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Epilepsy in the Twitter era: A need to re-tweet the way we think about seizures

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ABSTRACT

Seizures have long been associated with misconceptions and stigma. Exponential growth in Internet use has seen the rapid expansion of social media, such as Twitter, for health promotion. In view of the popularity of Twitter, we sought to explore how seizures are being portrayed on this social networking website and to consider its potential for information dissemination. A 48-hour Twitter search was used as a preliminary data set to determine an appropriate classification scheme of "seizure"-related posts ("tweets"). Analysis was then conducted using "seizure" tweets from a 7-consecutive day sample period. Tweets were analyzed and coded by two independent reviewers. Predominant categories were Metaphorical (32%), Personal Accounts (31%), Informative (12%), and Ridicule/Joke (9%). This study supports the notion that stigmatization associated with seizures continues to flourish, as 41% of "seizure" tweets were derogatory in nature. Although Twitter could be used to disseminate accurate information on seizures and epilepsy, this study suggests that it is currently propagating negative attitudes toward seizures with potential for fueling stigma. In recent years there have been significant advancements in technology offering many new methods of sharing information. Social networking sites allow real-time communication while providing the opportunity for exchange of information and opinions. Twitter, a website launched in 2006, allows users to communicate through “tweets” limited to 140 characters. Twitter's popularity has drastically increased since its inception, with approximately 110 million tweets per day from 200 million users worldwide, as of January 2011 (http://blogs.forbes.com/oliverchiang/2011/01/19/twitter-hits-nearly-200m-users-110m-tweets-per-day-focuses-on-global-expansion/). Such social media facilitate communication about an array of health-related topics including seizures and epilepsy.

1. Introduction

Internet use has infiltrated the field of medicine and public health information, with close to 100,000 health-related websites available to the public accessed by 113 million people in 2006 [1,2]. According to one study, 61% of American adults seek health information online and 37% search user-generated information [3]. With such widespread use and ease of access, the medical community must be aware of the quality and content of information that is accessible to the public through these ever-growing sources [4].

There has been increasing interest in the use of social networks for health promotion and dissemination of information to large populations. Some suggest that physicians could use Twitter to contact patients, update them on medical advancements, and answer questions [5]. Twitter has been adopted as a means of staying abreast of medical advancements in real time [6]. Twitter has also been proposed as a means of further nursing communication and continuing education [7]. A better understanding of Twitter content on medical topics is needed before its implementation as an educational tool. Twitter analyses have previously been used to examine public perceptions and attitudes around other health topics such as the H1N1 flu epidemic [8], mild traumatic brain injuries [4], and antibiotic use [3]. Such Web-based research, known as *infodemiology*, provides insight into health-related utility of social media and potential misconceptions on medical issues.

Although identified by the World Health Organization as one of the three most common neurological conditions, epilepsy has been fraught for centuries with myths, discrimination, stigma, and lack of public understanding. This seems shocking as epilepsy affects 50 million people, 1% of the world's population [9]. Over the years our mechanistic understanding of epilepsy has greatly improved, but fears and mystical views still remain [10]. People often associate violent, uncontrolled movements with epilepsy, though the majority of seizures are not as striking as frequently depicted by media [11]. Epilepsy and seizures have been portrayed in a dramatic fashion in both movies and television for years [12,13]. These illustrations may lead to significant misconceptions, discrimination, and stigma. Unfortunately, in contrast to many other medical conditions, media portrayal of seizures has not improved with increasing scientific knowledge. It has been proposed that because of the increasingly successful medical management of epilepsy, people are unlikely to witness a seizure. Indeed, only 8–9% of first-and third-year medical students in one study reported any personal experience with epilepsy [14]. Therefore, images of seizures are often based on fictional

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portrayals through the media and literature [15,16]. In view of the widespread popularity of Twitter, we sought to explore how seizures are being portrayed on this social networking website. Our goal was to learn more about public use of the term "seizure" on this Web-based social medium and to consider potential educational strategies using tweets about epilepsy and seizures.

2. Methods

Twitter (htpp://www.twitter.com) is a publically available website on which users can post comments referred to as *tweet*. Tweets that have been forwarded from one user to another are referred to as *re-tweets*. The Twitter website contains a search option to filter tweets for specific words. A *hashtag*, indicated by the symbol '#', can be added by the Twitter user to mark keywords or topics in a tweet [17]. The search engine stores tweets for only a few days, depending on the current volume of available tweets.

