

Title: „Narratives-in-Action“ of Women and Men living with Advanced Dementia. Findings and Methodological Aspects

Einleitung:

In Austria, approximately 130.000 people live with a neurocognitive disorder such as dementia. Many people living with dementia require some sort of long-term-care (LTC), especially in the moderate and severe phases. According to recent studies, up to 85% of people living in Long-Term-Care have a neurocognitive disorder. Despite the increased attention to dementia due to the rising number of afflicted people, the subjective perspective of people with moderate and severe dementia living in long-term-Care has not been sufficiently explored.

Since people living with severe dementia often have difficulties to express themselves verbally the methods for data collection have to be flexible and innovative. This study is based on a doctoral thesis [1] and explored the function of activities and occupation in promoting the experience of identity from the perspective of older people with advanced dementia living in LTC.

Methode:

Applying a qualitative research design in the ethnographic tradition, observations, interviews and informal talks while doing activities with four people with dementia and their carers were used for data collection in two different long-term-care settings over a prolonged period of time. A narrative analysis based on a “narrative-in action” approach was made to gain a deeper understanding of the participants’ experiences.

Ergebnisse:

The findings show the creative efforts of people with advanced dementia doing “identity work” in a confining environment. Thus they used narratives, objects and everyday activities to express their identities despite their cognitive and/or physical impairments. Fragmented narratives that are described as confabulation have an important function in constructing identity. Understanding narratives as enacted and grounded in everyday activities offers a potential to better understand the perspective of people with dementia who have problems with verbal communication.

Diskussion/ conclusio:

This study allows for a better understanding of the intricate relationship between meaningful activity and identity in people with advanced dementia. Thus meaningful occupation and its symbolic dimension should get more attention in the organization of Long-Term-care. The

„narrative-in-action-approach“ offers an innovative way to show complex transactions of the person, the activity and the environment in the given situation. Its application to other vulnerable groups is especially recommended.

- [1] Tatzert, V. C. (2017). "Das ist irgendwie mein Ding". Aktivität und Partizipation aus Sicht von Menschen mit mittelschwerer und schwerer Demenz in der Langzeitpflege. Eine narrative Studie. (Doctor of Philosophy, unpublished), Alpen-Adria-Universität Klagenfurt, Klagenfurt. ("This somehow my thing." Activity and Participation of People with moderate and severe Dementia living in Long-term Care - a narrative Study)
- [2] Tatzert V.C. (submitted) Narratives-in-Action of People with Moderate to Severe Dementia in Long-Term-Care. Understanding the Link between Occupation and Identity.