Annual Report 2014

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

Site Witten
Postfach 62 50
Stockumer Straße 12
58453 Witten

tel +49 23 02 - 926 237
fax +49 23 02 - 926 239

web: http://www.dzne.de/standorte/witten.html
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1. 2014 at a glance

1.1. Highlights in 2014

The year 2013 was a year of important changes for DZNE Witten: Martina Roes followed Sabine Bartholomeyczik as speaker and initiated a strategic process for the research team. In contrast to that, the main focus in 2014 laid on Internationalization and networking. By expanding our international research contacts during 2014, we improved our link to the international scientific canon, and DZNE’s work in Witten has become better known. First contacts to researchers in US, UK and NL were established on the occasion of DZNE’s interim scientific review in 2013. Those contacts were intensified and formalized in 2014. A highlight of the year was certainly the visit of a delegation of internationally recognized dementia researchers in Witten in July (see picture and description). A major focus of the joint work during these days was the topic of person-centeredness. Since the mid-1990s the concept of person-centeredness – often with reference to Tom Kitwood – has become more and more well-known, not only in the field of care for people with dementia but also in dementia research. The concept can be seen as an alternative to a widespread, primarily clinical and medical approach and can be seen as a consequent change of perspectives in the understanding and handling of challenging behavior. Based on the joint discussions, an ambitious work plan has been agreed on, for example: joint dissemination actions at international conferences, regular meetings, exchanges of knowledge on such topics as methodological questions and common research activities.

A further highlight of the year and an important step to the internationalization strategy was the visit of Myrra Vernooij-Dassen (NL) and Laura Damschroder (USA) on the occasion of DZNE Witten’s 5th
annual conference. The conference, held on October 8, 2014, was devoted to implementation, entitled “Sustainability in practice and research.”

Implementation research is a relatively new field of science in Germany and only a few researchers in nursing sciences and health services are working on questions of implementation. Having a working group specifically dedicated to questions of implementation and dissemination is one of the distinguishing features of DZNE Witten.

Even in the 1990s, researchers still believed that proving positive effects of, for example, interventions would lead automatically to an improvement in the field. In reality, only a small part of the scientific evidence in health care and health service research for people with dementia is systematically implemented in the field and develops its full potential effect. Laura Damschroder presented her internationally recognized contribution to the theoretical debate of implementation science during the conference and stayed in Witten afterwards for several days to share her experience of implementation studies with the DZNE Witten project teams and work groups.

Structure of this report

After this short introduction to the highlights in 2014, we are continuing with a more detailed presentation of DZNE Witten’s work. This includes two case studies on important research topics here in Witten: challenging behavior and quality of life of people with dementia. The idea of these case studies is to present dimensions and concrete working steps over the course of time through working groups and projects and to put them in a broader socio-political context (chapter 1.2). After this intense insight into Witten’s work over the last few years, the subsequent subchapters give some short information on the staff (1.3) and on the results of scientific work and on collaborations (1.4). The second major part of this report contains details of our current projects. As in the Annual Report 2013, the order of presentation follows the four main research fields of DZNE Witten.
For easy orientation in the respective chapter, a blue bubble naming the particular research area is located above each research project (see chart). Publications and speeches corresponding directly to a project can be found immediately after the corresponding project. Chapters three to seven contain information about publications with no clear connection to a research project, about staff members’ work on committees and as reviewers, as well as a list of all members of staff with their contact details.

1.2. Two case studies on main research themes: challenging behavior and quality of life of people with dementia

There is international discussion by researchers and research users, financiers and politicians on questions such as what benefits does research currently have, and what benefits should high quality research have. Closely related to this are questions concerning how these benefits are measured and how the measured impact can be reported in a comprehensive and unambiguous way. At the moment, the success of research is assessed - especially in the research community - on the basis of the number of publications in high-ranking research journals and on the number of corresponding citations. Nursing science, respectively health care and health service research are relatively new scientific branches. Thus, the respective impact factors (how often articles of a specific journal are cited in other publications) are still low in comparison to other research fields. This is one of the reasons why DZNE Witten decided to elaborate a different way of presenting the impact of their research. This different way of presentation should also take into account impacts beyond the scope of research,
i.e. possible social, societal, political and perhaps economic impacts. As DZNE Witten is not alone with the idea that different reporting formats should exist, some alternative reporting formats have recently been developed in the international field. The case study format used in the UK Research Excellence Framework (REF)\(^1\) seemed to be the most appropriate for Witten’s purpose. In the following, you will find the application of the case study format to the work of the DZNE Witten for the following two main fields of research at DZNE Witten “challenging behavior of people with dementia” and “quality of life of people with dementia”. The intention of this is not only to inform you about the state of the art of Witten's current research but also to show “how research is done” in this field, the complexity of several research steps and projects, and the development of research fields in the course of time.

1.2.1 Research for a better comprehension and handling of challenging behavior of people with dementia

a) Abstract

The care of people with dementia (pwd) in nursing homes is a challenge to all those who commit themselves to high quality, humane care. High professional and communicative skills are required, especially if the people cared for show behavior that is disruptive and challenging, such as wandering, aggression, screaming or apathy.

For nine years, researchers from the University of Witten/Herdecke (Department of Nursing) and, later, from the DZNE Witten have been working to improve the comprehension of challenging behavior of people with dementia and to find ways for better handling of such behavior. The basis of all further research steps were the following seven general recommendations for handling challenging behavior in nursing homes. They were developed by experts, (among others from the University of Witten/Herdecke) and were published in the form of guidelines by the Federal Ministry of Health in 2007.

Recommendations for challenging behavior of people with dementia in nursing homes:
Recommendation 1: understanding diagnostic
Recommendation 2: assessment instruments
Recommendation 3: validation

\(^1\) All universities and research institutes in the UK reported in 2014 about their work over the past five years in this format. On this basis, the quality of research in international comparison was evaluated. Look at [http://www.ref.ac.uk/](http://www.ref.ac.uk/)
Recommendation 4: memory care
Recommendation 5: contact, basal stimulation, snoezelen
Recommendation 6: promote physical activity
Recommendation 7: nursing processes in acute psychiatry crises

Between 2008 and 2013 to operationalize the guidelines (to make them usable in the field), the researcher team developed step by step an assessment instrument to capture potential reasons of challenging behavior as well as models for implementing case conferences. Using case conferences in the course of dealing with challenging behavior is recommended under the first point of the guidelines, “understanding diagnostics”. In several studies the effectiveness of the recommendations with respect to challenging behavior, the quality of life of people with dementia and the perceived exertion of nurses has been and is still being assessed. Parallel to this, the team in Witten is working on an interdisciplinary definition of the concept “challenging behaviors”. Furthermore, since 2010 a large longitudinal study has been surveying whether the guidelines are being realized in German nursing homes (whether the recommended tools are used, for example). The study also analyzes whether there are any relations of implemented recommendations to structural aspects of the nursing homes or to the personal characteristics of people with dementia (such as, for example, the occurrence of challenging behavior or their level of quality of life).

b) Research steps
In 2006/07 on behalf of the Federal Ministry of Health, members of the Department of Nursing Science at the University of Witten/Herdecke developed in collaboration with the Kuratorium Deutsche Altershilfe a report with recommendations on how to work with challenging behavior of people with dementia in nursing homes. The seven general recommendations, which were published by the Federal Ministry of Health as guidelines, were elaborated at that time and are today still the basis for continuing work on that topic. In several work packages this basis was developed further.

Work package 1: Definition and concept analysis
There is no generally accepted definition of “challenging behavior” but there are many surrogate terms. In a first working package, DZNE scientists have been elaborating since 2012 a concept analysis of challenging behavior in order to provide common ground for the work in practice and research (project HerVer).
Work package 2: Implementation of recommendations in practice

Do nursing homes in Germany work with the recommendations published in 2006? That was the research question of the so-called DementiaMonitor. The dementia monitor started in 2010 and consists of a longitudinal descriptive observational study which investigates - among other things - correlations between recommended concepts (such as understanding diagnostics) and implemented interventions, structural aspects of nursing homes (for example, special dementia units) and personal outcomes such as challenging behavior and quality of life (Palm 2013). Analyses show, for instance, that the size of the living area is related to staffing. In small houses and residential communities for people with dementia, fewer employees with a three-year training course are employed, but more nursing assistants and service personnel (Palm 2014).

Work package 3: Operationalization and testing of the first and second recommendation

A third area of work was devoted to the operationalization and testing of the first and second recommendations: using understanding diagnostic within the scope of case conferences and the use of assessment instruments. At the time when the basic recommendations were elaborated, the recommended models and processes of care were not available in the field as no operationalized version and no assessment instruments were obtainable on the market. Because of this obvious demand, Margareta Halek developed within the frame of her PhD from 2008 till 2010 a structured assessment tool for the collection and analysis of challenging behavior of people with dementia within the nursing home setting (the so-called innovative dementia orientated assessment instrument, IdA). This was based on the “Needs-Driven Dementia Compromised Model” (NDB-Modell)² by Ann Kolanoowski. Margareta Halek tested the instrument for content and construct validity and with regard to the practical use in nursing homes. The content of IdA was confirmed as valid. With regard to the construct validity, the stress-reducing effect of IdA could not be clearly proved. The major contribution of IdA, however, is its support for nurses in their decision-making process (Halek 2010).

In a parallel process, Daniela Holle investigated in the context of her PhD-thesis (Holle 2012) in collaboration with colleagues the effects of understanding diagnostics and the application of IdA in case conferences. This research was done as part of the project "Interdisciplinary implementation of quality tools for care of people with dementia in nursing homes (InDemA)" which was funded by the Federal Ministry of Health (Bartholomeyczik et al. 2013, among others).

The study results indicated that after the implementation of case conferences, professional carers had a better understanding of challenging behavior of people with dementia. At the same time, the results showed that nurses had difficulties with the stringent application of case conferences, which
is mainly due to the fact that explicit concepts for case conferences and their implementation are lacking (Holle et al. 2014).

In response to the results achieved in this work package, a following project (FallDem I) from 2010 to 2011 elaborated two different versions for implementing case conferences (a narrative approach and a second more structured one using IdA). A training module for professional carers (Reuther et al. 2012) was also elaborated on the basis of a literature review and expert interviews (Buscher et al. 2012). Since 2013 the subsequent project, FallDem II, examines the effectiveness today of these different versions of case conferences on residents and professional carers, using a cluster-randomized trial. In a stepped-wedged study design, each one of the two versions of case conference is implemented consecutively in 12 nursing homes and tested - among other things - on their impact on challenging behavior (Reuther et al. 2014).

