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Tweeting on dementia: A snapshot of the content and sentiment of tweets associated with dementia

by David Robertshaw and Ivana Babicova

Abstract

This study aimed to record and characterise tweets related to dementia, to investigate their content and sentiment. Data were extracted from Twitter over a period of six weeks during February and March 2019 and then analysed using Linguistic Inquiry and Word Count (LIWC) and AntWordProfiler. Using five search terms related to dementia, this study collected 860,383 tweets (more than 27 million words). Results have shown that out of all the collected tweets, 48.63 percent of tweets related to the search term 'dementia', 49.95 percent to 'Alzheimer's disease' and the remainder related to frontotemporal dementia, Lewy Body dementia and vascular dementia. People wrote more positively and personally about the term 'dementia' than the other terms, and more technically regarding the term 'Alzheimer's disease'. All search terms had a negative emotional tone overall. Dementia and related terms are commonly discussed on Twitter. The overall negative emotional tone associated with all dementia related search terms suggests that dementia is still largely stigmatised and talked about negatively. Recommendations for future research include the development of a health world list or a dementia world list, and to consider how the results of this research inform social change interventions going forwards.

Contents

Introduction

Dementia is one of the most important social issues of our time and is a public health priority (World Health Organization and Alzheimer's Disease International, 2012). The stigma associated with dementia can result in stereotyping, prejudice and discrimination (Phillipson, *et al.*, 2012; Corrigan and Watson, 2002). Worldwide more than 50 million people have dementia (World Health Organisation, 2020) and this number is expected to increase (Alzheimer's Society, 2019). Dementia is an umbrella term consisting of over 60 different syndromes and diseases. Prior to COVID-19, dementia was the leading cause of death in the United Kingdom (U.K. Office for National Statistics, 2020). Public perception and awareness of dementia have increased in recent years through a range of initiatives including dementia awareness weeks and initiatives for example Dementia Friends, a U.K.-based initiative which aims to transform how people think, act and talk about dementia (Alzheimer's Society, 2020). Dementia is having an increasing impact on everyday people, and it is now rare for someone to have not met someone with dementia. Although initiatives such as Dementia Friends are aimed at changing and improving the perceptions of dementia and dementia-related conditions, we do not yet have a full characterisation of these perceptions. Studies have been conducted to further investigate the public perceptions of dementia, however, these have generally taken place in closed fora such as classrooms, private surveys (NILT) or MOOCs (Annear, *et al.*, 2016; McInerney, *et al.*, 2018; Robertshaw and Cross, 2019a, 2019b).

Background

Investigators have characterised experiences of health conditions and illness, and there is emerging data regarding how the public at large perceives health conditions and illness (Pescosolido, *et al.*, 2019; Young, *et al.*, 2019; Klik, *et al.*, 2019). Small scale studies have been conducted using Twitter, a social media platform, to analyse a small number of tweets. Sinneberg, *et al.* (2016) identified 137 publications meeting their systematic review eligibility criteria. For example, a study by Robillard, *et al.* (2013) used Twitter to collect 9,200 tweets to examine who uses Twitter to share information about dementia, what sources of information are promoted and which themes related to dementia are most prevalent. Out of the 9,200 tweets, 10 percent were randomly selected and analysed. The researchers found the majority of the tweets either contained links to a third-party Web site rather than personal information or discussed recent research findings which focused on risk prevention. Furthermore, Cheng, *et al.* (2018) conducted a similar study into the themes arising from a total of 398 dementia-related tweets. The findings suggested the majority of tweets were categorised into a general public category, which was further broken down into a content analysis revealing that stigmatisation and mental health advocacy were the most prevalent themes. Additionally, a small-scale investigation of Alzheimer’s disease on Twitter collected 311 tweets and found that 21 percent of the tweets portrayed stigma associated with Alzheimer’s disease (Oscar, *et al.*, 2017). These findings were different to those outlined by Robillard, *et al.’s* (2013) study which identified information sharing, but most importantly the findings are concerning due to the percentage of tweets which were stigmatised. Although not everyone uses social media, these tweets from social media platforms may be reflective and representative of real views and opinions of a portion of society on Alzheimer’s disease.

