# Identifying unmet needs of dementia caregivers in clinical practice: A user-centered development of a digital assessment

Olga A. Klein, Jochen René Thyrian, Melanie Boekholt, Matthias Lindner, Wolfgang Hoffmann, Stefan J. Teipel, Ingo Kilimann

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# *Table of Contents*

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## Abstract

**Background:** Despite the increasing interventions to support family caregivers of people with dementia, service planning and delivery is still not effective.

**Objective:** Our aim was therefore to develop a digitally supported needs assessment for family caregivers of people with dementia that is feasible, time-efficient, understood by users, and can be self-completed in the primary care setting.

**Methods:** The development of the unmet needs assessment was part of a cluster-randomised, controlled trial examining the effectiveness of a digitally supported care management programme to reduce unmet needs of family caregivers of people with dementia (GAIN) and was conducted in three phases. Using an iterative participatory approach with caregivers, healthcare professionals including general practitioners, neurologists, psychologists, psychiatrists, nurses, and Alzheimer Society representatives, we developed a digital self-completion unmet needs assessment focusing on caregivers' biopsychosocial health und quality of life in connection to their caregiver responsibilities. Data were collected via group discussions, written feedback, protocols, think-aloud protocols, and interviews, and analysed thematically.

**Results:** Data from informal caregivers (n=18), healthcare professionals and Alzheimer Society representatives (n=9) were collected. Thematic analysis identified two main themes: Content of the assessment and usability/handling of the digital tablet-based assessment. The feedback provided by the stakeholders led to new aspects and changes of the assessment to make it comprehensive, easy to read and to handle. The overall completion time was reduced from initial 37 to 18 minutes, which renders the assessment fit to be self-completed in waiting rooms of primary care practices or other settings.

**Conclusions:** The input of the three stakeholder groups has supported the development of the assessment ensuring that all aspects considered important were covered and understood and the completion of the assessment was time-efficient and practically feasible. Further validation of the assessment will be performed with the data generated as part of the GAIN trial. Clinical Trial: ClinicalTrials.gov NCT04037501.

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# Original Manuscript

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## DEVELOPMENT OF A DIGITAL UNMET NEEDS ASSESSMENT

# Abstract

**Background and Objectives**
Despite the increasing interventions to support family caregivers of people with dementia, service planning and delivery is still not effective. Our goal was therefore to develop a digitally supported needs assessment for family caregivers of people with dementia that is feasible, time-efficient, understood by users, and can be self-completed in the primary care setting.

**Research Design and Methods**
The development of the unmet needs assessment was part of a cluster-randomised, controlled trial examining the effectiveness of a digitally supported care management programme to reduce unmet needs of family caregivers of people with dementia (GAIN) and was conducted in three phases. Using an iterative participatory approach with caregivers, healthcare professionals including general practitioners, neurologists, psychologists, psychiatrists, nurses, and Alzheimer Society representatives, we developed a digital self-completion unmet needs assessment focusing on caregivers' biopsychosocial health und quality of life in connection to their caregiver responsibilities. Data were collected via group discussions, written feedback, protocols, think-aloud protocols, and interviews, and analysed thematically.

**Results**
Data from informal caregivers (n=18), healthcare professionals and Alzheimer Society representatives (n=9) were collected. Thematic analysis identified two main themes: Content of the assessment and usability/handling of the digital tablet-based assessment. The feedback provided by the stakeholders led to new aspects and changes of the assessment to make it comprehensive, easy to read and to handle. The overall completion time was reduced from initial 37 to 18 minutes, which renders the assessment fit to be self-completed in waiting rooms of primary care practices or other settings.

**Discussion and Implications**
The input of the three stakeholder groups has supported the development of the assessment ensuring that all aspects considered important were covered and understood and the completion of the assessment was time-efficient and practically feasible. Further validation of the assessment will be performed with the data generated as part of the GAIN trial.

**Keywords**

Unmet needs, Assessment development, Family caregivers of people with dementia, Caregiver health, Dementia

# Introduction

The World Health Organization (WHO) estimates 55 million people living with dementia worldwide with an increase to 78 million by 2030 (WHO, 2021). In Germany, approximately two-thirds of the 1.8 million people with dementia (PwD) are cared for at home by an informal caregiver, most often a relative (Blotenberg, Hoffmann, & Thyrian, 2023). Numerous studies have shown that caring for a relative with dementia is associated with a multitude of time- and resource-intensive challenges (Michalowsky et al., 2016; Schulz & Martire, 2004; Zwingmann et al., 2018). Emotional stress, social isolation, depression, and financial burden are among the negative consequences that dementia family caregivers have reported (Baiyewu et al., 2003; Brodaty & Donkin, 2009; Marin et al., 2003; Murray, Schneider, Banerjee, & Mann, 1999; Schneider, Murray, Banerjee, & Mann, 1999). To alleviate these consequences, interventions for the reduction of caregivers' burden have been developed (Berwig et al., 2017; Lök & Bademli, 2017; Shata, Amin, El-Kady, & Abu-Nazel, 2017; Williams, Moghaddam, Ramsden, & De Boos, 2019), such as telephone-based as well as multi-component psychosocial and individualized support programmes (Berwig et al., 2017; Shata et al., 2017). With the growing consensus that caregiver support is an integral part of the care of patients with dementia, there was also an increase in interventions to support caregivers (Williams et al., 2019). However, each caregiver situation is different and requires an individual set of interventions. Individualised interventions are still under-used in care practice as they require time and dementia-specific expertise that is often lacking in primary care. A systematic and comprehensive yet individualised unmet needs assessment would be useful for healthcare professionals (HPs) to better plan services and interventions in clinical settings as it would flag areas where the individual caregiver needs support.

