The development of a tablet-based outpatient care for people with dementia – A feasibility study

Juliana Supplieth, Sonia Lech, Julie L. O'Sullivan, Robert Spang, Jan-Niklas Voigt-Antons, Johanna Schuster

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Abstract

Background: Dementia presents a significant challenge for individuals affected by it, as well as their families, caregivers, and healthcare providers.

Objective: This paper outlines the process of developing and assessing the feasibility of a tablet application aimed at addressing this challenge. It underscores the importance of incorporating input from general practitioners, stakeholders, and the needs of affected families to create a supportive healthcare app.

Methods: A qualitative approach was chosen, consisting of three interviews and an expert workshop. Both were recorded, transcribed and the qualitative content analysis was carried out according to the methodology described by Kuckartz with the support of MAXQDA. During the development phases of the app, team meetings and discussions took place bi-weekly.

Results: This paper emphasizes the necessity of considering multiple perspectives to ensure the high-quality development of supportive healthcare apps. General practitioners and relatives play pivotal roles in the treatment and care of Persons with Dementia, often expressing specific preferences and suggestions regarding supportive assistive technologies. Moreover, successful development of a useful tablet application requires robust scientific, multidisciplinary discussions, and teamwork within the healthcare community.

Conclusions: The collaboration among medical disciplines, social and technical sciences, as well as supporting organizations is essential to integrate relevant knowledge and expertise into the design and development of practical products tailored to the daily needs for healthcare of end users. Furthermore, adopting a spiral development approach inclusive of feedback loops is imperative for iterative refinement and enhancement of the application. Clinical Trial: ISRCTN 36542

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Abstract

Dementia presents a significant challenge for individuals affected by it, as well as their families, caregivers, and healthcare providers. This paper aimed at addressing this challenge. It underscores the importance of incorporating input from, stakeholders, and the needs of affected families. A qualitative approach was chosen, consisting of three interviews and an expert workshop. Both were recorded, transcribed and the qualitative content analysis was carried out according to the methodology described by Kuckartz with the support of MAXQDA. During the development phases of the app, team meetings and discussions took place. This paper emphasizes the necessity of considering multiple perspectives to ensure the high-quality development of supportive healthcare apps. General practitioners and relatives play pivotal roles in the treatment and care of Persons with Dementia, often expressing specific preferences and suggestions regarding supportive assistive technologies. Moreover, successful development of a useful tablet application requires robust scientific, multidisciplinary discussions, and teamwork within the healthcare community. Furthermore, adopting a spiral development approach inclusive of feedback loops is imperative for iterative refinement and enhancement of the application.

Keywords

dementia; tablet-app development; multidisciplinary healthcare; feasibility study; general practitioners

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Introduction

Dementia and healthcare

Dementia impacts approximately 47 million individuals globally, with nearly 10 million new cases emerging each year (1). In Germany, around 1.6 million people live with dementia (PwD) (2), posing a significant challenge not only for those affected but also for their families, caregivers, and healthcare providers. Dementia is characterized as *"a syndrome resulting from mostly chronic or progressive brain disease, disrupting various higher cortical functions, including memory, cognition, orientation, perception, arithmetic, learning capacity, language, and judgment. Consciousness remains unaffected. Cognitive impairments often coincide with changes in emotional control, social behavior, or motivation..."* (3). These extensive symptoms coincide with a gradual decline in the ability to independently perform daily activities. Consequently, there are physical, psychological, social, and economic repercussions, leading to disability and dependence among affected individuals (1). The substantial burden on (family) caregivers has been widely recognized (1, 4, 5). The majority of dementia caregivers are family members of PwD, who experience physical and psychological strain due to the health status and evolving health needs of PwD (2, 6). For instance, the German College of General Practitioners and Family Physicians (5) provides a brief overview of various health issues faced by caregivers, such as physical health problems (e.g., back injuries), mental health issues (e.g., depression), and a constant feeling of being overwhelmed. Moreover, previous research has revealed that family caregivers also grapple with violent behavior from PwD (7).

