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DESKK Study - Development and testing of a dementia-specific respite care concept with a mobility and counselling programme: study protocol

Steffen Heinrich,[1,2,3] Christoph Cavazzini,[1,3] Bernhard Holle[1,3]

¹German Center for Neurodegenerative Diseases, Witten site, Germany
²FHS St. Gallen - University of Applied Science, Institute of Applied Nursing Science, Switzerland
³Department of Health, School of Nursing, Witten/Herdecke University, Witten, Germany

Correspondence to
Dr Steffen Heinrich;
steffen.heinrich1@gmail.com

ABSTRACT

Introduction Specific mobility programmes can delay functional decline in people with dementia (PwD). Family caregivers (FCs) can be relieved from care-related burden by counselling services. Respite care is a short-term inpatient care service (1–8 weeks of stay). Respite care centres (RCCs) can function as support structures for dementia care arrangements through caring-based mobility training of PwD and counselling sessions for their FCs. However, no systematic mobility or counselling programmes exist in this setting in Germany or the rest of the world. The aim of the development and testing of a dementia-specific respite care concept (DESKK) study is the development and testing of an evidence-based mobility and counselling programme for PwD and their FCs that is suitable for the respite care setting.

Methods and analysis A pilot-based, quasi-experimental evaluation study will be conducted in a specialised RCC for PwD. To evaluate the acceptance and usability of the development and testing of a DESKK concept, qualitative data will be collected from the RCC staff and FCs via semistandardised interviews. Quantitative data will be collected using instruments to assess effect tendencies of the concept related to mobility (PwD) and burden (FCs). Furthermore, a mixed-methods triangulation approach will be conducted.

Ethics and dissemination The protocol, informed consent and accompanying material given to patients were submitted by the investigator to the Ethical Review Committee of the German Society of Nursing Science. The project was examined and finally approved on 31 January 2017 (Number: 16–27). Prior to obtaining written consent for study participation, information must be given to all of the study participants in verbal and written form. The results of the study will be presented at national and international conferences and published in peer-reviewed journals. After the concept is finalised, a practice-friendly manual will be developed in which implementation components are described for other RCCs.

Trial registration number NCT03578861

INTRODUCTION
Background

Around the world, family caregivers (FCs) play the most important role in caring for people with dementia (PwD) at home.[1]

Strengths and limitations of this study

► The study intervention is the first systematic approach that combines a mobility programme specifically for people with dementia (PwDs) with a counselling programme for family caregivers (FCs) in the respite care setting.

► The mobility and counselling intervention consists of modules than can be combined to enable a programme adaptation based on individual resources and preferences of the PwDs and FCs using objective assessments.

► The counselling and mobility programme can be carried out by nurses without further support from other health professionals (eg, physiotherapists).

► The study design will not provide a deep understanding of intervention effects but primarily of the feasibility and acceptance of the intervention for the intended setting.

In 2015, approximately 47 million people worldwide suffered from dementia, and this number is expected to increase to 75 million by 2030.[2] In Germany, the number of PwD in 2016 was approximately 1.7 million, with an expected growth of up to 2.1 million by 2030.[3] Some common symptoms of dementia include progressive and frequent memory loss, as well as confusion, personality change and apathy. Furthermore, the abilities to walk and stand become weaker because of balance dysfunctions,[4] and these symptoms lead to a loss of the ability to perform everyday tasks[5] and an increased risk for falling[6] among PwD. This home-based caring often leads to high burden for FCs,[7] which can destroy the stability of care arrangements at home and can lead to a transfer of PwD to long-term care, even though most PwD wish to stay at home if possible.[8]

Internationally, respite care describes different services to support FCs in their home care situation. These services are focused on different groups, such as children

or adults with special needs, and are based on different settings and working structures, for example, in-home services, out-of-home services, volunteer-based services and payment services.[9] There are also respite care centres (RCCs) with the primary aim of supporting and thereby stabilising home care arrangements for PwD and their FCs.[10] In this paper, respite care was performed by a short-term inpatient service centre specialised for PwD, where they can stay for approximately 1–8 weeks. During this time, the FCs can recover and experience relief of burden. A Cochrane review noted that there is a high demand for mobility-based rehabilitation programmes for PwD, with significant positive effects related to mobility-based activities of daily living (ADL), such as the use of cutlery, climbing stairs or walking.[11]

RCCs have the potential to support PwD through individually tailored mobility programmes. In Germany, the number of care dependents in RCCs has increased from 8545 (1999) to 24 000 (2015).[12] However, there are no existing evaluated or standardised mobility programmes that support PwD in the RCC setting.[13] This lack of programmes represents a particular problem because an increasing number of RCC residents are affected by cognitive impairments or dementia.[1] Regarding FCs, professional dementia-specific counselling services have positive effects on the psychological and psychosomatic symptoms of FCs, enabling them to better cope with stress and manage behavioural disturbances.[14] RCCs can reach FCs when they come to the RCC; these caregivers are often not reachable by other dementia support services because FCs are overburdened, and thus, have limited time resources.[15] These FCs have an especially strong need for counselling sessions about dementia and related support services.[16] Specific, individually tailored RCC concepts for PwD (mobility) and their FCs (counselling) could focus on the special needs of PwD and their FCs to provide effective assistance.

