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# “You Are Not Alone!”: A Thematic Analysis of Activist Goals and Antecedents of Online Dementia Activism

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## Abstract

While dementia-related content on Twitter (X) is often stigmatizing, social media also serves as a powerful platform for dementia advocacy. Using thematic analysis, we coded the posts of 23 dementia activists ($n$ = 2,026 tweets). Guided by two social psychological models, we examined four established *antecedents of collective action*—social identity, perceived efficacy, perceived injustice, and moral obligation—alongside four *activists’ goals*: information dissemination, influence, support provision, and personal experience sharing. We found empathic concern to be a powerful antecedent, manifesting as compassion, humanization of persons with dementia (PwDs), and co-production of knowledge. Social identity and perceived efficacy were more prominent than traditional antecedents like injustice or moral outrage. Activists often framed dementia in ways that fostered identification as a member of the dementia community, empowerment, and belonging. Support giving and experience sharing were the primary goals of dementia activists, indicating a strong focus on sustaining the ingroup rather than addressing injustice or fighting for societal change. These findings underscore the need for expanding existing models of collective action to better account for online identity-affirming and community-support actions in disability communities and emphasize empathic concern as a key mobilizing force in dementia activism. We discuss the implications of a new model of online dementia activism and the role of online dementia communities as effective platforms for activism and support.

## Keywords

#dementia, #Alzheimers, activism, dementia, collective action, dementia activists

## Non-Technical Summary

### Background

While dementia-related content on Twitter (X) is often stigmatizing, social media also serves as a powerful platform for advocacy on behalf of people with dementia. Because Twitter enables fast and convenient sharing of information and because tweets can be easily retweeted, Twitter offers an effective space for social change, including by activists who are living with dementia themselves.

**Why was this study done?**
This study explored why people engaged in online dementia activism on Twitter. By analyzing tweets from people with dementia, care partners, and allies, the current study revealed important insights into what drives activism in this community and how it differs from other types of social movements.

**What did the researchers do and find?**
We analyzed 2,026 tweets from 23 dementia activists. A key finding was that online dementia activism is shaped more by identity and efficacy (i.e., feeling like part of a group and believing that one's actions can make a difference) than by injustice or moral outrage, which are more common causes of collective action in other activist groups. People often used hashtags and symbols (e.g., color purple or kindness-themed mugs) to show they belong to the dementia community and to form connections and empower others. Rather than calling for broad political change, many users focused on smaller but meaningful acts, such as offering support, sharing personal stories, and helping others feel seen and understood. Another significant finding was the presence of empathic concern for the wellbeing of others as a major reason people engaged in dementia activism. Empathic concern is reflected in posts where users show compassion, teach others kindness, and embody understanding and care toward people with dementia and care partners. Support giving was the most common goal and included offering emotional encouragement, validating others' experiences, and sharing or amplifying personal stories to help others feel less alone. Activists also shared information and resources, ranging from caregiving tips to scientific facts, aimed at educating both the dementia community and the public. Sharing personal experiences was another key goal, with many tweets featuring first-person stories from people living with dementia or care partners. These narratives helped challenge negative stereotypes and showed that people with dementia can still make their own choices, have their own identity, and contribute meaningfully. However, tweets focusing on injustice, such as discrimination against people with dementia, were relatively rare and mostly came from users who held multiple identities (e.g., being both LGBTQIA+ and living with dementia).

**What do these findings mean?**
The current study calls for a new model of online dementia activism that reflects its unique characteristics: empathic concern, identity, self-efficacy, and a strong emphasis on support from one's own group. Online spaces are not only platforms for advocacy but also vital sources of emotional support and community-building for people living with dementia and their allies. Recognizing the power of these online networks could guide the development of better advocacy strategies and policies that amplify and validate the voices and needs of people with dementia.

> *"Compassion, empathy, moral good, personal experience. It's different for everyone. But it makes change happen. How big are your networks?"*
> (George Rook, December 18, 2015; https://georgerook51.wordpress.com/)

As suggested by George Rook, an activist living with dementia, social change can emerge through social networks where individuals mobilize to support people living with dementia (PwDs) and their care partners. In this paper, we examine what motivates online dementia activists to engage in collective action. While dementia-related content on Twitter is often stigmatizing (Ang et al., 2025; Oscar et al., 2017), social media platforms also offer unique opportunities to raise awareness about dementia, advocate for PwDs, and support care partners (Ang et al., 2025; Bacsu et al., 2024; Lazar & Dixon, 2019; Talbot et al., 2020). Importantly, Twitter (now X) enables collective action, not only for organized social movements (Wang & Chu, 2019), but also by individuals who are united by a common cause and a shared desire for social change (Smith et al., 2015). Such engagement can foster the development of new social identities as dementia activists (Prato et al., 2022).

Because Twitter allows for fast and convenient sharing of information and opinions, and because tweets can be retweeted, users have the potential to reach a vast and diverse audience as their messages spread through various social networks (Valenzuela et al., 2014). Moreover, the concise nature of tweets is preferred by PwDs, as this format accommodates their cognitive and communication needs better than other platforms (Talbot et al., 2025). Twitter is, thus, a powerful and convenient platform for social change and advocacy by dementia activists, some of whom have dementia (Talbot et al., 2020).

Research has recently begun to examine the content of tweets, posts, and blogs authored by PwDs (Talbot et al., 2020), their care partners (Anderson et al., 2017; Bartmess et al., 2022), and dementia activists and allies (Talbot et al., 2020). However, there is a scarcity of theory-based investigations of what drives engagement of PwDs and their advocates in online dementia activism. The present study addresses this gap by offering an initial exploration of the motivational processes underlying online dementia-related activism, with a focus on the goals and antecedents of collective action within this digital community. To this end, we conducted a thematic analysis of tweets and retweets posted by dementia activists on Twitter.

## Online Activism

Collective action has traditionally been defined as behaviors that individuals engage in with the goal of promoting, protecting, or enhancing a group's welfare (Louis et al., 2019). Online activism is now widely recognized as a legitimate form of collective action (Leonel et al., 2024; Theocharis & van Deth, 2018), with similar antecedents and goals as offline activism (Alberici & Milesi, 2013; Ayanian et al., 2021). Online activism encompasses both political and non-political behaviors including informal interpersonal acts, such as tweeting to show support or disseminate information, that are often undertaken by marginalized groups (Miron et al., 2022). These online actions facilitate offline activism and contribute to broader social change (Chon & Park, 2020; Leonel et al., 2024; Nasrin & Fisher, 2022).

