Projects 2012

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Research projects DZNE-site Witten (March 2013)

As projects in Witten are usually not carried out by only one working group or/and not only contain one single basic question, in the following the presentation of the current projects is grouped by the investigated (care) setting.

A finalised Project

Projects on people with dementia living at home
Projects on people with dementia in nursing homes
Projects on people with dementia in acute hospital
Dementia Networks
Literature

A finalised Project

The first and already finalised project looked into a future societal setting “Scenarios for dementia health care in 2030 (Sze-Dem)” (in cooperation with Fraunhofer ISI, Karlsruhe).

Objectives: Aim was to develop scenarios about the dementia health care situation in Germany in 2030. Scenarios offer coherent descriptions of future conditions; i.e., they consider several trends simultaneously and based on these, create portraits of alternative possible futures. The results of this complex process help to direct a society’s perception towards problems.

Achievements: As had been expected, three of the five resulting scenarios are (very) negative, these parts are well known and widely discussed. Surprisingly there are two scenarios showing more positive developments, although one implies the latent danger of a “state health control” in the background. Both are based on a moderate economic growth corresponding to the average of the last 20 years, i.e. the scenarios should be able to be realized with the existing resources. It seems that efficient research, especially in the fields of health care and health services, and a consistent implementation of the research findings is most important both on political and on structural levels. It also appears to be possible to provide adequate support, health service and care for those affected without “a break-through” in basic research. A prerequisite, however, is in general a societal rethink and the strengthening of health service research. The results of this project lead to actions recommended to be taken, which ought to improve health services for PwD in the long term (Vollmar et al. 2012).

Future plans: The project was finished in autumn 2011. Results may help to formulate new and better research questions and give recommendations for stakeholders and politicians. The results could also be used for developing a respective roadmap that could serve as a starting point for a forthcoming strategic dementia plan for Germany.
Projects on people with dementia living at home

Several projects are dealing with PwD living at home. Since investigations in private surroundings particularly in families with a PwD at home are very time-consuming there are more studies on dementia care in nursing homes. However, most PwD live at home and their situation, needs and demands are not well known.

“Self-perception and Intervention (SEIN)”

The project “Self-perception and Intervention (SEIN)” was completed in the end of 2012. **Objectives:** The aim was to develop and evaluate a modular self-help concept for people with early stage dementia and to find out how to encourage the self-determination of people with dementia individually. The project started with group discussions and single interviews in self-help groups using autobiographical narrative interviews with members of self-help groups and support groups and discourse analysis. The interviews with PwD were contrasted with those interviews conducted with people with Multiple Sclerosis (MS). A second survey phase was completed six months later. **Achievements:** Two results are to be noted: On the one side, the promoting and supporting effect of the self-help group on the self-determination capability of people with dementia could be clearly demonstrated. On the other side, it was possible to show precisely which individual strategies people with dementia develop to integrate their chronic disease into their daily life also in comparison to the approach people with MS take. Finally, key adjustment variables could be found which can be used in the follow-up study. **Future plans:** “Life trajectories and coping strategies (LEBE)” will help to understand what enables people to integrate their chronic disease individually into their future life course. In spring 2013 the LEBE-project (long-term study) will commence. Participants with dementia and MS will be contrasted to those who have been diagnosed with Parkinson’s. The key adjustment variables will be applied to find out which types of coping strategies are being used by participants with different neurodegenerative diseases at different stages of their illnesses.

“Developing recommendations for creating low-threshold support services for people with dementia and their family carers in a German community”

**Objectives:** The aim of the study is to develop research based recommendations for the project regions and general recommendations for creating low-threshold support in Germany. Using triangulation and combining different perspectives of all people involved (PwD, family caregivers, volunteers, professionals and managers), the complex picture of these services, their users with their reasons for and effects of utilization will be described. **Achievements:** An international literature review focusing on scientific projects and results concerning the implementation of low-threshold support services has been finished. Based on the results questionnaires for family caregivers, volunteers, coordinators and institutions’ representatives were developed. **Future plans:** At this point, the data collection has been finished. The analyzing process of the data is ongoing.
“Homecare arrangements for people with dementia: Utilization behaviour and use of formal and informal care services (VerAH-Dem)”

Objectives: How do family caregivers organize their support network to provide care for a relative with dementia at home. This project uses a triangulated approach to make homecare arrangements describable over the course of time and to reconstruct the every-day decision making of informal caregivers through a standardized questionnaire and qualitative interviews, respectively. Results should provide a data base to evaluate the situation in home-based care arrangements in Germany to give directions for further structural and political decisions as well as for planning, counselling and supporting home care arrangements for PwD.

