

Unpaid carers' experiences of supporting people with dementia to use social media

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Abstract

Objectives: The aim of this study was to explore unpaid carers' experiences of supporting people with dementia to use social media.

Methods: Unpaid carers ($n=234$) responded to an online survey about their attitudes towards people with dementia using social media and any experiences supporting this usage. Responses to closed questions were analysed using frequency analysis; qualitative data were analysed thematically.

Results: Fifty-five carers (23.5%) cared for someone with dementia who used social media. Thematic analysis produced four themes: (1) carers as social media navigators; (2) social media supports care; (3) carers as social media guardians; and (4) labour-intensive work. Carers valued the social connectivity and stimulation social media provided but remained vigilant about online safety. They carefully managed the online experiences of people with dementia, balancing perceived benefits with safety, security, and caring demands.

Conclusions: These findings shed light on the complexities of caring in the digital age. Many carers are supporting people with dementia in using social media, but there is little guidance on how best to do this. As older adults continue to embrace social media, carers, support organisations, and policymakers must adapt and work with technology developers to ensure safe and supportive online experiences.

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Introduction

Globally, more than 55 million people are living with dementia, with numbers estimated to rise to over 150 million in 2050 (GBD 2019 Dementia Forecasting Collaborators, 2022). A diagnosis of dementia can have a powerful impact on those affected, including people living with the condition and their unpaid carers. For example, people with dementia have reported isolation, loneliness, low mood, uncertainty, frustration, a ‘shrinking social world’, and shifting social roles following diagnosis (Górska et al., 2018; Spreadbury & Kipps, 2019; Ward et al., 2022). Compared with the general population, unpaid carers of people with dementia experience higher levels of physical and mental illness (including elevated rates of suicidal ideation), social isolation, and financial distress (Pinquart & Sorensen, 2003; Donnellan et al., 2017; O’Dwyer et al., 2021). In response to these challenges, dementia has been identified as a key priority in health and social care planning worldwide, with a growing emphasis being placed on timely diagnosis and appropriate provision of support throughout the disease trajectory (Department of Health and Social Care, 2022; National Academies of Sciences, Engineering, and Medicine, 2021; Welsh Government, 2018;). Despite this, a recent systematic review found that people with dementia and their carers still experience significant situational, psychological, interpersonal, structural, and cultural barriers to accessing care in the community (Giebel et al., 2023). Consequently, there is a pressing need to identify cost-effective, far-reaching means of supporting those affected by dementia to live with, and adjust to, the condition.

Digital technologies may provide some solutions by enabling social interaction, stimulation, enjoyment, peer support, self-development, and supporting activities of daily living (Beh et al., 2022; Cutler et al., 2016; Hicks et al., 2020, 2023; Wilson et al., 2022, 2023). The use of social media by people with dementia, in particular, has recently garnered interest from researchers (see Talbot & Dunne, 2024), with evidence of people with dementia using a range of platforms including Facebook (Craig & Strivens, 2016), Twitter (Thomas, 2017; Talbot et al., 2020, 2021), and online forums (Rodriquez, 2013; Talbot & Coulson, 2023). Craig and Strivens (2016) reported that a Facebook group provided people with young-onset dementia unique opportunities for expression and connection beyond their immediate networks. Similarly, Talbot et al. (2020, 2021) found Twitter to be a valued source of post-diagnostic support, providing access to self-relevant information, social connection to others affected by dementia, and a space where people with dementia could redefine their identities. In online forums, Rodriquez (2013) found that people with early-onset Alzheimer’s disease constructed a sense of community by sharing stories, providing advice and encouragement, and commiserating about their symptoms. This is consistent with Talbot and Coulson’s (2023) finding that an online forum facilitated self-disclosure, reciprocal support, and creative self-expression – regardless of dementia type or geographical location – filling an important gap in the provision of post-diagnostic support.

