“Narrative-in-action” with people with advanced dementia – better understanding the relation of occupation and identity

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Introduction The importance of meaningful occupation for people with dementia living in long-term-care (LTC) is well known, but the group of people with advanced dementia has been neglected in research. Exploring their subjective experience of activity and participation is a challenge because verbal communication may be impaired.

Objectives There is a need for innovative methods for data collection and analysis that capture the subjective experiences of people with dementia in a transactional way.

Method The use of narrative theory combined with an ethnographic approach led to better insight into the perspective of people with moderate and severe dementia in LTC. Using the narrative-in-action approach (Alsaker, Bongaardt, & Josephsson, 2009) in a qualitative flexible design led to four in-depth case studies.

The results help to create a better understanding of the perspective of the person with advanced dementia and allow for a more positive view of dementia that is urgently needed.

Conclusion The methodological and ontological challenges in research with people with advanced dementia can be tackled. The narrative-in-action approach is very useful in this regard and leads to deeper understanding of the connections between identity, narrative and occupation.