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The views of carers, people living with dementia and healthcare practitioners about the value of online information and peer support.

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Abstract

This paper reports on research into the development of a website (Caregiverspro-MMD) intended for carers and people living with dementia (PLWD). Carers, PLWD and healthcare practitioners were invited to explore a prototype of the website; information was sought about whether they thought the website would be useful; the functions and resources they would require; their views about using an online resource. Interviews and focus groups identified support for engaging with peers online and accessing information. Concerns about online safety and the tone of websites were also indicated. Support for learning was also highlighted as a need for some.

Keywords

Carers; People Living with Dementia; Online Technologies; Qualitative Research

Introduction

This paper reports on the views and wishes of carers, PLWD and healthcare practitioners in respect of dedicated online resources, and their responses and reactions to a prototype of a website intended to support people living with dementia (PLWD) and carers, during its early development.

As has been widely publicised, increasing numbers of people are living with dementia in our ageing society (Prince et al, 2014). A diagnosis of dementia impacts on the individual concerned, as well as family members who may assume caregiving roles. Following diagnosis individuals and carers may experience a need for adjustment, while transitioning into new roles, as well as needs for information (for example, about dementia, service provision); support to manage and respond to symptoms of dementia; social contact; emotional and peer support (Lauriks et al, 2007; Lee et al, 2019). These supports appear to be valued when available (Toms et al, 2015); however, there are gaps in the availability of information, and a paucity of support, with significant geographic variation reported (Robinson et al, 2005; Mountain and Craig, 2012; Campbell et al, 2016; Lee et al, 2019). Carers of PLWD have been identified as engaging in 'information work' in which they seek out, use, evaluate and share information; this requires time, effort and resources (Dalmer, 2018). They may experience difficulties in accessing the information they need, and may not know where to find information; further their information needs may change as dementia progresses, highlighting a need for timely provision, ensuring that they can access the 'right information at the right time' (Stokes et al, 2014; Sutcliffe et al, 2015; Peterson et al, 2016; Dalmer, 2018, p.17). Although less widely reported, PLWD have also identified information needs, and uncertainty about how to address these; they also report perceiving that information is primarily aimed at carers, which they experience as disempowering (Mountain and Craig, 2012); however the strategies they use to access information appear to have been little explored. Dementia is often associated with isolation for PLWD and carers, and an absence of social support (Rodriquez, 2013; Clemerson et al, 2014; Stokes et al, 2014; Spreadbury et al, 2017), potentially compounding difficulties in accessing both information and peer support.

Digital technologies play an important role in the self-management of long-term conditions such as dementia (NHS, 2019) and in enabling online communities of support; the potential of these have been recognised as an area for development in the UK National Health Service (NHS) and social care (Department of Health, 2015; Castle-Clark, 2018). Accordingly, web based, digital technologies may provide a means of addressing some of the information and social needs of carers and PLWD, as well as providing a source of support to which practitioners can refer people. Digital approaches to the self-management of health conditions currently available include websites providing health information; online peer communities for information and advice exchange; apps to facilitate peer support and medication adherence (Castle-Clarke, 2018). Online resources have been developed, primarily for carers; these have shown initial promise in respect of some outcomes (McKechnie et al, 2014; Hattink et al, 2015; Boots et al, 2018), and have been positively appraised by carers in respect of facilitating access to information, connecting with peers and reducing isolation (McKechnie et al, 2014; Ploeg et al, 2018). Such resources have provided a range of interventions (offered singly or in combination) including information or training, peer support, contact with professionals, support with decision making, and psychological support (Hopwood et al, 2018). Online support may fit well into carers' busy lives, being available round the clock and accessible at times and places convenient to them (McKechnie et al, 2014; Hattink et al, 2015; Boots et al, 2016; Hattink et al, 2016). Less attention has been given to the potential for such resources to benefit PLWD, although the use of Information and Communications Technology (ICT) for cognitive training,

monitoring and safety, reminiscence, and as memory aids has been explored (Lauriks et al, 2007; Garcia-Casel et al, 2017). A recent review (Lorenz et al, 2019) found that technologies for people with early stage dementia or mild cognitive impairment (MCI) are frequently concerned with supporting memory and the ability to live independently, with less emphasis on training or social purposes. The reasons why this population has been neglected in respect of online resources are unclear, however, they may reflect underlying assumptions about the abilities and willingness of PLWD to use and benefit from online information and support; the paucity of research into the information needs and seeking strategies of PLWD may also indicate prevailing assumptions that carers take the lead in accessing information.

