropping pin in the correct place	10 (6.6)
Maps would not zoom in or out	8 (5.3)
Lost internet connection	4 (2.2)
Other	10 (6.6)

[a] Some percentages do not sum to 100% because of some individuals refused to answer select items.

Technical Challenges While Completing the Survey

More than three-fourths (78.8% [119/151]) of the sample reported that they had had no problems completing the Web-based survey (Table 1). Of those who reported a problem, the most commonly reported problems were that the maps were slow to load (6.6% [10/151]); that it was difficult to drop the pin in the correct location (6.6% [10/151]); and that it was hard to use the *zoom* feature on the maps (ie, zoom in or out; 5.3% [8/151]).

Activity Space Missingness Analysis

Of the 151 participants, 88.7% (134/151) dropped pins for all locations they were asked to locate. All 151 participants were asked to drop a pin where they had slept most in the past 6 months, and 92.1% (139/151) dropped a pin in answer to this question (Figure 2; Table 2). Participants who worked full time were less likely to complete this item than part-time workers or others (78% [18/23], 92% [22/24], and 95% [89/94], respectively), as were participants who did not live in the county where the map was centered (76% [25/33] vs 96.6% [114/118]). Participants recruited by CARE2HOPE staff were more likely to drop a pin at their home than participants recruited by peers or others (96% [96/100], 83% [35/42], and 89% [8/9], respectively). There was a borderline statistically significant relationship (*P*=.07) suggesting that participants who had good car access were less likely to drop a pin at their home than others (87% [60/69] vs 96% [79/82]).

All 151 individuals were asked to map their current location (ie, where they were completing the survey), and 96.0% (145/151) reported this location either by dropping a pin or by noting it was the same location as their home (Table 2). There was a borderline statistically significant relationship (*P*=.09) suggesting that people who were recruited by CARE2HOPE staff members were more likely to report this location (98% [98/100] for staff referral; 93% [39/42] for peer referral; 89% [8/9] for other referral methods). Missingness on current location did not vary systematically by any other participant characteristics, including age, gender, homeless status, or educational attainment.

Figure 2. Location data missingness flowchart.

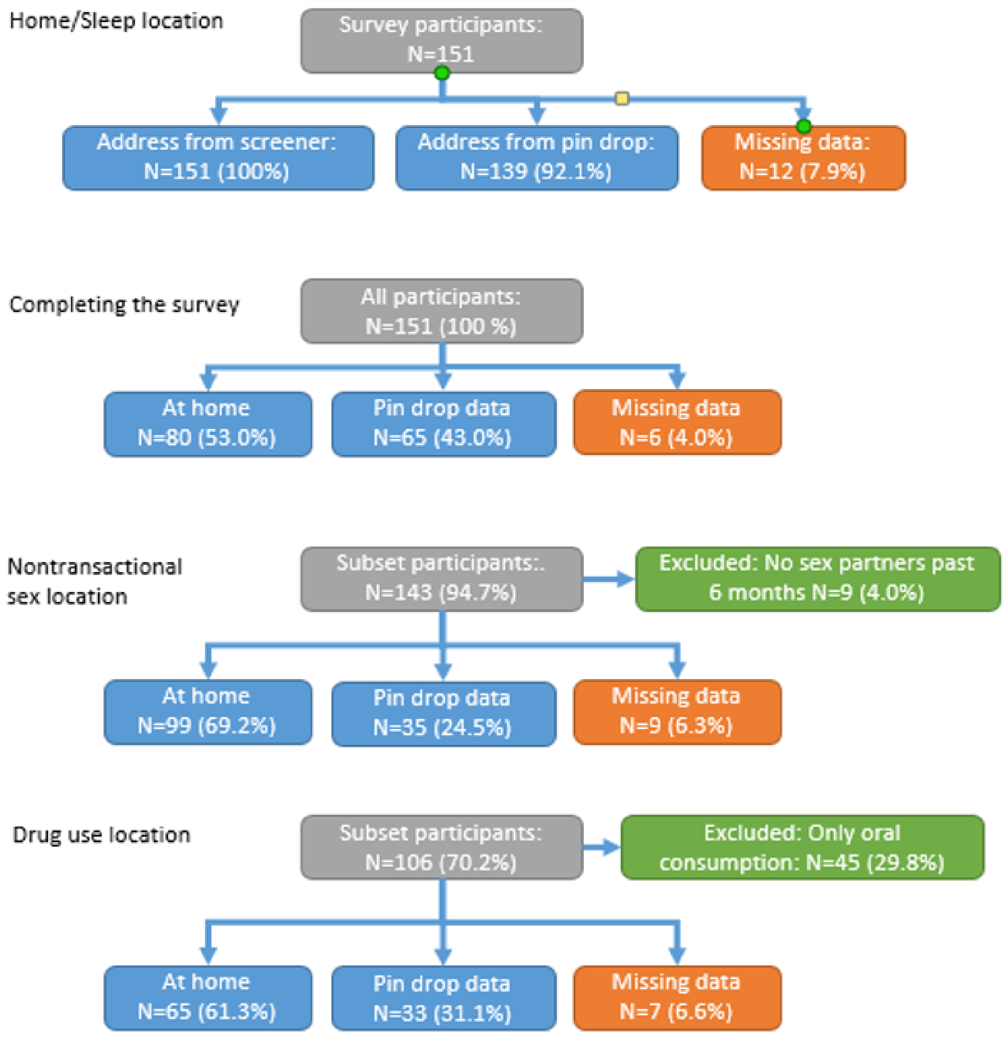


Table 2. Patterns of completion for pin-drop mapping items of home location and current location, completed by a sample of young adults in rural Appalachian Kentucky who use opioids to get high (N=151). Some percentages do not sum to 100% because of some individuals refused to answer select items.

Participant characteristics	Home		Current location	
	Dropped pin	*P* value	Dropped pin	*P* value
Age (years), mean (SD)		.85		.44
Dropped pin	28.9 (4.1)		28.8 (4.1)	
Did not drop pin	28.7 (4.3)		30.2 (3.7)	
Gender, n (%)		.21		.68
Man	88 (94.6)		90 (96.8)	
Woman	51 (87.9)		55 (94.8)	
Homeless, n (%)		.35		.41
Yes	61 (89.7)		64 (94.1)	
No	77 (95.1)		79 (97.5)	
High-school graduate, n (%)		.75		.65
No	43 (93.5)		44 (95.7)	
Yes	93 (91.2)		99 (97.1)	
Employment status, n (%)		.04		.31
Full-time	18 (78.3)		21 (91.3)	
Part-time	22 (91.7)		23 (95.8)	
Other	89 (94.7)		91 (96.8)	
Monthly income (US $), median (IQR)		.16		.94
Dropped pin	650 (300)		300 (664)	
Did not drop pin	100 (593)		300 (600)	
Usually drive myself, n (%)		.07		.41
Yes	60 (87.0)		65 (94.2)	
No	79 (96.3)		80 (97.6)	
Caregiver, n (%)		.39		.99
Yes	26 (89.7)		28 (96.6)	
No	105 (94.6)		108 (97.3)	
History of arrest, n (%)		.63		.63
Yes	58 (96.7)		59 (98.3)	
No	68 (89.5)		73 (96.1)	
Live in county where map centered, n (%)		.001		.12
Yes	114 (96.6)		115 (97.5)	
No	25 (75.8)		30 (90.9)	
Injected (past 6 months), n (%)		.99		.99
Yes	94 (94.0)		98 (98.0)	
No	41 (91.1)		45 (100.0)	
Recruitment method, n (%)		.03		.09
Staff contact	96 (96.0)		98 (98.0)	
Peer referral	35 (83.3)		39 (92.9)	
Other	8 (88.9)		8 (88.9)	
Device used, n (%)		.77		.34
Mobile phone	66 (91.7)		69 (95.8)	

Participant characteristics	Home		Current location	
	Dropped pin	*P* value	Dropped pin	*P* value
Computer	40 (83.0)		43 (100.0)	
Tablet	15 (93.8)		15 (93.8)	
Other	18 (13.0)		18 (100.0)	
Reported a technical problem with this survey, n (%)		.99		.34
Yes	28 (93.3)		28 (93.3)	
No	111 (91.7)		117 (96.7)	

Of the 143 participants who had been sexually active in the past 6 months, 93.7% (134/143) marked the place where they had (nontransactional) sex most often in the past 6 months, either by dropping a pin or by reporting that the location was the same location as their home (Table 3). People recruited by CARE2HOPE staff members or through *other methods* were more likely to report this location than other participants (97% [89/92] for staff referral; 100% [8/8] for other means; and 86% [36/42] for peer referral), as were participants who reported living in the county where the map was centered (96.5% [110/114] vs 83% [24/29]). Missingness on this item did not vary by other participant characteristics, though there were borderline statistically significant relationships (.05≤*P*≤.10) suggesting that women (*P*=.09) and housed (*P*=.08) individuals were more likely to report this location and that people who were employed full time were less likely to do so (*P*=.08).

Of the 106 participants who were asked the drug use location item, 93.4% (99/106) either dropped a pin in this location or reported that it was the same location as their home. Missingness varied by the device participants used to complete the survey, with higher completion rates for this item among participants using computers or mobile phones (100% [28/28] and 96% [52/54], respectively) than tablets and other devices (78% [7/9] and 85% [11/13], respectively). Participants who lived in the county the map was centered on were more likely to complete this item (96% [78/81] vs 84% [21/25]). Missingness on this item did not vary systematically by other participant characteristics.

Table 3. Patterns of completion for pin-drop mapping items of sex location and drug use location completed by a sample of young adults in rural Appalachian Kentucky who use opioids to get high (N=151). Some percentages do not sum to 100% because of some individuals refused to answer select items.

Participant characteristics	Sex location		Drug use location	
	Dropped pin	*P* value	Dropped pin	*P* value
Age (years), mean (SD)		.87		.83
Dropped pin	28.8 (4.1)		29.1 (4.3)	
Did not drop pin	29.0 (4.0)		29.4 (3.6)	
Gender, n (%)		.09		.60
Man	78 (90.7)		61 (92.4)	
Woman	56 (98.3)		38 (95.0)	
Homeless, n (%)		.08		.70
Yes	57 (89.1)		44 (91.7)	
No	75 (97.4)		54 (94.7)	
High-school graduate, n (%)		.99		.19
No	40 (93.0)		25 (100.0)	
Yes	91 (93.8)		72 (91.1)	
Employment status, n (%)		.08		.36
Full-time	18 (81.8)		14 (87.5)	
Part-time	22 (95.7)		18 (100.0)	
Other	84 (95.5)		59 (92.2)	
Monthly income (US $), median (IQR)		.28		.20
Dropped pin	300 (635)		300 (600)	
Did not drop pin	100 (400)		2.5 (800)	
Usually drive myself, n (%)		.74		.71
Yes	63 (92.7)		48 (92.3)	
No	71 (94.7)		51 (94.4)	
Caregiver, n (%)		.99		.57
Yes	27 (96.4)		22 (100.0)	
No	98 (94.2)		72 (94.7)	
History of arrest, n (%)		.70		.69
Yes	53 (96.4)		42 (95.5)	
No	68 (93.2)		49 (92.5)	
Live in county where map centered, n (%)		.02		.05
Yes	110 (96.5)		78 (96.3)	
No	24 (82.8)		21 (84)	
Injected (past 6 months), n (%)		.38		.22
Yes	91 (96.8)		77 (97.5)	
No	40 (93.0)		21 (91.3)	
Recruitment method, n (%)		.05		.17
Staff contact	89 (96.7)		70 (95.9)	
Peer referral	36 (85.7)		23 (88.5)	
Other	9 (100.0)		6 (85.7)	
Device used, n (%)		.59		.03
Mobile phone	64 (91.4)		52 (96.3)	

Participant characteristics	Sex location		Drug use location	
	Dropped pin	*P* value	Dropped pin	*P* value
Computer	39 (97.5)		28 (100.0)	
Tablet	14 (100.0)		7 (77.8)	
Other	16 (94.1)		11 (84.6)	
Reported a technical problem with survey, n (%)		.99		.64
Yes	21 (91.3)		27 (93.1)	
No	78 (94.0)		107 (93.9)	

Precision

Two-thirds of the pin-drop sex and drug use locations were within 100 m of a structure, as were 92.1% (128/139) of pin-drop home locations. As noted, we restricted the precision analysis of the distance between pin-drop home location and street-address home location to participants whose screener-reported home address was identical to the home address they reported on at least one other survey item (N=96). The median Euclidean distance between the pin-drop home location and the street-address home location was 2.0 miles (25th percentile: 0.8 miles; 75th percentile: 5.5 miles). The distance between these 2 home locations varied by educational attainment, recruitment method, injection status, and experiencing technical difficulties with the survey (Table 4). Specifically, the median distance was smaller for high-school graduates (1.6 miles for high-school graduates vs 2.5 miles for people who did not graduate high school); for people recruited by staff (1.8 miles for staff recruits; 4.0 miles for peer recruits; 11.3 miles for other recruitment methods); for people who injected drugs (1.9 miles for people who currently injected vs 3.6 miles for others); and for participants reporting no technical difficulties with the Web-based survey (1.8 miles vs 5.6 miles). There was a borderline statistically significant ($.05<P<.09$) relationship suggesting that participants completing the mapping items on tablets had a longer median distance (1.9 miles if completed on a computer; 2.1 miles on a mobile phone; 6.8 miles on a tablet).

Analyses that excluded participants reporting technical difficulties generated medians and 25th percentiles that were similar to those generated by the full sample (Table 4; N=80), but the values of the 75th percentiles were slightly lower than in the full sample. For example, the 75th percentile of the distance measure for participants who usually drove themselves was 2.8 miles in the reduced sample, whereas it was 6.5 miles in the full sample; it was 4.4 miles for women in the restricted sample, whereas it was 6.3 miles for women in the full sample. Individual-level correlates were similar across both samples.

Table 4. Distributions of the number of miles between pin-drop home locations and street-address home locations for a sample of young adults living in rural Appalachian Kentucky who use opioids to get high.

Characteristics	Sample (N=96)				Sample restricted to participants who reported no technical problems completing the survey (N=80)			
	Percentile			*P* value	Percentile			*P* value
	25th	50th	75th		25th	50th	75th	
Age (years)	27.0	29.0	32.0	.85	27.0	29.5	32	.88
Gender				.57				.52
Man	1.1	2.1	5.4		0.8	2.0	4.6	
Woman	0.5	1.6	6.3		0.5	1.6	4.4	
Homeless				.56				.46
Yes	1.2	2.2	5.7		0.8	2.1	4.6	
No	0.6	2.0	5.3		0.7	1.6	2.8	
High-school graduate				.03				.03
No	1.7	2.5	6.9		1.5	2.2	5.7	
Yes	0.5	1.6	4.9		0.5	1.6	4.1	
Employment status				.23				.34
Full-time	0.6	3.7	5.7		0.7	3.9	5.7	
Part-time	1.8	3.6	7.3		2.1	2.1	5.4	
Other	0.8	1.8	4.6		1.6	1.6	2.9	
Monthly income (US $)	100.0	300.0	661.5	.57	10.0	275.0	60.0	.71
Usually drive myself				.93				.46
Yes	0.8	2.1	4.8		0.8	2.1	4.6	
No	0.9	2.0	6.5		0.7	1.6	2.8	
Caregiver				.48				.58
Yes	0.4	1.9	5.3		0.4	1.3	4.6	
No	1.1	2.0	5.0		1.1	1.8	3.7	
History of arrest				.75				.72
Yes	0.8	2.0	5.1		0.6	1.7	4.3	
No	0.8	2.1	5.3		0.9	3.3	3.3	
Injected (past 6 months)				.047				.07
Yes	0.8	1.9	4.1		0.6	1.8	2.8	
No	0.8	3.6	14.1		0.8	2.5	16.4	
Live in county where map centered				.48				.41
Yes	0.8	2.0	4.8		0.7	1.8	4.1	
No	0.8	6.9	12.6		0.8	2.8	12.6	
Recruitment method				.03				.02
Staff contact	0.7	1.8	4.5		0.6	1.6	2.9	
Peer referral	1.3	4.0	14.2		1.4	4.0	17.7	
Other	2.0	11.3	31.2		2.0	2.4	2.2	
Device used				.07				.26
Mobile phone	0.6	2.1	5.4		0.6	2.1	5.4	
Computer	1.2	1.9	3.2		1.2	1.7	2.9	
Tablet	3.4	6.8	35.0		0.6	4.6	36.2	
Other	0.7	1.6	3.4		0.5	1.3	2.0	

Characteristics	Sample (N=96)				Sample restricted to participants who reported no technical problems completing the survey (N=80)			
	Percentile			*P* value	Percentile			*P* value
	25th	50th	75th		25th	50th	75th	
Reported technical problem with survey				.04				—[a]
Yes	1.6	5.6	7.8		—	—	—	
No	0.8	1.8	4.5		—	—	—	

[a] Not applicable.

Discussion

Principal Findings

In this sample of rural young adults who use opioids to get high, we find that self-administered pin-drop maps hold some promise as a tool to capture information on risk-related activity spaces. Response rates to mapping items were high, and most pin-drops were near structures, but the distance between pin-drop home locations and street-address home locations might be unacceptably large for some subpopulations and analytic purposes. We describe and contextualize these results and offer recommendations to strengthen future research.

Though participants were told that they could still receive their incentive if they skipped items, almost 90% of participants dropped pins for all the locations for which they were eligible, and item-specific response rates exceeded 92%. These results suggest that analyses of mapping items in Web-based surveys with rural young adults who use drugs should be as adequately powered as analyses of other survey items.

These high response rates may be attributed, in part, to the prominence of the study’s federal Certificate of Confidentiality in the survey. These Certificates “…protect the privacy of research subjects by prohibiting disclosure of identifiable, sensitive research information to anyone not connected to the research except when the subject consents or in a few other specific situations” [20]. Past research with rural people who use drugs suggests that they view these certificates as *trust agreements* that signal that the data will be kept private [21]. We ensured that the Certificate figured prominently in the survey. In addition to describing the Certificate in the informed consent, the survey contained repeated reminders about this certificate, and we strategically placed these reminders before sections querying sensitive and illegal behavior.

Past research has found that willingness to respond to location items varies by sociodemographic characteristics, a pattern that may introduce systematic bias [14]. Here, we found borderline statistically significant relationships suggesting that men and homeless individuals were less likely to report the location where they had sex. As Vaughan and colleagues have found [14], reporting this location may be particularly sensitive because it may reveal the identity of an intimately known person, if sex occurs at a primary partner’s home. Homeless individuals may be especially likely to have sex at another person’s home; possibly, heterosexual men were protective of female partners if they tended to have sex at this partner’s home. Individuals who were employed full time were less likely to drop pins at their sex and home locations, perhaps because they were especially fearful of losing their job if survey data became public.

We also found that response rates varied by whether individuals were recruited by staff members, and whether the individual lived in the county where the maps were centered. Past qualitative research conducted in rural Kentucky with people who use drugs provides possible explanations for the recruitment findings. Participants in that qualitative study reported that they would be more likely to disclose location data if they had a strong rapport with interview staff [21]. Our recruitment cookouts were designed to provide opportunities for potential participants to develop rapport with study staff. Cookouts were low-threshold community events in which local residents could choose if and when to approach study staff; if they chose to visit the cookout, they could sit, dine, and chat with study staff and other community residents before deciding whether to self-administer the Web-based screener. We also recruited at the CARE2HOPE project’s storefront; CARE2HOPE is conducted with local people who use drugs and staffed by team members who clearly communicate respect for the dignity of people who use drugs. The rapport developed with study staff at the cookouts and in the CARE2HOPE storefront may have increased participants’ willingness to report sensitive data. In contrast, when peers recruited participants into the study, they did so via digital peer referral (ie, invitations sent by text messages and emails). Individuals recruited through this method may have had multiple concerns, including about the authenticity of the texted or emailed coupons, and about the trustworthiness of faceless researchers. Overall, however, there were few differences in response rates by participant-level characteristics, including age, income, homeless status, or educational attainment, indicating that responses to these items should not be systematically biased by these participant characteristics.

Maps were centered on the county with the largest population size, and people living outside this county were more likely to have missing data on their home location and their sex and drug use locations. We attribute this missingness pattern to problems navigating the maps across the large 5-county surface area (1378 square miles).

We analyzed the precision of pin-drop home locations in 2 ways: examining their proximity to structures and assessing their distance from self-reported street addresses. In a set of rural counties where the vast majority of the 1378 square mile surface area is empty of structures, a high percentage (92%) of participants’ pin-drop home locations were within 100 m of a structure. These pin-drops were, however, a median of 2 miles from their reported home address. There is no gold standard for an acceptable magnitude of error for pin-drops, and this magnitude may vary by purpose. Errors of ≤2 miles between the pin-drop location and the actual location may be acceptable for analyses designed to identify optimal locations of health and social service sites in rural areas, which may necessarily be many miles from most potential clients' homes. Errors of this magnitude, however, may be unacceptably large when investigators are characterizing exposures whose influence depends on close proximity (eg, abandoned buildings). A median error of 2 miles may indicate that participants had trouble navigating to the precise point where their home was located or might have intentionally masked their home location. Supporting the latter interpretation and perhaps for the reasons offered above to explain correlations of missingness and staff recruitment, distances were shorter for staff-recruited participants. Supporting the former interpretation, participants experiencing no technical difficulties or participants who graduated from high school had smaller mapping errors. Rerunning the distance analysis on the subset of participants who reported no technical difficulties resulted in somewhat lower 75th percentile values, suggesting that there were fewer random pin-drops for this subgroup. Although people who injected drugs had shorter distances between their pin-drop and address-based home locations, this may have been an artifact of recruitment method: people who injected were disproportionately likely to have been recruited by staff (*P*=.008).

We found that 64% of pin-drop sex and drug use locations were within 100 m of a structure, a figure that is lower than the 92% found for pin-drop home locations. We conducted post hoc analyses of survey items querying the specific settings where participants engage in risk behaviors, and these post hoc analyses indicate that many participants reported having sex and using drugs outside in the past 6 months, though our unpublished qualitative data had suggested that they preferred to engage in these behaviors inside. For example, 26% reported having sex in a car; 7% reported having sex in a cemetery; and 11% reported having sex in another outdoor location. More than half of the sample (55.4%) reported injecting drugs in a car in the past 6 months; approximately one-fourth reported injecting in a cemetery and one-third reported injecting in another outdoor location. Many participants thus appear to use drugs and have sex in locations that may in fact have been far from a structure.

Few participants reported difficulties completing pin-drop items: 79% reported no technical problems with the Web-based survey whatsoever, and less than 7% of participants endorsed for any mapping-specific difficulties. We note, though, that other rural areas and other populations (eg, older rural adults) may have a poor internet service. For these populations, Web-based mapping items might load slowly or might not load at all; in addition, members of these populations may be unfamiliar with Web-based maps and thus less able to successfully navigate through them.

Limitations

Analyses were conducted on a convenience sample and thus might not be representative of the underlying population of young adults living in the 5-county area who use opioids to get high. Findings may not generalize to older people who use drugs, who may have poorer access to the internet and may be less able to navigate pin-drop maps because of poorer digital literacy [22]. Our measures of activity locations did not encompass the full range of activities in which this population engages (eg, locations where they socialized, shopped, and worked). Our measure did, however, capture locations that people who use drugs may be especially reluctant to disclose. In addition, we did not query the street address for drug use and sex locations and thus could not compare pin-drop and street-address locations for these activities. As noted, however, many participants used drugs and had sex outside in places without street addresses. Same-source bias is a possible limitation for our effort to assess the precision of pin-drop home locations using street address data: individuals may have simply reported someone else's home address and dropped a pin at that location. A high percentage (45%) of participants in this sample reported being homeless. Homeless populations are heterogeneous and may vary in ways that influence the geographic locations where they sleep and engage in risk behaviors, the characteristics of these places, and their willingness to report geospatial information. Future research should develop a larger sample of homeless individuals that is sufficiently powered to explore these variations.

Conclusions and Recommendations

Research methods must keep pace with expanding drug-related crises in rural areas. As public health theories and interventions increasingly recognize the roles of place characteristics in shaping disease and health service use [5-7], researchers have started using pin-drop maps to capture activity spaces among urban populations [14,23]. This analysis suggests that, with some methodologic improvements, pin-drop maps may also be a promising method of collecting data on risk-related activity spaces among rural young adults who use drugs, a population that is understudied and yet at high risk of a host of adverse health outcomes. Specific recommendations to strengthen pin-drop methods to define activity spaces in this population include the following:

- Clearly describing certificates of confidentiality and strategically highlighting it at various points in the survey
- Recruiting participants via staff who are trained to treat people who use drugs with dignity
- Centering maps on the county where the participant lives. This may require that survey programmers have significant technical skills
- Offering the option of completing mapping items with a staff member, if participants have not graduated from high school or encounter technical difficulties
- Gathering metadata on the number of attempts needed to drop each pin (or the number of seconds needed to drop each pin), and whether this number correlates with precision measures

- Including survey items querying participant concerns about providing specific location data for each location type
- Gathering metadata or self-report data on the extent to which participants zoom in or out on each map.

Future research should also expand the range of locations queried (eg, places where people who use drugs socialize, work, shop, worship, and seek health and social services) and populations sampled (eg, older rural people who use drugs) and continue to assess the extent to which missingness and precision vary across and within these new places and populations. As this novel line of inquiry advances into these new places and populations, conducting formative research (eg, cognitive interviews, as was done here) will be vital to address concerns about human subjects' protections, and to identify—and develop strategies to overcome whenever possible—barriers and potential biases in responses.

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Conflicts of Interest

None declared.

References

1. Havens JR, Young AM, Havens CE. Nonmedical prescription drug use in a nationally representative sample of adolescents: evidence of greater use among rural adolescents. Arch Pediatr Adolesc Med 2011 Mar;165(3):250-255. [doi: 10.1001/archpediatrics.2010.217] [Medline: 21041587]
2. Zibbell JE, Iqbal K, Patel RC, Suryaprasad A, Sanders KJ, Moore-Moravian L, Centers for Disease Control and Prevention (CDC). Increases in hepatitis C virus infection related to injection drug use among persons aged ≤30 years - Kentucky, Tennessee, Virginia, and West Virginia, 2006-2012. MMWR Morb Mortal Wkly Rep 2015 May 8;64(17):453-458 [FREE Full text] [doi: 10.3886/ICPSR25221.v9] [Medline: 25950251]
3. Valdiserri R, Khalsa J, Dan C, Holmberg S, Zibbell J, Holtzman D, et al. Confronting the emerging epidemic of HCV infection among young injection drug users. Am J Public Health 2014 May;104(5):816-821. [doi: 10.2105/AJPH.2013.301812] [Medline: 24625174]
4. Gesler WM, Albert DP. How spatial analysis can be used in medical geography. In: Albert DP, Gesler WM, Levergood B, editors. Spatial Analysis, GIS and Remote Sensing: Applications in the Health Sciences. Boca Raton, Florida: CRC Press; 2003:10-37.
5. Gelberg L, Andersen RM, Leake BD. The behavioral model for vulnerable populations: application to medical care use and outcomes for homeless people. Health Serv Res 2000 Feb;34(6):1273-1302 [FREE Full text] [Medline: 10654830]
6. Rhodes T. The 'risk environment': a framework for understanding and reducing drug-related harm. Int J Drug Policy 2002 Jun;13(2):85-94. [doi: 10.1016/S0955-3959(02)00007-5]
7. Gregson J, Foerster SB, Orr R, Jones L, Benedict J, Clarke B, et al. System, environmental, and policy changes: using the social-ecological model as a framework for evaluating nutrition education and social marketing programs with low-income audiences. J Nutr Educ 2001;33(Suppl 1):S4-15. [Medline: 12857540]
8. Williams CT, Metzger DS. Race and distance effects on regular syringe exchange program use and injection risks: a geobehavioral analysis. Am J Public Health 2010 Jun;100(6):1068-1074 [FREE Full text] [doi: 10.2105/AJPH.2008.158337] [Medline: 20395589]
9. Hembree C, Galea S, Ahern J, Tracy M, Piper TM, Miller J, et al. The urban built environment and overdose mortality in New York City neighborhoods. Health Place 2005 Jun;11(2):147-156. [doi: 10.1016/j.healthplace.2004.02.005] [Medline: 15629682]
10. Arcury TA, Preisser JS, Gesler WM, Powers JM. Access to transportation and health care utilization in a rural region. J Rural Health 2005;21(1):31-38. [doi: 10.1111/j.1748-0361.2005.tb00059.x] [Medline: 15667007]
11. ver Ploeg M. United States Department Agriculture: Economic Research Service. 2009. Access to Affordable and Nutritious Food: Measuring and Understanding Food Deserts and Their Consequences: Report to Congress URL: https://www.ers.usda.gov/webdocs/publications/42711/12716_ap036_1_.pdf [accessed 2019-09-09]

12. Sharkey JR, Horel S, Dean WR. Neighborhood deprivation, vehicle ownership, and potential spatial access to a variety of fruits and vegetables in a large rural area in Texas. Int J Health Geogr 2010 May 25;9:26 [FREE Full text] [doi: 10.1186/1476-072X-9-26] [Medline: 20500853]
13. Anderson M. Pew Research Center. 2018. About a Quarter of Rural Americans Say Access to High-speed Internet is a Major Problem URL: https://www.pewresearch.org/fact-tank/2018/09/10/about-a-quarter-of-rural-americans-say-access-to-high-speed-internet-is-a-major-problem/ [accessed 2019-09-09]
14. Vaughan AS, Kramer MR, Cooper HL, Rosenberg ES, Sullivan PS. Completeness and reliability of location data collected on the web: assessing the quality of self-reported locations in an internet sample of men who have sex with men. J Med Internet Res 2016 Jun 9;18(6):e142 [FREE Full text] [doi: 10.2196/jmir.5701] [Medline: 27283957]
15. Bunn T, Slavova S. University of Kentucky College of Medicine. 2012. Drug Overdose Morbidity and Mortality in Kentucky, 2000 - 2010: An Examination of Statewide Data, Including the Rising Impact Of Prescription Drug Overdose on Fatality Rates, and the Parallel Rise in Associated Medical Costs URL: http://www.mc.uky.edu/kiprc/PDF/Drug_Overdose_Morbidity_and_Mortality_in_Kentucky_2000_-_2010-final.pdf [accessed 2019-09-09]
16. SurveyGizmo. 2018. URL: https://www.surveygizmo.com/ [accessed 2019-09-09]
17. Ballard AM, Cardwell E, Young AM. Development and evaluation of a fraud detection protocol for web-based research among men who have sex with men. J Med Internet Res Public Health Surveill 2019:- (forthcoming).
18. ArcGIS. 2018. ArcMap URL: http://desktop.arcgis.com/en/arcmap/ [accessed 2019-09-09]
19. SAS: Analytics, Artificial Intelligence and Data Management. SAS/STAT® Software URL: https://www.sas.com/en_in/software/stat.html [accessed 2019-09-09]
20. Office of Extramural Research - National Institutes of Health. 2019. Certificates of Confidentiality (CoC) - Human Subjects URL: https://grants.nih.gov/policy/humansubjects/coc.htm [accessed 2019-09-09]
21. Rudolph AE, Young AM, Havens JR. A rural/urban comparison of privacy and confidentiality concerns associated with providing sensitive location information in epidemiologic research involving persons who use drugs. Addict Behav 2017 Nov;74:106-111 [FREE Full text] [doi: 10.1016/j.addbeh.2017.06.006] [Medline: 28609723]
22. Levy H, Janke AT, Langa KM. Health literacy and the digital divide among older Americans. J Gen Intern Med 2015 Mar;30(3):284-289 [FREE Full text] [doi: 10.1007/s11606-014-3069-5] [Medline: 25387437]
23. Koblin BA, Egan JE, Rundle A, Quinn J, Tieu HV, Cerdá M, et al. Methods to measure the impact of home, social, and sexual neighborhoods of urban gay, bisexual, and other men who have sex with men. PLoS One 2013;8(10):e75878 [FREE Full text] [doi: 10.1371/journal.pone.0075878] [Medline: 24146785]

Abbreviations

ARC: Appalachian Regional Commission
CDC: Centers for Disease Control and Prevention
GPS: global positioning system
HCV: hepatitis C virus
IRB: institutional review board
PIs: principal investigators
SAMHSA: Substance Abuse and Mental Health Services Administration

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Original Paper

Assessment of Temporary Community-Based Health Care Facilities During Arbaeenia Mass Gathering at Karbala, Iraq: Cross-Sectional Survey Study

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Abstract

Background: Arbaeenia mass gathering (MG) in Karbala, Iraq, is becoming one of the largest MGs in the world. The health care infrastructure in Iraq is inadequately prepared to serve the health needs of the millions of pilgrims.

Objective: This study aimed to describe the temporary health care facilities installed and run by the local community to provide health care services to Arbaeenia pilgrims in Karbala, Iraq.

Methods: A survey was conducted in all community-based health care facilities located along part of Najaf to Karbala road within Karbala governorate. A structured questionnaire was answered through an interview with the workers and direct observation. Data were collected on staff profile, type of services provided, use of basic infection control measures, medical equipment, drugs and supplies, and the most commonly encountered medical problems.

Results: The total number of health care facilities was 120, staffed by 659 workers. Only 18 (15.0%, 18/120) facilities were licensed, and 44.1% (53/120) of the workers were health professionals. The health care workers provided different services including dispensing drugs (370/1692, 21.87%), measuring blood pressure and blood sugar (350/1692, 20.69%), and caring for wounds and injuries (319/1692, 18.85%). Around 97% (116/120) health facilities provided services for musculoskeletal disorders and only 16.7% (20/120) provided services for injuries. The drugs available in the clinic were analgesics, drugs for gastrointestinal and respiratory diseases, and antibiotics, with an availability range of 13.3% to 100.0%. Infection control practices for individual protection, environmental sanitation, and medical waste disposal were available in a range of 18.1% to 100.0%.

Conclusions: Community-based health care facilities experienced a profound shortage of trained human resources and medical supplies. They can significantly contribute to health services if they are adequately equipped and follow standardized operation procedures.

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KEYWORDS

Arbaeenia mass gathering; community-based health care; Iraq

Introduction

Background

Mass gathering (MG) is the assembly of a large organized or unorganized population in a limited space for a specified period, which often strains available resources and services [1]. The World Health Organization (WHO) also defines MGs as "events attended by a sufficient number of people to strain the planning and response resources of a community, state or nation" [2]. The purpose of the assembly is often for a religious, sport, or social event.

MGs occur frequently around the world and pose a whole spectrum of challenges on local country systems. The public health systems can be compromised during MGs if not well prepared even in countries with appropriate resources to prevent and control endemic diseases [3]. Regardless of the type of MGs, various health problems were reported among MG participants and local communities who are at risk of acquiring infectious diseases or injuries [4-8]. Proper planning before the event can help to prevent causalities and health problems. Countries with abundant resources often develop disaster preparedness plans to address MGs; however, many developing countries cannot afford to allocate adequate resources for such events and may seek assistance from other countries [9].

The provision of basic health care and emergency services is essential for the safety of MG attendees. In Iraq, the task of providing these services is under the authority of the Ministry of Health (MOH).

In Iraq, millions of people gather annually on the 20th day of the lunar month of Safar in Karbala for the remembrance of Arbaeen of Imam Hussain from different countries, mainly from Iran, Afghanistan, Pakistan, and Arab Gulf countries, in addition to several millions of people from most provinces of Iraq walking for hundreds of kilometers en route to Karbala (Karbala is located 100 km southeast of the capital, Baghdad, with a population of approximately 1.2 million inhabitants) over many days that make them at risk of airborne, foodborne, and waterborne diseases and injuries. The Arbaeenia MG is expected to increase in size once the political and security situation of the country stabilizes, as the operation department at MOH declared that the density of participants increased during previous years. The country's capacity to support the health needs of the MG participants is a concern as the health care infrastructure in Iraq has been negatively impacted by ongoing wars and sanctions affecting the country since the 1990s. Health care facilities have been destroyed during violent conflict, some of which have been rebuilt. In addition, Iraq has lost approximately 50% of its workforce of physicians since 1990. There were 34,000 physicians registered in the Iraqi Medical Association in 1990, and only 16,000 physicians were registered in 2008 [10]. The local health care infrastructure in Karbala struggles to meet the needs of the local community and is ill-prepared to serve the health needs of the millions of participants in the Arbaeenia MG. Information on the public health in MGs is needed to support the government in planning for Arbaeenia; however, there have been few formal studies conducted on MGs in Iraq [11]. Adequate preparedness plans are essential for handling medical emergencies during the Arbaeenia MG to prevent causalities and harm to population health.

Objectives

This study aimed to describe the temporary health care facilities installed and run by the local community and provide health care services to the Arbaeenia MG attendees in Karbala, Iraq, as a first step for mapping available resources.

Methods

A cross-sectional survey was conducted from December 5, 2014, to December 14, 2014, to describe the health care services provided by the local community to participants in the Arbaeenia MG in Karbala, Iraq. Najaf and Karbala are neighboring governorates, and the distance between Najaf City (capital of Najaf governorate) and Karbala city (capital of Karbala governorate) is 80 km; 22 km are within the boundaries of Karbala governorate. All community-based health care facilities located along these 22 km within Karbala boundaries were chosen in this study. These health care facilities belonged to civil society organizations called Mawakeb Committees. They offered participants voluntary free-of-charge services such as food and bed as well as basic primary health care services. These facilities were visited and examined after the consent was obtained as part of the study.

Data Collection Tool

A structured questionnaire was used to collect information on the facilities, staff profile, type of services provided, and inventory of medical equipment and supplies. Data were collected by 5 trained data collectors, and information was collected through interviews with the health workers and observations. The questionnaire was pilot tested before the study was implemented.

Through the questionnaire and observation, information was collected on the health care facilities including licensure status given by the MOH, type of building, type of service offered (dispensing medicine, dressing and suturing wounds and injuries, blood pressure and blood sugar measurements, minor operations, and others), documentation and access to ambulance and mobile clinic services, and availability of clean running water.

In addition, the availability and expiration dates of drugs were recorded. Information on the number of doses and duration of antibiotics dispensed was collected, and their expiration dates were verified. Data collectors also obtained information on the health care facility staff, including age, gender, education, and occupation. Health care workers were asked to indicate the type of medical services they offered to the MG participants. Health care workers were also asked if the facility provided services to MG participants on 4 commonly expected illnesses: respiratory diseases, chronic diseases, injuries, and musculoskeletal disorders.

Information was collected on infection control measures and if these measures were used on all event days, including medical waste management; personal protection measures such as washing hands with soap or using alcohol and wearing disposable gloves, face masks, and goggles; and environmental sanitation. An inventory of medical equipment was also conducted.

Statistical Analysis

The data were entered and analyzed in Epi Info 7 developed by US Centers for Diseases Control and Prevention, Atlanta, Georgia. We estimated the mean age and average score of medical services, drugs, infection control measures, medical services, and medical equipment, in addition to the percentage distribution of health care facility attributes, primary health care services offered by the facilities, availability of drugs, and the sociodemographics of the health workers. We calculated the distribution of the primary health care services by category of health workers, available drugs, available medical equipment, and infection control materials by licensure status of the health care facility. Fisher exact test was used to compare the percentages. A *P* value of less than .05 was considered statistically significant.

Results

There were 120 health care facilities along the 22 km, toward Karbala from Najaf, that were included in the study. Only 18 (15.0%, 18/120) health care facilities were concrete buildings, whereas the majority (85.0%, 102/120) were tents or caravans. Moreover, 18 facilities (15.0%, 18/120) had MOH licenses, and 87 (72.5%, 87/120) had an identifiable health care facility signage. Presence of mobile clinic or ambulance services in proximity of the surveyed facilities was found only in less than 40% of the outlets.

Sociodemographic Characteristics

A total of 659 health care workers staffed these health care facilities, 164 (24.9%) for the licensed and 495 (75.1%) for the unlicensed health care facilities. Of the total health care workers, 293 (44.5%, 293/659) were health care professionals. The mean age of the health care workers was 37 years (range: 15-85 years), 84.9% were male (560/659), and 52.5% (349/659) had postsecondary education. Of the 164 health workers staffing the licensed facilities, 101 (61.6%) were health care professionals, compared with 192 (38.8%) professional health care workers in the unlicensed facilities (Table 1).

Table 1. Sociodemographic distribution of health care workers working in community-based health care facilities during Arbaeenia mass gathering in Karbala, Iraq, 2014.

Sociodemographic variables	Workers at the facilities		Total (N=659), n (%)
	Licensed facility (N=164), n (%)	Unlicensed facility (N=495), n (%)	
Sex			
Male	132 (80.5)	428 (86.5)	560 (85.0)
Female	32 (19.5)	67 (13.5)	99 (15.0)
Educational level			
Illiterate	3 (1.8)	20 (4.0)	23 (3.5)
Primary	4 (2.4)	68 (13.7)	72 (10.9)
Secondary	47 (28.7)	166 (33.5)	213 (32.3)
Postsecondary	110 (67.1)	241 (48.7)	351 (53.3)
Occupation			
Physician-pharmacist	8 (4.9)	33 (6.7)	41 (6.2)
Other health professionals	93 (56.7)	159 (32.1)	252 (38.2)
Nonhealth staff	63 (38.4)	303 (61.2)	366 (55.5)

Diseases Categories

Around 97% of health facilities (116/120) provided services for musculoskeletal disorders, 55.8% (67/120) provided services for gastrointestinal disorders, 23.3% (28/120) for respiratory disorders, 28.3% (34/120) for noncommunicable diseases and 16.7% (20/120) for injuries.

Provided Health Services

Health care workers provided some medical services to the participants of the Arbaeenia MG en route to Karbala (Table 2), which included dispensing drugs (21.87, 370/1692%), dressing and stitching wounds and injuries (18.85%, 319/1692), measuring blood pressure/blood sugar (20.69%, 350/1692), and providing injections (16.67%, 282/1692). The majority of these medical services were provided by paramedical health workers (≥57%), and 81.3% (301/371) of massaging services were provided by nonhealth care workers (Table 2).

Table 2. Distribution of provided medical services by type of personnel working at the community-based healthcare facilities during Arbaeenia mass gathering in Karbala, Iraq, 2014.

Medical services	Type of personnel working at community-based healthcare facilities			Total responses (n=1692), n (%)
	Physician-pharmacist, n (%)	Other health care professionals, n (%)	Nonhealth care staff, n (%)	
Dispensing drugs	40 (10.8)	212 (57.3)	118 (31.9)	370 (21.87)
Dressing or stitching	30 (9.4)	203 (63.6)	86 (27.0)	319 (18.85)
Measuring blood pressure or blood sugar	31 (8.9)	212 (60.6)	107 (30.5)	350 (20.69)
Injections	14 (5.0)	197 (69.9)	71 (25.2)	282 (16.67)
Providing massage	2 (0.5)	68 (18.3)	301 (81.1)	371 (21.92)

Available Medications

In terms of drug availability, analgesics, antispasmodic, antidiarrhea, antibiotics, and ointments (antibiotics, antiallergy, and others) were available in more than 90% of the health care facilities (Table 3). The antihypertensive drugs, oral hypoglycemic medicines, and cough syrups were available in less than 60% of the health care facilities. None of the drugs were expired. There was a wide disparity between the licensed and unlicensed facilities in the availability of all 10 drugs, 39% and 6%, respectively. On a scale of 0-10, the average number of drugs available in the health care facility was 7.3 (73%).

According to the inventory of medical equipment, 72.5% (87/120) of the facilities had a sphygmomanometer, 69.2% (83/120) had a glucometer, and 63.3% (76/120) had a stethoscope (Table 3). Less than 45% of the facilities had the remaining medical equipment: thermometer, tongue depressor, and torch. On a scale of 10, the average number of equipment available in the facility was 5 (50%). The average number varied by the type of facility, 7.4 (74%, 7.4/10) for licensed and 4.6 (46%) for unlicensed facilities.

Table 3. Types of drugs and medical equipment available at the community-based health care facilities during Arbaeenia mass gathering in Karbala, Iraq, 2014.

Drugs and medical equipment	Type of facility		Total (N=120), n (%)
	Licensed (N=18), n (%)	Not licensed (N=102), n (%)	
Drugs			
Analgesics	18 (100)	102 (100.0)	120 (100.0)
Antispasmodics	18 (100)	90 (88.2)	108 (90.0)
Antiemetic	15 (83)	79 (77.5)	94 (78.3)
Antidiarrheal	17 (94)	91 (89.2)	108 (90.0)
Antihypertensive	12 (67)	56 (54.9)	68 (56.7)
Oral hypoglycemic	12 (67)	59 (57.8)	71 (59.2)
Antibiotics	16 (89)	96 (94.1)	112 (93.3)
Ointments	18 (100)	94 (92.2)	112 (93.3)
Cough syrup	14 (78)	56 (54.9)	70 (58.3)
Oral rehydration salt	8 (44)	8 (7.8)	16 (13.3)
Medical equipment			
Stethoscope	16 (89)	60 (58.8)	76 (63.3)
Thermometer	10 (56)	43 (42.2)	53 (44.2)
Sphygmomanometer	17 (94)	70 (68.6)	87 (72.5)
Glucometer	15 (83)	68 (66.7)	83 (69.2)
Light source	11 (61)	23 (22.6)	34 (28.3)
Tongue depressor	11 (61)	18 (17.7)	29 (24.2)

Infection control practices

Table 4 shows the infection control practices in the health care facilities. Washing hands with soap and using antiseptic materials were practices observed by all facilities (100.0%, 120/120). Percentage availability and observed differences of the other 9 tracer elements were found to be much higher at licensed facilities and statistically significant, except for using disposable gloves and syringes and presence of a surgical set. Apart from facilities that only dispensing drugs, 90.5% (95/105) of remaining facilities used disposable syringes, 79.0% (83/105) used disposable latex gloves, 44.8% (47/105) used alcohol swabs for cleaning hands, and 41.9% (44/105) had surgical sets. The remaining infection control measures—medical waste disposal box, environmental disinfectants, facemask, and medical coat—were practiced in less than 22% of the facilities (Table 4). Only 5% of the facilities practiced all the infection control measures, 18% for the licensed and 2% for the unlicensed facilities. The average score of the infection control practices was 5.1 on a scale of 10 (51%), 7.8 (78%) for licensed and 4.6 (46%) for unlicensed facilities.

Table 4. Availability of infection control measures at the community-based health care facilities during Arbaeenia mass gathering in Karbala, Iraq, 2014.

Infection prevention control measures	Type of facility[a]		Total (N=105), n (%)	*P* value
	Licensed (N=17), n (%)	Not licensed (N=88), n (%)		
Washing hands with soap	17 (100)	88 (100)	105 (100.0)	>.99
Alcohol-based hand rub	17 (100)	30 (34)	47 (44.8)	<.001
Wear disposable latex gloves	16 (94)	67 (76)	83 (79.0)	.08
Use disposable syringes	16 (94)	79 (90)	95 (90.5)	.49
Safety box—medical waste	9 (53)	10 (11)	19 (18.1)	<.001
Receptacle with cover	13 (76)	20 (23)	33 (31.4)	<.001
Use environmental disinfectants	8 (47)	8 (9)	16 (15.2)	.001
Use antiseptic materials	17 (100)	88 (100)	105 (100.0)	>.99
Presence of a surgical set	11 (65)	33 (38)	44 (41.9)	.03
Wear face masks	10 (59)	9 (10)	19 (18.1)	<.001
Wear a medical coat	12 (71)	10 (11)	22 (21.0)	<.001

[a] Clinics that provide only drug dispensing were excluded from the analysis.

Discussion

Principal Findings

This study shows that the participants in the Arbaeenia MG had access to some form of health care services through facilities on the route to Karbala. The area covered by the study constituted one-fourth of the distance of the road from Najaf to Karbala, which is considered the main road taken by most of the participants, especially those from southern provinces and who come through the Najaf airport, whereas the remaining three-fourths of the road had a similar distribution to the distance covered by the study. Hence, approximately 460 facilities could be available to serve the 14 million visitors with a facility to population ratio of 1:30,000 [12]. This ratio is below the ratio of primary health care units to population in Iraq (ie, 1:10,000) [13]. Other studies indicate a similar facility-population ratio, that is, 7.4:100,000 [14]. Using a similar assumption as above, the expected number of health care workers available to serve the visits could be approximately 2400, with a health worker to population ratio of approximately 1:6000. Limiting the total expected health workers to expected health professionals of 1065, the adjusted health worker to population ratio would be 1:13,000. This is comparable with the ratio of professional health workers to population in Iraq, that is, 1:15,000. These estimates show that participants in the MG had similar access to health care workers as the general population. The health care facility to population ratio for the visitors is worse than that offered to the Iraq population [15].

The MG participants received limited medical emergency services from the health workers in the health care facilities, including injury management and dispensing drugs. Only one-tenth of the facilities had all the commonly used drugs for the situation. These drugs treat gastrointestinal, respiratory, and common chronic diseases such as hypertension and diabetes, which are common among the participants in Arbaeenia. Similarly, pain killers, antibiotics, and ointments used for multiple illnesses are needed when addressing the health needs of large masses that are at risk of respiratory infections and musculoskeletal pains because of walking long distances [16]; however, 32% of those who dispensed drugs were nonhealth care staff (Table 2), and this malpractice was reported in the Middle East countries [17-19], Saudi Arabia [20], and even in developed countries [21-25]. One-third and one-tenth of the Iraq population aged 25 years and older have hypertension and diabetes, respectively, and drugs to control the 2 diseases were available in almost three-fifths of the facilities [15]. Medical equipment for measuring blood pressure and blood sugar was also available in three-fourth of the health care facilities. For handling medical emergencies, only two-fifths of the facilities had access to mobile clinics and ambulance services for transporting patients to appropriate hospitals, which may not be adequate.

The facilities practiced infection control measures for individual protection, environmental sanitation, and disposing medical waste. However, only one-fifth of the facilities practiced all the identified infection control measures to protect individuals and environment and for proper disposal of medical wastes. The licensed facilities are relatively better than nonlicensed facilities in this area (Table 4). All facilities should practice all the infection control measures required to control the spread of infections and prevent hazards from the environmental and medical wastes. Medical waste disposal should follow special procedures developed by WHO [3,26]; however, less than one-fifth of the health facilities visited had a safe box for disposing medical wastes, which constituted one-half of the licensed facilities. Overall, there were weak medical waste disposal practices and infection control measures. The health facilities can be fertile grounds for spreading infectious diseases to the participants in the Arbaeenia MG and potentially within the region and at a global level.

MGs require well-planned health care services that are executed effectively, including outpatient care services for minor illnesses, care for medical emergencies, and access to ambulance services and designated hospitals for referrals. The temporary health care services for the MG participants traveling to Karbala were set up by local communities without guidance from the MOH. Thus, facility staffing, supply of drugs and medical equipment, and other necessary materials such as infection control materials were established without necessary compliance with MOH standards. The risk of mass causalities is high, and the government should develop an assessment and response preparedness plan that engages the temporary health clinics for future MGs to prevent causalities and health risks. As the event occurs every year, medical education for physicians and other paramedics should include management of medical problems related to MGs.

Limitations

The main limitation is difficulty in conducting the study among 80 km distances from Najaf to Karbala; therefore, the study was conducted by taking a convenience sample that covered only one-fourth of the distance of the road.

This is the first assessment of community-based health care facilities and resources serving the Arbaeenia MG participants traveling to Karbala. Further assessment of the adequacy, quality, appropriateness, and preparedness to respond to mass causalities is needed.

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Conflicts of Interest

None declared.