Although research provides initial evidence on the value of social media for people with dementia, researchers have not yet engaged with the perspectives of their unpaid carers who may act as gatekeepers and have unique concerns about their online engagement. In addition, the complex interfaces of social media may be physically and/or cognitively demanding for some people with dementia (Jodrell & Astell, 2016; Talbot & Briggs, 2022), meaning that carers must actively support their usage (Piper et al., 2016). This pattern is reflected in wider research on general digital technology usage among people with dementia

and their carers. For example, Hicks et al. (2023) found that supporting this usage heightened stress levels and exacerbated already heavy workloads. Specifically, carers described difficulties relating to information comprehension, navigating interfaces, following virtual conversations, and understanding social conventions within digital spaces. These challenges are likely exacerbated among carers who lack sufficient digital skills and technological infrastructure (Caprioli et al., 2023; Hicks et al., 2022, 2023). To our knowledge, however, there has been no research that has specifically focused on social media. To address this gap, we took a descriptive, exploratory approach to understand unpaid carers' experiences of supporting people with dementia in their use of social media.

Method

Sample

Self-identified unpaid carers were eligible to participate in this study if they lived in the United Kingdom and provided care for a friend or family member with mild to moderate dementia. Participants were recruited via social media and charity and research participation networks, including the Young Dementia Network and Join Dementia Research. Participants recruited via these means were given the opportunity to enter a prize draw to win a £50 shopping voucher. Additional participants were recruited via Prolific, an online participant recruitment platform. An initial survey was posted on Prolific to screen participants for eligibility and ensure the sample only included genuine carers. Those who met the eligibility criteria were then invited to complete the full survey. Participants recruited via Prolific were paid £4.50 as an incentive for participation. Following exclusion of ineligible respondents ($n=24$) and incomplete data ($n=7$), the sample comprised $n=234$ unpaid carers. The analysis reported in this paper focused only on those participants ($n=55$) caring for a person with dementia who used social media. A separate analysis, focused on participants caring for someone who did not use social media ($n=179$), will be reported elsewhere.

Data collection

The study was approved by Bournemouth University Research Ethics Committee (Ref: 45997). Between November 2022 and April 2023, Participants were directed towards an online survey hosted by Qualtrics, where they were informed about the study and asked to provide informed consent. They were then asked questions to capture demographic data (e.g., age, gender, ethnicity, living situation, relationship to the person with dementia, type of care provided), followed by closed and open-ended questions about attitudes towards social media use by people with dementia, experiences of supporting people with dementia to use social media, and training needs. Display logic was used to ask specific questions of those caring for someone who used social media (versus those caring for someone who did not), covering topics such as practicalities of support; concerns about usage; reasons for supporting usage; access to usernames and platforms; any changes over time; and any future plans for social media profiles and support provision. The survey questions were informed by previous research exploring use of social media among people with dementia (Talbot et al., 2020, 2021). These questions were also co-created with a person living with dementia, who is a paid advisor to our research project and an avid user of social media.

Data analysis

Demographic information and responses to closed questions were analysed using frequency analysis. Qualitative data were subjected to reflexive thematic analysis (Braun & Clarke, 2022) to identify patterns of meaning across the data. The first and second authors began by reading responses to support an in-depth familiarisation with the data. They then met to discuss their observations and create initial codes. These authors then independently coded the data using semantic codes, which were organised into an Excel document. The first author then reviewed, visualised, and organised these codes into initial themes using Miro, a visual online platform with a virtual whiteboard feature. Definitions were then created for each initial theme, which were reviewed by all authors. Themes were then refined (where appropriate) and named, with illustrative extracts selected for inclusion in this paper.

Results

Demographic characteristics, social media usage and support needs

Of the $n=234$ unpaid carers who completed our survey, $n=55$ carers (23.5%) reported that the person they cared for used social media. This sub-sample of carers ($n=55$) had an average age of 44.9 years (range: 20–74; $SD=13.39$) and included $n=28$ people who identified as female and $n=27$ who identified as male. The majority of carers were from a White ethnic background (89.1%; $n=49$). This sub-sample cared for someone with an average age of 74.4 years (range: 57–91; $SD=8.93$). Most respondents did not live with the person they cared for (66%; $n=36$) and the most common types of care provided were emotional (96.4%; $n=53$) and/or practical support (87.3%; $n=48$). Respondents most frequently reported providing care every day (52.7%; $n=29$) or a few days each week (40%; $n=22$), typically providing 1–2 hours (45.5%; $n=25$) or 3–5 hours (34.5%; $n=19$) of care each day. Most carers were caring for a parent or parent-in-law ($n=38$; 69.1%), followed by a spouse/partner ($n=6$; 10.9%), grandparent ($n=6$; 10.9%), friend ($n=4$; 7.3%), or cousin ($n=1$, 1.8%).

