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A Cross-Sectional Review of Cervical Cancer Messages on Twitter during Cervical Cancer Awareness Month

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Abstract

Objectives—The objectives of this study were to quantify personal stories about cervical cancer and to determine the proportion and sentiment (positive vs. negative) of messages (“tweets”) that discussed cervical cancer prevention strategies on Twitter.

Methods—This study was a cross-sectional Twitter review of English-language top tweets about cervical cancer during the cervical cancer awareness month, January 2016. Theme categories were identified and tweets were independently coded by two reviewers; discrepancies in coding were resolved by a third reviewer. Descriptive statistical analyses were performed.

Results—During January 2016, 348 top tweets about cervical cancer were identified. Professional health organizations produced 20.7% of tweets and individuals identifying themselves as healthcare professionals contributed an additional 4%. In addition to the tweet, 45.1% attached a photo or video; 54.6% included links to a larger article. Only 11.2% of tweets included personal stories from cervical cancer patients. Among the top tweets, 70.3% were focused on prevention through screening and/or HPV vaccination, with 97.4% recommending such practices. A substantial proportion of the Twitter traffic (24.7%) referenced the #SmearForSmear campaign by the patient-advocate organization Jo’s Cervical Cancer Trust, based in the United Kingdom.

Conclusions—Analysis of top tweets during the cervical cancer awareness month showed that although personal stories about cervical cancer were rare, cervical cancer prevention was a popular

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None of the authors have any conflict of interest.

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None of the authors have any conflicts of interest to declare.

The study was deemed exempt from IRB review by the University of Minnesota IRB since all data are publically available.

topic during the cervical cancer awareness month. This was largely driven by a picture-based twitter campaign from a single advocacy organization.

Keywords

Cervical cancer; HPV vaccine; social media; Twitter

Introduction

Public concern about cancer and motivation to seek preventative strategies are proportional to a population's perceived risk of developing a cancer [1]. Public perception is influenced to a greater degree by media coverage of health rather than the true incidence or mortality [1, 2]. Prior to the advent of social media, news coverage and presentation of health topics such as cancer were largely filtered by the interest of media organizations or individual reporters. Media coverage was often spurred by the diagnosis or death of a public figure due to a particular disease. This resulted in overrepresentation of certain forms of cancer, and underrepresentation of others [2]. Cervical cancer is a prime example of a disease that is underrepresented in traditional media. Cervical cancer affects approximately 13,000 women per year in the United States, and over 500,000 woman globally [3]. While United Kingdom celebrity Jade Goody's public battle against cervical cancer increased cervical cancer information seeking and cervical cancer screening in 2008–2009 [4], her cancer battle and others' (e.g. Eva Peron, Tamra Barney) are notable since few public figures openly discuss their treatment for cervical dysplasia or cancer. The birth and rapid growth of social media channels, especially the micro-blogging site Twitter, over the past decade has transformed the way the public gains access to information. In comparison to traditional media outlets, social media permits unfettered and unfiltered direct access from many original sources of information (researchers, physicians, healthcare agencies, advocacy organizations, professional medical organizations as well as individuals). Since most social media platforms are free of cost to the user, they may provide individuals from minority backgrounds and lower socioeconomic classes a greater collective voice than they had previously with traditional media [5]. However, because social media is an unchecked form of widespread public communication, there is potential that health information could be misrepresented, inaccurate, or outright false.

The primary objective of this study was to quantify personal stories about cervical cancer on Twitter during Cervical Cancer Awareness Month (January) in 2016. The secondary objective of this study was to determine the proportion of Twitter messages (aka "tweets") that discussed prevention (screening, vaccination) and to evaluate the positive or negative sentiment of these messages.