References

1. Locoh-Donou S, Guofen Y, Welcher M, Berry T, O'Connor RE, Brady WJ. Mass-gathering medicine: a descriptive analysis of a range of mass-gathering event types. Am J Emerg Med 2013 May;31(5):843-846. [doi: 10.1016/j.ajem.2013.01.016] [Medline: 23453125]
2. World Health Organization. 2008. Communicable Disease Alert and Response for Mass Gatherings: Key Considerations URL: https://www.who.int/csr/Mass_gatherings2.pdf [accessed 2019-09-03]
3. World Health Organization. 2015. Public Health For Mass Gatherings: Key Considerations URL: http://apps.who.int/iris/bitstream/10665/162109/1/ [accessed 2018-12-13]
4. Soomaroo L, Murray V. Disasters at mass gatherings: lessons from history. PLoS Curr 2012 Feb 2;4:RRN1301 [FREE Full text] [doi: 10.1371/currents.RRN1301] [Medline: 22453897]
5. Zumla A, Dar O, Kock R, Muturi M, Ntoumi F, Kaleebu P, et al. Taking forward a 'One Health' approach for turning the tide against the Middle East respiratory syndrome coronavirus and other zoonotic pathogens with epidemic potential. Int J Infect Dis 2016 Jun;47:5-9 [FREE Full text] [doi: 10.1016/j.ijid.2016.06.012] [Medline: 27321961]
6. Memish ZA. Meningococcal disease and travel. Clin Infect Dis 2002 Jan 1;34(1):84-90. [doi: 10.1086/323403] [Medline: 11731951]
7. Wilder-Smith A, Goh KT, Barkham T, Paton NI. Hajj-associated outbreak strain of Neisseria meningitidis serogroup W135: estimates of the attack rate in a defined population and the risk of invasive disease developing in carriers. Clin Infect Dis 2003 Mar 15;36(6):679-683. [doi: 10.1086/367858] [Medline: 12627350]
8. Razavi S, Ardakani HZ, Rajai S, Hollisaz M, Sadeghipoor H, Farshad A, et al. Trends in prevalent injuries among Iranian pilgrims in Hajj. Iran J Public Health 2011;40(2):110-115 [FREE Full text] [Medline: 23113080]
9. Thackway S, Churches T, Fizzell J, Muscatello D, Armstrong P. Should cities hosting mass gatherings invest in public health surveillance and planning? Reflections from a decade of mass gatherings in Sydney, Australia. BMC Public Health 2009 Sep 8;9:324 [FREE Full text] [doi: 10.1186/1471-2458-9-324] [Medline: 19735577]
10. International Committee of the Red Cross (ICRC). 2010. Iraq: Putting the Health-care System Back on Its Feet URL: https://www.icrc.org/eng/resources/documents/update/iraq-update-290710.htm [accessed 2018-12-13]
11. Al-Lami F, Al-Fatlawi A, Bloland P, Nawwar A, Jetheer A, Hantoosh H, et al. Pattern of morbidity and mortality in Karbala hospitals during Ashura mass gathering at Karbala, Iraq, 2010. East Mediterr Health J 2013;19(Suppl 2):S13-S18 [FREE Full text] [doi: 10.26719/2013.19.supp2.s13] [Medline: 24673093]

12. Centers for Disease Control and Prevention (CDC). Surveillance for early detection of disease outbreaks at an outdoor mass gathering--Virginia, 2005. MMWR Morb Mortal Wkly Rep 2006 Jan 27;55(3):71-74 [FREE Full text] [doi: 10.1001/jama.295.10.1115] [Medline: 16437057]
13. The WHO Regional Office for the Eastern Mediterranean. 2014. Iraq: Primary Health Care URL: http://www.emro.who.int/irq/programmes/primary-health-care.html [accessed 2018-12-13]
14. Morimura N, Katsumi A, Koido Y, Sugimoto K, Fuse A, Asai Y, et al. Analysis of patient load data from the 2002 FIFA World Cup Korea/Japan. Prehosp Disaster Med 2004;19(3):278-284. [doi: 10.1017/s1049023x00001874] [Medline: 15571204]
15. World Health Organization. 2008. Iraq: WHO Statistical Profile URL: http://www.who.int/gho/countries/irq.pdf?ua=1%5Baccessed [accessed 2019-04-20]
16. Alzahrani AG, Choudhry AJ, Al Mazroa MA, Turkistani AH, Nouman GS, Memish ZA. Pattern of diseases among visitors to Mina health centers during the Hajj season, 1429 H (2008 G). J Infect Public Health 2012 Mar;5(1):22-34 [FREE Full text] [doi: 10.1016/j.jiph.2011.10.003] [Medline: 22341840]
17. Sabry NA, Farid SF, Dawoud DM. Antibiotic dispensing in Egyptian community pharmacies: an observational study. Res Social Adm Pharm 2014;10(1):168-184. [doi: 10.1016/j.sapharm.2013.03.004] [Medline: 23665078]
18. Al-Faham Z, Habboub G, Takriti F. The sale of antibiotics without prescription in pharmacies in Damascus, Syria. J Infect Dev Ctries 2011 May 28;5(5):396-399 [FREE Full text] [doi: 10.3855/jidc.1248] [Medline: 21628818]
19. Abuirmeileh A, Samara S, Alkhodari A, Bahnassi A, Talhouni A, Hayallah AM. Antibiotic dispensing without prescription in Jordanian community pharma-cies: a pharmacist's perspective. Bull Pharm Sci 2014;37:51-63 [FREE Full text]
20. Bin Abdulhak AA, Altannir MA, Almansor MA, Almohaya MS, Onazi AS, Marei MA, et al. Non prescribed sale of antibiotics in Riyadh, Saudi Arabia: a cross sectional study. BMC Public Health 2011 Jul 7;11:538 [FREE Full text] [doi: 10.1186/1471-2458-11-538] [Medline: 21736711]
21. Roque F, Soares S, Breitenfeld L, López-Durán A, Figueiras A, Herdeiro MT. Attitudes of community pharmacists to antibiotic dispensing and microbial resistance: a qualitative study in Portugal. Int J Clin Pharm 2013 Jun;35(3):417-424. [doi: 10.1007/s11096-013-9753-4] [Medline: 23397322]
22. Amábile-Cuevas C. Antibiotic resistance in Mexico: a brief overview of the current status and its causes. J Infect Dev Ctries 2010 Mar 29;4(3):126-131 [FREE Full text] [doi: 10.3855/jidc.427] [Medline: 20351451]
23. Zapata-Cachafeiro M, González-González C, Váquez-Lago JM, López-Vázquez P, López-Durán A, Smyth E, et al. Determinants of antibiotic dispensing without a medical prescription: a cross-sectional study in the north of Spain. J Antimicrob Chemother 2014 Nov;69(11):3156-3160 [FREE Full text] [doi: 10.1093/jac/dku229] [Medline: 24966275]
24. Plachouras D, Kavatha D, Antoniadou A, Giannitsioti E, Poulakou G, Kanellakopoulou K, et al. Dispensing of antibiotics without prescription in Greece, 2008: another link in the antibiotic resistance chain. Euro Surveill 2010 Feb 18;15(7):19488 [FREE Full text] [doi: 10.2807/ese.15.07.19488-en] [Medline: 20184852]
25. Santa-Ana-Tellez Y, Mantel-Teeuwisse AK, Dreser A, Leufkens HG, Wirtz VJ. Impact of over-the-counter restrictions on antibiotic consumption in Brazil and Mexico. PLoS One 2013;8(10):e75550 [FREE Full text] [doi: 10.1371/journal.pone.0075550] [Medline: 24146761]
26. World Health Organization. Safe Management of Wastes from Health-care Activities. Second Edition. Geneva, Switzerland: World Health Organization; 2014.

Abbreviations

MG: mass gathering
MOH: Ministry of Health
WHO: World Health Organization

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Original Paper

Syndromic Surveillance of Communicable Diseases in Mobile Clinics During the Arbaeenia Mass Gathering in Wassit Governorate, Iraq, in 2014: Cross-Sectional Study

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Abstract

Background: Arbaeenia is the largest religious mass gathering organized annually in Karbala city, Iraq, and is attended by 8-14 million people. Outbreaks of communicable diseases are a significant risk due to overcrowding and potential food and water contamination. Syndromic surveillance is often used for rapid detection and response to disease outbreaks.

Objective: This study was conducted to identify the main communicable diseases syndromes among pilgrims during the Arbaeenia mass gathering in Wassit governorate, Iraq, in 2014.

Methods: This cross-sectional study was conducted in the 40 mobile clinics established within Wassit governorates along the road to Karbala during the Arbaeenia mass gathering. Six communicable disease syndromes were selected: acute watery diarrhea, bloody diarrhea, fever and cough, vomiting with or without diarrhea, fever and bleeding tendency, and fever and rash. A simple questionnaire was used to directly gather basic demographics and the syndromic diagnosis from the attendees.

Results: A total of 87,865 patients attended the clinics during the 10-day period, with an average of 219 patients/clinic/day. Approximately 5% (3999) of the attendees had communicable diseases syndromes: of these, 1693 (42%) had fever and cough, 1144 (29%) had acute diarrhea, 1062 (27%) presented with vomiting with/without diarrhea, and 100 (2%) had bloody diarrhea. The distribution of the syndromes did not vary by age or gender. Stool specimen cultures for *Vibrio cholerae* performed for 120 patients with acute diarrhea were all negative.

Conclusions: Syndromic surveillance was useful in determining the main communicable diseases encountered during the mass gathering. Expansion of this surveillance to other governorates and the use of mobile technology can help in timely detection and response to communicable disease outbreaks.

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KEYWORDS

Arbaeenia; mass gathering; syndromic surveillance; communicable diseases; Iraq

Introduction

Mass gatherings are defined as preplanned public events that are held for a limited time period and attended by more than 25,000 people. Mass gatherings can be festivals, religious activities, sporting events, concerts, political rallies, or other events. The duration of the event could range from several hours to several days [1].

Mass gatherings create favorable conditions for infectious disease transmission [2]. Participants in mass gatherings are at risk of infection, with the potential to transmit diseases to their local communities after returning from the event. Mass gatherings may also exacerbate noncommunicable disease conditions, which may lead to emergencies and hospital admissions [3]. Infectious disease outbreaks are common during mass gatherings [4-6]. Severe respiratory infections are major causes of hospitalizations during mass gatherings such as Hajj [7-10]. National surveillance systems are often incapable of monitoring the public health threats from mass gatherings [11]. Although mass gatherings pose challenges to health care systems worldwide [12], they provide an opportunity to strengthen both emergency and routine surveillance and response systems, which can benefit countries long after the event [13].

Several religious mass gatherings occur on an annual basis in Iraq, drawing up to 10 million pilgrims at a time. The mass gathering known as “Arbaeenia” is one of the largest annual mass gatherings in the world, during which individuals may walk up to 600 km through Iraqi governorates to visit the Imam Hussein’s shrine in Karbala to commemorate the 40th day after his martyrdom [14].

The use of appropriate surveillance systems ensures timely information management for effective planning and response to infectious diseases threats during the pilgrimage [15]. The influx of people places a strain on existing surveillance and response systems, and due to the media and political attention generated by mass gatherings, the adverse consequences of any negative health event may be greatly magnified [13].

As part of the health services delivered to pilgrims, Iraq’s Ministry of Health set up mobile clinics along the main roads leading to Karbala to provide ambulatory health services to the pilgrims. Public health surveillance during mass gatherings is essential to detect and respond to disease epidemics that could have pandemic potential, in a timely manner. Syndromic surveillance makes preliminary clinical information available in a much more timely manner and avoids a potentially lengthy delay required for definitive, laboratory-confirmed diagnoses.

Currently, the routine national surveillance system for the main communicable diseases in Iraq is not implemented in the temporary mobile clinics during mass gatherings events, as these clinics are more concerned with provision of basic curative services. To fill the gap in disease surveillance in these clinics, we introduced the syndromic surveillance that covers a spectrum of communicable diseases of concern to the national public health system during mass gatherings.

The objective of this study was to identify the main communicable disease syndromes reported among mass gathering attendees who seek care from the mobile clinics in Wassit governorate during the Arbaeenia mass gathering event. Information obtained from this study is expected to enhance future planning of mass gathering events and develop an effective surveillance system for the mass gatherings.

Methods

We conducted this cross-sectional study during the Arabeenia mass gathering that occurred on December 1-10, 2014, in Wassit governorate, Iraq. Wassit governorate is located in the middle of Iraq. Kut city is the center of the governorate, 180 km south of the capital Baghdad. The area of Wassit governorate is 17,012 km^2, and the population is 1,240,930 people.

The study was conducted in the 40 mobile clinics that were set up in Wassit governorate along the 140-km road from the southern borders of Wassit, with Misan governorate to the northern borders along Babylon governorate. Throughout the country, these mobile clinics are established during the mass gathering event and provided only ambulatory curative services to the pilgrims. Only a small proportion of these clinics are run by medical doctors.

In this study, a basic communicable disease surveillance system was started in these 40 clinics after obtaining official approval from Iraq’s Ministry of Health. Six communicable disease syndromes were selected: acute watery diarrhea, bloody diarrhea, fever and cough, vomiting with or without diarrhea, fever and bleeding tendency, and fever and rash.

A short form was developed to gather data from all patients who attended these mobile clinics and presented with any of the six syndromes. The form included the age (classified only in two categories: <5 years and >5 years), sex, the total number of patients attending the mobile clinic, and the diagnosis of communicable diseases classified into the six syndromes listed above. The information in the form was recorded in the mobile clinic’s registry book. All the health workers working in these clinics received a short training by the communicable disease surveillance officers in Wassit governorate on how to fill the form and call the surveillance officers when needed, based on the guidelines of the Iraq Communicable Diseases Control Centre.

Data entry and analysis were performed using Epi Info 7 software (Centers for Disease Control and Prevention, Atlanta, Georgia). Frequency distribution of different communicable disease syndromes and their distribution by age, sex, and days of data collection was performed.

Results

A total of 87,865 patients attended the mobile clinics in the 10-day period when the pilgrims walked through Wassit governorate on their way to Karbala city. The number of average daily attendees was 8786 patients, with 219 patients/clinic/day. There were 3999 patients with different communicable disease syndromes, constituting 4.6% of the total patients who attended the mobile clinics. Table 1 shows the number and proportion of patients who attended the clinic for the selected communicable disease syndromes.

Approximately 2% (1693/87,865) of the pilgrims attended the clinics for fever and cough, 1.3% (n=1144) attended for acute diarrhea, and 0.11% (100/87,865) attended for bloody diarrhea. During the 10 days of observation, none of the attendees to the mobile clinics presented with fever and rash or fever and bleeding syndromes. Moreover, 120 (10.5%) stool samples were randomly collected from patients with acute diarrhea for culture of *Vibrio cholerae*, all of which tested negative.

Fever and cough constituted the major proportion of communicable diseases presented at the mobile clinics (1693/3999, 42.3%), followed by acute diarrhea (1144/3999, 28.6%), vomiting with or without diarrhea (1062/3999, 26.6%), and bloody diarrhea (100/3999, 2.5%).

The reported syndromes were almost similarly distributed between the two age groups and both sexes, except acute diarrhea, where 61% (699/1144) of the cases were reported among attendees aged>5 years (Table 2).

The time distribution of the four syndromes is displayed in Figure 1. The highest proportion of the four syndromes was reported on the second day. Apart from the small increase in the proportion of fever and cough and vomiting on the eighth day and acute diarrhea on the ninth day, there was a gradual decrease over the study days.

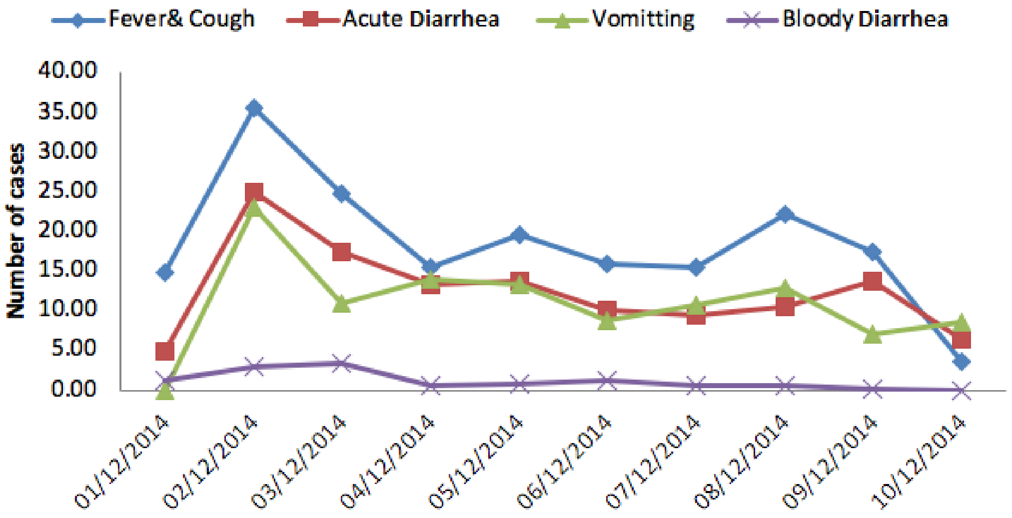
Table 1. Distribution of communicable disease syndromes among mobile clinics attendees during the Arbaeenia mass gathering in Wassit, Iraq, in 2014 (N=87,865).

Communicable disease syndrome	Total mobile clinic attendees, n (%)
Fever and cough	1693 (1.93)
Acute diarrhea	1144 (1.30)
Vomiting with or without diarrhea	1062 (1.21)
Bloody diarrhea	100 (0.11)
Fever and rash	0 (0.0)
Fever and bleeding	0 (0.0)

Table 2. Distribution of syndromes by sex and age groups at the Arbaeenia mass gathering in Wassit, Iraq, in 2014.

Syndrome	Gender		Age group		Total, n
	Male, n (%)	Female, n (%)	>5 years, n (%)	<5 years, n (%)	
Fever and cough	804 (47.5)	889 (52.5)	802 (47.4)	891 (52.6)	1693
Acute diarrhea	550 (48.1)	594 (51.9)	699 (61.1)	445 (38.9)	1144
Vomiting with or without diarrhea	502 (47.3)	560 (52.7)	502 (47.3)	560 (52.7)	1062
Bloody diarrhea	55 (55.0)	45 (45.0)	52 (52.0)	48 (48.0)	100
Total	1911 (47.8)	2088 (52.2)	2055 (51.4)	1944 (48.6)	3999

Figure 1. Distribution of the patients with reported communicable diseases syndromes over the 10-day study period in the Arbaeenia mass gathering in Wasit, Iraq, in 2014.



Discussion

Despite the increasing number of people attending the Arbaeenia mass gathering, the preventive health services, particularly surveillance, of important diseases that harbor the risk of mortality and potential spread is far beyond that expected for this important mass gathering. This is the first study that highlighted an attempt to initiate communicable disease surveillance during this mass gathering using the syndromic approach. Syndromic surveillance was used in mass gatherings besides its use to detect outbreaks such as the H1N1 influenza pandemic [16,17].

The study focused on six important communicable disease syndromes, considering the country’s common disease context. The findings of the study highlighted the importance of syndromes of respiratory and gastrointestinal infections. Although these infections were expected, considering the exposure of the mass gathering attendees to the crowded and unhygienic environments, which create favorable conditions for transmission of respiratory and food borne diseases, the proportion of the attendees with these syndrome was less than that expected.

Apart from the Early Warning, Alert and Response Network surveillance system that uses the syndromic approach and is implemented in a number of camps for the internally displaced people in northern Iraq, the national surveillance system for communicable diseases in Iraq reported diseases rather than syndromes. This reduced the value of comparing our findings to the national figures of communicable disease surveillance.

Fever and cough syndrome is caused by many pathogens that are transmitted mainly from person to person through the respiratory tract, and it was the leading reported syndrome in this study. The Arbaeenia mass gathering in the year of the study took place during the wintertime, which could explain the high proportion of respiratory syndrome in the study.

Many pathogens including bacterial, parasitic, or viral pathogens can lead to acute diarrhea; the most dangerous pathogen of interest during mass gatherings is *V. cholerae*. Fortunately, all collected stool samples tested negative for *V. cholerae*. In a previous study conducted in the country, *Escherichia coli* and *Salmonella* species were the predominant causes of acute diarrhea [18]. Acute diarrhea and vomiting in the mass gathering could be related to an unhygienic environment of serving foods and drinks. All foods and drinks served to the pilgrims are freely provided by the local people, but they are all unlicensed by the health authorities, with minimal monitoring and auditing. In general, acute diarrhea diseases affected young children more than older adults; we found that the number of affected individuals aged>5 years was higher than that of children aged<5 years. Besides the narrow grouping of ages into only <5 years and >5 years, we did not have a denominator, and the mass gathering clinics only reported incident cases of these syndromes.

Fever and rash syndrome, which might indicate measles or rubella, were not reported in this study. This finding coincided with the fact that southern Iraq was free of measles and rubella in 2014. There were also no cases of fever and bleeding syndrome. In Iraq, the most common cause of hemorrhagic fever is the tick-borne Crimean-Congo hemorrhagic fever, a few cases of which are reported annually. The winter season does not support transmission of this disease.

The observed peak of the four syndromes on the second day of surveillance that immediately followed a very low proportion on the first day is more likely due to overattendance after launching the clinics rather than a coincident outbreak of the four syndromes together. The investigation performed later by the surveillance officers did not reveal any clustering of cases in particular mobile clinics.

We can conclude that the syndromic surveillance of communicable diseases, installed during mass gatherings can provide timely data on important communicable disease of concern to public health officials, which, in turn, can help in timely response. It is also useful in determining the main communicable disease syndromes and their profile. This can help in developing preparedness plans for the coming mass gatherings. Iraq’s Ministry of Health should to expand this surveillance to other governorates involved in the mass gathering event and upgrade it by using mobile technology that can help in having detailed data on different diseases and injuries and ensure a timely response.

The study has some limitations. The population at risk for communicable disease syndromes was not known; thus, the rates of syndromes could not be estimated. The age group>5 years clubs together people of a wide age range with varied risk, which limits the comparison of syndromes by age. Since this study was limited to Wassit governorate and 40 mobile clinics, it is difficult to generalize the results to all mobile clinics in the country that provided basic medical services to the Arbaeenia mass gathering attendees.

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Conflicts of Interest

None declared.

References

1. Lombardo JS, Sniegoski CA, Loschen WA, Westercamp M, Wade M, Dearth S. Public health surveillance for mass gatherings. Johns Hopkins APL Technical Digest (Applied Physics Laboratory) 2008;27(4):347-355 [FREE Full text]
2. Centers for Disease Control and Prevention. 2013. Travel to Mass Gatherings URL: https://wwwnc.cdc.gov/travel/page/travel-to-mass-gatherings [accessed 2018-04-22]
3. Karimi M. Public Health Surveillance and Hajj Pilgrimage as a Mass Gathering. Iran J Public Health 2013;24(7):791-792.
4. Kutsar K. Public health preparedness in mass gatherings. EpiNorth 2012;13:88-90.
5. Sharifi-Mood B, Metanat M. Diagnosis, Clinical Management, Prevention, and Control of Cholera; A Review Study. Int J Infect 2014 Mar 31;1(1). [doi: 10.17795/iji-18303]
6. Botelho-Nevers E, Gautret P. Outbreaks associated to large open air festivals, including music festivals, 1980 to 2012. Euro Surveill 2013 Mar 14;18(11):20426 [FREE Full text] [doi: 10.2807/ese.18.11.20426-en] [Medline: 23517872]
7. Madani T, Ghabrah T, Albarrak A, Alhazmi M, Alazraqi T, Althaqafi A, et al. Causes of admission to intensive care units in the Hajj period of the Islamic year 1424 (2004). Ann Saudi Med 2007;27(2):101. [doi: 10.4103/0256-4947.51528]
8. Madani TA, Ghabrah TM, Al-Hedaithy MA, Alhazmi MA, Alazraqi TA, Albarrak AM, et al. Causes of hospitalization of pilgrims in the Hajj season of the Islamic year 1423 (2003). Ann Saudi Med 2006 Sep;26(5):346-351 [FREE Full text] [doi: 10.5144/0256-4947.2006.346] [Medline: 17019102]
9. Mandourah Y, Al-Radi A, Ocheltree AH, Ocheltree SR, Fowler RA. Clinical and temporal patterns of severe pneumonia causing critical illness during Hajj. BMC Infect Dis 2012 May 16;12:117 [FREE Full text] [doi: 10.1186/1471-2334-12-117] [Medline: 22591189]
10. Baharoon S, Al-Jahdali H, Al Hashmi J, Memish ZA, Ahmed QA. Severe sepsis and septic shock at the Hajj: etiologies and outcomes. Travel Med Infect Dis 2009 Jul;7(4):247-252. [doi: 10.1016/j.tmaid.2008.09.002] [Medline: 19717109]
11. Yom-Tov E, Borsa D, Cox IJ, McKendry RA. Detecting disease outbreaks in mass gatherings using Internet data. J Med Internet Res 2014 Jun 18;16(6):e154 [FREE Full text] [doi: 10.2196/jmir.3156] [Medline: 24943128]
12. Cariappa MP, Singh BP, Mahen A, Bansal AS. Kumbh Mela 2013: Healthcare for the millions. Med J Armed Forces India 2015 Jul;71(3):278-281 [FREE Full text] [doi: 10.1016/j.mjafi.2014.08.001] [Medline: 26288497]
13. World Health Organization. 2015. Public Health for Mass Gathering: key considerations URL: https://www.who.int/ihr/publications/WHO_HSE_GCR_2015.5/en/ [accessed 2019-08-31]
14. EMPHNET: The Eastern Mediterranean Public Health Network. Iraq Mass Gathering URL: http://emphnet.net/?page_id=4608 [accessed 2019-08-31]
15. Alotaibi BM, Yezli S, Bin Saeed AA, Turkestani A, Alawam AH, Bieh KL. Strengthening health security at the Hajj mass gatherings: characteristics of the infectious diseases surveillance systems operational during the 2015 Hajj. J Travel Med 2017 May 01;24(3). [doi: 10.1093/jtm/taw087] [Medline: 28355612]
16. Brownstein JS, Freifeld CC, Madoff LC. Influenza A (H1N1) Virus, 2009 — Online Monitoring. N Engl J Med 2009 May 21;360(21):2156-2156. [doi: 10.1056/nejmp0904012]
17. Severi E, Heinsbroek E, Watson C, Catchpole M, HPA Olympics Surveillance Work Group. Infectious disease surveillance for the London 2012 Olympic and Paralympic Games. Euro Surveill 2012 Aug 02;17(31) [FREE Full text] [doi: 10.2807/ese.17.31.20232-en] [Medline: 22874458]
18. Monteville M, Riddle M, Baht U. Incidence, Etiology, And Impact Of Diarrhea Among Deployed Us Military Personnel In Support Of Operation Iraqi Freedom And Operation Enduring Freedom. Am J Trop Med Hyg 2006;75(4):7. [doi: 10.4269/ajtmh.2006.75.762]

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Original Paper

Knowledge, Attitude, and Practices of Food Handlers on Food Safety and Personal Hygiene During Arbaeenia Mass Gathering, Baghdad, Iraq, 2014: Cross-Sectional Study

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Abstract

Background: Millions of pilgrims attend Arbaeenia mass gathering (MG) in Iraq each year. Thousands of individuals work voluntarily at temporary rest areas (locally called Mawakib), distributed in most of Iraq governorates, to provide food and other services to the MG attendees. The potential for improper handling of food at Mawakib increases the risk of waterborne and foodborne diseases.

Objective: This study was aimed to assess the knowledge, attitude, and practices (KAP) of food handlers in Mawakibs in Baghdad city during Arbaeenia MG.

Methods: A random sample of 100 Mawakibs was selected in Baghdad, 50 from the eastern side (Rusafa) and 50 from the western side (Kerkh), and five food handlers were randomly selected from each Mawakib. A questionnaire was used to collect demographic data and KAP for food safety and personal hygiene. The questionnaire included 25 questions addressing knowledge, 10 addressing attitudes, and 14 addressing practices of the food handlers with respect to food safety and personal hygiene. Questions on knowledge and attitudes were answered through direct interview with the food handlers, whereas the questions on practices were answered through direct observation while handling or serving the food. SPSS version 20 (IBM SPSS Statistics 20) was used for data analysis and describing proportions.

Results: There was a varied knowledge of food safety practices among the individuals interviewed. On a scale of 3, the overall average score for both the attitude and practices for food safety and personal hygiene was 2, which corresponds to fair attitude and practices. The attitudes varied significantly by location, age group, and education, whereas the practices varied by location, age groups, employment, and previous experiences.

Conclusions: The food handlers had unsatisfactory attitudes and practices toward food handling and personal hygiene. Their participation in food handling at Mawakib carries a potential risk of spreading foodborne and waterborne diseases. All individuals intending to serve in Mawakib as food handlers should be licensed from the Ministry of Health after completing a formal training in food safety and personal hygiene.

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KEYWORDS

food; hygiene; knowledge; attitudes; Iraq

Introduction

Background

Mass gatherings (MGs) are defined as the congregation of as few as 1000 individuals to upwards of 25,000 in a specific location for a designated period [1]. Such occurrences put a strain on the local resources, such as food, drinks, accommodation, and health care, and can pose a health risk to the population. Infectious diseases, such as foodborne and waterborne diseases, are considered a major public health concern during MGs, along with road traffic accidents, other injuries, and terrorism [2]. However, limited data are available on foodborne and waterborne disease outbreaks during MGs, largely because of poor health surveillance systems and limited research on population health during MGs.

Poor food safety and personal hygiene are the main risk factors for foodborne and waterborne illnesses; food handlers play an important role with regard to these risk factors [3]. Contaminated hands are vehicles for enteric virus transmissions, and food preparation and handling affect the safety of the food served [4]. In Iraq, religious MGs occur throughout the year, mainly in Karbala, Najaf, and Baghdad. Arbaeenia is the largest religious MG that annually convenes in Karbala, where more than 10 million people, mainly from Iraq, visit Imam Hussein's shrine in Karbala. Attendees walk hundreds of kilometers for many days to reach Karbala city.

Faith-based organizations and the general public are the main providers of water, food, shelter, accommodation, and, to a certain extent, health services in rest areas for pilgrims, locally called Mawakibs. Most of the individuals preparing and serving food are not certified food handlers, and Mawakibs are not regularly inspected by health authorities. The number of Mawakibs providing different services during the MGs has greatly increased over the last few years [5].

Objectives

The objective of this study was to assess the knowledge, attitude, and practices (KAP) of Mawakib food handlers with respect to food safety and personal hygiene during the Arbaeenia MG in Baghdad, Iraq, 2014.

Methods

Study Design

To assess the KAP of Mawakib food handlers with respect to food safety and hygiene, we conducted this cross-sectional study in Baghdad during the Arbaeenia MG, December 5 to December 9, 2014. A simple random sample of 100 Mawakibs was selected from a list, which included the names and locations of these Mawakibs; 50 from Rusafa (eastern side of Baghdad) and 50 from Kerkh (western side of Baghdad). A total of 5 food handlers were selected from each Mawakib to participate in the study. Overall, 8 surveyors were trained to collect the data. The study was approved by the research committee of Iraq's Ministry of Health. The Mawakibs were selected after obtaining a list of all the Mawakibs and assigning them a sequential number to draw a random sample according to the calculated sample size.

Questionnaire

A questionnaire was used to collect data on the 3 domains of KAP. The questionnaire also collected data on sociodemographics and previous experience in food handling. Previous experience was defined as any former serving or food handling during similar events and MGs. The questionnaire was translated from English into Arabic (local dialect) and translated back to English to ensure accurate translation.

The questionnaire had 49 questions in total. Overall, 25 questions addressed the knowledge of food safety and personal hygiene. Furthermore, 10 questions addressed the attitudes toward food safety and personal hygiene habits while handling and serving food. A total of 14 questions addressed the practices of food handlers on food safety and hygiene when serving food to the visitors of the Mawakib during Arbaeenia MG. The knowledge and attitude sections of the questionnaire were completed through face-to-face interview, during which the data collectors verbally asked the questions to the study participants and then recorded their answers. The practices section of the questionnaire was completed by the data collectors based on their observations of the food handling practices.

The knowledge section of the questionnaire required *yes* or *no* responses. The practices and attitude sections required a response of *always*, *sometimes*, *rarely*, or *never* /*refused*. We assigned a score of 3 to *always*, a score of 2 to *sometimes*, a score of 1 to *rarely*, and 0 to *never*. However, *refused* and missing responses were excluded from the analysis.

Data Analysis

Data were coded and entered into Epi Info 7 (CDC's Epi Info 7) and SPSS version 20 (IBM Corp, Armonk, NY, USA) was used for data analysis. The percentage of food handlers who correctly answered the questions was calculated in the knowledge domain. For the questions on attitude and practices, the average scores were calculated for the responses to each question, in addition to the overall average score. The attitude and practices sections were categorized into poor, fair, and good, corresponding to the average scores of <1.5, 1.5 to 2.4, and 2.5 to 3, respectively.

The percentage of respondents with poor, fair, or good attitudes and practices was estimated by sociodemographics. Chi-square tests and Fisher exact tests were used to test the association between KAP and sociodemographics. A *P* value of less than .05 was considered statistically significant.

Results

Food Handlers' Characteristics

A total of 504 food handlers were interviewed. One data collector interviewed 6 instead of 5 food handlers in 4 Mawakibs. The food handlers were predominately male, in total 498 (98.8%, 498/504). The average age of the food handlers was 37 (SD 12) years. Furthermore, 50.4% (254/504) had secondary or postsecondary education. Only 3.2% (16/504) were basically full-time food handlers (Table 1).

Table 1. Distribution of the food handlers during Arbaeenia mass gathering in Baghdad, Iraq, by sociodemographic characteristics and previous experience in food handling (N=504).

Sociodemographic characteristics	Statistics, n (%)
Sex	
Female	6 (1.2)
Male	498 (98.8)
Location	
Karkh	252 (50.0)
Rusafa	252 (50.0)
Education level	
Illiterate	58 (11.5)
Presecondary	192 (38.1)
Secondary	161 (31.9)
Postsecondary	93 (18.5)
Employment	
Full-time food handler	16 (3.2)
Unemployed or retired	14 (2.8)
Full-time employee	131 (25.9)
Student	62 (12.3)
Day laborer	281 (55.8)
Previous experience in food handling	
No	143 (28.4)
Yes	361 (71.6)

Knowledge

The percentage of food handlers who correctly answered questions related to food safety and personal hygiene ranged from 8% to 100%. Poor knowledge was mainly related to storing food using ice baths, contaminating food with watches and rings that were worn, and food poisoning from eating perishables left out (Table 2).

Knowledge scores of the study participants were categorized into 3 categories: *poor*, *fair*, and *good*. The results of this score categorization and the statistical association with background variables are shown in Table 3. Knowledge of food handlers about food safety and personal hygiene was significantly associated with location (*P*=.001) and job (*P*=.04); full time employees had the best knowledge scores.

Table 2. Responses to questions on knowledge by the study participants (N=504).

Number	Knowledge items	Correct answer, n (%)
1	It is OK to mix raw meat with processed ones.	41 (8.1)
2	Consumption of food in any container can be delayed.	44 (8.7)
3	Ice baths—used as cooling systems—are not safe to store food for a prolonged time.	167 (33.5)
4	Wearing rings and watch can contaminate food.	396 (78.6)
5	Eating perishables left out for more than 2 hours at room temperature can lead to food poisoning.	396 (78.7)
6	Multiple food tastings from the same dish can contaminate the dish with contagious microbes.	403 (80.3)
7	Multiple people drinking from the same cup can contaminate the cup with contagious microbes.	407 (82.9)
8	Certain ways of handling food can cause food poisoning and encourage the growth of bacteria, viruses, and parasites	426 (84.7)
9	It is essential for food handlers to have a dry storage unit.	422 (85.3)
10	Food handler with a cold can contribute to the spread of diseases while handling food.	431 (85.7)
11	Infected wound can increase the risk of food poisoning while handling food.	448 (88.9)
12	Food handler with a fever can contribute to the spread of diseases while handling food.	452 (89.7)
13	Open sores can contribute to the spread of diseases while handling food.	462 (91.7)
14	Vaccination is important to prevent the spread of diseases.	466 (93.3)
15	Washing body frequently is important.	469 (94.6)
16	Smoking is a bad practice while handling food at Mawakibs.	481 (95.6)
17	Food handlers should avoid preparing food if they are suffering from vomiting.	487 (96.6)
18	Proper food covering can help prevent contamination.	488 (96.8)
19	Food handlers should avoid preparing food if they are suffering from diarrhea.	493 (97.8)
20	Food preparation must be done using clean equipment.	493 (97.8)
21	Tidying hair and trimming finger nails contribute to your health positively.	494 (98.0)
22	It is a good practice to use disposal utensils when serving food.	495 (98.2)
23	The cooking equipment should be washed immediately after use.	496 (98.6)
24	Washing hands should be a frequent practice.	501 (99.4)
25	Food preparation must be done using potable water.	503 (99.8)

Table 3. Distribution of study participants by knowledge levels and background variables.

Background variables	Knowledge levels			
	Poor, n (%)	Fair, n (%)	Good, n (%)	*P* value
Location				**.001**
Karkh (N=252)	2 (0.8)	30 (11.9)	220 (87.3)	
Rusafa (N=252)	24 (9.5)	117 (46.4)	111(44.0)	
Age group (years)				**.22**
<20 (N=30)	3 (10)	13 (43)	14 (47)	
20-39 (N=275)	15 (5.5)	71 (25.8)	189 (68.7)	
40-59 (N=181)	7 (3.9)	56 (30.9)	118 (65.2)	
≥60 (N=18)	1 (6)	7 (39)	10 (56)	
Education level				**.57**
Illiterate (N=58)	2 (3)	21 (36)	35 (60)	
Subsecondary (N=192)	13 (6.8)	55 (28.6)	124 (64.6)	
Secondary (N=161)	9 (5.6)	43 (26.7)	109 (67.7)	
Higher education (N=93)	11 (12)	16 (17)	76 (82)	
Job				**.04**
Full-time food handler (N=16)	1 (6)	8 (50)	7 (44)	
Unemployed/retired (N=14)	0 (0)	4 (29)	10 (71)	
Full-time employee (N=131)	3 (2.3)	18 (13.7)	110 (83.9)	
Student (N=62)	4 (6)	16 (26)	42 (68)	
Day laborer (N=281)	8 (2.8)	52 (18.5)	221 (78.6)	
Previous experience				**.09**
No (N=143)	7 (4.9)	32 (22.4)	104 (72.7)	
Yes (N=361)	19 (5.3)	115 (31.9)	227 (62.9)	

Attitude

On a 3-point scale, the overall average score of the questions on attitude was 2. A total of 6 questions had an average score of 2, and 4 questions had 3. The distribution of responses to attitude questions is shown in Table 4.

The overall attitude of food handlers toward food safety and personal hygiene while handling and serving food was scored as fair.

Attitude scores of the study participants were categorized into 3 categories: *poor*, *fair*, and *good*. The results of this score categorization and the statistical association with background variables are shown in Table 5. Attitude scores were significantly associated with location (better in Kerkh; *P*=.001), age (*P*=.01), education (*P*=.008), and previous experience with food handling (*P*=.03).

Table 4. Distribution of responses to questions on attitude.

Number	Attitude items	Always, n (%)	Sometimes, n (%)	Rarely, n (%)
1	Staying home instead of going to Mawakib to serve food when having vomiting	373 (74.0)	81 (16.1)	50 (9.9)
2	Staying home instead of going to Mawakib to serve food when having diarrhea	373 (74.0)	81 (16.1)	50 (9.9)
3	Staying home instead of going to Mawakib to serve food when having open sores	383 (76.0)	66 (13.1)	55 (10.9)
4	Not wearing rings and watch during food handling	373 (74.0)	96 (19.1)	35 (6.9)
5	Staying home instead of going to Mawakib to serve food when having an infected wound	393 (78.0)	61 (12.1)	50 (9.9)
6	Staying home instead of going to Mawakib to serve food when having a cold	403 (80.0)	61 (12.1)	40 (7.9)
7	Encourage food handlers to get vaccinated	428 (84.9)	45 (8.9)	31 (6.2)
8	Tidying hair and trimming finger nails	423 (83.9)	76 (15.1)	5 (1.0)
9	Washing body	443 (87.9)	55 (10.9)	6 (1.2)
10	Washing hands as necessary	454 (90.1)	45 (8.9)	5 (1.0)

Table 5. Distribution of the study participants by attitude levels and background variables.

Background variable	Attitude levels			*P* value
	Poor, n (%)	Fair, n (%)	Good, n (%)	
Location				**.001**
Kerkh (N=252)	66 (26.2)	100 (39.7)	86 (34.1)	
Rusafa (N=252)	112 (44.4)	103 (40.9)	37 (14.7)	
Age group (years)				**.01**
<20 (N=30)	13 (43)	10 (33)	7 (23)	
20-39 (N=275)	77 (28.0)	122 (44.4)	76 (27.6)	
40-59 (N=181)	82 (45.3)	64 (35.4)	35 (19.3)	
≥60 (N=18)	6 (33)	7 (39)	5 (28)	
Education level				**.008**
Illiterate (N=58)	15 (26)	19 (33)	24 (41)	
Subsecondary (N=192)	77 (40.1)	83 (43.2)	32 (16.7)	
Secondary (N=161)	58 (36.0)	60 (37.3)	43 (26.7)	
Higher education (N=93)	28 (30)	41 (44)	24 (26)	
Job				**.11**
Full-time food handler (N=16)	2 (13)	11 (69)	3 (19)	
Unemployed or retired (N=14)	8 (57)	6 (43)	0 (0)	
Full-time employed (N=131)	45 (34.4)	53 (40.5)	33 (25.2)	
Student (N=62)	24 (39)	26 (42)	12 (19)	
Day laborer (N=281)	99 (35.2)	107 (38.1)	75 (26.7)	
Previous experience				**.03**
No (N=143)	59 (41.3)	60 (41.9)	24 (16.8)	
Yes (N=361)	119 (32.9)	143 (39.6)	99 (27.4)	

Practices

The overall average score for responses on practices for food safety and personal hygiene was 2; the average score of 7 of the questions was 2 and the remaining 7 averaged a score of 3 (Table 6). The overall practice of food handlers was therefore fair.

Practice scores of the study participants were categorized into 3 categories: *poor*, *fair*, and *good*. The results of this score categorization and the statistical association with background variables are shown in Table 7. The practice scores were significantly associated with the location (better in Kerkh; *P*=.001) and previous experience with food handling (*P*=.001).

Table 6. The distribution of responses to questions on practices.

Number	Practice items	Always, n (%)	Sometimes, n (%)	Rarely, n (%)	No response, n (%)
1	Not serving food for visitors, which has been kept in containers for a long time	359 (71.2)	55 (10.9)	30 (6.0)	60 (11.9)
2	Not using ice baths as a cooling system to store food for a prolonged time	277 (55.0)	76 (15.0)	10 (2.0)	141 (28.0)
3	Using dry storage unit to store food	418 (83.0)	40 (7.9)	15 (3.0)	81 (16.1)
4	Not allowing multiple visitors to taste food from the same dish	328 (65.0)	35 (6.9)	10 (2.0)	131 (26.0)
5	Not allowing multiple visitors to drink from the same cup	328(65.0)	30 (6.0)	10 (2.0)	136 (27.0)
6	Not smoking while handling food at Mawakib	333 (66.0)	35 (7)	5 (1)	131 (26)
7	Not reheating the food more than once before serving it	337 (67.0)	30 (6.9)	45 (8.9)	91 (18.1)
8	Using disposal units to serve food for visitors	343 (68.0)	25 (5.0)	5 (1.0)	131 (26.0)
9	Not serving perishables left out for more than 2 hours at room temperature for visitors	338 (67.0)	35 (6.9)	5 (1.0)	126 (25.0)
10	Washing cooking equipment immediately after use	358 (71.0)	10 (2.0)	5 (1.0)	131 (26.0)
11	Covering food properly to prevent contamination	358 (71.0)	10 (2.0)	5 (1.0)	131 (26.0)
12	Preparing food using potable water	358 (71)	15 (3.0)	2 (0.4)	129 (25.6)
13	Separating raw meat from processed ones	363 (72.0)	10 (2.0)	5 (1.0)	126 (25.0)
14	Preparing food using clean equipment	368 (73.0)	9 (1.8)	1 (0.2)	126 (25.0)

Table 7. Distribution of the study participants by practice levels and background variables.

Background variables	Practice levels			
	Poor, n (%)	Fair, n (%)	Good, n (%)	*P* value
Location				**.001**
Kerkh (N=252)	58 (23.0)	70 (27.8)	124 (49.2)	
Rusafa (N=252)	119 (47.2)	90 (35.7)	43 (17.1)	
Age group (years)				**.08**
<20 (N=30)	13 (43)	8 (27)	9 (30)	
20-39 (N=275)	83 (30.2)	88 (32.0)	104 (37.8)	
40-59 (N=181)	75 (41.4)	60 (33.1)	46 (25.4)	
≥60 (N=18)	6 (33)	4 (22)	8 (44)	
Education level				**.05**
Illiterate (N=58)	16 (28)	20 (34)	22 (38)	
Subsecondary (N=192)	54 (28.1)	70 (36.5)	68 (35.4)	
Secondary (N=161)	65 (40.4)	47 (29.2)	49 (30.4)	
Higher education (N=93)	42 (45)	23 (25)	28 (30)	
Job				**.06**
Full-time food handler (N=16)	3 (19)	8 (50)	5 (31)	
Unemployed or retired (N=14)	6 (43)	6 (43)	2 (14)	
Full-time employed (N=131)	38 (29.0)	40 (30.5)	53 (40.5)	
Student (N=62)	31 (50)	15 (24)	16 (26)	
Day laborer (N=281)	99 (35.2)	91 (32.4)	91 (32.4)	
Previous experience				**.001**
No (N=143)	33 (23.1)	43 (30.1)	67 (46.9)	
Yes (N=361)	134 (39.9)	117 (32.4)	100 (27.7)	

Discussion

Principal Findings

The study shows that the food handlers serving Arbaeenia MG attendees had satisfactory knowledge, fair attitudes, and fair practices with respect to food safety and personal hygiene. According to sociodemographics, the attitudes and practices of the food handlers varied.

Correct knowledge regarding food safety and personal hygiene varied among the food handlers. A lack of knowledge on food safety measures, such as proper preparation and storage, carries the risk for potential events of foodborne diseases. Similar findings of lack of knowledge were present in previously conducted KAP studies of food handlers [6,7]. Mawakib food handlers are volunteers and not all the handlers reported prior experience in food handling, which may explain a lack of knowledge in food safety and personal hygiene. Variation in knowledge may be because of the lack of training and information, as reported in similar studies [8,9].

The findings on the attitudes of the food handlers toward food safety and personal hygiene habits were similar to the findings on the practices. Attitudes have an impact on practices, as observed in other KAP studies [10]. Attitudes and practices varied significantly according to location and age, which suggests that attitudes may have shaped the observed practices of the food handlers. The results of this study indicated that the lowest education level (illiterate) had a higher percentage of food handlers with good attitudes toward food safety and personal hygiene than all other education levels. In the domain of practices, food handlers with secondary education had the highest percentage of good practices. These findings suggest that there is no strong correlation between the education level and the attitudes and practices of food handlers; similar findings in previous studies suggest that education level does not influence food safety and personal hygiene [11].

Conclusions

We can conclude that in spite of satisfactory knowledge, the current attitudes and practices of food handlers are not satisfactory; a finding that makes their participation in provision of food for MG attendees in Mawakib a noticeable risk. Iraq's Ministry of Health is requested to make rigorous standards and licensure mandatory for all individuals intending to serve in Mawakib as food handlers. They have to complete a formal training in food safety and personal hygiene.

The results of this study cannot be generalized on all Mawakibs throughout the country as the study was conducted in only 1 city. Hence, one of the recommendations to the Ministry of Health is to conduct a large-scale survey in all cities affected with the MGs and serving of food to have clear guidance on food safety and the needed regulations.

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Conflicts of Interest

None declared.

References

1. World Health Organization. 2009. Interim Planning Considerations for Mass Gatherings in the Context of Pandemic (H1N1) 2009 Influenza URL: https://www.who.int/csr/resources/publications/swineflu/h1n1_mass_gatherings/en/ [accessed 2019-09-03]
2. The WHO Regional Office for the Eastern Mediterranean. 2012. International Health Regulations (IHR): Health Preparedness at Mass Gatherings, October 2012, Iraq and Jordan URL: http://www.emro.who.int/international-health-regulations/ihr-events/health-preparedness-at-mass-gatherings.html [accessed 2019-08-30]
3. Aziz SA, Dahan HM. Food handlers' attitude towards safe food handling in school canteens. Procedia Soc Behav Sci 2013 Dec;105:220-228. [doi: 10.1016/j.sbspro.2013.11.023]
4. Lillquist DR, McCabe ML, Church KH. A comparison of traditional handwashing training with active handwashing training in the food handler industry. J Environ Health 2005;67(6):13-6, 28. [Medline: 15690900]
5. Global Sponsor Network. 2013. [Number of Processions and Husseini Organizations Participating in the Forty Season] URL: http://alkafeel.net/ar-news/index.php?id=1486 [accessed 2019-08-30]
6. Martins RB, Hogg T, Otero JG. Food handlers' knowledge on food hygiene: the case of a catering company in Portugal. Food Control 2012 Jan;23(1):184-190. [doi: 10.1016/j.foodcont.2011.07.008]
7. Chukwuocha UM, Dozie IN, Amadi AN, Nwankwo BO, Ukaga CN, Aguwa OC, et al. The knowledge, attitude and practices of food handlers in food sanitation in a metropolis in south eastern Nigeria. East Afr J Public Health 2009 Dec;6(3):240-243. [Medline: 20803912]
8. Liu S, Liu Z, Zhang H, Lu L, Liang J, Huang Q. Knowledge, attitude and practices of food safety amongst food handlers in the coastal resort of Guangdong, China. Food Control 2015 Jan;47:457-461. [doi: 10.1016/j.foodcont.2014.07.048]
9. Kibret M, Abera B. The sanitary conditions of food service establishments and food safety knowledge and practices of food handlers in Bahir Dar town. Ethiop J Health Sci 2012 Mar;22(1):27-35 [FREE Full text] [Medline: 22984329]
10. Abdul-Mutalib N, Abdul-Rashid M, Mustafa S, Amin-Nordin S, Hamat RA, Osman M. Knowledge, attitude and practices regarding food hygiene and sanitation of food handlers in Kuala Pilah, Malaysia. Food Control 2012 Oct;27(2):289-293. [doi: 10.1016/j.foodcont.2012.04.001]
11. Isara A, Isah E. Knowledge and practice of food hygiene and safety among food handlers in fast food restaurants in Benin city, Edo state. Niger Postgrad Med J 2009 Sep;16(3):207-212. [doi: 10.1016/j.puhe.2010.03.028] [Medline: 19767908]

Abbreviations

KAP: knowledge, attitude, and practices
MG: mass gathering

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Original Paper

Disease Burden on Health Facilities in Governorates South of Karbala During the Arbaeenia Mass Gathering in Iraq in 2014: Cross-Sectional Study

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Abstract

Background: Millions of Iraqi pilgrims travel annually from the southern governorates to Karbala and pass through Thiqar, Muthana, and Diwania Governorates to join the Arbaeenia mass gathering event. During this event, participants are at high risk for diseases and death and stifle local health care resources. In addition, the mass gathering causes considerable burden on health facilities in the hosting localities.