Recent research highlights the crucial role of online activism in rapidly mobilizing individuals from heterogenous communities as well as influencing corporate behavior, social policies, and practices (Leonel et al., 2024). Online platforms are thus not only effective at quickly activating participation (i.e., *high velocity*) but also facilitate *connective action*—the informal coordination of individuals with varied identities and beliefs that share personalized content through decentralized networks (Bennett & Segerberg, 2012; George & Leidner, 2019; Leonel et al., 2024). Through such networks, individuals may spontaneously form ad hoc coalitions by engaging in actions like signing or sharing e-petitions, which can successfully influence a broad range of stakeholders (Leonel et al., 2024). Moreover, social media facilitates both grassroots and organized social movements, allowing users to connect, mobilize, and amplify messages within their networks (George & Leidner, 2019; Wang & Chu, 2019).

One of the unique uses of social media is facilitating the dissemination of narratives and counternarratives about marginalized or disadvantaged groups (e.g., Ang et al., 2025; Satterlund et al., 2025; Talbot et al., 2020), therefore influencing research, practices, and policies (Talbot et al., 2025). Social media has provided a unique avenue for organizations supporting PwDs and their care partners to advance their social movement goals and "change ways of thinking, caring, and living with dementia" (Lazar & Dixon, 2019, p. 3). Moreover, social media has a strong social support function by providing activists living with dementia with a safe space for connecting with other PwDs and reaffirming their identity (Graf et al., 2025; Talbot et al., 2020; Talbot et al., 2025). These findings underscore the importance of studying online activism to better understand its antecedents and to assess whether existing models of collective action can adequately explain dementia activism in digital spaces.

## Antecedents of Online Activism

We focused on the four established antecedents of collective action proposed by van Zomeren and his colleagues (van Zomeren et al., 2008, 2018) as part of their Social Identity Model of Collective Action (SIMCA). According to SIMCA, identifying as a member of the group or feeling meaningfully connected to the group (*social identity*), appraised injustice of treatment of a group (*injustice*), perceived efficacy in achieving the goals of action (*efficacy*), and beliefs about the morality of group-based inequality or discrimination (*moral obligation*) predict collective action. Social identity and particularly activist identity predict collective action directly and indirectly through appraised injustice and perceived efficacy (van Zomeren et al., 2008). Identification as an activist predicts both traditional collective action (e.g., signing petitions) and small acts (e.g., "liking" a post about a social issue on Facebook) (Miron et al., 2022) and is particularly important because it involves embracing ingroup ideology (van Zomeren et al., 2018). Dementia activists endorse a shared ideology that emphasizes the personhood and self-advocacy of PwDs and acknowledges the challenges faced by PwDs and their care partners (Talbot et al., 2020; Weetch et al., 2021).

Support for SIMCA has been found across various social and political contexts, including collective action in oppressive regimes (Ayanian et al., 2021), engagement in online political discussion (Alberici & Milesi, 2013), and collective action support one year later in both advantaged and disadvantaged group members (Thomas et al., 2020). However, no work has yet explored whether online dementia activism is influenced by similar socio-psychological antecedents as the ones advanced by SIMCA. In the current study, we do that by conceptualizing *social identification* as degree of identification as a dementia activist or any other dementia-related identities (e.g., care partner of a PwD; an advocate for dementia care partners). Perceived *efficacy* is defined as perceiving oneself or one's group as being able to create social change or advocate for members of the dementia community. Perceived *injustice* refers to appraising the situation and treatment of PwDs as unjust or harmful.

A review by Weetch et al. (2021) of seven studies on dementia activism points to evidence for each of these antecedents, even though these studies did not purposely aim to examine them. Specifically, Weetch et al. (2021) found that activists living with dementia engage in action to challenge the stigma and inequities that come from others' perceptions of dementia as an illness (*injustice*). These issues constitute threats to identity, which motivate dementia activists to join others in collective action and to develop a sense of collective identity as dementia activists (e.g., evidenced by the use of the pronouns "we" and "us" instead of "I" and "me," as documented by Bartlett, 2014; *social identity*). Advocates also gain a sense of purpose and empowerment by joining the dementia movement, where they draw strength, knowledge, and inspiration from others, regain respect for themselves and others, and feel more powerful as a community (*efficacy*) (Weetch et al., 2021).

Whereas these antecedents have been documented in prior dementia work (Bartlett, 2014; Clare et al., 2008; Hillman et al., 2018; McConnell et al., 2020; Weetch et al., 2021), what is currently missing is a theory-driven systematic test of these antecedents in a single study. Recently, van Zomeren et al. (2018) revised their theoretical model to include *moral obligation*—beliefs about what is right and what is wrong about group-based inequality or discrimination—in the prediction of collective action. With a few exceptions (Sabucedo et al., 2018; Uysal et al., 2022), this added SIMCA antecedent has received little attention in collective action research. Therefore, the current study also examined the role of moral obligation in tweets posted by dementia activists by examining statements about moral convictions, values, and rights of PwDs and their care partners.

## Goals of Activists

One theoretical model that can be useful for testing dementia activists' goals comes from work on activism among U.S. college women (Fieck et al., 2020; Miron et al., 2022). These authors documented three goals in activists: information dissemination, social influence, and support giving. Dementia activists may be driven by an *information dissemination* goal, which motivates them to distribute facts about relevant group issues, correcting misbeliefs, or communicating with others about these issues (Bacsu et al., 2024; Clare et al., 2008; Talbot et al., 2020). For instance, during World Alzheimer's Month, users' Twitter posts take the form of educational-style lessons that debunk myths about dementia or include evidence from research related to treatment options or dementia symptoms (Bacsu et al., 2024). A *social influence* goal pushes activists to influence others' attitudes, beliefs, or actions. Many dementia activists push back against dementia misconceptions and stigma and attempt to reframe dementia narratives in terms of continuation of selfhood and adaptation (Clare et al., 2008; Hillman et al., 2018; Weetch et al., 2021). Moreover, Twitter users often engage in political lobbying by advocating for government support and funding for dementia research and the development of national dementia plans (Bacsu et al., 2024). Finally, a *social* s*upport* goal sustains support-giving and support-seeking behaviors (e.g., validating others' experiences). Tang et al. (2023) found that over half of dementia caregivers use Reddit to both share and seek health information, while others post solely to share. This suggests that dementia care partners turn to social media for support, seeking information from fellow caregivers rather than from healthcare professionals or offline support groups.

