Design Considerations for Self-Management Technologies for People Living with Dementia and Informal Carers - Perspectives of Healthcare Professionals and Charity Workers

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Abstract. Dementia is a neurodegenerative disorder that leads to decline in memory, language, reasoning, and the ability to perform daily activities. It is linked to poorer quality of life for the person with dementia and their informal (unpaid) carers. While early intervention and access to adequate care are critical in slowing dementia's progression and better managing associated symptoms, dementia is frequently only diagnosed at an advanced stage and care is often fragmented. To better understand how to meet the complex needs of persons living with dementia and their informal carers, 10 healthcare professionals and 10 charity workers from relevant community and charity organisations were interviewed. Topics covered included challenges and pain-points of the dementia journey, provision of care plans, communication amongst relevant stakeholders, and the impact of dementia on co-morbidities. A collaborative semantic thematic analysis was conducted and themes constructed included The Impact of Dementia; Gaps in Support for People living with Dementia and their Informal Carers; and Care and Collaboration, with subthemes of the impact of inadequate supports; reasons for support gaps; lack of formal, integrated care plans; and care strategies. Findings are discussed in terms of implications for the development of a holistic, multi-component digital platform to support persons with dementia and their carers.

Keywords: Dementia, Digital Health, Informal Caring, Care Networks.

1 Introduction

Dementia is a progressive neurodegenerative disorder characterized by a decline in cognitive functioning that affects memory, language, reasoning, and the ability to perform daily activities [1]. It primarily affects people aged 65 and over but can also occur in younger individuals (young onset dementia). Dementia negatively impacts quality of life for both the person living with dementia and their informal (unpaid) carers [2]. According to the World Health Organisation (WHO), more than 55 million people had dementia worldwide in 2023, with 10 million new cases diagnosed each year [3]. The estimated global cost of dementia in 2019 was US $1313.4 billion [4], with this cost expected to rise as prevalence increases [2]. Often resulting in a loss of independence, changes in behaviour, and social isolation, the disease can have a significant emotional impact on the person living with dementia [5]. Furthermore, informal carers, who make up 6% of the Irish population [6], face significant care burden, risks to their own health, and also experience social isolation [7]. In 2018, as the population ages and rates of dementia and cognitive decline or impairment increase, the U.S. Department of Health and Human Services recognised the impact of informal caring as a rising public health concern with the Recognise, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act [8] aimed at ensuring availability of critical carer supports.

The dementia journey spans diagnosis, management, and disease progression and people living with dementia and their carers require significant and varied resources as they face multiple challenges [9]. A multidisciplinary approach is required for effective management of this complex disease. Such an approach requires active collaboration between various healthcare professionals (HCPs), the person living with dementia, informal carers, and the range of community and charity organisations who care for those with dementia. However, multidisciplinary collaboration within and across clinical and community domains presents difficulties in practice, particularly where integration of care is minimal, which can result in fragmented care for the person living with dementia and negatively impact effective symptom and wellbeing management [10].

Another fundamental problem impacting the effective management of dementia is that of late diagnosis, which can ultimately lead to a faster rate of progression of cognitive and functional decline, as well as reduced quality of life [11]. Research by WHO estimates that 90% of people living with dementia in low- and middle-income countries are unaware that they have dementia [2]. However, underdiagnosis is not the preserve of countries of lower income. Dementia is also underdiagnosed in Ireland [12], where it is estimated that less than 50% of those living with dementia have received a diagnosis [13]. Compounding these challenges are an increased demand for health and community services, as dementia prevalence continues to increase, resulting in a strain on resources and longer waiting times for appointments and services, even for those with a dementia diagnosis. As a consequence, missed opportunities prevail for timely interventions and management, as individuals and families struggle to identify or access relevant services and resources. Consequently, stress and anxiety may also be heightened for the individual and their families, further negatively impacting health and wellbeing and contributing to carer burden.

In recent years, the concept of self-management for people living with dementia has emerged, defined as "*a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition*" [14] and it is recognised that individuals, particularly in earlier stages of dementia, can be supported in self-management [15, 16]. Leveraging technology, to deliver interventions and content for the support of dementia symptom management, may offer one solution to ameliorate existing and future dementia resource pressures, for example by delaying progression of the disease for persons living with dementia, whilst also addressing some of the care support needs of informal carers. However, evidence of the benefits of technology for dementia self-management and to support independence and autonomy is still limited [17], with most technologies for people living with dementia aiming to address security and safety, followed by memory aids and, finally, treatment and care delivery [18].

