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# Self-Disclosure and Social Media Use among Younger and Older People with Dementia: An Internet-Mediated Mixed-Methods Study

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## ABSTRACT

Social media can facilitate self-disclosure of a stigmatized identity. This mixed-methods study explores self-disclosure by people with dementia on social media, comparing patterns and purpose of use by those aged 65 and above versus those aged under 65. Of 143 internet-using respondents of an online survey, 77 (aged between 44 and 88 years) were users of social media. Facebook was the most commonly used platform (95%), followed by Twitter, Instagram, LinkedIn, YouTube, and TikTok. People with dementia aged under 65 used more platforms and used social media more frequently than older counterparts [ $\chi^2 = 5.58, p = .031$ ]. Content analysis of open-ended questions, validated and extended through qualitative interview data, showed younger users shared dementia-related information for purposes of advocacy and awareness whereas older users prioritized the dementia journey. Social media gives people with dementia a voice to share their experiences, raise awareness, and support themselves and other individuals affected by the condition.

## KEYWORDS

Advocacy; disclosure; internet-mediated research; social media use; survey; young-onset dementia



## 1. Introduction


Dementia is an umbrella term for the cognitive and functional impairments related to progressive neurodegenerative conditions such as Alzheimer's disease and Lewy Body dementia. It is estimated that approximately 57 million people globally live with dementia, a figure that continues to rise due to population ageing and growth (GBD 2019 Dementia Forecasting Collaborators, 2022). In the United Kingdom (UK), it is estimated that around 900,000 people have a diagnosis of dementia (Wittenberg et al., 2019). Although the incidence and prevalence of dementia increases with age, there is a significant minority (7.5%) of people diagnosed with a dementia before the age of 65 (Carter et al., 2022). Developing dementia in mid-life is associated with different psychological and social needs to people in later life (Rabanal et al., 2018), and in the dementia literature a distinction is commonly drawn between *younger people with dementia* (individuals who are under the age of 65) and *older people with dementia* (individuals who are 65 years and older).

As there is currently no known cure for dementia, it is important to focus on non-pharmacological interventions and strategies to enhance individuals' well-being, quality of life, and day-to-day activities (Livingston et al., 2017), and

recommendations for maintaining, or indeed enhancing, social health in dementia emphasize the importance of remaining cognitively, physically, and socially active (Dröes et al., 2017). Non-pharmacological treatments for people with dementia include a diverse range of interventions that can be categorized into physical, cognitive, physical/cognitive, and other psychosocial interventions (McDermott et al., 2019). Another category are interventions which make use of information and communication technology (ICT) on devices such as computers (Pinto-Bruno et al., 2017). Examples are interventions using virtual reality (Manera et al., 2016; Moyle et al., 2018), smartphone apps (Lee et al., 2023; Rai et al., 2020), and tablet devices (Astell et al., 2010; Tyack et al., 2017) to support people with dementia in their social and physical health.

In addition to using purposely designed technologies and interventions, many mainstream and everyday ICTs have the potential to support and improve social participation and health in people with dementia (Heins et al., 2021; Meiland et al., 2017). One such ICT is "social media" defined as "a group of Internet-based applications that build on the ideological and technological foundations of Web 2.0, and that allows the creation and exchange of User Generated Content" (Kaplan & Haenlein, 2010, p. 61). Social media

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have become a means of interpersonal communication allowing people to share their thoughts, emotions, and experiences.