Evidence-based guidelines and General Practitioners (GPs) training (8), treatment pathways and certain communication (9) as well as a multiprofessional team approach (10) may represent helpful instruments to support GPs with care provision. Information and communication technologies (ICTs) may represent a promising approach to improve dementia care at home. As a systematic review of ICT studies by D'Onofrio, Sancarlo (11) showed, ICT´s can support several activities of daily life for PwD, to remain in their own home as well as the quality of life of their caregivers and decrease healthcare costs.

GPs play a pivotal role in providing healthcare for PwD. Bohlken and Kostev (12) demonstrated that in 2015, GPs, on average, treated 29.9 PwD, marking a 40% increase compared to 2005 (21.3 PwD). However, the role of GPs in diagnosing and treating PwD is subject to debate. Despite their commitment to holistic care and long-term relationships (13), there are significant challenges, including knowledge gaps, reluctance to diagnose, and cost concerns (14), alongside differing care priorities and limitations within the healthcare system (13). For instance, in communication, GPs' decisions to disclose a dementia diagnosis to PwD or their families are influenced by personal beliefs, patient circumstances, systemic care factors, and cultural norms (8). Additionally, euphemistic terms like 'memory problems' are often used instead of medical terminology to describe dementia (8). Wangler and Jansky (9) observed that GPs' distance, negative attitudes, and reluctance towards dementia testing and diagnoses directly impact practical diagnostic outcomes. Consequently, GPs may disclaim responsibility, fear stigma, and avoid confrontations with patients, citing concerns over the effectiveness of interventions, low compensation, and lack of recognition (9). In summary, existing literature recognizes the indispensable role of GPs in caring for PwD and underscores the necessity for enhancing primary dementia care.

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Digitization and Technologies

Moreover, there are political initiatives aimed at expediting the digitalization of the healthcare system, such as the Digital Act (DigiG), with the goal of enhancing healthcare (15). However, for these efforts to be successful, the technical solutions must align with the needs of the target group. Developing and assessing assistive technologies necessitates an understanding of the diverse interactions between technology, users, and the contextual environment, as well as knowledge translation (16). Dugstad, Eide (17) highlight crucial aspects for the successful implementation of digital technology in dementia care, emphasizing the involvement of key stakeholders from the outset, allowing time for exchange and participation during the initial stages, and advocating for iterative refinement and skill development. Particularly in the development of assistive technologies for individuals with dementia, given their complex circumstances and requirements, extensive collaborative and transdisciplinary engagement is essential, as demonstrated by Boger, Jackson (16).

The research project "DemTab – Tablet-based outpatient care for people with dementia" aimed to develop and assess a tablet-based intervention to enhance primary care PwD by promoting guideline-based treatment (18). To achieve this goal, a tablet-based intervention was created as part of the research project. The project was a collaboration between the Institute of Medical Sociology and Rehabilitation Science (ISMR) at Charité Universitätsmedizin Berlin and the Quality and Usability Lab (QULab) at Technische Universität Berlin. Additionally, a cluster-randomized controlled trial (cRCT) was conducted to examine the impact of this tablet-based intervention on guideline adherence (primary outcome) and various health-related outcomes for patients and caregivers (secondary outcomes). For more comprehensive information about the DemTab study, please refer to the specified source (18).

Aim of the present study

The present paper focuses on the initial phase of the DemTab study: the development of a tablet application designed for PwD, their caregivers, and GPs in Berlin and the surrounding regions. The objective is to outline the process of application development within the framework of a feasibility study. The primary aim is to illustrate how pertinent healthcare providers (GPs and experts from supportive organizations in dementia care) contributed to the content development process, and how collaborative and interdisciplinary research efforts between the ISMR and the QULab led to the creation of a functional healthcare application. A key objective was to ensure the incorporation of diverse perspectives and professional insights, as well as to facilitate a continuous and iterative research process through feedback loops and team discussions.