Twitter and, more broadly, online social media offers some of the largest and richest datasets currently available. Twitter is an online public microblogging platform where users can post statuses of up to 280 characters. Twitter has over 326 million users per month who ‘tweet’ (write short messages) up to 500 million times per day (Cooper, 2019). Each tweet can consist of up to 280 characters therefore the amount of text produced each day could be up to 140,000,000,000 characters. A big data source, social media natural language data is vast with great variety (Ignatow and Mihalcea, 2017). This information can be investigated allowing the discovery of new insights into problems which present challenges unsolvable with manual analysis or to answer questions not yet asked (Tattersall, 2016). Social media data is reasonably obtainable by using commercially available products or software packages designed for academic purposes such as TAGS (Hawksey, 2019) or Tweetcatcher (Brooker, 2013). Access to Twitter data through its application programme interface is free, however it is not an exhaustive source of tweets. Commercial options provided by Twitter may provide higher numbers of tweets, but it is expensive.

This paper interrogates Twitter using dementia and dementia-related terms with a range of software packages available to academics. These software packages have been used previously for academic inquiry and they are validated for this purpose.

The study

Aims

This study, therefore, uses Twitter-derived natural language data, processed through academic software, to provide a snapshot of the content and sentiment of tweets related to dementia. This study uses a big data-approach to analyse and interrogate the perceptions and attitudes of the public towards dementia. This study aims to discover the nature, context and terminology used by Twitter users when talking about dementia and dementia-related terms. Discovery of this terminology may lead to increased understanding of their attitudes towards dementia, and whether dementia is viewed positively or negatively. The objective of this study is to provide a snapshot of the content and sentiment of tweets associated with dementia and dementia-related terms.

Design

This study adopted a netnographic approach, examining people’s interactions and contributions in the online environment (Kozinets, 2009). Netnography, sometimes known as digital ethnography, is a methodological approach which provides limited access to true participant identity and demographic information, but Kozinets (2002) sees this as a necessary and acceptable shift from traditional ethnographic approaches. This study uses an inductive logic approach, where the researchers began by analysing the data then allowing conclusions to emerge organically from the analysis (Ignatow and Mihalcea, 2017). This study used tweets as a data source to explore the attitudes (sentiment) and themes associated with the most common types of dementia as outlined by Alzheimer’s Research UK (Alzheimer’s Research UK, 2019). The five search terms used in this study were: dementia, Alzheimer’s disease, vascular dementia, frontotemporal dementia (FTD) and Lewy body dementia. Dementia is the leading cause of death in the U.K. and is responsible for more than one in eight of all deaths (U.K. Office for National Statistics, 2018). To obtain a fully rounded understanding of differences in attitudes (sentiments) towards types of dementia, the most common types of dementia were selected. This research focused on search terms rather than people or individual accounts, an approach taken by other studies (Talbot, *et al.*, 2020).

Participants

Twitter’s privacy policy and development agreement require reserarchers to delete personal identifying information and prevent the publication of original source tweets (Twitter, 2018a, 2018b). Because individual participant data were deleted during the collection, it is not possible to provide a breakdown or analysis of who participants were. The deletion of personal information about participants complies with Twitter’s policies when using Twitter as a platform for research and public data collection, and publishing personal information is forbidden under the policies.

Data collection

Data were collected during February and March 2019 using Twitter Archiving Google Sheet (TAGS), which is a free Google Sheet template allowing automatic collection of tweets based on a search term. TAGS collects tweets through the Twitter Application Programme Interface (API) (Hawskey, 2019). The Twitter API is governed by a developer agreement and policy which expressly permits extraction and analysis of data (Twitter, 2018a, 2018b). Data can only be obtained from the preceding seven days with this method, so data from a longer duration was collected using automatic hourly collections over six weeks preventing data gaps. In this step, keywords were chosen carefully and based on the frequency of condition associated with dementia:

- Dementia
- Alzheimer's disease
- Vascular dementia
- Dementia with Lewy Bodies
- Frontotemporal dementia

A search string was then constructed with Boolean operators. Private tweets were not collected through this method. A search string was then constructed with Boolean operators. Private tweets were not collected through this method.