Although social media use has increased by around 40% across all age groups since 2015, an age gradient remains. Whereas 92%–99% of internet-using individuals aged 16–54 used social media in 2022, equivalent figures for the 55–64 and 65+ age brackets are 86% and 70%, respectively (Ofcom, 2023). A motivating factor for social media use by adults over the age of 65 is to stay connected with family and friends (Newman et al., 2021). In light of the COVID-19 pandemic and government restrictions, these online spaces have become more important for people over the age of 65 (Haase et al., 2021) and for people with dementia (Talbot & Briggs, 2022) to stay socially connected, in addition to having widened people's use of ICT-based communication (Nguyen et al., 2020). In recent years, interest has grown in the use of social media to disseminate general dementia-related information (e.g., Robillard et al., 2013; Shu & Woo, 2021), mainly considering the use of social media by family caregivers of people with dementia (e.g., Anderson et al., 2017; Bachmann, 2020). A limited, but growing, number of studies have also explored the use of social media by people with dementia themselves such as online discussion forums (Johnson et al., 2020; Mehta et al., 2020; Rodriguez, 2013; Talbot & Coulson, 2023), blogs (Kannaley et al., 2019), Facebook (Craig & Strivens, 2016), Twitter (Mehta et al., 2020; Talbot et al., 2020a, 2020b, 2021; Thomas, 2017), as well as a variety of different platforms (Johnson et al., 2022; see Table S1 in the supplementary material for an overview). The majority of studies on social media and people with dementia focused on younger people with dementia (Craig & Strivens, 2016; Talbot et al., 2020b, 2021; Thomas, 2017) or did not specify the age of their samples, probably because they had collected and analyzed secondary data (Johnson et al., 2020; Kannaley et al., 2019; Mehta et al., 2020; Rodriguez, 2013; Talbot & Coulson, 2023). Studies that reported reasons for the use of social media platforms found that individuals used them for social support and community building (Craig & Strivens, 2016; Johnson et al., 2020, 2022; Kannaley et al., 2019; Mehta et al., 2020; Rodriguez, 2013; Talbot et al., 2020b; Talbot & Coulson, 2023; Thomas, 2017), sharing or discussing everyday life and experiences (Kannaley et al., 2019; Mehta et al., 2020; Talbot et al., 2020b; Talbot & Coulson, 2023), awareness raising (Craig & Strivens, 2016; Johnson et al., 2022; Kannaley et al., 2019; Talbot et al., 2020b), and (re)shaping one's identity post-diagnosis (Craig & Strivens, 2016; Talbot et al., 2020b, 2021; Talbot & Coulson, 2023; Thomas, 2017). Whilst these studies have provided evidence that people with dementia use social media, few studies have included or explicitly focused on older people with dementia and most research has been informed by publicly available social media content as opposed to data collected directly from individuals. In addition, their sample sizes are either relatively small or have not been reported.

The use of social media has the advantage of facilitating and enhancing connections with others, but also the

potential disadvantage of attracting negative reactions, or even personal attack (Naslund et al., 2020). People with dementia can face prejudice and experience discrimination in their everyday lives as a manifestation of the stigma of dementia (Herrmann et al., 2018), which may result in their choice to hide their diagnosis from others (O'Connor et al., 2018). Whilst the concealment or disclosure of one's illness status on social media has been explored among individuals with other chronic health conditions (Kaushansky et al., 2017; Sannon et al., 2019), less is known about how people with dementia use social media platforms to acknowledge their dementia diagnosis or share dementia-related information. In addition, we currently do not know if there are differences between people with young-onset dementia and people with dementia aged 65 and older who use social media. Therefore, in this exploratory research, we aimed to explore (1) how people with dementia use social media, (2) how social media use differs between people with young-onset dementia and older people with dementia, and (3) how people with dementia disclose their diagnosis or share dementia-related information on their social media accounts.

## 2. Methods

### 2.1. Study design

A convergent mixed-methods study design, combining quantitative and qualitative methods, was used to answer the research questions (Creswell & Plano Clark, 2018). A cross-sectional online survey comprising close-ended and open-ended questions was set up on the Qualtrics platform (<https://www.qualtrics.com>) to collect quantitative and qualitative data. Qualitative data was also collected through semi-structured interviews. The survey and the interviews were part of a larger research project exploring online and offline diagnosis disclosure by people with dementia to their social networks. Data collection took place between February and June 2022.

### 2.2. Recruitment

We applied a convenience sampling strategy. Recruitment took place through the Join Dementia Research platform (JDR; <https://www.joindementiaresearch.nihr.ac.uk>) and UK-based dementia organizations (e.g., DEEP Network, Young Dementia Network). Study details for the survey and interviews were advertised on websites, in newsletters, and on Facebook and Twitter. To increase diversity of the survey sample in terms of ethnicity, individuals registered on JDR who identified as being from an ethnic background other than "White" were approached via email to gauge their interest in taking part in the survey. In addition to survey respondents being invited to participate in interviews, there was additional recruitment for interviewees not participating in the survey. Eligibility criteria for the survey and interview samples included having a form of dementia, ability to read

and understand English, ability to provide informed consent, and having access to an internet-enabled device.

