Roles in the Discussion: An Analysis of Social Support in an Online Forum for People with Dementia

JAZETTE JOHNSON, University of California - Irvine, USA

REBECCA W. BLACK, University of California - Irvine, USA

GILLIAN R. HAYES, University of California - Irvine, USA

Social computing provides a variety of challenges and opportunities for people who are experiencing cognitive decline. Following a recent diagnosis of dementia, older adults sometimes engage in online communities designated for people with dementia. In this work, we analyzed all original posts from a seven-year period on a forum for persons with dementia to understand 1) who posts in this forum and 2) what kinds of social support posters seek to gain from this engagement. Our analyses indicate that, in addition to people with dementia, a variety of dementia-related stakeholders create original posts in this forum. Our results suggest that seeking and offering social support are key activities for all forum users, not just those with dementia for whom the forum was designated. Given these findings, we offer design implications for online spaces for vulnerable communities, with a focus on design that allows for external stakeholder participation while still maintaining the privacy and safety of vulnerable members of the community.

CCS Concepts: • **Human-centered computing** → **Collaborative and social computing design and evaluation methods**;

Additional Key Words and Phrases: Dementia, Alzheimer's, social support, online communities, discussion forum, emotional support, information support, companionship, network support

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1 INTRODUCTION

Dementia diagnoses have been steadily increasing, a trend that is predicted to continue through the year 2050 [2]. As a result, many individuals will begin navigating the “new normal” of trying to continue establishing independence while also trying to understand their experiences and progression through dementia. During this navigation period, social connectedness is an important part of staying and aging well [43]. Once a person is diagnosed with dementia, they may be hesitant to disclose their diagnosis to family or friends due to the fear of losing strong social connections with these individuals related to concerns about becoming a burden or the awareness of other stigmas surrounding the dementia diagnosis. People with dementia (PWD), especially when living alone, are at a high risk of becoming socially isolated due to mobility issues (e.g., not being able to attend community or social events because they are no longer driving), lack of community

Authors' addresses: Jazette Johnson, jazettej@uci.edu, University of California - Irvine, Irvine, California, USA; Rebecca W. Black, rwblack@ics.uci.edu, University of California - Irvine, Irvine, USA; Gillian R. Hayes, gillianrh@ics.uci.edu, University of California - Irvine, Irvine, California, USA.

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engagement (e.g., they may live in areas, such as rural communities, where dementia awareness or social events are rare), and social disconnection (e.g., they do not have continuous engagement with friends or family) [30, 37, 48]. The Covid-19 global pandemic only further emphasizes the challenges that someone living with dementia might experience in reaching for socialization, particularly if they or their peer group have other conditions that put them at high risk. Despite this reality for many people with dementia (PWD), we can combat social isolation through an emphasis on social connectedness for PWD and a variety of other chronic illnesses through interactive technologies like online discussion forums. Such online communities allow people with similar interests, experiences, and medical concerns to share and gain new knowledge, while also building a community [25–27, 44, 72]. However, much research still needs to be done to understand how developers can create safe, inclusive online communities for vulnerable populations, such as those with dementia, cancer, mental illnesses, and other chronic illnesses. Each of these communities have unique needs and norms that should be addressed in the design of online tools to support them.

Research in CSCW has focused on protecting individuals from vulnerable communities through implicit and explicit conversations of safe spaces online [3, 40, 63]. Safe online spaces that encourage respectful engagement within the community can allow individuals of marginalized backgrounds to share experiences with like individuals. Without such spaces, vulnerable people can be susceptible to bullying, misinformation, exclusion, and other cybercrimes [45, 63]. Safe spaces in the dementia community can be increasingly important as PWD transition into a stage of life with dementia, as they may experience various challenges navigating the “new normal.” Current research primarily has explored online communities of caregivers of PWD (e.g., [18, 56]). However, limited research has been dedicated to the experiences of PWD themselves in online communities [41, 42].

In this work, we draw from conceptual models of social support that researchers ([52, 75, 82]) identified in online discussion forums for cancer patients, to analyze an online discussion forum for people with dementia (PWD). The framework we have adopted includes three main categories: emotional support, informational support, and companionship support also known as network support. We focus on understanding who initiates interaction on the site and why, who is seeking and who is providing support, and how these forms of support are expressed. Based on our findings, we propose a design model for online discussion communities for vulnerable communities. The design model highlights the need for the creation of a safe space while still allowing people outside of the community to learn and interact without intruding on the safety and privacy of vulnerable members. We analyze posts from an online forum designed for older adults with dementia to understand 1) who posts in this forum, and 2) what kinds of social support posters seek to gain from this engagement.

2 RELATED WORK

There is an ever-growing body of literature focused on social support for vulnerable communities, assistive technology for people with dementia, and online discussion forums for vulnerable populations. In this work, we draw from each of these areas to inform our theoretical and conceptual understandings of social support, accessibility, and vulnerability in our methods, analysis, and subsequent implications for design. Notably, we do not review existing forums for people with dementia in this section. There are a limited number of such forums and identifying them could lead to an additional risk for posters to be identified, even with the other safeguards we have put in place to protect anonymity.

2.1 Social Support in Online Health Communities

Research on online health communities related to dementia has predominantly focused on social support for caregivers of persons with dementia [18, 56]. However, there has been little work that explores support forums for persons with dementia (PWD¹) themselves. We can take some lessons, however, from online health communities for other chronic conditions, such as cancer and HIV/AIDS, which have been more widely researched [19]. Studies in this domain point to the utility of community forums as spaces through which patients can benefit from a variety of social and health information-related support, such as sharing one's own experience or ways of coping [51, 81]. Additionally, studies in this space indicate that those coping with chronic illnesses can be substantially supported through online communities in terms of "finding information, feeling supported, maintaining relationships with others, affecting behavior, and experiencing health services" as well as through more novel experiences, such as "learning to tell the story and visualizing disease" [84].

Drawing from this work, we sought to understand the experiences of people with dementia explicitly and how those experiences might align or diverge from existing literature in other domains. Although a wide variety of approaches have been taken to exploring how online interactions impact patients in other health domains, we chose in this work to adopt a single framework to simplify and clarify analysis. This framework of social support has been used by various researchers, such as Wang [74], Winefield [81], and Mo [51] in their work on online social communities for people with cancer [74, 81] and HIV [51]. This framework well aligns with notions of phases of illness and informational approaches that have been explored in relation to technical approaches for supporting cancer care [31, 71] and chronic pain management [83].

In their work, Winefield et al. [81] focused on understanding the relationship between the level of a person's involvement in an online support group and the amount and type of support received (i.e., does the number of posts a person makes correlate to the types of support that is given or received?). The researchers analyzed messages, in the form of emails, between women with breast cancer to categorize the role and the types of social support received through their interactions. Winefield, much like Wang and Mo, employed a framework of social support that is "commonly identified by theorists" [81], that includes emotional support, informational support, and practical assistance. However, because the analysis was conducted online with participants across Australia, Winefield et al. did not use practical assistance in their categorization, which was inapplicable for people at long distances common to Australia. Results demonstrate that about 94% of the participants were low frequency users who, not surprisingly, sent fewer messages than high frequency users. In this work, however, there were two participants who sent messages at a higher frequency, and that these high frequency users voluntarily provided more support than they sought [81].

Wang's research involved using machine learning algorithms to analyze forms of social support embedded in posts from breast cancer survivors in an online health community called breast-cancer.org. The researchers built classification models to detect forms of social support in the posts. Similar to Winefield, Wang's [74] framework of social support includes emotional support and informational support. However, Wang also incorporates companionship support, also known as network support. Companionship support is defined as discussion and humor that is unrelated to the disease. The results showed that various types of social support aligned with the level of involvement on the forum. For instance, breast cancer survivors who were engaged in companionship or seeking emotional support had a higher level of engagement than survivors who sought or provided informational support.

¹For this paper we are grouping persons with mild cognitive impairments (MCI) with the category of persons with dementia because the symptoms can be similar to and in some cases may be a signifier of early stage Alzheimer's disease [1]

In addition to the social support framework used by Wang et al., Mo et al. [51] explored two other social support components, including tangible assistance (e.g., fundraising or bringing meals) and esteem support (e.g., messages that promote one's talents, skills, or inherent value). Using these five forms of social support, Mo et al. explored how social support is exchanged in an online support group for people coping with HIV/AIDS. Through content analysis of 1,138 messages, the researchers found that many of the posts provided more informational support (446 posts) than emotional support (369 posts). There were significantly fewer messages exchanging tangible assistance (10 posts). These results provide further evidence that informational and emotional support are types of exchanges that are commonly sought and provided by individuals who are coping with chronic diseases. Although not health-related, Ringland et al. [63], explored how parents constructed a safe online space for children with autism in a game called Autcraft. This positive and supportive gaming environment provides a space for children with autism to play games and interact with lower risk of discrimination or bullying, which provides insight into the larger questions of what online safety might look like for vulnerable populations, such as those with dementia. The design of Autcraft allows parents to set up rules and guidelines to allow their children's virtual gaming experience to be safe based on their unique personal conception of what safety looks like for their child [63]. Ringland et al. found that there were distinct conceptualizations of what a safe space meant for different parents; however, there were commonalities in that parents perceived risks to their children's safety across emotional, physical, and social domains. Ringland et al.'s work shows a parent/caregiver-moderated and centered approach to creating a safe space, but this construct of safety would be different for persons with dementia (PWD), as they are adults rather than children.

