

## POSTER ABSTRACT

# Family experiences with palliative care of people with severe dementia in Norwegian nursing homes

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**Introduction:** Dementia is a public health challenge worldwide related to that the number of people living with dementia will more than triple by 2050. Dementia does not just affect individuals; it also affects and changes the lives of the patients' family. Studies of location of death for older people with dementia show that the majority of dementia-related deaths in the United States and Europe occur in nursing homes. Knowledge about how healthcare professionals in nursing homes support and care for people with dementia and their family at the end of life is of great importance since such a high number of people with dementia live their final phase of life there.

Dementia is a progressive terminal illness for which there is currently no cure. Patient dying with dementia have significant healthcare needs, and palliative care should be made available to everyone, with its focus on comfort and quality of life. Earlier studies point out that many family members find the end-of-life experiences difficult and burdensome. They need more professional support during the course of the disease trajectory as well as in the terminal phase. More information is needed about the situation of family caregivers and how they experience the palliative care of their loved one. The aim of this study is therefore to explore family experiences with palliative care of people with severe dementia and how family members experience being taken care of.

**Method:** To describe the phenomenon under investigation we used a phenomenological research approach grounded in the philosophy of Husserl. Data was collected using in-depth interviews with 10 relatives from four Norwegian nursing homes. They are analysed by Giorgi's phenomenological method.

**Result:** Preliminary findings indicate that although the patient is in a nursing home the family experience a high burden of care. They struggle to combine caring of their loved one with other duties in everyday life. They also express a great grief caused by the continuing deterioration of the patient's disease. Despite challenges during the disease trajectory, the family experienced a well-function cooperation with the healthcare professionals and that their loved one received good palliative care in the terminal phase.

**Discussion/Conclusions:** The major findings are illuminated by a palliative care philosophy. Essentially in palliative care is to improve quality of life of the patient and his family through early identification of problems associated with life-threatening illness. Although relatives experienced a good teamwork with the healthcare professionals and were pleased with the care that their loved ones received, they wanted more support early in the disease course to handle their own burden.

**Lesson learned:** Families' experiences provide important knowledge about how professionals can cooperate with and understand the need of family caregivers and of their loved one with severe dementia.

**Limitations:** A small study including relatives from four Norwegian nursing homes.

**Suggestions for future research:** Further research is required on how to address the applicability of palliative care and appropriate care goals across all stages of dementia.

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**Keywords:** dementia; palliative care; nursing homes; qualitative methods

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