Facebook was the most commonly used platform by people with dementia (94.5%; $n=52$), followed by Twitter (10.9%; $n=6$), Instagram (7.27%; $n=4$), TikTok (5.45%; $n=3$), and online forums (3.64%; $n=2$). Most people with dementia used a smartphone (65.5%; $n=36$) or tablet device ($n=35$; 63.6%) to access social media, followed by a laptop (25.5%; $n=14$) or desktop computer (20%; $n=11$).

Among the sub-sample of carers ($n=55$), attitudes towards social media training and resources were mixed. Most carers reported not knowing where to access training and resources on how to support people with dementia to use social media (58.2%; $n=32$). More than half the sample (58.2%, $n=32$) agreed they would like to access training and resources on how to support people with dementia to use social media, with approximately one-third disagreeing (30.9%, $n=17$) and the remainder (10.9%, $n=6$) neither agreeing nor disagreeing.

Thematic Analysis

Our thematic analysis produced four themes illustrating unpaid carers' ($n=55$) experiences of supporting people with dementia to use social media: (1) Carers as social media navigators; (2) Social media supports care; (3) Carers as social media guardians; and (4) Labour-intensive work. These themes highlight how unpaid carers valued the stimulation and social functions of social media in supporting the wellbeing of people with dementia, while also being mindful of their vulnerability online. They carefully managed how people with dementia engaged with social media to create supportive and secure online experiences, striking a balance between the perceived social benefits, online safety and security, and the demands of care (see Table 1).

Table 1. Themes overview.

Theme name	Definition
Carers as social media navigators	Carers provided people with dementia with ongoing guidance and support on how to use social media.
Social media supports care	Carers helped people with dementia to use social media because they considered it a key aspect of care, fulfilling their role as a facilitator of social connections and cognitive stimulation.
Carers as social media guardians	Carers perceived people with dementia to be vulnerable in social media spaces and took actions to promote their online safety, security, and dignity.
Labour-intensive work	Carers reported that supporting people with dementia to use social media involved considerable time and effort, and was emotionally demanding.

“I guide them”: Carers as social media navigators

Carers frequently reported helping people with dementia navigate social media, providing regular guidance and support. Carers helped with a range of social media activities, including setting up profiles; creating and viewing posts; connecting with others; locating and following content of interest; navigating interfaces; and purchasing items through Facebook Marketplace.

She likes to buy things on [Facebook] market place, so I help her with conversations with sellers. (ID 11, Female, 53)

I show her how to comment, how to use GIFs, smilies, how to use messenger to be [in] contact with relatives, how to watch live videoclips. (ID 7, Female, 50)

This level of support was evident among people caring for family members with both mild and more advanced dementia. Those caring for someone with more advanced dementia also

described working with the person with dementia to decide what they wanted to communicate and to post messages on their behalf. Carers explained their role as a navigator was not a one-time occurrence but rather a process of *ongoing* technical support. They primarily attributed this to memory difficulties, as some people with dementia would regularly forget how to do certain tasks such as how to post content or navigate different platforms.

My grandma remembers that Facebook is a social media application which can be used to keep in touch with others but always forgets how to navigate through and use the application. She needs help reminding her how this needs to be done and will remember it for a day but then the next day she will have forgotten. (ID 32, Male, 31)

One commonly reported problem was that some people with dementia would forget their login information, leading to them being locked out of their accounts. Consequently, carers spent considerable time unlocking social media accounts and resetting passwords. Only one carer mentioned using a password manager to simplify the process.

My Mum's main problem is forgetting/losing her login details, and despite encouraging her to write details down she frequently finds herself unable to get onto Facebook. (ID 45, Male, 66)

Initial reliance [on my support] came about when they kept getting locked out of their accounts so I helped reset the security and asked permission to save the details going forward. (ID 15, Female, 33)

Another key challenge was encountered when social media platforms were updated and the interfaces changed. People with dementia struggled to adapt to these changes and carers were required to guide them through the updated features of platforms. This process was described as difficult and frustrating for both the carer and the person with dementia.

I sometimes help her to post her photos etc. when she forgets how to do it. She regularly needs reminding how to do it. Also, any changes on the site throw her, so she needs to be re-shown. (ID 29, Female, 41)

“Still connected with the world”: Social media supports care

Carers felt that supporting use of social media was part of their caring role. In particular, by helping the person with dementia maintain existing, and develop new, social connections, they saw themselves as fostering emotional wellbeing. Carers noted specifically how social media enabled people with dementia to remain involved in their family members' lives. Online social connections were viewed as particularly important for people with dementia who lived alone or for whom offline social interactions were limited.