Taken together, these results indicate that emotional and informational support impact the experiences and health of people with serious diseases in online health forums. We build on these insights in this work by explicitly examining who might benefit from these engagements, including but also beyond those for whom the forums are designated for (i.e., patients). Specifically, we adopt the social support framework used by Winefield and Wang to further understand who is seeking and providing social support, what types of support are offered, and how different participant groups engage in support seeking and provision.

2.2 Older Communities Online

There has been exciting growth in the production of content and participation in online communities and social media by older adults over the last several years. As a generation of adults used to engaging with computers and smartphones in both their work and personal lives age into the "elderly" population, we anticipate this kind of use will only grow. Most older adults do not have dementia; therefore, much of this work has been focused on broader groups. For example, Brewer and Piper described older adult bloggers [5], noting that participation in online content creation supports development—and redevelopment—of identities in older adulthood, as well as providing social engagement and avenues for self-expression. Notably, these bloggers also understood the online space to be a community that can support wellness in later life. Waycott et al. explored custom content creation software, through iPad usage by people 71-92 years old, finding similar results to the positive engagement from content creation through blogging [76]. Likewise, Rogers et al took it even a step further in terms of physical "making" beyond digital content creation [64]. It would be impossible to fully review the space of technologies for healthy older adults in the space of this article. Indeed, other excellent reviews on the subject already exist (e.g., [15, 20]). However, what we find notable here is the emphasis on empowerment through engagement and content creation, a theme that continues to be important as we examine such technologies specifically for people with dementia and cognitive impairments.

Although work in online communities for PWD has been limited, there has been research exploring online communities for caregivers of PWD. Responding to a lack of information on how caregivers should care for someone with dementia while at the same time caring for themselves, Pagán-Ortiz et al. designed and evaluated a bilingual website for Hispanic families. *Cuidate Cuidador*, which translates to “Caregivers, take care of yourself,” and seeks to increase caregivers’ knowledge of dementia, increase their perceived social support, and decrease the burdens experienced by these caregivers. In this study, researchers evaluated three concepts associated with caregiver’s perceptions of the website features, such as appeal, usability, and effective communication. The results indicated that users found the website to be user-friendly and easy to navigate. Results also suggest that use of the *Cuidate Cuidador* website may be associated with a higher sense of self-efficacy and less isolation for caregivers [56]. Within the same realm of increasing social support of informal caregivers of PWD, Dam et al evaluated a social support platform in the Netherlands called “Inlife” which was designed to improve information sharing and positive interactions in informal online spaces. Similar to the Pagán-Ortiz et al. study, Dam found positive impacts from website use, such as increased openness, empowerment, and involvement for caregivers [18].

Research also suggests that caregivers do immense work supporting people with dementia through co-work in such forums. For example, Piper et al found that caregivers must take on new levels of technological competencies and place themselves and those for whom they care at different risk levels using online supports [61].

Research related to online communities for PWD has become increasingly relevant in the CSCW domain. Lazar et al. [40], observed and interviewed people with dementia who were diarists on *Dementia Diaries*, a British online platform that allows people with dementia to share audio recording of their experiences. Lazar et al. aimed to understand the goals of these individuals when recording. They found that the goals of PWD included sharing “real and raw” experiences of PWD, changing attitudes towards the disease, and creating a safe space, but it also was apparent that many of these goals were in conflict sometimes [40].

Our study builds on and expands these research findings by applying a framework of types of support for relatively homogenous groups (people with cancer or HIV) to a heterogeneous grouping of both caregivers and PWD to understand how such a heterogeneous grouping may inform our notions of support, accessibility, and vulnerability for PWD in online spaces. To do this, we begin by detailing which types of users seek out and provide which types of support through original posts. We also attend to the possibility for new forms of interaction in this heterogeneous grouping of caregivers and PWD. In traditional online discussion forums, there exists a moderator to control the flow of information, but in our analysis, we found other roles and different types of people requesting and offering varying degrees of support. Our findings suggest that having a heterogeneous grouping in forums for PWD can lead to conversations that may be beneficial for PWD in some indirect way, however, such a grouping also poses some risks to this vulnerable population.

2.3 Technologies for PWD

Although this paper focuses on online health communities specifically, it is useful to understand these platforms within the broader context of technologies designed for people with dementia. Research on assistive technology for PWD have traditionally focused on technology that could assist in improving quality of life through a variety of approaches, such as robotic companions [10, 36, 70?], technologies to increase cognitive function [70], and reminiscent technologies [42].

Many robotic companions have been designed as animals such as a baby seal, *Paro* [10, 11], and realistic dog, *Aibo* [36], with the aim of improving social interactions and reducing social isolation. Chang et al, conducted an eight-week group study to analyze the impact *Paro* had on not just the

cognitive improvement, but also how Paro plays a part in social, environmental, and behavioral aspects of older adults with cognitive impairments. The researchers found an increase in verbal and physical interactions with Paro as a result of the participants interacting with Paro during a group session where a therapist passed the robot around to each participant to encourage engagement. Though positive effects were noticed during the group sessions, the therapist mentioned that there was no conclusive evidence that suggests a positive impact on participants overall because impact largely “depends on the mood of the individual” [11].

Researchers have also explored using humanoid robots as a way to increase cognitive function through games and music therapy [70]. Tapus et al. explored the increase of cognitive attention in aims of slowing the decline of people with mild cognitive impairment (MCI) or Alzheimer’s through playing cognitive simulation games. In this paper, the researchers also present a robotic system that alters the games’ difficulty level based on the player’s game history. The robot encouraged the participants to respond to questions as well as provided hints if needed by the participant. The results of the first six-month study to understand how people with dementia interact with both the game and the robot showed a positive effect, with all participants wanting the simulation game and robot to be an ongoing part of their weekly schedule.

The use of information and communication technologies (ICT) in terms of assistive technology has shown promising results in Europe via the COGKNOW system. This system assists persons with mild dementia to perform day to day activities. COGKNOW can be pre-programmed with familiar voices and uses touch screen capability to facilitate phone calls, but otherwise does not focus specifically on facilitating contact between persons [54]. Researchers also have explored engaging PWD and families in intergenerational learning using information and communication technologies (ICT) to share digital media [78] to promote connections between PWD and young people. A wide variety of human-computer interaction (HCI) research has focused on supporting people with dementia, including developing methods for co-designing new technologies [41, 42, 55], designing technology to assist in walking [32], and improving security online [49] due to high risk of attacks.

Despite numerous successes in the research space in terms of efficacy of technological approaches to support people with dementia, there has remained limited uptake of technology by PWD more broadly. Some of this may be an issue of familiarity, with online interactions being riskier and newer. However, a world that follows the Covid-19 global pandemic may well be one in which online interactions are more familiar and considered safer, an issue for the community to watch. Some of the challenges in this domain relate to approaches taken in engaging older adults in design in the first place. Morrissey et al note that such failures around issues of trust and exclusion can contribute to feelings of dementia “unfriendliness” in online platforms [52]. Others have likewise called for greater inclusion, respect, and engagement with the elderly community in design (e.g., [21, 39, 64]), an approach we applaud and recognize here.

Taken together, this body of work represents a variety of approaches to and perspectives on how technology can play an increasingly important role in providing support to and increasing the quality of life for individuals, such as PWD, who are struggling with chronic illnesses that impact their ability to safely participate in many social settings.

3 METHODS

The research team used a combination of deductive and inductive qualitative coding of original posts from an online discussion forum intended for people with dementia (PWD) and mild cognitive impairment (MCI) of any age, ethnicity, or gender. Data collection yielded 186 posts posted over approximately a seven-year period (July 11, 2012 to July 1, 2019). Data include the original post, the date the post was made, the posting history of the poster’s account (including total number

of original posts and comments), and date that the poster joined the forum. No other profile data was collected. All profile data were deidentified immediately upon collection, and no personally identifiable data were stored. In addition to analyzing only anonymous and deidentified data, the research team confirmed that the terms and conditions of the forum allowed the collection of data for research purposes. Finally, all posts were analyzed using exact wording as typed into the forum and then deidentified, as is appropriate and ethical treatment of data in qualitative analysis [23]. Specifically, before inserting any data into this article, words were changed to further deidentify the data. Each quote was then typed into a search engine to ensure that it was not traceable back to the forum at time of writing.