The results of the project will not only show the effectiveness of case conference models as compared to the control groups. It will also give a deep insight into factors influencing implementation in practice, which are investigated in a parallel process evaluation (Holle 2014).

Work package 4: Understanding diagnostic in frontotemporal dementia (FTD)
In a fourth work package the concept of understanding diagnostics will be further developed and adapted to specific target groups and, in the near future, to other care settings than nursing homes. Since 2010, in the context of the project AspektFTD, specific everyday needs from the perspective of people with frontotemporal dementia are investigated and analyzed with the help of interviews and videography. At the beginning of the project, a systematic review was conducted on self-rated needs and coping strategies of people with FTD. No publication on this subject could be identified, which illustrates impressively the existing research gap (Dinand et al. 2014).

Work package 5: Assessment scales
In a fifth work package, assessment scales are optimized and adapted to the needs of research and/or practice. This includes the translation of instruments in order to make them available for a wider community of researchers and care professionals. From 2012 to 2013, the above-described instrument IdA was translated into English (IdA-e), based on the translation process of ISOR (International Society of Pharmaco-Economics and Outcome Research). At the same time, the "Challenging Behavior Scale" (CBS), developed in the UK, has been translated from English to German and validated in a two-panel-approach.
References


Details of further impact

The person with dementia: focus on needs and demands

Before 2006, the main focus in Germany was on the so-called “disruptive behavior” of people with dementia and on finding effective ways to suppress this form of behavior. With DZNE Witten’s work, which based its first steps on the NDB-Model (see above), attention was drawn to the person and his/her needs and demands. The developed concepts and assessment instruments support the realization of consequent, person-centered orientation. If these concepts are implemented properly in the field, they will lead to a change of perspectives resulting in the long run in a higher quality of life of pwd.

The carers: contribution to the development of professional competences

The publication of the guidelines led to a rethinking in the professional care in nursing homes with regard to the understanding and handling of challenging behavior of pwd, going more in the direction of person-centered care. This is also reflected by the terms used. Before 2006, in the German-speaking area terms were used which described the behavior of pwd in a negative way, assuming implicitly a deviation from “the normal” (such as “behavioral disturbance”, or “problems”). Today the proposed term of “challenging behavior” prevails, which draws attention to the environment’s influence as a trigger of behavior.

Over the years, concepts and instruments were developed in Witten which today are available to carers in the field or which will be available in the near future: for example, the innovative dementia-orientated assessment instrument (IdA) in German and English, two ways to carry out case conferences in a systematic way as well as a training concept for implementing case conferences. The latter are currently being tested within a RCT. The factors which were identified in the research process and which have to be kept in mind in order to execute case conferences successfully will help to reduce side effects in the field. Speeches held by researchers at national and international congresses help to disseminate the results both to other care researchers and to those working in the field.

The fact that in accordance with §114 Code of Social Law XI external quality tests in residential care consider the execution of case conferences shows the high relevance of case conferences in the field of professional care. The Medical Review Board of the Statutory Health Insurance Funds (Medizinischer Dienst des Spitzenverbandes Bund der Krankenkassen (MDS)) is the umbrella organization of those organizations installed by the health insurance funds which are among other things
responsible for the external quality checks of nursing homes. The MDS reported in their third quality report in 2012 that 96% of nursing homes completed case conferences on a regular basis.  

The political agenda: benefits for pwd according to the social law
Not long ago, the existence of challenging behavior of pwd and corresponding higher needs for social care, supervision and guidance did not lead to higher benefits from the social security system. But in the last few years, the integration of benefits for pwd with and without physical care needs has been started. Thus, with the care-realignment-law of 2013 (Pflege-Neuausrichtungsgesetz), 100 to 200 Euros were available on request per month. For the first time, additional support services were introduced for people with dementia without physical care needs, a so-called care allowance (or level 0 of care). For the care levels I and II, increased care allowances were implemented (among other things). At the date of writing, two more reforms (Care Support Act I and II) have been completed or are in the planning stage. They will not only increase allowances, but will also introduce a new care concept. With this new concept, the individual needs and resources will be prioritized, so that hopefully the obvious disadvantages of people with dementia compared to people with physical impairments in need of care will be eliminated.

Figure 3: National and international political events relevant for dementia
Dementia has also been on the agenda of European and international politics for several years. In January 2011 the European Parliament adopted the resolution "A European initiative on Alzheimer's disease and other forms of dementia". In December 2013, representatives of the G8 countries met for a dementia summit and discussed the care and quality of life of people with dementia and the social adaptation of countries to the phenomenon of global aging and dementia.

http://www.mds-ev.de/media/pdf/MDS_Dritter_Pflege_Qualitaetsbericht_Endfassung.pdf

The societal level: a change in perception

Research in Witten contributed to the fact that in addition to important issues such as diagnostics, medical treatment and care, the social dimension of dementia is moving into focus. Issues such as the reduction of stigma and social inclusion are important topics in the debate on dementia today. The German Agenda of the Alliance for People with Dementia, which was published in September 2014, refers also to the model of inclusion, self-determination and participation of people with dementia\(^4\). In the long-term, not only positive effects on the quality of care itself, on the quality of life of people with dementia and on the perceived burden of professional carers should be achieved; a contribution should also be made to the social inclusion of people with dementia and their informal caregivers.

Underpinning research


Cäcilia-Schwarz-Förderpreis für Innovation in der Altenhilfe 2013 (award for innovation in care for the elderly), dedicated to Margareta Halek and Daniela Holle for their PhD-thesis on the topic of challenging behavior of people with dementia

1.2.2 Quality of life of people with dementia

a) Short description

Dementia is a progressive disease characterized by a decline of cognitive functions, to this day still incurable. The exclusive focus on interventions aiming at maintaining and/or increasing cognitive functioning leads in most cases to negative outcomes.

This is why the main focus of pharmacological and non-pharmacological interventions is moving from the exclusively medical perspective to a focus on maintaining and improving the quality of life (qol) of people with dementia (pwd). In comparison to the cognitive functioning, the outcomes here can be influenced. In this respect, qoL has become an important concept for measuring outcomes of intervention studies, as well as being an indicator of the quality of care provided for pwd. The problem is that until today a generally accepted definition von dementia-specific qoL does not exist. Without any doubt, this would be a very complex, highly individual and multi-dimensional construct. Additionally, the use of this concept for pwd raises special questions, such as in which situation a person with severe dementia can express him- or herself and when does a proxy have to take over.

Next to a generally accepted definition, instruments are needed which measure qol reliably. Although such instruments exist (even some with an explicit focus on pwd), those instruments differ greatly with regard to their underlying definition of qol, their feasibility, their psychometric properties as well as the stage of dementia for which the application of the instrument is recommended. Given the fact that the concept of qol is used more and more often in practice and research, it is absolutely necessary to further develop the theoretical concept as well as reliable and valid assessment instruments. Last but not least, these instruments are needed in order to identify those interventions which have a proved positive impact on the quality of life of pwd. Thus, development and testing of such instruments are a necessary precondition for the development of effective interventions for health care and health service research.

Researchers at DZNE Witten have been working since 2010 on the testing and (further) development of a selected instrument to measure qol in nursing homes as well as a corresponding model of dementia-specific qol. Furthermore, the QUALIDEM instrument has been used to measure qol in three extensive surveys. In one of the studies, the impact of dementia care mapping (an internationally widespread intervention for person-centered care) on qol is investigated, in the second one the impact of case conferences (project FAILDEM). The third project is called Demenzmonitor (Dementia Monitor) and assesses in a longitudinal survey the interrelations between structural characteristics of nursing homes and personal factors (as quality of life).

b) Research steps

Instrument testing and further development

Many of the existing instruments of pwd focus primarily on functional and cognitive abilities and neglect the psychosocial aspects – thus they assess more the state of health rather than quality of life. After a profound exploration of existing instruments, researchers of the DZNE Witte identified the QUALIDEM-questionnaire as an instrument that focuses on psychosocial dimensions while assessing qol of pwd. QUALIDEM was developed by Teake Ettema (Netherlands) especially for nursing homes and was translated into German by a research team from the Charité Universitätsmedizin. There are two versions of QUALIDEM, one for people with mild to severe dementia and one version for those with very severe dementia. As there was no sufficient evidence about the instrument’s psychometric properties in the German version, DZNE researchers in Witten undertook several steps to investigate the instrument’s reliability and validity in the project QoL-dem. Depending on the project’s findings, adjustments will be made to the questionnaire. In the following, the concrete steps of the research process are explained:
Meta-synthesis for a dementia-specific QoL model

A meta-synthesis was carried out including those qualitative studies which make a statement on quality of life from the perspective of people with dementia. The synthesis of these perspectives is used to develop a dementia-specific model of quality of life (publication in preparation). The findings were also used to establish a suitable strategy for investigating QUALIDEM’s validity.

Testing construct validity and internal consistency

During an explorative pre-study in 2010, a factor analysis was executed which proved a moderate to high internal consistency of the German version and gave first hints about the construct validity (Dichter 2011a). In a second step, a Mokken scale analysis was performed in order to analyze the scalability with a secondary data analysis of QUALIDEM data of 634 pwd from previous DZNE studies. First results showed good findings for scalability and internal consistency in seven out of nine subscales of the version for people with mild to severe dementia and for three out of six subscales of the version for people very severe dementia. First results indicated also good results with regard to validity (Dichter 2013a und Dichter 2011).

Testing the inter- and intra-rater reliability

During the following reliability testing, the inter-rater reliability of all dimensions used in QUALIDEM was insufficient. First and foremost, those questions aiming at assessing the individual situation were subject to substantial fluctuations if the situation was assessed at the same time by several carers. On the other hand, the intra-rater reliability was proved to be satisfactory; that means the answers of one carer over time were stable. Based on these findings, recommendations with regard to the instrument’s adjustment and application were elaborated: First, a precise definition and instruction for every item is needed – for this a manual is under preparation. Secondly, it is recommended that QUALIDEM is always executed by two persons at the same time (Dichter 2014b).

Testing of psycho-social interventions with regard to quality of life

In the pragmatic quasi-experimental study called Leben-QD II the impact of Dementia Care Mapping on qol of pwd was investigated with the help of QUALIDEM (Halek et al. 2013). Dementia Care Mapping (DCM) is a widespread method to assess the wellbeing of pwd in order to develop care interventions in a second step. DCM is based on work by Tom Kitwood on person-centered care, which established for the first time an alternative concept to the clinical-medical approach to dementia. Dementia care mapping aims explicitly at the wellbeing of pwd (as one dimension of qol) and was investigated for the first time with regard to its impact on qol as primary outcome (Dichter et al. 2013a).
In contrast to earlier studies, an effect on the participating groups could not be shown within the Leben-QD II study – even though carers who worked with DCM reported a noticeable effect with regard to the carers’ work processes as well as with regard to the residents. This discrepancy can have several reasons: one reason could be that the instruments used for the study were not yet sensitive enough to represent the changes. Or the carers’ perception of the caring situation has changed and influenced the perception of the effects (rater bias). Another explanation could be that a high enough implementation level could not be achieved.