In a mixed methods study, Stirling and colleagues (2010) used Bradshaw's taxonomy of need (Bradshaw & Care, 1972) to explore the relationship between different types of caregiver service need. Bradshaw (Bradshaw & Care, 1972) defined categories of need as measures of professionally identified carer burden (normative need), service use (expressed need), carer's stated need (felt need) and the comparison of groups using services with groups who do not (comparative need). It is argued that no single measure of the above needs is likely to capture all carer's unmet needs. In the light of person-centred care, the normative need has been increasingly challenged as paternalistic and inappropriate (Meaney, Croke, & Kirby, 2005; Stirling et al., 2010).

Therefore, a focus on caregivers' stated need (felt need) as well as service use (expressed need) would be an appropriate starting point to consider for an unmet needs assessment. An individualised, digitally supported self-assessment can aid in the efficient identification of health and support areas that should be addressed from the perspective of the caregivers. This allows collaborative intervention planning and reduces the risk of a paternalistic doctor-patient relationship (Asadi-Lari, Tamburini, & Gray, 2004). If a digital system is to truly ensure collaborative service planning, the digital assessments must be developed with the participation of the users themselves.

The direct input of family caregivers and other stakeholders into the content, structure, and handling of the digital assessment system provides crucial feedback regarding its content validity as well as comprehensiveness and technical usability. Through a greater level of involvement of stakeholders, healthcare services can be improved and be more applicable in real-world clinical settings and facilitate implementation (Seidel, Quasdorf, Haberstroh, &

Thyrian, 2022). A systematic review of instruments used to assess the needs of family dementia caregivers identified 36 instruments that were described in detail or in part in the 70 publications included (Novais, Dauphinot, Krolak-Salmon, & Mouchoux, 2017). The authors reported that only one instrument was partially validated to assess the needs of dementia caregivers, namely, the Carer's Needs Assessment for Dementia (CNA-D), a semi-structured interview not intended for clinical use with a completion time of about one hour. For conceptual clarity, researchers recommended establishing a theoretical model or framework to organize the diverse needs of family dementia caregivers (Kipfer & Pihet, 2020). In addition, researchers argue that a focus on the detection of changes in family caregivers' needs throughout disease progression is important (Bressan, Visintini, & Palese, 2020; Novais et al., 2017).

Therefore, the aim of the present study was to develop a digital unmet needs assessment that can be used in primary care settings. We conducted the study in collaboration with caregivers and other stakeholders. Our objectives were to (1) create a user-friendly and family dementia caregiver specific digitally supported assessment; (2) to develop an assessment that is understandable and comprehensive yet time-efficient; (3) to create an assessment that can be used at multiple locations such as GP offices and memory clinic waiting rooms. For this, a tablet computer was deemed most appropriate to serve as digital device due to its size, weight, flexibility, and ease of handling. Based on a previous study on the use of a tablet-based digital expert system (Thyrian et al., 2012; Thyrian, Hertel, et al., 2017; Thyrian, Winter, et al., 2017), we had taken several decisions on the hardware basis of our system before the participatory part of our study started. The content and usability aspects, however, were developed together with future users.

# Methods

The development of the assessment was embedded in a randomised controlled intervention trial examining the effectiveness of a digitally supported care management intervention for family caregivers. The trial was supported by the Federal Joint Committee (G-BA) – Innovation Fund (Gemeinsamer Bundesausschuss/Innovationsausschuss). The funding code (FKZ) is 01VSF18030). Ethical approval has been obtained from the Ethical Committee of the University Medicine Greifswald (Registry number BB 120/2019) and the Ethical Committee of the Rostock University Medical Center (Registry number A2020/0013).

## Participants

We involved individuals from three stakeholder groups, namely, family dementia caregivers, healthcare professionals (general practitioners, neurologists, psychiatrists, psychologists and nurses), and Alzheimer Society representatives. We approached healthcare professionals (HPs) of a medical university and memory clinic staff as well as Alzheimer Society representatives and asked for their feedback (phase 1). Family dementia caregivers who were visiting a memory clinic with their relative/friend with dementia were asked whether they would like to provide feedback on the paper-based version of the assessment regarding the content, clarity and comprehensiveness (phase 2) as well as the usability of the digital version of the assessment as a self-completion assessment on a PC-tablet (phase 3). No further demographic data were collected.

## Procedure

We used an iterative user-centered participatory approach with three phases. Previously used questionnaires (Mansfield, Boyes, Bryant, & Sanson-Fisher, 2017; Novais et al., 2017; Wancata et al., 2005) assessing unmet needs and care interventions from previous dementia care management studies (Dreier-Wolfgramm et al., 2017; Dreier, Thyrian, Eichler, & Hoffmann, 2016; Eichler et al., 2016; Thyrian et al., 2012; Thyrian, Hertel, et al., 2017; Thyrian, Winter, et al., 2017; Zwingmann et al., 2018; Zwingmann et al., 2019) in Germany were used as starting point.

