ANNUAL REPORT 2016

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# CONTENTS

1. **2016 AT A GLANCE** ............................................................................................................................... 3
   1.1 Highlights in 2016 ................................................................................................................................. 3
   1.2. Local Care Arrangements - A Future Concept .................................................................................. 7
      1.2.1 Introduction ..................................................................................................................................... 7
      1.2.2 People with Dementia Living in Neighborhood Communities .................................................... 8
      1.2.3 In between Home Care and Long-Term Care – People with Dementia in Short-Term Care ....... 8
      1.2.4 People with Dementia in Inpatient Care ...................................................................................... 9
      1.2.5 Conclusion ................................................................................................................................... 10
   1.3 Staff .................................................................................................................................................... 13
   1.4 Scientific Work .................................................................................................................................. 15
      1.4.1 Publications .................................................................................................................................. 15
      1.4.2 Boards and Consulting Activities ................................................................................................. 15
      1.4.3 Cooperation .................................................................................................................................. 15

2. **PROJECTS** ......................................................................................................................................... 17
   2.1 Psycho-Social Interventions for Different Dementia Forms and Stages ............................................. 17
   2.2 Quality of Care ................................................................................................................................... 33
   2.3 Methods and Measurements .............................................................................................................. 48
   2.4 Potentials of and in Care Arrangements .............................................................................................. 54

3. **WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016** ............................. 73
   3.1 Articles (peer-reviewed) ...................................................................................................................... 73
   3.2 Articles (not peer-reviewed) .............................................................................................................. 75
   3.3 Reports ............................................................................................................................................... 76
   3.4 Edited Book ....................................................................................................................................... 76
   3.5 Book Chapter ..................................................................................................................................... 76
   3.6 Presentations (peer-reviewed) ............................................................................................................ 77
   3.7 Presentations (invited) ......................................................................................................................... 78
   3.8 Self-Organized Events ....................................................................................................................... 80

4. **WORK IN BOARDS AND CONSULTING ACTIVITIES** ................................................................. 81

5. **WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS** .............................................................. 86

6. **TEAM** ............................................................................................................................................... 89

ATTACHMENT: PROJECT LIST ................................................................................................................... 93
1. 2016 AT A GLANCE

1.1 HIGHLIGHTS IN 2016

As in previous years, the team at DZNE Witten intensified their work in 2016, focusing on the topics Understanding Institutionalization of People with Dementia as well as Consultation. The Advisory Council on the Assessment of Developments in the Healthcare System of the Federal Ministry of Health (SVR) emphasized the need for consultation, especially for caregiving relatives. Moreover, further support on a local level in home and community-based long-term care was underlined (SVR, 2014). Based on these facts, the DZNE in Witten started three new projects. The project Vifa “Diversity of care services from one source” - A nursing home as the care planner, service, provider and gate keeper for elderly and care-dependent people living in the community, funded by third-party funds, links all the working groups in Witten. Its aim is to evaluate a so far unprecedented Gesamtversorgungsvertrag (healthcare provision contract) in accordance with §72 Abs. 2 SGB XI between the long-term care provider “Städtische Seniorenheime Krefeld” and the funding agencies. This contract offers a diversity of care services from one source within a particular region, which facilitates nursing care in inpatient care (SGB XI), as well as in outpatient care (SGB V). This allows an affected person to remain in a home care setting for as long as possible and, if needed, optimizes the transition from home to an institution.

Similarly, the third-party-funded project DESKK- Development and testing of a dementia-specific respite care concept aims to develop and evaluate a rehabilitation concept for people with dementia and their relatives in short-term care. The concept is based on a mobility rehabilitation program, which on the one hand aims to improve the mobility of its users and on the other hand gives informal caregivers structured and targeted advice about reducing their burden permanently. Thus, a transition to long-term care can be prevented.

AMEO-FTD, a project that likewise started in 2016, focuses on providing advice for people with behavioral variant frontotemporal dementia (bvFTD). In this feasibility study, MarteMeo® Counselling, a video-based intervention, is used. The purpose is to activate resources and to preserve the identity of the affected person. This program is being evaluated according to its usefulness for people with bvFTD and their caregivers in order to determine an optimal intervention format (e.g. doses and intensity) and to explore potential effects.
As in every year, the 7th annual conference constituted a highlight for DZNE Witten. It focused on the subject “Care Strategies for People with Dementia. Methods in Research and Practice to Strengthen Autonomy and Social Inclusion”. Around 140 representatives from research, associations and communities exchanged information and discussed care strategies for people with dementia. A special moment was the visit of the French photographer Carl Cordonnier, who presented his exhibition “J’existe encore/ I still exist” concerning everyday life of people with frontotemporal dementia.

The Practice-Research-Dialogue, which takes place twice a year in Witten, focused in 2016 on “Advisory Services for People with Dementia and their Informal Caregivers/ Social Network” and “Approaches of Cross-sectoral Care for People with Dementia”. These topics were links to the main topics of the year and joined together representatives of associations, hospitals and nursing homes for discussions with the researchers in Witten. Here, the relevance of research questions was pointed out and new research questions were identified from practical work.

Collaborations with international research institutes have been continued in 2016. Thus, the DZNE in Witten cooperates with the University of Wisconsin that facilitates the funding of the joint project “Computational Modeling of Caregiver/ Patient Interactions to Discern and Reconstruct Caring Procedures Using Sensor Technology” between the DZNE in Witten, the University of Wisconsin and the DZNE in Rostock/Greifswald. It is based on data from the project insideDEM and has been granted a total of 25.000$ in funding. The superordinate goal is the reconstruction of interaction between caregivers and people with dementia.
Further notable events for the DZNE in Witten were the nominations for three professorships. For a period of three years the leader of the working group Care Interventions, Dr. Margareta Halek, has been awarded a junior-professorship at the Faculty of Health at the Witten/Herdecke University with focus on the care of people with dementia. Furthermore, the former research assistant Dr. Silke Kuske from the University of Applied Sciences Düsseldorf has been nominated for the professorship in the teaching of nursing science. In addition, the former research assistant Dr. Sabine Nover has become a junior-professor for the topic of “Methodologie und qualitative Methoden der Pflege- und Gesundheitsforschung” (Methodology and Qualitative Methods in Nursing and Healthcare Research) at the Philosophisch-Theologische Hochschule Vallendar (PTHV). Finally, Witten’s Speaker, Prof. Martina Roes, has been appointed as the Department of Nursing Science’s representative on the board of the Interdisciplinary Centre for Healthcare Research (IZVF).
STRUCTURE OF THIS REPORT

First of all, an overview of the staff at the DZNE in Witten and the scientific activities and cooperation that took place there during 2016 is presented. On-going and completed projects are described in the second chapter. Scientific work at DZNE Witten is divided into four research topics (fig. 1). Project descriptions are therefore attached to the appropriate field of research.

![Diagram of Research Topics at DZNE Witten]

Figure 1: Research topics at DZNE Witten

In chapter three, publications without direct project reference, such as self-organized events, are listed, followed by a brief synopsis of the staff’s work on boards, their consulting activities and their work for scientific journals and publishers. Finally, you will find a list of the staff members and their corresponding working groups. An index of the projects can be found in the appendix.
1.2 LOCAL CARE ARRANGEMENTS – A FUTURE CONCEPT

1.2.1 INTRODUCTION

Living in one’s own household is of great importance for older people. Of those aged over 85, 85% live in their own household and more than 70% of them are cared for by their relatives or outpatient services. In contrast, only 7% of people over the age of 65 live in long-term care facilities, barrier-free apartments or forms of assisted living (Statistisches Bundesamt, 2017). In our society, social participation and independent living play an important role, especially in old age, as they are relevant factors in the quality of life. Structural conditions in the community are highly important in terms of quality of life of older people living at home, e.g. active neighborhoods, possibilities for social participation, volunteering, adapted infrastructure as well as medical care and support in case care is required. The structuring of these social resources in communities can contribute to an independent life in old age. Therefore, communities have to develop and adjust structures for the elderly living in their own households.

Since 2015, the Ministry of Health, Equalities, Care and Ageing of North Rhine-Westphalia has focused on developing communities that are adequate for elderly people. There are lots of such projects, but these possibilities often remain unclaimed due to physical constraints. This is why the involvement of long-term care facilities is necessary. Society’s view regarding these facilities is often more in terms of healthcare rather than “living”. Moreover, almost half of the residents express that assistance related to daily routine and mobility, e.g. support in going for a stroll or doing individual activities, is not being carried out (IQD, 2011). For that reason, long-term care facilities are required to adapt living conditions to the needs and demands of their residents so that the community can be seen as a place of social interaction and participation (Deutscher Bundestag, 2016).

The German government passed new laws to strengthen the support for people in need of care and their informal caregivers, especially in the domains of cognitive impairment and social inclusion. Furthermore, municipalities are being given support to extend care consulting as well as assistance measures in daily life (Bundesministerium für Gesundheit, 2017).

It is questionable whether living in communities is a future concept for people in need of care or if there are other types of care and accommodation that meet their needs, especially for people with dementia. The aim of the DZNE Witten is to assess care structures for people with dementia in all settings and thereby to conduct research with innovative care models and to contribute to the discussion, based on scientific findings, about future care structures.
1.2 LOCAL CARE ARRANGEMENTS – A FUTURE CONCEPT

1.2.2 PEOPLE WITH DEMENTIA LIVING IN NEIGHBORHOOD COMMUNITIES

A neighborhood is a living environment, which is the individual and social center of its residents’ daily life. It is an urban construct on a social level and therefore has the task of offering possibilities to live and work, for social contact and participation. Thus, a neighborhood plays an important role for the elderly (Deutscher Bundestag, 2016).

As mentioned above, in Germany the majority of people in need of care are cared for in their own home. The number of informal caregivers is approx. 7% of the German population (Statistisches Bundesamt, 2017), which involves a high need for support. Because of the legal separation of care settings in the German healthcare system, home care services are often not adequate for the needs and demands of the families affected. For that reason, it is extremely important that existing services should be coordinated and networked (GKV-Spitzenverband, 2011; SVR, 2012).

Within the project Vifa, the DZNE Witten is evaluating a structural innovation, the so-called Gesamtversorgungsvertrag (care service model) at the Städtische Seniorenheime Krefeld (SSK; long-term care facility), which enables offering a diversity of services that cover all settings (in-, semi- and outpatient care) from one contact point. The Gesamtversorgungsvertrag is the first of its kind and an innovation in the German healthcare system. The concept ensures the usage of existing services and also that people in need of care are able to remain in their own households (Schmidt & Wulbrand, 2016). DZNE Witten is evaluating the benefit for families in the home care setting and the perspectives of nurses and providers. Furthermore, they are analyzing the economic consequences resulting from the Gesamtversorgungsvertrag (Halek & Reuther, 2015). Apart from healthcare located nearby, short-term care plays another important role and is of great significance for the social environment of people in need of care and their families.

1.2.3 IN BETWEEN HOME CARE AND LONG-TERM CARE – PEOPLE WITH DEMENTIA IN SHORT-TERM CARE

The superior aim of short-term care is to maintain care at home for as long as possible and to prevent acute inpatient care following critical transition from hospital to home. The role of short-term care is becoming increasingly important for PwD and their social setting (Kuske, Roes & Bartholomeyczik, 2016). Increased use of short-term care might make home care more attractive for people concerned as well as for other persons involved. This affects not only caregiver burden but also the behavior of PwD (Vandepitte, Van Den Noortgate, Putman, Verhaeghe, Verdonck, & Annemans, 2016). However, utilization of this service has been decreasing, although the Long-Term Care Insurance was adjusted (Pflege-Neuausstichtungs-Gesetz – PNG) in 2012, so that half of the care allowance is paid out during a stay in a short-term care institution (IGES Institut, 2013).
1.2 LOCAL CARE ARRANGEMENTS – A FUTURE CONCEPT

In 2015, only 0.8% of affected persons made use of short-term care (Statistisches Bundesamt, 2017), which amounts to 24,400 persons and is evaluated as being extremely low (IGES Institut, 2013). In the same year, 37,322 beds were available in short-term care (Statistisches Bundesamt, 2017). At the same time, mobility concepts are lacking, which often leads to PwD remaining in nursing homes instead of returning to their own residence. Moreover, there are no standardized concepts for easing caregiver burden. For that reason, discussions are being held as to whether the concept of short-term care is used sufficiently to fulfill its function regarding the idea of continuous care. The IGES institute has been commissioned by the Federal Ministry of Health to scientifically evaluate the quality criteria for professional short-term care.