Study aims and research questions

The primary aim of the development and testing of a dementia-specific respite care concept (DESKK) study is for mobility (PwD) and counselling (FCs). A process evaluation will be conducted to analyse/evaluate the usability and integration of the RCC multicomponent concept in daily care routines. An explorative outcome evaluation will be performed to discuss the effect tendencies of the dementia-specific concept focused on RCC staff, PwD and FCs. The study was performed by the German Center for Neurodegenerative Diseases (DZNE) in Witten, Germany. To achieve these study aims, the following research questions will be answered:

1. What types of intervention components and RCC structures/processes are relevant for the development of a dementia-specific RCC concept focused on an ADL-based mobility programme for PwD and a counselling programme for FCs?
2. How can the DESKK mobility and counselling programme be integrated in daily routines that are suit-

able for the respite care setting, and how is the concept relevance and its usability rated by caring staff?
3. What outcome changes to mobility (PwD) and burden (FCs) occur during the DESKK mobility and counselling intervention?
4. How is the DESKK concept subjectively rated by FCs, and what changes related to mobility (PwD) and burden (FCs) take place after the stay at the RCC (follow-up)?

Setting

The study will be performed in the RCC nursing ward with ten rooms for PwD at the St. Antonius dementia-specific facility in Paderborn (North Rhine-Westphalia in Germany). This RCC already uses structures that are focused on the special needs of PwD. For example, this barrier-free RCC uses oval-arranged floors when possible for PwD to walk without getting lost. Furthermore, there are no visual barriers (eg, different colours) on the ground that could be irritating for PwD. A circadian light system simulates the course of daylight on sunny days to facilitate physical activity and a good day–night rhythm. A special sensory garden supports the cognition and activation processes of PwD. A basic counselling process for FCs and normal care activation procedures for PwD have already been established in this RCC before the start of the DESKK study. However, these actions are not performed systematically, either evidence based or protocolled. Thereby, the current processes are also hard to evaluate related to their usability, suitability or impact.

Inclusion criteria

Only dyads of PwD and their FC will be included in the DESKK intervention to have the opportunity to analyse the potential effects of the mobility and counselling programme related to the ADL level of PwD and the care-related burden of FCs. The RCC staff will be recruited or proposed by the centre management. The PwD and FCs will be recruited by the RCC staff using the following inclusion criteria.

Family caregivers
► Willingness to take part in the counselling intervention (informed consent) and the study.
► Possession of sufficient language skills to understand the counselling sessions.
► Acting as the primary caregiver for a PwD.

People with dementia
► Willingness to take part in the mobility programme (informed consent (if necessary, signed by the primary caregiver)).
  Every PwD will be informed as best as possible by a specially schooled nurse and with the help of an adapted informed consent with easy language. The willingness to participate will be re-evaluated during the intervention by the method of ongoing consent.[17]
► Ability to understand and follow training instructions with the support of the involved training assessors

(subjective basic preassessment by raters (special educated dementia care nurses)).

► Ability to stand and walk short distances (minimum 3 m) with the support of the involved training assessors.

► Participation in a minimum 2-week stay in the RCC (planned).

If a PwD or his/her FC is excluded, the whole dyad will be defined as excluded. Nevertheless, the PwD or FCs will still be able to participate in the offered intervention within their mental and physical capacities. The exclusion will take place only in reference to the scientific study data collection and use. This approach allows the realisation of a maximally inclusive design for FCs and PwD.

RCC staff

► Willingness to take part in the DESKK study (informed consent).

► Possession of suitable German language skills.

Sample

The number of involved dyads (PwD and their FC) will be determined by the number of available and suitable participants during the overall intervention time (11 months) and the individual intervention time for the dyads within the RCC. There is a maximum of 10 places for PwD in this RCC at one time. Approximately 50% of PwD stay 2 weeks or longer in the RCC, which is one of the inclusion criteria. It is estimated that approximately 80% of these residents will meet the remaining inclusion criteria. A drop-out rate of 10% is estimated. Therefore, n=30 dyads is a realistic recruitment aim for this study.

METHODS
Study design

DESKK is a quasi-experimental feasibility study that includes a process evaluation. The used data sources and data collection/analysis methods to investigate the research questions in detail are shown in table 1.