A prospective qualitative content analysis was conducted using seizure-related Twitter status updates. Searches for *seizure*, *seizures*, *seize*, *seizing*, and *seizuring* were conducted. *Seize* and *seizing* yielded results pertaining to alternate uses of words such as "seize the day" and were therefore excluded from further analysis. *Seizuring* produced very few results and was also excluded from analysis. We added a hashtag to each search term (e.g., "#seizure"), but this procedure did not yield additional results and was therefore excluded. No demographic restrictions were placed on age or location. Only English results were used because language translation was not feasible. Re-tweets and duplicates were excluded from analysis as it was felt that they would skew the data. In addition, tweets clearly using *seizure*(*s*) in a different context such as "seizure of drugs" or "seizure salad" were excluded.

A preliminary data set was collected from March 31 through April 2, 2011. Tweets from April 1, 2011 were excluded due to the predominance of April Fools Day comments. It was felt that these tweets might distort the data and would not be representative of a typical day.

A coding scheme was developed to allow further analysis of the content from seizure-related tweets. Searches on March 31 and April 2, 2011 were used as a 48-hour preliminary data set to determine the appropriate classification scheme of tweets. Specific themes were found repeatedly and were used to establish the coding scheme. "Metaphorical" tweets contained analogies to "seizure-like" movements or actions. Tweets that described a personal experience with a seizure or witnessing of a seizure were categorized as "Personal Accounts." Some tweets included information about seizures or medications and were classified as "Informative." Others posed medical-related questions and were designated "Advice Seeking." The "Ridicule/Joke" category, frequently accompanied by the abbreviation *LOL* ("laugh out loud") was used for tweets that either made fun of seizures/people with epilepsy or joked about feigning a seizure. Tweets that stated a personal viewpoint or judgment about seizures or about other posts were categorized as "Opinion." A final "Miscellaneous" category was included for those tweets where the meaning was not readily interpretable and could not be reliably coded. The final classification scheme with representative examples is outlined in Table 1.

Two of the authors (K.M. and P.B.) then reviewed the preliminary data sample and coded each tweet into one of the agreed on categories. Discrepancies were reviewed and discussion about the most appropriate categorization took place.

A final data set of seizure-related Twitter status updates for *seizure* and *seizures* from April 15 to April 21, 2011 inclusive was obtained and extracted to a Microsoft Word document. A subsample (targeted $N = 1500$) was selected each day through a random number generation using Microsoft Excel. The subsample data were analyzed and manually coded by two independent reviewers (K.M. and P.B.) using the previously agreed on categorization. Reviewer discrepancies were analyzed to come to a consensus on final categorization.

Table 1
Classification scheme for seizure-related *Tweets*.

Category	Example
Metaphorical	"My blackberry just had a seizure." "Mariah Carey looks like she has a seizure when she sings."
Informative	"Epilepsy is not just one condition; rather it is a diverse family of disorders comprising many seizure types."
Ridicule/Joke	"Some of the most memorable pranks that did not require gasoline and matches were faking seizures w/alka seltzer." "What do you do when someone's having a seizure in the bathtub? … Throw in a load of laundry"
Personal Accounts	"Six weeks today without a seizure. Hopefully I'll get my driver's license back in another 6." "I feel so helpless when my dog has a seizure."
Advice Seeking	"Has anyone taken Lyrica? Experiences?"
Opinion	"I absolutely hate it when people think it's funny to slag off people who have seizures. It's downright cruel." "That's why when people have seizures they hold their tongues so they won't swallow it."
Miscellaneous	"You ok over there? No seizures ok." "Digging this seizure room."

3. Results

3.1. Preliminary data set

A total of 1720 tweets were originally collected from a 48-hour period. Of these tweets, 389 contained the word *seizures* and 896 included the word *seizure*. Four hundred thirty-five tweets were excluded. One thousand two hundred eighty-five tweets were analyzed and independently coded into one of the seven developed categories (Table 1).

The reviewers were in agreement on tweet categorization in 1098 of 1285 cases (85.4%). For this preliminary study, the percentage agreement was considered acceptable.

3.2. Final data set

A total of 10,662 tweets were originally collected from the 7-day period in April 2011. The Twitter search for *seizure* yielded 6706 results, and the search for *seizures* produced 3956 tweets. After application of exclusion criteria to this data set, 5301 of the collected 10,662 tweets were suitable for analysis (~50%). An approximately 28% subsample was derived daily from all eligible tweets, for a final analysis sample of $N = 1504$.

