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Full length article

How people with dementia use twitter: A qualitative analysis

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ABSTRACT

People with dementia are publicly sharing their experiences of living with the condition and acting collectively to produce social change. Social media could support them in doing this, but no previous studies have comprehensively analysed their use of Twitter. The aims of this study were to identify how people with dementia use Twitter and examine the illness identities they create and promote online. Tweetcatcher was used to collect 2774 tweets posted over six months by 12 account holders with dementia, across three countries. Tweets were analysed thematically. Six themes were identified through the analysis: nothing about us without us, collective action, experts by experience, living with dementia not suffering from it, community, and stories of dementia. On Twitter, people with dementia are developing a collective illness identity to further a social movement that is focused on improving the lives of people with dementia. They are also communicating their personal identities by documenting their lived experiences. Twitter is being used to convey positive, rather than negative, messages about dementia. The findings of this study also show that thematic analysis can be applied to micro texts that can combine over time to form longer narratives.

1. Introduction

Over the last thirty years, the person-centred movement has recognised the importance of the lived experience in dementia research and championed research methods that consider the whole person, not just the disease process (Goldsmith, 1996; Kitwood, 1987, 1993, 1997). More recently, a growing emphasis has been placed on the rights and citizenship of people with dementia (e.g. Birt, Poland, Csipke, & Charlesworth, 2017; Shakespeare, Zelig, & Mittler, 2017). Recent medical and policy initiatives have focussed on diagnosing people with dementia at earlier stages of the disease (Department of Health, 2016), allowing the voices of a wider range of people with dementia to be heard. In line with this, qualitative researchers are increasingly engaging with the narratives of people with dementia (e.g. Hillman, Jones, Quinn, M Nelis, & Clare, 2018; Read, Toye, & Wynaden, 2017; Toms, Quinn, Anderson, & Clare, 2015) and also including them as advisers on research projects (e.g. Litherland et al., 2018).

As well as having their perspectives presented by researchers, people with dementia are communicating their personal experiences by speaking at conferences (Gilmour & Brannelly, 2010) and publishing books (e.g. Mitchell, 2018; Swaffer, 2016), in which they, crucially, can

control the narrative. By communicating their perspectives in this way, people with dementia are able to engage in a social dialogue that affirms their identity (Ryan, Bannister, & Anas, 2009), challenges stigma and stereotypes, and reframes their condition as a manageable disability rather than 'a living death' (Beard, Knauss, & Moyer, 2009; Cohen & Eisdorfer, 1986; Fontana & Smith, 1989; Woods, 1989). In addition to sharing their personal experiences, people with dementia have come together to seek opportunities for collective advocacy (Bartlett, 2014a, 2014b). Through their collective action, they are able to challenge traditional assumptions of dementia, have an impact on the practices and policies that affect their lives, and contribute to a greater social and political understanding of dementia.

Despite this progress towards a 'nothing about us without us' model of dementia, existing platforms for advocacy (such as books and public speaking) are not an option for all people with dementia. The freely available platforms of social media, however, may provide a more equitable path to advocacy and narrative, but only a few studies have explored this. Members of the Dementia Advocacy and Support Network International (DASNI), for example, have used email and on-line chat rooms to provide and receive support, tackle the challenges of living with dementia, and advocate for people with dementia (Clare,

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Rowlands, & Quin, 2008). Since DASNI was launched, social networking sites have been established and increased in popularity, and a small body of research has shown that people with dementia are also using Facebook, blogs, and online forums to increase their networks, share their experiences, provide and receive support, and advocate for themselves (Craig & Strivens, 2016; Kannaley, Mehta, Yelton, & Friedman, 2018; Rodriquez, 2013).

Research on the use of Twitter by people with dementia, however, is limited. Twitter is a microblogging platform that was first established in 2006 (Kaplan & Haenlein, 2010). On Twitter, account holders send short statements known as tweets. Tweets were originally limited to 140 characters until November 2017 when Twitter increased the character limit to 280 (Rosen & Ihara, 2017). On Twitter, account holders follow each other so they can see one another's tweets in their feed. In comparison to other social networking sites, such as Facebook which account holders mainly use to socialise (Hughes, Rowe, Batey, & Lee, 2012; Tosun, 2012), the primary focus of Twitter is sharing of information and opinions (Kwak, Lee, Park, & Moon, 2010). Public tweets can be retweeted by any account holder so that the original tweet can be quickly shared with followers. Tweets can be retweeted numerous times, which means that tweets have the potential to reach a vast audience (Highfield, 2016). Twitter could, therefore, be a useful platform for people with dementia to access information, express themselves, and further the dementia rights movement.

For other groups of people, Twitter has been a powerful platform for social change. The hashtag #BlackLivesMatter, for example, has been used to facilitate international conversations and political debate about racial inequalities (Highfield, 2016), while the hashtag #HelloMyNameIs has successfully raised awareness of the need for better communication in health care and changed National Health Service (NHS) practice across the UK (Granger, 2013). These powerful hashtags, and others like them, have been grass roots, user-led movements that have come directly from the lived experiences of individuals in oppressed, marginalised, or under-represented groups. For people with chronic health conditions, Twitter has also enabled them to share information, provide and receive support, raise awareness, challenge stigma, document their experiences, self-advocate, and identify with a community (Berry et al., 2017; Brunner, Palmer, Togher, & Hemsley, 2018; Hemsley, Dann, Palmer, Allan, & Balandin, 2015; Hemsley & Palmer, 2016; Sugawara et al., 2012; Taylor & Pagliari, 2018). Twitter has the potential to be equally valuable for people with dementia, providing a platform for them to be heard and influence the practices that affect their lives, but researchers have yet to examine this.