There are ethical concerns with using social media data in textual analysis because participants are not generally able to directly consent to participate in the study. Yet there is an expectation of public exposure by users (Sveningsson, 2004). This paper uses the approach posited by Sudweeks and Rafaeli (1996) that social media data is in the public domain and is therefore accessible for research purposes. Twitter's privacy policy (Twitter, 2018a), developer agreement and developer policy (Twitter, 2018b) adopt the same approach, expressly permitting the use of Twitter text data for analysis through its application programming interface (API). Twitter's privacy policy states: "Twitter is public and tweets are immediately viewable and searchable by anyone around the world" (Twitter, 2018a). Investigators were fully cognizant of the British Psychological Society's (BPS) 'Ethics guidelines for Internet-mediated research' (BPS, 2017). Consent is not obtainable from Twitter users: these authors used the philosophical position that consent is not required. Despite this, ethical approval was gained from the University of Derby's Health and Social Care ethics committee.

Data analysis

Tweets were extracted into a Microsoft Excel spreadsheet with personal data removed and deleted. Tweets were then processed with Linguistic Inquiry and Word Count (LIWC) software. LIWC is a text analysis program which determines the percentage of words reflecting varied emotions, perceptions and social issues (Tausczik and Pennebaker, 2010). This software allowed the research team to compare the emotional tone of voice, sentiment, strength of writing, and the analytical nature of the tweets.

The same data was then analysed using AntWordProfiler (Anthony, 2009). This software analyses a corpus using defined word lists: an analogy of this is using a pair of glasses to look at an object, with the varying lenses representing different word lists. General service lists are included with the software and include the first and second most common 1000 words in the English language. The first list, of the first 1,000 most common words, are generally shorter and less purposeful words like "I", "It", "She". The second list is more purposeful and meaningful words and was therefore used within this project. Finally, the output results of these two software packages were built into tables which are presented in the results section of this paper.

Inclusion and exclusion criteria

Any tweet between 12 February 2019 until 26 March 2019 containing the search terms were included in this study. All natural language data in the tweet were analysed including stop words. Private tweets were not collected. Only tweet natural language was processed, and usernames and other metadata were excluded from the analysis.

Validity, reliability and rigour

Rather than people analysing tweets manually and individually, which may result in subjective assessments of their nature and content, AntWordProfiler and LIWC used objective computer algorithms to make judgements. By using these software tools, validity, reliability and rigour were increased. LIWC has been developed to be objective, and has been tested in a range of environments and conditions (Cohn, *et al.*, 2004; Kacewicz, *et al.*, 2013; Newman, *et al.*, 2003; Pennebaker, *et al.*, 2014).

Results

Tweets overall

A total of 860,383 tweets were gathered (Table 1) using TAGS which generated a total of 27,695,933 words. Just under half of all tweets (48.63 percent) originated from the search term 'dementia', and 49.95 percent originated from the 'Alzheimer's' search term. The remainder of the tweets originated from the terms 'frontotemporal dementia', 'Lewy body dementia' and 'vascular dementia'.

Tone, sentiment, clout, analytical thinking and authenticity

Using LIWC, each search term was analysed and investigated for the emotional tone of voice, sentiment, clout, analytical thinking and authenticity. The results indicated that dementia and Alzheimer's disease were the two search terms which had the most tweets, suggesting that these were the two topics talked about the most.

Positive and negative emotional percentages of total words

Additional data investigated per term were positive and negative percentages of total words. It's interesting to note that the highest rate of used positive emotional words was used for search terms Dementia (3 percent) and LBD (2.2 percent), compared to the lowest percentage of positive words in search terms FTD (1.2 percent) and Alzheimer's disease (1.9 percent). Further to this, the percentage of negatively associated emotional words were also investigated per search term. The analysis suggested that the highest percentage of negatively associated emotional words was used in tweets about vascular dementia, where 2.3 percent of all words were negative, compared to Alzheimer's disease, where only 1.2 percent of all words were negative emotion words.