Objective: This study aims to estimate the disease burden on health facilities caused by the pilgrims passing through Thiqar, Muthana, and Diwania Governorates en route to Karbala in Iraq.

Methods: This cross-sectional study was conducted on all health facilities in three governorates (Thiqar, Muthana, and Diwania) situated along the southern way to Karbala from Basra. The study started on December 11, 2014, and ended on December 24, 2014. The morbidity and mortality were collected from surveillance logbooks and death registers. Drug purchase data were obtained from the personnel in charge of the pharmacies. The study period was divided into three phases on the basis of the timing of the mass gathering event: pre-event, the event, and postevent.

Results: There were 884,834 incidents reported during the study. The majority of incidents were reported during the event phase (95%) and were attended mostly at mobile clinics (77%). The average daily incidents during the pre-event, event, and postevent phases were 4300, 56,040, and 4548 incidents, respectively. Musculoskeletal disorders were the most common illness reported (55%). The average number of daily deaths was 43, 36, and 45 during the pre-event, event, and postevent, respectively, and these values did not differ significantly. Cardiovascular diseases (43.5%), injuries (29.8%), and respiratory illnesses (12%) were the leading causes of deaths. Approximately US $1.3 million was spent on drug purchases during this mass gathering in the three governorates.

Conclusions: The Arbaeenia mass gathering causes a tremendous disease and economic burden on governorates that pilgrims pass through to attend this mass gathering in Karbala. Although Iraq's Ministry of Health is aware of the high burden of this mass gathering on the health facilities in these governorates, more work is needed to ensure quality services during the event.

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KEYWORDS

mass gathering; Arbaeenia; Iraq; disease burden

Introduction

The World Health Organization defines mass gatherings as “events attended by a sufficient number of people to strain the planning and response recourses of a community, state or nation” [1,2]. Mass gatherings are one of the most significant items on the global health security agenda [3] and can occur spontaneously without previous alerts, such as political rallies, protests, or planned gatherings. They can be either periodic at different localities like the Olympics and World Soccer Cup or repeated events at the same place like the Hajj in Saudi Arabia, which is one of the largest mass gathering worldwide [4].

Studies on mass gatherings have concluded that the event type, duration, attendance, weather, mood, density, and other factors determine the medical services needed. Mass gatherings are a challenge to public health authorities and pose a significant burden for the preparedness and response to potential mass causalities and disease outbreaks [5]. Besides the risk of acquiring different infectious diseases, mass gathering attendees are at an increased risk for injuries that range from mild muscle cramps to severe injuries and exacerbation of pre-existing noncommunicable disease conditions that can be fatal [6-8].

Many religious mass gathering events take place in Iraq annually, mainly in Karbala, Najaf, and Baghdad [9]. The Arbaeenia mass gathering attracts millions of local and international Shiite Muslim pilgrims [10]. Around 3 million pilgrims travel on foot from Basra, Thiqar, Muthana, Diwania, and Babel Governorates to Karbala to join the Arbaeenia mass gathering event [11]. The distance from Basra to Karbala is about 600 km and passes through four governorates (Figure 1).

Figure 1. Iraq map and the three studied governorates.

There have been a few studies on the burden of religious mass gatherings on Iraq’s local health resources [12]. This study was conducted to estimate the burden of diseases on local health facilities along the way from Basra to Karbala during the Arbaeenia mass gathering. The Ministry of Health and local health directorates can utilize the data from this study to develop plans and strategies for logistics, plan financing, and provide technical support to the governorates during future mass gatherings.

Methods

We conducted this cross-sectional study on all health facilities including major referral hospitals, primary health care centers and units, faith-based health outlets, government mobile clinics, forensic units, and drugstores located along the road from Basra to Karbala. The selected facilities were limited to three governorates: Thiqar, Muthana, and Diwania. The surface area of Thiqar, Muthana, and Diwaniya governorates is 12,900, 19,980, and 8153 km^2, respectively, and their population is 2.8, 0.87, and 1.25 million, respectively. The study started on December 11, 2014, and ended on December 24, 2014. In Iraq, this is wintertime, and the weather, in general, is cold and dry with occasional rains. The data were collected in three phases: before the mass gathering event (pre-event), during the mass gathering event (event), and after the mass gathering event (postevent). The duration of data collection for the pre-event, event, and postevent phases was 5 days, 15 days, and 5 days, respectively.

The available surveillance system data were used for the study. Data were collected on health events from seven disease categories—cardiovascular, respiratory, musculoskeletal, gastrointestinal tract, central nervous system (including headache), injuries, and other disorders—were abstracted from surveillance logbooks and forms on a daily basis by using predesigned forms. Deaths from the seven disease categories were abstracted from death registers and coroner offices. Cost data on purchases of antibiotics, analgesics, antihistamines, antispasmodic, cough syrups, ointments, and others during the event phase were collected through direct interviews with the personnel in charge of the pharmacies in these facilities.

We used Epi Info 7 software (Centers for Disease Control and Prevention, Atlanta Georgia) for data entry and analysis. Data were entered daily and cleaned and edited before analysis. We calculated the means, frequencies, and percentages of disease categories and drug expenditures by study phase: pre-event, event, and postevent. The Chi-square test was used to test significant associations among categorical variables at *P*<.05, and the Fisher exact test was used when the Chi-square test was not applicable.

Results

There were 884,834 health incidents attended to at the selected health facilities in the three selected governorates during the study period. The majority were addressed in Diwania governorate health facilities (54.8%), and around 22% and 23% were addressed in the health facilities of Thiqar and Muthana Governorates, respectively. The majority (95%) attended the health facilities during the mass gathering event; 2%, in the pre-event; and 3%, in the postevent (Table 1). Musculoskeletal disorders were the most common disorder reported (55.2%), and injuries were the least commonly reported (3%). Cardiovascular disorders, gastrointestinal illnesses, and respiratory disease illnesses accounted for approximately 9% of the reported diseases (Table 1). The majority of the diseases (77%) were served at mobile clinics and 4.3% were served at hospitals. The disease categories varied significantly among the pre-event, event, and postevent periods (*P*<.001).

Table 1. Distribution of attendees to health facilities by disease categories, governorate, type of health facilities, and event phases.

Factors	Pre-event, n (%)	Event, n (%)	Postevent, n (%)	Total, n (%)	*P* value
Disease category					<.001
Cardiovascular disorders	3246 (15.1)	73,479 (8.7)	3670 (16.1)	80,395 (9.1)	
Central nervous system disorder	1453 (6.8)	33,083 (3.9)	786 (3.5)	35,322 (4.0)	
Gastrointestinal disorder	3143 (14.6)	72,773 (8.7)	2723 (12.0)	78,639 (8.9)	
Injuries	645 (3.0)	23,392 (2.8)	2145 (9.4)	26,182 (3.0)	
Musculoskeletal	4793 (22.3)	478,929 (57.0)	4583 (20.2)	488,305 (55.2)	
Respiratory disorders	4344 (20.2)	64,575 (7.7)	5919 (26.0)	74,838 (8.5)	
Others	3876 (18.0)	94,362 (11.2)	2915 (12.8)	101,153 (11.4)	
Governorate					<.001
Thiqar	11,180 (52.0)	178,206 (21.2)	7732 (34.0)	197,117 (22.3)	
Muthana	4300 (20.0)	194,177 (23.1)	4071 (17.9)	202,548 (22.9)	
Diwania	6020 (28.0)	468,210 (55.7)	10,938 (48.1)	485,169 (54.8)	
Type of health facility					<.001
Mobile clinic or unit	0 (0.0)	682,562 (81.2)	0 (0.0)	682,562 (77.1)	
Public health centers	17,683 (82.2)	129,086 (15.4)	17,090 (75.2)	163,859 (18.5)	
Public hospital	3817 (17.8)	28,945 (3.4)	5651 (24.8)	38,413 (4.3)	
Total number of incidents	21,500 (2.4)	840,593 (95.0)	22,741 (2.6)	884,834 (100.0)	

The daily average of events attended in the health facilities increased by 13 times during the mass gathering event compared to pre-event, of which musculoskeletal disorders showed the highest increase (33 times) followed by injuries (12 times). The average daily attendance varied among the pre-event, event, and postevent periods in disease categories (*P*=.001; Table 2).

Table 2. Average daily incidents attended by disease categories, governorates, type of health facilities, and event phase.

Factors	Pre-event, n (%)	Event, n (%)	Postevent, n (%)	*P* value
Disease category				<.001
Cardiovascular disorders	649 (15.1)	4899 (8.7)	734 (16.1)	
Central nervous system disorder	291 (6.8)	2206 (3.9)	157 (3.5)	
Gastrointestinal disorder	629 (14.6)	4852 (8.7)	545 (12.0)	
Injuries	129 (3.0)	1559 (2.8)	429 (9.4)	
Musculoskeletal	959 (22.3)	31,929 (57.0)	917 (20.2)	
Respiratory disorders	869 (20.2)	4305 (7.7)	1184 (26.0)	
Others	775 (18.0)	6291 (11.2)	583 (12.8)	
Governorates				<.001
Muthana	2,236 (52.0)	11,880 (21.2)	1546 (34.0)	
Thiqar	860 (20.0)	12,945 (23.1)	814 (17.9)	
Diwania	1204 (28.0)	31,214 (55.7)	2188 (48.1)	
Type health facility				<.001
Mobile clinic or unit	0 (0.0)	45,784 (81.7)	0 (0.0)	
Public health center	1806 (42.0)	6501 (11.6)	3130 (68.8)	
Public hospital	2494 (58.0)	3755 (6.7)	1418 (31.2)	
Total daily average incidents	4300 (100.0)	56,040 (100.0)	4548 (100.0)	

During the study period, 975 deaths were reported: 210 pre-event, 540 during the event, and 225 postevent. Cardiovascular diseases, injuries, and respiratory illnesses were the leading causes of death (43.5%, 29.8%, and 12%, respectively; Table 3). The average number of daily deaths in the pre-event phase was 43; 36 deaths were reported during the event, and 45 deaths were reported in the postevent phase. The number of daily average deaths did not vary between the pre-event, event, and postevent periods according to the disease categories.

Table 3. Distribution of average daily deaths by cause of death and event phase.

Disease category	Pre-event, n (%)	Event, n (%)	Postevent, n (%)	Total, n (%)
Cardiovascular disorders	19 (35.6)	17 (31.0)	18 (33.3)	54 (43.5)
Central nervous system disorder	2 (42.3)	1 (19.2)	2 (38.5)	5 (4.0)
Gastrointestinal disorder	0 (0.0)	1 (50.0)	1 (50.0)	2 (1.6)
Injuries	11 (29.9)	11 (30.4)	15 (39.7)	37 (29.8)
Musculoskeletal	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Respiratory disorders	6 (37.4)	4 (28.0)	5 (34.8)	15 (12.1)
Others	4 (37.7)	2 (22.6)	4 (39.6)	11 (8.9)
Average daily death	42 (34.4)	36 (29.3)	45 (36.3)	124 (100.0)

Around US $1.3 million was spent on drug purchases for the mass gathering attendees during this Arbaeenia mass gathering. The highest amount spent on drug purchases was recorded in Muthana Governorate (US $568,333), and the least spent on drug purchases was in Thiqar (US $243,750) Governorate during this mass gathering. Analgesics and antibiotics were on the top of the cost of drug purchased during this mass gathering (US $315,500 and US $242,500, respectively). The least amount of money spent on purchased drug was for antihistamines (US $95,833; Table 4).

Table 4. Drug purchases (US $) during the Arbaeenia mass gathering.

Drug items	Governorate			
	Thiqar	Muthana	Diwania	Total
Antibiotics	59,250	91,667	91,583	242,500
Analgesics	60,583	170,833	84,083	315,499
Antihistamines	11,917	12,500	71,583	96,000
Antispasmodic	30,500	136,667	51,583	218,750
Cough syrups	12,167	89,167	52,167	153,501
Ointments	41,417	20,000	92,417	153,834
Others	27,917	47,500	50,750	126,167
Total	243,750	568,333	494,167	1,306,250

Discussion

The Arbaeenia mass gathering puts a tremendous onus on local health resources. This study demonstrates the extra burden on the health facilities in the three governorates: Muthana, Thiqar, and Diwania. In the pre-event phase, the health attendance was maximum in Thiqar, lower in Diwaniya, and lowest in Muthana. This is a clear reflection of the total population and hence the total attendees at the health outlets.

During the event and postevent phases, the maximum number of attendees was noted in Diwaniya. As demonstrated in the map, Diwaniya is the center of cumulation of attendees coming from the southern governorates, besides the attendees coming through the second southern route from Wasit and Misan Governorates.

There was a 13-fold increase in the number of health incidents addressed the health facilities during the mass gathering event, but the daily average number of deaths during the mass gathering event did not differ from that of the pre-event. The leading causes of deaths were cardiovascular diseases, injuries, and respiratory diseases. Musculoskeletal ailments and injuries were attributed to the increased burden of health events managed at the clinics and hospitals.

The drug expenses incurred during the event were mostly from analgesics and antibiotics. A study by Chang et al [13] shows findings similar to those of this study. These medications are a suitable treatment for the common ailments experienced by the masses walking to Karbala. The journey to Karbala requires several days of walking, resulting in musculoskeletal pain and injuries, which explain the large amount of money spent on analgesics for controlling muscular pain. In addition, a considerable amount of money was used for purchasing antibiotics that mostly attributed to the frequently reported respiratory infection. Moreover, it is worth mentioning that prescribing antibiotics in Iraq, particularly during such an event, did not follow the standards of antibiotics prescription.

The health service burden during such events falls mainly on mobile clinics, where the cases are managed. This could be due to the high occurrence of minor illnesses during mass gathering as well as the accessibility of mobile clinics to the mass gathering participants. The burden on mobile clinics is consistent with that reported in a study from Australia, which shows that only one-fifth of mass gathering attendees are transferred to the hospital [14].

Intense physical activities during mass gatherings, such as walking long distances, could exacerbate cardiovascular diseases and may lead to sudden death. A study during the Hajj mass gathering indicated that cardiovascular disease is one of the leading causes of deaths [15], which was also observed in this study. Injuries were the least reported events but the second leading cause of death, which may indicate that a substantial portion of injuries were fatal.

We can conclude that the Arbaeenia mass gatherings caused a tremendous disease and economic burden to the governorates that the pilgrims pass through. In spite of the high increase in morbidity, there was no change in the pattern of mortality throughout the study period. In spite of the tremendous work done by Iraq Ministry of Health and faith-based organizations to serve pilgrims during mass gatherings, more work is needed to mitigate the burden on the health facilities in all governorates in charge of serving the pilgrims. This should be considered while developing a preparedness plan for the coming mass gatherings.

The study has certain limitations. The study covered only three governorates, which limits generalization of the study findings to other governorates and to Iraq. In addition, the data do not provide all the calculation of rates of event occurrence. Furthermore, information on health care resources in the three governorates was not available to assess the adequacy to manage the increased disease events. Finally, since most of the health outlets were concerned with provision of ambulatory health services, detailed data on risk factors and diseases were not collected.

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Conflicts of Interest

None declared.

References

1. WHO/CDS/EPR. Communicable disease alert and response for mass gatherings. Geneva, Switzerland: World Health Organization; 2008.
2. Shirah BH, Zafar SH, Alferaidi OA, Sabir AMM. Mass gathering medicine (Hajj Pilgrimage in Saudi Arabia): The clinical pattern of pneumonia among pilgrims during Hajj. J Infect Public Health 2017 May;10(3):277-286 [FREE Full text] [doi: 10.1016/j.jiph.2016.04.016] [Medline: 27262693]
3. Memish Z. A career in a Kingdom: Journeys in infection, Mass Gathering Medicine and public health diplomacy. Hum Vaccin Immunother 2017 Mar 04;13(3):494-498 [FREE Full text] [doi: 10.1080/21645515.2016.1226637] [Medline: 27559845]
4. Smith MWH, Fulde GWO, Hendry PM. World Youth Day 2008: did it stress Sydney hospitals? Med J Aust 2008;189(11-12):630-632. [Medline: 19061455]
5. Khan ID, Khan SA, Asima B, Hussaini SB, Zakiuddin M, Faisal FA. Morbidity and mortality amongst Indian Hajj pilgrims: A 3-year experience of Indian Hajj medical mission in mass-gathering medicine. J Infect Public Health 2018 Mar;11(2):165-170 [FREE Full text] [doi: 10.1016/j.jiph.2017.06.004] [Medline: 28668659]
6. Hadjichristodoulou C, Soteriades ES, Kolonia V, Falagas ME, Pantelopoulos E, Panagakos G, et al. Methodological aspects of a GIS-based environmental health inspection program used in the Athens 2004 Olympic and Para Olympic Games. BMC Public Health 2005 Sep 02;5:93 [FREE Full text] [doi: 10.1186/1471-2458-5-93] [Medline: 16138924]
7. Zhang Y, Wang Z, Chen X. Public health response to mass gathering. Zhonghua Liu Xing Bing Xue Za Zhi 2008 Jul;29(7):737-739. [Medline: 19031774]
8. Rainey JJ, Cheriyadat A, Radke RJ, Suzuki Crumly J, Koch DB. Estimating contact rates at a mass gathering by using video analysis: a proof-of-concept project. BMC Public Health 2014 Oct 24;14:1101 [FREE Full text] [doi: 10.1186/1471-2458-14-1101] [Medline: 25341363]
9. Al Lami F, Al Fatlawi A, Bloland P, Nawwar A, Jetheer A, Hantoosh H, et al. Pattern of morbidity and mortality in Karbala hospitals during Ashura mass gathering at Karbala, Iraq, 2010. East Mediterr Health J 2013 Dec 01;19(Supp. 2):13-18. [doi: 10.26719/2013.19.supp2.s13]
10. Wikipedia. 2018 Oct 10. List of largest peaceful gatherings in history URL: https://en.wikipedia.org/wiki/List_of_largest_peaceful_gatherings [accessed 2019-04-30]
11. Dearden L. Independent. 2014 Nov 25. One of the world?s biggest and most dangerous pilgrimages is underway URL: https://www.independent.co.uk/news/world/middle-east/one-of-the-worlds-biggest-and-most-dangerous-pilgrimages-is-underway-9882702.html [accessed 2019-04-30]
12. Al Nsour M, Fleischauer A. Public health considerations for mass gatherings in the Middle East and North Africa [MENA] region. East Mediterr Health J 2013 Dec 01;19(Supp. 2):42-46. [doi: 10.26719/2013.19.supp2.s42]
13. Chang EC, Koval E, Freer L, Kraus S. Planning for an annual episodic mass gathering: emergency department and clinic utilization in Yellowstone. Wilderness & Environmental Medicine 2000 Dec;11(4):257-261. [doi: 10.1580/1080-6032(2000)011[0257:pfaaem]2.3.co;2]
14. Zeitz K, Zeitz C, Kadow-Griffin C. Injury occurrences at a Mass Gathering Event. Australasian Journal of Paramedicine 2015 Jul 14;3(1). [doi: 10.33151/ajp.3.1.307]
15. Al Shimemeri A. Cardiovascular disease in Hajj pilgrims. J Saudi Heart Assoc 2012 Apr;24(2):123-127 [FREE Full text] [doi: 10.1016/j.jsha.2012.02.004] [Medline: 23960680]

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Original Paper

Perceived Stress Among Resident Doctors in Jordanian Teaching Hospitals: Cross-Sectional Study

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Abstract

Background: Medical residents in Jordanian hospitals are involved in many clinical and nonclinical tasks that expose them to various stress factors. High stress and burnout have the potential to negatively impact work performance and patient care, including medication errors, suboptimal care, clinical errors, and patient dissatisfaction.

Objective: This study aimed to determine the perceived stress among medical residents in Jordanian hospitals and its associated risk factors.

Methods: A cross-sectional study was conducted among residents in Jordanian hospitals. A cluster sample of 5 hospitals with residency programs was selected from different health sectors. All residents who were working in the selected hospitals were invited to participate in this study, during the period from April to July 2017. A total of 555 residents agreed to participate in this study, giving a response rate of 84%. The perceived stress scale (PSS) was used for assessment.

Results: A total of 398 male and 157 female residents were included in this study. The mean PSS score in this study was 21.6; 73% (405/555) of the residents had moderate level of stress, and 18% (100/555) had high level of stress. About 6.7% (37/555) of the residents had hypertension, 2.7% (15/555) had diabetes, 3.2% (18/555) had heart disease, and 8.5% (47/555) were anemic. 233 (42%) respondents complained of back pain, and 161 (29%) of the respondents complained of insomnia. Stress was associated with higher workload, sleep deprivation, and dissatisfaction in the relationship with colleagues, with income, and with the program. In multivariate analysis, the following factors were significantly associated with stress: female gender, dissatisfaction with working environment, and facing work-related, academic, and family stressors.

Conclusions: The majority of medical residents in Jordanian hospitals felt nervous and stressed. Conducting stress management programs during residency and improving the work environment are strongly recommended.

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KEYWORDS

psychology; physicians; teaching hospitals; Jordan

Introduction

Stress and psychosocial risk factors are considered critical issues in the field of occupational health [1]. Occupational stress is understood as the experience of stress that is caused by factors within the occupation or job. Occupational stress is a rational, physical, and emotional deterioration that is brought about by the dissimilarities between the job requirements and the personal skills, capabilities, and competencies. The impact of stress on the physical and mental health, as well as the productivity of both the organizations and the employees, is a growing concern of organizations. High stress and burnout have the potential to negatively impact work performance and patient care, including medication errors, suboptimal care, clinical errors, and patient dissatisfaction [2,3]. Many studies have looked into the stress and the burnout levels of medical personnel, and an extremely high level of stress has been observed in hospital nurses, surgeons, general practitioners, and resident doctors [4,5]. Physicians are exposed to many stressors, such as the burden imposed by the expectations of a high degree of professionalism, responsibility for patient well-being, and maintenance of relationships with patients and health workers, as well as concerns about medical errors and malpractice litigation [6]. Studies have demonstrated that up to 76% of residents meet the criteria for burnout and that they have expressed career dissatisfaction, as well as concern that they provide suboptimal patient care [1]. Residents report that the working conditions they are subjected to during residency lead to reduced attention, empathy, concern, and sensitivity, and increased irritability, abruptness, and a tendency to objectify patients [7]. The significance of this study emerges from the fact that the quality of health care can be extremely influenced by the stressed health staff. Residency involves long hours, large numbers of patients, and sleep deprivation [8,9]. When the level of stress exceeds a critical level, it can manifest as distress, resulting in psychological morbidity, impairment, and burnout [10]. This study aimed to assess the level of stress among residents and determine the main leading factors causing stress among resident doctors in Jordanian hospitals.

Methods

Study Design

This cross-sectional study was conducted among medical residents trained in different residency programs in Jordan, during the period from April to July 2017. All residents who were enrolled in different sectors, including public, private, and teaching programs, were eligible to be included in the study. Al-Bashir and Prince Hamza hospitals were selected from the public sector, Islamic hospital and Jordan hospital were selected from the private sector, and King Abdullah University hospital was selected from the teaching health sector. All residents who were working in the selected hospitals were invited to participate in this study. A total of 555 residents agreed to participate in this study, giving a response rate of 84%. The ethical approval was obtained from the Institutional Review Board at the Ministry of Health in Jordan.

Data Collection

A self-administrated questionnaire was used to collect the data. The questionnaire included data on sociodemographic characteristics (age, gender, and marital status), residency characteristics (specialty and year), diseases or symptoms experienced by medical residents in the last year, workload (number of inpatients and outpatients treated per day, sleep duration, and quality), recently faced stressors (work related and nonwork related), and job satisfaction. Perceived stress scale (PSS) was used to assess residents' perception of stress over the past month [11]. The respondents answered each PSS question on a Likert-type scale (never, almost never, sometimes, fairly often, or very often). We scored the answers to questions 1, 2, 3, 6, 9, and 10 by giving a score of 0 to the "never" answers and 4 to the "very often" responses. Questions 4, 5, 7, and 8 were scored by scoring "never" as 4 and "very often" as 0. The PSS score was calculated by summing up the scores of all the individual questions. Scores ranging from 0 to 13 would be considered low stress, scores ranging from 14 to 26 would be considered moderate stress, and scores ranging from 27 to 40 would be considered high perceived stress, with higher scores indicating higher levels of stress. The PSS had good internal consistency among its items, as indicated by an overall Cornbrash alpha value of .76. The study questionnaire was pilot tested on 30 participants (n=30). Necessary changes on the wording and phrasing of the questions were revised according to the pilot study findings. The face and content validity of the study questionnaire were evaluated by 3 experts.

Statistical Analysis

Data were coded and entered through IBM SPSS, version 20, software. Data were described using percentages and means. Variables were displayed through percentage frequency tables. Comparisons between 2 means and more than 2 means were tested for statistical significance by using an independent *t* test and a 1-way analysis of variance, respectively. General linear model was used to test the factors associated with stress level in the multivariate analysis. A *P* value <.05 was considered statistically significant.

Results

Characteristics of the Participants

A total of 398 (71.7%, 398/555) male and 157 (28.3%, 157/555) female residents were included in this study. Table 1 shows their sociodemographic and work characteristics.

The average (SD) age was 30.0 (3.0) years. More than half of respondents were residents in the fields of surgery, internal medicine, pediatrics, and radiology. A majority of the participants (92%, 511/555) worked night shift, and 95.3% (529/555) dealt with emergency cases. The median number of inpatients and outpatients treated by the residents per day was 15 and 35 patients, respectively. Approximately 78.9% (435/555) of the residents reported that they slept for less than 6 hours per day, and only 21.4% (119/555) of the residents reported feeling refreshed after sleep.

Depending on self-reported data, about 6.7% (37/555) of the residents had hypertension, 2.7% (15/555) had diabetes, 3.2% (18/555) had heart disease, 8.5% (47/555) were anemic, and 7.0% (39/555) had lung or breathing problems. 233 (42%) respondents complained of back pain, 161 (29%) complained of insomnia, 83 (15%) of stomach ulcer, 78 (14%) of gastritis, 67 (12%) of emotional problems, and 50 (9%) colitis.

Table 1. The sociodemographic and work characteristics of medical residents in Jordanian hospitals (N=555).

Characteristics	Statistics, n (%)
Gender	
Male	398 (71.7)
Female	157 (28.3)
Age (years)	
<30	267 (51.0)
≥30	257 (49.0)
Marital status	
Married	323 (58.2)
Single	232 (41.8)
Specialty	
Surgery	110 (19.8)
Internal medicine	85 (15.3)
Pediatrics	84 (15.1)
Radiology	61 (11.0)
Anesthesia	43 (7.7)
Obstetrics and gynecology	38 (6.8)
Orthopedics	35 (6.3)
Others	99 (17.8)
Residency year	
First	162 (29.2)
Second	124 (22.3)
Third	104 (18.7)
Fourth	103 (18.6)
Fifth	62 (11.2)
Night shift per month	
1-5	133 (24.0)
>5	378 (68.1)
Deal with emergency cases	529 (95.3)
Inpatients treated per day	
≤15	282 (50.1)
>15	241 (49.9)
Outpatients treated per day	
≤35	258 (50.1)
>35	257 (49.9)
Sleep duration (hours)	
≤5	225 (40.8)
6	210 (38.1)
7	80 (14.5)
≥8	36 (6.5)
Feeling refreshed after sleep	119 (21.4)

Stressors and Satisfaction

Table 2 shows stressors, job satisfaction, and ideation among the study participants. The most commonly reported stressors included work-related, financial, academic, and family stressors.

About 70.0% (388/555) of the participants were satisfied with their relationship with colleagues; 21.1% (117/555) of the participants were satisfied with the training program, whereas 14% (78/555) of the participants were dissatisfied. A total of 15.7% (87/555) of the residents frequently considered changing their specialty, and 23.6% (131/555) had frequent thoughts of quitting the medical profession.

Table 2. Stressors, job satisfaction, and ideation experienced by medical residents in Jordanian hospitals.

Characteristics	Statistics, n (%)
Comfortable working environment	86 (15.5)
Satisfied with income	30 (5.4)
Facing stressors experienced in the last month	
Work related	479 (86.3)
Financial	345 (62.2)
Academic	290 (52.3)
Family	126 (22.7)
Alienation	74 (13.3)
Death	19 (3.4)
Others	82 (14.8)
Satisfied with the relationships with colleagues	388 (70.0)
Satisfied with training program	117 (21.1)
Thoughts of changing specialty	
Very often	87 (15.7)
Sometimes	198 (35.7)
Rarely	104 (18.7)
Never	166 (29.9)
Thoughts of quitting	
Very often	131 (23.6)
Sometimes	205 (36.9)
Rarely	94 (16.9)
Never	125 (22.5)

Responses to Perceived Stress Scale

A majority of the medical residents (73%, 405/555) had moderate level of stress, 18% (100/555) of the medical residents had high level of stress, and 9% (50/555) had mild level of stress. Table 3 shows the responses to PSS.

During the last month preceding the survey, 76.2% (423/555) of the residents often ("fairly" or "very") felt nervous and stressed, 44.8% (249/555) felt upset because of unexpected events, 45.8% (254/555) felt angered by circumstances that were beyond their control, 42.4% (235/555) felt unable to control important things in their life, and 44.1% (245/555) felt that difficulties were piling up, which were too high to overcome. In contrast, 34.7% (193/555) of the residents often felt that things were going their way, 20.5% (114/555) felt that they were on top of things, 19.7% (109/555) had often been able to control irritations in their life, and 15.4% (85/555) often felt confident in their ability to handle personal problems.

Table 3. Medical residents' responses to perceived stress scale in Jordanian hospitals.

Perceived stress scale items	Never, n (%)	Almost never, n (%)	Sometimes, n (%)	Fairly often, n (%)	Very often, n (%)
In the last month, how often have you been upset because of something that happened unexpectedly?	41 (7.4)	63 (11.4)	202 (36.4)	150 (27.0)	99 (17.8)
In the last month, how often have you felt that you were unable to control the important things in your life?	44 (7.9)	96 (17.3)	180 (32.4)	147 (26.5)	88 (15.9)
In the last month, how often have you felt nervous and "stressed?"	8 (1.4)	19 (3.4)	105 (18.9)	197 (35.5)	226 (40.7)
In the last month, how often have you felt confident about your ability to handle your personal problems?	99 (17.8)	178 (32.1)	193 (34.8)	68 (12.3)	17 (3.1)
In the last month, how often have you felt that things were going your way?	25 (4.5)	104 (18.7)	233 (42.0)	129 (23.2)	64 (11.5)
In the last month, how often have you found that you could not cope with all the things that you had to do?	31 (5.6)	107 (19.3)	234 (42.2)	135 (24.3)	48 (8.6)
In the last month, how often have you been able to control irritations in your life?	66 (11.9)	195 (35.1)	185 (33.3)	82 (14.8)	27 (4.9)
In the last month, how often have you felt that you were on top of things?	53 (9.5)	179 (32.3)	209 (37.7)	79 (14.2)	35 (6.3)
In the last month, how often have you been angered because of things that were outside of your control?	22 (4.0)	75 (13.5)	204 (36.8)	171 (30.8)	83 (15.0)
In the last month, how often have you felt difficulties were piling up so high that you could not overcome them?	19 (3.4)	96 (17.3)	195 (35.1)	164 (29.5)	81 (14.6)

Thoughts of Changing Specialty and Quitting Work According to Stress Level

Figure 1 shows that a quarter of the residents with high level of stress were always thinking of changing specialty, whereas 43% (239/555) of the residents were sometimes thinking of changing specialty. About two-thirds of the residents (361/555, 65%) with low level of stress had never thought of changing specialty. Figure 2 shows that 37% (205/555) of the residents with high level of stress were always thinking of quitting work, whereas two-thirds (350/555, 63%) of the residents with low level of stress had never thought of quitting work.

Figure 1. Percentage of residents who thought of changing specialty according to stress level.

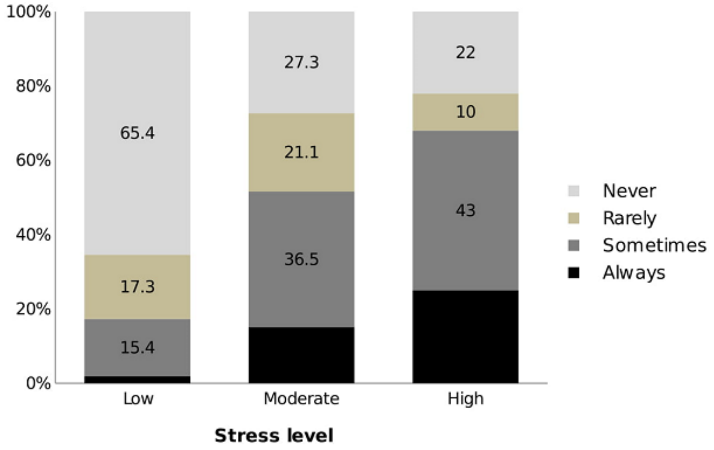
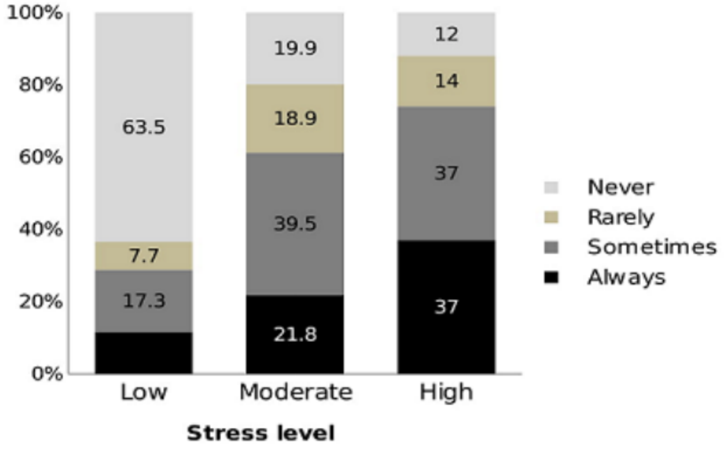


Figure 2. Percentage of residents who thought quitting work according to stress level.



Stress Level and Its Associated Factors

The mean (SD) of the PSS scores was 21.6 (5.8). The average PSS scores, according to sociodemographic and work characteristics and level of satisfaction, are shown in Table 4.

The average PSS score differed significantly according to gender, specialty, night shifts, number of inpatients treated per day, number of outpatients treated per day, satisfaction with working environment, satisfaction with income, satisfaction with the relationships with colleagues, and satisfaction with training program. Table 5 shows the average PSS score according to stressors experienced by residents. Stress level was significantly associated with work-related stressors, financial stressors, academic stressors, and family-related stressors.

Table 6 shows multivariate analysis of factors associated with mean PSS score. Stress level was significantly higher among females, in those working in uncomfortable environments, and in those with work-related, academic-related, and family-related stressors. Those with anemia also had a higher stress level.

Table 4. The average perceived stress scale score according to sociodemographic and work characteristics and level of satisfaction.

Characteristics	Mean (SD)	*P* value
Age (years)		**.49**
<30	21.8 (5.68)	—[a]
≥30	21.4 (5.86)	—
Gender		**<.001**
Male	21.0 (5.69)	—
Female	23.3 (5.88)	—
Marital status		**.74**
Married	21.7 (5.63)	—
Single	21.5 (6.13)	—
Specialty		**.02**
Surgery	21.6 (6.30)	—
Internal medicine	22.2 (5.98)	—
Pediatrics	22.2 (5.55)	—
Radiology	20.5 (6.42)	—
Anesthesia	19.2 (4.92)	—
Obstetrics and gynecology	23.6 (5.43)	—
Orthopedics	22.6 (5.14)	—
Others	21.4 (5.49)	—
Residency years		**.33**
First	21.3 (5.68)	—
Second	22.5 (5.93)	—
Third	21.8 (5.96)	—
Fourth	21.2 (5.94)	—
Fifth	21.0 (5.64)	—
Emergency cases		**.65**
Yes	21.6 (5.79)	—
No	22.1 (6.74)	—
Night shift		**.005**
1-5	20.2 (6.17)	—
>5	22.0 (5.69)	—
Inpatients treated per day		**.02**
≤15	21.0 (6.02)	—
>15	22.3 (5.61)	—
Outpatients treated per day		**.007**
≤35	20.8 (5.88)	—
>35	22.2 (5.56)	—
Comfortable working environment		**<.001**
Yes	17.7 (6.16)	—
No	22.3 (5.49)	—
Satisfied with income		**.002**
Yes	18.4 (5.94)	—
No	21.8 (5.78)	—

Characteristics	Mean (SD)	*P* value
Satisfied with the relationships with colleagues		**<.001**
Satisfied	20.9 (5.89)	—
Dissatisfied	23.5 (5.30)	—
Not sure	23.4 (5.36)	—
Satisfied with training program	**—**	**<.001**
Satisfied	19.2 (5.91)	—
Dissatisfied	22.6 (5.67)	—
Not sure	21.4 (5.32)	—

[a]Not applicable.

Table 5. The average perceived stress scale score according to stressors experienced by medical residents in Jordanian hospitals.

Characteristics	Mean (SD)	*P* value
Work related		**<.001**
Yes	22.2 (5.53)	—[a]
No	18.1 (6.47)	—
Financial		**<.001**
Yes	22.5 (5.92)	—
No	20.2 (5.42)	—
Academic		**<.001**
Yes	23.0 (5.65)	—
No	20.1 (5.69)	—
Family		**<.001**
Yes	23.8 (5.41)	—
No	21.0 (5.81)	—
Alienation		**.65**
Yes	21.9 (5.92)	—
No	21.6 (5.83)	—
Death		**.12**
Yes	23.7 (6.25)	—
No	21.6 (5.81)	—

[a]Not applicable.

Table 6. Multivariate analysis of factors associated with mean perceived stress scale score.

Characteristics	Mean (SE)	95% CI	*P* value
Gender			**.002**
Male	20.2 (0.6)	19.0-21.3	—[a]
Female	22.0 (0.6)	20.9-23.2	—
Specialty			**.15**
Anesthesia	19.3 (0.9)	17.5-21.1	—
Radiology	21.1 (0.8)	19.6-22.7	—
Surgery	21.7 (0.7)	20.3-23.1	—
Internal medicine	22.0 (0.8)	20.5-23.5	—
Obstetric	20.8 (1.0)	18.8-22.7	—
Orthopedic	22.2 (1.0)	20.2-24.3	—
Pediatric	20.7 (0.7)	19.3-22.2	—
Others	21.0 (0.7)	19.7-22.3	—
Comfortable working environment			**<.001**
Yes	19.2 (0.7)	17.8-20.5	—
No	23.1 (0.5)	22.0-24.1	—
Work related			**<.001**
Yes	22.4 (0.5)	21.4-23.8	—
No	19.9 (0.7)	18.5-21.3	—
Academic related			**<.001**
Yes	22.2 (0.5)	21.1-23.2	—
No	20.0 (0.5)	18.9-21.2	—
Family related			**.001**
Yes	22.0 (0.6)	20.7-23.3	—
No	20.2 (0.5)	19.2-21.2	—
Anemia			**.007**
Yes	22.3 (0.8)	20.6-23.9	—
No	19.9 (0.4)	19.1-20.8	—

[a] Not applicable.

Discussion

Work-related stress is very common among health care workers. Health care providers around the world are subject to pressures resulting from a sharp escalation of change, growing economic pressures, technological advances, increasing patient expectations, rationing of health care, and the requirement for more evidence-based and high-quality health care, improved performance, and productivity. It is well documented that health workers experience higher levels of stress and stress-related health problems than other occupational groups [12].

To the best of our knowledge, this study was the first to determine the magnitude of perceived stress among medical residents in Jordan. The study included residents of various specialties from different health sectors.

The study showed that the majority of medical residents had a moderate level of stress (405/555, 73%), and 18% (100/555) of the medical residents had a high level of stress. The perceived stress among residents in this study was comparable with the perceived stress reported among residents in other parts of the world. The mean PSS score in this study was 21.6. This mean is almost the same score for 938 medical residents in Saudi Arabia, where they reported a mean score of 22 [13]. Similarly, the mean PSS score was 21.7 in 106 cardiology residents in Argentina [14], and 19.9 among 159 anesthesia residents in Turkey [15]. A lower score of 16.1 had been reported among 168 family medicine residents in the United States [16]. On the other hand, a study among 84 doctors working in a tertiary care teaching hospital in India reported a mean of 18.3, and another study reported a mean of 18 among 303 physicians working in an Asser region in Saudi Arabia [17-19].

The variations in the PSS score in different studies might be explained by many factors, such as working environment, the specialty, and differences in sociodemographic and cultural characteristics. However, the variations among these studies are not clinically significant.

During the 30 days preceding the survey, 76.2% (423/555) of the residents (“fairly” or “very”) felt nervous and stressed, which can be considered higher than other countries in the region, such as Saudi Arabia, where the 68.2% of the medical residents reported being under stress. On the other side, 19.7% (109/555) of the residents in our sample had often been able to control irritations in their life, in comparison with 34.7% of the Saudi residents [13]. Unfortunately, there is a lack of studies that examine stress among residents in Jordan; therefore, the study compares the findings with the perceived stress among nursing students in Jordan, as the mean of the PSS was 45.9 [20].

According to stress and the personal characteristics, female residents had a significantly higher level of stress than male residents, which was identified by multiregression analysis. There are several studies in agreement with our findings [21,22]. The reasons for this difference should be considered, as more serious consequences might occur among the female physicians who face more workplace adversity compared with males experiencing the same level of occupational stress, in terms of mistrust from the patients, as well as having the dual responsibilities of career and family.

In our multivariate results, stress was significantly associated with anemia; one of the most common symptoms of anemia is a feeling of fatigue and a lack of energy, and although the pathogenesis of anemia-related fatigue remains unclear, some suggest that abnormalities in energy metabolism play a role in inducing fatigue [23]. The relationship between anemia and fatigue is universally accepted. However, early studies were unable to show a clear association between fatigue and hemoglobin levels. There was no evidence of an association between iron deficiency and fatigue in the absence of anemia, suggesting that iron deficiency is not a clinically relevant contributor to fatigue. This gives an important insight for the need to conduct further investigations on the association between anemia and fatigue.

Stress was significantly associated with obstetrics and gynecology residents, surgery, internal medicine, and pediatrics in most countries. It is a well-known fact that the obstetrics and gynecology residency has the highest prevalence of burnout among all specialties [22]. This is explained by the fact that residency in obstetrics and gynecology in most countries is characterized by sleep deprivation, long weekly working hours, postcall clinical responsibilities, and professional liability insurance crises.

The residents in this study, who shouldered higher workloads (dealing with more patients and working more night shifts) and who suffered from sleep deprivation (sleeping few hours and feeling unrefreshed after sleep), were at higher risk of stress. The findings of this study replicate findings from previous studies that used various stress measurement tools to identify the parameters associated with higher stress in residents, such as prolonged working hours, high patient load, critical patients assigned, night duty, poor sleep duration, and quality, poor work environment, and process failure [13,16]. The importance of prolonged working hours in causing fatigue and sleep deprivation, which consequently caused stress, led to the legal restriction of residents’ weekly working hours in the United States in 2003 [23]. This restriction probably had a positive impact on the well-being of the residents. Nonetheless, another study has shown that prolonged working hours may be responsible for both stress and decreased job satisfaction among residents. Unfortunately, most of the residents never received efficient or professional stress management.

The stressors associated with stress in this study covered the 3 groups of stressors described earlier: institutional, professional, and personal stressors [10]. The respondents’ stress was associated with dissatisfaction with colleagues and dissatisfaction with training program, income, and frequent thoughts of quitting the medical profession. This dissatisfaction might cause the stress or vice versa, which indicates a need for stress management programs during residency.

In conclusion, the degree of work-related stress among residents in Jordanian hospitals is considerably moderate to high. The most important significant risk factors identified by multiregression analysis were the following: facing work-related stressors, academic-related stressors, family-related stressors, and uncomfortable work environment. Establishment of professional counseling for the residents is highly recommended to deal with their issues in a timely manner that would support their needs. This could lead to an enhancement in the working environment.

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Conflicts of Interest

None declared.

References

1. Wallace JE, Lemaire JB, Ghali WA. Physician wellness: a missing quality indicator. Lancet 2009 Nov 14;374(9702):1714-1721. [doi: 10.1016/S0140-6736(09)61424-0] [Medline: 19914516]
2. West CP, Shanafelt TD, Kolars JC. Quality of life, burnout, educational debt, and medical knowledge among internal medicine residents. J Am Med Assoc 2011 Sep 7;306(9):952-960. [doi: 10.1001/jama.2011.1247] [Medline: 21900135]

3. Mumtaz Y, Jahangeer A, Habib A, Adnan S, Mumtaz Z. Stress in postgraduate trainee doctors of public and private Universities of Karachi. Pak J Med Sci 2010;26(2):420-425 [FREE Full text]
4. Potter P, Deshields T, Divanbeigi J, Berger J, Cipriano D, Norris L, et al. Compassion fatigue and burnout: prevalence among oncology nurses. Clin J Oncol Nurs 2010 Oct;14(5):E56-E62 [FREE Full text] [doi: 10.1188/10.CJON.E56-E62] [Medline: 20880809]
5. Beckman TJ, Reed DA, Shanafelt TD, West CP. Resident physician well-being and assessments of their knowledge and clinical performance. J Gen Intern Med 2012 Mar;27(3):325-330 [FREE Full text] [doi: 10.1007/s11606-011-1891-6] [Medline: 21948207]
6. Firth-Cozens J. Interventions to improve physicians' well-being and patient care. Soc Sci Med 2001 Jan;52(2):215-222. [doi: 10.1016/s0277-9536(00)00221-5] [Medline: 11144777]
7. Papp KK, Stoller EP, Sage P, Aikens JE, Owens J, Avidan A, et al. The effects of sleep loss and fatigue on resident-physicians: a multi-institutional, mixed-method study. Acad Med 2004 May;79(5):394-406. [doi: 10.1097/00001888-200405000-00007] [Medline: 15107278]
8. Rockey PH. Duty hours: where do we go from here? Mayo Clin Proc 2011 Mar;86(3):176-178 [FREE Full text] [doi: 10.4065/mcp.2011.0086] [Medline: 21364108]
9. Levey RE. Sources of stress for residents and recommendations for programs to assist them. Acad Med 2001 Feb;76(2):142-150. [doi: 10.1097/00001888-200102000-00010] [Medline: 11158832]
10. Cohen S, Kamarck T, Mermelstein R. A global measure of perceived stress. J Health Soc Behav 1983 Dec;24(4):385-396. [doi: 10.2307/2136404] [Medline: 6668417]
11. Lemaire JB, Wallace JE. Not all coping strategies are created equal: a mixed methods study exploring physicians' self reported coping strategies. BMC Health Serv Res 2010 Jul 14;10:208-217 [FREE Full text] [doi: 10.1186/1472-6963-10-208] [Medline: 20630091]
12. Alosaimi FD, Kazim SN, Almufleh AS, Aladwani BS, Alsubaie AS. Prevalence of stress and its determinants among residents in Saudi Arabia. Saudi Med J 2015 May;36(5):605-612 [FREE Full text] [doi: 10.15537/smj.2015.5.10814] [Medline: 25935183]
13. Waldman SV, Diez JC, Arazi HC, Linetzky B, Guinjoan S, Grancelli H. Burnout, perceived stress, and depression among cardiology residents in Argentina. Acad Psychiatry 2009;33(4):296-301. [doi: 10.1176/appi.ap.33.4.296] [Medline: 19690109]
14. Abut YC, Kitapcioglu D, Erkalp K, Toprak N, Boztepe A, Sivrikaya U, et al. Job burnout in 159 anesthesiology trainees. Saudi J Anaesth 2012 Jan;6(1):46-51 [FREE Full text] [doi: 10.4103/1658-354X.93059] [Medline: 22412777]
15. Lebensohn P, Dodds S, Benn R, Brooks AJ, Birch M, Cook P, et al. Resident wellness behaviors: relationship to stress, depression, and burnout. Fam Med 2013 Sep;45(8):541-549 [FREE Full text] [Medline: 24129866]
16. Sathiya N, Ruwaidha R, Nusrath FS, Fathima F, Gomathy T, Shailendra HK. Perceived stress levels and its sources among doctors and nurses working in a tertiary care teaching hospital, Kancheepuram, Tamil Nadu. Ntl J Community Med 2016;7(7):603-608 [FREE Full text]
17. Siddiqui AF, Zaalah MA, Alqahtani AA, Alqahtani MA. Perceived stress and its associated sociodemographic factors among physicians working in Aseer region of Saudi Arabia. J Liaquat Uni Med Health Sci 2017;16(1):10-18. [doi: 10.1177/1708538116636250] [Medline: 27083699]
18. Akhu-Zaheya L, Shaban I, Khater W. Nursing students’ perceived stress and influences in clinical performance. Int J Adv Nurs Stud 2015 Jun 17;4(2):44. [doi: 10.14419/ijans.v4i2.4311]
19. Kama AA, Sabbour SM, Habeel IS, Ghanem EA. Prevalence and risk factors of work related stress among residents at Ain Shams University Hospitals. Egypt J Commun Med 2015 Jul 1;33(3):81-98. [doi: 10.21608/ejcm.2015.704]
20. Alosaimi FD, Almufleh A, Kazim S, Aladwani B. Stress-coping strategies among medical residents in Saudi Arabia: a cross-sectional national study. Pak J Med Sci 2015;31(3):504-509 [FREE Full text] [doi: 10.12669/pjms.313.7490] [Medline: 26150833]
21. Sobrero A, Puglisi F, Guglielmi A, Belvedere O, Aprile G, Ramello M, et al. Fatigue: a main component of anemia symptomatology. Semin Oncol 2001 Apr;28(2 Suppl 8):15-18. [doi: 10.1016/s0093-7754(01)90207-6] [Medline: 11395847]
22. Martini S, Arfken CL, Churchill A, Balon R. Burnout comparison among residents in different medical specialties. Acad Psychiatry 2004;28(3):240-242. [doi: 10.1176/appi.ap.28.3.240] [Medline: 15507560]
23. Zaré SM, Galanko J, Behrns KE, Koruda MJ, Boyle LM, Farley DR, et al. Psychological well-being of surgery residents before the 80-hour work week: a multiinstitutional study. J Am Coll Surg 2004 Apr;198(4):633-640. [doi: 10.1016/j.jamcollsurg.2003.10.006] [Medline: 15051017]

Abbreviations

PSS: perceived stress scale

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Original Paper

Performance of Multidrug-Resistant Tuberculosis Surveillance in Yemen: Interview Study

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Abstract

Background: Multidrug-resistant tuberculosis (MDR-TB) is a major challenge to ending TB occurrence by 2035. In Yemen, the 2011 survey showed an MDR-TB prevalence of 1.4% among new cases and 14.4% among previously treated cases. The National Tuberculosis Control Program (NTCP) established four MDR-TB sentinel surveillance sites in 2013 to monitor the MDR-TB situation. In Yemen, the 2011 survey showed an MDR-TB prevalence of 1.4% among new cases and 14.4% among previously treated cases. The NTCP established four MDR-TB sentinel surveillance sites in 2013 to monitor the MDR-TB situation.

Objective: This study aimed to assess the performance of MDR-TB surveillance and determine its strengths and weaknesses.

Methods: We used the updated Center for Diseases Control and Prevention guidelines for evaluating public health surveillance systems. Interviews were conducted with NTCP managers and Regional MDR-TB centers' staff using a semistructured questionnaire. We used a 5-point Likert scale to assess the usefulness and other attributes (eg, simplicity and flexibility). The mean percentage was calculated for each attribute and used for the final rank of the performance: poor (<60%), average (60%-80%), and good (>80%).

