JMIR Public Health and Surveillance

Contents

Editorial

Perceptions and Sentiments About Electronic Cigarettes on Social Media Platforms: Systematic Review

Misol Kwon[1], BS, RN; Eunhee Park[1], PhD, RN

School of Nursing, University at Buffalo, Buffalo, NY, United States

Corresponding Author:
Eunhee Park, PhD, RN
School of Nursing
University at Buffalo
3435 Main Street
Buffalo, NY
United States
Phone: 1 716 829 3701
Email: eunheepa@buffalo.edu

Abstract

Background: Electronic cigarettes (e-cigarettes) have been widely promoted on the internet, and subsequently, social media has been used as an important informative platform by e-cigarette users. Beliefs and knowledge expressed on social media platforms have largely influenced e-cigarette uptake, the decision to switch from conventional smoking to e-cigarette smoking, and positive and negative connotations associated with e-cigarettes. Despite this, there is a gap in our knowledge of people's perceptions and sentiments on e-cigarettes as depicted on social media platforms.

Objective: This study aimed to (1) provide an overview of studies examining the perceptions and sentiments associated with e-cigarettes on social media platforms and online discussion forums, (2) explore people's perceptions of e-cigarette therein, and (3) examine the methodological limitations and gaps of the included studies.

Methods: Searches in major electronic databases, including PubMed, Cumulative Index of Nursing and Allied Health Literature, EMBASE, Web of Science, and Communication and Mass Media Complete, were conducted using the following search terms: "electronic cigarette," "electronic vaporizer," "electronic nicotine," and "electronic nicotine delivery systems" combined with "internet," "social media," and "internet use." The studies were selected if they examined participants' perceptions and sentiments of e-cigarettes on online forums or social media platforms during the 2007-2017 period.

Results: A total of 21 articles were included. A total of 20 different social media platforms and online discussion forums were identified. A real-time snapshot and characteristics of sentiments, personal experience, and perceptions toward e-cigarettes on social media platforms and online forums were identified. Common topics regarding e-cigarettes included positive and negative health effects, testimony by current users, potential risks, benefits, regulations associated with e-cigarettes, and attitude toward them as smoking cessation aids.

Conclusions: Although perceptions among social media users were mixed, there were more positive sentiments expressed than negative ones. This study particularly adds to our understanding of current trends in the popularity of and attitude toward e-cigarettes among social media users. In addition, this study identified conflicting perceptions about e-cigarettes among social media users. This suggests that accurate and up-to-date information on the benefits and risks of e-cigarettes needs to be disseminated to current and potential e-cigarette users via social media platforms, which can serve as important educational channels. Future research can explore the efficacy of social media–based interventions that deliver appropriate information (eg, general facts, benefits, and risks) about e-cigarettes.

Trial Registration: PROSPERO CRD42019121611; https://tinyurl.com/yfr27uxs

XSL•FO
RenderX

Introduction

Although the prevalence of cigarette smoking has been decreasing in the last decades, electronic cigarette (e-cigarette) use, on the contrary, has been increasing dramatically [1]. E-cigarettes have been portrayed on social media platforms as a means of providing craving relief or reducing cigarette consumption for those wanting to quit [2,3]. However, recent findings state that e-cigarettes' impact on users' health and well-being needs to be studied in depth and with a long-term follow-up to validate such conclusions [1,4]. Considering the drastic increase in e-cigarette use and the uncertainty of its usefulness and consequences, people are turning to social media platforms for up-to-date information.

As internet use and mobile phone ownership have become a nearly ubiquitous element of people's lives in the last decade, the internet has provided platforms where people search for information and create communities around a shared interest [5]. Social media platforms can be defined as internet-based or mobile app–based communities that facilitate the creation and exchange of user-generated content through activities that range from photo and video sharing to social networking and crowdsourcing [6]. They provide a framework for people to connect, network, build, and thrive on the Web [7]. Twitter, a free social networking service, primarily focuses on microblogging [8], where its users can communicate via short messages with a maximum of 280 characters called *tweets*. These *tweets* can be instantly transmitted to *followers* of the account via the Twitter website or mobile phone app, or email [8]. Facebook, online news sources, photography-based storytelling social networking apps (eg, Instagram), and community-style picture posting and organizing apps (eg, Pinterest) are other popular platforms, where people search and share the information [9]. Common social media platforms where smokers can share e-cigarette–related information include Twitter and Facebook.

Discussion-based social media platforms, which are often called online forums, host conversations between users who post messages. It allows asynchronous interactions through which participants can engage or observe discussions at their convenience on a topic of their interest. Reddit is an example of a collection of forums where users can share interesting links, images, and posts. JuiceDB is another example, which provides website- and app-based online forums that allow people to discuss their thoughts about e-cigarettes. In view of this, data from social media platforms can be used by public health researchers to gain insights and understand public opinion on current public health–related phenomena and inform the design of public health surveillance [10].

Social media platforms are a popular way for people to share personal experience and exchange information about health [11]. More than 70% of the population has reported using more than one social media platform, and the proportion of social media users who state difficulty living without these platforms continues to increase [12,13]. On social media platforms, people can easily share pictures, information, interests, experiences, sentiments, and opinions about health and risk-taking behaviors, including the use of e-cigarettes. Hence, the depiction of e-cigarettes on social media platforms is on the rise [9,14], and it may have contributed to the heightening of curiosity, approval, and experimentation among many routine internet users seeking reviews of the actual experience [15]. Interestingly, tobacco users are 5 times more likely to share information about e-cigarettes across social media platforms than nonusers [9]. These days, social media platforms have become a medium for both members of the medical community as well as general users in providing opportunities to voice their input about vaping devices and e-liquid products and obtain information from other users [11]. This may be related to the short supply of usage and safety guidelines on vaping devices and products for current and potential e-cigarette users and health care providers.

With limited knowledge of the public's perceptions and sentiments toward e-cigarettes, social media platforms can act as major sources of information for researchers, policy makers, and educators. A recent scoping review provides a review on the messages presented in e-cigarette–related social media promotions and discussions in the studies published in 5 developed countries [16]. McCausland et al provided important insights on e-cigarette–related messages depending on the social media account type and revealed the most common themes as health, safety, and harms [16]. In addition, selected studies were analyzed for emotional tone, affective content, or message attitudes [16]. However, we still have a limited understanding of this phenomenon, and there is a need for a systematic review on people's perceptions and sentiments on e-cigarettes as expressed on social media platforms and online forums. This review expands on the previous scoping review and contributes to the literature by (1) adding information on online forums based on discussions by the public, which have the potential to better understand the general population, as well as subgroups; (2) providing an understanding of people's perceptions and sentiments, including in-depth reasons for using or not using e-cigarettes based on the synthesis of the findings; (3) adding insights using different search engines; and (4) evaluating the methodological strengths and gaps in the literature. The aims of conducting this systematic review were to (1) provide an overview of studies examining perceptions and sentiments about e-cigarettes on social media platforms and online forums, (2) explore people's perceptions and sentiments about e-cigarettes on social media platforms and online forums, and their potential impact on public health, and (3) examine methodological limitations and gaps of the selected studies.

Methods

Overview

The authors followed the guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses [17]. This review is registered on PROSPERO (International Prospective Register of Systematic Reviews, CRD42019121611). Inclusion and exclusion criteria used for studies selected is shown in Figure 1.

Figure 1. Flowchart of the literature search process. CINAHL: Cumulative Index of Nursing and Allied Health Literature.
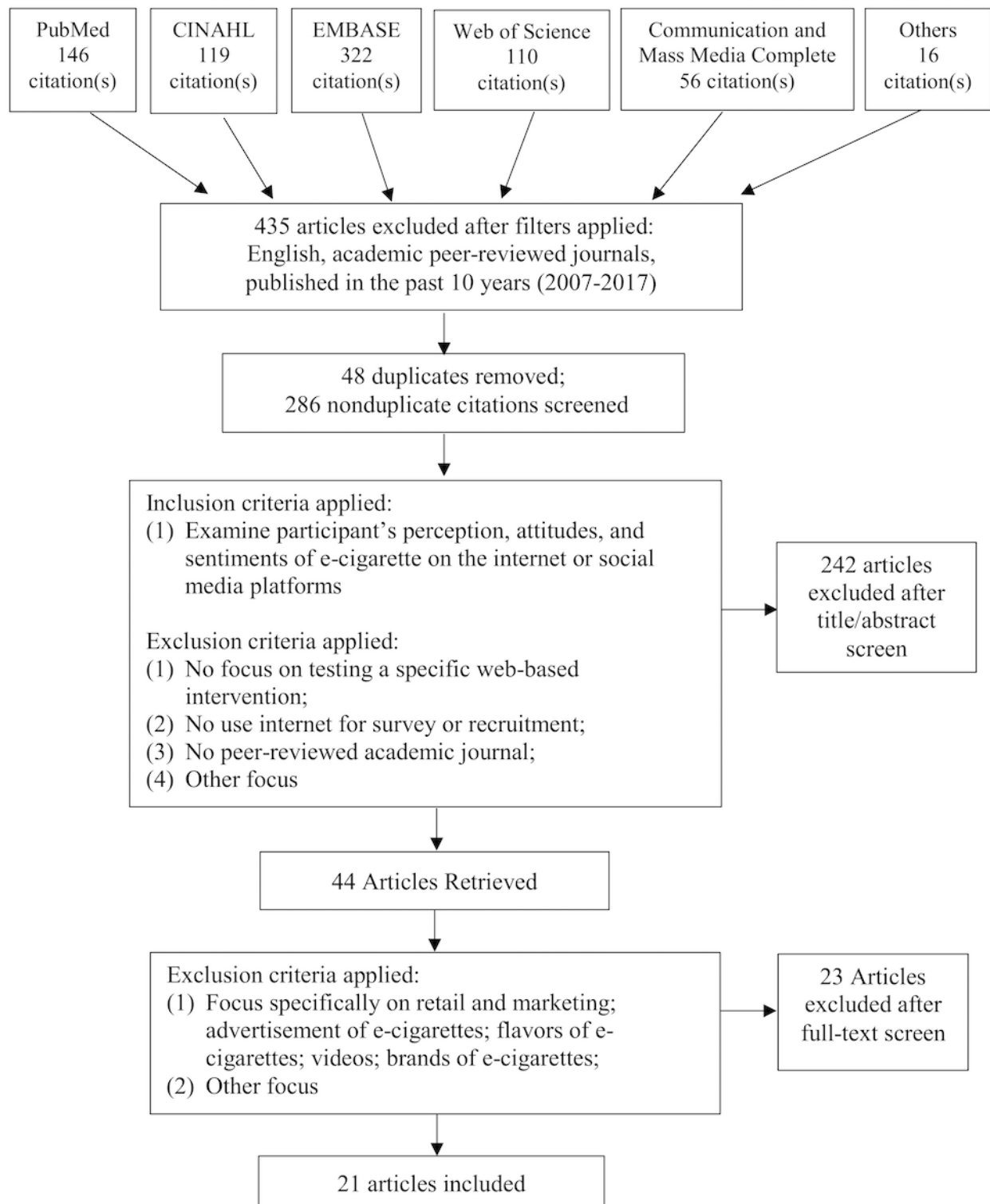
Search Strategy

Studies were searched from 5 major electronic databases: PubMed, the Cumulative Index of Nursing and Allied Health Literature, EMBASE, Web of Science, and Communication and Mass Media Complete. In addition, we conducted an additional search using a snowballing approach through Google Scholar. Search terms included the following keywords: e-cigarette-related terms ("electronic cigarette" OR "electronic

vaporizer" OR "electronic nicotine" OR "electronic nicotine delivery systems [MeSH]") AND social media platform-related terms ("internet [MeSH]," "social media [MeSH]," OR "internet use"). To obtain a more comprehensive and accurate search outcome, we used controlled vocabulary (ie, MeSH [Medical Subject Headings] terms). MeSH is a set list of terms that includes related search terms and are set to categorize and index articles in a systematic way. For instance, the MeSH term "electronic nicotine delivery systems" encompasses

"e-cigarettes" along with other related narrow terms such as "vaping." This was applied to the terms for social media platforms and online forums by using the MeSH terms "social media" and "internet."

Initial search was conducted from May to July 2017, and additional search was completed in May 2019.

Eligibility Criteria

Studies were included if:

1. They were published in peer-reviewed academic journals in the past 10 years (2007-2017).
2. They examined participants' perceptions and sentiments of e-cigarettes on the internet or social media websites.
3. They were written in English.

Studies were excluded if:

1. They were gray literature, including dissertations, conference proceeding papers, abstracts, or editorials.
2. They were using the internet as a survey tool or for participant recruitment.
3. They were focusing specifically on specific intervention, video analysis, retail and marketing or advertisement, e-cigarettes flavors, and e-cigarettes brands.

Data Extraction, Analysis, and Synthesis

The database searches yielded a total of 769 articles. Of these, 435 articles were excluded for not meeting the inclusion criteria (articles in English, from peer-reviewed journal articles, and published in the past 10 years), leaving 334 articles, which were then imported into a citation manager for the identification of duplicates [18]. The citation manager identified and excluded duplicates (n=48); thereafter, all nonduplicate articles (n=286) were compiled into an Excel spreadsheet. The titles and abstracts of all nonduplicate articles were then reviewed by 4 researchers (YB, MF, MK, and EP), including 2 authors (MK and EP) and 2 other researchers (YB and MF), who determined whether they met the predetermined inclusion criteria. Most articles were excluded in this first screening process if they did not focus on e-cigarettes, were not based on social media platforms or online forums, used social media platforms for survey or recruitment, and focused on methodological aspects of conducting social media data research. Disagreements were resolved through discussion when needed. This initial phase of screening further led to the exclusion of 242 articles, leaving 44 articles for review. Thereafter, the first and second authors (MK and EP) carefully read the full text of the articles (n=44) and screened them for eligibility. At this stage, 23 articles were excluded because they focused on online marketing of e-cigarettes, specific brands or flavor of e-cigarettes, and methodological aspects of conducting research using social media platforms instead of sentiments or perceptions of e-cigarettes. The same 2 authors (MK and EP) extracted data for the finally included articles (n=21) by coding them in a data display matrix. They extracted information pertaining to the following study characteristics: author, publication year, study method (study design, sampling method, data collection, and analysis), study purpose and relevant discussion, study navigation process (search queries, number of content or posts analyzed, data collection period, and social media platform), findings including the overall sentiment of discussion on e-cigarette use (categories: pro, anti, natural, mixed, and not applicable), themes of summarized message topics, and examples of health-related comments. This coded information was cross-checked by the authors.

The overall sentiments of discussion on e-cigarette use were categorized as *pro* (positive toward e-cigarettes), *anti* (negative), *neutral*, *mixed*, or *not applicable* for each study, depending on which category had the highest percentage or was most applicable. This was achieved by first identifying the percentage of each sentiment (pro, neutral, and anti) based on the quantitative findings regarding sentiments or perceptions of e-cigarettes that the individual study reported. Each study identified postings on social media platforms (ie, each tweet on Twitter) or online forums as a unit of analysis. When the data in the study revealed a higher percentage of positive sentiments about e-cigarettes (ie, portraying e-cigarettes as cool, beneficial, better, etc), they were coded as *pro*. Similarly, sentiments were coded as *anti* when the individual study reported a higher percentage of negative sentiments (ie, e-cigarette use is unhealthy, disgusting, uncool, etc). The studies reporting a higher percentage of neutral sentiments (ie, stating a general comment and asking questions about e-cigarette) were coded as *neutral*, whereas those with mixed results were categorized as *mixed* (ie, when 2 countries had different results, different results were reported at 2 time points). The studies that did not quantify any sentiments (positive, neutral, or negative) about e-cigarette use were coded as *not applicable (N/A)*.

Results

Description of the Included Studies

A total of 21 articles were included in the systematic review (search strategy illustrated in Figure 1). A total of 20 social media platforms and websites were used: Twitter (n=12), Reddit (n=5), 14 online forums (Electronic cigarette forum, Hookah forum, Vapor Talk, Vapors forum, UK Vapors, All About E-Cigarette, Aussie Vapors, Baby Gaga, Vaping Underground, What to Expect, Momtastic [pregnancy forum], Totally Wicked E-Liquid, Baby Centre [United Kingdom], and Baby Center [United States]), and other social media platforms, such as Instagram (n=1), Pinterest (n=1), JuiceDB (n=1), and GLOBALink (n=1). The studies that used Twitter [9,19-29] yielded 801,574 cumulative tweets. A detailed overview of the studies is presented in Multimedia Appendices 1 and 2.

Study Design

The studies utilized various data collection methods (Multimedia Appendix 1). Most studies (n=9) utilized the social media application programming interface (API) aggregation company such as GNIP, Inc [19,25,28], Twitter API [20,21,23,29], and JuiceDB API [22], and Instagram API [30,31] for data collection, whereas others (n=4) used analytics software such as NodeXL [26] and databases such as MDigitalLife Health Ecosystem [9], MySQL [30,32], and Sysomos HeartBeat [24]. Data were collected manually for 4 studies [33-36], whereas 1 study made use of a Web crawler to retrieve data from Web servers directly [37].

The most frequently used search queries included "electronic cigarettes," "e-cigarettes," "ecigs," "vaping," and "vape." Some articles used specific key terms, such as "e-cigarette ban," "e-cigarette FDA," "e-cigarette regulation," "vapelife," "e-juice," "flavor," "e-liquid," "cloud-chasing," "second hand vape," and "vaping during pregnancy," or the names of public health campaign using words such as *stillblowingsmoke* or *notblowingsmoke*, depending on the specific purpose of the study [19,26].

Although the most commonly used sampling strategy was purposive sampling (16/21, 76%) [9,20-22,24,26-29,33-37], a few studies (5/21, 24%) used stratified and random sampling methods [19,23,25,30,38]. When studies did not clearly indicate the type of sampling methods used (7/21, 33%) [21,23,25,27,37], we categorized study sampling based on the description that the study provided, and most were categorized as purposive sampling because they had specific purpose of sampling meeting their aims [39].

All studies were descriptive in design. In all, 9 of the included articles (43%) used both quantitative and qualitative approach [9,20,21,24-26,28-30]. Although some studies did not specifically mention whether they used qualitative or quantitative study design, the authors categorized each study based on the description of the study design and analysis [40]. For example, if the study used a qualitative approach, such as the thematic analysis when coding, the authors categorized it as qualitative (7/21, 33%) [19,22,27,31,33-35]. If the results were reported numerically, they were categorized as quantitative (5/21, 24%) [23,32,36-38]. Data analysis techniques included text mining and modeling [9,21,23,27,37], thematic analysis [23,33], content analysis [19-21,25,26,29,32,35,38], valence analysis [28], and image analysis [30], whereas quantitative approach included descriptive statistics (eg, to report the frequencies of data based on themes), f statistics, chi-square statistics, Kruskal-Wallis tests, and Dunn tests [19,20,23-26,28-32,35,38].

Major Themes About Electronic Cigarettes on Social Media Platforms

The main themes regarding e-cigarette use on social media platforms were motivation for using e-cigarettes and concerns about the health outcomes associated with their use. There were debates about their harmfulness and safety, for example, their effectiveness in promoting smoking cessation compared with conventional cigarettes, or harmfulness because of nicotine content, presence of chemicals, and the possibility of gateway effect to conventional smoking [9,19,21,22,24,26,32,34]. In addition, other major issues related to e-cigarettes were identified, which included policy, advertisement and marketing, flavor, feelings of e-cigarette use, and use among young people. These findings indicate the wide range of information available about e-cigarettes that people share on social media platform, in addition to the topics related to e-cigarettes that people are interested in and curious about (Multimedia Appendix 2).

Overall Perceptions About Electronic Cigarettes

The perceptions about e-cigarette use were depicted on various social media platform sources and online forum postings (Multimedia Appendix 2 and Table 1). Overall, 47.6% (n=10) of the studies were categorized as *pro* because they indicated positive perceptions about e-cigarettes [19,20,22-24,26,27,30,32,38], 19.0% (n=4) as *neutral* [21,28,31], 4.8% (n=1) as *anti* [36], and 9.5% (n=2) as *mixed* [9,25], and the studies with no data on perceptions about e-cigarette use were coded as *N/A* (19.0%, n=4) [33,37]. These details are presented in Table 1. In addition, the examples of health-related quotations are provided in Multimedia Appendix 2.

Table 1. Overall sentiment of discussion on electronic cigarette (e-cigarette) use (coded as pro, anti, neutral, mixed, and not applicable).

Overall sentiment and studies (first author, year)	Details
Pro	
Allem, 2017 [19]	Provaping=92%, neutral=6%, anti=2%
Lazard, 2016 [27]	Pro=68%, neutral=32%, anti=0%
Ayers, 2017 [20]	Reasons for using e-cigarette: quitting combustibles (43%), social image (21%), can vape indoors (17%), flavor choices (14%), safe to use (9%), low cost (3%), and favorable order (2%)
Zhan, 2017 [22]	Reddit: pro=60.7% opponents on e-cigarette bans, neutral=29.9%, anti=9.4% proponents on e-cigarette bans
Kavuluru, 2016 [23]	Proponents versus others: mean positive scores (0.92 and 0.79), mean negative scores (0.01 and 0.03)
van der Tempel, 2016 [24]	Attitude: complete sample versus industry-free sample (pro=79% versus 62%, anti=12% versus 17%, neutral=8% versus 21%); Affective content: complete sample versus industry-free sample (pro=46% versus 27%, anti=7% versus 15%)
Chu, 2015 [32]	Pro=61.9%, anti=47.7%, neutral=8.6%
Harris, 2014 [26]	Pro=89.2% opponents of e-cigarette regulation (antipolicy), anti=7.5% proponents of e-cigarette regulation (propolicy), neutral=3.4% unable to tell
Lee, 2017 [38]	—[a]
Chu, 2016 [30]	—
Anti	
Hua, 2013 [36]	Anti=80.5% (negative symptoms), pro=19.3% (positive symptoms), neutral=0.02% (neutral)
Neutral	
Burke-Garcia, 2017 [28]	Neutral=88%-90%, pro=6%, anti=4%-5%
Dai, 2016 [21]	Neutral=19.4%, anti=17.7%, pro=10.8%
Laestadius, 2016 [31]	Neutral: presence of social identity or vaping community (81.2%), depiction of e-cigarette=up to 62.4%; pro=48.3%
Unger, 2016 [29]	Neutral=39.24%, pro=34.96%, anti=25.81%
Mixed	
Glowacki, 2017 [9]	United States: anti=54%, pro=28%, neutral=18%; United Kingdom: pro=43%, anti=37%, neutral=19%
Cole-Lewis, 2015 [25]	Initially, pro=71.11%, neutral=16.78%, anti=12.11%, but showed steady decline in positive sentiment from December 2013
Not applicable	
Sharma, 2017 [34]	—
Wigginton, 2017 [33]	—
Li, 2016 [35]	—
Chen, 2015 [37]	—

[a]Cumulative percentage not provided.

Reasons and Motivations for Using Electronic Cigarettes

The main reasons for the popularity of e-cigarettes were identified as the benefits associated with their use, with e-cigarettes not only being used as smoking cessation devices but also being the cheaper and healthier alternatives to conventional cigarettes because of their content and environment-friendly nature [31]. The proponents viewed c-cigarettes as a harm reduction and smoking cessation aid with favorable features, such as the smoke-free vaping source with flavors [23]. In addition, e-cigarettes were depicted as more

economical and efficient nicotine delivery systems than conventional smoking [24].

Interestingly, the major reasons for e-cigarette use in tweets changed from 2012 to 2015 [20]. In the past (2012), the most prevalent reasons for using e-cigarettes were quitting combustibles (43%), caring for social image (21%), and being able to use them indoors (17%). Minor reasons included choices of flavor (14%), safety relative to combustibles (9%), low cost (3%), and favorable odors (2%) [20]. However, 3 years later, in 2015, a significant decrease was seen for the reasons quitting combustibles and being able to use indoors, and the most

prevalent reasons for using e-cigarettes changed to social image (37%, 95% CI 32-43), quitting combustibles (29%), and capability to smoke indoors (12%) on Twitter [20].

For people with mental illness, the motivation for using e-cigarettes was quitting smoking [34]. Particularly, with smoking cessation from other nicotine replacements with concurrent use of psychiatric medicine being unsuccessful, e-cigarettes began to be viewed as a healthier alternative. In addition, the switch to e-cigarette was made with the intention to relieve symptoms as either a self-medication or replacement of psychiatric drugs and to gain a sense of freedom, control, and social connectedness [34].

On the discussion regarding safety concerns of e-cigarette use during pregnancy, posts emphasized the dangers of abruptly stopping nicotine use (eg, physical and psychological harm of nicotine withdrawal for the mother and baby) [33]. Overall, e-cigarette use during pregnancy was viewed as a harm reduction approach, and vaping was seen as a safer alternative rather than focusing on the harmful effects of nicotine [33]. Nevertheless, some mentioned the unknown risks associated with vaping or that there was limited current scientific evidence to support vaping during pregnancy [33].

Smoking Aid, Cessation Method, and Harm Reduction

Discussion about e-cigarette use mainly centered on their use as a cessation aid and as a healthier alternative to combustors [9,20,26,29,31,33,37]. The proponents of e-cigarette use were more likely to tweet on the aspects of harm reduction of e-cigarettes [33], smoke-free aspects, and smoking cessation effect than other users [23], and this was also indicated in the tweets related to secondhand vaping [29]. Notably, only 6.3% of e-cigarette–related tweets were about e-cigarette use for smoking cessation [25].

Data from Vapor Talk and Reddit demonstrated extensive discussion on e-cigarette use for quitting conventional smoking [37]. E-cigarette users experienced less psychological difficulties in quitting smoking compared with combustible cigarette users [37]. The corporate users (vendors, brands, and representatives of tobacco companies or retailors) and the general e-cigarette users had positive views regarding the cessation effect on Instagram as shown in the 23.5% of the total posts [31]. In particular, Instagram posts (16.5%) depicted e-cigarettes to be healthier than tobacco products and more environment-friendly (1.2%) [31]. Similarly, the UK physicians' tweets placed emphasis on promotion of e-cigarettes (18%) because these could serve as an effective aid for smoking cessation, followed by the discussion on general practitioner to encourage patients who smoke conventional cigarettes to switch to e-cigarettes (13%) [9].

Limitations and Barriers to Using Electronic Cigarette

One of the major barriers identified was a concern regarding the possibilities of e-cigarettes serving as a gateway to conventional cigarette smoking among nonusers, especially with respect to the young population, and its effect on short- and long-term health outcomes [9,19,21,36,37]. People with mental illness uniquely reported limitations to use e-cigarettes such as health concerns for replacing psychiatric medicines,

drug interactions, practical difficulties, and costs, whereas the general population indicated concerns involving nicotine addiction, health effects, and e-cigarettes being an unsatisfactory substitute for tobacco products [34].

Health Effects and Safety

The effects on health outcomes was one of the major themes among the users of the online discussion forums and Twitter [9,19,29,31,33,36,37]. In all, 13% of tweets were related to health effects and safety issues [25]. Of the reported physical health symptoms across 10 organ systems (eg, respiratory and neurological) and 2 anatomical regions (chest and mouth/throat) among the e-cigarette users, more negative symptoms (82.2%) such as insomnia and dry lips and tongue were reported compared with the positive symptoms (17.8%) such as controlled appetite and eliminated snoring on the Electronic Cigarettes Forum [36]. Subsequently, among the groups of US and UK physicians, about 15% of tweets were regarding the effects on health outcomes such as the effect of flavoring chemicals on the lungs [9]. The effects of e-cigarettes on complications for breast reconstruction surgery were also discussed among the UK physicians [9].

Although health effects were a major concern for e-cigarette use and were seen as a barrier, mixed opinions and discussions about the ingredients of e-cigarettes were displayed. On Twitter, opponents claimed that some ingredients in e-cigarettes were carcinogenic, focusing especially with the increased use among teens (propolicy, 2.8%). However, the proponents argued that research had shown that e-cigarettes only contain nicotine and water and, hence, presented no danger with the secondhand vapor (antipolicy, 31.9%) [26]. The proponents' main claim was that e-cigarettes may not be more harmful than conventional cigarettes [26]. Health-related tweets related to secondhand vaping were mostly anti–e-cigarettes (70%) with mentions of short- and long-term health effects of exposure to e-cigarette aerosol, such as headache, eye irritation, nausea, and lung disease [29]. Moreover, women who smoke during pregnancy described quitting nicotine as more harmful to their body and baby than cutting down the dose or frequency of smoking, indicating that vaping can be used to not only reduce harm but also replace smoking as a safer and healthier alternative during pregnancy [33].

The pros and cons of e-cigarettes compared with those of conventional cigarettes were a major discussion theme among the UK physicians with 19% of tweets [9], whereas 12% of tweets were regarding Public Health England's recommendation that e-cigarettes were safer than the traditional forms of tobacco use [9]. Interestingly, there were no negative posts on Instagram and their posts (16.5%) that presented e-cigarettes as healthier alternative to conventional tobacco products and as environment-friendly (1.2%) [31].

Other Issues About Electronic Cigarettes on Social Media

In addition to the major discussions on the effects of e-cigarettes on smoking cessation and their potential health concerns, there were extended discussions on the policy and regulation, flavor and techniques, feelings, symptoms, features, marketing, and

youth e-cigarette use [9,19,22-26,35-37] (Multimedia Appendix 2).

Policy and Regulation

The debate on e-cigarette ban regulations was a commonly discussed topic [19,22,25-27]. One of the main platforms for the policy and regulation discussion was Twitter with 20.2% of tweets associated with policy and government-related issues [25]; the major proportion of those on antipolicy side discussed about the safety (52.4%) and lies/propaganda (32.8%), whereas those on the propolicy side focused more on regulation (6.4), science (2.8%), and safety (2%) [26]. In an attempt to understand the public's initial reactions to the Food and Drug Administration's new rule that extends their regulatory authority to include all tobacco products, including e-cigarettes, cigars, pipe tobacco, and hookah in May 2016, the study revealed many expressed comments, opinions, words, and phrases commonly associated with advocating for vaping and support for the use of e-cigarettes [27].

The frequent themes on Twitter campaigns using hashtags to express policy-related opinions included tax, individual freedom and rights, simple opposition, and call to action [22]. Most tweets generated for the California campaign were found to be mostly from outside of California [19]. Another study analyzed the responses to the campaign by the Chicago Department of Public Health [26] and presented with a considerably higher number of antipolicy tweets than propolicy tweets, which was contrary to the intention of the campaign. Higher percentage of propolicy tweets were from the Chicago residents, whereas antipolicy tweets were from outside residents. In addition, people wanted to use safer products compared with conventional tobacco products and expressed concerns about propaganda/lies spread by the health department or other government agencies (antipolicy, 32.8%) [26]. This trend was similar on Reddit, which showed 60.7% as opponents of e-cigarette bans and only 9.4% being the proponents [22].

Flavor and Technique

Flavor was identified as one of the main reasons why people used e-cigarettes and also as the common interest among e-cigarette users [22,26]. Specifically, Reddit and JuiceDB showed rich discussions about flavors [22,23], and 9.7% among 1800 Instagram and Pinterest images conveyed information about popular and new juice or flavors, including ideas for creating novel flavors [38]. According to Cole-Lewis et al, about 4.5% of tweets were about flavors [25]. Interestingly, proponents were 15% more likely to tweet about flavors than other users in 2013 and 20 times more likely to tweet in 2015 [23].

Zhan et al identified flavors that were most favored among the e-cigarette users, such as fruits, cream, tobacco, menthol, beverages, sweet, seasonings, nuts, rich, spiced, cool, nutty, and coffee discussed on Reddit and JuiceDB [22]. In addition, there were topics in the Vapor Forum regarding the techniques involved in using vapor products (ie, how to get a good taste, knowing different characteristics of the juices) [37]. There were mixed opinions about flavors on Twitter [26]. Although 0.3% tweets supported the idea that sweet flavors were for kids (propolicy, 0.3%), many opposed the notion of advocating

smoking to children and that adults also enjoy flavors (antipolicy, 3.7%) [26].

Overall, half of the social tweets on secondhand vaping were pro–e-cigarettes (57%), which included video links of vape performance and smoke tricks [29]. Among Instagram and Pinterest, 7.8% of images were those of performing vape tricks [38].

Feelings and Symptoms

Symptoms and feelings related to e-cigarette use were identified [22,35-37]. In total, 405 different symptoms related to e-cigarettes were reported and discussed, of which 318 were negative and 69 were positive [36]. Symptoms related to throat and mouth were most commonly reported [22,37]. There were different views about these symptoms, as many users enjoyed the feeling of slight throat hit, which is similar to that experienced with conventional cigarette smoking [22]; however, these symptoms were viewed as problematic experiences among users [37]. Negative symptoms were perceived as *persistent, worsened, or increasing*, whereas positive symptoms were *decreased, improved, or eliminated* (p. 4) [36]. Anti–e-cigarette tweets among the secondhand vape posts mentioned symptoms of headache, eye irritation, nausea, and lung disease [29].

Marketing and Promotion

Current e-cigarette marketing strategies and different kinds of promotion were identified [19,22,24,37]. Twitter was identified as the major source of advertisement and promotion among people because 26.3% of tweets were identified as being associated with marketing, advertisement, and promotion-related content, which was the single largest category [25]. People shared messages on specific products, coupons, vape shops for e-cigarettes, sale information, and small business on Twitter [19]. There were postings about production promotion and recommendations in the form of user review on JuiceDB and individual trades and vendor promotions on Reddit [22]. Furthermore, existing patterns of a large secondhand e-cigarette trading market, including sales from vendors to users and trades among site users was revealed [22]. In addition, vendors and end users were actively posting about specific products and sale information on e-cigarettes on the Vapor Talk and Hookah Forum [37] as well as Instagram and Pinterest [30,38].

Electronic Cigarette Use Among Youth

The likelihood of e-cigarette use among teenagers was another important theme [9,19,25]. The most common topic tweeted by the US physicians involved concerns about e-cigarette use among teens and the potential of tobacco addiction with the continual use of e-cigarettes among youth (21%) [9]. Similarly, organic-against tweets (17.7%) also prompted e-cigarette prevention for the general public and youth with educational information about harms associated with e-cigarettes [21].

However, although the most common topic among tweets by the US physicians was related to the dangerous rise in the use of e-cigarette among teens that displayed negative sentiment toward e-cigarette, tweets by the UK physicians had no mention of danger among youth [9]. The US physicians were also concerned that advertisement effort was aimed at teenagers and

supported the notion of raising the required age for purchasing e-cigarettes [9]. Youth e-cigarette use was also a concern in another study, particularly regarding the tobacco companies' marketing strategies among the anti–e-cigarette tweets [19], which is consistent with the fact that 4.2% of tweets were on issues regarding e-cigarette use by underage users [25].

Methodological Evaluation

Overall, most studies included in our review were satisfactory for methodological evaluation criteria suggested by the Agency for Healthcare Research and Quality (Table 2). However, a few methodological issues have been identified (Table 2). A few studies needed to provide clearer research questions, although their studies were exploratory in nature [31,33,38]. Most studies provided thorough descriptions of methodology, such as search tools, selection methods, search terms used, and capture period, along with the rationale for data collection procedures and analysis. Most studies used purposive sampling, whereas a few studies used random sampling. Most studies did not have problems with data analysis and results reported, although more detailed descriptions about the analytic methods may have been helpful. It is because some of the analytic techniques and software used for data analysis on social media platforms were relatively new to the readers, given that social media–based research is relatively an emerging area. In addition, procedures to ensure reliability of coding (eg, double-checking by multiple coders) may need to be included in the methods [36]. Moreover, some studies lacked the clear explanation of limitations of their studies, which would be critical for the readers to consider while interpreting the findings [26,33], and more in-depth discussions could have been provided on their findings [23]. Furthermore, it may be an issue related to the journal requirement, but a few studies did not provide information on funding source of their studies [21,26,31].

Table 2. Methodological evaluation.

First author, year	Domains					
	Study question[a]	Data collection[b]	Data analysis[c]	Results[d]	Discussion[e]	Funding or sponsorship[f]
Allem, 2017 [19]	DCA[g]	DCA	DCA	DCA	DCA	DCA
Ayers, 2017 [20]	DCA	DCA	DCA	DCA	DCA	DCA
Burke-Garcia, 2017 [28]	DCA	DCA	DCA	DCA	DCA	DCA
Chu, 2017 [30]	DCA	DCA	DCA	DCA	DCA	DCA
Glowacki, 2017 [9]	DCA	DCA	DCA	DCA	DCA	DCA
Lee, 2017 [28]	DPA[h]	DCA	DCA	DCA	DCA	DCA
Sharma, 2017 [34]	DCA	DCA	DCA	DCA	DCA	DCA
Wigginton, 2017 [33]	DPA	DCA	DCA	DCA	DPA	DPA
Zhan, 2017 [22]	DCA	DCA	DCA	DCA	DCA	DCA
Dai, 2016 [21]	DCA	DCA	DCA	DCA	DCA	DNA[i]
Laestadius, 2016 [31]	DPA	DCA	DCA	DCA	DCA	DNA
Lazard, 2016 [27]	DCA	DCA	DCA	DCA	DCA	DNA
Li, 2016 [35]	DCA	DCA	DCA	DCA	DCA	DCA
Kavuluru, 2016 [23]	DCA	DCA	DCA	DCA	DPA	DCA
Unger, 2016 [29]	DCA	DCA	DCA	DCA	DCA	DCA
van der Tempel, 2016 [24]	DCA	DCA	DCA	DCA	DCA	DCA
Chen, 2015 [37]	DCA	DCA	DCA	DCA	DCA	DCA
Chu, 2015 [32]	DCA	DCA	DCA	DCA	DCA	DCA
Cole-Lewis, 2015 [25]	DCA	DCA	DCA	DCA	DCA	DCA
Harris, 2014 [26]	DCA	DCA	DCA	DCA	DPA	DNA
Hua, 2013 [36]	DCA	DCA	DPA	DCA	DCA	DCA

[a]Study question: Was the purpose of the study clear and focused?

[b]Data collection: Was the data collection adequately described (eg, search tool, selection manual, search terms, and capture period)?

[c]Data analysis: Was the description of the data analysis clearly described (eg, coding process, analytic techniques, classification, and statistical tests)?

[d]Results: Were the outcomes specified (eg, domains or measurement of outcomes)?

[e]Discussion: Were conclusions supported by results, with limitations taken into consideration?

[f]Funding or sponsorship: Was the type and sources of support for study mentioned?

[g]DCA: domain completely addressed.

[h]DPA: domain partially addressed.

[i]DNA: domain not addressed.

Discussion

Summary of Findings

Our findings enable us to gain insights regarding people's experiences with e-cigarettes through the lens of social media platforms and discussions on online forums. Popular social media platforms such as Facebook, Instagram, and Twitter have the ability to quickly spread individual stances and opinions. They have the potential to attract the attention of daily users of social media and both indirectly and directly influence public health and global issues [19]. Overall, there was a higher volume of tweets and discussion threads for pro–e-cigarettes than anti–e-cigarettes. This finding is consistent with a previous study [16]. Positive perceptions relevant to the health effects were also seen when comparing e-cigarettes as a better

alternative to conventional cigarettes. This is consistent with previous studies on general users where the majority believed that e-cigarettes were a safer alternative to conventional cigarettes and acted as an effective smoking cessation aid [41-44]. The negative perceptions mainly arose from topics such as the potential health effects of e-cigarettes, the possible gateway effect to conventional cigarettes, and the risk for addiction.

One of the issues related to e-cigarette use appearing on social media platforms and discussions on online forums included content targeting youth social media users. With the increasing number of youth being exposed to e-cigarettes on popular websites and Web-based sources [45,46], social media use can potentially contribute to the perceptions and interests of smoking among this population [47]. The role of government, policy,

and propaganda appeared as another major theme. One study illustrated the power and reach of social media by suggesting how information can be easily disseminated in a short period and how even a state campaign can influence people all around the nation [19]. Furthermore, social media platforms, particularly Twitter, can be used by e-cigarette proponents, including tobacco companies and related business owners, for defending their positions [26].

The differences in perceptions on social media platforms across countries were also noted. For example, there was a difference between the UK and US physicians' attitudes toward e-cigarettes, in that the US tweets emphasized more on the dangers of its use among youth, whereas the UK tweets focused on the potentiality of e-cigarettes to be used as the smoking cessation aid [9]. When tweets among several countries were analyzed, the United Kingdom showed the highest rate of pro–e-cigarette tweets, whereas Hungary showed the highest rate of anti–e-cigarette tweets [21]. With discussion threads, Switzerland and Canada showed more positive sentiment scores for e-cigarette topics than thread posts by the users of the United States, Australia, the United Kingdom, Ireland, Colombia, Japan, Malaysia, and Pakistan [32].

Furthermore, social media platforms reflected upon the perspectives of some of the population subsets through their e-community such as the physician groups and people with mental health issues [9,24,34]. Motivation for people with mental illness to vape included self-medication and quitting smoking, feeling of self-control, and role for hobby and social connectedness, whereas barriers to vaping included e-cigarettes being considered a low-grade substitute for cigarettes and medicine, risk of addiction, difficulties in using, and cost [34]. This finding is inconsistent with a study on a national sample of US adults where reasons for the use of e-cigarettes among those with mental health conditions were *just because*, quitting smoking, safer mode compared with conventional cigarettes, ease of use, and cost [48].

Contradictory findings were noted with respect to the users of social media platforms, although only a few studies reported on characteristics and proportions of industrial users. One study identified the proportion of users from industry on social media platforms [19]. This study used social media platforms for a public health campaign, and almost half of the total users were industrial users [19]. Another study found strategies of tobacco companies, such as using popular hashtags to increase retweets and using specific hashtags such as #quitsmoking to purposefully reach tobacco users interested in quitting [24]. Most Twitter users were identified as everyday users, with tobacco companies and retailers representing only 7.77% and 1.97%, respectively, in another study [25]. In many cases, e-cigarette companies were targeting young people while promoting their events and popular venues largely via social media platforms, and policy may need to be put in place to reduce advertisements on popular social media sites [49].

Limitations

There are certain limitations to this review. Although we used search strategies and techniques to systematically find the articles from multiple search engines, there remains a possibility of some articles being missed. There can be potential errors in terms of incorrect categorization or elimination of relevant findings that may have contributed to the perceptions and sentiments of e-cigarettes on social media platforms despite multiple coders independently coding articles and analyzing the themes. In addition, we did not specifically include terms such as *perceptions* or *sentiments*, as we did not want to miss articles that had not used these terms in the title, abstract, or keywords by narrowing the search results with those search terms; for example, some articles explored e-cigarette sentiments or perceptions on social media platforms, but they did not use the term *sentiments* or *perceptions* in their titles, abstracts, or keywords [19-24,26-29,33,36-38]. With this search strategy, we had to screen more articles in the initial screening phase, but it yielded a broader pool of articles and lowered the chances of missing relevant articles.

Recommendations for Future Studies

Overall, social media platforms offer benefits in research by serving as data sources for researchers and health care professionals, making it possible to collect and access valuable information regarding perceptions and sentiments of people on social media platforms and online forums. However, owing to the anonymous nature of social media users, only a few studies revealed demographic information about the users [19,23-25]. As a result, we have limited knowledge on how perceptions and sentiments vary depending on subgroups of population. Thus, future studies may need to explore how perceptions and sentiments differ based on the user characteristics, such as age, gender, race/ethnicity, and socioeconomic status. In addition, future studies can benefit by including detailed descriptions of procedures used to ensure reliability of their coding and analytic methods for the readers that may be relatively new to the concept of social media data and research.

Conclusions

This study identifies overall trends of research regarding people's perceptions on e-cigarettes on social media platforms and online forums. People's perceptions and sentiments about e-cigarette use on social media platforms and online forums were more positive than negative. Positive sentiments about e-cigarettes dramatically increased on social media platforms [25], which contradicted the results of the Tobacco Products and Risk Perceptions survey in the same period where there was an increase in negative perceptions among the general public [50]. This may be related to the fact that social media platforms and online forums are being more frequently used by e-cigarette users and those who are interested in potential use or marketing. With the increasing popularity of social media use, it is possible that individuals who regard e-cigarette use as a salient social norm and helpful cessation device may post and comment and build e-communities about e-cigarettes. In addition, the positive views on social media platforms may be related to the steep increase in the use of e-cigarette among adolescents and young adults, who are more frequent social media users. Given the findings of this study, social media platforms can be important channels for intervention delivery. Web or app-based health interventions that deliver appropriate information about the harms and benefits of e-cigarette and

latest research updates on new vaping devices can prove to be   beneficial.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Overview of included articles.
[DOCX File , 29 KB - publichealth_v6i1e13673_app1.docx]

Multimedia Appendix 2
Sentiments and themes identified.
[DOCX File , 36 KB - publichealth_v6i1e13673_app2.docx]

References

1. Jamal A, Phillips E, Gentzke AS, Homa DM, Babb SD, King BA, et al. Current cigarette smoking among adults - United States, 2016. MMWR Morb Mortal Wkly Rep 2018 Jan 19;67(2):53-59 [FREE Full text] [doi: 10.15585/mmwr.mm6702a1] [Medline: 29346338]
2. Cahn Z, Siegel M. Electronic cigarettes as a harm reduction strategy for tobacco control: a step forward or a repeat of past mistakes? J Public Health Policy 2011 Feb;32(1):16-31. [doi: 10.1057/jphp.2010.41] [Medline: 21150942]
3. Farsalinos KE, Romagna G, Tsiapras D, Kyrzopoulos S, Voudris V. Characteristics, perceived side effects and benefits of electronic cigarette use: a worldwide survey of more than 19,000 consumers. Int J Environ Res Public Health 2014 Apr 22;11(4):4356-4373 [FREE Full text] [doi: 10.3390/ijerph110404356] [Medline: 24758891]
4. E-cigarettes.SurgeonGeneral. 2016. E-Cigarette Use Among Youth and Young Adults: A Report of the Surgeon General. URL: https://e-cigarettes.surgeongeneral.gov/documents/2016_sgr_full_report_non-508.pdf [accessed 2019-10-21]
5. Park E, Kwon M. Health-related internet use by children and adolescents: systematic review. J Med Internet Res 2018 Apr 3;20(4):e120 [FREE Full text] [doi: 10.2196/jmir.7731] [Medline: 29615385]
6. Kaplan AM, Haenlein M. Users of the world, unite! The challenges and opportunities of social media. Bus Horiz 2010 Jan;53(1):59-68. [doi: 10.1016/j.bushor.2009.09.003]
7. Helmond A. The platformization of the web: making web data platform ready. Soc Media Soc 2015;1(2):205630511560308. [doi: 10.1177/2056305115603080]
8. Prochaska JJ, Pechmann C, Kim R, Leonhardt JM. Twitter=quitter? An analysis of Twitter quit smoking social networks. Tob Control 2012 Jul;21(4):447-449 [FREE Full text] [doi: 10.1136/tc.2010.042507] [Medline: 21730101]
9. Emery SL, Vera L, Huang J, Szczypka G. Wanna know about vaping? Patterns of message exposure, seeking and sharing information about e-cigarettes across media platforms. Tob Control 2014 Jul;23(Suppl 3):iii17-iii25 [FREE Full text] [doi: 10.1136/tobaccocontrol-2014-051648] [Medline: 24935893]
10. Allem J, Ferrara E, Uppu SP, Cruz TB, Unger JB. E-cigarette surveillance with social media data: social bots, emerging topics, and trends. JMIR Public Health Surveill 2017 Dec 20;3(4):e98 [FREE Full text] [doi: 10.2196/publichealth.8641] [Medline: 29263018]
11. Glowacki EM, Lazard AJ, Wilcox GB. E-cigarette topics shared by medical professionals: a comparison of tweets from the United States and United Kingdom. Cyberpsychol Behav Soc Netw 2017 Feb;20(2):133-137. [doi: 10.1089/cyber.2016.0409] [Medline: 28118024]
12. Anderson M, Jiang J. Pew Research Center. Teens, Social Media & Technology 2018. URL: http://www.pewinternet.org/wp-content/uploads/sites/9/2018/05/PI_2018.05.31_TeensTech_FINAL.pdf [accessed 2019-10-21]
13. Anderson M, Smith A. Pew Research Center. 2018. Social Media Use in 2018. URL: http://www.pewinternet.org/wp-content/uploads/sites/9/2018/02/PI_2018.03.01_Social-Media_FINAL.pdf [accessed 2019-10-21]
14. Pearson JL, Richardson A, Niaura RS, Vallone DM, Abrams DB. e-Cigarette awareness, use, and harm perceptions in US adults. Am J Public Health 2012 Sep;102(9):1758-1766 [FREE Full text] [doi: 10.2105/AJPH.2011.300526] [Medline: 22813087]
15. Duke JC, Allen JA, Eggers ME, Nonnemaker J, Farrelly MC. Exploring differences in youth perceptions of the effectiveness of electronic cigarette television advertisements. Nicotine Tob Res 2016 May;18(5):1382-1386. [doi: 10.1093/ntr/ntv264] [Medline: 26706908]

16.   McCausland K, Maycock B, Leaver T, Jancey J. The messages presented in electronic cigarette-related social media promotions and discussion: scoping review. J Med Internet Res 2019 Feb 5;21(2):e11953 [FREE Full text] [doi: 10.2196/11953] [Medline: 30720440]

17.   Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. PLoS Med 2009 Jul 21;6(7):e1000097 [FREE Full text] [doi: 10.1371/journal.pmed.1000097] [Medline: 19621072]

18.   EndNote. URL: http://endnote.com/product-details/X7 [accessed 2019-10-21]

19.   Allem J, Escobedo P, Chu K, Soto DW, Cruz TB, Unger JB. Campaigns and counter campaigns: reactions on Twitter to e-cigarette education. Tob Control 2017 Mar;26(2):226-229 [FREE Full text] [doi: 10.1136/tobaccocontrol-2015-052757] [Medline: 26956467]

20.   Ayers JW, Leas EC, Allem J, Benton A, Dredze M, Althouse BM, et al. Why do people use electronic nicotine delivery systems (electronic cigarettes)? A content analysis of Twitter, 2012-2015. PLoS One 2017;12(3):e0170702 [FREE Full text] [doi: 10.1371/journal.pone.0170702] [Medline: 28248987]

21.   Dai H, Hao J. Mining social media data for opinion polarities about electronic cigarettes. Tob Control 2017 Mar;26(2):175-180. [doi: 10.1136/tobaccocontrol-2015-052818] [Medline: 26980151]

22.   Zhan Y, Liu R, Li Q, Leischow SJ, Zeng DD. Identifying topics for e-cigarette user-generated contents: a case study from multiple social media platforms. J Med Internet Res 2017 Jan 20;19(1):e24 [FREE Full text] [doi: 10.2196/jmir.5780] [Medline: 28108428]

23.   Kavuluru R, Sabbir AK. Toward automated e-cigarette surveillance: spotting e-cigarette proponents on Twitter. J Biomed Inform 2016 Jun;61:19-26 [FREE Full text] [doi: 10.1016/j.jbi.2016.03.006] [Medline: 26975599]

24.   van der Tempel J, Noormohamed A, Schwartz R, Norman C, Malas M, Zawertailo L. Vape, quit, tweet? Electronic cigarettes and smoking cessation on Twitter. Int J Public Health 2016 Mar;61(2):249-256. [doi: 10.1007/s00038-016-0791-2] [Medline: 26841895]

25.   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]

26.   Harris JK, Moreland-Russell S, Choucair B, Mansour R, Staub M, Simmons K. Tweeting for and against public health policy: response to the Chicago Department of Public Health's electronic cigarette Twitter campaign. J Med Internet Res 2014 Oct 16;16(10):e238 [FREE Full text] [doi: 10.2196/jmir.3622] [Medline: 25320863]

27.   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]

28.   Burke-Garcia A, Stanton CA. A tale of two tools: Reliability and feasibility of social media measurement tools examining e-cigarette twitter mentions. Inform Med Unlock 2017 May;8(5):8-12. [doi: 10.1016/j.imu.2017.04.001]

29.   Unger JB, Escobedo P, Allem J, Soto DW, Chu K, Cruz T. Perceptions of secondhand e-cigarette aerosol among Twitter users. Tob Regul Sci 2016 Apr;2(2):146-152 [FREE Full text] [doi: 10.18001/TRS.2.2.5] [Medline: 28090560]

30.   Chu K, Allem J, Cruz TB, Unger JB. Vaping on Instagram: cloud chasing, hand checks and product placement. Tob Control 2016 Sep;26(5):575-578 [FREE Full text] [doi: 10.1136/tobaccocontrol-2016-053052] [Medline: 27660111]

31.   Laestadius LI, Wahl MM, Cho YI. #Vapelife: An exploratory study of electronic cigarette use and promotion on Instagram. Subst Use Misuse 2016 Oct 14;51(12):1669-1673. [doi: 10.1080/10826084.2016.1188958] [Medline: 27484191]

32.   Chu K, Valente TW. How different countries addressed the sudden growth of e-cigarettes in an online tobacco control community. BMJ Open 2015 May 21;5(5):e007654 [FREE Full text] [doi: 10.1136/bmjopen-2015-007654] [Medline: 25998038]

33.   Wigginton B, Gartner C, Rowlands IJ. Is it safe to vape? Analyzing online forums discussing e-cigarette use during pregnancy. Womens Health Issues 2017;27(1):93-99. [doi: 10.1016/j.whi.2016.09.008] [Medline: 27773530]

34.   Sharma R, Wigginton B, Meurk C, Ford P, Gartner CE. Motivations and limitations associated with vaping among people with mental illness: a qualitative analysis of Reddit discussions. Int J Environ Res Public Health 2016 Dec 22;14(1) [FREE Full text] [doi: 10.3390/ijerph14010007] [Medline: 28025516]

35.   Li Q, Zhan Y, Wang L, Leischow SJ, Zeng DD. Analysis of symptoms and their potential associations with e-liquids' components: a social media study. BMC Public Health 2016 Jul 30;16:674 [FREE Full text] [doi: 10.1186/s12889-016-3326-0] [Medline: 27475060]

36.   Hua M, Alfi M, Talbot P. Health-related effects reported by electronic cigarette users in online forums. J Med Internet Res 2013 Apr 8;15(4):e59 [FREE Full text] [doi: 10.2196/jmir.2324] [Medline: 23567935]

37.   Chen AT, Zhu S, Conway M. What online communities can tell us about electronic cigarettes and hookah use: a study using text mining and visualization techniques. J Med Internet Res 2015 Sep 29;17(9):e220 [FREE Full text] [doi: 10.2196/jmir.4517] [Medline: 26420469]

38.   Lee AS, Hart JL, Sears CG, Walker KL, Siu A, Smith C. A picture is worth a thousand words: electronic cigarette content on Instagram and Pinterest. Tob Prev Cessat 2017 Jul;3:pii: 119 [FREE Full text] [doi: 10.18332/tpc/74709] [Medline: 28815224]

39. Collins KM, Onwuegbuzie AJ, Jiao QG. A mixed methods investigation of mixed methods sampling designs in social and health science research. J Mix Methods Res 2007;1(3):267-294. [doi: 10.1177/1558689807299526]

40. Thompson KS, Davis G, Frankfort-Nachmias C. Study Guide to Accompany Research Methods in the Social Sciences, Chava Frankfort-Nachmias, David Nachmias. Seventh Edition. New York, NY: Worth Publishers; 2007.

41. Adkison SE, O'Connor RJ, Bansal-Travers M, Hyland A, Borland R, Yong H, et al. Electronic nicotine delivery systems: international tobacco control four-country survey. Am J Prev Med 2013 Mar;44(3):207-215 [FREE Full text] [doi: 10.1016/j.amepre.2012.10.018] [Medline: 23415116]

42. Dockrell M, Morrison R, Bauld L, McNeill A. E-cigarettes: prevalence and attitudes in Great Britain. Nicotine Tob Res 2013 Oct;15(10):1737-1744 [FREE Full text] [doi: 10.1093/ntr/ntt057] [Medline: 23703732]

43. Etter J, Bullen C. Electronic cigarette: users profile, utilization, satisfaction and perceived efficacy. Addiction 2011 Nov;106(11):2017-2028. [doi: 10.1111/j.1360-0443.2011.03505.x] [Medline: 21592253]

44. Pepper JK, Brewer NT. Electronic nicotine delivery system (electronic cigarette) awareness, use, reactions and beliefs: a systematic review. Tob Control 2014 Sep;23(5):375-384 [FREE Full text] [doi: 10.1136/tobaccocontrol-2013-051122] [Medline: 24259045]

45. Duke JC, Lee YO, Kim AE, Watson KA, Arnold KY, Nonnemaker JM, et al. Exposure to electronic cigarette television advertisements among youth and young adults. Pediatrics 2014 Jul;134(1):e29-e36. [doi: 10.1542/peds.2014-0269] [Medline: 24918224]

46. Krishnan-Sarin S, Morean ME, Camenga DR, Cavallo DA, Kong G. E-cigarette use among high school and middle school adolescents in Connecticut. Nicotine Tob Res 2015 Jul;17(7):810-818 [FREE Full text] [doi: 10.1093/ntr/ntu243] [Medline: 25385873]

47. Kim M, Popova L, Halpern-Felsher B, Ling PM. Effects of e-cigarette advertisements on adolescents' perceptions of cigarettes. Health Commun 2019 Mar;34(3):290-297. [doi: 10.1080/10410236.2017.1407230] [Medline: 29236550]

48. Cummins SE, Zhu S, Tedeschi GJ, Gamst AC, Myers MG. Use of e-cigarettes by individuals with mental health conditions. Tob Control 2014 Jul;23(Suppl 3):iii48-iii53 [FREE Full text] [doi: 10.1136/tobaccocontrol-2013-051511] [Medline: 24824516]

49. de Andrade M, Hastings G, Angus K, Dixon D, Purves R. Cancer Research UK. 2013. The Marketing of Electronic Cigarettes in the UK. URL: http://www.cancerresearchuk.org/sites/default/files/cruk_marketing_of_electronic_cigs_nov_2013.pdf [accessed 2019-10-21]

50. Majeed BA, Weaver SR, Gregory KR, Whitney CF, Slovic P, Pechacek TF, et al. Changing perceptions of harm of e-cigarettes among US adults, 2012-2015. Am J Prev Med 2017 Mar;52(3):331-338 [FREE Full text] [doi: 10.1016/j.amepre.2016.08.039] [Medline: 28341303]

Abbreviations

API: application programming interface
e-cigarette: electronic cigarette
MeSH: Medical Subject Headings

Original Paper

Exploring Substance Use Tweets of Youth in the United States: Mixed Methods Study

Robin C Stevens[1], MPH, PhD; Bridgette M Brawner[2], PhD, MDiv; Elissa Kranzler[3], PhD; Salvatore Giorgi[4], MA, MS; Elizabeth Lazarus[5]; Maramawit Abera[5], BA; Sarah Huang[5], BSN; Lyle Ungar[5], PhD

[1]Department of Family and Community Health, University of Pennsylvania School of Nursing, Philadelphia, PA, United States

[2]University of Pennsylvania School of Nursing, Philadelphia, PA, United States

[3]Wharton Risk Management and Decision Processes Center, Philadelphia, PA, United States

[4]Department of Computer and Information Science, Philadelphia, PA, United States

[5]Crescenz Veterans Affairs Medical Center, Philadelphia, PA, United States

Corresponding Author:
Robin C Stevens, MPH, PhD
Department of Family and Community Health
University of Pennsylvania School of Nursing
418 Fagin Hall
Philadelphia, PA
United States
Phone: 1 2158984063
Email: robin2@nursing.upenn.edu

Abstract

Background: Substance use by youth remains a significant public health concern. Social media provides the opportunity to discuss and display substance use–related beliefs and behaviors, suggesting that the act of posting drug-related content, or viewing posted content, may influence substance use in youth. This aligns with empirically supported theories, which posit that behavior is influenced by perceptions of normative behavior. Nevertheless, few studies have explored the content of posts by youth related to substance use.

Objective: This study aimed to identify the beliefs and behaviors of youth related to substance use by characterizing the content of youths' drug-related tweets. Using a sequential explanatory mixed methods approach, we sampled drug-relevant tweets and qualitatively examined their content.

Methods: We used natural language processing to determine the frequency of drug-related words in public tweets (from 2011 to 2015) among youth Twitter users geolocated to Pennsylvania. We limited our sample by age (13-24 years), yielding approximately 23 million tweets from 20,112 users. We developed a list of drug-related keywords and phrases and selected a random sample of tweets with the most commonly used keywords to identify themes (n=249).