In the FAllDemII project (2013 – 2016), QUALIDEM is used to assess qol of pwd; in this case the impact of case conferences is investigated. Two ways of executing case conferences were implemented in a stepped-wedged study design in 12 different nursing homes in order to investigate the impact (among other things) on quality of life (Reuther et al 2014). For assessing qol, QUALIDEM and the Alzheimer’s Disease Related Quality of Life Instrument (ADRQL) are used. The collected data will allow not only a precise insight into the effects of case conferences but it will also be possible to compare the results achieved with these two different instruments.

Last but not least QUALIDEM is used in a third study: the descriptive, longitudinal observational study on German nursing homes DementiaMonitor (2010 - 2014). In this study, structural data (on the use of specific caring concepts for ex.) related to nursing homes as well as personal information on residents (as for example qol) was collected and their potential relations are analyzed (Palm et al. 2013). The results of the studies have not yet been published, as the projects are still in the phase of data collection and/or analysis. After this phase of analysis, the different experiences and results regarding the application of QUALIDEM will be integrated in the revised German version of QUALIDEM.

Collection and exchange of experience from experiences in practice and science
In the working group “Quality of life of people with dementia” researchers from DZNE Witten meet on a regular basis with representatives from nursing homes who use QUALIDEM in their working context. Not only decision-makers but also those employees who carry out the qol assessments for pwd attend the working group and are thus able to report about their experiences made in the field. In a second working group “Dementia-specific qol research”, researchers from different universities and research institutes meet two times a year to exchange experiences from their research work. Dissemination of common research work is realized through shared symposia during scientific conferences.
References


Details of further impact

The person with dementia: focus on quality of life instead of cognitive functioning

For a long time, research on dementia as well as caring for pwd was seen foremost from a disease-oriented and functional angle. This point of view changed during the 1990s with an upcoming focus on person-centeredness and quality of life. But these changes have not yet been realized in every
relevant field. Only if respective models and instruments continuously support this different perspective of focusing on qol, moving it into the foreground, can this change of perspective be realized in a sustainable way.

The political agenda: discussion on quality of care
The focus of external quality checks (executed by inspection organizations of the health insurance funds – Medizinischer Dienst der Krankenkassen - and the regional nursing home supervision organizations - Heimaufsicht) lies on the quality of the structure and the process instead of the quality of results of care, and for a few years now, this has been criticized in policy and practice. Since 2008 the Federal Ministry of Health and the Federal Ministry of Family, Senior Citizens, Women and Youth as well as the association of health insurance funds has mandated research institutes with the development and testing of indicators to assess the results of care with regard to quality. Aspects of quality of life can be found among the indicators. Up to now, the QUALIDEM instrument is not reliable to function as an instrument to assess qol from an external perspective. But nevertheless, the knowledge gained from the research process makes a significant contribution to the current debate.

Health care and health service research: contributing towards clear evidence for intervention research
In fact, more and more national and international studies assess the positive effect of (non-) pharmacological interventions on the qol of people with dementia. But several instruments are used which have weak methodological properties, which means they have not proven to be sufficiently valid and reliable. DZNE Witten makes a significant contribution to overcome these weaknesses so that a solid ground for research on interventions is realized.

Professional caring: higher certitude regarding the own professional handling
The evaluation of qol for residents with dementia can become an important indicator of the internal quality management and can support professional carers to reflect on the impact of their caring interventions. It is also a requirement of the institutions responsible for nursing homes’ external quality checks to assess the wellbeing of pwd and to integrate the results of this assessment into the caring process. The controlling institutions do not concretize which instrument should be used for the assessment of wellbeing.

DZNE Witten disseminates the results gained throughout the research process. This is why today, even without having finalized the research process, there is a considerable number of requests to the DZNE team asking for a version of QUALIDEM which can be used in practice.
Members of the DZNE Witten research team are working now on the realization of this preliminary version for the field in form of a data base (the so-called QUALIDEM easy). This is an IT-solution which can be used for the assessment so that results are shown automatically on two DINA4 sheets, including a figure showing changes of results over time. A broad dissemination of the adapted version as well as the user guide and the application solution will be realized and further disseminated after finalization of the project, when the final testing results become available.

1.3. Staff

The scientific staff of the DZNE Witten operates in four teams. How the staff is divided according to the teams is shown in the following table. The number of the full-time equivalents (28.31) was lower than in the previous year (28.64). In 2014 however, 3.39 of the full-time equivalents were financed by external funds.

<table>
<thead>
<tr>
<th>Gruppe</th>
<th>Persons</th>
<th>Full-time equivalents (total)</th>
<th>Full-time equivalents (without external funds)</th>
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</tr>
<tr>
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<td><strong>28.31</strong></td>
<td><strong>24.92</strong></td>
</tr>
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</table>

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

The qualifications of the scientific staff, including the management level, still embrace a broad field and contain the following disciplines: Nursing, sociology, gerontology, health science, economics, pedagogics, physiotherapy, occupational therapy, public health, communication science, political science, psychology and bioinformatics.
1.4. Scientific work

1.4.1 Publications

In 2014, the DZNE Witten was represented at diverse national and international scientific congresses about dementia care. 37 peer-reviewed contributions were made, of which 9 were posters and 28 were presentations. A highly important part of our task is to carry our research results into professional practice as far as possible. The 18 contributions we made during 2014 at congresses and events concerning practical nursing can be seen in this context.

The publication of the research results is of importance, too. Three books written exclusively or essentially by staff members were published. Altogether, contributions were made to eight books. 16 articles were published in peer-reviewed journals, ten in non-peer-reviewed journals. A detailed list of all research results can be found in Chapter 2, as far as they were published with a direct reference to an ongoing project. Presentations and publications without a direct reference to an ongoing or completed project are listed in Chapter 3.

1.4.2 Committees and consulting activities

As in previous years, in 2014 staff members at DZNE in Witten contributed with their expertise to numerous consulting activities. Furthermore, they acted as diverse administrative bodies on scientific consulting committees, management boards and executive committees. Chapter 4 contains a detailed list of all activities in 2014.

1.4.3 Cooperations

In addition to the above-mentioned international contacts, there are informal cooperations with representatives of foreign universities and colleges like the University of Vienna (Prof. Dr. Hanna Meyer), the Fachhochschule St. Gallen (Prof. Dr. Susi Saxer), the University of Bournemouth (Prof. Dr. Anthea Innes) or the Institute of Veteran Affairs USA (Laura Damschroder).

Employees of the DZNE Witten are furthermore members of international working teams like the “North Sea Dementia Research Group”, “DCM International Implementation Group” and the European research network “InterDem”. Beyond that, the DZNE Witten works closely with the cooperating University of Witten/Herdecke. The Department of Health, in particular the Department of Nursing Science as well as the Department of General Medicine and Family Medicine and the Chair for Geriatrics, is part of this cooperation. Within the DZNE, we collaborate especially with the DZNE site Rostock/Greifswald.

In order to enter into a dialogue with representatives from the care practice, the DZNE Witten initiated a practice-research-dialogue in 2014 (regular meetings of staff members with experts from the
field). A regular exchange provides insight into the question whether the themes investigated by the researchers are relevant for the daily care practice and - vice versa - which practical questions and phenomena should be considered in research. This also provides a basis for cooperation within the context of concrete research projects.

Other cooperations stretch all over Germany, for instance with the German Association for Nursing Research (Deutsche Gesellschaft für Pflegewissenschaft (DGP)), the Coordinating Center for Clinical Research (Koordinierungszentrum für klinische Studien) of the University Hospital Düsseldorf or the Johanniter Seniorenhäuser GmbH (welfare organisation which runs old people’s homes).
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 Frontotemporal Dementia (FTD) and their needs and demands in everyday life</th>
<th>AspektFTD</th>
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<tr>
<td>Duration</td>
<td>2010-2015</td>
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<tr>
<td>Funding</td>
<td>DZNE</td>
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<tr>
<td>Collaboration</td>
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<tr>
<td>Principal Investigator</td>
<td>Margareta Halek</td>
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<tr>
<td>Scientific Staff</td>
<td>Claudia Dinand, Sabine Nover, Daniela Holle (systematic review)</td>
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</tr>
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</table>

Introduction

Frontotemporal dementia (FTD) is an early-onset, progressive and atypical dementia associated with strong changes in judgment, behaviour, personality and emotions. These changes can cause significant problems in everyday life and have implications, different to those of Alzheimer’s disease, for people with FTD, their families and other actors involved in the caring process. Currently, there are no suitable evidence-based specific interventions for people with FTD. Research on needs and demands of people with FTD is rare and the perspective of people with FTD is lacking. Therefore a research approach with several steps appears to be necessary.

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.

The following research questions should be answered:

- What do people with FTD experience in their everyday life?
- What do the relatives of people with FTD experience in their (common) everyday life?
- Do existing interventions fit the needs of people with FTD and their families?
Methods

1 Scoping Review
We extended the search strategies in terms of a scoping review and updated the literature search to German and English publications between January 2000 and October 2014 with the focus on self-expressed needs and demands of people with FTD.

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

Status

1 Scoping review
Currently, only one poster abstract (IntConfFTD 2012) but no study has been published on the self-reported needs and demands of people with FTD. Based on this fact, an article has been written discussing the reasons for the research gap 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 evaluation and result analysis.

Results/ applicability
The project is the first step to close the described research gap by analysing self-expressions of people with FTD for the first time in a systematic way. A manuscript containing the results will be compiled by June 2015. The long-term objective is the development of supporting interventions.

Dissemination
Conferences

Publications


Introduction

Challenging behavior has a significant importance in the care of people with dementia. This behavior is also a key outcome of research on psycho-social interventions. The designation, description and definition of challenging behavior are heterogeneous, both in practice and research, and the relationship to other similar concepts unclear. Thus, the difficulty for the selection of the exact wording for each concept concerned lay in the fact that the different disciplines use different terms for seemingly the same phenomenon. So there is no one term for the concept “challenging behavior” but a lot of surrogate terms. The aim of this concept analysis is the clarification of the concept "challenging behavior"

Questions:

1. How does the concept "challenging behavior" develop in the course of the time?
2. How is “challenging behavior” currently defined?
3. Which influences on the definition of the concept do the different disciplines have?
4. Which similarities and differences does the concept "challenging behavior" have with other associated terms and similar concepts / synonyms?