Methods

This study was a cross-sectional Twitter review of the top tweets on cervical cancer during Cervical Cancer Awareness Month (January) 2016. Twitter is a microblogging (text limited to 140 characters) social media site with >300 million users worldwide [6]. Users, whether individuals or organizations, can follow other users who are identified by a unique handle

(unique identifier preceded by @). Users can also follow conversation about topics of interest, identified by hashtags (#). Although Twitter is text-based, the tweets can include links to photos or graphics, websites, videos or online articles. Top tweets are determined by a Twitter algorithm that utilizes metrics such as message clicks, re-tweets and number of followers as well as rankings that rate the interest of a tweet based on how it performs compared to expected performance over a period of time.

The study was deemed exempt from review by the University of Minnesota IRB since all information was publically available. A manual Twitter search was performed, first using the search term “cervical cancer,” limited to the English language and the time periods above. Searches were limited to the top tweets since they were viewed by the most social media users and thus were considered to be the most influential tweets. During the initial search, hashtags (#) which were used in the tweets were recorded, and additional searches were performed using these hashtags as well as an exhaustive list of hashtags generated through searches using the designated social media ontologies #gynccsm (*gynecologic cancer social media*) which includes cervical cancer [7] (Table 1). These terms were searched until no new messages were identified, with most tweets identified using the initial search term “cervical cancer”. The data collected included: 1) search strategy: search terms, date of tweet; 2) Tweet data: source of the tweet including the Twitter handle, whether it was posted by an individual (personal, healthcare professional, celebrity) or organization, and whether the organization was a professional health organization (e.g. American Society of Colposcopy and Cervical Pathology) or private organization/foundation which included commercial companies and advocacy groups; 3) Tweet content: whether the tweet included a video/audio file, link to a news story or professional organization data sheet or recommendations; 4) Tweet message: personal story, prevention (screening or vaccination), treatment, general awareness, fundraising; 5) positive or negative sentiment of the prevention message; 6) hashtags (#) used. An initial review of 5 days of tweets was performed to identify theme categories, with additional categories created as needed to accommodate themes that emerged during the data abstraction. The data were collected and reviewed independently by two reviewers (RS and DT) and discrepancies in coding were resolved by a third reviewer (EL). Duplicate posts were removed prior to statistical analysis.

Data were described using descriptive statistics; frequencies (percentages) and median (ranges) are provided as appropriate. Statistical analyses were performed using SAS 9.3 (SAS Institute, Cary, NC).

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Results

A total of 348 individual top tweets about cervical cancer were identified in January 2016. Of those, 226 (64.9%) tweets were from organizations, but only 31.8% (n=72; 20.7% of all tweets) of those were from professional health organizations. Of the 122 tweets from personal accounts, 35.1% (4.0% of all tweets) were from individuals who identified themselves as healthcare providers (e.g. doctor/physician, nurse), and 35.1% (4.0% of all tweets) were from national or international celebrities. Country of origin of these English-language tweets was primarily the United Kingdom (n=216; 62.1%) and the United States (99; 28.6%), the countries where January has been designated cervical cancer awareness month/cervical cancer prevention week; other countries represented are listed in Table 2.

Although Twitter is primarily a microblogging site, 151 tweets (43.4%) included a photo, 6 (1.7%) had a video and 190 (54.6%) linked to an article including online blogs/news, magazine stories and research publications. Thirty-six tweets (10.4%) raised awareness that cervical cancer exists without telling a personal story, advocating for prevention, research or treatment, and 14 tweets (4.0%) were advertisements for fundraising events (Table 3).

Only 39 tweets (11.2%) were personal stories about cervical cancer, and therefore there were merely 2 tweets (0.6%) about cervical cancer treatment. The majority of tweets (n=270, 70.3%) were about prevention. Of the prevention tweets, 221 (81.9%) were about screening, 28 (10.4%) were about vaccination, and 21 (7.8%) mentioned both. Among cervical cancer prevention tweets, 260 (97.4%) had a positive sentiment advocating for screening and/or vaccination and 7 (2.6%) expressed a negative sentiment; however 5 of these tweets conveyed a negative sentiment specifically about vaccination, which was 10.2% of all tweets mentioning vaccination. Among all tweets, 305 (88.9%) were fact-based while 13 (3.8%) propagated unproven beliefs (Table 3).