Results: We identified two broad classes of emergent themes: functional themes and relational themes. *Functional* themes included posts that explicated a function of drugs in one's life, with subthemes indicative of *pride*, *longing*, *coping*, and *reminiscing* as they relate to drug use and effects. *Relational* themes emphasized a relational nature of substance use, capturing substance use as a part of social relationships, with subthemes indicative of drug-related *identity* and *companionship*. We also identified topical areas in tweets related to drug use, including reference to *polysubstance use*, *pop culture*, and *antidrug* content. Across the tweets, the themes of *pride* (63/249, 25.3%) and *longing* (39/249, 15.7%) were the most popular. Most tweets that expressed *pride* (46/63, 73%) were explicitly related to marijuana. Nearly half of the tweets on *coping* (17/36, 47%) were related to prescription drugs. Very few of the tweets contained *antidrug* content (9/249, 3.6%).

Conclusions: Data integration indicates that drugs are typically discussed in a positive manner, with content largely reflective of functional and relational patterns of use. The dissemination of this information, coupled with the relative absence of antidrug content, may influence youth such that they perceive drug use as normative and justified. Strategies to address the underlying causes of drug use (eg, coping with stressors) and engage antidrug messaging on social media may reduce normative perceptions and associated behaviors among youth. The findings of this study warrant research to further examine the effects of this content on beliefs and behaviors and to identify ways to leverage social media to decrease substance use in this population.

XSL•FO
RenderX

Introduction

Background

Despite previous decline in alcohol and drug use among youth, the rates of substance use have generally plateaued in recent years [1]. Estimates indicate that 62.5% of underage alcohol users are binge alcohol users, 1.6 million youth aged between 12 and 17 years used marijuana in the past month, and 7.3% of youth aged between 18 and 25 years misused opioids (eg, hydrocodone and oxycodone) in the past year [2]. This is a significant public health concern given that substance use, particularly early in life, is associated with a host of negative outcomes such as increased sexual risk behavior [3], negative academic outcomes, and increased risk of substance abuse later in life [4,5].

Social media use has increased dramatically over the past decade, with near-ubiquitous use among adolescents and young adults [6,7]. At least 85% of adolescents use one or more of the several popular social media platforms (eg, YouTube, Instagram, and Snapchat) [6], and 88% of young adults (aged 18-29 years) report using any form of social media [7]. Compared with other age groups, youth report the highest rates of use within and across social media platforms, noting that they use social media to connect with friends and family, to obtain news and information, for entertainment purposes, and as a space for self-expression [6,7]. With such high levels of Web engagement and diverse usage patterns, social media has drastically changed how information, both in general and specifically about risk-related behaviors (eg, alcohol and other substance use), is received by and exchanged among youth [8,9].

Youth use social media to discuss and display substance use behaviors [10-15], which have been linked to their behaviors offline [16]. Substantial research has demonstrated associations between substance-related social media engagement and substance use behaviors in real life [12,15,17,18], suggesting that the act of posting substance-related content, or viewing such content posted by others, may influence substance use in youth. This potential model of effects aligns with empirically supported theories of behavior change, which posit that risk behavior adoption is influenced by behavioral modeling and perceived norms (eg, perceptions of what one's peers are doing) [19,20]. Through social media platforms, youth are connected to and are able to witness the beliefs and behaviors of a larger group of peers [21], where normative drug use may be featured and cultivated on the Web [22]. From a developmental perspective, adolescence is characterized by heightened attention to social norms and an increased desire for social approval [23,24]. Online discussions about drugs may be particularly impactful for this population as public posts can convey normative beliefs to other youth, particularly when posts support or promote drug use. Thus, the broadcasting of beliefs and behaviors related to drug use may influence youths' perceptions of normative behavior, thereby influencing decisions on drug use among youth who are exposed to such conversations.

Although previous research has examined social media usage by youth as it relates to health-related outcomes [17,25], few studies have explored how youth discuss content related to substance use on Twitter. In one study, researchers examined the relationship between young adults' alcohol-related tweets and self-reported cognitions and behaviors related to alcohol use; findings demonstrated that the proportion of one's overall tweets related to alcohol was significantly associated with the willingness to drink and use alcohol [26]. In a separate study, researchers surveyed young adults about their exposure to alcohol- and marijuana-related content on Twitter and their use of these substances [21]. Analyses demonstrated significant associations between current heavy episodic drinking and higher levels of exposure to proalcohol content and between current marijuana use and higher levels of exposure to promarijuana content. However, no previous research has specifically examined the content of youths' tweets about substance use, a potential predictor of beliefs and behaviors about substance use.

Objectives

The primary goal of this study was to identify youths' beliefs and behaviors related to drug use by characterizing the content of drug-related tweets by youth. Using a mixed methods approach, we investigated the relationships between the type of drug, language of the tweet, and reasons for drug use. This study provides insight into publicly stated beliefs about drugs and drug use on social media. Given the increased salience of social considerations (eg, social norms and external validation) during adolescence, youths' tweets about substance use may contribute to the perception of what is *normal*, leading youth to espouse distorted perceptions of normative behavior and to model that behavior in real life. Through this systematic examination of youths' beliefs about substance use, we can better understand the potential mechanisms driving substance use behavior.

Methods

Overview

This study employed a *sequential explanatory mixed methods* design to examine how popular drugs are discussed by youth on Twitter [27]. A mixed methods research approach was most appropriate given that quantitative or qualitative data, by themselves, would be insufficient to capture the nuances of youths' tweets about substances. The use of mixed methods in social media research has grown in popularity as researchers seek to capitalize on the strengths of each data source [28], gaining a better understanding of their phenomena of interest. We chose the sequential explanatory design, placing priority on the qualitative data, to obtain a general understanding of the tweets and to contextualize the results.

Following this approach, we first conducted quantitative data collection and analysis to identify an appropriate sample of youths' tweets, and then, we conducted qualitative data analysis to examine the content of these tweets. We used natural language processing (NLP) techniques to determine the frequency of use of drug-related words in public English-language tweets among the youth and emerging adult users of Twitter in Pennsylvania. We subsequently conducted a qualitative content analysis of a random sample of tweets for in-depth exploration of the context in which the words were used. This methodology provides a more nuanced view of substance use–related messages posted publicly by youth online, offering insights that may not be apparent through the analysis of quantitative or qualitative data in isolation. A key step in the mixed methods research is the integration of quantitative and qualitative data. We integrated data in two ways: (1) *connecting*, wherein the data were linked through the sampling frame such that we had quantitative and qualitative data for each participant, and (2) *merging*, wherein the two datasets were brought together for analyses [29]. For interpretation and reporting, we used a weaving approach whereby the NLP and content analysis results are presented together on a theme‐by‐theme basis [29]. See Figure 1 for the data flow diagram. This study was deemed exempt by the institutional review board of the University of Pennsylvania.

Figure 1. Data flow diagram. API: application programming interface; NLP: natural language processing.
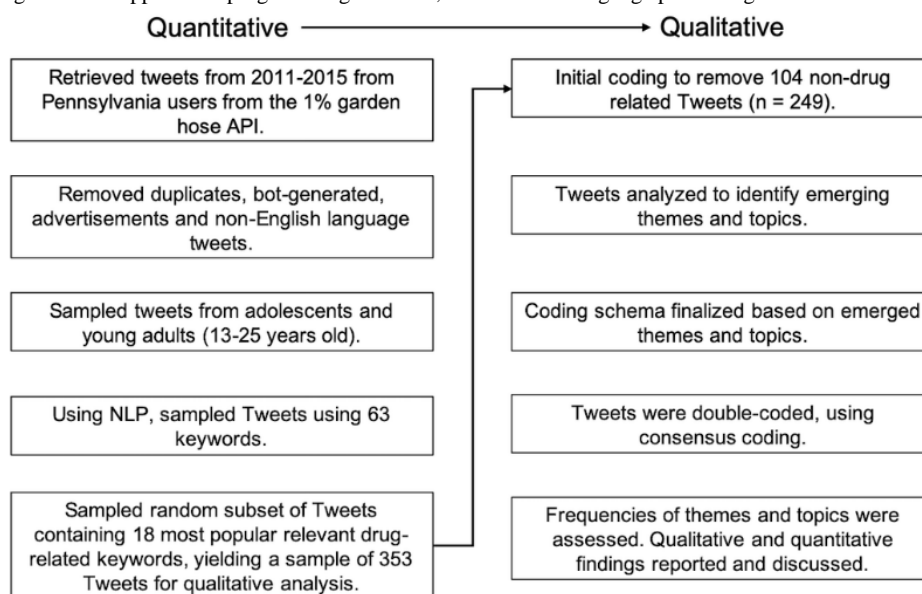
Twitter Dataset

Data analysis was conducted with a sample of drug-related tweets posted on Twitter over a 4-year period. Using Twitter's application programming interface, which provides broad access to public Twitter data, we drew a random sample of 1% of publicly available tweets posted between 2011 and 2015. Tweets were geolocated to US counties using tweet-specific latitude and longitude coordinates and self-reported location information in Twitter's user profiles [30]. Using the open source Python package TwitterMySQL [31], we pulled the most recent 3200 tweets for each user geolocated to Pennsylvania, resulting in a dataset of over 440 million tweets. After removing both non-English tweets and duplicate tweets [32,33], often from bots and advertisers, we produced age and racial affiliation estimates for each user based on our tested algorithms [34,35]. We limited our sample by predicted age (13-17 years) and predicted race (black or non-Hispanic white), yielding 10,056 distinct adolescent users. We then randomly sampled a comparable number of emerging adult users with a predicted age of 18 to 24 years to match the adolescent sample. This approach yielded approximately 23 million tweets from 20,112 adolescents and young adults in Pennsylvania.

Quantitative Retrieval of Drug-Related Tweets

To identify drug-relevant Twitter posts, we built lists of drug-related words and phrases, drawing from previous research [21], music lyrics, and slang dictionaries. We used these words and phrases to develop our classifier, which we iteratively improved using manual coders to assess the yields on a training dataset. Once we finalized the keyword list, comprising 63 drug-related words, we retrieved a random sample of tweets containing those keywords, yielding approximately 872 tweets for manual coding. The research team then identified which of the 63 keywords led to the retrieval of the largest number of relevant tweets. The 12 keywords that yielded the greatest proportion of drug-relevant tweets are listed in Table 1. We separated hashtagged versions of these words as well as word extensions (eg, "high" vs "highlife"), expanding our list to 18 keywords to capture potentially nuanced differences in usage.

We then selected a random sample of approximately 20 tweets containing each of the 18 frequently used drug-related keywords, totaling 353 tweets, for qualitative coding. As some keywords did not yield 20 relevant tweets, we coded the total number of tweets that were retrieved. Each tweet was coded independently by 3 coders to ensure it was drug-related (n=249). When coders could not reach agreement based on independent coding, they worked together to make a final determination. Nonrelevant tweets (n=104) were excluded from further analyses.

Table 1. Drug-related keywords, number of tweets sampled by keywords, relevant tweets, and keyword sensitivity.

Drug-related keywords	Tweets sampled by keyword (n=353), n	Relevant tweets (n=249), n	Keyword sensitivity[a], n (%)
#blunt(s)	19	13	13 (68)
Blunt	20	12	12 (60)
#high	20	13	13 (65)
#highlife	20	12	12 (60)
High	20	6	6 (30)
#marijuana	14	7	7 (50)
Marijuana	20	12	12 (60)
#wakenbake	16	9	9 (56)
Ganja	20	17	17 (85)
Pot	20	10	10 (50)
Pothead	20	17	17 (85)
Smoke	20	18	18 (90)
Stoned	20	17	17 (85)
Stoner	20	13	13 (65)
#stoner	12	9	9 (75)
Weed	20	19	19 (95)
Adderall	20	16	16 (80)
Valium	12	11	11 (91)
Xanax	20	18	18 (90)

[a]Keyword sensitivity is the percentage of tweets from the total sample that were deemed relevant during manual coding.

Qualitative Coding of Tweets Using Content Analysis

In the second stage of our mixed methods approach, we analyzed the sample of 249 drug-related tweets using established procedures for qualitative content analysis [36,37], a technique for making replicable and valid inferences from texts to the contexts of their use [22]. A total of 3 undergraduate students were extensively trained to code tweets for emergent themes. The relevant tweets were qualitatively analyzed in a multistage process that began with the identification of initial codes generated from prior literature and emerging themes. The team then coded the tweets until they reached consensus on thematic coding. Themes are not mutually exclusive; thus, tweets could be categorized under multiple themes. Inter-rater reliability was achieved at kappa=0.80 across key themes and topics, demonstrating acceptable reliability. We also calculated frequencies to describe the proportion of the sample categorized under each theme. In addition to emerging themes, we identified frequently occurring topics in tweets related to drug use and determined the proportion of tweets with antidrug content. All example tweets cited in the Results section were modified to retain their meaning, although they were rendered unsearchable on the internet [38]. The example tweets are accompanied by explanatory text, where appropriate, in brackets.

Results

Quantitative Findings

Table 1 lists the drug-related keywords used to retrieve the random sample of tweets and the number of tweets from each keyword included in the analysis. In total, we coded 249 tweets. As most of our keywords were specific to marijuana (12 out of 18), the majority of tweets in our analysis were also marijuana-related. Of the 6 keywords not explicitly related to marijuana, 3 were related to the prescription drugs Xanax, Percocet, and Adderall, and 3 keywords were nondrug-specific words related to substance use ("high," "#high," and "highlife"). We assessed the sensitivity of each keyword in retrieving relevant tweets. "Weed" was the most sensitive keyword, with the highest rate of retrieving drug-related tweets. "High" was the least sensitive keyword, retrieving relevant tweets 30.0% of the time.

We identified two broad classes of themes in our sample of tweets: *functional* themes and *relational* themes. Functional themes included posts that explicated a function of drugs in the user's life. Within this broader classification, we identified functional subthemes indicative of *pride*, *longing*, *coping*, and *reminiscing* as they relate to drug use or effects. The second class of themes emphasized a relational nature of substance use. Specifically, this theme captured substance use as a part of social relationships. The subthemes identified in this category were *identity* and *companionship* as they relate to drug use. In addition

to emergent themes, we also identified several topical areas in tweets related to drug use, which included reference to polysubstance use, pop culture, and antidrug content.

Across the sampled tweets, subthemes of *pride* (63/249, 25.3%) and *longing* (39/249, 15.7%) were the most popular. Thematic differences emerged between tweets about prescription drugs versus nonprescription drugs.

Functional Themes

Pride

As the most popular theme, approximately one-quarter of all tweets in the sample (63/249, 25.3%) expressed pride in drug use. Tweets such as "This was the #first #blunt I rolled that the mans didn't have to fix :) #wassoproud #smokeditsonice" and "Happy 420 !(: I just rolled my first blunt !! #RolledBlunt #Happy420" exemplify users' pride in their skills related to drug use. Most tweets that expressed *pride* (46/63, 73%) were explicitly related to marijuana.

Longing

In tweets related to longing, users expressed yearning, desire, or craving for either a drug or the effects of a drug. Tweets such as "I would rather be high right now" and "could really use me a #blunt #like #now" explicitly portray the user's desire for a substance or for the associated feeling. Although these tweets do not specify the actual intention or use of drugs in the future, the users communicated a desire to get high given their current circumstance.

Coping

Tweets related to coping described drug use as a coping strategy, often as a means to manage stressors and emotions, for example, "marijuana is useful for treating _____ INSERT whatev er the fuck your problem is here" and "Who ever said can't buy happiness obviously didn't kno w any pot dealers." In addition, many coping-related tweets were about prescription drugs: "If it was not for adderall idk [I don't know] how would deal with all of this college work rs [real shit]." Coping-related tweets are distinguished from longing-related tweets (eg, "I could use some Adderall right now...") to the extent that the users specifically stated that they were trying to manage a condition (eg, a stressor or emotion) with drugs. Nearly half of the tweets on *coping* (17/36, 47%) were related to prescription drugs. Very few of the tweets contained *antidrug* content (9/249, 3.6%).

Reminiscing

Reminiscing described tweets that expressed nostalgia or wistfulness or depicted a user looking back at a drug-related experience. The tweet "That night I was soo drunk...soo high...Can't even remember...#trippinBalls #MissThoseNights #HighLife" exemplifies how the user was fondly thinking back to a time when they used drugs. In the tweet "@[another user] yo go to the gram and look at that ganja i had last night lil," the user is remembering and referring to their past drug use posted on Instagram, another social media platform.

Relational Themes

Identity

Tweets were categorized under the identity category if the user classified himself/herself or another person with a drug-related label or name. For example, "She called me a pothead tho...Naaaah, I prefer stoner" labels the user as a pothead or a stoner. In the tweet "You know your boyfriends a pothead when he wakes up out of a dead sleep to smoke," the user has categorized another drug user as a pothead. In this class of tweets, these names do not necessarily carry a negative connotation; rather, they convey the user's pride in being thought of as a *stoner*.

Companionship

Tweets were categorized under the companionship theme if they expressed a feeling of fellowship or friendship, particularly when the tweet suggested that the user was looking for a companion to join in drug use. "Someone find me a #blunt and a cuddlebuddy" illustrates a Twitter user who indirectly asked the public for a companion to smoke with. "Burn riiiide with new friends???????? #bong #blunt #lovelife" portrays a different form of companionship where the user is not directly searching for a companion but describes the feeling of using drugs in fellowship with friends. The tweets in this category refer to the social connectedness component of substance use.

Associated Topics

Polysubstance Use

Tweets within this category contained content that implied the use of multiple substances. "Got that percaset, promenthasen with codeine, Xanax!" suggests that the user intends to take or sell the 3 drugs mentioned with codeine. Another tweet, "I like to chase a few xanax bars with A crown royal" more clearly models polysubstance use, with the user explaining the order in which they prefer to use alcohol and another substance.

Pop Culture

Tweets containing content that referred to song lyrics, celebrities, or trending topics were categorized under pop culture. For example, "Ain't a fucking sing along unless you brought the weed along" and "One by one, load up de van, all of a ganja it ram" are music lyrics. Although the tweets may or may not refer to the user's actual drug-related behavior, these examples demonstrate how references to drug use in song lyrics are disseminated on social media.

Antidrug

Of the 249 tweets in our sample, only 9 (3.6%) included antidrug messaging. Antidrug tweets contained only 4 drug-related keywords: "marijuana," "smoke," "weed," and "valium." One such tweet conveys a strong antidrug perspective: "I see so many people of our generation glorifying xanax and valium and perks. It's so fucking disgusting." In another tweet, "No amount of weed is worth a fucking life," the user links marijuana use with unspecified, though serious, repercussions.

Themes and Drug-Related Keywords

Figure 2 is a visual representation of the presence of themes for each drug-related keyword. Except for Adderall, Valium, and Xanax, all drug-related keywords were most frequently associated with *pride, identity,* and *companionship*. Tweets about prescription drugs (Adderall, Valium, and Xanax), however, were more frequently categorized under the themes of *coping* and *polysubstance use*.

Figure 2. Frequency of themes from tweets having drug-related keywords.
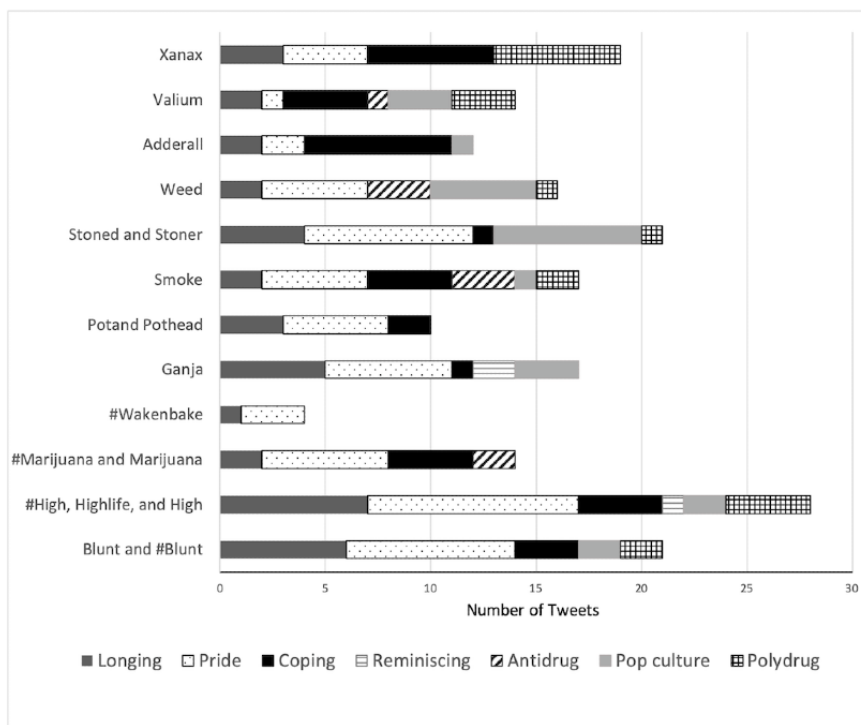
Discussion

Principal Findings

Youths' discourse about drug use on Twitter offers valuable insights into the normative beliefs and behaviors, as expressed online. Our systematic mixed methods approach to examine the use of Twitter by youth to discuss drugs furthers our understanding of the potential mechanisms driving substance use behavior, from an expression of pride to a means for coping with life stressors. In the tweets studied, we found that the most popular drug-related keywords were related to marijuana, followed in popularity by prescription drugs. The relative popularity of drug-related keywords related to these substances mirrors broader substance use patterns as marijuana is the illicit substance that is most commonly used among youth [1]. Thematic analyses indicate that drugs were typically discussed in a positive manner, including positive messages about previous experiences with drugs or one's desire to use drugs again. Our findings also suggest that users are comfortable posting public endorsements of drug use.

Youth expressed pride, confidence, or boastfulness online about their drug-related behaviors. Youth who boasted about their drug use on Twitter often linked drug use to their identities. In addition, online discussions of drug use were regularly associated with social contexts, mirroring the correlation of youths' substance use in offline settings. In many tweets, youth indicated a craving or desire for a drug or the effects of drug use. This is particularly notable as there was little discussion about the addictive nature of substances. Without this, the risks and negative outcomes associated with drug use are largely absent from peer online discussion.

We found that prescription drugs were used for coping, specifically as a tool to cope with challenges, grief, or stress. These tweets may help explain, in part, the rise in misuse of prescription drugs, with approximately 2200 youth misusing pain medications each day [2]. Youth online view Xanax, Percocet, and Valium as tools to cope with the challenges they face rather than as a part of peer social drug use (as was seen with marijuana). When youth opt to use these drugs for emotional regulation and to help deal with life stressors, they can increase their risk of future addiction [39]. The tweets also reveal that prescription drug–related tweets are mentioned along with other drugs and alcohol use. This echoes previous research, which found that almost 1 in 10 Adderall-related tweets contained reference to another substance [40].

Substance use among youth is a highly social behavior to the extent that the usage patterns are influenced heavily by perceived peer norms and behaviors [23]. Substance use messages posted on social media are related to youths' substance use behaviors offline and may also influence the normative beliefs of youth who are exposed to those messages [41-44]. When youth describe the frequency of their marijuana or prescription drug use online, these messages endorse substance use as normative behavior among youth. This holds true despite the potential legal implications of underage drinking or illegal substance use. For example, in Pennsylvania, recreational marijuana use is

illegal and medical marijuana use is highly regulated. However, on social media, youth discuss and disclose their drug use behavior, although these behaviors are illegal in the state. Thus, the perceived norm of substance use acceptability may outweigh the perceived consequences of such use.

Although our analysis uncovered posts about the negative consequences or effects of substance use, as demonstrated in previous research [16,45-48], these posts represented less than 3.6% (9/249) of our sample. In the absence of such antidrug messages, social media platforms may convey a meta-message to youth that the usage of drugs, specifically marijuana, is not associated with adverse consequences. It is notable that prescription drugs were not discussed with the same level of pride as marijuana. However, prescription drug–related posts often included reference to other substances, suggesting that the discussions of prescription drug use on social media are an indicator of polysubstance use. Strategies that address the underlying causes of drug use (eg, coping with stressors) and engage the positive drug messaging on social media are needed to help reduce the elevated prevalence of early polysubstance use behavior among adolescents [22].

Limitations

There are several limitations to this study. The subset of tweets we examined may not represent the entire population of youths' tweets containing drug-related content; thus, our results may not generalize beyond the study sample. It is possible that additional drug-related keywords were missed in the culling of the data and are thus missing from analyses. Social desirability may bias results, leading youth to post specific prodrug content such that they appear to endorse substance use beliefs and behaviors online that they may not actually hold. Moreover, the cross-sectional study design limits our ability to link the tweets to actual offline substance use behavior. Future longitudinal studies are needed to examine youths' social media posts overtime, correlating these posts with substance use–related behaviors and identifying predictors of future drug use based on social media use behavior.

Conclusions

With its great popularity among youth, social media is a fruitful platform for examining youth cognitions and behavior related to specific drug use. Through a mixed methods approach, we established the frequency with which drugs are discussed by members of this population on Twitter, generated a list of words and hashtags to contribute to analytical lexicons for others interested in similar research, and identified themes indicative of the ways in which youth discuss their support for (or opposition to) substance use on social media. Together, these findings contribute to the literature by indicating a critical need to leverage social media to challenge myths and unhealthy online substance use norms. Further inquiry is needed to better understand how exposure to drug-related content on social media influences youths' behavior and to identify ways to leverage positive aspects of social media (eg, group connectedness and sharing of health-related information) to decrease substance use and improve health outcomes.

Conflicts of Interest

None declared.

References

1. Johnston LD, Miech RA, O'Malley PM, Bachman JG, Schulenberg JE, Patrick ME. Deep Blue - University of Michigan. 2018. Monitoring the Future National Survey Results on Drug Use, 1975-2017: Overview, Key Findings on Adolescent Drug Use URL: https://deepblue.lib.umich.edu/bitstream/handle/2027.42/148123/Overview%202018%20FINAL%20print%201-30.pdf?sequence=1&isAllowed=y [accessed 2020-01-16]

2. Bose J, Hedden SL, Lipari RN, Park-Lee E. Substance Abuse Mental Health Services Administration. 2018 Sep. Key Substance Use and Mental Health Indicators in the United States: Results from the 2017 National Survey on Drug Use and Health URL: https://www.samhsa.gov/data/sites/default/files/cbhsq-reports/NSDUHFFR2017/NSDUHFFR2017.htm [accessed 2018-10-19]

3. Office of the Surgeon General, US Department of Health and Human Services. The Surgeon General's Call to Action to Prevent and Reduce Underage Drinking. Rockville, MD: US Department of Health and Human Services; 2007.

4. Volkow ND, Baler RD, Compton WM, Weiss SR. Adverse health effects of marijuana use. N Engl J Med 2014 Jun 5;370(23):2219-2227 [FREE Full text] [doi: 10.1056/NEJMra1402309] [Medline: 24897085]

5. Henry KL, Knight KE, Thornberry TP. School disengagement as a predictor of dropout, delinquency, and problem substance use during adolescence and early adulthood. J Youth Adolesc 2012 Feb;41(2):156-166 [FREE Full text] [doi: 10.1007/s10964-011-9665-3] [Medline: 21523389]

6. Anderson M, Jiang J. Pew Research Center. 2018 May 31. Teens, Social Media & Technology 2018 URL: https://www.pewinternet.org/2018/05/31/teens-social-media-technology-2018/ [accessed 2020-01-16]

XSL•FO

RenderX

7. Smith A, Anderson M. Pew Research Center. 2018 Mar 1. Social Media Use in 2018 URL: https://www.pewinternet.org/2018/03/01/social-media-use-in-2018/ [accessed 2020-01-16]

8. Yonker LM, Zan S, Scirica CV, Jethwani K, Kinane TB. 'Friending' teens: systematic review of social media in adolescent and young adult health care. J Med Internet Res 2015 Jan 5;17(1):e4 [FREE Full text] [doi: 10.2196/jmir.3692] [Medline: 25560751]

9. Mackey TK, Liang BA, Strathdee SA. Digital social media, youth, and nonmedical use of prescription drugs: the need for reform. J Med Internet Res 2013 Jul 26;15(7):e143 [FREE Full text] [doi: 10.2196/jmir.2464] [Medline: 23892156]

10. Boyd D. It's Complicated: The Social Lives of Networked Teens. New Haven, Connecticut: Yale University Press; 2014.

11. Livingstone S. Taking risky opportunities in youthful content creation: teenagers' use of social networking sites for intimacy, privacy and self-expression. New Media Soc 2008;10(3):393-411 [FREE Full text] [doi: 10.1177/1461444808089415]

12. Moreno MA, Parks M, Richardson LP. What are adolescents showing the world about their health risk behaviors on MySpace? MedGenMed 2007 Oct 11;9(4):9. [Medline: 18311359]

13. Moreno MA, Briner LR, Williams A, Brockman L, Walker L, Christakis DA. A content analysis of displayed alcohol references on a social networking web site. J Adolesc Health 2010 Aug;47(2):168-175 [FREE Full text] [doi: 10.1016/j.jadohealth.2010.01.001] [Medline: 20638009]

14. Moreno MA, Vanderstoep A, Parks MR, Zimmerman FJ, Kurth A, Christakis DA. Reducing at-risk adolescents' display of risk behavior on a social networking web site: a randomized controlled pilot intervention trial. Arch Pediatr Adolesc Med 2009 Jan;163(1):35-41. [doi: 10.1001/archpediatrics.2008.502] [Medline: 19124701]

15. Moreno MA, Parks MR, Zimmerman FJ, Brito TE, Christakis DA. Display of health risk behaviors on MySpace by adolescents: prevalence and associations. Arch Pediatr Adolesc Med 2009 Jan;163(1):27-34. [doi: 10.1001/archpediatrics.2008.528] [Medline: 19124700]

16. Moreno MA, Christakis DA, Egan KG, Brockman LN, Becker T. Associations between displayed alcohol references on Facebook and problem drinking among college students. Arch Pediatr Adolesc Med 2012 Feb;166(2):157-163 [FREE Full text] [doi: 10.1001/archpediatrics.2011.180] [Medline: 21969360]

17. Curtis BL, Lookatch SJ, Ramo DE, McKay JR, Feinn RS, Kranzler HR. Meta-analysis of The Association of Alcohol-Related Social Media Use with alcohol consumption and alcohol-related problems in adolescents and young adults. Alcohol Clin Exp Res 2018 Jun;42(6):978-986 [FREE Full text] [doi: 10.1111/acer.13642] [Medline: 29786874]

18. Cavazos-Rehg PA, Krauss M, Fisher SL, Salyer P, Grucza RA, Bierut LJ. Twitter chatter about marijuana. J Adolesc Health 2015 Feb;56(2):139-145 [FREE Full text] [doi: 10.1016/j.jadohealth.2014.10.270] [Medline: 25620299]

19. Bandura A. Social Foundations of Thought and Action: A Social Cognitive Theory. Englewood Cliffs: NJ: Prentice Hall; 1986.

20. Fishbein M, Ajzen I. Predicting and Changing Behavior: The Reasoned Action Approach. New York: Psychology Press; 2011.

21. Cabrera-Nguyen EP, Cavazos-Rehg P, Krauss M, Bierut LJ, Moreno MA. Young adults' exposure to alcohol- and marijuana-related content on Twitter. J Stud Alcohol Drugs 2016 Mar;77(2):349-353 [FREE Full text] [doi: 10.15288/jsad.2016.77.349] [Medline: 26997194]

22. Stoddard SA, Bauermeister JA, Gordon-Messer D, Johns M, Zimmerman MA. Permissive norms and young adults' alcohol and marijuana use: the role of online communities. J Stud Alcohol Drugs 2012 Nov;73(6):968-975 [FREE Full text] [doi: 10.15288/jsad.2012.73.968] [Medline: 23036215]

23. Gardner M, Steinberg L. Peer influence on risk taking, risk preference, and risky decision making in adolescence and adulthood: an experimental study. Dev Psychol 2005 Jul;41(4):625-635. [doi: 10.1037/0012-1649.41.4.625] [Medline: 16060809]

24. van Hoorn J, Crone EA, van Leijenhorst L. Hanging out with the right crowd: peer influence on risk-taking behavior in adolescence. J Res Adolesc 2017 Mar;27(1):189-200. [doi: 10.1111/jora.12265] [Medline: 28498538]

25. Jones K, Eathington P, Baldwin K, Sipsma H. The impact of health education transmitted via social media or text messaging on adolescent and young adult risky sexual behavior: a systematic review of the literature. Sex Transm Dis 2014 Jul;41(7):413-419. [doi: 10.1097/OLQ.0000000000000146] [Medline: 24922099]

26. Litt DM, Lewis MA, Spiro ES, Aulck L, Waldron KA, Head-Corliss MK, et al. #drunktwitter: examining the relations between alcohol-related Twitter content and alcohol willingness and use among underage young adults. Drug Alcohol Depend 2018 Dec 1;193:75-82 [FREE Full text] [doi: 10.1016/j.drugalcdep.2018.08.021] [Medline: 30343237]

27. Creswell JW, Clark VL. Designing and Conducting Mixed Methods Research. Third Edition. Los Angeles, CA: SAGE Publications; 2017.

28. Snelson CL. Qualitative and mixed methods social media research: a review of the literature. Int J Qual Method 2016;15(1):160940691562457 [FREE Full text] [doi: 10.1177/1609406915624574]

29. Fetters MD, Curry LA, Creswell JW. Achieving integration in mixed methods designs-principles and practices. Health Serv Res 2013 Dec;48(6 Pt 2):2134-2156 [FREE Full text] [doi: 10.1111/1475-6773.12117] [Medline: 24279835]

30. Schwartz HA, Eichstaedt JC, Kern ML, Dziurzynski L, Agrawal M, Park GJ, et al. Characterizing Geographic Variation in Well-Being Using Tweets. In: Proceedings of the Seventh International AAAI Conference on Weblogs and Social Media.

2013 Presented at: ICWSM'13; July 8–11, 2013; Cambridge, Massachusetts, USA URL: https://www.aaai.org/ocs/index.php/ICWSM/ICWSM13/paper/viewFile/6138Hansen/6398

31. Hurd NM, Zimmerman MA, Xue Y. Negative adult influences and the protective effects of role models: a study with urban adolescents. J Youth Adolesc 2009 Jul;38(6):777-789 [FREE Full text] [doi: 10.1007/s10964-008-9296-5] [Medline: 19636780]

32. Schwartz HA, Giorgi S, Sap M, Crutchley P, Ungar L, Eichstaedt J. DLATK: Differential Language Analysis ToolKit. In: Proceedings of the 2017 Conference on Empirical Methods in Natural Language Processing: System Demonstrations. 2017 Presented at: EMNLP'17; September 7–11, 2017; Copenhagen, Denmark. [doi: 10.18653/v1/d17-2010]

33. Lui M, Baldwin T. langid.py: An Off-the-shelf Language Identification Tool. In: Proceedings of the ACL 2012 System Demonstrations. 2012 Presented at: ACL'12; July 8-14, 2012; Jeju Island, Korea p. 25-30.

34. Sap M, Park G, Eichstaedt JC, Kern ML, Stillwell DJ, Kosinski M, et al. Developing Age and Gender Predictive Lexica over Social Media. In: Proceedings of the 2014 Conference on Empirical Methods in Natural Language Processing. 2014 Presented at: EMNLP'14; October 25–29, 2014; Dohar, Qatar p. 1146-1151. [doi: 10.3115/v1/d14-1121]

35. Preoiuc-Pietro D, Ungar L. User-Level Race and Ethnicity Predictors from Twitter Text. In: Proceedings of the 27th International Conference on Computational Linguistics. 2018 Presented at: COLING'18; August 20-26, 2018; Santa Fe, New Mexico p. 1534-1545.

36. Krippendorff K. Content Analysis: An Introduction to Its Methodology. Thousand Oaks: Sage Publications; 2004.

37. Corbin JM, Strauss A. Grounded theory research: procedures, canons, and evaluative criteria. Qual Sociol 1990;13(1):3-21. [doi: 10.1007/BF00988593]

38. Blandfort P, Patton D, Frey WR, Karaman S, Bhargava S, Lee FT, et al. Multimodal Social Media Analysis for Gang Violence Prevention. In: Proceedings of the Thirteenth International AAAI Conference on Web and Social Media. 2019 Presented at: ICWSM'2019; June 11-14, 2019; Munich, Germany p. 114-124.

39. Prosek EA, Giordano AL, Woehler ES, Price E, McCullough R. Differences in emotion dysregulation and symptoms of depression and anxiety among illicit substance users and nonusers. Subst Use Misuse 2018 Sep 19;53(11):1915-1918. [doi: 10.1080/10826084.2018.1436563] [Medline: 29465278]

40. Hanson MJ. The theory of planned behavior applied to cigarette smoking in African-American, Puerto Rican, and non-Hispanic white teenage females. Nurs Res 1997;46(3):155-162. [doi: 10.1097/00006199-199705000-00006] [Medline: 9176505]

41. Bleakley A, Hennessy M, Fishbein M, Jordan A. It works both ways: the relationship between exposure to sexual content in the media and adolescent sexual behavior. Media Psychol 2008 Oct 1;11(4):443-461 [FREE Full text] [doi: 10.1080/15213260802491986] [Medline: 20376301]

42. Huang GC, Unger JB, Soto D, Fujimoto K, Pentz MA, Jordan-Marsh M, et al. Peer influences: the impact of online and offline friendship networks on adolescent smoking and alcohol use. J Adolesc Health 2014 May;54(5):508-514 [FREE Full text] [doi: 10.1016/j.jadohealth.2013.07.001] [Medline: 24012065]

43. Yanovitzky I, Stryker J. Mass media, social norms, and health promotion efforts: a longitudinal study of media effects on youth binge drinking. Commun Res 2001;28(2):208-239 [FREE Full text] [doi: 10.1177/009365001028002004]

44. Miller J, Prichard I, Hutchinson A, Wilson C. The relationship between exposure to alcohol-related content on Facebook and predictors of alcohol consumption among female emerging adults. Cyberpsychol Behav Soc Netw 2014 Dec;17(12):735-741. [doi: 10.1089/cyber.2014.0337] [Medline: 25489875]

45. Moreno MA, Whitehill JM. Influence of social media on alcohol use in adolescents and young adults. Alcohol Res 2014;36(1):91-100 [FREE Full text] [Medline: 26259003]

46. Morgan E, Snelson C, Elison-Bowers P. Image and video disclosure of substance use on social media websites. Comput Human Behav 2010;26(6):1405-1411 [FREE Full text] [doi: 10.1016/j.chb.2010.04.017]

47. Egan KG, Moreno MA. Alcohol references on undergraduate males' Facebook profiles. Am J Mens Health 2011 Sep;5(5):413-420 [FREE Full text] [doi: 10.1177/1557988310394341] [Medline: 21406490]

48. Glassman T. Implications for college students posting pictures of themselves drinking alcohol on Facebook. J Alcohol Drug Educ 2012;56(1):38-58 [FREE Full text]

Abbreviations

NLP: natural language processing

XSL•FO
RenderX

Original Paper

Correlates of Successful Enrollment of Same-Sex Male Couples Into a Web-Based HIV Prevention Research Study: Cross-Sectional Study

Rob Stephenson[1,2], PhD; Tanaka MD Chavanduka[1], MPH; Stephen Sullivan[1], MPH; Jason W Mitchell[3], MPH, PhD

[1]The Center for Sexuality and Health Disparities, School of Nursing, University of Michigan, Ann Arbor, MI, United States

[2]Department of Systems, Population and Leadership, School of Nursing, University of Michigan, Ann Arbor, MI, United States

[3]Office of Public Health Studies, Myron B Thompson School of Social Work, University of Hawai'i at Manoa, Honolulu, HI, United States

Corresponding Author:
Rob Stephenson, PhD
The Center for Sexuality and Health Disparities
School of Nursing
University of Michigan
400 North Ingalls
Ann Arbor, MI, 48109
United States
Phone: 1 7346150149
Email: rbsteph@umich.edu

Abstract

Background: The recognition of the role of primary partners in HIV transmission has led to a growth in dyadic-focused HIV prevention efforts. The increasing focus on male couples in HIV research has been paralleled by an increase in the development of interventions aimed at reducing HIV risk behaviors among male couples. The ability to accurately assess the efficacy of these interventions rests on the ability to successfully enroll couples into HIV prevention research.

Objective: This study aimed to explore factors associated with successful dyadic engagement in Web-based HIV prevention research using recruitment and enrollment data from a large sample of same-sex male couples recruited online from the United States.

Methods: Data came from a large convenience sample of same-sex male couples in the United States, who were recruited through social media venues for a Web-based, mixed method HIV prevention research study. The analysis examined the demographic factors associated with successful dyadic engagement in research, measured as both members of the dyad meeting eligibility criteria, consenting for the study, and completing all study processes.

Results: Advertisements generated 221,258 impressions, resulting in 4589 clicks. Of the 4589 clicks, 3826 individuals were assessed for eligibility, of which 1076 individuals (538/1913, 28.12% couples) met eligibility criteria and were included in the study. Of the remaining 2740 ineligible participants, 1293/3826 (33.80%) were unlinked because their partner did not screen for eligibility, 48/2740 (1.75%) had incomplete partner data because at least one partner did not finish the survey, 22/2740 (0.80%) were ineligible because of 1 partner not meeting the eligibility criteria. Furthermore, 492/3826 (12.86%) individuals were fraudulent. The likelihood of being in a matched couple varied significantly by race and ethnicity, region, and relationship type. Men from the Midwest were less likely to have a partner who did not complete the survey. Men with college education and those who labeled their relationships as husband or other (vs boyfriend) were more likely to have a partner who did not complete the survey.

Conclusions: The processes used allowed couples to independently progress through the stages necessary to enroll in the research study, while limiting opportunities for coercion, and resulted in a large sample with relative diversity in demographic characteristics. The results underscore the need for additional considerations when recruiting and enrolling, relative to improving the methods associated with these research processes.

Introduction

Background

There is now substantial evidence for the role of male dyads in the US HIV epidemic, with primary partners identified as the source of approximately one-third [1] to two-thirds [2] of new HIV infections. Given these estimates, a significant paradigm shift in HIV prevention is needed. Programmatic efforts have traditionally focused on men who have sex with men (MSM), in particular, gay-identifying men as individuals rather than dyads, with a focus on casual sex as a risk for HIV acquisition. As a result of this individualistic approach, HIV prevention efforts have largely ignored the risk of HIV transmission that occurs within primary partnerships. Within the context of same-sex male couples' relationships, various research findings have illustrated high rates of sexual risk behavior for HIV (with primary and casual partners), low rates of disclosure of potentially risky episodes with casual partners to primary partners, and reduced frequency of HIV testing [3-9]. Historically, HIV prevention efforts have focused on reducing the number of casual sex partners [10], indirectly messaging a false sense of protection associated with primary partners [11,12].

There have been recent attempts to address this disproportionate focus on individualistic approaches to HIV prevention by focusing on the dyads and their relationship. Couples HIV testing and counseling (CHTC), originally developed for heterosexual couples in sub-Saharan Africa [13], has been adapted for same-sex male couples [14], as a Centers for Disease Control and Prevention Public Health Strategy [15]. There are several examples of dyadic interventions that aim to address HIV risk among same-sex male couples. Connect with Pride was an intervention for methamphetamine-using, black/African American male dyads that involved 7 in-person sessions to address issues, such as communication, joint problem solving, and condom negotiation [16]. 2GETHER was an intervention for young male couples aged 18 to 29 years, which involved 4 interactive weekly sessions focusing on enhancing communication skills, coping with relationship stress, applying problem-solving techniques to relationship issues, and formulating an agreement to reduce their risk for HIV [17]. Posttest decreases in sexual risk behaviors, increases in skills related to HIV prevention, and improvements in relationship investment were observed. We Prevent is a novel intervention for 15- to 19-year-old male dyads, which is currently being piloted in the United States [18], involving telehealth-delivered sessions to increase relationship communication skills around HIV prevention. The Male Couples Agreement Project is an electronic health tool kit intervention for male couples with a foundation in relationship science, including sexual agreements, sexual health education, and HIV prevention [19,20], and Stronger Together focuses on improving engagement in HIV care and antiretroviral treatment adherence among serodiscordant male couples by combining in-person CHTC with dyadic adherence counseling [21]. Although these interventions have the potential to improve relational dynamics and safeguard male couples against HIV and other sexually transmitted infections, the ability to successfully test the efficacy of these interventions rests on the ability to successfully enroll male couples into HIV prevention research. Representation of diverse samples of same-sex male couples—in terms of age, race, ethnicity, and relationship length—in dyadic HIV prevention interventions is critical for measuring the success of these projects and moving forward toward improving them.

Few studies have addressed the challenges encountered in recruiting same-sex male couples into research. To enroll a couple into research requires both members of the couple to successfully navigate parallel processes: both must screen for eligibility, provide consent, and complete some other data collection activity (eg, study survey) to enroll into a research project. These processes must be conducted separately to address and prevent coercion among partners to participate in research projects, especially when there are financial incentives for participation. Successful participation often requires the couple to share information (ie, partner A must inform partner B that they have completed their consent form) or to coordinate (ie, they must jointly schedule a study visit). At a minimum, both members of the couple must agree to participate in the research study, knowing that their partner will also be participating. These processes may result in studies obtaining a potentially selective group of couples with more functional communication styles or couples with reduced levels of conflict. In their study of 260 partnered gay/bisexual men recruited in New York City, Starks et al [22] found those who did not refer their partners were older, wealthier, and in longer relationships, whereas participants who successfully recruited their partners were significantly more satisfied in their relationship. This selectivity is important to consider in light of evidence illustrating associations between poor relationship characteristics and HIV prevention outcomes [3,5,23-27].

Objective

Missing from the literature is an understanding of the factors associated with successful enrollment of same-sex male couples in Web-based HIV prevention research studies. Although limited research has identified relationship factors associated with referring partners into Web-based HIV research, other factors associated with successful dyadic engagement in other parts of the research process (ie, eligibility and consent) have yet to be investigated. In general, Web-based studies may be associated with higher degrees of selectivity bias, with recent evidence suggesting that white MSM are more likely to join a Web-based study than black and Hispanic MSM [28]. The identification of such selectivity biases is equally important for Web-based research with couples. If Web-based HIV prevention research is to be successful in identifying unique risk factors or prevention opportunities for same-sex male couples, then research must be able to successfully enroll diverse samples of couples. This study used recruitment and enrollment data from a large sample of same-sex male couples, recruited online from the United States, to explore factors associated with successful

dyadic enrollment in Web-based HIV prevention research. This new information has the potential to shape recruitment and research designs for enrollment of dyadic HIV research.

Methods

Recruitment and Inclusion Criteria

Project Couples Health and Attitudes toward Preexposure Prophylaxis (CHAPS) is a mixed method Web-based study examining attitudes toward pre-exposure prophylaxis (PrEP) use and patterns of PrEP use among concordant seronegative and serodiscordant same-sex male couples in the United States. Participants were recruited through targeted Web-based advertisements and postings on commonly used social media websites and dating websites and mobile apps. Social media websites used for recruitment were Facebook and Instagram. Dating websites and mobile apps used for recruitment were Scruff and Grindr. Advertisements included images of a diverse (in age, race, and ethnicity) range of same-sex male couples, with text that promoted a study on the health of same-sex male couples (ie, Are you and your man on the same page about HIV prevention? We want to know, take our survey!). The advertisements did not mention PrEP to avoid recruiting a sample biased toward those with particular interests in or attitudes about PrEP. The advertisements included a link that led interested individuals to a landing page with detailed information about the study and a Web-based eligibility screener.

First, individual-level eligibility was established for both partners of the couple, and this had to have been met by both for enrollment. Individual eligibility self-reporting as (1) a cisgender male (assigned male at birth and currently identifies as male), (2) being in a relationship with another cisgender male for 3 or more months, (3) having an HIV seronegative or unknown status or known HIV seropositive status, and (4) having had condomless anal sex with their primary relationship partner within the last 3 months. Once eligible, an individual would then proceed to the consent webpage outlining the content and process of the study. Once consent was provided, the individual (partner A) would then be directed to the partner referral system, which entailed providing contact information (email and telephone number) and a name or nickname for his partner (partner B). Partner B would then receive an email informing him that his partner (partner A) had signed up for the study and had provided his contact information, along with a link to a landing page to access the same screener and consent process.

The link provided to partner B was connected to partner A's metadata, such that they both were assigned the same random study ID number as a hidden data field (as a couple). Once partner B had completed the same eligibility screener and consent process, partner B was then asked to provide contact information for his partner (partner A), to enable crossmatching of partner contact details.

Couple serostatus was also considered. Given the focus on PrEP, only concordant seronegative and serodiscordant couples were eligible. Once both A and B had completed the screener, their responses to the question on serostatus were compared. Couples who reported concordant seropositive status were deemed ineligible for the study.

Following successful completion of the eligibility and consent process by both partners A and B, as well as identification of concordant seronegative or serodiscordant HIV status, individual emails were sent to each partner of the couple, asking them to independently and individually complete a Web-based survey via a link. The survey Web link contained the same random study ID number they were assigned during eligibility screener to help link partners A and B's completed survey responses. Each partner was compensated US $50 for his time to complete the survey; compensation was not dependent on both partners completing the survey. The study protocol was approved by the University of Michigan Institutional Review Board (HUM00125711).

Matching and Verification of Participants

Upon completion of their individual surveys, couples' responses were compared with verify that they were real couples. First, individual surveys were linked as couples via the identifier included in the survey link. Couple status was verified using the relationship and contact information provided by each individual. A verified couple had to match on at least 4 of the following 6 criteria (identified through questions asked in the eligibility screener): (1) partner's age ($\pm$ 1 year), (2) partner's birthday month, (3) relationship length, (4) anal sex without a condom within the last 3 months, (5) initials of partner's first and last name, and (6) last 4 digits of partner's cell phone number. Matching of couple data was manually reviewed and checked for matching: each couple was assigned a score from 1 to 6, which represented the number of criteria on which they matched in their surveys.

Detecting Fraudulent Activity

All participant data were also manually reviewed and checked for mismatch, duplication, and fraud. Inconsistent information, such as name, internet protocol address, zip code, email, or phone number, was flagged for further inquiry. Participants were contacted directly by study staff for confirmation of their identity and relationship status. Individuals were classified as fraudulent if their identity could not be verified.

Match Status Categories

On the basis of the results of verification and matching, participants were categorized into 4 groups: eligible couple, incomplete, ineligible, and unlinked. *Eligible couples* comprised couples in which both relationship partners were eligible, consented, passed verification, and completed the study survey. *Incompletes* included couples in which 1 or both partners did not finish the study survey. *Ineligibles* were couples in which 1 partner met individual-level eligibility criteria and consented, whereas the other partner either did not meet this eligibility criteria or did not consent. *Unlinked* was defined as cases in which only 1 partner completed the enrollment process (eligible, consented, and completed the study survey), whereas the other did not enter the screening and enrollment process.

Study Survey

The survey was distributed via Qualtrics (Qualtrics International Inc) through an anonymous link embedded with a unique identifier that linked couples, and it took partners, on average, 35 min to complete. The survey contained a variety of measures geared toward understanding the dyadic patterns relative to PrEP. The aim of this study was to examine the factors associated with achieving a successfully matched and verified couple recruited online. The analysis models a 4-category outcome variable, representing the 4 possibilities encountered from enrollment: eligible couples (the reference category), ineligible, incomplete, and unlinked. Data analysis comprised individual-level data in which every line of data is an individual, to facilitate the inclusion of participants for whom no partner data were received (eg, unlinked). A multinomial model is fit for the 4-category matching status outcome. Key covariates included the sociodemographic characteristics of individuals: education, employment, housing status, race and ethnicity, age, relationship length, and relationship type. Relationship type was categorized to compare more informal relationship types (boyfriend or other) with more formal relationship types (husband or partner). The analysis was conducted in STATA v.15 [29].

Results

CHAPS advertisements generated 221,258 impressions (number of times it was shown on a social medial page), resulting in 4589 clicks (number of times the advertisement was clicked on: these may not be unique to individuals). Of the 4589 clicks, 3826 individuals were assessed for eligibility, of which 1076 individuals (538/1913, 28.12% couples) were matched eligible and included in the study. Of the remaining 2740 participants, 1293/3826 (33.80%) were unlinked because of their partner not enrolling into the screening, 48/2740 (1.75%) had incomplete partner data because at least 1 partner did not finish the survey, 22/2740 (0.80%) were ineligible because of 1 partner not meeting the eligibility criteria. Furthermore, 492/3826 (12.86%) individuals were fraudulent, and 885/3826 (23.13%) started the

screening but did provide any responses; therefore, they were deemed invalid. Fraudulent and invalid participants were removed from the sample, resulting in a sample of 2449 individuals, which includes 538 eligible and verified couples. Those who had missing data (n=911) from key covariates, including region, education, housing, and relationship length, were dropped from dataset, resulting in a final analysis sample of 1538 individuals.

Characteristics of the analysis sample (N=1538) are described in Table 1.

The sample was largely white (1140/1538, 74.12%) and between the ages of 25 and 34 years (875/1538, 56.89%). A majority of participants were from the South (495/1538, 32.18%) and the Midwest (457/1538, 29.71%) regions. A majority of individuals were college graduates (521/1538, 33.86%) or had graduate degrees (392/1538, 25.48%), worked full time (1215/1538, 79.00%), and lived in their own housing (1237/1538, 80.42%). Finally, 35.89% (552/1538) of the sample identified as boyfriends and 34.39% (529/1538) identified as husbands, with the largest portion of relationship lengths being between 1 and 3 years (494/1538, 32.12%) and more than 5 years (524/1538, 34.07%).

White-Hispanic participants were significantly more likely to have a partner who was ineligible for the study (relative risk ratio [RRR]=4.94; 95% CI 1.15-21.26) or to be in the incomplete partner status (RRR=2.55; 95% CI 1.02-6.42) compared with being in the eligible couple category. Those who reported being from the Midwest (RRR=0.25; 95% CI 0.08-0.72) were less likely to be in the incomplete category than have an eligible partner. Men with a college education or above (RRR=2.82; 95% CI 1.02-7.80) and having a husband/partner for a relationship type (RRR=2.35; 95% CI 1.06-5.25) were more likely to be in the incomplete category than have an eligible partner. There were no significant associations with the remaining covariates across the match status outcomes.

Results of the multinomial model are shown in Table 2.

Table 1. Descriptive statistics for participants and demographic variables (N=1538).

Characteristics	Eligible individuals[a] (n=1076), n (%)	Ineligible partners[b] (n=12), n (%)	Incomplete partner[c] (n=35), n (%)	Unlinked participant[d] (N=415), n (%)
Race/ethnicity				
Non-Hispanic white	804 (74.72)	7 (58)	25 (71)	303 (73.0)
Other[e]	197 (18.31)	2 (17)	3 (9)	73 (17.6)
White Hispanic	75 (6.97)	3 (25)	7 (20)	39 (9.4)
Age (years)				
18-24	160 (14.87)	5 (42)	7 (20)	83 (20.0)
25-34	630 (58.55)	4 (33)	19 (54)	222 (53.5)
35-44	215 (19.98)	2 (17)	7 (20)	91 (21.9)
45+	71 (6.60)	1 (8)	2 (6)	19 (4.6)
Region				
Northeast	186 (17.29)	1 (8)	12 (34)	70 (16.9)
South	333 (30.95)	4 (33)	10 (29)	148 (35.7)
West	220 (20.45)	2 (17)	8 (23)	88 (21.2)
Midwest	337 (31.32)	5 (42)	5 (14)	109 (26.3)
Education				
Up to high school/some college	321 (29.83)	6 (50)	5 (14)	152 (36.6)
College/some graduate school	755 (70.17)	6 (50)	30 (86)	263 (63.4)
Employment				
Work full time	857 (79.65)	8 (67)	24 (69)	326 (78.6)
Work part time/retired	219 (20.35)	4 (33)	11 (31)	89 (21.5)
Housing				
My own house or apartment	877 (81.51)	8 (67)	30 (86)	322 (77.6)
Other[f]	199 (18.49)	4 (33)	5 (14)	93 (22.4)
Relationship type				
Boyfriend/other[g]	645 (59.94)	8 (67)	15 (43)	244 (58.8)
Husband/partner	431 (40.06)	4 (33)	20 (57)	171 (41.2)
Relationship length				
More than 3 months but less than 1 year	132 (12.27)	3 (25)	4 (11)	60 (14.5)
More than 1 year but less than 3 years	347 (32.25)	5 (42)	7 (20)	134 (32.3)
More than 3 years but less than 5 years	228 (21.19)	1 (8)	12 (34)	81 (19.5)
More than 5 years	369 (34.29)	3 (25)	12 (34)	140 (33.7)

[a]Eligible couples: couples in which both relationship partners were eligible, consented, passed verification, and completed the study survey.

[b]Ineligibles: couples in which 1 partner met individual-level eligibility criteria and consented, whereas the other partner either did not meet the eligibility criteria or did not consent.

[c]Incompletes: included couples in which 1 or both partners did not finish the study survey.

[d]Unlinked was defined as cases in which only 1 partner completed the enrollment process (eligible, consented, and completed the study survey), whereas the other did not enter the screening and enrollment process.

[e]Includes 72 black and African American, 72 mixed, 64 Hispanic and Latino, 47 Asian, 7 Native American and Alaskan Native, 5 Middle Eastern, 5 Native Hawaiian and Other, Pacific Islander, 1 Caribbean, 1 Southern European, and 1 Indian.

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

[g]Includes friends with benefits, mates, best friend, bae, and better half.

Table 2. Multinomial logistic regression results for couple match status (N=1538).

Characteristics	Ineligible partners vs eligible couples, RRR[a] (95% CI)	Incomplete partner vs eligible couples, RRR (95% CI)	Unlinked participant vs eligible couples, RRR (95% CI)
Race			
Non-Hispanic white	Ref[b]	Ref	Ref
Other	1.08 (0.21-5.52)	0.51 (0.14-1.73)	0.93 (0.68-1.26)
White Hispanic	4.94 (1.15-21.26)[c]	2.55 (1.02-6.42)[c]	1.27 (0.84-1.94)
Age (years)			
18-24	Ref	Ref	Ref
25-34	0.34 (0.07-1.58)	0.51 (0.19-1.40)	0.74 (0.53-1.04)
35-44	0.54 (0.08-3.91)	0.58 (0.16-2.02)	0.88 (0.59-1.33)
45+	0.85 (0.07-10.58)	0.51 (0.09-2.94)	0.55 (0.30-1.02)
Region			
Northeast	Ref	Ref	Ref
South	2.25 (0.24-21.10)	0.50 (0.21-1.21)	1.16 (0.83-1.64)
West	1.39 (0.12-16.29)	0.55 (0.21-1.42)	0.99 (0.68-1.44)
Midwest	2.87 (0.32-25.58)	0.25 (0.08-0.72)[c]	0.83 (0.59-1.19)
Education			
Up to high school/some college	Ref	Ref	Ref
College/some graduate school	0.71 (0.20-2.53)	2.82 (1.02-7.80)[c]	0.80 (0.62-1.03)
Employment			
Work full time	Ref	Ref	Ref
Work part time/retired	1.30 (0.36-4.71)	2.05 (0.94-4.45)	0.97 (0.72-1.30)
Housing			
My own house or apartment	Ref	Ref	Ref
Other	1.37 (0.35-5.28)	0.78 (0.28-2.16)	1.17 (0.87-1.58)
Relationship type			
Boyfriend/other	Ref	Ref	Ref
Husband/partner	1.07 (0.26-4.39)	2.35 (1.06-5.25)[c]	1.10 (0.85-1.44)
Relationship length			
More than 3 months but less than 1 year	Ref	Ref	Ref
More than 1 year but less than 3 years	0.75 (0.16-3.58)	0.64 (0.18-2.33)	0.90 (0.62-1.32)
More than 3 years but less than 5 years	0.28 (0.02-3.18)	1.28 (0.37-4.47)	0.85 (0.56-1.30)
More than 5 years	0.54 (0.06-4.56)	0.70 (0.18-2.75)	0.92 (0.60-1.41)

[a]RRR: relative risk ratio.

[b]Reference category.

[c]$P<.05$.

Discussion

Principal Findings

The results illustrate several important facets of the recruitment of same-sex male couples into Web-based HIV prevention research. First, advertising through social media to recruit couples generated 3826 individuals who completed the eligibility screener. Of these, only 538 couples (1076 individuals) were successfully engaged in research (eligible, consented, completed a survey, and were matched with their partner). Therefore, 72% of responses failed to generate successfully matched couples.

This has significant resource implications given that the majority of social media recruitment involves paid advertising. Project CHAPS intentionally used images of same-sex male couples, which included representation of diverse ages, races, and ethnicities. These advertisements were based on those used previously to successfully enroll online samples of over 400 same-sex male couples in the United States [30]. However, further work is warranted to explore same-sex male couples' perceptions and desired content for online recruitment advertising, to help facilitate the creation of advertisements with optimal appeal to help with enrollment into Web-based research studies.

