Analyzing Twitter as a Platform for Alzheimer’s Dementia Awareness

Abstract

**Background:** Dementia is a prevalent disorder among adults and often causes negative stigmatization to the individual and his/her family. Social media websites provide a place to raise awareness for dementia and have allowed researchers to explore health-related data on social platforms.

**Objective:** This study examined the content and location of tweets containing the keyword “dementia” to better understand the reasons why individuals discuss dementia on the social media website Twitter. This approach examined location, Twitter user category, and tweet content subcategory to examine large publicly available datasets.

**Methods:** A total of 400 tweets were collected using the Twitter Search Application Programming Interface (API) with the keyword “dementia”, circulated between January and February of 2018. Twitter users were categorized into four categories: general public, healthcare field, advocacy organization, and public broadcasting. Tweets posted by “general public” users were further subcategorized into five categories: mental health advocate, affected persons, stigmatization, marketing, and other. Placement into the categories were done through thematically analysis.

**Results:** 400 Tweets were tweeted by 359 different screen names from 28 different countries. The top countries were the United States and the United Kingdom while the top states were California and Texas. The majority of Twitter users were categorized in the general public category (71%). The content analysis of Tweets from the general public category reveal stigmatization (41%) and mental health advocate (37%) themes. For tweets from California and Texas, California had more stigmatization tweets while Texas had more mental health advocate tweets.

**Conclusions:** The themes from the content of the tweets highlight the mixture of the political climate along with the supportive network present on Twitter. The ability to use Twitter to combat stigma and raise awareness of mental health indicates the benefits that can potentially be facilitated via the platform but negative stigmatizing tweets may interfere with the effectiveness of this social support.

**Introduction**

Dementia is a neurocognitive disorder that affects cognitive function and performing daily activities such as going to the bathroom, eating, and communicating. In 2017, an estimated 5.5 million people in the United States had Alzheimer’s dementia, one of the most common forms of dementia, and 96% of those are adults 65 years and older [1]. The increasing
number of adults living with dementia has simultaneously caused an increase in awareness
for the mentally debilitating disease. However, this recognition of dementia as a problem
amongst the elderly has caused both negative stigmatization and positive support amongst
communities. For instance, those living with dementia have reported experiencing various
degrees of shame, including avoidance, negative self perceptions, and uncertainty [2].
Interviews with individuals affected by dementia have shown that these individuals often
feel perceived as “stupid” [3]. These perceptions of individuals affected by dementia have
been perpetuated by the increased use of the Internet as a source of information and social
commentary. A study examining Alzheimer’s stigma on Twitter found that 21% of
Alzheimer’s related tweets used related keywords (i.e. “Alzheimer’s,” “senile,” “memory
loss,” and more) to perpetuate public stigma [4].

Nonetheless, technology has also become a platform for disseminating information about
dementia and the creation of education and support programs. This most often occurs in
the form of blogs, written by dementia caregivers, about their experiences and the impact
of caring for affected persons. These platforms have aided in the development of
intervention programs and services for caregivers [5]. Additionally, these platforms have
also helped in the creation of these same programs for affected persons. Studies discovered
that a dementia awareness campaign may be useful in decreasing mental health disparities
[6] while media outlets such as public radio stations would helpful in promoting dementia
awareness [7].

Twitter has been used as an online source for people to receive support [8] and for
physicians to share scientific information with the public [9]. Thus, upon analysis of tweets
mentioning the term ‘dementia’, we expect to find supportive online twitter discussions
about dementia. This study is notable for analyzing geotags associated with each tweet to
determine worldwide usage of ‘dementia’ in tweets. As the Western world has become
more involved in mental health advocacy, we specifically focus on states within America to
evaluate if states that have more open discussions on mental health and mental health
policy have more users involved in positive conversations.

The aim of this paper is to develop a better understanding of the online twitter discussion
about dementia, and to analyze the applicability of using twitter as an online support
system for individuals with dementia and their families.

Methods

Data Collection
400 publicly available tweets were collected on four different days at four different time
points during the months of January and February in 2018. Given the vast majority of
tweets available online and the ability of two researchers to manually code each tweet, a
sample of 400 tweets was chosen, which is comparable to the 311 tweets manually coded in
a similar paper [4]. The Twitter search application programming interface (API) and
Postman API Development Environment (www.getpostman.com, San Francisco, CA) were used to collect the data endpoints from Twitter that contain the keyword “dementia.” 100 Tweets were collected at each time point, a limit that is imposed on the Twitter Search API. Thus, we accessed only a portion of the tweets posted during each of the four time points. For each tweet, we collected data on the date, time, location, username, and tweet body text including hashtags, links, and emojis.