Methods

The meaning of the term "challenging behavior" has changed in the course of time, because the approach to the phenomenon has changed and is now 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

<table>
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<tr>
<th>Title</th>
<th>A concept analysis of challenging behavior</th>
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<tr>
<td>Duration</td>
<td>2012-2015</td>
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<td>Funding</td>
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<td>Principal Investigator</td>
<td>Margareta Halek</td>
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<td>Scientific Staff</td>
<td>Daniela Holle, Martin N. Dichter, Sabine Nover, Claudia Dinand, Erika Sirsch, Marjan Laekeman, Sven Reuther, Rabea Graf (until 03/2014), Ines Buscher (until 2013), Lena Köller (until 2013)</td>
</tr>
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</table>
change. This method allows the definition of the term in respect of its meaning, usage and application in the course of time.

The concept analysis involves the following steps:

1. Identifying the concept of interest and associated expressions
2. Identifying surrogate terms and relevant uses of the concept
3. Identifying and selecting an appropriate sample, a minimum of 20% of the identified literature, from the relevant discipline, using a systematic approach and a broad time frame
4. Identifying the attributes of the concept
5. Identifying the references, antecedents and consequences of the concept, if possible
6. Identifying a model, real case of the concept

A comprehensive search strategy was conducted combining search terms to challenging behavior, dementia and their related / surrogate terms (German and English), using the databases CINAHL (n=890), PubMed (n=3,475), PsychINFO (n=1,263), Cochrane Library (n=178) up to October 2012. The search included all publications such as reviews, concept analysis, discussion papers or theoretical explanations. After removing duplicates, 5,257 articles were screened by title and abstract. We identified 231 articles as relevant and grouped them into the main disciplines medicine, nursing and psychiatry. After a first process testing, subsequent rounds of selection tried to extract at least 30 "relevant" reviewed articles per discipline. These were included in a full-text analysis using MAXQDA 11 and analyzed by all project members with relation to definitions, attributes, antecedents and consequences, temporal aspects and context factors.

**Status**

Papers are currently being analyzed by the project staff (step 4-6). This will be finished in summer 2015 and summarized for publication in an article.

**Results**

The result of the project is an interdisciplinary concept clarification and description of challenging behavior. This could provide information for modification or development of new assessment instruments as well as for new ideas for psychosocial interventions.
Title | Case conferences for people with dementia living in nursing homes | FallDem
--- | --- | ---
Duration | 2010 - 2016 |  
Funding | - DZNE  
- Stiftung Wohlfahrtspflege |  
Collaboration | - Kaiserswerther Diakonie, Bereich Bildung und Erziehung  
- Kaiserswerther Seminare  
- Dr. Pablo Verde, Koordinierungszentrum für Klinische Studien (KKS), Universitätsklinikum Düsseldorf |  
Principal Investigator | Margareta Halek  
Daniela Holle (study coordinator) |  
Scientific Staff | Sven Reuther, Tina Quasdorf (until 06/2014), Ines Buscher (until 12/2014), Olga Dortmann (until 06/2014), René Müller, Ute Rosier, Rabea Graf, Diana Trutschel, Martina Roes |  

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. A national guideline in Germany recommends the use of case conferences for the professional handling of people with dementia and their challenging behavior in nursing homes. However, there is a lack of clear concepts as to how to conduct case conferences and how to implement these into daily care routines. Moreover, it is unclear how effective case conferences are for improving the quality of care. The project “Case conferences for people with dementia (FallDem)” aims to fill these research gaps outlined above by finding answers to the following research questions:

- What influence do assessment-based case conferences have on challenging behavior, quality of life of people with dementia and the burden of staff in comparison to the influence of a control group or narrative case conferences?
- What factors promote and inhibit the implementation of assessment-based case conferences compared to narrative case conferences?
• Which learning processes take place during case conferences based on an assessment instrument in comparison to narrative case conferences?

Methods
The study is conducted in two phases. The first phase was the development of the intervention (two models of case conferences: narrative & IdA) based on a systematic literature review, interviews and group discussions with experts in the field of case conferences. The development phase ended with piloting the two models in one nursing home. In the second phase of the project, the two models of case conferences were implemented in 12 nursing homes.

A Stepped-Wedge-Study design was used as a special form of cross-over design, since it provides a methodological alternative compared to conventional cluster randomized trials.

With the help of the results of a former study, a total number of 360 (300 +60 dropouts) participants were calculated as the sample size (using power calculation).

The primary outcome, challenging behavior of people with dementia, was measured with the Neuropsychiatric Inventory - Nursing Home Version (NPI - NH). As secondary outcomes, the following were assessed:

- the quality of life of people with dementia (measured with Qualidem),
- the competence development of the staff (measured with Kompetenz - Reflektions - Inventar (KRI))
- the burden of the staff (in general and dementia-specific, measured with the Copenhagen Burnout Inventory (CBI) and the burden resulting from dementia (the BelaDem instrument))

The intervention is accompanied by a process evaluation to identify factors that have an impact on the intervention’s implementation. Data are collected by questionnaires, semi-structured interviews and protocols of the case conferences. For the documentation of the learning process, audio recordings of case conferences and feedback interviews with a subgroup were conducted.

Status
Completion of the penultimate data collection (T5): longitudinal data were available (about 300 residents and 150 staff within each data collection) from 12 institutions over 12 months.

• Two nursing homes dropped out during the trial.
• The remaining 10 nursing homes are at the moment in the intervention phase of the trial.
• Development of a Mixed Method approach: qualitative data from the process evaluation are integrated in the statistical models for the effect measurement.
A simulation study in the statistic program R is in progress: the aim is to investigate the impact of different challenges common in healthcare research (e.g. delayed treatment effect, dropout of clusters during a trial) in order to estimate the intervention effect within a stepped-wedge trial.

Qualitative interviews in the facilities for the process evaluation are in progress.

Results

Knowledge about the impact of different forms of case conferences.

The developed R-code (because of the flexibility of the parameter settings, e.g. different effect size or more or less cluster) can easily be adapted to other studies working with the Stepped Wedge Design.

Development of a concept for the quantitative data analysis (using mixed effect models).

Advanced knowledge about the practical use of the stepped wedge design in healthcare research.

Dissemination

Conferences

Roes, M., Buscher, I., Holle, D., Reuther, S., Halek, M. (04.05.2014). Developing an Implementation Plan for Case Conferences in Nursing Homes. 29th ADI Conference, St. Juan, Puerto Rico.

Roes, M., Buscher, I., Holle, D., Reuther, S., Halek, M. (2014-11-06). Implementing a hermeneutic approach - a way to address challenging behavior in nursing homes. Symposia How to Identify needs of vulnerable people - contributions of qualitative research methodology. 67th Annual Scientific Meeting of the GSA, Washington, D.C.

Publications


**Title** | **Gestural communicative action as a link between language and action in persons with dementia** | **GesKom**
--- | --- | ---
**Duration** | 2011 - 2015 |  
**Funding** | DZNE |  
**Collaboration** | Department of Nursing Science, Faculty of Health, University of Witten/Herdecke: Prof. Dr. Sabine Bartholomeyczik |  
**Principal Investigator** | Martina Roes |  
**Scientific Staff** | Beatrix Döttlinger |  

**Introduction**

The aim of this study is to investigate the incorporated handling routine concerning gestural-communicative actions of caregivers for cognitively impaired persons. The practical perspective will be investigated, i.e. “how” the verbal and nonverbal interactional relationship is organised.

The study aims at widening the theoretical and practical knowledge about nonverbal communication in people with severe dementia in order to promote their self-determination and reduce their dependence. There are no current studies concerning this topic.

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

**Methods**

A reconstructive-praxeologic research approach was chosen, using videography that follows the principles of the documentary interpretation according to Bohnsack.

Random sample/setting: Care situations and interactions referring to regular day-to-day activities between persons with severe dementia and professional caregivers (trained in the specific perception of cognitively impaired persons and experienced in gestural communication).
Results
The results are expected to deliver characteristic features for gestural interaction and communication, which shall then serve as an empirical basis for the development of learning concepts for [qualified] caregivers.

Dissemination
Conferences
**Introduction**

The maintenance and promotion of quality of life and well-being for people with dementia is the major goal of dementia care. The aim of Dementia Care Mapping (DCM) is to capture and improve the well-being of people with dementia through the implementation of person-centered care. Available results on the effectiveness of the DCM-method showed heterogeneous results. Moreover, little is known about facilitating and hindering factors of the DCM implementation in the German elderly care.

The aim of the project LebenQD-II (ISRCTN43916381) 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.

**Research 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

In the three-armed quasi-experimental trial the given sample of residents with dementia was assigned to three groups, each with three wards. The nursing home provider was responsible for the assignment. The three groups were:

- **Group A**: DCM was applied at least two years prior to the study
- **Group B**: DCM was newly introduced during the study
- **Group C**: a control intervention based on a regular standardized Qol assessment

Data collection was carried out at three different times: T0 - before intervention, T1 - after 6 months and T2 – 18 months after intervention. The collection of data regarding the third and fourth research questions was done partly during the intervention phases. The primary outcome for the first research question is the quality of life for residents (QoL-AD-proxy). Secondary outcomes are challenging behavior (NPI-NH) and quality of life (QUALIDEM). The staff-related primary outcome to the second research question is the attitude to dementia care (ADQ). Secondary outcomes are job satisfaction (COPSOQ) and burnout (CBI).

As part of the process evaluation, the third research question about characteristics of implementation success was investigated by means of a theory-driven set of variables (process documents illustrating 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 was also guided by a theoretical model (CFIR) using different variables (attitudes to dementia care (ADQ) before implementation, team interaction (SYMLOG), interviews, staff survey, questionnaire of organizational factors (DIQ)). The fifth research question was answered by analyzing the resulting costs during the implementation process (DCM/regular standardized Qol-rating).

Status

The data analysis for the research questions one to four has been completed. A research report will be available early 2015. Publications referring to the effectiveness study and the process evaluation are in preparation. In 2015 the fifth research question will be analyzed.

Results

- All the participating wards took part completely in the study and thus all the residents (n = 234 (total), n=154 at T0) were included in the analysis. Based on an adjusted linear mixed model, no significant differences, whether between the DCM intervention groups and the control group or between the two DCM intervention groups, were found for the primary out-
come Qol-AD-proxy. In addition, after 18 months no significant differences were identified for the secondary outcomes.

- The process evaluation showed an insufficient intervention adherence in one ward of both group A and B as well as in all three wards in group C.