Analytical thinking

The analytical thinking function in LIWC focuses on scrutinising the language used and suggests the level of formality, logic and hierarchical thinking patterns present in the text. Higher scores are indicative of greater text preposition use and complexity of organised objects and concepts, whereas lower scores indicate greater use of pronouns and therefore personal narrative approach (Pennebaker, *et al.*, 2014). The analysis revealed that Alzheimer's disease had the highest analytical thinking score, compared to the lowest score for vascular dementia.

Emotional tone

Emotional tone is calculated through LIWC using an algorithm, which combines the positive and negative emotional language, and combines them into a single summary variable. Scores below 50 suggest an overall negative tone of the topic, whereas scores over 50 suggest and overall positive tone of the topic. The results of the present study have demonstrated that all search terms associated with dementia have demonstrated scores below 50, with the highest score of 48.2 for dementia search term, and the lowest score of 30 for FTD, suggesting an overall negative tone in the language used by Twitter users when tweeting about all types of dementia.

Clout

Clout in LIWC refers to relative social status, confidence or leadership. The language analysed in this section often investigates the use of personal pronouns, which often indicates not only confidence but also ownership of writing. The results demonstrated that language associated with the highest confidence and ownership score was dementia with a score of 73, compared to Alzheimer's disease which had the lowest score of 64.6. This suggests that people write more confidently about dementia, and least confidently about Alzheimer's disease. This can be interpreted in many ways, one of which focuses on the use of personal pronouns which is closely linked with the clout analysis. Higher use of personal pronouns and a therefore higher score of clout could indicate more personal narratives such as views and opinions about dementia, whereas lowest clout score for Alzheimer's disease could indicate more academic/educational or passive style of writing.

Authenticity

Authenticity refers to honesty, humbleness and more of a personal and vulnerable approach. LIWC uses several algorithms which were based on a series of studies by Newman, *et al.* (2003), who have induced participants in their studies to be either honest or deceptive. These findings were then used to create an algorithm which is programmed to differentiate between the levels of authenticity. Higher score of authentic tone means a higher tone of honesty, humbleness, vulnerability and personal approach. The results of this study have demonstrated that the search word dementia had the most authentic tone (19.66), compared to frontotemporal dementia which had the lowest authentic tone overall (7.92).

Table 1: Number of tweets, words, distribution, analytical thinking, clout, authentic tone, emotional tone per search term generated by LIWC.

Search term	*n* tweets	Distribution	*n* words	Analytic	Clout	Authentic	Tone	Positive emotion (percentage)	Negative emotion (percentage)
Dementia	418,432	48.63%	13,755,249	77.16454	72.98632	19.66066	48.21686	2.971999	1.754669
Alzheimer's disease	429,781	49.95%	13,486,607	85.74715	64.64508	10.00955	39.25733	1.867432	1.197973
Frontotemporal dementia	5,822	0.68%	225,139	82.21195	71.02641	7.918131	30.04111	1.233956	1.550359
Lewy-Body dementia	2,228	0.26%	73,625	81.4945	67.47467	11.95105	43.95986	2.214102	1.323214

Vascular dementia	4,120	0.48%	155,317	76.42826	67.84067	17.13605	35.68837	2.039643	2.322964
Total	860,383	100%	27,695,937	81.49	68.77	14.73	43.55	2.40	1.48

Word frequency and concepts

The full dataset of 27,695,933 words was analysed with AntWordProfiler. This corpus was analysed using three word lists covering the first and second most commonly occurring 1,000 words in the English language and an academic word list. There were 14,527,553 words matching word list 1; 1,120,860 words matching word list 2; and 752,278 words matching those on the academic word list. The 50 most common words in word list 2 are identified in Table 2.