Of importance, almost 34.00% (523/1538) of participants had partners who did not initiate the screening and enrollment process, whereas failure of having a partner not complete the survey only accounted for 2% (35/1538) of unmatched couples and a partner being ineligible accounted for less than 1% (12/1538) of the unmatched couples. Therefore, once both partners made it through the eligibility screener, there was a very high likelihood that they would become a successfully matched couple who would both complete the study survey. This suggests a need to strengthen partner referral methods early on in the study engagement process. Providing individuals with detailed information on the study that they can share with their partner, which clearly outlines the steps that their partner needs to take, is a fundamental step in increasing dyadic recruitment. Of course, this process must be careful not to cross over into coercion: systems need to be maintained, which allow both partners to independently screen and consent for studies.

The ability to identify and match couples was enhanced by the use of a series of fraud detection techniques, based on the standards recommended by Bauermeister et al [31]. An additional fraud technique was implemented, which is specific to the enrollment of dyads. Once surveys were completed, responses to 6 key questions regarding relationship and partner characteristics were compared: those who matched on fewer than 4 responses were deemed not to be a real couple. This form of couple verification has been recommended as a mechanism for reducing the degree of fraud in dyadic Web-based research [32]. However, further work is required to inform the content of couple verification surveys. Questions must represent a range of partner and relationship characteristics that partners may be expected to know, but these must also be sensitive enough to identify fraudulent couples.

Few factors were significantly associated with the successful engagement of male dyads, contrary to the work of Starks et al [22], which showed significant differences in partner referral into a research study be age, wealth, and relationship length. The likelihood of being an eligible couple versus having an ineligible partner, incomplete partner, or an unlinked partner did not vary by relationship length, suggesting our recruitment and enrollment methods were successful at engaging couples at range of relationship stages. Men who reported themselves as being in a more formal union (ie, husbands) were more likely to have a partner who did *not* complete the screening and enrollment process. This seems counter intuitive as it may be expected that those in more formal unions may have developed stronger, or at least more familiar, communication styles that

may lend themselves to successful enrollment in HIV research. However, it is possible that engagement in research about relationships and/or HIV prevention may not be one of those shared interests and values among partners. Although further research is required to understand this result, ideally qualitative work that examines perceptions of enrolling in HIV prevention research from a range of couple types, it is possible that more formal and established couples do not see themselves as at risk for HIV and therefore do not see the research as being suitable for them. Previous research has identified that coupled MSM perceive lower levels of HIV risk [5], and this may shape how couples view their eligibility or desire to enroll in an HIV prevention study.

White-Hispanic men were more likely to have an ineligible partner or a partner who did not complete the screening process. This result may reflect the myriad of interpersonal and structural barriers that men of color experience in enrolling in research. The sample for this study is overwhelmingly non-Hispanic white, limiting the ability to understand whether the ability to enroll in a survey for male couples varies for racial and ethnic minority couples. It seems plausible that couples with African American men may also be more likely to face difficulties in enrolling as couples in HIV prevention research, but the very small number of African American men in this study precludes such analysis. The advertisements used for CHAPS included a diverse range of races and ethnicities; however, this still resulted in a predominantly non-Hispanic white sample. Further qualitative work—with diverse racial and ethnic samples of same-sex male couples—would be needed to fully understand the perceptions of Web-based dyadic HIV prevention research, as well as their needs and desires that would lead them to participate in future studies.

It is important to note that Project CHAPS was a cross-sectional survey and did not require the participants to take part in an intervention or to take follow-up surveys over a period of time. Although this study has identified factors associated with successful enrollment into a 1-time survey, it is likely that factors shaping the ability of couples to actively participate in intervention research may differ. This may be particularly true for interventions that require members of the dyad to take the intervention together (ie, couples' counseling–focused interventions). There may also be differential follow-up over time among couples, with only 1 member of the couple completing follow-up surveys, leading to limitations to dyadic data analysis. Although this paper identifies processes for enrolling couples into surveys, further work is required to understand whether the process required for successful participation of couples in intervention-focused research differs.

Conclusions

This study is not without limitations. Using cross-sectional data from a convenience sample precludes us from making causal inferences or generalizing our results to other same-sex male couples in the United States, who may or may not use social media platforms or geospatial mobile apps. The collection of personal identifying information may have prompted social desirability to inaccurately report data on their partners or relationship characteristics. Although participants were

instructed to complete the survey separately from their partners, it is possible that couples answered questions together, potentially influencing each other's responses and overestimating the degree to which couples truly matched their knowledge of each other and their relationship. The sample was overwhelmingly non-Hispanic white, limiting the ability to make inferences about specific strategies for enrolling racial and ethnic minority couples into HIV prevention research. Given the higher incidence of HIV among MSM of color, work is clearly needed to understand the barriers that racial-ethnic minority male couples may experience in enrolling and participating in HIV prevention research.

Despite these limitations, the results presented here provide important new information on the processes required to successfully enroll same-sex male couples into Web-based HIV prevention research. The steps used in CHAPS allowed couples to independently progress through the stages necessary to enroll in the research study while limiting opportunities for coercion and resulted in a large, diverse sample (>500 couples). The results underscore the need for additional considerations when recruiting and enrolling, relative to improving the methods associated with these research processes. Further research is needed and is beneficial to fully understand the perceptions of same-sex male couples toward Web-based research. This information is vital for the continued refinement of dyadic recruitment and engagement methods.

Conflicts of Interest

None declared.

References

1. Goodreau SM, Carnegie NB, Vittinghoff E, Lama JR, Sanchez J, Grinsztejn B, et al. What drives the US and Peruvian HIV epidemics in men who have sex with men (MSM)? PLoS One 2012;7(11):e50522 [FREE Full text] [doi: 10.1371/journal.pone.0050522] [Medline: 23209768]

2. Sullivan PS, Salazar L, Buchbinder S, Sanchez TH. Estimating the proportion of HIV transmissions from main sex partners among men who have sex with men in five US cities. AIDS 2009 Jun 1;23(9):1153-1162. [doi: 10.1097/QAD.0b013e32832baa34] [Medline: 19417579]

3. Gomez AM, Beougher SC, Chakravarty D, Neilands TB, Mandic CG, Darbes LA, et al. Relationship dynamics as predictors of broken agreements about outside sexual partners: implications for HIV prevention among gay couples. AIDS Behav 2012 Aug;16(6):1584-1588. [doi: 10.1007/s10461-011-0074-0] [Medline: 22020757]

4. Hoff CC, Beougher SC, Chakravarty D, Darbes LA, Neilands TB. Relationship characteristics and motivations behind agreements among gay male couples: differences by agreement type and couple serostatus. AIDS Care 2010 Jul;22(7):827-835 [FREE Full text] [doi: 10.1080/09540120903443384] [Medline: 20635246]

5. Stephenson R, White D, Darbes L, Hoff C, Sullivan P. HIV testing behaviors and perceptions of risk of HIV infection among MSM with main partners. AIDS Behav 2015 Mar;19(3):553-560 [FREE Full text] [doi: 10.1007/s10461-014-0862-4] [Medline: 25081599]

6. Stall R, Mills TC, Williamson J, Hart T, Greenwood G, Paul J, et al. Association of co-occurring psychosocial health problems and increased vulnerability to HIV/AIDS among urban men who have sex with men. Am J Public Health 2003 Jun;93(6):939-942. [doi: 10.2105/ajph.93.6.939] [Medline: 12773359]

7. Chakravarty D, Hoff CC, Neilands TB, Darbes LA. Rates of testing for HIV in the presence of serodiscordant UAI among HIV-negative gay men in committed relationships. AIDS Behav 2012 Oct;16(7):1944-1948 [FREE Full text] [doi: 10.1007/s10461-012-0181-6] [Medline: 22460227]

8. Mitchell JW, Petroll AE. Patterns of HIV and sexually transmitted infection testing among men who have sex with men couples in the United States. Sex Transm Dis 2012 Nov;39(11):871-876 [FREE Full text] [doi: 10.1097/OLQ.0b013e3182649135] [Medline: 23060078]

9. Phillips G, Hightow-Weidman LB, Arya M, Fields SD, Halpern-Felsher B, Outlaw AY, et al. HIV testing behaviors of a cohort of HIV-positive racial/ethnic minority YMSM. AIDS Behav 2012 Oct;16(7):1917-1925. [doi: 10.1007/s10461-012-0193-2] [Medline: 22555382]

10. Kelly JA, St Lawrence JS, Diaz YE, Stevenson LY, Hauth AC, Brasfield TL, et al. HIV risk behavior reduction following intervention with key opinion leaders of population: an experimental analysis. Am J Public Health 1991 Feb;81(2):168-171. [doi: 10.2105/ajph.81.2.168] [Medline: 1990853]

11. Pruitt KL, White D, Mitchell JW, Stephenson R. Sexual agreements and intimate-partner violence among male couples. International Journal of Sexual Health 2015;27(4):429-441. [doi: 10.1080/19317611.2015.1037037]

12. Goldenberg T, Clarke D, Stephenson R. 'Working together to reach a goal': MSM's perceptions of dyadic HIV care for same-sex male couples. J Acquir Immune Defic Syndr 2013 Nov 1;64(Suppl 1):S52-S61 [FREE Full text] [doi: 10.1097/QAI.0b013e3182a9014a] [Medline: 24126448]

13. Chomba E, Allen S, Kanweka W, Tichacek A, Cox G, Shutes E, Rwanda Zambia HIV Research Group. Evolution of couples' voluntary counseling and testing for HIV in Lusaka, Zambia. J Acquir Immune Defic Syndr 2008 Jan 1;47(1):108-115. [doi: 10.1097/QAI.0b013e31815b2d67] [Medline: 17984761]

14. Sullivan PS, Stephenson R, Grazter B, Wingood G, Diclemente R, Allen S, et al. Adaptation of the African couples HIV testing and counseling model for men who have sex with men in the United States: an application of the ADAPT-ITT framework. Springerplus 2014;3:249 [FREE Full text] [doi: 10.1186/2193-1801-3-249] [Medline: 24877036]

15. Stephenson R, Grabbe KL, Sidibe T, McWilliams A, Sullivan PS. Technical Assistance Needs for Successful Implementation of Couples HIV Testing and Counseling (CHTC) Intervention for Male Couples at US HIV Testing Sites. AIDS Behav 2016 Apr;20(4):841-847. [doi: 10.1007/s10461-015-1150-7] [Medline: 26253221]

16. Wu E, El-Bassel N, McVinney LD, Hess L, Remien RH, Charania M, et al. Feasibility and promise of a couple-based HIV/STI preventive intervention for methamphetamine-using, black men who have sex with men. AIDS Behav 2011 Nov;15(8):1745-1754 [FREE Full text] [doi: 10.1007/s10461-011-9997-8] [Medline: 21766193]

17. Newcomb ME, Macapagal KR, Feinstein BA, Bettin E, Swann G, Whitton SW. Integrating HIV Prevention and Relationship Education for Young Same-Sex Male Couples: A Pilot Trial of the 2GETHER Intervention. AIDS Behav 2017 Aug;21(8):2464-2478 [FREE Full text] [doi: 10.1007/s10461-017-1674-0] [Medline: 28083833]

18. Gamarel KE, Darbes LA, Hightow-Weidman L, Sullivan P, Stephenson R. The development and testing of a relationship skills intervention to improve HIV prevention uptake among young gay, bisexual, and other men who have sex with men and their primary partners (we prevent): Protocol for a randomized controlled trial. JMIR Res Protoc 2019 Jan 2;8(1):e10370 [FREE Full text] [doi: 10.2196/10370] [Medline: 30602433]

19. Mitchell J, Lee J, Traynor S, Feaster D, Sullivan P, Stephenson R. Findings from a web-based, randomized controlled trial of an eHealth prevention toolkit to encourage at-risk, HIV-negative male couples to establish and adhere to a sexual agreement. 2017 Nov 13 Presented at: 13th International AIDS Impact Conference; 2017; Cape Town, South Africa.

20. Mitchell JW, Lee J, Godoy F, Asmar L, Perez G. HIV-discordant and concordant HIV-positive male couples' recommendations for how an eHealth HIV prevention toolkit for concordant HIV-negative male couples could be improved to meet their specific needs. AIDS Care 2018 Jun;30(sup2):54-60 [FREE Full text] [doi: 10.1080/09540121.2018.1465527] [Medline: 29848043]

21. Stephenson R, Suarez NA, Garofalo R, Hidalgo MA, Hoehnle S, Thai J, et al. Project Stronger Together: Protocol to Test a Dyadic Intervention to Improve Engagement in HIV Care Among Sero-Discordant Male Couples in Three US Cities. JMIR Res Protoc 2017 Aug 31;6(8):e170 [FREE Full text] [doi: 10.2196/resprot.7884] [Medline: 28860107]

22. Starks TJ, Millar BM, Parsons JT. Correlates of Individual Versus Joint Participation in Online Survey Research with Same-Sex Male Couples. AIDS Behav 2015 Jun;19(6):963-969 [FREE Full text] [doi: 10.1007/s10461-014-0962-1] [Medline: 25432879]

23. Marsack J, Kahle E, Suarez NA, Mimiaga MJ, Garofalo R, Brown E, et al. Relationship Characteristics and Dyadic Approaches to HIV Health-Enhancing Behaviours Among a Sample of Same-Sex Male Couples From Three US Cities. J Relatsh Res 2018 May 23;9:e10. [doi: 10.1017/jrr.2018.9]

24. Mimiaga MJ, Suarez N, Garofalo R, Frank J, Ogunbajo A, Brown E, et al. Relationship Dynamics in the Context of Binge Drinking and Polydrug Use Among Same-Sex Male Couples in Atlanta, Boston, and Chicago. Arch Sex Behav 2019 May;48(4):1171-1184. [doi: 10.1007/s10508-018-1324-2] [Medline: 30806868]

25. Parsons JT, Starks TJ. Drug use and sexual arrangements among gay couples: frequency, interdependence, and associations with sexual risk. Arch Sex Behav 2014 Jan;43(1):89-98. [doi: 10.1007/s10508-013-0237-3] [Medline: 24322670]

26. Mitchell JW, Harvey SM, Champeau D, Seal DW. Relationship factors associated with HIV risk among a sample of gay male couples. AIDS Behav 2012 Feb;16(2):404-411 [FREE Full text] [doi: 10.1007/s10461-011-9976-0] [Medline: 21614560]

27. Mitchell JW, Stephenson R. HIV-Negative Partnered Men's Willingness to Use Pre-Exposure Prophylaxis and Associated Factors Among an Internet Sample of US HIV-Negative and HIV-Discordant Male Couples. LGBT Health 2015 Mar;2(1):35-40 [FREE Full text] [doi: 10.1089/lgbt.2014.0092] [Medline: 26790016]

28. Sullivan PS, Khosropour CM, Luisi N, Amsden M, Coggia T, Wingood GM, et al. Bias in online recruitment and retention of racial and ethnic minority men who have sex with men. J Med Internet Res 2011 May 13;13(2):e38 [FREE Full text] [doi: 10.2196/jmir.1797] [Medline: 21571632]

29. StataCorp. Stata Statistical Software: Release 15. College Station, TX: StataCorp LLC 2017.

30. Stephenson R, Freeland R, Sullivan SP, Riley E, Johnson BA, Mitchell J, et al. Home-Based HIV Testing and Counseling for Male Couples (Project Nexus): A Protocol for a Randomized Controlled Trial. JMIR Res Protoc 2017 May 30;6(5):e101 [FREE Full text] [doi: 10.2196/resprot.7341] [Medline: 28559225]

31. Bauermeister JA, Pingel E, Zimmerman M, Couper M, Carballo-Diéguez A, Strecher VJ. Data Quality in web-based HIV/AIDS research: Handling Invalid and Suspicious Data. Field methods 2012 Aug 1;24(3):272-291 [FREE Full text] [doi: 10.1177/1525822X12443097] [Medline: 23180978]

32. Mitchell J, Lee J, Stephenson R. Metadata Correction of: 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 26;2(2):e155 [FREE Full text] [doi: 10.2196/publichealth.6689] [Medline: 27694099]

XSL•FO
RenderX

Abbreviations

CHAPS: Couples Health and Attitudes toward Preexposure Prophylaxis
CHTC: Couples HIV testing and counseling
MSM: men who have sex with men
PrEP: pre-exposure prophylaxis
RRR: relative risk ratio

XSL•FO
RenderX

Original Paper

Medical Conditions Predictive of Self-Reported Poor Health: Retrospective Cohort Study

M Soledad Cepeda[1], MD, PhD; Jenna Reps[1], PhD; David M Kern[1], PhD; Paul Stang[1], PhD

Janssen Research & Development, Titusville, NJ, United States

Corresponding Author:
M Soledad Cepeda, MD, PhD
Janssen Research & Development
1125 Trenton Harbourton Rd
Titusville, NJ, 08560
United States
Phone: 1 6097302413
Email: scepeda@its.jnj.com

Abstract

Background: Identifying the medical conditions that are associated with poor health is crucial to prioritize decisions for future research and organizing care. However, assessing the burden of disease in the general population is complex, lengthy, and expensive. Claims databases that include self-reported health status can be used to assess the impact of medical conditions on the health in a population.

Objective: This study aimed to identify medical conditions that are highly predictive of poor health status using claims databases.

Methods: To determine the medical conditions most highly predictive of poor health status, we used a retrospective cohort study using 2 US claims databases. Subjects were commercially insured patients. Health status was measured using a self-report health status response. All medical conditions were included in a least absolute shrinkage and selection operator regression model to assess which conditions were associated with poor versus excellent health.

Results: A total of 1,186,871 subjects were included; 61.64% (731,587/1,186,871) reported having excellent or very good health. The leading medical conditions associated with poor health were cancer-related conditions, demyelinating disorders, diabetes, diabetic complications, psychiatric illnesses (mood disorders and schizophrenia), sleep disorders, seizures, male reproductive tract infections, chronic obstructive pulmonary disease, cardiomyopathy, dementia, and headaches.

Conclusions: Understanding the impact of disease in a commercially insured population is critical to identify subjects who may be at risk for reduced productivity and job loss. Claims database studies can measure the impact of medical conditions on the health status in a population and to assess changes overtime and could limit the need to collect prospective collection of information, which is slow and expensive, to assess disease burden. Leading medical conditions associated with poor health in a commercially insured population were the ones associated with high burden of disease such as cancer-related conditions, demyelinating disorders, diabetes, diabetic complications, psychiatric illnesses (mood disorders and schizophrenia), infections, chronic obstructive pulmonary disease, cardiomyopathy, and dementia. However, sleep disorders, seizures, male reproductive tract infections, and headaches were also part of the leading medical conditions associated with poor health that had not been identified before as being associated with poor health and deserve more attention.

(JMIR Public Health Surveill 2020;6(1):e13018) doi:10.2196/13018

KEYWORDS

burden of illness; claims database studies; poor health

Introduction

Knowing which medical conditions are associated with perceived poor health is crucial to identify unmet needs and prioritize decisions for future research and interventions. However, assessing burden of disease in the general population is complex, lengthy, and expensive [1,2]. The Global Burden of Disease Study (GBD) created a framework for integrating and analyzing information on mortality and population health to compare the importance of diseases as measured by their impact on premature death and disability in different populations [3]. It requires assessing both the prevalence of each condition of interest and the impact of such conditions on a person's

overall health status, which often depends on collection of information that is not otherwise systematically collected in the larger population databases.

Claims databases contain data on millions of subjects that allow researchers to estimate the prevalence of a large number of medical conditions, including rare conditions that come to medical attention. Claims databases, however, usually lack information on self-reported outcomes needed to understand the impact of the medical conditions on overall health. This limitation can be overcome by linking a claims database with surveys that have information on health status and, unlike many electronic health record sources, are systematically collected in a defined population. The IBM MarketScan Health Risk Assessment (HRA) Database has self-reported health status information and can be linked to another IBM database—MarketScan Commercial Claims and Encounters (CCAE)—which contains data on health insurance claims of commercially insured individuals. This linkage allows researchers to efficiently study the burden of disease in a real-world setting in the employed population. Understanding the impact of disease in this population is critical to identify subjects who may be at risk of reduced productivity and job loss, a phenomenon that has been described extensively in the literature [4].

The impact of disease can be measured by self-reported health status, which in the HRA is captured in a single question: "How would you describe your overall health?" This single question has long been used to measure health status and health-related quality of life in national surveys or as part of multidimensional health status measures as it has been shown to be strongly associated with productivity [5], health care utilization, and mortality [6-10].

We sought to determine, in a commercially insured population, the medical conditions most highly predictive of poor health status.

Methods

Data Sources

To determine the medical conditions that are associated with self-rated poor health in a commercially insured population, we conducted a retrospective cohort study using 2 linked databases: CCAE and HRA.

The CCAE database represents data from individuals enrolled in US employer-sponsored insurance health plans. The data include adjudicated health insurance claims (ie, inpatient, outpatient, and outpatient pharmacy) as well as enrollment data from large employers and health plans who provide private health care coverage to employees, their spouses, and dependents. The database has inpatient and outpatient medical claims and medical diagnoses that are coded using the International Classification of Diseases (ICD) system ICD-9 or ICD-10.

The HRA database contains self-reported health-related behavioral data from surveys of employees of large US corporations and health plans. These questionnaires are administered as part of corporate health and wellness programs and are designed to help employees understand their own health risks and how they may be able to mitigate the risks. Participation is voluntary, although employers often provide incentives such as a credit toward the employee's share of medical premiums for completion of the survey.

Health Status

To determine the health status of the responder, we used the answer to the single question: "Over the past 6 months, how would you describe your overall health?" The 5 potential responses were excellent, very good, good, fair, and poor.

This single question is simple, easy to understand, [11] reliable [12], and, as mentioned above, has been shown to be strongly associated with productivity [5], health care utilization, and mortality [6-9].

We included survey responses from 2008 to 2016. When subjects responded to the survey in more than 1 year, we selected the most recent response. The date of the survey was considered the index date.

Medical Conditions

Diagnosis codes from medical claims occurring within the 6 months preceding the patients' survey date were included as candidate predictors of self-reported health. To group medical conditions, we used the Medical Dictionary for Regulatory Activities vocabulary (MedDRA). MedDRA is a rich and highly specific standardized medical terminology created to facilitate sharing of regulatory information internationally for medical products. It was developed in the late 1990s by the International Council for Harmonization of Technical Requirements for Pharmaceuticals for Human Use. The advantage of this vocabulary is that the terminology is hierarchically arranged from very specific to very general. We used the High-Level Group level to group the conditions. We used existing mappings of ICD-9 or ICD-10 codes to obtain MedDRA groups [13]. For example, the atrial fibrillation ICD-10 code (I48) is mapped to atrial fibrillation, which then rolls up to the High-Level Group cardiac arrhythmias.

Analysis

We built a least absolute shrinkage and selection operator (LASSO) logistic regression model [14] to assess which conditions were associated with poor versus excellent health at the time the subject responded to the survey. LASSO regression is similar to standard logistic regression except it adds a model complexity penalty to "shrink" the coefficients toward 0. Some of the coefficients are completely shrunk to 0, and therefore, LASSO reduces the number of variables used in the final model. The advantages are that it effectively does variable selection during model training, which reduces that occurrence of model overfitting and often results in a more parsimonious model. It is able to find the strongest predictors of having poor versus excellent health. We used the LASSO results to rank the medical conditions associated with poor outcomes.

We also performed a traditional logistic regression to include only MedDRA groups that were not highly correlated with one

XSL•FO

RenderX

another (r<0.70), and the results were consistent with the LASSO regression and thus, are not reported.

The regression model included medical conditions recorded in the claims data during the 6 months preceding the index date to reflect the same 6-month timeframe that is incorporated into the health status question. We included 260 medical conditions (MedDRA High Level Groups; Multimedia Appendix 1), and the outcome of interest was self-reported poor health status. The reference group included individuals self-reporting excellent health.

Odds ratios and 95% CIs were calculated using the beta coefficients and SEs of the logistic regression model and represent the independent association of each condition adjusted for the presence of all other conditions included in the model. We report the odds ratios from the logistic regression because the coefficients from the LASSO regression are shrunk and should not be interpreted as odd ratios. In addition, we present the prevalence of the conditions in subjects with and without the outcome of interest.

Validation

To validate the study findings, the model was trained using 3-fold cross validation on 75% of the data (training sample), and the study findings were validated on the remaining 25% of the data (test sample).

To assess the performance of the LASSO regression model, we calculated area under the curve (AUC) using the test sample. The AUC is a measure that quantifies the ability of the model to discriminate between subjects with and without the outcome [15]. The higher the AUC, the better the model discriminates between the subject with and without poor health.

Generalizability

To assess whether the results of the study generalize to a broader population, we compared the survey responders with the general commercially insured population.

We took a random sample of primary beneficiaries in the CCAE database of the same size as the survey responders stratified by year, and we required that the subjects be in the CCAE database at least 6 months before the index date. The index date for subjects who did not respond to the survey was a randomly selected date within the same calendar year.

We calculated age, number of distinct medical conditions, and number of visits to the health care system 6 months before the index date and the Charlson comorbidity index score [16] to further characterize the population for comparison. As comorbidities are major determinants of patient health status, we included the Charlson Index, which is a weighted sum of the presence of 19 medical conditions; each condition is assigned a weight from 1 to 6, with higher weights indicating greater severity and higher risk of mortality.

Results

Study Population

A total of 1,415,789 subjects answered the health status question, of whom 1,186,871 met the requirements of being in the CCAE database for at least 6 months before the day they responded to the survey. A total of 61.64% (731,587/1,186,871) of the responders reported having excellent or very good health; see Table 1.

The survey responders did not differ substantially from the subjects in the CCAE database with regard to age and gender. However, survey responders had more visits to the health care system (5.0 vs 3.3) and more medical conditions (3.8 vs 3.1) than the remaining subjects in the CCAE database; see Table 2.

Table 1. Health status of survey responders (N=1,186,871).

Self-reported health status	Survey responders, n (%)
Excellent health	239,734 (20.20)
Very good	491,845 (41.44)
Good health	365,083 (30.76)
Fair health	77,997 (6.57)
Poor health	12,212 (1.03)

Table 2. Characteristic of the survey responders and the source population.

Characteristic	Random sample of employees in CCAE[a] (N=1,186,871)	All survey responders (N=1,186,871)	Subjects reporting excellent health (N=239,734)	Subjects reporting poor health (N=12,212)
Sex, n (%)				
Male	616,901 (51.97)	623,668 (52.54)	128,748 (53.70)	5758 (47.15)
Female	569,970 (48.02)	563,203 (47.45)	110,986 (46.29)	6454 (52.84)
Age (years), mean (SD)	42.5 (12.35)	44.3 (11.43)	44.4 (11.64)	43.6 (11.56)
Charlson Index, mean (SD)	0.39 (1.63)	0.69 (1.1)	0.49 (1.32)	1.3 (2.51)
Distinct number of conditions 6 months preindex, mean (SD)	3.1 (5.72)	3.8 (5.28)	2.9 (4.12)	7.1 (9.41)
Number of visits 6 months preindex, mean (SD)	3.3 (7.23)	5.0 (8.02)	4.0 (6.34)	9.5 (15.12)

[a]CCAE: Commercial Claims and Encounters.

The outcome was initially defined as having a self-reported fair or poor health status, and these subjects were compared with subjects who reported having good, very good, or excellent health. The AUC model that used this delineation was 0.66. To improve the discrimination of the model, we implemented a different threshold where subjects who reported poor health were compared with subjects who reported excellent health. The performance of model improved with an AUC of 0.73.

A total of 251,892 subjects were included in the regression model that compared subjects who reported poor health (n=12,212) with subjects who reported excellent health (n=239,734). Subjects with poor health had more diagnosed conditions, more prior visits, and a higher Charlson index score than subjects with excellent health; see Table 2.

Leading Medical Conditions

The leading medical conditions that were associated with poor health were cancer-related conditions, demyelinating disorders, diabetes/diabetic complications, psychiatric illnesses (mood disorders and schizophrenia), sleep disorders, seizures, male reproductive tract infections, chronic obstructive pulmonary disease, cardiomyopathy, dementia, and headaches (Table 3). Substance use disorders, diabetes, mood disorders, sleep disorders, and obstructive pulmonary disease were the most prevalent among subjects with poor health. The association of all medical conditions assessed and their prevalence in subjects with poor and excellent health are listed in Multimedia Appendix 1.

Table 3. Leading medical conditions associated with poor health and their prevalence in subjects with poor or excellent health.

Medical condition	Prevalence in subjects with poor health, %	Prevalence in subjects with excellent health, %	Adjusted odds ratio (OR) from logistic regression model[a] (95% CI)
Metastases	1.56	0.05	7.15 (4.92-10.39)
Demyelinating disorders	0.66	0.08	3.16 (2.32-4.29)
Skeletal neoplasms malignant and unspecified	0.74	0.06	2.24 (1.37-3.68)
Glucose metabolism disorders	15.03	2.82	2.55 (1.98-3.29)
Diabetic complications	4.26	0.33	2.11 (1.79-2.48)
Manic and bipolar mood disorders and disturbances	1.55	0.24	1.98 (1.62-2.43)
Neoplasm-related morbidities	0.40	0.05	2.03 (1.28-3.22)
Sleep disturbances	10.79	2.53	1.93 (1.79-2.09)
Hepatobiliary neoplasms	0.55	0.02	1.99 (1.14-3.46)
Male reproductive tract infections and inflammations	0.49	0.36	1.73 (1.27-2.38)
Seizures	1.03	0.21	1.81 (1.41-2.32)
Increased intracranial pressure and hydrocephalus	0.17	0.02	2.09 (1.14-3.84)
Heart failures	3.49	0.51	1.69 (1.43-2.00)
Hematopoietic neoplasms (excluding leukemias and lymphomas)	3.77	0.93	1.65 (1.33-2.05)
Lymphomas non-Hodgkin T-cell	0.18	0.03	2.43 (1.17-5.04)
Gastrointestinal hemorrhages	1.62	0.63	1.47 (1.19-1.81)
Depressed mood disorders and disturbances	10.97	2.38	1.71 (1.45-2.01)
Bronchial disorders (excluding neoplasms)	10.63	3.58	1.60 (1.47-1.74)
Dementia and amnestic conditions	0.74	0.11	1.61 (1.17-2.21)
Lymphatic vessel disorders	0.45	0.05	2.20 (1.37-3.54)
Plasma cell neoplasms	0.29	0.04	1.93 (1.16-3.20)
Schizophrenia and other psychotic disorders	0.87	0.17	1.43 (1.10-1.85)
Substance-related disorders	22.58	8.24	1.52 (1.38-1.66)
Myocardial disorders	2.00	0.31	1.62 (1.31-1.98)
Headaches	7.75	2.73	1.26 (1.15-1.38)

[a]The odds ratios come from the logistic regression model that had all medical conditions with correlations <0.7.

Discussion

Principal Findings

Cancer-related conditions, demyelinating disorders, diabetes/diabetic complications, psychiatric illnesses (mood disorders and schizophrenia), sleep disorders, seizures, male reproductive tract infections, chronic obstructive pulmonary disease, cardiomyopathy, dementia, and headaches were the leading medical conditions associated with poor health.

Many of the medical conditions that had a strong association with poor health in our commercially insured population are similar to the conditions identified as the ones that affect the health of the general population using the GBD framework [1,2]. For example, cancer, diabetes, and mood disorders are the leading medical conditions associated with disability and mortality in the GBD study, and in our study, they were also some among the most predictive of having self-reported poor health status. This was of particular interest as the GBD made

extensive use of studies using screening questionnaires (eg, for mood, which would identify sufferers regardless of whether they sought medical attention), whereas our analysis was based on interactions with the health care system. Using claims data for these analyses comes with the conceptual acceptance that for many conditions such as diabetes and cancer, it is unlikely that there are undetected "cases" in the population, whereas for disorders such as mood or anxiety, only a portion of those affected seek care and are adequately identified. Nesting our analysis in an employed population with access to insurance also tempers the potential impact of access to care that is associated with health care–seeking behavior differences by reimbursement coverage.

Of interest, there are some notable differences between our findings and the GBD rankings. For example, stroke was not one of our top 25 conditions associated with poor health, but stroke has been identified as one the top 10 conditions with substantial impact on health measured by mortality or

XSL•FO
RenderX

disability-adjusted life-years [1,2]. One reason for these differences may be because of the populations being studied. Our study included employed individuals with commercial insurance who completed a survey, and thus, conditions that are acute and highly fatal or debilitating—such as stroke—or those that are more likely in an older population may not be well represented in a comparatively healthy workforce population (often referred to as the Health Worker effect). This is further reflected when comparing results with those from the general US population, as approximately 10% of the population self-report poor health status [17], but in our population, only 1% did, which may also reflect a relatively younger population. A second reason may be differences in how burden of disease was measured. For example, stroke drops from the 2nd position in the ranking for mortality to the 17th position when years lived with disability is used to assess the burden of disease. In this study, we used the magnitude of the association of the condition with poor health.

We also found some conditions at the top of our list for their association with poor health that are not in the top 25 conditions when the GBD framework is used. Focusing on a commercially insured population allowed us to identify conditions that are specifically relevant for that population and may otherwise be overlooked. This is important given a major health policy objective is to maintain a healthy workforce by reducing the impact of disease on disablement and productivity. One of the important predictors of poor health that have not been previously identified is sleep disorders. Sleep disorders are not among the 25 leading diseases that affect life expectancy or disability in the United States or globally [1,2]. Our finding adds to the body of evidence on the negative impact of sleep loss on health outcomes. Subjects who sleep less than or equal to 6 hours and subjects with insomnia not only have higher BMI but also have more cardiovascular problems [18] and increased rates of death [19]. Another condition predictive of poor health was reproductive tract infections, which includes chronic prostatitis. Chronic prostatitis affects men of all ages and demographics, and this study also confirms the substantial impact it has on quality of life [20].

This study also confirms the disease burden of infrequent conditions such as multiple sclerosis, which too was not on the top 25 conditions in the GBD study. Multiple sclerosis is a rare progressive chronic progressive autoimmune neurological disease [21]. Despite the availability of treatments, it is a leading predictor of poor health.

In this study, we are reporting the results of a comparison between subjects who reported poor health with subjects who reported excellent health because this model performed better than the model in which we grouped subjects who had poor and fair health and compared them with subjects who reported having good, very good, or excellent health. Studies that have assessed the reliability of the single self-reported health status have found that a large number of subjects inconsistently report their ratings when self-assessing health [22]. Most subjects who change ratings do it by only 1 category. So, the comparison between subjects who report poor health versus subjects who report excellent status, a comparison of the extreme responses, is likely to have less misclassification, and therefore, the model can better discriminate between the 2 groups.

Study Limitations

As mentioned above, this study used administrative medical claims to find the leading medical conditions associated with self-report of poor health. These medical conditions were identified through medical claims data, which are generated for administrative and reimbursement, not for research purposes, so the presence of a claim with a specific diagnosis does not necessarily indicate the presence of that condition. This misclassification, although it will not affect the ranking, would lead to underestimation of the association with poor health. In addition, the population studied is a commercially insured population that is healthy enough to work, so the prevalence of conditions that occur mainly in a nonworking or elderly population are likely to be underestimated.

Conclusions

Understanding the impact of disease in commercially insured subjects is critical to identify subjects who may be at risk of reduced productivity and job loss. Claims databases that have self-reported health status provide a very efficient and valid way to provide an overview of the impact of medical conditions on the health in a population and to assess changes overtime. Prospective collection of information is slow and expensive; however, this expensive approach could be tailored and focused to supplement the information that can be obtained from claims or similar databases. We found that leading medical conditions associated with poor health in a commercially insured population were the ones associated with high burden of disease in the World Health Organization GBD study such as cancer-related conditions, demyelinating disorders, diabetes/diabetic complications, psychiatric illnesses (mood disorders and schizophrenia), infections, chronic obstructive pulmonary disease, cardiomyopathy, and dementia. However, sleep disorders, seizures, male reproductive tract infections, and headaches were also part of the leading medical conditions associated with poor health that had not been identified before as being associated with poor health and deserve more attention.

Conflicts of Interest

All authors are employees of Janssen Research & Development, LCC; however, there is no assessment or mention of any products in this study.

Multimedia Appendix 1

Prevalence of each of the 260 medical conditions considered in the logistic regression model and their association with poor versus excellent health.

[DOCX File , 51 KB - publichealth_v6i1e13018_app1.docx]

References

1. Murray CJ, Lopez AD. Measuring the global burden of disease. N Engl J Med 2013 Aug 1;369(5):448-457. [doi: 10.1056/NEJMra1201534] [Medline: 23902484]

2. Murray CJ, Atkinson C, Bhalla K, Birbeck G, Burstein R, Chou D, Foreman, Lopez, Murray, Dahodwala, Jarlais, Fahami, Murray, Jarlais, Foreman, Lopez, Murray, US Burden of Disease Collaborators. The state of US health, 1990-2010: burden of diseases, injuries, and risk factors. J Am Med Assoc 2013 Aug 14;310(6):591-608 [FREE Full text] [doi: 10.1001/jama.2013.13805] [Medline: 23842577]

3. Murray CJ, Lopez AD. Mortality by cause for eight regions of the world: Global Burden of Disease Study. Lancet 1997 May 3;349(9061):1269-1276. [doi: 10.1016/S0140-6736(96)07493-4] [Medline: 9142060]

4. Bertram MY, Sweeny K, Lauer JA, Chisholm D, Sheehan P, Rasmussen B, et al. Investing in non-communicable diseases: an estimation of the return on investment for prevention and treatment services. Lancet 2018 May 19;391(10134):2071-2078. [doi: 10.1016/S0140-6736(18)30665-2] [Medline: 29627159]

5. Parker KM, Wilson MG, Vandenberg RJ, DeJoy DM, Orpinas P. Association of comorbid mental health symptoms and physical health conditions with employee productivity. J Occup Environ Med 2009 Oct;51(10):1137-1144. [doi: 10.1097/JOM.0b013e3181b8c155] [Medline: 19786901]

6. Idler EL, Benyamini Y. Self-rated health and mortality: a review of twenty-seven community studies. J Health Soc Behav 1997 Mar;38(1):21-37. [Medline: 9097506]

7. Burström B, Fredlund P. Self rated health: is it as good a predictor of subsequent mortality among adults in lower as well as in higher social classes? J Epidemiol Community Health 2001 Nov;55(11):836-840 [FREE Full text] [doi: 10.1136/jech.55.11.836] [Medline: 11604441]

8. Bierman AS, Bubolz TA, Fisher ES, Wasson JH. How well does a single question about health predict the financial health of Medicare managed care plans? Eff Clin Pract 1999;2(2):56-62. [Medline: 10538477]

9. DeSalvo KB, Bloser N, Reynolds K, He J, Muntner P. Mortality prediction with a single general self-rated health question. A meta-analysis. J Gen Intern Med 2006 Mar;21(3):267-275 [FREE Full text] [doi: 10.1111/j.1525-1497.2005.00291.x] [Medline: 16336622]

10. Abrutyn E, Mossey J, Berlin JA, Boscia J, Levison M, Pitsakis P, et al. Does asymptomatic bacteriuria predict mortality and does antimicrobial treatment reduce mortality in elderly ambulatory women? Ann Intern Med 1994 May 15;120(10):827-833. [doi: 10.7326/0003-4819-120-10-199405150-00003] [Medline: 7818631]

11. Bowling A. Just one question: if one question works, why ask several? J Epidemiol Community Health 2005 May;59(5):342-345 [FREE Full text] [doi: 10.1136/jech.2004.021204] [Medline: 15831678]

12. Lundberg O, Manderbacka K. Assessing reliability of a measure of self-rated health. Scand J Soc Med 1996 Sep;24(3):218-224. [doi: 10.1177/140349489602400314] [Medline: 8878376]

13. Reich C, Ryan PB, Stang PE, Rocca M. Evaluation of alternative standardized terminologies for medical conditions within a network of observational healthcare databases. J Biomed Inform 2012 Aug;45(4):689-696 [FREE Full text] [doi: 10.1016/j.jbi.2012.05.002] [Medline: 22683994]

14. Tian Y, Schuemie MJ, Suchard MA. Evaluating large-scale propensity score performance through real-world and synthetic data experiments. Int J Epidemiol 2018 Dec 1;47(6):2005-2014 [FREE Full text] [doi: 10.1093/ije/dyy120] [Medline: 29939268]

15. Hajian-Tilaki K. Receiver Operating Characteristic (ROC) curve analysis for medical diagnostic test evaluation. Caspian J Intern Med 2013;4(2):627-635 [FREE Full text] [Medline: 24009950]

16. Charlson ME, Pompei P, Ales KL, MacKenzie CR. A new method of classifying prognostic comorbidity in longitudinal studies: development and validation. J Chronic Dis 1987;40(5):373-383. [doi: 10.1016/0021-9681(87)90171-8] [Medline: 3558716]

17. National Center for Health Statistics. Centers for Disease Control and Prevention (CDC). 2017. Health, United States, 2016: With Chartbook on Long-term Trends in Health. URL: https://www.cdc.gov/nchs/data/hus/hus16.pdf [accessed 2019-12-05]

18. Cepeda MS, Stang P, Blacketer C, Kent JM, Wittenberg GM. Clinical relevance of sleep duration: results from a cross-sectional analysis using NHANES. J Clin Sleep Med 2016 Jun 15;12(6):813-819 [FREE Full text] [doi: 10.5664/jcsm.5876] [Medline: 26951419]

19. Sofi F, Cesari F, Casini A, Macchi C, Abbate R, Gensini GF. Insomnia and risk of cardiovascular disease: a meta-analysis. Eur J Prev Cardiol 2014 Jan;21(1):57-64. [doi: 10.1177/2047487312460020] [Medline: 22942213]

20. Schaeffer AJ, Landis JR, Knauss JS, Propert KJ, Alexander RB, Litwin MS, Chronic Prostatitis Collaborative Research Network Group. Demographic and clinical characteristics of men with chronic prostatitis: the national institutes of health chronic prostatitis cohort study. J Urol 2002 Aug;168(2):593-598. [Medline: 12131316]

21. Goldenberg MM. Multiple sclerosis review. Phys Ther 2012 Mar;37(3):175-184 [FREE Full text] [Medline: 22605909]

XSL•FO
RenderX

22.   Zajacova A, Dowd JB. Reliability of self-rated health in US adults. Am J Epidemiol 2011 Oct 15;174(8):977-983 [FREE
       Full text] [doi: 10.1093/aje/kwr204] [Medline: 21890836]

Abbreviations

AUC: area under the curve
CCAE: Commercial Claims and Encounters
GBD: Global Burden of Disease Study
HRA: Health Risk Assessment
ICD: International Classification of Diseases
LASSO: least absolute shrinkage and selection operator
MedDRA: Medical Dictionary for Regulatory Activities

XSL•FO
RenderX

Original Paper

A Web-Based Geolocated Directory of Crisis Pregnancy Centers (CPCs) in the United States: Description of CPC Map Methods and Design Features and Analysis of Baseline Data

Andrea Swartzendruber[1], MPH, PhD; Danielle N Lambert[1], MPH, PhD

Epidemiology and Biostatistics Department, College of Public Health, University of Georgia, Athens, GA, United States

Corresponding Author:
Andrea Swartzendruber, MPH, PhD
Epidemiology and Biostatistics Department
College of Public Health
University of Georgia
101 Buck Road
Athens, GA, 30602
United States
Phone: 1 7065838149
Email: aswartz@uga.edu

Abstract

Background: Crisis pregnancy centers (CPCs) are nonprofit organizations that aim to dissuade people considering abortion. The centers frequently advertise in misleading ways and provide inaccurate health information. CPCs in the United States are becoming more medicalized and gaining government funding and support. We created a CPC Map, a Web-based geolocated database of all CPCs currently operating in the United States, to help individuals seeking health services know which centers are CPCs and to facilitate academic research.

Objective: This study aimed to describe the methods used to develop and maintain the CPC Map and baseline findings regarding the number and distribution of CPCs in the United States. We also examined associations between direct state funding and the number of CPCs and relationships between the number of CPCs and state legislation proposed in 2018-2019 to ban all or most abortions.

Methods: In 2018, we used standard protocols to identify and verify the locations of and services offered by CPCs operating in the United States. The CPC Map was designed to be a publicly accessible, user-friendly searchable database that can be easily updated. We examined the number of CPCs and, using existing data, the ratios of women of reproductive age to CPCs and CPCs to abortion facilities nationally and by region, subregion, and state. We used unadjusted and adjusted negative binomial regression models to examine associations between direct state funding and the number of CPCs. We used unadjusted and adjusted logistic regression models to examine associations between the number of CPCs by state and legislation introduced in 2018-2019 to ban all or most abortions. Adjusted models controlled for the numbers of women of reproductive age and abortion facilities per state.

Results: We identified 2527 operating CPCs. Of these, 66.17% (1672/2527) offered limited medical services. Nationally, the ratio of women of reproductive age to CPCs was 29,304:1. The number of CPCs per abortion facility was 3.2. The South and Midwest had the greatest numbers of CPCs. The number of CPCs per state ranged from three (Rhode Island) to 203 (Texas). Direct funding was associated with a greater number of CPCs in unadjusted (coefficient: 0.87, 95% CI 0.51-1.22) and adjusted (coefficient: 0.45, 95% CI 0.33-0.57) analyses. The number of CPCs was associated with the state legislation introduced in 2018-2019 to ban all or most abortions in unadjusted (odds ratio [OR] 1.04, 95% CI 1.01-1.06) and adjusted analyses (OR 1.11, 95% CI 1.04-1.19).

Conclusions: CPCs are located in every state and particularly prevalent in the South and Midwest. Distribution of CPCs in the United States is associated with state funding and extreme proposals to restrict abortion. Researchers should track CPCs over time and examine factors that influence their operations and impact on public health and policy.

XSL•FO
RenderX

Introduction

Background

Crisis pregnancy centers (CPCs, also known as *pregnancy resource centers* and *fake women's health clinics*) are nonprofit organizations that primarily aim to dissuade people from seeking abortions [1,2]. Other aims include Christian evangelism and promoting sexual abstinence before marriage and marriage [2,3]. Most CPCs in the United States are affiliated with national organizations, such as Care Net and Heartbeat International, that have policies against promoting contraception [4]. CPCs have been operating in the United States since the 1960s and have traditionally provided pregnancy testing and counseling to influence individuals' pregnancy decisions and discourage people from seeking abortion [5]. CPCs in the United States are increasingly becoming medicalized, offering limited medical services, such as limited obstetric ultrasounds to confirm pregnancy and testing for some sexually transmitted infections [6]. However, CPC services do not align with national quality family planning service recommendations that define a core set of services to prevent missed opportunities for comprehensive prevention and treatment [7]. CPCs also often fail to adhere to standard ethical principles [5], such as respect and responsibility. For example, to attract individuals who may not otherwise seek their services, CPCs frequently advertise themselves in misleading ways [5-8]. For example, the centers often give the appearance that they offer services that they do not provide, such as abortion [5-8]. CPCs also frequently provide biased, misleading, and inaccurate health information in support of their objectives [1,4,6-11]. In particular, CPCs frequently provide misleading and inaccurate information about the risks of abortion and misinformation about contraceptives and condom effectiveness [1,4,6-11].

CPCs in the United States have increasingly gained government funding and political clout [6,12]. CPCs have received federal grants to support abstinence-only education in public schools for decades [13,14]. An increasing number of states support CPCs through the sale of *Choose Life* license plates and directly fund the centers through dedicated grant programs [6,14]. The Trump Administration appointed multiple CPC proponents to leadership positions. For example, the current Deputy Assistant Secretary for Population Affairs (DASPA) within the Department of Health and Human Services was formerly President and Chief Executive Officer of a network of CPCs [12]. In 2018, the DASPA was provided final decision-making authority over which organizations receive Title X grants intended to provide family planning and related preventive services to low-income or uninsured individuals [15]. In 2019, the Trump Administration announced changes to the Title X program that made CPCs eligible for the federal grants, despite the fact that CPCs do not provide contraception, and awarded funding to a California-based CPC network [16]. CPCs were also awarded federal grant funding through the Teen Pregnancy Prevention Program in 2019.

In addition to government support and funding, CPCs in the United States have also won important legal protections. CPCs are not subject to the same regulatory requirements as health facilities and are largely unregulated [5,14]. California was the first state to pass state-level legislation aimed at regulating CPCs. The 2015 California Reproduction Freedom, Accountability, Comprehensive Care, and Transparency Act mandated that unlicensed CPCs disclose that the centers are not health facilities and licensed CPCs provide information about state programs that provide abortion, prenatal, and family planning services at little or no cost to eligible individuals. In 2018, although, in a 5-4 decision in *the National Institute of Family and Life Advocates (NIFLA) versus Bacerra*, the US Supreme Court ruled in favor of CPCs' First Amendment rights and struck down the law [12].

To date, reported estimates of the total number of CPCs in the United States have widely varied. Antichoice groups' estimate of 2500-4000 CPCs [6] has commonly been cited in scientific articles published since the early 2000s. A 2017 study that compiled publicly accessible directories maintained by national umbrella organizations such as Care Net, Birthright International, and NIFLA reported >4500 CPCs nationally [17]. However, the investigators did not assess data quality or verify information reported by the organizations. Other maps and directories of CPCs have also suffered from key limitations. For example, state-level directories, by definition, are limited in scope. Furthermore, methods for producing these directories are not readily accessible leading to questions about rigor and comparability. As previously mentioned, umbrella organizations that support CPCs maintain directories of affiliated centers, but none is comprehensive of all CPCs currently operating in the country. Other national maps and directories of CPCs have been produced but are limited because they are known to be incomplete, their methods have not been reported, it is unclear if the data have been verified, they are not searchable, or they are difficult to navigate. Despite increasing medicalization of CPCs, to date, no comprehensive database has categorized or estimated the number of CPCs that provide information only or limited medical services in addition to information.

Given that CPCs often employ misleading and deceptive advertising tactics, some people may visit CPCs with misconceptions about the centers' mission and services [5]. Evidence suggests that CPC services may pose risk to individual and public health by impacting decision making about health behaviors and health care seeking and through delayed care [18]; however, evidence about CPCs' impact is limited. Furthermore, CPCs' role in the landscape of sexual and reproductive health services and abortion policy is not well understood. The number of facilities that provide abortion has declined over the past decade [19]. To date, no studies have compared the number of CPCs and facilities that provide abortion by state. Despite a rapidly changing policy environment, studies have not examined how government sponsorship influences the proliferation of CPCs or how CPCs might influence abortion policies. In 2018 and the first half of 2019, a record number of states introduced extreme legislation to ban all or most abortions [20-22]. As an active, grassroots part of the *pro-life* movement, a greater number of CPCs may signal a galvanized base of support for and potential legislative success in limiting abortion access.

Objectives

We created a CPC Map, a Web-based geolocated database of all CPCs currently operating in the United States, with the following goals: (1) helping individuals seeking health services know which centers are CPCs and (2) facilitating academic research related to CPCs. Here, we describe the methods used to create and maintain the database, key design features of the tool and related operating procedures, and baseline findings regarding the number and distribution of CPCs in the United States. Specifically, we examined the number of CPCs nationally and by state, subregion, and region and in relation to the number of women of reproductive age and abortion facilities. We also investigated associations between direct state funding for CPCs and the number of CPCs per state and relationships between the number of CPCs and legislation proposed in 2018 and from January through July 2019 to ban all or most abortions.

Methods

Data Sources

Potential CPCs were identified through multiple internet searches conducted in March-May 2018, by trained research assistants following a standard protocol. All searches were conducted using Google search engine in incognito mode. First, we accessed five Web-based directories of CPCs to create an unduplicated list of CPCs by state: Care Net, Heartbeat International, NIFLA, Birthright International, and Ramah International [23-27]. For each entry, we recorded the center's name, address, county, telephone number, and proprietary client-facing (ie, targeted to potential clients) website. If no website was provided, we searched for the site using the following keywords: [name of center], [city], and [state]. Next, we conducted keyword searches by separately entering [state] with "pregnancy resource center," "crisis pregnancy center," "pregnancy care center," and "pregnancy center." We reviewed the first five pages of results for each search (approximately 50 links per keyword search) and added unique entries to the master list. Next, we identified and reviewed existing maps by state to identify additional unique entries that were then added to the master list. We entered [state], "crisis pregnancy centers," and "map" and reviewed the first two pages of entries (approximately 20 links). We also reviewed an existing crowd-sourced Web-based directory of CPCs by state and added unique entries to the master list [28]. Finally, we searched websites of listed entries for additional potential CPC addresses and added unique entries to the master list. Each search and entry were independently verified. For all entries, we recorded the method(s) by which the center was identified.

Eligibility

From May to August 2018, trained research assistants evaluated each entry for eligibility and confirmed the name of the center and the center's address. Centers were eligible for inclusion if they were determined to be (1) currently in business and (2) a CPC. Mobile clinics and maternity homes were excluded.

First, we examined if the recorded name of the center was the exact same as the name listed on the center's website. If the center's name was not exactly as it appeared on its website, we corrected the center's name on the master list to match the name that appeared on the website. For centers with websites that did not clearly list the centers' names and for which no proprietary website was identified, we called the centers to confirm their names using a standard script and protocol.

A center was categorized as currently in business if (1) its address was listed on a live propriety domain or (2) a respondent confirmed the center's address during a telephone call to the center. Using a standard script and protocol, trained research assistants called all centers with addresses not listed on a proprietary domain. Centers with disconnected or out of service telephone numbers and those that could not be reached within five call attempts were categorized as not currently in business.

A center was categorized as a CPC if it (1) was identified through one of the search strategies, (2) advertised free pregnancy tests or testing and counseling on a live proprietary domain site or the center confirmed the availability of free pregnancy tests or testing during a telephone call to the center, (3) did not perform abortions or have *obstetrics/gynecology* in the site name, and (4) was not a family planning clinic or an informational directory that included local CPCs. Using a standard script and protocol, trained research assistants called all centers with websites that did not explicitly advertise free pregnancy tests or testing and centers with no identified client-facing proprietary website. Callers did not identify themselves as research assistants or explain the nature of the call.

Types of Services

We also identified whether each eligible CPC provided information or counseling only or limited medical services in addition to information or counseling. CPCs that advertised free limited ultrasound services (excluding referrals) on a proprietary domain or confirmed the availability of free limited ultrasound services for any type or group of clients during a telephone call to the center were categorized as providing limited medical services. All other CPCs were categorized as providing information only.

Design Features and Operating Protocols

The CPC Map's design features reflect our goals to aid people in determining which centers are CPCs and facilitate research. Intended users included individuals seeking health services, public health and medical professionals, social service organizations, researchers, and decision makers. Key features include (1) accessibility and an open-source widget that allows distribution of the CPC Map on existing websites and apps, (2) faceted search, (3) geo-tracking to facilitate localized search results, (4) Google map and data visualization, (5) categorization of CPCs that provide information only vs limited medical services, (6) enumeration of CPCs, (7) marker clustering, (8) a webform to provide updates about included CPCs, (9) a webform to suggest a CPC not already included, and (10) a webform to request access to the CPC Map data set. Below, we describe these features and related protocols in greater detail.

The CPC Map is a national directory of CPCs that is publicly available [29]. The website, which is both desktop and mobile responsive, was publicly released on September 10, 2018. In

addition, an open-source iFrame available on the site allows distribution of and access to the directory through existing websites and mobile apps. The directory, whether accessed through the main CPC Map website or widget display, is searchable by state, city, and zip code. Users who search by city or zip code are able to select radii of 5, 10, 25, 50, and 200 miles. CPC results can be presented in both map and list views. The homepage displays the map view with markers indicating locations of CPCs and includes a scroll panel that lists CPC names and addresses. Given the broadly recognized desire for and value of localized search results, the site includes geo-tracking, which, if allowed by the user, presents CPCs on the homepage at a resolution below city but above streets based on the user's internet protocol address. A separate, searchable list view can be accessed via an icon on the homepage. Both the list and map views allow users to select presentation of CPCs that offer information only or limited medical services in addition to information, or all CPCs. CPCs that offer information only are indicated via blue markers, and centers that offer limited medical services in addition to information are indicated via green markers. All search results include the total number of centers in the geographic area selected. To aid visual representation of a large number of markers on the homepage map, which presents all CPCs currently operating in the United States, the CPC Map utilizes marker clustering, a grid-based clustering technique that groups CPCs within close proximity and displays the number of CPCs within each cluster. As the user zooms out, the groups consolidate. As the user zooms in, individual centers are marked.

We intend to review and update the site annually. The CPC Map website also includes several webforms to facilitate maintenance and accuracy of the directory over time. Through webforms, users may suggest centers that should be included in the directory and submit changes to information (eg, name and address changes and types of services offered) about listed centers. Information provided via the webforms is sent to an email address maintained by the research team. Upon receipt of information about additional centers that should be included, the research team verifies the suggested information and determines whether the center is eligible for inclusion using the process described above. Centers that meet existing eligibility criteria are then added to the directory by research team members who have rights-based permission to make changes. Similarly, upon receipt of suggested information changes for centers already included in the directory, research team members verify the submitted information and update the directory, as necessary.

One of the goals underlying development of the CPC Map is to facilitate high-quality academic research related to CPCs. Users can request access to the database via a webform available on the CPC Map website. Individuals requesting access to the database are asked to provide their first and last name, organization, reason requesting access as specifically as possible, email address, and phone number. Requests are considered on a case-by-case basis. Access to the database is intended to be used for research and program planning purposes only. For example, researchers may use CPC Map data as a sampling

frame or use CPC Map data in analyses. Program planners may use the data to geographically target or inform their efforts.

Usability Testing

Before finalizing the website, five individuals including sexual and reproductive health researchers, a sexual and reproductive health policy expert, an organizer at a nonprofit women's organization, a public health student, and sexual and reproductive health care consumers conducted user testing. Testers were asked to attempt to complete six user tasks and report back on their experiences and any problems in completing the tasks. Feedback from the testers confirmed that the website and its functions were user-friendly and potential users were enthusiastic about the usefulness of the directory. Feedback was also used to finalize the site. For example, based on testers' feedback, we added a link to the webform to suggest a center to the *Contact Us* page and added tooltips that hover above the map and list view icons to explain their functions.

Data Analysis

We conducted analyses to describe the number of centers identified during data collection and final enumeration of eligible CPCs and distribution of CPCs in the United States. We also conducted analyses to examine policy factors related to CPCs, website user data, and search engine visibility. First, we used summary statistics to enumerate centers identified during collection and the number of CPCs currently operating in the United States, in total and by types of services offered. We also used descriptive statistics to assess the distribution of CPCs by region, subregion, and state. Next, we calculated the ratio of women of reproductive age (ages 15-49 years) to CPCs and the ratio of CPCs to abortion facilities nationally and by region, subregion, and state. Estimates of mid-year 2017 populations were obtained from the US Census Bureau [30]. The number of abortion facilities was obtained from a 2018 study that conducted a systematic Web-based search of abortion facilities in the United States [19].

Next, we examined policy factors related to the number of CPCs in each state and the District of Columbia. We examined the association between direct state funding for CPCs (yes/no) and the number of CPCs, a count variable, using unadjusted and adjusted mixed effect negative binomial regression models with a random intercept for region and robust standard errors. We used negative binomial regression models because analyses showed that Poisson models were not a good fit. Adjusted models controlled for the number of women of reproductive age and number of abortion facilities per state. Information about states that directly fund CPCs was obtained from a 2019 report released by a national advocacy organization [31]. States that directly funded CPCs (Florida, Georgia, Indiana, Kansas, Louisiana, Michigan, Minnesota, Missouri, New Mexico, North Carolina, North Dakota, Ohio, Oklahoma, Pennsylvania, Texas, and Wisconsin) were coded 1, and all others were coded 0.

We used unadjusted and adjusted logistic regression models to examine associations between the number of CPCs and state legislation to ban all or most abortions introduced in 2018 and from January through July 2019. Adjusted models controlled for the number of women of reproductive age and number of

abortion facilities per state. We separately assessed associations between the number of CPCs and legislation to ban all or most abortions introduced in 2018, 2019, and in either year (2018-2019). Information about states that introduced legislation to ban all or most abortions was obtained from the Guttmacher Institute [20]. The following states introduced legislation to ban all or most abortions in 2018: Colorado, Illinois, Iowa, Indiana, Kentucky, Minnesota, Mississippi, Missouri, New Hampshire, New York, Ohio, Oklahoma, Pennsylvania, South Carolina, and Tennessee. States that introduced legislation to ban all or most abortions in 2019 included: Alabama, Arkansas, Georgia, Florida, Illinois, Indiana, Iowa, Kentucky, Louisiana, Maryland, Michigan, Minnesota, Mississippi, Missouri, New York, Ohio, Oklahoma, South Carolina, Tennessee, Texas, Washington, and West Virginia. States that introduced legislation were coded as 1; all others were coded as 0.

