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# Dementia-Related Barriers to mHealth Use: Validation by Expert Opinion

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**Abstract.** mHealth use for people with dementia is fraught with factors influencing its implementation in care and daily life. A better understanding of these factors may provide guidelines to inclusive design. This study aimed to assess whether factors gathered in a literature-based model could be validated by opinions of experts. On basis of a questionnaire as part of a larger study, experts identified barriers that they considered to be related to aging and dementia influencing mHealth use. Nineteen barriers that were mentioned by the dementia experts were covered in our literature-based model. No adaptions to the model were required. The dementia experts acclaimed three barriers to mHealth use that could not be mapped onto the framework: the unavailability of (informal) caregivers to support the mHealth use, the stage and type of dementia of an mHealth user, and the fear of the unknown. These should be considered as prerequisites in the implementation phase of mHealth and explored more in future research.

**Keywords.** Dementia, Mobile Health, Design, Validation

## 1. Introduction

Digital health technologies (DHT) use for a wide range of end-users is increasing. To enable successful implementation, adoption, and retention of DHT for a wide range of end-users, it is important to ensure inclusive design and keep the needs, capabilities, and barriers of these end-users with respect to DHT use into account. Previously, a literature-based model has been developed capturing barriers to DHT use, more specifically to mHealth use, for older adults with dementia [1]. This model is based on a framework, MOLD-US, that defines general aging barriers to mHealth use [2] and extended with dementia-related barriers identified in clinical literature and usability studies of mHealth performed with older adults with dementia. To validate this model, from now on referred to as MOLDEM-US, a larger study is ongoingwith dementia experts to prioritize the actual impact of these barriers to mHealth use by these adults and how often these occur in practice. As part of this study, we gathered qualitative data with regards to these experts' experiences with barriers to mHealth use for these adults. With these data, we

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aim to perform an additional validation and potential refinement of MOLDEM-US based on real-life practice.

## 2. Methods

We performed a larger study with dementia experts (data gathered between April 12th 2021 till June 22th 2021) to prioritize the actual impact and occurrence of barriers to current mHealth use for older adults with dementia. The recruited dementia experts consisted of case managers, district nurses, hospital healthcare workers, informal caregivers, and researchers. Recruitment took place via various organizations related to dementia care and through snowball sampling. An introductory questionnaire was submitted to gain insights into the experience of dementia experts with barriers to DHT use for older adults with dementia. For this paper the responses of dementia experts to the question: "Which barriers related to aging and dementia influence the use of mHealth?" were analyzed. The questionnaire was distributed using Castor EDC [3]. The barriers appointed in the qualitative responses were extracted from the data and mapped, using a thematic analysis, on the barriers captured in MOLDEM-US related to cognition, perception, physical ability, frame of mind, or speech- and language. While completing the introductory questionnaire, participants were not aware of the barriers in MOLDEM-US and were asked to answer the questions based on their own experiences. Initial analysis was performed by AY, and this was adapted by TE and LWP until consensus was reached.

## 3. Results

### *3.1. Participant characteristics*

Fifty-four dementia experts were invited to participate in the questionnaire of which 48 responded. However, an additional four participants were excluded due to no meaningful response to the open-ended questions of the questionnaire. With a response rate of 81%, 44 participants were included in the data analysis to identify barriers to mHealth use. These participants were mainly female (90.9%), smartphone users (100%) and reported as main function: case manager (n=17), hospital or district nurse (n=15), geriatrician (n=1), researcher (n=5), informal caregivers (n=4) or project coordinator (n=2). Finally, 65% mentioned to have experience with mHealth use.

### *3.2. Validation of the model*

Nineteen barriers already included in MOLDEM-US were identified through qualitative data from our survey (Table 1). Most barriers were validated in the "frame of mind barrier" category (n=7), followed by "cognitive barriers" (n=6), "perception barriers" (n=3), "physical ability barriers" (n=2), and "speech- and language barriers" (n=1). Additionally, three barriers identified through the questionnaire did not match with any of the barriers in MOLDEM-US and could therefore not be mapped: 'no availability of

(informal) caregiver to support mHealth use', 'the fear for the unknown', and 'the stage and type of dementia'.