This institute identified the outcome of short-term care as being highly specialized with a professionally and organizationally demanding role within nursing care (IGES Institut, 2013), which includes a service of comparably high intensity and complexity (ibid.). Nevertheless, there are barriers in terms of benefit legislation on sectorial and organizational level. In addition, the term “nursing” is usually separated from the idea of rehabilitation and medical care in Germany. This impedes multi-professional care enormously, which is very important for the interfaces (IGES Institut, 2013). This becomes obvious in the exchange of information between the settings of short-term and home care, for instance in missing patient documentation concerning medication, information about the patient and the missing inclusion of the affected patients themselves (Kuske et al., 2016).

DZNE Witten takes these facts into account and contributes with its project DESKK (Development and testing of a dementia-specific respite care concept) to providing care in the short-term care setting. Primary aim of the concept is to develop and evaluate a rehabilitation concept for people with dementia and their informal caregivers. It relies on a mobility rehabilitation program, which focuses activities of daily life. Moreover, the program includes advisory services for informal caregivers.

1.2.4 PEOPLE WITH DEMENTIA IN INPATIENT CARE

In 2015, 783,000 people in need of care in Germany had inpatient treatments (Statistisches Bundesamt, 2017). Approximately 70% of the residents living in a longterm care institution suffer from dementia, around half of them of severe forms (Schäufele, Köhler, Hendlmeier, Hoell & Weyerer, 2013). However, societal change results in a lack of traditionally aligned forms of care service for PwD. Especially persons in early and mean stages of the disease are affected since they are often tended by family members. Though, care of suffering relatives is often hardly compatible with everyday working life due to increasing logistical requirements (Kricheldorff & Hewer, 2016). Furthermore, the progressive process of dementia may lead to the increase of transfers into long-term care settings. Therefore, dependency in activities of daily life, changes in behavior, for instance of aggressive manners as well as caregiver burden can influence the admission to long-term care (CORDIS, 2014). Consequently, the development of innovative concepts for inpatient long-term care, as well as their adaptation
in regard to the changing needs of PwD is needed (Kricheldorff et al., 2016). However, segregated areas as suggested in dementia-specific concepts are spreading increasingly in Germany (Palm & Holle, B., 2016).

The working group Care Structures at DZNE Witten focuses on the topic of specialized care for PwD, filling in existing knowledge gaps. Here, the question regarding characteristics of specialized care in German nursing homes is emphasized, such as the regulation of benefit legislation in the federal states. This fundamental knowledge is required to evaluate present structures as well as for giving recommendations for the future. This concept addresses people with severe dementia and distinct challenging behavior in need of dementia-specific care. These forms are often included in concepts in which care is given by particularly skilled staff (Palm & Bartholomeyczik, 2017). In some federal states, nursing homes are able to negotiate a separate contract that allows better staffing and higher qualification of employees. However, the concept is not without controversy. Often, additional costs have to be funded by the residents themselves and /or by the community (state or town) without any explicit evidence of efficacy (Lai, C. K., Yeung, J. H., Mok, V., & Chi, I., 2009). Concerning separate contracts in nursing homes, the regulation of benefit legislation certainly ensures special service provision on the one hand; on the other hand, in practice there is little evidence about the benefit of those special contracts compared to ordinary ones. The regulation of benefit legislation and definition of special care in dementia is not uniform due to differences in regional federal state laws. This complicates comparability among the diverse types of care.

1.2.5 CONCLUSION

Social inclusion as well as an individual and autonomous way of life in one’s domestic setting is relevant not only for aging in general, but also for persons with need of help and care. Hence, individual care, suitable for the needs of PwD, their relatives and professional caregivers, is necessary. Nevertheless, it appears that the segregation of benefit legislation evolves barriers that inhibit individual and continuous care service. Due to these facts, care orientated towards the needs and demands of affected people is greatly impeded. The problem is exacerbated through inadequate processing of well-known interface issues. Although politics support care services from a single source within a defined radius and the establishment of a regional network for dementia and although they react to needs as well as requests and wishes of PwD, it is still necessary to link informal and formal services in the various settings in a better way. This would facilitate high quality care continuously in the future.
REFERENCES


1.2 LOCAL CARE ARRANGEMENTS – A FUTURE CONCEPT


1.3 STAFF

The scientific staff at DZNE Witten operates together in four working groups: Methods in Healthcare Research, Care Interventions, Care Structures as well as Implementation and Dissemination Research. The number of full-time equivalent staff (25.23) was a little higher in 2016 than in the year before (24.31), of which 4.26 were financed by third party funds.

<table>
<thead>
<tr>
<th>Group</th>
<th>People</th>
<th>Full-Time Equivalent (FTE)</th>
<th>FTE Budget-Financed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administration</td>
<td>4</td>
<td>3.73</td>
<td>3.63</td>
</tr>
<tr>
<td>Methods in Health Care Research</td>
<td>5</td>
<td>4.11</td>
<td>3.91</td>
</tr>
<tr>
<td>Care Interventions</td>
<td>7</td>
<td>5.33</td>
<td>4.75</td>
</tr>
<tr>
<td>Care Structures</td>
<td>6</td>
<td>5.00</td>
<td>4.04</td>
</tr>
<tr>
<td>Implementation and Dissemination Research</td>
<td>6</td>
<td>4.94</td>
<td>3.04</td>
</tr>
<tr>
<td>Student Assistants</td>
<td>6</td>
<td>2.13</td>
<td>1.61</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>34</strong></td>
<td><strong>25.23</strong></td>
<td><strong>20.97</strong></td>
</tr>
</tbody>
</table>

Table 1: Number of employees and full-time equivalent staff (as of 31 Dec. 2016).

The interdisciplinary work at DZNE Witten requires scientific staff, including leadership positions, with a wide range of qualifications. The staff disciplines consist of nursing sciences, sociology, gerontology, health sciences/public health, psychology, educational sciences, bioinformatics, economics, political sciences and physical therapy. Students and research assistants from various disciplines and various universities in NRW are also employed at DZNE Witten.
The procurement of third-party funds is shown in the table below:

<table>
<thead>
<tr>
<th>Year</th>
<th>EUR</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td>35,000</td>
</tr>
<tr>
<td>2011</td>
<td>49,064</td>
</tr>
<tr>
<td>2012</td>
<td>80,293</td>
</tr>
<tr>
<td>2013</td>
<td>248,029</td>
</tr>
<tr>
<td>2014</td>
<td>256,225</td>
</tr>
<tr>
<td>2015</td>
<td>153,348</td>
</tr>
<tr>
<td>2016</td>
<td>387,131</td>
</tr>
<tr>
<td>2017</td>
<td>440,188</td>
</tr>
</tbody>
</table>

Table 2: Mandatory approved financial resources (as of 31 Dec. 2016).
1.4 SCIENTIFIC WORK

1.4.1 PUBLICATIONS

Results of the scientific work of the team in Witten have been published in 2016 at frequent intervals. Altogether 83 contributions were realized at national and international levels.

The DZNE Witten presented their work in 19 presentations and 11 poster presentations at national and international scientific congresses concerning health services research for people with dementia. The great importance of theory-practice-transfer is also conspicuous: 16 oral and poster presentations were held at several nursing practice congresses and events.

Moreover, the results were published in both German and English. In this context, two books and one book chapter were released. Furthermore, 18 articles were published in peer-reviewed journals, five articles in journals without peer-review procedures and also five reports and three dissertations. References of completed projects or references without direct relation to any projects in 2016 are listed in chapter 3.

1.4.2 BOARDS AND CONSULTING ACTIVITIES

In 2016, employees of the interdisciplinary team in Witten were represented in different functions on scientific boards, executive boards and steering committees. They brought their expertise in the field of dementia care in various consulting activities and worked for scientific papers and publishers. The staff’s activities, as of the end of 2016, are listed in chapter 4.

1.4.3 COOPERATION

DZNE Witten works closely with DZNE Rostock/Greifswald. Moreover, there is a close cooperation with Witten/Herdecke University which is emphasized in the Faculty of Health by Prof. Dr. Martina Roes who holds the chair of “Nursing Science and Health Care Research”, as well as by Dr. Margareta Halek, who became junior professor in nursing science with focus on “care of people with dementia”. Furthermore, most of DZNE’s scientific staff are members of the Faculty of Health and some give lectures in the degree programs.
Internationally, DZNE Witten is actively involved in the European research networks “InterDem” (Early detection and timely INTervention in DEMentia) and EANS (European Academy of Nursing Science). In addition, there is a close collaboration with the College of Nursing of the Pennsylvania State University, USA, and the School of Dementia Studies of the University of Bradford, UK.
2. PROJECTS

2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

<table>
<thead>
<tr>
<th>Title</th>
<th>APPLICATION OF MARTEMEO® COUNSELLING TO PEOPLE WITH BEHAVIOR VARIANT FRONTOTEMPORAL DEMENTIA AND THEIR CAREGIVERS – A FEASIBILITY STUDY</th>
<th>AMEO-FTD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Duration</td>
<td>2015 - 2017</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>DZNE</td>
<td></td>
</tr>
<tr>
<td>Collaboration</td>
<td>--</td>
<td></td>
</tr>
<tr>
<td>Principal Investigator</td>
<td>Margareta Halek (lead)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Martin Berwig (project coordination)</td>
<td></td>
</tr>
<tr>
<td>Scientific Staff</td>
<td>Claudia Dinand</td>
<td></td>
</tr>
</tbody>
</table>

INTRODUCTION

Behavior variant frontotemporal dementia (bvFTD) is associated with impaired social cognition abilities. Therefore it is often challenging to get in contact with people with bvFTD, particularly for their relatives. MarteMeo® Counselling (MMC) is a video-based intervention and was originally developed to improve the dyadic relationship between children with autism and their parents by promoting the sensitive adaptation of parental communication behavior to the impaired social cognitive abilities of their relatives. It is based on the presumption, that a good and reciprocal relationship is a prerequisite for the development and maintenance of social cognitive abilities. In the field of gerontopsychiatry, the aim of MMC is not to support development, but, here too based on a good quality of relationship, to activate resources for functioning and self-maintenance. In this feasibility study MMC is applied for the first time to people with bvFTD and their caregivers. The aim is to evaluate the usefulness of MMC for this population, to determine an optimal intervention format (e.g. dose and intensity) and to explore potential effects.
METHODS

The study uses a quasi-experimental one-group-pre-post-design with double pre-measurement and an embedded mixed-method approach. Five dyads will be enrolled. Outcomes are sensitiveness of the caregivers, quality of caregiver-patient relationship, quality of life and challenging behaviors of people with bvFTD. At three points of time during the study (T0, T1 after two weeks, and T2 after six weeks) a video of a dyadic interaction in a daily life situation (mealtime) will be recorded and data collection will be conducted. The following instruments for capturing the outcomes will be used: Quality of Carer-Patient Relationship (QCPR), Neuropsychiatric Inventory (NPI), QUALIDEM subscales positive and negative emotions and sensitiveness index (Feinfühligkeitsindex, FFI). The time between T0 and T1 serves as a control period. Between T1 and T2 the caregiver receives five MMC sessions. The video sequences will be micro-analyzed by means of video-interaction analysis to prove the assumed impact mechanism of the intervention. Variance of effects on outcomes will be determined. Moreover, the process data collected will be used to evaluate the benefit and acceptance of the intervention.

STATUS

Until the end of the year 2016 we were able to enroll and examine four dyads in the study. One final fifth dyad should follow as soon as possible in the year 2017. Parallel collected quantitative and qualitative data for process and result evaluation will be analyzed.

