The use of a bespoke website developed for people with dementia and carers: Users' experiences, perceptions and support needs

Abstract

Current policy emphasises the role of digital technologies in facilitating the management of long-term conditions. While digital resources have been developed for carers, there has been little attention to their development for people with dementia. The Caregiverspro-MMD website was developed as a joint resource for people with dementia and carers, delivering access to information, informal content, games and peer support. This study explored the experiences of dyads consisting of people with dementia and carers of using the website. Interviews and focus groups were conducted with forty three participants. Thematic analysis identified ten subthemes grouped under three superordinate themes which highlight participants' experiences of and responses to the website functions; important aspects of the website design and delivery; and barriers to use. Findings highlight the value of a credible information source which negated the need for arduous online searches, the pleasure associated with playing games and interacting with others online. However, participants were reluctant to share personal information online, preferring to create 'informal content' which celebrated everyday life, and were reluctant to 'friend' people online who they had not met in person. The importance of training and support to use the website was highlighted. Health problems, lack of interest or difficulties using technology, and time were all identified as barriers to use.

Keywords:

Introduction

Digital technologies play a significant role in the contemporary management of medical conditions, with a consequent requirement for the 'digitally engaged patient' (Lupton, 2013, p.258; NHS England, 2019). The use of digital technologies to support people with dementia (PWD) has been recommended within UK health and social care policy (Department of Health, 2015; NHS England, 2019).

People with dementia and carers experience a significant transition following diagnosis as they adjust to life with dementia (Ashworth, 2020; Clare et al., 2002; Hammar et al., 2021; Stokes et al., 2014; Toms et al., 2015). Post-diagnosis people with dementia and carers report difficulties accessing information, ongoing difficulties navigating and accessing services, and many experience isolation and diminishing social networks, and appear to value opportunities to develop new relationships with others in similar situations (Davies et al., 2019, 2020; Hammar et al., 2021; Powers et al., 2016; Stokes et al., 2014). Digital technologies may support people with dementia and carers, facilitating access to information and the development of virtual social networks, enabling them to share advice, information and experiences relevant to their new and changing circumstances.

Although older people (including many people with dementia and carers) are often identified as digitally excluded, internet use among older adults is increasing (Hunsaker & Hargittai, 2018). There is greater diversity in individuals' experiences of using digital technologies than is often

acknowledged; many have experience of using these for work or leisure, others are keen to learn new skills and recognise the importance of engaging with new technologies (Allen et al., 2020; Betts et al., 2019; White et al., 2020). This is evidenced in people with dementia and carers' use of online fora, social media and blogs to share their experiences, advice and information, create new support networks, raise awareness and engage in dementia activism (Hammar et al., 2021; Kannaley et al., 2019; McKechnie et al., 2014; McLennon et al., 2019; Rodriquez, 2013; Talbot 2020).

The internet is a valuable and accessible source of information, however the information available is variable in quality and broad in scope, necessitating effective search strategies (Allen et al., 2020); the potential value of the internet, coupled with older people's existing digital skills, experience and willingness to learn, suggests that dedicated online resources could help to address information needs, and facilitate connections with peers. Researchers have developed and explored the use and impact of online resources for carers of people with dementia (Dam et al., 2019; Boots et al., 2017; Hattink et al., 2015; McKechnie et al., 2014; Ploeg et al., 2018). In contrast, there has been a limited focus on developing resources for people with dementia, despite evidence of digital engagement. Two studies have explored the use of online resources developed jointly for people with dementia and carers; both were used more by carers. (Hattink et al., 2016; Killin et al., 2018). Killin et al (2018) identified that the lower use by people with dementia reflected a need to have 'accepted' a diagnosis and difficulties using the resource, which was perceived as more relevant to carers. Further, they found that the resource did not meet the carers' needs at the time it was introduced. These findings highlight the importance of careful design to ensure that technologies meet the needs of both groups, and provide the support required at the right time.

Despite these early findings, there appears to be potential for joint online resources for people with dementia and carers which can be used by and benefit both. Such innovations reflect how couples journey through dementia, working together to manage their new circumstances (Ashworth, 2020; Toms et al., 2015). This study concerns a website (Caregiverspro-MMD) which was developed as a joint resource for people living with dementia or mild cognitive impairment (MCI), and their carers, which could be used together and individually.