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Methods

Research Process and ISO Norm

Our methodological approach adheres to the International Organization for Standardization (ISO)

Norm ISO 9241-210, titled "Ergonomics of human-system interaction — Part 210: Human-centered design for interactive systems" (19). ISO has devised a framework aimed at ensuring systems are both usable and useful, with a focus on users, their needs, and requirements, by leveraging human factors/ergonomics and usability knowledge and techniques (19, p.vi). Similarly, the User-Centered Design (UCD) framework provides a structured methodology for translating ideas into products, prioritizing user preferences and interactions with the final product (20). The process aims to facilitate natural interactions without altering user behavior or expectations. UCD methodologies are rooted in the ISO 13.180 Ergonomics standards, with the standard 9241-210 playing a central role in the UCD framework. Our approach to developing the DemTab app aligns with the four general phases of the UCD process:

Firstly, we delineated the app's context, identifying primary user groups and their typical environments (step 1 in Figure 1). Secondly, we identified the requirements our solution must fulfill, encompassing content, usability, and regulatory compliance such as General Data Protection Regulation (GDPR) adherence (21). Thirdly, we formulated concepts and prototypes based on the identified requirements, marking the commencement of the design and development phase. Lastly, conducted concurrently, we continually evaluated our product through expert interviews and usability tests with the target user group. This iterative process provided feedback that we could incorporate into subsequent iterations of our development process. Figure 1, adapted from the ISO 9241-210 norm, illustrates the interdependence of human-centered design activities and our development process (19).

Following the process, we will provide a detailed account of the feedback activities that took place. Additionally, Figure 1 exhibits resemblances to the widely recognized qualitative circular research process, which permits some degree of flexibility and refers back to previous research steps, as it embodies a more dialogical approach (22).

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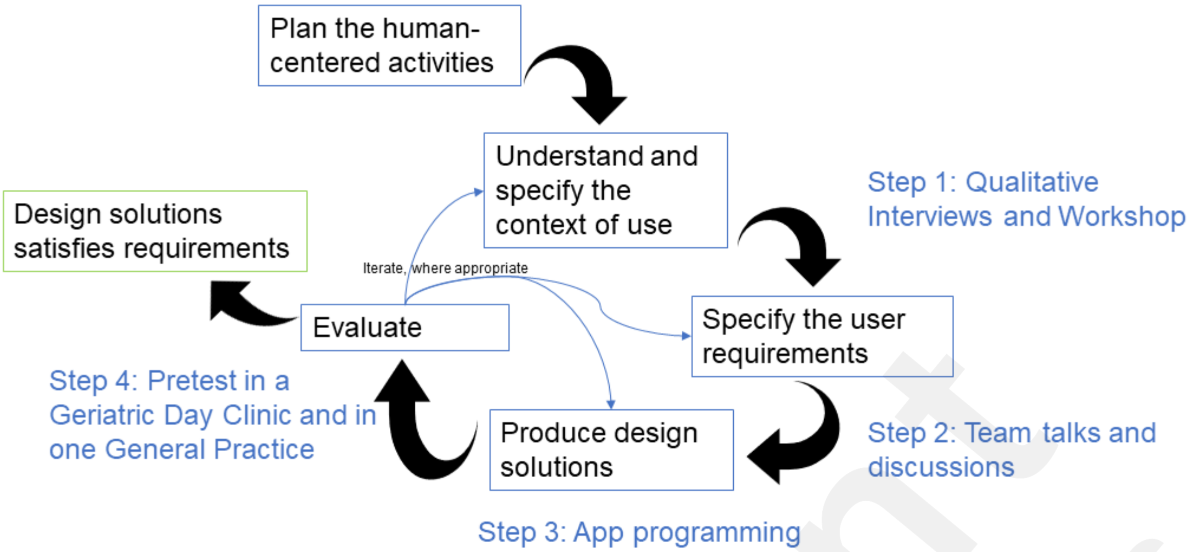