RESULTS/ APPLICABILITY

The expected results provide indications for the feasibility of the intervention as well as of a large-scale main study and will be used to prepare our application for the financing of such a definitive study.
2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

**DISSEMINATION**

**CONFERENCES:**


**PAPER/ BOOKS/ REPORTS:**

Studies show that 11 to 65 percent of the residents in nursing homes show challenging behaviors such as aggression, crying, apathy or aimless wandering in the course of their dementia. The behavior can be burdensome for the people with dementia themselves and for the staff working in nursing homes. A national guideline in Germany recommends the use of case conferences for the professional handling of people with dementia and their challenging behavior in nursing homes. However, there is a lack of clear concepts as to how to conduct case conferences and how to implement these into daily care routines. Moreover, it is unclear how effective case conferences are for improving the quality of care. The project “Case conferences for people with dementia (FallDem)” aims to fill these research gaps outlined above by finding answers to the following research questions:

1. Do the two different types of CCs (WELCOME-IdA; WELCOME-Neo) have an effect on the challenging behavior, the quality of life and the use of psychotropic medications (DDD) for people with dementia in nursing homes?
2. Do WELCOME-IdA and WELCOME-Neo have an effect on the risk of burnout, work-related stress and the vocational competence of staff that care for people with dementia in nursing homes?
3. Were the two different types of CCs (WELCOME-IdA; WELCOME-Neo) delivered as intended to each nursing home and how they were adopted by each nursing home?
4. What is the attitude of the staff in the nursing homes towards WELCOME-IdA and WELCOME-Neo?

5. Which learning processes did the staff experience in response to both interventions (WELCOME-IdA; WELCOME-Neo)?

6. What contextual factors promote or inhibit the implementation of both interventions (WELCOME-IdA; WELCOME-Neo)?

**METHODS**

The study was conducted in two phases. The first phase was the development of the intervention (two models of case conferences: narrative & IdA) based on a systematic literature review, interviews and group discussions with experts in the field of case conferences. The development phase ended with piloting the two models in one nursing home. In the second phase of the project, the two models of case conferences were implemented in 12 nursing homes. A Stepped-Wedge-Study design was used as a special form of cross-over design, since it provides a methodological alternative compared to conventional cluster randomized trials. With the help of the results of a previous study, a total number of 360 (300 +60 dropouts) participants were calculated as the sample size (using power calculation).

The primary outcome, challenging behavior of people with dementia, was measured with the Neuro-psychiatric Inventory - Nursing Home Version (NPI - NH). As secondary outcomes, the quality of life of people with dementia (measured with Qualidem), the competence development of the staff (measured with Kompetenz - Reflexions - Inventar (KRI)), the burden of the staff (in general and dementia-specific, measured with the Copenhagen Burnout Inventory (CBI) and the burden resulting from dementia (the BelaDem instrument)) were assessed.

The intervention is accompanied by a process evaluation (research questions 3-6) to identify factors that have an impact on the intervention's implementation. For the process evaluation a mixed method study was conducted within the effectivity study FallDem. Here longitudinal data were collected by questionnaires, semi-structured telephone interviews, group interviews and protocols of the case conferences.
STATUS

All seven data collections have been completed (T0-T6): longitudinal data were available (about 300 residents within each data collection) from 12 institutions over 19 months. For the survey of staff outcomes a return rate between 27-41% was achieved for all data collection time points. Furthermore, data collection for process evaluation was also completed in 12 nursing homes; 10 nursing homes successfully finished the intervention phase: two nursing homes dropped out during the trial. Moreover, a simulation study in the statistic program R was conducted: the aim was to investigate the impact of different challenges common in healthcare research (e.g. delayed treatment effect, dropout of clusters during a trial) in order to estimate the intervention effect within a stepped-wedge trial.

The results of process data were used to define the “time on treatment effect” of case conferences; the time on treatment effect will be used to model a possible error in the implementation of the intervention by allowing the design matrix for the estimation of the intervention effect of the linear mixed effect model for each time point (T1-T6) and cluster to be fractional.

At the moment, the data from the effect study (question 1 and questions 2) and question 3 and 4 of the process evaluation are being evaluated.

RESULTS/ APPLICABILITY

First results of the FallDem study on the patient level indicate that the intervention WELCOME-IdA has no statistically significant effect on the general prevalence of the challenging behavior of the people with dementia in comparison with the control phase of the intervention. However, a subgroup analysis has shown a significant reduction of the prevalence of the challenging behavior apathy. The intervention WELCOME-NEO has shown no significant effects concerning the primary outcome of challenging behavior. In both interventions (WELCOME – NEO, WELCOME – IdA), the secondary outcomes on the patient level (Quality of Life, Defined Daily Doses of drugs) have shown no significant effects.

On the patient level, when comparing the intervention and control phases WELCOME-Ida has shown a significant reduction (mean score) of the risk of work-related burnout which also continues (as a trend) in the follow-up phase.

The intervention WELCOME – NEO has shown no significant effects on outcomes at the staff level.
Besides the findings about the impact of different forms of case conferences, the project FallDem provides also an input for healthcare research.

Because of the flexibility of the parameter settings, e.g. different effect size or more or less cluster, the R-code developed within the project can easily be adapted to other studies working with the Stepped Wedge Design. Thus, there will be a development of a concept for the quantitative data analysis (using mixed effect models). The study also provides advanced knowledge about the practical use of the Stepped Wedge Design in healthcare research. This work by DZNE Witten’s team has been honored in the editorial of the Journal of the American Medical Directors Association (17(1)). Moreover, the relevance of the intervention for the US was emphasized.

**DISSEMINATION**

**CONFERENCES:**


2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

PAPER/ BOOKS/ REPORTS:


### INTRODUCTION

The care of people with dementia is often challenging due to behavioral problems of those affected. The so-called challenging behavior includes, for example, restlessness, aggressiveness or crying and screaming. Challenging behavior often occurs in people with dementia during the course of the disease, regardless of the setting in which they are cared for. The causes of challenging behavior are multi-causal and may vary intra- and inter-individually. For the development of tailored psychosocial interventions that focus on understanding and managing challenging behavior, approaches are needed that

- are person-centered, setting the perspective of the person with dementia at center,
- are carer focused,
- take into account the multi-causality of challenging behavior and
- include a thorough description and analysis of the challenging behavior.

In Germany, the term “understanding diagnostics” is used to describe such an approach. The aim of the study was to describe the current state of knowledge regarding person-centered approaches for the description and analysis of challenging behavior of people with dementia by nurses/therapists across different settings (e.g. nursing home, hospital, at home).

The following research questions were answered during the study:

1. Which different approaches of “understanding diagnostics” exist?
2. Which methods assist nurses/therapists in understanding challenging behavior?
3. What experience do nurses/therapists have when applying "understanding diagnostics"?
4. What effect do nurses/therapists have when applying "understanding diagnostics" on persons with dementia?
5. What effect do approaches related to “understandings diagnostics” have on informal and formal caregivers of persons with dementia?
2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

METHODS

In order to find answers to these questions, a systematic review was performed. All articles were included that make a statement about the description of the intervention, the outcomes, or the experiences made during the implementation of the intervention (across all settings). Quantitative as well as qualitative studies such were included which have been published between 1995 and 2014. Based on relevant studies a forward citation tracking was carried out in February 2015. A quality appraisal was conducted for all empirical studies.

STATUS

The systematic review was published in the Journal “Aging and Mental Health” in 2016.

Fourteen different approaches were found. Three of the 14 approaches are intended for using at home in the community, eight for using in nursing homes and three can be used in different settings. Neither approach was explicitly developed for the use in hospitals.

The effectiveness was tested for six of the 14 approaches, whereby the results and the quality of the studies vary. Findings regarding the experiences of nursing staff were found for three approaches. All studies except one were conducted in nursing homes.

RESULTS/ APPLICABILITY

The results indicate that the approach of “understanding diagnostics” is an undeveloped field in community care and hospitals. Existing approaches have to be modified for their use in the community and in hospital. Furthermore, studies are needed that test the effectiveness of the modified approaches in those settings.
DISSEMINATION

CONFERENCES:


PAPER/BOOKS/REPORTS:

**INTRODUCTION**

In Europe, nearly 7 million people are affected by dementia. Most of them live in their own homes, longing to maintain their independence and autonomy for as long as possible. To achieve this, people with dementia (PwD) are either supported by their relatives or professional health carers. However, this often results in high caregiver burden. Considering these aspects, industry and social sectors cooperate closely to cover the forms of technological assistance needed.

INDUCT supports 15 junior researchers to become experts for the social and health-related needs of PwD, such as for the effective use and usability of supporting technology. This idea is realized with the aid of diverse programs at several European research institutes.
(The primary aim of INDUCT is to develop a multi-disciplinary, inter-sectorial research framework for Europe, within which assistive technologies for pwd are being improved, and evidence is brought about how technologies can support the lives of pwd and their social settings. Moreover, knowledge about best practice and the implementation of those technologies in dementia research is to be promoted.)

The DZNE in Witten is involved in the content-related and organizational realization of seminars as a second-level partner of INDUCT and works closely with Prof. Nygård from the Karolinska Institute in Sweden.

**METHODS**

The 15 junior researchers will be carrying out diverse projects in three different research topics. They represent:

1. Technology in everyday life
2. Technology for meaningful activities
3. Healthcare technology.

**STATUS**

The first INDUCT school will take place in January 2017 in Maastricht. In October 2017, the DZNE in Witten will be hosting a junior researcher from the Karolinska Institute in Sweden for a period of four weeks.
INTRODUCTION

The behavioral variant frontotemporal dementia (bvFTD) is a young onset and progressive subtype of frontotemporal lobar degenerations (FTLD) and is associated with strong changes in judgment, behavior, personality and emotions. These changes vary individually and have an impact on the daily lives of those affected and their families. Psychosocial interventions are important and indispensable components in the care of people with FTD and are most effective if they match the specific needs and requirements of the persons concerned. Until now, the evidence of these interventions could not be demonstrated. Thus, it is essential to generate further knowledge and insights into frontotemporal dementia as a lived experience.

The aim of this study is the identifying, collecting and consolidating of practical knowledge and clinical expertise from multiprofessional perspectives to constitute the basis for further development and evaluation of psychosocial interventions for the care of people with bvFTD.

METHODS

An explorative and reconstructive design has been chosen and includes three steps:

1. Development of a literature-based guideline for conducting interviews

2. Consultation of selected informal and formal experts/stakeholders with multiprofessional backgrounds to explore hidden practical knowledge and clinical expertise using the following data collection methods:
   a) Focus groups with relatives / nurses or other therapists, possibly interdisciplinary
   b) Guided individual interviews (selected persons, interdisciplinary and cross-settings)
c) Analysis of self-presentations of people with bvFTD in blog entries

All conducted interviews are audio-recorded and transcribed verbatim, and controlled using software for qualitative data analysis (MAXQDA).

3. Data analysis and synthesis includes the identification, arrangement and classification of the categories of applied interventions for each data source using

- interpretative approach for thematic analysis of interviews with expert/stakeholders
- content-orientated multimodal approach for blog analysis

The findings will be compared with each other and synthesized by conceptual and theoretical interpretation regarding their potential for a good or best-practice.

**STATUS**

The study is in the process of data collection and analysis for the respective data source. This is followed by the comparison and aggregation of these results.
RESULTS/ APPLICABILITY

Through this project, previously inaccessible sources of knowledge and experience for the care of people with bvFTD are brought together, systematically ordered and recommended for further evaluation. This fills a gap in healthcare research.

The results are being prepared for publication. If necessary, an action guideline can be developed.

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

### 2.2 QUALITY OF CARE

**Title** | **DemenzMonitor: Longitudinal Survey of Dementia-related Institutional and Resident Characteristics in German Nursing Homes** | DemenzMonitor
---|---|---
**Duration** | 2010 – 2017 | 
**Funding** | DZNE | 
**Collaboration** | -- | 
**Principal Investigator** | Bernhard Holle (lead)  
Rebecca Palm (project coordination) | 
**Scientific Staff** | Christian G. G. Schwab, Diana Trutschel, Sarah Palmdorf (2016, April – October) | 

### INTRODUCTION

Nursing homes align their structure, supply and care concept with the needs of the growing number of residents with dementia. Specialized living arrangements as well as tailor-made psychosocial interventions are recommended by the German Federal Ministry of Health and the Medical Advisory Service of the German Long-Term Care Insurances. Dementia-oriented care aims at understanding challenging behaviors and preserving and fostering the resident’s quality of life.

