Safe Enough to Share: Setting the Dementia Agenda Online

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CSCW research is increasingly interested in the ways that people use technology to discuss health and disability online. In addition to studying how people share information and seek and provide emotional support, a growing area of interest is health activism. In this paper, we analyze how a project centered around sharing "real and raw" experiences with dementia provides a safe platform for people to share their authentic experiences. These accounts counter predominant depictions of dementia and push back on tokenistic involvement of people with this condition. In a study involving observations and interviews with members of this project, we find that people with dementia must negotiate several goals which at times compete with each other: sharing a "real and raw" look at dementia, changing attitudes, showcasing a polished presentation, and inhabiting a safe space. The paper concludes with a discussion of future directions for CSCW on configuring a space for dialogue on sensitive topics, health activism, and sharing online with dementia.

CCS Concepts: • **Human-centered computing → Human-Computer Interaction (HCI); Collaborative and Social;**

KEYWORDS: Health activism; Social movements; Lay expertise; Critical Dementia

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1 INTRODUCTION

In CSCW, the perspective of individuals with different health-related concerns is featured in a well-developed body of literature. Researchers have analyzed online communities for populations with diverse conditions: young people with cancer [24, 25], weight loss [12, 44], addiction recovery [48], diabetes [55], pregnancy [31] and mental health [57]. This past work highlights the benefits that people who share health conditions gain from learning from each other's experience. For example, matching people with breast cancer with peers can result in benefits due to the sharing of strategies, knowledge, and resources [17].

A focus on the perspectives of people with health conditions aligns with a shift in Western healthcare away from a paternalistic model where patients have limited capacity to manage their own health [26]. With this shift, the perspectives of people with health conditions are increasingly emphasized in what is sometimes called a patient centered care model [3]. In this model, rather than healthcare providers making decisions for a patient, the patient is involved in a shared decision-making process that incorporates their own preferences, needs, and unique lifestyle

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factors [3]. Patients' perspectives are increasingly being involved in the bigger picture decisions that affect them through involvement in policy, research, and service provision. Their involvement manifests in a number of different forms such as advisory boards, focus groups, and steering committees [37, 78]. Though this kind of involvement is increasingly common, even becoming expected in funding applications, there are open questions in terms of ensuring that involvement has real impact [14]. Researchers have identified surveys, opinion polls, focus groups, interviews, and participation in advisory committees without the power to vote as being particularly prone to tokenism because of their limited influence on policy-making [2, 37].

Dementia is an important case to evaluate in terms of patient involvement. As much as healthcare models are moving away from paternalism and are working to integrate patient preferences, dementia presents an edge case where preferences of people with the condition are often ignored. Rather than being involved in decision making, people with dementia are typically subject to the decisions made by family members and healthcare practitioners [29, 67, 70, 76]. Proxies are often used to assess the preferences of people with dementia, which does not always reflect the needs people with dementia have [56]. Even as the voices of patients with other conditions are increasingly represented in providing input to researchers and service providers, carers typically provide input on behalf of people with dementia [14]. When people with dementia are involved, issues exist due to paternalism, stereotyping, and a lack of equal opportunity [14, 30].

A growing international social movement opposes the routine disregard for the preferences of people with dementia, as well as the view of dementia as a death sentence rather than a disability that is entitled to accommodation [72]. In this perspective, people with dementia have been routinely denied basic civil, political, and social rights, in turn experiencing limited abilities to be active citizens [4]. This social movement appears through activists with dementia writing academic articles; the formation of networked groups linked through DEEP (the Dementia Engagement and Empowerment Project[1]; and spokespeople with dementia becoming increasingly visible to the public through media engagement.

In this paper, we study one project in this activist ecosystem, Dementia Diaries[2]. Dementia Diaries is a UK-based project with a goal of influencing attitudes through the sharing of authentic experiences of dementia. These authentic experiences are gathered from people with dementia through the form of audio messages, referred to as "diaries." To record a diary, people with dementia – "diarists" – make a phone call and leave a message on an answering machine. These recordings are reviewed by the facilitators of the project, then organized on a website and usually also posted on Twitter. In addition to moderating recordings, the two facilitators (who are individuals without dementia) provide support to diarists and engage in other activities related to running the Dementia Diaries platform.

Though the people with dementia sharing their stories on Dementia Diaries may not be representative of the population with dementia more broadly (for example, having retained verbal abilities due to being in earlier stages of the condition), analysis of this case provides insights into facilitating new kinds of dialogue around sensitive health contexts. Based on our analysis of a two-day event that brought together diarists, care partners, and facilitators of the organization, we found that people with dementia share their experiences with the intent of changing current ways of thinking about, caring for, and living with dementia. Tensions arose when sharing authentic expressions clashed with other goals such as having a safe and supportive community and shaping

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[1] https://www.dementiavoices.org.uk/about-deep/

[2] https://dementiadiaries.org/

the public perception of dementia. These findings advance opportunities for CSCW and HCI to study, design for, and support health-related social movements, cognitively accessible platforms, and the disclosure of sensitive, health and disability-related information.

2 RELATED WORK

Below, we review related literature on the sharing of health information and support online, health activism, and online sharing by people with dementia.

2.1 Sharing Health-Related Information and Support Online

Online health forums provide a platform for the sharing of patient perspectives and experiential knowledge. Researchers have analyzed online health forums for populations facing a wide variety of conditions or health concerns such as cancer [24, 25], weight loss [12, 44], addiction recovery [48], diabetes [55], pregnancy [31] and mental health [57]. In addition to online forums focused on specific conditions, researchers have studied how people share health information using many different platforms, including video logs on YouTube [45], online live video meetings [65], Twitter [63], Instagram [13], and Facebook [49]. Researchers have taken an equally broad approach to examining this content, scraping data [13, 45, 63], administering questionnaires and interviews [65], and creating online spaces for people to come together [49, 52]. Regardless of the medium, research has found that experiential knowledge is often shared in the form of personal stories, strategies, suggested approaches, and resources for dealing with challenges, all to help one another learn [18]. This shared information can even contain patient's medical records, where users reference data to find other users with similar experiences to answer their own medical questions [27]. Though this past work helps us understand the benefits of as well as how best to support online health information sharing, the focus is often on patients sharing information with each other for mutual benefit. There is less knowledge of how individuals strive to increase awareness of the broader population, a topic this paper takes up.

In terms of the motivations of users of online health forums, people using unique search techniques to find individuals with expertise, when compared to traditional expertise identification in organizational workplaces [17]. This expertise can come from the lay knowledge of individuals living with the condition [18] or from health professionals involved in online health communities [34, 35]. Moderators also play a role on these forums, and can include patients [22], people not living with the condition [34], and crowdsourcing [28]. In our work, we found the role of the moderator essential to ensuring a sense of safety and trust in the platform.