The median number of retweets for these top tweets was 5 (range 0–1,600), and the median number of likes was 4 (range 0–4,900). The tweet of Cara Delevigne participating in the #SmearForSmear campaign was the only tweet generating >1,000 likes and retweets. The median number of followers for the top tweets was 6,384 (range 46–26,900,000). The 5 tweets with >1 million followers were BBC radio (26,900,000), model Cara Delevigne (6,440,000), English television personality Amy Andrea Childs (1,500,000), the American medical center Mayo Clinic (1,310,000), and the cancer foundation Livestrong (1,030,000). All 5 of these tweets advocated for cervical cancer prevention, with the two celebrities participating in the #SmearForSmear campaign. There were no differences in the median number of followers, likes or retweets between prevention tweets with a positive versus negative tone, or fact-based versus non-fact-based tweets (Table 4).

The Twitter traffic was substantially driven by the #SmearForSmear campaign, initiated and promoted by Jo's Cervical Cancer Trust (@JoTrust), an organization based in the United Kingdom. #SmearForSmear is a Twitter-based campaign that shows individuals smearing their lipstick to remind women to get their screening Pap smear. Of the 348 total tweets on this cancer during Cervical Cancer Awareness Month, 86 (24.7%) were specifically associated with this campaign; among tweets from the UK, 37.3% were associated with this

campaign. @Jo'sTrust social media metrics showed that in the month following the peak of the campaign (the last week of January which is cervical cancer prevention week) there were 7,929 #SmearForSmear webpage visits, and that the hashtag was used 10,103 times. There were also 467 media coverage pieces about the social media campaign, extending the reach of the campaign beyond social media users.

Discussion

The primary objective of this study was to quantify personal stories about cervical cancer during the Cervical Cancer Awareness month. A review of top tweets showed that personal stories about cervical cancer were rare. A previous social media consumer survey showed that while 80% of young adult age 18–24 years would be willing to share their health information through social media, healthy individuals were more likely to share health information than individuals in poor health [8]. We postulate that this may be augmented further in the case of a disease associated with a sexually transmitted infection. Awareness of specific forms of cancer by traditional media has spiked at times when celebrities are diagnosed with or discuss cancer with media outlets. In 2008, British celebrity Jade Goody was diagnosed with cervical cancer, and her treatment journey and death were widely publicized. Content analysis of newspaper stories about Goody showed that less than 10% gave factual information about cervical cancer prevention through screening or vaccination, or about risk-factors, signs or symptoms of cervical cancer [9, 10]. However, there was still an increase in internet searches for “cervical cancer” and “smear tests [4], and a significant but transient increase in the number of Pap tests and colposcopies performed during the year her story was covered in the media [11]. This illustrates the ability of personal narrative to drive healthcare behavior, even when media coverage does not specifically promote such behavior.

There are other examples of how celebrity diagnosis or discussion of particular diseases influences health decisions and behavior. A study reviewing the effects of announcements of cancer diagnosis or death by public figures and celebrities showed that such media increased public information seeking both about the individual with disease and the disease itself, with 50% of survey respondents in one study reporting they obtained this information from social media [4]. This study also confirmed the transient increase in cancer screening following celebrity diagnoses of breast, colon and cervical cancer. Interestingly, two of the studies found that increased screening did not result in a subsequent increase in breast cancer diagnoses. This suggests that the additional screening occurred among women who were already being screened, possibly resulting in over-screening [12, 13]. Additionally, not all celebrity discussion of disease results in positive behavioral changes. One of the most popular examples is actress and model Jenny McCarthy's vocal opposition to vaccination, claiming that vaccination caused her son's autism [14]. Unfortunately celebrity claims are often more widely believed than scientific evidence, resulting in a resurgence of measles and other diseases once eradicated from the United States.