Only original posts, not replies nor threads, were collected for this work. The research questions for this study specifically relate to those community members who feel comfortable enough to act as an original poster. While lurkers, respondents, and even original posters acting as respondents to another post are certainly interesting, and their data should be analyzed, that analysis is out of scope for this specific work. In particular, we were interested in understanding the different roles that original posters take on when posting, as well as the types of support they might go to such a forum to seek.

Although comprehensive, 186 original posts over a seven-year period could be considered a limited dataset; however, low participation levels is an artifact of the domain under study and underscores the need for supportive, online spaces where PWD feel motivated and safe to participate. Low participation levels also make understanding the source and substance of original posts all the more important. Through a robust, qualitative analysis of these posts, we can begin to understand more about people who take the step to create a new thread and serve the important community role of original poster. In particular, we were intrigued to find the importance of people who do not have a dementia diagnosis on this forum, given its focus on those with dementia. In this work, we found that family and friends of people with dementia, those not yet diagnosed but self-described as likely to be diagnosed, and posters whose relationship to dementia is unknown, all have a role to play as original posters on the forum.

All authors analyzed all 186 posts and worked together to agree on definitions of support and on understanding how these forms of support are represented in the posts. The average word count for a post was 189 words per post, with the minimum word count being one word (e.g., a link to a web source), and the maximum word count being 1,674. During the first stage of the coding process, we categorized forum posts in three ways: (1) the poster's relationship to dementia, (2) the types of social support mentioned in the post, and 3) whether the poster provided or sought some type of support. During this process, five categories of posters were identified: person with dementia (PWD), undiagnosed, dementia trailblazer (DT)², family, friends, or caregivers (FFC), and anonymous, spam, or unknown diagnosis status (Unknown). In terms of social support, we developed deductive coding categories based on the common types of social support identified in cancer support forums research [51, 81?] that are summarized in Table 1. We also inductively coded the content of the posts, actively attending to the possibility that there may be social roles and forms of support that were not adequately captured by our deductive codes.

The first author conducted the first cycle of coding to generate initial codes. The first and third author then met to review code definitions and refine the codebook, collapsing, adding and deleting codes as necessary. The first author then recoded the data. Once all posts were coded, three members of the study team independently coded a subset of 20% of the total posts to calculate inter-rater

²The phrase Dementia Trailblazer is similar to but not the exact phrase invented by the participant who coined it. We have changed the phrasing for anonymity but believe the meaning is similar enough to make use of this phrase instead appropriate in this publication.

Table 1. Definitions and examples of support

Type of Support	Definition	Example
Emotional	seeking or providing understanding, encouragement, empathy, affection, affirming, validation, sympathy, caring, and concerns as it relates to dementia.	“Alzheimer’s runs in my family, my father has it. Yesterday I went home to visit him and he did not remember me as his son. It scares me to think that I may turn out like him. ”
Informational	seeking or providing advice, referrals, education, and personal experience with dementia.	“Is there any studies or research articles linking MCI to being an impairment that does not progress like dementia? ”
Companionship	posts such as random chat, humor, teasing, as well as description of offline activities that are not related to dementia	“I greatly enjoy watching movies and shows on Hulu. I’m currently watching old episode <insert show and description>. You may be able to find it on the web too, just look for season 3 episode 18.”
Other	posts that were not able to fit into a category above or were not related to dementia received the category of other.	“We should applaud naps!!”

reliability. Codes for the types of social support achieved a substantial 75% agreement among raters (Cohen’s kappa, $k = .796$). We then further revised the codebook based on codes and data for which the study team did not reach agreement. The first author then conducted a final round of coding which was used for generating the quantitative analysis of type and frequency of posts used to provide background and context in this article.

4 FINDINGS

Existing online discussion communities that focus on dementia are primarily designed for caregivers and family members of PWD; there has been much less attention paid to the design of online communities for PWD themselves. This gap in the research may be related to well-meaning but problematic perceptions of PWD. For example, many caregivers and general society may believe that, due to their disease, PWD are unable to think, create, and engage. Past research (e.g., [40–42, 55, 78]) has shown that PWD can create content and engage socially with one another when given the chance. Thus, having dedicated spaces to express frustration with the stigmas and biases PWD experience can be psychologically important to their well-being. In addition, having the opportunity to think, create, and engage, can be invaluable for this community, both cognitively and in terms of overall well-being.

Support groups for PWD are rare, but are sought after (e.g. “*most [support] programs are shut off from me [PWD] or doesn’t have a clue as how to help me. I’ve asked for help. This organization says it wants to help people, but giving me handouts and brochures doesn’t help.*”)³. In the later stages of the disease, PWDs must have a caregiver (either informal or professional). Such a person can help

³Details such as searchable identifiable phrasing, quotes, and terms throughout this paper have been changed to preserve anonymity.

Table 2. Frequency of Posts from Specific Posters

	PWD	Undiagnosed	DT	FFC	Unknown	
# of Posts	82	7	22	20	55	186
	44.09%	4.03%	11.83%	10.22%	29.57%	100%

engage with the social world, although they often may not know how to help. In the early stages, when PWDs are newly diagnosed, they generally live alone or with a partner, without the need of a caregiver, and can mostly engage with the world independently. Thus, there is a need for newly diagnosed PWDs to have a place where they can collectively learn from and support each other.

In this section, we describe the findings from our qualitative analysis of the original posts from a forum specifically labeled as being for PWD. In such a forum, one might expect that original posters would all be PWD, as requested in the forum description. What we found, however, were a variety of roles represented in these original posters. Additionally, these posters asked for and offered varied types of support as described in Table 1. While we approached this project initially with the intent of understanding how the social support offered and requested by people with other chronic conditions (e.g.,[51, 81?]) mapped to a space for PWD, we did not expect to find the variation we observed in the roles and engagement across the forum. We leave open for the future an examination of responses to these original posts, noting that here we are most interested in those people who took the time and effort to initiate a new conversation through the intentional act of creating an original post, and what their intentions were in posting.

4.1 Role Descriptions & Post Structure

Despite explicitly being described as a forum just for PWD, our analysis revealed five social roles for original posters including: persons with dementia (PWD), people who have not yet been diagnosed with dementia (pre-PWD or undiagnosed), dementia trailblazers (DT), family, caregivers, friends (FFC), and unknown/spam. It is worth noting that PWD posters appear to be aware of the non-PWD on the forum and will occasionally reach out explicitly to those for whom the forum was initially created. For example, one PWD posted a reminder about who the forum is for as part of a larger call to re-energize the group:

“Hi fellow PWDers. We need to reactivate this Board. It is designed for folks of about 60 and older who have been diagnosed with some form of dementia. Do check in.”

The percentage of posts made by posters of each role can be seen in Table 2, and Table ?? shows the unique breakdown between social role and the type of social support that was given. Each of these roles provided a unique insight into the forum, which will be discussed throughout the paper.

4.1.1 PWD. Posts that were categorized as being from a person with dementia or related disease were posts in which the poster self-identified as having some form of dementia, or we inferred a diagnosis if the poster discussed something about the disease followed by “I” statements (e.g. “Does anyone else have problems with sleeping? I know depression can cause insomnia but if dementia does too, I’m in trouble.”). The structure of many of the posts from these individuals began with a narrative of their own experiences with dementia—either past or current—including self- narrative). Self-narrative was followed by either 1) a positive outlook, 2) a statement declaring that they “don’t know what to do” or 3) a question. The last few sentences of posts were often where PWD asked or expressed some type of need, but sometimes posts were seeking implied support (i.e. poster did

not ask for any help or any questions explicitly). The presence of social support for persons with dementia or MCI were present in all categories.

4.1.2 Undiagnosed. Posts categorized as being from a person who has not been diagnosed with dementia (undiagnosed) yet, but includes explicit descriptions of themselves as in a pre-diagnosis stage or mentioned tracking warning signs or visiting a neurologist that has not yet given them a diagnosis (e.g. “...[I] am in need of a group to talk to people who are not my family or friends because I think they will leave. For many years I have been tracking symptoms and am now very sure that I may have dementia. If appropriate I want medicine to stay functional. Has anyone experienced this?”). These individuals, whom we refer to as “undiagnosed,” are responsible for a small 4.03% (N = 7) but salient set of posts. Their participation in the forum reminds everyone about the variety of specific symptoms and responses that individuals may experience in the early stages of dementia, but without the comfort and confirmation of a diagnosis. All posts that were made by undiagnosed individuals sought either emotional or informational support.