Development of the intervention

Before the development phase, a comprehensive literature search was carried out via the MEDLINE and Google Scholar databases. The current state of knowledge about suitable mobility programmes for PwD and counselling programmes for FCs was extracted; in addition, information was sought on valid instruments that are suitable for assessing the mobility level of PwD and the counselling demands of FCs caring for PWD. Unaddressed counselling needs on the subject of dementia and relief offers are associated with FCs' burden, which can destabilise the home-based care situation.[18 19] Thereby, a search was conducted for valid instruments designed to assess the burden and knowledge of FCs, and these assessments were modified to fit the DESKK counselling programme (see 'Intervention components and

data collection—Counselling programme'). Figure 1 displays the literature inclusion process, and the full search protocol can be viewed in online supplementary appendix 1 . During the development phase of the DESKK mobility and counselling programme, four workshops with four external scientists and eight practice experts (RCC staff of St. Antonius) were conducted. The scientists were requested by three German universities and were specifically selected for their expertise on the topics of mobility and counselling. The gained feedback of the practice experts and the scientists will be analysed by selective logging. Thereby, the protocolled text gets aggregated based on determined content definitions for a systematic extraction of the desired information.[20]

Intervention period

Figure 2 shows the individual intervention period, data collection times and instruments that will be used in the DESKK mobility and counselling programme. The overall DESKK intervention period will be 10 months, and the individual intervention time for every included PwD in the mobility programme will be 2–4 weeks at the RCC and thereby 6–8 weeks including the follow-up data collection at home. The data collection will end on 20 September 2018. Because of the variable time, the PwD will be assessed after 2 weeks (t1—inclusion criteria) and after every additional week. This method allows more details about changes over time to be collected in comparison with a single t0–t1 data collection approach. The counselling intervention will be performed one time in the RCC. We will collect follow-up data from the PwD and their FC 4 weeks after the intervention period and after the PwD has returned home.

Intervention components: general
Staff training

The RCC staff will be trained to conduct the concept elements in two different training sessions before the intervention begins. One session will focus on the mobility programme, and the other will focus on the counselling programme. The training will include guidance for the RCC staff on how to use the assessments and how to conduct the concept in practice. The training is intended to last 8 hours, including a practice section and a theoretical section.

DESKK initial assessment

This document will be filled out by the FC together with a staff nurse during the first visit to the RCC. The document serves as a care planning instrument in which the PwDs' preferences are integrated (eg, food preferences or medication, mobility preferences). For the DESKK study, preferred counselling topics of the FC will be addressed to prepare for the counselling session. Among other questions, the FC will be asked about the current or former mobility-based preferences of the PwD so that they can be considered in the compilation of the specific exercises. Preferences about counselling topics will be integrated

Table 1 Data collection/analysis related to the research questions

Research question	Data source	Responsibility	Theoretical basis	Data collection procedure	Analysis method
1. What types of intervention components and RCC structures/processes are relevant for the development of a dementia-specific RCC concept focused on an ADL-based mobility programme for PwD and a counselling programme for FCs?	Literature (Database search [PubMed/Google Scholar]) +Information material from the RCC	DZNE Witten	Search protocol	Systematic literature search related to suitable mobility and counselling programmes for PwD/FCs +validated assessments for the measurement of mobility (PwD) and counselling	Followed the PRISMA statement
	Expert workshops	DZNE Witten	Structured protocolling	Workshops with experts for counselling and mobility programmes for PwD and caring relatives (non-respite care) to obtain feedback on the developed DESKK programme components	Selective logging based on Mayring*
2. How can the DESKK mobility and counselling programme be integrated in daily routines that are suitable for the respite care setting, and how are the concept relevance and its usability rated by caring staff?	Interviews +quantitative questionnaires	DZNE Witten	CFIR	Systematic interviews about the development and process evaluation aspects + quantitative feedback questionnaire on the implementation aspects	Descriptive analysis + structured content analysis
3. What outcome changes to mobility (PwD) and burden (FCs) occur during the DESKK mobility and counselling intervention?	Quantitative data of the DESKK mobility and counselling assessments	RCC DZNE Witten	Data triangulation model (Creswell)	Data collection by the mobility and counselling assessments	Descriptive analysis
4. How is the DESKK concept subjectively rated by FCs, and what changes related to mobility (PwD) and burden (FCs) take place after the stay at the RCC (follow-up)?	+Interviews +quantitative questionnaires	DZNE Witten (At the home of PwD and FCs)	CFIR + data triangulation model (Creswell)	Data collection by the mobility and counselling assessments + systematic interviews with FCs about aspects of the process evaluation + quantitative feedback questionnaire about ratings of the suitability of the DESKK concept	Descriptive analysis + structured content analysis

*Mayring: Qualitative Sozialforschung. Weinheim und Basel: Beltz.

