Annual Report 2013

German Center of Neurodegenerative Diseases e.V. (DZNE)
Site Witten

web: http://www.dzne.de
Three activities marked the year 2013:

First: following my part-time role as head of the research group Implementation and Dissemination Research in October 2012, I also became Speaker of the DZNE site Witten in January 2013. I resumed this position from Professor Dr. Sabine Bartholomeyczik who founded the site in cooperation with colleagues from the Witten/Herdecke University, especially with colleagues from the Department of Nursing Science. Additionally, in October 2013 I was appointed as a full professor for Nursing Science and Health Care Research at the Witten/Herdecke University. Also, the 4th annual conference of the DZNE site Witten entitled “Health Care Strategies for People with Dementia - Self Determination and Quality of Life” took place in October receiving very positive feedback and resulting in many interesting discussions on issues of caregiving for people with dementia.

Second: our involvement in the external scientific evaluation of the DZNE, requested by the Helmholtz Association in March 2013 (POF). As a result of this evaluation, carried out by a panel of internationally accepted experts, the importance of our research questions at the DZNE site Witten related to the care of people with dementia was highlighted. Especially the research focuses on the whole care environment, the development and testing of health care interventions and analyses of care structures and care requirements were considered strength of the DZNE site Witten. Associated with this positive review was a recommendation to collaborate with other DZNE sites thereby actively implementing and practicing a ‘Translational Research’ culture! A further positive aspect of the POF review was that involvement of reviewers with an expertise in health service science - this was a good starting point to establish a sustainable collaboration between the DZNE site Witten and the reviewers from the USA (PennState University), the UK (University of Bradford), and from the Netherlands (Radboud University). This is an important step towards becoming more visible both within Europe and internationally beyond Europe.

Third: a discourse succeeding and concretizing the strategic process at the DZNE site Witten. The results of this continuous process can be found at the beginning of this annual report.

At this point I would like to express my sincere thanks to all colleagues for their willingness to give me deeper insights into their ongoing research projects at the DZNE site Witten. Moreover, the annual company outing gave me for the first time an insight into the green part of the Ruhr area. Concerning administrative issues starting with the organization of a coffee pot and finishing within online leave set-up and an outlook planning system, I would like to thank Cornelia Dünhöfter (site coordination), Sabine Möller (administration) and Bernd Albers (scientific assistance). Explicitly, I would like to thank Dr. Margareta Halek and Dr. Bernhard Holle for their tireless cooperativeness and commitment to engage in constructive discussions with me.

Prof. Dr. Martina Roes
Speaker
1. Research site concept and strategic process

1.1 Introduction

The DZNE started its research activities in June 2009. The nine DZNE centers are part of the Helmholtz Association, and represent fundamental, clinical, applied and public health research. Two of the nine DZNE centers (Rostock/Greifswald and Witten) focus on Health Service Research. The former speaker for the DZNE site Witten (Prof. Dr. S. Bartholomeyczik) initiated a 1\textsuperscript{st} strategic debate (2009). A 2\textsuperscript{nd} strategic discourse was started by the new the speaker (January 2013, Prof. Dr. M. Roes). In summary, the research strategy was newly discussed, pronounced and enhanced as well as the current ideas straightened and integrated in the research framework. This strategic process (Jan. ’13 till Jan. ’14) was initially started by the speaker and senior research group leaders but included the whole team at our site. Accompanying, the results from the Helmholtz-Survey’ (POF, March 2013 - in which all core research areas of the nine DZNE research centers were reviewed by an international panel), influenced this process too. Moreover in collaboration with the DZNE Rostock/Greifswald five health service research areas were defined: (1) Interventional health care / service research, (2) Clinical Biomarker Research, (3) Methodology, (4) Implementation & Dissemination research, and (5) Cross-sectional Topics (i.e. ethics/economy).

1.2 Scientific strategies and research framework

The results of the scientific strategic discussion at the DZNE site Witten can be seen in fig.1. Central focus of all research activities is the perspective of the person with dementia (person-centeredness). Three leading research areas were defined (first level):

1. Quality of Life (QoL),
2. (Bio) Behavior, and

These leading research areas can be seen as our input for the (inter)national scientific world in dementia research.
Subsequent the second and third level of the framework includes the two research groups ‘Care Interventions’ and ‘Care Structures’. The fourth level characterizes our research principals, regarding design, methods and instruments, including general requirements on ‘Health Care Interventions’ (described by the Institute of Medicine, 2011\(^1\)), and the ‘Person-Centered Outcome Research Framework’ (HHS/PCORI 2013\(^2\)).

Another important aspect of health service research is described on the fifth level, addressing implementation and dissemination requirements. Research questions are related to translational research, the analysis of how research findings change care practice; which implementation models are effective or which factors promote or hinder the implementation of effective interventions. This research group is in a way unique within all DZNE research centers and complements the (inter)national discourse, to bring light into this underrepresented topic.


The sixth level stands for our general scientific orientation: understanding that research on dementia is an issue across the health care system, with a need to integrate different professional groups, and all aspects of research (from fundamental research to applied research). The last level of our research strategy and framework refers to the fact that dementia is not a national but a global issue, which is predetermined by health care and research politics as well as (inter)national dementia strategies.

1.3. The four research focuses

The research strategy above was described on a rather abstract level, thus an operationalization of the framework started immediately (fig. 2). On one hand this represents the leading research framework in a very concrete way. On the other hand operationalizing the framework is necessary for the development of new research projects.

Fig. 2 Operationalization of the research framework

1) The research topic “psychosocial intervention in different levels and forms of dementia” focuses on testing and developing patient-centered care interventions: e.g. understanding diagnostic is referring to the project case ‘conferences for residents with dementia living in nursing homes’ (FallDem, pp. 12-14). The sub-group ‘HerVer’ (pp. 18-20) works on a definition of challenging behavior. Two projects are in the stage of development: translation of the effective concept of ‘understanding diagnostic’ for home care and acute care. Another
focus is the development of interventions for different forms of dementia, especially persons with Fronto-Temporal-Dementia (FTD), who are different regarding their need for care. As this group is underrepresented in dementia research, there is a need to develop psycho-social interventions for the person with dementia as well as for the family caregiver (Project AspektFTD, pp. 9-11). In the project GesKom (pp. 15-17) nonverbal and gestural communication with people with advanced dementia is investigated. These research projects are related to the question ‘how social inclusion of people with dementia (and their family caregiver) can be positively influenced’. Furthermore a systematic review about person-centeredness is planned. More and more attention in health service research is concentrating on ambient assisted living (AAL), referring to this need a collaborative project with the University of Applied Science Düsseldorf is planned (starting in 2014).

2) To analyze the quality of dementia care, two different approaches are relevant. One is the descriptive analysis and evaluation of the quality of dementia specific care. Two projects address questions regarding the quality of performance: DemenzMonitor (pp. 31-35) and Project DemNet-D (pp. 36-40). Moreover the development of a dementia specific minimal nursing datasets in planned for the near future. The first steps will be introduced in 2014. The other approach refers to the need to measure outcomes and to develop relevant quality indicators for dementia care. For our site it is important to take an active part in the development of nationwide dementia specific indicators and guidelines. Concerning guidelines, Witten takes already part in the development of a S3 pain guideline (project S3 LLSchmerzASS, pp. 44-45). Furthermore the development of a quality indicator set (to measure pain in persons with dementia) is currently running (project QiSavA, pp. 41-43).

3) Health Care and Health Service Research are in need for a broad bundle of methods and instruments, especially being sensible and practicable to the field of dementia research and practice. Some aspects are especially imperative for our work. For example, it is important to develop and to test evidence based implementation and dissemination strategies. Furthermore it has to be proven how far implementation aspects can be included in routine process evaluations while testing complex interventions. One research group in Witten is working exclusively on this topic. It becomes clear that, replication of existing research instruments, in our projects is (a) seldom possible without adapting the instrument to the health care context, (b) sometimes possible after an adaption of the content or (c) not possible at all. This concerns instruments e.g. referring to person centeredness, QoL, challenging behavior, pain, environmental factors, quality of care and dementia diagnostic. Considering the need for appropriate dementia diagnostics in health care settings a project on ‘cognition’ has
been initiated in 2014. A scientific translation of the Challenging Behavior Scale (CBS) already took place in 2013, and a pilot test of the CBS in the German context is also planned (pp. 46-47). Another important topic in Witten is the determination of QoL in persons with dementia especially the identification of QoL in people with advanced dementia is very challenging (Project QoL-Dem pp. 51-53). Another methodological difficulty is to combine research methods, which are based on different epistemic backgrounds. Some of the projects in Witten use mixed methods and multilevel designs. Because of the fact that we produce complex datasets, which are not only relevant for the actual research questions, it will be a relatively new step for us, to use these data for secondary analysis. Another important topic is to analyze the potential of support in care arrangements. Especially the social circumstances are important, because they influence participation and the way of live of people with dementia and their relatives. Project LEBE (pp. 60-61) is concentrating on this topic. Another aspect is to develop and test interventions, to stabilize care arrangements at home. In the two projects VerAH-Dem (pp. 67-70) and NisA-Dem (pp. 62-64) the acceptance of support in home care arrangements and aspects of low-threshold assistance and citizen engagement were investigated. This work will be continued in the new projects StiV Community Care and StiV transitional care management (planned for 2014). Another project with a similar topic is the Project Tapa-K (pp. 65-66).

1.4 Additional relevant aims

Within the strategic process, nine tasks were additionally identified being relevant for the site Witten to achieve its targets:

1. Science: Monitoring and development of the research framework and the strategic process.

2. Collaboration: in- and outside the DZNE need to be strengthened, this includes collaboration with scientific and practice partners.

3. Internationalization: One important strategic process is the expansion of international collaboration. In 2013 intensive discussions with three reviewers who actively participated at the POF review (Murna Downs from the Dementia Group at the Bradford University, UK; Anne Kolanowski, Center Director, Hartford Center of Geriatric Nursing Excellence at Penn State, USA; Myrra Vernooij Dassen, Head of the Alzheimer Research Institute at the Radboud University Nijmegen, NL) Memoranda of understanding (MoU) are on the way. Furthermore research groups from Penn State University, the Polisher Research Institute in the USA and Bradford University will visit Witten in July 2014.
4. Positioning in health service research: DZNE Witten will actively engage itself more in (inter)national health care research networks. Including cooperation’s referring to third-party funds. Moreover collaborations with politicians in Germany shall be expanded.

