Using Twitter to understand perspectives and experiences of dementia and caregiving at the beginning of the COVID-19 pandemic

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Abstract

The COVID-19 pandemic has placed a tremendous burden on all of society, particularly among vulnerable populations such as people living with dementia and their caregivers. Efforts to understand the impact of the COVID-19 pandemic on those living with dementia are crucial towards addressing needs during the pandemic and beyond. This qualitative descriptive study includes

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a thematic analysis of 6938 tweets from March 17–24, 2020, that included direct or indirect references to COVID-19 and at least one of the following terms/hashtags: Alzheimer, #Alzheimer, dementia, and #dementia. Five themes were identified: continuing care, finding support, preventing spread of COVID-19, maintaining human rights, and the impact of the pandemic on the daily lives of people living with dementia. People living with dementia and their families faced unique challenges related to caregiving, maintaining social connectedness while trying to follow public health guidelines, and navigating the convergence of COVID-19 and dementia-related stigma. Data from Twitter can be an effective means to understand the impacts of public health emergencies among those living with dementia and how to address their needs moving forward by highlighting gaps in practice, services, and research.

Introduction

The COVID-19 pandemic caused significant global disruption, affecting all aspects of society. Those most vulnerable in society faced heightened risks (Centers for Disease Control & Prevention, 2020), and people living with dementia and their caregivers were among this cohort (Azarpazhooh et al., 2020). People living with dementia reported symptom deterioration and a loss of skills during periods of lockdown, which they attributed to a lack of cognitive stimulation and limited opportunities for rehearsal of everyday activities (Canevelli et al., 2020; Giebel et al., 2020a; Talbot & Briggs, 2021). Disruptions in service delivery, including closing or limiting availability of care centers for people living with dementia and respite services for family caregivers, further amplified the challenges for this population throughout the pandemic (Giebel et al., 2020a). Unpaid caregivers also reported having to make difficult choices on whether to continue paid home care during the pandemic. The decision to discontinue paid care often resulted in unpaid caregivers taking on additional caregiving responsibilities, which had a negative impact on levels of stress and wellbeing (Giebel et al., 2020b).

Social media platforms play a role in shaping the social environment, including for older adults, and provides access to information about public attitudes, experiences, and behaviors (Snelson, 2016; Talbot & Branley-Bell, 2021). These platforms are online applications, such as Facebook, Twitter, blogs, and forums, that allow for the creation and exchange of content generated by users (Kaplan & Haenlein, 2010). These platforms allow for personalization and presentation of information, as well as interactive participation in information exchange, making them powerful tools in the health information sphere. Health care researchers are increasingly using social media platforms to monitor infectious disease outbreaks (Aslam et al., 2014), disseminate health information (Harris et al., 2013), and engage with specific patient and caregiver populations (Rabarison et al., 2017). People living with chronic conditions use social media to share information, garner social support, and raise awareness and advocate for themselves and others (Berry et al., 2017; Gabarron et al., 2015; Hemsley et al., 2015; Himelboim & Han, 2014; Tsuya et al., 2014). Consistent with this, an emerging body of research has focused on the social media posts of people living with dementia and their caregivers (Bachmann, 2020; Craig & Strivens, 2016; Du et al., 2020; Anderson et al., 2017; McLennon et al., 2021; Talbot et al., 2020a; 2020b). People living with dementia use social media platforms as a way to participate in activism, connect and share support, and disseminate information (Clare et al., 2008; Craig & Strivens, 2016; Lorenz et al., 2017; Rodriquez, 2013). Similarly, in an analysis of family caregivers' blogs,

Anderson et al. (2017) argued that these blogs contained rich narratives that could be used to develop understandings of the psychosocial impact of caring. Thus, it is reasonable to assume that the social media posts of people living with dementia and their caregivers could hold unique insights into their experiences of the COVID-19 pandemic.

Twitter is one of the most widely used social media platforms (Smith & Anderson, 2018). Dementia, Alzheimer's disease, and related terms are frequently discussed on Twitter (Cheng et al., 2018; Oscar et al., 2017; Robertshaw & Babicova, 2021; Robillard et al., 2013). Research has examined what sources of information are promoted and which themes related to dementia are most prevalent on Twitter (Robillard et al., 2013), with studies finding a significant amount (~20%) of stigmatizing dementia-related content from the general public on Twitter (Cheng et al., 2018; Oscar et al., 2017).

