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What Can We Learn about Mental Health Needs from Tweets Mentioning Dementia on World Alzheimer's Day?

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Abstract

Background—Twitter can address the mental health challenges of dementia care. The aims of this study is to explore the contents and user interactions of tweets mentioning dementia to gain insights for dementia care.

Methods—We collected 35,260 tweets mentioning Alzheimer's or dementia on World Alzheimer's Day, September 21st in 2015. Topic modeling and social network analysis were applied to uncover content and structure of user communication.

Results—Global users generated keywords related to mental health and care including #psychology and #mental health. There were similarities and differences between the UK and the US in tweet content. The macro-level analysis uncovered substantial public interest on dementia. The meso-level network analysis revealed that top leaders of communities were spiritual organizations and traditional media.

Conclusions—The application of topic modeling and multi-level network analysis while incorporating visualization techniques can promote a global level understanding regarding public attention, interests, and insights regarding dementia care and mental health.

Keywords

social media; big data; dementia; Alzheimer's; cognitive aging; mental health; natural language processing; social network analysis

Introduction

Although dementia is predominantly a neurological disorder, it has profound mental health implications for both those living with the condition and those who care for them. One in nine people over the age of 65 suffers from Alzheimer's disease and more than 15 million caregivers provide these individuals with more than 18 billion hours of unpaid care annually. This number will continue to grow as the baby boomer generation ages. (Association, 2016)

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Disclaimer: This study used publically available data, and analyses meet the criterion for exemption 46.101(b)4 research, involving the collection or study of existing data, documents, records, pathologic specimens, or diagnostic specimens. If these sources are publically available, or if the information is recorded by the investigator in such a manner that subject cannot be identified, directly or thought identifiers linked to the subjects.

Developing novel research strategies to support and strengthen population-level cognitive aging is urgently needed.

With the advancement of smartphones and improved software usability, social media platforms such as Facebook and Twitter have become easier to use and now even penetrate the lives of older adults. Approximately 35% of adults over the age of 65 and 51% of adults between the ages of 50 and 64 use social media (Perrin, 2015). Researchers in social science and humanities domains are rapidly applying emerging analytic techniques to gather population-level insights from social media data. Common big data analytic strategies include: 1) sentiment analysis to uncover tendencies of emotional learnings of populations 2) topic modeling to detect topics discussed among social media users, and 3) social network analysis to discover macro and meso level of users' interaction behavior (Yoon & Bakken, 2012; Yoon, Elhadad, & Bakken, 2013). Because the elderly are now using social media, data mining can provide insights about population-level cognitive aging.

Almost 70 studies regarding social media use and mental health have been published in English in the past five years. The studies describe social media as: (a) a monitoring tool for mental health conditions (Cavazos-Rehg et al., 2016; McIver et al., 2015; Prieto, Matos, Alvarez, Cacheda, & Oliveira, 2014; Toseeb & Inkster, 2015; Whitehill, Brockman, & Moreno, 2013; Yin, Fabbri, Rosenbloom, & Malin, 2015) or sensing population-level emotion (Larsen et al., 2015; Rodrigues, das Dores, Camilo-Junior, & Rosa, 2016; Settanni & Marengo, 2015; Yang & Srinivasan, 2016), (b) a platform for peer support (Martinez-Perez, de la Torre-Diez, Bargiela-Florez, Lopez-Coronado, & Rodrigues, 2015; Naslund, Aschbrenner, Marsch, & Bartels, 2016), mental health education (Peek et al., 2015), and interventions (Di Napoli, Nollo, Pace, & Torri, 2015; Shepherd, Sanders, Doyle, & Shaw, 2015) or (c) a recruitment source for mental health research (Pedersen et al., 2015). The scope of most studies has been limited to a few mental illnesses such as depression (Cavazos-Rehg et al., 2016; Jelenchick, Eickhoff, & Moreno, 2013; Morgan, Jorm, & Mackinnon, 2013; Reavley & Pilkington, 2014; Whitehill et al., 2013). Research applying novel analytic techniques has seldom been conducted on the broad landscape of cognitive aging or dementia. Therefore, our study sought to explore the contents and user interactions of tweets mentioning dementia to gain insights for dementia care.