Figure 1: Interdependence of human center design, adapted

Process and data collection

The current DemTab project and the application development process build upon the foundation laid by the previous project PflegeTab. PflegeTab was a tablet-based intervention designed to engage nursing home residents with dementia, with the aim of enhancing their Quality of Life and addressing behavioral symptoms (23). The PflegeTab App consisted of various adaptive tablet applications tailored to cognitive, functional, and emotional self-regulation abilities. Leveraging this prior work, the primary objective of the DemTab project was to expand upon this application, creating a comprehensive platform for the outpatient care of dementia. In addition to features for PwD, the DemTab application also incorporated additional functionalities specifically designed for GPs and informal caregivers (18, 24).

In the initial phase of app development, Two GPs from Berlin, one with expertise in technology approaches in primary care and the other operating in rural areas, both with experience in dementia primary care, were interviewed alongside one managing director of the Alzheimer's Association Berlin, responsible for providing consultations and support to PwD and their relatives. These participants were selected based on their valuable insights and were directly approached by the researchers. A semi-structured interview guide was collaboratively developed by the research team.

The interviewees were prompted to discuss key aspects of medical and social needs for PwD and their informal caregivers, as well as the role of technical support systems in practice. The objective was to gain a deeper understanding of the potential benefits of a tablet-based application for PwD, their caregivers, and GPs. The interviews were transcribed in full, and content analysis was conducted following the methodology outlined by Kuckartz (25), utilizing the MAXQDA 2018 software (26) for data analysis.

For the expert workshop, the researchers extended invitations to two practicing GPs in Berlin, two advisors from a support organization based in Berlin offering voluntary assistance for PwD, and one researcher from the Institute of General Medicine at Charité - Universitätsmedizin Berlin. The workshop was held in September 2018, with participants selected based on their expertise and directly approached by the researchers. While three GPs were initially invited, one was unable to attend. The workshop commenced with a presentation outlining the DemTab project study, followed by participants testing version 0.5 of the app and engaging in a focused group discussion. This discussion included a presentation of the results pertaining to the four app functions: dementia guideline, data representation, messaging, and games. Additionally, all workshop attendees completed a questionnaire detailing their personal information and their respective contexts of working with PwD and their informal caregivers.

Following the workshop, members of the research team also completed a brief written survey to capture immediate reflections. The survey comprised three questions: 1) How did you perceive the workshop? 2) Which app features or discussion topics were quickly dismissed? and 3) What topics were extensively discussed?

(Figure 1, step 2), team talks and discussions, as well as mutual agreements between researchers from the ISMR and the QULab, were integral. Bi-weekly team meetings were held throughout the development period, following a structured procedure: The QULab presented new feature increments, the ISMR researchers assessed it, and all team members engaged in discussions regarding the user-friendliness of the tool, potential changes and additions, informed by insights from interviews and the expert workshop. Central questions included: What valuable knowledge

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from the previous project PflegeTab should inform our approach? What insights from qualitative interviews and workshops should shape specific app functions? How can we enhance the implementation of the application in real-world settings? What technical features can feasibly be implemented within the timeframe and how? Additionally, a pretest (Figure 1, step 4) of the DemTab-App (version 0.5) was conducted in a geriatric day clinic in Berlin, PwD and staff utilized the application for seven days. Furthermore, the application was tested once by a GP who provided feedback and recommendations on content and visualization.

Results

The principal results are presented following the steps shown in Figure 1.

First step: Preparation. Interviews and workshop findings

The results of the three interviews can be summarized into three main categories: 1) "General Practitioners", 2) "Technology", and 3) "Relatives and Caregivers".