2.2 Health Activism

Health activism is a movement borne out of the shift towards valuing lay experiences with health and illness [1], involving "attempts to change the status quo including targets such as social norms, embedded practices, policies, or the dominance of certain social groups" [80]. This attempt to change the status quo distinguishes health activism from health advocacy, which focuses on education and working within the existing system [10]. Health activists engage in direct actions to challenge the medical paradigm [10]. In the present paper, we view Dementia Diaries as a case of health activism, as it supports the sharing of lived experiences of people with dementia to challenge existing paradigms.

CSCW and HCI researchers are increasingly concerned with activism and social movements, with health activism being one domain receiving increased attention over recent years. In response to the dominant focus research takes to change individual behaviors, Parker challenges the HCI community to look more broadly at the social structures and environmental factors that create health inequalities [59]. Parker urges researchers to focus on communities as a unit of analysis because "each community is a microcosm of larger societal trends" [59]. Research has followed suit, with an emphasis on activist approaches to address social considerations and health. Talhouk et al. study how refugee-led community radio shows influence the understanding of healthcare by refugees, increasing their agency in interactions with healthcare professionals [74, 75]. In the area of reproductive health, Michie et al.'s study on abortion rights advocacy in Ireland sheds light on how sharing stories can help reject false narratives and raise awareness of the realities of abortion laws [54]. Similar to past work, we find that individuals are concerned with challenging narratives around the realities of living with a particular condition – in this case, cognitive impairment.

Though dementia activism has not yet been discussed in the CSCW literature, it appears to be a movement that has been growing over the course of a couple decades. Projects have emerged such as the Dementia Engagement and Empowerment Project[3] (DEEP), a UK-based network of over 100 groups of people with dementia dedicated to creating change. Dementia Alliance International[4] (DAI) is a non-profit organization created by and for people with dementia to advocate for their voice and needs. In addition to emerging organizations, there is growing academic literature advocating for the voices of people with dementia to be heard on a diverse array of topics: the process of diagnosis [47, 72]; the ownership of creative copyright and intellectual property [74]; research [23] and the stigma around dementia, language, and dementia friendly communities [62, 73].

2.3 Sharing Authentic Experiences with Dementia

The voices of individuals with dementia, such as dementia activism leaders Christine Bryden and Kate Swaffer, have challenged stigma [62] by providing written accounts of the realities of living with dementia [11]. Research in gerontology has considered the wealth of first-person accounts of living with dementia as a valuable source of insight into dementia. Basting analyzed three autobiographies written by people with dementia and found their narratives contrary to depictions of loss traditionally associated with dementia [5]. A meta-analysis of 12 autobiographies written by people with dementia reveals the desire that authors had to stand up and bear witness to living with dementia [58]. The motivation of these individuals to keep dementia in the public eye include connecting with those going through similar experiences and maintaining a record of the ways an individual with dementia copes with their condition. The act of writing is seen as benefitting the writer as much as the readers: allowing them to reclaim their social identity and personhood [19, 66]. By writing and sharing experiences with others with dementia they express their unique social identities, allowing them to move past being seen as a sufferer to a survivor [66].

Though researchers have traditionally studied narratives such as poems or books published by people with dementia, digital platforms are becoming another way that people with dementia share accounts with others. Recent work has used a mobile application to bridge intergenerational gaps by providing guided questions for younger people to ask those with dementia in order to understand their life experiences [78]. Social media platforms like Twitter, Facebook, and various blogs are being used by some people with dementia to express themselves and advocate. Through an analysis of blogs, Kannaley found people with dementia were advocating for research by others

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[3] http://www.dementiavoices.org.uk

[4] http://www.dementiaallianceinternational.org

with dementia and empowering others to combat stereotypes and misconceptions about their condition [36]. However, as Cheng et al. identified, negatively stigmatized Tweets may interfere with the effectiveness of this type of social support for people with dementia [16]. The general public often assigns attributes of dementia to people (without dementia) that they find disagreeable, therefore perpetuating negative stigmas of dementia and overshadowing the more positive activists' Tweets [16].

In addition to studies examining existing systems used by people with dementia to share, research in CSCW and HCI is examining how technology should be designed to support sharing online for this population. Lazar et al. designed a digital-physical photo-sharing tool and analyzed its use through case studies with individuals with dementia [43]. Other research has examined special considerations in designing sharing technologies for people with dementia, such as the involvement of caregivers [21] and the supportive role that others play in creating an environment conducive to sharing [40]. The importance of a supportive and non-judgmental environment are themes that run throughout our findings.

3 METHODS

Below we describe the Dementia Diaries platform, the fieldwork involved in gathering the data, and analysis procedures.

3.1 Dementia Diaries

Dementia Diaries is a UK-wide project that aims to support people with dementia in sharing their stories online. The project was started by a non-profit journalism agency, On Our Radar, and handed over to an organization focused on the rights and needs of people with dementia, Innovations in Dementia.

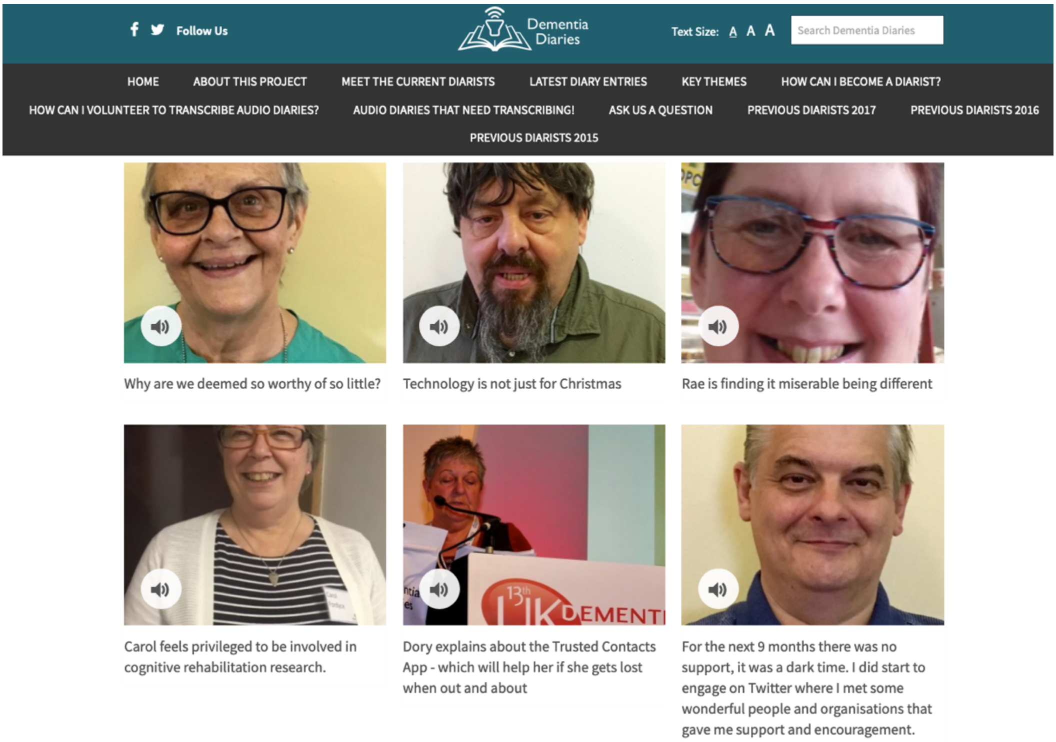
Dementia Diaries is a platform for people with dementia to share audio recordings of their experiences. People who share their stories on Dementia Diaries, referred to as diarists, have a number of ways of sharing these stories. The most common way is through people calling a number and leaving a message. An individual that we refer to as a facilitator in this paper (an individual without dementia that is involved in running the platform) then listens to the recording and posts it online. Individuals with dementia must register with the organization to become diarists, and audio stories are posted with the image of the diarist on the Dementia Diaries website (Figure 1) – diaries are rarely anonymous. The earliest diary was posted in 2015, and the average number of monthly posts from June 2018-May 2019 was close to 60 (standard deviation 16.7).

