

Developing a Digital Assistive Tool for Dementia Patients and their Caregivers – A Qualitative Study on Needs, Potential Functions, Practical Requirements, User Acceptance, and Ethical Considerations

Lenka J. Wichmann, MSc, Nele Reiff, BSc, Sophie Zintl, BSc, Prof. Matthias Berking, PhD (2021)

Department of Clinical Psychology and Psychotherapy, Friedrich-Alexander-University Erlangen-Nürnberg (FAU)

Corresponding Author: lenka.wichmann@fau.de

Background: Digital smartphone assistants for the care and support of people with dementia (PwD) have great potential due to the wide availability of smartphones and a growing number of users aged above 65. Research has mainly focused on the development of applications for only one user group (patients, caregivers, or relatives respectively), and with only one or a few functions included (Yousaf et al., 2020). A more integrative, multi-user, and multifunctional application would be beneficial because it could be adapted to the users' needs more flexibly. This qualitative interview study was the first step in a co-creative process with a user-centered approach aimed at developing a multifunctional digital assistant.

Method: Qualitative content analysis (Mayring, 2010) combining deductive and inductive techniques was applied to identify burdens, needs, functions, ethical considerations, and acceptance aspects. 14 semi-structured interviews were conducted with three participant groups (relatives of PwD; caregivers and nursing staff; psychologists). Interviews were conducted via video conferences due to Covid-19 restrictions. After the completion of all interviews, participants received several questionnaires on acceptance aspects (Technology Usage Inventory [TUI], acceptance rating of specific functions), and technological affinity (TA-EG questionnaire) via letter. Interviews were transcribed verbatim with the software MAXQDA. Coding was done by two independent researchers. A coding frame was generated using the interview guide as a theoretical basis and the collected data for building inductive categories. The coding frame was pilot-tested before the final analysis and intercoder reliability was sufficient (k=.81).

Result: Preliminary results showed that dealing with symptoms of dementia in everyday life was burdening. Emotional needs in patients and needs for additional care resources in relatives and caregivers were the most important unanswered needs. 53 functions were suggested in the areas: digital care, support, training, monitoring, navigation, leisure activities, and social contacts. Participants had ethical requirements (i.e. data protection, privacy, and autonomy) that if met, would enhance acceptance. Results on questionnaires showed positive attitudes towards, curiosity about, and no insecurity with regards to technology. The overall acceptability of suggested functions was high.

Conclusion: Participants showed a large interest in the digital assistant. The importance of data protection was underlined.