Results: The MDR-TB surveillance system achieved good performance in usefulness (87%), acceptability (82%), and data quality (91%); average performance in flexibility (61%) and simplicity (72%); and poor performance in stability (55%). The overall performance score was average (74%). Although strong commitment, good monitoring, and well-trained staff are the main strengths, depending on an external fund is a major weakness along with unavailability of the MDR-TB unit at the governorate level.

Conclusions: Although the MDR-TB surveillance system has achieved an average overall performance, more efforts are required to improve its stability by ensuring constant power supply to enable laboratories to perform necessary diagnostic and follow-up tests. Gradual replacement of donors' funds by the government is recommended. Scaling up of MDR-TB services and removing access barriers are crucial.

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KEYWORDS

multidrug-resistant tuberculosis; surveillance evaluation; Yemen; field epidemiology program

Introduction

Tuberculosis (TB) is one of the major causes of morbidity and mortality worldwide, with more than 10 million newly reported cases and 1.7 million deaths in 2015 [1]. With an estimated 480,000 new multidrug-resistant (MDR) TB cases every year, developing drug resistance to anti-TB drugs becomes a major challenge for the global prospect of ending TB by 2035 [2]. Although MDR-TB is defined as the resistance to rifampicin and isoniazid, extensively drug-resistant TB (XDR-TB) is an MDR-TB with resistance to fluoroquinolone and at least one of the injectable second-line anti-TB drugs [3]. As MDR-TB is more difficult and costly to treat, there are increasing concerns about its continued spread and negative impact on the population and health systems [4]. Effective response to MDR-TB should not only focus on treating drug-susceptible tuberculosis, but also include strong surveillance systems, drug susceptibility testing for all patients with tuberculosis, rapid linkage to effective treatment, and patient-centered care throughout the treatment course [5].

Globally, in 2015, 4% of all new patients and 20% of previously treated patients with TB had MDR-TB. China, India, and the Russian Federation account for nearly half of the global MDR-TB prevalence [6]. The data on MDR‐TB from eight countries of the Eastern Mediterranean Region (Egypt, Islamic Republic of Iran, Jordan, Lebanon, Morocco, Oman, Qatar, and Yemen) showed an MDR-TB prevalence of 2.0% among new cases and 35.3% among previously treated cases [7]. Although most countries in the region had established MDR-TB management in line with World Health Organization (WHO) guidance, it estimated that the region has only detected 12% of MDR-TB cases and has enrolled 72% of them on treatment.

In Yemen, TB is the fourth biggest public health problem, with an incidence of 48 per 100,000 people [8]. However, there were no systems in place for the management of MDR in Yemen before 2013, as shown by two surveys performed in 2005 and 2011. The 2004-2005 survey showed an MDR-TB prevalence of 2.9% among new smear-positive cases and 11.3% among previously treated cases compared to 1.4% and 14.4%, respectively, in the 2010-2011 survey [9]. By the end of 2013, the National TB Control Program (NTCP) started the DR-TB Management and Surveillance program. This study aimed to evaluate the performance of MDR-TB surveillance in Yemen and determine its strengths and weaknesses.

Methods

Evaluation Design

A descriptive evaluation study was conducted to assess the performance of MDR-TB surveillance system in Yemen using the Updated CDC guideline for evaluation of public health surveillance system [8]. The study was conducted at Sana’a city from November to December 2016. Data on MDR-TB were collected from the NTCP and the four Regional MDR-TB centers.

The Multidrug-Resistant Tuberculosis Surveillance System

The MDR-TB is a sentinel system through four regional MDR-TB centers at Sana’a City, Aden, Taiz, and Al Hodaidah, with an aim to cover the whole country. The centers provide detection, diagnosis, treatment, and follow-up through a community-based outpatient treatment-delivery strategy that consists of a community supporter, community nurse, drug provider, coordinator, and lab technician. The community supporter is one of the patient’s family members who observes the patient daily, has contact with the community nurse regularly, and fills monthly reports for daily treatment intake. The community nurse follows the community supporters on a monthly basis, directly contacts patients during the follow-up visits, and is responsible for registration of DR-TB. The drug provider is a nurse responsible for supplying drugs to patients with MDR-TB and for the drug supply registry. All patients have monthly clinical assessments by a specialist doctor. The lab technician is responsible for performing the smears and cultures or others lab tests in addition to completing the lab registry and reports. The MDR-TB coordinator is responsible for sending the reports to the NTCP. All centers have equipped labs for drug susceptibility testing (DST) and culture. Due to a total breakdown of the electricity network that is needed for DST, the regional MDR-TB centers were provided with the GenXpert, except for the Taiz MDR-TB center, which still sends samples to Sana’a City for diagnosis.

At the MDR-TB centers, there are three hard-copy registers: the DR-TB case register, the lab register, and the MDR-TB drug supply register. The DR-TB cases register contains a set of variables including demographic variables, previous TB registration number, type of drug resistance, starting category 4 treatment date, and use of previous second-line drugs, DST result, smear and culture follow-up results, and HIV status.

Data Collection and Analysis

The MDR-TB documents were reviewed to describe the system. The mangers of the NTCP were interviewed to assess usefulness, flexibility, and stability of the MDR-TB system. Semistructured questionnaires were used to collect data from staff of the four MDR-TB centers to evaluate simplicity and acceptability of the system. Specific items were used to evaluate each performance attribute. Respondents from the four centers were requested to rate the items measuring the system usefulness as well as the simplicity, flexibility, acceptability, and stability using the 5-point Likert scale (1=strongly disagree, 2=disagree, 3=not sure, 4=agree, 5=strongly agree). The mean percentage score was calculated for each attribute, where a higher score indicates a higher level of performance. The performance was interpreted using the following scoring system that was used in previous similar studies: <60%, poor; 60%-80%, average; and >80%, good [10-12]. To assess the data quality, we reviewed 10% of randomly selected MDR-TB cases’ files and registers. The selected files were reviewed for any missing data or discrepancies between data on cases’ files and register. Epi info version 7.2 (Centers of Disease Control and Prevention, Atlanta, Georgia) was used for data entry and analysis.

Results

Data Flow of Multidrug-Resistant Tuberculosis Surveillance

Figure 1 shows the data flow of the MDR-TB surveillance system, where the suspected case is sent to the nearest regional DR-TB center for lab confirmation and treatment. According to the tests results, the lab sends immediate reports for positive cases to the NTCP to be included in their drug supply for the reporting regional DR-TB. Each regional DR-TB center sends quarterly reports to the NTCP regarding MDR-TB cases during that quarter including lab report, drug supply, and treatment outcome. The NTCP sends quarterly and annual reports to the WHO.

Usefulness

The NTCP managers agreed that the data are useful. They reported that they used the data to estimate needs of the NTCP in terms of drugs and lab tests. Furthermore, all managers agreed that the MDR-TB data are used to estimate the TB magnitude, incidence, and mortality rates in order to monitor the trend of MDR-TB over time; identify areas at greater risk; update and develop the strategic direction for MDR-TB activity; and plan the resources for detection, prevention, and control activities. The usefulness percentage score was 87%, which indicates that the system is useful (Table 1).

Flexibility

All NTCP managers agreed that the system is able to adapt any change in case definition. Four managers (80%) reported that the system is flexible and can be integrated with other surveillance systems. For example, the system is integrated with the HIV program, where all MDR-TB cases are tested for HIV, and positive cases are reported to the HIV program. The flexibility score of the system was 61%, indicating average flexibility (Table 2).

Figure 1. Data flow of multiple drug-resistant tuberculosis cases in Yemen. WHO: World Health Organization; TB: tuberculosis.

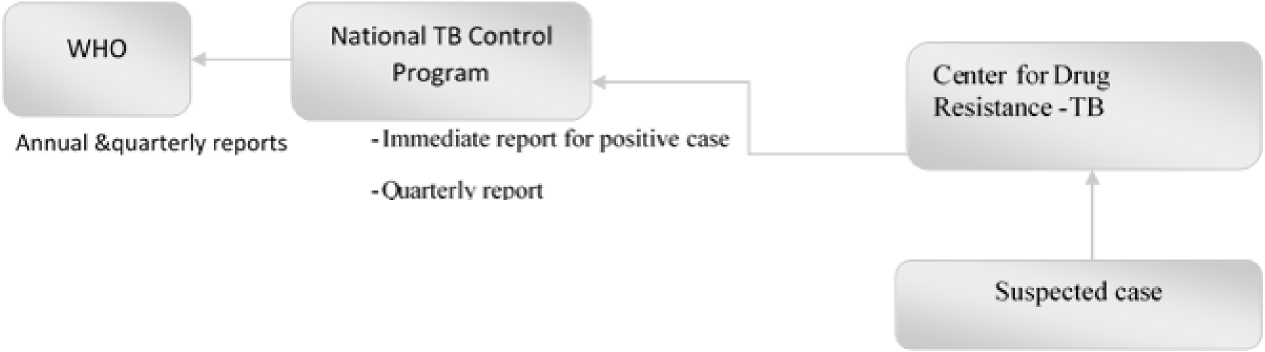

Table 1. The usefulness of the multidrug-resistant tuberculosis surveillance system as assessed by the five managers of the National Tuberculosis Control Program in Yemen.

Statements	Score	Proportion	Rank
The MDR-TB[a] data are used to estimate the MDR-TB magnitude, incidence, and mortality rates	4.4	88	Good
The data are used to monitor the trend of MDR-TB spread over time	4.0	80	Good
The data are used to identify areas at greater risk	4.2	84	Good
The data are used for planning the resources for detection, prevention, and control activities	4.6	92	Good
The data are used to update and develop the strategic direction for MDR-TB activity	4.4	88	Good
The collected data are used to estimate the drugs and laboratory test needed	5.0	100	Good
The data are used to identify research priorities	4.0	80	Good
Average	4.4	87	Good

[a] MDR-TB: multidrug-resistant tuberculosis.

Table 2. The flexibility of the multidrug-resistant tuberculosis surveillance system as assessed by the five managers of the National Tuberculosis Control Program in Yemen, 2016.

Statements	Score	Proportion	Rank
The system can be adapted to accommodate addition/change to case definitions.	4.0	80	Good
The system can be integrated with other surveillance such as HIV	3.6	72	Good
The system is not affected by outside funding	1.6	32	Poor
Average	3.1	61	Average

Stability

All participants said that unscheduled outages have been rarely occurred before the war. Three (60%) managers said that the system would collapse if the donor fund stops. The stability of the system was poor, as evidenced by the stability score of 55% (Table 3).

Weakness and Strength of the Multidrug-Resistant Tuberculosis Surveillance System

According to the NTCP managers, the strengths of the system include the program’s commitment to provide a treatment for cases, good monitoring system, well-trained staff, and strong donor support. On the other hand, the managers stated that dependence on the external fund is a major weakness of the system, especially if stopped. Other weaknesses included unavailability of the MDR-TB center at the governorate level, absent inpatient department, no refresher training or training for new staff, absence of an electronic system, no trained staff for data analysis at the regional MDR-TB centers levels, and no constant electrical power supply for the lab.

Simplicity

All the 16 regional MDR-TB staff agreed that the case definitions are easy and clear. Although 71% reported that the guidelines are easy and understandable, 50% reported that it is preferable to have these guidelines written in Arabic. Regarding data collection, 44% respondents reported that this is difficult because, sometimes, the data are needed to call the patient and 66% reported that the data require regular follow-up. All the respondents agreed that transferring data to the NTCP is easy. However, 56% of the respondents reported that there is shortage in lab tests, especially the routine follow-up lab tests (eg, liver function, renal function, and eye and hearing tests) that are only available at the Sana’a regional MDR-TB center. The majority (94%) stated that they received training only once in 2014, and all stated that they need refresher training. The simplicity attribute has been scored 72%, which means that the system is average in simplicity (Table 4).

Table 3. The stability of the multidrug-resistant tuberculosis surveillance system as assessed by the five managers of the National Tuberculosis Control Program in Yemen.

Statements	Score	Proportion	Rank
Unscheduled outages/electrical power off rarely occur	1.4	28	Poor
You have your own source	1.6	32	Poor
There is planned resources for maintenance of the system	4.0	80	Poor
The system is stable even with cutting foreign fund	1.4	28	Poor
Trained staff rarely turnover	4.0	80	Good
Data release regularly	4.0	80	Good
Average	2.7	55	Poor

Table 4. The simplicity of the multidrug-resistant tuberculosis surveillance system as assessed by 16 service providers in Yemen.

Statements	Mean score	Percentage score	Rank
Case definition is available and easy to apply	4	80	Good
You have easy guide to use	3.5	70	Average
Registers or form is easy to fill	4	80	Good
Collecting case detailed information don’t need telephone or visit	3	60	Poor
Data compiling time, place and person.	4	80	Good
Collecting data do not need much time	3	60	Poor
You received training on MDR[a] surveillance	3.8	76	Average
Transferring data to high level is very easy	4	80	Good
Data do not need regular follow up	2.6	52	Poor
Registers and forms always available	4	80	Good
Laboratory media, solutions and equipment always available	2.7	52	Poor
No shortage in supplying drugs happened	3.5	70	Average
Average	3.6	70	Average

[a] MDR: multidrug resistant.

Acceptability

All the respondents indicated that they receive quarterly incentives for their work and that they are willing to continue participating in the MDR-TB surveillance system. Overall, 81% of the respondents were satisfied. Acceptability scored 82%, which indicates that the system has good acceptability (Table 5).

Data Quality

By reviewing the regional Sana'a city DR-TB center's registers and cases files, we found that 5% and 20% had missing data, respectively. However, comparison of data on case files and register did not show any discrepancies.

Overall Performance of the Multidrug-Resistant Tuberculosis Surveillance System

The performance of the surveillance system is illustrated in Table 6.

Table 5. The acceptability of the multidrug-resistant tuberculosis surveillance system as assessed by 16 service providers in Yemen.

Statements	Mean score	Percentage score	Rank
You are willing to participate in MDR-TB[a] surveillance	4.3	86	Good
You are satisfied with MDR[b] surveillance	3.9	79	Average
Average	4.1	82	Good

[a] MDR-TB: multidrug-resistant tuberculosis.

[b] MDR: multidrug resistant.

Table 6. Performance of the multidrug-resistant tuberculosis surveillance system.

Attributes	Performance	
	Percentage score	Rank
Usefulness	87	Good
Flexibility	61	Average
Stability	55	Poor
Simplicity	72	Average
Acceptability	82	Good
Data quality	91	Good
Total	74	Average

Discussion

MDR-TB is a growing concern for TB programs, especially in developing countries [13]. Therefore, evaluation of MDR-TB surveillance is crucial. Our findings demonstrated good performance regarding the usefulness, especially for estimating the need for drugs to ensure case enrollment. It is also useful to ensure proper diagnosis and treatment for MDR-TB cases, which is one of the main goals for NTCP.

Based on the findings of this study, the flexibility of the system is average, as it can accommodate changes in case definitions and any updated guidelines. For example, case definition of rifampicin-resistant TB was added after GenXpert was introduced as a recommendation by the WHO [14]. Similar findings were reported from a previous evaluation in Pakistan that found that the MDR-TB surveillance can integrate with other systems [15].

Regarding the stability, we found that the MDR-TB surveillance system is unstable, mainly due to its sole dependence on donor support with a lack of governmental support. Furthermore, the frequent electricity cutoff in addition to the shortage of laboratory equipment at the regional centers negatively influenced the performance and made the system unstable, thereby affecting its sustainability. Therefore, constant power supply should be ensured for labs and appropriate laboratory equipment are essential.

The MDR-TB surveillance system seems like a simple system. Nevertheless, multiple registers and reports and the lack of a computerized system could make data collection more difficult. The acceptability of MDR-TB surveillance is good, which is reflected through the good data quality. The good acceptability might be a result of quarterly incentives for staff. However, cessation of such incentives will negatively impact acceptability and data quality. Previous similar evaluation in Pakistan found that both data quality and acceptability are good.

This study has some limitations. It did not shed light on the quantitative attributes and did not cover XDR-TB. Those limitations are attributed to the unavailability of all required lab tests for XDR-TB in addition to the specificity of MDR-TB that leads to inapplicability of some lab-related quantitative attributes.

In conclusion, the MDR-TB surveillance system provides useful data. However, dependence on donor funds affects stability and sustainability. MDR-TB centers or units should be expanded to cover all governorates. It is also recommended that constant power supply for labs is supplied and that there is a decrease in sole dependence on donor support through gradual replacement with governmental support.

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Conflicts of Interest

None declared.

References

1. World Health Organization. Tuberculosis. URL: http://www.who.int/mediacentre/factsheets/fs104/en/ [accessed 2019-03-23]
2. World Health Organization. Multidrug-/ rifampicin-resistant TB (MDR/RR-TB):Update 2017. Tuberculosis 2017. [doi: 10.1183/1393003.congress-2017.oa1944]
3. Bastos ML, Cosme LB, Fregona G, do Prado TN, Bertolde AI, Zandonade E, et al. Treatment outcomes of MDR-tuberculosis patients in Brazil: a retrospective cohort analysis. BMC Infect Dis 2017 Nov 14;17(1):718 [FREE Full text] [doi: 10.1186/s12879-017-2810-1] [Medline: 29137626]
4. van Duin D, Paterson DL. Multidrug-Resistant Bacteria in the Community: Trends and Lessons Learned. Infect Dis Clin North Am 2016 Jun;30(2):377-390 [FREE Full text] [doi: 10.1016/j.idc.2016.02.004] [Medline: 27208764]
5. World Health Organization. 2015. Guidelines for surveillance of drug resistance in tuberculosis. URL: http://apps.who.int/iris/bitstream/handle/10665/174897/9789241549134_eng.pdf?sequence=1 [accessed 2019-09-18]
6. World Health Organization. 2016. Global tuberculosis report. URL: https://apps.who.int/medicinedocs/documents/s23098en/s23098en.pdf [accessed 2019-09-18]
7. World Health Organization. Strategic plan for the prevention and control of multidrug-resistant and extensively drug-resistant tuberculosis in the Eastern Mediterranean Region. 2010.
8. World Health Organization. 2016. Global Health Observatory Data Repository URL: http://gamapserver.who.int/gho/interactive_charts/tb/treatment/atlas.html [accessed 2019-09-18]
9. Yemen MOPH, Guidelines OMODRTB. NTCP. In: Guidelines on Management of Drug Resistant-TB. NTCP. Yemen: Yemen Ministry of Public Health and Population; 2012.
10. Safdar R, Khan S, Asghar R. Evaluation of hepatitis surveillance systems in Pakistan. International Journal of Infectious Diseases 2008 Dec;12:e192. [doi: 10.1016/j.ijid.2008.05.478]
11. Saeed K, Bano R, Asghar R. Evaluation of national tuberculosis surveillance system in Afghanistan. East Mediterr Health J 2013 Feb 01;19(02):200-207. [doi: 10.26719/2013.19.2.200]
12. Ansari J, Kazi B, Salman M, Asghar R. Evaluation of the existing bacterial meningitis surveillance system in Islamabad, Pakistan. International Journal of Infectious Diseases 2008 Dec;12:e192. [doi: 10.1016/j.ijid.2008.05.477]
13. Zaman K. Tuberculosis: a global health problem. J Health Popul Nutr 2010 Apr;28(2):111-113 [FREE Full text] [doi: 10.3329/jhpn.v28i2.4879] [Medline: 20411672]
14. World Health Organization. 2016. Tuberculosis, drug-resistant types URL: http://www.who.int/tb/areas-of-work/drug-resistant-tb/types/en/ [accessed 2019-09-18]
15. Khudaidad F, Saeed A. Evaluation of drug resistant tuberculosis (DR-TB) surveillance system in Balochistan Province, in six emphenet regional conference. 2016. [doi: 10.2196/10536]

Abbreviations

DST: drug susceptibility testing
MDR: multidrug resistant
MDR-TB: multidrug-resistant tuberculosis
NTCP: National Tuberculosis Control Program
WHO: World Health Organization
XDR-TB: extensively drug-resistant tuberculosis

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Original Paper

Real-Time Surveillance of Infectious Diseases and Other Health Conditions During Iraq’s Arbaeenia Mass Gathering: Cross-Sectional Study

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Abstract

Background: The most common religious mass gatherings in the Middle East are the Hajj at Mecca in Saudi Arabia, which occurs annually, and the Arbaeenia in Karbala. The importance of developing public health surveillance systems for mass gatherings has been previously emphasized in other reports.

Objective: This study aimed to describe the common illnesses and health conditions affecting people during the Arbaeenia mass gathering in Iraq in 2016.

Methods: A total of 60 data collectors took part in the field data collection over a period of 11 days, from November 12, 2016 to November 22, 2016. Data were collected from 20 health outlets along the major route from Najaf to Karbala (10 health facilities in each governorate). Two digital forms, the Health Facility Survey and the Case Survey, were used for data collection.

Results: A total of 41,689 patients (33.3% female and 66.7% male) visited the 20 health care facilities over a period of 11 days from November 12, 2016 to November 22, 2016. More than three quarters of patients (77.5%; n=32,309) were between 20-59 years of age, more than half of patients were mainly from Iraq (56.5%; n=23,554), and about 38.9% (n=16,217) were from Iran. Patients in this study visited these health care facilities and presented with one or more conditions. Of a total 41,689 patients, 58.5% (n=24,398) had acute or infectious conditions and symptoms, 33.1% (n=13,799) had chronic conditions, 23.9% (n=9974) had traumas or injuries, 28.2% (n=11,762) had joint pain related to walking long distances, and 0.3% (n=133) had chronic dermatologic conditions.

Conclusions: The Arbaeenia mass gathering in 2016 exerted a high burden on the Iraqi health care system. Therefore, efforts must be made both before and during the event to ensure preparedness, proper management, and control of different conditions.

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KEYWORDS
mass gathering; Arbaeenia; surveillance; Iraq

Introduction

The World Health Organization (WHO) defines mass gatherings as "events attended by a number of people sufficient to strain the planning and response resources of a community, state or nation[1]."

Such occurrences put a strain on local resources like food, drinks, accommodations, and health care, and they can pose a health risk to the population. Masses gather for many reasons, including religious activities, festivals, sporting events, and political rallies, among other reasons. The most common religious mass gatherings in the Middle East are the Hajj at Mecca in Saudi Arabia, which occurs annually, and the Arbaeenia in Karbala.

Iraq hosts one of the largest religious mass gatherings in the world. Every year, people from around the world visit Karbala in Iraq to observe the death anniversary of Imam Hussain ibn Ali, who was a revered Muslim leader. Millions of people gather at the Arbaeenia to mark this important event. The approximate number of visitors increased from 3 million people in 2003 to 25 million in 2016, with about 20% coming from countries other than Iraq [2]. According to 2014 estimates, Karbala City, where the gathering is hosted, has a local population of about 1.1 million individuals in an area of approximately 43.7 km^2 [3,4].

Like other types of mass gatherings, the large number of individuals at this event poses communicable disease health risks and strains the limited health care infrastructure and services of the area. The risk of transmission and importing infectious diseases is high during the mass gathering, due to poor border crossing security [5]. The growing number of individuals who attend the event annually, the changing dates of the anniversary, and the short duration of the event highlight the importance of national and local authorities having preparedness plans in place and the resources to effectively manage the gathering. However, services for the Arbaeenia mass gathering, including health care, are not well developed in Iraq, thus hampering the ability of workers to both stop the spread of pathogens and detect and respond to outbreaks in a timely manner [6].

Although this mass gathering has complex challenges and is associated with an elevated risk for illnesses, there have been few studies done on the burden of religious mass gatherings on Iraq’s local health care resources. The importance of developing public health surveillance systems in mass gatherings was previously emphasized in other reports [7]. Therefore, the Eastern Mediterranean Public Health Network (EMPHNET) collaborated with the Iraq Field Epidemiology Training Program (FETP) and the Iraq Ministry of Health to apply real-time surveillance to several common health conditions (infectious or acute conditions, injuries, and chronic diseases) during the Arbaeenia mass gathering in Iraq between November 12, 2016 and November 22, 2016. This study aims to describe the common illnesses and health conditions affecting people during the Arbaeenia mass gathering in Iraq in 2016.

Methods

A total of 60 data collectors took part in the field data collection over a period of 11 days (between November 12, 2016 and November 22, 2016). Data were collected from 20 health care facilities along the major route from Najaf to Karbala (10 health care facilities in each governorate). All patients that visited the facilities over this period of 11 days were interviewed. Figure 1 shows the map indicating the major routes for visitors travelling on foot during the annual mass gathering. EMPHNET conducted one set of training for the team of survey supervisors, which was followed by two subsequent sets of training by supervisors for data collectors in both Najaf and Karbala. The team of data collectors were overseen and supported technically by four surveillance supervisors (two in each governorate).

A total of 20 tablets were provided to the field team (1 for each health care facility), and the Data4Action platform was used to put the survey tool on the tablets. The information technology team at EMPHNET, with input from the technical team, worked on digitizing the survey tool for real-time surveillance. Two forms (the Health Facility Survey and the Case Survey) were published online at 12:00 midnight on November 12, and the official surveillance activity (field data entry) started at 8:00 AM on November 12, 2016. For data that needed to be entered for testing purposes (eg, in case of the tablets malfunctioning), the data collectors were told to put [TEST] in response to the very last question on the last page of the Case Survey Form before submission. Those TEST case entries were later dropped from the analysis.

Given the simplicity of the survey form, the duration of each case interview ranged from as short as 15 seconds to a few minutes. However, the average duration of the interviews was about 1 minute and 21.3 seconds. This is a valuable piece of information for planning any similar events on an even larger scale.

The case form included information on facility identification (ID), medical staff ID, case ID, age of patients in years, gender, and educational level. The health conditions or complaints (Symptomatic Surveillance) included acute infectious conditions like acute watery diarrhea, acute bloody diarrhea, vomiting with or without diarrhea, fever and cough or flu, fever and bleeding tendency, and fever and rash. Dermatological conditions including itching and skin rash without fever were part of the form. We included conditions related to trauma and walking for long distances. like wounds, blisters, accidental injuries (fracture, car, trolley, or araba accident, overcrowding, falling, etc), and joint pain. Health complaints related to chronic conditions like blood pressure and blood glucose problems, ischemic heart pain or symptoms, and asthma symptoms were also included.

Figure 1. Map indicating the major routes for visitors travelling on foot during the annual Arbaeenia religious mass gathering.

The two teams of surveillance supervisors (in both Najaf and Karbala) were told to provide regular daily briefings to the technical support team. These daily briefs were sent at the end of each day (usually after 5:00 PM) via email. Any major highlights of the day were included in these briefs. These highlights included, but were not limited to, the following: overcrowding of cases in any of the health care facilities during that specific day, issues faced by data collectors alongside their solutions from the supervisors' team, specific challenges in the field, how support was sought from the central or technical team, and so on.

Real-time access to the collected online data was provided to the surveillance supervising team in Iraq. This enabled the technical staff to watch the data collection in real time and take any actions in case the need arose. The field data collection officially ended at midnight on November 21, although some cases were recorded during the early morning hours of November 22.

Extensive algorithms and carefully structured logical formulas were used throughout the database to clean, validate, process, and prepare the data for analysis. All implausible values were dropped during the data cleaning process. Global Positioning System coordinates of all locations (such as countries of origin, or governorate in case they came from inside Iraq) were added to the dataset to enable visualization of the spatial data on map. For this study, data were analyzed using SPSS (IBM Corp, Armonk) and described using percentages and graphs. Excel (Microsoft, Redmond) was used to develop the graphs.

Results

Patients' Characteristics

A total of 41,689 patients (33.3% female and 66.7% male) attended the 20 health care facilities over a period of 11 days between November 12, 2016 and November 22, 2016. The total number of patients, according to each facility, ranged from 383 to 4346, showing that some health facilities recorded considerably more cases than the others due to their locations. More than three quarters of patients (77.5%; n=32,309) were between 20-59 years of age. A total of 41,482 patients had information on their nationality. More than half of patients were from Iraq (56.5%; n=23,554), 38.9% (n=16,217) were from Iran, and 1.4% (n=584) were from Bahrain, followed by small percentages of people from Lebanon, Saudi Arabia, Kuwait, Pakistan, India, Oman, and Afghanistan, and a total of 45 cases were recorded from 21 other countries. Among the recorded 23,444 Iraqis, the larget proportion of people (65.5%; n=15,356) came from Basra, Najaf, Dhi Qar, and Maysan governorates.

Main Conditions and Complaints at Presentation

Overview

Patients visited the health care facilities for one or more conditions. Of a total of 41,689 patients, 58.5% (n=24,398) had acute or infectious conditions and symptoms, 33.1% (n=13,799) had chronic conditions, 23.9% (n=9974) had traumas or injuries, 28.2% (n=11,762) had joint pain related to walking long distances, and 0.3% (n=133) had chronic dermatologic conditions.

Acute or Infectious Conditions and Symptoms

There were 24,398 patients with acute or infectious conditions and symptoms during the event. About two thirds of those patients (68.5%; n=16,711) had fever and cough or flu. Other major categories were food poisoning cases with vomiting and diarrhea (6.3%; n=1526), acute dermatological conditions including itching and skin rash without fever (6.0%; n=1465), acute watery diarrhea (5.0%; n=1214), and fever and rash (2.6%; n=624). Table 1 shows the distribution of acute or infectious conditions and symptoms among patients who attended health care facilities for these conditions during Iraq's Arbaeenia mass gathering in 2016.

Table 1. The distribution of acute or infectious conditions among patients who attended health care facilities for these conditions during Iraq's Arbaeenia Mass Gathering, November 2016.

Acute conditions or symptoms	Count, n (%)
Fever and cough or flu	16,711 (68.49)
Food poisoning	1526 (6.25)
Acute bloody diarrhea	1470 (6.03)
Acute dermatological conditions	1465 (6.01)
Acute watery diarrhea	1214 (4.98)
Fever and bleeding tendency	982 (4.03)
Fever and rash	624 (2.56)
Other acute illnesses	2610 (10.69)

Chronic Conditions

The reasons for visiting health care facilities among those with chronic conditions included problems such as hypertension (55.3%), diabetes mellitus (26.1%), asthma (11.8%), ischemic heart pain or symptoms (3.5%), and other chronic illnesses.

Traumas and Injuries

Out of the total 9974 cases of injuries, the most prevalent complaints reported were blisters due to walking long distances (68.5%; n=6836), wounds (26.2%; n=2614), accidental injuries (4.3%; n=424), and fractures (1%; n=100).

Discussion

Main Findings

This study showed that the Arbaeenia mass gathering placed tremendous pressure on local health care resources and extra burden on health care facilities in Iraq. A total of 41,689 patients visited the 20 health care facilities during a period of 11 days throughout the mass gathering. Of those, 58.5% (n=24,398) had acute or infectious conditions, 33.1% (n=13,799) had chronic conditions, 23.9% (n=9974) had traumas or injuries, 28.2% (n=11,762) had joint pain related to walking long distances, and 0.3% (n=133) had dermatologic conditions.

Mass gatherings create favorable conditions for infectious disease transmission. This study showed that more than half (58.5%) of patients presented with acute symptoms or infectious conditions. Other studies have previously emphasized that there is an increased risk of infectious disease outbreaks during mass gatherings [8-10]. The risk of infectious disease outbreaks during mass gatherings is high because people are exposed to crowded and unhygienic environments, and most of the individuals preparing and serving food are not certified food handlers. Water and food safety, and compliance with health conditions, should be ensured both before and during the event. Food handlers should be trained and provided with working guidelines for safe food handling, and their practices should be inspected and monitored during the event.

Mass gatherings may also exacerbate noncommunicable diseases (NCDs) and chronic conditions, which may lead to emergencies and hospital admissions [11]. The incidence of severe acute cardiovascular events is more than doubled during mass gatherings for people exposed to intense stress [12-14]. High rates of morbidity and mortality from NCDs, including cardiovascular diseases, diabetes mellitus, and asthma, have previously been reported during the Hajj mass gatherings. Our study showed that 33.1% (n=13,799) of people that visited any health care facilities for chronic conditions had problems including hypertension, diabetes mellitus, asthma, and ischemic heart disease or symptoms. Walking long distances, changes in daily activities, and intense physical activity during mass gatherings may also worsen any preexisting conditions. Moreover, poor adherence to diet and medications could negatively affect NCD control, particularly asthma, hypertension, diabetes mellitus and ischemic heart diseases.

About one quarter (23.9%; n=9974) of patients presented at health care facilities with traumas or injuries. Most injuries occurring during mass gatherings are due to overcrowding [15,16]. Other important causes of injuries include some people practicing self-harm, like laceration of their scalp using sharp knives or other risky practices, because of cultural or religious beliefs [17]. Moreover, the journey to Karbala requires several days of walking, resulting in musculoskeletal pain and injuries. This might explain why our findings showed that one quarter of patients presented with joint pain. Given the high percentage of injuries during this event, the government should prepare traffic plans, enforce traffic safety and security laws, assign special streets for visitors that direct them away from traffic, raise visitors' awareness regarding road safety, improve ambulance services, and train volunteers on emergency first aid and safe transportation of injured people.

Conclusions

In conclusion, the Arbaeenia mass gathering in 2016 exerted a high burden on the health care system of Iraq. Therefore, efforts must be made both before and during the event to ensure preparedness, proper management, and control of different conditions. Such activities should include determining the essential services to be provided, determining the organizational structure of medical units and their human resources, creating a standard list for needs, essential medical equipment, and drugs, and inspecting the availability of the preceding requirements during mass gatherings. Moreover, other activities should ensure proper disposal of medical waste as well as infection control practices. Other recommendations include encouraging scientific research into the subject of mass gatherings to gather more information on their effects. Regarding a health surveillance and documentation system, there needs to be improvement in the process of documenting medical cases, which can be achieved by applying documented referral systems from medical units to other institutes, and documenting drug prescriptions, medical needs, and other logistic issues to calculate their financial costs. Furthermore, all districts that are visited by mass gathering attendees are urged to provide various forms of support (ie, financial, logistical, human resources), considering the density of the visitors. Finally, renewing the communicable syndromic surveillance system in medical units during mass gathering events, constructing complementary laboratories in major medical centers, providing transportation, and ensuring transportations of specimens to central laboratories are all recommended measures.

Conflicts of Interest

None declared.

References

1. World Health Organization. Communicable disease alert and response for Mass Gatherings: key considerations. 2008 Jun. URL: http://www.who.int/csr/Mass_gatherings2.pdf [accessed 2019-01-15]
2. David Sim. International Business Times. 2016 Nov 21. Arbaeen: World's largest annual pilgrimage as millions of Shia Muslims gather in Karbala URL: https://www.ibtimes.co.uk/arbaeen-worlds-largest-annual-pilgrimage-millions-shia-muslims-gather-karbala-1531726 [accessed 2019-01-30]
3. Memish ZA. The Hajj: communicable and non-communicable health hazards and current guidance for pilgrims. Euro Surveill 2010 Sep 30;15(39):19671 [FREE Full text] [Medline: 20929658]
4. City Population. 2014. Iraq: Governorates, Regions & Major Cities - Statistics & Maps on City Population URL: http://www.citypopulation.de/Iraq-Cities.html [accessed 2019-01-15]
5. Aitsi-Selmi A, Murray V, Heymann D, McCloskey B, Azhar EI, Petersen E, et al. Reducing risks to health and wellbeing at mass gatherings: the role of the Sendai Framework for Disaster Risk Reduction. Int J Infect Dis 2016 Jun;47:101-104 [FREE Full text] [doi: 10.1016/j.ijid.2016.04.006] [Medline: 27062983]
6. Cetorelli V, Shabila NP. Expansion of health facilities in Iraq a decade after the US-led invasion, 2003-2012. Confl Health 2014 Sep 11;8(1):16 [FREE Full text] [doi: 10.1186/1752-1505-8-16] [Medline: 25221620]
7. Al Nsour M, Fleischauer A. Public health considerations for mass gatherings in the Middle East and North Africa [MENA] region. East Mediterr Health J 2013 Dec 01;19(Supp. 2):42-46. [doi: 10.26719/2013.19.supp2.s42]
8. Kutsar K. Public Health Preparedness in Mass Gatherings. EpiNorth journal 2012;13:88-90 [FREE Full text]
9. Sharifi-Mood B, Metanat M. Diagnosis, Clinical Management, Prevention, and Control of Cholera; A Review Study. Int J Infect 2014 Mar 31;1(1). [doi: 10.17795/iji-18303]
10. Botelho-Nevers E, Gautret P. Outbreaks associated to large open air festivals, including music festivals, 1980 to 2012. Euro Surveill 2013 Mar 14;18(11):20426 [FREE Full text] [doi: 10.2807/ese.18.11.20426-en] [Medline: 23517872]
11. Karami M. Public health surveillance and hajj pilgrimage as a mass gathering. Iran J Public Health 2013 Jul 01;42(7):791-792 [FREE Full text] [Medline: 24455498]
12. Wilbert-Lampen U, Leistner D, Greven S, Pohl T, Sper S, Völker C, et al. Cardiovascular Events during World Cup Soccer. N Engl J Med 2008 Jan 31;358(5):475-483. [doi: 10.1056/nejmoa0707427]
13. Al Shimemeri A. Cardiovascular disease in Hajj pilgrims. J Saudi Heart Assoc 2012 Apr;24(2):123-127 [FREE Full text] [doi: 10.1016/j.jsha.2012.02.004] [Medline: 23960680]
14. Luiz T, Kumpch M, Metzger M, Madler C. [Management of cardiac arrest in a German soccer stadium. Structural, process and outcome quality]. Anaesthesist 2005 Sep;54(9):914-922. [doi: 10.1007/s00101-005-0889-z] [Medline: 16021391]
15. Ahmed QA, Arabi YM, Memish ZA. Health risks at the Hajj. The Lancet 2006 Mar;367(9515):1008-1015. [doi: 10.1016/s0140-6736(06)68429-8]
16. Burkle FM, Hsu EB. Ram Janki Temple: understanding human stampedes. The Lancet 2011 Jan;377(9760):106-107. [doi: 10.1016/S0140-6736(10)60442-4]
17. Al Lami F, Al Fatlawi A, Bloland P, Nawwar A, Jetheer A, Hantoosh H, et al. Pattern of morbidity and mortality in Karbala hospitals during Ashura mass gathering at Karbala, Iraq, 2010. East Mediterr Health J 2013 Dec 01;19(Supp. 2):13-18. [doi: 10.26719/2013.19.supp2.s13]

Abbreviations

EMPHNET: Eastern Mediterranean Public Health Network
FETP: Field Epidemiology Training Program
ID: identification
NCD: noncommunicable disease
WHO: World Health Organization

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Original Paper

Impact of Training of Primary Health Care Centers' Vaccinators on Immunization Session Practices in Wasit Governorate, Iraq: Interventional Study

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Abstract

Background: Immunization averts more than 2.5 million deaths of children annually. The World Health Organization (WHO) and the United Nations Children's Fund estimates of immunization coverage in Iraq in 2015 revealed a 58% coverage for the third dose of the diphtheria-tetanus-pertussis vaccine and a 57% coverage for the measles vaccine. High-quality immunization session practices (ISPs) can ensure safer, more effective vaccination and higher coverage rates.

Objective: The goal of this study was to assess the impact of training of primary health care centers' (PHCs) vaccinators on the quality of ISPs.

Methods: This was an interventional study conducted on 10 (18%) PHCs in Wasit Governorate. Two PHCs were randomly selected from each health district. ISPs were assessed by direct on-job observation, using modified WHO immunization session checklists. Findings were grouped into seven domains: vaccine and diluent management, cold chain management, session equipment, registration, communication, vaccine preparation and administration, and waste management. The vaccinators were enrolled in a one-day training session using the WHO module, "Managing an Immunization Session", and one month later a second assessment was conducted using the same tools and techniques. We then calculated the median differences of the domains' scores.

Results: A total of 42 vaccinators were trained, with 25 (60%) of them having graduated from technical health institutes, but only 15 (36%) having had previous training on standard ISPs. Following training, a significant improvement was noticed in three domains: vaccines and diluents management (P=.01), cold chain management (P=.01) and vaccine preparation and administration (P=.02).

Conclusions: The training of the PHCs' vaccinators for a single day was effective in improving some ISPs. We would recommend using this training module, or a more in-depth one, for other PHCs to improve utilization of immunization services.

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KEYWORDS

immunization; primary health care; intervention; practices; Iraq

Introduction

Vaccination is one of the greatest public health achievements [1], with the greatest impact on human health and longevity compared to any other [2]. Apart from safe water, nothing other than vaccination, not even antibiotics, has had such a major effect on the reduction of mortality and on population growth [3]. Globally, vaccines prevent more than 2.5 million deaths of children each year [4], with one good example being the global reduction in deaths from measles by 79% between 2000 (651,600 deaths) and 2015 (134,200 deaths) [5].

Although vaccines are considered safe, they are not risk-free, and adverse events following vaccination may occasionally occur. Public trust in vaccine safety is key to the success of any vaccination program [1], thus, health care professionals must develop and maintain the highest possible competency with vaccination procedures. However, this process is becoming increasingly difficult due to a lack of resources and due to continuous pressure on professionals' time. Knowledge is vital in maintaining comprehensive vaccination programs and strengthening best practices during daily work, and the goal is to use this knowledge to build vaccinators' abilities and to improve immunization session practices (ISPs) [6].

Unfortunately, in Iraq, enrolling newly assigned vaccinators in routine training courses is not part of their training system, and while this might happen occasionally it is not scheduled. Thus, vaccinators can handle the challenges they may encounter during routine daily work by getting into close contact with senior vaccinators, at their sites, to gain further skills and build up their skills.

In addition to factors related to knowledge, skills, attitudes, and training of health care professionals, another factor that may play a role in strengthening vaccination competence is the vaccination environment. It should be quiet, safe, spacious, warm, private, and soundproof. However, excess amounts of work and staff shortages may weaken this competence [6].

World Health Organization (WHO) and United Nations Children's Fund (UNICEF) estimates of immunization coverage in Iraq in 2015 revealed a 58% coverage for the third dose of diphtheria-tetanus-pertussis vaccine, a 63% coverage for the third dose of oral polio vaccine, and a 57% coverage for the first dose of measles containing vaccine [7] against a 95% national target for each antigen [8]. Ensuring high quality ISPs can lead to safer and more effective vaccination as well as higher coverage rates. Thus, it is of paramount importance to assess these practices and to ensure they are all the best quality, particularly when, according to our knowledge, such an assessment had never been done before in Iraq or in Wasit governorate.

The aim of this study was to assess ISPs in selected primary health care centers (PHCs) in Wasit governorate and to assess the impact of training of their vaccinators on the quality of ISPs.

Methods

Study Design and Setting

This interventional study was conducted in 10 PHCs in Wasit Governorate, one of the 18 governorates in Iraq. Wasit is in eastern Iraq, 160 km to the south east of the capital, Baghdad. It occupies an area of 17,153 km^2, with a total population of 1,149,059. It has six health districts: Kut-1 (10 PHCs), Kut-2 (13 PHCs), Hai (10 PHCs), Suwayrah (13 PHCs), Numaniyah (3 PHCs), and Aziziyah (6 PHCs).

The 10 (18%) PHCs were selected by simple random sampling from the six health districts in Wasit Governorate. Two PHCs were randomly selected from each health district (except for Numaniyah and Aziziyah districts, as they were instead treated as a single district and only two PHCs were randomly selected from both). All the selected PHCs regularly provide immunization services.

We visited each of these PHCs once to assess ISPs with direct on the job observation, using modified WHO immunization session checklists [9]. Then, the vaccinators were enrolled in a one-day, UNICEF-funded training program using the WHO module *Managing an Immunization Session* [9]. The same tools and techniques were used again one month later to assess ISPs in the same PHCs.

Immunization Session Checklists

We developed three checklists using Epi Info 7 (Centers for Disease Control and Prevention [CDC], Atlanta) based on the WHO immunization session checklist [9], the WHO checklists for vaccines and immunization [10], and the national guidelines for vaccines and immunization [8,11,12]. The developed checklists were a checklist for setting up the immunization session (see Multimedia Appendix 1), a checklist for the conduct of the immunization session (see Multimedia Appendix 2), and a checklist for concluding the immunization session (see Multimedia Appendix 3). These checklists were used to assess 62 ISPs.

Immunization Session Practices

ISPs are the tasks a health worker needs to perform to ensure the quality of an immunization session. They covered the following aspects: preparation for the session, communication with clients and caregivers during each encounter, assessment of infants before vaccination, correct technique for giving vaccines, closing the session, and recording data [9]. Each of the 62 ISPs was given a score of one when correctly practiced, or zero if not. For analytic purposes, these ISPs were grouped into seven domains: Vaccine and diluent management (12 ISPs), cold chain management (6 ISPs), session equipment (7 ISPs), card review and registration (14 ISPs), communication with clients and caregivers (4 ISPs), vaccine preparation and administration (14 ISPs), and waste management (5 ISPs).

Questionnaires

Two questionnaires were developed using Epi Info 7. The first was the vaccinator's questionnaire, which was used to collect data on health care workers' (HCWs) age, gender, level of education (classified as intermediate school, high school, nursing school, technical health institute, college of nursing, and nonmedical college), number of years of working in the field of immunization, and if they received any formal training on standard ISPs. The second questionnaire was used to collect information from PHCs, such as the district's name, the number of doctors in the PHC, the number of vaccinators working in the immunization unit, the number of people served by the PHC according to 2016 population, and the average daily number of people receiving vaccinations in the PHC.

Training Program

Vaccinators in the selected PHCs were enrolled in a one-day training program that was conducted in the hall of the Center for Training and Development-Wasit Directorate of Health. A total of 42 vaccinators from the selected sites were trained after dividing them into two groups, with each group including half the number of vaccinators working in each PHC (in order to not create a shortage in the manpower working in the immunization unit in any of these PHCs on the day of training). The first group received training on Monday, November 28, 2016 and the second on Wednesday, November 30, 2016.

The training material was adopted from the WHO immunization training resource,*Managing an Immunization Session* [9]. We translated this module into Arabic and presented it as a PowerPoint show supported by three video clips about: (1) how to give the Bacille Calmette-Guerin vaccine to an infant; (2) the correct technique for giving intramuscular injections to infants; and (3) how to manage the immunization session as a whole. The presentation also had many pictures that were adopted from the CDC website.

Ethical approval was obtained from the Public Health Department at Wasit Directorate of Health, and UNICEF funded the training over its two days with an average cost of about 35 United States Dollars per vaccinator.

Statistical Analysis

First, collected data were entered into Epi Info 7 (because the checklists and questionnaires were developed using the software), and then further processing and analyses were done using Excel (Microsoft, Redmond) to calculate the mean and median scores for each domain. Each single domain had a specific number of ISPs that were each given a score of one when correctly practiced or zero if not. After that, the mean and median for all practices contained in a single domain were calculated, giving a final score for that domain which ranged from 1-0 for the perfect domain and for the least achieving one, respectively. The above calculation was performed twice, once before and another time following the training. Then, the differences between pre- and posttraining domains' scores were calculated and the Wilcoxon signed-rank test was used to determine statistical significance. A $P<.05$ was considered statistically significant.

Results

The study was conducted among 10 PHCs with 42 vaccinators. A total of 25/42 vaccinators (60%) had graduated from technical health institutes (two years following high school). All others had a lower education level, and none were college graduates. Only 15 (36%) of them had previous training on ISPs. The range of years of experience as vaccinators was 1-25 years, with a median of 3 years. Overall, 10 (24%) of the vaccinators were newly assigned, with less than one year of experience in the field of immunization. The main characteristics of the studied PHCs and vaccinators are shown in Tables 1 and 2, respectively.

Among the 10 studied PHCs, six (60%) showed a statistically significant improvement in immunization session practices following the training of vaccinators, two (20%) showed an improvement that was not significant, and the remaining two (20%) PHCs showed some unexpected decline in their ISP scores (Table 3).

Table 1. Characteristics of 10 primary health care centers in Wasit Governorate, 2016.

Primary health care center	District	Doctors, n	Vaccinators, n	Catchment area population, n	Vaccinators' density (vaccinators/10,000 people)
Badr Ul-Kubra	Kut-1	3	4	33,934	1.2
Badra	Kut-1	4	4	15,605	2.6
Falahiyah	Kut-2	0	3	40,865	0.7
Al-Hakiem	Kut-2	2	3	11,500	2.6
Muwaffaqiyah	Hai	3	6	33,107	1.8
Asskary	Hai	3	5	22,307	2.2
Numaniyah	Numaniyah and Aziziyah	5	11	72,403	1.5
Ahrar	Numaniyah and Aziziyah	3	3	26,588	1.1
Mazraa	Suwayrah	3	2	10,660	1.9
Shuhaymiyah	Suwayrah	3	1	19,189	0.5

Table 2. Characteristics of vaccinators working in 10 primary health care centers in Wasit Governorate, 2016 (N=42).

Characteristics	Distribution, n (%)
Sex	
Male	22 (52)
Female	20 (48)
Educational status	
Technical health institute	25 (60)
Nursing school	14 (33)
High school	1 (2)
Intermediate school	2 (5)
Service duration	
<1 year	10 (24)
1-5 years	20 (48)
>5 years	12 (28)
Previous training on immunization session practices	
Trained	15 (36)
Not trained	27 (64)

Table 3. The change in scores of immunization session practices following training of vaccinators in 10 primary health care centers in Wasit Governorate, 2016.

Primary health care center	Pretraining, mean (SD)	Posttraining, mean (SD)	Change, mean (SD)	*P* value
Badr Ul-Kubra	0.73 (0.45)	0.63 (0.49)	–0.10 (0.47)	.11
Badra	0.63 (0.49)	0.76 (0.43)	0.13 (0.50)	.045
Falahiyah	0.71 (0.46)	0.68 (0.47)	–0.03 (0.48)	.60
Al-Hakiem	0.60 (0.49)	0.84 (0.37)	0.24 (0.59)	.002
Muwaffaqiyah	0.68 (0.47)	0.84 (0.37)	0.16 (0.52)	.02
Asskary	0.76 (0.43)	0.84 (0.37)	0.08 (0.49)	.20
Numaniyah	0.56 (0.50)	0.66 (0.48)	0.10 (0.39)	.06
Ahrar	0.60 (0.49)	0.94 (0.25)	0.34 (0.48)	<.001
Mazraa	0.53 (0.50)	0.92 (0.27)	0.39 (0.49)	<.001
Shuhaymiyah	0.53 (0.50)	0.85 (0.36)	0.32 (0.47)	<.001
Total	0.632 (0.081)	0.795 (0.108)	0.163 (0.160)	.01

There were varying degrees of improvement among the domains following the training. Three domains that were originally among the lowest scoring showed the most significant improvement, including: vaccine and diluent management, cold chain management, and vaccine preparation and administration. Other domains with higher scores included: session equipment, waste management, and card review and registration. These later domains showed a less remarkable and statistically nonsignificant improvement. Despite originally being a mid-level domain with a mean 0.5 (SD 0.5), communication with clients and caregivers increased only a small, nonsignificant amount following the training (Table 4).

All ISPs, with the percentage of PHCs correctly practicing them as well as the difference following the training, are shown in Table 5.

Table 4. The change in scores of immunization session practices, by domains, following training of vaccinators in 10 primary health care centers in Wasit Governorate, 2016.