The primary aim of our work is to co-design and develop a holistic, integrated digital health platform to support people living with dementia to self-manage their health and wellbeing with support from those who care for them. A second aim is for the platform to support informal carers in providing effective care, whilst also caring for themselves. We envisage end users of the platform will also include HCPs as well as individuals working in charity organisations who also provide care to people living with dementia and their carers in the community. Work to date has involved interviews and focus groups with people living with dementia, informal carers, HCPs and charity workers. This paper focuses on findings from interviews and focus groups with the latter two stakeholder groups. Findings from interviews with people living with dementia and informal carers will be published elsewhere. Drawing on interview findings and the literature, this paper presents design considerations for this digital health platform.

2 Related Work

2.1 Technologies for the Person Living with Dementia

Before designing new technological interventions for use by people living with dementia we first look to the use of mainstream technologies adapted, repurposed, and utilised to meet a range of needs, including memory support, psychological distress, and engagement in daily activities, and that are typically targeted at people living with early-stage dementia or mild cognitive impairment (MCI) [18]. Such technologies include electronic calendars, online information provision, and video-calling [19, 20], global positioning system (GPS) locators, medication reminders, and voice cues to initiate engagement in a daily activity, which aim to support memory and the ability to live independently [21-24]. In a systematic review of digital technologies to support self-management and social participation of people living with dementia or MCI, Neal et al. [17] identified three categories of technologies, virtual reality, wearable technologies and software applications, finding the aim of the majority of technologies studied was to improve cognition. However, this review and others found little high-quality evidence that technological solutions were impactful in the improvement of self-management, cognitive functioning or social participation for those living with dementia or MCI [25]. Furthermore, few technologies were found available for people at the early stage of dementia or with MCI in the areas of training, care delivery and social [18]. Dementia is progressive and, therefore, the needs of those living with this disease change over time, along with the ability to cope with and manage symptoms. As such, different technologies may be more suitable and effective at different stages of the disease [18].

It has been demonstrated that people living with dementia hold positive views towards assistive technology, are open to exploring its potential in terms of maintaining independence and are receptive to participating in design [26, 27]. A crucial factor to consider for proposed technology use, is the impact the disease has on individual capacity to learn and retain new information. This has implications for designers with regard to key facets of usability such as learnability and memorability, further highlighting the need for any technology to adapt to the individual's changing circumstances such that usability and effectiveness are maintained [28, 29].

2.2 Technologies to Support Informal Carers

Informal carers of people living with dementia or MCI are often juggling multiple demands including physical, emotional and financial challenges. The demands associated with providing full-time and unpaid care are considerable and varied, frequently resulting in feelings of isolation, psychological distress (anxiety, depression, stress), loss of self-esteem, and a tendency to neglect one's own health and wellbeing due to time constraints and feelings of exhaustion [30, 31]. Carers often experience stress and burnout, due to the progressive nature of dementia and the shifting demands of providing care and support [32]. These issues can then negatively affect the carer's capacity to provide adequate care, increasing the likelihood of negative health outcomes for both the carer and the care recipient [33].

Digital health technologies have potential to mitigate some of these challenges and alleviate the burden associated with caring, by facilitating the provision of care as well as enabling carers to effectively manage their own wellbeing and sustain an optimal quality of life. The literature to date has examined various technologies for use by informal carers or family members, including applications to support health and wellbeing self-management [34], management of mental health [35, 36], social connection [37], and education and training resources [38, 39].

Mobile health applications can offer accessible and practical tools to help carers in managing their own self-care, as well as in providing effective care to the person living with dementia. The use of mobile and Internet technologies to deliver programmes which aim to increase carer competence and knowledge, delay institutionalization, and enable better care provision, has grown somewhat in popularity in recent years [40, 41]. Such interventions are particularly important for people who may find it more difficult to access traditional, face-to-face support, such as those who are living in rural areas or in a position where a care recipient cannot be left unattended for significant periods of time. Such tools can be accessed and used independently, while others are effectively used as part of a digitally-mediated in-person care intervention. For example, a blended care intervention, described by Boots et al. [42], consisted of a face-to-face session with a coach to set goals and preferences, online psycho-education and behavioural modules, and face-to-face feedback from a coach. In a randomized control trial, where carers using this intervention were compared to a control group, participants in the experimental group experienced significant improvements in care management, service use, self-efficacy and quality of life following use of the intervention. This suggests that there is potential for the right digital tools to meet some of the self-care needs of carers.

It is worth noting, that even with the greatest motivation, the progression of cognitive deterioration is likely to affect the ability of a person living with dementia to continue engaging with a technology in a manner that is useful and effective. Work by [18], focused on mapping existing technologies onto the dementia care pathway, found that interventions are, therefore, more likely to become targeted at family carers and HCPs as dementia progresses. Examples include platforms which allow for the ability to interact with other carers and HCPs [43-45]. Since it is probable the carer will become the primary user of any assistive technology, Lorenz et al. [18] highlight the need for such technologies to be accessible immediately, flexible with regard to changing needs, easy to use, and available at low-cost. Considering the demands on carers themselves, future technology-mediated solutions must critically consider the interrelated needs and requirements of both the person living with dementia and their carer.