ADL, activities of daily living; CFIR, Consolidated Framework for Implementation Research; DESKK, development and testing of a dementia-specific respite care concept; DZNE, German Center for Neurodegenerative Diseases; FCs, family caregivers; PRISMA, Preferred Reporting Items for Systematic Reviews and Meta-Analyses; PwD, people with dementia; RCC, respite care centres.
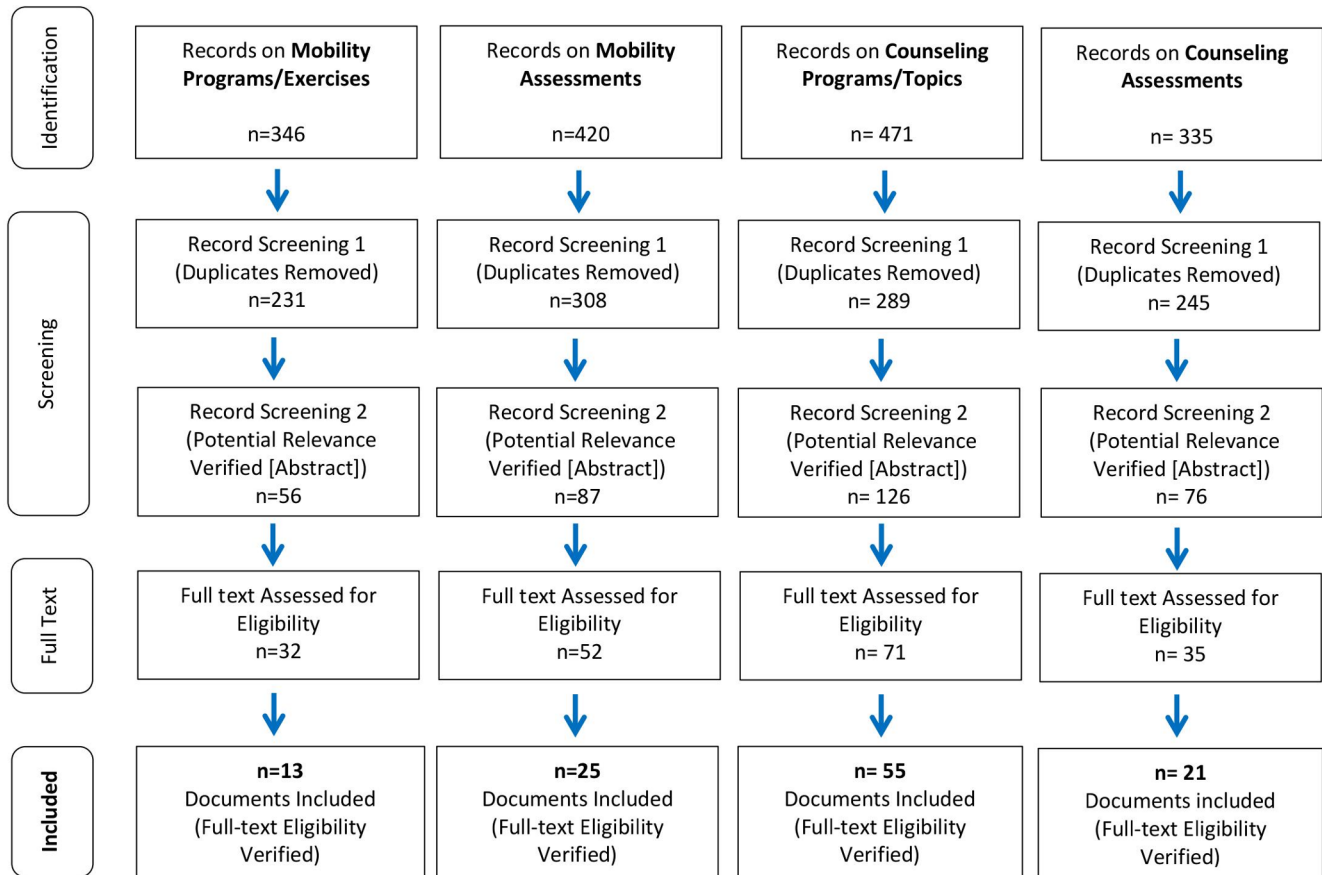
Figure 1 Flow chart of the DESKK literature search (PubMed+Google Scholar). DESKK, development and testing of a dementia-specific respite care concept.

into the preparation of the counselling programme for the FC.

Intervention components and data collection: mobility programme

The DESKK mobility programme is based on the existing daily structure of the RCC, which has two slots each day for activities related to physical activation (1.5 hours before noon and 1.5 hours after noon). The programme will structure these activities based on specific developed exercises that are focused on the individual mobility level of the PwD and his/her mobility preferences, which are solicited during the initial assessment.