Previous research examining dementia-related discussions on Twitter has concluded that the majority of tweets are posted by health professionals, health information sites, and news and advocacy organisations (Robillard, Johnson, Hennessey, Beattie, & Illes, 2013). Examination of the use of Twitter by people with dementia is notably absent from this research, except for three preliminary studies ((Cheng, Liu, & Woo, 2018; Thomas, 2017; Talbot, O'Dwyer, Clare, Heaton, & Anderson, 2018). The findings of these studies suggest that people with dementia are using Twitter for advocacy, support, and to document their experiences. This preliminary research, however, has focussed on the 'bios' of people with dementia rather than their tweets (Talbot et al., 2018), used a small sample of two people with dementia (Thomas, 2017), or grouped the tweets of people *with* dementia with those *affected* by dementia (e.g. friends or family members; Cheng et al., 2018). More research is therefore required to gain a better understanding of how and why people with dementia are using this microblogging platform.

The aims of this research were to: (1) identify how people with dementia use Twitter; and (2) examine the extent to which people with dementia use Twitter to create and promote identities related to their illness. This study was approved by the Human Research Ethics Committee of the University of Exeter Medical School.

2. Method

2.1. Sample

On 12th June 2017 16:42 (GMT), Tweetcatcher (Brooker, Barnett, & Cribbin, 2016) was used to identify tweets posted in the previous 24 h that contained the search terms 'dementia' or 'Alzheimer'. The search was repeated every 24 h for 30 consecutive days. A total of 416,826 tweets containing the terms 'dementia' or 'Alzheimer' were identified during this 30-day period. These tweets and associated account holder data were imported into Microsoft Excel for analysis, and the profile descriptions of the account holders were searched for any evidence of a dementia diagnosis. Of the 217,623 individual account holders tweeting about dementia, 30 publicly identified themselves as having a diagnosis of dementia.

Account holders were sampled from this population of Twitter users who identified themselves as having dementia. To ensure the amount of data collected for this study was not unwieldy, we aimed to purposively select a diverse sample of 12–15 account holders according to their type of dementia (Alzheimer's disease, vascular, Lewy body, frontotemporal, mixed, rare, not specified), location (UK and Ireland, Australia, North America), and sex (man, woman). A sampling framework was developed using these dimensions to accommodate as much variation as possible within the sample. Only accounts set to 'public' (i.e. that were not private) were included in the sample.

Using this framework, one man and one woman from each of the locations and dementia types were sampled. When a cell contained more than one account holder, random sampling was used to select a single account holder. Some cells in the sampling framework were not filled. Using this framework, 13 account holders were included in the initial sample. One account holder was excluded from the sample because of their involvement in the analysis. Instead, a different account holder with the same demographic variables was included in the sample. A second account holder had to be excluded due to a change in personal circumstances, and was replaced with another individual with the same demographic variables. In the course of the analysis, it became evident that one account was owned jointly by a person with dementia and their carer. Consequently, this account was excluded from the analysis. The final sample therefore comprised 12 account holders.

2.2. Procedure

Prior to data collection, the first author tweeted account holders to inform them that their tweets were being used for research purposes. Account holders were invited to direct message the researcher if they wanted to opt out of the analysis or ask questions about the research. On 2nd November 2017, the data extraction software programme Tweetcatcher (Brooker et al., 2016) was used to identify tweets and retweets posted by the 12 account holders over the preceding six months. Tweets were collected before Twitter increased its character limit to 280 characters, when tweets were limited to 140 characters. A total of 11,527 tweets were collected, comprising 4739 original tweets and 6788 retweets. For the purpose of the present qualitative analysis, retweets without comments were excluded in order to focus on the more substantive tweets. For the purpose of this analysis, tweets aimed at specific account holders (i.e. tweets beginning with '@') were excluded from the analysis because the complete conversation was not available. A total of 2774 tweets was included in the analysis. Some of the tweets identified by Tweetcatcher were incomplete. To obtain the full tweet, the first author followed the hyperlink identified by Tweetcatcher to the original tweet and manually imported the full tweet into the dataset. Emojis were retained in tweets manually imported into the dataset. As well as identifying tweets, Tweetcatcher also collected hyperlinks to images posted by account holders; however, only the tweet itself was analysed in this study (i.e. not the image).

2.3. Analysis

Tweets were analysed qualitatively using thematic analysis. The thematic analysis followed the steps identified by Braun and Clarke (2006, 2013, 2014): data familiarisation through reading a sample of tweets; generating initial codes and coding the entire dataset in NVivo; collating codes and relevant tweets together; examining codes to identify themes across the data; reviewing and refining the themes; and defining and naming the themes.

The first author (CT) conducted the initial analysis. After the initial analysis was complete, the second author (SOD) reviewed the themes and a proportion of the coded tweets. Any issues raised by the second author were discussed and addressed. The revised analysis was discussed with the rest of the research team and revisions were made to the analysis. Following this, coding was checked by the first author who searched the data in Nvivo to ensure the index had been systematically applied to the data. Errors in coding were corrected and any data that had been missed during the earlier stages of the analysis were coded. The first author reread the tweets of three account holders to check the themes accurately reflected the data, and the themes were discussed with a person living with dementia to check that the findings were consistent with that person's experience. Codes and themes were organised into frameworks so comparisons could be made between account holders in relation to the demographics reported in their Twitter profile descriptions. A coding framework was developed throughout the course of the analysis to provide a clear trail of evidence. Direct quotes of tweets sent by account holders are presented in this paper to illustrate themes.