Methods

This study was conducted with participants in a Randomised Control Trial (ISRCTN15654731), which explored the usage, efficacy and impact of the Caregiverspro-MMD website across four trial sites in the UK, France, Italy and Spain. The website sought to address information needs and isolation, through provision of information about dementia and caring, and a social network to facilitate peer support. In accordance with best practice when designing new technologies (Meiland et al., 2017) its development involved people with dementia and carers in usability testing, and interviews about their experiences of early versions of the website (Zafeiridi et al., 2018; ., White et al., 2020). These influenced the subsequent design, delivery and content of Caregiverspro-MMD. The website incorporated a 'newsfeed' similar to those used on social media sites; this delivered information created by the researchers, and could be used by participants to post content, 'like' and comment on posts (Figure 1). Additional features included a calendar, a resources section with information about local and national agencies, the ability to save 'favourite' information for future use, and 'brain training' games developed for the project, along with links to games on external websites (e.g. online jigsaws, Mahjong).

Following early participant feedback (White et al., 2020) a training and support programme was developed (Cunnah et al., 2021); this included an initial home-based training session, written user-guides, and regular (optional) group training delivered by the researchers throughout the trial. Participant engagement with Caregiverspro-MMD varied from occasional to frequent use (Howe et al., 2020).

Figure 1: Caregiverspro-MMD newsfeed
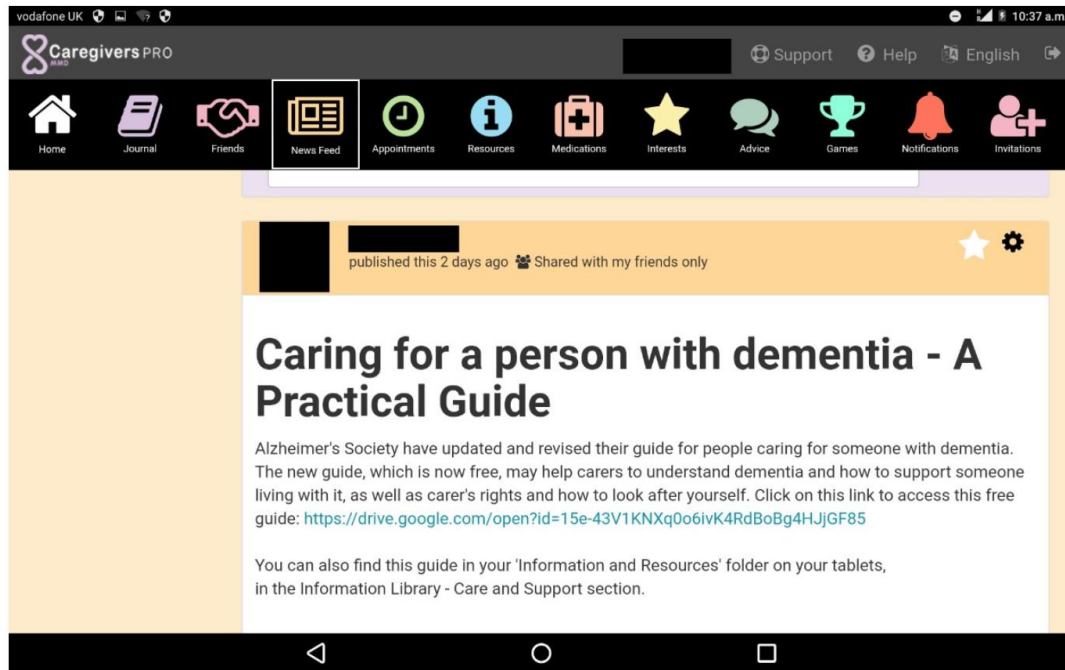
People with dementia and carers were recruited to the trial as dyads and randomly allocated to the intervention group (51 dyads), who were provided with a tablet device, which gave access to the Caregiverspro-MMD website only, or to the control group (49 dyads), who did not receive tablets or website access. Eligibility criteria are summarised in Table 1. The UK site also conducted qualitative data collection with the intervention group, during the final weeks of the trial. The aim of this stage of the research was to explore participants' experiences of using the CGP website and asked the following questions:

- What were participants' experiences of using the various website functions?
- What factors supported participant engagement with the website?
- What were the barriers to engagement?
- What were participants' learning and support needs?