Factors that facilitated DCM implementation were well-functioning networks, a dementia-friendly culture, flexible organizational structures, positive attitudes of involved individuals towards DCM, precise planning of the intervention and its implementation, recruitment of supporters advocating DCM implementation, and well-qualified, experienced project coordinators.

**Dissemination**

**Conferences**


Introduction

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

For the development of tailored psychosocial interventions that focus on understanding and managing challenging behavior, approaches are needed that: 1) are person-centered, setting the perspective of the person with dementia at center, 2) are carer focused, 3) take into account the multi-causality of challenging behavior and 4) include a thorough description and analysis of the challenging behavior. In Germany, the term “understanding diagnostics” is used to describe such an approach.

The aim of the study is to describe the current state of knowledge regarding person-centered approaches for the description and analysis of challenging behavior of people with dementia by nurses/therapists across different settings (e.g. nursing home, hospital, at home)

The following research questions shall be answered during the study:

- Which different approaches of “understanding diagnostics” exist?
- Which methods assist nurses/therapists in understanding challenging behavior?
- What experience do nurses/therapists have when applying "understanding diagnostics"?
- What effect do approaches related to “understanding diagnostics” have on persons with dementia?
What effect do approaches related to “understandings diagnostics” have on informal and formal caregivers of persons with dementia?

**Methods**

In order to find answers to these questions, a systematic review is performed. All articles are included that make a statement about the description of the intervention, the outcomes, or the experiences made during the implementation of the intervention (across all settings). Quantitative as well as qualitative studies are included which have been published between 1995 and 2014.

**Status**

The search and selection of relevant full texts have been completed. This will be followed by the analysis of relevant articles and the dissemination of the results in terms of publication and presentation.

**Results**

The results of the review will form the basis for studies that aim to modify the concept of “understanding diagnostics” for its use in the community (VerDi-H) and in the acute care setting (VerDi-KH).
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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<tr>
<td>Duration</td>
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<td>Funding</td>
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<td>Collaboration</td>
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<tr>
<td>Principal Investigator</td>
<td>Bernhard Holle</td>
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<td></td>
<td>Rebecca Palm (study coordinator)</td>
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<td>Scientific Staff</td>
<td>Christian Schwab</td>
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**Background**

Nursing homes align their structure, supply and care concepts with the needs of the growing number of residents with dementia. Specialized living arrangements as well as tailor-made psychosocial interventions are recommended by the German Federal Ministry of Health and the Medical Advisory Service of the German long-term care insurance companies (medizinischer Dienst der Krankenkassen). Dementia-oriented care aims at understanding challenging behaviors, and preserving and fostering the residents’ quality of life.

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

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

In detail, the following research questions will be answered:

1. How is dementia care provided in German nursing homes? Which living arrangements are implemented? Which recommended interventions are in use? Who gets which interventions?

2. Are there any differences between residents of different living-units regarding their demographic data, cognition, care dependency? Are there any differences between the residents of different living-units regarding the interventions provided?
3. Which of the investigated variables are associated with the outcomes behavior and quality of life of the residents when checking for resident-related covariates such as age, sex, length of stay? Are there differences between the results of the whole population and those of certain groups?

4. Are the residents’ outcomes behavior and quality of life of the residents stable over time or do they change? 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 in the outcomes?

**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 home staff using standardized questionnaires. The outcomes behavior and quality of life are assessed by nurses using the instruments Neuropsychiatric Inventory (NPI-Q) and QUALIDEM.

Data analysis performed is 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 nested structure of data due to different levels of data and points of time, generalized linear mixed-effects models are used.

**Status**

Since in 2012 and 2013 approximately 50 nursing homes, 100 living-units and 1700 residents have taken part in the study. In 2014 no new nursing homes were included in the study but 19 nursing homes, 50 living-units and 784 residents took part repeatedly. Of these, 337 residents took part in the data collection a third time.

With the data collection in 2014 we succeeded in collecting longitudinal data over a time period of two years. This enables us to analyse the change of the outcomes behavior and quality of life. The corresponding data analysis will be performed in 2015.

In selected nursing homes the newly developed questionnaire DemCare-Q was tested for its reliability. Based on the results of this, the questionnaire will be further developed and improved.

For 2015 no new data collection is planned. In this year, the data analysis and the improvement of the instruments are in the focus of the research team.
Results

The questionnaires that were developed for the study were used a third time in 2014. After 2012, the newly developed parts of the questionnaires were adapted only marginally, so that most of the data were comparable over three points of time. The questionnaires were tested for their content validity and practicability, and the development process has been published internationally. The results from the reliability testing will contribute to improve the questionnaires’ validity.

The cross-sectional data from 2013 were used to answer the research questions 1 and 2. The description of the institutions’ structural conditions, the residents’ structure and the application of recommended interventions are the subjects of the first scientific report (in process). The report addresses mainly the participating institutions, but will also be available to the public.

Results on structural characteristics of different types of living-unit in nursing homes have been published internationally. In this investigation we were able to show the diversity of living-units in nursing homes with the help of measurable criteria. We used criteria for the definition of different types of living-unit that are important characteristics of different living concepts and have an impact on the structural conditions: the size of the living-unit ($\leq/>$ 15 places), specialization for residents with dementia (segregated versus integrated living concept) and an additional funding for the specialized care arrangement (yes or no). We investigated the difference of core characteristics of different living concepts. In the sample of 103 living-units, 40 were especially for residents with dementia; 31 of these offered more than 15 places. An additional funding was negotiated for 16 living-units, in which only residents with dementia were living and that offered more than 15 places. Of the 63 integrated living-units, 15 had 15 or less places, which also applied to nine of the segregated living-units.

The results showed that large living-units with an additional funding had more nursing staff available during the day shifts and more nurses with a special qualification compared to other large living-units. In general, small living-units had a more beneficial staff relation than large living-units, but it seemed as if the nursing staff was not always in attendance.

Small living-units offered more single rooms, the meals were more often prepared in the living-unit and were served in a homelike manner. Regarding other aspects, such as the interior or the possibility to go outside, we did not find any differences between the types of living-unit.

The results are a basis for further analysis on the relationship between structural conditions of institutions and relevant outcome parameters such as behavior and quality of life.

Further analysis of the relationship between the residents’ characteristics, structural conditions and the application of recommended interventions will be prepared for international publication.
Dissemination

Conferences
Palm, R.; Bartholomeyczik, S. & Holle, B. (03. - 06.12.2014). What is special about Dementia Special Care Units in German Nursing Homes? IPA European Regional Meeting, Brüssel, Belgien.

Publications
Title: Development and pilot testing of a set of quality indicators for the pain assessment in older persons in long term care

QiSavA

<table>
<thead>
<tr>
<th>Duration</th>
<th>2012 - 2015</th>
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<tr>
<td>Funding</td>
<td>DZNE</td>
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</table>
| Collaboration | - German Pain Society (formerly German Pain Society for the Study of Pain, DGSS)  
- Prof. Dr. Sabine Bartholomeyczik – Faculty of Health - Department of Nursing Science – University of Witten/Herdecke  
- Subproject “Pain Assessment in Patients with Impaired Cognition especially Dementia: BAck Pain Scale (PAIC-BAPS)”: Professor Stefan Lautenbacher (Chair of the project: COST TD 1005 Pain Assessment in Patients with Impaired Cognition, especially Dementia) |
| Principal Investigator | Martina Roes |
| Scientific Staff | Marjan Laekeman |

Introduction

The systematic pain assessment is a basic step towards improving pain management. In order to evaluate the implementation and application of pain assessments, clinical performance measures in the form of quality indicators are needed. The aim of the QiSavA project is to develop such a set of quality indicators and to pilot it.

Which appropriate indicators can be derived from existing national and international guidelines and indicator sets to evaluate the implementation of a pain assessment for older persons?

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

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

2) What quality indicators (QI) of the newly developed indicator set are already applied in the healthcare practice?

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

The QiSavA project is carried out in several steps:

1) Theoretical development: literature review
2) Expert survey for the quality indicator set
3) Practical development and test phase: 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 used in practice. Test phase of the sets of indicators in these three institutions and development of the final version.

Status

Currently, the project is in the theoretical phase. First of all, a literature review was carried out with the aim of acquiring methodological knowledge concerning the development of quality indicators and identifying possible indicators from the publications. Contrary 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, geriatric care or the development of quality indicators in different countries.

At present, the recommendations of several manuals and methods reports with the topic "Development of QI" are being revised to construct the "conceptual framework" for the QiSavA-Project.

The preliminary literature analysis shows a lack of observational scales for pain assessment in people with dementia with specific causes of pain, such as back pain. Therefore, an add-on project has been started: the development of a "Pain Assessment in Patients with Impaired Cognition especially Dementia BAnck Pain Scale (PAIC-BAPS)". This is an international project in collaboration with Professor S. Lautenbacher (Chair of the COST TD 1005 Action “Pain Assessment in Patients with Impaired Cognition, especially Dementia ” s. http://www.cost-td1005.net/ ).

A preliminary item pool for the PAIC-BAPS was created on the basis of expert opinions, recommendations derived from the literature and from existing pain and back pain scales (for people without cognitive impairment) and is currently being evaluated by the expert group of the COST Action TD 1005.

Results

At the end of the project, a QI-set will be available that is suitable for the evaluation of pain assessment in nursing home residents. Furthermore, items will be developed for the observation of back pain in people with dementia.
**Dissemination**

**Conferences**


Table 1

<table>
<thead>
<tr>
<th>Title</th>
<th>Pain assessment in older people in nursing homes</th>
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<tbody>
<tr>
<td>Duration</td>
<td>2011 - 2015</td>
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<tr>
<td>Funding</td>
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<tr>
<td>Collaboration</td>
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<tr>
<td>Principal Investigator</td>
<td>Margareta Halek</td>
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<td></td>
<td>Erika Sirsch (study coordinator)</td>
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<tr>
<td>Scientific Staff</td>
<td>Marjan Laekeman</td>
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Introduction

The implementation of an assessment of acute pain in inpatient geriatric care facilities is required by the German Nursing Care Reform Act. The currently available standards and guidelines in Germany focus mainly on the self-assessment of acute pain. The research results of the last few 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

The development is aligned with the procedure described by the AWMF and ÄZQ and the DELBI instrument of AWMF: [http://www.awmf.org/leitlinien/detail/leitlinie/1II/145-001.html](http://www.awmf.org/leitlinien/detail/leitlinie/1II/145-001.html)

Status

The source guidelines search and the analysis of the 39 clinically relevant questions of the guideline has been completed, as well as the search for primary literature to the nine prioritized clinically relevant questions. After the title and abstract screening, a full text analysis is carried out with regard to pain screening, pain assessment and course of pain assessments in order to include or exclude full texts appropriately. Currently, the methodological assessment and analysis of full text of this primary literature search is being completed. Recommendations linked to clinically relevant questions are being worked on. Delphi surveys for consenting results and recommendations of the S3 guideline are in preparation.
Expected results
The completion of the project is scheduled for 2015, and could be followed by implementing the S3 guideline in nursing homes.
2.3 Methods and measurements

<table>
<thead>
<tr>
<th>Title</th>
<th>Cognitive assessment in the case of neurocognitive impairments aiming at case finding in health care and health service research</th>
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<tr>
<td>Duration</td>
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<tr>
<td>Funding</td>
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<td>Collaboration</td>
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<tr>
<td>Principal Investigator</td>
<td>Margareta Halek and Bernhard Holle</td>
</tr>
<tr>
<td>Scientific Staff</td>
<td>Saskia Jünger</td>
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</table>

Introduction

Research in the field of dementia is confronted with the challenge to delineate a proper definition of the study population; valid and reliable criteria for the sample selection need to be substantiated accordingly. Health service research is hence requested to operationalize the concept of dementia appropriately in order to (a) define which persons should be included in the study sample or in a specific sub-sample (e.g. intervention vs. control group), (b) differentiate between persons with different types of dementia (such as Alzheimer’s dementia or frontotemporal dementia) and (c) define the severity of cognitive impairment (mild or severe dementia; distinction of prodromal forms such as ‘mild cognitive impairment’ from changes in cognitive function attributable to ‘normal aging’).