Achievements: Development of a standardized questionnaire (D-IVA) based on an international literature review, D-IVA has proved to be applicable to other study designs in the community setting and is currently used in an evaluation study of dementia networks in Germany (DemNet-D). In total, 102 care arrangements could be assessed in the survey. Statistical analysis is completed, results are available and a publication is prepared for submission. Overall, it can be stated that our study sample had broad access to formal services (only 14.7% did not use any kind of formal service at all) and utilization often started within the first year since the appearance of first symptoms. Only 10.4% of the persons with dementia had no care level according to the German long-term care insurance law. On average, 1.54 informal caregivers where involved in the provision of care. Most care-dependents showed dementia symptoms since three years or longer and primary carers stated to assume their role since 3.45 years, which proves a high consistency concerning the responsibility of primary carers in the care arrangements. Qualitative in-depth interviews have been conducted with a sub-sample of nine caregivers.

Future plans: Qualitative data analysis is expected to finished in the second quarter of 2013.

“Changing attitudes towards dementia in family practice (CADIF)”

General practitioners (GPs) play a major role in providing health care and psycho-social support for the elderly. From 2011 until 2012 the study “Changing attitudes towards dementia in family practice (CADIF)” was conducted at the DZNE site Witten in cooperation with the Institute of General Practice and Family Medicine at the University of Witten/Herdecke and the Institute of General Practice at the University of Düsseldorf as part of the Competence Network of Degenerative Dementias (KNDD). With CADIF participating researchers focus on GPs’ attitudes towards dementia.

Objectives: Findings from quantitative and qualitative research suggest shortcomings in general practice with regard to dementia recognition, adequate treatment, and patient and caregiver support (Vollmar, et al. 2010). Efforts to improve GPs’ dementia management have been undertaken but the focus of those interventions has been mainly on knowledge transfer but less on attitudes. Therefore, the main objective of CADIF is to develop an intervention to change GPs’ attitudes towards dementia based on a comprehensive understanding of dementia in daily general practice and of GPs’ cognitive, emotional, and attitudinal barriers towards this illness.

Achievements: GPs’ attitudes towards dementia as well as existing interventions on changing those attitudes are being identified with two systematic literature searches (one systematic review, one meta-synthesis) resulting in the review of 16.000 titles and abstracts.
“Needs and demands in everyday life of people with frontotemporal dementia from their own perspective (AspektFTD)”

Frontotemporal dementia (FTD) is one of the most common presenile causes of dementia. In the early stage, FTD is associated with less impairment of cognitive skills but strong changes of judgment, behavior, personality and emotions. These changes cause significant problems in caring for those persons, recommendations for the care of this special group are lacking.

Objectives: The project “Needs and demands in everyday life of people with frontotemporal dementia from their own perspective (AspektFTD)” aims at the exploration of the perspective of PwFTD themselves. Results of a systematic literature review conducted beforehand and of an initial thematic analysis of three semi-structured interviews with family caregivers of PwFTD indicate a lack of evident information about their perspective. In the intended qualitative case related research project the specific needs and demands of PwFTD will be explored using video supported observations. Additionally, semi structured interviews with PwFTD and their family caregivers will be conducted.

Achievements: The result of this review shows that themes concerning quality of life of PwFTD seem to be a marginal problem in the scientific community and not at the focus of increasing research interest at the moment – which discloses the obvious gap to the distress of the involved people and their need of precise support. If the quality of life for people with FTD shall be improved, it is necessary to know about the influences of this disease on their everyday life.

Future plans: The results of this study will be the basis for the further development of FTD-specific interventions.

Projects on people with dementia in nursing homes

In German nursing homes about 70% of the residents are PwD since dementia presents a high risk for moving into a nursing home.

“Strengthen Quality of Life of people with Dementia (Leben-QD)”

The Project (partly third party funded) is a cooperation with a big agency of nursing care services.

Objectives: It is a quasi-experimental study, which investigates the effects and the implementation process of Dementia Care Mapping (DCM) in nursing homes (a complex observational instrument to assess QoL and well-being of residents with dementia). During the course of the study, one group of nursing homes will implement DCM (intervention group). A second group has already been using DCM for some time and will go on using it during the study (DCM comparison group), while a third group will implement QUALIDEM as an alternative intervention for measuring QoL of PwD (QUALIDEM comparison group). Each of the project groups comprises three nursing homes, each represented by one unit. The effect outcomes are QoL and challenging behavior of PwD as well as perceived stress and attitudes of staff members.