Finally, recent work suggests the presence of an additional goal, *sharing personal experiences,* which was documented in #ActuallyAutistic Twitter activists (Satterlund et al., 2025). Dementia activists are often motivated to share stories of dementia on different online platforms (Bacsu et al., 2024; Lazar & Dixon, 2019; Talbot et al., 2020). Bacsu et al. (2024) found that sharing the voices of lived experiences of PwDs and their care partners on Twitter is a predominant strategy used for dementia advocacy. These lived experiences often include sharing personal challenges as well as success stories. Experience sharing is associated with the development of a positive identity in people living with disabilities (Dunn & Burcaw, 2013) and with online identity development for PwDs (Talbot et al., 2020).

No research so far has explored the prevalence of these four activists' goals in dementia activism. To fill this gap in literature, we explored the nature and prevalence of these goals in dementia activists' tweets. Moreover, only a handful of prior studies have examined online activism on social media platforms using the original SIMCA model (Alberici & Milesi, 2013; Satterlund et al., 2025). None of these studies focused on dementia activism nor tested the revised SIMCA model. Only one study has systematically tested *both* the antecedents and activists' goals in a single study (Satterlund et al., 2025), but the focus of attention was online activism by Twitter activists posting under the #Autism and #ActuallyAutistic hashtags.

The only study that has investigated the experiences of dementia activists on Twitter (Talbot et al., 2020) explored the online tweets of 12 dementia activists, who themselves had dementia, posted over a 6-month period. Based on thematic analyses of these tweets, the authors identified six themes: nothing about us without us, collective action, experts by experience, living with dementia not suffering from it, community, and stories of dementia. Talbot et al. (2020) concluded that these activists were motivated by a desire to improve the lives of PwDs as part of a collective illness identity-based social movement. Talbot et al. (2020)'s work, which showed that thematic analysis can be used to analyze and interpret micro texts (tweets), is important and underscores the need for more systematic research to understand the emerging online dementia movement.

## Study Overview and Research Questions

The current study's goal was to understand what mobilizes online dementia activists to engage in actions designed to promote the rights and wellbeing of PwDs and care partners. Specifically, the current study examined the antecedents and goals underlying online dementia activism via three research questions: 1) What is the prevalence of themes related to social identity, efficacy, injustice, and moral obligation (i.e., antecedents of collective action) in tweets posted by dementia activists?; 2) What is the prevalence of themes related to information dissemination, social support, social influence, and personal experience sharing (i.e., activists' goals of action) in tweets posted by dementia activists?; and 3) Are there any additional antecedents and goals that are specific to online dementia activism?

# Method

## Selection of Dementia Activists and Twitter Messages

To identify dementia activists for this study, we used TwitterCatcher and the following combination of keywords: dementia and advocate; dementia and action; dementia and caregiver; dementia and care; dementia and caregiving; dementia and assistance; dementia and support; dementia and help; dementia and carer; dementia and community; dementia and encourage; and dementia and promote. In addition, we employed a snowball sampling method by examining the Twitter networks (followers and followings) of the initially identified activists to uncover additional relevant users. To be included in the study, users had to meet two criteria, assessed via their Twitter bios and a brief review of recent posts: 1) Self-identification as a dementia activist, advocate, author, or caregiver; and 2) A primary focus on dementia-related content in their tweets.

This process resulted in an initial pool of 53 dementia activists. However, due to the volume of tweets and the study's focus on posts from the prior five months, we refined the sample to a smaller representative group. The first three authors reviewed the initial pool and recommended users for the final sample based on demographic information, with the goal of ensuring diversity across the following dimensions: 1) People living with dementia and those without the diagnosis; 2) Geographic location (country), gender identities, sexual orientations, and ethnic backgrounds; 3) Various activist roles, such as family care partners, researchers, authors, healthcare professionals, and advocates. The final sample of 24 activists was selected based on majority agreement and further discussion among the authors.

We selected all tweets posted between January 1 and June 1, 2023. During the tweet selection process, we excluded one user from the final sample of 24 participants because she had not posted any tweets during the sampling period. Thus, in total, we analyzed 2,026 tweets from 23 activists (number of tweets ranged from 3 to 176 tweets per activist). The activists had posted on average 3,187.7 tweets (range = 187–92,700). The activists had on average 3,069.5 followers (range = 433–61,100) and were following on average 2,573.1 Twitter users (range = 389–44,800). Six activists had dementia and eight were current or former care partners of a family member with dementia (see Table 1 for demographics).

**Table 1**

*Participant Demographics*

| | Pseudonym | Type of Activist | Gender | Followers | Following |
|---|---|---|---|---|---|
| 1 | Sophia | Scientist/Researcher | Woman | 5587 | 2502 |
| 2 | Mia | Advocate | Woman | 684 | 1821 |
| 3 | Ethan | Person with dementia | Man | 15100 | 15700 |
| 4 | Violet | Scientist/Researcher | Woman | 4480 | 1938 |
| 5 | Hazel | Advocate | Woman | 2150 | 1619 |
| 6 | John | Advocate/Scientist/Family care partner | Man | 61100 | 44800 |
| 7 | Liam | Family care partner | Man | 6571 | 4138 |
| 8 | Harper | Family care partner | Woman | 4508 | 4346 |
| 9 | Isla | Family care partner | Woman | 433 | 429 |
| 10 | Emily | Advocate & Medical Professional | Woman | 3770 | 3531 |
| 11 | Zoey | Dementia book author/Family care partner | Woman | 2325 | 1513 |
| 12 | Ruby | Medical Professional & Dementia book author | Woman | 8698 | 8545 |
| 13 | Casey | Advocate + Dementia book author | Unknown | 2756 | 2487 |
| 14 | Taylor | Person with dementia | Unknown | 1338 | 869 |
| 15 | Aurora | Family care partner | Woman | 1663 | 985 |
| 16 | Jamie | Person with dementia | Unknown | 993 | 475 |
| 17 | Alex | Family care partner & Scientist/Researcher | Unknown | 1614 | 389 |
| 18 | Aubrey | Advocate | Woman | 2294 | 2550 |
| 19 | Ava | Person with dementia | Woman | 2471 | 1150 |
| 20 | Henry | Person with dementia | Man | 11100 | 9832 |
| 21 | Nora | Person with dementia | Woman | 5148 | 2648 |
| 22 | Mary | Person with dementia | Woman | 18700 | 904 |
| 23 | Noreen | Family care partner | Woman | 837 | 1363 |

The authors' university IRB determined that this project did not meet the definition of human subject research because the data were public. Therefore, informed consent was not deemed necessary. Nevertheless, to protect the identity of dementia activists, we decided to avoid direct quotes from the participants that could be easily tracked. When needed, paraphrased tweets and aggregated quotes were offered as examples. In addition, we used pseudonyms instead of actual names and excluded any identifying participant information.

