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Tweeting About Pain: Toothache compared to Backache, Earache, and Headache

Dr. Kristina Ahlwardt, BS, DDS,
School of Dentistry, University of California San Francisco, San Francisco, California

Dr. Natalie Heavilin, DDS [General Practice Resident],
VA Palo Alto Health Care System, Palo Alto, California

Dr. Jennifer Gibbs, DDS [Assistant Professor],
Department of Endodontics, New York University, New York City, New York

Mr. Jen Page [Software developer],
Datajockety.org, New York City, New York

Dr. Barbara Gerbert, PhD [Professor Emeritus], and
Department of Preventive and Restorative Dental Sciences, University of California San Francisco, San Francisco, California

Dr. Janice Y. Tsoh, PhD* **[Associate Professor]**
Department of Psychiatry, University of California San Francisco, 401 Parnassus Avenue, Box 0984-TRC, San Francisco, CA 94143

Introduction

In the United States, pain affects 100 million adults and costs $560 to $635 billion annually[1]. Previous research estimated up to 40% of the annual cost of chronic pain could be linked to orofacial pain[2]. Toothaches were the most prevalent dental problem, as experienced by 26% of U.S. adults in the past 6 months[3]. Toothaches have been described as painful, and as having negative impacts on quality of life with interference in mood, sleeping, eating, and occupational and social functioning[2,4–7]. Yet, a sizable portion (30% to 54%) did not seek needed dental care[4,8,9]. Cost-related reasons only account for 33% of the unmet dental needs among those with toothaches[3]. To further address unmet dental care needs, we need to understand the reasons for underutilization of dental care from the patient's perspective, and thereby identify effective channels to reach individuals in need.

Social media websites are used for sharing personal health experiences and they provide a new source of data to fill in gaps not yet covered by traditional research. Twitter, a free social media service with more than 200 million active users posting 400 million tweets daily to communicate thoughts and behaviors[10] offers rich population-based data to allow new venues for tracking disease activity or concerns of public health significance[11–14].

*Address reprint requests to Dr. Tsoh, jtsoh@lppi.ucsf.edu.

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Heaivilin and colleagues[7] pioneered the use of Twitter as a new source of data for dental pain experiences. Using a sample of 772 relevant tweets, the study found a majority (73%) of Twitter users experiencing toothaches expressed distress. Impacts on daily living and actions taken to manage toothache-associated pain, such as seeking professional help or using self-care remedies, observed in Twitter users were similar to previous reports using other data collection methods[3,4,8].

The purpose of this study is to better understand toothache pain in the context of three other common pain types in overall experiences of pain intensity, actions taken for pain relief, and perceived causes and impacts, from the perspective of the pain sufferers who shared their experiences using Twitter. This study compares experiences of toothache to backache, earache, and headache, which were among the top 20 primary reasons for outpatient visits[15]. Findings will offer new insights into understanding toothache pain and may help researchers to further understand factors related to dental care utilization.

Methods

Data Source

Data were obtained from the social media website Twitter, where users post tweets of 140 characters or less. Tweets are intended to be viewed by users who follow the posters of the tweets, but are also publically available and subject to public searches. The Committee on Human Research (institutional review board) of the University of California San Francisco approved the study protocol and its qualification for exempt certification.

Search Terms Generation

An initial sample of tweets was identified by first collecting 100 tweets per pain type using both anatomical words (tooth, teeth, back, head, ear, and ears) and pain words (ache, aches, ached, and aching). In addition, all hyperlinks (http:// and https://) and Re-tweets (RT) were excluded. Other exclusion terms were identified as appearing frequently in tweets that met our inclusion terms, but were evaluated as not relevant because the contents did not refer to any one of the 4 pain types. For example the word “earrings” was identified as an exclusionary term to exclude tweets such as “put new earrings in last night and now my **ear** lobe **hurts**” as the pain was not earache. Investigators identified irrelevant tweets from the initial sample (100 tweets per pain type) as described above, each irrelevant or excluded tweet was reviewed and discussed. The final set of excluded tweets was submitted to a word frequency calculator to identify the most frequent words apart from the search terms that appeared in the excluded tweets. These terms were then added to an initial list of exclusion terms. Using an iterative process by reviewing relevancy rates with addition of each candidate inclusion and exclusion search term, starting with the most frequent word or word-combination from the initial tweet sample, a final set of search terms yielding high relevancy rates was generated (Table 1).