The page showing the individual diaries does have a form to leave comments, tweet, like, or share on Facebook, but this function was not working at the time of this study. Though we do not have details on listenership or dissemination of diaries outside of the platform beyond what was shared during the study, we learned that the organization regularly posts links to the diaries on Twitter, where the general public and other diarists often comment or share.

3.2 Data Collection

In the summer of 2018, the first author attended a Dementia Diaries gathering in the UK. Gatherings, held approximately once a year, bring together diarists and facilitators for community-building and to address questions that diarists and facilitators have. Some individuals such as spouses, referred to in the gathering as "supporters," also attended. The gathering included formal discussion time as well as social time. Social time consisted of activities such as optional exercise in the mornings, meals, and a bonfire. The topics for formal discussion included an array of topics related to Dementia Diaries, including "Recruitment" (how did it feel to start as a diarist?

How can diarists help recruit others?), “Opportunities for income generation and influence” (ideas such as performing dementia diaries live at events), and “How can we encourage and support each other.” Sessions each lasted around 45 minutes, and included periodic “comfort breaks.” The gathering officially lasted one and a half days, but some diarists and facilitators came a day early and engaged in informal interactions over dinner, and both facilitators and the first author stayed until the day after the gathering formally ended.



Why are we deemed so worthy of so little?

Technology is not just for Christmas

Rae is finding it miserable being different

Carol feels privileged to be involved in cognitive rehabilitation research.

Dory explains about the Trusted Contacts App - which will help her if she gets lost when out and about

For the next 9 months there was no support, it was a dark time. I did start to engage on Twitter where I met some wonderful people and organisations that gave me support and encouragement.

Figure 1: Home page of dementia diaries featuring recent stories by diarists.

All participants were informed that we would be collecting data through observations, and had an option to consent to being observed, photographed, and interviewed. The majority of participants consented to participate in the research, and their details are below. We took notes during our observations of sessions and interviewed people during breaks, meals, and after sessions. Interviews were semi-structured and included questions such as how diarists began to be involved in Dementia Diaries and whether there was anything they wanted to share about their experience at the gathering. All procedures were approved by our University Institutional Review Board, and our conducting the study was approved by the facilitators of Dementia Diaries.

3.3 Participants

Fourteen diarists with dementia, three supporters, and two facilitators consented to take part in this study. This number represented all the diarists and about half the supporters that attended. The average diarist age was 60.18 years (SD = 7.72 years). Twelve diarists identified as female and five as male. All participants lived in the UK. In the findings section, diarists with dementia are denoted by P[#] and facilitators as F1 and F2.

We did not formally gather data on the stage or type of people's dementia, but during the gathering diarists disclosed a range of dementias, including mixed dementia, Alzheimer's disease, Frontotemporal dementia, and Posterior Cortical Atrophy. Many diarists have early onset dementia, defined as dementia that first occurs in a person under the age of 65 [53]. All participants were assumed to have capacity to consent for themselves given their participation in the gathering, and there was no evidence to indicate that we should approach any authorized representatives for proxy consent.

Since leaving a recording on Dementia Diaries is primarily done by leaving a message after calling a telephone number, this study does not only involve the perspectives of those who are avid technology users (a focus on technology users has been described as a limitation in other papers studying online activism, such as work on older bloggers [41]). However, there are a number of other ways in which diarists are not representative of the broad population of individuals affected by dementia. Having early onset dementia and capacity to consent meant that these individuals may have very different experiences with the condition than people diagnosed at a later age or at more advanced stages of the condition. This aspect is not particular to this work: other research has noted the rise of the "young, active person with dementia" involved more publicly on sharing information about their condition to researchers and other organizations [14]. Additionally, participants were all from the UK, and many were part of a number of activist organizations including DEEP groups. Though an analysis of the data at this gathering provides useful insights for CSCW, there are opportunities for future work that focuses on other geographical contexts as well as people with dementia who are older, at later stages of dementia, and not already involved in an activist or advocate ecosystem.

3.4 Analysis

We took a constructivist grounded theory approach to analyze the data [15]. The first author open-coded three transcripts and the first four pages of observation notes to create initial codes, which were then grouped into higher level themes. Examples of initial codes included "shares things that come to mind," "think about audience when forming," and "doesn't want to give false impressions." The first author coded the remaining transcripts and observation notes with these sets of codes and themes, which were updated to reflect emerging themes. The research team then related the codes to each other through an iterative process of memoing and theorizing, engaging in constant comparison of data to understand and refine a set of high-level themes. Much of this theorizing centered around tensions between the themes of realness and rawness, and safety and changing attitudes.

A constructivist grounded theory approach was chosen as a method that allows us to build a conceptual framework through an inductive approach [15]. With this approach, the "grounded theory" can be a formal theory generalizable across different areas of study, or an abstract theoretical understanding of the studied experience. Given the specifics of our study setting, our study is aligned with the latter category, rather than providing a formal, generalizable theory [15]. A second reason we chose constructivist grounded theory as a method was because of the way it explicitly acknowledges the role the researchers' perspectives play in the data analysis process [15]. We disclose our own stance as follows. While understanding that interactions with people with dementia are complex, we consider the ways that people with dementia are currently treated, for example the ways that their rights are routinely denied [68], as a human-rights issue. We have been influenced by perspectives emerging in social and critical gerontology, anthropology, and HCI (e.g., [6, 39, 51, 77]) that critique the predominant view of people with dementia as "losing themselves" and as having limited value to society. This stance surely influences our findings.

