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

Klapwijk, M.S.

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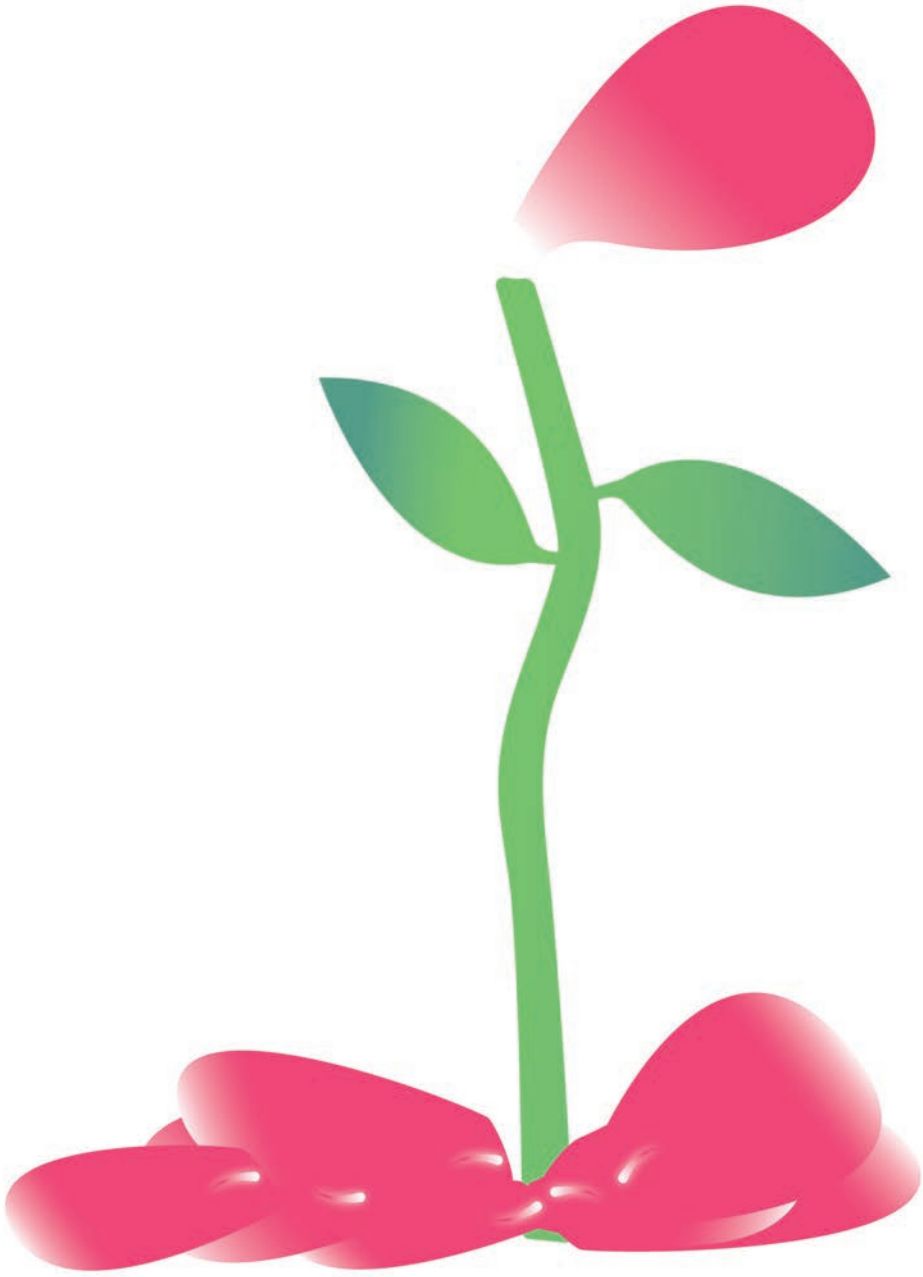
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# Chapter 8