4.1.3 Dementia Trailblazer. One extremely active person with dementia, with 16,088 total posts, comments, and replies made on the forum, coined a new term for the specific role they played, a term that we, for purposes of anonymity, have adjusted to be “dementia trailblazer” (DT). The vast majority of these posts were excluded from our analysis, either because they were too old (beyond the seven years of our scope) or were replies to other messages. However, this unique role is worthy of discussion in so much as it is differentiated from a formal moderator. The first DT coined the term to support their own mental health during a deep depression following a diagnosis of dementia. Subsequent to this initial self-labeling, the first DT then began to identify others on the forum as being “dementia trailblazers” in an effort to draw attention to the work they were doing. DTs, and in particular the original DT, are often the first people to respond to an original post, something worthy of more exploration in future work. In practice, the role of DTs mimics the role of a moderator, but without the formal specification. Notably, formal moderators were nearly absent from the forum, making no posts themselves. Instead, evidence of moderators’ existence only emerged in the comments from others on the forum noting actions they had taken. For example, a moderator deleted an original post by a poster they deemed to be “in distress” and posting inappropriate content. Although moderators never posted any description of the actions they undertook, others in the community noted that the actions had been taken by moderators. Overall, DTs provided more informational support than any other type of support.

4.1.4 Family, Friends, Caregivers. Family members, friends and caregivers (FFC) also posted threads in the forum, despite its designation as a space for older adults with dementia. Original posts from FFC included self-identifying statements that demonstrate their caregiver, friend, or family status (e.g., “[I’m] a new caregiver”, “primary care partner for my mom with MCI”, “My mother was diagnosed with dementia 7 years ago” etc.), followed by a description of the way their loved ones have been affected by the disease. These posts typically end with the expression of 1) a desire to understand how they (FFC) can provide better care for their loved one or 2) a desire to understand their loved one’s experience through the experience of PWD who are actively speaking about their disease.

4.1.5 Unknown/Spam. The Unknown category accounts for nearly a third of the overall posts (N = 55) analyzed. Posts were categorized as Unknown if we were unable to determine if the poster was someone with dementia, undiagnosed, a dementia trailblazer, a family member, friend, or caregiver. The majority of posts from unknown posters provided information (N=35, which is 16.28% of posts made on the forum), such as posting an excerpt from a book or article. When providing information, it is not necessarily important to provide a self-narrative of why you are providing this information. Similar to posts by PWD, the posts from the Unknown category were found into include all the

Table 3. Frequency of Specific Support for Difference Roles

		PWD	Undiagnosed	Dementia Trail-blazer (DT)	Family, Friends, Care-giver (FFC)	Non-PWD, Spam (Unknown)		
Emotional Support	Seeking (ES)	22 (10.23%)	4 (1.86%)	4 (1.86%)	9 (4.19%)	1 (0.47%)	40 (18.61%)	62 (28.83%)
	Providing (EP)	10 (4.65%)		3 (1.39%)	3 (1.39%)	6 (2.79%)	22 (10.22%)	
Informational Support	Seeking (IS)	22 (10.23%)	6 (2.79%)	4 (1.86%)	12 (5.58%)	4 (1.86%)	48 (33.42%)	120 (55.81%)
	Providing (IP)	22 (10.23%)		12 (5.58%)	3 (1.40%)	35 (16.28%)	72 (33.49%)	
Companionship	EC	10 (4.65%)		4 (1.86%)	1 (0.47%)	2 (0.93%)	17 (7.91%)	17 (7.91%)
Other	O	6 (2.79%)		1 (0.47%)		9 (4.19%)	16 (7.45%)	16 (7.45%)
		92 (42.78%)	10 (4.65%)	28 (13.02%)	28 (13.02%)	57 (26.52%)	215 (100.00%)	215 (100.00%)

types of social support that were defined in Table 1. Although posters in the unknown category may be PWD or have a relationship to PWD that could be inferred from other posts (e.g., comments and replies), we chose to classify them as unknown if someone reading only the original post under analysis would not be able to infer the relationship. The key issue here is in the way that many people experience online forums by taking the original post as a self-contained unit, particularly those users of the forum who may be less technologically savvy and unfamiliar with online forums.

4.2 Seeking Support by Role Types

Although this forum is described as a space specifically for people with dementia, our analysis revealed there was minimal difference in the amount of support-seeking behaviors between people without dementia (N=36) (e.g. FFC, Undiagnosed, and Unknown) and PWD (N=52) (e.g. PWD and DT). Specifically, people without dementia made only sixteen fewer requests for support than PWD (see Tables 3 for a breakdown). While not a robust statistical test, this descriptive numeric

indicator means that PWD are not the only people in the forum seeking some form of support, either informational or emotional. That said, although the difference in the number of posts seeking support is small, the content of and reasons for support-seeking posts varies based on the role of the poster.

4.2.1 PWD. When seeking emotional support, PWD primarily used the forum space for expressing negative emotions (e.g., fear about the future), venting (e.g. expressing frustration with increasing cognitive decline), expressing fears of revealing their diagnosis to others, and expressing concern about the “lack of support” that exists for PWD.

It is worth noting that a request for emotional support might also be for the caregiver in the life of the PWD. For example, PWD often expressed concerns about wanting to understand how to “help family navigate as it relates to me having dementia.” One PWD described their experience of caring for their mother, also a PWD, with their partner, and watching friends who were “crushed” taking care of spouses with dementia. These experiences led the poster to seek support in understanding how to live at home without overburdening their spouse:

“My partner and I were primary caregivers for my Mom, who had Alz. We finally ended up putting her in a care facility, where she ultimately died from [something else]... we have friends who have had spouses with Alz, and we watched it crush the spouse taking care of them...I want to stay at home for as long as possible, but I don’t want to crush my wife by doing so. ...I don’t plan on ever entering a facility for PWD, so anything that can allow me to stay at home and not crush my wife is literally a life saver for me.”

Many posts that sought informational support focused on ways of dealing with the “dementia day to day.” Posters would often preface such support requests with a description of their current mental state, as an attempt to find others who were in similar states or who had “been there.” For example, one person diagnosed with MCI described their symptoms, reported their age, and then noted their physician’s timeframe before requesting support:

“told me I might go on like this for several years or more and not progress to Alzheimer’s at all. Anyone else at this stage and what are you doing about it?”

These efforts at finding common ground to test out methods have been seen in a variety of other platforms, most notably PatientsLikeMe [6]. This specialized platform was initially designed explicitly to support patients in meeting with others with similar diagnoses and symptoms. The platform eventually evolved away from these specialized “verticals” or topics into an attempt at a generalized platform [79], a move that likely limited the ability for patients to commiserate in the ways we observed within this online PWD community.

PWD authoring original posts also sought pragmatic information directly related to disease progression and treatment, such as about pharmaceutical medications, holistic medicine, ways to participate in clinical trials, and information about support groups and finding help. Some of these questions, like those related to connecting to others more generally, focused on finding common ground and shared experiences with people:

“I have early onset dementia. I switched to a different medication. Has anyone noticed a difference in themselves or their loved one with any medications?”

In this case, the PWD is explicitly asking questions of both other PWD, for whom the forum was built, and family members, who the community knows have joined and participate.

Other posts request informational support of a kind that requires no particular experience with the disease. For example, this PWD posted something that might reasonably be answered by a student or clinician:

“Are any clinical trials about [this drug], checked in March 2019 available?”

The poster then goes on to request that people read the post entirely, pointing to specific articles from a well-known medical school. The poster calls the research “comprehensive and excellent,” again imploring readers to seek out the research and read it in its entirety but notes specific portions to read more carefully. Finally, the poster provides a link to the research. This particular link is to a health information aggregation site and not to the research article, which is both more easily consumed by most forum participants than a journal article and less comprehensive.

As the previous example illustrates, seeking support in online forums can be a way for PWD to garner much needed information, particularly in a world in which most scientific research is either behind paywalls, incomplete, or too dense to consume. For many PWD, however, the connection with others appears to be the key outcome of interest from the post. The posters likely have experts at their disposal in the form of clinicians, local dementia organizations, and social workers. Connecting on a social media platform, by contrast, provides a human connection with someone who has been where they are or who is currently having similar experiences. Online forums can be powerful platforms that allow for the combination of seeking and providing both informational and emotional support, something less commonly seen in a healthcare system that must cope with the realities of billable time, limited connection to patients, and shorter visits than most patients and clinicians would like [59, 66, 77].

4.2.2 Undiagnosed. All posts from the undiagnosed role (N=10) only sought support, with informational support (N = 6) being the most sought out form for this group. The lack of offering support from this group is notable and begs questions about the time surrounding initial experiences of dementia-like symptoms, particularly for those who believe themselves to be likely to receive a diagnosis. It is possible that immediately following the diagnosis of a chronic illness, patients are so stressed and uninformed, that no concept of offering support is possible for them. However, some research indicates that the more positive the affect at the time of diagnosis, the better the outcomes for some chronic illnesses [53]. This insight, coupled with the lack of such posts in our dataset, suggest that researchers would do well to understand how we might intervene to create more positive and supportive relationships around a potential diagnosis. One might imagine peer support, volunteerism, or other engagement with the forum by those who do not have a diagnosis as a means of supporting those who have progressed further. These roles may serve as a form of social reciprocity and sense of purpose for newly diagnosed and undiagnosed posters who are receiving support from community members with more advanced diagnoses.

