DemNet-D — Multicenter Interdisciplinary Evaluation of Dementia Care Networks in Germany

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Research partners:
- German Center for Neurodegenerative Diseases (DZNE) site Rostock
- University of Bremen
- Institute for Applied Social Sciences at the Baden-Wuerttemberg Cooperative State University

Collaborating dementia care networks in North Rhine-Westphalia:
- Ahlener System
- Arnsberger Lernwerkstatt
- Demenznetzwerk Krefeld
- Demenznetzwerk im Kreis Minden-Lübbecke

Other collaborating dementia care networks in Berlin, Brandenburg:
- Demenzfreundliche Kommune Lichtenberg
- Initiative „Demenzfreundlich!“ Treptow-Köpenick
- Qualitätsverbund Netzwerk im Alter Pankow e.V.
- "Unsere Kommune ist demenzfreundlich" Charlottenburg-Wilmersdorf
- Demenznetzwerk Teltow-Fläming
- Demenznetzwerk Uckermark
- Demenznetzwerk MemoClinic® Stralsund
- Demenznetz Aachen
- Demenznetz Düsseldorf
Background

In Germany, the majority of people with dementia is being cared for at home by people with dementia and their informal caregivers in the best possible way. For example, regional dementia care networks: specialists and service providers with different professional expertise work together in supporting people with dementia and their families.

Research questions and methodology

The study – a multidimensional, multi-professional evaluation of dementia care networks – aimed to determine factors of successful networks. The different basic conditions as well as different types of cooperation under which dementia care networks operate were taken into consideration. Baseline data were collected in interviews with more than 500 people with dementia and their caregivers between January and August 2013 with follow-up interviews being conducted 12 months later. Furthermore, qualitative data were collected in interviews with the coordinators of the 13 participating dementia care networks, followed by semi-structured group interviews with different stakeholders of these networks in spring 2013 and follow-up questionnaires 12 months later.

- Which supports do people with dementia and their informal caregivers utilize?
- What is life like with dementia or living with a person with dementia?
- Where is additional support needed?
- How do dementia care networks differ from one another?
- How and why are dementia care networks successful in their work?

In order to answer these questions extensive data on, e.g., quality of life, dementia, supports in managing day-to-day life, stress, medical care, burden, and social isolation were collected. Also, data regarding the organizational structures of dementia care networks (e.g., number of co-operations, degree of networking, and conveyance of specific knowledge), and health economic data (sponsor, financing structure) were collected.

At the DZNE site Witten the focus is on aspects of informal caregiving and knowledge management in dementia care networks:

- How do informal caregivers organize the care of a person with dementia?
- In which aspects of care do informal caregivers of people with dementia experience burden and how do they experience burden?
- How do dementia care networks translate and disseminate knowledge?

To answer these questions, caregiver burden was assessed using the “BIZA-D” (“Berlin Inventory of Caregivers’ Burden of Dementia Patients”) and care arrangements were evaluated using the “D-IVA” (“Questionnaire for Assessing Care Arrangements for People with Dementia”). Qualitative data on knowledge management were collected using...
semi-standardized one-on-one interviews with dementia care network coordinators. In close cooperation with the IfaS in Stuttgart an interview manual was developed.

Conclusion

The DemNet-D study and data analyzing was finalized successfully. Research findings were also translated in practice related information and disseminated through a "dementia toolbox". The toolbox offers support to anyone interested in setting up or optimizing dementia care networks.

The findings of the DemNet-D Study suggest that dementia care networks can optimize the support of people with dementia and their caring relatives by informal as well as formalized processes. Due to these findings, German policymakers now decided to make funding available for dementia care networks from January 2017 on.