The findings were anticipated to provide insights into the ways in which participants engaged with the Caregiverspro-MMD website specifically, as well as their responses to and needs in respect of online technologies more broadly, highlighting factors which should be considered when designing and delivering online resources to this group.

Table 1 –Eligibility criteria for the Caregiverspro-MMD trial

For PWD	Aged over 50 years
	Living in the community
	Able to provide informed consent at the outset of the trial

	Self-reported diagnosis of MCI or mild to moderate dementia
	Have an informal carer also participating in the study
For carers	Aged 18 years or older
	Self-reported carer of the PWD (no minimum hours per week of caring were specified; not required to be co-resident)
	No symptoms of dementia, MCI or depression
For both	Able to speak sufficient English to participate
	Able or willing to learn to use ICT
	Both willing to take part in the study as a dyad

Recruitment

Withdrawals and deaths occurred over the course of the trial; all remaining members of the intervention group (35 dyads and 1 carer) were invited to attend a focus group, as a dyad or individually, with the option to participate instead in an interview according to individual preferences. Additionally, purposive sampling (based on usage data) was used to identify a small number of participants to be interviewed. This was to try to ensure a diverse sample, by inviting higher and lower frequency users. Participation of non-users, and those who make minimal use of digital resources, is important in exploring reasons for non-use/abandonment of technologies, which may highlight gaps between developers' and potential users' perspectives, and consequent barriers to uptake (Greenhalgh et al., 2010). Interviews were conducted with dyad members individually or together depending on their preferences. Interviews took place in participants' homes, the focus groups in the venues used for training; thus data collection was conducted in familiar locations. A semi-structured interview schedule/focus group guide was designed; questions were based around the different website functions, and key aspects of its delivery, to identify what supported adoption and use, as well as barriers. Average duration of interviews was 33 minutes (range 6–47 minutes); focus groups 56 minutes (range 46-72 minutes). Interviews and focus groups were audio recorded and transcribed verbatim, and took place in September and October 2018.

Participants

A total of 43 people participated in this study. This included:

- 30 participants in five focus groups (15 people with dementia, 15 carers). This included 13 dyads, two people with dementia and two carers who attended independently of their partner/carer.
- 13 interview participants (7 people with dementia, six carers); 5 were interviewed as a dyad, 1 dyad was interviewed separately, 1 person with dementia participated independently of their partner.

42 participants were British and one Irish; all were recruited from the Yorkshire and Humber region in England. The majority were retired (N=35). Three people with dementia were unemployed, one was a part-time student. Four carers were in full or part-time employment.

Demographic details of participants are outlined in Tables 2 and 3:

Table 2: Demographics of people with dementia

Number of people with dementia:		22
Average age:		70.86 years (SD = 7.72)
Age range:		52-82 years
Gender:		11 female, 11 male
Type of dementia / diagnosis:	Alzheimer's disease	7
	Vascular disease	4
	Stroke-related dementia	4
	Mild Cognitive Impairment	5
	Unspecified	2

Table 3: Demographics of carers of people with dementia

Number of carers:		21
Average age:		67.10 years (SD = 10.92)
Age range:		38 – 83 years
Gender:		16 female, 5 male
Relationship to person with dementia:	Husband / wife / partner	17
	Son / daughter	3
	Friend	1

Participants had diverse levels of online experience, ranging from those with considerable experience to digital novices. Participants' domestic Wi-Fi access and internet use is detailed in Table 4; this indicates greater levels of internet access and use by carers (although 50% of people with dementia were regular users), with diversity in usage among both groups. A few participants lacked home internet access, but were not excluded on these grounds. All participants were provided with mobile internet (simcards), enabling internet access to those without domestic WiFi or who had connectivity problems, ensuring that the trial was inclusive of people with a range of online experience, skills and Internet access.