There is clear evidence that people living with dementia use Twitter to access support, educate others, engage in social and political advocacy, and document their lived experiences (Talbot et al., 2020b; Talbot et al., 2021; Thomas, 2017). In a recent study, Bacsu et al. (2021) analyzed the tweets of people living with dementia and their care partners that were related to COVID-19. Twitter users living with dementia described feelings of despair and abandonment, while caregivers described the stress and exhaustion of caring for someone with dementia, as well as the feelings of separation and loss (Bacsu et al., 2021). Giebel and colleagues (2021) found that people living with dementia were confused by public health guidelines given limited comprehension, which led to frustration both for caregivers and the people with dementia themselves. However, this previous research misses a broader understanding of the perceptions and experiences immediately following the declaration of the pandemic, not only of people living with dementia and caregivers, but also other self-identified stakeholders and the general public. These views are important given the social context of aging and stigma related to dementia (Oscar et al., 2017). Thus, the aim of this qualitative descriptive study was to understand the concerns related to the care of people living with dementia during the initial stages of the COVID-19 pandemic by identifying and analyzing tweets about dementia.

Methods

Data collection

Data were collected on 24 March 2020, using Twitter's Search Application Programming Interface (API) to identify tweets using the following search terms: Alzheimer, #Alzheimer, dementia, and #dementia. This was 1 week after the World Health Organization (WHO) declared COVID-19 a pandemic (11 March 2020) and identified Europe as the epicenter (13 March 2020). It was 3 weeks after lockdowns began in Italy and a few days after the declaration of a national emergency in the U.S. and the issuance of public health guidelines in the U.S. and U.K. (New York Times, 2021; The Guardian, 2020).

Use of the Twitter API search interface garners approximately 10% of available tweets including the search terms (Robertshaw & Babicova, 2021). Tweets were collected using NCapture (QSR International). For each tweet, the contents of the tweet and the date and time of posting were collected. The following information was collected from the Twitter profile of the account holder who posted the tweet: username, location, and "bio" (Twitter, 2017). Tweets were classified as "unknown location" if no location information was provided rather than using the content of the tweet to make an assumption regarding the location of the user.

Tweets were included in the sample if the content of the tweet included direct or indirect terms for COVID-19 or the pandemic, including words and phrases identified from the tweets in the sample

such as isolation, stay at home, "these difficult times," "unprecedented times," "important now more than ever", distancing, remote and virtual services or work in relation to COVID, and digital offerings of support and help.

Data analysis

Tweets and account holder data were imported into NVivo (version 12) for analysis. Demographic characteristics of account holders were established based on available information gleaned from Twitter bios or tweet content. For example, account holders were considered a caregiver if they self-identified as such and discussed having someone in their life whom they were either personally caring for or anticipated caring for during the pandemic, including those providing care remotely. These bios and tweet content were used to categorize Twitter users in the sample as either caregivers, people living with dementia, care workers, family members, researchers, service organizations, or the general public (i.e., no other discernible role in dementia care). For caregivers and professionals, no limits were placed on the type or amount of care provided. Dialogues specifically about formal health care and paid or professional care workers were categorized separately. In line with qualitative descriptive methodology as applied by Sandelowski (2010), the final sample of tweets ($n = 6938$) was viewed with a "factist" perspective (p. 80), regarding tweets as truthful accounts of reality.

Tweets were analyzed using an inductive thematic analysis approach following the steps identified by Braun and Clarke (2006; 2013). These steps included familiarization with the data by 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 (MB) conducted the initial analysis. After this initial analysis, codes and themes were discussed and refined with two other members of the research team (CT and JGA). This revised analysis was discussed with the remaining members of the research team and revisions were made where appropriate. Techniques to support qualitative rigor (Cohen & Crabtree, 2006) included the following: analyst triangulation (as described above), thick description of experiences, and triangulation of sources (i.e., including people with different viewpoints from various geographic locations). Exemplar tweets were chosen to illustrate the findings related to each theme via consensus among the research team.

Ethical considerations

Ethical guidelines for social media research suggest publicly accessible data can be used for research purposes without informed consent (British Psychological Society, 2017; Paulus & Wise, 2019). Social media data are generally considered to exist within the public domain, making it available for research (Paulus & Wise, 2019). Twitter's policies take a similar stance, allowing for the use of Twitter data for research (Twitter, 2018a; 2018b). The Institutional Review Board considered the study exempt because tweets were posted by public profiles within the public domain. Therefore, in this study, informed consent was not obtained. However, we recognize the use of directly quoted tweets can potentially make account holders identifiable and that it is good practice to paraphrase quotations to reduce the likelihood of users being identified via search engines (e.g., Talbot & Branley-Bell, 2021). Consequently, exemplar tweets presented in this paper are paraphrased to protect the anonymity of account holders. This approach is in alignment with Twitter's privacy policy and developer agreement requiring researchers to remove personally identifying information and to refrain from publishing original tweets (Twitter, 2018a; 2018b).

