

#Alzheimer's and Dementia

Expressions of Memory Loss on Twitter

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The authors performed Twitter data analysis to explore content relative to Alzheimer disease and dementia and then qualitatively coded tweets to explore themes. During a 1-month period, the authors collected 2739 tweets that referenced #alzheimer's, #Alz, #dementia, or #dementia. Content was posted by (1) caregivers (n = 1391), (2) caregiving organizations (n = 214), (3) general public (n = 854), and (4) news outlets (n = 66). Twitter content themes referenced social support and advocacy. Results show people document experiences with Alzheimer disease and memory loss on Twitter. Twitter could be used to broadly reach persons affected by memory impairment for social support and services, warranting future research.

Key words: caregivers, data mining, dementia, social media

The number of older adults in the United States population is rapidly increasing, and by 2030, approximately 20% of the population will be older than 65 years.¹ With aging, the risk for Alzheimer disease and other dementias increases. Alzheimer disease is the sixth leading overall cause of death in the United States,² is associated with \$259 billion in annual health care costs,³ and resulting physical and cognitive deficits often necessitate caregiver support for tasks required for functioning, safety, and well-being.⁴

Caregiving is associated with substantial physical and emotional stressors. Unfortunately, health care providers do not often address the health of caregivers. Only 16% of caregivers report that a health care provider has addressed their own personal health, and more than half of caregivers

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desire information about stress management.⁵ In light of these concerns, caregivers often turn to sources of health information outside of health care providers, such as the Internet.

Social media use is integrated into the daily lives of most Americans and is emerging as a resource for health care users.⁶ One such nontraditional mechanism of reporting health information is Twitter, a microblogging platform with a worldwide reach. Twitter generates an extremely large amount of data (eg, >6000 tweets sent every second)⁷ and as such is a publicly accessible source of “big data” providing valuable information about natural interactions of people in real time. This is in contrast to somewhat artificial or constrained interactions via traditional research approaches such as surveys or interviews.

Twitter is an emerging tool for surveying and intervening a large groups of people in real time due to the publicly available tweets, a message posting of 140 characters or fewer. Twitter has been used for public health surveillance in conditions such as influenza,⁸ suicide,⁹ and depression.¹⁰ Individuals with breast cancer have used Twitter to find health resources and express a personal narrative.⁶ Twitter also provides an opportunity for social activism in coordinating activities and linking groups with related interests together.⁶ However, the use of Twitter in expressing the lived experience of those affected by Alzheimer disease or other dementias has not been studied. Roughly 25% of all Internet users have a Twitter account, and the publicly available nature of Twitter profiles makes this an ideal medium by which to investigate how memory impairment is reported through social media. Thus, the purpose of this study was to explore how Alzheimer disease and other dementias are reported on Twitter, determine themes related to Twitter data, and generate an understanding of the perceived needs and assets of the Twitter community.

METHODS

Design and data collection

This was a mixed-methods study involving an initial quantitative Twitter data mining process, followed by a qualitative analysis of tweets grounded in a phenomenological approach. The researchers used this approach to

examine the experience of Twitter users whose lives were impacted by Alzheimer disease and other dementias.

This study occurred in 3 stages: data collection, preprocessing, and qualitative analysis. In the data collection stage, the researchers downloaded publicly available tweets meeting our search inclusion criteria, making this nonhuman subject research. During preprocessing, the researchers extracted tweet text and available metadata such as the tweet time stamp and user geographic location. Conventional content analysis was used to code tweets, analyze themes, and provide code frequency.

Stage 1: Data collection

The Twitter Application Program Interface (API) provides 2 means to download tweets in near real-time: Twitter Streaming API and Twitter Firehose. The Twitter Firehose is handled by 2 companies in cooperation with Twitter. The Firehose is a paid service that grants access to 100% of the tweets. On the contrary, Twitter's Streaming API provides free access to roughly 1% of all Twitter content at the time of download. To capture tweets related to a specific topic search, key words are used to exclude unmatched tweets from the downloaded stream.