I encourage mum to use social media because one of her daughters lives a long way away down South. She has a huge family down there and she used to be right on top of her game what with sending cards and gifts, even to the newest members of the family. Nowadays it has been reduced to sending messages through [social media] posts made. (ID 42, Female, 60)

He occasionally likes to see what his friends and family have posted and to see the photos they have uploaded. This is important for his mental well-being as it helps him feel connected because he doesn't get out often to see them in person. So, I help him to do this. (ID 3, Female, 56)

Certain carers also noted, when they had to be away, the utility of social media in keeping people with dementia occupied or socially connected during their absence. This reduced some of the pressure on carers by providing additional sources of social interaction, support, and entertainment.

We are not there sometimes during the day and social media helps combat loneliness, and keeps her in-touch with the family. (ID 45, Male, 66)

Carers also felt a sense of responsibility for keeping people with dementia connected to their local communities and harnessed social media to support this need. Facebook community groups, in particular, provided an important means of accessing localised information and fostering a sense of belonging within local communities, thereby combatting isolation.

I have joined the same village group that mum joined and now keep her up to date with events. (ID 42, Female, 60)

Because it provides them with some sense of being involved in the community even if only very little. They can stay in the loop with what's going on locally and keep in touch with relatives. Without this I think they would feel more isolated. (ID 35, Male, 35)

In addition to supporting the social connectedness of people with dementia, carers also felt responsible for maintaining their cognitive abilities. They recognised the importance of keeping people with dementia mentally engaged and so turned to social media for a range of cognitive stimulation activities, including social interaction, following hobbies and interests, and staying informed on current events. Carers also noted how social media supported reminiscence, by providing stimuli such as photographs that could trigger memories, encourage conversations, and foster positive emotions.

It also gives her real pleasure to talk about the village where she used to live and seeing some of the photos will jog her memory a bit and we get the chance to see our real mum talking about clear memories that she had when she was a child and young adult. (ID 42, Female, 60)

I found that when my grandma uses social media, it allows her to enjoy old memories which she may have forgotten and this continuous cycle I think helps keep her mind stable. (ID 32, Male, 31)

“They are vulnerable”: Carers as social media guardians

While carers recognised the benefits of social media for people with dementia (see Theme 2), they also recognised their vulnerability within these spaces. Carers expressed concerns that people with dementia would unintentionally disclose personal information on social media (e.g., financial details) or click on malicious links that could make them a victim of fraud.

Additionally, some carers were concerned about people with dementia being vulnerable to the emotional manipulation tactics employed by some scammers.

Because of how vulnerable my dad actually is nowadays. I am petrified that he will end up getting romance scammed. (ID 1, Male, 39)

He talks to too many “friends” who aren’t his friends and I’m worried he may share too many details. I am also extremely wary of any scams and misleading ads. (ID 28, Male, 28)

In addition to concerns about fraud and scams, carers voiced concerns about people with dementia being inadvertently exposed to misinformation or ‘fake news’ on social media. Specifically, carers worried that people with dementia were less able to process and critically evaluate this content, making them more susceptible to believing misleading information, increasing their vulnerability and potentially influencing decision-making.

I explain the concept of false news, and I am logged into their accounts to delete false information or comments. (ID 31, Female, 37)

I am concerned that they do not have a lot of natural scepticism, and will believe anything and everything they read. (ID 24, Female, 60)

In light of these concerns about vulnerability, carers implemented various strategies to preserve the online safety of people with dementia. Carers described how they carefully monitored the social media usage of the person they cared for, including authorising follower/friend requests, implementing strict privacy settings, checking messages and notifications, and restricting access to social media when they were unavailable.

I have access to the Facebook account and can ensure that she doesn’t get any phishing or random messages. I get alerted whenever a new post is published and again, I can ensure it wasn’t one by mistake or giving away details not wanted. (ID 49, Male, 39)

Another common concern among carers was the possibility of the person they cared for making inappropriate comments or engaging in inappropriate behaviour on social media. They attributed this concern to two factors: limited digital literacy skills and behavioural disinhibition associated with dementia. To address these concerns and uphold the dignity of people with dementia, some carers chose to delete comments they viewed as inappropriate, particularly if the person with dementia was unable to recall posting them.