2.4. Ethical considerations

The British Psychological Society (2014) states that unless consent has been sought, observation of public behaviour must take place in public situations where people would expect to be observed by strangers. Twitter is considered a public platform and there is a general consensus among researchers that the content posted on Twitter can be used for research purposes (e.g. Moreno, Goni, Moreno, & Diekema, 2103). In this study, informed consent was not obtained because tweets were posted on public accounts and, therefore, located within the public domain.

Ethical approval was obtained for the use of directly quoted tweets in this analysis. The use of direct quotes of tweets could potentially make account holders identifiable. To maintain respect for account holders, the first author tweeted each account holder to inform them of the study and give them the opportunity to opt out of the analysis. This tweet was subsequently deleted after data collection. This approach has been successfully used in previous research (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017) and is consistent with recent research on account holders' attitudes towards using social media data in research (Fiesler & Proferes, 2018). Five account holders responded to the researcher's tweet asking for more information. None of these account holders asked to opt out of the analysis.

An advisory group comprising three people with dementia was consulted on the ethical framework and search terms for this study. One member of this advisory group who has an active Twitter account commented on the themes. This person agreed that the themes presented in this paper reflect her experience.

3. Results

3.1. Account holders

Four women and eight men were included in the analysis. Only four account holders reported their age, which ranged from 58 to 65. Six account holders were located in the UK, five in the USA, and one in Australia. Account holders had been on Twitter for an average of 6.08

Table 1
Participant demographics.

ID	Sex	Age	Location	Type of dementia	Advocate	Years on Twitter
1	M		UK	Alzheimer's	N	4
2	M		UK	LBD ^a	Y	6
3	M	60	UK	FTD ^b	N	5
4	W		UK	Rare	N	6
5	M		UK	Not specified	Y	6
6	W	65	UK	Not specified	Y	2
7	W		Aus	Not specified	Y	9
8	M		USA	Alzheimer's	Y	9
9	M		USA	LBD ^a	Y	8
10	M		USA	Rare	Y	9
11	W	58	USA	Mixed	Y	2
12	M	58	USA	Not specified	N	7

^a Lewy body dementia.

^b Frontotemporal dementia.

years ($SD = 2.50$, range: 2–9) and most ($n = 8$) self-identified as dementia advocates (i.e. they described themselves as advocates in their profiles or affiliated themselves with a dementia working group). Table 1 contains details of the account holders, using data collected from their profiles.

3.2. Themes

Six themes were generated from the data: nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia. These themes are discussed below with direct quotes of tweets to illustrate each theme.

All themes except for stories of dementia concern the collective identity of account holders as a result of their diagnosis, with their tweets considered to be contributing to a wider social movement about, for, and by people with dementia. In comparison, stories of dementia concern the individual identities account holders communicate through tweets that document their personal experiences. Most account holders used Twitter for collective action and to share their stories of dementia, as illustrated in Table 2. After the sample was selected and tweets were collected, it became evident that one account holder (ID = 11) only retweeted information and did not produce any individual tweets.

3.2.1. Nothing about us without us

Five account holders used Twitter to represent the needs and experiences of people with dementia. Four of these account holders identified themselves as dementia advocates, which suggests that representation is an important part of advocacy. Some advocates ($n = 2$) used Twitter to contribute their lived experiences to conference hashtag discussions and to hold local NHS trusts and conference organisers publicly accountable when the voices of people with dementia were not represented. One account holder, for example, used Twitter to comment on a lack of representation of people with dementia on a conference panel.

Table 2
The mapping of each theme within account holders' tweets.

Theme	Account holder ID											
	1	2	3	4	5	6	7	8	9	10	11	12
Nothing about us without us				X	X		X	X	X			
Collective action	X	X	X		X	X	X	X	X	X		X
Experts by experience	X	X			X							X
Living with dementia not suffering from it	X	X			X		X		X			X
Community	X				X		X	X	X			X
Stories of dementia	X	X	X	X	X	X	X	X	X	X		X

One half of the consumer coin is there - a carer. The other half is obviously missing in action

Advocates also tweeted positively when people with dementia were adequately represented. Through their use of Twitter, these advocates were able to maintain a voice in discussions about them and evoke social change by commenting publicly on a lack of representation.

Thank you @DementiaAustralia for creating the change #onthespot #beTheChange2017 by making room 4 a person with dementia to join the panel

3.2.2. Collective action

Ten account holders tweeted about collective actions such as fundraising, political lobbying, and raising awareness. Almost all the self-identified dementia advocates used Twitter for fundraising ($n = 7$) and political lobbying ($n = 6$), which could be considered an important part of advocacy. Both advocates ($n = 3$) and non-advocates ($n = 2$) used Twitter to raise awareness, suggesting that this is important for both groups.

June is Alzheimer's and Brain Awareness Month. Get involved, be part of the cure. @alzassociation #ENDALZ

Account holders largely raised funds for established organisations (e.g. the Alzheimer's Association) rather than individuals (e.g. GoFundMe pages), suggesting that these advocates see themselves as part of a larger movement. Almost all fundraising was for dementia-specific charities, indicating that these advocates identify with a dementia-specific movement, which occasionally includes other health conditions.