Methods

A total of 35,260 unique tweets mentioning Alzheimer's or dementia (tweets: 15,615, retweets: 19,645) were randomly collected on World Alzheimer's Day, September 21st in 2015 via NCapture (QSR International; Melbourne, Australia). Key words used to identify dementia related data included, #Alzheimer's, Alzheimer, #Dementia, #WAD (World Alzheimer's Day). Each tweet included content, user-generated keywords, time stamp, geocodes, user name, type of message and number of followers. First, the top user generated keywords (hash tagged by the user) and location hot spots were visualized on a world map to identify areas of concentrated tweeting. Next, content analysis was conducted to detect topics discussed by Twitter users within hotspots in the United Kingdom (UK) and the United States (US) by applying natural language processing with a topic modeling algorithm

(Blei, Ng, & Jordan, 2003). Then, social network analysis was used to uncover the multi-level social network of Twitter users.

Results

User-generated keywords

The top 200 of 1263 user-generated keywords from a total 35,260 (unique tweets: 15,615, retweets: 19,645) tweets mentioning dementia or Alzheimer's fell into four categories, mental health, care, technology, and general terms (Figure 1). Top keywords related to mental health included #aging (n=89), #brain (n=42), #memory (n=42), #mental health (n=41), #loneliness (n=30). Top keywords related to care were #caregiving (n=269), #caregiver (n=93), and #care (n=84).

Content mining

Content mining showed different topics of tweets between the two location hotspots, the UK and the US. The word clouds on the top of figure 2 were generated from natural language processing and illustrate the overall differences between the most frequently tweeted words from each country. The UK tweet corpus contained caring, carers, people, essex, supporting, and researchers as highly frequent words. Whereas, twitter chat, cerebral, cluster headache, marijuana, treatment, MME (Medical Marijuana Exchange), caregiving, and caring occurred most frequently in US tweets. Figure 2 further details topics within the UK and the US tweet corpus detected by a topic modeling algorithm.

Structure mining

Macro-level network analysis shows a core-periphery network type where half of the tweets in the center of the network were actively retweeted while the messages at the periphery were not reciprocated (Figure 3). Meso-level network analysis depicted majority communities at the core in the diagram and approximately one third of the network consisted of small communities. The top leaders (who have most responses) of the communities were from spiritual care (@3spirittraining, @3spirituknz, @7sealsoftheend) followed by organization (@aarp; ranking 6, @alzassociation; ranking 28), traditional media (@abcnews; ranking 8) and government (@alzheimers_nih; ranking 33).

Discussion

User-generated keywords

Within the Twitter corpus mentioning dementia on World Alzheimer's day, we found that global users (unit: world) generated keywords related to mental health and care including #psychology, #peersupport, #grief, #anxiety and #mental health. These user-generated keywords may act as guideposts for mental health providers and researchers to explore and address possible public needs related to dementia. This widespread interest in expressing concerns regarding dementia and caregiving for patients with dementia confirms to mental health providers and researchers that there are numerous mental health needs among these individuals. Future dementia research can apply emerging data science techniques, such as using targeted keywords (e.g., #data4dementia), to gather and disseminate data

internationally to bolster our understanding and support of affected individuals and their caregivers. Health research institutions and health providers in the US are encouraged to disseminate accurate and scientific information for patients and their caregivers as in the UK.