2.3 Technologies to Support Care Network Collaborations

For those without a carer, coping with the transitions and challenges inherent in the dementia journey can result in significant dependence on HCPs as the primary members of their care network. By contrast, dyadic caregiving is characterized as an interdependent emotional system of care (between carer and cared for) where an event or circumstance affecting one person also, essentially affects the other. In the context of dementia care the most frequently found dyads comprise the person living with dementia (or MCI) and an informal carer, usually a family member.

HCPs, people living with dementia, and their informal carers can exchange relevant care information with the support of technologies including sensors and assistive robots [46]. Technology can be also used for communication and information-sharing within care networks as a means to co-ordinate care [47]. Recognising the essential and interrelated nature of the dyadic care relationship, interventions have been developed to engage both the person with dementia and their informal carer, simultaneously [48]. However, there has been little progress in the development or evaluation of technology-based dyadic interventions to date. In a randomized control trial of sixty-three care dyads, Laver et al. [49] found no significant difference between telehealth and face-to-face delivery of a single didactic intervention to support management of activities of daily living. However, multi-component interventions, providing multiple simultaneous intervention elements, have been found beneficial in reducing psychological and behavioral symptoms in people with dementia as well as carer distress with these symptoms [50]. Indeed, Shaffer et al., [51] argue that despite the complexity and challenges associated with delivering effective technology-mediated dyadic interventions, collaboratively designed solutions that meet the needs of all stakeholders can '*more comprehensively promote individuals' well-being'* with potential benefits outweighing costs (such as user effort or burden) (p. 190). While there remains a gap in the development of effective technology-mediated dyadic interventions for those on the dementia journey, there is some evidence that user-centred design holds promise for the development of effective dyadic interventions of this kind [52]. In light of existing work in this area, this paper presents findings that will inform the development of a multi-component technology-mediated dyadic dementia care intervention.

3 Methods

A qualitative study was conducted with HCPs and charity workers who care for people living with dementia and MCI. Ethical approval for the study was granted by three ethics committees, including two academic committees and a health service committee. Participants were recruited through existing links with various healthcare and community organisations using a snowball sampling method. A participant information leaflet was provided and informed consent was received from each participant. Participants took part in a semi-structured interview or focus group, in-person or online (depending on participant preference). Interviews and focus groups lasted between 45 and 90 minutes. The same interview protocol was used with all participants. Topics included the challenges and pain-points of the dementia journey (diagnosis, management, progression) for people living with dementia and those who care for them, whether care plans are provided and what these entail, communication amongst relevant stakeholders about a person's care and the impact of dementia on co-morbidities and care. All sessions were audio-recorded and transcribed using Microsoft Word's dictation function, with all resulting transcripts reviewed by a researcher for accuracy and to remove any identifying information.

A collaborative semantic thematic analysis was conducted [53] by two researchers (JD and OM) using NVivo. An initial broad coding was conducted on a small number of transcripts, followed by axial coding. Following discussion, a preliminary codebook was developed. The codebook was pilot tested by each researcher (JD, OM) coding the same previously uncoded transcript, followed by discussion and refinement of the codebook. This process was repeated on the remaining transcripts, with regular meetings to refine the codebook and eventually construct themes and sub-themes.

4 Findings

A total of 20 participants took part, including 10 HCPs and 10 charity workers. Within the HCP group there was one general practitioner, one psychologist of old age, one consultant psychiatrist of old age, two clinic-based nurses, one community nurse, one dementia day centre nurse, an occupational therapist (OT), a social worker and a manager of older person services. The charity workers group included representatives from the Alzheimer's Society of Ireland, including community dementia advisors; as well as support coordinators, befrienders, volunteers and a health and wellness coordinator from four different charity organisations supporting older people, including people living with dementia and their family carers. Three themes and four sub-themes, were constructed from the data (Table 1). These themes are discussed further in the following sub-sections. Quotes from HCP participants are denoted by (HCPid), while quotes from charity workers are denoted by (CWid).