## Data Coding and Analysis

Twitter messages were analyzed, by the first and second authors, using a reflexive thematic analysis, following the steps outlined by Braun and Clarke (2014) and employed by other researchers (Bacsu et al., 2024; Talbot et al., 2020) to analyze tweets posted by PwDs. In the first step, tweets from each of the 23 activists were analyzed by identifying the antecedents and goals using the two theoretical frameworks discussed in the introduction. The tweets from each activist were analyzed holistically in the context of that activist's life story and experiences, as discerned from the tweets and Twitter profile. In the second step, a classification of antecedents and goals of activism was produced. This classification was further revised after reviewing the original themes and subthemes and after further discussion. In the third step, the most illustrative excerpts were selected; however, to protect the identity of the participants, messages were paraphrased or described broadly. Moreover, frequency of each antecedent and goal was calculated to understand their prevalence in this sample.

# Results

## Antecedents of Online Dementia Activism

Some antecedents of action (social identity and efficacy) were more ubiquitous than others (injustice, moral outrage, and empathic concern). Tables 2 and 3 include the themes/subthemes related to the antecedents and goals, respectively, expressed by the dementia activists in their tweets and retweets. Table 1S in Supplemental Materials includes examples of paraphrased participant tweets for each of these themes/subthemes (see Miron et al., 2025S).

**Table 2**

*Dementia Activism Antecedents: Themes and Subthemes*

| Antecedent | Conceptualization | Operationalizations | Evidence-based Themes and Subthemes |
|---|---|---|---|
| **Identity (Self-expression) (20/23)** | Perception of being part of a group; feeling strong ties and common fate with the group | • Themes related to expression of dementia-related social identities: dementia caregiver, dementia activist, person with dementia<br>• Use of inclusive pronouns ("we") and other identity words/cues | • Different activist identity profiles/prototypes<br>• Simultaneous operation of multiple social identities (intersectionality)<br>• Use of different identity markers<br>• Activism goals as identity-expression<br>• Rejecting dementia as a self-defining identity dimension |
| **Efficacy (19/23)** | Seeing collective action as effective | • Themes related to perceptions of self or ingroup as capable of engaging in various actions and behaviors<br>• Themes related to power, empowerment, competence, or ability of PwDs, care partners, and activists | • Efficacy takes many forms of expression: highlighting others' collective action efforts; efficacy as a self-defining identity characteristic, empowering others; validating others' experiences/supporting others; modeling efficacy in personal stories<br>• Use of "hope" as efficacy cue<br>• Seeing collective action as effective (infrequent) |
| **Injustice (5/23)** | Perceiving injustice against the group | • Themes related to perceptions of unfairness of treatment of PwDs and/or their care partners<br>• Themes related to expression of anger or frustration at injustice | • Primarily present in narratives of activists with multiple identities<br>• Different injustice concerns get tweeted/ retweeted about marginalized groups and dementia-related issues |
| **Moral Obligation (9/23)** | Moral convictions, values, and rights; group morality | • Themes related to perceptions of treatment of PwDs and care partners as immoral, morally wrong, or dehumanizing<br>• Themes related to expression of moral outrage at dehumanization of PwDs<br>• Themes related to morality, values and moral standards and rights of PwDs and care partners | • Moral outrage and pushing against dehumanization of PwDs<br>• Sustaining and highlighting personhood of PwDs and care partners<br>• Providing evidence of their own personhood despite dementia<br>• Advocating for personalized care options |
| **Empathic concern (10/23)** | Empathy and concern for others' welfare | • Themes related to expressions of empathy, compassion, and empathic concern for PwDs and care partners | • Teaching empathy and compassion towards PwDs and care partners<br>• Activists are motivated by concern for the wellbeing of PwDs and care partners<br>• Embodying values of empathic concern, love, and kindness towards PwDs and care partners (activists as role models for others) |

*Note.* Numbers in parentheses denote the number of activists (out of the total number) who include a particular theme in their tweets.

**Table 3**

*Dementia Activism Goals: Themes and Subthemes*

| Goal | Conceptualization | Operationalizations | Evidence-based Themes and Subthemes |
|---|---|---|---|
| **Information Dissemination (21/23)** | Distributing information about relevant group issues, correcting misinformation, or communicating with others about these issues | • Themes related to the dispersion of dementia-related information | • Tweeting and retweeting scientific information about research studies, recruitment for dementia research, conferences, and workshops<br>• Clarification and interpretation of scientific information<br>• Providing tips and resources to PwDs and care partners |
| **Social Influence (13/23)** | Attempts to influence others' attitudes, beliefs, or actions | • Themes related to changing others' dementia knowledge, attitudes, and values<br>• Themes related to personal involvement within the wider dementia community | • Urging others to carefully process and discount dementia myths and messages<br>• Encouragement others to share dementia facts and resources<br>• Calls to action<br>• Influencing outside of social media; being recognized as an influencer in the dementia community |
| **Support Giving (22/23)** | Providing support to PwDs/care partners and receiving support from others | • Themes related to encouragement, support, and care for PwD and care partners | • Providing uplifting and caring messages to PwD and care partners<br>• Providing direct support, resources, and encouragement to PwD and care partners<br>• Facilitating the sharing of first-person experiences or stories of others with dementia<br>• Fundraising for/promoting others<br>• Providing support through modeling |
| **Experience Sharing (17/23)** | Disclosing personal experiences with PwDs | • Themes related to the sharing of personal experiences with dementia | • Sharing direct experiences as a PwD<br>• Relaying direct experiences as a care partner of a PwD<br>• Sharing stories of *others*' personal experiences with dementia |

*Note.* Numbers in parentheses denote the number of activists (out of the total number) who include a particular theme in their tweets.

## Social Identity

Most of the dementia activists include social identity themes/subthemes in their posts (20 out of 23). First, different *prototypes of activists* emerged from the data: "the scientist," "the influencer," "the moral guide," or "the amplifier of others' messages." Many activists have *multiple social identities*, which are expressed using dementia- and non-dementia related hashtags, but also via self-reporting of personal life experiences (e.g., as a person living with dementia, a dementia author or researcher, but also a traveler, nature lover, photographer, cyclist; Violet, Ruby, Taylor, Nora, Jamie). Importantly, the activists' interests may be very specific, emerging from their life experiences and their specific skills. For instance, Ethan frequently posts about disability rights, Taylor, who is transgender, posts about racism, violence against women, and rights of LGBTQIA+, and Sophia posts messages about fighting for health equity. Hazel is a researcher who translates dementia research for followers and Harper is an established Alzheimer's author and supporter of other authors.

