Discourse about human papillomavirus (HPV)-associated oropharyngeal cancer (OPC) on Twitter: Lessons for public health education about OPC and dental care

Jae Eun Chung a,*, Indra Z. Mustapha b, Jiang Li c, Xinbin Gu b

a Cathy Hughes School of Communications, Howard Univ, USA
b College of Dentistry, Howard Univ, USA
c Department of Electrical Engineering and Computer Science, Howard Univ, USA

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ABSTRACT

Objectives: Public understanding of human papillomavirus (HPV)-associated oropharyngeal cancer (OPC) is minimally understood. Therefore uncovering communication gaps between the public and healthcare professionals regarding this disease is vital. Social media provide an unobtrusive way to understand public perception about health issues.

Study design: Computer-assisted quantitative content analysis.

Methods: Tweets about HPV-associated OPC (N = 3,112) were collected for 40 weeks using the standard real-time streaming Application Programming Interface (API). The collection of tweets was not limited to one specific geographic location but worldwide. All tweets were entered into nVivo 12.0 to conduct computer-assisted quantitative content analysis. We used an inductive method to develop a coding scheme and examined the frequency of specific keywords, terms, and phrases in texts.

Results: Findings show that (a) the majority of discourse on Twitter focused on risk factors and prevention with little information on diagnosis, treatment, and prognoses; (b) many tweets promoted HPV vaccination among boys and emphasized the risk of HPV-associated OPC among males; (c) the role of dental care professionals in the prevention and detection of OPC minimally appeared; (d) the public referred to OPC as oral cancer, head and neck cancer, or throat cancer; and (e) health organizations in New Zealand, Australia, and the United Kingdom led the discussion on HPV-associated OPC on Twitter.

Conclusions: The current study unravels the utility of social media data and data mining techniques in understanding public perception and understanding of HPV-associated OPC. The outcomes from the current study provide baseline knowledge of where communication gaps exist in terms of HPV-associated OPC, without which the planning of potential interventions and much-needed social media-based campaigns cannot be effectively undertaken.

1. Introduction

The purpose of the current research is to distill public understanding of human papillomavirus (HPV)-associated oropharyngeal cancer (OPC) by using social data mining and a software-assisted quantitative content analysis. Our research is predicated on two facts: (a) Rates of HPV-associated OPC have increased, creating an urgent need to understand what the public knows and discusses [1–3]; and (b) Many people actively use social media sites to obtain cancer information [4,5].
survival; in fact, the American Dental Association [7] recommends dentists screen all adolescent patients for HPV infection.

1.2. Social media for surveillance of HPV-Associated OPC

Twitter has become a venue for the informal sharing of cancer information and advice [8]. About 12% of e-patients use Twitter or other social media sites to share health-related updates about themselves or to see others’ health-related updates [9]. As more people use social media like Twitter for health information, the platform provides a venue to identify public knowledge, attitudes, and behaviors with respect to cancer [10]. Social media are a great source of useful data for oral health and care [11].

Among various social media platforms, Twitter presents itself as a novel source for cancer and dental care communication and information surveillance because the majority of its content is publicly available [12], thus offering itself as a tool to capture an “epidemiological snapshot” [13]. Several researchers have studied Twitter to predict and monitor infectious diseases such as flu [14,15], yet studies in which Twitter was used as a tool to monitor cancer and dental care communication have been limited [16]. What remains largely unknown and untested is the utility of Twitter as an information surveillance tool for cancer: what and how messages about cancer and its prevention are disseminated and circulated via social media platforms and where communication gaps exist between patients and healthcare practitioners.

