

Participatory Design of an Advance Care Planning Toolkit for People with Dementia: A Three-Phase Co-Design Study

Meklav Zala¹, Milošič Ana¹, Mlakar Izidor¹

¹ Faculty of Electrical Engineering and Computer Science, University of Maribor, Maribor, 2000, Slovenia, zala.meklav2@um.si, ana.milosic1@um.si, izidor.mlakar@um.si

Abstract

This study presents the first participatory design iteration of the Dementia Journey Companion (DJC), an advance care digital toolkit application, developed within the AI4Hope European research project. Developing accessible digital solutions for people with dementia requires careful methodological adaptation, as cognitive impairment, limited digital literacy and sensory limitations present significant barriers to conventional usability testing. This study investigates how iterative participatory design methods can be applied to develop visual and interaction design elements of an mHealth application that meet the accessibility needs of older adults with dementia. An iterative three-phase participatory design approach was employed, comprising a focus group with thematic analysis, a paper prototyping workshop and digital prototype testing in Figma, conducted with eleven older adults aged 65 and above, including individuals with mild to moderate dementia, at the Day-Care Centre Žalec, Slovenia. Results indicate that participants consistently preferred large icons with descriptive text labels, high-contrast visual design and voice interaction over text-based input. The conversational assistant prototype was received positively across all phases, with participants reporting increased motivation and sense of personal connection. These findings informed the conceptual and design foundations of the DJC and contribute to emerging evidence on participatory, human-centred design of mHealth applications for people with dementia.

Keywords: dementia, advance care planning, participatory design, co-design

Introduction

Dementia is a progressive neurodegenerative condition affecting over 50 million people worldwide, with prevalence projected to reach 150 million by 2050 [1]. As the condition advances, it significantly impairs the ability to perform both basic and instrumental activities of daily living, increasing dependence on others and reducing quality of life [1], [2]. Advance care planning tools are increasingly recognised for their potential to support autonomy and daily functioning in this population, yet developing accessible and usable solutions remains challenging [3]. People with dementia present specific cognitive, sensory and motor limitations that must be carefully considered in interface design, and existing applications are frequently criticised for being visually complex, poorly navigable and cognitively demanding [2], [4]. For people with dementia, supporting independence in activities of daily living through technological interventions aligns with an ethical imperative to preserve autonomy for as long as possible [5]. Yet end-user evaluation of such tools remains scarce, and people with dementia are rarely included as active participants in the design process [6], [7]. Participatory design offers a promising methodological response to these challenges by involving end-users as active co-designers rather than passive study subjects [4], [8]. In the context of dementia, this approach shifts focus from clinical deficits to lived experience and personal values while producing more usable and acceptable solutions [9]. However, practical implementation remains difficult, as cognitive impairment, limited digital literacy and communication barriers require significant methodological adaptation [4].

This study presents a first design iteration of the Dementia Journey Companion (DJC), an advance care planning toolkit developed within AI4Hope, a European research project

dedicated to the human-centred, value-sensitive design of AI-powered solutions for people with dementia and their caregivers. The application framework comprises three modules: (1) a Life Story Builder, enabling users to document memories, values and personal history, (2) a Quality of Life Builder, supporting the documentation of daily preferences and wishes across key life domains and (3) an Information Centre, providing on-demand, evidence-based dementia information. Throughout all three modules, a conversational AI chatbot companion guides users by asking questions one at a time, offering supportive prompts adapted to the needs of individuals with cognitive impairment. Through an iterative participatory design approach, this study investigates how visual and interaction design elements of the application can be developed to meet the accessibility needs of older adults with dementia, examining iconography, navigation, layout and interaction modalities across three successive phases: a focus group, a paper prototyping workshop and a digital prototype testing.

Data and Method

This study adopted a qualitative participatory design framework grounded in user-centred design principles. The methodological approach combined focus group inquiry, thematic analysis following Braun and Clarke's [10] framework, low-fidelity paper prototyping and digital prototype testing. The study was approved by the relevant institutional ethics committee (Faculty of Arts of the University of Maribor). All participants provided written informed consent prior to participation. Eleven older adults (aged 65+) attending the Day-Care Centre Žalec participated in the study. Participants represented varying levels of cognitive functioning, including individuals with early to middle-stage dementia. Inclusion criteria required the ability to participate in group discussion with facilitator support. Recruitment was conducted in collaboration with centre staff. In Phase 1, a 60-minute focus group was conducted with all eleven participants, audio-recorded, transcribed verbatim and analysed using thematic analysis. In Phase 2, conducted one week later, participants were divided into two groups of five and six for a 90-minute co-design workshop. To reduce the cognitive burden of abstract thinking, pre-prepared paper UI elements were provided, including navigation buttons, menu items, a conversational assistant dialogue box and input method options, which participants freely arranged on blank screen templates. In Phase 3, one week later, a 60-minute usability testing session was conducted with eleven participants using an interactive Figma prototype encompassing all three main DJC modules (Life Story Builder, Quality of Life Builder and Information centre) and the home screen, developed from Phase 2 outcomes, with feedback gathered through facilitated group discussion and direct observation.