Table 1 - Themes and Sub-themes Constructed from the Data

Theme	Sub-theme
The Impact of Dementia	
Gaps in Support for People living with Dementia and their Informal Carers	The impact of inadequate supports
	Reasons for support gaps
Care and Collaboration	Lack of formal, integrated care plans
	Care strategies

4.1 The Impact of Dementia

Stakeholders consistently described the overall devastation associated with a dementia diagnosis: *"The emotional devastation of this disease gets some recognition but not a lot"* (HCP8), particularly given the incurable nature of dementia: *"It's certainly life-changing for them, especially with the family.. They know it's not going to get any better. It's devastating"* (CW7). One dementia nurse spoke about the knock-on effects of a dementia diagnosis on the future plans and financial affairs of the informal carer, spouse, or person living with dementia's family: *"You have the anger issues you know and that their retirement or you know the life they planned yeah is gone"* (HCP8). Participant CW2 noted that the impact of dementia on the person living with dementia and their informal carers and their ability to manage was very dependent on the disease stage, the person with dementia's age, and overall family circumstances.

Stakeholders also specifically discussed the direct impact of dementia on the person living with dementia. One such area was their health and ability to manage any comorbid conditions, including medications: *"Went in, did a full assessment. I said 'What about your medications?' 'Oh, yes, yes, I have my tablets. They're upstairs'... We went upstairs anyway – now she had at least 20-25 bags of medication that the pharmacy had been delivering monthly – she hadn't been taking them. There was no family. She was so vulnerable"* (HCP13). Likewise, people living with dementia were also reported to be at an increased risk of becoming under-nourished, as well as increased risk of falls: *"With a cognitive impairment the individual can be less safety conscious and maybe not use say their walking frame or maybe not do their home exercise program for example, and then as a result there can be a physical knock on where they are more at risk of falls or maybe have more falls"* (HCP2).

However it was noted that despite negative beliefs, it remains possible to slow the progression of dementia and maintain some quality of life: *"... people often think when they receive that diagnosis that there's nothing to be done.. their cognitive function will decline and their independence and ability to enjoy their life will decline - people think I think that it happens quite starkly.. but the majority of cases there's maybe a period of a plateau where actually they live life as normal.. doing the things they enjoy."* (HCP2); *"There is a little bit of a.. paternalistic kind of view of dementia and this notion that, why do you tell someone they have dementia that we can't do anything about. That really should be abandoned, because there are things you should do and can be done to make sure you improve your brain health, at any stage of the dementia"* (HCP7).

The impact on informal carers and families of the person living with dementia was also noted as a considerable issue by stakeholders: *"This is worrying and draining on both the person with dementia and their carer and their family"* (CW2) with burnout noted as a considerable issue: *".. never having downtime, sort of carer burnout and things like this. I noticed that they won't have as much patience after a while.. it kind of wears them down a bit"* (HCP12). Both physical and mental health concerns are common among carers: *"There'd be an awful lot of ongoing issues.. some carers end up with depressive symptoms.. and physical ill health as well… so they're finding it very very difficult to get support*" (HCP11). Moreover many informal carers are older adults with multimorbidity taking on the role of caring for their spouse: *"It's extremely difficult for.. spouse partners and for older carers in their 70s and 80s who themselves would have health conditions and some with multiple morbidity"* (CW2).

4.2 Gaps in Support for People Living with Dementia and their Informal Carers

Various community supports and services for people living with dementia and their carers were described by participants. These included day centres, which provide opportunities for social interaction, engagement in meaningful activities, and meal provision, while offering a period of respite for carers; cognitive rehabilitation classes for people living with dementia; support groups for carers and dementia cafés. Community-based HCPs and charity workers were noted as particularly important sources of support, information and signposting to relevant services, for example, the public health nurse, the Alzheimer's Society community dementia advisors and the OT-led memory technology resource rooms that recommend technologies and technological strategies for memory compensation and living well with dementia. Despite this, all participants spoke of challenges in accessing supports and services for both people living with dementia and carers, noting inadequate supports and the reasons for gaps in supports.

The Impact of Inadequate Supports

The impact of inadequate support on all stakeholders was highlighted by participants. A significant issue impacting access to supports and services is the lack of timely diagnosis for individuals: *"So we're talking about person centered care, and we start at the beginning when we're diagnosed, one of the key things is we're not getting to people early enough"* (HCP8); *"I can't refer somebody in to the* [day centre] *if they've got clear signs of cognitive decline but haven't been actually assessed"* (CW1). Participants consistently spoke of how, as a result, individuals with MCI or dementia are not getting access to the information, interventions and supports they need in a timely manner, and that ultimately this leads to faster progression, poorer prognosis and increases the likelihood of them entering long-term care: *"If you have a mild cognitive impairment.. this is where you see primary care could come in.. we would run coping with everyday memory loss working group.. And that can probably interrupt the progress for another six to twelve months.. it is taking so long to get a diagnosis, generally by the time the diagnosis has arrived, crisis has hit*" (HCP14); *"So by the time the referral is coming* *in to us it can be less about the cognitive stimulation and more about care, minding you know"* (CW1).