1.3. Study goals and research questions

Our understanding of what the public knows about HPV-associated OPC is minimal. What does the public know about HPV-associated OPC? What does the public discuss about HPV-associated OPC on social media? A strong need exists to understand communication gaps between the public and healthcare professionals regarding HPV-associated OPC. The goal of this paper is to bridge such gaps by demonstrating public knowledge of HPV-associated OPC through social data mining, identifying the overarching themes of tweets about HPV-associated OPC using a software-assisted content analysis method, and seeking an understanding of public perception of and attitudes toward HPV-associated OPC. In doing so, we also pay special attention to gender and racial-ethnic disparities and discourse on the role of dental care professionals in the prevention of HPV-associated OPC. In our study, we particularly aim to answer the following questions:

RQ1. With regard to HPV-associated OPC, what are the most and least discussed types of health information on Twitter?
RQ2. Do the tweets about HPV-associated OPC refer to any specific gender, sexual preference, or race/ethnicity?
RQ3. How often are the roles of dental care health professionals (e.g., dentists, dental hygienists, dental therapists, etc.) discussed on Twitter with regard to HPV-associated OPC?
RQ4. What are the most commonly used Twitter hashtags in the discourse regarding HPV-associated OPC?
RQ5. Who are the most often mentioned Twitter users in the discourse regarding HPV-associated OPC?

2. Methods

2.1. Data collection

Tweets were collected using the standard real-time streaming Application Programming Interface (API) over 41 weeks from October 16, 2017, to July 29, 2018. The 41-week period includes the National Cancer Prevention Month of February and the Oral Cancer Awareness Month of April. In order to retrieve tweets relevant to HPV-associated OPC, we used a combination of the following key terms for the search: HPV or papilloma and mouth or oral or throat or pharyngeal or oropharyngeal or oropharyngeal or pharynx or neck or tonsil. Among them we selected unique tweets that were not retweets. The 41 weeks’ retrieval resulted in 3,229 unique tweets, excluding retweets. Other than the search terms mentioned above, no other parameters were included so the collection of tweets was not limited to one specific geographic location but worldwide. Since the study used publicly available tweets or data and did not involve any involvement of human participants, the current study was exempt from ethics committee review.

2.2. Analysis

All tweets were entered into nVivo 12.0 [17] to conduct computer-assisted quantitative content analysis. Among the different types of content analysis methods, we used word frequency analysis, that is, counting the appearance of certain keywords, terms, or phrases in texts [18], which was explored as indicators of themes in an inductive process [19]. As with the previous studies where the first or the last period of data were used for training and development of coding scheme (e.g., [20]), the list of keywords, terms, and phrases relevant to our research questions was developed based on the reading of tweets from the final week of tweet collection (N = 117). The results appearing in the following section are based on the remaining 40 weeks of tweets excluding three bot-generated tweets (N = 3,109). Using Botometer’s [21] Complete Automation Probability (CAP) as a threshold, bot-generated tweets were excluded from our analysis. Among the 40-week tweets of 3,112 tweets, three Twitter accounts had CAP above 95% and thus the three tweets from these three accounts were not included in our analysis.

To understand the characteristics of Twitter users who posted tweets about HPV-associated OPC, Twitter users were coded into the following eight categories: individuals, private organizations, nonprofit organizations, media organizations, research organizations, governments, online communities, and others. A research assistant was trained using 2% of the data and coded the remaining. Another coder coded another 5% of data (N = 1,554) and the intercoder reliability was checked (98.7% agreement). The two coders discussed any discrepancies and ambiguous cases together and reached a consensus on them.

3. Results

3.1. Description of data

The average numbers of favorites and retweets were 7.5 (SD = 41.3) and 5.9 (SD = 14.3) respectively. The majority of tweets included a minimum of one website linked in the tweets (N = 2,918, 93.9%) and were from individual accounts (N = 1,601, 51.5%), followed by private organization’s accounts (N = 456, 15.0%), non-profit organization’s accounts (N = 361, 11.6%), and media organization’s accounts (N = 264, 8.5%).

3.2. Results on research questions

3.2.1. With regard to HPV-associated OPC, what are the most and least discussed types of health information on Twitter?

We identified the types of health information using several key terms (Table 1). The most often mentioned type of information was prevention (1,679 times), followed by causes or risk factors for OPC (910 times). Treatment and diagnosis-related terms appeared 141 and 97 times, respectively. Health information relating to prognosis (25 times) and symptoms (42 times) were minimal. Table 1 lists sample tweets as well as selected key terms associated with each type of health information.

