ANNUAL REPORT 2017

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1. 2017 AT A GLANCE

1.1 HIGHLIGHTS IN 2017

As the year 2017 comes to an end, we can look back on many highlights and challenges at the DZNE in Witten: innovative projects were completed, new interesting projects started, our scientific work has been honored and, furthermore, we got inspiring perspectives from researchers around the world.

As in recent years, the topic of international collaboration has been a special focus at DZNE Witten and has also been pursued in 2017. With a grant from the German Research Foundation (DFG) to initiate international cooperation on the topic “Comparison of an implementation strategy for improving continuity of person-centered care (PCC) for behavioral and psychological symptoms of dementia (BPSD) during transitions between acute and sub-acute care settings”, site speaker Prof. Martina Roes and her research team had a lively exchange with Prof. Ann Kolanowski from the Pennsylvania State University, USA. Mutual visits took place and specific aims for a research grant were refined: Specifically these were to discuss implementation strategies suitable to the requirements of nursing homes in both countries, to discuss outcome measures related to the implementation strategy including a concept for the process evaluation, and to identify methods regarding the effectiveness of the implementation strategy. Moreover, PhD-students and research associates from both institutions participated in various lectures and a journal club held by Prof. Roes and Prof. Kolanowski. Furthermore, Prof. Kolanowski visited two care facilities to gain a better understanding about the differences of dementia-specific care concepts in Germany. Her next visit is planned for January 2018.

In addition, qualitative researchers from the DZNE Witten presented and discussed audio-visual procedures and their potentials for research with people with dementia during a workshop on qualitative methods and instruments, which we organized with international experts. Beside presentations on video-interaction-analysis by our researchers, we had two special guests: Prof. Ann Kolanowski pre-
1.1 HIGHLIGHTS IN 2016

Presented the reliability of video-based behavior-related data and the professional French photographer and visual artist Carl Cordonnier showed the process of his creative transmedia project “I still exist”, a project he conducted over a period of two years with people with dementia and their families.

In collaboration with Prof. Kimberly van Haitsma (PennState University, USA), the DZNE in Witten started a new project on the assessment preferences in daily life of people receiving care either at home, in a nursing home or at an adult care facility (PELI). The aim of the project PELI-D is to translate the PELI instruments for the different care settings into German and to test the applicability of PELI-D in a pilot study.

Further international collaboration took place within the project INDUCT – Interdisciplinary Network for Dementia Using Current Technology (funded by the European Commission/ Marie Skłodowska-Curie actions), in which DZNE Witten acts as a second level partner. Additionally, we hosted 1 of the 15 Early Stage Researchers (ESR). The ESR, originally based in the U.K., is now studying at the Karolinska Institute Sweden (her supervisor is Prof. Nygård). Besides meeting with different researchers from Witten and Rostock, since Oct. 2017 the ESR visited a few facilities, which were either involved in a research technology project (InsideDem) or were working on the use of innovative everyday technology (e.g. Gute Hoffnung, Oberhausen-Sterkrade). Moreover, the 3rd INDUCT school, which will be conducted in Witten in January 2018, was prepared during the year.

Shortly before the Christmas season, a team of researchers from University of Wisconsin and from different sites of the DZNE met for a 2-day workshop. The overarching goal of this collaboration was to identify, develop, and/or implement innovative novel care approaches, to promote the quality of life and outcomes of people with dementia and their significant others/family caregivers. We came up with some potential international research pilot projects. One is directly linked to a research project here in Witten: the on-line US/German Delphi Survey on Best Definition of ‘Stability’ in and of Care Arrangements.

Besides that, the project “Exper-Dem-DNQP” was completed successfully. A research team in Witten conducted a literature study for the development of the expert standard with the topic “Beziehungs- gestaltung in der Pflege von Menschen mit Demenz” (Fostering and sustaining relationships in care for people with dementia) in collaboration with the German Network for Quality Development in Nursing (DNQP) and the Osnabrück University of Applied Sciences. Furthermore, over the period of 1 1/2 years the researchers in Witten worked closely with 12 experts from practice and science to define the quality how to foster and sustain relationships in care for people with dementia. A national consensus conference with ~750 participants took place at OsnabrückHalle on October 6, 2017. Un-
1.1 HIGHLIGHTS IN 2016

Under the lead of the DNQP a six-month pilot implementation project started in December 2017. Results will be presented at the beginning of 2019.

This year, we again organized our annually occurring events. Professionals from research, associations and communities were invited to the 8th annual conference. Around 140 participants discussed the main topic “In- or outpatient care setting? Perspectives on dementia specific care”. A special highlight here was the short interview with the nationally well-known cartoonist Peter Gaymann together with his exhibition ‘Demensch’, which focuses on the daily life of people with dementia.

Next to the annual conference, the Practice-Research-Dialogue in 2017 addressed the topics ‘Communication with people with dementia’ and ‘People with dementia in early years’. The Practice-Research-Dialogue takes place twice a year and aims to connect healthcare professionals with researchers from the DZNE Witten to discuss the current state of research and to identify new relevant research questions.

Additionally, the research team of the project “DemNet-D” which, inter alia, involved the DZNE sites Witten and Rostock/Greifswald, has been honored with the “Hufeland-Prize” by the Deutsche Ärzteversicherung.

One of the most important milestones this year was the opening ceremony of the new building of the DZNE headquarters in Bonn, attended by Federal Chancellor Angela Merkel and Science Minister of North-Rhine Westphalia Svenja Schulze. Furthermore, Prof. Nicotera (Scientific Director of the DZNE) announced the initiative of the “German Dementia Foundation” (Deutsche Demenz Stiftung e.V.).
In spite of all the work during the year, Witten’s team explored the Ruhrgebiet by canoe and had a BBQ afterwards – it was their annual works outing. It was an enjoyable adventure, strengthening the recently expanded team for a motivating and inspiring year in 2018.

Staff of the DZNE Witten during the canoe trip in Hattingen
STRUCTURE OF THIS REPORT

The first chapter gives an overview of the staff at the DZNE in Witten, the scientific activities and cooperation that took place during the year 2017. The second chapter describes ongoing and completed projects. Since the scientific work at DZNE Witten is divided into four research topics (fig. 1), the project descriptions in the report are structured in the appropriate field of research.

![Figure 1: Research topics at DZNE Witten](image)

Chapter three lists publications without direct project reference, such as self-organized events, followed by a brief synopsis of the staff’s work on boards, their consulting activities and their work for scientific journals and publishers. Finally, there is a list of the staff members and their corresponding working groups and the report closes with an appendix containing an index of the projects.
1.2 PERSON-CENTEREDNESS – A NECESSITY IN DEMENTIA CARE AND RESEARCH

1.2.1 INTRODUCTION

Kitwood’s key contribution to understanding dementia and, in the process, was the development of the term ‘personhood’, defined as ‘a status or standing bestowed upon one human being, by others, in the context of social relationship and social being. It implies recognition, respect and trust.’ (Kitwood, 1997a, p. 8). Consequently, to maintain personhood other people need to enter into partnership with that person and assist them to maintain an identity and worth through their interactions and communications (Cowdell, 2006; Dewing, 2008). ‘The uniqueness of persons - in any context - is an extremely complex matter. We need to take account of temperament, innate ability, interests, tastes, beliefs, values, commitments, lifestyle, biography, gender, class and culture at the very least. To incorporate even a small part of this into a social science framework requires the eclectic use of several bodies of theory, crossing the conventional boundaries between psychology and sociology. Some of the variability is captured in the concept of personality; the key point is that just as each personality is unique, so also is the nature and color of experience’ (Kitwood, 1997b, p. 14).