Category "General Practitioners": It was evident that GPs play a crucial role in the comprehensive care of individuals living with dementia and their families. Serving as primary care providers, they are trusted figures who facilitate communication and serve as intermediaries. GPs also act as hubs for interdisciplinary and sectoral information sharing. It was emphasized that collegial exchanges with specialists and collaboration with family members are vital for ensuring comprehensive home-based care. Moreover, there was a call for increased utilization of dementia-specific advisory and support services. One GP highlighted the need for quick access to reliable information, noting the impracticality of consulting extensive guidelines on short notice. One GP described the following factors influencing care: *“Accessing fast, secure information is essential; however, it's impractical to review all the extensive guidelines on short notice. “ (1- 205)*

Category “Technique”: GPs emphasized the importance of having concise, practical, and filtered information to ensure guideline-oriented treatment and cooperative specialist care. They suggested that data collected in the app should be prioritized and presented graphically for easy comprehension. GPs stressed the significance of choice and self-determination in using the tablet, as well as decisions regarding its functionality. They also advocated for greater integration and

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networking to facilitate the sharing of information on available assistance and support services. Additionally, there were concerns about the potential for relatives to inadvertently overload the technical application, particularly with communication functions, which could inadvertently burden GPs. One GP also commented on potential future technologies: *"The advantage of video calling is being able to see the person; that adds a different level compared to just talking." (2- 130)*

Category "Relatives and caregivers": Thirdly, relatives and caregivers play a significant and multifaceted role in the care of PwD at home. Family caregiving occurs under diverse circumstances and can be accompanied by significant stress. Consequently, family members of PwD require guidance on medical, psychosocial, and legal matters, as well as access to support services aimed at alleviating stress and fostering social connections tailored to their individual situations and needs. Empowering individuals to help themselves and enhancing their ability to act independently are recognized as crucial objectives. As illustrated by the following quote: "*The psychosocial counseling of relatives, aiming to empower them to help themselves and to raise awareness of their own competencies." (8- 15)* Conclusively, caregivers should be actively engaged in diagnostic and therapeutic processes.

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The workshop results encompass information within two primary categories: 1) "Perceptions and Associations", which encompass experiences and concerns, and 2) "Desires and Proposals", which include considerations regarding data content, visualization, and innovative ideas. The principal findings and examples are detailed in Figure 2.

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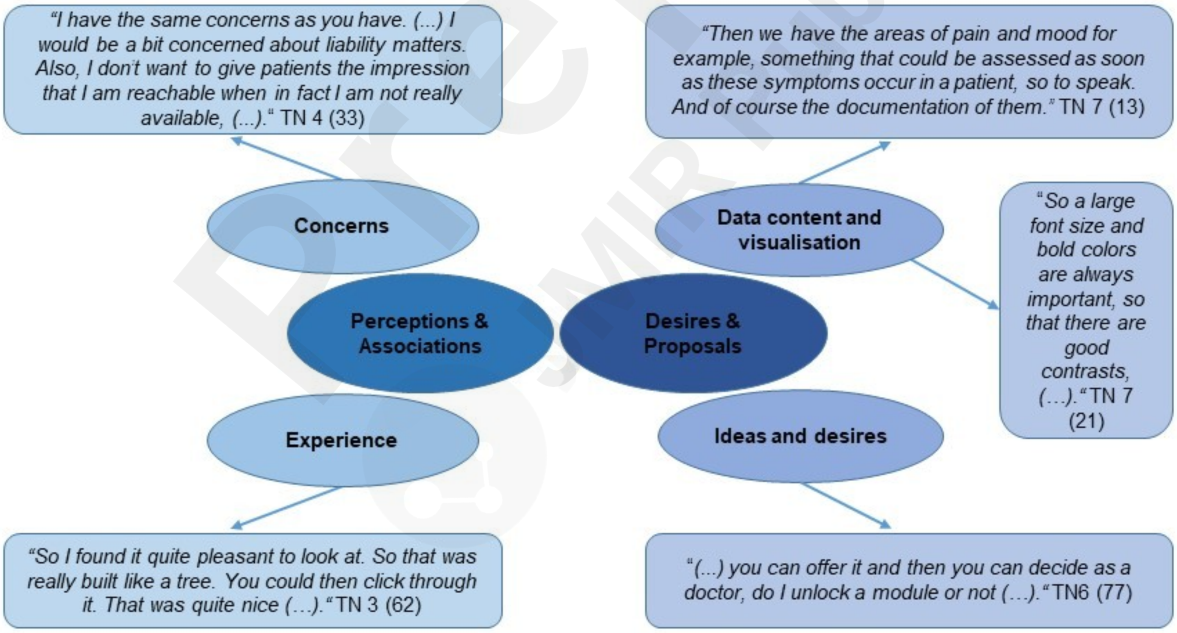