Codebook Development

Two investigators (KA, BG) used an initial codebook adapted from a previous study[7] and coded tweets independently in sets of 10 to 25 tweets generated by the final search terms.

Investigators refined the code categories and their definitions through an iterative process until no further refinement could be made. The final codebook was developed based on 220 sample tweets (55 tweets per pain type).

The definition of the pain intensity subcategories was refined based on findings from an anonymous online survey (Appendix 1) completed by a convenience sample of 92 adults recruited by word of month. The survey asked respondents to match a list of 26 terms describing pain ("pain words"), which was generated from the sample tweets used in developing the final codebook, to one of the four pre-defined intensity mutually exclusive subcategories: "neutral" (including absence of pain intensity description provided), "mild," "moderate," and "severe.". For example, the term "MAJOR headache" was coded as "moderate" because "MAJOR" was rated by the majority of survey respondents as moderate pain (68% moderate, 13% severe, 11% mild, 0% neutral). The final codebook defined nine primary categories and 69 subcategories (Appendix 2).

Using the final codebook, two coders independently coded a test sample of 25 tweets generated from the search terms. The degree of agreement between the two independent raters was assessed in terms of their agreement in the binary coding of the presence or absence of each primary category and its subcategory. The inter-rater agreement was high as indicated by both Cohen's kappa (kappa=0.98), and the prevalence-adjusted, bias-adjusted kappa (PABAK)[16] that adjusted for the low prevalence of some of the primary categories or subcategories in the tested sample (PABAK= 0.96).

Extraction of Tweets

A data collection programming script was created (JP) and was submitted to the Twitter Search API (application programming interface) (https://dev.twitter.com/docs/api/1/get/search) to extract tweets for the study. The data collection script included a specified query that consisted of search terms and logical operators (Table 1). The Twitter Search API's time-based parameters were used to confine the selected date range of tweet extraction to seven non-consecutive days over four weeks (8/30- 9/24/2011) to minimize over sampling of any one day of the week using the constructed week methodology[17]. Furthermore, the sampling time period was selected to exclude the tweets that were used in search term generation, codebook development or inter-rater agreement evaluation described earlier. The data collection script was programmed to run on the selected dates to repeatedly poll the Twitter Search API and retrieve all the specified tweets from the selected dates.

Tweets meeting our search terms, that were not in English, incoherent, posted by a user already included in our study, posted by someone other than the original poster, or spam were excluded. If a tweet mentioned two pain types, the first pain mentioned was the pain type used to code that tweet. Tweets meeting the inclusion criteria were randomly selected until 43 relevant tweets per pain type were collected from each of the seven days. The final data set consisted of 1,204 tweets, with 301 relevant tweets per pain type.

Coding and Data Analyses

One investigator (KA) coded the 1,204 tweets in the final data set. Forty tweets were randomly selected from the final data set and were independently coded by a second

investigator (BG) to verify coding accuracy. Sample coding is shown in Table 2. For this study, the four most frequently coded primary categories of pain intensity, actions, causes, and impacts and their subcategories were included in the analyses. Descriptive statistics, Pearson chi-square tests and logistic regression models were used to compare differences among pain types on selected primary categories and their subcategories.

Results

A total of 508,591 tweets were extracted (28,401 toothache; 103,701 backache; 18,149 earache; 358,340 headache) using the inclusion and exclusion search terms listed in Table 1. Of the 1,204 tweets included in the study, a majority (50.6%, n=609) were from North America (Table 3). Figure 1 depicts the most frequent terms, such as pain types and pain words, that appeared in the final data set with font size reflecting the word frequency. The average number of primary categories coded per tweet was 1.29 (SD=0.50, range from 1 to 4). Per our inclusion criteria, all 1,204 tweets were coded for pain intensity. A majority (72.5%, n=873) was coded with pain intensity as the only code, 25.7% (n=310) was coded for pain intensity and one additional category, and the remaining 1.8% (n=21) was coded for 2 or 3 categories in addition to pain intensity. Other most frequently coded categories were actions taken for pain (13.0 %, n=155), causes of pain (11.0%, n=132), and impacts from pain (5.4%, n=64). These four primary categories and their subcategories were included in the analyses. Table 4 shows the distribution of the coded categories by pain types.