4 FINDINGS

The goals shared by diarists and facilitators is to use Dementia Diaries “to bring the real and raw voice of people with dementia to a wider audience and by doing that, to influence attitudes and understanding” [F1]. The emphasis on “real and raw” refers to the genuine voices of people with dementia sharing “authentic concerns and priorities” [F1].

During the gathering, diarists spoke to interactions with organizations that felt tokenistic. In these interactions, as P9 explained, “it's so easy for the dementia voice not to be heard.” Others set the agenda for what issues need to be addressed and decided whether and how to incorporate feedback from people with dementia – it becomes almost a “consultation model” [F1]. A model that features authentic priorities of people with dementia is in stark opposition to the way other organizations operate.

Through our analysis, we found that Dementia Diaries provides a space for the sharing of authentic voices and priorities of people with dementia. The safety of the platform allows these expressions to unfold, and allows people to achieve their key goals of influencing attitudes of people with and without dementia. However, the sharing of “real and raw” expressions is sometimes in tension with other goals, such as safety, attracting listeners, and influencing attitudes.

4.1 A Safe Environment for Revealing the Real and Raw

The word “safe” came up again and again in the gathering and during interviews as a way of describing Dementia Diaries. Dementia Diaries as a whole – the experience of recording a diary, the physical gathering, interactions with the facilitators and even the website felt safe to participants.

This sense of safety was essential to the sharing of “real and raw” expressions of dementia for a number of reasons that we describe further below. There are three key ways Dementia Diaries becomes a safe space for people with dementia: through a sense of community that grows through in-person and digital engagement, a non-judgmental separate space to talk about dementia, and trust in facilitators that is built up over time. Running through these three mechanisms is a pervasive sense of a non-judgmental environment that accepts people as they are and values what they have to say. P13 describes this non-judgmental and accepting aspect as, “values [that] flow through everything Dementia Diaries does.”

4.1.1 A sense of community. Diarists feel a sense of community with other diarists that translates to feeling safe in sharing authentic expressions in person and online. This sense of community exists even when diarists had never met in person. Just knowing that they shared a condition, were part of the same organization, and listening to others’ recordings appears to create a sense of kinship between diarists. This sense translates to experiences using Dementia Diaries: some diarists describe a sense of having someone “there” when they leave a recording, or even feeling like they are talking to friends. This was contrasted with other digital platforms: P5 said that she might not put on Twitter how she was feeling, but on Dementia Diaries, even knowing that her diaries might end up getting posted to Twitter, “it is more connected and more personal.”

The in-person meeting had a non-judgmental dynamic that led to a sense of safety. In particular, diarists did not worry about the “rawness” of how they might come across with their condition. P2 explained that, “If you have a bad moment, you know that other people are the same… we haven’t got to worry about whether people can understand us or whether people are a bit stumbling. We can just be us.” During the gathering, there was lots of laughter, with jokes about dementia thrown in. It was F2’s birthday that weekend, and it became a running joke to break out into the Happy Birthday song spontaneously. After we had done this several times, one person commented, "you may not know that people with Alzheimer's repeat things," which added to the laughter. This comfort with each other and with the topic of dementia meant that "nobody bats an eye really at anything," [P1]. Diarists could be authentic about their dementia – they did not have to hide or tiptoe around the topic.

The in-person meeting gave people opportunities to bolster each other's confidence in ways that directly impacted their ability to be vulnerable enough to share authentic expressions online. P9 said that there were some things only her family knew about her and her dementia, and she wondered if this was something other people brought up. At lunch, she mentioned that she had gotten the courage to bring this up because other people she spoke to had it as well – she said "I need to be braver and talk about it" – "it" being incontinence associated with dementia. After this discussion, another diarist mentioned she would start bringing that important but under-discussed topic up in the talks that she gave. In these cases, we see people growing in their ability to share raw and vulnerable experiences due to supportive interactions with fellow diarists.

4.1.2 A separate time and place to talk about dementia. Individuals appreciate that Dementia Diaries provides a space that they could talk about dementia. Having this space was mentioned as particularly important by people who lived alone and therefore did not feel that they had other outlets for these expressions at a random time of day or night. But some others who had spouses and children that they could reach out to with these expressions also value the platform, though for different reasons. Dementia Diaries enables people to share experiences that they do not wish to share with loved ones. P1 described having different places where dementia content existed as being helpful because, "One of my daughters is not ready to look because it's too close to home. So it enables us [diarists] to be open safely, where I'm not hurting other people if they don't want to listen to it." This sentiment of "Dementia and family life, I have to keep that separate" [P2] is shared by others, such as P2 whose wife was still coming to terms with his diagnosis, and P3 whose wife sometimes experienced "dementia overload." And P5 said that she liked to make diaries to share a bad day without bothering her daughter because she knew her daughter would worry about her if she reached out to her with those stories, "although I tell her not to." A way to keep dementia life separate was not limited to diaries: some diarists do similar things on the other platforms they used, such as Twitter and Facebook (e.g., having separate groups for family and dementia, not following family on Twitter). And some individuals create "semi-permeable" boundaries between others and their life with dementia. For example, individuals described strategies such as having links to their diaries in their email signature, but not emailing the links directly to certain family members. This strategy allows them to share their real expressions online where anyone could see them, but also provide loved ones with the opportunity to choose whether or not to engage with this content.

Some individuals described other contexts in which they could talk about dementia – where dementia was even the focus – but where they did not feel that they could share their real concerns and priorities. P7 explained that she values that Dementia Diaries provides a space where, "This is just my time to talk. I don't want to be guided or given information. It's my time just to say what I feel… nobody really wants to listen to how I feel, they want to tell me what to do, how to live well with dementia… nobody's there to listen except Dementia Diaries." Another diarist shared an experience where he had tried to inform a dementia advocacy organization about how to make the venue more accessible to people with dementia, and they became upset with him. In contrast with these negative experiences, creating a Dementia Diaries recording gives people the time to talk about whatever they wish, based on their own agendas, without needing to worry about how others might respond.

4.1.3 Trust earned by the facilitators. Another factor contributing to the sense of safety diarists had that directly impacted their sharing of real and raw experiences of dementia was the relationship they have with the facilitators of the project. F1 and F2 have intentionally divided their roles so that F2 was diarist-facing (F1 focuses more on external-facing roles such as seeking funding). F1 noted that diarists have "a real sense of trust" in F2. It was evident during the gathering that F2's genuine interest in supporting diarists is integral to the safety that people feel in sharing whatever is in the "here and now." P5 said, "She's very good and she cares, as [other participant] was saying, that's why we trust her... through these meet ups, we've got to know her. We actually know she does care. If she didn't care, if we didn't get that feeling that she does care and trust, I don't think we'd do it [post diaries]." She continued, saying that "if you don't have the trust in someone who is going to do something with them [diaries], then you wouldn't put it up [to go online]."