Results

A total of 36,337 tweets were collected, covering a period from March 17 to 24, 2020. Tweets written in a language other than English ($n = 7424$) and those with no content related to COVID-19 or the pandemic were excluded from analysis ($n = 21,975$). The final sample ($n = 6938$) consisted of tweets from users located in Europe ($n = 3597$), the Americas ($n = 1603$), Asia and the Pacific ($n = 67$), Africa ($n = 10$), and the Middle East ($n = 3$). Additionally, there were 1658 from users from unknown locations. The largest number of tweets were posted by users in the UK ($n = 3474$). The hashtag #dementia was more frequently used in tweets related to COVID-19 than #Alzheimer. Users included self-identified people living with dementia ($n = 416$), informal caregivers ($n = 2082$), family members ($n = 1318$), service organizations and agencies ($n = 1041$), researchers ($n = 486$), health care workers and facilities ($n = 901$), and the general public ($n = 694$).

Caregivers and family members of people living with dementia were tweeting COVID-related content throughout the sample period. Tweets from service organizations and agencies focused on supporting families caring for and people living with dementia did not appear in the sample until March 19 and 20, 2020. The number of tweets from these organizations and agencies increased over the course of the sample period. Five themes highlighting areas of concern were derived from the data: continuing care, finding support, preventing spread of COVID-19, maintaining human rights, and the impact of the pandemic on the daily lives of people living with dementia.

Continuing care

Caring for someone with dementia during the COVID pandemic was a major focus of tweets in the sample, including by those identifying themselves as caregivers; organizations, agencies, and health care systems serving caregivers; and people living with dementia. Tweets included suggestions for stimulation and activities during periods of increased isolation, such as music and sharing tips and information for those providing care for someone with dementia. Some tweets included links to infographics and resources from service organizations and public health entities focused on these care practices.

> If you are taking of someone with #dementia and you cannot go outside, I have tips to support you. #coronavirus

A key challenge faced by caregivers was the need for and lack of respite care during the early stages of the pandemic:

> Got through the first day of #CoronavirusLockdown. It's tough when you live with someone with dementia who can be a bit surly and you have no respite care.

Access to food, basic supplies (e.g., medications, toiletries), and the Internet was discussed frequently, particularly among caregivers and family members of those living with dementia:

> Shopping is kind of crazy. Supermarkets should consider a system like when boarding planes. Glad I had prepared meals in advanced for my mother with #dementia.

Helped set up grocery deliveries for my elderly parents because of isolation. But panic is setting in because there were no delivery times available for weeks. How will they be prioritized? Hard on my dad who is a dementia caregiver.

Caregivers also faced difficulties in obtaining the food preferred by family members living with dementia. More than just having enough food, it was clear the challenge of securing food to which family members with living dementia were accustomed, as well as making nutritious food choices, added another level of difficulty, particularly in response to "panic buying."

She wanted me to buy her favorite pastry and told me how she likes to eat these all over again. But I told her I'm not sure if I can get the pastries because of all of the panic buying going on. #dementia

Caregivers tweeted about the challenges of keeping themselves and the person living with dementia "isolated" or "distanced" during the pandemic, highlighting particularly the lack of clear information from governments and health professionals about how to approach this aspect of caregiving. This was especially true for those who did not live with the family member with dementia.

Mum can't understand #isolation because of her #dementia. Keeping her busy with tasks around the house so she'll keep occupied.

I am trying to follow public health guidelines, but it is so hard because I must visit my mum throughout the day to give her medications. I am her only caregiver. I love my mum, but she doesn't understand what is going on. #SOexhausted

Caregivers and family members turned to Twitter to seek advice on how to continue caring through the pandemic, including the added responsibility of explaining COVID to someone living with dementia. Indeed, users tweeted about the challenge of explaining the pandemic and associated restrictions (e.g., social distancing) to people who were confused by and repeatedly asked questions about the pandemic or public health guidelines, describing the emotional toll that accompanied being the "bearer of bad news", viewing public health guidelines as adding another layer of complexity to caregiving.