5. Human resource development: addresses a competence based encouragement approach to support our staff and junior/senior researchers.

6. Dialogue between practice and research: We believe that a dialog on a regular basis between health care workers and researcher is helpful to gain better understanding of the challenge in dementia research. Therefore we initiate a new way of dialog between practice and research in 2014.

7. Public Relations: This relates to publishing in scientific and practice journals as well as annual conferences and annual reports. There is also a website, where actual information can be found and close working relations with the Press Office of the DZNE.

8. Reporting and monitoring: The DZNE Headquarter in Bonn, the DZNE Senate, and the Members Meeting require regular reports. Thus internal processes are needed to establish a systematic monitoring process and to identify necessary adjustments. The goal is to develop and establish a monitoring system in 2014.

9. Administration: The administration is focused on a plurality of topics. Of great relevance are the optimization of the IT- and library environment, the administration of third-party funds, the structure contract designs and proposals.

In the following a detailed description of the sites activities will be given. The research projects will be dedicated to the four main researches as described above.

1.5 Personnel

Since 01.01.2013 Prof. Dr. Martina Roes is the new speaker of the DZNE site Witten and succeeded Prof. Dr. Sabine Bartholomeyczik who was seen off in style in Jan. 2013. Prof Roes also inherited the senior research group leader position of the group ‘methods in health care research (HCR)’ and of the group ‘implementation and dissemination science’.

The qualifications of the different scientific staff members and the leadership are based on a plurality of disciplines: Nursing, sociology, gerontology, health science, economics, pedagogics, physiotherapy, occupational therapy, public health, communication science, psychology and biometrics. Furthermore many students and scientific trainees were working at our site.
<table>
<thead>
<tr>
<th>Group structure</th>
<th>Persons</th>
<th>Fulltime-equivalents</th>
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<tbody>
<tr>
<td>Administration</td>
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<tr>
<td>RG Care interventions</td>
<td>9</td>
<td>6,55</td>
</tr>
<tr>
<td>RG Care structures</td>
<td>8</td>
<td>6,45</td>
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<td>RG Implementation and dissemination research</td>
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<td>4,05</td>
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<td>RG Methods in HCR</td>
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<tr>
<td>Student staff</td>
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<td>2,21</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>34</strong></td>
<td><strong>28,64</strong></td>
</tr>
</tbody>
</table>

*Table 1: Number of persons being employed and fulltime equivalents (March 2014)*

1.6 Scientific work

1.6.1 Publications

Also in 2013 scientist from Witten were guests at several national and international scientific congresses referring to the topic dementia care. All about 37 presentations were held, 31 of them were oral presentations. Moreover 29 Journal publications could be placed (more than half in peer reviewed journals). It is of extraordinary important for Witten site to give its results back to care praxis. This can be seen in the high quantity of presentations on health care praxis congresses (44). We deem the publication of our results as important because of our duty to influence practice work by our results.

1.6.2 Boards and consulting activities

Scientific staff from our site was and is actively engaged in different consulting activities in 2013. The German Nursing Council delegated Prof Roes into several workgroups of the “Federal Joint Committee (G-BA)” (e.g. quality management, indicators, §63.3c SGB V). Dr. Magareta Halek is a member of the scientific advisory board of the Federal Ministry for Health project “Needs and Demands of persons with severe dementia” since 2013.

1.6.3 The annual conference

150 attendants joined the 4th annual conference (on 9th October 2013). The topic of this conference was “Care strategies for people with dementia – self-determination and quality of life”. The annual conference was introduced by presentations, which gave a theoretical background referring to the conference topic. After this introduction 10 so called future cafés were conducted. During the future cafés the participants discussed about their own practical experience concerning the conference theme. At the end of the conference a panel discussion with qualified persons from sciences, politics, practice, ethics and substitutes of PwD took place. At 08.10.2014 Witten invites every interested person to the 5th annual conference with the topic “Care strate-
gies for people with dementia - Sustainability in Health Care and Health Service Research” in 2014.

1.7 Collaborations

According to the DZNE`s Helmholtz POF survey an intense effort was started to build up collaborations with the international reviewers representing nursing science and health service research. At the end of 2013 first drafts of “Momoranda of Understanding” with the University Bradford (Prof. Dr. Murna Downs), the Penn State University (Prof. Dr. Ann Kolanowski) and the Radboud Universität Nijmegen (Prof. Dr. Myrra Vernooij Dasser) were formulated. The next step is to formalize this juristically, which will be signed in mid-2014. Further the DZNE site Witten is in negotiation of collaboration with representatives of different international universities. Some of them are: University Wien (Prof. Dr. Hanna Meyer, A), University of Applied Science St. Gallen (Prof. Dr. Susi Saxer, CH), Bournemouth University (Prof. Dr. Antea Innes, UK) or the Institute of Veteran Affairs USA (Laura Damschroder, USA). Representatives of the DZNE were also members of international groups like the “North Sea Dementia Research Group”, the “DCM International Implementation Group” or the European research network “InterDem” or “EANS”.

Moreover the DZNE site Witten collaborates with the Witten/Herdecke University, especially with the Faculty of Health, the Department of Nursing Science, the Institute for General Medicine and the chair for Geriatrics.

Within the nine DZNE research centers the main collaboration partner of Witten is the site Rostock/Greifswald (see p 1). There are many other partners: e.g. “Deutsche Gesellschaft für Pflegewissenschaft” (DGP) or the “Johanniter Seniorenhäuser GmbH”.


2. Projects

2.1 Psycho-social Interventions for different Dementia forms and -stages

<table>
<thead>
<tr>
<th>Title</th>
<th>The perspective of people with Fronto-Temporal Dementia (FTD) and their needs and demands in everyday life</th>
<th>AspektFTD</th>
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<td>Duration</td>
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<td>Collaboration</td>
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<td>Principal Investigator</td>
<td>Margareta Halek</td>
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</tr>
<tr>
<td>Scientific Staff</td>
<td>Claudia Dinand, Sabine Ursula Nover, Daniela Holle (systematic review)</td>
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Introduction

Frontotemporal dementia (FTD) is the clinical term for a pathological, heterogeneous set of neurodegenerative disorders that together are known as frontotemporal lobar degenerations (FTLD). These disorders impact behavior and language in various ways. Characteristically, the onset of FTD is early with a wide range from the third to the ninth decade. The disease shows a progressive course with a life expectancy of 1.3 to 6.5 years after diagnosis. Prevalence rates varied widely, with figures from 2 - 31 people per 100,000 aged between 45 and 64 years. Although a differential diagnosis remains difficult, the early stage of the disease is associated less with impairment of cognitive skills and more with various strong changes in judgment, behavior, personality and emotions. These challenges often include financial problems and a high caregiver burden.

Currently, pharmacological interventions are sparsely effective, psycho-social interventions are not evidence based, and care services are mostly prepared for people in later life with other types of dementia besides FTD. There is evidence that their care provisions do not fit the needs of people with FTD and their families.

Aims

The central aim of this study is to gain information about needs and demands of people with FTD from the perspective of people with FTD themselves and their relatives. It is the first step towards the development of a need-based psycho-social intervention for people with FTD.
Questions

- What are the experiences of people with FTD?
- What are the experiences of the relatives of people with FTD in everyday life?
- Do existing interventions fit the needs and demands of people with FTD and their families?

Methods

Systematic review

The literature search was conducted to German and English publications between January 2000 and March 2012 with the focus on self-expressed needs and demands of the people with FTD.

Empirical investigation

An explorative case-related and ethnographic design was used. In respect of the disease progression problem-centered interviews were conducted with people with FTD and their relatives (6 cases) in addition to ethnographic interviews or videotaped observations. Narrative and content analysis as well as videography are used for data analysis.

Status

Systematic review

Currently, no study has been published on the self-reported needs and demands of people with FTD. Based on this result an article was performed and reasons for this research gap are discussed with respect to disease related and methodological aspects. The manuscript is under submission.

2. Empirical investigation

The project is now in the phase of data analysis. Results will be expected till June 2014.

Results

The results will deliver recommendation about suitable interventions for people with FTD, which should be developed and evaluated in further studies.
Dissemination

Conferences:


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 themselves and for the staff working in nursing homes. The application of case conferences is recommended (national guideline in Germany) as a professional task while working with people with dementia and to influence their challenging behavior in nursing homes. However, there is a lack of clear concepts how to a) conduct and b) implement case conferences for dementia care into daily care routines. Moreover it is unclear c) how effective case conferences are to improve the performance of dementia care.

The project case conferences for people with dementia in nursing homes (FallDem) aims to fill these outlined research gaps by addressing the following research questions.

Questions

- What influence does an assessment-based case conference has on challenging behavior, quality of life of residents with dementia, and the burden of staff in comparison to control group using a narrative case conference approach?
- What factors promote and inhibit the implementation of an assessment-based case conferences compared to a narrative case conference?
• What learning processes take place within a case conference, based on an assessment instrument in comparison to a narrative case conference?

Methods
The study will be conducted in three phases: In a first phase - the development of the intervention (two models of case conferences: narrative & IdA) - is based on a systematic literature review, interviews and group discussions with experts in the field of case conferences. The 2nd phase – the development of two dementia specific case conferences - was finished with piloting the two models in one nursing home. In a 3rd phase the two models of case conferences are implemented and evaluated in 12 nursing homes.

Study design
The Stepped - Wedge - Design is a special form of crossover designs and provides a methodological alternative compared to conventional cluster randomized trials. The aim is a census of the participating living areas.

Power calculation
Based on the results of a former study, a total of 360 (300 +60 dropout) have to be recruited for the study.

Primary outcome
The challenging behavior of people with dementia measured with the Neuropsychiatric Inventory - Nursing Home Version (NPI - NH).

Secondary outcomes
• Quality of life of persons with dementia (measured with Qualidem)
• The competence development of the staff (measured with the competence-reflexion-inventory (KRI, in German only))
• The burden of staff (in general and dementia specific) using the Copenhagen Burnout Inventory (CBI) and the instrument Burden of dementia (BelaDem, German only).

The intervention is accompanied by a process evaluation to identify factors, which impact the implementation of the intervention has. For this question, semi-structured interviews and protocols of the case conferences will be conducted. For the analysis of the documentation of the learning process, audio recording of case conferences and feedback interviews from a subgroup will be used.
Status

- Baseline Data (T0) completed: Data from 362 residents with dementia and 243 nursing staff members from the 12 nursing homes were collected.
- Start of the intervention in two nursing homes
- Preparation of the next data collection T1
- Qualitative interviews in the nursing homes as part of the process evaluation have been conducted.