Tweets were collected at various time points to account for differences in online usage time and events that may occur, such as political scandals or book publications.

Data Analysis & Manual Coding
Upon completion of data collection, all tweets were imported into a password-protected Excel (Microsoft) file for analysis. Retweets were considered as individual data points because the more retweets a particular tweet has, the more likely it is to appear at the top of a Twitter search. Thus, retweets are vital for understanding which category of tweets is more readily visible and available for users searching for ‘dementia’ and the diffusion of tweets through follower-friend connections [10]. Tweets in languages other than English were inputted into Google Translate to identify subject matter.

User profile information was used to determine the location of the twitter user. Tweets coming from the United States were further categorized by state. Thematic analysis was utilized to determine the key purpose of each tweet. A hierarchical structure of categories and subcategories was produced to normalize the comparison between tweets. Tweets were divided into four categories based on user profile information: general public, healthcare field, advocacy organization, and public broadcasting. Further classifications were made if the user was considered general public. General public tweets were divided into five categories based on the content of the tweet itself: mental health advocate (posting about ways to prevent dementia, raising money for dementia), affected persons (person living with dementia, family member or friend), stigmatization (using the word ‘dementia’ to accuse people of certain qualities), marketing (using dementia to promote a business) and other (not belonging to any of the above named subsections). To be considered in the healthcare field category, the twitter user profile was analyzed for a link to their website on their profile or an explicit statement in the description. Below are a few examples of the users and tweets in the categories mentioned:

Example of healthcare field user:
Example of advocacy organization user:

Example of mental health advocate post:

“Even when you have Alzheimer’s disease, you need ways to participate in our community and so often caregivers, too, can become socially isolated.” Dr. Debra Sheets (Nursing)

Example of stigmatization post:
Results

Data Collection
400 Tweets were collected. Of these 400, 57% of them were re-tweets and 359 were posted by different user screen names. 7.2% of the tweets were posted by the same user screen name at least two or more times.

Data Analysis & Manual Coding
Upon analysis of geotag locations, there were tweets posted from 28 different countries. The top two were the United States (n=119) and United Kingdom (n=111). Of the 119 tweets from the United States, the top two states were from California (n=22) and Texas (n=12).

Categorization of Twitter users showed a majority classified as general public (70.6%, 281 out of 398) and advocacy organizations (14.3%, 57 out of 298). 41 tweets (10%) were from users associated with the healthcare field, such as psychologists, nurses and researchers while 14 tweets (3.5%) were associated with public broadcasting, such as newspapers and radio stations. 5 of the Twitter user profiles (1.3%) were deleted when analysis began and, thus, could not be classified.

Further analysis of the “general public” category demonstrated that a majority of the tweets were identified as stigmatization (40.2%, 113 of 281) or mental health advocate (36.3%, 102 of 281). 26 tweets (9.3%) were tweeted by affected persons while 13 tweets (4.6%) were tweeted for marketing purposes. 25 tweets (8.9%) could not be classified by the four main subcategories and were subsequently placed in the “other” category.

Analysis based on top 2 most Tweeted states in the United States, after adjusting for missing data values, showed that Californians (n=14) had more stigmatization-related tweets (n=9) while Texans (n=5) had more mental-health-advocate-related tweets (n=3).

Discussion

Principal Results

Less than a third of the tweets were posted by advocacy organizations or health professionals. These tweets aim to raise awareness about dementia, provide dementia prevention information, and give advice for caretakers. However, many of these tweets are eclipsed by the many more tweets generated by the general public. Online users seeking
support from dementia tweets may not see all of the information offered to them by advocacy organizations or health professionals but rather see the information provided by the general public. This leads to the dangers of online misinformation as many are willing to believe news that align with their own beliefs and provide them with a greater sense of hope and control [11]. While many of the posts from the general public may be helpful, those posted by organizations or professionals are more likely to contain credible and trustworthy information that will be better received and followed by the public.

Furthermore, many of the Tweets posted by the general public in the “mental health advocate” and “affected persons” category also provide sentimental tweets that raise awareness or seek support, respectively. Having these become eclipsed by negative tweets reduces the effectiveness of using Twitter as a supportive online community for dementia.