Given that the undiagnosed group in our dataset was made up of people who self-identified as expecting to be diagnosed with dementia soon, it is perhaps unsurprising that many of the posts in this category sought information about preparing for an official diagnosis of dementia. For example, one poster, who fears being diagnosed due to their family history and current symptoms that they are showing, sought ways to make a “*care plan*,” which would prepare their family not only for “*end of life decisions, but also provide details about how I would like to continue, including where I want to live and want kinds of clothing are comfortable, etc.*” In this case, the poster is asking for pragmatic advice about having their wishes expressed. This post was addressed towards PWD but could as easily be answered by caregivers who might offer advice based on their own receipt of such information from a PWD.

Original posts by undiagnosed community members also sought information about PWDs’ experiences on the journey to a diagnosis, such as understanding when a person should get cognitive testing based on warning signs. As in posts by PWD, undiagnosed posters often sought out people with similar experiences. For example, this undiagnosed poster reported being “*scared and really alone right now*” while reaching out and asking for help:

“... Has anyone experienced anything similar, if so what point did you seek medicine. I’m scared and really alone right now”

Another sought specific information about support groups while providing enough biographical information to help readers match them to such groups:

“... I’m pre-diagnosis, but have I tracked my symptoms for years. Are there any support groups for people like me?”

Undiagnosed individuals expressed their fear of developing dementia based on their current symptoms. They also sought emotional support as a way of validating their warning signs and expressed a fear of losing a connection with others. Undiagnosed individuals sought support from the forum in a way that rhetorically compelled responses from PWD in the forum. Undiagnosed posters expressed fear, despair, and loneliness, and looked to PWD for comfort and validation of their experiences. Although it may be burdensome in some ways for PWD to provide this kind of support to those without a diagnosis, these interactions can be beneficial to both parties. PWD can support undiagnosed individuals on a journey that they were once on. Reflecting on and recounting on their past experiences can be helpful for PWD both cognitively and in terms of mental well-being [22, 60].

4.2.3 Dementia Trailblazer. Dementia Trailblazers, so nicknamed by one particularly active member of the community, predominantly serve the community by providing support through their original posts. When DTs sought support, they primarily did so by expressing frustration about life experiences with the disease. For example, one DT described a difficult experience with medication changes:

“The pharmacist has stopped given me name brand patches for generic patches. These new ones are not working as the others did and this frustrates me (sigh).”

Whereas a less informed PWD or someone without a diagnosis might ask for recommendations at this point— a form of informational support— DTs’ posts seemed solely intended to elicit emotional support, as they generally did not provide enough detail for others to provide information.

In a similar post, another DT expressed confusion about their diagnosis classification being *“eliminated in the latest version of DSM-5 [4].”* In this case, it is unlikely that anyone in the forum was in any way a part of creating the DSM-5, nor even particularly adept at reading and using it. Thus, the expectation of an informational response is minimal, seeking instead the emotional connection that shared frustration from others with similar experiences might bring.

Although seeking support was the lowest percentage of posts made by DTs, it is important to recognize that they still need help. They are still, after all, PWD themselves. Despite their predominant role in the community of inspiring and providing support based on their own experiences, these individuals also need a space where they can seek out support and not always have to be the support providers.

4.2.4 Family, Friends, and Caregivers. Posts from FFC (N= 21) sought a little less than half the amount of support, either emotional or informational, than PWD (N = 44) sought. This smaller volume, however, eclipses the point that 75% of original posts made by FFC, sought support. Not actually a part of the community this forum is meant to serve, they acted predominantly as seekers of support not givers, a stark contrast to their lives offline as caregivers.

Our analyses found that FFC sought informational and emotional support through asking questions that could help them to understand the experiences of their loved ones. For example, one caregiver described staying up late at night imagining a conversation with her parent, trying to envision what her parent’s life is like and what her parent might want her to know. She then translated these musings into a direct request to PWD on the forum:

"I was thinking... what other PWD, who are earlier in their journeys than my parent would want to say to their care partners in the future. So, I thought I should ask y'all: what would you tell your [them]? What information about your preferences in how you life, what you eat, what you listen to, what you do, would you want them to know in five years? What insight do you want them to have about you? ... Maybe knowing your responses might help me stop obsessing!"

These posts show that FFC know they are limited in their own knowledge and demonstrate that forums built explicitly for FFC are insufficient for supporting their needs. Questions such as those posed by an adult poster about their parent can only be answered by PWD, not by other caregivers, indicating the need for cross-group engagement.

Likewise, FFC sometimes asked questions to help them understand how they can effectively care for or support someone in their lives with a diagnosis. For example:

"My friend recently revealed to me that they have dementia. What should I say to them?"

PWD tend to lose friends following a diagnosis [29], in part due to the awkwardness associated with how people who are not cognitively impaired deal with the reality of a friend or peer who is [28]. Such posts might also refer to supporting a family member, for whom there is greater direct responsibility, such as in response to navigating the complexities of the healthcare system:

"Why can't the doctor give us a definite answer about my mom's diagnosis?"

FFC sought more informational support than emotional support. One might imagine that FFC have more outlets for emotional support than PWD and undiagnosed individuals, having their own caregiver forums as well as potential access to a wide variety of other forms of social support [50, 80]. The specific types of information that FFC sought were variable but tended towards requests focused on their caregiving responsibilities. As with the emotional support requested by the caregiver staying up late at night, who wanted to stop obsessing, informational support requests often included queries for information specifically from the perspective of the person with dementia. Sometimes these were broad requests for any information on what might help a caregiver who is new to this role, such as one family member who implored:

"I'm new to caring for a person with dementia. <Insert symptoms> I don't know what to do anymore."

In other cases, FFC might seek specific advice related to their loved one's specific stage of dementia or pre diagnosis. For example, one adult-child caregiver described an interaction that created emotional turmoil:

"Due to mom's symptoms for the past year, I contacted my doctor to help relieve some concerns, but this backfired because the doctor contacted my mother forcing her to get testing done. Although I have been begging her to get test for the past few months she refuses and is very angry with me. For those with a diagnosis, what are your thoughts?"

At times these requests that appear to be informational can also include an implicit request for emotional support. Often, these requests indicate the guilt they feel as caregivers, especially when they are peers to the PWD, such as a partner or friend. For example, one friend asked the group *"How can I still be a supportive friend?"* an inherently informational request that might be quite pragmatic in the responses it would garner. This post ended, however, with an emotional plea, *"I wrestle with guilt every moment of the day. What's been helpful to you on this path?"* This final question can be interpreted as a follow up to the original question, seeking help on being a *"good friend,"* but it can also be interpreted as a plea for help in overcoming guilt. The specific phrasing and positioning of these questions in the same post appears to do the work of positioning the poster as seeking help for the PWD and for themselves at once. This dual need again indicates

the importance of placing both PWD and non-PWD in the same forums but with explicit spaces for each alone and explicit spaces to mingle and support one another.

4.2.5 Unknown/Spam. Nearly all posts from unknown persons provided support. Indeed, from the posts that were categorized as having an unknown connection to dementia, only one post sought emotional support. In this case, the original poster sought tangible support in the form of a monetary donation link as well as emotional support for someone else, not for themselves:

<payment campaign link> A very close friend is caring a loved one with a rare dementia diagnosis. Please support and share a kind word through this difficult time."

More, but still few (N=6), posts by unknown posters included requests for informational support. In these cases, the posts tended to involve understanding how a specific disease progresses and seeking ways to cope with symptoms that may not be directly related to a neurocognitive disease, such as insomnia, depression, or anxiety. For example, one poster who, based on their interactions, could easily be a PWD, Undiagnosed, or FFC poster, asked the group for "suggestions on how to get more sleep" after describing their age, noting they had struggled to sleep for 20-30 years, and stating that clinicians have not been able to provide the support they need:

"My primary care physician has been no help. I went to a behavioral psychologist and tried their suggestions but it didn't seem to help. I went to a sleep disorder specialist, and he told me to 'deal with it.' I maybe get three or four hours of sleep each night. It's not enough."

The challenge to requesting support while anonymous can be readily seen in these examples. In the first post, without providing some identifiable information, at least about the caregiver the poster is describing, neither tangible nor emotional support could be provided. Similarly, in the sleep example, the responses one might give are markedly different if the person has a dementia diagnosis or not. Certainly, there are times when anonymous support is helpful (e.g., [62, 82]), but in the case of dementia, its utility is limited, likely leading to the limited quantity of such requests we observed in these data.

4.3 Visibility While Offering Support

Accounts with both anonymous or unidentifiable (e.g. pumpkin_76) and identifiable usernames offered support through original posts. In a forum explicitly built for a vulnerable population such as PWD, one might find the sheer amount of posts w/ anonymous usernames surprising. While the moderators and dementia trailblazers did engage on the forum, there was little policing of posts by unidentified posters. In fact, more than a quarter of the overall original posts were from people who did not identify themselves nor their relationship to dementia in their original post. Of these unidentified posts, the majority offered support of some kind to the community, which may explain why posting by people who are either anonymous or who identify themselves but not their relationship to dementia appeared to be considered a relatively positive or at least benign act in this forum.