Considerable challenges were also highlighted for those with young onset dementia. As dementia services fall under the remit of older person services, an individual needs to be aged 65 or over to access them: "*We have a dearth of services for the younger onset dementia. Big time. Big time. So they're left out there floating free.. so we really need to put a lot of focus and support in the early onset and the young person with dementia, in the 50 years plus group"* (HCP8). Many community services, such as day centres, were also noted as being unsuitable for this group, due to the age difference with attendees.

Participants noted inadequacies in the supports available to people living with dementia, highlighting, for example, how home care is functional, not meaningful: *"Even just what's meaningful to the person because at the moment it's very procedural.. do you need you a shower, do you need a bath, do you need to get dressed? Yes I do but also I need these other things as well"* (CW9); "*We are so far from pleasure and purpose. We're down at the bottom we're not even managing that bit"* (CW1).

Inadequate supports necessitate that informal carers must often provide 24/7 care: *"We're asking people of 80 years plus to be carers, like these people are supposed to be retired and yet they're expected to care 24/7, up at nighttime"* (CW4). Informal carers therefore experience significant stress, burnout and ill health as a result, and this also impacts on the quality of the relationship they have with their loved one: "*I've said that to an older lady there not that long ago.. if you weren't so stressed you would be able to take your mom to do little walks or you know spend quality time with her, but you're not getting quality time because you're on top of your head"* (CW1). Meanwhile, HCPs and charity workers expressed frustration at how the lack of supports limited their ability to provide care: *"It's the frustration you know that you can't do what you want to do to help people. It's the absolute frustration"* (CW4).

Reasons for Support Gaps

The primary reason noted for the lack of supports and services available to people living with dementia and their carers related to resources, namely a lack of funding and a lack of staff: *"Your public health nurse is a great source of information but she's overworked and overloaded"* (CW1); *"The rise in referrals is exponential and the resources have not followed and we don't have enough MASS (memory assessment support services) yet at all"* (HCP9). As a consequence, when a person living with dementia or carer is referred into a service, there are typically very long waiting times: *"I've a huge waiting list* [for day centre support] *... probably 100 on a waiting list. The person with dementia won't thrive in a big group given the complexity of what they may be dealing with. So you are limited by the number that you want em and then you have staffing. So funding is one of the key things"* (HCP8). A charity worker noted how difficult it is having to tell people who are badly in need of a service that they will be waiting a significant length of time: *"We could sign post all we like.. and then I say sorry but there's a year's waiting list, sorry there's actually 6 months waiting, sorry I actually don't even know if they're accepting referrals, I don't know how long you're gonna be waiting*" (CW9).

Linked to this, stakeholders spoke of how a person living with dementia or carer's geographic location might hinder them from accessing services. It was noted how services are sparse in certain parts of the country, particularly rural areas: *"It's very inequal throughout the country, especially all around the western seaboard.* [organisation name] *is working hard to kind of get into that area and develop centers there"* (CW2). Transport was also consistently noted as an issue preventing peoples' access to services: "*If you're in a very very isolated rural part of the country there mightn't be transport for example to the day centres"* (CW8).

While not as prevalent as resource and access issues, stakeholders noted that people living with dementia and carers sometimes do not access the supports they need as they are in denial of a diagnosis: *"Some people don't want to face into these things and some people shy away from them"* (CW1); *"Sometimes families won't admit that someone's got dementia, 'my mum's ok, there's nothing wrong with her'"* (CW7). Participants linked this to stigma: *"We've come a long way but there's still a lot of stigma attached to receiving a dementia diagnosis* (HCP2). Many participants, particularly from the charity organisations, noted that a significant part of their role was to raise awareness of dementia in communities in an effort to breakdown such stigma: "*We work with community groups and different organizations to do talks on brain health.. to kind of get the word out there on ways you can reduce your risk of developing a dementia but also.. to support communities to understand what dementia actually is and what are the signs and symptoms to look for"* (CW9). A further issue noted was that people living with dementia and carers simply might not be aware of the services and supports available or may not be able to advocate for themselves.

4.3 Care Challenges and Strategies

The challenges associated with providing care to someone living with dementia are varied and are exacerbated by a lack of formal, shared care plans. Despite this, participants noted various strategies used in their care, including technological supports. There was recognition by all participants of the importance of providing care not only for the person living with dementia, but their informal carers and family members: "*We look at every dementia referral as having two sets of needs really. There's the needs of the person involved and there's also the needs of the family or the care network that the person sits within. And we would talk to both parties if at all possible and then refer on supports pertaining to both"* (CW1).