Figure 2: Main and subcategories of the workshop with examples

Second and third step: App development. Accompanying team talks and discussions

The outcomes of the second step represent the culmination of frequent interdisciplinary team discussions, which are deemed as the core of app development. During these team deliberations, in conjunction with the findings of qualitative content analyses, the team concentrated on the study interests and objectives, feasibility, and implementation of content, as well as presentation styles, considering time and resource constraints.

The discussions were marked by their vibrant and emotionally charged nature, especially when deliberating the development of the app's features. This negotiation of feature development emerged as the primary focus within the team and was carried out in an interdisciplinary manner. For instance, decisions regarding medical content originated from the ISMR, while those concerning technical aspects were made by the QULab.

A substantial portion of the discussions drew upon insights gathered from interviews and workshops. For instance, based on these insights, the team opted to incorporate ten questions related to the "state of health" that PwD, with or without the assistance of their caregivers, should respond to at least weekly. These questions centered on daily activities such as wellbeing, hydration, and sleep patterns. Formulated by the IMSR team, these questions aimed to furnish GPs with valuable health information and were crafted to be easily comprehensible and answerable by individuals.

The fourth step: App Testing. Feedback and finalization

The pretest occurred in a geriatric day clinic, involving PwD, a social worker, physicians, and one GP who had previously participated in interviews and the workshop. They provided comprehensive feedback on individual sub-apps, focusing on aspects such as user-friendliness, effects on PwD and themselves, identification of missing or redundant content, and suggestions for useful additions. Given the constraints of the tight project schedule and limited financial resources, discussions on prioritization and timelines were significant. Throughout the development process, there was a consistent emphasis on ensuring good usability and an appealing presentation style.

Discussion

The findings can be summarized as follows: GPs and relatives bear primary responsibility for the treatment and care of PwD. They harbor specific desires and proposals concerning supportive

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assistive technologies. Interdisciplinary discussions are essential to address these needs and develop a practical tablet application. The primary objective of this paper was to delineate the process and the multi- and partial interdisciplinary approach in the development of an application aimed at enhancing primary care for PwD and their caregivers.

In conclusion, the present paper yields various results and implications. Firstly, the paper highlights the significant contribution of individuals with diverse disciplinary and professional backgrounds in the development of supportive technical healthcare applications. In addition to researchers from various disciplines, professionals working in different domains of dementia care provided invaluable insights into care aspects for PwD and their family caregivers. These experts should be integrated into the development process as specialists possessing implicit knowledge and contributory expertise (27), as well as experts in local knowledge to leverage the potentials and mitigate the risks of such a study project (28). It is essential for potential users and beneficiaries of the application to be involved from the outset of the development process (19).

We chose to interview employees of Alzheimer's Societies Association instead of individual PwD and their caregivers. While this approach does not replace the deep, individual perceptions and experiences of affected individuals and their caregivers, it allowed us to gather consolidated information and comprehensive insights accumulated over years of work. Moreover, factors such as time constraints, personal resources, and the challenges of accessing interviewees influenced this decision. While much is known about the progressive and multifaceted challenges and needs of PwD, the healthcare system, professional care institutions, and society still fall short in providing full-time emotional and practical support for PwD, their caregivers, and their GPs (1). Additionally, there remains ambiguity surrounding technical solutions (11).