Results

- Developing, piloting and evaluating of two models of cases conferences for dementia care.
- Developing a new statistical analysis using the Bayesian - Statistics within the stepped wedge design.
<table>
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<th>Title</th>
<th>Gestural Communicative action, as a link between language and action in persons with dementia</th>
<th>GesKom</th>
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<td>Duration</td>
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<td>Collaboration</td>
<td>Sabine Bartholomeyczik, Department for Nursing Science, Witten/Herdecke University</td>
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<td>Principal Investigator</td>
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**Introduction**

The aim of this study is to point out “how” verbal and non-verbal interactions are practiced, using gestural-communicative actions between nurses and cognitively impaired persons. Furthermore, the investigation plans to extend the theoretical and practical knowledge of non-verbal communication with people with severe dementia. The aim is to promote their self-determination and to reduce their dependency. To our knowledge, there are no other empirical studies yet addressing this specific question.

**Question**

How are verbal and non-verbal interactions between nurses and people with advanced dementia performed, when nurses use symbolic gestures to stimulate an action? The overall aim is to make the person with dementia to act on their own.

**Methods**

The study is designed as a reconstructive-practeological research approach using videography. Analysis follows the principles of the documentary interpretation described by Bohnsack. Elements of the “Grounded Theory” are implied.

**Sample/ Setting**

Care situations and interactions referring to normal und regular day-to-day activities between persons with severe dementia and nursing staff (trained in the specific perception of cognitively impaired persons and experienced in gestural communication).
Status to Date:
A pilot phase has been conducted. An algorithm to evaluate the videos with the video transcription-system ELAN has been modified and programmed. Data collection of 6 cases has been conducted. The central case is micro-analytically analyzed in 4 steps. Attributes of the central case are in described below.

Results
The nursing expert is responsible for the gestural and communicative action. Responsibility is described by the following characteristics:

1. Visual concentration.
2. Immediate responsiveness.
3. Synchronizing “affect attunement”.
4. Foreseen simulation.

Change of the speaking person
The change of the speaking person can be described as follows:

1. Visual concentration
2. Physical pause back
3. Waiting bearing
4. Giving time
5. Radiate calmness
6. Smiling-gesture

The empirical analysis has not been finished yet. There are two further orientation frames identified:

1. To call for action and communication by gestural/ verbal acting.
2. To accompany the action and to reformulate.

Expected Results
Being able to ascertain if characteristics of non-verbal communication can be used to develop an educational concept and to teach this kind of perception and care to nurses more effectively.

Next steps:
A similar case has been identified and has been prepared for analyzes.
Dissemination

Conferences:
Introduction
Challenging behavior has a significant importance in the health care of people with dementia. This behavior is also a key outcome of psychosocial interventions. The designation, description, and the definition of challenging behavior are heterogeneous both in practice and research. The relationship to other similar concepts remains unclear. Thus the difficulty lies in the fact that the different disciplines use dissimilar terms for seemingly the same phenomenon. So there is not one term for the concept “challenging behavior” but a lot surrogate terms. Aim of this analysis is the clarification of the concept "challenging behavior".

Questions
- How has the concept "challenging behavior" evolved over the course of time?
- How is “challenging behavior” currently being defined?
- How do different disciplines influence the definition of the concept “challenging behavior”?
- Which similarities and differences has the concept "challenging behavior" and which other associated terms and similar concepts / synonyms are used?

Methods
The meaning of the term "challenging behavior" changes over time, because the approach changed to the phenomenon and is highly dependent on the current paradigm of care for people with dementia. The evolutionary concept analysis according to Rogers (2000) follows this temporal instability of phenomena and assumes that concepts/ terms continue to evolve and change. This method allows the definition of the term in respect of its meaning, usage and application of the lapse of time.
The concept analysis involves the following steps

- Identify the concept of interest and associated expressions
- Identify surrogate terms and relevant uses of the concept
- Identify and select an appropriate sample, a minimum of 20% of the identified literature, from the relevant discipline, using a systematic approach and a broad time frame
- Identify the attributes of the concept
- Identify the references, antecedents and consequences of the concept, if possible
- Identify a model, real case of the concept

The search strategy combined challenging behavior, dementia and their related terms and all publication types of interest such as reviews, concept analysis, discussion papers or theoretical explanations. A first PubMed analysis was performed to test the search strategy in regard to their practicality. This first search resulted in n=19,014 articles and was reduced after the revision of the search strategy. This enabled through a literature search in CINAHL (n=890), PubMed (n=3,475), PsychINFO (n=1,263), Cochrane Library (n=178) minus the duplicates n=5,257 articles identified.

After performing the search, the number of hits was reduced by Journal screening. Journals of those disciplines that not significant contributed to the research on “challenging behavior” were removed. A parallel discipline search identified the most prominent disciplines in challenging behavior research. The research covered a period up to and including October 2012. After this limitation (n=3,380) a title abstract screening was performed. The following article selection was also orientated to Rogers (2000) "evolutionary concept analysis". According to the maxim, every discipline contains at least 20% of the total item or included 30 articles. The articles, which are evaluated in the title abstract screening as relevant (n=231), were included in the step-wise analysis. In a first step n=48 articles were analyzed. After this first process testing, subsequent rounds of selection tries to extract at least 30 as "relevant" reviewed articles per main disciplines medicine, nursing, psychiatry. These were included in a full-text analysis by MAXQDA.

Status

Review process is running.
Results

The result of the project is an interdisciplinary concept aiming for clarification and a clear description of challenging behavior. This could contribute relevant information and support the process of modification or development of new assessment (research) instruments as well as for the development of new ideas for psychosocial interventions.
### 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. 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 was 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 its 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):

1. **Preparation**: Permission was obtained to use and translate IdA and 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 experiences in nursing and dementia were recruited for the translation.

2. **Forward translation**: IdA was translated independently by the two translators from German (source language) into English (target language).
(3) **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.

(4) **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.

(5) **Harmonization**: Back translations were reviewed against the source language of IdA to ensure the conceptual equivalence to the translation. Discrepancies between the two translations and between the original version of IdA and the back-translations were discussed with the developer of IdA and the two translators.

(6) **Cognitive debriefing**: Cognitive debriefing of the final English translation of IdA was carried 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**

Finalized

**Results**

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 experiences 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

Conferences

**Introduction**

**Problem/ Background**

The conservation and promotion of quality of life and wellbeing for people with dementia is a central goal of nursing care. The aim of Dementia Care Mapping (DCM) is to capture and improve the relative wellbeing of people with dementia through the implementation of person-centered care. Little is known about the effectiveness and the supporting and hindering factors of the DCM implementation in the German elderly care.

**Aims**

The aim of the project Leben-QD-II is to investigate the effectiveness and conditions of the implementation of person-centered care through the use of Dementia Care Mapping (DCM) in residential nursing homes.

**Questions**

1. Does the DCM method positively affect the QoL of people with dementia and reduce their challenging behavior?
2. Does the DCM method positively affect staff attitudes to dementia, job satisfaction and burnout?
3. To what extent could the intervention be implemented (degree of implementation)?
4. What are facilitators and barriers to DCM implementation?
5. What are the costs of the DCM implementation and how high are they compared to both comparison groups?
Methods

Design
This study evaluates the DCM implementation in residential wards of nursing homes using a quasi-experimental design.

Sample/ Setting
Nine nursing home units of Johanniter Seniorenhäuser GmbH are involved in the study, each with one ward. They were divided into three groups each with 3 living areas:
- Intervention group: DCM is initially introduced and applied.
- Comparison group B: Continuation of DCM, which is implemented for several years.

Data collection was carried out at 3 times:
- T0 - before intervention,
- T1 - after 6 months
- T2 – 18 months after intervention.

The collection of data to the 3 & 4 research question was partly done during the implementation phases.

The investigation of the effectiveness during the study period was separated from the implementation. The blinding of staff to the respective other part avoids unwanted assumptions on the results.

Outcomes
Primary outcome for the first research question is quality of life for residents (QoL-AD). Secondary outcomes are challenging behavior (NPI-NH) and quality of life (QUALIDEM).

The staff related primary outcomes to the second research question are attitudes to dementia Care (ADQ). Secondary outcomes are job satisfaction (COPSOQ) and burnout (CBI).

The third research question about characteristics of implementation success is investigated with a theory driven set of variables (process documents to image the implementation process, interviews, staff survey, changes in care documents, dementia-friendly environment (DMA), DCM data).

The fourth research question about facilitators and barriers of the DCM implementation is also guided by a theoretical model (CFIR) using different variables (attitudes to dementia care (ADQ) before implementation, team interaction (SYMLOG), interviews, staff survey, and a questionnaire of organizational factors (DIQ)).

The fifth research question is answered by the analysis of resulting costs during the implementation process (DCM/QUALIDEM). 
Delineation of the analysis
Data analyses were first conducted separately for the effectiveness and implementation research parts and were then compiled.

Status
Status to date
The baseline data collection of the main study was done in autumn 2011. T1 measurement took place in February / March 2012. The final measurement was held between January 2013 and March 2013. A total of n=234 residents and n=201 staff members were included. Triple measurement data is existent for n=81 residents and n=25 staff members. For the evaluation of the implementation process (research question 3 & 4) were conducted: n=27 interviews with staff members during the project, n=18 environment inspections (DMA), n=81 care document analyses and n=24 observations of feedback sessions/ case conferences (SYMLOG). In addition n=111 staff questionnaires and n=63 questionnaires of organizational factors (DIQ) could be used for the process evaluation.

Next steps
The Leben-QD study is in the stage of completion of the final report and several articles.

Results
The findings of this pilot study provide indications for potential effects of DCM and QUALIDEM. This can be used for example to schedule a randomized controlled trial.

Results about the implementation success of DCM and QUALIDEM and about influencing factors will be incorporated into further practice and research projects

Dissemination
Conferences
Publications


### Introduction

More and more nurses take care of older patients, many who increasingly often suffer from dementia. These persons require additional efforts for an appropriate pain assessment when the disease progresses. The use of systematic external assessment has been recommended for years, but there is a lack of specific recommendations, such as when these should be used. The aim of this work was to develop a pathway that supports the decision-making on the use of self-assessment and external assessment in this group.

