Exploring the needs and user experience of people with early-stage dementia for mobile-health applications for cognitive and physical activation - a qualitative study in Germany

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Abstract

Background: The demand for support among people with dementia (PWD) is increasing with a diminishing capacity for providing care. As the trend of aging at home continues, technologies can help maintain PWD's autonomy, enabling them to live independently for as long as possible. Furthermore, digital applications can have numerous positive biopsychosocial effects on the health of PWD, including physical, cognitive, and social functions.

Objective: The aim of this study is to examine the needs and requirements of people with dementia regarding a prototype application for the promotion of cognitive and physical activity on a tablet computer.

Methods: We conducted a methodical triangulation combining semi-structured interviews with people with dementia, as part of the testing of a tablet-based application, with overt external participant observations during usage. The chosen method for analysis was qualitative content analysis according to Kuckartz.

Results: The participants had varying abilities and prior experience with technology. While most participants were initially hesitant to use the tablet independently, they were more willing to try it after receiving encouragement. Some individuals required more assistance during usage than others, indicating the need for individualized adjustments. Connecting biographically to the content is crucial for cognitive tasks to minimize overload for PWD. The Participants appreciated social interaction with the researchers and direct communication. Therefore, it is important to consider the role of personal support when developing and implementing technology.

Conclusions: The successful implementation and use of technology require acceptance and a working interaction between PWD, technology, and caregiver (CG) or caring relatives (CR) acting as personal support. The acceptance of the application was found to be less influenced by the types and presentation of tasks, but rather by their content and the social interaction. Ideally, PWD would receive one-to-one support during use. However, this requires additional time and financial resources, which are often limited in care settings.

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Short Paper

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Keywords: touch-based digital technology; tablet-based technology; digital care application; mobile-health application; health app; mobile technology; home care setting; caring relatives; dementia; mild cognitive impairment

Introduction

Dementia is a leading cause of disability and care dependency among the elderly worldwide [17]. Currently, about 50 million people are living with dementia. Projections indicate that dementia prevalence will increase to 152 million cases by 2050 [1]. Consequently, the demand for support for people with dementia (PWD) is growing. This may become a key challenge for care due to the

simultaneous decrease in care capacity. In Germany, most PWD live in their own homes [3] and receive care from family members acting as caring relatives (CR) and from caregivers (CG). They provide support and play a crucial role in dementia care by acquiring the ability to manage challenging behavior [2].
With the current trend of aging at home, technology can help preserve the autonomy of PWD to remain independent in their familiar environment for as long as possible [12]. The integration of technology into dementia care can assist in maintaining physical functions [4] and strengthen cognitive functions of PWD [10]. The utilization of personalized digital technologies has the potential to enhance the well-being of PWD, leading to improvements in behavior, mood, sense of identity and social relationships [5]. A holistic bio-psycho-social approach is necessary for the care and support of PWD. The frequent occurrence of multimorbidity in PWD presents additional challenges for care and support [8].

The aim of this study is to examine the needs and requirements of PWD regarding interactive videos on a tablet computer to maintain their independence.

Methods

Study Design

We conducted a qualitative triangulation of observations and interviews, with the results from each methodically aligned. Our study took place in Germany and follows the Standards for Reporting Qualitative Research (SRQR).

Sampling, recruitment, and field access

The study included participants with mild cognitive impairment or early-stage dementia between 50 and 90 years old. They had to reside in Germany and were required to communicate verbally, as well as have adequate vision and hearing. Previous technical experience with mobile devices was intentionally not defined as an inclusion criterion. We achieved recruitment and field access by attending events, presentations at support groups, and visits to outpatient, semi-inpatient, and inpatient care facilities in South-West Germany. The characteristics of the participants are presented in Table 1.

Table 1: Sample composition of PWD

Participant characteristics, total N = 24			
Sex	male = 10	female = 14	
Owning a smartphone or tablet	yes: n = 10	no: n = 14	
Using a smartphone or tablet	often n = 5	rarely n = 5	never n = 14

Data collection

We conducted overt external participant observations and guided context interviews, which were recorded using a sound recorder. The process of data collection was divided into three phases:
a) Discussion about previous experience with digital technologies
b) Interactive testing of the application on a tablet computer (A section of the application's content is depicted in Multimedia Appendix 1)

c) Guideline-based interview on the user experience

We selected the interview questions considering the limited cognitive abilities of the participants. Therefore, they were formulated in a language that was easy to understand. Two researchers conducted the data collection process. One researcher provided support during the use of the application by offering verbal assistance and aiding in the execution of the tasks in order to promote its usage (Multimedia Appendix 2). The other researcher observed the process and created field notes. These field notes were based on predefined criteria.