Because many tweets mentioned information pertaining to causes and prevention, we looked closely into each category. Among the diverse risk factors mentioned, oral sex was mentioned 216 times. Smoking (smoker, cigarettes, tobacco, etc.) and drinking-related terms
Types of health information, relevant keywords, and sample tweets (N = 3,109).

| Types of Health Information/Keywords | n  | % | Tweets |
|--------------------------------------|----|---|--------|
| Prevention                           | 1679 | 54.0 | The #HPV vaccine (9vHPV) could prevent 70% of oropharyngeal cancer. #ADAATL https://t.co/wM3EcXgTy |
| Screening, #screening, screen, screened, screenings, screens | 82 | 2.6 | Oral CA Screening save lives! 7 M men, 1.4 M women have HPV 16 - virus associated with oral Cancer according to: Ann Intern Med. Oct 2017. https://t.co/C8f9Yo8Xa |
| Immunisation, immunisation, immunise(s), immunised, immunize(s), immunising, immunizing | 19 | 0.6 | Get immunized. HPV is causing an oral cancer epidemic in men by outwitting natural defenses https://t.co/IIu1jPhxT |
| Cause(s)/Risk Factors                | 910 | 29.2 | Oral Sex and Smoking Increase Oral HPV Cancer Risk https://t.co/ApVYk1DLXI |
| treatment(s), treat, treated, treating | 141 | 4.5 | Novel approach to de-escalating treatment for HPV-positive head and neck cancer shows excellent response and survival: https://t.co/71CeCgDyXx |
| Diagnosis                            | 97 | 3.1 | Which diagnostic test is most specific for confirmation of human papilloma virus (HPV) positive head and neck squamous cell carcinoma? $$$ #QOTW https://t.co/CgGAd4NWNW |
| Prognosis                            | 25 | .8 | Latest #HPV vaccination data 2014-15: 80.1% & 78.6% of 15yo girls & boys now vaccinated against “a range of cancers linked to HPV.” Link with cervical cancer is well-known but many unaware of HPV-related head&neck cancers. Progress, but in 5 still unprotected. $$$ @JulieMcCrosin https://t.co/Slhmowh1dIA |
| Symptom(s)                           | 42 | 1.4 | We need a public health & GP media campaign to help general public & GPs recognise symptoms of HPV-related Head & Neck Cancers: earache, lump on neck, oral & throat changes etc @Beyondfiveorg @CancerAustralia @RACGP @throatsurgeon @RACSurgeons Help! #https://t.co/9E3jKP9AWx |

Types of Health Information/Keywords | n  | % | Tweets |
|--------------------------------------|----|---|--------|
| asymptomatic                         | 3  | .1 | most ppl who have (& SPREAD) HPV are asymptomatic but I’d enjoy seeing you tell a family who’ve lost a loved one to any of the above that they died from a benign disease. |

#### 3.2.2. Do the tweets about HPV-associated OPC refer to any specific gender, sexual preference, or race/ethnicity?

Mention of specific demographic groups in terms of gender and sexual preference was also examined. When comparing women and men, three times more tweets mentioned men or man compared to women or woman (729 times vs. 237 times). When comparing boys and girls, the reference to boy occurred 2.3 times more often (438 times vs. 191 times). As shown in Table 2, more than 120 tweets included hashtags that included boy(s) (such as #hpv4boys), whereas only one hashtag included girl(s) (#vaccineboystandgirls). Several tweets specifically mentioned homosexual populations: gay or gaymen appeared eight times, whereas lesbian appeared one time. #msm (men who have sex with men) was mentioned six times, whereas no tweet included wsw (women who have sex with women). Sample tweets that mention specific homosexual groups appear in Table 3.

Some tweets mentioned specific racial and ethnic groups, such as Black and Hispanic. Twelve tweets mentioned Blacks or African Americans, whereas Whites or Caucasians and Hispanics were mentioned ten times and twice, respectively. Asians were not mentioned in the collected tweets. Table 3 shows sample tweets that mentioned specific racial/ethnic groups.