The sample size for the survey was determined through power analysis using G\*Power (version 3.1.9.7; Faul et al., 2007) for multiple linear regression, based on independent variables that were collected but fall outside of the scope of this article. With power set to 80%, a medium effect size ( $f^2 = 0.15$ ), and a significance level of 0.05, it was calculated that a sample of 116 would be required. The sample size for the interviews was guided by information power, which proposes that the more information a sample holds, the smaller the number of participants needs to be (Malterud et al., 2016). Based on the study aims, sample specificity, quality of dialogue, and experience of the research team, it was decided that a sample size of eight to twelve participants would provide sufficient information power.

### 2.3. Data collection

Socio-demographic information collected from individuals taking part in the survey and the interviews consisted of close-ended questions and included age, gender, ethnicity, living situation, type of dementia diagnosis, and time since diagnosis. In addition, survey respondents were asked to provide information on their education level, employment status, marital status, and country of residence. Survey respondents' use of social media and whether they used social media to share dementia-related information was explored using open-ended and closed-ended questions created for this study. If respondents answered "yes" to the question if they used social media, they were asked about their frequency of use, which platforms they used, if they shared dementia-related content on them, and if so, the kinds of dementia-related content they published on them. Respondents were invited to provide their contact details if they were interested in taking part in a semi-structured interview. The semi-structured interviews took place over Zoom or the phone. A topic guide was used, consisting of open-ended questions regarding participants' decision to disclose their dementia diagnosis to other people both online and offline. Participants were also asked if and in what ways they used social media to disclose their diagnosis to others. Throughout the interviews, participants were encouraged to expand on their answers.

### 2.4. Patient and public involvement

In the course of the project development, we consulted members of the European Working Group of People with Dementia (EWGPWD) about the research topic and accessibility of the online survey. The EWGPWD was established by Alzheimer Europe and its partner associations and consists of people with dementia who are active advisers on international research projects (Alzheimer Europe, 2022). During the meeting, the group highlighted the importance of the study topic, describing some of their personal experiences of disclosing their diagnosis. They advised us to shorten the Participant Information Sheet and Informed

Consent form, to increase the font size of all text, and to add more space between items to increase readability. They also suggested recruiting survey respondents based outside of the UK as the EWGPWD members, who are all based in different European countries, felt this topic was relevant for people with dementia across various countries. Based on their suggestions and recommendations, the survey was revised and an ethics amendment was submitted to the UCL Ethics Committee; all amendments were approved and incorporated into the study.

### 2.5. Ethical approval

The Research Ethics Committee at University College London approved both the online survey [ethics ID: 19537/001] and interviews [ethics ID: 16961/001]. Participation was voluntary, and the survey respondents and interviewees provided either online or written informed consent prior to taking part. Survey respondents had the option of resuming the survey within seven days once paused.

### 2.6. Data analysis

We analyzed quantitative data in IBM SPSS Statistics version 25. Demographic data were summarized using descriptive statistics. Social media users and non-users were compared based on their age using the independent sample *t*-test or Chi-squared test. Results were considered significant at  $p < .05$ . Qualitative data were analyzed using qualitative content analysis, which is a systematic method that enables researchers to broadly describe and quantify phenomena for the purposes of building a conceptual map or categories (Elo & Kyngäs, 2008). Verbatim transcriptions of the interview data and responses to the open-ended questions of the survey were entered into separate NVivo 12 documents and analyzed inductively (Elo & Kyngäs, 2008). We followed the qualitative content analysis approach described by Erlingsson and Brysiewicz (2017). Two authors (GK and WQK) familiarized themselves with the data by reading the transcripts and survey responses several times. All descriptions of social media use and the types of dementia information posted or shared on social media were considered meaning units. If the same type of information shared was described multiple times, these descriptions were conjoined into a single meaning unit. The authors then condensed the meaning units, labelled each with a code, reviewed and refined the codes, and grouped them into categories on the basis of similarities. Frequencies were counted for codes and categories related to types of dementia-related information posted or shared on social media.