Lack of Formal, Integrated Care Plans. A significant issue impacting the care of people living with dementia and those who care for them is the lack of a formal, detailed care plan, that is shared between all relevant stakeholders, including the person with dementia and their carers. Some HCPs reported not creating any type of care plan: *"I suppose it wouldn't be a formal care plan as such and like there's very good reasons for all that kind of stuff especially if you think of medical things"* (HCP6); whereas others spoke of creating very basic care plans: "*So we start off with a basic care plan… but they are very basic. I do feel there could be an awful lot more done in relation to this"* (HCP13). One HCP noted that she would provide a list of recommendations to the person living with dementia (e.g. a recommendation of a particular cognitive rehabilitation course, use of equipment to prompt for medications and other important tasks) as well as to the carer (e.g. attend a carer's support group, attend a dementia café), but added "*I feel that could be improved like it could be more structured"* (HCP2). Charity organisations did not refer to developing a 'care plan', however they do provide information, recommendations for services and technologies, and facilitate referrals to support people living with dementia and their carers.

Where care plans or recommendations are created, they are specific to a particular service or individual HCP: *"If I met a patient I'll complete the care plan for them in the realms of occupational therapy But then also there will be a separate care plan with my physiotherapy colleagues who might say okay recommend that this person completes home exercise plan. They might see the dietician who'll recommend a specific type of nutritional plan and they'll all be separate, they won't be together"* (HCP2). There is no mechanism for sharing the care plan with other HCPs or charity workers who might also be caring for the person living with dementia: *"Sometimes I feel that we're doing our thing – acute services are doing their thing, mental health services are doing their thing, and it's about bringing…I think, I always think, like an MDT* [multidisciplinary team]*, bringing people around a table"* (HCP13). A further challenge is that the care plan is often not shared with the person living with dementia or their carers: *"You see, at the moment I don't think it* [the care plan] *is* [useful for the person living with dementia and carer]*. Because… it's sort of kept by us and we update it every 6 months"* (HCP13); *"The patients generally don't have their care plan, like they won't have a physical copy of that.. of what they're doing you know unless you write it out for them which we can do but.."* (HCP2).

The resulting fragmentation has several implications for all stakeholders. HCPs and charity professionals have to spend time and resource tracking down information about individuals: "*There's quite a lot of liaison like a lot of phone calls a lot of emails but it's challenging to make sure everyone gets the information* (HCP2); *"It's either phone, email… referrals, that type of thing, you know"* (HCP13). Further, given the informal nature of the care plans, the lack of timely follow-up and the challenges of sharing information between organisations, HCPs are often unaware of whether people living with dementia and carers are following their recommendations: *"So I have no way of knowing did that intervention do well for them, did it not do well, actually did they not access it. Some services are very good and they do feed that back, but a lot don't and it's the joining up of care"* (HCP2). The impact of this on people living with dementia and carers is that *"the person could be going through the same type of assessment in another hospital whereas it's already been.. and you're relying on someone who has a cognitive impairment to tell the healthcare professional in the other hospital that's been done before, or they might say I think that's been done before but they won't be able to recall where it's been done or maybe not the action"* (HCP2).

Care Strategies. Adding to the complexity of dementia care is the presence of comorbidities. Participants highlighted the importance of holistic assessment of needs to guide appropriate care: "*It is very much a holistic sort of an approach"* (HCP9); *"Someone who's got dementia may have other issues as well, so we do a general* *assessment.. there may also be co-morbidities that we would have to address"* (CW1). Co-morbidities may necessitate alterations to the dementia care plan to accommodate the current most pressing health concern: *"We would say right what's the biggie at the minute, they've maybe dementia but they're type one diabetes and they just can't manage their injections anymore. Well then.. they become a priority one for the public health nursing who then have to administer the injections every day. So what we do is we risk assess and you identify what is the biggest risk and that's the bit that has to be prioritised. And sometimes other stuff just has to em hang back until you can get that bit under control. So the care plan is constantly shifting and moving"* (HCP14). HCP14 further noted the potential for communication between different providers to breakdown. "*You'll see in so many charts consults from the cardiologist had to come in, the respiratory guy had to come in, the oncologist had to come in. But through all of that it has to be very clear who is the primary provider at any given time and that when they consider they are no longer the primary provider of care that it isn't assumed somebody else knew they were taking them back. That can't be assumed. It's the communication, things have to be tied up"* (HCP14). One HCP emphasised the importance of simplifying healthcare, such as ensuring a manageable medication regime: *"I suppose if they kind of had a complicated medication regime like obviously gonna try simplify that as much as you can you know prevent medication overdoses but that goes for other things as well like"* (HCP6).

