Quality until we die: quality of life and quality of dying in nursing home residents with dementia

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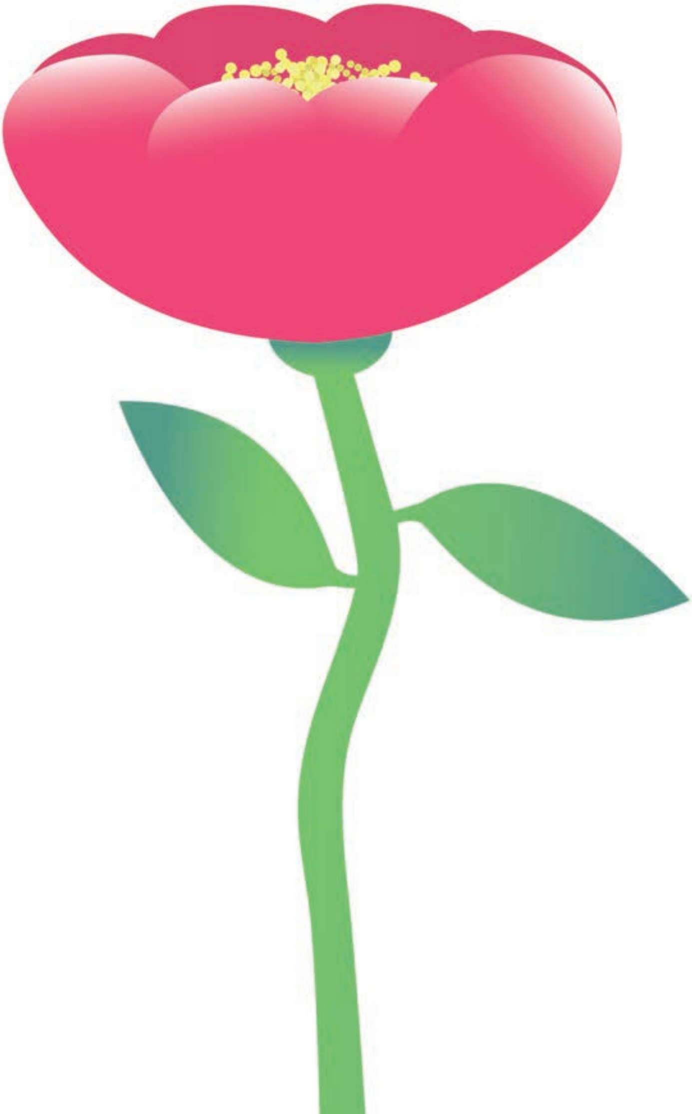


Chapter 1

General introduction

1.1 Dementia

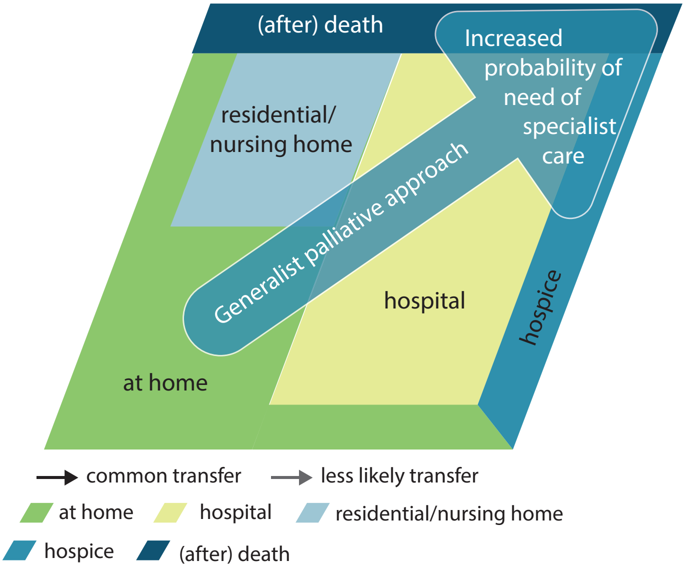
Despite a decline in incidence and prevalence, the total number of people with dementia is growing worldwide due to the increased life expectancy. [1-3] This tangible growth has led to a sharp increase in research on dementia as well as knowledge about the disease and its impact on the people with dementia and their relatives. [4-6] Many researchers are looking for answers regarding the origins of the disease in order to find ways to prevent the onset of the disease, to stop progression, or even better, to find a cure. [7-9] In addition to research on how to combat and end dementia, another focus of research is the care for those who already have dementia and gaining more insight into the needs of these persons and their relatives. The problems that arise for people affected by dementia are caused by damage to their brain, which leads to a deterioration of physical and cognitive functioning. As a result, behavioral and psychological symptoms of dementia (BPSD) are also common and include delusions, agitation, motor hyperactivity and apathy. [10, 11] These symptoms can affect the well-being of the person with dementia considerably and can negatively influence their quality of life (QOL). [12-14] Progression of the disease ultimately leads to an increase in care dependency caused by physical and mental changes. This can put an enormous burden on the person with dementia but also on their partners, children or other relatives. When the care that is needed cannot be provided at home or the caregiver burden is too high for the caregiver, people with dementia are frequently admitted to a nursing home for 24-hour care, which is often a difficult decision to make for relatives. [15]