One author (R.A.) used an application account to access Twitter's Streaming API and stored the downloaded tweets in a MySQL database. The Twitter API provides a random selection sample of tweets representing roughly 1% of all Twitter content at the time of download. We first curated a general list of the following search terms: Alzheimer's, dementia, and dementia. We included a misspelled version of the dementia key word to achieve a high coverage of tweets, while not exceeding the 1% threshold allowed by the Twitter API. After initially gathering content using those 3 key words, we further refined inclusion and exclusion criteria to filter extraneous content. Definitive inclusion criteria were US geolocation and/or public Twitter profile location, publicly available account, and tweets mentioning 1 or more Alzheimer's or dementia-related key words. Exclusion criteria were non-US Twitter account, private Twitter account, no Alzheimer's or dementia-related key words mentioned in the tweet, and retweets (reposts of other people's original content). We collected all tweets meeting the inclusion criteria for a 1-month period during March 2017. Given that this is the first known investigation of Twitter content relative to Alzheimer disease and other dementias, a 1-month initial time period was used for data collection for the purposes of establishing feasibility.

Stage 2: Preprocessing

One author (R.A.) extracted various tweet-associated metadata such as geolocation, application used to post the tweet, and time stamp. Each tweet was processed using JSON (JavaScript Object Notation; a lightweight self-

describing data exchange format) to extract the metadata and text. Data were stored into the MySQL database in separate tables based on the key words used in the initial search (Alzheimer's, dementia, and dementia) (Figure).

Stage 3: Content analysis

The authors (J.T. and M.D.) analyzed tweets through conventional content analysis¹¹ using a spiral, iterative approach.¹² The authors used a conventional content analytic approach to derive codes directly from the Twitter data in an inductive approach. All tweets were initially downloaded into a Microsoft Excel spreadsheet, read, an emergent coding scheme was developed on the basis of initial reading, and then tweets were reread with codes applied to each tweet for categorization. Codes were then analyzed to identify meaningful thematic patterns. The 2 authors involved in data coding and analysis independently coded all content and then met to discuss any areas of disagreement. We also calculated frequency rates of each code to provide quantitative outcomes on the various types of content downloaded.

RESULTS

Summary data characteristics

During a 1-month period, we found 2739 tweets that used the hashtag Alzheimer's, dementia, or dementia. Tweets centered around 4 major categories: (1) tweets sent by individuals who specifically referenced providing care for persons with Alzheimer disease or dementia (n = 1391); (2) tweets sent by caregiving agencies, business, or other organizations (n = 214); (3) tweets sent by individuals who referenced Alzheimer disease or dementia (n = 854); and (4) news outlets (n = 66).

Alzheimer disease or dementia caregiving

During the 1-month data collection period, 1391 tweets or 51% of all content meeting inclusion criteria, referenced

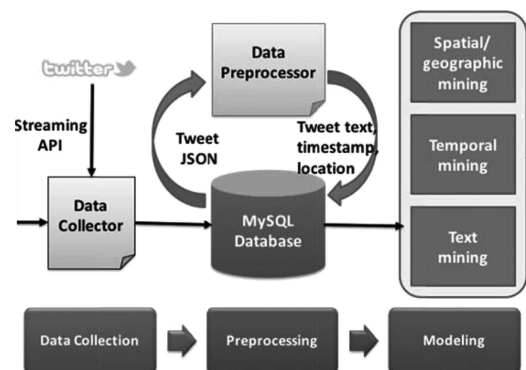


Figure. Preprocessing diagram. JSON indicates JavaScript Object Notation.

providing care for persons with Alzheimer disease or dementia. Most of this care-related content referenced providing social support for other caregivers, political advocacy, raising public awareness of Alzheimer disease or dementia, and formal caregiving supports. Individuals tweeted supportive statements to other Twitter users in 6% of content (n = 157), while other times, individuals directly asked for assistance. Examples of such content were as follows:

So fun to hear your story. I helped care for mother in law with dementia for seven years.... Brutal. You rock. ... Love no BS.

I'm so sorry to hear that. My dad also has dementia and while he doesn't have the effects your dad has, it is sad to see....

I know how you must have felt ... my mom had dementia and bipolar as I had to take care of her from 16 years old #dontregretit.

If any of my fellow twitter friends have any family or friends going through dementia please get a hold of me!

Users most commonly tweeted about the general experience of caring for someone with Alzheimer disease or dementia (n = 903; 33% of all content):

It's hard to put into words (or Tweet) but dementia caregiving is a profound experience. I am still figuring out how it has transformed me.

Twitter users expressed mixed emotions regarding the caregiving experience. Some content reflected negative aspects, stressors, and burden, whereas other content highlighted the positive aspects of caring for someone with memory impairment. Users tweeted:

Dementia and Alzheimer's are such cruel diseases, especially when you have to watch a loved one suffer from them.