As to how F2 built these trusting and supported relationships, P10 discussed her early hesitance about whether she was recording the "right" thing and how F2 helped her feel more comfortable sharing:

> "When I first started to use 'em I wasn't sure what was doing properly, I was sitting in my garden and it was a beautiful day and I was waffling on about sunshine and I could feel the sun in my face, and I was like, I'm not sure, because P8 does things differently, he's very informative. But when I had a word with F2 recently and she's 'yes P10, that's what we want to hear!' It gave me the- I forget the word- to go back and do it again... now I can talk about anything that's the 'here and now' with me and I can say it and I haven't got a thing 'I'm not sure if its informative enough to anybody or not.'"

Here and in other anecdotes shared by diarists, F2 reassures individuals that whatever they want to share – whether recounting a beautiful day or sharing information – is exactly right, just by the fact that it was something they wished to share. Below, we relate the support of someone with dementia in sharing whatever they wish to share to key components of health activism: changing attitudes and influencing understanding.

4.2 Changing attitudes and influencing understanding

A key goal that diarists share is to have their recordings raise awareness. However, the kind of awareness raised by diarists is very different from the way awareness about dementia and other health conditions is typically raised. Past research has recognized that raising awareness of dementia – often focused on prevalence or teaching people to recognize symptoms – can draw on and perpetuate fear of the condition [20]. With Dementia Diaries, at a most basic level, diarists wish to raise awareness of the fundamental humanity of people so often said to have lost themselves [5, 6] – "yes, you may have dementia, but you're still a person" [P5]. This was done by showing that "life [with dementia] goes on" [P1] in two key ways: through the sharing of tips and strategies related to dementia as well as showing mundane, everyday life with dementia.

4.2.1 Sharing strategies and support. Like previous work on older adults reframing aging through blogs [41], Dementia Diaries is used by individuals with dementia to reframe the ways that people think about their condition. And, similar to those older bloggers, diarists aim to change attitudes both with the ingroup (others with dementia) as well as the outgroup (the rest of the world) [41].

For the ingroup, the sharing of strategies for coping with dementia can be seen as an act of resistance to the existing way that people with dementia are advised to live life. P2 explained that when he received a diagnosis, his situation had been similar to Kate Swaffer's notion of Prescribed Disengagement, which describes how post-diagnostic support in dementia is limited to advice to set up power of attorneys and wait for death [72]. When P2 came across Dementia Diaries, "it was a window on what could be." The diaries provided a glimpse, even a guide, to a life with dementia that included continuing to contribute rather than disengaging from life.

Importantly, the platform allows people with dementia to act as experts on their condition. P7's experience at a memory clinic provides a counter case that shows how people with dementia are regularly positioned: "they want to tell me what to do, how to live well with dementia." She continues, saying that the way they interact with her implies "We [practitioners at the clinic] know everything. You, the one with Alzheimer's and dementia, you're the idiot."

As experts in their condition, diarists acknowledge that living well with dementia sometimes requires facing challenges. They use diaries to share social services and benefits, and strategies and resources (e.g., using smart speakers) that they find helpful in coping with dementia, but hard to come by. They also provide emotional support to each other through their diaries. Several diarists described reaching out to others after hearing people expressing difficult experiences to provide support. Diarists explained that these supportive exchanges, though taking place outside of Dementia Diaries in contexts such as Twitter, the phone, or in person, likely would not have happened if not for Dementia Diaries: "What would we have done if we didn't have dementia diaries? We wouldn't be picking up the phone, we wouldn't be sharing these emotions, we won't be sharing these good days and bad days." [P3].

Being able to help others through sharing information or social support signifies to diarists that they can continue contributing back to society. P5 said that, "doing the diaries helps me cause I feel I've got a purpose. And I feel valued… I feel good that I'm of use, and I'm not just nothing but dementia. It gives me good feeling, value to develop purpose." Diarists challenge the assumptions they, along with others, hold regarding the ability of people with dementia to contribute to the betterment of society [6, 39].

4.2.2 Challenging perceptions of dementia through mundane accounts. Diarists have ambitions of reaching far and wide with their messages, beyond those who have or might develop dementia. When asked if there was a particular population they'd like to reach with their recordings, diarists responded "the whole world," [P4] and "the universe" [P8]. As opposed to raising awareness of dementia by calling attention primarily to the severity or symptoms of the condition, diarists push people to reconsider what it means to live with dementia. Often, this involves sharing mundane accounts of life with dementia. P8 described making an audio recording about his journey to the gathering, describing how "we had such a wicked time on the train, educating those people on the train. It was a bunch of old fogies with dementia and we were completely blowing away their young concepts of what dementia meant." Challenging these ideas meant showing "dementia isn't sitting in the corner dribbling and not able to do anything… We were having a real good laugh. And we were able to interact with each other and have a conversation" [P14]. In these quotes, something as taken for granted as having a laugh with friends becomes radical when it is a person with dementia doing it: P8 explained that, "people are gobsmacked that we are articulate." Just sharing an authentic, mundane experience can spur a reconsideration of what one knows about dementia. At the same time, this emphasis on dominant norms of expression and engagement can marginalize those who cannot engage in this way – specifically, people with more advanced dementia, when verbal communication becomes more difficult [39]. The barriers to inclusion in Dementia Diaries for people with more advanced dementia was something noted by some diarists and facilitators. The tension between challenging existing views of people with dementia as unable to express meaningful opinions, and how the pressure to do so obscured some of the realities of dementia, is a topic that we return to in the following section.

Past research has noted the tremendous fear that people have towards developing dementia [60]. In changing attitudes towards dementia by showing the possibilities of continuing to engage in everyday life, diarists are changing the way that the condition may be experienced by others, as anyone might develop dementia (with increasing prevalence the longer they live). P5 described a time she played diaries to a group, and, "There was an... elderly lady, and on the way out she said, it's one of the things she'd always been frightened of is getting a diagnosis of dementia. And she said, 'I won't be frightened anymore.'" P2 described a vision where practitioners such as providers, "will start to point people to Dementia Diaries and say, 'Go and have a listen. See what you can do.'"

4.3 Shaping Diaries

The goals of Dementia Diaries — influencing attitudes and understanding towards dementia — was based on the premise that "real and raw" expressions should be shared. However, we find that in practice, there are competing goals that lead to the filtering and shaping of diaries. This filtering and shaping occurs in several ways: through the Dementia Diaries infrastructure, moderating by facilitators, and self-editing. We describe the three primary purposes of filtering and shaping diaries: in pursuit of the goals of drawing a wide audience, changing attitudes about dementia, and maintaining a safe, non-judgmental space for people with dementia.