The aim of this work package on “cognitive assessment” was to develop guidance on the substantiated selection of instruments for the assessment of dementia, whereby diverse trade-offs between the anticipated benefit and possible disadvantages or limitations of the instruments had to be taken into consideration. The expected outcome was a decision guide to support the selection of instruments for the assessment of cognitive impairment in dementia in future health service research projects.

Methods

Based on literature search, an inventory of existing instruments for the assessment of dementia and cognitive function was made and individual tests were characterized, using relevant evaluation criteria (rationale, psychometric properties, practicality, etc.). If available, validation studies or systematic reviews were used; otherwise, we referred to papers describing the respective instrument or reporting on its use in a study. Furthermore, criteria that are relevant for the selection and evaluation of
cognitive assessment instruments were compiled from reviews and textbooks on assessment methods.

**Status**

A synopsis of relevant selection and evaluation criteria for the appraisal of pre-selected assessment instruments has been developed. This overview is used to inform a tabular evaluation system while evaluation criteria primarily applicable to clinical practice were adapted to a health service research context.

A list of questions was outlined to guide the decision process for researchers and to support the selection of the appropriate instrument(s). For each question, considerations regarding the instrument itself, as well as trade-offs concerning the benefits and costs of each procedure, are detailed.

Based on the relevant selection and evaluation criteria, in a next step a range of instruments for more specific appraisal regarding their applicability at the site Witten will be pre-selected. Building on the available evidence in the literature and linking this information back to current health service research projects in dementia, we will examine to what degree the evaluation criteria are met in the practical application of the respective assessment instrument. Using a specifically developed evaluation system, the advantages and limitations of each instrument will be identified and a profile regarding its practical use for a particular purpose will be deduced.

On this basis, a decision guide for the selection of assessment instruments will be developed, taking into account the respective research question, the study population, the addressees of the study aim, and the setting as well as the available resources of the respective project. A brief dossier for each instrument including a conclusion on its practical application in health service research projects in Witten will provide additional support in facilitating the selection of the appropriate assessment instrument.

**Expected results**

- Analysis, problem outline and inventory of relevant aspects in relation to the assessment of dementia in health service research.
- Tabular synopsis of relevant selection and evaluation criteria for cognitive assessment instruments for the assessment of dementia in health service research.
- Tabular summary of questions guiding the decision process for the selection of adequate instruments considering the trade-off between costs and benefits.
- Draft decision guide including an outline of a brief dossier for each instrument or assessment procedure.
Introduction

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

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

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 QUALIDEM proved?
3. To what extent is the internal consistency of the German QUALIDEM proved?
4. What is the interrater reliability of the German QUALIDEM?
5. What is the intrarater reliability of the German QUALIDEM?
6. To what extent is the validity of the German QUALIDEM proved?

Methods

This study is divided into 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.
This phase is used also for 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.

Figure 4: Phases of the Qol-Dem Project

**Status**

The investigation of the scalability and one reliability study of the QUALIDEM have been completed. In 2014 a user manual to increase the interrater reliability of the QUALIDEM was developed. This was followed by a new investigation of the interrater reliability using the developed user manual as part of the data collection. A publication of the results of the metasynthesis is in preparation. Following this, the evaluation of the construct and criterion validity will start in 2015.

**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), nega-
tive affect and social relations (very severe dementia) and social isolation (both instrument versions) showed an insufficient scalability.

- The reliability investigation showed insufficient results for the interrater reliability (Intraclass Correlation coefficient ≤ 0.70) but sufficient results for the intrarater reliability of all subscales (Intraclass Correlation coefficient ≥ 0.70).
- A user guide for the use of the QUALIDEM and to increase its interrater reliability is available and will be published in 2015.

As a preliminary result of the meta-synthesis, the 14 following quality of life domains for people with dementia were identified: family, social contact and relationships, self-determination and freedom, living environment, positive emotions, negative emotions, privacy, security, self-esteem, health, spirituality, care relationship, pleasant activities and future prospects.

**Dissemination**

**Conferences**


Publications


2.4 Potentials in and of care arrangements

<table>
<thead>
<tr>
<th>Title</th>
<th>Analysis of communication processes between settings about the care of people with dementia</th>
<th>CareSafeD</th>
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<td>Duration</td>
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<tr>
<td>Collaboration</td>
<td>Department of Nursing Science, Faculty of Health, University of Witten/Herdecke: Prof. Dr. Sabine Bartholomeyczik</td>
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<tr>
<td>Principal Investigator</td>
<td>Sabine Bartholomeyczik, Martina Roes (project monitoring)</td>
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<td>Scientific Staff</td>
<td>Silke Kuske</td>
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</table>

Introduction

Handovers or transitions between healthcare settings are associated with care fragmentation, poor coordination and communication failures. In particular, the vulnerable elderly with cognitive impairment and complex healthcare needs, e.g. people with dementia (PwD), are likely to be subject to 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, deliria, fractures or decubitus. There is meager information about the quality of transitions at admission and discharge in respite care.

The aim of the study is to describe and to analyze communication structures and processes at transitions of PwD between home and respite care and also to develop recommendations which could be implemented and evaluated in a subsequent study.

Methods

A descriptive study design considering nursing facilities with respite care and respite care facilities, including the following steps:

- Systematic review to identify safety-relevant communication structures and processes between healthcare settings, also between home and respite care
- Expert interviews to describe communication structures and processes between home and respite care
- A Delphi survey to evaluate and select relevant quality criteria
- An online survey to describe and analyze selected defined communication structures and processes at the transition of PwD between home and respite care, and for the development of recommendations

**Status**
The project is completed. Further results will be published.

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

**Dissemination**

**Conferences**

**Publications**
<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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<tr>
<td>Duration</td>
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<td>Funding</td>
<td>The Federal Ministry of Health (BMG) – as part of the funding program 'Zukunftswerkstatt Demenz’</td>
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<td></td>
<td>Project sponsor: Deutschen Zentrum für Luft- und Raumfahrt (PT-DLR, Project Management Agency – part of the German Aerospace Center)</td>
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<tr>
<td>Collaboration</td>
<td>DZNE in Rostock/Greifswald and the E.-M. Arndt University Greifswald (Professorship of Health Science at the University of Greifswald), Prof. Dr. W. Hoffmann</td>
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<td></td>
<td>Institute for Applied Social Sciences (IfaS) at the dual university Baden-Wuerttemberg (DHBW), Prof. Dr. S. Schäfer-Walkmann</td>
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<tr>
<td></td>
<td>University of Bremen, Department 11, Human and Health Sciences, course of study Nursing Science, Prof. Dr. K. Wolf-Ostermann</td>
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<tr>
<td></td>
<td>The following dementia networks belong to the composite evaluation in DemNet-D:</td>
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<tr>
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<td>1. Demenznetzwerk Uckermark</td>
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<td></td>
<td>2. Demenznetzwerk Memo Clinic (Stralsund)</td>
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<td></td>
<td>3. Qualitätsverbund Netzwerk im Alter e.V. (Berlin)</td>
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<td></td>
<td>4. Gerontopsychiatrisch-Geriatrischer Verbund Charlottenburg-Wilmersdorf e.V., (Berlin)</td>
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<td></td>
<td>5. Initiative „Demenzfreundlich Treptow-Köpenick“ (Berlin)</td>
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<td></td>
<td>6. Demenzfreundliche Kommune Lichtenberg (Berlin)</td>
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<td>7. Demenznetzwerk des Landkreises Teitow-Fläming</td>
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<td>8. Arnsberger Lernwerkstatt Demenz</td>
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<td>10. DemenzNetz Kreis Minden-Lübbecke</td>
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<td>12. Demenznetz Aachen</td>
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<td>13. Demenznetz Düsseldorf</td>
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<tr>
<td>Principal Investigator</td>
<td>Am DZNE Witten: Bernhard Holle</td>
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<tr>
<td>Scientific Staff</td>
<td>Franziska Laporte Uribe (project coordinator)</td>
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<td>Steffen Heinrich</td>
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Introduction

The 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, including also the care situation in these regions as well as the cooperation and network structures. In 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. Analyses regarding the characteristics of network users, i.e. PwD and their family-caregivers
2. Analyses 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 the financial capacity of a dementia care network; furthermore, the conditions and requirements for the 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 a cooperation partner in several dementia care networks ($N = 13$). The DZNE in Witten cooperates closely with four dementia care networks 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 using qualitative and quantitative methodologies (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 were generated which will provide a basis for a) setting up effective new dementia care networks, 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 in Witten is primarily responsible for caregiver-related outcomes (burden and care arrangements), for 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 were collected using standardized questionnaires (BIZA-D, D-IVA). “Knowledge management” processes were primarily investigated using qualitative data from interviews with key-persons of the dementia care networks. A structured content analysis (Mayring, 1990) was applied. In a mixed-methods approach, relevant quantitative and qualitative data were combined. The analysis of results as well as the development of the “dementia tool-box” will be conducted in close cooperation with all research partners. Quantitative data were collected at baseline and at the 12-month follow-up.

**Status**

Follow-up interviews with 397 PwD and their primary family-caregivers were conducted between January and August 2014 (quantitative data collection). At the same time, quantitative baseline data were analyzed ($N = 560$ dyads) both on population level as well as in reduced complexity on network level. Multi-level analyses on the potential impact of the types of dementia care network on clinical outcomes are currently being carried out at the University of Bremen (sub-contract).