Table 2: Top 50 most common words with frequency of use.

Word	Frequency
disease	79,681
brain	36,810
grandma	36,663
health	35,466
risk	21,361
thank	13,056
patient	12,685
elderly	12,443
thanks	12,170
diseases	9,680
grandfather	8,965
sentence	8,782
sad	8,316
ice	8,155
grandpa	8,042
treatment	7,326
joke	7,101
cure	6,967
check	6,866
warning	6,407
nursing	5,901
wandering	5,742
hit	5,717
police	5,636
healthy	5,354
lot	5,285

tips	5,284
deserve	5,277
worse	5,121
cures	5,104
slow	5,040
aunt	5,015
hospital	4,928
information	4,831
hate	4,796
improve	4,711
review	4,393
combination	4,320
mice	4,263
hall	4,198
probably	4,069
pour	4,064
staff	4,001
hey	3,946
proud	3,905
hi	3,662
forward	3,612
billion	3,600
government	3,535
program	3,517

Discussion

This study proposed to use a big data approach to analyse and interrogate the perceptions and attitudes of the public towards dementia. It aimed to discover the nature, context and terminology used by Twitter users when talking about dementia and dementia-related terms. This study has provided a snapshot of the content and sentiment of tweets associated with dementia and dementia-related terms.

Dementia and its related terms are frequently discussed on Twitter. This is probably because dementia is a common experience for many people, and they use Twitter to express their thoughts and feelings on a day-to-day basis. As a topic, 860,383 tweets on dementia were collected over a six-week period. This is higher than average for most terms, although not as high as some terms. For example, 'Brexit' as a search term yields many millions of results each day which are not fully collectable.

There were differences in the tone, 'clout' and authenticity of tweets relating to the different terms. For example, people wrote more strongly in dementia-related tweets than any of the other tweets. Their tone was also generally the most positive (48.2) when referring to dementia, with tweets relating to frontotemporal dementia having the lowest tone (30.0). This is interesting because public agencies and charities have spent a lot of time and resources breaking down the stigma associated with the term 'dementia' but not with the related terms such as frontotemporal dementia. The data would appear to support this. Interestingly most tweets were related to the term 'dementia' (48.63 percent) or 'Alzheimer's disease' (49.95 percent). The other terms accounted for just 1.42 percent of tweets. This reflects the greater usage of the terms 'dementia' and 'Alzheimer's disease' but would seem to indicate that more work needs to be directed at raising the awareness of these other important conditions.

The words arising out of the world list analysis were also interesting. ‘Disease’ was the most frequently used words (79,581), followed by ‘brain’ (36,810). These terms make sense because dementia and related conditions are diseases of the brain. But the words following were a surprise to the researchers: people were referring to their family members and loved ones (grandma, grandfather) and using words related to the experience disease and illnesses more generally (sad, sentence). There were also words relating to research and treatment (treatment, cure, cures, review, mice, billion, government, program). There were references to negative terms (sentence, joke, sorry, severe, shock, anxiety) which expressed some of the negativity Twitter users were writing about in relation to the dementia-related terms. Our study supports some of the findings by Cheng, *et al.* (2018), which was much smaller than this. Cheng, *et al.* (2018) also found the main themes of stigmatisation and mental health advocacy. Because this study has been larger, more concepts have been identified in Twitter data.

Risk was found to be the fifth most frequently used words among all tweets. These findings support research previously conducted by Robillard, *et al.* (2013), who stated that majority of tweets in their analysis either included third-party links to external Web sites or focused on risk prevention for developing dementia. This is a very interesting finding, as it suggests that Twitter users still largely focus on how to prevent developing the condition, rather than supporting and increasing quality of life of those who are already been diagnosed and are living with dementia. This finding could also suggest that tweets from organisations promoting third-party links to external Web sites and tweets about research conducted in the field of dementia might still be dominating the dementia discussion on Twitter.