### Methods

This is a development of a complex intervention, based on Grypdonck, methodically oriented to the Ethnographic life-world analysis. Phase I was carried out by an integrative review to clarify the definition and to analyze the problems and the needs. This was followed by a methodological triangulation in phase II. Participant observations on a surgical, an internal and a special ward for the care of patients with dementia were carried out. There were 70 observations units investigated, supplemented by seven group discussions in five clinics, with a different defined and developed status of pain management implemented. A concept for nursing decision-making of self-assessment and external assessment in form of a flow model and a pathway was developed on this basis in phase III.

### Status

The literature review (Phase I) showed that stepped approaches on the decision making process for an appropriate pain assessment without empirical verification is state of the art, as well as to
consider key phenomena such as cognition, co-morbidities or the status of mobility. Results of phase II revealed how the communication process about of pain usually goes: (a) the “signalization” of pain expressed by the patients and the "reception and the interpretation" of this expression by the nurses. (b) The balance between the patients’ pain expression and the observation, reception and interpretation of this expression by the nurse failed, thus (c) the pain remained undetected. Disturbances were caused e.g. by knowledge gaps and the unclear role assignments of caregivers as well as other characteristics. Impeding context conditions and outdated regulations have a special impact - or orientation of the pain assessment to other target groups. In phase III a screening tool [Screening Tool for Making Decisions on Pain Assessment for People with Dementia in Hospital (SEE-Pain)] was developed to support the decision making process. The challenge lies in the fact, that a decision does not follow a linear algorithm. Final report (dissertation thesis) is almost finalized. Additional publications are in preparation. Further steps for a pilot-study to test the screening tool (IV phase) are planned.

**Dissemination**

**Conferences**


Sirsch, E. (15.06.2013). Geriatrische Patienten – was gibt es zu bedenken Schmerzassessment bei Senioren und dementen Patienten. Schmerz und Funktion Kongress zu 50-jährigen Bestehen der Klinik für Manuelle Therapie Hamm, Hamm.


**Publication**

2.2 Quality of care

<table>
<thead>
<tr>
<th>Title</th>
<th>Longitudinal survey of dementia-related institutional and resident characteristics in German nursing homes</th>
<th>DemenzMonitor</th>
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<td>Duration</td>
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<tr>
<td>Principal Investigator</td>
<td>Bernhard Holle</td>
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<td></td>
<td>Project coordinator: Rebecca Palm</td>
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<tr>
<td>Scientific Staff</td>
<td>Kerstin Köhler, Christian Schwab, Mirjam Hoyer</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 arrangement’s 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 a different manner. Today, little is known, which concepts and interventions are applied in the practice and which factors influence the application and if the application is associated with the desirable outcomes. Furthermore, there is a research gap, which factors are associated with the behavior and quality of life of residents and therefore need to be considered when investigating quality of care.

The aim of the study DemenzMonitor is to identify resident- and facility-related factors and covariates that are associated with the resident’s behavior and quality of life.

In detail, the following research questions will be answered:

1. How is dementia care provided in German nursing homes? Which living arrangements are implemented? Which recommended interventions are used? 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?
3. Which of the investigated variables are associated with the resident’s outcome behavior and quality of life when controlling for resident-related covariates such as age, sex, and length of stay? Are there differences between the results of the whole population and certain groups?

4. Are the resident’s outcome 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 resident’s outcome?

Methods

The „DemenzMonitor“ study is a descriptive longitudinal observational study. Data collection is performed annually in nursing homes (convenient sample). Data concerning the nursing homes, the living-units and the residents are collected by trained nursing homes staff using standardized questionnaires. The nurses assess the outcome behavior and quality of life by using the instruments Neuropsychiatric Inventory (NPI-Q) and QUALIDEM.

Data analysis is performed primarily explorative, using predominantly data mining techniques (such as visualization and classification of data) as well as association and regression analysis. To account for the complex structure of data due to different levels of data and time points, mixed effects generalized linear models are used.

Status

In 2012 and 2013 50 nursing homes, 100 living-units and ≈1700 residents participated in the study. Data from 2 points in time are available from ca. 800 residents.

The first three research questions will be answered using the data available; it is aimed to finish the data analysis till Dec. 2014.

To answer all fourth research questions, longitudinal analysis are possible using the data from two points in time. In 2014 it is aimed to gather data from residents who participated already in 2012, this makes a longitudinal analysis over three years possible. Final Results can be expected in 2015.

Results

In 2011 the instrument for the data collection was developed and tested. It comprises three different questionnaires, that assesses data on the level of the nursing home, the living-unit and
the resident. On nursing home und living-unit level, beside general characteristics, characteristics of the living concept, the living environment and the care concept are assessed. On the resident level the instrument comprises several standardized instruments to assess the care dependency (PSMS), the behavior (NPI-Q), the cognition (DSS, FAST), the quality of life (QUALIDEM) and a questionnaire to assess delivered dementia-specific care (DemCare-Q).

To collect the data, an online-based survey method was developed, that enables a fast and secure data collection of high quality. Once finished, the institutions get’s an individual automatically generated report with their results. At present, results concerning the first question complex are available.

The results reflect the variety of existing care structures in nursing homes. More than half of the nursing homes implemented special living-units for residents with dementia, for which the selection of residents is based on fixed criteria. Three-fourths of the nursing homes have a theoretically based care concept for people with dementia, which includes the recommended psychosocial interventions. The participating living-units differ with respect to their living arrangement (integrated vs. segregated) and their size (≤/> 15 beds). Large-scale units differ also with respect to their funding; some are financed with special reimbursements.

Whether one of the recommended interventions is applied, depends on several factors. Dementia severity seems to play a role. Some of the assessed interventions are more often applied on residents with dementia: Multisensory stimulation interventions and validation are more often applied on residents with dementia, especially with severe dementia. Case conferences were more often held for residents with severe dementia than without dementia; assessments of pain, behavior and quality of life were also more often applied for residents with dementia. An assessment of depression was in almost none of the nursing homes performed. A biography assessment is performed for all residents. No differences were found in the participation of physical activities. If an intervention is applied or not also depends to a great extent on the context of the living-unit. Big differences were found regarding the prevalence of applied interventions between the living-units.

The knowledge derived from this study is important for the further development of quality tools, including national guidelines and instruments to enhance the quality of care, such as quality indicators.
Dissemination

Conferences


Publication

<table>
<thead>
<tr>
<th>Title</th>
<th>Multi-centered, interdisciplinary evaluation study of dementia care networks in Germany</th>
<th>DemNet-D</th>
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<td>Duration</td>
<td>01.04.2012–31.03.2015</td>
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</table>
| Funding | The Federal Ministry of Health (BMG) — as part of the funding program 'Zukunftswerkstatt Demenz'  
Projekträger im Deutschen Zentrum für Luft- und Raumfahrt (PT-DLR, Project Management Agency – part of the German Aerospace Center) | |
| Collaboration | Research partners:  
- DZNE site Rostock / Greifswald and the E.-M. Arndt University Greifswald, Prof. Dr. W. Hoffmann  
- Institute for Applied Social Sciences at the Baden-Wuerttemberg Cooperative State University Stuttgart, Prof. Dr. S. Schäfer-Walkmann  
- Alice Salomon University of Applied Sciences in Berlin, Prof. Dr. K. Wolf-Ostermann  
The following dementia care networks take part in the DemNet-D study:  
1. Demenznetzwerk Uckermark  
2. Demenznetzwerk Memo Clinic (Stralsund);  
3. Qualitätsverbund Netzwerk im Alter e.V. (Berlin);  
4. Gerontopsychiatrisch-Geriatrischer Verbund Charlottenburg-Wilmersdorf e.V., Ansprechpartner (Berlin);  
5. Initiative „Demenzfreundlich Treptow-Köpenick“ (Berlin);  
6. Demenzfreundliche Kommune Lichtenberg (Berlin);  
7. Demenznetzwerk des Landkreises Teltow-Fläming;  
8. Arnsberger Lernwerkstatt Demenz;  
10. DemenzNetz Kreis Minden-Lübbecke  
12. Demenznetz Aachen;  
| Principal Investigator | At the DZNE site Witten: Bernhard Holle  
Project Coordinator: Franziska Laporte Uribe | |
| Scientific Staff | Steffen Heinrich | |
Introduction
DemNet-D (Multi-centered, interdisciplinary evaluation study of dementia care networks in Germany) aims at evaluating regional networks for people with dementia (PwD) and care outcomes related to those networks, the care situation on these regions as well as the cooperation and network structures. For this study, 13 well-established dementia care networks in Germany will be analyzed and compared with each other to determine those factors contributing towards a sustainable network. The following analyses will be conducted for this study:

1. Analysis regarding the characteristics of network users, i.e., PwD and their family-caregivers;
2. Analysis regarding the structure and processes within and beyond the dementia care networks (e.g., service providers, key-persons, cooperation partners); evaluation of knowledge management, i.e., providing an overview of measures to disseminate and implement knowledge on dementia in dementia care networks;
3. Health economic analyses to determine factors that contribute towards financial capacity of a dementia care network; furthermore conditions and requirements for financial and economic sustainability of a network structure will be identified;
4. Recommendations, information material, and best practice examples etc. will be collated in a “dementia toolbox” which will provide practical advice and support for existing and future networks.

Methods
The DemNet-D study is conducted in close cooperation by a research consortium consisting of four research institutes. Each of the four research institutes is cooperation partner of several dementia care networks ($N = 13$). The DZNE site Witten cooperates closely with four dementia care networks, which are located in North Rhine-Westphalia (Ahlen, Arnsberg, Krefeld und Minden-Lübbecke).

In this multi-centered, multi-professional and multivariate follow-up study a mixed-method approach is applied with qualitative and quantitative methodologies being utilized (methodology triangulation). Using primary data (quantitative and qualitative data regarding network structures, network processes, network governance, and knowledge management, quantitative and qualitative PwD and caregiver parameters [face-to-face interviews, questionnaires]), outcomes will be generated which will provide a basis for a) setting up effective new dementia care net-
works, b) for raising the quality of existing dementia care networks, and c) for gaining scientific understanding of such networks.

Each research institute focuses on a different aspect of the study and the related research questions. The DZNE site Witten is primarily responsible for caregiver related outcomes (burden and care arrangements), questions with regard to knowledge management as well as for the implementation and dissemination of results, i.e. providing recommendations and practice support by developing a “dementia tool-box”. Quantitative caregiver data will be collected using standardized questionnaires (BIZA-D, D-IVA). “Knowledge management” processes will primarily be investigated using qualitative data from interviews with key-persons of the dementia care networks. The DZNE site Rostock/Greifswald is overall coordinator for this study and covers health economic research questions. The Alice Salomon University of Applied Sciences in Berlin (ASH) has responsibility for questions related to the PwD, which will be investigated using quantitative data. Researchers of the Institute for Applied Social Sciences at the Baden-Wuerttemberg Cooperative State University Stuttgart (IfaS) will collect and analyze qualitative and quantitative data regarding the structure, operational processes, and governance of dementia care networks. The analysis of results as well as the development of the “dementia tool-box” will be conducted in close cooperation of all research partners.