Content mining

The content analysis identified some common messages in the US and the UK that have been identified in tweets internationally such as, 'loss', 'memory', 'caregiver', 'life', 'brain', 'endalz' (end alzheimer's). Additionally, the majority of tweets in the UK were 'care' oriented messages including population-level health outcome concepts such as incidence ("1 in 3 people born in the UK this year projected to develop #dementia according to Alzheimer's Research UK, " or "1 in 3, wow. Frightening. #dementia") or related to community based care environment ("70% of people with dementia live in the community; building #dementia friendly communities is a priority for us all"). One major difference that we saw in tweets from the U.S. is that there were a substantial number of tweets related to the medical use of marijuana. It was notable that the US tweets were related to marijuana ("Blocking brain's 'internal #marijuana' may trigger early #Alzheimer's deficits, study #MME") as opposed to scientifically approved treatments such as Donepezil (Jelic & Winblad, 2016), a common and approved treatment for Alzheimer's. Mental health providers should be aware of the non-scientific content of the public messages (e.g., spams) which dementia patients and caregivers are frequently exposed to. (Subrahmanian et al., 2016)

Structure mining

The macro-level analysis showed that individual (located at the periphery in Figure 3) were interested in Alzheimer's disease and sent out messages although they did not receive any response from others. The meso-level network analysis revealed surprising results that top leaders of communities on an official Alzheimer's day were spiritual organizations or traditional media, not scientifically rigorous or established organizations such as the Alzheimer's Organization or NIH.

Conclusion

The application of topic modeling and multi-level network analysis while incorporating visualization techniques can promote a global level understanding regarding public attention, interests, and insights regarding dementia care and mental health.

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References

- Association As. 2016 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2016; 12(4): 459–509.
- Blei DM, Ng AY, Jordan MI. Latent dirichlet allocation. *Journal of machine Learning research*. 2003; 3(Jan):993–1022.
- Cavazos-Rehg PA, Krauss MJ, Sowles S, Connolly S, Rosas C, Bharadwaj M, Bierut LJ. A content analysis of depression-related Tweets. *Comput Human Behav*. 2016; 54:351–357. DOI: 10.1016/j.chb.2015.08.023 [PubMed: 26392678]
- Di Napoli WA, Nollo G, Pace N, Torri E. Can clinical use of Social Media improve quality of care in mental Health? A Health Technology Assessment approach in an Italian mental health service. *Psychiatr Danub*. 2015; 27(Suppl 1):S103–110. [PubMed: 26417743]
- Jelenchick LA, Eickhoff JC, Moreno MA. "Facebook depression?" social networking site use and depression in older adolescents. *J Adolesc Health*. 2013; 52(1):128–130. DOI: 10.1016/j.jadohealth.2012.05.008 [PubMed: 23260846]
- Jelic V, Winblad B. Alzheimer disease. Donepezil and nursing home placement--benefits and costs. *Nat Rev Neurol*. 2016; 12(1):11–13. DOI: 10.1038/nrneurol.2015.237 [PubMed: 26714658]
- Larsen ME, Boonstra TW, Batterham PJ, BOD, Paris C, Christensen H. We feel: mapping emotion on Twitter. *IEEE J Biomed Health Inform*. 2015; 19(4):1246–1252. DOI: 10.1109/JBHI.2015.2403839 [PubMed: 25700477]
- Martinez-Perez B, de la Torre-Diez I, Bargiela-Florez B, Lopez-Coronado M, Rodrigues JJ. Content analysis of neurodegenerative and mental diseases social groups. *Health Informatics J*. 2015; 21(4): 267–283. DOI: 10.1177/1460458214525615 [PubMed: 24698768]
- McIver DJ, Hawkins JB, Chunara R, Chatterjee AK, Bhandari A, Fitzgerald TP, ... Brownstein JS. Characterizing Sleep Issues Using Twitter. *J Med Internet Res*. 2015; 17(6):e140.doi: 10.2196/jmir.4476 [PubMed: 26054530]
- Morgan AJ, Jorm AF, Mackinnon AJ. Internet-based recruitment to a depression prevention intervention: lessons from the Mood Memos study. *J Med Internet Res*. 2013; 15(2):e31.doi: 10.2196/jmir.2262 [PubMed: 23403043]
- Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. *Epidemiol Psychiatr Sci*. 2016; 25(2):113–122. DOI: 10.1017/S2045796015001067 [PubMed: 26744309]
- Pedersen ER, Helmuth ED, Marshall GN, Schell TL, PunKay M, Kurz J. Using facebook to recruit young adult veterans: online mental health research. *JMIR Res Protoc*. 2015; 4(2):e63.doi: 10.2196/resprot.3996 [PubMed: 26033209]
- Peek HS, Richards M, Muir O, Chan SR, Caton M, MacMillan C. Blogging and Social Media for Mental Health Education and Advocacy: a Review for Psychiatrists. *Curr Psychiatry Rep*. 2015; 17(11):88.doi: 10.1007/s11920-015-0629-2 [PubMed: 26377948]
- Perrin, A. Social Media Usage: 2005–2015. 2015.
- Prieto VM, Matos S, Alvarez M, Cacheda F, Oliveira JL. Twitter: a good place to detect health conditions. *PLoS One*. 2014; 9(1):e86191.doi: 10.1371/journal.pone.0086191 [PubMed: 24489699]
- Reavley NJ, Pilkington PD. Use of Twitter to monitor attitudes toward depression and schizophrenia: an exploratory study. *PeerJ*. 2014; 2:e647.doi: 10.7717/peerj.647 [PubMed: 25374786]
- Rodrigues RG, das Dores RM, Camilo-Junior CG, Rosa TC. SentiHealth-Cancer: A sentiment analysis tool to help detecting mood of patients in online social networks. *Int J Med Inform*. 2016; 85(1): 80–95. DOI: 10.1016/j.ijmedinf.2015.09.007 [PubMed: 26514078]
- Settanni M, Marengo D. Sharing feelings online: studying emotional well-being via automated text analysis of Facebook posts. *Front Psychol*. 2015; 6:1045.doi: 10.3389/fpsyg.2015.01045 [PubMed: 26257692]
- Shepherd A, Sanders C, Doyle M, Shaw J. Using social media for support and feedback by mental health service users: thematic analysis of a twitter conversation. *BMC Psychiatry*. 2015; 15:29.doi: 10.1186/s12888-015-0408-y [PubMed: 25881089]