Innes (2009) pointed out, that we’re confronted with a web of understanding of dementia, depending on which perspective we use: a biomedical research perspective understands dementia as a disease and addresses interventions and their impact on symptoms of dementia, while care practices may focus on how to alleviate the symptoms of dementia. From a social-psychological research perspective dementia is seen as an individual experience and we are interested in tailoring the interventions to the individual preferences and needs. Research will include the perspective of the person with dementia and their social network. The psycho-social perspective is grounded in Kitwood’s idea that valuing the experience of people with dementia is of high relevance. He suggested six access routes to gain insight in the experience of people with dementia; ‘(1) take into account what have been written by people with dementia; (2) carefully listening to what people say, (3) attending carefully and imaginatively to what people say and do in the course of their ordinary life, (4) consulting people who have undergone an illness with dementia-like features, (5) through the use of our own poetic imagination and (6) using role play: that is, actually taking on the part of someone who has dementia, and living it out in a simulated care environment’ (1997, pp. 15-18).
1.2 PERSON-CENTEREDNESS – A NECESSITY IN DEMENTIA CARE AND RESEARCH

1.2.2 PERSON-CENTEREDNESS AS AN OVERARCHING GOAL OF DEMENTIA CARE

Presently, there are a variety of comprehensive, empirically and conceptually derived frameworks of the dimensions of person-centeredness and person-centered care specifically across long-term services and supports. One root lies within Kitwoods (1997a) work. He pointed out, that personhood is a standing or status that is bestowed on one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust. In general, there is also a need to address aspects like sustaining autonomy and supporting social inclusion, especially if people with dementia are living at home as long as possible and social isolation may occur as a side effect of stigmatizing people with dementia. The added value of a social health perspective includes several core features: (1) the ability to manage daily life with a maximum degree of independence; and (2) the capacity to fulfill one’s potential and obligations as well as participating in social activities (3) (Droes et al., 2016).

Examining the content and structure of existing person-centered care tools is necessary as well as developing a national quality frame for people with dementia.

1.2.3 CURRENT PROJECTS AT THE DZNE WITTEN ADDRESS PERSON-CENTEREDNESS

Quite a few current research projects focus on the lens of professionals when analyzing and improving person-centered approaches. We started in 2014 with the analysis of the understanding of personhood in the literature, mainly because we missed the operationalization of personhood (based on Kitwoods and other authors understanding) in person-centered care approaches (PerDem). One side effect of this conceptual discourse stimulated a discussion of personhood within the social health dementia research initiative across Europe.

Another side effect of the conceptual discourse about personhood led to a literature review conducted in 2016, which was used as an underlying background search on care approaches related to relationships with people with dementia. Together with a national dementia expert group and in collaboration with the German Network for Quality Development in Nursing we defined a national expert standard (sustaining and fostering relationship with people with dementia) and developed 25 criteria to describe the quality of care (ExperDem). The publication of this National Expert Standard was followed by broad coverage in the professional social media and the professional community. The overall goal and these criteria have been presented at a national consensus conference (Oct. 2017). Pilot implementation in 29 health care facilities started in Dec. 2017.
1.2 PERSON-CENTEREDNESS – A NECESSITY IN DEMENTIA CARE AND RESEARCH

Regarding person-centeredness encouraging older adults to direct their care contributes to a sense of autonomy and maintained independence. We were granted funding to translate and test an item based instrument to analyze everyday preferences of elder people living in nursing homes, at home or use adult day care services (PELI-D). Analyzing preferences and integrating them into daily care is another strategy to implement person-centered approaches. The applicability of the instrument will be tested in care facilities (nursing homes, home care and adult day care) of two major providers in North-Rhine-Westphalia.

CONCLUSION

We are initiating more and more research to hear the voice of the person with dementia. In two early initiated research projects (LEBE/SEIN) a longitudinal approach was conducted to gain insight into adjustment processes of people with dementia. In another project (ASPECT FTD) social media content was analyzed as well as daily life activities of people with bvFTD using video sequences analysis. The perspective of the family caregiver as a valuable care partner has been involved in most of our research projects since the DZNE was established. Next steps will be to conduct studies using co-design approaches (e.g. we are involved in two JPND proposals with the University of Bradford).

REFERENCES


1.3 STAFF

At the DZNE in Witten the scientific staff works together in four working groups: Methods in Healthcare Research, Care Interventions, Care Structures as well as Implementation and Dissemination Research. In 2017 the number of full-time equivalent staff (25.73) was a little higher in 2017 than in the year before (24.31), of which 5.67 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>3</td>
<td>2.50</td>
<td>2.50</td>
</tr>
<tr>
<td>Methods in Healthcare Research</td>
<td>4</td>
<td>3.03</td>
<td>3.03</td>
</tr>
<tr>
<td>Care Interventions</td>
<td>8</td>
<td>6.99</td>
<td>4.78</td>
</tr>
<tr>
<td>Care Structures</td>
<td>9</td>
<td>6.85</td>
<td>4.75</td>
</tr>
<tr>
<td>Implementation and Dissemination Research</td>
<td>5</td>
<td>4.43</td>
<td>3.63</td>
</tr>
<tr>
<td>Student Assistants</td>
<td>6</td>
<td>1.93</td>
<td>1.93</td>
</tr>
<tr>
<td>Total</td>
<td>35</td>
<td>25.73</td>
<td>20.63</td>
</tr>
</tbody>
</table>

Table 1: Number of employees and full-time equivalent staff (as of 31 Dec. 2017).

The interdisciplinary team at DZNE Witten is made up of scientific staff with a wide range of qualifications. The disciplines of the scientific staff, including leadership positions, consist of nursing sciences, sociology, gerontology, health sciences/public health, psychology, educational sciences, bioinformatics, economics, political sciences, physical and occupational therapy. Likewise, the students and research assistants employed the DZNE Witten are from various disciplines and various universities in NRW.
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>278,920</td>
</tr>
<tr>
<td>2017</td>
<td>552,188</td>
</tr>
<tr>
<td>2017 (provisionally)</td>
<td>527,249</td>
</tr>
</tbody>
</table>

Table 2: Mandatory approved financial resources (as of 31 Dec. 2017).
1.4 SCIENTIFIC WORK

1.4.1 PUBLICATIONS

Results of the scientific work by the team in Witten have been published in 2017 at frequent intervals. Altogether 99 contributions were realized at national and international levels. The DZNE Witten presented their work in 14 presentations and 11 poster presentations at national and international scientific congresses concerning research into health services for people with dementia. From a dissemination point of view: presentations of 38 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, four book chapters were released. Furthermore, 15 articles were published in peer-reviewed journals, 10 articles in journals without peer-review and also two reports. References of work results in 2017 are listed after the respective project in chapter 2. References of completed projects or references without direct relation to any projects in 2017 are listed in chapter 3.

1.4.2 BOARDS AND CONSULTING ACTIVITIES

Employees of the interdisciplinary team in Witten were represented in various functions on scientific boards, executive boards and steering committees in 2017. They brought with them their expertise in the field of dementia care in various consulting activities and worked for scientific papers and publishers. The staff’s activities, as at the end of 2017, are listed in chapter 4.

1.4.3 COOPERATION

DZNE in Witten collaborates closely with DZNE Rostock/Greifswald. Moreover, there is close cooperation with the Faculty of Health at Witten/Herdecke University, especially with the School of Nursing Science, which is underlined in the Faculty of Health by Prof. Dr. Martina Roes who holds the chair of “Nursing Science and Healthcare Research”, as well as by Dr. Margareta Halek, who became junior professor in nursing science focusing on “the care of people with dementia”. Furthermore, most of DZNE’s scientific staff are members of the Faculty of Health and 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 FRONOTEMPORAL 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, Martin Berwig</td>
<td></td>
</tr>
</tbody>
</table>

INTRODUCTION

Behavior variant frontotemporal dementia (bvFTD) is associated with impaired social cognition abilities. Therefore, it is often challenging being 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 neurodegenerative diseases, 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 was 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 used a quasi-experimental one-group-pre-post-design with double pre-measurement and an embedded mixed-method approach. Five dyads were enrolled. Explorative outcomes were sensitivity of the caregivers, quality of caregiver-patient relationship, quality of life and challenging behaviors of people with bvFTD. At three points of examination (T0, T1 after two weeks, and T2 after six weeks) a video of a dyadic interaction in a daily life situation (mealtime) was recorded and data collection was conducted. The following instruments for capturing the outcomes were 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 served as a control period. Between T1 and T2 the caregiver received five MMC sessions. The video sequences were or will be micro-analyzed by means of video-interaction analysis to prove the assumed impact mechanism of the intervention. The variance of effects on outcomes has been determined. Moreover, the process data collected will be used to evaluate the benefit and acceptance of the intervention.

STATUS

The study project was carried out as planned. The evaluations of the data are well-advanced. The results of the video interaction analyses are expected by the end of 2017. The evaluation of the science, process, management and resource data collected in the study will be collated, structured and finalized in 2017 so that the results may be published in at least two publications in early 2018.