Second, activists use different *identity markers* that signal their strong dementia-related identities: 1) use of pronouns (e.g., we, us, ours: "When our loved one with dementia does not recognize us anymore…"; John); 2) use of hashtags in the self-description at the top of Twitter feed or embedded in messages or video descriptions (e.g., #Alzheimer's, #Advocate #Awareness, #Caregiver #Dementia); and 3) use of identity cues such as the color purple (the color associated with the dementia movement) or messages embedded in the environment (e.g., uplifting messages on mugs).

Third, *some goals of activists* (e.g., information dissemination, social influence, or support) *are part of identity expression* as they are communicated both directly in posts and indirectly via hashtags (e.g., #dementia truths; #dementia education). Hazel writes about her recent activities of debunking dementia myths and educating others about dementia (e.g., *information dissemination* and *social influence goals*). Support as an activism goal is an intrinsic aspect of some activists' identities. Emily is interested in finding sustainable dementia care options (*support*) and Zoey writes presentations to prepare others for dealing with a future potential diagnosis of dementia (*dissemination*, *support,* and *social influence*).

Finally, for activists living with dementia, a common theme is the belief that *dementia is an identity characteristic rather than a self-defining identity dimension.* These activists (Tommy, Nora, Mary) all express this belief directly by telling others not to give up on themselves, to not be defined by dementia, and to live their lives fully. This belief is also expressed indirectly by activists living with dementia by sharing personal experiences about what they can do despite the disease (e.g., publish books, travel, or have meaningful relationships with others, etc.). In either form, these narratives empower others for living meaningfully with dementia or continuing the fight for the rights and wellbeing of PwDs and care partners.

### Efficacy

Efficacy was prevalent in activists' online narratives (19 out of 23 activists). For some activists, the focus is on *collective action undertaken by others,* which they highlight in their posts (Ethan). For others, efficacy is a *self-defining characteristic* listed in the self-description at the top of their Twitter feed (Hazel). For some activists, efficacy is not explicit but rather *implied by empowering others* through practical advice, science-based information, and correcting misinformation. For example, John asks pointed questions ("Is it okay to correct someone with dementia?") and provides links to empirical journal articles or infographics, which are very effective visual vehicles for disseminating information. Isla and Zoey speak directly to care partners, offering pertinent information in the form of book recommendations, presentations, or snippets of knowledge, whereas Henry posts about the power of attorney, Nora retweets dementia action info, and Zoey writes about the power of religious faith.

Efficacy is also expressed when the activists address the audience, *directly validating their experiences and supporting them.* Zoey, Casey, and Aurora validate dementia care partners by noting that caregivers' needs are often not expressed and therefore unmet, urging care partners to take time for themselves and never doubt their intuition and ability as care partners. Often, they relay their own experiences of caregiving to reinforce these messages. For both dementia activists who have dementia and care partners, *modeling efficacy* by describing personal stories of daily living is a very powerful strategy to engage with the audience. Both Taylor and Mary, who have dementia, post daily messages and photos detailing their personal stories of ups and downs. Alex, whose spouse has Alzheimer's, provides regular updates about the adjustments they have implemented that made a difference in their lives.

An interesting form of empowering others is using *the word "hope" (and derivatives) as an efficacy cue.* Many activists write about hope: Isla and Ruby explicitly state that their goal in sharing inspiring dementia personal stories is to give the audience hope; Aubrey describes herself as someone motivated to "offer hope and encouragement" to PwDs and care partners; and Henry hopes that, in the future, prejudice against dementia will be reduced. *Seeing collective action as effective*—the typical conceptualization of efficacy in current models of collective action—appears very infrequently. Ethan calls for clear action for all countries to move forward on accessible support and inclusive policies for PwDs and both Aurora and Noreen urge the passing of laws. Thus, efficacy takes on very different forms of expression in the online messages of dementia activists.

### Injustice

Injustice is the most infrequent antecedent (5 out of 23 activists) and typically occurs in the narratives of *activists with multiple or intersectional identities* (e.g., being a LGBTQIA+ dementia activist or a dementia activist of color). Consequently, their injustice concerns pertain to the rights of multiple marginalized groups and are expressed in posts pointing to racism in healthcare, tweets expressing outrage in response to gender affirming care bans, violence against women, or discrimination against LGBTQIA+ people. Activists also retweet *dementia-specific injustice concerns* about lack of representation of minority group members in dementia clinical trial studies (Sophia; Taylor). A common injustice concern centers around treatment of PwDs. Noreen calls out a comedian who used the term "demented" to refer to PwDs, whereas Hazel feels offended by the term "adult day care." Another common injustice concern revolves around barriers to equal and fair treatment faced by PwDs, which prompt activists to urge readers to sign petitions, send letters to members of Congress, and push for action and support for FDA-approved medical treatments and coverage for drugs for Alzheimer's (Ruby, Noreen). Activists also disseminate information or personal stories about abuse of older PwDs (Noreen).

### Moral Outrage

Moral outrage is present in the narratives of 9 out of 23 activists and was conveyed via messages that *push against dehumanization of PwDs* (Hazel), but also via messages *highlighting and sustaining personhood and humanness of PwDs and care partners*. John, for instance, asks the audience to focus on what PwDs can do rather than on what they cannot do, retweets empowering messages ("while we are all a little broken, broken crayons still color"), and urges the audience to replace the term "caregiver" with "care partner" to help preserve their dignity and humanness. *Activists living with dementia provide evidence of their own personhood* via frequent updates about their lives, interests, and values. Taylor posts photos of themselves going out and spending time with their family, Ava and Mary posts photos of nature and buildings and marvel at their beauty, Henry uses humor to relate with his audience, and Mary posts photos of nature, birds, and scenery from her travels. Another strategy employed to fight for the rights of PwDs and their personhood is to *advocate for personalized care options*, including accommodating care partners' needs (Emily; Violet; Zoey).