Of the 94 posts categorized as providing some form of support, 40 of them came from people who were categorized as Unknown, meaning their relationship to dementia is unknown based on their interactions and the limited profile information we collected, and another 22 from PWD themselves. It is unclear whether posters who were Unknown intended to be less visible or identifiable, or if it is an artifact of the design of the forum. Either way, it is notable that those whom the forum is meant to serve (PWD) and those who are unknown make up the bulk of those offering support. Perhaps as notable, pre-PWD or undiagnosed posters, those who self-describe as likely to receive a diagnosis but have not yet, provided no original posts offering support, only requesting it.

4.3.1 Informational Support. Both unknown posters and PWD tended to offer informational support in their original posts. Many of these posts included resources such as links to recent articles and videos to provide helpful information about to disease to others. These posts could at times be detailed and elaborate, such as this one providing information about expanded helpline hours:

"AFA's National Toll-Free Helpline is Now Open 7 Days a Week! Starting today, AFA's National Toll-Free Helpline will be available to provide support, assistance and referrals to families affected by Alzheimer's disease seven days a week. The new helpline hours are: Monday-Friday: 9 am to 9 pm (ET) Saturday: 9 am to 1 pm (ET) Sunday: 9 am to 1 pm (ET) Call 866-232-8484 to speak with one of AFA's licensed social workers if you have questions or need help!" [from an unknown poster]

In this case, the poster not only provided the headline news that the helpline is now available seven days a week but also the expanded information of detailed hours and a phone number, thereby allowing for readers to get the information without additional clicks or looking information up on other sites. The lack of spelling out the acronym AFA (Alzheimer's Foundation of America) still implies some key ingroup behavior that makes the poster read as safe to other community members.

In other cases, an original poster might describe a lecture they have attended or a book they read in detail, such as this post by an unknown poster:

"I just read [THIS BOOK] by [THIS AUTHOR] He talks about inflammation being behind illness (including Alzheimer's, heart disease, cancer and more) and weight gain. [QUOTE FROM THE BOOK]Dr. X has spent most of his career in research on connections between diet and inflammation. For Alzheimer's, he says that there is a coming [QUOTE FROM BOOK INDICATING MAJOR CHALLENGES FOR NEXT SEVERAL DECADES FOLLOWED BY TWO PARAGRAPHS OF SUMMARY]. I cannot summarize the content of a [VERY LONG] book (with X pages of references) here so suggest you read it yourself. Synopsis is that diet has a great deal to do with health, including Alzheimer's."

In this post, the original poster also included a detailed example diet at the end of the post for those who want to adhere to the teachings of the book. Here, the poster is certainly providing a strong advertisement for a book they believe in, but they are also providing relevant content in an easily digestible format, a style common to informational support provided in this space. Content such as personal tips and strategies from PWDs' personal journeys, links to articles, sharing internet etiquette, and ways of navigating this "new normal" were commonly found when these individuals provided informational support. For example, one PWD noted:

"Exchanging emails addresses with people online is not a very good idea. I recently shared my information with someone who seemed to be dealing with being newly diagnosed with dementia, but it turned out to be a scam. I was hacked, so think twice before sharing this type of information."

At other times, an informational post may be quite brief with only a link out to another resource or a journal article title followed by its scientific citation. For example, the following from an unknown poster, edited to remove searchability to the forum:

Researchers discovered that for people who carry a specific genetic variation [EDITED] donepezil could accelerate cognitive decline. Journal Reference: Louis De Beaumont, Sandra Pelleieux, Louise Lamarre-Theroux, Doris Dea, Judes Poirier. Butyrylcholinesterase K and Apolipoprotein E-e4 Reduce the Age of Onset of Alzheimer's Disease, Accelerate

Cognitive Decline, and Modulate Donepezil Response in Mild Cognitively Impaired Subjects. *Journal of Alzheimer's Disease*, 2016; 54 (3): 913 DOI: 10.3233/JAD-160373

Here we see behaviors likely to be influenced by the forum's technical design. By allowing accounts with a wide variety of usernames that prompt for very little in the form of specific identification or content, the forum allows for posts with minimal information connecting the original poster to the community. Posting such content may be helpful for some, but it also may be frustrating and harmful to people who would prefer some explanation of what has been provided. To make matters worse, in this particular case, the article sits behind a paywall, making anything more than the abstract inaccessible to most readers. Of course, not all quick and easy posts linked to paywalled and dense academic articles. For example, one unknown poster drew people's attention to a blog post and a movie with a simple note, emoji, and link to the post. In this case, the entire post is less than 20 characters, excluding the URL.

4.3.2 Emotional Support. Posts that provided emotional support generally included positive sentiments and links to uplifting videos (e.g. "<insert youtube link>, this gave ways to make living with dementia easier." From an unknown poster). PWD, in particular, when providing emotional support, tended to share content encouraging positive outlooks, such as sharing positive experiences related to living with dementia. For example, in one post, the PWD writes several paragraphs about their experiences, remarking at the end of the post that there are "gifts" in this experience, noting specifically a support group, being involved in a group that walks regularly, the diagnosis itself, and the medication that came along with that diagnosis. Through this description, the poster highlights the differences between early experiences with dementia and their current situation:

"I have medication that helps me to function better. OMG, that is thrilling in and of itself. To have something, anything that actually helps... you have no idea... I don't think my heart will ever stop leaping and singing inside from that."

The same post goes on to praise the home health aides, physicians, and other supporters and then reflects again on the journey of their own life:

*"After a lifetime of service to others... I have to say, that there is such a beauty and grace and love in witnessing others do for me what I did for others. I would never witnessed the receiving end of this *LOVE* seeing others hearts that way... it may be the single most beautiful thing I have ever witnessed"*

The connection of posters' lived experiences to those that their readers may be having is a powerful form of emotional support being offered, albeit indirectly. Of course, PWD also made many direct appeals for people in need of support to reach out:

"You are all loved. You are all still living I may not know you, but I care about all of you. There are some terrible and mean people in this world. There are also kind people. I will always be here if you need someone to talk to. This journey is tough. No one should go through it alone <3"

When providing emotional support, FFCs often shared positive thoughts from a caregiver's perspective in an attempt to "*dispel the stigmas of dementia*." They also shared information and resources that were helpful for their loved one in order to help persons who are currently experiencing the disease.

4.3.3 Companionship Support. Informational and emotional support were highly relevant to understanding how to cope with the disease, relating to experiences of others on the journey, and working to keep community members' spirits up. While emotional support refers to various forms of encouragement and validation relating to the common issue or disease, companionship, or

network support, however, allowed PWD to engage in or share in random chatter, humor, teasing, as well as description of activities that are not related to current challenges a person may be experiencing [16]. Such companionship or network supports allows the posters to make social connections with others without explicitly focusing on dementia.

Companionship posts often use humor to improve feelings of well-being or focus attention on aspects of their lives that are outside their dementia diagnoses. For example, one poster described her response to the new, at that time, trend of adult coloring books, while another encouraged people to watch a TED talk on communication. Such posts may include reminiscences about the positive connections that community members have made through the forum, often pointing people to popular media articles about some of the more “famous” PWD who have been active in their forums.

Importantly, companionship support allows for community connections and common ground that go beyond Alzheimer’s or dementia. For example, from a DT:

“Every New Year I journal to think about that the things that happened in the past year and set goals to accomplish in the new year. Does anyone else have New Year’s traditions?”

Although companionship support was the least represented form of social support in the posts we analyzed, it plays a crucial role in allowing posters from each social role to express their identities and form social bonds without the relation to dementia. In future analyses, the role of companionship support should be further examined in so much as it may be more or less present in replies than it has been in original posts.

4.4 Other

A very small number of original posts did not seek or offer support of any kind. These posts were sometimes an opportunity for someone to vent briefly about the state of the world or to point people to another post on the forum. In other cases, however, those original posts that did not request nor offer any support, were such that might be considered harassment. For example, one unknown poster could be perceived to be encouraging suicide, a behavior banned by most social media and online forums:

“I am looking for people living with dementia who are thinking about taking their life. Let’s work to change laws in more states.”

In another case, a family member argued in an unknown post for stopping the “*stigma in language about dementia*” with links to articles on stigma prevention. Such links could be considered an informational support of sorts, but in the end, we did not categorize them as such given their content being focused more on advocacy than providing dementia-related information.

In both the negative behaviors seen in “other” posts (e.g., encouragement of self-harm) and those that are more positive (e.g., those focused on destigmatizing dementia), the design of the forum itself does little to prevent the potential targeting or addressing the particular concerns of this at risk population. The frustration of such an experience, much like in other online forums for vulnerable populations, comes through at times in posts also categorized as “other.” For example, some posts simply point the reader to another post:

“I’m tired of writing this out. Please read the question I posted on one of the other boards and help if you have information. Thanks.”