Reviewers 1 and 2 analyzed the final data set independently. The reviewers were in agreement on tweet categorization in 1349 of 1504 cases (89.6%). The κ agreement coefficient was 0.866 (SE = 0.01) for the sample ($P < 0.001$). The final classification data are presented in Table 2. The predominant category was Metaphorical ($n = 477$, 32%). The second most prevalent was Personal Accounts ($n = 462$, 31%). Informative was the third most common ($n = 185$, 12%) followed by Ridicule/Joke ($n = 138$, 9%). Miscellaneous, Opinion, and Advice Seeking accounted for 8, 6, and 2% of tweets, respectively.

Table 2
Categorization of seizure tweets.

Tweet category	Frequency
Metaphorical	477 (32%)
Personal Accounts	462 (31%)
Informative	185 (12%)
Ridicule/Joke	138 (9%)
Miscellaneous	119 (8%)
Opinion	84 (6%)
Advice Seeking	39 (2%)

4. Discussion

Though our media world continues to rapidly evolve our speed of communication, public conceptions about seizures remain decades behind. Misconceptions and stigmatization associated with epilepsy and seizures continue to flourish [10,18]. Our qualitative evaluation of Twitter posts supports this notion. An astounding 41% of "seizure(s)" tweets were either Metaphorical or Ridicule/Joke themes, which were generally derogatory in content. The metaphorical use of "seizure" appears to be very common among the population using Twitter. Such tweets addressed primarily three main themes: (1) the appearance of someone dancing, (2) phone/personal digital assistant (PDA) vibrating or malfunctioning, and (3) sexual experiences. Although these statements were not directly ridiculing those with epilepsy, they often had very negative connotations. It appears that the use of "seizure(s)" in reference to unusual movements, dancing, or losing control is widely accepted among the population using Twitter. For example, tweets such as "I can't tell if this guy's having a seizure or dancing" perpetuate stereotypes and are demeaning to those living with seizures. Even more shocking were the abundance of jokes related to seizures; for example, "What do you do when someone's having a seizure in the bath tub? … throw in a load of laundry" was commonly posted during the study period. It was re-tweeted an astonishing 77 times in a 24-hour period. In the past few decades there have been significant strides in eliminating offensive terms for other medical conditions, but there is a definite lag in this regard for seizures and epilepsy.

In contrast to many medical conditions, the portrayal of seizures on television and movies has not improved with increased understanding of the disease [15]. Several other conditions such as diabetes and breast cancer have made progress in decreasing stigma [19]. A correlation has been found between low levels of knowledge about epilepsy and higher perceptions of stigma [20]. Derogatory tweets highlight the need for further public education on epilepsy to reduce the associated humor and "seizure" metaphors, which foster stigma.

Fortunately there were a few tweets that spoke out against mocking those with seizures. The tweet "Why do people joke about epilepsy and seizures? Do they joke about cancer? Attach your brain 2 a car battery & see how funny it is!" articulates this point emphatically. Another example is "Second Most Unfunny Thing In The World? Makin Fun Of Seizures. I Used To Have Them. Don't Do It, At Least Around Me" and "BACK OFF THE SEIZURES. It's disrespectful of those living with seizure disorders. Would you use cancer as a tool?" These tweets demonstrate the extent to which demeaning comments about seizures can affect the online population. The online voice of those speaking out against such negative stereotypes and disparaging remarks needs to be stronger. This emphasizes a need for improved epilepsy education and motivation for people with epilepsy as the foundation to improve public knowledge and behavior [21].