### Empathic Concern

Empathic concern is a newly documented antecedent of action that may be specific to dementia activism. It was present in tweets posted by 10 out of 23 activists. Some activists *teach empathic concern and kindness and include practical advice for care partners* out of concern for the wellbeing of PwDs and their care partners. For instance, John reminds the readers that they can love and be the biggest cheerleader of their PwDs even when they cannot solve problems. Other messages are teachings about kindness and *using compassion and self-compassion as moral guides* in caregiving (Aurora, Casey, Henry). Activists living with dementia teach the audience the importance of compassionate and empathetic communication in living well after a dementia diagnosis (Taylor). Finally, some activists who are care partners embody values of empathic concern, love, and kindness and therefore *serve as role models for compassionate caring* (Aurora; Henry).

## Goals of Online Dementia Activism

Although many activists' messages focus on a subset of goals of dementia activism, 10 of the 23 activists used all four goals in their posts. A single tweet can encompass all four goals. For instance, in a tweet, Aurora describes what worked for her when her mother was upset (*information dissemination*), she teaches others important values (*social influence*), provides support to others by normalizing caregiving (*support*), and is sharing her own experience (*experience sharing*). We describe these goals in the next section (see also Table 3).

### Information Dissemination

Information dissemination was a prevalent goal for many of the activists (21 out of 23). Activists are embedded in a network and most of the information that they share gets propagated through a central network, where retweeting of important information is common. John is a central figure in sharing information, with many activists retweeting what he shares. He also encourages his network to retweet his tweets. The type of information that activists distribute takes on *three primary forms*: a) relaying scientific information, b) clarifying and interpreting scientific information; and c) providing resources, tips, and opportunities.

For example, Hazel and Noreen advocate for the recruitment of diversity in research for PwDs by posting links to active research studies, whereas Mary promotes available jobs to her network. John and Sophia spend time explaining the information from scientific studies they reference. This type of translational work helps make scientific information more accessible to the larger dementia community. Noreen, Hazel, Casey, and Emily speak directly to care partners, offering them resources and tips to help them, thereby empowering them. Noreen shares her experiences of being a care partner and provides resources, such as information on guardianship and conservatorships, to empower others to take control of the caregiving process. Hazel takes a similar approach by providing resources that help care partners, such as knowing their options when it comes to hospice care or organizations that provide support for those with a parent diagnosed with dementia.

### Social Influence

Social influence emerged as a less frequently pursued goal of dementia activists, with this goal appearing in the tweets of 13 of the 23 activists. When social influence was present, it was in the form of *messages encouraging others to process misinformation carefully* and/or *to share accurate information* or *messages mobilizing others for dementia action.* Some activists attempted to influence others by offering concrete examples of scientific information. Sophia asks that people consider the clear scientific evidence that shingles vaccines prevent some dementia cases and urges her audience to read the available scientific information. Noreen urges her audience to get informed about abuse of older people and how it is hard to detect and track. Other activists utilized social influence to encourage further dissemination of information. John used his social influence to encourage his audience to amplify key messages about health promotion, caregiving, and healthy living through retweets. Lastly, activists aim to reach the broader dementia community, beyond Twitter (Taylor, Mary, Hazel). For example, Hazel mentioned that although she had not been very active online, she was engaged in the "offline world," working on improving #dementiaeducation.

### Support Giving

Support is the most prevalent of all goals, with 22 of the 23 activists providing support in their messages. Support took many forms, often revolving around the *themes of uplifting and caring messages, empowerment, and direct care.* Some activists, like John, provide validation for PwDs and care partners, encouraging them to find and share their unique self, whereas others, like Nora, shared memes and proverbs to help encourage and support. Activists commonly retweet inspirational, motivational, and validating posts, often accompanied by relevant hashtags (e.g., #dementia; #caregiver). These retweets teach the audience about the strength and perseverance of PwDs, indirectly validating their experiences and offering implicit support.

Many of the activists also provide support for each other. When Mary was having problems with her Twitter feed, she received support and encouragement from her network. Many activists promote books, conferences, and research papers. To show support, Nora posts pictures of winners at dementia activism events and Aubrey promotes reviews of books. Noreen is motivated by a support goal when she advocates that PwDs are *not* their diagnosis. She emphasizes this by highlighting how her friend likes to canoe, which is part of their identity beyond dementia.

### Experience Sharing

Although the sharing of personal experiences is a goal of dementia activists, it can also be conceptualized as a strategy for achieving other goals (i.e. social influence, moral guide, seeking support, etc.). Many activists (17 out of 23) shared personal experiences over the timeframe assessed. The activists *recount their own personal experiences* as either a care partner or a PwD, and/or share other people's personal experiences. For activists living with dementia, sharing their stories helps to normalize dementia experiences and provide support to others, but is also a means for them to receive support. Mary focused on the daily realities of living with dementia and highlighted that some tasks, like using Twitter, can be difficult. Nora expressed similar experiences (e.g. feeling nervous about going to the dentist) but points out that not every experience is a challenge and that she experiences beauty as well.

*The sharing of caregiving experiences* is also a common theme. Although Alex frequently shares his experiences as a care partner for his wife, he urges others to do what works for them rather than simply following his example. By sharing his experiences, Alex lets others know that there is no "one size fits all" approach to caregiving. Alex is not only sharing his first-person experiences as a care partner, but he is also sharing the experiences of his wife. Aurora provides a similar message to her audience, emphasizing that each day as a care partner will be different and highlights the importance of reassurance and support for the PwD. The sharing of *other people's* experiences was also a common theme for the activists. Jamie's story is told through the lens of Amelia (his wife), and he retweets what she posts about him. Ruby, Aubrey, and Ava all retweet about others' experiences with dementia and advocate for their audience to gain further insights into dementia by reading about others' first-person experiences.

# Discussion

Analysis of tweets revealed unique forms of expression of collective action antecedents and activists' goals as well as the prevalence of a fourth antecedent (empathic concern), which is missing from existing models of collective action and was present in about half of the activists' tweets in our data. Some antecedents of action such as social identity and efficacy appear more frequently than injustice and moral outrage in activists' tweets, suggesting unique patterns of mobilization on social media by dementia activists.