DESKK mobility assessment battery

To assess the mobility level of PwD, an assessment battery will be used, which consists of criterion-validated instruments for the functional analysis of the lower and upper extremities. The DESKK assessment battery includes cut-off scores and related recommendations for staff regarding which exercises should be selected for a certain PwD. These cut-off scores were developed based on the literature regarding the used assessments.[21–24] For this reason, the assessment scores for seniors with 'weak' physical abilities were used as reference cut-off scores in the DESKK mobility assessment. Weak was defined as the weakest third of the tested sample related to the

functional abilities of the tested areas in the group of individuals who were 80 years or older. Scores under the cut-off thresholds were rated as 0, and scores above these levels were rated as 1. A score of 0 implies that training for that specific tested area is obligatory, and 1 implies that physical training for that area is optional. The DESKK mobility assessment battery will be used to compile the exercises for the PwD and to simultaneously collect scientific data as part of the outcome evaluation. The mobility assessment consists of four assessments:

Short physical performance battery

The short physical performance battery (SPPB) can be used to analyse the ADL-related abilities of elderly people related to gait performance, strength and static balance.[25] This test is also used for people with cognitive decline. The instrument is valid and reliable for community dwelling older adults, analysed by different systematic reviews,[26 27] and it has a good inter-rater reliability for PwD, analysed as a subgroup (n=24 PwD (69–97 years]) in a cross-sectional study with an intraclass coefficient (ICC) of 0.84 for its summary score and ICCs ranging from 0.74 to 0.96 in its subtests.[28]

Box and blocks test

The bx and blocks test (BBT) can be used to assess rough coordination skills related to the upper extremities, arms

Intervention Process and Data Collection Points	Instruments Used
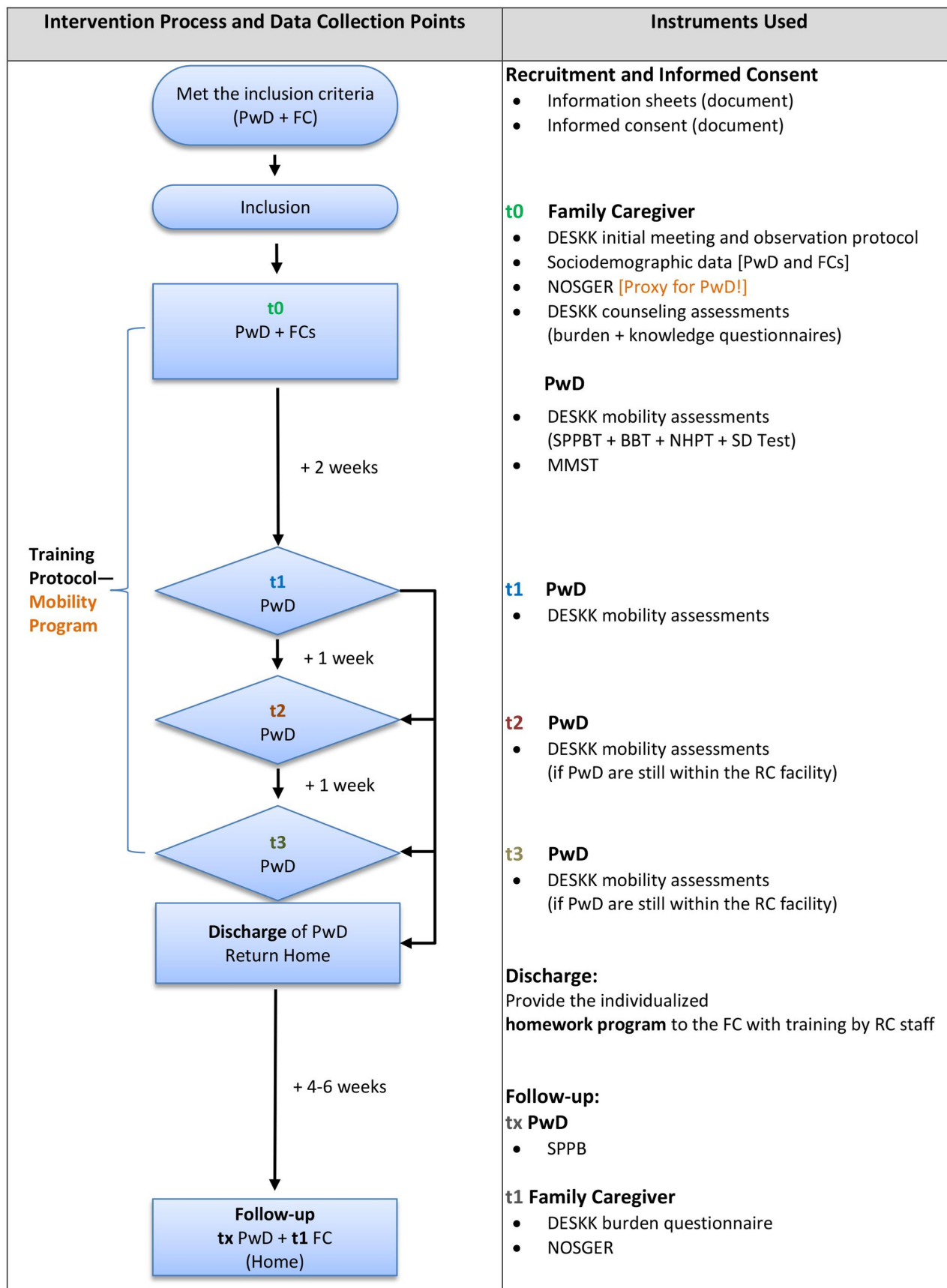
Figure 2 DESKK intervention flow chart. BBT, box and blocks test; DESKK, development and testing of a dementia-specific respite care concept, FC, family caregivers; MMST, Mini Mental Status Test; NHPT, nine-hole peg test; NOSGER, Nurses' Observation Scale for Geriatric Patients; PwD, people with dementia; RC, respite care; SD, strength-dexterity; SPPB, short physical performance battery.

