

User participation for elderly persons with dementia living at home

<https://www.neurodegenerationresearch.eu/survey/user-participation-for-elderly-persons-with-dementia-living-at-home/>

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Research Abstract

Over the last few decades, dementia care has moved from a paternalistic care where the persons with dementia were regarded as patients and passive receivers of care, to a care where the persons with dementia are now seen as active “users” of health care services. There is an expectation that persons with dementia should be actively involved in decisions around the care they are receiving, and the concept of user participation is highlighted in several policy documents in dementia care. The motives to emphasize user participation are several. Social movements have contributed to increased democratization of society, with recognition that all citizens should have autonomy and opportunity to influence the conditions that shape their lives.

Other motives are economical and efficiency motives. The research on user participation for persons with dementia is limited, especially in the context of home care. This project therefore aims at describing how user participation is understood and practiced in home care for persons with dementia, and will include views from the persons with dementia, family and professional caregivers. The design is a best case study, with the cases being the dementia care in two different municipalities in Norway. The data collection consisted of a questionnaire and interviews with eight persons with dementia, ten carers, and twelve professional caregivers. In addition, a literature review has been conducted on factors affecting user participation for persons with dementia living at home.

Further information available at:

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