1.2 Dementia and palliative care

Many people in the community assume that people with dementia have a chronic disease that affects older people. Recent research has provided more insight into the natural course of dementia and we now know it is not a chronic disease. In reality, dementia progresses as a terminal disease. [16]
Palliative care is defined by the World Health Organization as '*an approach that improves the quality of life of patients and their families facing the problem with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.*' [17] The knowledge that people can die due to the progression of dementia raises the question: '*When exactly is palliative care needed?*' Providing a prognosis on life expectancy in the case of dementia is very difficult compared to e.g. cancer. [18] People with Alzheimer's disease, the most common type of dementia, have a median survival of three to seven years after onset of dementia, also depending on the age at that moment. [19, 20] To indicate the precise start of the last months of life is very difficult in general and even more so for dementia. Research shows that less than half of the people diagnosed with dementia reach the final advanced stage of the disease, and that pneumonia and intake problems are important factors for mortality for all residents with dementia in nursing homes. [21] This suggest that a palliative approach should be considered for

residents with dementia, with a focus on improving quality of life for patients and their families who are facing problems associated with this life-threatening illness.[17, 22-24] A Delphi study by the European Association for Palliative Care (EAPC) published in 2014 provided more insight into the important domains in palliative care for people with dementia and provided clear recommendations for clinical practice, policy and research.[25] The eleven domains relate to applicability of palliative care; person-centred care; setting care goals and advance care planning; continuity of care; prognostication and timely recognition of dying; avoiding overly aggressive, burdensome or futile treatment; optimal treatment of symptoms and providing comfort; psychosocial and spiritual support; family care and involvement; education of the health-care team; and societal and ethical issues. The explanation of the different domains involved in providing good palliative care to people with dementia, emphasizes the importance of using a palliative approach for people with dementia at the time of admission to a nursing home. Prolongation of life and maintenance of function are less important care goals, as over time focus changes to maximization of comfort while the disease progresses to a more advanced stage. Transition to a nursing home with 24/7 oversight is often necessary, as shown in figure 1. Initially, when someone is still living at home, a more generalist palliative approach may be necessary, but as the disease progresses with multiple changes in condition and as death comes nearer, a more specialist palliative approach is indispensable. In Dutch nursing homes over 51% of residents have moderately severe to very severe cognitive impairment and over half of the people die within two years after admission.[26] When relatives and professional caregivers acknowledge that dementia is a progressive and terminal disease, residents die more comfortably.[27]

Figure 1 Possible journey for person with dementia and health-care service transitions (From Davies N., Klapwijk M.S., van der Steen J.T. (2018) Palliative Care in Dementia. In: MacLeod R., Van den Block L. (eds) Textbook of Palliative Care. Springer, Cham. https://doi.org/10.1007/978-3-319-31738-0_113-1)



1.3 Quality of life and quality of dying for people with dementia

Both research and clinical practice agree that there is a need to improve care and quality of life for people with dementia, especially when they live in a nursing home, which is often associated with a lower quality of life compared to people living at home. [25, 28, 29] Quality of life is defined by the World Health Organisation (WHO) as: '*An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, personal beliefs, social relationships and their relationship to salient features of their environment.*' [30] The updated definition of palliative care developed by the International Association for Hospice and Palliative Care still included a clear focus on improving quality of life of patients, their families and their caregivers. [31] But do we know how people with dementia experience their own quality of life? They are frequently, no longer able to verbally express themselves, especially in the more advanced stages, due to the neuropathological changes. We therefore have to rely on behavioral indicators and their interpretation by professional caregivers to determine whether or not a person is comfortable, for example, whether a person is experiencing feelings like pain. To measure quality of life, several observational instruments have been developed. Based on different models or definitions, all try to include the relevant domains that influence the quality of life of persons with dementia, but also items related to global function and skills in daily living. [32-35]