In this case, although we see a call for information, without doing some research—going through the username to list of posts and finding the likely one referenced—the reader cannot easily respond with the information being requested. Additionally, this post is doing more work than simply

pointing the reader to another post. This post helps the author to express frustration at the very design and social norms of the forum that have required rewriting information multiple times.

4.5 Summary, Ethics, and Limitations of Findings

The data used in this study was publicly available. Before gathering data, we reviewed the website's terms and conditions to ensure that the data we collected could be used for research. To protect the posters' identities and information, all quotes included in this paper have been paraphrased, and any names have been removed. To ensure that the quotes presented cannot be traced back, we conducted a reverse search of each quote and changed terminology and typos that were unique to posters in ways that do not change the meaning but do affect the searchability.

The primary limitation of this work lies in our limited knowledge about the posters beyond what they have provided in the forum. Although there are few online discussion forums designated for people with dementia to interact and share experiences, we only analyzed 186 posts from one forum, which does not account for the many other posts that are on this specific forum. We only analyzed the original forum posts, nor responses, which also limits our understanding of how the community perceived specific posts.

Overall, our findings suggest that individuals in many social roles contribute to the conversation in a forum designated for PWD. Each role can benefit from forum usage in various ways. However, some of these benefits can detract from the purpose of the forum, which is designating a safe space for PWD. For instance, while FFC are seeking support from PWD, their needs can come across as aggressive. Any aggression or neediness is understandable given the load that comes with caregiving for a loved one with dementia. The question then becomes, should PWD need to shoulder this additional labor for those without dementia, whether caregivers, pre-diagnosis or undiagnosed, or anyone else? Should PWD have to spend time educating people about their disease while also coping with that disease themselves? Educating the majority and able-bodied individuals is an ongoing conversation and one of the primary reasons such safe spaces have been created in the first place [12, 46, 67].

Likewise, people using online forums to discuss other chronic health conditions reported a different kind of safe space. In this articulation, the space may be safe for the PWD to be upset about their experiences or seek care without having others in their lives be subjected to these rants. Hayes et al described this phenomenon in chronic cancer patients who sought out online forums as a way to protect the caregivers in their lives from their pain [31].

Whatever the reasons for needing differentiated space, the very fact that they exist indicates a desire for them. At the same time, the use of these spaces by people without a diagnosis of the disease is also consistent and telling. Completely shutting people out is not a realistic solution. Thus, in the following section, we propose a model that allows PWD to have a safe space to engage with only each other while also allowing FFC and other undiagnosed people to be a part of a subset of these conversations.

5 DISCUSSION

Over the last two decades, research on online discussion forums has demonstrated that community participants can receive social and other types of support from others with shared social experiences [51, 74, 81]. In this work, we were specifically interested in understanding how a forum built for a limited population of people can be appropriated by both those in the target population and those surrounding them. Building on Winefield's work with cancer communities [81], we found that a wide variety of stakeholders in the dementia community make use of a forum for persons with dementia to seek and provide various forms of social support.

Overall, we found that in a space that was specifically designated for PWD, there were many other social roles involved, including persons who have not been diagnosed with dementia, but have warning signs, dementia trailblazers, family, friends, caregivers, and people whose relation to the disease were unidentifiable through their posts. Each of these roles provided a unique perspective, but many, such as undiagnosed and FFC, seek more support from PWD. This support seeking by people without dementia in a space explicitly designated to be for them can become a burden. These engagements may clutter a forum in which people with new diagnoses are attempting to use the space for understanding the experiences of their peers. Furthermore, PWDs in this space must constantly explain themselves to others, creating work to be done by the very people this forum is meant to support. This kind of labor is regularly performed by vulnerable communities, such as those with mental health conditions, underrepresented racial and ethnic communities, and people with disabilities. Seeking support is multidimensional, meaning anyone is allowed to seek support, but the frequency of support requests from a person without dementia towards the community with dementia indicates some challenges in the way of this online space, and indeed many such public but focused forums, function in general. PWD deserve to have a place for them to express and learn from each other, as evidenced by the literature on safe spaces [40], but so too do people without dementia. The tension of regulation after the fact, rather than designing to support these different but intertwined communities, should be addressed by the online health communities' platforms and designers. The design of future online discussion communities for PWD should allow these individuals to have a space that fosters relationships and allows them to gain knowledge from each other. These spaces should also allow people not related to PWD to learn from PWD in a non-intrusive way, such as the model we propose here.

5.1 Design Model

The traditional roles of online discussion forums include a moderator or set of moderators whose role directs, filters, and in extreme cases halts conversations, as well as a series of readers and posters from some defined community. These communities include people of many backgrounds who hold different values but have a specific goal or interest in common. In this study, we observed a many to one relationship between the roles that were presented in the forum for PWD in terms of original posts (see Figure 1). Many people not diagnosed with dementia sought some form of social support from PWD, but PWD did not seek information from people outside of the community (i.e. FFC, Undiagnosed, Unknown). Specifically, all original posts were addressed to the dementia community not to any other people, despite their clear presence in the forums.

It is probable that in responding to original posts, those other community members interacted with one another, though we did not examine that part of the communication flow. What is notable here is that the notion of the community and forum being "for PWD" seems to have permeated at least so far in the community as to make it such that original posters only address PWD. This both makes the space more "for them" even when outsiders are present but also likely adds to the burden of responses and other engagement.

We propose a design model (see Figure 2) for online communities for PWD that considers three main goals: 1) how to control the flow of original posts into the inner space, which we have commonly referred to as the "safe space," 2) how to enable the outside community to engage and interact with information provided by PWD, and 3) ways we might protect PWDs' privacy and security.

5.1.1 Design Model Overview. As described above, our results revealed five main roles performed by people engaging in conversations on the online forum, including the PWD, Undiagnosed, DT, FFC, and Unknown. For this design model, we grouped those roles into three main stakeholder

Fig. 1. Current Flow of Original Posts

groups, which are represented by circles in Figure 2. Group 1, which we consider the focus of the model, consists of PWD, Undiagnosed, and DT. We grouped these roles together due to the circle of information that they provide. Each of these individuals have or will have similar experiences at some point and each of them can benefit directly from others' experiences. Group 2 includes family, friends, and caregivers, and Group 3 is the grouping of individuals that are unknown or the general population, meaning their relationship to the disease is unidentifiable. The arrows of the model represent the flow of posts from one type of user to another. For instance, (following the dashed arrows in Figure 2) when a post is made by a person in Group 1, they are required to set their privacy settings before the content posts to the forum. The default post privacy setting will be set by PWD during sign up, but PWD will have the option to change to one of the following: 1) FFC, which means the post will only be viewed by Group 2 (FFC), moderators, and other individuals in Group 1, 2) PWD only, which makes the content private to everyone except Groups 1 and moderators, and 3) public, which will allow everyone to access the posts and engage. Allowing Group 1 to set specific privacy settings to their post allows them to express their issues about family, friends, and caregivers without worrying if their loved one will see it and decreases the potential for attacks by outside members that could be made on their posts.

The solid line represents the flow of information from the FFCs and the public to the PWDs. When posts are made by Group 2 or 3, moderators must approve them before Group 1 sees them. In this model, moderators can be either dementia trailblazers or dementia friends, matching in some ways models used by other protected communities, such as the virtual world Autcraft [63], but expanding to ensure that the person with the diagnosis is at the center of the forum's mission and has an equally central role in moderation. Dementia trailblazers already serve as informal moderators through directing conversations, providing support, information, and tips, while seeking their own support at times as well. This model makes the DT role a formal moderator, so that PWD can have representation in deciding what type of content can be sent to the forum. This assignment is a key element of this model that must be considered carefully in design and implementation. Dementia trailblazers are, by definition, people with dementia, who will eventually lose the capacity to moderate the forum successfully. A key design consideration must be how to scaffold these super-users during their duties, as well as to identify the point at which such scaffolding is no longer sufficient, and they must be removed from moderator duties and privileges.

The second type of moderator consists of people who do not have dementia, but have been noted as being a trusted person involved in service, such as having the dementia friend certification

Fig. 2. Design Model — Dashed lines represents the flow of information/post to the public based on PWDs post privacy settings. Solid lines represent the flow of information/posts from the public (i.e. FFC Unknown) to the PWDs

[73] or being a loved one of person who has passed on with dementia. When posts are sent to these moderators to be approved, moderators have the option to approve the post for the forum or answer the post themselves. Posts sent from the unknown group may be rejected by the system if the message includes some form of negative targeting, spam, or other problematic content, a source of major concern for many older adults [49]. Other posts from the unknown group would be reviewed in the same manner as the posts from FFC. These moderators serve as a partition between the forum and the public to limit the work PWD have to do to educate the public about their disease, positioning instead these moderators as the front line for answering questions from FFC and Unknown groups. At the same time, this structure still allows a broader group to have access to the forum.