In phase 1, the authors developed a list of previously used questionnaires assessing unmet needs in family dementia caregivers as well as a list of available care interventions offered in Germany. The selection of questionnaires was based on a comprehensive review of the literature covering the databases OVID, Medline, and PsycInfo searching for unmet needs, caregiver needs assessments and family dementia caregivers. With respect to available care interventions, we used work from previous dementia care management studies (4, 29-35) offering a list of interventions to family dementia caregivers in Germany. We used Germany-based intervention studies as these are health care system specific. Criteria for the inclusion of questionnaires were the content they covered (e.g., quality of life, psychosocial factors, health-related domains), their previous use in research and interventions, and their completion time. We also considered questionnaires based on either their recommendation by the EU Joint Programme in Neurodegenerative Research (JPND) Working Group on Longitudinal Cohorts or common use in larger German trials such as IDemUck (35), DelpHi-MV (17, 18, 22), intersec-CM (23), or DemNet-D (36). These questionnaires are validated and allowed comparison with German and international studies. The authors then further discussed these selections in meetings, tested five separate versions of a possible unmet needs assessment and checked whether items would cover interventions offered as part of the dementia care management conducted in previous primary care studies (Thyrian et al., 2016; Thyrian et al., 2012; Thyrian, Hertel, et al., 2017; Zülke et al., 2019; Zwingmann et al., 2018). With this approach, we wanted to ensure that the operationalization of problem-centered needs were connected to available services within the German healthcare system and could therefore be addressed in this framework accordingly.

The authors selected different assessment versions aiming to cover all biopsychosocial aspects and compared different scales for caregiver burden, for instance (e.g., Zarit Burden Interview, ZBI vs the Berlin inventory of the burden on relatives, BIZA-D). The need items were then compared and matched with the list of caregiver interventions from previous studies– these were marked according to a match or no match. This allowed the calculation of percentages of "items covered" from the dementia caregiver intervention list for each version of questionnaires. The five versions of combinations of questionnaires were checked by three authors/researchers for plausibility. The results of this item-intervention matching process were used to identify which versions covered most unmet needs with matched possible interventions. These are shown in Table 1.

**Table 1**

*Selection of Questionnaires for the Unmet Needs Assessment*

| | Version 1 | Version 2 | Version 3 | Version 4 | Version 5 |
|---|---|---|---|---|---|
| | Personal caregiving situation | Personal caregiving situation | Personal caregiving situation | Personal caregiving situation | Personal caregiving situation |
| | Questionnaire for the Use of Medical and Non-Medical Services | Questionnaire for the Use of Medical and Non-Medical Services in Old Age (FIMA) (Seidl et al., 2015) | Camberwell Assessment of Need for the Elderly (CANE) | Camberwell Assessment of Need for the Elderly | Healthy Aging Brain Care (HABC) |

| | | | | | |
|---|---|---|---|---|---|
| | in Old Age (FIMA) (Seidl et al., 2015) | | (Reynolds et al., 2000; Stein et al., 2016) | (CANE) (Reynolds et al., 2000; Stein et al., 2016) | Monitor – Caregiver Version (Monahan, Alder, Khan, Stump, & Boustani, 2014) |
| | Caregiver unmet resource needs scale (King, Hartke, Lee, & Raad, 2013) | Caregiver unmet resource needs scale (King et al., 2013) | Health-related quality of life (EQ-5D-5L) ("EuroQol - a new facility for the measurement of health-related quality of life," 1990) | The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) (Oliveira, Vass, & Aubeeluck, 2018) | The Dementia Quality of Life Scale for Older Family Carers (DQoL-OC) (Oliveira et al., 2018) |
| | Health-related quality of life (EQ-5D-5L) ("EuroQol - a new facility for the measurement of health-related quality of life," 1990) | Health-related quality of life (EQ-5D-5L) ("EuroQol - a new facility for the measurement of health-related quality of life," 1990) | Zarit Burden Interview (ZBI) (Hébert, Bravo, & Préville, 2000) | - | Zarit Burden Interview (ZBI) (Hébert et al., 2000) |
| | Zarit Burden Interview (ZBI) (Hébert et al., 2000) | The Berlin inventory of the burden on relatives - dementia (BIZA-D) – Module 3 (Zank, Schacke, & Leipold, 2006) | Lubben Social Network Scale (LSNS) (Lubben et al., 2006) | - | - |
| | Lubben Social Network Scale (LSNS) (Lubben et al., 2006) | The Berlin inventory of the burden on relatives - dementia (BIZA-D) – Module 5 (Zank et al., 2006) | - | - | - |
| | - | The Berlin inventory of the burden on relatives - dementia (BIZA-D) – Module 6 (Zank et al., 2006) | - | - | - |
| Proportion of match with family dementia caregiver interventions (in %) | 47% | 17% | 96% | 94% | 39% |

Versions 3 and 4 covered most items whereas versions 1, 2 and 5 covered less than 50% of the dementia specific items. The two versions covering most unmet needs were then presented and discussed at an advisory board meeting with input from healthcare professionals (e.g., neurologists, psychiatrists, psychologists and nurses) and Alzheimer Society representatives. Meeting minutes were recorded of all points raised and discussed. This input was used to select the final version of the assessment.

In phase 2, the chosen assessment version covering most unmet needs was tested in a memory clinic. The authors approached family dementia caregivers in a memory clinic to provide feedback and suggestions on a paper-based version of the assessment. The changes were primarily focused on the CANE questionnaire as well as the demographic and caregiver specific questions as these were items that could still be adapted. Caregivers who were interested in contributing were given a short version comprising 7 questions of the CANE questionnaire. Together with a researcher, they were asked to read the questions and share their thoughts with respect to each question and their understanding thereof. The researcher noted the caregivers' comments and thoughts in a think-aloud protocol. The focus was on comprehension, words/sentence structure, answer options, descriptions, and additional comments. In the second round, both caregivers and healthcare professionals were approached to provide feedback on the whole printed version of the assessment. Those who agreed to provide feedback were asked to mock-complete the assessment and write down their notes and questions. In this round, caregivers and healthcare professionals were asked to measure the time needed to complete the assessment. We provided written questions such as "Are the questions clear and easy to understand?"; "Where did you encounter problems when completing the assessment?"; "Did you have issues understanding the questions?"; "Are there questions or areas that should be in the assessment but are currently missing?" Based on the feedback received, the first draft of the assessment was modified resulting in a second draft. When adapting the first draft, our focus was on the assessment being clear and easy to understand for family caregivers in terms of the way questions are phrased. Based on the feedback we received, several parts of the assessment were adapted, resulting in the final draft.