1.4 Aim and outline of this thesis

Measuring quality of life in people with dementia can be a challenge because especially in the more advanced stages of the disease, people often cannot communicate their perceptions. Different dimensions are important, varying from aspects related to physical or more psychological well-being, to social interaction and, for instance, positive or negative affect. To gain more knowledge on the experienced quality of life of people with dementia living in a nursing home, and to determine whether methods are available to improve their quality of life, we conducted a series of studies. The overall aim of the studies in this thesis was to explore different aspects of quality of life and quality of dying for people with moderate to advanced dementia in the nursing home.

The first two chapters of this thesis address quality of life and the course of quality of life in people with dementia living in nursing homes. The research questions are:

1. **Can we identify patient characteristics associated with a lower quality of life in people with moderate to very severe dementia in nursing homes?**
2. **What is the effect of the STA-OP! intervention on the different domains of quality of life measured with the QUALIDEM over time?**

Chapters 2 and **3** describe the results of the STA-OP! intervention, a randomized controlled trial with a stepwise intervention, which explores the effect of the intervention on quality of life. Quality of life was measured with the QUALIDEM at baseline, and after three and six months. The QUALIDEM, a 37-item observational instrument, is often used in the Netherlands in research on quality of life for people with dementia in nursing homes and it is based on the adaptation-coping theory, which includes the level of adaptation to the consequences of the disease. [36, 37]

Chapters 4, 5 and **6** of this thesis address the last days of life of people with moderate to advanced dementia living in a nursing home. In the last phase of life, when the dying phase actually starts, the care goals shift focus towards quality of death; how to make the last days or even hours as comfortable as possible? Symptom control and evaluation of practical goals and spirituality are more important than long-term care goals such as survival or cardiovascular risk prevention. The research questions of these chapters are:

1. **What are physicians' and nurse practitioners' experiences using the 'Liverpool care pathway for the dying patient' in nursing home residents, including those with dementia?**
2. **What is the incidence and course of observed symptoms and treatment in the last days before an expected death in people with dementia?**
3. **What are the trends in the last 14 years in quality of care and quality of death experienced by family caregivers of nursing home residents with dementia?**

Regular symptom assessment is one of the components of the 'Liverpool care pathway for the dying patient' (LCP), an observational instrument to be used in the last days of life until death. In the Netherlands the LCP was introduced by the IKNL (Netherlands Comprehensive Cancer Organisation) as 'Zorgpad Stervensfase'. It can be used at home, in the nursing home or in the hospital. The tool is a structured patient portfolio, that can be initiated in the last days of life. It starts with a checklist of points to discuss in part 1. Subsequently, part 2 of the LCP can be used for regular symptom assessment. As the LCP may impact quality of care for people dying from or with dementia, an online survey was conducted among physicians and nurse practitioners about the use and experiences of the LCP on different wards in Dutch nursing homes, including dementia wards. The results are described in **Chapter 4**.
In **Chapter 5** we present the results of a prospective observational study among people with an expected death within 7 days, to assess the incidence and course of symptoms in the last days of life. Various observational instruments were used, some focusing on quality of life, but also instruments with a focus on quality of dying, including a focus on comfort and symptom control in this last phase. [38] Data was also collected on treatment decisions that were made in this period to examine medical decisions in the dying phase.
Besides the perspectives of professional caregivers, the perspective of the family caregivers of people with dementia is very important. They are part of the so-called caregiver triangle that connects the resident with dementia to the professional caregiver and the third important person in relation to organizing the necessary care: the family caregiver. They are close to the person with dementia and often

fulfil increasing care needs for prolonged periods. Therefore it is important to include the family perspective. [39-41] How do these family caregivers experience the care their relative receives? And are any trends discernible in the care received by people with dementia in the last few years from the perspective of the family caregiver? **Chapter 6** presents the results of a study into the changes over time in quality of care and quality of dying for people with dementia. The primary family caregiver received a questionnaire in the months following the death of their relative in the nursing home. Between 2005 and 2019 these questionnaires were sent to family caregivers of different nursing homes in the Netherlands. **Chapter 7** presents the general discussion on the main findings and methodology of these studies on quality of life and quality of dying for people with dementia in a nursing home. Recommendations for future research are made, and clinical implications for daily practice, education and organization are explained.

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