Every day all day she asks me about the #pandemic and I have to break the bad news all over again. #dementia

In response to this challenge, some users tweeted valuable sources of COVID-related information for caregivers and people living with dementia. Large service organizations and agencies tended to share more tweets about caregiving while allies, caregivers, and smaller organizations tended to share more information for peer support and how to explain COVID-related situations to people living with dementia. This information was shared in direct response to queries from caregivers, as well as in independent tweets from service organizations and agencies disseminating information.

Hello out there. If someone has some good tips for how to explain #COVID19 to a family member with #dementia, please let me know. Thanks!

Our organization has compiled a list of advice to support caregivers of folks with dementia during #COVID19. [link to tip sheet]

Finding support

People within the sample were using Twitter to seek support and/or describe their experiences of changes to support during the pandemic. For example, some tweets included mentions of virtual support groups to assist caregivers in the transition of caregiving services to a virtual environment while others offered something for free (such as an information hotline) to support caregivers or people living with dementia. Support services and activities for caregivers and people living with dementia referenced in tweets included Twitter- and blog-based social support from a likeminded community, virtual support groups, agencies providing care services and hotlines, organizations and individuals willing to deliver supplies through mutual aid, freely available resources and services, and those agencies and individuals willing to check in on people living with dementia. Caregivers shared instances of supporting each other and neighbors when no other formal support was available.

> One of my coworkers who kind of lives in the area just volunteered to drop of some things from the pharmacy for a woman we support who can't leave home because her husband is high risk. We can all make a difference. #dementia #COVID19

The Alzheimer's Society in the U.K. posted Twitter threads asking people living with dementia and caregivers about their needs. It was unclear whether this organization and others like it planned to continue this Twitter-based outreach throughout the pandemic. The largest number of tweets subsumed under this theme was posted by users in the U.K., particularly those offering direct support and hotlines during periods of distancing for caregivers and people living with dementia, as in this exemplar tweet:

> We want to support you during COVID. Let us know new ways of helping you take care of your family member with #dementia through Facebook, Twitter, or video call.

Several health care workers shared their perspectives of the impact of the pandemic on their ability to support families and people living with dementia. The struggles of care workers were well documented. These tweets highlighted the challenges care workers faced in doing their jobs safely and effectively during the pandemic, particularly as facilities dealt with fewer resources and decreased financial support.

> My spouse cares for older people, some with dementia. She's borrowing supplies from friends because she can't get any at work. She's so afraid of getting COVID because of the danger to the people she cares for if they get it

Preventing spread of COVID-19

Tweets within the sample included individuals expressing concerns of spreading COVID-19 to people living with dementia. Most often these tweets came from self-identified caregivers and family members of people living with dementia, but occasionally from the general public as well. Tweets included queries from caregivers about what other families were doing during the pandemic to keep people living with dementia safe from COVID. Tweets frequently included links to infographics and informative resources from public health authorities and dementia service organizations focused on prevention of COVID-19 and information about the virus. The tweets often centered around the need

for, and failure of the wider population to, isolate and distance to protect vulnerable older populations:

> People aren't paying attention. There are so many cases in the country. What's happening in Italy and Spain should care us! I pray that my family and mom with Alzheimer's stays safe. I hope we all do.

There also was a trend of people sharing information and concern about a family member or friend who either was living with dementia at home and was vulnerable or was living in a nursing home, as well as for the care workers of people with living with dementia. These account holders shared personal stories on Twitter about people living with dementia, expressing fears of them contracting COVID-19 and urging others to follow safety procedures, often using the government's public health catchphrases such as "stay home to stop the spread."

> My nan with dementia doesn't understand why she's stuck in the nursing home and why we can't visit. She's alone all day and isn't doing activities anymore. It's heartbreaking. Stay home to protect her please.

Maintaining human rights

Tweets from users in the U.K. and U.S. included discussions related to the human rights of people living with dementia and their access to care (including ventilators) in the event of a life-threatening COVID-19 infection. However, this discussion was most prevalent among users in the U.S. in response to social and political rhetoric about "sacrificing the weak" for the economy. Some family members and caregivers of people living with dementia expressed feeling as if the government was choosing the economy over humanity. For example, one person tweeted the following:

> My mother lives in care and has Alzheimer's. Her life matters and she would tell you if she could. Life is more important than money. To hell with leaders who want to sacrifice people for political gain.