Data analysis

After transcribing the meaning of the collected data, we carried out a qualitative content analysis according to Kuckartz [7]. We structured key aspects within the observation protocols and supplemented deductive categories with inductive categories. The study design is presented in Figure 1.

Figure 1.

Results

Participants' general perceptions of the technology and their usage patterns

The participants showed great heterogeneity in terms of skills and previous experience with technology, resulting in varying levels of proficiency in tablet use. This is likely influenced by their prior experience, such as owning or not owning a mobile device. Overall, the participants demonstrated a high level of engagement during use, as indicated by focused attention on videos and comments related to the content. The majority of the participants expressed positive feedback regarding the application, however, many were unable to envision using the tablet on their own.

Role of technology use

Most participants were proficient in recognizing visual elements, including both images and videos. The findings from observing the different effects of auditory stimuli on the participants highlight the challenge of developing a design that is balanced and accessible to different user groups.

Role of the content within the application

Cognitive tasks: When evaluating preferences for task types, the participants demonstrated indifference towards task type, including arithmetic, pictorial, and auditory. The content's relevance to the participants’ biographies more important for successful use. Tasks fell into three categories: those that can be solved based on personal experience, those that can only be solved in the context of the story, and tasks that require acquired knowledge or skills.
The individual biography of the PWD played a crucial role in recognizing places within the application scenes. In particular, visual and haptic experiences, such as walking through a meadow, and associated memories of the perceived feeling acted as triggers for verbal expressions from the participants. Familiar memories evoked by the content may have promoted interest and concentration.

Role of personal support during use

Initially, most participants were hesitant to use the tablet independently but were open to trying it after receiving positive reinforcement from the researcher.
It was noticeable that the participants often sought contact with the researchers for personal support

and reassurance. During use, participants shared personal stories from their lives, even while watching videos or receiving task instructions. They had a strong desire for communication.
In cases of uncertainty, participants appreciated clear instructions from the researchers and were not hesitant to ask further questions (Figure 2). The data suggests that the presence of the researchers and the participants' sympathy for them impacted the perceived acceptance and evaluation of the application. In addition to a general feeling of sympathy, participation in the study and the resulting change in the participants' daily routine may have had a positive influence on the evaluation of the application.

Figure 2.

Discussion

Principal Results

The results indicate that personal support is crucial for a successful overall interaction. If it is not possible for PWD to use the application alone, alternative usage scenarios must be considered. One possible scenario is one-to-one support by CR or CG. This would create a social interaction, which could motivate the user and encourage device usage. However, providing direct support requires time, which is often limited for CG [11]. Additionally, one-to-one support can be a financial burden, as CR perceive the associated costs as high and may therefore refrain from using the application [14].
We discovered that the type of task and the visual presentation of cognitive tasks (image-based, text-based, auditory) were of secondary importance. The content of the tasks were more crucial. To develop tasks that activate cognition, it is necessary to choose content that establishes an emotional connection with PWD and their biography and interests. This is essential for the acceptance of the technology.

Limitations

The reliability of the study may be reduced due to participants potentially adopting a desirable response behaviour during interviews. To address this, we triangulated the interviews through observations and mutual verification by the researchers. The researchers' reflexivity regarding their own role in the field ensures a higher level of objectivity.

Comparison with Prior Work

In a previous study, expert interviews were conducted to analyse requirements for an application for PWD. The tested application is based on those findings [15].
According to our study, acceptance is the base for a successful interaction with the application. A systematic review found similar results, emphasizing the importance of acceptance [4]. For a successful interaction, the social context is another crucial factor, as our study highlighted. Smith et al. discovered that technology interactions are perceived more as social events when individuals are in the presence of others or in groups. The tablet serves as a catalyst for conversations, facilitating the exchange of interesting anecdotes [13].

Woods et al. demonstrate that biographical reference plays an important role in solving cognitive tasks for PWD. Although PWD often struggle to recall recent events, they often retain memories of their childhood. Tasks that include biographical references can be easier for PWD, leveraging their cognitive strengths and minimizing overload [16].