In phase 3, a digitalised tablet-based version of the final version of the assessment was tested for its technical usability. In this phase, we asked both caregivers and healthcare professionals to test the digital assessment with a focus on the handling of the tablet. Data was collected through interviews and think-aloud protocols. Caregivers in a memory clinic were asked to complete the digital assessment in the waiting room and share their thoughts and comments with a study nurse or researcher who protocolled the comments. Similarly, healthcare professionals of a medical university and a memory clinic were asked to complete the digital assessment and write down feedback on the handling and any possible bugs or problems they noticed while testing the digital system.

### Analysis

All data collected through written feedback, protocols, think-aloud protocols, and interviews were analysed thematically following the steps by Braun and Clarke (2006). The 6 phases involved (1) familiarizing ourselves with the data, (2) generating initial codes, (3) constructing themes, (4) reviewing themes, (5) defining and naming themes, and (6) producing the report (Braun & Clarke, 2006).

## Results

Results of the development of the assessment of the 3 phases are divided in the subsections presented below. The process of phases 2 and 3 was iterative comprising several rounds through which we collected feedback, made changes based on feedback received and then moved to the next round of collecting feedback.

### Participants

Twenty-seven family caregivers of people with dementia (n=18), healthcare professionals (n=7) and Alzheimer Society representatives (n=2) participated. Among the healthcare professionals were general practitioners, neurologists, psychologists, psychiatrists, and nurses. The caregivers’ mean age was 57 years (range: 35-88) and 9 (50%) were women. The healthcare professionals’ and representatives’ mean age was 41 (range: 28-50) and 6 (67%) were women. As this was a participatory approach, no further demographic data were collected.

Phase 1: Structure and content of the assessment

After the input from the advisory board including neurologists, psychiatrists, psychologists, nurses and Alzheimer Society representatives, the final structure of the assessment was selected. It was the one with the highest percentage of matches between problem-centered needs and the associated interventions (96%, Version 3, see Table 1).

The unmet needs assessment comprised several validated questionnaires with a total of 57 questions examining a person’s self-reported demographic information, use of medical and non-medical services, unmet needs (Camberwell Assessment of Need for the Elderly, CANE), health-related quality of life (EQ-5D-5L), caregiver burden (Zarit Burden Interview, ZBI), and social support (Lubben Social Network Scale, LSNS). It can be completed using a digital version or a paper based version. In total, the assessment covers 51 health and support related aspects.

Domains covered by the unmet needs assessment are the following:

(i) Health and care
(ii) Employment
(iii) Information and knowledge
(iv) Emotional support
(v) Social support
(vi) Caregiver burden

The structure of the unmet needs assessment can be seen in Table 2.

**Table 2**

*Structure of the Unmet Needs Assessment*

| Instrument | Domain |
|---|---|
| Socio-demographic information | |
| Caregiver specific information | Individual situation of caregiver |
| Camberwell Assessment of Need for the Elderly (CANE) | Unmet needs I – Information, physical, mental |
| EQ-5D-5L | Health-related quality of life |
| Lubben Social Network Scale (LSNS) | Unmet needs II – Social network |
| Zarit Burden Interview (ZBI) | Unmet needs III – Caregiver burden |

The number of unmet needs addressed the participants’ medical needs, home care needs, psychosocial needs, and needs connected to the caregiver role. This needs assessment included selected parts of the Camberwell Assessment of Need for the Elderly (CANE) (26, 27).

Health-related quality of life was assessed using the EQ-5D-5L (28, 29). This instrument comprises five dimensions: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension has five levels varying from no problems to extreme problems. Each level corresponds to a 1-digit number that expresses the level selected for that dimension ranging from 1 to 5 with higher numbers indicating more severe problems. The digits for the five dimensions can be transferred into an overall score that describes the participant's health-related quality of life. It also contains a vertical visual analogue scale, the EQ VAS, with endpoints that are labelled 'Best imaginable health state' and 'Worst imaginable health state'. The VAS reflects the patient's own judgement and can be used as a quantitative measure of health outcome.

Social support was assessed using the Lubben Social Network Scale (LSNS-6) (31). This scale is a self-report measure of social engagement including contact to and interaction with family and friends on a six-item scale. Total scores range from 0 to 30 with an equally weighted sum of the six items. The family and friends subscales include questions regarding the number of friends and family one has regular contact with as well as their availability for help and support in private matters (32). High scores indicate strong social networks.

Informal caregiver burden was assessed using the 7-item version of the Zarit-Burden Interview (ZBI-7). The short version ZBI is a caregiver self-report measure to examine burden which is associated with functional/behavioural impairments in the social, psychological and physiological context and home care situation (30). It contains seven items using a 5-point scale. Response options range from 0 (Never) to 4 (Nearly/Always). Total scores range from 0 indicating no burden to 28 indicating severe burden.