Resources which can be used together by carers and PLWD may be valuable. Research suggests that, although a dementia diagnosis may affect each partner differently, dementia is a relational condition, affecting both partners; consequently couples travel on a 'shared journey' through dementia, together carrying out tasks and making sense of the changes they experience (Robinson et al, 2005; Molyneaux et al, 2012; Evans and Lee, 2014). A meta-analysis on interventions with family carers of PLWD suggested that joint approaches may be more effective in improving carer outcomes than approaches targeting carers only (Brodaty et al, 2003). Further, recent research has indicated that older adults' internet use benefits their partners in respect of preventative health behaviours, indicating that the needs of couples should be taken into account in website design (Nam et al 2019). These findings suggest scope for developing a shared resource which is available and accessible to both partners (with the potential to be used together and separately); this is consistent with relationship-centred models of care, reflecting how couples (and potentially other caring dyads) manage together post-diagnosis, as well as offering benefits to both partners. However, findings from existing studies suggest that careful design and planning are required if such resources are to be effective and accessible to both parties. We identified two resources jointly developed for PLWD and carers (Hattink et al, 2016; Killin et al, 2018); both provided access to information, with peer support, communication with professionals (Hattink et al, 2016), online care coordination and appointment booking (Killin et al, 2018) as additional features. Hattink et al (2016) concluded that both carers and PLWD are willing to use online resources, and frequently demonstrate the skills to do so. Participants rated the resource positively in respect of usability and usefulness. However, despite these positive appraisals, overall usage was low, with carers using it more than PLWD, as also found in Killin et al's study. Reported reasons for non-use included not needing the resource; technical issues; lack of time; lack of familiarity; difficulties in using (Hattink et al, 2016). Killin et al (2018) found that PLWD perceived the online information provided to be primarily targeted at carers, further, their adoption of the resource required them to have 'accepted' their dementia diagnosis. Their study also found a mis-match between the stage of the dementia caring journey experienced and the information and resources provided. While the potential for digital technologies to support patient groups in understanding their condition and accessing peer support has been recognised (Castle-Clark, 2018), the results from these studies suggest that for some groups there may be distinct disincentives and challenges associated with such tools. Additionally, some individuals lack digital skills and confidence, and may therefore be unable to engage with technologies without support (Castle-Clark, 2018). These studies suggest that further research is required to explore what resources are perceived and experienced as useful by carers and PLWD; barriers to uptake and engagement; the kinds of learning support required, how this should be delivered, and by whom. Such research can help identify what is required to support adoption and ongoing engagement, and whether there are populations unlikely to engage with online resources, for whom different supports are indicated.

The study

This research formed an early stage of the Caregiverspro-MMD study; an EU Horizon 2020 project, taking place across four European sites, in the United Kingdom (located in the North of England), France, Italy and Spain ((ISRCTN15654731). These sites were diverse in respect of rural/urban locations; access to services; the types of services from which potential participants were recruited. The overall aim of the study was to develop and trial a website which could be used by people with mild to moderate dementia or MCI, and their carers, to access proposed functions such as:

- Information (for example, information about memory loss, caring, local sources of support)
- Social networking opportunities, enabling users to share information, advice and experiences with peers
- A reminder system, providing prompts (e.g. for appointments, medication reminders)
- Online games to provide cognitive stimulation and enjoyment.

The aim of the stage of the research reported here was to explore participants' responses to a prototype website, to inform subsequent development. This included exploration of the following questions:

- What were participants' experiences of using the Internet (prior to taking part in the study)?
- What were participants' perceptions and experiences of interacting with the prototype website?
- What were their views about whether the proposed website and suggested functions would be useful to them?
- What functions and resources would they want from online support more broadly?

The prototype was an early version of the proposed website, which was not at this stage fully functional or 'live'. Participants were able to interact with the website in a limited way; for example they could click on and read from a small sample of pre-populated information, or type information into a sample thread; however they could not save information or interact with others. Interacting with the prototype enabled participants to discuss with the researchers their perspectives on the value of the proposed functions and the likelihood that they would use them.

Figure 1 – here

Representatives of potential user groups (PWL and carers) were included in the data collection, along with health care practitioners. Practitioners have a potential role in providing advice and information about technological resources, and support to use these (Malinowsky et al, 2014). However, they may have limited knowledge about the availability of such resources, and may assume that older people lack knowledge or interest in using technological approaches, such that carers have reported receiving little advice regarding technologies from health and social care practitioners (Grant et al, 2015, Newton et al, 2016). Their inclusion ensured that practitioner perspectives on online resources, the factors that prompt them to encourage and support their adoption, as well as potential barriers, were considered.

This early work was consistent with the widely recognised importance of involving potential users in the design of new technologies, ensuring that they are user-friendly and meet individuals' needs (Meiland et al, 2012; Span et al, 2014; Kerkhof et al, 2017; Meiland et al, 2017). Furthermore, it provides insights into the acceptability for carers and PLWD of using online resources, and the extent to which these are endorsed by healthcare practitioners, as well

as potential barriers and facilitators of use. As digital resources are becoming increasingly promoted in respect of self-management and carer support, these are important questions to explore.

Methods

Design of the website

This stage of the research invited participants to view and comment on a prototype of the Caregiverspro-MMD website; this gave examples of a range of possible functions that could be developed, and sought participants' views on the proposed layout and functions. Its development was based on the developers' and researchers' prior experience of working to support PLWD. This included following recommendations for good interface design for PLWD, which include avoiding complexity, ensuring simplicity of navigation (requiring as few 'clicks' as possible), ensuring that interfaces are uncluttered, and that fonts and graphics are an appropriate size for the intended user-group (Jodrell and Astell, 2016). The development and subsequent testing of the website occurred in four culturally distinct European pilot sites. The basic layout and functionality of the website was intended to be the same across all sites; with the content (such as the information made available) to be tailored to the needs of participants at each site, reflecting the specific resources available in each locality and the information available in each country. Thus the proposed design was universal, but the specific information and content was to be locally developed.

