Co-designing a Care Plan Guide App to Support Early Conversations About End-of-Life Care in Dementia

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Abstract. Talking about death and end-of-life care (EoLC) can be a sensitive topic for people affected by dementia and their families. However, recent research [1] has identified the need for people living with dementia (PLwD) to start planning timely discussions about their future care to help their family and professional carers to confidently make decisions on their behalf when they are no longer able to do so themselves [2]. This paper describes a five-stage iterative co-design approach aimed at understanding the type and nature of these sensitive discussions and developing a resource to support PLwD, their families and carers. The resource took the form of a Care Plan Guide app, as a tool to help initiate early discussions about anticipatory care planning [3] in dementia for PLwD to ensure good personalized care and that important wishes were honoured. The paper highlights the importance of the involvement and active collaboration of families living with the illness. It discusses lessons learned, reflections and recommendations for approaching co-designing healthcare digital resources for sensitive EoLC issues that may have wider applications than for PLwD alone.

Keywords: Co-design research · Patient and families’ engagement · Prototyping digital resources

1 Introduction

Over the last decade there has been a considerable effort in Design to make a contribution to quality of care and living well by focusing on engaging people in processes to redesign healthcare services, products and experiences [4–6]. Engaging people who are living with a health condition is especially important when designing healthcare improvements, as they are the individuals who receive care and treatment in their
everyday lives [7]. The SEED (Supporting Excellence in End-of-life care in Dementia) programme [8], one of the largest studies of its kind to date, explored how best to enable service providers and commissioners to deliver better quality, community-based care to people living with dementia (PLwD) towards the end of life [9, 10]. Findings from a large qualitative study within SEED identified seven key components which contributed to the provision of good quality end-of-life care in dementia [1] (see Fig. 1). In this paper we describe the co-design approach and present recommendations from SEED’s design-led work package, whose researchers were based in the School of Design at The Glasgow School of Art (GSA). We particularly focus on the challenges, benefits and implications of the co-design approach, to address one of these key components, ‘timely planning discussions’.

2 Context: End-of-Life Care in Dementia

Research focused on improving dementia care should involve people living with the illness and their families, in addition to care professionals. Facilitating such engagement with people living with severe dementia is challenging, as their memory and speech deteriorates [11]; in addition, their families may find talking about end-of-life issues upsetting. Regardless, it is particularly important for PLwD to have the opportunity to talk about their wishes and beliefs about their future care whilst they are able to do so to enable their family and professional carers to anticipate care planning and to confidently make decisions on their behalf when they are no longer able to do so themselves [2]. If such discussions, usually called ‘advance care planning’ by professionals, are to be had, PLwD and their families need to feel confident that their

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**Fig. 1.** The SEED intervention showing key components, main users and purposes.
wishes and preferences will be acted upon; this will be assisted by formally recording, in writing, such discussions and decisions, and sharing this information with healthcare professionals [12]. However, research to date has shown that having such sensitive discussions with people with dementia about planning ahead for future care is difficult; healthcare professionals struggle to find the right time, whilst patients and families may be reluctant to record their wishes in case they change their minds at a later date [13, 14]. There thus appears to be a need for resources and/or tools to help initiate these early anticipatory care planning discussions, not only for families living with the illness but also for healthcare professionals [15]. Using the findings from [1], the SEED study developed a dementia nurse-led intervention which was tested in primary care settings [16]. The SEED findings also suggested the need for a ‘care resources kit’ targeting the seven key components in Fig. 1, which would help the dementia nurse specialists deliver the intervention, work more effectively with patients and their families and improve the knowledge and skills of the PLwD’s usual healthcare team. This paper now describes in detail the development of key component 1, a resource to support timely planning discussions, the Care Plan Guide (CPG) [17].

3 A Co-design Approach to Developing a Care Plan Guide App

A co-design approach was seen as essential to ensure a meaningful and useful resource was created to support planning end-of-life care for PLwD and their families and to ensure, as far as possible, the views and needs of all stakeholders were represented in its design. The concept of co-design “enables a wide range of people to make a creative contribution in the formulation and solution of a problem... A key tenet of co-design is that users, as ‘experts’ of their own experience, become central to the design process.” [18, 19]. All relevant stakeholder groups (PLwD, family carers, paid carers, doctors, nurses, support workers and occupational therapists) were involved in our co-design approach which comprised two main phases (see Fig. 2):

1) Development of an initial prototype of the CPG via internal project workshops with i) the multidisciplinary SEED team which included a patient and public involvement (PPI) representative, and ii) the project’s external PPI advisory group (PPIAG), and

2) Refinement of the prototype through external workshops involving newly recruited participants from the key stakeholder groups listed above.