Table 4: Previous Internet experience

		Person with dementia	Carer
Do you have an internet connection at home?		17 (77.3%) Yes 5 (22.7%) No	20 (95.2%) Yes 1 (4.8%) No
How often do you use the internet?	Never	11 (50%)	2 (9.5%)
	Once a month	0 (0%)	1 (4.8%)
	Once a week	4 (18.2%)	3 (14.3%)
	Every day	7 (31.8%)	15 (71.4%)

Data analysis

A thematic analysis (Braun & Clarke, 2006) was undertaken, which adopted a combined deductive and inductive analysis as described by Fereday & Muir-Cochrane (2006); this utilised pre-defined codes, based on the questions in the interview schedule/focus group guide, with additional codes identified through close reading of the transcripts, to capture emergent themes. Three researchers initially read a sample of the transcripts to enable familiarisation with the data and develop the coding framework. They then applied the coding framework to a sample of transcripts to check the framework and identify further emerging codes. The revised coding framework was then applied to the full data set. The emerging themes were checked and refined by a fourth member of the research team not involved in the initial analysis, to check the robustness and coherence of the analysis and presentation of data.

Ethics

The UK study received a favourable opinion from NHS Health Research Authority (Yorkshire & The Humber—Leeds East Research Ethics Committee. Ethical considerations for this study included providing participants with written information about this stage of the study, and collecting written consent (in addition to consent already given to participate in the trial); this was required to ensure that participants consented to the new data collection methods, and retained capacity to consent. Permission was sought for the use of anonymised quotes from all participants.

Findings

The analysis identified three superordinate themes and ten subthemes; these highlight participants' responses to website functions, important aspects of its design and delivery, and barriers to use.

Table 5: Superordinate themes and sub-themes

Superordinate theme 1: Responses to, and experiences of, website functions	▪ Meeting and interacting with peers online ▪ Accessing information ▪ Accessing and creating informal content ▪ Accessing games
Superordinate theme 2: Design and delivery of the website	▪ Training and support to learn ▪ Balance and tone of content ▪ Using together or apart
Superordinate theme 3: Barriers to use	▪ Health related barriers ▪ Technology related barriers ▪ Time related barriers

Superordinate theme one - Responses to, and experiences of, website functions

This superordinate theme details participants' responses to and perceptions of website functions.

Interacting with peers online

Participants valued meeting and interacting with others. This reflected the perceived importance of peer support, sharing advice and information, and meeting others in similar circumstances:

I think it teaches you that there's not only you in that particular circumstances so therefore you're not sort of on your own (Carer FG4)

I do see this as a fantastic information source, a way to share information and to help other people and that's what I want to do (Carer FG5).

However, the desire to share experiences was tempered by clear boundaries about what participants considered appropriate to share in an online context. A reluctance to share information about personal circumstances or problems was evident:

I wouldn't feel happy discussing [PWD] with a stranger on a pad [tablet] (Carer 213, interview)

It appeared that sharing such information would only be considered *in extremis,* and was perceived as daunting*:*

You'd only post it online if you were at your wits end and didn't know what to do. Wouldn't you? Then you would post online 'look, my husband's done this, why? Somebody please help.' If you was desperate then you'd post it online (PWD, 175, interview).

Instead, participants appeared to enjoy and prefer posting less problem focussed content.

Some participants reported that the website had enabled them to make friends, which they valued:

What I like out of it is I feel as though I've made a good few friends…not friends to where we go here or there, but through [the website] and I meet some at the cafés now (Carer 246, interview).

Others were reluctant to engage in online friendships, or did not perceive a need for this due to existing social networks. The importance of meeting others face-to-face was also highlighted:

I think that's the generation; if you look at the people that were there [training groups], a lot of people do like face to face, it's better for you. And they've proven it, haven't they, over years, you know, talking over garden fence and all that. So I think our generation are used to, going and having a little chat in corner or whatever it were and making tea or whatever (Carer 175, interview).

Participant feedback suggested that many felt uncomfortable initiating interaction and friendship on-line. For several, the training groups provided an important opportunity to meet people prior to 'friending' them:

Unless you've met them in the group .....I don't feel as if I can be friends with them 'cause I don't know them (Carer FG2)

The term 'friending' as typically used online, may not reflect everyday understandings of friendship, suggesting that virtual and real-world friendships may be perceived as fundamentally different:

I mean I've sent things to friends... Plenty of that... But I've not actually made friends (PWD 268, interview).

Accessing information

The website provided information about living with dementia/MCI; caring; local groups and resources; financial and legal issues; social and leisure opportunities.