The utility of technology was highlighted in both supporting the person living with dementia with activities of daily living and ensuring safety: *"So technology, yes. Certainly, in relation to say, maybe, prompting of medication… reminder to have a little wash in the morning, have something to eat*" (HCP2); *"But, certainly, you know, clocks, calendars, you know digital clocks that remind them of the time. It certainly has a role to play. A big role to play"* (HCP13). Alexa was regularly mentioned as being beneficial to people living with dementia: *"Even the Alexa and stuff like that, you'd go out, 'please take your medications'. We've seen it first-hand"* (HCP10); *"Alexa developed a good bit yeah. And you know when it started it was a challenge, but it has developed where patients are actually using it with early dementia, very effectively"* (HCP9). Technology could also provide a means of allowing the person living with dementia to still engage in activities they enjoy: *"if somebody maybe perhaps used to enjoy reading but they don't have the concentration for reading, technology such as audiobooks… that they continue to enjoy that storytelling and connect with their peers and their family in that way*" (HCP2). Fewer technologies for informal carers were discussed, however, participants did note the importance of online support and activities: "*.. care support and linking in with groups for themselves, linking in online with meditation.. yoga you can do lots of different classes online when the person* [with dementia] *maybe is asleep or is quiet or you may not be able to get out of the house"* (CW1).

There was a belief by participants that technology can support the person to live at home for longer: *".. there are cases where everybody thinks that the patient can't live at home but there are things* [technologies] *that if used effectively can actually help the patient maintain in their own homes for the longest period of time so at the very early stage"* (HCP9). Despite this, various challenges with the use of technologies by people living with dementia and their carers were mentioned, with a significant gap being training and ongoing support, meaning technologies often go unused. The need for training was highlighted: *"They literally just need the time to be shown and if they can get accustomed to it then then they will use it"* (HCP2).

5 Discussion

This paper has outlined findings from interviews and focus groups with 10 HCPs and 10 charity workers who provide care for people living with dementia and their informal carers. Three themes were constructed from the data. Our findings show the significant impact of dementia on those who live with it and on their care networks. Considerable gaps in services and supports were noted, with the impact of these gaps on stakeholders outlined. Finally, the challenges in provision of dementia-related care were highlighted, particularly a distinct lack of effective care plans and the impact of co-morbid conditions on dementia care. Drawing on our findings and the literature, we outline three design considerations for a multi-component digital health platform to meet the needs of people living with dementia, informal carers, and those who care for them throughout their dementia journey.

5.1 Design Considerations

One of the most striking findings from our study is the existence of significant gaps, within the healthcare system and community, in supporting people living with dementia and their carers and the implications of these gaps for all stakeholders involved in care. Crucially, a lack of timely diagnosis delays access to supports and services that could help to delay the progression of dementia. Under-diagnosis of dementia is a global concern, with 90% of those living with dementia in low- and middle-income countries undiagnosed [2], while an estimated 50% of those living with dementia in Ireland do not have a diagnosis [13]. Compounding this is the general lack of services available for both people living with dementia and their carers due to funding and resource issues, as well as significant access issues for those in rural areas or who are unable to travel. The situation for individuals with young onset dementia is equally challenging, with many services not being available or suitable because of their age.

This is concerning given that, as noted by our study participants, and as is highlighted in the literature, it is possible to delay the progression of dementia with the right interventions and supports [15]. Participants in our study spoke of the need for timely supports for both people living with dementia and those who provide care, including cognitive rehabilitation, information and education on living well with dementia, psychological supports, support groups, and training for carers. Such content and interventions are easily digitised, and there are many examples of this in the literature to date [18, 54]. However, a weakness of such solutions is their disparate, disjointed nature, with a vast array of technologies and applications being designed to meet single needs (for example, only memory support, or only carer training) but not offering a holistic solution. As a result, there is little evidence of the practical use of such custom-designed technology interventions by people living with dementia and their carers, who instead repurpose existing technologies to suit their needs [18]. Other research has also found that self-management technologies for dementia care tend to be more beneficial for carers than those living with dementia [55]. Limited evidence of the effectiveness of such technologies in terms of improving cognitive function, self-management or social participation, as highlighted by others [17, 25] is of concern.

Our first design consideration is therefore to *co-design a holistic, multi-component digital platform that can be used by people in the early stages of dementia with or without a diagnosis, people with MCI, those with young onset dementia or those interested in brain health to delay the progress of dementia through the self-management of symptoms and engagement in interventions.* Such a platform should contain a wide range of content and interventions that are known to be beneficial to delaying the progression of symptoms, living well with dementia, and planning for the future. Such a platform could serve the unmet needs of people with MCI or undiagnosed early-stage dementia, and those with a diagnosis (including of young-onset dementia) but unable to access supports and services for other reasons. The primary end user of this platform is the person living with dementia or MCI (with or without a diagnosis), potentially with support from an informal carer as there are times when a more dyadic model of interaction may be most beneficial [48]. The platform will enable users to self-assess their current level of need or severity of symptoms and the platform could suggest appropriate content and interventions, adaptable over time as needs change, or with the progression of symptoms. This digital platform has potential to be most useful when there is limited human support or clinical intervention. However, the design will support HCPs and charity workers to recommend specific modules or interventions based on a person's needs.