## Summary

With an expected increase in the number of people with dementia, there is also a growing need for more research into people who already have this disease. It is important to gain more insight into their quality of life and their quality of death and how we can improve both. In the introduction of this thesis, **Chapter 1**, it is described how changes in the brain in people with dementia can lead to different manifestations of the disease, with a decline in physical and cognitive functioning. These changes often also lead to changes in the behavior of the person with dementia. Progression of the disease leads to an increase in care dependency, often resulting in admission to a nursing home to provide 24-hour supervision and care. Dementia progresses as a terminal disease. The course of the disease and life expectancy are difficult to predict. That is why timely introduction of a palliative approach is important for people with dementia. A palliative approach refers to care aimed at quality of life instead of healing, which is no longer possible. A palliative approach is not purely about care in the dying phase, but about providing the most appropriate care during the entire final phase of life. In this process, choices are made that are aimed at increasing the quality of life of the person with dementia, family and loved ones. Especially in an advanced stage of dementia, it is often no longer about extending life. In Dutch nursing homes, just over half of the residents have serious to very serious cognitive impairments, including problems with memory. They often die within two years after being admitted to a nursing home. Given the progressive course of dementia, palliative care goals can change rapidly and require regular evaluation. Towards the dying phase, it is important to know that the resident with dementia in a nursing home will die more comfortably if the relatives and professional caregivers are aware that dementia is a progressive and terminal disease.

Both research and practice agree that there is a need to improve care and quality of life for people with dementia in nursing homes. Quality of life is defined by the WHO as: 'The perception of individuals of their position in life in the context of the culture and value system in which they live and in relation to their goals, expectations, standards and concerns.' But how do we know how people with dementia experience their own quality of life? As they are less able to express themselves verbally, they can, for example, no longer indicate whether they are in pain. Various observation instruments have been developed to gain more insight into the quality of life in people with dementia. These are often based on different models and definitions for measuring (quantifying) quality of life. It is important to use these tools when caring for people with dementia. Improving quality of life, of patients and their families who are dealing with a life-threatening condition or frailty, is one of the core elements of palliative care. This is done through the prevention and alleviation of suffering, through early identification and careful assessment and treatment of problems of a physical, psychological, social and spiritual nature. Various dimensions are important in quality of life, ranging from aspects related to physical and psychological well-being, to social interaction and, for example, positive or negative affect. In order to gain more knowledge about the perceived 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 this thesis was to investigate different aspects of quality of life and quality of death for people with often advanced dementia in the nursing home.

**Chapter 2** of this thesis intends to answer the question whether patient characteristics can be identified that are associated with a lower quality of life in people with moderate to very severe dementia in nursing homes. Quality of life was measured with the QUALIDEM, an observation instrument consisting of 37 questions that can be answered about a specific resident. The questions relate to six different domains of quality of life. The study involved 288 nursing home residents. The care teams received extra training about behavior and pain. Several features believed to be related to the six QUALIDEM domains were examined. Analysis of the data showed associations with age in the domain 'Social isolation'; with activities of daily living (ADL level) in the domains 'Positive affect' and 'Social relations'; with dementia severity in the domains 'Social relations' and in 'Social isolation'; with psychiatric disorders in the domain 'Positive affect'; and with lung diseases in the domain 'Negative affect'. Neuropsychiatric symptoms were independently associated with all six domains of the QUALIDEM, and pain was associated with the domains 'Care relationship' and 'Negative affect'. These results show that quality of life in dementia is independently associated with age, ADL, dementia severity, pain, psychiatric disorders, lung disease and neuropsychiatric symptoms. This means that it is possible to identify persons with dementia who are at risk for a lower quality of life by examining whether they have one or more of these characteristics. Research also shows that underlying conditions and pain can affect quality of life. Moreover, this study shows that quality of life must be assessed in different domains to see this influence and it will not be found by, for example, calculating a total score. This information is important for the development of personalized interventions to improve the quality of life in persons with dementia in nursing homes.