Achievements: The project started in May 2010 and will be finished in September 2013. A feasibility study and the baseline data collection have been conducted. Furthermore, the DCM institutions completed the first DCM cycle, and the QUALIDEM institutions started the execution of the QUALIDEM intervention. The first results of the baseline data analysis of the residents’ characteristics show no considerable differences between the study groups. Meaningful differences are found between the units in terms of size, milieu, staff amount and qualification and staff-resident ratio. There are also significant differences in attitudes towards PwD between registered nurses (RNs) and care assistants. Care assistants’ attitudes are less-person oriented than those of RNs (ADQ instrument).

Future plans: The implementation process will be evaluated by investigating different factors, which are supposed to have an influence on the success of the implementation. These will, for example, be structural data of the project institutions and characteristics of staff members. On this basis we will develop an instrument for the evaluation of the implementation requirements of nursing home units.
“Quality of Life (QoL-Dem)”

Objectives: Aim is to evaluate the psychometric quality of the German version of the QUALIDEM. This is a standardized dementia specific proxy-measurement of QoL of PwD developed and validated in the Netherlands. This project is a sub-project of Leben-QD

Achievements: Studies on the psychometric properties of the German version are in the very early stages (Dichter et al. 2011). Based on the absence of a universal definition of QoL and a gold standard to verify the validity of QoL-measures the study is divided into three phases. In the first theoretical phase, a synthesis of qualitative studies on QoL from the perspective of PwD is conducted. This meta-synthesis analyzes the identified papers on the basis of Grounded Theory.

Future plans: The empirical phase consists of three steps: (a) an investigation of the scalability and internal consistency based on a big sample of approximately 630 PwD, (b) an evaluation of the inter-rater and intra-rater reliability and (c) an extensive evaluation of the construct validity of the instrument. For this step, the results of the meta-synthesis will be used for the selection of the appropriate comparison constructs for the investigation of construct validity. In the final phase, the QUALIDEM will be adapted if necessary based on the summarizing results. As a next step, the evaluation of the use of Qualidem in nursing homes and its effects on QoL of persons with dementia and on care quality of the institutions is planned.

“Impact of case conferences for the care of people with dementia and challenging behavior in nursing homes (FallDem)”

Few studies show that case conferences can be an effective way to help nurses to understand the behavior of persons with dementia. Due to the poor quality of the studies, these results must be interpreted carefully. This highlights the need for methodologically well designed intervention studies to provide conclusive evidence on the effects of case conferences for PwD and the caring staff.

Objectives: The project “Impact of case conferences for the care of people with dementia and challenging behavior in nursing homes (FallDem)” evaluates the effect of two different kinds of case conferences for the care of people with challenging behavior (e.g. Halek & Bartholomeyczik 2011) in German nursing homes.

Achievements: In the first part of the study, the concepts of case conferences were developed and pretested. These concepts are based on the results of two “Lighthouse Projects” (“Leuchtturmpojeekte”) on dementia care funded by the German Ministry of Health as well as a systematic literature review, expert interviews, an expert workshop and validation by caregivers in nursing homes.

Future plans: The Implementation study of these concepts uses a stepped-wedge design, a kind of cluster-based design that enables all participating facilities to receive the intervention and therefore increase the compliance. This design has some advantages compared to a traditional cRCT. It implies controlled data elements (control group, randomization, blinding). The stepped implementation creates a waiting period and this waiting time provides useful “control” information for inclusion in the data analysis. The main outcome is challenging behavior. The calculated sample size (power 90%, drop-out 20%) is 360 residents within 6 clusters with 12 nursing homes. An important part of the study is the comprehensive implementation plan and process controlling, which includes a triangulated approach (interviews, questionnaires, case studies). The project will start in Mai 2013 and end at the beginning of 2016.
“DemenzMonitor – Monitoring dementia care in nursing homes in Germany”

Objectives: The project aims at monitoring the quality of care for PwD in nursing homes, its organizational conditions as well as investigating associations with residents’ conditions. The study is designed as a quantitative longitudinal study.

Achievements: In May 2012, the first data collection was conducted. 47 nursing homes took part, collecting data from 1689 residents. In 2013, 36 nursing homes participate a second time moreover 19 new institutions could be enlisted.

Future plans: Methods of data collection and management will be optimized to realize an enlargement of participants. The used instruments will be adjusted by further testing of psychometric properties.

