Enhancing Inclusive mHealth Design for People Living with Dementia: Examples from Literature

Thomas ENGELSMAa,b,c,1, Monique JASPERS a,b,c and Linda PEUTE a,b,c

a Amsterdam UMC location University of Amsterdam, Department of Medical Informatics, Meibergdreef 9, Amsterdam, The Netherlands
b Amsterdam Public Health, Aging & Later Life, Amsterdam, The Netherlands
c Center for Human Factors Engineering of Health Information Technology, Amsterdam, The Netherlands

ORCiD ID: Thomas Engelsma https://orcid.org/0000-0001-8889-1669
Monique Jaspers https://orcid.org/0000-0001-8040-9153
Linda Peute https://orcid.org/0000-0002-9859-0912

Abstract. The availability of mHealth technologies for older adults living with dementia is increasing. However, due to highly complex and varying clinical presentations of dementia, these technologies do not always meet their needs, wishes and capabilities. An exploratory literature review was performed to identify studies that applied evidence-based design principles or provide design choices that aim to improve mHealth design. These were categorized as a unique design choice to tackle barriers to mHealth use related to cognition, perception, physical ability, frame of mind, or speech and language. Through thematic analysis, themes of design choices were summarized per category in the MOLDEM-US framework. Thirty-six studies were included for data extraction, leading to seventeen categories of design choices. This study pushes the need to further investigate and refine inclusive mHealth design solutions for populations with highly complex symptoms, such as those living with dementia.

Keywords. Dementia, mHealth, Human-centered design, Usability

1. Introduction

Dementia can introduce complex barriers to mHealth use related to decreased cognition, perception, physical ability, frame of mind, and speech and language [1]. The clinical presentation of dementia varies on an individual level, caused by differences in type(s) and severities of symptoms. This introduces additional issues when designing innovative digital tools to support activities of daily living and care processes for this population. Due to the variety in clinical presentation of dementia, a one-design-fits-all or universal approach will not suffice in realizing usable mHealth. This may lead to challenges for inclusive design and applying methodologies such as co-design and participatory design...
It is impossible to include sufficient variations in clinical presentations when applying these methodologies. To support the use of these methodologies and enhance inclusive design, guidance should be provided to software developers and researchers during mHealth development for those living with dementia. To contribute to this guidance, the aim of this explorative literature review is to identify design choices from studies that designed, evaluated, or reviewed mHealth applications and the user-experience of users living with dementia.

2. Methods

An explorative review (through PubMed, Google Scholar, and IEEE) was performed in January 2022 to identify design choices made during the development and evaluation of mHealth tools for people living with dementia, using three search topics: mHealth, dementia and design (Table 1). Articles were eligible if the study described the design process of an mHealth application or performed usability testing and provides suggestions to improve usability. Papers were excluded if the focus was (1) not on mHealth, (2) on the prevention or diagnosis of dementia, (3) on (informal) caregivers only, or (4) on mHealth functionalities rather than design. For each eligible article, design choices were extracted by two researchers. Using the MOLDEM-US framework, that captures barriers to mHealth use for older adults living with dementia, these were grouped individually by two researchers as a design choice that tackles either cognition, physical ability, perception, frame of mind or speech- and language barriers [1]. Afterwards, consensus on this grouping was reached through discussion with the research team. Through thematic analysis, design choices were summarized per category from the MOLDEM-US framework, leading to different themes of design choices per category.

Table 1. Overview of Medical Subject Headings and keywords used per topic (mHealth, dementia, and design).