RESULTS/ APPLICABILITY

Preliminary results show descriptive changes for quality of relationship, quality of life and challenging behaviour favouring the intervention period. Carer-Patient Relationship and positive affect effects were even marginally significant. Results provide indications for the feasibility of the intervention as well as for a large-scale main study and will be used as our own prior work for an application to finance such a definitive study.
2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES

<table>
<thead>
<tr>
<th>Title</th>
<th>CASE CONFERENCES FOR PEOPLE WITH DEMENTIA LIVING IN NURSING HOMES</th>
<th>FallDem</th>
</tr>
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<tbody>
<tr>
<td>Duration</td>
<td>2010 - 2018</td>
<td></td>
</tr>
<tr>
<td>Funding</td>
<td>DZNE and Stiftung Wohlfahrtspflege NRW (Foundation Wohlfahrtspflege)</td>
<td></td>
</tr>
</tbody>
</table>
| Collaboration | • Kaiserswerther Diakonie (sector training and education)  
• Dr. Pablo Verde, Coordination Center for Clinical Trials (KKS), Faculty of Medicine at Düsseldorf’s Heinrich Heine University  
• Prof. Dr. Reinhold Wolke, Esslingen University of Applied Sciences |         |
| Principal Investigator | Margareta Halek (lead)  
Daniela Holle (project coordination) |         |
| Scientific Staff | Daniela Holle, René Müller, Sven Reuther, Martina Roes, Diana Trutschel, Sonja Teupen (as from 11-01-2017), Tina Quasdorf (until 3-31-2017) |         |

INTRODUCTION

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 (PwD) 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 PwD 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 PwD 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 PwD 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 PwD, was measured with the Neuropsychiatric Inventory - Nursing Home Version (NPI - NH). As secondary outcomes, the quality of life of PwD (measured with Qualidem), the competence development of the staff (measured with Kompetenz - Reflektions - 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 effectiveness study FallDem. Here longitudinal data were collected by questionnaires, semi-structured telephone interviews, group interviews and protocols of the case conferences.

STATUS

At the moment, several publications about the effectiveness of the study for residents and at staff level (research questions 1 and 2) are under preparation. The data concerning the research question of the process evaluation are still being analyzed.

Additionally, the developed model of case conference (WELCOME-IDA) is being compared with similar case conference models from Norway “TIME” (Bjørn Lichtwarck, Innlandet Hospital Trust, Centre for Old Age Psychiatric Research) and the Dutch Care Programm “GRIP” (Sandra Zwijsen, Universität Amsterdam, VU Medical Center). The idea was developed during an international symposium orga-
nized by the BPSD Forum of the International Psychogeriatrics Association (IPA). A publication about the difference and similar aspects of the models is in preparation.

Moreover, the methodological aspects in conducting and analyzing studies with a cluster randomized stepped-wedge design are being discussed together with the University of Basel, Institute of nursing science (Prof. Dr. Michael Simon). Up to now, two meetings have been held in Witten and Basel.

### RESULTS/ APPLICABILITY

The results of the data analysis have not shown any statistical effects on the prevalence of at least one challenging behavior, measured with the NPI-NH (primary outcome), in comparison with the control phase of the intervention.

Moreover, the difference in prevalence rates between the groups for each sub score of the NPI-NH was conducted with the help of a linear mixed effect model as a further exploratory data analysis. However, these results must be treated with caution due to the number of tests and the lack of multiple test correction.

In the idA group, a p value < 0.05 was identified and a non-significant reduction for follow-up for the item apathy between the control and intervention period was found. In the Welcome-Neo group for the items eating, hallucination and delusion, p values < 0.05 were detected.

For the secondary outcome Quality of life (measured with the Qualidem) for several dimensions of the instrument, statistically significant changes were found. In the intervention WELCOME-idA a reduction in the mean score in the dimension positive self-image compared to the control group was measured within the group of mild to severe dementia (FAST < 7). In contrast, the group of very severe dementia (FAST stage 7) showed an improvement in the scores of quality of life for the dimensions care relationship and social isolation in comparison to the control group. For the intervention WELCOME-NEO within the subgroup mild to severe dementia (FAST<7), a statistically significant reduction in the mean score of the Qualidem was observed for the dimensions care relationship, positive affects, positive self-image and social interaction. No statistical changes in the mean score of the Qualidem were found within the group of the people with very severe dementia (FAST=7).

Moreover, no significant changes were detected concerning the Defined Daily Doses (DDD) for psychotropic medication compared to the control group.
For the secondary outcome work-related burn out, only in the WELCOME-IDA group were weak “significant” effects found regarding the control, intervention and follow-up phase. No significant effects were discovered for the other risk factors of burnout (measured with the CBI), the dementia related burden (measured with the BelaDem) and for the vocational action competence (measured with the KRI) in both intervention groups WELCOME-IDA and WELCOME-NEO.

The importance of the topic case conference especially for the US-American Health Care System was mentioned by an Editorial of the Journals of the American Medical Directors Association 17(1).

REFERENCES

Albert, S. M. (2016). Role of Case Conferences in Dementia-Specific vs Traditional Care Units in German Nursing Homes. Journals of the American Medical Directors Association, 17(1), 12-13. doi:10.1016/j.jamda.2015.10.005

DISSIMINATION

CONFERENCES:


2.1 PSYCHO-SOCIAL INTERVENTIONS FOR DIFFERENT DEMENTIA FORMS AND STAGES


**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 in becoming experts on the social and health-related needs of PwD, such as for the effective use and usability of supporting technology. This idea is being 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 implementation 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

In October 2017, DZNE Witten hosted a junior researcher from the Karolinska Institute Sweden for a period of four weeks. Furthermore, the INDUCT-school to be conducted in January 2018 in Witten has been organized.
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

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 good or best-practice.

**STATUS**

The project is in the phase of data analysis. Results are expected at the end of March.
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:

### INTRODUCTION

The care of people with dementia (PwD) 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 in PwD often occurs 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 PwD 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 approaches related to “understanding diagnostics” have 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 published between 1995 and 2014 were included. Based on relevant studies, a forward citation tracking was carried out in February 2015. A quality appraisal was conducted for all the 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 use at home in the community, 8 for use in nursing homes and 3 can be used in different settings. Neither approach was explicitly developed for use in hospitals.

The effectiveness was tested for 6 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 of the 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 that test the effectiveness of the modified approaches in those settings are needed.

DISSEMINATION

PAPER/ BOOKS/ REPORTS

### 2.2 QUALITY OF CARE

<table>
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<th>Title</th>
<th>DEMENZMONITOR: LONGITUDINAL SURVEY OF DEMENTIA-RELATED INSTITUTIONAL AND RESIDENT CHARACTERISTICS IN GERMAN NURSING HOMES</th>
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<td>Bernhard Holle (lead)</td>
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<td>Scientific Staff</td>
<td>Diana Trutschel, Rebecca Palm</td>
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### 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 implemented 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 was 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 were 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 newly developed questionnaires. The outcomes behavior and quality of life were assessed by nurses using the instruments Neuropsychiatric Inventory (NPI-Q) and QUALIDEM.

Data analysis was 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 were used.

STATUS

The project team is working on the analysis and publication of results answering the research questions. Based on the results and the experiences, the project team will design a follow-up study (BeSTaDem).

RESULTS/ APPLICABILITY

Based on the results that were published in the past years, in 2017 the work on further analysis and the publication of results regarding the research questions 1 and 2 was continued. The focus was set on the comparison of the implementation of pain assessments in dementia care units and integrative units. The results show that in dementia care units instruments that are recommended for PwD are used more often than in integrative care units. In many integrative care units, instruments are used...
that are not recommended for PwD. However, it is necessary to improve pain assessments in both care unit types.

The analysis of the DemenzMonitor data gave reason to reflect methods used in observational studies critically and to develop strategies to account for occurring bias in the results. A methodological article discusses and describes the advantages and disadvantages of different methods for bias adjustment and used models for analysis of observational data in healthcare research. The article is a practical example for practitioners on how to follow the different analysis steps and to adapt the implementation code for examples in their own setting.

The analysis of the relationship between structural characteristics and the quality of life of people with severe dementia was continued. The team is looking for an answer to the question whether there is a difference between the quality of life of residents with severe dementia who live in dementia care units or in integrative care units. The results do not indicate a difference. The publication has been submitted and is under review.

The work on the prevalence and associated factors of challenging behavior was continued. Currently, the work on a publication that reports the prevalence and associated factors of severe agitation is ongoing.
2.2 QUALITY OF CARE

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:


2.2 QUALITY OF CARE

<table>
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<th>Title</th>
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<td>Scientific Staff</td>
<td>Bernd Albers</td>
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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 aimed to establish and to evaluate telephone-based support groups. The support group sessions were conducted by the team at Leipzig University, the evaluation of the project was done by the team at the DZNE in Witten within a randomized controlled trial. The evaluation encompassed 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 was conducted as a cluster adjusted randomized controlled trial. To reach this, the intervention group was controlled by a waiting group at t(0) baseline, t(1) post intervention. All standardized interviews were done by telephone. Participants were randomized into clusters of four persons.
Target group of the intervention were relatives caring for PwD. Relatives were eligible if they cared for the PwD for more than 4 h/d, or lived in the same household for the last 6 months and did not suffer from an acute psychiatric disease. Precise inclusion and exclusion criteria are available on request.