A second design consideration is to *co-design a holistic, multi-component digital platform for informal carers of people living with dementia (including those with or without a diagnosis).* Our findings and the literature identify that stress, ill-health and burnout are high where there is limited clinical and community support [33, 42]. As noted by participant HCP14, a crisis has often occurred by the time a diagnosis is received. Further, prior work has emphasized that reaching carers of people with early-stage dementia could prevent high levels of burden and psychological distress at later stages of the disease [42]. Informal carers should also therefore have access to information and interventions to help them support their loved one whilst also managing their own health and wellbeing throughout the dementia journey. We envisage this being part of the same platform outlined in the previous design consideration, with a dedicated informal carer section.

Another notable finding was the lack of formal, integrated care plans for both the person living with dementia and their informal carer(s) even when the person is on a dementia care pathway and liaising with HCPs and/or charity workers. Lack of integration of dementia care in health systems is a considerable challenge [10] exacerbated by the presence of co-morbid conditions [56]. There is a clear need for structured care plans accessible not only by other HCPs and charity workers providing dementia and co-morbid care, but also by the person living with dementia and their carers. To support more efficient and effective care, completion of tasks, activities or interventions should be monitored. Furthermore, comparatively little research has explored how digital solutions might address comorbid dementia care. One study has explored the design of a patient empowerment platform to support people with early-stage dementia or MCI to follow and adhere to complex care plans [57]. Features, derived from interviews with relevant stakeholders, included daily tasks to be completed as part of the care plan (e.g. monitoring symptoms, medication intake, appointments), as well as a diet and exercise plan. The authors report creating mockups of these features, but it is unclear whether the platform was ever developed or evaluated.

A further issue noted with existing care activities is that they are often clinical or procedural. Participant CW1 emphasized that care activities for the person living with dementia should also include those that are meaningful and foster pleasure and purpose. Our previous work has explored the design of a digital application for meaningful activities [58], and how to monitor engagement in meaningful activities through the use of sensing systems [59]. Other research has also highlighted the importance of including such activities in care planning [60].

Our third design consideration is therefore to *include a formal care plan component to the digital platform for both the person living with dementia and their carer(s) when an individual is diagnosed with dementia and is on a dementia care pathway. This should be one cohesive care plan, that clearly outlines recommended tasks or interventions, both clinical and non-clinical, notes which HCP or charity worker has made the recommendation, monitors progress and completion of these activities, and enables relevant stakeholders to contribute to and use the platform to support more effective follow-up and care.* Potential end users of this component of the platform are people living with a dementia diagnosis / on a dementia care pathway, their informal carers, HCPs and charity workers involved in their care.

There are still several open questions that will be addressed in our future work, that will include a series of co-design sessions with all stakeholders, including for example how to initiate a care plan, who is responsible for it at any given time, how it can be updated, how can it be shared, and how progress and completion of tasks or interventions can be monitored. Further consideration and exploration will also be given to the suite of technologies and interaction modalities that will be most suitable to stakeholders, taking account of those technologies and technology-based strategies that are currently being recommended to and repurposed by people living with dementia and their carers, such as voice assistants, reminders and scheduling assistants.

5.2 Limitations

There are some limitations to this work which should be noted. Firstly, all interviews and focus groups took place in Ireland, and therefore some findings may not be transferable to other countries and health care systems. Furthermore, we will develop additional design considerations as the next phases of our work are conducted (including the final analysis of interviews with people living with dementia and informal carers, as well as co-design sessions with all relevant stakeholders).

6 Conclusion

In this paper, insights from HCPs and charity workers highlight the impact of living with dementia on both persons with dementia and their informal carers. More critically, the findings highlight considerable gaps in necessary supports and the difficulty accessing adequate care in an Irish context. Digital health technology offers an accessible and viable means of supporting persons living with dementia and their carers. Moving forward, co-design workshops will be used to design a holistic digital health platform to support the person with dementia and those in their care collaboration network. These will involve perspectives from persons with MCI and dementia (diagnosed and undiagnosed), their informal carers/family members, as well as relevant HCPs and charity workers. The intervention will include a digital application, including key support information and a tailored care plan, with potential to link with existing assistive technology, such as wearables and sensors, offering a new holistic solution for integrated collaborative care and self-management.

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