4.3.1 Shaping diaries to attract listeners. Though some diarists describe shaping diaries or even targeting them to attract listeners, drawing a wide audience is a concern primarily handled through editing and the sociotechnical infrastructure of the platform, as well as outreach efforts by diarists and F1. One concern about reaching broad audiences is diary length. F1 explained how important it is to "keep it snappy" to attract readers, as "we are in a very clicky society." She introduced statistics about listenership: that audio recordings longer than a couple minutes saw a steep drop-off of listeners. In addition to stressing this point at the gathering, the infrastructure was set up to guide short recordings: the audio message platform beeped when recordings reached two minutes, and the answering machine message asked people to keep messages to under three minutes if possible.

For some, keeping diaries short was no problem. Others said that they feel rushed by the message and the beep. To minimize the anxiety of sticking to a time, some diarists recommended changing the wording on the answering machine to a "suggestion." Diarists related difficulty with sticking to the time directly to dementia: P14 said "I've now got to deal with my condition being about... perseveration, which is not knowing when to stop talking. And I just go on and on and on. And in the end, people have to go, 'Shh!'... You can almost imagine that shepherd's crook coming across and pulling me off." Though some diarists understood the need for a time limit, shaping the form of diaries in this way means that some experiences might not be shared, or some people might not be able to contribute.

When diaries are not "snappy" enough, facilitators struggle with decisions to shorten or split long diaries, or to delete long pauses. F1 explained that, "We don't [edit] lightly," as "the whole point is the raw and real voice... we don't want us to decide what's important." This quote indicates that F1 sees editing as somewhat in tension with sharing the real voices of people with dementia. Ultimately, facilitators justify editing in two ways. First, they recognize it is necessary to reach a big audience, a "common goal" [F1] of diarists and facilitators. Additionally, facilitators see these tensions as not specific to dementia, but rather as applying to anyone directing creative expression: "Those are the sort of challenges that any editor faces in making a film, or a book, or whatever... You have to be thinking about how to get maximum impact on your audience while staying true to the subject and the people." And, facilitators found that diarists are accepting of these edits during the gathering: most diarists said that they would be comfortable if facilitators decided to shorten their messages, though P4 wanted to be contacted regarding what to take out. But participants were also enthusiastic about alternatives that would guide them to shorten recordings, such as using an egg timer to keep track of the time.

4.3.2 Changing attitudes versus revealing the real. Diarists discussed choices they made while recording to depict particular narratives of dementia – choices that can be seen as in tension with sharing the "real" face of dementia.

P9 shared that she kept her diaries "positive," as "so many people kind of turn their faces to wall or think that life has ended [when they are diagnosed], and I don't want to continue that. I have other places where I can moan, but I don't think Dementia Diaries is the place to do it." Diarists sought to challenge the doom and gloom narrative of dementia that dominates dementia discourse [51, 66]. Throughout the gathering, diarists identified positive aspects of living with dementia: life as "richer" (P3) or increased confidence in the public spotlight.

Because of this emphasis on positivity, some diarists described hesitance to share difficult times or "moan" on Dementia Diaries, and one diarist questioned whether events in her life were interesting enough to share. In response to these sentiments, diarists and facilitators were quick to respond that the diversity of experiences with dementia was important to show, and that given that this was someone's authentic truth – their real account – it deserved to be expressed and heard. F2 said, "there is no right way" to use diaries except to "talk about what [you] want to talk about" [F1]. P8's statement reinforces this idea that diaries don't need to fit a particular agenda of what it means to have dementia: "whether they are right or wrong we feel them." This message – that diarists should use the diaries to express whatever they wished to – was reinforced throughout the gathering by facilitators and fellow diarists. Overall, partly due to this encouragement from other diarists and facilitators, Dementia Diaries has become a space where the full complexity of life with dementia can be shown: the positive, the mundane, and the challenges.

4.3.3 A polished presentation versus revealing the raw. There were many unresolved discussions throughout the gathering that centered around the tension between sounding "raw" (i.e., the way someone with dementia actually sounds) and striving for a polished presentation. Though some diarists record spontaneously, and do not mind stumbling or leaving pauses that might be linked to cognitive impairment, others do not feel comfortable leaving raw sounding recordings. One approach some diarists described taking was to write out what they wanted to say, then reading off of that script to create a recording. P14 said he liked having a script written ahead of time, "Because then there aren't those gaps of – well, you can almost feel it sometimes. You can feel the cogs going 'round and you want to get a little bit of 3-in-1 oil and go and get it moving again." P14 also mentioned that with dementia, he has become such a perfectionist that it sometimes took him "hours and hours" to perfect a transcript for a recording, as "I want to make sure that the language is correct, that I'm not tripping up over any of the words that I normally do, that I'm getting it in the right sequence and all that sort of thing."

Some diarists believe that these professional sounding diaries give an inauthentic portrayal of what life with dementia is like to listeners. P5 said that, "people don't see [a polished sounding diarist] as dementia's affecting him… he doesn't seem to be struggling. But actually, he is struggling." P5 described these diarists as giving off "a bit of a false impression," rather than "getting the rawness out, dementia as it is." Even diarists who write transcripts ahead of time to sound more polished acknowledged that it does obscure reality somewhat. P14 made an analogy that reading from the script is like a "superman version" that doesn't look like dementia, but he is more like Clark Kent. This critique over their own diaries reveals a tension they felt between wanting to make diaries more presentable and having an authentic sounding recording.

4.3.4 Moderating to maintain safety. Another place tension arises between authentic expression and other goals was in protecting a sense of safety in the community. Though F2 acknowledged that everyone "self-edits," much of the filtering to promote safety discussed at the gathering takes place through facilitator efforts.

F1 referred to concerns that arise when people experience 'heightened emotions': "And of course all human beings can have those ... But they [diarists] also made the point that when you have dementia you often, not always, tend to experience heightened emotion more often. You're more sensitive to different things that happen to you, or maybe react a bit more than you would have in your previous life, and get upset more easily." This change in emotional experience was brought up by several other diarists and has also been discussed in past work on dementia and HCI [39]. In addition to heightened emotion, the sense that one could express whatever one was feeling in the "here and now" in a safe space may have contributed to revealing content that might affect the safety of the space. Specifically, F1 described "the risk that they might say things or present things that in the cold light of day, or in a couple of days time they might feel 'Oh, I wish I hadn't said that,' or that they are offensive to other people and that they regret that." The facilitators are particularly careful when it came to diaries that "slag people" [F1] (say rude things about people). At last year's gathering, the group had come to a conclusion that diaries that criticize named individuals should not be posted online, and this sentiment was reaffirmed this year. P14 mentioned that this was particularly important given that "we are spreading our influence in the world" – the goal of having real, far reaching impact – as well as the permanence of content online, as once content is online, "it remains there like a dirty moth on the wall that's never going away."

F1 told us that F2 had to reach out to diarists a couple times who were speaking about others "in an aggressive way." P5 shared her own experience on the receiving end: "A couple of times I have said, I didn't realize, or I was quite upset, maybe I was having a bad day, or I might have mentioned a name and [F2], I think she's messaged me twice and said, 'Are you sure you want that to go out?' ... then I'd think, 'oh yeah, maybe.' You know when you say something, as I say I'm just [doing it] to offload, you may not want that."