While there were ethical considerations being discussed in other countries, such as ventilator use and social care practices in the U.K., users in the U.S. seemed specifically to focus on balancing the dignity and value of people living with dementia against the worth of the economy. Many tweets from U.S. users reflected a concern for the right to life and dignity of vulnerable populations within the context of the U.S. political climate. Most of these tweets were not explicit statements from people living with dementia. Rather, caregivers and the general public were expressing for, and on behalf of, people living with dementia.

> They've told me my dad with dementia has a fever. They're asking about DNR orders before doing a test and do I want him at the hospital or care home. This is so hard.

> My grandma is over 90, has dementia, and lives in a nursing home. She's so polite and nice. But if you wanted her to die for the economy, I hope she'd tell you to go to hell.

The impact of the pandemic on the daily lives of people living with dementia

Twitter users posted tweets describing the reactions and behaviors of their family members or friends living with dementia during the pandemic. These tweets seemed to be mainly from caregivers, family members, or health care workers and the reactions or behaviors were varied. Some tweeted

that the pandemic seemed to increase the frequency and/or severity of behavioral and psychological responses to distress:

> My nan has been in lockdown for a week. She may not know where she is or who we are, but she remembers that we go to the café after she's dressed. She had a bit of a meltdown today when we reminded her that we can't go out. #dementia

In contrast, some caregivers tweeted that the person living with dementia was unaware of the pandemic and expressed gratitude for this lack of awareness.

Maybe my mother is lucky during quarantine because she won't know why. She lives in the moment and time is lost to her. She doesn't remember my last visit or her husband. She doesn't worry about what is on the news. #dementia

Tweets included comments about the impact of isolation and distancing on people living with dementia. This was discussed in relation to social distancing measures at care homes or nursing facilities, with account holders describing alternative ways of visiting family members such as getting to see them through windows. However, for some, this same activity was viewed negatively because it limited physical contact and made things more difficult for people living with dementia by increasing isolation and limiting social engagement. Many expressed their worry that their family member with dementia would forget them during the separation of social isolation.

> Mum has #dementia and lives in a care home and can't understand all of the extra cleaning and visitor restrictions. She's really upset and explanations or trying to distract isn't working. We'll Skype later to see if that calms her down.

> I went to my father's window and said his name.

> Me: Look out the window!

> Dad: *looks out window* Hi! I see you!

> Me: It's so good to see you!

> We had a good visit. #COVID #dementia

In terms of people living with dementia sharing their experiences in response to COVID, many spoke of altering plans to remain socially engaged during isolation. Tweets from people living with dementia were all related to this particular theme rather than any of the others derived from the analysis. Owing to the fact that these Twitter users living with dementia had a certain level of comfort with digital technology, many spoke of virtual support either through formal groups, Twitter chats, or spontaneous invitations for virtual coffee or tea breaks with each other. This was particularly true of those people living with dementia involved with patient and public advocacy.

> Now that things are cancelled and I can't travel, I've lost a lot of the stimulation that keeps my brain active and slows the dementia. But I'm determined. So if you'd like to meet online for a virtual cup of coffee, join me!

Discussion

The aim of this qualitative descriptive study was to understand the concerns related to the care of people living with dementia during the initial stages of the COVID-19 pandemic. We analyzed tweets from March 2020 and identified five themes: continuing care, finding support, preventing spread of COVID-19, maintaining human rights, and the impact of the pandemic on the daily lives of people living with dementia.

Family caregivers provide the majority of care for people living with dementia. During the COVID-19 pandemic and as a result of public health guidelines for social distancing, self-isolation, and sheltering in place, these caregivers have faced challenges in accessing formal health and social services and respite care, as well as reductions in the informal support provided by family and friends (Giebel et al., 2021; Greenberg et al., 2020; Savla et al., 2020). These challenges are in line with sentiments expressed by the caregivers in the current sample as caring for someone living with dementia was a major focus of tweets in the sample. A lot of this challenge in care was in response to public health guidelines, both in terms of gaining support and performing caregiving duties, as well as the challenges of helping the person they cared for understand the situation imposed by the COVID-19 pandemic. Caregivers in a study by Giebel and colleagues (2021) described how those family members living with dementia for whom they provided care only partially understood or did not understand at all the various public health guidelines, particularly during the beginning of the pandemic. Caregivers also faced challenges in response to reductions in the informal support provided by family and friends. Even during the initial stages of the pandemic, family members and friends who may have provided assistance with caregiving tasks decreased visits and support out of fear of exposing people living with dementia to the virus. Public health guidelines also made it difficult for community and service organizations to provide traditional services and community outreach (Giebel et al., 2021; Williamson et al., 2020).

