Per-Dem: Person-centeredness and concepts of the person in the context of dementia

Duration: 2014 - 2017
Funding: DZNE Witten
Principal investigator: Prof. Dr. Martina Roes
Project coordination: Jonathan Serbser
Scientific staff: Jan Dreyer

Collaboration:
- Hartford Center of Geriatric Nursing Excellence (USA)
- Pennsylvania State University (USA)
- Polisher Research Institute (USA)
- The School of Dementia Studies - University of Bradford (UK)
- Die Zieglerschen – Geschäftsbereich Altenhilfe
- Center of Excellence Cognitive Interaction Technology (CITEC) – Se

Background
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.

Aims and Research Interests
In order to do justice to the complexity of the field of person-centeredness 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, 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 project 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:

- What does the concept of person-centeredness mean with regard to dementia in the research literature?
- Which concepts of personhood underlie the research literature concerning person-centeredness with regard to dementia?
- 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 review will be conducted as a scoping study in nine scientific databases. Apart from that, relevant publications will be additionally gathered through hand search and consultation of experts. Subsequently the full texts will be analyzed with MAXQDA. For dealing with the first research question and order to describe in this way the different ideas of person-centeredness the study will be used to deal with the second and third research question in the 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.

**Conclusions**

The results of the project Per-Dem provide a systematic overview of the research literature and to generate a systematic literature search as comprehensive as possible, the review will be conducted as a scoping study in nine scientific databases. Apart from that, relevant publications will be additionally gathered through hand search and consultation of experts. Subsequently the full texts will be analyzed with MAXQDA. For dealing with the first research question and order to describe in this way the different ideas of person-centeredness the study will be used to deal with the second and third research question in the 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.

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