Finally, we used Google Analytics to describe the total number of views and unique views of the CPC Map within the first 10 months following release of the website. We also examined the number of domains that contained links to the CPC Map and the number that embedded the CPC Map widget. In addition, we used SEMRush to analyze search engine results and catalog relevant queries (keywords) with notable volume that drove organic traffic to the site. We then identified and quantified the number of queries that ranked on Google's first page.

Results

Enumerating Crisis Pregnancy Centers

Using the multiple data sources described above, 4379 CPCs were initially identified through the search procedures. The compiled list was then reviewed for duplicate entries. A total of 14.20% (622/4379) of duplicate listings were identified, resulting in 3754 unique entries. These entries were then further reviewed for eligibility to determine if they were currently in business, offered free pregnancy tests or testing, and were a CPC. Of the unique sites found through the search procedures, 67.3% (2527/3754) were identified as eligible and operating CPCs. Of these, 66.17% (1672/2527) offered limited medical

services in addition to pregnancy testing and counseling. Nationally, the ratio of women of reproductive age to CPCs was 29,304:1 per center. The number of CPCs per abortion facility was 3.2 nationally.

Distribution of Crisis Pregnancy Centers in the United States

The distribution of CPCs varied across region (Table 1). The South had the greatest number of CPCs and the highest proportion of centers that offered limited medical services. The Northeast had the fewest CPCs and lowest proportion that offered limited medical services. The Midwest had the lowest ratio of women of reproductive age to centers, and the West had the highest. The Midwest had the highest ratio of CPCs to abortion facilities, and the Northeast had the lowest.

The distribution of CPCs also varied by state: Rhode Island, Delaware, and Hawaii were among the states with the fewest CPCs along with the District of Columbia. None of these was categorized as directly funding CPCs. The five states with the greatest number of CPCs included Texas, Florida, California, Pennsylvania, and Ohio. Of these, only California was categorized as not directly funding CPCs.

States with the highest proportion of centers that provided limited medical services included Rhode Island, Louisiana, Nevada, North Dakota, and Delaware. States with the lowest proportion included District of Columbia, Connecticut, New York, Vermont, and Maine. Wyoming, Montana, Iowa, South Dakota, and Kansas had the lowest ratio of women of reproductive age to CPCs, whereas New Mexico, District of Columbia, Nevada, Rhode Island, and California had the highest.

In only two states, Massachusetts and New Jersey, and the District of Columbia, the ratio of CPCs to abortion facilities was less than 1. There were approximately equal numbers of CPCs and abortion facilities in California and Rhode Island. In all other states, CPCs outnumbered abortion facilities. The ratio was highest in Missouri, Kentucky, and Mississippi, each of which had only a single abortion facility.

Table 1. Number of crisis pregnancy centers in the United States, by region and state, in 2018.

Region and state	CPCs[a], n	CPCs that offer limited medical services, n (%)	Population of women of reproductive age (ages 15-49 years) per CPC, n	Ratio of CPCs to abortion facilities
United States	2527	1672 (66.17)	29,304	3.2
Northeast	352	168 (47.7)	36,820	1.5
New England	83	40 (48)	40,706	1.1
Connecticut	21	7 (33)	38,613	1.1
Maine	11	5 (46)	25,445	0.6
Massachusetts	25	11 (44)	64,611	1.3
New Hampshire	15	11 (73)	19,360	2.5
Rhode Island	3	3 (100)	82,094	1.0
Vermont	8	3 (37)	16,985	1.3
Middle Atlantic	269	128 (47.6)	35,621	1.7
New Jersey	37	22 (59)	55,330	0.7
New York	107	37 (34.6)	44,028	1.2
Pennsylvania	125	69 (55.2)	22,591	7.4
Midwest	724	474 (65.5)	21,073	7.9
East North Central	455	321 (70.6)	23,234	6.7
Indiana	96	73 (76)	15,688	16.0
Illinois	86	59 (68)	34,859	3.4
Michigan	99	64 (64)	22,339	4.3
Ohio	119	85 (71.4)	21,724	10.8
Wisconsin	55	40 (72)	23,110	18.3
West North Central	269	153 (56.9)	17,417	11.2
Iowa	49	28 (57)	13,911	5.4
Kansas	36	17 (47)	17,880	9.0
Minnesota	77	39 (51)	15,969	15.4
Missouri	69	47 (68)	19,769	69.0
Nebraska	20	12 (60)	21,037	6.7
North Dakota	7	6 (86)	23,446	7.0
South Dakota	11	4 (36)	16,484	11.0
South	1003	745 (74.28)	28,031	5.2
South Atlantic	486	361 (74.3)	29,906	3.3
Delaware	6	5 (83)	35,298	2.0
District of Columbia	2	0 (0)	99,643	0.7
Florida	160	132 (82.5)	27,590	2.7
Georgia	90	70 (78)	27,540	5.3
Maryland	48	38 (79)	29,464	1.9
North Carolina	83	60 (72)	28,253	5.5
South Carolina	32	18 (56)	34,763	10.7
Virginia	51	31 (60)	38,600	3.4
West Virginia	14	7 (50)	27,850	14.0
East South Central	200	142 (71.0)	21,642	13.3
Alabama	52	39 (75)	21,452	10.4

Region and state	CPCs[a], n	CPCs that offer limited medical services, n (%)	Population of women of reproductive age (ages 15-49 years) per CPC, n	Ratio of CPCs to abortion facilities
Kentucky	54	34 (63)	18,477	54.0
Mississippi	29	18 (62)	23,929	29.0
Tennessee	65	51 (78)	23,403	8.1
West South Central	317	242 (76.3)	29,188	10.2
Arkansas	37	27 (73)	18,095	12.3
Louisiana	29	25 (86)	37,452	9.7
Oklahoma	48	37 (77)	18,324	12.0
Texas	203	153 (75.4)	32,597	9.7
West	448	285 (63.6)	39,656	1.7
Mountain	196	128 (65.3)	27,370	3.6
Arizona	53	35 (66)	28,786	6.6
Colorado	58	38 (66)	22,009	2.8
Idaho	19	11 (58)	19,270	4.8
Montana	18	11 (61)	12,017	3.6
Nevada	7	6 (86)	95,375	0.9
New Mexico	22	13 (59)	20,849	4.4
Utah	7	4 (57)	104,029	3.5
Wyoming	12	10 (83)	10,441	6.0
Pacific	252	157 (62.3)	49,212	1.2
Alaska	9	5 (56)	18,790	1.5
California	147	93 (63.3)	63,665	1.0
Hawaii	6	4 (67)	51,811	2.0
Oregon	43	26 (60)	21,214	3.6
Washington	47	29 (62)	35,117	1.4

[a]CPC: crisis pregnancy center.

Policy Analyses

We found significant positive associations between direct state-level funding for CPCs and the number of centers in states in both unadjusted (coefficient: 0.87, 95% CI 0.51-1.22; P<.001) and adjusted models (coefficient: 0.45, 95% CI 0.33-0.57; P<.001). Table 2 presents associations between the number of CPCs in each state and the District of Columbia and legislation to ban all or most abortions proposed in 2018 and through July 2019. A greater number of CPCs was positively associated with legislation to ban all or most abortions introduced in 2018, 2019, and 2018-2019 in both unadjusted and adjusted analyses.

Table 2. Associations between the number of crisis pregnancy centers in each state and the District of Columbia and legislation proposed in 2018 and January-July 2019 to ban all or most abortions.

The year in which legislation to ban all or most abortions was introduced	Unadjusted analysis		Adjusted[a] analysis	
	OR[b] (95% CI)	P value	OR (95% CI)	P value
2018	1.01 (1.00-1.03)	.09	1.08 (1.02-1.14)	.005
2019	1.03 (1.01-1.05)	.004	1.06 (1.01-1.12)	.01
2018 or 2019	1.04 (1.01-1.06)	.002	1.11 (1.04-1.19)	.002

[a]Adjusted for the number of abortion facilities and women aged 15 to 49 years per state.
[b]OR: odds ratio.

Website Analytics

With no paid advertising, the CPC Map website received 9516 unique views and 11,872 total views in the initial 10 months after release, and views steadily increased over time. During the same period, 177 domains contained links to the CPC Map, including major and regional news outlets. In July 2019, the CPC Map ranked for more than 3100 keywords, indicating a very high degree of relevant and valuable content. The CPC Map ranked for 13 terms with significant search volume on Google's first search engine results page. For example, the site ranked sixth for *crisis pregnancy center near me* and *crisis pregnancy locations*, seventh for *what are CPCs*, and eighth for *teen pregnancy center near me*. Searches that include *near me* indicate strong signals of user intent and suggest that the CPC Map is successfully reaching people seeking to identify local CPCs.

Discussion

Principal Findings

Individuals facing or at risk for unintended pregnancy require quality sexual and reproductive health information and services. CPCs frequently provide inaccurate health information and do not adhere to medical or ethical practice standards, which could pose risk to individual and public health [18]. CPCs are becoming more medicalized and increasingly gaining government support. The purpose of the CPC Map is to identify the number and locations of CPCs currently operating in the United States. We identified over 2500 CPCs currently operating in the United States, about two-thirds of which offered limited medical services. However, the distribution of centers was not uniform by region or state.

The South and Midwest had the highest numbers of CPCs and lowest ratios of reproductive-aged women to CPCs. We found that state funding was positively associated with a greater number of CPCs per state. In total, 88% (14/16) of the states that directly fund CPCs were located in the South and Midwest. As this study is cross-sectional, temporality cannot be established. It is currently unknown whether state funding attracts more centers or whether states with more centers are more successful in attracting state funding. Over time, the CPC Map may be useful for longitudinally tracking how the number of CPCs changes and the potential impact of state government support. That approximately one-third of states directly fund the centers despite lack of evidence of public health benefit and potential risks point to additional factors that may also influence the numbers and locations of CPCs. Political climate and religious context likely underlie whether states directly fund CPCs, the number of CPCs, and the ratio of CPCs to abortion facilities in a state. Future studies that more fully explore state-level factors related to the number of CPCs per state and changes over time would be helpful to better understand contexts that limit and facilitate CPC operations.

Nationally, there are over three times as many CPCs as abortion facilities. In only four states and the District of Columbia, the ratio of CPCs to abortion facilities was approximately 1 or less, suggesting that in most of the United States, people have better access to CPCs than abortion care. Access to abortion is a function of residence. The Midwest and South have the fewest abortion facilities [19] and greatest number of CPCs resulting in nearly eight times as many CPCs in the Midwest and over five times as many in the South.

We also found that a greater number of CPCs was associated with state abortion bans introduced in 2018 and 2019. An unprecedented wave of legislation restricting access to abortion has been enacted since 2011 [21]. Following Supreme Court changes, 2019 marked a new level of proposed legislation to ban abortion [22]. The current findings show that a greater number of CPCs predicted the most extreme legislation introduced in 2019 that aimed to ban all or most abortions, including legislation to ban abortion completely and to ban abortion after 6 to 8 weeks of gestation. CPCs are one facet of a movement eager to make abortion unlawful nationally. Although this study was not able to thoroughly explore factors associated with where and what types of abortion bans were introduced, CPCs may represent a significant base of support and mobilization for this type of legislation. What impact such bans and other abortion restrictions, if enacted and implemented, would have on the number of CPCs in each state is unknown. If abortion was completely banned in only some states, CPCs may strategically focus their efforts in states where abortion remained legal. Alternatively, CPCs may see their objectives of promoting sexual abstinence before marriage and childbearing as unchanged or perhaps perceive an even greater need for their pregnancy support services if abortion became illegal in some states or nationally. The CPC Map is well suited to track these potential changes over time and to facilitate analyses related to how state policy environments are influenced by and influence CPCs.

Strengths and Limitations

The CPC Map is subject to several limitations. Although our team followed standard protocols to create the tool, the CPC Map is dependent on the accuracy of publicly available information about centers and their locations. Rigorous data collection occurred in April-June 2018. Although we intend to maintain the CPC Map over time, the tool is not updated constantly, and we cannot guarantee the completeness and accuracy of the CPC Map, particularly as CPCs do change names and locations and increasingly offer limited medical services. However, the CPC Map's design facilitates a process for obtaining and verifying updates submitted by users. In addition, the current analysis focused on between-state comparisons. Investigating locations of CPCs within states might also be important for better understanding factors that influence where CPCs operate, groups that might be most impacted by CPC services, and access to sexual and reproductive health services and information in different areas. For example, examining factors such as proximity to schools, racial composition of the population, rural and urban differences, and proximity to hospitals, abortion facilities, and other sources of health care may provide further insights about where CPCs locate, contexts that facilitate and constrain CPC operations, and individuals and groups that might be most impacted by CPC services. Finally, although our adjusted analyses controlled for multiple potential confounders, the findings may be limited by

unidentified sources of confounding, which may have led to inflated or underestimated results.

Conclusions

In an era of volatile policy dynamics and intense change related to sexual and reproductive health care access and rights, the CPC Map was designed to help raise awareness about CPCs and track the extent to which CPCs change in number, location, and types of services offered over time. The purpose of the CPC Map was to create an accessible, user-friendly Web-based geolocated database of all of the CPCs operating in the United States to help make sexual and reproductive health care consumers aware of which centers are CPCs and to facilitate and grow the evidence base related to CPCs, particularly in a period when CPCs are benefitting from significant US government support and funding. Direct, organic, and referral traffic to the site incrementally increased since the release of the CPC Map despite no paid advertising, indicating increasing reach and potentially increased awareness about CPCs and their locations. This study revealed that CPCs are located in every state and are particularly prevalent in the South and Midwest, which also have the fewest abortion facilities. Nationally, CPCs outnumber abortion facilities by a factor of 3.2. We found that state funding for CPCs was positively associated with the number of CPCs, and a greater number of CPCs predicted introduction of extreme state legislation restricting abortion. Given increasing government investment in CPCs, researchers should continue to track CPCs and examine factors that influence CPCs' operations, strategies, and impact on public health and policy.

Conflicts of Interest

None declared.

References

1. Rosen JD. The public health risks of crisis pregnancy centers. Perspect Sex Reprod Health 2012 Sep;44(3):201-205. [doi: 10.1363/4420112] [Medline: 22958665]
2. Family Research Council. -. 2009. A Passion to Serve, A Vision for Life: Pregnancy Resource Center Service Report 2009 URL: http://downloads.frc.org/EF/EF09I51.pdf [accessed 2017-08-31]
3. Kelly K. In the name of the mother: renegotiating conservative women's authority in the crisis pregnancy center movement. Signs 2012;38(1):203-230. [doi: 10.1086/665807]
4. Swartzendruber A, Steiner RJ, Newton-Levinson A. Contraceptive information on pregnancy resource center websites: a statewide content analysis. Contraception 2018 Apr 24. [doi: 10.1016/j.contraception.2018.04.002] [Medline: 29702081]
5. Bryant AG, Swartz JJ. Why crisis pregnancy centers are legal but unethical. AMA J Ethics 2018 Mar 1;20(1):269-277 [FREE Full text] [doi: 10.1001/journalofethics.2018.20.3.pfor1-1803] [Medline: 29542437]
6. Lin V, Dailard C. Crisis pregnancy centers seek to increase political clout, secure government subsidy. Guttmacher Rep Public Policy 2002 Nov;5(2):4-6 [FREE Full text]
7. Swartzendruber A, Newton-Levinson A, Feuchs AE, Phillips AL, Hickey J, Steiner RJ. Sexual and reproductive health services and related health information on pregnancy resource center websites: a statewide content analysis. Womens Health Issues 2018;28(1):14-20. [doi: 10.1016/j.whi.2017.10.007] [Medline: 29158038]
8. Bryant AG, Levi EE. Abortion misinformation from crisis pregnancy centers in North Carolina. Contraception 2012 Dec;86(6):752-756. [doi: 10.1016/j.contraception.2012.06.001] [Medline: 22770790]
9. Bryant AG, Narasimhan S, Bryant-Comstock K, Levi EE. Crisis pregnancy center websites: information, misinformation and disinformation. Contraception 2014 Dec;90(6):601-605. [doi: 10.1016/j.contraception.2014.07.003] [Medline: 25091391]
10. Bryant-Comstock K, Bryant AG, Narasimhan S, Levi EE. Information about sexual health on crisis pregnancy center web sites: accurate for adolescents? J Pediatr Adolesc Gynecol 2016 Feb;29(1):22-25. [doi: 10.1016/j.jpag.2015.05.008] [Medline: 26493590]
11. Kelly K. The spread of 'Post Abortion Syndrome' as social diagnosis. Soc Sci Med 2014 Feb;102:18-25. [doi: 10.1016/j.socscimed.2013.11.030] [Medline: 24565137]
12. Rubin R. At 'crisis pregnancy centers,' critics say, ideology trumps evidence. J Am Med Assoc 2018 Aug 7;320(5):425-427. [doi: 10.1001/jama.2018.8661] [Medline: 30027265]
13. Hartshorn MH. Foot Soldiers Armed with Love: Heartbeat International's First Forty Years. Virginia Beach: Donning Company Publishers; 2011.
14. Ahmed A. Informed decision making and abortion: crisis pregnancy centers, informed consent, and the first amendment. J Law Med Ethics 2015;43(1):51-58. [doi: 10.1111/jlme.12195] [Medline: 25846038]
15. Department of Health and Human Services, Office of Population Affairs. The US Department of Health and Human Services. 2018. Announcement of Anticipated Availability of Funds for Family Planning Services Grants URL: https://www.hhs.gov/opa/sites/default/files/FY-17-Title-X-FOA-New-Competitions.pdf [accessed 2019-09-09]
16. Department of Health and Human Services, Office of Population Affairs. The US Department of Health and Human Services. HHS Title X Family Planning Service Grants Award by State Fiscal Year 2019 Grantees URL: https://www.hhs.gov/opa/grants-and-funding/recent-grant-awards/index.html [accessed 2019-09-09]

XSL·FO

RenderX

17.   McVeigh R, Crubaugh B, Estep K. Plausibility structures, status threats, and the establishment of anti-abortion pregnancy centers. Am J Sociol 2017 Mar;122(5):1533-1571. [doi: 10.1086/691127]

18.   Swartzendruber A, English A, Greenberg KB, Murray PJ, Freeman M, Upadhya K, et al. Crisis pregnancy centers in the United States: lack of adherence to medical and ethical practice standards; a joint position statement of The Society for Adolescent Health and Medicine and The North American Society for Pediatric and Adolescent Gynecology. J Pediatr Adolesc Gynecol 2019 Dec;32(6):563-566. [doi: 10.1016/j.jpag.2019.10.008] [Medline: 31679958]

19.   Cartwright AF, Karunaratne M, Barr-Walker J, Johns NE, Upadhyay UD. Identifying national availability of abortion care and distance from major US cities: systematic online search. J Med Internet Res 2018 May 14;20(5):e186 [FREE Full text] [doi: 10.2196/jmir.9717] [Medline: 29759954]

20.   Guttmacher Institute. 2019. State Policy Updates URL: https://www.guttmacher.org/state-policy/ [accessed 2019-07-05]

21.   Nash E. Guttmacher Institute. 2019. Unprecedented Wave of Abortion Bans is an Urgent Call to Action URL: https://www.guttmacher.org/article/2019/05/unprecedented-wave-abortion-bans-urgent-call-action [accessed 2019-07-05]

22.   Nash EC, Campello O, Naide S, Mohammed L, Ansari-Thomas Z. Guttmacher Institute. 2019. Radical Attempts to Ban Abortion Dominate State Policy Trends in the First Quarter of 2019 URL: https://www.guttmacher.org/article/2019/04/radical-attempts-ban-abortion-dominate-state-policy-trends-first-quarter-2019 [accessed 2019-09-09]

23.   Free Resources - Care Net. 2018. Find a Pregnancy Center URL: http://www.care-net.org/find-a-pregnancy-center [accessed 2018-03-02]

24.   Heartbeat International. 2018. Worldwide Directory URL: https://www.heartbeatinternational.org/worldwide-directory [accessed 2018-03-02]

25.   NIFLA | National Institute of Family and Life Advocates. 2018. URL: http://www.nifla.org/ [accessed 2018-03-02]

26.   Ramah International. Help in your area. 2018. URL: https://ramahinternational.org/help-in-your-area/georgia [accessed 2018-03-02]

27.   Birthright International. 2018. URL: https://birthright.org/ [accessed 2018-03-02]

28.   Expose Fake Clinics. 2018. URL: https://www.exposefakeclinics.com/ [accessed 2018-03-02]

29.   Crisis Pregnancy Center Map & Finder - CPC Map. 2018. URL: https://crisispregnancycentermap.com/ [accessed 2020-01-23]

30.   United States Census Bureau Population Division. American FactFinder - Census Bureau. 2017. URL: https://factfinder.census.gov/faces/tableservices/jsf/pages/productview.xhtml?pid=ACS_17_5YR_B01001&prodType=table [accessed 2018-12-26]

31.   NARAL Pro-Choice America. 2019. Who Decides? The Status of Women's Reproductive Rights in the United States URL: https://www.prochoiceamerica.org/wp-content/uploads/2019/02/WhoDecides2019-DigitalEdition.pdf [accessed 2019-04-21]

Abbreviations

CPC: crisis pregnancy center
DASPA: Deputy Assistant Secretary for Population Affairs
NIFLA: National Institute of Family and Life Advocates
OR: odds ratio

XSL•FO

RenderX

Original Paper

Predictors of User Engagement With Facebook Posts Generated by a National Sample of Lesbian, Gay, Bisexual, Transgender, and Queer Community Centers in the United States: Content Analysis

William C Goedel[1], BA; Harry Jin[1], MPH; Cassandra Sutten Coats[2], MSc; Adedotun Ogunbajo[2], MPH, MHS; Arjee J Restar[2], MPH

[1]Department of Epidemiology, School of Public Health, Brown University, Providence, RI, United States

[2]Department of Behavioral and Social Sciences, School of Public Health, Brown University, Providence, RI, United States

Corresponding Author:
William C Goedel, BA
Department of Epidemiology
School of Public Health
Brown University
121 South Main Street
Box G-S121-3
Providence, RI, 02906
United States
Phone: 1 4018633713
Email: william_goedel@brown.edu

Abstract

Background: Lesbian, gay, bisexual, transgender, and queer (LGBTQ) community centers remain important venues for reaching and providing crucial health and social services to LGBTQ individuals in the United States. These organizations commonly use Facebook to reach their target audiences, but little is known about factors associated with user engagement with their social media presence.

Objective: This study aimed to identify factors associated with engagement with Facebook content generated by LGBTQ community centers in the United States.

Methods: Content generated by LGBTQ community centers in 2017 was downloaded using Facebook's application programming interface. Posts were classified by their content and sentiment. Correlates of user engagement were identified using negative binomial regression.

Results: A total of 32,014 posts from 175 community centers were collected. Posts with photos (incidence rate ratio, [IRR] 1.07; 95% CI 1.06-1.09) and videos (IRR 1.54; 95% CI 1.52-1.56) that contained a direct invitation for engagement (IRR 1.03; 95% CI 1.02-1.04), that expressed a positive sentiment (IRR 1.11; 95% CI 1.10-1.12), and that contained content related to stigma (IRR 1.16; 95% CI 1.14-1.17), mental health (IRR 1.33; 95% CI 1.31-1.35), and politics (IRR 1.28; 95% CI 1.27-1.29) received higher levels of engagement.

Conclusions: The results of this study provide support for the use of Facebook to extend the reach of LGBTQ community centers and highlight multiple factors that can be leveraged to optimize engagement.

XSL•FO
RenderX

Introduction

Lesbian, gay, bisexual, transgender, and queer (LGBTQ) individuals in the United States experience significant disparities in physical and mental health and in access to health care relative to their cisgender and heterosexual counterparts [1]. Communication plays an important role in eliminating health disparities [2], but health promotion messages are only effective if they reach and resonate with their target audiences. It has been argued that many communication campaigns create messages that employ the surface structure approach to reach their target audience's culture by matching messages and channels to observable social and behavioral characteristics of their target audience's members (eg, through the use of familiar people, music, and language) [2]. Effective messaging will also resonate with the historical, social, psychological, and environmental factors that affect the health and well-being of an audience (known as its culture's "deep structure") [2]. This entails knowing the kinds of framings (eg, positive vs negative framing [3], gain vs loss framing [4], and 1- vs 2-sided framing [5]), the contents (eg, mental health and sexual health promotion), format (eg, photo and video), frequency or duration, and the context (eg, social or political issues) of the messages that work best to engage individuals with the recommended health behavior [6]. Organizations, particularly those who may not have the capacity for public health programming, may create health communication materials for LGBTQ communities that may not be attuned to their health, information, and communication needs. As such, these organizations may lack an understanding about which channels, contents, and contexts of communication effectively reach their audiences [7], leading to ineffective messaging that does little to improve the health of LGBTQ individuals.

As affirmative and inclusive health services for LGBTQ individuals are lacking in many locations [8], particularly in rural areas [9], LGBTQ community centers remain important venues for reaching and providing crucial health and social services to LGBTQ individuals [10]. LGBTQ community centers are diverse in terms of their mission and structure, and many are independent nonprofit organizations that aim to provide educational, social, and health programming for their clients [10]. Most LGBTQ community centers are physical venues, but regardless of their physical presence, these organizations rely heavily on social media and other digital platforms to reach their clients [10]. Social media represents a common form of digital networking that LGBTQ individuals engage with frequently. In a national probability sample, lesbian, gay, and bisexual adults in the United States were more likely to have a profile on Facebook and use Facebook on a daily basis compared with their heterosexual peers [11]. A significant body of research has shown that LGBTQ individuals use social media sites for many of the same purposes one may access a community center in person, including providing spaces to explore identity, form communities with their peers, access affirming health resources, and engage in political causes [12-15].

The effective use of social media has become a key priority in public health, particularly in reaching populations (eg, LGBTQ

communities) that have been overlooked by conventional non-Web-based public health campaigns [16]. Although the use of social media by community centers and community-based organizations (CBOs) is common, the ability of these messages to reach their intended audience and encourage user engagement is varying [17]. Increasing user engagement has become a primary objective of many social media campaigns, but few studies have sought to identify predictors of user engagement [18,19]. A recent study found that social media profiles focused on sexual health promotion that posted often, engaged with individual users, that encouraged interaction and conversation by posing questions, and that shared multimedia content had higher levels of engagement [18]. In general, the reach of social media posts depends on the ability of content to engage and resonate with users. However, because the content produced by LGBTQ community centers may address sensitive, identity-specific topics, the ability of this content to reach its audience could be further constrained by users' willingness to disclose their identities by publicly engaging with this content [20-22]. As such, we aimed to understand the predictors of user engagement with Facebook content generated by LGBTQ community centers in the United States.

Methods

Data were collected from Facebook pages administered by 175 LGBTQ community centers in the United States. Facebook pages were purposively selected based on their inclusion in a national directory of LGBTQ community centers maintained by CenterLink, a member-based coalition of LGBTQ community centers formed with the goal of improving the organizational and service delivery capacities of these centers [23].

On the basis of methods used in prior studies [19], data (eg, posts and metrics of engagement with these posts) were downloaded using Facebook's public application programming interface (API) accessed through the Netvizz application [24]. Posts made in 2017 (January 1 to December 31) were collected and organized by page and post. At the page level, we identified the number of followers for each page. At the post level, we identified the number of likes, reactions, comments, and shares on each post. The study was considered not to be human subjects research and was deemed exempt from institutional review board review. As an extra precaution on behalf of the users who may have interacted with these posts, the names of the Facebook pages included in this study have been omitted. LGBTQ community centers included in the sample were located in 45 of 50 states as well as the District of Columbia.

The content of each post was then analyzed using informatics-based methods [25]. First, using researcher-generated search terms, we identified posts based on 6 topics (with example keywords for each topic in parentheses), related to the missions of LGBTQ community centers, including posts related to stigma experienced by LGBTQ communities eg, stigma, discrimination, and banned), mental health concerns and services (eg, anxious, depressed, counseling, and therapy), education and skill-building (eg, learn, training, and information), youth development (eg, youths, children, and kids), social programming (eg, support, friend,

event, and community), and political engagement (eg, vote, election, government, and law). In addition, we identified posts with LGBTQ identity terms (eg, lesbian, transgender, nonbinary, and nonconforming) and posts with explicit invitations for engagement (eg, comment, like, share, visit, click, and take). Posts were able to be identified as belonging to multiple categories.

Each sentence of each post was scored using the Bing Liu sentiment lexicon [26]. This sentiment lexicon is widely used in sentiment analysis and opinion mining and was selected because it provides a freely accessible word database that assigns positive and negative values to keywords. After each word within each sentence of a post was scored, an average sentiment score was assigned to each post indicating whether the post had an overall negative or positive affect. A score of 0 would represent a post with neutral affect, whereas a positive score represents a post with a positive affect, and a negative score represents a post with a negative affect.

Hierarchical negative binomial regression was used to identify post characteristics associated with greater user engagement. In this analysis, the engagement score generated by Facebook was used as an outcome as this is likely an important variable in their algorithm that determines which posts are made visible most frequently. According to the Facebook API, this score is the combined total number of reactions, shares, and comments on each post. Hierarchical negative binomial regression modeling was selected as the statistical approach for this study because the Facebook engagement count data were overdispersed, highly skewed toward 0 and 1, and came from 175 separate Facebook pages—each with a varying number of Facebook "fans" and with differing rates of activity. Incidence rate ratios (IRRs) were calculated based on these analyses.

Results

During the study period, 32,014 posts were shared by 175 pages. Overall, each page contributed a median of 151 unique posts (IQR 78-264) and had a median of 3347 fans (IQR 1886-5746). These posts received a combined total of 546,492 likes and 32,353 comments and were shared 108,204 times.

Table 1 provides an overview of the posts analyzed. A variety of post types were utilized, with the majority of posts being photos (48.39%, 15,493/32,014) or links (38.26%, 12,250/32,014). Most posts (65.10%, 20,842/32,014) could be classified as containing content related to one of the 7 searched topics (stigma, mental health, education, youth, identity, social, and politics), with identity-related content (42.73%; 13,680/32,014) and content related to social events and socializing (37.01%; 11,850/32,014) being the most common. Example posts from each content area are displayed in Table 2. A total of 1 in 10 posts (11.10%; n=3556/32,014) contained a direct invitation for engagement. Among all posts, the median sentiment score for these posts was 0.2 (IQR 0.1-0.4). Each post received a median of 4 likes (IQR 1-11) and 0 comments (IQR 0-0) and was shared 0 times (IQR 0-2).

Table 1. Characteristics of Facebook posts by lesbian, gay, bisexual, transgender, and queer community centers, 2017 (n=32,014).

Post characteristics	Value
Post type, n (%)	
Link	12,250 (38.26)
Photo	15,493 (48.39)
Status	2399 (7.49)
Video	1872 (5.84)
Post date (day of week), n (%)	
Weekday (Monday-Friday)	26,331 (82.24)
Weekend (Saturday, Sunday)	5683 (17.70)
Post content type, n (%)	
Stigma	700 (2.18)
Mental health	857 (2.66)
Education	3450 (10.77)
Youth	4237 (13.23)
Social	11,850 (37.01)
Politics	1445 (4.51)
Mentions an identity term, n (%)	13,680 (42.73)
Direct invitations for engagement, n (%)	3556 (11.10)
Sentiment score, median (IQR)	0.2 (0.1-0.4)
Post engagement, median (IQR)	
Likes	4.0 (1.0-11.0)
Reactions	5.0 (2.0-14.0)
Comments	0.0 (0.0-0.0)
Shares	0.0 (0.0-2.0)
Engagement score	6.0 (2.0-17.00)

Table 2. Examples of Facebook posts by lesbian, gay, bisexual, transgender, and queer community centers classified by content type.

Content type	Example post
Stigma	"The [blinded local legislature] passed [blinded] earlier this week. This discriminatory legislation seeks to give taxpayer-funded agencies a license to discriminate against LGBTQ people under the guise of religion, the dangerous anti-LGBTQ proposal will now move to the [blinded] senate for consideration." (A link that received 7 likes, 5 comments, and 391 shares)
Mental health	"Meet our mental health team. With their compassion and expertise, this amazing group is the lifeline to many in our community. This team works tirelessly to assure that each person seeking our services gets the support resources and care they need and, when needed, this team goes above and beyond their daily work providing support and guidance for the staff and volunteers at [blinded]. Our mental health programs include couples and family therapy; suicide prevention; support groups for youth, trans men and women. We could not provide this team or our services without the help of our generous donors. Help us maintain our team and services. Help us keep this essential lifeline open. Click on the link below to give today!" (A photo that received 491 likes, 19 comments, and 8 shares)
Education	"Did you see us last night on [blinded]? They visited us to learn more about the expansion of our [blinded] program for trans and gender non-conforming youth that takes place every Tuesday and Thursday!" (A video that received 98 likes, 10 comments, and 44 shares)
Youth	"[Blinded] is a statewide summit for LGBTQ+ youth! We anticipate over 750+ youth will attend. All LGBTQ+ youth ages 14-18 are welcome. Affirming friends are also welcome. Pre-register for shorter lines the day of. This is a summit where all of [blinded]'s youth and their affirming friends ages 14-18 can gather together to build community and foster creativity and ignite their excitement for the future. Affirming parents, counselors, and school administrators are welcome to attend and will have breakout sessions including a Q&A with executive director [blinded]." (A video that received 183 likes, 18 comments, and 71 shares)
Social	"[Blinded] Pride Week is just around the corner and we are excited to announce 2017's official theme: Connect. In times of uncertainty, building connections is as vital as it is difficult. This Pride Week, we encourage you to keep celebrating being LGBTQ and take time to reflect and plan and connect. Continue following us on social media for event updates. Learn more and register and volunteer." (A link that received 274 likes, 31 comments, and 100 shares)
Political	"Click 'Like' to thank [blinded] City Council for advancing our proposal to ban conversion therapy! The final vote is next Wednesday at 7pm." (A link that received 368 likes, 2 comments, and 51 shares)

Table 3 presents the unadjusted and adjusted associations of post type, date, content, and sentiment with the Facebook's user engagement score. Posts containing photos (IRR 1.07; 95% CI 1.06-1.09), links (IRR 1.23; 95% CI 1.21-1.24), and videos (IRR 1.54; 95% CI 1.52-1.56) received higher levels of engagement compared with posts containing status updates only. Posts on weekends also received higher engagement (IRR 1.07; 95% CI 1.06-1.08) compared with posts on weekdays. A total of 6 of 7 content classifications and direct invitations for engagement were associated with increased engagement, with only educational content receiving less engagement (IRR 0.81; 95% CI 0.80-0.81). In addition, positive sentiment was associated with increased engagement (IRR 1.11; 95% CI 1.10-1.12).

XSL•FO
RenderX

Table 3. Associations of post characteristics with user engagement with Facebook posts by lesbian, gay, bisexual, transgender, and queer community centers in the United States, 2017.

Post characteristics	Engagement score, IRR[a] (95% CI)
Post type	
Status	Reference
Link	1.23 (1.21-1.24)
Photo	1.07 (1.06-1.09)
Video	1.54 (1.52-1.56)
Post date (day of week)	
Weekday (Monday through Friday)	Reference
Weekend (Saturday and Sunday)	1.07 (1.06-1.08)
Post content type	
Stigma	1.16 (1.14-1.17)
Mental health	1.33 (1.31-1.35)
Education	0.81 (0.80-0.81)
Youth	1.13 (1.13-1.14)
Social	1.03 (1.02-1.04)
Politics	1.28 (1.27-1.29)
Mentions an identity term	1.10 (1.10-1.11)
Direct invitations for engagement	1.03 (1.02-1.04)
Sentiment score	1.11 (1.10-1.12)

[a]IRR: incidence rate ratio.

In sensitivity analyses (Table 4), we assessed the association of the post characteristics with specific types of user engagement (likes, comments, and shares). Several differences from the main analyses were found. Posts containing links (IRR 0.59; 95% CI 0.56-0.61) and photos (IRR 0.56; 95% CI 0.53-0.58) received fewer comments than posts containing status updates only. Posts with content regarding mental health (IRR 0.86; 95% CI 0.80-0.92), education (IRR 0.86; 95% CI 0.83-0.89), and posts with more positive sentiment (IRR 0.70; 95% CI 0.67-0.74) also received fewer comments. Third, posts containing photos (IRR 0.88; 95% CI 0.86-0.91) were shared fewer times than posts containing status updates only. Posts on weekends (IRR 0.96; 95% CI 0.94-0.97) and posts with more positive sentiment (IRR 0.65; 95% CI 0.63-0.67) were also shared less often. Posts with educational content received fewer likes and comments but were shared more (IRR 1.13; 95% CI 1.11-1.16).

Table 4. Associations of post characteristics with specific types of user engagement with Facebook posts (likes, comments, and shares) by lesbian, gay, bisexual, transgender, and queer community centers in the United States, 2017.

Post characteristics	Likes, IRR[a] (95% CI)	Comments, IRR (95% CI)	Shares, IRR (95% CI)
Post type			
Status	Reference	Reference	Reference
Link	1.34 (1.32-1.36)	0.59 (0.56-0.61)	1.16 (1.13-1.20)
Photo	1.31 (1.29-1.33)	0.56 (0.53-0.58)	0.88 (0.86-0.91)
Video	1.65 (1.62-1.68)	1.30 (1.23-1.37)	1.11 (1.07-1.15)
Post date (day of week)			
Weekday (Monday through Friday)	Reference	Reference	Reference
Weekend (Saturday and Sunday)	1.10 (1.09-1.11)	1.01 (0.98-1.05)	0.96 (0.94-0.97)
Post content type			
Stigma	1.13 (1.11-1.16)	1.16 (1.09-1.24)	1.26 (1.22-1.30)
Mental health	1.32 (1.30-1.35)	0.86 (0.80-0.92)	1.73 (1.68-1.79)
Education	0.73 (0.73-0.74)	0.86 (0.83-0.89)	1.03 (1.01-1.05)
Youth	1.13 (1.12-1.14)	1.18 (1.14-1.22)	1.13 (1.11-1.16)
Social	0.97 (0.96-0.98)	1.32 (1.29-1.36)	1.15 (1.13-1.17)
Politics	1.19 (1.17-1.20)	1.55 (1.48-1.62)	1.41 (1.38-1.44)
Mentions an identity term	1.10 (1.10-1.11)	1.10 (1.07-1.12)	1.11 (1.09-1.12)
Direct invitations for engagement	0.92 (0.91-0.93)	1.25 (1.21-1.30)	1.59 (1.56-1.62)
Sentiment score	1.68 (1.66-1.71)	0.70 (0.67-0.74)	0.65 (0.63-0.67)

[a]IRR: incidence rate ratio.

Discussion

The study collected post data from 175 Facebook pages associated with LGBTQ community centers across the United States. In total, these pages had approximately 1.1 million fans and shared over 30,000 posts in the span of a year, receiving nearly 700,000 engagements.

We identified a number of factors associated with increased user engagement, and these findings offer practical recommendations as to how LGBTQ community centers can effectively use Facebook to increase the reach of their messages. First, we found that including multimedia content (eg, photos, videos, and links) was associated with higher user engagement compared with text-only status updates. This finding is consistent with a previous study identifying correlates of user engagement with health-related Facebook posts from CBOs serving gay and bisexual men in British Columbia [19] and with the media richness theory [27], which suggests that media that is able to handle multiple information cues simultaneously, facilitates rapid feedback, and establishes a personal focus will be more effective in communicating its message to its audience. Second, in contrast to this previous research in British Columbia [19], we found that direct invitations for engagement (ie, directly asking users to comment, like, or share a post) were associated with increased user engagement.

The content of posts was also significantly associated with user engagement, where posts related to stigma, mental health, and politics received higher levels of engagement. In line with

previous research, these topics represent the "deep structure" of the culture of LGBTQ communities and may, therefore, be most salient to the target audience [2]. We note significant temporal variation in the frequency at which key themes were included in posts. For example, a spike in the daily number of stigma-related posts was observed with the announcement of an executive order banning transgender individuals from military service [28], whereas a spike in the daily number of mental health-related posts was observed with the signing of this executive order [28] (Multimedia Appendix 1). Although we are unable to connect these types of events to increases in user engagement with such posts, the presence of such spikes in content production highlights the responsiveness of LGBTQ community centers in their Web presence to events affecting the well-being of their clients.

These findings should be considered in light of their limitations. First, Facebook pages were selected based on their inclusion in a nationwide member-based directory of LGBTQ community centers in the United States and, therefore, these findings may not be generalizable to LGBTQ community centers in the United States who are not part of this directory and LGBTQ community centers outside of the United States. Second, the keyword-based method for classifying the content of posts render the results subject to measurement error, as the selection of key terms may limit the accuracy of content classification. Future research should use more advanced approaches to classify the content of posts, including topic modeling, a statistical technique aimed at discovering latent semantic structures within extensive bodies of text. Third, although we identified correlates of engagement

(including specific types of engagement), further research is needed to better understand how each type of engagement promotes the diffusion of health- and nonhealth-related Facebook content within Web-based LGBTQ communities. Fourth, these analyses do not consider user-specific factors that may be associated with engagement (eg, number of Facebook friends who also "like" a page for an LGBTQ community center, whether an individual chooses to disclose their sexual orientation or gender identity in Web-based spaces). Furthermore, research should study post engagement at the individual level to better understand what types of digital content resonate better with their target audiences. Fifth, because the posts were sampled from Facebook, these correlates of user engagement cannot be extended to other social media platforms (eg, Twitter and Instagram) as these platforms have different processes for post content and engagement. Finally, Facebook uses an algorithm to show a user posts that they are likely to interact with. Given the proprietary nature of this algorithm, we are unable to control for how likely a post was to be seen by a given user and note that users are only able to engage with posts that are shown to them. As such, our analyses are restricted to identifying correlates of user engagement conditional on a post being seen by a given set of users.

These results provide support for the use of Facebook by LGBTQ community centers to extend their reach beyond the falls of physical venues and reach their target audiences and highlight multiple factors that can be leveraged to optimize user engagement and enhance the diffusion of information generated by these crucial community institutions. Furthermore, there is potential for public health as a field to engage with these organizations to further build capacity in using evidence-based communication strategies.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix 1
Daily time-series of the number of Facebook posts containing content related to stigma and mental health by LGBTQ community centers in the United States.
[PNG File , 1453 KB - publichealth_v6i1e16382_app1.png]

References

1. Institute of Medicine, Board on the Health of Select Populations, Committee on Lesbian Gay Bisexual and Transgender Health Issues and Research Gaps and Opportunities. The Health of Lesbian, Gay, Bisexual, and Transgender People: Building a Foundation for Better Understanding. District of Columbia: National Academies Press; 2011.

2. Freimuth VS, Quinn SC. The contributions of health communication to eliminating health disparities. Am J Public Health 2004 Dec;94(12):2053-2055. [doi: 10.2105/ajph.94.12.2053] [Medline: 15569949]

3. Parvanta C, Nelson D, Parvanta S, Harner R. Essentials of Public Health Communication. Burlington, Massachusetts: Jones & Bartlett Learning; 2011.

4. Rothman A, Bartels R, Wlaschin J, Salovey P. The strategic use of gain‐ and loss‐framed messages to promote healthy behavior: how theory can inform practice. J Commun 2006;56(S1):S202-S220 [FREE Full text] [doi: 10.1111/j.1460-2466.2006.00290.x]

5. Rucker DD, Petty RE, Briñol P. What's in a frame anyway?: A meta-cognitive analysis of the impact of one versus two sided message framing on attitude certainty. J Consumer Psychol 2008;18(2):137-149. [doi: 10.1016/j.jcps.2008.01.008]

6. Edgar T, Volkman JE. Using communication theory for health promotion: practical guidance on message design and strategy. Health Promot Pract 2012 Sep;13(5):587-590. [doi: 10.1177/1524839912450879] [Medline: 22923771]

7. Park H, Rodgers S, McElroy JA, Everett K. Sexual and gender minority's social media user characteristics: examining preferred health information. Health Mark Q 2018;35(1):1-17. [doi: 10.1080/07359683.2017.1310553] [Medline: 28467288]

8. Bonvicini KA. LGBT healthcare disparities: what progress have we made? Patient Educ Couns 2017 Dec;100(12):2357-2361. [doi: 10.1016/j.pec.2017.06.003] [Medline: 28623053]

9. Whitehead J, Shaver J, Stephenson R. Outness, stigma, and primary health care utilization among rural LGBT populations. PLoS One 2016;11(1):e0146139 [FREE Full text] [doi: 10.1371/journal.pone.0146139] [Medline: 26731405]

10. Movement Advancement Project. Boulder, Colorado: Movement Advancement Project; 2017. 2016 LGBT Community Center Survey Report: Assessing the Capacity and Programs of Lesbian, Gay, Bisexual, and Transgender Community Centers. URL: https://www.lgbtmap.org/file/2016-lgbt-community-center-survey-report.pdf [accessed 2019-11-28]

11.   Seidenberg A, Jo C, Ribisl K, Lee J, Buchting F, Kim Y, et al. A national study of social media, television, radio, and internet usage of adults by sexual orientation and smoking status: implications for campaign design. Int J Environ Res Public Health 2017 Apr 21;14(4):pii: E450 [FREE Full text] [doi: 10.3390/ijerph14040450] [Medline: 28430161]

12.   Ybarra ML, Mitchell KJ, Palmer NA, Reisner SL. Online social support as a buffer against online and offline peer and sexual victimization among US LGBT and non-LGBT youth. Child Abuse Negl 2015 Jan;39:123-136 [FREE Full text] [doi: 10.1016/j.chiabu.2014.08.006] [Medline: 25192961]

13.   Craig SL, McInroy L. You can form a part of yourself online: the influence of new media on identity development and coming out for LGBTQ youth. J Gay Lesbian Ment Health 2014;18(1):95-109. [doi: 10.1080/19359705.2013.777007]

14.   Fox J, Ralston R. Queer identity online: informal learning and teaching experiences of LGBTQ individuals on social media. Comput Human Behav 2016;65:635-642. [doi: 10.1016/j.chb.2016.06.009]

15.   Becker AB, Copeland L. Networked publics: how connective social media use facilitates political consumerism among LGBT Americans. J Inf Technol Politics 2016;13(1):22-36. [doi: 10.1080/19331681.2015.1131655]

16.   Kontos EZ, Emmons KM, Puleo E, Viswanath K. Communication inequalities and public health implications of adult social networking site use in the United States. J Health Commun 2010;15(Suppl 3):216-235 [FREE Full text] [doi: 10.1080/10810730.2010.522689] [Medline: 21154095]

17.   Korda H, Itani Z. Harnessing social media for health promotion and behavior change. Health Promot Pract 2013 Jan;14(1):15-23. [doi: 10.1177/1524839911405850] [Medline: 21558472]

18.   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]

19.   Card KG, Lachowsky N, Hawkins BW, Jollimore J, Baharuddin F, Hogg RS. Predictors of Facebook user engagement with health-related content for gay, bisexual, and other men who have sex with men: content analysis. JMIR Public Health Surveill 2018 Apr 6;4(2):e38 [FREE Full text] [doi: 10.2196/publichealth.8145] [Medline: 29625953]

20.   Rubin JD, McClelland SI. 'Even though it's a small checkbox, it's a big deal': stresses and strains of managing sexual identity(s) on Facebook. Cult Health Sex 2015;17(4):512-526. [doi: 10.1080/13691058.2014.994229] [Medline: 25587894]

21.   Duguay S. 'He has a way gayer Facebook than I do': Investigating sexual identity disclosure and context collapse on a social networking site. New Media Soc 2016;18(6):891-907. [doi: 10.1177/1461444814549930]

22.   Fox J, Warber KM. Queer identity management and political self-expression on social networking sites: a co-cultural approach to the spiral of silence. J Commun 2014;65(1):79-100. [doi: 10.1111/jcom.12137]

23.   CenterLink: The Community of LGBT Centers. 2018. URL: https://www.lgbtcenters.org/ [accessed 2019-11-28]

24.   Rieder B. Studying Facebook via data extraction: the Netvizz application. In: Proceedings of the 5th Annual ACM Web Science Conference. Paris, France: Association for Computing Machinery; 2013 Presented at: WebSci'13; May 2 - 4, 2013; Paris, France p. 346-355. [doi: 10.1145/2464464.2464475]

25.   Bellazzi R, Diomidous M, Sarkar IN, Takabayashi K, Ziegler A, McCray AT. Data analysis and data mining: current issues in biomedical informatics. Methods Inf Med 2011;50(6):536-544. [doi: 10.3414/me11-06-0002]

26.   Liu B. Sentiment Analysis and Opinion Mining. San Rafael, California: Morgan & Claypool Publishers; 2012.

27.   Kahai SS, Cooper RB. Exploring the core concepts of media richness theory: the impact of cue multiplicity and feedback immediacy on decision quality. J Manag Inf Syst 2003;20(1):263-299. [doi: 10.1080/07421222.2003.11045754]

28.   Coon D, Neira PM, Lau BD. Threats to United States fully reviewed and strategic plan for integration of transgender military members into the armed forces. Am J Public Health 2018 Jul;108(7):892-894. [doi: 10.2105/AJPH.2018.304454] [Medline: 29874519]

Abbreviations

API: application programming interface
CBO: community-based organization
IRR: incidence rate ratio
LGBTQ: lesbian, gay, bisexual, transgender, and queer

XSL•FO

RenderX

Stigma and Web-Based Sex Seeking Among Men Who Have Sex With Men and Transgender Women in Tijuana, Mexico: Cross-Sectional Study

Cristina Espinosa da Silva[1], MPH; Laramie R Smith[1], PhD; Thomas L Patterson[2], PhD; Shirley J Semple[2], PhD; Alicia Harvey-Vera[3], PhD; Stephanie Nunes[1], BSc; Gudelia Rangel[4,5], MPH, PhD; Heather A Pines[1], MPH, PhD

[1]Department of Medicine, University of California, San Diego, La Jolla, CA, United States
[2]Department of Psychiatry, University of California, San Diego, La Jolla, CA, United States
[3]Universidad Xochicalco, Tijuana, Mexico
[4]United States-Mexico Border Health Commission, Tijuana, Mexico
[5]El Colegio de la Frontera Norte, Tijuana, Mexico

Corresponding Author:
Heather A Pines, MPH, PhD
Department of Medicine
University of California, San Diego
9500 Gilman Drive, MC-0507
La Jolla, CA, 92093-0507
United States
Phone: 1 8588224831
Email: hpines@health.ucsd.edu

Abstract

Background: Stigma toward sexual and gender minorities is an important structural driver of HIV epidemics among men who have sex with men (MSM) and transgender women (TW) globally. Sex-seeking websites and apps are popular among MSM and TW. Interventions delivered via Web-based sex-seeking platforms may be particularly effective for engaging MSM and TW in HIV prevention and treatment services in settings with widespread stigma toward these vulnerable populations.

Objective: To assess the potential utility of this approach, the objectives of our study were to determine the prevalence of Web-based sex seeking and examine the effect of factors that shape or are influenced by stigma toward sexual and gender minorities on Web-based sex seeking among MSM and TW in Tijuana, Mexico.

Methods: From 2015 to 2018, 529 MSM and 32 TW were recruited through venue-based and respondent-driven sampling. Interviewer-administered surveys collected information on Web-based sex seeking (past 4 months) and factors that shape or are influenced by stigma toward sexual and gender minorities (among MSM and TW: traditional machismo, internalized stigma related to same-sex sexual behavior or gender identity, and outness related to same-sex sexual behavior or gender identity; among MSM only: sexual orientation and history of discrimination related to same-sex sexual behavior). A total of 5 separate multivariable logistic regression models were used to examine the effect of each stigma measure on Web-based sex seeking.

Results: A total of 29.4% (165/561) of our sample reported seeking sex partners on the Web. Web-based sex seeking was negatively associated with greater endorsement of traditional machismo values (adjusted odds ratio [AOR] 0.36, 95% CI 0.19 to 0.69) and greater levels of internalized stigma (AOR 0.96, 95% CI 0.94 to 0.99). Web-based sex seeking was positively associated with identifying as gay (AOR 2.13, 95% CI 1.36 to 3.33), greater outness (AOR 1.17, 95% CI 1.06 to 1.28), and a history of discrimination (AOR 1.83, 95% CI 1.08 to 3.08).

Conclusions: Web-based sex-seeking is relatively common among MSM and TW in Tijuana, suggesting that it may be feasible to leverage Web-based sex-seeking platforms to engage these vulnerable populations in HIV prevention and treatment services. However, HIV interventions delivered through Web-based sex-seeking platforms may have limited reach among those most affected by stigma toward sexual and gender minorities (ie, those who express greater endorsement of traditional machismo values, greater levels of internalized stigma, lesser outness, and nongay identification), given that within our sample they were least likely to seek sex on the Web.

XSL•FO

RenderX

Introduction

Background

Men who have sex with men (MSM) and transgender women (TW) are at increased risk of HIV infection worldwide, including those in low- and middle-income countries (LMIC) [1,2]. Stigma toward sexual and gender minorities is an important structural driver of the HIV epidemics among MSM and TW in LMIC, with evidence suggesting that such stigma is linked to increased sexual risk behaviors [3-6] and limits the provision and uptake of HIV prevention and treatment services within these socially marginalized populations [7-10]. Use of sex-seeking websites and mobile apps among MSM and TW has grown in popularity globally, with prevalence estimates ranging from 36% in Latin America [11], 44% in North America [12], 39% to 62% in Africa [13,14], and 41% to 77% in Asia [15-18]. This has sparked interest in and led to the development of interventions that harness these Web-based platforms to engage MSM and TW in safer sex practices [19], HIV testing [20,21], and HIV care [22]. Given that sex-seeking websites and apps allow MSM and TW to meet new sexual partners with more anonymity than physical venues where they may risk being outed, discriminated against, or harmed because of their sexual or gender identity [13,14], interventions delivered through Web-based sex-seeking platforms may be particularly effective for engaging MSM and TW in HIV prevention and treatment services in regions with widespread stigma toward these vulnerable populations [19-21].

Stigma stems from power structures that promote or maintain social inequity [23-25] and manifests at the structural, interpersonal, and individual levels [24,25] as prejudice and discrimination toward persons with socially devalued characteristics, such as sexual and gender minorities [23,24,26-28]. Sexual and gender minorities often face significant stigma in heteronormative societies where cultural values enforce traditional gender roles [23,26-29]. In these settings, sexual and gender minorities may experience discrimination [25,30], internalize or adopt negative feelings and shame about their own sexuality or gender identity over time [28], and anticipate future stigmatizing experiences [28,31], which may cause some to conceal their sexual or gender identity [32]. Although several exploratory studies in LMIC have examined the relationship between factors that shape or are influenced by stigma and Web-based sex seeking [11,13-18], findings are mixed regarding whether these Web-based platforms are being used by MSM who are more or less affected by stigma. Studies in Peru [11] and China [15,17,18] found that Web-based sex seekers were more likely to be MSM who identified as gay, which is more common among MSM less affected by stigma. Studies that measured a history of discrimination and perceived or anticipated stigma among MSM in Nigeria [14] and Vietnam [16], on the other hand, found that

Web-based sex seeking was associated with a history of discrimination in Nigeria and perceived or anticipated stigma in both Nigeria and Vietnam, suggesting that Web-based sex seeking may be more common among MSM more affected by stigma. Furthermore, a study conducted among MSM in Swaziland and Lesotho [13] measured gay identification, history of discrimination, and perceived or anticipated stigma and found that all 3 were associated with Web-based sex seeking. However, few studies have examined how a range of factors that shape or are influenced by stigma are related to Web-based sex seeking, and less is known about the role of internalized stigma or social norms that perpetuate stigma toward sexual and gender minorities.

Mexico's HIV epidemic is concentrated within key populations [33,34], including MSM and TW in the Mexico-United States border region. HIV prevalence among MSM and TW in Tijuana, which lies along Mexico's northern border with San Diego, California, is estimated to be approximately 20%, with nearly 90% of those testing HIV positive reporting no prior knowledge of their HIV status [35,36]. Stigma toward sexual and gender minorities is common in Mexico [37-40] and may be partially attributed to the cultural norm of *machismo* [41-44], which defines rigid gender roles and reflects heteronormative expectations of male behavior [41,45]. Findings from a recent cross-sectional study in Tijuana suggest that MSM who are less out about their same-sex sexual behavior and have higher levels of internalized stigma are less likely to seek HIV testing, which may contribute to the high prevalence of undiagnosed HIV infection among sexual and gender minorities in this setting [46]. Given that MSM and TW most affected by stigma in Tijuana are least likely to undergo HIV testing, Web-based strategies may help increase their frequency of HIV testing and support their timely linkage to HIV prevention and treatment services. Web-based strategies may also represent a feasible method to increase uptake of these services, considering that 54% of adults in Mexico reported owning a smartphone or using the internet as of 2015 [47].

Objectives

To assess the potential utility of this approach and inform the development of HIV prevention efforts for MSM and TW in Tijuana and other comparable low-income settings, we aimed to determine the prevalence of Web-based sex seeking and examine the effect of stigma on Web-based sex seeking among MSM and TW in Tijuana. We hypothesized that Web-based sex seeking would be more common among MSM and TW most affected by stigma toward sexual and gender minorities (ie, MSM and TW with greater endorsement of traditional *machismo* values, greater levels of internalized stigma related to same-sex sexual behavior or gender identity, and lesser outness about same-sex sexual behavior or gender identity and MSM who do not identify as gay or report a history of discrimination related to their same-sex sexual behavior).

XSL•FO

RenderX

Methods

Study Population and Design

Data for this analysis came from 2 studies conducted in Tijuana, *Proyecto Enlaces* (Links Project) and *Proyecto Redes* (Networks Project). *Proyecto Enlaces* was designed to compare the effectiveness of 2 recruitment methods—venue-based sampling (VBS) and respondent-driven sampling (RDS)—for the identification of undiagnosed HIV infection among MSM and TW. *Proyecto Redes* was embedded in *Proyecto Enlaces* and was designed to characterize the sexual networks of MSM and TW. *Proyecto Enlaces* was conducted between March 2015 and November 2018, whereas *Proyecto Redes* was conducted between March 2016 and September 2017.

VBS was performed using time-location sampling across 36 venues identified during formative research as locations frequented by MSM and TW in Tijuana (eg, nightclubs, bars, public spaces, and motels). Individuals identified via VBS were eligible for HIV testing if they were aged at least 18 years, cisgender male or transgender female, reported anal sex with a cisgender male or transgender female in the past 4 months, and did not report a previous HIV diagnosis. RDS is a chain-referral sampling technique often used to recruit hard-to-reach populations [48,49]. A total of 33 individuals identified through VBS or referrals from Tijuana's municipal HIV clinic were selected to initiate RDS recruitment chains (ie, seeds). Seeds were further selected to be diverse with respect to HIV status, age, socioeconomic status, sexual orientation, gender identity, and recruitment venue. Individuals were eligible to be seeds if they were aged at least 18 years, cisgender male or transgender female, reported anal sex with a cisgender male or transgender female in the past 4 months, lived in Tijuana, and reported social networks that included at least 15 MSM or TW who also lived in Tijuana (changed to 5 MSM or TW in April 2017 to boost RDS recruitment). Seeds were given 3 coupons to recruit their MSM or TW peers (eg, sex partners, acquaintances, friends, and family members) to participate in the study. Peer recruits were then given 3 coupons to recruit peers themselves if they provided their referral coupon, were aged at least 18 years, were cisgender male or transgender female, and reported anal sex with a cisgender male or transgender female in the past 12 months. Those who did not report a previous HIV diagnosis were also eligible for HIV testing. Beginning in January 2018, seeds and peer recruits were given 6 coupons to boost RDS recruitment. A Microsoft Access database was used to track peer recruitment and store biometric information to prevent duplicate enrollment. Seeds and peer recruits were given Mexican pesos (Mxn) $100 (approximately US $5) for every eligible peer they referred to the study.

As individuals could be identified multiple times via the same or a different recruitment method, those who were identified more than once and who remained eligible for HIV testing were retested if it had been at least 3 months since their last test. Eligible individuals identified via VBS underwent rapid HIV testing (Advanced Quality HIV 1/2 Test Kits, Intec Products Inc) at recruitment venues or at the study site if they preferred, whereas those identified via RDS underwent rapid HIV testing

at the study site. All rapid HIV test results and appropriate posttest counseling were delivered within a few days (VBS) or 20 min (RDS) at the study site. All rapid test–negative individuals identified via VBS and rapid test–negative individuals identified via RDS who reported anal sex with a cisgender male or transgender female in the past 4 months (for comparability with those identified via VBS) were offered enrollment in *Proyecto Redes*. Rapid test–positive individuals provided an additional blood sample for confirmatory testing via immunofluorescence assay at the San Diego County Public Health Laboratory and were offered enrollment in *Proyecto Enlaces*. Confirmatory HIV test results were delivered to rapid test–positive individuals within 2 weeks, and those confirmed HIV positive were referred for free HIV care at Tijuana's municipal HIV clinic.