Domain	Pretraining		Posttraining		*P* value
	Mean (SD)	Median	Mean (SD)	Median	
Vaccine and diluent management	0.5 (0.1)	0.5	0.8 (0.1)	0.8	.01
Cold chain management	0.3 (0.2)	0.3	0.8 (0.3)	1.0	.01
Session equipment	0.9 (0.1)	0.9	0.9 (0.1)	0.9	.26
Communication with clients and caregivers	0.5 (0.5)	0.4	0.6 (0.4)	0.6	.67
Card review and registration	0.7 (0.1)	0.7	0.8 (0.1)	0.8	.13
Vaccine preparation and administration	0.6 (0.1)	0.6	0.8 (0.1)	0.8	.02
Waste management	0.8 (0.2)	0.8	0.8 (0.1)	0.8	.52

Table 5. Percentage of primary health care centers (PHCs) with standard immunization session practices (ISPs) in Wasit Governorate, 2016

Domains and ISP	PHCs with pretraining standard practices (%)	PHCs with posttraining standard practices (%)
Vaccine and diluent management		
Vaccine quantity checked	100	100
Vaccines out refrigerator in required quantity	50	60
Vaccines out refrigerator in order	20	80
Diluent quantity matched	50	60
Diluent type matched	90	100
Label checked	10	70
Expiry date checked	10	70
VVM[a] checked	40	60
Unopened vials returned to refrigerator	100	100
Unopened vials returned to USE FIRST[b] box	20	80
Opened vials discarded	90	100
Vaccine stock for next session	40	50
Cold chain management		
Icepacks conditioned	0	80
Freeze indicator checked	40	90
Carrier conditioned icepacks	0	80
Carrier vaccine vials in middle	70	70
Carrier pad on top	30	70
Carrier lid closed tightly	40	80
Session equipment		
AD[c] syringes collected	100	100
Reconstitution syringes collected	90	90
Safety box collected	100	100
AEFI[d] medications collected	40	50
Permanent register collected	100	100
Daily register collected	90	100
New cards collected	100	100
Card review and registration		
Review DOB[e] and age	90	100
Review vaccines previously received	70	100
Review vaccines eligible for	90	90
Permanent register ID[f]	100	100
Permanent register DOB	100	100
Permanent register address	0	10
Permanent register date and dose of vaccine	100	100
Permanent register date and dose of vitamin A	80	60
Daily register vaccine dose	100	100
Daily register vaccine information	20	40
Card registered given vaccine	100	100

Domains and ISP	PHCs with pretraining standard practices (%)	PHCs with posttraining standard practices (%)
Card marked date of next immunization	70	100
Summary report	20	40
Children missed vaccination listed	80	40
Communication with clients and caregivers		
Client and caregiver greeted	70	60
Messaged date of next visit	50	70
Messaged AEFI	40	50
Messaged what to do in AEFI	40	40
Vaccine preparation and administration		
Wash hands with soap	10	60
Vaccine prepared on clean table	90	90
Reconstituted with correct type of diluent	100	100
Reconstituted with correct quantity of diluent	90	100
Reconstituted with new disposable needle and syringe	80	100
Reconstitution needle and syringe disposed in safety box immediately	70	90
Membrane or opening not touched	40	90
Reconstituted vial in pad of vaccine carrier	20	60
Fill syringe just before administration	100	100
Alcohol not used	100	100
Needle not touched	90	90
Recommended technique	50	90
Correct injection site	50	90
Contraindication checked	0	10
Waste management		
AD syringe disposed immediately	80	100
AD syringe disposed without recapping	100	100
Safety box within reach of Staff	80	100
Safety box closed when full	100	100
Safety box out of reach of children	30	20

[a] VVM: vaccine vial monitor.

[b] USE FIRST: a box in the refrigerator to which unopened vaccine vials with acceptable VVMs should be returned at the end of the session to be used first in the next session.

[c] AD: auto-disable.

[d] AEFI: adverse event following immunization.

[e] DOB: date of birth.

[f] ID: identification.

Discussion

Six (60%) of the studied sites showed significant improvement in ISPs following the training of their vaccinators. The most significant improvement was in the domains that got the lowest scores during the first assessment, which included: vaccine and diluent management, cold chain management, and vaccine preparation and administration. The posttraining assessment revealed an overall small improvement in ISPs' mean score, from 0.63 (SD 0.08) to 0.80 (SD 0.11), which might be related to what was concluded by one review evaluating the effects of educational meetings (eg, courses, conferences, lectures, workshops), in that any improvement they cause is most likely to be small [13].

All the studied PHCs were major ones (supposed to be run by physicians) and all were supplying immunization services through routine sessions on a regular basis. The observed number of vaccinators working in these sites is not relative to the number of people whom they serve. This might cause the quality of the provided health service to vary, because the imbalance in the supply, deployment, and composition of human resources may lead to a lack of equality in the provision of health services [14]. On the other hand, health care systems managing a balanced provider workload and staff mix may result in better patient care delivery [15].

Ten (24%) of the vaccinators were new to working in immunization units, with an average service duration of less than one year. Thus, it was expected that those vaccinators would be less competent as they had less practical work experience [6]. While training could improve their professional practice and the health care outcomes for their patients [13], lack of training for 27 (64.3%) of the vaccinators might seriously affect their competence, thus resulting in low quality practices.

The two PHCs that showed decline following training were further assessed to discover the causes behind it. One of these PHCs was unexpectedly supplied with a large quantity of influenza vaccine, and to dispense the vaccine as fast as they could the vaccinators decided to vaccinate everybody attending the PHC, regardless of their risk status for influenza. The posttraining assessment was implemented during this time, while many people were inside the immunization room with no control over their entry or presence, which negatively affected vaccinators’ performance. In the second PHC, two of the three trained vaccinators were immediately moved away following the training and were replaced by only one of the newly assigned staff. Thus, the immunization unit lost much of its workforce as well as the skills gained from the training, which had an obvious adverse effect on the vaccinators’ performance and on ISPs.

The three significantly improved domains were those dealing with aspects related to the vaccine itself: handling, storage, preparation, and administration. Practices under these domains might be considered (from vaccinators' perspectives) the most important and might have the most major consequences on the vaccinees. Other practices that might be considered of less serious impact showed a less remarkable, statistically nonsignificant improvement. The impact of educational meetings may be smaller for outcomes that health professionals may perceive as not having serious consequences for patients compared to outcomes that they may perceive as having moderately or highly serious consequences for patients [13]. On the other hand, our training was supported by three video clips as well as many pictures dealing with the practices belonging to the three most improved domains, which might help the vaccinators be more competent in these areas.

The WHO states that ice pack conditioning is a process that takes time and advanced planning, but cold chain surveys have shown that this practice is widely ignored [16]. This was the exact situation in our settings, revealing that ice pack conditioning was the most problematic among cold chain practices.

Adrenaline was not available in half of our sites even following the training, even though it is the responsibility of the health district to supply its PHCs with these adverse events following immunization (AEFI) medications. Thus, for this practice to improve it might require the health district to include these drugs in its priority list that could be bought from the local market when they are not centrally supplied by the department of pharmaceuticals and medical equipment, a measure that the system never allows a PHC to do independently. Thus, this practice might be considered a complex behavior (complexity of behavior may depend on whether there was a need for change by the individual, a communication change, or a change in systems and thus, whenever a change in the system is required to change certain behavior, the latter might be considered more complex) that is unlikely to change much [13].

In one study conducted in the United Kingdom, they found that communication strategies to date have lacked clear evidence of efficacy in vaccination settings [17]. In our settings, communication with clients and caregivers only improved a little with training, which is like the results of another study conducted in Vietnam where 83.3% of health care providers do not communicate about vaccination when giving an injection [18].

From all of the above, we can conclude that ISPs were doing variably in our immunization sites before training, but none were being practiced to standard. Training of vaccinators was effective in improving some practices, especially those dealing with the technical aspect of vaccination (ie, vaccine management, cold chain management, and vaccine preparation and administration). However, it is important to remember that the pre- and posttraining assessments were each conducted during a single visit in any of the selected sites, which might be a limitation of the study. In addition, the vaccine coverage rate was not included in the study even though it is an important variable that might be correlated to ISPs, leaving open the possibility for another study to be conducted.

Therefore, we would recommend this training, after some refinement, for other PHCs in Wasit governorate and on the national level, as well as for other countries or settings that use the Arabic language, to improve vaccinators’ abilities and thus ISPs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Checklist for setting up the immunization session.
[PNG File 229 KB - publichealth_v5i4e14451_app1.png]

Multimedia Appendix 2
Checklist for the conduct of the immunization session.
[PNG File 297 KB - publichealth_v5i4e14451_app2.png]

Multimedia Appendix 3
Checklist for concluding the immunization session.
[PNG File 137 KB - publichealth_v5i4e14451_app3.png]

References

1. World Health Organization: Vaccine Safety Basics. 2017. Module 1: Introduction to vaccine safety URL: https://vaccine-safety-training.org/Importance-of-immunization-programmes.html [accessed 2019-01-05]
2. Rappuoli R. Vaccines: science, health, longevity, and wealth. Proc Natl Acad Sci U S A 2014 Aug 26;111(34):12282 [FREE Full text] [doi: 10.1073/pnas.1413559111] [Medline: 25299004]
3. Plotkin S, Orenstein W, Offit P. A short history of vaccination. In: Vaccines, 6th ed. Philadelphia: Elsevier-Saunders; 2013.
4. WHO, UNICEF, World Bank. State of the world's vaccines and immunization, 3rd ed. Geneva: World Health Organization; 2009.
5. World Health Organization. Measles: Fact sheet URL: http://www.who.int/mediacentre/factsheets/fs286/en/ [accessed 2019-01-05]
6. Nikula A, Rapola S, Hupli M, Leino‐Kilpi H. Factors strengthening and weakening vaccination competence. International Journal of Nursing Practice 2009;15(5). [doi: 10.1111/j.1440-172x.2009.01781.x]
7. Burton A, Monasch R, Lautenbach B, Gacic-Dobo M, Neill M, Karimov R, et al. WHO and UNICEF estimates of national infant immunization coverage: methods and processes. Bull World Health Organ 2009 Jul;87(7):535-541 [FREE Full text] [doi: 10.2471/blt.08.053819] [Medline: 19649368]
8. Ministry of Health-Iraq, US Agency for International Development. Guidelines for the Workers in the Expanded Program on Immunization, 1st ed. Baghdad: Ministry of Health-Iraq; 2014.
9. WHO. Module 5: Managing an immunization session. In: Immunization in practice: A practical guide for health staff- 2015 update. Geneva: World Health Organization; 2015.
10. Mantel C. World Health Organization. Checklists for vaccines and immunization URL: http://www.who.int/pmnch/activities/jointactionplan/tf2_checklists_vaccines_and_immunization.pdf?ua=1 [accessed 2019-01-05]
11. Ministry of Health-Iraq, US Agency for International Development. Vaccine and Cold Chain Management in Health Institutions, 1st ed. Baghdad: Ministry of Health-Iraq; 2014.
12. Ministry of Health-Iraq, US Agency for International Development. Field Guideline for Adverse Events Following Immunization Surveillance, 1st ed. Baghdad: Ministry of Health-Iraq; 2014.
13. Forsetlund L, Bjørndal A, Rashidian A, Jamtvedt G, O'Brien M, Wolf F, et al. Continuing education meetings and workshops: effects on professional practice and healthcare outcomes. Cochrane Database Syst Rev 2009;2. [doi: 10.1002/14651858.cd003030.pub2]
14. WHO. Monitoring the building blocks of health systems: a handbook of indicators and their measurement strategies. Geneva: World Health Organization; 2010.
15. Mohr DC, Young GJ. Slack resources and quality of primary care. Med Care 2012 Mar;50(3):203-209. [doi: 10.1097/MLR.0b013e318241e3e6] [Medline: 22193414]
16. PATH. 2013. Optimize: Preventing Freezing in Cold Boxes and Vaccine Carriers URL: http://www.path.org/publications/files/TS_opt_handout_freeze_safe.pdf [accessed 2019-01-05]
17. Leask J, Kinnersley P, Jackson C, Cheater F, Bedford H, Rowles G. Communicating with parents about vaccination: a framework for health professionals. BMC Pediatr 2012 Sep 21;12:154 [FREE Full text] [doi: 10.1186/1471-2431-12-154] [Medline: 22998654]
18. Ngoc N, Hoàn V. Health Strategy and Policy Institute. Vietnam: Ministry of Health; 2009. Current Situation Assessment of Human Resources in the Expanded Program of Immunization URL: https://tinyurl.com/y3sntwxz [accessed 2019-01-05]

Abbreviations

AD: auto-disable
AEFI: adverse event following immunization
CDC: Centers for Disease Control and Prevention
DOB: date of birth
EMPHNET: Eastern Mediterranean Public Health Network

HCW: health care worker
ID: identification
ISP: immunization session practice
PHC: primary health care center
UNICEF: United Nations Children’s Fund
VVM: vaccine vial monitor
WHO: World Health Organization

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Original Paper

Evaluation of the Yield of Histopathology in the Diagnosis of Lymph Node Tuberculosis in Morocco, 2017: Cross-Sectional Study

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Abstract

Background: The frequency of occurrence of extrapulmonary tuberculosis (EPTB) has been increasing globally over the last two decades. In Morocco, EPTB cases account for 46% of the patients reported with a new episode of tuberculosis (TB). Lymph node TB (LNTB) is the most common form of EPTB. In line with the guidelines of the National TB Program, the diagnosis is mainly based on clinical evidence, including histopathology.

Objective: This study aimed to evaluate the yield of histopathology testing in the diagnosis of LNTB.

Methods: This cross-sectional, prospective study was conducted among patients with cervical lymph node who were enrolled in the study from November 2016 to May 2017 in three regions of Morocco. We compared the outcomes of histopathological testing with those of bacteriology. Sensitivity (Se), specificity (Sp), positive predictive value (PPV), and negative predictive value (NPV) of histopathology testing were calculated. Culture and Xpert tests were used as the gold standard Laboratoty Testing.

Results: A total of 262 patients were enrolled in this study. The Se, Sp, PPV, and NPV of histopathology testing were 95.6% (129/135), 64.6% (82/127), 74.1% (129/174), and 93.2% (82/88), respectively, in the presence of granuloma with or without caseous necrosis and were 84.4% (114/135), 74.8% (95/127), 78.1% (114/146), and 81.9% (95/116), respectively, in the presence of granuloma with caseous necrosis. The granuloma with caseous necrosis was associated with increased PPV and Sp of histopathology testing (P<.05).

Conclusions: The presence of the granuloma with caseous necrosis in the histopathological examination had significantly improved the yield of histopathology testing for the diagnosis of LNTB. The findings recommend to maintain histopathology testing in establishing the LNTB diagnosis and to explore other techniques to improve it.

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KEYWORDS

lymph node tuberculosis; yield; histopathology; positive predictive value; Morocco

Introduction

Tuberculosis (TB) continues to challenge the international community. The global burden is estimated by the World Health Organization (WHO) at 10.4 million incident cases in 2016 [1]. The proportion of extrapulmonary TB (EPTB) cases has not exceeded 15% among all notified patients with TB for many years [1-3]. However, there are some differences across the WHO regions and across countries within these regions. The WHO Eastern Mediterranean Region (EMR) has the highest percentage of notified EPTB cases; 22% to 24% of patients diagnosed with TB each year have EPTB [1-3]. Among the EMR countries, Tunisia has the highest proportion of EPTB cases with 60% [3]. Significantly, high proportions are also reported in Algeria (63%), Syria (47%), Egypt (43%), and Saudi Arabia (26%) [1].

In Morocco, TB remains a major problem of public health. The WHO estimates for the year 2016 indicate that approximately 36,000 people were affected with a new episode of TB, with an estimated incidence of 103 per 100,000 population [1]. The National TB Program (NTP) of Morocco reported for the same year that 31,542 patients were diagnosed with a new episode of TB, and the notified incidence was 90 per 100,000 population [4]. The frequency of EPTB cases was high and accounted for 46% of all notified cases with a new episode of TB [1]. Between 1980 and 2016, the proportion of notified EPTB cases increased from 23% to 46% [5]. Lymph node TB (LNTB) is the most frequent form of EPTB and represents 37% of all EPTB cases reported in 2016 in Morocco.

According to the NTP guidelines of Morocco, the diagnosis of LNTB should be based on clinical arguments, including histopathological evidence. In fact, the diagnosis of 90% of notified LNTB cases is established through histopathology testing; bacteriological evidence contributes rarely to setting the diagnosis of LNTB [5]. Histopathology tests typically show epithelioid granulomas with or without caseous necrosis, which are usually used by clinicians as a strong argument to establish the diagnosis of TB. However, this histopathological aspect is not bacteriological evidence for TB and is encountered not only in TB but also in many other diseases such as sarcoidosis, leprosy, schistosomiasis, syphilis, and others.

The histopathology is highly sensitive but not very specific for TB diagnosis, in general. Therefore, using histopathology alone may result in a false diagnosis of EPTB. In addition, EPTB is characterized by a low presence of *Mycobacterium tuberculosis* (MBT) within the tissues because of an anaerobiosis environment. Therefore, the identification of MBT in biopsy fragments, through bacteriological techniques such as a culture or polymerase chain reaction (PCR), is not easy because of the paucibacillary nature of biopsies, and these examinations cannot provide optimal sensitivity [6]. This study aimed to evaluate the yield of histopathology testing for the diagnosis of LNTB in Morocco to help the NTP readjust the ongoing clinical procedures used to establish the diagnosis of LNTB.

Methods

Study Design

We conducted a cross-sectional, prospective study from November 2016 to May 2017 in otorhinolaryngology outpatient departments belonging to 4 university hospitals in 3 regions of Morocco (Rabat, Casablanca, and Fez). These regions have a high notified incidence of TB and appropriate laboratory facilities for histopathology and well-developed TB laboratory capacities. The study compares the outcomes of histopathological tests with those of bacteriological examinations using a culture and Xpert tests as the gold standard. The Xpert test was combined with the culture to strengthen the bacteriological gold standard, as its sensitivity (Se) and specificity (Sp), using lymph node biopsies, were, respectively, 96.6% and 88.9% [7].

Sample

The study population consisted of all consenting patients with cervical lymph nodes, irrespective of their age and gender, for whom a biopsy was indicated to carry out histopathological testing to establish a diagnosis, including that of TB. All patients for whom the biopsy was contraindicated were excluded.

Sample Size

In 2015, approximately 2000 new cases of LNTB were notified in 3 regions. Using an expected proportion of the bacteriological confirmation with histopathological characteristics suggesting TB of 68% [6], the sample size needed an alpha of .05, and power of 80% was estimated at 262 study participants.

Laboratory Testing

Each lymph node biopsy carried out was examined by a histopathology test and by a culture on the Lowenstein-Jensen (LJ) solid medium and Xpert testing to provide the bacteriological evidence associated with TB. A bacteriological examination was considered positive when a culture or Xpert test or both were positive in a lymph node biopsy. A bacteriological examination was considered as negative when a culture and Xpert test were both negative in a lymph node biopsy. A histopathology test was considered positive when its outcome shows a presence of inflammatory granuloma with or without caseous necrosis. The presence of caseous necrosis in the granuloma was considered as suggestive of TB, whereas its absence as less suggestive, without ruling out the possibility of TB diagnosis. A histopathology test was considered negative when it shows no granuloma with or without nonspecific inflammatory lesions.

Data Collection

The data to describe the population study were collected using a questionnaire filled by consenting patients, which included the demographic data (age, sex, and residence area [rural or urban area]), the socioeconomic data (education level, occupation/job, and income), and the clinical characteristics (previously treated for TB [having received TB medicines for ≥1 month], contacts of TB patients [household contacts or having close contact with TB patients], affected by diabetes, and HIV status). The results of histopathological and bacteriological tests were collected in the laboratories involved in the study using specific results sheets. All the staff involved in the process of data collection were trained to use the case definitions and collect the relevant information, in line with the study protocol, to standardize the data collection process.

Informed consent was obtained for each study participant, and all data obtained during the study were treated confidentially. The study was approved by the National Ethical Committee established by the Ministry of Health of Morocco.

Data Analysis

The data were coded, verified, and analyzed using Epi Info version 7.2.1.0 (developed by Centers for Disease Control and Prevention in Atlanta, Georgia, US). We calculated the Se, Sp, positive predictive value (PPV), and negative predictive value (NPV) for each of the histopathological outcomes, namely (1) the granuloma with or without caseous necrosis and (2) the granuloma with caseous necrosis. To calculate these indicators, the outcomes of the histopathological tests were compared with the results of the gold standard (the culture and Xpert test). A chi-square test was used for the comparison of proportions. A chi-square test was considered statistically significant when the *P* value is less than .05.

Results

Sociodemographic and Clinical Characteristics

The study enrolled 262 patients with cervical lymph nodes from the following locations: 41.2% (108/262) in Casablanca, 35.1% (92/262) in Fez, and 23.7% (62/262) in Rabat. Their mean age was 25 years. Among the study participants, 151 were females (58.1%, 151/260), with a sex ratio (male/female) of 0.72. A total of 223 (87.4%, 223/255) patients were living in urban areas, 26 (10.2%, 26/255) were previously treated for TB, 6 (2.4%, 6/255) had diabetes, and 2 (1.7%, 2/115) were HIV positive (Table 1).

Table 1. Sociodemographic and clinical characteristics of study population.

Characteristics	Patients with lymph node (N=262), n (%)
Age group (years; n=244)	
0-14	63 (25.8)
15-44	150 (61.5)
≥45	31 (12.7)
Gender (n=260)	
Male	109 (41.9)
Female	151 (58.1)
Residency area (n=255)	
Urban	223 (87.4)
Rural	32 (12.6)
Education (n=231)	
None	49 (21.2)
Coranic school	4 (1.7)
Primary school	72 (31.2)
Secondary school	75 (32.5)
University	31 (13.4)
Income (n=171)	
Stable	17 (9.9)
Not regular	34 (19.9)
No income	120 (70.2)
Contact TB[a] patient (n=243)	
Yes	25 (10.3)
No	218 (89.7)
Previously treated for TB (n=255)	
Yes	26 (10.2)
No	229 (89.8)
Diabetes (n=255)	
Yes	6 (2.4)
No	249 (97.6)
HIV status (n=115)	
Positive rapid test	2 (1.7)
Negative rapid test	113 (98.3)

[a] TB: tuberculosis.

Outcomes of Histopathological and Bacteriological Examinations

Among the 262 enrolled patients, 174 (66.4%) had a positive histopathology test (granuloma with and without caseous necrosis), among whom 146 (83.9%, 146/174) had granuloma with caseous necrosis. Xpert testing was positive for 124 study participants (47.3%, 124/262) and culture, for 27 (10.3%, 27/262; Table 2).

Table 2. Histology, culture, and GeneXpert results.

Diagnostic technique	Patients with lymph nodes (N=262), n (%)
Positive histology	174 (66.4)
Granuloma with caseous necrosis	146 (83.9)
Granuloma without caseous necrosis	28 (16.1)
Negative histology	88 (33.6)
GeneXpert	
Positive	124 (47.3)
Negative	138 (52.7)
Culture	
Positive	27 (10.3)
Negative	235 (89.7)

Histology Performances Compared With the Gold Standard

The Se, Sp, PPV, and NPV were 95.6% (129/135), 64.6% (82/127), 74.1% (129/174), and 93.2% (82/88), respectively, for the outcomes of histopathological tests, showing granuloma with or without caseous necrosis, whereas the Se, Sp, PPV, and NPV were 84.4% (114/135), 74.8% (95/127), 78.1% (114/146), and 81.9% (95/116), respectively, for the granuloma with caseous necrosis (Table 3). The PPV and Sp of histopathological outcomes were significantly higher for granuloma with caseous necrosis than for granuloma with or without caseous necrosis (*P*=.02 and *P*<.001, respectively).

Table 3. Performances of different histological entities in the diagnosis of lymph node tuberculosis.

Parameter	Histological entities				*P* value
	Granuloma with or without caseous necrosis, n/N (%)		Granuloma with caseous necrosis, n/N (%)		
	N	n (%)	N	n (%)	
Sensitivity	135	129 (95.6)	135	114 (84.4)	<.001
Specificity	127	82 (64.6)	127	95 (74.8)	.008
Positive predictive value	174	129 (74.1)	146	114 (78.1)	.02
Negative predictive value	88	82 (93.2)	116	95 (81.9)	.006

Discussion

EPTB has much less visibility than pulmonary TB and receives less attention because of its low infectiousness [8,9]. However, it is a serious problem of public health because of its increasing frequency for the last 2 decades [1] and therefore contributing to morbidity, mortality, and disability associated with TB.

Significant variations in reporting notified EPTB cases have been observed among WHO regions and countries [1,3]. They might be related to differences in clinical practices to establish a diagnosis of EPTB, registration, and cases reporting.

In the context of Morocco, undertaking biopsy and histopathological testing is fully integrated in the clinical practices to establish the diagnosis of LNTB; the diagnosis of 90% of LNTB cases is based on histopathology evidence, whereas bacteriology testing is rarely used to confirm TB diagnosis [5] because of the very low yield of microscopy and time-consuming procedures to perform a culture on lymph node specimens; Xpert testing on such specimens has been recently introduced in the NTP services.

Our study has assessed the performances of histopathology against the established bacteriological gold standard. In general, the results of the study are comparable with those of other similar studies. In our study, the culture made on lymph node biopsies was positive in 10.3% (27/262) cases. According to the various studies, the culture positivity varied from 10% to 69%; it was 10.8% in Tunisia [10] and 45% in a study by Marais et al [11]. Other similar comparative studies had shown a positive culture of 22% [12], 26% [13], and 44% [14]. In these studies, a culture was performed on an LJ solid medium. Although a culture is the gold standard for the diagnosis of EPTB, a negative culture outcome cannot exclude the LNTB diagnosis [15].

Several studies reported Xpert testing on extrapulmonary biopsies with a positive outcome for TB of 11.5% [10], 33%, and 39% [10,14]. In our study, 47.3% (124/262) of Xpert tests performed on lymph node specimens were MTB positive.

The granuloma with caseous necrosis was observed in 83.9% (146/174) of the patients whose histopathology tests show a granuloma, irrespective of the caseous necrosis status. This proportion was more important than what was reported in the study by Lisbet et al (42.5%) [16]. Although a culture of MTB is generally used as a reference standard to validate the performance of new diagnostic tests, this test has a limited Se in extrapulmonary tissues [17]. In lymph node biopsies, the Se has been estimated at 71% to 88% whereas Sp, at 100% [18]. In our study, Xpert testing was used in addition to a culture to strengthen the bacteriological gold standard because its Se for EPTB ranged from 75% to 100% and its Sp, from 99% to 100% [19,20]. Its Se and Sp, using lymph node biopsies, were 96.6% and 88.9%, respectively [7]. Therefore, the gold standard based on a culture and Xpert testing may still have some limitations to evaluate the performance of histopathology in the diagnosis of LNTB.

With regard to the bacteriological gold standard used in our study, the outcomes of histopathology in favor of LNTB diagnosis were significantly better in the presence of granuloma with caseous necrosis than in the presence of granuloma with or without caseous necrosis.

Our study findings report that the Se, Sp, PPV, and NPV were 84.4% (114/135), 74.8% (95/127), 78.1% (114/146), and 81.9% (95/116), respectively, when the histopathological testing showed a granuloma with caseous necrosis, whereas these indicators were 95.6% (129/135), 66.4% (174/262), 74.1% (129/174), and 93.2% (82/88), respectively, when it showed a granuloma with or without caseous necrosis. These results were comparable with a study using a culture alone as the gold standard; this study carried out in Ethiopia reported an Se, an Sp, a PPV, and an NPV of 92%, 88%, 77%, and 97%, respectively, for LNTB when histopathology testing identifies a granuloma with or without caseous necrosis [21]. The Sp and PPV in our study were higher than those in another study using PCR as the gold standard with Se, Sp, PPV, and NPV estimated at 92%, 37%, 60%, and 81%, respectively [22]. The Se and Sp in our study were similar to those reported in another study (96% and 78%, respectively) [23].

Our study reported a 78% PPV in the presence of a granuloma with caseous necrosis; this indicates that 22% of patients might be considered as having LNTB whereas their culture and/or Xpert test are negative. The presence of caseous necrosis may represent a more comfortable argument for the diagnosis of LNTB than the situation when it is absent; however, it is still not compelling evidence that allows clinicians to set the diagnosis of LNTB with confidence because a significant proportion of the patients might not have TB (22% in our study).

The NPV exceeded 90% in the presence of granuloma with or without caseous necrosis and 83% in the presence of granuloma with caseous necrosis. Therefore, the proportion of false-negative cases would be 10% to 17%.

In conclusion, the presence of granuloma with caseous necrosis in a histopathological examination had significantly improved the yield of histopathology for the diagnosis of LNTB. The evaluation of clinical practices, including the histopathological examination in the diagnosis of LNTB in Morocco, indicates a better yield of histopathology when the histopathological testing shows a granuloma with caseous necrosis. Therefore, it is recommended to maintain the histopathology testing to establish the diagnosis of LNTB, explore other diagnosis techniques, and duplicate this study in other country settings.

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Conflicts of Interest

None declared.

References

1. World Health Organization. 2017. Global Tuberculosis Report-2017 URL: https://www.who.int/tb/publications/global_report/gtbr2017_main_text.pdf [accessed 2019-01-15]
2. World Health Organization. 2016. Global Tuberculosis Report - 2016 URL: http://apps.who.int/medicinedocs/documents/s23098en/s23098en.pdf [accessed 2019-01-15]
3. World Health Organization. 2015. Global Tuberculosis Report - 2015 URL: http://apps.who.int/iris/bitstream/handle/10665/191102/9789241565059_eng.pdf?sequence=1 [accessed 2019-01-15]
4. World Health Organization. 2017. Tuberculosis Country Profile: Morocco - Population 2017 URL: https://tinyurl.com/y5vfcnye [accessed 2019-01-15]
5. Ministère de la Santé. 2017. Bulletin Epidémiologique URL: http://www.sante.gov.ma/Publications/Pages/Bullten_%C3%89pid%C3%A9miologique.aspx [accessed 2019-01-15]
6. Causse M, Ruiz P, Gutierrez-Aroca JB, Casal M. Comparison of two molecular methods for rapid diagnosis of extrapulmonary tuberculosis. J Clin Microbiol 2011 Jun 8;49(8):3065-3067. [doi: 10.1128/JCM.00491-11] [Medline: 21653775]
7. Ligthelm LJ, Nicol MP, Hoek KG, Jacobson R, van Helden PD, Marais BJ, et al. Xpert MTB/RIF for rapid diagnosis of tuberculous lymphadenitis from fine-needle-aspiration biopsy specimens. J Clin Microbiol 2011 Aug 31;49(11):3967-3970. [doi: 10.1128/JCM.01310-11] [Medline: 21880965]
8. Asghar RJ, Pratt RH, Kammerer JS, Navin TR. Tuberculosis in South Asians living in the United States, 1993-2004. Arch Intern Med 2008 May 12;168(9):936-942. [doi: 10.1001/archinte.168.9.936] [Medline: 18474757]
9. Cailhol J, Decludt B, Che D. Sociodemographic factors that contribute to the development of extrapulmonary tuberculosis were identified. J Clin Epidemiol 2005 Oct;58(10):1066-1071. [doi: 10.1016/j.jclinepi.2005.02.023] [Medline: 16168353]

10. Marrakchi C, Maâloul I, Lahiani D, Hammami B, Boudawara T, Zribi M, et al. [Diagnosis of peripheral tuberculous lymphadenitis in Tunisia]. Med Mal Infect 2010 Feb;40(2):119-122. [doi: 10.1016/j.medmal.2009.10.014] [Medline: 19945809]
11. Wright CA, van der Burg M, Geiger D, Noordzij JG, Burgess SM, Marais BJ. Diagnosing mycobacterial lymphadenitis in children using fine needle aspiration biopsy: cytomorphology, ZN staining and autofluorescence—making more of less. Diagn Cytopathol 2008 Apr;36(4):245-251. [doi: 10.1002/dc.20788] [Medline: 18335554]
12. Pahwa R, Hedau S, Jain S, Jain N, Arora VM, Kumar N, et al. Assessment of possible tuberculous lymphadenopathy by PCR compared to non-molecular methods. J Med Microbiol 2005 Sep;54(9):873-878. [doi: 10.1099/jmm.0.45904-0] [Medline: 16091440]
13. Portillo-Gómez L, Murillo-Neri MV, Gaitan-Mesa J, Sosa-Iglesias EG. Nested polymerase chain reaction in the diagnosis of cervical tuberculous lymphadenitis in Mexican children. Int J Tuberc Lung Dis 2008 Nov;12(11):1313-1319. [Medline: 18926043]
14. Deveci HS, Kule M, Kule ZA, Habesoglu TE. Diagnostic challenges in cervical tuberculous lymphadenitis: a review. North Clin Istanbul 2016;3(2):150-155. [doi: 10.14744/nci.2016.20982] [Medline: 28058405]
15. Bayazıt YA, Bayazıt N, Namiduru M. Mycobacterial cervical lymphadenitis. ORL J Otorhinolaryngol Relat Spec 2004;66(5):275-280. [doi: 10.1159/000081125] [Medline: 15583442]
16. Purohit MR, Mustafa T, Mørkve O, Sviland L. Gender differences in the clinical diagnosis of tuberculous lymphadenitis—a hospital-based study from Central India. Int J Infect Dis 2009 Sep;13(5):600-605. [doi: 10.1016/j.ijid.2008.06.046] [Medline: 19111495]
17. Lee JY. Diagnosis and treatment of extrapulmonary tuberculosis. Tuberc Respir Dis (Seoul) 2015 Apr 14;78(2):47-55 [FREE Full text] [doi: 10.4046/trd.2015.78.2.47] [Medline: 25861336]
18. Long R. Canadian Tuberculosis Standards. Seventh Edition. Ottawa, Canada: Public Health Agency of Canada; Feb 2014.
19. Tortoli E, Russo C, Piersimoni C, Mazzola E, dal Monte P, Pascarella M, et al. Clinical validation of Xpert MTB/RIF for the diagnosis of extrapulmonary tuberculosis. Eur Respir J 2012 Jan 12;40(2):442-447. [doi: 10.1183/09031936.00176311] [Medline: 22241741]
20. Suzana S, Ninan MM, Gowri M, Venkatesh K, Rupali P, Michael JS. Xpert MTB/Rif for the diagnosis of extrapulmonary tuberculosis - an experience from a tertiary care centre in South India. Trop Med Int Health 2016 Jan 19;21(3):385-392. [doi: 10.1111/tmi.12655] [Medline: 26671654]
21. Iwnetu R, van den Hombergh J, Woldeamanuel Y, Asfaw M, Gebrekirstos C, Negussie Y, et al. Is tuberculous lymphadenitis over-diagnosed in Ethiopia? Comparative performance of diagnostic tests for mycobacterial lymphadenitis in a high-burden country. Scand J Infect Dis 2009;41(6-7):462-468. [doi: 10.1080/00365540902897697] [Medline: 19382003]
22. Mustafa T, Wiker HG, Mfinanga SG, Mørkve O, Sviland L. Immunohistochemistry using a Mycobacterium tuberculosis complex specific antibody for improved diagnosis of tuberculous lymphadenitis. Mod Pathol 2006 Sep 15;19(12):1606-1614. [doi: 10.1038/modpathol.3800697] [Medline: 16980944]
23. Linasmita P, Srisangkaew S, Wongsuk T, Bhongmakapat T, Watcharananan SP. Evaluation of real-time polymerase chain reaction for detection of the 16S ribosomal RNA gene of Mycobacterium tuberculosis and the diagnosis of cervical tuberculous lymphadenitis in a country with a high tuberculosis incidence. Clin Infect Dis 2012 Apr 20;55(3):313-321. [doi: 10.1093/cid/cis401] [Medline: 22523265]

Abbreviations

EMR: Eastern Mediterranean Region
EPTB: extrapulmonary tuberculosis
LJ: Lowenstein-Jensen
LNTB: lymph node tuberculosis
MTB: mycobacterium tuberculosis
NPV: negative predictive value
NTP: National TB Program
PCR: polymerase chain reaction
PPV: positive predictive value
Se: sensitivity
Sp: specificity
TB: tuberculosis
WHO: World Health Organization

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Viewpoint

Preventing Emerging and Re-emerging Infections in the Eastern Mediterranean Region: Gaps, Challenges, and Priorities

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Abstract

Background: The Eastern Mediterranean Public Health Network, supported by the Biosecurity Engagement Program, contributed significantly to strengthening the preparedness and response to the emerging and re-emerging infections in the region.

Objective: This study aimed to determine the gaps, challenges, and priorities for preventing the emerging and re-emerging infections, with a focus on biosafety and biosecurity in four countries of the region, namely, Egypt, Iraq, Jordan, and Morocco.

Methods: A total of two different methods were used to determine the gaps and priorities for preventing the emerging and re-emerging infections. The first method was a rapid assessment for the preparedness and response to the emerging and re-emerging infections in four countries of the region, with a focus on biosafety and biosecurity. The second method was a face-to-face round table meeting of the participating teams for two days, where the teams from all countries presented their countries' profiles, findings, priorities, and gaps based on the countries' assessments.

Results: The assessment and meeting resulted in several priorities and recommendations for each of the countries in the areas of legislation and coordination, biosafety and biosecurity, surveillance and human resources, case management and response, infection control and prevention, and risk communication and laboratory capacity.

Conclusions: Many recommendations were relatively consistent throughout, including improving communication or building collaborations to improve the overall health of the country.

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KEYWORDS

emerging; infectious; diseases; Eastern Mediterranean

Introduction

Background

The Eastern Mediterranean region is a hotspot for emerging and re-emerging infectious diseases [1]. Almost half of the countries in the region have witnessed epidemics from emerging infectious diseases over the past years [2]. Many outbreaks were detected, investigated, and contained in some countries of the region in the last few years, including yellow fever [3], Middle East respiratory syndrome [4], cholera [5], avian influenza A (H5N1) infection [6], dengue fever [7], and chikungunya [8-10]. These epidemics had a high burden on the health system and the socioeconomic development of the region.

The risk of the emerging and re-emerging infectious diseases has increased significantly in the past years owing to different factors, some of which are related to humanitarian emergencies, wars, fragile health systems, weak surveillance, and limited laboratory diagnostic capacity [11]. A high number of internally displaced persons and refugees living in overcrowded and overburdened spaces, with little or no access to basic health care services [12], has contributed to the emergence and reemergence of epidemic diseases in the region [13].

The regional preparedness, response, and control efforts face major challenges such as poor vector surveillance capacities, lack of integrated vector management approaches, weak multidisciplinary and intersectoral collaboration, and the absence of comprehensive preparedness and response plans.

Protecting people’s health by combating outbreaks remains a national priority for all countries in the region. This is also important to ensure maximum protection of the people against the international spread of these diseases and its role in global health security. A regional collective approach to address the emerging and re-emerging infections as a health security issue will permit the rapid detection of novel biological threats and assist in identifying innovative and locally crafted solutions for the management of these disease threats, both from a security and safety perspective as well as from a disease control standpoint.

Objectives

The Eastern Mediterranean Public Health Network (EMPHNET), supported by the Biosecurity Engagement Program, contributed significantly to strengthening the preparedness and response to the emerging and re-emerging infections in the region. This study aimed to determine the gaps, challenges, and priorities for preventing the emerging and re-emerging infections, with a focus on biosafety and biosecurity in 4 countries of the region, namely, Egypt, Iraq, Jordan, and Morocco.

Methods

Gaps and Priorities Identification

A total of two different methods were used to determine the gaps and priorities for preventing the emerging and re-emerging infections in 2015. The first method was a rapid assessment for preparedness and response to the emerging and re-emerging infections in 4 countries of the region, with a focus on biosafety and biosecurity. The second method was a face-to-face round table meeting of the participating teams for two days, where the teams from all the countries presented their countries’ profiles, findings, priorities, and gaps based on the countries’ assessments.

Rapid Assessment

The EMPHNET team developed a questionnaire to obtain up-to-date information on the status of the participating countries regarding preparedness and other capacities required to detect and respond to the outbreaks of the emerging and re-emerging infections. The team comprised experts in emerging and re-emerging infections, biosafety and biosecurity, outbreak investigation, and response. The questionnaire tackled the following areas: legislation and coordination (4 questions), biosafety and biosecurity (13 questions), surveillance and human resources (12 questions), case management and response (2 questions), infection control and prevention (7 questions), risk communication (4 questions), and laboratory capacity (4 questions). The questionnaire included yes, no, remarks and percentage for responses and a section for listing the priorities and gaps for urgent consideration. It was structured as Web-based link that was sent to the focal points of each participating county. The focal points met with their respective teams in their own countries and filled the questionnaire. The individuals included in the country teams that responded to the questionnaire were surveillance officers, animal health officers, officers from the Central Public Health Laboratory, International Health Regulations (IHR) focal points, communicable diseases control officers, and Field Epidemiology Training Program (FETP) coordinators.

Round Table Meeting

A round table on *Preventing Emerging and Re-emerging Infections*, which aimed at improving the biorisk management and best practices in relation to disease control efforts for emerging pathogens, was conducted. The round table session was intended for the public health officials from the region as part of strengthening the preparedness and response to emerging and re-emerging infections. The organizing team invited director generals, senior surveillance officers, animal health officers, directors of the Central Public Health Laboratories, IHR focal points, director for communicable diseases, FETP coordinators, and senior officers of the United Nations Relief and Works Agency’s health section to participate in the round table meeting. In this round table meeting, the experts gave an overview of the region and provided some information on the main known threats to the region; then, the countries’ representatives presented their countries’ profiles and findings of the rapid assessments. The country teams discussed their findings and the countries’ strengths, gaps, weaknesses, and recommendations. The representatives, delegates, and facilitators of all countries came up with areas of priority for immediate consideration and areas for short- or long-term consideration. Finally, they recommended several short-, medium-, and long-term activities to improve the preparedness and response to the emerging and re-emerging infectious diseases’ threats at the subregional level. At the round table sessions, special attention was given to biosafety, biosecurity, and biorisk management issues related to the emerging and re-emerging infections. The organizing team transcribed discussions, comments, questions, and answers throughout the round table.

Results

Responses of Countries

On the basis of the rapid assessment responses and the round table discussions of the representatives from Egypt, Iraq, Jordan, and Morocco, the major gaps, challenges, and priorities for the different focus areas are discussed below.

Legislation and Coordination

The countries’ representatives reported that they have a public health law that allows for the detection and investigation of the emerging and re-emerging diseases’ cases and outbreaks, an assigned high-level intersectoral coordination body at the national level, and a functional emergency operations center at the central level. Overall, 3 countries confirmed that they have a biorisk management plan and that they update their plans regularly. Moreover, 3 countries reported that they regularly conduct risk assessment of major health facilities at the national level. Morocco reported that they do not have a biorisk management plan, and Iraq reported that they do not have mechanisms to detect any violation of the biorisk management plan. Iraq also reported that they do not conduct regular risk assessment of major health facilities.

Biosafety and Biosecurity

All countries reported that they have logbooks to record toxins and biological agents where necessary, measures are in place to identify and manage risk associated with general safety, staff are handling dangerous substances with enough care, and their general surveillance systems are based on proper risk assessment. In addition, they reported that they have enough controls in place for the physical security of infectious materials of all kinds commensurate with the assessed risks.

Surveillance and Human Resources

Countries reported that they have comprehensive public health surveillance systems, and 2 out of the 4 countries reported that they have early warning and response surveillance systems as well. The surveillance system in Jordan reports on weekly and monthly basis, but outbreaks are reported immediately. The frequency of reporting of surveillance sites in Iraq, Morocco, and Egypt are immediate and daily for notifiable diseases and weekly and monthly for other diseases. In addition, all countries reported that the public health surveillance systems are linked with animal health surveillance systems. Furthermore, 3 out of the 4 countries reported that their public health surveillance systems are linked with response units and the same number reported that they have rapid response teams at the provincial and governorate levels. Iraq reported that the surveillance system is not linked with response teams, and Morocco reported that they do not have rapid response teams at the provincial and governorate levels. All countries reported that they have specific investigation, response, and medical teams for the management of emerging and re-emerging infections, which have capacities for contact tracing, isolation, and quarantine. Furthermore, 3 countries revealed that they have a regular feedback system to health facilities, whereas Jordan reported informal feedback system.

Case Management and Response

Only 2 countries reported that they have generic protocols for the treatment of the emerging and re-emerging infections. Countries lacking these protocols were Morocco and Egypt. All countries reported that they have updated protocols for the sample collection of the emerging and re-emerging infections. A total of 3 countries reported that they completed the risk assessment of main laboratories; in addition, the same number reported that the risk mitigation and control measures in the laboratories are in place, and they confirmed that the standard operating procedures (SOPs) for waste management in laboratories are practiced. Furthermore, they reported that they have strong links with the regional reference laboratories.

Infection Control and Prevention

A total of 3 out of the 4 countries reported that they have a national infection prevention and control program. All countries reported that they have trained provincial infection control and prevention teams, a national policy for medical waste management, and enough personal protective equipment for general use and for the use of infection control and prevention teams. Morocco reported that they do not have a functional infection control and prevention program at the ministry level and that no entity regularly reports on the status of the national infection control and prevention goals and strategies.

Risk Communication and Laboratory Capacity

A total of 2 out of the 4 countries reported that they have World Health Organization–certified (WHO-certified) point of entry, whereas Jordan and Egypt reported not having any WHO-certified point of entry. All participating countries reported that they have a national risk communication plan, well-known national spokesperson, and 2-way real-time communication with media.

The participants of the round table highlighted that the interdisciplinary coordination and communication within the health sector and throughout the board with other actors are weak. They also agreed that the responses to the events are not on time. They mentioned that the delay in the detection of first few cases (surveillance), sample collection, transportation and confirmation, and the limited technical resources and financial means are major challenges to provide a proper response to public health events. Participating representatives also reported that they face multidrug-resistant infections in their countries. In addition, they identified gaps in specimen packaging and shipment and raised concerns over public health surveillance and other capacities required for the points of entry and exist in all countries. Risk communication and involvement of media were identified to be weak. The media tend to publish unrealistic negative news more than the realities in the field, as reported.

The public health laboratories are functioning in Iraq but with limited diagnostic kits and limited laboratory supplies. Jordan's team identified other problems, such as limited number of qualified trained personnel and high staff turnover rates, which lead to under reporting or incomplete reporting of surveillance data, biosafety events and incidents, financial shortfall for procurement of infection control materials, and financial shortfalls in implementing infection control measures. The main gaps identified by the Moroccan team included the lack of institutional link with animal health surveillance and the inadequate coordination to implement an integrated surveillance system for zoonotic diseases between the Ministry of Health and the Ministry of Agriculture (animal husbandry).

Discussion

Principal Findings

Representatives from the participating countries reported that they have surveillance systems, laboratories, and infection control and prevention programs in place, although these systems were not perfect and needed support in many areas. Strengthening of the surveillance systems by adding components such as the disease early warning system was one of the requests. The risk assessment and risk mitigation of main health facilities and laboratories should be conducted regularly. Bridges for communication and collaboration between animal and human health to detect, confirm, and respond to outbreaks of animal origin should be built or improved at the national levels. The limitation of these findings is that they may not reflect all or the most pressing gaps, challenges, and priorities of the countries.

Many recommendations were relatively consistent throughout; they included improving the communication or building collaborations to improve the overall health of the country. The general recommendations by countries can be summarized as follows:

- Improve coordination, communication, and interaction among partners, stakeholders, and donors and adopt a systematic approach based on the accepted national and regional guidelines and standards while dealing with emerging and re-emerging infections
- Establish outbreak management teams, and not only outbreak investigation teams, to improve timely and effective response
- Develop and agree on the detailed SOPs for operational issues and challenges
- Strengthen the links with mass media and user-friendly social media
- Improve and strengthen public health surveillance systems.

Highlights by Country

The country-specific priorities and recommendations are presented in Textbox 1.

Textbox 1. Country-specific priorities and recommendations to support the prevention of emerging and re-emerging diseases.

Egypt

- Review the surveillance and response system
- Improve and update public health surveillance guidelines
- Establish and improve electronic surveillance systems, for example, early warning system and event-based surveillance
- Develop general and generic guidelines and protocols for the management of emerging and re-emerging infections
- Improve biosafety and biosecurity through training and capacity building of concerned staff
- Technical and financial support to establish disease early warning system
- Technical and financial support to establish event-based surveillance and its related guidelines
- Build capacity through training
- Technical and financial support to prepare and devise national preparedness and response to outbreaks and pandemics

Iraq

- Stronger links between animal and human health surveillance systems
- Response strategies should include animal health authorities to implement better response measures while facing zoonotic diseases
- Specific trainings activities, for example, training of rapid response teams and refresher trainings, are required for better response to outbreaks and events
- Review, assessment, and evaluation of the infection control and prevention programs
- Improve connections and links with regional and global laboratory networks to improve the on-time detection and confirmation of diseases and improve the specimen transportation and delivery
- National communication and risk communication strategies should be developed
- Biorisk management plan should be developed, enforced, and implemented and a mechanism should be emplaced to detect any breach of the biorisk management plan and its related standard operating procedures
- Training of health care workers on biosafety and biosecurity and emerging and re-emerging infections
- Coordination meetings with the neighboring countries on the emerging and re-emerging infections such as Ebola
- Provision of laboratory diagnostic kits, training, and monetary motivation

Jordan

- Improve the awareness of decision and policy makers and obtain their commitment to improve available gaps
- Improve biorisk management (biosafety and biosecurity risk management) by a national plan implementation
- Strengthen infection control and prevention in hospitals
- Establishment of public health surveillance systems at the point of entries and improve the shipment of biological samples
- Improve laboratory capacity for the early detection of the emerging and re-emerging infections
- Training of health care workers on biorisk management (biosafety and biosecurity), emerging and re-emerging infections, and importance of surveillance and timely reporting

Morocco

- Update the existing public health law in Morocco
- Establish a multidisciplinary and multisectorial technical committee responsible for documenting, monitoring, and tracking the international epidemiological situations, conducting risk analysis, and prioritizing the emerging diseases that have a greater risk in Morocco
- Develop specific programs or guides to be able to act upon the emerging diseases
- Bridge gaps and improve communication between animal and human health services to pave road for establishing an animal/human health unit in the Ministry of Health
- Establish a national program with all components for infection prevention and control
- Improve surveillance system by updating the list of notifiable diseases
- Improve the laboratory-based surveillance system to monitor the activities of certain pathogens and improve the diagnostic capacity
- Conduct refresher training activities for health professionals

- Conduct seroprevalance studies to estimate the prevalence of diseases such as leptospirosis, brucellosis, West Nile fever, and dengue fever in Morocco
- Establishment of animal/human health unit (zoonotic diseases unit)
- Develop a national plan to prevent health care–associated nosocomial infections

Conflicts of Interest

None declared.