The value of information

Information was identified as interesting and useful. Participants appeared to gain new knowledge, understanding and insights:

I found an awful lot out about dementia and how you deal with it and places that you can contact (Carer FG2)

The thing I found most interesting in that she [blog writer featured on platform] was describing .....how dementia affected her as well in the home...And the things she's put right, she had to put right. It was, it was a bit scary but very illuminating (PWD 268, interview).

For some, the information accessed was new and helped address the paucity of information for carers and people with dementia post-diagnosis:

I never had access to anything like this before and my wife's condition has sort of quite recently, become noticeable recently and it's getting worse, and it's given me a lot of information (Carer FG4)

This enabled some to access support, social and leisure opportunities; others encountered barriers to acting on such information, due for example to no longer being able to drive, reliance on others, lack of confidence. The ongoing availability of the information also appeared to provide reassurance and security:

The tablet, you have 24/7, and I guess because there's so much information on there, you could turn to it at any time so that is a benefit, so it's good to know it's there, almost like a comfort blanket (Carer FG5).

Facilitating access to information

Participants appreciated the ease with which they could access information without undertaking extensive and potentially overwhelming searches:

If I want information on Alzheimer's dementia, I Google it and it comes up with 8,527,000 sites which I'm not gonna trawl through (PWD 175, interview)

Furthermore, the website delivered information participants would not otherwise have known was available, and could not therefore seek out:

The information, I would've never have gone out and looked for that information because for one, I wouldn't have known where to go (Carer 175, interview)

Present/future orientation of information

Participants valued information relevant to their current circumstances; some also valued receiving future focussed information to save in anticipation of needs, as dementia progressed and caring roles evolved. Knowing such information was available provided reassurance and security for some:

You see, that information is there if I need it. And that is…well, it's more like a lifeline really than anything else, it's there as a backup if I do need it (Carer 225, interview)

The stroke thing applies now to us - but the Alzheimer's contact groups, café meetings, societies - that's interesting because we might be there one day (PWD 175, interview)

However, the comment below suggests that, for some, managing their current situation was sufficient, and they were unable to absorb information for the future, highlighting diversity in the extent to which participants valued and could tolerate information that focussed beyond their immediate circumstances:

I've looked at some information. I don't think I've digested it to be honest, I just seem to float from one day to another at the minute (Carer FG5).

Accessing and creating informal content

In addition to factual information, 'informal content' was also shared. This included researcher-generated content, including local history information and local (non-dementia focussed) leisure opportunities and events. Participants also created informal content, sharing and celebrating families, special occasions, gardens, craft projects and holidays. Although not universally liked, such content promoted enjoyment, interaction and reminiscence:

I'm just reading this little bit about [name] on her holiday in Lundy and I found that very interesting 'cause I went there years ago,...... I did a survey on the peregrine falcon...... that's the reason I went there that time but I, you know, you just find things interesting (PWD FG2)

Informal content was perceived to facilitate getting to know other website users:

When people are putting their own pictures on and you're commenting, you're getting to know people (Carer FG4)

However, for some, there was uncertainty about whether others would be interested in their lives:

I love to hear, read, what people have wrote in and I often think I should, then I think oh no, they won't want to know what I've done. I haven't done anything! (Carer 143, interview).

These are important observations given participants' uncertainty and lack of confidence in forming online friendships and posting problem focussed content. It is possible that as people

get to know each other through informal content, they may gain confidence to seek and offer support with difficulties and challenges.

Accessing online games

Playing games promoted enjoyment and a sense of achievement:

They're addictive (laughter).....The dinner gets a bit later, you know, just, just, just finish this. Going to bed gets a bit later (Carer FG4).

Some perceived that games provided stimulation and 'brain training'. Further, they could replace activities lost as a result of dementia or conditions such as stroke:

It helps with your hand/eye coordination, and it helps with your memory, and things like that....It's very good. I used to knit...can't knit with one hand (PWD FG1).

Games provided a shared activity to enjoy together;

I like the jigsaws and [PWD's] a bit slower, he does the bigger pieces, but sometimes he'll come behind me and he'll say, "That piece there goes in there," and it does (Carer FG4)

However, they could also be carried out separately; this carer identified how games provided respite:

I also use it as a bit of an antisocial thing that when I get fed up or I get a bit depressed I'll sit and play the games - which takes me, you know, it sort of takes me away from my current situation (Carer FG4)

Super-ordinate theme two – Design and delivery of the website

This theme relates to aspects of the design and delivery of the website that could facilitate uptake and usage.