The primary endpoint of the effectiveness evaluation is the health-related quality of life of the participating relatives. This was assessed with the General Health Survey Questionnaire Short Form 12 (SF-12). Furthermore, as secondary endpoints the (1) perceived social support of caregivers on the basis of the perceived social support caregiving scale, (2) the caregiver response scale of the caregivers and the (3) possible challenging behavior of PwD with the Neuropsychiatric inventory were recorded.

With regard to the process evaluation, the following questions were clarified:

1. How were the study participants recruited and which study participants could be enrolled?
2. Was the intervention carried out as planned?
3. In how many sessions did the relatives participate? Were there any dropouts? If so, what reasons led to the termination of the intervention?
4. How important and good do participants feel about the intervention and its components (e.g. the telephone as an innovative core element of the intervention)?
5. Were there hindering factors in the context of the intervention?
6. How good was the implementation of the intervention?
7. What kinds of health and care services were used before and after the intervention by the family caregiver to care for PwD?

To measure the efficacy of the intervention on the primary and secondary endpoints, descriptive and inferential statistics at two measurement times (T0, T1,) were used. The data analysis during the process evaluation was done descriptively. For all analyses, the principles of intent-to-treat analysis were applied.

STATUS

Recruitment and T0 and T1 are complete. In total, only 38 relatives could be included and were divided into five blocks (four each in waiting and intervention group pairs). Analyses of effect measurement and process evaluation were carried out at the end of 2017. Initial analyses show that phone-based support groups provide a new way to relieve and to pay tribute to caregivers of PwD. To finally examine the effectiveness a larger study should be carried out/is recommended.
2.2 QUALITY OF CARE

RESULTS/ APPLICABILITY

Of the included 38 dyads, 36 participated in the study until the end. In the adjusted mixed linear model, the differences between T0 and T1 showed a positive, non-significant trend for the outcomes. For the primary endpoint (0-100) the difference for the intervention group was 3.3 (confidence interval 95%: -0.9 - 7.6) compared to the control group -2.4 (CI95%: -7.3 - 2.4). The process evaluation shows the practicability of the intervention and provides hints for the further development of the intervention components.

DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

INTRODUCTION

Nurses in hospitals often do not feel well prepared for the care of patients with cognitive decline. This is because the professional training in acute care provides little expertise and confidence concerning the use of psychosocial interventions. Furthermore, the fragmented and multi-professional care is focused on the acute illness, which hampers an individualized and person-centered approach for these patients who depend on safety and orientation. Hence, the main interest of this project was to discover how nurses experience this working situation and what strategies they develop for coping with it. The aim of the study was to analyze the subjective view of nurses concerning their care of patients with cognitive decline in hospitals. The overall question was:

1. What does it mean for nurses in hospitals to care for patients with dementia?

METHODS

The study is a secondary analysis using the data from the DemAkut study (Vienna) and the DemKH study (Witten). There were five group discussions with nurses in German hospitals as well as seven with nurses in Austrian hospitals during 2015. The data were analyzed using content analysis.

STATUS

The project has been finished. A research article has been published.
2.2 QUALITY OF CARE

RESULTS/ APPLICABILITY

Nurses experience their possibilities as limited when considering their ability to care adequately for patients with cognitive impairments. The barriers are both individual limits such as attitudes or emotions, but also higher-level barriers such as work pressure, perceived roles and team structures. Nurses develop different strategies to ensure patient care under limited conditions. The strategies do not always lead to positive consequences for the nurses themselves (e.g. bad conscience), but also for the patients (e.g. encouraging challenging behaviors). To overcome these limitations, a fundamental change of perspective in hospitals would be necessary among other things, which would actually put the interests of the patient at the center.

DISSEMINATION

PAPER/ BOOKS/ REPORTS

INTRODUCTION

The procedure 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 to commission the development of a new expert standard with the topic “Fostering and sustaining relationships in care for people with dementia” (“Beziehungsgestaltung in der Pflege von Menschen mit Demenz”) (DNQP, 2015, S.4). Contrary to previous expert standards (e.g. decubitus or fall prevention) the challenge was to concretize which outcome is relevant in the care of people living with dementia. This definition of the relevant outcome is important for the literature study, because in the literature study interventions aiming at this outcome have to be identified. To define the outcome, the global construct quality of life was used. In 2015 O’Rourke et al. published a meta-synthesis on quality of life from the perspective of people living with dementia. In this synthesis the authors discovered four dimensions, which constitute and influence quality of life: “Agency in Life Today (Purposeful vs. Aimless)”, “Relationship”, “Sense of Place (Located vs. Unset led)” and “Wellness Perspective (Well vs. Ill)”. To define all four dimensions as relevant outcomes for the literature study would be too broad and unspecific. Therefore, only the dimension “Relationship” was used as an outcome for the literature study and building up successful relationships was chosen as the overall topic for the expert standard. Taking into account that person-centeredness is required as a base for relationship care, this project is strongly connected to the project PerDem.

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1 Nursing Care for People with Dementia (DNQP, 2015, S. 4, translated by the author).
2.2 QUALITY OF CARE

METHODS

Referring to the method paper of the DNQP (2015), a search strategy was developed and described as well as applied in relevant literature databases. After selecting relevant publications by two independent researchers, all the included studies were descriptively summarized. The methodical quality of the included studies was appraised by two independent researchers. The content-related assessment was done by the members of the expert working group.

In every expert standard, explanatory comments for every criteria-level are formulated for nursing praxis. These comments help to concretize and adapt the standard criteria to the specific conditions in different care settings. The comments for the expert standard “Nursing care for people living with dementia” were formulated by the members of the expert working group and the principal investigator. The discussions of the expert working groups were moderated by members of the DNQP.

STATUS

The literature study was completed in the second quarter of 2017. Based on this literature study the members of the expert working group developed a draft of the expert standard. The expert standard was completed in the fourth quarter of 2017.

RESULTS/ APPLICABILITY

Based on the literature study and the knowledge of the members of the expert working group, a draft of the expert standard “Building up successful relationships in the nursing care for people living with dementia” was developed. This expert standard was presented to professionals in the field of nursing at a consensus conference at the 6. October 2017 in Osnabrück.

The consented expert standard will be published at the beginning of 2018. From January until June 2018 the expert standard will be implemented in 29 different healthcare organizations to test its acceptance and practicality.
2.2 QUALITY OF CARE

REFERENCES


DISSEMINATION

CONFERENCES:


2.2 QUALITY OF CARE

PAPER/ BOOKS/ REPORTS:


INTRODUCTION

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, and the costs and effects of special care concepts for dementia. The question is how should structures be organized to achieve a high quality of care, how could legal regulations support this and how could a service-oriented payment be realized.

Due to their high implementation degree and the additional costs they cause, DSCU evaluation studies from Germany are scarce. Evaluation studies of DSCUs face the challenges that randomization is neither practical nor ethical and that due to the variety in their characteristics, DSCUs are hardly comparable. Predominant research models seem too simplistic to reflect the complexity that is inherent in this field of health service research. Therefore, alternative research frameworks and methodologies are needed to explore complex relationships in DSCUs. The Realist Evaluation Approach by Pawson & Tilley (1997) is a theory-driven multi-method generic approach that goes beyond the experimental paradigm by providing an in-depth exploration of generative causal mechanisms and their social and contextual influences (Salter & Kothari, 2014).

Objective: The Realist Evaluation aims at identifying and explaining which aspects of DSCUs are working, for whom, and under what circumstances the intended outcomes are reached. The evaluation will lead to a middle-range theory of relationships between contextual factors, mechanisms and outcomes of DSCUs.
2.2 QUALITY OF CARE

METHODS

This multi-method study will be conducted in 4 phases. Phase 1 will lead to the development of an initial program theory that contains testable descriptions of the context, mechanisms and outcomes (CMOs) and proposes assumptions about their relationship. Therefore, a Rapid Realist Review will be conducted and enriched with data that were generated in expert interviews with program stakeholders. In Phase 2, a survey study will be used to describe the context of DSCUs. Based on the descriptive data, distinctive types of DSCUs will be developed and further investigated within a multiple case study. In Phase 3, empirically derived CMO-configurations will be compared within a cross-case analysis to scrutinize pre-developed assumptions of what works, for whom and under what circumstances. As a result of the synthesis process, the initial program theory will be refined and generalized (Phase 4).