Participants

Three participant groups took part in the research; PLWD living in the community, informal carers, and healthcare professionals. PLWD were included if they self-reported a diagnosis of dementia or MCI, and were aged 60 or over. This age limit was applied as people living with young onset dementia were considered to have potentially different needs in respect of information and design, and different experiences of technologies. Carers were eligible if they self-identified as a carer of a PLWD/MCI and were aged 18 or over. No minimum hours of caring were specified, enabling inclusion of diverse caring roles and relationships, and an exploration of the potential uses and benefits of online resources in different caring contexts. Although the overall aim of the research was to develop a resource which could be used jointly by carers and PLWD, at this early stage participants could take part individually, and were not required to have a partner also participating. Healthcare professionals working across the dementia care pathway, who had regular contact with PLWD and carers as a substantive part of their role were also included. All were required to speak sufficient English to participate in an interview or focus group, and to be able to give informed consent.

Participant recruitment

A convenience sample of PLWD and carers (including spouses/partners; adult children; other family members or friends) was recruited from the North of England through statutory agencies, voluntary organisations, local networking events, and advertising on social media. Healthcare practitioners (including clinical psychologists, occupational therapists, nurses and pharmacists) were recruited via a local Memory Clinic, community mental health teams and a local university, and were purposively selected in order to sample a range of professional disciplines. Members of the research team visited memory clinics, community groups and practitioner team meetings in person, to share information verbally and in writing about the study.

Data collection

PLWD and carers' views were elicited via individual in-depth interviews, in order to allow rich data collection and time to interact with the website. Healthcare practitioners were offered a choice of focus group or interview to allow for flexibility and efficiency within their service. Nineteen interviews (four PLWD; eight carers; seven practitioners) and two practitioner focus groups were conducted, these were facilitated by two members of the research team (RD and EZ).

Participants were shown demonstration videos and an early prototype website on laptop computers prior to the focus group or interview. Participants had at least 30 minutes to interact with the website, with researcher support, however some elected to spend longer. Focus groups and interviews followed a semi-structured guide, which was developed and tailored for each participant group. The PLWD and carer interview schedules included questions about; previous experiences of using the Internet; what content and information they would like; design preferences; their views about sharing information, meeting others, managing appointments and playing games online. The healthcare practitioner schedule focussed on their thoughts on the current provision of online resources for this group, and what content, information and design features they believed PLWD and carers would like or find helpful. Interviews and focus groups lasted for 30-60 minutes, and took place in participants' homes or workplaces.

Data analysis

Interviews and focus groups were audio recorded and transcribed verbatim. Transcripts were analysed using thematic analysis which enables the identification and analysis of patterns in qualitative data (Braun and Clarke, 2006; Fereday and Muir-Cochrane, 2006), and is an accessible and theoretically flexible approach. A combined deductive-inductive approach to the data analysis was adopted, as outlined by Fereday and Muir-Cochrane (2006). This is an established analytic method which has been used in health and social care research (Nowell et al, 2017; Duffield et al, 2020; Roberts et al, 2019; Wildman et al, 2019); this 'hybrid' approach enables the exploration of specific issues of interest to the researchers, while allowing space to explore unanticipated issues, enabling further analysis of the data (Gale et al., 2013; Roberts et al., 2019), The coding process employed an existing model of 'user experience' for digital technologies (Guo 2011). This was chosen as it provided a framework for exploring key factors which promote or inhibit uptake and ongoing use of online resources, highlighting the importance of:

- Adoptability; the ease with which individuals can access and begin using new technology
- Usability; the ease with which the technology can be used
- Value; the extent to which the product is experienced as useful
- Desirability; the extent to which the technology is enjoyable to use.

Further codes were developed inductively through a close reading of the transcripts. As in Nowell et al. (2017) the deductive analysis structured the main themes, with the inductive analysis identifying sub-themes. All transcripts were coded independently by three researchers (CW, RD, EW), before meeting to discuss and refine the coding and analysis. Transcripts for each participant group were initially analysed separately; summaries of the analyses were then placed into an analytic chart, enabling key points of convergence and divergence among the groups to be identified.

Ethics

The study received approval from the University of Hull Faculty of Health Sciences Research Ethics Committee. Prior to taking part in the research participants were provided with a Participant Information Sheet, and asked to sign a written consent form.

Results

Participants

Information about the three participant groups is detailed in Table One. It was notable that the data collected from individual participants often contained multiple perspectives, in which individuals discussed their own views and the perceived views of others. For example, carers frequently discussed their own perspectives as well as the perceived perspectives of other carers and PLWD. Healthcare practitioners shared their own views and discussed the perceived needs of PLWD and carers. PLWD primarily focussed on their own perceptions and those of other PLWD.