Previous research has described how people living with dementia and their caregivers use social media platforms to garner support (Anderson et al., 2017; Talbot et al., 2020b; Talbot et al., 2021), and this was also evident during the early stages of the pandemic. Support during the pandemic was a key theme among tweets, but the timing of those tweets varied across different types of users. For example, while caregivers and people living with dementia were discussing the impact of the pandemic on their daily lives and highlighting reduced access to care and services from the very beginning, service organizations and providers were slow to acknowledge and respond to these needs. By the end of the data collection period, however, more tweets from these organizations began to appear. This illustrates a potential gap on the part of these organizations to promptly recognize and respond to the needs created by the pandemic (Giebel et al., 2021), as well as an opportunity to understand how those living with dementia and those managing their care use social media as a resource for self-management, social support, and caregiving (Anderson et al., 2017; Anderson et al., 2019; Talbot et al., 2020b), as well as how social media can be used as to inform interventional support (Friedman et al., 2016; Yoon et al., 2020).

The Internet has fostered the emergence of a community of people living with dementia and their caregivers unbound by geographical location and congruent with Wellman's (2001) definition as "networks of interpersonal ties that provide sociability, support, information, [and] a sense of belonging and social identity" (p. 228). Consistent with previous research, Twitter was providing a space for stakeholders to connect to those going through similar experiences (Høybye et al., 2005) and, as a result, may have increased social support and feelings of connectedness (Idriss et al., 2009; Wangberg et al., 2008). Future research using qualitative methods could focus on understanding the pros and cons of using social media in this way during a pandemic.

Twitter and other social media platforms represent valuable spaces for the dissemination of information related to dementia care and support (Cheng et al., 2018). This is important given that people living with dementia and family caregivers use social media as a tool to gather information for support and self-management (Anderson et al., 2017; Talbot et al., 2020b), as in the current study. Participation in these online conservations provides an opportunity for health care providers, researchers, and service organizations to identify community-level issues to target with tailored interventions and services (Sewalk et al., 2018).

The vulnerability of people living with dementia to COVID-19 and advocacy on their behalf in terms of dignity and human rights was a topic of tweets from caregivers, family members, and the general public. People living with dementia experience increased vulnerability to COVID-19 given their age, increased levels of frailty, and comorbidities often associated with dementia (e.g., cardiovascular disease, hypertension, or diabetes) that may increase the risk of COVID-related complications (Azarpazhooh et al., 2020; Brown et al., 2020; Centers for Disease Control & Prevention, 2020). Public health guidelines promoting social isolation may exacerbate the risk of hospitalization and mortality for people living with dementia; limited interactions with caregivers (formal or informal) may increase risks of depression and adverse events that could occur during periods of limited support (e.g., falls, aspiration related pneumonia) (Azarpazhooh et al., 2020). Cognitive impairment may foster challenges carrying out or understanding protocols related to mask wearing, hand washing, and physical distancing (Giebel et al., 2021; Vaitheswaran et al., 2020; Wang et al., 2020). Future research could explore how social media serve as a way to provide educational materials and support to families caring for someone living with dementia to overcome these hurdles. The variety and adaptability of social media platforms provides multiple options for health care and service organizations to present and disseminate reputable information. This feature of customization is highly congruent with principles that underpin the successful translation of knowledge (Graham et al., 2006).

Dignity and dignifying care are of high importance to people living with dementia and their family caregivers (Anderson et al., 2021). In contrast to findings from others (Bacsu et al., 2021), the concept of maintaining the human rights of people living with dementia was a theme within our sample. While many Twitter users in the present sample were advocating for the attributed dignity for people living with dementia, some seemed to be more concerned with social care functions and rights to COVID-related care (e.g., ventilators), particularly among users in the U.S. where responses to a public health emergency were highly politicized (Halpern, 2020). This politicization of COVID has effects on those living with dementia and their families, who were faced with the task of defending the rights of people living with dementia to COVID-related care while simultaneously navigating the increasingly difficult impact of the pandemic. Among U.S.-based tweets in particular, there was an overarching sense of users trying to protect those living with dementia from the virus and from societal/political pressures meant to detach people living with dementia from the rest of society because of their age or physical conditions. This advocacy may be in response to continued stigmatizing language associated with dementia on social media platforms (Cheng et al., 2018; Oscar et al., 2017; Robertshaw & Babicova, 2021) and the perception among society of those living with dementia lacking value within society itself (Anderson et al., 2021; Heggestad et al., 2013). Social media offers health care providers, researchers, and service organizations platforms to disseminate education and reputable information to combat stigma in an effort to support the dignity and human rights of people living with dementia (Cheng et al., 2018). Future research could explore how these platforms may be successfully used for targeted messaging campaigns and the impact of these campaigns on perceived stigma experienced by caregivers and people living with dementia (Friedman et al., 2016; Low & Purwaningrum, 2020).