All study procedures occurred at the study site located in an unmarked office building staffed by local Spanish-speaking individuals with extensive experience working with sexual and gender minorities in Tijuana who were also trained to foster a nonjudgmental environment. In our previous research with key populations in Tijuana, our study site was recognized as a nonstigmatizing setting where participants felt comfortable visiting without fear of discrimination. All participants provided written informed consent, and all study procedures were approved by the Human Subjects Protection Committees at the Universidad de Xochicalco in Tijuana and the University of California, San Diego.

Data Collection

Surveys collected sociodemographic, psychosocial, and behavioral data and were interviewer administered using computer-assisted personal interviewing.

Exposures of Interest

A total of 5 variables measured different factors that shape or are influenced by stigma toward sexual and gender minorities, including traditional *machismo,* internalized stigma related to same-sex sexual behavior or gender identity, sexual orientation, outness about same-sex sexual behavior or gender identity, and history of discrimination related to same-sex sexual behavior (only measured among MSM participants; Multimedia Appendix 1). *Machismo* is a common social norm in Mexico and is composed of positive and negative constructs (termed *caballerismo* and traditional *machismo*, respectively) [50]. Traditional *machismo* is relevant to this study because it reflects a heteronormative version of masculinities that may be at odds with stereotypes associated with sexual behaviors (eg, receptive anal sex) and the sexual or gender identity of MSM and TW, and it likely shapes stigma toward sexual and gender minorities in Mexico. Traditional *machismo* was measured using a 10-item scale [50,51] that captures the negative characteristics typically associated with *machismo,* including hypermasculinity, aggressivity, and being domineering (eg, "It is necessary for a man to fight when challenged" and "A man should be in control of his wife"; Cronbach alpha=.90). Participants indicated their level of agreement with these items using 4-point Likert scale responses (1=strongly disagree, 2=disagree, 3=agree, and 4=strongly agree). A mean score was calculated from item responses, with higher scores indicating greater endorsement

XSL•FO

RenderX

of traditional *machismo* values [51]. Internalized stigma related to same-sex sexual behavior or gender identity refers to an individual's internalization of society's negative view of sexual and gender minorities. MSM participants were asked to provide their level of agreement with 9 items assessing internalized stigma toward same-sex sexual behaviors (eg, "I have tried to stop being attracted to men in general" and "I would like to get professional help in order to change my sexual attraction from men to women exclusively") using 5-point Likert scale responses (1=strongly disagree, 2=somewhat disagree, 3=neither agree nor disagree, 4=agree, and 5=strongly agree; Cronbach alpha=.93) [52]. To measure internalized stigma related to gender identity, we adapted the 9 items presented to MSM to reflect experiences of TW (eg, "I have tried to stop being attracted to men in general" was changed to "I have tried to stop identifying as a woman in general"; Cronbach alpha=.89). Participants' responses to items measuring internalized stigma were summed to create a score, where higher scores indicate greater levels of internalized stigma. Sexual orientation was assessed by asking participants, "What is your sexual orientation?" (1=gay or homosexual, 2=heterosexual, 3=bisexual, and 4=not sure). Participants who reported being gay or homosexual were classified as gay identifying and all others were considered nongay identifying. We hypothesized that participants may have reported being unsure of their sexual orientation because of greater levels of internalized stigma. Owing to the small number of participants who reported being unsure of their sexual orientation (only 13 MSM participants), we combined this group with other MSM hypothesized to be more affected by stigma (ie, nongay identifying). Outness was measured by asking MSM and TW to describe how "out" they are about having sex with men [53] and being a transgender woman, respectively. Participants responded on a scale of 1 to 7 (1=not out to anyone, 4=out to about half the people I know, and 7=out to everyone). History of discrimination related to same-sex sexual behavior was assessed among MSM participants only by asking "In your day to day life, how often does discrimination related to your sexual orientation/having sex with men happen to you?" (0=never, 1=less than once a year, 2=a few times a year, 3=a few times a month, 4=at least once a week, and 5=almost every day).

Outcome of Interest

Web-based sex seeking was measured by asking, "In the past 4 months, how many different men did you meet online with the intention of having sex?" Participants who reported meeting at least one man online with the intention of having sex were classified as Web-based sex seekers.

Other Covariates

Sociodemographic data were collected on participants' gender identity (0=transgender female and 1=male), age (in years), highest level of education completed (1=cannot read or write, 2=some grade school but no certificate, 3=grade school, 4=some secondary school but no certificate, 5=secondary school, 6=some high school but no certificate, 7=high school, 8=some university but no title, 9=university, and 10=advanced degree such as doctorate or masters), average monthly income in Mxn pesos in the past 4 months (1=no income, 2<Mxn $1000, 3=Mxn

$1000-Mxn $1499, 4=Mxn $1500-Mxn $1999, 5=Mxn $2000-Mxn $2499, 6=Mxn $2500-Mxn $2999, 7=Mxn $3000-Mxn $3500, and 8>Mxn $3500, which was dichotomized at Mxn $3000 based on the national monthly well-being lines representing federal poverty limits for urban areas during our study period) [54], years of residence in Tijuana, and marital status (1=married to a woman, 2=married to a man, 3=separated or filing for divorce, 4=divorced but not remarried, 5=widowed but not remarried, 6=never married, 7=common-law marriage with female partner, and 8=common-law marriage with male partner). Social support was measured via 8 items that make up the Modified Medical Outcome Study Social Support Survey assessing help and support received from others (eg, "If you needed it, how often is someone available to turn to for suggestions about how to deal with a personal problem?" and "If you needed it, how often is someone available to help with daily chores if you were sick?"; Cronbach alpha=.97) [55]. Participants provided their level of agreement using 5-point Likert scale responses (1=none of the time, 2=a little of the time, 3=some of the time, 4=most of the time, and 5=all of the time). A mean score was calculated from item responses and transformed to a 100-point scale, where higher values indicate greater social support [56]. Participants were asked with how many people they engaged in sexual (vaginal or anal) intercourse in the past 4 months and whether they had given or received money, drugs, or other goods in exchange for sex in the past 4 months (0=did not give or receive money, drugs, or other goods for sex and 1=gave or received money, drugs, or others goods for sex), which has been shown to be a reliable period of recall for self-reported sexual contact and behavior data [57-59]. HIV testing in the past 12 months was assessed by asking 2 questions: "Have you ever been tested for HIV?" (0=no and 1=yes) and "How long ago was your last HIV test?" Participants were categorized as undergoing HIV testing in the past 12 months if they responded that they had ever been tested for HIV and their last HIV test was within 12 months of the interview date.

Statistical Analysis

This analysis includes all *Proyecto Redes* participants (n=396; excluding 11 identified via RDS or VBS more than once who later tested HIV positive and enrolled in *Proyecto Enlaces*) and newly diagnosed HIV-positive participants enrolled in *Proyecto Enlaces* (n=165). Analyses considering 3 of the 5 stigma measures (ie, traditional *machismo*, history of discrimination related to same-sex sexual behavior, and sexual orientation) were restricted to specific subgroups of our sample because (1) HIV-positive *Proyecto Enlaces* participants completed baseline and supplemental (approximately 2 weeks post baseline when they returned for their confirmatory HIV test results) surveys, whereas HIV-negative *Proyecto Redes* participants only completed baseline surveys and (2) some survey questions were phrased for both MSM and TW, whereas others were only phrased for MSM. Data on traditional *machismo* and history of discrimination related to same-sex sexual behavior were collected via the supplemental survey among HIV-positive *Proyecto Enlaces* participants. As 27.3% (45/165) of *Proyecto Enlaces* participants did not return to complete the supplemental survey, analyses examining traditional *machismo* and history of discrimination related to same-sex sexual behavior were

restricted to HIV-negative *Proyecto Redes* participants to reduce the potential for selection bias that could have been introduced by only including those *Proyecto Enlaces* participants who had returned. Analyses examining history of discrimination were then further restricted to MSM participants because the phrasing of the question was specific to experiences of MSM and not TW (Multimedia Appendix 1). Finally, analyses examining sexual orientation were restricted to MSM because we hypothesized that MSM and TW less affected by stigma would identify as gay or homosexual and heterosexual, respectively. Restricting these analyses to MSM allowed us to examine sexual orientation without potentially including participants who were more or less affected by stigma in the same category.

Descriptive statistics were calculated to characterize the study population by Web-based sex seeking. Next, bivariate associations between factors that shape or are influenced by stigma toward sexual and gender minorities were examined using linear and logistic regression models for continuous and categorical dependent variables, respectively. Separate unadjusted and adjusted logistic regression models were then used to examine the total effect of each stigma measure on Web-based sex seeking. A review of the literature was conducted to identify covariates that may confound the total effects of interest. Directed acyclic graphs (DAGs) [60] were then generated to depict interrelationships among each exposure of interest, Web-based sex seeking, and the identified covariates. Westreich et al have shown that it is inappropriate to interpret effect estimates for exposures of interest from a single adjusted model (ie, one that includes all exposures of interest) as their total effects on the outcome of interest because adjusting for an exposure of interest that lies on the causal pathway between another exposure of interest and the outcome of interest would yield an estimate of the direct effect of that exposure of interest on the outcome of interest [61]. Therefore, given the highly interrelated nature of our exposures of interest and the cross-sectional nature of our data (making it difficult to determine the directionality of the relationships among our exposures of interest), our DAGs considered 1 exposure of interest at a time to facilitate the identification of confounders for inclusion in adjusted models for the total effect of each exposure of interest on Web-based sex seeking. On the basis of these DAGs, sociodemographics (gender identity, age, education, and monthly income) and social support were identified as confounders and selected for inclusion in adjusted models. We were unable to stratify models by gender identity because of the small number of TW included in our sample (n=32). However, as controlling for gender identity in our adjusted models could have resulted in sparse data bias (because of the small number of TW), we conducted a sensitivity analysis excluding TW and found qualitatively similar results. In another sensitivity analysis, we examined the potential impact of grouping MSM who reported being unsure of their sexual orientation with those who did not identify as gay by excluding those who reported being unsure of their sexual orientation from models examining the effect of sexual orientation on Web-based sex seeking, and we found qualitatively similar results. Finally, we examined whether any of the relationships of interest were modified by HIV status or age by including product terms between the potential effect measure modifier and the exposures of interest in each of their respective models. Unstratified results are presented because none of the product terms were statistically significant. All statistical analyses were conducted using SAS V.9.3. (SAS Institute, Inc).

Results

Sample Characteristics

Approximately half of our sample was recruited via VBS (311/561, 55.4%; Table 1). Most participants identified as male (529/561, 94.3%), and participants had a mean age of 37 years (SD 11.2). Nearly half of the participants (239/561, 42.6%) reported at least a high school education, and 69.2% (387/561) of the participants reported an average monthly income of at least Mxn $3000 (approximately US $150). A total of 29.4% (165/561) of participants reported seeking sex partners on the Web in the past 4 months.

Table 1. Characteristics of men who have sex with men and transgender women in Tijuana, Mexico, by Web-based sex seeking in the past 4 months (N=561).

Characteristics[a]	Total (N=561)	Web-based sex seeking (n=165)	No Web-based sex seeking (n=396)	P value[b]
Stigma measures				
Traditional *Machismo* (range: 1-4)[c], mean score (SD)	2.1 (0.4)	1.9 (0.4)	2.2 (0.4)	<.001
Internalized stigma related to same-sex sexual behavior or gender identity (range: 9-45), mean score (SD)	23.9 (8.7)	20.5 (8.4)	25.3 (8.3)	<.001
Sexual orientation[d], n (%)				<.001
Gay or homosexual	202 (38.2)	96 (61.9)	106 (28.3)	
Bisexual, heterosexual, or not sure	327 (61.8)	59 (38.1)	268 (71.7)	
Outness about same-sex sexual behavior or gender identity (range: 1-7), mean score (SD)	4.2 (2.5)	5.1 (2.1)	3.8 (2.5)	<.001
History of discrimination related to same-sex sexual behavior[e], n (%)	147 (38.4)	52 (46.0)	95 (35.2)	.05
Covariates				
Sociodemographics				
HIV status, n (%)				.61
Newly diagnosed HIV positive (*Proyecto Enlaces*)	165 (29.4)	46 (27.9)	119 (30.1)	
HIV negative (*Proyecto Redes*)	396 (70.6)	119 (72.1)	277 (70.0)	
Cisgender male, n (%)	529 (94.3)	155 (93.9)	374 (94.4)	.81
Age (years), mean (SD)	37.0 (11.2)	31.0 (9.0)	39.6 (11.0)	<.001
Completed at least a high school education, n (%)	239 (42.6)	96 (58.2)	143 (36.1)	<.001
Average monthly income ≥Mxn $3000, n (%)	387 (69.2)	135 (82.3)	252 (63.8)	<.001
Years of residence in Tijuana, mean (SD)	12.7 (12.6)	14.9 (11.3)	11.7 (13.0)	.004
Marital status, n (%)				.01
Married, including common-law marriage[f]	83 (14.8)	21 (12.7)	62 (15.7)	
Separated or divorced	72 (12.9)	12 (7.3)	60 (15.2)	
Widowed	6 (1.1)	0 (0.0)	6 (1.5)	
Never married	399 (71.3)	132 (80.0)	267 (67.6)	
Social support (range: 0-100), mean score (SD)	56.6 (34.6)	67.1 (27.6)	52.3 (36.3)	<.001
Sex partners (past 4 months), mean (SD)	11.9 (32.7)	11.3 (29.0)	12.1 (34.2)	.76
Exchanged money, drugs, or other goods for sex (past 4 months), n (%)	271 (48.7)	51 (30.9)	220 (56.1)	<.001
Tested for HIV (past 12 months), n (%)	224 (43.4)	76 (50.0)	148 (40.7)	.05
Recruitment method, n (%)				.30
Respondent-driven sampling	250 (44.6)	68 (41.2)	182 (46.0)	
Venue-based sampling	311 (55.4)	97 (58.8)	214 (54.0)	

[a]Numbers may not sum to total because of missing data; percentages may not sum to 100 because of rounding.

[b]P value from chi-square test (if categorical) or 2-sided *t* tests (if continuous).

[c]Restricted to HIV-negative participants (n=396).

[d]Restricted to men who have sex with men participants (n=529).

[e]Restricted to HIV-negative men who have sex with men participants (n=383).

[f]A total of 43 men who have sex with men reported being married to a woman, 34 men who have sex with men reported being married to a man, and 6 transgender women reported being married to a man.

Bivariate Associations Between Stigma Measures

Bivariate associations between factors that shape or are influenced by stigma toward sexual and gender minorities were in the expected directions (Table 2). Positive associations were observed between traditional *machismo* and internalized stigma related to same-sex sexual behavior or gender identity (beta coefficien*t* =.019; 95% CI 0.015 to 0.024). Outness about same-sex sexual behavior or gender identity was positively associated with gay identification (beta coefficient=2.35; 95% CI 1.96 to 2.73) and history of discrimination related to same-sex sexual behavior (beta coefficien*t* =.93; 95% CI 0.42 to 1.43). Traditional *machismo* was negatively associated with outness about same-sex sexual behavior or gender identity (beta coefficient=−.04; 95% CI −0.06 to −0.03) and gay identification (beta coefficient=−.25; 95% CI −0.33 to −0.17). Internalized stigma related to same-sex sexual behavior or gender identity was inversely associated with outness about same-sex sexual behavior or gender identity (beta coefficient=−1.84; 95% CI −2.08 to −1.59) and sexual orientation (beta coefficient=−8.94; 95% CI −10.25 to −7.63).

Table 2. Associations between factors that shape or are influenced by stigma among men who have sex with men and transgender women in Tijuana, Mexico.

Stigma Measures	Traditional *machismo*[a]		Internalized stigma[a]		Outness[a]		Gay identifying[b]	
	β[c]	95% CI	β	95% CI	β	95% CI	β	95% CI
Internalized stigma	.019[d]	0.015 to 0.024	—[e]	—	—	—	—	—
Outness	−.04[d]	−0.06 to −0.03	−1.84	−2.08 to −1.59	—	—	—	—
Gay identifying	−.25[f]	−0.33 to −0.17	−8.94[g]	−10.25 to −7.63	2.35[g]	1.96 to 2.73	—	—
History of discrimination	−.01[f]	−0.10 to 0.07	.29[f]	−1.48 to 2.07	.93[f]	.42 to 1.43	.41[f]	−0.03 to 0.85

[a]Unadjusted linear regression.

[b]Unadjusted logistic regression.

[c]Beta coefficient.

[d]Restricted to HIV-negative participants.

[e]Not Applicable.

[f]Restricted to HIV-negative men who have sex with men participants.

[g]Restricted to men who have sex with men participants.

Stigma Measures and Web-Based Sex Seeking

On average, Web-based sex seekers reported less endorsement of traditional *machismo* values (mean 1.9 vs mean 2.2, range 1 to 4; *P*<.001; Table 1), less internalized stigma related to same-sex sexual behavior or gender identity (mean 20.5 vs mean 25.3, range 9 to 45; *P*<.001), and they were more out about their same-sex sexual behavior or gender identity (mean 5.1 vs mean 3.8, range 1 to 7; *P*<.001). Compared with MSM participants who did not seek sex partners on the Web, a greater proportion of Web-based sex seekers identified as gay (61.9% vs 28.3%, *P*<.001) and reported a history of discrimination related to their same-sex sexual behavior (46.0% vs 35.2%; *P*=.05).

After adjusting for sociodemographics and social support (Table 3), the odds of Web-based sex seeking were lower for participants who reported greater endorsement of traditional *machismo* values (adjusted odds ratio [AOR] 0.36, 95% CI 0.19 to 0.69) and greater levels of internalized stigma related to their same-sex sexual behavior or gender identity (AOR 0.96, 95% CI 0.94 to 0.99), whereas the odds of Web-based sex seeking were higher for those who reported greater outness about their same-sex sexual behavior or gender identity (AOR 1.17, 95% CI 1.06 to 1.28). Among MSM participants, the odds of Web-based sex seeking were higher for gay-identifying participants (AOR 2.13, 95% CI 1.36 to 3.33) and those who reported a history of discrimination related to their same-sex sexual behavior (AOR 1.83, 95% CI 1.08 to 3.08).

Table 3. Associations among factors that shape or are influenced by stigma and Web-based sex seeking among men who have sex with men and transgender women in Tijuana, Mexico.

Stigma measures	Unadjusted odds ratio (95% CI)	Adjusted[a] odds ratio (95% CI)
Traditional *machismo*[b]	0.20 (0.11 to 0.36)	0.36 (0.19 to 0.69)
Internalized stigma related to same-sex sexual behavior or gender identity	0.93 (0.91 to 0.96)	0.96 (0.94 to 0.99)
Gay identifying[c]	4.11 (2.77 to 6.10)	2.13 (1.36 to 3.33)
Outness about same-sex sexual behavior or gender identity	1.25 (1.15 to 1.35)	1.17 (1.06 to 1.28)
History of discrimination related to same-sex sexual behavior[d]	1.57 (1.01 to 2.45)	1.83 (1.08 to 3.08)

[a]Adjusted models for each stigma measure of interest included the following: gender identity (male vs transgender female in models not restricted to men who have sex with men), age (years), education (less than a high school education vs at least a high school education), monthly income (<Mxn $3000 vs ≥Mxn $3000), years of residence in Tijuana (years), and social support (score on the Modified Medical Outcome Study Social Support Survey) [55].

[b]Restricted to HIV-negative participants.

[c]Restricted to men who have sex with men participants.

[d]Restricted to HIV-negative men who have sex with men participants.

Discussion

We examined the relationship between stigma and Web-based sex seeking using cross-sectional data collected from MSM and TW in Tijuana, Mexico. Nearly one-third of our sample reported seeking sex partners on the Web in the past 4 months, which is consistent with estimates from Peru (36%) [11] but is not as high as those from the United States (44%) [12], Africa (39%-62%) [13,14], or Asia (41%-77%) [15-18].

Our a priori hypothesis was that Web-based sex seeking would be more common among MSM and TW most affected by stigma toward sexual and gender minorities. However, for the most part, our findings do not support this hypothesis. More specifically, participants who met sex partners on the Web reported less agreement with traditional *machismo* values, less internalized stigma related to same-sex sexual behavior or gender identity, were more gay identifying, and were more out about their same-sex sexual behavior or gender identity compared with those who did not seek sex on the Web. Prior research suggests that MSM and TW most affected by stigma often isolate themselves from other sexual and gender minorities to conceal their minority status [28,32]. As such, those most affected by stigma in our sample may be less connected to communities of MSM and TW and, thus, less aware of or less comfortable using sex-seeking websites and apps used by MSM and TW. Although MSM participants with a history of discrimination were more likely to seek sex partners on the Web, as was our a priori hypothesis, it seems plausible, given our other findings, that this result may have an alternative explanation. As reported in other settings [13,14], we initially hypothesized that MSM with a history of discrimination would be more likely to seek sex partners on the Web, partly to avoid future discrimination that they could face by meeting sex partners in traditional physical venues. However, given our other findings, it is possible that having a history of discrimination was associated with Web-based sex seeking in our sample because MSM who identify as gay or are more out about their same-sex sexual behavior (both of which were

positively associated with Web-based sex seeking and history of discrimination) may be more susceptible to discrimination.

Overall, our findings suggest that Web-based sex seeking is more common among MSM and TW in Tijuana who are less affected by stigma toward sexual and gender minorities. Our findings are similar to those from exploratory studies in Peru [11], China [15,17,18], Lesotho [13], and Swaziland [13], which found that MSM who used the Web to meet sex partners were more gay identifying [11,13,17,18]. Our findings also align with those from a study in Nigeria [14], which found that MSM who sought sex partners on the Web were more likely to report a history of discrimination. We also expanded on previous literature by examining a wider range of factors that shape or are influenced by stigma, including a social norm that influences societal stigma (traditional *machismo*) and internalized stigma related to same-sex sexual behavior or gender identity. Including a broader scope of factors that shape or are influenced by stigma provides a more multidimensional understanding of the role of stigma with respect to Web-based sex seeking, which may have been underappreciated by prior studies that considered only 1 or 2 factors [24,25].

Our study has several limitations. First, because of the cross-sectional design of our study, we cannot establish a temporal relationship between the exposures of interest and Web-based sex seeking. Therefore, we cannot infer that the observed associations represent causal associations. Second, our use of nonprobability sampling methods may limit the generalizability of our findings. These sampling methods, however, were critical to our ability to recruit MSM and TW who are socially marginalized and often hidden in Tijuana. However, even with the use of these sampling methods, TW were underrepresented in our sample, which precluded us from stratifying our analyses by gender identity. As such, our results do not shed light on potential differences in Web-based sex seeking or its relationship with stigma between MSM and TW, which should be examined in future research. Third, our assessment of Web-based sex seeking was exclusive to meeting male partners. As a result, we may have underestimated the prevalence of Web-based sex seeking among MSM and TW in

Tijuana because those who only met TW partners on the Web would not have been classified as Web-based sex seekers. Fourth, we did not collect data on smartphone or computer use, both of which are likely associated with Web-based sex seeking and should be considered in future research. Fifth, although surveys were interviewer administered to alleviate respondent burden, interviewer-administered surveys may have introduced social desirability bias if participants underreported sensitive information related to the exposures of interest or Web-based sex seeking. However, to minimize the potential for social desirability bias, all interviewers had extensive experience working with sexual and gender minorities in Tijuana and were trained to create a nonjudgmental environment and build rapport with participants to enhance their comfort with respect to responding openly and honestly. Finally, it is possible that poor recall could have led to the misclassification of history of discrimination related to same-sex sexual behavior and Web-based sex seeking in the past 4 months. However, such misclassification was likely nondifferential with regard to the outcome or exposure and, thus, may have only biased effect estimates toward the null.

Despite these limitations, our findings suggest that Web-based sex seeking is relatively common among MSM and TW in Tijuana and that it may be feasible to leverage Web-based sex-seeking platforms to engage these vulnerable populations in HIV prevention and treatment services. However, such Web-based interventions may still poorly engage those most affected by stigma toward sexual and gender minorities, given that within our sample they were least likely to seek sex on the Web. Further research is needed to identify effective and acceptable strategies to link MSM and TW most affected by stigma to HIV prevention and treatment services. As trends of Web-based sex seeking among nationally representative samples of MSM in the United States have dramatically increased over time [12], future research should also monitor changes in the use of Web-based sex-seeking platforms among MSM and TW in LMIC.

Acknowledgments

Conflicts of Interest

None declared.

Multimedia Appendix 1
Scale items and survey questions for the 5 stigma measures used in this analysis.
[DOCX File , 18 KB - publichealth_v6i1e14803_app1.docx]

References

1.   Baral S, Sifakis F, Cleghorn F, Beyrer C. Elevated risk for HIV infection among men who have sex with men in low- and middle-income countries 2000-2006: a systematic review. PLoS Med 2007 Dec;4(12):e339 [FREE Full text] [doi: 10.1371/journal.pmed.0040339] [Medline: 18052602]

2.   Baral SD, Poteat T, Strömdahl S, Wirtz AL, Guadamuz TE, Beyrer C. Worldwide burden of HIV in transgender women: a systematic review and meta-analysis. Lancet Infect Dis 2013 Mar;13(3):214-222. [doi: 10.1016/S1473-3099(12)70315-8] [Medline: 23260128]

3.   Ha H, Risser JM, Ross MW, Huynh NT, Nguyen HT. Homosexuality-related stigma and sexual risk behaviors among men who have sex with men in Hanoi, Vietnam. Arch Sex Behav 2015 Feb;44(2):349-356. [doi: 10.1007/s10508-014-0450-8] [Medline: 25617010]

4.   Magno L, Dourado I, Silva LA, Brignol S, Amorim L, MacCarthy S. Gender-based discrimination and unprotected receptive anal intercourse among transgender women in Brazil: a mixed methods study. PLoS One 2018;13(4):e0194306 [FREE Full text] [doi: 10.1371/journal.pone.0194306] [Medline: 29641528]

5.   Melendez RM, Pinto R. 'It's really a hard life': love, gender and HIV risk among male-to-female transgender persons. Cult Health Sex 2007;9(3):233-245 [FREE Full text] [doi: 10.1080/13691050601065909] [Medline: 17457728]

6.   Sugano E, Nemoto T, Operario D. The impact of exposure to transphobia on HIV risk behavior in a sample of transgendered women of color in San Francisco. AIDS Behav 2006 Mar;10(2):217-225. [doi: 10.1007/s10461-005-9040-z] [Medline: 16362237]

7.   Beattie TS, Bhattacharjee P, Suresh M, Isac S, Ramesh B, Moses S. Personal, interpersonal and structural challenges to accessing HIV testing, treatment and care services among female sex workers, men who have sex with men and transgenders in Karnataka state, South India. J Epidemiol Community Health 2012 Oct;66(Suppl 2):ii42-ii48 [FREE Full text] [doi: 10.1136/jech-2011-200475] [Medline: 22495772]

8.   Fay H, Baral SD, Trapence G, Motimedi F, Umar E, Iipinge S, et al. Stigma, health care access, and HIV knowledge among men who have sex with men in Malawi, Namibia, and Botswana. AIDS Behav 2011 Aug;15(6):1088-1097. [doi: 10.1007/s10461-010-9861-2] [Medline: 21153432]

9.   Grant JM, Mottet L, Tanis JE, Harrison J, Herman J, Keisling M. National Center for Transgender Equality. Washington: National Center for Transgender Equality and National Gay and Lesbian Task Force; 2011. Injustice at Every Turn: A Report of the National Transgender Discrimination Survey URL: https://www.transequality.org/sites/default/files/docs/resources/NTDS_Report.pdf [accessed 2019-11-28]

10. Lambda Legal. New York: Lambda Legal; 2010. When Health Care Isn't Caring: Lambda Legal's Survey of Discrimination Against LGBT People and People With HIV URL: https://www.lambdalegal.org/sites/default/files/publications/downloads/whcic-report_when-health-care-isnt-caring.pdf [accessed 2019-11-28]

11. Chow JY, Konda KA, Calvo GM, Klausner JD, Cáceres CF. Demographics, behaviors, and sexual health characteristics of high risk men who have sex with men and transgender women who use social media to meet sex partners in Lima, Peru. Sex Transm Dis 2017 Mar;44(3):143-148. [doi: 10.1097/OLQ.0000000000000566] [Medline: 28178111]

12. 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 1;75(Suppl 3):S288-S295 [FREE Full text] [doi: 10.1097/QAI.0000000000001404] [Medline: 28604430]

13. Stahlman S, Grosso A, Ketende S, Mothopeng T, Taruberekera N, Nkonyana J, et al. Characteristics of men who have sex with men in southern Africa who seek sex online: a cross-sectional study. J Med Internet Res 2015 May 25;17(5):e129 [FREE Full text] [doi: 10.2196/jmir.4230] [Medline: 26006788]

14. Stahlman S, Nowak RG, Liu H, Crowell TA, Ketende S, Blattner WA, TRUST/RV368 Study Group. Online sex-seeking among men who have sex with men in Nigeria: implications for online intervention. AIDS Behav 2017 Nov;21(11):3068-3077 [FREE Full text] [doi: 10.1007/s10461-016-1437-3] [Medline: 27233248]

15. Bien CH, Best JM, Muessig KE, Wei C, Han L, Tucker JD. Gay apps for seeking sex partners in China: implications for MSM sexual health. AIDS Behav 2015 Jun;19(6):941-946 [FREE Full text] [doi: 10.1007/s10461-014-0994-6] [Medline: 25572834]

16. Krishnan A, Nguyen M, Giang LM, Ha TV, Bhadra M, Nguyen SM, et al. Finding sex partners through social media among men who have sex with men in Hanoi, Vietnam. J Community Health 2018 Feb;43(1):146-156. [doi: 10.1007/s10900-017-0397-5] [Medline: 28677027]

17. Pan S, Xu JJ, Han XX, Zhang J, Hu QH, Chu ZX, et al. Internet-based sex-seeking behavior promotes HIV infection risk: a 6-year serial cross-sectional survey to MSM in Shenyang, China. Biomed Res Int 2016;2016:2860346 [FREE Full text] [doi: 10.1155/2016/2860346] [Medline: 28105415]

18. Tang W, Best J, Zhang Y, Liu F, Tso LS, Huang S, et al. Gay mobile apps and the evolving virtual risk environment: a cross-sectional online survey among men who have sex with men in China. Sex Transm Infect 2016 Nov;92(7):508-514 [FREE Full text] [doi: 10.1136/sextrans-2015-052469] [Medline: 27288414]

19. Muessig KE, Nekkanti M, Bauermeister J, Bull S, Hightow-Weidman LB. A systematic review of recent smartphone, internet and web 2.0 interventions to address the HIV continuum of care. Curr HIV/AIDS Rep 2015 Mar;12(1):173-190 [FREE Full text] [doi: 10.1007/s11904-014-0239-3] [Medline: 25626718]

20. Blas MM, Alva IE, Carcamo CP, Cabello R, Goodreau SM, Kimball AM, et al. Effect of an online video-based intervention to increase HIV testing in men who have sex with men in Peru. PLoS One 2010 May 3;5(5):e10448 [FREE Full text] [doi: 10.1371/journal.pone.0010448] [Medline: 20454667]

21. Cao B, Gupta S, Wang J, Hightow-Weidman LB, Muessig KE, Tang W, et al. Social media interventions to promote HIV testing, linkage, adherence, and retention: systematic review and meta-analysis. J Med Internet Res 2017 Nov 24;19(11):e394 [FREE Full text] [doi: 10.2196/jmir.7997] [Medline: 29175811]

22. Young SD, Cumberland WG, Nianogo R, Menacho LA, Galea JT, Coates T. The HOPE social media intervention for global HIV prevention in Peru: a cluster randomised controlled trial. Lancet HIV 2015 Jan;2(1):e27-e32 [FREE Full text] [doi: 10.1016/S2352-3018(14)00006-X] [Medline: 26236767]

23. Altman D, Aggleton P, Williams M, Kong T, Reddy V, Harrad D, et al. Men who have sex with men: stigma and discrimination. Lancet 2012 Jul 28;380(9839):439-445. [doi: 10.1016/S0140-6736(12)60920-9] [Medline: 22819652]

24. Hatzenbuehler ML, Phelan JC, Link BG. Stigma as a fundamental cause of population health inequalities. Am J Public Health 2013 May;103(5):813-821 [FREE Full text] [doi: 10.2105/AJPH.2012.301069] [Medline: 23488505]

25. Link BG, Phelan JC. Stigma and its public health implications. Lancet 2006 Feb 11;367(9509):528-529. [doi: 10.1016/S0140-6736(06)68184-1] [Medline: 16473129]

26. Katz-Wise SL, Hyde JS. Victimization experiences of lesbian, gay, and bisexual individuals: a meta-analysis. J Sex Res 2012;49(2-3):142-167. [doi: 10.1080/00224499.2011.637247] [Medline: 22380586]

27. Meyer IH. Minority stress and mental health in gay men. J Health Soc Behav 1995 Mar;36(1):38-56. [doi: 10.2307/2137286] [Medline: 7738327]

28. Meyer IH. Prejudice, social stress, and mental health in lesbian, gay, and bisexual populations: conceptual issues and research evidence. Psychol Bull 2003 Sep;129(5):674-697 [FREE Full text] [doi: 10.1037/0033-2909.129.5.674] [Medline: 12956539]

29.   Herek GM. Beyond 'Homophobia': thinking about sexual prejudice and stigma in the twenty-first century. Sex Res Soc
       Policy 2004;1(2):6-24 [FREE Full text] [doi: 10.1525/srsp.2004.1.2.6]

30.   Gamarel KE, Reisner SL, Laurenceau J, Nemoto T, Operario D. Gender minority stress, mental health, and relationship
       quality: a dyadic investigation of transgender women and their cisgender male partners. J Fam Psychol 2014
       Aug;28(4):437-447 [FREE Full text] [doi: 10.1037/a0037171] [Medline: 24932942]

31.   Major B, O'Brien LT. The social psychology of stigma. Annu Rev Psychol 2005;56:393-421. [doi:
       10.1146/annurev.psych.56.091103.070137] [Medline: 15709941]

32.   Pachankis JE. The psychological implications of concealing a stigma: a cognitive-affective-behavioral model. Psychol Bull
       2007 Mar;133(2):328-345. [doi: 10.1037/0033-2909.133.2.328] [Medline: 17338603]

33.   Secretaria de Salud Centro Nacional para la Prevención y el Control del VIH y el SIDA (CENSIDA). The unique government
       portal | gob.mx. 2015. Informe Nacional de Avances en la Respuesta al VIH y el SIDA: Mexico 2015 URL: https://www.
       gob.mx/cms/uploads/attachment/file/199665/GARPR_Mx_2016.pdf

34.   UNAIDS. The Joint United Nations Programme on HIV/AIDS (UNAIDS). Country: Mexico URL: http://www.unaids.org/
       en/regionscountries/countries/mexico [accessed 2019-11-28]

35.   Pitpitan EV, Goodman-Meza D, Burgos JL, Abramovitz D, Chavarin CV, Torres K, et al. Prevalence and correlates of HIV
       among men who have sex with men in Tijuana, Mexico. J Int AIDS Soc 2015;18:19304 [FREE Full text] [doi:
       10.7448/IAS.18.1.19304] [Medline: 25669423]

36.   Salas-Espinoza KJ, Menchaca-Diaz R, Patterson TL, Urada LA, Smith D, Strathdee SA, et al. HIV prevalence and risk
       behaviors in male to female (MTF) transgender persons in Tijuana, Mexico. AIDS Behav 2017 Dec;21(12):3271-3278
       [FREE Full text] [doi: 10.1007/s10461-017-1931-2] [Medline: 29032411]

37.   Cheney MK, Gowin MJ, Taylor EL, Frey M, Dunnington J, Alshuwaiyer G, et al. Living outside the gender box in Mexico:
       testimony of transgender Mexican asylum seekers. Am J Public Health 2017 Oct;107(10):1646-1652. [doi:
       10.2105/AJPH.2017.303961] [Medline: 28817317]

38.   Cuadra-Hernández SM, Zarco-Mera A, Infante-Xibillé C, Caballero-García M. The organization of key populations
       connected to HIV transmission: an intervention to abate stigma; Mexico, 2005-2009. Salud Colect 2012;8(2):191-204. [doi:
       10.1590/S1851-82652012000200007] [Medline: 23995546]

39.   Diehl A, Vieira DL, Zaneti MM, Fanganiello A, Sharan P, Robles R, et al. Social stigma, legal and public health barriers
       faced by the third gender phenomena in Brazil, India and Mexico: Travestis, hijras and muxes. Int J Soc Psychiatry 2017
       Aug;63(5):389-399. [doi: 10.1177/0020764017706989] [Medline: 28552025]

40.   Ortiz-Hernández L, Granados-Cosme JA. Violence against bisexuals, gays and lesbians in Mexico City. J Homosex
       2006;50(4):113-140. [doi: 10.1300/J082v50n04_06] [Medline: 16723343]

41.   Castañeda M. El Machismo Invisible Regresa. Madrid: Taurus; 2007.

42.   Kendall T, Herrera C, Caballero M, Campero L. HIV prevention and men who have sex with women and men in México:
       findings from a qualitative study with HIV-positive men. Cult Health Sex 2007;9(5):459-472. [doi:
       10.1080/13691050601183629] [Medline: 17687672]

43.   Verduzco IL, Sánchez TE. Lozano Verduzco I, Rocha Sánchez TE. La homofobia y su relación con la masculinidad
       hegemónica en México. Rev Puertorriquena Psicol 2011;22:101-121 [FREE Full text]

44.   Steffens MC, Jonas KJ, Denger L. Male role endorsement explains negative attitudes toward lesbians and gay men among
       students in Mexico more than in Germany. J Sex Res 2015;52(8):898-911. [doi: 10.1080/00224499.2014.966047] [Medline:
       25369554]

45.   Panitz DR, McConchie RD, Sauber SR, Fonseca JA. The role of machismo and the Hispanic family in the etiology and
       treatment of alcoholism in Hispanic American males. Am J Fam Ther 1983;11(1):31-44 [FREE Full text] [doi:
       10.1080/01926188308250109]

46.   Pines HA, Goodman-Meza D, Pitpitan EV, Torres K, Semple SJ, Patterson TL. HIV testing among men who have sex with
       men in Tijuana, Mexico: a cross-sectional study. BMJ Open 2016 Feb 4;6(2):e010388 [FREE Full text] [doi:
       10.1136/bmjopen-2015-010388] [Medline: 26846899]

47.   Pew Research Center. 2014 Feb 13. Emerging Nations Embrace Internet, Mobile Technology URL: https://www.
       pewresearch.org/global/2014/02/13/emerging-nations-embrace-internet-mobile-technology/ [accessed 2019-11-28]

48.   Heckathorn DD. Respondent-driven sampling: a new approach to the study of hidden populations. Soc Probl
       1997;44(2):174-199 [FREE Full text] [doi: 10.2307/3096941]

49.   Heckathorn DD. Extensions of respondent-driven sampling: analyzing continuous variables and controlling for differential
       recruitment. Sociol Methodol 2007;37(1):151-208 [FREE Full text] [doi: 10.1111/j.1467-9531.2007.00188.x]

50.   Arciniega GM, Anderson TC, Tovar-Blank ZG, Tracey TJ. Toward a fuller conception of Machismo: development of a
       traditional Machismo and Caballerismo Scale. J Couns Psychol 2008;55(1):19-33 [FREE Full text] [doi:
       10.1037/0022-0167.55.1.19]

51.   Estrada F, Rigali-Oiler M, Arciniega GM, Tracey TJG. Machismo and Mexican American men: an empirical understanding
       using a gay sample. J Couns Psychol 2011 Jul;58(3):358-367. [doi: 10.1037/a0023122] [Medline: 21534655]

52.   Herek GM, Cogan JC, Gillis JR, Glunt EK. Correlates of internalized homophobia in a community sample of lesbians and
       gay men. J Gay Lesbian Med Assoc 1997;2:17-25 [FREE Full text]

53. Centers for Disease Control and Prevention (CDC). HIV/STD risks in young men who have sex with men who do not disclose their sexual orientation--six US cities, 1994-2000. MMWR Morb Mortal Wkly Rep 2003 Feb 7;52(5):81-86 [FREE Full text] [Medline: 12588004]

54. Coneval. 2019. Consejo Nacional de Evaluación de la Política de Desarrollo Social. Evolución de las líneas de probreza por ingresos URL: https://www.coneval.org.mx/Medicion/MP/Paginas/Lineas-de-bienestar-y-canasta-basica.aspx

55. Moser A, Stuck AE, Silliman RA, Ganz PA, Clough-Gorr KM. The eight-item modified Medical Outcomes Study Social Support Survey: psychometric evaluation showed excellent performance. J Clin Epidemiol 2012 Oct;65(10):1107-1116 [FREE Full text] [doi: 10.1016/j.jclinepi.2012.04.007] [Medline: 22818947]

56. Dean G, Orford A, Staines R, McGee A, Smith KJ. Psychosocial well-being and health-related quality of life in a UK population with Usher syndrome. BMJ Open 2017 Jan 12;7(1):e013261 [FREE Full text] [doi: 10.1136/bmjopen-2016-013261] [Medline: 28082366]

57. Carey MP, Carey KB, Maisto SA, Gordon CM, Weinhardt LS. Assessing sexual risk behaviour with the Timeline Followback (TLFB) approach: continued development and psychometric evaluation with psychiatric outpatients. Int J STD AIDS 2001 Jun;12(6):365-375 [FREE Full text] [doi: 10.1258/0956462011923309] [Medline: 11368817]

58. Kauth MR, St Lawrence JS, Kelly JA. Reliability of retrospective assessments of sexual HIV risk behavior: a comparison of biweekly, three-month, and twelve-month self-reports. AIDS Educ Prev 1991;3(3):207-214. [Medline: 1834142]

59. Schroder KE, Carey MP, Vanable PA. Methodological challenges in research on sexual risk behavior: II. Accuracy of self-reports. Ann Behav Med 2003 Oct;26(2):104-123 [FREE Full text] [doi: 10.1207/S15324796ABM2602_03] [Medline: 14534028]

60. Greenland S, Pearl J, Robins JM. Causal diagrams for epidemiologic research. Epidemiology 1999 Jan;10(1):37-48. [doi: 10.1097/00001648-199901000-00008] [Medline: 9888278]

61. Westreich D, Greenland S. The table 2 fallacy: presenting and interpreting confounder and modifier coefficients. Am J Epidemiol 2013 Feb 15;177(4):292-298 [FREE Full text] [doi: 10.1093/aje/kws412] [Medline: 23371353]

Abbreviations

AOR: adjusted odds ratio
DAGs: directed acyclic graphs
LMIC: low- and middle-income countries
MSM: men who have sex with men
MXN: Mexican pesos
RDS: respondent-driven sampling
TW: transgender women
VBS: venue-based sampling

Original Paper

Media Reports as a Source for Monitoring Impact of Influenza on Hospital Care: Qualitative Content Analysis

Daphne F M Reukers[1], MSc; Sierk D Marbus[1], MD; Hella Smit[1], BSc; Peter Schneeberger[2], MD, PhD; Gé Donker[3], MD, PhD; Wim van der Hoek[1], MD, PhD; Arianne B van Gageldonk-Lafeber[1], PhD

[1]Centre for Infectious Disease Control, National Institute for Public Health and the Environment, Bilthoven, Netherlands

[2]Regional Laboratory for Medical Microbiology and Infection Prevention, Jeroen Bosch hospital, 's-Hertogenbosch, Netherlands

[3]Nivel, Netherlands Institute for Health Services Research, Utrecht, Netherlands

Corresponding Author:
Daphne F M Reukers, MSc
Centre for Infectious Disease Control
National Institute for Public Health and the Environment
Postbus 1
3720 BA
Bilthoven,
Netherlands
Phone: 31 302743419
Email: daphne.reukers@rivm.nl

Abstract

Background: The Netherlands, like most European countries, has a robust influenza surveillance system in primary care. However, there is a lack of real-time nationally representative data on hospital admissions for complications of influenza. Anecdotal information about hospital capacity problems during influenza epidemics can, therefore, not be substantiated.

Objective: The aim of this study was to assess whether media reports could provide relevant information for estimating the impact of influenza on hospital capacity, in the absence of hospital surveillance data.

Methods: Dutch news articles on influenza in hospitals during the influenza season (week 40 of 2017 until week 20 of 2018) were searched in a Web-based media monitoring program (Coosto). Trends in the number of weekly articles were compared with trends in 5 different influenza surveillance systems. A content analysis was performed on a selection of news articles, and information on the hospital, department, problem, and preventive or response measures was collected.

Results: The trend in weekly news articles correlated significantly with the trends in all 5 surveillance systems, including severe acute respiratory infections (SARI) surveillance. However, the peak in all 5 surveillance systems preceded the peak in news articles. Content analysis showed hospitals (N=69) had major capacity problems (46/69, 67%), resulting in admission stops (9/46, 20%), postponement of nonurgent surgical procedures (29/46, 63%), or both (8/46, 17%). Only few hospitals reported the use of point-of-care testing (5/69, 7%) or a separate influenza ward (3/69, 4%) to accelerate clinical management, but most resorted to ad hoc crisis management (34/69, 49%).

Conclusions: Media reports showed that the 2017/2018 influenza epidemic caused serious problems in hospitals throughout the country. However, because of the time lag in media reporting, it is not a suitable alternative for near real-time SARI surveillance. A robust SARI surveillance program is important to inform decision making.

KEYWORDS

XSL•FO
RenderX

Introduction

Surveillance of Severe Acute Respiratory Infections

The long and intense influenza epidemic in winter 2017/2018 in a number of European countries, including the Netherlands, led to substantial morbidity and increased mortality, especially because of pneumonia as a complication of influenza virus infection [1]. A sudden increase in the number of patients requiring hospitalization for (complications of) acute respiratory infections may pose a significant burden for hospitals in managing bed and staff capacity. It may also severely limit the possibilities to isolate patients suspected of influenza [2,3]. Surveillance of severe acute respiratory infections (SARI), defined as an acute respiratory infection requiring hospitalization, is considered a priority by the European Centre for Disease Prevention and Control, the World Health Organization, and individual countries. However, establishing surveillance systems in hospitals has proven difficult in many countries [4-6].

Ideally, surveillance of complications from influenza virus infection in sentinel hospitals would mimic the well-organized surveillance of influenza-like illness (ILI) or acute respiratory infections and influenza infection by sentinel general practitioners (GPs) in primary care [1]. However, in the European region, very few countries have established syndromic SARI surveillance in combination with testing for influenza virus [7]. In the Netherlands, limited real-time data on SARI are available from a pilot project in 2 hospitals [8], but this does not yet provide a nationally representative picture. Therefore, with a lack of national hospital surveillance data to guide health care measures, individual hospitals had to revert to ad hoc crisis management when patient numbers started to increase beyond capacity.

Alternative Surveillance Methods

In the absence of nationally representative SARI surveillance, nontraditional Web-based data sources could improve the SARI surveillance. We could not identify previous reports in which media content was analyzed to assess impact on hospital capacity. However, in recent years, several studies have explored the use of alternative surveillance methods for influenza based on internet search terms. An example of internet-based surveillance system is Google Flu Trends, which monitors health-seeking behavior by using data on influenza-related searches to estimate the incidence of ILI in a specific region [9]. It has shown promising results during regular winter seasons [9]; however, it did not predict the 2009 influenza pandemic [10,11]. Multiple other internet-based surveillance systems have been developed over the years; however, it is often complex and cumbersome for epidemiologists to extract the relevant information from large amounts of data on social media or search engine queries [12]. Furthermore, media reports, in comparison with internet queries, have shown to contain more specific and official data in relation to influenza and other public health problems. In a study based on the 2009 pandemic, media reports were analyzed in relation to several influenza surveillance methods [11]. A study by Olayinka et al [13] showed that media reports were useful as a supplemental data source for the real-time mortality monitoring related to Hurricane Sandy. As the capacity problems that hospitals faced were reported in local, regional, and national media, these could potentially be a suitable supplemental data source to specifically assess the impact of hospitalized SARI patients during an influenza epidemic.

Objectives

The aim of this study was to assess whether media reports during the 2017/2018 influenza epidemic provided relevant information for estimating the impact of influenza on hospital care as an indicator of the severity of the epidemic in the absence of traditional hospital-based epidemiological data.

Methods

Search Strategy for Media Reports

A search was conducted using Coosto (Coosto), which is a Web-based media monitoring and analytics program. The search term in Dutch *griep EN ziekenhuis* (in English: *flu/influenza AND hospital*) was used. There is only 1 word for flu/Influenza in Dutch used in media reporting, that is, *griep*. Only articles from the Netherlands published on regional or national news websites during the influenza season (week 40 of 2017 until week 20 of 2018) were selected. Trend in weekly number of news articles from the Coosto search was plotted against trends in the different influenza surveillance systems that were available on a weekly basis. A content analysis was performed on a selection of news articles with data on influenza in hospitals during the 2017/2018 influenza season. The relevance of the news articles and possible duplicates was only assessed for the content analysis.

Available Respiratory Surveillance Systems in the Netherlands

Influenza-Like Illness

The basis for the weekly, near real-time surveillance of influenza in the Netherlands is the incidence of ILI as reported by approximately 40 GP sentinel practices participating in the Nivel Primary Care Database [14]. The population of these sentinel practices covers 0.7% of the Dutch population and is nationally representative for age, sex, regional distribution, and population density [15]. The ILI incidence is calculated as the number of patients with a new episode of ILI divided by the total number of enlisted patients in the participating sentinel GP practices. As all Dutch residents are registered in a general practice, the number of enlisted patients represents the general population. An influenza epidemic is declared when the ILI incidence is >5.1 per 10,000 inhabitants for a consecutive 2 weeks and when influenza virus is detected in swabs from ILI patients.

Community-Acquired Pneumonia in Primary Care

Pneumonia data are also obtained from Nivel Primary Care Database but from a larger group of GPs (approximately 400) based on automatic extraction of weekly number of patients consulting their GP for pneumonia (International Classification of Primary Care code R81) divided by the total number of enlisted patients in the participating GP practices [1].

Severe Acute Respiratory Infections

Data on SARI incidence is currently limited to information from 3 hospitals participating in a pilot SARI surveillance program. In our study, data from 1 hospital were used, the Jeroen Bosch hospital (JBH) in 's-Hertogenbosch, as these were the most robust data available. The SARI incidence was retrospectively based on a selection of financial codes that every Dutch hospital must use for reimbursement from health insurance companies related to the clinical syndrome SARI divided by the number of persons (approximately 323,000) in the catchment area of JBH [16].

Mortality Monitoring

In the Netherlands, all-cause deaths are notified to municipalities and then reported to Statistics Netherlands, which collects and monitors all Dutch vital statistics [1].

Virological Surveillance

Finally, on a weekly basis, about 19 Dutch virological laboratories report the number of positive diagnoses of several viral pathogens, including influenza. Details on the different surveillance systems for the 2017/2018 influenza season can be found in Reukers et al [1].

Media Content Analysis

After the search in Coosto, 2 researchers separately scanned all titles for relevance. Articles were excluded if the title was unrelated to influenza in hospitals in the Netherlands or if it was a duplicate news article. Subsequently, full-text articles were assessed and excluded if irrelevant or duplicate. A qualitative content analysis was performed on the remaining articles. In each news article, the following information was identified: whether (1) the article was recently published, (2) it came from a designated spokesperson, (3) the name and place of the hospital was mentioned, (4) it was about a specific hospital department, and (5) the specific problems pertaining to influenza and the implemented preventive/response measures were mentioned. This was guided by the paper from Groeneveld et al who already listed the most common problems and prevention/response measures during the 2017/2018 influenza epidemic [17]. These were applied into the content analysis by categorizing and counting the number of problems and prevention/response measures reported by each hospital in the news articles. The problems reported by hospitals in the news articles were categorized as (1) hospital admission stops, (2) postponing nonurgent surgical procedures likely caused by the high number of influenza patients, (3) staff capacity problems because of influenza, and/or (4) other influenza epidemic-related

problems [17]. Prevention or response measures were categorized as (1) ad hoc crisis management, (2) regional cooperation, (3) point-of-care testing (POCT), (4) cohort isolation for influenza patients, or (5) other prevention and control measures [17].

Statistical Analysis

Using SAS version 9.4, Pearson correlation coefficients (significant at .05 level) were computed between the weekly number of media reports and the weekly ILI incidence, weekly number of pneumonia consultations per 10.000 inhabitants, weekly SARI incidence, weekly number of all-cause deaths, and weekly influenza diagnoses reported in the virological laboratory surveillance.

Ethics

The Dutch Medical Research Involving Human Subjects Act (WMO) does not apply to this study, and therefore, an official approval by a Medical Ethical Research Committee is not required under the WMO. Furthermore, all data are publicly available. Surveillance data used in this study are available on the Nivel website (ILI incidence and pneumonia), the National Institute for Public Health and Environment (RIVM) website (SARI incidence and virological data), and the website of Statistics Netherlands [18].

Results

Comparisons of Media Reports With Surveillance Systems

The large majority of the weekly number of news articles from the Coosto search (n=730) during the 2017/2018 influenza season in the Netherlands coincided with the influenza epidemic as defined by the ILI incidence (Figure 1). The peak in ILI incidence preceded the peak in the number of articles by 5 weeks. The ILI incidence reached a peak in week 4 of 2018 and remained high until week 10 of 2018, while the media coverage increased later from around week 9 and reached a peak in week 11 of 2018. Both trends show a steep decrease after week 10 and 11, respectively. On visual inspection, similar trends were observed for the number of news articles in relation to weekly pneumonia consultations in primary care, SARI surveillance, all-cause mortality, and influenza laboratory diagnoses (Figure 1). The trends in ILI incidence and media reports are significantly correlated (Table 1). Correlations were even stronger for pneumonia in primary care, SARI in the JBH, influenza laboratory diagnoses, and all-cause mortality (Table 1).

Figure 1. Weekly number of news articles and (A) influenza-like illness incidence per 10,000 inhabitants in general practitioner (GP) practices, (B) of patients consulting their GP for pneumonia per 10,000 inhabitants, (C) severe acute respiratory infections incidence per 10,000 inhabitants in Jeroen Bosch Hospital, (D) number of deaths, and (E) number of influenza diagnoses reported in the virological laboratory surveillance during the 2017/2018 influenza season in the Netherlands. ILI: influenza-like illness; SARI: severe acute respiratory infections.
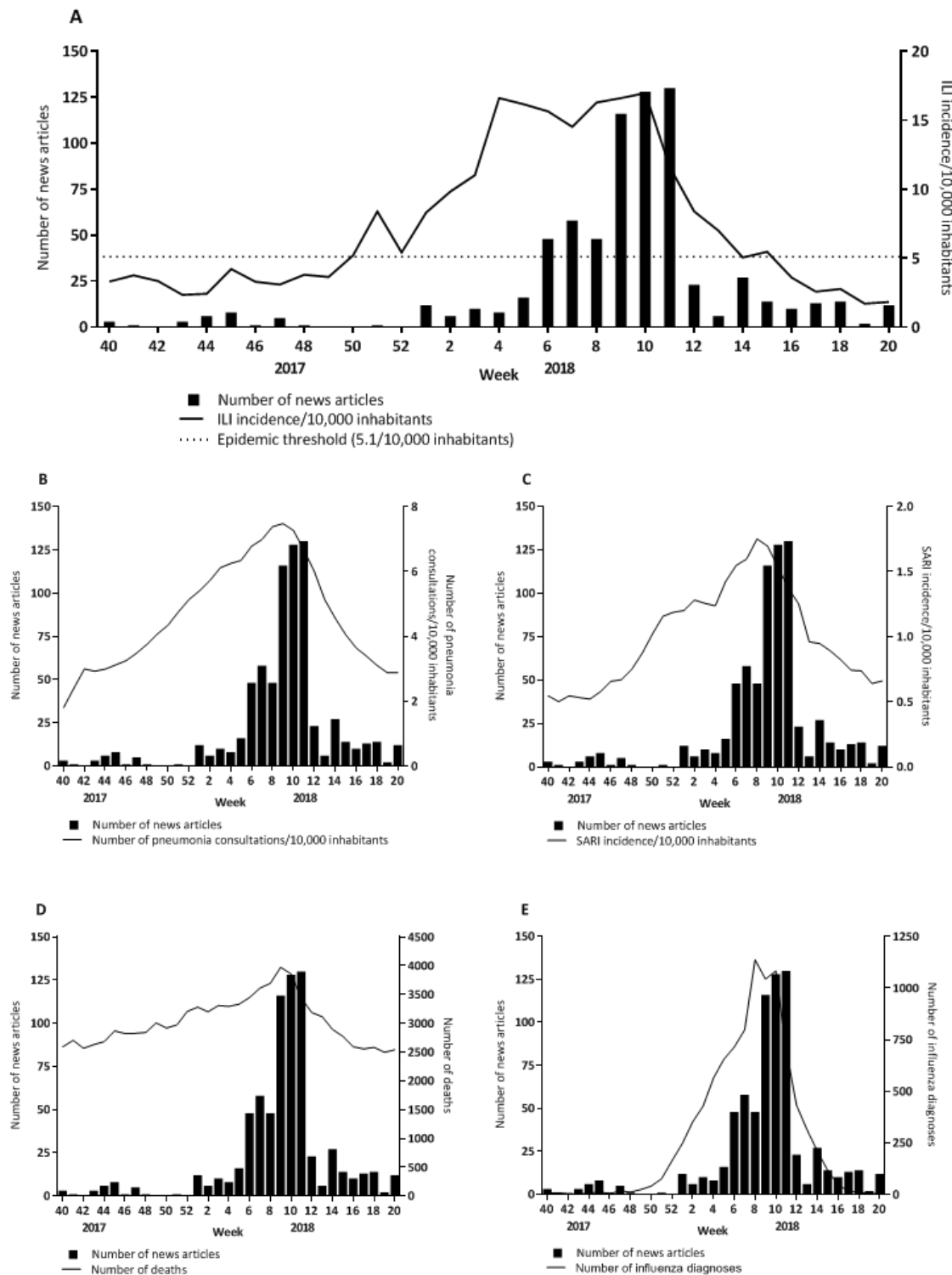
Table 1. Correlation between the weekly number of news articles on influenza in hospitals and the weekly influenza-like illness incidence, pneumonia consultations, severe acute respiratory infections incidence, number of deaths, and influenza laboratory diagnoses.

Weekly number of news articles correlated with	Correlation coefficient	*P* value
Influenza-like illness incidence[a]	0.65	<.001
Number of pneumonia consultations[a]	0.67	<.001
Severe acute respiratory infections incidence[a]	0.77	<.001
Number of all-cause deaths	0.72	<.001
Number of influenza laboratory diagnoses[b]	0.79	<.001

[a]Per 10.000 inhabitants.

[b]Reported in the virological laboratory surveillance.

Selection of Media Reports

For the content analysis, 147 of the 730 news articles were excluded based on the title (Figure 2). The remaining 583 articles were screened for duplicates, leaving 302 news articles to be assessed in full text. Ultimately, 165 (165/717, 23.0%) news articles were included in the qualitative content analysis (Figure 2).