3.1 Phase 1: Determining the Content and Format

In Phase 1, a paper-based prototype (in the form of a printed booklet) was constructed to take to the PPIAG. This prototype contained the following five key planning materials identified from [1] initial scoping research: 1) lasting power of attorney (health & welfare; and property & financial); 2) advance statement (a written document that explains the PLwD preferences and wishes regarding future care); 3) advance decision to refuse treatment (including non-resuscitation); 4) making a will; and 5)
funeral planning. Current resources for each of the above comprise disparate documents, located separately with no overall style, coherence or consistency of accessibility or language. The ambition was to bring these together into a single coherent and unified resource where recorded wishes and progress on decisions were kept together in a single place. For the initial prototype presented to the PPIAG, each of the above plans comprised an overview, general introduction to each plan, details and links to further information, and space for a record of progress of – and decisions against – each plan.

While the concept was welcomed, and a paper-based version was seen as only one option, feedback from the PPIAG suggested the need also for a digital form of the CPG. We then developed a first stage digital prototype app to be tested, discussed and refined in the subsequent co-design workshops.

3.2 UX, UI and App Development

Feedback from the PPIAG was translated into tablet “wireframes” (see Fig. 3) to share with GSA’s app developers in order to show the content of each of the desired screens. These helped open up a discussion around the app programme/software (e.g. android type), key interactions such as menu, navigation (e.g. pop-up keyboard enabling the simple type-in of information when prompted), commands (back, next, send e-mail function, etc.). In doing so, it also highlighted other app-related issues that required our attention such as: How is personal data protected? What information is seen and by whom? What if legal advice is required - is it provided by phone or a pop-up message on the app? What if the PLwD loses capacity at some point? Should a person that s/he selected to act on her/his behalf receive a letter or a text message? Or should the care
services receive this information first? Also, in the preparation of the prototypes, guidelines were referred to for age- and dementia-appropriate design [20–22].

3.3 Phase 2: Iterative Refinement of the Prototype

In Phase 2, using an iterative co-design process, we conducted three external workshops involving the key stakeholders, i.e., people with mild/moderate dementia and their family cares and professional carers (see Fig. 2). For workshop 2, a group of professionals (registered nurse and support workers) was recruited from a specially designed community complex with six supported households, which aimed to create a family atmosphere for older people requiring full-time care, including those with dementia. This service had participated in the earlier qualitative work by [1]. Participants in the remaining two groups (workshops 3 and 4) were invited to participate through the support of the project manager at Alzheimer Scotland for Dementia Circle groups, to identify potential participants and introduce the researchers to the groups.

20 participants in total participated in these three workshops. Workshop 2 comprised 9 participants: 8 support workers and 1 registered nurse; Workshop 3 comprised 7 participants: 2 PLwD, 3 family carers and 2 occupational therapists; and Workshop 4 included 4 participants: 2 family carers and 2 PLwD. The format for each workshop was similar (see Fig. 4). Here the aim was to engage participants in collective dialogues, by using the prototype CPG app, on how this could be improved.

In each of the workshops, tablets with the prototype CPG app installed were made available to participants to interact with and to express their own suggested improvements. Participants were also each asked to complete a workbook questionnaire to capture their individual comments on key aspects of the CPG (see Fig. 5).

Feedback on the general CPG format (see Fig. 6), with its overview, general introduction to each plan, detail and links to further information, with all information kept in a single place together with the record of progress and decisions against each plan, were all seen as helpful. Suggested improvements, such as to the navigation, the way colour was used to differentiate different sections, font size, and arrangement and
amount of text, were embodied in further versions of the CPG app for subsequent workshops. The initial use of acronyms and formal legal language were regarded as unhelpful and later revised. Although some individuals in these workshops were unable to use, or were not at ease in using, apps, preferring the printed version, tablet- or smartphone-based interaction was regarded by the younger generations in the families as convenient, enabling them to make direct links to further web-based resources. Other suggestions included customising the format and text-size and voice-command features to enhance usage.

We used the stakeholder feedback from each workshop to brief the app developers on improvements required and to collectively reflect with them on the best CPG app configurations to achieve optimum user, technical and care requirements.
3.4 Usability Testing; Accommodating Feedback from Different Stakeholders

As the use of the CPG app would involve all stakeholder groups in end-of-life discussions at some point, its development required input from each of these groups. Although there was an overlap of interests, in feedback we found that each stakeholder group had particular interests typified in Fig. 7. For example, PLwD tended to be concerned more with the terminology used (to avoid unfamiliar jargon), legibility, layout and navigation within and between sections. Family carers were more typically concerned with alternative (to paper-based) formats such as websites and apps, to enable more interactive and engaging discussions and to enable access to further web-based resources. The concern of support workers and specialist nurses typically related more to how the resource could best help them to support family carers. All of these factors were considered and developed iteratively between workshops with the app developers.