Pain Intensity

Using the pre-defined coding subcategories for pain intensity, 5.3%(n=64) was coded as “severe” pain intensity, 33.6% (n=405) was “moderate,” 29.3% (n=353) was “mild,” and 31.7% (n=382) was “neutral” that included tweets providing no pain intensity description. Given our interest in the reports of high pain intensity and the data distribution, we re-categorized pain intensity into a dichotomous variable to indicate “High” (moderate or severe) or “Low” (mild or neutral) level of pain intensity. This new re-categorization allowed us to focus the comparison by pain types on reports of high pain intensity.

Using the dichotomous pain intensity variable, 39.0% (n=469) of all the tweets reported high pain intensity. A significantly higher portion of tweets on toothache (43.2%, n=130), and backache (47.2%, n=142) described high pain level than tweets about earache (33.2%, n=100), and headache (32.2%, n=97), $\chi^2(3)=20.7$, $p<0.001$. Toothache and backache were rated at similar pain intensities ($\chi^2(1)=0.97$, $p=0.326$).

Given that pain intensity levels differed across pain types, in the subsequent analyses of comparing differences in actions, causes, and impacts across pain types, pain intensity (high versus low) was included as a covariate in the analyses using multiple logistic regression models.

Actions

Overall, 13.0% (n=156) of the tweets mentioned an action to relieve pain, and even fewer (5.2%, n=63) reported seeking health care or using medication for pain relief. Out of the 155 tweets that mentioned taking an action in response to pain, 40.6% (n=63) reported seeking

health care and/or using medication, others (59.4%, n=92) mentioned home- or self-care actions such as going to sleep, or getting a massage (Table 4). However, few (0.03%, n=5) mentioned getting pain relief from the actions taken (not shown in table). When an action was reported, tweets describing pains with high pain intensity had higher odds of describing seeking health care or using medication (OR = 2.20; 95% CI, 1.10 – 4.44; Wald's $\chi^2(1)=4.89$, p=0.03). Independent of pain intensity, those suffering from a toothache were more likely to report seeking health care than those with a backache (OR=3.91, 95% CI, 1.57 – 9.71; Wald's $\chi^2(1)=8.63$, p=0.003) or headache (OR=6.11, 95% CI, 2.16 – 17.25; Wald's $\chi^2(1)=11.66$, p=0.001). The odds of seeking healthcare or using medication were similar among toothache and earache sufferers (Wald's $\chi^2(1)=2.03$, p=0.15).

Causes

Among the 132 tweets across all pain types that mentioned a cause of the pain, 50.8% (n=67) described the pain being caused by the person reporting the pain or something inherent, including an accident, an anatomical abnormality, or emotional distress; the remaining 49.2% (n=65) described pain being caused by other elements such as a bacterial infection, food, or environmental factors (Table 4). The types of causes reported were associated with pain types but not with pain intensity. Specifically, those with backache were more likely to mention that they were the source of their own pain when compared to those reporting toothache (OR=9.62; 95% CI, 2.98 – 31.01; Wald's $\chi^2(1)=14.36$, p<0.001), headache (OR=10.42; 95% CI, 3.27 – 33.11; Wald's $\chi^2(1)=15.77$, p<0.001), and earache (OR=12.02; 95% CI, 3.22 – 44.91; Wald's $\chi^2(1)=13.67$, p<0.001). Users reporting toothache, headache or earache were similar in terms of their perception of the causes (by self versus other elements).

Impacts

Of the 64 tweets reporting impacts from the pain experienced across all pain types, 51.6% (n=33) described an impact on daily functioning, such as going to work or getting dressed, 23.4% (n=15) described sleep problems, 14.1% (n=9) reported mood impacts, and 10.9% (n=7) described dietary impacts (Table 4). Pain type was associated with the report of impacts on daily functioning but not with other impact types. Pain intensity was not associated with impact types. Specifically, toothache sufferers were less likely to report an impact on daily functioning than those with backache (OR=0.13; 95% CI, 0.03 – 0.56; Wald's $\chi^2(1)=7.50$, p=0.006) and earache (OR=0.19; 95% CI, 0.05 – 0.77; Wald's $\chi^2(1)=5.36$, p=0.02).

Discussion

Using data collected from Twitter, this is the first study to the best of our knowledge that compared self-reported experiences of toothache to other common pains experienced including backache, earache, and headache. There were more than 500,000 English language tweets over 7 days that communicated pain experiences, which suggested a sizable amount of communications on Twitter on this topic. Previous findings have shown that people experiencing pain are more likely to engage in online resources, including sharing their pain experiences and remedies for pain on social networking sites[18]. Our results suggest that the

use of social media to communicate about pain may be an important coping strategy for pain sufferers.