Several other diarists shared times that they appreciated when F2 reached out, whether to check on them or make sure they didn't share something that might offend others. P7 shared her enthusiasm at having a moderator in the context of changes she had experienced with dementia, saying, "It's nice to know that you [Dementia Diaries] are going to soften it because I've always been blunt but I've gotten more blunt and irritable with the dementia." P8 appreciated that Dementia Diaries provided "buffers" as he felt that "... living on [my] own there's nobody to really bounce things off of ... and particularly with vascular dementia or... FTD, your social filters vanish and you're more likely to say things out of place without really thinking about [it]..."

In addition to reaching out directly to the diarist, there are several other strategies facilitators utilize to ensure that diarists are sure they want to share raw, emotionally charged diaries. First, facilitators gather the name of an emergency contact when people sign up to be diarists so that they can reach out if someone leaves a recording that indicates an emergency. But P1 reacted to this idea strongly, saying "Ask me first before you contact my daughter." This reaction is not surprising given the ways that some diarists – including P1 – intentionally keep their family lives and diaries separate so as not to worry family members. A second strategy involves waiting to see if people still want to share something once time has gone by. F1 shared an anecdote of when a diarist’s wife had died and:

> “about half an hour after she died, he sent a diary...And then he kept sending them all through the week… We thought that he wanted them published, but we waited and then after a few days we checked back with him … when he was ready to have them published, then we did. We didn’t want to do it straightaway because we weren’t quite sure that he was in a state to make that decision.”

This strategy was appreciated by P9, who shared an anecdote of when she had left a recording indicating she was bothered about something, F2 phoned her to ask her if she was alright. P9 said, “I felt that I could have a second chance if I hadn’t wanted to say that... Because your mood changes and you might feel very down when you make a recording. But there’s always the sense with Dementia Diaries that there's someone looking out for you…”

Despite the general group consensus that it is acceptable to moderate these kinds of posts – summarized by P5’s comment, “we trust you to make that sort of decision that its acceptable to put on or not” – F1 shared that some individuals had reacted negatively to F2’s reaching out about a post being problematic as they, “felt they were being censored.” F2 herself responded to enthusiasm for her judgement saying that she appreciated the faith in her, but she had made mistakes before and “gotten slapped on the head.” She said “I’m going to muck up one day. And you’ll be cross.” Having to decide when to moderate a diary – and the negative reaction she sometimes gets from diarists – weighs heavily on F2. And some concern was present even for diarists who had expressed positive sentiments about moderation in the gathering. For example, even the individuals who were most enthusiastic about moderating wanted the facilitators to reach out to them to check with them, rather than just deleting a diary. Though overall, the sensitive way in which facilitators interacted with diarists to ensure they did not make hurtful statements to other diarists or post something that they would later regret contributed to the safety of the community and consequently the willingness diaries had to share, these interactions also pose complex challenges in terms of the organization’s goal of supporting “real and raw” expressions.

5 DISCUSSION

Our findings reveal a case where through a sense of safety, community, and a non-judgmental space, people with dementia are facilitated in new forms of engagement online – specifically, sharing their authentic priorities in order to influence change and shape attitudes. This work relates to the growing interest in supporting people in discussing sensitive and stigmatized health and disability-related conditions, as well as what different forms of health activism look like and how they can be fostered. In this section, we discuss the relevance of our findings to CSCW.

5.1 Configuring a Space for Dialogue on Sensitive Topics

Dementia Diaries provides a space for people with a stigmatized health condition to share authentic concerns and priorities, in turn challenging existing ways of thinking about their condition. Below, we describe the sociotechnical factors that we believe were essential for the success of this platform.

First, a sense of safety was essential for diarists to share authentic, vulnerable expressions. Key to this sense of safety was the perception of Dementia Diaries as a non-judgmental environment that accepts people as they are. Because they trusted the platform, diarists were willing to share vulnerable thoughts even knowing that their recordings would be shared far and wide, where anyone might listen to them. An important consideration for CSCW is that the, as P13 put it, "values [that] flow through" different platforms affect what individuals are willing to disclose about their health conditions. This is particularly salient for researchers using methods such as Asynchronous Remote Communication (ARC), where participants may be brought together for research activities around sensitive topics such as living with rare diseases [50] or HIV [52] on commercially available platforms such as Facebook.

A second, related factor that contributed to the success of the platform can be discussed by further investigating the safety diarists felt despite knowing in theory, anyone might be able to see their diaries (i.e., diaries were not shared in a private online group). Though some diarists shared all of their experiences with loved ones, we can see how others work to establish boundaries around their dementia-related content online to protect family members working through real pain and loss or dealing with "dementia overload." Past work has considered the ways that others, such as therapists, think of how family and friends might be vulnerable when viewing expressions of loved ones with dementia [43]. Here, we see the strategies that people with dementia themselves use to navigate this situation. Design efforts can be inspired by the semi-permeable boundaries created by diarists, where links to dementia-related content were placed in email signatures so that the recipient could decide whether, when, and how to engage. As researchers continue to widen their support and investigation of health activism, considering the feelings of those closest to these individuals will be important. It is important to note, however, that for individuals who are not comfortable revealing that they have dementia to the public, and entirely different configuration would be necessary to support sharing expressions widely (for example, developing the ability to anonymize recordings while preserving affect).

A third element essential for the success of this ecosystem was the sensitivity with which moderators engaged the community. Facilitators strike a delicate balance between providing a sense of safety for individuals by ensuring that diarists do not say hurtful things or post things that they will later regret, while minimizing diarists' feelings that they are censured by moderation (which both causes them to lose trust in Dementia Diaries and also prevents sharing of real and raw expressions). This tension hearkens back to the classic tradeoff oft-discussed with dementia, between autonomy and safety [38, 64, 69]. Here, we find that diarist trust in the moderator is essential for their acceptance of decisions that they make. This trust develops over time, with close online and offline engagement, and a sense that the best interests of people with dementia are indeed being looked out for. Past work has found that moderators are often focused on community management and preventing misinformation – where community members are typically the ones providing the emotional support – and that moderators can inadvertently end conversations when they step in [34]. Our work suggests that in some contexts, moderators can do important emotional support work that may lead to an increased sense of safety and comfort sharing for the community. The key difference may be that facilitators in the Dementia Diaries context encourage people to share whatever they wish, positioning them as the experts in their own lives, while health moderators may indicate that people need to seek answers elsewhere (i.e., from their doctors [34]) or attempt to give conclusive answers.