Being a caregiver for someone with dementia has to be the most stressful job I have ever done. Love is what is holding me together.

The heartache you endure when you have family with Alzheimer's or dementia is so indescribable.

I really really hate dementia. Feeling sad after trying to speak to my mum on phone—feeling sad.

My dad might have dementia I actually wish I was dead rn (right now).

Tired. Being a caregiver for mom, who has Alzheimer's is as rewarding as it is draining. She deserves our best! Life is good!

My mom has advanced early-onset Alzheimer's. I'm her caregiver. She's a handful, but I spoil her because that's what my grandma would want.

To care for those who once cared for us is one of the highest honors.

My parent has dementia AND yet continues to enrich my life and spirit, every day.

Twitter users reported various coping strategies including prayer and utilization of educational resources:

My Mom suffered from it dementia also. I kept my faith that she would be ok. Strong woman. Prayers to you. Love ya.

My mother has dementia, I google dementia to learn about it then I got dementia treatment junk mail.

Almost one-third of Twitter content (n = 854) using the hashtags Alzheimer's or dementia was tweeted by individuals who did not explicitly tweet about being a care provider to another person. These users tweeted social support for others or interactions with those with Alzheimer disease or dementia in the community (n = 234 or 9%):

That is so sad. Dementia is an awful disease which robs a person of their whole personality. I hope your Dad gets well soon.

Prayers for many who are caretaking for Alzheimer's or dementia stressing family resources and provisions to provide appropriate care.

Helped an old man with dementia get home in his broken down mobility scooter. Lovely man.

Users feared getting Alzheimer disease or dementia with aging (n = 178 or 7%):

Dementia, Alzheimer's, and the like are all very terrifying to me.

I really just want to hug and kiss my mom right now idk what id do if my mom ever got dementia or anything like that.

I just saw a video of a dude whose mom has Dementia and didn't know who he was. Pray that doesn't happen to my folks. That's scary.

Our inclusion criteria and search also returned Twitter content that used cognitive decline as an insult or speculation against a person's mental capacity in an unconstructive manner (n = 56 or n = 2%):

#trump reminds me of my dad towards the end of his life would talk in vague generalities becuz he had no clue. ALZ.

@realDonaldTrump His actions smacks of stages 4-5 out of 7 of ALZHEIMERS. Witnessed it as a caregiver.

You are so out of touch. Must be the family dementia creeping up on you.

Next weekend, instead of Palm Beach, take your father to @MayoClinic and get him a dementia workup. The US is counting on you.

Raising political awareness about health policies specific to memory decline was also a goal of tweets (n = 339 or 12%). Tweets were directed to lawmakers from the state level to the President:

@senrobportman please vote NO on Trumpcare. My mother is 60 has dementia and is in a nursing home. Medicaid is all she has #healthcare.

Thanks to GOP plan, millions of seniors who need help will be screwed as Medicaid is destroyed. Dementia care is expensive.

Why doesn't Medicare pay for Dementia care physical/financial family costs are staggering.

Why should I have to pay for Alzheimer care cvg? I don't have Alzheimers! I'm young, my risk for that is next to non-existent!

Twitter is a real-time source of news, allowing people to share their reactions to current events in real time. Users shared news stories and reacted to portrayals of memory impairment in the media during our 1-month observation period (n = 247 or 8%).

Too many elderly people in hospital with dementia taking up beds who need to be in care homes. It's not fair on anyone. #TheOneShowBBC.

Happy to see that Quebec is considering assisted death for dementia patients. #CompassionAndChoices #Death-WithDignity.

Beautifully eloquent account of the family experience of dementia by @ARUKnews and how music can help people with the disease.

Fear of dementia has spread far #Logan takes up day job to care for Prof X #DefeatDementia.

Logan (Film) has the most accurate depiction of caring for someone with Dementia that I've ever seen in a film. It's a truly amazing film.

The portrayal of dementia care in #eastenders (TV show) is disgusting. Not watching anymore.

Feel bad for David hope he lives a happy healthy life having Dementia would be a very hard pill to swallow. #DrPhil (TV show)

Research about Alzheimer disease and dementia was infrequently posted (n = 15 or 0.5%):

Life expectancy of someone with dementia in a care home is the same as someone with metastatic breast cancer.

60% of Alzheimer's caregivers rate emotional stress of caregiving as high or very high. About 40% have depression.