Figure 2. Flowchart presenting the inclusion and exclusion of regional or national Dutch news articles related to influenza in hospitals in the Netherlands during the 2017/2018 influenza season (week 40 of 2017 and until week 20 of 2018) from the Coosto database search using the term flu AND hospital.
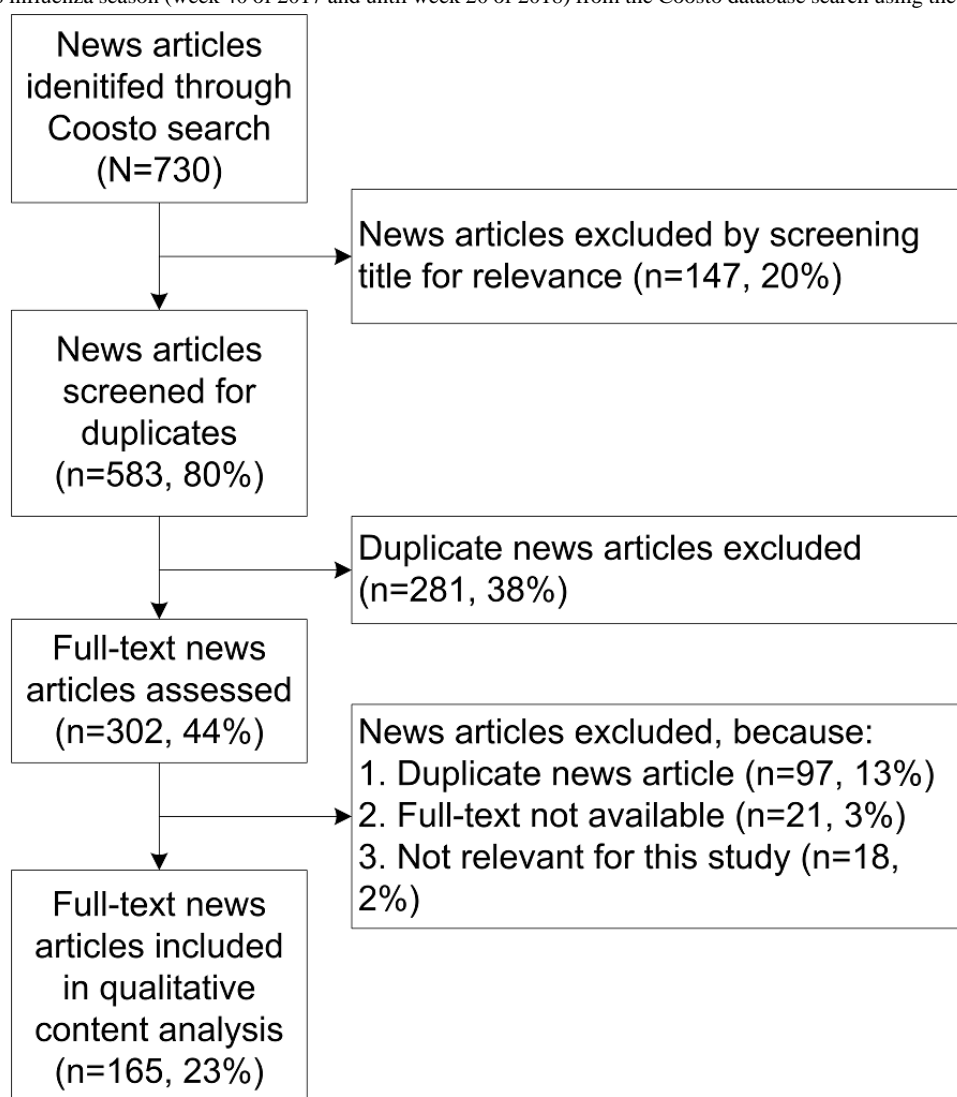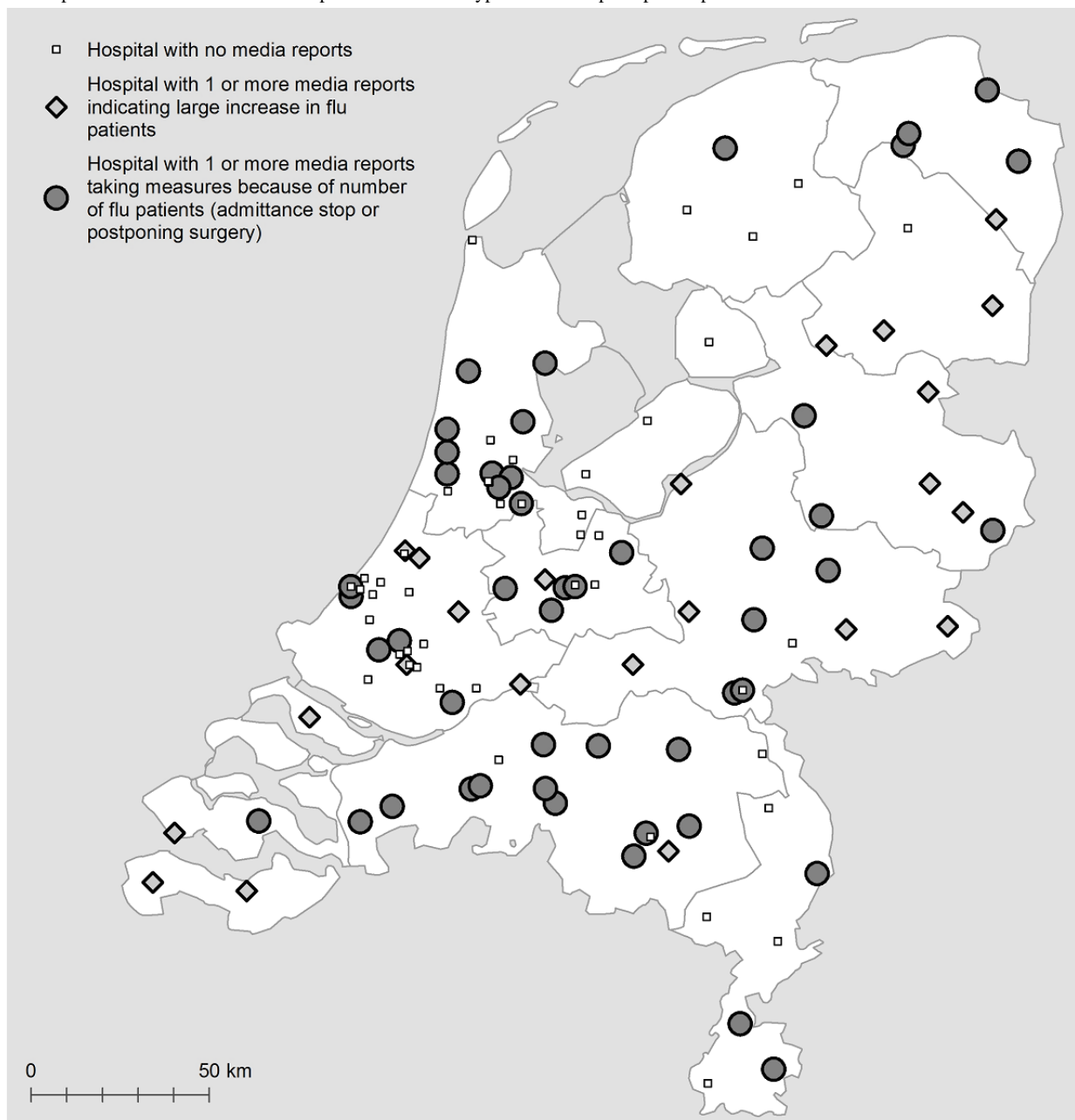
Content of Media Reports

The 165 news articles included 77 articles citing 1 or more specific hospitals or contained a statement from 1 or more hospitals, often by designated spokespersons. The other 88 news articles contained more general information about influenza and/or hospitals.

Geographical Distribution and Type of Reported Problems

Results from the content analysis show that 52 different hospital organizations were named in the included news articles with 69 hospital locations. These included 5 academic teaching hospitals, 1 children's hospital, 35 top clinical teaching hospitals, and 28 general hospitals. These locations were spread across the Netherlands (Figure 3). Of the 69 hospital locations, 23

(33%) reported a large increase in influenza patients but were still able to cope with the number of admitted patients. The remaining 46 (46/69, 67%) hospitals had to take measures at least once during the influenza season; 29 (29/69, 63%) hospitals had to postpone nonurgent surgical procedures, 9 (9/69, 20%) instated a temporary admission stop, and 8 (8/69, 17%) had to take both of these measures (postponing surgery and admission stop). Of these 46 hospital locations, 20 (43%) indicated that the epidemic caused the largest problems in the emergency department (ED). A total of 25 of the 46 hospitals also indicated problems because of staff shortages towing to sick leave caused by influenza. Furthermore, 13 hospitals mentioned a stagnating flow of patients from the hospital to nursing homes. This concerned elderly patients for whom ongoing hospitalization was not medically indicated but who could not be discharged because of social reasons.

Figure 3. Map of the Netherlands with all hospital locations and type of media reports per hospital location.

Media Reports on Response and Preventive Measures

Of all the 69 hospital locations, 29 (42%) mentioned no specific response or preventive measures; 34 (49%) hospitals implemented some form of crisis management, such as flexible deployment of staff (working overtime) and flexible bed occupancy; and 8 (12%) hospitals mentioned a regional cooperation between hospitals. Furthermore, 5 (5/69, 7%) hospitals used POCT to accelerate clinical management (Admiraal de Ruyter hospital in Goes and Vlissingen, Albert Schweitzer hospital in Dordrecht, Amphia hospital in Breda, and JBH in 's-Hertogenbosch), and 3 (3/69, 4%) hospitals set up a separate influenza ward to isolate the influenza patients (JBH in 's-Hertogenbosch, Sint Antonius hospital in Woerden, and Waterland hospital in Purmerend).

Media Reports on Mortality and Vaccination

In the 88 news articles containing general information about influenza and hospitals, an important topic (13/88, 15%) was the high mortality rates, especially among the elderly, related to the influenza epidemic. An influential Dutch senior organization (KBO-PCOB) called this a silent disaster and started lobbying for a "winter mortality plan" to be better prepared in the future. Furthermore, several articles (7/88, 8%) discussed the effectiveness of the influenza vaccine, the low vaccine uptake (especially among hospital staff), and the possibility of mandatory influenza vaccination of hospital and nursing home staff.

The remaining news articles (68/88, 77%) included news on regional cooperation among hospitals to cope with the influenza epidemic, the pressure on ambulance care, crisis exercise to prepare for a large influenza epidemic, respiratory syncytial virus in very young children compared with influenza, general staff capacity issues causing problems during a major (influenza) epidemic, or only included general information on influenza or the current influenza epidemic.

Discussion

Principal Findings

Even though this study showed that trends in media reports are not a suitable timely surveillance measure, they do provide relevant information on the impact of influenza on hospitals. Media reporting clearly showed the severity of the epidemic with a large number of hospitals having problems with capacity and staff shortages affecting patient care in terms of admission stops and postponement of nonurgent procedures. Media reports are suitable for retrospective analysis of the impact of an influenza epidemic on hospitals; however, real-time data are still necessary for preparedness and response.

Implications of Study Results

On the basis of media reports, the 2017/2018 influenza season clearly had a big impact on Dutch hospitals throughout the country. It confirms that real-time data on influenza-related hospital admissions are needed at local, regional, and national level to inform decision making for preparedness and public health response. Improving SARI surveillance was also one of the recommendations of the Outbreak Management Team that was convened by the Dutch Centre for Infectious Disease Control in response to the severe influenza epidemic. In the absence of a sustainable and robust SARI surveillance program, retrospective analysis of media reports on hospitalized influenza patients offers useful information about the impact of an influenza epidemic. However, using media reports for near real-time surveillance of hospitalized influenza cases with respect to preparedness and emergency control is less suitable because of the longer time lag between detection of the event and published media reports compared with other available surveillance systems. This is in line with a study by de Lange et al [11] comparing traditional routine ILI surveillance with other systems of surveillance and trends in pandemic-related newspaper and television coverage and showed that the increase and peak in media coverage did not precede increases in ILI incidence.

Health Care Interventions

In the Netherlands, there was a lack of real-time nationally representative data that could have guided hospital management in preparing and implementing mitigating action. No national guidelines were issued, in contrast to the United Kingdom, where hospitals were advised by the National Health Service to defer nonurgent operations [19]. Hospitals already participate in training programs on how to deal with emergency situations, such as an influenza pandemic or Ebola outbreak [20]. However, there seems to have been no concerted effort in dealing with the large influx of patients during the 2017/2018 influenza epidemic. When there is pressure on hospital capacity, it seems that hospitals refer to ad hoc crisis management. It shows that there is a need for influenza outbreak response plans for hospital preparedness in managing outbreaks of SARI. An important problem mentioned in the media reports by 13 hospitals was that elderly patients could often not be discharged because of the social situation of the patient or because no beds were available in nursing homes. Furthermore, many informal caregivers of these elderly patients were possibly unavailable because of influenza [17]. This is a growing problem with an ageing population and the prevailing policy that elderly persons should be encouraged to live independently at home as long as possible. Therefore, the pressure on informal caregivers and hospital care will likely continue to increase.

Influenza Point-of-Care Testing

Most SARI patients admitted to a hospital are not routinely tested for influenza virus infection. Without national hospital guidelines on influenza diagnostics, influenza testing occurs mainly at the discretion of the treating physician. Even in intensive care units, only about half of such patients are tested [21]. Influenza POCT can be performed by nurses in the ED and are available with a turnaround time of 20 min. It was demonstrated that implementation of POCT in combination with a designated ward for influenza-positive patients during the 2017/2018 epidemic led to a marked reduction in length of hospital stay [2]. Such a policy may have additional benefits by a decrease in costs and unnecessary use of antibiotics [22].

Limitations of the Study

A limitation of using media reports for surveillance purposes is the potential selectivity of media reporting and thereby, the introduction of selection bias. Especially, reporting on response measures is of concern because it is unclear whether the report was initiated by a specific health event or by the hospitals' aim for media attention. Moreover, performing qualitative content analysis on media reports is time consuming, and the choice of items to be analyzed is still rather arbitrary. Developing an automated surveillance system would be better to extract information.

Conclusions

This study showed that the 2017/2018 influenza epidemic caused serious problems affecting hospitals throughout the country. Media reports are not suitable for near real-time surveillance because of the longer time lag compared with other surveillance systems. This stresses the importance of a robust SARI surveillance program to inform decision making, which is especially important in seasons with high or long-lasting influenza activity.

Conflicts of Interest

None declared.

References

1. Reukers DF, van Asten L, Brandsema PS, Dijkstra F, Donker G, van Gageldonk-Lafeber AB, et al. National Institute for Public Health and the Environment (RIVM). Bilthoven; 2018. Surveillance of influenza and other repiratory infections in the Netherlands: winter 2017/ URL: https://www.rivm.nl/bibliotheek/rapporten/2018-0049.pdf

2. Lankelma JM, Hermans MH, Hazenberg EH, Macken T, Dautzenberg PL, Koeijvoets KC, et al. Implementation of point-of-care testing and a temporary influenza ward in a Dutch hospital. Neth J Med 2019 Apr;77(3):109-115 [FREE Full text] [Medline: 31012428]

3. Centers for Disease Control and Prevention (CDC) National Center for Immunization and Respiratory Diseases (NCIRD). Prevention Strategies for Seasonal Influenza in Healthcare Settings 2018 URL: https://www.cdc.gov/flu/professionals/infectioncontrol/healthcaresettings.htm [accessed 2019-05-06] [WebCite Cache ID 78AW8aKdh]

4. van den Wijngaard CC, van Pelt W, Nagelkerke NJ, Kretzschmar M, Koopmans MP. Evaluation of syndromic surveillance in the Netherlands: its added value and recommendations for implementation. Euro Surveill 2011 Mar 03;16(9) [FREE Full text] [Medline: 21392486]

5. World Health Organization. Global epidemiological surveillance standards for influenza. Geneva: World Health Organization; 2013.

6. European Center for Disease Prevention and Control (ECDC). Meeting report surveillance and studies in a pandemic. 2009 Jul Presented at: Fourth meeting of the SSiaP working group; 2009; Stockholm URL: https://www.ecdc.europa.eu/sites/portal/files/media/en/publications/Publications/0908_MER_Surveillance_and_Studies_in_a_Pandemic_Meeting_Report.pdf

7. Meerhoff TJ, Simaku A, Ulqinaku D, Torosyan L, Gribkova N, Shimanovich V, et al. Surveillance for severe acute respiratory infections (SARI) in hospitals in the WHO European region - an exploratory analysis of risk factors for a severe outcome in influenza-positive SARI cases. BMC Infect Dis 2015 Jan 08;15:1 [FREE Full text] [doi: 10.1186/s12879-014-0722-x] [Medline: 25567701]

8. Marbus SD, Oost JA, van der Hoek W, Meijer A, Polderman FN, de Jager CPC, et al. Ernstige acute luchtweginfecties: de ontbrekende bouwsteen in de surveillancepiramide. [Severe acute respiratory infections: the missing building block in the surveillance pyramid]. Ned Tijdschr Med Micrbiol 2016;24(1):52-56.

9. 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]

10. Cook S, Conrad C, Fowlkes AL, Mohebbi MH. Assessing Google flu trends performance in the United States during the 2009 influenza virus A (H1N1) pandemic. PLoS One 2011;6(8):e23610 [FREE Full text] [doi: 10.1371/journal.pone.0023610] [Medline: 21886802]

11. de Lange MM, Meijer A, Friesema IH, Donker GA, Koppeschaar CE, Hooiveld M, et al. Comparison of five influenza surveillance systems during the 2009 pandemic and their association with media attention. BMC Public Health 2013 Sep 24;13:881 [FREE Full text] [doi: 10.1186/1471-2458-13-881] [Medline: 24063523]

12. Velasco E, Agheneza T, Denecke K, Kirchner G, Eckmanns T. Social media and internet-based data in global systems for public health surveillance: a systematic review. Milbank Q 2014 Mar;92(1):7-33 [FREE Full text] [doi: 10.1111/1468-0009.12038] [Medline: 24597553]

13. Olayinka OO, Bayleyegn TM, Noe RS, Lewis LS, Arrisi V, Wolkin AF. Evaluation of real-time mortality surveillance based on media reports. Disaster Med Public Health Prep 2017 Aug;11(4):460-466 [FREE Full text] [doi: 10.1017/dmp.2016.170] [Medline: 28031073]

14. Verheij RA, Koppes LLJ. 2016. Nivel Zorgregistraties Eerste Lijn [Nivel Primary Care Database] URL: https://www.nivel.nl/nl/nivel-zorgregistraties-eerste-lijn/nivel-zorgregistraties-eerste-lijn

XSL•FO
RenderX

15.   Donker GA. NIVEL Primary Care Database. Utrecht: NIVEL; 2016. NIVEL Primary Care Database - Sentinel Practices URL: https://www.nivel.nl/sites/default/files/bestanden/Peilstations_2014_Engels.pdf

16.   Dutch Hospital Data. URL: https://www.dhd.nl/klanten/Paginas/home.aspx

17.   Groeneveld GH, Spaan WJ, van der Hoek W, van Dissel JT. [The severe flu season of 2017-2018: making a case for the vaccination of healthcare professionals]. Ned Tijdschr Geneeskd 2018 Sep 06;162. [Medline: 30306764]

18.   Netherlands Institute for Health Services Research (Nivel), National Institute for Public Health and the Environment (RIVM), Statistics Netherlands (CBS). URL: http://www.nivel.nl/griep; https://www.rivm.nl/luchtweginfecties/sari; http://www.rivm.nl/virologische-weekstaten; http://opendata.cbs.nl

19.   NHS England. 2018 Jan 02. Operational update from the NHS National Emergency Pressures Panel (NEPP) URL: https://www.england.nhs.uk/2018/01/operational-update-from-the-nhs-national-emergency-pressures-panel/ [accessed 2019-05-06] [WebCite Cache ID 78AWUe39x]

20.   Adeoti AO, Marbus S. The European Respiratory Society course on acute respiratory pandemics: how to plan for and manage them. ERJ Open Res 2018 Jan;4(1) [FREE Full text] [doi: 10.1183/23120541.00156-2017] [Medline: 29450202]

21.   van Someren Gréve F, Ong DS, Cremer OL, Bonten MJ, Bos LD, de Jong MD, MARS consortium. Clinical practice of respiratory virus diagnostics in critically ill patients with a suspected pneumonia: a prospective observational study. J Clin Virol 2016 Oct;83:37-42 [FREE Full text] [doi: 10.1016/j.jcv.2016.08.295] [Medline: 27567093]

22.   Dautzenberg P, Macken T, van Gageldonk-Lafeber AB, Lutgens S. [Wave of flu under control with hospital-wide approach: Jeroen Bosch Hospital manages capacity problems.]. Medisch Contact 2018 Oct [FREE Full text]

Abbreviations

ED: emergency department
GP: general practitioner
ILI: influenza-like illness
JBH: Jeroen Bosch hospital
POCT: point-of-care testing
SARI: severe acute respiratory infections
WMO: Medical Research Involving Human Subjects Act

XSL•FO

RenderX

Editorial

The Role of the Global Health Development/Eastern Mediterranean Public Health Network and the Eastern Mediterranean Field Epidemiology Training Programs in Preparedness for COVID-19

Mohannad Al Nsour[1], PhD; Haitham Bashier[1], PhD; Abulwahed Al Serouri[2], PhD; Elfatih Malik[3], MBBS; Yousef Khader[4], SCD; Khwaja Saeed[5], MSc; Aamer Ikram[6], PhD; Abdalla Mohammed Abdalla[7], MPH; Abdelmounim Belalia[8], PhD; Bouchra Assarag[8], PhD; Mirza Amir Baig[9], MPH; Sami Almudarra[10], PhD; Kamal Arqoub[11], MD; Shahd Osman[12], PhD; Ilham Abu-Khader[13], MPH; Dana Shalabi[13], MBA; Yasir Majeed[14], FETP

[1]Global Health Development/Eastern Mediterranean Public Health Network, Amman, Jordan

[2]Yemen Field Epidemiology Training Program, Sana'a, Yemen

[3]University of Khartoum, Khartoum, Sudan

[4]Jordan University of Science and Technology, Irbid, Jordan

[5]Afghanistan Field Epidemiology Training Program, Kabul, Afghanistan

[6]National Institute of Health, Islamabad, Pakistan

[7]Federal Ministry of Health, Khartoum, Sudan

[8]National School of Public Health, Rabat, Morocco

[9]Pakistan Field Epidemiology and Laboratory Training Program, Islamabad, Pakistan

[10]Saudi Field Epidemiology Training Program, Riyadh, Saudi Arabia

[11]Jordan Field Epidemiology Training Program, Amman, Jordan

[12]Sudan Field Epidemiology Training Program, Khartoum, Sudan

[13]Eastern Mediterranean Public Health Network, Amman, Jordan

[14]Iraq Ministry of Health, Baghdad, Iraq

Corresponding Author:
Yousef Khader, SCD
Jordan University of Science and Technology
Ar Ramtha 3030
Irbid, 22110
Jordan
Phone: 962 796802040
Email: yskhader@just.edu.jo

Abstract

The World Health Organization (WHO) declared the current COVID-19 a public health emergency of international concern on January 30, 2020. Countries in the Eastern Mediterranean Region (EMR) have a high vulnerability and variable capacity to respond to outbreaks. Many of these countries addressed the need for increasing capacity in the areas of surveillance and rapid response to public health threats. Moreover, countries addressed the need for communication strategies that direct the public to actions for self- and community protection. This viewpoint article aims to highlight the contribution of the Global Health Development (GHD)/Eastern Mediterranean Public Health Network (EMPHNET) and the EMR's Field Epidemiology Training Program (FETPs) to prepare for and respond to the current COVID-19 threat. GHD/EMPHNET has the scientific expertise to contribute to elevating the level of country alert and preparedness in the EMR and to provide technical support through health promotion, training and training materials, guidelines, coordination, and communication. The FETPs are currently actively participating in surveillance and screening at the ports of entry, development of communication materials and guidelines, and sharing information to health professionals and the public. However, some countries remain ill-equipped, have poor diagnostic capacity, and are in need of further capacity development in response to public health threats. It is essential that GHD/EMPHNET

XSL•FO
RenderX

and FETPs continue building the capacity to respond to COVID-19 and intensify support for preparedness and response to public health emergencies.

Introduction

Background

The World Health Organization (WHO) declared the current COVID-19 a public health emergency of international concern on January 30, 2020 [1]. As of March 19, 2020, a total of 220,351 confirmed cases and 8987 deaths were reported [2]. Coronaviruses are a large family of respiratory viruses that can cause diseases such as the Middle East Respiratory Syndrome (MERS) and the Severe Acute Respiratory Syndrome (SARS) [3,4]. The causative agent of the current outbreak, which has originated in Wuhan City in China, was identified as a novel coronavirus on January 7, 2020 [5], and the disease has been named COVID-19.

Many countries worldwide are making every effort to prevent the spread of COVID-19. Several reports of clusters of cases among families and infection of health care workers pointed to the human-to-human transmission of the virus. Infected patients presented mostly with fever, cough, and dyspnea within 7-14 days of exposure to the infection, and few showed upper gastrointestinal symptoms [6]. About 25% of the infected patients, especially the elderly and those with comorbidities, needed intensive care support for acute respiratory symptoms, multiorgan failure, or coinfections [7].

The case fatality rate in the first published report of 99 cases from Wuhan was 11% [8]. Another study reported a mortality rate of 4.3% [9]. It was also estimated that more than 2 new cases are generated by a single infected patient [10]. The probable transmission from individuals before the onset of symptoms or very early minimal symptoms makes COVID-19 much more difficult to control. It reduces the impact of temperature screening and highlights the critical need for accurate contact tracing starting from the day before the onset of symptoms as well as strict quarantine measures and monitoring before more chains of contagion are established.

Because of the exponential increase in the number of cases and deaths, many countries have adopted pandemic preparedness activities and proactive approaches, such as entry restrictions from affected countries; temperature screening at land, air, and sea checkpoints; mandatory leave of absence for travelers within 14 days of their return from affected countries; quarantine of contacts or those deemed to be in the incubation period; and public education and awareness.

A recent study showed that many countries in Africa including some countries that are part of the Eastern Mediterranean Region (EMR) have variable capacity to respond to outbreaks and high vulnerability [11]. Beside the protracted conflicts in many countries in the region, lack of infrastructure, limited resources, inadequate prevention control practices, poor preparedness capacity, and inadequate laboratory infrastructures and resources in many countries in the EMR are among the main barriers to adequately detect and respond to COVID-19. Many of the EMR countries addressed the need for increasing capacity in the areas of surveillance and rapid identification of suspected cases, patient transfer and isolation, rapid diagnosis, tracing and follow-up of potential contacts, strict health facility infection prevention and control, and other active public health control interventions. Moreover, countries addressed the need for communication strategies that provide general populations and vulnerable populations with actionable information for self-protection, including identification of symptoms, and clear guidance for seeking treatment.

Objectives

This viewpoint aimed to highlight the contribution of the Global Health Development (GHD)/Eastern Mediterranean Public Health Network (EMPHNET) and the EMR's Field Epidemiology Training Programs (FETPs) to the preparedness capacities in countries in the EMR to respond to the current COVID-19 threat.

The Role of the GHD/EMPHNET in Preparedness and Response to COVID-19

Overview

GHD/EMPHNET has been playing an active role in supporting the FETPs across the EMR in their efforts to combat COVID-19 threats. On a technical level, EMPHNET's Public Health Emergency Management Center (PHEMC) has been the hub for collecting technical information from the programs, disseminating relevant information, and coordinating response efforts. The center also directed attention to new publications and guidelines issued by the WHO and Centers for Disease Control and Prevention (CDC).

GHD/EMPHNET is escalating efforts and activities to support countries in the EMR in preparedness and response to COVID-19 outbreak, through its countries' FETP graduates and residents. GHD/EMPHNET has the scientific expertise to contribute to elevating the level of country alert and preparedness in the EMR and to provide technical support through promotional material (leaflets and brochures), workshops on contact tracing, dissemination of guidelines, regular sharing of technical updates, development of teaching case-studies to educate public health professionals on COVID-19, and rapid response team training.

A core team was formed to discuss the current situation and updates on COVID-19 emergency on a daily basis and subsequent steps in its response plan. The group comprises the

XSL•FO

RenderX

PHEMC and Center of Excellence for Applied Epidemiology alongside representatives from supporting domains like the Knowledge Exchange and Networking. In the regular weekly teleconference communications with FETP's directors from 10 countries in the EMR, the team discusses updates and any other response activities, discusses and exchanges information, explores and shares the latest technical tools and guidelines with the FETPs, coordinates response efforts at the national and regional levels, and explores additional support and collaboration with partners regarding COVID-19 activities. This team coordinates with the rest of the organization to ensure that efforts made are in their place and of relevance. All these activities are just the first steps taken by the GHD/EMPHNET, FETPs, and other stakeholders to alleviate the effects of coronavirus in the region.

Considering that sharing of relevant knowledge is key in such instances, GHD/EMPHNET has activated its networking platform EpiShares [12] to its full capacity for this cause. Not only has it created a page titled "COVID-19 Updates" to post hourly updates on the virus and its spread, but it has also created a private group titled "FETP Professionals," which serves as a space for FETP directors, advisors, and coordinators to discuss key issues of concern in this regard. The group also allows its members to upload documents, and it is a space for sharing meeting minutes, meeting agendas, and activities planned in response to the outbreak. Although the group is exclusive to specific members, the page is open for public viewing.

In the area of knowledge sharing, the GHD/EMPHNET also produces daily news round-up that it disseminates widely. The purpose of this update is to provide authentic news and ensure that it is filtered from the rumors that are provided by crowdsourced news platforms. Believing in the significance of FETPs and their work in such instances, GHD/EMPHNET is also publishing weekly bulletins to highlight their achievements.

The Efforts of FETPs to Respond to COVID-19

The purpose of the FETPs is to increase the epidemiologic capacity of a country's public health workforce in order to detect and respond to health threats and develop internal expertise in area of field epidemiology [13]. As service-based training programs implement competency-based training under the supervision of qualified mentors/supervisors, these programs focus on the practice of epidemiology in real time and real place. These programs are focused on building workforce capacity to contribute to strengthening their country's health system to detect, notify, report, and respond to events that threaten the national and international health. They focus on public health surveillance, outbreak investigations, epidemiological methods, laboratory and biosafety, risk communications, health-related surveys, and evaluation of the impact of prevention and control programs. The FETPs' curricula aim to improve public health systems and develop professional skills to ensure the country meets the surveillance and response requirements. The programs are established within the Ministries of Health and access technical assistance from the CDC.

They play an instrumental role in responding to the current emergency. Being embedded within the ministries of health, national public health institutes, and other public health agencies, the FETPS in Afghanistan, Bangladesh, Egypt, Iraq, Jordan, Morocco, Pakistan, Saudi Arabia, Sudan, Tunisia, and Yemen have been deeply involved in actions responding to COVID-19, including case investigations, points of entry/arrivals screening, isolation protocols, transferring cases, risk communication, and training on infection control.

Management Functions

For years, FETP graduates have been leading key positions in the public health system in the Ministry of Health at central, governorate, and district levels. During the current event, FETPs in many countries are members of technical committees in Ministries of Health, coordination platforms with various stakeholders, and advisory/higher committees. This enabled the FETPs to directly contribute to the national efforts in managing the COVID-19 threat.

FETPs are directly involved in developing preparedness plans using different scenarios for preparedness and response. In addition, FETP residents and graduates in the region have assisted in developing/adapting local guidelines, protocols, and case definitions for health professionals to implement with various interventions against COVID-19. They have directly assisted in assessing the needs in health facilities and for isolation rooms as well as the preparedness activities, and evaluating the surveillance system to identify the gaps and needs.

Surveillance

All FETPs in the region play crucial roles in supporting the surveillance functions in their countries at this time of COVID-19 pandemic. Their support is documented at the central, provincial, and even local levels. They are actively engaged in setting up and running the event and case-based surveillance. Moreover, they are engaged in searching for rumors that appear on social media and communicate them to the concerned bodies in the Ministry of Health.

FETP fellows are involved in close monitoring of the global trends of COVID-19 and mortality through relevant websites, with daily monitoring of results of surveillance systems and entry point reports for identifying and following up on suspected cases.

FETPs advisors, graduates, and residents are involved in the management of surveillance data, data analysis, reporting of cases, and development and distribution of a standard case definition for the COVID-19.

The FETP fellows in many countries have been working with hospitals to develop isolation and infection control protocols. They assisted in collecting samples and sent them for laboratory testing to confirm suspected COVID-19 cases.

Screening and Isolation Centers

FETPs are participating in screening passengers at different points of entries. Their roles range from running the thermal scanners installed at entry points, interviewing arrivals, filling-in surveillance forms, and contacting the arrivals in the follow-up period. FETPs have a direct role in developing and conducting training programs for all those who work at the points of entries,

XSL·FO

RenderX

including health workers and workers from other sectors. In addition, FETP fellows participate in training of health workers and organizing and managing the isolation of suspected cases and quarantines for confirmed cases.

Health Promotion and Education

FETPs have significantly contributed to the design and development of health education messages and promotional materials. FETPs are supporting the direct communication and follow-up with arrivals from abroad and providing them with the needed health messages. In some countries, FETP residents and graduates are responding to public queries through the specified hotlines. FETP residents are also playing a leading role in developing "Question & Answers" documents with standard appropriate information to be used by hotline personnel in response to the expected public's questions as well as the development of communication materials including brochures and posters.

In some countries, FETPs conducted a series of specialized orientation sessions for health professionals to standardize the protocols, agree on the case definition, and unify the message to the public.

Research

All residents of the advanced and intermediate levels were engaged in searching for published scientific literature, standard operating procedures, and guidelines, and supported development of the national guidelines for the COVID-19 epidemic. As one of the core competencies, FETPs have started working on different operational research and documents. These research topics are to study the system readiness, knowledge, attitudes, and practices of the health workforce with regard to COVID-19, epidemiology of the disease at the national level, best practices at the points of entries and isolation centers, and infection-control measures.

Training

FETPs in the entire region are directly and significantly involved in developing training materials and conducting training events for various health professionals. These trainings cover rapid response teams, points of entries, contact tracing, lab and sample management, infection control, cases management, and other processes. The modalities range from in-site training to simulation exercises to practice the countries' readiness to face the threat of COVID-19.

Conclusions

The FETPs in the EMR have implemented and are currently working on many activities to strengthen countries' preparedness against COVID-19. The FETPs participated actively in airport surveillance; implemented temperature screening at ports of entry; developed communication materials and guidelines; and shared information to health professionals and the public, often with a 24-hour dedicated hotlines. However, some countries remain ill-equipped, have poor diagnostic capacity, and are in need of further capacity development in response to public health threats. It is essential that GHD/EMPHNET and FETPS continue building the capacity to respond to COVID-19 and intensify support for preparedness and response to public health emergencies.

Conflicts of Interest

None declared.

References

1. World Health Organization. 2020 Jan 30. Statement on the second meeting of the International Health Regulations (2005) Emergency Committee regarding the outbreak of novel coronavirus (2019-nCoV) URL: https://tinyurl.com/rjdtx2k [accessed 2020-02-22]
2. Worldometer. COVID-19 coronavirus pandemic URL: https://www.worldometers.info/coronavirus/ [accessed 2020-03-19]
3. de Wit E, van Doremalen N, Falzarano D, Munster VJ. SARS and MERS: recent insights into emerging coronaviruses. Nat Rev Microbiol 2016 Aug;14(8):523-534. [doi: 10.1038/nrmicro.2016.81] [Medline: 27344959]
4. Yin Y, Wunderink RG. MERS, SARS and other coronaviruses as causes of pneumonia. Respirology 2018 Feb;23(2):130-137 [FREE Full text] [doi: 10.1111/resp.13196] [Medline: 29052924]
5. Lipsitch M, Swerdlow DL, Finelli L. Defining the Epidemiology of Covid-19 — Studies Needed. N Engl J Med 2020 Mar 26;382(13):1194-1196. [doi: 10.1056/nejmp2002125]
6. Zhang J, Dong X, Cao Y, Yuan Y, Yang Y, Yan Y, et al. Clinical characteristics of 140 patients infected with SARS-CoV-2 in Wuhan, China. Allergy 2020 Feb 19. [doi: 10.1111/all.14238] [Medline: 32077115]
7. Special Expert Group for Control of the Epidemic of Novel Coronavirus Pneumonia of the Chinese Preventive Medicine Association. An update on the epidemiological characteristics of novel coronavirus pneumonia（COVID-19). Article in Chinese. Zhonghua Liu Xing Bing Xue Za Zhi 2020 Feb 14;41(2):139-144. [doi: 10.3760/cma.j.issn.0254-6450.2020.02.002] [Medline: 32057211]
8. Chen N, Zhou M, Dong X, Qu J, Gong F, Han Y, et al. Epidemiological and clinical characteristics of 99 cases of 2019 novel coronavirus pneumonia in Wuhan, China: a descriptive study. The Lancet 2020 Feb;395(10223):507-513. [doi: 10.1016/s0140-6736(20)30211-7]
9. Wang D, Hu B, Hu C, Zhu F, Liu X, Zhang J, et al. Clinical Characteristics of 138 Hospitalized Patients With 2019 Novel Coronavirus-Infected Pneumonia in Wuhan, China. JAMA 2020 Feb 07;323(11):1061. [doi: 10.1001/jama.2020.1585] [Medline: 32031570]

XSL•FO

RenderX

10.   Wu J, Leung K, Leung G. Nowcasting and forecasting the potential domestic and international spread of the 2019-nCoV outbreak originating in Wuhan, China: a modelling study. The Lancet 2020 Feb;395(10225):689-697 [FREE Full text] [doi: 10.1016/S0140-6736(20)30260-9]

11.   Gilbert M, Pullano G, Pinotti F, Valdano E, Poletto C, Boëlle P, et al. Preparedness and vulnerability of African countries against importations of COVID-19: a modelling study. The Lancet 2020 Mar;395(10227):871-877 [FREE Full text] [doi: 10.1016/S0140-6736(20)30411-6]

12.   Epishares. URL: https://epishares.net/ [accessed 2020-03-26]

13.   White ME, McDonnell SM, Werker DH, Cardenas VM, Thacker SB. Partnerships in international applied epidemiology training and service, 1975-2001. Am J Epidemiol 2001 Dec 01;154(11):993-999 [FREE Full text] [doi: 10.1093/aje/154.11.993] [Medline: 11724714]

Abbreviations

CDC: Centers for Disease Control and Prevention
EMPHNET: Eastern Mediterranean Public Health Network
EMR: Eastern Mediterranean Region
FETP: Field Epidemiology Training Program
GHD: Global Health Development
MERS: Middle East Respiratory Syndrome
PHEMC: Public Health Emergency Management Center
SARS: Severe Acute Respiratory Syndrome
WHO: World Health Organization

XSL•FO
RenderX

Original Paper

Follow-Up Investigation on the Promotional Practices of Electric Scooter Companies: Content Analysis of Posts on Instagram and Twitter

Allison Dormanesh[1], MS; Anuja Majmundar[1], MBA; Jon-Patrick Allem[1], MA, PhD

Keck School of Medicine of USC, Los Angeles, CA, United States

Corresponding Author:
Jon-Patrick Allem, MA, PhD
Keck School of Medicine of USC
2001 N Soto Street, 3rd Floor
Los Angeles, CA, STE K318
United States
Phone: 1 13234427921
Email: allem@usc.edu

Related Article:

Comment in: https://publichealth.jmir.org/2020/4/e18945/

Abstract

Background: Electric scooters (e-scooters) have become a popular mode of transportation in both the United States and Europe. In the wake of this popularity, e-scooters have changed the commuting experience in many metropolitan areas. Although e-scooters offer an efficient and economical way to travel short distances in traffic-congested areas, recent studies have raised concerns over their safety. Bird and Tier Mobility are 2 popular e-scooter companies in the United States and Europe, respectively. Both companies maintain active social media accounts with hundreds of posts and tens of thousands of followers. Recent studies have shown that consumer behavior may be influenced by the content posted to popular social media platforms, such as Instagram and Twitter.

Objective: This study aimed to examine the official Instagram and Twitter accounts of Bird and Tier Mobility to determine whether these companies promote and demonstrate the use of safety gear in their posts to their consumers.

Methods: Posts to Bird's (n=287) and Tier Mobility's (n=190) official Instagram accounts, as well as Bird's (n=313) and Tier Mobility's (n=67) official Twitter accounts, were collected from November 9, 2018, to October 7, 2019. Rules for coding content of posts were informed by previous research.

Results: Among posts to Bird's Instagram account, 69.3% (199/287) had a person visible with an e-scooter, 9.1% (26/287) contained persons wearing protective gear, and there were no mentions of protective gear in captions corresponding to the post. Among posts to Tier Mobility's Instagram account, 84.7% (161/190) contained a person visible with an e-scooter, 36.3% (69/190) contained persons wearing protective gear, and 4.2% (8/190) of captions corresponding to posts mentioned protective gear. Among posts to Bird's Twitter account, 71.9% (225/313) had an image, of which 44.0% (99/225) contained a person visible with an e-scooter and 15.1% (34/225) contained persons wearing protective gear. Among posts to Tier Mobility's Twitter account, 78% (52/67) had an image, of which 52% (27/52) contained a person with an e-scooter and 21% (11/52) contained persons wearing protective gear.

Conclusions: Findings show that modeling and promoting safety is rare on Bird's and Tier Mobility's official social media accounts, which may contribute to the normalization of unsafe riding practices. Social media platforms may offer a potential avenue for public health officials to intervene with rider safety campaigns for public education.

XSL·FO

RenderX

Introduction

Background

Over the past 3 years, electric scooters (e-scooters) have become a popular mode of transportation in both the United States and Europe [1]. In the wake of this popularity, the commuting experience in many metropolitan areas has changed. E-scooter companies offer rentable, dockless, generally affordable, single-rider e-scooters that can reach speeds of 15 miles per hour and traverse 30 miles on 1 charge. Consumers can access these e-scooters through Web or downloadable apps on their smartphones. Once logged in, each user can be directed to the closest e-scooter available via global positioning system. After finishing their ride, users can leave the e-scooter anywhere within the legal parking zones, indicated on their mobile app.

Although e-scooters offer an efficient and economical way to travel short distances in traffic-congested areas [1,2], recent studies have raised concerns over their safety. For instance, the Austin Public Health Department and Center for Disease Control and Prevention recently published a study on injuries and risk factors associated with rentable, dockless e-scooter use [3]. They found that often the injuries sustained were to the rider's head (48%), and only 1 in 190 riders were wearing a helmet [3]. A second study on e-scooter injuries from Southern California recorded 249 injuries associated with e-scooter use over the course of 1 year [4]. It found that 80% of riders were injured from a fall, and 10 out of 249 riders were wearing a helmet (only 4% of all riders) [4]. European countries like Germany have also experienced a rise in the use of e-scooters, and subsequent reports of injuries. Within a 3-month period, police statistics showed that 74 e-scooter-related accidents occurred in Berlin, and over 200 e-scooter riders were cited for traffic violations [5]. Taken all together, the growing number of injuries from the use of e-scooters highlights the importance of promoting safe riding practices among e-scooter customers.

Previous research has suggested that the promotional activities from companies on popular social media platforms may influence consumer behavior [5], and this influence may extend to the perceived norms relating to e-scooter safety, for example, wearing safety gear [6]. In a previous study analyzing data from 2017 to 2018, Allem and Majmundar demonstrated that posts to Bird's (one of the leading US e-scooter companies) official Instagram account rarely (6% of the time) showed users wearing protective gear when photographed with an e-scooter [6]. Although this study was the first to characterize any social media activity from an e-scooter company, additional research is needed that considers multiple social media platforms from multiple e-scooter companies to better understand promotional practices pertaining to e-scooter safety.

The e-scooter industry is characterized by high growth [4] and intense competition inside and outside of the United States [1]. Bird, for example, is valued at over US $2 billion [2,7], and as of October 2019, has been funded US $275 million to expand further [8]. Similarly, European countries are experiencing demand for e-scooter options to lower traffic congestion, increase parking availability, and improve air quality [1]. For instance, as of May 2019, Germany legalized e-scooters [9],

and as a result, Tier Mobility (a Berlin-based start-up company) has made efforts to change Germany's public transportation infrastructure, including partnerships with public transport, municipal service, and private mobility providers [10]. Their main goal is to use these partnerships to change the status quo of urban mobility [10]. Tier Mobility, which started about a year after Bird in 2018, has quickly received 10 million rides in the 11 months since they have launched, a majority of which occurred between June and October of 2019 [11]. This user activity is comparable with Bird's user activity in the United States (Bird achieved 10 million rides in its first year) [12]. Although other companies, for example Uber, provide e-scooters as modes of transportation in the United States and abroad, Uber offers and promotes bicycles and other ridesharing services. Bicycles are distinct from e-scooters—subjected to different laws and risks from riding on the road. As a result, this study examined the safety promotions of companies (Bird and Tier Mobility) that prioritize e-scooters over other ridesharing options.

The promotion of safe riding practices on behalf of e-scooter companies is ever pressing, especially on popular social media platforms. In 2018, Bird went on record stating that it utilizes, "targeted advertising with safety messages on social media platforms" [13]. Tier Mobility has also been on record encouraging its consumers to wear helmets, as well as engage with their introductory tutorial to learn how to avoid accidents [14].

Objective

This study revisits the promotional practices of Bird on Instagram to include their most recent posts, and goes beyond previous research by including the Instagram posts from a second comparable company, Tier Mobility. In addition, this study includes Twitter posts from Bird and Tier Mobility. Findings could inform health communication campaigns aimed at promoting safe e-scooter practices.

Methods

Posts, including images and captions, were collected from Bird's (n=287) and Tier Mobility's (n=190) official Instagram accounts and Bird's (n=313) and Tier Mobility's (n=67) official Twitter accounts between November 9, 2018, and October 7, 2019.

Instagram Analysis

Similar to previous research [6], each Instagram post was reviewed by 1 author and characterized as to whether (1) person(s) was or were visible in the post with an e-scooter, (2) person(s) in the post was or were wearing any protective gear (eg, if any of the following were present on the person(s): helmet, wrist guards, elbow pads, or knee pads, then protective gear was coded as present), (3) protective gear was visible anywhere in the post, (4) protective gear or safety was mentioned in the captions corresponding to the post, (5) the post was a *repost* or the photo credited to a customer of the company and adopted for their own use, and (6) number of likes. To establish interreliability, a second investigator coded a subsample of posts (n=50) from Bird's Instagram account. Agreement ranged from 92% to 100% for the coded categories.

The number of followers from each Instagram account were also recorded.

Twitter Analysis

Each Twitter post was reviewed by 1 author and characterized as to whether (1) it contained an image (eg, pictures and videos), (2) person(s) was or were visible in the post with an e-scooter, (3) person(s) in the post was or were wearing any protective gear (eg, if any of the following were present on the person(s): helmet, wrist guards, elbow pads, or knee pads, then protective gear was coded as present), (4) protective gear was visible anywhere in the post, (5) protective gear or safety was mentioned in the post, (6) the number of likes, and (7) the number of *retweets*. To establish interreliability, a second investigator coded a subsample of posts (n=50) from Bird's Twitter account. Agreement ranged from 90% to 100% for the coded categories. The number of followers from each Twitter account were also recorded.

All analyses relied on publicly available data, accessible through Instagram's or Twitter's website or mobile device app. This study adhered to the terms and conditions, terms of use, and privacy policy of Instagram and Twitter. Descriptive statistics were reported for each category.

Results

Analysis of Instagram Posts

The Instagram accounts of Bird and Tier Mobility had approximately 89,000 followers and 12,000 followers, respectively. Among posts to Bird's Instagram account, 69.3% (199/287) had a person visible with an e-scooter, 9.1% (26/287) contained persons wearing protective gear, 11.5% (33/287) contained protective gear somewhere in the post, and there were no mentions of protective gear in the captions (see Multimedia Appendix 1 for example posts). About 53.3% (153/287) of Bird's posts were reposts, and among reposts, 2.9% (4/153) had persons wearing protective gear. Likes per post ranged from 89 to 28,926 (mean 1155.69, median 598).

Among posts to Tier Mobility's Instagram account, 84.7% (161/190) contained a person visible with an e-scooter, 36.3% (69/190) contained persons wearing protective gear, 44.7% (85/190) had protective gear somewhere in the post, and 4.2% (8/190) of captions corresponding to the post mentioned safety. About 8.9% (17/190) of Tier's posts were reposts, and among reposts, 2% (1/17) had persons wearing protective gear. Likes per post ranged from 34 to 5190 (mean 367.88, median 139.50).

Analysis of Tweets

The Twitter accounts of Bird and Tier Mobility had about 17,000 followers and 2000 followers, respectively. Among Bird's Twitter posts, 71.9% (225/313) had an image, of which 44.0% (99/225) had a person visible with an e-scooter, 15.1% (34/225) contained persons wearing protective gear, and 21.3% (48/225) contained protective gear somewhere in the post. Among all posts, 5.8% (18/313) mentioned safety. Likes per post ranged from 0 to 398 (mean 25.58, median 16.00), whereas retweets per post ranged from 0 to 83 (mean 4.57, median 2.00). Among Tier Mobility's Twitter posts, 78% (52/67) had an image, of

which 52% (27/52) contained a person visible with an e-scooter, 21% (11/52) contained persons wearing protective gear, and 25% (13/52) had protective gear somewhere in the post. Among all posts, 5% (3/67) mentioned safety. Likes per post ranged from 1 to 54 (mean 12.04, median 8.00), whereas retweets ranged from 0 to 16 (mean 3.49, median 2.00).

Discussion

Overall Findings

Posts to the official social media accounts of Bird and Tier Mobility seldomly showed e-scooters being used with protective gear. In addition, findings showed that Bird and Tier Mobility utilize customers' photos of their e-scooter experiences in promotions through reposts on Instagram. These reposts rarely showed e-scooters being used with safety in mind. Posts from both companies on both platforms received likes from their followers demonstrating engagement with the promotional content.

Findings from this study are similar to an earlier report demonstrating that posts to Bird's Instagram account rarely showed riders wearing protective gear when photographed with e-scooters [6]. Findings from this study call into question Bird's claims regarding their use of advertising with safety messages on social media platforms [13]. Taken all together, rider safety does not seem to be modeled or promoted on the social media accounts of popular e-scooter companies.

Although e-scooter companies state that they always encourage riders to wear a helmet [15], such companies could take advantage of the popularity of their social media accounts, and the impact of social media, by highlighting the advantages of using protective gear while riding e-scooters, and through other forms of education (eg, short videos). Educating consumers about the functional benefits of each type of protective gear can help reduce the impact of injuries from accidents (eg, kneepads can help prevent serious bruises in case of a fall and helmets can help prevent severe head injuries).

Bird's primary avenue for providing users with safety suggestions is through their mobile phone app or website, which includes (1) suggestions of where to ride and park, (2) requiring users to be older than 18 years to ride, (3) allowing only 1 rider per vehicle, (4) providing traffic rules, and (5) suggesting helmet use [13]. Bird users can click on a safety tab, on the mobile app, and get directed to a page that allows them to order a helmet for US $9.99 (shipping cost). They also provide an optional *how to ride* safety tutorial. Similarly, Tier Mobility urges helmet use through their *how Tier works* tab on their website [16]. In contrast to Bird, Tier Mobility does not currently offer free helmets. Although both companies give indication of safety measures for their users, posts to social media platforms could further influence their users' attitudes and behaviors [17]. The majority of e-scooter injuries are among those who are 18 to 29 years of age, an age group that often engages with social media [3]. In this study, engagement was measured by recording the number of *likes* and *retweets* received by Bird's and Tier Mobility's followers. Retweets represent approval for the

content of the post [18] and can perpetuate such content throughout the Twittersphere [19].

Previous studies have highlighted the importance of safety gear as a preventive measure for rider injuries. Thompson et al analyzed 5 case-control studies and determined that helmets can reduce the risk of head, brain, and severe brain injury by 63% to 88% [20]. Although their study focused on bicyclists, protective gear could provide similar protection for other 2-wheel vehicles like e-scooters. Bird's and Tier Mobility's lack of promotion of safety gear on social media, in combination with a lack of warnings within post's corresponding caption, may influence how riders understand the safety of these emerging modes of transportation.

Limitations

Our findings are limited to posts on Instagram and Twitter and may not pertain to posts on other social media platforms like Snapchat. Our findings are also limited to 2 e-scooter companies (Bird and Tier Mobility) and may not pertain to other companies. Although companies like Lime, Lyft, and Uber offer numerous modes of transportation, including ridesharing cars, bicycles, and e-scooters, Bird and Tier Mobility focus on e-scooters. E-scooters have a specific set of risks from use, as well as specific laws to follow, and as a result, Bird and Tier Mobility were the focus of this study. The posts in this study were collected from an 11-month period and may not extend to other time periods. This study could not determine whether posts to Twitter or Instagram directly influenced consumer behavior and did not determine if protective gear would be effective in preventing injuries. However, previous research has shown that wearing helmets can mitigate the extent of injuries from motorized vehicles [20], and that communications on social media platforms may influence behavior [21].

Conclusions

Findings from this study show that modeling and promoting safety is rare on Bird's and Tier Mobility's official social media accounts. These promotional practices may contribute to the perceived norms relating to e-scooter safety. Social media may offer a potential avenue for public health officials to intervene with promotional messages of their own to increase safe riding practices.

Conflicts of Interest

None declared.

Multimedia Appendix 1
Example posts from Instagram and Twitter.
[DOCX File , 684 KB - publichealth_v6i1e16833_app1.docx]

References

1. Hardt C, Bogenberger K. Usage of e-Scooters in urban environments. Transp Res Procedia 2019;37:155-162. [doi: 10.1016/j.trpro.2018.12.178]

2. Choron RL, Sakran JV. The integration of electric scooters: useful technology or public health problem? Am J Public Health 2019 Apr;109(4):555-556. [doi: 10.2105/AJPH.2019.304955] [Medline: 30865508]

3. Austin Public Health, Center for Disease Prevention and Control. Government of Austin Texas. 2019. Dockless Electric Scooter-Related Injuries Study URL: http://www.austintexas.gov/sites/default/files/files/Health/Web_Dockless_Electric_Scooter-Related_Injury_Study_final_version_EDSU_5.14.19.pdf [accessed 2020-01-01]

4. Trivedi TK, Liu C, Antonio AL, Wheaton N, Kreger V, Yap A, et al. Injuries associated with standing electric scooter use. JAMA Netw Open 2019 Jan 4;2(1):e187381 [FREE Full text] [doi: 10.1001/jamanetworkopen.2018.7381] [Medline: 30681711]

5. Giordano C. Published September 27. 2019 Sep 17. Electric Scooters Cause 74 Accidents and Hundreds of Traffic Offences in Three Months Since Legalisation in Berlin URL: https://www.independent.co.uk/news/world/europe/electric-scooter-accidents-berlin-germany-legalisation-police-a9108916.html [accessed 2020-01-01]

6. Allem JP, Majmundar A. Are electric scooters promoted on social media with safety in mind? A case study on Bird's Instagram. Prev Med Rep 2019 Mar;13:62-63 [FREE Full text] [doi: 10.1016/j.pmedr.2018.11.013] [Medline: 30515366]

7. Griffith E. The New York Times. 2019 Jun 22. Bird Is Said to Raise New Funding at $2.5 Billion Valuation URL: https://www.nytimes.com/2019/07/22/technology/bird-scooters-valuation.html [accessed 2020-01-01]

8. Bird - Enjoy the Ride. 2019 Oct 3. Bird Announces $275 Million Series D Funding URL: https://www.bird.co/press/bird-announces-275-million-series-d-funding/ [accessed 2020-01-01]

9. Bloomberg. Scooter Startup Tier Eyes European Market as it Raises $60 Million URL: https://www.bloomberg.com/news/videos/2019-10-07/scooter-startup-tier-eyes-european-market-as-it-raises-60-million-video [accessed 2019-10-16]

10. TIER – change mobility for good. How We Utilise Partnerships to Drive Sustainable Access to Mobility URL: https://www.tier.app/2019/09/26/how-we-use-technology-to-drive-sustainable-and-inclusive-mobility-2/ [accessed 2019-10-28]

11. Lunden I. TechCrunch. 2019 Oct 7. Berlin's Tier Mobility Scoops Up $60M as Its Scooter-based Transportation Service Passes 10M Rides URL: https://techcrunch.com/2019/10/07/berlins-tier-mobility-scoops-up-60m-for-its-scooter-based-transportation-service/ [accessed 2019-10-16]

12. Dickey MR. TechCrunch. 2018 Sep 20. Bird Hits 10 Million Scooter Rides URL: http://social.techcrunch.com/2018/09/20/bird-hits-10-million-scooter-rides/ [accessed 2019-10-23]

13. Holley P. The Washington Post. 2018 Dec 21. Bird Says Safety is Its 'Top Priority.' So Why is the E-scooter Company's Instagram Page Nearly Devoid of Helmets? URL: https://www.washingtonpost.com/technology/2018/12/21/bird-says-safety-is-their-top-priority-so-why-is-e-scooter-companys-instagram-page-nearly-devoid-helmets/ [accessed 2019-10-23]

14. Connolly K. The Guardian. 2019 May 16. Eco Wonder or Safety Nightmare? Germany to Vote on E-scooters URL: https://www.theguardian.com/cities/2019/may/16/germany-to-vote-on-law-allowing-e-scooters-on-roads [accessed 2019-10-25]

15. Bird - Enjoy the Ride. 2019 Oct 16. Safety URL: https://www.bird.co/safety/ [accessed 2020-01-01]

16. TIER – change mobility for good. 2019 Oct 23. How TIER works URL: https://www.tier.app/how-tier-works/ [accessed 2020-01-01]

17. Scholz C, Jovanova M, Baek EC, Falk EB. Media content sharing as a value-based decision. Curr Opin Psychol 2019 Aug 12;31:83-88. [doi: 10.1016/j.copsyc.2019.08.004] [Medline: 31542712]

18. Majmundar A, Allem JP, Cruz TB, Unger JB. The Why We Retweet scale. PLoS One 2018;13(10):e0206076 [FREE Full text] [doi: 10.1371/journal.pone.0206076] [Medline: 30335827]

19. Chu K, Unger JB, Allem JP, Pattarroyo M, Soto D, Cruz TB, et al. Diffusion of messages from an electronic cigarette brand to potential users through Twitter. PLoS One 2015;10(12):e0145387 [FREE Full text] [doi: 10.1371/journal.pone.0145387] [Medline: 26684746]

20. Thompson D, Rivara F, Thompson R. Helmets for preventing head and facial injuries in bicyclists. Cochrane Database Syst Rev 2000(2):CD001855. [doi: 10.1002/14651858.CD001855] [Medline: 10796827]

21. Kumar A, Bezawada R, Rishika R, Janakiraman R, Kannan P. From social to sale: the effects of firm-generated content in social media on customer behavior. J Mark 2016;80(1):7-25. [doi: 10.1509/jm.14.0249]

Abbreviations

e-scooter: electric scooter

<u>Original Paper</u>

Distracted Driving on YouTube: Categorical and Quantitative Analyses of Messages Portrayed

Marko Gjorgjievski[1], MD; Sheila Sprague[1], PhD; Harman Chaudhry[2], MSc, MD; Lydia Ginsberg[3], BSc; Alick Wang[4], BSc, MD; Mohit Bhandari[3], MD, PhD; Bill Ristevski[3], MSc, MD

[1]Centre for Evidence-Based Orthopaedics, McMaster University, Hamilton, ON, Canada

[2]Division of Orthopaedic Surgery, University of Toronto, Toronto, ON, Canada

[3]Division of Orthopaedic Surgery, McMaster University, Hamilton, ON, Canada

[4]Department of Neurosurgery, University of Ottawa, Ottawa, ON, Canada

Corresponding Author:
Marko Gjorgjievski, MD
Centre for Evidence-Based Orthopaedics
McMaster University
293 Wellington Street North
Hamilton, ON
Canada
Phone: 1 6474609692
Email: markogjorgjievski@gmail.com

Abstract

Background: Distracted driving is a global epidemic, injuring and killing thousands of people every year. To better understand why people still engage in this dangerous behavior, we need to assess how the public gets informed about this issue. Knowing that many people use the internet as their primary source of initial research on topics of interest, we conducted an assessment of popular distracted driving videos found on YouTube.

Objective: This study aimed to gauge the popularity of distracted driving videos and to assess the messages portrayed by classifying the content, context, and quality of the information available on YouTube.

Methods: We conducted a search on YouTube using 5 different phrases related to distracted driving. Videos with more than 3000 views that mentioned or portrayed any aspect of distracted driving were identified, collected, and analyzed. We measured popularity by the number of videos uploaded annually and the number of views and reactions. Two independent researchers reviewed all the videos for categorical variables. Content variables included distractions; consequences; orthopedic injuries; and whether the videos were real accounts, reenactments, fictitious, funny, serious, and graphic. Context variables assessed the setting of the events in the video, and quality of information was measured by the presence of peer-reviewed studies and inclusion and referencing of statistics. Discrepancies in data collection were resolved by consensus via the coding authors. A comparative subanalysis of the 10 most viewed videos and the overall results was also done.

Results: The study included a total of 788 videos for review, uploaded to YouTube from 2006 to 2018. An average of 61 videos with greater than 3000 views were uploaded each year (SD 34.6, range 3-113). All videos accumulated 223 million views, 104 million (46.50%) of them being among the 10 most viewed videos. The top 3 distractions depicted included texting, talking on the phone, and eating and/or drinking. Motor vehicle crashes (MVCs) and death were depicted in 742 (94.2%) videos, whereas 166 (21.1%) of the videos depicted injuries. Orthopedic injuries were described in 90 (11.4%) videos. Furthermore, 220 (27.9%) of the videos contained statistics, but only 27 (3.7%) videos referenced a peer-reviewed study.

