

'I Pull Myself Together, But It Is No Use' – Experiences of Activity, Occupation and Participation of People with Advanced Dementia Living in Long-Term-Care

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Introduction: People with advanced dementia living in long-term-care are rarely involved in research despite the fact that it is a growing clientele group for occupational therapy.

Objectives: The focus of this paper is therefore to investigate the experience of activity and participation of people with moderate to severe dementia living in long-term care.

Methods: Using a **qualitative design** in the **ethnographic tradition**, data were collected in two institutions by means of **observations, interviews and informal talks while doing activities** with people with dementia and their carers. This was followed by a thematic **analysis**.

The **results** show the efforts of people with dementia to develop despite their diminishing skills and the confining environment of the institutions. Many of the activities offered were seen as not meaningful, relevant or were simply too difficult for the participants. Activities that were judged as appropriate were linked to the experience of continuity and identity. They were meaningful and offered potential to care for or be together with others. Reciprocity was an important need that led to increased participation.

Conclusion: The social environment was supportive, but also restraining and disturbing the daily routine activities of the participants in the institutions. Already existing knowledge about fostering activity and participation of people with advanced dementia should be implemented. Thus more attention must be paid to the organization of meaningful occupation in the daily routine of long-term care facilities and the remaining abilities of people with advanced dementia.