The COVID-19 pandemic highlighted the need for social policy reform as allies advocated for dementia charities and organizations to have financial support during times of crisis as well as paid leave for caregivers of people living with dementia. Additionally, this analysis identified that while government officials often discussed the need for basic supplies like food, toiletries, and medicines to be prioritized for vulnerable populations, there were problems in the roll out of this process. Stakeholders took notice of this inefficiency and were quick to share their concerns about this on Twitter. Moving forward, it will be important for governments to coordinate with vulnerable people themselves to identify the most effective ways to prioritize people and distribute supplies and services.

Twitter users in our sample, particularly caregivers and family members of those living with dementia, shared their fears and experiences of the impact of the pandemic on the daily lives of people living with dementia, particularly in regard to the cognitive function and behavioral symptoms of distress. Our findings are similar to those of others who reported how the inability to comprehend public health restrictions left many people living with dementia frustrated and agitated, leading to an increase in caregiver stress (Giebel et al., 2021). Those Twitter users living with dementia shared similar stories and concerns, which subsumed the sample of tweets posted by people living with dementia themselves. This mirrors research findings showing that people living with dementia and their caregivers reported decreasing cognitive function because of the isolation and lack of cognitive stimulation during the pandemic (Canevelli et al., 2020; Giebel et al., 2020a; Talbot & Briggs, 2021) and the negative impact on the daily lives of those living with dementia (Giebel et al., 2021). The longitudinal effects of the pandemic on people living with dementia, caregivers, and other stakeholders requires a centering of their voices, particularly the voices of those living with dementia. Our findings suggest that Twitter may provide one useful avenue of accessing these voices when making decisions regarding allocation of services and resources.

While this analysis identified many similarities in the needs and concerns across stakeholders, including caregivers and people living with dementia, individual situations were unique and differed by geography (e.g., U.S. versus U.K.) and caregiving situation (e.g., caring from a distance). These unique needs could be aided by an increase in individualized dementia caregiving guidance and counseling during periods of increased distress, during the pandemic and beyond (Giebel et al., 2021). Additionally, as society continues to navigate the pandemic and beyond, organizations may consider continuing to offer hotlines and virtual support services to caregivers and people living with dementia. For example, the AARP and many local and state departments of aging launched additional outreach services to connect with older adults and to answer questions and concerns regarding the COVID-19 pandemic and the ever-changing CDC guidelines (Angel & Mudrazija, 2020; Hedges, 2020). Such services with a specific focus on providing information to caregivers and people living with dementia beyond the general information for older adults would go a long way toward addressing the needs identified in our analysis as well as those of others (Giebel et al., 2021). Ensuring adequate supplies and services to meet the needs of people living with dementia and their families during times of crisis is crucial. Service providers need to keep tweeting support and tips. Moreover, there is a clear need to ask caregivers consistently, both on and off Twitter, about what they need during the pandemic instead of assuming all necessary information has been provided. Caregivers and people living with dementia should be regarded as the experts of their needs and the organizations as the facilitators for help.

The present study does have several limitations that must be acknowledged. Only about 10% of tweets including the search terms were retrievable given the limitation of using the Twitter API search function to collect the data. Therefore, other themes and topics of importance to dementia stakeholders may have been missed. However, our findings are in line with those of others exploring

the impact of COVID-19 on people living with dementia and their caregivers (Bacsu et al., 2021; Talbot & Briggs, 2021). We only analyzed those tweets written in English, which excluded tweets from users identified as living in countries like Spain and Italy that were already under strict lockdown during the time of data collection (i.e., March 2020). This approach also does not take into account the disproportionate impact of the pandemic on culturally and ethnically diverse groups who might tweet using a language other than English, as well as those in developing nations. Future analyses with multi-lingual teams would broaden our understanding of the experiences of these diverse individuals. The sample represents only 1 week during the beginning of the pandemic. Longitudinal data collected over the course of the pandemic would offer insight into whether the needs and experiences of people living with dementia, caregivers, and other stakeholders varied over time.