Semi-structured interviews with the dementia care network coordinators were analyzed in the first quarter of 2013. The analysis of qualitative data on knowledge management has been finalized and two articles have been submitted to peer-reviewed journals. Additional funding has been provided by the BMG for the development of a “dementia tool-box” as a homepage. This add-on project will be conducted by the DZNE in Witten and Rostock/Greifswald between January and October 2015.

In the next steps, the analysis of the quantitative follow-up data will be finalized and articles on caregiver burden and care arrangements will be submitted to peer-reviewed journals. The final report to the BMG and PT-DLR will be written and the “dementia tool-box” homepage will be developed further.

**Results**

Based on the quantitative and qualitative data collection, a number of different findings are to be expected that will by far exceed the singular characterization of just one network. 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 con-
verging, diverging, and complementary findings regarding factors for the success of dementia care networks, thus allowing for a greater generalizability of the findings.

Findings will be disseminated in four different ways: 1) via an expert workshop with key-persons, stakeholder and service providers of dementia care networks; 2) via a homepage, i.e. a modular “dementia tool-box” providing evidence-based, matching support information, which takes into consideration the regional specifications for the set-up, operating, and optimizing of dementia care networks; 3) by making the results available to the participating dementia care networks (fact-sheets) and 4) through public relations, utilizing both the scientific and non-scientific sectors.

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 is to be 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, managed and sustained in the medium and long term. The “dementia tool-box” homepage will be developed in an add-on project following the end of the DemNet-D project in March 2015.

**Dissemination**

**Conferences**


First results were presented at a meeting of the “Zukunftswerkstatt Demenz” with representatives of BMG, PT- DLR, research partners, participating dementia care networks and representatives of research projects on informal caregivers on 27th January 2014 in Bonn.

Publications


30. April 2014: Zweiter Zwischenbericht des Forschungsverbundes
Introduction
Currently, there are no specific trajectory models in a long-term study for people with dementia in the early and middle stages of their disease compared to people with multiple sclerosis and Parkinson’s disease. To understand what enables people to integrate their chronic illness into their future life requires as a first step the reconstruction of their needs and demands from their own point of view. In a second step, it is possible to develop precisely which offer of support they need during their life trajectory.

The study aims to develop intervention concepts for people with dementia, multiple sclerosis and Parkinson’s to support their coping strategies during their lifetime in an individual way. Graduation modes are to be found.

Which graduation modes are important for managing the process of coping with dementia, multiple sclerosis or Parkinson’s during life trajectory?

Methods
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.

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 in up to at least four stages they are interviewed on their observations while dealing with the disease. The population of persons interviewed is at least twelve and the number of interviews at least 48. The secondary analysis of interviews from the parent study SEIN (Self-perception and Intervention) includes a further 16 interviews.
The reconstruction of coping strategies based on reports made by people with dementia, multiple sclerosis and Parkinson’s disease themselves during their lifetime is founded on an important subjective factor of quality of life, namely well-being.

Different methods of analyzing 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 cohorts, detecting differences and similarities.

**Status**

The second phase of survey has been completed and the data have been evaluated. A book template has been created.

In 2015, the third data collection phase will be conducted and evaluated. The fourth phase of the survey will be carried out in 2016. A questionnaire is to be developed, which elevates the individual support needs of people with dementia, people with multiple sclerosis or Parkinson’s disease.

**Results**

The conceptional basis for creating individually suitable support services for people with dementia, multiple sclerosis or Parkinson’s disease has been found.

**Dissemination**

**Conferences**


Introduction
Since the mid-nineties, person-centeredness – often cited in connection with Tom Kitwood – is a well-known concept in the field of care for people with dementia (pwd) as well as in dementia research. As an alternative concept for a primarily clinical and medical approach, person-centeredness marks a shift of perspective in dealing with pwd. Instead of treatment and cure of dementia the focus lies on the psychosocial consequences of the disease and therefore aims at improving quality of life. Under the label of person-centeredness, a broad and heterogeneous field can be found, ranging from concrete practical care and support measures to theoretical considerations and on to the approaches of care providers and research organizations. Since the nineties, the number of publications referring to person-centeredness has been growing; however, they refer to the concept in very different ways. In view of this development, the question arises whether and how person-centeredness can be understood as a coherent approach and whether it is based on a reliable common theoretical ground. Furthermore, in the case of dementia the concept of person-centeredness poses special challenges for theory and practice. For the affected people the progressive course of the disease has direct implications on their world-experience and learning abilities. This has implications on personal identity, which becomes more and more fragile with further progression. Consequently, it seems that there is no common agreement on how “being a person” could be conceptualized, considering the background of dementia.
In order to do justice to the complexity of the field of person-centeredness in dementia the research project Per-Dem presented here is divided into two parts. In the first part of the project, an inventory
of the concept of person-centeredness will be undertaken. In doing so, the following questions should be considered: What does the concept of person-centeredness with regard to dementia mean in the research literature? What ideas of person-centeredness currently exist? Are there commonalities and/or differences in the definition of the concept? Is there a common theoretical reference framework to be identified?

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

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

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

The following research questions shall be answered during the project:

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

Methods

To cover a wide range of literature and to generate a systematic literature search as comprehensive as possible, the search will be conducted as a scoping study. A search strategy for a total of nine databases will be designed and corresponding search runs will be carried out. Apart from that, relevant publications will be additionally gathered through hand search and consultation of experts. Subsequently the full texts will be analyzed with MAXQDA. For dealing with the first research question, categories will be formed from the identified publications following the Grounded Theory (Glaser and Strauss) in order to describe in this way the different ideas of person-centeredness in appearance and content and, moreover, to quantify them numerically.
The results of the scoping study will be used to deal with the second and third research question in a next step. To identify the underlying concepts of the person and personhood from the research literature and to compare them differentially, the search strategy of the first research question may possibly have to be modified and a further research conducted. The subsequent analysis will also be carried out in MAXQDA.

**Status**

With reference to relevant publications on the subject of person and dementia (for example the opinion of the German Ethics Council on Dementia and self-determination 2012) keywords were generated and a search strategy (with adjustments to the particular databases) was developed. A systematic literature search was conducted in nine databases (Medline, PsychInfo, PubPsych, Cinahl, Scopus, Web of Science, Cochrane, Sowiport, EBSCO-Geisteswissenschaften; overall hits n=3517), the duplicates were removed and a title/abstract screening with regard to the first research question was completed. Currently, the selection process for full text screening proceeds. This work package will be completed in the first quarter of 2015. After the identification of all relevant publications, the content-related analysis will start. Furthermore, the first results will be presented to potential (inter)national cooperation partners. The planned completion date of the first project phase (scoping study) is the end of 2015.

**Results**

The results of the project Per-Dem provide a systematic overview of the actual debate on person-centeredness with regard to pwd. Alongside a concept clarification, the results enable a critical analysis of the consequences for existing care-concepts and of the basis of theory within dementia research in general. For the DZNE in Witten the results also contribute to position itself within the international debate on person-centeredness and dementia regarding both research and care practice.
**Introduction**

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

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

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

The short-term objective of StiV-H is to develop a definition for the phenomenon “stability of home-based care arrangements” with a focus on informal caring trajectories and the needs and demands of people with dementia and their families. Furthermore, it aims a) to identify and operationalize influencing factors on stability and b) to empirically validate the phase model of informal caring trajectories.

**Research questions:**

- How can the stability of home-based care arrangements for people with dementia be defined and what constitutes and influences stability?
- How can the identified influencing factors be operationalized and analyzed?
• Is the phase model developed in the VerAH-Dem pilot valid and generalizable? Are there phase-specific influencing factors on stability? Is the stability of home-based care arrangements particularly vulnerable in certain phases?

Methods

• A systematic review about influencing factors on the stability of home-based care arrangements for people with dementia over the course of time.

• A validation study on the pre-existing phase model of informal caring trajectories in home-based-care arrangements for people with dementia (focus groups with informal carers).

Status

A definition of stability of home-based care arrangement has been developed (publication submitted); systematic review is in progress (planned date for submission: end 2015).
Access to the field for the validation study (focus groups) will be initiated in autumn 2015.

Results

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

The results can be used to develop a stability assessment in order to develop interventions for promoting and maintaining stability so that people with dementia can remain at home for as long as possible under satisfying conditions for all parties involved.
Title | Day care center for care-dependent relatives of employees in an acute care hospital | TAPA-K
--- | --- | ---
Duration | 2013 – 2015 |  
Funding | - Ministry of Health, Emancipation, Nursing and Age North-Rhine-Westphalia (NRW) within the European Regional Development Fund (EFRENRW target 2 program 2007 – 2013)  
- IuK & Gender Med.NRW  
- Project executive organization Forschungszentrum Jülich (ETN) |  
Collaboration | - University of Witten/Herdecke  
- Evangelisches Krankenhaus Witten |  
Principal Investigator | Wilfried Schnepp (University of Witten/Herdecke), Bernhard Holle (DZNE) |  
Scientific Staff | Medlin Mogar |  

Introduction
Many employees are facing the challenge of balancing their professional duties with the responsibility for a care-dependent relative, which is often associated with major efforts and limitations. Employed caregivers are mostly women so the responsibility of care is unequally distributed across the sexes.

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

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

Research Question: What contribution can a day-care center for care-dependent relatives located at an informal carer’s workplace bring in order to ensure 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 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
• Qualitative interviews with experts on the reconcilement of family care and employment and with participants of comparable best-practice models
• Based on the theoretical and empirical results, the development of a concept for implementing the support service (day-care center) at the collaborating hospital
• Qualitative interviews with responsible actors from the management and organization and with users of the support service for the purpose of a process evaluation

Status

The two literature studies on the needs, demands and burden of employed informal caregivers as well as examples of best practice to relieve this target group have been conducted. Based on the literature, a questionnaire to identify and assess the specific needs of affected employees in the collaborating hospital (EVK Witten) has been developed. Data collection is completed (n=126) and the descriptive statistical analysis is being conducted. Some of these results are being summarized and presented to the collaborating hospital.

Up to the end of 2014, a total of 15 in-depth interviews with employed caregivers were conducted. The content analysis of the Interviews has been finished.

Furthermore, a total of 10 expert interviews were conducted. The Interviews have been transcribed and are currently in the process of content analyzing.

More interviews with employees at the level of management and organization and dealing with process evaluation are being conducted.