Based on the unsolicited data collected from Twitter in this study, results revealed similarities as well as differences in Twitter users experiences with toothache versus other common pains. Consistent with previous research where dental patients described their tooth pain with high intensity[5], our findings showed that Twitter users described toothache with high pain intensity descriptors, at a level comparable to backache, and higher than headache or earache. While our findings showed that high pain intensity and toothaches were both independently associated with twice the odds of reporting seeking health care or use of medication, only one in ten (9.6%) of the toothache sufferers mentioned managing pain by dental or health care options.

Tooth pain is often a consequence of dental caries with pulpal involvement, endodontic infection, and/or periodontal disease. These conditions, if left untreated, lead to tooth loss and potentially significant health consequences[2,8]. Previous studies found the most frequently used strategies to relieve toothache were nonprescription medication and home remedies (80%), and talking with friends and relatives for advice and support (63%)[4]. Although persons will attempt self-management pain strategies prior to visiting a dentist, it is interesting that relative to other pain types, persons with toothache mention seeking health care more often than with other types of pain. This could be due to persons more readily associating a toothache experience with a specific health care provider, i.e. a dentist. With the current popular utilization of social media and the known preference of toothache sufferers for self-help and social support, social media could be an effective outreach channel to encourage utilization of needed dental care.

Although the reasons for underutilization of dental care are not completely understood, previous studies have suggested the lack of affordable dental care as a key reason for underutilization[5]. However, the National Health Survey revealed that only one in three unmet dental needs could be explained by cost[3]. Our analyses did not reveal financial burdens as a concern for seeking dental care. Only 9% of twitter users are discussing their personal finances on Twitter[19], which may be a limitation to using social media as a data source for this topic. However, our findings suggested that toothache sufferers were less likely to report impacts on daily functioning when compared to those who had backache and earache, which could be a reason for delaying dental care and its underutilization.

Other limitations to social media research also applied to the current study include misinterpretation of message content, sporadic nature of sharing on social media, and the brief nature of the communications. It should be noted that only a single tweet per non-duplicate user was analyzed. It is possible that Twitter users might have described additional actions, causes, or impacts from the pain or other experiences in a separate tweet as part of a Twitter conversation but were not included in the analyses. The study findings, based on in-depth qualitative content analyses and quantitative analyses conducted using a random sample of 1,204 tweets, represented 0.02% of more than half a million tweets extracted during the study period and should not be interpreted to represent an epidemiological description of pain experiences. In addition, the findings related to actions taken for pain,

causes of pain, and impacts from pain should be interpreted with cautions because they were based on 5 to 13% of the tweets analyzed that provided the relevant contents. Nonetheless, the relatively small percentage of tweets in the sample provided a sufficient sample size to conduct comparisons across pain types under the same set of selection criteria, and revealed significant differences in pain experiences associated with pain types. Lastly, the generalizability of the findings is limited to individuals who access and use Twitter, who represent 18% of adults who use the Internet, and is more highly adopted by African Americans, and those below 30 years old[20]. It is important to point out that although the identity of this population is a moving target, making rigorous characterization difficult or impossible, clearly access to the internet and usage of social media is increasing, especially with the concomitant increased availability of low-cost smart mobile devices. Thus, although difficult to define, this dynamic population is none the less important to study.

Findings from this study offer new understanding of patients' experiences with dental pain shared through Twitter, which may be applicable to individuals who share personal health-related experiences on Twitter or other social media venues. Moreover, we performed a direct comparison of several facets of the pain experience with toothache versus other types of pain. In the future we also hope that studies such as these can be used to inform efforts to target at risk persons for health information or intervention using social media.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

Acknowledgments

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Figure 1.

Word cloud depicting the most used words from 1,204 coded tweets with font size representing frequency of use. Created using www.tagxedo.com. Image from www.twitter.com

Table 1

Inclusion and exclusion terms used in final query to generate the data set.