Fig. 6. Sample CPG app prototype screens showing the registration page (left side top), a menu page with recommended plans (left side below), a plan page with sections to fill with information (right side top) and the summary page with an overview of the completed plan to validate and send it to family carers/healthcare professionals by email (right side below).
4 Reflections and Recommendations for Co-designing Healthcare Digital Resources

In developing new digital resources, the tendency has been for devices to be created by technologists for older people with little reference to the specific requirements of end users [23]. The involvement of PLwD in co-design and co-development approaches has been increasing [24–27], but is limited in the area of assistive technologies which have the potential to improve quality of life and sustain independence. However, expectations are changing with the realisation that older people can continue to contribute, even when compromised by illness and/or disability. In dementia care, international consensus recently advocated user engagement at all stages of technology development as an extension of the principles of person-centered care [28]. Although our research contributed to the issue of engaging PLwD in co-designing digital resources, a number of practical considerations still remain that make a participatory co-design approach quite challenging. Other priorities in the SEED programme precluded us from trialing the app in a stand-alone form. However, from our experience in this work, we can provide the following conclusions and recommendations.

4.1 Provide Time and Space to Explain Unfamiliar Technology

Undertaking ‘user’ research projects for digital resources involving older people presented certain challenges. We had to be adaptable and flexible, as our older participants did not always know much about apps or digital resources. Although apps and digital resources are common in our lives, this does not mean everyone knows enough about them. By the same token, we could not assume that they were not familiar with aspects
of digital technology. We found it important to provide the appropriate time and space up front to determine people’s level of familiarity with digital technology and to provide more information about apps if required.

4.2 Provide Appropriate Tools for Engagement

Providing tablets with the mock-up of the interactive CPG app helped participants to engage with and to navigate through the content via the user interface. This actively stimulated their thinking and discussion about the redesigning of improvements. The iterative evaluation, by the different stakeholder groups, of the app-based prototypes, helped us identify early not only what was effective, but also what was problematic, and how features could be improved. Following these three external workshops, the prototype app was brought back and presented to the PPIAG. This discussion helped identify, distinguish and clarify two separate needs: 1) ‘how’ to initiate these difficult conversations about timely planning discussions; and 2) ‘what’ needs to be discussed, decided and recorded, as well as the legality of any documents. The final CPG prototype had addressed the latter, but not the former, highlighting the need for this aspect to be addressed in future work. The varied discussion around the prototype reflected the different degrees of ‘comfort’ with apps that different generations have with these kinds of digital resources.

4.3 Create a Positive Experience for Exploring Sensitive Topics

Our observations showed that the co-design process proved to be a positive experience for participants. For example, participants mention at the end of workshops, “it shows that people care about things like that” and “it shows lots of information I didn’t know”. The project manager of Dementia Circle also mentioned “It was a good step in helping families in a gentle and thoughtful way. We don’t talk or think enough about the practicalities of death. We all left the session with good intentions”. Despite our concerns and anxiety around the highly sensitive research topic, the most important insight that we gained from this project was the form of active collaboration in the workshops. A more convivial workshop experience was created along the lines of an intimate ‘death café’ [29, 30] but with a sharper focus on the five plans in the app, where discussions could happen while everyone ate cake and drank tea in a calm environment. This stimulated PLwD and their families to create something together. Fundamentally, this demonstrated – through our practice – that we care about people’s sensitive and emotional issues and that we appreciated this as an opportunity for mutual learning for both the participants and the researchers. Participants were enthusiastic and indeed welcomed and valued research addressing the sensitive and potentially distressing area of end-of-life and planning ahead for future care. Our model of stakeholder involvement has helped move the discourse from that of designing ‘for’ to that of designing ‘with’ [31] its stakeholders in these very sensitive matters around end-of-life care.
5 Conclusion

Developing digital resources and services around the complexities of healthcare contexts such as for end-of-life care for PLwD with all of the accompanying issues of sensitive data, and ethical and usability issues presents a considerable challenge. Rather than presenting our work as a solution, our exploratory process served to enable the stakeholders and the wider SEED team to probe, comprehend and highlight some of the challenges involved in – and recommendations for - developing apps for such a complex issue as end-of-life dementia care. Overall, participants indicated that the CPG, as a general concept, would not only positively address the intended purpose of facilitating timely planning discussions between PLwD and their families and carers, but would also be helpful for many other individuals needing difficult and sensitive discussions to anticipate appropriate care planning for the end of life. With the current COVID-19 epidemic, it is perhaps timely that these types of discussions are able to be more widely held and the tools to support these are made more appropriate and widely available [32].

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