Providing training and support to learn

The initial home-based training was perceived as a helpful introduction, although some reported subsequently forgetting information. Repeated, regular training groups were positively evaluated by participants for whom they provided useful ongoing learning:

You do need the group training. Yeah, you do because people forget. You know, they come back this month and they've forgot what you told them last month (PWD 175, interview)

Participants appeared to value the opportunity to learn together, receiving support from the researchers and one another:

I think in the group, if [researcher] weren't available.... - you'd sort of ask someone else....and I think that helped.......Well, we were all in the same boat together weren't we (Carer FG4)

The groups also had an important social function; participants valued meeting others face-to-face, making friends, and sharing experiences with others in similar situations:

I think these, these meetings are really good..... because you, you suddenly find you're not so alone you know, you're all going really down the same road (Carer FG5)

Well, for me, it's just meeting new friends isn't it. Because that means an awful lot to me (PWD FG1).

Both home and group training sessions were supported by written user guides and handouts. These supported participant recall when using the website independently:

You get told here how to use it and then you go home, you've forgotten it by then but we, you had the...the handouts what went with it...that we logged up and things, I found it great from there (PWD FG2).

Providing content which is balanced in tone

Early research with users highlighted the importance of diverse content, in which issues such as dementia and caring were considered alongside 'lighter' material (White et al., 2020); therefore both formal and informal content was created. Some participants expressed preferences for serious or lighter material; however, many appreciated the range and balance of content:

Rather than just dementia, dementia you know like shoving it in your face.....there's other things that you've been able to keep your interest going (Carer 268, interview)

That's the lighter side, isn't it... the bit that takes you out of, out of worrying about the dementia.... you're into the real world, aren't you? (PWD 268, interview)

Although lighter content was appreciated, some did not shy away from the inclusion of content which might have been considered unwelcome:

It would have been nice to have known more about preparing for...death, I suppose (Carer FG 1).

Using the website together or individually

Caregiverspro-MMD was designed to be used by people with dementia/MCI and carers individually and together; we explored participants' views about this shared resource.

Some enjoyed using the website together:

We've worked well with it though, haven't we, don't you think? To say that we do so much separate, it's been good actually working together...and I'll read something and I'll say, "Oh, so and so and so and so," and he'll say, "Oh alright, come here and have a read of it" or he'll read it something and say the same back to me. (Carer 175, interview)

Participants' views about the possibility of separate areas or threads for carers and people with dementia were sought. Many were emphatic that this was not desirable, as the joint resource gave dyads the opportunity to share information and ideas:

For me, that would negate what I've just been talking about...about open discussion, because if we don't have open discussion, that's it.......So if you had two separate sides, you'd be hiding things from each other, so no way (Carer FG1).

The value of a shared resource reflected that this was a journey undertaken together:

If you're talking about us, where one is, you'll find the other (Carer 246, interview)

What affects me I need [daughter] to know and what affects [daughter] I'll need to know that as well (PWD 268, interview).

However, some carers indicated they would also have found a separate carers' section helpful. Carers were aware of the potential for posts to be hurtful or cause conflict, and therefore sometimes censored or limited posts:

I made a comment about [a post] yesterday and I wish it had been just for carers that one and I could have written more…..Because (PWD) would then read and then there would have been conflict between us (Carer FG2).

The ability to share information in a more restricted circle was perceived as enabling carers to support one another and be more open about difficulties.

Superordinate theme three – Barriers to use

Some participants made limited or no use of the website; barriers related to health, technology, and time.

Health related barriers

Barriers to use included periods of illness, health problems or hospitalisation. Changed abilities, due to dementia and conditions such as stroke, also made using the website difficult:

I don't use it for looking through the – what people have said [newsfeed]. Because I can't read so well. So I use the games (PWD FG1).