Conclusions: This study demonstrates that there is a high interest in viewing distracted driving videos, and the popularity of these videos appears to be relatively stable over time on a forum that fluxes based on the current opinions of its users. The videos mostly focused on phone-related distractions, overlooking many other equally or more common forms of distracted driving. Death, which in reality is a far less common distracted driving consequence than injuries, was portrayed 1.7 times as much. Surprisingly, orthopedic injuries, which lead to a massive source of long-term disability and often result from MVCs, are vastly underrepresented.

Introduction

Background

Distracted driving is a global epidemic and has become the number one killer of teenagers [1]. In North America alone, distracted driving plays a role in approximately 4 million road traffic accidents a year [2]. According to Mark Edwards, Director of Traffic Safety at the American Automobile Association, somewhere between 25% and 50% of all motor vehicle crashes (MVCs) in the United States are directly related to driver distraction as the root cause of automobile accidents [3]. In addition, injuries resulting from MVCs are in the top 10 causes of disability and are expected to climb to the top 3 by 2030 [4]. The World Health Organization estimates that in 2016, there were 1.35 million road traffic fatalities [5], and it recommended that future research focus on traffic injuries.

Data from the National Highway Traffic Safety Administration for 2015 suggested that for every traffic fatality that occurred because of distracted driving, approximately 113 people were injured (3477 fatalities to 391,000 accident-related injuries) [6]. Many of these acute injuries secondary to this type of high-energy trauma lead to permanent impairments and/or disabilities. In addition, MVCs in the United States are estimated to total US $40 billion in direct costs and US $123 billion in societal costs [6,7].

Distracted driving is anything that diverts a driver's attention from safely operating a vehicle and subsequently reduces the driver's awareness and driving ability, leading to a potential risk of compensating actions or crashing [8]. The diversion of attention should not be because of alcohol, drugs, fatigue, or a health condition [9,10]. Texting or talking on a mobile phone, daydreaming, eating and/or drinking, and using a navigation system while driving are just a few examples of distracted driving. Wickens' Multiple Resource Theory (MRT) [11] explains driving as a visual-spatial-motor task, using cognitive, visual, and motor resources concurrently [12,13]. According to MRT, tasks that compete for the same resource can cause dual-task interference in any or all 3 resources, leading to decreased driving ability.

Cognitive distractions happen when a driver's mind concentrates on mental tasks other than driving, for instance, daydreaming or talking on a hands-free mobile phone.

Visual distractions occur when a driver shifts their gaze away from the safe operation of the vehicle, such as looking at a map.

Manual distraction occurs when the driver takes one or both hands off the steering wheel for any reason. Some common examples include eating and drinking or adjusting the radio in the car.

An activity such as texting while driving is especially dangerous as it combines all 3 elements of distraction—cognitive, visual, and manual [14]. In fact, text messaging while driving may increase the relative risk of being involved in a collision 23 times [15-18]. The National Safety Council estimates that in 2013, 26% of crashes involved mobile phone use [15]. Although mobile phone use while driving may be the catalyst for renewed concern of distracted driving, some studies have estimated the use of mobile phone devices as the second most common distraction in fatal crashes with 14%, compared with daydreaming with 61% [6,19].

Objectives

It is clear from the data that distracted driving is very dangerous and also very prevalent. Knowing that most people use the internet as their primary source of information on such topics, we directed our research focus on YouTube, the most popular video sharing platform on the internet [20]. A previous study has examined whether YouTube can be used as an educational platform for curbing adolescent cell phone use while driving [21]. However, no studies have assessed the general messages being portrayed in distracted driving videos and the most common elements in them, such as types of distractors portrayed, consequences of distracted driving, and statistics about distracted driving. Understanding this core information that is presented to viewers is novel and will be critical in mitigating the harms of distracted driving.

The specific goals of the study were to gauge the popularity and to categorize and assess the messages being delivered by distracted driving videos, by methodically classifying the content, context, and quality of the information available on YouTube.

Methods

Study Design

The *Distracted Driving on YouTube* study is a cross-sectional study examining popular distracted driving videos found on the video sharing platform YouTube. The following 5 different combinations of keywords and phrases were employed to search YouTube for distracted driving videos: "distracted driving", "car distractions", "cell phone and driving", "drivers not paying attention", and "texting and driving". In the development of our search phrases, we relied on YouTube's smart search, which autopopulates potential searches with the most common terms containing those words. Owing to public opinion, government campaigns, and the focus of distracted driving literature on mobile phone distractions, we also included phrases that covered these types of distractions. We conducted the search on a single day, June 13, 2018, and sorted the search results by view count.

Screening and Collection of Videos

YouTube videos uploaded after 2006, with more than 3000 views, that discussed or demonstrated any aspect of distracted driving were collected and analyzed. We excluded from the study any videos that did not demonstrate or mention distracted driving, videos about reckless, careless, or impaired driving, and videos not in English. User channels that appeared in the search results and copies of collected videos were not included

in our review. Identical videos appearing in the results of multiple search phrases were analyzed and coded only once.

Data Acquisition and Analysis

The videos were examined by 2 independent reviewers, and any discrepancies in data collection were resolved by consensus via the coding authors. The overall interrater reliability measurement was calculated as the mean from all the kappa results for the examined variables, which were calculated using the Cohen kappa formula for 2 raters. The study recorded the popularity of the videos via quantitative variables, such as the date and year the video got uploaded and the number of views, likes, and dislikes it received. Videos from a different uploader, but with identical content, were labeled as duplicates and only contributed data for the quantitative variables. They were not included in the final analysis of the categorical variables.

We recorded categorical variables under the categories of content, context, and quality of information. Content variables included type (eg, phone, texting, talking on a phone, talking with a passenger, eating/drinking, and daydreaming) and form (eg, cognitive, visual, manual, or combinations) of the distraction; consequences (eg, crash, death, injury, and legal);

orthopedic injuries specifically; and whether the videos were real accounts, reenactments, fictitious, funny, serious, and/or graphic. We considered a video to be graphic when there was an explicit or visual depiction of a serious injury or death. Context variables included whether the video was a public safety announcement (PSA), television show or newscast, advertisement, or an amateur video. Finally, the quality of information variables included whether the video contained statistics and/or studies, and whether the studies were peer reviewed and the statistics referenced. In addition, we conducted a subanalysis of the 10 most viewed videos and performed a comparison with the overall results.

Results

The search methods generated 5,520,000 results for all 5 search phrases, out of which 987 videos met our eligibility criteria. Once we removed the identical videos appearing in multiple searches, a total of 788 videos uploaded to YouTube from 2006 to 2018 were included for review. An average of 61 videos with greater than 3000 views were uploaded each year (SD 34.6, range 3-113). Table 1 shows the number of videos uploaded per year matching the search and inclusion criteria.

Table 1. Number of YouTube videos uploaded per year matching search and inclusion criteria.

Years	Number of videos with >3000 views per year
2006	3
2007	17
2008	20
2009	51
2010	61
2011	93
2012	74
2013	87
2014	85
2015	93
2016	113
2017	63
2018	28

We performed an analysis of the videos using various categorical variables listed in Table 2. Our interrater reliability measurement showed substantial agreement between the reviewers (κappa=0.73). The review demonstrated that PSAs accounted for 37.3% (294/788) of the videos, and more than half of the videos (440/788, 55.8%) were a depiction of a real account. Furthermore, an evaluation of the video's content revealed that the vast majority of the videos were not comedic/funny in nature and were coded as serious (643/788, 81.6%).

Cognitive distractions, depicted in 91.0% (717/788) of the videos, were the most common form of distraction recorded, whereas manual and visual distractions were depicted in 82.6% (651/788) and 81.6% (643/788) of the videos, respectively. Further review showed that 27.9% (220/788) of the videos contained statistics, and 10.0% (79/788) referenced the source of the statistics, while 3.4% (27/788) videos mentioned a peer-reviewed study. In addition, 21.1% (166/788) of the videos included some form of an injury, whereas orthopedic injuries specifically were depicted in 11.4% (90/788) of the videos.

Table 2. Videos depicting examined categorical variables.

Categorical variables	Videos depicting variables, n (%)
Public safety announcement	294 (37.3)
Television show or newscast	135 (17.1)
Amateur	272 (34.5)
Advertisement	68 (8.6)
Real account	440 (55.8)
Reenactment	12 (1.5)
Fictitious	219 (27.8)
Cognitive distraction	717 (91.0)
Visual distraction	643 (81.6)
Manual distraction	651 (82.6)
Funny	89 (11.3)
Serious	643 (81.6)
Graphic	65 (8.2)
Contains statistics	220 (27.9)
Statistics referenced	79 (10.0)
Study mentioned/discussed[a]	60 (7.6)
Peer-reviewed study[b]	27 (3.4)
Orthopedic injury	90 (11.4)
Injury	166 (21.1)

[a]A study about distracted driving was mentioned in the video.

[b]The mentioned study in the video was published in a peer-reviewed journal.

All included videos were reviewed for specific distractions. Table 3 demonstrates the number and percentage of videos that portrayed a particular type of distraction. Overall, the 2 most depicted distractions were mobile phone related, and included texting and talking. Texting while driving was the number one distracting activity present in 64.6% (509/788) of all videos. Phone conversations, both handheld and hands free, were calculated together and were depicted in 24.5% (193/788) of the videos. Eating and/or drinking and radio manipulation each occurred in 9.4% (74/788) of videos, whereas talking with a passenger was displayed in 9.1% (72/788) of the videos. Daydreaming was present in 2.0% (16/788) of all videos. It should be noted that many videos contained more than one form of distraction.

Table 4 illustrates the consequences depicted in the videos. The 3 most common outcomes were crash or an accident, seen in 58.4% (460/788) of the videos, followed by death and injury at 35.8% (282/788) and 21.1% (166/788), respectively. Similar to the specific distractions, multiple consequences were often shown in a single video.

Table 3. Videos containing a specific driving distraction.

Driving distractions	Value, n (%)
Texting (phone)	509 (64.6)
Talking (phone)	193 (24.5)
Eating/drinking	74 (9.4)
Radio	74 (9.4)
Talking with a passenger	72 (9.1)
Unknown[a]	67 (8.5)
Phone (app, Web, music, pic, video, reading)	59 (7.5)
In-vehicle distraction+reaching for an object	57 (7.2)
Grooming	55 (7.0)
Other[b]	51 (6.5)
Programming navigation/GPS systems	34 (4.3)
Outer-vehicle distraction	32 (4.1)
Interacting with children	24 (3.0)
Electronic device (laptop, computer, Mp3, iPod)	21 (2.7)
Reading	18 (2.3)
Daydreaming	16 (2.0)

[a]Distractions were not visible.

[b]Distractions were too few to categorize independently.

Table 4. Videos containing a specific consequence of distracted driving.

Consequences	Value, n (%)
Car crash/accident	460 (58.4)
Death	282 (35.8)
Injury	166 (21.1)
None	130 (16.5)
Orthopedic injuries	90 (11.4)
Fine (ticket)	82 (10.4)
Near crash/accident	32 (4.1)
Incarceration	27 (3.4)
Police pull over	23 (2.9)
Legal	13 (1.6)
Warning	9 (1.1)
Other	38 (4.8)

As the 10 most viewed videos accounted for nearly half of all the views garnered, a separate review of these videos was conducted. Table 5 represents the various distractions recorded in these videos. The use of mobile phones was once more the most common distracting activity, especially texting, which was present in all (10/10, 100%) videos.

Table 6 describes the consequences depicted in the 10 most viewed videos. A car crash or an accident was the most common consequence depicted in 70% (7/10) of the videos. Death was depicted in 60% (6/10) of videos, and injury was shown in 40% (4/10) of the videos.

Table 5. Specific distractions in the 10 most viewed videos.

Distractions	Value, n (%)
Texting (phone)	10 (100)
Talking with a passenger	4 (40)
Eating/drinking	3 (30)
Talking (phone)	1 (10)
Radio	1 (10)
Interacting with children	1 (10)
Other	1 (10)

Table 6. Specific consequences in the 10 most viewed videos.

Consequences	Value, n (%)
Car crash/accident	7 (70)
Death	6 (60)
Injury	4 (40)
Orthopedic injury	2 (20)
None	1 (10)

Table 7 presents a comparative analysis of all the categorical variables between the 10 most viewed videos and all the videos reviewed. In terms of context, the majority of the 10 most viewed videos were PSAs (8/10, 80%). However, the percentage of total videos that were PSAs was substantially lower at 37.3% (294/788). In addition, 60% (6/10) of the top 10 videos viewed depicted fictitious events, compared with 27.8% (219/788) for the combined data. The character of the content was more evenly distributed among the top 10 videos, with 60% (6/10) being serious, 40% (4/10) funny, and 30% (3/10) considered as graphic, as opposed to all the videos, where the vast majority were serious in nature (643/788, 81.6%).

Our comparative analysis also included quantitative variables, which are displayed in Table 8. There were more than 223 million views distributed across all 788 examined videos (mean 17,211,395.2, SD 16,838,381.6), and 104 million (46.50%) of those views belonged to the 10 most popular videos. In addition, 48.94% (545,628/1,114,680) of all the reactions (likes/dislikes) and 50.76% of all likes (535,600/1,055,070) were among the top 10 videos.

XSL•FO
RenderX

Table 7. Videos depicting examined categorical variables in the 10 most viewed videos and all videos.

Categorical variables	Ten most viewed videos depicting variable, n (%)	All videos depicting variable (N=788), n (%)
Public safety announcement	8 (80)	294 (37.3)
Television show or newscast	2 (20)	135 (17.1)
Amateur	0 (0)	272 (34.5)
Advertisement	2 (20)	68 (8.6)
Real account	3 (30)	437 (55.8)
Reenactment	0 (0)	12 (1.5)
Fictitious	6 (60)	219 (27.8)
Cognitive distraction	10 (100)	717 (91.0)
Visual distraction	10 (100)	643 (81.6)
Manual distraction	9 (90)	651 (82.6)
Funny	4 (40)	89 (11.3)
Serious	6 (60)	643 (81.6)
Graphic	3 (30)	65 (8.2)
Contains statistics	1 (10)	220 (27.9)
Statistics referenced	0 (0)	79 (10.0)
Study mentioned/discussed[a]	0 (0)	60 (7.6)
Peer-reviewed study[b]	0 (0)	27 (3.4)
Orthopedic injury	2 (20)	90 (11.4)
Injury	4 (40)	166 (21.1)

[a]A study about distracted driving was mentioned in the video.

[b]The mentioned study in the video was published in a peer-reviewed journal.

Table 8. Videos depicting examined quantitative variables in the 10 most viewed videos and all videos.

Quantitative variables	Ten most viewed videos	All reviewed videos
Views, n (%)	104,057,183 (46.50)	223,748,138 (100.00)
Likes, n (%)	535,600 (50.76)	1,055,070 (100.00)
Dislikes, n (%)	10,028 (16.82)	59,610 (100.00)
Total reactions, n (%)	545,628 (48.94)	1,114,680 (100.00)
Ratio of likes/dislikes	53.4	17.7

Discussion

Principal Findings

In this study, the 788 YouTube videos on distracted driving had more than 223 million combined views distributed across all years, demonstrating that there is a high interest in this topic. The number of videos with 3000 views or more uploaded per year was also relatively stable throughout the years. The increase in the number of uploaded videos after 2006 follows with YouTube inception and growth in popularity. In addition to the fact that 2018 was truncated in June, and represents approximately 6 months of videos rather than a full year, the decline in 2017 to 2018 also has to be viewed in the context that the newest videos have the least amount of time to garner views (and will gain views with additional time).

A large proportion of the videos were PSAs (294/788, 37.3%), with more than one-third of the videos (272/788, 34.5%) having amateur content. Videos containing statistics with a referenced source were 10.0% (79/788), and only 3.4% (27/788) videos quoted peer-reviewed studies, signifying most videos were opinion based. Therefore, the videos demonstrated a significant disparity between the information presented on this forum and the current data available on distracted driving. For instance, the results showed texting as the most commonly observed distracting activity (509/788. 64.6%). However, using data from the Fatality Analysis Reporting System, Erie Insurance reports that among the top 10 distractions involved in fatal car crashes, mobile phone use ranked as second with 14%, behind *lost in thought* or daydreaming with 61% [6,19]. In this study, daydreaming was the least represented type of distraction. This discrepancy is in alignment with data that demonstrate that the majority of people believe that mobile phones are the number

one distraction when driving [22]. It should be noted that commonality is not to be mistaken for the magnitude of distraction that can occur. Studies have placed programming navigation/GPS systems and texting while driving as the most distracting tasks [23,24]. In this study, programming a navigations/GPS system was seen in only 4.3% (34/788) of all videos, whereas texting while driving was depicted in 64.6% (509/788) of the videos. Both tasks are obviously exceedingly dangerous, but it is interesting to see that mobile phones are dominating this public forum, although some of the more common and potentially equally dangerous distractions identified garner so little spotlight.

In the videos, death as a result of distracted driving is grossly overrepresented (282/788, 35.8%) relative to injuries sustained in the same circumstances (166/788, 21.1%). Information available from reported MVCs suggests that injuries from distracted driving crashes are nearly 113 times more likely than fatalities [6]. Furthermore, according to 2011 Canadian data from the National Trauma Registry [25], the most common cause of major injury were MVCs, with 79% of these people having sustained musculoskeletal injuries. However, in this study, 21.1% (166/788) of the videos depicted some form of injury, whereas orthopedic injuries were depicted in only 11.4% (90/788) of the videos, representing once again a huge disparity from available data on distracted driving.

A possible reason for the dominance of serious outcomes such as death is the uploader's goal of reaching and engaging people for more views, reactions, and comments or demonstrating the extremes to get viewers to think about distracted driving. Although we hope this may build awareness around the risks of distracted driving, it presents messages that can certainly be dramatically different from reality, for example, directing one's attention to death as a consequence of distracted driving but massively underrepresenting a life-altering injury with permanent impairment and/or disability.

Furthermore, because of the fact that the 10 most viewed videos garnered 46.5% (104,057,183/223,748,138) of all the views and more than half of all likes (535,600/1,055,070, 50.76%), we performed a subanalysis of these videos and found similar results. Car crashes and death were the 2 most common outcomes. Mobile phone use, particularly texting, was present in all 10 videos. Interestingly, there were no studies or statistics referenced in the 10 most viewed videos.

Limitations

This study had several limitations. Data gathering for categorical variables relied on the investigator's ability to scan and detect for the variables, allowing for the possibility to overlook some information. Furthermore, there are no standardized methods for analyzing YouTube videos; thus, the interpretation of various variables depended on the researcher's judgment, which could lead to bias. We minimized these issues by assigning 2 independent reviewers to analyze each video and resolved any discrepancy between the coded data by consensus via the coding authors. To our knowledge, this is the largest YouTube study

on distracted driving, and the large sample size would decrease the potential data skewing that can be observed with smaller sample sizes.

Comparison With Prior Work

YouTube is the second most visited website in the world, with 5 billion videos and 1 billion hours of content viewed daily, and it is by far the most used video sharing platform on the internet [20,26]. It is available in 76 languages in 88 countries, which is 95% of all internet users [20], and offers a unique opportunity to reach an audience of millions. Other studies have investigated the sharing potential of YouTube for information on various medical issues, such as immunizations [27], concussions [28], heart transplantation [29], and sedentary behaviors [30]. A recent study about videos on distracted driving on YouTube in 2017 analyzed 100 videos specifically on mobile phone use as it applies to adolescents [21]. However, they only focused on 1 form of distraction only in adolescents, compared with this study, which examined multiple forms and types of distractions and the messages portrayed in them.

Conclusions

This study demonstrates the overall messages portrayed in videos on YouTube focused on distracted driving and shows discrepancies between current data on distracted driving and what is described.

The popularity of viewing videos on this topic appears to be high and relatively stable over time on a forum that fluxes based on the current opinions of its users. This is encouraging in the sense that people are being exposed to the dangers of distracted driving. However, overall information presented in these videos can mostly be classified as opinion based, with a paucity of referenced statistics or data from peer-reviewed studies.

Videos most often focused on texting while driving and the most dramatic consequences such as MVCs and death. Although we hope this brings attention to the seriousness of distracted driving, it is not representative of the known data on distracted driving. In studies, the most demanding task while driving is potentially programming a navigation/GPS system and/or texting while driving [23,24], whereas the most common distraction is thought to be daydreaming [19]. Unfortunately, daydreaming and programming a navigation/GPS system are largely ignored in these videos and represent critical information to know about distracted driving. In addition, death was portrayed more than 1.7 times compared with injury in terms of potential consequences of distracted driving. In reality, injuries are 113-fold more common compared with fatalities [6]. Similarly, injuries in general and specifically orthopedic injuries, which are exceedingly common and can lead to a massive source of long-term disability and/or impairment, are vastly underrepresented compared with reality.

Future research may be aimed at potentially harnessing this interest on YouTube with respect to distracted driving to ascertain whether perspectives and behaviors can be favorably altered to minimize distracted driving.

Conflicts of Interest

None declared.

References

1. Bailin A, Adesman A, Sunday S. 134. Texting While Driving Among High School Students in the United States: Analysis of 2011 Data From the National Youth Risk Behavior Survey (YRBS). J Adolesc Health 2013;52(2):S85-S86. [doi: 10.1016/j.jadohealth.2012.10.201]
2. Seiden D. Royal Canadian Mounted Police. 2014 Jul 4. Distracted Driving URL: http://www.rcmp-grc.gc.ca/en/gazette/distracted-driving [accessed 2019-12-30]
3. Waterdown Collision.: Waterdown Collision The Leading Causes of Car Accidents URL: https://www.waterdowncollision.com/blog/safe-driving/leading-causes-of-car-accidents/ [accessed 2019-12-30]
4. World Health Organization. Geneva: World Health Organization; 2004. Global Burden of Disease Report 2004 URL: https://www.who.int/healthinfo/global_burden_disease/GBD_report_2004update_full.pdf [accessed 2019-12-30]
5. World Health Organization. Geneva: World Health Organization; 2018. Global Status Report on Road Safety 2018 URL: https://www.who.int/violence_injury_prevention/road_safety_status/2018/en/ [accessed 2019-12-30]
6. CrashStats - NHTSA - DOT. Washington, DC: National Highway Traffic Safety Administration; 2017 Mar. Distracted Driving 2015 URL: https://crashstats.nhtsa.dot.gov/Api/Public/ViewPublication/812381 [accessed 2019-12-30]
7. National Highway Traffic Safety Administration. The Economic and Societal Impact of Motor Vehicle Crashes, 2010 (Revised). Ann Emerg Med 2015;66(2):194-196. [doi: 10.1016/j.annemergmed.2015.06.011]
8. Regan M, Hallett C, Gordon C. Driver distraction and driver inattention: definition, relationship and taxonomy. Accid Anal Prev 2011 Sep;43(5):1771-1781. [doi: 10.1016/j.aap.2011.04.008] [Medline: 21658505]
9. Transport Canada. Ottawa, ON: Government of Canada; 2019. Distracted Driving URL: https://www.tc.gc.ca/en/services/road/stay-safe-when-driving/distracted-driving.html#what [accessed 2019-12-30]
10. Canadian Council of Motor Transport Administrators. Ottawa, ON; 2006. Distracted driving sub-group goes to work URL: http://ccmta.ca/images/publications/pdf/ccmta_news_summer_2006.pdf [accessed 2019-12-30]
11. Wickens C. Multiple resources and performance prediction. Theor Issues Ergon Sci 2002;3(2):159-177. [doi: 10.1080/14639220210123806]
12. Regan MA, Lee JD, Young K. Driver Distraction: Theory, Effects, And Mitigation. Boca Raton, FL: CRC Press; 2008.
13. Esurance Insurance Service. Triple Threat: The 3 Types of Distracted Driving Esurance. URL: https://www.esurance.com/info/car/3-types-of-distracted-driving [accessed 2019-12-30]
14. Vegega M, Jones B, Monk C. National Highway Traffic Safety Administration. Washington, DC: National Highway Traffic Safety Administration; 2013 Dec. Understanding the Effects of Distracted Driving and Developing Strategies to Reduce Resulting Deaths and Injuries: A report to congress URL: https://www.nhtsa.gov/sites/nhtsa.dot.gov/files/812053-understandingeffectsdistracteddrivingreporttocongress.pdf [accessed 2020-01-01]
15. National Safety Council. Itasca, IL: National Safety Council; 2015. Annual Estimate of Cell Phone Crashes 2013 URL: https://www.nsc.org/portals/0/documents/distracteddrivingdocuments/attributable-risk-estimate.pdf [accessed 2019-12-30]
16. Olson R, Hanowski R, Hickman J. Federal Motor Carrier Safety Administration. Washington, DC: US Department of Transportation; 2009. Driver Distraction in Commercial Vehicle Operations URL: https://www.fmcsa.dot.gov/sites/fmcsa.dot.gov/files/docs/DriverDistractionStudy.pdf [accessed 2019-12-30]
17. Olsen E, Shults R, Eaton D. Texting while driving and other risky motor vehicle behaviors among US high school students. Pediatrics 2013 Jun;131(6):e1708-e1715. [doi: 10.1542/peds.2012-3462] [Medline: 23669511]
18. Farmer C, Braitman K, Lund A. Cell phone use while driving and attributable crash risk. Traffic Inj Prev 2010 Oct;11(5):466-470. [doi: 10.1080/15389588.2010.494191] [Medline: 20872301]
19. Erie Insurance. 2018 Apr 3. Erie Insurance releases police data showing daydreaming #1 on top 10 list of fatal distracted driving behaviors URL: https://www.erieinsurance.com/news-room/press-releases/2018/distracted-driving-survey [accessed 2019-12-30]
20. Omnicore. 2019 Sep 5. YouTube by the Numbers: Stats, Demographics & Fun Facts URL: https://www.omnicoreagency.com/youtube-statistics/ [accessed 2019-12-30]
21. Basch C, Mouser C, Clark A. Distracted driving on YouTube: implications for adolescents. Int J Adolesc Med Health 2017 May 18;31(2):pii: /j/ijamh. [doi: 10.1515/ijamh-2016-0158] [Medline: 28525349]
22. Travelers Institute. Washington, DC: The Travelers Institute; 2018. Every Second Matters URL: https://www.travelerscanada.ca/iw-documents/Travelers_Institute_Distracted_Driving_Conversation_Starter_EN.pdf [accessed 2019-12-30]
23. Canadian Automotive Association. Distracted Driving: Statistics URL: https://www.caa.ca/distracted-driving/statistics/ [accessed 2019-12-30]
24. Strayer D, Cooper J, Goethe R, McCarty M, Getty D, Biondi F. The American Automobile Association. Washingon, DC: The American Automobile Association; 2017 Sep. Visual and Cognitive Demands of Using In-Vehicle Infotainment Systems URL: https://aaafoundation.org/visual-cognitive-demands-using-vehicle-information-systems/ [accessed 2019-12-30]

25.   Haas B, Poon V, Waller B, Sidhom P. Canadian Institute for Health Information. Toronto, ON: Canadian Institute for Health Information; 2011. National Trauma Registry 2011 Report: Hospitalizations for Major Injury in Canada, 2008–2009 Data URL: https://secure.cihi.ca/free_products/NTR_CDS_2008_2009_Annual_Report.pdf [accessed 2019-12-30]

26.   Alexa: The Web Information Company. 2019. YouTube Competitive Analysis, Marketing Mix and Traffic URL: https://www.alexa.com/siteinfo/youtube.com?ver=classic [accessed 2019-12-30]

27.   Ache K, Wallace L. Human papillomavirus vaccination coverage on YouTube. Am J Prev Med 2008 Oct;35(4):389-392. [doi: 10.1016/j.amepre.2008.06.029] [Medline: 18675530]

28.   Williams D, Sullivan J, Schneiders A, Ahmed O, Lee H, Balasundaram A, et al. Big hits on the small screen: an evaluation of concussion-related videos on YouTube. Br J Sports Med 2014 Jan;48(2):107-111. [doi: 10.1136/bjsports-2012-091853] [Medline: 23446643]

29.   Chen HM, Hu ZK, Zheng XL, Yuan ZS, Xu ZB, Yuan LQ, et al. Effectiveness of YouTube as a source of medical information on heart transplantation. Interact J Med Res 2013 Nov 21;2(2):e28 [FREE Full text] [doi: 10.2196/ijmr.2669] [Medline: 24263225]

30.   Knight E, Intzandt B, MacDougall A, Saunders T. Information seeking in social media: a review of YouTube for sedentary behavior content. Interact J Med Res 2015 Jan 20;4(1):e3 [FREE Full text] [doi: 10.2196/ijmr.3835] [Medline: 25604433]

Abbreviations

MRT: Multiple Resource Theory
MVC: motor vehicle crash
PSA: public safety announcement

Original Paper

Trend of Cutaneous Leishmaniasis in Jordan From 2010 to 2016: Retrospective Study

Mohammad Alhawarat[1], MD; Yousef Khader[2], SCD; Bassam Shadfan[3], MD; Nasser Kaplan[2], PhD; Ibrahim Iblan[1], MD

[1]Jordan Field Epidemiology Training Program, Jordan Ministry of Health, Amman, Jordan

[2]Jordan University of Science and Technology, Irbid, Jordan

[3]Parasitic and Zoonotic Disease Department, Communicable Disease Directorate, Ministry of Health, Amman, Jordan

Corresponding Author:
Mohammad Alhawarat, MD
Jordan Field Epidemiology Training Program
Jordan Ministry of Health
Pr. Hamzah St
Amman, 11118
Jordan
Phone: 962 772300390
Email: fazza200079@yahoo.com

Abstract

Background: Cutaneous leishmaniasis (CL) is endemic in the Middle East, with countries such as Syria reporting high incidence rates.

Objective: This study aimed to assess the trends in the incidence of cutaneous leishmaniasis (CL) in Jordan from 2010 to 2016.

Methods: This retrospective study included all cases of CL that had been reported to the Leishmaniasis Surveillance System in the Department of Communicable Diseases at the Jordan Ministry of Health during the period from 2010 to 2016. A total of 1243 cases were reported and met the case definition.

Results: A total of 1243 cases (60.65% [754/1243] males and 39.34% [489/1243] females) were diagnosed during the study period. Of this sample, 233 patients (19.13%) were aged <5 years old, 451 (37.03%) were aged between 5-14 years old, 190 (15.60%) were aged between 15-24 years old, and 344 (28.24%) were aged ≥25 years old. Of those, 646 (51.97%) were Jordanians and 559 (44.97%) were Syrians. The average annual incidence rate of 1.70 per 100,000 people between 2010 and 2013 increased to 3.00 per 100,000 people in the years 2014 to 2016. There was no difference in incidence rates between Jordanians and Syrian refugees between 2010 and 2012. After 2012, the incidence rate increased significantly among Syrian refugees from 1.20 per 100,000 people in 2012 to 11.80 per 100,000 people in 2016. On the contrary, the incidence rate did not change significantly among Jordanians.

Conclusions: The incidence rate of leishmaniasis in Jordan has increased in the last three years because of the influx of Syrian refugees into Jordan. A massive effort toward reservoir and vector control, along with actively pursuing diagnosis in endemic foci, will be helpful. Proper and studious reporting of cases is also a necessity for the eradication of this disease.

Introduction

Background

Leishmaniasis is a vector-borne disease that is transmitted via female sandflies and caused by an intracellular protozoon called Leishmania. It is endemic in 98 countries and 3 continents [1]. Out of 30 mammal-infecting Leishmania species, 21 are known to infect humans [1]. Leishmaniasis is subdivided into 3 types: cutaneous, mucocutaneus, and visceral. Cutaneous leishmaniasis (CL) is the most common type, and almost 95% of its cases are found in North and South America, the Mediterranean region, the Middle East, and Central Asia [2]. It usually manifests in the form of skin lesions, particularly ulcers, which leave permanent scars and cause severe disability. An estimate of

XSL•FO
RenderX

around 0.7 to 1.3 million new cases are reported each year, and more than two-thirds of the new cases are found in 6 countries: Afghanistan, Algeria, Brazil, Colombia, Iran, and Syria [2].

Poverty, overcrowding, immigration, and other risk factors have a great role in increasing the incidence of CL. There are currently no available drugs or vaccines to prevent infections, and despite numerous preventative measures, leishmaniasis remains an important, neglected, zoonotic disease and a big challenge to public health, especially in underdeveloped countries [3]. The trends of CL vary from one country to another in the Middle East. The incidence rate has decreased in Saudi Arabia, whereas it has increased in Iraq and Syria, especially during the civil war [4]. In general, previous studies in the Middle East have shown that males are more likely to be affected with CL [5-7].

In Jordan, it has been an emerging disease since the 1980s, and is still an important public health problem despite existing control and prevention measures. In a previous study in the last decades, the incidence rate of CL in Jordan has been shown to be increasing [8]. One study had assessed the spatial and temporal characteristics of CL in the years from 1999 to 2010, pre–Arab Spring in Jordan and Syria, and it showed that the risk of CL varied both spatially and temporally in both countries [9]. That study showed that the patterns of the disease in Jordan could be described as relatively low and heterogeneous whereas those in Syria were relatively much higher and less heterogeneous.

Objectives

The CL surveillance system in Jordan receives reports on a weekly basis from 21 reporting sites from all districts and governorates in the country. This study aimed to assess the trend in the incidence of CL in Jordan from 2010 to 2016.

Methods

This retrospective study included all cases of CL that had been reported to the Leishmaniasis Surveillance System in the Department of Communicable Diseases at the Jordan Ministry of Health during the period from 2010 to 2016. A total of 1243 cases were reported and met the case definition.

A suspected case is defined as a person who was in Jordan during the study period and showed clinical signs (skin lesions) of infection, wherein the papule appears and may enlarge to become an indolent ulcerated nodule. A confirmed case is a person who was in Jordan during the study period and showing clinical signs of infection, with paracytological confirmation of the diagnosis by a positive smear or culture from a skin lesion [10].

The necessary and available data were retrieved from the surveillance system. Data included patient's age, gender, address, nationality, occupation, reporting site, reporting month, reporting year, and location of lesion. The Ethical Committee at the Ministry of Health approved the study. Data were entered into an Excel (Microsoft, Redmond, Washington, United States) file and analyzed using SPSS Statistics for Windows, Version 23.0 (IBM Corporation, Armonk, New York, United States).

Results

Patients' Characteristics

A total of 1243 CL cases were reported. Of the total reported cases, 754 (60.65%) were males, 489 (39.34%) were females, and the mean age of the patients was 18.6 years old (SD 16.8). Overall, 233 (19.13%) patients were aged <5 years old, 451 (37.03%) were aged between 5-14 years old, 190 (15.60%) were aged between 15-24 years old, and 344 (28.24%) were aged ≥25 years old. Half of reported cases were from the southern region of the country (Table 1). A total 563 (45.29%) patients had head lesions, 186 (14.96%) had trunk lesions, 382 (381.60%) had leg lesions, and 426 (34.27%) had arm lesions.

Table 1. Distribution of leishmaniasis cases in Jordan from 2010 to 2016 by age, gender, and region.

Characteristics	Frequency, n (%)
Age (years)	
0-4	233 (19.1)
5-14	451 (37.0)
15-24	190 (15.6)
≥25	344 (28.2)
Gender	
Male	754 (60.7)
Female	489 (39.3)
Region	
South	575 (49.4)
North	179 (15.4)
Middle	410 (35.2)

Incidence and Trend

The average annual incidence rate was 1.70% among 100,000 people during the period from 2010 to 2013. In the period from 2014 to 2016, when Syrian refugees entered the country, the average incidence rate increased to 3.00% in every 100,000 people (Figure 1). The incidence rate was higher among those aged less than 15 years old compared with those aged ≥15 years old (Figure 2), and it was higher among males compared to females in all studied years. In both genders, the incidence decreased during the period from 2010 to 2012, following which it started to increase again (Figure 3). In total, 646 (51.97%) of reported leishmaniasis cases were Jordanians and 559 (44.97%) were Syrians. There was no difference in incidence rates between Jordanian and Syrian refugees between 2010 and 2012, but after 2012, the incidence rate increased significantly among Syrian refugees from 1.20 per 100,000 people in 2012 to 11.80 per 100,000 people in 2016. On the contrary, the incidence rate did not change significantly among Jordanians (Figure 4).

Figure 1. The trend of the overall incidence rate of cutaneous leishmaniasis per 100,000 people in Jordan from 2010 to 2016.
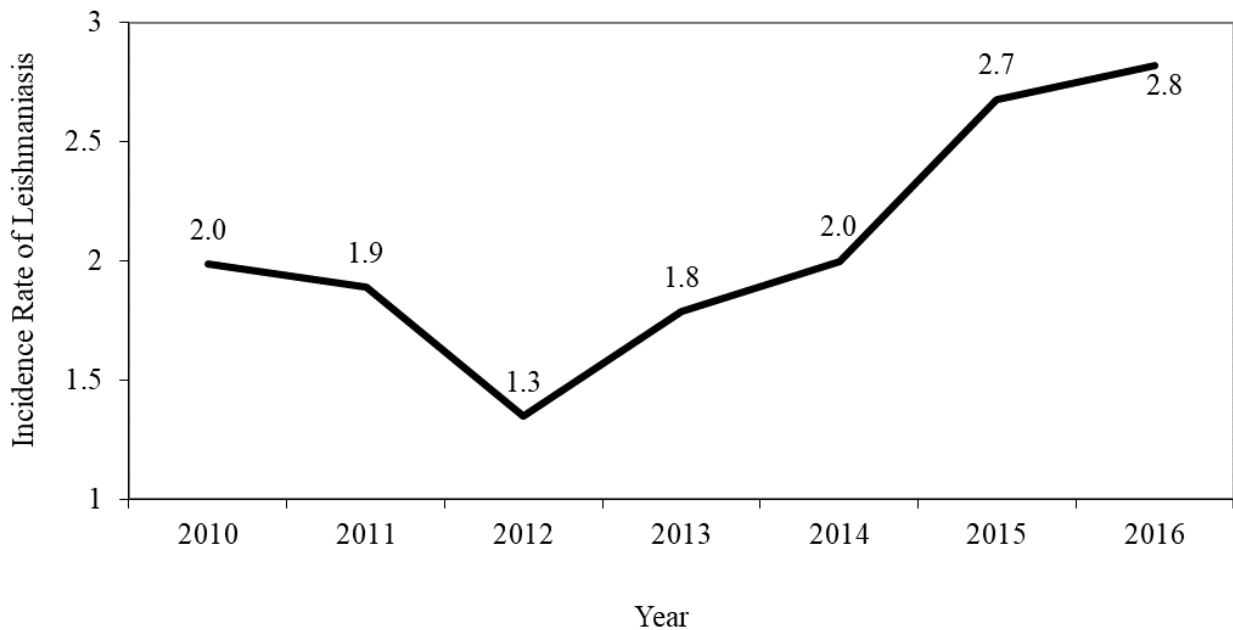
Figure 2. The incidence rate of cutaneous leishmaniasis per 100,000 people in Jordan by age categories from 2010 to 2016.
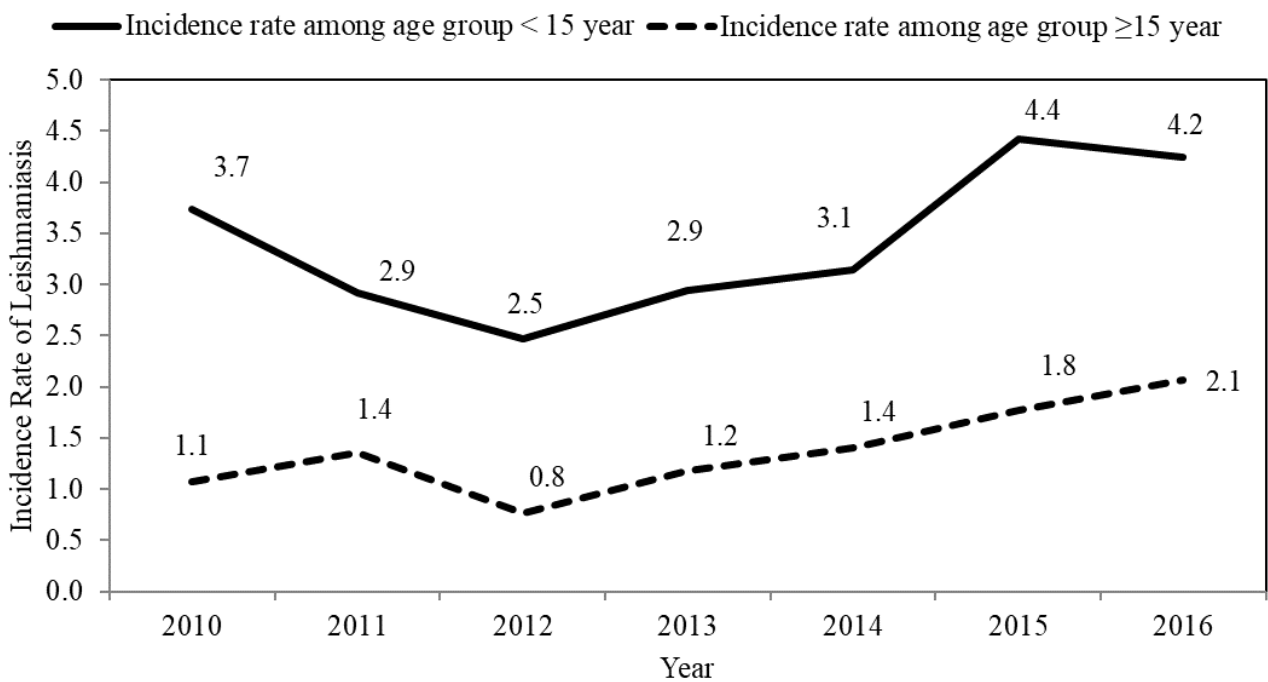
Figure 3. The incidence rate of cutaneous leishmaniasis per 100,000 people in Jordan by gender from 2010 to 2016.

Figure 4. The incidence rate of cutaneous leishmaniasis per 100,000 people in Jordan by nationality from 2010 to 2016.
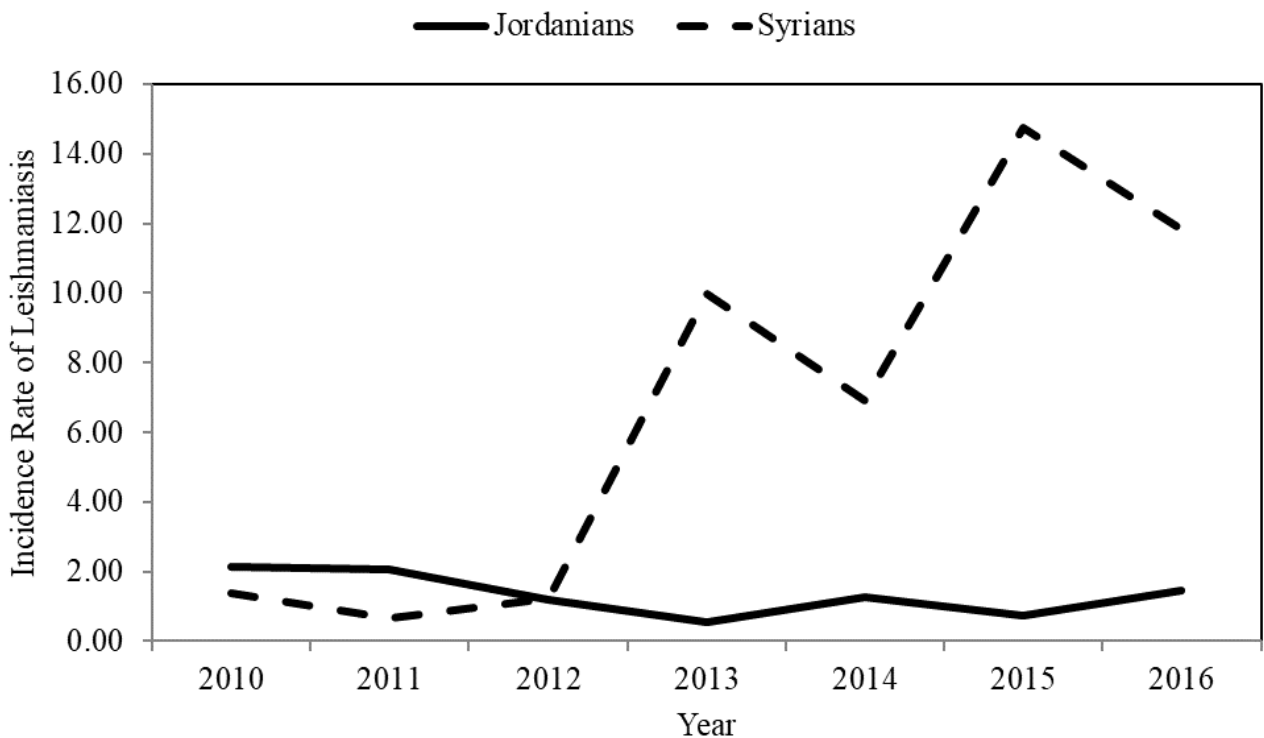
Discussion

Principal Findings

This study assessed changes in the incidence of CL in Jordan between 2010 and 2016. Males were predominant among affected cases in all age categories, and this finding was also reported in other countries, including Saudi Arabia and Iran [5-7]. The increased infection rates among males in Jordan might be explained by the fact that males are usually responsible for outdoor work and work in farms. Moreover, most females

in Jordan traditionally cover most parts of their bodies, thus they are fairly well protected from sandflies.

During the study period, the highest incidence rate was among subjects aged less than 15 years old. This finding is consistent with the findings from a longitudinal study in the endemic area in the eastern region of Saudi Arabia [11], and with the findings of other studies in Saudi Arabia and Iran [5-7]. This finding is probably explained by the fact that children spend more time outdoors, and therefore are more likely to be exposed to sandfly bites. However, other studies in Saudi Arabia [12], Iran [13], and Kuwait [14] have shown that people aged between 21-30 years old are the most susceptible because most laborers are in this age group.

On the basis of the geographic distribution of CL, the southern region of Jordan was an endemic area. However, the Zarqa governorate is now a new hot reporting site because of the presence of the Syrian refugees' camp in this governorate. In agreement with the findings of studies in Lebanon [15] and Turkey [16], this study showed an increasing trend in the incidence rate of CL in Jordan during the study period. The increased rate of CL in Jordan in the past few years is explained by an increasing number of Syrian refugees in Jordan over time. Poor housing, absence of clean water, inadequate sanitation, deficient medical facilities and services, and abundant sandfly populations have contributed to CL among Syrian refugees.

CL emerged in areas where displaced Syrians and disease reservoirs coexist. In 2013, 1033 new cases were reported in Lebanon, of which 96.6% occurred among the displaced Syrian refugee populations [15]. In Turkey, nonendemic parasite strains (*Leishmania major* and *Leishmania donovani*) were introduced by incoming refugees [16]. Other studies in Saudi Arabia and Iran have shown a decline in the number and incidence rate of CL in the same period [5,6]. The main limitation of this study is the underreporting of CL cases.

Conclusions

In conclusion, CL is increasing in Jordan, especially after the Syrian war, but countries with ample resources, like Jordan, have taken measures to control the spread of the disease. However, challenges still remain to be solved because of huge refugee movement into the country. A massive effort toward reservoir and vector control, along with actively pursuing diagnosis in endemic foci, will be helpful. Proper and studious reporting of cases is also a necessity for the eradication of this disease, as health care practitioners rely on these data for framing health policies. Future research is needed to determine the main risk factors contributing to the increasing trend of the occurrence of leishmaniasis, and to implement and evaluate control and prevention measures in Jordan. Moreover, there is an urgent need for developing national health policies and action plans for combating CL in Jordan.

Conflicts of Interest

None declared.

References

1. Centers for Disease Control and Prevention. Parasites - Leishmaniasis URL: https://www.cdc.gov/parasites/leishmaniasis/ [accessed 2019-01-15]
2. World Health Organization. Leishmaniasis URL: http://www.who.int/mediacentre/factsheets/fs375/en/ [accessed 2019-01-15]
3. Pace D. Leishmaniasis. J Infect 2014 Nov;69(Suppl 1):S10-S18. [doi: 10.1016/j.jinf.2014.07.016] [Medline: 25238669]
4. Salam N, Al-Shaqha WM, Azzi A. Leishmaniasis in the middle East: incidence and epidemiology. PLoS Negl Trop Dis 2014 Oct;8(10):e3208 [FREE Full text] [doi: 10.1371/journal.pntd.0003208] [Medline: 25275483]
5. Amin TT, Al-Mohammed HI, Kaliyadan F, Mohammed BS. Cutaneous leishmaniasis in Al Hassa, Saudi Arabia: epidemiological trends from 2000 to 2010. Asian Pac J Trop Med 2013 Aug;6(8):667-672 [FREE Full text] [doi: 10.1016/S1995-7645(13)60116-9] [Medline: 23790342]
6. Khosravani M, Moemenbellah-Fard MD, Sharafi M, Rafat-Panah A. Epidemiologic profile of oriental sore caused by Leishmania parasites in a new endemic focus of cutaneous leishmaniasis, southern Iran. J Parasit Dis 2016 Sep;40(3):1077-1081 [FREE Full text] [doi: 10.1007/s12639-014-0637-x] [Medline: 27605840]
7. Khazaei S, Hafshejani AM, Saatchi M, Salehiniya H, Nematollahi S. Epidemiological aspects of cutaneous leishmaniasis in Iran. Arch Clin Infect Dis 2015;10(3):e28511. [doi: 10.5812/archcid.28511]
8. Khoury S, Saliba EK, Oumeish OY, Tawfig MR. Epidemiology of cutaneous leishmaniasis in Jordan: 1983-1992. Int J Dermatol 1996 Aug;35(8):566-569. [doi: 10.1111/j.1365-4362.1996.tb03656.x] [Medline: 8854153]
9. Jaber SM, Ibbini JH, Hijjawi NS, Amdar NM. An exploratory comparative study of recent spatial and temporal characteristics of cutaneous leishmaniasis in the Hashemite kingdom of Jordan and Syrian Arab Republic pre-Arab spring and their health policy implications. Appl Spat Anal Policy 2014;7(4):337-360. [doi: 10.1007/s12061-014-9113-3]
10. World Health Organization. Neglected Tropical Diseases URL: http://www.emro.who.int/neglected-tropical-diseases/ information-resources-leishmaniasis/cl-factsheet.html [accessed 2019-01-15]

11. Al-Tawfiq JA, AbuKhamsin A. Cutaneous leishmaniasis: a 46-year study of the epidemiology and clinical features in Saudi Arabia (1956-2002). Int J Infect Dis 2004 Jul;8(4):244-250 [FREE Full text] [doi: 10.1016/j.ijid.2003.10.006] [Medline: 15234329]

12. Elmekki MA, Elhassan MM, Ozbak HA, Qattan IT, Saleh SM, Alharbi AH. Epidemiological trends of cutaneous leishmaniasis in Al-Madinah Al-Munawarah province, western region of Saudi Arabia. J Glob Infect Dis 2017;9(4):146-150 [FREE Full text] [doi: 10.4103/jgid.jgid_16_17] [Medline: 29302149]

13. Karami M, Doudi M, Setorki M. Assessing epidemiology of cutaneous leishmaniasis in Isfahan, Iran. J Vector Borne Dis 2013 Mar;50(1):30-37 [FREE Full text] [Medline: 23703437]

14. Al-Taqi M, Behbehani K. Cutaneous leishmaniasis in Kuwait. Ann Trop Med Parasitol 1980 Oct;74(5):495-501. [doi: 10.1080/00034983.1980.11687374] [Medline: 7469563]

15. Alawieh A, Musharrafieh U, Jaber A, Berry A, Ghosn N, Bizri AR. Revisiting leishmaniasis in the time of war: the Syrian conflict and the Lebanese outbreak. Int J Infect Dis 2014 Dec;29:115-119 [FREE Full text] [doi: 10.1016/j.ijid.2014.04.023] [Medline: 25449245]

16. Koltas IS, Eroglu F, Alabaz D, Uzun S. The emergence of Leishmania major and Leishmania donovani in southern Turkey. Trans R Soc Trop Med Hyg 2014 Mar;108(3):154-158. [doi: 10.1093/trstmh/trt119] [Medline: 24449479]

Abbreviations

CL: cutaneous leishmaniasis

<u>Original Paper</u>

Occupational Exposure to Needle Stick Injuries and Hepatitis B Vaccination Coverage Among Clinical Laboratory Staff in Sana'a, Yemen: Cross-Sectional Study

Nabil Al-Abhar[1,2], MD; Ghuzlan Saeed Moghram[3], MD; Eshrak Abdulmalek Al-Gunaid[2], MD; Abdulwahed Al Serouri[1], PhD; Yousef Khader[4], SCD

[1]Field Epidemiology Training Program, Sana'a, Yemen

[2]National Center of Public Health Laboratories, Sana'a, Yemen

[3]Al Thawra Hospital, Sana'a, Yemen

[4]Jordan Field Epidemiology Training Program, Jordan Ministry of Health, Amman, Jordan

Corresponding Author:
Yousef Khader, SCD
Jordan Field Epidemiology Training Program
Jordan Ministry of Health
Pr. Hamzah St
Amman, 11118
Jordan
Phone: 962 796802040
Email: yskhader@just.edu.jo

Abstract

Background: Laboratory staff handling blood or biological samples are at risk for accidental injury or exposure to blood-borne pathogens. Hepatitis B virus (HBV) vaccinations for laboratory staff can minimize these risks.

Objective: The aims of this study were to determine the prevalence of occupational exposure to needle stick injuries (NSIs) and assess HBV vaccination coverage among clinical laboratory staff in Sana'a, Yemen.

Methods: A cross-sectional survey was conducted among clinical laboratory staff who were involved in handling and processing laboratory samples at the main public and private clinical laboratories in Sana'a. Data collection was done using a semistructured questionnaire. The questionnaire was divided into 3 parts. Part 1 included information on sociodemographic characteristics of participants. Part 2 included information on the availability of the personal protective equipment in the laboratories, such as lab coats and gloves. Part 3 included questions about the history of injury during work in the laboratory and the vaccination status for HBV.

Results: A total of 219/362 (60%) participants had been accidentally injured while working in the laboratory. Of those, 14.6% (32/219) had been injured during the last 3 months preceding the data collection. Receiving the biosafety manual was significantly associated with lower risk of injury. Out of those who were injured, 54.8% (120/219) had received first aid. About three-quarters of respondents reported that they had been vaccinated against HBV. The vaccination against HBV was significantly higher among laboratory staff who were working at private laboratories (*P*=.01), who had postgraduate degrees (*P*=.005), and who received the biosafety manual (*P*=.03).

Conclusions: Occupational exposure to NSI is still a major problem among laboratory staff in public and private laboratories in Sana'a, Yemen. The high incidence of injuries among laboratory staff and the low rate of receiving first aid in laboratories combined with low vaccination coverage indicates that all laboratory staff are at risk of exposure to HBV. Therefore, strengthening supervision, legalizing HBV vaccinations for all laboratory staff, and optimizing laboratory practices regarding the management of sharps can minimize risks and prerequisites in Yemen.

XSL•FO
RenderX

Introduction

Laboratory staff handling blood or biological samples are at risk for accidental injury or exposure to blood-borne pathogens [1,2]. This may occur through exposure to aerosols, spills and splashes, accidental needle stick injuries (NSIs), cuts from sharp objects and broken glass, oral pipetting, and centrifuge accidents [3,4].

The World Health Organization reported that about three million health care workers worldwide experience percutaneous exposure to blood-borne viruses. Consequently, 2.5% of HIV cases and 40% of Hepatitis B and C cases occurred among health workers worldwide [3,5]. Furthermore, different NSI prevalence were reported among laboratory staff from Kenya (25%), Saudi Arabia (14%), and Iran (2.3%) [6-8].

Laboratory staff are at high risk of blood-borne viruses including HIV and hepatitis B and C because of the limited vaccination of hepatitis B virus (HBV) among health care workers, the lack of personal protective equipment, and unsafe work practices such as improper management of sharp waste [9-11].

There is a scarcity of data in Yemen about occupational exposure to NSIs and HBV vaccination coverage among laboratory staff. One study reported that 55% of staff had been injured during their work in the laboratory, with NSIs being the commonest injury, and only 47% of staff had been vaccinated against HBV [12]. This study aimed to determine prevalence of occupational exposure to NSIs and assess HBV vaccination coverage among clinical laboratory staff in public and private laboratories in Sana'a, Yemen.

Methods

Study Design and Study Population

A descriptive cross-sectional study was conducted among all laboratory staff who were involved in processing laboratory samples in the main public and private laboratories in Sana'a. The study included those who were working in the National Center of Public Health Laboratories as well as three of the main public laboratories (Al-Thawra, Al-Jomhory, and Al-Kuwait) and three of the main private laboratories (Saudi Germany, University of Science and Technology, and Azal). Staff who were not involved in processing laboratory samples, such as administrative staff, were excluded.

Data Collection and the Study Questionnaire

Data was collected between September 1 and October 31, 2015, using a self-administered semistructured questionnaire. The quality control officers at each laboratory were trained to distribute the questionnaires to the participants, collect the necessary data, and review the filled questionnaires on the spot. Ethical approval was obtained from the National Committee for Medical and Health Research at the Ministry of Public Health and Population. Informed consent was obtained from all participants.

The questionnaire was pilot tested on 10 respondents, who were not included in this study, and necessary changes were made. The questionnaire was developed based on the available standard guidelines and practices and the reviewed literature [3,6,8-10], as well as feedback from some experts in the field. The questionnaire was divided into 3 parts. Part 1 included information on sociodemographic characteristics of participants. Part 2 included information on the availability of the personal protective equipment in the laboratories, such as lab coats and gloves. Part 3 included questions about the history of injury during laboratory work and the vaccination status for HBV.

Statistical Analysis

Data was analyzed using SPSS version 18 (SPSS Inc, Chicago, IL). Data was analyzed using frequencies and percentages. The differences between proportions according to studied characteristics were tested using the chi-square test. A $P<.05$ was considered statistically significant.

Results

Of 385 laboratory staff, 362 (292 from public laboratories and 70 from private laboratories) completed the study questionnaire with a response rate of 94.0%. Table 1 shows the respondents' sociodemographic characteristics. About half of the respondents were 30 to 39 years of age. More than two-thirds (298/362, 82.3%) had received a bachelor's degree, and 47.5% (172/362) had more than 10 years of work experience.

A total of 219/362 (60.5%) respondents had been accidentally injured during their work in the laboratory (Table 2). Of those, 32/219 (14.6%) had been injured during the 3 months preceding data collection.

Table 3 shows the availability of personal protective equipment in public and private laboratories. The majority of laboratory staff reported wearing gloves and lab coats with no significant difference between private and public laboratories. Although other personal protective equipment (eg, masks, goggles, safety cabinets, and eye washers) were generally less available; however, private laboratory staff reported significantly higher availability ($P<.001$). Receiving a biosafety manual was the only factor that was significantly associated with lower injury incidence. Out of those who were injured, 120/219 (54.8%) had received first aid. Those who were working at private laboratories and those who had received a biosafety manual and biosafety training were significantly more likely to receive first aid.

About three-quarters of respondents reported that they had been vaccinated (ie, received the recommended 3 doses) against HBV (Table 4). The vaccination against HBV was significantly higher among laboratory staff who were working at private laboratories, those who had postgraduate degrees, and those who received the biosafety manual.

Table 1. Sociodemographic characteristics of laboratory workers (N=362).

Variable	Laboratory workers, n (%)
Gender	
Male	178 (49.2)
Female	184 (50.8)
Age (year)	
20-29	83 (22.7)
30-39	188 (51.9)
40-49	70 (19.3)
50-59	20 (5.5)
>59	1 (0.3)
Education	
Diploma	64 (17.7)
Bachelor's	223 (61.6)
Higher than Bachelor's	75 (20.7)
Work experience (years)	
1-4	60 (16.6)
5-10	130 (35.9)
11-15	74 (20.4)
>15	98 (27.1)

Table 2. History of injury among laboratory staff during their work, and associated factors (N=362).

Variables	Injured, n (%)	Not injured, n (%)	*P* value
Type of laboratory			**.30**
Public	181 (62.0)	111 (38.0)	
Private	38 (54.3)	32(45.7)	
Gender			**.41**
Male	112 (62.9)	66 (37.1)	
Female	107 (58.2)	77 (41.8)	
Education			**.45**
Nonpostgraduate	177 (61.7)	110 (38.3)	
Postgraduate	42 (56.0)	33 (44.0)	
Work experience (years)			**.91**
1-10	116 (61.1)	74 (38.9)	
>10	103 (59.9)	69 (40.1)	
Received biosafety manual			**.01**
No	189 (63.6)	108 (36.4)	
Yes	30 (46.2)	35 (53.8)	
Received biosafety training			**.13**
No	141 (63.8)	80 (36.2)	
Yes	78 (55.3)	63 (44.7)	

Table 3. Availability of personal protective equipment in public and private laboratories.