References

1. Haq Z, Mahjour J, Khan W. Communicable diseases in the eastern Mediterranean region: prevention and control 2010-2011. East Mediterr Health J 2013 Oct;19(10):888-891 [FREE Full text] [doi: 10.26719/2013.19.10.888] [Medline: 24313154]
2. Abubakar A, Malik M, Pebody RG, Elkholy AA, Khan W, Bellos A, et al. Burden of acute respiratory disease of epidemic and pandemic potential in the WHO eastern Mediterranean region: a literature review. East Mediterr Health J 2016 Oct 2;22(7):513-526. [doi: 10.26719/2016.22.7.509] [Medline: 27714746]
3. Soghaier MA, Hagar A, Abbas MA, Elmangory MM, Eltahir KM, Sall AA. Yellow Fever outbreak in Darfur, Sudan in October 2012; the initial outbreak investigation report. J Infect Public Health 2013 Oct;6(5):370-376 [FREE Full text] [doi: 10.1016/j.jiph.2013.04.007] [Medline: 23999341]
4. Mohd HA, Al-Tawfiq JA, Memish ZA. Middle east respiratory syndrome coronavirus (MERS-CoV) origin and animal reservoir. Virol J 2016 Jun 3;13:87 [FREE Full text] [doi: 10.1186/s12985-016-0544-0] [Medline: 27255185]
5. Mukhopadhyay AK, Al Benwan K, Samanta P, Chowdhury G, Albert MJ. Vibrio cholerae O1 imported from Iraq to Kuwait, 2015. Emerg Infect Dis 2016 Sep;22(9):1693-1694 [FREE Full text] [doi: 10.3201/eid2209.160811] [Medline: 27532267]
6. Kayali G, Kandeil A, El-Shesheny R, Kayed AS, Maatouq AM, Cai Z, et al. Avian influenza A(H5N1) virus in Egypt. Emerg Infect Dis 2016 Mar;22(3):379-388 [FREE Full text] [doi: 10.3201/eid2203.150593] [Medline: 26886164]
7. Humphrey JM, Cleton NB, Reusken CB, Glesby MJ, Koopmans MP, Abu-Raddad LJ. Dengue in the middle east and north Africa: a systematic review. PLoS Negl Trop Dis 2016 Dec;10(12):e0005194 [FREE Full text] [doi: 10.1371/journal.pntd.0005194] [Medline: 27926925]
8. Thabet AA, Al-Eryani SM, Aziz NA, Obadi M, Saleh M, Al-Kohlani A, et al. Epidemiological characterization of chikungunya outbreak in Lahj Governorate, southern Yemen. J Community Med Health Educ 2013;3(7):247. [doi: 10.4172/2161-0711.1000247]
9. Markoff L. Yellow fever outbreak in Sudan. N Engl J Med 2013 Feb 21;368(8):689-691. [doi: 10.1056/NEJMp1300772] [Medline: 23387798]
10. Seita A. Complex emergencies in the eastern Mediterranean region: impact on tuberculosis control. Int J Mycobacteriol 2016 Dec;5(Suppl 1):S12 [FREE Full text] [doi: 10.1016/j.ijmyco.2016.10.040] [Medline: 28043499]
11. Santoro A, Abu-Rmeileh N, Khader A, Seita A, McKee M. Primary healthcare reform in the United Nations Relief and Works Agency for Palestine Refugees in the near east. East Mediterr Health J 2016 Jun 1;22(6):417-421. [doi: 10.26719/2016.22.6.417]
12. Mokdad AH, Forouzanfar MH, Daoud F, El Bcheraoui C, Moradi-Lakeh M, Khalil I, et al. Health in times of uncertainty in the eastern Mediterranean region, 1990-2013: a systematic analysis for the global burden of disease study 2013. Lancet Glob Health 2016 Oct;4(10):e704-e713 [FREE Full text] [doi: 10.1016/S2214-109X(16)30168-1] [Medline: 27568068]
13. Malik MR, Mahjour J. Preparedness for Ebola: can it transform our current public health system? East Mediterr Health J 2016 Nov 2;22(8):566-567 [FREE Full text] [doi: 10.26719/2016.22.8.566] [Medline: 30387105]

Abbreviations

EMPHNET: Eastern Mediterranean Public Health Network
FETP: Field Epidemiology Training Program
IHR: International Health Regulations
SOP: standard operating procedure
WHO: World Health Organization

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Viewpoint

Rapid Response Teams’ Initiative: Critical Role and Impact on National and Eastern Mediterranean Regional Emergency Management Capacity Building

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Abstract

Rapid response teams (RRTs) are essential to contain the harmful effects of emergency situations and to coordinate actions in the fragile environment of the Eastern Mediterranean region (EMR). The Global Health Development and the Eastern Mediterranean Public Health Network (EMPHNET) implemented RRTs to fill the human resources gap and to enable the member states to build their capacity in rapid assessment and response to public health events to reduce human suffering. To build the capacity of the member states in the field of rapid response and to build a strong team of rapid response specialists at the regional level, EMPHNET implemented this initiative at two levels. The first was a basic regional RRT course (July 2012). It was an introductory course for the selected candidates to provide insight and to enhance the knowledge and skills needed to be part of an RRT. The training included 32 participants from nine EMR countries. The course was designed to allow the facilitators and selection committee to select 15 to 20 potential candidates for the advanced RRT course. The second was the advanced RRT course (September 2010 to October 2012) for training the trainers and preparing the RRTs for deployment. A series of RRT training workshops were held, with more than 650 health staff from 12 countries trained. In all workshops that were conducted during 2016-2017, the trainees showed significant improvement in their knowledge and skills.

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KEYWORDS

response teams; emergency; management; capacity building; training

Outbreaks and Conflict

In 2017, more than 76 million people were directly or indirectly affected by political conflict, war, displacement, environmental threats, famine, and natural disasters across the Eastern Mediterranean region (EMR) [1]. These conflicts and threats have resulted in many infectious disease outbreaks because of overcrowded living conditions, limited access to safe water and sanitation, and limited access to health care services [2]. Such threats necessitate effective rapid response mechanisms, training, equipment, and access to information [3].

With the 2005 revisions of the International Health Regulations (IHR, 2005), epidemic alerts and responses are critical to ensuring global health security [4]. Consequently, rapid response teams (RRTs) are essential to contain the harmful effects of emergency situations and to coordinate actions in the fragile environments, such as that of the EMR. The Centers for Disease Control and Prevention and the World Health Organization (WHO) recommended RRT training to rapidly contain outbreaks, such as avian influenza outbreaks in Southeastern Asia and the Middle East. According to the WHO’s assessments, the EMR needs better coordination of qualified individuals and increased capacity to detect and respond to disease outbreaks in a timely manner. Such individuals can serve in RRTs.

Rapid Response Teams Initiative in the Eastern Mediterranean Region

RRT is a multistage collaborative project initiated by the Global Health Development (GHD) and the Eastern Mediterranean Public Health Network (EMPHNET) to fill the human resources gap and to enable the member states to build their capacity in rapid assessment and response to public health events to reduce human suffering. The GHD/EMPHNET had established the RRT initiative in 2012 to support the countries of EMR to effectively respond to public health events, including emerging infectious diseases and other biological threats in line with IHR [4]. The RRT initiative aims to increase the alert, investigation, and response capacity of the countries' public health workforce, particularly graduates of the Field Epidemiology Training Program and the Public Health Empowerment Program, from both human and animal health sectors. Moreover, it aims to develop internal expertise in emergency preparedness and response operation, which will contribute to building stronger preparedness and response capacity of the countries and contribute to health security at the national, regional, and global levels. In addition, RRTs aimed to improve disease surveillance, outbreak investigation, and public health responses to disasters and disease outbreaks in the EMR, utilize skilled human resources in the EMR by developing a roster of well-trained RRTs at the national and subnational levels, and increase linkages among the public health institutions in the EMR for cross-border investigations of diseases/outbreaks.

Strategy of Capacity Building in Rapid Response Teams

To build the capacity of the member states in the field of rapid response and to build strong teams of multisectoral rapid response specialists, EMPHNET first supported an intercountry training workshop, followed by the provision of technical support to some countries to replicate the training and build their rapid response framework (RRT at national and subnational levels). The intercountry workshop was a basic RRT course (July 1 to July 5, 2012). It was an introductory course for the selected candidates to provide insight and enhance the knowledge, competencies, and skills needed to be part of an RRT. The training included 32 participants from 9 EMR countries. The course was a good opportunity for the GHD/EMPHNET to identify potential future regional RRT members, as well as 15 to 20 potential candidates for the RRT course replication in respective countries. This activity was followed by an advanced RRT course (September 16 to October 4, 2012), where potential future regional RRT members were targeted. The advanced course was conducted over a 3-week duration and trained 19 professionals demonstrating commitment, knowledge, and enthusiasm to perform fieldwork under diverse situations.

The RRT trainings tackled issues related to the composition of an outbreak team, intersectoral coordination, IHR, surveillance systems, outbreak investigation and control measures, risk assessment, risk communication, role of the laboratory in outbreak investigation, biosafety and biosecurity, data management and report writing, and soft skills, among other topics.

After the regional RRT network was developed and fully functional, the trained RRT members continued training the national RRTs. The number and composition of these teams depended on each country's needs. The EMPHNET aimed to provide a response platform at the national and subnational levels. The teams included epidemiologists, laboratory technicians, and other qualified public health officers from the ministries of health and individuals from the ministries of agriculture, including those who were working in animal husbandry, veterinary medicine, and disaster management. The strategy in training these national RRTs was to enable subregional trainings that mobilize a larger number of people and maximize resources where they are most needed.

Achievements

The EMPHNET has successfully conducted both introductory and advanced courses on RRT training in the EMR. The introductory course included 32 participants from 9 countries: Afghanistan, Egypt, Iraq, Jordan, Lebanon, Saudi Arabia, Pakistan, Sudan, and Yemen. EMPHNET conducted a pretest, 3 quizzes, and a posttest, with a class average of 58.7%, 80.3%, and 89.6%, respectively. Comparison of pretests and posttests demonstrated an average class improvement of 30.9%. The participants' grading of the workshop demonstrated a high level of satisfaction based on the postworkshop satisfaction survey. More than 95% of the participants strongly agreed that the workshop met their expectations.

On the basis of the results of the basic RRT training course, 19 participants scored at least 72% on the posttest and, therefore, they were qualified for the more extensive and advanced training. The 19 individuals included 4 from Yemen; 3 each from Afghanistan and Iraq; 2 each from Lebanon, Pakistan, Sudan, and Jordan; and 1 from Saudi Arabia. The evaluation of the 3-week advanced course also demonstrated a high level of satisfaction among the participants. The goal of these courses was to develop a highly qualified public health RRT to be ready to respond to disease outbreaks in the region and arrange subsequent RRT trainings at the national and provincial/governorate levels in their respective countries. This worked toward achieving the ultimate goal of having qualified regional and national RRTs in the EMR.

A series of RRT training workshops were held, where more than 650 health staff from 12 countries were trained. In all 10 workshops that were conducted during 2017-2018, the trainees showed significant improvement in their knowledge and skills, evaluated using pretest and posttest assessments (Table 1).

Table 1. The average pretest and posttest scores for participants who participated in 10 rapid response teams training workshops during 2016-2018.

Country	Date	Trainees, n	Pretest score (%), mean (SD)	Posttest score (%), mean (SD)
Egypt	April 24 to April 28, 2016	24	60 (13)	68 (7)
Egypt	July 29 to August 2, 2018	30	56 (11)	84 (6)
Egypt	September 23 to September 27, 2018	30	16 (9)	93 (3)
Egypt	April 14 to April 19, 2018	24	62 (10)	86 (12)
Egypt	July 8 to July 12, 2018	30	77 (11)	95 (3)
Tunisia	May 1 to May 11, 2018	73	60 (6)	69 (7)
Tunisia	November 6 to November 10, 2017	35	62 (10)	77 (6)
Sudan	June 24 to June 28, 2018	40	53 (8)	74 (14)
Morocco	October 30 to November 3, 2017	32	62 (10)	77 (6)
Jordan	March 12 to March 16, 2017	24	61 (15)	76 (8)

Conclusions

Through the RRT initiative, the GHD/EMPHNET has developed a highly qualified public health RRT, which can roll out subsequent RRT trainings at the national and provincial/governorate levels in the EMR countries and contribute to responding to unexpected events in the region. For this developed capacity to be sustained and functional, the RRTs will need to be continuously engaged with the activities of public health stakeholders by participating in different efforts such as outbreak investigations or even simulation exercises.

Conflicts of Interest

None declared.

References

1. ReliefWeb. 2017. WHO EMRO | Emergencies in the Eastern Mediterranean Region in 2017: The Year in Review URL: https://reliefweb.int/sites/reliefweb.int/files/resources/emergencies-in-the-eastern-mediterranean-region-2017-the-year-in-review.pdf [accessed 2017-12-15]
2. The WHO Regional Office for the Eastern Mediterranean. 2015. Refugees and Internally Displaced Persons in the Eastern Mediterranean Region: A Health Perspective URL: http://www.emro.who.int/images/stories/eha/documents/migrants_refugees_position_paper.pdf?ua=1 [accessed 2019-01-15]
3. The Eastern Mediterranean Public Health Network (EMPHNET). Biosafety and Biosecurity URL: http://emphnet.net/?page_id=4767 [accessed 2019-01-15]
4. World Health Organization. 2005. Revision of the International Health Regulations URL: https://www.who.int/csr/ihr/IHRWHA58_3-en.pdf [accessed 2019-01-15]

Abbreviations

EMPHNET: Eastern Mediterranean Public Health Network
EMR: Eastern Mediterranean region
GHD: Global Health Development
IHR: International Health Regulations
RRT: rapid response team
WHO: World Health Organization

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Original Paper

The Impact of War in Yemen on Immunization Coverage of Children Under One Year of Age: Descriptive Study

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Abstract

Background: After 2 years of war that crippled the capacity of the Yemeni National Health System and left only 45% of health facilities functioning, Yemen faced increasing vaccine-preventable disease (VPD) outbreaks and may be at high risk of polio importation.

Objective: The aim of this study was to determine the impact of the 2015 war on the immunization coverage of children under 1 year.

Methods: Data on vaccination coverage for 2012-2015 were obtained from the national Expanded Program on Immunization (EPI). The vaccination coverage was calculated at the national and governorate levels by dividing the number of actually vaccinated children by the estimated population of children under 1 year.

Results: Although there was an increase from 2012 to 2014 in the national coverage for penta-3 vaccine (82% in 2012 vs 88% in 2014) and measles vaccine (70% in 2012 vs 75% in 2014), the coverage was still below the national target (≥95%). Furthermore, the year 2015 witnessed a marked drop in the national coverage compared with 2014 for the measles vaccine (66% in 2015 vs 75% in 2014), but a slight drop in penta-3 vaccine coverage (84% in 2015 vs 88% in 2014). Bacillus Calmette–Guérin vaccine also showed a marked drop from 73% in 2014 to 49% in 2015. These reductions were more marked in governorates that witnessed armed confrontations (eg, Taiz, Lahj, and Sa'dah governorates). On the other hand, governorates that did not witness armed confrontations showed an increase in coverage (eg, Raymah and Ibb), owing to an increase in their population because of displacement from less secure and confrontation-prone governorates.

Conclusions: This analysis demonstrated the marked negative impact of the 2015 war on immunization coverage, especially in the governorates that witnessed armed confrontations. This could put Yemen at more risk of VPD outbreaks and polio importation. Besides the ongoing efforts to stop the Yemeni war, strategies for more innovative vaccine delivery or provision and fulfilling the increasing demands are needed, especially in governorates with confrontations. Enhancing EPI performance through supportable investments in infrastructure that was destroyed by the war and providing decentralized funds are a prerequisite.

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KEYWORDS

immunization coverage; 2015 war; impact; Y-FETP; Yemen

Introduction

Background

Vaccination, one of the greatest achievements in medicine and public health, has greatly reduced morbidity, mortality, and health care costs [1]. Although many developing countries have seen a major reduction in vaccine-preventable diseases (VPD) owing to sustained use of vaccines, vaccination has not reached its full potential and at least 2 million people die every year from VPD [2]. Therefore, for vaccination programs to be effective, high rates of coverage must be maintained.

The World Health Organization and the United Nations Children’s Fund developed the Global Immunization Vision and Strategy (GIVS) 2006-2015. One of the set goals of GIVS for any country is to reach at least 90% national vaccination coverage and at least 80% vaccination coverage in every district or equivalent administrative unit [3].

In Yemen, the strategy for the national Expanded Program on Immunization (EPI) 2011-2015 was to reach 95% coverage at the national level, and not less than 80% for diphtheria, tetanus, and pertussis at the district level by 2015 [4]. However, a major demographic challenge for reaching this target is a very scattered population, with more than 130,000 population sites all over the country [5]. Although, the political crisis that started in 2011 with the Arab Spring had negatively affected the health system and accessibility to health services, including vaccination, the political situation stabilized after 2012. However, in March 2015, a major war broke out and left only 45% of health facilities functioning. Yemen, which had a fragile health care system before the onset of war, did not have the infrastructure to withstand such a catastrophe and is currently on the brink of collapse. In the past 2 years, continuous war has led to the destruction of health care facilities and has made access to the ones standing difficult for those in need. Before the war, Yemen had a relatively stable vaccination rate reaching 70% to 80% of the target population; however, this dropped remarkably after the war [6,7]. VPD such as measles, cholera, and diphtheria saw a sudden surge after the beginning of the war [7-11]. Polio importation in such a critical situation also remains a major threat not only for Yemen but also for its neighboring countries.

Objective

This study aimed to determine the immunization coverage of the children under 1 year, during the 2015 war.

Methods

A soft copy of data aggregated by EPI during 2015-2015 was obtained from EPI in Excel format, which collected data from all 23 governorates, 333 districts, and 3096 vaccination sites in Yemen. The data included the following variables: the total population, targeted children, and the number of vaccinated children by each vaccine type and governorate. The vaccination coverage was calculated at the national and governorate levels by dividing the number of actually vaccinated children by the estimated population of children under 1 year. The governorates were divided into confrontation and nonconfrontation governorates depending on the battle on the ground. Analysis was carried out using Epi Info 7.2 (CDC) and Excel. Data were described using graphs and percentages.

Results

The immunization coverage increased for penta-3 vaccine and measles coverage of vaccination (MCV) during 2012-2014, but coverage dropped in 2015. Compared with the national target, the coverage was still below the national target (Figures 1 and 2).

Figure 1. Immunization coverage for penta-3 vaccine compared to the national target, 2012-2015.

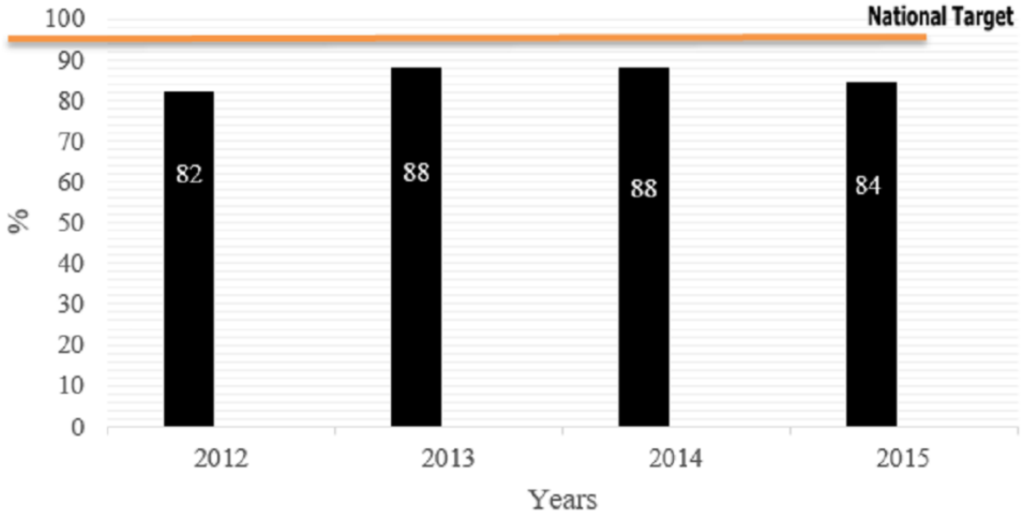
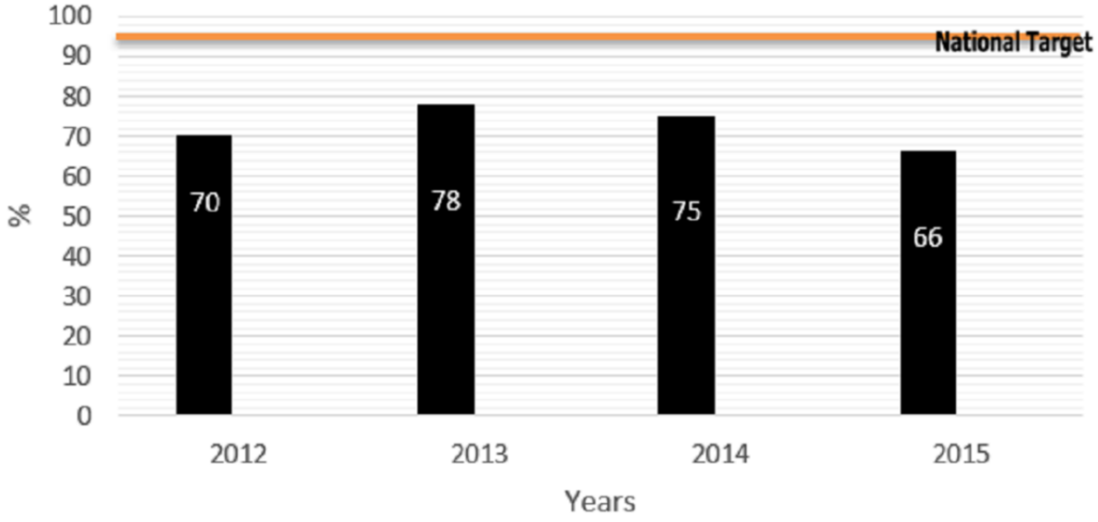


Figure 2. Immunization coverage for measles compared to the national target, 2012-2015.



The first table in Multimedia Appendix 1 summarizes the immunization coverage by vaccine type for 2012-2015, which shows some increase in the coverage from 2012 to 2014 for all vaccines; however, there is a drop in the coverage in the year 2015 that witnessed the war (out of 3096 vaccination sites, 2577 sites reported of providing vaccination).

The second table in Multimedia Appendix 1 shows penta-3 vaccine coverage by governorates. There was an increase in the vaccination coverage in most governorates between 2011 and 2014, except for some governorates such as Al Jawf and Sa'dah. With the eruption of war in 2015, there was a marked drop in the vaccination coverage in some governorates such as Al Jawf, Sa'dah, Lahj, and Taiz. On the other hand, some governorates showed an increase in the coverage (eg, Ibb, Raymah, and Sana'a governorates).

Discussion

Principal Findings

Despite recent progress in vaccination coverage in Yemen, a very scattered population, with more than 130,000 population sites all over the country, poses a major challenge. Furthermore, the current political situation and insecurity have negatively affected the progress. Our findings showed a gradual increase in the coverage of penta-3 vaccine and MCV during 2012-2014, compared with the year 2011 that witnessed the political crises and the Arab Spring. Such an increase might be owing to the relative political stability and improvement of security after the uprising came to a successful conclusion. However, Al Jawf and Sa'dah governorates did not show such an increase as they continue to suffer from insecurity and fights, in addition to having sparse population with difficult access to vaccines and poor community awareness and wrong beliefs regarding immunization [12]. Furthermore, in all these years the coverage was still below the national target [4] and lower than the coverage in the neighboring countries, including Saudi Arabia (96%) and Oman (99%), but better than that in Somalia (65%) [13,14].

The coverage remarkably dropped in 2015 owing to the eruption of the war. Such a drop was more apparent in governorates that witnessed confrontations such as Sa'dah, Lahj, and Taiz. For example, Taiz governorate showed a drop in penta-3 vaccine coverage from (102,455/110,755) 92.51% in 2014 to (83,182/113,535) 73.27% in 2015 and Sa'dah from (17,511/26,779) 65.64% to (13,849/27,754) 49.90%. However, the coverage increased in Ibb and Raymah governorates that were less affected by the war and showed an increase in their population because of displacement from less secure and confrontation-prone governorates. For example, Raymah showed an increase in penta-3 vaccine coverage from (15,868/18,255) 86.92% to (19,871/18,810) 105.64% and Ibb from (93,106/99,919) 93.18% to (103,435/102,417) 100.99% in 2015.

Conclusions

In conclusion, this analysis shows the marked negative impact of the 2015 war on immunization coverage, especially in the governorates that witnessed armed confrontations. This could put Yemen at more risk of VPD outbreaks and polio importation. Besides the ongoing efforts to stop the Yemeni war, strategies for more innovative vaccine delivery/provision and fulfilling the increasing demands are needed, especially in governorates with confrontations. Enhancing EPI performance through supportable investments in infrastructure that was destroyed by the war and providing decentralized funds are a prerequisite. Further studies to assess the effect of continuous war on vaccination coverage and to measure the resilience are recommended.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Immunization coverage (percentage) by vaccine type 2012-2015 and penta-3 coverage by governorates, 2012- 2015.
[PDF File (Adobe PDF File), 218 KB - publichealth_v5i4e14461_app1.pdf]

References

1. Richard G. Skeptical Inquirer. Vaccine Safety: Vaccines Are One Of Public Health’s Great Accomplishments URL: https://skepticalinquirer.org/2007/11/vaccine_safety_vaccines_are_one_of_public_healths_great_accomplishments/ [accessed 2019-09-30]
2. Ba'amer A. Coverage of and barriers to routine child vaccination in Mukalla district, Hadramout governorate, Yemen. East Mediterr Health J 2010 Mar;16(2):223-227 [FREE Full text] [doi: 10.26719/2010.16.2.223] [Medline: 20799579]
3. WHO, UNICEF. World Health Organization. 2015. Global Immunization Vision and Strategy : 2006-2015 URL: https://apps.who.int/iris/handle/10665/69146 [accessed 2019-09-30]
4. Ministry of Public Health & Population. Country Planning Cycle Database. 2011. Comprehensive Multi-Year Plan cMYP URL: http://www.nationalplanningcycles.org/sites/default/files/planning_cycle_repository/yemen/yemen_cmyp_doc.pdf [accessed 2019-09-30]
5. Encyclopedia. Yemen URL: https://www.encyclopedia.com/places/asia/arabian-peninsula-political-geography/yemen [accessed 2018-08-23]
6. Burki T. Yemen's neglected health and humanitarian crisis. Lancet 2016 Mar 20;387(10020):734-735. [doi: 10.1016/s0140-6736(16)00389-5] [Medline: 26913305]
7. Qirbi N, Ismail SA. Ongoing threat of a large-scale measles outbreak in Yemen. Lancet Glob Health 2016 Jul;4(7):e451 [FREE Full text] [doi: 10.1016/S2214-109X(16)30070-5] [Medline: 27340001]
8. Raslan R, El Sayegh S, Chams S, Chams N, Leone A, Hajj Hussein I. Re-emerging vaccine-preventable diseases in war-affected peoples of the Eastern Mediterranean region-an update. Front Public Health 2017;5:283 [FREE Full text] [doi: 10.3389/fpubh.2017.00283] [Medline: 29119098]
9. World Health Organization EMRO. Emergency preparedness and response URL: http://www.emro.who.int/annual-report/2015/emergency-preparedness-and-response.html [accessed 2019-09-30]
10. World Health Organization EMRO. Outbreak update – cholera in Yemen, 8 February 2018 URL: http://www.emro.who.int/pandemic-epidemic-diseases/cholera/outbreak-update-cholera-in-yemen-8-february-2018.html [accessed 2018-08-18]
11. World Health Organization. Diphtheria – Yemen URL: http://www.who.int/csr/don/22-december-2017-diphtheria-yemen/en/ [accessed 2018-07-16]
12. Bashamakha G, Alemad M, Taqi N. , Al Serouri AW. Explosive Measles Outbreak among unvaccinated children due to parent refusal in Al Jawaf Governorate, Yemen, March 2015. 4th EMPHENT Regional Conference, Aqaba-Jordan, September 28- October 2015:1.
13. UNICEF, WHO. World Health Organization. Immunization Summary URL: https://www.who.int/immunization/monitoring_surveillance/Immunization_Summary_2013.pdf [accessed 2018-08-26]
14. World Health Organization. National programmes and systems URL: https://www.who.int/immunization/programmes_systems/en/ [accessed 2016-03-12]

Abbreviations

EPI: Expanded Program on Immunization
GIVS: Global Immunization Vision and Strategy
MCV: measles coverage of vaccination
VPD: vaccine-preventable diseases

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Viewpoint

A Collaborative Initiative to Strengthen Sustainable Public Health Capacity for Polio Eradication and Routine Immunization Activities in the Eastern Mediterranean Region

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Abstract

The many challenges in the Eastern Mediterranean region put the involved countries at risk of polio transmission and affect their ability to meet progress targets in eliminating vaccine-preventable diseases. The Global Health Development (GHD) and Eastern Mediterranean Public Health Network (EMPHNET) are working together on the project "Strengthening sustainable public health capacity in the Eastern Mediterranean region for polio eradication and routine immunization activities" with an overall goal of improving routine immunization, eradicating poliovirus, and controlling/eliminating or eradicating other vaccine-preventable diseases in the Eastern Mediterranean region. The aim of this manuscript is to describe the project and the achievements of GHD/EMPHNET over the last 3 years (2016-2018) to build effective surveillance and immunization systems in the Eastern Mediterranean region through the development of a sustainable and competent public health system to eradicate polio and control/eliminate vaccine-preventable diseases. This project assists the targeted Eastern Mediterranean region countries to build effective surveillance and immunization systems in an effort to expand their capacities to eradicate polio and control/eliminate other vaccine-preventable diseases. The project is streamlined with the Global Polio Eradication Initiative, the Centers for Disease Control and Prevention's Strategic Framework for Global Immunization 2016-2020, and the Polio Eradication and Endgame Strategic Plan 2013-2018. The project also supports the Global Health Security Agenda by focusing on efforts to accelerate progress toward a world safe and secure from infectious disease threats. Project activities were designed to respond to countries' needs and assist them in building their institutional and workforce capacity to effectively plan, implement, and evaluate activities to eradicate polio and strengthen routine immunization activities. The project activities covered a set of areas including surveillance of acute flaccid paralysis and other vaccine-preventable diseases, family and community engagement, workforce capacity building, improvement of data quality, management and use of information systems, use of polio assets to control/eliminate other vaccine-preventable diseases, support of countries to develop national strategies, piloting of innovative initiatives, program evaluation and accountability, and immunization strengthening. The project adopts the Global Polio Eradication Initiative strategies for assisting countries to strengthen routine immunization services, maintain highly sensitive acute flaccid paralysis surveillance, and sustain polio eradication functions.

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KEYWORDS

GHD/EMPHNET; Global Polio Eradication Initiative; acute flaccid paralysis; vaccine-preventable disease; VPD; surveillance; Eastern Mediterranean region; EMR; Global Vaccine Action Plan; demand creation; microplans; polio transition

Introduction

The global efforts to eradicate polio since the launch of the Global Polio Eradication Initiative in 1988 have resulted in a 99% decrease in the number of reported wild polio cases [1]. The Eastern Mediterranean region aimed at achieving at least 90% routine immunization coverage nationally and 80% in every district by 2020 to be in line with the Global Vaccine Action Plan [2]. The Eastern Mediterranean region countries had a remarkable achievement in improving the routine vaccination coverage. However, several Eastern Mediterranean region countries experience immense challenges due to political unrest, complex emergencies and humanitarian crises, and socioeconomic hardships affecting this region. Thus, many of these countries witness a significant population movement, mainly because of forced displacement, flow of large numbers of asylum seekers, and refugees and migration of workers. These challenges have been associated with the collapse of health care systems; limited institutional and human resources; and disruption of surveillance, outbreak response, immunization systems, and other disease control measures [3]. The infrastructure damage, loss of trained personnel, and equipment shortages in the affected countries resulted in an increased vulnerability of the populations to communicable diseases [4,5].

The political crisis and wars in the region caused coverage of the Diphtheria, Tetanus, and Pertussis (DTP3) vaccine and third dose of oral polio vaccine (OPV3) to drop from 86% in 2010 to 80% in 2015, with wide inter- and intracountry differences. The quality of storage and cold-chain management, suboptimal compliance with recommended microplanning activities [6,7], insufficient funding, lack of transportation, and insecurity were the main challenges to the routine immunization programs in the region [8].

The challenges in the region put the countries at risk of polio transmission and affect their ability to meet progress targets in eliminating vaccine-preventable diseases (VPDs). Therefore, maintaining the minimal standardized performance of the Expanded Program on Immunization (EPI) in each of the targeted countries is essential to overcome the current and potential challenges. In this respect, strengthening of health systems requires improving accessibility and affordability of services as part of the universal health coverage efforts.

Countries in the Eastern Mediterranean region are at different levels of risk of polio transmission. Two countries within this region remain polio endemic (Afghanistan and Pakistan); other Eastern Mediterranean region countries are either ranked as very-high-risk (Syria, Yemen, and Somalia) or high-risk (Iraq, Sudan, and Libya) countries, and the remaining are classified as low-risk countries.

The Global Health Development (GHD) and the Eastern Mediterranean Public Health Network (EMPHNET) are working together on the project “Strengthening sustainable public health capacity in the Eastern Mediterranean region for polio eradication and routine immunization activities” with an overall goal of improving routine immunization, eradicating poliovirus, and controlling/eliminating or eradicating other VPDs in the Eastern Mediterranean region. The project is a 5-year funded project by the Centers for Disease Control and Prevention (CDC).

The aim of this paper is to describe the project and the achievements of GHD/EMPHNET over the last 3 years (2016-2018) in building effective surveillance and immunization systems in the Eastern Mediterranean region through the development of a sustainable and competent public health capacity to eradicate polio and control/eliminate VPDs.

Project Overview

This project aims at assisting the Eastern Mediterranean region countries to build effective surveillance and immunization systems in an effort to expand their capacities to eradicate polio and control/eliminate other VPDs. Sustainability of services, on the other hand, is an essential part of the projects’ activities, where government involvement and community engagement play a major role in shaping national health policies to respond to the immunization-related challenges. Thus, the project is streamlined with the Global Polio Eradication Initiative, the CDC Strategic Framework for Global Immunization 2016-2020, the Polio Eradication and Endgame Strategic Plan 2013-2018, and the national policies and multiyear plans in relation to immunization. The project also supports the Global Health Security Agenda by focusing on efforts to accelerate progress toward a world safe and secure from infectious disease threats.

Project activities were designed to respond to countries’ needs and assist them in building their institutional and workforce capacity to effectively plan, implement, and evaluate activities to eradicate polio and strengthen routine immunization interventions. Accordingly, geographic targeting was initiated to prioritize the neediest populations in high-risk countries as well as countries that have specific weaknesses in their national systems but are not sufficiently addressed and do not receive adequate external support. The project activities covered a set of areas including surveillance of acute flaccid paralysis and other VPDs, family and community engagement, workforce capacity building, improvement in data quality, management and use of information systems, use of polio assets to control/eliminate other VPDs, supporting countries to develop national strategies, piloting of innovative initiatives, program evaluation and accountability, and immunization strengthening.

The project adopts the Global Polio Eradication Initiative strategies to assist countries to strengthen routine immunization services, maintain highly sensitive acute flaccid paralysis surveillance, and sustain polio eradication functions.

Project Planning and Management

GHD/EMPHNET recruited and hired qualified staff at the headquarter and country levels to work with targeted countries for establishing connections with stakeholders in these countries. All core project staff hired were trained on EMPHNET policies and procedures, project strategy, objectives, and work plan.

Building on GHD/EMPHNET’s human resources assets in the region, Field Epidemiology Training Program graduates and residents were involved in the project’s activities to ensure sustainability and efficient implementation of the activities. Information sharing was guaranteed to all concerned health workers through the network of health care professionals, and data were timely provided to field workers.

Subregional and country-specific work plans to strengthen polio eradication and routine immunization were developed for six countries in the Eastern Mediterranean region. The subregional and country-specific work plans were developed by more than 20 experts and representatives from ministries of health of Jordan, Yemen, Iraq, Egypt, Afghanistan, and Somalia and EMPHNET key partners—World Health Organization (WHO) and United Nations Children's Fund (UNICEF). The development of the subregional and country-specific work plans was preceded by providing countries with a set of reporting format, collecting a set of information-rich resources from the countries, analyzing the collected information and existing situation, and identifying the gaps and unmet needs in routine immunization services and polio eradication and the proposed solutions. In the years 2016 and 2017, three regional workshops were conducted and attended by a total 78 participants from different countries including Jordan, Yemen, Iraq, Egypt, Sudan, Lebanon, Morocco, Sudan, Tunisia, Afghanistan, Pakistan, and Somalia. The workshops aimed to strengthen polio eradication and routine immunization, build a pool of consultants, and analyze the training needs.

Conducting Research to Inform Vaccine Preventable Disease Eradication, Surveillance, and Routine Immunization Activities

A Cross-Sectional Serosurvey Among Children Aged <5 Years in Jordan

A serosurvey was conducted to assess population immunity in Jordan's high-risk areas following the Middle East Polio outbreak response. GHD/EMPHNET, in collaboration with the CDC and Jordan's Ministry of Health conducted a 5-day training for the data collectors, phlebotomists, and EPI managers to conduct the household serosurvey in 2016. The study sample included 479 children below 5 years of age from high-risk areas in the 12 governorates of Jordan and 277 children from Syrian refugee camps. The serosurvey provided data on immunization coverage in Jordan, determined the unimmunized pockets of children in high-risk areas, and estimated the population's immunity levels to polio and other VPDs viruses. The seroprevalence among children in high-risk areas and refugee camps was 98% and 100%, respectively, for the three types of polio virus (types 1, 2, and 3). In addition, all children in Jordan, regardless of nationality, received three doses of OPV and three doses of inactivated polio vaccine during the first 9 months of life. The demand for these vaccines in Jordan was reported to be high. Results also indicated the Jordan Ministry of Health's vigilance in locating and vaccinating high-risk populations has been successful in maintaining high levels of vaccination, which has, in turn, maintained high population immunity and averted polio outbreaks despite the influx of Syrian refugees. The study results primarily provided decision makers in Jordan with scientific evidence necessary to make informed decisions on effective interventions to prevent poliovirus outbreaks.

Vaccination Coverage Survey in Iraq

One of the unmet needs in routine immunization identified by Iraq Ministry of Health is the unavailability of reliable data for immunization coverage in Baghdad Resafa and the recurrent outbreaks of VPDs over the past 3 years. Iraq experienced two cases of polio in 2014 and a measles outbreak in 2015-2016 and was more severely affected by the mumps outbreak in 2016. GHD/EMPHNET closely worked with Iraq Ministry of Health officials to a conduct immunization coverage evaluation survey in Baghdad Resafa. The survey protocol and tools were revised and finalized by GHD/EMPHNET and the WHO based on the standard WHO guidelines. GHD/EMPHNET supported a two-day training for 20 teams of data collectors. The survey provided data on the immunization coverage among children aged 12-23 months and identified the causes of never or delayed vaccination. The survey served as a baseline to monitor vaccination coverage and provide reliable and accurate data needed to strengthen the routine vaccination strategies and plans.

Training Needs of Expanded Program on Immunization Staff

GHD, in collaboration with the CDC, conducted a training needs analysis to identify capacity building and the training needs of EPI staff in the five targeted countries: Morocco, Tunisia, Jordan, Egypt, and Sudan. The necessary tools were developed based on the Analysis, Design, Development, Implementation, and Evaluation Framework to help countries prioritize their training needs. GHD successfully conducted the training needs analysis workshop that was attended by 20 participants, 4 from each target country (Morocco, Tunisia, Jordan, Egypt, and Sudan). The participants included Directors, EPI Managers, EPI training and supervision officers, VPD surveillance officers, and EPI focal persons at the provincial/governorate level from each country. During the workshop, countries successfully presented their situation analysis and a summary of their country's training needs.

The Afghanistan Demand Creation Project

GHD/EMPHNET worked with the CDC on the activities of the Afghanistan Demand Creation Project (DCP). The DCP aimed to determine the effect of a three-pronged intervention on knowledge, attitudes, and practices toward routine immunization and polio, Supplementary Immunization Activities in Afghanistan, and determine the effect of the interventions on vaccine demand/uptake in Afghanistan. GHD/EMPHNET assisted in developing the training package for data collectors and supported the preintervention knowledge, attitudes, and practices survey and the development of interpersonal communication materials including materials for voice messages. In total, 1040 households from 20 districts (10 case districts and 10 control districts) were surveyed. The main findings of the baseline knowledge, attitudes, and practices survey were translated into local language and shared with field supervisors, which enabled them to address weaknesses in these areas during the community-based intervention. Following the completion of the preintervention baseline survey, GHD continued supporting and overseeing the community-based interventions in close collaboration with the Afghanistan field teams, Ministry of Public Health, and the CDC. GHD developed health communication training package material that was used to train Community Health Workers and community members on delivering effective and culturally appropriate immunization messages as well as developing voice messages. This was followed by successfully conducting the Communications Training of Trainers Workshop in 2017. A total of four DCP field supervisors in the eastern region and southern region and two national emergency operations center focal points were trained.

The DCP field supervisors conducted follow-up and field visits to the targeted districts. During these visits, supervisors collected feedback on the community intervention field activities, the mobile voice messages, and replacing the inactive phone numbers with the active phone numbers to ensure that voice messages reach the targeted audience. A total of 548 individuals were reached through the community meetings. The messages were broadcasted over 5 days per week over a month. The community-based intervention and broadcasting of mobile health messages were completed by the end of January 2018.

In total, 133 persons in Afghanistan were trained on data collection, analysis, and reporting (19 trained on advanced techniques in data management, analysis, and reporting; 98 trained on the EPI Management Information System database to improve the quality of EPI data; 6 trained on postintervention knowledge, attitudes, and practices survey; and 10 trained on data collection and using Epi Info 7 software).

Strengthening Routine Immunization and Building the Capacity of Expanded Program on Immunization Staff

Training Potential Consultants for Strengthening Routine Immunization

GHD/EMPHNET planned and successfully conducted a 6-day training workshop to build a pool of potential consultants for strengthening routine immunization at the regional level in 2016. The training workshop was attended by 37 participants selected from eight countries: six from Afghanistan, three from Egypt, five from Iraq, one from Jordan, one from Lebanon, five from Pakistan, eight from Sudan, and eight from Yemen. GHD/EMPHNET and representatives from the CDC, the WHO, UNICEF, the International Federation of Red Cross and Red Crescent Societies, and the Ministry of Health of Oman facilitated the workshop. A list of potential consultants was developed and added to the regional roster of potential consultants in the case of future deployment opportunities.

Building the Capacity of National/Subnational Expanded Program on Immunization Staff on the Implementation of Routine Immunization Activities

GHD worked closely with the CDC on implementing training strategy to improve the competencies of EPI staff to contribute to the improvement of EPI activities and achieving national program objectives. The following activities were conducted to build the capacity of staff in targeted countries:

- GHD/EMPHNET supported the Yemen Ministry of Health to conduct an EPI situation analysis and identify implementation strategies for high risk areas. Three 5-days workshops for 54 supervisors of the Routine Immunization and Supplementary Immunization Activity services in 18 districts with low immunization coverage were conducted.
- GHD/EMPHNET supported training workshops to refresh knowledge and skills of vaccinators/health workers in Yemen to provide high-quality immunization services (eighteen 3-day refresher trainings workshops for 329 vaccinators/health workers in districts with low routine coverage).
- Cascade training of frontline health workers from 175 districts in 18 governorates of Egypt were trained on routine immunization.
- Training 25 master trainers in Jordan and 25 master trainers in Iraq on microplanning for routine immunization.
- Eleven training workshops on microplanning for routine immunization and development of microplans for 236 EPI staff from 115 health centers in 10 high-risk provinces and districts in Jordan.
- GHD in cooperation with the Ministry of Health successfully conducted 58 cascade training workshops and trained 1188 participants from 10 provinces in Iraq for routine immunization microplanning.

Expanded Program on Immunization Communication Strategy and Implementation Plans

GHD supported Yemen and Iraq with the development of an EPI communication strategy and implementation plans. The identified strategic directions were as follows:

- Integrating Primary Health Care programs in health communication–related activities to improve EPI performance and meet the coverage challenges;
- Developing an integrated communication tools for all public health programs, which influence routine immunization/polio coverage;
- Communicating EPI health massages through education programs and curricula of schools and health institutes;
- Supporting studies and researches on communities' attitudes and behaviors toward immunization;
- Evaluating and supervising all EPI activities in relation to communications and practices;
- Capacity building of health staff, with emphasis on EPI employees, in health communication;
- Unifying the health messages in relation to EPI at all levels to avoid discrepancies and misperceptions;
- Developing national information management tools in relation to health communication with emphasis on EPI;
- Announcing a national alliance for health communication with emphasis on EPI; and
- Ensuring the continuation of health communication at all levels of the health system during emergencies in relation to EPI and redesigning the messages based on local needs.

In Iraq, GHD maintained collaboration and communication with the Iraq Ministry of Health and UNICEF to do all necessary preparation to support the implementation of the activities. A workshop was conducted on dissemination and development of provincial level plans of the EPI communication strategy. A total of 45 participants from the Ministry of Health directors of immunization and health promotion in 16 provinces, Health Information Officers, and representatives from UNICEF attended the workshop. In January 2018, a workshop to develop the strategic direction and EPI communication strategy was held and attended by 28 persons.

Supportive Supervision and Monitoring

GHD successfully trained a total of 43 managers/supervisors in Iraq and Yemen (23 Iraq Ministry of Health EPI managers/supervisors from 16 provinces, 20 EPI coordinators from 13 northern governorates, and central level EPI supervisors in Yemen) to form a team of supervisors/trainers to train district EPI focal point on supportive supervision, conduct in-service monitoring, and develop provincial and district Supervision & Monitoring (S&M) plans. In addition, GHD supported Yemen's Ministry of Public Health and Population in conducting a national meeting on EPI monitoring and supervision that was attended by 50 participants from central and governorate levels. In the meeting, participants discussed main strengths, weakness, threats, and opportunities in relation to supervision and monitoring. The following issues were highlighted in the national meeting:

- The supervisory activities play an important role to augment the provision of immunization services.
- With exceptional geographic challenges and limited human resources, periodic intensification of supervision is expected to pave the way for enhanced systematic vaccination outreach, which is now carried out six times per year.
- Intensification of routine immunization and polio activities needs to focus more on remote and difficult-to-access populations that are traditionally underserved by routine services.
- Working with stakeholders for more engagement and community participation is essential to improve the vaccination coverage and maintain Yemen as a polio-free country.
- Coordination in implementing immunization campaigns is a vital element of planning and resource mobilization for periodic intensification of routine immunization.
- Setting priorities, securing funding, and identifying additional partners for joint planning to achieve mutual benefits are all vital elements that require well-designed supervision and monitoring system.

The meeting was concluded with an implementation plan for improving supervision at the national level to be followed with a national training for EPI coordinators from all governorates of Yemen with the support of GHD.

In a workshop held in Iraq, 15 persons attended the workshop and presented EPI supervision results, drafted an improvement plan, developed policy paper and updated S&M tools to assist the Ministry of Health in strengthening routine immunization S&M. On the other hand, GHD successfully conducted three refresher trainings for Afghanistan Ministry of Public Health provincial-level supervisors on conducting supportive supervision and monitoring to strengthen routine immunization performance. The 3-day trainings were conducted for a total of 45 EPI staff from 7 provinces. The strengthening of routine immunization performance activities has continued. Supportive supervision field visits were conducted for 15 provinces by country team in addition to provision of support for provincial supervisors to conduct S&M visits for 345 health facilities within 11 priority provinces.

Appreciative Inquiry for Immunization Adaptation

GHD worked with the CDC to pilot an appreciative inquiry for immunization in Iraq to mobilize local communities and resources and build ownership among these communities with the aim of increasing vaccination coverage. The GHD team conducted a training workshop on appreciative inquiry for immunization adaptation for 30 health promotion EPI staff and other sectors in Baghdad to train and develop skills and abilities to facilitate national-, subnational-, and community-level appreciative inquiry workshops for full immunization and build local communities' capacities to promote and engage households in full immunization activities and gain their commitment toward ensuring vaccination of every child, followed by two workshops to implement appreciative inquiry initiative. A total of 100 participants (40 in the Al Hur district and 60 in the Al Mahweel district) from the community, the Ministry of Health, nongovernmental organizations, and the development sector attended the workshops. The workshops aimed at developing aspirational goals, strategies, and breakthrough plans for full immunization and strengthen the leadership capacity to effectively mobilize communities toward full immunization in the two selected districts. The district workshops ensured enrollment of the whole system and stakeholders in full immunization initiative in the district, developed clear understanding and know-how about full immunization program, developed overarching vision by community and stakeholders in line with the national vision and strategy, and identified and committed key actions to be taken in communities. Furthermore, they defined the role, responsibility, and function of stakeholders in full immunization initiative and developed collaborative environment between demand and supply side to act together to achieve full immunization. GHD will continue working with the CDC and coordinate with the Iraq Ministry of Health on finalizing the Monitoring and Evaluation plan along with implementing the initiative and its evaluation.

Strengthening Surveillance Systems

Training on Acute Flaccid Paralysis and Vaccine-Preventable Disease Surveillance

GHD, in collaboration with the countries' Ministries of Health, the CDC, and the WHO, supported the strengthening of the countries' surveillance system for acute flaccid paralysis, measles, and other VPDs through capacity building activities. These activities aimed to enhance early detection and response to polio virus, measles, and other VPDs, thus supporting in sustaining polio eradication and reducing risks of measles and other VPDs outbreaks. A total of 71 persons (37 from Morocco and 34 from Iraq) were trained to be master trainers on acute flaccid paralysis and VPDs surveillance. A total of 1076 persons

(311 from Iraq, 419 from Yemen, and 346 from Morocco) were trained on acute flaccid paralysis/VPD surveillance.

The training in Yemen aimed at introducing the community-based model in high-risk districts to improve the relationship between communities and the local health system through the technical and administrative link between the volunteers and health care providers and to enhance the reporting system and increase the sensitivity of the epidemiological surveillance, thus improving overall performance of acute flaccid paralysis surveillance. The training in Morocco aimed to address weaknesses, refresh knowledge, build capacity of the newly recruited officers at regional and provincial levels, train focal persons from major educational hospitals, and enhance the capacity of the Field Epidemiology Training Program graduates and residents to provide technical support, mentoring, coaching, and progress monitoring of acute flaccid paralysis surveillance activities against the regional acute flaccid paralysis operational plans and support improving key acute flaccid paralysis surveillance indicators, achieving and sustaining progress.

On the other hand, GHD developed a digital acute flaccid paralysis surveillance system including digital acute flaccid paralysis notification, investigation, and active surveillance forms in Morocco and installed it to the Ministry of Health server. The system was also further developed to generate reports and have a feature of sending email notifications directly to surveillance supervisors once cases are reported. GHD technical support will continue and the development of a mobile app of the system is planned once the system is ready and in use, and the mobile app design will be in synchronization with the system Web version.

Assisting Egypt’s Ministry of Health in Establishing a Congenital Rubella Syndrome Surveillance System

GHD worked with Egypt’s Ministry of Health and Population (MOHP) to establish and support running congenital rubella syndrome surveillance system in Egypt. The congenital rubella syndrome surveillance system will provide the MOHP with surveillance data to monitor the impact of the national rubella vaccination strategy as well as the progress toward rubella/congenital rubella syndrome elimination and take necessary measures to reach targets of rubella elimination. The program was officially launched in Cairo on October 17, 2017, in an official ceremonial event attended by the Deputy Minister, the Director General of Communicable Diseases Control, the EPI Manager, and GHD/EMPHNET senior management alongside the central EPI team and the representatives of the targeted provinces.