The participation of GPs and employees from Alzheimer's Societies provided practical insights from healthcare providers engaged in daily interactions with PwD and their caregivers. They shared professional experiences and highlighted daily challenges and needs for improvement. This collaborative process can enhance the acceptance and utilization of the application (19).

Secondly, the process of developing a health app underscores the necessity of multidisciplinary

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(MD) and interdisciplinary (ID) teamwork. It's crucial to differentiate between intermittent MD, characterized by juxtaposed disciplinary work, and ID teamwork, which entails proactive, interactive collaboration (29). However, both MD and ID teamwork entail a circular scientific endeavor in social care research and involve a process of social negotiation. Effective collaboration involves not only managing co-working due to separate work locations, formal team meetings, and the exchange of information and data but also engaging in discussions and informal team meetings to address preferences, relevancies, and disagreements. Given that each scientific discipline possesses its own specific domain, concepts, and methodologies, multiple constraints and barriers between different disciplines must be dismantled and integrated (30). Successful MD and ID teamwork necessitates openness to the knowledge, structures, and practices of other disciplines (31) while consistently advocating for one's own discipline. Continuous communication and compromise solutions are essential requirements for effective collaboration (19).

Thirdly, future generations are expected to rely more heavily on technical applications for various aspects of life, including healthcare (32). Therefore, it is crucial to examine and delve into the development of technical tools, even though the current older generation may not be as technologically savvy as today's adults and youth. However, it is anticipated that the usage and acceptance of digital technologies will grow in the future (32).

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Conclusion

This paper underscores the necessity of multiple perspectives, including scientific, clinical, and technical, to ensure the high-quality development of supportive healthcare apps. The content and design of such apps for GPs, PwD, and their caregivers must be informed by the expertise and experiences of various professional disciplines involved in healthcare provision and the utilization of such apps in real healthcare settings. Therefore, multidisciplinary and interdisciplinary collaboration is indispensable in the realm of healthcare-supporting apps. Medical disciplines, social sciences, technical expertise, and supporting organizations are all essential to integrate relevant knowledge and competencies into the design and development of useful products, facilitating daily use and active support for healthcare needs. Furthermore, such development processes require a spiral approach and feedback loops, as well as professional and emotional critical discussions, to reach consensus and make informed decisions.

Authors' contributions

JS was the primary contributor to data analysis, data interpretation, and manuscript drafting. SL, JLO, JNVA, and RS assisted with writing and interpreting findings. JN and JNVA designed and led the DemTab study in which the present study was embedded. All authors contributed to the present study and critically revised and approved the final manuscript.

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We utilized the generative AI tool ChatGPT 3.5 by OpenAI* to correct and improve the English language. The original ChatGPT transcripts are provided as Multimedia Appendix.

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Conflicts of interests

none declared

Declarations

Ethics approval and consent to participate

Ethical approval was obtained by the ethics committee of the Charité – Universitätsmedizin Berlin (EA1/085/19). Written informed consent was obtained from all participants or legal guardians prior to data collection.

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Consent for publication

Not applicable

Availability of data and materials

Data is stored in a non-publicly available repository. Data are however available from the corresponding author on request.

Authors' information (optional)

Not applicable

Abbreviations

cRCT	cluster randomized trial
GP	general practitioner
PwD	people with dementia
MD	multidisciplinary
ID	interdisciplinary