Buy a Walk to Remember T-Shirt by July 24th to help us raise funds for our Walk to Remember Friend Raiser event customink.com/fundraising/wa...

Seven account holders shared petitions on Twitter and engaged with politicians. Through their political lobbying, these account holders sought to influence the policies that affect their lives by gaining support for their cause and engaging with people who make important decisions about the lives of people with dementia.

I've united with @alzheimerssoc to end the #DementiaTax. Sign the petition now and call on the Government to act

3.2.3. Experts by experience

Four of the account holders used Twitter to educate others about dementia, thus identifying themselves as experts by experience. These account holders tweeted about a range of topics, such as symptoms, diagnostic information, dementia-friendly communities, advice on caring, and tips for interacting with people living with dementia.

#DiverseAlz It annoys me is when I hear "People who have Alzheimer's or dementia" what's that about? Alzheimer's is a type of dementia

Advocates ($n = 2$) and non-advocates ($n = 2$) used Twitter to educate others, indicating that education about dementia is important to both groups. Account holders used Twitter to educate carers, health care providers, researchers, and members of the public. By educating other account holders about dementia, the account holders in this study identified themselves as authority figures who are knowledgeable about their condition and able to use their experiences to educate both the general public and those who are traditional sources of knowledge (e.g. clinicians, researchers). All of the account holders who used Twitter to educate others about dementia were men. While it is important that people are educated about dementia, an absence of female voices may be leading to a lack of education about the needs and experiences of women.

A pilot decision-making tool for GPs | YoungDementia UK Do look at this ... it's really good.

3.2.4. Living with dementia, not suffering from it

Six account holders tweeted about stigma and the need for more positive language around dementia. Advocates ($n = 4$) and non-advocates ($n = 2$) tweeted about stigma, suggesting this is an important issue for both groups. These account holders rejected negative language used to describe dementia, such as 'suffering' and 'demented', and language that framed them as a burden.

#DiverseAlz I don't want to read/hear words which implies how much of a 'burden' we are or how challenging our behaviour is for loved ones.

Two account holders made comparisons between the stigma of other health conditions (e.g. cancer) and dementia. These tweets highlight an inequality between dementia and other health conditions, such as cancer, where people with dementia are sometimes the subject of jokes and treated as sub-human.

#Diversealz Can you imagine a comedian standing up and making a joke about someone with cancer?

Three account holders tweeted suggestions for appropriate language and two advocates held people who used stigmatising language publicly accountable. By challenging stereotypical beliefs and negative language, these account holders could potentially change public perceptions of dementia and reaffirm their identities as people who can live well with the condition. Five of the six account holders who tweeted about stigma were men, so it is difficult to determine whether women with dementia who use Twitter also experience this kind of stigma.

@abcnews Oh, and NOT calling us #sufferers would be respectful. @AlzheimersAus should have made sure that word was NOT used & @abcnews knows better.

3.2.5. Community

Six account holders tweeted support to other people with dementia and carers. Because account holders also supported carers, this suggests that this online community includes people who have or are otherwise affected by dementia.

#ENDALz @alzheimersmanh @alzassociation Do you know a caregiver please give them a call, let them know you are there for them. HELP THEM!!

Both advocates ($n = 4$) and non-advocates ($n = 2$) tweeted messages of support, indicating that Twitter could be a source of support for both groups. Only one account holder, a non-advocate, tweeted direct support to a person struggling with symptoms.

I told you I'm speaking from experience and you can learn to tame it, make sure you talk about how you feel even if it writing it down 🤔.

Advocates tweeted messages of congratulations to other advocates for giving talks, setting up working groups, writing articles, and winning awards, but did not give direct support to people struggling with symptoms. This could be because advocates are more focused on promoting their cause, because this level of support takes place privately (e.g. over direct message), or because tweets aimed at specific people were not included in the analysis.


I've read your story on the Elder interview and it's inspirational so you keep telling it especially to those newly diagnosed

Account holders tweeted information about dementia cafés and Dementia Engagement and Empowerment (DEEP) group meetings. These tweets highlight that DEEP group meetings are a valuable source of support. People with dementia could be tweeting about this initiative

to support others with a diagnosis. By tweeting information about local DEEP group meetings, these account holders could also be improving their own lives by increasing their number of offline social connections.

New DEEP group mtg first Thursday of month. Social group for people with dementia, esp but not only young onset

Some account holders ($n = 2$) also acknowledged the importance of Twitter as a source of support, highlighting the value of this support network for people with dementia following a diagnosis to reduce feelings of loneliness and isolation.

I'm lucky I got/get the right help & support which prevented me from going into a shell & I get great support here on Tweeter from you all 

3.2.6. Stories of dementia

Almost all account holders ($n = 11$) tweeted about their personal experiences of dementia. Advocates ($n = 7$) and non-advocates ($n = 4$) tweeted about positive aspects of their lives, such as publishing books, engaging with advocacy work, taking part in research, and passing a driving assessment. By sharing their positive life experiences and documenting life after a diagnosis, these account holders constructed a narrative that identified them as people living well with the condition.

Passed my driving assessment today. Just the DVLA to confirm now. so one more year of driving now. Dementia not taking me off road yet.

Seven advocates documented their offline advocacy work, suggesting that evidencing offline advocacy work is important for creating an online advocate identity.