Phases 2 and 3: Feedback received on the assessment

**Themes**

Two main themes were derived from the analysis: (1) Content of the assessment and (2) digital tablet usability for the assessment. Each theme had further sub-themes and sub-theme categories and were divided in either caregivers or healthcare professionals and Alzheimer Society representatives as these groups had different areas they paid special attention to. Almost all sub-themes had one to 3 sub-theme categories shown in Table 3.

*(1) Content of the assessment*

Regarding the assessment's content, caregivers provided information on four sub-themes regarding the (1.1.) comprehension, (1.2) assessment structure, (1.3) reduction of completion time, and (1.4) areas important to them.

1.1 Comprehension (Caregiver perspective)

Regarding the clarity of the assessment to them, caregivers commented on the simplification of questions and answer options. Instead of "This is an unmet need" or "This is a need met" (as suggested in the CANE) they preferred to answer "Yes" or "No", for instance. They also commented on being sometimes confused whether a question was referring to themselves or to the person diagnosed with dementia indicating that questions had to be framed specifically.

1.2 Assessment structure (Caregiver perspective)

Regarding the assessment's structure, caregivers commented that multiple questions in a table format were confusing. In addition, some commented that they would like to self-identify the areas where they needed help rather than having professionals assume that they needed help or support in an area, which was incorporated into the assessment by first asking whether there is a problem in a specific area and secondly asking whether the respondent receives enough help with respect to this problem. A yes – no response to these questions would then indicate the presence or absence of an unmet need.

1.3 Reduction of completion time (Caregiver perspective)

The majority of caregivers commented on the length of the initial versions of the assessment and reported that they became a bit tired towards the end of the assessment. One caregiver stated: *“For the last few questions my focus was a bit lost.”* (caregiver, woman)

1.4 Areas important to caregivers (Caregiver perspective)

Caregivers commented on some of the areas that they found particularly important such as psychological support, mobility, social life and psychoeducation.

One caregiver stated: *“I would say that there should be a question for psychological support. Self-help groups should be offered locally and it should be asked whether advice or support is needed in this regard. Another thing that I would still find important is to ask how mobile you are and whether you need help in this regard. For example, I don't have a car and have to use public transport to get everywhere. And there are also people who don't even have a driver's license. And if you have to go somewhere and have to pick up things from the pharmacy (e.g., incontinence pads), these are sometimes large packages that are also heavy and you have to get them home first. It would be a good idea to ask whether you need help in this regard.”* (caregiver, woman)

Another caregiver reported: *“The social life is very important, my father is hardly involved in it anymore. Because of his swallowing problems, he can no longer even go to a restaurant, which is difficult.”* (caregiver, man)

Another one stated: *“Since we have not yet come into contact with services, I would like a lot of information so that you know what you have to do. And also so that you know why behavior changes, how people then think and what is going on inside you. I'd be very interested in that.”* (caregiver, man)

Regarding the (1) content of the assessment, healthcare professionals and Alzheimer Society representatives provided information on two sub-themes, namely, (1.1) assessment structure and (1.2) reduction of completion time.

1.1 Assessment structure (HPs and Alzheimer Society representatives)

Healthcare professionals and Alzheimer Society representatives considered the order of instruments within the assessment and argued that the instrument covering most unmet needs (CANE) should be moved to the front to prevent that important healthcare domains received less attention due to fatigue.

They also reported that the caregivers’ own health as well as factors influencing their health due to their caregiver role should be a focus since a caregiver’s unmet needs can arise from two sources: either from the personal needs of the family caregiver or from his or her care responsibilities for the PwD.

1.2 Reduction of completion time (HPs and Alzheimer Society representatives)

Regarding the reduction of completion time, the goal was to cover as many as necessary and as few as possible areas. Avoiding duplicate questions across instruments was important to reduce the length of the assessment, which was a crucial aspect to consider as time is of the essence in clinical practice. We also made technical adaptations to the questionnaire which would skip follow-up questions if participants clicked that they do not have a problem in this specific area. The average completion time of the assessment was reduced from 37 minutes to about 18 minutes.

(2) *Digital tablet usability of the assessment*

Regarding the assessment's tablet usability, caregivers, healthcare professionals and Alzheimer Society representatives identified two sub-themes, namely, (2.1) simple layout and (2.2) handling with slightly different sub-theme categories.

### 2.1. Simple layout

Caregivers commented on the font size, often taking out their reading glasses to be able to read the questions.

Healthcare professionals commented that one question per screen would allow the large font and button size needed. Some clinicians stated that it would be helpful to allow caregivers to go back within the assessment in case they changed their mind regarding a previous answer. Going forward should only be possible if the question on the screen was completed. The majority of healthcare professionals stated that an indication bar within the assessment would be helpful for caregivers to receive information on their progress as well as how much of the assessment is still in front of them.

### 2.2 Handling

The majority of caregivers reported that selecting answers via clicking worked well after adjustments were made to the font size and the size of the answer option buttons. Regarding the handling, all healthcare professionals and Alzheimer Society representatives agreed that the selection of answers should be as straight forward as possible allowing caregivers to complete the assessment without technical issues.

The adaptations made to the digital tablet-based assessment are shown in Figure 1 and Figure 2. Figure 1 shows the initial, first version of the tablet-based assessment. Figure 2 shows the final tablet-based assessment version after the feedback was incorporated into the development by the IT team.

After completion, the outcome of the assessment can be viewed by the study nurse as well as the GP. These professionals can then use the outcome to work together with the caregiver toward a reduction of the unmet needs identified. The study nurses provide the caregivers with a summary of the consultation where points discussed are listed.