It was important for us to obtain reasonably precise estimates of the categorized twitter responses. We drew on our estimates derived from our preliminary 48-hour sample and proposed a final sample size of 1500. Use of Internet and, by association, Twittter varies over the day and over the week (day by day). We felt that variation over weeks or months was either less likely or, if present, small. Our design is nearly that of Sullivan et al., who examined a subsample of 1000 tweets from 3488 tweets about concussion accumulated over 1 week. The remarkable agreement in profile of seizure-related tweets observed in the preliminary analysis and final data set suggests relative consistency over time and reliability of the coding scheme, potentially justifying our 7-day sample period. However, during the preliminary sample period, we noticed a drastic climb in "joke"-related *tweets* for April Fools Day that were excluded. Social media sites are prone to such news and event-related trends which could impact the validity of the data collected. For instance, the possibility that the Kanye West song *All of the Lights* could induce seizures became a popular topic in the preliminary analysis. During the final sample collection, a large concert event was occurring and many tweets concerned the music or performers "giving" people in the audience "seizures." This is a potential limitation of our study sample as daily results may be skewed depending on popular events. However, the same general themes appear congruent from one day to the next, with many of the comments being metaphorical, ridiculing, or personal experiences. We made an effort to avoid dates that were likely to strongly influence content such as holidays and the internationally recognized Purple Day for Epilepsy on March 26th. Another important illustration of this was the discarded April 1st data. These tweets were very frequently associated with April Fools Day and a startling number were jokes about seizures. There were also many jokes about faking seizures and these often carried over to the subsequent day. For instance, the April 1st comment "April Fools Day is for amateurs. I like to fake a good seizure on a regular old weekday when they're least expecting it" was re-tweeted 179 times on April 2nd. Such a large number of re-tweets of an offensive statement reinforces the observation that Twitter may perpetuate stigma associated with seizures.

The demographics of the Twitter users may also have an impact on the results obtained from analysis. Thirty-nine percent of tweets are non-English and hence excluded. Our conclusions are restricted to the views and opinions on seizures of English-speaking Twitter users. Age may also be important, as 66% of Twitter users are under the age of 25 [22]. It is possible that this high proportion of youth and young adult users, not being representative of the general population, may skew the results.

Lo et al. previously examined other forms of Web-based media that may be promoting the stigma of seizures. In their analysis of epilepsy videos on YouTube they found that although there were many empathetic comments, many viewers found seizures comedic [11]. Twitter allows users to post links to websites, including YouTube. These links reinforced the previous findings. In one instance, a link to a video was posted with the tweet "hold down 4 it looks like he's having a seizure." Another tweet in our sample posted a YouTube link of someone pretending to have a seizure as a joke. Such comments and links facilitate widespread propagation of misconceptions and stigma surrounding epilepsy. Although traditional media forms like TV, radio, and film transmit large volumes of health-related information governed by regulatory bodies, the Web 2.0 is largely unregulated. It has infiltrated the public media domain with demands for easy, rapid, and user-generated information with inherent potential to be educational or destructive.

Stigma remains an unfortunate reality for those living with seizures. Overall, studies show improved public attitudes toward epilepsy, but negative images and misunderstanding sadly remain pervasive [18,23,24]. That stigma remains at the forefront of concerns of people with epilepsy is certainly justified. Because some experts believe that stigmatizing prejudices negatively impacts people with epilepsy only if they personally accept these derogatory notions, we cannot be certain of the true impact of negative Twitter comments related to seizures [23]. Fernandes et al. developed a Stigma Scale of epilepsy to allow for quantification of the perception of stigma among patients and community members [25]. Further analysis using such a scale may provide insight into the impact of seizure-related tweets on individuals with and without epilepsy.

Within the Personal Account category, our data showed a trend to refer to seizures as being frightening to watch. A good example of this is "This lady is having a seizure on this bus! Just freaked me the Hell out!" This reinforces the notion that seizures remain a foreign concept to many people who are shocked by witnessing an episode. The majority of the Personal Account comments showed empathy or concern rather than LOL or offensive posts. Personal experiences often referred to witnessing a seizure of a friend, relative, pet, or stranger. The tweet "Our hound dog Harley just had a seizure. It lasted

about 90 seconds. We felt so helpless" illustrates a common personal account. This shows the concern and fear frequently associated with a personal experience with seizures.

Our study results demonstrate significant barriers to using Twitter as a means of public education about seizures. Only 12% of the tweets, mostly those containing information on anticonvulsants or epilepsy in general, were considered informative. Additional research would be necessary to examine the content of the "informative" tweets to explore the accuracy and credibility of the Web links. Unfortunately there is huge potential for dissemination of unreliable information regarding seizures, a potential problem with all Web-based media that are unregulated. In addition, because a significant proportion of the tweets could be considered offensive, it is likely that accurate educational information would be overshadowed by the inappropriate seizure tweets. Clearly there is a need for more education regarding seizures, but Twitter may not be the optimal social medium for this endeavor.

In the design phase of the study we also explored the use of the term *epilepsy* on Twitter and were reassured to find primarily informative comments or links to epilepsy websites. Though the accuracy of this information was not analyzed, there were very few negative or stigmatizing tweets using the word *epilepsy*. This may reflect more common public knowledge of the term *seizure*, but argues against patients' reluctance to adopt the term *epilepsy* for fear of discrimination or negative connotations.