Supporting the Congenital Rubella Surveillance System in Afghanistan

As a joint activity with the CDC, GHD logistic support to the congenital rubella syndrome system was provided by contacting the congenital rubella syndrome project coordinator in Afghanistan who supported the implementation of study to determine the burden of congenital rubella syndrome in order to inform the initiation of routine immunization and prospective congenital rubella syndrome surveillance system in Afghanistan. GHD played a key role in facilitating communication, coordination, and progress follow-up of project activities with the Ministry of Health and the CDC through regular reporting. GHD provided a platform to further engage the Ministry of Health EPI staff in this activity. The congenital rubella syndrome coordinator was provided with capacity-building opportunity to support his work pertaining to cleaning datasets, rechecking/validating data for accuracy, and performing various analysis tasks on datasets. The project coordinator also attended the training workshop on Advanced Techniques in Data Management, Analysis, and Reporting conducted and facilitated by GHD in Afghanistan in June 2017.

Increasing the Number of Programs Focusing on Outbreak Response, Systems Strengthening, and Workforce Development

The Public Health Empowerment Program for Surveillance Polio Officers

As indicated by the Federal Ministry of Health of Sudan, Sudan has a shortage in trained human resources responsible for public health surveillance, and there is a need to empower the management and leadership skills for the workforce at the district levels. To bridge this gap, the Federal Ministry of Health planned to train health workers in 179 localities to build their capacity in areas of public health surveillance, leadership, management, and other public health skills to enable them to undertake additional tasks to support the health system. The Public Health Empowerment Program for Surveillance Polio Officers was accordingly developed to build the capacity of polio and EPI staff to equip themselves with competencies essential to public health surveillance and managerial skills. Thus, the program supported the implementation of polio transitional planning and assisted expansion of the technical capacity of polio program staff to fill gaps in manpower that are usually encountered at the district level for various public health services, without compromising their original roles and functions.

Moreover, GHD developed the curriculum for Yemen’s Public Health Empowerment Program to train governorate surveillance polio officers. GHD conducted an orientation workshop and a stakeholder’s workshop to build consensus on the Public Health Empowerment Program for Surveillance Polio Officers and enhance coordination among partners. The orientation meeting was attended by 39 officials including Directors of Health Offices, Local Council Representatives, and senior officials from the central level. The stakeholders’ workshop was attended by 24 officials and partners including the Minister of Health, Deputy Minister, General Director of Disease Control, other Ministry of Public Health and Population officials, and other partners such as the WHO and UNICEF. The workshop aimed at enhancing coordination among the development partners on the Public Health Empowerment Program for Surveillance Polio Officers in Yemen and to harmonize efforts with the Ministry of Public Health and Population, donors, and development partners for training at the governorate and district levels.

As a result of this program implementation, a total of 22 Public Health Empowerment Program for Surveillance Polio Officers mentors were trained in Yemen and 30 mentors were trained in Sudan. The program trained a total of 101 polio/EPI surveillance officers (83 in Sudan and 18 in Yemen), and it established a solid platform for capacity building at the subnational level, which is planned to target different key public health priorities.

Vaccination Services at Refugee-Populated and High-Risk Areas in Jordan

GHD has maintained support to the vaccination center in the Zaatari camp for Syrian refugees. The center provides measles vaccines; OPV and inactivated polio vaccine; Bacillus Calmette–Guérin vaccine; and measles, mumps, and rubella vaccine to children below 2 years of age. The GHD support to the center maintained its engagement in the Syrian crisis health response and improved immunization coverage in the camp.

Transition Polio Program Assets to Support Reaching Targets for Measles/Rubella Elimination in Egypt

GHD, in cooperation with the CDC, supported Egypt's MOHP in strengthening measles and other VPDs surveillance and response through utilization of domestic polio assets for low population immunity for measles in three frontier governorates—Matrouh, Red Sea, and Aswan—and also through provision of evidence-based data and methods of reaching high-risk populations for surveillance and routine immunization. Orientation and training activities were conducted for the central three governorates and five district-level EPI staff as well as for community-level informants. GHD and the MOHP conducted a 1-day orientation for the central 10 EPI epidemiologists in their role to train, supervise, and monitor activities in selected governorates. In total, 149 EPI staff were trained from the three governorates on how to utilize skills and assets from polio eradication to accelerate measles elimination.

Improving Routine Immunization Performance in Afghanistan

The continued technical support to the Ministry of Public Health throughout the project period included but was not limited to the collection and analysis of routine immunization coverage reports from provinces and the provision of feedback to the provincial and EPI teams in the eastern, northern, and southeastern regions. Furthermore, support was provided by conducting scientific analysis to inform action by different departments. Highlight of other support completed include training of the Monitoring and Evaluation department staff on the EPI Management Information System; maintenance and reinstallation of the database; participation in a comprehensive EPI performance review study; and data/information collection at national, provincial, and health facility levels. Also, GHD actively participated in the National Emergency Action Plan review meeting with the WHO, UNICEF, Gavi, the Vaccine Alliance, the CDC, and the Ministry of Public Health.

Conclusions

The performed projects efficiently contributed to enhancing the acute flaccid paralysis and national surveillance systems in the targeted countries based on the improved indicators. The progress made in the efficient utilization of local resources and strong community engagement toward universal health coverage reveals the importance of building on successful programs to enhance the health system, and polio legacy is an example of this progress. Additionally, addressing high-risk areas with immunization services benefited the targeted communities and vulnerable groups in accessing the basic service package with improved health indicators in the areas of interventions.

In this regard, GHD maintained a successful collaboration with different stakeholders, mainly the CDC, and worked closely to plan, develop, and implement the activities of these projects. To accomplish the tasks associated with the activities, GHD and the CDC identified country-focal persons and introductions were made to further enhance collaboration and coordination. The team members within GHD and the CDC engaged in frequent conference calls and exchanged email communications to organize and coordinate meetings and joint country visits for technical support and training workshops in terms of the production of technical materials and activity plans. The CDC support visits to GHD also allowed face-to-face discussions on project activities, implementation, and long-term plans. Through this cooperation, the CDC project team was always receptive to each country's perspectives in all discussions and provided support to ensure smooth implementation of activities. GHD also maintained and continued close coordination with ministries of health in Afghanistan, Egypt, Iraq, Jordan, Morocco, Somalia, Sudan, and Yemen. Furthermore, GHD involved key partners in joint meetings and continued coordination efforts to harmonize activities throughout the project implementation with UNICEF and the WHO.

Conflicts of Interest

None declared.

References

1. World Health Organization. Poliomyelitis. URL: https://www.who.int/topics/poliomyelitis/en/ [accessed 2019-10-09]
2. World Health Organization. Immunization, Vaccines and Biologicals. Global Vaccine Action Plan 2011-2020 URL: https://www.who.int/immunization/global_vaccine_action_plan/GVAP_doc_2011_2020/en/ [accessed 2019-10-09]
3. Gayer M, Legros D, Formenty P, Connolly MA. Conflict and emerging infectious diseases. Emerg Infect Dis 2007 Nov;13(11):1625-1631 [FREE Full text] [doi: 10.3201/eid1311.061093] [Medline: 18217543]
4. Abbara A, Blanchet K, Sahloul Z, Fouad F, Coutts A, Maziak W. The effect of the conflict on Syria's health system and human resources for health. World Health & Population 2015;16(1):87-95. [doi: 10.12927/whp.2015.24318]

5. Ben Taleb Z, Bahelah R, Fouad FM, Coutts A, Wilcox M, Maziak W. Syria: health in a country undergoing tragic transition. Int J Public Health 2015 Jan;60 Suppl 1:S63-S72. [doi: 10.1007/s00038-014-0586-2] [Medline: 25023995]
6. World Health Organization & UNICEF. 2009. Microplanning for immunization service delivery using the reaching every district (RED) strategy URL: https://www.who.int/immunization/sage/9_Final_RED_280909.pdf [accessed 2019-10-09]
7. Gammino VM, Nuhu A, Chenoweth P, Manneh F, Young RR, Sugerman DE, et al. Using geographic information systems to track polio vaccination team performance: pilot project report. J Infect Dis 2014 Nov 01;210 Suppl 1:S98-101. [doi: 10.1093/infdis/jit285] [Medline: 25316882]
8. Mbaeyi C, Kamawal NS, Porter KA, Azizi AK, Sadaat I, Hadler S, et al. Routine Immunization Service Delivery Through the Basic Package of Health Services Program in Afghanistan: Gaps, Challenges, and Opportunities. J Infect Dis 2017 Dec 01;216(suppl_1):S273-S279. [doi: 10.1093/infdis/jiw549] [Medline: 28838158]

Abbreviations

CDC: Centers for Disease Control and Prevention
DCP: Demand Creation Project
DTP3: Diphtheria, Tetanus, and Pertussis
EMPHNET: Eastern Mediterranean Public Health Network
EPI: Expanded Program on Immunization
GHD: Global Health Development
MOHP: Ministry of Health and Population
OPV3: oral polio vaccine (third dose)
S&M: Supervision & Monitoring
UNICEF: United Nations Children’s Fund
VPD: vaccine-preventable disease
WHO: World Health Organization

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Original Paper

An Electronic Disease Early Warning System in Sana’a Governorate, Yemen: Evaluation Study

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Abstract

Background: Electronic Disease Early Warning System (eDEWS) is one of the effective programs in epidemiological surveillance.

Objective: This study aimed to identify the strengths and weaknesses of eDEWS in Sana’a governorate, determine its usefulness, and assess its performance in terms of the system attributes, including simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability.

Methods: Updated guidelines on the evaluation of public health surveillance from the Center for Disease Control and Prevention (CDC) were used to evaluate the eDEWS in Sana’a governorate. Stakeholders from different levels were interviewed about the performance of the eDEWS.

Results: The overall score for the usefulness of the eDEWS was good (mean=83%). The overall system performance was good (86%). The highest attribute score was 100% for representativeness and the lowest score was 70% for stability. The system simplicity and acceptability were good. Although the system representativeness and flexibility were excellent, the stability was average. System completeness and timeliness were 100%.

Conclusions: In conclusion, eDEWS in Yemen is useful and met its main objective. The overall level of system performance was good.

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KEYWORDS

evaluation; eDEWS; field epidemiology; Yemen

Introduction

Background

Communicable diseases remain the most common cause of death, disability, and illness in many developing countries [1]. The most critical step to prevent and control epidemics effectively is the timely detection of outbreaks, which depends on effective disease surveillance systems.

Electronic Diseases Early Warning System (eDEWS) is an electronic system for data collection, compilation, and analysis from the health facilities to detect outbreaks at an early stage and take necessary response measures to prevent or limit disease occurrence. This can minimize the morbidity and mortality owing to communicable diseases through the detection of potential outbreaks at their earliest possible stage and facilitate timely interventions [2,3]. eDEWS is based on a mobile app. It enables health workers to report in real time about public health threats such as acute watery diarrhea, polio (Acute Flaccid Paralysis), measles, meningitis, and viral hemorrhagic fevers, including Ebola. Through eDEWS, data are collected using software installed on mobile phone, tablets, or laptops and immediately sent to a central level for analysis and rapid response. With faster reporting, increase in the number of patients with diseases of public health concern can be spotted more quickly, enabling prompt follow-up action [4].

Surveillance systems in most of the Eastern Mediterranean countries are traditional and still depend on manual recording, which causes delay in reporting and also missing data. In response to the need for strengthening the existing surveillance systems and improving the speed and efficiency of data collection, analysis, and public health response, World Health Organization (WHO) in collaboration with the Ministries of Health decided to implement the eDEWS in several countries [3,5].

eDEWS was launched in Yemen in March 2013, at 4 governorates, Aden, Lahij, Abyan, and Taiz, in 100 health facilities for 16 priority infectious diseases [5-7].

The various surveillance activities are integrated into 1 system within the broader national health information to enhance the speed and efficiency of data collection, analysis, and public health response [3].

Since the beginning of the War in March 2015, limited access to health care services and a breakdown in safe water supply and sanitation services has triggered the spread of endemic diseases such as malaria and dengue fever, as well as acute diarrheal diseases.

In response to the need for electronic expansion of the existing public health surveillance system and improving the speed and efficiency of data collection, analysis, and public health response, WHO in collaboration with the Ministry of Public Health and Population has scaled up the system in all Yemen's governorates, with sentinel sites expanded from 408 health facilities in 16 governorates to 1186 facilities in 23 governorates after the third expansion at the end of 2016 [3,8].

Objective

This study is the first evaluation study conducted in Sana'a governorate to identify the strengths and weaknesses of eDEWS, determine its usefulness, and assess its performance in terms of the system attributes, including simplicity, flexibility, data quality, acceptability, representativeness, timeliness, and stability.

Methods

Study Design

The CDC's updated guidelines [9] on the evaluation of public health surveillance were used to evaluate the eDEWS in Sana'a governorate during November to December 2016. Sana'a governorate was covered by eDEWS in 2015. Its population was 918,379 inhabitants, living in 16 districts. The health facilities were at 25 sites in 2015, and with expansion at the end of 2016, health facilities reached 149 sites. Only the first 25 sites were subjected to the evaluation as the expansion happened few months before this evaluation took place.

Evaluation Approach

To conduct the evaluation, stakeholders from different levels (WHO and Ministry of Public Health & Population (MoPHP), eDEWS central, governorate, and health facility levels) were included. Stakeholders at the central level (national coordinator of eDEWS and staff, including data management officer, data follow-up officer, and the Information Technology (IT) officer), governorate level (coordinator), and health facility level (focal points) in 16 districts were included.

Data Collection

A total of 4 questionnaires were designed and used to collect data from participants at the 4 levels of eDEWS using face-to-face interview. Each questionnaire comprised items assessing the performance attributes of the system according to the activity of eDEWS at the 4 levels. The assessment of usefulness was limited to governorate, central, and high levels, whereas the assessments of timeliness and completeness were limited only to the central level. Usefulness was assessed by 8 items using 5-point Likert scale (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, and 5=strongly agree) for governorate, central, and high levels. Qualitative and quantitative system attributes were assessed. The qualitative attributes included simplicity, flexibility, acceptability, representativeness, and stability. The quantitative attributes included data quality and timeliness. Weekly reports of eDEWS and available documents of the system were reviewed for completeness and timeliness and to describe the eDEWS surveillance system.

Data Analysis

The mean percentage scores for usefulness and other performance attributes were calculated by dividing the sum of the items measuring each performance attribute by the maximum score. The scores were interpreted as excellent (>90%), good (80%-90%), average (60%-79.9%), poor (40%-59.9%), and very poor (<40%). The overall attribute score was calculated by summing all items over all attributes and dividing it by the maximum score. During the analysis, the attitude was considered as positive, if the responses were strongly agree or *agree*, whereas the attitude was considered as negative, if the responses were strongly disagree or disagree.

Ethical Issues

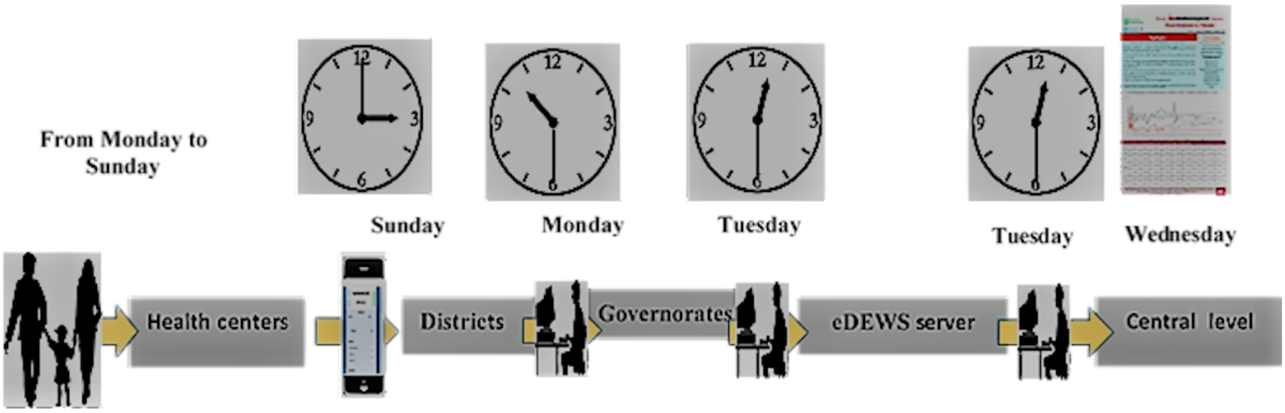
Institution approval for using the program data was obtained from the eDEWS program before beginning the evaluation. Confidentiality of the gathered information was assured by anonymity and using passwords on the computer. Participation was absolutely voluntary.

Results

Description of the Electronic Diseases Early Warning System's Surveillance System

The eDEWS is a program in the Diseases Control and Surveillance Directorate. Figure 1 shows the mechanism of the report flow and feedback. eDEWS has 2 main components: (1) immediate alert component for diseases which should be reported within 24 hours after detection such as AFP/polio, cholera, and hemorrhagic fever and (2) weekly reporting component. Weekly data aggregated by the health facilities are reported through the hierarchy of administrative levels (eg, health facility sites, governorates, and central level). At the central level, the system is operated by eDEWS national coordinator, data management officer, IT officer, and data follow-up officer. The program has a governorate coordinator in each governorate and focal point in each health site.

Figure 1. The flow of reports and feedback for the electronic disease early warning system (eDEWS) in Sana'a governorate, Yemen.



Usefulness

At the governorate level, the governorate coordinator was asked to appraise the usefulness of eDEWS based on 6 items. The mean percentage was 93% for usefulness. He scored 5 for 5 items and 3 for 1 item. He strongly agreed that the main aim of eDEWS is to detect diseases and outbreaks at an early stage and that data are used to monitor the trends of disease, to estimate the morbidity and mortality for diseases, and to detect outbreaks for rapid action to be taken. However, receiving epidemiological bulletin on time was scored as neutral.

At the high and central levels, the overall score of usefulness was good (mean percentage=83%). All 6 participants strongly agreed that the main aim of eDEWS is the early detection of diseases and outbreaks and all agreed that the data of the system are used to detect morbidity and mortality. All except 1 participant (83.3%) agreed that the data of the system are used to show trends of communicable diseases. In addition, 4 out of 6 (67%) respondents strongly agreed and 2 (33%) agreed that the data are used to facilitate rapid action to be taken.

The governorate coordinator was asked to appraise the simplicity of eDEWS according to 13 items. A total of 8 items were scored 5, 1 item was scored 4, 2 items were scored 3, and 1 item was scored 2. The mean percentage of simplicity was 83%, on which the governorate coordinator strongly agreed that the data entry in the electronic system is easy and clear. In addition, he strongly agreed that the notification process and transferring of data to the central level are easy. The coordinator agreed that the data follow-up is necessary, and analysis of data is conducted with respect to person, place, and time. He also reported that he receives a feedback from the central level. However, he reported that the phone and internet are not always available at his site and training courses are not performed frequently.

Performance by Attributes

Simplicity

The responses of 25 focal points on the simplicity items are shown in Table 1. The simplicity items (15 items) were scored positively by 25 focal points. The overall score of simplicity was good (82%).

Acceptability

Table 2 shows the responses of the focal points for each acceptability item (4 items). The overall score of acceptability was 81%, indicating good acceptability.

At the governorate level, the coordinator was asked to appraise the acceptability according to 3 items in which he scored 2 items as 5 and scored 1 item as 3. He strongly agreed that he was willing to support the system and was completely satisfied with eDEWS. However, he was neutral with the program being responsive to his suggestions. The mean percentage of acceptability was 87%.

Table 1. The responses of 25 focal points on the items measuring the simplicity of the electronic disease early warning system in Sana'a governorate, Yemen (N=25).

Items	Agree/strongly agree, n (%)	Neutral, n (%)	Disagree/strongly disagree, n (%)
Case definitions for diseases in eDEWS[a] are available	22 (88)	1 (4)	2 (8)
Case definitions for diseases in eDEWS are easy to apply	22 (88)	2 (8)	1 (4)
Laboratory tests for each disease are always available in your facility	1 (4)	4 (16)	20 (80)
The reporting form is clear to fill	23 (92)	1 (4)	1 (4)
The reporting form is easy to fill	22 (88)	0 (0)	3 (12)
Data entry in the electronic system or phone is clear	22 (88)	2 (8)	1 (4)
Data entry in the electronic system or phone is easy	22 (88)	2 (8)	1 (4)
Notification process is very easy	16 (64)	7 (28)	2 (8)
Phone and internet are always available in your facility	15 (60)	7 (28)	3 (12)
Transferring data to high level is very easy	16 (64)	7 (28)	2 (8)
Data follow-up is necessary to update data on the cases	23 (92)	0 (0)	2 (8)
Involving you in training for eDEWS surveillance	19 (76)	4 (16)	2 (8)
Training courses are performed frequently	20 (80)	4 (16)	1 (4)
The program provided you with phone to facilitate entering and sending of data	22 (88)	3 (12)	0 (0)
Donors provide you with a monthly account to facilitate entering and sending of data	20 (80)	5 (20)	0 (0)

[a] eDEWS: electronic disease early warning system.

Table 2. The responses of 25 focal points on the items measuring the acceptability of the electronic disease early warning system in Sana'a governorate, Yemen (N=25).

Items	Agree/strongly agree, n (%)	Neutral, n (%)	Disagree/strongly disagree, n (%)
You are willing to participate in eDEWS[a] surveillance	24 (96)	1 (4)	0 (0)
You are completely satisfied with eDEWS as a surveillance system	24 (96)	1 (4)	0 (0)
Responsiveness of the system to your suggestions	20 (80)	4 (16)	1 (4)
You receive a feedback report from a governorate level	9 (36)	8 (32)	8 (32)

[a] eDEWS: electronic disease early warning system.

Representativeness

At the governorate level, the governorate coordinator was asked to appraise the representativeness of eDEWS based on 2 items; he scored both the items as 5. The mean percentage of representativeness was 100%, in which the participant strongly agreed that the system covered the public and private centers and hospitals (private sites include private hospitals and clinics which have a focal point in each site).

The mean percentage of representativeness in high and central levels was 100%, in which all stakeholders strongly agreed that the system covered the public and private centers and hospitals.

Stability

With regard to the stability of eDEWS, the governorate coordinator scored 9 items as follows: 5 for 1 item, 4 for 5 items, 3 for 1 item, and 2 for 2 items. The mean percentage for stability was 71%. The coordinator strongly agreed that there was stable staff, the system was operating in full time, data processing and release were done on a weekly basis, and the electrical power cut rarely occurred because of their own source. He disagreed that the unscheduled outages rarely occurred and that the system would be stable even if the sponsors withdrew their support.

The mean percentage of stability as scored by 6 persons at high and central levels was 69%. All stakeholders agreed that the electrical power cut rarely occurred because of their own source, the staff received monthly incentives to facilitate tasks related to the system, and trained staff were available. A total of 5 out of 6 respondents (83%) were neutral on the unscheduled outage that rarely occurred during the last month. Half of the respondents (50%) disagreed that the system would be stable even if sponsors withdrew their support. All disagreed that there were planned resources for the maintenance of the system.

Flexibility

The mean percentage of flexibility reached 91%, in which the 6 stakeholders at high and central levels strongly agreed that the system could accommodate additional information to case definition, could be adapted to integrate with other surveillance programs, and could accommodate new health-related events. A total of 5 out of 6 respondents (83%) agreed that the staff could accommodate changes in data with minimum cost and efforts.

Completeness

We checked the completeness of reporting by reviewing the dataset. The reporting rate and completeness during the last 2 months were 100%.

Timeliness

According to the responses of the central level, the timeliness of the system was achieved 100%, which was measured as the number of reports that enter the system on time during Sunday evening to Wednesday.

Summary of the System Performance and Strengths and Weaknesses

The overall system performance was good (86%). The highest attribute score was 100% for representativeness and the lowest score was 70% for stability (Table 3).

Table 3. The overall performance of the electronic disease early warning system in Sana’a governorate, Yemen.

Attributes	Health facilities level, %	Governorate level, %	High and central levels, %	Overall percentage, %
Simplicity	82	83	N/A[a]	83
Representativeness	N/A	100	100	100
Acceptability	81	87	N/A	84
Flexibility	N/A	N/A	91	91
Stability	N/A	71	69	70
Overall percentage	82	86	87	86

[a] Not applicable.

All stakeholders at high and central levels were given a chance to express their opinions concerning the strengths and weaknesses of the system. All stakeholders reported that the main strength was the rapid detection and response to diseases and outbreaks. Half of them reported that the data had high accuracy owing to validation that passed through 4 levels and 50% reported that the processing and analysis of data automatically was one of the strengths. On the other hand, all stakeholders in high and central levels said that the main weakness was the network weakness in some remote areas aggravated by war. The director of the system at the central level said that “there is no operational cost for maintenance the electronic instruments and mobiles.”

Discussion

Our finding revealed that eDEWS is a useful system. This finding is in agreement with the findings of similar evaluations conducted in Sudan [10], Nigeria [11], and Pakistan [12]. However, this finding is not consistent with the eDEWS evaluation that had been conducted in Sana’a city governorate (the capital of Yemen) in 2014, in which the level of usefulness of the system in Sana’a city governorate was poor (54%) [13].

On the basis of the findings of this study, simplicity of the system is good. This finding is in agreement with the findings from previous evaluations in Sana’a city [13] and Madagascar [14].

This study showed that the system had a good acceptability. Similar findings were reported in previous eDEWS evaluations in Sana’a city [13] and in Sudan [10]. The positive appraisal of the system acceptability might be owing to the responsiveness of the program to suggestions and comments of related participants or might be owing to financial support.

The flexibility of the system was found to be excellent. One of the main items of flexibility on which all participants responded positively was the integration of eDEWS with other surveillance programs. Similarly, eDEWS evaluation in Sana’a city [13] and in the Pacific Island countries and territories [15] reported excellent flexibility.

According to the opinions of stakeholders, our evaluation revealed that the stability of the system is average. Poor eDEWS stability was reported in previous evaluation reports in Sana’a city and Madagascar [14]. The low stability found in our study might be explained by that the system relies on the supporting donors completely.

In our evaluation, the completeness was 100% and the reporting rate was 100% in the last 2 months. This finding is in agreement with the finding of a previous eDEWS evaluation in Sana’a city, which revealed that the completeness was 100% [13].

Timeliness in our evaluation received a score of 100%. With regard to timeliness, our finding is nearly in agreement with Sana’a city’s evaluation findings which revealed that the timeliness of the system was 92% in 2014. A study in Madagascar [14] revealed that the timeliness of the system was 68% in 2011.

This evaluation did not include the actual quantitative analysis for some attributes such as positive predictive value and sensitivity. With regard to data quality, accuracy was not assessed owing to the obstacles of comparing the hard reporting forms data with the soft reporting forms data.

In conclusion, our study indicated that eDEWS is a useful system and the overall performance according to the studied attributes was good. As our evaluation was limited to health facilities before the expansion, further evaluation after the expansion is recommended for generalizing the findings on all sites. It is recommended that sending feedback to health facilities focal points should be done in a regular and timely basis (weekly). As the program is completely supported by donors, strengthening the stability of the system by ensuring governmental support is recommended.

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Conflicts of Interest

None declared.

References

1. Gupta I, Guin P. Communicable diseases in the South-East Asia Region of the World Health Organization: towards a more effective response. Bull World Health Organ 2010 Mar;88(3):199-205. [doi: 10.2471/BLT.09.065540] [Medline: 20428387]
2. Alyusfi R, Khanbari L, Nasser A, Obadi M. Mostafa O, Alharazi E. Annual eDEWS Report and Disease Situation in 16 Governorates, MoPHP,Yemen 2015.
3. The ROY. MoPHP. WHO. eDEWS 2016.
4. World Health Organization | Regional Office for Africa. 2017. Liberia Introduces Electronic Reporting to Detect Disease Outbreaks Early. URL: https://www.afro.who.int/news/liberia-introduces-electronic-reporting-detect-disease-outbreaks-early [accessed 2019-10-08]
5. World Health Organization EMRO. 2013. Health Emergency Response Annual Report 2013. URL: http://www.emro.who.int/yem/yemeninfocus/health-emergency-response-annual-report-2013.html [accessed 2019-10-08]
6. Alyusfi R. eDEWS. eDEWS introductory presentation for Y-FETP 2015.
7. Mayad M, Alyousefi R, Assabri A. Descriptive analysis of dengue fever and malaria vector- borne disease at eDEWS in 2015-2016. Descriptive analysis of dengue fever and malaria vector- borne disease at eDEWS in 2015-2016 2016:29.
8. World Health Organization EMRO. 2018. WHO Scales Up Electronic Disease Early Warning System in Yemen. URL: http://www.emro.who.int/yem/yemen-news/edews-scaleup.html [accessed 2019-10-08]
9. German RR, Lee LM, Horan JM, Milstein RL, Pertowski CA, Waller MN, Guidelines Working Group Centers for Disease Control and Prevention (CDC). Updated guidelines for evaluating public health surveillance systems: recommendations from the Guidelines Working Group. MMWR Recomm Rep 2001 Jul 27;50(RR-13):1-35; quiz CE1. [Medline: 18634202]
10. Dlane F, Morof, ALaa A, Mireann B. An Evaluation of an Early Warning Alert and Response Network (EWARN) in Darfur, Sudan. Med J Cairo Univ 2013;81:209-217.
11. Isere EE, Fatiregun AA, Ajayi IO. An overview of disease surveillance and notification system in Nigeria and the roles of clinicians in disease outbreak prevention and control. Niger Med J 2015;56(3):161-168 [FREE Full text] [doi: 10.4103/0300-1652.160347] [Medline: 26229222]
12. World Health Organization. 2011. Evaluation of the Disease Early Warning System in Crisis Affected Areas of Pakistan. URL: https://www.who.int/hac/crises/pak/pakistan_dews_evaluation_report_mar2011.pdf [accessed 2019-10-08]
13. Alfalahi EN, Dureab F, Alyousefi R, Alsamee A, Qayad M, Al SAW. Evaluation of the Electronic Diseases Early Warning System-Yemen. Abstract text 2014.
14. Rajatonirina S, Rakotomanana F, Randrianasolo L, Razanajatovo NH, Andriamandimby SF, Ravolomanana L, et al. Early-warning health and process indicators for sentinel surveillance in Madagascar 2007-2011. Online J Public Health Inform 2014;6(3):e197 [FREE Full text] [doi: 10.5210/ojphi.v6i3.5400] [Medline: 25598869]
15. Paterson JB, Durrheim DN. Surveillance system evaluations provide evidence to improve public health practice. Online J Public Health Inform 2015;7(1). [doi: 10.5210/ojphi.v7i1.5959]

Abbreviations

AFP: Acute Flaccid Paralysis
CDC: Center for Disease Control and Prevention
eDEWS: Electronic Diseases Early Warning System
IT: Information Technology
WHO: World Health Organization

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Original Paper

The Acute Flaccid Paralysis (AFP) Surveillance System in Yemen, 2010-2015: Descriptive Study Based on Secondary Data Analysis

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Abstract

Background: Acute flaccid paralysis (AFP) surveillance is an essential strategy for poliovirus eradication.

Objective: This study aimed to evaluate the performance of the AFP surveillance system in Yemen from 2010 to 2015, identify components that require strengthening, and compare the indicators by year and governorates.

Methods: This descriptive study was based on secondary analysis of AFP surveillance data reported during 2010-2015 from all Yemeni governorates. The World Health Organization (WHO) minimum performance standards were used to evaluate the performance of the AFP surveillance system.

Results: A total of 3019 AFP cases were reported between January 2010 and December 2015. At the national level, AFP surveillance achieved WHO targets throughout the evaluating period for the nonpolio AFP rate of cases per 100,000 members of the population younger than 15 years of age, proportion of AFP cases reported within 7 days, proportion of AFP cases investigated within 48 hours of notification, proportion of AFP cases with two adequate stool specimens, and proportion of stool specimens from which nonpolio enterovirus was isolated. However, the proportion of specimens that arrived at the central level within 3 days of the first sample collection and the proportion of stool specimens with results sent from the reference laboratory within 28 days of receipt did not reach targets in 2011 and 2015, respectively.

Conclusions: The AFP surveillance system in Yemen has met most of the WHO indicator levels. Nevertheless, the evaluation showed areas of weakness regarding the arrival of specimens at the central level within 3 days of the first sample collection and delays in processing of the results and submitting feedback by the laboratory. Therefore, there is a need to strengthen the follow-up of specimens submitted to the laboratory.

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KEYWORDS

evaluation; acute; flaccid; paralysis; surveillance; Yemen

Introduction

Background

Poliomyelitis is a highly infectious disease caused by an enterovirus that is transmitted through the fecal-oral route or, less frequently, by a common vehicle. It affects the nervous system and can cause total paralysis in a matter of hours [1]. Paralytic polio occurs in less than 1% of children infected with poliovirus. The paralysis can cause weakness of the limbs, usually in the legs, and while some patients subsequently recover, around two-thirds suffer permanent paralysis [2]. Among those paralyzed, 5%-10% die when their breathing muscles become immobilized [1]. Polio mainly affects children under 5 years of age. Polio cases have decreased by over 99% since 1988, from an estimated 350,000 cases in more than 125 endemic countries to 74 reported cases in 2015. Recently, polio has become endemic in three countries: Afghanistan, Pakistan, and Nigeria [1,3]. There are three types of polio virus: type 1, type 2, and type 3. Cases of type 3 dropped to the lowest level, where the last case was reported in November 2012 in Nigeria [1].

Acute flaccid paralysis (AFP) is a clinical syndrome characterized by rapid onset of weakness, including weakness of respiratory function and swallowing, progressing to maximum severity within several days to weeks. This weakness is considered flaccid (ie, no spasticity) because the lesion affects the lower motor neuron, decreasing muscle tone and diminishing tendon reflex [4,5]. Because poliomyelitis causes AFP, highly sensitive surveillance for AFP with immediate case investigation and specimen collection are critical for the detection of wild poliovirus circulation, with the ultimate objective of polio eradication. AFP surveillance is also critical for polio-free certification [4,6,7].

Acute Flaccid Paralysis Surveillance in Yemen

Yemen is located in the Middle East on the southern tip of the Arabian Peninsula, bordered on the west side by the Red Sea, on the north side by Saudi Arabia, on the south side by the Arabian Sea, and on the northeast side by Oman. The area is 527,970 km^2 in size. In 2016, the total population of Yemen was about 26 million and the population of children less than 15 years of age was estimated to be 13.3 million. Yemen is divided into 22 governorates and 333 districts. The AFP surveillance system covers all 22 governorates, 333 districts, and about 1857 reporting sites, including the main hospitals and health centers in the country.

The AFP surveillance system was launched in Yemen in 1998 as part of the polio eradication initiative announced by the World Health Organization (WHO) in 1988. The last poliovirus outbreak in Yemen was in February 2005, when 479 cases of wild polio were reported during that outbreak; the last case reported was in February 2006. Yemen had three different outbreaks of circulating vaccine-derived polio viruses (VDPV) since April 2011: one type 2 VDPV and two separate emergencies of type 3 VDPV outbreaks [8].

Evaluation Rationale

Regular analysis of data generated from an AFP surveillance system is important in evaluating and improving the performance of the system. This ensures optimal performance of the system and guarantees timely detection of wild poliovirus reimportation. The WHO has developed a set of performance indicators in order to ensure that AFP surveillance is adequately conducted to accurately guide the polio eradication initiative [4,6,7]. To our knowledge, the AFP surveillance system has not yet been evaluated at the central level; it was evaluated only in the Ibb and Hadhramout governorates [9,10]. This study aimed to evaluate the performance of the AFP surveillance system in Yemen from 2010 to 2015, identify components that require strengthening, and compare the indicators by year and governorates.

Methods

This descriptive study was based on secondary data of AFP surveillance from all Yemeni districts and governorates over 6 years: 2010-2015. WHO standard indicators were used as reference to evaluate the performance of the AFP surveillance system [4].

The following seven WHO standard indicators were used:

1. Annualized nonpolio AFP rate: ≥2 AFP cases/100,000 members of the population under 15 years of age.
2. Adequacy of stool specimens: proportion (≥80%) of AFP cases with two adequate stool specimens.
3. Timeliness of case notification: proportion (≥80%) of AFP cases reported within 7 days.
4. Timeliness of case investigation: proportion (≥80%) of AFP cases investigated within 48 hours of notification.
5. Timeliness of specimen's arrival at the central level: proportion (≥80%) of specimens that arrived at the central level less than 3 days from first sample collection.
6. Nonpolio enterovirus isolation rate: proportion (≥10%) of stool specimens from which nonpolio enterovirus was isolated.
7. Timeliness of specimen processing in the laboratory: proportion (≥80%) of stool specimens with results sent from Naval Medical Research Unit Three (NAMRU-3) less than 28 days after receipt.

Data were analyzed using Microsoft Excel software. Descriptive analyses were conducted to describe the epidemiology of AFP in Yemen and to generate statistics based on the standard WHO-specified performance indicators for AFP surveillance.

Results

Distribution of Acute Flaccid Paralysis Cases

A total of 3019 AFP cases were reported between January 2010 and December 2015. Most cases were from Alhudaidah (363/3019, 12.02%) and Ibb (274/3019, 9.08%), while Almahara had the lowest number of cases (29/3019, 0.96%). Figure 1 shows the distribution of AFP cases by governorate in Yemen from 2010 to 2015. A total of 20.34% of cases (614/3019) were reported in 2013 and 12.79% (386/3019) were reported in 2011 (see Figure 2).

Figure 1. Distribution of acute flaccid paralysis (AFP) cases by governorate in Yemen from 2010 to 2015.

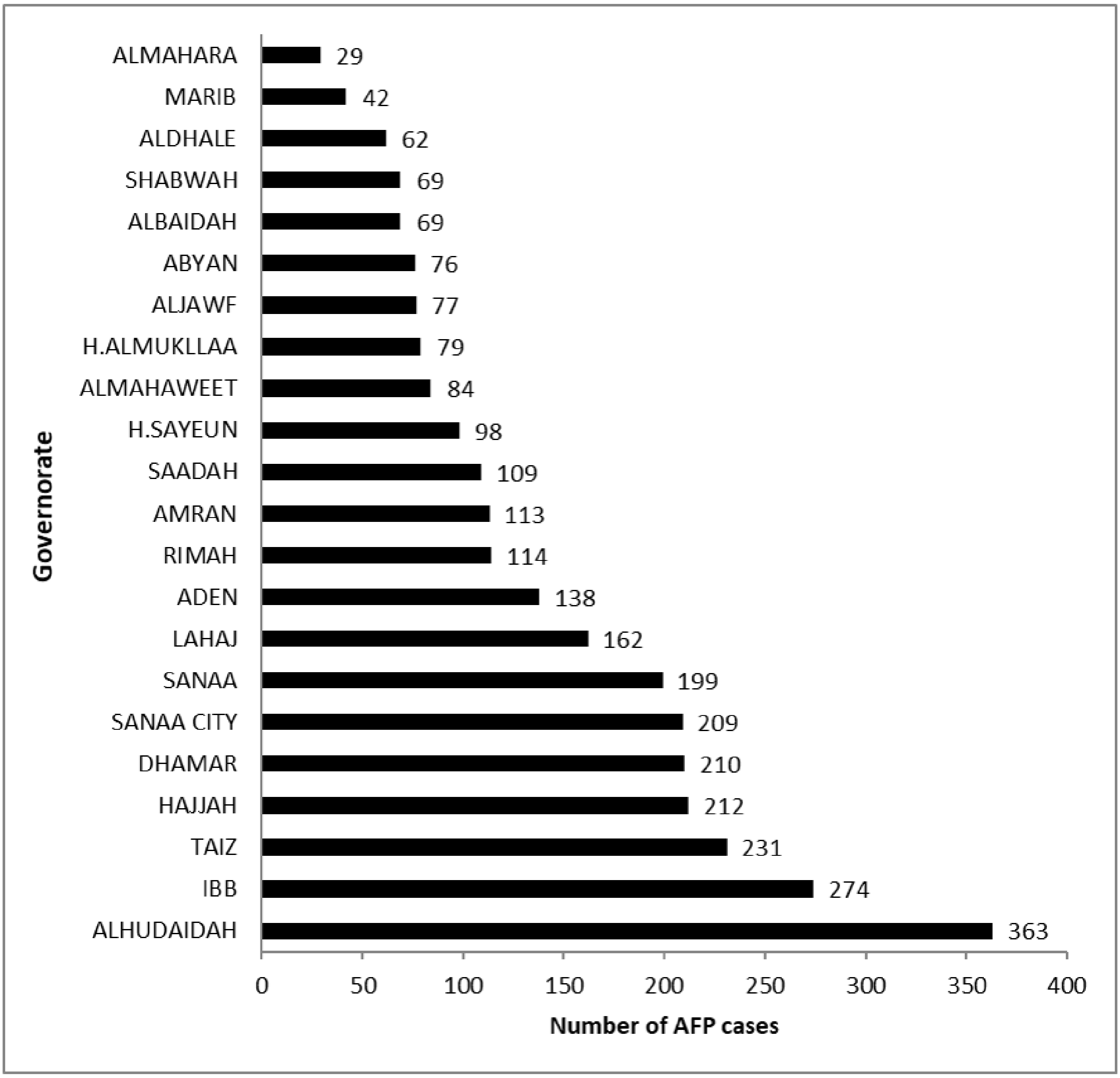
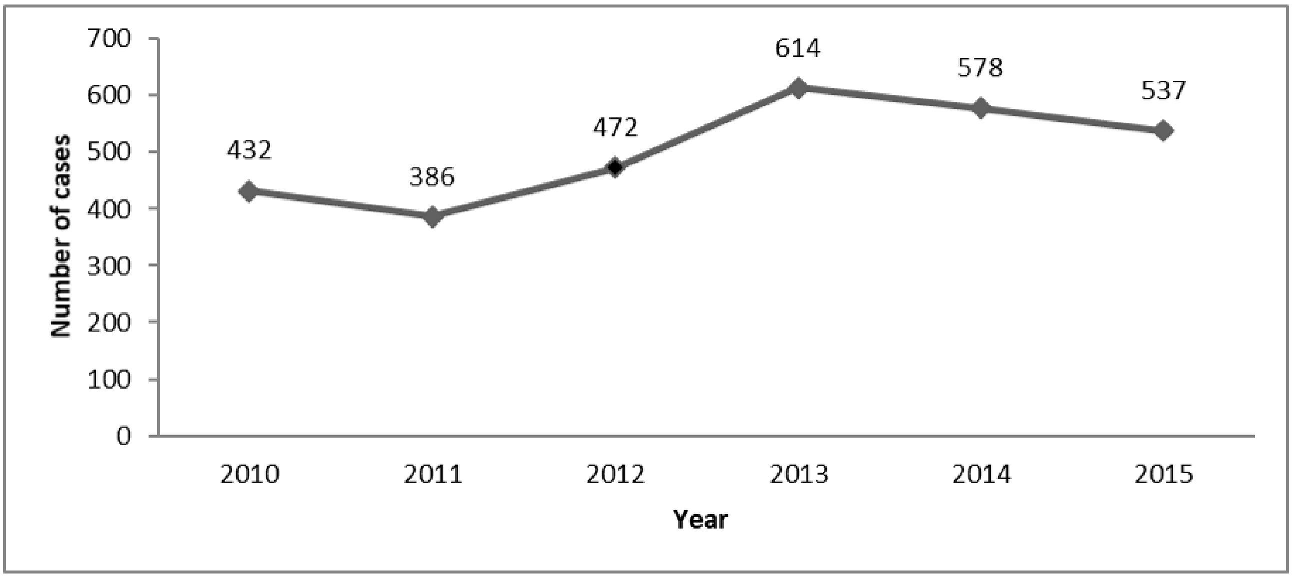


Figure 2. Distribution of acute flaccid paralysis (AFP) cases per year in Yemen from 2010 to 2015.



Performance Indicators at the National Level

Table 1 shows the performance indicators of the AFP surveillance system in Yemen from 2010 to 2015. All performance indicators of the AFP surveillance system reached the WHO standard indicator levels in 2010, 2012, and 2014. In 2011, the proportion of specimens that arrived at the central level less than 3 days from the first sample collection was below the WHO standard indicator of 80%. During this year, this indicator level was achieved only in 75% of specimens. In addition, the proportion of stool specimens with results sent from the laboratory less than 28 days after receipt was 76% in 2013 and 48% in 2015, which are lower than the WHO standard indicator of 80%.

Table 1. Performance indicators of the acute flaccid paralysis (AFP) surveillance system, Yemen, 2010-2015.

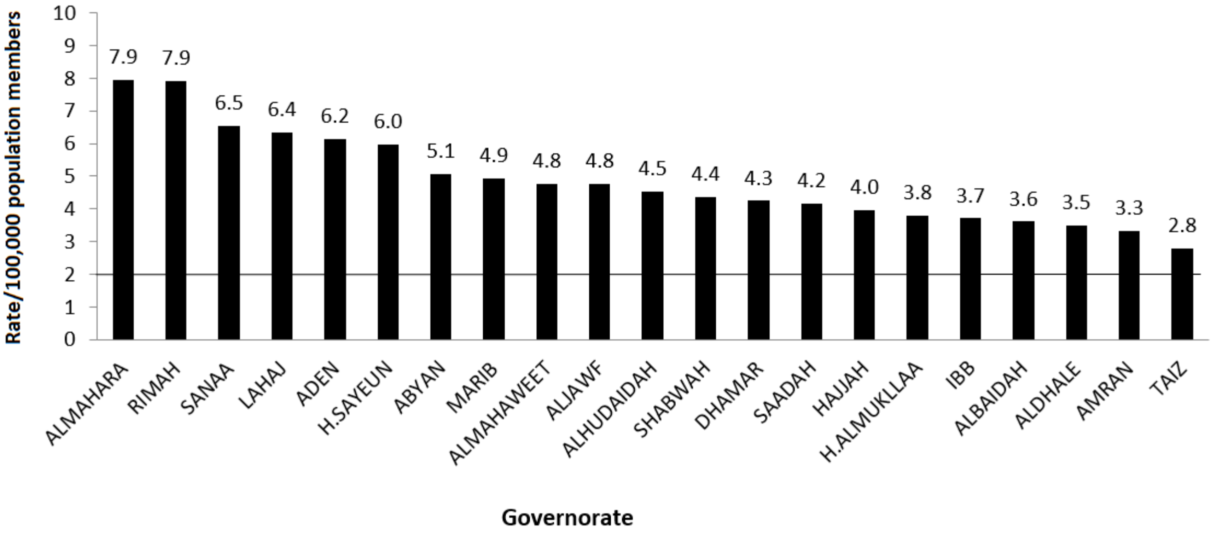
Indicator	Target	Year					
		2010	2011	2012	2013	2014	2015
Nonpolio AFP detection rate/100,000 population members under 15 years of age, number of cases	≥2	3.9	3.4	4.0	5.1	4.6	4.1
Proportion of AFP cases reported within 7 days, %	≥80	89	85	84	82	86	85
Proportion of AFP cases investigated within 48 hours of notification, %	≥80	100	100	99	100	98	99
Proportion of AFP cases with two adequate stool specimens, %	≥80	97	91	93	91	95	91
Proportion of specimens that arrived at the central level within 3 days of first sample collection, %	≥80	92	75	91	87	87	85
Proportion of stool specimens from which nonpolio enterovirus was isolated, %	≥10	17	16	22	17	18	18
Proportion of stool specimens with results sent from laboratory within 28 days of receipt by laboratory, %	≥80	84	85	88	76	83	48

Performance Indicators at the Governorate Level

Nonpolio Acute Flaccid Paralysis Detection Rate per 100,000 Members of the Population Under 15 Years of Age

The nonpolio AFP detection rate in all governorates met the WHO standard indicator level of ≥2 AFP cases per 100,000 members of the population under 15 years of age during the sixth year. Both Almahara and Rimah governorates had the highest nonpolio AFP rates while Taiz had the lowest rate (see Figure 3).

Figure 3. Average nonpolio acute flaccid paralysis (AFP) rate/100,000 members of the population by governorate in Yemen from 2010 to 2015.



Proportion of Acute Flaccid Paralysis Cases Investigated Within 48 Hours of Notification

Similar to nonpolio AFP detection rate, the percent of AFP cases that were investigated within 48 hours of notification met the WHO standard indicator level of ≥80% in all governorates during the evaluation years.

Adequacy Rate of Stool Specimens

A total of 17 out of 22 governorates (77%) achieved the WHO standard indicator level (≥80%) of proportion of AFP cases with two adequate stool specimens. A total of 5 governorates (23%) failed to achieve this indicator level, namely, Aldhalae, Abyan, Alhudaidah, Amran, and Dhamar.

Proportion of Acute Flaccid Paralysis Cases Notified Within 7 Days

Only 9 out of 22 governorates (41%) notified officials of AFP cases within 7 days at the WHO standard indicator rate of ≥80% during the evaluation years.

Proportion of Stool Specimens From Which Nonpolio Enterovirus Was Isolated

Aljawf and Hajjah were the only governorates that met the WHO standard indicator level of ≥80% of stool specimens from which nonpolio enterovirus was isolated during all evaluation years. Although Alhudaidah, Lahj, and Sana'a governorates failed to reach the WHO standard indicator level in 1 year, they were considered the top 3 governorates regarding this indicator, following Aljawf and Hajjah.

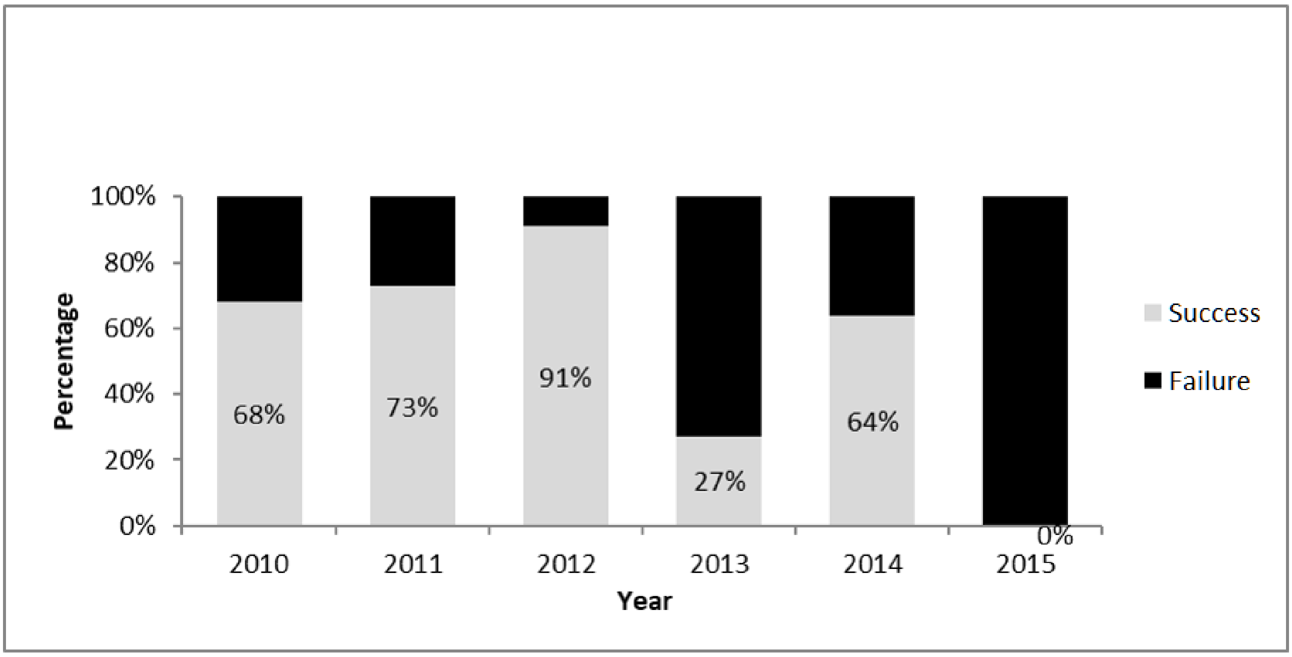
Proportion of Specimens That Arrived at the Central Level Less Than 3 Days of the First Sample Collection

The proportion of specimens that arrived at the central level within 3 days from the first sample collection reached the WHO standard indicator level (≥80%) in 7 of the 22 governorates (32%) during all evaluation years. These governorates were Aldhalae, Hadhramout Sayeun, Lahj, Rimah, Sa'adah, Sana'a, and Taiz. The other 15 governorates failed to achieve this indicator level in some years.