Results

Based on the theoretical (literature review) and the empirical (staff survey and interviews with employed caregivers) findings, substantive adjustments of the support service in the collaborating hospital were carried out. To deal with the diverse needs of employed caregivers the compatibility model for family care and employment was developed, consisting of information, advice and support. These three components have been designed and implemented and are currently being tested.

In addition to the final analysis of the ongoing interviews, the next step will be the development of an implementation guideline with practical recommendations for interested companies. At the end of the project in May 2015, a final event will be organized and a final report created.
3 Work results (without direct link to projects)

3.1. Articles (peer reviewed)


3.2. Articles (not peer reviewed)


3.3. Reports

3.4. Books


3.5. Book chapters


3.6. Presentations (peer reviewed)


Roes, M., Laporte-UrIBE, F., Riesner, C., Quasdorf, T., Buscher, I. (04.05.2014). Implementation and Dissemination Research in Germany - the missing gap in dementia care. 29th ADI Conference, St. Juan, Puerto Rico.


### 3.7. Presentations (invited)


4 Boards and consulting activities

**Buscher I.**
- German Society of Gerontology and Geriatrics (Deutsche Gesellschaft für Gerontologie und Geriatrie)
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft e.V.), section dissemination and implementation (SDI), leader
- European Academy of Nursing Science (EANS)

**Dichter M.**
- German Nursing Association North-West (Deutscher Berufsverband für Pflegeberufe Nordwest), COE
- The German Society for Epidemiology (Deutsche Gesellschaft für Epidemiologie)
- European Academy of Nursing Science (EANS)
- International Psychogeriatrics Association (IPA)
- International Society of Quality of Life Research (ISOQOL)

**Dinand C.**
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)

**Döttlinger B.**
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- International Association for the Promotion of Basal Stimulation (Internationaler Förderverein Basale Stimulation)

**Graf R.**
- German Nursing Association (Deutscher Berufsverband für Pflegeberufe)

**Halek M.**
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- Department of Health, University Witten/Herdecke
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- Interdisciplinary Centre of Health Services Research (IZVF, University Witten/Herdecke)
- Project “Development of a list of criteria for recording palliative needs of people with advanced dementia in old people’s homes” (Entwicklung eines Kriterienkataloges zur Erfassung palliativer Bedürfnisse von Menschen mit fortgeschrittener Demenz in der stationären Altenhilfe) funded by the Ministry of Health, scientific advisory board
- Editorial board for the homepage of the Federal Ministry of Family Affaires, Senior Citizens, Women and Youth, section people with dementia in the hospital
- Care Foundation (Stiftung Pflege), advisory board

Hochgraeberr I.
- German Nursing Association North-West (Deutscher Berufsverband für Pflegeberufe)

Holle B.
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- Honor Society of Nursing, Sigma Theta Tau International

Holle D.
- German Society of Gerontology and Geriatrics (Deutsche Gesellschaft für Gerontologie und Geriatrie)
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft), internal auditor
- European Academy of Nursing Science (EANS)
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- International Psychogeriatric Association (IPA)
- Member of the expert group to update the expert standard “nutrition management for securing and supporting oral nutrition in care”, German Network for Quality Development in Care (Deutsches Netzwerk für Qualitätsentwicklung in der Pflege)
- Member of the working group “Dementia Outcome Measures; charting new territory” supported by the EU Joint Programme – Neurodegenerative Disease Research (JPND)

Köhler K.
- German Society of Gerontology and Geriatrics (Deutsche Gesellschaft für Gerontologie und Geriatrie)
Kuske S.
- Coalition for Patient Safety (Aktionsbündnis Patientensicherheit)
- Network for Healthcare Research (Netzwerk für Versorgungsforschung)

Laekeman M.
- German Pain Society (Deutsche Schmerzgesellschaft):
  - Work group „pain and age“
  - Work group „pain and movement“ spokesperson
- German Assoziation for Physiotherapy and Physical Therapists (Deutscher Verband für Physiotherapie Zentralverband der Physiotherapeuten / Krankengymnasten), section North Rhine-Westphalia
- University Network for Healthcare Professions (Hochschulverbund Gesundheitsfachberufe)
- International Association for the Study of Pain (IASP): Special Interest Groups “pain and movement”, “pain in older persons” and “pain education”
- Cost Action TD1005 Pain Assessment in Patients with Impaired Cognition, especially Dementia, Workgroup I Psychometrics and Algesimetry

Laporte Uribe F.
- Global Young Faculty, initiative of the Mercator Foundation in cooperation with the UA Ruhr (Stiftung Mercator in Zusammenarbeit mit der Universitätsallianz Ruhr)
- Alzheimer’s Association International Society to Advance Alzheimer’s Research and Treatment (ISTAART)

Nover S.
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- German Sociological Association (Deutsche Gesellschaft für Soziologie)

Palm R.
- German Nursing Association North-West (Deutscher Berufsverband für Pflegeberufe)
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- European Academy of Nursing Science (EANS)
- International Psychogeriatric Association (IPA)
- German National Academic Foundation (Studienstiftung des deutschen Volkes), Alumni
Panke-Kochinke B.
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)

Pinkert Ch.
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)

Quasdorf T.
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft), Section Dissemination und Implementation (SDI)

Roes M.
- AcademyHealth - Advancing Research, Policy and Practice
- German Society of Gerontology and Geriatrics (Deutsche Gesellschaft für Gerontologie und Geriatrie)
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft), section dissemination und implementation (SDI), vice chairperson
- German network for quality development in nursing (DNQP), founding member
- INTERDEM Network (European network of researchers on early detection and psycho-social interventions in dementia)
- Federal Joint Committee (Gemeinsamer Bundesausschuss), 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, Alumi Commonwealth Foundation
- 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)
- International Psychogeriatric Association (IPA)
- Project: Implementation of a new documentation model in long-term care (Praktische Anwendung des Strukturmodells - Effizienzsteigerung der Pflegedokumentation in der ambulanten und stationären Langzeitpflege), member of the steering committee of the ministry of health
- Robert Bosch Fellow, Alumi
- Scientific advisory board of the „Bremer Pflegekongress“, speaker
Schwab C. G. G.

- German Nursing Association (Deutscher Berufsverband für Pflegeberufe)
  - Delegate of the managing committee
  - Revisor
  - Member of the work group nursing chamber
- German Nursing Association, section North-West;
  - Member of the steering committee
  - Deputy member of the nursing council (North-Rhine Westphalia (NRW))
  - Member of the working group “Knowledge Management”
  - Examiner for the advanced training of nursing experts for PwD
  - Member of the working group of the Ministry of Health (North-Rhine Westphalia (NRW)) to develop an inspection catalogue for the new law on accommodation and participation
- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft)
- German Network for Healthcare research (Deutsches Netzwerk Versorgungsforschung)
- Honor Society of Nursing – Sigma Theta Tau International (STTI)
- International Council of Nurses (ICN)

Serbser J.

- German Society for Human Ecology (Deutsche Gesellschaft für Humanökologie)

Sirsch E.

- German Society of Nursing Science (Deutsche Gesellschaft für Pflegewissenschaft), board member
- German Pain Society (Deutsche Schmerzgesellschaft), working group “pain and old age”
- German Network for Quality Development in Nursing (Deutsches Netzwerk für Qualitätsentwicklung in der Pflege), development of a guideline for “chronic pain management in care” member of the scientific advisory board
- German Society of Gerontology and Geriatrics (Deutsche Gesellschaft für Gerontologie und Geriatrie)
- Cost Action TD1005 Pain Assessment in Patients with Impaired Cognition, especially Dementia, Workgroup II Nursing
- European Academy of Nursing Science (EANS)
• International Association for the Study of Pain (IASP), Special Interest Group (SIG) Pain in Older Persons

Von Kutzleben M.
• Mixed Methods International Research Association (MMIRA)
• Alzheimer’s Association International Society to Advance Alzheimer’s Research and Treatment (ISTAART)
5 Work for scientific papers and publishers

Dichter M.
- Archives of Gerontology and Geriatrics: peer reviewer
- BMC Geriatrics: peer reviewer
- Clinical Interventions in Aging: peer reviewer
- Cochrane Database for Systematic Reviews: peer reviewer
- Health and Quality of Life Outcomes: peer reviewer
- International Journal of Nursing Studies: peer reviewer
- International Psychogeriatrics: peer reviewer
- Pflege (Huber): peer reviewer
- Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen: peer reviewer

Dinand C.
- Scandinavian Journal of Caring Sciences (SJCS): peer reviewer

Halek M.
- Aging and Mental Health: peer reviewer
- Pflege (Huber): peer reviewer
- Scandinavian Journal of Caring Science: peer reviewer
- Zeitschrift International Journal of Nursing Studies (IUNS): peer reviewer

Holle B.
- Pflege (Huber): peer reviewer
- Pflege & Gesellschaft (Juventa): peer reviewer

Holle D.
- International Journal of Nursing Studies (IUNS): peer reviewer
- International Psychogeriatrics: peer reviewer
- Pflege (Huber): peer reviewer

Kuske S.
- Journal of Public Health: peer reviewer
Laekeman M.
- Clinical Rehabilitation: peer reviewer

Laporte Uribe F.
- International Psychogeriatrics: peer reviewer

Palm R.
- Journal of Nursing Home Research Science: peer reviewer

Reuther S.
- International Psychogeriatrics: peer reviewer

Roes M.
- Gerontology Society of America: review of abstracts
- Healthcare Policy: peer reviewer
- Managementhandbuch Pflege, medhochzwei Verlag: co-editor
- PADUA, Huber Verlag: co-editor
- Pflege und Gesellschaft, Juventa: peer reviewer
- Pflegewissenschaft, hps media: editorial, peer reviewer
- Zeitschrift für Gerontologie und Geriatrie: Peer Reviewerin

Schwab C. G. G.
- Pflege (Huber): peer reviewer

Von Kutzleben M.
- International Psychogeriatrics, peer reviewer

6 Organisation of conferences

8.10.2014: 5th annual conference of DZNE Witten, Witten
## 7 Team (April 2015)

E-Mail Address: first name.last name@dzne.de

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<td>Albers, Bernd</td>
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<td>Venia legendi Soziologie, Dr. phil., Staatexamen Sek.2</td>
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<td>Trutschel, Diana</td>
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<td>Rosier, Ute</td>
<td>Scientific staff</td>
<td>MSc clinical psych.</td>
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<td>Köhler, Kerstin</td>
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<td>Mogar, Medlin</td>
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<td>Palm, Rebecca</td>
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<td>Dreyer Jan</td>
<td>Scientific staff</td>
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<td>Laporte Uribe, Franziska</td>
<td>Scientific staff</td>
<td>Ph.D. HlthSc M.A. language &amp; communication</td>
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## Attachments Project list

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