In **Chapter 3** we look at how the different domains of quality of life change over time during an intervention (as in chapter 2), after 3 and 6 months. Half of the departments involved received extra training with regard to behavior and pain, and each individual resident was treated according to a step-by-step multidisciplinary and multicomponent method. Quality of life was again measured with the QUALIDEM observation instrument. After both 3 and 6 months, no change and no difference in change between the 2 groups in the domains 'Care relationship', 'Positive affect', 'Negative affect' and 'Social relations' was found. After 3 months, we observed a positive effect in the domain 'Restless tense behavior'. Between 3 and 6 months, a negative effect was seen in the domain 'Restless tense behavior' and a positive effect in the domain 'Social isolation'. This may be due to the completion of the study after 6 months and because not all residents could be included as a result of the step-by-step method. Ultimately, 39% of the residents were included in the study period. Nevertheless, the results were found in the whole study group. The study, as a result of the entire team receiving training, may have contributed to a positive effect for all residents on the ward. It has also shown that it remains important to continue to look at the different domains of quality of life in any future interventions as well. In addition, it is important

to look at the effects of interventions on quality of life in different stages and types of dementia (Alzheimer's disease, Lewy Body dementia, Frontotemporal dementia).

During the stay in the nursing home, care goals often shift as the dementia progresses. The goals can thus change from maintaining functioning to care focused on comfort. This comfort often refers to the absence of negative symptoms, such as pain or shortness of breath. Limiting the burden of symptoms is an important goal, especially in the dying phase. Quality of dying is often determined by the presence or absence of symptom burden. Sometimes the 'Liverpool care pathway' is used during this period. This care pathway consists of three parts. In part 1, information on general matters and care goals is obtained and recorded. In part 2, the symptom burden is charted every 4 hours with the help of a list, and part 3 contains questions for the period after death. The 'Liverpool care pathway' can be used by all disciplines (care, doctor, spiritual counselor, psychologist, etc.) and originates in oncological-oriented hospice care. Versions of the pathway have also become available for nursing homes and home care. In **Chapter 4** we investigate how the use of this care pathway is experienced by doctors and nurse specialists who work in the nursing home and are responsible for medical care. Using a digital survey consisting of nine questions, supplemented with ten semi-structured interviews, we investigated how the use of the care pathway was experienced in practice and what people thought of the content. Ultimately, 159 doctors and nurse specialists in three different regions in the Netherlands completed the questionnaire. The analysis of the questionnaires showed that it was difficult to determine when an individual had really reached the dying phase, especially in the case of a person with dementia. The respondents indicated a reluctance to start the 'Liverpool care pathway' too early for fear of having to withdraw it again. They were very satisfied with the content of the 'Liverpool care pathway', which suggests that it was experienced as an important tool in providing good quality care. People were less positive about the practical application of the care pathway, especially since the introduction of the electronic health record. The care pathway is often not integrated in the electronic health record. In the busy daily practice this raised the threshold to initiate the care pathway, which led to it no longer being used on a regular basis. Regular monitoring of symptom burden was seen as a very important part of good care. However, there was a clear need for a shorter instrument that could be deployed earlier, not just in the last hours or days before death. Also indicated was the need for integration of the care pathway in the electronic health record, so that everyone can use it correctly. An adjusted version of the care pathway that can be started earlier means it is less important to determine the exact moment that the dying phase starts. People with advanced dementia already meet 3 of the 4 criteria used in the 'Liverpool care pathway' to determine whether someone is in the dying phase. A good care pathway for the dying phase in the nursing home must therefore be adapted for application to nursing home residents, and certainly for people with dementia.