Proportion of Stool Specimens With Results Sent From the Laboratory Less Than 28 Days After Receipt

In 2015, this WHO standard indicator level was not achieved by any of the governorates. In 2013, this indicator level was achieved by only 5 out of 22 (23%) governorates (see Figure 4).

Figure 4. Percent of governorates that received laboratory results less than 28 days after receipt by the laboratory in Yemen from 2010 to 2015.



Discussion

Principal Findings

During the study period, Yemen was facing a threat of polio reintroduction from countries where the virus was still circulating [8]. A strong AFP surveillance system is critical for the early detection of wild poliovirus circulation, with the ultimate objective of polio eradication. The findings of this study showed that the nonpolio AFP detection rate reached the WHO standard indicator level (≥2 AFP cases/100,000 members of the population under 15 years of age) throughout the study period. Furthermore, on disaggregating the nonpolio AFP rates by governorates, all governorates performed well. These results indicate that the AFP surveillance system was sensitive and able to detect any polio case reimported into the country during the study period [4,7]. Compared with other studies in different countries and periods, the nonpolio AFP rate in Yemen was similar to that in Sierra Leone (2005-2012) [11] and Akwa Ibom State, Nigeria (2004-2009) [12], and higher than that in Iraq (1997-2011) [13], Hamdan, Iran (2002-2009) [14], South Africa (2005-2009) [15], Italy (1997-2007) [16], and Brazil (1990-2000) [17].

Increasing the proportion of AFP cases notified within 7 days increases the chance of timely investigation and response needed to prevent further transmission of infection. This study showed that the proportion of AFP cases notified within 7 days in Yemen was slightly higher than the WHO standard of ≥80% throughout the study period. This finding is better than that from Iraq (1997-2011) [13]. The positive performance of this indicator indicates that there would be a better chance of collecting stool specimens within 14 days.

The AFP surveillance system succeeded in investigating more than 98% of AFP cases within 48 hours of notification at the national level and more than 96% at the governorate level, exceeding the WHO standard indicator level of ≥80%. These proportions are higher than the reported proportions from South Africa and Iraq and are similar to the proportions reported in Akwa Ibom State, Nigeria [12,15]. When investigating AFP cases, many important data are collected, such as notification data, clinical case history, and vaccination status; collection of two adequate stool specimens also occurs at this time.

The proportion of AFP cases with collection of two adequate stool specimens is an important indicator for any AFP surveillance system. In this study, Yemen's AFP surveillance system exceeded this indicator level throughout the study period. The rate of adequate specimens collected in Yemen was 93% of total cases. This rate was high when compared to that in many countries around the world. However, 5 out of 22 (23%) governorates were not strong in this indicator. A total of 13 out of 22 (59%) governorates that failed to surpass the WHO standard indicator level (≥80%) of AFP cases notified within 7 days were able to reach the WHO standard indicator level (≥80%) of AFP cases with collection of two adequate stool specimens, except the Alhudaidah governorate in 2013.

At the national level, the proportion of specimens that arrived at the central level within 3 days of the first sample collection reached the WHO standard indicator level (≥80%) during all evaluation years except 2011 (75%), when a political revolution occurred. Because of that revolution, the internal situation of the country deteriorated, the main roads were closed, and fuel supply deliveries decreased and sometimes stopped. As a result, the proportion of specimens that arrived at the central level within 3 days of the first sample collection decreased dramatically from 2010 (92%) to 2015 (85%). This performance was also reflected at the governorate level, where most of the governorates failed to maintain the specimens' arrival rate above the WHO standard. Surprisingly, Sana'a City failed to achieve this indicator level for 4 years out of 6, although that was at the central level of the system.

After the arrival of stool specimens at the central level, they were sent to the NAMRU-3 laboratory in Egypt for diagnosis.

Nonpolio enterovirus should be isolated from at least 10% of stool specimens received at the laboratory in order to meet WHO standards [4,7]. This indicator evaluated the quality of the reverse cold chain process and how well the laboratory was able to perform the routine isolation of enterovirus. Yemen's AFP surveillance system would have been able to achieve this indicator level throughout the study period; however, the electricity was suspended for some lengthy periods in the country, particularly in 2011. Only 2 governorates out of 22 (9%)—Aljawf and Hajjah—achieved this indicator level during the entire study period, while 20 (91%) governorates failed in some of the years: 13 governorates in 1 year, 2 governorates in 2 years, and 5 governorates in 3 years. The diagnosis of AFP cases and the feedback via results from the NAMRU-3 to Yemen's AFP surveillance system is an essential step to control and investigate polio outbreaks when they occur. The performance of the NAMRU-3 failed to fulfill the WHO standard indicator level (≥80%) regarding sending back results within 28 days of stool specimen receipt in 2013 and 2015. This performance standard indicator level was achieved less in Yemen than in Iraq, Nigeria, and South Africa [2,13,15].

Conclusions

The AFP surveillance system in Yemen has met most of the WHO standard indicator levels. One of its weaknesses is the delay in receiving results from NAMRU-3 laboratory. This delay could lead to negative consequences regarding detection of poliovirus. Supporting the reference lab in Yemen in testing AFP specimens is strongly recommended.

Conflicts of Interest

None declared.

References

1. World Health Organization. 2019 Jul 22. Poliomyelitis. URL: https://www.who.int/immunization/diseases/poliomyelitis/en/ [accessed 2019-11-05]
2. European Centre for Disease Prevention and Control. Poliomyelitis. URL: https://www.ecdc.europa.eu/en/poliomyelitis [accessed 2019-11-08]
3. Centers for Disease Control and Prevention. 2019 Oct 24. Polio. URL: http://www.cdc.gov/polio/ [accessed 2019-11-08]
4. WHO-Recommended Standards for Surveillance of Selected Vaccine-Preventable Diseases. Geneva, Switzerland: World Health Organization; 2003 Feb. URL: http://www.vhpb.org/files/html/Meetings_and_publications/VHPB_Meetings/Kyiv2004/backgrounddoc/B1EWHOrecommendedstandardsforsurveillance.pdf [accessed 2019-11-08]
5. Growdon J, Fink J. Paralysis and movement disorder. In: Braunwald E, Isselbacher KJ, editors. Harrison's: Principles Of Internal Medicine. 13th edition. New York, NY: McGraw-Hill; 1994:115-125.
6. Heymann DL. Polio eradication: Finishing the job, guaranteeing the investment. J Neurol Sci 2005 Jan;238:S18 Article number: IS108. [doi: 10.1016/s0022-510x(05)80073-5]
7. Weekly Epidemiological Record. Volume 73, issue 16. Geneva, Switzerland: World Health Organization; 1998 Apr 17. Acute flaccid paralysis (AFP) surveillance: The surveillance strategy for poliomyelitis eradication. URL: https://www.who.int/docstore/wer/pdf/1998/wer7316.pdf [accessed 2019-11-08]
8. World Health Organization. 2016. EMRO | Yemen | Countries | Polio eradication initiative. URL: http://www.emro.who.int/polio/countries/yemen.html
9. Alabhar N, Al-Serouri A, Break A, Al-Mohamadi K, Alseragy A. Ministry of Public Health and Population in Yemen. 2013. Evaluation of acute flaccid paralysis surveillance system in Ibb Governorate, Yemen. URL: https://www.dropbox.com/s/k9htb1zifucu6wl/1st%20Y-FETP%20National%20Conference%20Book%2028-29%20Feb%202014.pdf?dl=0 [accessed 2019-11-25]
10. Saleh M, Al-Serouri A, Break A. Ministry of Public Health and Population in Yemen. 2013. Evaluation of acute flaccid paralysis surveillance system in Costal Hadramaut Governorate, Yemen. URL: https://www.dropbox.com/s/k9htb1zifucu6wl/1st%20Y-FETP%20National%20Conference%20Book%2028-29%20Feb%202014.pdf?dl=0 [accessed 2019-11-25]
11. Sowa D. Evaluation of the acute flaccid paralysis surveillance (AFP) system in Sierra Leone, 2012. Int J Infect Dis 2014 Apr;21:144. [doi: 10.1016/j.ijid.2014.03.725]
12. Bassey B, Gasasira A, Mitula P, Frankson U, Adeniji J. Surveillance of acute flaccid paralysis in Akwa Ibom State, Nigeria 2004-2009. Pan Afr Med J 2011 Oct 26;9(1). [doi: 10.4314/pamj.v9i1.71208]
13. Jasem JA, Marof K, Nawar A, Khalaf Y, Al-Hamdani F, Ali S, et al. An epidemiological analysis of acute flaccid paralysis and its surveillance system in Iraq, 1997-2011. BMC Infect Dis 2014 Aug 20;14:448 [FREE Full text] [doi: 10.1186/1471-2334-14-448] [Medline: 25141887]
14. Poorolajal J, Ghasemi S, Farahani L, Hosseini A, Bathaei SJ, Zahiri A. Evaluation of acute flaccid paralysis in Hamadan, Iran from 2002 to 2009. Epidemiol Health 2011;33:e2011011 [FREE Full text] [doi: 10.4178/epih/e2011011] [Medline: 22111031]
15. Khuzwayo LS, Kuonza LR, Ngcobo NJ. Evaluating the acute flaccid paralysis surveillance system in South Africa, 2005-2009: An analysis of secondary data. Pan Afr Med J 2013;14:86 [FREE Full text] [doi: 10.11604/pamj.2013.14.86.2032] [Medline: 23646222]

16. D'Errico MM, Barbadoro P, Bacelli S, Esposto E, Moroni V, Scaccia F, AFP Study Group. Surveillance of acute flaccid paralysis in the Marches region (Italy): 1997-2007. BMC Infect Dis 2008 Oct 09;8:135 [FREE Full text] [doi: 10.1186/1471-2334-8-135] [Medline: 18844987]
17. Teixeira-Rocha ES, Tavares-Neto J. Indicators of the effectiveness of epidemiological surveillance for acute flaccid paralysis in Brazil from 1990 through 2000 [Article in Portuguese]. Rev Panam Salud Publica 2003 Nov;14(5):325-333. [doi: 10.1590/s1020-49892003001000007] [Medline: 14766032]

Abbreviations

AFP: acute flaccid paralysis
NAMRU-3: Naval Medical Research Unit Three
VDPV: vaccine-derived polio viruses
WHO: World Health Organization

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Original Paper

Perception of the Progressing Digitization and Transformation of the German Health Care System Among Experts and the Public: Mixed Methods Study

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Abstract

Background: Health care systems worldwide are struggling to keep rising costs at bay with only modest outcome improvement among many diseases. Digitization with technologies like Artificial Intelligence or Machine Learning algorithms might address this. Although digital technologies have been successfully applied in clinical studies the effect on the overall health care system so far was limited. The regulatory ecosystem or data privacy might be responsible, but other reasons may also predominate.

Objective: We analyzed how the digitization of the German health care market is currently perceived among different stakeholders and investigated reasons for its slow adaption.

Methods: This was a mixed methods study split into a qualitative Part A using the conceptual approach of the Grounded Theory and a quantitative Part B using the Delphi method. For Part A we interviewed experts in the health care system and converted the results into 17 hypotheses. The Delphi method consisted of an online survey which was sent to the participants via email and was available for three months. For the assessment of the 17 hypotheses, the participants were given a six-point Likert scale. The participants were grouped into patients, physicians, and providers of services within the German health care market.

Results: There was a strong alignment of opinions on the hypotheses between experts (N=21) and survey participants (N=733), with 70.5% overall agreement on 12/17 hypotheses. Physicians demonstrated the lowest level of agreement with the expert panel at 88% (15/17) disagreement, with the hypotheses “H8: Digitization in the health care system will free up jobs,” and “H6: Digitization in the health care system will empower the patients,” perceived to be in profound disagreement (P=.036 and P<.001, respectively).

Conclusions: Despite the firm agreement among participants and experts regarding the impact of digitization on the health care system, physicians demonstrated a more negative attitude. We assume that this might be a factor contributing to the slow adoption of digitization in practice. Physicians might be struggling with changing power structures, so future measures to transform the market should involve them to a larger degree.

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KEYWORDS

digitization; health care sector; transformation; mixed method; delivery of health care; diffusion of innovation; reform

Introduction

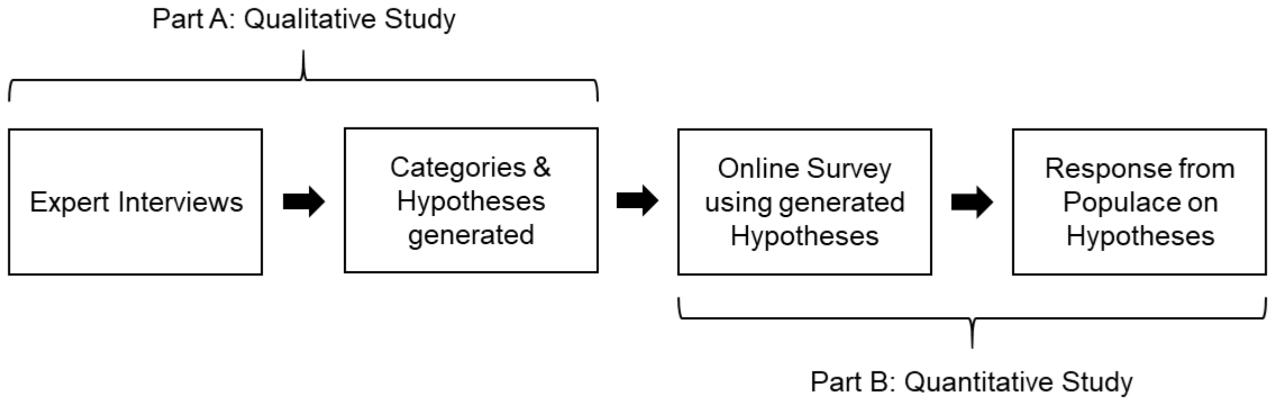
Health care systems worldwide are struggling, with aging societies and the western lifestyle leading to increasing health care expenditures [1-3]. Outcome-based reimbursement models have so far not gained the expected traction in the markets to compensate for higher levels of spending [4]. Particularly in the case of chronic conditions such as heart failure, chronic respiratory conditions, or diabetes, both hospitalizations and the continuum of care remain major cost drivers [5]. One problem is that innovations in the past were mainly based on medical therapy and inpatient treatment of acute diseases [6]. However, research has shown that many chronic condition outcomes can be improved by a lifestyle change and therapy adherence [7].

Several studies have shown the positive effects of technologies and digitalization in improving patient outcomes. For example, Schmier et al and Givertz et al demonstrated reduced hospitalization times and a reduction in costs using a remote monitor (CardioMEMS) for telemetric guided treatment of heart failure patients [8,9]. Furthermore, telehealth and telemedicine applications have demonstrated that they fill gaps, such as in the treatment of patients living in rural areas [10,11]. In some instances, higher therapy adherence induced by wearable sensors and mobile devices has been demonstrated [12-15].

As early as 2010, the Obama Administration set the mark with the Affordable Care Act (ACA) with the aim of transforming the health care system; for example, electronic health records [16]. Although the ACA focuses on technology, it remains unclear why many technologies have still not been implemented in clinical routine [17].

This raises the question of whether the slow adoption of digital technologies might be caused by a lack of understanding of the benefits of these new technologies between the innovating experts who create them and the practitioners who will use them. Based on this question we conducted a two-stage mixed methods study, as seen in Figure 1.

Figure 1. Flowchart study design.



In Part A, innovating experts (senior leaders) from different sectors within the health care market were interviewed to generate hypotheses on various aspects of the digitization of the health care system and any potential hurdles for the implementation of various technologies. In part B we performed a survey with more than 600 participants, differentiating between stakeholders in the health care system such as physicians, patients, and service providers.

Methods

Overview

This study was approved by the ethics committee of Witten/Herdecke University, Faculty of Medicine (application No. 169/2016), and conducted using an instrument development model which was divided into Part A and Part B, as described by Schifferdecker [18]. Part A was a qualitative study consisting of the conceptual approach of the Grounded Theory developed by Glaser and Strauss [19-21]. Interviews were done via telephone or face-to-face using an open interview guide (see Multimedia Appendix 1). The recorded responses were anonymous and were qualitatively evaluated using MAXQDA 13 (VERBI Software GmbH, Berlin, Germany) until saturation of hypotheses was reached. Part B represents a quantitative study using an online survey, based on the Delphi method, to test the generated hypotheses on the general public [22]. The results were then analyzed using MiniTab, version 17.1.0 (Minitab GmbH, Munich, Germany).

Recruitment of Participants

For Part A, expert participants were chosen using the criteria of their job position in the German health care system. According to Glaser and Strauss, a heterogenic sample of participants is recommended to maximize the variations of experience within the group [19]. Therefore, we approached as many different healthcare experts that were concerned with innovation as possible to be participants in our study, to ensure a wide variety of insights for defining hypotheses. We also included senior executives and other senior stakeholders who were focused or had knowledge of the German health care system.

For Part B, surveyed participants from academia (eg, university medical centers) and private hospitals were asked to fill out four questions regarding their demographic background (age group, role in the health care system, job position, and country). We further reached out to patients and service providers (eg, employees of insurance companies). A six-point Likert scale ranging from one to six was used to assess each hypothesis.

Data Collection

Part A data was collected from February 2017 to May 2017 via telephone or face-to-face interviews. Each interview was audio recorded with the permission of the participants. For Part B, the survey was published on SoGoSurvey and data was collected from November 2017 to February 2018.

The participants of this mixed methods study were informed upfront about data storage, the scope of the study, and the interviewer.

Data Analysis

To assess the impact and influence of digitization on the German health care system and to obtain a general perception about it, an open interview guide was developed based on literature research and an expert panel consisting of members with multi-professional backgrounds in medicine, pharmaceuticals, and economics. Before using the interview guide for the study, it was tested in five pilot interviews, reviewed, and revised by the expert panel. The coding was performed based on the conceptual approach of the Grounded Theory [19] and the process was supported by literature research. The Grounded Theory approach was designed in three stages, starting with open coding, followed by axial coding, and then selective coding. The process was documented in memos to capture the progress and the ideas that emerged while creating the conceptual approach and analyzing the data [19-21]. For the analysis of the interviews, MAXQDA®13 was used to perform comparative data analysis of the quantitative data by two examiners. The interviews were coded without transcription. Further, the derived hypotheses were grouped into categories afterward to further distinguish the impact field of the different hypotheses. Values of the responses from the survey participants higher than 3.5 were considered to be in agreement with the experts, whereas values lower than 3.5 were considered to be in disagreement.

Statistical Analysis

The data from the Delphi study was analyzed using MiniTab, version 17.1.0. For the calculation of the *P* value, a one-way analysis of variance (ANOVA) was applied under the assumptions of unequal variances and a statistical significance of *P*<.05.

Results

Part A: Expert Interview Results

Summary

In total, 30 experts were identified for this study. The interviews were conducted subsequently and stopped when saturation for the hypotheses was reached (N=21). The background of the experts is shown in Multimedia Appendix 2. Health Care Researchers represented the largest group, followed by pharmaceutical industry senior executives (Figure 2).

The experts responded to a total of nine questions in the interview guide (Multimedia Appendix 1). Based on these answers, 17 hypotheses (Table 1) were classified, which resulted in four categories (please see appendices for a full illustration of all hypotheses).

Figure 2. Number of experts.

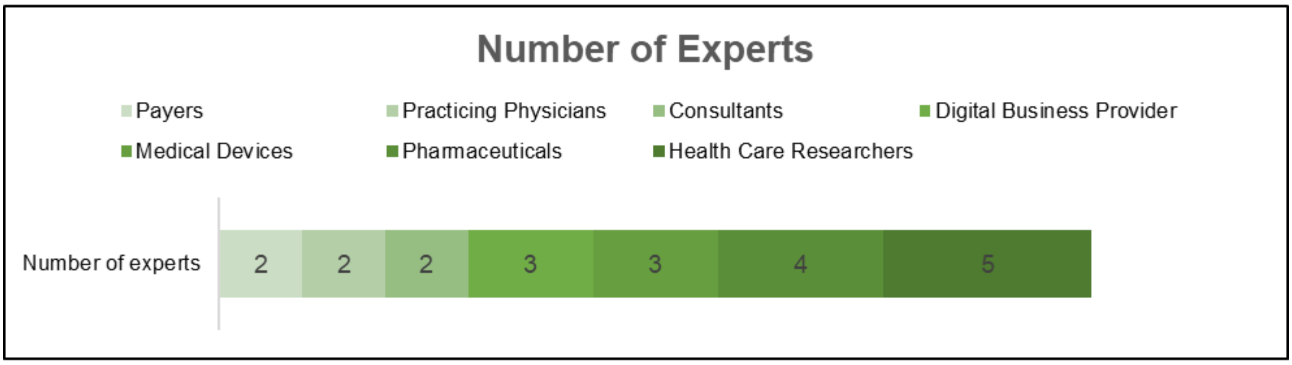


Table 1. List of hypotheses.

Number	Hypothesis
H1	Digitization will enable a disruptive structural change in the health care system.
H2	Key stakeholders in the health care system slow down digitization on purpose.
H3	Digitization in the health care system will improve the medical treatment of patients.
H4	Digitization in the health care system will bring more benefits to those with compulsory health insurance.
H5	Digitization in the health care system will establish new and homogenous communication structures which will increase transparency.
H6	Digitization in the health care system will empower the patients and change the power structures.
H7	Digitization in the health care system will increase self-monitoring and treatment of patients using digital devices.
H8	Digitization in the health care system will free up jobs and replace them with artificial intelligence, robots, etc.
H9	Digitization in the health care system will force pharmaceutical companies to develop products beyond the pill, (eg, hybrid models with additional service, or other applications or services) and further offer precision medicine.
H10	Big Data analysis of medical data, eg, interfacing between different professions will reduce malpractice and improve coordination of therapies.
H11	Digitization will secure medical care in underserved areas (eg, remote and rural areas).
H12	Digitization will increase the networking of stakeholders (eg, Physicians, Hospitals, Insurance and Pharmaceutical companies) within the health care system.
H13	Digitization will push the specialization of stakeholders (eg, Physicians, Hospitals, Insurance and Pharmaceutical companies) within the health care system.
H14	Digitization will offer opportunities to better differentiate caretakers from their competitors.
H15	Digitization in the health care system cannot replace the personal contact between stakeholders, such as between physicians or nurses and their patients.
H16	Digitization in the health care system will change existing job profiles.
H17	Digitization in the health care system leads to a depreciation of expert knowledge.

System

This category refers to hypotheses which influence the health care system in a holistic manner, such as, “H1. Digitization will enable a disruptive structural change in the health care system,” and about problems and opportunities caused by digitization, including, “H2: Key stakeholders in the health care system slow down digitization on purpose”. This category is the largest, with eight hypotheses in total.

Physician-Patient Relationship

This category covers all hypotheses dealing with the interaction of physicians and patients which will be significantly impacted by digitization, including, “H6: Digitization in the health care system will empower the patients and change the power structure,” and “H15: Digitization in the health care system cannot replace the personal contact between stakeholders, such as between physicians or nurses and their patients”. Three hypotheses were classified under this category.

Technology

This category represents all hypotheses which imply changes caused by digitization due to the availability of new technologies. Within the study, four hypotheses were identified for this category, such as, “H8: Digitization in the health care system will free up jobs and replace them by artificial intelligence,” and “H7: Digitization in the health care system will increase self-monitoring and treatment of patients using digital devices.”

Industry

This category deals with hypotheses which imply changes caused by digitization that will affect companies in the health care system and their provided services, including, “H9: Digitization in the health care system will force pharmaceutical companies to develop products beyond the pill (eg, hybrid models with additional services, or other applications or services) and further offer precision medicine,” and “H14: Digitization will offer opportunities to better differentiate caretakers from their competitors”. Two hypotheses are linked to this category.

Part B: Delphi Study Results

Summary

A response rate of 20.9% (733/3500) was achieved. Among all surveyed participants, 1% (7/733) were under the age of 20, 5% (37/733) were between 20-29 years old, 27.5% (202/733) were between 30-39 years old, 27.1% (199/733) were between 40-49 years old, 21.8% (160/733) were between 50-60 years old, and 17.4% (128/733) were over 60 years old. A total of 63.5% (466/733) were physicians, 19.4% (142/733) were patients, and 17.1% (125/733) were service providers. Figure 3 shows that the largest group overall was represented by physicians between the ages of 40-49, with 19.3% (142/733). For service providers (6.68% [49/733]) and patients (9.14% [67/733]), their largest age group was 30-39 years old.

Overall, there was a 70.5% (12/17) agreement between the survey participants and the experts regarding changes in the health care system in Germany caused by digitization. Figure 4 shows the level of agreement using the mean from the survey participants regarding the hypotheses generated by the experts.

Figure 3. Number of survey participants.

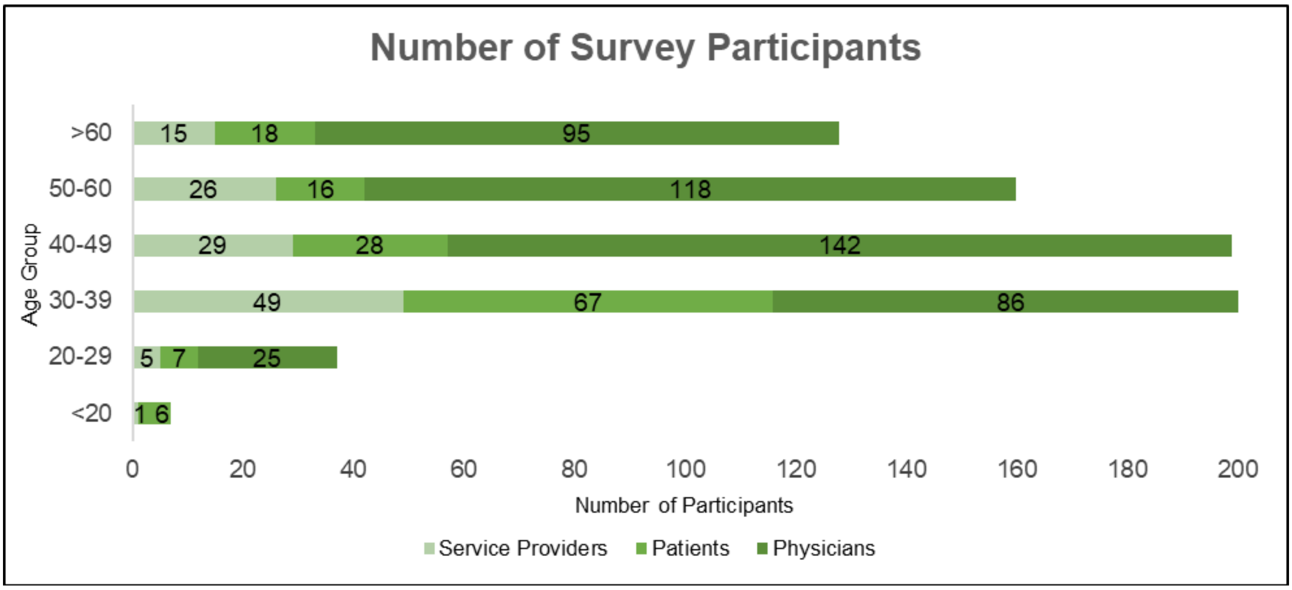
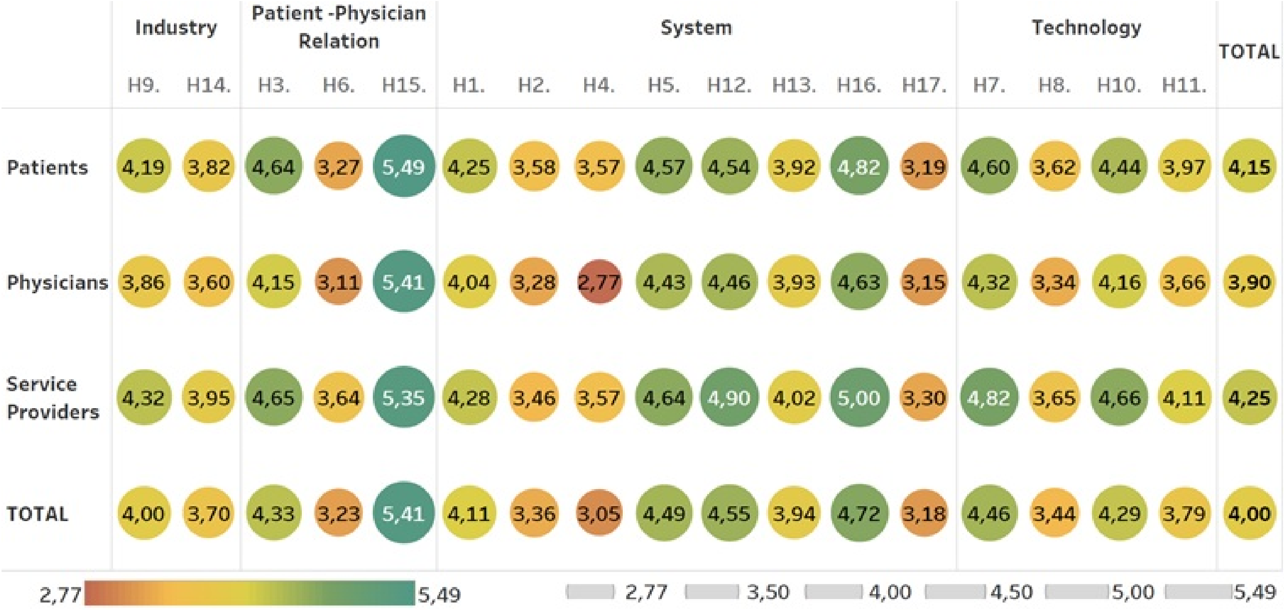


Figure 4. Level of agreement.



	Industry		Patient -Physician Relation			System								Technology				TOTAL
	H9.	H14.	H3.	H6.	H15.	H1.	H2.	H4.	H5.	H12.	H13.	H16.	H17.	H7.	H8.	H10.	H11.	
Patients	4,19	3,82	4,64	3,27	5,49	4,25	3,58	3,57	4,57	4,54	3,92	4,82	3,19	4,60	3,62	4,44	3,97	4,15
Physicians	3,86	3,60	4,15	3,11	5,41	4,04	3,28	2,77	4,43	4,46	3,93	4,63	3,15	4,32	3,34	4,16	3,66	3,90
Service Providers	4,32	3,95	4,65	3,64	5,35	4,28	3,46	3,57	4,64	4,90	4,02	5,00	3,30	4,82	3,65	4,66	4,11	4,25
TOTAL	4,00	3,70	4,33	3,23	5,41	4,11	3,36	3,05	4,49	4,55	3,94	4,72	3,18	4,46	3,44	4,29	3,79	4,00

System

Among the System category, all survey participants agreed on 62.5% (5/8) of the hypotheses. Service providers showed the highest agreement, with a mean of 4.15 on the 6-point Likert Scale compared to patients (mean 4.06) and physicians (mean 3.84) (see Multimedia Appendix 3). The hypothesis, “H16: Digitization in the health care system will change existing job profiles,” had the highest approval, with a mean of 4.81 among survey participants. Regarding “H2: Key stakeholders in the health care system slow down digitization on purpose,” only patients agreed with it, with a mean of 3.58. In addition, for “H4: Digitization in the health care system will bring more benefits for those with compulsory health insurance,” only service providers and patients agreed, with a mean of 3.57 for both. However, the physicians demonstrated disagreement with this hypothesis with a mean of 2.77, which also represents the lowest mean for all 17 hypotheses. Moreover, the response on “H17: Digitization in the health care system leads to a depreciation of expert knowledge,” was the lowest in the category, with a mean of 3.18 among the survey participants. For this hypothesis, the physicians had the lowest mean of 3.15. H2 (*P*=.05), H4 (*P*<.001), H12 (*P*<.001) and H16 (*P*=.003) showed statistically significant differences (see Multimedia Appendix 1).

Physician-Patient Relationship

In total, the survey participants agreed on 66% (2/3) of the hypotheses regarding the Physician-Patient Relationship. Overall, the service providers demonstrated firm agreement, with a mean of 4.55 for this category compared to patients (mean 4.47) and physicians (mean 4.22). Concerning, “H15: Digitization in the health care system cannot replace the personal contact between stakeholders, such as between physicians or nurses and their patients,” this hypothesis had the highest mean of all 17 hypotheses (5.41) (see Multimedia Appendix 3). Regarding, “H6: Digitization in the health care system will empower the patients and change the power structures,” only the service providers agreed with a mean of 3.64. However, patients (mean 3.27) and physicians (mean 3.11) both disagreed. Statistically significant differences among the survey participants were found in H3 ($P<.001$) and H6 ($P<.001$) (see Multimedia Appendix 3).

Technology

The results for the Technology category showed an agreement among the survey participants of 75% (3/4) for all hypotheses. In total, the service providers had the highest mean (4.31) in this category compared to patients (mean 4.16) and physicians (mean 3.87). The highest agreement was identified for, “H7: Digitization in the health care system will increase self-monitoring and treatment of patients using digital devices,” with a mean of 4.58 (see Multimedia Appendix 3). With regards to, “H8: Digitization in the health care system will free up jobs and replace them by artificial intelligence, robots, etc,” only the physicians disagreed (mean 3.34). Overall, H7 ($P<.001$) and H10 ($P<.001$) showed statistical significance between the survey participants, and further for H8 ($P=.036$) and H11 ($P=.002$) (see Multimedia Appendix 3).

Industry

Looking at the Industry category, the results showed an agreement between the survey participants and the experts towards both hypotheses. The level of agreement in this category is again lead by the service providers (mean 4.13) compared to patients (mean 4.01) and physicians (mean 3.73) (see Multimedia Appendix 3). The hypothesis with the highest agreement was, “H9: Digitization in the health care system will force pharmaceutical companies to develop products beyond the pill (eg, hybrid models with additional service or other applications or services) and further offer precision medicine,” with a mean of 4.12. Statistically significant differences were detected between the survey participants for H9 ($P<.001$) and H14 ($P=.011$).

The service providers demonstrated the strongest agreement with the hypotheses, with the highest mean of 88% (15/17). In contrast, the physicians had the least agreement with the hypotheses, with a mean of 88% (15/17). Further, every category had one hypothesis where the survey participants were not aligned (ie, “H2: Key stakeholders in the health care system slow down digitization on purpose,” “H4: Digitization in the health care system will bring more benefits to those with compulsory health insurance,” “H6: Digitization in the health care system will empower the patients and change the power structures,” and “H8: Digitization in the health care system will free up jobs and replace them by artificial intelligence, robots, etc“). The physicians particularly disagreed on all four hypotheses. Moreover, all three groups disagreed with hypothesis, “H17: Digitization in the health care system leads to a depreciation of expert knowledge,” with a mean of 3.18 (see Multimedia Appendix 3). Overall, the results show an average mean of 4.25 for service providers, 4.15 for patients and 3.90 for physicians (see Multimedia Appendix 3).

Discussion

Key Findings

The results of this study demonstrate an overall limited impact and influence of digitization on the German health care system, based on the perception of the different participating groups. We found great agreement but also areas of incongruity between the various groups.

As Figure 4 shows, the survey participants agreed on the majority of the 17 hypotheses, although to different degrees. There particularly seemed to be a misalignment of opinions between the physicians and the experts. Compared to the service providers with a mean of 4.25, and patients with a mean of 4.15, the physicians had the lowest mean of 3.90 (see Multimedia Appendix 3). Interestingly, in a large study conducted by the US Physician Foundation in 2018, half of the respondents demonstrated a pessimistic attitude about the future [23]. This pessimistic view could be at least one reason the physicians had such a low mean. With respect to the category system, we observed interesting results related to the slow adaption of digitization. Patients agree with the experts from our panel, that main stakeholders are blocking a faster implementation, but physicians and service providers are significantly different and disagree. Nevertheless, if we look at Germany, the reluctance to implement a national electronic health record system due to data privacy issues raised by the German Government postponed this development significantly [24]. Further, the lowest level of agreement within our study was between experts and physicians. This result could indicate that physicians are particularly slowing down digitization, as this group will be among the most impacted in practice. Interestingly, the medical association slowed down the implementation of both telemedicine and the electronic health record in Germany [24,25].

We found great alignment between the survey participants and experts regarding the benefits associated with new technologies. The broad agreement regarding an increase of self-monitoring is one example showing how well digital devices are accepted. As Roess et al stated, more than 1200 mobile Health (mHealth) tools or apps are available that help patients obtain information and monitor their health status [26].

Apart from the technological advantages, the survey participants were not aligned on who would benefit the most from digitization. Although service providers and patients showed agreement with the experts that compulsory insured patients will benefit, physicians significantly disagreed. This could be based on German specifications, since as of 2018 there are 72.8

million people compulsory insured compared to 8.75 million with private health insurance in Germany [27]. Here, physicians have an incentive to treat privately insured patients and especially to provide them with treatments which are not covered by public insurance. Thus, these new forms of treatment often reach only a minority of patients. In comparison to other health care systems, characterized by generally high out-of-the-pocket payments, this might slow down innovation [28].

The relationship between physicians and patients is a very sensitive topic. Experts and survey participants both agreed that technology cannot replace personal contact, however, this data contrasts preexisting research. There are several studies which have demonstrated the benefits of robot applications for nursing and social interaction among older adults, and the high satisfaction of patients who used telemedicine visits or chat-bots [29-31]. In contrast, 78.7% of the physicians who participated in the US Physician Foundation survey pointed out that working with patients is the most satisfying factor in medical practice [23].

In addition to the potential loss of personal interaction, we found misalignment of opinions regarding patient empowerment. According to Topol et al, the introduction of smartphones and applications will empower patients, since they will be able to control all their relevant health care data on one device [32,33]. However, the data showed significant differences between the survey participants, with patients and physicians especially not supporting this hypothesis. This could be explained by a lack of understanding of the opportunities on behalf of the patients and a potential negative attitude among the physicians. There are major initiatives aiming at patient empowerment, eg, Patients Empowerment Campaign from the European Patients Forum and the Patient empowerment and health care guidelines from the World Health Organization. Both define processes and activities to enable patients to have greater control over decision making and consequential actions related to their health [34,35].

We also found disagreement among the survey participants regarding the depreciation of expert knowledge. Physicians seemed especially concerned, since they disagreed with the hypotheses about the replacements of jobs using AI applications. On the one hand, the physicians agreed with the results of recent studies which have already demonstrated technological potential for improved diagnostics and surgical decision making [36,37]. However, the responses indicate an underlying negative attitude among physicians regarding digitization when technology is no longer supporting but instead limiting or replacing their activities. This is problematic in two ways: (1) they could be detached from technological progress, with the threat being replaced in some areas; and (2) they are missing the opportunity to actively participate and enhance these new technologies with their experiences to achieve higher quality standards for their patients.

Limitations

This study was performed within the German health care system with experts in Germany. While patient needs are comparable to other western societies, specific aspects in Germany (eg, a diverse payer and provider landscape compared to the United Kingdom) might limit its applicability to other systems. Therefore, the implications derived from this study concerning the common understanding of the impacts and influences of digitization might not be applicable to other health care systems in the world.

Conclusion

The digitization of the health care sector in Germany could cause significant changes, and only the future will tell how different stakeholders will be able to adapt. According to our research, the current adaptation level varies strongly among different participants in the market. For some of them we found significant alignment of opinions between experts and survey participants (eg, referring improved medical treatment, standardized communication structures, increased self-monitoring of patients and the importance of the personal contact between patient and physician in a digitized relationship). However, substantial agreement gaps exist regarding the empowerment of patients, the application of artificial intelligence and robots and thus the replacement of expert knowledge, particularly between physicians and our expert panel.

Physicians showed a negative attitude towards the empowerment of patients that comes with the process of digitization. They also failed to recognize that, in some areas, they might be replaced by technology. To generate the highest value for patients and to bring the technological advances to patients as fast as possible, it is crucial to involve all stakeholders. This is especially important in cases where job profiles will change. Physicians should acknowledge the change introduced by technological transformation and play a more active and positive role.

Acknowledgments

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Conflicts of Interest

None declared.

Multimedia Appendix 1
Open Interview Guide.
[PDF File (Adobe PDF File), 56 KB - publichealth_v5i4e14689_app1.pdf]

Multimedia Appendix 2
Job Profile & Industry Sector Expert Panel.
[PDF File (Adobe PDF File), 91 KB - publichealth_v5i4e14689_app2.pdf]

Multimedia Appendix 3
Overview Results Delphi Method Survey.
[PDF File (Adobe PDF File), 118 KB - publichealth_v5i4e14689_app3.pdf]

References

1. Porter M, Teisberg E. Watertown: Harvard Business School Press. 2006. Redefining Health Care: Creating Value-Based Competition on Results URL: https://www.hbs.edu/faculty/Publication%20Files/20060502%20NACDS%20-%20Final%2005012006%20for%20On%20Point_db5ede1d-3d06-41f0-85e3-c11658534a63.pdf [accessed 2019-04-11] [WebCite Cache ID 77YQKwbhV]
2. Aluttis C, Bishaw T, Frank MW. The workforce for health in a globalized context--global shortages and international migration. Glob Health Action 2014;7:23611 [FREE Full text] [doi: 10.3402/gha.v7.23611] [Medline: 24560265]
3. Schütte S, Acevedo PNM, Flahault A. Health systems around the world - a comparison of existing health system rankings. J Glob Health 2018 Jun;8(1):010407 [FREE Full text] [doi: 10.7189/jogh.08.010407] [Medline: 29564084]
4. Porter ME. A strategy for health care reform--toward a value-based system. N Engl J Med 2009 Jul 09;361(2):109-112. [doi: 10.1056/NEJMp0904131] [Medline: 19494209]
5. Martinson M, Bharmi R, Dalal N, Abraham WT, Adamson PB. Pulmonary artery pressure-guided heart failure management: US cost-effectiveness analyses using the results of the CHAMPION clinical trial. Eur J Heart Fail 2017 May;19(5):652-660 [FREE Full text] [doi: 10.1002/ejhf.642] [Medline: 27647784]
6. Lu H, Tong M, Chen K, Lee F, Chiang JY, Chung S, et al. Entresto therapy effectively protects heart and lung against transverse aortic constriction induced cardiopulmonary syndrome injury in rat. Am J Transl Res 2018;10(8):2290-2305 [FREE Full text] [Medline: 30210671]
7. Benjamin RM. Medication adherence: helping patients take their medicines as directed. Public Health Rep 2012;127(1):2-3 [FREE Full text] [doi: 10.1177/003335491212700102] [Medline: 22298918]
8. Schmier JK, Ong KL, Fonarow GC. Cost-Effectiveness of Remote Cardiac Monitoring With the CardioMEMS Heart Failure System. Clin Cardiol 2017 Jul;40(7):430-436 [FREE Full text] [doi: 10.1002/clc.22696] [Medline: 28272808]
9. Givertz MM, Stevenson LW, Costanzo MR, Bourge RC, Bauman JG, Ginn G, CHAMPION Trial Investigators. Pulmonary Artery Pressure-Guided Management of Patients With Heart Failure and Reduced Ejection Fraction. J Am Coll Cardiol 2017 Oct 10;70(15):1875-1886 [FREE Full text] [doi: 10.1016/j.jacc.2017.08.010] [Medline: 28982501]
10. Portnoy JM, Waller M, De Lurgio S, Dinakar C. Telemedicine is as effective as in-person visits for patients with asthma. Ann Allergy Asthma Immunol 2016 Sep;117(3):241-245. [doi: 10.1016/j.anai.2016.07.012] [Medline: 27613456]
11. Davis AM, Sampilo M, Gallagher KS, Dean K, Saroja MB, Yu Q, et al. Treating rural paediatric obesity through telemedicine vs. telephone: Outcomes from a cluster randomized controlled trial. J Telemed Telecare 2016 Mar;22(2):86-95 [FREE Full text] [doi: 10.1177/1357633X15586642] [Medline: 26026186]
12. Frias J, Virdi N, Raja P, Kim Y, Savage G, Osterberg L. Effectiveness of Digital Medicines to Improve Clinical Outcomes in Patients with Uncontrolled Hypertension and Type 2 Diabetes: Prospective, Open-Label, Cluster-Randomized Pilot Clinical Trial. J Med Internet Res 2017 Jul 11;19(7):e246 [FREE Full text] [doi: 10.2196/jmir.7833] [Medline: 28698169]
13. Yawn BP, Wollan PC, Rank MA, Bertram SL, Juhn Y, Pace W. Use of Asthma APGAR Tools in Primary Care Practices: A Cluster-Randomized Controlled Trial. Ann Fam Med 2018 Mar;16(2):100-110 [FREE Full text] [doi: 10.1370/afm.2179] [Medline: 29531100]
14. Kvedar J, Coye MJ, Everett W. Connected health: a review of technologies and strategies to improve patient care with telemedicine and telehealth. Health Aff (Millwood) 2014 Feb;33(2):194-199. [doi: 10.1377/hlthaff.2013.0992] [Medline: 24493760]
15. Roumia M, Steinhubl S. Improving cardiovascular outcomes using electronic health records. Curr Cardiol Rep 2014 Feb;16(2):451. [doi: 10.1007/s11886-013-0451-6] [Medline: 24408676]
16. Healthcare.gov. 2010. Compilation of Patient Protection and Affordable Care Act URL: https://www.govinfo.gov/content/pkg/PLAW-111publ148/pdf/PLAW-111publ148.pdf [accessed 2019-09-19] [WebCite Cache ID 77YOpMqKy]
17. Safavi K, Mathews SC, Bates DW, Dorsey ER, Cohen AB. Top-Funded Digital Health Companies And Their Impact On High-Burden, High-Cost Conditions. Health Aff (Millwood) 2019 Jan;38(1):115-123. [doi: 10.1377/hlthaff.2018.05081] [Medline: 30615535]
18. Schifferdecker KE, Reed VA. Using mixed methods research in medical education: basic guidelines for researchers. Med Educ 2009 Jul;43(7):637-644. [doi: 10.1111/j.1365-2923.2009.03386.x] [Medline: 19573186]
19. Glaser B, Strauss A. The discovery of grounded theory; strategies for qualitative research. In: Chicago: Aldine Pub. Co. Chicago: Aldine Pub. Co; 1967.

20. Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 4th ed. Thousand Oaks, CA: Sage Publications; 2015.
21. Charmaz K. Constructing Grounded Theory: A Practical Guide Through Qualitative Research. 2nd ed. London; Thousand Oaks, Calif: Sage; 2014.
22. Atherton CR. Group Techniques for Program Planning: A Guide to Nominal Group and Delphi Processes. Group & Organization Studies 2016 Sep 15;1(2):256-256. [doi: 10.1177/105960117600100220]
23. Physicians Foundation. 2018. 2018 Survey of America's Physicians Practice Patterns & Perspective URL: https://physiciansfoundation.org/wp-content/uploads/2018/09/physicians-survey-results-final-2018.pdf [accessed 2019-04-11] [WebCite Cache ID 77YnNw1vs]
24. Lang A, Mertes A. [Introduction of the electronic health card in Germany: influence of interest positions and sector membership on the establishment of an implementation network]. Gesundheitswesen 2011 Jan;73(1):e12-e20. [doi: 10.1055/s-0029-1246177] [Medline: 20169528]
25. Marx G, Beckers R. [Telemedicine in Germany]. Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 2015 Oct 21;58(10):1053-1055. [doi: 10.1007/s00103-015-2232-4] [Medline: 26293221]
26. Roess A. The Promise, Growth, and Reality of Mobile Health - Another Data-free Zone. N Engl J Med 2017 Nov 23;377(21):2010-2011. [doi: 10.1056/NEJMp1713180] [Medline: 29116869]
27. Statista. 2018. Number of members and insured persons of the statutory and private health insurance in the years 2012 to 2018 (in millions) URL: https://de.statista.com/statistik/daten/studie/155823/umfrage/gkv-pkv-mitglieder-und-versichertenzahl-im-vergleich/ [accessed 2019-04-11] [WebCite Cache ID 77YNwJFnh]
28. Latkovic T. 2012. Using payments to drive cost-reducing innovations URL: https://www.mckinsey.com/~/media/mckinsey/dotcom/client_service/healthcare%20systems%20and%20services/health%20international/issue%2012%20pdfs/hi12_16-29%20paymentinnovation_r6.ashx [accessed 2019-04-11] [WebCite Cache ID 77YQ5OnHZ]
29. Pu L, Moyle W, Jones C, Todorovic M. The Effectiveness of Social Robots for Older Adults: A Systematic Review and Meta-Analysis of Randomized Controlled Studies. Gerontologist 2019 Jan 09;59(1):e37-e51. [doi: 10.1093/geront/gny046] [Medline: 29897445]
30. Alkatout I. [Communicative and ethical aspects of physician-patient relationship in extreme situations]. Wien Med Wochenschr 2015 Dec;165(23-24):491-498. [doi: 10.1007/s10354-015-0385-2] [Medline: 26329722]
31. Reed ME, Parikh R, Huang J, Ballard DW, Barr I, Wargon C. Real-Time Patient-Provider Video Telemedicine Integrated with Clinical Care. N Engl J Med 2018 Oct 11;379(15):1478-1479. [doi: 10.1056/NEJMc1805746] [Medline: 30304654]
32. Topol E. The Patient Will See You Now: The Future Of Medicine Is In Your Hands. New York: Basic Books; 2016.
33. Topol E. Digital medicine: empowering both patients and clinicians. Lancet 2016 Aug 20;388(10046):740-741. [doi: 10.1016/S0140-6736(16)31355-1] [Medline: 27560260]
34. World Health Organization. WHO Guidelines on Hand Hygiene in Health Care URL: https://apps.who.int/iris/bitstream/handle/10665/44102/9789241597906_eng.pdf;jsessionid=3DEC2D7452656830AE20D91A949623E6?sequence=1 [accessed 2019-04-11] [WebCite Cache ID 77YP1xi4q]
35. European Patients Forum. 2019. A Strong Patients Voice to Drive Better Health in Europe URL: http://www.eu-patient.eu/About-EPF/whoweare/ [accessed 2019-04-11] [WebCite Cache ID 77YPvYFmH]
36. Tang A, Tam R, Cadrin-Chênevert A, Guest W, Chong J, Barfett J, Canadian Association of Radiologists (CAR) Artificial Intelligence Working Group. Canadian Association of Radiologists White Paper on Artificial Intelligence in Radiology. Can Assoc Radiol J 2018 May;69(2):120-135 [FREE Full text] [doi: 10.1016/j.carj.2018.02.002] [Medline: 29655580]
37. Lyra D, Ribeiro G, Torquetti L, Ferrara P, Machado A, Lyra JM. Computational Models for Optimization of the Intrastromal Corneal Ring Choice in Patients With Keratoconus Using Corneal Tomography Data. J Refract Surg 2018 Aug 01;34(8):547-550. [doi: 10.3928/1081597X-20180615-01] [Medline: 30089185]

Abbreviations

ACA: Affordable Care Act
ANOVA: analysis of variance
mHealth: mobile Health

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