I am concerned that mum may make herself look foolish by posting strange comments or getting in touch with old friends - I am embarrassed for her - on her behalf if that makes sense. She also has a weird way of viewing the posts. She thinks that everybody is her friend and that she has a personal connection to events and situations online. (ID 42, Female, 60)

Another concern is if they write comments or statuses whilst feeling confused/agitated/angry and that the sentiments don't really reflect the person they are at heart or at least, once was. (ID 15, Female, 33)

It was evident the majority of carers took a paternalistic approach to supporting the safety and security of people with dementia within social media spaces. One carer, however, described

the need to carefully balance the safety and security of people with dementia with their rights to privacy and autonomy, while also upholding their dignity.

I think the main challenge is their comprehension of the reasons why you are doing it i.e. for their own benefit. My relative is still entitled to privacy and sometimes this can feel invaded or she thinks that I am being intrusive. (ID 15, Female, 33)

Although carers felt personally responsible for ensuring the online safety and security of people with dementia, they also felt social media companies could take greater responsibility. They specifically called for technological innovations to support vulnerable adults' safety needs. For example, some carers suggested versions of social media platforms and controls could be specifically developed for vulnerable adults, similar to existing controls currently in place to protect young people.

I think that Facebook and other companies should release a version which is targeted to an elderly demographic which is much better signposted and intuitive for them to use. (ID 13, Female, 45)

“I’ve had to become more involved”: Labour-intensive work

Carers noted the intensity of work involved in supporting people with dementia to use social media, particularly as the symptoms of dementia progress. They explained how prior to diagnosis or during the early stages of the disease, those with dementia were typically able to use social media independently or with only minimal assistance. However, as the symptoms of dementia progressed and the person experienced greater difficulties with memory, comprehension, perception, motor skills, and/or behavioural challenges, carers were required to provide increased levels of support so the person could remain engaged with social media. This was challenging for the carer and sometimes a source of additional stress in the caring role.

[I’m] repeating myself many many times, making sure she fully understands everything and if she is crystal clear/has any questions, only to have her seemingly forget in a few days and all the time and effort I have put into teaching her gets wasted. (ID 13, Female, 45)

I’ve had to become more involved, it’s become more labour intensive and stressful. (ID 46, Male, 49)

The level of support provided by carers tended to follow a clear trajectory. Initially, carers helped people with dementia create social media profiles and provided occasional technical support. Over time, their support progressed to providing regular reminders and spending an increasing amount of time and effort supporting social media usage.

It has just gradually got more demanding from having a 5-minute overlook to now it is taking about 30 minutes every time I visit my dad. (ID 1, Male, 39)

More time has been given by me as the carer to the person with dementia explaining how the platform works, how to access the people's feeds they want to see, how to create a post and post it. I have witnessed frustration by the person with dementia

when they can't work it out and on some occasions I have had to go and see the person in person to sort it out and calm them down, whereas before the onset of dementia I could have helped over the phone. (ID 52, Female, 50)

As dementia progressed and the person was no longer able to use social media, some carers reported taking control of their social media profiles. This tended to involve posing as the person with dementia, creating posts and responding to messages on their behalf.

As mum finds it very difficult to use social media now I will go online for her and pop comments in on her behalf. In fact the whole family will do it. In regards to younger family birthdays etc. (ID 42, female, 60)

I take photos and post them on her social media, from her account. I will write, and read messages, reply to direct messages, and reply to people on her Facebook wall. I also post on her social media wall, posing as herself. (ID 23, Male, 26)

Supporting individuals with dementia to use social media required significant time and energy and took an emotional toll on both carers and those with dementia. For example, carers described how people with dementia would often become confused, frustrated, or upset when they encountered difficulties using social media.

They want to remain independent and do things for themselves and get upset when they cannot do now what was once easy and need to ask for help. Can be a source of difficulty for us both. (ID 53, Male, 74)

Similarly, it was not uncommon for carers to report feelings of frustration when people with dementia needed to be regularly reminded of how to do certain activities that the carers viewed as intuitive. This process was described as requiring considerable levels of patience, which was particularly challenging for the carers who were already feeling exhausted and felt this time could be better spent on self-care.