It can be assumed that the majority of nursing homes implement corresponding concepts and interventions in different ways. Today, little is known about which concepts and interventions are applied in the practice, which factors influence the application and whether the application is associated with the desirable outcomes. Furthermore, there is a research gap about which factors are associated with the behavior and quality of life of residents and these therefore need to be considered when investigating the quality of care.

The aim of the study DemenzMonitor is to identify resident- and facility-related factors and covariates that are associated with the residents’ behavior and quality of life. In detail, the following research questions will be answered:

1. How is dementia care provided in German nursing homes? Which living arrangements are implemented? Which recommended interventions are in use? Who gets which interventions?
2. Are there any differences between residents of different living-units regarding their demographic data, cognition, care dependency? Are there any differences between the residents of different living-units regarding the interventions provided?
2.2 QUALITY OF CARE

3. Which of the investigated variables are associated with the residents’ outcomes behavior and quality of life when controlling for resident-related covariates such as age, sex, length of stay? Are there differences between the results of the whole population and certain groups?

4. Are the residents’ outcomes behavior and quality of life stable over time or are they changing? If they change, are there differences in associated factors and covariates between the two points of time so that time needs to be considered as an influencing factor? Which factors are associated with the change of the residents’ outcomes?

METHODS

The “DemenzMonitor” study is a descriptive longitudinal observational study. Data collection was performed annually in nursing homes (convenient sample). Data concerning the nursing homes, the living-units and the residents were collected by trained nursing home staff using standardized and partly new developed questionnaires. The outcomes behavior and quality of life were assessed by nurses using the instruments Neuropsychiatric Inventory (NPI-Q) and QUALIDEM.

Data analysis is performed primarily explorative, using predominantly descriptive statistics as well as association and regression analysis. To account for the nested structure of data due to different levels of data and time points, generalized linear mixed effects models are used.

STATUS

In 2016, another question was answered that belongs to the complex 1 resp. 2 of the research questions mentioned above. Focus was set on the implementation of pain assessments in Dementia Care Units and Integrative Units. The publication also encompasses characteristics of the residents of both unit types.

Furthermore, the work on the association between quality of life and structural factors of nursing homes was continued. Emphasis is set on people with very severe dementia and how their quality of life develops over a period of two years. Another topic of interest is whether the change in quality of life differs between residents who live in a Dementia Care Unit, and residents who live in an Integrative Care Unit.

The work concerning prevalence and associated factors of challenging behavior has started. A master thesis focuses on the relationship between challenging behavior and resident-related factors.
2.2 QUALITY OF CARE

The analysis of the DemenzMonitor data gave reason to reflect critically the methods used in observational studies and to develop strategies to account for occurring bias in the results. In a methodological article, the advantages and disadvantages of different methods to adjust bias and models used to analyze observational data in healthcare research are described and discussed. The article represents a convenient example for practitioners on how to follow the different analysis steps and to adapt the implementation code for examples in their own setting.

RESULTS/ APPLICABILITY

The description of structures of the participating nursing homes, the residents and implementation of recommended interventions is reported in a scientific report. The report was published in 2016 and is available for download on the project home page.

Results on the question about potential differences regarding the frequency and implementation of case conferences between Dementia Care Units that receive extra funding (higher costs were negotiated for these care units) and traditional care units were published in January 2016 in the Journal of the American Medical Directors Association. The article received the publication award “Witten’s first 2016” from the Witten/Herdecke University.

The results on the question whether there are differences between the two kinds of care units regarding the implementation of pain assessments were reported on at different national and international conferences. The manuscript has been submitted for publication and is currently under review.

The methodological article has also been submitted for publication and is currently under review.
DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

Palm, R. (2016). Dementia specific care in German nursing homes - structures and processes. (DISS), Witten/Herdecke University, Witten.

Palm, R., Trutschel, D., Simon, M., Bartholomeyczik, S., & Holle, B. (2016). Differences in Case Conferences in Dementia Specific vs Traditional Care Units in German Nursing Homes: Results from a Cross-Sectional Study. Journal of the American Medical Directors Association, 17(1), 91.e99–91.e13. doi:10.1016/j.jamda.2015.08.018
INTRODUCTION

The aim of this study is to investigate the incorporated handling routine concerning the gestural-communicative actions of caregivers for perceptually impaired persons. The practical perspective is to be explored, i.e. “how” the verbal and nonverbal interactional relationship is organized. The study aims at widening the theoretical and practical knowledge about nonverbal communication in people with severe dementia in order to promote their self-determination and reduce their dependence. There are no current studies concerning this topic. The following research question is being investigated:

1. How is the verbal and nonverbal interaction between the caregiver and her patients with advanced dementia performed, if the caregiver allegorically simulates an action as guidance for the patient who, in return, may be led to become active by mirroring the previously shown action?

METHODS

Reconstructive-praxeologic research approach: the video-graphical study follows the principles of the documentary interpretation according to Bohnsack.

Random sample/Setting: care interactions between people suffering from severe dementia and caregivers in habitual and periodic daily life situations; the caregivers are experts for perceptually impaired persons and are experienced in giving gestural-communicative actions for patients with severe dementia.
2.2 QUALITY OF CARE

STATUS

The empirical investigation will be completed in January 2017.

RESULTS/ APPLICABILITY

The results indicate that the nursing practitioners assume the responsibility for the communicative impact in an interaction process. This becomes evident on the performative level through various distinguished attributes. Caregivers adopt the role of an auxiliary-ego by using gestural simulation to evoke the missing I-function of a course of action. In relation to distinctive characteristics of orientation and interaction, different constitutive criteria in relationships and interactions have been identified. Thus, the results of this study show “that” and “how” interaction partners encounter each other at eye level, establish a common interaction sphere, create a common relationship, develop a common frame and how they behave when the speakers change (i.e. those people who are currently speaking). This research outlines how professional caregivers incorporate sensitive stages of interaction and support the endeavor of a person with dementia for self-determination. It has been reconstructed, HOW and in what manner the nursing practitioners communicate using gestures. The results of this study expand our understanding about professional nursing practices on the interactional and intercorporeal dimension. The categories of the documentary method have been differentiated at the level of embodied practices.
INTRODUCTION

The support of and the care for persons with dementia (PwD) requires an enormous amount of time, organization and commitment. Informal caregivers, most-times relatives, of PwD often feel a high burden. Relief and recognition of their own effort is often denied. Support groups are desired, but either relatives have no time or opportunity to leave the PwD alone or such groups are not organized in the vicinity. Telephone-based support groups are one opportunity to fill this gap. As yet unknown in Germany, international studies show that a telephone network of informal caregivers can have positive effects. The project REDEZEIT aims to establish and to evaluate telephone-based support groups. The support group sessions will be conducted by the team at Leipzig University, the evaluation of the project will be done by the team at the DZNE in Witten within a randomized controlled trial. The evaluation encompasses two levels:

1. The effectiveness of telephone-based support groups
2. The process evaluation concerning the practicability and acceptance of telephone-based support groups

METHODS

The evaluation is planned as a cluster adjusted randomized controlled trial. To reach this, the intervention group is controlled by a waiting group at t(0) baseline, t(1) post intervention and t(2) three-month post intervention follow-up. All standardized interviews will be done by telephone. Participants will be randomized into clusters of five persons.

Target group of the intervention are relatives caring for PwD. Relatives are eligible if they care for the PwD for more than 4 h/d, or have lived in the same household for the last 6 months, and do not suf-
fer from an acute psychiatric disease. Precise inclusion and exclusion criteria are available on request.

The primary endpoint of the evaluation of effectiveness is the health-related quality of life of the participating relatives. This is covered by the General Health Survey Questionnaire ShortForm 12 (SF-12). Secondary endpoints are (1) the perceived social support of caregivers (measured with the Perceived Social Support Caregiving scale), (2) the reaction of the informal caregiver regarding the care situation (assessed with the Caregiver Reaction Scale) and (3) the possible challenging behavior of people with dementia (measured with the Neuropsychiatric Inventory Questionnaire, NPI-Q). The data analysis will be based on the original treatment assignment (intention to treat). With regard to the evaluation of the effectiveness, primary and secondary endpoints will be compared at each data point using descriptive and inferential statistics. Process evaluation will be done descriptively.

### STATUS

Participant recruitment and the baseline assessment T0 have been completed. As a first result, 38 informal caregivers were included representing five cluster pairs. The T1 measurement is ongoing until February 2017. The data analysis for the effectiveness and process evaluation will be done in March 2017.

### RESULTS/ APPLICABILITY

The planned telephone-based support groups provide a new opportunity to relieve and pay tribute to the caring relatives of people with dementia. The efficacy of telephone-based support groups will be investigated in the REDEZEIT study.
DISSEMINATION

CONFERENCES:

## 2.2 QUALITY OF CARE

<table>
<thead>
<tr>
<th>Title</th>
<th>CREATION OF A LITERATURE STUDY FOR THE DEVELOPMENT OF THE EXPERT STANDARD WITH THE TOPIC “NURSING CARE FOR PEOPLE WITH DEMENTIA”</th>
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<tbody>
<tr>
<td><strong>Duration</strong></td>
<td>2015 – 2017</td>
</tr>
<tr>
<td><strong>Funding</strong></td>
<td>German Network for Quality Development in Nursing (DNQP)</td>
</tr>
<tr>
<td><strong>Collaboration</strong></td>
<td>German Network for Quality Development in Nursing (DNQP), Osnabruck University of Applied Sciences</td>
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<tr>
<td><strong>Principal Investigator</strong></td>
<td>Martina Roes (lead) Daniel Purwins (project coordination)</td>
</tr>
<tr>
<td><strong>Scientific Staff</strong></td>
<td>Jan Dreyer, Daniel Purwins, Jonathan Serbser, Silke Völz</td>
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</tbody>
</table>

## INTRODUCTION

Since 1999, the German Network for Quality Development in Nursing (DNQP = Deutsches Netzwerk für Qualitätsentwicklung in der Pflege) has been working in close collaboration with the German Nursing Council on the development and implementation of expert standards (DNQP, 2015).

The DNQP describes expert standards as evidence-based, monodisciplinary instruments,

“[...] that demonstrate specific nursing input for essential quality risks for patients’/ residents’ healthcare and their relatives. Furthermore they provide a basis for continuous nursing care improvement in healthcare facilities and nursing homes. Expert standards represent a professional coordinated proficiency level which is adapted to the requirement and needs of the addressed population. It also includes result-testing criteria for this kind of nursing. Expert standards demonstrate the purpose of complex, highly interactive nursing duties as well as action alternatives and scopes for the direct care of patients or residents. They claim to be effective instruments of quality development and to contribute to the development and professionalization of nursing practice by transferring theory into practice (DNQP, 2015, p.6, translated by the author).” (DNQP, 2015, p. 6).

The procedure in the context of the development and implementation of expert standards is specified in a method paper by DNQP (DNQP, 2015). In 2015, the DNQP-steering group decided on the development of a new expert standard for the topic “Pflege von Menschen mit Demenz” (DNQP, 2015, p. 4)\(^1\).

Prof. Dr. Martina Roes has been appointed as leader of the expert working group to develop this expert standard. The compilation of a literature study, which serves for identification and preparation of available evidence for topics of expert standards, is one of the responsibilities in the scientific

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\(^1\) Nursing Care for People with Dementia (DNQP, 2015, S. 4, translated by the author).
supervision of expert working groups. The compilation of this literature study is the key aspect of the project “Exper-Dem-DNQP”.

**METHODS**

According to the DNQP method paper, relevant research questions must be pursued systematically in appropriate databases within the scope of the literature study. Moreover, the search strategy has to be described explicitly (DNQP, 2015).