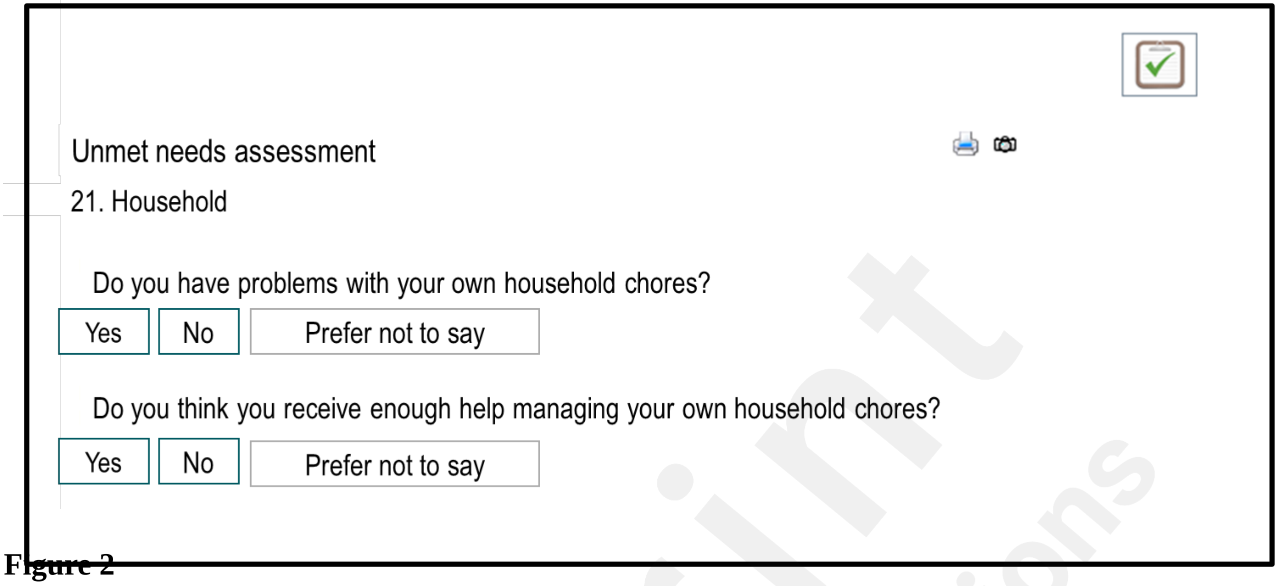
Figure 3 depicts a caregiver filling out the digital version of the assessment on a tablet.

**Table 3** *Themes, Sub-themes and Sub-theme Categories*

| Theme | Sub-theme | Sub-theme category |
|---|---|---|
| | **Caregivers** | |
| 1. Content of the assessment | 1.1 Comprehension | 1.1.1 Simplification of questions |
| | | 1.1.2 Simplification of answer options |
| | | 1.1.3 Separate questions for caregiver health and caregiver care responsibilities in relation to the person with dementia |
| | 1.2 Assessment structure | 1.2.1 No multiple questions in a table |
| | | 1.2.2 Questions whether help is needed in a specific domain for clear identification of unmet needs |
| | 1.3 Reduction of completion time | 1.3.1 Fatigue |
| | 1.4 Areas important to caregivers | |
| | **Healthcare professionals** | |
| | 1.1 Assessment structure | 1.1.1 Order of instruments |
| | | 1.1.2 Focus on caregivers' health and care responsibilities |
| | 1.2 Reduction of completion time | 1.2.1 Avoiding duplicate questions across instruments |
| | **Caregivers** | |
| 2. Digital tablet usability of the assessment | 2.1 Simple layout | 2.1.1 Large font and buttons |
| | 2.2 Handling | 2.2.1 Manual answer selection |
| | **Healthcare professionals** | |
| | 2.1 Simple layout | 2.1.1 One question per screen |
| | | 2.1.2 Option to go back and forth within the assessment |
| | | 2.1.3 Progression bar |
| | 2.2 Handling | |