Table 1 – here

Information was collected about the extent of participants' online experiences (focussing on their general use of the Internet prior to taking part in the study, rather than use for specific purposes); this varied between the groups. Among the four PLWD, two identified as non-users, a third as very digitally connected. The fourth said they did not use the Internet, however, later described using Facebook, games and digital photography, suggesting that some people may underestimate the extent to which they are digitally engaged.

In contrast, all but one carer reported using the Internet. For the majority, this included accessing information about dementia online:

That's my only source of information. There's nobody else seems to be able to help you (Carer 7).

For many using the Internet appears to have become part of everyday life:

'Oh I just Google the problem' (Carer 2)

The everyday place of going online was echoed in practice to some extent, with some practitioners reporting that they recommend websites to patients and carers, although this was not standard practice for all.

Participants' views and perceptions of the website and using online resources

This section details participants' responses to the prototype website, as well as their views on the functions they would like.

Adoptability

The data suggested two important factors that might facilitate or act as barriers to taking up and using online resources for carers and PLWD; learning and support needs, and the importance of understanding the purpose and potential benefits of such resources.

Learning to use

Some PLWD highlighted the need for support to learn to use the website, indicating a need to develop resources, including written user manuals and video tutorials. One perceived that learning would take effort and time:

I could use it just like that in a years' time...that's if I'm learning it every day for the year (PLWD 3).

In contrast, carers' comments suggested greater confidence in their ability to learn to use the website and to experiment:

I just dabble away until I've found it (Carer 8).

This was also reflected by one carer who identified as relatively new to the Internet, and as still learning; *'you learn by using it and experimenting don't you'?* (Carer 3).

Some carers were however unsure of the ability of PLWD to learn to use the website:

Just take my husband as an example. I can't see [him] really being able to use it very much at all, because he just gets so muddled up with what to do (Carer 2).

Understanding the purpose of the website

One PLWD did not appear to fully understand the purpose of the website and what it could be used for:

I don't fully understand what is going on here yet (PLWD 2)

This suggests that, in addition to enabling people to access support to learn to use new technologies and resources, some will also need support to understand how these could provide benefits and value to them.

Usability

Ease of use is clearly essential to facilitate learning and ongoing engagement. Participants identified important aspects of design which they considered would facilitate use of the website for PLWD and older people (including older carers) more generally.

The need for a clear interface was identified by all participant groups, who highlighted the need for:

- A clear, large font
- Careful choice of colour, and good contrast between the colours used
- A clear, uncluttered screen.

Practitioners also noted the importance of using pictures in addition to words.

Additionally, all groups highlighted the importance of being able to navigate easily between different areas of the website without 'too many clicks'.

Language

Each participant group identified the importance of user-friendly language. Examples were given of terms used within the prototype website which were confusing, as they could have multiple meanings, for example the terms 'cafe' (for the social forum) and 'support' (for the help function) were considered unhelpful:

Where it says cafe – that doesn't necessarily mean anything, you know – I thought cafe, what's that?" Maybe that could do to be altered..... instead of that could it be called "a caregiver's forum", so then you know exactly what that is for (Carer 9)

Participants identified that symbols also need to be clear; when used in tandem words and symbols may facilitate understanding and provide additional clarity.

Value

The prototype website demonstrated a variety of functions. Participants were asked about the functions they might value in a website for carers and PLWD, and their perceptions of the specific functions available.

Interacting with others

A potential platform function suggested by the developers was the provision of a social forum (Figure 2) to enable users to contact and interact with others online; we sought information from participants about the acceptability of this proposed feature.

Figure 2 – here

Among PLWD and carers there was interest in this function:

Like the social network aspect. Especially with it being with people with dementia (PLWD 4)

One carer highlighted the value of the website for carers who become socially isolated:

Because once [PLWD] gets to the stage where I can't leave him, then I might be desperate for someone to chat to, and all the rest of it. And by then presumably, I have built up friends (Carer 2).

However, several participants also highlighted the importance of face-to-face contact, in addition to being able to meet people online. One PLWD noted that they:

Would like a video facility to see people face to face. Because if I say 'do you like it?' you would say 'yes', but you maybe didn't like it and it would show on your face (PLWD 3).

Practitioners perceived benefits to individuals in being able to meet online, but also anticipated risks:

People can really hide behind lots of comments on the Internet ; people aren't always who they say they are and I think we'd want to make sure that there wasn't potential danger of someone coming on and sharing malicious information (Practitioner focus group).

Finding information

A further suggested function of the website was to enable people to access information. While this received little attention among PLWD, its potential importance was highlighted by carers who identified the difficulty of finding the information they needed, at the right time. This included not always knowing what information they needed:

In the beginning when you're faced with a diagnosis, and I'm talking from a carer point of view, where do you go to get help? What are the questions that you have to ask? Because you are on your own with this, nobody tells you, "Oh you need to contact this person, you need to ask that question", you don't know what question. So basically me and Google became very good friends, we did, and that's how I started and then started questioning and fighting for my mum (Carer 7).