- Subrahmanian V, Azaria A, Durst S, Kagan V, Galstyan A, Lerman K, ... Menczer F. The DARPA Twitter Bot Challenge. 2016 arXiv preprint arXiv:1601.05140.
- Toseeb U, Inkster B. Online social networking sites and mental health research. *Front Psychiatry*. 2015; 6:36.doi: 10.3389/fpsy.2015.00036 [PubMed: 25814958]
- Whitehill JM, Brockman LN, Moreno MA. "Just talk to me": communicating with college students about depression disclosures on Facebook. *J Adolesc Health*. 2013; 52(1):122–127. DOI: 10.1016/j.jadohealth.2012.09.015 [PubMed: 23260845]
- Yang C, Srinivasan P. Life Satisfaction and the Pursuit of Happiness on Twitter. *PLoS One*. 2016; 11(3):e0150881.doi: 10.1371/journal.pone.0150881 [PubMed: 26982323]
- Yin Z, Fabbri D, Rosenbloom ST, Malin B. A Scalable Framework to Detect Personal Health Mentions on Twitter. *J Med Internet Res*. 2015; 17(6):e138.doi: 10.2196/jmir.4305 [PubMed: 26048075]
- Yoon S, Bakken S. Methods of knowledge discovery in tweets. *NI 2012*. 2012; 2012:463. 2012. [PubMed: 24199142]
- Yoon S, Elhadad N, Bakken S. A practical approach for content mining of Tweets. *Am J Prev Med*. 2013; 45(1):122–129. DOI: 10.1016/j.amepre.2013.02.025 [PubMed: 23790998]

Clinical Implications

- Mental health care needs and opinions were found on Twitter in the context of dementia.
- Patients and family members are often exposed to nonscientific clinical information by scammers. Mental health clinicians should be aware of the quality of information that their patients are exposed to in social media.
- Data science techniques such as natural language processing or social network analysis help clinicians capture communication structures and contents of big data.

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Figure 3. Macro level structure of tweets mentioning dementia or Alzheimer’s and the ranking of leaders within tweeting communities (unit of analysis: global scale)