## 3. Results

### 3.1. Characteristics of survey sample

Among the 165 internet-using individuals who consented to take part in the survey, 143 successfully completed it,

and 27 of these respondents were under the age of 65. The total sample consisted of 88 males, 54 females, and one person who did not disclose their gender. Respondents' age ranged from 44 to 95, with a mean age of 71 years ( $M = 71.81$ ,  $SD = 9.48$ ). Alzheimer's disease was the most common form of dementia ( $n = 69$ ). Of the 28 respondents who had been diagnosed with other forms of dementia, most ( $n = 13$ ) had mixed dementia followed by posterior cortical atrophy ( $n = 5$ ). Sixty respondents had been living with the condition for more than three years (42%). Eighty-six respondents had continued their education after secondary or high school. Other types of education included specific qualifications ( $n = 3$ ), certificates ( $n = 2$ ) or college ( $n = 2$ ). The majority were retired ( $n = 119$ ) or unable to work ( $n = 12$ ), and two respondents stated they worked full time as dementia advocates. Most respondents lived with their partner ( $n = 109$ ). Other living situations included living with a partner and children ( $n = 2$ ), assisted living or care ( $n = 2$ ), and living in close proximity to family ( $n = 1$ ).

### 3.2. Characteristics of social media users

Out of the whole sample, 77 respondents identified as social media users and 66 as non-users. The demographic characteristics of the social media users and non-users are detailed in Table 1. Of these respondents, 22 were younger than 65 years, which is 81.5% of all younger respondents, and 55 were 65 years and older, which is 47.4% of all older respondents. A comparison of users and non-users revealed a significant difference for age,  $t(141) = 5.047$ ,  $p < .001$ , with users being younger ( $M = 68.4$ ,  $SD = 9.5$ ) than non-users ( $M = 75.8$ ,  $SD = 7.7$ ).

### 3.3. Social media platforms and frequency of use

Of the 77 social media users, two older respondents did not report which social media platforms they used. Figure 1 provides an overview of the platforms that 75 respondents reported using. Facebook was the most commonly used social media platform for both younger and older respondents ( $n = 71$ ), followed by Twitter ( $n = 24$ ), Instagram ( $n = 10$ ), and LinkedIn ( $n = 7$ ). Most respondents ( $n = 43$ ) reported using only one platform. Two platforms were used by 18 respondents, three platforms by 10 respondents, and four platforms by three respondents, with one respondent using five platforms. A higher proportion of younger people than older people posted on all forms of social media with the exception of LinkedIn, which was only used by older respondents.

When asked about their frequency of use, a large proportion (51/77) indicated that they used social media frequently (several times per week or more; see Table 2). Younger respondents used social media more frequently than older respondents,  $\chi^2(1, N = 77) = 5.58$ ,  $p = .031$ .

### 3.4. Disclosure of dementia-related information on social media

Half of the respondents ( $n = 39$ ) reported that they disclosed their diagnosis and/or shared dementia-related information on their accounts; seven individuals did not respond to this question. Thirty-eight respondents commented on the kinds of information they posted or shared on their accounts; however, one response was deemed ineligible because the respondent did not clearly clarify what type of information they posted or shared. This resulted in the analysis of 37 responses, of which 14 had been provided by respondents under the age of 65. Twenty codes were derived from respondents' descriptions of their social media posts. These codes were further clustered into three categories: (1) advocacy and awareness, (2) the dementia journey, and (3) peer support. An overview of the categories and codes, along with their descriptions and the frequencies of comments for each category and code, are provided in Table 3. Examples of respondents' quotes for each code can be found in Table S2 in the supplementary material. The majority of respondents (26/37, 70.3%) posted or shared information that falls into just one of the three categories identified. Ten respondents (one younger and nine older respondents) posted or shared content relevant to two categories, and one younger respondent posted or shared content relevant to all three categories. Of those who had a prevailing purpose for posting (i.e., activities fall within a single category), a higher proportion of younger respondents focused on advocacy and awareness (5/12, 41.7%) or peer support (2/12, 16.7%) compared to older respondents (advocacy and awareness: 4/14, 28.6%; peer support: 1/14, 7.1%). Older respondents (9/14, 64.3%) were proportionately more likely to focus on sharing the dementia journey compared to their younger counterparts (5/12, 41.7%).

Interviews were conducted with ten people with dementia, with a mean age of 65.3 years (see Table 4). Most of the participants were female ( $n = 7$ ), had Alzheimer's disease ( $n = 5$ ), were living with their spouse ( $n = 9$ ), and had been diagnosed more than five years ago ( $n = 6$ ).