This study demonstrated the prevalence of stigmatizing comments related to seizures on the rapidly growing website Twitter. Highly popular social media like Twitter could be used productively to disseminate accurate information on seizures and epilepsy, but are currently propagating negative attitudes toward seizures with potential for fueling stigma.

References

[1] Dearness KL, Tomlin A. Development of the National Electronic Library for Mental Health: providing evidence-based information for all. Health Info Libr J 2001;18:167–74.

[2] Khechine H, Pacot D, Premont P. Use of health-related information from the Internet by English-speaking patients [survey]. Health Info J 2008;14:17.

[3] Scanfield D, Scanfield V, Larson EL. Dissemination of health information through social networks: Twitter and antibiotics. Am J Infect Control 2010;38:182–8.

[4] Sullivan SJ, Schneiders AG, Cheang CW, et al. "What's happening?" A content analysis of concussion-related traffic on Twitter. Br J Sports Med 2011 Epub ahead of print March 15, 2011.

[5] Vance K, Howe W, Dellavalle RP. Social Internet sites as a source of public health information. Dermatol Clin 2009;27:133–6.

[6] Kubben PL. Twitter for neurosurgeons. Surg Neurol Int 2010;2:28.

[7] Billings DM, Kowalski K, Bristol TJ. Twitter: consider the possibilities for continuing nursing education. J Contin Educ Nurs 2010;41:199–200.

[8] Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of tweets during the 2009 H1N1 outbreak. PLoS One 2010;5:e14118.

[9] Saraceno B, The WHO. World Health Report 2001 on mental health. Epidemiol Psichiatr Soc 2002;11:83–7.

[10] Baxendale S, O'Toole A. Epilepsy myths: alive and foaming in the 21st century. Epilepsy Behav 2007;11:192–6.

[11] Lo AS, Esser MJ, Gordon KE. YouTube: A gauge of public perception and awareness surrounding epilepsy. Epilepsy Behav 2010;17:541–5.

[12] Baxendale S. Epilepsy at the movies: possession to presidential assassination. Lancet Neurol 2003;2:764–70.

[13] Kerson TS, Kerson L. Implacable images: why epileptiform events continue to be featured in film and television. Epileptic Disord 2006;8:103–13.

[14] Caixeta J, Fernandes PT, Bell G, Sander JW, Li LM. Epilepsy perception amongst university students: a survey. Arq Neuropsiquiatr 2007;65(Suppl. 1):43–8.

[15] Kerson TS, Kerson LA. Truly enthralling: epileptiform events in film and on television – why they persist and what we can do about them. Soc Work Health Care 2008;47:320–34.

[16] Krauss GL, Gondek S, Krumholz A, Paul S, Shen F. "The scarlet "E": the presentation of epilepsy in the English-language print media. Neurology 2000;54:1894–8.

[17] http://support.twitter.com/entries/49309-what-are-hashtags-symbols. Accessed: July 15, 2011.

[18] Austin JK, Shafer PO, Dering JB. Epilepsy familiarity, knowledge, and general perceptions of stigma: report from a survery of adolescents in the general population. Epilepsy Behav 2002;3:368–75.

[19] Fernandes PT, Salgado P, Noronha AL, Barbosa FD, Souza E, Sander JW. Prejudice towards chronic diseases: Comparison among epilepsy, AIDS and diabetes. Seizure 2007;16:320–3.

[20] Jacoby A, Austin JK. Social stigma for adults and children with epilepsy. Epilepsia 2007;48(Suppl. 9):6–9.

[21] Fernandes PT, Snape DA, Beran RG, Jacoby A. Epilepsy stigma: what do we know and where next? Epilepsy Behav 2011;22:55–62.

[22] Cheng A, Evans M. Inside Twitter: an In-depth look inside the Twitter world. Accessed: May 1, 2011. Available at: http://www.sysomos.com/insidetwitter/#demographics. June 2009.

[23] Morrell MJ. Stigma and epilepsy. Epilepsy Behav 2002;3(6, Suppl. 2):S21–5.

[24] Bandstra NF, Camfield C, Camfield P. Stigma of epilepsy. Can J Neurol Sci 2008;35:436–40.

[25] Fernandes PT, Noronha ALA, Sander JW. Stigma scale of epilepsy. Arq Neuropsiquiatr 2007;65(Suppl. 1):35–42.