Not all people use social media and, among social media users, not everyone uses Twitter. While one in five adults in the U.S. uses Twitter, only 31% of those age 50 years and older do so (Greenwood et al., 2016). Older adults are more likely to use YouTube and Facebook (Smith & Anderson, 2018), representing another potential data source to understand the impact of the pandemic on families living with dementia. Additionally, only 14% of adults were likely to share opinions online, which could be related to stress about backlash and potential loss of social support (Hampton et al., 2014). Conversational tweets or threads were not included in the analysis. Conversations are an integral aspect of Twitter and it is likely these conversations contain important information about how caregivers, people living with dementia, and other stakeholders are navigating the pandemic. Similarly, the 280-character threshold on Twitter may limit the ability of users to express their experiences fully. In-depth interviews with people living with dementia and their caregivers would provide a more rich and comprehensive understanding of the impact of the COVID-19 pandemic on this population. It is difficult to know how many "lurkers" may have been observing the discussion on Twitter without participating, which prevents the inclusion of their ideas (Moorley & Chinn, 2014). Finally, people may use different identities and personas on social media. Given the nature of social media, it is not possible to verify the identities of the users in the present sample.

Despite these limitations, the present study has multiple strengths. Because social media users are writing in the moment, there is a lack of recall bias that can come with traditional research methods such as interviews, focus groups, or surveys. The data obtained using these more traditional methods are based on predefined questions that might influence or bias the answers provided. By contrast, social media data represent the major concerns of stakeholders "in the moment," offering a novel, person-centered insight into their experiences. Given that social media platforms such as Twitter are used by a racially and ethnically diverse population of users (Greenwood et al., 2016), a wide range of stakeholders' perspectives can be identified from the data, significantly extending our understanding of the needs of those living with dementia. Additionally, examination of attitudes and perceptions of the general public with regard to dementia and the COVID-19 pandemic broadens comprehension of the social context of aging, particularly as it relates to dementia, advocacy, and stigma.

Perhaps most importantly, the present study demonstrates how social media data can be used to generate discussion on topics of relevance to current practice and the future of health care. While adults may be less likely to share a controversial opinion online, they are more likely to share online versus in person (Hampton et al., 2014), emphasizing the utility and equity of Twitter-based discussions in including a diverse range of individuals (Richardson et al., 2016). Analyses of social media data, particularly Twitter data, are increasing among health sciences researchers in an effort to understand health-related topics and attitudes toward behaviors and diseases, providing insight into

the illness experience (Wakamiya et al., 2019a, 2019b; Hendriks et al., 2018; Kolliakou et al., 2016), and given rise to what has been termed infodemiology (Eysenbach, 2009). Moreover, tweets provide a rich data source given the numerous data elements of each tweet (e.g., content, time, and geo-location), creating a unique insight into a health-related topic (Sinnenberg et al., 2016; 2017).

This study provides a rich description of the perspectives and experiences of dementia and caregiving at the beginning of the COVID-19 pandemic. The pandemic placed a spotlight on the inefficiencies and breaking points in social care systems; this was particularly true regarding the vulnerability and needs of those living with dementia. Throughout the COVID-19 pandemic and beyond, the voices of those living with dementia and their caregivers are essential for informing researchers, health care providers, and policy makers as to the best ways of supporting these individuals. The use of social media provides a window into the world of those living with and caring for someone living with dementia, highlighting significant gaps in services and care and aiding in the identification of targets for intervention development, practice change, and policy.

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Dr. Ruth Palan Lopez is the Jacques Mohr Endowed Professor in Gerontological Nursing, the Associate Dean for Research, and the Director of the Office of Nursing Research and Scholarship at the MGH Institute of Health Professions in Boston, MA, USA. Her research focuses on care of people with dementia and their family caregivers.

Dr. Karen M. Rose is Professor and Director of the Center for Healthy Aging, Self-Management, and Complex Care in the College of Nursing at the Ohio State University in Columbus, OH, USA. Her research focuses on technology use for persons with dementia and their family caregivers, with a special emphasis on the unique needs of underserved and vulnerable (older adults and family caregivers.

Dr. Joel G. Anderson is an associate professor in the College of Nursing at the University of Tennessee, Knoxville, USA. His research program aims to support family caregivers of people with Alzheimer's disease and dementia, particularly marginalized caregiver populations such as LGBTQ+ (lesbian, gay, bisexual, transgender, and queer [or questioning] and others) caregivers. He also studies how caregivers use social media and technology as part of the caregiving experience.