Information was described by one carer as helping them to anticipate and prepare themselves for future needs and challenges:

Information, you know, is more than important because we are still struggling with the first year of this.....and I know by talking to the ladies at [carers' group], that it's going to go down and down and down and down, and you know, that is more than a bit scary. But as you've got a forefoot in what the other ladies are talking about, you can try to not imagine it in your mind, but you know what's coming and so you can say to yourself I will be ready and I can see it when it's coming, and I know what's coming and it's less scary (Carer 4).

However, other carers and PLWD appear to prefer to avoid this future-focused orientation, instead preferring to live in the present, sometimes storing information for future use (Bielsten et al, 2018; Dalmer, 2018), highlighting diversity among individuals in respect of the information they find helpful and acceptable.

Carers and practitioners identified extensive lists of potentially useful information, including information about:

- Finance and benefits
- Power of Attorney
- Sources of support
- Local events and groups
- Dementia
- Assistive technology and equipment
- Research.

Sharing information, advice and experiences among peers

The opportunity to meet others online can enable peer support, and the sharing of information and advice, in addition to the more formal information created by researchers or practitioners.

Among PLWD, one reported that they would find sharing experiences embarrassing, and that they felt cautious about doing so; in contrast, another reflected on their experiences of using social media, highlighting the value of online connections and advice sharing:

Usually use Twitter to ask people advice, and people come back to me through Twitter. So Twitter's been a huge way of connecting with people that you don't normally ... you're not normally able to connect with. So it gives you access to people that you wouldn't be able to otherwise (PLWD 4).

Some carers perceived a value in this function (further reinforced by practitioner comments);

I think to be able to support each other and to have ideas off each other, what's working for them, what's not working for them and where they are in their journey, I think it's a brilliant idea to be able to share that information (Carer 5).

Having a chat thing, so that people can say, "does anybody else do this?" would be helpful, so knowing that it's a bit more normal sometimes to do certain things (Practitioner 7).

The importance of ensuring that information is accurate and up to date was also highlighted:

Somebody might talk about Power of Attorney and there might have a lot of waffle on it, but then they might be wrong and they might not have said it right. I'd like it to be factual and have confidence that it's...' (Carer 8).

Accuracy and currency of information is important whether information is created by professionals or within a peer forum, and indicates the need for monitoring and oversight.

Alerts and reminders

Another potential use of the website discussed was to help people set reminders, for example, for appointments, medication reminders. PLWD and carers appeared to have different perspectives on this. Among PLWD there was uncertainty about whether they would use this function; only one person appeared interested. Carer views were more varied; some perceived this function as useful; *'it could be almost like your lifeline'* (Carer 8). Others did not consider they would use this, although some perceived potential value for other carers:

My mum barely knows what a computer is, so that wouldn't work, it's not something for my personal circumstances, it might be good for other people, not for me (Carer 7).

Both PLWD and carers noted that they already have strategies in place to enable them to remember and keep track of information, where these are in place, this may render alerts unnecessary:

I can't see it improving on what I am doing. But if I wasn't that way organised, and someone was coming to it fresh, so say you get a diagnosis, and you have got to sort out how you are going to cope with it... You have got to put a system in place. Well to anybody who is on this system right at the beginning, great, just use that. I have set up what I am doing because I needed something that would work, that [name of PLWD] can understand, he knows what I do. But to do it on here, yes it could work, and it could help, providing it was done before anything else was put in place (Carer 2).

Existing strategies reported by participants included 'high tech' resources such as (unnamed) apps to provide appointment or medication reminders, and, more frequently, everyday, 'low-tech' solutions, such as print calendars, notice boards to display appointments, sticky notes to provide prompts, and Nomad boxes, which indicate what medication should be taken, and when. In contrast, practitioners did not mention the importance of existing strategies, such as those identified by carers and PLWD.

All participant groups noted potential difficulties with alarm functions; these included the need to be logged onto and near the system to receive the reminder; the need to accurately populate the relevant information (and update it if necessary); the potential for people to be worried or frightened by the alarm going off '*she'd be going round wondering what the noise was*' (Carer 7). These views highlight the paradox of alerts and reminders for PLWD and their carers; they have the potential to enable people to remember important things and remain independent and in control, reducing the need for carers to provide prompts, however people need to remember to use this function, including remembering to log on, accurately enter data, and update information, for which some may require the support of carers. Thus alarms may not alter the need for carer support, but alter the way in which this is provided.

Games

The potential inclusion of games was discussed with participants. PLWD had mixed views about these; some were interested, especially in being able to play games with others, others were not especially interested in this function. The majority of carers did not seem interested in playing games; however, some appeared more interested if these were reframed as 'brain training'. Other carers were more enthusiastic and perceived games to have value in providing relaxation:

I think the game's a really good idea because you can get some brilliant memory games and it's a bit of a chill out time, especially if you can play against each other on people... friends that are already on there, that could maybe keep up relationships and contacts (Carer 5).

Practitioners also noted the potential for games to provide enjoyment and the opportunity for 'brain training'.