Technology related barriers

Technical difficulties, including problems with connectivity at home, militated against use. A lack of digital skills, interest or confidence, and fears of technology, also limited use, and some struggled to use the tablet and website despite the provision of training:

When I finished all my work was on computers, I decided that when I retire that no, so I don't use it as much (Carer FG4)

I'm not very clever with it at all really, I don't usually do anything like that, [carer] mainly does any computering that needs doing, he usually does it, so I don't do anything like that…. (PWD 225, interview)

Some reported concerns regarding online security. The closed membership of the group (website access was for research participants only) was perceived as providing safety from other users, unwanted advertising and associated risks:

There's a limited group of people so you know you are safe to add anybody….because you know where everybody is…..it's a safe way of meeting new people (Carer FG1).

So you also know that you can't really make a mistake with it either, it's saying you're not gonna press a button and order an elephant! (Carer FG4).

Such comments suggest that, for some, awareness of risk might lead to reticence to use online resources, if open to wider membership.

Time related barriers

Many participants cited a lack of time to use the website. This frequently reflected the fact that they were continuing to 'get on with life', fulfilling other caring responsibilities, and enjoying activities such as holidays, gardening, leisure activities:

We've just had so much going on really and we've got a huge garden and [PWD's] busy with his going to the gym and his swimming........and then, holidays and things...cos of where we are at the beginning, it's not been, we're not too far advanced, we're still carrying on as normal and we always have had a busy life so, that's the way we've taken it (Carer FG4).

Discussion

Digital approaches to supporting people living with long term conditions, and carers, are increasingly advocated; the findings from this study suggest that online technologies have a role in supporting access to information and peer contact, and highlight important issues to be considered when designing and delivering digital resources for people with dementia and carers.

Although the internet is perceived as an accessible and trusted information source (Allen et al., 2020), in common with other research findings, participants noted that the range of information delivered through online searches can be overwhelming, and successful searches rely on people knowing what information is available, identifying trustworthy websites, and developing effective search strategies (Allen et al., 2020, Davies et al., 2020; Peterson et al., 2016). Participants were able to use the website to easily access, use and save information, without lengthy searches, illustrating the value of a credible resource to deliver reliable and relevant information.

The findings suggest a need for balance in respect of the time-orientation of information, with diversity among participants regarding the information they want and feel able to receive. For some, limiting information to that which is relevant to their present circumstances is an important means of avoiding anxiety and feeling overwhelmed; others have more 'future-focussed' orientations, and are receptive to information which enables them to prepare and plan for the future (Ashworth, 2020; McKechnie et al., 2014; Nilsson and Olaison, 2017; Stokes et al, 2014). Clare et al. (2002, p.146) have underscored the importance of individuals being able to access the information they need, without detail which they cannot bear, and the need to 'find a balance between hope and despair'. Barnes & Henwood (2015) position information provision as an ethical issue, arguing that its emotional impact must be considered, and that information must be provided 'with care', recognising individuals' different situations, needs and preferences. Together these findings highlight diversity in respect of information people feel ready to receive and the extent to which they can accept information which goes beyond immediate circumstances, and a consequent challenge in respect of optimal information provision, whether delivered digitally or in person.

Ensuring balanced tone and content of online resources for people with dementia and carers is an important element of design and delivery, which may help promote engagement. Our findings indicated that, in addition to finding dementia and carer focussed information helpful, participants valued the inclusion of more informal content (and the provision of games). These enabled participants to get to know each other in an online environment, and provided

enjoyment, and a more celebratory and positive tone. This positive focus appeared to reflect how many people approach life with dementia, especially during the early stages. For many, there is an important focus on 'getting on with life', 'taking one day at a time', maintaining hope, positivity and humour (Ashworth 2020; Clare et al., 2002; Genoe & Dupois, 2014; Hickman et al. 2020; Toms et al., 2015; Wolverson et al., 2010). This was reflected in participants' reasons for not using the website as much as anticipated, as they were busy with non-dementia focussed activities, including supporting other family members, and enjoying time with families, hobbies and holidays.