The included studies are illustrated descriptively and based on various categories (i.e., study design, sample, methodology and results) in the form of a chart. Furthermore, the included studies are rated methodically “[...]It involves search terms, in- and exclusion criteria and literature sources (e.g. electronic data bases like CINAHL and MEDLINE as well as databases for systematic reviews such as Cochrane Library) (DNQP, 2015, p. 8, translated by the author).” (DNQP, 2015, p. 8)

The conclusive descriptive representation of the included studies as well as their methodical evaluation will be carried out by at least two reviewers working independently of each other. However, the evaluation of the content of the included literature is the task of the expert working group (DNQP, 2015).

**STATUS**

At the beginning of the literature study, the topic “Nursing care for People with Dementia”, which is a complex and at first generally verbalized topic [...]” (DNQP, 2015, S. 10, translated by the author). [...]”, required an exact determination and topical limitation to concretize the actual matter of the development.

The challenge regarding a topic-defined range was that contrary to previous expert standards, such as “prevention of pressure ulcers”, “fall prevention”, it was not clear about which outcome the researched interventions should refer to.

A research question was developed based on the defined range, as well as a search strategy derived from the research question. Subsequently, the actual research was done in the topic-based databases Cinahl, Cochrane, Medline and Psycinfo.
2.2 QUALITY OF CARE

Afterwards, in- and exclusion criteria were defined analogue to the research question and search strategy. In addition, two more steps were initiated: (1) title/abstract screening and (2) full-text screening. The next step after completion of the full-text screening will be the methodical rating of the included studies as well as the representation of results.

Fig. 3: Overview of the included and excluded publications about interventions (own diagram)

As illustrated in figure 3, 182 publications were included and 2726 excluded by method of title/abstract screening and supplied in full text to identify publications about interventions\(^2\). According to the full-text screening, another 136 publications were excluded and 46 included. Moreover, a literature search by hand offered a further seven publications, which were then included.

After the full-text screening, the 53 included articles about interventions were elaborated in a descriptive representation. The next step will be the methodical evaluation of the included studies.

\(^2\) The illustration does not consider the status of work in other ranks of the expert standard (assessment, evaluation etc.)
2.2 QUALITY OF CARE

RESULTS/ APPLICABILITY

The expert working group will develop recommendations for central nursing interventions related to this topic on the basis of the literature study. The recommendations will be adopted within a group consensus. The agreement of the respective expert standard will take place at OsnabrückHalle on October 6, 2017.

LITERATURE

**INTRODUCTION**

Most people with dementia live at home and receive domestic support and care. The admission/transition into a nursing home occurs for many people at a late stage of the disease, when dementia-related symptoms and behavioral changes are rather severe. This encompasses a severe impairment of cognitive and functional abilities, the incidence of psychiatric symptoms and challenging behavior.

A needs oriented care for people with severe dementia who live in nursing homes requires a special concept. Many examples of special dementia care concepts have been developed and implemented into practice in the past few years.

Against the background that the number of people with severe dementia in nursing homes will rise and the public resources for financing nursing home care are constrained, there is a need to look into the subject of nursing home services, costs and effects of special care concepts for dementia. One may ask how structures have to be organized to achieve a high quality of care, how legal regulations can support this and how a service-oriented payment can be realized.

The project BeStaDem pursues the aim of describing and evaluating special dementia care in Germany programmatically. The project encompasses various studies that are built on each other.

The first study is BeStaDem I (qualitative expert evaluation of special dementia care in German nursing homes). The study’s objective is to evaluate from different perspectives the aim and the feasibility of special dementia care in German nursing homes that are designated as a Dementia Special Care Unit / Nursing Home by a special contract.

The evaluation sets the services provided, the legal context and the needs of the target group in relation (Policy Evaluation). The focus is on the question whether Dementia Special Care...
seems appropriate to reach the set goals under the given circumstances and the given needs profile of the users. The evaluation of the implementation focuses on the question of feasibility. With regard to the goals of the Dementia Special Care Concept, problems occurring in the practice are elaborated (Implementation Evaluation) and suggestions for improvement are worked out. The evaluation is carried out from the perspective of nursing home providers and representatives of cost bearers.

As a second study, a survey is planned for collecting data on the Dementia Special Care Services provided in nursing homes in North-Rhine Westphalia.

**METHODS**

BeStaDem I is a qualitative study. Expert interviews are conducted and analyzed using the technique of content analysis.

**STATUS**

To date, interviews with representatives from seven nursing homes and five funding agencies were conducted. More interviews are planned.

**RESULTS/ APPLICABILITY**

Results will be published in scientific and practice journals. To date, no results are available.
2.3 METHODS AND MEASUREMENTS

<table>
<thead>
<tr>
<th>Title</th>
<th>MEASURING THE QUALITY OF LIFE OF PEOPLE WITH DEMENTIA IN NURSING HOMES IN GERMANY</th>
<th>Qol-Dem</th>
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<td>Duration</td>
<td>2010 – 2017</td>
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<td>Funding</td>
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<td>Collaboration</td>
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<tr>
<td>Principal Investigator</td>
<td>Margareta Halek (lead)</td>
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<td></td>
<td>Martin N. Dichter (project coordination)</td>
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<tr>
<td>Scientific Staff</td>
<td>Martin N. Dichter, Christian G.G. Schwab</td>
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</table>

INTRODUCTION

Quality of life (Qol) is a major outcome in intervention studies in dementia research. Available measurements are heterogeneous in relation to their operationalization of Qol, their feasibility, psychometric properties, and stage of dementia in which the application of the measurement is possible. The measurement QUALIDEM is recommended for the Qol assessment in institutional long-term care and for assessing Qol longitudinally. For this, QUALIDEM consists of two consecutive versions. Qol among people with mild to severe dementia is assessed using the 37 item-version (9 subscales) and very severe dementia with the 18-item version (6 subscales).

The aims of the Qol-DEM project are the investigation of the reliability and validity of the QUALIDEM in Germany and a meta-synthesis of relevant Qol domains from the perspective of people with dementia (PwD), which result in a model of dementia-specific Qol. Based on this, the following research questions are to be pursued:

1. Which domains of Qol are described as relevant from the perspective of PwD?
2. To what extent is the German QUALIDEM scalable?
3. What is the internal consistency of the German QUALIDEM?
4. What is the inter-rater reliability of the German QUALIDEM?
5. What is the intra-rater reliability of the German QUALIDEM?
6. To what extent is the German QUALIDEM valid?
2.3 METHODS AND MEASUREMENTS

METHODS

This study is divided in three methodological phases. (1) The aim of the first theoretical phase is the development of a dementia-specific Qol model as a result of a meta-synthesis of qualitative studies. On this basis, a selection of adequate strategies for the evaluation of the construct validity of the QUALIDEM is made. (2) The second empirical phase consists of the following three steps: (a) an investigation of the scalability and internal consistency based on a sample of 634 PwD, (b) an evaluation of the inter-rater (n = 161) and intra-rater reliability (n = 159), and (c) based on the results of the theoretical phase, a cross-sectional investigation of the construct and criterion validity of the QUALIDEM. (3) In the third phase, the QUALIDEM will be adapted, if necessary, based on the knowledge generated in the first two phases.

STATUS

The investigation of the scalability and two reliability studies of the QUALIDEM have been completed. In one reliability study, a User Guide for the German QUALIDEM was developed. In cooperation with the original QUALIDEM authors, an additional User Guide was developed for the English QUALIDEM version. Both User Guides have been published and are available free of charge. Based on the application of the QUALIDEM user guide, the inter-rater reliability is excellent.

For the preparation of the validity study, the two measurements MEDLO Tool (Maastricht Electronic Daily Life Observation Tool) and the QOLAS (Quality of Life Assessment Schedule) were translated into the German language.

The investigation of the construct validity of the German QUALIDEM will start in 2017.

RESULTS/ APPLICABILITY

German and English versions of the user guide for the application of the QUALIDEM have been published and are available free of charge.

The application of the user guide yielded an increase in the inter-rater reliability of the QUALIDEM. Based on the application of the QUALIDEM, the proxy-rating by one single nurse can be recommended.
2.3 METHODS AND MEASUREMENTS

German versions of the Maastricht Electronic Daily Life Observation Tool incl. Unser Guide and the Quality of Life Assessment Schedule are available.

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:


INTRODUCTION

For the diagnosis of dementia, several definitions and diagnostic manuals are available. In primary care, which means at the general practitioner’s or clinical specialist’s, the diagnosis of dementia is evaluated mainly symptom-oriented and is supported by imaging methods or blood or liquor tests. A differential diagnosis that involves the evaluation of the cause of the disease and a specification of the etiological type is very resource-intensive and complex; it requires a very profound knowledge about the patient and the symptom development in recent years. An absolutely certain diagnosis can sometimes only be made several years after the first symptoms occur.

Dementia is a disease which affects mainly very old people, who develop the Alzheimer’s disease or vascular dementia. In the elderly population, the diagnostics are especially difficult, because other morbidities or age-related sensory impairments exacerbate the performance of cognitive tests. Additionally, a distinction between an age-associated cognitive decline and the development of a dementia is difficult to determine.

The quality of existing dementia diagnoses is suboptimal in primary care in Germany. Studies showed that the diagnostics are seldom performed according to the latest guidelines and quite often existing diagnoses are no longer valid when they come under scrutiny. It is also assumed that many persons who suffer a dementia do not have a valid dementia diagnosis.

For health service research, this situation poses a severe challenge. Empirical studies require a precise definition of its population; a correspondent study sample should be determined and selected in a practicable, ethically justifiable and valid way and reported transparently. To improve the comparability of studies, a consistent approach of identifying the study sample would be of value to the research community.

The project aims to develop a theoretical- and empirical-based reference for the case identification in health services research on dementia. It is aimed to contribute to the development of best-practice
standards for the assessment of in- and exclusion criteria as well as the reporting in scientific journals. Additionally, the professional discussion about the operationalization of dementia and neurocognitive disorders should be enhanced. The developed reference should support health service researchers to decide about their sampling strategy (decision aid).

**METHODS**

As a first step, a literature review on methods used to identify the study population of people with dementia who live in nursing homes was conducted. The review is considered as a basic work that justifies the necessity of the whole project.

For developing the decision aid, other steps are planned. First, an overview of different methods to identify people with dementia/ neurocognitive disorders will be developed. The overview is based on empirical literature on the validity of the different methods. The overview will be judged by clinical experts in dementia diagnostics with respect to practicability. Empirical results on test accuracy and expert knowledge on practicability will be used to evolve the decision aid. The decision aid should be developed specifically for different healthcare settings in the form of an algorithm. Representatives from German health service research are invited to consent the decision aid in a Delphi-process.

**STATUS**

The literature review was published in 2016.

Initial preparatory work has been conducted for the development of the decision aid.

**RESULTS/ APPLICABILITY**

The decision aid should alleviate and standardize the definition of in- and exclusion criteria and the recruitment process. In future health service research studies, the sample size and the represented study population will be determined more precisely; this will improve the quality of health service research studies in the field of dementia.
2.3 METHODS AND MEASUREMENTS

DISSEMINATION

PAPER/ BOOKS/ REPORTS:

**2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS**

<table>
<thead>
<tr>
<th>Title</th>
<th>DIVERSITY OF CARE SERVICES FROM ONE SOURCE – A NURSING HOME AS THE CARE PLANNER, SERVICE PROVIDER AND GATE KEEPER FOR ELDERLY AND CARE-DEPENDENT PEOPLE LIVING IN THE COMMUNITY. AN EVALUATION STUDY OF AN INNOVATIVE CARE SERVICE MODEL IN GERMANY</th>
<th>Vifa</th>
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<td>Duration</td>
<td>2016 - 2018</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>Stiftung Wohlfahrtspflege NRW, DZNE</td>
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</tr>
</tbody>
</table>
| Collaboration | • Städtische Seniorenheime Krefeld, Andreas Kutschke  
• Hochschule Esslingen, Reinhold Wolke | |
| Principal Investigator | Margareta Halek (lead)  
Milena von Kutzeleben, Ina Hartwig (both project coordination) | |
| Scientific Staff | Bernd Albers, Ina Hartwig, Bernhard Holle, Daniel Purwins, Martina Roes, Anna Waldhausen (until 10-31-2016) | |

**INTRODUCTION**

Organizing home-based care arrangements and providing care for older people in the need of care and support at home presents several challenges for informal as well as for formal carers. One of the main reasons is the fragmentation within the German social security system and especially within the long-term care insurance law with its strict separation between inpatient, semi-inpatient and outpatient care. The consequence is a variety of service providers and institutions providing services underlyng different logics of provision, financing and sourcing. This often leads to a care situation that may not be needs-oriented or cover objective demands.