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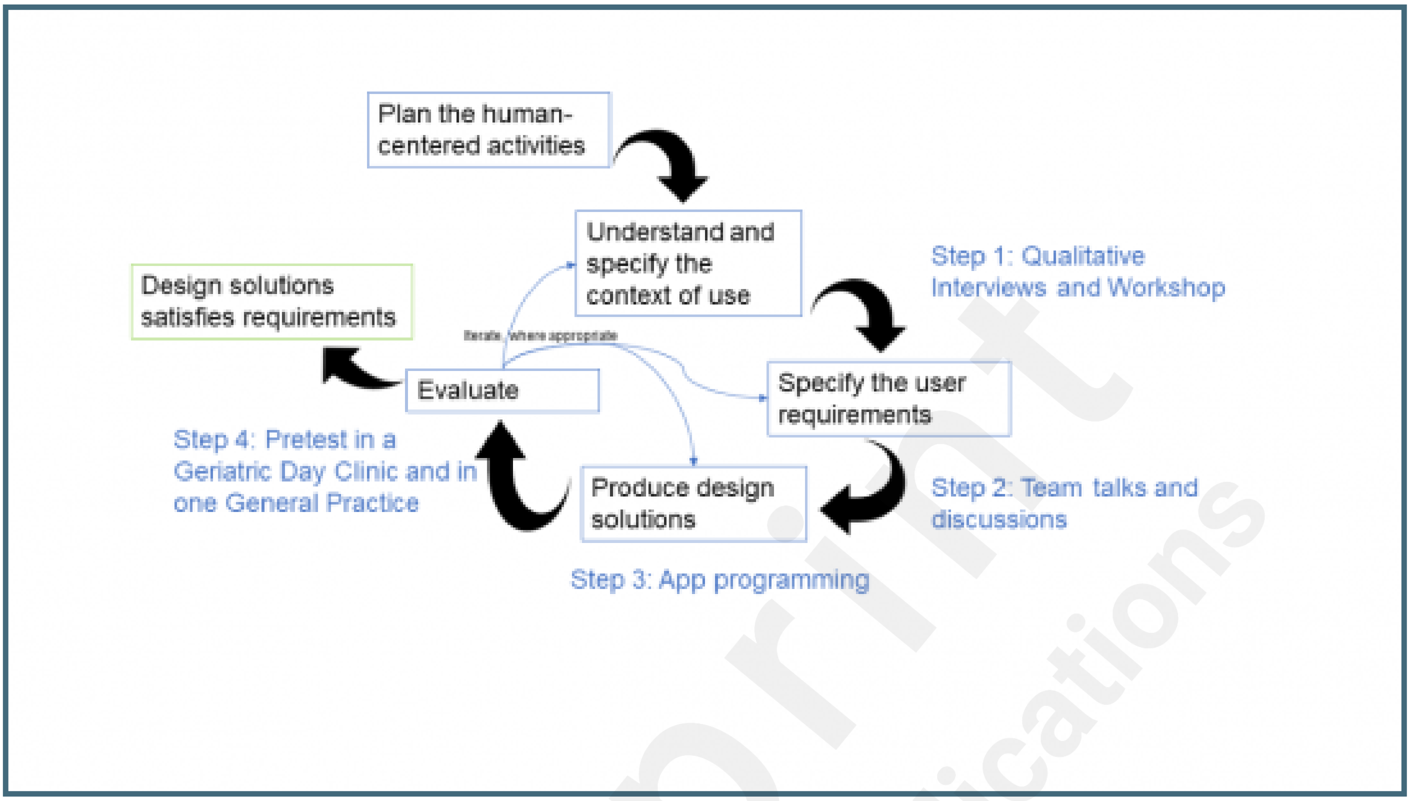
Interdependence of human center design, adapted.



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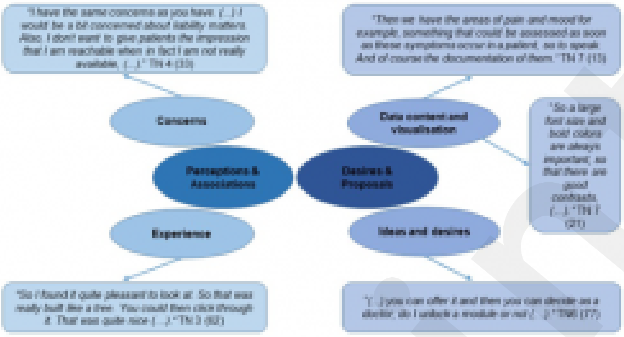
Main and subcategories of the workshop with examples.



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Multimedia Appendixes

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