“Pain assessment in the elderly in long term care”

Despite the high prevalence of pain among older persons in residential care, an interdisciplinary guideline on assessment and treatment of pain in the elderly, especially in persons with cognitive impairment, is lacking in Germany. A continuous monitoring of pain in long-term care residents is needed. For the pain assessment in older persons only a limited number of international guidelines exist.

Objectives: The aim of the project is to develop an evidence-based guideline according to the specifications of the Association of the Scientific Medical Societies AWMF “Pain assessment in the elderly in long term care” and to adapt it for the German healthcare situation. The guideline development follows the recommendations of the German Instrument for Methodological Guideline Appraisal (DELBI), the guideline developer's handbook from the Scottish Intercollegiate Guidelines Network (SIGN) and the Grading of Recommendation Assessment, Development and Evaluation working group (GRADE).

Achievements: The first expert panel has been conducted. A systematic search and critical appraisal of fifteen national and international guidelines regarding this topic was carried out. The method paper has been submitted. The finalization of the guideline is planned for 2014.

Further plans: An additional project with the topic “Development and pilot test of a Set of Quality Indicators for the "Pain Assessment in the Elderly in long-term care guideline" is in the process of being prepared. The following steps are planned, a) analysis of existing guidelines and published quality indicator sets for the identification of appropriate indicators, b) construction of the quality indicator set, c) evaluation of these recommendations by a multidisciplinary expert group and the development of a consensus version, d) testing of the results in a pilot study and e) adapting of these indicator sets to the guideline in a subsequent study. Provided that the results are positive, an evaluation study of the implementation of the guideline using the quality indicators is planned. It is a cooperation project between the DZNE Witten and the German Pain Society.
“Gestical Communication”

**Objectives:** The aim of the project is to increase theoretical and practical knowledge about nonverbal communication with PwD, thereby increasing their autonomy. It focuses on the loss of the ability to communicate verbally. Using video analytic techniques based on the theoretical framework of Documentary Interpretation and Grounded Theory, the description of symbolic reflection in the communication between PwD and nurses in nursing homes is investigated.

**Achievements:** The pilot phase is completed. A mask for video observation and analysis is created. The evaluation of data from six study cases is carried out. The main study case was investigated in the first two working steps with microanalyses. Prominent features of the study case will be identified. A study case is selected and prepared for a comparing analysis.

**Future plans:** Further video tape’s for comparative analysis have been made and are evaluated.

Projects on people with dementia in acute hospital

The care of people with dementia (PwD) is one of the outstanding challenges for acute hospitals in the near future. For these patients a hospital stay can lead to adverse outcomes, such as functional and cognitive decline, delirium or nosocomial infections. The special clinical setting, the increased use of sedative drugs and the lack of normal daily routines seem to favor these critical situations. The health care professionals in Germany are not well prepared for caring for older patients with cognitive impairment and psycho-geriatric disorders.

“Dementia care in acute hospitals in Germany (DemKH)”

**Objectives:** The project focus on the identification and analysis of existing approaches in the care of PwD in hospitals. The aim of this research is to get an in-depth view of general conditions (structure, financial conditions, staff qualification), core aspects, implementation barriers and expected outcomes of different approaches. The results could lead to recommendations and references for all hospitals wanting to improve the care of patients with dementia.

**Achievements:** A literature review was performed to get a first overview of the different approaches, which are used in German hospitals. 17 interviews with experts and 6 group discussions with nurses and physicians in 7 hospitals were conducted. The analysis of the expert interviews is finished; currently the group discussions are being analyzed. The previous results show that hospitals focus mainly on the qualification of staff members and on environmental changes. Also the integration of family members and volunteers in care plans characterize most of the new concepts. But there is still a lack of commitment on the part of all professionals and hospital managers to adjust acute hospital care to the needs of people with dementia.

**Future plans:** Based on the results, further studies with focus on the care of PwD in hospitals will be developed and planned.

“Decision-making on self or external assessment of pain by persons with moderate dementia in hospital (SMeDeK)”

Pain in hospital is a significant problem especially for patients with communication difficulties. Self report is the gold standard but limited for patients with moderate to severe dementia. Without accepted guidance, nurses have to decide whether to use self report tools or proxy assessment tools for pain.

**Objectives:** The aim of this project is to discover skills which nurses need to decide when to use self or proxy pain assessment for patients with moderate dementia in acute care settings. The project is
divided into three phases: literature review providing an overview on the current state of the situation, analyze the current praxis through observations and focus group interviews, and to develop an intervention, a pathway to guide the decision-making on self- and proxy pain assessment.