5.1.2 Privacy & Security. A variety of research has focused on understanding the privacy and security implications for older people using the Internet [47], smarthomes [35], wearables [38], and healthcare technologies [58]. Privacy concerns are one of the primary reasons older adults report for being hesitant to adopt online technologies as a way to communicate with others [24, 33]. Of course, people with dementia are not all elderly, and most elderly people do not have dementia. Rosenfield et al examined existing privacy policies, with a specific eye towards dementia in 2017 [65], finding that most apps for dementia lacked a privacy policy at all, and those that had them were insufficient and unclear. Solutions have been proposed for “privacy-aware” monitoring, such as m-Care [69] or specific location-obfuscation approaches [8]. However, we are still somewhat limited in thinking about dementia in online social communities specifically.

In such communities, posts can negatively target PWD about ways to be “assisted in suicide,” buy questionable products, or otherwise place PWD at risk. These posts are difficult to moderate against, a problem demonstrated in the larger discourse around social media, trolling, and bullying. Such harmful behavior can also bleed into the physical world. For example, one post in those we reviewed

included a primer on “internet etiquette” in response to a scam by a poster who falsely claimed they “wanted to connect with [a fellow PWD] offline.” People on these forums are willing to share their experiences with others, and they are all adults who have led successful, independent lives who are now coping with a variety of limitations on their interactions with others, both self-imposed and mandated by carers. However, following a diagnosis and as their disease progresses, they become ever more vulnerable both online and off. Designers must consider how to balance the autonomy and decision-making authority typically afforded to adults, while still blocking risky data from being exposed, such as personally identifiable information, including combinations of full name, hometown, and detailed medical information.

At the same time, our work has focused on people already using dementia forums despite the risk. Future research must more deeply consider those who have opted out of such spaces. Common wisdom and stereotypes about elderly people indicate that they may be fearful because of what they do not understand about such spaces. However, many of the most informed amongst us choose not to engage in such spaces. It is not necessarily a low-information choice to avoid online forums in light of the existing privacy and security options that most afford their users. Additionally, although many older adults may be fully informed about privacy considerations, research has shown that more instructions are needed for older adults to be able to effectively interact in these contexts [17]. The paucity of instructions for use on most online forums becomes an issue of access for anyone needing additional support, such as PWD. Designers must consider not only basic instructions but other kinds of training ramp-ups, perhaps like those from the gaming community [68]. Although online games have been explored for education [57] and for dementia [13, 14, 34], slowly increasing difficulty and exposure as well as other game-based learning techniques have not yet been explored for online communities for people with dementia. Likewise, designers and managers of online communities might benefit from the kind of participation seen in Wikipedia’s early days [7], in which people might start with small engagements and then grow into a role like Dementia Trailblazer. Whatever approaches used, they must consider the cultural and generational contexts of these users as well as their distinct concerns with a condition that diminishes their decision-making capacity over time. Hence, our model suggests shared governance with the moderators, more senior peers, and other community members in which people might flexibly flow between a stronger ruleset in certain cases and the ability to override in others.

This kind of shared governance model would help to combat two other key concerns for dementia forums: misinformation and norm violation. Neither of these concerns is a traditional security and privacy issue, but for patients with dementia, these issues are central to the formation and reformation of their online identities. PWD and others in the community must correct one another more when observing these types of posts, an issue worth exploring in further depth in future work focused on the responses to original posters. Even in just examining original posts, however, we can see the ways in which nefarious actors might take advantage of the community by intentionally posting misinformation, or a PWD or caregiver might do it by accident. The kind of “blasting” you might see in other online communities to combat misinformation and norm violation is less likely to work in one focused on a shared experience like dementia or other health related concerns [9]. Thus, our model focuses on a positive cycle of interaction and correction both by PWD and others in the community.

5.1.3 Model Challenges. Although we expect this model, and others that deviate from traditional online communities, would go a long way to address online health challenges for people with dementia and mild cognitive impairment, this approach is not without its own challenges. Furthermore, as an intentional provocation and reimagining, it has not yet been built nor empirically tested. However, by logical inspection, we can identify some challenges already. Specifically, verifying

users for explicit groups while still protecting their choice not to be visible within a stigmatized diagnosis and to not share health information unnecessarily is a hard balance to strike. Likewise, training moderators and establishing moderator policies and norms take many communities a long time. In this section, we discuss these challenges and future streams of research that could possibly address these challenges.

How do you verify that each person is part of the right group? There are a variety of potential approaches available for verification that designers might consider in light of the specific community they seek to serve and the affordances and availability of functionality on their particular platform. An honor system requires trust that people will respect the spaces and enter the group that they closely identify with but allows the easiest access to the needed information for those who might be in crisis. Requesting moderator approval might slow the access to such information but would provide more human checks for bots, bad actors, and others who should not be a part of the community. However, this approach asks a lot of moderators who may not be emotionally or informationally equipped to deal with this selection process. Finally, the strongest option would be to require proof of a diagnosis. This approach risks the moderator being asked to understand medical documentation outside their area of expertise and puts the poster at the most risk in terms of sharing protected medical data and being blocked from potentially necessary support. Algorithmic approaches can be used to audit communities following access. For example, machine learning algorithms have already been used to evaluate the social support in posts [74, 75]. Our preliminary analysis of how each role structures their posts provides some indicator that machine learning technologies could be used to identify privately whether the user is a part of the correct group.

What are the challenges with moderation in a dementia space? Although this paper primarily focuses on the structure and flow of information from the FFC and public to the PWD, moderation for the dementia community is pivotal in designing safe spaces for this community. PWD must be allowed to have agency, whether as moderators or as community members. However, even community members with no moderator duties will at some point be unable to interact with the forum as usual. Thus, designers and researchers should explore ways to help PWD through the transition period without the feeling of isolation, such as creation of more protected transitional spaces or shared spaces to be used with a caregiver or other supporters. Our preliminary analysis again suggests that machine learning and natural language processing can be of help in this case. If PWDs are active members in the forum, their changes in linguistic patterns could help moderators determine who are progressing to the later stages, an area of important future work for both health informatics and CSCW researchers.

How can posters dynamically and flexibly assert their preferences around security, privacy, and visibility? People with dementia should be empowered to change privacy settings on a post to allow different groups to view it. However, this kind of approach can become a challenge due to the number of steps that it takes to complete the goal, remembering to change the privacy settings, and limiting the amount of vulnerable information in each post to those outside of their private community. Many adults without dementia struggle with a post-by-post solution on other platforms. The added cognitive difficulties of this choice on every post would likely be a burden to a forum for PWD. Some personally identifiable information, such as a user's first name, is likely not particularly harmful if posted. Likewise, mentioning a specific physician who sees many patients is unlikely to track back to an individual. However, when PWD begin to post combinations of vulnerable information such as first name, hometown, and physician information, the risk increases dramatically. Researchers must explore how intelligent approaches as well as human assisted supports could identify these risky combinations of vulnerable information and notify the PWD that it is harmful and should not be posted in its current form. Researchers should also explore

ways to allow PWD to write posts while automatically blocking vulnerable information or alerting them to the potentially risky combinations that might exist given what they have already posted on the forum. This approach would allow for some assistance while still focusing on a design that privileges respect for and education of PWD over infantilization.

6 CONCLUSION AND FUTURE WORK

This paper describes the results of a research project in which we analyzed the roles of individuals posting on a forum for PWD. Original posters inhabited a variety of roles, seeking and providing social support in this online community. The public—including family, friends, and caregivers—sought more support than they provided. This imbalance has the potential, particularly over time, to overload the PWD with explaining and comforting others about their disease. Our findings also indicate that posters who were not able to be identified as PWD or FFC provided more support than they sought, indicating the potential benefits of including such people in a forum that was not created for them in the first place. Based on these findings, we propose a model to streamline posts by people without dementia and create a safe space for those with dementia. Although the forum studied in this work is designated for PWD, the public (i.e. family, caregivers, friends, and people with no relation to the disease) could all benefit from the conversation.

In the future, researchers, designers, and developers alike must find ways to support all of these various stakeholders in participating without burdening the most vulnerable members of the community. The model we present here should be tested for PWD as well as other similar communities coping with long-term disability or illness. These platforms must then be tested for their appropriateness, utility, and level of respect they afford to both the vulnerable population themselves and their allies. A variety of additional supports, both in terms of human policy and intelligent systems, will likely be needed to bring such a model fully to fruition. However, parts of it can work with existing tools. Future research should seek to develop these new tools as well as test this model with existing ones.

Finally, in this work, we identify a variety of challenges that could arise in moderation of spaces for PWD. This work serves as a base model to understanding how we can design online communities with focal points not just for PWD, but also other vulnerable communities. In our future work, we will seek to expand this model following additional analyses, such as of responses to original posters and in other communities, as well as through testing functional platforms.

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