Conclusions

When dealing with dementia, it is important to consider the heterogeneity of this group and their dependence on the cognitive state of the day. Therefore, the possibility of individual adaptations of the technology is crucial in order to address different interests and abilities. The participants in the study shared a common interest in social contact. Thus, it is important to consider the role of personal support when developing and implementing technology. Also it is essential to ensure easy access. Potential users, CR and caregivers should face as few barriers as possible when obtaining information, purchasing an application, and using it. This is particularly important given the short period of use due to the changing cognitive state.

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Data Availability: Anonymized data sets generated or analyzed during the study are available from the corresponding author on reasonable request.

Conflicts of Interest

None declared.

Abbreviations

CG: Caregivers
CR: Caring relatives
PWD: People with dementia

Ethics

The study was approved by ethic committee of the German Society for Nursing Science (EK-22-038) and it complies with the Declaration of Helsinki.

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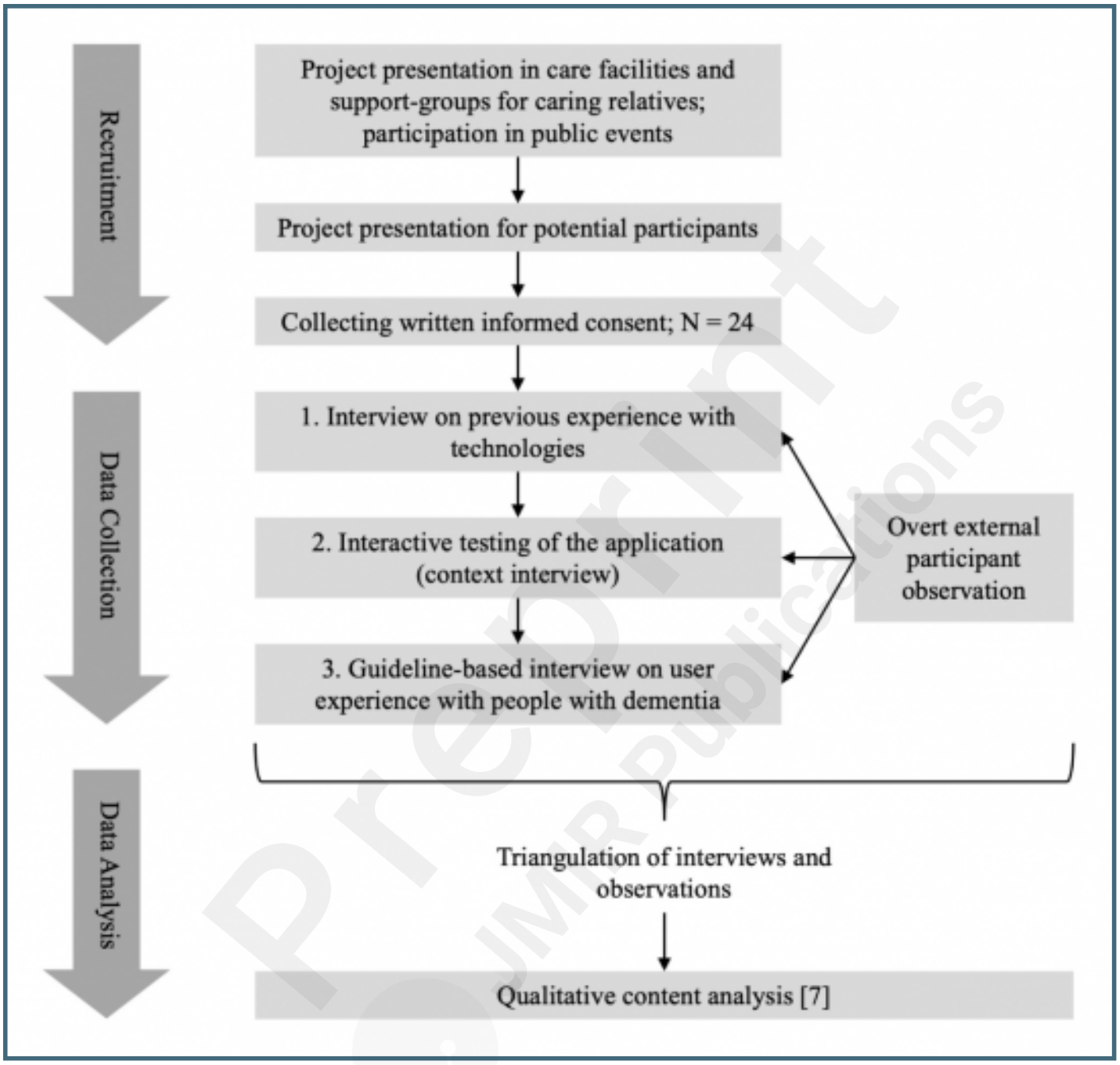
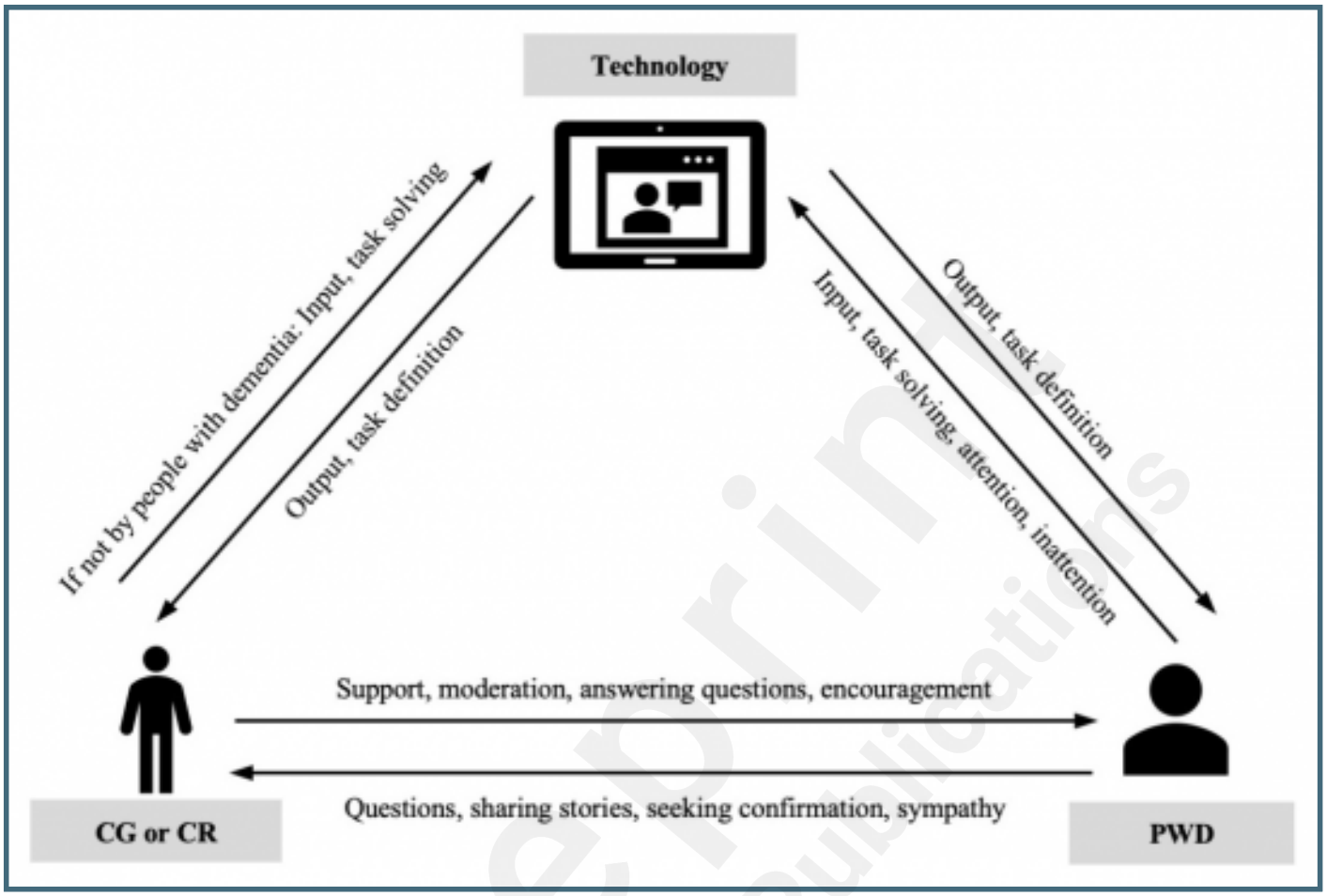
Supplementary Files

Figures

Methodical approach of presented study.



Interaction between technology, PWD and CG or CR [6].



Multimedia Appendixes

A section of the application's content.
URL: http://asset.jmir.pub/assets/9110c496c76faa9f5d6565890a3e594e.png

The provided personal support during use of the application.
URL: http://asset.jmir.pub/assets/41f87ece8b26b8a16b86c52d0e2fa56d.png

TOC/Feature image for homepages

Old woman using the tablet-based mobile application.