Findings from the qualitative responses to the online survey were supported by the interviewees. A key motivation for participants to disclose their dementia diagnosis on social media and posting dementia-related information was to raise awareness about the condition. They felt that dementia was not well understood by society and wanted to combat the negative assumptions they felt many people without dementia had about the condition:

It's just really to raise awareness and to break down the stigma that's attached to having a dementia diagnosis (...) that it's okay to talk about it. Because it's a bit like the C word would have been at one time. You know, nobody mentioned cancer. It was taboo. If somebody had a cancer diagnosis, they wouldn't actually say the word. And dementia can be a bit like that where I don't think it should be.

(Woman with Alzheimer's disease, age 62)

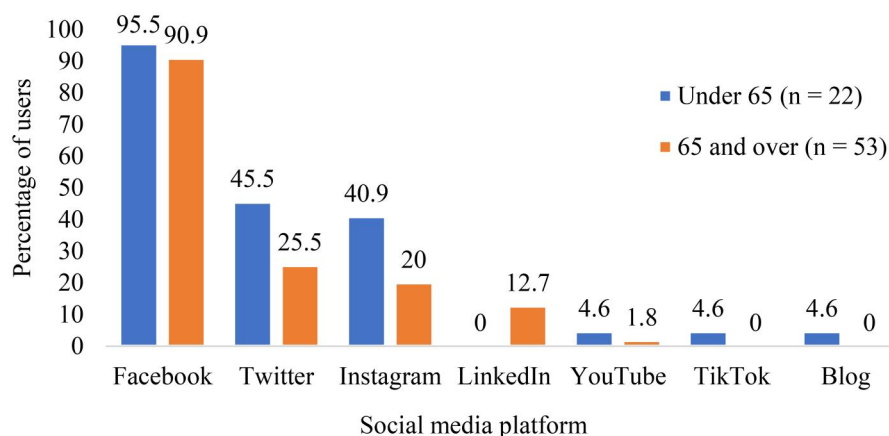
In addition to raising awareness on a personal level, participants used their social media accounts to share general dementia information and fundraising opportunities posted

**Table 1.** Characteristics of social media users ( $n = 77$ ) and non-users ( $n = 66$ ).

Characteristics	Users	Non-users
Gender, $n$ (%)		
Male	49 (63.6)	39 (59.1)
Female	28 (36.4)	26 (39.4)
Not specified	0	1 (1.5)
Age in years, $M$ (SD), min-max	68.39 (9.5), 44–88	75.80 (7.84), 58–95
Ethnicity, $n$ (%)		
White	74 (96.1)	66 (100)
Black	1 (1.3)	0
Mixed	1 (1.3)	0
Jewish	1 (1.3)	0
Type of dementia, $n$ (%)		
Alzheimer's disease	33 (42.9)	36 (54.6)
Vascular dementia	11 (14.3)	8 (12.1)
Lewy Body dementia	9 (11.7)	3 (4.6)
Frontotemporal dementia	11 (14.3)	4 (6.1)
Other	13 (16.9)	15 (22.7)
Time since diagnosis, $n$ (%)		
0–12 months	14 (18.1)	17 (25.8)
1–3 years	27 (35.1)	25 (37.9)
3–5 years	20 (26.0)	13 (19.7)
>5 years	16 (20.8)	11 (16.7)
Country of residence, $n$ (%)		
UK	71 (92.2)	65 (98.5)
Ireland	0	1 (1.5)
Canada	3 (3.9)	0
USA	2 (2.6)	0
Netherlands	1 (1.3)	0
Level of education, $n$ (%)		
University	34 (43.6)	27 (40.9)
Technical/trade school or apprenticeship	14 (17.9)	11 (16.7)
Secondary/high school	24 (31.2)	22 (33.3)
Primary/elementary school	0	3 (4.6)
No schooling	1 (1.3)	0
Other	4 (5.2)	3 (4.6)
Employment status, $n$ (%)		
Employed <sup>a</sup>	9 (11.7)	1 (1.5)
Unable to work	10 (13.0)	2 (3.0)
Retired	56 (72.7)	63 (95.5)
Other	2 (2.6)	0
Marital status, $n$ (%)		
Married/in a relationship	62 (80.5)	49 (74.2)
Divorced	5 (6.5)	7 (10.6)
Widowed	6 (7.8)	10 (15.2)
Single/never married	4 (5.2)	0
Living situation, $n$ (%)		
With partner	60 (77.9)	49 (74.2)
With family member	4 (5.2)	3 (4.6)
Alone	9 (11.7)	13 (19.7)
Other	4 (5.2)	1 (1.5)

$M$ : Mean;  $SD$ : Standard deviation.