Desirability

Desirability relates to how people feel about using new technology, for example, in this case would they find a website for carers and PLWD enjoyable to engage with?

Perceived risks

Perhaps not surprisingly, in considering a resource which enabled participants to interact with others and share information online, risks and concerns were identified. Concerns about privacy and sharing information safely were noted by all groups. Among PLWD there was an awareness of risk *'you've got to be very careful what you put in public'* (PLWD 1); with risks noted in respect of sharing medical or financial information. However, one PLWD did not appear aware of or concerned about privacy and risk. Carers identified risks in respect of sharing certain information (such as medical matters), and wanted to be able to choose who they shared information with:

With respect for my mum I wouldn't discuss her real personal stuff. The general stuff, the ideas, I've bought this or I got this piece of equipment or whatever, I mean I might talk about me, I've had a hard day today, or something like that, but nothing that's confidential (Carer 7)

Practitioners appeared the most concerned about online risks, and stated concerns about people sharing information and their potential vulnerability. They noted that people may not understand the issues associated with information being visible to others, and the risks associated with online friendships. They also highlighted the importance of the website being secure, to reduce the risks of people being targeted for online fraud and spam. The difficulties of balancing the need for ease of access and security (with some people finding remembering and managing pin numbers/passwords) were also noted.

An additional risk concerned the potential for online information and interactions, and the language used, to cause distress. Practitioners especially appeared acutely aware of the potential emotional impact of information (online and in general). They noted that much information online and in online forums can be alarming, especially if taken out of context:

You can direct [to] specific websites but I think it's that fear, I mean we've all done it, you put in something and then just get back horrendous amounts of.....You're looking for support and actually what you get is more anxiety.....And if it's somebody that's just been diagnosed I think, that kind of anxiety, that they're going to whack it in the Internet and get all sorts of horrendous stuff back (Practitioner Focus Group).

One PLWD reported that looking up information online could be upsetting, stating that their wife looked up information about dementia, but that they did not: *I can't do anything like that, it just upsets me (PLWD 1)*. Participants identified ways of addressing perceived online risks. The need for moderators was noted by practitioners, to ensure that people are not including information which might make them vulnerable, to reduce risks of malicious behaviour online, and in the event of poor advice sharing among users. A report button enabling people to highlight problems was also advocated by a PLWD. The potential for PLWD to be upset by things shared by carers online was noted; accordingly, separate forums for carers and PLWD were suggested:

Much better having them parallel. Just so.....one doesn't upset the other.... they don't feel restricted on what they say, or some people don't feel restricted anyway, and might say the inappropriate thing (PLWD 4).

Further:

It's very demoralising, or it can be very demoralising for people with dementia to see carers ranting, just ranting off and ... you know, it's a need for them, but it's a parallel need, rather than a joint thing (PLWD 4).

Tone and content

Although not frequently mentioned, comments from small numbers of participants in each group suggest that websites, such as the one outlined here, should not focus solely on negative and challenging aspects of dementia and caring. For example, participants identified the desire to search for 'friends' on the site by hobbies and interests (rather than by medical issues or diagnoses); for information about activities not to be restricted to those specifically for PLWD, and to include information about activities open to all; for 'lighter' information (such as recipes); for forums not to focus exclusively on dementia:

I'm very aware it's important to not let dementia take over your life. And I've seen it on forums whether (sic) people live and breathe it (Carer 7)

Not using the word 'burden' anywhere (PLWD 4).

Discussion

The findings from this study present multiple perspectives which evidence the diversity in peoples' needs and wishes for information and social interaction to help self-manage dementia or care for PLWD.

The development of shared digital resources have received limited attention to date, and appear initially to have been used more by carers, highlighting the importance of ensuring that the needs of both parties are addressed and that the resources developed are accessible and acceptable to both. However, as dementia can be a journey shared by PLWD and carers, articulated by one carer in the study as *'a joint hammer that hits you both'*, there appears to be potential in further exploring the development of a resource that provides support to both.

The data highlighted multiple issues which need to be considered in order to promote successful adoption and ongoing use of online resources. These provide valuable insights to those introducing new technologies or promoting online resources among carers and PLWD.

The ability to 'get started' with new digital technologies appears critical. The interviews with PLWD in particular suggest that, for some, learning to use new technology requires time, effort and support; therefore it cannot readily be assumed that people have the confidence to simply 'log on and play' (Greenhalgh et al, 2010, p9). Training for carers has also been identified as important (Lamura et al, 2019), although was not identified as a priority for carers in this study. Our study sample included people with a range of prior experiences of using the Internet and digital technologies; this was also observed in the subsequent Caregiverspro-MMD trial in which both PLWD and carers had diverse experiences and skills (Cunnah et al., 2019). While older people are often reported to be digitally excluded, with limited experience of using the Internet (Friemel, 2013; Richardson, 2018), within this population there is considerable diversity, meaning that individuals have different support needs and skills. It should not be assumed that older people (including PLWD and older carers) lack ability or interest in learning to use new digital technologies (c.f. Hattink et al, 2016), but equally it should not be assumed that all have the skills, confidence and experience to try out and learn readily. The provision of good information and support, which recognises diversity of experience and learning needs, and which is available in a range of formats, appears important, to help individuals engage with and learn to use new technologies. A further important aspect of adoption highlighted relates to the extent to which potential users understand the purpose of new technologies, indicating the importance of support to identify *why* these might be beneficial, in addition to learning *how* to use them.