Quantitative data will be collected at baseline and 12-month follow-up. Each participating dementia care network aims at including 55 PwD-caregiver dyads into the study with at least 25 of these dyads being persons who utilize the dementia care network for the first time. Another 25 dyads should be persons who have been enrolled into the network for a longer period of time.

**Status**

**Status to date**

Questionnaires were printed and distributed in December 2012. In total, interviews with 574 PwD and their primary family-caregiver were conducted between January and August 2013 (quantitative data collection). Semi-structured interviews with the dementia care network coordinators were analyzed in the first quarter of 2013. The following semi-structured group interviews with key-persons and stakeholders of the 13 networks were conducted in April and May 2013 (knowledge management: qualitative data). The audio records of these interviews were then transcribed and are currently being analyzed applying the principles of a structured content analysis (Mayring, 1990). At the DZNE site Witten, a concept for the “dementia tool-box” has
been developed and discussed with the other research partners, with the DLR, and with the BMG.

**Next steps**

Quantitative follow-up data will be collected during interviews in the dementia care networks between January and August 2014. At the same time, quantitative baseline data will be analyzed (DZNE site Witten: BIZA-D and D-IVA) and a paper will be published in a peer-reviewed journal. The follow-up knowledge management data collection is scheduled for mid-2014. During that time, the concept of the “dementia tool-box” will be developed further.

**Results**

Based on the quantitative and qualitative data collection, a number of different findings are to be expected that will exceed the singular characterization of just one network by far. Applying methodology triangulation, the connectivity of different outcomes is ensured, thereby aiming at providing a comprehensive picture of the object of investigation. The evaluation will result in a number of converging, diverging, and complementary findings regarding factors for success of dementia care networks thus allowing for greater generalizability of the findings.

Findings will be disseminated in four different ways: 1) an expert workshop with key-persons, stakeholder, and service providers of dementia care networks; 2) a guideline, i.e., a modular “dementia tool-box” providing evidence-based, matching, the regional specifications-considering practical support information on the set-up, operating, and improving of dementia care networks; 4) public relations utilizing the scientific and non-scientific sector.

The results of the DemNet-D study will be used for the development of the “dementia tool-box” containing recommendations and best-practice examples. This toolbox will become a guideline for all those who are (interested in) setting up, managing, or supporting a dementia care network providing information on how care structures that build a network can be implemented, governed, and in the medium and long term be sustained.

**Dissemination**

**Conferences**


Publication

Reports for the BMG:

- 30. April 2013: Erster Zwischenbericht des Forschungsverbundes
- 31. Oktober 2013: Zwischenanalyse
  - Präsentation der Zwischenanalyse auf einem Treffen mit dem BMG, des DLR und von Vertretern des Forschungsverbundes am 08. November 2013 in Berlin
<table>
<thead>
<tr>
<th>Title</th>
<th>Development and pilot testing of a set of quality indicators for the pain assessment in older persons in long term care</th>
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<td>Duration</td>
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<td>Collaboration</td>
<td>German Pain Society and Prof. Dr. Sabine Bartholomeyczik, University of Witten / Herdecke, Faculty of Health, Department of Nursing Science</td>
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<tr>
<td>Principal Investigator</td>
<td>Martina Roes</td>
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<td>Scientific Staff</td>
<td>Marjan Laekeman</td>
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Introduction

An important step towards improving pain assessment in the elderly in the inpatient geriatric care is the development of an S3 guideline (s. project: S3 LL SchmerzAss). In order to evaluate the implementation and application of the guideline clinical performance measures such as quality indicators are needed. The aim of the QiSavA project is to develop such a set of quality indicators and to test the identified indicators in a pilot study.

Question

Which, for the guideline appropriate indicators, can be derived from existing national and international guidelines and existing indicator sets to evaluate the quality of care regarding pain assessment in older persons?

The main research question is divided into three sub-questions:

1) Is it possible to derive appropriate indicators from the already existing national and international guidelines and sets of indicators to evaluate the quality of the use of a pain assessment in the inpatient geriatric care? Moreover and if so, which ones?

2) Which of the newly developed quality indicators (QI) are already being applied in the health care practice?

3) To what extent is it possible to implement such a quality indicator set into care practice?

Methods

The QiSavA project is carried out in several steps:

1) Theoretical development: literature review and expert survey for the draft preliminary quality indicator set (QI Set Version 1)
2) Practical development: empirical study consisting of an exploratory cross-sectional study (qualitative and quantitative data collection) in three different institutions of inpatient geriatric care to evaluate which of the indicators are already being used in the health care practice. Based on these results modification of the existing set and subsequent expert evaluation (QI Set Version 2).

3) Test phase of the new sets of indicators in three institutions and development of a final indicator set.

**Status**

In preparation for this project several expert interviews and a preliminary review of literature, guidelines and manuals were conducted to explore the significance and feasibility of this topic. Currently, the project is in the theoretical phase. In a first step, a literature review was carried out with the aim of:

a) Acquiring methodological knowledge concerning the development of quality indicators,

b) Identifying possible indicators from the publications.

Different to conventional literature reviews in this study not only the usual medical databases will be searched but also the websites of organizations and institutions that deal with pain, the elderly or the development of quality indicators (e.g., pain societies, geriatric societies, Guidelines International Network GIN) in different countries.

The content of several manuals / guidelines / methods papers regarding the development of quality indicators has been analyzed. The search for suitable source guidelines has been finalized and a "citation tracking" for other suitable guidelines were also performed. Twelve source guidelines were evaluated methodically for creating the guideline synopsis and the analysis of content of the existing quality indicators in the 12 included guidelines were also achieved.

**Results**

At the end of the project, a quality indicator set will be available, which is suitable for the evaluation of the implementation of the Guideline "Pain assessment in elderly nursing home resident’s".
**Dissemination**

**Conferences**


Introduction
The German Nursing Care Reform Act requests the implementation of a self-assessment of acute pain in geriatric acute care. The currently available standards and guidelines in Germany are focusing mainly on the self-assessment of acute pain. The research results of the last years demand a re-evaluation of the pain assessment in the older population living in nursing homes. Therefore members of the interdisciplinary working group "pain and age" of the German Pain Society developed a guideline for "Pain assessment in older people in nursing homes" in cooperation with the German Centre for Neurodegenerative Diseases (DZNE), Witten.

Methods
Aligned on by the AWMF and ÄZQ procedure described and the DELBI instrument of AWMF: http://www.awmf.org/leitlinien/detail/anmeldung/1/ll/145-001.html

Status
Synopsis report of the source guidelines is available. Delphi Survey (2 of 4 planned) is completed on priority key questions. Primary literature search on the prioritized key questions is in process. Delphi Survey on the results of the primary literature search is in preparation.

Results
After completion of the project, S3 guideline on pain assessment in older people in nursing homes can be implemented.

Dissemination
Conferences
Sirsch, E. (29.11.2013). Leitlinie zum Schmerzassessment bei älteren Menschen in der stationären Altenhilfe. VIII. Akutschmerzkongress Köln

Publication
2.3 Methods and Measurements

<table>
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<tr>
<th>Title</th>
<th>Translation and Validation of the Challenging Behavior Scale</th>
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<td>Professor Esme Moniz-Cook, Center of Dementia Research and Practice, East Yorkshire, UK Nursing homes in Witten</td>
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<td>Margareta Halek</td>
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<td>Scientific Staff</td>
<td>Lena Köller, Daniela Holle</td>
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Introduction

The DZNE strives to optimize the assessment of outcomes for care interventions and to adapt existing outcomes to the need of health care research and care practice. For the assessment of challenging behavior of people with dementia 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 people with dementia 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 unambiguity 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 further introduced to the translation method and conducted the first translation of the CBS within a guided group discussion. Subsequently, a focus group, consisting of six nurses and nursing assistances of different nursing homes, evaluated the first interim translation of the CBS regarding its adequacy of wording and comprehensibility.
of the formulations used. The focus group was also informed in advance about the CBS and the translation method. No information was given about the original English version of the CBS. Criticisms and proposals for modifications propounded by the focus group were discussed and included into 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
Finalized

Results
A German Version of the CBS is now available for its use in health care research and care practice. The translation for the CBS using the Two-panel approach was perceived to be very beneficial and effective in comparison 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. Less understandable were the instruction given for the analysis and interpretation of the result of the CBS.

The further steps are the examination of practicability, validity and reliability of CBS-D practice and for research purposes.

Dissemination
Conferences
In preparation
Introduction

Problems

Dementia care Mapping (DCM) is an observational instrument used for the process-oriented evaluation of person-centered care in dementia. The instrument has been used in Germany since 1998 for persons with dementia in settings such as day care facilities, long-term care, and hospitals. DCM is utilized as an instrument for the development of person-centered practice and as a research tool. The objective is to increase relative wellbeing of persons with dementia. The DCM implementation is a complex intervention. The success of the DCM implementation depends on various factors.

Aims

Based on a cross-national survey of DCM users in the United Kingdom and in the USA by Douglass et al. (2010) the goal of this project is to conduct a similar survey of DCM users in Germany. This survey is supplemented by questions about user behavior on the use of media for the generation of knowledge.

Questions

1. To what extend execute DCM user the instrument in practice?
2. What challenges experience DCM user in each of the four DCM phases: briefing, mapping, data analysis and feedback?
3. What access-paths do DCM users select in order to generate knowledge?

Methods

Design

The DCM user questionnaire (mainly Likert Scales) contains next to demographic variables four content parts with a total of 119 items. Each section contains also one question with open space.
**Sample/ Setting**
The posting of the questionnaires was done in cooperation with the University Witten/Herdecke who provided the address data of German DCM users. The shipping was added with a postpaid envelope.
- When indicated dependent variable (primary and secondary (most important)) incl. data source /type of data

A descriptive analysis will be conducted using SPSS Version 21. Qualitative data will be analyzed by thematic coding.

**Status**

**Status to date**
Ethical clearing was done by the DZNE (May 2012) and by the Ethic Committee of the German Society of Nursing Science (August 2012). The survey was conducted till February 2012. 208 DCM-User questionnaires could be included into the subsequent analysis, which are a representative sample for use in all German states. Users are with 76 % female, the age average is on 48.4 years (SD 9.1).