All ready for another three mornings talks to graduate nurses at Northumbria University, on living with dementia starting tomorrow.

Only four account holders shared negative experiences of living with dementia. One account holder, for example, described experiencing problems with memory. While this shows that some people with dementia are using Twitter to discuss negative experiences, the dominant narrative on Twitter was one of positivity and living well.

Not a good week at all, and have just realised how bad my memory has been. It's been a shock to the system to be told what I've been like.

Account holders ($n = 6$) shared links to other social media platforms (e.g. personal blogs, YouTube, Facebook, Soundcloud) where they also documented their experiences of dementia. It seemed that people with dementia were using these other social media platforms to share their stories of dementia in greater detail than is available within Twitter's (then) character limit, including the more negative experiences.

Please visit my blog site to learn about my journey living with Alzheimer's disease.

4. Discussion

Researchers have started to examine the use of social media by people with dementia (Craig & Strivens, 2016; Kannaley et al., 2018; Rodriguez, 2013), but little is known about how people with dementia use Twitter. This study makes a unique contribution to the literature by specifically examining the tweets of people with dementia. Six themes were generated from the tweets of people with dementia: nothing about us without us; collective action; experts by experience; living with dementia not suffering from it; community; and stories of dementia. Each of the themes except for 'stories of dementia' concerns a collective identity resulting from the diagnosis. In their tweets, these account holders collectively identify with a wider social movement which is focused on making social change to improve the lives of people with

dementia. Some account holders also constructed individual identities on Twitter by sharing their personal experiences of dementia, and in these narratives, they presented themselves as dementia activists and people who were living well with dementia.

The majority of account holders' tweets focused on a shared collective illness identity, rather than their personal experiences. Previous research has shown that dementia activists are creating networks offline, developing a collective identity, and becoming politicised (Bartlett, 2014a, b). The findings of this study suggest that this is also happening on Twitter where people with dementia are using the platform to create networks and support their advocacy work. More than half of the advocates in this study used Twitter for representation, fundraising, political lobbying, and documenting their offline advocacy work, suggesting that these activities are an important part of online advocacy. Although Twitter advocacy work does not seem to be replacing offline advocacy, it is providing dementia advocates with an additional platform through which they can share their messages with a wider audience and challenge public perceptions of dementia. Future research conducted with dementia advocates should, therefore, also account for their online advocacy work.

In this study, the use of Twitter by people with dementia was highly political, as evidenced by tweets about representation and political lobbying. This level of political engagement has not been evident for people with dementia on other social media platforms (Craig & Strivens, 2016; Kannaley et al., 2018; Rodriguez, 2013), which highlights the uniquely political nature of Twitter and is consistent with previous research showing that people with other chronic illnesses and members of the public use Twitter to influence policy-making and draw attention to social issues (Granger, 2013; Highfield, 2016). It is unclear whether people with dementia have seen any societal changes as a result of their Twitter activism, but future qualitative research conducted with people with dementia could examine this.

The findings of this study suggest that people with dementia are using Twitter to become visible and broadcast an activist and positive perspective on living with dementia to a wider audience. This finding is mirrored in research examining the use of Twitter by people with communication disabilities who have used Twitter to communicate their experiences to a wider audience (Hemsley et al., 2015; Hemsley & Palmer, 2016). Like people with cancer, the findings of this research also suggest that people with dementia are using Twitter to influence societal change through their online collective action (Granger, 2013). In comparison to people with other chronic health conditions, such as depression (Berry et al., 2017) and diabetes (Liu, Mei, Hanauer, Zheng, & Lee, 2016), the use of Twitter by people with dementia appears to be more political and focused on the creation and promotion of a social movement (Berry et al., 2017). This reflects a recent emphasis within policy-making that has identified dementia as a political priority (Department of Health, 2016). People with dementia could also be more motivated to change perceptions because they often face the double stigma of dementia and old age (Milne, 2010). By challenging perceptions of dementia on Twitter and educating others about the condition, people with dementia may be able to change how they are viewed by others and uphold both their own personhood and that of other people with dementia.

The findings of this study suggest that there is a community of people with dementia who are using Twitter to support one another as well as those affected indirectly by dementia, supporting Cheng and colleagues', 2018 finding that those affected by dementia are using Twitter to access support. Following a diagnosis, many people with dementia also experience a loss of identity (Naue & Kroll, 2009); however, membership in online Twitter communities might help to reinstate a sense of identity among people with dementia, provide social connection, and potentially reduce feelings of isolation and loneliness that often follow a diagnosis (Spreadbury & Kipps, 2017). Future research could examine the benefits of using social networking sites for people with dementia.

In this study, it was mostly men who challenged stigma and educated others about dementia on Twitter. Consequently, the challenges faced by women with dementia are not being discussed on Twitter, which might further perpetuate the marginalisation experienced offline by this group (Mears, 2018). It is also consistent with the fact that men are overrepresented as advocates in the dementia rights movement offline (Ludwin & Parker, 2015). So, while Twitter could be providing a way for some people with dementia to have their voices heard, challenge stereotypes, and re-affirm their identities, it may not be doing this for all groups of people with dementia. It is also unclear from the findings of this study, given a lack of demographic data, whether the voices of people with dementia from other marginalised groups (e.g. Black, Asian, and minority ethnic; LGBTQ+) are represented on Twitter. Research which engages with marginalised groups of people with dementia could examine their use of Twitter and the challenges they face in being heard online.