With their Gesamtversorgungskonzept (Care service model) the Städtische Seniorenheime Krefeld (SSK) provide outpatient care to people in the need for care and support living in private households within a defined radius in direct proximity to the four nursing homes of the SSK.

In order to be able to do so, the SSK negotiated contracts with the respective social insurance agencies as the legal framework for their project. This contract allows the SSK to offer a “basket” of services that covers all three settings (inpatient, semi-inpatient and outpatient care) without having to implement a separate ambulatory nursing service as well as social and household-related services from one source. Such a Gesamtversorgungsvertrag (Healthcare provision contract) is a radical inno-
vation within the German long-term care systems and is unprecedented in North Rhine-Westphalia so far.

The DZNE’s task within this project is to evaluate the SSK’s approach. The aim of this evaluation study is to gain a wide insight into how the organization of home-based care arrangements is performed. Therefore, the evaluation of this project focuses the perspectives of the users and service providers as well as the system and economic perspectives.

**METHODS**

The study has a prospective multi-perspective longitudinal design and uses qualitative and quantitative methods. The user perspective is comprised of case studies focusing on the experiences the SSK clients and their families gained throughout the implementation process of the Gesamtversorgungskonzept. This data collection will be complemented by the use of a quantitative assessment. Standardized questionnaires, single and focus group interviews are used to evaluate the service provider’s perspective. Data from the system perspective is provided by expert interviews with relevant stakeholders in the local and regional care system. In the economic perspective, data will be collected by analyzing documents, evaluating routine documentation and by conducting interviews with the SSK. Data concerning the client’s use of services will be collected by using standardized questionnaires.

All conducted qualitative interviews will be transcribed verbatim. Data collected for the part of the user perspective will be analyzed with thematic coding as described by Flick. The interviews conducted in the context of the service provider perspective will be analyzed by using problem-analysis according to Witzel. A content analysis in line with Mayring will be applied in analyzing the system perspective. The quantitative data analysis will use mainly descriptive statistics.

Quantitative and qualitative data will be used to inform and complement each other and will therefore be integrated taking the underlying research questions into consideration in order to be able to draw a comprehensive picture of the evaluation.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

**STATUS**

For the service provider and user perspectives, the data collection for T0 has been completed, including 10 cases in the qualitative and 37 in the quantitative strand. Data analysis in both strands is ongoing. In the system and economic perspectives, the data collection for T0 has been partially completed and is ongoing.

The next steps are the completion of the T0 data analysis and the preparation of T1 (starting in March 2017).

**RESULTS/ APPLICABILITY**

Evidence obtained during the analysis may serve the cost units as an important foundation for decisions about their orientation in future healthcare provision contracts. Moreover, interested funding institutions get a valuation basis and references for the implementation of a similar concept.
INTRODUCTION

Since the mid-nineties, person-centeredness – often cited in connection with Tom Kitwood – is a well-known concept in the field of care for people with dementia (PwD) as well as in dementia research. As an alternative concept for a primarily clinical and medical approach, person-centeredness marks a shift of perspective in dealing with PwD. Instead of treatment and cure of dementia the focus lies on the psychosocial consequences of the disease and therefore aims at improving quality of life. Under the label of person-centeredness, a broad and heterogeneous field can be found, ranging from concrete practical care and support measures to theoretical considerations and on to the approaches of care providers and research organizations. Since the nineties, the number of publications referring to person-centeredness has been growing; however, they refer to the concept in very different ways. In view of this development, the question arises whether and how person-centeredness can be understood as a coherent approach and whether it is based on a reliable common theoretical ground.

Furthermore, in the case of dementia the concept of person-centeredness poses special challenges for theory and practice. For the affected people the progressive course of the disease has direct implications on their world-experience and learning abilities. This has implications on personal identity, which becomes more and more fragile with further progression. Consequently, it seems that there is no common agreement on how “being a person” could be conceptualized, considering the background of dementia.
In order to do justice to the complexity of the field of person-centeredness in dementia, the research project Per-Dem presented here is divided into two parts. In the first part of the project, an inventory of the concept of person-centeredness will be undertaken. In doing so, the following questions should be considered: What does the concept of person-centeredness with regard to dementia mean in the research literature? What ideas of person-centeredness currently exist? Are there commonalities and/or differences in the definition of the concept? Is there a common theoretical reference framework to be identified?

The findings of these first steps will build a solid ground for a thorough discussion of the concept of personhood during the second part of the project. Considering the background of dementia, it seems to be questionable in general how personhood can be understood conceptually. Therefore the question is examined which concepts of personhood underlie the research literature with regard to dementia.

The resulting systematic substantial overview of the topic “person and dementia” will enable a critical examination of theories within dementia research as well as of existing care concepts. This will improve the appropriateness of the theories of person-centeredness and the concepts of “being a person” with dementia, which might lead to more theoretical grounding in research and practice.

In the medium term the preceding analysis provides the basis for a conceptual paper, which enables a concrete positioning of the DZNE in Witten within the international debate on person-centeredness.

The following research questions shall be answered during the project:

1. What does the concept of person-centeredness mean with regard to dementia in the research literature?
2. Which concepts of personhood underlie the research literature concerning person-centeredness with regard to dementia?
3. What are the consequences of the underlying concepts of personhood for dementia research and care?
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

METHODS

To cover a wide range of literature and to generate a systematic literature search as comprehensive as possible, the search will be conducted as a scoping study. A search strategy for a total of nine databases will be designed and corresponding search runs will be carried out. Apart from that, relevant publications will be additionally gathered through hand search and consultation of experts. Subsequently the full texts will be analyzed with MAXQDA. For dealing with the first research question, categories will be formed from the identified publications following the Grounded Theory (Glaser and Strauss) in order to describe in this way the different ideas of person-centeredness in appearance and content and, moreover, to quantify them numerically.

The results of the scoping study will be used to deal with the second and third research question in a next step. To identify the underlying concepts of the person and personhood from the research literature and to compare them differentially, the search strategy of the first research question may possibly have to be modified and a further research conducted. The subsequent analysis will also be carried out in MAXQDA.

STATUS

With reference to relevant publications on the subject of person and dementia (for example, the opinion of the German Ethics Council on Dementia and self-determination 2012) keywords were generated and a search strategy (with adjustments to the particular databases) was developed. A systematic literature search was conducted in nine databases (Medline, PsychInfo, PubPsych, Cinahl, Scopus, Web of Science, Cochrane, Sowiport, EBSCO-Geisteswissenschaften; overall hits n=3517), the duplicates were removed and a title/abstract screening with regard to the first research question was completed. Currently, the analysis of the included articles with MAXQDA is proceeding and first results have been presented to (inter)national cooperation partners. The planned completion date of the first project phase (scoping study) is 2017.

Autonomy is a central aspect of the status of personhood. Building on the first results of the scoping study, it has been possible to provide a contribution to the debate about social health\(^3\) and dementia. The identified literature of the scoping study was analyzed in a multi-step approach using discourse analytical methods. Heterogeneous conceptions of autonomy in the context of dementia

\(^3\) For further information see Dröes et al. (2017) Social health and dementia: a European consensus on the operationalization of the concept and directions for research and practice. Aging and Mental Health vol. 21, issue 1: 4-17.
were identified. This contributes to the consolidation of the concept of social health by stressing social attribution and perception of personhood. These results were presented at an international conference in Copenhagen in 2016.

RESULTS/ APPLICABILITY

The results of the project Per-Dem provide a systematic overview of the current debate on person-centeredness with regard to PwD. Alongside a concept clarification, the results enable a critical analysis of the consequences for existing care-concepts and of the theoretical background within dementia research in general. For the DZNE in Witten the results also contribute to positioning DZNE within the international debate on person-centeredness and dementia with regard to both research and care practice.

DISSEMINATION

CONFERENCES:


**2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS**

<table>
<thead>
<tr>
<th>Title</th>
<th>REVIEW OF EMPIRICAL STUDIES ON THE TOPIC „SOCIAL INCLUSION OF PEOPLE WITH DEMENTIA“</th>
</tr>
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<tbody>
<tr>
<td>Duration</td>
<td>2015 - 2017</td>
</tr>
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<td>Funding</td>
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<tr>
<td>Principal Investigator</td>
<td>Bernhard Holle (lead)</td>
</tr>
<tr>
<td>Scientific Staff</td>
<td>Christoph Cavazzini, Iris Hochgräber, Kerstin Köhler, Rebecca Palm, Christiane Pinkert, Milena von Kutzleben</td>
</tr>
</tbody>
</table>

### INTRODUCTION

The concept *social inclusion* in combination with dementia has rarely been examined in empirical studies. Up to now, only theoretical approximations can be found in Germany, if anything. Nevertheless, the concept is linked with an increasing amount of political and societal discussion. This reveals the need of operationalizing the concept as a topic for research. The planned review about social inclusion of PwD aims to achieve the following goals:

1. Examine how the definition and theoretical background of *social inclusion* and *exclusion* is embedded in studies
2. Understanding of the methodological and methodical approaches used for research of social inclusion and exclusion to date
3. Analyze relevant results from empirical studies concerning social inclusion and exclusion

The key issue of research is how the concepts *social inclusion* and *exclusion* of people with dementia are understood and applied.

### METHODS

To answer these questions, a literature research will be conducted. The literature will be screened, the inclusion criteria are empirical studies or reviews based on empirical studies (n=9) in the German or English languages.

### STATUS

At present, the articles found are being analyzed.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

RESULTS/ APPLICABILITY

The aim is to publicize the review in an international journal and hence provide a foundation for the further examination of the definition *social inclusion*, the ability for research and development of interventions and tests with regard to social inclusion. This base serves not only for the scientific work at DNZE site Witten, but also for the whole scientific community.
INTRODUCTION

The majority of people with dementia (PwD) in Germany lives at home and is cared for by family members and other informal carers. These care arrangements, which are coordinated mostly by informal carers, are the backbone of home-based dementia care.

StiV-H is a follow-up study of the VerAH-Dem study, which was conducted at the DZNE Witten between 2010 and 2013. One of the main results of VerAH-Dem is a phase model illustrating informal caring trajectories from the onset up to the late phases of a dementia-associated disorder; creating and maintaining stability was identified as being an underlying theme over the whole course of the trajectory.

The StiV-H study takes up these results and aims at a deeper understanding of what constitutes stability of home-based care arrangements and the development of a methodological approach to assess stability in the future.

The short-term objective of StiV-H is to develop a definition for the phenomenon ‘stability of home-based care arrangements’ with a focus on informal caring trajectories and needs and the demands of PwD and their families. Furthermore, the aim is a) to identify and operationalize influencing factors on stability; and b) to empirically validate the phase model of informal caring trajectories. The project investigates the following research questions:

1. How can the stability of home-based care arrangements for PwD be defined and what constitutes and influences stability?
2. How can identified influencing factors be operationalized and analyzed?
3. Is the phase model developed in the VerAH-Dem pilot study valid and generalizable? Are there phase-specific influencing factors on stability?
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

METHODS

The development of a definition of stability of home-base care arrangements will be made in a consensus process (focus groups with experts) in Witten de. Moreover, a systematic review about the stability of home-based care arrangements for PwD and their influencing factors over the course of time will be conducted. Finally, a validation study on the pre-existing phase model of informal caring trajectories in home-based care arrangements for PwD (focus groups with informal carers) will be performed.

STATUS

A definition of stability of home-based care arrangement has been developed and published. This definition serves as the theoretical starting point for the meta-study, which is in progress. The validation study (focus groups) is in progress, data collection has been completed. Both strands of the study, the meta-study and the validation of the phase model of informal caring trajectories, will be completed by the end of 2017.