<table>
<thead>
<tr>
<th>mHealth</th>
<th>Dementia</th>
<th>Design</th>
</tr>
</thead>
<tbody>
<tr>
<td>smartphone [MeSH]</td>
<td>Neurocognitive Disorders [MeSH]</td>
<td>design*</td>
</tr>
<tr>
<td>cell phone use [MeSH]</td>
<td>Alzheimer Disease [MeSH]</td>
<td>criteria*</td>
</tr>
<tr>
<td>mobile applications [MeSH]</td>
<td>Dementia [MeSH]</td>
<td>guideline*</td>
</tr>
<tr>
<td>telemedicine [MeSH]</td>
<td>Frontotemporal Dementia [MeSH]</td>
<td>rule*</td>
</tr>
<tr>
<td>telehealth [MeSH]</td>
<td>Lewy Body Disease [MeSH]</td>
<td>usability</td>
</tr>
<tr>
<td>m-health OR mHealth</td>
<td>Cognitive Dysfunction [MeSH]</td>
<td>framework</td>
</tr>
<tr>
<td>eHealth OR e-Health</td>
<td>Cognition Disorders [MeSH]</td>
<td>recommendation</td>
</tr>
<tr>
<td></td>
<td>Memory Disorders [MeSH]</td>
<td>requirement*</td>
</tr>
<tr>
<td></td>
<td>Dementia</td>
<td>barrier*</td>
</tr>
<tr>
<td></td>
<td>ADRD</td>
<td>specification*</td>
</tr>
<tr>
<td></td>
<td>Alzheimer*</td>
<td>principle*</td>
</tr>
</tbody>
</table>

3. Results

After scanning the title and abstract of 733 unique citations, 36 studies were eligible for data extraction. An overview of the included studies can be found via: https://figshare.com/s/64cd86abf7d0e09b4fd. From these studies seventeen themes of design choices emerged through thematic analysis, which are shown in bold in the sections 3.1 – 3.4.
3.1. Cognition

To tackle cognitive barriers to mHealth use, the first theme of cognitive design choices that emerged from various studies is the implementation of **action progress monitoring incorporating memory aids**. This can be applied through configurable reminders, auto-prompt features, checklists, auto-save functionalities and confirmations of successful task completions. This progress monitoring can support the user’s declining working memory, recognition skills, the (diminished) ability to organize thoughts and actions, (diminished) attention and thinking speed. Minimization of steps for data entry should be considered during progress monitoring. Second theme includes the implementation of **tutorials** with short instructions. This can be of use when for example working memory and learnability skills are declining. Limited information should be shown on a single screen, providing and repeating simple step-by-step instructions. It can also be useful to filter irrelevant information if a user does not want or is unable to use certain functionalities or absorb content. Third, **personalization** is important when designing for people living with dementia, to allow adaptation of functionalities and task difficulty to a user’s cognitive skills. Personalization can also be achieved by allowing the user to determine their individual information needs, by providing simple information items with the option to get more information and minimize distraction. Fourth, **easy and consistent navigation** should be ensured. This can be achieved by using linear navigation, but also by avoiding strong hierarchical menu structures. In line with personalization, more control methods may be implemented to allow the user to select their preferred method of interaction, such as drag-and-drop or tap. The last emerging theme concerns the **use of icons**. These should be consistent (same button for one functionality), representable and understandable (buttons should look like buttons). Icons can also be used to show successful task completion. When using icons, these should all be visible on one screen to prevent the need for scrolling.

3.2. Perception

With respect to perception, the first theme that emerged relates to **compartmentalization** of the information content and differentiation of objects from other visual items. This can be achieved through the use of bold colors, mixture of both typo- and iconography, and headings. Another important consideration in the design is how to provide **interactive system feedback**. Due to the complexity and variety in clinical presentation of dementia, studies have shown the implementation of text-to-speech modules, audio-based cues, and vibrations in case of decreasing visual acuity and text-based instructions and feedback in case of decreasing auditory acuity. With respect to **color use**, considerable barriers mHealth use for people living with dementia are glare, (diminished) color vision and contrast detection. Studies implemented the use of clear, color-neutral and distinguishable colors, increased contrasting colors compared to the interface background, and recommend avoiding excessively glaring colors. Due to the loss of touch sensation, **visual intuitive cues that show click-sensitive areas** should be provided, in combination with audible system feedback. Finally, to allow **processable elements**, the possibility to (automatically) magnify these elements, use large font sizes in general and “touch interface screen readers” should be considered. Moreover, when using reminders, the pop-up size should be increased when the user interacts with the mHealth app.
3.3. Frame of Mind