One account holder in this study only retweeted information and did not produce any individual tweets. A similar finding was identified in research on the use of Twitter by people with communication disabilities (Hemsley et al., 2015). While this could simply be how the account holder has always used Twitter, it may also be a reflection of advancing symptoms of dementia. Account holders who use social media to view information but not post original content have been referred to as 'lurkers' in previous social media research (see Edelman, 2013; Sun, Rau, & Ma, 2014); however, it seems unhelpful to apply the negative connotations associated with 'lurking' to people with dementia. Instead, becoming less active on Twitter but continuing to be involved by retweeting information could be a valuable source of social connection for some people with dementia as their symptoms progress. Future research which analyses the use of Twitter by people with dementia at different stages of the disease trajectory could help to elucidate the impact of progressive illnesses on the use of social media.

While the account holders in this study tended to focus on a collective social movement, they also used Twitter to document their personal experiences of living with dementia. The findings of this study suggest that people with dementia are using Twitter to communicate their experiences of illness in less than 140 characters, supporting Thomas' (2017) finding that the tweets of people with dementia provide important information about their experiences. Illness narratives have traditionally been considered to be long-form expressions (e.g. journal entries), but the findings of this study suggest that narratives can be created in shorter messages over time. Taken together these 'short stories' form an illness narrative through which people with dementia are communicating their experiences to the world. The lived experience of dementia shared on Twitter may be qualitatively and quantitatively different from that shared in offline spaces. Qualitative researchers could, therefore, analyse these tweets about personal experiences to gain further insight into the lived experience of dementia. Likewise, while thematic analysis has traditionally been applied to longer pieces of text (e.g. (Anderson, Hundt, Dean, Keim-Malpass, & Lopez, 2017); Toms et al., 2015), this study shows that it can also be applied to micro texts that combine over time to create longer narratives.

The dominant narrative across all of the tweets analysed in this study is one of activism and living well. Other narratives, such as those of people who are struggling with their symptoms, were notably absent from the data. This is consistent with the traditional illness narrative literature, in which there is a focus on recovery (Garden, 2010). It is possible that a lack of negative experiences being present in account holders' tweets could be an artefact of people who are living well with dementia, being those who choose, or are able, to interact on Twitter. This finding could also be due to account holders' use of Twitter to produce social change, where tweeting about the negative aspects of their lives could further perpetuate the stereotypes they are trying to challenge. Negative stories of dementia might be present in more private digital spaces, such as Twitter's direct message or closed groups on other social media platforms. Researchers could engage with people

with dementia to examine why they focus on the positive in their tweets and identify which digital spaces they use to document their negative experiences.

The account holders in this study often shared links to other social media platforms where they also shared their experiences of living with dementia. By managing multiple social media accounts, these account holders demonstrate an ability to use technology, thus challenging stereotypical assumptions of dementia. It is clear that the account holders in this study cannot be viewed as victims who experience a loss of self and 'a living death' (Cohen & Eisdorfer, 1986; Fontana & Smith, 1989; Woods, 1989). People with dementia could be using these different forms of social media for a variety of reasons, revealing different aspects of their identities on each platform. While the findings of this study show that the use of Twitter by people with dementia is focused on furthering a collective social movement, blogs written by people with dementia (Kannaley et al., 2018), for example, might contain more detailed information about personal identities and everyday experiences than is possible on Twitter due to the character limit. Social media platforms do not operate in isolation, so in future researchers could analyse the use of different social media platforms by people with dementia to gain a comprehensive understanding of their identities and how these online identities intersect.

4.1. Limitations

While this study provides an in-depth examination of the tweets of people with dementia, it does have some limitations. Firstly, conversational tweets were not included in this analysis. Conversations are an integral aspect of Twitter and it is likely that these conversations contain important information about how people with dementia use Twitter. These conversational tweets could contain information about who people with dementia interact with on Twitter as well as the support they receive. Future research could examine conversational tweets to gain a more complete understanding of how people with dementia use Twitter. Likewise, retweets comprised a large proportion of the data but were excluded from the analysis. Future research examining the retweets of people with dementia could identify what information people with dementia are promoting on Twitter and the credibility of this information.

The tweets analysed in this study were all publicly available data; however, the public side of Twitter is only one aspect of an account holder's experience. Conversations which take place in private (i.e. via direct message) might be used by people with dementia for other purposes, such as private support. Future research could engage people with dementia to examine their reasons for having private conversations on Twitter.

Only four women were included in this study, meaning that any firm conclusions about gender are limited by the small sample size. The different experiences of men, women, and diverse groups of people with dementia should therefore be considered in future research.

It was not possible to verify the diagnosis of account holders in this study, which means that we did not have information about their symptoms, stage of dementia, or quality of life, which could have influenced how they use Twitter. In research examining the use of Twitter by a person with terminal cancer, for example, Taylor and Pagliari (2018) found that the person focused more on social relationships and support during the dying phase than in the other cancer phases. This could also be the case for people with dementia. Future research could examine change in Twitter usage by people with dementia as the disease progresses and the impact this has on their identity.

In addition, the findings of this study only focus on the content of public tweets which were largely positive. People with dementia could experience relational and practical problems when using Twitter, such as trolling and issues with accessibility. One account holder (ID = 11), for example, only retweeted information. This finding highlights that some people with dementia might find it easier to retweet information

than write personal tweets. In future research, reflective interviews could be conducted with people with dementia to identify the problems they face when using Twitter, which could inform platform developers about how they can make social networking sites more accessible for people with dementia.