#### Table 2

| Mention of men/man/boy/male vs. women/woman/girl/female |
|---------------------------------------------------------|
| men/man                                                 | 729 |
| boy(s)                                                  | 438 |
| male(s)                                                 | 51  |
| women/woman                                            | 237 |
| girl(s)                                                 | 191 |
| female(s)                                               | 44  |

#### Table 3

| Hashtags which included men vs. women                   |
|---------------------------------------------------------|
| #menhealth                                              | 4 |
| #menhealthmonth                                         | 1  |
| #menhealthweek                                          | 1  |

| Hashtags which included boy(s) vs. girl(s)              |
|---------------------------------------------------------|
| #hpv4boys                                               | 20 |
| #hpv4boys                                              | 3  |
| #protecorboys                                           | 2  |
| #hpv4forcedays                                         | 1  |
| #hpv4refenden                                          | 1  |
| #hpv4refenden                                           | 1  |
| #hpv4refenden                                           | 1  |
| #hpv4refenden                                           | 1  |
| #hpv4refenden                                           | 1  |
| #hpv4refenden                                           | 1  |
| #hpv4refenden                                           | 1  |
4. Discussion

The current study distills public understanding of and discourse about HPV-associated OPC from Twitter with innovative techniques. The outcomes from the current study provide baseline knowledge of where communication gaps exist in terms of HPV-associated OPC, without which the planning of potential interventions and much-needed social media-based campaigns cannot be effectively undertaken. Our findings also offer a detailed understanding of public discourse regarding HPV-associated OPC and testing of the utility of a social media platform as a surveillance tool. The proposed work builds upon work that raised the epidemiological advantages of tying computerized text analysis to social media mining [22].
4.1. Summary of findings

4.1.1. Discourse on Twitter focused on prevention and risk factors. Little about diagnosis, treatment, and prognosis appeared

Analysis showed that the majority of the discussion focused on prevention and risk factors. Relatively little information was available on how to detect, treat, and diagnose HPV-associated OPC. Given that early detection and diagnosis lead to much higher rates of survival and treatment [23], it is vital to provide more information about diagnosis and treatment.

4.1.2. Tweets emphasized the risk of HPV-associated OPC among men and the need for vaccination among boys

Recent statistics show that men are not only more likely to be infected with oral HPV than women also but are less likely to clear the infection [24]. Findings reflect such statistics, raising awareness that HPV is not limited to cervical cancer. Tweets that referred to males outnumbered tweets that referred to females at a rate of 3 to 1 among the retrieved tweets. Many hashtags promoted the HPV vaccination for boys. We find the frequent mentions of males compared to females and the emphasis on the need for vaccination for boys as encouraging. Given the low rates of HPV vaccination among boys compared to girls [25] and the majority of the past public health campaigns advocating HPV vaccine targeting girls [24], Twitter can help alleviate gender disparities apparent in the discourse relating to HPV prevention. HPV-associated OPC is almost twice more common in men than women [26], raising the need for more health education about HPV and OPC targeting males and demystifying the misconception that HPV could only affect females and cause cervical cancer [27].

4.1.3. Several tweets discussed the risks of HPV-associated OPC among homosexual men and among specific racial-ethnic groups

A few tweets discussed HPV-associated OPC in connection with homosexual populations (Table 3). For example, gay or men who have sex with men or MSM was mentioned 14 times for the linkage between HPV and sexually transmitted disease. A small number of tweets (12 times for Blacks, 10 times for Whites, and 2 times for Hispanics) noted and compared the risk of contracting HPV among racial and ethnic groups. With more research findings reported on the link between sexual orientation and OPC [28] and racial disparities [29,30], it will be beneficial to use widely used social media, such as Twitter and Facebook, as channels for public awareness campaigns about OPC risk factors, especially for high-risk groups [31,32]. We also need to utilize social media channels to acknowledge, understand, and reduce stigmatization faced by minorities in receiving the care needed for cancer screening and treatment.

4.1.4. The role of dental care professionals in the prevention and detection of OPC minimally appeared

Some tweets acknowledged the role of dental care professionals in the screening and detection of OPC and encouraged the public to seek help from dental care professionals for the prevention of OPC (e.g., “HPV vaccination needs to be taken place in the dental office, not just the medical office”); however, the mention of dental care professionals were rare and minimal (Table 4). Given the role dental care professionals can play in the prevention and detection of OPC [33-35], the infrequent mention of dental care professionals in the public discourse on Twitter was disheartening. Disuse on Twitter may reflect hesitancy among dental care professionals in making vaccine recommendations for HPV [36] or providing screening for OPC [37]. As dental care professionals play a critical role in the early-stage detection of OPC [38], social media can be utilized as a venue to publicize the important roles dental care professionals can play in OPC examination so that patients and dental care professionals can more openly and comfortably discuss HPV vaccine and OPC examinations. Training and continuing education for dental care professionals can also help improve their knowledge on OPC and facilitate their conversation with patients [39,40].