One must also remember that the media also shapes our perception of disease and disease risk. The cause of death is often undisclosed when public figures die of stigmatized disease [13] resulting in underrepresentation of these diseases. Furthermore, the media often

highlights unique cases which are not representative of the true epidemiology of disease. For example, young celebrities with breast cancer receive more media coverage than older celebrities despite the fact that the disease is more prevalent at older ages [15]. This biased coverage provides the public with a false sense of risk.

While personal stories about cervical cancer dysplasia and cancer are relatively rare among celebrities, in 2016, 105 local, national and international celebrities participated in the #SmearForSmear campaign. A single tweet from model Cara Delevigne had the furthest reach with more than 6 million followers, 4,900 likes and 1,600 retweets. Although the exact impact of the campaign on cervical cancer screening is unknown, Jo's Trust received a number of reports from individual women who called their healthcare providers to schedule a Pap test. Many of these women were told that the wait time would be several weeks due to a sharp increase in the number of requests for cervical cancer screening following the 1-month campaign (communication from Jo's Trust CEO Robert Music 4/25/17). While it is unknown whether these women were new to screening or whether they were already receiving appropriate screening or even over-screening, the reports reveal how a popular social media campaign can drive social media traffic to increase awareness of cervical cancer. The positive effect of such campaigns has been shown previously, with the "ice bucket challenge" during the summer 2014 raising \$79.7 million in the first month of the campaign (compared to \$2.5 million during the same time period the previous years), and raising over \$140 million overall for amyotrophic lateral sclerosis (ALS) research worldwide [16, 17].

The majority of top tweets in this study were about cervical cancer prevention, and most were positive in tone. This positive or neutral sentiment regarding cervical cancer screening and HPV vaccination has been demonstrated in other studies [18] [19]. However, message tone varies by region, with one study showing higher exposure to negative messaging about the HPV vaccine in areas with low vaccination rates [20]. In addition to the negative messages found in our search (Table 5), opponents of the HPV vaccine have also linked the vaccine to premature ovarian failure and autoimmune diseases such as Guillain-Barré Syndrome. Post-marketing surveillance has found no evidence that the HPV vaccine caused any of the reported events [21]. Regardless, the minority of messages recommending against vaccination have the ability to generate a large amount of negative sentiment among users in their responses [22]. More research is needed to determine the impact that such messaging has on user behavior beyond the standard social media metrics.

Our study provides a cross-sectional view of top Twitter messages during Cervical Cancer Awareness Month 2016. A manual Twitter search provided a view of <1% of all tweets posted during the study time period, compared to Firehose Application Programming Interface (API) data which retrieves a much more comprehensive view of messaging. However, this manual review does give a more accurate representation of what a user would see if s/he were to search for cervical cancer messaging using a particular search term or hashtag. All messages were coded by two independent reviewers with consensus of two reviewers for all categorizations in order to achieve accurate assessment to the extent possible. It is notable that January was designated the Cervical Cancer Awareness month by the United States Congress, and the last week of January has been designated Cervical

Cancer Prevention Week in the United Kingdom. Thus, while there may be increased cervical cancer messaging by these two countries during the time period of this study, other countries may not increase their cervical cancer awareness activities during this same time period, limiting generalizability of the results. Other limitations of the study include the fact that only English-language tweets were reviewed; this may have eliminated a substantial number of tweets since the largest burden of cervical cancer is in Africa, Asia and South America. The study was also limited to Twitter, whereas many young adults who are candidates for both cervical cancer screening and HPV vaccination currently favor other social media platforms such as the picture-based sites Instagram and SnapChat. Lastly, certain topics may have been over- or under-represented due to the search terms used. For example terms related to cervical cancer prevention were specifically searched, which may have contributed to the large proportion of tweets about prevention. However, the search terms used were generated from an initial search for “cervical cancer” messages, and thus were driven by the top tweets.