However, content showed that Twitter users did not simply report research but rather advocated for further research in this area:

What's needed in dementia care trials? More emphasis on exploring attributes of people who care well. Lots to learn from them.

It's sad but Dementia currently only attracts 1 in 6 researchers when compared to Cancer.

DISCUSSION

The findings presented in this article document, to our knowledge, the first reported analysis of Alzheimer disease and dementia Twitter content in the literature. Results show Twitter is a mechanism used by those affected with memory decline to share and receive support, a medium for advocacy efforts, and that users document both negative and positive aspects of the lived experience of Alzheimer disease.

The findings in this article are congruent with that of other researchers who have shown that family caregivers of persons with dementia use online tools for social support through communication and engagement, information gathering and seeking, and reminiscing and legacy building.¹³ Furthermore, caregivers often face loneliness due to diminished social interaction imposed by their caregiving role.¹⁴ Loneliness is a health concern, as sentiments of powerlessness, helplessness, and sole responsibility are associated with morbidity and premature mortality in caregivers.¹⁴ Some research studies show that caregivers prefer to utilize the Internet compared with other sources of caregiving support,¹⁵ which provides timely information tailored to specific caregiver needs and emotional states. This work supports that Twitter is one such tool that caregivers use to ease caregiving-associated loneliness by expanding one's social network size to feel appreciated, gain support, and learn about other supportive services.

Whether caregiving imparts a positive or negative health impact on caregivers remains undetermined. There is a wealth of evidence that caregiving for persons with dementia is associated with profound physical and mental health stressors.¹⁴ These stressors can impact caregivers' nutritional intake and are associated with increased prevalence of smoking and drinking,^{16,17} higher insulin levels,¹⁸ and poorer self-care.¹⁹ However, other research has supported the healthy caregiver hypothesis, which posits that the act

of caregiving stimulates physical and cognitive health outcomes and improvements. Some studies theorize that caregiving can be a potentially positive and growth-enhancing²⁰ experience by developing a sense of gratification, pride, and confidence.^{21,22} Caregiving may also forge stronger social relationships²² between the caregiver and the care recipient and provide a stronger sense of purpose in life²³ through facilitating feelings of accomplishment in working together. Our findings document that caregivers express both positive and negative aspects of caregiving on Twitter, although negative responses occurred more frequently.

The use of dementia and Alzheimer disease as an insult was a surprising finding in this work and one with potential ramifications for a lay understanding of these conditions. Twitter users tended to attribute behavioral and speech patterns of various politicians to dementia but in a more flippant than concerned manner. This finding is notable as it identifies an area for public health education on the true symptoms of Alzheimer disease and other dementias. If behaviors are wrongly attributed to Alzheimer disease and this becomes a social norm, timely screening, evaluation, and diagnosis may be delayed. For example, dementia is a pathological age-related change, but if the societal norm is that cognitive impairment is normal among older adults, people may be less inclined to have symptoms appropriately evaluated, delaying necessary care. Furthermore, using dementia as an insult or in jokes emphasizes the negative stereotypes that surround people with memory impairment and their caregivers, which may serve to further exclude, strain, and harm this vulnerable population.

There are several limitations to this work. Tweets were purposefully filtered to track specific hashtags of Alzheimer's, dementia, and dementia in order to focus the Twitter search on directly related content. It is possible that people may tweet content about cognitive impairment without using these hashtags, and these data would have been missed in the existing search strategy. Data were collected for a 1-month period, and seasonal variations in content cannot be ascertained. Given the inherent short nature of tweets (140 characters), in-depth details of the persons, situations, and environment context of cognitive impairment are unknown. Conclusions cannot be drawn about the characteristics of health care systems users are embedded in, nor can results correlate sources of stress directly to the intensity of caregiving roles. Health care systems often have services such as respite or support groups available for caregivers, and the access to and use of these services may influence how people express the lived experience of caregiving for someone with memory impairment on Twitter.

Despite these limitations, this research provides initial evidence that people do, in fact, use Twitter to report the lived experience of Alzheimer disease or dementia, as well as use social media to advocate for these conditions. Further research should explore caregiver identification and

longitudinal approaches to monitoring Twitter content in these persons to determine how social media use varies over time. From a policy perspective, Twitter appears to be a tool that persons affected by Alzheimer disease or dementia utilize for social support and advocacy. National and government organizations may wish to expand resource services through social media channels. Further research is needed to determine the therapeutic effectiveness of using social media as a coping tool.

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