A frequently mentioned theme to tackle frame of mind barriers is to implement opportunities to receive easy access to help, through for example a help-desk or mechanisms that support recovery from errors smoothly. Second, the aspect of time is approached from various angles in relation to mHealth design. One angle suggests that users should have orientation to time (clock-time). Another angle state that, with respect to task completion, users should have ample time to respond or react to an interactive system, with triggers implemented for time-based tasks. Moreover, if timers are used, these should run up instead of down. Third, to ensure positive system feedback, it has been suggested to provide failure-free content only. Positive feedback from a system can be achieved through brief encouragements while completing tasks, the use of rewards when a user has attained a pre-set goal, and by confirming correctly taken steps. Fourth, as with cognition, personalization emerged as a theme to tackle frame of mind barriers. Personalization could be considered in terms of varying difficulty levels of functionalities, individual features based on needs and wishes, sets of functionalities based on capabilities, and when appropriate the privacy settings. Finally, to prevent stigmatization, the language used for the content in a mHealth app should be appropriate to the user characteristics.

3.4. Speech- and language

Two themes emerged related to speech- and language disabilities in relation to design of mHealth for people living with dementia. First, the language use should be explicit and consistent with everyday words and foreign language and technical terms should be avoided. Difficult terminology that cannot be avoided should be explained through for example a glossary. Second, related to user-input, the mHealth technology should adhere to recommendations for clear speech and it should have both text-to-speech and speech-to-text implemented. Finally, free text should be avoided as user-input when possible.

4. Discussion

This paper provides an overview of literature-based design choices for mHealth aimed at those living with dementia. Seventeen themes of design choices emerged, mainly related to cognition, perception, and frame of mind issues. Because the themes have emerged through a literature-based approach, it implies that the themes of design choices are considered to lead to improved user-experience of mHealth applications for the intended end-users. However, these still need further validation and refinement to further support software developers and academics in mHealth development.

Through this approach, there were no design choices identified in relation to the physical ability of end-users. This may be due to the fact that this review looked at software design rather than hardware design of mHealth. Other research indeed found that hardware choices are important for the user experience for dementia patients [3]. They concluded that electronic devices should not be heavy or slippery because of physical limitations of those living with dementia in a care setting.

Two strengths of this study were the use of multiple search engines to explore literature and the use of a framework to individual group the extracted design choices.
and gaining consensus with the research team afterwards. Even though this search has been performed in January 2022, the results show a comprehensive set of seventeen design themes that may increase the usability of mHealth technologies for people living with dementia.

In future research, validation of the emerged themes will comprise heuristic evaluations of novel and currently available mHealth implementations. The results of these evaluations, violations of the proposed themes, will be compared with usability problems identified from usability testing with the actual end-users, those living with mild cognitive impairment or early stages of dementia. Also, the researchers will further explore the effectiveness, and investigate potential improvements, of usability testing methods when including people living with dementia. Usability testing methods such as the think aloud methodology may need adaption to increase the reliability of data when including people living with dementia. Completing a task and thinking aloud simultaneously requires a higher cognitive load, which might be too high for people living with dementia [4]. Moreover, previous research indicated observations and recording task completion rates and times produce the most reliable results when conducting usability tests with people living with dementia [4]. Finally, the applicability of the design choices may depend on the distinguished types of mHealth to support patients, which include apps to check personal health records, personal care apps, social networking apps, educational health apps, and apps to contact healthcare professionals [5]. The usefulness of design themes per type of mHealth should be further researched to improve applicability of this study’s findings.

5. Conclusion

Seventeen themes of design choices emerged from literature that can support software developers and academics in designing mHealth for people living with dementia. By applying these themes methodologies such as co-creation and participatory design can be supported in the mHealth design process. In future work, the design themes should be refined and validated through user testing and mHealth implementation studies.

References