Declining memory means a lot of repetition which takes a lot of time and patience! Due to a fluctuating cognitive problem some days are better than others. Sometimes, particularly when I am tired I get frustrated with the person I care for as everything they do on social media is so slow...Sometimes, I have to say let's leave Facebook and go back to it later! (ID 52, Female, 50)

I find it frustrating sometimes as I struggle to believe that she could find it so difficult. I also question if she would be able to do it on her own if she knew I could not help her and wonder if it is some kind of learned helplessness and it would benefit her overall if I did refuse....but then I feel bad thinking like that and go and help. (ID 13, Male, 34)

Discussion

It is clear from these findings that some carers are regularly helping people with dementia navigate the complex interfaces of social media, providing ongoing technical support and guidance. The carers in the study felt that when the person with dementia used social media, it supported them in their caring role, by facilitating social connections and stimulation. However, carers also recognised the vulnerability of people with dementia on

social media and took actions to uphold their dignity, safety, and security. While carers generally saw the benefits of supporting social media usage, they also found it to be labour-intensive and emotionally demanding. They carefully managed how people with dementia engaged with social media to create supportive and secure online experiences, striking a balance between the perceived benefits, online safety and security, and the demands of care. This work is situated within a broader landscape of increasing digitalisation of dementia care (e.g., Giebel, 2023; Hicks et al., 2020; 2023; Wilson et al., 2022; 2023). The carers in this study noted the utility of social media in fulfilling their caring role. However, digital technologies, including social media, are not a panacea. Carers experienced clear challenges, particularly in relation to the intensity of work involved in supporting social media usage. Similarly, other researchers have documented the barriers associated with digitised care, noting how digital technologies are not always accessible, usable, sufficient, or appropriate (Caprioli et al., 2023; Giebel et al., 2021). While social media and other digital technologies may not be appropriate for, or of interest to, all people with dementia, it is essential that these tools are accessible and inclusive. This is so a wider range of people with dementia and their carers can benefit, thus preventing existing inequalities from being exacerbated (Giebel, 2023). Beyond social media, it is crucial services cater to the diverse needs, preferences, and technological abilities of people with dementia and their carers to uphold their social inclusion. As noted by Hicks et al. (2023), this may involve services increasingly supporting digital access and literacy where appropriate. The reality of the continued growth of social media and wider digital technologies usage among an ageing population means that carers, organisations, policymakers, and technology developers must prepare for the increasingly prevalent role of digital technologies in dementia care. In particular, they must work together to find strategies for harnessing the benefits of social media and wider digital technology usage while also addressing the associated challenges and ultimately enhancing the quality of dementia care

Many carers in this study were concerned about the vulnerability of people with dementia to cybercriminals, a concern echoed in previous work with older adults with cognitive impairments (Mentis et al., 2019; Piper et al., 2016). This vulnerability is further compounded by recent increases in online scams, particularly those targeting older adults (Burton et al., 2022). However, simply limiting or removing access to social media is not advisable given that social media can offer many benefits for people with dementia (e.g., Talbot et al., 2021; Talbot & Coulson, 2023). Social media is also an integral part of modern society, and it is likely that as more technologically savvy generations (e.g., Baby Boomers, Gen X) reach later life, they will want to maintain their social media presence (Chee, 2023). We recommend future efforts focus on co-producing tailored educational initiatives for people with dementia, and the carers who support them, on how to use social media safely. While some educational resources currently exist for older adults (Age UK, n.d.), to our knowledge there are no resources specific to dementia.

A substantial proportion of carers (58.2%) in this study were interested in accessing training and resources on how to support people with dementia in using social media. When developing training, researchers may find it beneficial to draw upon existing initiatives for people with other conditions sharing similarities with dementia (e.g., Brunner et al., 2022; Holmes & O'Loughlin, 2014). For example, research involving people with acquired brain injury highlights the importance of goal setting, personalisation, and having an interactive