**Achievements:** An integrative literature review has been conducted. Seventy structured observations have been carried out on three wards (surgical, internal and a special dementia ward) during day- and night-shifts. Additionally, seven focus group interviews were done. The findings of the study “showed that the nurses’ sensitivity and awareness towards this theme very often differs widely. This partially lacking or insufficient sensitivity of nurses, together with subsequent inadequate pain assessment, has relevant consequences for treating patients with dementia for pain. For this reason, the screening tool See-Pain was developed during a previous study with which nurses can make more systematic decisions about carrying out an external assessment.

**Future plans:** To find out whether the screening tool See-Pain is capable of influencing the sensitivity and attention of nurses/caregivers towards the pain suffered by persons with dementia. Because See-Pain was developed on a theoretical and empirical basis and could not yet be used in a wider scope, first an expert-based content validity test is needed, including the examination of the applicability and practicability.

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**“CareSafeD”**

**Objectives:** Especially people with Dementia (PwD) suffer from adverse events that are associated with communication failures during transition. Purpose of the “CareSafeD” project is to describe and to analyze the communication structures and processes of handovers between home and respite-care settings considering PwD and to develop recommendations for improvement.

**Achievements:** Performing two systematic reviews, evidence gaps became obvious with regard to the research question. Only a few publications were identified considering communication and transition between home and respite care (first review). An all-encompassing review considering all settings resulted in 73 relevant publications (second review). Interviewing experts of respite care institutions and analyzing different documents showed further need for action.

**Future plans:** Currently Delphi-based interviews are being prepared. Those interviews will help to prioritize the previous results for developing a nationwide online-based questionnaire for respite care facilities.

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**Dementia Networks**

**“DemNet-D”**

**Objectives:** “DemNet-D” (Multizentrische, interdisziplinäre Evaluationsstudie von Demenznetzwerken in Deutschland) aims at evaluating 13 dementia networks in Germany. A multi-centred, multi-professional and multivariate approach is being applied in this study where qualitative and quantitative data are being collected at baseline and 12-month follow-up. For this study the DZNE site Witten collaborates with the Alice Salomon University of Applied Sciences in Berlin, the Institute for Applied Social Sciences at the Baden-Wuerttemberg Cooperative State University Stuttgart and the DZNE site Rostock/Greifswald. Prof. Dr. Wolfgang Hoffmann (DZNE site Rostock/Greifswald) is overall coordinator for this project which started on 1st April 2012 and will run until 31st March 2015. The DZNE site Witten functions as coordinator and project partner for 4 out of the 13 dementia networks with all 4 of them being located in North Rhine-Westphalia: Ahlener System, Arnsberger Lernwerkstatt, Demenznetzwerk Krefeld and Demenznetzwerk Minden/Lübbecke. The focus of this research site lies on questions regarding the knowledge transfer within and beyond the networks; on the availability and utilization of support services offered by the networks for family caregivers and for
people with dementia, and on the effects these support services might have on the burden of caregivers.

**Achievements:** The four research partner organisations successfully applied for funding with the Federal Ministry of Health (BMG) for this study that is embedded in the funding scheme “Zukunftswerkstatt Demenz”. Details of the data collection process and methodological issues were discussed between research partners in a number of work meetings that have taken place in Berlin, Greifswald and Bonn. The DZNE-site Witten meets with three of the four networks every 3 months and keeps close contact and communicates regularly with all four networks. Representatives of the participating dementia networks, research institutes, the BMG and the Projektträger im Deutschen Zentrum für Luft- und Raumfahrt (PT-DLR, Project Management Agency – part of the German Aerospace Center) came together at the kick-off meeting in Frankfurt a.M. on 25th October 2012. After questionnaires and consent sheets were printed and distributed at the end of last year networks are now enrolling people with dementia and their caregivers into the study. It is planned to enrol 55 dyads per network – altogether 715 people with dementia and their caregivers – until 30th June 2013. First interviews have been conducted. Qualitative data from interviews with the managers of all 13 networks are currently being analysed and the interview guideline for the following group interviews with key persons and stakeholders is being adjusted accordingly.

**Future Plans:** In April and May this year, Witten, together with the team from Stuttgart, will conduct group interviews with network stakeholders collecting data on knowledge transfer (Witten) and governance and structure of networks (Stuttgart). Baseline data will be collected until 30th June 2013 and analysed for a preliminary report until October. Furthermore, the DZNE-site Witten is setting up a project homepage that will also integrate the digital version of a “dementia toolbox”. This “toolbox” will provide practical advice and support for existing and future networks and it is – in addition to the scientific report and a workshop with experts – one of the main outcomes of this study.

**Literature**