**Next steps**
The data analysis process is completed. The publication of the results is currently being prepared.

**Results**
The German DCM-User survey gives insight into the actual use of DCM. The DCM-User perspective of DCM can be gathered for the first time in Germany. The findings will be used to develop measures to improve the practice application of DCM. Additionally, the findings are intended to investigate DCM implementation processes and inhibiting and promoting factors.

**Dissemination**

**Conferences**


**Publication**

Final report in preparation
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, stage of dementia in which the application of the measurement is possible. The measurement \textit{QUALIDEM} is recommended for the Qol assessment in institutional long-term care and to assess Qol longitudinally. For this \textit{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).

Aims

(1) Investigation of the reliability and validity of the \textit{QUALIDEM} in Germany (2) synthesis of relevant Qol domains from the perspective of people with dementia and (3) development of a concept for the investigation of the construct validity for dementia-specific Qol measurements

Questions

1. Which domains of Qol are described as relevant from the perspective of people with dementia?
2. To what extent is the scalability of the German \textit{QUALIDEM} given?
3. To what extent is the internal consistency of the German \textit{QUALIDEM} given?
4. What is the interrater reliability of the German \textit{QUALIDEM}?
5. What is the intrarater reliability of the German \textit{QUALIDEM}?
6. To what extent is the validity of the German \textit{QUALIDEM} given?

Methods

This study is divided in three methodological phases. 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 and the selection of adequate strategies for the evaluation of the construct validity of the QUALIDEM. The second empirical phase consists of the three following steps: (a) an investigation of the scalability and internal consistency based on a sample of 634 people with dementia, (b) an evaluation of the interrater (n = 161) and intrarater 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. 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 reliability of the QUALIDEM is completed. The meta-synthesis of qualitative studies is almost done. In 2014 an item manual and a standardized education program will be developed to increase the inter-rater reliability. This is followed by the data collection for the validity study.

Results
The scalability analysis confirmed the scalability and internal consistency of most of the QUALIDEM subscales. The subscale having something to do (mild to severe dementia), negative
affect and social relations (very severe dementia) and social isolation (both instrument versions) showed a insufficient scalability.

The reliability investigation showed insufficient results for the inter-rater reliability (Intraclass Correlation coefficient ≤ 0.70) but sufficient results for the intra-rater reliability of all subscales (Intraclass Correlation coefficient ≥ 0.70).

**Dissemination**

**Conferences**


**Publication**


2.4 Potentials in and of care arrangements

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<td>Collaboration</td>
<td>Prof. Dr. S. Bartholomeyczik Department of Nursing Science, Witten/Herdecke University</td>
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<td>Principal Investigator</td>
<td>Sabine Bartholomeyczik Monitoring: Martina Roes,</td>
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<td>Scientific Staff</td>
<td>Silke Kuske</td>
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Introduction

Handovers or transitions between health care settings are associated with care fragmentation, poor coordination and communication failures. In particular, the vulnerable elderly with cognitive impairment and complex health care needs, e.g. people with dementia (PwD), are at risk for poor information exchange and its consequences. The risk of adverse events can increase depending on the physical and cognitive impairment and can have an impact on the general state of health, malnutrition, delir, fractures or decubitus. There is poor information about the quality of handovers at admission and discharge in respite care.

Objective

The aim of the study is to describe and analyze communication structures and processes at handover of PwD between home and respite care and also to develop recommendations for further evaluation.

Methods

A descriptive study design considering nursing facilities with respite care and respite care facilities.

The following steps are planned:

- Systematic Review to identify safety relevant communication structures and processes between health care settings, also between home and respite care;
- Expert interviews and analyzing handover documents to describe communication structures and processes between home and respite care;
• Evaluation of the results from evidence, expert interviews and handover documents to define quality criteria, fields of action as well as facilitating and inhibiting factors;
• Delphi-survey to evaluate and to select relevant fields of action;
• Online-survey to describe and to analyze selected defined communication structures and processes at handover of PwD between home and respite care;
• Descriptive analysis and development of recommendations;

**Status**

The expert interviews, the analysis of handover documents, the evaluation of the results from evidence, expert interviews and handover documents as well as the delphi-survey have been finalized. The ethical approval is given. The conduction of the online-survey is planned as a next step.

**Results**

The need for action with regard to the quality of handover at admission and discharge of PwD is defined and recommendations are provided.

**Dissemination**

**Conferences**


**Publication**

Introduction

Problems
It is estimated that currently more than 10% of the hospitalized patients are affected with dementia. The care processes in hospitals are focused on the treatment of people with acute somatic diseases. For people with dementia (PwD), the hospital stay may lead to disorientation and restlessness, to a lack of adherence, to defensive behavior, to self-harm and aggressiveness. In addition, further risks have been identified for people with dementia in hospitals, for example, nosocomial infections, development of delirium, prolongation of hospital stay, higher readmission rates and increased mortality. To address these risks, hospitals in Germany are developing special care concepts for people with cognitive impairments.

Aim
1. Analysis of various projects in terms of the basic principles and differences on the basis of empirical data
2. Identification of difficulties and need for development and research
3. Deduction of recommendations for the development of care concepts to improve the care and treatment of people with dementia in acute hospitals.

Questions
1. How do hospitals face the challenge to treat people with dementia in the hospital?
2. Which concrete measures are introduced to improve the care of people with dementia?
3. What are the characteristics of these concepts?
4. What recommendations result from the previous findings for the introduction of specific dementia care concepts in hospitals?

Methods

Design
Qualitative cross-sectional study

Sample/Setting
For data collection staff from clinics was recruited that had already developed a dementia-specific concept and tested for a long time. We excluded hospitals that could be considered as known by a scientific evaluation or publication regarding their concept. The convenience sample consisted of 15 experts (project managers or coordinators, physicians and nurses in senior positions) and 23 nurses from seven clinics in Germany.

Data source /type of data
The experts were interviewed by the means of expert interviews, the nurses participated in a total of 5 group discussions. Additionally, structural data (sponsorship, catchment area, care level, number of beds, medical departments, cooperation) has been collected by questionnaire in the hospitals.

Delineation of the analysis
The interviews and focus group discussions were analyzed by applying qualitative content analysis according to Mayring. Here, from the text material thematic categories were built.

Status
The project was completed in 2013

Results
First, problem areas were identified: which behavior does the hospital staff perceive as difficult or challenging. These included, on the one hand the dementia specific limitations and behaviors of patients, for example disorientation, high motor activity and challenging behavior, as well as insecurity, lack of time and lack of dementia-specific knowledge on the part of professionals. But even setting-specific characteristics, such as limited resources, poor information on interfaces or confusing structural conditions often lead to escalating situations that burden both the professionals and the patients concerned. The conditions for the development of dementia specific care concepts show some unfavorable features such as a mono-professional (nursing) orien-
tation, lack of personnel and material resources as well as problems of competence and acceptance. The development of the concepts was not always oriented primarily to the professional objectives, but to the limiting options. However, a variety of approaches have been developed and tested. These include both structural changes (e.g. the establishment of special care units), as well as provision of qualification of employees, improvement of the nutritional status of patients, adaptation of the physical and social environment, promotion of physical and cognitive function in patients and the involvement of family members. The use of technical aids (e.g. GPS) and networking with other care settings (e.g. long-term care) were also elements of the dementia specific care concepts. Different strategies have been applied for the development and implementation of concepts. In acute care settings knowledge and experience in relation to dementia-specific approaches were hardly available. Concepts that were developed and used in other care settings (e.g. nursing homes) could not easily be integrated or transferred to the acute care setting. Often, the development and implementation was carried out through a permanent process of trial and error, including adjusting. Only occasionally the dementia concept for acute care was based on a previous problem analysis. Usually, the development and implementation process was accompanied by external consulting and coaching. Many factors have complicated the implementation of changes. This includes little willingness to change in terms of care processes and tasks, low priority of the concepts within the different professional groups, lack of freedom to act and appreciation for the staff involved as well as low visibility of effects. However, positive changes for the patients as well as for the professionals and institutions were effected from the perspective of the participants. Among other things, an increase in wellbeing and a more rapid recovery of patients, increased job satisfaction of nurses and a positive public image of the hospital were observed. From the results of the study the following recommendations have been derived amongst others: development of care policies for all hospitals with defined minimum standards; qualification and participation of all professional groups involved in the treatment and care of person with dementia; provision and financing of necessary resources. For future research in this field the testing of effectiveness of dementia-specific care concepts is encouraged.
Dissemination

Conferences

Publication
Introduction
Problems
Specific trajectory models for person with dementia (PwD) in the early and middle stage of their disease compared to people with Multiple Sclerosis and Parkinson’s in a long-term study do not exist currently. To understand what chronically ill people enables to integrate their chronic illness into their future life course requires as a first step the reconstruction of their needs and demands from their own point of view. As a second step it is possible to develop a precise understanding about what kind of support they need during their life trajectory.

Aims
This study aims to support the development of tailored interventions for people with dementia and to learn more about their individual coping strategies during lifetime. Additionally, it aims to identify graduation modes.

Questions
Which graduation modes are important to manage the coping process to integrate dementia, multiple sclerosis or parkinson during life trajectory?

Methods
Design
The study LEBE is designed as a qualitative empirical long-term study over a period of at least three years. It is based on the analysis of narrative biographical interviews and episodic interviews.

Sample/ Setting
At least four and up to eight people with dementia, Multiple Sclerosis or Parkinson’s disease are included. Over a period of three years and up to at least four stages they were interviewed on 60
their survey dealing with the disease. The population of persons interviewed is at least twelve. The number of interviews is at least 48. The secondary analysis of interviews from the current study SEIN (Self-perception and Intervention) includes additional 16 interviews.

The reconstruction of coping-strategies based on self-expressions of people with Dementia, Multiple Sclerosis and Parkinson's disease during lifetime is based on an important subjective factor of quality of life: well-being.

**Delineation of the analysis**

Different methods to analyze the interviews were chosen and combined according to the data basis.

1. Reconstructive hermeneutic analysis (three perspectives: content-analysis, structure and trajectory models).
2. Categorical analysis to find individual graduation modes.

The qualitative analysis of the interviews follows a three step cohort analysis:

1. For each person and each disease separately according to the point of survey.
2. Compared to each other within the cohort of disease
3. Compared with the other cohort. Differences and similarities are detected.