In conclusion, Twitter-based messaging during Cervical Cancer Awareness Month primarily encouraged prevention through screening via Pap tests and vaccination against HPV. However, the disease itself remains underrepresented. Since nearly 90% of young adults report obtaining health information via social media, and 33% report that information found on social media would likely influence their decision to undergo a specific procedure or test [8], it is imperative that social media messaging be driven by fact-based messages encouraging recommended health practices. Additional research is needed to optimize fact-based messaging and to determine the impact of social media messaging on preventive health behaviors.

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Table 1

Search Terms

Cervical Cancer
#CervicalCancer
#cervicalCA
#CervicalCancerSurvivor
#CervicalCancerPrevention
#Cervical
#CervicalHealthMonth
#CCPW¹
#PapSmear
#Pap
#PearlofWisdom
#SmearforSmear
#Smear4Smear

¹CCPW, Cervical Cancer Prevention Week

Table 2

Twitter Source (N=348)

	n (%)
Source	
Professional organization ¹	72 (20.7)
Private organization ²	154 (44.3)
Healthcare Professional ³	14 (4.0)
Personal account	94 (27.0)
Celebrity personal account	14 (4.0)
Country	
Australia	3 (0.87)
Balkans	1 (0.29)
Canada	5 (1.45)
Ethiopia	1 (0.29)
Germany	1 (0.29)
Hong Kong	1 (0.29)
India	8 (2.31)
Kenya	1 (0.29)
Malaysia	1 (0.29)
Nigeria	4 (1.2)
Philippines	1 (0.29)
Serbia	1 (0.29)
Switzerland	2 (0.58)
Thailand	1 (0.29)
United Kingdom	217 (62.4)
United States	100 (28.7)

¹Professional organization defined as professional healthcare organizations (e.g. medical/hospital systems, professional health organizations).

²Private organizations defined as commercial companies, advocacy groups.

³Healthcare professionals defined as personal Twitter accounts in which the user identifies him/herself as a healthcare professional (e.g. physician, nurse).

Table 3

Tweet Content (N=348)

	n (%)
Media	
Photo	151 (43.4)
Video	6 (1.7)
Link to article	190 (54.6)
Message¹	
Personal story	39 (11.2)
Treatment	2 (0.6)
Fundraising	14 (4.0)
Prevention	270 (70.3)
Awareness	36 (10.4)
Fact-Based	
Yes	305 (88.9)
No	13 (3.8)
NA	30 (7.0)
Message Sentiment (N=270)²	
Positive	260 (97.4)
Negative	7 (2.6)

¹ Some tweets had >1 message, so total >100%

² Message tone/sentiment assessed only for prevention messaging (i.e. cervical cancer screening or HPV vaccination).

Table 4

Social Media Metrics

Metric	All Tweets (N=348)	Prevention tone (+) (N=260)	Prevention tone (-) (N=7)	Fact-based (N=305)	Non-Fact-based (N=13)
Median (Minimum-Maximum)					
Followers	6,384 (46–26,9M)	6,427 (24–26,900,000)	3,314 (1,414–106,000)	6,465 (46–26,900,000)	3,295 (274–800,000)
Likes	4 (0–4,900)	4 (0–4,900)	5.5 (1–23)	4 (0–4,900)	5 (1–23)
Retweets	5 (0–1,600)	5 (0–1,600)	5 (3–12)	5 (0–1,600)	5 (2–12)

Table 5

Non-fact based cervical cancer tweets

Causes of cervical cancer:
Genetic susceptibility/family history
Abortion
Prevention of cervical cancer:
Soy milk
Papaya
Organic diet
HPV vaccine:
Deaths linked to the vaccine
Promotes development of cervical cancer in girls exposed to HPV prior to vaccination