STATUS

At the time of reporting, Phase 1 is in progress; Phase 2 is in preparation.

RESULTS/ APPLICABILITY

The results of the study are intended to inform providers of DSCUs and policymakers about contextual aspects that are needed to facilitate an effectively working DSCU and which mechanisms enhance or hinder their successful implementation. The results will also provide information about the question for whom which DSCU model may be the most beneficial.

REFERENCES


Palm, R., & Holle, B. (2017, October 4). *Dementia Special Care Units in German nursing homes – study protocol of a realist evaluation*. 27th Alzheimer Europe, Berlin, Germany.
### 2.3 Methods and Measurements

<table>
<thead>
<tr>
<th>Title</th>
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### 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 into 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. In 2017 a first investigation of the construct validity based on a secondary data analysis was performed.

The investigation of the construct validity of the German QUALIDEM will start in 2018.

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

No matter what the healthcare setting, person-centered care and its implementation in caring for the elderly is a central issue. To provide individualized and person-centered care, healthcare professionals need knowledge about individual preferences of the persons cared for. Up to now, there are no German-language tools available to assess these preferences.

The instrument PELI is based on self-assessment of the persons concerned. The inventory offers items referring to the preferences of the elderly with a wide spectrum of areas in everyday living. The PELI was originally developed to measure the preferences of people living at home. However, it has been successfully adapted for use in further healthcare settings, so that the following four versions of the PELI are now available:

1. PELI-NH Full©: Extended version for the use in long-term care facilities
2. PELI-NH Mid-Level©: Short version for the use in inpatient care
3. PELI-HC©: Version for the use in outpatient care
4. PELI-AD©: Version for the use in day care

Altogether, study results to date indicate that PELI is a practicable, meaningful and valid instrument that facilitates person-centered care of the elderly in diverse settings and thereby improves quality of healthcare. The PELI version for the long-term care facilities has been tested since July 2016 in two American states by researchers of the Miami University and the University of Pennsylvania.

At the moment, there is no comparable research instrument to the PELI in German. As part of the proposed project all versions of the PELI-D (nursing homes, day care and home care service) ...

1. ... will be culturally sensitively translated into German.
2. ... will be examined in a pilot study for their applicability and their usefulness.
2.3 METHODS AND MEASUREMENTS

The project PELI-D will be supported by the "Diözesan-Caritasverband für die Erzbistum Köln e.V." (contact: Dr. Heidemarie Kelleter) and the "Diakonie Düsseldorf" (contact: Dr. Nada Radic) as cooperation partners.

By linking preferences in the context of person-centered care, overlaps can be found with the project "Per-Dem", which is also located in Witten. "Per-Dem" focuses the concepts of persons in the context of dementia.

METHODS

The project PELI-D is divided into two phases.

Phase 1 includes the translation and linguistic validation of the specific PELI versions. The process of translating into German follows the recommendation for the translation and cultural adaptation of the ISPOR Task Force for Translation and Cultural Adaption (Wild et al., 2005). This includes, for instance, a Forward-Translation, Backward-Translation, the integration of Expert-Committees and a Cognitive-Debriefing. For example: With the involvement of caregivers, who are provided by the cooperation partners, the PELI versions will be evaluated context-sensitively within the Cognitive Debriefing and for all specific PELI versions.

In Phase 2 the specific PELI versions (nursing homes, day care and home care service) will be checked for their applicability. The piloting will take place in institutions run by each of the project partners (nursing homes, adult day care, and home care). Both qualitative (semi-standardized interviews, focus group interviews, documentary analysis) and quantitative methods (interclass correlation, reliability analysis etc.) will be used. People in need of care but without severe cognitive impairment (MMSE> 16) are included in the study. Furthermore, a close relative or alternatively also a close caregiver is involved for each person in need of care. The nursing staff will complete the specific PELI version with the people in need of care.

The selection of the methods and instruments is based on the research questions. In addition to the specific PELI versions, satisfaction, cognitive status and demographic aspects will be recorded by separate questionnaires. Quantitative analysis will be based mainly on descriptive statistical methods. Qualitative data will be analyzed with a variant of the qualitative-content-analysis. Furthermore, the simultaneous application of qualitative and quantitative research strategies should create synergies that increase the scientific knowledge. For example, results of the translation process will be
included in the validation of the instrument. Results regarding the reliability of the instrument are related both qualitatively and quantitatively.

**STATUS**

Currently, the project is in Phase 1, in which the two translators will discuss the results of their translations and highlight problematic items to be translated. Subsequently, the results will be discussed critically by an Expert Committee. Furthermore, discussions with the cooperation partners and the developers of the PELI instrument are taking place. The goals set are intended to match the requirements and challenges of the practice.

With the end of the translation phase (03/2018) the project will be submitted for ethical approval to the DGP. Then the piloting phase starts (10/2018); training and other preparation will be carried out before the piloting starts. The pilot ends with a focus group interview attended by the participants of the piloting (10/2019). Finally, the evaluation and writing of the results will take place until the end of the project (08/2020).

**RESULTS/ APPLICABILITY**

The PELI-D will provide free of charge an instrument to measure preferences of persons in need of care in out- and inpatient settings in a standardized way for nursing facilities. The information collected should serve as a base for the systematic planning and implementation of care that is adequate to the individual preferences of the person concerned. This contributes to optimizing the process of care services and to enabling older people in their autonomy and social participation.

**REFERENCES**

INTRODUCTION

The DZNE strives to optimize the assessment of outcomes for care interventions and to adapt existing outcomes to the need of healthcare research and care practice. For the assessment of challenging behavior of people with dementia (PwD), only a few German instruments exist that are adapted to the context of nursing. An alternative to instruments such as NPI and CMAI is the Challenging Behavior Scale (CBS). The CBS was developed in the UK on the basis of descriptions of professional caregivers for elder people. Thus, the scale focuses on behaviors of PwD that are relevant and understandable for nurses. The instrument assesses incidence and prevalence of a wide spectrum of challenging behavior (e.g. aggression, insomnia or restlessness) as well as the perceived difficulties and challenges of nurses provoked by challenging behavior. The CBS further shows adequate psychometric properties. Aim of the project is to translate the CBS into German and to evaluate the translated German version of the CBS in relation to its comprehensibility and clarity of items.

METHODS

The translation procedure is based on the two-panel approach. A translation team, consisting of six people with different expertise in translation, was informed about the content and the underlying concepts of the CBS. The team was introduced into the translation method and the first translation of the CBS was conducted within a guided group discussion. Subsequently, a focus group, consisting of six nurses and nursing assistants from different nursing homes, evaluated the first interim translation of the CBS with regard to its adequacy in the wording and to the comprehensibility of the phrasing used. Moreover, the focus group was informed in advance about the CBS and the translation method. No information was given about the original English version of the CBS. Criticism and proposals for modifications propounded by the focus group were discussed and included in the first translation of the CBS.
Finally, 23 professional caregivers were interviewed to evaluate the comprehensibility, clarity and fluency of the wordings used for the German CBS using a semi-standardized questionnaire.

**STATUS**

The translation and linguistic validation of the CBS-G has been completed. A paper about the translation and linguistic validation of the CBS-G has been accepted for publication.

**RESULTS/ APPLICABILITY**

A German Version of the CBS is now available for use in healthcare research and care practice. The translation for the CBS using the two-panel approach was perceived to be very beneficial and effective in comparison with the traditional forward-backward translation.

The evaluation of the translated version of the CBS showed that the majority of items were easy to understand and clear in their meaning. The instructions given for the analysis and interpretation of the results of the CBS were less understandable.

**DISSEMINATION**

**PAPER/ BOOKS/ REPORTS:**

Holle D, Köller L, Moniz-Cook E, Halek M (2017 accepted for publication). Translation and linguistic validation of the German Challenging Behaviour Scale for formal caregivers of people with dementia in nursing, *Journal of Nursing Measurement*. 
### INTRODUCTION

The Innovative Dementia-Orientated Assessment tool (IdA) guides nursing staff systematically through the process of identifying possible triggers and causes of challenging behavior of people with dementia (PwD). IdA was developed on the basis of an international literature review and the decision to integrate the ‘need-driven dementia-compromised behavior model’ (NDB-model). It was tested in relation to its practicability, content validity and construct validity in different nursing homes in Germany. IdA is recommended as a guideline for team meetings and dementia-specific case conferences. The use of IdA has been limited to the German-speaking context because of its restriction to the German language.