**Figure 1**

*Outline of the First Digital Assessment Version*



Unmet needs assessment

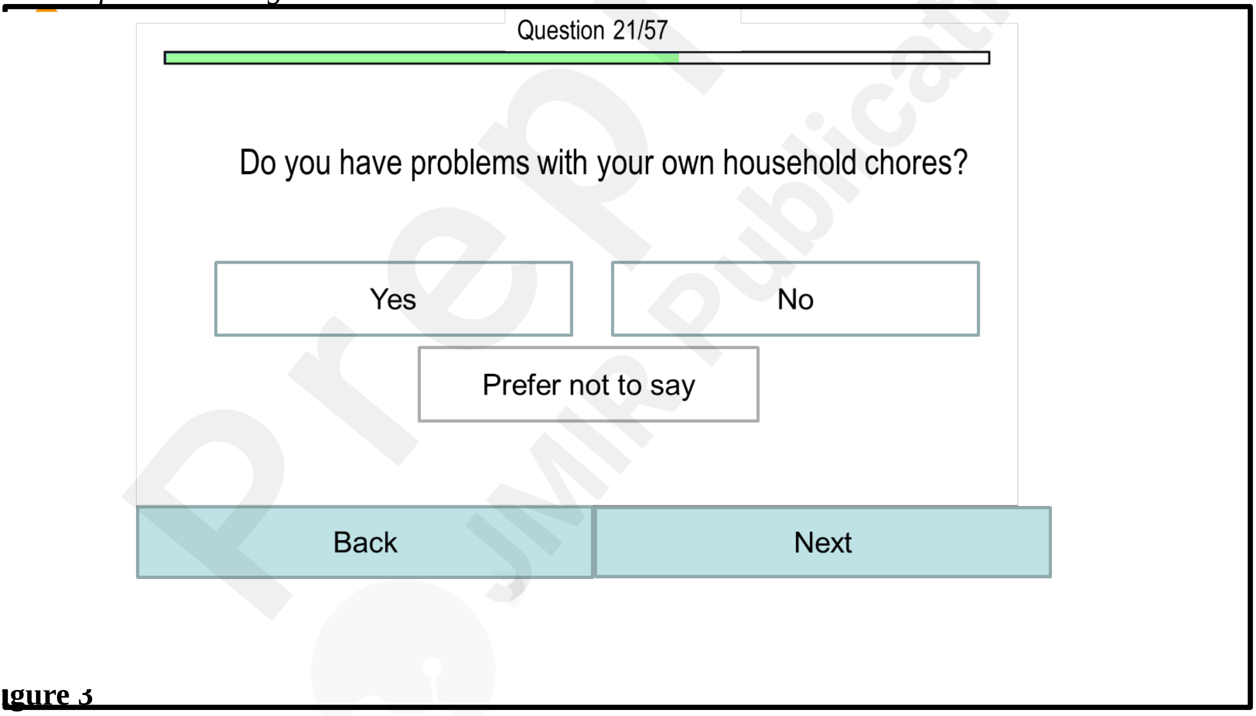
21. Household

Do you have problems with your own household chores?

Do you think you receive enough help managing your own household chores?

**Figure 2**

*Outline of the Final Digital Assessment Version*

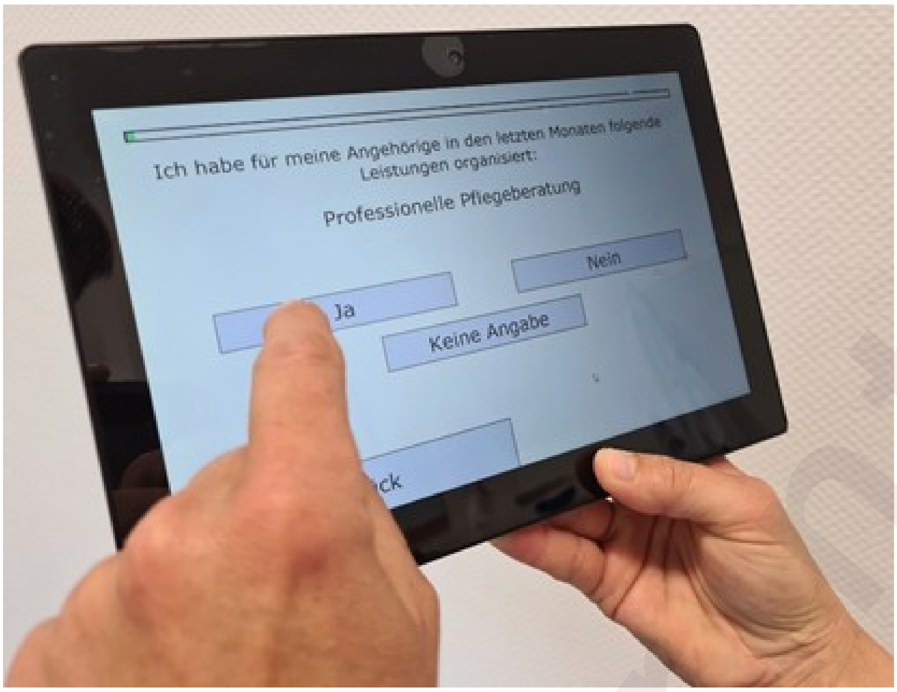


Question 21/57

Do you have problems with your own household chores?

**Figure 3**

*A Caregiver Completing the Digital Tablet Based Assessment*



Ich habe für meine Angehörige in den letzten Monaten folgende Leistungen organisiert:

Professionelle Pflegeberatung

## Discussion

This article describes the phases of an iterative, participatory process we used to develop a digital tablet-based assessment designed to comprehensively identify the needs of caregivers of people with dementia in clinical practice. Through the collaboration with family dementia caregivers, healthcare professionals, and Alzheimer Society representatives, we developed a digital unmet needs assessment that consists of a set of standardised instruments but also includes additional questions and adaptations that were incorporated along the iterative development process. The unmet needs assessment focuses on needs that can arise from two sources: either from the personal needs of the family caregiver or from the care responsibilities for the PwD. With contribution of caregivers and other stakeholders, we designed an assessment that covers a comprehensive range of needs considered important. At the same time, with the input of the stakeholders, the time to complete the assessment was substantially reduced from initial 37 to 18 minutes. This indicates that we reached our goal of developing a comprehensive, feasible and time-efficient assessment device.
With respect to the content of the assessment, we identified important aspects regarding clarity, assessment structure, the reduction of completion time as well as content areas important to caregivers. We took the feedback in multiple rounds and incorporated changes along the way. Similar approaches have been conducted successfully by other research teams developing assistive technologies to support self-management of people with dementia (Øksnebjerg et al., 2020).

Regarding the digital tablet-based assessment, we could incorporate crucial aspects regarding the layout and the handling of the tablet. The difference between our first digital assessment version compared with the final digital assessment version illustrates the importance of involving multiple perspectives, especially of those for whom the assessment or technology is intended. In the literature, there is an increase of studies involving patients and stakeholders in the development or testing of technology (Hettinga, Boer, Goldberg, & Moelaert, 2009;

Øksnebjerg et al., 2020; van de Vijver et al., 2022).