4.2. Conclusion

In conclusion, people with dementia are using Twitter to identify with a collective social movement focused on producing social changes which improve the lives of people with dementia. These account holders are using Twitter to fight for representation, fundraise, lobby politicians, raise awareness, challenge stigma, educate others, and provide support. People with dementia are also constructing personal identities on Twitter by documenting their personal experiences. These narratives tend to focus on dementia activism and 'living well' rather than the negative aspects of living with dementia. Future research could examine what motivates people with dementia to use Twitter, the challenges they face, and how their Twitter use changes as their symptoms progress.

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References

Anderson, J. G., Hundt, E., Dean, M., Keim-Malpass, J., & Lopez, R. P. (2017). "The church of online support" examining the use of blogs among family caregivers of persons with dementia. *Journal of Family Nursing*, 23(1), 34–54.

Bartlett, R. (2014). The emergent nodes of dementia activism. *Ageing and Society*, 34(4), 623–644.

Bartlett, R. (2014b). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29(8), 1291–1304.

Beard, R., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227–235.

Berry, N., Lobban, F., Belousov, M., Emsley, R., Nenadic, G., & Bucci, S. (2017). #WhyWeTweetMH: Understanding why people use twitter to discuss mental health problems. *Journal of Medical Internet Research*, 19(4), e107.

Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199–211.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London, England: Sage.

Braun, V., & Clarke, V. (2014). What can "thematic analysis" offer health and wellbeing researchers? *International Journal of Qualitative Studies on Health and Well-Being*, 9, 26152. <https://doi.org/10.3402/qhw.v9.26152>.

British Psychological Society (2014). *Code of human research Ethics*. British Psychological Society.

Brooker, P., Barnett, J., & Cribbin, T. (2016). Doing social media analytics. *Big Data Society*, 3(2), 1–12.

Brunner, M., Palmer, S., Togher, L., & Hemsley, B. (2018). 'I kind of figured it out': The views and experiences of people with traumatic Brain injury (TBI) in using social media—self-determination for participation and inclusion online. *International Journal of Language & Communication Disorders*, 0(0), 1–13. <https://doi.org/10.1111/1460-6984.12405>.

Cheng, T. Y., Liu, L., & Woo, B. K. P. (2018). Analyzing twitter as a platform for alzheimer-related dementia awareness: Thematic analyses of tweets. *JMIR Aging*, 1(2), e11542.

Clare, L., Rowlands, J. M., & Quin, R. (2008). Collective strength: The impact of developing a shared social identity in early-stage dementia. *Dementia*, 7(1), 9–30.

Cohen, D., & Eisdorfer, C. (1986). *The loss of self*. New York, NY: WW Norton & Co.

Craig, D., & Strivens, E. (2016). Facing the times: A young onset dementia support group: Facebook™ style. *Australasian Journal on Ageing*, 35(1), 48–53.

Department of Health. *Prime minister's challenge on dementia*. (2016). Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/414344/pm-dementia2020.pdf 12th November 2018 .

Edelmann, N. (2013). Reviewing the definitions of "lurkers" and some implications for online research. *Cyberpsychology, Behavior, and Social Networking*, 16(9), 645–649.

Fiesler, C., & Proferes, N. (2018). "Participant" perceptions of twitter research Ethics. *Social Media + Society*, 4(1), 1–14.

Fontana, A., & Smith, R. W. (1989). Alzheimer's disease victims: The "unbecoming" of self and the normalization of competence. *Sociological Perspectives*, 32(1), 35–46.

Garden, R. (2010). Telling stories about illness and disability: The limits and lessons of narrative. *Perspectives in Biology and Medicine*, 53(1), 121–135.

Gilmour, J. A., & Brannelly, T. (2010). Representations of people with dementia – subaltern, person, citizen. *Nursing Inquiry*, 17(3), 240–247.

Goldsmith, M. (1996). *Hearing the voice of people with dementia: Opportunities and obstacles*. London, England: Jessica Kingsley Publishers.

Granger, K. (2013). Healthcare staff must properly introduce themselves to patients. *BMJ British Medical Journal*, 347, 1–2. <https://doi.org/10.1136/bmj.f5833>.

Hemsley, B., Dann, S., Palmer, S., Allan, M., & Balandin, S. (2015). "We definitely need an audience": Experiences of twitter, twitter networks and tweet content in adults with severe communication disabilities who use augmentative and alternative communication (AAC). *Disability & Rehabilitation*, 37(17), 1531–1542.

Hemsley, B., & Palmer, S. (2016). Two studies on twitter networks and tweet content in relation to amyotrophic lateral sclerosis (ALS): Conversation, information, and 'diary of a daily life'. *Digital health innovation for consumers, clinicians, connectivity and community: Selected papers from the 24th Australian national health informatics conference (HIC 2016): Vol. 227*, (pp. 41–47). . <https://doi.org/10.3233/978-1-61499-666-8-41>.

Highfield, T. (2016). *Social media and everyday politics*. Cambridge, England: Polity Press.

Hillman, A., Jones, I. R., Quinn, C., M Nelis, S., & Clare, L. (2018). Dualities of dementia illness narratives and their role in a narrative economy. *Sociology of Health & Illness*, 40(5), 874–891.

Hughes, D. J., Rowe, M., Batey, M., & Lee, A. (2012). A tale of two sites: Twitter vs. Facebook and the personality predictors of social media usage. *Computers in Human Behavior*, 28(2), 561–569.