and hands. The BBT is easy and fast to use, and it is validated and has a good inter-rater reliability for seniors without dementia but with multiple scleroses and rheumatoid arthritis.[22] ICCs are >0.89 (people without disability (n=35/60–89 years)) to >0.96 (people with disability (n=34/60–89 years)).[29] To our knowledge, there are no available validated physical function assessments suitable for the inpatient care setting to assess the rough coordination of the upper extremities of PwD.

Strength-dexterity test

The strength-dexterity (SD) test is a hand muscle strength test that can be performed very fast and easily. Thereby, the hand grip level can be assessed. The SD has been validated and has a good inter-rater reliability for assessing mild, moderate and severe affected PwD (ICCs in all subgroups >0.95 (n=76 PwD/82.4 years mean;±6.8 SD)).[23]

Nine-hole peg test

The nine-hole peg test (NHPT) can be used to analyse fine coordination related to hands and fingers. The NHPT is easy and fast to use and is a validated instrument for seniors without dementia; it is often used by persons with multiple sclerosis.[30] It has a good inter-rater reliability for assessing persons after stroke (ICC >0.75 (n=56/68,1 years mean±11.4 SD))[31] or persons with multiple sclerosis (ICC >0.93 (n=32/43.1 years mean±8.3 SD]).[32] The NHPT has also been used to assess PwD.[33 34]

Based on the cut-off scores of the DESKK mobility assessment battery, selected exercises will be written down on a training card, including the preferences of the PwD, which were extracted from the initial assessment. The card will function as an overview list for the RCC staff to outline which exercises should be conducted for an individual PwD. A poster has been developed and will be displayed in the RCC to provide a brief overview of the different exercises. These exercises are also described in detail in a special manual.

DESKK training protocol and homework programme

During the training, the RCC staff will complete a daily training protocol in which the performed exercises and their training times will be listed. Furthermore, it will be possible to note potential problems during a training session and to modify exercises to better fit the needs of a PwD. Based on the recommendations in the completed training protocol, a manual with a detailed description of the individually tailored mobility exercises will be given to the FC when the PwD returns home (homework programme). The aim of this approach is to establish continued training for the PwD at home.

Nurses' Observation Scale for Geriatric Patients and Mini-Mental State Examination: assessments

The Nurses' Observation Scale for Geriatric Patients (NOSGER) and the Mini-Mental State Examination (MMSE) are exclusively used to obtain scientific data about the cognition level and disturbing behaviours of PwD. The NOSGER assessment is a validated and fast instrument used to measure challenging behaviour during the last 14 days. The NOSGER can be completed by nursing staff as well as by FCs, and it has an ADL focus.[35] The MMSE is a common and validated instrument designed to obtain information about the cognitive status of persons; it includes a rating scale that ranges from not cognitively impaired to severely cognitive impaired.[36]

Intervention components and data collection: counselling programme

The DESKK counselling programme is an effort to structure and systemise counselling processes focused on the RCC setting. For this purpose, instruments for data collection, logging, preparation and documentation have been developed. These tools can be used flexibly by the consultants (RCC staff).

The counselling topics most frequently asked during counselling sessions were determined in interviews with counselling experts. The following topics were noted:
1. Explanation and illustration dementia and the medical treatment and nursing care.
2. Communication and interaction with PwD.
3. Nursing tasks at home.
4. Offers for PwD and FCs.
5. Financial matters and care services.
6. Legal matters.
7. Improvements in living conditions and technical aids.
8. Social environment.
9. Psychosocial situation.

DESKK counselling assessment

The nine above-displayed counselling areas are linked with the DESKK counselling assessment to create individual counselling recommendations for the RCC staff. Like the DESKK mobility assessment battery, the DESKK counselling assessments will be used to structure the counselling process in practice and to obtain scientific data for the outcome evaluation. The DESKK counselling assessment will be completed by the FC before the counselling session starts and will consist of two parts. In the first part, knowledge about dementia and related care strategies for the topics that were most frequently requested in consultation will be determined with 18 items (two items per topic). The second part measures the subjective burden of the caregiver within these subject areas via 18 additional items. These items were taken from validated survey tools. The knowledge part of the counselling assessment is based on items the 'Dementia Knowledge Assessment Tool Version Two'[37] and the 'The Alzheimer's Disease Knowledge Test',[38] which are validated instruments that assess FCs' knowledge about dementia. The section on assessing the burden of the FC in the DESKK counselling assessment is based on selected five-point Likert scale items from the following assessment:

Berlin inventory on relatives' burden in dementia

The Berlin inventory on relatives' burden in dementia (BIZA-D) can be completed in a relatively

efficient manner, and it measures the subjective and objective burden of FCs for PwD. The BIZA-D is validated as well as mobility based and ADL related.[39]

DESKK module sheets
These documents will provide the RCC staff with an introduction to the topics of the different counselling modules. Additional literature sources are also referenced at the end of every module sheet so that RCC staff can engage in deeper preparation for the specific counselling session.