As much as moderation was appreciated for leading to a civil and caring online community, a concern around applying findings from this study to others is the scalability of this kind of moderation. This concern was noted by facilitators and some diarists. Further work in similar contexts can investigate community members as moderators (as in [22]) or even crowdsourced moderation (as in [28]). It will be essential to assess receptiveness of community members to such an approach, whether trust would need to be established with each moderator or trusting an organization is enough, and how such an approach would affect the sense of community.

5.2 Health Activism

We present the work of the diarists as a case of health activism, where those involved are attempting to change the status quo through raising awareness and challenging social norms, practices, and policies [80]. Traditional dementia awareness methods that focus on what dementia is or how to recognize it can be seen as health advocacy, as they work within the system. In contrast, diarists are engaging in direct action to challenge the medical paradigm [10]. This includes spreading awareness that a person living with dementia is still a person (which may be taken for granted in other contexts, but a dominant narrative of dementia implies a loss of one's "self" [5, 6]), and that life with dementia is not a downward spiral, but contains complexity and emotional valence. Below we discuss several considerations for CSCW.

First, we can consider how, for a group who is often spoken for by others, *expression is activism.* And, the sharing of even the most mundane accounts is a radical act for a population who is seen as having lost their personhood [6]. Yet, even as individuals shared daily occurrences and thoughts in the moment, they considered what their expressions said to others about dementia. The ways diarists shape their messages have implications for what impression management – a topic well-studied in CSCW – means in the context of health activism. To date, research on impression management has focused on how people disclose information related to their own disability (e.g., [61]) or health condition (e.g., [7]). In our data, however, people are managing impressions not only of how their condition affects them, but also of the condition itself – deciding whether to share sad stories, or only positive ones, whether to show stumbles or keep their presentation perfectly polished. Understanding the decisions people make reveals their assessments of what is most damaging in narratives of the condition as well as the image they find important for others to see.

Considering impression management of a condition leads us to consider what perspectives might be silenced, inadvertently or intentionally, in order to shape a desired image of a condition. Research has found that there is a reluctance in the Deaf community to have people with dementia in public-facing involvement, due to a fear that their inclusion may reinforce negative stereotypes of Deaf people [79]. Even movements centered around dementia sometimes lean towards featuring only the most polished stories, or at least those who can share verbal accounts that challenge perceptions of dementia. Opening up the movement to diverse expressions, particularly non-verbal ones [42], is a long-term goal of the facilitators of Dementia Diaries for exactly this reason. Doing so will also require facing complex questions about decision making and ways to share non-verbal expressions online.

Second, this work encourages us to take note of the entire activism ecosystem when considering any single organization or platform. Many of the messages shared about dementia echo and reinforce broader activist messages, and diarists explicitly mention the work of dementia activists Agnes Houston and Kate Swaffer in connection to the narratives that they were working to spread. Further, given that diarists' engagement in health activism pervaded their online and offline lives, we can see several ways for individuals to move up the rungs of the "stepping stones" of health activism [54] using multiple technological and analog entry points. Accessing content produced by instrumental figures such as Houston and Swaffer provides people with models of activism as well as new frames for understanding dementia. This approach aligns with past work, where people are more likely to engage in activism when they see "power users" engage in actions such as signing online petitions [33]. And an in-person gathering can be an important way of moving people "up the engagement pipeline" [54], and help us further understand how online interactions translate to the offline context [32] in the domain of activism.

Our analysis of the different factors involved was dependent upon us, as researchers, attending to conversations between people involved in the platform. And, we believe that attending an in-person event yielded particularly fruitful findings. Other approaches, such as an analysis of the content of diaries or comments people write to each other on Twitter likely would yield a rich set of results on what diarists wish to share, but not of the sense of safety necessary for them to post a diary, the ways they attempt to shape attitudes, and the tradeoffs that are made when doing so. Though the approach of being in the room where discussions about the use of a platform requires buy-in (both in terms of building a relationship with the organization over time, and ensuring mutual benefits for both parties –in our case, this involved contributing to workshop costs), we find that studying interactions between users of a platform as a valuable approach to understanding online ecosystems.

As useful as this approach was, additional research is needed to assess the impact of the work Dementia Diarists do, which cannot be studied by attending an in-person gathering or even scraping online data. We join Parker's call for studies that measure how health activist tools create change [59]. One approach might measure attitudes toward dementia using standardized instruments or interviews before and after exposure to diary recordings. It will be useful to draw on the fields of communications and media studies in order to extend CSCW's ability to develop "closed loop" understandings of the technologies that we build and study. This is particularly important given potential unintended consequences – in this case, to give an example, considering whether exposure to diaries might actually increase stigma towards the condition.

5.3 Sharing Online and Dementia

Past work has examined the importance of sharing for people with dementia [21] and has begun to examine how to interpret preferences of less verbal individuals with dementia for sharing online [43]. The present work adds a number of considerations to these discussions.

Accessibility is necessary to support people with dementia in sharing online, but we are currently lacking a comprehensive understanding of how to create accessible systems and environments for people with dementia. Diarists shared how even organizations devoted to dementia may not understand or take precautions necessary for accessibility. A further analysis of how projects such as Dementia Diaries create accessible physical and digital spaces is required, but there are some relevant findings in this paper. First, the "here and now" approach to recording appears to work well for diarists, an idea supported by past work on "in the moment" programs for people with dementia that promote interaction that does not rely on people's ability to recall particular facts or events [46]. Being able to use their phone to call and leave a recording, rather than navigating to a particular website or application seems to have contributed to the ability to make these recordings in the here and now, and introduces a link to other phone-based systems (e.g., [9]) as avenues to explore for this population. Using traditional phone-based interfaces may increase access to online platforms for people who are not regular or proficient technology users – currently, many studies that analyze online discourse highlight the voices of the tech proficient. Second, dementia impacts people very differently, resulting in different needs for a platform. Some diarists have trouble sticking to a brief time limit while others find that this works well for the way they now communicate. And while many diarists find spoken communication an approach that works well, others prefer starting with written communication. One approach to addressing these differences might direct longer form content towards other platforms so that individuals can benefit from affordances that long-form expressions provide (described in [8]). Another approach might investigate ways to "translate" content to fit the platform (e.g., allowing someone to select a synthesized voice to read their text aloud). Further work is needed to ensure that individuals with different needs and abilities in dementia can access the places in which agendas are being set.

CONCLUSION

Researchers, policy-makers, and designers are looking to avoid tokenism and instead support active involvement from individuals with myriad health conditions and disabilities. This paper presented a case study of a project in which people with dementia share their authentic priorities in order to achieve a goal – to influence change. We found that individuals felt comfortable sharing "real and raw" accounts due to having a non-judgmental community, a separate place and space to share dementia-related thoughts, and trustworthy facilitators. However, tensions emerged when pursuing the goal of influencing attitudes, reaching a broad audience, and maintaining a safe space. Based insights from this work, we can better understand and design systems for people to share sensitive health information, engage in health activism, and share online with dementia.

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