## Antecedents of Online Dementia Activism

Our analysis revealed that Twitter-based dementia activism was predominantly driven by identity and efficacy, which were the most prevalent in the data. This finding aligns with prior research, which revealed the predominance of efficacy and social identity in the tweets of autistic activists (Satterlund et al., 2025). Additionally, themes related to social identification with the broader dementia movement were commonly observed in the tweets of dementia activists (Talbot et al., 2020). Overall, our findings align with studies highlighting the crucial role of virtual spaces in fostering and reinforcing social identities as well as in expressing and amplifying shared beliefs and values (Mundt et al., 2018; Nasrin & Fisher, 2022). We also found that social identities emerge from the spontaneous, uncoordinated use of hashtags and other dementia-related symbols, such as the color purple and background messages (e.g., kindness messages on mugs). This supports existing research suggesting that social media features like hashtags (e.g., #dementiatruths; #LivingWithDementia) serve as a powerful self-labeling mechanism that allows users to signal their affiliation with social and political causes and connect with like-minded individuals, thereby contributing to the formation of collective identities (Barron & Bollen, 2022; Nasrin & Fisher, 2022).

Perceiving oneself as efficacious is another important antecedent of collective action and is closely linked to social identity (van Zomeren et al., 2008). Nevertheless, perceived efficacy of politicized acts such as changing legislation was an infrequent theme in our data, suggesting that other forms of efficacy are in play. In our study, efficacy manifested through more localized forms of action, ranging from validating others' experiences, modeling efficacy by sharing personal stories of struggles and success, or highlighting other people's collective action efforts. Efficacy thus is closely tied to ability *and* disability in online dementia activism networks. This association is not unique to dementia activism, as a similar link was documented in Twitter autism activism (Satterlund et al., 2025). This association makes efficacy a central antecedent in disability activism as illness narratives and counternarratives have been used by activists to push back against common misconceptions about loss of selfhood, agency, and competence in PwDs (Hagan & Campbell, 2021; Hillman et al., 2018). These counternarratives instead advocate for a more nuanced understanding of both disability and personhood and the detrimental role that the social and psychological expectations have for PwDs (Graf et al., 2025; Reed et al., 2017). Given cultural norms that often socialize disabled individuals to adopt passive roles and defer to medical professionals (Satterlund et al., 2025), it is crucial to understand efficacy of dementia activists in virtual spaces within this broader socio-cultural context. Social media platforms should be harnessed to amplify the voices of PwDs and their allies, positioning them not just as participants but as empowered agents of change (Talbot et al., 2025).

Highlighting ingroup injustice can mobilize online activists and motivate efforts to challenge misconceptions (Satterlund et al., 2025). In our data, ingroup injustice themes were rare and appeared primarily in the messages of activists with multiple identities—users who had dementia but also other central social identities (e.g., racial identity or LGBTQIA+ identity). However, these messages were infrequent, suggesting that focusing on injustice may not be an effective strategy for mobilizing *all* dementia activists. Quantitative research is needed to examine all SIMCA antecedents, along with empathic concern, to evaluate their relative predictive power in online dementia advocacy. Such investigations could clarify whether dementia activism is shaped by a distinct configuration of motivational factors compared to online collective action by other groups.

The posts of about half of the activists include moral obligation themes, while messages on the dehumanization of PwDs were rare and often overlapped with injustice themes. This is because dementia activists choose to focus in their posts on *humanization* of PwDs by highlighting and sustaining the personhood of PwDs and their care partners and providing evidence of their own selfhood despite dementia challenges. This is consistent with the current focus in dementia activism research, which advocates for a more nuanced approach to the self in PwDs, away from a tragedy discourse about a complete loss of self (Bomilcar et al., 2021; Reed et al., 2017). This work shifts away from dehumanizing views of dementia, as reflected in the choice of dementia activists to post positive rather than messages about dementia on Twitter (Talbot et al., 2020). This approach also transpires in the online narratives of our dementia activists that focus on humanizing PwDs and care partners and highlight empathy, kindness, and empathic communication.

Empathic concern was a key antecedent for almost half of our dementia activists, aligning with research showing how prosocial emotions transform "apathy into movement" and motivate collective action (Thomas et al., 2009). Batson (2023) defines empathic concern as "an other-oriented emotion elicited by and congruent with the perceived welfare of someone in need" (p. 11). It includes feelings of compassion, sympathy, tenderness, warmth in response to another person's suffering or vulnerability. Compassion and empathy have been linked to increased engagement in health-protective behaviors during the COVID-19 pandemic, particularly those aimed at safeguarding vulnerable populations (Karnaze et al., 2022). These findings highlight the powerful role of empathic concern in mobilizing support for members of disability communities. Empathic concern is notably missing from models like SIMCA (van Zomeren et al., 2008, 2018) or the Social Identity Model of Deindividuation Effects (SIDE; Postmes & Brunsting, 2002). Our findings call for expanding existing models of collective action to better account for the key role of empathic concern for others, particularly among members of disability communities, where valuing others' welfare may drive engagement as much as shared group identity.

## Activists' Goals

The current study reveals the multifaceted nature of online dementia activists' goals. Support giving was the most pursued goal by the participants. The prevalence of this goal underscores the importance of helping and sustaining one another in the dementia community (Clare et al., 2008; Hagan & Campbell, 2021; Talbot et al., 2020; Weetch et al., 2021). Recent work has pushed for a reconceptualization of the forms of collective action (Miron et al., 2022), indicating that not all actions undertaken by ingroup members are outgroup-oriented (e.g., directed towards other groups to develop solutions) but rather many are ingroup-oriented (e.g., encouraging ingroup members). Stroebe et al. (2019), for instance, found that such ingroup-oriented behaviors were very frequent in their study. These behaviors included cooperative or helping actions that were organized toward their ingroup or behaviors directed at communicating with others who experience the same injustice. Similarly, in our study, support giving was oriented towards the online dementia community and manifested in acts of providing direct support and encouragement to PwDs and their care partners but also indirectly by facilitating and further disseminating first-person stories of others, thereby validating and normalizing their experiences. Multiple studies found that online interactions are beneficial for PwDs and care partners. Clare et al. (2008), for instance, examined how the experience of belonging to the self-help network *Dementia Advocacy and Support International* (DASNI) facilitates the development of a shared social identity among a group of people with early-stage dementia. This identity, in turn, helps counteract the challenges to self and identity posed by developing dementia, provides mutual support and collaborative advocacy, and influences social attitudes about PwDs.