	Inclusion Terms	Exclusion Terms	Relevancy Rate*
Tooth	"Teeth AND hurt" OR "tooth AND hurt" OR "toothache" OR "tooth AND hurting" OR "teeth AND hurting" OR "tooth AND pain" OR "teeth AND pain" OR "tooth AND hurts" OR "teeth AND hurts" OR "tooth AND ache" OR "tooth AND killing" OR "tooth AND aches" OR "tooth AND aching" OR "toothaches"	http://, https://, RT, cure, whitening	90%
Back	"back AND hurt" OR "back AND hurts" OR "back AND hurting" OR "back AND killing" OR "back AND pain" OR "back AND killin" OR "back AND sore" OR "backache" OR "back AND ache", "back AND aches"	http://, https://, RT, karma, love, cure, treatment	85%
Ear	"ear AND hurts" OR "ears AND hurts" OR "ear AND hurt" OR "ears AND hurt" OR "ear AND hurting" OR "ears AND hurting" OR "ear AND pain" OR "ears AND pain" OR "earache" OR "ear AND ache" OR "ear AND killing" OR "ear AND throbbing"	http://, https://, RT, sing, singing, song, headphones, earphones, pierce, pierced, gauges, stretched, stretch, stretching	90%
Head	"Headache" OR "head AND hurts" OR "head AND hurt" OR "head AND ache" OR "headaches" OR "head AND hurting" OR "migraine" OR "migraines"	http://, https://, RT	92%

Note:

*Relevancy rate is the percentage of tweets, out of the sample extracted, that was evaluated as relevant (which has a description or a clear reference one of the 4 pain types of focus).

Table 2

Example of tweet categorization

Tweet	Pain Type	Primary Category	Secondary Category
My teeth hurt to anunbearable extent	Toothache	1. Pain Intensity	1.1 Severe
Man I hope these aches go away, I got stuff to do. Ear ache, head hurt, throat itch!	Earache	1. Pain Intensity 2. Action Taken	1.1 Mild 2.1 Hope/Ignore
My lower back killing me from all this lifting!! #StillGrateful	Backache	1. Pain Intensity 2. Cause	1.1 Moderate 2.1 Physical Activity
Couldn't go to school today cuz i had a serious pain in my tooth ahhhhh it still kinda hurts. Maybe some drawing will take the pain away,..	Toothache	1. Pain Intensity 2. Action Taken 3. Impact	1.1 Moderate 2.1 Distract 3.1 Missed School/Work
I have the worst headache ever. Poppin' advils like they're candy~	Headache	1. Pain Intensity 2. Action	1.1 Severe 2.1 Medication OTC

Table 3

Geographic locations of study tweets (N = 1,204)

GPS location (by continent)	Percentage (number) of Tweets
Africa	0.3% (4)
Asia	3.3% (40)
Australia	1.6% (19)
Europe	6.9% (83)
North America	50.6% (609)
South America	17.4% (210)
Unreported	19.6% (239)

Table 4

Distribution of primary coding categories and subcategories by pain types

Primary coding categories/ subcategories	Pain Types (n= number of tweets coded)				Pearson χ^2 (df = 3)	p-value
	Toothache	Backache	Earache	Headache		
Pain Intensity	(n=301)	(n=301)	(n=301)	(n=301)	20.72	<0.001
High	43.2%	47.2%	33.2%	32.2%		
Low	56.8%	52.8%	66.8%	67.8%		
Action Taken	(n = 47)	(n = 41)	(n = 34)	(n= 33)	16.17	0.001
Health care/ medication	61.7%	29.3%	44.1%	21.2%		
Homecare/other	38.3%	70.7%	55.9%	78.8%		
Cause	(n= 35)	(n = 37)	(n= 21)	(n= 39)	26.51	<0.001
Outside Elements	60.0%	13.5%	66.7%	64.1%		
Self	40.0%	86.5%	33.3%	35.9%		
Impact	(n= 20)	(n = 18)	(n = 17)	(n= 9)	25.38	0.003
Daily Functioning	25.0%	72.2%	64.7%	44.4%		
Sleep	25.0%	27.8%	23.5%	11.1%		
Food/Drink	30.0%	0.0%	5.9%	0.0%		
Mood	20.0%	0.0%	5.9%	44.4%		

Note.

1. All primary categories are non-mutually exclusive.
2. The subcategories within each primary category are mutually exclusive.
3. Percentages are computed using the number of tweets coded for the corresponding primary category and pain type as the denominator. The percentages may not add up to be 100% due to rounding error.
4. Pearson chi-square tests were conducted to compare pain intensity, action taken, cause, and impact by the 4 pain types with degree of freedom (denoted as “df”) and p-values as shown in the table.
5. Pain Intensity was re-categorized into 2 subcategories: high (“moderate” or “severe”) and low (“mild” or “neutral”, which included no pain intensity description).