Kannaley, K., Mehta, S., Yelton, B., & Friedman, D. B. (2018). Thematic analysis of blog narratives written by people with Alzheimer's disease and other dementias and care partners. *Dementia*, 0(0), 1–20. <https://doi.org/10.1177/1471301218768162>.

Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of social media. *Business Horizons*, 53(1), 59–68.

Kitwood, T. (1987). Dementia and its pathology: In *Brain, mind or society? Free Associations*, 1(8), 81–93.

Kitwood, T. (1993). Person and process in dementia. *International Journal of Geriatric Psychiatry*, 8(7), 541–545.

Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Milton, England: Open University Press.

Kwak, H., Lee Changhyun, H., & Moon, S. (2010). What is twitter, a social network or a news media? *Proceedings of the 19th world-wide web (WWW) conference* (Raleigh, North Carolina).

Litherland, R., Burton, J., Cheeseman, M., Campbell, D., Hawkins, M., Hawkins, T., ... Clare, L. (2018). Reflections on PPI from the "action on living well: Asking you" advisory network of people with dementia and carers as part of the IDEAL study. *Dementia*, 17(8), 1035–1044.

Liu, Y., Mei, Q., Hanauer, D. A., Zheng, K., & Lee, J. M. (2016). Use of social media in the diabetes community: An exploratory analysis of diabeted-related tweets. *JMIR Diabetes*, 1(2), e4.

Ludwin, K., & Parker, G. M. (2015). *Women and dementia: All but forgotten? A literature review*. York, England: Social Policy Research Unit, University of York.

Mears, J. (2018). 'Nobody cares about me': Older women, caring and dementia. In G. Macdonald, & J. Mears (Eds.). *Dementia as social experience: Valuing life and care* (pp. 46–57). Abingdon, England: Routledge.

Milne, A. (2010). The 'D' word: Reflections on the relationship between stigma, discrimination and dementia. *Journal of Mental Health*, 19(3), 227–233.

Mitchell, W. (2018). *Somebody I used to know*. London, England: Bloomsbury Publishing.

Moreno, M. A., Goni, N., Moreno, P. S., & Diekema, D. (2013). Ethics of social media research: Common concerns and practical considerations. *Cyberpsychology, Behavior, and Social Networking*, 16(9), <https://doi.org/10.1089/cyber.2012.0334>.

Naue, U., & Kroll, T. (2009). "The demented other": Identity and difference in dementia. *Nursing Philosophy*, 10(1), 26–33.

Read, S. T., Toye, C., & Wynaden, D. (2017). Experiences and expectations of living with dementia: A qualitative study. *Collegian*, 24(5), 427–432.

Robillard, J. M., Johnson, T. W., Hennessey, C., Beattie, L. B., & Illes, J. (2013). Aging 2.0:

- Health information about dementia on twitter. *PLoS One*, 8(7) e69861.
- Rodriguez, J. (2013). Narrating dementia: Self and community in an online forum. *Qualitative Health Research*, 23(9), 1215–1227.
- Rosen, A., & Ihara, I. (2017). Giving you more characters to express yourself. Retrieved from: https://blog.twitter.com/en_us/topics/product/2017/Giving-you-more-characters-to-express-yourself.html.
- Ryan, E. B., Bannister, K. A., & Anas, A. P. (2009). The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies*, 23(3), 145–157.
- Shakespeare, T., Zeilig, H., & Mittler, P. (2017). Rights in mind: Thinking differently about dementia and disability. *Dementia*, 0(0), 1–14. <https://doi.org/10.1177/1471301217701506>.
- Spreadbury, J. H., & Kipps, C. (2017). Measuring younger onset dementia: What the qualitative literature reveals about the 'lived experience' for patients and caregivers. *Dementia*, 0(0), 1–2. <https://doi.org/10.1177/1471301216684401>.
- Sugawara, Y., Narimatsu, H., Hozawa, A., Shao, L., Otani, K., & Fukao, A. (2012). Cancer patients on twitter: A novel patient community on social media. *BMC Research Notes*, 5(1), 699.
- Sun, N., Rau, P. P. L., & Ma, L. (2014). Understanding lurkers in online communities: A literature review. *Computers in Human Behavior*, 38, 110–117.
- Swaffer, K. (2016). *What the hell happened to my Brain?* London, England: Jessica Kingsley Publishers.
- Talbot, C., O'Dwyer, S., Clare, L., Heaton, J., & Anderson, J. (2018). Identifying people with dementia on Twitter. *Dementia*, 0(0), 1–10. <https://doi.org/10.1177/1471301218792122>.
- Taylor, J., & Pagliari, C. (2018). #Deathbedlive: The end-of-life trajectory, reflected in a cancer patient's tweets. *BMC Palliative Care*, 17(1), 17.
- Thomas, B. (2017). Whose story is it anyway? Following everyday accounts of living with dementia on social media. *Style*, 51(3), 357–373.
- Toms, G. R., Quinn, C., Anderson, D. E., & Clare, L. (2015). Help yourself: Perspectives on self-management from people with dementia and their caregivers. *Qualitative Health Research*, 25(1), 87–98.
- Tosun, L. P. (2012). Motives for Facebook use and expressing "true self" on the internet. *Computers in Human Behavior*, 28(4), 1510–1517.
- Woods, R. T. (1989). *Alzheimer's disease: Coping with a living death*. London, England: Souvenir Press.