Additionally, information dissemination, another prevalent user goal, both facilitated the creation of an online knowledge base about dementia and sustained the support-giving goal, with activists sharing scientific information, resources for caregivers, and tips to help caregivers and the broader dementia community. Some activists were motivated by a social influence goal, using their platform to amplify key messages such as how to protect and enhance the humanness of PwDs and urged care partners to take care of themselves. These activists also posted messages encouraging broader engagement in dementia advocacy, in line with previous research that links online activism with offline consequences of participation (Chon & Park, 2020; Leonel et al., 2024; Nasrin & Fisher, 2022). Talbot et al. (2020) found that educating care partners, health care providers, researchers, and members of the public was one of the primary goals of online dementia activists. This goal also took the form of teaching others the appropriate and destigmatizing language for describing PwDs and their experiences. Similarly, in our study, social influencers like John and moral guides like Alex reach the members of the online dementia community via sharing scientific facts and experience-based information, while their moral messages, albeit present, are covert. These strategies, based on systematic processing of relevant information, are more effective in producing high user engagement compared to users who use mental shortcuts and superficial treatment of topics (Eslami et al., 2024), and therefore more likely to produce social change as part of an online grassroot movement.

Finally, experience sharing is an important goal for marginalized members on Twitter and was a prevalent theme in our data set. Activists shared their own dementia experiences as a PwD or as a care partner but also posted and reshared personal stories of others to normalize and validate dementia experiences. These findings echo prior findings indicating that PwDs share their lived experiences with dementia on Twitter through personal stories and updates and often use their online networks to promote a more nuanced understanding of dementia and challenge stereotypes (Talbot et al., 2020). Nevertheless, more work is needed to further explore the role of sharing of personal experiences in mobilizing users who do not have dementia to join the online dementia movement.

## Limitations, Implications, and Future Directions

One limitation of this study stems from our tweet selection strategy. For practical reasons, we did not collect replies to posts, nor did we assess how the users are connected to one another on Twitter. Future studies could collect tweets, replies, and shares of the original tweets and assess how activists relate to each other to examine how messages move through social networks and activate users. In addition, collecting data from different online platforms (e.g., blogs or Facebook postings) and triangulating the data may offer a more comprehensive analysis of online dementia activists' forms and antecedents of activism. While our study sampled tweets across a five-month period, we did not examine changes across time in activist goals and strategies. Such longitudinal analysis can produce a more nuanced understanding of how advocacy by activists living with dementia may change as dementia symptoms worsen. Studies have shown that PwDs develop multiple social identities, including dementia activist identity, to cope with progressive dementia-triggered changes in the self (Graf et al., 2025).

Despite these limitations, the current study is useful for illuminating the prevalence of antecedents of collective action and the goals driving activists in online dementia communities. While different activist prototypes were motivated by distinct goals of action, some activists evidenced strategic integration of all antecedents and goals, crafting narratives designed to inspire broader mobilization. Future work could explore how messages get propagated through social networks by activists with different goals. Exposure to counternarratives about dementia may be facilitated by those who are at the periphery of these networks and serve as bridges between different networks (e.g., by network connectors such as Ruby and Aubrey; see Satterlund et al., 2025). In contrast, dementia influencers (like Aurora and Taylor) may have the function of mobilizing members of the dementia community by providing evidence for and validating counternarratives to misguided or false mainstream narratives about dementia.

Recently, autistic activists have begun fighting for self-advocacy as they felt their voices had been drowned out by doctors, therapists, and parents undertaking a medicalized approach to autism (Satterlund et al., 2025). In dementia activism, a similar trend has emerged with activists living with dementia asking for their voices to be heard and considered in the process (see "nothing for us without us" theme in Talbot et al., 2020; also, see member-led dementia empowerment services in McConnell et al., 2020). In the case of disability movements, self-advocacy can help members of disability groups to counteract narratives and develop a sense of self via establishing connections with the rest of the community. The current study provides an integrated view of advocates and self-advocates. Future work should systematically explore how having multiple identities (e.g., as a person with dementia, dementia activist, *and* transgender or as a dementia activist and a person of color) may facilitate the operation of multiple antecedents of action. Unfortunately, the small sample size of such activists in our study ($n$ = 2; Sophia and Taylor) prevented us from drawing conclusions about their unique contributions. Future work should particularly explore how the multiple identities of activists and the diverse social networks they belong to affect their power to influence and mobilize other users for social change. Moreover, research has just begun addressing the potential of social networks for facilitating transformative learning among activists, which often results in changes in how they experience and interact with the world. These changes, in turn, mobilize activists for creating social change online and offline (Schroeder et al., 2020).

Our findings underscore the need to expand current models of collective action (e.g., SIMCA; SIDE) to better account for the unique features of online dementia activism. We propose a new social psychological model that highlights the distinct aspects of dementia-related advocacy—namely, identity, efficacy, empathic concern, and support—while accounting for the affordances and constraints of online networks for people with dementia (PwDs) and their allies. Specifically, our findings point to three core processes underlying this form of activism: 1) *Empathic Concern for Others:* Unlike traditional models of collective action that focus on anger or injustice (e.g., SIMCA), dementia activism is rooted in empathic concern, motivating individuals to engage in support giving, knowledge sharing, and community-building activities; 2) *Social Identity and Efficacy:* Activists with dementia and their allies forge collective identities from shared experiences, empowering both individuals and communities through localized action that reinforce their sense of agency; and 3) *Ingroup-Oriented Actions and Support*: In contrast to more traditional forms of collective action, which are often outgroup-oriented and focus on societal-wide social change, dementia activism prioritizes ingroup-oriented actions that emphasize mutual support, ingroup community-building, and validating others' experiences.

This new model has practical implications for designing advocacy campaigns and training programs that leverage the characteristics of online platforms to empower PwDs and their supporters. Effective strategies include listening to the perspectives of PwDs, prioritizing their wellbeing, and recognizing them as co-creators of knowledge in research and policy making (Hagan & Campbell, 2021; McConnell et al., 2020). These approaches can mobilize support even from those outside the immediate community or with differing viewpoints (Guevara Beltran et al., 2024; Karnaze et al., 2022). Finally, prior research has shown that a greater number of social identities and stronger social support networks promote wellbeing during major life transitions (Haslam et al., 2021). In light of our findings, online dementia community networks should be re-envisioned not only as platforms for advocacy and collective action but also as critical infrastructures for fostering psychological resilience and improving the welfare of their members.

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**Data Availability:** Disidentified data are available from the first author upon request.

## Supplementary Materials

This Supplementary Materials file contains a table of paraphrased tweets that illustrate the antecedents of action and the goals of dementia activists (see Miron et al., 2025S).

### Index of Supplementary Materials

Miron, A. M., Knepple Carney, A., Tennessen, B. J., & Graf, A. A. R. M. (2025S). *Supplementary materials to "“You are not alone!”: A thematic analysis of activist goals and antecedents of online dementia activism"* [Paraphrased tweets]. PsychOpen GOLD. https://doi.org/10.23668/psycharchives.21196

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