The value of new technologies to potential users is also an important area to explore; lack of perceived benefits may act as a disincentive to adoption and use (Meiland et al, 2017). The aims

of Caregiverpro-MMD included supporting people to access information, social networks and peer support. Carers' fora have enabled carers to connect with others in similar circumstances, reducing isolation and loneliness and facilitating access to advice and support (McKechnie et al., 2014); social media and blogs have also enabled carers to share ideas and experiences, and develop new, virtual relationships which are untethered to geographic location (Anderson et al, 2017). Such online spaces have the potential to provide 'comradery and a non-judgmental space for expressing the ups and downs of caregiving' (Anderson et al, 2017, p14). PLWD may also use social media and blogs for similar purposes, gaining access to communities of support, encouragement, solidarity and information sharing (Rodriquez, 2013; Talbot et al, 2018; Lorenz et al, 2019). This suggests that the inclusion of online fora or social networking functions within an online resource for carers and PLWD is a valuable element of online support, and participants expressed interest in interacting with others online. However they also highlighted the importance of face-to-face contact; this is consistent with the findings of research with carers in which online training, supplemented by direct contact with practitioners, was well received (Boots et al, 2016; Boots et al, 2017). This suggests that online support may be optimally used as an addition to face-to-face support rather than as a replacement.

The value of accessing information online was also highlighted by carers who reported their difficulties in obtaining the information they need in a timely manner. Although several carers already used the Internet to seek health related information, the difficulty of knowing what information might help them was highlighted; *"you need to ask that question", you don't know what question'* (Carer 7). Carers have identified needs for information sources which are trustworthy, accessible and address specific questions; while well-informed practitioners are a preferred information source, they are perceived as inaccessible in comparison to the internet (Allen et al, 2018). However, Internet searches can be overwhelming, and online information is not always trusted (Peterson et al, 2016). This suggests that well-designed, up to date and accurate web based resources, reached through a single and credible point of access (rather than a generic search engine) may have potential to make a significant contribution to addressing the current paucity of post-diagnostic support and information provision identified, in tandem with ongoing practitioner support. The potential for online information to cause distress was noted by all participant groups, therefore, there is an important role for moderators in checking the accuracy and appropriateness of information and advice shared among peers; this requires ongoing financial resources.

PLWD and carers identified existing strategies for dealing with memory loss, highlighting their resourcefulness in actively adapting to changing circumstances together. Where carers and PLWD have found successful ways of meeting their needs, they may not wish or need to adopt new approaches (c.f. Killin et al, 2018), thus any new technologies introduced need to fit in with or go beyond their existing strategies. It was notable that practitioners in this study did not mention the significance of existing approaches, such as calendars, commercially available apps, Nomad boxes, identified by participants; this highlights an important difference of perspective which needs to be considered, in order to ensure that existing solutions and preferences are not ignored or undermined, but are recognised and supported by health and social care practitioners.

The opportunity to interact with the prototype website exposed concerns about risk and safety, including concerns about inappropriate sharing of personal information and vulnerability to fraud. This highlights a need for good design in order to minimise risk, as well as ensuring that potential users have information and support to enable them to understand risks and develop safety strategies for themselves and those they support. Practitioners appeared especially risk averse in comparison to the other participant groups; this suggests the need to achieve a

balance between highlighting concerns (and enabling people to consider ways of addressing these) while not being overly protective or restrictive when recommending resources.

Reflecting on the tone of websites and the information conveyed, ensuring that they do not focus solely on 'doom and gloom' accounts, such as the 'burden' of caring and 'personal disaster' narratives of dementia is important. While the difficulties and demands of living with dementia and providing care and support have been well-documented, there are also accounts of living well with dementia and positive experiences of caring (Mitchell et al, 2013; Lloyd et al, 2016; Wolverson et al, 2016; Macbride et al, 2017; Mitchell, 2018). Achieving a balance in online resources, ensuring that they reflect the richness and complexity of living with dementia and caring, recognising both challenges and positive experiences appears important, and is consistent with analysis of older people's social networking sites which are considered to achieve a balanced tone, ranging from posts which are for fun and those which are more serious or problem focused (Nimrod, 2009). Boots et al (2017) found that carers made limited use of an online discussion forum due to reluctance to read about other people's 'misery', illustrating the need for balanced content and tone. Carers' fora may be used to 'share and let off steam'; this may be helpful, but also distressing to other carers (McKechnie et al, 2014, p9), and to PLWD who may value a separate 'safe' space, which shields them from carers' comments (Rodriquez, 2013). This risk could be alleviated, as suggested by one participant, by having separate fora or threads for carers and PLWD, as has also been highlighted in previous research (Rodriquez, 2013; Span et al, 2014). Separate fora may provide benefits and 'safe spaces' for each group within a shared online resource, which can be used together. Further research to explore the relative merits of separate or shared spaces appears important.