In 2009, the National Alliance on Mental Illness (NAMI) produced a report card for each state, grading them in four categories related to their mental health policies [12]. This standard was utilized to compare the mental health system in both California and Texas (Table 1). Because California has a higher grade in each category, it demonstrates that California has more resources and ability to advocate for those living with mental illnesses. Thus, we would expect a larger amount of mental health advocates amongst Twitter users residing in California rather than Texas. However, results demonstrate that there are more stigmatization posts from Twitter users residing in California than those in Texas. This contradicts what is expected based on the grades given to each state.

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<tr>
<th>CATEGORY</th>
<th>CALIFORNIA GRADE</th>
<th>TEXAS GRADE</th>
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<td>I. Health Promotion &amp; Measurement</td>
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<td>II. Financing &amp; Core Treatment/Recovery Services</td>
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<td>III. Consumer and Family Empowerment</td>
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<td>IV. Community Integration &amp; Social Inclusion</td>
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*TABLE 1. 2009 NAMI Category Grades*

NAMI Category Grades are based on four categories. Health Promotion and Measurement considers the services states provide, the development of mental health policy planning and data collection. Financing and Core Treatment/Recovery Services entails the accessibility and availability of mental health services, reimbursement for these services through state Medicaid
programs, the severity of current shortages in the mental health workforce, and state efforts to improve the cultural competence of their mental health care systems. Consumer and Family Empowerment grades are determined by the states' opportunities for family and consumer education and empowerment. Community Integration and Social Inclusion determines if states are compensating for extreme mental illnesses that go beyond those addressed by mental health agencies; this includes data on public health education and housing resources.

Limitations
In exploring the global conversation surrounding dementia, a majority of the Tweets were posted from the United States and the United Kingdom. Though the United States and the United Kingdom are amongst the top countries that have the most Twitter users, there are other countries such as Japan and Spain that may engage in the dementia conversation [13]. Since the search term used was “dementia” in English, this may have limited the searched Tweets to those written in English. Furthermore, the United States and the United Kingdom are often at the forefront of increasing awareness for mental health awareness. As one of the first countries to establish a mental health policy in 1996, the United States has seen its residents hold increasingly positive attitudes toward seeking professional help for mental health problems over time [14]. Another factor to consider is the role of culture in mental health awareness and seeking out professional help [15]. This may influence the lack of other countries actively participating in the dementia discussion.

In relation to the deviance from data suggesting that California would generally have more mental health advocates than Texas, data collected during the month of January followed large political events or wrongdoings. Thus, Twitter users might have used the term ‘dementia’ to express negative attitudes towards those involved in the political event.

Comparison to Prior Works
A similar study on Twitter that was performed in 2012 studying types of social media users and dementia themes found that most of the information on Twitter came from health professionals, health information sites, new organizations and commercial entities and that most tweets contain links to news and health information sites [16]. From 2012, the number of Twitter users has greatly increased from 167 million Twitter users to the current 330 million users worldwide. Now that there are more users, there can be more actively voiced, differing opinions and misinformation that may affect how others perceive dementia and bar access to dementia support systems. Thus, as the world uses more technology, it becomes more relevant and important to study how the online Twitter discussion may have changed over time.

Conclusion
Twitter as a social media platform has great potential for disseminating information on care, creating support systems and raising awareness for Alzheimer’s dementia. With the popularity of the internet growing with each generation, future generations may turn to Twitter seeking comfort and knowledge about the onset of this disease. However, it has
thus far been used as a readily available method for perpetuating stigma by attributing traits associated with dementia to normal, healthy people that Twitter users may find disagreeable.

Further research is warranted to determine the full impact and number of Tweets addressing dementia in a negative light or as a method to raise awareness. In particular, older generations that may actually be affected by dementia do not use the internet as a platform for discussion as much as younger generations do. Thus, research on dementia on social media platforms should also be pursued in the future as the younger generations grow older. The search for Tweets would also have to be broadened to be more inclusive in addressing language differences in tweets (“dementia” in different languages), the time of day the tweets were posted as well as the time of year. Furthermore, in the efforts to raise awareness of mental health issues, the conversations surrounding dementia should be expanded from the United States and United Kingdom, changing cultural beliefs that affect views on mental health. With more than 330 million users on Twitter, understanding the ability of Twitter as a readily available, popular, free source of information to better disseminate important information about Alzheimer’s dementia may be the key in building supportive and knowledgeable communities for the future.

References
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