**Status**

**Status to Date**

The first phase of interviews are finished. The data were evaluated. A book template was created.

**Next steps**

In 2014, the second data collection phase will be conducted and evaluated. The third and fourth phase of survey will be done in 2015 and 2016. A final report is planned.

**Results**

The conceptional basis to create individual suitable support services for people with Dementia, Multiple Sclerosis or Parkinson was found: a combination of adjustment factors and graduation modes. Based on these results it will be possible, to reduce the already existing instruments and to create new tailored interventions.
Introduction

The future formal and informal long-term care potential will decrease while at the same time the number of people with dementia increases. The German low-threshold support services are a part of additional services to relieve family caregivers and to provide social activities to people with dementia. The care is offered by volunteers in groups in the community or in individual care situations at home. The barrier for utilization should be as low as possible. The scientific literature concerning low-threshold support services is very limited. Therefore, in the study NisA-Dem low-threshold support services are investigated from the perspectives of the different stakeholders (providers, coordinators, volunteers, family caregivers and people with dementia). The research question is: What is necessary for a needs-based development of low-threshold support services from different stakeholder perspectives?

Methods

Quantitative and qualitative methods were used to gain an insight into the different perspectives. For the quantitative part, four standardized questionnaires were developed. Descriptive statistical analyses were carried out to describe frequencies of characteristics of the participants, structural data about low-threshold support services and an evaluation of aspects found in the literature using a 4point scale.

Furthermore, qualitative interviews and group discussions with the different stakeholder groups were conducted. The aim was to get a deeper insight using a flexible interview guide. The data was analyzed using the content analysis. The data collection was conducted in two regions in North-Rhine Westphalia and admission was effected by means of the providers.
Status

The quantitative and qualitative data collection and analysis is completed. The publication of the study results is in preparation. Furthermore, a special study report is written.

Results

Of the 747 distributed questionnaires 164 were received. Only the volunteers’ (92) and the family-caregivers’ (53) questionnaires are analyzed because the number of providers’ (4) and coordinators (15) questionnaires were too small. One result was that aspects of low-thresholdness such as reachability, flexibility, service admission and cheapness played in the view of family caregivers and volunteers a minor part. For both the most important aspects were the ones concerning the content organization and the care of the person with dementia as well as his or her wellbeing. Furthermore, volunteers show high motivation for their voluntary engagement. Their engagement seemed to play an important role in their lives. Interesting is also, that half of the volunteers were not voluntary engaged but employed by service providers. These volunteers had a contract with the providers and a regular salary.

The qualitative results (7 group discussions, 4 individual interviews) point into the same directions. Volunteers talked about their “job”, meanwhile coordinators and providers tended toward two different directions. The one direction was the classical service based on voluntary engagement. The costs for care were as low as possible, so that everybody had a chance to utilize the service. The services of the other direction demonstrated a tendency toward professionalization while they employed their volunteers and trained them comprehensively. The costs for care are higher. The providers argued that they want to provide a high quality care and also certain continuity. Family caregivers confirmed those two directions, while some prefer an outcome-oriented approach with a therapeutically occupation; others tend to see the leisure and well-being of people with dementia in company with others as a main goal (meaning low-threshold support services). The group discussion with people with dementia could just be partly analyzed. But they emphasized the company with other people in the same age in a group care situation.

Dissemination

Conferences

Hochgraeber, I.; Bartholomeyczik, S. & Holle, B. (10.-12.10.2013). Low-threshold support services for community dwelling people with dementia in Germany - Volunteers turning into professionals. 23rd Alzheimer Europe Conference, Malta.
**Title** | Day Care Center for Care-Dependent Relatives of Employees in an Acute Care Hospital | TAPA-K
---|---|---
**Duration** | 26th month (April 2013–May 2015) | 
**Funding** | Ministry of Health, Emancipation, Nursing and Age North-Rhine-Westphalia (NRW)  
NRW Ziel 2 Program 2007–2013 EFRE  
IuK & Gender Med.NRW  
Project executive organization Forschungszentrum Jülich (ETN) | 
**Collaboration** | Prof. Dr. Wilfried Schnepp Department of Nursing Science Witten/Herdecke University  
Evangelisches Krankenhaus Witten | 
**Principal Investigator** | Bernhard Holle | 
**Scientific Staff** | Medlin Mogar | 

**Introduction**

Many employees are facing the challenge to deal with the compatibility of their professional duties and the responsibility for a care dependent relative. This is partly associated with major efforts and limitations. Employed Caregivers are mostly women. So the responsibility of care is unequally distributed across the sexes.

**Aim**

To develop and establish low-threshold support service (a day care center located at the workplace) for employed caregivers of an acute care hospital (Evangelisches Krankenhaus Witten).

Also, this new support service should relieve caregiving employees’ in their double role. In addition the aim of the project is to secure long-term ability to work and to remain in gainful employment and to promote equal opportunities for men and women.

**Question**

Which Contribution can a workplace located day-care center for care dependent relatives perform for a better reconciliation of work and care?
Methods

- Literature Studies on the needs, demands and burden of employed informal caregivers as well as examples of already implemented best practice models to relieve this target group
- Questionnaire Survey of all employees in the collaborating hospital (n=430) to identify and assess the specific needs regarding of a support service (day care center located at workplace)
- Qualitative Interviews with employees who deal with the compatibility of their professional duties and the responsibility for a care dependent relative
- Based on the theoretical and empirical results, the development of a concept for implementation the support service (day care center) at the collaborating hospital
- Qualitative interviews with responsible actors of the management and organization and users of the support service for the purpose of a process evaluation

Status

The two literature studies on needs, demands and burden of employed informal caregivers as well as examples of best practice to relieve this target group were conducted. Based on the literature, a questionnaire to identify and assess the specific needs of affected employees in the collaborating hospital (EVK Witten) was developed. Data collection is completed (n=126). Descriptive statistical analysis was conducted. Some of these results have already been presented to the collaborating hospital. Furthermore a guide for in-depth interviews with employed caregivers was developed. So far three of 12 total planned interviews were conducted. Based on the theoretical (literature review) and empirical (employees survey) findings a concept for implementation the support service (day care center) located at workplace is developed in cooperation with the project partners. This process is still ongoing. Appropriate rooms for the new support service have already been selected.

Next steps

Developing the final concept for the support service and the implementation (planned for March 2014). In addition further interviews with employed caregivers are planned. First contacts with potential experts and actors of similar projects have been made and the development of an interview guide is planned.
Introduction

The majority of persons with dementia (PwD) lives at home and is cared for predominantly by family members (informal carers). Informal carers assume the role of key care providers and are often the primary decision makers. The study VerAH-Dem focuses on the every-day care actions and decisions of informal carers over the course of the disease. It was examined how informal carers organize home-based care arrangements in view of the framework conditions of the German statutory long-term care insurance law, at which time and triggered by which events they decide to seek professional help and services and how the "care mix" of informal and formal care is composed.

The aims of the study were:

- The assessment and description of the structures and relevant services and supporting persons in home-based care arrangements for PwD (self-organization of informal help structures and utilization of formal services).
- Reconstruction of the every-day care actions and decisions of informal carers in home-based care arrangements over the course of the disease (typical courses and constellations)

Methods

A Mixed-Methods design was chosen. In a provincial-rural setting, the views of informal cares of a PwD were assessed in a cross sectional survey as regards organization and utilization of informal and formal services in home-based care arrangements (n=102). Item development, pretesting and pilot testing were components of the study. Descriptive statistics and association analysis were carried out to analyze the quantitative data. Narrative guided interviews (n=9) were
used to gain a deeper insight the every-day care actions of informal carers. A subsample of contrasting cases (n=4) was interviewed again after 14 months. Qualitative data was analyzed with a case constructive approach using objective hermeneutics.

**Status**

- The project was finalized at the end of 2013. Extensive case reconstructions (n=4) are processed further within the scope of a PhD thesis.

**Results**

In VerAH-Dem an instrument to assess home-based care arrangements for PwD (D-IVA was) developed and pilot tested. The D-IVA was proofed to be suitable for the use in the community and is currently applied in an evaluation study on dementia networks in Germany (DemNet-D). The analysis of data from the qualitative strand provided us with a model of trajectories in every-day care actions of informal carers of community-dwelling PwD over the course of the disease.

Summary of most significant results: Information about 102 care arrangements was gathered, including socio-demographics about the primary carer and the PwD. Overall, the characteristics of the sample did not differ substantially from the results of other studies: PwD were on average 80+ years and were mostly cared for by their children or by their partners. The majority of informal cares were female. The most common living arrangement was the person with dementia living in his or her own household together with a partner (43.1%). According to the participants the care arrangements existed for 3-4 years on average and in most cases the PwD were dependent on help and support to perform activities of daily living to a high extend. The investigated sample represents a group of PwD, which have already had contact with the health care system in most cases. The majority had received a dementia diagnosis (89.2%), a care level according to the German statutory long-term care insurance law (89.6%), and a legal guardian (60.9%). In most cases the families received several types of formal services, only 14.7% did not receive any professional help and support at all.

Furthermore, utilization of formal services often started within the first year since the appearance of first symptoms. Nevertheless, the types of services used might change over the course of the disease. Overall, home care nursing services are the most prominent formal service, utilized in 52% of the arrangements.
The vast majority of participants were optimistic to be able to care for the person with dementia at home, even if the dementia progresses without changing the current circumstances (40.7%) or with some additional support (49.5%). Associated analyses have shown a statistical significance between a optimistic perception of the care situation and a rather high care level (2 or 3). It became clear that the amount of informal caring time is high and that different people from the social network are involved in the care arrangement in this sample. In 71 care arrangements informal care was provided on a daily basis, informal caring time in these arrangements amounted to 12.2 hours per day on average. Perhaps this engagement is one of the reasons, why the care situation was perceived as reasonable stable in most cases. However, at the same time it becomes clear, how much home-based care arrangements are vitally dependent on the support of families. Accordingly, thematic analysis of open-ended questions identified over burdening of the primary-carer or the need for recreational time as the two most often stated reasons to seek professional support.

The analysis of the qualitative data shows a phase-shaped course in the every-day care actions of informal-carers which is characterized in particular at the beginning of the illness by “stormy waters”, which either stabilize into care routines or can cause the referral of the person with dementia into an institution. In accordance with the results from the quantitative strand, the interviewees perceived the early and middle stages of the disease as particularly challenging.

The case reconstructions will represent four typical appearances of every-day care actions of informal-carers living at home with a person with dementia.