4.1.5. The public uses oral cancer, head and neck cancer or throat cancer to denote OPC

The following were found to be much more commonly used by the public to refer to OPC than oropharyngeal cancer: oral cancer, head and neck cancer, and throat cancer. OPC is a type of head and neck cancer that affects structures in the middle part of the pharynx, called oropharynx, behind the mouth [41]. Anatomically, the pharynx includes the three sites of nasopharynx, oropharynx, and hypopharynx, and cancers in these sites have distinct epidemiologic characteristics [42]. Thus, clinically it is inappropriate to group them together. As we see an increase in the number of OPC patients [1-3], we need to put more effort into familiarizing the public with the term OPC, its accurate terminology, and its relation to other types of head and neck cancer.

4.1.6. Organizations located in New Zealand, Australia, and the UK were most frequently mentioned

The five most mentioned users were from New Zealand, Australia, and the UK and their tweets were specific to their geographic areas (e.g., “the UK is ignoring the latest scientific evidence that boys need the HPV vaccine as well”). It is no surprise that these countries have a prominent presence on social media as these countries launched public health campaigns that led to high HPV vaccine uptake [43]. For example, 7 out of 10 teens in Australia completed HPV vaccine, whereas only about half completed it in the United States [44]. With many people being on social media, we should utilize social media as a channel to raise awareness about the HPV vaccine and take preventive measures against cancer.

4.2. Practical implications

The analysis of public discourse on Twitter indicates that (a) the public can benefit from more information regarding detection, treatment, and prognosis being presented on social media; (b) more educational campaigns need to be developed to teach the public about the roles of dental care professionals and the importance of dental care for the prevention of OPC, and (c) organizations working to raise awareness about OPC and its prevention should learn from social media campaigns run by several organizations such as Head and Neck Cancer Support Network in New Zealand (@headnecknz) and Beyond Five (@beyondfiveorg, 82 times) in Australia.

4.3. Methodological implications

Social media data mining can replace or complement traditional methods (such as survey, interviews, and focus groups) to understand public knowledge and perception. In industry, data mining from social media has become a standard (e.g., see [45]), yet in public health and dental care communication, we have now just begun to see a drive to generate effective methods to mine the social web. The current research introduced a cross-sectional, systematic social media analytics to gain insights about HPV-associated OPC by mining relevant tweets and using computerized text analysis. The approach is novel in that it proposes a method of gathering and analyzing tweets on a large scale to identify public perception about an important health topic.

4.4. Limitation and directions for future research

The brevity of tweets made it challenging to understand the full context behind messages. This study used tweets as an indicator of what people hear or understand; however, some tweets may not be taken at face value. Still, as previous research has shown, information shared on microblogging platforms provides important insights into how people think and what they know about a health topic [46]. Another limitation results from the characteristics of the used sample. The current study captured the views of Twitter users. Twitter users are not representative
of the general population. Future research should use the triangulating analysis from social media sites with other methods such as a survey and an experiment. The triangulation can provide further insights into public perception and knowledge of HPV-associated OPC.

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Conflict of interest

The authors declare that there is no conflict of interest.

Ethics approval

The current work used publicly available data on the Internet and was exempt from IRB review.

Author agreement

This work is the authors’ own original work, which has not been previously published elsewhere. The paper is not currently being considered for publication elsewhere. The paper reflects the authors’ own research and analysis in a truthful and complete manner.

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Jae Eun Chung, PhD is an associate professor in the School of Communications at Howard University.

Indra Z. Mustapha, DDS, PhD is an assistant professor in the College of Dentistry at Howard University.

Jiang Li, PhD is an associate professor in the Department of Electrical Engineering and Computer Science at Howard University.

Xinbin Gu, MD, PhD is a professor and associate dean for research in the College of Dentistry at Howard University.