Limitations

While this study has provided useful insights and responses from multiple viewpoints, there are some limitations. In line with an exploratory study, the research involved a small sample size, and means that data saturation may not have been reached. This was especially the case for PLWD and for male carers. A larger group may have enabled a greater variety of responses, and promoted consideration of the developments required to meet the needs of a more heterogeneous group, and their willingness to engage with digital technologies. Further the research was conducted in a single geographic location.

Conclusions

This study sought the views of three different groups in respect of a website developed for carers and PLWD. All participant groups provided significant feedback and responses, highlighting important areas to be taken into consideration during the design of online resources. The study provides valuable information about the resources that carers and PLWD considered would be beneficial, as well as identifying concerns, and things that need to be in place to support their adoption and use of online technologies.

Overall the study highlighted that support would be required by some to enable them to learn and use online technologies, and to help them appreciate the potential benefits of adoption. The ability to access information from a reliable online resource was valued by carers, who reported difficulty both in finding information, and knowing what information was available to them. Both carers and PLWD responded positively to the concept of meeting peers online and offering information and advice; however this form of interaction was not necessarily perceived as replacing face-to-face contact. There was less support for online calendars and alerts among those used to living with dementia, although these were seen as potentially beneficial for those starting their dementia journey, and who had not yet established practical strategies.

Participants also highlighted issues which need to be considered by those developing and populating online resources. All participant groups identified risks associated with websites focusing on dementia and caring. In addition to security concerns, these reflected the potential of online information and content to provoke anxiety and distress. The need for websites to include 'lighter' content alongside dementia and caring focussed content appeared an important element of developing an appropriate and acceptable emotional tone.

As digital approaches for supporting PLWD and carers are increasingly advocated within health and social care, these factors need to be attended to, in order that potential benefits can be delivered, and to ensure that potential users are not at risk of being 'left behind' and isolated from new sources of information and peer support, while also recognising that many do not wish online resources to replace face to face contact.

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Declarations

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Table One - Characteristics of the participant groups

PLWD	Number	Percentage
Gender		
Male	3	75%
Female	1	25%
Age range	60-89 years (mean - 75.75 years)	
Percentage of participants with access to Internet at home	3	75%
Carers		
Gender		
Male	0	0
Female	8	100%
Age range	29-89 years (mean 64 years)	
Relationship to PLWD		
Spouse	3	37.5%
Daughter	3	37.5%
Friend	1	12.5%
Volunteer (with family experience of dementia)	1	12.5%
Employment		
Retired	6	75%
Employed part time	2	25%
Participants with access to the Internet at home	7	87.5%
Healthcare practitioners		
Gender		
Male	3	18.75%
Female	13	81.25%
Years working with PLWD	2-25 years (mean 11.09 years).	
Participants reporting recommending online resources to PLWD and carers as part of routine practice	12	75%

Figure 1 – The Caregiverspro-MMD login page

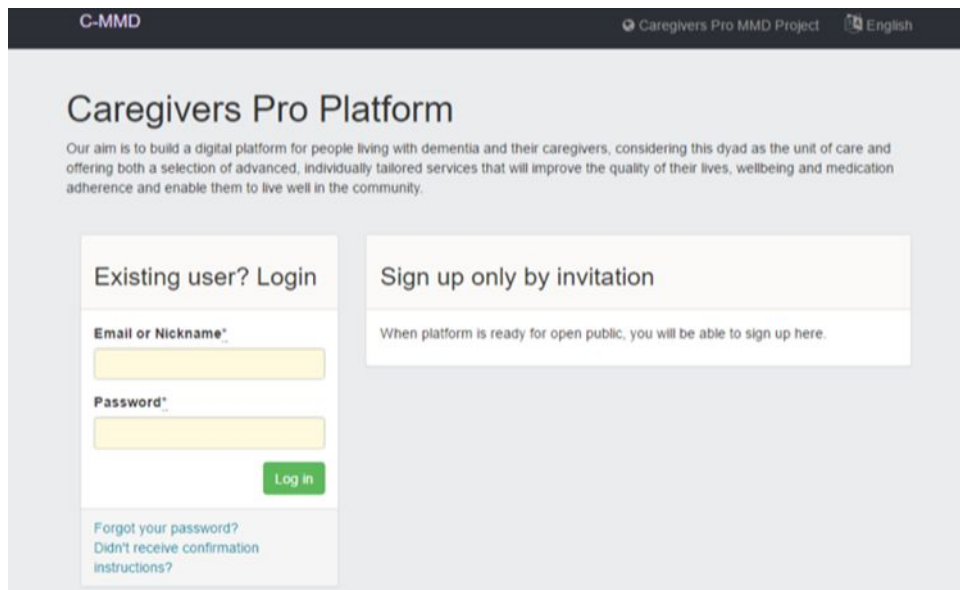


Figure 2 – The Social Forum