Conclusions: The instrument D-IVA developed and piloted in VerAH-Dem is currently applied in DemNet-D in several data collection waves with a bigger sample size (n= 455 at T0). Thus the results from both studies can be compared and possibly pooled for further analysis. The Mixed-Methods approach in VerAH-Dem turned out to be useful to assess home care arrangements regarding their structure and the appearance of typical constellations. In addition, phenomena such as stability and normality in families with dementia could be identified, which gives impulses for other research.
Dissemination

Conferences


Publication

### 2.5 Finalized Projects

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<td>Claudia Dinand</td>
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<td>Pfrimmer Nutricia GmbH/ DZNE</td>
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<td>Sven Reuther</td>
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<td>Sabine Bartholomeyczik, Stefan Wilm</td>
<td>Margareta Halek, Daniela Hardenacke (now Daniela Holle)</td>
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<td>Michael Pentzek, Heinrich-Heine Universität Düsseldorf, Institute for ???</td>
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3. Work results

3.1 Book chapters


3.2 Books


3.3 Articles (peer reviewed)


3.4 Articles (not peer reviewed)


3.5 Presentations (invited)

Dichter M


Halek M.


Halek, M. (15.03.2013). Fallbesprechungen im Praxiseinsatz. Gewaltprävention in der Praxis Mülheim an der Ruhr


Holle B

Holle D

Kuske S.

Laekeman M.

Panke-Kochinke B.

Riesner C.


Roes M.


Sirsch E.


3.6 Presentations (peer reviewed)


Roes, M. (25.06.2013). Learning from each other - using Case Reviews to solve problems in Nursing Homes. 20th IAAG World Congress of Gerontology and Geriatrics, Seoul, South Korea.

Roes, M. (27.06.2013). Impact of Private Social Networks on Home Care Settings. 20th IAAG World Congress of Gerontology and Geriatrics, Seoul, South Korea.


Roes, M. (20.11.2013). National Dementia Strategy for Germany. AL-SIG and ResQCare pre-conference: Assuring that Innovative Research Impacts Policy in Residential Long-term Care Setting. 66th GSA Annual Scientific Meeting, New Orleans, LO.

4. Boards and consulting activities

Buscher I.
- German Society of Gerontology and Geriatrics (DGGG)
- German Society of Nursing Science (DGP), section dissemination and implementation (SDI), leader
- European Academy of Nursing Science (EANS)

Dichter M.
- German Nurses Association North-West (DBFK), COE
- German Society of Nursing Science (DGP), Section Research Methods
- German network for Evidence-Based Medicine
- European Academy of Nursing Science (EANS)

Dinand C.
- German Association for Nutrition (DGE)
- German Society for Nutritional Medicine Deutsche Gesellschaft für Ernährungsmedizin (DGEM)
- German Society of Nursing Science (DGP)
- European Society for clinical Nutrition and Metabolism (ESPEN)

Döttlinger B.
- German Society of Nursing Science (DGP)
- International Association for the Promotion of Basale Stimulation.

Halek M.
- German Society of Nursing Science (DGP)
- Early detection and timely INTERvention in DEMentia (INTERDEM)
- Project “Bedürfnisse bei schwerer Demenz” (Needs of people with advanced dementia) funded by the Ministry of Health, scientific advisory board

Hochgraeber I.
- German Nurses Association (DBfK)
Holle B.
- German Society of Nursing Science (DGP)
- Sigma Theta Tau International, Honor Society of Nursing

Holle D.
- German Society of Gerontology and Geriatrics (DGGG)
- German Society of Nursing Science (DGP)
- Early detection and timely INTERvention in DEMentia (INTERDEM)
- European Academy of Nursing Science (EANS)
- International Psychogeriatric Association (IPA)

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

Kuske S.
- Aktionsbündnis Patientensicherheit e.V. (alliance for patient safety)
- Network for healthcare research

Laekeman M.
- German Pain Society:
  - Work group „Pain and Age“
  - Work group „pain and exercise“ deputy speaker
- International Association for the Study of Pain (IASP): Special Interest Groups „Pain and Movement“, „Pain in Older Persons“ and “Pain Education”
- Network of colleges for healthcare professions (HVG e.V.)
- German association of physiotherapists

Laporte Uribe F.
- Global Young Faculty, a collaboration of the Mercator Foundation and an alliance of the universities in the ruhr area

Nover S.
- German Sociological Association (DGS)
Quasdorf T.
- German Society of Nursing Science (DGP), Section Dissemination und Implementation (SDI)

Palm R.
- German Nurses Association (DBfK)
- German Society of Nursing Science (DGP)

Pinkert Ch.
- German Society of Nursing Science (DGP)

Riesner C.
- German Society of Nursing Science (DGP), Section Dissemination und Implementation (SDI),
- Dementia Care Mapping (DCM), Strategic Lead Germany, DCM International Implementation Group (IIG), Bradford Dementia Group, UK
- North Sea Dementia Research Group, http://www.northseadementiagroup.eu/ member

Roes M.
- AcademyHealth - Advancing Research, Policy and Practice
- German Society of Gerontology and Geriatrics (DGGG)
- German Society of Nursing Science (DGP), Section Dissemination and Implementation (SDI),
- German council for education in nursing (DBR) (until 12/2013)
- German network for quality development in nursing (DNQP), steering group
- Early detection and timely INTERvention in DEMentia (INTERDEM)
- "Fellowship for innovations academic education" association for the promotion of science, jury member (2011-2013)
- German Federal Joint Committee (G-BA), member in three working groups
  - Identification of relevant indicators for cross-sectorial quality management (§ 137 SGB V)
  - Guideline for quality management in primary care(§ 9 SGB V)
  - Guideline for cross sectional quality management (§ 299 SGB V)
• Gerontological Society of America (GSA)
• Harkness Fellow, Commonwealth Foundation, Alumni
• Honor Society of Nursing, Sigma Theta Tau International (XI Chapter)
• Institute for Quality and Efficiency in Health Care (IQWiG), board of trustees
• Improvement Science Research Network (ISRN)
• 'Lehren - Das Bündnis für die Hochschullehre' (alliance of professors), an initiative of the association for the promotion of science, the Joachim Herz foundation, the Nordmetall foundation and the Alfred Toepfer foundation F.V.S. (2012-2013), advisory board
• „Praktische Anwendung des Strukturmodells - Effizienzsteigerung der Pflegedokumentation in der ambulanten und stationären Langzeitpflege“ (applications of the structural model-enhancing efficacy of the documentation in longtime-care) member of the steering committee of the ministry of health
• Robert Bosch Fellow, Alumni
• Scientific advisory board of the „Bremer Pflegekongress“, speaker

Schwab C.G.G.
• German Nurses Association (DBFK)
  • Delegate of the managing committee
  • Revisor
  • Work group nursing chamber
• German Nurses Association North-West (DBfK NW):
  • Member of the steering committee
  • Deputy member of the nursing council (North Rhine Westphalia (NRW))
  • Work Group Knowledge management
  • Examiner for the advanced training of nursing experts for PwD
  • Work group of the ministry of health (North Rhine Westphalia (NRW)) for the state support plan NRW
  • Work group of the ministry of health (North Rhine Westphalia (NRW)) to develop an inspection catalog for the law concerning accommodation and participation
• German Society of Nursing Science (DGP)
• German Network for Health care research (DNVF)
• Honor Society of Nursing – Sigma Theta Tau International (STTI)
• International Council of Nurses (ICN)

Sirsch E.
• Cost Action TD1005 Pain Assessment in Patients with Impaired Cognition, especially Dementia, **Workgroup II Nursing**
• German Society of Nursing Science (DGP), **board member**
• German Pain Society
• German Society of Gerontology and Geriatrics. (DGGG)
• European Academy of Nursing Science (EANS)
• German Network for quality development in nursing (DNQP), guideline for “nursing management of chronic pain” **member of the scientific advisory board**
5. **Work for scientific papers and publishers**

**Dichter M.**
- Health and Quality of Life Outcomes: Peer Reviewer
- International Psychogeriatrics: Peer Reviewer
- Pflege (Huber): Peer Reviewer
- Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen: Peer Reviewer

**Halek M.**
- Pflege (Huber): Peer Reviewer
- Pflege und Gesellschaft: Peer Reviewer
- International Journal of Nursing Studies (IJNS): Peer Reviewer

**Holle B.**
- Pflege & Gesellschaft (Juventa): Peer Reviewer
- Pflege (Huber): Peer Reviewer

**Holle D.**
- International Journal of Nursing Studies (IJNS): Peer Reviewer
- Pflege (Huber): Peer Reviewer

**Köhler K.**
- Zeitschrift ARBEIT (Lucius): Peer Reviewer

**Kuske S.**
- Journal of Public Health: Peer Reviewer

**Laekeman M.**
- Clinical Rehabilitation: Peer Reviewer

**Riesner C.**
- pflegenetzmagazin, Wien, editorial,
Roes M.

- Gerontology Society of America: review abstracts
- Healthcare Policy: Peer Reviewer
- Managementhandbuch Pflege, medhochzwei Verlag: editorial
- PADUA, Huber Verlag: editorial
- Pflege und Gesellschaft, Juventa: Peer Reviewer
- Pflegewissenschaft, hps media: editorial, Peer Reviewer
- Zeitschrift für Gerontologie und Geriatrie: Peer Reviewer

6. **Organization of conferences**

- 08.10.2013: External Workshop for research methods, Witten
- 09.10.2013: 4. Annual Conference of the DZNE site Witten, Witten
7. **Team (April 2014)**

**E-Mail Adresse:** first name.last name@dzne.de

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<td>CBS-D</td>
<td>Translation and Validation of the Challenging Behavior Scale</td>
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<td>DemKH</td>
<td>Dementia-specific approaches for the care of people with dementia in hospitals - empirical analysis of the current care situation and recommendations for further development</td>
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<td>Multi-centered, interdisciplinary evaluation study of dementia care networks in Germany</td>
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<td>DCM Survey’13</td>
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<td>DemenzMonitor</td>
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<td>FallDem</td>
<td>Case conferences for residents with dementia</td>
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<td>GesKom</td>
<td>Gestural Communicative action, as a link between language and action in persons with dementia</td>
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<td>HerVer</td>
<td>A concept analysis of challenging behavior</td>
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<td>Development and pilot testing of a set of quality indicators for the pain assessment in older persons in long term care</td>
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<td>Decision to self or external assessment of pain in people with moderately severe dementia in an acute hospital</td>
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