The aim of the project IdA-E was the translation of IdA into the English language as a first step to make IdA available for use in English-speaking countries.

### METHODS

The translation of IdA was carried out according to the translation process of ISPOR (International Society for Pharmacoeconomics and Outcomes Research):

**Preparation:** Permission was obtained to use and translate IdA. Additionally, the developer of IdA was involved within the translation process. Information about the conceptual basis of the items in IdA were gathered and discussed with the developer of the instrument and subsequently summarized in a manual for use by the translators. Two translators with experience in nursing and dementia were recruited for the translation.

**Forward translation:** IdA was translated independently by the two translators from German (source language) into English (target language).
2.3 METHODS AND MEASUREMENTS

Harmonization: Forward translations were reconciled into a single forward translation. Discrepancies between the two translations were discussed with the developer of IdA and the two translators.

Back-translation: Two back translations of the reconciled English translation of IdA into German took place by the same translators who conducted the forward translations.

Harmonization: The back translations were reviewed against the source language of IdA to ensure the conceptual equivalence to the translation. Discrepancies between the two translations and the original version of IdA as well as the back-translations were discussed with the developer of IdA and the two translators.

Cognitive debriefing: Cognitive debriefing of the final English translation of IdA was carried out with two registered nurses from Great Britain who represent the target population of IdA. Cognitive debriefing was undertaken to assess the level of comprehensibility and to identify items that may be inappropriate at a conceptual level.

A supplemental IdA-Manual was translated into English using forward translation harmonization.

STATUS

The translation of the Innovative Dementia-Orientated Assessment tool and the manual has been completed. The translation process and the English version of IdA (IdA-E) have been published.

RESULTS/ APPLICABILITY

An English version of IdA is now available for use in nursing research and nursing practice. It was of great importance that the translators were informed about the underlying concepts of the assessment and that each item of IdA was described in detail in a manual before translation took place. A further advantage was that both translators had experience in nursing and dementia. The harmonization processes were time-consuming steps and they took longer than expected.

Translation of IdA into English has to be understood as a first step within the adaptation process of IdA for an English-speaking country. Further studies are needed to pilot IdA within the specific context of the target population and to test its linguistic appropriateness as well as its face and content
validity. In addition, psychometric testing is needed to evaluate the scientific merit of IdA in the target countries.

**DISSEMINATION**

**PAPER/ BOOKS/ REPORTS:**

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 underlying 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 (Healthcare 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 service contract) is a radical innova-
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

...tion 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 system perspective will be analyzed using a structured content analysis (Schreier, 2012), the analysis of the user perspective is based on the thematic coding as described by Flick (2016). A structured content analysis in line with Schreier (2014) will be applied for the interviews with the service provider. 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

In the user’s perspective, 15 case studies were conducted, while the quantitative part compasses round about 40 cases. At the moment, the quantitative and qualitative data collected in t1 is analyzed. Furthermore, the preparation for the last data collection period within the user’s perspective is ongoing.

The team focusing on the service provider’s perspective is also still engaged in analyzing the t0 and t1 data. Moreover, the last data collection period is going to be prepared within the next few weeks. The system’s perspective team is dealing with the analysis of the expert interviews. The economic evaluation part of the study is focusing on the current operating costs. Additionally, the Controlling Data is being analyzed in view of proceeds and cost development. Besides which, t1 data is also being analyzed.

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.

REFERENCES


2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

DISSEMINATION

CONFERENCES:


### 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 on the 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, the concept of person-centeredness poses special challenges for theory and practice as it seems that there is no common agreement on how “being a person” could be conceptualized considering the background of dementia. 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.

In this discussion on the conceptualization of “being a person”, the concept of autonomy is one central aspect, which has a special relevance both in the provision of care and care research. Here the question is not only if and how long PwD could act independently or live a self-determined life (see also German Ethics Council 2012), but in particular how autonomy per se is discussed with regard to dementia.
In order to meet the complexity of the topic of person-centeredness in dementia, the research project Per-Dem pursues three different strands (research questions and aims). In the first project strand, an analysis and inventory of the concept of person-centeredness within the relevant literature will be undertaken. The findings of these first steps will build a solid ground for a thorough discussion of the concept of personhood during the second strand of the project. Parallel to this and also based on the first project strand, a conceptual analysis of autonomy and self-determination will be carried out.

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. How is the concept of autonomy discussed in the literature on person-centered dementia research and care?

**METHODS**

To cover a wide range of literature and to generate a systematic literature search as comprehensively 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 and for the purpose of a conceptual analysis, categories will be formed from the identified publications in order to describe the different ideas of person-centeredness in appearance and content and hence to quantify them numerically.

The results of the scoping study will be used to deal with the second 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.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

The body of literature gathered in the first project strand is used parallel for a discourse analytical examination on the topic of autonomy and self-determination. Data preparation and analysis are also undertaken with MAXQDA.

STATUS

A systematic literature search was conducted in nine databases (Medline, PsychInfo, PubPsych, Cinahl, Scopus, Web of Science, Cochrane, Sowiport, EBSCO-Geisteswissenschaften; the duplicates were removed from the overall hits (n=3517) and a title/abstract screening with regard to the first research question was completed. Currently, the analysis of the included articles with MAXQDA is ongoing and first results have been presented to (inter)national cooperation partners. The planned completion date of the first project phase (scoping study) is 2018.

Building on the first results of the scoping study, a contribution to the debate about social health and autonomy in the context of dementia was possible. 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 were identified. With a forthcoming publication the completion of the project strand concerning the topic autonomy and self-determination is planned for the beginning of 2018.

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, which could be exemplified in the aforementioned contribution to the social health discourse. 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.

Furthermore, based on the topic person-centeredness contextual links arise to two other projects at the DZNE-site Witten. Since person-centeredness is a prerequisite for building up successful care relationships, preliminary results from the project Per-Dem contributed to the development of the German national expert standard “Beziehungsgestaltung in der Pflege von Menschen mit Demenz” in
the project Exper-Dem. Perspective, there are connections to the research project PELI-D. The aim of PELI-D is the translation of an instrument to capture preferences of care-dependent people. The knowledge of these preferences can be seen as a requirement for person-centered care.

**DISSEMINATION**

**CONFERENCES:**

INTRODUCTION

The concept “social inclusion” has scarcely been investigated in empirical research in the context of dementia. In Germany there are some theoretical approaches to this concept. Nevertheless, the concept is used in political and social debates. However, it seems necessary to operationalize the concept in order to make it measurable and applicable to research. A literature review with the focus on social inclusion of people with dementia (PwD) is being conducted. It aims to investigate:

1. How social inclusion is defined and theoretically embedded in empirical research
2. How social inclusion is approached methodologically
3. What the relevant findings with regard to social inclusion are

The main research question was: How are the concepts of social inclusion and exclusion of PwD in empirical studies understood and applied?

METHODS

In order to answer the research question, an integrative review has been conducted. Only empirical studies in German and English language as well as reviews based on empirical studies were included (n=9).

STATUS

The literature analysis has been completed. An English-language article is in preparation.
RESULTS/ APPLICABILITY

The review is to be published in an international journal, thus providing a basis for further research on the concept of social inclusion as well as offering a consideration of social inclusion in intervention development and testing at the DZNE site Witten.
INTRODUCTION

Most people with dementia (PwD) live at home. It is their expressed wish to stay in their familiar environment and the majority of informal carers also tend to keep the person with dementia at home for as long as possible. The *ageing in place* policy of today’s social security systems favors and supports community care over institutional care. In most care arrangements, an informal carer assumes the role of the key care provider. Informal carers shoulder a vast amount of hands-on care and are also in charge of coordinating the care arrangement and different forms of support. Furthermore, informal carers often have to take responsibility for crucial decisions during the dementia care trajectory. However, until now it remains unclear how the involved actors establish sustainable care arrangements and what factors influence this process.

The preceding research project VerAH-Dem (2010-2013) aimed at describing home-based care arrangements from a time-course perspective. A core result of the VerAH-Dem project was a phase model of informal caring trajectories. In this model, creating and maintaining stability crystallized as a guiding principle of informal carers. The subsequent project StiV-H builds on these results and aims to develop a theory-based understanding of stability of home-based care arrangements for people living with dementia. It should serve as a basis for the development and design of future care structures.