DESKK counselling documentation
This tool enables counselling to be documented in a structured manner. At the end of the consultation, the FC will receive part of the document as an information leaflet. On this piece of the document, the consultant (RCC staff) can write down all important recommendations and addresses of additional dementia care service providers for the FC. If the caregiver desires it, an appointment for another counselling session may also be noted in the document.

Process evaluation of the overall DESKK concept
RCC staff
The RCC staff will be asked about their usability and satisfaction rating to the concept by a self-developed semi-standardised interview guideline.

The specific content areas of the guideline were designed according to the structure of the Consolidated Framework for Implementation Research (CFIR) instrument.[40] This framework can be used to structure the process evaluation and the integration of interventions in daily routine care. The framework can also be used as a toolbox compilation; however, not all CFIR constructs have to be used because they do not all fit every research approach. Different settings, groups and intervention characteristics are considered within this model.

To evaluate the intervention, all of the constructs provided in the CFIR were first examined for their relevance and suitability for the study design and the intervention. Through a multistep process, various constructs were included in the interview guideline. Table 2 displays the included CFIR constructs for the DESKK process evaluation including the priority groups (RCC Staff and FC).

Group interviews with RCC staff will be conducted during the intervention phase with the help of the self-developed, CFIR-based, structured interview guideline. The group interviews will be documented with audio recordings. A member of the scientific team will also document important aspects by paper and pencil, for example, if an interviewee seems under emotional pressure in an interview or if someone seems to be very unwilling to answer a question. After an interview session, each interviewee will complete a short, structured, self-developed quantitative and ordinal-scaled questionnaire. This provides the opportunity to describe changes in essential aspects of the intervention and its integration into the daily routine over time. Furthermore, 5–8 single interviews with staff

Table 2 Consolidated Framework for Implementation Research (CFIR) constructs used for the DESKK interview guidelines

CFIR construct	Construct area	Priority group
Intervention characteristics	Complexity	Respite care centres (RCC) staff/family caregivers (FCs)
	Adaptability	RCC staff/FCs
	Design quality and packaging	RCC staff
	Relative advantage	RCC staff/FCs
Outer setting	Patient needs and resources	RCC staff
	Cosmopolitanism	RCC staff/FCs
Inner setting	Readiness for implementation	RCC staff/FCs
	Available resources	RCC staff/FCs
	Structural characteristics	RCC staff/FCs
	Access to information	RCC staff/FCs
Process	Reflecting and evaluating	RCC staff/FCs

DESKK, development and testing of a dementia-specific respite care concept.

will also be conducted 3 and 9 months after the start of the intervention to gain a deeper insight into specific implementation barriers and facilitators for the project from the perspective of different occupational groups.

Family caregivers
FCs will also be interviewed at home via a self-developed semistandardised questionnaire based on the CFIR structure.

Data management
All of the study participant-related data will be pseudonymised for the investigators by using a code number. Only the study coordinators within the nursing homes will have access to the names of the study participants. All of the electronic data will be archived securely for ten years by DZNE Witten and DZNE Rostock.

Data analyses: qualitative
Based on the interview guideline and the CFIR structure, a code tree will be created in a deductive procedure via structured content analyses, following Mayring.[41]