<sup>a</sup>Includes full-/part-time work and self-employment.



**Figure 1.** Percentage of social media platforms used by age.

by dementia organizations or other individuals. One participant, who had become a vocal dementia advocate since he received his diagnosis, had set up a local dementia support group. He posted on both his own and the support group's Facebook page:

The pandemic never really affected me much on social media because on my own personal Facebook page, I don't use it that much. I use it if I'm advertising something that's to do with dementia or the peer support group. (...) It's only if I want to spread the word about something like the conference. I'll put that up on my Facebook page and that will get shared on by my pals and that sort of stuff. It's for business like that sort of thing.

(Man with Alzheimer's disease, age 59)

Participants reported that being active on social media about dementia put them in touch with other people with dementia, reflecting the category of peer support:

And also, I suppose it benefits me because I can contact with other people. So, you've got that contact with others. And I've met some wonderful people that have dementia, and they've inspired me to do things as well, it's not only me inspiring people. It's sort of... we bounce off one another. I think it's really good to be in contact with people that have dementia as well.

(Woman with Alzheimer's disease, age 57)

Peer support was possible over social media even at a distance and during the COVID-19 pandemic: "To be honest,

it's one of the only ways I can talk to some of my dementia friends, because we live so far away" (man with Alzheimer's disease, age 59).

A diagnosis of dementia brings changes to day-to-day life; some participants had given up work or had lost friends. Turning to social media gave a new sense of purpose for some:

I suppose it gives me a purpose because I've always worked full time, and it was giving me something to do. It's also keeping my brain occupied because I'm having to think of where I've been, what I've done, hence why I take a lot of photographs as well, because photographs are now my memory and so I can look back on the photographs that I've taken through the day ... I blog every day apart from weekends, I have two days off [laughing].

(Woman with Alzheimer's disease, age 57)

Through posting content on social media, interviewees described assuring other people with dementia that not every day was the same and positive things were part of living with dementia too:

And you hope by putting on [to Facebook] something that has happened to you, that you help somebody else, that somebody else is able to say, "Oh, that happened to me and that worked for them or whatever", you know? So, you get tips about how to cope with things or problems that will sort of arise. Somebody else will have had the same problem. And they would say, "Look, this works for me or that works for me or whatever." It is something you can try then. It's a good platform.

(Woman with Alzheimer's disease, age 62)

Posting videos of new hobbies, such as arts and crafts, triggered inspiration in others leading to a sense of appreciation:

I shared things right at the beginning of the lockdown. I shared how to make things on YouTube, and people were contacting me and saying "You've got dementia, how do you do that?" And I said, "Watch the video and you'll be able to do it." And

**Table 2.** Frequency of social media use by age.

Response	Under 65 (n = 22), n (%)	65+ (n = 55), n (%)
Once every few months or less	1 (4.5)	5 (9.1)
About once a month	2 (9.1)	5 (9.1)
Several times per month	0	6 (10.9)
About once per week	0	7 (12.7)
Several times per week	5 (22.7)	5 (9.1)
Daily	14 (63.6)	27 (49.1)

**Table 3.** Frequencies of comments by category and code for dementia-related information posted and shared on social media by younger (n = 14) and older people with dementia (n = 23).