Results

The thematic analysis of the focus group identified three main themes, summarised in Table 1. Participants reported using digital devices primarily for basic functions such as calling and text messaging and frequently relied on family members for more complex tasks. Low digital confidence was widespread, with participants describing themselves as too old to learn new technologies and expressing reluctance toward unfamiliar devices. Key usability barriers in existing solutions included small buttons, small screens and complex navigation, alongside distrust resulting from unresponsive or unreliable interface elements. Regarding desired functionalities, participants expressed strong preference for medication and task reminders, visual content over written text and voice interaction as an alternative to typing, particularly for those who can no longer write.

Table 1. Thematic analysis of the focus group.

Theme	Subthemes	Illustrative quotes
Digital literacy and prior technology experience	Low digital confidence	“We are not used to this.” “This is for the younger generation who followed technology from the beginning.” “We are a bit too old...our brains don’t cooperate anymore.”
	Barriers to use	“If there was just one button for everything, maybe it would work.”
	Reliance on family members	“I only use the phone for calling. My daughter handles the rest.”
Barriers in existing digital solutions	Design issues	“The screens are too small.” “Phones all work the same way, but for older people there should be bigger buttons and fewer things.”
	Interaction issues	“Maybe voice (<i>commands</i>) would be easier than typing.” “You feel safer when you see that it works (<i>after trying to complete a task</i>).” “I would rather see pictures than read a lot of text.”
Desired functionalities	Reminders	“If it reminded me to take my medication, that would be fine.” “If the app told me where I left something, that would be great.”
	Voice interaction	“For those who can no longer write, it is easier if you can just tell (<i>the application</i>).”

The paper prototyping workshop confirmed and extended these findings. Both groups consistently selected larger icons with descriptive text labels over icon-only alternatives and included all four core application modules on the home screen. The help button was placed in a prominent and immediately visible position by both groups. Both groups included the conversational assistant dialogue box on the home screen, reflecting the preference for guided, supported interaction expressed during the focus group. For the input method screen, voice command was ranked as the most preferred interaction modality by both groups, followed by photo and video upload, with keyboard typing ranked lowest, as participants perceived it as the most demanding input method.

Digital prototype testing in Figma produced four key findings. First, participants expected all visible interface elements to be interactive; where elements were non-responsive, confusion and frustration were observed, indicating a need for full consistency between visual signifiers and actual functionality. Second, participants expressed a clear preference for large typography and high-contrast colours, with one participant specifically noting that the text in the current prototype was too small to read comfortably. Third, a strong preference for voice interaction was reiterated, with participants suggesting the application should ask questions and allow simple spoken responses at a natural conversational pace, avoiding fast or mechanical speech. Fourth, the conversational assistant prototype was received very positively; participants engaged readily with prompted questions, responding verbally and noting that this form of interaction gave them a sense of personal connection and increased their motivation to use the application.

Conclusion

This study demonstrates that iterative participatory design is both a feasible and effective methodology for developing accessible digital applications for older adults with dementia. Across three successive phases, older adults with varying levels of cognitive functioning

actively contributed to the design of visual and interaction elements, producing consistent and coherent design preferences that closely aligned with established accessibility guidelines. The findings indicate that voice interaction, large iconography with descriptive labels, high-contrast visual design and a guided conversational interface are essential features for this population. The positive reception of the conversational assistant prototype across all three phases suggests that AI-guided interaction, when designed to follow a natural conversational pace and structure, can meaningfully support engagement and reduce cognitive and motor demands. These insights informed the conceptual foundation of the Dementia Journey Companion, contributing to the human-centred, value-sensitive design principles that guide the ongoing development. The study also confirms that participatory design methods require deliberate adaptation when working with cognitively impaired participants. The use of visual tools such as pre-prepared paper UI elements, icon cards and screen templates enabled active participation among individuals who would likely have been excluded from conventional usability testing. This methodological contribution extends current evidence on how participatory approaches can be practically implemented with vulnerable populations in dementia research. Several study limitations should be acknowledged. The study involved a small, homogeneous sample from a single day-care centre in Slovenia, which limits generalisability across different cultural and care contexts. The focus on early design preferences did not include longitudinal assessment of usability over time. Future research should validate these findings with larger and more diverse samples across further iterative development cycles.

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