The participatory approach allowed us to incorporate aspects into the development of the digital assessment that we, as researchers, would have missed otherwise as can be seen in the first digital tablet-based assessment version in Figure 1 when compared to the final version in Figure 2. The input of caregivers, healthcare professionals, and Alzheimer Society representatives has broadened our perspective and has given us important hints and advice towards aspects that are important for a digital, self-completion unmet needs assessment. They identified questions that were unclear, suggested possible answer options, and gave us ideas on how to simplify the navigation throughout the assessment. Some researchers have used similar procedures for the development of instruments to assess patients' needs (Reynolds et al., 2000; Wancata et al., 2005) or to facilitate implementation (Seidel et al., 2022). A review by Fischer and colleagues (2020) reports on the importance of user involvement, particularly the involvement of older adults in technology design. In their review of 40 empirical studies published between 2014 and 2018, these authors examined the consequences of involving older adults in technology design and stated that learning, adjusted design and improved sense of participation were outcomes frequently stated in studies (Fischer et al., 2020). Not only did they report that involvement facilitated learning about the needs of older adults (Johnson and colleagues 2014, Pollmann et al., 2018, Nielsen et al., 2018) but it also led to the generation of new technology ideas such as a companion robot (Leong and Johnston, 2016), for instance, which was not in the researchers' mind before involving older adults. Newly gained insights then lead to iterative adjustments of the prototype design (Fischer et al., 2020) (Le et al., 2014, Chevalier et al., 2018, Wallisch et al., 2018, Guo et al., 2016). This was also the process that we followed making adjustments to the unmet needs assessment. With respect to the quality of technology developed with user involvement, Kopeć and colleagues (2018) noticed that the overall quality of the technology could be improved. They argued that teams who involved users to develop a mobile application were rated higher by an independent jury in a competition than teams who did not. Lastly, Fischer and colleagues (Fischer et al., 2020) report that older adults appreciated the sense of participation and felt that they were being treated as experts on their own lives and equal partners (Maaß & Buchmüller, 2018). Researchers reported that involved users enjoyed their experience and some users described their involvement as “happy memories” (Eftering and Frennert, 2016, Lee and colleagues, 2017, Alaoui and colleagues, 2014).

In contrast to already existing unmet needs assessments, our digital assessment identifies a caregiver's self-reported unmet needs and ties them directly to interventions most of which are offered within the German healthcare system. Through the matching process of possible unmet needs with interventions in phase 1 of our assessment development process, we aimed to overcome the pitfalls of identifying problem-centered needs without having support services to meet them at hand. In addition, the digital assessment acknowledges the intertwined nature of the dyad, namely the caregiver and the person with dementia focusing on not only the health and support needs of the caregiver but also the caregiver's care responsibilities. Although we did not include the CNA-D, we did compare the content and ensured that no important aspect was missed in the assessment.

## Limitations

The stakeholders who contributed to the development of the assessment were a convenience sample. We have asked caregivers, healthcare professionals and Alzheimer Society representatives who either visited a memory clinic with their significant other, worked at the memory clinic or who were already known to us due to previous collaborations. Moreover, the sample is limited to people living in a specific region in Northern Germany (Mecklenburg-Western Pomerania). In addition, our level of involvement was limited to stakeholders sharing their feedback on the assessment, which is a lower level of involvement (Arnstein, 1969). The notion to find rather lower levels of involvement in studies was also highlighted by Fischer and colleagues (Fischer et al., 2020) arguing for further research on the actual practices of user involvement in dementia research. For future projects, a higher level of involvement is sought, especially since current results indicate that an elaborated, theory-based participatory approach including people with dementia, caregivers and regional stakeholders might raise the chances of successful implementation in routine care (Seidel et al., 2022).

## Declarations

### Ethics approval and consent to participate

The study is conducted in accordance with the criteria (valid at present) of the Declaration of Helsinki, the ICH-guidelines for Good Clinical Practice, the Memorandum for Safeguarding Good Scientific Practice (German Research Foundation/DFG), and the International Ethical Guidelines for Biomedical Research Involving Human Subjects (CIOMS/WHO).

Ethical approval has been obtained from the Ethical Committee of the University Medicine Greifswald (Registry number BB 120/2019) and the Ethical Committee of the University Medicine Rostock (Registry number A2020/0013). The trial is registered at ClinicalTrials.gov (NCT04037501).

### Availability of data and material

There is no plan to provide public access to the data collected as part of this trial. Researchers who request the full protocol and/or the dataset may be granted access to anonymised data.

### Competing interests

The authors declare that they have no competing interests.

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### Authors’ contributions

Each author has made substantial contributions to this work, has approved the submitted version and has agreed both to be personally accountable for their own contributions and to ensure that questions related to the accuracy or integrity of any part of the work, even ones in which the author was not personally involved, are appropriately investigated, resolved, and the resolution documented in the literature.

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## List of Abbreviations

**CMS:** Care Management System
**cRCT:** Cluster Randomised Controlled Trial
**DelpHi-MV:** Dementia: life- and person-centered help in Mecklenburg-Western Pomerania
**DCM:** Data Monitoring Committee
**EQ-5D:** EuroQol- 5 Dimension
**FIMA:** Questionnaire for the Use of Medical and Non-Medical Services in Old Age
**GP:** General Practitioner/General Physician
**ICER:** Incremental-Cost-Effectives-Ration
**ITT:** Intention-to-treat
**JPND:** EU Joint Programme in Neurodegenerative Research
**LSNS:** Lubben Social Network Scale
**PwD:** People with Dementia
**QALY**: Quality-Adjusted-Life-Years
**RUD:** Resource Utilisation in Dementia
**ZBI:** Zarit-Burden Inventory