Categories and codes	Description	Frequency of comments, n (%)	
		Under 65	65+
Advocacy and awareness, total		n = 17	n = 17
Dementia in general	General information and facts about dementia	2 (11.8)	5 (29.4)
Personal advocacy work	Own work as a dementia advocate or activist	2 (11.8)	5 (29.4)
Fundraising	Own and other people's fundraising campaigns	4 (23.5)	0 (0)
Dementia events	Information about events related to dementia	2 (11.8)	2 (11.8)
Awareness campaigns	Sharing awareness campaigns or videos made to raise awareness about dementia	2 (11.8)	1 (5.8)
Research findings	Results of studies on dementia	0 (0)	2 (11.8)
Research opportunities	Studies currently recruiting participants	1 (5.8)	1 (5.8)
Answering questions	Answering questions about dementia	1 (5.8)	0 (0)
News	News items about dementia	1 (5.8)	0 (0)
Thoughts on stigma	Sharing personal thoughts on dementia stigma	2 (11.8)	1 (5.8)
The dementia journey, total		n = 7	n = 20
Living with dementia	Personal experiences of having dementia	4 (57.1)	9 (45.0)
Own diagnosis	Informing others of one's dementia diagnosis	1 (14.3)	4 (20.0)
Explaining symptoms	Own symptoms to explain behavior and make others understand	0 (0)	2 (10.0)
Mental state	Current feelings and well-being	0 (0)	2 (10.0)
Living well with dementia	Positives about having dementia	1 (14.3%)	1 (5.0)
Poetry	Poems about dementia and living with it	0 (0)	2 (10.0)
Crafts	Posts about crafts made by the participant	1 (14.3)	0 (0)
Peer support, total		n = 4	n = 5
Support group information	Sharing details about support group meetings	2 (50.0)	2 (40.0)
For others affected by dementia	Supporting other people with dementia or caregivers	2 (50.0)	1 (20.0)
For oneself	Receiving support from other people with and without dementia	0 (0)	2 (40.0)

**Table 4.** Characteristics of interviewees.

Characteristics	Interviewees ( $n = 10$ )
Age, $M$ ( $SD$ ), min-max	65.3 (6.4), 57–80
Gender, $n$	
Female	7
Male	3
Living situation, $n$	
With spouse	9
Alone	1
Type of dementia, $n$	
Alzheimer's disease	5
Frontotemporal dementia	2
Mixed dementia	1
Posterior cortical atrophy	1
Vascular dementia	1
Time since diagnosis, $n$	
1–3 years	2
3–5 years	2
5–7 years	4
>7 years	2

they were picking things up and they were doing things. So, it's sort of inspires people to have a go at things. So that's why I'm always on social media, really. It's just to inspire people to keep going and have a go at doing things.

(Woman with Alzheimer's disease, age 57)

Interviewees who had not completed the survey described some additional opportunities due to a social media presence, for example, taking part in research and subsequently becoming a co-researcher (Tanner, 2012), an activity that was thoroughly enjoyed and increased a feeling of being valued.

In summary, this study aimed to compare the social media use in people with dementia above and below the age of 65, and found that over half of the survey respondents used social media, with younger people with dementia being more likely to be active social media users than older people with dementia. Facebook was the most popular platform for both age groups, but younger users used a more diverse range of platforms than older users. Around 50% of respondents disclosed their diagnosis or shared other dementia-related information on their accounts.

#### 4. Discussion

In this convergent mixed-methods research, we gained insights into the use of social media by people with dementia and how they acknowledge their diagnosis or share other dementia-related information on their accounts. The proportion of social media users in our sample was comparable with proportions observed in the general population for those aged 55–64 (86% vs. 81.5%), but much lower for those over the age of 65 (70% vs. 47.4%; Ofcom, 2023). Our sample was relatively small and more people with dementia aged 65 and above took part in our internet-mediated research. However, it may be that younger people with dementia are more likely to have adopted social media prior to the dementia onset, whereas older people with dementia might have actively or passively avoided adopting new technology. Also, similarly aged counterparts might have continued to learn new technologies, with research suggesting that trainings can be useful to improve digital literacy in older

people (Bevilacqua et al., 2021) We found that social media were perceived as a valuable place for people with dementia to advocate for themselves and other people affected by dementia, raise awareness about the condition, and fight the negative stereotypes associated with dementia. Users were also able to share their life with dementia, their symptoms, feelings, and current state of mind. It was also a space for them to engage in reciprocal peer support as well share creative activities that some users were pursuing.

Most of the existing research studies which explored the use of social media by people with dementia have primarily harvested social media data (e.g., Craig & Strivens, 2016; Kannaley et al., 2019) or had relatively small sample sizes (Craig & Strivens, 2016; Kannaley et al., 2019; Talbot et al., 2020a). Our study built upon these limitations by collecting primary data directly from people with dementia and having a larger sample size. To our knowledge, this study made use of the largest sample of younger and older people with dementia so far that contributed to this kind of research. Globally, there is a higher percentage of women than men with dementia (Beam et al., 2018). However, like previous social media research among people with dementia (Talbot et al., 2020a), our sample consisted of more men than women. The high proportion of men in our sample could suggest that internet-mediated dementia research amplifies the male voice.