In the study described in **Chapter 5**, we look at the frequency and occurrence of symptom burden before death in people with dementia. The research question focused

on examining the occurrence and course of observed symptoms, including pain and shortness of breath. In addition, we examined decisions that were made regarding treatment in the last days before an expected death of people with dementia in a nursing home. Elderly care physicians in two nursing homes, scored the symptom burden twice a day for residents with dementia and an expected death within a week. Various components of quality of life and quality of death, based on questions regarding comfort and symptoms. In addition, questions were answered about treatment decisions during this period. Twenty-four residents were observed for several days until death. Most of them died of dehydration/malnutrition (dehydration/cachexia), which did not include a high symptom burden. The mean scores on all four instruments used showed a fairly low symptom burden. However, the individual symptom scores showed that pain, shortness of breath and discomfort were scored fairly frequently. In this study, the symptom burden was observed twice a day. Unlike some other studies, no increase in symptom burden was found just before death. One of the conclusions of this study is that structural observations twice a day resulted in a positive effect thanks to increased attention from the care team and the treating physicians for palliative care.

**Chapter 6** describes research into the experiences of informal caregivers with the care provided to and the quality of death of residents with dementia. Informal caregivers are part of the care triangle (resident/care provider/informal caregiver) and are therefore an important discussion partner. This is particularly the case in the care for people with dementia, who are frequently no longer able to express themselves verbally. Informal caregivers have often known the resident with dementia for a long time and provide intensive care to the person. In the study involving informal caregivers, two questionnaires were used to ask about their experiences with the provided care. One with questions regarding quality of care just before death, and one about quality of death. In order to find trends in caregivers' experiences over a longer period of time, data from eight different studies that used these questionnaires were combined. In all eight studies, caregivers received a questionnaire in the months after death which they were asked to complete and return. This made it possible to analyze data from 2005 to 2019. This study showed a difference in care satisfaction over the years, but no difference in the quality of death. Additional research is therefore needed to gain a clearer understanding of how dying, and possibly suffering, is perceived by informal caregivers and to investigate how to further reduce symptom burden during the dying phase.

**Chapter 7** describes conclusions and recommendations for future research. Based on the studies described in this thesis, we conclude that it is important to investigate quality of life and to develop a short and practical, validated tool that is suitable for the nursing home setting. The aim is to develop an instrument that enables drawing conclusions about quality of life at a personal level and can also provide recommendations for interventions to improve this quality of life. In addition, observational research is needed that looks at the symptom burden in the days before the death of residents with dementia in a nursing home. We recommend that the perspective of the caregivers is also taken into account. One way to investigate

the experiences of informal caregivers could be to send them questionnaires on a structural basis after the death of the person with dementia. This can be especially important at times when circumstances of the stay in the nursing home for resident and family change due to, for example, infectious diseases like the COVID-19 pandemic. Although more attention is already being paid to the palliative perspective, we believe that in the case of dementia, thinking about choices and options aimed at quality of life should start at an earlier stage. An instrument such as the 'Liverpool care pathway' is now often initiated too late in practice because it is insufficiently adapted to the daily practice of care for people with dementia in a nursing home. There is a need for a 'Dementia Care Pathway' that follows residents in the nursing home from the moment of admission and that provided the entire care and treatment team and informal caregivers with practical tools for anticipatory conversations (advance care planning), symptom control and improving communication. One possibility is to translate the IPOS-Dem, an instrument developed in England, and implement it in the Dutch situation. In addition, it would be good to not only focus on what is not done, for example treatment in hospital, but to show more clearly what is being done about physical and psychological symptoms, during the entire stay and in the days before death. In the nursing home it is very important to involve the care team and the informal caregivers/family from the start of admission and to inform them the expected course of dementia. Every resident with dementia is unique, and the course of the disease process is largely determined by the combination of the character and personal characteristics of the individual and the type of dementia. In practice, the care team and the informal caregivers/family are often insufficiently informed about the expected course of dementia. Involving the relevant people in the care at an early stage can be expected to have a positive effect on the stay and quality of life of the resident with dementia on the nursing home ward. The studies described in this thesis were performed to generate more insight and to gain knowledge about quality of life and quality of death in people with dementia in the nursing home. It also contains a clear message for the future: more research is needed to improve the quality of life and quality of death for the growing group of people with dementia.