RESULTS/ APPLICABILITY

The StiV-H study will provide a validated trajectory model of informal caring over the course of a dementia-related disorder in home-based care arrangements and also a compilation of influencing factors on stability for this setting.

The results can be used to develop a stability assessment in order to develop interventions to promote and maintain stability so that PwD can remain at home for as long as possible under satisfying conditions for all parties involved.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

## 2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

<table>
<thead>
<tr>
<th>Title</th>
<th>insideDEM - UNDERSTANDING THE BEHAVIOR OF PERSONS WITH DEMENTIA WITH ASSISTIVE TECHNOLOGIES USING DIAGNOSTIC AND DECISION PROCESSES</th>
<th>insideDEM</th>
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<tr>
<td>Duration</td>
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<tr>
<td>Funding</td>
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</table>
| Collaboration | • German Center for Neurodegenerative Diseases (DZNE) with sites in Witten and Rostock/Greifswald  
  • euregon AG, Augsburg  
  • Städtische Seniorenheime Krefeld  
  • University of Rostock, Institute of Computer Science, Mobile Multimedia Information Systems Group  
  • University of Applied Sciences Dusseldorf, Faculty of Media |          |
| Principal Investigator | Margareta Halek (lead),  
  Sven Kernebeck (project coordination) |          |
| Scientific Staff | Sven Kernebeck, Daniela Holle, Martina Roes |          |

## INTRODUCTION

Handling challenging behavior is one of the most demanding burdens of caring for persons with dementia. Understanding diagnostic is a method of analyzing possible reasons for challenging behavior for professional nursing staff. However, the IdA Assessment is a systematic method for understanding diagnostic which is only available for professional nurses. A method for informal caregivers is not yet available. The particular focus of insideDEM is to adapt the IdA Assessment as a part of an assistive technology for understanding diagnostics for informal caregivers. The following aims are to be achieved:

1. To increase the quality of care for persons with dementia by adapting the IdA Assessment as a part of an assistive technology for informal caregivers
2. Real-time sensor-based activity recognition of challenging behavior of persons with dementia.
3. Efficient computer-based implementation of an assistive technology in the working processes between informal and formal caregivers
4. To present an exemplary and user-centered approach to develop assistive technologies for persons with dementia
5. Analyzing ethical and legal consequences of the insideDEM assistive technology
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

METHODS

An assistive technology is being developed by using a stepwise and user-centered approach. After the development phase, the assistive technology will be evaluated in a Stepped-Wedge-Study.

STATUS

To summarize the dementia-specific knowledge for the assistive technology, a comprehensive review of the literature has been conducted, focused on the reasons for challenging behavior. Furthermore, we are conducting discussions between dementia experts at the DZNE in Witten to adapt IdA for the use of informal caregivers. In addition, we are initiating the process to conduct the pilot study and the study to analyze the social and legal implications of the technology.

RESULTS/ APPLICABILITY

At the end of the project, it will be possible to support informal caregivers in managing the challenging behavior of their relatives in their homes with the help of the developed assistive technology.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

DISSEMINATION

CONFERENCES:


### INTRODUCTION

Caregiving for people with dementia (PwD) is often very challenging, particularly for family members. This situation is associated with the compensation of functional limitations and insufficient use of supporting structures for family caregivers of people with dementia. Mobility programs potentially delay the functional decline of dementia, and structured information material may help families to identify appropriate supporting structures in the healthcare system. While short-term care is frequently used in Germany, its potential for the rehabilitation of PwD and for informing family caregivers is widely unused.

Study aim is the development and testing of a rehabilitation concept for PwD and their family caregivers in short-term care. The concept is based on a mobility rehabilitation program for PwD with a) interventions addressing functional limitations and b) the provision of information for family caregivers regarding the use of dementia health services in Germany. The concept will be evaluated with respect to its usability and implementation requirements. This leads to the following research questions:

1. What kind of interventions are relevant for developing a dementia-specific short-term care concept addressing the delay of functional limitations and counseling services for caring relatives?
2. What personal resources are required for the study participants for the execution of the program as originally planned?
3. What subjective rating about the quality and usability of the dementia-specific respite care concept can be concluded by the respite care staff?
4. What subjective rating about the quality and usability of the respite care concept can be concluded by the caring relatives?
METHODS

A pilot based, quasi-experimental evaluation study will be conducted. The intervention will be structured by a one-group pre-post design.

The program will be conducted within a specialized respite care facility at the Caritas in Paderborn. The number of involved dyads will be based on the number of available participants meeting the inclusion criteria. During the intervention time (10 months) there will be a maximum of 10 PwD at one time. About 100 Dyads will be available during the 10-month intervention period. About 40% of the PwD will be staying two weeks or longer at the center, which is an inclusion criterion. Based on the number of dropouts (10%) and size of the facility (10 beds), it is expected to recruit 30 dyads (PwD + Family caregiver) during a 10-month period.

As a primary outcome, the ADL abilities of PwD related to mobility will be examined for which the assessments Short Physical Performance Battery, Box-and-Plot Test and Strength Dexterity Test will be utilized. The primary outcome of caring-associated burden in caring relatives is provided by the Berlin Inventory of Caregivers’ Burden with Dementia Patients. In addition to the quantitative measurements, it is planned to collect information about the feasibility of the rehabilitation concept. Therefore, a qualitative study design with semi-structured interviews will be used. The participants will be a) staff members b) and family caregivers.

The quantitative data will be analyzed using SPSS. The interviews will be transcribed and analyzed using the content analysis method.

STATUS

It is planned that the literature search will be finished by December 2016. Currently (December 2016), the intervention parts related to the mobility and counseling program are being developed based on the literature research. After this, the intervention parts will be fed back into the main respite care concept. This first concept draft will be reviewed by an expert panel by April 2017. Based on this evaluation round, the concept will be optimized and potentially modified.
RESULTS/ APPLICABILITY

It is expected that the concept will be successfully applicable for PwD in the short-term care setting. Together with the information for family caregivers, the concept has the potential to stabilize the caring situation at home. The concept will be structured in the form of a practice-friendly manual. Based on this manual, a broader implementation of this concept into other respite care facilities should become possible.
3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016

3.1 ARTICLES (PEER-REVIEWED)


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016


3.2 ARTICLES (NOT PEER-REVIEWED)


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016


3.3 REPORTS


3.4 EDITED BOOK


3.5 BOOK CHAPTER

3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016

3.6 PRESENTATIONS (PEER-REVIEWED)


Schneider, K., Palm, R., & Hotze, E. (2016, November 9 – 10). *Nursing home residents experiences of living together and sharing daily lives with cognitively impaired fellow residents - results from a qualitative study*. Nursing home Research International Working Group Meeting, Barcelona.


### 3.7 PRESENTATIONS (INVITED)


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2016

3.8 SELF-ORGANIZED EVENTS

<table>
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<tr>
<th>Event</th>
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<th>Location</th>
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<tbody>
<tr>
<td>4th</td>
<td><strong>Practice-Research-Dialogue</strong>: “Approaches of Cross-sectoral Care for People with Dementia”</td>
<td>March 17, 2016</td>
<td>DZNE Witten</td>
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<tr>
<td>5th</td>
<td><strong>Practice-Research-Dialogue</strong>: “Advisory Services for People with Dementia and their Informal Caregivers/ Social Network”</td>
<td>November 16, 2016</td>
<td>DZNE Witten</td>
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<tr>
<td>7th</td>
<td><strong>Annual Conference of DZNE site Witten</strong>: “Care Strategies for People with Dementia. Methods in Research and Practice to Strengthen Autonomy and Social Inclusion”</td>
<td>September 28, 2016</td>
<td>Witten/Herdecke University</td>
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</table>
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

Most of the scientific staff are members of the Faculty of Health at Witten/Herdecke University. Moreover, the site is a member of the Interdisciplinary Centre for Health Services Research (IZVF, Witten/Herdecke University). Employees and their activities are listed below as at the end of 2016.

DICHTER M.
- German Nurses Association Northwest (DBfk, executive board member)
- German Society for Epidemiology (DGEpi) e.V.
- German Society of Nursing Science (DG Pflegewissenschaft)
- European Academy of Nursing Science (EANS)
- International Psychogeriatrics Association (IPA)
- International Society of Quality of Life Research (ISOQOL)

DINAND C.
- German Society of Nursing Science (DG Pflegewissenschaft)
- Working Group Digital Health, Deutsches Netzwerk Versorgungsforschung e. V. (DNVF) (German Network Health Care Research)

DÖTTLINGER B.
- German Society of Nursing Science (DG Pflegewissenschaft)
- Internationaler Förderverein Basale Stimulation e. V.

GRAF R.
- German Nurses Association (DBfk)
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

HALEK M.
- German Society of Nursing Science (DG Pflegewissenschaft)
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- Member of the project advisory board: Persönliche Lebensdokumentation für Menschen mit Demenz und Pflegepersonen (PERLEN, Personal documentation of life for people with dementia and caregivers) (2016 - 2018)
- Member of the expert group „Expertenstandard zur Pflege von Menschen mit Demenz“ (Expert standard for nursing care for people with dementia) of DNQP (German Network for Quality Development in Nursing) (2015 - 2017)
- Editorial board of the BMFSJF (Federal Ministry of Family, Senior Citizens, Women and Youth) website, people with dementia in hospital
- Advisory board, Stiftung Pflege e.V. (Foundation for nursing care)

HOLLE B.
- German Society of Nursing Science (DG Pflegewissenschaft)

HOLLE D.
- German Society of Gerontology and Geriatrics (DGGG)
- German Society of Nursing Science (DG Pflegewissenschaft), (Vice Delegate for AWMF-Guidelines, cash auditor)
- European Academy of Nursing Science (EANS)
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- International Psychogeriatric Association (IPA), member of the BPSD forum
- Member of the expert working group for updating the expert standard “Ernährungsmanagement zur Sicherstellung und Förderung der oralen Ernährung in der Pflege” (Nutrition management for ensuring and promoting oral nutrition), DNQP
- Member of the working group “Dementia Outcome Measures; charting new territory” supported by the EU Joint Program – Neurodegenerative Disease Research (JPND)
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

- Member of the expert working group for updating the DEGAM-guideline „Pflegende Angehö- rige“ (caring relatives), delegate of DGP
- REFLECTION Network

KERNEBECK S.
- Deutscher Verband für Gesundheitswissenschaften und Public Health e.V. (DVGPH) (Association for health sciences and public health)
- German Network for Evidence-based Medicine
- Society for the scientific investigation of parasciences (GWUP)
- German Society of Gerontology and Geriatrics (DGGG)
- Deutsches Netzwerk Versorgungsforschung e. V. (DNVF) (German Network Health Care Research)

KÖHLER K.
- German Society of Gerontology and Geriatrics (DGGG)

LAPORTE URIBE F.
- Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART)

PALM R.
- German Nurses Association (DBfK)
- German Society of Nursing Science (DG Pflegewissenschaft)
- European Academy of Nursing Science (EANS)
- International Psychogeriatric Association (IPA)
- German Academic Scholarship Foundation, Alumni
- Deutsche Expertengruppe Demenzbetreuung e.V. (DED)
- Deutsches Netzwerk Versorgungsforschung e. V. (DNVF) (German Network Health Care Research), Speaker of the Working group Youth Development
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

PANKE-KOCINKE B.
- German Society of Nursing Science (DG Pflegewissenschaft)

PINKERT CH.
- German Society of Nursing Science (DG Pflegewissenschaft)

PURWINS D.
- German Society of Nursing Science (DG Pflegewissenschaft)

QUASDORF T.
- German Society of Nursing Science (DG Pflegewissenschaft)
- German Nurses Association (DBfK)

ROES M.
- Dementia Doctoral Training Centre (University of Bradford, UK), member of the scientific board
- Academy Health - Advancing Research, Policy and Practice, member of the program committee
- German Society of Gerontology and Geriatrics (DGGG)
- German Society of Nursing Science (DG Pflegewissenschaft), section dissemination and implementation (SDI)
- German Network Healthcare Research (Deutsches Netzwerk Versorgungsforschung e. V.) (DNVF), founder member of the section health literacy
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- Federal Joint Committee (G-BA), member of three working groups
- Gerontological Society of America (GSA)
- Harkness Fellow, Alumi Commonwealth Foundation
- Institute for Quality and Efficiency in Health Care (IQWiG), board of trustees
- Improvement Science Research Network (ISRN)
- International Psychogeriatric Association (IPA), member of the program committee
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

- Robert Bosch Fellow, Alumi
- Society for Implementation Research Collaboration (SIRC), Founding Member
- Scientific board of the care congress Bremen, speaker

**SCHWAB C. G. G.**
- German Nurses Association Northwest (DBfk, board member)
- German Society for Epidemiology (DGEpi) e.V.
- German Society of Nursing Science (DG Pflegewissenschaft)
- German Network Healthcare Research (Deutsches Netzwerk Versorgungsforschung e. V.) (DNVF)
- Honor Society of Nursing, Sigma Theta Tau International (STTI), Rho Chi Chapter
- International Council of Nurses (ICN)

**SERBSER J.**
- German Society for Human Ecology (DGH)
- INTERDEM Academy

**TRUTSCHEL D.**
- German Association for Medical Informatics, Biometry and Epidemiology (GMDS) e. V.

**VON KUTZLEBEN M.**
- Mixed Methods International Research Association (MMIRA)
- Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART)
5. WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS

Employees and their activities as peer reviewers in scientific journals are listed below. Further tasks are listed additionally (as at the end of 2016).