From the clout analysis which measures relative social status, the strength of the writing and use of pronouns in the writing, the highest score was associated with the search term ‘dementia’ and the lowest was for Alzheimer’s disease. This would seem to indicate that people writing about dementia are writing in a more personal and informal way, using pronouns. People writing about Alzheimer’s disease are writing in a more technical way, writing in the third person and using less personal speech. Again, this may echo the awareness and social change agenda supported by charities and governments around the term ‘dementia’. This partially supports the findings of Robillard, *et al.* (2013) who suggested that people tweeting about Alzheimer’s disease post professional links.

To our knowledge, this is the largest scale study of its kind. This study collected 860,383 tweets over a six-week period. Other authors have conducted shorter or smaller studies, or only examined samples of their collected tweets (Robillard, *et al.*, 2013; Cheng, *et al.*, 2018; Al-Bahrani, *et al.*, 2017; Danilovich, *et al.*, 2018; Oscar, *et al.*, 2017). This study is unique because it analyses all the tweets collected. The strength of this study is that it has deployed a methodological and objective collection system, and a word frequency and natural language processing system which was also objective.

Limitations

This paper has several important limitations. The results from this paper are influenced by the framework and apparatus in which the data has been collected. The Twitter API does not guarantee access to all tweets related to a search term, so some tweets may not have been collected. In addition, Tweets can become clustered which means tweets on the periphery may not be collected. The API permits a maximum of 3,000 tweets per hour and it is possible there were more than 3,000 tweets per hour on the higher frequency terms of dementia and Alzheimer’s. The risk of this was mitigated by hourly collection, which ensured a consistent and coherent body of data.

Tweets on the chosen topics may also not be available because users may not have used the search terms: for example, a user may have been discussing dementia but not used the term ‘dementia’ in their tweet. The converse may also have happened: Tweets not related to the search term, but including the search term, may have been identified. Arguably though these tweets are still relevant because users are using language related to the term. These issues arise particularly when users or news events influence data: for example, in March 2019 Donald Trump referred to Nancy Pelosi as being ‘demented’. This tweet was re-tweeted many times and will have influenced the dataset.

The software used to analyse the tweets have their limitations: both are off-the-shelf products using natural language processing algorithms which are proprietary. Of the two programmes, AntWordProfiler has a great level of customisation as word lists may be constructed for use. The authors used the general service list of the first most popular 1,000 words and the second most popular 1,000 words. This word list is validated with a long history of use. It was designed by a professor of linguistics and was, therefore, a good choice to use. It would have been better to use a ‘medical’- or ‘health’-related word list. Because of the software conducted analysis, this improved objectivity in language analysis. In previous studies using manual interpretation and coding of text, the subjectivity of researchers has been an identified issue (Robertshaw and Cross, 2019a).

Conclusion

Conducting research with data collected from social media platforms such as Twitter is crucial to help us understand perceptions on topics such as dementia. Large scale studies, such as this one, can offer a further insight into the public views of a condition which in turn can help guide researchers and practitioners to potentially develop frameworks and further initiatives to decrease stigma and increase knowledge. These findings are useful because they can potentially influence policy, education, and clinical guidelines. The findings provide a platform for ongoing dialogue and debate about the nature of dementia, and the words used in relation to it by everyone in society. In our sample, Twitter users do not talk about the breadth of diseases under the umbrella of dementia, focusing mostly on the term ‘dementia’ and ‘Alzheimers’. As members of society, we should use the correct names and terminologies for diseases.

Additionally, people spoke negatively about dementia: society should continue to increase the positivity around dementia rather than focusing on the negative aspects. This in turn could influence stigmatisation. We should also increase our confidence in talking and writing about diseases under the umbrella of dementia: we should continue to write authentically and have meaningful conversations about dementia.

This study has shown that people discuss dementia and dementia-related tweets as part of their everyday conversations on Twitter. This paper has important findings for social change interventions such as Dementia Friends in the United Kingdom, which has focused on changing attitudes towards dementia. Our findings show that change interventions aimed at dementia like Dementia Friends, Dementia Action Week, World Alzheimer's Month and Dementia Friendly Communities may be having an effect.

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