Personal protective equipment	Total (N=362), n (%)	Public laboratories (n=292), n (%)	Private laboratories (n=70), n (%)	P value
Gloves	346 (95.6)	276 (94.5)	70 (100.0)	.09
Lab coats	350 (96.7)	280 (95.9)	70 (100.0)	.18
Masks	89 (24.6)	51 (17.5)	38 (54.3)	<.001
Goggles	28 (7.7)	13 (4.5)	15 (21.4)	<.001
Safety cabinet	122 (33.7)	68 (23.3)	54 (77.1)	<.001
Eye washer	70 (19.3)	38 (13.0)	32 (45.7)	<.001

Table 4. Hepatitis B virus vaccination status and associated factors (N=362).

Variables	Not vaccinated, n (%)	Vaccinated, n (%)	P value
Type of laboratory			**.01**
Public	77 (26.4)	215 (73.6)	
Private	8 (11.4)	62 (88.6)	
Gender			**.75**
Male	40 (22.5)	138 (77.5)	
Female	45 (24.5)	139 (75.5)	
Education			**.005**
Nonpostgraduate	77 (26.8)	210 (73.2)	
Postgraduate	8 (10.7)	67 (89.3)	
Work experience (years)			**.09**
1-10	52 (27.4)	138 (72.6)	
>10	33 (19.2)	139 (80.8)	
Received biosafety manual			**.03**
No	77 (25.9)	220 (74.1)	
Yes	8 (12.3)	57 (87.7)	
Received biosafety training			**.36**
No	56 (25.3)	165 (74.7)	
Yes	29 (20.6)	112 (79.4)	

Discussion

Occupational exposure to NSI increases the risk of acquiring serious blood-borne infections among health care workers. Our findings showed that 60% of the laboratory staff had been injured while working in laboratories. Similar prevalence rates were reported from studies in Sana'a and India [12,13]. However, lower rates were reported from other countries including Kenya (25%), Saudi Arabia (14%), and Iran (2.3%) [6-8].

Our findings showed low availability of some key personal protective equipment (eg, masks, goggles, safety cabinets, and eye washers) especially in public laboratories. Injury in the laboratory was significantly less likely among laboratory staff who had received the biosafety manual. This indicates that training on biosafety helped to raise awareness as well as improve attitudes and protective practices [14]. Therefore, training of laboratory staff on biosafety manuals and making

personal protective equipment available are crucial to reduce exposure to NSIs and its possible grave consequences. Furthermore, strengthening the biosafety program and policies in laboratories together with enforcing use of personal protective equipment should be a cornerstone for reducing high NSIs in Yemen.

Half of the injured staff had received first aid. A lower percentage (28.8%) was reported in other counties including India [15]. There is a scarcity of data regarding HBV vaccination coverage among laboratory staff. Our study showed that only three-quarters of laboratory staff were vaccinated against HBV. In Saudi Arabia and Libya, studies showed that 97% and 82% were vaccinated against HBV, respectively [6,16]. In a previous study among laboratory staff in three public laboratories in Sana'a, 47% were vaccinated against HBV [12]. The coverage of the HBV vaccine was found to be significantly higher among postgraduate laboratory staff and those who had more than 10 years of experience, which may reflect their better knowledge of vaccination importance and the grave consequences of not

being vaccinated. In addition, there was significantly higher vaccination coverage among laboratory staff in private laboratories, which may reflect better biosafety practices and strict HBV vaccination requirements. Furthermore, laboratory staff who received the biosafety manual had higher vaccination coverage, which also reflects the influence of biosafety knowledge on vaccination.

In conclusion, occupational exposure to NSIs is still a major problem among laboratory staff in public and private laboratories in Sana'a, Yemen. The high incidence of NSIs among laboratory staff combined with not receiving first aid in nearly half of reported injuries increased the risk of HBV infection particularly among the nonvaccinated. Therefore, strengthening supervision, legalizing HBV vaccination for all laboratory staff, and optimizing laboratory practices regarding the management of sharps can minimize risks and prerequisites in Yemen.

Acknowledgments

Conflicts of Interest

None declared.

References

1. CDC. Infection prevention & control in dental settings URL: https://www.cdc.gov/oralhealth/infectioncontrol/index.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Foralhealth%2Finfectioncontrol%2Findex.htm

2. Salmanzadeh S, Rahimi Z, Goshtasbipour M, Meripoor M. The prevalence of needle-stick injuries among healthcare workers in Dasht-e-Azadegan, southern west of Iran. Int J Pharm Res Allied Sci 2016;5(2):417-422.

3. De Carli G, Abiteboul D, Puro V. The importance of implementing safe sharps practices in the laboratory setting in Europe. Biochem Med (Zagreb) 2014;24(1):45-56 [FREE Full text] [doi: 10.11613/BM.2014.007] [Medline: 24627714]

4. Attaullah S, Khan S, Ayaz S, Khan S, Ali I, Hoti N, et al. Prevalence of HBV and HBV vaccination coverage in health care workers of tertiary hospitals of Peshawar, Pakistan. Virol J 2011;8(1):275. [doi: 10.1186/1743-422x-8-275]

5. Alice T, Akhere A, Ikponwonsa O, Grace E. Knowledge and practice of infection control among health workers in a tertiary hospital in Edo state, Nigeria. Direct Res J Health Pharm 2013;1(2):20-27.

6. Masoumi-Asl H, Rahbar M, Soltani A, Pezeshki Z, Khanaliha K, Kolifarhood G. Epidemiology of needlestick injuries among healthcare workers in Tehran, Iran: a cross-sectional study. Arch Clin Infect Dis 2016 Nov 13. [doi: 10.5812/archcid.37605]

7. Akhter J, Al Johani S, Hammad L. Laboratory work practices and occupational hazards among laboratory health care workers: a health and safety survey. J Pharm Biomed Sci 2011;9(4):1-4.

8. Mbaisi EM, Ng'ang'a Z, Wanzala P, Omolo J. Prevalence and factors associated with percutaneous injuries and splash exposures among health-care workers in a provincial hospital, Kenya, 2010. Pan Afr Med J 2013;14:10 [FREE Full text] [doi: 10.11604/pamj.2013.14.10.1373] [Medline: 23504245]

9. Batra V, Goswami A, Dadhich S, Kothari D, Bhargava N. Hepatitis B immunization in healthcare workers. Ann Gastroenterol 2015;28(2):276-280 [FREE Full text] [Medline: 25830669]

10. Prüss-Ustün A, Rapiti E, Hutin Y. Estimation of the global burden of disease attributable to contaminated sharps injuries among health-care workers. Am J Ind Med 2005 Dec;48(6):482-490. [doi: 10.1002/ajim.20230] [Medline: 16299710]

11. U.S. Department of Health and Human Services. Biosafety in Microbiological and Biomedical Laboratories. 2009. URL: https://www.cdc.gov/labs/pdf/CDC-BiosafetyMicrobiologicalBiomedicalLaboratories-2009-P.PDF

12. Al Eryani Y, Nooradain N, Alsharqi K, Murtadha A, Al Serouri A, Khader Y. Unintentional injuries in the three references laboratories: Sana'a, Yemen. Int J Prev Med 2019;10(1):174 [FREE Full text] [doi: 10.4103/ijpvm.IJPVM_160_17]

13. Anupriya A, Manivelan S. KAP study on the assessment of needlestick injuries and occupational safety among health-care workers. Int J Med Sci Public Health 2015;4(3):342. [doi: 10.5455/ijmsph.2015.1810201464]

14. Khabour OF, Al Ali KH, Mahallawi WH. Occupational infection and needle stick injury among clinical laboratory workers in Al-Madinah city, Saudi Arabia. J Occup Med Toxicol 2018 May 21;13(1):15 [FREE Full text] [doi: 10.1186/s12995-018-0198-5] [Medline: 29942343]

15. Zaveri J, Karia J. Knowledge, attitudes and practice of laboratory technicians regarding universal work precaution. National Journal of Medical Research 2012;20(29):25-28 [FREE Full text]

16. Ziglam H, El-Hattab M, Shingheer N, Zorgani A, Elahmer O. Hepatitis B vaccination status among healthcare workers in a tertiary care hospital in Tripoli, Libya. J Infect Public Health 2013 Aug;6(4):246-251 [FREE Full text] [doi: 10.1016/j.jiph.2013.02.001] [Medline: 23806698]

Abbreviations

HBV: hepatitis B virus

NSI: needle stick injury

XSL·FO

RenderX

Original Paper

How Motivations for Using Buprenorphine Products Differ From Using Opioid Analgesics: Evidence from an Observational Study of Internet Discussions Among Recreational Users

Stephen F Butler[1*], PhD; Natasha K Oyedele[2*], MPH, MSc; Taryn Dailey Govoni[1*], MPH; Jody L Green[1*], PhD

[1]Inflexxion, Costa Mesa, CA, United States

[2]Office of Disease Prevention, National Institutes of Health, Rockville, MD, United States

[*]all authors contributed equally

Corresponding Author:
Stephen F Butler, PhD
Inflexxion
3070 Bristol Street
Suite 350
Costa Mesa, CA, 92626
United States
Phone: 1 6033057068
Email: sfbutler@inflexxion.com

Abstract

Background: Opioid use disorder (OUD) poses medical and societal concerns. Although most individuals with OUD in the United States are not in drug abuse treatment, buprenorphine is considered a safe and effective OUD treatment, which reduces illicit opioid use, mortality, and other drug-related harms. However, as buprenorphine prescriptions increase, so does evidence of misused, abused, or diverted buprenorphine. Users' motivations for extratreatment use of buprenorphine (ie, misuse or abuse of one's own prescription or use of diverted medication) may be different from the motivations involved in analgesic opioid products. Previous research is based on small sample sizes and use surveys, and none directly compare the motivations for using buprenorphine products (ie, tablet or film) with other opioid products having known abuse potential.

Objective: The aim of the study was to describe and compare the motivation-to-use buprenorphine products, including buprenorphine/naloxone (BNX) sublingual film and oxycodone extended-release (ER), as discussed in online forums.

Methods: Web-based posts from 2012 to 2016 were collected from online forums using the Web Informed Services internet monitoring archive. A random sample of posts was coded for motivation to use. These posts were coded into the following motivation categories: (1) use to avoid withdrawal, (2) pain relief, (3) tapering from other drugs, (4) opioid addiction treatment, (5) recreational use (ie, to get high), and (6) other use. Oxycodone ER, an opioid analgesic with known abuse potential, was selected as a comparator.

Results: Among all posts, 0.81% (30,576/3,788,922) discussed motivation to use one of the target products. The examination of query-selected posts revealed significantly greater discussion of buprenorphine products than oxycodone ER (*P*<.001). The posts mentioning buprenorphine products were more likely than oxycodone ER to discuss treatment for OUD, tapering down use, and/or withdrawal management (*P*<.001). Buprenorphine-related posts discussed recreational use (375/1020, 36.76%), although much less often than in oxycodone ER posts (425/508, 83.7%). Despite some differences, the overall pattern of motivation to use was similar for BNX sublingual film and other buprenorphine products.

Conclusions: An analysis of spontaneous, Web-based discussion among recreational substance users who post on online drug forums supports the contention that motivation-to-use patterns associated with buprenorphine products are different from those reported for oxycodone ER. Although the findings presented here are not expected to reflect the actual use of the target products, they may represent the interests and motivations of those posting on the online forums. Buprenorphine-related posts were more likely to discuss treatment for OUD, tapering, and withdrawal management than oxycodone ER. Although the findings are consistent with a purported link between the limited availability of medication-assisted therapies for substance use disorders and use of diverted buprenorphine products for self-treatment, recreational use was a motivation expressed in more than one-third of buprenorphine posts.

Introduction

Background

Opioid use disorder (OUD) poses medical and societal concerns, contributing to an increasing economic burden [1]. Approximately 11.8 million individuals older than 12 years misused opioids in 2016, with 11.5 million misusing prescription pain relievers [2]. The same source notes that nearly 2.1 million individuals received past-year specialty treatment for OUD, where only 1 in 5 individuals (21.1%) with OUD received such a treatment. A majority of individuals with OUD in the United States are not enrolled in drug abuse treatment [3]. Nevertheless, the amount of prescribed buprenorphine continues to increase [4-7], as does evidence of use of misused/abused/diverted buprenorphine [8-10]. Previous research suggests that users' motivations for extra-treatment use of buprenorphine (ie, misuse/abuse of one's own prescription or use of diverted medication) may be different from motivations to misuse, abuse, or divert analgesic opioid products [3,8,11-14]. All these studies are based on relatively small sample sizes and use surveys, and none directly compare the motivations for using buprenorphine products (ie, tablet or film) with other opioid products having known abuse potential. This study is an effort to use spontaneously occurring Web-based discussion among recreational drug users to better understand the various motivations for use, misuse, and diversion of buprenorphine and empirically examine whether and how the motivations observed for buprenorphine products differ from an opioid analgesic with known abuse potential.

Buprenorphine has been shown to be a safe and effective treatment for OUD, as well as for use in acute detoxification, stabilization, and long-term maintenance of individuals with OUD [15,16]. Opioid maintenance therapy with buprenorphine reduces illicit opioid use, mortality, and other drug-related harms among opioid-dependent individuals [17,18].

Buprenorphine has also been associated with diversion, misuse, and abuse, as the amount of prescribed buprenorphine has increased [4-7]. There is evidence that diversion, misuse, and abuse might vary across buprenorphine products. For example, a recent multi-dataset study [19] found evidence to conclude that prescription-adjusted abuse of the sublingual film was less than the single-entity tablet. Nevertheless, the abuse of buprenorphine quadrupled between 2008 and 2013, when buprenorphine was the fourth most commonly diverted prescription drug in law enforcement cases, behind oxycodone, hydrocodone, and alprazolam [20]. This raises the paradoxical situation: although buprenorphine is intended as a treatment for OUD, it is also likely to be abused, misused, and diverted.

As the prevalence of buprenorphine use outside the context of participation in an authorized, therapeutic program for treatment of OUD increases, evidence is emerging on the differences in the patterns of extra-therapeutic buprenorphine use versus analgesic opioids. Early work by Cicero and colleagues of individuals surveyed in substance abuse treatment [20] found that more than 30% of the individuals reported using buprenorphine to get high, yet only 1.6% of the individuals indicated buprenorphine as their primary drug of choice, compared with 32.4% of the individuals selecting oxycodone as their primary drug, with 29.8% of the individuals selecting heroin. A total of 50% to 60% of those using buprenorphine cited motivations, such as maintenance of abstinence, to aid in weaning off other drugs and manage situations when they needed to function (eg, work or social events). In a more recent survey [8], 52% of the survey respondents reported using buprenorphine to get high, and 4% of the respondents reported it as their drug of choice. In this subsequent survey, 79% of the respondents reported using buprenorphine products to maintain abstinence, and 53% of the respondents reported trying to wean themselves off other drugs. Self-medication for pain (37%) and treatment of emotional problems (19%) were also endorsed by survey respondents as motivations for using buprenorphine. More than 80% of the respondents who used diverted buprenorphine indicated that easier access to a buprenorphine prescriber would increase the likelihood of them procuring a prescription rather than obtaining buprenorphine on their own [8]. These findings are supported by a recent survey of individuals in Rhode Island [3]. This study revealed that the primary motivations underlying the use of diverted buprenorphine were management of withdrawal symptoms and self-treatment of OUD. These authors conclude that restrictive regulations limiting treatment capacity and inaccessibility of existing services have led to diversion of buprenorphine, largely for self-treatment. Other studies have reached similar conclusions [11-14], suggesting the possibility that illicit use of buprenorphine in the United States is motivated, at least for some, by the desire to self-detoxify, self-treat, or manage opioid cravings and other withdrawal symptoms. It is worth noting that in the studies cited, the authors have assumed that the motivations observed with respect to buprenorphine products are different from the motivations for nonmedical use (NMU) of analgesic opioids. Although this is understandable, to our knowledge, this assumption has not been empirically tested.

Discussion on the Web among recreational substance users who post on online drug forums is a method for understanding how drug users express their own motivations for using drugs. Online forums have been considered an ideal medium for individuals who abuse and misuse prescription drugs to communicate with each other [21-23], offering their uncensored ideas and beliefs, discussing trends and preferences, and providing education about recreational drug use [24]. Public online forums can be monitored unobtrusively and may reveal the methods, reasoning, and associated sentiment regarding the misuse of prescription drugs [25,26]. These spontaneous, peer-to-peer discussions also represent a different perspective than obtaining beliefs and

practices reported in consented surveys. Discussions regarding prescription opioids on these websites may provide insights into how individuals who post on these online forums view the impetus for use of specific prescription opioid products. Furthermore, the attitudes, preferences, and opinions shared on these online forums can be expected to inform those who view the websites but do not post messages. It is generally believed that most (over 50%) of those who visit online forums are "lurkers," individuals who frequently read message boards but do not post messages [27]. Thus, discussion about a particular substance or product on these message boards may not only represent the views and interests of those who post messages but also influence the attitudes and interests of the lurkers. Finally, relative to other media sources, such as Twitter, Facebook, or YouTube, online forums appear to retain their relevance on discussions on antisocial topics, such as substance abuse, where anonymity for those who post or read can be maintained.

Objectives

The aim of this study is to describe the motivations for buprenorphine use, as reported in discussions on the Web. To contextualize the findings of reported motivations and provide a stark contrast, we compared the motivational profile of buprenorphine products with oxycodone extended-release (ER), a nonbuprenorphine, prescription full μ-opioid agonist indicated for analgesia, known to be desirable for euphoric purposes or to get high [28]. Oxycodone ER is consistently reported as highly abused in samples of individuals in chemical dependence treatment [20,29]. In addition, a subanalysis examined for any differences with respect to motivations for using buprenorphine/naloxone (BNX) film as compared with other buprenorphine products. Quantitative and qualitative analytic approaches were used to compare the patterns of motivation-related discussion associated with each product group.

Methods

Study Design and Population

This study was a 2-part evaluation comprising (1) retrospective, quantitative analyses of Web-based drug discussion levels of buprenorphine products compared with oxycodone ER and (2) a retrospective, qualitative coding of internet post content regarding the motivation to use these products. A subanalysis was conducted to test for any motivational differences between BNX sublingual film and other buprenorphine formulations.

The study sample was drawn from an archive of internet posts extracted from publicly accessible online forums, which represent a population of recreational substance users and their Web-based communications regarding both illicit and prescription drugs. Posts were identified on 7 online forums that are monitored by National Addictions Vigilance Intervention and Prevention Program (NAVIPPRO's) Web Informed Services. The forums were chosen based on predefined criteria [25], specifying that the forum must (1) include a message board component; (2) be unedited; (3) promote free discussion of illicit and/or prescription drug use; (4) be open to the public; (5) be privately funded (eg, private donations); (6) be maintained/moderated by volunteers; and (7) be an English-language website (although not all authors who post messages on the Web-form reside in the United States). The posts written between January 1, 2012, and December 31, 2016, were archived in a database for further sampling and analysis. No personal identifiable information related to the author was saved. All research activities conducted for this study were deemed exempt from review by the New England Institutional Review Board.

Data Sample and Coding

Sampling Process for Quantitative Analyses

All the posts referencing a buprenorphine product or oxycodone ER during the study period were collected (product categories are defined in Table 1).

Oxycodone ER was selected to represent a full μ-opioid agonist product with a different medical indication (ie, treatment of pain), which is also known to be desirable for euphoric purposes or to get high [20,28,29]. Product-specific posts were identified from the entire archive of messages posted during the study period using standardized queries to identify posts that contained text matching search-string criteria. Search-string criteria for products included common misspellings, slang, and/or wildcard characters (eg, suboxone%, _xone, sub%, and bupe%). Search-string criteria were also generated to capture possible motivation-related discussion following a review by the research team of the literature and a manual review of a sample (approximately 500) of buprenorphine and oxycodone ER posts. In addition, consensus criteria were generated (eg, therapy%, detox%, rehab%, sober%, quit%, abuse%, rush%, high%, euphor%, nod%, relax%, and buzz%). These criteria were used to identify relevant query-selected posts, along with exclusion terms, to minimize the number of posts that did not pertain to the specified product or contain motivation-related discussion. Note that multiple posts may be submitted by the same author and multiple motivations may be mentioned by the same author in a single post or across multiple posts. In addition, more than one of the target products may be mentioned in a single post. The posts mentioning BNX sublingual film were classified as such and excluded from the other buprenorphine product categories. The posts that mentioned a buprenorphine product and oxycodone ER were included in both categories, so these categories are not mutually exclusive.

Table 1. Query inclusion terms.

Product	Inclusion terms
Buprenorphine/naloxone film[a]	Suboxone film; associated slang and common misspellings
Other buprenorphine products	Subutex; Zubsolv; Bunavail; Suboxone tablets; generic buprenorphine/naloxone and single-ingredient buprenorphine tablets; and associated slang and common misspellings
Any buprenorphine product	Buprenorphine/naloxone (film or other buprenorphine products)
Oxycodone extended-release[b]	Original OxyContin extended-release; reformulated OxyContin extended-release; oxycodone extended-release; and associated slang and common misspellings

[a]Posts containing specific mention of buprenorphine/naloxone sublingual film were classified in this category even if the posts also included a discussion of other buprenorphine products.

[b]It is possible for a post to mention a buprenorphine product and oxycodone extended-release. In those cases, the post would be captured in both categories, so there may be some level of overlap with the buprenorphine category.

Analytic Methods for Quantitative Analyses

Percentages and 95% CIs of posts (ie, number of motivation-to-use posts per total posts in archive×100) and authors (ie, number of motivation-to-use authors per total authors in archive×100) were included for each product category. Analyses compared the extent to which motivation was discussed and the number of people discussing motivation of the target products relative to the total discussion/authors in the Web Informed Services archive.

Sampling Process and Sample Size Calculations for Qualitative Evaluation

The posts to be analyzed for motivation-to-use comparisons were selected from the pool of query-selected posts as described above. Power analyses required 500 posts per prescription opioid category. To have a sufficient sample size for the subanalysis to examine differences between BNX sublingual film and other buprenorphine products, N=1500 was proposed to ensure 100 posts across each year of the 5-year study period for BNX sublingual film, other buprenorphine, and oxycodone ER. From among the pool of query-selected messages discussing the motivation to use the target products, posts were randomly selected for the evaluation of the motivation-to-use analyses. As some posts may not meet the inclusion criteria, a total of 2089 posts were sampled and manually reviewed to ensure that all posts coded pertained to the specified product and contained motivation-related content (see the flowchart in Figure 1). The primary analyses compared any buprenorphine and oxycodone ER. The category of any buprenorphine was created by combining the BNX sublingual film and other buprenorphine categories (Table 1).

Figure 1. Motivation-to-use content analysis flow chart. BNX: buprenorphine/naloxone; ER: extended-release.
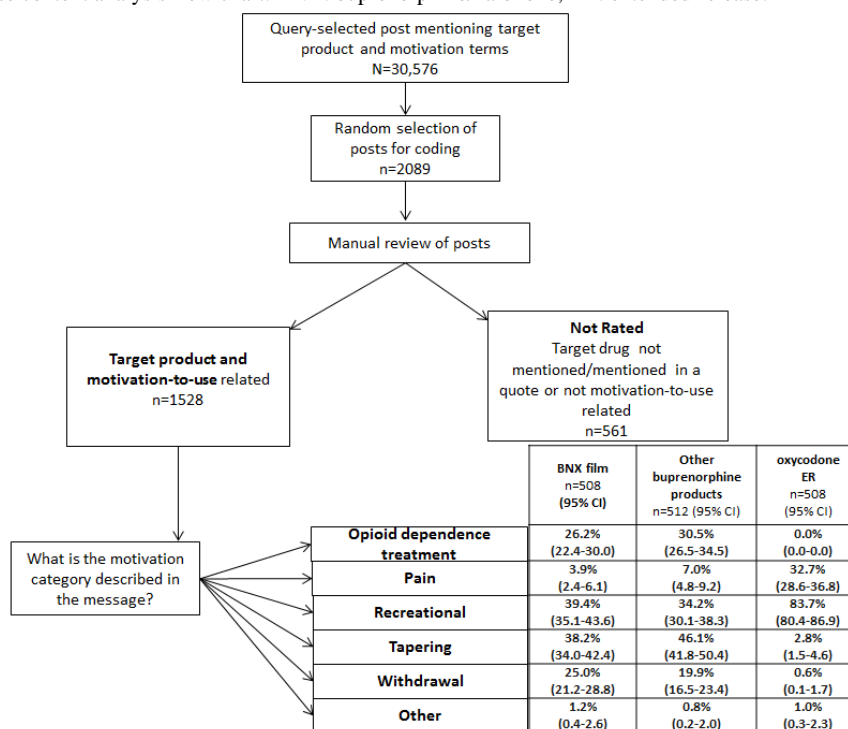
Content Analysis and Qualitative Evaluation of Motivation

A formal content analysis of the motivation to use was conducted on the random sample of posts related to any buprenorphine (BNX sublingual film and other buprenorphine) and oxycodone ER. Motivation to use was defined as any post discussing the rationale behind the use of a prescription opioid compound, including use as prescribed. The posts were reviewed by 2 trained coders. Each post was first categorized by coders as having content that was motivation related or not motivation related and relevant to one of the target products (Figure 1). The posts that were determined to contain motivation-to-use discussion were further coded into 6 categories: use to avoid withdrawal symptoms, use for pain relief, use to taper from other drugs, use to treat OUD, use for recreational purposes, and/or other motivations (Table 2). The posts that were determined not to pertain to the target drug of interest or have any motivation-related content were omitted from coding. Thus, posts were sampled, reviewed, and then resampled to ensure that the number of posts in each category was consistent with the power analysis requirements.

Table 2. Motivation-to-use category definitions and examples used to code motivation of use.

Motivation-to-use category[a]	Definition and examples
Opioid use disorder treatment	Pertains to any post that discusses the use of a product for opioid use disorder treatment or maintenance, using only products prescribed by a medical professional. For example, I was prescribed product X to get off product Y; My doctor gave me product X to help me get clean.
Pain	Posts that discuss the use of a product to treat physical pain. The source of the product is not considered within the context of this category; only the fact that it was discussed as being taken to mitigate pain is considered. For example, Product X is strong enough to alleviate pain symptoms; I was surprised that product X helped with my chronic pain.
Recreational	Posts that reference the recreational use of a product, including references to getting high, obtaining enjoyable sensations, and using for general enjoyment. For example, This is my first-time using product X to get high; I took product X to feel euphoric.
Tapering	Posts that discuss the use of a product to reduce or eliminate the use of another product. This includes self-medication. For example, If you want to taper down, you might consider taking product X; Product X helped me reduce my use of product Y.
Withdrawal	Pertains to posts that discuss the use of a product to mitigate or treat opioid withdrawal symptoms. For example, I use product Y to treat withdrawal symptoms; I need to wait until withdrawal symptoms start before using product Y.
Other	Pertains to posts that contain references to use a product for a purpose not described in the other motivation categories (eg, as they could not afford another prescription opioid product or to self-medicate depression). For example, I take product X to help with depression and anxiety; I regularly use product Y, but I did not have the money and restored to using product X.

[a]Motivation-to-use categories are not mutually exclusive, a single post may contain more than one motivation.

Analytic Methods

Intercoder Agreement

To assess the reliability of the coding, a random subsample of at least 20% of all posts was coded by both the primary and secondary coder, with the remaining posts coded by the primary coder [25]. The posts were assigned to the primary or secondary coder by a random-number generator. The coders were unaware of the posts coded by the other coder. For the overlapping sample, intercoder agreement was assessed. When coders disagreed, a consensus decision achieved a single set of codes for analysis. Intercoder agreement was calculated using the Kappa statistic [30]. Reliability was separately calculated for 2 buprenorphine categories (BNX sublingual film and other buprenorphine), along with oxycodone ER. Acceptable intercoder Kappa values were obtained for 2 coders across motivations and products, with an overall Kappa of $\kappa=0.85$ (Kappa ranged from $\kappa=0.77$ to $\kappa=0.91$), suggesting excellent agreement.

An Analytic Approach Toward Qualitative Post Analyses

Comparisons of the types of motivation discussed were calculated as percent and CIs (motivation-to-use category divided by the total sample randomly chosen to be coded). Comparisons of percents and percentages across product categories utilized the Chi-square statistic. The Type I error was set at alpha=.05. These comparisons were intended to compare the types of motivations discussed for the target products for the primary analyses (any buprenorphine versus oxycodone ER) and between BNX sublingual film and other buprenorphine products.

Results

Data Evaluation

A total of 3,788,922 posts were collected on the Web on all topics between January 1, 2012, and December 31, 2016, on the monitored online forums. Among all posts, 1,393,059 query-selected messages contained motivation-to-use–related mentions by a total of 67,156 unique authors (ie, posts submitted by the same username). Of the 3,788,922 motivation-related posts, 30,576 posts by 10,889 unique authors (some people

authored multiple posts) contained a query-identified reference to one of the target product categories and motivation-related term(s)—Table 3.

Table 3. Post and author counts of evaluated product categories (between January 1, 2012, and December 31, 2016).

Evaluated categories	Post counts (N=3,788,922)		Unique author counts (N=84,711)	
	Frequency, n (%)	95% CI	Frequency, n (%)	95% CI
Posts discussing motivation-to-use target product categories	30,576 (0.81)	0.80-0.82	10,889 (12.86)	12.63-13.08
Any buprenorphine product	18,170 (0.48)	0.47-0.49	6337 (7.48)	7.30-7.66
Buprenorphine/naloxone sublingual film[a]	3522 (0.09)	0.09-0.10	1772 (2.09)	2.00-2.19
Other buprenorphine products	14,648 (0.39)	0.38-0.39	4565 (5.39)	5.24-5.68
Oxycodone extended-release	12,406 (0.33)	0.32-0.33	4552 (5.37)	5.22-5.53
Total posts including motivation key words	1,393,059 (36.77)	36.72-36.82	67,159 (79.28)	79.01-79.55

[a]Posts containing specific mention of buprenorphine/naloxone sublingual film were classified in this category, even if the posts also included a discussion of other buprenorphine products. It is possible for a post to mention a buprenorphine product and oxycodone extended-release. In those cases, the post would be captured in both categories, so there may be some level of overlap.

Quantitative Evaluation of Online Forum Discussion

Estimates of the level of drug motivation-to-use discussion relative to all discussions on these online forums and 95% CIs derived from percents of target posts/total archive per 100 posts for each product category are presented in Table 3. The primary analysis of any buprenorphine versus oxycodone ER product revealed a significantly greater level of discussion (ie, mentions of the product, along with at least one motivation keyword) regarding any buprenorphine product (18,170/3,788,922, 0.49%) than oxycodone ER (12,406/3,788,922, 0.33%; *P*<.001). Similarly, buprenorphine was discussed by more authors (6337/84,711, 7.50%), compared with oxycodone ER (4552/84,711, 5.44%; *P*<.001; Table 3).

Within buprenorphine products, significantly fewer posts discussed motivation to use BNX sublingual film (3522/3,788,922, 0.09%) than other buprenorphine products (14,648/3,788,922, 0.40%; *P*<.001; Table 3). Table 3 also shows that BNX sublingual film had fewer authors (1772/84,711, 2.18%) than the other buprenorphine product group (4565/84,711, 5.4%; *P*<.001).

Qualitative Evaluation of Motivations for Use and Discussion Themes

The primary comparison of interest was motivation to use any buprenorphine product versus motivations discussed in posts referencing oxycodone ER. As can be seen in Table 4, the pattern of references for motivation to use buprenorphine products was very different from oxycodone ER.

Every coded motivation category, except other, was significantly different for these 2 product categories (*P*<.001; Table 4). Unsurprisingly, the motivations coded for buprenorphine posts reflecting buprenorphine use in a way that is consistent with self-medication aims, such as tapering (430/1020, 42.20%), managing withdrawal (230/1020, 22.50%), and opioid dependent treatment references (289/1020, 28.30%), were much more likely to be observed than in posts referencing oxycodone ER. Oxycodone ER posts discussed these self-medication–related motivations in 0 posts for OUD treatment to 14 out of the 508

coded posts (2.8%; *P*<.001 for all comparisons except for the other category, which was not significant; Table 4).

Discussion related to the use of buprenorphine products for OUD treatment largely mentioned procuring the product via a prescription from a medical professional. References included use as prescribed through current participation in a maintenance program or past participation in a treatment program, which could no longer be afforded. Nearly 25% of the posts were coded for both OUD treatment and tapering motivations, particularly when there was mention of past participation in an OUD treatment program. However, discussions of current use tended to be associated with discussions of self-detoxification (ie, managing withdrawal or tapering from other drugs).

Recreational use, on the other hand, was much more likely to be mentioned in oxycodone ER posts (425 out of 508 posts, 83.7%) than in buprenorphine posts (375 out of 1020 posts, 36.76%; *P*<.001). However, it should be noted that this suggests that more than one-third of buprenorphine posts mentioned use to get high, second only to tapering (430/1020 or 42.20%). An informal content review of posts referencing buprenorphine products' (BNX sublingual film and other buprenorphine products) recreational use suggests a wide range of subtopics, including seeking or obtaining feelings of euphoria and experiencing hallucinations and sickness. Recreational use posts also discussed the ease of accessibility and difficulties while abusing buprenorphine products formulated with naloxone. Several recreation-related buprenorphine posts referenced use by alternative routes of administration, including intravenous (n=54), intranasal (n=23), rectal (n=6), and smoking (n=3; see Multimedia Appendix 1 for some examples).

The use of oxycodone ER to treat past and/or present physical pain accounted for nearly one-third of the Web-based discussion of this product compared with less than 5.50% (56/1020) for buprenorphine (Table 4). There were several mentions of use for both pain relief and recreational use, where an individual could be prescribed oxycodone ER for pain management but could also subsequently progress to recreational use over the course of therapy (see Multimedia Appendix 1). The use of buprenorphine products for pain was infrequently discussed

(56/1020, 5.50%) and, when discussed, generally reflected the authors' unfamiliarity of their use for pain management. Other unspecified motivation to use buprenorphine was rarely coded (10/1020, 1.00%) and included off-label use of the product to treat depression and social anxiety.

We also compared the discussion specific to BNX sublingual film with other buprenorphine products. As can be seen in Table 5, the motivation to use other buprenorphine products for tapering (236/512, 46.1%) was significantly greater than for BNX sublingual film (194/508, 38.2%; P=.01; Table 5). The use of other buprenorphine products to treat physical pain (36/512, 7.0%) was also significantly different from BNX sublingual film (20/508, 3.9%; P=.04). Discussion of OUD treatment, recreational use, withdrawal, and other topics for other buprenorphine products were not significantly different from sublingual BNX sublingual film (Table 5).

Table 4. Percentage of posts mentioning specific motivation-to-use categories and Chi-square *P* values for pairwise differences.

Motivation-to-use category	Buprenorphine products (N=1020)[a,b]		Oxycodone extended-release (N=508)[a,b]		Buprenorphine versus oxycodone extended-release
	Frequency, n (%)	95% CI	Frequency, n (%)	95% CI	*P* value[c]
Opioid use disorder treatment	289 (28.30)	25.6-31.1	0 (0.0)	0.0-0.0	*<.001*
Pain	56 (5.50)	4.1-6.9	166 (32.7)	28.6-36.8	*<.001*
Recreational	375 (36.80)	33.8-39.7	425 (83.7)	80.5-86.9	*<.001*
Tapering	430 (42.20)	39.1-45.2	14 (2.8)	1.4-4.2	*<.001*
Withdrawal	230 (22.50)	19.9-25.0	3 (0.6)	0.1-1.9	*<.001*
Other	10 (1.00)	0.4-1.6	5 (1.0)	0.3-2.3	.99

[a]Number of posts coded for motivation content for each product category.

[b]As posts may mention more than one motivation-to-use, percentages do not add up to 100%.

[c]*P* values in italics are significant.

Table 5. Percentage of posts mentioning specific motivation-to-use categories and Chi-square *P* values for pairwise differences in buprenorphine/naloxone sublingual film versus other buprenorphine products.

Motivation-to-use category	Buprenorphine/naloxone sublingual film (N=508)[a,b]		Other buprenorphine products (N=512)[a,b]		Sublingual film versus other buprenorphine
	Frequency, n (%)	95% CI	Frequency, n (%)	95% CI	*P* value[c]
Opioid use disorder treatment	133 (26.2)	22.4-30.0	156 (30.5)	26.5-34.5	.14
Pain	20 (3.9)	2.4-6.1	36 (7.0)	4.8-9.2	*.04*
Recreational	200 (39.4)	35.1-43.6	175 (34.2)	30.1-38.3	.09
Tapering	194 (38.2)	34.0-42.4	236 (46.1)	41.8-50.4	*.01*
Withdrawal	127 (25.0)	21.2-28.8	102 (19.9)	16.5-23.4	.06
Other	6 (1.2)	0.4-2.6	4 (0.8)	0.2-2.0	.55

[a]Number of posts coded for motivation content for each product category.

[b]As posts may mention more than one motivation-to-use, percentages do not add to 100%.

[c]*P* values in italics are significant.

Discussion

Principal Findings

This study compared the motivations to use expressed by recreational substance users in Web-based posts for buprenorphine products and an opioid analgesic product with known abuse potential (oxycodone ER). As expected, based on previous analyses of Web-based discussions of oxycodone ER use for recreational purposes [25,26], motivations to use oxycodone ER were primarily related to recreational use and treating pain (the labeled indication). It is unsurprising to note that on an online forum dedicated to recreational use of substances, recreational use of oxycodone ER (83.7%) was the most frequently coded category for this medication, with the second most often coded motivation being pain treatment (32.7%). In contrast, although recreational use of buprenorphine products was observed, at 36.8%, it was coded much less often than oxycodone ER–related posts.

The finding that motivation-to-use patterns of buprenorphine are different from a prescription opioid indicated for the treatment of pain is consistent with other studies [11-14] using different data sources and populations. However, to our knowledge, this study is the first to directly compare motivation to use oxycodone ER with buprenorphine products. This direct comparison confirms the notion that buprenorphine products are discussed differently than oxycodone ER by those who post

messages on online forums dedicated to recreational substance use. Although it would have been interesting to examine additional analgesics, the intensive work involved in coding required that we identify a single reasonable representative of an opioid analgesic with known abuse potential, in this case, oxycodone ER. The study period (2012 to 2016) was well after the 2010 reformulation of oxycodone ER, although it is possible that some oxycodone ER discussion involved references to the preformulation version. Although not tested directly, it may be reasonable to speculate that the motivation-to-use pattern observed for oxycodone ER would be similar to other full μ-opioid agonists. Consider, for instance, a study by McNaughton and colleagues [25], who coded posts from the Web Informed Services archive for the extent to which various opioid compounds were endorsed for recreational use; they found endorsement for abuse to be greatest for oxymorphone, followed by hydromorphone, hydrocodone, oxycodone ER, morphine ER, and tramadol. Oxycodone ER was in the middle of this group of products and was significantly less endorsed for abuse than oxymorphone and hydromorphone, and it was significantly more endorsed than tramadol. The calculated endorsement ratio for oxycodone ER was not significantly different from hydrocodone or morphine ER. Thus, one might expect that, with the exception of tramadol, the other compounds' posts would be similarly discussed in a recreational context on the Web.

Furthermore, although some differences were observed in this study between BNX sublingual buprenorphine and other buprenorphine products, the overall pattern of motivations examined was quite similar. The examination of both posts referencing BNX sublingual film and posts referencing other buprenorphine products revealed a range of motivations related to addiction management, including OUD treatment, and self-management of tapering and withdrawal. Although some interest in pain relief was detected, this tended to be at much lower levels than the discussion of efforts to quit or manage opioid withdrawal.

Despite the clearly articulated interest in the use of buprenorphine products for withdrawal management and self-tapering, the recreational use of BNX sublingual film and other buprenorphine products was discussed just as frequently as the use of these products for addiction management, underscoring the dual use of these products for both recreational and self-medication intent. Therefore, self-medication in this context does not necessarily imply that the aims of the user is to decrease or stop using opioids. Furthermore, the way the authors discuss recreational substance use of buprenorphine products (BNX sublingual film or other buprenorphine) may be different from the way products such as oxycodone ER are discussed. The presence of naloxone, as well as the film or sublingual tablet formulations, may impact the overall sentiment expressed in Web-based posts regarding recreational use, which have been shown to be different for different products [25,31]. Further studies are required to investigate whether the nature of recreational-use discussions of buprenorphine differ from recreational-use discussions about opioid analgesics.

Owing to the unstructured nature of the online forum content, the source of procurement could not be reliably determined. It is possible that a lack of reference to obtaining a buprenorphine product as a part of an addiction treatment program potentially involved diverted buprenorphine products. It is also possible that some references to tapering and withdrawal in these posts may be related to appropriate OUD treatment. On the basis of post content, it was not always possible to distinguish appropriate medically supervised treatment from the use of diverted product to self-medicate. Nevertheless, this study's findings are consistent with studies specifically investigating diverted buprenorphine use [3,8]. These authors and others [32] suggest that health insurance coverage, limited Medicaid coverage, and stigma against pharmacotherapy for OUD have resulted in a shortage of treatment capacity and led to inaccessibility of existing services. Consequently, the persistence of these societal conditions is likely to ensure that the individuals in need of treatment will continue to self-treat with diverted medications. Although we concur, generally, with this conclusion, recreational use (ie, use to get high) was cited relatively frequently in the coded posts—a finding consistent with other studies [8]. It may be a mistake to assume that legitimate access alone accounts for buprenorphine use outside of a treatment program.

Limitations

This study has limitations that should be considered. A common concern with respect to data collected from online forums is that those who post may not be truthful. Although the veracity of any individual post cannot be ascertained, it should be noted that individuals who participate in the examined forums represent stable communities of drug users who are self-policing; therefore, the posted information that is inconsistent with others' experiences tends to be corrected by the online community [33]. As with any self-report data, self-report biases cannot be ruled out. However, the anonymity that is inherent on these forums, as well as the fact that the opinions expressed are targeted to peers and not researchers or other authorities, renders self-report bias in a different light for these data.

Although the online forums included were selected according to a priori criteria, they were not randomly selected. Sampling bias may exist in trends discussed and users' traits of selected forums versus unsampled forums; however, the included forums were selected based on the volume of recreational-use discussion, making it a saturated sample. The forums used in this study may differ in the amount and tone of discussion devoted to using and potentially abusing pharmacological products. This study's findings may only be reflective of communities of recreational drug users who participate in online forums and may not be representative of all Web-based discussion. In addition, although discussions on the Web may capture the interests, intentions, and motivations expressed by those who post on the Web, these data are not intended to capture the actual use of the target products.

We have noted that the examination of post content from online forums provides many advantages for the researcher, including the ability to eavesdrop on conversations among individuals who use drugs illicitly rather than obtain information through some authority (ie, researchers, law enforcement, and health

care workers). However, a disadvantage of the method is that the anonymity prevents us from being able to characterize who the authors are and place them within the context of known populations of illicit and NMU of substances. A study [34] attempted to characterize visitors to a single, large online forum, Bluelight.org, using a survey. Most (63%) of the respondents from a sample 897 respondents were from the United States; the remaining 37% of the respondents were from the United Kingdom (12%), Australia (9%), Canada (6%), and 11% were from *other*. The respondents had an average age of 25 years (SD 12) and were mostly male (76%) and white (86%), and almost 80% of them had some college education, graduated college, or had postgraduate training. About 35% of the respondents reported some alcohol or drug treatment and 31% of the respondents reported past 30-day NMU of a prescription opioid. To place these demographics into context, we compared them with recent NAVIPPRO Addiction Severity Index-Multimedia Version substance use treatment center data [35]. Compared with the demographics of the internet responders cited above, fewer of the 217,240 treatment patients were male (65%) and white (60%), and 22% of these patients reported past 30-day prescription opioid NMU, compared with 31% of the online forum respondents. Another NAVIPPRO treatment center study [36] of prescription opioid NMU reported on education level and found 30% of the patients with some college or higher level of education and an older population (nearly 80% of them were older than 24 years). Although the inability to precisely describe the population of authors in this study remains a limitation, it seems likely that the present sample is younger and more well educated than the individuals in treatment for substance use disorder.

We acknowledge that the selection of the specific query terms used to identify posts discussing the target products and potential motivations may have excluded terms that omitted relevant posts to an unknown extent. Furthermore, differentiating among the motivation categories presented in Table 2 requires some interpretation of motives. Tapering or managing withdrawal symptoms does not imply a desire on the part of the author to stop using drugs or seek treatment. However, the high intercoder reliability obtained while coding these categories, as well as the clear differentiation between the results for buprenorphine and oxycodone ER, suggests that the findings presented here are reliable and valid.

Only a sample of posts was selected from the 5-year study period, and longitudinal motivations for use trends were not analyzed. The identification of product-specific posts by querying based on keywords is incomplete; it may conflate some posts discussing more than one of the target products and may have missed some motivations that were not captured in the keyword list. Furthermore, as querying methods capture posts that are determined to be irrelevant to the target topic upon review by trained coders (in this case, specific product mentions and discussion of motivation-to-use), the quantitative analyses based on querying results may overestimate the amount of the Web-based discussion presented here. However, it is unlikely that this lack of precision differentially impacts the products compared, as human review of the sampled posts resulted in almost identical proportions of excluded posts for the products

examined. It is also possible that there are terms and slang that are unknown to us or references to a product or motivation that were not captured in this study. However, coders spend considerable time following threads and discussions on the online forum and becoming familiar with the unique communication styles of these communities on the Web. Therefore, it is likely that coders for this study were able to capture the essence of the meaning available to the majority of forum visitors [31].

The posts analyzed here were posted over several years, ending in 2016. It is acknowledged that much has changed since then. In recent years, the use of illicit fentanyl has increased dramatically [37], although at the same time, the prescriptions dispensed for opioid analgesics have decreased, largely as a response to Centers for Disease Control and Prevention guidelines published in 2016 [38,39]. The recent introduction of buprenorphine subcutaneous formulations [40] may further impact the Web-based discussion of buprenorphine products. Future investigations should examine how these changes are reflected in the Web-based discussion of opioids in general, particularly buprenorphine.

Strengths

The study strengths include the use of a relatively large sample size, inclusion of quantitative and qualitative analyses, and the use of systematic and consistent methods that build on previously published studies. Additional strengths include the use of a standardized coding methodology, analysis of Web-based post discussions with acceptable interrater agreement, and the systematic archiving and storage of forum posts over time, allowing for retrospective evaluation of data and circumventing bias of forum moderators who may delete older posts.

Conclusions

Although prior studies have suggested that the motivation to use diverted buprenorphine products is different from the motivations for abuse of opioid analgesics [20,28,29], none have directly compared motivations for abuse of these products. In this study, we directly compared motivations for using or abusing buprenorphine products with those expressed for one, widely abused prescription opioid indicated for analgesia and known to be desirable for euphoric purposes or to get high (ie, oxycodone ER). Compared with oxycodone ER, discussion of buprenorphine was significantly more likely to reflect OUD treatment, tapering, and withdrawal management. Buprenorphine products were associated with less discussion of use for recreational purposes or pain relief relative to oxycodone ER. These findings are consistent with the work of others. Some authors have suggested a link between the limited availability of medication-assisted therapies and use of diverted buprenorphine products [3,8,32]. However, this study and others [4-7] found evidence for a meaningful level of misuse, abuse, and diversion of the product, which may or may not be associated with the availability of medication-assisted therapy. We observed little difference in motivation-to-use patterns between BNX sublingual film and other buprenorphine products. Finally, this study also supports the value of Web-based discussions among a population of interest, namely, recreational

users of drugs, to better understand motivations for using   different prescription opioid products.

Acknowledgments

Conflicts of Interest

All authors are (or were) employed by Inflexxion, an IBH Company, which provides independent consultation to the pharmaceutical industry. Inflexxion, an IBH Company, routinely provides such services to a number of pharmaceutical companies.

Multimedia Appendix 1
Examples of motivation-to-use internet discussion posts.
[DOCX File , 17 KB - publichealth_v6i1e16038_app1.docx]

References

1. Strassels SA. Economic burden of prescription opioid misuse and abuse. J Manag Care Pharm 2009 Sep;15(7):556-562 [FREE Full text] [doi: 10.18553/jmcp.2009.15.7.556] [Medline: 19739878]
2. Ahrnsbrak R, Bose J, Hedden SL, Lipari RN, Park-Lee E. Substance Abuse and Mental Health Services Administration. 2017. Key Substance Use and Mental Health Indicators in the United States: Results from the 2016 National Survey on Drug Use and Health URL: https://www.samhsa.gov/data/sites/default/files/NSDUH-FFR1-2016/NSDUH-FFR1-2016.htm [accessed 2019-10-21]
3. Carroll JJ, Rich JD, Green TC. The more things change: Buprenorphine/Naloxone diversion continues while treatment remains inaccessible. J Addict Med 2018;12(6):459-465 [FREE Full text] [doi: 10.1097/ADM.0000000000000436] [Medline: 30095563]
4. Cassidy TA, DasMahapatra P, Black RA, Wieman MS, Butler SF. Changes in prevalence of prescription opioid abuse after introduction of an abuse-deterrent opioid formulation. Pain Med 2014 Mar;15(3):440-451. [doi: 10.1111/pme.12295] [Medline: 24330279]
5. Dasgupta N, Bailey EJ, Cicero T, Inciardi J, Parrino M, Rosenblum A, et al. Post-marketing surveillance of methadone and buprenorphine in the United States. Pain Med 2010 Jul;11(7):1078-1091. [doi: 10.1111/j.1526-4637.2010.00877.x] [Medline: 20545875]
6. Lavonas EJ, Severtson SG, Martinez EM, Bucher-Bartelson B, Le Lait M, Green JL, et al. Abuse and diversion of buprenorphine sublingual tablets and film. J Subst Abuse Treat 2014 Jul;47(1):27-34 [FREE Full text] [doi: 10.1016/j.jsat.2014.02.003] [Medline: 24680219]
7. Larance B, Lintzeris N, Ali R, Dietze P, Mattick R, Jenkinson R, et al. The diversion and injection of a buprenorphine-naloxone soluble film formulation. Drug Alcohol Depend 2014 Mar 1;136:21-27. [doi: 10.1016/j.drugalcdep.2013.12.005] [Medline: 24461476]
8. Cicero TJ, Ellis MS, Chilcoat HD. Understanding the use of diverted buprenorphine. Drug Alcohol Depend 2018 Dec 1;193:117-123 [FREE Full text] [doi: 10.1016/j.drugalcdep.2018.09.007] [Medline: 30359928]
9. Lin LA, Lofwall MR, Walsh SL, Gordon AJ, Knudsen HK. Perceptions and practices addressing diversion among US buprenorphine prescribers. Drug Alcohol Depend 2018 May 1;186:147-153 [FREE Full text] [doi: 10.1016/j.drugalcdep.2018.01.015] [Medline: 29573649]
10. Lofwall MR, Walsh SL. A review of buprenorphine diversion and misuse: the current evidence base and experiences from around the world. J Addict Med 2014;8(5):315-326 [FREE Full text] [doi: 10.1097/ADM.0000000000000045] [Medline: 25221984]
11. Bazazi AR, Yokell M, Fu JJ, Rich JD, Zaller ND. Illicit use of buprenorphine/naloxone among injecting and noninjecting opioid users. J Addict Med 2011 Sep;5(3):175-180 [FREE Full text] [doi: 10.1097/ADM.0b013e3182034e31] [Medline: 21844833]
12. Mitchell SG, Kelly SM, Brown BS, Reisinger HS, Peterson JA, Ruhf A, et al. Uses of diverted methadone and buprenorphine by opioid-addicted individuals in Baltimore, Maryland. Am J Addict 2009;18(5):346-355 [FREE Full text] [doi: 10.3109/10550490903077820] [Medline: 19874152]
13. Monte AA, Mandell T, Wilford BB, Tennyson J, Boyer EW. Diversion of buprenorphine/naloxone coformulated tablets in a region with high prescribing prevalence. J Addict Dis 2009 Jul;28(3):226-231. [doi: 10.1080/10550880903014767] [Medline: 20155591]

XSL·FO
RenderX

14. Schuman-Olivier Z, Albanese M, Nelson SE, Roland L, Puopolo F, Klinker L, et al. Self-treatment: illicit buprenorphine use by opioid-dependent treatment seekers. J Subst Abuse Treat 2010 Jul;39(1):41-50. [doi: 10.1016/j.jsat.2010.03.014] [Medline: 20434868]

15. Johnson RE, Jaffe JH, Fudala PJ. A controlled trial of buprenorphine treatment for opioid dependence. J Am Med Assoc 1992 May 27;267(20):2750-2755. [Medline: 1578593]

16. Jaffe JH, O'Keeffe C. From morphine clinics to buprenorphine: regulating opioid agonist treatment of addiction in the United States. Drug Alcohol Depend 2003 May 21;70(2 Suppl):S3-11. [doi: 10.1016/s0376-8716(03)00055-3] [Medline: 12738346]

17. Fullerton CA, Kim M, Thomas CP, Lyman DR, Montejano LB, Dougherty RH, et al. Medication-assisted treatment with methadone: assessing the evidence. Psychiatr Serv 2014 Feb 1;65(2):146-157. [doi: 10.1176/appi.ps.201300235] [Medline: 24248468]

18. Thomas CP, Fullerton CA, Kim M, Montejano L, Lyman DR, Dougherty RH, et al. Medication-assisted treatment with buprenorphine: assessing the evidence. Psychiatr Serv 2014 Feb 1;65(2):158-170. [doi: 10.1176/appi.ps.201300256] [Medline: 24247147]

19. Butler SF, Black RA, Severtson SG, Dart RC, Green JL. Understanding abuse of buprenorphine/naloxone film versus tablet products using data from ASI-MV substance use disorder treatment centers and RADARS® System Poison Centers. J Subst Abuse Treat 2018 Jan;84:42-49. [doi: 10.1016/j.jsat.2017.10.010] [Medline: 29195592]

20. Cicero TJ, Ellis MS, Surratt HL, Kurtz SP. Factors contributing to the rise of buprenorphine misuse: 2008-2013. Drug Alcohol Depend 2014 Sep 1;142:98-104. [doi: 10.1016/j.drugalcdep.2014.06.005] [Medline: 24984689]

21. Boyer EW, Lapen PT, Macalino G, Hibberd PL. Dissemination of psychoactive substance information by innovative drug users. Cyberpsychol Behav 2007 Feb;10(1):1-6. [doi: 10.1089/cpb.2006.9999] [Medline: 17305442]

22. Wax PM. Just a click away: recreational drug web sites on the internet. Pediatrics 2002 Jun;109(6):e96. [doi: 10.1542/peds.109.6.e96] [Medline: 12042590]

23. Zinkham GM, Kwak H, Morrison M, Peters CO. Web-based chatting: consumer communication in cyberspace. J Consum Psychol 2003;13(1-2):17-27 [FREE Full text]

24. Nielsen S, Barratt MJ. Prescription drug misuse: is technology friend or foe? Drug Alcohol Rev 2009 Jan;28(1):81-86. [doi: 10.1111/j.1465-3362.2008.00004.x] [Medline: 19320680]

25. McNaughton EC, Black RA, Zulueta MG, Budman SH, Butler SF. Measuring online endorsement of prescription opioids abuse: an integrative methodology. Pharmacoepidemiol Drug Saf 2012 Oct;21(10):1081-1092. [doi: 10.1002/pds.3307] [Medline: 22777908]

26. Vosburg SK, Haynes C, Besharat A, Green JL. Changes in drug use patterns reported on the web after the introduction of ADF OxyContin: findings from the Researched Abuse, Diversion, and Addiction-Related Surveillance (RADARS) System Web Monitoring Program. Pharmacoepidemiol Drug Saf 2017 Sep;26(9):1044-1052. [doi: 10.1002/pds.4248] [Medline: 28653782]

27. Nonnecke B, Preece J. Lurker Demographics: Counting the Silent. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. 2000 Presented at: CHI'00; April 1-6, 2000; The Hague, Netherlands p. 73-80 URL: https://www.cc.gatech.edu/classes/AY2003/cs6470_fall/demographics.pdf

28. Butler SF, Fernandez KC, Chang A, Benoit C, Morey LC, Black R, et al. Measuring attractiveness for abuse of prescription opioids. Pain Med 2010 Jan;11(1):67-80. [doi: 10.1111/j.1526-4637.2009.00736.x] [Medline: 20002325]

29. Butler SF, Black RA, Cassidy TA, Dailey TM, Budman SH. Abuse risks and routes of administration of different prescription opioid compounds and formulations. Harm Reduct J 2011 Oct 19;8:29 [FREE Full text] [doi: 10.1186/1477-7517-8-29] [Medline: 22011626]

30. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [doi: 10.2307/2529310] [Medline: 843571]

31. McNaughton EC, Black RA, Weber SE, Butler SF. Assessing abuse potential of new analgesic medications following market release: an evaluation of Internet discussion of tapentadol abuse. Pain Med 2015 Jan;16(1):131-140. [doi: 10.1111/pme.12547] [Medline: 25244069]

32. Mitchell SG, Gryczynski J, Schwartz RP. Commentary on 'The More Things Change: Buprenorphine/Naloxone Diversion Continues While Treatment is Inaccessible'. J Addict Med 2018;12(6):424-425 [FREE Full text] [doi: 10.1097/ADM.0000000000000437] [Medline: 30095564]

33. McNaughton EC, Coplan PM, Black RA, Weber SE, Chilcoat HD, Butler SF. Monitoring of internet forums to evaluate reactions to the introduction of reformulated OxyContin to deter abuse. J Med Internet Res 2014 May 2;16(5):e119 [FREE Full text] [doi: 10.2196/jmir.3397] [Medline: 24800858]

34. Chiauzzi E, Dasmahapatra P, Lobo K, Barratt MJ. Participatory research with an online drug forum: a survey of user characteristics, information sharing, and harm reduction views. Subst Use Misuse 2013 Jun;48(8):661-670. [doi: 10.3109/10826084.2013.800117] [Medline: 23750771]

35. Butler SF, McNaughton EC, Black RA, Cassidy TA. Evaluation of the Relative Abuse of an OROS Extended-release Hydromorphone HCI Product: Results From 3 Postmarket Surveillance Studies. Clin J Pain 2018 Jul;34(7):618-628. [doi: 10.1097/AJP.0000000000000585] [Medline: 29298186]

36.   Cassidy TA, Thorley E, Black RA, DeVeaugh-Geiss A, Butler SF, Coplan P. Abuse of reformulated OxyContin: updated findings from a sentinel surveillance sample of individuals assessed for substance use disorder. J Opioid Manag 2017;13(6):425-440. [doi: 10.5055/jom.2017.0419] [Medline: 29308589]

37.   Centers for Disease Control (CDC). Opioid Overdose: Fentanyl. 2019. URL: https://www.cdc.gov/drugoverdose/opioids/fentanyl.html [accessed 2019-10-07]

38.   Dowell D, Haegerich TM, Chou R. CDC Guideline for Prescribing Opioids for Chronic Pain - United States, 2016. MMWR Recomm Rep 2016 Mar 18;65(1):1-49. [doi: 10.15585/mmwr.rr6501e1] [Medline: 26987082]

39.   Finnegan J. FierceHealthcare. 2019 Jul 18. Decline in Opioid Prescriptions Translates to Drop in Drug Overdose Deaths for the First Time in Decades URL: https://www.fiercehealthcare.com/practices/decline-opioid-prescriptions-translates-to-drop-drug-overdose-deaths-for-first-time [accessed 2019-10-07]

40.   Albayaty M, Linden M, Olsson H, Johnsson M, Strandgården K, Tiberg F. Pharmacokinetic evaluation of once-weekly and once-monthly buprenorphine subcutaneous injection depots (CAM2038) versus intravenous and sublingual buprenorphine in healthy volunteers under naltrexone blockade: an open-label phase 1 study. Adv Ther 2017 Feb;34(2):560-575. [doi: 10.1007/s12325-016-0472-9] [Medline: 28070862]

Abbreviations

BNX: buprenorphine/naloxone
ER: extended-release
IBH: Integrated Behavioral Health
NAVIPPRO: National Addictions Vigilance Intervention and Prevention Program
NMU: nonmedical use
OUD: opioid use disorder
PLC: public limited company

XSL•FO

RenderX