**Table 1.** Validation of barriers from the extended MOLD-US model by dementia experts order by most mentioned.

| Barriers from extended MOLD-US model | n | Quotes from questionnaire |
|---|---|---|
| **Cognitive barriers** | | |
| Learnability | 13 | *"Can people with dementia still learn new things such as the use of mHealth?"* |
| Working memory | 11 | *"The decline in cognition affects the processing of the large amount of information that mHealth asks of someone"* |
| Recognition | 6 | *"Ability to remember actions for a longtime."* |
| Ability to organize thoughts or actions | 3 | *"Forgetfulness, forgetting passwords, not knowing where something is stored."* |
| Reasoning | 2 | *"Dementia makes it more difficult to distinguish between cause and effect"* |
| Making decisions and judgements | 1 | *"Little problem-solving ability. For example, as soon as the WiFi freezes, panic and mistrust arises in the functions."* |
| **Physical ability barriers** | | |
| Hand-eye coordination | 3 | *"In Parkinson's (dementia) the (fine) motor skills fail. So you can no longer operate it. Operating the telephone was one of the first things my husband could no longer do."* |
| Tremor | 3 | *"But also, for example, tremors in parkinsonism can cause difficult situations when using a telephone or tablet."* |
| **Perception barriers** | | |
| Color vision | 2 | *"Dark colors"* |
| Touch sensation | 1 | *"Difficulty with buttons/touch screens"* |
| Ability to say what has been seen | 1 | *"Delusions and/or visual hallucinations may be enhanced"* |
| **Frame of mind barriers** | | |
| Computer literacy | 13 | *"If people with dementia themselves have to do something with a tablet or mobile phone, it often becomes difficult, because they did not grow up with it. Keep in mind that this might be easier for future generations."* |
| Trust in own ability | 5 | *"People [with dementia] dread learning it and think they can't"* |
| Efficiency in seeing benefits | 5 | *"Most older people come from a generation with little technology. Older people with dementia are therefore even less able to understand how mHealth can be used and what its benefits are."* |
| Perceived complexity | 5 | *"Dealing with technology can quickly become overwhelming."* |

| | | |
|---|---|---|
| Fluctuating attention / Concentration issues | 3 | *"People are easily distracted from possible pop-ups, or advertisements in apps"* |
| Restlessness and agitation | 2 | *"Can't be patient anymore and get frustrated faster."* |
| Stigmatization | 1 | *"They themselves do not notice what is going wrong/different than before."* |
| **Speech- and language barriers** | | |
| Semantic knowledge | 2 | *"Difficulty using and functioning of a smartphone, etc. due to difficulty with the language used"* |

## 4. Discussion

This paper sought to gain insights into known barriers to mHealth use for older adults with dementia according to dementia experts. Nineteen barriers were identified and already covered in MOLDEM-US, which supports its validation and no additional refinements to the model were necessary. According to the dementia experts in this study, a barrier to mHealth use for older adults with dementia is the unavailability of (informal) caregivers to support the mHealth use. It can be implied that this barrier is rather a prerequisite for older adults with dementia to use mHealth. The need for support can be traced back to other frequently mentioned barriers by the dementia experts such as difficulties with learning new skills (*learnability*), *perceived complexity*, *trust in own abilities*, and low *computer literacy*. One or more of these four barriers were mentioned by 59% of participants.

A second acclaimed barrier which can be considered a prerequisite to mHealth use is the stage and type of dementia of an mHealth user. The current version of MOLDEM-US model does not discriminate on the severity of barriers per stage of dementia, but found that participants in usability studies were mostly diagnosed with mild cognitive impairment or early-mild dementia [1]. However, it is relevant for future research to investigate how inclusive design approaches can contribute to increase the durability of mHealth technologies as the disease progresses. This is in line with findings from a scoping review by Guzman-Perra et al. who state durability is a factor that can influence the adoption of smart health technology for people with dementia [4].

A third barrier and final prerequisite to mHealth use, "the fear of the unknown" was mentioned by few participants. The interpretation of this barrier is rather broad, but might relate to barriers in MOLDEM-US such as *trust in own abilities* and *computer literacy.* Previous research suggests that older adults who do not use digital devices may experience computer-related anxiety which makes them feel technophobic or unconfident in using digital solutions [5].

Finally, the MOLDEM-US barriers *learnability, working memory,* and *computer literacy* were most often mentioned by experts. It is important to acknowledge that this does not indicate the frequency of such barriers in practice, but rather the best-known barriers by the dementia experts in this study. However, in the larger Delphi study that is being performed by the authors we aim to prioritize these barriers in contribution to the development of design guidelines supporting future mHealth innovations.

A strength of this study is the inclusion of a broad range of dementia experts with various experiences with older adults with dementia, but also various settings in which

mHealth is or can be implemented. Another strength is the initial and secondary analysis that have been performed by three researchers to reach consensus on the mapping of the responses to the known barriers. A limitation might be that not all experts reported to have mHealth experience. However, their experience with working with older adults with dementia provided valuable responses to the questionnaire as mentioned barriers were covered in our model.

Future work consists of further investigating the impact of barriers to mHealth use and the development of inclusive design suggestions for the barriers that most affect current mHealth use in order to improve the implementation, adoption, and retention of mHealth in dementia care.

## 5. Conclusions

Barriers covered in MOLDEM-US influence mHealth use according to the experiences of dementia experts in this study. This ensured no additional refinements to the model were required. Three barriers were acclaimed to influence mHealth use, but should be considered as prerequisites for the actual implementation of mHealth. These should be accounted for during implementation, to tackle barriers such as learnability, perceived complexity, trust in own abilities, and computer literacy. Future work needs to provide practical insights for mHealth developers to contribute to inclusive design for older adults with dementia.

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