The interviews will be coded by 2–3 scientists independently. In this process, the material will be subdivided into content paragraphs and codes. Through a circular process, the statements of the interviewees will be reduced to the essential content. The coding and analysis process will be performed with MaxQDA V.13. At regular intervals, the codes and the coded material will be synthesised
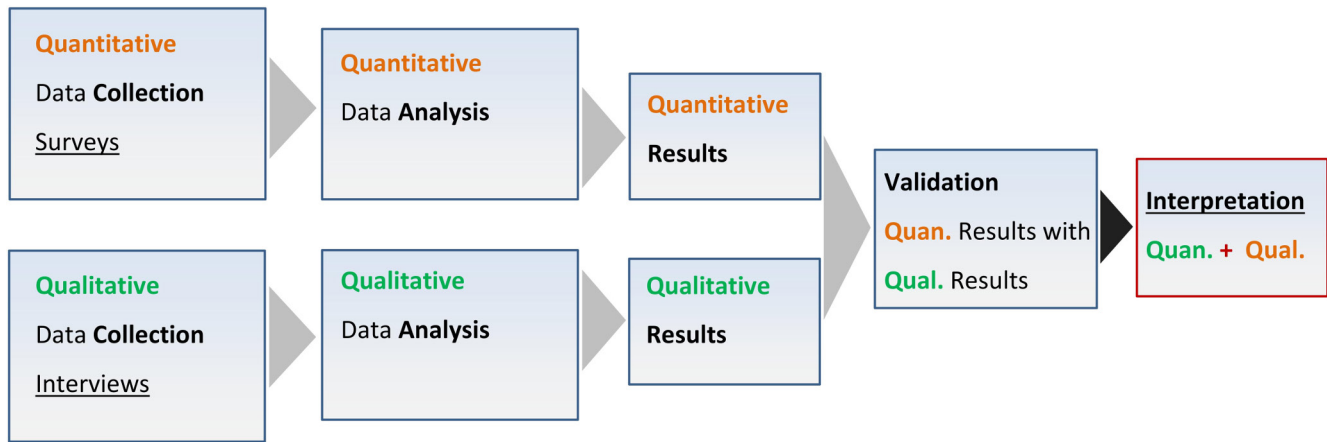
Figure 3 Mixed-methods triangulation design—convergence model.

in a systematic discussion process between the involved project scientists.

Data analyses: quantitative

Descriptive analyses and methods, such as crisp-set qualitative comparative analysis (QCA),[42] will be used to analyse the quantitative data with respect to the expected small number of cases (n=30). The descriptive analyses will be performed with IBM SPSS, and the QCA will be performed with TOSMANA.

By a mixed-methods approach, the quantitative data will be further validated by complementary qualitative data on the same topic. Based on the qualitative and quantitative data, the effect tendencies of the DESKK concept will be discussed in detail. The schematic process of this design is displayed in figure 3. Thereby, it will be possible to compare the different data sources to gain better insights into the findings or to obtain new hints for the discussion of potentially conflicting data. This mixed-methods design will be based on the convergence model of the triangulation approach.[43]

Patient and public involvement

PwD and FCs were not involved in the design of the study protocol, but the RC staff was directly involved in the development process of the DESKK concept. FCs and PwD will provide feedback and comments to the DESKK concept during the intervention phase of the feasibility study. This feedback will be used for potential concept modifications to reach an optimal adaptation of the mobility and counselling programme to the priority groups.

DISCUSSION
Expected results

It is expected that the RCC concept will be suitable and understandable for staff and can therefore be implemented in the RCC. As a result of the mobility programme, the physical abilities of PwD should improve. Similarly, the burden of caregivers should be reduced by the combined effects of the counselling programme and the higher mobility level of the PwD. The FCs should gain

valuable information and resources on how to continue the mobility programme at home, and it is expected that they will find this information usable and easy enough for the home care setting.

Broader dissemination

After the concept is finalised, a practice-friendly manual will be developed in which implementation components are described in a comprehensible and understandable way. The manual will help in the implementation of the RCC concept without personal guidance and will serve as a reference book. Based on this manual, the DESKK concept will also be presented in the form of a practice-friendly website so that other RCCs can view the programme and easily use it in their RCCs.

Limitations

Because of the feasible study design (no control group, small sample, possible modifications/optimisations during the intervention), the quantitative results will be limited regarding their information value related to effect statements.

The cut-off scores for the mobility assessment battery that are used had to be chosen based on sample scores of seniors without dementia. Therefore, these cut-off scores are not validated for PwD, and it is not ultimately clear whether they are optimal cut-off scores for the mobility assessment.

Like in many other studies, it is expected that primarily highly motivated people will participate in the study. Similarly, FCs without German language skills will not be included. This issue is a limitation because multicultural care is becoming more important in Germany and beyond. There is a need to translate the DESKK concept into different languages, but translation was not covered by the funding. Furthermore, the selected RCC is well established and maintains a high degree of professionalism. Other RCCs might differ in their structure and the quality of care provided. The counselling assessments used to obtain data about burden and dementia-related knowledge have not been validated in the form for

which they will be used in this project. The NHPT and BBT, which will be used to obtain data on the rough and finger-fine coordination abilities of PwD, have not been validated for this specific group of people. The NHPT was used to assess PwD in different studies, and the BBT was not.

The DESKK study is the first attempt to develop and test a mobility programme for PwD and a counselling programme for FCs in a dementia-specific RCC setting in Germany. These results are also expected to be adaptable (language translation) for other RCCs or similarly built structures internationally. The results of the study can provide important information on the feasibility of the performed DESKK mobility and counselling programme in an RCC setting. Furthermore, recommendations can be given about preconditions and the necessary resources for the successful implementation of the whole DESKK concept. A successful implementation and execution of the DESKK concept can be a relevant step in the optimisation of home care support for PwD and their FCs.

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