Thus, the StiV-H project is a multiphase project with different phases building upon each other. The aim of the first phase of the research project StiV-H was to define the complex phenomenon *stability*. This phase has been completed successfully. In the second phase, a meta-study will be conducted to theorize how stability is constituted. Furthermore, crucial influencing factors on stability will be identified by this knowledge synthesis. Additionally, the phase model developed in the VerAH-Dem project will be validated and refined.
The project investigates the following research questions concerning the meta-study:

1. How is stability of home-based care arrangements for people living with dementia constituted?
2. What are the essential factors that influence stability?

The validation of the phase-model is based on the following question:

1. Is the phase model developed in the VerAH-Dem pilot study valid and generalizable?
2. Are there additional phases or themes that have to be complemented?

**METHODS**

The meta-study methodology – rooted in the tradition of qualitative meta-synthesis – is used to identify and integrate knowledge about the complex phenomenon stability. This methodology provides a framework for analyzing theories, methods and results of the included primary studies and to integrate these analyses in a final synthesis. A cyclic, iterative and hermeneutic strategy is used to identify and analyze relevant studies. Thematic synthesis is used for the analysis. The original meta-study methodology will be extended to include qualitative, quantitative and mixed-method studies as well as literature reviews. For more information regarding the design and method cf. PROSPERO (CRD42016041727).

Informal carers will be asked about their experiences and caring actions during the dementia care trajectory. These interviews will be conducted as focus group discussions or individual interviews. They will be recorded, transcribed and analyzed with qualitative methods (content analysis/thematic analysis). The inclusion criterion for participation is that the informal carer cares for a PwD, who still lives at home, died at home or recently moved to a nursing home. Thereby, a heterogeneous sample regarding socio-demographic data and living situation of the PwD and his/her informal carers is required.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

STATUS

The literature search and screening for the meta-study have been completed and an initial coding for all included studies (n=144) has been performed. The study protocol has been submitted for publication. Currently, the analysis phase has started and first results will be published mid-2018. This project strand will be completed in 2018.

For the validation study n=3 focus group discussions (with n=14 participants) and n=15 individual interviews were performed. The interviews are being transcribed for analysis. The publication of the results and the conclusion of this project strand are planned for 2018.

In 2018, two complementary project strands will be initiated. The first strand is a qualitative informal carer study that investigates the perspective of family carers on the stability of their home-based care arrangement by using qualitative methods (content analysis/thematic analysis). For this study the interviews already performed for the validation study will be analysed, addressing this specific focus. The second strand is a quantitative secondary analysis of data derived from different projects of the DZNE (VerAH-Dem, StiV-H, ViFa and DemNet-D). Using unbiased conditional inference trees (C-Trees), crucial influencing factors on the perceived stability of home-based care arrangements will be uncovered. Both strands will start in 2018 and will be completed in 2019.

RESULTS/ APPLICABILITY

The results of the ongoing project strands (meta-study, validation study) as well as the two projected strands (informal carer study, quantitative secondary analyses) will provide a profound theoretical understanding of the complex phenomenon of stability, support the identification of crucial influencing factors on stability and facilitate a deeper understanding of informal dementia care trajectories. This core of knowledge enables operationalizing stability (e.g. development of an assessment instrument for research and practice) and allows differentiating between stable and instable caring arrangements. The long-term goal of the project StiV-H is to identify and/or develop customized and stability-promoting care structures and interventions for families living in the community setting.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

DISSEMINATION

CONFERENCES:


2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

PAPER/ BOOKS/ REPORTS:


INTRODUCTION

Handling challenging behavior is one of the most demanding burdens of caring for persons with dementia (PwD). 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 PwD 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 PwD
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 PwD
5. Analyzing ethical and legal consequences of the insideDEM assistive technology
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

METHODS

The development phase of the Assistive Technology (AT), applying a user-centered design process with iterative cycles, was finished in July 2017. Caregivers of PwD were included as the future user group in this process by applying different methods. To adapt and assign the IdA assessment to a tablet-based digital version, cognitive interviews with caregivers of PwD were conducted. The results of these interviews are the essential foundation for the linguistic description and the design of the questions inside the tablet app. Furthermore, on the basis of literature and expert organizations such as the Alzheimer Association, the content of the recommendation module was conceptualized in cooperation with the University of Rostock. Depending on the answers in the assessment, the recommendation module will present recommendations for caregivers to cope with the challenging behaviors of PwD. Subsequently, after development and programming the AT will be tested in a first feasibility study using the MRC framework for the development of complex interventions with a nested extensive process evaluation. Especially in the early stages of the development of such technologies, ethical considerations are highly important and will be evaluated by conducting a comprehensive workshop in accordance with the MEESTAR model.

STATUS

The feasibility study was ethically approved by the German Nurses Association in the first half of the year. Currently, the feasibility study and the nested process evaluation are being conducted. Data collection will be finalized at the end of April in 2018. The ethical evaluation is planned for May 2018.

RESULTS/ APPLICABILITY

The results of the feasibility study and the nested process evaluation will reveal information about the mechanisms of impact of the intervention and the practicability of the study procedure. Furthermore, the factors of user acceptance of the intervention and study procedure will be evaluated. In addition, the results will give first indications of possible outcomes of the intervention. The results of both study parts are the main basis for further developments of the intervention and the design of future pilot studies and randomized-controlled trails on a larger scale.
DISSEMINATION

CONFERENCES:


PAPER/ BOOKS/ REPORTS:

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 PwD. 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 of 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?

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<td>Bernhard Holle (lead), Steffen Heinrich (project coordination)</td>
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2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

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. It is planned to include a total of about 30-40 dyads in the study. 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, Nine Hole Peg 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. On the basis of the measured values, an individualized mobility program for PwD will be developed, which will be carried out during their stay in the facility. Similarly, a homework program with effective exercises will be created, which can be continued at home by the caring relatives. Using self-developed questionnaires with items based on existing, validated instruments, the dementia-specific knowledge and care-related burden of the relatives will be assessed. In addition, the counseling wishes of the family caregivers will be queried and the PwD observed and assessed in the respite care facility. Based on this data and the staff expertise, an individualized and dementia-specific counseling program for the caring relatives will be designed and carried out.

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 and b) family caregivers.

The quantitative data will be analyzed using SPSS. The interviews will be transcribed and analyzed using the content analysis method.
2.4 POTENTIALS OF AND IN CARE ARRANGEMENTS

STATUS

The development of the intervention components was completed and the intervention started in “Haus St. Antonius” after prior training of the participating staff. At the same time, an evaluation methodology based on the evaluation tool "Consolidated Framework for Implementation Research (CFIR)" was developed. 15 dyads (PwD & caring relatives) have been included up to now (February 2018). During the next few months, further dyads are to be included successively and the acceptance and user-friendliness of the short-term care concept will be evaluated on an ongoing basis.

RESULTS/ APPLICABILITY

It is expected that the concept will be successfully applicable for PwD in the short-term care setting. In combination with the information for family caregivers, the concept has the potential to stabilize the caring situation at home. A user manual for the respite care concept will be developed after all the project data has been analyzed. This manual will be structured in the form of a practice-friendly website. Based on this website, a broader implementation of this concept in other respite care facilities should become possible.

DISSEMINATION

CONFERENCES


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017

3.1 ARTICLES (PEER-REVIEWED)


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017


### 3.2 ARTICLES (NOT PEER-REVIEWED)


### 3.3 BOOK CHAPTERS


Halek, M. (2017). Herausforderndes Verhalten im Fokus - Können pflegerische Interventionen helfen?. In E. Gräßel & A. Pendergrass (Eds.), *Forschungsplattform Demenz - Ergebnisse eines*
3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017


3.4 PRESENTATIONS (INVITED)


Dinand, C. (2017, November 30). *Menschen mit Demenz im jüngeren Lebensalter - Wer ist gemeint, was ist das Problem und was ist zu tun?*. Praxis-Forschungs-Dialog, Gerontopsychiatrisches Zentrum, Alexianer Münster.


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017


Roes, M. (2017-10-06). Nationaler Expertenstandard ‘Beziehungsgestaltung in der Pflege von Menschen mit Demenz’ (KeyNote), Konsensuskonferenz, Osnabrueck.

Roes, M. (2017, November 15) *How can we ensure our research leads to real world change?* Public Presentation at the JSB lecture theatre, Bradford, UK.