and practical format (Newman et al., 2016; Brunner et al., 2023). While these interventions provide a valuable foundation, it is equally important that any training is also attuned to the unique needs of people with dementia and their carers, such as those tied to ageing, disease progression, and carer workload. Therefore, researchers should actively work with people with dementia and their carers to gain valuable insights into the preferred format, content, and delivery of future social media training, thus ensuring it meets their needs. This training may be integrated into a programme encompassing a wider range of digital technologies in dementia care. It is also important to consider the roles that various organisations may play in developing and implementing training. Future engagement with organisations, such as charities, healthcare institutions, community support groups, and advocacy groups will provide valuable insights to ensure the effective implementation of any social media training and resources. In addition to educational initiatives aimed at empowering people with dementia to use social media safely and effectively, there is an equally pressing need to develop technological innovations that prioritise safety by design. Notably, our work is situated within a time of critical debates surrounding the UK Parliament Online Safety Bill (2021), which intends to make social media companies more responsible for their users' safety. Critics of the bill have raised concerns about its emphasis on media literacy, noting how this shifts the responsibility for online safety from social media companies to the users themselves (Livingstone, 2021). While enhancing digital literacy among people with dementia and their carers is important, social media companies must also proactively identify and implement innovative solutions that uphold their safety and well-being. Some researchers in human-computer interaction studies have already put forward viable solutions, such as the introduction of family accounts, tailored access settings, and designing for transitions in vulnerability (Mentis et al., 2019; Piper et al., 2016). Future co-design work with people with dementia and their carers holds the potential to create safer and more inclusive social media spaces, mitigating risks while preserving the benefits of online engagement.

In this study, there was a benevolent paternalism among carers who sought to protect people with dementia within social media spaces. While carers appeared to be driven by a genuine concern for safety, there appeared to be a trade-off between ensuring safety and dignity while also trying to preserve autonomy and privacy. Comparable findings have been documented in research with older adults, with Murthy et al. (2021) noting the presence of 'self-appointed technology managers' within families of older adults, who moved between paternalistic oversight and responsible stewardship. Similarly, McNeil et al. (2017) highlighted how assumptions around diminished privacy needs are often made and acted upon within this demographic. In light of our findings, it is evident that a pivotal aspect of supporting people with dementia in using social media involves shared decision-making to uphold safety, autonomy, dignity, and privacy. This may involve an explicit and ongoing process of consent by carers who engage with or manage the social media account of people with dementia. However, initial research indicates variability among carers in seeking approval for online actions (Piper et al., 2016). Future research could further examine the decision-making processes that carers engage in, which could inform the future integration of consent-seeking practices with the design of social media platforms. This approach may serve to establish more ethical approaches to supporting people with dementia in their engagement with social media while preserving their autonomy and privacy.

Limitations

Despite our promising findings, there are some limitations of our work. Firstly, while the survey method generally elicited detailed responses, it did not allow for follow-up discussions on points of interest. Future research could employ interview methods to provide a more comprehensive understanding of carers' experiences of supporting people with dementia in their social media usage or a more iterative process of collecting responses (e.g., modified Delphi methodology). Secondly, our sample comprised individuals with early-stage dementia, as per our inclusion criteria. While carers did note escalating challenges as dementia progressed, carers of people with more severe dementia will likely have distinct experiences and support needs. Future research could include a purposive sample of carers of people living with more advanced dementia to explore in-depth how their social media usage compares. Moreover, our data are cross-sectional, and the absence of longitudinal data restricts our ability to examine how support for social media usage evolves over time as dementia progresses. The sample was also predominantly White, so the findings may not apply to carers from racial or ethnic minorities. Lastly, while our research focused on carers who support someone with dementia to use social media, it is important to acknowledge that a large proportion of respondents (76.5%) did not care for someone who uses social media. Our survey was also solely online, which may have biased the sample towards carers who are more adept with technology. In future, exploring the attitudes of people with dementia who do not use social media and their carers could uncover barriers to adoption, offering valuable insights for future interventions and policymaking.

Conclusions

In conclusion, the findings of this research highlight the crucial role played by carers in supporting people with dementia to use social media. They offered ongoing guidance and support, recognising the value of social media in fulfilling their caring role as a facilitator of cognitive stimulation and social interaction. However, carers were concerned about the vulnerability of people with dementia within social media spaces, particularly in relation to scams, misinformation, and posting inappropriate content. Consequently, they carefully managed the social media experiences of people with dementia, balancing the perceived benefits with safety, security, dignity, and caring demands. Many carers were interested in accessing training on how to support social media usage but were not aware of any existing resources. The continued growth of social media usage among older adults requires carers, support organisations, and policymakers to collaborate with technology developers to create social media environments which are safe, supportive, and inclusive of people with dementia and their carers.

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