Meeting others in similar situations was valued. However, the virtual context influenced the ways in which people interacted, with participants reluctant to share personal information in this online and public sphere (although it is possible that confidence to do this would have evolved over time), only considering this acceptable in desperation. Participants appeared reluctant to initiate contact with strangers and highlighted the importance of meeting people face-to-face. In this context, the training groups provided a bridge to facilitate online engagement between users; for many meeting in person was a precursor to online friending. The importance of groups as a critical element of technological intervention and usage is described by Hanson et al. (2007) who found that, while participants benefitted from technology introduced, the concurrent group sessions were the aspect of the intervention most valued. They concluded that the effects of technology provision and groups could not be disentangled. Responses of some Caregiverspro-MMD participants, along with those in Davies et al's (2019) study, suggest that for some, the concept of online friending is at odds with their perceptions of friendship. Therefore, the language used by developers and trainers may require consideration, to better reflect users' understandings of the kinds of relationships represented within online interactions.

Attending training groups also enabled participants to develop the skills and confidence to use or try out the website, and was associated with greater engagement (Cunnah et al., 2021; Howe et al., 2020). Given the diversity in older people's digital confidence and experience (Betts et al, 2019), some can initiate use independently, while others require initial support. Some reported forgetting what they had learned during the early training, underscoring the importance of repetition through ongoing training and reinforcement through accessible written user-guides. It is essential that potential users' learning and support needs are considered when developing and delivering online resources, that it is not assumed that people will necessarily have the skills and confidence to learn independently, and that a range of strategies are employed to meet users' needs.

The findings highlight a need for further research on the optimal balance between shared and separate digital resources or spaces for people with dementia and carers. The ability to use the website jointly appeared, for some, an extension of their shared dementia journey. However, it was also evident that this dual focus constrained some carers' use, through their awareness of the potential for their comments to hurt people with dementia. A separate carer space may have facilitated increased peer support. However, even when greater privacy is assured, carers may continue to feel ambivalent about sharing problems. Participants in Boots et al's (2017) study made limited use of an online carers' forum, and were constrained by feelings of disloyalty in sharing information about their partners and a wish to avoid others' accounts of 'misery'; a reluctance to hear about other people's problems has been documented elsewhere (Davies et al., 2019; McKechnie et al., 2014; Stokes et al., 2014). Although not evident here, some people

with dementia have also highlighted the need for separate spaces away from carers 'ranting' (Rodriquez, 2013; White et al., 2020). Further exploration of the optimal balance between shared and separate resources or spaces is therefore required.

Limitations

Different ways of participating in the data collection were offered, with focus groups, individual and joint interviews available. However, all were reliant on verbal communication which may be challenging for some (Pesonen et al., 2011). While collecting data from people with dementia and carers together may provide a supportive context, this also risks carers' perspectives overshadowing the voices of people with dementia (Pesonen et al., 2011), although attempts were made to facilitate the inclusion of both parties. Therefore, the use of additional methodologies which are reliant on 'more than talking' is advocated (Philipson & Hammond, 2018: 2); the inclusion of visual or observational methodologies may have enhanced the contributions of people with dementia.

The UK arm of the study took place in an area of low ethnic diversity. Research has identified a lack of information within Black, Asian and Minority Ethnic (BAME) communities about dementia, services and how to access support, which is compounded by language issues (Kenning et al., 2017; Parveen et al., 2017), highlighting the importance of accessible information provision. Further work, in respect of websites generally, and Caregiverpro-MMD specifically, with a more diverse group, or specific community groups, is required to develop culturally appropriate resources, identify barriers to use, and the extent to which such resources may provide effective and acceptable information and peer support.

Conclusion

This qualitative data complements the trial data, providing insights into the reasons underpinning participants' engagement (or non-engagement) with the website, and confirming the potential of online resources to deliver information and peer contact to people with dementia and carers. However, the findings suggest that such resources may work best when delivered as part of group interventions, enabling people to maintain contact outside group meetings and to gain access to a reliable information source. This echoes the need for psychosocial interventions which provide a 'mixed model of technology with an element of human interaction' advocated by Davies et al. (2019, e231). Further, the findings confirm the importance of training and support, and of ensuring that online content reflects both the challenges experienced when living with dementia and caring, as well as reflecting and acknowledging the positive experiences and orientation of many, who continue to engage with daily life and celebrate their experiences. This appears to provide a welcome balance in a context in which the future may feel uncertain and daunting. Barriers to use included lack of time, as people with dementia and carers do not focus solely on dementia, often remaining busy and active, and also indicate that digital resources do not represent an engaging option for all, so are not a universal solution to addressing needs.

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The Authors declare that there is no conflict of interest.

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