3.5 POSTER PRESENTATIONS


3. WORK RESULTS WITHOUT DIRECT RELATION TO PROJECTS IN 2017

3.6 SELF-ORGANIZED EVENTS


Method Workshop DZNE Witten: “Audio-visual procedures and their potentials of research with people with dementia”, September 14, 2017, Moderation: Claudia Dinand, DZNE Witten. Initiated and invited by the speaker of the DZNE/Witten site

8th Annual Conference of DZNE site Witten: “In- or outpatient care setting? Perspectives on dementia specific care”, September 27, 2017, Witten/Herdecke University

7th Practice-Research-Dialogue: “People with dementia in early years” November 30, 2017, DZNE Witten, at the Gerontopsychiatrisches Zentrum, Alexianer Münster GmbH
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 2017.

DICHTER, M.
- German Nurses Association Northwest (DBfk, executive board member)
- German Society of Nursing Science (DG Pflegewissenschaft)
- European Academy of Nursing Science (EANS)
- International Psychogeriatrics Association (IPA)

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

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: PERLEN, Personal documentation of life for people with dementia and caregivers) (2016 - 2018) (Persönliche Lebensdokumentation für Menschen mit Demenz und Pflegepersonen)
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

- Member of the expert group “Expert standard for nursing care for people with dementia” „Expertenstandard zur Pflege von Menschen mit Demenz“ 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.
- Association of the Scientific Medical Societies in Germany (AWMF), vice delegate of the DGP German Society of Nursing Science (DG Pflegewissenschaft), (Delegate for AWMF-Guidelines, cash auditor)
- European Academy of Nursing Science (EANS)
- Helmholtz Akademie für Führungskräfte, Alumni
- 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)
- Member of the expert working group for updating the DEGAM guideline „Pflegende Angehörige“ (caring relatives), delegate of DGP
- Member of the expert working group for development of the guideline „Evidenz- und konsensbasierte Indikationskriterien zur Hüfttotalendoprothese“, delegate of the DGP
- REFLECTION Network
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

KERNEBECK, S.
- German Association for Health Services and Public Health (Deutscher Verband für Gesundheitswissenschaften und Public Health e.V. (DVGPH))
- German Network for Evidence-based Medicine (DNEbM)
- 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 Association of University Professors and Lecturers (DHV)
- 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

PANKE-KOCHINKE, B.
- German Society of Nursing Science (DG Pflegewissenschaft)
4. WORK IN BOARDS AND CONSULTING ACTIVITIES

**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)
- 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, Alumni Commonwealth Foundation
- Institute for Quality and Efficiency in Health Care (IQWiG), board of trustees
- Improvement Science Research Network (ISRN)
- International Psychogeriatric Association (IPA)
- Robert Bosch Fellow, Alumni
- Society for Implementation Research Collaboration (SIRC), Founding Member
- Scientific board of the care congress Bremen, speaker
## Work in Boards and Consulting Activities

**SCHWAB, C. G. G.**
- German Nurses Association Nordwest (DBfK NW) (Deutscher Berufsverband für Pflegeberufe Nordwest e.V. (DBfK NW), member of the executive board
- German Society for Epidemiology (DGEpi)
- 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

**TEUPEN, S.**
- Deutsche Gesellschaft für Soziologie (DGS)
- Sektion Wissenssoziologie der DGS

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

**VÖLZ, S.**
- Deutscher Verband der Ergotherapeuten e.V. (DVE)

**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 2017).

BERWIG, M.
- Aging and Mental Health

DICHTER, M.
- Alzheimer Disease & Associated Disorders
- Archives of Gerontology and Geriatrics
- BMC Geriatrics
- Clinical Interventions in Aging
- Dementia and Geriatric Cognitive Disorders
- Health and Quality of Life Outcomes
- International Journal of Nursing Studies
- International Psychogeriatrics: Associate Editor
- Klinische Pflegeforschung
- Neuropsychiatric Disease and Treatment
- Pflege & Gesellschaft
- Quality of Life Research
- German Journal for Evidence and Quality in Health Care

DINAND, C.
- Scandinavian Journal of Caring Sciences (SJCS)

HALEK, M.
- Aging and Mental Health
- Pflege (Huber)
- Scandinavian Journal of Caring Science
- International Journal of Nursing Studies (IJNS)
### 5. WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS

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5. WORK FOR SCIENTIFIC PAPERS AND PUBLISHERS

- Sage Open Medicine
- The Gerontologist
- Trials

PINKERT, C.
- Pflege und Gesellschaft
- Journal of Clinical Nursing

REUTHER, S.
- International Psychogeriatrics

ROES, M.
- Gerontology Society of America: review abstracts
- BMC Healthcare Policy
- Managementhandbuch Pflege, medhochzwei Verlag: co-editor
- PADUA, Huber Verlag: co-editor
- Pflegewissenschaft, hps media: reviewer
- Zeitschrift für Gerontologie und Geriatrie

SCHWAB, C.G.G.
- Pflege (Huber)

VON KUTZLEBEN, M.
- International Psychogeriatrics
- Scandinavian Journal of Caring Sciences
6. TEAM

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

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<tr>
<th>Name</th>
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<td>Roes, Martina</td>
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<td>Prof. Dr. phil., Dipl. Sociologist</td>
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<td>Zimmermann, Marit</td>
<td>Scientific assistant to the site speaker</td>
<td>MSc Evidence-based Health Care</td>
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<tr>
<td>Halek, Margareta</td>
<td>Senior research group leader Care Interventions and co-speaker</td>
<td>Dr. rer. medic., MScN</td>
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<td>Holle, Bernhard</td>
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<td>Dr. rer. medic., MScN</td>
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<td><strong>Administration</strong></td>
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<td>Dünhölter, Cornelia</td>
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<td>Möller, Sabine</td>
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<td>Industrial business management assistant</td>
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<td>Bauer, Sabine</td>
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### Research Group Methods in Health Service Research

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<td><strong>Roes, Martina</strong></td>
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<td><strong>Albers, Bernd</strong></td>
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<td><strong>Bergmann, Johannes Michael</strong></td>
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<td><strong>Müller-Widmer, René</strong></td>
<td>Data Management</td>
<td>Medical documentarian</td>
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<td><strong>Panke-Kochinke, Birgit</strong></td>
<td>Scientific staff, Qualitative methods</td>
<td>Venia legendi Sociology, Dr. phil., Staatexamen Sek.2</td>
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<td><strong>Schwab, Christian G. G.</strong></td>
<td>Scientific staff</td>
<td>MScN., Dipl.-Kfm. (FH)</td>
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<tr>
<td><strong>Ströbel, Armin</strong></td>
<td>Scientific staff</td>
<td>Dr. rer. biol. hum.</td>
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<td><strong>Teupen, Sonja</strong></td>
<td>Scientific staff</td>
<td>MA social science</td>
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<td><strong>Trutschel, Diana</strong></td>
<td>Scientific staff, Quantitative methods</td>
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### Research Group Care Interventions

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<td><strong>Halek, Margareta</strong></td>
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<td>Dr. rer. medic., MScN</td>
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<td><strong>Berwig, Martin</strong></td>
<td>Scientific staff</td>
<td>Dr. Dipl. Psych.</td>
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<td><strong>Dichter, Martin N</strong></td>
<td>Scientific staff</td>
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<td><strong>Dinand, Claudia</strong></td>
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<td><strong>Hartwig, Ina</strong></td>
<td>Scientific staff</td>
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<td><strong>Holle, Daniela</strong></td>
<td>Scientific staff</td>
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<td><strong>Kernebeck, Sven</strong></td>
<td>Scientific staff</td>
<td>MScPH</td>
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<td><strong>Reuther, Sven</strong></td>
<td>Scientific staff</td>
<td>Dr. rer. medic., MScN</td>
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6. TEAM

<table>
<thead>
<tr>
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<tr>
<td><strong>Holle, Bernhard</strong></td>
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<td><strong>Cavazzini, Christoph</strong></td>
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<td><strong>Hochgraebner, Iris</strong></td>
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### Student Assistants

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<thead>
<tr>
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<tr>
<td><strong>Bleckmann, Anne</strong></td>
<td>Student assistant</td>
<td>Nursing Science, Witten/Herdecke University</td>
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<tr>
<td><strong>Horstmannshoff, Caren</strong></td>
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<td>Evidence-based Health Care, Hochschule für Gesundheit Bochum</td>
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<td><strong>Manietta, Christina</strong></td>
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<td><strong>Meyer, Laura</strong></td>
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<td><strong>Nebowsky, Anna</strong></td>
<td>Student assistant</td>
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<td><strong>Oude Hengel, Luca Janina</strong></td>
<td>Student assistant</td>
<td>Occupational Therapy, Hochschule für Gesundheit Bochum</td>
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<td><strong>Rommerskirch, Mike</strong></td>
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