BERWIG M.
- Aging and Mental Health

DICHTER M.
- Alzheimer Disease & Associated Disorders
- Archives of Gerontology and Geriatrics
- BMC Geriatrics
- Clinical Interventions in Aging
- Cochrane Database for Systematic Reviews
- Dementia and Geriatric Cognitive Disorders
- Health and Quality of Life Outcomes
- International Journal of Geriatric Psychiatry
- International Journal of Nursing Studies
- International Psychogeriatrics: Associate Editor
- Journal of Evaluation in Clinical Practice
- Klinische Pflegeforschung
- Neuropsychiatric Disease and Treatment
- Pflege (Huber)
- Pflege & Gesellschaft
- Quality of Life Research
- Scandinavian Journal of Caring Science
- German Journal for Evidence and Quality in Health Care
### 5. WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS

<table>
<thead>
<tr>
<th><strong>DINAND C.</strong></th>
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</tr>
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<tbody>
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<td>• Scandinavian Journal of Caring Sciences (SJCS)</td>
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<td>• International Journal of Nursing Studies (IJNS)</td>
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<td>• American Journal of Alzheimer Disease &amp; Other Dementia</td>
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<td>• BMC Health Services Research</td>
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<td>• International Journal of Nursing Studies (IJNS)</td>
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<td>• International Psychogeriatrics</td>
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<td>• Journal of Aging and Health</td>
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</tbody>
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### 5. WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS

<table>
<thead>
<tr>
<th>NAME</th>
<th>Publications and Contributions</th>
</tr>
</thead>
<tbody>
<tr>
<td>PALM R.</td>
<td>• American Journal of Alzheimer’s Disease and other Dementias&lt;br&gt;• BMC Geriatrics&lt;br&gt;• BMJ Open&lt;br&gt;• International Psychogeriatrics&lt;br&gt;• International Journal of Nursing Studies&lt;br&gt;• Palliative Medicine&lt;br&gt;• Sage Open Medicine</td>
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<td>REUTHER S.</td>
<td>• International Psychogeriatrics</td>
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<td>ROES M.</td>
<td>• Gerontology Society of America: review abstracts&lt;br&gt;• Healthcare Policy&lt;br&gt;• Managementhandbuch Pflege, medhochzwei Verlag: co-editor&lt;br&gt;• PADUA, Huber Verlag: co-editor&lt;br&gt;• Pflege und Gesellschaft, Juventa&lt;br&gt;• Pflegewissenschaft, hps media: editorial&lt;br&gt;• Zeitschrift für Gerontologie und Geriatrie</td>
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<tr>
<td>SCHWAB C.G.G.</td>
<td>• Pflege (Huber)</td>
</tr>
<tr>
<td>VON KUTZLEBEN M.</td>
<td>• International Psychogeriatrics&lt;br&gt;• Scandinavian Journal of Caring Sciences</td>
</tr>
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</table>
6. TEAM

E-Mail: name.surname@dzne.de  ·  Phone: +49 2302/ 926-

<table>
<thead>
<tr>
<th>Name</th>
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<tr>
<td><strong>Management</strong></td>
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<td><strong>Roes, Martina</strong></td>
<td>Site speaker</td>
<td>Prof. Dr. phil. Dipl. Soziologin</td>
<td>147</td>
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<tr>
<td><strong>Waldhausen, Anna</strong></td>
<td>Scientific assistant to the site speaker</td>
<td>MSc European Studies, Dipl.-Soz. Wiss.</td>
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<tr>
<td><strong>Zimmermann, Marit</strong></td>
<td>Scientific assistant to the site speaker</td>
<td>MSc Evidence-based Health Care</td>
<td>244</td>
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<td></td>
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<tr>
<td><strong>Halek, Margareta</strong></td>
<td>Senior research group leader Care interventions and co-speaker</td>
<td>Dr. rer. medic., MScN</td>
<td>108</td>
</tr>
<tr>
<td><strong>Holle, Bernhard</strong></td>
<td>Senior research group leader Care structures</td>
<td>Dr. rer. medic., MScN</td>
<td>241</td>
</tr>
</tbody>
</table>

| **Administration**          |                                               |                                             |             |
| **Dünhölter, Cornelia**     | Site coordination                             | Dipl. oec. MScCM                            | 236         |
| from January 2015           |                                               |                                             |             |
| **Freudewald, Heike**       | Administration                                |                                             | 235         |
| **Karwatzki, Sigrid**       | Administration (on sick leave)                |                                             | 235         |
| **Möller, Sabine**          | Administration                                | Industrial business management assistant    | 237         |
## Research Group Methods in Health Service Research

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
<th>Additional Qualifications</th>
<th>Code</th>
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<tbody>
<tr>
<td><strong>Roes, Martina</strong></td>
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<td><strong>Albers, Bernd</strong></td>
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<td><strong>Döttlinger, Beatrix</strong></td>
<td>Scientific staff</td>
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<td></td>
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<tr>
<td><strong>Müller, René</strong></td>
<td>Data Management</td>
<td>Medical documentarian</td>
<td>209</td>
</tr>
<tr>
<td><strong>Panke-Kochinke, Birgit</strong></td>
<td>Scientific staff, Qualitative methods</td>
<td>Venia legendi Soziologie, Dr. phil., Staatexamen Sek.2</td>
<td>227</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<tr>
<td><strong>Schwab, Christian G. G.</strong></td>
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<td>258</td>
</tr>
<tr>
<td></td>
<td></td>
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<td><strong>Trutschel, Diana</strong></td>
<td>Scientific staff, Quantitative methods</td>
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<td>249</td>
</tr>
</tbody>
</table>

## Research Group Care Interventions

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<td><strong>Halek, Margareta</strong></td>
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<td>108</td>
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<td><strong>Graf, Rabea</strong></td>
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<td>269</td>
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<tr>
<td>from November 2016</td>
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<td>Dr. rer. medic., MScN</td>
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<td><strong>Segschneider-Rosier, Ute</strong></td>
<td>Scientific staff</td>
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### 6. TEAM

#### Research Group Care structures

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<th>Name</th>
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<td>241</td>
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<td>213</td>
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</tr>
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<td>MScN</td>
<td>252</td>
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<td>228</td>
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<td>von Kutzleben, Milena</td>
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<td>MScEMPH</td>
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</table>

#### Research Group Implementation and Dissemination

<table>
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<tr>
<th>Name</th>
<th>Position</th>
<th>Qualification</th>
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<tr>
<td>Laporte Uribe, Franziska</td>
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<td>Ph.D. HlthSc M.A. language &amp; communication</td>
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<td>Quasdorf, Tina</td>
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</table>
### Student Assistants

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<th>Name</th>
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<tr>
<td><strong>Abdel-Ghani, Lea</strong></td>
<td>Student assistant</td>
<td>Evidence-based Health Care,</td>
<td>Hochschule für Gesundheit Bochum</td>
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<td><strong>August – November 2016</strong></td>
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<tr>
<td><strong>Book, Verena</strong></td>
<td>Student assistant</td>
<td>Public Health, Bielefeld</td>
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<td><strong>Hartwig, Ina</strong></td>
<td>Student assistant</td>
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### ATTACHMENT: PROJECT LIST

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Title</th>
<th>Page</th>
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</thead>
<tbody>
<tr>
<td></td>
<td><strong>Psycho-social interventions for different dementia forms and stages</strong></td>
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<tr>
<td>AMEO-FTD</td>
<td>The perspectives of people with Frontotemporal Dementia (FTD) and their needs and demands in everyday life</td>
<td>17</td>
</tr>
<tr>
<td>FallDem</td>
<td>Case conferences for people with dementia living in nursing homes</td>
<td>20</td>
</tr>
<tr>
<td>Verdi-H; Verdi-KH</td>
<td>“Understanding diagnostics” in the care of people with dementia and challenging behavior</td>
<td>25</td>
</tr>
<tr>
<td>INDUCT</td>
<td>Interdisciplinary network for dementia using current technology</td>
<td>28</td>
</tr>
<tr>
<td>Best-for-FTD</td>
<td>Best-practice-strategies for the care of people with behavioral variant Frontotemporal Dementia (BVFTD)</td>
<td>30</td>
</tr>
<tr>
<td></td>
<td><strong>Quality of Care</strong></td>
<td></td>
</tr>
<tr>
<td>DemenzMonitor</td>
<td>Longitudinal survey of dementia-related institutional and resident characteristics in German nursing homes</td>
<td>33</td>
</tr>
<tr>
<td>GesKom</td>
<td>Gestural communicative action as a link between language and action in persons with dementia</td>
<td>37</td>
</tr>
<tr>
<td>REDEZEIT</td>
<td>REDEZEIT-Telephone based support groups for informal caregivers caring for persons with dementia</td>
<td>39</td>
</tr>
<tr>
<td>Exper-Dem-DNQP</td>
<td>Creation of a literature study for the development of the expert standard with the topic “Nursing Care for people with dementia”</td>
<td>42</td>
</tr>
<tr>
<td>BeStaDem</td>
<td>Special Dementia Care in Nursing Homes</td>
<td>46</td>
</tr>
<tr>
<td></td>
<td><strong>Methods and Measurements</strong></td>
<td></td>
</tr>
<tr>
<td>Qol-Dem</td>
<td>Measuring the quality of life of people with dementia in nursing homes in Germany</td>
<td>48</td>
</tr>
<tr>
<td>Cognition</td>
<td>Identification of people with neurocognitive disorders (dementia) in health service research</td>
<td>51</td>
</tr>
<tr>
<td></td>
<td><strong>Potentials in and of Care Arrangements</strong></td>
<td></td>
</tr>
<tr>
<td>Vifa</td>
<td>Diversity of care services from one source – A nursing home as the care planner, service, provider and gate keeper from elderly and care dependent people living in the community. An evaluation study of an innovative care service model in Germany</td>
<td>54</td>
</tr>
<tr>
<td>Per-Dem</td>
<td>Person-centeredness and concepts of the person in the context of dementia</td>
<td>57</td>
</tr>
<tr>
<td>Review Social Inclusion</td>
<td>Review of empirical studies on the topic “Social inclusion of people with dementia”</td>
<td>61</td>
</tr>
<tr>
<td>StiV-H</td>
<td>Stability in home care arrangements for people with dementia</td>
<td>63</td>
</tr>
<tr>
<td>insideDEM</td>
<td>Understanding the behavior of persons with dementia with assistive technologies using diagnostic and decision processes</td>
<td>66</td>
</tr>
<tr>
<td>DESKK</td>
<td>Development and testing of a dementia specific respite care concept</td>
<td>69</td>
</tr>
</tbody>
</table>