Our findings suggest that people with dementia, especially those with young-onset dementia, use social media to make their voices heard, advocate for change, and change the perspective of living with dementia into a positive one. This is in line with existing research on the use of Twitter by people with dementia (Talbot et al., 2020b, 2021), where individuals used their accounts to combat stereotypes and raise awareness about dementia among society. Activism and advocacy in people with dementia have previously been linked to the formation of a “collective illness identity” (Hillman et al., 2018). This suggests that sharing space, including online spaces, with other people with dementia who share the goal of fighting dementia stigma, can contribute to forming an identity post diagnosis. In addition, social media might give people with dementia the opportunity of supporting their personhood as they are in control of the content created on social media (Astell, 2006; Hennelly & O'Shea, 2022).

We found that social media platforms were used by both younger and older people with dementia as an avenue to share their experiences of living with dementia as well as for peer support, which mirrors previous research (Johnson et al., 2022; Talbot & Coulson, 2023). Since appropriate in-person dementia support services are often lacking or are difficult to access (Giebel et al., 2021), our findings indicate that social media is a promising virtual medium of support for people with dementia. This may especially be the case for people with rare forms of dementia such as Lewy body dementia (Killen et al., 2016) or young-onset dementia (Stamou et al., 2021), or those who live in rural areas (Arsenault-Lapierre et al., 2023).



#### 4.1. Implications

Corroborating recent research on social media use (e.g., Talbot et al., 2020a) and people with dementia adopting and adapting everyday technologies (Gibson et al., 2019), and contrary to the stereotype that older people lack technological ability (Mariano et al., 2022), a large proportion of people with dementia seem to be active on social media. Subsequent generations will have more experience using technology and, therefore, be more technologically savvy. As such, social media may become increasingly important for this population. This may be particularly relevant for clinicians, dementia organizations, and policymakers who could signpost people with dementia to social media as one useful medium for (peer) support. For future research, we recommend exploring the proportion of posts created on each platform to gain a deeper understanding of which platforms are especially important to people with dementia. We also recommend exploring why internet-using people with dementia are not active on social media, and why those who do have one or more social media accounts decide not to disclose their dementia identity on them. This may be useful to increase the accessibility of social media as a tool for support for people with dementia.

The majority of survey respondents and interviewees for this study were recruited through social media, an avenue that has previously been proposed as useful in dementia research (Bartlett et al., 2019). This study highlights the potential of this recruitment strategy, which could be relevant for other researchers wishing to explore the personal experiences of people with dementia.

#### 4.2. Limitations

While this research has promising findings, it is subject to some limitations. Firstly, participants in this study were convenience samples, with the majority of survey respondents being male and well-educated, and almost all were from a White ethnic background. It is likely that people with dementia from a minority ethnic or cultural background, whose experience of living with dementia or the stigma associated with it may differ (Berwald et al., 2016; Giebel et al., 2015), will use social media differently, including their decision to disclose their condition or share other dementia-related information on their social media accounts. Secondly, we used a cut-off of 65 years to differentiate between younger and older people with dementia. However, a portion of older individuals may have been diagnosed before reaching the age of 65, potentially impacting the categorization of participants in these age groups. Finally, participants who took part in the survey were given the opportunity to take part in a semi-structured interview. It is, therefore, possible that some individuals took part in the survey as well as in an interview, and that their experiences align. Due to the anonymity of the survey, it is not possible to establish which individuals took part in both studies. As such, the codes established for the qualitative strand (i.e., dementia-related information posted or shared on social media) may have been duplicated for participants who took

part in both studies. Nevertheless, since the purpose of the qualitative strand was to gain a deeper understanding of how participants disclose their diagnosis and share or post dementia-related information on social media, the codes or their frequency are not critical to the understanding of this phenomenon.

#### 4.3. Conclusion

People with dementia adopt and adapt everyday technologies for their own purposes, including the use of technology-mediated social networking. Our findings show that social media are being used by both younger and older people with dementia. It has the ability of giving people with dementia a platform to make their voices heard to raise awareness, share their personal experiences of living with the condition, and provide and receive social support. Our findings suggest that social media could be an important source of post-diagnostic support for people with dementia.

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